

City Research Online

City St George's, University of London

Citation: Jeavons, C. A. (2019). Parents' perceptions of the consent arrangements for dental public health programmes in North London: a qualitative exploration.. (Unpublished Doctoral thesis, City, University of London)

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: https://openaccess.city.ac.uk/id/eprint/25705/

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to City Research Online policy.

City Research Online: http://openaccess.city.ac.uk/ publications@citystgeorges.ac.uk

Parents' perceptions of the consent arrangements for dental public health programmes in North London: a qualitative exploration.

Charlotte Ann Jeavons

Thesis submitted for the degree of Doctor of Philosophy

City, University of London

School of Health Sciences

Date of submission: November 2019

Contents

List of tables 10

List of figures 11

List of abbreviations 12

List of appendices 13

Acknowledgement 14

Declaration 15

Abstract 16

Thesis structure 17

Chapter 1 – Subject and context background 19

1.1 Introduction 19

1.2 Defining public health 21

1.2.a Public health 21

1.2.b Dental public health 25

1.3 Dental public health activities in the UK 26

1.3.a Example 1 Fluoridation 26

1.3.b Example 2 National epidemiological programme 27

1.3.c Example 3 Fluoride varnish programme 29

1.4 Consent 34

1.4.a International evolution of lay person consent In research and health care 34

1.4.b Individual consent for health care in the UK 36

1.4.c Consent processes used in dental public health programmes 38

1.4.d The legal right to information 44

1.4.e Assault and battery 46

1.4.f The Mental Capacity Act (2005) 49

1.4.g Validity of consent 50

1.4.h Informed consent 53

1.5 Conclusion 54

Chapter 2 – Theoretical and philosophical underpinning of autonomy and consent 56

2.1 Introduction 56

2.2 Moral philosophy 58

2.2.a Ethical theory: consequentialism and deontology 58

2.2.b Deontology 58

2.2.c Immanuel Kant's theory of deontology 59

2.2.d Consequentialism 61

2.3 Old Adversaries – paternalism and autonomy 62

2.3.a Paternalism 63

2.3.b Autonomy 64

2.3.c Rejection of Mill's theory as strongly individualist 65

2.3.d A hybrid notion of autonomy 67

2.4 Development of modern ethical frameworks 71

2.4.a Rejection of 'principlism' and 'stewardship' 72

2.5 A new approach: relational autonomy 73

2.5.a Procedural relational autonomy 75

2.5.b Substantive relational autonomy 78

2.6 Justification for a pluralistic relational approach to autonomy 81

2.6.a The States refusal to acknowledge structural determinants of health that substantively influence a person's ability to choose 82

2.6.b Government secured capabilities enabling personal autonomy: a pluralistic approach 86

2.6.c Increasing individualism of UK society 88

2.7 Conclusion 90

Chapter 3 – Review of empirical literature 93

3.1 Introduction 93

3.1.a Summary of literature about consent for dental public health programmes in the UK 95

3.2 Methods 99

3.2.a Search strategy 99

3.2.b The search process 107

3.2.c	Quality assessment	108
3.2.d	Approach to analysis	110
3.3 Results		112
3.3.a	Data	112
3.3.b	Critique of research methods	118
3.3.c	Summary of literature content related to influences on parental consent	124
3.4 Findings		127
3.4.a	Synthesis of findings; factors affecting parental consent	127
3.5 Discussion		137
3.5.a	Critique of literature	138
3.5.b	Strategies employed to maximise consent	138
3.5.c	Approaches to consent informed by theory	142
3.5.d	Applicability to thesis	143
3.6 Conclusion		145
Chapter 4 – Methodology		**148**
4.1 Introduction		148
4.2 Research question, aim and objectives		148
4.3 Qualitative research methods		149
4.3.a	Research paradigm	149
4.3.b	Research design	150

4.4 Sample selection 152

4.4.a Site selection 152

4.4.b Sample population 153

4.5 Data collection 163

4.5.a Semi-structured interviews 164

4.5.b Focus groups 170

4.6 Data management 173

4.7 Data analysis 174

4.7.a Stages of analysis 176

4.7.b Data collection outcomes 179

4.8 Research ethics 180

4.8.a Ethics approval 183

4.9 Quality 183

4.10 Reflexivity 187

4.11 Conclusion 191

Chapter 5 – Findings and interpretations of parents' experiences 193

5.1 Introduction 193

5.2 Summary of findings 194

5.2.a Participant details 194

5.2.b Enablers and barriers 198

5.3 Themes 200

5.3.a THEME 1: Protecting children from harm is viewed by parents as their role 201

5.3.b THEME 2: Parents have the ability to make consent decisions but can lack confidence 210

5.3.c THEME 3: Sharing responsibility for children's health between parent and State is viewed positively by parents 221

5.3.d THEME 4: Existing relationships within parents' social networks strongly influence their consent decisions 228

5.3.e THEME 5: Official dental information is not communicated in a way that parents find useful 238

5.3.f THEME 6: The current consent processes are problematic for parents 248

5.4 Typology of decision makers 256

5.5 Addressing the research question, the aim and the objectives 261

5.6 Conclusion 263

Chapter 6 – Discussion of consent practice and underpinning theory 265

6.1 Introduction 265

6.2 Reflective discussion 268

6.2.a Protecting children from harm is viewed by parents as their role 268

6.2.b Parents have the ability to make consent decisions but can lack confidence 271

6.2.c Sharing responsibility for children's health between parent and State is viewed positively by parents 276

6.2.d Existing relationships within parents' social networks strongly influence their consent decisions 279

6.2.e Official dental information is not communicated in a way that parents find useful 282

6.2.f The current consent processes are problematic for parents 285

6.3 Usefulness of typology of decision makers 288

6.4 Implications for theory and practice 289

6.4.a Implications for the ethical theory of autonomous consent 289

6.4.b Implications for consent practice 293

6.4.c Opt-in versus opt-out 298

6.5 Recommendations for practice 300

6.5.a National recommendations 304

6.5.b Local recommendations 307

6.5.c Recommendation for further research 311

6.6 Strengths and Weaknesses 312

6.6.a Strengths of this thesis 312

6.6.b Weaknesses of this thesis 316

6.7 Conclusion 318

Chapter 7 – Conclusion 321

Appendices 327

List of references 401

List of tables

3.1 PICO component parts

3.2 Search terms

3.3 Inclusion and exclusion criteria

3.4 Outline of literature reduction process

3.5 Master summary of literature

4.1 Parents' responses shown by school from the 2016/17 year

4.2 Question map

4.3 Schematic representation of quality measure

6.1 Recommendations

List of figures

1.1 Stages of consent process for dental public health programmes

3.1 Literature search and selection process

4.1 Potential consent responses

4.2 Stages of theme development

5.1 Response behaviour typology

5.2 Themes mapped against response behaviour typology

List of abbreviations

BASCD	British Association for the Study of Community Dentistry
CDS	Community Dental Service
DPH	Dental public health
FV	Fluoride varnish
HPV	Human papilloma virus
NHS	National Health Service
OHP	Oral health promotion
PCSDS	Primary Care Salaried Dental Service
PICO	Population / patient, Intervention, Comparison, Outcome
PHE	Public Health England
UK	United Kingdom
UN	United Nations
UNCRC	United Nations Convention of the Rights of the Child
US	United States

List of appendices

3.1 Summary of dental literature

3.2 Electronic search log from 10 Oct 2016 – PsychARTICLES

3.3 Electronic search log from 10 Oct 2016 – PsychINFO

3.4 Electronic search log from 23 Oct 2016 – MEDLINE

3.5 Electronic search log from 20 Nov 2016 – International Bibliography for the Social Sciences

3.6 The reduction in literature using the inclusion and exclusion criteria and critical appraisal.

3.7 Example Literature Abstraction Table

3.8 Data extraction table

4.1 Summary of public involvement activity responses

4.2 Focus group guide

4.3 Interview topic guide

4.4 Example of thematic data reduction

4.5 Example interview transcript with coding

4.6a Public information sheet

4.6b Public information flyer

4.7 Participant consent form

4.8 NHS Health Research Authority confirmation

4.9 City, University of London ethics committee approval

5.1 Whittington Health NHS parent information and consent form

Acknowledgements

I would like to acknowledge several people who have helped me to write this thesis and carry out the research contained within it.

I would like to thank the dental service staff from Enfield and Haringey who work for Whittington NHS Health. Without their willingness to share their contacts with me and provide me with background data, the work conducted in schools would have been a lot more difficult. On this note, I would also like to acknowledge all of the schools who allowed me into their world and the parents who gave up their time to speak to me. These conversations were definitely a highlight of this experience.

I would also like to whole-heartedly thank my supervisors; Dr Charitini Stavropoulos, Dr Katherine Curtis-Tyler and Dr Nick Drey. Their guidance has been invaluable in shaping this work, in particular Charitini's clear and practical advice that was always useful, Katherine's qualitative eye and Nick's encouragement to delve deeper into ethical theory.

Lastly, but most importantly, I would like to thank my husband. I have been somewhat 'missing' over the last six plus years of the life of this PhD. In that time he has built us a beautiful home from the ground up with almost no input from me, which cannot have been easy. He has attended numerous social events alone. He has endured me taking work on every holiday we have had, including one year in Cornwall when he gave up his new year's day to sit in a hotel room proof reading my reference list! I have only been able to complete this thesis because of this support and for that I am, and will always be, immensely grateful.

Declaration

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or part without further reference to the author. This permission covers single copies made for study purposes, subject to normal conditions of acknowledgements.

Abstract

Introduction. Dental caries among primary school-age children in the UK is widespread (Davies *et al.*, 2014). The Health and Social Care Information Centre states that dental caries is the most common reason children aged between five and nine were admitted to hospital accident and emergency units (HSCIC, 2013). Dental public health programmes are delivered via schools, including the application of fluoride varnish (FV) to children's teeth. For children to take part parents must provide their consent. A large number of parents do not respond to the consent request (Davies *et al.*, 2014) and this results in their children being excluded.

Research question. What barriers or enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?

Methods. An initial exploration of the evolution of autonomy and consent practices was conducted. A literature review of international research revealed little information on consent from a parent's perspective. Qualitative methods were used to explore parents' views of consent, including four focus groups with 21 parents and 18 semi structured interviews across eight different schools in North London. Interactions with parents were transcribed verbatim and data from these were manually coded before being analysed thematically.

Findings. Six themes emerged from the qualitative data including; parents acting as their children's protector, their own confidence levels to provide or refuse consent, the influence of social networks on decisions, the expectation to share some responsibility for children's health with the State, the dislike of a consent process involving letters and the usefulness of information provided. A typology of parent decision makers was developed from these themes.

Discussion. The current approach to consent for FV programmes is problematic. It does not enable independent decision making by parents. Parents experience barriers the lack of face to face information and the way that consent requests are made. Parents navigate this process by drawing on their social network, including teachers to provide guidance. Health professionals' practice of neutrality is experienced as a barrier and parents expect a level of paternalism towards their children.

Conclusion. The current approach to consent for FV programmes is flawed. Changes are needed to facilitate more informed decision making by parents that ultimately enables more active decisions.

Key words: consent, autonomy, parents experiences, dental public health.

Thesis structure

This thesis is organised as follows. Chapter 1 provides background information to explain the context of consent arrangements for health care, and more specifically for dental public health. It also outlines how approaches to individual consent have developed and how arrangements in the UK, specifically in England, are closely aligned to a legal and political view of autonomy, rather than a richer ethical account. Chapter 2 (Theory) explores the theoretical, philosophical and ethical debates related to autonomy and paternalism. In this chapter, the current approach to autonomy and consent is analysed and subsequently rejected as insufficiently rich, particularly for public health activities, before a new relational way of conceptualising autonomy and paternalism is suggested. Chapter 3 (Literature Review) is a systematic review of current research literature on parental decision making for public health. The purpose of this is to specifically highlight parents' views on consent for public health. The common themes from this chapter, generated from a meta-synthesis of the literature, are used as the basis for further exploration via parent interviews in subsequent chapters. How this is done is detailed via the research methodology discussed in Chapter 4 (Methodology), specifically focus groups and qualitative interviews with parents. The results produced by these research activities were analysed and these are discussed in detail from a practical and theoretical perspective in the subsequent chapters. Chapter 5 (Findings), starts with a summary of the parent participants including their ethnicity, level of spoken English and response behaviour. This is followed by an analysis of the qualitative data that is organised into six discrete themes, although there is some overlap between these. Verbatim quotes from parents have been included to illustrate specific points. Chapter 6 is a discussion of these themes from a practice and theoretical perspective, followed by recommendations for action at both national and local levels. This chapter concludes with reflections on the research itself, including its strengths and weaknesses. Chapter 7 concludes this thesis with a summary of al salient points.

Aim

To examine parental experiences related to consent procedures for a school-based fluoride varnish programme in North London

Research question

What barriers or enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?

Thesis objectives

- To investigate parents' views and experiences of the consent arrangements for the fluoride varnish programme taking place in their child's school
- To investigate parents' views about the consent processes for the school-based fluoride varnish programmes that would best support their preferred methods of engagement, for example a system of opt-out consent, or one of opt-in
- To investigate what support, if any, parents would like in relation to their consent decision making as part of school-based fluoride varnish programmes in the future

Chapter 1 – Subject and context background

1.1 Introduction

This chapter provides the background to the two main concepts discussed in this thesis: public dental health and consent. I start by clarifying the definitions of public health and dental public health before describing the organisation of dental public health activities that commonly take place in the UK. Moreover, I highlight how the implementation of dental public health has taken an increasingly individualised approach. This mirrors the evolution of health professionals' approach to consent in Western culture over the last 70 years that has become progressively more individualised. I have also included information on the law in relation to consent, specifically regarding the Mental Capacity Act 2005 (Great Britain, 2005), which summarised the English common law approach to consent when it was introduced, and how UK medical law has evolved and been enacted in cases where consent is the central issue. Consent as it is commonly understood and generally used within dental public health (DPH) is discussed, including how the organisation and delivery of DPH programmes has changed in recent times, resulting in the exclusion of large numbers of children from low-income families from dental public health initiatives.

Untreated dental caries (tooth decay) is the most prevalent disease worldwide (Marmot and Fenton, 2015) and approximately 3.9 billion people are affected by an adverse oral condition (Marcenes *et al.*, 2013). It is estimated that oral disease is the fourth most expensive condition to treat, and curative dental care is a significant economic burden for many developed countries (Petersen, 2008; Department of Health, 2005a). In 2009 it was estimated that the National Health Service (NHS) would spend approximately £2.25 billion on dentistry with a further £550 million of costs paid for via patient charges (Steel, 2009).

In 2013 the Children's Dental Health (CDH) survey carried out in England, Wales and Northern Ireland, commissioned by the Health and Social Care Information Centre (HSCIC) (2015), reported that nearly a third (31%) of five-year-old children and nearly half (46%) of eight-year-olds had obvious dental caries experience. It was reported that 41% of children eligible for free school meals had obvious caries experience in their primary teeth and 21% of eligible five-year-olds had severe or extensive tooth decay, compared with 11% of five-year-olds who were not eligible. In the same year as the CDH survey (2013), the HSCIC stated in a separate report that dental caries was the most common reason children aged between five and nine were admitted to hospital accident and emergency units (HSCIC, 2013). Indeed, a report from the International Centre for Oral Health Inequalities Research and Policy states that children from disadvantaged backgrounds are disproportionally more likely to be admitted to hospital to have teeth extracted (Shieham, Conway and Chestnutt, 2015). According to the HSCIC, one fifth of all childhood admissions to hospital for dental extractions in England came from the most deprived tenth of the population, whereas only 4% of children from the most affluent 10% were admitted for the same reason (HSCIC, 2013).

The burden of dental caries is felt not only by the individual child, with the potential for them to experience pain, sleepless nights, absence from school, social isolation and difficulties with eating and speaking, as well as the possibility of stigma and embarrassment, but also by the child's family and the wider community (Mostofsky, Forgione and Giddon, 2006). This may be expressed in the anxiety, cost and inconvenience associated with absence from work for parents when looking after their child (HSCIC, 2015) and in the increased NHS treatment costs to the State and therefore to UK tax payers (Steele, 2009). We can assume, therefore, that good oral health is not only of utility, *i.e.* of benefit, to the person enjoying it, but that it is also of value to society (Listl and Wildman, 2015). A person free from dental disease is more able to contribute positively to the labour market (now or in the future) and therefore pay taxes, and they will not unduly use NHS resources for a disease that is

largely preventable (Felton, 2009). Additionally, they will enjoy a better quality of life free from pain, and subjective wellbeing will be improved or sustained through the ability to form close personal relationships (Inglehart, 2006).

1.2 Defining dental public health

1.2.a Public health

The broad purpose of public health is to prevent disease, promote health and prolong life among the population as a whole (World Health Organization, 2015). However, much of public health work is aimed not at whole populations but at reducing inequalities faced by specific groups within them (Marmot, 2010). The socio-economic determinants that lie beneath these inequalities can often only be addressed through policy initiatives at a structural or societal level (Dahlgren and Whitehead, 1991). A DPH example of this is the introduction of water fluoridation to mitigate some dental health inequalities (British Fluoridation Society, 2012). The danger with an approach that favours population benefit over individual interests is that when judged against dominant thinking on medical ethics, such as that articulated by Gillon (2003) who believes that personal autonomy is 'first among equals' of ethical principles, this form of public health could be considered unethical at worst and negatively paternalistic at best (Dawson, 2011). In *Public Health Ethics* (2011) Angus Dawson addresses this dilemma. He postulates that instead of viewing the problem as one of existing public health practice being at odds with ethical thinking and conduct, it is in fact the way in which we understand what 'public health' is that is important to consider before identifying and applying appropriate ethical theory, which may not be one that is necessarily grounded in clinical medicine. In an earlier publication, Verweij and Dawson (2009, p.21) characterise public health as

'*collective interventions that aims to promote and protect the health of the public.'*

'Public' is further defined by Dawson (2011) in two senses, the first being 'the public' as a social entity or group with similar characteristics and not just an aggregate of individuals. The many individual children included in DPH programmes have multiple similarities, both biological and social. For example, Watt and Sheiham (1999) claim that area-based indicators are a better predictor of oral health status than many other measures, and that it is common for targeted schools to be located in specific communities with small catchment areas that have cultural and social norms extending to diet, personal care and use of services. The second sense of 'public' that Dawson (2011) put forward is as a mode of intervention that requires collective action. An example of this is public health work, such as a fluoride varnish programme carried out in schools, that targets a population or group collectively, *i.e.* improving the health of children in a specific area, *e.g*. a school or a small cluster of schools. Collective action such as this, which often requires structural change via the implementation of policy or law, will improve the health of individual children and, therefore, of the target group overall. But conversely, if the whole school approach is abandoned, with no structural or social change taking place, and children and parents are targeted to take individual action (*e.g.* advertising that encourages parents to take children to a high street dental surgery to receive the same fluoride varnish treatment), the health of the group overall will not improve, and inequalities will remain, or indeed grow, as the oral health of other groups improves. In this sense of 'public', collective action has the advantage of population health improvement. This is because of the significant impact that the structural and social determinants have on health, which can only be overcome by collective action, and State intervention on behalf of society is often the only way to facilitate this (Dawson, 2011). The end point benefit of receiving fluoride varnish to help prevent tooth decay in this instance can be very difficult for individuals to achieve on their own because of the substantial structural barriers they face, *i.e*. access to routine oral care (Dawson, 2011; Watt, 2002).

It is the elements of 'similarity' and 'collectiveness' found in Dawson's (2011) definition that Prainsack and Buyx (2015, p.5) believe are crucial to the context of public health, which they call solidarity. They define this as

'*practices reflecting a commitment to carry "costs" (financial, social, emotional or otherwise) to assist others with whom those engaged in these practices recognise similarity in a relevant respect'.*

Prainsack and Buyx (2015) recognise three tiers of solidarity:

1 = between individuals,

2 = group or community based, and

3 = contractual provisions, or administrative or legal norms.

It is in the third tier of solidarity, which is the most formal, that dental epidemiological surveys and fluoride varnish programmes can be identified. For example, the government's Statutory Instrument 3094 (Great Britain. The NHS Bodies and Local Authorities [Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch] Regulations 2012) states:

'Each local authority shall have the following functions in relation to dental public

health in England.

(i) the assessment and monitoring of oral health needs,

(ii) the planning and evaluation of oral health promotion programmes, [defined as health promotion and disease prevention]

(iii) the planning and evaluation of the arrangements for provision of dental services as part of the health service, and

(iv) where there are water fluoridation programmes affecting the authority's area, the monitoring and reporting of the effect of water fluoridation programmes.'

Statutory Instrument 3094 is a clear demonstration of Prainsack and Buyx's (2015) third tier of solidarity, which stems from practices that articulate particular values (in this case that of promoting oral health and preventing dental disease in geographically defined population groups, specifically including children) that have solidified through long-standing arrangements into contractual, administrative or legal norms. Here, formal solidarity is being demonstrated through reciprocal arrangements whereby the State is obliged to provide the functions listed above in return for the income it receives from taxes. This type of formal solidarity is often seen in traditional public health initiatives such as those that improve environmental health, *e.g.* through State laws and regulations to limit the level of pollutants that industry can produce, for the benefit of the population (Great Britain. Clean Air Act, 1956). But, the dental public health programmes under discussion in this thesis also meet the additional definition clarification from Dawson (2011) that specifies 'characteristic similarity', as mentioned above, which some large interventions that are traditionally thought of as 'public health' do not. Nonetheless, Dawson's (2011) collective action as interpreted through Prainsack and Buyx's (2015) first and second tiers of solidarity are harder to identify in regard to DPH. For example, it is not possible to tell whether individuals are willing to carry the costs (financial, emotional or social) of assisting others, or indeed whether there are any individual or collective costs with regard to these programmes, that is unless one considers the voting rights of individuals that provide governments with their mandate to act collectively on behalf of communities and populations. However, this type of solidarity is more easily linked to tier three. As such, if viewed in this way, *i.e.* where the solidaric context of public health is thought of as tier one or two, these dental public health programmes could be seen as health care rather than as public health. However, Prainsack and Buyx (2015) do not state that all three tiers need to be met before solidarity is expressed; equally, Verweij and Dawson's (2009) definition of what constitutes public health and

Dawson's later clarification (2011) of the two senses of what 'public' means have been satisfied at a national level by these programmes. It seems that interventions like the application of fluoride varnish to children's teeth is individual health care but, crucially, the mode of intervention, *i.e.* via targeted population-specific programmes, is public health. This type of 'border crossing' situation, in which health care is delivered in ways that meet the definitions and specifications of what is deemed public health, can be seen in other public health interventions too, for example in programmes that deliver the HPV vaccination to teenagers in school settings (Public Health England, 2015a). It is this *cross-border* position that some dental public health programmes hold that has potentially contributed to confusion when designing consent policies and processes, and the appropriate ethical considerations of such, this issue is discussed throughout this thesis.

1.2.b Dental public health

Dental public health (DPH) is a specialised strand of general public health and of dentistry that is largely carried out by DPH Consultants, Dental Officers and Oral Health Improvement Practitioners (Department of Health, 2010; General Dental Council, 2010). In England it is practised under the auspices of publicly funded organisations such as Public Health England, the NHS and local authorities (NHS, 2015). NHS Primary Care Salaried Dental Services (PCSDS) ,often referred to as Community Dental Services, across England have a remit to treat people who are not easily able to access high street care, for example population groups classed as vulnerable, such as people who are homeless or have physical or mental disabilities or, in some circumstances, children, such as those with untreated decay (NHS, 2015). This service is distinct from NHS-commissioned dental care that is delivered by the General Dental Service (GDS) and commonly found on the UK's high streets, which is aimed at the mainstream population without specific additional needs (Steele, 2009). Additionally, as an adjunct to the clinical care they provide, part of the remit of the PCSDS is to implement population-wide dental public health programmes. These

dental public health activities are mandated by Statutory Instrument 3094.These activities would not be easy for the GDS to implement due to the specialist skills, equipment and population-wide organisation required (NHS, 2015)

Key examples of three different dental public health activities are described below in Section 1.3. These activities broadly meet the criteria set out by Prainsack and Buyx (2015) and by Dawson (2011), despite sharing some features with clinical health care. However, through changes to their organisation and delivery, it appears that in recent years the underpinning ethos has moved from one of solidarity and some degree of shared responsibility between State and individual to one that promotes an individual responsibility.

1.3. Dental public health activities in the UK

1.3.a Example 1: Fluoridation

The most well-known dental public health activity is that of water fluoridation. If implemented, this meet the requirements of all three of Prainsack and Buyx's (2015) tiers of solidarity. Despite fluoridation's almost universal endorsement by the dental profession in the UK, most of Europe and the USA, there remains a section of society that vigorously opposes it (Griffin, Shickle and Moran, 2008). Fluoridation is advocated by the World Health Organization (Petersen, 2008) and by the Department of Health (2009) in England. In opposition to this, a large pan-European study carried out by Griffin, Shickle and Moran (2008, p.98) reported that many European citizens saw fluoridation as an '*imposition on their freedom of choice*'. Interestingly, in the same study, UK citizens also reported that they wanted to be informed of plans for fluoridation but they did not want to be involved in the decision making, preferring such policy to be left to experts (Griffin, Shickle and Moran, 2008). This demonstrates the tension between the potential desire for autonomy versus some level of paternalism from others towards individual and population health.

In 2003 the Water Act (Great Britain, 2003) came into force, enabling Strategic Health Authorities (SHA) to require water companies to fluoridate water supplies, provided there was support from the local population following consultation. But, research by Lowry, Thompson and Lennon (2000) found that the public were unlikely to demand fluoridation because they did not feel sufficiently skilled to make final judgements on its efficacy, nor did they feel that delegating this decision to them was fair. In the nine years between the Act coming into force and the abolition of SHAs in 2012, only one SHA (Southampton) came close to introducing water fluoridation, but due to opposition from the two local councils that would have been affected – Hampshire County Council and Southampton City Council – this did not go ahead (Public Health England, 2014). This is an example of where a recent change in policy appears to have shifted the responsibility for water fluoridation from the State to the population, or more specifically to individuals living in any given area. This transfer of responsibility has been seen elsewhere in dental public health too and this is explored further in later chapters. However, as individual consent is not currently a requirement for water fluoridation, this aspect of dental public health policy will not be included in the empirical research for this thesis.

1.3.b Example 2: National dental epidemiological programme

Dental inspections of primary school-age children are carried out as part of a rolling programme in the UK, under the Health and Social Care (Community Health and Standards) Act 2003 (Great Britain, 2003). The history of annual primary school dental inspections, whether for the purpose of surveillance or for screening, stretches back 100 years, with such inspections being implemented from 1907 until 2006 (Great Britain. Education (Administrative Provisions) Act, 1907). The imperative to inspect and record the status of children's oral health is described in the Health and Social Care Act (2003). Oral health surveys of primary school-age children provide an insight into the status of children's teeth at a key transition period in their lives. The information gained from these surveys provides national data on the progress

towards the government's aims to improve the oral health of children (Department of Health, 2005a). The nature and purpose of these inspections and subsequent surveys has changed in recent years, with the focus moving from dental screening to surveillance (Department of Health, 2006). Screening has been defined as:

'*The systematic application of a test or enquiry, to identify individuals at sufficient risk to benefit from further investigation or direct preventive action, amongst persons who have not sought medical attention on account of symptoms of that disorder*'. (Wald, 2001, p.1)

Furthermore, the World Health Organization (2003, p.45) has endorsed dental screening of children in the school setting, stating that

'*screening of teeth and mouths enables early detection, and timely interventions towards oral diseases and conditions, leading to substantial cost savings. It plays an important role in the planning and provision of school oral health services as well as [general] health services',*

whereas surveillance was defined at the UK National Screening Committee conference in 2004 as *'[e]xamination of all or part of a population, in order to assess the particular (oral) health of that population over time*'.

The usual process for requesting consent from parents is to send a letter including a consent slip home via the child for them to sign, indicating whether they consent, before returning it to the school via their child. Dental staff carrying out this programme rarely speak to, or meet, parents. In 2006 the Department of Health issued a change in policy, whereby instead of parents indicating that they do not want their child to be included (*i.e.* opt-out negative consent) they now have to indicate whether if they do want their child to be included (*i.e.* opt-in positive consent) (Department of Health, 2006). Since 2006, annual inspection programmes have all but ceased due to a decrease in participation resulting from this change in consent

arrangements. It is this process that has been adopted and implemented as part of the newer fluoride varnish programmes.

The change from 'screening' to 'surveillance', along with the adoption of an opt-in policy for consent, demonstrates a key ethical shift towards a stronger individual liberal stance in the underlying purpose of these programmes (Mill, 1859). The responsibility for child dental care has been discharged solely to parents via a programme of opt-in surveillance. This indicates a change from the State being viewed as (partly) responsible for the health of children to a view that reduces State input and emphasises individual parental responsibility and, therefore, accountability. Yet, these changes, specifically the policy on opt-in consent and the subsequent wide-scale cessation of screening programmes, are at odds with the UNCRC (UN General Assembly, 1989). This states, in Article 3, that

'…the best interest of the child should be the primary concern, particularly with regard to budget, policy and law makers'.

It is difficult to see how the child's 'best interest' concerning their dental care is being met by the current implementation of policies that appear to be disabling parental decision making and at the same time reducing State intervention.

1.3.c. Example 3: Fluoride varnish programmes

The use of fluoride on an individual level is advocated by the Department of Health in the UK (2009). In recent years there has been a focus on the twice-yearly application of fluoride varnish as an effective way to reduce the amount of dental caries among the UK's child population. In 2007/8, a dental public health programme was initiated in Scotland that involved the application of fluoride varnish to children's teeth (Childsmile, 2008). The programme, called Childsmile, was delivered via a settings-based approach, in which dental care professionals (DCPs) visited nurseries and schools to apply fluoride varnish to children's teeth, among other activities. Since 2008 several similar programmes have started across the UK, such as 'Designed to

Smile' in Wales (Welsh Government, 2009) and smaller more localised schemes in parts of England. An example of such a scheme is in operation in the North London boroughs of Enfield and Haringey, which share a PCSDS (Whittington Health NHS, ND). The majority of the community fluoride varnish programmes now in operation are aimed at young primary school-aged children and require parents to provide written positive, *i.e.* opt-in, consent (Primary Care Commissioning, 2009). A similar process is used to request consent from parents as in the inspection programmes previously described, *i.e.* via letter (Kubiangha, 2015; Hardman *et al.*, 2007).

The first record of fluoride use dates back to the 1870's, but conclusive evidence of its preventive effect on dental caries was not published until the mid-1940's after much work in the USA, first by McKay and subsequently by Dean (1940). Since then extensive research has been conducted to examine the efficacy of fluoride when used topically by individuals. In 2003 Marinho *et al*. carried out a systematic review that concluded the evidence to support the use of topical fluoride was moderate and that the studies included in the review had a high risk of bias. Nevertheless, the outcomes from this review act as the evidence base on which the Department of Health (2017) recommend the application of fluoride varnish (2.2%fl concentration), which was first published in 2003. Subsequently another systematic review was published by Petersson *et al*. in 2004 that looked specifically at available evidence for the reduction of dental caries through the use of fluoride varnish. The reviews of Marinho *et al.* (2003) and Petersson *et al*. (2004) is further supported by a more recent systematic review published by the Cochrane data base of systematic review in 2013 that updates Marinho *et al's*. original work. All three reviews suggest that dental caries can be reduced by as much as 30-46% with the use of topical fluoride varnish.

However, the use of fluoride varnish as a population based dental public health measure is less well researched, with the earliest example of such a programme in the UK only being in existence since 2007/8 (Childsmile, 2008). Some international research exploring the effectiveness of FV programmes when delivered in a school

setting indicates positive outcomes. Examples include research by Dohnke-Hohrmann and Zimmer (2004), Moberg Sköld *et al*. (2005) and Borutta *et al*. (2006). Moreover, the positive conclusions of these authors are supported by the more recently published evaluation of FV application as part of the Childsmile programme in Scotland (Wright *et al.*, 2015). But, crucially for this thesis, although there appears to be evidence for the use of FV to improve oral health in a clinical setting, and emerging evidence of this as a public health intervention, a cluster-randomised trial carried out in England by Hardman *et al* (2007) stated that:

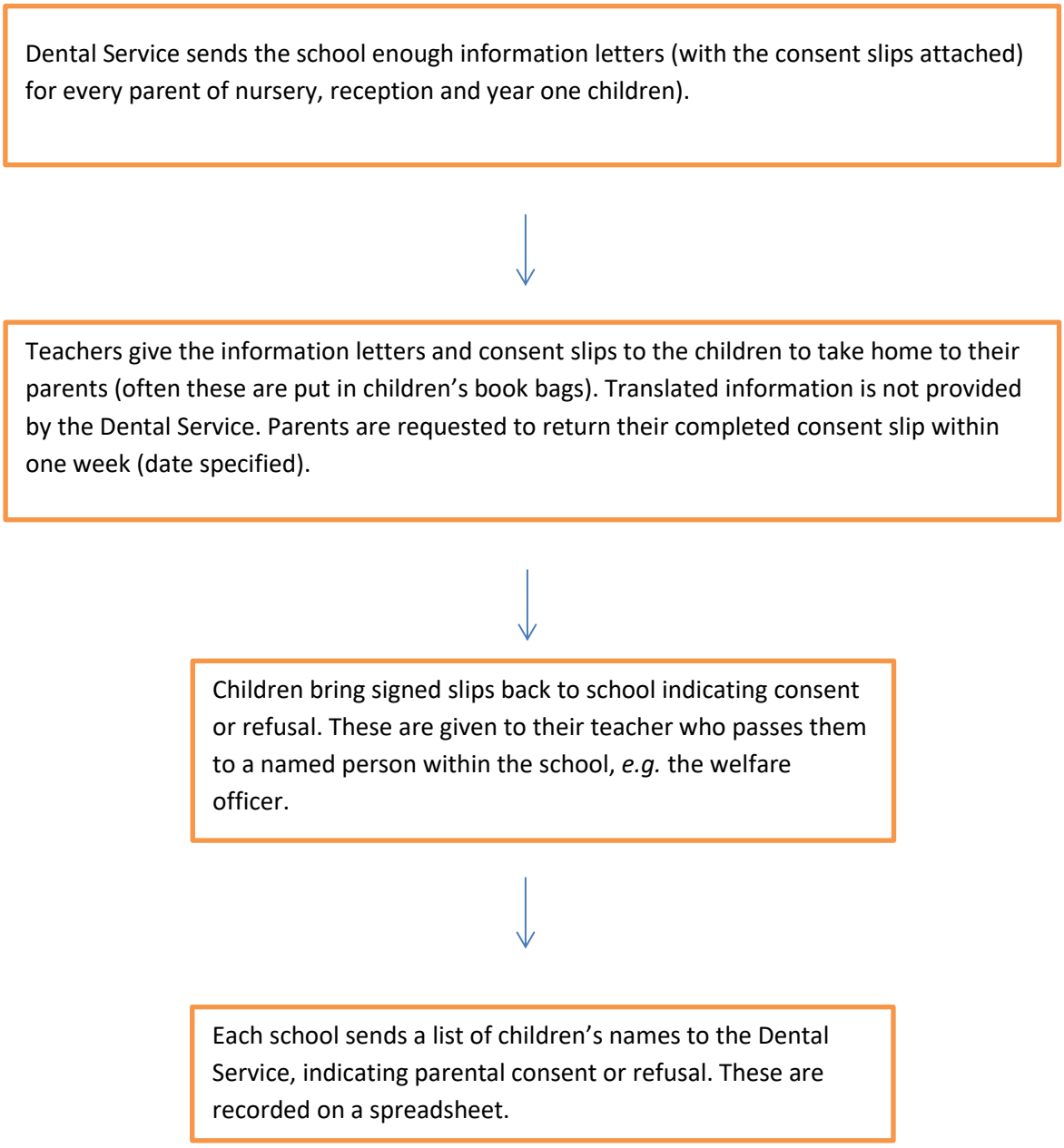
'*fluoride varnish intervention cannot be recommended as a public health measure for reducing caries.'*

The authors identified the low rate of positive consent received from parents as one of the two main reasons for this statement (Hardman *et al*., 2007). This paper has been included in the dental literature summarised in Appendix 3.1 that focuses on consent for dental public health programmes in the UK.

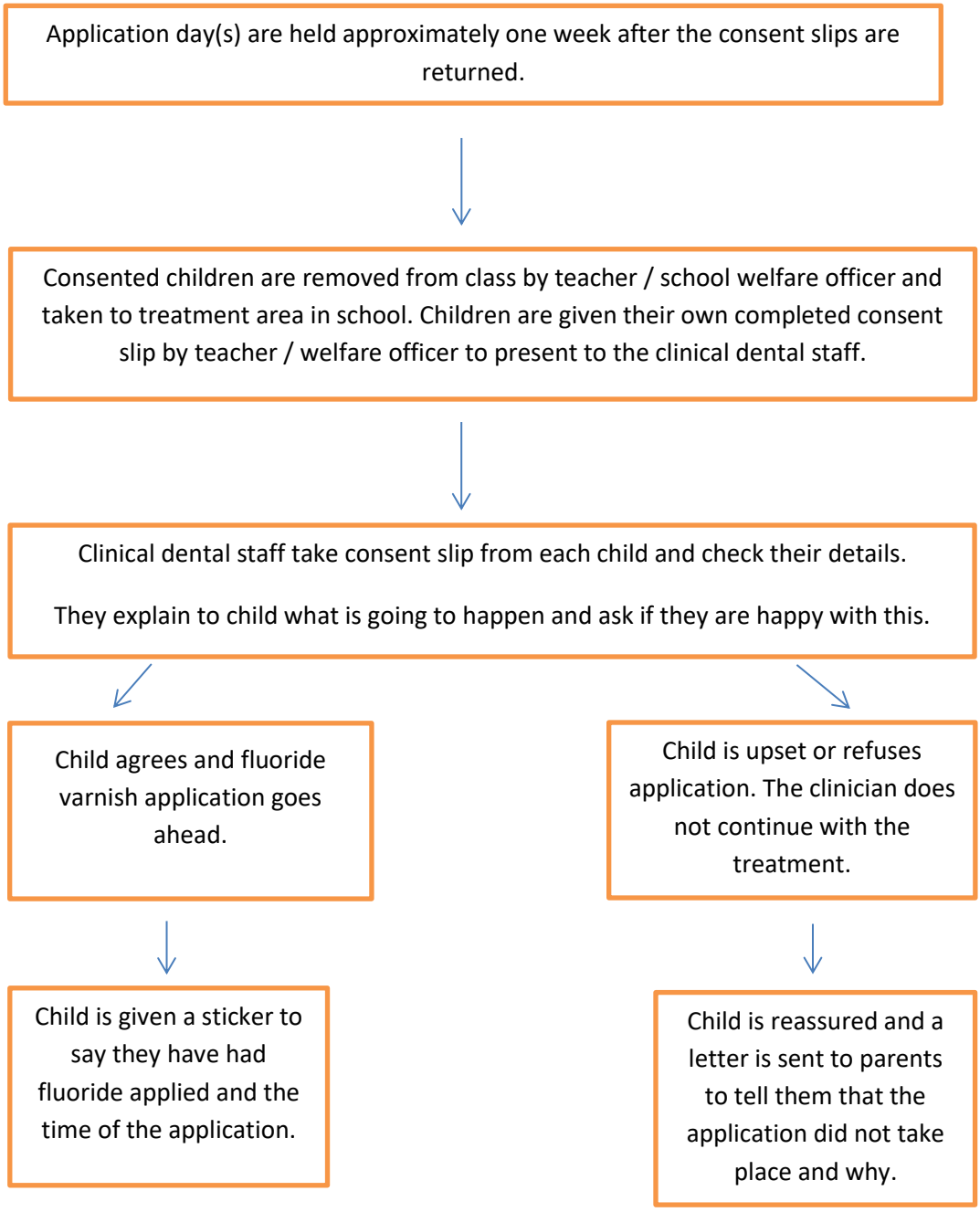
Individual parental consent for public health activities is investigated in subsequent chapters of this thesis and, specifically, the letter-based approach outlined above for DPH programmes is explored from the parents' perspective. The diagram below shows the separate stages within this process (Figure 1.1). This thesis includes an analysis of parents' experiences of making consent decisions on behalf of their children. Equally, in the following theory chapter the increasingly individualised approach to (oral) health and consent, as seen here, is discussed from an ethical theoretical perspective. This includes a discussion of how the political context of health in the UK is shaped by ethical theory and, in turn, shapes the implementation of (dental) public health.

Figure 1.1 Stages of the consent processes for school-based dental public health programmes

Part 1: Parental consent request prior to fluoride varnish treatment



Part 2: Parental consent and child assent on application day



1.4 Consent

1.4.a International evolution of lay person consent in research and health care

From a legal perspective consent is, effectively, a power of veto. But, until the second half of the 20th century, the prevailing approach to decision making in health care was 'Doctor knows best' (Hope, Savulescu and Hendrick, 2008). This paternalistic practice was widespread and decisions were routinely made by doctors, dentists or health care providers in the absence of any discussion with the patients, or their family members (Katz, 2002). Paternalism, as it is widely understood by the general public and defined by the Oxford Dictionaries (2015a), is:

'The policy or practice on the part of people in authority of restricting the freedom and responsibilities of those subordinate to or otherwise dependent on them in their supposed interest'.

The contemporary American philosopher Gerald Dworkin (2014) takes a more negative view, describing paternalism in general terms as follows:

'*Paternalism is the interference of a State or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm'.*

Today, this type of paternalism is also viewed with negativity when applied to health care (Duncan, 2010). Patients and lay people are becoming more involved in the decisions surrounding their care, and indeed this has come to be seen as a 'right' (Lesser, 1991), with the now common practice of 'respecting patients' autonomy' being considered 'best practice' by many health care regulators, including the General Dental Council (GDC) (2005) the General Medical Council (GMC) (2013) and the Nursing and Midwifery Council (NMC) (2010). The international medical community's first formal recognition of the need to 'respect patients' autonomy' was as a result of the Nuremburg trial of Nazi doctors immediately after World War II, which led to the

creation of the Nuremburg Code of 1946 (The Evolution of Medical Ethics, 1946). Interestingly, in Germany government guidelines about consent had been in existence for many years, with the Prussian government, as it was at the time, issuing regulations on human experimentation in 1900 (cited in Sass, 2003) and a Circular from the Reich Minister of the Interior in Germany outlining consent guidelines being issued in 1931 and remaining in place until 1945, despite being largely ignored by Nazi doctors at the time. The Nuremburg Code (United States Government, 1949) is a set of 10 principles covering the conduct of doctors when carrying out medical research and, although it did not carry the force of law, it was the first international document that advocated voluntary participation and informed consent. The first of these 10 principles states:

'The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice...'. (p.1)

The Nuremberg Code is not without its critics. For example, a recent paper by Ghooi (2011) stated that not only was it was open to misinterpretation but that it had been superseded in the international community by the Declaration of Helsinki that was developed in 1964 by the World Medical Association (2013). This declaration, unlike the Nuremberg Code, is updated regularly and has therefore kept pace with the development of modern research ethics (Ghooi, 2011). Clinical health care has largely adopted the ethical practices outlined in these documents, which were originally intended for research purposes. Indeed, the language used in the Nuremburg Code from 1946 and the emphasis on individual patient rights as discussed by Lesser in 1991, is evident in the General Dental Council's guidance to DCPs (2005, p.3), which states:

'*It is a general legal and ethical principle that you must get valid consent before starting treatment or physical investigation[…]. This principle reflects the right of*

patients to decide what happens to their own bodies and is an essential part of good practice.'

This quote, along with similar statements made by the GMC (2013) and the NMC (2010), clearly demonstrates that individual patients' rights and autonomy should be promoted by health professionals. Despite having no legal weight, these 'codes of conduct', including the Declaration of Helsinki, which specifically outlines consent requirements for medical research (World Medical Association, 2013), have considerable influence over individuals' practice and, as such, over the implementation of dental public health programmes. Statutorily registered health professionals are held accountable for their actions by the appropriate regulating body, *e.g.* the General Dental Council (GDC, 2005). Such regulatory bodies have the power to impose sanctions on a health professional's practice or remove them from the register (effectively ending their legal right to practice) if their conduct falls below the prescribed standard (GDC, 2015). The result is that clinical practice is directed by codes of conduct that view consent from a perspective originally developed for research, which is to misunderstand the differences between these two activities.

1.4.b Individual consent for health care in the UK

In the late 1990s and early 2000s concerns were raised about the consent process used for health care. These came to light after two public scandals involving poor or non-existent consent procedures. The two incidents were linked, and took place at the Bristol Royal Infirmary (Parliament. House of Commons. 2001a) and the Royal Liverpool Children's Hospital at Alder Hey (Parliament. House of Commons. 2001b). As a result, in the same year as the public inquiry reports were published following these incidents, a general NHS circular was issued to staff outlining 'good practice' when requesting consent, along with seven accompanying documents (NHS Executive, 2001). These documents provided guidance and pre-drafted forms for NHS staff to use when requesting consent from specific patient groups (*e.g*. children, older people and people with learning disabilities), in an attempt to have a more unified

approach to consent across the health service. It is noteworthy that all of the documents mentioned above omit any information or discussion about the issue of consent in relation to population-wide prevention-based interventions, the implication being that such programmes are either not of sufficient concern or, perhaps more likely, it being thought that processes used for individual treatment can be extrapolated and applied en masse, with no further consideration of appropriateness at a population level needed. Moreover, this point is further evidenced as a result of a Freedom of Information request that was made as part of the background work for this thesis (Coundley, 2015). Public Health England was asked to provide copies of documents detailing conversations or meetings during which the change in consent for dental public health programmes was discussed. In response to this request, the letter received from Public Health England stated that

'an issue [was] raised by North West SHA where a parent complained to the PCT [primary care trust] and the BDA [British Dental Association]; that caused the Chief Dental Officer to consider the guidance issued in 1992 by the NHS Management Executive. In light of the complaint, the guidance was refreshed so that it was compliant with the Health Circular on consent and published on the DH [Department of Health] website with copies to commissioners'. (Coundley, 2015)

A web link to the circular mentioned by Coundley was also included in the response letter. This circular, which was used as the reference point for this decision about consent for dental public health programmes, is the same one that was developed and issued after the consent scandals at Bristol Royal Infirmary and the Royal Liverpool Children's Hospital at Alder Hey mentioned above, which involved clinical health care (NHS Executive, 2001). Therefore, dental public health programmes are now being required to use and comply with consent arrangements developed for individual clinical practice, with no consideration for their appropriateness at a population level, which, as noted in the section above, originated from research. This use of individualised clinical models of care applied to public health programmes

demonstrates in practice the confusion that exists around the foundation of what is public health, which is outlined using theories from Prainsack and Buyx (2015) and Verweij and Dawson (2009) earlier in this chapter.

1.4.c Consent processes used in dental public health programmes

Prior to the public and professional concerns raised when details of the Bristol Royal Infirmary and the Royal Liverpool Children's Hospital at Alder Hey cases above were made known, dental inspections had historically developed arrangements that allowed a child to be examined '…*provided the parents had not refused*' (Great Britain. Education Act, 1944). This opt-out form of consent is often referred to within the dental profession as 'negative consent'. This arrangement was first included within the 1944 Education Act and was then restated in 1996 in the Education Reform Act (Great Britain, 1996). As a result of the growing concern around consent procedures following these scandals, arrangements were reviewed by the Chief Dental Officer for England, and in Wales the Department of Health lawyers reviewed them against both the Education Reform Act (1996) and more recent case law on consent (National Public Health Service for Wales, 2010). The advice was that it was no longer appropriate to use negative consent and that positive (*i.e.* opt-in) parental consent should be sought from parents prior to the inclusion of young children. The assumption from this is that, if in the future a problem occurred and legal action was taken, it would be difficult to prove that consent had been obtained without proof, solely on the basis that a letter had been sent to the child's parents and no objection had been received (O'Carolan, 2006).

It would appear that in this instance the Department of Health has adopted a 'legally conservative' position with regard to consent, wherein despite the fact that a signed consent form is not a requirement of the law (Lynch, 2011) proof of consent in this format would help to deter or halt any potential claims of unlawful intervention or treatment, thus considerably minimising the department's exposure to expensive litigation (Furedi and Bristow, 2012). Consent is deemed lawful not on the basis of a

consent form but on the basis that the person concerned meets specific criteria for mental capacity and competency, and from a legal standpoint verbal consent is as valid as written, but is crucially difficult to prove (Lynch, 2011). It appears that the Department of Health has adopted a position wherein competency and capacity on the part of the individual to provide consent are not sufficient to access care, but the ability to provide a signed consent form is, whether or not this demonstrates a person's competency and capacity in this regard. The actual reason for the department's stance is unknown; however, complaints to the General Dental Council against dentists and DCPs increased by 110% between 2010 and 2014 (Moyes, 2014), mirroring a general upward trend in litigation involving health care in the UK population (Furedi and Bristow, 2012) and revealing a potential mistrust of dental personnel (Costley and Fawcett, 2010).

At the point at which the 2006 Department of Health guidance was issued, many PCSDS withdrew their annual dental inspection programmes in order to review the organisation and delivery of future programmes, moving from screening to surveillance as mentioned earlier (O'Carolan, 2008) This change to the consent processes, *i.e*. from negative opt-out to positive opt-in consent, ultimately saw the end of wide-scale annual school dental examinations, with only a few isolated programmes continuing. Interestingly, at the same time as the consent processes for dental epidemiology were changed, the government introduced the National Child Measurement Programme (NCMP), which operates an opt-out negative consent process (Information Centre for Health and Social Care [ICHSC], 2013). This negative consent was in opposition to the positive consent advocated in the Department of Health's 2006 guidance for DPH, with the first statistics for the NCMP being produced concurrently in 2006/7 (ICHSC, 2013). In spite of their juxtaposed consent approaches, there are a number of similarities between these two public health programmes: both are carried out collectively in a school setting; both include young children in their first year of school, *i.e.* at age five; both record and monitor health trends over time, *i.e.* dental caries and obesity; both involve some, albeit limited,

physical contact between the child and the health professional; both involve the participation of individual children; and both require parental consent (Public Health England, 2015b). This highlights an absence of consistency in practice that further indicates a lack of understanding about public health and consent.

In consequence, it is difficult to understand what the justification for the different approaches to parental consent that have been adopted may be. The timings of the change to consent for dental epidemiology programmes and the introduction of the NCMP are analogous. The wider social context within which these were introduced had been shaped by two high profile cases involving consent with regard to health (Bristol Royal Infirmary and Royal Liverpool Children's Hospital at Alder Hey). As such, it would seem that this cannot be the only reason for the more cautious approach to consent taken by the Department of Health and the dental community.

The dental surveys that continued post 2006 experienced a dramatic reduction in the number of participants, as witnessed by Monaghan and Morgan (2010) and by Gizzi (2007). This reduction appears to be due to the change in consent processes and it has been greater in families on lower incomes. For example, when the 2007/8 epidemiological survey was conducted (the first to use positive opt-in consent as a result of the Department of Health's guidance) there was a 35% reduction in the consent responses compared with the previous survey in 2005/6 (Davies *et al.*, 2011). Positive consent response rates varied across the country, with some areas, including Rushcliffe in the East Midlands, receiving 96.5% returns, compared with 31.7% in Bath and North East Somerset (Davies *et al.*, 2011). Indeed, the Acting Chief Dental Officer for Northern Ireland was so concerned about the drop in participation that he issued a statement outlining possible alternative arrangements for gaining consent that met the positive consent criteria of the new guidance (O'Carolan, 2006). He proposed obtaining positive opt-in consent at the beginning of the school year, *i.e.* when the child first starts school, followed up by a reminder to parents near to the time of the inspection, thus giving them the opportunity to withdraw their consent if they choose.

This process is effectively one of positive consent followed by negative consent, which would meet the requirements of the Department of Health (2006). It would also fulfil the condition that consent is not a one-off action but an ongoing process (Lynch, 2011). In this case, the decision to consent is reviewed and either reaffirmed or declined by parents shortly before the inspection takes place. This sequence also allows parents a time of reflection and further deliberation on their decision, which David Corless-Smith, writing in *Dental Law and Ethics* (Lambden, 2002), suggests is an element of competent decision making. However, what is not clear from the statement by O'Carolan (2006) is the exact process for gaining consent in the first instance, *i.e.* is this discussed in person with parents as part of the usual pre-school process or is the usual system for dental consent followed, with letters being sent to parents? If the latter process is adopted it is difficult to see how O'Carolan's (2006) proposal will improve the current situation of a high number of non-responders.

Additionally, in this 2006 statement O'Carolan expressly acknowledges the effect of the changes from opt-out to opt-in consent on participation levels:

'…positive consent is required for examinations, but we are aware that this has had an adverse impact on the uptake of school dental screening, particularly amongst those groups with the most need'. (p.1)

Equally, inspection programmes were also forced to recognise the impact of these changes on the data collected, with the national protocol (The Dental Observatory, 2012, p.7) stating:

'*There is potential for consent bias to impact upon the validity of the result.'*

Furthermore, in a report by Monaghan and Morgan (2010, p.7) for the Welsh Assembly it was stated:

'*It is not possible to estimate with accuracy what the reported incidence of dental caries would have been in 2007/8 if the old consent arrangements had been used. There is no information available on the actual condition of the teeth of children*

not examined. The best information available to us at the moment is the 2005/6 data'

.

Moreover, dental targets for 2020 set by the Welsh Assembly prior to the Department of Health's 2006 guidance on consent appeared to have been met as early as 2007/8, well ahead of schedule (National Public Health Service for Wales, 2010). This was due to the reported reduction in the levels of decay in children's teeth, despite these targets being challenging when they were first announced. It is likely that this apparent reduction is due to the consent bias mentioned in the national protocol (The Dental Observatory, 2012) and the impact of the changes on groups in most need, as highlighted by the Acting Chief Dental Officer for Northern Ireland, O'Carolan (2006). It would appear that the results of recent dental inspection programmes significantly under-report the amount of dental caries present in the population of five-year-olds and, as such, render the surveillance programme ineffective. Interestingly, under the rules of devolution the Scottish government were not required to adhere to the Department of Health's guidance and, as a result, the consent protocols that allow opt-out negative consent continue to be implemented (Davis *et al.*, 2011). Indeed, the Scottish Dental Epidemiology Coordinating Committee (2011) produced a paper that reaffirmed section 57(2) of the Education (Scotland) Act 1980, which states that the

'*Secretary of State has a duty to secure the proper dental inspection of pupils and that this means that an education authority may require "the parent of any pupil in attendance at any school under their management to submit the pupil for … dental inspection".'*

This Act of Scottish law clearly outlines the responsibility of parents in this process and meets the requirements of Article 3 of the UNCRC, as quoted in Section 1.3.c of this chapter, in a way that the changes made in the rest of the UK do not.

The Scottish Dental Epidemiology Coordinating Committee (2011, p.1) paper went on to say:

'…the NHS Scotland Act 1978 places a duty on the Secretary of State (for health) to provide for the dental inspection, at appropriate intervals, of pupils in attendance at any school under the management of an education authority unless a parent gives notice to the authority that positive consent was not required stating that they object to the child's participation in the dental inspection. Hence, positive consent is not required.'

From the government publications mentioned and the anecdotal evidence of colleagues (Gizzi 2014), it can be seen that the possible passivity of parents meant that under the old system, in England, only a few parents actively opted-out of the programme, resulting in wide-scale participation and coverage. This same passivity now seems to be having the opposite effect, with a reduced number of parents actively opting in; this has resulted in flawed data that does not capture the true extent of the dental caries present in the mouths of primary school-age children.

The concerns outlined above about the social patterning of low levels of participation in dental epidemiological surveys and surveillance programmes can also be applied to fluoride varnish programmes, which use the same letter-based consent processes. Large numbers of children from the most needy communities could be excluded from these potentially disease-preventing programmes, resulting in the likelihood of dental inequalities as a result of the 'inverse care law', as seen in other areas of health care provision (Watt, 2002; Hart, 1971). Indeed, evidence from the fluoride programme delivered in Enfield and Haringey that was mentioned earlier appears to support this view, with commissioners now questioning the low uptake (Kubiangha, 2015). So, although both opt-in and opt-out consent are legal and appear to provide parents with the opportunity to exercise their autonomy, the new process has moved responsibility completely on to the individual, *i.e.* the parents, with the State taking no responsibility for child oral health other than for service provision, and even this is sometimes dependent on sufficient numbers of individuals asking for it.

1.4.d The legal right to information

If individuals are to take responsibility for themselves, in the way the State would wish, they need to be able to exercise their autonomy. The 'right' to self-determination is often seen as a modern concept that is implemented through legalistic and formal routes. However, there are no specific legal cases in which the law on behalf of the State has intervened to protect the rights of an individual in a matter of dental public health. Therefore, the legalities of consent in this regard are open to some interpretation and, as with the NHS policies discussed above, much of our understanding has been 'borrowed' from clinical care and the litigation surrounding it.

The growing status of an individual's 'right' to self-determination as applied to health care in the latter half of the 20th century was confirmed by the case of *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985]*. In this case, an attempt was made by the legal profession in the UK to attach weight to a patient's right to self-determination and Lord Scarman argued that

'*a doctor's duty to supply information on risks and alternatives stems from the patient's right.*'

The test advocated in this case is sometimes called the 'prudent patient test', a phrase borrowed from a leading case earlier in the USA (*Canterbury v Spence [1972]*). However, despite acknowledging the patient's right to information, the UK judges in the Sidaway case (1985) did not go as far as the US courts in *Canterbury v Spence [1972]*; they recommended that an older test case drawn from UK courts was more appropriate (*Bolam v Friern Hospital Management Committee [1957]*). This case set the parameters for the 'Bolam test', which determines the amount of information a doctor has a duty to disclose. The Bolam test was developed in 1957 after a court concluded that a doctor cannot be held negligent if

'*he has acted in accordance with a practice accepted as proper by a responsible body of medical men*'.

Therefore, the decision by the judges in the 1985 Sidaway case to use the 1957 Bolam test meant that any headway on shared decision making or a patient's 'right' to information was legally hindered. However, in the years between the Sidaway case and today, general medical opinion has swung in favour of routinely providing patients with information so that they are able to make an autonomous 'informed choice' about their care (Department of Health, 2013). Indeed, despite this practice quietly becoming routine in these intervening years, it has only very recently been made part of UK law as a result of *Montgomery v Lanarkshire Health Board [2015]*, a case in which the court awarded damages after concluding that the patient (a labouring mother) had not been given all the information needed to make an 'informed decision' before providing her consent to the vaginal delivery recommended to her. This decision confirms that it is no longer legally acceptable for health professionals to act paternalistically by deciding on behalf of the patient how much and what information they are privy to, as was the previous legal position permitted by the Bolam test (1957), and this ultimately places the responsibility for the final decision on the individual patient. This demonstrates that the law related to consent has largely been developed in the context of considering clinical care for individuals, with the apparently simple premise that

'*a patient has the right in law to give or withhold consent to medical examination or treatment'* (Lynch, 2011, p.1).

This statement by Lynch (2011) uses the term 'patient', but it can equally be applied to the dental public health programmes outlined above, *i.e*. a child who is examined as part of a surveillance programme, or receives treatment administered in the context of preventive programmes, such as fluoride varnish. The complexity of providing information that individuals can understand and obtaining their consent

decision is significantly increased when this is a requirement of population-wide programmes such as these.

1.4.e Assault and battery

Like other health care professionals, dentists and DCPs, such as dental nurses, can be held accountable for their action under civil or criminal law in the UK (Lambden, 2002). The civil courts deal with matters of negligence, battery and breach of statutory duty. Negligence includes the breach of the duty to care (Lynch, 2011), and in relation to consent can be as a result of failure to obtain consent or failure to warn of potential risks or provide adequate information (*Border v Lewisham and Greenwich NHS Trust [2015]*). Dentists and DCPs are required by the General Dental Council to gain consent prior to examination or treatment (GDC, 2005, p.3). This is asserted by the GDC, based on the principle that it

'*…reflects the right of patients to decide what happens to their own bodies, and is an essential part of good practice'*.

If no consent has been obtained, the dentist or dental care professional could be liable for a charge of battery (Lambden, 2002). If the person being examined or treated so desires (usually if injury has occurred), they may make a claim via the civil courts for compensation. Criminal courts deal with situations that give rise to criminal charges in relation to health care, for example where deliberate harm has been caused to a patient, such as in the case of *Appleton v Garrett [1997]* (cited in Lambden, 2002, p.77) where extensive and unnecessary dental treatment was carried out on healthy teeth for financial gain. Criminal charges can be brought for either assault or battery if health professionals treat without consent a patient who then wishes to use the law to hold them to account if the consequences are considered 'grave' (Lynch, 2011). Assault and battery are both common law and statutory offences (Hope, Savulescu and Hendrick, 2008). In the Criminal Justice Act 1988 (Great Britain, 1988), assault is classed as

'any act by which a person intentionally or recklessly causes another person to apprehend immediate and unlawful violence'.

Therefore, assault can be thought of as the fear of being struck, for example if a dentist or DCP lunges towards a person while holding a dental instrument. In the same Act, battery is classed as

'any act by which a person intentionally or recklessly inflicts unlawful personal violence upon another person'.

Therefore, battery can be thought of as unlawful physical contact between the dentist or DCP and the person, *e.g.* when a dental instrument physically touches the person's mouth without consent.

There are three possible defences to a charge of assault or battery – self-defence, accident and consent – thus, where consent has been obtained, this is a permitted defence in law (Lynch, 2011). The exception to this is when action is considered necessary, *e.g*. in the case of cardio-pulmonary resuscitation. Consent must be provided either verbally or in a written format. The completion of a consent form itself is not a legal necessity (Lynch, 2011).

The use of a consent form is commonplace in the delivery of (oral) health care and the Department of Health has produced guidance (Department of Health, 2009; 2005b). The purpose of obtaining a signed consent form is twofold. Firstly, it provides a mechanism for ensuring that consent has been given and communicates this to others. Secondly, perhaps more importantly with regard to the law, it provides evidence that consent has been obtained (Hope, Savulescu and Hendrick, 2008). Consent can be rescinded by the individual at any point, which means that at each contact with a dental health professional the issue of consent needs to be revisited to make sure that any decision made by the individual is current. Equally, a person's capacity to provide consent may change over time and therefore a decision made previously may change (Lynch, 2011). In addition to this, new information may come

to light that may not have been available when the existing decision to provide or refuse consent was given. In this situation, the individual will need to be made aware of this information in order to make an informed decision based on knowledge and understanding of all the information available. Interestingly, as part of the Scottish dental public health programme, Childsmile, this need for consent to be an ongoing process that is periodically revisited appears to have been overlooked. The information for professionals that is provided on the Childsmile website states that consent that has been obtained for children in nursery can be used without review once the child enters primary school (Childsmile, 2015). Only persons with parental responsibility can provide consent for a child. Mothers have automatic parental responsibility unless the court has deemed otherwise. Fathers have parental responsibility if they are married to the mother at the time the child is conceived, or if they marry at any point afterwards. Unmarried fathers have parental responsibility if they are named on the birth certificate or have formally acquired responsibility at a subsequent point. Legally appointed guardians can also have parental responsibility (GOV.UK, 2016). The dental public health activities of surveillance and fluoride varnish programmes have adopted a consent process that does not consider who may or may not be providing consent and whether they have parental responsibility to legally do so. Again, this is another problem of using consent arrangements intended for individual health care in a public health context where it is considerably more difficult to consider parental responsibility.

1.4.f The Mental Capacity Act (2005)

The law relating to decision-making capacity for persons over the age of 16 is the Mental Capacity Act 2005 (MCA), and because parents are the substitute decision maker for their young children in regard to DPH programmes, it is this law that applies. This Act has been in force since 2007 and it applies specifically to England and Wales (Lynch, 2011). DCPs are legally required to have regard to the MCA (2005) when acting in relation to a person who lacks capacity. The MCA's test for capacity has two elements. The first of these is a diagnostic test, whereby a person is assessed as

'*…unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'* (Great Britain, 2005)

If the diagnostic test is satisfied then a test of functionality is applied, which requires a person to be able:

- *'to understand the information relevant to the decision*
- *to retain that information*
- *to use or weigh up that information as part of the process of making the decision, or*
- *to communicate his decision (whether by talking, using sign language or any other means)'.*

Within this Act there is a presumption of capacity and this is required to be rebutted if a person is considered to lack capacity and fails to satisfy the first test (diagnostic) or both tests (diagnostic and functionality).

In terms of the consent process for DPH programmes, there is no reason why those implementing these programmes should suspect that parents do not have capacity to make a decision and therefore provide or refuse consent on behalf of their children but, crucially, the current process does not allow for any form of judgement to be made about whether a person's capacity should be investigated further and then

facilitated if necessary. However, it is unrealistic to expect that those implementing population-wide dental public health programmes could, or should, be able to make such an assessment or, indeed, facilitate individual capacity if required. This highlights a deficiency in the form of a legal 'grey area' and the inappropriateness of using individual consent processes for population-wide programmes. Furthermore, the MCA (2005) criteria demonstrate that a medico-legally constructed version of capacity with regard to autonomous decision making is narrow, with the primary concern being a person's cognitive functional ability to make a decision. However, from an ethical perspective, to be an autonomous person one should have not just the capacity to make a decision but also the ability to enact it and have control over one's life. Many of the barriers to an autonomous life, *e.g.* culture, religion and socio-economic status, cannot be identified by the legal application of the MCA (Woolley, 2005). Therefore, a person's ability to have capacity and make a decision should not be conflated with personal autonomy, which is a broader concept. It is this wider, more complex notion of autonomy that will be discussed in the next chapter (Theory).

1.4.g. Validity of consent

If consent is to be considered 'valid' it must be given voluntarily, without duress, and free from pressure or undue influence (Hope, Savulescu and Hendrick, 2008). The person providing their consent should also have capacity to do so and be in possession of all relevant information, for example the risks and benefits of the proposed action and the potential alternatives (NHS, NDa). If these conditions cannot be met, any consent provided will be invalid (Lynch, 2011). The wishes of a person's family or the pressure exerted by them, or a professional ought not to override the wishes of the person being asked for their consent, despite the often well-meaning intentions of those involved. For example, the providers of DPH programmes will be immersed in a professional culture in which the improvement of oral health is of primary concern and the clinical evidence points towards the use of fluoride as a safe and effective way to address this (Marinho, *et al*., 2003). There may be a temptation on the part of

the dentist or DCP to exert their influence to persuade parents to consent by providing information about only the benefits of participation and not any of the potential risks (because in their view these are extremely minimal) or, indeed, the alternatives. Conduct of this type would invalidate any consent provided by parents (General Dental Council, 2005b). Indeed, in 2015, UK courts found consent to be invalid in similar circumstances and compensation was awarded to the patient who had not been provided with sufficient information (*Montgomery v Lanarkshire Health Board [2015]*).

Consent can also be rendered invalid is if it is gained via coercive methods (Lynch, 2011). Coercive methods to gain consent may include offering the person something they want in return for their agreement. A closed environment such as a prison or a nursing home is a more conducive location for this type of transaction due to the power dynamic between the professional and the person being asked for consent (Lynch, 2011). In dental public health programmes it is much less likely that coercion can occur due to the relative distance between dental professional and parent, who often never meet in person.

In addition to the points above, consent is also invalid if the person giving their consent does not do so actively but merely acquiesces to requests for their permission. Acquiescence, or assent, is where a person is submissive to another's request, or provides their agreement when they do not fully know or have not considered their view on what the intervention entails (Lynch, 2011). However, the term 'assent' is not well defined enough for it to be seen as distinct from 'consent' in everyday use, and the two are often used synonymously. Moreover, the definition itself is contested. For example, Cheah and Parker (2014) define child assent as involving the child in decision making but not obtaining the child's permission to proceed, whereas some definitions recognise that both assent and consent connote a degree of agreement or permission (Oxford Dictionaries, 2015b). More specifically, it has been suggested by some that assent is the agreement to participate in an action

by those not able to provide consent that meets the legally defined criteria outlined above; therefore, the only practical difference between the two is that consent holds legal weight whereas assent does not (Fisher, 2013). The current process for requesting consent from parents for dental public health programmes make this scenario, *i.e*. one of acquiescence or assent, a potentially more plausible one than that of coercion, if one considers the power dynamics between the dental profession, schools and parents (Tickle *et al.*, 2006). This scenario is also potentially facilitated by the close relationship that many parents have with their child's primary school (Glenny *et al.*, 2013).

The medical profession is legally bound to seek consent from parents prior to examination or treatment until a child reaches 16 years old (NHS, NDa). Some children under this age can be deemed competent to provide or decline consent; this is known as 'Gillick competence' (*Gillick v West Norfolk and Wisbech AHA [1986]*). In 2006 the Department of Health specifically stated that Gillick competence should be used for dental treatment with older children (Morgan and Monaghan, 2010), but the very young age of the children targeted by epidemiological surveys and fluoride varnish programmes – typically around five years old – means that parents are assumed to be the best persons to decide on their behalf because children at this age will not be Gillick competent. Parental proxy decision makers are required to balance the best interests of the child with any other competing interests, to maximise benefits and minimise harms. Family values, beliefs and expectations shaped to some extent by the wider community will influence parents' decision making and should not be ignored, but the primary concern is the best interests of a child, although what is in the child's best interest is sometimes difficult to differentiate from these other considerations. The younger the child, the more involvement the parent has in the decision-making process. In DPH programmes, the parents have a full decision-making role due to the age of the child, but a parent's decision to consent can be overruled by the child on the day of participation if he or she is uncooperative. In this scenario, the clinician would not proceed and the parents would be informed

(Kubiangha, 2015). However, children are not in a position to overrule a parent's refusal to consent. The notion that parents should make decisions on behalf of their child is evident in the Children Act 1989 (Great Britain, 1989), which sets out the guiding principles accordingly, for England. This is also supplemented by the Children Act 2004 (Great Britain, 2004).

1.4.h Informed consent

Directly related to the legal concept of 'valid consent' is that of 'informed consent' based on the notion of making an informed choice (Hope, Savulescu and Hendrick, 2008). If valid consent has been obtained a patient or person cannot later claim trespass of person or battery. If insufficient information about the risks, benefits or alternatives of a particular intervention is given, any decision to withhold or give consent cannot be deemed to be 'informed'. This may constitute a breach of 'a duty of care' or negligence, as in the case of *Montgomery v Lanarkshire Health Board [2015]*, and a claim for damages can be made (Lynch, 2011). In 2011, The National Health Service Litigation Authority reported that financial payouts had trebled in the previous decade and stood at £911 million in 2010/11, of which £863 million was paid in connection with negligence claims. So, although it seems unlikely that all of these claims for negligence were related to consent, the figures do provide an indication of the population's growing ease with having recourse to legal action, specifically negligence claims.

As with other areas of consent, disagreement exists over what constitutes an 'informed choice' and how this buttresses consent. Lidz *et al.* (1984, p.23) state that

'…for consent to be valid the doctor [or dentist] discloses information to a patient who is competent, the patient understands the information and voluntarily makes a decision.'

This is a similar view to that taken by the GDC (2005a) and the GMC (2013). Others, such as Faden and Beauchamp (1986), cited in Hope, Savulescu and Hendrick's 2008

text entitled *Medical Ethics and Law*, which is used as part of the core medical curriculum in the UK, have argued that this view is too simple and that too much emphasis is being placed on the provision of information with little regard being given to the patient's or person's understanding. Indeed, Manson and O'Neill make a similar point in their 2007 book, *Rethinking Informed Consent in Bioethics*, in which they discuss in detail the complexities of communication with regard to consent. However, despite the practical difficulties of ensuring that decision makers are not only 'informed' but also understand the information given, the language of requesting and receiving 'informed consent' is common to both research and health care.

1.5 Conclusion

This chapter provides background information on the subject of consent in relation to dental public health programmes in the UK. This area of study is set within a complex context that spans the disparate disciplines of dentistry and ethics, as well as some elements of the law – specifically negligence. The points of relevance and interest to this thesis are small niche areas within these umbrella subjects, *i.e.* those of dental public health and autonomy (or consent in a practical sense). These two subjects become further specified and refined as the thesis progresses, and the information in this chapter forms the backdrop for subsequent chapters, where related theoretical points are explored in more detail and practical research techniques and findings are discussed.

However, before further research is carried out it is important to understand the political climate surrounding consent and dental public health, including how these two things are becoming ever more individualised. If the programmes identified above, *i.e.* epidemiological surveys and fluoride varnish schemes, are deemed 'dental public health' by the Department of Health and as confirmed by the exploration of this as a concept at the start of this chapter, consent arrangements that reflect a population approach should be considered. This chapter has described both the inadequacy of the current arrangements that mimic consent for clinical medicine and

how these have been implemented with what appears to be little thought for the public health nature of the activities. Equally, the logistics of how positive opt-in consent can be facilitated do not appear to have been considered, resulting in a process that fails many of the legal and non-legal criteria for valid and informed consent. The emphasis placed on providing written information and receiving a parent's signature to ensure a child's participation seems disproportionate, given that this is no indication of validity or the absence of coercion. Adopting an individual (medical model) approach to consent for epidemiological programmes has had a dramatic and detrimental impact on the data collected and, more importantly, on the children who would have benefitted from the resulting better planned services based on robust data. The transference of the consent process (with all its inherent flaws) from long-standing epidemiology surveys to the more recent fluoride varnish programmes has the potential to increase dental inequalities further. To date, there appears to be no dental literature from the UK that investigates parents' decision-making processes for dental public health programmes, although some research has been undertaken into the impact of changes to consent processes (Davies *et al.*, 2014). As such, investigating from the parents' perspective the enablers and barriers they face and how consent decisions can be facilitated is of importance. This information is used to underpin the recommendations made at the end of the thesis to help minimise passive exclusion due to low consent response rates. It is, therefore, a legitimate area of research that adds to the body of knowledge in this field. Yet, as demonstrated here, consent has a legal dimension to it and, although this will not be investigated in the remainder of this thesis, any recommendations made as a result of this research will need to be mindful of this important aspect.

Chapter 2 – Theoretical and philosophical underpinning of autonomy and consent for treatment

2.1 Introduction

In this chapter I explain the philosophical ideas that underpin the concept of autonomy, specifically as it relates to consent and how it is understood in Western societies. I make use of the ideas of Immanuel Kant (1785) and John Stewart Mill (1859), insofar as they are relevant to autonomy and consent. I explore how particular readings of these two philosophies have become merged to the point at which complete independence in decision making is seen as the ideal and anything other than this in the form of support from health professionals or the State is viewed negatively and classed as paternalism. I argue that this stance is unrealistic and impoverishes personal autonomy. I also argue that the current arrangement for parents to exercise their autonomy via the consent process is inadequate, and in fact *dis*ables autonomy rather than enabling it. The information and arguments in this chapter are presented in the conventional way for philosophical discourse, where strong statements are made initially and subsequently explored.

I reject the dominant concept of autonomy that is a hybrid of Kant's ideas about rationality and a narrow Millian stance of non-interference. My rejection has two motives, the first is that the current conception of autonomy is founded on an idea of reason and rationality that assumes the decision to provide or refuse consent is made in individual isolation, where a parent transcends emotion and their lived experience to review and weigh up only objective facts. This view of decision making is highly intellectualised and bears little resemblance to how decisions are made in real life. My second motive is that the process used to request parental consent comes from a professional stance of 'non-interference' that promotes the sovereignty of the individual to the point of fetishism. The widespread and unquestioned faith in these two intertwined concepts is the product, I believe, of the increasing value placed on individualism over the past 150 years. As a result, any form of assistance from

professionals or the State is left open to accusations of negative paternalism. I propose that a pluralistic approach that encompasses individual decision making within a wider societal structure of support will enable autonomy to flourish, with autonomy and paternalism viewed not as starkly oppositional but as complementary. Society is both care-giving and care-receiving, with people experiencing different levels of dependency, on each other and on the State, at different times in their lives (Nussbaum, 2003).

In place of the hybrid account of autonomy I introduce relational autonomy, which is an emerging area of ethical study. This has two major elements: procedural and substantive. However, because this is an embryonic field of study, and because philosophy thrives on debate, there is no widely agreed account of either of these concepts. Therefore, my understanding of procedural autonomy, and the way in which I will use it within this chapter, is that it recognises that authentic autonomy can be realised only if individuals are free from oppressive socialisation. Substantive autonomy is understood to mean distal influences on autonomy and decision making that come from the wider determinants of health. This, then, makes substantive autonomy a rich area to be explored for the purposes of public health, which aims to mitigate structural inequalities that shape a person's ability to live a healthy life, including the ability to *act* according to one's own desires. It is for these reasons – the relevance to public health and the underdevelopment of this concept – that I have used events from the last 150 years to demonstrate how substantive influences impact the choices available to everyday people, including how substantive paternalism can, on occasion, enhance individual autonomy.

2.2 Moral philosophy

2.2.a Ethical theory: consequentialism and deontology

Until the Enlightenment period of the 18th century, virtue ethics, the moral code developed by Aristotle (384–233 BCE), was the dominant approach to moral philosophy (Hursthouse and Pettigrove, 2016). Virtue ethics are concerned with the way in which a person should behave to be considered 'good' or virtuous, as well as being about what type of society and social norms would most likely lead to human flourishing and the ability of individuals to lead 'a good life'. However, since the 1800s two additional approaches to normative ethics have appeared, namely deontology (Kant, 1785), which emphasises duties or rules, and consequentialism (Darwall, 2003), which emphasises the consequence of one's actions. The rise of these two approaches led to virtue ethics being eclipsed in the 19th century. The increasing recognition of these two action-based ethical theories coincides with the industrial revolution in the UK, when a person's ability to labour became a defining feature of self-identity, and therefore of individual self-expression or, as sociologist Zygmunt Bauman puts it, 'individualisation of yore' (Bauman, 2001). As I am concerned not with what it is to be a virtuous person but with how and whether personal autonomy can be exercised in reality, virtue ethics will not be explore further in this thesis.

2.2.b Deontology

Deontology and consequentialism both outline what we ought to do in contrast to what type of person we should be, but here any obvious similarity between the two ends. Deontology is a normative theory that stipulates which choices are morally required, forbidden or permitted (Alexander and Moore, 2012). For deontologists, what makes an act morally right is its conformity with a moral norm. Moral norms are to be followed by each moral agent. Therefore, what is morally 'right' takes priority over what may be considered 'good' (Alexander and Moore, 2012). For example, in

the UK it has become the norm for consent to be sought by dental personnel (acting in this case as the moral agent) from parents using a written format. Therefore, seeking individual consent is considered morally 'right' because it conforms with the norm of seeking a decision in advance from parents. Deontology can be further subdivided into agent-centred and person-centred theories. At the heart of the agent-centred theory is the notion of agency and the idea that morality is personal. The obligation is not to focus on what an action may or may not cause other agents to do, but to keep one's own agency free from moral taint. This is a highly individualised theory that focuses on the self. A deontologist is a person who is concerned only with following the moral norms of society in order to be free from moral taint. The 'Bolam test' mentioned in Chapter 1 (Background) is a good example of this (*Bolam v Friern Hospital Management Committee [1957]*). Here, the doctor was considered not to be negligent or, in deontological terms, he was 'free from moral taint' because he acted in accordance with the norms of what others in his position would do, *i.e.* the moral norms set by the medical society at the time. Conversely, a person-centred theory, which is based on rights, posits that a person should not be used as a means for producing good consequences without their consent, *i.e.* used instrumentally (Alexander and Moore, 2012). For example, a person-centred deontologist would argue that a dental epidemiological survey that produced data but no tangible good for those taking part was morally wrong, unless participants were fully aware and agreed to take part knowing that the sole intended outcome was the production of data.

