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A feasibility randomised controlled trial of elaborated Semantic Feature Analysis delivered in the virtual world, EVA Park

Volume 2

by
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This is submitted in fulfilment of the requirements for the
degree of Doctor of Philosophy



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April 2023

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Appendix 1 | Research Proposal

Title:

A feasibility randomised controlled trial of adapted Semantic Feature Analysis delivered in EVA Park.

Abstract:

Background: Nearly half (45%) of the people who have a stroke will experience aphasia, a language disorder (Ali et al. 2015). The most common feature of aphasia is word finding difficulties (Azhar, 2017). This difficulty in retrieving the word for what you mean contributes to conversation breakdown and frustration in aphasia. The presence of aphasia reduces social networks (Northcott and Hilari, 2011) and negatively affects quality of life (Hilari et al. 2012).

Semantic feature analysis (SFA) aims to boost activation in the semantic lexicon of the target word to improve the retrieval of that word. In addition, SFA suggests that by activating the whole semantic network, gains will generalise beyond the treated words. Systematic reviews of SFA have shown improvement in the retrieval of target words (Maddy et al. 2014, Efstratiadou et al. 2018), however generalisation to untreated words was evident in only 40% of studies (Efstratiadou et al. 2018). EVA Park is a 3D virtual world where people with aphasia can practice everyday conversations in simulated environments. It allows for remote delivery of therapy for those who find travel prohibitive. EVA Park has been used in a single case study of SFA with gains that match face to face delivery of this intervention (Marshall et al. 2018). A conversation based intervention in EVA Park showed gains in functional conversation (Marshall et al. 2016). Thus, SFA in conjunction with supported situated conversations and groups in EVA Park may support the generalisation of treatment gains from SFA to functional conversations.

Methods: The adapted SFA in EVA Park trial is a single-blind, randomised controlled, feasibility trial comparing SFA delivered remotely in a virtual environment (EVA Park) with no treatment. Feasibility outcomes will explore recruitment, willingness to be randomised, compliance with and acceptability of the treatment and of the outcome measures. Treatment outcomes will be assessed on measures of word finding. All participants will complete baseline measures and will be randomised to the intervention or to the control group. Outcome measures will be repeated 1 week post randomisation, 7 weeks post randomisation and 13 weeks post randomisation.

Discussion: Despite good evidence for word retrieval gains from SFA interventions many studies have not demonstrated carryover of these gains into discourse. Supported one to one conversations and conversations in groups in EVA Park have shown improvements in functional conversation. It is worth exploring the feasibility of treating word retrieval with SFA alongside situated conversation tasks and group work in EVA Park as it may lead to improved word retrieval in functional conversations.

Research context and literature review:

Aphasia affects a person's use of language; speaking, understanding what people say, reading and writing. It occurs following brain injury, most commonly stroke. It is estimated that 350,000 people are living with aphasia in the UK (Stroke Association). Consequences of aphasia include reduced social networks (Northcott and Hilari, 2011) and reduced quality of life (Cruice et al. 2006, Lam and Wodchis, 2010).

The most prevalent feature of aphasia is word finding difficulties. This difficulty in retrieving the word for what you mean contributes to conversation breakdown and frustration in aphasia. Retrieving a word requires processing of both the semantic representation, its meaning, and its phonological representation, the sounds used to produce it. Word retrieval therapies target either of these elements or a combination of both (Nichols, 2002, Wisenburn and Mahoney, 2009). SFA is a semantic therapy that improves the retrieval of the words treated by activating the network of semantic links around a given target. It has been shown to improve word retrieval for treated words across a number of studies (Maddy et al. 2014, Efstratiadou et al. 2018). However, the evidence for the generalisation of therapy gains into conversation is less clear. Palmer et al. (2017) identifies two potential forms of generalisation in naming therapies. Applied to SFA, firstly the treatment of the semantic networks around the target word may lead to gains in retrieving words that were not directly targeted in therapy. The most recent systematic review (Efstratiadou et al. 2018) indicates that this generalization occurred in 40% of studies reviewed. Secondly, the words learnt in therapy may be used in conversations and thus show functional improvement. However, gains in discourse have been explored in a number of studies, with mainly negative results (Wisenburn and Mahoney, 2009).

EVA Park provides a multi user, sunny and fantastical virtual reality setting for functional conversations. There are houses, a town square, a restaurant and bar - all spaces to role play functional conversations. It was developed with people with aphasia employed as consultants in a codesign process (Wilson et al. 2015). A study of supported conversations, including group interactions, in this environment improved functional conversations as measured by the CADL-2 (Marshall et al. 2016). A single case study of SFA delivered in EVA Park showed improvements in treated items (Marshall et al. 2018). This research can now be taken to the next stage to explore the feasibility and acceptability of delivering SFA therapy through EVA Park on a larger scale. Moreover, we will adapt SFA to include functional situated conversations and group therapy in EVA Park as such adaptations may lead to improved word retrieval in functional conversations.

Research objectives:

The aim of the study is to assess the feasibility of conducting a future definitive trial investigating the clinical and cost effectiveness of Virtual, Elaborated SFA (VESFA) for people living with chronic post-stroke aphasia. Primary objectives of the trial are to evaluate the acceptability of the intervention to participants; the feasibility of recruitment and retention; the acceptability of research procedures; and the feasibility of delivering the intervention remotely in a virtual environment. Secondary objectives are to evaluate the appropriateness of outcome measures; estimate a sample size for the definitive trial; and assess the processes for evaluating treatment fidelity. Clinical outcomes will investigate whether the retrieval of words treated in therapy improves and whether gains generalise to discourse.

Research methods:

Design: The VESFA study is a single-blind, randomised controlled feasibility trial comparing SFA delivered remotely in a virtual environment (EVA Park) with no treatment.

Work plan:

	Year 1												Year 2												Year 3											
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36
Literature review																																				
Gain ethical clearance																																				
Recruit user group																																				
Run user group consultation																																				
Consult expert clinicians																																				
Develop the intervention manual																																				
Recruit participants with aphasia																																				
Recruit student blind testers																																				
Administer the time 1 measures with participants with aphasia (in sets of 3)																																				
Run the intervention for participants in the immediate condition (6 sets of 3)																																				
Administer the time 2 measures with participants with aphasia																																				
Administer the post intervention questionnaires																																				
Transcribe and analyse the interview data																																				
Administer the time 3 measures with participants with aphasia																																				
Supervise student projects for checking fidelity of the intervention																																				
Analyse data from the quantitative measures																																				
Write up																																				
Journal submission																																				
Make conference submission																																				
Disseminate to participants																																				

In year one the study will develop and manualise the adapted SFA treatment, including a literature review, and expert clinician and user group consultation. Fidelity processes and forms, and measures for detecting the use of treated words in discourse will also be finalised based on recent reviews (Pritchard et al. 2018). The first student assessors will be trained, ethics approval will be obtained and all processes to run the feasibility trial in year 2 (e.g., trial advisory groups, development of trial protocol etc) will be determined.

In year two the feasibility trial will begin, involving 36 people (see sample size below) with chronic aphasia (>4 months post stroke). They will not be receiving any other speech and language therapy for the duration of the study. They will have word finding as the primary feature of their aphasia, scoring <60 on the Western Aphasia Battery measure of object naming. All participants will be assessed using the measures determined in year one, which will include measures of word retrieval and the core outcome set for aphasia intervention research (Wallace et al. 2018): the Western Aphasia Battery (Kertesz 1982), the Stroke and Aphasia Quality of Life test (Hilari et al. 2003), the General Health Questionnaire (Goldberg, 1972) and the Scenario Test (Van der Meulen, 2010). Questionnaires will explore the satisfaction and feasibility of receiving treatment remotely in a virtual environment.

In year three of the study the trial will be concluded, the data analysed and written up. For ethical reasons, we will seek to make therapy opportunities available to the control group at the end of their involvement in the study. Participants in the control arm will be offered referral to the LCS aphasia clinic. Additionally/alternatively the candidate will seek to offer a programme of remote SFA delivered by student volunteers.

Outputs will include journal articles, conference presentations and dissemination to people with aphasia and speech and language therapists.

Participants: Participants will have a diagnosis of ischaemic or haemorrhagic stroke, be at least four months post stroke, 18 years old or over, and presenting with anomia as a result of aphasia.

Participants will be excluded if they: have other diagnoses affecting cognition such as dementia; have severe uncorrected visual or hearing problems; have severe or potentially terminal co-morbidity; are currently receiving speech and language therapy intervention; were non-fluent English speakers prior to the stroke (based on self or family report); or do not have mental capacity to consent to take part.

Recruitment and consent process: 36 participants will be recruited from community stroke groups and the City Aphasia Research Register (CARR). Methods of community recruitment include visiting stroke and aphasia groups; accepting self-referrals (e.g., where a potential participant has learnt

about the project from twitter or word of mouth); distributing information about the project to third sector organisations; contacting people known to the University who have given permission for their details to be shared for this purpose e.g., CARR. Written informed consent will be obtained from all participants. All information sheets and consent forms will be developed using standard aphasia-accessible principles (e.g., presenting one idea at a time, using short simple sentences, presenting key ideas with a suitable pictorial image).

Randomisation: Participants will be randomly assigned to the intervention group or control group. The randomisation will be stratified (or minimised) by severity of aphasia. We will use Oxmar or a similar software.

Blinding: The participants and the research clinician will be aware of group allocation. Outcome measures will be carried out by speech and language therapy students blinded to group allocation and time of assessment. Speech and language therapy students have previously volunteered on all three EVA Park research projects to gain clinical and research experience. We will ask the participants not to reveal group allocation to the testers during testing visits.

Intervention: Participants randomised to the intervention group will receive 36 hours of treatment; three one to one (60min) sessions and two group (90min) sessions per week (6 hours per week) for 6 weeks. The dose is in line with evidence that high intensity SLT (defined as 4 – 15 hours per week) improves aphasia severity more than low intensity therapy (Brady et al, 2016). One to one sessions will consist of 30 minutes of naming practice with SFA and 30 minutes of situated word retrieval practice within conversations e.g., ordering dinner in the EVA Park pizza place, making tea in the EVA Park house kitchen, buying flowers from the EVA Park market stall.

Treatment will be delivered in sets of three participants at a time to allow for three members in each group. Six sets of treatment will be delivered over the 15 month intervention period (total = 18 participants)

Words targeted in therapy will be from the list of 100 words that people with aphasia want to work on (Palmer 2017) plus 10 personally relevant targets.

Outcomes: As a feasibility study the main endpoints relate to feasibility objectives. We outline four primary and three secondary endpoints. We also state pre-specified criteria for three of the four primary endpoints to guide the decision as to whether to proceed to a future definitive trial: the extent to which these thresholds have been met will be considered in conjunction with qualitative evidence. The pre-specified criteria are based on published trials investigating complex behavioural interventions with people with aphasia (Thomas et al., 2013, Palmer et al., 2012): reported recruitment, retention and adherence rates have informed what we consider to be realistic progression criteria.

Primary outcomes:

1) Acceptability of treatment to participants:

Evaluation based on rates of adherence to intervention where participants considered to have adhered if they elect to receive at least 80% of intervention (28 of the 36 hours).

2) Feasibility of recruitment and retention to the trial:

The proportion of participants who consent; the rate of participants randomised each month; attrition rates (overall, by stage and by study arm) and reasons for attrition if known

3 and 4) Acceptability of research procedures and feasibility of delivering the intervention remotely in a virtual environment:

This will be based on questionnaires with participants at end of the study. Aphasia friendly questionnaires will be developed that explore satisfaction with the method of delivery and accessibility/usability of the technology. Answers will be collected via rating scales with

opportunities for comments. The questionnaires will be carried out independently or with the support of a carer. Previous EVA Park studies have employed these methods (Galliers et al. 2017).

4) Treatment outcomes

Preliminary clinical outcomes will be measured by the core outcome set for aphasia research (see above) and a measure of word retrieval and a measure of discourse determined in the first year of the study.

Secondary outcomes:

1) Determine and evaluate measure of word retrieval in discourse

Evaluating the retrieval of words within conversation and/or meaningful measurement of discourse is multifaceted. Discourse requires a number of skills on multiple linguistic levels and therefore the range of potential assessments is large (Dipper & Pritchard, 2018). Research in LCS has provided evidence on the psychometric properties of a range of discourse measures (Pritchard et al. 2018). In the first year of the study discourse measures will be reviewed and a measure finalised. This measure will be evaluated in the trial (e.g., usability and acceptability to people with aphasia, % missing data, administration and scoring time).

2) Estimate a sample size for the definitive trial

We will recruit 36 participants in total, 18 participants allocated to each arm of the study. Based on retention rates of 85%, 30 participants will be followed up at 13 weeks post randomisation. This sample is adequate to inform the parameters of a larger trial such as recruitment rates, consent rates, completion rates, acceptability, and standard deviation of outcome measures (Julious, 2005).

3) Assess the processes for evaluating treatment fidelity

The process of assessing fidelity will provide further insight into the extent to which intervention was delivered as intended. Student projects will check fidelity of the intervention. They will develop a checklist of the core treatment components using the manual and in consultation with the project lead. A random selection of 20% of treatment sessions will be scored for fidelity against the checklist.

Data management and monitoring: All study data will be hosted at City, University of London on a password protected database accessed only by the project team. The data will be anonymised, with each participant being identified by a unique number. Data will be monitored for completeness and accuracy and a random selection of at least 20% of the data double checked.

Service user involvement: The study will recruit a user group and expert clinician consultants to support the development of the adapted intervention. This group will review the protocol and treatment manual and advise on whether the measures reflect the hypothesised changes.

Impact of this research:

The study will evaluate the feasibility of delivering a virtual enhanced SFA (VESFA). If results are positive this will lay the foundations for a definitive trial exploring the potential of VESFA to achieve word finding gains that generalise to discourse. The Cochrane review of speech and language therapy following stroke (2016) outlines generalisation of treatment gains into real-world communication as a priority for aphasia intervention.

What does the candidate bring to this PhD?

The candidate is an experienced research fellow with a strong academic track record and a career long enthusiasm for aphasia intervention (please see appendix two for cover letter).

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Appendix 2 | PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p.43
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	n/a
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p.49
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.49
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p.50
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p.51
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix 3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	p.52
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	p.52-54
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p.53
	10b	List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p.53
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p.53
Effect measures	12	Specify for each outcome the effect measure(s) (e.g., risk ratio, mean difference) used in the synthesis or presentation of results.	n/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g., tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	p.54
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	p.55
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p.55
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	p.55
	13e	Describe any methods used to explore possible causes of heterogeneity	n/a

Section and Topic	Item #	Checklist item	Location where item is reported
		among study results (e.g., subgroup analysis, meta-regression).	
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	n/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	p.56
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p.55
Study characteristics	17	Cite each included study and present its characteristics.	p.56
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p.59
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g., confidence/credible interval), ideally using structured tables or plots.	n/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p.72
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g., confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p.77
	23b	Discuss any limitations of the evidence included in the review.	p.81
	23c	Discuss any limitations of the review processes used.	p.81
	23d	Discuss implications of the results for practice, policy, and future research.	p.82
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	p.50
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p.50
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	p.132
Competing	26	Declare any competing interests of review authors.	-

Section and Topic	Item #	Checklist item	Location where item is reported
interests			
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

Appendix 3 | Systematic Review Searches

Search	Query	Records retrieved
	EBSCOhost CINAHL, 1 st July 2020	
#1	(MH "Aphasia") OR (MH "Aphasia, Broca") OR (MH "Aphasia, Transcortical Sensory") OR (MH "Aphasia, Conduction") OR (MH "Aphasia, Wernicke") OR (MH "Anomia")	6,883
#2	"aphasi*" OR "dysphasi*" OR "cognitive communication"	6,322
#3	#1 OR #2	8,706
#4	(MH "Rehabilitation") OR (MH "Rehabilitation, Speech and Language") OR (MH "Speech Therapy") OR (MH "Research, Speech-Language-Hearing Therapy") OR (MH "Therapy, Computer Assisted") OR (MH "Research, Rehabilitation") OR (MH "Language Therapy") OR (MH "Support, Psychosocial")	117,966
#5	AB rehabilitation OR AB "speech therap*" OR AB interven* OR AB treat* OR AB train* OR AB program* OR AB "language therap*" OR AB "social support" OR AB stimulat* OR AB "speech patholog*" OR AB "language patholog*"	1,635,844
#6	#4 OR #5	1,701,841
#7	(MH "Virtual Reality") OR (MH "Virtual Reality Exposure Therapy") OR (MH "Augmented Reality")	5,462
#8	AB "virtual reality" OR AB "virtual world*" OR AB "virtual environment" OR AB "video game*" OR AB "computer simulat*" OR AB "augmented reality" OR AB "augmented virtuality" OR AB "mixed reality" OR AB "virtual reality exposure therapy" OR AB cyberspace OR AB "immersive environment" OR AB "multi user virtual world"	7,245
#9	#7 OR #8	10,791
#10	#9 AND #6 and #3	24

Search	Query	Records retrieved
	EBSCOhost Academic search complete, 30 th June 2020	
#1	DE "APHASIA" OR DE "TRANSCORTICAL motor aphasia" OR DE "WERNICKE aphasia" OR DE "ANOMIA" OR DE "JARGON aphasia" OR DE "DIAGNOSIS of aphasia" OR DE "CONDUCTION aphasia" OR DE "TRANSCORTICAL sensory aphasia" OR DE "APHASIC persons" OR DE "AGRAMMATISM"	6,061
#3	AB aphasi* OR AB dysphasi* OR AB "cognitive communication"	9,709
#4	#1 OR #3	10,708
#5	((DE "REHABILITATION" OR DE "VOCATIONAL rehabilitation" OR DE "NEUROREHABILITATION" OR DE "REHABILITATION of aphasic persons" OR DE "NEUROPSYCHOLOGICAL rehabilitation" OR DE "STROKE patients -- Rehabilitation" OR DE "TREATMENT programs") AND (DE "SPEECH therapy" OR DE "COMPUTERS in speech therapy")) OR (DE "SOCIAL support")	36,518
#6	AB rehabilitation OR AB "speech therap*" OR AB intervent* OR AB treat* OR AB train* OR AB program OR AB "language therap*" OR AB "social support" OR AB stimulat* OR AB "speech patholog*" OR AB "language patholog*"	5,140,285
#7	#5 OR #6	5,152,744
#8	(DE "MASSIVELY multiplayer online role-playing games" OR DE "MIXED reality" OR DE "VIRTUAL reality" OR DE "SHARED virtual environments" OR DE "VIRTUAL reality therapy" OR DE "AVATARS (Virtual reality)") OR (DE "CYBERSPACE")	19,235
#9	AB "virtual world*" OR AB "virtual reality" OR AB "virtual environment" OR AB "video game*" OR AB "computer simulat*" OR AB "multi user virtual world*" OR AB "augmented reality" OR AB "augmented virtuality" OR AB "mixed reality" OR AB "virtual reality exposure therapy" OR AB cyberspace OR AB "immersive environment"	73,381
#10	#8 OR #9	80,678
#11	#9 AND #6 AND #3	19

Search	Query	Records retrieved
	EBSCOhost Communication Source, 1 st July 2020 (Mesh terms under 'thesaurus')	
#1	DE "APHASIA" OR DE "ANOMIA" OR DE "JARGON aphasia" OR DE "CONDUCTION aphasia" OR DE "AGRAMMATISM"	2,894
#2	AB aphasi* OR AB dysphasi* OR AB "cognitive communication"	3,847
#3	#1 OR #2	4,155
#4	((DE "VOCATIONAL rehabilitation") OR (DE "SPEECH therapy")) OR (DE "SOCIAL support")	4,170
#5	AB rehabilitation OR AB "speech therapy" OR AB interven* OR AB treat* OR AB train* OR AB program* OR AB "language therap*" OR AB "social support" OR AB stimulat* OR AB "speech patholog*"	109,035
#6	#4 OR #5	110,532
#7	(DE "CYBERSPACE") OR (DE "VIRTUAL communities")	1,387
#8	AB "virtual reality" OR AB "virtual world*" OR AB "augmented reality" OR AB "augmented virtuality" OR AB "video game*" OR AB "computer simulat*" OR AB "mixed reality" OR AB "virtual reality exposure therapy" OR AB "virtual environment" OR AB "immersive environment" OR AB "multi user virtual world" OR AB "cyberspace"	4,912
#9	#7 OR #8	5,879
#10	#3 AND #6 AND #9	5

Search	Query	Records retrieved
	EBSCOhost Medline complete, 1 st July 2020	
#11	(MH "Aphasia") OR (MH "Aphasia, Broca") OR (MH "Aphasia, Wernicke") OR (MH "Aphasia, Conduction") OR (MH "Anomia")	11,578
#12	AB aphasi* OR AB dysphasi* OR AB "cognitive communication"	13,279
#13	#11 OR #12	19,135
#14	MH "Rehabilitation") OR (MH "Neurological Rehabilitation") OR (MH "Rehabilitation, Vocational") OR (MH "Stroke Rehabilitation") OR (MH "Rehabilitation Research") OR (MH "Rehabilitation of Speech and Language Disorders") OR (MH "Telerehabilitation") OR (MH "Speech Therapy") OR (MH "Social Support") OR (MH "Language Therapy") OR (MH "Speech-Language Pathology")	120,491
#15	AB rehabilitation OR AB "speech therap*" OR AB "language therap*" OR AB "speech patholog*" OR AB "treat*" OR AB "train*" OR AB "interven*" OR AB "program*" OR AB "social support" OR AB stimul*	6,952,501
#16	#14 OR #15	7,010,446
#17	(MH "Virtual Reality") OR (MH "Virtual Reality Exposure Therapy") OR (MH "Telerehabilitation") OR (MH "Computer Simulation")	189,994
#18	AB "virtual reality" OR AB "virtual world*" OR AB "augmented reality" OR AB "augmented virtuality" OR AB "video game*" OR AB "computer simulat*" OR AB "mixed reality" OR AB "virtual reality exposure therapy" OR AB "virtual environment" OR AB "immersive environment" OR AB "multi user virtual world" OR AB "cyberspace"	40,758
#19	MH Augmented Reality	98
#20	#17 OR #18 OR #19	215,936
#21	#13 AND #16 AND #20	31

Search	Query	Records retrieved
	EBSCOhost APA PsycINFO, 2 nd July 2020	
#1	(DE "Aphasia" OR DE "Wernicke's Syndrome") OR (DE "Dysphasia")	11,522
#2	AB aphasi* OR AB dysphasi* OR AB "cognitive communication"	13,409
#3	#1 OR #2	15,353
#4	((DE "Rehabilitation" OR DE "Vocational Rehabilitation" OR DE "Telerehabilitation" OR DE "Neurorehabilitation") AND (DE "Speech Therapy" OR DE "Language Therapy" OR DE "Speech Language Pathology")) OR (DE "Social Support")	57,379
#5	AB rehabilitation OR AB "speech therapy" OR AB "language therapy" OR AB interven* OR AB treat* OR AB train* OR AB program* OR AB "social support" OR AB stimulat* OR AB "speech patholog*"	1,502,342
#6	#4 OR #5	1,521,917
#7	((DE "Virtual Reality" OR DE "Virtual Reality Exposure Therapy" OR DE "Augmented Reality" OR DE "Avatars") AND (DE "Computer Games" OR DE "Role Playing Games")) OR (DE "Computer Simulation")	12,999
#8	AB "virtual world*" OR AB "virtual reality" OR AB "virtual environment" OR AB "augmented reality" OR AB "mixed reality" OR AB "augmented virtuality" OR AB "video game*" OR AB "computer simulat*" OR AB "virtual reality exposure therapy" OR AB "multi user virtual world" OR AB "cyberspace" OR AB "immersive environment"	13,874
#9	#7 OR #8	25,953
#10	#3 AND #6 AND #9	16

Search	Query	Records retrieved
	OVID Embase '74-'20, 3 rd July 2020	
#1	Exp aphasia	28,624
#2	Exp dysphasia	3,136
#3	Exp traumatic brain injury	49,716
#4	(aphasi* or dysphasi* or "cognitive communication").ab.	22585
#5	1 or 2 or 3 or 4	85048
#6	speech rehabilitation/ or stroke rehabilitation/ or "speech and language rehabilitation"/ or psychosocial rehabilitation/ or vocational rehabilitation/ or exp rehabilitation/ or virtual rehabilitation system/ or community based rehabilitation/	388185
#7	exp speech therapy/	13450
#8	exp language therapy/ or "speech and language"/	1790
#9	exp social support/	90674
#10	(rehabilitation or "speech therapy" or "language therapy" or intervent* or treat* or train* or program* or "social support" or stimulat* or "speech patholog*").ab	9603843
#11	6 or 7 or 8 or 9 or 10	9800185
#12	exp virtual reality/ or exp computer simulation/	134088
#13	exp augmented reality/	347
#14	exp virtual reality exposure therapy/	636
#15	("virtual reality" or "virtual world*" or "multi user virtual world" or "virtual environment" or "augmented reality" or "mixed reality" or "virtual virtuality" or "video game*" or "computer simulation" or "immersive environment" or cyberspace or "virtual reality exposure therapy" or virtual).ab.	84086
#16	12 or 13 or 14 or 15	194992
#17	5 and 11 and 16	276