2.2.c Immanuel Kant's theory of deontology

The most well-known philosopher linked to deontology is Immanuel Kant, the author of *The Critique of Pure Reason* (1785). In this text he described how reason is the highest faculty of the human subject and that to which all other faculties are subordinate. Kant held the view that all people are fundamentally rational and that actions based on rationality are ultimately good. According to Kant, a reasonable

person is one in whom the cognitive faculty of understanding can act independently from the faculty of sensibility (or experience) and, in his view, it is this ability that is the foundation for rational thought. Kant's ideas encompassing the 'categorical imperative' (Kant, 1785) continue to influence ethical actions today, including informing international declarations and laws and most codes of conduct for dental and medical personnel that are concerned with lay person consent (Garbutt and Davies, 2016; Schonfeld and Thompson, 2014). Simply put, the 'categorical imperative' states that we must (*i.e.* it is imperative to) act in accordance with morality without regard for the consequences (*i.e.* categorically) because it is rational to do so if we wish to be moral (Johnson, 2008). For example, if respect for lay person autonomy is seen as a normative value, it can be considered imperative that we seek opt-in parental consent for DPH programmes, and that we must always (categorically) do this, regardless of whether the outcome is low participation levels (Davies *et al.*, 2014). This idea that what is right, or moral, for one is right for another has a naïve feel of natural fairness about it, and it has been widely accepted on these grounds. Kant believed that all people are rational agents and he insisted that everyone has the ability to reason, compare options and make a rational individual choice. Indeed, Bauman (2001, p.143) states that Kant believed if reason is used 'properly' everyone will arrive at a similar conclusion and therefore accept one 'best' way of living based on reason and rational choice.

I disagree with Kant on two counts. Firstly, the evidence I present in the following pages demonstrates that reason can be exercised and rational decisions made by individuals using *both* faculties of understanding and experience. Equally, a person's understanding is generally predicated on their previous experience, or the experience of those around them, but this does not make them irrational and their decisions unreasonable. Indeed, one could argue that this sort of decision making, *i.e.* one built on previous experience, is more 'fully informed' than one based purely on 'facts' provided by others and is, therefore, epistemically relational. The second reason for my objection to Kant's view of rationality is that he makes a large assumption in his

assertion that if reason is used 'properly' everyone will arrive at a similar conclusion and therefore accept one 'best' way of living. This takes no account of the different values that people hold. A person's values can stem from culture, age, gender, personal circumstance, religion and so on. Kant has assumed that decision makers are a homogenous group. This assumption implies that the best way of living is a life built of factual deliberation devoid of human emotion.

2.2.d Consequentialism

In contrast to deontology, consequentialists argue that a person's actions should be judged as morally right or wrong solely by the state of affairs, or consequences, they bring about. In this way of thinking, the 'good' is said to take priority over the 'right' (Alexander and Moore, 2012). The paradigm case of consequentialism is utilitarianism, whose most famous proponents are Jeremy Bentham and subsequently John Stewart Mill (Sinnott-Armstrong, 2011). The commonly known phrase associated with utilitarianism is '*the greatest happiness (or good) for the greatest number*', often referred to in ethics literature as the 'greatest happiness principle' (Darwall, 2003, p.33). This encapsulates classic utilitarianism (Sinnott-Armstrong, 2011). If we apply a consequentialist utilitarian approach to consent for dental public health, we can see that in the case of pre-2006 DPH programmes the 'good', *i.e.* high levels of participation, was put before what may be considered the moral norm (opt-in positive consent) and therefore the 'right'.

The concept of utilitarianism describes the normative theory that naturally appears to best 'fit' the aims of public health (although the focus on individual 'lifestyle choices' is increasing in public health practice and policy) (Exworthy *et al.,* 2012). The utilitarian approach that particular public health initiatives take can be justified, because the primary aim of public health work is to improve population health and, by doing so, limits on individual liberty may be imposed in order to achieve a common good (Dawson, 2011). Therefore, it may be thought of as 'right' to respect individual autonomy, but for utilitarians this can be sacrificed for the 'good' of the population's

health (*i.e.* the greatest number). For example, the individual autonomy of people living in an area with fluoridated water can be sacrificed for the improved oral health of the many who are thought will benefit if fluoridation is introduced (British Fluoridation Society, 2012).

Yet, in reality, the dominance of individual autonomy throughout health care has led to many public health programmes maintaining its privileged status, as we can see in the DPH programmes described in Chapter 1 (Background) (The Dental Observatory, 2012). An added advantage of maintaining the primacy of individual autonomy in (dental) public health practice is that any intervention can avoid the accusations of the 'nanny state', or more specifically paternalism, that litter the popular press (Jochelson, 2005). But, the implementation of a population-wide programme that requires individual autonomy and choice to be exercised is attempting to satisfy both masters, *i.e.* Kant's deontological approach and what is considered 'right' according to moral norms (opt-in parental consent) and Bentham's original principle of utility written in 1789, which as a consequentialist theory prioritises what is 'good' (mass participation to improve population health).

2.3 Old adversaries – paternalism and autonomy

Two key ethical concepts that can be applied within the theoretical framework of consequentialism are paternalism and autonomy. In ethics literature these two are commonly framed as being in conflict with each other (Dawson, 2011). Moreover, many ethical tensions in public health can be understood in terms of a conflict between using paternalistic means to promote public health and respecting individual autonomy, as described above (Jennings, 2009). This situation can be traced back to the establishment of modern medical ethics as the cornerstone of health care practice in the 20th century. The rise of liberal medical ethics in the latter half of the 20th century was a response, in part, to abuses of trust and power, such as the atrocities inflicted by Nazi doctors and the Tuskegee syphilis scandal (Tuskegee University, 2016), and was intended to end all forms of medical paternalism in favour of

individual autonomy (O'Neill, 2002). As a result, paternalism is often considered to be a *prima facie* wrong but, in public health ethics and if seen through the lens of utilitarianism, this is not necessarily the case.

2.3.a Paternalism

Paternalism can be viewed in different ways and the scholar Gerald Dworkin makes a distinction between various modes of paternalism, including hard and soft modes (Dworkin, 1988). A hard paternalist will justify intervention to prevent harm even if individuals know and understand the risk involved in their behaviour. Some State-sanctioned public health policies can be deemed hard paternalism, such as the legal enforcement of Statutory Instrument 176 on the wearing seatbelts in cars, because few people in the UK today can claim ignorance of the risks involved (Great Britain. The Motor Vehicles [Wearing of Seat Belts] Regulations, 1993). In contrast, a soft paternalist will justify intervention only if the person(s) at risk of harm are unaware of all relevant information when making their decision, *i.e.* risks as well as benefits, or if they lack capacity to make such a decision. Dworkin does not make any assumptions about how people acquire their 'knowledge and understanding' in the way that Kant does; he only states that the level of knowledge and understanding of risk that a person has can be used to determine whether hard or soft paternalistic action is justified.

I accept Dworkin's differentiation between hard and soft paternalism in theory although in reality this separation is not so clear cut. It represents another complex area when applied to dental public health because population knowledge and understanding is logistically impossible to measure. As a result, I suggest that some degree of paternalism is justified with regard to DPH programmes because of the vulnerability of children who are not able to decide for themselves. In this instance, the State may act 'in the best interest' of the child if the parent has failed to make an active decision (UN General Assembly, 1989). This is founded on the assumption that

not all people will have sufficient information or agency to make a decision based on knowledge and understanding of risk.

Public health activities that utilise paternalistic means are often set in opposition to activities that favour individual rights and autonomy, leading to an either/or situation. Sutrop (2011) states that this polarisation has occurred because of a narrow understanding of autonomy, which makes it difficult to see the often close relationship between these two concepts. Indeed, the academic ethicist Angus Dawson has argued that paternalism should not always be seen as a negative concept when applied to public health, stating that many (common) goods can be achieved only through paternalistic actions (Dawson, 2011), for example increasing taxes, and therefore potentially the price of drinks that contain a high amount of sugar, in an attempt to limit consumption and hence obesity (Taylor, 2017).

The fear of appearing paternalistic could be seen as a contributory reason for why parents' written signatures are required according to the Department of Health's guidance (2006) for dental public health programmes. A signature provides a level of evidence that parents have engaged with the information provided, resulting in action, *i.e*. a consent signature. As such, the knowledge criterion of paternalism has been satisfied. But a signature does not confirm understanding; therefore, we cannot say that Dworkin's (2014) criterion for justification has been fully met.

2.3.b Autonomy

Autonomy or 'self-rule' also stems from the consequentialist stable of philosophy and subsequent liberal ethical theory (Mill, 1859). The most notable of contemporary philosophers who subscribed to and promoted the principle of liberty was John Stuart Mill. In Mill's seminal work *On Liberty*, published in 1859, he suggested that individuals should be largely free to act autonomously according to their own will. However, Mill did make exception to this philosophy in that autonomy could, and should, be overruled if the person in question, or their actions, were likely to cause

harm to others. This is often referred to as the 'harm principle' (although Mill did not use this term [Dawson, 2016]).

Using this interpretation of Mill's theory, it could be argued that dental public health interventions aimed at young children may be justified under these terms with or without a parent's consent, but this would need to be balanced against any potential harm from the State interfering in family life. The child in these instances can be seen as the third party because they are not the decision marker. This appears to be the view taken by the authors of the UNCRC, which advocates that all adults, therefore including those who deliver dental public health, should act in the 'best interest' of the child, whether they have parental responsibility or not (UN General Assembly, 1989). In this case, a decision would need to be made about what constitutes 'best interest', *i.e.* whether it is served by participation in a disease-prevention programme without the active consent of parents.

2.3.c Rejection of Mill's theory as strongly individualist

The commonly understood reading of Mill's work as outlined above is, according to Dawson and Verweij (2008, p.193), a narrow interpretation of liberalism:

'Mill explicitly includes action to preserve public goods within the list of acceptable reasons to restrict liberty'.

The view that Mill is the champion of liberty, autonomy and minimal interference is based on specific isolated paragraphs in his work, for example:

'*The only freedom which deserves the name, is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it.'* (Mill, 1859, cited in Gray, 1991, p.17)

Dawson and Verweij's (2008) view is echoed by Onora O'Neill (2002), who is sceptical of the acceptance that individual autonomy based on the notion of non-interference is the central value of all medical ethics. She argues that a broader understanding of

'Millian liberalism', and of where it is permissible in some circumstances, should be used; this includes coercion, *i.e.* to *not* 'respect autonomy'. In the delivery of health services, which I argue is today based on a narrow liberal philosophy, the autonomous person free to make decisions about their own care is the current ideal (Department of Health, 2013). However, let us not forget that Mill was also a utilitarian and that much of his work is based on this broader philosophy. Conflict exists in Mill's work where he does not appear to reconcile these two views, *i.e*. utilitarianism and liberty, but one understanding is he believed that liberty was the best means to secure the long-term wellbeing of humanity, which he understood as utility (Freyenhagen, 2015). For example, in *On Liberty* Mill writes:

'*Mankind are greater gainers by suffering each other to live as seems to good themselves, than by compelling each to live as seems good to the rest*' (Mill, 1859, cited in Gray, 1991, p.17).

Here, through the use of the word 'mankind' we can see that Mill is taking a broader, more global approach than many of those who have interpreted his work. Nevertheless, it is his comments on personal autonomy that have had the biggest impact, certainly within the health sector, but also beyond to politics and the shape of social norms in Western societies, including the UK as a whole. Indeed, the gradual disregarding of the 'Bolam test' over the past 50 years (discussed in Chapter 1: Background), with priority now given to the views of the patient, is an example of the increasing value placed on individual choice and therefore autonomy (*Bolam v Friern Hospital Management Committee [1957]*). Furthermore, in a recent paper by Walter and Ross (2014, p.17) health professionals who had previously made decisions for patients were described as '*experts who provide information,'* that is the provision of medical facts to facilitate individual decision making by autonomous persons. However, challenges to the degree of autonomy that some individuals can exercise in particular circumstances has been debated in ethical and philosophical literature, such as in Brazier and Lobjoit's book *Protecting the Vulnerable* (1991) and in

Beauchamp and Childress' *Principles of Biomedical Ethics* (2009). There are many facets to this debate, but one of the central themes in health literature is an individual's capacity to comprehend information before making their own decisions. This is outlined in UK law via the Mental Capacity Act (MCA) (2005), under which the functionality test, as described in Chapter 1 (Background), perpetuates Kant's idea of rationality, *i.e.* one built on knowledge and the ability to compare options.

2.3.d A hybrid notion of autonomy

This concept of decision making is common in the health sector and it is considered an individual's 'right' to have clear information prior to giving their consent. Correspondingly, the health professionals have a duty to provide such information in a way that the individual can understand and assimilate (Lesser, 1991), therefore acting as the *'experts who provide information'* (Walter and Ross, 2014, p.17). However, even if we leave to one side those people who do not have sufficient capacity, as described in the Mental Capacity Act (2005), the way in which information is made available and conveyed by health professionals has come under criticism by some academics, most notably Manson and O'Neill in their book *Rethinking Informed Consent in Bioethics* (2007). Here, the authors use the 'conduit and container' metaphor to describe the often one-way transfer of information from the health professional, upon which the notion of 'informed consent' rests (Hope, Savulescu and Hendrick, 2008; Lambden, 2002; NHS Executive, 2001). This metaphor illustrates how parents are expected to 'receive' this information and make an objective decision based on facts, with little or no additional input from health professionals or anyone else. Parents are expected to be self-sufficient rational adults who make decisions accordingly, but fully informed consent of this type is not realistic or achievable. Thus, informed consent practised in this way can be seen as the functional implementation of a narrow reading of 'Millian' liberalism and its widely accepted central tenet of non-interference that prioritises individual rational autonomy as understood from a

Kantian perspective. The merging of these two concepts is summarised by Code (1991, pp.77-78):

'…the autonomous man is, and should be, self-sufficient, independent and self-reliant, a self-realising individual who directs his efforts toward maximises his personal gains. His independence is under constant threat from other (equally self-serving individuals): hence he devises rules to protect itself from intrusion. Talk of rights, rational self-interest, expediency, and efficiency permeates his moral, social and political discourse. In short, there has been a gradual alignment of autonomy with individualism.'

This right to information is met by dental professionals by sending information written in simple English and free from dental jargon to parents, along with the consent request. In addition to this, telephone numbers and email addresses are supplied for parents to use should they want further information. This process is outlined in Chapter 1 (Background) and is demonstrated in Figure 1.1. Providing written information in this way is currently considered 'good practice' within the NHS (NHS Executive, 2001).

It is clear that Kant's conception of reason from the 1800s still resonates today. It underpins the way in which legal and medical professions see an autonomous person operating via a cognitive linear process of decision making. I reject this notion of an autonomous person and autonomous choice. Making a decision for oneself is seldom an activity that is undertaken only by oneself and only after cool deliberation and the weighing up of all the objective facts, with disregard for one's previous experience. But, that does not mean that it is devoid of reason and is irrational. From the information above, I suggest that Kant's accepted view of a rational person has been overlaid with a narrow understanding of Mill's theory, produced approximately 100 years after Kant, and which focuses on non-interference as a requirement of individual autonomy. It is this hybrid made of two independent theories that has led

us to the notion of what it is to be autonomous today and which has resulted in the overemphasis on individual opt-in consent for DPH.

This amalgam of Kantian rationality and Millian non-interference can be seen in liberal democratic politics, where the principle of 'respect for autonomy' is widely accepted as guiding public policy and practice, and has grown in importance over the past 100 years as the individualisation of society has increased (Mackenzie, 2008). However, there is a lack of clarity about how to 'respect autonomy' (Walter and Ross, 2014). Making an autonomous choice such as whether to provide consent is essentially seen as an individual activity – objective and free from influence – which has no relation to anything other than one's own desires (Walter and Ross, 2014). All too often subscribers to this view believe that information is the enabling factor that allows individuals to operate in this way and to be 'fully informed'. But, as will be demonstrated from the history described later in this chapter, this 'information paradigm' predicated on the Kantian idea of knowledge required for rational thought is naïve (Felt, Strassing and Wagner, 2009). Indeed, some researchers in this area go as far as to say it is an 'illusory goal' (Dixon-Woods *et al.*, 2006), while Dawson (2011) posits that it is a deeply implausible view of human psychology. This opinion is also mirrored by Atkins (2000, p.76) who, when writing about the subjective autonomy of individuals and their experiences, stated that

'…making way for the subjective character of experience is not achieved by offering more facts for the person to "face", it is achieved by allowing a place for the expression of a person's perspective of [what] they are being offered'.

Stoljar (2011) suggests that the premise of informed consent is that health professionals make all relevant information available before adopting a position of neutrality towards the decision-making process. This view aligns with the suggested hybrid notion of autonomy. The framing of autonomy in health care in this way is seen as an 'informed independent choice' (Mackenzie and Stoljar, 2000). Moreover, this approach to autonomy, and therefore decision making, has been criticised, most

notably by feminist researchers who take issue with individuals being seen as 'self-sufficient rational choosers', independent of influence from society and others (Baumann, 2008). This view of autonomy may be appropriate in some, albeit rather limited, circumstances, but it does not sufficiently capture the complexity of influences on the decision-making process. The 'in-control agent', as Walter and Ross (2014) call this, requires individuals to 'transcend emotions and experience', focus on the objective of what is at stake, and by sheer act of will overcome emotions in the social and historical context of making a decision. In addition, any information that may influence a person's choice that is provided by a clinician, family or friends (with the exception of medical facts) is considered suspicious.

Furthermore, Owens and Cribb (2013) make a distinction between autonomous choice and autonomous action. They suggest that offering people the opportunity to make a choice based on the conception of autonomy as exercised by an 'independent rational in-control agent' but without supporting them to achieve this (*i.e.* adopting the stance of neutrality), falls short of what is considered morally or politically important about promoting autonomy. It seems that this approach is flawed even in the clinical and research arenas from which it originated, let alone in the complex world of (dental) public health that has competing values such as common goods, *i.e.* social justice and the type of solidarity proposed by Prainsack and Buyx (2015), described in Chapter 1 (Background). This view is clearly expressed by Baylis, Kenny and Sherwin (2008, p.12) in a paper written for *Public Health Ethics*. Here, Baylis and colleagues assert:

'In medicine, patients are not self-contained units in terms of their health needs, for their health status is inevitably affected by their particular historical, social and economic position. Hence, even in ordinary medical interactions the traditional individualistic model of persons is limited.'

2.4 Development of modern ethical frameworks

In the absence of anything better, public health practice has largely adopted the ethics first formalised in the Declaration of Helsinki, which has been hugely influential in the development of research ethics, codes of conduct for medical profession and, more broadly, the approach used within the health sector from the 1960s onwards (World Medical Association, 2013). These ethics have been mostly focused on the relationship between doctor and patient, which remains deontological at its core (Garbutt and Davies, 2011). This provides only a thin understanding of autonomy and the complexities of decision making (Baylis, Kenny and Sherwin, 2008). However, in an attempt to better reflect the ethos of public health, several 'frameworks' or 'models' have been developed to guide practice and set a standard for public health activities. But, some academics argue that within these there remains (to a greater or lesser extent) an understanding of health ethics that has been borrowed from research and medicine (ten Have *et al.*, 2010). Indeed, Dawson (2011) comments that the public health frameworks that have been developed to date remain locked within the parameters of traditional biomedical ethics.

Some of these frameworks, such as those developed by Kass (2001), Tannahill (2008) and the Nuffield Council on Bioethics (2007), include analytical tools for practitioners. In contrast, others, such as those developed for the Public Health Leadership Society (Thomas *et al.*, 2002), and by Upshur (2002), Gostin (2005) and Childress (2008), provide only a set of principles or values for consideration. Moreover, all of these frameworks include some version of Mill's 'harm principle' and non-interference, or at the very least they articulate that priority should be given to the least restrictive means (Mill, 1859). Interestingly, none of the frameworks for public health focus on core public health values as outlined in Chapter 1 (Background), *e.g.* common goods, public benefit and solidarity (Prainsack and Buyx, 2015; Dawson, 2011). Hence, they do not seem radically different from ethical frameworks or principles developed for

bioethics and research. As such, they are of limited value to advancing *public health* ethics.

2.4.a Rejection of 'principlism' and 'stewardship'

Possibly the most well-known and widely taught of the principle-based ethical frameworks is a refined version of the seminal work first published some 30 years ago by Tom Beauchamp and James Childress (Beauchamp and Childress, 1977, cited in Beauchamp and Childress, 2009, p.vii), who pioneered the 'four principles' approach to ethics. The use of Beauchamp and Childress' four principles has many supporters and the framework is generally applied to all areas of health care, including public health (Gillon, 2003). It also forms the basis of a number of professional codes of conduct (GMC, 2013; NMC, 2010; GDC, 2005a). But several commentators (although not the authors themselves) have said that the Millian principle of non-interference, which infuses health professionals' understanding of autonomy, receives privileged status within this approach (Dawson, 2011; Gillon, 2003; Upshur, 2002). The use of a framework that is understood to favour non-interferences is therefore misguided, and would only serve to perpetuate a flawed notion of autonomy.

Recently, and in an attempt to develop a more public health specific framework, the Nuffield Council on Bioethics (NCB) (2007) has proposed a concept of 'stewardship', which it interprets as the State having some responsibility to look after the important needs of people, both individually and collectively, who fall under its jurisdiction. It states that

> *'…stewardship gives expression to an obligation on States to seek to provide conditions that allow people to be healthy, especially in relation to reducing inequalities'.* (NBC, 2007, p.25)

The stewardship model affirms that public health policy should be compatible with the views of the public and it creates conditions that allow these policies to be scrutinised in terms of appropriateness. But, in the authors' own words, stewardship

as they have understood it is a '*revised version of the* [Millian] *harm principle'* (NCB, 2007, p.26) and, as such, still adheres to the narrow view that individual independent autonomy is the primary value. Therefore, instead of a framework based on stewardship, it appears to be more akin to libertarianism. The 'intervention ladder' included in this publication, which advocates 'least restriction of liberty', is a good example of this (NBC, 2007). Movement up or down the ladder in terms of a justification for action is predicated on the level of liberty any action allows. This highlights the primacy given to this value within the framework. Consequently, there has been some public criticism of the stewardship framework for continuing to promote a narrow understanding of Mill's theory. Public health ethicists Angus Dawson and Mercel Verweij (2008, p.193) denounce these individualistic liberal underpinnings and claim that

'…it is not clear that the model (or even the metaphor) of stewardship provides enough substantive content to ground public health ethics'.

Nevertheless, to date and somewhat surprisingly, the emerging field of public health ethics and the resultant frameworks all advocate maximising individual liberty more than perhaps would be expected, based on the utilitarian origins of public health. This exhibits the inherent and largely unquestioned Western narrative that understands autonomy from a rational, technical and reductionist point of view based on Kantian ideas and a narrow Millian approach.

2.5 A new approach: relational autonomy

On inspection, it appears that the in-control rational agent approach to autonomy is currently being used by dental teams when implementing their programmes (Childsmile, 2015; British Association for the Study of Community Dentistry, 2014; Whittington Health NHS, ND). But, if we accept that there are limitations to this conception of autonomy, as set out above, an approach to decision making that is more nuanced and reflective of the lives that people lead, and which includes a

sensitivity to the myriad influences, both personal and environmental, that affect a person's decision making, is required (Owens and Cribb, 2013).

An alternative to the 'independent rational in-control agent' approach to decision making and autonomy has emerged within the last five to 10 years in academic literature: relational autonomy (Stoljar, 2011; Mackenzie, 2008; Christman, 2004). This approach to autonomy also rejects the Kantian idea of rationality and is rooted in an understanding of people and the complexity of their lives. In contrast to the primacy afforded to 'non-interference' exhibited by the traditional narrow understanding of Mill, it rests on the notion of people being embedded within communities in particular ways. The notion of non-interference in decision making is almost impossible because the very views, opinions, beliefs and values that these decisions are predicated on are shaped by a person's environment and experience, so 'interference', or influence, may on occasion be subtle but it is always present. Relational autonomy embraces the fact that people are inherently social beings that are politically and economically located (Kenny, Sherwin and Baylis, 2010). Indeed, Mackenzie and Stoljar (2000, p.4) state that underpinning relational autonomy is the understanding that

'…persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity.'

Christman (2004) and Mackenzie and Stoljar (2000) explain that, in their view, relational autonomy does not refer to a single account but is instead an 'umbrella term' that refers to all approaches to autonomy that acknowledge the social embeddedness of people and their choices. Furthermore, according to Christman (2004) and Mackenzie (2008) among others, relational autonomy is motivated by two distinct but interrelated claims: firstly, it is a rejection of the notion of the independent rational in-control agent; and secondly, relational approaches are premised on the belief that decisions are made based on a person's own identity,

which is formed out of values influenced by interpersonal relationships and the social environment. This approach to autonomy seems to reflect how decisions are made in real life, with behaviour being subject to an array of influences. This approach can be further dissected into two distinct domains: procedural and substantial autonomy.

In this new academic area of study no singular definition of procedural or substantive autonomy exists. These are emerging and contested concepts. Below I explain my understanding of these terms and articulate their meaning within this thesis.

2.5.a Procedural relational autonomy

Procedural accounts of relational autonomy are still highly individual and are based on a person's ability to reflect on and evaluate information, and then make a choice relative to their authentic self. Frankfurt (1971) proposes that autonomy 'resides within agents'. But, to act autonomously an individual must be able to critically deliberate while reflecting on which subsequent actions will be most in line with their true desires. This view does not appear to be very different from that which went before, *i.e.* autonomy as exercised via an 'independent in-control agent' and, although procedural autonomy does embrace and reflect influences on a person's choice, it still requires individuals to balance this information, including the potential consequences. As such, it can be criticised in a similar way to the 'rational in-control agent' model, in which an examined way of life that could be seen as overly intellectualist is imposed on individuals. However, Christman (2004), who has written extensively about procedural autonomy, argues that, although individualist conceptions of autonomy understand authenticity, any practical identity of authentic self is shaped by complex social determinants and within the context of interpersonal relationships. A good example of a person exercising their autonomy based on the desires of their true authentic self, shaped in the way Christman (2004) described, can be found in a legal case from the Family Division of England and Wales High Court (*Ms B v An NHS Hospital Trust [2002]*). In this case the appellant, Ms B, brought a case of unlawful trespass against a hospital. Ms B wanted her ventilator to be turned off after

she had become tetraplegic, whereas the hospital staff wanted her to be moved to a 'weaning programme'. Ms B maintained that the weaning programme would rob her of her dignity and be distressing for her relatives. In her judgement, Dame Elizabeth Butler-Sloss made reference to Atkins (2000), mentioned previously, and went on to find in favour of Ms B, citing that respecting autonomy involves

'…recognition of the subjective character of our first-person experience and the differences that separates us as subjects'.

While this is an example from clinical health care and not (dental) public health, it does put into context how a person's self-identity and experience influence their decision making, something previously dismissed by Kant (1785). So, although there are similarities between procedural relational autonomy and the earlier 'independent in-control agent' notion, within a procedural account a person is not expected to 'transcend their emotions and experience'.

Moreover, with regard to the dental public health programmes that are central to this thesis, it is not implausible to assume that, among other things, a parent's experience of dentistry, such as familiarity with the UK health care system or the importance placed on oral health within their personal networks, will influence their decision making. It seems improbable that parents will act solely as independent rational in-control agents who transcend their own identities and lived experience when deliberating about providing or refusing consent. In a paper by Tickle *et al.* (2006, p.270) that focuses specifically on dental public health, the influence of experiences and emotions is reflected in the following statement made by a parent in one of the focus groups:

'People fear going to the dentists but I think doing it through the school situations like that…it might take a bit of the fear away.'

Parents recognise that their decisions and actions are based on emotions and previous experiences and on how they conceive of themselves, as being dentally

phobic for example. Interestingly, parents' reference to emotions and lived experience when making decisions is something that dental professionals are aware of; furthermore, they acknowledge that this influences the decision of parents to provide or refuse consent for DPH programmes. For example, in a paper by Monaghan, Jones and Morgan (2011, p.4), dental professionals state that the low participation rates could be because parents are

'*…deliberately excluding children because the children have caries experience and the parents know it'.*

Both of these statements indicate that parents are not acting as independent rational in-control agents. However, we do not know whether these parents are making decisions that are in line with their 'authentic selves', which at a population level would be very difficult to determine. If parents' decisions are directed by fear, or the feeling that they will somehow be stigmatised because their children have decay, their ability to act 'rationally' could be compromised. Their authentic self that desires their child's oral health to be good may be overridden by other more immediate desires, such as fear or not wanting to be stigmatised or thought a bad parent. In this situation, their authentic selves are being oppressed. This places a limitation on the usefulness of procedural autonomy in this situation, beyond that of the recognition by dental staff that parents' decisions are subject to influence. That said, parents in these scenarios are making decisions and exercising choice of a sort – they are consenting, refusing or passively not responding – and so even if their decisions are not representative of their authentic selves they *are* exercising epistemic autonomy that is relational to *their* known world. Interestingly, despite realising that it is a relational (procedural) conception of autonomy that is being exercised to some extent by parents (authentic or not), dental professionals have yet to relinquish their pursuit of the independent rational in-control agent approach to autonomy. Furthermore, the hands-off approach to requesting consent from parents via a letter outlining 'facts', which assumes that all parents will make an objective 'rational' (Kantian)

choice, could be seen as dental perfectionism, with professionals promoting one view of a 'good life', *i.e.* examined and intellectual, which is in fact in opposition to the 'self-rule' they are advocating. Here, parents are not being permitted to live their lives, including the way in which they make decisions, as they choose. If autonomy is valued, this should mean that lives can be lived foolishly, and that decisions based on epistemic autonomy or gut instinct are equally as valid as those based on careful deliberation of facts.

Adopting the independent in-control agent approach requires analysis of facts and deliberation, but this downplays the importance of social interaction with others, which may be supported or provided by a dialogue with health professionals (Owens and Cribb, 2013). Furthermore, research from Austria by Felt *et al.* (2009, p.95) demonstrates how patient participants opted to discuss consent issues with health professionals in person every time they were given the opportunity to do so, and many of them '*hardly read the form'* when provided with written factual information. Felt *et al.* (2009, p.101) report that patient participants

> *'integrate the act of consenting with previous experiences, and they build on divergent sources of knowledge that enable them to ignore technical information provided in the consent form and to keep the focus on what counts as relevant to them at that specific point in time'.*

This demonstrates the differing conceptions of autonomy that are held by professionals and lay people. I suggest that it is time to abandon the concept of an 'independent rational in-control agent'. Parents are making decisions that are influenced by other people, experiences and emotions, and the fact that missing from this milieu is the voice of health professionals will be an influencing factor in itself.

2.5.b Substantive relational autonomy

Owens and Cribb (2013) argue that procedural autonomy is undeniably an improvement on the independent rational in-control agent approach, but that it

captures only part of what is important about the concept of autonomy, *i.e.* that it is subject to influence. Indeed, some aspects of self-identity are bound up with the socio-economic features of a person's life (Baylis, Kenny and Sherwin, 2008). Oshana (2006) has written an extensive account of substantive autonomy that affirms people can act autonomously only when social conditions permit significant options to be available. Indeed, this is seen as a matter of social justice, with the State having a duty to facilitate social conditions such as political, legal and economic environments that are conducive to autonomous action. Therefore, social determinants should be structured in a way that does not impair or undermine the capability or attitude necessary to act autonomously (Mackenzie, 2008). This view of the enabling factors required for autonomous action can be said, therefore, to depend on substantive elements such as the environment and culture (Raz, 1994). Moreover, without these, limitations to individual procedural autonomy can be masked, because a person may not have the capability to act according to their desires and cannot therefore be said to be truly autonomous.

From dental literature (Davies *et al.*, 2014) we know that the largest proportion of children excluded from participation in dental public health programmes is found in community groups that have lower incomes. This situation has arisen only since the introduction of opt-in positive consent (Department of Health, 2006). It seems incongruous that this is the result of these communities autonomously choosing, at the exact same time as the policy change, not to participate. It is more likely to be the result of impaired substantive relational autonomy, *i.e.* the environment or culture that these families are embedded within has undermined their capability to *act* autonomously. The importance of structural determinants to a person's capability to adopt particular behaviours and be healthy is well documented in public health literature (Marmot, 2010; Dahlgren and Whitehead, 1991) and, as such, the capacity to act autonomously must also refer to the material and social conditions that enable or constrain actions (Owens and Cribb, 2013).

It is the promotion of this relational conception to autonomy, *i.e.* that which is substantive, that most closely aligns with the wider ethical and public health goal of social justice and, therefore, of public health. If social justice is defined by an opposition to inequality and by the equal distribution of 'goods', whether material or common, this must include enablement of individuals and communities to act autonomously. In the Department of Health's (2006) policy on consent for DPH programmes, substantive autonomy does not feature; it is neither promoted nor enabled. This policy is an attempt to prioritise choice, *i.e.* parents must actively choose to give their agreement before their child is included, but it is premised on choosers being 'independent rational in-control agents' and health professionals adopting a stance of non-interference. It falls short, therefore, of *enabling* that choice and, as such, does not provide parents with the capability to act autonomously. Furthermore, implementation does not recognise the substantive *dis*abling factors that some communities and parents face, *e.g.* low levels of literacy or religious cultures that instinctively refuse procedures involving fluoride products because they believe them to contain alcohol or materials derived from animals such as pork, *e.g.* Islam (Murray and Jeavons, 2006; Whittington Health NHS, ND). Indeed, the opt-in policy itself and the implementation process is clearly an example of the Kant-Millian hybrid.

It is indeed these conceptions of autonomy, *i.e*. procedural and substantive, that are underpinned by a background of social components and dynamic power structures, which influence a person's capability to be autonomous (Christman, 2004). Therefore, a person's ability to act autonomously will be jointly determined by both internal and external factors of authentic self-identity and structural determinants (Owens and Cribb, 2013). The ongoing reliance that health professionals place on the individualistic rational in-control agent model of autonomy that is steeped in the individualism of clinical care and research is not a realistic or attainable goal, particularly in a community public health setting (Kenny, Sherwin and Baylis, 2010). Indeed, when writing about public health ethics in 2000, Buchanan (2000, p.15)

argues that public health would be better served if, instead of justifying why paternalistic actions were necessary, it sought '*to expand the notion of autonomy through promoting social justice'*.

2.6 Justification for a pluralistic relational approach to autonomy

If we seek to *'expand the notion of autonomy'*, as Buchanan suggests (2000, p.15), to beyond the realms of the 'independent in-control agent', caution should be exercised not to repeat the mistakes of the past, by taking a purely cognitive linear approach concerned only with individual choice. I propose that relational autonomy allows us a more realistic approach to autonomy that acknowledges and embraces the relatedness of humans, to each other and to their social environment. Relational autonomy better reflects the human condition and how a person operates in real life. It is this view of autonomy that will be explored in the following pages and not the Kant–Millian hybrid. The approach to autonomy that I am advocating is consequentialist and pluralistic and, I believe, more in line with Mill's full account of utility and the role of personal autonomy within it (Mill, 1859). I posit that people have liberty to pursue their own values and conceptions of 'the good life', and that the State's goal ought to be to secure the capabilities required so that they have the ability to *act* autonomously. Essentially, this view recognises that while people may be able to choose their own values and distinguish their true desires, motivations and wishes, they may not be able to act on these because of their life circumstances does not allow freedom of action. In this situation, the government ought, in so far as is possible, to enable through substantive structural means equity of action for the population, and in order to do this some degree of paternalism may be required. Therefore, this approach promotes autonomy but uses the structural framework of paternalism to enable equity of autonomy for all. Procedural autonomy is acknowledged though the recognition of authentic desires, but these are set within the social and structural context of a substantive approach.

Consequently, this pluralistic approach encompasses elements of procedural and substantive relational autonomy. However, relational autonomy is a new and as yet undeveloped area of ethical debate; as a consequence, some literature can be found on procedural autonomy and what this means for individuals within the confines of clinical care and decision making but much less exists on substantive autonomy. To date, this concept is not as well developed, possibly because it extends beyond the clinical field where most ethical discussion related to health takes place. But, securing substantive relational autonomy can be seen as a matter of social justice and it is, therefore, directly related to the wider values and aims of public health. If procedural autonomy becomes a more widely adopted concept to the detriment of substantive autonomy, we will still fail to capture the complexities of people's lives in full, and one narrow individualistic approach will be replaced with another, albeit an improved one. Equally, the dominance of the individualised stance of the medical model that has been criticised when used for public health purposes will remain unchallenged.

As with many areas of ethical debate, but particularly as this is an area that is just emerging in the literature (Walter and Ross, 2014; Owens and Cribb, 2013; Felt *et al.,* 2009; Baumann, 2008; Baylis, Kenny and Sherwin, 2008; Mackenzie, 2008), no singular definition or agreed concept of substantive autonomy exists. So, to help explore this as a discrete but significant element of autonomy and to justify why it is worthy of further investigation, I have selected key illustrative moments from history when substantive elements have either enabled or impeded personal autonomy.

2.6.a The State's refusal to acknowledge structural determinants of health that substantively influence a person's ability to choose

A refusal to acknowledge the influence of structural determinants of health on a person's ability to choose can be seen from the inception of public health practice right through to today. For example, State action to improve public health was in its infancy in the 1800s and, although it had its champions, some affluent people in Victorian and Edwardian society were worried that Britain's individualism and right to

an autonomous life was being eroded through these collective means (Hatchet *et al.,* 2012). Among the champions were John Snow, who famously traced the spread of cholera to a single water supply, which he then rendered unusable for the benefit of the community (London School of Hygiene and Tropical Medicine, 2013), Joseph Bazalgette, the engineer responsible for London's sewer system that ultimately rid the capital of 'King Cholera', and sanitary reformer Edwin Chadwick (who had worked as a secretary to Jeremy Bentham) and on whose ideas the first Public Health Act of 1848 was founded (Hatchett *et al*., 2012). Objectors did not like this 'highhanded' and paternalistic approach and their view was reflected in an editorial in *The Times*:

'We prefer to take our chances with cholera and the rest than be bullied into health. There is nothing a man hates so much as being cleansed against his will,…all at the command of a sort of sanitary bombaliff'. (British Library, NDa)

Indeed, one such person was the Prime Minister, Disraeli (Warren, 2000). Disraeli's libertarian view, and the view of many others at the time, was that poverty (which led to poor health), was due to both ignorance and a failure of character, *i.e*. that people actively chose to live in poor conditions. He thought that individuals were, and should be, responsible for themselves, that this was not the role of the State. Despite Disraeli's view, it was these early State actions in the 1800s that enabled the labouring classes to actively 'choose' to live in more sanitary conditions, with clean water, which prior to this had been beyond their means, whatever their personal desires. The view that poor health is due to ignorance and is a matter of personal responsibility is still commonplace today and is often reported in popular media (British Broadcasting Corporation, 2010).

In the latter half of the 19th century, public health legislation and intervention was gaining pace and the State increased actions to improve the population's health, including free school meals and a system of benefits and insurances that remained until the 1950s (Warren, 2000). This was in large part due to the discovery of the poor health exhibited by the rank and file men attempting to enlist to fight in the Boer War

(Hatchett *et al*., 2012). Six percent of these recruits were rejected due to '*loss or decay of many teeth'* (British Dental Association, 2011). By using legislation and policy to change environmental and social structures, *i.e.* substantive influences, the State took on a small but important element of responsibility in the protection and promotion of population health. This proved particularly beneficial to those less able (economically or socially) to pursue optimum health through individual choice and self-determination as Disraeli and others would have wished.

Parallel to the narrow belief held by Disraeli and others, that individuals should be able to independently determine how they live their lives, is the assumption that everyone, given the choice, would choose health (Skrabanek, 1994), which stems from Kant's theory of reason, according to which everyone, if rational, would choose one 'best' way of living (Kant, 1785). Today, individuals who do not appear to 'choose health' and therefore act accordingly are either thought of as lacking capacity as defined in law (Lynch, 2011; Mental Capacity Act, 2005), deemed to be ignorant of the information needed to make the 'correct' (rational) choice or, worse still, wilfully neglectful. For example, the opinion that poor oral health is due to parental ignorance was clearly articulated in a recent BBC report on children's oral health, in which Dr Carter (Chief Executive of the British Dental Health Foundation) stated:

'*It's a case of child neglect. They're not giving the correct diet, they're getting sugary drinks. There's no attention to their oral hygiene regime…'.*

In the same article, Professor Susan Jebb went on to explain that in her view this 'neglect' could be overcome by giving more information to parents:

'*It comes back to simple advice to parents – encourage your children to drink water.'* (British Broadcasting Corporation, 2014)

These views are not uncommon in the dental literature and they indicate a lack of understanding from those in the dental profession of the procedural and substantive influences on parents' 'choices'. If ignorance is one of the reasons for poor oral health

then it follows that hard paternalistic actions, as defined earlier by Dworkin (2014), can be justified. But, it would appear from the information here that those who claim poor health is a result of ignorance are also the most vocal opponents of utilitarian action that necessitates paternalism. This exhibits a status quo bias in some dento-medical and political spheres of policy development (Samuelson and Zeckhauser, 1988) based on a notion of Millian non-interference, which does not appear to have evolved since the Victorian era.

This situation is not new. Examples of the belief that individual behaviour based on ignorance is the cause of ill-health litter the pre-welfare state period up to the start of World War II in 1939. One such example can be found in the government's response to rising maternal deaths, despite evidence to the contrary regarding individual responsibility. In 1934, a *Times* editorial entitled 'Maternal Mortality' stated that the problem lay in the *'…ignorance of many young mothers…*' (p.13). However, this opinion was countered in 1938 when the Women's Health Committee published 'Working Class Wives', a report that included data from women and doctors demonstrating that a woman's life circumstances (*i.e.* her socio-economic status) were a greater predictor of health than individual behaviour (Spring Rice, 1981). But Neville Chamberlain, the Prime Minister of the day, dismissed the evidence in the report and instead advocated an increase in the availability of qualified midwives to instruct new mothers (Todd, 2014). Thus, Chamberlain echoed Disraeli in failing to acknowledge the effect of substantive influences, and in perpetuating the widespread belief that individuals are solely responsible for their own health and that providing information to overcome the problem of 'ignorance' is sufficient to bring about specific behaviour (Manson and O'Neill, 2007). This assumption still underlies the way in which we approach the issue of consent. Individuals are given ever more detailed information in the belief that this will eradicate any ignorance on the matter in hand and they will choose to act 'rationally' and provide their consent (Code, 1991). Much of the dental literature on consent for DPH highlights information giving and receiving (Davies *et al.*, 2014; Glenny *et al.*, 2013; Davies *et al.*, 2011; Morgan and Monaghan,

2010; Monaghan and Morgan, 2009; Dyer *et al.*, 2008; Hardman *et al.*, 2007; Tickle *et al.*, 2006). Indeed, the proffering of a 'patient information sheet' is *de rigour* in advance of all research and medical interventions and, as discussed in this thesis, prior to many public health activities too.

2.6.b Government-secured capabilities enabling personal autonomy: a pluralistic approach

A short hiatus in the advance of individual and personal responsibility came as a result of World War II. Around this time and immediately afterwards, the government took a more paternalistic approach to what a UK government should, and could, provide for the benefit of the population (Marr, 2007). Again, as was the case of the Boer war 40 years earlier, the catalyst for action was war and the need to improve the health of those upon whom victory would depend. For example, of all the recruits who joined the Army at the start of World War II, 95% did not meet the required standard for oral health (British Dental Association, 2011).

Between June 1940 and the general election of July 1945, the UK underwent a social transformation and the government struck a 'social contract' with the people: individual sacrifice in return for State provision of universal social goods, including health services (Marr, 2007). By 1942, the Beveridge Report promising 'cradle to grave' welfare for all was widely supported, as faith in State intervention grew. This was based on two simple, overriding principles: universality and comprehensiveness (British Library, NDb). It applied to everyone and all working people had to contribute. In other words, the scheme was both utilitarian and paternalistic. Individuals no longer had to shoulder full responsibility for their own welfare.

It was six years later in 1948 when the NHS was finally established by Minister for Health, Aneurin Bevan (NHS, 2014). But, free dental services for all were withdrawn just three years later in 1951, due to alarm at the rising costs from the volume of people now in a position to 'choose' to have dental care that had previously been financially prohibitive (British Library, NDb). This demonstrates that the belief,

founded on Kant's idea of reason and rationality (Kant, 1785) and held by Disraeli, Chamberlain and others, that ignorance is the barrier to individuals adopting healthy behaviour is misguided. The people who sought dental care in those first three years of the NHS were not ignorant or irrational; the barrier they faced was substantive, *i.e.* their socio-economic position and the pre-NHS dental service arrangements, wherein ability to pay was the major determinant, had influenced their ability to *act* according to their own desires. It was through the inception of a paternalistic and utilitarian NHS that this barrier had been removed and people were now *able* to exercise their free will and choose to seek individual care should they wish.

It was the NHS and other reforms in welfare provision that, although utilitarian and paternalistic to some formed an important safety net for many of the most vulnerable (Todd, 2014). It was within this safety net that many individuals could become more autonomous, not less, particularly those previously less economically and socially able to exercise their authentic desire because of the might of the substantive influences they faced. At the most basic level, individuals could now choose to seek care from qualified health professionals in the new NHS or continue with more 'traditional' forms of care. Autonomy was expressed via their preferred choice or need, rather than their ability to pay. This type of autonomy, *i.e.* not only whether they accessed care but also the method of this care, is exemplified by Beryl Gotifried (born in 1929). Gotifried is quoted in Selina Todd's book (2014, p.157) as saying that the biggest difference after 1948 was that

'…you don't have to pay for the doctor [or dentist] anymore.' Her father, a railway signalman, *'…used to take people's teeth out for them because they couldn't afford the dentist*.' (The restriction of dentistry to only qualified persons did not become law until 1921, but a loophole allowed any unqualified 'dentists' who had practised before this time to continue, so barbers, blacksmiths and others similarly unqualified, like Beryl's father, continued for years to come [British Dental Association, 2011; Hansard, 1922].)

Before the NHS, there would have been no choice for the people who visited Beryl's father. The notion of autonomy was hypothetical, not actual, for many, until structural substantive barriers that constrained a person's ability to *act* autonomously were addressed.

2.6.c Increasing individualism of UK society

In the latter half of the 20th century, Clement Attlee's post-war government were radical in their policies and actions, establishing many 'common goods' that remained in place until the election of Margaret Thatcher in 1979 (Marr, 2007). However, the primacy of the individual, seen from Victorian times, remained a driving force, if somewhat abated. Attlee promoted equality of opportunity, not equity, *i.e.* a country based on the notion of a meritocracy of selected able individuals (Todd, 2014). But as we can see in the consent processes currently in place for dental public health programmes (Chapter 1: Background), providing formal equality of opportunity to exercise autonomy is not the same as providing equity in the capabilities people have to act autonomously, *i.e.* authentic autonomy. Opportunity alone will not overcome the negative procedural and substantive influences.

This individualisation of society has been continued by successive governments. However, the greatest leap forward in this way of thinking, *i.e.* privileging the individual, came from the election of Margaret Thatcher in 1979 onwards. The old ideas of 'solidarity' and 'social contracts' have now largely been pushed out of mainstream discourse in favour of individuality and self (Dawson, 2013; Bauman, 2001). Indeed, Margaret Thatcher herself famously proclaimed *'There is no such thing as society'* after the 1987 general election (Margaret Thatcher Foundation, 2016). The Conservative government policies of the 1980s and early 1990s were aimed at 'rolling back' the paternalistic State provision, instead promoted

> *'a climate in which British people, as individuals and industry, can prosper and can build their own independence'* (Margaret Thatcher cited in Todd, 2014, p.319).

But, from the 1980s onwards inequalities started to grow for the first time in decades, and this continued throughout the 1990s and into the new millennium (Wilkinson and Pickett, 2010). The belief that individuals are solely responsible for their own health has remained a resilient one throughout the 20th century and beyond, save for a short hiatus in the post-war years. Indeed, by 2016, the NHS had a whole webpage called 'CHOICES. Your Health, Your Choices', which was dedicated to providing information to promote individual responsibility for health, including oral health (NHS, NDb). The very title of this site implies that it is an individual's autonomous 'choice' to be healthy. This thinking is also evident in recent government-sponsored documents such as 'Choosing Better Oral Health' (Department of Health, 2005a), which promotes an individualised approach focusing on 'lifestyle choices', whereas similar reports such as the Black Report of the 1980s (Black *et al.*, 1988) or more recently the Marmot Review (2010), which emphasise wider influences on health, have been somewhat sidelined (Hann, 2012). This means that government(s) can claim that any issues with poor health are as a result of the behaviour of the individual and are not the responsibility of the State.

The longevity and influence of this belief are paradoxically both surprising and predictable: surprising, given the weight of evidence from the last 150 years that demonstrates the undeniable impact that a person's circumstance has on their ability to exercise their autonomy and 'choose' to be healthy; and predictable because over the same time span prioritisation to the point of fetishism of the individual as an independent autonomous rational agent has become the accepted norm. Indeed, Bauman (2008, cited in Dawson, 2013, p.88) observes that currently

'*[b]eing an individual (that is, being responsible for your choice in life, your choice among choices, and the consequence of the choices you choose) is not itself a matter of choice, but rather a decree of fate.'*

Amid this increasing individualisation of society in the latter half of the 20th century the Declaration of Helsinki revisited the ethical basis for medical interventions and

research, and the rights of the individual with regard to consent were confirmed (World Medical Association, 2013). The consensus that health care had been too paternalistic resulted in the *de facto* establishment of 'respect for individual autonomy' as the dominant principle, which is underpinned by a collective understanding of Kantian autonomy predicated solely on a cognitive assessment of knowledge and fact, dismissing other influences. This cemented the narrow understanding of Mill's work in the psyche of researchers and the medical professions (Dawson, 2011), and thus the Kant-Millian hybrid we use today was established.

2.7 Conclusion

In the latter half of the 20th century, the locus of society in the UK became increasingly narrow, orientated away from public goods and community solidarity and towards individualisation and individual benefits (Hann, 2012). At times this has led to a convergence of the prioritisation of the hybrid notion of autonomy within health and the individualisation of society through increasing demands for personal choice and self-determination. The focus on individual responsibility and the promotion of choice based on rational decision making by independent agents (who merely need to be given sufficient information in order to act) appears to be an unswerving belief. In support of this, the National Institute for Health and Care Excellence (2014) has recently produced an 'evidence-based' guide to individual behaviour change, reaffirming the view that independent autonomous rational choices are made with little relation to a person's circumstances. In 21st century, the preoccupation with individuals can be found in political, intellectual and mainstream worlds, in, for example, the proliferation of (dental) public health activities that focus solely on 'individual lifestyles choices', the increase in academic post-graduate study that focuses on 'self-identities', and the invention of a whole new genre of photography by the so-called 'iPhone generation', dedicated to the celebration of the individual with 'selfies' (Giddens, 2015; Layton, 2015; Shah, 2015; Department of Health, 2005a; 2004; Bauman, 2001).

Returning to the subject of this thesis, in light of the above being the way in which UK society operates, it is little wonder that current ethical guidelines on consent prioritise individual autonomy, often above all other considerations (Gillon, 2003). Indeed, Callahan (2003) has claimed that autonomy has a place of honour in health care ethics because of the thrust of individualism. And yet, as evidenced by the public health laws of the 19th century and the inception of the NHS in the 20th century, it is only when substantive elements of the structural determinants of health are addressed that some people are able to exercise an authentic autonomous choice (Dawson, 2013). Autonomy, therefore, can be seen as a product of social relations, rather than as purely based on individual achievements and will (Baylis, Kenny and Sherwin, 2008). As such, there is evidence to assume that instead of paternalism and individual autonomy being in tension, as framed in much of the literature, these two concepts can, in some circumstances, be complimentary. It is for this reason that we need to consider a pluralistic approach.

Through unpicking the common understanding of the philosophies on which the prevailing hybrid notion of autonomy is built, I have laid bare some of the hidden flaws in our current consent processes. I have discussed the emerging area of relational autonomy as an alternative approach and have found it to be both realistic in its view of decision making and a better 'fit' that is reflective of the core values and aims of public health. I have presented evidence from the past 150 years, which has served two purposes. The first of these has been to explain how value in the sovereignty of the individual has increased out of proportion to the point at which the work of John Stewart Mill has become distorted, leading to the inappropriate use in a public health arena of frameworks developed for research and medical settings. The second use of historical events has been to demonstrate that complete non-interference impoverishes autonomy rather than enhances it, whereas government paternalism at a structural level can mitigate some of the negative substantive influences that less-advantaged communities face. Human flourishing requires individual procedural autonomy but this can be truly realised only within the bounds

of a just society, where social structures enable a person's capabilities to be autonomous. It is through this lens that I have proposed the use of a pluralistic approach to autonomy, *i.e.* one that is both proceduralist and substantive. I believe that this is a realistic alternative to the current reductionist approach. However, to date the use of relational autonomy appears to be debated within a small cohort of academic philosophers and ethicists but not widely applied in any way and, as such, it remains a hypothetical notion. It lacks the empirical evidence that would be required by the dental public health community before it was considered a potential rival to the current hybrid notion. Therefore, in the remainder of this thesis I will explore though interviews and focus groups with parents what barriers or enablers parents face when exercising their autonomy and making a choice to consent to or refuse their child's participation in a dental public health programme.

Chapter 3 – Review of empirical literature

3.1 Introduction

This chapter contains a systematic review of existing research on parents' decisions to provide or refuse consent for their children to take part in public health interventions. This research has been analysed using meta-synthesis in order to bring a new insight to this body of work. The purpose of this chapter is threefold. It aims, firstly, to demonstrate how existing literature was searched and reviewed to enable me to identify specific areas of consent practice for public health that until now have not been explored via research and, secondly, to present the synthesis of findings and results from existing research that enabled me to analyse this as a collective body of work that will add to the evidence base in this area. Thirdly, carrying out these tasks gave me the opportunity to review what research methods had been used previously, including their strengths and weaknesses in this context. Reviewing the literature in this way helped to advance my knowledge of parents' experiences when making decisions within community public health programmes. Additionally, it allowed me to test for relevance in this situation some of the theoretical points made in the previous chapter (Theory) before embarking on the empirical work necessary for this thesis. The information produced from this review was used when planning the research design outlined in the next chapter (Methodology), including in the steering of specific areas for investigation with parents.

To date, no systematic reviews have been published in this area, nor is there any specific published research that looks at what influences parents when they are making consent decisions for dental public health programmes. Therefore, evidence from the broader field of general public health has been looked at in this review. I have used 'parents' in this thesis as an umbrella term but it can also be understood to mean a child's primary caregiver, *e.g.* a legal guardian.

The aim of reviewing the current literature on this subject is to systematically source and critically evaluate peer-reviewed research that investigates influencing factors with regard to parental consent for school-age children to participate in public health programmes.

In order to meet this aim, the literature review seeks to answer the following question:

What influences parents' decisions to provide or refuse their consent for inclusion in public health programmes aimed at their school-age children (4-18 years) in developed national health care systems?

This question was used as the driver for this review and, to help answer it, the following objectives were formulated:

I. To systematically identify empirical research that is used to investigate influences on parental decision making for public health programmes aimed at school-age children

II. To systematically identify and analyse research that documents whether, and how, approaches to parental consent are informed by ethical theory

III. To systematically meta-synthesise findings from a range of research that investigates influences of parental consent, developing third order constructs

IV. To review the strengths and weaknesses of research methods documented in the literature to investigate parental consent for public health programmes aimed at school-age children

3.1.a Summary of literature about consent for dental public health programmes in the UK.

I conducted a review of dental literature related to consent for school-based programmes in the early stages of this thesis. In total ten papers were found to be relevant to consent for dental public health programmes. The focus of these papers was mostly on the uptake of dental epidemiological programmes. Only one paper included parents' views and experiences of dental public health interventions and, although consent was mentioned by parents it was not the focus of the research. I therefore took the decision to widen the focus of the review for this thesis, to include parents' experiences of consent processes for public health programmes in general and not just those specific to dentistry. This is discussed below in Section 3.2.a. Nevertheless the dental literature did provide a useful body of knowledge about consent processes and response patterns for dental public health and this is also summarised below. Further information about these papers can be found in Appendix 3.1.

Out of the ten papers identified, nine examined the issue of consent as a discrete and specific entity, and this was largely related to uptake of services *i.e.* how many parents consent or refuse and the impact of this on service outcomes. One paper discussed parental responses (but not specifically consent) to letters sent home from school as part of the process to implement a school based epidemiological survey (Tickle *et al*., 2006). This was the only paper that recruited parents as participants to explore their experiences. In the papers by Hardman *et al* (2007), Dyer *et al* (2008), Monaghan *et al* (2009), Morgan *et al* (2010), Monaghan *et al* (2011), Davies *et al* (2011), Glenny *et al* (2013), Davies *et al*, (2014) and Morgan *et al* (2014), the issue of consent was examined in detail and all papers commented on the changes to consent guidelines made by the Department of Health (2006). Typically, the introduction to these studies included statements such as:

'*The hypothesis is that consent bias, caused by the new requirements that all sampled children must have positive written consent provided by their parents to be*

included in the examination, has resulted in a non-representative sample' (Davies. *et al*, 2014)

My preliminary review of dental literature did not seek to test the effectiveness of any particular intervention or research method. My intention was to explore what published research was available specifically on consent for DPH programmes and to identify any possible gaps in knowledge. However, almost all papers reported that non-representativeness of samples resulting from the new consent arrangements is a serious consideration not just for their research, but also for service design and ultimately oral health. For example, dental epidemiology is used as the basis for targeting resources by Commissioners. Therefore, if parents do not consent to their children's participation, (as demonstrated by the papers reviewed in appendix 3.1), any data produced is non-representative of the population. Using this epidemiological data will mean that strategic or commissioning decisions will be based on incorrect assessments of the level of dental disease. The underestimation of dental need is clearly demonstrated in the paper by Monaghan *et al*. (2011), who report:

'positive consent was associated with…larger than expected reductions in average dmft (decayed, missing and filled teeth)*'*.

Almost all of the papers included cite sending a letter home to parents as the usual protocol for gaining consent, with each of them providing brief and largely speculative details why the uptake of dental public health programmes are low when written 'opt-in' consent is required. Nine of the studies that focused specifically on consent as a core point of analysis recommended further detailed research to better understand parents response behaviour to consent requests (Glenny *et al.*, 2013: Davies *et al.*, 2011: Davies *et al*., 2014: Monaghan *et al*., 2011: Dyer *et al.*, 2008: Morgan *et al*., 2010: 2014 and Monaghan *et al*., 2009). For example, Glenny *et al.* (2013) suggested additional quantitative research in the form of a 'nested trial' to test different methods of improving consent rates in school-based research and health surveillance. Whereas Davies, *et al*.

(2011) suggested additional qualitative work in the form of focus groups with parents 'not providing consent' would be helpful.

All papers cite a lack of understanding about why responses to written communications were low. The exception to this was Tickle *et al.* (2006) whose paper recruited parent participants and was published before the change in consent arrangements. This demonstrates a lack of understanding by the authors into the complexity of family lives where written communication can get overlooked amongst competing demands. It also doesn't it acknowledge the nuances of decision making. This is discussed later in Chapter six (point 6.4.b). Only one paper specifically focused on fluoride varnish as a public health measure (Hardman *et al*., 2007). This paper is different from the others in that no concerns were raised about gaining consent from parents, or the possible impact that this may have on the effectiveness of FV programmes as part of their rationale. However, future programme design that considers how to increase parental consent is discussed later in the paper with the authors concluding they:

'…cannot recommend Fluoride varnish as a public health measure to reduce caries as a result of the poor positive consent rate achieved which significantly affected the research outcome, particularly for those most likely to benefit'. (Hardman *et al*., 2007).

This lack of consideration at the start of the project by Hardman *et al* (2007) is further evidence that programme designers and dental researchers have not fully grasped the importance of consent arrangements that meet the needs of parents, that is until non-response starts to impact research or epidemiological outcomes.

None of the papers discussed ethical theories, concepts or frameworks of any kind, nor did they refer to 'enabling parental autonomy'. This was intended by the Department of Health (2006) consent guidance, which all the referenced studies implemented. In all but one paper by Glenny *et al.* (2013), the authors have not made any attempt to adjust their methods so that the information received by parents is based on a more equitable

opportunities for parents to make a decision. This is interesting because several of the researchers have displayed results after modelling their data into socio-economic quintiles for the communities concerned, so a level of awareness around wider inequalities exists, but this concept has not been extended to parents' ability to respond. The large study carried out in England by Davis *et al*. (2014) suggests that letters sent to parents that are followed up with one additional written communication, which appears to be the unofficial norm. How many times parents should be sent consent letters is the focal point of two other papers by Morgan and Monaghan (2014) and Glenny *et al*. (2013) but results from these papers are inconclusive. As such the optimum number of times that parents receive a written request for consent is still unknown.

Most of the papers, with the exception of Glenny *et al*. (2013) and Tickle *et al.* (2006), report on the different patterns of uptake within geographic areas (delineated by the boundaries of NHS organisation) in relation to the effect this has on data sets. There appears little enthusiasm to facilitate parental engagement. For example, only papers by Monaghan *et al*. (2011) and Davies *et al.* (2011) recommend further research involving parents to explore the reasons for non-response. Equally, research outlined in these papers has universally employed an arm's length approach to engaging with parents using variations of a letter-based system to gain consent. None of the papers investigated other methods to engage with parents to ask for their consent, such as face to face or school cohort meetings.

Reviewing the literature related to consent for dental public health programmes has provided a sound knowledge base of current practices. It has also highlighted the negative views held by some in the dental profession towards parents who do not respond to written requests for their consent.

3.2 Methods

3.2.a Search strategy

This section demonstrates how objectives (I) and (II) above have been achieved.

The context of this topic area was broadly outlined in Chapter 1 (Background) and Chapter 2 (Theory), where population-wide activities aimed at school-age children that require individual parental consent were identified as public health and the international development of autonomy manifest as consent was described, as was the law related to this. Dental public health programmes delivered in the UK for which parental consent is required were also discussed and used as an exemplar for some of these key points. However, this literature review in intended to be broader than this in scope and to consider influences on parental decision making with regard to providing or refusing consent for any community public health programme aimed at primary school-age children. The reason for this is that dental public health is a niche field within both dentistry and public health. As such, the literature related to it is minimal and is not sufficient to draw any robust conclusions. Equally, the focus of this literature review is to find out what may influence parents' decisions and, as this is not exclusive to dental public health, valuable information and insights can be identified from a wider field of enquiry. An exploratory search was conducted to assess the possible quantity of publications specific to this topic area before a question was formed and the more detailed search commenced. The purpose of this was to broadly assess the volume and focus of research in this area to ensure that papers of sufficient quantity and relevance would be available for critical review. This included investigating which of the data platforms that City, University of London subscribes to may be relevant. Fifteen platforms were identified, of which two were categorised as 'nursing' and 13 as 'health services'. A review of potentially relevant e-journals was also conducted as part of this preliminary phase. This demonstrated the breadth of publications that research papers could be sourced from. The Cochrane

Library was also searched to confirm whether any previous systematic reviews on this or similar subjects existed. None were found.

An adapted version of the PICO (Patient/population, Intervention, Comparison/Control and Outcome) *i.e.* without the control / comparison component, was the starting point of the question-forming process (Schardt *et al.*, 2007). PICO is recommended to help structure research questions when investigating areas of medicine and dentistry, including public health (Centre for Evidence-Based Dentistry, 2015). It can also be adapted for use when a particular health-related phenomenon, rather than a clinical outcome, is the focus of the investigation, which is often the case when researching qualitatively focused questions (University of Oxford, ND). This made it relevant for use in this thesis. The topic area was split into the component parts shown in the table below (Table 3.1).

Table 3.1 PICO component parts

	Component	**Meaning relevant to this topic**
P	Population	Parents of school-age children
I	Intervention	Public health programmes
C	Comparison/control	*Not applicable*
O	Outcome	Consent on behalf of the child

The comparison/control component was not applicable in this instance because the research subject, *i.e.* influences on consent decision making, does not have an identifiable alternative. The population, intervention and outcome components were then used to write several variations of a possible research question as the central focus of this review. Each iteration refined the question (shown on page 94), distilling the broad topic knowledge into an answerable question using the easily identifiable component parts. In addition, a fourth component was added to reflect the specificity

of the research question and the subsequent searches, *i.e.* that of 'influence' (or variations of this word with a similar meaning).

PICO was further used prior to the searching phase to identify potential key search terms for each component in order to make the search as comprehensive as possible and avoid missing any papers because of idiosyncratic terminology. Initially, these terms were taken from the research question, before being entered into the 'explore MeSH vocabulary' facility of the MEDLINE database to find variant terms and spelling (U.S. National Library of Medicine, 2016). These terms were also searched in a general, non-medical thesaurus to expand the list further. Table 3.2 below shows the search terms and their variants that were identified.

Table 3.2 Search terms

PICO	Population	Intervention	Comparison/ control	Outcome	Additional component
Initial terms identified	*Parent**	*Public health*	*Not applicable*	*Consent*	*Influence*
Search terms identified through database thesauri	Guardian*	Population health	*N/A*	Autonom*	Effect*
	Decision maker*	Community health	*N/A*	Permi*	Impact*
	Person responsible	Health promotion	*N/A*	Acquies*	Stimul*
	Step parent*	Prevention	*N/A*	Allow*	Pressur*
	Famil*			Refus*	Persuad*
	Father*			Compl*	Prompt*
	Mother*			Agree*	Motivat*
	Maternal			Decision*	Shap*
	Paternal				Guid*

*Indicates that variant words will also be searched via truncation, *e.g.* Parent and Parents

Using these terms, the search and selection strategy put forward by Ridley (2010) was deployed to find papers for inclusion in this review. Briefly, this advocates three main stages. The first is largely exploratory and sets the parameters for inclusion/exclusion; the second is more focused and narrows the search to specific topic areas while

providing the opportunity for the initial critical appraisal of the literature; and the third stage includes using appraisal tool(s) to critically analyse the literature in detail prior to designing the architecture for the flow of analysis and discussion. A flow chart of the different stages of the search strategy using these terms can be found in Figure 3.1.

Before investigating any databases, inclusion and exclusion criteria were formulated to refine the sourced material to only that of direct relevance. It was also considered that, by using explicit inclusion and exclusion criteria, any reader would more easily be able to judge the reliability and validity of this review. Once selected, all papers were assessed for institutional or commercial bias and if this was present the paper was discarded. Alternatively, if the publication was felt to be of importance, the decision was taken that any potential bias of this kind would be noted and made apparent to readers.

Priority was given to research undertaken in developed countries with national health care systems. These countries were identified from the Organization for Economic Co-operation and Development's (OECD) membership (2016). Specifically, these were USA, Canada, New Zealand, Australia, Chile, Japan, Turkey and all countries in Europe. The reason for this is that parental consent is being requested within the context of liberal societies that prioritise individual autonomy but also (to a greater or lesser extent) have government structures that take some responsibility for child health through the delivery of public health programmes and services. The justification for giving priority to research carried out in these countries is borne out by Durkheim (1897, cited in Mostofsky, Forgione and Giddon, 2006, p.265), who demonstrated that healthiness is a population characteristic and that social environment determines individual behaviour. The inclusion and exclusion criteria used are listed below, in Table 3.3. The criteria were all given equal importance, *i.e*. there was no hierarchy.

Table 3.3 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Published in the English language	A letter to an editor and/or an editor's published response, or a published opinion piece or other non-peer-reviewed paper
Published in a peer-reviewed journal	The publication is a systematic review or literature exposition
Published within the last 10 years	Research is about mental capacity (as defined by the MCA, 2005) to make a decision, not about personal and/or social influences on parents' decisions
Research must be carried out in countries that are members of the OECD (USA, Canada, New Zealand, Australia, Chile, Japan, Turkey and all countries in Europe)	The publication is about the use of a decision tool or aid
Parents must be making decisions about school-age children (4-18 years old)	
Research is about public health programmes	
Research must be empirical	

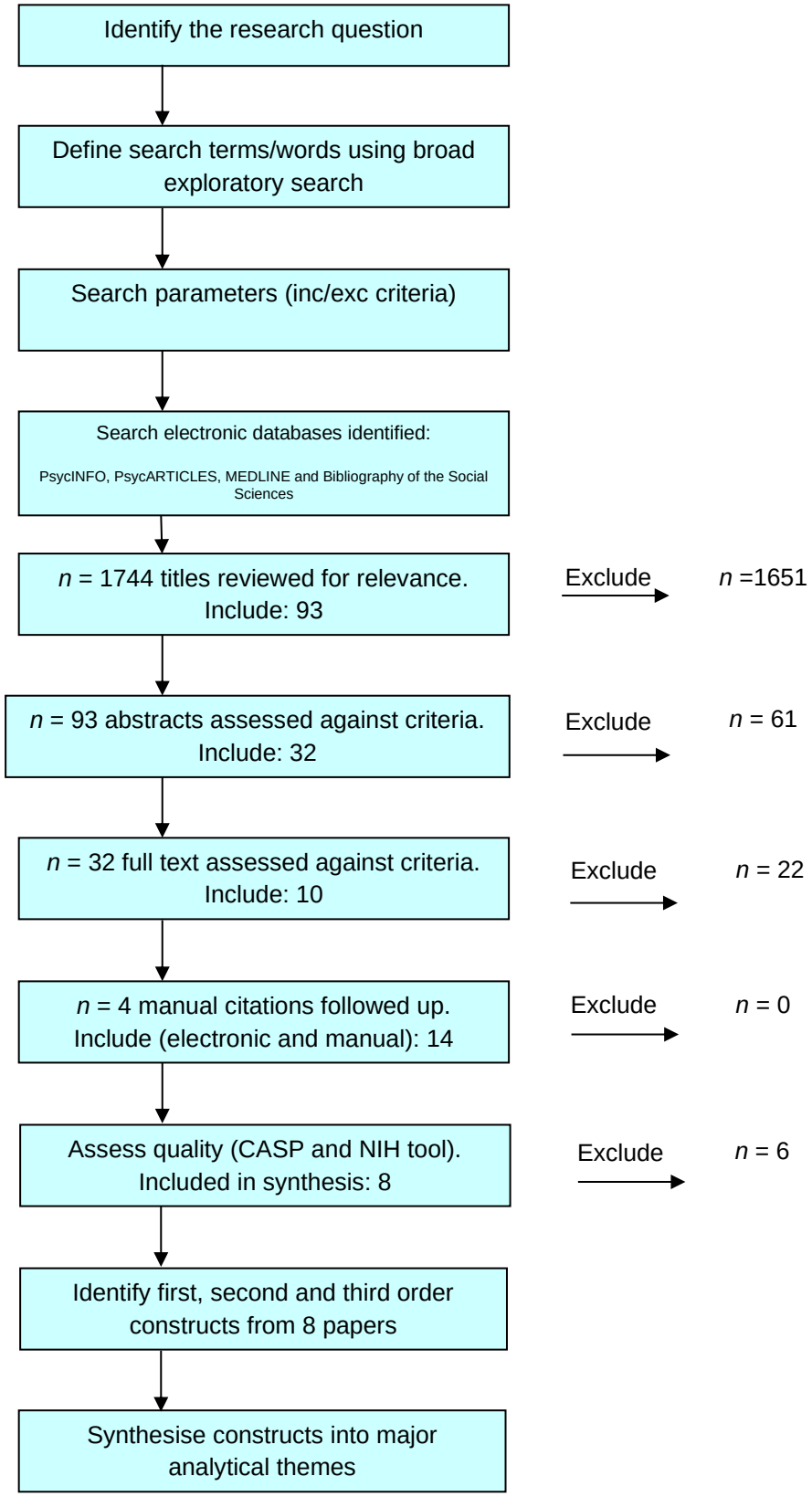
The decision was taken to include both quantitative and qualitative studies so as not to exclude any potential sources of information. However, it was anticipated that because the research question begs information that is reflective of parents' experiences, opinions and behaviour, which is the territory of qualitative research, more papers of this nature would be found. The decision was taken to include papers

from only the previous 10 years for two reasons. Firstly, it is within this timeframe that the role of relational autonomy as discussed in Chapter 2 (Theory) has entered the academic literature; prior to this, autonomy was thought of more simplistically and often conflated with availability of choice. This review is interested in how and why consent decisions are made, which is the focus of relational autonomy. Secondly, it was in 2006 that the Department of Health in England introduced the changes to consent for dental public health programmes and a previous literature review conducted as part of my MSc programme found no papers related to this topic prior to this date (Jeavons, 2012).

Information was sourced from electronic medical databases and academic web search engines. The electronic databases PsycINFO, PsycARTICLES and MEDLINE were accessed via the search platform EBSCOhost. The International Bibliography of the Social Sciences was also searched. This is a stand-alone database that was directly accessed from the library at City, University of London. Initial searches were conducted from August to November 2016. Subsequent to this, electronic searches were set up in each database. This was to alert me when any new papers were published that matched the search criteria. Between November 2016 and submission of this thesis in 2019, 69 alerts were received, and six additional papers were put forward for further assessment. Each paper was reviewed individually as part of an ongoing process to keep the evidence presented in this review current. Additionally, citation follow-up was carried out, with potential papers being identified from the initial review of electronically sourced literature. Papers located in this way were subject to the same inspection processes as the others, *i.e.* the use of a research quality assessment tool and comparison against the inclusion and exclusion criteria. A flow diagram (Figure 3.1) of the process followed for this review can be found below.

Figure 3.1 Search and selection process (adapted from Moher *et al*., 2009)

NB: Critical Appraisal Skills Programme (CASP) and National Institute of Health (NIH) quality assessment tools are explained later in section 3.2.c.



3.2.b The search process

The process for this review follows the PRISMA guidelines (Moher *et al*., 2009). Searches were undertaken using the university's online library facility. Electronic searches were recorded manually in logs detailing the date, search platform, database, search limits, key terms and number of results; these can be found in Appendices 3.1 to 3.4. All papers identified via electronic searches were available from the university library or from Google Scholar and there was no need to pursue inter-library loans.

When conducting electronic searches, the Boolean operators 'OR and 'AND' were employed to increase the precision of the search (Greenhalgh, 1997). The alternative key words identified in Table 3.2 were utilised to ensure that no relevant papers were missed due to idiosyncratic use of language. However, this led to a large number of irrelevant papers being included in the initial stages of the searches, *e.g.* 86,368 matches were achieved via EBSCOhost in the PsycINFO database when searching for 'parent* OR any of the alternative key words' identified in Table 3.2 above. Therefore, search precision was further increased through the use of search strings. These can be found in Appendices 3.1 to 3.4. Electronic alerts of forward citations were also set up within database platforms in order to keep the review current throughout the life of this thesis.

Inductively identified material was selected initially from the publication title. Publications considered useful were examined more closely, with abstracts being read online. At this point, the inclusion and exclusion criteria were used to assess broad suitability and any duplicated texts were excluded. Those publications thought to be relevant were downloaded and printed and these hard copies were filed, building up a small library of literature specific to this thesis.

The full text of each paper deemed relevant as a result of the abstract review was read and compared with the inclusion and exclusion criteria. To facilitate this, an abstraction table was developed and piloted, with further information prompts being

added early in the process (Appendix 3.7). This table was completed and filed with the hardcopy articles. As part of this more detailed consideration, those papers that did not meet the inclusion criteria, or breached the exclusion criteria, were discarded. Ridley's (2010) SQ3R method of handling literature was employed to facilitate this process. Briefly, this advocates: Surveying the text; Questions it should answer; Reading it in detail; Recalling it by taking notes; and Reviewing it for further details. This detailed cataloguing of individual texts strengthens the methodical and systematic approach of this literature review. A master summary table of all relevant papers and texts was compiled using information from the individual abstraction tables (Table 3.5). This table was created primarily for ease of reference for the later stages of this review and not as a substitute for further detailed re-reading.

3.2.c Quality assessment

No agreed quality criteria exist with which to judge qualitative research (Atkins *et al.,* 2008; Thomas and Harden, 2008). Furthermore, Sandelowski and Barroso (1997) argue that the lack of consensus about what can be considered 'good quality' qualitative research means that such a judgement cannot be used as justification for exclusion from a literature review. However, similarly to Thomas and Harden (2008), to avoid drawing unreliable conclusions the decision was taken that an assessment of quality was of value. Furthermore, this would provide an opportunity to respond to objective (IV), as set out at the start of this review. Therefore, the quality checklist developed by the Critical Appraisal Skills Programme (CASP) (2013) for qualitative papers was used. Quantitative papers were assessed in terms of quality via the National Institute of Health's (NIH) assessment tool (2014). Any papers that received negative responses for more than half of the assessment questions were excluded. This reduced the body of literature further.

The CASP assessment tool for qualitative papers can be used to assess interpretivist research that uses a variety of methods, ranging from grounded theory to descriptive observational studies. Initially, all qualitative papers were read and assessed against

the two 'screening' questions posed at the start of the CASP checklist. Once papers had passed this hurdle, the remaining eight questions were used. In an attempt to be as inclusive as possible in the spirit of Sandelowski and Barroso (1997) and others (who argue that it is more important not to miss relevant papers than to reject them due to quality issues), qualitative papers were excluded only if the information they provided did not clearly articulate the aim or purpose of the study, or if other substantial areas of the report were missing details, for example if there was little interpretation or discussion of the results. This would have made the later meta-synthesis difficult, particularly when using first and second order constructs. These papers were essentially rejected due to the quality of the research *report*, rather than necessarily due to an objection to or a flaw within the research itself. Papers were retained for inclusion in the final analysis for heuristic reasons even if one or more of the critical assessment questions was answered 'no' or 'can't tell'. Despite this, a quality assessment tool was felt useful because it provided the opportunity to evaluate the potential contribution the papers would make to the final synthesis (Malpass *et al.,* 2009).

CASP (2013) assessment tools also exist for quantitative papers but none of these are specifically aimed at cross-sectional studies. Therefore, the NIH (2014) assessment tool designed for this type of research (as well as jointly for cohort studies) was used. All quantitative papers selected for critical appraisal assessment were cross-sectional. There are no 'pre-screening' questions with this tool, so all quantitative papers were assessed against the full set of questions, although some of these were more geared towards cohort studies and therefore were not included in the critical appraisal. For example, '*For analysis in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?*' (NIH, 2014). The tool itself indicates that for cross-sectional studies the answer to this question, along with that to others that are similar in focus, should be 'no' because it is not relevant.

3.2.d Approach to analysis

Meta-synthesis was employed to analyse all papers (Sandelowski and Barroso, 1997). This was based on the interpretative strategy for thematic synthesis first described by Thomas and Harden (2008) and later included in the Economic and Social Research Council's critical review of qualitative synthesis (Barnett-Page and Thomas, 2009). The meta-synthesis involved reading the papers in detail and identifying broad recurring descriptive themes. Ward, House and Hamer (2009) recommend creating a master summary table of these themes to help provide a framework for synthesising literature. This recommendation was implemented in this review and the table is presented in Appendix 3.8. After this, to help create a detailed appraisal of the literature, the themes were subdivided and categorised as 'first, second and third order' constructs (Malpass *et al.*, 2009). First order constructs were taken as participant views and were usually represented in the papers as direct quotes. Some quotes have been used in the discussion section of this chapter to highlight particular points being made and to demonstrate the root of the interpretation. Descriptive themes or interpretations put forward by the papers' authors were deemed second order constructs. These have been described in some literature as 'analytic commentaries' on the first order constructs, *i.e.* the original views and opinions (Lee, Ayers and Holden, 2014). These second order constructs were usually located in the 'findings' or 'results' section of the papers. Commonalities within the second order constructs were identified and these were grouped into major analytic themes that provided the first layer of synthesis (Appendix 3.8). These newly synthesised 'analytic themes' were then used to bring new insight to the data and produce a coherent body of knowledge across all papers. These insights and the resulting knowledge are classed as third order constructs by Malpass *et al.* (2009) and they form a distinctly separate phase of analysis, *i.e.* interpretation of the synthesised literature. This process is an attempt to push beyond the original data to a fresh interpretation of the phenomena under review (Economic and Social Research Council, 2009; Thomas and Harden, 2008; Walsh and Downe, 2005). These third order constructs are far removed

from the original data. Therefore, quotes that capture first and second constructs were used to buttress the synthesis of these and to support the validity of the final argument (Jensen and Allen, 1994).

A similar process to that outlined above for qualitative papers was used to synthesise the quantitative papers. Detailed reading of the papers took place before any recurring themes were identified. These themes were also subdivided into first and second order constructs. First order constructs here are somewhat different from those described above in that they largely consisted of statistical data. These statistical data are not a 'social construct' in that it represents a participant's view or opinion, but it can be considered a construct of sorts in that the statistical analysis has been influenced by the decision to use particular variables and statistical calculations. However, these statistics do represent participants' actions, albeit identified and reported by others, *e.g.* the percentage of participants who provide positive opt-in consent. As with the qualitative first order constructs, these quantitative 'constructs' were not the focus of the synthesis, but were used in a supporting role. Second order constructs in this instance were taken from the written analysis and discussions found in these papers, and they are akin to the second order constructs used for qualitative papers. By using the technique of identifying descriptive themes from second order constructs to then identify third order constructs, the meta-synthesis required to develop an overarching body of knowledge was made possible, despite the original data coming from disparate forms of research. This ultimately enabled the aim set out at the start of this review to be met, using all relevant literature.

Through detailed reading and analysis of the content of these papers, 26 third order constructs were initially identified. Further analysis showed that some of these overlapped to such an extent that maintaining them as separate constructs added little value to the synthesis. For example, 'weight of proxy decision' and 'desire to make the "right" choice', were merged. As part of this process, all first and second order constructs were reviewed to ensure that any identified third order constructs

that were merged still reflected the original data. Third order constructs were then grouped into six overarching analytical topics for discussion: Professional input, Information/knowledge, Perceived threat/susceptibility, Responsibility, Internal beliefs, and Social and community networks. These topics are interpretations and, as such, might not be mentioned explicitly in the original research papers; rather, they are a synthesis and are derived from all eight papers included in this review (Sandelowski and Barroso, 2007). The data extraction table (Appendix 3.8) shows all first, second and third order constructs.

3.3 Results

The section contributes to meeting objectives (I), (II) and (IV).

I. To systematically identify empirical research that is used to investigate influences on parental decision making for public health programmes aimed at school-age children

II. To systematically identify and analyse research that documents whether, and how, approaches to parental consent are informed by ethical theory

IV. To review the strengths and weaknesses of research methods documented in the literature to investigate parental consent for public health programmes aimed at school-age children

3.3.a Data

Searches showed that a large volume of irrelevant literature outside the realms of public health was routinely identified by databases, and this was easily and quickly discarded. However, studies that initially appeared useful from their title consistently focused on end-of-life care, decision-making tools for individuals and professionals, or programmes delivered in Africa, specifically those related to HIV and ethical

decision making with regard to genetics. Many fewer papers were found that detailed influences on parental decisions related to consent or preventive public health or, indeed, on the views of parents themselves.

In this PsycARTICLES database there was little focus on influencing factors, consent or decision making for public health and this resulted in 242 papers being discarded on the basis of their title alone (Appendix 3.2). Three papers put forward for full text review were not available via the PsycINFO database; they were, however, obtained and included (Appendix 3.3). Two came from City's library and one was sourced via Google Scholar. Additionally, papers in the PsycINFO database often focused on clinical decision making and not decision making for public health. However, after its title or abstract was read, unless a paper was very obviously not suitable according to the inclusion and exclusion criteria it was accepted and put forward to the next stage of the filtration process, *i.e.* review via abstract or full text read. Many of the 643 papers that were discarded because of their title were concerned with adult health, with common subjects being decision making for cancer treatment (colorectal cancer was often cited), genetic screening and HIV treatment in African countries. Equally, a number of papers were discarded because they were concerned with the care of infants, *i.e*. children below school age. Common themes included decision making with regard to birth choices, breast feeding and screening in pregnancy.

Regarding the MEDLINE database, the exclusion of papers on the basis of their title (714) was largely for the following reasons: country of origin; a focus on a decision aid or tool; research into newborns or pre-term babies; or the fact that they were clinical, *e.g.* on decision making regarding acute treatment (Appendix 3.4). The final database that was searched was the International Bibliography of the Social Sciences. This was done directly rather than via a platform such as EBSCOhost as with the other three databases. The results of this search are shown in Appendix 3.5.

Below are the results of the online literature reduction process used to filter the papers found in each database.

Table 3.4 Online literature reduction process

Database	Search term(s)	Total number of papers found (titles reviewed using inclusion and exclusion criteria)	Number accepted after title read (using inclusion and exclusion criteria)	Number accepted after abstract read (using inclusion and exclusion criteria)	Number accepted after full text read (using inclusion and exclusion criteria)
PsycARTICLES	Parent* OR alternative key terms AND public health OR alternative key terms AND consent OR alternative key terms AND influenc* OR alternative key words	260	18	6	0
PsycINFO	Parent* OR alternative key terms AND public health OR alternative key terms AND consent OR alternative key terms AND influenc* OR alternative key words	693	50	15	5
MEDLINE Complete	Parent* OR alternative key terms AND public health OR alternative key terms AND consent OR alternative key terms AND influenc* OR alternative key words	737	23	10	5
International Bibliography of the Social Sciences	Parent* OR alternative key terms AND public health OR alternative key terms AND consent OR alternative key terms AND influenc* OR alternative key words	54	2	0	0
Total number of papers accepted at each stage		1744	93	32	10
Total put forward for quality assessment					**10 (plus 4 sourced via citation follow-up)**

References cited in already identified papers that had direct relevance to the subject were also investigated. As a result, 44 papers were reviewed by title, with 28 being rejected due to duplication or irrelevance and 16 downloaded for further investigation. Of these, 10 were rejected after comparison with the inclusion and exclusion criteria and six were put forward to be read in full, a which stage two were rejected, leaving four to be scrutinised for quality.

In total, 37 full-text papers were read for relevance, but 23 of these were excluded once compared against the inclusion and exclusion criteria. Papers were excluded for the following reasons: two detailed the use of a decision aid; three were not about parental consent for children aged 4-18 years old; three were literature reviews themselves and these were not wholly relevant to the subject; two did not detail empirical research; two were about consent for adult treatments; nine were about the uptake of vaccination services rather than influences on parental decisions; and one was a duplicate. As a result, 14 full-text papers were put forward to be assessed for the quality of the research methods. Appendix 3.6 shows details of the 14 papers that were excluded after critical appraisal using either the CASP tool for qualitative (2013) research or the NIH tool for cross-sectional studies (2014). As a result of this process, a further six papers were excluded and eight were included in the final review. A summary table of all eight papers that comprise the final analysis is shown below. This includes the key features of identification for each paper (Table 3.5).

The 69 papers identified via electronic alerts (from 2016-2019) were reviewed in the same way as those in the initial search *i.e.* by title, abstract, and full text comparison to the inclusion and exclusion list. No papers were put forward for further assessment via the quality tools because all of them failed to meet the required criteria. As such no additional papers were added to the final review. From this set of 69 papers the majority were not relevant to the subject matter and dismissed quickly. However, six were considered for inclusion in more detail and compared against the inclusion and exclusion criteria, but ultimately they were rejected. The reasons for this were; two

papers detailed research outside of the OECD area (Zambia and Croatia), one paper was about parental decisions in a clinical, not public health context, one was a systematic review of parents' decisions about medical care for their children, and two were linked to the same study about adolescent decision making.

Table 3.5 Master summary of all papers included in the final analysis for this review

Author(s)	Date	Research design	Country
Shelton, R., Snavely, A., De Jesus, M., Othus, M. and Allen, J.	2013	Cross-sectional study investigating consent decisions by parents for the HPV vaccine. Online survey sent to participants selected through multi-stage probability sampling and random digit dealing.	United States of America
Krawczyk, A., Knauper, B., Gilca, V., Dube, E., Perez, S., Joyal-Desmarais, K. and Rosberger, Z.	2015	Cross-sectional study investigating consent decision by parents for the HPV vaccine. Questionnaire sent to a random sample of participants selected from the Quebec Medical Health Insurance Board database.	Canada
Dorell, C., Yankey, D. and Strasser, S.	2011	Cross-sectional study investigating consent decisions by parents for the HPV/tetanus-diptheria-acellular pertussis (Tdap) and meningococcal conjugate (MenACWY) vaccines. Two-stage data collection was conducted, with participants selected via random digit dialling, and subsequently a questionnaire was posted to those eligible.	United States of America
Vandenberg, S. and Kulig, J.	2015	Grounded theory study investigating consent decisions for childhood vaccinations (the specific vaccinations were not identified). Data collected from 8 mothers who had chosen not to provide consent and 12 health care professionals using semi-structured interviews.	Canada
Dempsey, A., Abraham, L., Dalton, V. and Ruffin, M.	2009	Structured interviews with open-ended questions were used to investigate consent decisions by mothers for the HPV vaccine, targeted at girls (11-17 years) and analysed via thematic analysis.	United States of America
Cooper Robbins, S., Bernard, D., McCaffery, K., Brotherton, J. and Skinner, S.R.	2010	Semi-structured focus groups were conducted with girls from nine purposively selected schools, along with interviews with parents, teachers and nurses to investigate consent decisions for the HPV vaccine. Thematic analysis was used.	Australia
Gottvall, M., Grandahl, M., Hoglund, A., Larsson, M., Stenhammer, C., Andrea, B. and Tyden, T.	2013	27 interviews with parents of children aged 11-12 years who had consented to HPV vaccination were conducted and thematic content analysis was used.	Sweden
Hofman, R., Empelen, P., Vogel, I., Raat, H., Ballegooijen, M. and Korfage, I.	2013	Four focus groups were conducted with parents of daughters aged 8-15 years to investigate consent decisions by parents for HPV vaccine. Three groups consisted of Dutch parents and one of Turkish parents. Thematic analysis was performed.	The Netherlands

3.3.b Critique of research methods

The research methods employed in the identified papers is discussed below. Due to the different paradigms and quality markers of quantitative and qualitative research, these two types of study have been discussed separately.

Quality – quantitative papers

Three of the research papers included in this final review employed quantitative methods and they all used a cross-sectional research design (Krawczyk *et al.*, 2015, Shelton *et al.*, 2013 and Dorell, Yankey and Strasser, 2011). All three papers explicitly defined the issues they were investigating and clearly stated their respective research questions. Authors from all three papers began by describing the demographic details and characteristics of the potential participants. As the papers all used a cross-sectional design, these descriptions followed a similar formula, *i.e.* who the potential participants were and where they were recruited from, and during what period the recruitment took place. Shelton *et al.* (2013) recruited participants who were parents with at least one daughter aged 9-17 years old and were identified from a nationally representative database in the USA. These participants were recruited over a five-month period and 67% of the potential 836 participants were included. This percentage provides a level of representative security for all those included on the database. However, not all parents of daughters in this age range are included in this database, which is held and managed by a commercial research company with expertise in internet-based surveys. As such, the initial sample (database members) is self-selected and although the authors state that the database is nationally representative, no further details are provided. This introduces an element of difficulty in assessing the potential bias of research based on a sample of parents willing to be included in a commercial database, particularly when the subject under investigation is participatory decision making. Parents who are passive decision makers are more likely to be excluded from this database and, therefore, the sample. All database members are provided with a free internet service and a webTV, to

facilitate participation. Krawczyk *et al*. (2015) recruited parent participants with daughter(s) aged 9 or 10 years old living in the Canadian province of Quebec. Recruitment was via the Medical Insurance Health Board database over a six-month period in 2010. This study achieved 33% participation, with 834 parents returning a completed questionnaire. This response rate is well below the 50% suggested for representativeness in the NIH assessment tool (2016). Notably this was identified by the authors of the paper as a limitation. Dorell, Yankey and Strasser (2011) used data from the National Immunization Survey – Teen in the USA to identify potential parent participants with daughter(s) aged between 13 and 17 years who had not received vaccination for tetanus-diptheria-acellular pertussis (Tdap), meningococcal conjugate (MenACWY) or human papilloma virus (HPV). Recruitment took place over a 13-month period in 2009-10. Participation rates in this paper are not presented as a whole but are broken down into the three vaccination groups. However, the potential number of participants is not clearly identified, making it difficult to assess the representativeness of the sample. Additionally, authors have stated that participation was predicated on a landline telephone and the 2009 National Health Interview Survey reported that 25.9% of households were wireless-only, which may have contributed to non-coverage bias. Understandably all three papers here report on data collected from parents who responded in some way to a request to participate but, as already alluded to, this is likely to exclude those parents who do not provide a definite response, *i.e.* active agreement or disagreement to participate. Therefore, how much the research reported here is representative of parents who may be passively excluded from vaccination or similar types of public health programme is not known. The emphasis, therefore, is definitely on data provided by the type of person who is a 'responder', be that positively or negatively.

Potential confounding variables were adjusted for in two of the quantitative studies (Shelton *et al.,* 2013 and Dorell, Yankey and Strasser, 2011) this demonstrates that the authors were concerned with producing results that were free from external influence as much as possible. Shelton *et al.* (2013) applied weights to parents as the

unit of recruitment and then also to daughters as the unit of analysis. Some parents made different vaccination decisions with different daughters, so this took account of that variability. Dorell, Yankey and Strasser (2011) also applied weighting as part of their statistical analysis, with application to reflect the distribution of race/ethnicity, age and maternal educational attainment. However, in both these papers little information about the weighting was given other than stating that this has taken place. Krawczyk *et al.* (2014) make no mention of weighting or other 'statistical adjustments', but their random sampling from a large potential sample of 2500 parents will have ensured an element of variable control.

Additional validity was considered if the outcome measures, data collection and corresponding results were described in detail by authors. Among the three papers included, this was the case with Shelton *et al*. (2013), who looked at the influence of religion and provided all the questions and the answer options that were included in the online self-administered questionnaire for parents, although no details were provided of how the questions were developed or whether they were piloted prior to use. The outcome was measured via participants' self-identification with a religion, *e.g.* Catholic or Protestant, and the frequency of attendance at religious services was an indicator of involvement. Statistical results were presented after logistic regression had been performed. Dorell, Yankey and Strasser (2011) also used a survey of parents to gather their data and the questions asked were provided with the published paper, but in contrast to Shelton *et al.* (2013) the potential answers were not provided because the questions were open-ended. In this instance, responses were coded into categories before univariate analysis was performed to describe the sociodemographic characteristics of unvaccinated adolescents, and bivariate analysis carried out to show the significant differences in parental reasons for non-receipt of vaccine by recommendation status. Results were provided in two tables of statistics. Krawczyk *et al.* (2015) specifically identified the outcome measure for their study as '*HPV vaccine uptake'* and data was collected via a piloted questionnaire with the main question of '*Has your daughter received the HPV vaccine*?' being measured via a Likert

scale. Additional factors related to vaccine acceptance that were found in the literature were also assessed and included in the published paper. In this section, parents were required to answer '*true, false, or don't know*' to statements such as '*HPV is the most common sexually transmitted infection*. Descriptive statistical analysis was performed and this included chi-square and the independent-sample *t*-test, which were used to identify significant sociodemographic differences between parents who obtained the vaccine for their daughter and those who did not. Additionally, univariate logistic regression was performed to test the author's hypotheses. Results were presented in three tables, with the uptake of the HPV vaccine being the focus.

The cross-sectional design of all three studies is observational and this is appropriate in this situation, where a specific phenomenon is being looked at that is not time sensitive, *i.e.* vaccination. One decision is made and cannot be changed after the vaccination has taken place; it is a one-off event. In this respect, this quantitative study design is similar to that of the qualitative papers that were included, because each of the research projects was analysing and reporting within a specific context that was evident in that place at that time with those participants. However, by using this study design, the researchers were not able to take account of or report on parental decisions that change from one child to the next, or where parents have made one decision, *i.e.* to vaccinate or not, and have then changed their mind for subsequent doses. This sort of information would be useful with regard to parents' decision making and how it may change depending on external influences. This could have been studied if a longitudinal design had been used to follow parents up at a later stage. As it stands, the three studies included in this review provide some, albeit limited, information about the decisions made by parents. The contextual depth of data about the process of decision making found in qualitative papers cannot be expected to be seen in these three quantitative papers, but they do provide an insight into the proportions of parents from various parent groups who respond positively or negatively. The focus in the analysis of all three papers appeared to be largely on

uptake, with reasons for consent or refusal a secondary point. This focus mirrors that found in dental papers, *i.e.* one of uptake rather than of looking at potential reasons why parents may or may not consent (Appendix 3.1).

Quality – qualitative papers

The remaining five papers adopted a qualitative approach to their research, and all five produced positive answers to the initial CASP (2013) screening questions, *i.e. 'Was there a clear statement of the aims of the research?',* and *'Is a qualitative methodology appropriate?*' Despite this, none of the papers explicitly discussed the ontological or epistemological underpinnings of the research, as might be expected by the inclusion of this question. All five did provide details of the research design that was used, and this varied from grounded theory (Vandenberg and Kulig, 2015) through structured (Dempsey *et al.*, 2009) and semi-structured interviews (Gottvall *et al.,* 2013; Cooper Robbins *et al.,* 2010) to focus groups (Hofman *et al.,* 2013). However, none of these papers' authors justified or discussed why a particular method was used. Therefore, it is difficult to assess whether the choice of method was driven by the context of the research, the authors' interest and expertise, or any other reason. This is also true for the various recruitment strategies that were used in the papers by Dempsey *et al.* (2009) and Cooper Robbins *et al.* (2010), in which the specific details of the methods were limited. Qualitative research is particularly sensitive to the methods used to collect data, including who is or is not recruited and how this is done, in a way that quantitative research is not because of the buffering effect of potentially large sample sizes that quantitative research attempts to use. With qualitative studies, many of which are based on small sample sizes, such as Vandenberg and Kulig (2015) who recruited eight mothers and 12 health care professionals, the process used to gather data from start to finish is an important element of the research context, which in turn influences the results. While small sample sizes and influence are not problematic for qualitative research, it should be considered good practice to include details of these processes in the published papers

so that the reader can understand the full context of the research. On a similar note, almost all of the studies included here omitted to provide details of how, or even whether, researchers had considered their relationship with the participants and any potential implications of this for the research. This seems strange, given that qualitative research by its very nature is subjective and a construct of the researchers who study, analyse and report it. The only exception to this was Dempsey *et al.* (2009, p.537), who state that the technique described below was used to avoid '*interviewer-imposed bias,'* and they;

'*…relied on spontaneous maternal responses to open-ended questions to identify reasons underlying decision about HPV vaccination (as opposed to querying mothers directly about specific reasons)'.*

Ethics committee approval for the research was mentioned by all authors, as was gaining participants' consent prior to inclusion, although Dempsey *et al.* (2009) state that the University of Michigan's Human Subject Committee approved a waiver of consent for addresses and other information to be shared with the research team. It is unlikely that such access to personal data would have been agreed to in the UK at that time because of the Data Protection Act (Great Britain, 1998) that was in place (now superseded by the Data Protection Act [2018]).

Another area of apparent weakness in these papers, and a contributing factor to the rejection of others, was the lack of detail about how the data was analysed. The papers by Vandenberg and Kulig (2015), Cooper Robbins *et al.* (2010) and Dempsey *et al.* (2009) all mentioned that the data was organised into themes. Vandenberg and Kulig (2015) provide very little information on the analysis techniques used, and the whole paper is more descriptive than analytical. Cooper Robbins *et al.* (2010) state that these themes were grounded in both the literature and the data, but the results presented in the paper do not make this clear, nor are they presented as themes. Furthermore, Dempsey *et al.* (2009) state that 11 themes were identified, but only nine were discussed in the published paper. In contrast, Gottvall *et al.* (2013) provide

a detailed description of the analysis process and an example of how descriptive codes were organised into three main themes, before they discuss the themes in detail. This makes it clear to readers how the authors produced their findings and, as such, readers can be confident in the recommendations of this paper. Hofman *et al.* (2013) also describe their analysis process, which led to a list of descriptive codes and themes. Additionally, parents' quotes from the original data are provided as exemplars of these codes and themes. This inclusion of quotes makes it clear to the reader that the subsequent discussion is rooted in the data. All five qualitative papers were thought to have added both value and (otherwise not known) information to this review.

Overall, it appears to be the lack of justification and detail concerning the research processes that are reported, *i.e.* research design, methods and recruitment analysis, that warrants the most critical appraisal, not necessarily the research itself. Often processes or methods are mentioned or implied but not explicitly described or discussed. As a result, it is likely that more papers from the wider field of public health were rejected when the research was sound but unfortunately the published paper was not.

3.3.c Summary of literature content related to influences on parental consent

All eight of the papers included in this review examined the issue of parental decision making as a specific and discrete entity. However, none of them discussed ethical theories, concepts or frameworks of any kind. In fact, a theoretical basis appeared to be missing in almost all of the papers, with the exception of Krawczyk *et al.* (2014) who mentioned the Health Belief Model (Rosenstock, 1974, cited in Krawczyk *et al*., 2014, p.323) with regard to health behaviour in the text of the article but failed to present any results in relation to this. Had the authors done so, the extent to which perceived susceptibility or threat influenced parents' consent behaviour would have added useful details to their results.

Cooper Robbins *et al.* (2010), Gottvall *et al.* (2013) and Krawczyk *et al.* (2014) report on vaccination programmes that take place outside of a medical setting, for example in a school, where parents are contacted in advance of the vaccination itself. The study by Cooper Robbins *et al.* (2010, p.619) takes place in Australia and although the paper states that *'…information sheets and consent forms are disseminated to parents…'* no further details are provided about this process. In the Swedish study by Gottval *et al.* (2013, p.263), the authors reported that *'information about HPV vaccinations and informed consent is distributed to parents by School nurses*'. Krawczyk *et al.* (2014, p.327) state that *'…parents may consent to in-school vaccination for their daughter via a signed permission slip that is returned to school with their child'*, but give no details of who has signed, or whether any information is first discussed or disseminated to parents. The study by Hofman *et al.* (2013), which took place in the Netherlands, does not explicitly state that the programme is delivered via a school, but this is implied as the parents were recruited for the study via primary schools. An additional two papers (Vandenberg and Kulig, 2015 and Dempsey *et al.,* 2009) reported on vaccination programmes that were administered in a doctors surgery, clinic or office. Programmes such as these have the added advantage of providing parents with the opportunity to ask questions and discuss the vaccination procedure with a health care professional. This is at odds with the situation in the UK, in that vaccination and dental public health programmes are often delivered within a school environment where little or no face-to-face contact takes place between parents and health care professionals. In these instances (and potentially similarly to Krawczyk *et al.*, 2014 and Cooper Robbins *et al.*, 2010) a letter is sent home to parents to consider and then provide their consent (or not) by signing it and returning it to the school. This is a considerably more 'arm's-length' approach to consent, with parents expected to come to a decision in isolation without the help of a health care professional. The papers by Dorell, Yankey and Strasser (2011) and Shelton *et al.* (2013) make no mention of how the vaccination programmes are

delivered. However, both papers are based on studies in the USA, where it is common to attend a doctors surgery or clinic for vaccinations.

The majority of papers included here focused on decisions regarding HPV vaccination. Although this was not the intention of this review, there are parallels with dental public health. For example, the vaccine is not mandatory and refusal does not therefore prohibit any usual childhood activities such as school attendance. Similarly, inclusion in epidemiological surveys and fluoride varnish schemes is voluntary. Three doses of the HPV vaccine are needed for it to be fully effective and, as such, parents (and children) have the opportunity to agree initially but then change their mind. Fluoride varnishes should be repeated six monthly to provide full preventive advantage, meaning parents can initially provide consent but then change their mind and refuse it for subsequent doses. Both HPV vaccine and fluoride varnish are preventive, *i.e.* they will not halt or cure a disease already established but they will limit the chances of disease developing. Therefore, consent decisions are made on consideration of hypothetical scenarios that may or may not happen in the future, not on imminent situations or current disease experience. Also, the diseases that the HPV vaccine and fluoride varnish are targeted at are linked to personal behaviour that is not considered unusual in most Western societies, *e.g.* sexual activity with more than one partner (although not specifically for teenagers) and regularly consuming sugary food and drinks.

The papers that were identified and selected for this review were shaped by the inclusion and exclusion criteria set out at the start, prompting the inclusion of particular types of research paper. For example, the HPV vaccine is relatively new, particularly for boys, and the parental decision about if and when to provide consent is an obvious area of academic and practical interest due to the link with sexual activity. This provides a fertile area for research into parents' reasoning and their actions as the potential outcome of their decisions. It is likely that those interested in

decision making, ethics, sociology, public health, health care delivery, sexual health, religion and parenting (among other topics) will find research in this area of interest.

3.4 Findings

3.4.a Synthesis of findings: factors affecting parental consent

Information in this section aims to meet objective (III), set out earlier.

III. To systematically meta-synthesise findings from a range of research papers that investigates influences of parental consent, developing third order constructs

The information presented below is a synthesis of third order constructs based on all eight papers. For the purpose of clarity, the six identified overarching topics have been discussed individually, but as there is an overlap between topics, none should be viewed as a completely discrete entity when evaluating the influences on parental decision making. From the papers reviewed here, it was not possible, or indeed necessary, for this review to determine whether the influencing topics identified should be arranged or reviewed in a hierarchy. However, one additional topic, that of 'trust', was clearly evident within almost all six topics. Initially, this was analysed and presented similarly to the others, but because of the universality of trust as an influencing factor in many different scenarios, it should be seen as a thread through all six topics. First and second order construct quotes are provided to help illustrate the points being made and to provide a route from the interpretation back to the original data.

Professional input

Two inferences related to professional input can be drawn from the third order constructs identified in Appendix 3.8. The first of these is practical and can be seen from a public health perspective as being connected to the wider structural determinants of health. The literature indicates that parents are more inclined to

provide active positive consent if vaccine programmes are designed to be minimally disruptive to their usual routine and activities, *i.e.* parents are not required to *do* anything additional. Programmes are structured in such a way as to facilitate participation, taking account of busy family lives. This demonstrates how structural influences such as service design by professionals and ease of access impact decision making and therefore substantive relational autonomy. For example, one parent quoted in the paper by Gottvall *et al.* (2013, p.266) states that

'it becomes more accessible, it rolls along by itself, automatically without having to make an appointment, driving yourself there….it is really good for us parents with limited time and so no…its great…'

Substantive factors such as this do not necessarily change a person's desire to be autonomous, or their capacity to make autonomous decisions, but they can influence their ability to *act* autonomously, therefore prompting active decision making. For example, parents may want to protect their child through vaccination, but their work/life situation hinders them or prohibits them from acting on this desire and, as such, limits their substantive autonomy. A quote from the paper by Cooper Robbins *et al.* (2010, p.262) encapsulates how programmes designed to overcome structural barriers can facilitate substantive autonomy:

'All I had to do was sign the form and I knew it was taken care of. It wasn't something I had to then think about having to do after school or make an appointment. It wasn't anything extra. It was something that was done.'

Additionally, the literature reviewed indicates that parents' views can be influenced by the input of individual professionals too, *i.e.* procedural relational autonomy is influenced. For example, the paper by Dorell, Yankey and Strasser (2011, p.1118) reported high percentages of non-vaccination, with parents reporting that

'…they did not receive a recommendation from a health care professional for their adolescent to receive the vaccine…'.

Equally, a positive association can be seen in the papers by Hofman *et al.* (2013) and Gottvall *et al*. (2013), in which parents attached importance to the views of health professionals in general, and conferred a level of trust in their opinions as 'experts' who would act in the best interests of their children. Parents seemed to accept that health professionals provide advice and recommendations paternalistically and, indeed, seemed to expect them to. One parent is quoted in the paper by Gotvall *et al.* (2013, p.265) as saying:

'It has been discussed and investigated and they have finally decided that this is what people must do, so I feel that we must, in any case, I trust that the recommendations are right.'

However, the weight or level of influence on parental decision making varies; greater influence can be seen where professionals and parents have a pre-existing relationship. Indeed, Dempsey *et al.* (2009) reported that mothers who had declined vaccination for their child had not seen their regular health care provider. This indicates that the depth of influence is based less on *what* is said or recommended, and more on *who* says it. This is an important point when considering public health programmes that convey information via written format and from an anonymous organisation rather than a named and known health professional, *e.g.* dental public health programmes delivered via the NHS.

Information and knowledge

Parents appear to gain information from both formal and informal routes, some of which they actively source, *e.g.* via the internet and from friends, and which tend to be more informal and ad hoc routes. Other more formal routes were often unsolicited by parents, such as information provided by the school or a health professional. As with professional input above, the level of trust that a parent places in the source of the information determines the degree of influence its content has on their decision making. Vandenburg and Kulig (2015), whose research took place in Canada, report that mothers used a variety of sources of information to assist their decision making,

including books, journals, anecdotes, and media and internet sources. Hofman *et al.* (2013) also reported that parents sought additional information before making a decision, whereas in a somewhat more egalitarian culture such as that of Sweden, parents were more willing to accept formally provided information at face value, for example Gottvall *et al*. (2013, p.267) stated that *'information from the school was satisfactory according to many parents…'.* This indicates that for some cultures, to make an autonomous decision the very information on which this is based must be obtained autonomously from multiple sources. This is a highly individualised approach that suggests that accepting information as it is formally presented is considered naïve by parents in equally highly individualised societies. The desire for additional information seems at odds with the level of influence trusted health professionals have, as pointed out previously; however, on closer inspection, much of the desire for supplementary information stems from a mistrust of the 'business' of health care, rather than of the individual professionals themselves, *i.e.* of pharmaceutical companies, or private payments to doctors in market-driven health economies (Vandenberg and Kulig, 2015).

Nonetheless, whatever the source of the information, parents expressed a preference for face-to-face communication over receiving information in written format. Indeed, in the study by Gotvall *et al.* (2013, p.267) the authors remarked that

'due to limited knowledge parents requested a dialogue with the school nurse in addition to the written information provided'.

So here it seems that, even though the (formal) source was acceptable, parents still felt the format of the information to be lacking and insufficient to facilitate their decision making. The formal, one-way transfer of information used by health care providers is in contrast to the often personalised informal routes of information favoured by parents. Both the first and second order constructs identified in these papers indicate that personalised face-to-face communication of information has

most influence on decision making, both positively and negatively. Indeed, Cooper Robbins *et al.* (2010, p.621) commented that

'…girls that were not vaccinated often described the negative things they had heard from friends and family…'.

As such, the degree to which formally provided information that is communicated in written format influences parental decisions is limited in contrast to a person-to-person approach. This situation has also been observed in dental public health programmes in England, where uptake is very low in contrast to in Scotland, where a more personalised approach is used and the reverse has been observed (Glenny *et al.,* 2013).

Additionally, several of the papers reported that parents felt they did not have sufficient information or knowledge and so actively delayed their decision or passively abdicated this responsibility altogether by neither refusing nor consenting. Parental knowledge plays an important part in decision making. This is supported by the work of Dorell, Yankey and Strasser (2011, p.1118) who report that '*a significantly higher proportion of parents responded that "lack of knowledge" was the main reason for not receiving the MenACWY vaccine'.* Equally, the first order constructs of parents' quotes in the paper by Dempsey *et al.* (2009, p.535) include statements such as '*I just don't know enough about it'* and *'I don't think there is enough information out there about it'.* Indeed, the authors of this paper themselves remark that parents felt they lacked the knowledge needed to make an informed decision. In this situation it appears that if parents do not hold a strong existing belief about vaccination they can find it difficult to make any kind of choice because of the uncertainty they feel. This group of parents are unable to exercise their procedural autonomy and to make a decision that is reflective of their true identity and choice because they are easily convinced by the merits of multiple competing influences; some of these may be their own, such as the desire to protect their child, while others are likely to be external. These parents are vulnerable to external persuasion, or even coercion. Ironically, this

may arise as a result of their seeking additional information in order to make the 'informed choice' that health care dictates, particularly when health professionals adopt a stance of non-interference. This effectively tips the scales of influence in favour of other external forces of persuasion, be they positive or negative. For example, in the paper by Cooper Robbins *et al.* (2010, p.266), parents are quoted as saying:

'*My sister showed me some articles about there being cancer in the vaccine*' and '*I heard it killed like 11 people*'.

Conversely, for parents who actively decide not to vaccinate their children any information provided has very little influence on their decision making. A parent in the study by Vandenberg and Kulig (2015, p.91) expresses this point of view well:

'*…we are flat out, like, we aren't immunizing, so I've always kind of just pushed it out as fast as they try to give it to me'.*

So, by not communicating information on a more personal level from a trusted source, health care services may be failing to support undecided parents to access unbiased information and make informed autonomous choices.

Perceived threat and susceptibility

Two separate but linked inferences can be drawn in relation to parents' perception of threats and susceptibility. The first of these stems from a fear of the potential side effects of the intervention itself. For some parents this fear was grounded in personal experience, while for others it manifested itself in a distrust of pharmaceutical companies and research programmes. Fear did negatively influence some parents who refused their consent but, importantly, in many cases the impact of parental fear was on the timing of decisions. Some parents exercised their right to decide but in doing so they actively chose to delay the decision to vaccinate. From this it seems that while parental fear does influence decision making in general, the strategy for making

the consent decision is also influenced, rather than just the decision itself. The quote below from the paper by Dempsey *et al.* (2009, p.535) exemplifies this well:

'I was going to take a year or possibly two as a wait and see approach to see what other studies come about regarding this vaccination'.

Parents' perceived levels of susceptibility for their daughters also influenced their decisions. While some parents had personal or family experience of cervical cancer, which strongly influenced their decision to vaccinate, others appeared to externalise any susceptibility their daughter might face. For some this was due to their daughter's age (vaccination took place at approximately 11/12 years old) and despite knowing that the vaccination is most effective when administered prior to any sexual activity, parents seemed to feel that this was still too young for *their* daughter, and that it was therefore not relevant to them. Some parents also felt that the decision was one of irrelevance to them because their daughters would have sex only with their husbands and, as such, they would not be susceptible to the disease. In both situations this was a decision that forced parents to consider their young daughters as independent sexual beings. First and second order constructs indicated that this was not something these parents were ready for, or willing to do. Parents would rather trust that the way in which they had raised their child, *i.e.* to not have sex early or out of marriage, would protect them. For example, Cooper Robbins *et al.* (2010, p.622) reported:

'*My understanding is that the more partners you have the greater the risk you have of picking up a sexually transmitted disease. Not just that one. I am confident my girls will not be like that.*'

As such, perceived threat and susceptibility affect how relevant parents feel particular decisions are to them and they then act accordingly. Lack of relevance felt by parents can lead to active refusal or, in some cases, passive non-decisions.

Responsibility

Parents universally felt that it was their responsibility to protect their children. Feelings of parental responsibility influenced consent decisions and motivated parents to both provide and refuse them. In tandem with the strong desire to make the 'right' decision was the stimulus to avoid future guilt if anything went wrong with regard to long-term side effects or contracting the disease. For example, Krawczyk *et al.* (2015, p.352) reported an odds ratio of 0.61 for parents anticipating regret over accepting the vaccine. For some parents this motivation meant that they took advantage of their position as proxy decision maker, thus recognising their current position of power in a dynamic relationship. This resulted in a sense of urgency to act before their window of opportunity to do so closed. This was more apparent in parents who provided consent. One parent in the paper by Dempsey *et al.* (2009, p.536) expressed this well, when she said:

'*I figured now is the best time because it's a time that I can make the decision for her…'* These parents appeared happy to exercise their relational (procedural) autonomy based on *their* true authentic wishes and not necessarily those of their daughters, now or in the future, trusting that they as parents knew best.

Conversely, for others the weight of making this proxy decision bore down on them. Parents in this position often delayed their decision so that either a joint decision could be made between parents and daughter, or their daughter could decide for herself when older. These parents were considerably less confident about exercising their autonomy. Despite this, parents are expected to make health-related decisions for their young children and on many occasions there is no opportunity for them to wait until their child is older. These parents seem unable to trust themselves to make a decision; for example, a participant in the study by Dempsey *et al.* (2009, p.536) commented: *'I'm just so bothered by my decision having an impact on her in later life'.* Moreover, added to the feeling of responsibility was pressure from internal and external sources. Some parents appeared to internally wrestle with their decision; however, daughters also applied unconscious external pressure, and therefore

influence, on their parents' decision making. For example, Hofman *et al.* (2013, p.871) quote one participants as saying, *'Mom, cervical cancer, you wouldn't want me to get it would you?'* For parents who more keenly feel the weight of their responsibility, external pressure such as this is likely to sway their decision regardless of their true internal beliefs, whether they are conscious of them or not.

Internal beliefs

Consent decisions by parents are strongly influenced by their existing internal beliefs. The more strongly held the belief, the greater the influence. No papers reported or inferred that a parent's belief, or indeed decision choice, was amended by information provided by health services or other sources if the belief was deeply held. Therefore, the Kantian (1785) view that decisions are based on the rational weighing up of information is not supported by the actions of parents with existing and ardently held views. For some parents, this decision was not one they needed to make, because they viewed 'health' fatalistically. For example, the following first order constructs were identified in the paper by Vandenburg and Kulig (2015, p.89):

'If my child [were to] get sick, I would consider that…God's hand', and *'I mean, you go through a couple of days, but it's no big deal really.'*

For others, pursuing 'health' was an ideology and something to be actively courted, whether through natural means such as eschewing vaccines in favour of boosting one's own immune system, or embracing medicine and any opportunity to benefit from its advances, *e.g*. *'I think vaccines against anything are worthwhile'* (quoted in Cooper Robbins *et al.*, 2010, p.621). The underpinning motivations for these beliefs varied from personal experience of disease to something more intangible such as parents' assumptions about their daughter's future lifestyle. Parents with existing internal beliefs such as these are likely to make active decisions, which are less pervious to external professional influence than those of parents without such convictions. Equally, this demonstrates that emotion cannot be separated from parents' decisions regarding their child's health. As such, decisions are open to

influence from internal as much as, or perhaps more than, from external forces. They are based on more than the mere evaluation of objective facts and the weighing up of information.

Social and community networks

A person's primary and secondary socialisation influence their views and actions, and this was evident in the papers reviewed here. For example, belonging to a religious community and the influence this has on parents' decisions was specifically researched by Shelton *et al.* (2013). Those parents who were active in such a community were less likely to provide their consent for the HPV vaccine. The influence of religion was also highlighted by Cooper Robbins *et al.* (2010) and Krawezyk *et al.* (2015). However, the papers here are concerned largely with HPV, which can be linked to sexual activity, and this may prompt stronger reactions in some religious communities than other public health interventions. That said, the evidence here is not conclusive regarding whether religious affiliation always results in refusal of consent for HPV. What can be inferred is that the very action of belonging to a community group with commonly held views means that collective community endorsement is highly influential, for example: *'It's not [a decision you make] on an individual basis'* (Cooper Robbins *et al*., 2010, p.622). These parents adhere to an unwritten code of community accepted behaviour in which decisions are based on trusted social norms. Parents in these situations, especially with regard to some religious communities, are often unquestioning of these norms. This raises a question about the authenticity of their choices. Here, individual and community choice cannot be separated and therefore the influence of community ideals is great. Hofman *et al.* (2013, p.872) report:

'With us, in our [Turkish Muslim] community it's unusual to have sex before marriage…That is the way it is in our culture, you marry only once and only have sexual contact with each other once you're married. So that's another reason not to do it'.

However, this type of collectivism is different to that of parents living in a community with a culture of egalitarianism. For these parents, decisions are influenced by social norms that prioritise community solidarity, *e.g*. individuals are accountable to each other rather than to a religious entity or teaching: '*I think it's a social responsibility…not to participate…I think, is irresponsible to others'* (Gottvall *et al.*, 2013, p.267). Here the influencing factors are less about adherence to accepted individual behaviour and more to do with collective responsibility. In this situation parents trust that others will act similarly to protect the community population. Nonetheless, whether the influence of social norms stems from religion or solidarity or any other collective belief, it is difficult to know whether parents are exercising their true autonomy, which is reflective of their authentic views, or whether those views have been so shaped by the social norms of their community networks that they cannot be differentiated from one another. Indeed, in the examples provided here it seems incongruous that parents are asked to provide their individual independently considered consent by health services that are delivering a programme that by its very nature requires collective action to achieve herd immunity for the population. The prerequisite of active positive consent seems particularly at odds with influential social and community networks that thrive on homogeneity in their actions.

3.5 Discussion

The information presented here specifically addresses objective (II) of this review, initially presented:

II. To systematically identify and analyse research that documents whether, and how, approaches to parental consent are informed by ethical theory

This information, combined with that presented in 3.2 Methods, 3.3 Results and 3.4 Findings, contributes to answering the overall review question, which is revisited in the next section: 3.6 Conclusion. The validity of the points made is dependent on the quality of the research from which they are drawn. This has been discussed in Section

3.3.b. However, below is a critique of the literature, specifically with regard to the research question set out at the start of this review.

3.5.a Critique of research literature

The prominent feature of the papers that were included in the final review is that almost all of them (seven papers in total) are researching parental decision making in one way or another in relation to the HPV vaccine. The only paper that deviates from this is that of Dorell, Yankey and Strasser (2011), who look at parents' decisions not to provide consent for the vaccination of their teenage daughters across a range of vaccines. However, even in this paper HPV is repeatedly discussed and some statistical results of the uptake of the vaccine are presented. No papers were identified in the dental literature that looked at consent issues over and above reporting the uptake of particular dental public health programmes and none looked at parental decision making; hence, no dental literature made it into the final eight of this review.

3.5.b Strategies employed to maximise parental consent

The extent to which interventions such as those reviewed here actually facilitate parents to exercise their autonomy is questionable. None of the research specifically set out to maximise parental consent, only to investigate what existing influences there were on parents' decisions. All papers gathered data from real-life programmes, *i.e.* the vaccination programmes were part of established public health services provision. This provided an opportunity to review the consent arrangements that were in operation. However, the details of these arrangements were not discussed in detail by any of the authors and any information about this was, therefore, implied or only briefly mentioned. But, it appears that there are two types of consent arrangement: the first is via a conventional encounter with a health professional in person, who makes the request for consent, and the second is via a letter or information that is sent to parents via the school. This second arrangement is similar to those outlined in Chapter 1 (Background) for DPH programmes. Neither of these

arrangements explicitly employs additional strategies to maximise consent. Both are based on a traditional view of decision making whereby the provision of information by health services is the core of the process. This review has identified that there is an inherent tension in how information is supplied as well as in who supplies it. It is interesting to note that the more individualistic the society as a whole, the greater the importance that seems to be placed on informal sources of information. For example, in the individualised culture of the USA and Canada, parents were often sceptical about the formal information they received and supplemented this with informally sourced information. This demonstrates that to maximise consent the content of the information (often heavily scrutinised before being issued) is not the crucial constituent in informed decision making. This does not reflect the current emphasis that is placed on information content by the law (*Montgomery v Lanarkshire Health Board [2015]*) or codes of practice for health professionals, as described in Chapter 1 (Background) (NMC, 2010; GMC, 2013; GDC, 2005b).

Traditional programmes based on a medical model of health care that are delivered in a surgery or clinic by families' existing health professionals are more likely to facilitate an active decision if parents can draw on an existing reservoir of trust. This may indeed be the case to some extent, but if we assume that all vaccination and similar programmes should be delivered in this way, there is a risk of only superficially considering the implications. Delivery modes such as this may assist parents to exercise their procedural autonomy, but this does not account for the substantive barriers faced by some, as discussed earlier and in Chapter 2 (Theory), *e.g.* accessing services that may require transport to get to, or time off work during 'office hours' (Mackenzie and Stoljar, 2000).

Yet, trust in professional recommendation should not be overlooked and substantive barriers could be mitigated if a broader approach to this were used (Owens and Cribb, 2013). This research indicates that other, 'non'-health professionals can influence health decisions in a similar way to those who are medically trained. For example,

teachers with whom children and parents have an existing relationship hold a similarly valued position to that of health professionals; paternalistic actions are accepted and expected, but with the added advantage of regular contact with families. Arguably, because of the regular and routine contact that parents and children have with teachers, their potential impact on a parent's procedural autonomy may be greater than that of a health professional. Thus, some of the structural and substantive issues of accessing health professionals can be overcome. The trusted role that non-health professionals can play in influencing parents' decision making is clearly seen in several of the papers, particularly in Cooper Robbins *et al.* (2010).

Parents with strong internal beliefs are not easily influenced by the provision of information by health services, whether this information is in accordance with their beliefs or in opposition to them (Vandenberg and Kulig, 2015). The origin of parents' beliefs is not always clear, *i.e.* they can stem from social or cultural norms, religion or solidarity. The implication of these views shows little or no change in parents' consent decisions; therefore, exercising their procedural autonomy is not dependent on the receipt of formal information. This is further contributory evidence that parents' consent decisions regarding their children are not solely based on an ability to 'transcend emotion and objectively weight up facts' as a Kantian (Kant, 1875) view of autonomous choice would have it (Walter and Ross, 2014). No evidence was presented in the research that outlined any additional strategy or action on the part of health services that appealed to parents' emotions to make a decision, regardless of the decision outcome, despite the obvious role that procedural autonomy, as described in Chapter 2 (Theory), has here (Owens and Cribb, 2013; Mackenzie and Stoljar, 2000).

Parents who do not have robust internal beliefs or do not belong to a strong community are not being served well by health services. The Millian stance of 'non-interference' (save for the provision of formal information) that is demonstrated by

all of the programmes in this review leaves some parents decisionally vulnerable. It is this group of parents who are more likely to seeks informal information, including garnering the opinions of family and friends to fill the void. Parents in this position are also more likely to either passively make no decision or delay making a decision, potentially increasing the health risk for their child. The impact of passive non-decisions on inequalities and on the future of the programmes themselves has been described in Chapter 1 (point, 1.4.c) with regard to DPH programmes, but there is no reason why this may not also be the case for other areas of health, such as HPV vaccinations (Davies *et al.*, 2014; Kubiangha, 2014) In this scenario, not only do health services not actively attempt to maximise consent, they in fact do the opposite and impoverish parents' ability to make a consent decision. This situation is potentially exacerbated by the level of trust that parents place in health professionals and the expectation of paternalism. By health professionals adopting a stance of neutral non-interference, parents may infer that the intervention being offered is not important because otherwise they would have been more strongly encouraged to take advantage of it. This Kant-Millian hybrid way of operating, which was first put forward in Chapter 2 (Theory), raises a question about health services responsibility. By leaving parents vulnerable in this way, they are not meeting Article three of the UNCRC, which states that the best interest of the child must take priority. It appears that an outdated and ill-conceived mode of operating has been prioritised instead, even if based on good intentions.

Some undecided parents in this position abdicated their responsibility to act as the proxy decision maker for their children and did not actively consent or refuse. But actively deciding not to consent or refuse is, in fact, a decision in itself. So although responsibility for the outcome of a vaccination decision was rejected by some parents, the process of making a decision to do this was not. This could be seen as a parent exercising their autonomy by not actively choosing (Baumann, 2008). However, this raises more questions: if parents take this option are they consciously but passively excluding their children so that responsibility for any potential

vaccination downsides is diffused? Also, if a parent's decision is not to decide, are parents then in the best position to make these decisions on behalf of children and, if not, what is required to facilitate their decision making, or should this role be taken on by the State? Ethical questions such as these mean that the implication of parents decision not to choose is potentially greater at a population level than if they actively refuse to provide consent.

3.5.c Approaches to consent informed by ethical theory

It is noteworthy that none of these papers mentioned parental autonomy, ethics or ethical theory in any way, with the exception of the mandatory approval needed by an ethics committee for the research to take place. This omission, coupled with a general absence of detail from the authors about the delivery methods employed by these programmes, indicates a lack of consideration of applied ethics and its place in the practice of public health. Furthermore, it also seems remiss that none of the papers mentioned the socio-economic status of parents and how this may or may not affect their decisions. The role of the wider determinants of health on a person's ability to act on their true desires was discussed in Chapter 2 (Theory) with regard to relational substantive autonomy (Christman, 2004). Some authors specifically looked at different religious affiliations and one paper singled out a group of parents from a particular ethnic minority, so research activity around the classification of parents into 'types' or 'groups' did take place, but these classifications did not appear to shape the research in any way and participants were viewed for the most part as rational agents removed from their substantive social context (Kenny, Sherwin and Baylis, 2010). This implies that there is a deficit in the authors' consideration of structural influences on parents providing or refusing their consent. So, despite vaccination programmes being an established public health activity, they are being delivered against a backdrop of individual clinical care. Little or no attention has been paid to the wider influences of health that public health seeks to redress or mitigate, and it would therefore be foolish to assume that these programmes would be informed by anything other than an ethical perspective that is grounded in liberal individualism

(Mill, 1859). This is interesting, given that parents themselves have highlighted their preference for collectively delivered school-based programmes, along with their duty to adhere to the principle of solidarity with others in their community, both of which echo Dawson's (2011) definition of 'public' and Prainsack and Buyx's (2015) second tier of solidarity from Chapter 1 (Background). Therefore, it does not seem that stand-alone action based on the primacy of the individual is always the preferred choice of parents, even though it is the default position of many of the programmes researched here. Moreover, these points raised by parents clearly demonstrate that some feel comfortable with elements of utilitarianism, but this was not mentioned by authors. Indeed, all of the researchers appeared to investigate what influences consent decisions in individuals as a discrete activity, devoid of any ethical theory or of any understanding of the nuances of consent decisions in a public health context that requires a different ethical starting point.

3.5.d Applicability to thesis

This literature review has been useful in many respects, not least to test out the theoretical points made in Chapter 2 (Theory) for relevance in real-life scenarios before these are investigated further in the following chapters. It is clear that knowledge has a key role in parental consent decisions, whether that means tangible information gathered from formal or informal sources, or more ephemeral and subtle forms such as that picked up from social and community networks, *e.g.* unwritten social norms. Conversely, the formally produced information that health services disseminate has less influence than perhaps is assumed and attributed to it, not only on parents with strongly held views but also on those who are undecided. This means that we can no longer think of 'informed consent' in simplistic terms, *i.e.* where information (usually written) is provided by health professionals with little additional input and with the assumption that this will override other sources of information that may influence parents. Health professionals use the term 'informed consent' to mean 'consent provided after receipt of formally produced information', when in fact parents can become 'informed', positively or negatively, from any number of routes.

Additionally, formally provided information may leave parents feeling only 'partially informed', leading them to seek supplementary information elsewhere before making a decision. Therefore, parents can be 'informed' but not necessarily of the risks, benefits and alternatives in equal measure. Linked to this is the concept of trust, which has been shown to be an overarching influencing factor. Parents are social beings with emotion, some of which is attached to their existing relationships. It is these relationships, whether with health or other professionals, friends or family, that influences their choices. The level of trust directly affects the level of influence that the information they receive from these people has with regard to their decision to provide or refuse consent.

However, there is a limit to the applicability of this review when considered in the context of this thesis. The number of papers included in this review is small and all of them report on vaccination programmes, particularly that of HPV. While there are commonalities, as pointed out previously, the link between HPV and sexual activity makes this a potentially more attractive topic for participants due to their strongly held views. As such, parents may be less inclined to participate in similar research about the less reaction-provoking topic of dental public health, and if they do participate the factors that influence their decisions may be less stridently felt. Equally, none of the research included in this review took place in the UK, therefore the social, political and structural context within which the research for this thesis is set has not been explicitly explored, including the health economy, of England in particular. Lastly, several of the papers researched vaccination programmes that were delivered via doctors surgeries or clinics, and while such programmes are considered the province of public health, this delivery mode is markedly different from the population approach that is in operation for dental public health that utilises a school setting. Therefore, the influencing factors seen in these papers may differ considerably from those that influence a UK population.

Nevertheless, knowledge gained from undertaking this review was applicable to the empirical portion of this thesis; specifically, the third order constructs that were developed indicate potential points of further investigation with parents via interviews, and the research methods used in these papers informed the research design. Explicitly, the six factors identified as influencing parents' decisions were used to inform the content of the interview topic guide for parents, with each of these topics being explored. The qualitative papers included in this review provided a richer source of data from which interpretations were made than those that used quantitative methods. As such, qualitative methods were also used for the research for this thesis, and semi-structured interviews and focus groups were utilised as part of the design. However, as a result of the methods information gleaned from this chapter and the subsequent data produced, fewer questions than first anticipated were used, and an open-ended format with less structure than previously thought necessary was employed. The purpose of this is to not prompt or steer parents' thinking, and therefore their answers, in a way that inhibits their own voice and opinions. Additionally, the analysis techniques used here were also adapted and employed for use with the transcripts, making use of different layers of constructs to extract and formulate the final interpretations based on themes. I also gained some confidence from using thematic analysis in this activity before employing it in a similar way later on but with a much larger data set. The research design and methods for this thesis are discussed in more detail in Chapter 4 (Methodology).

3.6 Conclusion

The literature search performed as part of this review identified no research that specifically looked at consent decision making in relation to dental public health programmes. Therefore, none of the papers reviewed here directly relate to the area of health that this thesis is focusing on, and decision making in other, similarly organised, public health programmes has been used to highlight this under-researched area.

Consent has been discussed by some dental researchers, but as an adjunct point when investigating the 'uptake' of screening services. A review of this literature formed the basis for my master's dissertation that was later written up into a research paper and published in the *Annual Clinical Journal of Dental Health* (Jeavons, 2012). As part of the background work for this thesis I have revisited the dental literature and, although four more papers have been published since 2012, only one from the total collected includes the views of parents (Tickle *et al.*, 2006). Several of these studies make speculative suggestions as to the reasons why a consent request may be refused or ignored, but researchers largely cite inadequate parenting in a way that harks back to common view in the 19th century discussed earlier. As such, there is a gap in the literature that this thesis can contribute towards filling.

Returning specifically to this review, *i.e.* decision making in relation to consent to participate in a public health programme, the analysis and synthesis of papers included here has provided the opportunity to bring new insights to these existing studies when viewed as a whole. The inclusion and discussion of these separate but linked overarching topics has demonstrated the complexity not only of this subject matter, *i.e.* what influences parents' consent decisions, but also of the context within which the empirical work for this thesis will take place. In doing this, the research question set out at the start of this review has been answered:

What influences parents' decisions to provide or refuse their consent for inclusion in public health programmes aimed at their school-age children (4-18 years) in developed national health care systems?

Six overarching influencing factors based on the interpretation of first, second and third order constructs have been identified and discussed in detail. These are; Professional input, Information and knowledge, Perceived threat and susceptibility, Responsibility, Internal beliefs, and Social and community networks. Additionally, trust has been identified as an overarching influence that adds further weight to all

six factors. Consent decisions are not abstract actions devoid of emotional content, so it seems that the current Kant-Millian hybrid view of autonomy that advocates a purely rational choice based on objective facts and a stance of non-interference by health professionals is redundant. All the while the health professions cling to this skewed and outdated notion any advances in maximising consent will be severely hampered.

This review shows that parental decisions are contextual and complex and that they require more from health services than information if consent is to be maximised. *Who* provides information and *where* the information comes from was shown to be more important than the content of the information, as a result of the trust that many parents have in existing relationships. This is something that has been largely overlooked in the design of public health interventions, particularly with regard to dental public health programmes. Additionally, the tension that exists between parents' commonly held expectation that professionals and health services act paternalistically for the benefit of their children and the widespread belief in the primacy of the individual evident in the practice of non-interference by health professionals, has been highlighted. The points raised here validate the ethical argument put forward in the previous chapter (Theory), *i.e.* that the Kant-Millian hybrid notion of autonomy is not fit for purpose, and a relational approach, both substantive and procedural, better reflects the complexities faced by parents when providing or refusing their consent. As such, it is this notion of relational autonomy that will be used when discussing the findings from this research and which will therefore be revisited in the following chapters.

Chapter 4 – Methodology

4.1 Introduction

The purpose of this chapter is to provide information on how the empirical portion of this thesis was conducted. The intention is to supply the reader with the necessary information with which to assess the quality of the research process. Included are details of how the planned aim and objectives have been achieved in order to answer the overall research question. This research is based on paradigms of constructionism and interpretivism (Al-Saadi, 2014; Crotty, 2009). It is exploratory, and uses the qualitative methods of focus groups and interviews (Stebbins, 2001). The methods outlined in this chapter were designed to investigate parents' views on parental consent in order to increase knowledge of this under-researched area.

4.2 Research question, aim and objectives

Research question

The overall research question this thesis is seeking to answer is:

What barriers or enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?

Aim and objectives

To help guide the exploratory activities described in this chapter, the aim and objectives below were planned.

Aim: To examine parental experiences related to consent procedures for a school-based fluoride varnish programme in North London

Objectives:

1) To investigate parents' view and experiences of the consent arrangements for the fluoride varnish programme taking place in their child's school
2) To investigate parents' views about the consent process for the school-based fluoride varnish programme that would best support their preferred method of engagement, for example, a system of opt-out consent, or one of opt-in
3) To investigate what support, if any, parents would like in relation to their consent decision making as part of school-based fluoride varnish programmes in the future

4.3 Qualitative research methods

4.3.a Research paradigm

The ontological and epistemological assumptions made in this research are those of constructionism and interpretivism (Al-Saadi, 2014). Ontology and epistemology do not operate independently from one other. According to this view, reality does not exist independently from human practice and our understanding of it. The world view adopted here is that our way of 'being' is subjective and socially constructed and, as such, there can be different 'truths' or 'realities', as we know them. These realities are based on the social context of our lived experience. A singular notion of reality cannot be discovered and measured in quantifiable objective terms, as is postulated by quantitative, positivist research. This is the dominant ontological position in much of the research into consent for dental public health programmes published to date (Appendix 3.1). I take the view that there can be multiple social realities that are sculpted into meaning by our interactions, which inevitably will differ depending on culture and society (Robson, 2002). My own knowledge of this world view is influenced by the research itself and vice versa. For example, my knowledge of this subject has been produced by understanding public health ethics as applied to fluoride varnish programmes through the history of Western liberal society, as well as through exploring and understanding parents' views and experiences, *i.e.* their

lived experience of the FV programmes, which is individual and subjective. It is through reflection on the meaning of these knowledg*es* that I have created an interpretation of the 'truth' about what barriers or enablers parents face when asked to provide their consent.

4.3.b Research design

A qualitative approach was taken because the focus of the research is on establishing experience and meaning rather than causality (McCusker and Gunaydin, 2015). My intention was to understand how a community of parents understands the issue of consent and what enablers and barriers to participation they may face after receiving a consent request. As such, this research was driven by the desire to understand a particular aspect of social life, and this can be more deeply investigated within a qualitative rather than a quantitative paradigm (Braun and Clarke, 2013). This approach was adopted because it is interpretative of social phenomena. Specifically, with regard to the issue of parental participation in the consent process, the 'what', 'how' and 'why' of this issue have not, to date, been explored via research (McCusker and Gunaydin, 2015), whereas a number of published papers in the dental literature demonstrate 'how many' parents provide or refuse consent for their children using more traditional experimental or observational methods within a quantitative model (Pope and Mays, 2008) (Appendix 3.1). Moreover, a specifically exploratory approach was adopted because to date no research has investigated this area of dental public health (Stebbins, 2001).

The rational was that this approach would generate data that would enable examination of this issue from an as yet unknown perspective, *i.e.* that of parents. Ritchie and Lewis (2003) argue that exploratory research is unique in that it allows researchers to look in depth at what lies behind a decision, attitude or behaviour, in a way that cannot be captured via quantitative means because of its sensitivity towards the contextual situation of the research participants, in this case the parents. From the information presented in Chapters 1, 2 and 3 of this thesis, which discuss

the current and historical political environment of community-based public health, it is clear that this research is highly contextual, not only to dental public health but also Western liberal culture.

Parents' views and experiences have been selected as a priority because it is only by exploring these that we will be better able understand the enablers and barriers that bring about, or influence, parents' decisions to consent to or refuse their child's participation. Research with parents about their consent request response for DPH programmes has not been reported in the literature and the parents' voice is, therefore, missing from the discourse around this subject. 'Giving a voice' to rarely heard people is a key feature of qualitative research (Denzin and Lincoln, 1994). Currently, the literature on parental consent for DPH programmes is dominated by the voices and opinions of experts, *i.e.* dentists (Appendix 3.1). Exploratory research such as this is often used when there is an inadequate understanding of a particular problem or phenomenon, and this is the situation here, with only one view being represented (Manerika and Manerika, 2014).

The purpose of this type of research is to identify the enablers and barriers that parents face, not to offer a single definitive answer to the research question. Focus groups and interviews were designed to 'flesh out' consent participation and what this entails for parents (Alexander *et al.*, 2016). These methods were used concurrently, although one parent who had previously participated in a focus group but who had to leave early, was interviewed at a later date. This parent was forthright in his views about the varnish programme and had refused his consent. Some research theorists, such as Greene, Caracelli and Graham (1989) like to use the term 'complementary' for research that includes more than one method of investigation, while others suggest that 'multiple methods' is more appropriate, particularly when more than one form of qualitative method is used (Tashakkori and Teddlie, 2010). Alexander *et al.* (2016) state that the term 'mixed methods' has multiple meanings, *e.g*. it could be used to denote more than one data-collection method or analysis

technique being used within one study (Cronin *et al.*, 2008) or, more traditionally, a combination of research paradigms, *i.e.* positivist and interpretivist.

Using two methods of enquiry was a pragmatic choice, based, in part, on the background work for this thesis. A small 'public involvement' exercise was conducted in order to judge with more certainty the feasibility of parents' willingness to engage with this subject matter (INVOLVE, 2009). The purpose of this was also to ask parents how they would feel most comfortable expressing their views, *e.g.* individually or in a group. A summary of the parent responses to questions posed as part of this exercise can be found in Appendix 4.1. Seven parents participated in this activity.

4.4 Sample selection

Purposive and convenience sampling have been used for this research (Palys, 2008) in two stages. Initially the selection of the schools and parent cohorts was purposive and then from this selection, convenience sampling of individual parent participants was used (Polit and Tatano Beck, 2014).

4.4.a Site selection

In England, the introduction of the fluoride varnish scheme in schools is not centrally organised and universal as it is in other parts of Great Britain, *e.g.* Scotland. Implementation is decided locally and is usually concentrated in areas of high dental need. London has the highest caries rate in England and several schemes have been commissioned and implemented across the capital (Public Health England, 2015b). London was chosen as an area within which to conduct this research because of the density of parents from different cultural and demographic groups living and schooling their children in close proximity. This was a pragmatic choice that enabled a wide variety of parental views and experiences to be captured in one research project, a variety that might not be as easily accessible in other parts of England with more homogenous populations. Furthermore, the North London Borough of Enfield was selected as the site for this research because of the diversity of its population and

the range of inequalities within one geographic area, described below, and because of the longevity of the fluoride varnish scheme in that area.

4.4.b Sample population

This research focuses on the collection and analysis of qualitative data, and so the sample size does not need to be statistically 'generalisable' in the way it would need to be in quantitative research. This thesis is concerned with 'analytic generalisability', which is appropriate for research operating within a qualitative paradigm. However, research samples can have a significant impact on the quality of the final analysis (Coyne, 1997); therefore, in addition to the site selection, a sample population drawn from different schools with potentially different sub-cultures, views and experiences will add to this analytic generalisability. Twenty-two of the borough's 71 primary schools are included in the DPH programme because of their high dental need (reported in Chapter 1: Background). These schools were, therefore, initially eligible to be included in this project (Kubinagha, 2017). Nine schools of varying sizes ultimately participated, and these were located across all four of the borough's geographically designated wards that are targeted by the dental team.

The following information regarding the research site provides context within which this research was conducted (Boeree, 2006). Information is presented about the oral health of children from the sample site (London Borough of Enfield) and how this compares to London as a whole. Information on children's oral health in the UK in general has been provided in the opening pages of this thesis (Chapter 1: Introduction).

This research took place within the London Borough of Enfield, which is located 12 miles from the centre of London and covers an area of 82.2km^2. In 2014 the population was estimated to be 324,574, of which 21.3% was aged 0-14 years (Enfield Council, 2016). This was 21.2% higher than the rest of London (Enfield Council, 2014). Enfield is multicultural with 60% of the population being classed as 'non-white' (Enfield Council, 2014). In 2015 the top five non English languages spoken were

Turkish, Somali, Bengali, Polish and Albanian (Enfield Council, 2016). There are 21 individual wards within the borough with inequalities in many areas, including income, education and health (Enfield Council, 2014).

Across the borough, 12 of the 21 wards fall within 25% of the most deprived (Enfield Council, 2014). Three wards (Upper Edmonton, Edmonton Green, and Lower Edmonton) located in the south east of the borough are within 10% of the most deprived areas in England. Conversely, some wards located near the west of the borough, fall within 20% of the least deprived wards in England. Enfield has the highest number of children (almost one third) living in poverty in London and a third of all social housing tenants have incomes below the poverty line (Enfield Council, 2014). Life expectancy varies within the borough, with men in the more affluent wards living on average 8.7 years longer than those in the most deprived, while women experience a life expectancy gap of 8.6 years (Enfield Council, 2014). There are 71 primary schools in Enfield, one of which is a fee paying preparatory school (Enfield Council, 2013). 27.8% of primary school age children received free school meals in 2013 (Enfield Council, 2014)

43 dental practices are listed on the local council's website (Enfield Council, 2014). In addition, Whittington Health NHS has two dental clinics that treat vulnerable people, *e.g.* people with special or complex needs. Treatment under general anaesthetic for children is carried out at North Middlesex Hospital, which is located in the south east of the borough (Enfield Council, 2014). In a recent briefing paper presented to the Council's Health and Wellbeing Board, 30.5% of children under the age of five resident in Enfield have experienced tooth decay and only 51% of children have visited a dentist in the past year up to March 2019 (Wright, 2019). Dental extractions are one of the main causes of non-emergency hospital admissions in children aged 6-10 years in Enfield, with 436 children admitted to hospital for tooth extraction in 2017/18 (Wright, 2019). The relationship between deprivation and dental decay levels is well

established and higher rates of tooth decay are seen in the most deprived wards in Enfield (Wright, 2019).

Sample selection

Purposive sampling is common in qualitative research and it can be seen a series of strategic choices made by the researcher (Palys, 2008). This type of sampling is sometimes called non-probability sampling because the choice of units to be investigated is based on the judgement of the researcher (Lund Research Ltd, 2012). Purposive sampling can be further categorised into the different ways in which these purposeful choices are made, including maximum variation, deviant case and criterion (Coyne, 1997). From this perspective, participants are not seen as interchangeable quantifiable numbers as in quantitative research and sampling (Palys, 2008). From the 22 eligible schools, 11 were purposefully chosen for inclusion. This choice was based on data supplied by the dental team (presented in Table 4.1 below), with the intention of capturing maximum variation, *i.e.* if they had a strong consent response profile based on how the majority of the parent population had responded in the previous academic year (positively, negatively or no response). This was intended to ensure as far as possible that parents from each of the potential response groups had the opportunity to participate, so that the research could include and explore parent views from different perspectives (Polit and Tatano Beck, 2014).

The second stage of sampling was a convenience sample. Parents whose children attended the participating schools, and who had received a request for their consent within the 2017/18 academic year, were invited to participate in this research. Parents from different response groups were not specifically targeted. Furthermore, the FV programme is aimed at children in nursery, reception and year one and the decision was taken to invite parents from all three year groups. This was also calculated to maximise the variation of parents willing to participate (Polit and Tatano

Beck, 2014). For example, often parents with more than one child reported making their decision based on different considerations between the first and second child.

Table 4.1 Parental responses (actual and percentages) shown by school from the 2016/17 school year.

(Ordered from lowest % of consents received to highest)

School Code	Ward	Total contacted	Consent	Refuse	No Resp*	% Consent	% Refuse	% No Resp*	Included in research sample (invited to participate) (2017/18)	Agreed to participate (Included in the final sample) (2017/18)
P	PE	113	50	0	63	44.25	0	55.75	X	X
O	EG	228	110	0	118	48.25	0	51.75	✓	✓
U	UE	308	149	1	159	48.38	0.32	51.62	✓	✓
M	EG	382	187	0	195	48.95	0	51.05	✓	✓
H	EG	320	169	1	150	52.81	0.31	46.88	X	X
K	PE	60	32	0	28	53.33	0	46.67	X	X
F	PE	263	143	1	119	54.37	0.38	45.25	✓	✓
N	Sb	210	119	11	80	56.67	5.24	38.10	✓	✓
S	UE	301	179	0	122	59.47	0	40.53	✓	✓
E	Sb	245	147	0	98	60.00	0	40.00	X	X
D	Sb	206	124	0	82	60.19	0	39.81	✓	✓
L	EG	225	138	1	86	61.33	0.44	38.22	X	X
V	EG	171	109	0	62	63.74	0	36.26	X	X
C	PE	196	125	1	70	63.78	0.51	35.71	X	X
Q	EG	254	162	2	90	63.78	0.79	35.43	X	X
I	EG	404	262	1	141	64.85	0.25	34.90	✓	✓
J	UE	163	111	0	52	68.10	0	31.90	✓	✓
R	PE	203	147	4	52	72.41	1.97	25.62	X	X
B	UE	171	125	0	46	73.10	0	26.90	X	X
T	PE	166	131	5	30	78.92	3.01	18.07	✓	X
G	EG	238	189	1	48	79.41	0.42	20.17	X	X
A	PE	165	143	1	23	86.67	0.61	13.94	✓	X

*No resp = number of responses

Some schools had no or almost no active refusals for consent, but more than half of the parents did not respond and communicate their decision, for example, in schools P, O, U and M. The purpose of this table is to demonstrate the size of the issue being investigated.

Selection criterion

- Parents who have been contacted by the dental team during the 2017/18 academic year and asked for consent for their child to participate in the school-based dental public health fluoride varnish programme

Recruitment

The co-operation of the Clinical Dental Director at Whittington Health NHS was obtained and in August 2017 a meeting was held with the Oral Health Promotion (OHP) team who coordinate and deliver this programme in Enfield. It was decided that I would approach the schools independently from the OHP team at a time close to when, but after, they had carried out their visit to apply fluoride varnish (FV) to children's teeth. The purpose of this was to avoid confusion in parents between the FV programme itself and my research, and so that the research could have no impact on the parents' consent decisions at that time. A list of the targeted schools along with contact details and dates for the planned OHP visits was supplied by the team, who also agreed to mention my research to the school staff, by way of a soft verbal introduction. This also helped to affiliate me with the OHP team who had existing relationships with each school and it provided me with an element of 'insider status', which helped me to gain school participation (Braun and Clarke, 2013; Wilkinson, 1988).

Schools were initially contacted via email, which included an explanation of the research, a request to the school to participate and a flyer to be passed to parents (Appendix 4.6b). I also offered to meet with school staff prior to approaching any

parents, to introduce myself in person. The school staff were effectively gatekeepers to the parents and it was important that I spend time gaining their trust and co-operation (Abrams, 2010). The response to this initial email was mixed, with some schools replying enthusiastically and others only responding once I had followed it up with a telephone call. Ultimately, nine of the 11 schools targeted for this research participated. The school that had the highest number of parents who had provided consent in the previous academic year did not respond at all, despite repeated attempts at contact. All school staff took me up on the offer of a meeting before agreeing to participate and five of them invited me to various coffee mornings and breakfast clubs with parents, all of which I accepted. The gatekeeper role was taken very seriously by all the schools; in four of them staff remained present during the interaction between me and parents and in one school a senior staff member spent a long time asking me questions and explaining how she worked with parents and the OHP team to achieve a high consent response.

Once the agreement of the individual schools was in place, flyers were distributed to eligible parents (*i.e*. those with children in nursery, reception and year one) by the schools. This written information and the request for participants was supplemented by my attendance at the coffee mornings, breakfast clubs and other parent meetings as mentioned, several of which I attended more than once to capture different parents (some schools held groups targeting parents from different minority ethnic communities, *e.g*. Turkish or Somali, and some schools held morning and afternoon sessions on the same day to attract parents with varying work schedules). At these events, parents provided their name and contact details if they were interested in participating. This face-to-face recruitment was more effective than flyers alone, which yielded very few participants, but the flyers did provide initial information to parents, which some recalled later. Subsequently, parents who had shown an interest were contacted and dates arranged for either an interview or for them to attend a focus group meeting, and a participant information sheet and consent form were supplied (Appendices 4.9a and 4.10).

Prior to my return to schools to collect data, I contacted each of the parents individually to confirm and remind them, either by telephone or text message. At this point, some parents actively withdrew and others did not respond, indicating perhaps that they had changed their mind about participating. Also, the number of parents who confirmed their participation was higher than the number who actually arrived at school for an interview or focus group. On several occasions, interviews had to be re-scheduled due to the parents' other commitments. In addition to the direct recruitment I conducted, school staff assisted by approaching parents on the day of my return visit and asking whether they were happy to participate. This *ad hoc* recruitment by school staff increased the participant numbers, particularly for the focus groups. From this experience, it seems that parents are willing to participate in this type of research but often do not operate on an appointment-type system, preferring to be involved if and when they have time on any particular day. All interviews or group sessions took place face to face.

In addition, the use of 'snowball sampling' was attempted (Hunt and Lathlean, 2015). The purpose of this was to increase the sample of parent participants, particularly from the consent non-responder group, who can be thought of as 'hard to reach'. This is an established and accepted reason for using this sampling strategy (Shaghaghi, Bhopal and Sheikh, 2011). Its stated advantage is that engaged parents already taking part can act as motivators for others who may not otherwise be accessible to the researcher, in their position outside of their social group. In addition, this method for increasing the sample size is compatible with purposive sampling, which is the overarching strategy (Denscombe, 1998). However, in this instance and similarly to with the written information alone, this method of recruitment yielded no additional participants. Recruitment worked best once I had established an initial rapport with parents through informal conversation. Some parents offered to participate if the interview or group could be conducted immediately, *i.e*. at the recruitment event, but if this was not possible they withdrew. This experience adds to my belief that in some instances parents operate on an immediate, unplanned *ad hoc* basis that does not

easily lend itself to including activities that they have to decide on and commit to in advance. It was not an objection to the research itself that inhibited participation; the advanced organisation that this required created the barrier.

Recruitment of parents continued until data from groups or interviews failed to generate new information, *i.e.* saturation point had been reached (Braun and Clarke, 2013). This required 29 visits across the nine schools involved. The purpose of this somewhat open-ended sample was to provide a comprehensive and rich data set that could be used to describe the parents' views in detail. All participating parents were given a small 'oral health pack' to thank them for their time. This included toothbrushes and toothpaste for them and their children.

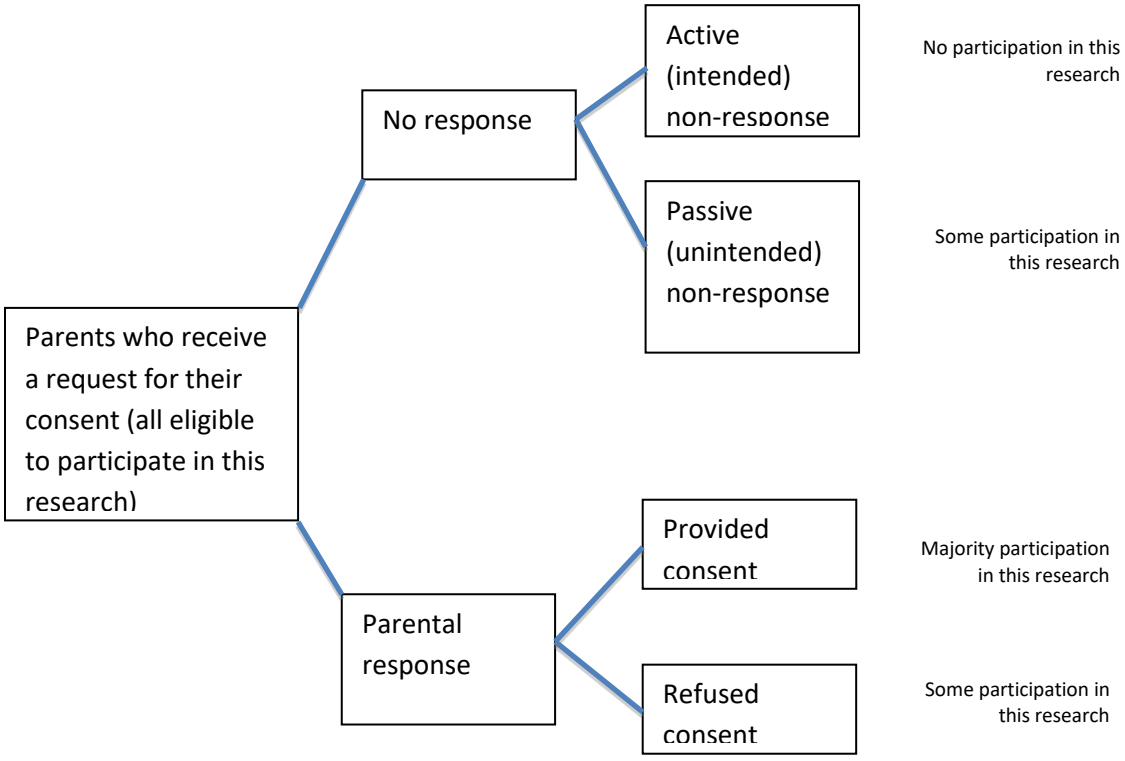
Potential for selection bias

It was anticipated that parents who had previously failed to respond to a consent request (intentionally or unintentionally) would be less likely to participate in this research, which was indeed the case. As a result, the data collected was biased towards parents who had previously responded. Two parents shared that they had not responded to the consent request because they had forgotten (Lund Research Ltd, 2012). (These two parents were passive non-responders, *i.e.* the action of not responding was not a conscious act). However, while the potential bias created from the majority of active responding participants should not be ignored, the data collected is still of value. It has been used to demonstrate what barriers and enablers parents face to participating in the current consent process. There is potential for the barriers and enablers experienced by these parents to be similar to those in the non-response group, but it is also possible that parents who have not responded experience these differently. Additionally, parents in the non-response group may have experienced these enablers and barriers more keenly, or they may have experienced some level of indecisiveness or ambiguity that manifested in their non-response behaviour. Ultimately, it is not possible to know what enablers or barriers this group faces from this research. A similar situation was seen in the literature

reviewed in Chapter 3 (Literature review), with some parents delaying making their consent decision because of competing influences. The use of participants identified via the 'snowball' method can introduce an element of bias, with a potentially large percentage of the research cohort coming from the same close-knit social network with similar characteristics, beliefs and experiences. However, as no parents were recruited this way, this is not of concern.

The potential implication of missing data from the 'double non-responders', *i.e.* parents who did not respond to the consent request and the request for their participation in this research, has been considered in the final analysis and in the recommendations made. The figure below (Figure 4.1) demonstrates all potential consent response behaviour, *i.e*. parents who actively provide or refuse consent, as well as parents who do not respond at all, either intentionally or unintentionally.

Figure 4.1 Potential consent-response groups



4.5 Data collection

Data was collected from September to December 2017. There was an opportunity to continue after this period and into 2018, but this was not necessary.

It was originally anticipated that approximately four or five focus groups would be conducted with no more than eight parents participating in each (Gill *et al.*, 2008), and somewhere between 15 and 30 interviews (Baker and Edwards, 2012). However, the number of interviews needed to reach saturation was 18, at which point four focus groups had also taken place. These methods of data collection, *i.e.* focus groups and semi-structured interviews, have the potential to provide many hundreds of 'bites' of information for analysis even with a relatively small number of parents when

compared with the number of participants traditionally needed for quantitative research (Ritchie and Lewis, 2003).

4.5.a Semi-structured interviews

Interviews of this type are commonly used in qualitative research (Denzin and Lincoln, 1994). Indeed, King and Horrocks (2010) have stated that interviews are a ubiquitous aspect of contemporary life. This makes them ideal for research with members of the public. The basic premise of an interview is familiar to professionals and parents alike, and this should enable the participants' focus to be on the content of the interviews and not on the data-collection process itself. The advantage of using a semi-structured interview is the flexibility that the format can take while retaining the scope of the research question, and this is important when investigating experiences, beliefs and opinions with members of the public (Willig, 2008).

Each of the participants was interviewed with the use of a topic guide (King and Horrocks, 2010). This guide was developed to include open-ended questions that elicited information relevant to the research objectives. In addition, the themes identified from the meta-analysis of literature in Chapter 3 were considered, and these formed the basis for question probes. This enabled the evidence from current literature on parental consent to be explored in a dental public health context (Appendix 4.3) These themes were:

i. Professional input
ii. Information/knowledge
iii. Perceived threat/susceptibility
iv. Responsibility
v. Internal beliefs
vi. Social and community networks

There was no particular way in which questions were asked, as would be the case with more structured interviews (Fontana and Frey, 1994). However, although the interviews were open-ended in order to enable participants to bring up unanticipated

perspectives or areas for discussion, the interview guide was intended to be comprehensive (Pope and Mays, 2008). The purpose of this was twofold: firstly, the use of the guide ensured that the research question was driving the interview and, secondly, the act of designing the guide itself prompted careful consideration of the meaning and form of each of the questions in advance of the interviews. This helped to eliminate leading questions, or controversial wording (Willig, 2008). The order of the questions decided on in advance of the interviews was also intentional, with a naturalistic feel to the flow of the interview being the aim. However, the guide was intentionally used as such and not as a script (Appendix 4.3).