Search	Query	Records retrieved
	Ovid Emcare ('95-'20), 3 rd July 2020	
#1	exp aphasia/	9769
#2	exp dysphasia/	752
#3	exp traumatic brain injury/	20369
#4	(aphasi* or dysphasi* or "cognitive communication").ab.	6825
#5	1 or 2 or 3 or 4	31278
#6	speech rehabilitation/ or virtual rehabilitation system/ or "speech and language rehabilitation"/ or psychosocial rehabilitation/ or stroke rehabilitation/ or exp rehabilitation/	211002
#7	exp speech therapy/	6565
#8	exp language therapy/ or exp "speech and language"/	132737
#9	exp social support/	47799
#10	(rehabilitation or "speech therapy" or "language therapy" or "Speech patholog*" or train* or treat* or program* or interven* or "social support" or stimulat*).ab.	2072619
#11	6 or 7 or 8 or 9 or 10	2248916
#12	exp virtual reality/	9319
#13	exp computer simulation	22805
#14	exp augmented reality/	141
#15	exp virtual reality exposure therapy/	277
#16	("virtual world*" or "virtual reality" or "virtual environment" or "multi user virtual world" or "augmented reality" or "mixed reality" or "immersive environment" or "computer simulation" or cyberspace or "virtual reality exposure therapy" or "augmented virtuality" or "video game*").ab.	11917
#17	12 or 13 or 14 or 15 or 16	27243
#18	5 and 11 and 17	147

Search	Query Ovid Online	Records retrieved
#1	DE "APHASIA" OR DE "ANOMIA" OR DE "JARGON aphasia" OR DE "CONDUCTION aphasia" OR DE "AGRAMMATISM"	2,894
#2	AB aphasi* OR AB dysphasi* OR AB "cognitive communication"	3,847
#3	#1 OR #2	4,155
#4	((DE "VOCATIONAL rehabilitation") OR (DE "SPEECH therapy")) OR (DE "SOCIAL support")	4,170
#5	AB rehabilitation OR AB "speech therapy" OR AB interven* OR AB treat* OR AB train* OR AB program* OR AB "language therap*" OR AB "social support" OR AB stimulat* OR AB "speech patholog*"	109,035
#6	#4 OR #5	110,532
#7	(DE "CYBERSPACE") OR (DE "VIRTUAL communities")	1,387
#8	AB "virtual reality" OR AB "virtual world*" OR AB "augmented reality" OR AB "augmented virtuality" OR AB "video game*" OR AB "computer simulat*" OR AB "mixed reality" OR AB "virtual reality exposure therapy" OR AB "virtual environment" OR AB "immersive environment" OR AB "multi user virtual world" OR AB "cyberspace"	4,912
#9	#7 OR #8	5,879
#10	#3 AND #6 AND #9	5

Total papers: 523

Appendix 4 | Supplementary table. Rationales for VR

Study	Treatment fidelity	Increases dose	Accessibility	Intensive	Cost effective	Socially embedded	Motivating	Generalisation / Functional recovery	Stimulates conversation	Ecological validity	Multi modal environment
Carragher et al., 2020			✓		✓				✓		
Cherney et al., 2019	✓										
Cherney et al. 2021		✓		✓							
Giachero et al., 2020										✓	✓
Grechuta et al., 2017				✓							
Grechuta et al., 2019				✓		✓					
Grechuta et al., 2020											
Kalinyak-Fliszar et al. 2015				✓	✓			✓			
Maresca et al., 2019				✓			✓	✓			✓
Marshall et al., 2016				✓		✓	✓	✓			
Marshall et al., 2018							✓	✓	✓	✓	
Marshall et al., 2020							✓	✓	✓	✓	
Snell et al. 2017								✓		✓	
Thompson et al., 2010		✓									

Table A: Rationales given for the use for VR in the studies included

Appendix 5 | Examples of forms of VR used in aphasia rehabilitation

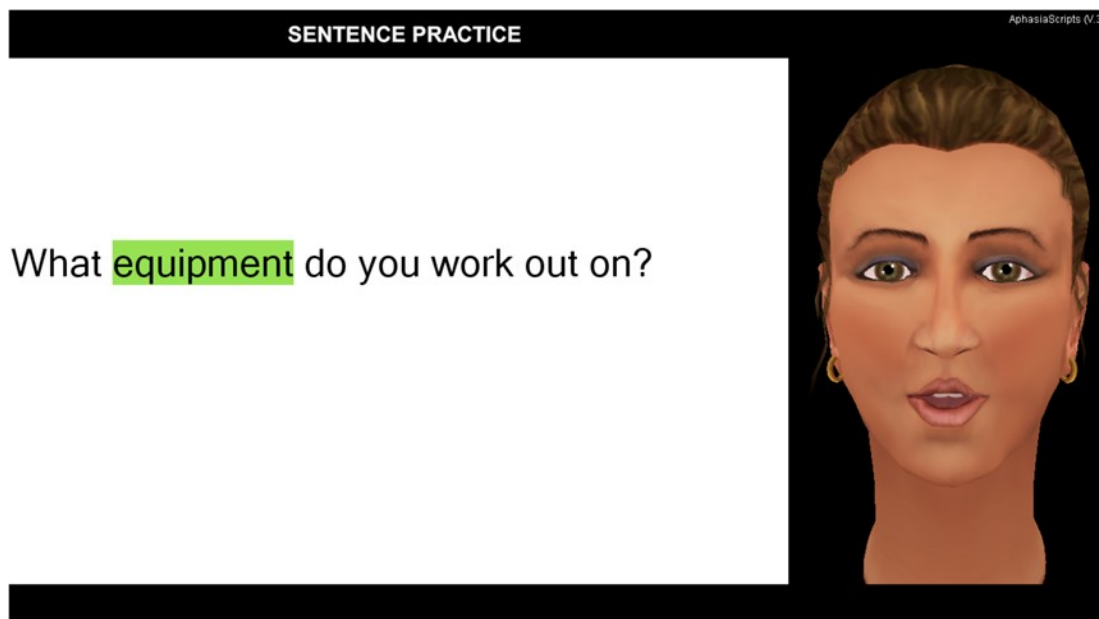


Image 1. Virtual Clinician: One of the virtual therapists used in AphasiaScripts® during Sentence Practice. The virtual therapist “speaks” the words with mouth movements similar to that of a real person. Each word is highlighted as it is spoken. Figure courtesy of AphasiaScripts®.



Image 2. Virtual barrier game: illustration of the therapeutic set up of the Rehabilitation Gaming System (RGS). © 2017 IEEE. Reprinted, with permission, from Grechuta, K., Bellaster, B. R., Munne, R. E., Bernal, T. U., Hervas, B. M., Segundo, R. S., & Verschure, P. (2017). The effects of silent visuomotor cueing on word retrieval in Broca's aphasia: A pilot study. *IEEE ... International Conference on Rehabilitation Robotics : [proceedings]*, 2017, 193–199.



Image 3. Virtual Scenario: ScenePlayer NeuroVR “Supermarket”. Copyright © 2020 A.Giachero et al. This is an open access article distributed under the Creative Commons Attribution License



Image 4. Multi-User Virtual World: EVA Park is virtual island where multiple users, represented as avatars, can meet and walk to locations such as a café, restaurants, health centre and houses. Figure courtesy of the EVA Park research team

Appendix 6 | Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251.

No.	Topic	Item	Page No.
Title and abstract			
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	121
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	n/a as thesis chapter
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	121
S4	Purpose or research question	Purpose of the study and specific objectives or questions	122
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	122
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	123
S7	Context	Setting/site and salient contextual factors; rationale ^a	122
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^a	122
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	122 and Appendix 11
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^a	117, 118

S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	123, 124
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	124
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	124
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^a	124
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^a	124
Results/Findings		
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	125
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	125 126
Discussion		
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	127
S19 Limitations	Trustworthiness and limitations of findings	129
Other		
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	n/a as thesis chapter
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	n/a

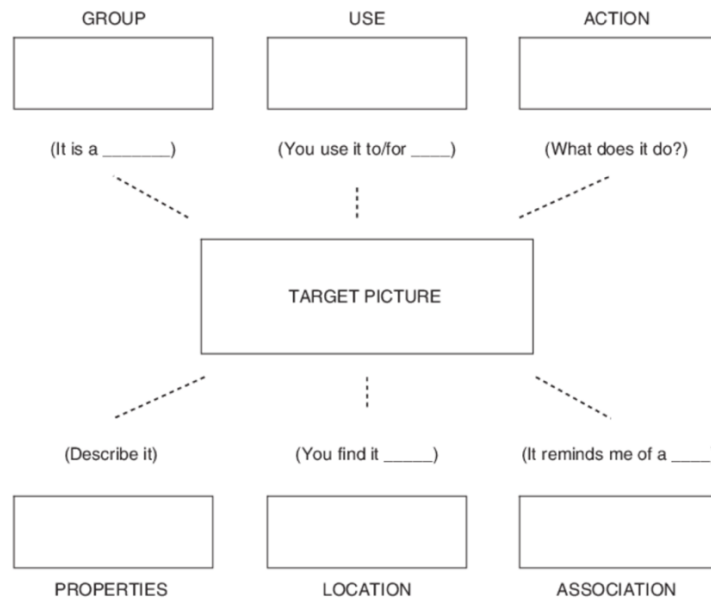
^aThe rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Appendix 7 | VESFA TIDieR

1	Brief Name	VESFA (Virtual Elaborated Semantic Feature Analysis)
2	Why	A study of Elaborated Semantic Feature Analysis (ESFA) demonstrated improvement in word retrieval but showed inconsistent evidence of generalisation to functional communication (Efstratiadou et al., 2019). A study of situated conversations in EVA Park improved functional communication (Marshall et al., 2018). VESFA aims to improve both word retrieval and functional communication by delivering ESFA with conversation groups in functional settings in the virtual world EVA Park. Why ESFA Semantic Feature Analysis (SFA) is a semantic naming treatment. In SFA the participant works on a set of target words. The participant builds up the semantic network around a word by identifying associated semantic categories, the supraordinate category, use, verb, description, location, and personal association (Boyle, 2004). This task mimics our understanding of the neural basis of semantics as described by the hub and spoke model (Woollams, 2012). In this model the hub is the core concept, and the spokes represent the features of that concept, for example the motion, the colour, the shape, the name. These representations are processed by a common set of neurons and synapses (Woollams, 2012). The mechanisms of change in SFA are therefore based on the principles of neuroplasticity (Kiran & Thompson, 2019) priming (Martin et al., 2004) and Hebbian learning (Hebb, 1949). In summary there are clear underlying mechanisms and good naming outcomes for SFA. Elaborating SFA to practicing a phrase or sentence with the target word, ESFA, prepares the participant for the use of the phrase in conversation. Why conversation groups We know that situated language, using your words in the context of daily conversation, is a more complex task (Doedens & Meteyard, 2018) than using words to name pictures, as is done in SFA. Studies that treat words in isolation and test for use of those words in context often get negative results for words in context (Carragher et al., 2012). Using the target words in a variety of structured and unstructured conversations aims to train the use of words in context. The Articulate and Bingo game require the retrieval of the target words within a scaffolded conversation task. The conversation topics for the groups are unstructured. This is the most challenging task. Participants can choose what they share with the group within the topic. They are encouraged to think about what they will share before the group (Marshall, J. & Cairns, 2005). The vocabulary will have been primed by the preceding task. Placing the groups in the

		virtual surroundings of the topic increases salience. For example, the gardening group takes place in the virtual greenhouse. Aphasia groups are also known to support wellbeing through the mechanisms of opportunities for support, learning and communication (Attard et al., 2015).
3	What materials	EVA Park: A multi-user virtual island with virtual spaces connected to conversation topics. In VESFA there are four topics They are: Food and drink, Travel, Gardening and Nature, Daily Living. Topic: Food and Drink Virtual Places: Pizza restaurant, picnic tables, dining table and kitchen table in the houses, café, rooftop café, bar Topic: Travel Virtual Places: ship, car, campfire, lighthouse, raft, ticket office Topic: Daily Living Virtual Places: sitting room, dining table, deck Topic: Gardening and Nature Virtual places: greenhouse, waterfall garden, lake PowerPoint board with target items and SFA chart for each of the items. There are four boards in EVA Park, one board per topic, with 30 words in each topic. Therapy manual: includes rationales, session plans with topic and virtual place for each group Participants handbook: includes group times and dates, SFA chart, vocabulary lists, BINGO cards
4	What procedures	VESFA therapy approach is based on the ESFA therapy protocol (Kladouchou et al., 2017) and is delivered in a virtual world with one-to-one (1:1) ESFA sessions and conversation groups. The vocabulary topics practiced in the ESFA sessions are the topics of the conversation groups. <u>ESFA 1:1 sessions</u> Work through the target word list focussing on one topic per session. Treat one topic list (30 items) for two weeks (three topics with two weeks per topic covers sessions 1-12). Session 13-15 are recap sessions, each going back over one of the three topics. In the final session all 90 words are rehearsed. Picture Naming

		The first picture is shown. Pictures are ordered randomly using the list randomiser (www.random.org) at the beginning of each treatment set. Ask the participant 'what is this?'. If the client makes a phonemic or phonological paraphasia or circumlocution use the phonemic cueing hierarchy. 1. production of the word's first phoneme 2. production of the word's first syllable 3. production of the word's first and second syllables 4. production of the target word If the client produces a semantic paraphasia use the semantic cueing hierarchy: 1. Repeat client's production and ask if correct 2. Ask questions semantically related with the target word 3. hints e.g. This is cutlery with three prongs 4. sentence-completion cue e.g., he used a knife and _____ If the client is not able to produce the word after cueing, work through the entire SFA chart, with cues provided as needed, to produce the target word. If the client cannot produce the target word even when all features have been listed, the SLT produces the word orally and the client repeats it and names all of its features. Semantic Feature Generation Work through semantic features chart (Boyle, 2004). Prompt the client to think of and say words semantically related to the target word (semantic features) by working through the questions on the SFA chart:
--	--	--



The chart includes six categories: superordinate category, use, action, physical properties, location and association. To elicit feature production, the therapist asked questions or provides the client with sentence-completion cues.

After the oral word production prompt, the client wrote down the target word in the instant messaging (IM) function. For clients who cannot write, the therapist provides the written words.

After the chart completion and the retrieval of the word by the client, when the SFA procedure is complete for the target word, the SLT summarises the target word and it's features and asked the client to 'make a sentence using the word ____'. Encourage the client to produce a phrase with the target word and some of its features. For example, for the item 'table', the individual can use features such as: furniture, for dining, wooden, kitchen, chair, tea, eat, and then elaborate these features in sentences such as: we eat at the table, we have tea at the table, the table is for dining, the table is a piece of furniture in the kitchen, etc. The client can choose as many features as they want (one as a minimum) and put them together into a sentence.

Write sentence

Clients are encouraged to write the sentence down, if they can. It does not matter if people make errors in their sentences, e.g., syntactic or morphological errors as long as the sentence was meaningful. The therapist writes the phrase for those who struggle to write.

	If generating sentences was a challenge, share the list of sentences generated with the client for practice. Beginnings and endings At the beginning of each therapy session, ask the client to name the pictures that they had not named correctly in the previous session. If the client cannot name the picture correctly, the chart analysis was repeated with these targets before moving on to new targets. At the end of each session ask the client to name all the words worked so far. <u>Conversation groups</u> The conversation groups are made up of 3 people with aphasia and the therapist. Each group covers one topic. Functional role play targets the vocabulary in the virtual settings e.g., ordering food and drink in café/restaurant, discussing what to plant in the greenhouse. Personal associations to the target vocabulary will be optimised, using conversational contexts and the simulated physical context to cue the target word. Stories that arose in the individual ESFA sessions e.g. 'I saw an octopus in Spain!' when targeting 'octopus' were brought into the groups to share with the others.
--	---

		Activity	Place	Content	Materials	Time (min)
		Welcome / news	Town square	Technical set up	Have clients phone numbers	10
		Topic 'Articulate!'	Topic context	Recap target words		20
		Topic conversation	Topic context	See conversation groups below	SFA chart	45
		Topic Bingo	Topic context	Use words in short story	Bingo Cards	10
		Close: Three good things	Lake loungers	'What have you been pleased to notice today?'	SLT to share responses in IM function	5
	Welcome Each group will have a 10 minute window for people to arrive, arrange their microphone settings, and a share news. Topic activities The 16 groups will cover 3 topics. Before the therapy block the participants will agree on three of the four topics to work on. Each topic will be worked on for two weeks and all participants will move on to a new topic together regardless of the number of items covered in their individual ESFA sessions. There are three topic activities in each group, 1) Articulate 2) Conversation 3) Bingo. These are described below. Articulate: Topic vocabulary will be recapped. Encourage members to identify items targeted within the topic in individual ESFA sessions. A game of 'Articulate!' will support this. One member describes a target item without using the target word, the other members must guess what they are describing. Each group member has a turn describing an item.					

		Topic conversation: After the vocabulary has been recapped, the conversation activity will be carried out. Each member has turn to contribute to the conversation. Each topic has four activities (past, dream, process, personal story). Each group will focus on one activity, for example in one group all three members share a past travel experience. Conversation topics for each group is outlined in the manual. The SFA chart and vocabulary lists will be available to the participants as a prompt in the participant handbook. The clinician uses predictable prompts (What do you use it for? Where might you find it?) to support word finding difficulties in conversations. Bingo: In the topic Bingo game, each participant takes a turn to create a small story using all the items on the bingo card. For example, the Bingo card shows <i>calendar</i>, <i>bus</i>, <i>pool</i> and <i>map</i>. The participant might say that they saw it was the day for swimming on the <i>calendar</i>, so they looked at the <i>map</i>, took the <i>bus</i> and went to the <i>pool</i>. When all items on the card have been mentioned the other members can call 'BINGO!'. Close The SLT will give feedback on the use of targets in conversations. Each group will close with an adapted Three Good Things task (Seligman et al. 2005). Each client will be asked what they were 'pleased to notice' this session. Challenge tasks The challenge tasks are given in between groups and encourage participants to take what they are practicing in the virtual world into real world situations. For example, a challenge task after the 'dream meal' conversation is to share their dream meal in a real word conversation with family or a friend.
5	Who provided	A speech and language therapist with 15 years of clinical experience.
6	How provided	Treatment was provided via an internet based virtual world, EVA Park. EVA Park is built in the software OpenSim and viewed through the 3D browser 'Firestorm'. Participants need a laptop or computer (not tablet) to access the virtual world and an internet connection.
7	Where	Participants and therapist worked from a computer at home. This research project was carried out during the global pandemic in 2020-2021 when all face-to-face research was stopped.
8	When and how much	16 1hr sessions of ESFA (16hrs), 16 1.5hr conversation groups (24hrs) delivered over 8 weeks (total 40hrs). We know that successful SLT

		treatment have a dose of 20-50hrs (ref). The schedule was 4 sessions per week: 2 ESFA and 2 groups. For example: <table><tr><td>Monday</td><td>Tuesday</td><td>Wednesday</td><td>Thursday</td><td>Friday</td></tr><tr><td>1hr ESFA</td><td>1.5hr group</td><td>1hr ESFA</td><td>1.5hr group</td><td></td></tr></table> 6 sets of 8 weeks were carried out with 3 participants treated in each set.	Monday	Tuesday	Wednesday	Thursday	Friday	1hr ESFA	1.5hr group	1hr ESFA	1.5hr group	
Monday	Tuesday	Wednesday	Thursday	Friday								
1hr ESFA	1.5hr group	1hr ESFA	1.5hr group									
9	Tailoring	Aphasia Type: Non-fluent For participants with agrammatic aphasia who were doing well with noun naming in the ESFA sessions the focus moved more to ‘actions’. For example: one participant had goal to retrieve two verbs for each target Aphasia Severity: Severe In ESFA sessions forced alternatives were often used to support the generation of features e.g., is this round or square? In group sessions, the articulate game, SLT will ask questions to elicit cues. For example: is it an animal? In Bingo game participant is required to name items on the card only. Phonological/morphological errors accepted if message is clear. Moderate Group: In the Bingo task a participant with moderate aphasia was required to use each item on the card in a phrase or sentence, without the need for coherence in a narrative. Mild ESFA: Request generation of two verbs or two pronouns per target. Group: In the Bingo tasks participants with mild aphasia were requested to use all the items on the card in a coherent narrative.										
10	Modifications	The ‘articulate’ activity was added to the groups after set 1 as the open conversation activity was challenging and opportunities for using target words in group context were limited.										
11	How well: planned	Treatment fidelity project. A fidelity checklist was developed to explore if treatment was delivered as intended. 18% sessions across all 6 sets of treatment were checked.										
12	How well: actual	The mean adherence to the protocol for both individual and group sessions was 81%.										

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Appendix 8 | The VESFA Therapy Manual



Virtual Elaborated Sematic Feature Analysis | VESFA Therapy Manual



November 2020

Background

VESFA therapy is Elaborated Semantic Feature Analysis (ESFA) (Efstratiadou et al., 2019) therapy delivered via a multi-user virtual world, EVA Park (Carragher et al., 2020; Marshall et al., 2016; Marshall et al., 2018; Marshall et al., 2020). ESFA is based on the semantic feature analysis (SFA) protocol (Boyle, 2004) and extends the protocol to invite the client to use the words elicited on the SFA chart into a sentence. It includes cueing hierarchies to elicit features when participants cannot produce them. VESFA additionally includes conversation groups that run alongside the individual therapy ESFA sessions and target the same topics. The SFA treatment approach was applied to improve word retrieval of object nouns in aphasia. The purpose of the VESFA approach is to improve the transfer of naming abilities into functional conversations.

Stimuli

Therapy stimuli consist of four topics with thirty nouns in each topic.

Food and Drink	Daily Living	Nature and Gardening	Travel
can	can opener	pumpkin	pool
Plate	curtains	hose	shell
octopus	dustpan	cabbage	globe
frying pan	fire	snail	desert
pineapple	floor	carrot	bus
salt	mirror	fly	tent
pie	mixer	spider	cloud
wheat	mop	owl	canoe
bowl	mousetrap	boot	rainbow
cherry	bucket	plant	city

table	picture	fox	road
spoon	roof	leaf	rock
glass	rug	chair	lake
pepper	sink	fence	train
cup	stairs	daffodil	rain
fish	vacuum	ant	book
pot	washing machine	bird	volcano
asparagus	bathtub	squirrel	mountain
walnut	doctor	butterfly	boat
cheese	priest	potato	sunset
scale	pen	tree	camera
kettle	church	bee	car
sandwich	pencil	flower	map
fork	fan	caterpillar	castle
egg	window	frog	sailboat
corn	lamp	sun	skis
butter	iron	swing	backpack
tomato	toilet	watering can	lighthouse
peach	basket	bench	calendar
onion	key	rake	waterfall

Topics were chosen based on the existing literature on what people with aphasia choose to talk about (Palmer, Hughes and Chater, 2017; Holland, Halper and Cherney, 2010) and a user consultation (n=12) project investigating the topics people with aphasia find most meaningful to talk about. Images for each item came from published word lists with name agreement, frequency and imageability data (Roach et al., 1996; Snodgrass and Vanderwart, 1980). The 30 least imageable items were selected for each topic in line with the complexity hypothesis (Thompson et al., 2003). However, the items remain images of objects and are therefore concrete.

Three of the topics are treated and one topic remains untreated and acts as a control. Each participant in the group gives their preference for treated topics and the control topic is decided based on the group preferences e.g., 2 of the 3 didn't want to work on 'gardening' set so this became the control topic.

Intervention provider

The VESFA therapy provider in this study is a research speech and language therapist (SLT). The SLT has an undergraduate speech and language therapy degree, 15 years of clinical experience and has worked with people with aphasia for 12 years.

Modes of delivery, location, dose

VESFA therapy is delivered through two different modes: individual therapy and group therapy. All sessions take place online with participants and the therapist logging in to the virtual world from a computer in their own homes. Participants are randomised to receive either 40hrs of VESFA (16hrs of individual ESFA therapy and 24hrs of conversation groups) or a usual care control group. Participants can log into EVA Park between therapy sessions and access the therapy materials. This self-directed use of EVA Park is recorded e.g., the number of hours participants use EVA Park outside of scheduled sessions and objects they click while in EVA Park.

Treatment:	Hours per week:	Over 8 week period:
ESFA	2x 1hr	16hrs
Conversation	2x 1.5hr	24hrs
		Total: 40hrs

Main therapy procedures

VESFA therapy approach is based on the ESFA therapy protocol (Kladouchou *et al.*, 2017) and is delivered in a virtual world with one-to-one (1:1) ESFA sessions and conversation groups. The vocabulary topics practiced in the ESFA sessions are the topics of the conversation groups.

ESFA 1:1 sessions

Work through the target word list focussing on one topic per session. Treat one topic list (30 items) for two weeks (three topics with two weeks per topic covers sessions 1-12). Session 13-15 are recap sessions, each going back over one of the three topics. In the final session all 90 words are rehearsed.

Picture Naming

The first picture is shown. Pictures are ordered randomly using the list randomiser (www.random.org) at the beginning of each treatment set.

Ask the participant 'what is this?'.



If the client makes a phonemic or phonological paraphasia or circumlocution use the **phonemic cueing hierarchy**.