The guide was useful as an aide-memoire to help keep the interviews on track and to time, but it was used flexibly so that a natural conversational flow was encouraged. Some feminist researchers advocate helping to develop a sense of intimacy when interviewing women (as the majority of the participants were) (Oakley, 1981). In many of the interviews, I felt it was an advantage being a woman interviewing other women in a female-dominated environment. The commonalities of our gender experiences, even though I do not have children, meant that developing a rapport between me and the participants was easy and happened quickly. The interviews I carried out with men had a less intimate 'feel' and were a little more formal.

In order to maintain the open exploratory style, questions were worded simply and on occasion reworded if parents did not understand what was being said. Whenever possible, parents were courage to talk freely so that they could direct their answer as they wished, thus reducing the asymmetrical nature of the interview to some degree and allowing space for new information or ideas to emerge (Jacob and Furgerson, 2012). This worked better with parents who had a good command of English. Those who were less fluent needed more direction and prompting. According to the National Institute for Health Research's publication *Using Interviews in a Research Project* (Fox, 2009), encouraging openness in this way increases the chance of 'real' questions being answered and not ones for which the answer is already known in

some way. Using this technique was intended to enrich the data available (Gill *et al.*, 2008). The pre-determined probes included in the guide were also used flexibly and were supplemented with follow-up questions that were developed on the spot. The intention of this was that no lines of exploratory enquiry were closed off prematurely.

The three-phase approach to qualitative interviews advocated by the National Institute for Health Research (Fox, 2009) was originally used to plan the interviews. This is based on the work of Seidman (1998) and, broadly speaking, follows thus:

Phase 1 Focused life history. Questions relating to participant's experiences in context are asked. Answers are descriptive. Questions focus on 'how' not 'why'.

Phase 2 Details of experience. Details (via question probes) of specific points explored and/or clarified. Re-construction of past experience, usually of a single action.

Phase 3 Reflection on meaning. Participants (via question probes) encouraged to reflect on meaning and to make intellectual and emotional connections with experience. The purpose is to make sense of experience.

The interview guide was developed to broadly mirror this approach and it can be found in the question map below (Table 4.3).

The first two interviews were used to test the interview guide (Turner, 2010). The purpose of this was to highlight any weaknesses in the guide, or any interview technique that could be improved (Kvale, 2007). After these 'pilot' interviews, I decided not to ask the initial 'life history' question, '*How important to you is dental care for young children?*' , or two of the related question probes, '*How do you look after your children's teeth?*' and '*Is tooth decay something that you worry about?*' (Appendix 4.3), as they seemed somewhat value laden and artificial. Much of this information came out in the interviews in a more naturalistic and conversational way without the need for specific questioning and so the guide was amended. These direct questions could have been taken as too intrusive by parents as well as presenting a

more formal feel at the outset of the interviews; they did not seem needed when most parents seemed happy to provide this sort of information voluntarily.

Reflecting, after each interview or focus group, on my own performance I realised that I needed to leave more gaps in the conversations. I needed to become more comfortable with silence, to allow parents time to think and formulate an answer; this was particularly important given that for most parents English was not their first language. Early on in the process, after listening to the recordings, I noticed that after a participant voice I would say 'okay'. For my part, I was attempting to be neutral but encouraging further dialogue by actively showing that I was listening and interested. On reflection I realised that my 'okay' was giving the impression that the conversation should move on to the next point. It appeared to be signifying that the comments made by parents were sufficient and nothing more was needed. I consciously tried to change this, and instead of saying 'okay' I included 'hmm', 'yes' or 'I see' to demonstrate that I was listening to what was being said as well as being happy for the parent to continue. Additionally, I was conscious that I needed to perfect asking more in-depth questions about the parents' own decision-making processes, *e.g.* I needed to probe what they found enabling or what barriers to making a decision they encountered. In the subsequent interviews and focus groups I consciously attempted to explore this area in more detail, with some (but not total) success.

The interviews lasted between 30 minutes and one hour and they were conducted over a period of three months. The majority took place on school premises but occasionally they were carried out in a café nearby or in the participant's home. All bar one of the interviews were digitally recorded at the time (with consent from the interviewees) ready for verbatim transcription and analysis later. Reflective notes were also written immediately after each interaction (Polit and Tatano Beck, 2014). These notes included non-verbal aspects of each interview, such as the wider context. For example, notes were made about the setting and the attitude of the participant as well as the level of engagement by school staff (King and Horrocks, 2010).

Table 4.2 Question map

<table>
<tr><td colspan="2">Research question:

What barriers or enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?</td></tr>
<tr><td colspan="2">Research aim:

To examine parental experiences related to consent procedures for a school-based fluoride varnish programme in North London</td></tr>
<tr><td colspan="2">Researcher objectives:

• To investigate parents' views and experience of the consent arrangements for the fluoride varnish programmes taking place in their child's school

• To investigate parents' views about the consent process for the school-based fluoride varnish programme that would best support their preferred method of engagement, for example a system of opt-out consent, or one of opt-in

• To investigate what support, if any, parents would like in relation to their consent decision making as part of school-based fluoride varnish programmes in the future</td></tr>
<tr><td>Themes from literature</td><td>Interview questions/probes</td></tr>
<tr><td></td><td>Focused 'life history' questions</td></tr>
<tr><td>Information/knowledge
Internal beliefs
Perceived threat/susceptibility</td><td>Q – How important to you is dental care for young children?

• Have you got a family dentist?
• Have you taken your child to the dentist?

Q – Tell me about your experience of the dental project carried out at [insert name] school.

• How did you hear about this project? What do you understand about it?
• What can you remember about the information that you got/were sent?
• Do you remember being asked for your consent (permission)?
• What is your opinion of the school/NHS carrying out this project?</td></tr>
</table>

	Details of experience-type questions
Information/knowledge Social and community networks Professional input Responsibility	**Q –** Tell me about how you made your decision as to whether [inset child's name] could take part? • Did you understand what you were being asked to do/sign and why? • Was this decision based on experience or something else? • Do you feel you had enough information to make this decision? • What type of information helped you to make your decision? • Did you talk to anyone else about it before you made your decision? • Were you influenced in any other way? (*e.g*. how did your friends respond?) • Do you think the system of parents opting in is best, or would you prefer it if the project went ahead but you had the opportunity to opt out if you did not want your child involved?
	Reflection on meaning-type questions
Internal beliefs Professional input	**Q –** Tell me, in your opinion, what parent support and information about fluoride varnish in schools and the consent process you would like to see in the future. • Do you think dental professionals or schools have a role to play in helping parents make decisions like this? • Do you think that the information provided could be improved to help parents make their decision? • What could the dental team or school do better in the future? (*e.g.* face-to-face information / translation) • How can we support you when you are considering your decision? • What would be the best way for you to indicate your decision? (*e.g.* text, email, consent slip) • Do you think parents should be asked to confirm/repeat their decision in each year and for each application? Could this be done differently? (*e.g.* at the start of school life)

4.5.b Focus groups

Focus groups are routinely used when views of members of the public are wanted. This method of data collection makes few demands of the participants, with the exception of their time. There is no need or pressure for participants to respond throughout the discussion, but at the same time the discussion should enable participants to express their opinions and prioritise their agenda (Goodman and Evans, 2015). This is in contrast to other methods that prioritise researcher needs, *e.g.* questionnaires. This is a dynamic activity that has the potential to embolden participants through collective consideration and interaction with their peers. It was for this reason (along with the results from the public involvement group, Appendix 4.1) that focus groups were felt to be a complementary data-collection tool to interviews. It was also hoped that using focus groups would provide a window on to the social context of parents' experiences, understanding and behaviours that was of interest to this research.

Initially, the plan was to divide the parents who were willing to take part in the focus groups into those who had consented and those who had not. The purpose of this was so that neither sub-set, *i.e*. consenters or refusers, would feel inhibited if they found themselves as a minority in a group of parents who had responded differently to them. However, this was not possible due to the difficulty of getting parents to commit to taking part in an activity that needed planning and an appointment time to be kept. I found parents more than willing to participate if they had time on the particular day they were asked, but anything more than that was asking too much of them and they eventually declined. In addition to this, the number of parents who had refused their consent but were willing to participate in a focus group was too few to divide the groups in this way. Across the whole sample, *i.e.* 39 participants in total with 21 taking part in four focus groups, only six people were non-consenters. As such, a focus group specifically for these parents, who came from different schools, proved too difficult to organise with sufficient participation. Therefore, all four focus groups

were made up of parents who were willing to participate, regardless of their previous consent decision.

A key feature of focus groups is that the discussion may be more open and 'free ranging' than in a one-to-one interview scenario. The interaction between group members can be particularly potent if they know each other (Kitzinger, 1994). The focus groups in this study were located within individual schools, which are often close-knit environments where parents know each other, either personally or through their children. It is within these sorts of environment that parents may naturally discuss the fluoride varnish scheme or their response decision. It was hoped that the familiarity of these sorts of interaction would highlight any enablers or barriers to their decision at a societal level that may not surface in an interview. This consideration also added weight to the decision to abandon uniform decision groups for which parents would be brought together from different schools. From this vantage point, it was a shame that the snowball sampling discussed earlier (4.4.b Sample population) had not been successful, with more closely associated 'friendship groups' being recruited, as this may have produced more nuanced interactions that were less polite that those between acquaintances, which is what most participants seemed to be (Kitzinger, 1994).

One practical disadvantage of using focus groups to collect data is that groups have the potential to be dominated by one or more strong individuals, which can inhibit contributions from others who are less assertive in their views, particularly if participants know each other (Goodman and Evans, 2015). With this in mind, it was important to consider whether, as a result of the 'mixed response' groups, any minority views around the reasons why some people refused their consent were being silenced (Kitzinger, 1994). In fact, the opposite was true in one group. No single parent appeared to dominate in three of the groups, but in one a father who had refused his consent (in contrast to the others in the group) was very vocal in his opinions. However, this father had to leave the group early and a follow-up interview

was arranged with him. After his departure, the group dynamics changed somewhat and group members showed consideration of others' 'turns' at taking part. The dynamics of each group were noted for later consideration in a research journal immediately after the activity.

The broad questions that were used were designed in a similar way to those used in the interviews. They were discussed with academic supervisors before the wording was refined. At this point, more opening questions to 'settle' participants into the group were added (see Appendix 4.2 for the focus group questions). To help initiate discussion in the early stages, a copy of the dental literature sent to parents by the dental team was used as a prop (Curtis Taylor, 2017). Discussions were recorded and transcribed verbatim as soon as possible after the event.

It was planned that the five-stage approach to focus groups advocated by Gilbert and Stoneman (2016) would be broadly followed. Briefly, this advocates: (1) providing an introduction to the subject and the purpose of the research, and an outline of the format of the focus group discussions; (2) initiating an 'opening circle' in which each participant is invited to introduce themselves (although sometimes this was not necessary because parents knew each other); (3) opening the discussion with three pre-planned introductory questions and using the dental literature to refresh parents' memories; (4) introducing the five pre-planned questions, which are used to drive the discussion; and (5) using an ending question to signify to the group that the activity is coming to a close. However, although the discussion was sometimes between participants, often comments were directed towards me as the researcher. Participants seemed more comfortable with a question-and-answer scenario, especially in the beginning, when a group interview seemed to be developing rather than a focus group. This may have been partly because of the wide range of languages of the participants who all had varying levels of spoken English. On occasion, participants helped each other translate when understanding was missing. I found that those with less-developed spoken English were often reluctant to volunteer

information unless directly asked. I attempted to maximise parents' participation as well as their interaction with each other but on reflection this added to a more interventionist style than is ideal. When participants did discuss points among themselves they rarely challenged or contradicted each other, preferring to make their comment as a statement or to agree with other(s) before adding their views. The area that appeared to generate most discussion between participants was dental phobia or fears. This was often raised by participants and acted to mobilise group engagement among participants quite easily. Each group lasted no longer than one hour.

4.6 Data management

Prior to the data collection, a database of files was created in order to increase the reliability of this project (Yin, 2009). This consisted of electronic files for each stage of the data collection and analysis.

File 1: Created to store parents' contact details, along with a spreadsheet that was developed to record which school(s) and parents had been contacted and when, and if and when they had participated. This file also included field notes taken after each visit to the research site.

File 2: Included storage of original digital recordings; the raw, un-analysed transcription of the recordings; transcriptions with initial coding added; transcriptions with codes and candidate themes; the complete set of codes, candidate themes and overarching themes.

File 3: A master copy of the codes, candidate themes and themes removed from the transcriptions.

The purpose of this was to allow independent inspection or retrieval of the raw data to supplement the final thesis if required (Yin, 2009). This catalogued information is available to assist external observers such as academic supervisors, who may wish to

follow the derivation of evidence from initial raw data to final thesis. It will also help to maintain the chain of evidence required to ensure the dependability of the research (Polit and Beck, 2014).

All data has been maintained in accordance with the Data Protection Act (1998) and then the updated Data Protection Act (2018), and the standards set out in the Medical Research Council's *Good Research Practice: Principles and Guidelines* (2012). All raw data is stored securely in its original form and will be kept for a further 10 years after the final version of this thesis is produced. The confidentiality of the interviewees was assured at the time of their participation and any personally identifiable data or information has been removed from the transcripts. Research records and data are held on a secure server at City and accessed via a password-protected computer. No data has been or will be transported on remote memory devices, *e.g*. memory sticks. Any documents that have needed to be forwarded as part of this research have been sent as pdf email attachments. Any personal information that is in hardcopy, *e.g.* signed participant consent forms, is kept in a locked filing cabinet.

4.7 Data analysis

The data from the focus groups and interviews was analysed as one data set. This integration of meaning from different methods has been called 'crystallisation' by O'Cathain, Murphy and Nicholl (2007). This was a pragmatic choice that was made after the data collection started when it became apparent that the focus groups often took the format of a group interview. This scenario was described in point 4.5.b (focus groups). The hoped-for nuanced communication that can sometimes arise from focus groups where the participants know each other did not occur. No key points of information were revealed in the way that sometimes happens when people know each other well that by-pass some of the usual social conventions that acquaintances use. Existing relationships between participants could have been a useful and fertile area to explore with regard to relational decision making and procedural autonomy. But, as this sort of interaction did not occur, the data generated from these two

activities was very similar, *i.e.* largely the result of a question and answer format. Any focus group information stemming from the interaction between participants was minimal and not enough to warrant separate analysis. The limited social engagement between participants that did take place was unlikely to produce any meaningful interpretations that could be considered 'credible' and different from those produced via interviews. The possible reasons for the limited focus group data has been discussed previously in point 4.5.b (focus groups), not least because snowball sampling was not successful and friendship groups were not recruited.

The data produced was analysed thematically, with the interpretation of data clustered into overarching ideas or themes. There are different versions of thematic analysis that are more or less complex – for example, Boyatzis (1998), Roulston (2010), King and Horrocks (2010) and Braun and Clarke (2013) – and academic texts do not appear to report a universally preferred method. This research adopted the method described by Braun and Clarke (2013) in their book *Successful Qualitative Research*.

Thematic analysis was selected because of its flexibility as a method. It can be successfully applied to data sets that are relatively small and where the research is not purely theoretical but applied to an area of practice, as is the case in this project. An additional reason for using thematic analysis in this instance is to more easily communicate the findings and interpretation of meaning to colleagues within the dental profession who almost exclusively use positivistic methods (Stewart, 2008). Silverman (2011) suggests that thematic analysis can assist in bridging the gap between positivistic and interpretative science.

All interviews and focus groups were recorded (save for one interview mentioned earlier during which notes were taken) and these recordings were listened to within a day or two of the activity before being transcribed verbatim, and at this point initial thoughts or 'noticings' were logged (King and Horrocks, 2010; Braun and Clarke, 2013). These notes reflect tacit knowledge that was brought to the data before

complete immersion made this more difficult to distinguish (Boyatzis, 1998). These notes were revisited later. Every word from the recordings was transcribed but non-linguistic artifacts such as the length of pauses or voice intonation, as would be expected in discourse analysis, were not included (Willig, 2008). This 'familiarisation' with the data from the outset of the process helped to shape the remaining interviews and focus groups because specific points of interest or omission were raised at the next interaction with parents (King and Horrocks, 2010). When saturation point had been reached and interview and focus group transcriptions were complete, the entire data set was collated into one document, which was then tabulated, forming one tangible entity. Transcripts were read and re-read to ensure that familiarisation beyond the audio information continued, and the context for the data set as a whole was known before any detailed coding took place (Pope and Mays, 2008).

4.7.a Stages of analysis

Stage one – Descriptive codes

Complete descriptive coding, as opposed to selective coding, was conducted in order to identify every feature within the data that was potentially relevant to the research question (Braun and Clarke, 2013). The codes were written directly on to each data item (*i.e.* the transcript). The advantage of this was that proximity to the data facilitated complete immersion in the process (Denzin and Lincoln, 1994; Crabtree and Miller, 1992). The codes used were brief phrases or words with the intention that they captured the kernel of a particular datum (Boyatzis, 1998). In this way, these descriptive codes remained close to the data. Often data extracts were coded in more than one way because the datum fitted with more than one code (King and Horrocks, 2010). For example, the data item, *'Well yes, because if they do it and something goes wrong, who is to blame?'* was coded as *'*Belief in the parents as custodian' and 'Decision maker' (Int.2:123).

Recordings were listened to again, this time in tandem with the descriptive coding being hand-written on to each transcript. This helped when interpreting any nuances

in the way in which parents responded that could not be picked up by written text alone. At this point, specific parts of the text that were reflected in the codes were underlined. The purpose of this was to help identify example or clarifying quotes that might be useful later. Each interview or focus group took up to three hours to code. This process was completed over a number of weeks. Once the initial coding of the entire data set was complete, this was revisited in full to unify any codes with the same or a very similar meaning but written differently, for example, '*influence of friends'* and '*trust in friends opinion'* (King and Horrocks, 2010). All codes were transferred from the hardcopy of the transcripts to the electronic version. In total, 365 descriptive codes were created across the data set.

Stage two – Candidate themes

In stage two, the entire fully coded data set was reviewed again and any emerging commonalities between descriptive codes was noted using reflective phrases. These formed the basis for the development of candidate themes, whereby descriptive codes that shared common meaning were grouped to create a smaller number of interpretative points. Braun and Clarke (2013) state that candidate themes should be broader than codes but also reflect a deeper interpretation of the information.

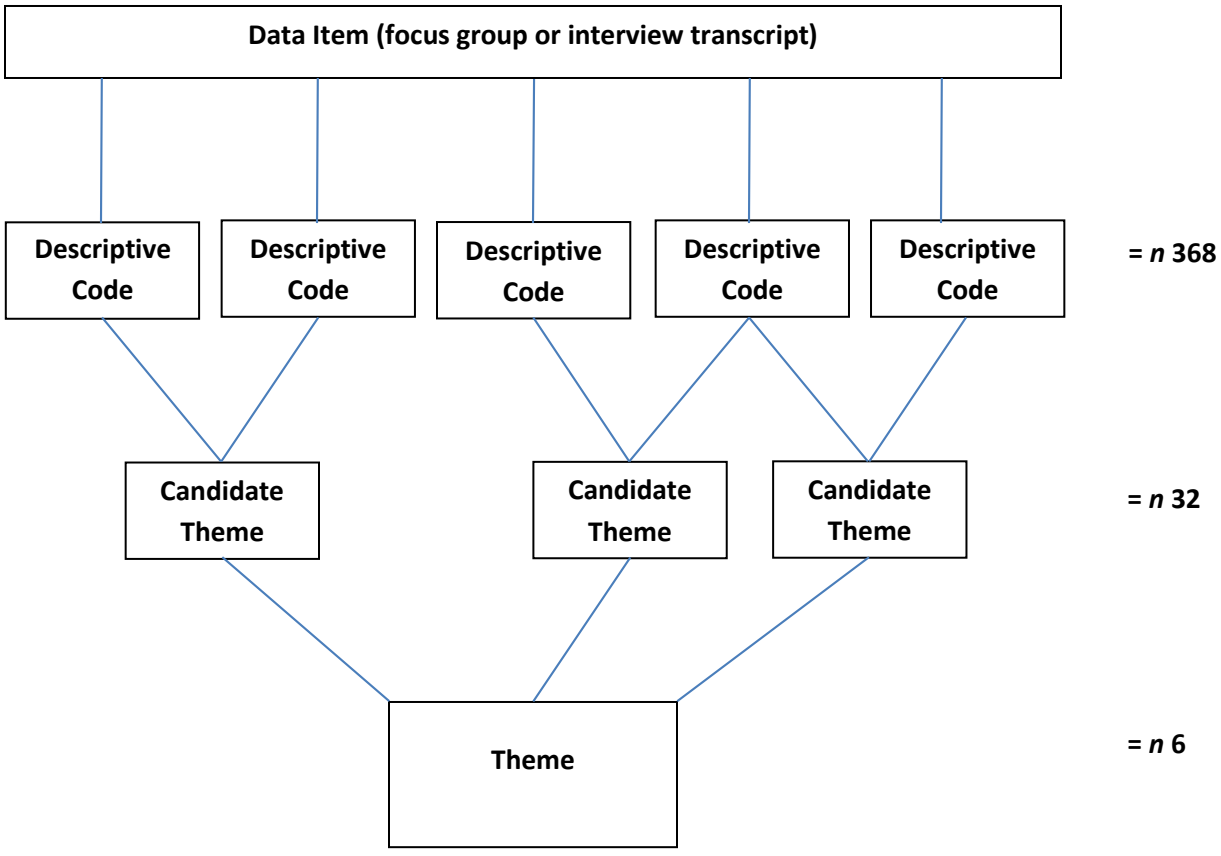
Once all descriptive codes had been encapsulated into the various candidate themes, any weak or 'thin' candidate themes were considered individually. At this point some were deemed distinct enough to remain, but others were merged with similar candidate themes. The purpose of this was to reduce the data through abstractive analysis and interpretation. At the end of this process, 368 codes were grouped into 32 candidate themes.

Stage three – Themes

Overarching global themes were developed from the candidate themes. Themes differ from candidate themes in that they are at a higher level of abstraction (King and Horrocks, 2010). These themes should be broad enough to encapsulate several

candidate themes grouped around one central concept. A similar process of grouping as described in stage two was followed for the development of themes. Some themes came directly from the candidate themes, *i.e.* candidate themes were 'promoted' to become themes. Others were an amalgamation of candidate themes when, through extraction, meaning was found in overarching concepts, *e.g.* the theme '*dental information'* centres around the concept that the information given to parents prior to asking for their consent can create either a barrier or an enabler to consent regardless of any other social or psychological influences. However, underpinning this theme are several candidate themes, *e.g.* information format, information content, professional impartiality and preference for face-to-face information. Using this abstraction and interpretation process, six final themes were developed. These are discussed in detail in Chapter 5 (Findings). In Figure 4.2 below is a visual representation of the thematic analysis method used in this thesis (Braun and Clarke, 2013). This is an example of how themes are developed from data.

Figure 4.2 Three-stage theme development from initial data (example)



All descriptive codes, candidate themes and themes were entered into the summary table to show how the themes can be traced back to the initial codes and original data, and how they were developed through interpretation (Appendix 4.4). These are provided as examples of how the descriptive codes, candidate themes and themes were developed.

Interpretation of qualitative data

The data from both focus groups and interviews was analysed as one data set, with attention being paid to the overall interpretation. This information will be presented in the following chapter (Findings). The intention was the integration of insights from focus groups and interviews that crystallised any points of convergence or divergence (O'Cathain, Murphy and Nicholl, 2007). This is not to be confused with other forms of integration found in some mixed methods approaches, or where corroboration of findings is the overriding purpose, as with triangulation, which focuses on a single point that reflects one reality (Turnball and Lathlean, 2015). Here the focus was on an overall comprehensive interpretation that included multiple realities to answer the research question. In the penultimate chapter of this thesis (Chapter 6: Discussion) this interpretation will move on to consider these findings when viewed through a theoretical ethical lens.

4.7.b Data collection outcomes

Twenty-two exploratory interactions with parents took place as part of this research, which produced more than 400 pages of verbatim text. From this and through careful analysis, 368 codes were developed, the meaning of each of which was considered and organised into 32 candidate themes that still reflected the meaning of the data but was a further step in the abstraction process. Overall, six themes were developed from the candidate themes, each one having a central organising concept that reflects

the barriers and/or enablers that parents encounter when asked for their consent. The intention was to produce a list of themes that when viewed in isolation from the transcripts, codes and candidate themes would broadly indicate the enablers and barriers to a parental consent response. The research question was used as an anchor in this process and was returned to many times to ensure that codes, candidate themes and particularly themes reflected parental barriers and enablers and could contribute to the formulation of an answer. These themes are:

- Protecting children from harm is viewed by parents as their role
- Parents have the ability to make consent decisions but can lack confidence
- Sharing responsibility for children's health between parent and State is viewed positively by parents
- Existing relationships within parents' social networks strongly influence their consent decisions
- Official dental information is not communicated in a way that parents find useful
- The current consent processes are problematic for parents

4.8 Research ethics

There were four ethical issues to consider in association with conducting this research: informed consent of participants, confidentiality, anonymity and conflict of interest. The first three of these are of particular importance in relation to the group discussions and the interviews with parents. The last point, 'conflict of interest', applies to the entire project.

Consent of participants

Once parents had expressed an interest in taking part they were given a participant information sheet (PIS), which explained the overall purpose of the research and provided details of the methods involved (Braun and Clarke, 2013) (Appendix 4.6a). This included my contact details for the parents to use if they had additional questions

at a later date. At this point participants were asked to confirm whether they were happy to continue as part of a focus group or via an interview and all those in favour were given a consent form to complete and return (Appendix 4.7). Ideally, there would have been at least a week between participants receiving this information and their actual participation, and in some cases this did happen. However, because of the way in which some parents operated, *e.g.* agreeing to participate if they could be interviewed there and then, the time between agreement and actual participation was sometimes very short. This was more common among those who participated in the focus groups. Where participants had agreed in advance, I contacted all of them either the day or morning before the event to confirm their attendance at our meeting. At this point I was also able to answer any questions they had.

At the time of the interview or focus group the purpose of the research was explained again, and the format clarified, including assurances of confidentiality. Participants were told that they could stop taking part at any time. An additional copy of the PIS was offered and participants were asked to sign two copies of the consent form, one of which was returned to the participant and the other held in the research records (Polit and Tatano Beck, 2014). Those parents who initially expressed an interest but did not respond to further contact were followed up on one additional occasion to establish whether the non-response was an oversight. If no response was forthcoming it was assumed that the individual did not wish to participate and no further contact was made.

Confidentiality

All participants were assured from the outset that their personal information would be held as confidential. It was made clear that although no identifiable information, such as individuals' names or the names of their children, would be included in the transcripts, their views and opinions would be reported as part of the research results and anonymised quotes might be included in the final thesis (Polit and Tatano Beck, 2014).

All participants were assured that the utmost care would be taken to omit obviously identifiable or personal data from the PhD thesis, or related dissemination artifacts. Personal data, such as names or schools attended, were coded at the first available opportunity. A confidential list has been kept showing the corresponding codes and persons. This will be kept for the duration of the PhD study, after which it will be destroyed and only the unidentifiable coded data will remain. This list is being kept in the short term to allow for clarification, if needed, until the writing-up stage has been completed (King and Horrocks, 2010). In addition, transcript data is being held on a password-protected computer and will not be transported on remote memory devices, *e.g*. memory sticks. Any documents that need to be forwarded as part of this research will be sent as pdf email attachments.

The exception to this respect for participant confidentiality would have been if a parent had disclosed unsafe practice (for example, if a parent had stated that they explicitly had not provided consent but their child had been included in the FV programme anyway). Participants were advised that if such a situation arose it would be reported to the most appropriate person and/or the organisation involved, *e.g.* Whittington NHS Health Dental Service managers and/or the school head teacher. However, this was not necessary and confidentiality was maintained at all times.

Conflict of interest

Findings from this research will be disseminated via journal articles and conference presentations. It is anticipated that dissemination will include local and national routes. A conflict of interest may occur if the findings are at odds with the views of dental professionals who assisted this project by supplying local response data for the previous academic year and a list of school contacts. To minimise the potential negative consequences of such a situation, a copy of any dissemination artifacts will be sent to those involved prior to any external dissemination. However, it was made clear from the outset that all findings would be reported and included as part of a PhD thesis (King and Horrocks, 2010).

To date, two conference presentations (one in poster format and one oral) have been made. The poster presentation was awarded first prize at the annual scientific meeting of the British Association for the Study of Community Dentistry and the oral presentation was delivered in Amsterdam to the International Dental Ethics and Law Society. On both occasions the final presentations were made available in advance to the dental team in Enfield.

4.8.a Ethical approval

The Health Research Authority (HRA) was contacted regarding this project and confirmation has been received that NHS-generated data used to provide contextual information (as presented in Chapter 1: Background) for this thesis is classed as 'audit'; ethical approval from the NHS Health Research Authority is, therefore, not required (Appendix 4.8). For the qualitative investigation, participants were to be recruited via school premises and an application for ethical approval of this was submitted to and approved by City, University of London, School of Health Sciences Research Ethics Committee (Appendix 4.9).

4.9 Quality

Quality measures for qualitative research are not universally agreed upon in the same way as those used for quantitative research. However, this is generally understood to mean the 'trustworthiness' of the research. Guba and Lincoln's (1994) criteria to demonstrate quality in qualitative research appears to be commonly referred to in the literature. Therefore, the quality measures used in this research have been based on these long-established criteria, which although more than 20 years old are still in use. For example, the criteria are extensively discussed in the 2012 book *Essentials of Nursing Research* by Polit and Tatano Beck. Equally, the four criteria of credibility, transferability, dependability and confirmability are similarly discussed by Shenton (2004) in his paper on trustworthiness in qualitative research and in Clive Searle's philosophical paper 'Quality issues in qualitative inquiry' (2002). Morse *et al.* (2002)

claim that the quantitatively derived terms of 'reliability' and 'validity' have been replaced by the above four criteria, with the addition of a fifth, *i.e.* authenticity.

Credibility refers to the confidence that readers can have in the truth of the data and its interpretation. Here this is demonstrated by themes that have been developed from manually defined codes and which maintain a closeness to the original data. The abstraction from original data to themes can be viewed via Appendix 4.5 that contains an example interview transcript.

Dependability is similar to the quantitative term of reliability, *i.e.* it refers to the stability of the data. Here this has been ensured through the synthesis of data from different sources and by using different collection methods, *i.e.* from multiple parents at different locations (schools) taking part in parent discussion groups and interviews. Thirty-nine parents were involved in this study through four focus groups and 18 interviews across nine schools.

Confirmability denotes that the data represents information provided by the participants that can be checked via the audio files kept as part of the chain of evidence prior to verbatim transcription (See Appendices 4.7 and 4.8 for transcription examples).

Transferability is analogous to generalisability in quantitative research, *i.e.* findings can be transferred or have applicability in other settings. The sources of data in this research are local to Enfield, but this location was chosen because it represents a 'typical case', both in the way in which it requests consent and through the diverse range of parents living in a multicultural area with significant inequality (described earlier in Section 4.4. Sample selection).

Authenticity signifies that the research has shown a range of different realities, which has been achieved through the use of purposive sampling to recruit parents who have responded differently to the consent request, *i.e.* most parents in this sample

expressed actively providing and refusing their consent, while a minority passively refused it and one reluctantly consented.

The quality of the methods and results of this research has been ensured through the implementation of specific measures, some of which have been discussed elsewhere in this chapter. Table 4.3 below is a schematic representation of the quality measures that are inherent in this research design.

Table 4.3 – Schematic representation of quality measures (adapted from Polit and Tatano Beck, 2014)

	Credibility	**Dependability**	**Confirmability**	**Transferability**	**Authenticity**
Method used					
Reflexive journaling via a diary	x				x
Maintained chain of evidence via database		x	x		
Audiotaping and verbatim transcripts from focus groups and interviews	x				x
Interpretation integration	x	x	x		
Peer review via dissemination	x		x		
Documentation of quality enhancement efforts	x			x	
Analytic generalisability				x	
Use of multiple sources of evidence					x

4.10 Reflexivity

I have a dental background, having qualified as a dental nurse more than 25 years ago. Almost 10 years ago I worked for the dental service in Enfield as an Oral Health Promotion Manager. The service was not under the management of Whittington Health NHS at that time. However, the programme that is the focus of this research is not something I have participated in. Additionally, I have worked on a number of Department of Health (dental) projects over the last 10 years. As a result of this familiarity it is likely that I may be considered part of the dental community by some of the local dental professionals and, therefore, have 'insider status' (Braun and Clarke, 2013). This status is potentially a privileged position in which relationships with the potential gatekeepers to information are already established, and this in turn may lead to disclosures that may not otherwise be forthcoming. This has been referred to by Wilkinson (1988) as functional reflexivity. However, the impact of this on the research is minimal, in that participants were recruited via schools that were not known to me. It is only regarding the initial contact details of school personnel and the response data presented in Chapter 1 (Background) where this existing relationship has been beneficial.

My professional identity as a dental care professional is also likely to have influenced how the participants view me and therefore how they respond to the initial invitation to participate, and during the research encounter. As such the epistemological implication is that any knowledge that is constructed from these encounters is positioned within this relationship *i.e.* that of health professional and lay person (McGarry, 2016). This relationship is traditionally based on an unequal distribution of power, alluded to in Chapter one where even the law promoted the 'doctor knows best' ethos via the Bolam test (*Bolam v Friern Hospital Management Committee [1957]*). In this scenario, my position as a dental nurse researcher could have been viewed by participants as more knowledgeable and therefore more powerful, thus requiring them to take on the traditionally subordinate role of lay person. The

interplay of power dynamics is a complex characteristic of researcher and participant interactions (Foucault, 1982). This is likely to have been further influenced by my position as a dental nurse researching a dental subject. This could raise suspicion of the FV programme itself in some people. Equally, some participants may not feel able to voice criticism of the programme to someone with obvious links to dentistry, although this did not appear to be the case in the interviews and focus group I conducted.

However, the knowledge - power difference was evident on some occasions when parents asked me for advice about fluoride and the fluoride varnish programme, despite having already made their decision to consent or refuse. By this, parents could be seen to be demonstrating their deference to expert knowledge in this subject and seeking reassurance that they had made the 'right' choice. In this scenario parents who had already officially made their decision were in fact revisiting it. In practical terms, consent had already been given or refused and many children had already received the fluoride varnish. So, there was no opportunity for parents to act on a change of mind, but this type of reflection on a choice already made demonstrates that decisions are often not a single event. Decision making is part of a process that can be revisited with decision being affirmed or revised, even if the opportunity to act on this has passed. Pre-existing decisions can be changed based on new information, a change of circumstances, or simply a different way of looking at an issue. My position as a dental nurse researcher enabled parents to revisit their decision and potentially reconsider it based on new information. New information could be either gained from seeing me as an information resource and asking specific questions, or from more subtle information. Parents may have revisited their original decision because knowledge of my research may have sparked some doubts about the programme overall. Parents may have wondered why such a programme needed to be researched if it was 'safe' and 'good for children' in the way the information previously sent to them had claimed. Revisiting decisions already made in this way *i.e.* hypothetically to confirm or amend an original choice is reflective and it may influence

parents' actions when asked for their consent a second time. When viewed in this way my role as a dental nurse researcher in the research setting could be viewed as an additional influence on the parents' future choices, particularly as parents may be asked for their consent up to six times during the life of the FV programme.

On several occasions' parents wanted to explain to me in detail how they looked after their children's teeth, and some even insisted that I look at the teeth of the young children they had with them. Here, parents were potentially presenting themselves as 'good' parents in a conventional sense by demonstrating their adherence to 'rules' of good oral care set out by more knowledgeable professionals. These are practical and obvious examples of how my position as a dental nurse may have influenced the relationship between me and the participants. My response to situations like this was to acknowledge what the parent has said and then explain to them that I would answer any questions they had about FV after the interview or focus group. I did not want parents to be influenced by anything that was said prior to their interview or FG response, nor did I want the research time to be taken up with general questions and answers about dental care. But, as the disclosure had been made, I felt it was my professional duty to answer their questions. All parents seemed happy with this response. It seemed unethical to make such a disclosure and potentially capitalise on any credibility that this may have engendered but then refuse to answer parents' questions. This would contradict the values held by dental care professionals.

My position as a health professional may have created an underlying level of trust that parents felt towards me and potentially anything they told me (McKinstry *et al*., 2006). As a result more parents may have felt comfortable agreeing to participate in the first instance and indeed several invited me to interview them in their homes, which is certainly an act of trust (by both parties). Moreover, a number of female participants disclosed details of their relationship with partners and how this influenced the way they made their consent decision. This sort of disclosure may not

have been forthcoming without the general presumption of trustworthiness that is afforded to health professionals.

On reflection, the relationship between me as a researcher and parents (without the disclosure of my status as a health professional) would have created a different dynamic. Parents may have felt freer to offer negative views of the consent process without fear of offense to someone from the same professional group. Conversely parents may not have been so forthcoming in their comments about aspects of their personal lives. Without the status of a 'health professional' I may have appeared less trustworthy or credible to them when asking about their experiences of the FV programme. I acknowledge there are implications to making this fact known to parents in advance; their view of me will have been shaped by this and thus, their interview or FG responses too. Furthermore, with hindsight I can see that I easily and unconsciously slipped on my old professional identity *i.e*. experienced dental nurse used to working in the community with members of the public, and on reflection, it is evident that this gave me a 'shield' of confidence. At the time I felt very aware that I was performing the role of researcher, which was new and unfamiliar to me. I do not feel these roles *i.e*. health professional and researcher are conflicting in qualitative research if this relationship is acknowledged as shaping any resulting knowledge.

Personal reflexivity (Lofland *et al.,* 2006; Wilkinson, 1988) is considered to have influenced the shape of the knowledge produced by this piece of research. For example, my initial dental training is likely to be very similar to the dental education and training of most of the professionals implementing this DPH programme, which is biomedical with little or no emphasis on population health and very little education about ethics or consent above ensuring that autonomy is respected via signed consent forms. However, as a result of the work conducted for this thesis, I now appreciate that the traditional stance of non-interference by health professionals may in fact be detrimental to facilitating individual autonomy.

A field log maintained as part of this research includes personal notes with regard to the reflexivity (Braun and Clarke, 2013; Lofland *et al.,* 2006). This was used when analysing the data and when writing the research discussion, in order to reflect on my interpretation of the information. In addition, any potential underpinning assumptions have been discussed during supervision sessions with senior colleagues in order to identify and challenge any vestigial influences from clinical dental training. However, given my immersion in public health over the past 20 years, it is my knowledge and views on the importance of a social, not a medical, model of health that comes into play.

4.11 Conclusion

This chapter explains why I have made specific methodological choices in relation to this research project. It demonstrates some of the background work that has taken place that underpins these, *e.g*. the public involvement group. I have also discussed how the literature review conducted earlier in this project – outlined in Chapter 3 – has been used to inform this investigation, with the identified themes helping to guide the interview questions and therefore explicitly rooting this chapter within the thesis. Contextual information has been provided on the site and sample selection using data relevant to the subject being researched, which can be viewed in addition to the background information included in Chapter 1 (Background) (*i.e.* statistics provided by Whittington NHS Health showing the number and percentage of parents who consent, refuse and do not respond). This information is intended to help orientate the reader to the location, current parental behaviour, and the scale of the issue being investigated and to ground this research in a real-life environment. I have made reference throughout this chapter to research methods literature in relation to the techniques and processes used. This has been discussed in a practical sense, for example when designing the interview questions and applying the National Institute for Health Research's approach to help devise the wording and organise the interview guide via a question map with specific sections. I have also made use of research

literature to stimulate my consideration of some of the potential problems, for example the strong possibility for bias in the data due to the participant selection process and the likelihood of 'double non-responders'. In this vein, I have also outlined the parameters of this research and considered how parents with different response behaviour may or may not participate in this project, and the potential for bias that this may create has been explicitly discussed. Using literature in this way has prompted me to explore some of the more difficult aspects of this project early in the research process, enabling me to amend my original ideas and to plan a measured, thoughtful methodology. The intention of exploring these points in detail in this chapter is to show the reader that I have considered the implications and appropriateness of my plans prior to taking any action. This chapter also details the quality measures that have taken place, such as the application for ethical approval and how this research can be viewed using the recognised markers of quality for qualitative research. Lastly, in this chapter I have reflected on my own role within the research process and on how this may or may not influence my interpretation of the findings, which are discussed in the next chapter (Findings).

Chapter 5 – Findings and interpretations of parents' experiences

5.1 Introduction

In this chapter I present my interpretation of the experience parents have when making a consent decision, specifically with regard to any enablers or barriers they may face. I show how these expose the inherent tension that exists between parents as decision makers and the practical delivery of fluoride varnish programmes as a dental public health measure that operates an opt-in system of consent. These experiences and tensions are summarised in Section 5.2 to help orientate the reader, and to explain my understanding of the situation before the more detailed discussion of each theme is presented. Themes were developed from the participants' data. Verbatim quotes have been used from the transcripts in order to allow the parents to speak for themselves and to better illustrate the points being made while remaining true to the data. The function of these themes is to identify areas of interpretative synthesis or dissonance across the data set. All six themes are more complex than they would first appear, with each one containing elements of tension. For example, parents expect professionals to be paternalistic towards them and their children, but at the same time see it as their 'right' to decide what happens to their child. This does not mean that overall a clear understanding of how parents experience making this decision has not been possible, just that each theme contains some elements that are experienced as a barrier and some as an enabler. How these points were experienced depended to some extent on parents' individual agency and I have captured this as far as is possible to demonstrate the nuances within each theme. Towards the end of the chapter, an understanding of the experience of parents is put forward in alignment with the objectives set out in the previous chapter (Methodology).

Research question

'What barriers and enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?'

I have included some reflections on my experience of being in the research environment and navigating the individual school systems as well as my impressions of the people involved (parents and school staff). These are based on the field notes I kept throughout this process, which have aided my understanding and interpretation of the subject.

5.2 Summary of findings

In this section I have provided a brief overview of the parents who took part in this research, including personal details, *i.e.* gender, ethnicity and level of spoken English, as well as information about their previous response behaviour and consent decisions. This information is intended to provide some context to the findings. I have also summarised the main enablers and barriers, that parents navigate when making a consent decision for the FV programme. This is to give some indication of how the different individual themes presented in detail later interact with each other. This is also discussed in more detail in Chapter 6 (Discussion).

5.2.a Participant details

A total of 39 parents were recruited through 11 face-to-face recruitment events. Eighteen parents were interviewed, 17 of whom were happy for me to digitally record the interview. One parent agreed to take part but did not want to be recorded and so written notes were taken. Among the 17 interviews, four parents were interviewed in two pairs, and one parent was interviewed individually after initially being part of a focus group. This parent had to leave the focus group early and was someone who had actively refused to consent, so I felt that an additional interview to explore this

further would be useful. Four focus groups were held and 21 parents participated in this way; all the focus groups were recorded. The minimum number of parents in these groups was four, and the maximum eight.

Of the 39 participants, six were male and 33 were female. One participant was not a parent but a hereditary aunt who held legal parental responsibility after being appointed as a 'special guardian' by the court for the participating child. For 34 of the parents English was a second language and they spoke it to a greater or lesser extent; on one occasion translation was necessary for the entire interview and this was provided by a fellow parent. At other times, translation was provided for clarity of specific points during the focus groups, either by school staff or other parents, and on one occasion 'Google translate' was used during an interview to help with specific words. One parent stated that she was illiterate in her native language. Ten parents were British born with the remaining 29 coming from a variety of minority ethnic communities born outside of the UK including Somali, Turkish, Kurdish, Albanian, Lithuanian, Congolese and Brazilian. Religious affiliation was not requested from participants but some parents from the Muslim community raised this in relation to their decision to consent or refuse. For those parents who did mention their religious beliefs, the inclusion of alcohol was of concern to them, despite authorisation for this from the Sharia Council being included in the information provided by the dental team (Appendix 5.1).

Most participants (33) had consented for their child to take part in the FV programme, although one parent stated that she did not agree but had provided her consent so that her child was not left out, thus demonstrating 'reluctant consent'. Four parents had actively refused their consent, with one stating that he felt applying fluoride varnish to his children's teeth was not necessary due to their young age (the child did not yet have her permanent dentition) and the temporary nature of the varnish. The remaining active refusers said that they would agree to their children participating when they were older, but they felt that children in nursery (three years old) were

too young and concerns about their children's ability to spit out was given as an explanation by two parents. These parents were worried about their children ingesting the fluoride varnish. By delaying their consent they were, in effect, 'temporary refusers', and therefore mirrored some of the parental behaviour seen in the literature reviewed in Chapter 3. Two parents who participated in this research said that they had not responded to the consent request. Both of them stated that they had intended to consent but had forgotten to return the form to school, *i.e.* they were passive non-responders. This could be seen as a temporary situation, but it is certainly not one that parents have actively chosen, in contrast to the refusers mentioned above; this situation has come about unintentionally. The response profile outlined above demonstrates the variety of consent response behaviour that was captured by this research. However, no 'active non-responders' were recruited, as anticipated and discussed earlier in Chapter 4 (Methodology, Section 4.4.b Sample population). This demographic data is shown in the summary table (Table 5.1) below:

Table 5.1 Participants' demographic data

Gender	Ethnicity	English spoken	Response behaviour	Consent/Refuse
6 x Male	2 x Albanian	21 x Fluent/good	37 x Active response	32 x Active consent
33 x Female	4 x Arabic	15 x Limited	0 x Active non-response	1 x Reluctant consent
	1 x Bangladeshi	3 x Very limited	2 x Passive non-response	4 x Active refuse
	1 x Brazilian			2 x Passive refuse
	7 x British (White)			
	2 x British (Black)			
	1 x British (Other)			
	1 x Bulgarian			
	1 x Congolese			
	1 x Iraqi (Kurdish)			
	1 x Lithuanian			
	1 x Pakistani			
	7 x Somali			
	6 x Turkish			
	2 x Turkish Cypriot			
	1 x Unknown			

The sample population in this study is ethnically different when compared against the general population of Enfield (as described in the methodology, Chapter 4, point 4.4.b sample population). There is a higher percentage of people from minority ethnic communities in the research sample. For the general population 60% of the total population are classed as 'non-white' (Enfield Council, 2016), whereas in the sample population, this rises to 82% if all ethnicities that are not 'white British' are classed as 'non-white'. Differences in how ethnicity is classified can be problematic but may explain this variation to some extent (Bhopal, 2004). In this sample, parent participants' ethnicity is self-identified. As a result, parents from the 'white British' community could be potentially under-represented. For example, parents with who could be considered 'white' and who are born in the UK may self-identify as 'white-British', or they may self -identify as the ethnicity of their heritage *e.g*. Albanian. The wards of Edmonton Green, Upper Edmonton, and Ponders End all have between 55-61% Black, Asian and Minority Ethnic (BAME) populations. The exception to this is Southbury ward, where the percentage of families classified by Enfield Council as BAME is 36% (2016). Schools and parents from all four wards are included in this research. Wards such as Highlands that are more affluent and have a lower percentage of BAME residents are not included in this research. Only schools targeted by Whittington NHS Health for the FV programme were included and this is targeted towards areas of dental need. The data included from Enfield Council is made up from all wards and as such the percentage of BAME families is expected to be lower than in this targeted sample. The largest minority ethnic groups in the general population of Enfield are Turkish and Somali, which is the same as in this research sample.

Enfield Council collect data on the number of families where no one speaks English as a first language. This ranges from 22.7% to 12% in the four wards included in this research (Enfield Council, 2016). This cannot be used as a measure of spoken English, merely as an indicator of households where English may be spoken in addition to another language. The data above identified as 'spoken English' is not intended to try to demonstrate any type of representativeness of the general population. It has been

included to provide context for the qualitative interactions that are analysed below, which require verbal communication, understanding and interpretation.

5.2.b Enablers and barriers

Parents navigated a variety of enablers and barriers in order to make and communicate their consent decision. Overall, the enablers to parents' decision making came from their innate desire to protect their children from harm, now or in the future. Parents' considerations around this were physical and emotional, *i.e.* prevention of both tooth decay and distress. All parents felt that it was their duty or 'right' to be the main decision maker with regard to their children. This was a role they took on willingly, save for one parent who was reluctant to make a decision on behalf of her child. Moreover, parents expressed confidence in their capability to make surrogate decisions generally, but some said that they lacked confidence regarding this particular decision. While all parents sought information that was supplementary to the official dental information they received, indicating that they wanted more knowledge about this programme, some parents felt this knowledge gap more keenly and this affected their confidence to make an independent decision. These parents often also looked for guidance, particularly from authority figures, *e.g.* teachers. A significant number of parents also expressed the desire to know the views and choices of other parents. The bond of parenthood between individuals also acted as an enabler to decision making, with parents being influenced by friends and family with children they saw regularly. The experience of others 'like them' was valued by all parents, whether this was related to their friends' dental histories or their friends' children's participation in the FV programme.

While parents saw themselves as their child's protector, all of them expressed a belief, to a greater or lesser extent, in sharing responsibility for their children's health with public services, *i.e.* schools and the NHS. Interestingly, all parents, including those who actively refused their consent, felt that these public services would not harm children. The role of teachers in particular was mentioned frequently by

parents, with many turning to them for additional information and guidance about the FV programmes. Parents had an expectation of paternalism from public services, and due to the regular and personal contact that parents have with teachers, they saw them as key to providing this. All parents valued face-to-face information over written information, and so the conversations that parents had with each other and with teachers often carried more weight than the dental information that was sent to them anonomously. This was also the situation with other information sources, for example some parents reported seeking supplementary information via the internet (although this was not as prevalent as expected) but this was easily usurped by personal face-to-face information. Personal relationships and the trust that parents have in these are a significant enabler to their decision making.

All parents used a range of both formal and informal information to help them make a decision. The information sent to parents from the dental team was largely viewed as a barrier that parents had to navigate. A significant minority reported that it raised more questions than answers, including some they had not previously thought of, *e.g.* whether the alcohol content was permitted by the Islamic faith. A number of parents reported that they were not able to read, or not able to read English, and so had to have the information translated for them. This was a significant barrier that parents overcame through recourse to their personal networks, *e.g.* asking friends or teachers, or even their older children on occasion. Many parents also reported that the letter format was problematic for them, with it either never reaching them or, once at home, being too easily overlooked. Indeed, two parents in this sample intended to consent but forgot to send the letter back to school on time. The majority of parents also felt that they did not need to be sent the same information to sign and return twice in one academic year. Most would have been happy to confirm or withdraw their initial decision via a text message, a method they felt was more convenient amid busy family life. However, parents did want the flexibility to consent or withdraw as and when they wished; for example, some parents had not consented for the initial application but were intending to do so later. Overall, parents favoured

an opt-in system of consent, but a significant and vocal minority felt that consent was not needed at all. These parents wanted to be told in advance what was going to happen, but were happy to relinquish their decision-making role in this instance, believing that the school and the NHS would not introduce a programme that would harm children.

5.3 Themes

Detailed coding of all transcripts was carried out. These codes were subsequently grouped into 36 candidate themes which, after thematic analysis, were organised into six overarching themes:

5.3.a Protecting children from harm is viewed by parents as their role

5.3.b Parents have the ability to make consent decisions but can lack confidence

5.3.c Sharing responsibility for children's health between parent and State is viewed positively by parents

5.3.d Existing relationships within parents' social networks strongly influence their consent decisions

5.3.e Official dental information is not communicated in a way that parents find useful

5.3.f The current consent processes are problematic for parents

Each overarching theme contains a cohort of candidate themes, including substantial and supporting candidate themes. The overarching themes are discussed individually below for the purposes of clarity, and no theme should be viewed as a completely discrete entity when appraising the enablers and barriers to parental consent decision making. There is some overlap between themes. These are not intended to provide a definitive theory or concept as the outcome of this thesis; they are a first attempt to understand consent for DPH programmes from parents' perspective. The

interconnectedness between all six of them is pointed out below and discussed in more detail in Chapter 6 (Discussion). Furthermore, the presentation of the individual themes should not be viewed as hierarchical; there is no one prominent theme. Broadly speaking, the first four themes can be viewed as enablers to decision making while the remaining two are presented as barriers.

In order to aid interpretation of the quotes included below the type of response (*i.e.* consent or refuse) and the parents response behaviour has been identified after each quote. These include active *i.e.* a deliberate action is taken in reply to the consent request, and passive responders *i.e.* parents who do not a deliberate choice.

5.3.a THEME 1: Protecting children from harm is viewed by parents as their role

All parents who participated, regardless of how they responded to the consent request, positioned themselves as their children's protectors. Some parents described how they wanted to shield their children from the physical harm of possible dental problems or the need for treatment in the future, while for others their primary concern was the more immediate threat posed by fluoride. A significant minority worried about the potential for their child to experience emotional distress at having the varnish applied in school, with parents anticipating their child's negative reaction. The universal desire to protect was a motivator for parents to make a decision and therefore acted as an enabler, with parents viewing this as a duty they had to execute through the choices they made. No parent appeared to doubt their ability to carry out this protective role for their children and several made reference to trusting their parental instincts. However, a minority of parents, while not questioning their overall ability to protect, did hesitate with regard to this particular decision and often expressed the need for more information. Parents in this situation described how they sought information from other sources to buttress their decision. This demonstrates how a parent's belief in their ability to be their child's protector can remain unwavering but the need for further information can undermine the trust they have in their instincts to perform this role.

This parental positioning as children's protectors was often signalled by parents offering me unsolicited information about supervising their children's tooth-brushing or their involvement in school life, as if 'proving' they were good parents by explaining how they looked after their children and therefore protected them from poor oral health. However, it is possible that this view of traditional parenting may have been overtly adopted as a result of this research. My presence as a 'professional', asking questions about how parents made decisions concerning their children and their oral health, could have pushed parents into the position of wanting to present themselves as 'good' parents in a conventional sense.

This theme, 'Protecting children from harm is viewed as a parent's role', is made up of three substantial and three supporting candidate themes. The substantial candidate themes are Duty to protect from (physical) harm, Child's experience and emotional wellbeing and Concerns about fluoride.

Duty to protect from (physical) harm

The transcripts for this research show that some parents' decisions were influenced by their own fear of dental treatment. A significant number of parents described how they had poor experiences of oral health and dental care and they stated that they did not want this for their children. These parents all reported providing their consent for their children to participate. For example, in one focus group the parents discussed feelings of fear and one parent commented: *'Scared-ness is to do with your experiences and stuff like that'* (FG1:224. Active consenter). Moreover, the comment below is a response from one parent to another's suggestion that participation in the FV programme should be made mandatory. She explained how her own experience had shaped her views:

'*I am young, I am twenty-three…. I have no teeth. When I go to the dentist he is in shock. He say: "Where are your teeth? You don't have teeth, but you are twenty-two?" Bottom too? See? Because nobody looked after my teeth…when I am small, I*

not go to dentist, and then when I grew up, I am scared. When I look at machine I am scared of machine and she is the same!' (FG1:203,224. Active consenter)

The majority of parents in this sample responded positively to the consent request, at least in part to protect their children from potential future harm caused by tooth decay. This appeared to be the case whether children had seen a family dentist or not. In this regard, parents supplied the following comments about the programme being a 'safety net'. These parents are placing their trust in the FV programme to protect their children from dental problems:

'*Because, like myself, being busy sometimes you forget…. My son needs to… Or my child needs to have a check-up, have a dental check-ups, and what not, until they say to you: "Mummy, my tooth hurts." And then you take them down obviously to your dentist and have them checked out, but as well as, where it is being done in the school, I don't remember it being done in my time…. So, I think that it is good because it keeps an eye on them and on their teeth, and how they are doing, and…'* (Int.9:10,12. Active consenter)

Another parent commented similarly:

'For some parents, if they can't get into a dentist this can kind of put their mind at ease as well. If that makes sense…but to me, it gives me that little bit of comfort and reassurance until I get her to the dentist and everything.' (Int.2:151,372. Active consenter)

Other parents saw the FV programme as additional protection. One father explained this succinctly when he said:

'*I thought… Because I think that we wanted probably to give them the extra protection that might be beneficial in the long term.'* (FG2:73 Active consenter)

Likewise, the comment below was made later by a mother in the same focus group. This typifies parents' wish to protect their children now and in the future:

'My son is three or four teeth, I want to keep my son's teeth and I want to keep his teeth. That is why I wanted to get it.' (FG2:477 Active consenter)

However, despite the majority of parents in this sample providing their consent to protect their child from potential future dental problems, a small minority of parents had a more fatalistic view and refused their consent. These parents believed that protection should come from within the children themselves. These parents trust that the natural biological resilience of children will act as the protecting force. One mother explained her view via the comments below:

'I just think…. I am not being funny, years ago… you never had all that. How did we get through it all? I don't want him having to get used to that when his immune system should fight off certain things... I wasn't asked why, so I just picked the box: no……Yes, I just think years and years and years, centuries, how we have been bringing up kids without it?' (Int.5:337,341 Active responder: consent then refuse)

Another parent, a father who also refused his consent, commented:

'*And I think we say, kind of genetic things, that one, my genes have passed over to my son… naturally has got the strong teeth!'* (FG4:67 Active refuser)

Whether parents saw their consent as a tangible action they were taking to protect their children's oral health or they refused because they were sceptical of FV and were protecting their children from unnecessary intervention, parents' decisions were motivated to some extent by their desire to protect from physical harm.

Child's experience and emotional wellbeing

Parents often expressed the desire to protect their children from being 'upset' immediately before or after having the varnish applied. Some parents refused consent or at least considered their decision very carefully with a view to withdrawing consent for the second application due to concerns that their child would be frightened by the process. This was also the situation for parents who anticipated that

their children would not like the application process itself. This can be seen in the comments below made by two separate parents:

'I think that it is good to have that option, because if your child has had it done the first time and you know how they have react, and if they react badly, you are not going to put them through again, are you? So, it is good to say: "D'you know what? No thank you".' (Int.2:429 Active consenter)

When asked to clarify what 'react badly' meant, this parent responded: '*If they get upset and frightened*' (Int.2:430 Active consenter).

The second parent commented similarly:

'If he doesn't like it. Because he did tell me it tasted funny…. I said, "That's ok, you don't have to brush your teeth," and then after a while he said: "It's ok mum." I'm like, "Ok, as long as you are ok…" But if he come home saying he don't like it and someone is touching his mouth or whatever and "I don't want to do that no more" and he is really adamant about it, then I say, "Ok, we are not doing it anymore".' (Int.13:141-142 Active consenter)

These comments are taken from interviews in which parents felt strongly that their children's independence as individuals was acknowledged. Not all parents felt this way, with some acknowledging that their children perhaps did not want to participate but they (the parents) provided their consent anyway, overruling their children's wishes. This point is examined in more detail later in theme two (Section 5.3.a). Many parents reported that they anticipated in advance that their children might not co-operate with the varnish application and that this figured in their decision making. These parents explained that their children were more likely to co-operate and have the FV treatment if they were among their peers. For example:

'…the big one is fine and the only time that she doesn't open her mouth is when I am with her!' (Int.3:199 Active consenter)

'…because [he] sees other kids doing certain things he seems fine to do it…' (Int.5:149 Active responder: consent then refuse)

'My one, like, if I am not next to them, they are ok, they are not frightened, they are not scared, but when I am next to them, they start crying' (Int.8:10 Active consenter)

The influence of the school setting is discussed in themes three and four, but here the point being made is that parents' desire to protect their children enabled a positive consent decision because they anticipated their children's behaviour and felt that FV application with their peers was more likely to be successful (and therefore of benefit) and less upsetting than if they had to take their children to the family dentist for the same thing.

Concerns about fluoride

Several parents described researching fluoride as a substance before making a decision, including its potential risks and benefits, rather than looking into the varnishing programme as a whole. It is the protective feelings that parents have, coupled with the unknown effects of fluoride, that led a minority of parents to hesitate in their decision making. Parents who felt this way commented:

'But I think that we just don't know enough about fluoride as it is… Do you know what I mean?' (Int.5:104 Active responder: consent then refuse)

'Yes, I had to google online a bit more about it really… The actual fluoride… Yes… If you put all the ingredients down, I wouldn't know what half of them were anyway.' (Int.5:108 Active responder: consent then refuse)

These comments relate specifically to the substance of 'fluoride', rather than to the FV programme in general. The parents quoted above went on to explain that they did provide their consent because they wanted to protect their child from dental problems despite remaining unsure about the safety of fluoride. The reason they gave

for this was that they trusted the school FV programme and this outweighed any concerns they felt (a point included in detail later in theme three). For example, one mother expressed her concerns, stating:

'Yes, I mean, I am still… There was a list about fluoride and the downsides and they have got everything on there, from this to that… Cancer… Jesus Christ! This is depressing. But yes, to be honest with you I am still a bit like that when it comes to fluoride. I am not a hundred percent about it.' (Int.5:118 Active responder: consent then refuse)

A small minority of parents were not concerned about the safety of fluoride per se, but they did want to protect their young children from swallowing it. All the parents who reported feeling this way stated that when their children were older they would have no concerns about providing their consent. For example, one parent said,

'Because they had told me the toothpaste they put on the teeth has a fluoride I think, and problem is, that my one is three but the thing is that she cannot draw up and she cannot rinse with water….' (FG3:25 Active refuser),

and another in the same focus group commented,

'No, I was the same my friend. I think that because her son as well, they are in the same group, he cannot rinse his mouth as well, same obviously, as my daughter, that is the reason that we didn't agree but for the future, yes, I would like to have because she will know that she can rinse and that she will not swallow inside.' (FG3:103 Active refuser)

Here, parents were not protecting their children from FV because of fundamental safety concerns, but merely delaying the process until they felt their children were better able to cope with it and would not swallow the fluoride excessively. These parents trust their knowledge of their children's abilities over the information provided that states that FV is safe for children of this age. The trust in their own knowledge, and the natural inclination to protect their children manifested itself in

their decision to refuse their consent on this occasion, but as the children grow their protective actions are likely to change. Parents' ability to exercise flexibility in when to consent and when to refuse is considered in detail later in theme six (Section 5.3.f). The point being highlighted here is that flexibility in the decision-making process would enable parents to respond to a consent request in a way they felt best protected their children from physical harm at any given time, which is clearly important to these parents.

Other parents wanted to protect their children from the alcohol that is contained within the varnish (this is also considered in relation to theme five). A father commented:

'After I received the letter saying about the alcohol on the tongue, is this for Muslim, and things like this…maybe because of this the parents that are Muslim, they don't want it?' (Int.6:181 Active consenter)

Two other parents in one of the focus groups commented similarly:

'What is the ingredient in that… varnish? Do you know what it is? Is there alcohol inside it?' (FG2:50 Active consenter)

'Well, amount or lot, is not making a difference… That is why we are asking you…Any amount that makes you drunk, that is not allowed, but a tiny one like a medicine is ok?' (FG2:57,59 Active consenter)

Here, parents are concerned about protecting their children (and possibly themselves) from breeching specific rules of the Muslim faith that prohibit individuals from ingesting alcohol (Qur'an 5:90). Approval for the FV was granted by the Sharia Council, an organisation set up by Muslims, and which adherents of the faith consider an authority on Islamic law (Islamic Sharia Council, 2019) (Appendix 5.1). This information is supplied with the wider information sent to parents, but as evidenced here parents do not seem to trust this approval and want more information about specific ingredients. One mother I spoke to who did not want to be recorded was

adamant that any amount of alcohol was not permitted by the Muslim faith and would not have been approved by the Council, and she refused her consent on this basis. This mother was protecting her children based on her understanding of what is and is not permitted, trusting her own belief above others.

However, concerns about protecting children from FV were not restricted to just safety or issues of faith; they also included concerns about the efficacy of the programme. Some parents expressed protective feelings regarding the unnecessary exposure of their children to something that might not have any benefit. This was felt most strongly by parents who refused their consent. For example, one father stated:

'Number one, it is not the permanent teeth, and the number two, it is a coating… It's going to be on a month, maximum, and then the saliva and you eat and you drink…Lots of things… And the fluorine is a kind of chemical as well. In that sense, I said: No. It is an unnecessary coating.' (FG4:6-12 Active refuser)

Other parents who felt similarly but who were perhaps less ardent in their views described how they felt that this programme was 'new', with one father commenting:

'…the only thing that I would have liked to have known if kids that had had it before…. And I wondered if we were the first that were being….so, that is interesting that this still feels new…' (FG2:348,472 Active consenter)

Other comments made about the programme being experimental were:

'In my eyes, it is an experimental trial, still…' (Int.11:13 Active refuser)

'I wondered if we were just… I wasn't sure if we were guinea pigs here… just an idea…' (FG3:493 Active consenter)

The data shows parents' desire to protect their children from any potential negative effects of fluoride varnish, whether based on the child's age, faith or anything else. These comments also show a lack of belief by some in any tangible proven benefit resulting from the exposure of their children to fluoride. These concerns were

seriously considered by several parents when making their consent decisions, and for some they led to a refusal. However, regardless of the decision made, the process of making it was rendered more difficult because of parents' universal inclination to protect their children from any potential physical harm. Parents had to consider competing demands and decide whether consenting or not would provide more or less protection for their children as they saw it. This decision was further complicated by the positive and negative influence of parents' social networks (theme four) and access to dental information (theme two). The lack of trust in the programme itself that is expressed here is interesting because it is at odds with the views of the majority of parents, who reported trusting public services (a point raised again in theme three). Interestingly, one parent who refused their consent because they felt the programme was an experimental trial and of little proven benefit asked me whether I worked for the manufacturer of the varnish, thus demonstrating their suspicion of the formal information they had received previously about the FV programme and my research (Int.15:30).

It is a universal desire for parents to want to protect their children. However, what a child needs to be protected from and the best way of doing this is interpreted by parents and based on where they place their trust, *e.g*. in their faith, in fluoride, in biology or even in collective school activities. It is this that acts as an enabler to parents' decision making regardless of the way in which they choose to protect their children.

5.3.b THEME 2: Parents have the ability to make consent decisions but can lack confidence

This theme is closely linked to the one above. Previously, however, the role of parents as decision makers was discussed as a function to protect children from harm, whereas here decision making on behalf of children is seen as intrinsic to parenthood.

All parents in this sample had the ability to make a consent decision, but some lacked confidence in their knowledge of and expertise in this particular subject. Confidence

(and lack of) was demonstrated in both consenters and refusers, and although most parents felt confident in their ability to be the decision maker for their child in general, some expressed uncertainty and sought additional guidance on this specific issue. However, almost all parents (save for one) expressed their expectation that as parents they could and should make decisions on behalf of their children, or at the very least guide their children's decisions. This was an expectation they had of parenthood.

This theme is made up of three substantial candidate themes and three supporting candidate themes. All six candidate themes are interconnected with the concept of a parent's ability and confidence to be a decision maker. The substantial candidate themes are Parents as the decision maker, Confidence in own approach to consent decision making and Child as participant.

Parents as the decision maker

A strong sense of parents' recognition of their role as decision maker for their children came through all transcripts but parents' willingness to make surrogate decisions on behalf of their children was more keenly felt by some than by others. For many parents, the confidence they felt in themselves to be the ultimate decision maker was expressed through an innate belief that by virtue of the fact that they were the child's parent (usually the mother) they were the best person to make decisions about their health. This is demonstrated by one mother, who stated that '*mother's intuition*' played a role in her decision making (Int.3:310), with another mother remarking:

'And anything that is good for my daughter is good for me. Every mummy looks for her daughter.' (FG1:72 Active consenter)

Another parent from a different school commented similarly, with:

'*Because we are parents and we are still responsible for our children and we have to do the best thing because what is for the children and what is best for us…'* (FG2:437 Active consenter)

Parents who felt this way appeared to see no real distinction between themselves and their children as individuals. These parents did not question whether they *should* make these decisions; it was taken for granted that this was what they ought to do as parents. It was seen as simply part of being a parent and not something difficult or 'extra'. Parents often described making decisions for their children as their responsibility, while others expressed this more as a duty or a 'right'. For example:

'*I know it isn't harmful but parents need to have that choice, it is their right as parents to have that choice.'* (Int.10:133 Active consenter)

Interestingly, there appeared to be a gender split regarding who took on this decision-making role within families. Overwhelmingly, among the parents I interviewed this task fell to mothers, and on the whole they embraced it willingly. Some parents indicated that they discussed the decision together with their partner before deciding to consent or refuse, but even in these situations the final say would often be left to the mother. One father demonstrated this well when he said:

'So, my Mrs… she was like, we're having it done… yes that is fine, so we done it.' (Int.6:7 Active consenter)

Another father who was interviewed together with the one above had a similar experience:

'*Fluorine…. what's that? She told me. Ok. I didn't read it, I signed it.'* (Int.6:128 Active consenter)

On several occasions, mothers indicated that they told the father about the programme and their preferred decision in advance of responding officially, but that they did not expect any assistance from fathers in making the final choice. Indeed, it was not uncommon for mothers to tell me that they had not told the father at all and had made a solo decision. For example:

'Mum knows everything and even if I tell him he don't know what it is and he is not bothering and I am thinking why am I telling him, let's just do it!' (Int.7:168 Active consenter)

This comment was made by a mother from the Somali community whose child attended a school where the staff told me it was the men who made all the decisions. However, her comments were not unusual among the Somali parents I spoke to, who typify the attitude and confidence that many women felt regarding making decisions for their children.

One mother summed up the apparent gender split well, when she observed:

'Most men leave it up to the ladies to deal with it, because obviously he is just busy working, so you do what is best.' (Int.13:21 Active consenter)

These quotes demonstrate not only how many families divide up the different parenting roles, but also how these mothers innately felt that they knew what was 'best'. Their own confidence in their own ability to carry out this role was unquestioned. Moreover, similar feelings of confidence in this role were evident when parents (mothers) were talking about their children's desire to participate or not. For example:

'I tell them that it is good for them. They are going to have to have it…Yes, I do…They are not bossing me around!' (Int.7:70,72 Active consenter)

Again, this is illustrative of how the majority of mothers I spoke to see their role within the family, *i.e.* decision maker with regard to their children's health, with their decisions taking precedence over the opinions of other family members. One mother put this succinctly when she said: '*Because I am wife. House…and for children it is my responsibility'* (Int.15:72,74 Active consenter). The role of family nurturer with responsibility for children's health appears to be part of the identity of mothers. That is not to say that all fathers are excluded or absent from the decision-making process altogether, merely that the mother has the primary role. A good example of this is in

the conversation below, in which the father is required to facilitate the mother's decision making because she is not able to read the information (the barrier created by information provided in English only is discussed in more detail later in theme five, Section 5.3.e). This parent was illiterate in her native language, so the issue here is more complex than a simple barrier created by the inability to understand written English, but regardless of this hurdle she did not question her decision-making ability and her self-confidence to consent or refuse remains:

Parent 1: *'I have to ask my husband. Every time he is reading for me, then he is explaining to me.'*

Interviewer: *'And you decide?'*

Parent 1: *'Yes.'*

Parent 2: *'You are the boss.'*

Parent 1: *'Yes.'*

(FG1: 105-109 Active consenter)

This interaction clearly demonstrates that although the father is involved (at least at the level of a gatekeeper to the information) it is the mother's role to make the final decision and she is confident in her ability to do so.

However, a minority of parents found being cast in this role, *i.e.* that of decision maker for their children, a burden. Parents in this situation often expressed a lack confidence in their own opinion of the FV programme, *e.g. 'My opinion is nothing'* (Int.15:149 Active consenter), and sometimes deferred their decision to someone in a position of authority, usually their child's teacher, although sometimes their local dentist. For example, one parent commented:

'Teacher…she say if this one is good because teacher is clever and not me!' (Int.4:44 Active consenter)

A small number of parents who expressed such comments acknowledged their role and ability as the decision maker for their children, but lacked confidence in their own knowledge to make the 'right' decision with specific regard to the FV programme. These parents looked for reassurance outside of the family. One parent expresses this clearly in the quote below:

'I have to make sure that everything is fine with them… to make sure that I am doing my role correctly' (Int.1:98,140 Active consenter)

Parents often sought some level of reassurance or confirmation of their decision about the FV programme and that it was in line with what others thought. For some this came from other parents but for a large number it came from professionals, *e.g.* family dentists or school staff. The influence of health and education professionals is discussed later in theme four (Section 5.3.d), but the point being made here is that parents constructed social mechanisms to fuel their feelings of confidence and that they were meeting the requirements of what it is to be a parent and making the 'right choice'. This shows that while most parents are certain of their position and their capability to make decisions, the experience of actually doing so can be an isolated one, with confirmation of choice and reassurance from others acting as enablers.

A significant minority of parents felt ambivalent about being cast as the decision maker in this instance. These parents did not express strong feelings of duty or 'rights' with regard to this position in the way that most other parents had. For these parents, decisions such as this could be left to the State. This view was mostly held by parents with experience of similar school-based dental public health programmes from their own childhood, all of which took place in other countries. For example, when asked whether parents' consent should be requested prior to the FV application, one parent commented:

'I take it as a common thing, like it is just a part of the life of my son and nothing is wrong. I don't see anything… wrong with that….' (Int.8:44 Active consenter)

Later in the same interview this father explained:

'*Over there* [in Brazil] *it is normal, not at three years old, but at five, like they come in the school and do things like this and check and everything. But there they don't ask for permission or anything! It's like… Normally….*' (Int.8:135-137 Active consenter)

This small group of parents were more willing to relinquish the role of decision maker for this specific purpose. It should be made clear that this was not due to a lack of parental confidence in their own decision-making abilities, nor because they were actively seeking to abdicate from this position as parents. Their ambivalence towards the privileging of parents as decision makers was due to their view of the State and of the level to which the care of children should be a shared responsibility, with the normalisation of children's participation in school-based public health programmes. The role of the State is explored in more detail in theme three (Section 5.3.c).

The unquestioned confidence shown by the majority of parents in their ability and position as decision maker for their children acts as an enabler, regardless of the decision they make. Parents who lack self-assurance in making specific decisions are not *dis*abled, but they do require additional support to avoid their lack of confidence becoming a barrier. In the current situation, no additional support is provided by the dental team and so they have to find the support they need for themselves. Furthermore, those who are ambivalent may need to be prompted to act but this is not forthcoming as part of the current consent system.

Confidence in own approach to consent decision making

Parents who indicated their confidence in making decisions for their child, almost always demonstrated a confidence in their ability to make what they felt was an independent decision. One parent noted:

'You have to have your own mind because you can be influenced by a lot of people and it might not even be the right one…the right advice.' (Int.5:269 Active responder: consent then refuse)

Some parents felt confident knowing their decision was made on the basis of their own experience or that of close family or friends, while others drew self-assurance from their ability to seek additional independent information that helped them to make a decision. For example, comments such as those below were not uncommon:

'I already had some experience with this and my parents, they really take care of my teeth….and my sister did, and that is why it was clear… everything, for me…' (FG3:98-99 Active consenter)

'Yes, because for a parent… If I wanted to do research on it, I could go and do my research, on it, and then make that informed decision; I don't think that this will benefit her…I am not going to do it. Or, do you know what…this will benefit her, let me do it.' (Int.2:160-161 Active consenter)

Interestingly, when the parent quoted earlier in this theme who stated that she sought professional advice to check that she was '*doing [her] role correctly'* (Int.1:140 Active consenter) was asked whether she would make her decision in the same way again, she stated:

'No, I think that I am working now… I have experience… I will go to the internet to have a look….' (Int.1:255 Active consenter)

This shows how parents' confidence in themselves to make independent decisions grows as their experience increases. The mother quoted above no longer needed the reassurance of an authority figure to tell her she had made the right choice; she felt able to source and appraise the information she needed and make her own decision independently, without approval.

Some parents felt more confident to make a decision once they had spoken to either the school or a dental professional. For example, one parent commented how she was enabled to make a decision that was different to her friend's and to disregard advice once she had spoken to a dental professional:

'You have to ask someone who is experienced about that. I listened then, but not… I am asking the proper people who now give me the information about that. Because she is my friend I listened to her, but not… not ….do what she say.' (FG2:87 Active consenter)

Few parents had the certainty of mind to make their decision based on just the information provided by the dental service. The need for additional information is discussed in more detail in theme five (Section 5.3.e); however, the point here is that parents demonstrated confidence in their consent choice if they had additional information that they themselves had gained from a trusted source. Whether parents' self-assurance in their knowledge was gained from experience, written information, or indeed from speaking to a teacher or dental professional, the outcome of increased confidence in their approach to the decision acted as an enabler to their decision making. Moreover, confidence was not limited to those parents who provided their consent. One parent who refused consent also expressed self-assurance in his decision-making ability, when he commented simply:

'I checked through the things first but then after that, I made up my mind.' (Int.11:22 Active refuser)

Whenever parents gain their confidence from knowing the experiences of friends and family, or from independently sourced information, it appears that this confidence in their approach to decision making is an enabling factor in respect of their ability to make and communicate a decision, regardless of how they respond to the consent request. Parents want to feel that they have considered the decision in the appropriate way. When they are comfortable with their approach to this, they are enabled to decide and to have confidence in the decision itself.

Child as participant

Some parents in this sample felt that their decisions should override those of their children, without discussion. Parents expressing such views felt confident that their children were too young to make the decisions and that parents were best placed to choose to consent or not. For example, one parent who felt that her decision to consent for her child to participate took precedence over her child's objection commented:

'But when my child was complaining that she didn't like it, I said, "You are just a child, you need to be patient".' (Int.1:155 Active consenter)

However, comments were more commonly made about how parents liked to involve children in the decision-making process, even if the ultimate decision came from the parents. For example:

'*Because she is a little person. If she… She is very independent and I am not going to force her to have something done…'* (Int.2:449 Active consenter)

In these situations, parents acknowledged that although they were in the decision-making role their children's agreement and participation were important to them. Comments such as those below were frequently made:

'So, I kind of like make sure that he is comfortable with it as well.' (Int.13:59 Active consenter)

'I feel that I have all the information, I know what to tell her, so I am not worried…' (Int.2:467 Active consenter)

Many parents expressed the view that including children in this way was important to their feelings of confidence about the decision they made, as their children would then not be upset by taking part and would know what was going to happen. The impact of children's emotional responses to having the FV application on parents' decision making has already been raised in theme one (Section 5.3.a). However, with

respect to this theme, knowing that their children were happy to participate added to parents' feelings of confidence and their ability to respond positively. Parents who anticipated that their child would be upset were more likely to report refusing their consent. Nevertheless, none of the refusers indicated that they did so solely because they were concerned about their child's unwillingness to participate, although one parent did say that he felt it was '*hassle to the little ones as well*' (Int.11:37 Active refuser).

The exception to these two scenarios, *i.e.* where parents' decisions overrule children and where children are actively involved prior to the dental team's visit, was just one parent who had provided her consent but felt some unease about having had to make this decision on behalf of her child. She explained:

'… it is his teeth, not mine! Do you know what I mean? So, obviously I have to give the permission but overall it is his teeth, so he needs to understand that it is his and he can make that decision.' (Int.13:152 Active consenter)

The lack of certainty that this parent felt about making a decision on behalf of her child did not prohibit her from responding to the consent request, *i.e.* communicating a choice to the dental team, but it did hinder her authentic choice being communicated, and she provided consent despite saying that she did not agree:

'I wasn't really agreeing, but I kind of agreed, but yeah, that is a bit of another story….' (Int.13:24 Active consenter)

Ultimately, this parent provided her reluctant consent, indicating that she would prefer to leave the decision to her son – '*I want to let him make that decision himself*' (Int.13:54 Active consenter) – but commenting that she felt some pressure to respond positively (Int.13:51 Active consenter). This parent's child attended a school with a very high uptake of the FV programme. In fact, one staff member spent a long time explaining to me how she achieved this and that it was a source of great pride.

For many parents, consent decisions are not exclusively an adult activity; they have a junior partner in the form of their child. For some this means gaining agreement from them in advance and for others it is more about preparing their children so that they give their assent on the application day, but either way the inclusion of children in this process is part of the experience for many parents.

The information presented in this theme demonstrates that, on the whole, parents are self-assured when it comes to their ability to make a decision on behalf of their children. Confidence is particularly felt in relation to their position as the decision maker within the family, and being cast in this position is, for many, a natural consequence of having children. However, that does not mean that all decisions are made with confidence, and providing consent to participate in a fluoride varnish programme is one of those decisions regarding which parents often exhibit hesitation around their own expertise, and reassurance or additional information is sought. Parents value their own ability to seek out independently sourced information and it is their recognition of this that further boosts their confidence and enables decision making. For the minority of parents who feel differently from this, it appears that their discomfort at being expected to make such a decision is polarised; either they believe in the individual as sovereign (even if a child), or they believe that public health programmes such as this should be implemented collectively, with all children involved and without the need for parental consent. However, these parents are united in that the current system demands their input regardless of whether they as parents would prefer their child or the State to take the position of decision maker. In the current system, if parents lack confidence and therefore do not make a decision (refuse or consent), their children will be excluded from the programme. Confidence, therefore, can be seen as an enabler to consent decision making.