5. production of the word's first phoneme
6. production of the word's first syllable

7. production of the word's first and second syllables
8. production of the target word

If the client produces a semantic paraphasia use the **semantic cueing hierarchy**:

5. Repeat client's production and ask if correct
6. Ask questions semantically related with the target word
7. hints e.g. This is cutlery with three prongs
8. sentence-completion cue e.g., he used a knife and _____

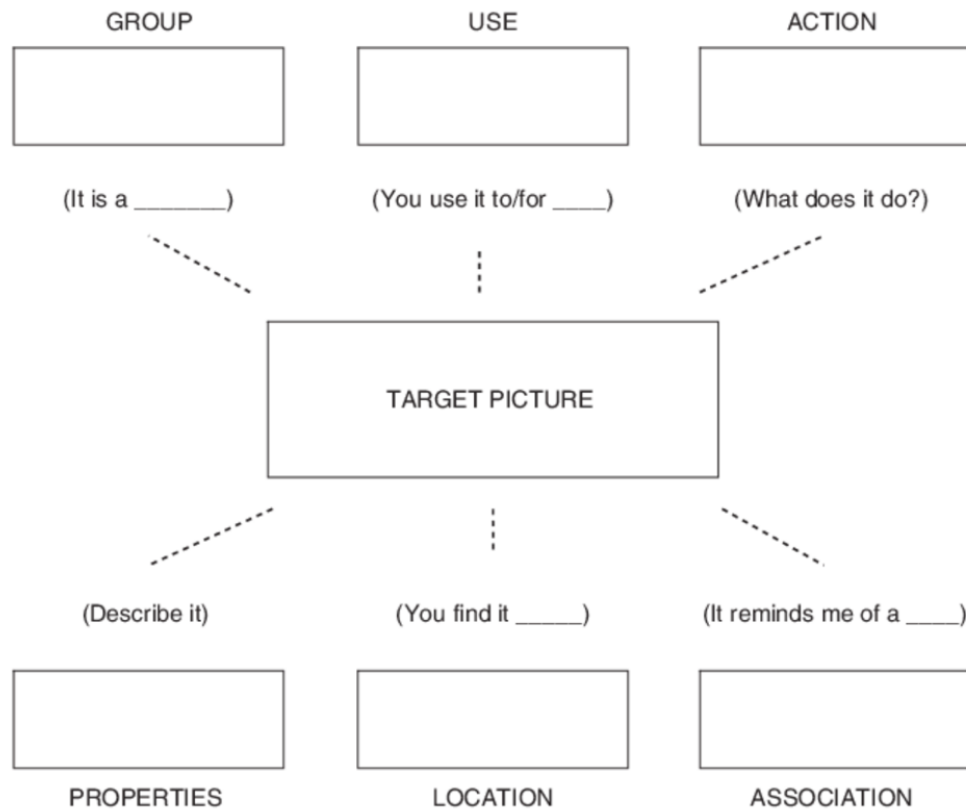
If the client is not able to produce the word after cueing, work through the entire SFA chart, with cues provided as needed, to produce the target word. If the client cannot produce the target word even when all features have been listed, the SLT produces the word orally and the client repeats it and names all of its features.

Semantic feature generation

Work through semantic features chart (Boyle, 2004). Prompt the client to think of and say words semantically related to the target word (semantic features) by working through the questions on the SFA chart:



The chart includes six categories: superordinate category, use, action, physical properties, location and association. To elicit feature production, the therapist asked questions or provides the client with sentence-completion cues.



Write the target

After the oral word production, prompt the client to write down the target word in the instant messaging (IM) function. For clients who cannot write, the therapist provides the written words.

Sentence/phrase generation

After the chart completion and the retrieval of the word by the client, when the SFA procedure is complete for the target word, the SLT summarises the target word and its features and asked the client to 'make a sentence using the word ____'. Encourage the client to produce a phrase with the target word and some of its features. For example, for the item 'table', the individual can use features such as: furniture, for dining, wooden, kitchen, chair, tea, eat, and then elaborate these features in sentences such as: we eat at the table, we have tea at the table, the table is for dining, the table is a piece of furniture in the kitchen, etc. The client can choose as many features as they want (one as a minimum) and put them together into a sentence.

Write sentence

Clients are encouraged to write the sentence down, if they can. It does not matter if people make errors in their sentences, e.g., syntactic or morphological errors as long as the sentence was meaningful. The therapist writes the phrase for those who struggle to write.

If generating sentences was a challenge, share the list of sentences generated with the client for practice.

Beginnings and endings

At the beginning of each therapy session, ask the client to name the pictures that they had not named correctly in the previous session. If the client cannot name the picture correctly, the chart analysis was repeated with these targets before moving on to new targets.

At the end of each session ask the client to name all the words worked so far.

TAILORING

The number of words practiced in each session will differ depending on the rate of naming of each participant. The use of writing will depend on whether some ability to write is spared. A focus on a particular feature can be used dependent on need. For example, an agrammatic participant whose noun naming was approaching ceiling named at least two verbs for every target to maintain an appropriate challenge.

Conversation groups

The conversation groups are made up of 3 people with aphasia and the therapist. Each group covered one topic.

Functional role play will target the vocabulary in the virtual settings e.g., ordering food and drink in café/restaurant, discussing what to plant in the greenhouse.

Personal associations to the target vocabulary will be optimised, using conversational contexts and the simulated physical context to cue the target word. Stories that arose in the individual ESFA sessions e.g. 'I saw an octopus in Spain!' when targeting 'octopus' were brought into the groups to share with the others.

Activity	Place	Content	Materials	Time (min)
Welcome / news	Town square	Technical set up	Have clients phone numbers	10
Topic 'Articulate!'	Topic context	Recap target words		20
Topic conversation	Topic context	See conversation groups below	SFA chart	45
Topic Bingo	Topic context	Use words in short story	Bingo Cards	10
Close: Three good things	Lake loungers	'What have you been pleased to notice today?'	SLT to share responses in IM function	5

Simple session plan (detailed session plan on page 15)

Welcome

Each group will have a 10 minute window for people to arrive, arrange their microphone settings, and a share news.

Topic Activities

The 16 groups will cover 3 topics. Before the therapy block the participants will agree on three of the four topics to work on.

Each topic will be worked on for two weeks and all participants will move on to a new topic together regardless of the number of items covered in their individual ESFA sessions. There are three topic activities in each group, 1) Articulate 2) Conversation 3) Bingo. These are described below.

Articulate:

Topic vocabulary will be recapped. Encourage members to identify items targeted within the topic in individual ESFA sessions. A game of 'Articulate!' will support this. One member describes a target item without using the target word, the other members must guess what they are describing. Each group member has a turn describing an item.

Topic conversation:

After the vocabulary has been recapped, the conversation activity will be carried out. Each member has turn to contribute to the conversation. Each topic has four activities (past, dream, process, personal story). Each group will focus on one activity, for example in one group all three members share a past travel experience. The SFA chart and vocabulary lists will be available to the participants as a prompt in the user manual. The clinician uses the same, predictable prompts (What do you use it for? Where might you find it?) to support word finding difficulties in conversations.

Conversation activity:

- | | |
|----------------------|-----------------------|
| 1. Topic 1 - past | 9. Topic 3 - past |
| 2. Topic 1 - dream | 10. Topic 3 – dream |
| 3. Topic 1 - process | 11. Topic 3 - process |
| 4. Topic 1 -story | 12. Topic 3 - story |
| 5. Topic 2- past | 13. Topic 1 -recap |
| 6. Topic 2 - dream | 14. Topic 2 - recap |
| 7. Topic 2 - process | 15. Topic 3 - recap |
| 8. Topic 2 - story | 16. EVA Park Party |

Activity	Travel	Place in EVA
1.	Past travel. Tell us about the last time you travelled	Camp fire
2.	Dream travel. Describe your perfect holiday	Yacht
3.	Process. Directions from the nearest train station to your house	Cadillac
4.	Anecdote/ personal story about travel	Camp fire behind disco

Activity	Food & Drink	Place in EVA
1.	Past meal. Tell us what you ate last night.	Dining table
2.	Dream meal. Describe your favourite meal / you are creating a dinner party – what be on the menu	Pizza place
3.	Process Share a recipe	Kitchen
4.	Funny Story /anecdote about food	Dining table

Activity	Gardening and Nature	Place in EVA
1.	Past garden Tell us about a garden or park	Greenhouse
2.	Dream garden Describe your dream garden	Waterfall
3.	Process How to plant something; bulb, flower, veg	Greenhouse
4.	Story/anecdote about gardens	Lake loungers

Activity	Daily living	Place in EVA
1.	Tell me about your day yesterday	House sitting room
2.	Dream day Describe your dream day	House deck chairs
3.	Process Typical daily routine	Dining table
4.	Personal story /anecdote	Dining table

Bingo:

In the topic Bingo game, each participant takes a turn to create a small story using all the items on the bingo card. For example, the Bingo card shows *calendar*, *bus*, *pool* and *map*. The participant might say that they saw it was the day for swimming on the *calendar*, so they looked at the *map*, took the *bus* and went to the *pool*. When all items on the card have been mentioned the other members can call 'BINGO!'.

Close

The SLT will give feedback on the use of targets in conversations.

Each group will close with an adapted Three Good Things task (Seligman et al. 2005). Each client will be asked what they were 'pleased to notice' this session.

Challenge tasks

The challenge tasks are given in between groups and encourage participants to take what they are practicing in the virtual world into real world situations. For example, a challenge task after the 'dream meal' conversation is to share their dream meal in a real word conversation with family or a friend.

Additional therapy principles

There is flexibility in terms of the order of the chart completion. Features can be completed in any order. If a category is not appropriate for a target e.g., Squirrel – what do you use it for? This can be skipped. More than one feature can be identified for a category e.g., Physical features of a peach – furry, soft, round. If the client can produce the word the features are still elicited.

Detailed Session Plan

Activity	Materials	Aim	Supports	Rationale
Hello / News	Verbal prompt: Do you have any news?	Ppts will share personal news or comment on world events	SLT writes key words of contributions, checks back, gives all participants a chance to share news	Develop rapport and a collaborative working space. Giving time to get to know ppts supports the development of a bond
Signposting	Verbal + written key words (bold): Today we will recap all the words we have been working on Play the game Articulate! Here you <i>describe</i> but <i>don't say</i> a target word Then we will have our conversation . Today we are sharing ____ (give topic e.g., dream holidays) If there is time we will play BINGO . Here you have to sneak target words into a real or imagined story.	For ppts to understand the structure of the group session		For shared ownership of the session content / collaboration

Vocabulary Recap	Verbal prompt: What are the words we have been working on?	Ppts will retrieve all topic words worked on to date in the group context without picture support	Semantic clues	Retrieving the word in a group context without the image is a step harder than the retrieval in ESFA sessions. Extends the work of the individual sessions
Articulate!	Verbal prompt: Can you describe a word from our ____ topic? You give clues and we will try and guess. Think about what goes in the boxes around the word in the chart	Ppts will describe features of target words	Questions from the SFA chart e.g. - What do you use it for? - Where might you find it? - Can you describe it Feedback: This game helps us think about the features of our target words	Retrieving features in a group context extends the work of the session. The game provides a genuine communicative exchange. This activity demonstrates and provides practice for the use of the SFA chart as a communication strategy
Conversation	Topic based virtual environment e.g., tall ship for dream travel conversation, or café for requesting food and drink items	Ppts will use target vocabulary to share personal information with a group Ppts will experience communication success	Contributions will be planned in the individual session before the group. Where appropriate ppts will be encouraged to practice a script to use in the conversation Each member gets space to share planned content e.g., with key words, with SVO sentences, with scripted monologue	Embeds the word retrieval in real world communicative tasks Scaffold output to enable communication success: - Use target (single word) in group conversation in context with written cue/image/object - Use target in sentence in group conversation in context with image/object - Use target in sentence in group conversation in context

BINGO	Bingo cards in participant handbook	Ppts name items / use words in sentence / create a story including all items	Hierarchy of cues	Practice the use of target words in scaffolded activity. Image supports naming. Sentences or story context adds challenge. Group context adds challenge.
What have you been pleased to notice?	Clinician asks, "what have you been pleased to notice?"	Ppts will identify something they were proud of in the session	Rephrase: 'This could be something you were proud of today'	Develop a practice of reflecting on progress / identifying small wins. Adapted from Siegelman 'three good things'
Challenge tasks	Offer challenge tasks: "You could start this conversation with someone in your life." Share experiences of doing the challenge task	Encourage participants to take skills practiced in EVA Park into real world settings.	Give opener phrase e.g., "remember when..."	Explicit carry over into real world tasks

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Appendix 9 | GRIPP2 Short Form

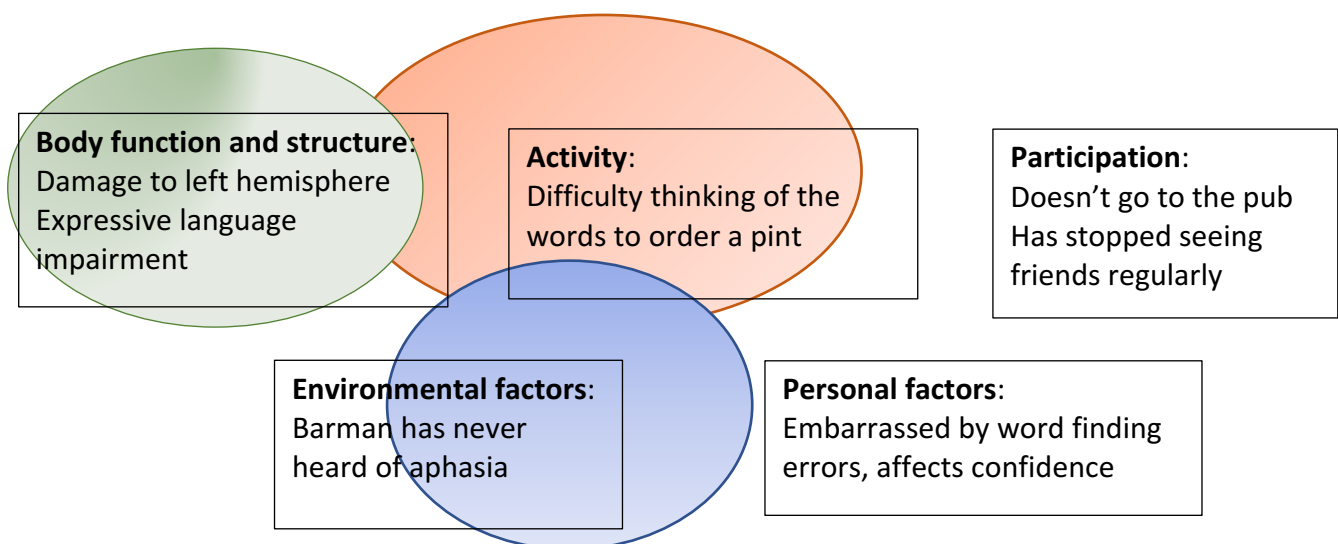
Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	105
2: Methods	Provide a clear description of the methods used for PPI in the study	108-111
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	113-118
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	118
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	119

Appendix 10 | Aphasia Accessible Research: Which outcomes are important to people with aphasia and their families?

Wallace, S.J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Kong, A.P.H., Simmons-Mackie, N., Scarinci, N. and Gauvreau, C.A. (2017)

'Which outcomes are most important to people with aphasia and their families? an international nominal group technique study framed within the ICF', *Disability and rehabilitation*, 39(14), pp. 1364-1379.

	Asked:	Answers:
1	39 people with aphasia (for themselves)	Activity/participation (39%) and body functions (36%)
2	29 family members (for themselves)	Activity/participation (49%) and environmental (28%)
3	29 family members (for their relative with aphasia)	Body function (60%)



Appendix 11 | Ethics form ETH1920-0148

Ethics ETH1920-0148: Jennifer Whiddett (Low risk)

Date: 31 Aug 2019

Researcher:

Jennifer Whiddett
Chelsie Fox
Shannon Buxton
Deirdre Staunton

Project: Investigating an ecologically valid word list for naming therapy in aphasia

Department: Division of Language & Communication Science, School of Health Sciences

Ethics application

Risks

R1) Does the project have funding?

No

R2) Does the project involve human participants?

Yes

R3) Will the researcher be located outside of the UK during the conduct of the research?

No

R4) Will any part of the project be carried out under the auspices of an external organisation, involve collaboration between institutions, or involve data collection at an external organisation?

No

R5) Does your project involve access to, or use of, material that could be classified as security sensitive?

No

R6) Does the project involve the use of live animals?

No

R7) Does the project involve the use of animal tissue?

No

R8) Does the project involve accessing obscene materials?

No

R9) Does the project involve access to confidential business data (e.g., commercially sensitive data, trade secrets, minutes of internal meetings)? No

R10) Does the project involve access to personal data (e.g., personnel or student records) not in the public domain?

No

R11) Does the project involve deviation from standard or routine clinical practice, outside of current guidelines?

No

R12) Will the project involve the potential for adverse impact on employment, social or financial standing?

No

R13) Will the project involve the potential for psychological distress, anxiety, humiliation or pain greater than that of normal life for the participant?

No

R15) Will the project involve research into illegal or criminal activity where there is a risk that the researcher will be placed in physical danger or in legal jeopardy? No

R16) Will the project specifically recruit individuals who may be involved in illegal or criminal activity?

No

R17) Will the project involve engaging individuals who may be involved in terrorism, radicalisation, extremism or violent activity and other activity that falls within the Counter- Terrorism and Security Act (2015)?

No

Applicant & research team T1) Principal Applicant Name

[Jennifer Whiddett](#)

T2) Co-Applicant(s) at City Name

[Chelsie Fox](#)

Name

[Shannon Buxton](#)

Name

[Deirdre Staunton](#)

T3) External Co-Applicant(s) T4) Supervisor(s)

[Ms Niamh Devane](#)

T5) Do any of the investigators have direct personal involvement in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest? No

T6) Will any of the investigators receive any personal benefits or incentives, including payment above normal salary, from undertaking the research or from the results of the research above those normally associated with scholarly activity? No

T7) List anyone else involved in the project.

N/a

Project details P1) Project title

Investigating what conversation topics are meaningful for people with aphasia

P1.1) Short project title

What topics are meaningful to people with aphasia?

P2) Provide a lay summary of the background and aims of the research, including the research questions (max 400 words).

Aphasia is a complex communication disorder that affects your ability to use or understand language. Aphasia can also affect your ability to read and write. Aphasia is a common problem after stroke and around a third of stroke survivors have it. (Stroke Association, no date).

Word finding difficulties are common for the majority of people with aphasia (Palmer et al, 2017). Being unable to access the words that you want affects all aspects of everyday communication. This breakdown of communication that can occur, dramatically reduces quality of life for a person with aphasia (Laine and Martin, 2006). Aphasia also appears to create challenges in maintaining strong social relationships, e.g., conversations were less likely to be two-way (Northcott & Hilari, 2011). Accessing the words you want in order to talk about a chosen topic is important in many ways, allowing people to communicate effectively.

Establishing or preserving meaningful social relationships has been identified as key to “living successfully” with aphasia (Brown, Davidson, Worrall, and Howe, 2013). Our study will aim to identify conversation topics that are meaningful for people with aphasia and why. Palmer et al (2017) used a quantitative content analysis of words chosen by 100 participants in a computerised word finding therapy trial. The aim of the study was to provide insights into words that people with aphasia perceive to be personally relevant. As highlighted in the paper, the analysis identifies categories of words that are important to people with aphasia but does not help us to understand why. Further qualitative research needs to be conducted to explore the reasons behind personal relevance of words. Unlike the Palmer et al (2017) study, we will be conducting face-to-face focus groups and through this, we will be exploring participants’ views and perspectives in-depth through group interaction. Participants will then have opportunities to build on ideas and thoughts expressed by others, therefore generating insightful information (Litosseliti, 2003). Whilst the Palmer et al (2017) study looked at personally relevant words, as mentioned above our study will aim to identify conversation topics that are meaningful for people with aphasia and why.

After a stroke, people with aphasia often have access to naming therapy as a way to increase their vocabulary, as well as assist with their understanding of words. Identifying themes in the conversation topics that people with aphasia find meaningful and want to be able to talk about may inform future therapy, maximising the usefulness by making it more relevant. It may also inform the topics for future conversation groups.

The research questions for this study are:

Chelsie Fox - What is meaningful for people with aphasia to be able to say and why?

Deirdre Staunton - What meaningful topics do people with aphasia want to be able to talk about and why?

Shannon Buxton - What conversation topics do people with aphasia want to be able to talk about and why?

Jennifer Whiddett - What communication topics are meaningful to people with aphasia, and why?

P4) Provide a summary and brief explanation of the research design, method, and data analysis.

This is a qualitative research design using focus groups to explore 'what conversation topics are meaningful to people with aphasia', supporting us in understanding what topics are meaningful and why. Our data will be analysed using framework analysis. This gives a systematic way of exploring the themes that arise in the discussion (Ritchie et al, 2014).

Method:

The inclusion criteria were formed to ensure that the research question 'what conversation topics are meaningful to people with aphasia' can be answered. This involves using purposive sampling as the participants are involved due to having particular characteristics or features which will enable detailed exploration and answering of the question that the research wishes to explore (Bryman, 2012).

See H5 for inclusion criteria.

Recruitment and Consent Process:

Please see P4.1 for recruitment process and informed consent process

Please see H12 for consent process

Data Collection (framework analysis):

The data will be obtained from 2 focus group discussions with 6 people with aphasia.

2 focus groups will be conducted, each with 2 student speech and language therapists as moderators and with 6 participants with aphasia. We will recruit from local community aphasia groups.

Researchers have attended training on 'how to run a focus group' which was led by the project supervisor. This was to ensure that both focus groups run in the exact same manner, including dealing with issues that arise and facilitation strategies.

The focus groups will be conducted with a flexible use of a topic guide exploring participants' perspectives and opinions in depth. This format allows the topic to be discussed in detail while making use of cues and prompts, that are agreed on prior to the focus groups and included within the topic guide. This is in order to guide the discussion to ensure that the

research area is discussed in detail and an in-depth data set is obtained to answer the research question (Wolf et al. 2018).

The agreed on facilitation methods and prompts support conversation through the following forms: multi modal communication including gesture use, writing key words and drawing. There will be adequate time given for participants to respond and these responses will then be verified by the moderator (Palmer, 2012).

Analysis:

For people with aphasia, gesture is often used as a means of communication. In order to capture and accurately transcribe this communication method, the focus groups will be video recorded (Marshall et al, 2013). Non-verbal communication such as gestures and drawing will be captured in detail by video and this will be interpreted to aid in transcription accuracy. The transcriptions will be transcribed by hand by the researcher verbatim. To ensure consistencies in transcription, conventions of conversation analysis will be used to aid with accurate transcriptions (Sidell, 2010). Accuracy of transcription will be ensured by 10% of the transcription data being double transcribed by one of the other researchers.

These transcriptions will then be subject to framework analysis and this will be carried out using software NVivo 12. Inter-rater reliability between coders will be ensured by double coding 10% of the data.

Outcomes (Themes):

Using the Framework approach, we aim to initially gain an overview of all the material then develop an index of the key issues and patterns. Following this, we will synthesise and summarise the data (Ritchie et al, 2014). With the purpose being to answer the research question: what conversation topics are meaningful for people with aphasia.

Impact (Informs Therapy):

The final step would be to develop descriptive and explanatory accounts of the data by compiling a list of the most common topics that came up which could indicate why particular topics are meaningful for people with aphasia, with the hope of informing future therapy (Ritchie et al, 2014).

P4.1) If relevant, please upload your research protocol.

P5) What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?

Consent: Please see question H12 for details of how the researchers will ensure informed consent is gained.

Confidentiality:

Data protection and confidentiality are a further issue. Reassurances will be given that responses will not be reported in such a way that could cause an individual to be identified and that the research findings will be used solely for the purposes of the Research Project and will not be made public in any other way. All Personal Data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulations.

Taking notes instead of making recordings is not sufficiently accurate or detailed for most qualitative projects (Bailey, 2008). Video data will be recorded as this will allow the

researchers to record non-verbal modes of communication such as gesture, written and visual in detail. People with aphasia may find it challenging to verbally communicate during the focus group due to word finding difficulties. Using video recording will therefore aid inclusion of contributions from all participants. The use of video recording will provide visual data and aid accurate, detailed transcription of all modes of communication used (Heath, 2009). Video footage or quotations will not be used in the future for student teaching or conferences. Participants will have given consent to video recording.

Devices will be loaned from City University. Video data will be removed from devices on site and transferred to an encrypted, password protected drive, and stored securely. Transcription will be carried out in a private space, with no windows/with blinds closed and using headphones, for example, in a privately booked City University Speech and Language Therapy Lab, where no one who is unauthorized will be able to view/listen. We will ensure consistencies in transcription by using the conventions of conversation analysis that will also aid in the accuracy of gesture transcription (Sidell, 2010). All personal identification information will be removed or changed during transcription. Digital copies of the files will be encrypted, password protected and stored securely. Video recordings will not be taken off site from City University. Transcribed, anonymized coded data will be taken off site using an encrypted and password protected memory stick. Anonymised transcriptions will only be saved to this encrypted, password protected memory stick and as a password protected computer file on the University drive. Participants will be allocated a code by the researchers. Codes P1A, P2A, P3A, P4A, P5A and P6A for focus group 1 and P1B, P2B, P3B, P4B, P5B and P6B for focus group 2 will be used. The one document that links participant names to codes will be password protected and kept in a different folder from the data.

Data collected during focus groups will only be accessed by the researchers and academic supervisor. All contact details and copies of written consent forms will be held in a participant file identified by a numerical code only and stored in a locked file within the named supervisor's office at City University. All names and identifying information will be removed from the focus groups transcriptions (coded P1A etc as detailed above). No identifiable information will be used. Data will only be accessed by the researchers and academic supervisor.

Confidentiality between the participants will be managed by setting ground rules at the start of the focus group. Ground rules will include discussing confidentiality, for example, 'Help protect others' privacy by not discussing details outside the group. Participants will be required to agree not to discuss other people's thoughts and views outside of the focus group.

Potential distress:

The potential distress to participants talking about loss of function (although this may come up it will not be the focus of the questions) should also be considered. Due to the flexible nature of the focus group, there is potential for participants to find some aspects of the research project challenging or distressing. However, this is deemed to be low risk. For example, the focus groups discussions may

raise the loss of their pre stroke self and abilities. Participants may also experience anxiety associated with attending group session, or in disclosing information. However, participants will be recruited from aphasia community groups where the topic of these groups is speaking about what it is like to live with aphasia. Recruiting from these groups will therefore reduce any potential emotional distress during the focus groups. If necessary, the focus group facilitator will direct participants for support from their GP if required.

Withdrawal:

Withdrawal from the project raises concerns. We are clear that all participants can leave the project at any time, without penalty (see Participant Information Sheet). If a participant chooses to leave during the focus group, the procedure outlined on page 2 and 5 of the Participant Information Sheet (H10) will be followed.

P6) Project start date

22 Jul 2019

P7) Anticipated project end date

29 May 2020

P8) Where will the research take place?

City University campus

P10) Is this application or any part of this research project being submitted to another ethics committee, or has it previously been submitted to an ethics committee?

No

Human participants: information and participation

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The options for the following question are one or more of:

'Under 18'; 'Adults at risk'; 'Individuals aged 16 and over potentially without the capacity to consent'; 'None of the above'.

H1) Will persons from any of the following groups be participating in the project?

None of the above

H2) How many participants will be recruited?

12

H3) Explain how the sample size has been determined.

Researchers will conduct 2 focus groups, each with 6 participants.

Focus groups typically involve 6-8 participants (Ritchie et al, 2014). The optimum group size of 6 was determined for people with aphasia as "a smaller group is more accessible to people with communication difficulties" (Ritchie et al, 2014). The smaller group will also allow more even participation due to more opportunity to speak for everyone.

H4) What is the age group of the participants? Lower Upper

18

H5) Please specify inclusion and exclusion criteria.

Participants must be 18+ Years old and a fluent English speaker pre stroke – can be bilingual. Participants must have aphasia as a result of a stroke, which must have occurred a minimum of 4 months prior to recruitment into the study. Participants must have no additional cognitive impairments or neurological diagnoses that could impact on cognition. Where possible we will aim to represent a range of gender and ethnicity.

H6) What are the potential risks and burdens for research participants and how will you minimise them?

Potential risks and burdens for research participants are likely to be minimal but could include a time and travel burden, potential for psychological distress, and data protection.

Time and travel:

Participants will be giving up their time in order to participate in the focus group. This burden will be minimised by holding the focus groups at a convenient location and time for participants. The venue and day of the week for focus groups will be the same as participants already attend for their community aphasia group. Participants will only be required to attend one focus group for a maximum of 2 hours, which will be clearly stated in the advertisement and participant information sheet.

Potential distress:

The focus group has a potential risk for distress to participants, for example, the focus groups discussions may raise the loss of their pre stroke self and abilities. Should this happen, the focus group facilitator and note taker will be present to assist. Additionally, participants can be signposted to support services such as their GP as necessary. Time will be explicitly allocated to a 'debrief' period at the end of each focus group for participants to reflect upon the session, ask any questions or raise anything that may be of concern.

Participants may experience anxiety associated with attending a focus group and disclosing information as part of a research project. Every effort will be made to minimise any psychological risk to the participant. If a participant discloses an emotional, psychological, health, education or other issues during the course of the research or is identified by the researcher to have such a need, the researchers will signpost the participant to their GP. If participants have offered to take part, and are then deemed unsuitable for cognitive reasons, the procedure outlined in the Research Protocol will be followed (See P4.1).

Data protection:

Data protection will be managed as detailed in question P5, paragraphs 7,8,9 and 10.

If participants have offered to take part, and are then deemed unsuitable for cognitive reasons, the procedure outlined in the Research Protocol will be followed.

Confidentiality between the participants will be managed as outlined in P5, paragraph 11.

Participants will be encouraged to contact the researchers at any point should they wish to discuss any issues or concerns associated with their participation in the project. Participants will be made aware that they are at no disadvantage if they decide to not participate in the project.

H7) Will you specifically recruit pregnant women, women in labour, or women who have had a recent stillbirth or miscarriage (within the last 12 months)?

No

H8) Will you directly recruit any staff and/or students at City?

None of the above

H8.1) If you intend to contact staff/students directly for recruitment purpose, please upload a letter of approval from the respective School(s)/Department(s).

H9) How are participants to be identified, approached and recruited, and by whom?

Researchers to attend community aphasia groups. Researchers will explain the aim of the study to the group in an aphasia friendly way, highlighting key words and using visuals, gesture and drawing.

Participants with aphasia will be approached individually by the researchers at the community stroke group. Individuals will be given an aphasia friendly advert (See enclosed H10). If the individual shows an interest, they will be invited to have an informal conversation with a researcher during their time slot at the group. The informal conversation will aim to answer any questions that the individual may have, as well as identify whether the individual meets the inclusion criteria (see H5).

If the individual meets the inclusion criteria, the individual will be invited to participate and will be able to collect a participant information sheet (see enclosed H10) from the group leader to take home in case they wish to discuss participation with a significant other. Individuals will have 1 week to decide if they want to participate, to identify any further questions they wish to ask.

If they wish to opt-in to the study, they will be given the opportunity to ask the researchers any questions that they may have. It will be made clear that they are under no obligation to participate.

If the individual expresses an interest in participating however does not meet the inclusion criteria, there will be a supported discussion with the individual to explain why they do not meet the inclusion criteria for this study. Inform the individual that we want the focus group to be a positive experience which will require them to follow and actively participate in the group, and that on this occasion we do not feel they would be able to do so, which could lead them to having a negative experience.

Inform the individual that we will share the findings of the study with the community group if they would like to hear the outcome. Inform the participant that we can refer them to our supervisor to be put on the City aphasia register if they want to participate in future research projects through the university.

H10) Please upload your participant information sheets and consent form, or if they are online (e.g., on Qualtrics) paste the link below.

H11) If appropriate, please upload a copy of the advertisement, including recruitment emails, flyers or letter.

H12) Describe the procedure that will be used when seeking and obtaining consent, including when consent will be obtained.

Mental Capacity:

It is important to ensure all information presented to participants is accessible and informed consent is gained. The capacity to make one's own decisions is a key component of

informed consent. For a person to have capacity about a specific decision, they must demonstrate: an ability to understand

information relevant to the decision; retain the information; use or weigh up the information; and communicate their decision (MCA, Department of Health, 2005).

The Mental Capacity Act (MCA, Department of Health, 2005) states provision should be in place to ensure that the service user is able to understand the information relevant to a decision and is given in a way that is appropriate to the service user's circumstances. People with aphasia may experience difficulties in expressing themselves using spoken language or understanding the information provided to them verbally. For each specific decision, aphasia friendly information will be provided to the participant. Provisions for this include using simple language and visual aids.

The Mental Capacity Act, 2005 states 'A person must be assumed to have capacity unless it is established that he lacks capacity.' Participants will therefore be assumed to have capacity unless indicated otherwise and all practicable steps to help them to do so have been taken without success. Indications that the participant may not have capacity would include if they cannot understand the information provided to them (with all practical steps to support them being in place), if they are unable to retain this information, if they are unable to weigh up this information and communicate their decision to others.

Informed Consent:

In line with the enclosed research protocol (P4.1) if a person with aphasia who meets the inclusion criteria wishes to take part in the study, the following steps must occur in order to decide if they are suitable for the study and to ensure informed consent is obtained.

The researchers will attend community aphasia groups held at City, University of London. Researchers will explain the aim of the study to the group in an aphasia friendly way, highlighting key words and using visuals, gestures and drawing. Individuals will see an aphasia friendly advert.

If the individual shows an interest, they will be given the opportunity to have an informal conversation with a researcher during their time slot at the group. Researchers will have an informal conversation with those that express an interest in participating. The informal conversation will ensure the following: to answer any questions they may have and identify whether the individual meets the inclusion criteria (see H5).

If researchers identify the individual to meet the inclusion criteria, the person will be informed that they can collect a participant information sheet from the group leader to take home in case they wish to discuss participation with a significant other. Individuals will have 1 week to decide if they want to participate and to identify any further questions they wish to ask. The students will recap the discussion with the individual, clarifying understanding of the discussion and details of the study. If the individual does not meet the inclusion criteria for this study, researchers will follow the appropriate route detailed in the research protocol (P4.1). The following week the student will return to the group to answer any further questions from the individuals and collect the details of interested group members who will be invited to take part.

Consent Forms:

If they then wish to participate, they will be invited to the focus group and will sign a formal consent form on the day of the focus group. An aphasia friendly consent form will be given to

participants who agree to participate. Participants will have to tick the relevant boxes and sign the consent form. If the participant is unable to sign the form themselves, we will obtain verbal consent on video and a significant other can be elected to sign the consent form on their behalf. A copy of the signed consent form will be given to the participant and a copy will be kept by the researchers on a secure drive.

H13) Are there any pressures that may make it difficult for participants to refuse to take part in the project?

No

H14) Is any part of the research being conducted with participants outside the UK?

No

Human participants: method

*The options for the following question are one or more of:
'Invasive procedures (for example medical or surgical)'; 'Intrusive procedures (for example psychological or social)'; 'Potentially harmful procedures of any kind'; 'Drugs, placebos, or other substances administered to participants'; 'None of the above'.*

M1) Will any of the following methods be involved in the project:

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None of the above

M2) Does the project involve any deceptive research practices?

No

M3) Is there a possibility for over-research of participants?

Yes

M3.1) What steps will be taken to safeguard the participants from over-research?

Potential participants will be asked if they are or have been involved in other research. If they have the researchers will ensure that they are not feeling overburdened. People with aphasia report a loss of social activity and we have found that most value the opportunity to be involved in research. If participants are recruited from the City Aphasia Research Register (CARR) it is likely they have been involved in other research. However, people on the City Aphasia Research Register join the register in order to take part in research projects.

M4) Please upload copies of any questionnaires, topic guides for interviews or focus groups, or equivalent research materials.

M5) Will participants be provided with the findings or outcomes of the project? Yes

M5.1) Explain how this information will be provided.

All participants will be asked if they would like to be provided with the findings or outcomes of the project. The researchers will create an aphasia friendly leaflet to share the findings of the study. This will be presented at the aphasia community group.

M6) If the research is intended to benefit the participants, third parties or the local community, please give details.

The project will impact 1) those people with aphasia who take part in the focus groups 2) the participants who receive the therapy in a future trial 3) our understanding of the validity of treatment stimuli in speech and language therapy.

The people who volunteer to be part of the focus groups will play a part in contributing to the development of healthcare research. They will receive accessible current research on naming therapy, and studies on the conversations of people with aphasia compared to age matched peers. Participation in the group will develop a skillset as 'expert through experience' researchers. This may in turn add to a positive post-stroke self-identity.

The findings of this study will inform the topics to target in a feasibility trial of semantic feature analysis delivered in groups. Drawing on user experience during the development of this trial should support feasibility outcomes in the next phase of the research.

The research should provide evidence as to why certain topics are important to target. Understanding why topics are meaningful will add personal relevance from the perspective of people with aphasia to the current research and potentially inform future therapy and conversation group topics.

M7) Are you offering any incentives for participating?

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No

M8) Does the research involve clinical trial or clinical intervention testing that does not require Health Research Authority or MHRA approval?

No

M9) Will the project involve the collection of human tissue or other biological samples that does not fall under the Human Tissue Act (2004) that does not require Health Research Authority Research Ethics Service approval?

No

M10) Will the project involve potentially sensitive topics, such as participants' sexual behaviour, their legal or political behaviour, their experience of violence? No

M11) Will the project involve activities that may lead to 'labelling' either by the researcher (e.g., categorisation) or by the participant (e.g., 'I'm stupid', 'I'm not normal')?

No

Data

D1) Indicate which of the following you will be using to collect your data.

Focus groups Video recording

D2) How will the privacy of the participants be protected?

Any other method

D2.1) Provide details of 'any other method' used.

Participants privacy will be protected using the following methods:

-Researchers will save participant identifiable information separately to a secure password protected server, or to password protected PCs or on encrypted USBs.

-Participants will only be identifiable by number. Participants will be allocated a code by the researchers. P1A, P2A, P3A, P4A, P5A and P6A for focus group 1 and P1B, P2B, P3B, P4B, P5B and P6B for focus group 2.

-The number to participant will be saved separately to data

-Transcribed data and written reports will remain anonymous by the use of participant numbers only.

- Transcription will be carried out in a privately booked space with no windows/with blinds closed and using headphones, for example, in City University's Speech and Language Therapy Labs, where no one who is unauthorized will be able to view/listen.

Video recordings will not be taken off site from City University. Transcribed, anonymized coded data will be taken off site using an encrypted and password protected memory stick. Anonymised transcriptions will only be saved to this encrypted, password protected memory stick and as a password protected computer file on the University drive.

D3) Will the research involve use of direct quotes?

Yes

D5) Where/how do you intend to store your data?

Password protected computer files

Storage on encrypted device (e.g., laptop, hard drive, USB Storage at City)

D6) Will personal data collected be shared with other organisations?

No

D7) Will the data be accessed by people other than the named researcher, supervisors or examiners?

No

D8) Is the data intended or required (e.g., by funding body) to be published for reuse or to be shared as part of longitudinal research or a different/wider research project now or in the future?

No

D10) How long are you intending to keep the research data generated by the study?

As per City University recommendations, research data will be kept for 10 years. The data will not be used for student teaching or conferences during the future.

D11) How long will personal data be stored or accessed after the study has ended?

As per City University recommendations, data will be stored for 10 years.

D12) How are you intending to destroy the personal data after this period?

As per City University's current destruction policy, hard copies of personal data will be shredded within City University using a cross cut shredder which conforms to standard DIN level 5 (maximum size of paper is 0.8mm x 12mm) and then disposed of via City University's confidential waste management contract. Confidential waste sacks will be kept securely until they can be collected.

Audio and video data will be removed from devices as soon as it is possible, encrypted, password protected and stored securely. Digital copies of the files will be encrypted, password protected and stored securely. For University owned electronic media, destruction requests will be logged and carried out by City University's Information Services.

Health & safety

HS1) Are there any health and safety risks to the researchers over and above that of their normal working life?

No

HS3) Are there hazards associated with undertaking this project where a formal risk assessment would be required?

No

Appendix 12 | Participant Information Sheet Focus Groups



ETH1920-0148,

Project title – Investigating what conversation topics are meaningful for people with aphasia

Names of researchers: Shannon Buxton, Chelsie Fox, Deirdre Staunton, Jennifer Whiddett.

We would like you to take part in a research study.

First, we want you to know and understand the research we are doing and what it involves for you.

You can keep this information sheet.



Please read the information carefully.



Please talk to others about this information if you wish.



Please ask us questions If anything is unclear.

Please ask us If you want more information.

What is the purpose of the study?

After a stroke, people can have word finding difficulties, this is as a result of aphasia.

Aphasia can make people unable to express their emotions, give an opinion, or speak about a topic that is of interest to them.

The aim of this study is to identify topics that people with aphasia want to talk about and why.

This information could inform future therapy.

The study is part of a Masters program ran by student Speech and Language therapists.

Why have I been invited to take part?

Participants must meet the following inclusion criteria to take part:

- 18+ Years old
- Fluent English speaker pre stroke – can be bilingual
- A minimum of 4 months post stroke
- Have aphasia
- Have no additional cognitive impairments or neurological diagnoses that could impact on cognition

There will be 12 participants in total, 6 in each group.

Do I have to take part?

No, it is your choice.

Participation in the project is voluntary.

You can withdraw at any stage of the project without being disadvantaged in any way.

It will not affect any other services that you receive.

If you decide to take part, you will be asked to sign a consent form.

This tells us that you consent:



- To take part in the study
- That you consent to being video recorded.

You can change your mind and leave the study at any time without giving a reason.

You can leave the focus group at any point if you decide you do not want to take part.

If you no longer want to be in the study after it has started, we will ask you what you would like us to do with your contribution to the group.

You can choose to allow your contribution to be removed or to remain within the study.

We will not use any of your direct quotes if you choose to leave the study.

You can choose for your contribution to be removed and for your consent form to be destroyed.

If you choose to leave during the focus group, the recording will be stopped, and you can leave the room.

It is your choice.

What will happen if I take part?



- You will sign a consent form



- You will attend a group discussion at City, University of London.



- It will last 2 hours.



- There will be 5 other people with aphasia in your group.
The focus group will be led by questions from a researcher.



- The focus group will be video recorded



- You will talk about:
 - Who you like to communicate with
 - What you like to communicate about
 - How confident you feel to communicate
 - What you do in a typical day/week
 - Your social activities
 - Have your social activities changed since your stroke
 - How your aphasia impacts on participation on social activities

- What is meaningful to you to be able to communicate about
- Why are these things meaningful
- Barriers that aphasia has on your communication
- What things help you to communicate

What are the possible disadvantages and risks of taking part?

You will give up your time to attend and travel to the group.

We will talk about your experience of living with aphasia.

We may talk about things you would like to be able to talk about but cannot.

Some people may find this upsetting.

What are the possible benefits?

There are no direct benefits for your participation in this study.

There will be no monetary benefits for your participation.

Taking part may benefit people with aphasia in the future.

Contributing your personal experience could help identify changes that would impact the words taught in naming therapy in the future.

How is the project being funded?

The project is not receiving any funding.

Conflicts of interests

There are no conflicts of interests identified for this study.

What should I do if I want to take part?

If you want to take part, you should inform the researchers when they return to your community group the following week.

You should ask the researchers any questions that you have about the study.

You will have an informal conversation with the researchers regarding what is required to take part.

If you still want to take part, you will be invited to take part in the study.

Will my taking part in the study be kept confidential?

The researchers and project supervisor will be the only people with access to any of your personal data.

Participants will be anonymized.

Each participant will be allocated a code e.g. P1A – participant 1 group A.

Only the researchers will have access to the code allocation document.

Participants will only ever be referred to as their code during the write up of the research project.

The focus group will be video recorded.

Only the researchers will have access to the recording.

The recording will be viewed in a booked room with only researchers present.

The consent forms will be stored in a locked cabinet on the City University Campus.

The video will be stored on an encrypted drive which only the researchers and project supervisor will have access to.

The data will be stored for 10 years before being destroyed.

Physical copies of consent forms will be shredded and disposed of at City University.

Data stored on an encrypted drive will be permanently deleted from the drive.

Participants will be asked to respect each other's confidentiality and not disclose the names of the other participants to third parties.

Confidentiality will be listed in the group rules at the beginning of the session.

What will happen to the results?

The results will be written as part of a research project for a Masters degree.

When we report on the work, we will not use your name.

We will share the findings with the people that took part in the study.

We will create a leaflet with the findings of the study.

What will happen when the research study stops?

Following the completion of the research study, researchers will provide an information leaflet on what the study found.

What will happen if I do not want to carry on with the study?

You can change your mind and leave the study at any time without giving a reason.

You can leave the focus group at any point if you decide you do not want to take part.

If you no longer want to be in the study after it has started, we will ask you what you would like us to do with your contribution to the group.

You can choose to allow your contribution to be removed or to remain within the study.

We will not use any of your direct quotes if you choose to leave the study and consent for your contributions to remain in the study.

You can choose for your contribution to be removed and for your consent form to be destroyed.

If you choose to leave during the focus group, the recording will be stopped, and you can leave the room.

It is your choice.

What if there is a problem?

If you are very concerned you can complain about the study. City, University of London has a procedure for complaints.

You can contact the clinical supervisor of the project, Niamh Devane -

Niamh.Devane.2@city.ac.uk. 020 7040 8821.

If you want to complain:

- phone: 020 7040 3040
- ask for the Secretary to the Research Ethics Committee
- Tell them that your project is called: To investigate what conversation topics are meaningful for people with aphasia
- You could also write to the Secretary at:

Anna Ramberg

Secretary to Senate Research Ethics Committee

Research Office, E214

City University London

Northampton Square

London

EC1V 0HB Email: Anna.Ramberg.1@city.ac.uk

City 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 the Ethics Committee of the School of Health (Language and Communication Science Proportionate Review).

This study is additionally being supervised by Niamh Devane - Clinical supervisor.

Further information and contact details

Chelsie Fox – MSc Speech and Language Therapy student – Researcher

Chelsie.Fox@city.ac.uk

Jennifer Whiddett - MSc Speech and Language Therapy student – Researcher

Jennifer.Whiddett@city.ac.uk

Shannon Buxton - MSc Speech and Language Therapy student – Researcher

Shannon.Buxton@city.ac.uk

Deirdre Staunton - MSc Speech and Language Therapy student – Researcher

Deirdre.Staunton@city.ac.uk

Data privacy statement

City, University of London is the data controller of this study based in the United Kingdom.

This means that we are responsible for looking after your information and using it properly.

The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate.

To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/>).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose.

The only people at City who will have access to your identifiable information will be the researchers and the project supervisor. City will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how City handles data by visiting

<https://www.city.ac.uk/about/governance/legal>. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) <https://ico.org.uk/>.

Thank you for taking the time to read this information sheet.

Appendix 13 | Focus Group Topic Guide

Topic guide developed by the student researchers for the two focus groups on:

What conversation topics are meaningful for people with aphasia?

Introduction:

- ❖ Welcome
- ❖ Hi everyone, our names are X. We are speech and language therapy students at city university. We have seen a few of you already. So today we are here to find out from you 'what conversation topics are meaningful for people with aphasia'.
- ❖ We will start by: (write key words on board)
 - Saying some **rules**
 - Then we will do a **warm-up** activity
 - Then we will talk about **communication** in everyday life
 - Look at rating our own ideas in terms of **what is meaningful**
 - Have a short **break**
 - Then we will have a **group discussion**

And when we are finished, we just need to collect a little bit more information from each of you

Rules:

Ok so first let's go through some group rules

Throughout the group, please communicate however you feel comfortable, we have pens and paper if you want to write or draw

- We need to listen and wait for each other
- Everyone's thoughts are important
- There are no right or wrong answers
- And finally, whatever we say today stays within the group

Housekeeping – where the toilets are, not expecting a fire alarm

Warm-up:

First of all, we're just going to do a quick warm-up activity.

For this activity we are each going to pick a picture of a musical instrument and describe it using words, or gesture, or writing – or whatever way is easiest.

Communication:

Let's start by thinking about communication

Q1: Firstly, we want to ask: Who do you communicate with?

You can write them down if you'd like
You can have as many answers as you'd like
We will help you if needed.

Q2: Where do you communicate?

Does anyone have anything they want to share?... about where they communicate

So, it looks like we communicate in lots of places
Ok so the next question is...

Q3: What do you communicate about?

For this one you can put your ideas on the post-it notes in front of you

Ok so we have lots of ideas, we're going to think more about these conversations now and we'd like to ask

Q4: How do these conversations make you feel?

Does anyone have anything they want to share?

Ok so we have a few different ideas, now we are going to do something a little different

Q5: Looking at "what we communicate about" on the post-it notes, we want to know what is more meaningful to you

We have a scale, with "most meaningful" and "not as meaningful". We want you to stick you post-its on the line... What is most meaningful and not as meaningful to you.

We just want to take a moment to look at everyone's rating scales.

Does anyone want to share their "top topic?"

Can you give an example of when you spoke about X?

Break – be back in the room in 20 minutes (time)

Discuss as a group when we come back.

Ok so before the break we thought about the idea of communication and what we found 'most meaningful' to talk about.

Look at these ideas as a group

Using the same scale, can we decide as a group what is meaningful and not as meaningful to us.

Q6: Where do we think as a group this should go on the scale?

End: Palmer et al, 2017

We've come up with some really interesting topics today

There was a study in 2017, looking at what words people with aphasia wanted to be able to say.

The top 10 topic areas that people with aphasia talked about were:

1. *Food and Drink*
2. *Nature and Gardening*
3. *Entertainment*
4. *Places*
5. *People*
6. *House*
7. *Clothes*
8. *Travel*
9. *Actions*
10. *Money and numbers*

Q7: How do we feel about these?

They looked at what was ‘**useful**’, we looked at what is ‘**meaningful**’ – write key words above.

Summary:

Ok so we have come up with lots of topic ideas

Let’s have a look at all of our topics we have come up with

Q8: Looking at the scale, we’ve got x, y and z as the top topics.

Does this sound right?

Anything else?

End:

Thank you all for coming in today

We have gathered some interesting information from the group

We will hopefully have the results by June/July

We would love to come and share them with you

We can come to your groups and give you a summary of what we found

Complete demographic information forms

Appendix 14 | CONSORT checklist



CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial*

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	n/a as thesis
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	n/a/ as thesis
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	p.37
	2b	Specific objectives or research questions for pilot trial	p.41
Method			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	p.131
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	n/a
Participants	4a	Eligibility criteria for participants	p.134
	4b	Settings and locations where the data were collected	p.135
	4c	How participants were identified and consented	p.135
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	p.136
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	p.141
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	n/a
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	p.141
Sample size	7a	Rationale for numbers in the pilot trial	p.149
	7b	When applicable, explanation of any interim analyses and stopping guidelines	n/a

Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	p.150
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	p.150
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	p.150
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	p.150
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	p.150
	11b	If relevant, description of the similarity of interventions	-
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	p.150
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	p.176
	13b	For each group, losses and exclusions after randomisation, together with reasons	p.176
Recruitment	14a	Dates defining the periods of recruitment and follow-up	p.176
	14b	Why the pilot trial ended or was stopped	-
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	p.177
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	p.179 & p. 192
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	p.169 & p.193
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	p.188
	19a	If relevant, other important unintended consequences	
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	p.209

Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	p.211
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	p.200
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	p.183
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	-
Protocol	24	Where the pilot trial protocol can be accessed, if available	-
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	p.132
	26	Ethical approval or approval by research review committee, confirmed with reference number	p.132

Citation: Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, et al. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ. 2016;355.

*We strongly recommend reading this statement in conjunction with the CONSORT 2010, extension to randomised pilot and feasibility trials, Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see www.consort-statement.org.

Appendix 15 | Ethics form ETH1920-1223

Ethics ETH1920-1223: Niamh Devane (High risk)

Date	18 Mar 2020
Researcher	Niamh Devane
Project	A feasibility randomised control trial of elaborated semantic feature analysis delivered in EVA Park
School	School of Health Sciences
Department	Division of Language & Communication Science

Ethics application

Risks

R1) Does the project have funding? Yes

R2) Does the project involve human participants?