5.3.c THEME 3: Sharing responsibility for children's health between parent and State is viewed positively by parents

Most parents in the interviews and focus groups that I conducted indicated that they believed that public services, *e.g*. schools and the NHS, would not act in any way that would harm children. Moreover, parents did not believe that public services for children ought to be delivered with a stance of neutrality; indeed, there was an expectation of paternalism towards the health of children. This was a universally held belief among consenters, refusers and those who did not respond. This meant that, for the most part, the FV programme was viewed positively by parents and, although this sample was largely made up of consenting parents, even those who actively refused made few negative comments about it. At best, parents were positive and enthusiastic about the programme and, at worst, they felt that although not harmful, it was simply not necessary. The degree to which parents expected the paternalism of public services to extend differed, but they all indicated that they felt the State had a role to play, with some responsibility for their children's health. This theme is made up of two substantial and three supporting candidate themes. The substantial candidate themes are Convenience for parents and Trust placed in public services.

Convenience for parents

An uncontroversial area of 'shared responsibility' that all parents agreed on was the delivery of specific services to support families to improve the health of children. While acknowledging that it was their responsibility to look after their children, parents felt that they should be supported to do this by the State. This was demonstrated by comments made in favour of the FV programme being delivered in school settings. For example:

'Because my tooth are very bad, before in my country going to school no teacher helped me, not help me…. My mum go to hospital. All my tooth is very bad, but here there is help for the children and for the mum and it is good and I am happy.' (Int.4:47 Active consenter)

'We have to look for child… But we have no dentist. Read and then sign. First thing… All of the time he was… All the time that I was filling in the form because I know

that for my child it was better…. It is better when you go to dental, it is good. Not only the school. Both together is better.' (FG1:141,144,149 Active consenter)

Parents felt that if they had had to take their children to their own dentist for the same treatment they would have found this more challenging, despite the treatment being the same in both locations and NHS dentistry being free for children regardless of where it is delivered. The busy nature of family life was a common thread in all interviews and focus groups, and this influenced parents' actions to some extent (this point is also mentioned in relation to themes two and five). All parents who provided their consent reported that the convenience of a school-setting delivery was a contributing factor, and even those who refused or failed to respond were supportive of the convenience of a school programme. Parents commented:

'*Rather than have to make an appointment and go to a dentist and all of that… Getting it done, it's more convenient… more convenient. There's no arguments with the children or screaming when you are walking through a door, and there is none of that. Yes, I think that is what it is. It is convenience a lot of it. So…*' (Int.5:169 Active responder: consent then refuse)

'*I think that it is more convenient and it is more helpful…when they do need to go to a dentist and so it just makes our life a little bit easier.*' (Int.5:316 Active responder: consent then refuse)

It is noteworthy that when parents commented on the convenience of a school-based DPH programme they often confused the FV programme with a dental examination, which exposes a misunderstanding on the part of parents about what they are being asked to provide consent for. This raises questions about the effectiveness of the dental information that parents receive. This is addressed in theme 5 later. Parents frequently commented that knowing that their child had been seen by a dental professional without the requirement for them to make any additional arrangements was helpful to them. Parents acknowledged that, for some of them, taking children to a high street dentist was difficult. For example:

'For some parents, if they can't get into a dentist this can kind of put their mind at ease as well. If that makes sense'. (Int.2:157 Active consenter)

The introduction of children to dentistry within the school environment, where children are with their peers instead of their parents, was also considered helpful to parents. For example, one mother explained how this experience would help her in the future,

'… It's easier if it is done without parents when you are at school, it gets them used to a dentist. Because I'll use that now… See, it wasn't that bad when you got it done at school?' (Int.5:321 Active responder: consent then refuse)

and another commented,

'I think that it is good. Because… My little one freaks out when she has to go to the doctors. So, with the school, it is a calming and nice environment, and for some kids a friendly environment is a good thing, because they might then go along and open up their mouth. Whereas if you were to take that child to a dentist…. "No, no, no!" kind of thing. But it is better than going to a cold building.' (Int.2:145 Active consenter)

Parents identified that twin barriers to their children receiving dental care are created by the busy-ness of family life and parents' negative experiences of attending high street dental practices with young children. However, through the notion of shared responsibility with the State in the form of targeted services that are easy for parents to access, these barriers are removed. All parents in this sample experienced the convenience of this programme as a positive benefit and, when asked, they stated that the programme should be made available in all schools. The convenience of the settings-based delivery acted as an enabler, particularly for positive consent decisions.

Trust placed in public services

In addition to the convenience of the school setting, some parents stated that they would be happy if the FV programme was delivered in a more paternalistic and universal way, with the State playing a more active role in children's health care, rather than just providing the location for it. For example:

'In my opinion, I think, it should just be made, "this is what your children are going to have".' (FG1:203 Active consenter)

'I think just a letter should be written and say this is… "For you to know that reception is going to have their dentist check on that day and if you have got any issues, can you come and see the nurse".' (FG1:217 Active consenter)

Some parents went so far as to say that they felt the programmes should be made mandatory, therefore negating the need for parental decisions at all. One parent, when explaining how important she felt the role of the government was in children's oral health, said that participation in the FV programme should be made law:

'It is a very big concern and they play a very big role. They have to make laws…and people… This is the law and we have to put this twice a year and the kids are not going to have a big problem. So, if they have a law, people are going to do what they say, but if no one cares, no one is going to care. It is like they play a big role, I think.' (Int.3:341,343 Active consenter)

The issue of mandatory participation is also raised in theme six (Section 5.3.f). However, here the point being made is that parents understand the implicit duty of care that schools have towards their children and are comfortable about this manifesting itself in paternalistic actions – in fact, they expect it to. Some parents felt that this ought to be more comprehensive in school settings and to extend from education and general safeguarding to include health, *e.g.* via the FV programme. One mother demonstrates this well through her acknowledgment of the *loco parentis* status that schools have, which she wanted to extend to children's inclusion in the FV programme:

'…at the end of the day, if you are coming to this school that is a government thing, and the child must attend school, it is the same thing, they must get their teeth checked because they are coming under the government at that time. When they are in the school, they are under the government, isn't it?' (FG1:219 Active consenter)

Although a significant but vocal minority of parents felt this way, most thought that responsibility and, therefore, the ultimate decisions in such situations are the province of parents themselves, as already identified in theme two. Nevertheless, the data indicates that parents' confidence to make a decision and provide their consent was buttressed by their trust in public services not to harm their children, *i.e.* the NHS or the school would not ask them to consent to something that was harmful. The expectation that parents have of these institutions is one of paternalism towards their children. This belief was expressed by almost all parents. Some examples of this can be seen in the comments below:

'I just say yes! Because, you know, you cannot do something bad for the children…' (Int.1:49 Active consenter)

'Well, I think because it's NHS London, I feel it's really good…. That is what I thought, you know?' (Int.7:54 Active consenter)

'School is never bad for a child. School every time thinking good for the child.' (FG1:91 Active consenter)

In these comments and others like them, parents indicated a belief that government-funded public services would act in the best interests of their children. This trust is extended to teachers and dental professionals. This point is a thread in several of the themes included in this chapter. For example, it was raised in theme two and is discussed again in relation to theme four. However, for this theme the point being highlighted is that parents' trust and expectations extend beyond individual staff members, and even beyond their own children's school, where they have personal relationships. It is more ideological, with parents expressing a belief that government-

funded public services come from a higher authority (than individuals), and have the purpose to protect and advance the health of children. One parent who was very negative about 'high street' dentists in general as a result of her own poor experience went on to say:

'And I don't think that government wants people to suffer and have more problems! They don't want to have problems with the kids… So, they are trying to cut it. I don't think the government will think…. and that is it. So, it comes from somewhere that is bigger! The dentist is one person…' (Int.2:327-330 Active consenter)

This comment exemplifies the way in which parents view public services in contrast to private individuals. It is this belief in the good of public services that enabled parents in this sample to make a decision that was free (for the most part) from concerns over the trustworthiness of the programme. So widespread was this belief that even a parent who actively refused their consent made similar comments about governments working in the best interest of children:

'…things like what the government needs to do I think that it is confident because they want to do it for the children's best…. and they are not going to do nothing that is going to harm the children…' (Int.12:137 Active consenter)

The information presented under this theme demonstrates how the convenience of the school setting, alongside the parents' trust in public services, exposes the ease with which parents are happy, and indeed expect, to share a degree of responsibility for their children's health with the State. It also shows how all parents making the decision to consent to or refuse their child's participation are enabled by this view. Parents can consent without additional consideration being given to the logistical arrangements of getting to a dental surgery, for example. This means that decisions are more likely to be focused on the actual benefits or drawbacks of a fluoride varnish application and not on peripheral structural barriers.

5.3.d THEME 4: Existing relationships within parents' social networks strongly influence their consent decisions

Parents' social networks have an influence on their consent decisions and subsequent actions. The strongest influence comes from those closest to them, *i.e.* the members of their community who they see regularly, for example family, friends and other parents. The degree of influence that different players in parents' social networks have appears to be based on layers of trust, with the most influence coming from the experiences of friends and family. The second layer of trust, and therefore influence, is that of school teachers. This is perhaps to be expected, particularly given the themes already discussed above, but parents also reported being influenced by the trust they had in the school as an institution. The extent of this influence was surprising, but when considered together with theme three and the expectation that parents have of public services, the key role that schools have in the (oral) health of children can be clearly seen. This theme is made up of two substantial and three supporting candidate themes. The substantial candidate themes are Social connectedness among parents and Parents' relationships with professionals.

Social connectedness among parents

Many of the participating parents in this study talked about feeling comfortable with giving their consent or refusal based on the experience of their family, friends or other parents. Parents often courted the opinions of family and friends if they felt unsure or were undecided about their own choice. In this situation, the opinions, values and experiences of people closest to parents acted as an enabler, through personal testimony from a trusted source being added to parents' information on this topic. For some parents, this type of information had added value because it came from the perspective of other parents who were 'on the same level' as those making the decision. One parent stated:

'…and when you are speaking to a friend, they speak to you on a different level than a professional is, so….' (Int.2:351 Active consenter)

Later in the conversation, this parent was asked whether official information provided by another parent would be helpful. The response was:

'Course it would, because you know that you are on the same level, where this is where… Finding out from another parent… "Oh do you know what… they was a bit tearful, but when they got home they were perfectly fine…. there's nothing wrong….".' (Int.2:483 Active consenter)

Parents' need for supplementary information is discussed in detail later in theme five (Section 5.3.e), but the point being highlighted here is the 'added value' that information passed from one parent to another has. This stems from the connectedness felt by parents as a result of their shared experience of raising children. So influential are the opinions and experiences of other parents in similar situations, that one father reported signing the consent form on the spot with little consideration and limited information, based on the opinion of his neighbour. He described this thus:

'And erm, and the, before even signing it I looked around and I saw a neighbour who has three kids and she is a very good mum as well, and I said to her: "Do you know about this?" And she said: "Yes, I have done it to my three kids," and all that, and with that I was happy to sign.' (FG4: 28 Active consenter)

In this situation it appears that it is more than just the supplementary information that parents are providing that is the decision enabler; indeed, little additional information was provided, but reassurance came from knowing that the neighbouring parent had consented. Parents experienced comfort from knowing what others had decided, or would decide. Comfort is rooted their feelings of connectedness between parents and this makes a positive difference to their response behaviour. Almost all parents sought out additional information before making their decision and for the majority this meant talking to family and friends but, interestingly, it was more often information from other parents that acted as the enabler to their decisions, particularly from parents of children of a similar age.

Regarding asking parents what had helped them decide to consent or not, the data clearly shows that spoken supplementary information from other parents was given a lot of consideration. This way of spreading information from parent to parent through social connection was the norm and was reflected in almost every interview and focus group and across all schools. For example, one parent commented,

'…it is just mouth to mouth and word to word type of thing,' (Int.9:120 Active consenter)

and parents themselves recognised this way of operating:

'So, if one parent has made it to this meeting in the school, or the little workshop that you do, and the other parent hasn't, the chances are they will talk…' (Int.10:79 Active consenter)

The passing of information in this way between parents is more influential than the mere dissemination of information among peers. When parents seek the opinion of someone they know and trust, they are not looking for impartial information. It is the very subjective nature of the information that parents value. Conversations such as this extend influencing opinions from one parent to another. For example, when one mother relayed a conversation she had had with her friend about her child's oral health, she stated that the friend had asked, *'What should I do?'* (FG1:207). Moreover, the data shows that parents do not have to be close friends with others in similar situations to be influenced by them. For example, one father described a contributing reason for his positive consent decision:

'People whose kids had had it and hadn't had any problems with their teeth seemed ok, and only benefitted….' (FG2:265 Active consenter)

Here it is the general feeling he had of parity with these other families that was the influencing factor, rather than any specific information from a close friend.

Furthermore, data from parents in this sample shows that the influence of other parents is not always positive or in favour of the FV programmes. For example, one parent commented:

'…some…parent told me… don't use it because it is not good for kids.' (FG2:82 Active consenter)

This quote demonstrates that information does not have to be detailed or specific to have an impact. Again, the influence of what is being said can be attributed to the source of the information rather than the content. Here it is the general negative attitude of other parents towards the FV that is exerting influence, not details of the specific ingredients or their effect on children. Later in the same focus group another parent explained how her Muslim friends were also concerned about the content of the varnish and that this made her consider her decision more carefully:

'…some people like said… why are you giving it to your child there is something on it… Pork or something like that…' (FG2:469 Active consenter)

The impact on decision making of parents' specific concerns about the fluoride has already been identified in theme one. This quote is included here to highlight how parents' concerns can influence decision making among specific social groups, in this case that of parents who are Muslim. Parent sub-groups, based on shared faith or ethnicity for example, often have a stronger sense of connectedness with others deemed to be 'like them', and this adds to the strength of influence.

The influence and importance of the collective views of specific sub-groups can spread beyond the dissemination of information, with decisions being influenced through community judgement. In one focus group, it was acknowledged that some parents might feel an element of stigma around their child's oral health and that this might hinder decision making. This stigma appears to be based on the fear of being seen as an inadequate parent. For example, when asked whether the decision to provide consent was difficult, one parent responded:

'Some people, I think that they feel, stigma around the parent not looking after the child. Because they are going to think…do they think that I am neglecting my child…? Are they going to think that? So, because of that, some parents might not want to check their child's teeth. They are scared of all that.' (FG1:234) Active consenter

Interestingly, while stigma was not explicitly spoken about in this way by the majority of parents, the judgement of some parents towards others in their own community was mentioned on a number of occasions, *e.g. 'Some people are just too lazy to sign a form'* (Int.6:179 Active consenter). Negative comments about other parents' actions seemed particularly prevalent in the Turkish community. For example, the comments below were made by Turkish mothers about others in their social groups:

'*Let me tell you the truth, most Turkish families, they just leave their kids inside the school and they are gone. They don't care what is going on…*' (Int.8:169 Active consenter)

'So otherwise they will put it in their bag and they don't sign it. They don't know. And especially Turkish people, they do that.' (Int.8:77 Active consenter)

'Yeah. I was brought up by my nan, and you know what Turkish nans are like, they have got… She told you, you had to keep clean and stuff but the teeth…' (Int.5:99,101 Active responder: consent then refuse)

These types of view can be particularly powerful, given the significance of parent-to-parent relationships. However, it should be noted that within this sample there appeared to be an element of parents presenting themselves in a good light and doing the 'right thing', and the comments above could be seen as an extension of this, *i.e*. their positioning themselves as the opposite of those they were judging.

A small group of parents reported that the opinions of friends were sometimes unsolicited. This was made reference to when discussing online information. For example, one parent said:

'Like I said, someone put up on Facebook the downsides of fluoride and there was a massive list, loads of stuff on it… I don't even use it that much but you get all these little things that come up, you know, and so I just go through it!' (Int.5:221,244 Active responder: consent then refuse)

This type of unsolicited information from 'internet friends' appears to be less influential with parents than the experiences and opinions of friends that parents see regularly and it was not mentioned as frequently in the interviews and focus groups. This situation mirrors that discussed below in theme five (Section 5.3.e) about the format of official dental information, with parents favouring face-to-face information over written information alone. The mother who made the comments above about unsolicited information from 'internet friends' went on to say:

'I normally make my… I'll listen to what they say obviously but it is… I still make my own sort of decisions.' (Int.5:250,252 Active responder: consent then refuse)

Nevertheless, the influential role that social media plays in parents' lives should not be underestimated, and for parents with few alternative ways to interact with others the impact is potentially more potent, particularly if they are not feeling confident in their decision and are seeking reassurance (see Section 5.3.b). For example, one father made the following comments about how he took his decision:

'*Yes…There is a big community on the internet. It is huge! I mean, other parents experience all about it, and then just….Decided. After that, I will not get it done.*' (FG4:135-139 Active refuser)

Some parents used the online experience of other parents as a supplementary source of information to double check their decision by seeing whether it was in line with that of others, and this seemed to act as form of reassurance. For example:

'First, we checked the internet, ok, what the other parents think about it…' (Int.11:37 Active refuser)

For those who were undecided or were considering refusing their consent, the views of online communities of parents seemed to play a more significant role in their decision making. One parent commented:

'I did look on the internet about fluoride because obviously you hear a lot about fluoride poisoning and that is not really actually good for you, but like… I wasn't really agreeing…' (Int.13:24 Active consenter)

Another parent who refused their consent commented similarly:

'Everybody is… There are lots of rumours on the internet… they are killing half with the fluoride…' (Int.11:41 Active refuser)

These comments demonstrate that although parents are seeking information online, what they actually want to find out are the views and experiences of other parents. That is the point of interest to them and the internet is merely a vehicle to enable them to do it.

Social networks stretch beyond family and friends, but from the information above it is clear that parents who are in regular contact do influence one another's action in ways that can be enabling to decision making through the spread of supplementary information, a feeling of connectedness or embedded social norms. The frequency of exposure to other parents' views, which appears to intensify the strength of influence, is highlighted by the quote below:

'All day my friend I see because she…. her daughter is going to school and every day I see… I talk to my friend… about this one….' (Int.4:177 Active consenter)

Parents' relationships with professionals

Health and education professionals can influence parents' decisions. This has been discussed in terms of the State sharing responsibility for children's health in an ideological way (theme three), but in this theme the focus is on the personal

relationships that some parents have with particular professionals and, by extension, the organisations they work for.

The influence of family dentists as part of parents' social networks was mentioned by some. There is some overlap between this and elements of themes one and five, *i.e.* parents' need to protect their children and how dental information is delivered. In this theme, the data shows that the influence of family dentists is different to that of friends. The influence of friends was underpinned by the commonality of parenthood, whereas the influence of family dentists is more formal, with parents placing their trust in dentists as professionals. The regularity of six-monthly appointments for children does enable a professional relationship to form. For example:

'*The dentists everywhere, they talk about the fluoride so basically, because the dentist is about helping our teeth, they are supposed to do… My daughter is like, which one do we have to trust? Only the dentist is the one that we trust!'* (Int.3:270,277 Active consenter)

'…. I don't know what to say…. Maybe yes, but even if it is for outside and I have to go to a dentist and he says you have to do this, I would say yes, because he is a professional.' (Int.12:43 Active consenter)

The influence of the school in parents' decision making was clearly evident in almost all interview and focus groups transcripts. In particular, the role of teachers was singled out for discussion but, the school itself can have an enabling impact on parents' potential to make a decision and respond to a consent request, particularly those parents with little social capital to draw from. For example, one parent I spoke to had few friends in England and no family in the country other than her partner. This mother summed up how important the school was in her life when she said:

'I don't have a long time to live here and I am not familiar with this information and most of the time I am at home, and the school is like home…' (Int.15:8 Active consenter)

Another parent felt strongly about the role of the school going beyond education, and she described the school as a community in itself that has a position of influence with parents:

'I think the school…I know schools are taking on more and more but schools are part of the community… I, so you have already got that small community base, so keep it there and try and develop it a bit more, because where else are parents going to get the information? (Int.10:89,91 Active consenter)

Another example of the influence of the school on parents' actions can be seen in comments about the lack of relevance that information without a school logo had. This is linked to the information presented later in theme five (Section 5.3.e), where generalised written information is discussed, but the point here is that, regardless of the information itself, parents already have a relationship with the schools and it is this existing connection that has influence. For example, when asked what they thought about a leaflet disseminated via the school from the dental service but without a school logo, parents commented:

'That makes a difference, because it's not anything to do with the school because there is nothing on there to prove that it is from the school.' (Int.9:114 Active consenter)

This indicates how easily information can be dismissed when it is not readily identified as coming from a relevant and trusted source. The magnitude of the personal relationship that parents have with their child's school can be seen in the comment below about similar information bearing an NHS logo. The trust placed in public services has already been established in theme three (Section 5.3.c), so here the only difference is the more personal relationship that parents have with individual schools than with an abstract idea of the NHS:

'If I just got an NHS leaflet through my door I probably wouldn't read it….' (FG3:177 Active consenter)

This demonstrates how schools' involvement in public health programmes can act as an enabler for parents. Parents are more likely to consider information sent via the school as being endorsed by the school if it contains the school logo, and therefore the information carries additional influence.

In addition to this, many parents commented on how the teachers acted as advocates of the programme and how this enabled them to feel more confident about making a decision and responding positively to the consent request. For example:

'The teacher, when I saw…. I remember… My child brought it… And when I saw the teacher… And the teacher had the time to explain to me… You know? I remember. She explained to me and said, ok, that it was fine, and I wanted to do the right thing for my children… So, that is why I decided to sign it and send it back to the school.' (Int.1:144 Active consenter)

This comment encompasses several of the themes and points already covered about parental decision making, but with regard to theme four it is the trust that this parent has in this particular teacher, and their personal relationship, that makes the difference. This parent was not persuaded to respond because of a respect for the professional role of teachers, or because of some notion of shared responsibility, although these factors may have contributed; the outcome was primarily because this teacher invested her time and built on the relationship she had with this parent. Other parents also commented on the role of the teacher. For example, one simply stated, *'I trusted the teacher'* (Int.1:183 Active consenter), and another said:

'…I have always been happy to go along with whatever…. To allow my child to participate in anything that the teacher comes up…' (FG4:26 Active consenter)

Some parents felt that the teacher could take on a more active role in notifying parents that the children had information for them. For example:

'*The teachers; when they open the door, could just say: "We have got a form that we need you to fill out and please have a read".'* (Int.1:194 Active consenter)

Information dissemination is explored in more detail in theme six (Section 5.3.f); however, the point of note here is the influence that this has on parents as part of their most frequently encountered social network. The trust that is placed in schools and teachers discussed here, coupled with that already mentioned in theme three (Section 5.3.c), shows that this is a key but also overlooked aspect of the FV programme implementation. Parents expect schools and teachers to act paternalistically towards their children, but what is perhaps unrecognised is the paternalistic nature of the relationship that teachers have with parents. Interestingly, this is not considered negatively by parents, who accept and trust this aspect of the relationship and on occasion actively seek out this type of guidance.

From the information above, it can be seen that it is the existing and often close relationships in which contact is frequent, between parents and their friends or their children's teachers, that influence parents' decisions. It is these existing relationships and the trust that is already present between individuals that enables parents to draw on a shorthand of shared understanding, *i.e.* that they both want what is best for the child, and it is this that enables decision making.

5.3.e THEME 5: Official dental information is not communicated in a way that parents find useful

The written information that the dental service provides is intended to ensure that all parents have some knowledge of FV before they provide or refuse their consent, *i.e*. fulfilling the requirement of 'informed consent'. This information is provided in the English language only and it was clear from the parents I spoke to that it did not always increase their knowledge and understanding in the way it which it is intended. A large number of parents felt it was unhelpful, raised more questions than it answered, or simply left them confused and looking for clarification. For example, on several occasions I was asked to provide additional information about FV and the programme itself, despite parents having made their decision by the time of the interview or focus group. In this situation parents were taking advantage of the opportunity to speak to

a dental care professional, thus displaying their need for supplementary face-to-face information. However, this overarching theme focuses on the written leaflet that parents receive and react to, and not the source of that information, which has been covered in theme four (Section 5.3.d).

This theme (five) is made up of two substantial candidate themes and four supporting candidate themes. The substantial candidate themes are Information content and Information format. The 'content' in this instance is understood as anything that is in the leaflet, *i.e*. written text, pictures, etc, whereas 'format' is understood as the vehicle for this, in this instance the written leaflet itself. These two substantial candidate themes are closely linked, with some overlap, and together they form the overarching theme.

Information content

The majority of parents in this sample were not native English speakers and this was a significant barrier for some when it came to their ability to understand and consider the information before making a decision. Most of the parents who participated spoke English, with varying ability, but many reported that they did not read English. One parent who could understand some English but not speak or read it clearly demonstrates below how a lack of language skills hinders knowledge and understanding when information is provided only in English:

'*I haven't made any questions because I don't know how to make any questions!*' (Int.3:216 spoken through a translator Active consenter)

Parents who experienced language difficulties navigated this barrier with the help of partners (as seen in theme four above), friends or sometimes their own children, who all acted as facilitators through their translation of information. For example, the parent quoted above went on to say:

'But I have given to my friends and she has read it for me and she said it was very, very good for the kid.' (Int.3:217 spoken through a translator Active consenter)

Another parent described to the group how her elder child (aged 10) took the lead on making the consent decision because she herself was unable to read the information:

'My son is year 5 and his reading is nice….And he says: Mum, this this and this and you sign….for teeth for my sister? And I said, Ok, no problem.' (FG3:111-113 Active consenter)

This demonstrates how information provided only in English to a multilingual community such as the population of Enfield forces parents to make use of the resources they have at their disposal, *i.e.* friends and family, to overcome this specific barrier. The result is that the information takes on a more informal status and may not be translated accurately. But perhaps more importantly, this also raises questions about who is actually making the decision: the parent as intended or the facilitator? The dental information supplied is meant to be impartial but parents seem happy to accept the explanations and views of their facilitator friends and family without any concerns about independent decision making. This is linked to the point raised previously in themes three and four about parents' desire for more guidance. Parents do not have the same level of concern about independent decision making as those in the dental and other health professions.

The impact of parents not being able to read the information provided was pointed out by the parents themselves, regardless of whether they could read English or not. For example, one parent explained this well by saying:

'So, obviously understanding the language, which are in this area a big thing… I don't think that it is a difficult decision, but it is a decision that is not being made because they [other parents] don't know what it is.' (Int.10:159,162 Active consenter)

English-speaking parents felt empathy with those who were not able to understand the information, and the need for translated information was raised in almost all of the interviews and focus groups. Interestingly, discussions on this subject highlighted not only the potential barrier to parents' understanding, but also parents' perception

that information written in English was not relevant to non-native English speakers and their children. This view seemed particularly prominent among Turkish participants. One parent described the reaction of others in her community to information written in English as:

'Because you know, in English, they don't care, but if they read in Turkish then they say, "Oh, that is important".' (Int.8:190 Active consenter)

Similar comments were made by other parents. For example:

'I mean obviously if it is written in Turkish so they might feel like, Oh. You know? It might be concerning "us", kind of thing…' (Int.9:99 Active consenter)

It is this 'added value' in terms of the importance placed on translated information that could act as an enabler for parents, but in the current situation, in which information is supplied only in English, this is in fact a barrier to knowledge and understanding and, ultimately, to decision making. The information and the corresponding consent requests are disregarded by some parents as irrelevant. This seems more common among parents who are used to having important information translated into their own language. The impression parents have when they receive information in English is that it is not intended for them.

Parents also made negative references to the relevance of the images that are included in the official information, which show a white child with good oral health. This was less to do with the relevance of these images to particular minority ethnic groups, which no one commented on, and more to do with the condition of the child's teeth. From the parents' perspective, these pictures did not convey the situation in Enfield, nor did they stimulate parental action by highlighting the seriousness of the problem. For example:

'And a lot more pictures instead of this one. He has got nice teeth, I am sorry!' (FG1:266 Active consenter)

'…and show pictures and explain…again to raise awareness and wake them up.' (FG1:268 Active consenter)

Moreover, in terms of content, although a minority of parents felt that the written information was sufficient and enabled them to consider their options and make a decision, a larger number reported that they had read the information but were confused by it. Interestingly, those who felt that the information they received was sufficient made few additional comments other than that it was enough for them to base their decision on. But, later in my interaction with them they often confirmed that they had supplemented this material with additional information via the internet or explanations from others in their social networks. It appears that the official dental information was used as a starting point from which to seek supplementary material, rather than, as first thought, being the only information parents used. It is also worth considering that these parents did not feel comfortable making negative comments to me (a dental care professional) about the leaflet they had received and so initially said that it was sufficient, with little other comment.

Some parents stated that the information had in fact raised concerns that they had not previously had. In particular, Muslim parents were concerned about the alcohol content of the varnish, which they had not considered prior to reading the leaflet. For example:

After I received the letter saying about the alcohol on the tongue, is this for Muslim…?' (Int.6:181 Active consenter)

The content of the information did appear to provoke rather than answer questions for a number of parents. Below is a typical comment about this:

'I found that when you read the leaflet, and you are still in two minds, like what does this do, and what is it like…' (Int.9:60 Active consenter)

A large proportion of the parents I spoke to sought additional information, either from me or from other sources (as mentioned in theme four above), but parents were

looking for more than just additional details – they wanted guidance. Finding out more details was not the goal for many parents; they simply wanted to know 'was this a good idea for their child or not?' It was clear and explicit opinion they were seeking and in their view this was missing from the information provided. On the whole, parents expected a greater degree of direction to enable them to consider their decision in the context of *their* child. For example, one parent expressed this well when she said:

'If it would benefit her…that is all I need to know…that is what I need to know. If it is going to benefit her. Because she is one of those kids that does not have a lot.' (Int.2:367-371 Active consenter)

Universally, parents reported seeking additional information from an education or health professional, family, friends or the internet. The influence the information source has on parental decisions has already been raised in theme four. However, the point being made here is not about where the information came from; it is to show that the information neutrality as experienced by parents is not sufficiently enabling them to make a consent decision. It is, in fact, leading them to find supplementary and opinion-based information elsewhere. One parent held strong views about the inadequacy of the explanatory leaflet that parents receive and the need for supplementary information. She commented:

'…because you can't ask a parent to make a decision. Give them a leaflet home, and the parent has no clue what it is, and not then offering some kind of conversation or dialogue between the parent about what this is, they are never going to understand. They might not even have the time to go and research it until… and then obviously the language barriers so they are just going to leave it: "If it is not important then leave it".' (Int.10:144 Active consenter)

This last comment, reflecting on the behaviour of others, is interesting, given the earlier point made about how some parents (particularly those in the Turkish community) view information written in English as unimportant. The omission of

dialogue or guidance mentioned here coupled with the low relevance to some of English-language information could exacerbate some parents' feelings of irrelevance and increase their likelihood of not responding.

Information that is intended to be impartial so that parents are free to weigh up the facts was not well received by parents. Parents reported that this impartiality undermined not only the written information but also any verbal information that was conveyed. One parent said that health professionals choose their words too carefully and that this was not helpful. When asked for an example, she responded by saying:

'Like sometimes they say, for example, that fluoride is really good for us, and the kids' teeth, and then they say: "We think that fluoride is very good for the teeth." So, do you "think" it is good for your teeth? Or it "is" good for the teeth. Like this kind of thing…. And you are like, do you think… or are you not sure?...Which one? So, when they talk they have to be more… like… Obviously, because when you are not like this or this, it means you are not sure for yourself… But when you know that this is good, you have only one way to explain. You say: This is good! Everyone has to do it.' (Int.3:363,365 Active consenter)

Official dental information is well intended in its aim to allow parents to make independent decisions, but it appears that it is this very impartiality that creates a void for parents that can lead to confusion and non-decision. The reality found in this research is that parents fill this void with information from other sources, therefore navigating this barrier as they experience it in an ad hoc and informal way. The information that parents find most useful is that which clearly shows a preference and helps to answer their most pressing question: 'will this benefit my child?'

Information format

Overwhelmingly, parents reported that they preferred spoken face-to-face information, either instead of, or as a supplement to, the written information

provided. This is linked to some of the points mentioned above regarding the relevance of generalised information and the desire by parents to ask questions and be guided to a greater extent than at present. Interestingly, parents in this sample indicated that they consider information provided in person to carry more weight than written information that is sent to them; again, this was universally felt across almost all of the parents I spoke to. For example, the parents quoted below described how important face-to-face contact was to the relevance and, therefore, the importance they attached to the consent request leaflet. These comments were made in response to a question about how the request could be improved:

'Every time you hand in the blue leaflet you can come and talk with the people… Yes, because you can explain, otherwise lots of people I am sure….to be honest, I am sure, because they always think, what is this letter for…?' (Int.8:71,73 Active consenter)

'If you see someone and they come to talk to you but if you have got the letter you say this is nothing.' (Int.7:195 Active consenter)

'…because it is very serious, it has to be more serious! And this paper doesn't show serious….' (Int.3:421 Active consenter)

The preference for face-to-face information was universal across parents of all ethnicities, genders and schools, regardless of whether they could read English or not. Interestingly, parents made little distinction between information provided by dental professionals and by education professionals. The data shows that the lack of face-to-face information is a barrier to parents' decision making and response. Parents who spoke to someone about FV said that this helped them to decide and gave them confidence in the choice they ultimately made. It is the value placed on personal relationships that helps to elevate the importance of informal verbal information. The current impartial written information creates multiple barriers for parents with regard to relevance and resonance, creating an information void. Many parents in this community come from cultural groups with strong oral traditions, and this is not

recognised by consent information leaflets. Social norms and face-to-face information take precedent over other formats, even when these personal encounters are new and potentially one-off.

Parents were completely negative about the written information provided. A small number of them commented that it was convenient and could spark discussion among family members, but this was overwhelmingly outweighed by comments about how written information can be overlooked. This seemed to be particularly strongly felt if the information was sent home to parents via the child's book bag, which is the normal practice. For example, one parent summed this up well when they said:

'Sometimes, to be honest, sorry, yes, we do get busy and we are busy and we forget to check the child's book bag… and they could be going to an after-school club and they put it in their bags, and as a parent I am rushing because I am working full time and picking them up from a child minder and running home with them and never checking their bag… three days, four days later I am still not checking and there's papers piled up in there.' (FG1:228 Active consenter)

Another parent was more forthright when making a similar point:

'It is junk! It's junk mail… When you open up your child's book bag, if you do open it up, and there's all these bits of paper, and you just throw it away.' (Int.10:120 Active consenter)

This unpopular dissemination method is discussed in more detail later in theme six (Section 5.3.f) in relation to the consent process. Nevertheless, the point to consider here is that the format of the information, *i.e.* a leaflet, is experienced by parents as another barrier to their knowledge and subsequent decision making. One father explains his experience of receiving letters from school in this way:

'…I get enough letters sent home for three girls, and you just put it down and think, I'll read that later, and before you know it, it has been moved and you don't bother looking for it.' (Int.6:77 Active consenter)

Parents were similarly unconvinced by the use of email or text message, when this was raised as an alternative to overcome some of the practical logistical issues outlined above. However, text messages were considered useful by most parents if used to remind them to respond, but not as the main source of information and not as an initial consent response mechanism. On this point, all parents reported that family life was busy and that they would benefit from being reminded to respond to the consent request. The 'busy-ness' of family life came strongly through the data and certainly appeared to be a significant barrier to parental consent response (also explored in theme six). For example, comments such as the one below were not uncommon:

'You definitely need a reminder, and like you say with the consent at the bottom, again. Definitely…' (Int.5:145 Active responder: consent then refuse)

It was made clear that a text message was the favoured medium with regard to parental reminders. Text messages are used routinely by the schools for other matters and parents expressed that they felt comfortable with this format when used as a reminder. For example:

'Yeah. A text definitely. We get texts from the school…."Don't forget! Blah, blah, blah…" Yes… "Oh, I have got to do that".' (Int.6:82,84,87 Active consenter)

Parents said that they favoured text messages over emails. For example:

'*Because email…. I am not on the email… I forgot my password…. Plus, all of the time she is watching on my phone… cartoons…'* (FG1:133 Active consenter)

'Probably not email…. Because not everyone checks their email. Text message again, I think it is more of a reminder than asking us.' (FG1:197 Active consenter)

The familiarity, immediacy and convenience of text messages seemed to resonate with most parents, enabling action. From the data collected for this research it is clear that both the information content and the information format are important to parents when providing their consent or not for the FV programme. The points discussed in this theme create barriers to decision making. In this study, parents had made a decision (albeit two of them being passive non-responders), and any barriers they faced had already been overcome, but these barriers presented an extra layer of complexity to their decision making.

5.3.f THEME 6: The current consent processes are problematic for parents

This theme is largely about the practical ways in which parents are asked for and communicate their consent decisions that appear to create barriers. These barriers are often structural and are embedded within the programme design and implementation processes. Parents and members of the dental team do not routinely meet. Schools act as a conduit for the official dental information and parent consent responses, with the children themselves playing a key role in transporting information back and forth. This theme is made up of three substantial and four supporting candidate themes. The substantial candidate themes are Types of consent, Consent process and Flexible decision making.

Types of consent

Initially, parents expressed varying preferences when asked whether they favoured an opt-in or opt-out system of consent, although in general they wanted to make the ultimate decision regardless of how this was framed. However, parents' preferences changed, or at least crystallised, after explicit explanation of what these two systems would mean for them. For example, parents indicated that they were happy with an opt-out system until I explicitly asked: 'Would you be happy if your child was automatically included unless you said, "no I don't want my child to have the varnish"?' At this point the majority of parents indicated a preference for opt-in positive consent, in effect acting as the gatekeeper for their child's participation.

Parents with experience of similar school-based programmes in other countries where parental consent is not requested, or where an opt-out (negative) system is used, seemed quite happy for the implementation of the FV programme to follow suit. For example, one father who has other children living in Brazil, and who was also quoted in theme three as an example of parents' confidence in shared parental responsibility between themselves and the State, said:

'I take it as a common thing, like it is just a part of the life of my son and nothing is wrong. I don't see anything… wrong with that….' (Int.6:44 Active consenter)

He went on to explain:

'Over there it is normal, not at three years old, but at five, like they come in the school and do things like this and check and everything…. But there they don't ask for permission or anything! It's like… normally….' (Int.6:135,137 Active consenter)

This kind of experience was mentioned by a minority of parents when recalling their own childhood, particularly if they had attended school in other countries. Two mothers from Latvia who were interviewed together commented:

Parent A: '*I mean, if it is something good, you don't need to ask the permission.'* (Int.3:257 Active consenter)

Parent B: *'It is good to let us know first, but not for permission… it is not very important for permission…something that will help….just to let us know what is going to happen and how is….'* (Int.3:265 spoken through a translator Active consenter)

These parents did not feel strongly about consent but they did want to be told in advance that the FV application was going to take place, so that they could tell their child what was going to happen, to 'prepare them'. This has already been discussed in theme two in relation to parents' confidence, but the point of interest here is that these parents, and others like them, did not feel that their consent (or 'permission' as they put it) was needed for the FV programme. For these parents, once they felt

confident that the FV was going to benefit their children the issue of consent diminished in importance.

Conversely, the majority of parents, who had more experience of UK schools, either as children themselves or as a parent with older children, felt strongly that they should be asked for their consent, *i.e.* they wanted to be the decision maker in this situation (this was raised in themes one and two earlier). What is important to note for this group of parents is that they favoured opt-in (positive) consent. This requires parents to take a more active role to indicate their consent preference than an opt-out system, despite both systems enabling parents to make the ultimate decision to consent or refuse. For example, one parent who was also a teacher (on maternity leave) was asked whether she would be happy with an opt-out system of consent and she responded with the following comments:

'No. That will get a lot of parents' back up. That would get my back up…[It's] very important….that you get permission first….' (Int. 10: 124,136,138 Active consenter)

Another parent commented similarly:

'You have to ask the parents. You have to ask all of them, one by one!' (FG4:221 Active consenter)

However, interestingly, several parents who favoured an opt-in process commented that in their opinion consent was seen as an exercise in protection, *i.e.* knowing where to potentially apportion blame if something went wrong, and in particular parents felt that their consent provided an element of protection for either the school or the dental service. Parents who felt this way, *i.e.* wanting an opt-in system so that they were the gatekeeper to their child but equally believing that the consent was for protection from blame, fit the role of protector for their children that is discussed in theme one. For example, when asked whether consent was important, one parent replied succinctly by saying:

'Well yes, because if they do it and something goes wrong, who is to blame?' (Int.2:123 Active consenter)

Opinions such as this are somewhat at odds with the apparent trust that parents universally expressed in public services and in particular in their child's school (this point is explored in detail earlier in theme three). The point here in relation to this theme is not one of trust or distrust; it is more about how parents view consent and the purpose for which it is sought, *i.e.* that they should be the ultimate decision maker for their child (as per theme one), with this decision being practically recorded by a signature in order to protect others. Parents do not view consent in this situation to be for their or their child's benefit. Some parents did talk about their right to make a decision, as already shown, but no parents framed this in terms of their autonomy, or autonomous choice to consent or refuse. This follows when parents' preference for guidance and their expectation of paternalism shown earlier in this chapter are considered. From this it would seem that parents do want to actively make a choice but within quite narrow parameters; they want to decide whether their child should participate, but they do not want to have to decipher whether FV is of benefit, *i.e.* they do not want to weigh up lots of complex or detailed information.

Consent process

Regardless of the current 'opt-in' system, the logistics of the process clearly created barriers for some parents. On more than one occasion parents reported confusion with regard to what needed to be signed, when, by whom and for what purpose. This seemed to be particularly prominent for non-native English speakers. For example, one mother commented how she found the process difficult but her English-speaking husband did not. This comment was given in answer to a question about parents' opinion of the consent process:

'For my husband, it was easy because he is reading and after he can fill in the form, but for me, because I not read, it was hard.' (FG1:160 Active consenter)

In addition to language issues, the process also proved problematic for parents who were not relationship partners but co-parented and played an active role in their child's school life. Confusion between co-parenting mothers and fathers in this study was found, with parents reporting that they had not received the written information, only to find out later that it had been given to the child's other parent. Without this information, parents are unable to make a decision and respond; indeed, they are often unaware that a decision needs to be made at all. It is the practice of giving the written information to the child to take home that creates this barrier because often the parent who picks the child up from school is the sole recipient. It cannot be assumed that parents will communicate on this subject, not least because of the busy nature of family life, added to the complexities of sharing information and making a decision across separate households. One father explained this well when he reported that the child's mother picked the child up from school and received the information, leaving him unaware:

'No…I didn't get it… I said earlier on, I didn't know you had given a leaflet to parents prior and coming the next day for the coating… And the next day, my boy had it…' (FG4:2,24,30 Active consenter)

In this situation, this father was asked by the teacher to make an immediate decision to consent or refuse when he dropped his child off at school, meaning that he did not have time to consider his response, as is expected when making an 'informed decision'. Moreover, one parent commented insightfully that there was no follow-up of parents who did not respond, at least not in the same way as for other similar programmes, *e.g*. flu immunisation. As already noted in several of the themes above, family life is busy and things like this can get overlooked. Indeed, two parents in this sample wanted to consent but forgot to send their signed consent back in time and so their children were excluded and they themselves were recorded as 'non-responders'. If they had received a follow-up communication they may have been more successful at remembering to respond:

'This one ask you and ask you again…. You have to answer it back and say you don't want to…. Or you do want it…. But this one it is not like that…. Isn't it? It's like you send it if you don't want it and if you do not return it they are not going to send it back.' (Int.7:222 Active consenter)

It is likely that the lack of follow-up also adds to parents' view that this programme, and therefore their decision, is not important. Perceived importance was discussed in theme five.

This consent process is not helped by the information format that is used to communicate with parents, *i.e.* a paper leaflet, which, as parents noted themselves in theme five (Section 5.3.e), is often overlooked. The dissemination process of giving information to the child to pass on to their parents at the end of the school day creates a barrier to effective dissemination and to awareness that a decision is required.

For example, two parents discussed this in one of the focus groups (FG3:179-180,182 Active consenters):

Parent 4: *'Because there are so many leaflets….'*

Parent 2: *'And because your child comes out and gives you what they are holding…. Well my son threw it at me!'*

Parent 4: *'So much stuff to carry out! It's going to disappear!'*

The data here shows that it is the process used to request consent that creates a considerable barrier to parents making a decision, regardless of the complexity of the decision itself.

Flexible decision making

The inflexibility of the consent process also appeared to create problems for some parents. In this programme, children can receive two applications of FV per school

year, and parents are asked prior to the first application whether they consent. If no response, or a refusal, is received the parent will not be offered the opportunity again that school year, and therefore an assumption has been made that the parent's response will not change. However, from the data for this research, it can be seen that parents want, and assume that they have, the flexibility to change their minds. This was demonstrated quite clearly by the two parents in this sample who were passive non-responders (because they forgot to send the information back in time). Both fully intended to consent prior to the second application in the same academic year, but due to the process in place they did not get this opportunity. One mother explains her oversight below:

'No, they didn't have it because my little one, she didn't have it because I sign it and forgot you know… And next time we will come you have to sign it. I didn't sign and she complain to me and say: "Every child they got it…." "Sorry! It is my fault." Because I was rushing and I fill in the form, and I didn't sign it for her.' (FG1:44 Passive refuser)

Moreover, some parents who had refused their consent confirmed that they would reconsider prior to the next application because their child would be a little older by then and more able to tolerate the fluoride application, but again these parents would not get the opportunity to reconsider their decision in this academic year. One mother explained on behalf of herself and her friend who was also part of the focus group:

'No, I was the same my friend. I think that because her son as well, they are in the same group, he cannot rinse his mouth as well, same obviously as my daughter, that is the reason that we didn't agree but for the future, yes, I would like to have because she will know that she can rinse and that she will not swallow inside.' (FG3:103 Active refuser)

Parents who had provided their consent also expressed their desire for flexibility with regard to their decision. One father commented:

'*Just so they can decide whether to have it done at that particular time. Because they might want to miss one, like the lady said, once a year, or twice a year, but sometimes you are not sure. What if the child… If it feels like their teeth are fine and not causing any problems, and they are cleaning well and brushing their teeth well for months….*' (FG2:157,159 Active consenter)

This comment, and others like it, demonstrates that the barriers to parents' decisions and responses here are the assumptions that are built into the implementation process about these decisions. It is assumed that parents who do not respond or who refuse will not change their mind or respond differently in the future, but the data indicates that this is not the case. Parents are prohibited from making a decision later in the academic year because in the current system they are excluded from being asked a second time. This creates an additional barrier for some but not all parents, *i.e.* first application refusers and non-responders. This is a structural inequality within the programme.

Interestingly, until I contacted the Whittington NHS dental service to ask for data on parents who has previously refused, consented and not responded, all non-responders were recorded as refusing. The process has now changed and all three categories are recorded.

The information put forward to explain this theme shows how both types of consent, *i.e.* opt-out or opt-in, were discussed positively by parents to varying degrees, but the emphasis by all parents was on their being kept informed of what was planned for their children. This was a universally held view, including by those parents who felt that their consent was not necessary. In addition, the consent request process itself was problematic and did not seem to enable decision making in any way, with no parents commenting positively about it. The most concerning point raised in this theme was the lack of decision flexibility in the process, which almost all parents expected. The built-in assumption that those who do not respond or who refuse at first asking will not change their mind sets up a structural inequality of opportunity

for these parents to reconsider their decision at the second application. It also has the potential to increase already existing oral health inequalities for children.

5.4 Typology of decision makers

The themes explored show that all parents encounter enablers and barriers, but that the way in which they experience them differs from parent to parent and it is this individual experience that influences their response behaviour. From the thematic analysis of the data, four broad types of decision maker have been identified. These 'types' reflect the complex relationship between a parent's personal characteristics and capabilities (procedural autonomy) and their environment (substantive autonomy), and how these are translated into action, *i.e.* consent response behaviour. The identified decision-making types are: weak responders, strong responders, passive non-responders and active non-responders. Each category has elements of procedural and substantive autonomy, but one will always be dominant. The likelihood of a parent responding to a consent request depends on the balance of these two elements of their relational autonomy. For example, parents with weak procedural autonomy will be more likely to respond if they also have an enabling environment that facilitates their substantive autonomy by helping them to overcome any barriers. But, if the environment is unsupportive, any barriers faced may not be overcome, so their substantive autonomy is low too and this is likely to lead to a non-response.

The role of an individual's relational autonomy in their response behaviour and the four identified types are shown below in figures 5.1, and 5.2. The first diagram (Figure 5.1) highlights the four types and provides a short profile of the sorts of decision maker they are. In these diagrams an attempt has been made to include information for active non-responders, but as this comes from the literature review and not the empirical research, this is greyed out indicating the reduced certainty of characteristics of this group. The second diagram (Figure 5.2) maps the themes from this chapter onto the different response types. It should be noted that this is a

schematic diagram of the four identified types of response behaviour, but in reality the boundaries between each quadrant is less defined than shown here. Equally, parents may have greater or lesser degrees of autonomy *e.g*. some parents may have low procedural autonomy, while others who also fall into the same response behaviour quadrant may have even less, or perhaps more (but still low) procedural autonomy. These diagrams are not a measure of autonomy. They are merely an attempt to outline characteristics of different response behaviour. However, in figure 5.2 themes are positioned relative to their relationship with procedural and substantive autonomy continuums *i.e.* strong to weak, high to low.

Figure 5.1 Response behaviour typology

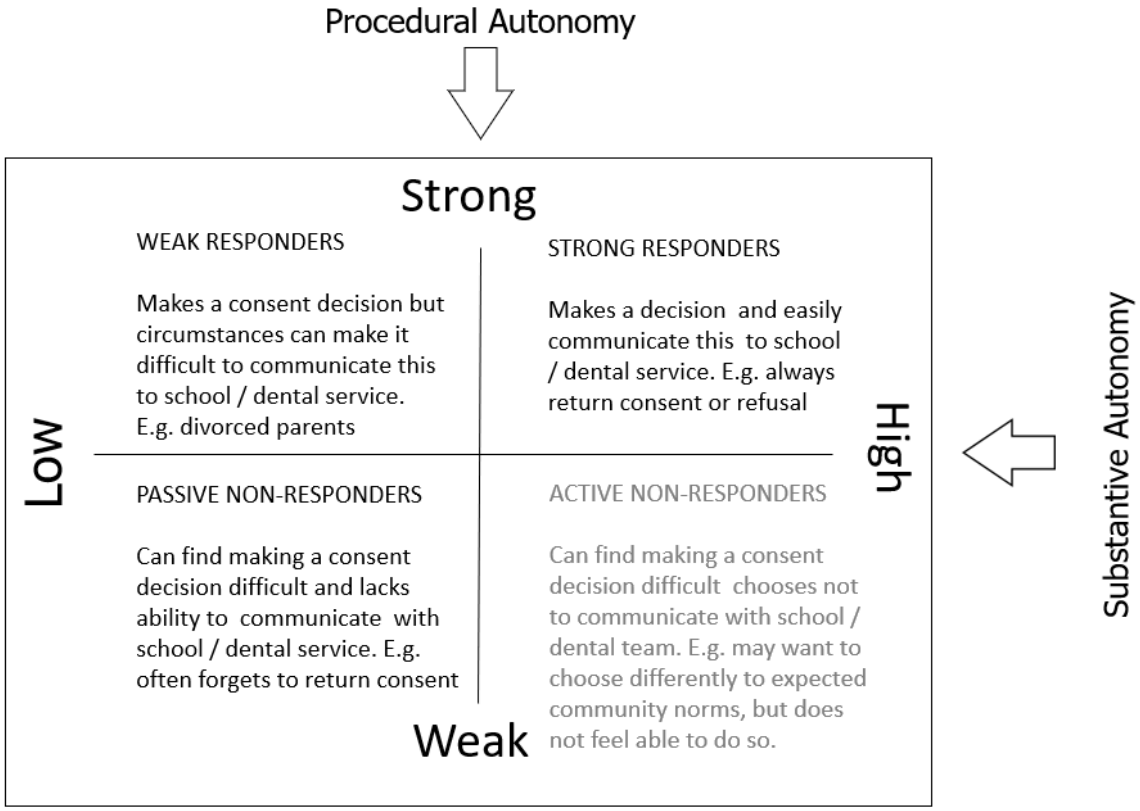
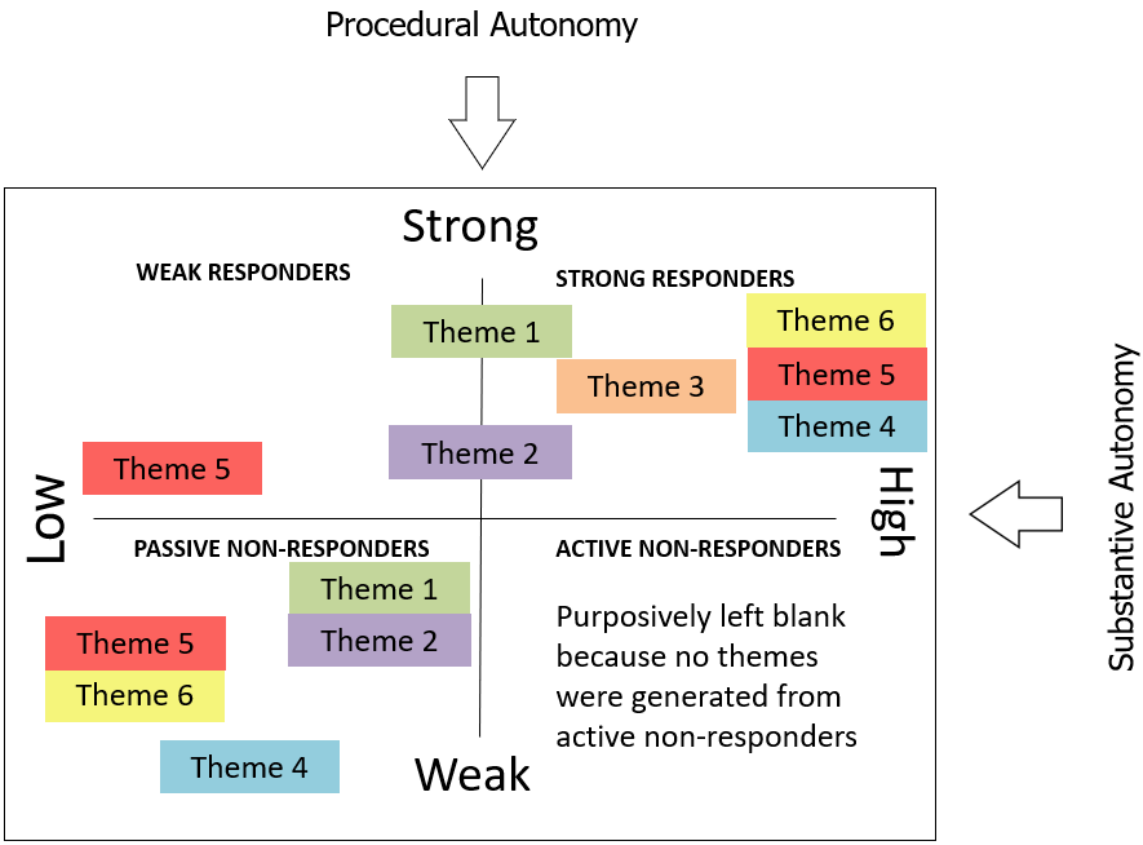


Figure 5.2 Themes mapped against response behaviour typology



Key:

Themes have been colour coded for ease of reference.

Theme 1: Protecting children from harm is viewed by parents as their role

Theme 2: Parents have the ability to make consent decisions but can lack confidence

Theme 3: Sharing responsibility for children's health between parent and State is viewed positively by parents

Theme 4: Existing relationships within parents' social networks strongly influence their consent decisions

Theme 5: Official dental information is not communicated in a way that parents find useful

Theme 6: The current consent processes are problematic for parents

Parents with both a strong desire and the capability to make a decision can sometimes face barriers that make acting on these personal characteristics difficult, *i.e.* they have strong procedural but low substantial autonomy; therefore, they may be considered weak responders because the barriers they face to act on their authentic choice may be significant. A typical example of someone in this category is a parent who wants to act as the decision maker (theme one, protecting children from harm) and is able to make a decision about the inclusion of their child that they are comfortable with and confident about (theme two, decision making) but is not able to act in this way because they cannot communicate their views to the school because they do not speak English (theme five, dental information). Parents in this category may or may not respond to the consent request. They are weak responders.

Conversely, the 'strong responder' category describes parents who have similar characteristics to the weak responders, *i.e.* their procedural autonomy is strong. They want to be the decision maker for their child in this instance and they have the personal capabilities to make a firm decision (themes one, protecting children from harm and two, decision making). But, differently to weak responders, those in the strong responder category also have a high level of substantive autonomy. Their environment creates few, if any, barriers for them to act and to make their choice known to the dental team (they benefit from enablers in theme three, sharing responsibility, and easily overcome any barriers in themes four, social networks, five, dental information, and six, consent processes). Parents who are strong responders are often engaged in a variety of school and/or community activities that facilitate their substantive autonomy.

Passive non-responders have both weak procedural autonomy and a low level of substantive autonomy, making any type of deliberate response behaviour difficult. Parents may find making a decision of this type troublesome; they can be swayed by competing information, which leads to indecision. Parents in this category often want to defer to experts for guidance on what to do. If no expert support is available the

parent is not prompted to respond and they miss the deadline before they can decide, often not realising that this has happened. An example of a passive non-responder parent is one who is not confident in their own knowledge and ability to make the 'right' choice (themes one, protecting from harm and two, decision making) and so listens to conflicting advice from their social network (theme four, social networks) and remains undecided, or makes a choice late after a lot of consideration. This parent is not prompted to make a decision by the consent process (theme six, consent processes) and so delays to the point at which any response they do finally make is too late and their children have missed the opportunity.

Lastly, no data on active non-responders was gathered as part of the empirical research. However, for the sake of completeness the characteristics in this quadrant have been developed from the limited information found in the literature in chapter three. Individuals in this quadrant are likely to have weak procedural autonomy but a have a high level of substantive autonomy. For example, parents in this category can find making a consent decision difficult, similarly to the passive non-responders, but whereas passive non-responders often try but are not able make a decision and then act on it, these parents actively choose not to engage with the programme or school rather than actively refusing their consent, because they may be unsure what to decide as a result of competing arguments, or their preferred choice being in opposition to their community norms. In this situation, the environment has facilitated their non-response, for example not having a follow-up procedure to the initial consent request enables them to act as they choose, which is to reject the programme altogether by not responding.

To ensure that a high number of parents respond to the consent request, both procedural and substantive autonomy need to be in operation. But, if procedural autonomy is an expression of authentic choice and substantive autonomy is a person's ability to act autonomously, then parents can be enabled to express their authentic choice, and to act on it, if the environment in which they are being asked to

respond to a consent request is supportive. This does not guarantee parental response, particularly as some parents actively choose not to respond, but it is possible to increase the likelihood of parents' responses if parents' substantive autonomy is facilitated through careful programme design.

5.5 Addressing the research question, the aim and the objectives

Parents' views and experiences of the consent arrangements for fluoride varnish programmes taking place in their children's schools have been investigated via four focus groups and 18 interviews, with a total of 39 participants. Based on the information above, I submit that the aim and objectives listed in Chapter 4 (Methodology) have been met.

Aim: To examine parental experiences related to consent procedures for a school-based fluoride varnish programme in North London

Thirty-nine parents provided information about their experience of considering and communicating their consent decision for their children to take part in the FV programme. The information these parents provided was examined and organised thematically after detailed analysis. This information is presented above and discussed further in Chapter 6 (Discussion).

Objective 1: To investigate parents' view and experiences of the consent arrangements for the fluoride varnish programme taking place in their child's school

An interpretation of the data related to this objective was explored in all themes, but particularly in themes one (protecting from harm) and five (dental information). Parents overwhelmingly viewed themselves as their child's protector, which extended to their seeing themselves as the best person to make the decisions about their child's participation in the FV programme. However, parents' experience of carrying out this role was hindered by the use of written information that had little resonance for those who felt that it did not convey the seriousness of the issue, and some parents from

particular minority ethics groups felt that it was not relevant to them. Indeed, some parents were able to make a consent decision only if facilitated by others, *e.g.* friends who acted as translators. These barriers were exacerbated by the problematic implementation of the consent process, whereby schools act as a conduit between parents and the dental team and children are used to carry information and consent responses back and forth. No parents viewed this positively.

Objective 2: To investigate parents' views about the consent process for the school-based fluoride varnish programme that would best support their preferred method of engagement, for example, a system of opt-out consent, or one of opt-in.

This objective was explicitly explored with parents and an interpretation of their views and experiences is put forward in theme six (consent processes). Parents' views on the system that should be used were mixed, although on balance most preferred opt-in consent. Parents' views were shaped by their own personal experience of similar school-based programmes. A small minority felt that the FV programme should be made mandatory with no need for parental consent. Interestingly, although most parents had some difficulty with the written consent leaflet that is currently in use, when asked if an electronic system would be better, *e.g.* email or text message, very few parents replied positively, although almost all parents wanted to have the opportunity to discuss the programme with a member of the dental team before they made their decision, regardless of which system was in place.

Objective 3: To investigate what support, if any, parents would like in relation to their consent decision making as part of school-based fluoride varnish programmes in the future

Interpretation of the data relating to this objective was discussed in themes three (sharing responsibility), four (social networks) and six (consent processes). All parents expected a level of paternalism towards their children from staff working for public sector organisations, *i.e.* schools and the NHS. Parents expressed positive feelings towards the FV programme being delivered in schools and felt that making health

services like this available and easy to access for families was a responsibility of the State. All parents favoured face-to-face information and felt that this would give them the opportunity to gain more personal information. They did not like the impartial approach that health professionals take; this was not considered helpful. Additionally, parents felt that they would benefit from reminders to respond, and flexibility to change their minds, consenting and withdrawing permission as they felt appropriate.

5.6 Conclusion

The six themes presented in this chapter have been developed from the transcripts of interviews and focus groups with parents, all of whom had experience of being asked for their consent for their child to participate in a school-based fluoride varnish programme. The majority of these parents provided their consent, one parent provided her reluctant consent and at least two agreed in principle but forgot to return the form. A minority actively refused their consent but, since two of these parents said that they would agree when their children were older, they had, in effect, delayed their consent.

Some of the themes, such as those discussing 'dental information' and the 'consent process', are clearly defined and made explicit in the data, whereas others such as theme four relating to parents' social networks or theme two about parents' capability to make a consent decision required more interrogation of the data before the final set of six themes came into focus. These six themes, and the substantial candidate themes within them, provide information on a range of issues that have been identified as enablers or barriers for parents.

The information in this chapter is the result of an analysis of the context within which parents are being asked to make their consent decision. It demonstrates that, although parents make their decision for different reasons and in different ways, there are commonalities among them, for example all parents want to protect their children from harm, all parents want detailed information on which to base their

decision, and all parents prefer personal face-to-face information, with all of them trusting schools, and teachers in particular. Moreover, through the sometimes contradictory comments that were made by parents, the data demonstrates that decision making in this regard is not a simple process, and that parents have competing priorities and demands that they need to balance before they can make a choice. This 'messiness' of life, in which ideas, opinions, thoughts and experiences are not discrete entities, is demonstrated by the overlap between themes. These points have been highlighted, partly so that the reader can understand the context and complexity of how, and potentially why, consent decisions like this are made by parents, and partly to demonstrate the interconnectedness of the themes.

In addition, the themes acted as a starting point from which to identify four types of responder. These were presented in a diagram to show how parents' decision making and response behaviour is shaped by their procedural and substantive autonomy, which may or may not be strong or weak, high or low, depending on parents' ability to express their authentic choices and act on them.

The information analysed and presented above will be used, along with the information from previous chapters, in the following discussion.

Chapter 6 – Discussion of consent practice and underpinning theory

6.1 Introduction

The purpose of this chapter is to discuss the findings presented in the previous chapter (Chapter 5) and to give meaning to these within the overall context of the thesis, specifically with regard to the ethical theory outlined Chapter 2 and the existing research about consent reviewed in Chapter 3 and, importantly, relative to the research question below:

What barriers and enablers, or both, do parents experience when they are asked for consent for their child to participate in a school-based dental public health programme?

The overall aim of this thesis was:

To investigate what influences parents' decision making about the participation of their primary school-age children in community dental public health programmes in England

The objectives below were used as a framework for the activities carried out to achieve this aim and, therefore, to answer the research question:

- To investigate parents' views and experiences of the consent arrangements for the fluoride varnish programme taking place in their child's school
- To investigate parents' views about the consent processes for the school-based fluoride varnish programme that would best support their preferred method of engagement, for example a system of opt-out consent, or one of opt-in
- To investigate what support, if any, parents would like in relation to their consent decision making as part of school-based fluoride varnish programmes in the future

This chapter starts with a discussion of the empirical findings presented in Chapter 5. This information demonstrates how parents experience the current understanding of

autonomous decision making, and how the professional practice of non-interference is operationalised by dental teams into a Kant-Millian hybrid approach to consent (Section 2.3.d). This approach is grounded in the ideas of Immanuel Kant (1785) that assume that people make decisions that are objective and rational, *i.e.* free from emotion or the influence of experience and based only on 'facts'. This idea of how decisions are made has been fused with a particular way of understanding the work of John Stewart Mill, who promoted 'self-rule', *i.e.* autonomy (1859). Mill's work has been understood to mean that it is not considered 'good practice' for health professionals to influence another person's decision making. These two powerful philosophies have been adopted by Western health professionals and they form the Kant-Millian hybrid approach, which is discussed in more detail in Chapter 2 (Theory). This approach is one in which individuals are given neutral facts related to a health decision and any additional advice given is impartial, thus allowing the individual to make an 'informed and unbiased' decision. However, the findings from this research demonstrate that this approach to decision making is flawed. It is not grounded in people's lived experience and does not enable the intended outcome of an independent autonomous decision.

The barriers and enablers demonstrated here, *e.g.* the suspicion with which parents view health professionals' neutrality, the influences of parents' social networks, parents' difficulty in understanding and making use of written factual information and their desire for more personal advice, all add weight to my earlier rejection in Chapter 2 (Theory, Section 2.5) of the notion that parents operate as 'independent in-control agents' when making decisions, which is the assumption made by the Kant-Millian hybrid (Walter and Ross, 2014). This way of conceptualising what constitutes 'good' decision making does not reflect the reality experienced by parents.

I have included a discussion of the implications of this rejection from both a theoretical and a practice perspective (Section 6.3 below). This challenges the accepted norms in the medical ethical debate, that acts as the umbrella under which

public health ethics sit, and asks the reader, specifically those in the dental profession, to consider a different way of conceptualising autonomy. This, by extension, will mean that current professional practice when implementing consent processes for DPH programmes will need to be reconsidered in order to provide supportive and enabling processes for parents to indicate their choices, based on how parents actually make decisions and not on an idealised notion of how decisions are made. I revisit the idea of relational autonomy from Chapter 2 (Theory, section 2.5) and the usefulness of understanding and recognising this when planning consent processes. To further advance the idea that the current hybrid approach ought to be rejected and that in its place should be one that acknowledges the embeddedness of people, and therefore their decision making, within a social environment, *i.e.* an approach based on a relational notion of autonomy, I make suggestions for how the consent processes for dental public health programmes can be improved in a practical sense, so that parental autonomy is maximised and the number of non-responses to consent requests reduced. This uses the pluralistic approach outlined in the theory chapter (Section 2.6), which includes procedural and substantive elements that are both paternalistic and autonomy promoting.

Relational autonomy as a concept is an emerging area of ethics that, although discussed in the literature by a small number of academics as philosophical theory, has not been 'applied' in research or practice (Section 3.3.c). I believe this adds value to the research and findings examined in this thesis beyond that of an academic exercise. This research is unique on two counts: firstly, it applies specific philosophical ideas of ethics to a real-life scenario to explore their usefulness; and, secondly, it prioritises the views and opinions of parents in dental public health research, which is dominated by professional voices (Appendix 3.1: Summary of dental literature).

Lastly, before concluding the chapter I discuss the strengths and weaknesses of this research as a whole. I review the methods it has employed and the contribution it has

made to the body of knowledge on this subject, and outline/detail any areas in which I would act differently if I were starting again.

6.2 Reflective discussion

Below is a discussion of the key points from this research. Overall, parents want to be the decision makers for their children, and they see this as a way of protecting them from harm, whatever that harm may be. But, in order to carry out this responsibility as parents see it, they want, and need, some assistance. At times, this is practical help, such as providing information they can understand, from a source they recognise as credible and trusted. At other times, parents want more personal assistance, such as reassurance from an expert and someone who will answer their specific questions about their child. Often, they want someone who will guide them through the process but not make the decision for them. They also want a consent process that is easy to navigate and does not require them to remember to do anything 'extra', but also one that is flexible to their changing circumstances and decisions.

This discussion has been structured to mirror the themes of the previous chapter and is intended to draw together areas of practice (Chapter 1), ethical theory (Chapter 2), existing literature (Chapter 3) and empirical work with parents (Chapter 5).

6.2.a Protecting children from harm is viewed by parents as their role

Universally, parents position themselves as their children's protectors and one way they can do this is through their consent response behaviour. This interpretation is evident in both the literature reviewed in Chapter 3 regarding parents considering the HPV vaccine and the findings in Chapter 5. Parents felt that their decisions reflected what was in the best interest of their children regardless of whether they consented or not. In both chapters, themes were developed around parents' sense of responsibility to protect their children, which acted as an enabler that prompted their actions. However, the harm that parents wanted to protect their children from varied, as did the way in which they acted in order to do this. Parents' concerns focused on

the twin issues of physical and emotional harm caused to their children, and a small minority of Turkish Muslim parents considered spiritual harm related to sexual activity and alcohol consumption, that was related to their desire not to transgress the teaching of their Islamic faith. In addition, parents considered both immediate and future harm, whether from the treatments to guard against disease, *e.g*. vaccines or fluoride varnish, or from the disease itself (in this instance, HPV or dental caries).

Consent response behaviour based on parents' inclination to protect their children conflicts with the view of some in the dental profession. Dental literature mentioned in the introduction of this thesis cites the view that parents are lazy with regard to their children's oral health (Monaghan, Jones and Morgan, 2011), or that parents are trying to deliberately conceal their children's poor oral health from dental professionals by not responding to consent requests, *i.e.* actively denying their children dental care and therefore not protecting them (Davies *et al*., 2014) (Appendix 3.1). The authors of these papers have made assumption about parents' motivations and actions based on statistical and epidemiological data on consent responses, without speaking to parents themselves. This view shows a lack of appreciation that parents' consent response action may indeed be motivated by the responsibility they feel to protect their child but that how children need protecting and what from is understood differently by parents and dental professionals. This is an example of dental perfectionism, whereby parents' choices that are true to them and their ideas of what constitutes harm for their children are not being acknowledged. This then demonstrates a lack of respect for parents' autonomy. For example, some parents did not consent because, as they saw it, they were protecting their children from the immediate harm of ingesting fluoride varnish. This is not a demonstration of laziness as Monaghan, Jones and Morgan (2011) and Davies *et al.* (2014) suggest. These parents are making a choice that is authentic to them, that is reflective of their reality and their understanding of harm, but this is being dismissed in the literature because it does not fit with the values that health professionals hold, *i.e*. the importance of accessing evidence-based oral health care for children. Dental perfectionism was first

discussed in Chapter 2 (Theory, Section 2.5.a), where it was outlined that the prevailing notion of an independent choice is reflective of the assumption that there is only one way to live a 'good life', *i.e.* based on rational facts, not on feelings (Kant, 1785). It is this idea that underpins the current consent practice, which relies almost exclusively on parents' ability to make and communicate an intellectualised choice, *i.e.* a rational one based on factual information and in which emotions are transcended, ignoring, therefore, protective feelings in favour of evidence-based information.

Parents are exercising their sense of responsibility towards their children and making decisions that are not solely based on objective facts but are open to influence from an array of information from different people and sources that taps into their protective feelings. However, to criticise these parents because they are not exercising their responsibility as some dental professionals would like them to is to deny them their autonomous choice. If this denial is acceptable, then perhaps fluoride varnish programmes in England could more easily be implemented with mandatory inclusion for children. This would result in a traditional utilitarian public health measure (Verweij and Dawson, 2009), rather than the current situation in which FV programmes borrow elements of health care practice, specifically the need for individual consent, as described in Chapter 1 (Background, Section 1.2.a). This would remove all notions of choice that enable parents' protective decisions. Instead, we are currently in the situation where individual choice is privileged and parents being given a choice, albeit a potentially illusionary one (Dixon-Woods *et al.*, 2006) and then blamed when they do not act 'responsibly' and comply, when, in fact, parents are overwhelmingly acting on their understanding of parental responsibility and protecting their children accordingly. This situation echoes the change in emphasis for dental epidemiology programmes that was outlined in Chapter 1 (Background, Section 1.3.b), with a shift from dental screening (with population benefit) to surveillance (for the production of data) based on the underlying notion that it is individual parents responsibility to care for their children's oral health.

6.2.b Parents have the ability to make consent decision but can lack confidence

Following this parental positioning as protectors, it is perhaps unsurprising that most parents across the research describe seeing it as their role to be the main decision maker for their children. The level of confidence that parents feel to make consent decisions varies. Many parents express feelings of confidence in their ability based on an innate belief that they are the best person to make this decision, even citing 'mother's intuition' as the qualifier for them to act in this role. Similarly, views reported in Chapter 3 (Literature review, section 3.4.a) indicate that (usually) mothers felt they were better able to make decisions for their daughters than the daughters themselves. These children were typically older than those included in the FV programmes (*e.g.* approximately 12 years old as opposed to five) and so potentially at the age when 'Gillick competence', as described in the background to this thesis (Section 1.4.g), could be considered for individual children, even if not fully present in all children (*Gillick v West Norfolk and Wisbech AHA [1986]*). But, any such competence in children to consider and make a decision about their own health was often overlooked or even actively disregarded by parents, as demonstrated by the quote from Dempsey, *et al*.'s (2009) paper discussed in Chapter 3:

'I figured now is the best time [to make the decision] because it's a time that I can make the decision for her…'

When the research from Chapter 3 (Literature Review) and Chapter 5 (Findings) is viewed as a whole it seems that making decisions on behalf of children is an expectation of parenthood, in particular motherhood, and one that most mothers do not relinquish easily. Mothers in this situation are comfortable exercising *their* authentic (procedural) autonomy *because* they are the child's mother. This exemplifies the theoretical point discussed in Chapter 2 (Theory), based on the work of Christman (2004) and MacKenzie (2008), that decisions are made based on a person's own identity that is formed out of values influenced by interpersonal relationships and their environment. (Chapter 2: Theory, Section 2.5)

For a large proportion of parents, inhabiting the role of mother appears to confer confidence, and even fathers indicated that they deferred to mothers about the care of their children. Across the evidence, it is the mother who makes the final decision and the responsibility for looking after children is seen as her domain. Mothers' decisions about their children are trusted, by themselves and by their partners. As a result, perhaps health professionals should pay attention to enabling not just parents in general but specifically mothers when thinking about designing DPH consent processes. It is their autonomy that needs to be enabled in order to make the choices that families appear to expect of them (Section 5.3.b).

Some parents are hesitant to make a consent decision. These parents often have confidence in their ability to decide on behalf of their children in general, so their self-identity is not lacking in this respect, but they lack confidence in their knowledge of this specific subject. However, it seems that this barrier too can be mitigated if parents have confidence in their approach to making the decision. For most, this meant actively seeking out additional information from other trusted sources. This featured prominently in the literature as well as in the empirical work. Even parents who did not do this seemed to take confidence from the fact that they could if they chose to, for example, *'If I wanted to do research on it, I would go out and do my research'* (Int.2:160 Active consenter). The idea that parents are independent choosers is a strong one, but parents who lack confidence in this way are potentially more vulnerable because they are expected to make a choice without professional help. As a result, they may be more open to undue influence from outside sources, meaning that their decisions may not be robust if challenged. Seeking clarity or reassurance is not necessarily a problem in itself, but if outside influences are in opposition to parents' internal choice, or if parents adopt the choice of others in lieu of making their own decision, this may be problematic. For example, some parents may provide their consent when privately they do not agree but their social environment is such that going against the expected norm is too difficult. These decisions are not autonomous if viewed from a Kantian perspective that requires the

individual to 'transcend emotions and experience' (Section 2.2.c), but if viewed through the lens of relational autonomy the picture is not so clear; individual parents' procedural autonomy may be low, but having access to other sources of information, particularly from a variety of sources, helps to enable autonomy to be exercised. When parents are open to a variety of influences and not just one way of thinking, they are more likely to choose for themselves. Nevertheless, regardless of how parents' decisions are viewed in these circumstances, they may be enacted individually but they are not made independently, and therefore parents are not 'independent rational choosers' (Walter and Ross, 2014). The significance of this situation is that when parents are not supported by health services to make a decision in the way that they would like, they seek reassurance elsewhere, leaving them open to undue influence that may not be reflective of their own choice.

To different degrees, parents also see a contributory role for the children themselves in decision making, although not going so far as to exercise the 'Gillick competence' that was mentioned earlier (*Gillick v West Norfolk and Wisbech AHA [1986]*). Children's influence on consent decisions often goes unnoticed by parents and, for the most part, it is unacknowledged in the literature, making this an area ripe for future research. For example, some parents will withdraw consent, thereby reversing their decision, if their children express any emotional upset. Here, children are not acting in the role of decision makers in the traditional sense, but they are influencing parents' consent choices and actions. This is an example of how decisions are always subject to some form of influence. The social (or familial) embeddedness of decision makers and the influence that their relationships have is recognised by the concept of rational autonomy in a way in which they are not in the current hybrid system (Section 2.5). The context and influence of social relationships, such as that between parent and child, is pointed out by Kenny, Sherwin and Bayliss (2010) and MacKenzie and Stoljar (2000) when describing the key features of relational autonomy. Here, the relationship between parent and child is more important than the parent's consent decision, so if a child is upset by their parent's choice some of these parents will

change their consent decision to maintain a more harmonious relationship. Their choice is influenced by the relationship they have with their child and their identity within this, *i.e.* that of protector and decision maker. As such, emotion can be seen as an enabler to decision making and not as something separate to it as Kant would have it (Kant, 1875). Current UK guidance on consent processes does not acknowledge emotional motivations on parents' decisions (NHS Executive, 2001).

The notion of children as autonomous beings was rarely mentioned in the literature, that focused on teenagers, despite the court ruling about 'Gillick competence' being in existence for more than 30 years. While this Gillick competence isn't relevant for consent for FV being applied to 3-5 year olds, this lack of focus does demonstrate the largely unquestioned idea that parents ought to be the decision maker for their child, although a small minority of parents are concerned that through their decisions children do not have sovereignty over their own bodies. This view was expressed strongly in one of the interviews I conducted and by some parents in the research by Dempsey *et al.* (2009) reviewed in Chapter 3. In this paper a parent remarked: '*I'm just too bothered by my decision having an impact on her…*'. The majority of parents sought their children's tacit agreement prior to giving their consent, by explaining to them what was going to happen and why. This can help parents to reduce any feelings of imposing decisions on their children, while still retaining the position of decision maker. This behaviour demonstrates Cheah and Parker's (2014) definition of 'child assent' that was discussed in Chapter 1 (Background, Section 1.4.g), *i.e.* including children in decision making but not obtaining their explicit permission. In the empirical work, parents acknowledged that their consent (and any tacit agreements) could be overruled by the child at the point of FV application if they did not co-operate and refused the treatment. In these situations, the clinician would respect the child's wishes, thus demonstrating that in practice clinicians seek more than assent – they require the child's permission. So, although parental consent carries weight and is required in a legal sense, for parents who have consented it is their children who hold the upper hand in a practical sense by potentially vetoing a prior consent decision

(Medical Research Council, 2016; Fisher, 2013). This point is overlooked in the literature.

Children of parents who have refused consent or do not respond cannot overrule their parents in the same way. This means that parents who have provided their consent have, in fact, helped to enable their children to be in a position to assent or not via their active consent. These children's substantive autonomy has been facilitated because they have been enabled to *act* autonomously. In this scenario, children can exercise their autonomy in a way in which the concerned minority of parents mentioned above would wish, *i.e.* they have sovereignty over their own bodies.

Parents who refuse consent require no input at all from their children. Indeed, child participation in or agreement with the decision making was not mentioned in this regard in any part of the research. It would seem that parents who consent are more aware of the position they hold as proxy decision makers for their children, whereas active refusers do not recognise this in the same way, perhaps assuming that refusing is a neutral decision because nothing for the child has changed, when in fact refusal is not neutral – it is an expression of parental choice.

6.2.c Sharing responsibility for children's health between parent and State is viewed positively by parents

Across the research is the evidence that parents expect a level of paternalism from professionals towards their children. Parents expect more of public services than simply that they will not cause harm; they expect these services to actively benefit children. Moreover, almost all parents whose children had the opportunity to participate in a public health programme at school felt this collective and State-organised way of delivering preventive programmes was a good idea. This reflects Prainsack and Buyx's (2015) definition, discussed in Chapter 1 (Background), of what is a crucial element of public health: specifically the third tier of solidarity, which is formal and includes 'contractual provision, or legal norms'. By expressing their support for school-based delivery, parents are demonstrating their solidarity in terms of the 'contractual provisions' for public health, *i.e.* in the UK this can be seen as a demonstration of support for the NHS being contracted to deliver the FV programme. This was made possible by the implementation of Statutory Instrument 3094 (Great Britain. The NHS Bodies and Local Authorities [Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch] Regulations 2012). The alternative to contractual arrangements of this kind is that parents are left to choose if and when they take their child for vaccination or FV treatment via a primary care setting. Parents from different countries and across the research explained how this activity was more stressful than accessing the school-based programme (Gottvall *et al.*, 2013; Cooper Robbins *et al.*, 2010).

An important area of difference between the literature and the empirical research was that a minority of significantly vocal parents felt that this paternalism towards their children should be extended, with participation in the FV programme becoming mandatory. This view was not reported in any of the papers for the literature review, despite some being located in the USA, where mandatory vaccination programmes are in place (Centre for Disease Control and Prevention, 2016). All parents who felt

this way had experience from their own childhood outside of the UK, where participation in similar programmes is not always predicated on parental consent, and so this view is not necessarily a UK cultural norm. It may be a reflection of parents' experience of less individually focused public services than those that have developed in the UK since the late 1970s.

The research shows that parents from different countries and cultures have similar paternalistic expectations of health professionals and school staff, *i.e.* that they work in the best interests of children. Parents believe that professionals who have more knowledge in specific areas (*e.g.* about FV) ought to provide their expert opinion for parents to consider before they make their decision. This can be seen in the articles by Dorell, Yankey and Strasser (2011), Hofman *et al.* (2013) and Gotvall *et al*. (2013), all three of which discuss the importance placed by parents on the opinions of professionals. Parents do not expect to have to consider the deeper, more complex decisions about whether a particular programme, product or vaccine is of benefit. Parents expect expert decisions like this to be made for them by professionals, before they are even asked whether they want their child to take part. Parents make a decision that is proximate to them and their needs based on the assumption that general risks and benefits have already been weighed up, with the balance in favour of benefit. The paper by Gotvall *et al.* (2013, p.265) included a comment that demonstrates how an individual decision is made based on the belief that what is being offered by public services is of benefit:

'*It has been discussed and investigated and they have finally decided that this is what people must do, so I feel that we must, in any case I trust that the recommendations are right*'.

When this theme is considered alongside the two previous ones, there appears to be a contradiction, *i.e*. between parents' desire to make the ultimate participation decision and their expectation of paternalism, but it is possible for these two potentially opposing demands to co-exist. A pluralistic approach was discussed in

Chapter 2 (Theory, Section 2.6) as a way to reconcile the two. Briefly, this advocates that parents' autonomy can, and ought to, be facilitated within a wider paternalistic environment that enables individual choice. This expectation of paternalism is not restricted to the UK or to particular sub-groups of parents. It spans the evidence in this thesis, and I posit that this view should be acknowledged and considered a parental norm by policy makers and professionals.

This normative parental view of health professionals rests on the belief that they will act in a way they understand to be in the best interests of children. This parental view aligns to the UNCRC discussed in the background to this thesis (Section 1.3.b), but it is at odds with the Millian practice of 'non-interference' that health professionals have adopted, discussed in Chapter 2 (Theory, Section 2.3.b). For example, Article 3 of the UNCRC states;

'*In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.'* (UN General Assembly, 1989)

This is understood to mean that all adults [therefore including health professionals] should act in the best interest of children. This acknowledges and legitimises parents' expectation of paternalism. Health professionals' practice of not providing advice that could be thought of as paternalistic is based on an interpretation of Mill's work. This advocates non-interference as a prerequisite of autonomy, and interference is viewed negatively as paternalism (Gray, 1991). The situation is complicated further because it is the children's best interest that ought to be prioritised if we accept the UNCRC, but it is non-interference in parental choice that is being practised by health professionals. Parental choice is being privileged over children's interests. Parents' views of what services do, and how they act, is different to the reality of how they are organised by health professionals. This means that parents' decisions are based on

assumed information that is incorrect, and therefore the notion that parents are making 'fully informed' decisions is flawed.

6.2.d Existing relationships within parents' social networks strongly influences their consent decisions

Across the research, all parents described drawing on, and navigating, a very wide range of resources, processes and structures, and this was equally the case for consenters and refusers, although not all parents accessed the same sort of resources. All parents, regardless of their consent decision, were influenced to a greater or lesser extent by informal information provided through their social networks, including from friends, family, teachers and the family doctor or dentist. This was a significant feature of the literature (Chapter 3, themes: 'information and knowledge' and 'social and community networks') and a rich theme in the empirical research (Findings, Theme 4, Section 5.4.d). It shows how parents actively subvert the formal expectation of what it is to make an autonomous choice, *i.e*. decisions made independently of influencing factors. The experience of family and friends provided most parents with reassurance to act on their preferred choice, thus acting as an enabler to their decision making.

In the existing literature and in the empirical research, parents consistently use their social networks as a source of information. Almost all parents feel the need to access additional information to that provided by health professionals, with supplementary information often being more experiential and less 'factual'. In this regard, the Kantian belief that rational decisions are made by people operating independently from their faculty of sensibility, *i.e.* their experience, is shown to be an idealised one and not a reality for parents (Section 2.2.c). The potency of the influence from family and friends on parents' decisions was demonstrated clearly by one parent I spoke to, who made their consent decision solely based on a brief conversation with their neighbour at the school gate. It is the common bond of parenthood and the existing level of trust felt in these established relationships that allow parents to short-cut many of the considerations they might otherwise have to navigate when making a

decision. This enabled swift and timely decisions, which is seen as an advantage in busy households. This type of short-cut was viewed positively by parents, particularly when the ways of living of others and their general choices reflected those of the deciding parents themselves.

Throughout the research, teachers are identified as having a strong influence on parents' decisions because of the position of trust they hold within families, *e.g*. in the paper by Cooper Robbins *et al*. (2010) this is articulated particularly strongly. But, in this situation the advice that teachers give regarding specific health or dental information may be no different from that of a lay person. This has the potential to put teachers in a difficult position, with actions being based on their advice as trusted authority figures but their advice is 'unauthorised'. Teachers do not have medical or dental training, but parents trust that they will know what to do. Parents both expect and accept paternalistic advice about their children from teachers. Moreover, parents are used to entrusting their children to the care of teachers on a daily basis and so their expectation of paternalism by teachers towards children is an extension of this existing relationship. In the research, teachers were seen as an everyday part of parents' social networks; they were embedded in family life.

The considerable role of parents' social networks was a recurring theme in both the literature (Social and Community networks, Section 3.4.a) and the empirical research (Theme 4, Section 5.3.d). This shows how individual parents' choices are influenced by trusted sources in their social environment. In this research, parents reported this experience only as a positive and as an enabler. It appears that they do not have the same level of concern that this will mean their decisions are not truly independent as supporters of the hybrid approach to decision making.

This demonstrates that parents are not acting a 'rational choosers' (Walter and Ross, 2014). For them, the views of those in their social network were as valued as any official 'factual' information and were included equally in their considerations, which by Kantian logic must make their choices 'irrational', that is if rational choices are

predicated on a 'cognitive deliberation of understanding independent of a person's sensibility' (Section 2.2.c). But, to accept and value the autonomy of individuals one must accept that this may include the choices of others, including those based on emotion and experience. These parents were not making irrational choices; they simply used a different type of information on which to base their decision, *i.e.* information that included sensibility. Parents made choices based on an array of information stemming from emotion, experience and the views of trusted others, as well as from facts provided by health professionals. In fact, these choices are more complex because of the need to consider competing information, all of which may have a different value weight. These choices are more than the balancing of objective information in a somewhat sterile and simplistic way.

One interesting point is that, by including research from different countries with different social norms, the literature review shows how the level of individualisation within a society influences parents to be more or less likely to seek additional information. The organisation of UK services by government has become more individually focused since the late 1970s (Section 2.6.c) and parents' information-seeking behaviour as seen from the research in North London aligns with this notion. This echoes the view of Code (1991), which was discussed in the theory chapter (Chapter 2), who argues that there has been '*a gradual alignment of autonomy with individualism*' (Section 2.3.d). Similar behaviour is found in the highly individualised culture of the USA and Canada (Vandenburg and Kulig, 2015; Hofman *et al.*, 2013), but less so among the more egalitarian behaviour of parents in Sweden, reported in the paper by Gottvall *et al*. (2013, p267), but this was an exception. For example:

'I think it's a social responsibility…not to participate…I think, is irresponsible to others.'

Generally, individualism has increased in the way that services are organised and delivered, and the arrangements under which people are required to exercise their

autonomy have followed suit. But, the evidence shows that this is not how parents choose to operate, or indeed do operate.

6.2.e Official dental information is not communicated in a way that parents find useful

Much of the research confirms that barriers were experienced by parent due to both the information content and the way in which it was communicated. Hofman *et al.* (2013) and Gotvall *et al.* (2013) state that parents favour face-to-face communication, while Dorrell *et al.* (2011) and Dempsey *et al.* (2009) report that parents did not feel the written material they received gave them sufficient information. This supports parents' preference for a more personalised approach found in the FV programme research. This is also buttressed by the research carried out by Glenny *et al.* (2013) into the uptake of epidemiological DPH programmes. In this paper, the more personalised approach to consent that is used in Scotland yields far greater uptake than the anonymous letter-based approach used in England for the same intervention. Throughout the research, parents expressed a desire to talk about their choices with a health professional before making a decision. For example, parents in the paper by Gotvall *et al.* (2013) requested a face-to-face meeting with the school nurse after finding the anonymous written information to be inadequate. As such, parents are rejecting the 'conduit and container' style of communication that underpins the 'arm's-length' way of communicating with parents that uses impersonal written information (Manson and O'Neill, 2007). This format is often used under the misunderstanding that detailed factual written information will make parents 'fully informed' and free from any potential bias that may be conveyed from other sources. But, it is simplistic to think that parents are empty vessels to be filled with objective information that they can intellectualise and then use rationally. Any information that parents receive is considered alongside their existing knowledge and experience, as already discussed. The 'conduit and container' approach to communication is another example of perfectionism, whereby professionals are

promoting their view of a 'good life,' *i.e.* one that is intellectualised and based on objective facts and not on emotion, experience or trust. It is assumed that this will lead to a 'good choice', *i.e.* one that is approved of from the health professional's perspective. Written information is, in fact, experienced as a barrier by the majority of parents.

Moreover, the neutrality of written health information does not carry the intended benefit because of the difference between the value bases of those providing and receiving it. This is not helped by the lack of human communication, for example many parents reported that they wanted decisively to be told dental or health professionals' view of the programme, *e.g*. '*this is good, everyone must do it'.* For parents, the neutral stance that professionals take conveys the impression that they do not fully support the programmes themselves. The objectiveness of the official information is viewed with suspicion by some, and this was evident in the paper by Vandenberg and Kulig (2015) and in several of the interactions I had with parents. It is face-to-face two-way communication with health professionals that enables parents to feel supported and more able to make a decision free from confusion and uncertainty. This was demonstrated by the number of parents who asked me questions in lieu of contact with a member of the dental team. This is summed up well by Atkins (2000, p.76) discussed in Chapter 2 (Theory) who believes that autonomy is not achieved by,

'…*offering more facts for the person to face* [but by] *allowing a place for the expression of a person's perspective on* [what] *they are being offered.'*

The objective factual information provided by health professionals comes from a source that is trusted by professionals, *i.e.* peer-reviewed scientific evidence conducted often in a positivist tradition. Parents want opinion-based information from a trusted source with whom they have a personal relationship. It is this juxtaposition of what is considered a trusted source that is credible and therefore of value that creates barriers for parents when what they want contrasts with what they receive. Throughout this research, parents have expected professionals to act in the

best interest of their children (*i.e.* paternalistically) by giving them their expert opinion and advice from their professional perspective. This includes providing parents with the 'right' information for them to make the final decision, but the 'right' information for health professionals (factual, objective and free from opinion) is not necessarily the 'right' information for parents (expert opinion-based guidance). This difference in perspective between professionals and parents has not been identified in the literature on consent for public health, and yet it is a thread that runs through several of the points raised in this discussion.

For some parents in the research, the gap in their knowledge came from their inability to read the information provided and they needed additional help to enable them to know what was being asked and to respond to the consent request. Parental decisions made under these circumstances are autonomously vulnerable if viewed from the perspective of the Kant-Millian hybrid. They are made based on another (lay) person's interpretation of the information, and so potentially undermine the unbiased decisions that health professionals strive for when providing information. Therefore, depending on how the information is conveyed, the hybrid notion of what is it to make an autonomous decision is diminished because the neutral information that this rest on has not been provided in a way that can be independently 'understood and assimilated', as stated by Lesser (1991) in Chapter 1.

For parents without access to translation, written information in English constitutes a structural barrier to their ability to communicate an active decision. These parents are unable to *act* autonomously, even if they have the desire to do so. Some dental literature (Appendix 3.1; Davies *et al.*, 2014; Monaghan, Jones and Morgan, 2011) regards non-response to be the fault of individual parents and not a result of the structure of the consent process. The structural barrier of information being available only in written English is a particularly pertinent one for the designers of the FV programme in North London given the diversity of the population, as outlined in the methodology (Section 4.4). This specific barrier was not mentioned in the literature,

but it could be applied to any programme that provides single-language information to a multilingual community.

Cultural considerations appear to have been largely overlooked in the implementation of all the programmes in this research. One paper, by Hofman *et al.* (2013), looks at parents' experiences of consent in relation to the HPV vaccine in a Turkish community (not living in the UK). Interestingly, and similarly to the Turkish population in North London, this community's members also seemed to operate differently from others, with information being rejected without consideration because it did not resonate with their community identity, *i.e.* that Turkish Muslim girls do not have sex outside of marriage, therefore the HPV vaccine was not necessary. This situation demonstrates that overlooking cultural self-identity and norms impacts how information is perceived by communities, creating barriers to parental decision making and response actions (Owens and Cribb, 2013).

The points raised so far in this section demonstrate a disjointed approach to communication, in which health professionals place great faith in the notion that information is the cornerstone of an 'informed consent' decision (Hope, Savulescu and Hendrick, 2008) but at the same time information is not made accessible to all members of society equally because of their varying needs.

6.2.f The current consent processes are problematic for parents

All programmes examined in the literature used an opt-in system of consent, which is the same as in the DPH programmes in the UK. The type of consent, *i.e.* opt-out (negative) or opt-in (positive), was not discussed in the literature reviewed in Chapter 3, but the empirical research shows a tension in parents' views, with trust being placed in public services to act in the best interests of their children but parents also wanting to be the decision maker who exercises their responsibility to protect their child. However, whether the system in place is opt-out or opt-in, parents are still asked to make a decision, so in fact their position as the decision maker has not changed. It is merely that an opt-in system *appears* to facilitate parents' decision

making, but this is an illusion. It is inaccurate to see opt-in consent as favourable on the grounds that it is autonomy promoting. It is not, or at least no more so than opt-out consent, in which parental choice is still privileged, it is the outcome for the child that changes and not the requirement for parents to make a decision.

In the process used for DPH programmes the opt-in system provides the impression of maximising parental choice, but parents do not have equality of opportunity as a result of language barriers for example, as mentioned in the previous section. Nor is there equity regarding who gets included and asked for their consent and who is denied this, *i.e.* parents who have previously consented are privileged over those who have not (previous consenters are asked to make the choice again prior to the second application, whereas those who refuse when first asked are excluded altogether from the second request and the subsequent FV application round). Owens and Cribb (2013) have claimed that offering people a choice but not supporting them to make it, as is the case here for some parents, falls short of what is considered morally important about promoting autonomy. Parents are expected to know how to act when faced with this decision. This assumption runs through the literature and the empirical work. Moreover, the systems of consent implemented as part of these programmes do nothing to promote autonomy through social justice (Buchanan, 2000), which is a key part of public health (Section 2.5.b).

Almost all parents in the FV research said that they needed to be asked for consent only once, and not twice a year as is the current practice. In general, the reason for this was practical, with parents expressing the need for simplicity in their busy lives. The busy nature of family life was also a strong feature in the literature (Chapter 3, Theme: professional input). A two-stage approach to consent may suit most consenting parents, with opt-in consent sought in the first instance followed by an opt-out system for the second application of the year, allowing those who have changed their mind to make this known, with the rest not required to take any action. This system was suggested on several occasions by parents. Interestingly, it mirrors

the two-stage process mentioned in Chapter 1 (Background) that O'Carolan (2006), the Acting Chief Dental Officer for Northern Ireland, suggested when considering the drop in response rate after the swap from opt-out to opt-in consent for epidemiological DPH programmes (this system has not been adopted). But, although this may help some busy families, it will not noticeably increase parent's autonomy. For example, if the letter-based process remained in place, this two-stage system would have no impact on parents' procedural autonomy and would represent only a minimal improvement in their substantive autonomy, and only then if they were consenters who had not changed their minds. These parents would not be required to *do* anything, but for all others the system would not have changed and any existing barriers would remain. Furthermore, parents do not understand what constitutes consent, with many disliking the letter-based system and preferring communication that is more immediate and less likely to be overlooked, but there is a belief that consent is legal only if a written signature is provided. If an opt-out system were to be implemented, this belief (if not addressed) could result in parents assuming incorrectly that their children would not be included. This is all the more likely for parents who either do not receive the letter from their child (reported by many in the research) or do not read English. Therefore, introducing a system of opt-out consent may introduce additional inequalities and barriers for parents.

Across the research, parents wanted flexibility in the decision-making process, *i.e*. the ability to refuse or consent as and when they wished. This was discussed in Chapter 5 (Findings, Section 5.3.g) with regard to FV programmes and it is particularly prominent in the paper by Dempsey *et al.* (2009), where parents indicated that they wanted to be able to change their mind as and when circumstances changed. This shows that implementation processes are not aligned to 'best practice' where consent is viewed a fluid and something that can and does change over time (Hope, Savulescu, and Hendrick, 2008). By not revisiting consent decisions as part of the FV programme, another inequality and barrier is created, only this time the inequality is between parents who initially consent and those who refuse or do not respond. Parents who

initially consent are rewarded with further opportunities to consider their position, but all other parents are denied this privilege, thus significantly limiting their autonomy.

6.3 Usefulness of typology of decision makers

The framework presented in Chapter 5 (Findings, Section 5.4) shows the four types of consent responder identified from this research. The intention of this is to consider what amendments to the design of DPH programme will reduce barriers for parents and facilitate responses. Identifying these responder types and disseminating the framework to the wider dental public health discipline may promote debate about the systems currently in place. Demonstrating the interplay between procedural and substantive autonomy regarding parental response challenges the current view that all non-responders are lazy or ignorant parents. Moreover, although the types that have been developed are not perfect, and information about 'active non-responders' is limited, this typology is intended to be useful when designing public health programmes. The architects of dental public health programmes, especially those with high non-response rates, may find this tool useful when considering what actions they can take in their area to increase the number of responses.

Improving a person's overall procedural autonomy in any sizable way is beyond the remit of dental public health programmes. However, the influence of self-identity, experience and emotion on a person's ability to make an authentic choice can, and should, be acknowledged by health professionals. Making improvements to substantive autonomy is perhaps more realistic, with changes to the programme design, *i.e.* the consent processes, being the most straightforward way for dental professionals to have an impact here. Consideration needs to be given to how structural elements of programme design can be either autonomy promoting or inhibiting with regard to a person's ability to act autonomously. For example, parents who fall into the weak responder and passive non-responder categories can be assisted through changes to the implementation of the programme, and specifically

the consent process, such as moving the point when parents are asked for their consent from mid-way through the child's school year to before the child starts school, when the request can be included in the usual discussion that school staff and parents have. This decision can then be confirmed or withdrawn later via a text message.

Parents who fall into the strong responder quadrant are enabled parents already and although improvements like this may benefit them by making the process easier their response profile will be unlikely to change a great deal. Parents who fall into the active non-responders quadrant are more difficult, not least because the empirical research has failed to produce information on these parents. The information in this quadrant is based solely on minimal information from the literature. However, as with the strong responders, improvement to the process may increase the likelihood of some of these parents responding, *e.g.* if the information content and the dissemination methods are culturally sensitive, but it is anticipated that this will not make a big change to the response profile. To date we do not know the proportion of parents who actively choose not to respond, so this is difficult to predict at this stage. It should also be acknowledged that an active non-response is a decision, and to respect autonomy is to respect all decisions. The purpose of this typology is to help in the consideration of why people who would want to respond do not, so that structural changes can be made to improve their ability to act autonomously. It is not intended to be used to force parents to act in a way that is not authentic to them or to stigmatise them because they do not choose to act as others may wish them to.

6.4 Implications for theory and practice

In this section I consider the implication of the findings from this thesis for ethical theory and consent practice.

6.4.a Implications for the ethical theory of autonomous consent

This thesis challenges the Kantian notion of rational decision making. This is an idealised view of how decisions are made that bears little resemblance to how they are actually made. It is an intellectualised and, I believe, oversimplified view of how humans operate. Nevertheless, it is an idea that has been adopted by those in positions of power as the way in which decisions ought to be made, with factual deliberation followed by action on the part of the individual being at the heart of many health care and public health policies. This has contributed to, and benefitted from, the growing emphasis placed on individualisation in UK society.

I suggest that the sovereignty of the individual is, in part, an illusion. This is based on evidence from this thesis of the embedded nature of parents' decision making within social networks and their use of these to overcome barriers when considering their consent decisions. I believe that Kant's idea of rationality is outdated and should be abandoned as a credible ethical theory to underpin ideas of decision making, and evidence from this thesis support this view. In addition to this is the selective and abridged view of Mill's work (Mill, 1859), that has infused notions of health-related consent since the middle of the 20th century (Section 1.4.b). Non-interference and neutrality on the part of health professionals is laudable, particularly when considered in the context of consent evolution that started with an international desire to avoid a repetition of the sort of practices that took place in Nazi Germany (United States Government, 1949) but, this stance should not be adopted to the detriment of providing support and guidance for parents, which they ought to be able to reasonably expect from health professionals.

Adherence to the Kant-Millian hybrid constrains what support health professional are able to provide and expects too much from choosers (in this case parents). In place of this hybrid, a more pluralistic and enabling concept ought to include the twin notions of paternalism and autonomy. These two notions can be seen in the idea of relational autonomy first discussed in Chapter 2 (Theory, Section 2.5) of this thesis. I suggest that this theory not only describes more realistically how decisions are made based

on an individual's circumstance but it also provides cues to action to help planners of consent processes facilitate and enable authentic decisions via substantive means. My reasons for this are based on the research conducted for this thesis. Throughout the history described in Chapter 2 (Theory, Section 2.6), from the review of the existing literature in Chapter 3 (Section 3.4.a), and most notably from the empirical work in Chapter 4 (Methodology) and Chapter 5 (Findings), evidence has been presented that supports individuals as autonomous choosers, but many people are able to act autonomously only when the environmental structures that anchor their lives permit it. For example, for some being able to 'choose' to visit a qualified dentist was made possible only after the inception of the NHS, which meant that ability to pay was no longer a barrier to an individual's chosen action. Equally, evidence from the parents who took part in the interviews and focus groups I conducted described many situations in which ability to choose was undermined by their difficulty in navigating the consent process. For example, parents reported that the only way they were able to understand the information sent to them and to communicate a response to the dental team was if another person read the leaflet for them. These parents were able to make an autonomous authentic choice about their child's participation but they are only able to act on this if the structural barrier of English-only information was overcome. This research strengthens the notion that relational autonomy better reflects the reality of decision making as experienced by parents. However, despite this, it should be acknowledged that the concept of relational autonomy still assumes that parents want to be autonomous, even though the evidence in this research does not always suggest this.

Overarching supportive structures that acknowledge social and environmental barriers are needed to assist parents to make and to communicate their decisions. Parents are not 'independent rational choosers' and so we should stop approaching the concept of decision making, specifically for consent, as if this were the case. Parents seek out paternalistic advice from those less bound by codes of conduct written for health professionals that are based on notions of non-interference as the

ideal. Paternalism, to some extent, is expected by parents and perhaps it is time, therefore, to look again at what this ethical concept has to offer to public health instead of defaulting to individual autonomy as an example of 'good practice' (O'Neill, 2002; NHS Executive, 2001). Public health interventions have traditionally been utilitarian and a utilitarian approach to improving people's health has always been viewed by some as paternalistic (Dawson, 2011; Gillon, 2003). But, more and more, as outlined in the background and theory chapters earlier (Sections 1.3 and 2.3), there has been a shift from a population-wide approach in public health to one that favours individualism and personal responsibility (Exworthy *et al.,* 2012). However, when looked at more closely, there is evidence to say that when utilitarian programmes, projects or laws are implemented the initial claims of paternalism or the 'nanny state' subside, indicating that perhaps people are not always as opposed to this approach as first appears. A rare recent example is the ban on smoking in public places contained in the Health Act 2006 (Great Britain, 2006), which took a considerable amount of time against strong opposition to be introduced, but once it had been in operation for a relatively short while it became an accepted intervention and one that has had a significantly positive impact on rates of smoking. It is now supported by the majority of smokers as well as non-smokers (ASH, 2017; British Heart Foundation, ND). Up to the introduction of the ban, anti-smoking information was made available to smokers but it was up to individuals to choose to seek out help if they wanted to quit. The ban is an example of a pluralistic approach that includes both paternalism and autonomy. Smokers are still able to exercise their autonomy to choose to smoke, but this is buttressed by paternalistic parameters of where this can take place, *i.e.* not in enclosed spaces.

The notion of autonomy should not be rejected altogether, but a relational approach that encompasses *both* paternalistic and autonomy-promoting means should be adopted when planning consent processes for DPH programmes. By adopting a relational approach to consent the social and environmental influences on a person's decision making are acknowledged, with substantive autonomy and individual

freedom equally valued through procedural autonomy. For these reasons, this more sophisticated way of conceptualising and promoting 'self-rule' ought to become the dominant way to facilitate autonomy via consent decision making, rather than through the provision of objective facts and non-interference. The often-opposing notions of paternalism and autonomy can be married under this one universal idea, in which substantive and procedural autonomy co-exist and thrive through the link between people and their environment, in a way that the hybrid notion does not acknowledge. I submit that we cease to unquestionably use the Kant-Millian hybrid when discussing public health ethics and move away from trying to bend it into awkward and unworkable frameworks, such as the stewardship model from the Nuffield Council on Bioethics (2007), which perpetuate this flawed concept. Some bioethicists and others from the political and health arenas may find this suggestion difficult in two very particular ways. Firstly, relinquishing what has gone before in favour of a new way of thinking about and promoting autonomy will mean giving up what we thought we knew about decision making, and this can be an uncomfortable process. Equally, ceasing to believe that people make decisions separately from the influence of their environment will mean that foolish choices can no longer be entirely the 'fault' of the individual but rather shaped to some extent by an environment that is beyond their control. This challenges the current thinking of some in health politics and policy that prioritise individual responsibility.

6.4.b Implications for consent practice

The use of a consent system that has been 'borrowed' from clinical practice, and which itself was developed for use in research, is inappropriate and damaging for public health. The drop in participation in DPH programme is directly linked to the implementation of consent guidelines developed for an acute setting (Monaghan and Morgan, 2010) (Section 1.4.b). When the previous Chief Dental Officer issued the instruction for dental teams to adopt these guidelines, little consideration was given to how they may or may not work in a public health setting (Coundley, 2015; NHS

Executive, 2001). The result is that non-responders are being branded either 'lazy' or 'deliberately trying to hide dental caries' by some in the dental profession (Davies *et al*., 2011; Monaghan, Jones and Morgan, 2011), mirroring the Victorian views about health and individual ignorance (Section 2.6). Moreover, the evidence for FV programmes as a dental public health intervention is being questioned because of the large number of non-responders, which has the potential to lead to the decommissioning of current programmes (Kubiangha, 2015; Hardman *et al.*, 2007).

Exploring and examining parents' experiences of navigating this system has confirmed that individual consent decision making is anything but individual. Parents across the research repeatedly explained how they actively involved others in their deliberations and how the actual process of understanding what was being asked and communicating their response was subject to social and environment influences. Parents' autonomy and their ability to act autonomously are not facilitated by the Kant-Millian hybrid model. Indeed, for many, the arm's-length approach adopted by DPH teams impoverishes parents' ability to make and to communicate an authentic choice. Parents do not want to make decisions without guidance or personal input from health professionals. This creates a void that some parents seek to fill by other means, while some make no decision at all. Parents are willing to take advice from dental professionals about what is in the best interest of their children's oral health. Health professionals and their codes of conduct need to acknowledge this and consider it when planning DPH programmes. This research has demonstrated the key role that schools play, not only in family life but also in the delivery of DPH programmes. It would appear that this important role has been further enlarged, perhaps in some cases beyond the bounds of what is appropriate (given that school staff have no dental training), due to the 'hands-off' style of this programme that leaves parents wanting. This situation was also evident in much of the literature about HPV programmes, and particularly in the paper by Cooper-Robbins *et al* (2010). Health professionals using current practices cannot be sure that the responses they receive from parents are their considered authentic choices, particularly if those

choices are based on translated information. Lack of cultural relevance and language barriers mean that whole groups of parents do not even know there is a choice to be made, which automatically excludes their children. Others choose in the same way to friends and neighbours because of convenience or because of the personal connection that is missing from the current remote and abstract request process.

Moreover, the consent that this programme rests on is questionable from a legal perspective and may not be valid. This is something that planners will need to consider very carefully for all current and future programmes. Using this system means that clinicians are not in a position to know who is providing the signature, *i.e.* whether it the person who has legal parental responsibility for the child or another person in the household who has indirectly assumed this, for example, an older sibling, because they are the ones in the family who understand the information (GOV.UK, 2016). It is assumed that the signature is from a parent with legal responsibility. This is not part of normal practice for public health programmes aimed at populations, but 'normal' public health practice is often delivered on more strongly utilitarian grounds, *e.g.* mandatory inclusion with individual consent not required. This programme, however, has borrowed an individualistic approach to consent and applied it at a population level, therefore crossing the border of what is clinical practice and public health (Section 1.2.a). In addition, some parents are providing their consent based solely on the opinions and translations of their older children, friends or partners because information is not provided in a way they can understand and use, and therefore their 'right to information' is not being met (Section 1.4.d). Moreover, the information that parents do receive does not meet the requirement to outline risks, benefits and potential alternatives, which means that their consent is, by this measure, invalid (Lynch, 2011). To correct this would necessitate an overly long information sheet that would likely be confusing under the current system in which there is almost no opportunity for parents to ask questions. If the need for individual consent is retained, the programme ought to build in face-to-face opportunities for conversations covering these topics. Furthermore, although it is not

'illegal' to deny active or passive refusers the opportunity to change their mind and consent to their child's participation, this has not been tested in the courts. The NHS cannot deny a person services without good reason, and access for all is the first principle of the NHS constitution (Department of Health, 2015). It is possible that someone may decide to contest their right to change their mind from refuse to consent. So, although consent for DPH programmes was changed from opt-out to opt-in to promote individual autonomy, seemingly to avoid potential legal challenges of assault or battery, programmes could still be open to challenge because a process designed for clinical settings is not being fully implemented in a public health arena.

Ultimately, the barriers created by the current Kant-Millian practice and letter-based system have resulted in some schools having a high proportion of non-responders (Table 4.1). These parents are not actively deciding that they do not want their children to participate; they are not indicating any decision at all. This demonstrates that the current approach to consent that was intended to promote autonomy has not done so. However, this research has been unable to capture the views and experiences of non-responders in detail; no one who actively chose not to respond participated and only minimal information was gleaned from the literature, therefore their experience remains a gap in our current knowledge.

Some parents are able to exercise their desire to protect their children in whichever way they choose, *i.e.* to refuse or consent, but a larger number are not in this position simply because the current implementation practices make this too difficult. Consent systems for DPH, and in particular for FV programmes, should be based on the public health goal of reducing inequalities (World Health Organization, 2019). Indeed, this was a key element of the most recent edition of 'Delivering Better Oral Health' published by Public Health England, which states that everyone should have *'…equity of access to improved preventive advice and care'* (2017, p1). This will mean that dental professionals will need to acknowledge environmental influences on parents' decision making and consider how best to work with schools, as well as paying greater

attention to parents' priorities, such as delivering oral as well as written information, sending reminders and using different languages.

The dental literature included in appendix 3.1 explores how many parents respond to consent requests for school based DPH programmes. The results presented in these papers are often stratified into different socio-economic groups. Information from these studies demonstrate that families on lower incomes are much less likely to respond to a consent request (Jeavons, 2012). When this is considered alongside the information from Chapters 3 and 4 (points 3.1.a Summary of literature about consent for dental public health programmes in the UK, and 4.4.b Sample population), where the link between low income and poor oral health in children is discussed, it is highly probable that the number of non-responses to consent requests for the FV programme will be greater for children in more dental need. It appears that the policy of individual letter-based 'opt-in' consent is further disadvantaging children who are already disadvantaged and as such oral health inequalities will rise (Wright, 2019).

The primary role of the school fluoride varnish programme is to improve children's oral health by redressing the existing injustice of dental inequalities. The findings (Chapter 5) from this research and the dental literature summarised earlier (Chapter3, point 3.1.a and shown in the appendix 3.1) demonstrate that individual 'opt-in' consent does not help to fulfil this goal, and it fails on two counts. The first is a failure to enable all parents' fundamental liberty to act autonomously. For example, parents who experienced difficulties understanding the information they were sent because of poor English language skills or low levels of literacy were often not able to understand what they were being asked, or to communicate their choice. Functionally this means that only those who have existing skills and knowledge and who can read, understand and respond without additional help can exercise their liberty to make an autonomous choice. Low levels of language skills and literacy are linked to poverty therefore the design of this letter-based consent request is in fact perpetuating the existing disadvantage that children and families face (Gilbert *et al*., 2018). Children of

parents not able to read, understand and, respond will be automatically excluded from this preventive programme. Parents more able to engage with the existing consent process are more likely to benefit from the programme demonstrated through the inverse care law (Hart, 1971).

The second failure is that any programmes designed to mitigate socio-economic inequalities should be arranged to give the greatest possible benefit to the worst off whilst providing fair and equal opportunities (Kukathas and Pettit, 2007). The arm's length approach to explaining the programme and asking for consent does not do this. Individual schools are targeted based on epidemiological data of dental need but, the programme itself, including the consent process, makes no allowance for parents with different levels of need to fully engage. One method of requesting consent is used (a letter) and if parents fail to respond to this, for whatever reason, they will not be asked again in that academic year. The result is that children from these families are excluded. For the programme to be of 'greatest possible benefit to the worst off', a more tailored approach is needed with information provided in different languages using different formats (oral and written), and with more guidance from dental professionals to help parents understand the importance of making a choice. Interestingly, the previous system of 'opt-out' negative consent would benefit the worst off from a dental perspective. Under this system participation is prioritised over consent responses and disadvantaged children with most dental need are more likely to benefit from inclusion by default.

6.4.c Opt-in versus opt-out consent

I do not recommend that we return to a system of opt-out consent. Simply reverting to the opt-out system used in DPH programmes prior to 2006 would not eliminate the need for parents to make a decision and so the barriers to decision making that parents face would remain (Department of Health, 2006). If an opt-out system were implemented, it would likely increase the number of children included in the programme, and from a dental perspective this has merit but, if parental autonomy

is valued, parents should be enabled to choose whether their children are included and not given this 'illusionary choice' to opt out, when children are included by default simply because the barriers are too great for parents to object (Dixon-Woods *et al.*, 2006).

Two options can be considered here; the first is simply to make the inclusion of all children mandatory. This would be a strongly utilitarian move and in line with traditional public health values. It is paternalistic in the extreme with little regard for individual autonomy. It would meet the UNCRC's ethos of putting the best interests of the children first from a dental perspective, which in this case are defined by clinical need. However, based on the parents who participated in this research, the majority of parents would feel strongly against this move. All parents saw themselves as their child's protector and they enacted this role through their decisions. Admittedly some parents were happy with mandatory inclusion, but the majority were not. There is evidence from previously unpopular utilitarian public health interventions that once established they have ceased to be controversial for the majority of the public. For example, 40% of smokers were in support of the ban on smoking in public places prior to its introduction, whereas in 2017 (10 years after the ban came into force) this had risen to 55% (ASH, 2017). The compulsory participation of children in the FV programme would not be easy to mandate because it would require a change in the law that requires consent from individuals (or parents in this instance) prior to any treatment so that it is not possible to make a claim of battery against dental care professionals who have physical contact with children as part of a dental public health programme (Great Britain, 1988). This would be difficult to achieve in the current social and political climate of the UK, which is increasingly individual. As such, while it may be desirable from a utilitarian dental perspective, it is not perhaps a realistic option.

The second option for consideration is more realistic. This is for parents to continue to be asked for their individual consent but with substantial changes made to the

implementation of this process that would enable parents to make and communicate authentic choices. Parents should be asked for their consent at the pre-school meeting that already takes place before children start school. This will enable the face-to-face delivery of information that parents want, along with the opportunity for them have any questions answered. Subsequent to this, before each FV application parents ought to be asked to confirm or change their consent decision via a text message. This can be sent prior to each application to all parents regardless of their previous response. If parents want to change their consent decision this can be followed up in writing and all information (verbal and written) should be made available in the dominant languages of each targeted geographic area. This system will eliminate many of the barriers expressed by parents. It is facilitative of parental autonomy at procedural and structural levels, making it pluralistic. Moreover, it will also ensure that NHS organisations and dental professionals are operating within the current legal framework. In the literature discussed in Chapter 3, HPV implementation schemes that involved one-to-one dialogue between parents and practitioners achieved higher uptake than those implemented in a similar way to FV programmes in England, *i.e.* via impersonal written information sent home with the child for the parent to read, sign and return.

Individual decisions require individualised support; mandatory participation with no need for a decision requires no decisional support. If mandatory inclusion is not a realistic option for the FV programmes and individual consent continues to be a requirement, an individual approach to receiving a response from parents is needed and more must be done to facilitate this. It is the juxtaposition of the current requirement for individual consent and its being operationalised to a population without any individual support systems that has caused a problem.

6.5 Recommendations for practice

The recommendations below are specifically aimed at improving the understanding of dental professionals with regard to consent for dental public health programmes

and at developing a process that will enhance the current consent practice used for these programmes in a way that improves parents' ability to make and communicate a consent decision. It should be noted that these recommendations have assumed, because of the information above and because they are intended to be practical in the current situation, that individual consent is a requirement. As such, they retain an element of Millian liberalism in that they promote and prioritise individual autonomy, but the modern narrow interpretation of this that espouses non-interference is rejected (Mill, 1859). Instead, there is an understanding of Millian liberalism that is broader and more akin to the work of Onora O'Neill (2002), with 'interference' in the form of advice and guidance being permissible. These recommendations acknowledge the experienced reality of family life but also the principle of the UNCRC that puts the best interests of the child before an idealised notion of how consent should be requested by professionals and considered by parents.

These recommendations have been divided into two levels of action: national and local.

National recommendations are intended to improve the understanding of dental professionals with regard to consent for DPH programmes and the dental culture within which they operate. It is the (mis)understanding of how decisions are made and the use of flawed processes that are based on this that have led to the situation in which parents face barriers that make it potentially more difficult for them to respond. If this understanding can be re-orientated to a more relational idea of autonomy and decision making and the practical consent process amended to reflect this, parents will receive the support they are seeking and be in a stronger position to provide a response.

Local recommendations are intended to improve the operationalisation and implementation of consent processes for DPH programmes within England by local councils and Primary Care Salaried Dental Services (known as community dental

services). The purpose of these activities is to facilitate parents to make a decision and communicate a response, including when they change their mind.

Recommendations are shown in Table 6.1 below. Each recommendation is discussed underneath the table. Another point to note before the recommendations below are considered is that these are suggestions for practical improvements to the FV programme and consent process. However, before these can be taken forward, additional background work will be required. For example, it would be useful to conduct an economic evaluation of the programme including a prediction of increased participation from the suggested recommendations (Smith, 1968). Similar programmes in Scotland that include FV use a more personalised approach and have published positive outcomes (Wright *et al.*, 2015). Whereas the evidence from England (where the blanket letter-based system is used) concludes that implementation of FV programmes cannot be supported due to poor levels of participation (Hardman *et al.*, 2007). But, the positive outcomes from Scotland are not specific to FV alone. They form part of a wider DPH campaign. An economic evaluation of just the FV programme implemented in the way suggested below would provide a more detailed information on which to base any decisions. As part of this evaluation, the potential for increased participation leading to a potential reduction in caries (estimated by Marinho *et al* (2014) as between 30-46%) and the associated treatment cost to the NHS needs to be balanced against the additional costs, for example, employing more trained personnel to deliver the recommended personalised approach. An economic evaluation would provide this information to commissioners and programme designers before any of the suggested changes are made.

Recommendations for further subject specific research are also included.

Table 6.1 National and local recommendations

National recommendations		**How they could be operationalised**	
1	Develop professional norms, rules and responsibilities for dental professionals that acknowledge and include consent processes suitable for dental public health programmes that are separate from those used for surgery-based one-to-one dental care	a	Amendments to the General Dental Council's code of conduct
		b	Amend the General Dental Council's 'continued professional development' to include mandatory training on consent
		c	New Department of Health guidance to be developed on how to implement DPH consent processes in a public health setting
Local recommendations		**How they could be operationalised**	
2	PCSDS and local authorities to work in partnership to commission the design, development and dissemination of public information campaigns to promote fluoride varnish treatment for young children	a	Oral Health Promotion staff to deliver face-to-face information sessions in all schools at various times, *e.g.* during and after school hours, and to have oral translation if necessary
		b	Engage 'parent community champions' to informally promote parental decisions and responses among their social groups
		c	Parent information to be provided in dominant languages of the targeted area, *i.e.* the borough
		d	Parent information to include school logos
3	Mandatory inclusion of schools in the design and delivery of local DPH programmes	a	Consent for the FV programme to be included in the pre-school visit made to parents (initial consent request)
		b	Oral health consent training session for school staff involved in pre-school visits to families
4	All parents, regardless of previous decision and response profile, sent consent decision confirmation by text message prior to each FV application	a	Text alert system used to automatically contact parents to confirm their consent prior to all applications, after the initial one
		b	Inclusion of one follow-up phone call for parents who do not respond to the confirmation text

6.5.a National recommendations

These recommendations and the specific actions I have outlined to operationalise them are intended to improve the landscape that dental professionals are required to operate within.

Recommendation 1: Develop rules, professional norms and responsibilities for dental professionals that acknowledge and include consent processes suitable for dental public health programmes that are separate from those used for surgery-based one-to-one dental interventions.

To implement this recommendation, there are three distinct actions:

a. *Amend the General Dental Council's code of conduct*. This was extended in 2005 from applying just to dentists to encompassing all dental care professionals, *e.g*. dental nurses. Since then, the 'code of conduct' has been revised and is now called 'Standards for the Dental Team' (2013). Principle three of this document, 'obtain valid consent', is specifically related to what a dental professional must and should do with regard to consent when treating patients. The document makes the distinction between 'must', which it states is a duty for the dental professional, and 'should', which it stipulates is a guideline, or where a duty usually signified by 'must' may not apply in all situations. The responsibilities in this document meet the legal requirements related to consent when treating patients. However, a number of its points that are written with 'must', *i.e*. they are the duty of the dental professional, but I anticipate they will be extremely difficult to adhere to when delivering FV as part of a dental public health programme. For example, the document states that dental professionals must *'obtain valid consent before starting treatment, explaining all the relevant options and the possible costs'* (GDC, 2013, p.6) but, as discussed above in Section 6.4.b, the validity of consent provided by parents is not questioned by dental professionals under the current system. It is difficult to see how this would be possible when treating hundreds of children as part of this programme. This is just one of the consent-related duties stipulated in this document that are intended for individual

clinical care and do not easily translate to population-wide dental public health. As such, dental professionals carrying out FV programmes are technically in breach of the professional standards required for their registration and continued legal practice. Amendment should be included in the Standards (GDC, 2013) document, specifically that all 'must' stipulated duties are revisited and consideration given to their appropriateness for use in dental public health, along with whether some of them ought to be changed to 'should' to allow for some flexibility when implementing for dental public health. An explanatory note will also need to be included to provide examples of when 'should' ought to become 'must'.

b. *Amend the General Dental Council's 'continued professional development' (CPD) to include mandatory training on consent.* The General Dental Council updated its requirements for dental professionals to undertake regular CPD in 2017 and introduced the new arrangements from 2018. There is no requirement for dental professionals to update and extend their knowledge in specific areas of practice. However, the GDC does 'encourage' four areas of development and provides 'examples of CPD content' in these areas. For example, area of development A is '*Effective communication with patients, the dental team and others across dentistry, including when obtaining consent, dealing with complaints, and raising concerns when patients are at risk'* and one of the five examples of this that is provided is based on 'consent' (GDC, 2017, p.2). However, no other details are provided to help or guide dental professionals. The GDC could stipulate that a small proportion of the time that dental professionals are required to spend undertaking CPD in each of their five-year cycles should be used to keep up to date with legal, ethical and practical issues related to consent. When the 'enhanced CPD' was introduced in 2018, the GDC removed the requirements for dental professionals to undertake mandatory subjects and instead stated that they should undertake learning opportunities that meet the needs of their role (GDC, 2017). All working dental professionals will need to have knowledge of, and understand, the up-to-date legal and ethical requirements of consent, and even those who are desk-based are likely to be in positions where they are designing

services and interventions, *e.g.* work at Public Health England. I recommend that the GDC stipulate that 5% of each dental professional's CPD time requirements are spent on this area of practice. This could be as little as two and a half hours for dental nurses, who are required to spend 50 hours of their time on verifiable CPD in a five-year cycle, or as many as seven and a half hours for dentists, who must complete 150 hours. As part of this recommendation, the inclusion of a requirement for part of this time to be spent learning about the consent needs and processes for dental public health programmes and how these differ from what is possible in individual clinical care. Without the specific content being mandated by the GDC, there is a risk that CPD related to consent will focus on individual patients in a surgery setting and ignore the requirements and complexities of community-based dental public health. Furthermore, if this is not included, there is a risk that outdated notions of consent and how people make decisions will continue, meaning that the current operational problems are more likely to continue too.

c. *New Department of Health guidance to be developed on how to implement DPH consent processes*. Currently, there are no specific guidelines for dental public health professionals about how they should implement consent processes at a population level. The only information available is the directive given by the Chief Dental Officer in 2006, which was discussed in Chapter 1 (Section 1.4.c) (Department of Health, 2006). This stated that positive opt-in consent must be obtained for children to participate in dental public health programmes. No further guidance about how this directive should be operationalised has been made available to dental teams. Developing clear guidance about how processes should be set up will help to unify the processes used by current programmes in England, therefore establishing a norm in an area of dentistry that at the moment has no set operating standards or guidance. Furthermore, it will help to establish that the needs and operations of dental public health programmes are different from those of individualised clinical care.

6.5.b Local recommendations

There are three recommendations that can be implemented at a local level, *e.g.* within the boundaries of each local authority. Each has a minimum of three specific actions to operationalise it. These recommendations and actions are intended to be practical, and they are based on the information provided by parents for this research. Each has been linked to a theme so that the reader can identify the basis for each action.

Recommendation 2: PCSDS and local authorities to work in partnership to commission the design, development and dissemination of public information campaigns to promote fluoride varnish treatment for young children

To implement this recommendation, there are four distinct actions:

a. *Oral Health Promotion staff to deliver face-to-face information sessions in all schools at various times, e.g. during and after school hours, and to have oral translation if necessary* (this action relates to theme five in Section 5.3.e). Parents in this research repeatedly indicated that they preferred oral face-to-face communication to receiving a written information leaflet. In part, this was due to the oral tradition that exists in some ethnic groups and cultures, *e.g.* Turkish. Parents also wanted the opportunity to ask questions at the time they received the information. In addition, all parents, whether native English speakers or not, commented that any information provided to parents should be translated to minimise language barriers. It is anticipated that this will also help to overcome the perception by some ethnic minority groups that the information is not intended for then unless it is translated.
b. *Engage 'parent community champions' to informally promote parental decisions and responses among their social groups* (this action relates to theme 2, Section 5.3.b and theme 4, Section 5.3.d).

   In the findings from this research, all parents expressed how important their social networks were when making a decision and responding or not to the consent request. This action uses the existing social structures and contacts that parents have to

support decision making and promotes the need to respond to the consent request. Using this kind of 'insider' contact will mean that parents will be supported by others 'like them' from their own community. It is anticipated that this will increase the relevance of the FV programme to parents' own lives and their children's health.

c. *Parent information provided in dominant languages of the targeted area, i.e. the borough* (this action relates to theme 5, Section 5.3.e). Parents who do not read English are currently reliant on the assistance of friends, partners and sometimes their children to read and translate the information and the consent request. This situation raises questions related to the validity of who is making and communicating the decisions and whether they are fully informed. Moreover, some parents do not know that a decision is required because they cannot read the information. Providing information in relevant languages will remove this barrier for parents and increase the visibility of the programme's relevance to others.

d. *Parent information to include school logos* (this action relates to theme 3, Section 5.3.c). The findings show that parents often throw away the information about FV, or at least do not recognise it as important because of the lack of a school logo. Parents reported that this was important to them and indicated that, whatever the content, if information had the school logo they would know that no harm would be done to their child. Parents reported trusting the school to only do good for their child and, by extension, a consent request with a school logo carries more value when a parent is considering whether this is a decision they should prioritise and respond to.

Recommendation 3: Mandatory inclusion of schools in the design and delivery of local DPH programmes. This recommendation is based on the findings of theme one and theme three, as well as the literature reviewed in Chapter 3. The role of schools, and in particular teachers, also featured strongly in other themes, *e.g*. as part of parents' social network (theme three). Themes one and three were developed from data that showed that parents expected and wanted public services such as schools to play a part in the care of their children, specifically through enabling parents to

carry out their role as their children's protector. However, until now schools have not been consulted on the overall design or the delivery methods of DPH programmes.

To implement this recommendation, there are two distinct actions:

a. *Consent for the FV programme to be included in the pre-school visit made to parents (initial consent request).* Implementing this action, with a short discussion about the FV programme and a request for parental consent taking place as part of the existing pre-school routine when school staff meet with parents, will help to eliminate several of the barriers highlighted. Moreover, it will increase convenience for parents; almost all parents commented on this and, in particular, on the busy-ness of family life. Specifically, parents universally preferred face-to-face meetings over receiving written information alone. This will eliminate problems associated with using children as the messengers of information and consent responses, *e.g.* information being 'lost' in children's book bags or parents forgetting to return the response slip until after the application date has passed. In addition, parents indicated that information that came from the school was deemed more relevant than information from the NHS alone. Parents expect schools to work in the best interests of their children. Including DPH information and a consent request with this visit will emphasise the school's involvement in the programme. Schools' implementation of this action will mean that parents are more likely to make an active decision and respond to the request.
b. *Oral health consent training session for school staff involved in pre-school visits to families.* This action is very closely linked to the one above. If school staff do include FV information and a consent request in their pre-school visits they will need to be equipped to answer parents' questions. Parents indicated that they wanted the opportunity to ask questions about their child and this would give them a specified opportunity to do that with a trained member of the FV delivery team. Parents repeatedly talked about how they asked the teachers or school staff for advice and guidance, but at the moment school staff are not given any additional training or

information that would help them to answer parents' questions. This leaves school staff vulnerable and parents without the information they are looking for.

Recommendation 4: *All parents, regardless of previous decision and response profile, should be sent consent decision confirmation by text message prior to each FV application.* This recommendation has been developed from data used in theme six, specifically around flexible decision making. Regardless of how they responded, parents indicated that they wanted this, but it is not possible under the current system for those parents who refuse or do not respond. Some parents also indicated that the lack of follow-up to consent requests meant that on occasion, despite good intentions, they forgot to return their response slip, and for other parents this indicated a lack of importance given to their involvement and to the programme itself.

To implement this recommendation, there are two distinct actions:

a. *Text alert system used to automatically contact parents to confirm their consent prior to all applications, after the initial one*. This action is intended to enable all parents, regardless of their initial consent decision (made at the pre-school meeting with school staff as indicated above), to reconsider their choice and confirm or change their response. Most parents indicated that they would be happy to confirm their consent decision using a text message, and this method was favoured over email or letters. This enables flexible decision making for all parents, not just those who have initially consented, as at present. In addition, the use of text messages is easy for most parents and it is regularly used by schools to communicate with parents.

b. *Inclusion of one follow-up phone call for parents who do not respond to the confirmation text.* This action is intended to convey the importance of responding to confirm or change consent responses, as well as to increase response rates from parents who have forgotten to respond, which is something parents reported did happen. In addition, it provides one more opportunity for parents to discuss their

child's participation, if they are considering changing their mind but would like to talk about the implications of this. At the moment, the same information leaflets are re-sent only to parents who have previously responded. This excludes refusers and non-responders and does not provide any additional information over and above what the parents have already, nor is this information personalised to their child or their situation.

6.5.c Recommendation for further research

I have identified one area of applied research that will be of practical use to commissioners and planners of FV programmes, and three areas in which further research will help to improve knowledge related to parental consent for (dental) public health interventions in general. These are:

a. There is a need to carry out a full economic evaluation of the programme and local recommendations above (point 6.5.b) prior to any changes being made. This requires detailed economic research that will involve statistical predictions of the potential increase in participation and hence the percentage of parents who will provide consent. This will enable an estimation of the total caries reduction as a result of changes to the consent system. Any estimations made will need to be based on current evidence from the systematic review that states FV application provides 30-46% reduction in caries (Marinho, *et al*., 2014). This improvement can be monetised to show potential saving to the NHS in treating caries, and although this is not the only way to measure the economic benefits, it does provide a simple way to compare this against the predicted costs of implementing the local recommendations outlined *e.g.* employing additional staff to speak with parents and commissioning a text messaging system. By carrying out this evaluation many of the areas of uncertainty about the 'value' of the programme can be addressed (Chapter 3, point 3.1.a).
b. Specific qualitative research that targets parents who are 'active non-responders' would help to find out their motivations for choosing this option, which may or may

not be different from those of parents who actively refuse. It would also help planners of DPH or similar programmes to estimate the proportion of parents who actively choose not to respond.

c. Given the key role that schools play in this process, research with school staff would be helpful to explore their experiences of both helping parents with their decision and implementing DPH programmes in their working environment. This will help planners of DPH programmes, which will be a particularly useful starting point if the local recommendations stated above are acted upon.

d. I have presented evidence that shows that children are influencing parents' consent decisions but also that this has been largely overlooked in the literature, and I recommend this as a potential area for further research too. This could be planned to include children who have experience of a wide range of public health programmes, meaning that it would be easily applicable outside of dentistry, to general health and child development orientated audiences.

6.6 Thesis strengths and weaknesses

This research has strengths and weaknesses, which I have presented below. I have looked at these from two perspectives: the methodological robustness of the research and the potential contribution it makes to this sub-section of public health.

6.6.a The strengths of this thesis

Contribution to knowledge

The ethical theory of relational autonomy has been discussed in only a small number of papers, written by philosophical academics such as Christman (2004), Mackenzie (2008), Stoljar (2011) and, Owens and Cribb (2013) dominating the discourse. It is a relatively new ethical concept that is still being developed, with the substantive elements of relational autonomy yet to be clearly defined. To date, the discussion about relational autonomy has been theoretical and has not been applied in any practical way within research or public health practice. This research starts from the

viewpoint that autonomy is relational, as discussed at length in Chapter 2 (Theory, Section 2.5), where the twin concepts of procedural and substantive relational autonomy are used retrospectively to demonstrate their relevance to public health. This places the notional theory of relational autonomy within the public health context, which is a new and unexplored area of public health practice. This contribution to the field of public health ethics is further developed through the direct application of relational autonomy to the findings from interviews and focus groups put forward in Chapter 5 (Findings, Section 5.3). Furthermore, towards the end of Chapter 5 (Section 5.4) a new framework that identifies different types of decision maker has been developed as a result of the application of relational autonomy theory to the barriers and enablers that parents encounter when making a consent decision. This framework uses the theory of relational autonomy in a practical way that has not yet been discussed in the literature. The practical use of this relatively new and niche theory makes this research unique and, if published in a research paper, it will add to the body of knowledge of public health ethicists and philosophy academics interested and working in this field. Interest was already shown in the application of this theory when I presented my findings from this study at the International Dental Ethics and Law Society Congress in Amsterdam in 2018. Acceptance of my application to present was via peer review.

This research also makes a contribution to the field of dental public health, and to the discipline of dentistry as a whole. It explores the views and experiences of parents rather than of dental professionals, which is the norm in dental literature. I could find only one other paper, by Tickle *et al.* (2006), that included the views of parents about a DPH programme, and this was not specifically related to consent. Several papers published in dental literature look at the uptake of DPH programmes but they have not considered the process by which parents are invited to participate and the barriers and enablers that parents may face. As such, not only is the information generated from this research new to dental professionals but so are the voices of parents, in a research landscape that is dominated by quantitative enquiry. Moreover,

the findings from this research, that consent decisions are only minimally influenced by written dental information and that parents do not make objective choices based on this, preferring subjective information that they glean from conversations with others, is a new area of consideration for planners of DPH programmes. The interest that dental personnel have in this emerging area of work is evidenced by the prize awarded to me for a poster presentation on this research that I presented at the 2018 scientific meeting of the British Association for the Study of Community Dentistry (BASCD). The BASCD is the key organisation for dental public health in the UK. Acceptance of my poster at this meeting was conferred via peer review, as was the judging that awarded me first prize.

This research has highlighted the important role that schools play in the delivery of this programme, which until now has been unacknowledged in the literature. This information can be used to justify the future involvement of schools in strategic elements of designing and planning DPH programmes that take place in schools. At present, this is the province of dental personnel and schools have minimal input. Moreover, this research demonstrates that parents are seeking guidance from school staff who at present have no formal training in this area of health, possibly because their input has up until now been unrecognised. This adds weight to the recommendations to make changes to the current consent processes, as set out in Section 6.4 above. In addition, this research provides background information on the need for future research to investigate the views and experiences of school staff who assist in the implementation of these programmes. Information from this research can be used when compiling a funding bid to carry out research with school staff. Any future research with school staff has the benefit of not just focusing on DPH programmes but investigating the role that schools and their staff play in the implementation of all health interventions that involve parental consent, *e.g.* vaccination programmes. This will make the research more easily applicable outside the sphere of dentistry and therefore of wider interest to public health organisations implementing similar school-based programmes.

Methodological strengths

This research is analytically generalisable, which is a key feature of qualitative research and one that makes any key findings applicable to other similar areas outside of the immediate context of the research. The findings from this research put forward in Chapter 5 (Section 5.3) have many commonalities with those found in the literature review in Chapter 3 (Section 3.4.a). Several of the comments made to me in interviews or as part of focus groups mirrored those reported by the authors of the papers reviewed. This supports the action taken in Chapter 3 (Section 3.2.a) to extend the literature search beyond that of just dental public health. Parental consent decisions made about children's involvement in public health programmes for general health issues (*e.g.* HPV vaccine) have much in common with those made for dental public health. The commonalities in programme design have already been discussed in Chapter 3, but similarities in the findings from the literature review and the empirical research are highlighted in this chapter. For example, the papers included in Chapter 3 (Table 3.5) outline consent processes for programmes that are based on the Kant-Millian hybrid, similarly to the current approach used for FV programmes. The parents' experiences and views reported in these papers all point towards their exercising their relational autonomy to a greater or lesser degree, as was the case with those I spoke to and reported on in Chapter 5 (Findings, Section 5.3). This demonstrates the ubiquitous belief in the hybrid approach to autonomous decision making that spans health disciplines and countries. It also shows that parents are universally rejecting the expected way of making a decision. Parents are not 'transcending their emotions' to consider only the objective information that has been provided to them by health professionals, as Kant would have it (Section 2.2.c). Parents consult friends and family, they consider their culture and community norms, they seek additional information from people they have an existing relationship with, such as teachers, and sometimes they make no decision at all, be it as a deliberate action to delay or a passive one because family life is busy. These are common features of parents' consent decisions and they are as relevant for parents

considering the HPV vaccine or similar ones (as seen in Chapter 3) as they are for those thinking about fluoride varnish. Moreover, none of the papers reviewed in Chapter 3 (Table 3.5), nor the FV programme in North London, actively facilitate parental autonomy or consent decision making over and above the provision of written information. This demonstrates a widespread misunderstanding of autonomy and a belief by those who design such interventions in the information paradigm suggested by Felt *et al.* (2009) and discussed in Chapter 2 (Theory, Section 2.5.a).

The use of two different data-collection methods, *i.e.* semi-structured interviews and focus groups, has increased the level of dependability for this research. This is further enhanced because multiple locations for the data collection (schools) were also included, which adds to the stability of the data. Themes were developed across the sample from different locations and via different collection methods, meaning that these themes are not dependent on small and very specific contexts or realities but traverse individual schools and parents, providing consistency to the findings. Maximum variation was achieved in the participant cohort for this research, which included parents from eight different schools, 16 different ethnicities, parents with one or more children (one Somali mother had eight), working parents and stay-at-home mothers, as well as fathers, step-parents and a legal guardian. The participants also included those who had previously provided consent, active refusal and passive non-response, and parents who intended to change their decision when next asked plus one parent who gave her reluctant consent. The result of this is that the data is rich with a wide variety of parents' views and experienced realities represented in the findings, signifying authenticity.

6.6.b The weaknesses of this thesis

Contribution to knowledge

This thesis clearly indicates that more guidance is expected by parents and support from health professional is needed. This thesis has not explored the differences between guidance and persuasion in detail (Section 1.4.g). Parents want to know

what health professionals advise. But, if based on the recommendations from this thesis we moved to a point where this was the norm and health professional routinely gave explicit advice based on their professional opinions *e.g. "My advice is you should agree to the varnish, there is nothing to worry about, but without it your child is at risk of tooth decay",* a clear definition of what constitutes guidance and what spills over into persuasion will need to be developed.

Methodological weakness

Despite all the efforts made, I was not able to recruit any 'active non-responders', *i.e.* parents who actively chose not to respond to the consent request and to the invitation to participate in this research. Attempts were made to use 'snowball' sampling via friends and school contacts to try to entice parents to participate but this was unsuccessful. The lack of active non-responder who would volunteer to participate in this research was anticipated and discussed in Chapter 4 (Methodology, Section 4.4.b); nevertheless, this is still a disappointing outcome. The result is that the views and experiences of this group of 'double non-responder' parents are still unknown. This has resulted in a gap in the knowledge that has emerged from this research, meaning that the typology of decision makers developed in Chapter 5 (Findings, Section 5.4) is incomplete at this stage. This also limits any recommendations for practice that can be made specifically in relation to this cohort of parents. We still do not know whether their decision-making processes are similar to those of other parents or different, or whether they face similar or different barriers and enablers. This remains a gap in the knowledge about parental consent. Moreover, only two parents from the overall number of participants in this research were '(passive) non-responders' to the consent request. So although a wide range of parents' views were represented across different schools, types of parent and types of responder, the barriers and enablers experienced and reported may not be fully representative of this non-responder group. If I were to extend this research, I would focus my efforts on this particular group and, if funds permitted, consider employing and training a parent member of the community to carry out the recruitment and

interviews, in the hope that this 'insider status' would allow greater access into parent friendship groups that were not accessible to me but were likely to include parents with different response behaviours, including active and passive non-responders. This kind of friendship group would also be useful to generate additional information, perhaps more nuanced than I was able to collect from the focus groups.

School staff were not included as a participant group for this research. This possibility was considered early in the planning stages but it was felt to be outside the core area of investigation, *i.e.* parents' experiences and views. However, from the findings it seems that school staff play a larger than anticipated role in parents' experience of FV programmes. This thesis intentionally focused on parents, so not including school staff does not negatively impact on the ability of this work to answer the research question, but this is an area of exploration for the future. Finding out more information from this group of key people will help to further understand any structural and operational enablers or barriers as schools experience them. This information would assist in providing a fuller picture of the current situation that could be used to formulate more holistic recommendations.

6.7 Conclusion

In conclusion, parents feel it is their role to make consent decisions for their children, and this is a universal belief spanning existing research in this area and the parental experiences explored for this thesis. Parents want a straightforward system in which they can make their choice known with minimal effort but that also allows flexibility for them to change their minds. The current DPH process, in which letters are sent to parents, is problematic and creates barriers to decision making because of its arm's-length approach that eliminates personal contact between health professionals and parents. Information delivered in this way lacks resonance and does not provide sufficiently detailed information for parents. It is the existing relationships that parents have that seem to provide the most valued information, which in turn acts as an enabler to their decisions. This situation is exacerbated for parents whose first

language is not English. The barriers encountered are both structural and individual and, as such, diminish parents' procedural autonomy and hinder their ability to act autonomously via substantive means. The need, expressed by all parents, to find supplementary information demonstrates the inadequacy of the information provided but also the strong influence that social relationships have on parents' decision making in general.

The consent arrangements for this DPH programme and others like it show how parents are required to navigate barriers created by unsupportive systems. It is parents' own ingenuity and their trust in their social networks that enable them to exercise their autonomy and to make the choice that is asked of them. This research has demonstrated that there is a bias in the design of consent arrangements towards parents whose first language is English, not only in the format of information but also in the fact that there is no acknowledgement of cultures that value oral above written information. There is also a bias towards parents who consent, and this is seen in the flexibility for initial consenters to review their decision. These parents are considered to be living a 'good life' and making 'good choices' and are so rewarded, whereas the view in dental literature of parents who do not consent is a negative one. It would seem, therefore, that we want parents to make an independent choice free from paternalistic interference, but we also want that choice to be the one we would have chosen for them. The consent arrangements for this DPH programme mean that it is operating within the current understanding of 'best practice' for consent, but this research shows that parents are being let down by this. They face many barriers to making and communicating their autonomous choices, not least because they are largely unsupported by health professionals, including in the design of DPH programmes.

The current social and political environment in the UK is individualistic. Exercising parental autonomy via a choice for children to participate in a dental public health programme is a demonstration of this. Parents operating in this ethos want to make

this decision but expect to be supported in doing so. Changing from an individualistic system to a utilitarian one of mandatory inclusion is not a feasible option in this environment. However, adopting a pluralistic approach that makes use of relational autonomy will retain the priority given to individual choice but within a more supportive and paternalistic atmosphere. This provides a middle ground that will benefit parents and ultimately their children. It is not so strongly oppositional to the current system that it will be immediately dismissed by people in positions of power, *e.g.* law or policy makers, and it will free health professionals from the confines of restrictive codes of conduct.

Chapter 7 - Conclusion

The aim of this research was to examine parental experiences related to consent procedures for a school-based fluoride varnish programme in North London. This was an important topic to investigate because existing research shows that dental caries amongst school age children is widespread. There are a large number of parents who do not respond the consent request for these programmes, which results in their children being excluded (Davies, *et al.,* 2014). Moreover, until now parents' experiences when making this decision have not been examined in dental literature (Appendix 3.1). This research focused on parents' consent for a community based fluoride varnish programme in North London, where the caries rate in children is high (Public Health England, 2015). The application of fluoride varnish to children's teeth is recommended by the Department of Health (2009) to help protect against caries. However, with so few parents responding the consent request (Table 4.1) this programme was at risk of being de-commissioned (Kubiangha, 2015). To help improve this situation so that children are getting as much assistance with their oral health as possible instead of requiring help from Accident and Emergency departments for what is a preventable disease (HSCIC, 2013), I wanted to find out; what barriers and enablers, or both, do parents experience when asked for their consent for their child to participate in a school based dental public health programme?

To answer this question existing dental literature was reviewed, but this did not provide me with any information about parents' views on this subject (Appendix 3.1). Dental literature details the scale of the problem but to explore parents' opinions and experiences of consent decision making I had to review evidence from further afield, outside the sphere of dentistry. International literature on parental consent decision making for public health programmes was not plentiful but I was able to find a small body of work. This mostly focused on decisions made for HPV vaccinations, and within this I found several similarities to dental public health in the way that consent is requested and considered by parents, as well as the way that programmes are organised. This information gave me a starting point on which to build for my own

investigation with parents. I carried out 17 recorded interviews and four focus groups with parents who had recent experience of making this decision, to gather data that I analysed thematically. I found the enablers and barriers that these parents faced when considering their consent for FV, corresponded to a large extent with the experiences of parents detailed in the literature. The findings from these two activities were then examined from a theoretical ethical perspective before I returned my thoughts to the research location to consider how this information could be used to improve the consent response rate.

The findings from this research demonstrate that most parents experience barriers and enablers to their decision making, although often the decision itself is not the most difficult part of the process. More specifically, parents report experiencing enablers in the form of; a desire to protect their children from harm and the belief that they ought to be the decision maker because as a parent they know what was in the best interest of their child. Parents also experience enabling influences from the personal relationships they have with trusted members of their social networks, including other parents and supportive teachers willing to provide guidance. Barriers are experienced in the form of; the neutrality of official information that does not provide sufficient information and guidance. The written format is also a significant barrier for some parents if they do not speak English. In addition the arm's length process of receiving the impersonal consent request with no additional support from health professionals is barrier for many parents who want to discuss their options.

A key, but unanticipated, finding from this research was the enabling role that teachers and school staff have and how this was experienced positively by parents. Parents valued the more paternalistic guidance that teachers provided rather than the neutrality of the information they received from health professionals. Another unanticipated finding from this research, but not supported by the literature, is that a vocal minority of parents reported that they would be happy *not* being asked for their consent and for their children to be automatically included in the FV programme.

These key points demonstrate how parents trust that public services will operate in the 'best interests' of their children. All parents expressed this belief to some extent and they are happy with a more paternalistic implementation of public health programmes. Parents do not understand the Millian stance of non-interference adopted by health professionals (Mill,1859, cited in Warnock, 2003, p88-180). On occasion parents expressed suspicion at the lack of guidance they received from health professionals. Neutrality is experienced largely as a barrier that parents need to overcome by finding guidance elsewhere and for this they consult their friends, family, teachers, all the while listening to their experiences and opinions. These findings demonstrate how parents do not make decisions in a Kantian (1785) style *i.e.* where they 'transcend their emotions' and weigh up rational objective 'facts' provided to them via neutral written dental information. Parents decisions are based on their own and others experience and views. Parents are embedded within their social environment and their consent decisions reflect this.

The majority of parents from the existing literature and from this research want to be the ultimate decision makers for their children, but they want to be free to choose within a wider system that is supportive and operates explicitly in their children's best interested. Parents want to make a proximate decision about what is right for their children and family *i.e.* "is participation in this programme right for *my* child at this moment in time?" They do not want to consider the broader aspects of whether the fluoride varnish itself is of general benefit. Parents want this sort of consideration to have already taken place by the time the programme is offered to them by professionals who have expert knowledge and can better understand of the risks and benefits.

The implications of this research are twofold; theory and practice. The intended publication and dissemination of the findings will add to the emerging area of public health ethics, and whilst I have not posited a new theory as part of this research, I have considered the current approach to consent requests and explained how this is

in fact a hybrid approach made up of two philosophical theories *i.e*. Kant's ideas of rationality (1785) and a particular understanding of Mill's work on autonomy (Mill, 1859; Dawson and Verwiji, 2008). I have explored a newer way of conceptualising autonomy *i.e*. that it is relational (Christman, 2004). This concept has, until now, has remained theoretical and has not been applied to a real world scenario, which I have done. As such this thesis will add strength to the argument of those who have put forward a relational approach as an alternative to the existing view of autonomy. It will help to challenge those who are yet to be convinced that the current hybrid approach should be rejected because it does not reflect reality. The academic discipline of ethics thrives on debate and authors are not averse to putting forward strident views on each other's work. Therefore, if published, I hope that any papers stemming from this thesis will generate similar debate.

The medical model of health that underpins health professionals training, codes of conduct including what is considered current 'best practice', and general ways of operating, does not acknowledge the embeddedness of people within their environment. It is this aspect that makes autonomy, and therefore decision making, relational. Current consent processes have been borrowed from a clinical setting and merely applied *en-masse* to a public health setting. This has been done without any consideration for the differences between clinical and public health environments, most significantly the lack of personal contact between health professional and parent. This research demonstrates how important consideration of wider structural and social determinants of health is, even to a very specific individual action such as giving or refusing consent. Parents have articulated their desire to retain their current decision maker status but they have also strongly appealed for more paternalistic guidance from health professionals, although the majority do not want an opt-out system. I have explained how these two positions have traditionally been viewed as oppositional, but that they can operate together under a pluralistic arrangement *i.e*. one that is supportive for parents by providing expert opinion based advice, but

where parents are enabled through face to face communication to make an individual decision, which they can revisit and change later if they so choose.

This research advocates a pluralistic approach to designing consent processes for dental public health programmes. This will mean changes to policy and operational practices for dental teams. The implications of this could be significant with organisations at a national level reviewing their documents and guidance. For example, in this situation the GDC will need to review its 2005 publication on consent. Moreover operational guidance to NHS PCSDS will need to be developed and issued. Local planners and dental teams will need to work with education colleagues to adopt a more holistic approach to implementing FV programmes. In addition to the development of more supportive consent systems planners and dental teams will need to pay attention to ensure that any new processes meet the legal (and moral) requirements of parental consent, such as allowing for parents to change their mind at any point regardless of their previous decision and providing information in the most dominant languages thus reducing current inequalities and barriers.

If the changes suggested in Chapter 6 (Discussion, Section 6.4) are implemented the implication for parents and children will be positive. Parents will face fewer barriers with regard to making their consent decisions. They will be better supported in their position as decision makers and therefore enabled to carry this out with confidence. Parents will have the opportunity to ask questions and talk through their choice with a dental care professional. Parents will also be enabled to communicate their choice including any changes of mind easily and in a way that makes sense to them. As such many of the barriers to parental consent response will be eliminated and the response rates shown at the start of this thesis ought to improve. An aside to this will be that the dominant view in dental literature that low response rates are due to 'lazy parenting' will be refuted (Monaghan *et al*, 2011 and Davies *et al*, 2014). However, the most important implication as a result of the recommendations being adopted is likely to be for children. As the number of responses increases, it is anticipated that

so will the number of parents providing their consent. This means that more children will benefit from receiving fluoride varnish and ultimately the oral health of this age group will improve from the situation described at the start of this thesis.

This research is not without fault and a weakness is the failure of this research to recruit any 'active non responders'. As such it is possible that the enablers and barriers identified and described in chapter 5 (Findings, Section 5.3) may not capture the full picture. In particular there may be additional barriers that the 'active non-responder' group encounter or those that are already identified may be experienced more acutely than has been considered. If this is the situation, any positive implications may be tempered by as yet unidentified barriers that parents are still experiencing and that still need to be addressed. Additionally, this thesis does not include the views of school staff in relation to the implementation of FV programmes. I did not set out with this activity in mind, but as the data analysis progressed it became clear that teachers play a kay role in this process. This means that while the research objectives have been met, in the future exploring consent for DPH programmes from this perspective maybe useful. This is an area ripe for further research and the work conducted in this research can act as supporting material and background on which to develop.

In this thesis I have applied recent theoretical thinking on autonomy to a real world problem. It challenges existing traditional notions of what it is to make and autonomous decision and sets this within the context of dental public health. It draws on existing evidence from history and literature, and supports this with the views and opinions of parents making contemporary consent decisions and provides realistic recommendations for changes to theory and practice ultimately to benefit children's oral health.

Appendices

Appendix 3.1 Summary of dental literature

Author(s)	Date	Research design	Method of consent request	Number of total participants	Number of responders	Conclusions
M.Tickle, K.M.Milsom, K.Buchanan and A.S.Blinkhorn	2006	Focus groups / interviews with parents, School Nurses and Teachers	Discuss single letter sent via school	64 parents 8 teachers 8 School Nurses	N/A	'School dental screening as it is currently delivered has been shown to be ineffective. Now is the time to consider if the statutory access to school and the resources supporting this national programme could be more effectively used for some other purpose.'
M.C.Hardman, G.M Davis, J.T.Duxbury and R.M.Davis	2007	Intervention Experimental RCT	Positive 'opt-in' consent form sent to parents	2091 children in 24 school	No response - 1023 Consented - 914 Refused consent - 154	'The results of this study suggest that this type of fluoride varnish intervention cannot be recommended. This is a bold statement bearing in mind the clear evidence for the effectiveness of fluoride varnish: two systematic reviews. Poor positive consent rate excluding those most likely to benefit.'
T.A.Dyer, Z.Marshman, D. Merrick, C Wyborn and J.H.Godson	2008	Observation Cross sectional Descriptive	Positive 'opt-in' consent. Single letter sent to parents via school	3658 children	No response – not recorded independently Consented – 722 Refused – 2836 (including no response)	'Positive consent requirements may have compromised the validity of findings of the dental survey and the effects were more marked in groups where dental caries is most prevalent. It is probably that caries experience will be underestimated and particularly in area of high socio-economic deprivations and certain ethnic minority groups.'
N. Monaghan and M.Z.Morgan	2009	Experimental Pragmatic trail	Negative 'opt-out' consent supplemented by 'Gillick' competent child consent	13142 children (6393 2002-03 from survey and 6749 from 2004-05 survey)	Child consent – 12781 Child or parent refused consent - 361	'The use of 'Gillick competent' consent in Wales did not affect participation rates adversely. There are uncertainties over how examining dentists should judge competence of children who are asked to consent to participating in epidemiological studies. The authors would suggest that indication of assent as used in Wales in these two surveys is appropriate.'