Yes

R3) Will the researcher be located outside of the UK during the conduct of the research?

No

R4) Will any part of the project be carried out under the auspices of an external organisation, involve collaboration between institutions, or involve data collection at an external organisation? No

R5) Does your project involve access to, or use of, material that could be classified as security sensitive?

No

R6) Does the project involve the use of live animals?

No

R7) Does the project involve the use of animal tissue?

No

R8) Does the project involve accessing obscene materials?

No

R9) Does the project involve access to confidential business data (e.g., commercially sensitive data, trade secrets, minutes of internal meetings)?

No

R10) Does the project involve access to personal data (e.g., personnel or student records) not in the public domain?

No

R11) Does the project involve deviation from standard or routine clinical practice, outside of current guidelines? No

R12) Will the project involve the potential for adverse impact on employment, social or financial standing?

No

R13) Will the project involve the potential for psychological distress, anxiety, humiliation or pain greater than that of normal life for the participant?

No

R15) Will the project involve research into illegal or criminal activity where there is a risk that the researcher will be placed in physical danger or in legal jeopardy?

No

R16) Will the project specifically recruit individuals who may be involved in illegal or criminal activity?

No

R17) Will the project involve engaging individuals who may be involved in terrorism, radicalisation, extremism or violent activity and other activity that falls within the CounterTerrorism and Security Act (2015)? No

[Applicant & research team](#)

T1) Principal Applicant

Name

[Niamh Devane](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Experience: Niamh is a senior specialist speech and language therapist who has spent the past seven years working in research on clinical aphasia projects. She has been managing the EVA Park projects at City, University of London from the development of the technology (2012) to the first functional communication intervention trial (2013-2015) to the single case studies (2016) and the aphasia groups project (2017-2019). Thus, she has managed three complex intervention research projects from beginning to end. She has successfully recruited to a wide range of roles: participants, testing therapists, treating therapists, and students as either conversation partners, group volunteers or speech and language therapy assistants. She has developed intervention manuals. She has trained therapists, group leaders, student volunteers and people with aphasia to use the technology for this virtual reality platform. She has trained students in supported conversation skills and therapists to run the interventions developed in the first and third EVA Park projects. She has supported fidelity checking projects, managed data collection, organisation and management and supported data analysis and write up activities. She has experience of a range dissemination

activities including presentations, organising large dissemination events and delivering short films that describe the research.

Training: first class BSc (hons) degree in Speech and Language Therapy and two MSc modules; one in research methods (mark: 71) and one in acquired language impairments (mark: 73).

T2) Co-Applicant(s) at City

T3) External Co-Applicant(s)

T4) Supervisor(s)

[Prof Katerina Hilari](#)

[Prof Jane Marshall](#)

[Prof Stephanie Wilson](#)

T5) Do any of the investigators have direct personal involvement in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

No

T6) Will any of the investigators receive any personal benefits or incentives, including payment above normal salary, from undertaking the research or from the results of the research above those normally associated with scholarly activity?

No

T7) List anyone else involved in the project.

Project user group: Adrian Cumberworth, Chris Greenhough, Barry McIlroy, Paul Stocken

Blinded testers: Researchers or Speech and Language Therapy (SLT) students will be invited to the role of blinded tester periodically throughout the intervention period e.g., every university term. As student SLT's and/or researchers they will have DBS clearance.

Amendments to name these testers will be submitted as required. Alternatively, this testing will contribute to student projects and will therefore be linked to this project but covered by their own ethical approval.

[Project details](#)

P1) Project title

A feasibility randomised control trial of elaborated semantic feature analysis delivered in EVA Park

P1.1) Short project title

VESFA (Virtual Elaborated Semantic Feature Analysis)

P2) Provide a lay summary of the background and aims of the research, including the research questions (max 400 words).

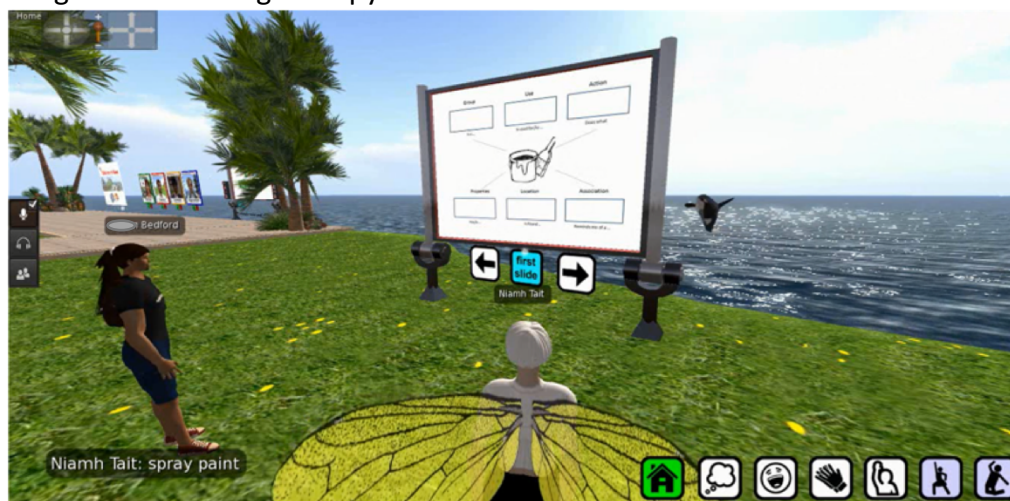
Anomia (impaired word finding) is almost ubiquitous in aphasia, with profoundly negative consequences for communication. Semantic Feature Analysis (SFA) is a treatment for anomia. It involves repeated retrieval of target words, coupled with reflection on the meaning of those words. The evidence base for SFA shows that it improves production of practised words, but generalisation to unpractised words and to discourse is often poor. The supervisory team has explored different administrations of SFA, including integration with group therapy. An exciting development explored the administration of SFA in EVA Park, our virtual world for people with aphasia. This allows for remote delivery of therapy (ideal for patients who cannot travel) and may promote generalisation, given the opportunities for communication practice in the virtual environment.

EVA Park is a multi-user virtual reality platform designed with and for people with aphasia (Wilson et al. 2015). EVA Park runs on a 3D browser via an internet connection allowing for remote delivery of treatment. Its simulated everyday spaces (café, restaurant, hairdressers, clinic) offer a unique opportunity for practice of everyday conversations.

Users are represented by an avatar that can navigate around the virtual spaces.

Communication is in real time via a headset, so similar to a phone conversation. Instant messaging can additionally be used.

Image: Word finding therapy in EVA Park



It was created at City, University of London. Research has shown that EVA Park can host a range of communication, language and support interventions (Marshall et al. 2016 & 2018). A single case study of SFA delivered in EVA Park saw changes in naming but not functional communication. This study, VESFA, will deliver SFA with conversation groups with the aim of improving word retrieval in conversation.

Research Questions:

RQ1: Is it feasible to run a definitive future trial of VESFA as measured by recruitment and retention rates, fidelity of intervention and client report of acceptability?

RQ2: Are the outcome measures appropriate and will they allow us to estimate a sample size for a definitive trial?

RQ3: Does the retrieval of words treated in therapy improve and do gains generalise to discourse?

References:

- Grechuta, K., Rubio Ballester, B., Espín Munne, R., Usabiaga Bernal, T., Molina Hervás, B., Mohr, B., Pulvermüller, F., San Segundo, R. and Verschure, P. (2019) 'Augmented Dyadic Therapy Boosts Recovery of Language Function in Patients With Nonfluent Aphasia', *Stroke* (00392499), 50(5), pp. 1270-1274. doi: 10.1161/STROKEAHA.118.023729.
- Maples-Keller, J. L., Bunnell, B. E., Kim, S. J., & Rothbaum, B. O. (2017). The Use of Virtual Reality Technology in the Treatment of Anxiety and Other Psychiatric Disorders. *Harvard review of psychiatry*, 25(3), 103–113. <https://doi.org/10.1097/HRP.000000000000138>
- Marshall, J., Booth, T., Devane, N., Galliers, J., Greenwood, H., Hilari, K., Talbot, R., Wilson, S. and Woolf, C. (2016) 'Evaluating the Benefits of Aphasia Intervention Delivered in Virtual Reality: Results of a Quasi-Randomised Study', *PloS one*, 11(8), pp. e0160381. doi: 10.1371/journal.pone.0160381.
- Marshall, J, Booth, T, Devane, N, Greenwood, H, Hilari, K, Talbot R, Wilson S and Woolf, C (2016) Evaluating the Benefits of Aphasia Intervention Delivered in Virtual Reality: Results of a Quasi-Randomised Study. *PLoS ONE*, 11(8)
- Marshall, J., Devane, N., Edmonds, L., Talbot, R., Wilson, S., Woolf, C. and Zwart, N. (2018) 'Delivering word retrieval therapies for people with aphasia in a virtual communication environment', *Aphasiology*, 32(9), pp. 1054-1074. doi: 10.1080/02687038.2018.1488237.
- Wilson S, Roper A, Marshall J, Galliers J, Devane N, Booth T, Woolf C. (2015) Codesign for People with Aphasia through Tangible Design Languages. *CoDesign*, 11: 21–34.

P3) BRIEFLY explain how this project will further existing knowledge.

This project will further our understanding of three areas, 1) SFA 2) remote delivery of speech and language therapy and assessment and 3) the potential for virtual environments to support functional generalisation of new skills.

The supervisory team has explored an elaborated SFA (ESFA) protocol which included practicing retrieving words in phrases and sentences and ESFA carried out in groups to see if gains could be extended to discourse. They found gains in word finding and quality of life measures but no change to discourse. This project builds on that work to include not just practicing words in phrases but also in conversation-based group tasks alongside individual ESFA sessions.

This project will be delivered entirely remotely. Participants will receive both testing and intervention in their homes via the internet. Assessments will be delivered via videoconferencing technologies and therapy will be delivered via EVA Park. Feasibility measures will further our knowledge of whether this is an acceptable and accessible means to deliver assessment and therapy and whether it is possible to run a definitive trial investigating the clinical and cost effectiveness of this intervention. Previous EVA Park

studies have had positive feasibility outcomes. The addition of remote testing is novel in this project.

A functional goal-directed intervention in EVA Park (Marshall et al 2016) has demonstrated functional communication gains. That study showed that practice in the simulated EVA Park environments improves functional communication. This study aims to exploit the functional conversation opportunities of EVA Park alongside individual ESFA sessions with the hypothesis that linguistic gains will generalise to functional communication. The generalisation of linguistic skill into functional communication contexts is frequently cited as the overall aim of SLT interventions but is difficult to demonstrate.

P4) Provide a summary and brief explanation of the research design, method, and data analysis.

Design

The VESFA study is a single-blind, randomised controlled feasibility trial comparing SFA delivered remotely in a virtual environment (EVA Park) with no treatment.

This feasibility study will compare 'usual care + intervention (UCI) vs. 'usual care control (UCC)'.

Ultimately the research team are interested in whether the treatment can improve functional communication in *chronic* aphasia, that is in participants who no longer meet the criteria for NHS services. Therefore, participants will be more than 4 months post stroke. Typically stroke services' early supported discharge teams offer 6 to 12 weeks of rehabilitation after discharge from hospital. The Sentinel Stroke Audit Programme (SSNAP) shows that only 6% of stroke survivors are receiving more than 12 weeks of therapy after discharge (Royal College of Physicians, 2015). People with aphasia can then be referred to an outpatient team if they have ongoing goals. A recent study investigated what therapy people with aphasia receive in the community (Palmer et al. 2018) and found that on average community dwelling people with aphasia received 1 hour of speech therapy every 2 weeks. A stroke association survey (2016) revealed that 45% of stroke survivors feel abandoned when they leave hospital because they don't receive the help and support they need.

We do not know exactly what the usual care will be for each participant. We anticipate they will be accessing aphasia support services such as communication groups. We will ask what services they have accessed during their 4month involvement at the final testing point (T3, follow up).

If a participant is interested in taking part but has not completed their NHS care they can wait and join the study when their therapy is complete, or this research project may not be right for them at the given time. No participant will be denied their usual care. We are offering targeted therapy to people who have been discharged from therapy services.

This study will investigate if treatment in the chronic stage post stroke (>4m) is better than usual care in the chronic stage

Method

36 participants with aphasia will be screened, recruited and randomised into a treatment or no treatment group in 5 sets. There will be 18 participants in each group. Outcome

measures will be carried out remotely at three time points: T1 one week post randomisation (baseline), T2 ten weeks post randomisation (post 8 weeks therapy for those in intervention arm), and T3 nineteen weeks post randomisation.

The researcher and the participants will not be blinded to group allocation. Testers will be blind to both group allocation and testing time.

Intervention group

Participants randomised to the intervention group will receive T1 testing, 8 weeks of usual care plus VESFA, T2 testing, 8 weeks of usual care and T3 testing. They will be involved in the project for approximately 4 months.

VESFA will consist of 40 hours of treatment; two one to one (60min) sessions and two group (90min) sessions per week (5 hours per week) for 8 weeks. The dose is in line with evidence that high intensity SLT (defined as 4 – 15 hours per week) improves aphasia severity more than low intensity therapy (Brady et al, 2016). All treatment will be delivered remotely in EVA Park. One to one sessions will consist of 45 minutes of naming practice with ESFA and 15 minutes of situated word retrieval practice within conversations e.g., ordering dinner in the

EVA Park pizza restaurant, making tea in the EVA Park house kitchen, buying flowers from the EVA Park market stall. Group sessions will consist of topic-based conversations situated in EVA Park settings e.g., talking about gardening in the greenhouse.

Treatment will be delivered in sets of three or four participants at a time to allow for a small group per set. Five sets of treatment will be delivered over a 15-month intervention period (3 sets with 4 participants and 2x sets with 3. Total = 18 participants). It is anticipated that the therapy sets will run from October 2020 – December 2021, however there may be delays due to COVID-19.

Words targeted in therapy will be informed by a focus group discussion investigating the topics people with aphasia find meaningful, and from a previous research that investigates words that people with aphasia have identified as useful therapy targets (for example, Palmer et al. 2017) plus 10 personally relevant targets, chosen by each individual participant.

Control group

The study design compares a control group receiving usual care (UCC) with an experimental group receiving usual care plus augmented SFA delivered in EVA Park (UCI).

Participants randomised to the UCC group will undergo T1 testing, have usual care for 8 weeks, undergo T2 testing, have usual care for 8 weeks and undergo T3 testing. They will be involved in the project for approximately 4 months.

For ethical reasons, the control group will be offered intervention after the study is complete. This intervention will comprise online supported conversations, It will not form part of the study, and outcome data will not be collected.

Time commitment for participants

Recruitment is staggered, recruiting in sets of 6 or 8 participants every 3 months. This allows for 4 participants in each arm for an 8week treatment/no treatment phase, followed by 8week follow up. The intervention period runs for 15 months for the researcher (5 overlapping sets), but each participant is involved in the project for a period of 4 months.

Outcomes

The study explores the feasibility of running a future definitive trial. As a feasibility study the main endpoints relate to feasibility outcomes.

Primary objectives of this trial are to evaluate:

1. the acceptability of the intervention to participants
2. the feasibility of recruitment and retention
3. the acceptability of research procedures
4. feasibility of delivering the intervention remotely in a virtual environment.

Secondary objectives are to:

5. evaluate the appropriateness of outcome measures
6. estimate a sample size for the definitive trial
7. assess the processes for evaluating treatment fidelity

Clinical outcomes will indicate:

8. whether the retrieval of words treated in therapy improve
9. whether gains have potential to generalise to discourse

Acceptability of the treatment will be based on rates of adherence to the intervention and qualitative interviews (see below). Participants will be considered to have adhered if they receive at least 80% of the intervention (32 of the 40 hours).

Comparing UCI to UCC allows the researchers to investigate whether it is feasible and acceptable to recruit to a definitive trial. This includes the feasibility of recruiting when there is a control group (i.e., when individuals are not guaranteed to receive the experimental therapy), and retaining controls post randomisation.

Acceptability of research procedures and feasibility of delivering the intervention remotely in a virtual environment will be based on qualitative interviews with participants at end of the study. Interviews will explore satisfaction with the method of delivery of the intervention and accessibility/usability of the technology. The interviews will also explore the transfer of skills learnt in EVA Park to real world environments. The interviews will be carried out for an MSc dissertation project.

Comparing UCI to UCC allows the researcher to investigate the appropriateness of the outcome measures. Standard deviations (SD) on primary outcome measures and the difference in SD between groups can be determined. The difference in SD between the groups allows for a power calculation for the definitive trial.

Treatment integrity (fidelity) will be tested by rating videos of intervention sessions against fidelity checklists. The existing fidelity checklists for ESFA will be adapted for VESFA. An MSc student project will rate a subsample of intervention sessions, comprising at least one individual and one group session per participant (~25-30 sessions) against the fidelity checklists. Feasibility will be based on the proportion of participants who consent, rates of participants randomised and attrition rates.

Clinical outcomes will be measured using the core outcome set for aphasia research (Western

Aphasia Battery, Stroke and Aphasia Quality of Life Scale, the Scenario Test-UK, and the General Health Questionnaire-12 item version), a treatment specific measure of word retrieval and a measure of words in discourse (Nicholas and Brookshire, 1993).

References:

Nicholas, L.E. and Brookshire, R.H. (1993) 'A System for Quantifying the Informativeness and Efficiency of the Connected Speech of Adults With Aphasia', *Journal of speech and hearing research*, 36(2), pp. 338-350. doi: 10.1044/jshr.3602.338

Palmer, R., Hughes, H. and Chater, T. (2017) 'What do people with aphasia want to be able to say?

A content analysis of words identified as personally relevant by people with aphasia', *PloS one*, 12(3), pp. e0174065. doi: 10.1371/journal.pone.0174065.

P4.1) If relevant, please upload your research protocol.

P5) What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?

The ethical considerations in this study relate to informed consent, participant's willingness to be randomised to a no treatment group, an increased risk of emotional distress and the protection of personal data including cyber security.

- Informed consent

Aphasia is not a cognitive impairment. People with aphasia therefore have the capacity to give informed consent, providing there are no co-morbidities that affect cognition and providing that information is presented in an accessible manner. If there are doubts about capacity, an individual will not be consented into the trial. Consent and information materials have been designed to be accessible to people with aphasia. To be eligible to take part in the study participant's comprehension will be screened (6/10 in auditory comprehension in FAST), which means that participants should be able to understand the information on the project (given by researcher and on information video). The researcher is a speech and language therapist who is experienced in working with people who have aphasia and in recruiting research participants from this population.

- Randomisation

Half the participants recruited will be randomised to a no treatment usual care group. This will be clear in the information provided to participants as they may not wish to undergo the testing burden without the benefit of the novel treatment. Nevertheless, participants will be offered online supported conversations after they complete T3 by a referral to the City Aphasia Clinic, City Aphasia Reconnect or student projects/placements in EVA Park.

- Risk of distress

Sometimes engaging in speech and language therapy highlights the stroke deficits for a stroke survivor. This can lead to an increased need for emotional support. The research team need to consider what support is available for participants who are at home and will never meet the researchers face to face.

For individuals who become distressed, we will pause the session and discuss, and discontinuing where appropriate. We acknowledge this may be more challenging online, and testers will be briefed on facilitating good communication and therapeutic alliance in telerehabilitation. Some participants may wish to speak over the phone rather than Zoom, and the staff member may instead follow up with the participant over the phone. Where appropriate and with the participant's consent, the staff member may follow up the concern with a nominated individual from the participant's support network e.g., partner, family member, or friend. Testers will have a check-in check-out system each session with the researcher (Devane) and can contact them for help during a session (e.g., email outside of Zoom) as needed.

For individuals who disclose social, emotional or health needs, we will offer the same support and process as above. We will also agree a course of action with the participant and support them to implement this and monitor it. It may involve encouraging them to seek support with GP and may involve supporting them to make contact and complete e-health consultation requests. Where appropriate, we may recommend and support participants to contact The Stroke Association, whose helpline continues to operate and who also have some support operating in different areas which can be accessed by contacting clubtogether@stroke.org.uk. Where appropriate, we will also encourage participants to make contact with other freely available services such as Aphasia Reconnect <https://aphasiareconnect.org/> who are providing a range of support (phone befriending, Zoom befriending, virtual groups, conversation groups, and other support).

Such instances will be reported to the researcher (Devane) and noted. Such instances will also be followed up with a communication (email, Zoom, phone) the following day to check in with the participant.

- Data protection

Data will be collected via the University licenced videoconferencing technology 'zoom'. Zoom allows users to annotate the shared document which makes it ideal for language assessment where comprehension is tested by items being selected.

To minimise the risk of participants personal information being collected by zoom the following steps will be taken:

- Participants will be invited to join a web browser instead of downloading the zoom app.
- They will be advised not to use Facebook to sign in. This reduces the amount of personal data zoom has access to.
- The researcher will keep her zoom app up to date. Recent updates do not use a remote web server that was known to leave user's computer open to hacking.

Zoom meets the privacy and security standards of the American Health Insurance Portability and

Accountability Act (<https://zoom.us/docs/doc/Zoom-hipaa.pdf>) and the European Union's General Data Protection Regulation (<https://support.zoom.us/hc/en-us/articles/360000126326-OfficialStatement-EU-GDPR-Compliance>). Zoom has been recommended by previous research investigating remote assessment (Maria et al. 2020) and has proved acceptable and accessible in a UK Group Pilot with people with language and communication needs as a result of dementia: <https://www.dementiavoices.org.uk/deep-virtual-peer-support-pilot-report-and-film/>

Following an email consultation with Michael Cann the following plan to capture, store and encrypt video recordings was agreed.

Capture:

1. All devices the research data is held on will be encrypted. City device Service desk can advise on how to check the encryption.
2. All devices must be password protected with a suitable password greater than 8 characters.
3. QuickTime (mac) or BB Flashback (windows) will be used to record the screen, provided the recording is only held on the local (encrypted) device.
4. Zoom recordings may be used on the proviso any recording is immediately downloaded to the encrypted local device and the original Zoom recording deleted.
5. Any recordings imported / exported by researchers must be encrypted.

To optimise data collection and reduce recording unnecessary personal details participants will be advised to 1) not have a light source behind them 2) use a virtual background / background blur feature.

Store:

Video files will be kept on a university drive. If video's need to be shared e.g., from the tester to the researcher, this will be done via a Teams site, OneDrive or an encrypted USB stick.

Encrypt:

Back up recordings will be held on an encrypted hard drive (the Buffalo drive as they are encrypted at a hardware level) and kept in a locked cabinet in the university department.

All study data will be hosted at City, University of London on a password protected database accessed only by the project team. The data will be pseudo-anonymised, with each participant being identified by a unique number. Data will be monitored for completeness and accuracy and a random selection of at least 20% of the data double checked. Screen recordings of a selection of EVA Park sessions will be viewed by an MSc student for the purpose of fidelity checking. They will be briefed about confidentiality. For example, videos should only be viewed in a secure location and, if necessary, transported on

encrypted devices. Note that participants will only be identifiable by voice on these videos, as they are visually represented by avatars.

References:

Maria, D., Braun Emily, J., Anne, B., Lindsey, F. and Swathi, K. (2020) 'Videoconference Administration of the Western Aphasia Battery–Revised: Feasibility and Validity', American Journal of Speech-Language Pathology, doi: 10.1044/2019_AJSLP-19-00023.

P6) Project start date

The start date will be the date of approval.

P7) Anticipated project end date

31 Mar 2023

P8) Where will the research take place?

The study investigates remote delivery of a speech and language intervention. The researcher and testers will be based at City, University of London or their own homes and participants will be based in their own homes. Testing will take place on the videoconferencing technology zoom (zoom.us) and therapy will be delivered via the 3D virtual world, EVA Park.

P10) Is this application or any part of this research project being submitted to another ethics committee, or has it previously been submitted to an ethics committee? No

Funding

F1) Funder

School of Health Sciences doctoral studentship. City, University of London

F2) Does the funder require external membership on the approving REC?

No

F3) Has the funding been approved? Yes

F4) Value of grant £

64831

Human participants: information and participation

The options for the following question are one or more of:

'Under 18'; 'Adults at risk'; 'Individuals aged 16 and over potentially without the capacity to consent'; 'None of the above'.

H1) Will persons from any of the following groups be participating in the project?

Adults at risk

H2) How many participants will be recruited?

H3) Explain how the sample size has been determined.

Sample size was calculated in discussion with the school of health statistician based on the minimal clinically significant important difference in the Scenario Test of 8 units between the control and intervention group. To achieve 80% power in this study we need a sample size of 18 per group at a 5% level of significance.

H4) What is the age group of the participants?

LowerUpper

18

H5) Please specify inclusion and exclusion criteria.

Participants will have a diagnosis of ischaemic or haemorrhagic stroke, be at least four months post stroke, 18 years old or over, and presenting with anomia as a result of aphasia. Anomia will be screened using the naming subtest of the Western Aphasia Battery and participants will be included if they score <60. Auditory comprehension will be screened using the Frenchay Aphasia Screening Test (FAST). A minimum comprehension score of 6/10 will ensure participants can understand what the project entails and can follow instructions in the virtual surrounding without the context that supports auditory comprehension (facial expression, natural gesture).

Participants will be excluded if they: score <6/10 on the FAST comprehension subtest; have other diagnoses affecting cognition such as dementia; have severe uncorrected visual or hearing problems; have severe or potentially terminal co-morbidity; are currently receiving speech and language therapy intervention; or were not fluent English speakers prior to the stroke (based on self or family report).