M.Z.Morgan and N.Monaghan	2010	Experimental Pragmatic trail	Negative 'opt-out' consent supplemented by 'Gillick' competent child consent	13142 children (6393 2002-03 from survey and 6749 from 2004-05 survey)	Child consent – 12781 Child or parent refused consent - 361	The analysis in this paper suggests that exclusion of children who have not fully understood and explanation of the nature and purpose of the examination would have a small impact on the results and the utility of the data produced. Other approaches intended to cope with low capacity would require considerably more training of the dental staff and more time to be used communicating with the children.
N.P.Monaghan, S.J.Jones and M.Z.Morgan	2011	Observation Cross sectional Descriptive	Negative 'opt-out' consent in years 2001-2, 2003-4, 2005-6. Positive 'opt-in' consent in years 2007-8	6714 children. (2001-2 = 1693 2003-4 = 1766 2005-6 = 1631 2007-8 = 1624	% of consented children dropped between 2005-6 and 2007-8. Drop in consent increased with decreasing deprivation. 2005-6 (most deprived) 79.5% examined. 2007-8 (most deprived) 46.3% examined.	'Among children examined there was a significant increase in the proportion of five year olds with no decay in 2007-8 compared with 2005-6 across all deprivation fifths. Reasons for this could include a desire to avoid parental or child embarrassment.'
G.M.Davies, C.M.Jones, N.Monaghan, C.M.Pine, N.B.Pitts, J.S.Neville and E.Rooney	2011	Observation Case series Descriptive	Positive 'opt-in' consent. Single letters sent via the school	209,172 children from England 12662 children from Wales	139,727 examined in England (66.8%) No response – 48,110 (23%) Refused consent – 10,459 (5%) 7100 examined (56%) No response - not independently reported Refused consent – not reported	'Comparing findings in the various countries demonstrates that the large reported improvements in decay level in England and Wales are unlikely to be real, and at least partially result from non-response bias. The analysis in Wales suggests that positive consent of parents is less likely to be provided if he parents re aware that their child has or is at risk of decay. Further research such as focus group work parents not providing consent might be able to confirm whether this is a factor.'
A.M.Glenny, H.Worthington, K.Milson, E.Rooney and M.Tickle	2013	Intervention Experimental RCT	Positive 'opt-in' consent using five methods - Multiple letters to parents; providing additional information to	11088 children from 335 schools	No response and refused consent were not reported. Consent was reported as % Multiple letters to parents = 63% consented	'Multiple letters targeting non-responders were shown to produce a statistically significant higher consent rate than providing one form of financial incentive. However, the consent rate achieved using multiple letters was not statistically higher than that in the control group suggesting there is insufficient evidence to support a change in current recruitment strategies. Letters should be distributed by the school

			parents and children; financial incentive to the school; financial incentive to the school administrator plus direct mailing to parents; and control of usual practice i.e. single letter to parents via the children		Providing additional information to parents and children = 58% consented Financial incentive to the school = 54% consented Financial incentive to the school administrator plus direct mailing to parents = 47% consented Control of usual practice i.e. single letter to parents via the children = 57% consented	and sent to the child's parent / guardian via he child. Further evaluation of techniques to maximise consent rates needs to be undertaken possibly with parallel qualitative components.'
G.M.Davies, M.Robinson, J.Neville and G.Burnside	2014	Observation Cross sectional Descriptive	Positive 'opt-in' consent. Up to two letters sent to parents via school	Actual number not reported	No response – 23% Consented – 71% Refused – 5%	'It should be notes that a lack of consent only rarely came about as a result of parents sending back a form with indicated that they did not want their children be included. There are a number of possible reason for this; some parents may have difficulty understanding and replying because of reduced literacy skills; some parents may have not looked in school bags; some may be due to lack of motivation. Another possibility is that parents who knew they children had poor oral health might have wanted to conceal this fact.'
M.Z.Morgan and N.P.Monaghan	2014	Observation Cross sectional Descriptive	Positive 'opt-in' consent. Up to two letters sent to parents via school	11461 children	No response – not independently recorded Consented and examined – 7734 (6678 after 1st mailing. 1056 after 2nd mailing) Consented but absent of day of examination – 860 Refused – 2867 (including no response)	'It is clear that the requirement for positive parents' consent for caries surveys of younger children in Wales since 2006 do underestimate the true caries level. Consideration should be given to a third mailing of a consent form'.

Appendix 3.2 Electronic search log from 10th October 2016 – PsychARTICLES

Database searched via Ebscohost. Keys words used are show in table 3.3

Search limits: Published between 2006-2016, peer reviewed (scholarly), human and all methodology

Search number	**Search term(s)**	**Publications found**
1	Parent*	3,414
2	Search 1 OR any of the alternative key words	8,312
3	Public health	1,434
4	Search 3 OR any of the alternative key words	5,913
5	Consent	100
6	Search 5 OR any of the alternative key words	12,512
7	Searches 2 AND 4 AND 6	448
8	Influenc*	5178
9	Search 8 OR any of the alternative key words	23,758
10	Search 7 AND 9	260
Initial filtration		
	Selected from paper title	18
	Selected from paper abstract	**6**

Appendix 3.3 Electronic search log from 10th Oct 2016 – PsychINFO

Database searched via Ebscohost. Keys words used are show in table 3.3 above.

Search limits: Published between 2006-2016, peer reviewed (scholarly), human and all methodology

Search number	**Search term(s)**	**Publications found**
1	Parent*	86,368
2	Search 1 OR any of the alternative key words	24,626
3	Public health	84,259
4	Search 3 OR any of the alternative key words	217,545
5	Consent	6866
6	Search 5 OR any of the alternative key words	400,298
7	Searches 2 AND 4 AND 6	19,428
8	Influenc*	125,178
9	Search 8 OR any of the alternative key words	683,633
10	Search 7 AND 9	11,471
Initial filtration		
	Selected by Subject: Major Heading – *Decision making*	699
	English	693
	Selected from paper title	50
	Selected from paper abstract	**16**

Appendix 3.4 Electronic search log from 23rd October – MEDLINE

Database searched via Ebscohost. Keys words used are show in table 3.3 above.

Search limits: Published between 2006-2016, all types of publication, full text and human.

Search number	**Search term(s)**	**Publications found**
1	Parent*	53,151
2	Search 1 OR any of the alternative key words	221,547
3	Public health	105,642
4	Search 3 OR any of the alternative key words	319,749
5	Consent	11,320
6	Search 5 OR any of the alternative key words	684,596
7	Searches 2 AND 4 AND 6	18,704
8	Influenc*	89,799
9	Search 8 OR any of the alternative key words	1,026,510
10	Search 7 AND 9	11,114
Initial filtration		
	Selected by Subject: Major Heading – *Decision making* *Health behaviour* *Patient compliance* *Patient acceptance of health care* Total	 *160* *184* *193* *236* 737
	Selected from paper title	23
	Selected from paper abstract	**10**

Major subject headings; health behaviour, patient compliance and patience acceptance of health care were included in case any papers of relevance had been misclassified under these headings.

Appendix 3.5 Electronic search log from 20th November 2016 – International Bibliography for the Social Sciences

Keys words used are show in table 3.3.

Search limits: English language, journal articles, scholarly journals, published between 2006-2016

Search number	Search term(s)	Publications found
1	Parent* OR any of the alternative key words	17,467
2	Public health OR any of the alternative key words	24,403
3	Consent OR any of the alternative key words	18,365
4	Searches 1 AND 2 AND 3	91
5	Influenc* OR any of the alternative key words	168
6	Search 4 AND 5	54
Initial filtration		
	Selected from paper title	2
	Rejected as duplicate (after abstract read)	2

Appendix 3.6 The reduction in literature using the inclusion and exclusion criteria and critical appraisal.

Literature source	**Number full text papers**	**Number excludes after quality assessment**	**Total submitted for detailed analysis & inclusion**
International Bibliography of the Social Sciences	0	0	0
PsycARTICLE	0	0	0
PsychINFO	5	3	2
MEDLINE Compete	5	3	2
Citations followed up	4	0	4
Total	14	6	**8**

Appendix 3.7 Example Literature Abstraction Table

Catalogue Number: 1

Title: *Immunization Rejection in Southern Alberta: A comparison of the Perspectives and Mothers and Health Professionals*

Sourced via: *Ebscohost - PsycINFO* Date: 10TH Oct 2016

Country of origin: *Canada*

Type of Literature: *Research journal article*

Inclusion / Exclusion & rationale: *Meets inclusion criteria*

CASP screening: *Meets screening question criteria*

Likelihood of bias: *Qualitative research*

Primary outcome / opinion: *Views of what influences parents to reject immunizations differs between health professionals and Mothers.*

Citations to be followed up: *2*

Author(s)	Publication	Publication Date	Research Method	Cohort Size	Analysis type
Vandenberg, S. and Kulig, J.	*Canadian Journal of Nursing Research*	*2015*	*Semi-structured interviews*	*8 Mothers and 12 Health Professionals*	*Grounded Theory*

Summary / Key points	Strengths	Weaknesses
Mothers revealed distrust of some health professionals	*Semi-structured interview method used to allow for unanticipated topics to be discussed*	
4 Mothers responded to recruitment posters & 4 came from snowball sampling		*Potential for homogeneity in views. No Mothers from Mennonite, Hutterite or Frist Nations responded to recruitment efforts.*
Rigor of data analysis	*Specific method identified*	*Grounded theory mentioned but limited information about how this was conducted e.g. no data related to themes / categories presented*
Credibility of findings *Little interpretation. Largely descriptive.*		*No triangulations or respondent validation.*

(These were completed by hand at the time. This has been replicated using typed front for neatness)

Appendix 3.8 Data extraction table

Author(s)	Date	Data extracts 1st Order constructs	Descriptive themes 2nd Order constructs	Analytic themes 3rd Order constructs
Shelton, R. Snavely, A. De Jesus, M. Othus, M. and Allen, J.	2011	Odds Ratio = 3.09, 95% Confidence Interval = 1.13, 8.43	Compared to parents who do not attend religious services, parents with moderate attendance were more likely to have already vaccinated their daughters than be undecided	Active decision making Internal beliefs - religion Influence of social networks
		Odds Ratio = 3.05, 95% Confidence Interval = 1.41, 6.58	Parents who reported frequent attendance were more likely to have decided against vaccination than be undecided	Active decision making Internal beliefs - religion Influence of social networks
		Rao-Scott chi-squared P = 0.02, (data not shown in paper)	Parental beliefs regarding who should be vaccinated also varied by religious attendance	Internal beliefs - religion Influence of social networks
		Data not shown for non-affiliated parents in paper	Catholic parents were more than three times as likely as those with no religious affiliation to have vaccinated their daughters (vs. being undecided)	Active decision making Internal beliefs - religion Influence of social networks
Krawczyk, A. Knauper, B. Gilca, V. Dube, E. Perez, S. Joyal-Desmarais, K. and Rosberger, Z.	2015	X^2 (1, n = 774) = 34.65, p < .001	French speaking participants were more likely to obtain the vaccine than English speaking participants	Influence of culture Influence of social networks Social norms
		X^2 (2, n = 774) = 12.26, p < .01, and x^2 (2, n = 774) = 10.70, (p < .01)	White/European and Christian participants were more likely to obtain the vaccine than Non-White/European or Non-Christian participants	Internal beliefs – religion Ethnic difference

		Regret accepting vaccine Odds ratio 0.61 95% Confidence interval (0.54–0.69) P <.001 Regret not accepting vaccine Odds ratio 1.69 95% Confidence interval (1.50–1.91) P <.001	Other factors not directly included in the Health Belief Model (such as anticipated regret) were also associated with vaccination uptake.	Parental responsibility – to make 'right' decision (weight of proxy decision)
Dorell, C. Yankey, D. and Strasser, S.	2011	% reported as not receiving recommendation 87.9% Td/Tdap 90.9% MenACWY 60.3% HPV	Parents reported that they did not receive a recommendation from a health care provider for their adolescent to receive the vaccine.	Recommended by health professional – not received / recalled
		19.1% reported lack of knowledge for MnACWY v 7.4% of parents who received a recommendation	Among those without a provider recommendation, a significantly higher proportion of parents responded that "lack of knowledge" was the main reason for not receiving MenACWY.	Knowledge – insufficient information from health professional Source of knowledge
		1.3% vs 0.1% of parents who received a recommendation	Parents without a provider recommendation for HPV were more likely to respond "no doctor/ no doctor's visit scheduled"	Access to health care – limited. Result in no / little opportunity for recommendations by health professional or discussion
		13.0% vs 2.6% of parents who received a recommendation	Among those parents with a provider recommendation, a significantly higher proportion of parents responded "child already up-to-date" as a main reason for not receiving Td/Tdap.	Access to health care – available. Results in health care professional recommendation and acceptance / participation by parents.
		Not appropriate date 15.2% vs 4.4% of parents who received a recommendation Family / parental decision	Some of the parental reasons for refusal significantly associated with a provider recommendation for MenACWY included "not the appropriate age",	Access to health care – elsewhere *e.g*. college Social / familial influences Parental autonomy exercised to refuse vaccination – against recommendation

		9.4% vs 1.3% of parents who received a recommendation for a college shot 4.3% vs 0.9% of parents who received a recommendation Family / parental decision 9.3% vs 4.8% of parents who did not received a recommendation More information needed / new vaccine 8.3% vs 4.3% of parents who did not received a recommendation	"family/parental decision" and "college shot" Regarding HPV, a significantly higher proportion of parents with a provider recommendation responded "family/parental decision" and "more information needed/new vaccine"	Social / familial influences Parental autonomy exercised to refuse vaccination – against recommendation Information – insufficient / lack of knowledge Safety / fear
Vandenberg, S. and Kulig, J.	2015	I didn't feel secure doing it. To me it was kind of a scary thing. I think that if I went along with it and something happened, that [it] was my responsibility, just the guilt would be huge. I mean, you go through a couple of days, but it's no big deal really. We asked quite a few different people when we were trying to decide whether to immunize or not, like, our friends . . . probably [it was] how the people around me think about immunizations that led to [my] being okay with the decision not to immunize.	Mothers discussed fear of the unknown and fear of vaccine effects, in addition to fear resulting from negative experiences with immunization. Mothers also discussed feelings of guilt and the inability to forgive themselves should harm result from immunization Feelings of indifference due to the belief that diseases are not as serious as they are thought to be, as a result of tolerable personal experiences with vaccine-preventable diseases. Pressure from family, friends, and religious or cultural groups regarding childhood immunization.	Fear Personal experience Responsibility - to make the 'right' decision Perceived threat Social belonging Pressure from immediate family and friends to 'confirm'

		If my children [were to] get sick, I would consider that . . . God's hand. It's more important for me to build up the immune system rather than bombard it with something that could be prevented just by having a stronger immune system.	Mothers identified a combination of religion, natural health beliefs, and mistrust as factors in their decision about immunization. Clearly, religion was a factor. Mothers believed that the body's immune system is designed to ward off vaccine-preventable diseases.	Internal belief system - religion / natural health
		I think HCPs are seen as, well, of course, they are for that [immunization] because that is what HCPs are taught to think, so maybe you discredit it a little bit"; "There's a lot of literature out there how the pharmaceutical companies really push the doctors into pushing vaccines, and they get their perks and their trips.	Mothers openly acknowledged a mistrust. They believed that HCPs provide biased information, given the role of HCPs in health care, and described government and pharmaceutical companies as being financially motivated to promote vaccines.	Sceptical of information sources that parents' do not personally know. External to immediate family and friends. Mistrust – scientific information and health care professionals Mistrust – large organisations driven by profit
		Over time, all the chemicals and things that have been added, that's what kept us from doing it.	Vaccine ingredients were a significant obstacle for the mothers.	Perceived threat of vaccine itself. Responsibility – protect child from harm
		I remember thinking there were an awful lot in the first 2 years . . . it seems like an awful lot to bombard . . . especially because their immune system isn't fully mature yet.	Mothers believed that the decline in vaccine-preventable diseases is a result of improvements in personal health and hygiene rather than the introduction of vaccines.	Internal beliefs – health behaviour not scientific advances improve public health
		I don't really know, because . . . we are flat-out, like, we aren't immunizing, so I've always kind of just pushed it out as fast as they try to give it to me.	The mothers admitted that, based on their decision to not immunize their children, they subsequently had not conducted a thorough inquiry into immunization.	Formal and informal information sources Advanced decision & not willing to engage with subject

			Mothers indicated they used a variety of information sources for their decision-making, including books, journals, anecdotes, and HCPs, with media and the Internet identified as a key source. Family and friends were seen as an important source.	
Dempsey, A. Abraham, L. Dalton, V. and Ruffin, M.	2009	I just don't know enough about it. That's reason number one and then I don't want her to fall into a category where she gets this done and then ten years down the line they find that it reacts a different way. So it's a little bit frightening for me. I don't think there's enough information out there about the vaccine. I was going to take a year or possibly two as a wait-and-see approach to see what other studies come about regarding this vaccination. I don't think there's been enough study yet about what the implications are for the long term for giving this vaccine to young adolescent girls. I am nervous because it is a new vaccine and I would hate to see In 10 years down the road them come back and talk about devastating effects it has, so I'm trusting that they've done enough testing and that they've looked at this long enough.	Vaccine safety was mentioned frequently but views on this issue differed on the basis of the daughter's vaccination status. Among mothers declining the vaccine, safety concerns were often the primary reason for doing so. Feeling that they personally lacked the knowledge needed to make an informed decision about HPV vaccination for their daughter Mother's felt that the medical establishment in general lacked sufficient knowledge about HPV vaccines to ensure safety Vaccine-accepting mothers also described how they believed the testing / licensure process to evaluate new vaccines was adequate to identify significant risks to vaccination	Safety Fear Responsibility – protect child from harm Responsibility - to make the 'right' decision Knowledge – insufficient information Feeling uninformed. Insufficient knowledge leading to delayed decision making and / or passive decision' *i.e*. no decision' Mistrust – scientific information and health care professionals Safety Trust - scientific community and regulation arrangements. Leap of faith

		The only reservation I had about it was that it is new. I want other people to try it out first and make sure there are no side effects and that sort of thing.[But then I thought]'Why wouldn't I get extra protection if I can have it?	Mothers accepting the vaccine seemed to often be overcome by a belief that benefits from vaccination outweighed the risks	Internal beliefs - weighing up risk / benefits Responsibility – to protect child from harm
		Even though we try to practice that she's only going to have sex with her husband, I'm a little more realistic than that. Even if she only does have sex with one man in her life, there's no guarantee that he hasn't had other partners and that he might not be a carrier.	Mothers uniformly discussed risk within the context of their daughter's sexuality. Mothers declining the vaccine perceived their daughters to be at low risk for HPV primarily. These mothers lacked a sense of urgency. Mothers who accepted the vaccine perceived their daughters to be at high risk of acquiring HPV infection.	Perceived threat and susceptibility – Mothers externalise risk / relevance to own daughters
		If she were older and there could be a competent discussion on it and she could choose. I would definitely allow it. But at 11, I'm just so bothered by my decision having an impact on her later in life	Of the vaccine-declining mothers some described how they wanted their daughter, when older, to play a role in the decision to vaccinate. This wish was related to concerns about vaccine safety and apprehension about the implications of their decision for their daughter in the future.	Responsibility - to make 'right' decision Desire for joint control/decision making Delayed decision making Fear
		I figured now is the best time because it's a time that I can make the decision for her and I wanted to make sure she was protected before there was any chance of her becoming sexually active	Vaccine-accepting mothers who cited this as a factor in their decision wanted to take advantage of their current control over their daughter's health-related decisions	Responsibility - to protect their children from harm Mother's exercising control over child's choice. Time limited proxy decision window – sense of urgency
			Many more mothers who declined HPV vaccination had not seen their child's	Recommended by health professional has little influence if no existing relationship between Mother and health professional.

			regular provider when compared to mothers accepting the vaccine.	
Cooper Robbins, S. Bernard, D. McCaffery, K. Brotherton, J. and Skinner, S Rachel.	2010	I gave the forms to mum and she read them and explained it to me and I was like, yeah, I should get it. She kind of explained why it was important	One or several discussions with family members and/or friends about HPV vaccination. The decision was one mainly made by parents, but girls were often a part of the process. A number of girls made mutual decisions based on discussion with their mothers	Time limited proxy decision window – power imbalance changes over time. Parent as 'expert' facilitator for child Influence of family and friends Information – informal sources
		I mean . . . we didn't take much notice of the forms, and we handed it to our parents and they make the choice . . .' It's like your parents are the boss of you, sort of. You don't choose, 'oh I'm going to get a cervical cancer vaccination.' It's not your choice. They like try and do what's best for you	Some girls were happy for their parents to make the decision for them; this happened more often with younger girls.	Responsibility - placed on parents by daughters Parent as 'expert' facilitator for child
		I did some research (on the net) at the time my Mum said no. So I went in to learn more about it . . . she seemed to be thinking at the moment it is relatively new, and she didn't have much confidence in that I needed it yet	Other girls were not happy that their parents assumed a decision-making role for them. When non-congruence of parent and child choice occurred, it was most often resolved by the parent's decision.	Time limited proxy decision window – power imbalance changes over time. Parental autonomy prioritised above child's choice
		I think vaccines against anything preventable is worthwhile	Prevention, as a health ideology, was a common core belief among the active decision-making/vaccinated group and seemed to be a facilitator of vaccination.	Internal belief system – priority given to health / disease prevention Trust in vaccines
		Well I don't get immunizations. I've never had any. My dad believes in boosting our own immune system, not getting help…..like helping you,	Individuals in the anti-vaccination group had strong core health beliefs of natural therapies over vaccination.	Internal belief - natural health Influence of family - primary socialisation of health beliefs

		but it means your own immune system isn't working as hard. So that's why I don't get them so I can fight it off myself and make my immune system stronger. That's what I see as the advantage of not getting		
		I'm very happy to have the vaccine so I won't get cervical cancer as my grandmother had it and my mum had it	Personal experiences facilitated the decision for vaccination.	Immediate personal experience Perceived susceptibility
		It's the preservative side of it that worries me. It's either mercury or lead or whatever it is. That is the part I worry about that usually causes a lot of problems for people. Personally for me I have had two family members that have been affected by prescription drugs and I'm skeptical . . .	Parents with friends or family who had negative outcomes as a result of vaccines or medical treatments generalized this negativity to all medical treatments, including HPV vaccination	Perceived threat from intervention(s) Safety Mistrust - scientific information and community
		They pump all these things into kids . . . Do they really know how it will affect them later? I don't trust the government. Why would they need [the vaccination] when we didn't get it? What aren't they telling us? My sister showed me some articles about there being cancer in the vaccine	Individuals often expressed some level of mistrust, in particular related to the government or the new vaccine. This was in sharp contrast to the individuals who actively chose to vaccinate, who often trusted the school or government implicitly.	Perceived threat from intervention(s) Safety Mistrust - scientific information and community Mistrust – large organisations Formal and informal sources Information bias – trusting sources to suit personal beliefs influenced by source e.g. family members
		The advantages for me at school were that the organizing was taken away. All I had to do was sign the form and I knew it was taken care of. It wasn't something I had to then think about having to do after school	Some also talked about being happy to have the vaccine since the school supported it. Parents described the ease of the decision, since the school was providing	Ease of access facilitates positive decisions Influence of existing personal relationship – e.g. with school

		or make an appointment. It wasn't anything extra. It was something that was done	the vaccine and doing all of the "work" associated with receiving a vaccine.	
		I heard it killed like 11 people	Parents and girls in that were not vaccinated often described the negative things they had heard from friends, family, and/or media.	Perceived threat from intervention(s) Mistrust - scientific information and community Formal and informal sources Information recall bias – trusting sources to suit personal beliefs influenced by source e.g. family members
		If it hadn't come to school it wouldn't have crossed my mind to do it . . . it's not [a decision you make] on an individual basis, and that [having it at school] makes you more comfortable . . . because of our religion and according to Muslim law, we don't have any sexual contact out of marriage—but it can happen . . . anything can happen- . . . and so we hope girls won't need [HPV vaccination], but there is no harm in getting it My understanding is that the more partners you have the greater the risk you have of picking up a sexually transmitted disease, not just that one. I am confident my girls will not be like that	Parents and girls from certain cultural (Muslim) or religious (Catholic and strongly Christian) backgrounds, felt the girls would not need the vaccination since their daughters would either refrain from premarital sex or would not have several sexual partners.	Internal belief system – religion Religion influences perceived level of susceptibility based on assumed lifestyle choices of the future Perceived threat and susceptibility – Mothers externalise risk / relevance to own daughters
		I remember I didn't want to get the needle but my parents said you are better off getting it than the disease so I thought, even though I don't like needles, I should get it because it's for the better	Fear was a common issue. Girls were able to moderate this fear with the assistance of parental, teacher, or peer encouragement that the benefits of the vaccine were greater than the initial pain of receiving the vaccine.	Existing personal relationship e.g. teachers, can influence and mitigate fear in recipient Social belonging. Normalised behaviour

		I can't remember discussing it. I think it was just the case that she brought it home, fill this out. But in the business of life, forms come home and you just complete them	Some parents talked about signing consent forms without reading all the information. Parents were familiar with signing forms that come home, and an implicit trust of the school facilitated this process. These parents did not discuss the information with their daughters. Competing demands (of work, life and parenting) may also have played a role in this routine response.	Trust placed in organisation that have an existing relationship with decision maker Trust more important than information scrutiny as decision influencer Parental autonomy exercised Passive rather than active decision making Busy lives / convenient/ ease of access
Gottvall, M. Grandahl, M. Hoglund, A. Larsson, M. Stenhammer, C. Andrea, B. and Tyden, T.	2013	It has been discussed and investigated and they have finally decided that this is what people must do, so I feel that we must, in any case, I trust that the recommendations are right.	Parents expressed a trust in vaccine recommendations from authorities and experts and said that the HPV vaccination was an offer they had decided to accept. They believed the authorities make decisions that are good for the people; therefore, a vaccine included in the school-based vaccination programme is likely to be reliable.	Recommended by a health professional Responsibility – to make the 'morally right' decision Sense of obligation / obedience to authorities Trust in authorities / organisations Social belonging / responsibility
		It becomes more accessible, it rolls along by itself, automatically without having to make an appointment, driving yourself there . . . it is really good for us parents with limited time and so on . . . it's great . . . smoother.	It was also expressed that school-based vaccinations are very convenient and accessible for the parents. They believed that the vaccine coverage would increase through this system since it makes it easier for parents to accept the vaccine merely by filling in 'yes' on a piece of paper. Parents also viewed school based vaccination as efficient from a socioeconomic perspective, since the vaccination took place during school hours and parents did not have to be present.	Social belonging Busy lives / convenient/ ease of access Practicality of decision process Trust in intervention(s) / scientific community

		I was not particularly well informed but I think side effects are important, it seems pretty clear since there are so many people who have been vaccinated that the side effects should have been evident . . . so for me, it was obvious to vaccinate.	Even though many parents felt they had limited knowledge about the vaccine, they expressed trust in the vaccine's effectiveness and safety. Parents believed that the vaccine was well-tested in other parts of the world and that a large number of girls had already been vaccinated without severe side effects.	Safety Trust more important influencer in decision making that information
		Vaccinations are good and bad, think about the swine flu from recent memory. The hysteria and how it was after, so one can feel that it has become difficult with vaccinations . . . but now I have become more observant about what I am going to put in her.	A worry about unknown side effects was expressed, and parents compared it to the mass swine flu vaccination in 2009–2010, which caused narcolepsy in several Swedish children.	Safety Immediate personal experience Responsibility - to make the 'right' decision
		The industry maybe has other purposes than to help people; they earn money too . . . they earn money in the first place.	Some parents were concerned about the underlying purpose of profitmaking by the pharmaceutical industry. They discussed whether one could trust the vaccine trials or if the vaccine company could have influenced it.	Mistrust – scientific information and health care professionals Mistrust – large organisations driven by profit
		I mean, a flu if you are normal, that you can overcome, but cervical cancer, that maybe you can't overcome. It is such a serious disease . . . if I say no to the vaccine and she gets sick, I would never be able to forgive myself.	Parents had accepted HPV vaccination for their daughter to preserve her future health and to protect her from cancer. They felt that vaccination against cancer was an offer they had to accept.	Responsibility - to protect from harm Responsibility – to make the 'right' decision Perceived threat from disease
		I have myself had cervical cancer, so I think there is even more reason that my daughter will be vaccinated. There was no doubt, just a YES.	A common reason for accepting the HPV vaccination for their daughter was that they themselves or someone close to them had experienced the negative	Immediate personal experience Perceived susceptibility Influence of friends and family

			consequences of cancer and, therefore, felt that it was important to provide the best possible protection for their daughter.	
		I think that it's a social responsibility since many of the diseases that we are vaccinated against under the general vaccination programme can cause a great havoc in our population and to not participate in the vaccination programme, I think, is irresponsible towards others.	Some also felt a responsibility to vaccinate her out of concern for others. They stated that in Sweden many childhood infections have been eliminated through the general vaccination programme which gives protection even for unvaccinated children.	Social belonging/solidarity Egalitarian culture – social responsibility
		I thought it was a pretty hard decision. I got quite insufficient information in the papers that came home from school . . . and the worst part, I think, is that when you have a school nurse who is going to vaccinate hundreds of children, and who is not well informed . . . because if you put a name and telephone number on a paper, then you should be able to answer parents' questions. I think that it would have been great if someone from the health care field could have come to a parent meeting . . . so that as a parent, one had the opportunity to ask questions . . . one of these papers can easily become lost in the backpack.	Information from the school was satisfactory according to many of the parents, but some requested further information about the virus, including the seriousness of cervical cancer, and the risks and benefits of the vaccination. Due to their limited knowledge about the virus and the vaccine, they requested a dialogue with the school nurse in addition to the written information they had received from the school. One parent requested more neutral information that addressed uncertainties with the vaccine	Information - source & quality Preference for personalised face to face information rather than written – relationship with health care professional Responsibility - to make the 'right decision' Weighing up risks and benefits
		My daughter and her friend came home and were a little sad and wondered if there was rat poison in the vaccine.	Several girls had also heard Scaremongering rumours and were worried about serious side effects of the vaccination. Their parents therefore	Responsibility to make the 'right' decision Formal / informal sources of information – 'local' sources from social networks can influence an prior decision due to existing levels of trust

			felt unsure of the decision they had made and were uncertain of which sources to trust.	
Hofman, R. Empelen, P. Vogel, I. Raat, H. Ballegooijen, M. and Korfage, I.	2013	I went to check websites to see what it is. It's a virus—I've heard something about it. But first you have to get into it. I don't only rely on what I can find on websites. I think I have to find more information. So if I have to say: I'll do it now, or I will not do it—then I would say not now.	Some parents used an approach of systematically seeking information to arrive at an informed decision	Responsibility - to make the 'right decision' Weighing up risks and benefits Parental autonomy exercised only after independent information seeking. Mistrust – information bias from health care professionals / scientific community
		I think a lot of research has been done by the time we'll receive an invitation, right? That won't happen just like that if there are big risks attached to it. So I'll just trust that it'll be all right.	Other parents seemed to use trust or distrust in the message source as a strategy to prepare a decision about uptake. Parents who trusted the NIP and the government thought that the vaccine would not have been introduced into the NIP if it was not safe.	Trust / faith in research process / authorities influences decision making
		As a parent, I'll do everything I can do to protect my child. What have I done to my child? She might end up with something else. Then I'll be feeling guilty. So I'd rather wait longer and get the right information: what is this substance that's being injected? And what are the disadvantages and the advantages?	Those expressing a negative attitude wanted to protect their daughter against possible side effects on the long term, as was expressed during the discussion on fear of anticipated regret if one's daughter was not vaccinated.	Responsibility – to protect from harm Perceived threat of vaccine Delayed decision making to avoid future regret Insufficient information to feel confident in decision
		Because she's not of an age to make such decisions, I would try to convince her in a good way. An 11 or 12-year-old girl is too young to make decisions on her own. That's my opinion	Most parents thought they should decide about their daughter's uptake, either with or without discussion with their daughter. Some parents saw it as their responsibility because they considered a 12-year-old girl incapable of making such a decision	Responsibility – to protect from harm Parents autonomy exercised Time limited proxy decision window – power imbalance changes over time.

		I've already had my daughter vaccinated. We had discussions like "Mom, cervical cancer, you wouldn't want me [daughter] to get it, would you?" We discussed it for an hour and looked at the pros and cons together. So even children can be involved in the decision making at a very early age, if you inform them honestly and use understandable language.	Other parents preferred a shared decision and thought that children can be involved in the decision	Responsibility – to protect from harm Child's autonomy fostered Time limited proxy decision window – power imbalance changes over time.
		In that case she'll go [to get the vaccination]. I'll leave that decision with her. I'll inform her and tell her about the pros and cons. I always try to be as neutral as possible and then I really think it's up to her. It's her body and her life.	Some parents thought that their daughter could make her own decision about the uptake of HPV vaccinations, even if she did not share her parents' opinion.	Child's autonomy exercised Delegated decision making
		I think that besides this [vaccination] many other possibilities are available to prevent cervical cancer, by having an HPV test or by regularly having a smear taken. That way I think you'll cover it for a large part. That's not the case with other vaccinations. I mean, you can't do anything else to prevent mumps, measles or rubella. I think that's a big difference. In my view there's a good alternative in this case.	Some parents thought it was irrelevant to have their daughter vaccinated.	Alternatives to proposed intervention – no sense of urgency to decide. Ambivalence. Lack of perceived susceptibility
		And with a 12-year-old child, imagine that such a thing will work for five years, it will have worn off by the time she's 17. My oldest is 16 and	Vaccinating was considered irrelevant because of its unknown length of protection.	Immediate personal experience Lack of perceived susceptibility Intervention not important because time limited effectiveness

		she's not yet sexually active. Imagine she had got it [the HPV vaccination] when she was 12, then it would had worn off by the time she turned 16. Well, then it would have been useless.		
		With us, in our [Turkish] community it's unusual to have sex before marriage… let's hope that they really will not have it. That's the way it is in our culture, you marry only once and only have sexual contact with each other once you're married. So that's another reason not to do it	Most Turkish parents considered HPV vaccination as irrelevant because their daughters are supposed to have sexual contact only with their husband and only after marriage	Influence of culture – social norms Lack of perceived susceptibility Threat of disease externalised
		I read somewhere that 200–250 women die of cervical cancer every year. Of course, those are 200–250 too many.	HPV vaccinations were considered relevant by some parents who expected their daughters to become sexually active (although not at 12 years of age) and thus become vulnerable for HPV infections. Parents also related the relevance of vaccinating their daughter to the perceived severity of cervical cancer	Perceived threat and susceptibility Responsibility – to protect from harm
		For me that would really tilt the scales [if daughter refuses to be vaccinated]. I'm from a family of six children, of whom three have different kinds of cancer. So that's what I grew up with. If she would say "no", I'd find that very difficult. Then I'd still try to persuade her.	To most parents, knowing someone who had cancer was a reason to consider vaccinating.	Perceived susceptibility Immediate personal experience Time limited proxy decision window – power imbalance changes over time. Parent as 'expert' facilitator for child
		What I find difficult is to be the first. You don't know what the long-term consequences are. Actually you	Some parents felt insecure about the long-term side effects because the	Safety - Unknown threat from intervention(s) Cultural influences – social norms

		should have vaccinated thousands of girls and should have followed them for 15 years … maybe … I wonder if it'll have unwanted consequences for the fertility of my daughter. Can she still become pregnant later on? I have my doubts about that … What if this vaccination has a side-effect and I had her vaccinated? In our [Turkish] community you want to become grandmother and grandfather when your daughter marries. What if she'll not be able to have children … I'm serious.	vaccine is new and long-term research is lacking.	Responsibility – to make the 'right' decision to avoid future regret. Responsibility – to protect from arm
		Isn't it true that it [the HPV vaccine] was tested on a very different age category and it is projected on youngsters just like that, without knowing anything about it. I have a big problem with that	One parent found the lack of research on the target group for HPV vaccination difficult	Mistrust in scientific community to carry out appropriate testing. Formal / informal information sources all influence decision maker opinions
		You want the best for your child. So what do I keep my child from—or what do I give to her? You keep on weighing it up …	Parents' perceived insecurity and responsibility to protect their daughter's health sometimes resulted in ambivalence toward uptake intentions	Responsibility – to protect from harm Responsibility - to make the 'right' decision. Weighing up the risks and benefits

Appendix 4.1 Summary of public involvement activity responses

Public involvement group questions						
Do you think parents would be interested in talking to me about this?	Yes	No	Don't know			
	7	*0*	*0*			
What do you think is the best way for me to contact parents to invite them to talk about this?	Letter	Email	Poster	At School	Parent Mail	Other
	1-via child	*1-sch email*	*1*	*2*	*1*	*1*
Do you think parents would want to talk to me in a group or individually?	Group	Individually	Both	Don't know		
	2	*2*	*2*	*1*		
Would you agree to be part of something like this?	Yes	No	Maybe			
	4	*1*	*2*			
What can I do to encourage parents to take part?	Outline benefits	Enthuse children	Give freebies	Send invite via sch	Don't know	
	2	*1*	*2*	*3*	*1*	
Once I have planned the questions, would you be happy to give me your opinion of these?	Yes	No	Don't know			
	4	*0*	*3*			

Appendix 4.2 Focus group guide

Introduction

- Introduce self, purpose of the research, format of discussions and set ground rules *e.g.* no private conversations and confidentiality.

- Initiate the 'opening circle' by asking one participant to introduce themselves including any relevant information they want to say.

- Open the discussion with non-challenging question *e.g.* How do you usually look after your children's teeth?

Key questions

- What is your experience of the dental project carried out at [*insert name*] school?
- What helped you to take part and make the decision for your children?
- Did anything make it difficult for you to take part and make the decision for your children?
- Why did you decide to consent / refuse permission?
- What do you think could help parents take part and make a choice in the future?

Ending question / summary

- Is there anything else that anyone would like to say at this point?

- To give a brief summary, we discussed…

- Thank the participants for their time and input.

- Confirm that they can contact me at any time if they have any further questions.

Appendix 4.3 Interview topic guide

Introduction

- Introduce self & thank parent for their participation. Explain case research and interview process. Provide PIS (hard copy). Ask parent to sign consent form.
- To start to create a rapport with the parent start by;
  - confirm their relationship to the child (father, mother, carer) asking their child's name and age, and clarify school year attended by child.
  - confirm if the family have a dentist outside of school

Focused 'life history' questions

Questions: How important to you is dental care for young children?

Planned probes:

- Have you taken your child to the dentist?
- How do you do to look after your children's teeth?
- Is tooth decay something that you worry about?

Question: Tell me about your experience of the dental project carried out at [insert name] school?

Planned probes:

- How did you hear about this project? What do you understand about it?
- What can you remember about the information that you were sent / got?
- Do you remember being asked for your consent (permission)?
- Why do you think you were asked for your consent?

Details of experience type questions

Question: Tell me about how you made your decision whether [inset child's name] could take part or not?

Planned probes:

- Did you understand what you were being asked to do / sign and why?
- Was this decision based on experience or something else?
- Do you feel you had enough information to make this decision?
- What type of information helped you to make your decision?
- Did you talk to anyone else about it before you made your decision?

- Were you influenced in any other way? (e.g. agreeing and going alone with your friends decision choices)
- Do you think the system of parents opting – in is best, or would you prefer if the project went ahead, but you had the opportunity to opt-out if you did not want your child involved? (like when children are measured for height and weight)

'Refection on meaning' type questions

Question: Tell me in your opinion, what parent support and information about fluoride varnish in schools and the consent process, you would like to see in the future?

Planned probes:

- Do you think dental professionals or schools have a role to play in helping parents make decisions like this?
- Do you think that the information provided could be improved to help parents make their decision?
- What could the dental team or school do better in the future? (e.g. face to face information / translation)
- How can we support you when you are considering your decision?
- What would be the best way for you to indicate your decision (e.g. text, email, consent slip)?
- If you were asked this question (or similar) again, would you make your decision in the same way?
- Do you think parents should be asked to confirm / repeat their decision in each year and for each application? Could this be done differently? (e.g. at the start of school life)

Close

- Is there anything else that you would like to add?
  Thank the parent for their time and remind them that they can contact me at any time of they have any questions.

Appendix 4.4 Example of thematic data reduction

Initial Codes =*n*81 Candidate Themes = *n*8 Theme = *n*1

(Step) Father gives formal consent Agreed, but child has FV application at family dentist Agrees in principle but child has Asthma Assumed would only consent once Concern about getting the correct parent choice matched to the correct child – process Consent as protection for dental service Consent as protection for school Consent as protection Confusion caused by dual parenting from separate parents Consent dependant of treatment / action Consent given in principle Consent signed twice by mistake Consent given without dental info / letter Consent process is easy Consent process is hard for non-native English speaker – language barrier Contra-indicated – child has special needs Decision felt rushed Defensive of giving personal details Dissemination via children is flawed Dissemination via children okay Distribution by teachers and children is flawed Electronic consent unreliable – not part of everyday life Give written info before face to face meeting Give written info after face to face meeting FV not offered at the dentist If left to parents to take children to the dentist for FV- it would take longer Immediate decision In favour of 2 consent requests per year	Consent process Flexible decision making Consent in principle Consent as protection Convenience for parents Shared responsibility (State and Parent) Parent's knowledge & understanding Type of consent	Consent Process

In favour of opt-in consent In favour of opt-out consent In favour of single (annual) consent In favour of school FV programme – convenient for parents Intention and action are not always the same Leaflet is preferred format for consent request – convenient Leaflet with signature is best format for consent Leaflets would benefit from being translated Leaflets get 'lost' among other things Letter preferred communication method Letters are easily forgotten Multiple reminder formats beneficial No need for consent for vaccinations Not teachers job to give out letters No preference for 1 or 2 consent requests per year No preference for opt-out or opt-in No reminder needed No reminder received No consequence to parent is they do not respond Opportunity to ask questions Parent agrees but forgot to sign Parent did not receive written information Parent unaware of info given out by school Parental consent needed to protect the school Parents are busy Parents are short of time Parents benefit from reminders Parents decision is contextual to their circumstances Parents may change their mind from one consent request to the next Parents view consent differently, there is no one best way Phone calls are not convenient reminders Postponed decision until child is older Pressure from children for parents to sign Programme seen as safety net Reminder about oral health for parents Refused but happy to agree in future		

Same day return School collection system flawed School disseminated info has influence Single consent request per year okay Single consent okay if parents informed before second application Teachers to alert parents to letters Text are vulnerable to deletion Text as reminder only Text communication is preferred for reminders Text communication is convenient Text message can be misunderstood Text message can be used to indicate parental consent Text messages are convenient Text reply is not permission Text is too personal (personal numbers) for permission Timing of giving parents information is important Written information not received		

Appendix 4.5 Example interview transcript with coding

Interview 2: 30th October

Exchange number	Interviewer / participant voice	Initial code	Candidate theme	Theme
1	**Right, so I will just ask you a few questions. It's just really your opinion, that's all I am interested in, and there is absolutely no right and no wrong.**			
2	Ok.			
3	**Just your opinion, as a mum.**			
4	Yes.			
5	**Ok, could you just to start with, a few things…. Can you confirm you are the mum of…? How old is your daughter?**			
6	Ella. She is four. But I am classed as the carer.			
7	**Oh, yes. You are. That's a carer by law, isn't it?**			
8	Yes. I have a special guardianship order.			
9	**Special guardianship… Ok. Brilliant, thank you.**			
10	**And what school does she go to?**			
11	Wilbury.			
12	**And what year is she in?**			
13	Reception.			
14	**Does she like it?**			
15	Yes, because it has been half term she thinks that she can't go back, and the teachers said: "You are not here next week." And she said: "I can't go!" "You can!"			
16	**Bless her.**			
17	It is kind of…. Because with her, you have to explain things and she gets one thing in her head and you have to… "No, it is this…"			
18	**So, she… Did she go back today?**			
19	No, tomorrow.			
20	**Have they got an inset day or something?**			
21	Yes.			

22	**Ah!**			
23	So, she has got one more day of relaxing!			
24	**Sweet. I wanted to talk to you about the fluoride varnish scheme that is happening in Wilbury.**			
25	**That is the main thing that I wanted to talk to you about. Can I just ask you a few questions about dentistry, in general to start with?** **So, first of all, how important is dental care for children? How important do you think that it is?**			
26	Well, it's very. It helps them with their talking and their confidence.			
27	**Ok.**			
28	**Are you taking Ella to the dentist?**			
29	She has a dentist and we have managed to get an appointment for the 21st of November.	Parent values dental care	Parental priorities	Parents felt responsibility as protectors
30	**Is that her first appointment?**			
31	Yes, because she has…. Got behavioural problems…			
32	**Right.**			
33	It is very hard to take her to places. I try to do it before but at the time we couldn't do it because she would cry herself…	Child's experience important to parent Child's fear of the dentist	Child's experience of the programme Family oral health history	Parents felt responsibility as protectors Influencing social networks
34	**Because she was younger then?**			
35	LOUD DRILLING IN BACKGROUND			
36	Kind of but…She…. When you walk her to the doctors she thinks that she is getting injections, so she gets upset. So, we have to say that you are going to the pretend doctors, not the real doctors.			
37	She does well when she goes to the hospital because she knows that it is nothing scary, so the dentist is going to be a completely different…			
38	**See how that goes….** **Is she going to the community dentist or the family dentist?**			
39	High Street one.			
40	**Right, ok. That will be quite a big thing, won't it?**			
41	Yes.			
42	**Oh!**			

43	I think that she will be fine. When we walked in with her, we are going to visit the dentist, and then she was like: "He is going to take my teeth out."			
44	"No, he is not going to take your teeth out." So, we are trying to ease her in, we have to do it step by step…			
45	**So, just lots of reassurance about everything. She is only little as well.**			
46	She doesn't do well with changes and things that are new… So, before we do that, I will walk up to the dentist and will say this is where you will be going.	Parent values dental care Child's experience important to parent	Parental priorities Child's experience of the programme	Parents felt responsibility as protectors Parents felt responsibility as protectors
47	**Ok. So, how do you look after her teeth?**			
48	We brush twice a day. She doesn't have any fizzy drinks. But if she does it is because we are having a meal, she doesn't sit there drinking them. We use a fluoride toothpaste.	Parent values oral health	Parental priorities	Parents felt responsibility as protectors
49	**Ok. Does she brush? Or do you brush?**			
50	I let her brush, and then I brush.			
51	**Ok, so you both have a go.**			
52	Because she is very independent. Or she will let me brush first, to get to the back and tops and then she will…brush both…	Child's individual autonomy exercised	Child as an individual	Parents felt responsibility as protectors
53	**And she is ok with that, is she?**			
54	Yes. She… We have worked out a system how she will like it. We had a phase where she wouldn't let me touch her teeth. She would only let my daughter.	Child's individual autonomy exercised	Child as an individual	Parents felt responsibility as protectors
55	**Right.**			
56	"Or nanny do it."	Child's individual autonomy exercised	Child as an individual	Parents felt responsibility as protectors
56	**How old is your daughter?**			
57	Eighteen now.			
58	**Oh, right, so a grown-up daughter!**			
59	So that works but I did kind of listen to Bruno Mars, this song for a long time and we danced around brushing teeth!	Parent values oral health	Parental priorities	Parents felt responsibility as protectors
60	LAUGHTER			

61	To make it fun. Because she wouldn't… She wanted to dance. "Let's dance!" So, brushing was with Bruno Mars!	Child's experience important to parent Parent values oral health	Child's experience of the programme Parental priorities	Parents felt responsibility as protectors Parents felt responsibility as protectors
62	**And it worked?**			
63	It worked!			
64	**Excellent!**			
65	Then she got a bit older and … No! So, we found tricks, but she lets me brush.			
66	**Excellent.**			
67	**Do you worry about…. When you take her to the dentist, that she might…. Obviously, this is the first time, do you worry that she might have dental problems? Tooth decay? Or? Is that something that you think about? Or not really.**			
68	No. Because she doesn't have a lot of sweets. She eats fruit, but not too much, and so drinks with a straw… I say that, and we'll go, and there might be problems!	Parent values oral health	Parental priorities	Parents felt responsibility as protectors
69	**Not worried?**			
70	No.			
71	**Ok. So, thinking about the dental project and the fluoride varnish that is going on in Wilbury then, how did you hear about the project?**			
72	When the letter come out.	No prior knowledge / experience of FV programme	Parent's knowledge & understanding	Dental information
72	**Ok.**			
73	That was it, we had the form, and then a letter. It was a bit confusing because the letter said that if you want to do it, it was either yes or no, and we said, yes. And I thought, do I need to fill this form out…. So….	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
74	**The leaflet, you mean?**			
75	I handed the blue leaflet in, instead of the paper.	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
76	That had more information on it.			
77	**Ok.**			
78	But a lot of the parents were just handing in the letters for it to be done…	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information

79	**Ok…**			
80	And the poor old teachers were coming out……	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
81	**So, it was a yes or no on the letter, and a yes or no on the leaflet? Is that what you mean?**			
82	It was a consent form, and on the letter, it said do you want to take part in the fluoride varnish, yes, or no?	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
83	**Yes.**			
84	So, I thought this has got more information on it and so I thought I will hand that one in.	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
85	**Ok.**			
86	For some parents, who might not speak English, they would find that a bit confusing.	Confusion over what needs to be signed Consent process is hard for non-native English speaker – language barrier	Process of consent / information format Process of consent / Info format / English language difficulties	Consent process Dental information Consent process Dental information
87	**Yes, ok.**			
88	But I didn't really hear… there was nothing said, she just came home with the leaflet one day and that was it.	No prior knowledge / experience of FV programme	Parent's knowledge & understanding	Dental information
89	**Ok. So… You have got the letter and you have got the leaflet, so did you understand what it was all about then?**			
90	Briefly. A little bit. Just knew someone was coming in to paint the teeth.			
91	**Ok! Alright. Do you think…maybe… How could they have improved it then? Because it sounds like the information is a bit confusing…**			
92	I mean, when you read the consent form and you get the information, for some people who don't have time: 'Oh it is painting the teeth and that is it.' There was a coffee morning but I didn't feel that that was advertised much…if that makes sense, it was, we are having a coffee morning on this day and we will find out…	Confusion over what needs to be signed No prior knowledge / experience of FV programme More advertising needed	Process of consent / information format Parent's knowledge & understanding Belief in something 'bigger' / Professional impartiality	Consent process Dental information Dental information Trust in Government institutions Dental information

93	Some people…. A lot of parents had had it in nursery, so if you are coming in from a different nursery, which Ella was, you wouldn't know nothing about it.	No experience with children to draw from	Influencing social network / family oral health history	Influencing social networks
94	**Right, I see.**			
95	So maybe something could have been done where they just said, 'for the children who have never had it done, this is a coffee morning and this would be good for you attend'. Because you are like, 'my child is at nursery…' and they didn't say nothing else.	No experience with children to draw from More advertising needed	Influencing social network / family oral health history Belief in something 'bigger' / Professional impartiality	Influencing social networks Trust in Government institutions
96	**Yes. So, there is a difference then, if you have already had it once, through the school nursery or if you come from a different nursery you might want different information, or more information.**			
97	I think that it is… It is good… But I think it is just if you have never had it done before and you come in, maybe for the teachers to say: 'This is for you to attend.'	No experience with children to draw from More advertising needed School as advocate of the programme	Influencing social network / family oral health history Belief in something 'bigger' / Professional impartiality Influence of school	Influencing social networks Trust in Government institutions Influencing social networks
98	**Yes… So, they did do a coffee morning?**			
99	They did.			
100	**Ok. And did you go to that?**			
101	I did go to it.			
102	**And was it….? Did it help you?**			
103	It did because it was very… You could ask questions that you might not think you could ask.	Face to face information useful Opportunity to ask questions	Information format Information format / consent process / Supplementary information needed	Consent process Dental Information Consent process
104	**Right, ok.**			
105	But all of the information was given on that coffee morning and I had a bit more knowledge of what was happening.	Face to face information useful	Information format	Dental information
106	**So, with the information that came out, about the fluoride varnish, did you know… Did you have any questions? Did you know what they meant by**			

	that? Did you know what they were doing? Was it enough?			
107	I found that when you read the leaflet, and you are still in two minds, like what does this do, and what is it like, when you go there, you were shown what the fluoride varnish… what it looked like, and what it does.	Face to face information useful Opportunity to ask questions Preference for spoken information Unsure of knowledge / conflicting messages	Information format Information format / consent process / Supplementary information needed Information format Parent's knowledge & understanding Parent's knowledge & understanding	Consent process Dental Information Consent process Dental information Dental information Dental information
108	**Yes….**			
109	Ok…. Because the picture; I think it is like an egg cup… I think I have got it here…	Visual image suggested to get parents attention Visual images would add clarity	Information format / Information content Information format / Information content	Dental information Dental information
110	**Yes.**			
111	So, you think, that is quite a lot to go on little teeth, but then you are kind of shown what it is and…			
112	**At the coffee morning?**			
113	Yes.			
114	**Right, ok. So that was helpful then, by the sound of it?**			
115	Yes.			
116	**Ok. And…**			
117	**So, obviously you remember filling in the yes or no consent form?**			
118	Yes.			
119	**Do you think that had enough information to make your decision?**			
120	On that paper, no, but consent form explained it all and obviously because she is four and she has never had it, so you kind of want that extra protection and so by them doing it through the school, you think, 'ok…'	Trust in school to only do good for children Mother as protector	Influence of school / Belief in something 'bigger'	Influencing social networks Trust in Government institutions

		In favour of school FV programme Information influential and reassuring	Parents duty to protect from harm Shared responsibility (State & parent) / Convenience for parents Information content	Parents felt responsibility as protectors Trust in Government institutions Consent process Dental information
121	**Do you think that it is important that the dental team ask the parents' permission?**			
122	**Or consent?**			
123	Well yes, because if they do it and something goes wrong, who is to blame?	Belief in parent as custodian / decision maker Consent as protection	Parent as decision maker Consent as protection	Parents confidence to be a decision maker
124	**Right, ok.**			
125	You can blame them for not asking consent, but then it is not their fault if they are coming in and providing a service. But you also need to know if the child has got allergies.	Parents responsibility to inform dental service of any allergies in advance	Parent's duty to protect from harm	Parents felt responsibility as protectors
126	**Yes.**			
127	**So, is that what you think? Is that your opinion of the consent process? It is working out who is ultimately to blame if something goes wrong?**			
128	Well, you have that if there is a problem, and so as a parent, if you know that your child is ill, and you don't put that on the consent form, you have made that mistake. Right. If you don't contact them, you are putting your child at risk. But also, with anything, if you go to your doctor or dentist, you sign a form, so they are keeping themselves safe as well.	Consent as protection Parents responsibility to inform dental service of any allergies in advance Consent as protection for dental service	Consent as protection Parent's duty to protect from harm Consent as protection	Consent proces Parents felt responsibility as protectors Consent process
129	Consent forms are everywhere! You have to say if your child suffers from anything, because what happens if your child reacts?	Consent as protection Parents responsibility to inform dental service of any allergies in advance	Consent as protection Parent's duty to protect from harm	Consent process Parents felt responsibility as protectors

130	**So, when you were saying: 'to keep themselves safe', do you mean… Who do you mean?**			
131	It's everyone, keeping everyone safe, they need to keep the child safe, and they are keeping it safe by not putting my child in danger.	Consent as protection Consent as protection for dental service	Consent as protection	Consent process
132	**You mean the dental team?**			
133	Yes.			
134	**Right. Ok, I understand.**			
135	I see it in my head and I am not very clear….			
136	**It's fine, I just need to be really clear and you are explaining it perfectly… It's just me, I just need to be really clear.**			
137	**Would you say that you understood what you were being asked to sign? And why you were being asked to sign it?**			
138	Yes, and it was an option.	Understood consent process	Parent's knowledge & understanding	Dental information
139	If I didn't want to do it, I don't have to sign it.	Understood consent process	Parent's knowledge & understanding	Dental information
140	**Yes. Ok.**			
	So, they are giving me an option and they are going to provide a service for your child and this helps to protect their teeth. It is not harmful to them. Yes, or no?	Understood consent process	Parent's knowledge & understanding	Dental information
141	Because sometimes you might not… Because of how she is, she has got a dentist, but we have not been able to get into the dentist so for me this covering a little bit until I get to I get to my dentist's appointment, because if there is something wrong, then they can see it.	Participation to mitigate future problems	Parent's duty to protect from harm	Parents felt responsibility as protectors
142	**Right.**			
143	Where if I don't go… What if I can't get to the dentist appointment because she plays up? But I know when it is a problem I can kind of treat her differently and there are different ways of getting in there without her worrying.	Programme seen as safety net	Convenience for parents / Parent's duty to protect from harm	Parents felt responsibility as protectors
144	**So, you think… I am assuming that you think that it is helpful? It is a good thing?**			

145	It is a good thing, because if you don't have a dentist.	In favour of school FV programme	Shared responsibility (State & parent)	Trust in Government institutions
146	**Yes.**			
147	Like some parents don't go to the dentist just yet with kids because they don't think that they need them, because they are still baby teeth…	Unnecessary due to child's age (baby teeth)	Too young for dental care	Parents felt responsibility as protectors
148	**Yes…**			
149	Because I was speaking to a parent and they were… It doesn't matter. It kind of does! Because it gives them confidence to talk, smile, eat, drink and so on, so if there is a problem then the child won't be happy and I wouldn't want to put her through any problems…	Participation to mitigate future problems Belief that children are too young to need dental care	Parent's duty to protect from harm Too young for dental care	Parents felt responsibility as protectors Parents felt responsibility as protectors
150	**So, it is a kind of safety net really… Because you haven't been to the dentist yet, but I know that it is coming up…**			
151	Yes. For some parents, if they can't get into a dentist this can kind of put their mind at ease as well. If that makes sense.	Programme seen as safety net	Convenience for parents / Parent's duty to protect from harm	Parents felt responsibility as protectors
152	**Yes, yes… That makes sense.**			
153	Because some parents don't have dentists for any of their kids and this could be their fifth child and this is them having a dentist. I am… Six months later, I will be back, kind of thing.	Programme seen as safety net	Convenience for parents / Parent's duty to protect from harm	Parents felt responsibility as protectors
154	**Yes.**			
155	**It is different, isn't it? Some people go to the dentist, and some people just leave it, for whatever the reason is.**			
156	**So, you were saying that it gave you the option, so do you feel that that is important to have the option?**			
157	It is, because I am one of these people that if someone says if I have got to do something I am not going to do it! I will rebel! But having an option; you are making that choice, so it is standing on your shoulders at the end of the day, so…. I will weigh it all up, on all sides and then make my decision that way, and if you are told you have to sign and do this, then	Belief in parent as custodian / decision maker Confident in decision method Weighs up information	Parent as decision maker Confidence in own decision Parent as decision maker	Parents confidence to be a decision maker Parents confidence to be a decision maker Parents confidence to be a decision maker

	you are going to think: I am not going to do it! Dig your heels in… Kind of thing…			
158	But having the options…			
159	**Having the choice…. Whether you agree or not, it is sort of a signed thing… but the choice to agree or not, you feel that that is important, as an individual?**			
160	Yes, because for a parent… If I wanted to do research on it, I could go and do my research, on it, and then make that informed decision; I don't think that this will benefit her…	Belief in parent as custodian / decision maker Confident in decision method Weighs up information Parent's know what is in child's 'best interest'	Parent as decision maker Confidence in own decision Parent as decision maker Parent as decision maker	Parents confidence to be a decision maker Parents confidence to be a decision maker Parents confidence to be a decision maker Parents confidence to be a decision maker
161	**Yes…**			
	LOUD DRILLING			
162	'I am not going to do it.' Or, do you know what? 'This will benefit her, let me do it.'	Parent's know what is in child's 'best interest' Belief in parent as custodian / decision maker	Parent as decision maker Parent as decision maker	Parents confidence to be a decision maker Parents confidence to be a decision maker
163	And other parents as well, it is… If they don't mind using fluoride in their toothpaste but they still have that option to do it at home.	Parent's know what is in child's 'best interest' Belief in parent as custodian / decision maker	Parent as decision maker Parent as decision maker	Parents confidence to be a decision maker Parents confidence to be a decision maker
164	**Yes, the choice is key?**			
165	I think you need a choice. I do think that you need that. I mean, even if you say: 'Yes.' You can always change your mind…	Parent's know what is in child's 'best interest' Belief in parent as custodian / decision maker	Parent as decision maker Parent as decision maker Flexible decision making	Parents confidence to be a decision maker Parents confidence to be a decision maker Consent process

		Parents may change their mind from one consent request to the next		
	LOUD DRILLING			
166	**So, what about if the dental team decided, or whoever decided that you were still going to get a choice, but at the moment you have to say: 'yes, I agree', what if they changed it to all the children are included and are going to have the fluoride varnish, unless the parent had the choice but said: 'No, I don't agree with this.' You have still got a choice but it is changing… Instead of saying: Yes, I want it', you are saying: 'No I don't want it.' Do you see what I mean? What do you think of that?**			
167	I would probably be stubborn and say: no, because I like to have that choice first. If I am saying yes, you are taking that, that is it, and my child is signed up and that. But what happens if you couldn't get to them to school because we all have busy lives, and as a parent…. 'tomorrow are they are coming in…oh, tomorrow?!'	Parents are busy In favour of opt-in consent	Convenience for parents Consent process / Parents as decision makers	Consent process Consent process Parents confidence to be a decision maker
168	**Oh ok.**			
169	You might not have that chance to say no.			
170	**Mmm.**			
171	And you are going to be really annoyed afterwards. I would rather have the first choice, yes or no, than be told, you have to say yes, but you can change your mind…	In favour of opt-in consent	Consent process / Parents as decision makers	Consent process Parents confidence to be a decision maker
172	People might not want to do it that way.			
173	**So, you think that it is… You personally would prefer to keep things as they are, where you say yes, I agree to it, rather than no, I don't agree to it.**			
174	Yes…			
175	**Ok. And do you think that there will be lots of people who feel like you?**			
176	Well, I think that there would be, because you are having that option at the beginning and you are weighing up, yes and no, where if you are told that you have to sign up for it, why do I have to sign up for	Parents are busy Parent's know what is in child's 'best interest'	Convenience for parents Parent as decision maker	Consent process Parents confidence to be a decision maker

	it? You kind of get that defence: 'It is my child, I decide…. You are making that choice for me.' Where…. As I say, we are all busy, and sometimes I kind of forget I have got appointments until the day before. So…	Belief in parent as custodian / decision maker	Parent as decision maker	Parents confidence to be a decision maker
177	Remembering to opt out of something it is not going to be the forefront of your mind. Because what happens if your child, or something beforehand, has a reaction to something, but you have not put that on the form.	In favour of opt-in consent	Consent process / Parents as decision makers	Consent process
178	**Yeah.**			
179	What happens then? I like to decide: yes or no, first of all.	In favour of opt-in consent	Consent process / Parents as decision makers	Consent process Parents confidence to be a decision maker
180	**That's alright!**			
181	**That is what I want to know.** **Ok. So, do you think that it is difficult thinking about that then, because you are saying that if people have busy lives and sometimes people might forget, which is true, it is true of everybody sometimes.**			
182	**Do you think that it is difficult for parents to remember to fill in the form and send it back to school?**			
183	I think that if because… my form will come back in the book bag.			
184	**Right.**			
185	Some kids will come out with it in their hands.			
186	**Ok.**			
187	So, if you don't see some kids coming out with it in their hands… Some parents are not that kind, I check the book back every day, so I am lucky, but some parents… if they don't see it…. But the school have actually said: 'Have you signed the forms and they were going up to the parents' and… 'Have you done the forms?'	Presenting as good parent School as advocate of the programme Distribution by teachers and children is flawed	Influencing social network * Influence of school Consent process	Consent process Influencing social networks Consent process Dental information

		Leaflets can be missed/overlooked	English language difficulties / Information format	
188	**Ok, so you were prompted to return the form one way or another? Whether you agree or disagree, you were prompted to return the form by the school?**			
189	Yes.			
190	Which is good, because sometimes you kind of need that with kids… She had a… to go and see Jack and the Beanstalk, and the teacher was saying to some parents, you haven't done it yet, you need to do it or the places are going to go, and so that prompting on anything is good for parents, especially if you are a working parent. You just need that reminder.	Parents are busy Parents benefit from reminders Leaflets can be missed/overlooked	Convenience for parents Convenience for parents / Consent process English language difficulties / Information format	Consent process Consent process Dental information
191	**Yes.**			
192	The whole…..			
193	**So, what do you think about how it is organised then? If you are saying that sometimes that kids get it in their hand or some kids get it in their book bag, and you know, parents might be working, or even if they are not working, they are busy…. Just being a parent is busy. How do you….? What is your opinion of sort of how it is organised? Do you think it could be done differently or better to make it easier for parents?**			
194	I don't know, because she is in Reception, so… I think for some kids you can't be coming out of school with it in their hands, but I think, if it is in there…The teachers; when they open the door, could just say: 'We have got a form that we need you to fill out and please have a read.' Maybe do it that way.			
195	In her… there is like four classes in Reception and kids…. For parents that take it off their kids, or let the kids hold them, and if they drop it, or…	Distribution by teachers and children is flawed Teachers to alert parents to letters Leaflets can be missed/overlooked	Consent process Consent process / Influence of school English language difficulties / Information format	Consent process Consent process Influencing social networks Dental information
196	**Yes.**			

197	Book bags are very known to keep a load of rubbish in… I remember with my older two, they would come home and there would be loads of pictures and then you have also got to… That has got to be binned, by tomorrow! Kids, unless they tell you… But I think if the teacher stands at the door; 'we have given these out today, please have a look, and hand it back in…' Maybe just that way. But can you put that on the teachers if it is not to do with them? So, you have got to find a way…	Distribution by teachers and children is flawed Teachers to alert parents to letters Not teachers job to give out letters Leaflets can be missed/overlooked	Consent process Consent process / Influence of school Consent process English language difficulties / Information format	Consent process Consent process Influencing social networks Consent process Dental information
198	**So, whether it is the teachers, or could it be somebody else that did that then?**			
199	Like who?			
200	**I don't know. I am just thinking… You know… It is that sort of face to face reminder… Not a reminder but a sort of face to face prompt that something is coming out and parents need to take a look at…**			
201	And it is like, who can do it, is it someone from school, or the dental part? But then you don't know… how busy they are, or if they are going to free up someone to come and the end of school… By that stage you might have had someone who… have parents say, let me fill it out and do it now, or here is a form and then you are putting that on… to hand back…if it is a teacher at school…. It is a hard situation. You can put it on the school, because they are having it in the school, they are inviting us to be seen, but then you could put it on the service to say, you are coming and you have to do everything, so if you work together, you might get somewhere.	Schools and dental service need to work together	Shared responsibility	Trust in Government institutions
202	**But…. I understand what you are saying about who's sort of role is it. I am just thinking about the mechanics of it, so, you know, a letter is ok, but you said that you weren't one hundred percent sure which bit, whether it was the letter or the leaflet that we had to fill in, and then you mentioned that things might get overlooked because they are in book bags and things like that. I am just thinking about how things may be**			

	organised better, and it might be that there is some other way and I don't know what that would be.			
203	When we have had the coffee morning he did explain to hand the consent form in, and there was some consent forms if you want to fill them out right then and there.	Information needed clarification in person Immediate decision	Information format Consent process	Dental information Consent process
204	**Ok.**			
205	You could have done it.			
206	**Right.**			
207	In some ways, he did clear that up.	Information needed clarification in person	Information format	Dental information
208	**Right, ok.**			
209	Which was like a good thing, but…			
210	I think if you could have a coffee morning, it does help and get you to understand what the pros and cons of it. It helps you make… When I was there, quite a few parents were like, 'let me fill in the form'.	Information needed clarification in person Immediate decision	Information format Consent process	Dental information Consent process
211	**Mmmm.**			
212	So, for some parents it is easier to hand the form in there and do it there than go home…	Immediate decision	Consent process	Consent process
213	**Take it away…**			
214	Yes.			
215	**Yes, ok. So, thinking about that then, and filling the form in, and making the decision, did you make the decision based on your previous experience with your other children? I know you were saying that they are grown up…**			
216	We didn't have that. We never had those options. We had the dentists coming in and that annoyed me, because they had so many kids but they were… We had a letter saying I had problems with my teeth, and I took them straight to the dentist, panicking, and he said: "Look their teeth are fine." And I am thinking, so why have I got this…? So, that kind of threw me off the dentist coming into school, and so when it come to her, I was like, right… That was years ago, and let me have a different view on it. This was something different and they weren't coming in checking their	No prior knowledge / experience of FV programme Child's experience important to parent	Parent's knowledge & understanding Child's experience of the programme	Dental information Parents felt responsibility as protectors

	teeth, it was putting something on the teeth, and so I had to wait, and because I know how she is and would she have it done? Because I don't want to stress her out, but I thought, it is just painting, kind of, so she should be alright, and brushing it, ok… kind of…			
217	**So, with your… when you made the decision then, obviously your older children didn't have it done, but they did have something else to do with dental in the school…**			
218	It was just quickly looking in the mouth and check up…			
219	**Right. So, when you made the decision for Ella, how did you… how did you decide? Did you talk to other…? like your friends with kids? Or did you…? How did you make that decision?**			
220	I know that my friend's sister, her kids went to a different school…			
221	**Right…**			
222	And they actually had it, so I asked her like… Because she has got a child who has got behavioural problems and how were they? And she said perfectly fine. And I said: "Would you recommend it?" And she said yes. For her, she had never been to the dentist, so that was her way of having the dentist check if that…	Additional information sought from friends Programme seen as safety net	Influencing social network / Supplementary info needed Convenience for parents / Parent's duty to protect from harm	Influencing social networks Dental information Parents felt responsibility as protectors
223	**Right…**			
224	Makes sense…. Until they have… If they have got a tick, she said, then I needed to go and take them, so I was like, I have got that information, read it, and kind of done the pros and cons, and so then my daughter, she is quite a reasonable child, my daughter, she is… "What do you think?" And she was like, yes… Because when they used to go to the dentist, she used to have it, so for someone who has had it….	School programme helps parents familiarise children with going to the dentist Weighs up information	Influence of school Parent as decision maker	Influencing social networks Parents confidence to be a decision maker
225	**Oh, your other daughter you mean?**			
226	Yes. She used to go to the dentist and she had it done.			
227	**Right.**			

228	What do you think? And she was like, 'yes, she will be fine with it mum, don't stress.'			
229	**Ok.**			
230	I spoke to someone who had had it, a parent whose child has the same kind of… Yes. I did think about it, I didn't just sign the form straight away.	Weighs up information Additional information sought from friends Presenting as 'good' parent	Parent as decision maker Influencing social network / Supplementary info needed Influencing social network *	Parents confidence to be a decision maker Influencing social networks Dental information
231	**Yes.**			
232	It took a couple of days.			
233	**Yes, course.**			
234	And I got the information that I needed.			
235	**Were you concerned about making the decision? I am just thinking that your older daughter said: 'Mum, don't stress!' I am just wondering, were you concerned about the decision?**			
236	I was only concerned because I know how she reacts. So, my concern was about… It was about how she would behave to it. Because I don't want to put her in a situation where she is going to get stressed and if they can't apply it… I don't want to put everyone in that stressful… Because know how she behaves. But then, my daughter was like, Mum, she will be fine. Yes. She was brushing her teeth, every five minutes she wants to brush her teeth anyway.	Child likes brushing their teeth Child's experience important to parent	Family oral health history Child's experience of the programme	Influencing social networks Parents felt responsibility as protectors
327	LAUGHTER			
328	I spoke and I said… This week I believe that it is happening…?			
329	**Ok.**			
330	So, I will say to her, you are going to have some stuff painted on your teeth, and just break it down. I didn't rush into the decision which is quite good for me, because normally I can sometimes… But…	Child's experience important to parent Parent prepares / explains to child	Child's experience of the programme Parent's duty to protect from harm / Child's experience of the programme	Parents felt responsibility as protectors Parents felt responsibility as protectors
331	**Why was this decision different to making other decisions? If normally you rush into things but this one you kind of considered a bit more?**			

332	Because it was to do with Ella's teeth.	Mother as protector	Parents duty to protect from harm	Parents felt responsibility as protectors
333	**Right.**			
334	And she has never been to the dentist yet. So, I was a bit worried about how she would behave.	Child's experience important to parent	Child's experience of the programme	Parents felt responsibility as protectors
335	**Yes.**			
336	And…. So, I was worried about how she would….			
	LOUD DRILLING NOISE			
337	But my daughter said it is in a different environment, it is in her school, and it is not a dentists' chair, so that might be a better way to introduce her to it.	School programme helps parents familiarise children with going to the dentist School environment influences children	Influence of school Influence of school	Influencing social networks Influencing social networks
338	**But did you get any information from anywhere else?**			
339	**Did you look anything up on the internet? Or did you talk to anybody else?**			
340	I spoke to the person who done the coffee morning.	Face to face information useful	Information format	Dental information
341	**Yes.**			
342	I spoke to…			
343	**That was the dental person?**			
344	Yes. Then I spoke to a parent who has had both of her children who have had it done, so I have got how she was.	Additional information sought from friends	Influencing social network / Supplementary info needed	Influencing social networks Dental information
345	**So, you have got quite a lot of information, before you made your decision then?**			
346	I didn't Google it though.			
	LAUGHTER			
347	I did not Google it!			
348	**Ok. So, what type of information did you get…. Was there any difference from the type of information that you got from the dental person at the coffee morning or from your friend, or a parent at a different school? How does that… Or was it similar?**			

349	Obviously, it was… When you are reading the information… What…? But when he explained it, it was ok, that don't sound too bad… I think that you kind of think, like how they do it in dentists, you kind of think that it is going to be like that.	Formality of information make a difference	Information format	Dental information
350	**Yes.**			
351	But it is not, it is done a different way. And because it is in a different environment as well, and when you are speaking to a friend, they speak to you on a different level than a professional is, so…. Yes.	Formality of information make a difference School environment influences children	Information format Influence of school	Dental information Influencing social networks
352	**Was there… Did you… Was there one of them that you felt a bit more persuaded by? Or someone was a bit more trusting?**			
353	I think the coffee morning, with the dental team. I think, because… with a friend, they can tell you what you want to hear… kind of thing…	Parents want professional advice / guidance	Defer to dental expertise / shared responsibility (State & parent) / Information content	Parents confidence to be a decision maker Trust in Government institutions Dental information
354	**Ok.**			
355	They can look at your face, 'Oh, bloody hell, it is going to be this and that, but when you are with the dental team you are kind of looking at… You can see how their body is as well…	Parents want professional advice / guidance Body language of professional has influence on confidence in advice given & parents decision	Defer to dental expertise / shared responsibility (State & parent) / Information content Information format / Professional impartiality	Parents confidence to be a decision maker Trust in Government institutions Dental information
356	**Ok…**			
357	Their body language is…			
358	**Ok.**			
359	So, when they are relaxed and you are thinking, oh it is not too bad… Whereas if they were tense, you would be thinking, what are they hiding?	Body language of professional has influence on confidence in advice given & parents decision	Information format / Professional impartiality	Dental information
360	**Ok.**			
361	What are you hiding from me?			
362	LAUGHTER			

363	But it was quite relaxed, if that makes sense, and you could ask what questions that you had, he answered them really well, and it… "Do you have any other questions?" It was nice. Because if there was a question that you wanted to ask and you weren't sure someone else might have asked it… Or, you know, you are free to ask, so…	Body language of professional has influence on confidence in advice given & parents decision Face to face information useful Opportunity to ask questions	Information format / Professional impartiality Information format Information format / consent process / Supplementary information needed	Dental information Dental Information Dental information Consent process
364	**Did you get everything…? Did you get all of your questions answered? Did you get enough information that you needed from that?**			
365	Yes.			
366	**Ok. Was there anything else… Just thinking about how you made the decision and you obviously took a couple of days….**			
367	If it would benefit her.			
368	**Right.**			
369	That is all I need to know.			
370	**Right.**			
371	That is what I need to know. If it is going to benefit her. Because she is one of those kids that does not have a lot. Is it worth her having? Is it worth her not having? Do I put her through that? So are we… Do you know what? It is not harmful, it is a quick paint on, it's going to take less than a minute. She can handle that.	Weighs up information Child's experience important to parent	Parent as decision maker Child's experience of the programme	Parents confidence to be a decision maker Parents felt responsibility as protectors
372	It will help because if she does go to the dentist, and they do apply it, she knows that there is nothing too stressful about it. But to me, it gives me that little bit of comfort and reassurance until I get her to the dentist and everything.	School programme helps parents familiarise children with going to the dentist Programme seen as safety net	Influence of school Convenience for parents / Parent's duty to protect from harm	Influencing social networks Parents felt responsibility as protectors
373	**So, you have got sort of… Yeah… So, you are taking to the dentist anyway, in a little while,**			

	aren't you? And so, this is like a pre-sort of thing?			
374	Yes.			
375	**Is there anything else that you think that would have helped you with the decision? Is there any more support that you think could be given to you or to other parents in a similar situation?**			
376	I think… I could say yes, and I could say no, but the only thing that I might say is to have the information just before the consent forms come out, because we had the consent form and then we had a coffee morning.	Give written info after face to face meeting Timing of giving parents information is important	Consent process Consent process	Consent process Consent process
377	**Yes.**			
378	Maybe if we had a coffee morning first, and then the consent form…	Give written info after face to face meeting Timing of giving parents information is important	Consent process Consent process	Consent process Consent process
379	**Right…**			
380	Because I felt that the consent forms come out, and then the coffee morning a bit after, maybe do it the other way around where… Because some parents what with work, so might not have a chance to have a coffee morning…. So, maybe there is an after-school session? Especially because she came from a different private nursery and if you don't know anything about it, you think what is this? So, I think an information session before the consent forms come out.	Give written info after face to face meeting Timing of giving parents information is important	Consent process Consent process	Consent process Consent process
381	**Ok, so the information first, and then ask if you agree or not? Rather than the other way around?**			
382	Yes, because, for some parents, may look at the form and not bother… a coffee morning… I can't go to that. It is very hard. I have never had it done, and so for me it would be nice to have the information first, and then have the consent forms.	Timing of giving parents information is important	Consent process	Consent process
383	**Yes.**			
384	That way, you have the consent forms and then you have a coffee morning, and what happens… if you	Timing of giving parents information is important	Consent process	Consent process

	have said yes, and then you go to the coffee morning and think, oh no…			
385	**And change your mind?**			
386	Yes.			
387	**So, is there a mechanism there if you change your mind?**			
388	Well, there was a number on the back to call, so if you have any questions, which is really good, because sometimes you might have questions like there and then, and you can go… there is a number that you can contact… which is a good thing, and so if you change your mind then you can give them a call, and say please can you take blah, blah, blah, out of it.	Opportunity to ask questions	Information format / consent process / Supplementary information needed	Consent process Dental Information
389	**Ok, and do you think that using a consent form, you know, a paper form, do you think that is the best… Was that ok for you? Or do you think that there are other ways that parents could let the school or the dental team know what their decision is, it might be easier than filling in a form and sending it back?**			
390	Well, no, I think that the form is better because it asks questions, if you child has allergies, and…	Leaflet is preferred format for consent request - convenient	Information format / Convenience for parents	Dental information Consent process
391	**Right.**			
392	Because if your emailing or something, then you are not having all that information really are you? So, the form is good…	Leaflet is preferred format for consent request - convenient	Information format / Convenience for parents	Dental information Consent process
393	**So, that is medical information…**			
394	I think that the consent form is good because it gives you information about what is happening as well. Well, if you had a text: 'Do you want this, press one to opt in, or two to opt out…' That is the right way of doing it, anyway… But… I can't think of anything different because…	Leaflet is preferred format for consent request – convenient Parents responsibility to inform dental service of any allergies in advance	Information format / Convenience for parents Parent's duty to protect from harm	Dental information Consent process Parents felt responsibility as protectors
395	**So, that worked for you?**			
396	**The hard copy paper consent form?**			
397	Just not the white letter that come with it, because that was like…			
398	**That was the confusing bit…**			

399	Well, it says do you want to opt in, yes or no, and if you say yes, the teacher comes out: "Oh you need to fill this in." So, some parents are like: "Oh?" Do you know what I mean? "I thought I had done it."	Confusion over what needs to be signed Information needed clarification in person	Process of consent / information format Information format	Consent process Dental information Dental information
400	**So, do you think that some parents might not…fill in the blue consent form then, because they think that they have already done it.**			
401	I noticed a lot of parents had given the white form in, and not done the blue form, so I did see a lot of teachers coming… "You need to fill this one out."	Confusion over what needs to be signed Information needed clarification in person	Process of consent / information format Information format	Consent process Dental information Dental information
402	**Right.**			
403	So…			
404	**There is a bit of confusion there.**			
405	Because parents might just thing that that is just information… there is no consent form in there, but until you open up and read it: Oh, this is what I have to hand in. But I think that is more parents who don't speak much English though.	Information needed clarification in person Confusion over what needs to be signed Consent process is hard for non-native English speaker – language barrier	Information format Process of consent / information format Process of consent / Info format / English language difficulties	Dental information Consent process Dental information Consent process Dental information
406	**Right.**			
407	Because it was Turkish parents and Somalians who hadn't done it. So…	Consent process is hard for non-native English speaker – language barrier	Process of consent / Info format / English language difficulties	Consent process Dental information
408	**Do you think the information that is in that leaflet then, was it written in a way, you know, that was quite straightforward to understand…?**			
409	If that came back by itself…. No problems… But if it comes back with two things, yes or no… You are kind of… 'Do you want your child to go on a school trip, yes or no?' You just think that is just information about it, so parents are not… So, it's… And if you have never had it done before, you won't know to do	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information

	the form as well, because you have some kids who have had it done in Nursery, so they know what to do….			
410	**Yes, because they have got experience…**			
411	Yes.			
412	**Yes.**			
413	I think that maybe it is just having that little… like not all kids have come from that Nursery and some parents have not had it, so maybe not have had a different form…just have that.	Confusion over what needs to be signed	Process of consent / information format	Consent process Dental information
414	**Just that one blue form?**			
415	Yes, yes…	Confident in decision method	Confidence in own decision	Parents confidence to be a decision maker
416	**So, if you were asked a simpler question again, would you make a decision in the same way?**			
417	I would do my research…So, yes.			
418	**Do you always do that?**	Confident in decision method	Confidence in own decision	Parents confidence to be a decision maker
419	Things that I am not sure about, I do.	Confident in decision method	Confidence in own decision	Parents confidence to be a decision maker
420	**Right.**			
421	So, I do have… Because you don't know… And also, she has never had before but I have known about my friend's sister…. Her kids had had it done, and so that is why I asked her because she is a parent… she knows what it was so….	Confident in decision method Additional information sought from friends	Confidence in own decision Influencing social network / Supplementary info needed	Parents confidence to be a decision maker Influencing social net Dental information works
422	**Do you feel that generally you are able to make those decisions without too much difficulty?**			
423	Yes. But also, because I am a special guardian, I have to make sure that I am making the right decision for her. If it was my kids I would still do the same research.	Parent's know what is in child's 'best interest'	Parent as decision maker	Parents confidence to be a decision maker
424	**Right…**			
425	Because my son is asthmatic and Ella is asthmatic and I need to make sure that everything is ok.	Mother as protector	Parents duty to protect from harm	Parents felt responsibility as protectors
426	**I know that the fluoride varnish is done twice in one school year, isn't it?**			
427	Yes.			