In order to take part in a remote study, each participant needs to have:

- A named person readily available to assist with technical glitches
- A computer with minimum specification or be willing to receive a laptop posted from the City, University of London
- Teamviewer software that allows the researcher to provide remote support
- An internet connection of >5mbps download speed as measured by www.speedtest.net

Other diagnoses and visual and/or hearing difficulties will be identified by participant self-report. Adults with aphasia do not have cognitive impairments and have capacity to make their own decisions. Their aphasia does, however, put them at risk of not comprehending if adjustments to language are not made. Co-morbidities will be identified by self-report and there is precedence for this. We will have a simple screening tool to assist self-report i.e., yes/no response to named conditions.

In line with the mental capacity act mental capacity is assumed unless proved otherwise. The researcher is a speech and language therapist who has worked with people with aphasia both clinically and in a research capacity for 15 years. The project will be presented in an accessible format (multimodal; verbal description with written and picture support).

If an interested person demonstrates difficulty comprehending the project or expressing their views after adjustments have been made then they will not be consented to the trial.

H6) What are the potential risks and burdens for research participants and how will you minimise them?

Potential risks are minimal.

There is a burden of the time committed to the testing and treatment sessions. The commitment will be made clear during the information and consent stage, to ensure only participants willing to give 5 hours a week will consent. Previous research indicates that word finding gains are often achieved from SFA intervention, and from intensive practice. This rationale will be shared with participants.

There is a low risk of accidents or theft when setting up computer equipment in participants homes. Where possible the project will use the participants own computer. Where necessary a laptop will be loaned. A safety checklist will aim to minimise risks in the home. For example, this will make sure there are no trailing wires, that computers are not obstructive or easily visible from outside.

Potential participants will be asked if they are, or have been, involved in other research. If they have the researchers will ensure that they are not feeling overburdened. People with aphasia report a loss of social activity and we have found that most value the opportunity to be involved in research.

Regular supervision sessions during the intervention will give the researcher the opportunity to discuss any concerns about the needs of participants. Serious issues that come to light, e.g., giving rise to safeguarding concerns, will be followed up immediately by the researcher or a supervisor. They will discuss the concerns with the participants and agree a course of action. For example, the problem may be raised with the participant's GP or referral made to social services.

H7) Will you specifically recruit pregnant women, women in labour, or women who have had a recent stillbirth or miscarriage (within the last 12 months)?

No

H8) Will you directly recruit any staff and/or students at City?

None of the above

H8.1) If you intend to contact staff/students directly for recruitment purpose, please upload a letter of approval from the respective School(s)/Department(s).

H9) How are participants to be identified, approached and recruited, and by whom?

Thirty-six participants will be recruited from the community by the researcher (Devane). Methods of community recruitment include accepting self-referrals (e.g. where a potential participant has learnt about the project from twitter or word of mouth); distributing information about the project to third sector organisations; contacting people known to the University who have given permission for their details to be shared for this purpose. If current social distancing guidelines are lifted, the researcher will visit stroke and aphasia groups. Written informed consent will be obtained from all participants. All information

sheets and consent forms will be developed using standard aphasia-accessible principles (e.g., presenting one idea at a time, using short simple sentences, presenting key ideas with a suitable pictorial image).

H10) Please upload your participant information sheets and consent form, or if they are online (e.g., on Qualtrics) paste the link below.

https://cityunilondon.eu.qualtrics.com/jfe/form/SV_aXcu9U5hHXlKvQh

H11) If appropriate, please upload a copy of the advertisement, including recruitment emails, flyers or letter.

H12) Describe the procedure that will be used when seeking and obtaining consent, including when consent will be obtained.

Potential participants will receive detailed information from the SLT researcher with, if relevant, the participant's significant other. Potential recruits will be given the project information sheet outlining the detail. They will be advised to read it carefully and discuss it with others where appropriate. If requested the sheets will be read aloud to them. Additionally, a video explaining the project can be shared with them. They will also be directed to the project website for further, self-directed investigation, if required. Further videos that illustrate using EVA Park are available here. All information and consent materials have been designed specifically to be accessible to people with aphasia. If the person wants to take part, they will be asked to sign the consent form. Participants will have one week from receiving the information and deciding if they wish to take part (minimum 24 hours). The consent form will be explained by the SLT researcher. Participants can give consent via a Qualtrics survey or a scanned paper copy. Participants will receive a scanned email attachment of their signed consent form or a posted hard copy if requested. An electronic signature will be accepted.

H13) Are there any pressures that may make it difficult for participants to refuse to take part in the project?

No

H14) Is any part of the research being conducted with participants outside the UK?

No

Human participants: method

The options for the following question are one or more of:

'Invasive procedures (for example medical or surgical)'; 'Intrusive procedures (for example psychological or social)'; 'Potentially harmful procedures of any kind'; 'Drugs, placebos, or other substances administered to participants'; 'None of the above'.

M1) Will any of the following methods be involved in the project:

None of the above

M2) Does the project involve any deceptive research practices?

No

M3) Is there a possibility for over-research of participants?

Yes

M3.1) What steps will be taken to safeguard the participants from over-research?

We will ask potential recruits if they are involved in any other research projects and if they are feeling overburdened. People approached are under no obligation to take part in the research and this will be made clear. People with aphasia report feelings of isolation following the stroke and value the opportunity for both altruism and additional therapy and/or social contact that come with being involved in research.

M4) Please upload copies of any questionnaires, topic guides for interviews or focus groups, or equivalent research materials.

M5) Will participants be provided with the findings or outcomes of the project?

Yes

M5.1) Explain how this information will be provided.

Project findings will be disseminated to study participants and other people with aphasia in a variety of ways including:

- Offer visits to the groups where participants were recruited to share findings. I will aim to co-present with any willing participants!
- Quarterly leaflet to all participants keeping them up to date with project progress throughout the life of the project and including a results leaflet at the end.
- Talks at user-facing conferences e.g., Aphasia United, UK Stroke Forum

M6) If the research is intended to benefit the participants, third parties or the local community, please give details.

It is hoped that those who receive therapy in this study will experience some improvement in their word finding skills, although this cannot be guaranteed. Those who receive therapy in a larger follow up trial may similarly benefit. This research should progress our understanding of how to support generalisation in the field of speech and language therapy interventions. The recent Cochrane review of SLT following stroke called for research to focus on these real word changes (Brady et al. 2016).

Feasibility outcomes of online testing will support the delivery of services to hard to reach clients e.g., geographically remote or physical and/or economic barriers to travel.

M7) Are you offering any incentives for participating?

No

M8) Does the research involve clinical trial or clinical intervention testing that does not require Health Research Authority or MHRA approval? Yes

M9) Will the project involve the collection of human tissue or other biological samples that does not fall under the Human Tissue Act (2004) that does not require Health Research Authority Research Ethics Service approval? No

M10) Will the project involve potentially sensitive topics, such as participants' sexual behaviour, their legal or political behaviour, their experience of violence?

No

M11) Will the project involve activities that may lead to 'labelling' either by the researcher (e.g., categorisation) or by the participant (e.g., 'I'm stupid', 'I'm not normal')?

No

Human participants: vulnerable

V1) Please provide details of enhanced ethical procedures to safeguard these participants.

Aphasia is a language impairment, therefore, participants are at risk of not being informed fully if information and consent materials are not adjusted. Aphasia is not a cognitive impairment. People with aphasia therefore have the capacity to give informed consent, providing there are no comorbidities that affect cognition and providing that information is presented in an accessible manner. If there are doubts about capacity, an individual will not be consented into the trial. Consent and information materials have been designed to be accessible to people with aphasia. The researcher is a speech and language therapist who is experienced in working with people who have aphasia and in recruiting research participants from this population.

V2) Please give details of the vulnerable participant protection procedures you propose to adopt should there be any evidence or suspicion of harm (physical, emotional or sexual) to a vulnerable person. Include a referral protocol identifying what to do and who should be contacted.

All research will be undertaken either by, or under the supervision of a qualified Speech and Language Therapist, able to discuss relevant issues in an accessible manner. Evidence &/or suspicion of harm will be raised immediately with the researcher's supervisors (Katerina Hilari or

Jane Marshall). Steps taken will meet the responsibilities of The Care Act 2014. For example, the researcher will: Assess the situation; Ensure the safety and wellbeing of the participant; Establish the participant's views and wishes about the safeguarding issue; Ensure that any evidence is maintained; Make appropriate reports and referrals, e.g., to the Participant's G.P. or relevant Social Services or Health Trust Officer; Inform the participant about what information is being shared and why; Document the episode using the participant's own words, and Record what has been seen and any actions taken. If there are concerns about the participant's immediate safety the researcher will ensure that protection (e.g., from the police) or medical assistance has been sought. Any referrals may be made initially by phone (to ensure speed) but will be confirmed in writing within 2 working days. We will follow the guidance laid out in 'Safeguarding Adults' (NHS England):

<https://www.england.nhs.uk/wp-content/uploads/2017/02/adult-pocket-guide.pdf>. If unmet health needs are disclosed, we will ask consent of the participant to write to their GP informing them of the unmet need. If unmet care needs are disclosed, we will seek consent to discuss these with relevant family members &/or Social Services.

V3) Please give details of how you propose to ensure the well-being of the vulnerable participant, particularly with respect to ensuring that they do not feel pressured to take

part in the research and that they are free to withdraw from the research without any prejudice to themselves at any time.

Participants will be informed that they are free to withdraw at any time without giving any reason, and that this will not affect any other care that they might be receiving. Participants are not in a dependent relationship with the researchers. Participants recruited through communication or stroke support groups are typically discharged from Speech and Language Therapy services. Participation will not, therefore, impact upon other forms of rehabilitation. However, participants will be reassured that not participating will not affect their support or attendance at the support groups.

V4) Will carers, parents, teachers or other parties be present during the research?

No

V5) Are participants able to give informed consent?

Yes

V6) Please give details of any City staff or students who will have contact with adults at risk and/or will have contact with young people (under the age of 18) and the details of current (within the last 3 years) Disclosure and Barring check.

Name

Ms Niamh Devane

DBS reference number

001696639370

Date of DBS

16 Apr 2020

Type of Disclosure

Enhanced Certificate

V7) Please give details of any non-City staff or students who will have contact with adults at risk and/or will have contact with young people (under the age of 18) and the details of current (within the last 3 years) Disclosure and Barring check.

Name

Institution

Address of organisation that requested disclosure

DBS reference number

Date of DBS

Type of disclosure

I will not be recruiting any participants who fall under the Mental Capacity Act 2005.

Data

D1) Indicate which of the following you will be using to collect your data.

Questionnaire

Interviews

Video recording

Computer-based tasks, screen recording or software instrumentation

D2) How will the privacy of the participants be protected?

De-identified samples or data

D3) Will the research involve use of direct quotes?

Yes

D5) Where/how do you intend to store your data?

Data (de-identified paper copies of assessment record forms) to be kept in a locked filing cabinet

Data and identifiers to be kept separate. Identifiers will be in a password protected document on the university's hard drive.

Password protected computer files

Storage on encrypted device (e.g., laptop, hard drive, USB)

Storage at City

D6) Will personal data collected be shared with other organisations?

No

D7) Will the data be accessed by people other than the named researcher, supervisors or examiners?

Yes

D7.1) Explain by whom and for what purposes.

Students of speech and language therapy and computer science at City, University of London will have access for student projects e.g., fidelity projects.

Anonymised research data (e.g., scores on outcome measures) may be shared with other aphasia rehabilitation researchers, e.g., the Collaboration of Aphasia Trialists Aphasia Datasets project <https://www.aphasiatrials.org/aphasia-dataset/>

D8) Is the data intended or required (e.g., by funding body) to be published for reuse or to be shared as part of longitudinal research or a different/wider research project now or in the future? No

D10) How long are you intending to keep the research data generated by the study?

Data will be kept for 10 years

D11) How long will personal data be stored or accessed after the study has ended?

The one file that holds participant personal data will be kept on a password protected file on the university network for 3 years. Consent forms will be archived securely at City according to University guidelines, for 10 years.

D12) How are you intending to destroy the personal data after this period?

This password protected document will be deleted from the server after 3 years. Any hard copy data (e.g., consent forms) will be shredded according to University guidelines.

Health & safety

HS1) Are there any health and safety risks to the researchers over and above that of their normal working life? No

HS3) Are there hazards associated with undertaking this project where a formal risk assessment would be required?

No



Participant information sheet, ETH1920-1223, April 2020
Researcher: **NIAMH DEVANE**

VESFA

Virtual Elaborated Semantic Feature Analysis

Do you want to join our research study?

Before you decide, we want you to understand:

- **Why** the research is being done
- What you **do**, if you take part

Please **read** this sheet carefully

Ask **questions** if it is not clear, or if you want to know more.

Discuss it with other people. Take your time to decide.
You can keep this information sheet.

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

What is the purpose of the study?

Aphasia is caused by stroke. Aphasia makes **communicating difficult**.

We have created **EVA Park** for people with aphasia. It is a **virtual island** on the internet. You access EVA Park using a **computer**.

EVA Park is a **safe** communication environment to **receive therapy**.



We want to see if **therapy** in EVA Park supports **conversations**.

We will **compare** people who have received the **therapy** with people who have **no therapy**. This way we can check that they wouldn't have improved anyway. This study is a doctoral research project.

Why have I been invited to take part?

We are looking for:

- **English** speakers
- People with **word finding difficulties** because of **aphasia**
- People who can **follow a conversation** on the **phone**
- People who are at least **4 months** post stroke
- People with a **computer**, reliable **internet** and **someone who can support** setting up new software

We will do a screening test to see if you are right for the study.

Do I have to take part?

No, it is your choice.

You can say 'yes' now, then **change your mind**. You don't have to say why, and you will not be penalised in any way.

This will **not** affect any other treatment or service you have.

If you **decide** to take part, you will be asked to sign a **consent form**.

What will happen if I take part?



This project is **delivered remotely**. Tests and interviews will happen on zoom (page 4 has more information). Therapy will happen in EVA Park, an online virtual world.

You access both by going online from a **computer at home**.

Screening:

You will be invited to a 30minute **zoom screening session**. In this session you will do a short picture naming task.

You will be **randomly** put into either:

1) a group that receives **therapy**

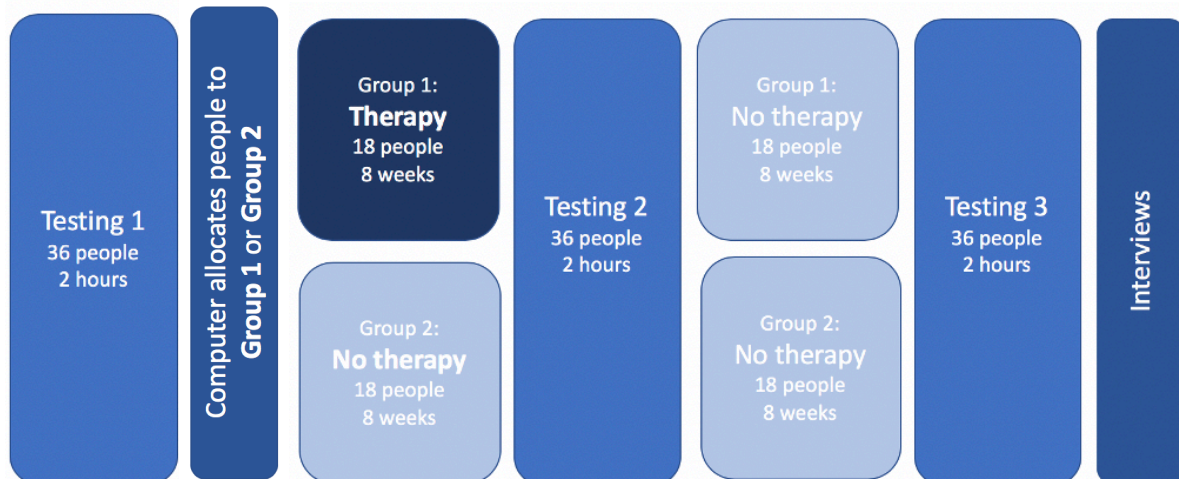
or

2) a group that **doesn't** receive therapy

A **computer programme** will decide which group you join.

Testing:

You will undergo 2 hours of tests in a zoom session. These will be **repeated 3 times** to see if there is any **change** over time.



Therapy:

- 1) The **therapy group** will receive 2 one-to-one therapy sessions of **word finding therapy** per week and 2 **group conversation therapy** sessions a week in EVA Park. This will be a total of 5 hours of therapy a week for 8 weeks.

The conversation group will consist of 3 or 4 participants with aphasia and the speech and language therapist researcher. Participants will be introduced to each other by their first names. They will see an avatar representation of the other group members and hear their voices in real time. Group members are likely to share personal details.

- 2) The **no therapy group** will be offered online supported conversation groups **after testing 3**.

Interviews:

Everyone who takes part in the study will be **interviewed** after testing 3.

The interviewer will be a new researcher. S/he will not be part of the therapy team.

You can feel free to say positive or negative things about the project.

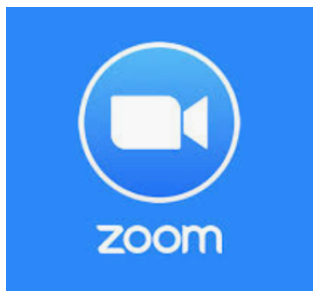
The interviewer will ask about **your experience** of being involved in the study, for example, what it was like to be allocated a group by the computer and what it was like to do the assessments online. The interviews will last approximately 45 minutes.

Time:

If you choose to take part, you will be involved in the project for about **4 months**.

Technology explained:

What is Zoom?



Zoom (www.zoom.us) is videoconferencing technology like Skype or Facetime. You use Zoom on a computer. You can call a friend (or lots of friends) and talk to them via Zoom. It uses a video camera so you can see your friend's face and they can see you. We use Zoom for assessments because the researcher can share their screen with you, and you can mark your responses on the document.

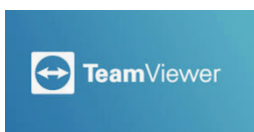
Assessments will be carried out on City, University of London's Zoom licence to ensure security and data protection.

What is EVA Park?

EVA Park is a **private online space** where the therapy will take place. You will be set up by the researcher e.g., create an account, create an avatar, put the software on your computer. You can see videos of EVA Park by clicking [here](#).



What is TeamViewer?



TeamViewer (www.teamviewer.com) is software for **technical support**. It allows the researcher to access your computer to see and change settings on your screen.

This will be used as back-up if we get stuck. The researcher can only see your computer if you allow access. Access must be granted every time.

What do I have to do?

You will be asked to do **three testing sessions**. They will involve:

- **Describing** pictures
- **Describing** an event in your life
- Answering questions about your **mood**
- Doing a test which looks at your **day-to-day** communication (e.g., in a shop, at the doctors)

The researcher will **record the screen** during this session. This will film you doing the tests and allows the researcher to score the tests afterwards. The researcher will always tell you when the screen recording is happening.

If you join the therapy group, you will do **4 therapy sessions** a week;

- 2 individual sessions with the speech and language therapist and
- 2 with a group of up to 4 people with aphasia.



You will access the EVA Park therapy by logging on to the **internet** on a **computer**. If necessary, we can post you a laptop. Niamh will help you. She can log in to your computer remotely to set up the software. She will **set-up** the computer and show you how to use EVA Park.

During therapy, Niamh will **record** one individual and one group session each

week. She will record what is happening on the screen. The recordings will be used to check that the therapy sessions match the therapy plan (therapy fidelity).

Money

You will not be paid for your time. If you need equipment this can be loaned. The project is being funded by a doctoral studentship from the School of Health Sciences at City, University of London.

Are there any risks to taking part?

There are no medical **risks** or dangers.

You will have to give up some of your **time**.

Some of the tasks may be tiring, or frustrating. If this happens, we can:

- have a break, or
- stop and carry on another time

You can leave the study at any time without having to continue later.

Will the project help me?

Therapy in EVA Park may help you, but it may not. We cannot promise. The research will help us to understand more about how to do therapy on the internet, EVA Park and aphasia therapy. This may help other people in the future.

Is it confidential?

Your **videos** and **test scores** will be seen by the **research team**, the researcher and her supervisors.

They may be seen by **students** working with us on the research.

Your **test scores (without your name)** may be **shared with other researchers** interested in aphasia rehabilitation.

Students may look at your videos and your test scores after this project is finished, so that we can understand more about the benefits of EVA Park.

Students will be working under our **supervision**. We will ensure that their work is confidential.

The information we collect has to be kept **privately** for 10 years securely at City University London. Then it will be destroyed.

Data Protection

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly.

City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

City, University of London considers the lawful basis for processing of special category data relating to health to fall under Article (9)(2) (a) of GDPR (Explicit Consent) as the research participants given their explicit consent for the processing of health information by volunteering to take part in the research and the completion of the consent form. The research participants are able to withdraw from the research project at any time.

What are my rights under data protection legislation?

City, University of London is the data controller for the personal data collected for this research project. The rights you have under the data protection legislation are listed below but not all of the rights will apply to the personal data collected in each research project:

Right to be informed, right of access, right to rectification, right to erasure, right to restrict processing, right to object to data processing, right to data portability, right to object, rights in relation to automated decision making and profiling.

For more information, please visit www.city.ac.uk/about/city-information/legal

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance, you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at dataprotection@city.ac.uk or phone 0207 040 4000, who will liaise with City's Data Protection Officer Dr William Jordan to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

What will happen to the results of the research study?

We will **tell you** what we found out.

We may also:

- write articles in scientific journals
- write articles in magazines for people who have had strokes
- write articles on the internet
- talk about the research at conferences
- talk about the study at community groups

When we report on the work, we will not use your name.

Anonymised research data (e.g., scores on outcome measures) may be shared with other aphasia rehabilitation researchers, e.g., the Collaboration of Aphasia Trialists Aphasia Datasets project <https://www.aphasiatrials.org/aphasia-dataset>

What will happen when the research study stops?

When the study finishes data will be **kept securely** on the server (digital) and in locked filing cabinets (paper) at City, University of London for **10 years**.

After 10 years the data will be **destroyed**.

If there is a problem or you are not happy you can:

Talk to the researcher:

- **Niamh Devane** 020 7040 8821 niamh.devane.2@city.ac.uk

Talk to the person in charge of the research:

- **Katerina Hilari** 020 7040 4660 K.Hilari@city.ac.uk

If you are very concerned you can complain about the study. City University London has a procedure for complaints.

If you want to complain:

- phone 020 7040 3040
- ask for the Secretary to the Research Ethics Committee
- Tell them that your project is called:

VESFA: Virtual Elaborated Semantic Feature Analysis

You could also write to the Secretary at:

Anna Ramberg, Secretary to Senate Research Ethics Committee, Research Office, E214, City University London, Northampton Square, London, EC1 0HB

Email: anna.ramberg.1@city.ac.uk

Who has reviewed the study?

Senate Research Ethics Committee, City, University of London.

Insurance

City, University of London holds insurance policies which apply to this study, subject to the terms and conditions of the policy.

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.

Further information and contact details

Thank you for taking the time to read this information sheet.

We will give you a copy to **keep**.

If you are interested our researcher will talk to you and answer your questions.

Researcher:

Niamh Devane:	Niamh.devane.1@city.ac.uk	020 7040 8821
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Supervisors:

Katerina Hilari:	k.hilari@city.ac.uk	020 7040 4660
Jane Marshall:	j.marshall@city.ac.uk	020 7040 4668
Stephanie Wilson:	s.m.wilson@city.ac.uk	020 7040 8152

If you want to join the research, we will ask you to sign a **consent form**.
We will give you a copy of the form to keep.

Appendix 17 | Consent form



Consent form for participants with aphasia, ETH1920-1223
Researcher: Niamh Devane

Title: **VESFA | Virtual Elaborated Semantic Feature Analysis**

1. I confirm that I have had the project explained to me, and I have read the participant information sheet (ETH1920-1223, April 2020) which I may keep for my records. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.

I understand the project will involve:

- completing questionnaires about my language, my mood and my use of communication in an online interview
- using a computer for speech & language therapy in a virtual world or supported conversation online
- some sessions being screen recorded
- being interviewed about my experience of the therapy by a researcher
- anonymous usage data being collected e.g., how long I log in for, where I click



please initial

-
2. I understand that my participation is **voluntary** and that I am **free to withdraw** without giving a reason without being penalised or disadvantaged.

-
3. I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) explained in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).



5. Additionally, I consent to:
*(initial as appropriate)

- **screen recordings** being used for **teaching** purposes, with students or other professionals
- sharing **screen recordings** with researchers and professionals at **conferences**
- sharing screen recordings with the project on public **online** platforms e.g., the project website, twitter
- Anonymous direct **quotes** from my interviews to be **published**
- **Anonymised data**, like scores on outcome measures, to be **shared** with other aphasia rehabilitation researchers
- My **contact details** being **kept** so that I can be **informed of the results** of the study.

6. I agree to take part in the above study

(Your name)

(Date)

(Signature – electronic
signature is accepted)

(Name of researcher)

(Date)

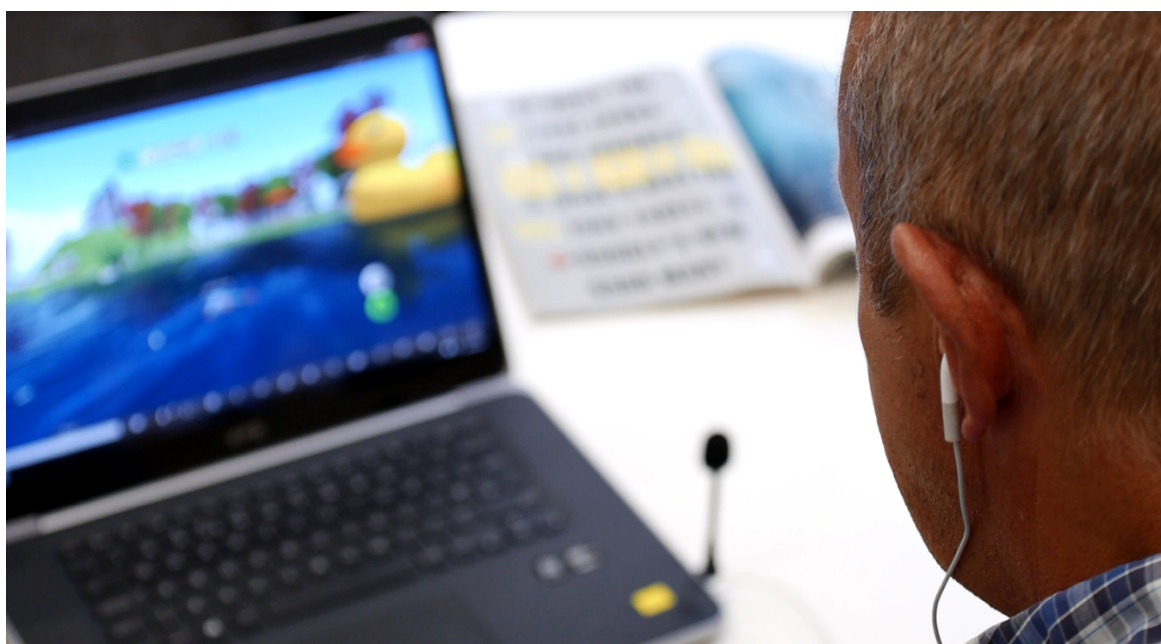
(Signature – electronic
signature is accepted)

When completed 1 copy for participant and 1 copy for researcher file.



Virtual Elaborated Semantic Feature Analysis

Handbook for participants



December 2021

Thank you for taking part in this aphasia research project. Doing so will help us learn about the potential for people with aphasia to use on-line virtual technologies. We hope that it will be an interesting and enjoyable experience. This handbook has been written to give you the information you need to use EVA Park. If anything is not clear, or you have further questions, feel free to ask us.

VESFA

VESFA is a **word finding therapy** with phrase and **conversation practice**. It is delivered in the **virtual world** EVA Park.

Treatment:	Hours per week:	Over 8 weeks:
Words	2x 1hr	16hrs
Conversations	2x 1.5hr	24hrs
		Total: 40hrs

EVA Park

EVA Park is a virtual island designed for people with aphasia. It can be used by several people at the same time. Each person is represented by an avatar. There are green spaces, functional locations such as a hairdressers and quirky elements, such as a Tardis with a surprise inside.



You access EVA Park from a computer at home.
You talk to others via a headset.

Project aims

The project aims to find out if it's possible to run a large clinical trial in EVA Park, in the future. In this project, we want to find out:

1. if **people will volunteer** and are **willing to be randomised**
2. what do people think about VESFA, i.e., is it **acceptable?**
3. if the **word finding improves** with VESFA therapy
4. how VESFA supports **word finding in conversations**
5. if taking part in VESFA makes people **feel better**

One-to-one sessions

You will receive 16 one-to-one naming therapy sessions. You will have two sessions a week for eight weeks.

The naming therapy is called Semantic Feature Analysis (SFA). This therapy strengthens the links between related words to improve word finding.

Why SFA works:

When you think of a word the brain sends a signal to *related* words to be ready. This is called priming. So, if you think of 'red', signals go to fire, rose, cherry and fire engine. If you think 'fire', signals go to house, hot, fire engine. If you then think 'bus', fire engine has received priming from the previous words and the thing that will jump into your head is most likely to be 'fire engine'.

These links between words get disrupted in aphasia.

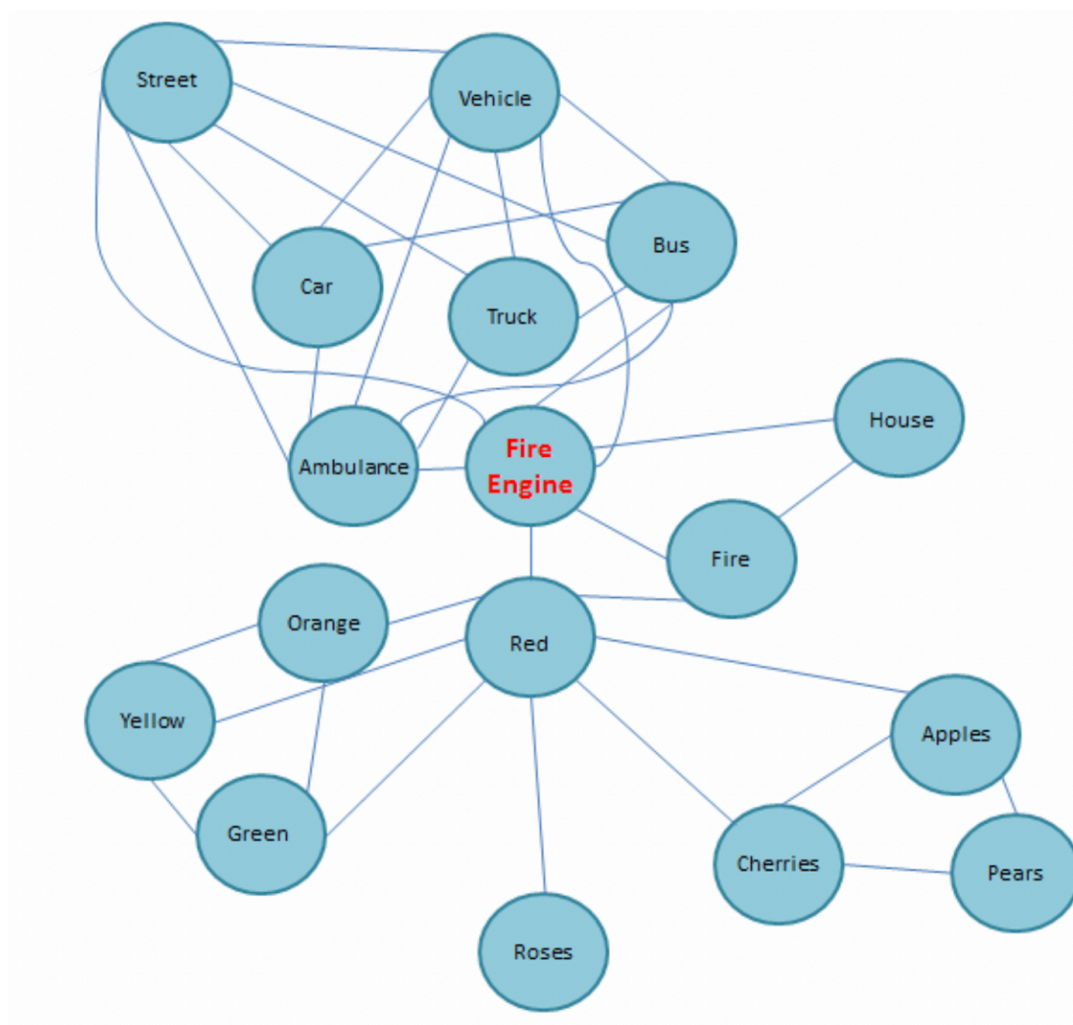
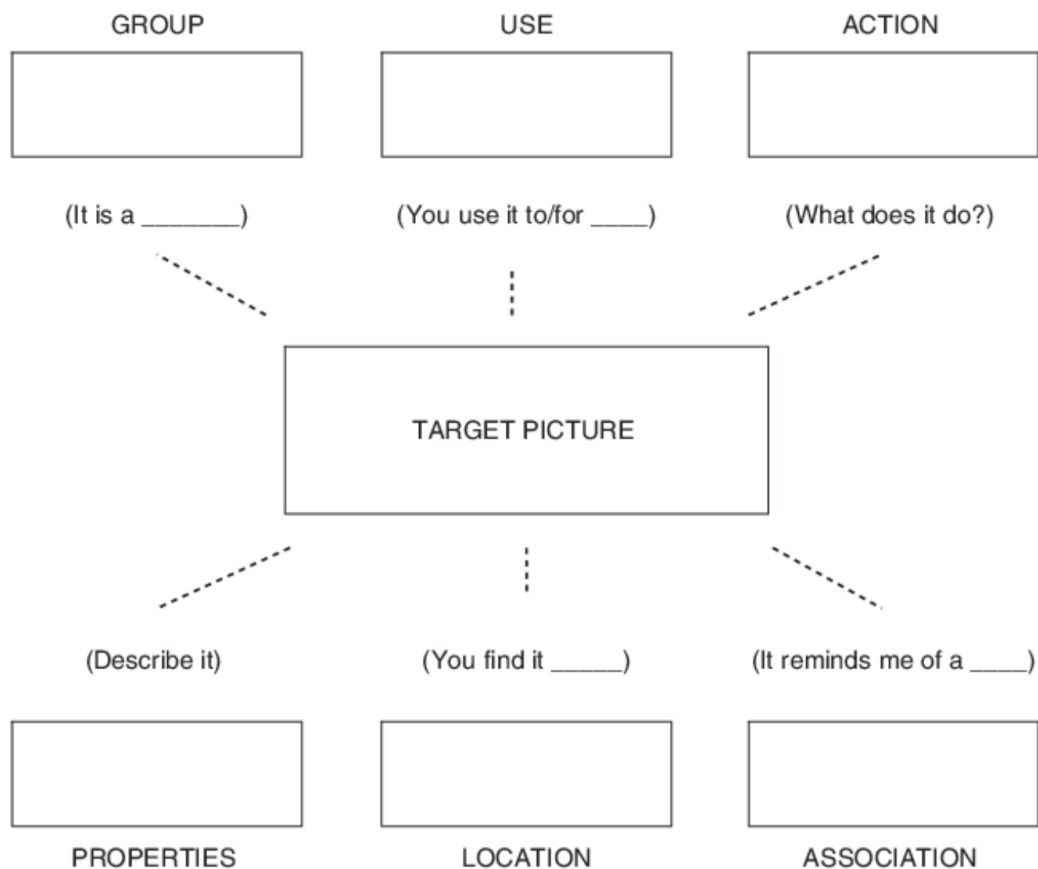
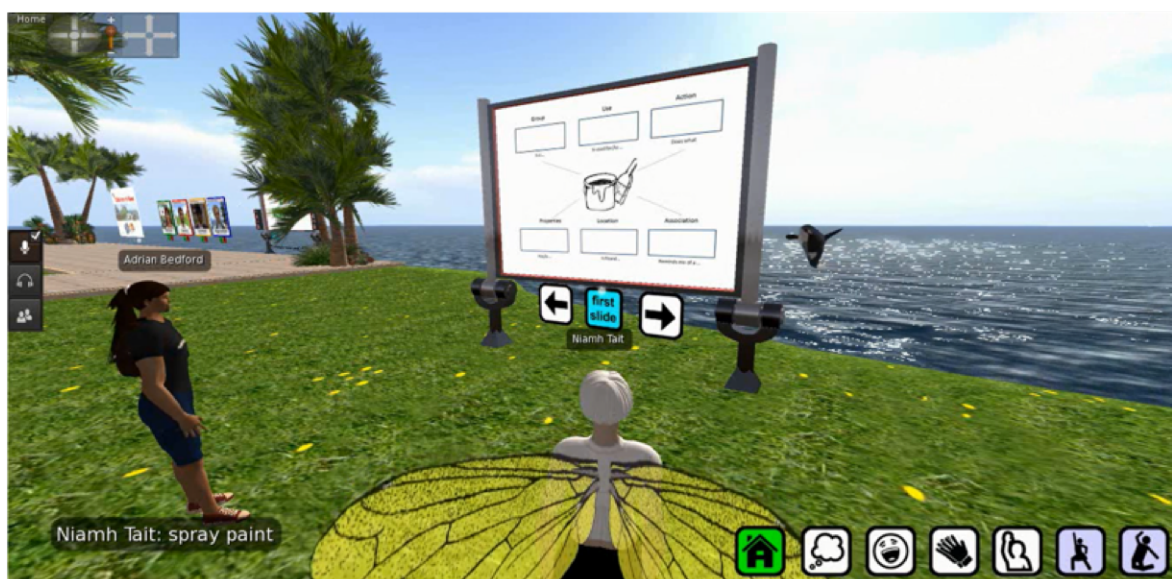


Image from Collins and Loftus, 1975

We will **work through a list of words** finding all their related features using the SFA chart:



We will use the word in a phrase or sentence. Adding a phrase makes it *elaborated* SFA (ESFA).



The conversation groups

There are 16 groups that will take place twice a week for 8 weeks. Each topic is the focus of 4 groups before moving to the next topic (groups 1-12). There is one recap group per topic (groups 13, 14 and 15) and the final group (16) is a party. In the party group we have a mini 'EVA island discs'. Each member brings a piece of music to share and tells the group what it means to them.

Each group will have

- A **welcome**: 10 minutes to arrive, say hello, share news and get settings ready.
- Articulate game: describe a topic word without naming it for others to guess
- A **topic-based activity**: we will work on the topic words in conversations and role play activities.
- Bingo game: Tell a story using all the words on your bingo card (see page 12). It can be real or imagined.
- A **summary**: to reflect on the activity and close the group.

You can do **challenge tasks**. These are small challenges to help to progress and prepare for the next session.

1. Food and Drink

Date and Time: Tuesday 7th December

11.30am-1pm

Past meal: tell us about what you ate last night

Challenge task: Think about your favourite meal. Prepare some prompts to support you on Thursday. For example: drawing, written words, recipe book

2. Food and Drink

Date and Time: Thursday 9th December

11.30am-1pm

Dream meal: describe your favourite meal

Challenge task: Tell someone in your house what your favourite meal is

3. Food and Drink

Date and Time: Tuesday 14th December

11.30am-1pm

Process: share a recipe

Challenge tasks: Make your recipe at home

4. Food and Drink

Date and Time: Thursday 16th December

11.30am-1pm

Story: share a personal story about food

Challenge tasks: Tell someone new your story

- 2 week break -

5. Travel

Date and Time: Wednesday 5th January

1.30-3pm

Past: tell us about the last time you travelled

Challenge task: Start a conversation at home about travel, "Remember when..."

6. Travel

Date and Time: Friday 7th January

11.30am-1pm

Dream: describe your perfect holiday

Challenge task: Tell someone in your house your perfect holiday

7. Travel

Date and Time: Tuesday 11th January

11.30am-1pm

Process: give us directions to your house

Challenge tasks: Think about a travel story. Prepare resources to help you on Thursday.

8. Travel

Date and Time: Thursday 13th January

11.30am-1pm Story: tell us a personal story about travel

Challenge tasks: Tell someone new your story

9. Gardening

Date and Time: Tuesday 18th January

11.30am-1pm Past: tell us about your garden or local park

Challenge task: Tell someone in your life about your garden or park

10. Gardening

Date and Time: Thursday 20th January

11.30am-1pm

Dream: describe your perfect garden

Challenge task: Use a phrase from your perfect garden. Sneak it into a real life conversation!

11. Gardening

Date and Time: Tuesday 25th January

11.30am-1pm

Process: tell us how to plant a vegetable from seed

Challenge tasks: Think about a story you can share on Thursday. Prepare some prompts to help you.

12. Gardening

Date and Time: Thursday 27th January

11.30am-1pm

Story: tell us a personal story

Challenge task: Share your story with someone new

13. Food and Drink recap

Date and Time: Tuesday 1st February

11.30am-1pm

Café: Request a drink and snack.

14. Travel recap

Date and Time: Thursday 3rd February

11.30am-1pm

Tardis: Plans for upcoming travel (where, why and how).

15. Gardening recap

Date and Time: Tuesday 8th February

11.30am-1pm

House: tell us your gardening plans (can be garden, houseplants etc)

Challenge task: Tell Niamh which piece of music to play. Be ready to talk to the others about why

16. EVA Park party!

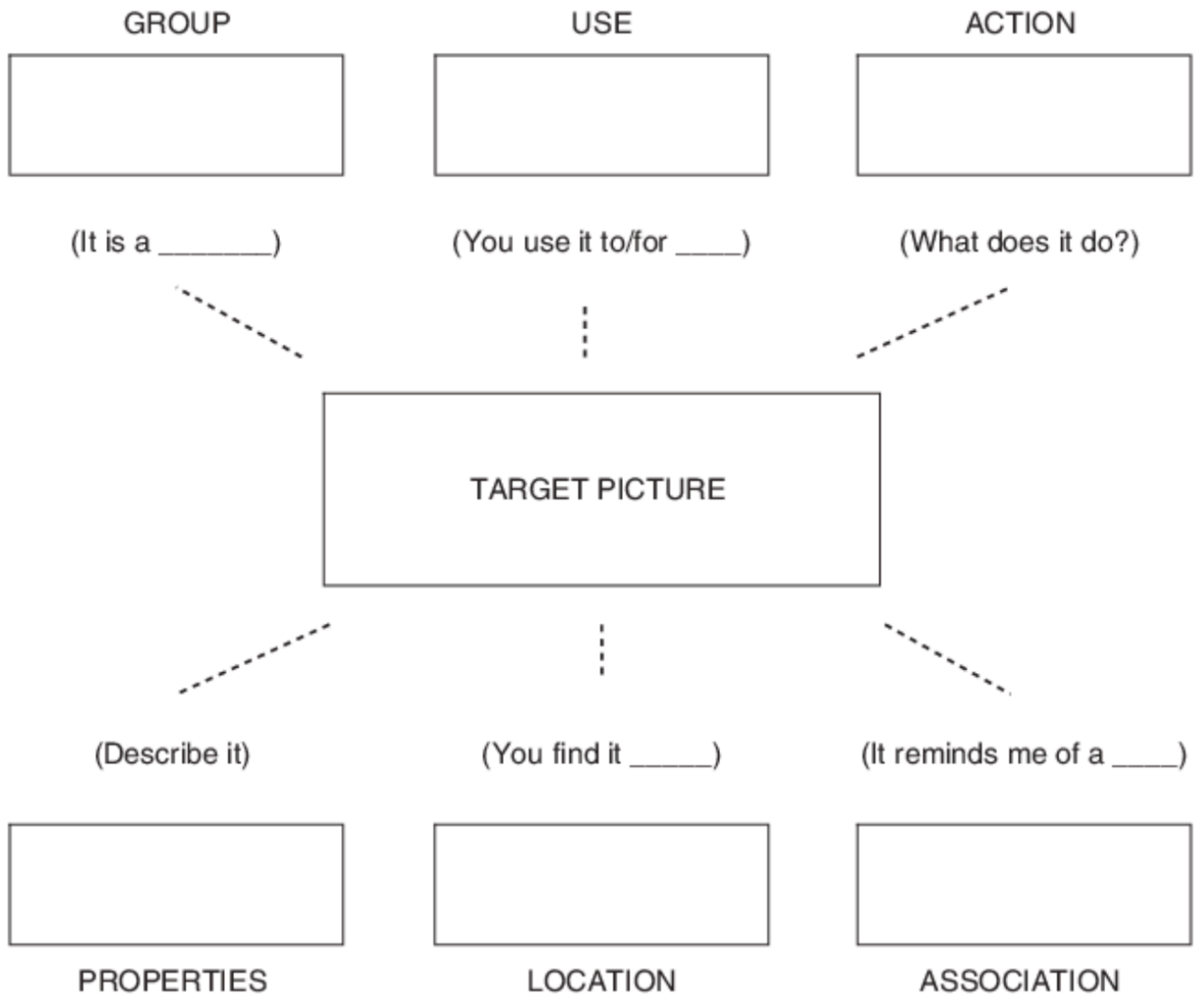
Date and Time: Thursday 10th February

11.30am-1pm

EVA Island Discs: Each participant shares a piece of music. Tell us something about why it's important to you. Final session together in EVA Park..

RESOURCES

SFA Chart:



Vocabulary by topics:

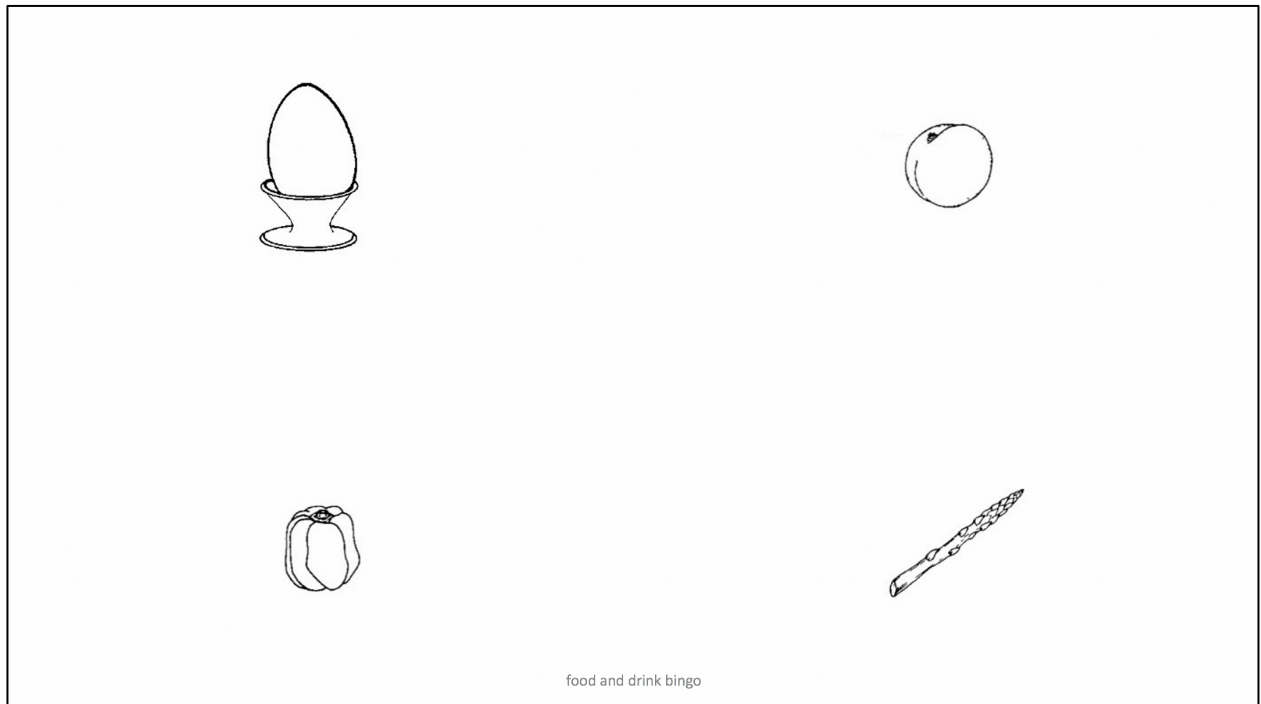
Food and Drink		Nature and Gardening	
Can	Pot	Pumpkin	Bird
Plate	Asparagus	Hose	Squirrel
Octopus	Walnut	Cabbage	Butterfly
Frying pan	Cheese	Snail	Potato
Pineapple	Scale	Carrot	Tree
Salt	Kettle	Fly	Bee
Pie	Sandwich	Spider	Flower
Wheat	Fork	Owl	Caterpillar
Bowl	Egg	Boot	Frog
Cherry	Corn	Plant	Sun
Table	Butter	Fox	Swing
Spoon	Tomato	Leaf	Watering can
Glass	Peach	Chair	Bench
Pepper	Waiter	Fence	Rake
Cup	Fish	Daffodil	Ant

Daily Living		Travel	
Can opener	Washing machine	Pool	Volcano
Curtains	Bathtub	Shell	Mountain
Dustpan	Doctor	Globe	Boat
Fire	Priest	Desert	Sunset
Floor	Pen	Bus	Camera
Mirror	Church	Tent	Car
Mixer	Pencil	Cloud	Map
Mop	Fan	Canoe	Castle
Mousetrap	Window	Rainbow	Sailboat
Bucket	Lamp	City	Skis
Roof	Iron	Road	Backpack
Rug	Toilet	Rock	Lighthouse
Stairs	Basket	Lake	Calendar
Vacuum	Key	Train	Waterfall
Picture	Sink	Rain	Book