428	**So, do you think that parents… How do you feel, do you agree or not agree, both of those times, or do you think that it should just be once, or do you think….?**			
429	I think that it is good to have that option, because if your child has had it done the first time and you know how they have react, and if they react bad, you are not going to put them through again, are you? So, it is good to say: 'D'you know what? No thank you.' Where, if you know that your kid is ok, you know that it is fine for them to have it again, but I think that if a kid reacts badly, it is good to have that…	Child's experience important to parent In favour of two consent requests per year	Child's experience of the programme Information format / Consent process	Parents felt responsibility as protectors Dental information Consent process
430	**What do you mean by react badly?**			
431	If they get upset and frightened.	Child's experience important to parent Parents may change their mind from one consent request to the next	Child's experience of the programme Flexible decision making	Parents felt responsibility as protectors Consent process
432	**Right.**			
433	Or, if they have it and they are sick or something, you don't want to put them through that. Because you know when they come a second time: "Oh it is those people again!" And that fear…. That way it is good to Parents may change their mind from one consent request to the next have that option, because as a parent you… You know, they reacted really badly, and they were sick, fever, whatever, and you are not going to do it again. So, it is good to have that option again! Options!	Concern over child's physical reaction e.g. sick Parents may change their mind from one consent request to the next Belief in parent as custodian / decision maker	Parent's duty to protect from harm Flexible decision making	Parents felt responsibility as protectors Consent process
434	**So, having the choice, basically, is important.**			
435	Yes.			
436	**Ok.**			
437	**And so, it sounds like the choice obviously is important, and you have said… It sounds like that you weren't too worried… And when you were making the decision it was more about how she would react and any concerns about the treatment itself… Is that what you were saying, or not?**			

438	Yes. Yes.			
	Because she has behavioural issues… So, I am not… If I know that everything is fine, I can break it down to her and explain everything that is going to happen on that day…	Parent prepares / explains to child	Parent's duty to protect from harm / Child's experience of the programme	Parents felt responsibility as protectors
439	**Ok.**			
440	So, for instance, it is on Wednesday… So, you are going to see a special person and she is going to paint your teeth, nothing to worry about.	Parent prepares / explains to child	Parent's duty to protect from harm / Child's experience of the programme	Parents felt responsibility as protectors
441	**Yes.**			
442	And then when she gets there, she knows what I have taught her.			
443	**Yes.**			
444	There is nothing to be scared of. Because as long as it is not going to affect her so that she has a reaction to it as well, but I need to make sure that she is ok with having it done… Because I don't want her to have it done if she screams and is sick… I am going to be thinking, is that the fluoride, or is that just because of her behaviour? But…	Parent prepares / explains to child Concern over child's physical reaction e.g. sick Child's experience important to parent	Parent's duty to protect from harm / Child's experience of the programme Parent's duty to protect from harm Child's experience of the programme	Parents felt responsibility as protectors Parents felt responsibility as protectors Parents felt responsibility as protectors
445	**So, if she decides on the day…. You have said…**			
446	"Yes…"			
447	**But she has decided on the day that she doesn't want it done… She goes into school and she says I don't want it done, so she doesn't have it done. How would you feel about that?**			
448	I am not going to push her into something. So, if… "Why didn't you have that?" I will wait for my dentist appointment and make him… I don't want the stress of it!	Child's experience important to parent Respect for child's autonomy	Child's experience of the programme Child as an individual	Parents felt responsibility as protectors Parents felt responsibility as protectors
449	Because she is a little person. If she… She is very independent and I am not going to force her to have something done… Because that is her school, and I don't want to have that fear at all… Because if	Child's experience important to parent Respect for child's autonomy	Child's experience of the programme Child as an individual	Parents felt responsibility as protectors

	someone else… We have the nurse coming in to do the flu, and that is going to be a nightmare as it is… Because I know that it is a spray up the nose and she is going to react differently to that, so…			Parents felt responsibility as protectors
450	**Do you think… Thinking about that then, do you think that the school has a role to play in this? Do you think in making the decision… you making your decision… and the sort of, you know, obviously it is done in a school setting, do you think that is important…? How do you feel about it being done through the school?**			
451	I think that it is good. Because… My little one freaks out when she has to go to the doctors. So, with the school, it is a calming and nice environment, and for some kids a friendly environment is a good thing, because they might then go along and open up their mouth. Whereas if you were to take that child to a dentist…. "No, no, no!" Kind of thing. But it is better than going to a cold building.	In favour of school FV programme School environment influences children School programme helps parents familiarise children with going to the dentist	Shared responsibility (State & parent) / Convenience for parents Influence of school Influence of school	Trust in Government institutions Consent process Influencing social networks Influencing social networks
452	**Ok. What do you mean?**			
453	Well, dentists are not… and doctors… they are horrible really. I hate them!	Parents phobia of dental care	Family oral health history	Influencing social networks
454	**What do you mean by horrible?**			
455	Well, with the doctors, they have that kind of sickly feel… So…. She won't go and see the nurse at my doctors, because she thinks that she is going to have an injection and so as soon as we get near that door: "No, no, no… I don't want to be here… I don't want to come to the doctor!"			
456	"We are not seeing the real doctor, we are seeing the pretend doctor!"			
457	**Ah.**			
458	So, to her, I kind of have to change it around, and so she has got a bit… of the fear.			
459	But she did pull out the needle herself…			
460	**Oh dear.**			

461	That is what I mean. I have to prepare her for the situation, so I know that she likes school, and I know that they aren't going to be sitting in a chair, and no one is having a mask on….	Parent prepares / explains to child School environment influences children	Parent's duty to protect from harm / Child's experience of the programme Influence of school	Parents felt responsibility as protectors Influencing social networks
462	**Right.**			
463	So, it is more friendly.	School environment influences children	Influence of school	Influencing social networks
464	**Yes.**			
465	So that is a good thing.	In favour of school FV programme	Shared responsibility (State & parent) / Convenience for parents	Trust in Government institutions Consent process
466	**Are you a bit concerned about how she is going to react? Or do you feel comfortable with it now?**			
467	I feel that I have all the information, I know what to tell her, so I am not worried, but ask me on the day and I could tell a different story.	In favour of school FV programme	Shared responsibility (State & parent) / Convenience for parents	Trust in Government institutions Consent process
	LAUGHTER			
468	Until I pick her up. So… I am not worried. But I need to make sure that she is ok, and I know that it is not going to harm her. No injections and no nothing. It is just like a little brush….	Child's experience important to parent	Child's experience of the programme	Parents felt responsibility as protectors
469	**Yes…**			
470	It is just painting it, as they say.			
471	**And if she decides herself, on the day, that she doesn't want it done, as you say, it is her choice anyway…**			
472	Yes…			
473	**So, choice is quite important then, isn't it?**			
474	Yes. Because I don't want her to feel like… You know, when you go to a dentist you have to sit in the chair, this is old school dentist, but my dentist that I have now, he is more… friendly, and so if she doesn't want it, he is not going to push her. Whereas some dentists will be: "No, you have to have this done."	Child's experience important to parent	Child's experience of the programme	Parents felt responsibility as protectors
475	**Yes. Ok, so thinking about the way that you made your decision and where you got your information**			

	from before you formally made your decision and put your signature down…			
476	Yes, yes, yes…			
477	**Is there anything that would… that dental team could do, to help you? Or do you feel that they did enough, or the school could do? Is there anything that you want to add about sort of making the decision itself?**			
478	I think that maybe having a coffee morning, before giving the consent forms out.	Timing of giving parents information is important Face to face information useful	Consent process Information format	Consent process Dental information
479	**Right.**			
480	That might get more parents. Because when you had the consent forms, you don't know much…	Parents want professional advice / guidance	Defer to dental expertise / shared responsibility (State & parent) / Information content	Parents confidence to be a decision maker Trust in Government institutions Dental information
	LOUD DRILL			
481	I have got the form now…maybe do it the other way around? Or even have some parents who have had it done before, could get involved with parents' point of view…. That could be nice as well.	Timing of giving parents information is important Formality of information make a difference Other parents experiences useful to know when making decision	Consent process Information format Influencing social network	Consent process Dental information Influencing social networks
482	**Do you think that other parents would like to hear it from a parent whose children have had it?**			
483	Course you would, because you know that you are on the same level, where this is where… Finding out from another parent… "Oh do you know what… They was a bit tearful, but when they got home they were perfectly fine…. There's nothing wrong…." And they are being told by a professional. But having a parent…. That will be nice. Especially for a parent who has come in Reception and you don't know nothing about it…. Having… Even a parents evening	Formality of information make a difference Other parents experiences useful to know when making decision	Information format Influencing social network	Dental information Influencing social networks

	we had that, and so when someone has information…who has already been there…			
484	**It is having that common experience…**			
485	Yes.			
486	**Right, ok. So, you think that is quite important then, in the sort of parent… when you are thinking about things for your child?**			
487	Yes, because if you know that a parent has been through it, you are hearing how they feel first hand, where if you are being told by the professional… 'Really? How do we know that you are telling the truth?' Kind of thing. Again, there is body language as well…	Formality of information make a difference Other parents experiences useful to know when making decision	Information format Influencing social network	Dental information Influencing social networks
488	**Ok. So, would you potentially…. Maybe sometimes sceptical about what the professionals say?**			
489	Yes…and no.			
490	Because I have had it from years ago, and maybe a professional will say something to me, and maybe they have got it wrong, so….			
491	**Right…**			
492	You kind of… That's why I go from both sides…			
493	That is why I went to the coffee morning, got the information that I needed from there, spoke to a friend and got their information and then that, and they are both kind of on the same page…	Information needed clarification in person Additional information sought	Information format Supplementary info needed	Dental information Dental information
494	**Right…**			
495	Let's go with it.			
496	**Because they were both sort of confirming what the other one was saying?**			
497	Yes, that was a good thing for me.			
498	**Is there anything else that you think is important for me to know about how you made the decision or the process, you know, the filling in the forms? I know you have said about the coffee mornings… Or you know, having that choice or anything else that you need to know?**			

499	Just having one form, not two forms, because again it is coming out like a letter, yes or no, so I am yes, just the one form. It is straight to the point, which is what you need because parents sometimes don't have that time to sit in the evenings, but I do think that a coffee morning before the forms come out, and then maybe after, and that is kind of pushing it. That has a phone number and so if you do have any questions, you can just say: "Excuse me." This and that.	Confusion over what needs to be signed Timing of giving parents information is important Opportunity to ask questions	Process of consent / information format Consent process Information format / consent process / Supplementary information needed	Consent process Dental information Consent process Dental Information Consent process
500	**Would you do that?**			
501	If I had any questions, yes.			
502	**Ok.**			
503	If I did and I wasn't in that coffee morning, I would have gone: Right, let me call them.	Opportunity to ask questions	Information format / consent process / Supplementary information needed	Consent process Dental Information
504	**Right, thank you very much, unless there is anything else at all that you would like to add to do with this, that you think that I should know?**			
506	I will wait to Wednesday and see what happens.			
507	**Yes.**			
508	I may have a different story!			
509	**Ok, thank you very much. If I need to clarify any points I will get back to you!**			
510	Thank you very much!			
	END OF RECORDING			

Appendix 4.6a Public information sheet

Whittington Health NHS

CITY UNIVERSITY LONDON

Title of study Influences on parental consent decision making

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Parents are required to provide their written consent before their children can be included in dental public health programmes carried out in schools *i.e*. fluoride varnish projects. Some parents provide their consent and some parents refuse. We would like to know what influences parents to decide one way or the other.

This research project is being undertaken as part of a doctoral programme of study facilitated by City, University London (School of Health Sciences).

Why have I been invited?

Parents whose children go to school in Enfield and who have received a request for their consent from the dental service in the last academic year are being invited to participate.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate. If you do participate, you can withdraw at any stage of the project without being penalised or disadvantaged in any way.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part and sign this form you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

- Each parent can agree to take part in a group discussion or they can speak to the researcher individually. It is anticipated that a group discussion with other parents will take no more than 1.5 hours, if you choose to speak to the researcher individually this should not last longer than 1 hour.
- The researcher will be in contact with you on two separate occasions. Initially researcher will confirm that you are happy to be included and to make arrangements, and then at another time when you take part.
- Anyone taking part will be asked questions about their experience participating in the consent process and about how they came to the decision to refuse or consent for their child. The group discussion and interviews will be recorded by the researcher and written up at a later date.
- The researcher will analyse the taped interviews of all participants and attempt to identify common themes amongst them.
- No information that can personally identify individuals will be included. But, some anonymized quotes may be used.

- Group discussion or interviews will take place in a quiet place and at your convenience. If the researcher needs to clarify information after the face to face interview has taken place, you may be contacted on one final occasion.

Expenses and Payments (if applicable)

No expenses or other payments will be made to participants, but everyone who takes part will receive a 'dental pack' that contains a toothbrush and toothpaste. This is to thank you for your participation.

What's the next step?

If you agree to take part the researcher will contact you to arrange a time and date for the interview to take place. If for any reason you need to reschedule a planned meeting please contact the researcher as soon as is possible. During the group discussions or interview you are asked to engage fully in the process by answering questions honestly.

What are the possible disadvantages and risks of taking part?

There are no personal disadvantages to taking part.

What are the possible benefits of taking part?

There are no personal benefits for participants. However, the indirect benefits are likely to include a better understanding of how the parental consent process can be supported leading to increased number of parent actively making a decision to consent or refuse and fewer people not responding.

What will happen when the research study stops?

Any data that identifies individual participants will be stored securely by the researcher *i.e.* on a password protected computer and on a secure server which is part of City, University of London. This will be kept for the duration of the researcher's doctoral programme, and for a further 10 years in accordance with City, University London guidelines. Therefore it is anticipated that data will be stored until 2029. After this period data will be destroyed.

Will my taking part in the study be kept confidential?

- The researcher alone will have access to identifiable data and this will be stored securely as mentioned above. Information included in the research report will be anonymized prior to use, this includes any quotes. No personally identifiable data will be shared with others. The only exception to this is if data needs to be accessed by senior academic staff at City, University London if necessary for the progression of the researchers' doctorate study.

- Audio taped interviews will be transcribed soon after the interview takes place and at this stage all personal details will be removed. Individual interviews will be allocated a code to identify one from another. Audio files will be stored in encrypted files and paper copies stored in locked cabinet for the duration of the researcher's doctoral study, after which they will be destroyed. Anonymized transcribed interviews will be kept electronically on a secure server at City, University of London for 10 years after the researchers doctoral study has finished.

- Personal information will not be used in the future by the researcher. However anonymised data will be used as part of the researcher's doctoral programme of study and may be disseminated in either journal articles or conference papers. This may include anonymous quotations, but it should be stressed that whole interviews or personal data will *not* be shared in this way.

What will happen to results of the research study?

Once completed, the analysed information from this study will be written up to form part of the researcher's overall doctoral thesis. Additionally, a shorter summary of this study and the findings will

be written as a journal article and submitted for publication to professional journals such as 'Community Dental Health', 'Dental Health', or the 'British Dental Journal'. Any personally identifiable information that relates to participants will not be included in any of these formats *i.e*. thesis or journal article. Prior to publication the information will be made available to participants. This will be sent to them via email using a pdf attachment.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study without an explanation or penalty at any time. Any information already collected from the participant prior to this decision will not be included in the final analysis or report. All data related to the application will be destroyed.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate City, University of London School of Health Sciences Research Ethics Committee and inform them that the name of the project is: Influences on parental consent decision making
……

You could also write to the Secretary at:
[redacted]
Secretary to Senate Research Ethics Committee
Research Office, E214
City, University of London
Northampton Square
London
EC1V 0HB
[redacted]

City, University of London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City, University of London School of Health Sciences Research Ethics Committee

Further information and contact details

[redacted]

Charlotte Jeavons – Research Student
[redacted]

Appendix 4.6b Public information flyer

CITY UNIVERSITY LONDON

Whittington Health NHS

[redacted]

[redacted]ut the health decisions that you make for your children

PARENT VOLUNTEERS NEEDED!

A researcher from City, University of London wants to learn about how parents' make decisions about their children's participation in school based dental projects. This research study is for parents with children in nursery, reception or year 1. Research participation is always voluntary.

What is the purpose of the study?

As a parent you are asked to provide your consent before your children can be included in dental projects carried out in schools *i.e.* fluoride varnish projects. Some parents provide their consent, some parents refuse, and some do not respond at all. We would like to know why and how parents make these choices.

What will happen if I take part?

- You will be asked questions by the researcher either individually or as part on a group discussion
- This is likely to take anywhere between one and one and a half hours
- The discussion to be audiotaped for the researcher to listen to later
- **Everyone who takes part will receive a 'dental pack'.**

Will my taking part in the study be kept confidential?

All conversations will be kept confidential. Information will be used for the research only. Some unidentifiable quotes that maybe used in the research report. No individual names or identifiable information will be used.

What's the next step?

If you want to take part please contact Charlotte Jeavons for more information and to arrange to meet at and time and place that suits you. Email: [redacted] Please send your name and contact details. ***Thank you!***

This research study has been granted ethical approval from City, University of London Research Ethics Committee for the School of Health Sciences. If you have any complaints about this study you can telephone [redacted], or email at [redacted]

Appendix 4.7 Participant consent form

CITY UNIVERSITY LONDON

Whittington Health NHS

Title of Study: Gaining parental consent for dental public health programmes: a case study

		Please initial box
1.	I agree to take part in the above City, University of London research project. I have had the project explained to me, and I have read the participant information sheet (13th August 2017, V1), which I may keep for my records. I understand this will involve : • being interviewed by the researcher individually or taking part on a group discussion • allowing the discussion to be audiotaped • making myself available for a further clarification via email should that be required	
2.	This information will be held and processed for the following purpose(s): I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party, but that anonymised quotations may be included. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. I understand and agree that an electronic copy of the transcript will be held on a secure server provided by City, University of London.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.	
4.	I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

_____ _____ _____

Name of Participant Signature Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix 4.8 NHS Health Research Authority confirmation



Appendix 4.9 City, University of London ethics committee approval

Research Office
Northampton Square
London EC1V 0HB
[redacted]

Ref: PhD/17-18/05

10 October 2017

Dear Charlotte,[redacted]

Re: Parental Consent

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once
the project has been completed, and may be asked to complete a brief progress report six
months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely

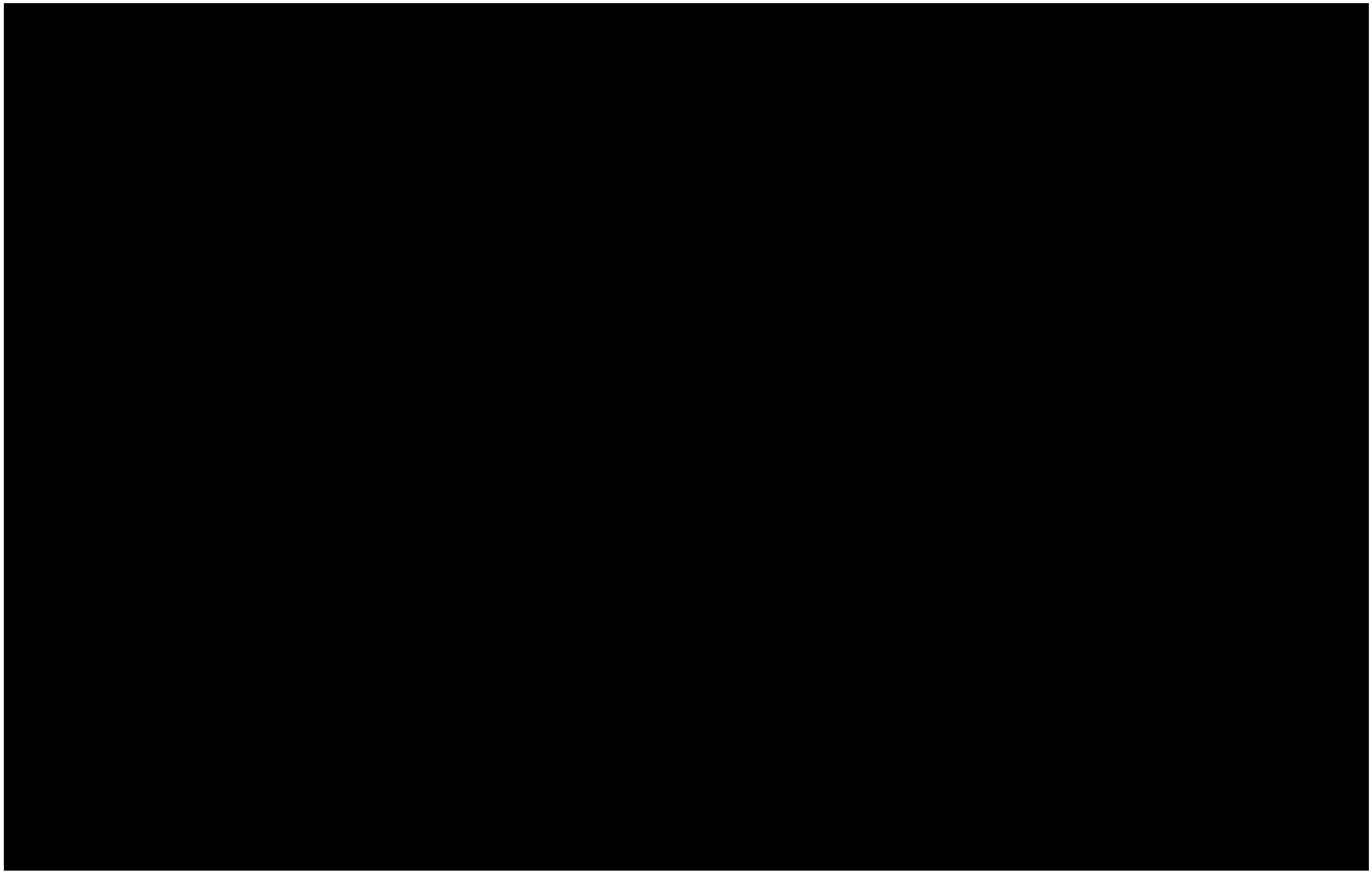
[redacted]
Research Governance Officer
[redacted]

Appendix 5.1 Whittington Health NHS parent information and consent form

Pages 1 and 2



Pages 3 and 4



Pages 5 and 6



List of References

Abrams, L. (2010) 'Sampling "hard to reach" populations in qualitative research', *Qualitative Social Work*, 4, pp.536-550.

Alexander, L. and Moore, M. (2012) *Deontological Ethics*. Available at: http://plato.stanford.edu/entries/ethics-deontological/ (Accessed: 27 August 2015).

Alexander, V., Thomas, H., Cronin, A., Fielding, J. and Moran-Ellis, J. (2016) 'Mixed Methods', in Gilbert, N. and Stoneman, P. (eds.) *Researching Social Life*. 4th edn. London: Sage. pp.119-138.

Al-Saadi, H. (2014) *Demystifying Ontology and Epistemology in Research Methods*. Available at: https://www.researchgate.net/publication/260244813_Demystifying_Ontology_and_Epistemology_in_Research_Methods (Accessed: 17 February 2019).

Appleton v Garrett [1997] in Lambden, P. (2002) *Dental Law and Ethics*. Oxon: Radcliffe Publishing Ltd. p.77.

ASH (2017) *Smokefree: The First 10 Years. Tackling the smoking epidemic in England: the views of the public*. Available at: https://ash.org.uk/wp-content/uploads/2017/06/170107-Smokefree-the-first-ten-years-FINAL.pdf (Accessed: 16 September 2019).

Atkins, K. (2000) 'Autonomy and the subjective character of experience', *Journal of Applied Philosophy*, 17, pp.71-79.

Atkins, S., Lewin, S., Smith, H., Engel, M., Frethiem, A. and Volmink, J. (2008) 'Conducting a metaethnography of qualitative literature: Lessons learnt', *BMC Medical Research Methodology* [Online]. Available at: https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-8-21 (Accessed: 9 February 2017).

Baker, S. and Edwards, R. (2012) *How many qualitative interviews is enough?* Discussion Paper. Available at: http://eprints.ncrm.ac.uk/2273/ (Accessed: 1 March 2017).

Barnett-Page, E. and Thomas, J. (2009) *Methods for the synthesis of qualitative research: a critical review.* Economic and Social Research Council. Available at:

http://eprints.ncrm.ac.uk/690/1/0109%2520Qualitative%2520synthesis%2520methods%2520paper%2520NCRM.pdf (Accessed: 6 November 2016).

Bauman, Z. (2001) *The Individualized Society*. Cambridge: Polity Press.

Bauman, Z. (2001) *The Individualized Society*. Cambridge: Polity Press. p.143.

Bauman, Z. (2008) in Dawson, M. (2013) *Late Modernity, Individualisation and Socialism*. Basingstoke: Palgrave Macmillan. p.88.

Baumann, H. (2008) 'Reconsidering relational autonomy. Personal autonomy for socially embedded and temporally extended selves', *Analyse and Kritik*, 30. pp.445-468 [Online]. Available at: http://www.analyse-und-kritik.net/2008-2/AK_Baumann_2008.pdf (Accessed: 10 October 2016).

Baylis, F., Kenny, N. and Sherwin, S. (2008) 'A relational? account of public health ethics', *Public Health Ethics*, 1(3), pp.196-209.

Beauchamp, T. and Childress, J. (2009) *Principles of Biomedical Ethics*. 6th edn. Oxford: Oxford University Press.

Bentham, J. (1789) 'The principle of utility', in Warnock, M. (ed.) (2003) *Utilitarianism and On Liberty*. Oxford: Blackwell Publishing Ltd. pp.17-51.

Bhopal, R. (2004) 'Glossary of terms relating to ethnicity and race: for reflection and debate'. *Journal Epidemiology Community Health*. 58 pp. 441–445.

Black, D., Morris, J., Smith, C. and Townsend, P. (1988) 'The Black Report', in Townsend, P., Davidson, N. and Whitehead, M. (eds.) *Inequalities in Health*. London: Penguin Books. pp.31-209.

Bolam v Friern Hospital Management Committee [1957] 1 WLR 583. Available at: http://www.e-lawresources.co.uk/Bolam-v--Friern-Hospital-Management-Committee.php (Accessed: 22 September 2013).

Border v Lewisham and Greenwich NHS Trust [2015] EWCA Civ 8. Available at: http://www.bailii.org/ew/cases/EWCA/Civ/2015/8.html (Accessed: 11 August 2019).

Borutta. A., Reuscher. G., Hufnagl. S., Möbius. S. (2006) 'Caries prevention with fluoride varnishes among preschool children'. *Gesundheitswesen*. 68 (11) pp. 731-4.

Boyatzis, R. (1998) *Transforming Qualitative Information*. California: SAGE Publications Inc.

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research*. London: SAGE Publications.

Brazier, M. and Lobjoit, M. (1991) *Protecting the Vulnerable: Autonomy and Consent in Health Care*. London: Routledge.

British Broadcasting Corporation (2010) 'Personal responsibility health agenda "welcomed"', 2 August. Available at: http://www.bbc.co.uk/news/health-10816574 (Accessed: 17 May 2016).

British Broadcasting Corporation (2014) 'Dental charity blames bad baby teeth on "child neglect"', 14 July. Available at: http://www.bbc.co.uk/news/health-28292448 (Accessed: 18 May 2016).

British Dental Association (2011) *What was the condition of people's dental health in the early 20th century?* Available at: http://www.rpharms.com/museum-pdfs/dentistry-information-and-enquiry-sheets.pdf (Accessed: 17 May 2016).

British Fluoridation Society (2012) *One in a Million: the facts about water fluoridation*. Available at: http://www.bfsweb.org/onemillion/onemillion2012.html (Accessed: 30 September 2013).

British Heart Foundation (no date) *Has the smoking ban changed our health?* Available at: https://www.bhf.org.uk/informationsupport/heart-matters-magazine/news/smoking-ban (Accessed: 16 September 2019).

British Library (no date) *Beveridge Report*. Available at: http://www.bl.uk/onlinegallery/takingliberties/staritems/712beveridgereport.html (Accessed: 22 May 2016).

British Library (no date) *Opponents to sanitary reform*. Available at: http://www.bl.uk/learning/histcitizen/21cc/publichealth/sources/source17/economist.html (Accessed 18 May 2016).

Buchanan, D. (2000) *An Ethic for Health Promotion: Rethinking the Sources of Human Bell-being*. New York: Oxford University Press.

Callahan, D. (2003) 'Principlism and communitarianism', *Journal of Medical Ethics*, 29, pp.287-291.

Canterbury v Spence [1972]. Available at: http://www.stanford.edu/group/psylawseminar/Canterbury.htm (Accessed: 22 September 2013).

Centre for Disease Control and Prevention (2016) *State Vaccination Requirements*. Available at: https://www.cdc.gov/vaccines/imz-managers/laws/state-reqs.html (Accessed: 15 July 2019).

Centre for Evidence-Based Dentistry (2015) *Question, Asking Questions*. Available at: http://www.cebd.org/practising-ebd/question/ (Accessed: 22 July 2015).

Cheah, P.Y. and Parker, M. (2014) 'Consent and assent in paediatric research in low-income settings', *BMC Medical Ethics* [Online]. Available at: https://bmcmedethics.biomedcentral.com/articles/10.1186/1472-6939-15-22 (Accessed: 12 December 2016).

Childress, J. (2008) 'Harmful rights-doing? The perceived problem of liberal paradigms and public health', *Journal of Medical Ethics*, 34, pp.798-801.

Childsmile (2008) *How did it start?* Available at: http://www.child-smile.org.uk/professionals/about-childsmile/how-did-it-start.aspx (Accessed: 12 May 2014).

Childsmile (2015) *Childsmile – Improving the oral health of children in Scotland*. Available at: http://www.child-smile.org.uk/ (Accessed: 11 November 2015).

Christman, J. (2004) 'Relational autonomy, liberal individualism, and the social constitution of selves', *Philosophical Studies*, 117(1-2), pp.143-164 [Online]. Available at: https://link.springer.com/article/10.1023%2FB%3APHIL.0000014532.56866.5c?LI=true (Accessed: 29 November 2017).

Code, L. (1991) *What Can She Know? Feminist Theory and the Construction of Knowledge*. New York: Cornell University Press.

Cooper Robbins, S., Bernard, D., McCaffery, K., Brotherton, J. and Skinner, S.R. (2010) '"I just signed": factors influencing decision-making for school-based HPV vaccination of adolescent girls', *Health Psychology*, 29(6), pp.618-625.

Costley, N. and Fawcett, J. (2010) *Public Attitudes Research Report*. London: General Dental Council.

Coundley, A. (2015) Personal communication to Jeavons, C.

Coyne, I. (1997) 'Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries?', *Journal of Advanced Nursing*, 26, pp.623-630.

Crabtree, B. and Miller, W. (1992) *Doing Qualitative Research*. London: SAGE Publications.

Critical Appraisal Skills Programme (2013) *Making sense of evidence*. Available at: http://www.casp-uk.net/ (Accessed: 9 October 2016).

Cronin, A., Alexander, V.D., Fielding, J., Moran-Ellis, J. and Thomas, H. (2008) 'The analytic integration of qualitative data sources', in Alasuutari, P., Bickman, L. and Brannen, J. (eds.) *The Sage Handbook of Social Research Methods*. London: SAGE Publications. pp.572-584.

Crotty, M. (2009) *The Foundations of Social Research*. London: SAGE Publications.

Curtis Taylor, K. (2017) Personal communication to Jeavons, C.

Dahlgren, G. and Whitehead, M. (1991) *Social Model of Health*. Available at: http://www.nwci.ie/download/pdf/determinants_health_diagram.pdf (Accessed 12 May 2014).

Darwall, S. (2003) *Consequentialism*. Malden MA: Blackwell Publishing.

Davies, G.M., Jones, C.M., Monaghan, N., Morgan, M.Z., Pine, C.M., Pitts, N.B., Neville, J.S. and Rooney, E. (2011) 'The caries experience of 5 year-old children in Scotland, Wales and England in 2007-2008 and the impact of consent arrangements. Reports of co-ordinated surveys using BASCD criteria', *Community Dental Health*, 28 (1),pp.1-7.

Davies, G.M., Robinson, M., Neville, J. and Burnside, G. (2014) 'Investigation of bias related to non-response of consent for a dental epidemiological survey of caries among five-year-olds', *Community Dental Health*, 31 (1), pp. 21-26.

Dawson, A. (2011) 'Resetting the parameters: public health as the foundation for public health ethics', in Dawson, A. (ed.) *Public Health Ethics*. Cambridge: Cambridge University Press.

Dawson, A. (2016) Personal communication to Jeavons, C.

Dawson, A. and Verweij, M. (2008) 'The steward? of the Millian State.' *Public Health Ethics*, 1(3)?, pp.193-195.

Dawson, M. (2013) *Late Modernity, Individualisation and Socialism*. Basingstoke: Palgrave Macmillan.

Dean, H. T. (1940) 'Fluorine, mottled enamel and dental caries', *The Journal of Pediatrics*. 16 (6) pp.782-794

Dempsey, A., Abraham, L., Dalton, V. and Ruffin, M. (2009) 'Understanding the reason why mothers do or do not have their adolescent daughters vaccinated against human papillomavirus', *Annals of Epidemiology*, 19(8), pp.531-538.

Denscombe, M. (1998) *The Good Research Guide*. Buckingham: Open University Press.

Denzin, N. and Lincoln, Y. (1994) *Handbook of Qualitative Research*. California: SAGE publications Inc.

Department of Health (2004) *Choosing Health*. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4094550 (Accessed: 4 November 2010).

Department of Health (2005a) *Choosing Better Oral Health*. Available at: http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4123251 (Accessed: 1 January 2014).

Department of Health (2005b) *Information to Assist in Amending Consent Forms*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138297/dh_103652.pdf (Accessed: 17 July 2015).

Department of Health (2006) *GUIDANCE: Dental Screening (Inspection) in Schools and Consent for Undertaking Screening and Epidemiological Surveys*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_064173 (Accessed: 4 November 2013).

Department of Health (2007) *Delivering Better Oral Health.* Available at: https://dentallawandethics.co.uk/wp-content/uploads/2016/03/DH-delivering-better-oral-health.pdf (Accessed: 25 May 2020).

Department of Health (2009) *Reference guide to consent for examinations or treatment*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653__1_.pdf (Accessed: 6 June 2014).

Department of Health (2010) *Improving Oral Health and Dental Outcomes: Developing the Dental Public Health Workforce in England.* Department of Health.

Department of Health (2013) *Helping people make informed choices about health and social care*. Available at: https://www.gov.uk/government/policies/helping-people-make-informed-choices-about-health-and-social-care/supporting-pages/giving-people-more-choice-and-control-in-health-and-social-care (Accessed: 22 September 2013).

Department of Health (2015) *The NHS Constitution*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf (Accessed: 16 September 2019).

Department of Health (2017) *Delivering Better Oral Health*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/605266/Delivering_better_oral_health.pdf (Accessed: 25 May 2020)

Dixon-Woods, M., Williams, S.J., Jackson, C.L., Akkad, A., Kenyon, S. and Habiba, M. (2006) 'Why do women consent to surgery, even when they don't want to? An interactionist and Bourdieusian analysis', *Social Science and Medicine*,62 (11), pp.2742-2753.

Dohnke-Hohrmann. S., Zimmer. S. (2004) 'Change in Caries Prevalence after Implementation of a Fluoride Varnish Program'. *Journal of Public Health Dentistry*. 64 (2) pp 96-100.

Dorell, C. Yankey, D. and Strasser, S. (2011) 'Parent reported reasons for nonreceipt of recommended adolescent vaccinations, National Immunization Survey - Teen, 2009', *Clinical Pediatrics*, 50(2), pp.1116-1124.

Duncan, P. (2010) *Values, Ethics and Health Care*. London: SAGE Publications.

Durkheim, E. (1897) in Mostofsky, D.I., Forgione, A.G. and Giddon, D.B. (eds.) (2006) *Behavioural Dentistry*. Iowa: Blackwell Publishing Group.

Dworkin, G. (1988) *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press

Dworkin, G. (2014) Paternalism. Available at: http://stanford.library.usyd.edu.au/archives/sum2014/entries/paternalism/ (Accessed 15 July 2015).

Dyer, T.A., Marshman, Z., Merrick, D., Wyborn, C. and Godson J. (2008) 'School-based epidemiological surveys and the impact of positive consent requirements', *British Dental Journal*, 205, pp.589-592.

Economic and Social Research Council (2009) *Methods for the synthesis of qualitative research: a critical review*. Available at: http://eprints.ncrm.ac.uk/690/1/0109%2520Qualitative%2520synthesis%2520methods%2520paper%2520NCRM.pdf (Accessed: 6 November 2016).

Exworthy, M., Peckham, S., Powell, M. and Hann, A. (eds.) (2012) *Shaping Health Policy*. Bristol: The Policy Press.

Felt, U., Bister, M., Strassing, M. and Wagner, U. (2009) 'Refusing the information paradigm: informed consent, medical research and patient participation', *An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13 (1), pp.87-106.

Felton, S. (ed.) (2009) *Basic Guide to Oral Health Education and Promotion*. Oxford: Wiley-Blackwell.

Fisher, H. (2013) 'Assent to participate in healthcare research', *Current Allergy & Clinical Immunology*, 26(3), pp.145-150 [Online]. Available at: http://www.allergysa.org/Content/Journals/August2013/EthicsCPD.pdf (Accessed: 7 December 2015).

Fontana, A. and Frey, J. (1994) 'Interviewing', in Denzin N. and Lincoln, Y. (eds.) *Handbook of Qualitative Research*. California: SAGE. pp.361-376

Foucault, M. (1982) 'The subject and power'. *Critical Inquiry*. 8 pp. 777–795

Fox, N. (2009) *Using Interviews in a Research Project*. National Institute for Health Research.

Frankfurt, H. (1971) 'Freedom of the will and the concept of a person', *The Journal of Philosophy*, 68, pp.5-20.

Freyenhagen, F. (2015) 'Autonomy's substance', *Journal of Applied Philosophy*, 32, pp.1-16

Furedi, F. and Bristow, J. (2012) *The Social Cost of Litigation*. Chichester: Centre for Policy Studies.

Garbutt, G. and Davies, P. (2011) 'Should the practice of medicine be a deontological or utilitarian enterprise?', *Journal of Medical Ethics*, 37, pp.267-270.

General Dental Council (GDC) (2005a) *Principles of Patient Consent*. Available at: http://www.gdc-uk.org/Dentalprofessionals/Standards/Documents/PatientConsent[1].pdf (Accessed: 10 May 2015).

General Dental Council (GDC) (2005b) *Standards for Dental Professionals*. Available at: http://www.gdc-uk.org/dentalprofessionals/cpd/Pages/default.aspx (Accessed: 1 November 2013).

General Dental Council (GDC) (2010) *Specialists lists*. Available at: http://www.gdc-uk.org/dentalprofessionals/specialistlist/documents/dphcurriculum.pdf (Accessed: 28 February 2014).

General Dental Council (GDC) (2013) *Standards for the Dental Team*. Available at: https://www.gdc-uk.org/information-standards-guidance/standards-and-guidance/standards-for-the-dental-team/ (Accessed: 22 September 2019).

General Dental Council (GDC) (2015) *Fitness to Practice Panel*. Available at: http://www.gdc-uk.org/Aboutus/Thecouncil/Pages/FTP-panel.aspx (Accessed: 20 July 2015).

General Dental Council (GDC) (2017) *Enhanced CPD guidance for dental professionals.* Available at: https://archive.gdc-uk.org/professionals/cpd (Accessed: 22 September 2019).

General Medical Council (GMC) (2013) *Good Medical Practice*. Available at: http://www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#gmp (Accessed: 22 September 2013).

Ghooi, R. (2011) 'The Nuremberg Code—A critique', *Perspectives in Clinical Research*, 2, pp.72-76.

Giddens, A. (2015) *Modernity and Self-Identity*. Cambridge: Polity Press.

Gilbert, L., Teravainen, A., Clark, C., and Shaw, S. (2018) '*Literacy and life expectancy*'. The National Literacy Trust. London.

Gilbert, N. and Stoneman, P. (eds.) (2016) *Researching Social Life*. 4th edn. London: Sage.

Gill, P., Stewart, K., Treasure, E. and Chadwick, E. (2008) 'Methods of data collection in qualitative research: interviews and focus groups.', *British Dental Journal*, 204, pp.291-295.

Gillick v West Norfolk and Wisbech AHA [1986]. Available at: http://www.bailii.org/uk/cases/UKHL/1985/7.html (Accessed: 23 September 2013).

Gillon, R. (2003) 'Ethics needs principles – four can encompass the rest – and respect for autonomy should be "first among equals"', *Journal of Medical Ethics*, 29, pp.307-312.

Gizzi, C. (2007) Personal communication to Jeavons, C.

Gizzi, C. (2014) Personal communication to Jeavons, C.

Glenny, A-M., Worthington, H., Milsom, K., Roony, E. and Tickle, M. (2013) 'Strategies for maximising consent rates for child dental health surveys: a randomised controlled trail', *BMC Medical Research Methodology* [Online]. Available at: https://www.researchgate.net/publication/256450100_Strategies_for_maximizing_consent_rates_for_child_dental_health_surveys_A_randomised_controlled_trial (Accessed: 7 June 2014).

Goodman, C. and Evans, C. (2015) 'Focus groups', in Gerrish, K. and Lathlean, J. (eds.) *The Research Process in Nursing*. 7th edn. Chichester: Wiley Blackwell. pp.401-412.

Gostin, L.O. (2005) in Knobler, S., Mack, A., Mahmoud, A., and Lemon S.M. (eds) Institute of Medicine. The Threat of Pandemic Influenza: Are We Ready? Workshop Summary. Washington, DC: The National Academies Press. pp 357-372

Gottvall, M., Grandahl, M., Hoglund, A., Larsson, M., Stenhammer, C., Andrea, B. and Tyden, T. (2013) 'Trust versus concerns—how parents reason when they accept HPV vaccination for their young daughter', *Upsala Journal of Medical Sciences*, 118, pp.263-270.

GOV.UK (2016) *Parental Right and Responsibilities*. Available at: https://www.gov.uk/parental-rights-responsibilities/who-has-parental-responsibility (Accessed: 8 February 2017).

Gray, J. (ed.) (1991) *John Stewart Mill: On Liberty and Other Essays*. Oxford: Oxford University Press.

Great Britain. Public Health Act 1848: Victoriae Reginae (1848) Available at https://www.legislation.gov.uk/ukpga/Vict/11-12/63/enacted (Accessed: 30 October 2019).

Great Britain. Education (Administrative Provisions) Act (1907) Available at: http://www.educationengland.org.uk/documents/acts/1907-education-admin-prov-act.html (Accessed: 4 November 2013).

Great Britain. Education Act (1944) Available at: http://www.legislation.gov.uk/ukpga/Geo6/7-8/31/section/48/enacted (Accessed: 4 November 2013).

Great Britain. Clean Air Act 1956: Elizabeth II. Chapter 52 (1956) London: The Stationery Office.

Great Britain. Education (Scotland) Act 1980: Elizabeth II. Chapter 44 (1980) London: The Stationery Office.

Great Britain. Criminal Justice Act 1988: Elizabeth II. Chapter 33 (1988) London: The Stationery Office.

Great Britain. Children Act 1989: Elizabeth II. Chapter 41 (1989) London: The Stationery Office.

Great Britain. The Motor Vehicles [Wearing of Seat Belts] Regulations. (1993) London: The Stationery Office.

Great Britain. Education Reform Act 1996: Elizabeth II (1996). Chapter 56 (1996) London: The Stationery Office.

Great Britain. Data Protection Act 1998: Elizabeth II (1998) London: The Stationery Office.

Great Britain. Health and Social Care (Community Health and Standards) Act 2003: Elizabeth II. Chapter 43 (2003) London: The Stationery Office.

Great Britain. Water Act 2003: Elizabeth II. Chapter 37 (2003) London: The Stationery Office.

Great Britain. Children Act 2004: Elizabeth II. Chapter 31 (2004) London: The Stationery Office.

Great Britain. Mental Capacity Act 2005: Elizabeth II. Chapter 9 (2005) London: The Stationery Office.

Great Britain. Health Act 2006: Elizabeth II. Chapter 28 (2006) London: The Stationery Office.

Great Britain. The NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations 2012 (SI 2012/3094). London: The Stationery Office.

Great Britain. Data Protection Act 2018: Elizabeth II. (2018) London: The Stationery Office.

Greene, J., Caracelli, V.J. and Graham, W.F. (1989) 'Towards a conceptual framework for mixed methods evaluation designs', *Educational Evaluation and Policy Analysis*, 11(3), pp.255-274.

Greenhalgh, T. (1997) 'How to read a paper: the Medline database', *British Medical Journal*, 315, pp.180-183.

Griffin, M., Shickle, D. and Moran, N. (2008) 'European citizens' opinions on water fluoridation', *Community Dentistry and Oral Epidemiology*, 36, pp.95-102.

Guba, E. and Lincoln, Y. (1994) 'Competing paradigms in qualitative research', in Denzin, N. and Lincoln, Y. (eds.) *Handbook of Qualitative Research*. California: SAGE. pp.105-117

Hann, A. (2012) 'The individualisation of health: health surveillance, lifestyle control and public health', in Exworthy, M., Peckham, S., Powell, M. and Hann, A. (eds.) *Shaping Health Policy*. Bristol: The Policy Press. pp.233-248

Hansard (1922). Dentists Act 1921. Available at: http://hansard.millbanksystems.com/commons/1922/mar/02/dentists-act-1921-regulations (Accessed 22 May 2016).

Hardman, M.C., Davies, G.M., Duxbury, J.T. and Davies, R.M. (2007) 'A cluster randomised controlled trial to evaluate the effectiveness of fluoride varnish as a public health measure to reduce caries in children', *Caries Research*, 41, pp.371-376.

Hart, J.T. (1971) 'The inverse care law', *The Lancet*, 1, pp.405-412.

Hatchet, W., Spear, S., Stewart, J., Greenwell, A. and Clapham, D. (2012) *The Stuff of Life: Public Health in Edwardian Britain*. Highworth Press Ltd.

Health and Social Care Information Centre (HSCIC) (2013) *Provisional Monthly Hospital Episode Statistics for Admitted Patient Care, Outpatients and Accident and Emergency Data – April 2013 to June 2013*. Available at: http://www.hscic.gov.uk/article/2021/Website-Search?productid=12494&q=a%26e+addmissions+for+dental+caries&sort=Relevance&size=10&page=1&area=both#top (Accessed: 3 June 2015).

Health and Social Care Information Centre (HSCIC) (2015) *Child Dental Health Survey 2013, England, Wales and Northern Ireland*. Available at: http://www.hscic.gov.uk/catalogue/PUB17137 (Accessed: 10 May 2015).

Hofman, R., Empelen, P., Vogel, I., Raat, H., Ballegooijen, M. and Korfage, I. (2013) 'Parental decisional strategies regarding HPV vaccination before media debates: a focused group study', *Journal of Health Communication*, 18(7), pp.866-880.

Hope, T., Savulescu, J. and Hendrick, J. (2008) *Medical Ethics and Law*. Edinburgh: Churchill Livingston.

Hunt, K. and Lathlean, J. (2015) 'Mixed methods research', in Gerrish, K. and Lathlean, J. (eds.) *The Research Process in Nursing*. 7th edn. Chichester: Wiley Blackwell. pp.173-184.

Hursthouse, R. and Pettigrove, G. (2016) *Virtue Ethics*. Available at: https://plato.stanford.edu/entries/ethics-virtue/ (Accessed: 22 November 2019)

Information Centre for Health and Social Care (2013) *National Child Measurement Programme, 2006-2007*. Available at: https://discover.ukdataservice.ac.uk/catalogue/?sn=6787&type=Data%20catalogue (Accessed: 17 November 2015).

Inglehart, M. (2006) 'Oral health and quality of life', in Mostofsky, D.I., Forgione, A.G. and Giddon, D.B. (eds.) *Behavioural Dentistry*. Oxford: Blackwell Munksgaard. pp.19-28

INVOLVE (2009) *Research Design Services and Public Involvement*. Eastleigh: INVOLVE

Islamic Sharia Council (2019) *Islamic Sharia Council*. Available at: http://test.islamic-sharia.org/ (Accessed: 18 August 2019).

Jacob, S. and Furgerson, S. (2012) 'Writing interview protocols and conducting interviews: tips for students new to the field of qualitative research', *The Qualitative Report*, 17, pp.1-10.

Jeavons, C. (2012) 'Parental consent and fluoride varnish schemes: lessons from dental screening', *Annual Clinical Journal of Dental Health*, 2, pp.38-42.

Jennings, B. (2009) 'Public health and liberty: Beyond the Millian paradigm', *Public Health Ethics*, 2, pp.123-134.

Jensen, L. and Allen, M. (1994) 'A synthesis of qualitative research on wellness-Illness', *Qualitative Health Research*, 4, pp.349-369.

Jochelson, K. (2005) *Nanny or steward? The role of the government in public health*. Available at: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/nanny-steward-role-government-public-health-working-paper-karen-jochelson-kings-fund-6-october-2005.pdf (Accessed: 28 September 2015).

Johnson, R. (2008) *Kant's moral philosophy*. Available at: http://plato.stanford.edu/entries/kant-moral/ (Accessed: 28 August 2015).

Jones, L. (2002) 'What is health?', in Katz, J., Peberdy, A. and Douglas, J. (eds.) *Promoting Health Knowledge and Practice*. Oxford: Open University Press. pp18-36

Kant, I. (1785) *The Critique of Pure Reason*. Great Britain: Amazon.co.uk Ltd.

Kass, N. (2001) 'An ethics framework for public health', *American Journal of Public Health*, 91, pp.1776-1782.

Katz, J. (2002) *The Silent World of Doctor and Patient*. Maryland: The Johns Hopkins University Press.

Kenny, N., Sherwin, S. and Baylis, F. (2010) 'Re-visioning public health ethics: a relational perspective', *Canadian Journal of Public Health*, 101(1), pp.9-11.

King, N. and Horrocks, C. (2010) *Interviews in Qualitative Research*. London: SAGE Publications.

Kitzinger, J. (1994) 'The methodology of focus groups: the importance of interaction between research participants', *Sociology of Health and Illness*, 16 (1) pp.103 -121.

Krawczyk, A., Knauper, B., Gilca, V., Dube, E., Perez, S., Joyal-Desmarais, K. and Rosberger, Z. (2015) 'Parents' decision-making about the human papillomavirus vaccine for their daughters: I. Quantitative results', *Human Vaccines and Immunotherapeutics*, 11, pp.322-329.

Kubiangha, M. (2014) Personal communication to Jeavons, C.

Kubiangha, M. (2015) Personal communication to Jeavons, C.

Kubiangha, M. (2017) Personal communication to Jeavons, C.

Kukathas, C., Pettit, P. (2007) '*Rawls. A Theory of Justice and its Critics'*. Polity Press. Cambridge

Kvale, S. (2007) *Doing interviews*. Thousand Oaks, CA: SAGE Publications.

Lambden, P. (2002) *Dental Law and Ethics*. Oxon: Radcliffe? Publishing Ltd.

Layton, R. (2015) *Socratic Teaching & The Millennials: Has Socrates' Care of the Self Become the Millennials' Care of the Selfie?* Available at: http://epublications.bond.edu.au/cgi/viewcontent.cgi?article=1009&context=learn_teach_posters2015 (Accessed: 1 June 2016).

Lee, S., Ayers, S. and Holden, D. (2014) 'A metasynthesis of risk perception in women with high risk pregnancies', *Midwifery*, 30(4), pp.403-411.

Lesser, H. (1991) 'The patient's right to information', in Brazier, M. and Lobjoit, M. (eds.) *Protecting the Vulnerable: Autonomy and Consent in Health Care*. London: Routledge. pp150-160

Lidz, C., Meisel, A., Zerubavel, E., Carter, M., Sestak, R. and Roth, L. (1984) *Informed Consent: A study of Decision Making in Psychiatry*. Guildford: Guildford Press.

Listl, S. and Wildman, J. (2015) 'Economics of oral health and inequalities', in Watt, R.G., Listl, S., Peres, M. and Heilmann, A. (eds.) *Social Inequalities in Oral Health: From Evidence to Action*. International Centre for Oral Health Inequalities Research and Policy. London: University College London. pp.10-11

Lofland, J., Snow, D., Anderson, L. and Lofland, L. (2006) *Analyzing Social Settings*. 4th edn. Belmont CA: Thomson Wa?dsworth Learning.

London School of Hygiene and Tropical Medicine (2013) *John Snow 1813-1858*. Available at: http://johnsnowbicentenary.lshtm.ac.uk/about-john-snow/ (Accessed 17 May 2016).

Lowry, R.J., Thompson, B. and Lennon, M.A. (2000) 'How much do the general public want to be involved in decisions on implementing water fluoridation?', *British Dental Journal*, 188, pp.500-502.

Lund Research Ltd. (2012) *Purposive sampling*. Available at: http://dissertation.laerd.com/purposive-sampling.php (Accessed: 29 December 2015).

Lynch, J. (2011) *Consent to Treatment*. Oxon: Radcliffe? Publishing Ltd.

Mackenzie, C. (2008) 'Relational autonomy, normative authority and perfectionism', *Journal of Social Philosophy*, 39 (4), pp.512-533.

Mackenzie, C. and Stoljar, N. (2000) *Relational Autonomy in Context: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press.

Malpass, A., Shaw, A., Sharp, D., Feder, G., Ridd, M. and Kessler, D. (2009) '"Medication career" or "Moral career"? The two sides of managing antidepressants: a meta-ethnography of patients' experience of antidepressants', *Social Science & Medicine*, 68, pp. 154–168.

Manerika, V. and Manerika, S. (2014) *A note on exploratory research*. Available at: http://www.welingkar.org/Corporates/pdfs/aWEshkar/march2014/aWEshkar_11_ResearchCommunication_VijayaManerikarNSumeetManerikar.pdf (Accessed: 19 July 2017).

Manson, C. and O'Neill, O. (2007) *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press.

Marcenes, W., Kassebaum, N.J., Bernabe, E., Flaxman, A., Naghavi, M., Lopez, A. and Murray, C.J. (2013) 'Global burden of oral conditions in 1990-2010: a systematic analysis', *Journal of Dental Research*, 92(7), pp.592-597.

Margaret Thatcher Foundation (2016) Interview for *Woman's Own*, 'no such thing as society' Available at: http://www.margaretthatcher.org/document/106689 (Accessed: 22 May 2016).

Marinho, V.C.C., Higgins, J., Logan, S. and Sheiham, A. (2003) 'Fluoride toothpastes for preventing dental caries in children and adolescents (Review)', *Cochrane Database of Systematic Reviews*, Issue 2, Art.: CD002278 DOI: 10.1002/14651858. Available from: http://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002278/epdf/full (Accessed: 9 November 2019)

Marinho. V.C.C., Higgins. J.P.T., Logan. S., Sheiham. A., (2003) 'Topical fluoride (toothpastes, mouthrinses, gels or varnishes) for preventing dental caries in children and adolescents (Review)', *Cochrane Database of Systematic Reviews*. Available at: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002782/epdf/standard (Accessed: 16 April 2020).

Marinho, V.C.C., Worthington, H., Walsh, T., Clarkson, J. (2013) 'Fluoride varnishes for preventing dental caries in children and adolescents (Review)' *Cochrane Database of Systematic Reviews*. Available from: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002279.pub2/epdf/full (Accessed: 23 May 2020)

Marmot, M. (2010) *Fair Society Healthy Lives*. Available at: http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review (Accessed: 20 May 2016).

Marmot, M. and Fenton, K. (2015) 'Forward', in Watt, R.G., Listl, S., Peres, M. and Heilmann, A. (eds.) *Social Inequalities in Oral Health: From Evidence to Action*. International Centre for Oral Health Inequalities Research and Policy. London: University College London. p2

Marr, A. (2007) *A History of Modern Britain*. London: Macmillan.

McCusker, K. and Gunaydin, S. (2015) 'Research using qualitative, quantitative or mixed methods and choice based on the research', *Perfusion*, 30(7), pp.537–542.

McGarry, O. (2016) 'Repositioning the research encounter: exploring power dynamics and positionality in youth research'. *International Journal of Social Research Methodology*. 19 (3) pp. 339–354

McKinstry, B., Ashcroft, R.E., Car, J., Freeman, G.K., Sheikh, (2006) 'A. Interventions for improving patients' trust in doctors and groups of doctors'. *Cochrane Database Systematic Review*. CD004134

Medical Research Council (2012) *Good Research Practice: Principles and Guidelines*. Available at: http://www.mrc.ac.uk/publications/browse/good-research-practice-principles-and-guidelines/ (Accessed: 8 January 2014).

Medical Research Council (2016) *Consent and Participant Information Sheet*. Available at: http://www.ctu.mrc.ac.uk/news/2016/new_patient_information_sheet_12042016 (Accessed: 16 March 2017).

Mill, J. (1859) 'On liberty', in Warnock, M. (2003) (ed.) *Utilitarianism and On Liberty*. Oxford: Blackwell Publishing Ltd. pp.88-180.

Mill, J. (1863) 'Utilitarianism', in Darwall, S. (2003) *Consequentialism*. Malden MA: Blackwell Publishing. pp.32-63.

Moberg Sköld. U., Petersson. L.G., Lith. A., Birkhed. D. (2005) 'Effect of school-based fluoride varnish programmes on approximal caries in adolescents from different caries risk areas'. *Caries Research*. 39 (4) pp. 273-279.

Moher, D., Liberati, A., Tetzlaff, J. and Altman, D. (2009) *Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement*. Available at: http://www.bmj.com/content/339/bmj.b2535.full?view=long&pmid=19622551 (Accessed: 2 January 2015).

Monaghan, N. and Morgan M.Z. (2009) 'Consent of older children participating in BASCD coordinated dental epidemiology surveys in Wales' *Community Dental Health*, 26 (3), pp.157-161.

Monaghan, N. and Morgan, M. (2010) *Impact of Consent Changes on Reported Tooth Decay Indices*. National Public Health Services for Wales.

Monaghan, N.P., Jones, S.J. and Morgan, M.Z. (2011) 'Do parents of children with caries choose to opt out of positive consent in dental surveys in Wales?', *British Dental Journal*, 26, pp.1-5.

Montgomery v Lanarkshire Health Board [2015] UKSC 11. Available at: http://www.bailii.org/uk/cases/UKSC/2015/11.html (Accessed: 17 July 2015).

Morgan, M.Z. and Monaghan N. (2010) 'Trends in children's ability to consent to a dental examination and the potential impact on reported caries indices', *Community Dental Health*, 27 (4), pp.1-6.

Morse, J., Barratt, M., Mayan, M., Olsen, K. and Spires, J. (2002) 'Verification strategies for establishing reliability and validity in qualitative research', *International Journal of Qualitative Methods*, 1, pp.13-22.

Mostofsky, D.I., Forgione, A.G. and Giddon, D.B. (2006) *Behavioural Dentistry*. Oxford: Blackwell Munksgaard.

Moyes, W. (2014) *Pendlebury lecture*. London, Royal College of Surgeons of England: General Dental Council. Online lecture. Available at: https://www.gdc-uk.org/Newsandpublications/viewfromthechair/Documents/PENDLEBURY%20LECTURE-William%20Moyes-June2014-FINAL.pdf (Accessed: July 2014).

Ms B v An NHS Hospital Trust [2002] EWHC 429 (Fam). Available at: http://www.bailii.org/ew/cases/EWHC/Fam/2002/429.html (Accessed: 12 February 2017).

Murray, S. and Jeavons, C. (2006) 'Preventive dentistry', in Ireland, R. (ed.) *Clinical Textbook of Dental Hygiene and Dental Therapy*. Oxford: Blackwell Munksgaard. pp253-276

National Health Service Litigation Authority (2011) *Report and Accounts 2010-2011*. Available at: http://www.nhsla.com/aboutus/Documents/NHS%20LA%20Annual%20Report%20and%20Accounts%202010-11.pdf (Accessed: 8 August 2015).

National Institute for Health and Care Excellence (2014) *Behaviour Change: general approaches*. Available at: https://www.nice.org.uk/guidance/ph6 (Accessed 31 May 2016).

National Institute of Health (2014) *Quality Assessment Tool for Observational Cohort and Cross-sectional Studies*. Available at: https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort (Accessed: 6 November 2016).

National Public Health Service for Wales (2010) *Impact of consent changes on reported tooth decay indices*. Available at: http://www2.nphs.wales.nhs.uk:8080/DentalPublicHTDocs.nsf/Main%20Frameset?OpenFrameSet&Frame=Right&Src=%2FDentalPublicHTDocs.nsf%2FCategoryPublic2%2F80b958554cffadbd802576b00054514c%3FOpenDocument%26AutoFramed (Accessed: 25 November 2015).

NHS (2014) *The history of the NHS in England*. Available at: http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx (Accessed: 22 May 2016).

NHS (2015) *Dental treatment for people with special needs*. Available at: http://www.nhs.uk/NHSEngland/AboutNHSservices/dentists/Pages/community-dental-services.aspx (Accessed: 5 June 2015).

NHS (NDa) *Does my child have the right to refuse treatment?* Available at: http://webcache.googleusercontent.com/search?q=cache:mP9Tt57Cl7wJ:www.nhs.uk/chq/Pages/900.aspx%3FCategoryID%3D62%26SubCategoryID%3D66+&cd=9&hl=en&ct=clnk&gl=uk (Accessed: 23 September 2013).

NHS (NDb) *Your health, your choices*. Available at: http://www.nhs.uk/Livewell/Pages/Livewellhub.aspx (Accessed: 19 May 2016).

NHS Executive (2001) *Good practice in consent*. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012286.pdf (Accessed: 2 July 2015).

Nuffield Council on Bioethics (2007) *Public Health: Ethical Issues*. London: Nuffield Council on Bioethics.

Nursing and Midwifery Council (NMC) (2010) *Standards of Conduct, Performance and Ethics for Nurses and Midwives*. Available at: http://www.nmc-uk.org/Documents/Standards/nmcTheCodeStandardsofConductPerformanceAndEthicsForNursesAndMidwives (Accessed: 22 September 2013).

Nussbaum, M. (2003) 'Capabilities as fundamental entitlements: Sen and social justice', *Feminist Economics*, 9, pp.33-59.

Oakley, A. (1981) 'Interviewing women: a contradiction in terms', in Roberts, H. (ed.) *Doing Feminist Research*. London: Routledge. pp.30-61

O'Carolan D. (2006) *Consent for School Dental Inspections and Dental Epidemiological Surveys*. Available at: http://www.dhsspsni.gov.uk/consent_notice_2006_12.pdf (Accessed: 4 November 2013).

O'Carolan, D. (2008) *School Dental Screening*. Department of Health: Social Services and Public Safety.

O'Cathain, A., Murphy, E. and Nicholl, J. (2007) 'Integration and publications as indicators of 'yield' from mixed methods studies', *Journal of Mixed Methods Research*, 1, pp.147-163.

O'Neill, O. (2002) 'Public health or clinical ethics: thinking beyond borders', *Ethics and International Affairs*, 16(2), pp.35-45.

Organisation of Economic Co-operation and Development (2016) *List of OECD Member countries – Ratification of the Convention on the OECD*. Available at: http://www.oecd.org/about/membersandpartners/list-oecd-member-countries.htm (Accessed 3 October 2016).

Oshana, M. (2006) *Personal Autonomy and Society*. Aldershot: Ashgate.

Owens, J. and Cribb, A. (2013) 'Beyond choice and individualism: understanding autonomy for public health ethics', *Public Health Ethics*, 6, pp.262-271.

Oxford Dictionaries (2015a) Paternalism. Available at: http://www.oxforddictionaries.com/definition/english/paternalism (Accessed: 15 July 2015).

Oxford Dictionaries (2015b) Assent. Available at: http://www.oxforddictionaries.com/definition/english/assent (Accessed: 7 December 2015).

Palys, T. (2008) 'Purposive sampling', in Given, L.M. (ed.) *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles: SAGE Publications. (2) pp.697-698

Parliament. House of Commons (2001a) *The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995*. Available at: http://webarchive.nationalarchives.gov.uk/20090811143745/http:/www.bristol-inquiry.org.uk/final_report/the_report.pdf (Accessed: 2 July 2015).

Parliament. House of Commons (2001b) *Royal Liverpool Children's Inquiry Summary and Recommendations*. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250914/0012_i.pdf (Accessed: 2 July 2015).

Petersson. L.G., Twetman, S., Dahlgren. H., Norlund. A., Holm. A.K., Nordenram. G., Lagerlöf. F., Söder. B., Källestål. C., Mejàre. I., Axelsson. S., Lingström. P. (2004) 'Professional fluoride varnish treatment for caries control: a systematic review of clinical trials.' *Acta Odontologica Scandinavica*, 62 pp. 170–176.

Petersen, P.E. (2008) 'World Health Organization global policy for the improvement of oral health for the World Health Assembly 2007', *International Dental Journal*, 58, pp.115-121.

Polit, D. and Tatano Beck, C. (2014) *Essentials of Nursing Research*. 8th edn. Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins.

Pope, C. and Mays, N. (2008) *Qualitative Research in Health Care*. 3rd edn. Massachusetts: Blackwell Publishing Ltd.

Prainsack, B. and Buyx, A. (2015) Background paper: Solidarity in public health. Available from: https://www.researchgate.net/publication/298317042_Solidarity_in_public_health (Accessed: 9 November 2019)

Primary Care Commissioning (2009) *The use of fluoride varnish by dental nurses to control caries*. Available at: https://www.pcc-cic.org.uk/sites/default/files/articles/attachments/the_use_of_fluoride_varnish.pdf (Accessed: 28 February 2014).

Public Health England (2014) *Southampton Water Fluoridation Scheme*. Available at: https://www.gov.uk/government/news/southampton-water-fluoridation-scheme (Accessed: 2 July 2014).

Public Health England (2015a) *Human papillomavirus (HPV) immunisation programme review: 2008 to 2014*. Available at: https://www.gov.uk/government/publications/human-papillomavirus-hpv-immunisation-programme-review-2008-to-2014 (Accessed: 15 November 2015).

Public Health England (2015b) *National Dental Epidemiology Programme for England: oral health survey of three-year-old children 2013. A report on the prevalence and severity of dental decay*. Available at: http://www.nwph.net/dentalhealth/reports/DPHEP%20for%20England%20OH%20Survey%203yr%202013%20Report%20FINAL%20260914%20Appx%20140115.pdf (Accessed: 7 December 2015).

Public Health England (2017) *Delivering Better Oral Health: an evidence based toolkit for prevention*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/601833/delivering_better_oral_health_summary.pdf (Accessed: 22 September 2019).

Qur'an 5:90

Raz, J. (1994) *The Morality of Freedom and Ethics in the Public Domain: Essays in the Morality of Law and Politics*. Oxford: Clarendon Press.

Ridley, D. (2010) *The Literature Review*. London: Sage Publications.

Ritchie, J. and Lewis, J. (2003) *Qualitative Research Practice*. Thousand Oaks: Sage Publications.

Robson, C. (2002) *Real World Research*. 2nd edn. Malden: Blackwell Publishing.

Roulston, R. (2010) *Reflective Interviewing*. Los Angeles: SAGE Publications.

Samuelson, W. and Zeckhauser, R. (1988) 'Status quo bias in decision making', *Journal of Risk and Uncertainty*, 1, pp.7-59.

Sandelowski, M. and Barroso, J. (2007) *Handbook for Synthesizing Qualitative Research*. New York: Springer.

Sass, H-M. (2003) 'Ambiguities in judging cruel human experimentation: arbitrary American responses to German and Japanese experiments', *Journal of Asian and International Bioethics*, 13, pp.102-104.

Schardt, C., Adams, M., Owens, T., Keitz, S. and Fontelo, P. (2007) 'Utilization of the PICO framework to improve searching PubMed for clinical questions', *Biomed Central*, 7, Art. 16.

Schonfeld, M. and Thompson, M. (2014) *Kant's Philosophical Development*. Available at: http://plato.stanford.edu/entries/kant-development/ (Accessed: 28 August 2015).

Scottish Dental Epidemiology Coordinating Committee (2011) *Report of the 2011 National Dental Inspection Programme of Primary 7 Children in the Basic Inspection of Primary 1 and Primary 7 Children*. Scotland.

Searle, C. (2002) 'Quality issues in qualitative inquiry', *Qualitative Social Work* [Online]. Available at: http://qsw.sagepub.com/content/1/1/97.full.pdf+html (Accessed: 29 December 2015).

Seidman, I. (1998) *Interviewing as Qualitative Research*. New York: Teachers College Press.

Shaghaghi, A., Bhopal, R. and Sheikh, A. (2011) 'Approaches to recruiting "hard-to-reach" populations into research: a review of the literature', *Health Promotion Perspectives*, 1(2), pp.86-94.

Shah, P. (2015) 'Selfie – a new generation addiction disorder – literature review and updates', *International Journal of Emergency Mental Health and Human Resilience*, 17(3), p.602.

Sheiham, A., Conway, D. and Chestnutt, I. (2015) 'Impact of oral diseases and oral health inequalities', in Watt, R.G., Listl, S., Peres, M. and Heilmann, A. (eds.) *Social Inequalities in Oral Health: From Evidence to Action*. International Centre for Oral Health Inequalities Research and Policy. London: University College London. pp.4-5.

Shelton, R., Snavely, A., De Jesus, M., Othus, M. and Allen, J. (2013) 'HPV vaccine decision making and acceptance: does religion play? a role?', *Journal of Religious Health*, 52, pp.1120-1130.

Shenton, K. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects', *Education for Information*, 22, pp.63–75.

Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985]. Available at: http://swarb.co.uk/lisc/Helth19851989.php (Accessed: 22 September 2013).

Silverman, D. (2011) *Interpreting Qualitative Data: Methods for Analysing Talk, Text, and Interaction*. 4th edn. London: SAGE Publications.

Sinnott-Armstrong, W. (2011) *Consequentialism*. Available at: http://plato.stanford.edu/entries/consequentialism/ (Accessed: 28 August 2015).

Skrabanek, P. (1994) The *Death of Humane Medicine and the Rise of Coercive Healthism*. Suffolk: Social Affairs Unit.

Smith, W. (1968) '*Cost-Effectiveness and Cost-Benefit Analyses for Public Health Programs*' Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1891827/pdf/pubhealthreporig00011-0011.pdf (Accessed: 23 May 2020)

Spring Rice, M. (1981) *A Classic Account of Working Women's Lives in the 1930s*. United Kingdom: Virago.

Stebbins, R. (2001) *Exploratory Research in the Social Sciences*. California: Sage.

Steele, J. (2009) *NHS Dental Services in England. An independent review led by Professor Jimmy Steele*. Available at: http://www.sigwales.org/wp-content/uploads/dh_101180.pdf (Accessed: 3 June 2015).

Stewart, A. (2008) *Basic Statistics and Epidemiology*. 2nd edn. Oxford: Radcliffe? Publishing.

Stoljar, N. (2011) 'Informed consent and relational conceptions of autonomy', *Journal of Medicine and Philosophy*, 36, pp.375-384.

Sutrop, M. (2011) 'Changing ethical frameworks: from individual rights to common goods', *Cambridge Quarterly Healthcare Ethics*, 20, pp.533-545.

Tannahill, A. (2008) 'Beyond evidence to ethics: a decision-making framework for health promotion, public health and health improvement', *Health Promotion International*, 23(4), pp.380-390.

Tashakkori, A. and Teddlie, C.B. (2010) *Handbook of Mixed Methods in Social Research and Behavioural Research*. 2nd edn. London: Sage.

Taylor, E. (2017) 'Sugar: a taxing problem', *Annual Clinical Journal of Dental Health*, 6, pp.40-47.

ten Have, M., de Beaufort, I., Mackenbach, J. and van der Heide, A. (2010) 'An overview of ethical frameworks in public health: can they be supportive in the evaluation of programs to prevent overweight?', *BMC Public Health*, 10, pp.638. Available at: http://www.biomedcentral.com/1471-2458/10/638 (Accessed: 9 August 2014).

Thatcher, M. in Todd, S. (2014) *The People: The Rise and Fall of the Working Class*. London: John Murray. p.319.

The Dental Observatory (2012) *NHS Dental Epidemiology Programme Oral Health Survey of three year old children, 2012/13*. Available at: http://www.nwph.net/dentalhealth/reports/3yearold/Final%20National%20Protocol_3%20yr%20olds_2012-13.pdf (Accessed: 8 August 2013).

The Evolution of Medical Ethics (1946) *The Nuremburg Code*. Available at: https://owlspace-ccm.rice.edu/access/content/user/ecy1/Nazi%20Human%20Experimentation/Pages/the%20code.html (Accessed: 17 July 2015).

The Times (1934) 'Maternal Mortality', 23 June, p.13.

Thomas, C.J., Sage, M., Dillenberg, J. and Guillory, V.J. (2002) 'A code of ethics for public health', *American Journal of Public Health*, 92 (7) pp.1057-1059.

Thomas, J. and Harden, A. (2008) 'Methods for the thematic synthesis of qualitative research in systematic reviews', *BMC Medical Research Methodology* [Online]. Available at: https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-8-45 (Accessed: 30 January 2017).

Tickle, M., Milsom, K.M., Buchanan, K. and Blinkhorn, A.S. (2006) 'Dental screening in schools: the views of parents, teachers and school nurses', *British Dental Journal*, 201, pp.769-733.

Todd, S. (2014) *The People: The Rise and Fall of the Working Class*. London: John Murray.

Turnball, J. and Lathlean, J. (2015) 'Mixed methods research', in Gerrish, K. and Lathlean, J. (eds.) *The Research Process in Nursing*. 7th edn. Chichester: Wiley Blackwell. pp.371-383.

Turner, D. (2010) *Qualitative Interview Design: A Practical Guide for Novice Investigators*. Available at: https://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1178&context=tqr (Accessed: 28 December 2015).

Tuskegee University (2016) *About the USPHS Syphilis Study*. Available at: http://www.tuskegee.edu/about_us/centers_of_excellence/bioethics_center/about_the_usphs_syphilis_study.aspx (Accessed: 3 June 2016).

UK National Screening Committee (2004) Dental Screening Conference. UK National Screening Committee.

UN General Assembly (1989) *Convention on the Rights of the Child*, United Nations, Treaty Series, vol. 157. Available at: https://www.refworld.org/docid/3ae6b38f0.html (Accessed: 30 October 2019).

United States Government (1949) *The Nuremberg Code*. Available at: https://history.nih.gov/research/downloads/nuremberg.pdf (Accessed: 6 April 2017).

University of Oxford (ND) *Cochrane Library Tutorial*. Available at: http://learntech.physiol.ox.ac.uk/cochrane_tutorial/cochlibd0e84.php (Accessed: 22 July 2015).

Upshur, R.E.G. (2002) 'Principles for the justification of public health interventions', *Canadian Journal of Public Health*, 93(2), pp.101-103.

U.S. National Library of Medicine (2016) *MeSH*. Available at: https://www.nlm.nih.gov/mesh/2016/mesh_browser/MBrowser.html (Accessed 24 August 2016).

Vandenberg, S. and Kulig, J. (2015) 'Immunization rejection in Southern Alberta: a comparison of the perspectives of mothers and health professionals'. *Canadian Journal of Nursing Research*, 47(2), pp.81-96.

Verweij, M. and Dawson, A. (2009) 'The meaning of "public" in "public health"', in Dawson, A. and Verweij, M. (eds.) *Ethics, Prevention and Public Health*.. Oxford: Oxford University Press. pp.13-29

Wald, N. J. (2001) 'The definition of screening', *Journal of Medical Screening* [Online]. Available at: http://msc.sagepub.com/content/8/1/1.full.pdf+html (Accessed: 4 November 2015).

Walsh, D. and Downe, S. (2005) 'Meta-synthesis method for qualitative research: a literature review', *Journal of Advanced Nursing*, 50(2), pp.204-211.

Walter, J. and Ross, L. (2014) 'Relational autonomy: moving beyond the limits of isolated individualism', *Paediatrics*, 133(1), pp.16-23.

Ward, V., House, A. and Hamer, S. (2009) 'Developing a framework for transferring knowledge into action: a thematic analysis of the literature', *Journal of Health Service Research Policy*, 14(3), pp.156-164.

Warren, M. (2000) *A Chronology of State Medicine, Public Health, Welfare and Related Services in Britain 1066-1999*. London: Faculty of Public Health Medicine of the Royal Colleges of Physicians of the United Kingdom.

Watt, G. (2002) 'The inverse care law today', *The Lancet*, 360, pp.252-254.

Watt, R. and Sheiham, A. (1999) 'Inequalities in oral health: a review of the evidence and recommendations for action', *British Dental Journal*, 187, pp.6-12. Available at: http://www.nature.com/bdj/journal/v187/n1/full/4800191a.html (Accessed: 7 December 2015).

Welsh Government (2009) *Designed to Smile*. Available at: http://www.designedtosmile.co.uk/home.html (Accessed: 2 July 2015).

Whittington Health NHS (no date) *Islington Community Fluoride Varnish programme*. Available at: http://www.whittington.nhs.uk/default.asp?c=10531 (Accessed: 16 November 2015).

Willig, C. (2008) *Introducing Qualitative Research in Psychology*. Berkshire: Open University Press.

Wilkinson, R. and Pickett, K. (2010) *The Spirit Level: Why Equality is Better for Everyone*. London: Penguin Books.

Wilkinson, S. (1988) 'The role of reflexivity in feminist psychology', *Women's Studies International Forum*, 11, pp.493-502.

Woolley, S. (2005) 'Children of Jehovah's Witnesses and adolescent Jehovah's Witnesses: what are their rights?', *British Medical Journal*, 90, pp.715-719.

World Health Organization (2003) *WHO Information Series on School Health*. Available at: https://apps.who.int/iris/bitstream/handle/10665/70207/WHO_NMH_NPH_ORH_School_03.3_eng.pdf?sequence=1&isAllowed=y (Accessed 3 November 2019).

World Health Organization (2015) *Public Health*. Available at: http://www.who.int/trade/glossary/story076/en/ (Accessed 5 June 2015).

World Health Organization (2019) *Reducing Inequalities*. Available at: http://www.euro.who.int/en/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being/about-health-2020/strategic-objectives/reducing-inequalities (Accessed: 22 September 2019).

World Medical Association (2013) *Declaration of Helsinki*. Available at: http://www.wma.net/en/60about/70history/01declarationHelsinki/ (Accessed: 22 May 2016).

Wright, D. (2019) '*Briefing paper on oral health and dental services for the Enfield HWBB*'. Available at: https://governance.enfield.gov.uk/documents/s77618/Oral%20Health%20Enfield%20HWBB%20paper%202019%20003.pdf (Accessed: 23 May 2020)

Wright.W., Turner.S., Anopa.Y., McIntosh.E., Wu. O., Conway.D., Macpherson.L., McMahon.A. (2015) 'Comparison of the caries-protective effect of fluoride varnish with treatment as usual in nursery school attendees receiving preventive oral health support through the Childsmile oral health improvement programme — the Protecting Teeth@3 Study: a randomised controlled trial'. *BioMed Central Oral Health*. Available at: https://bmcoralhealth.biomedcentral.com/track/pdf/10.1186/s12903-015-0146-z (Accessed: 16 April 2020)

Yin, R. (2009) *Case Study Research*. 4th edn. California: SAGE Publications.