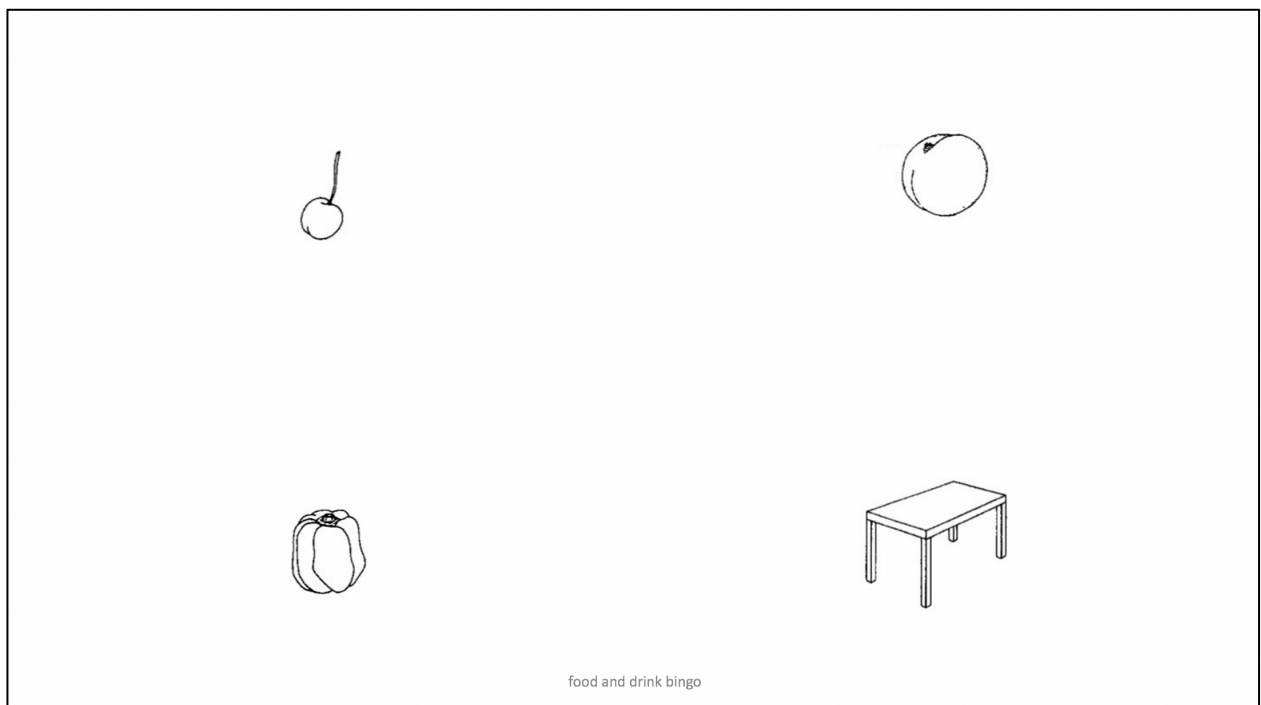
Bingo cards

Food and drink

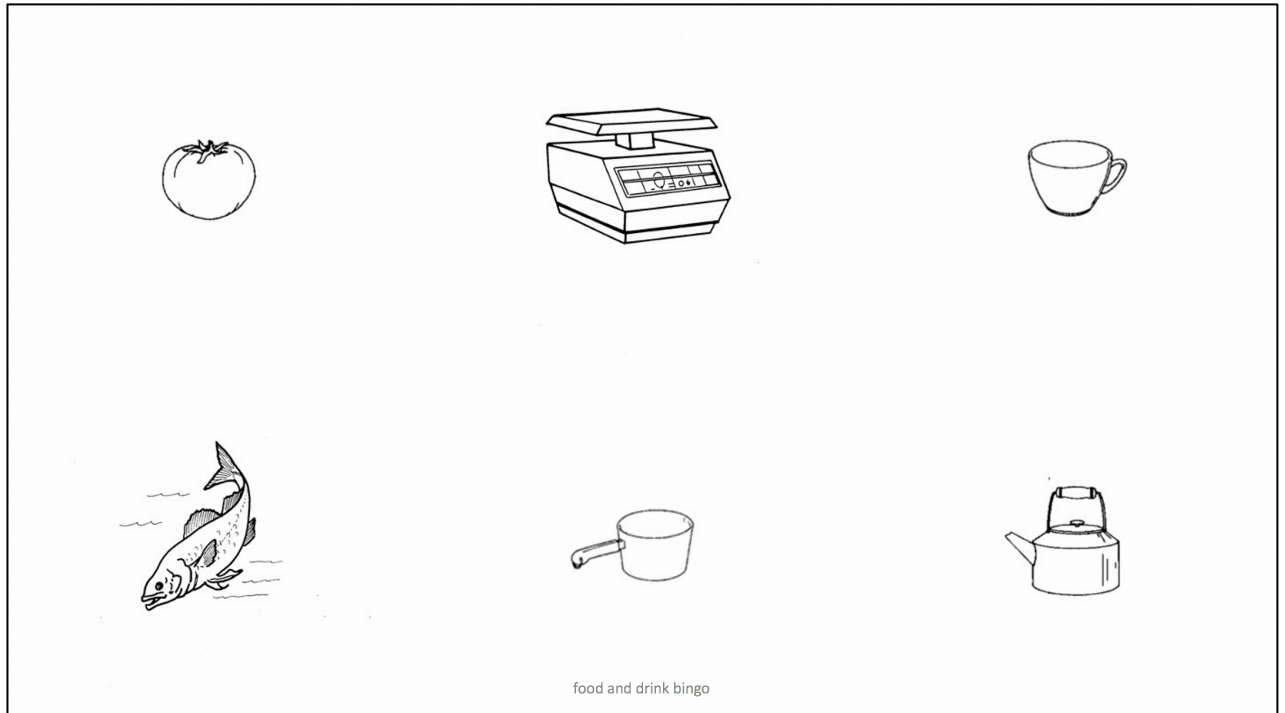
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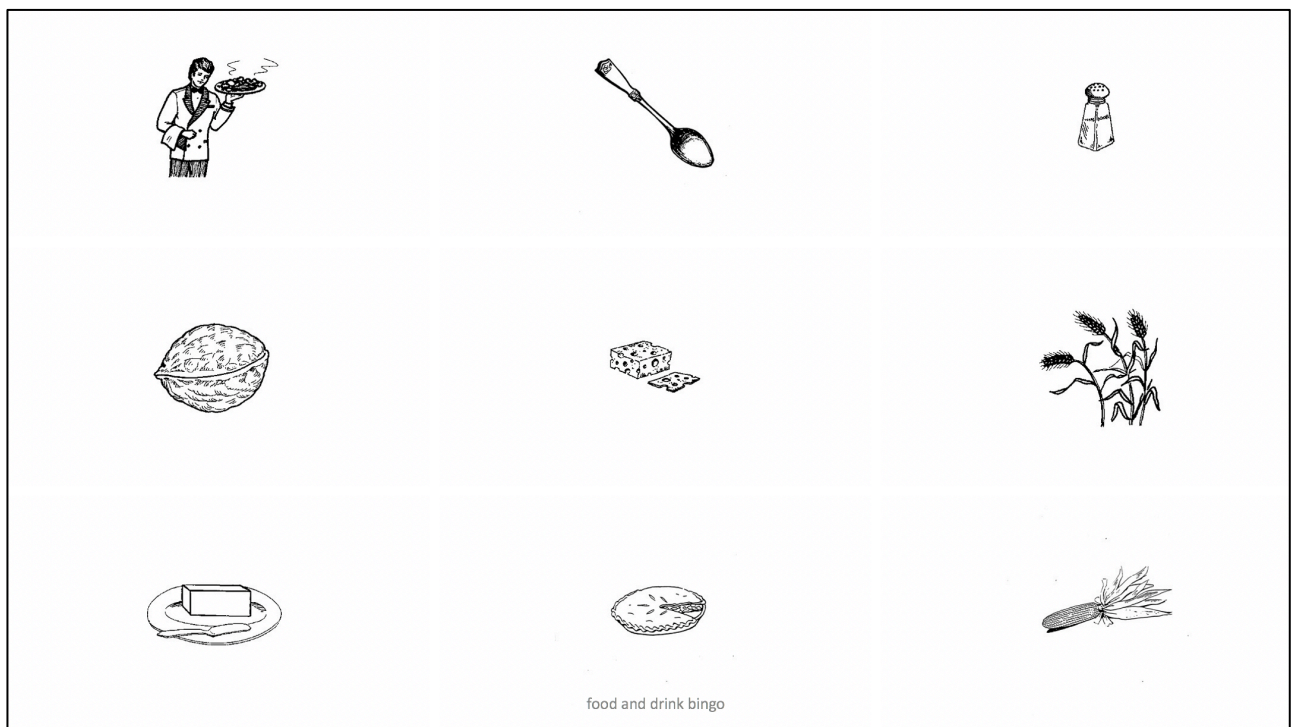
2.



3.



4.

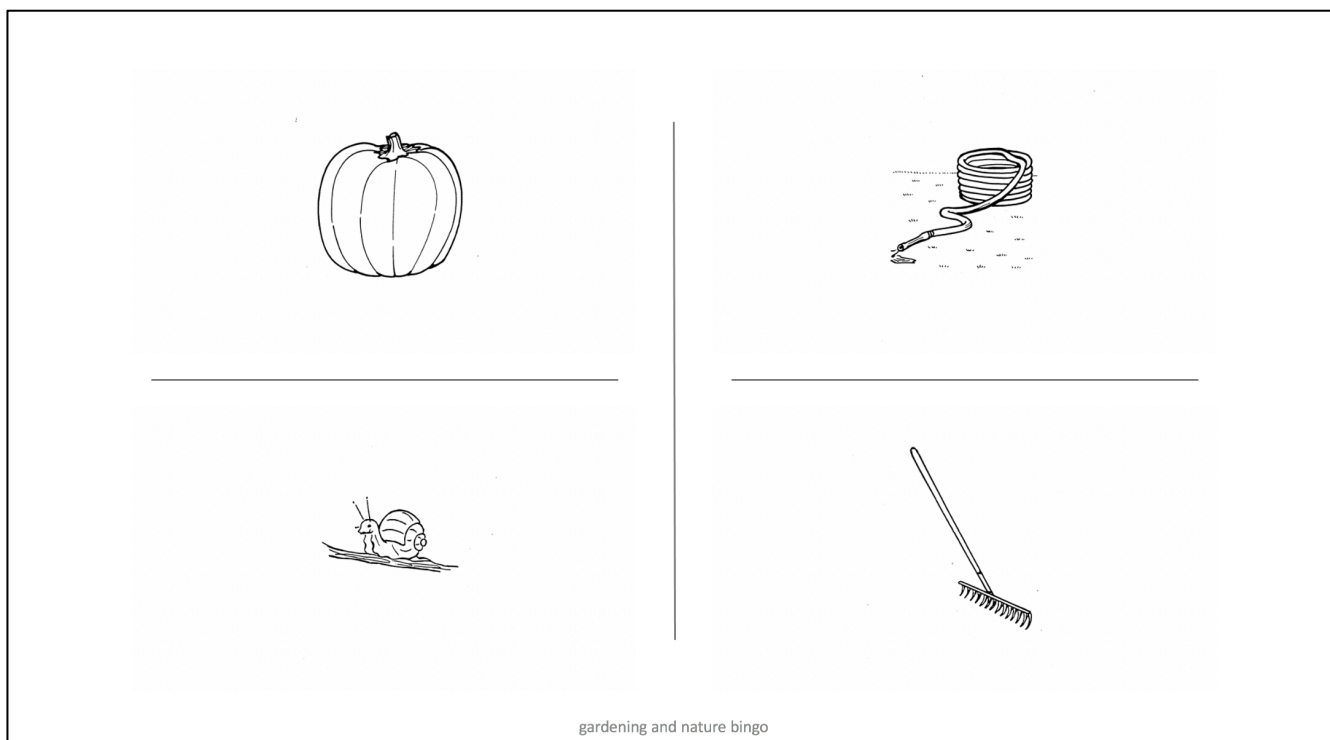


5.



Nature and gardening

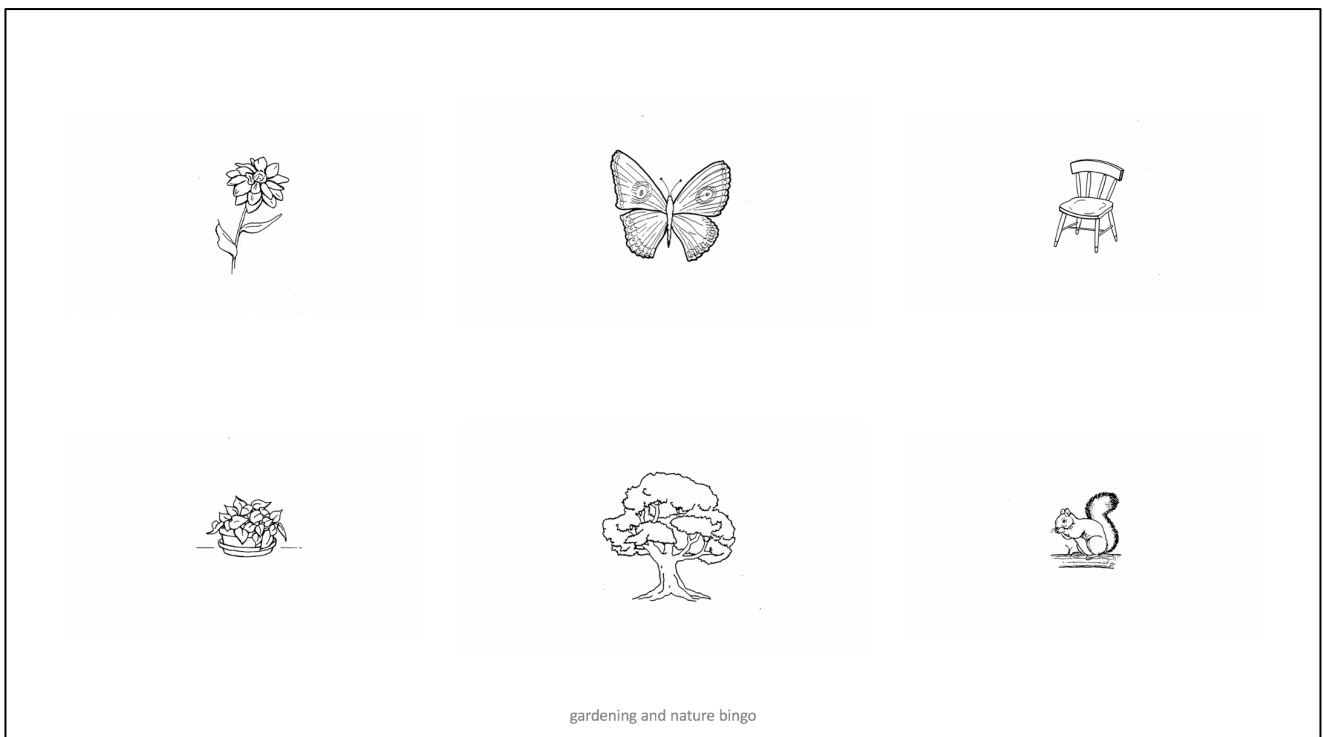
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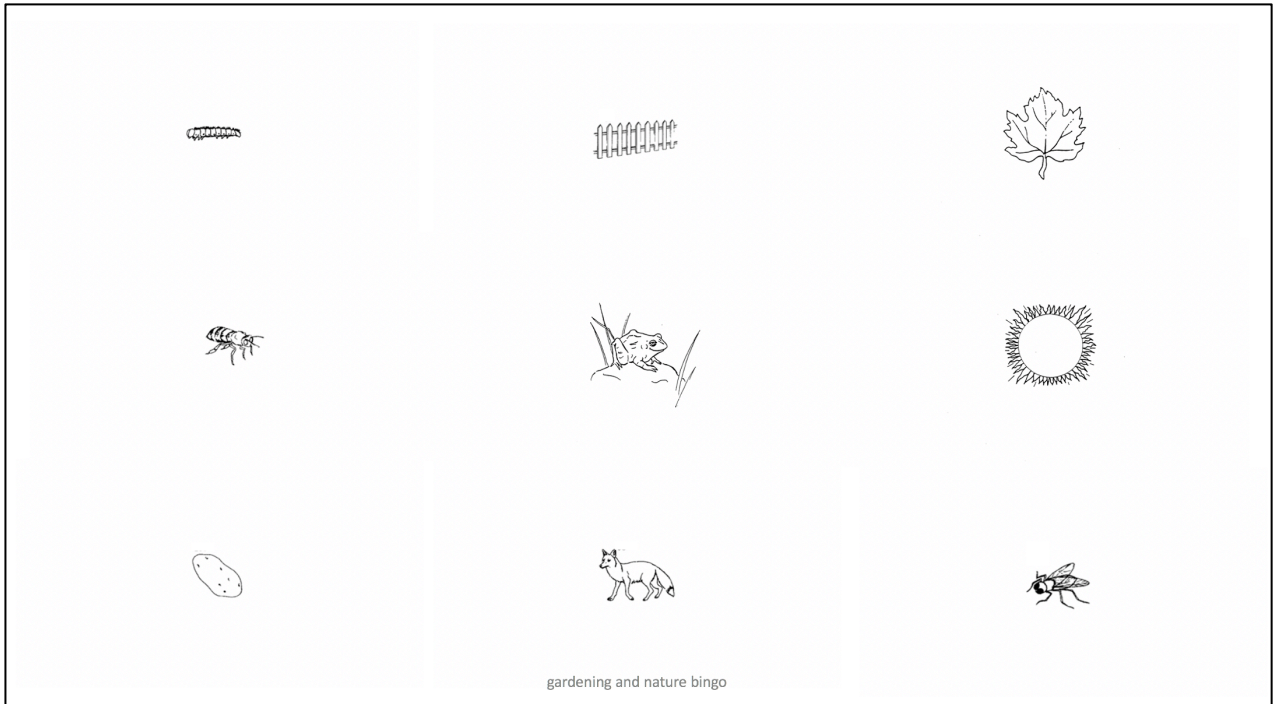
2.



3.



4.

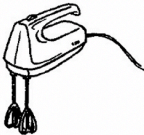


5.



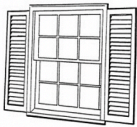
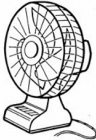
Daily Living

1.

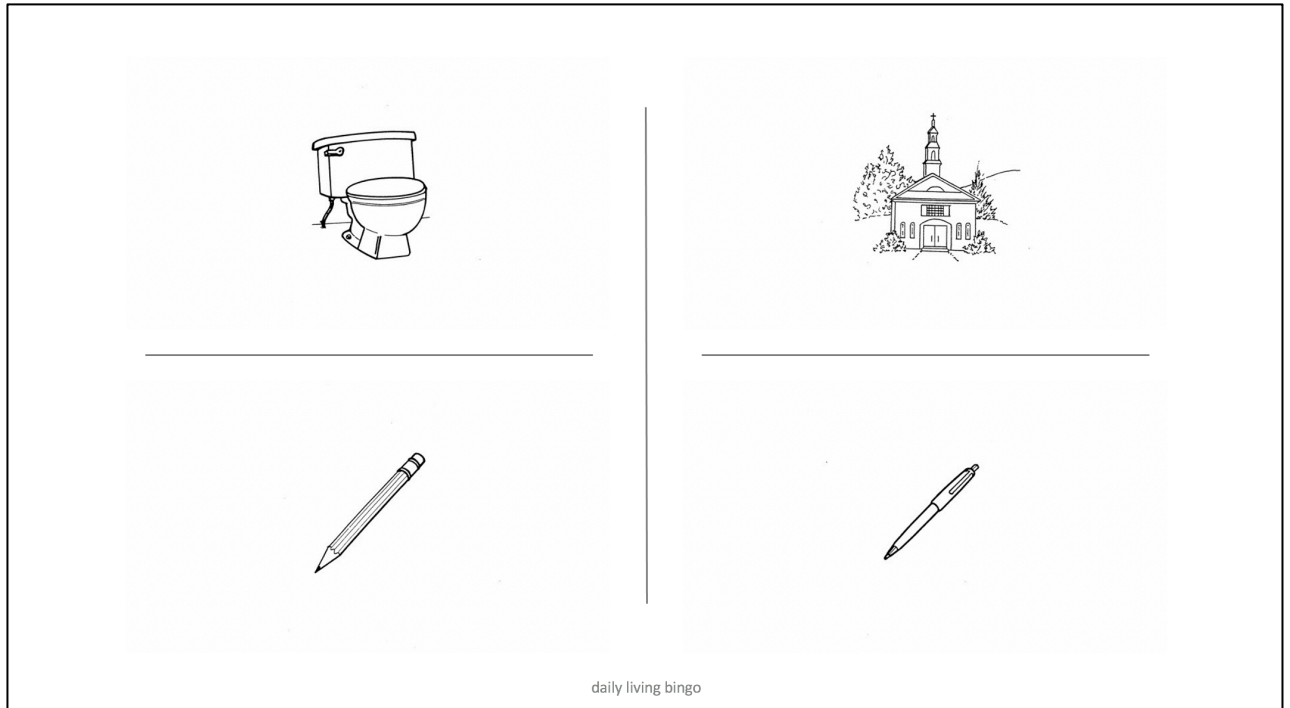
daily living bingo

2.

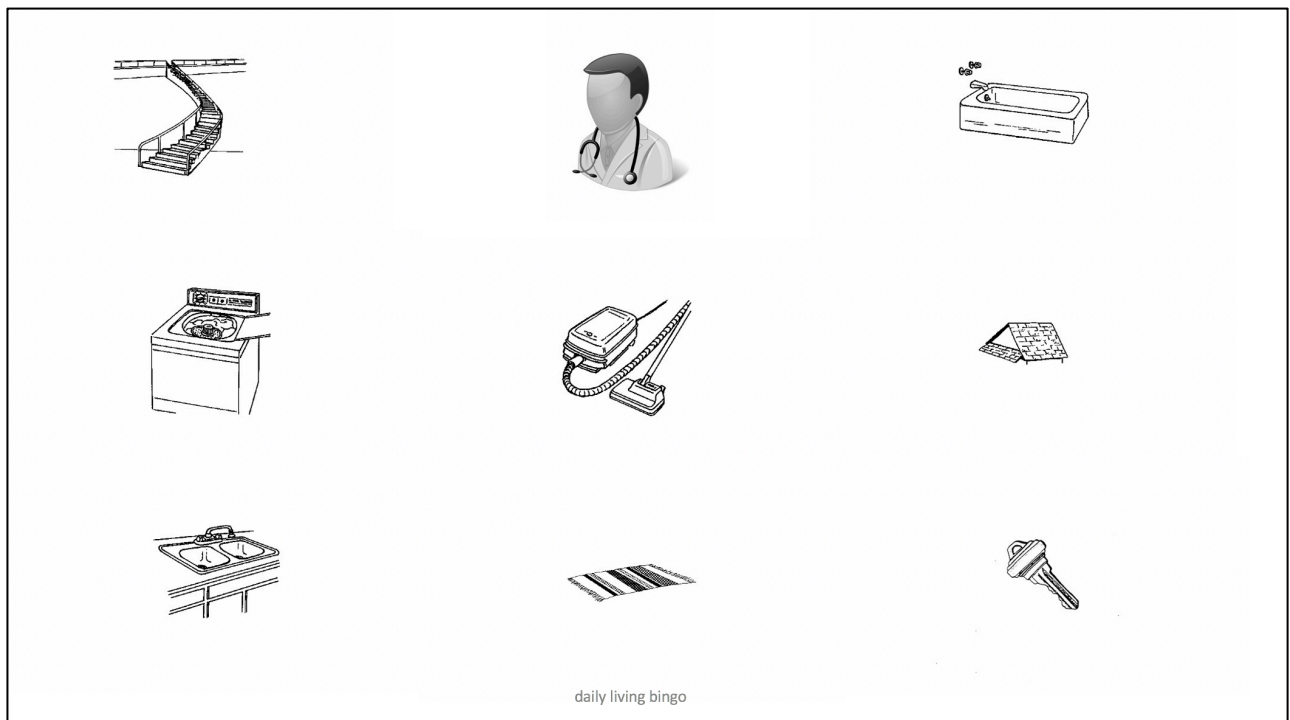
 	
 	

daily living bingo

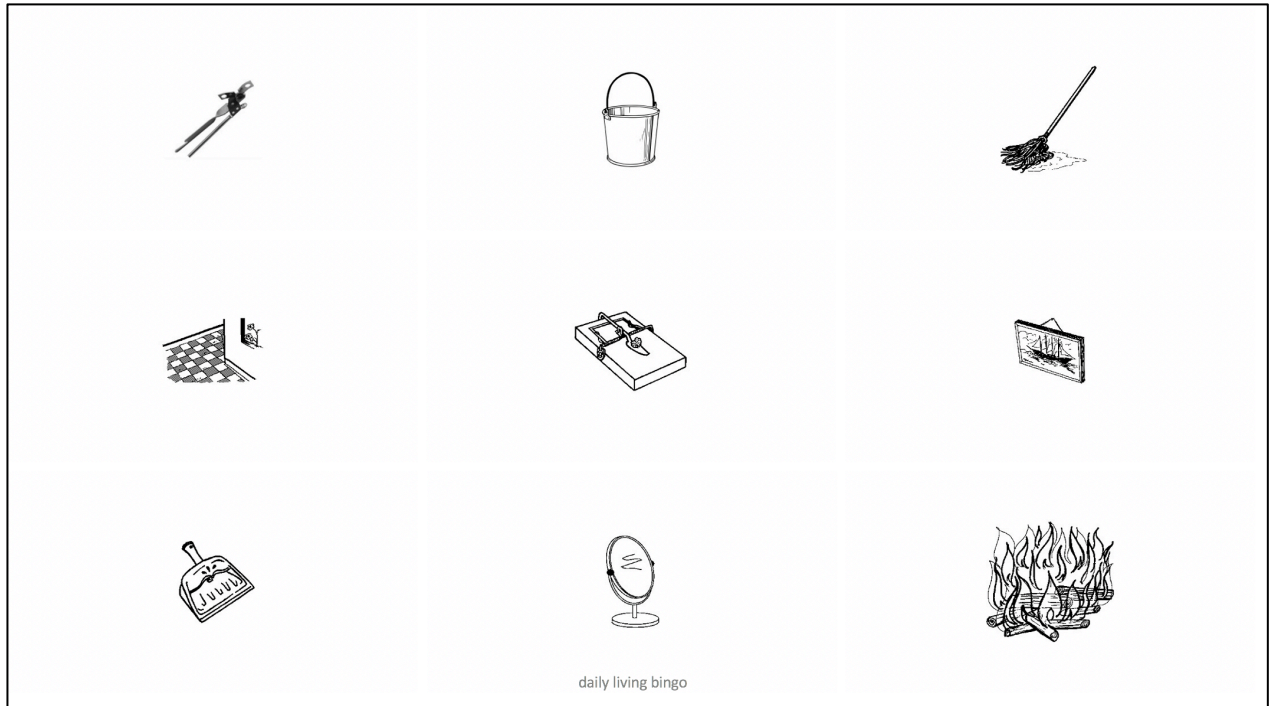
3.



4.

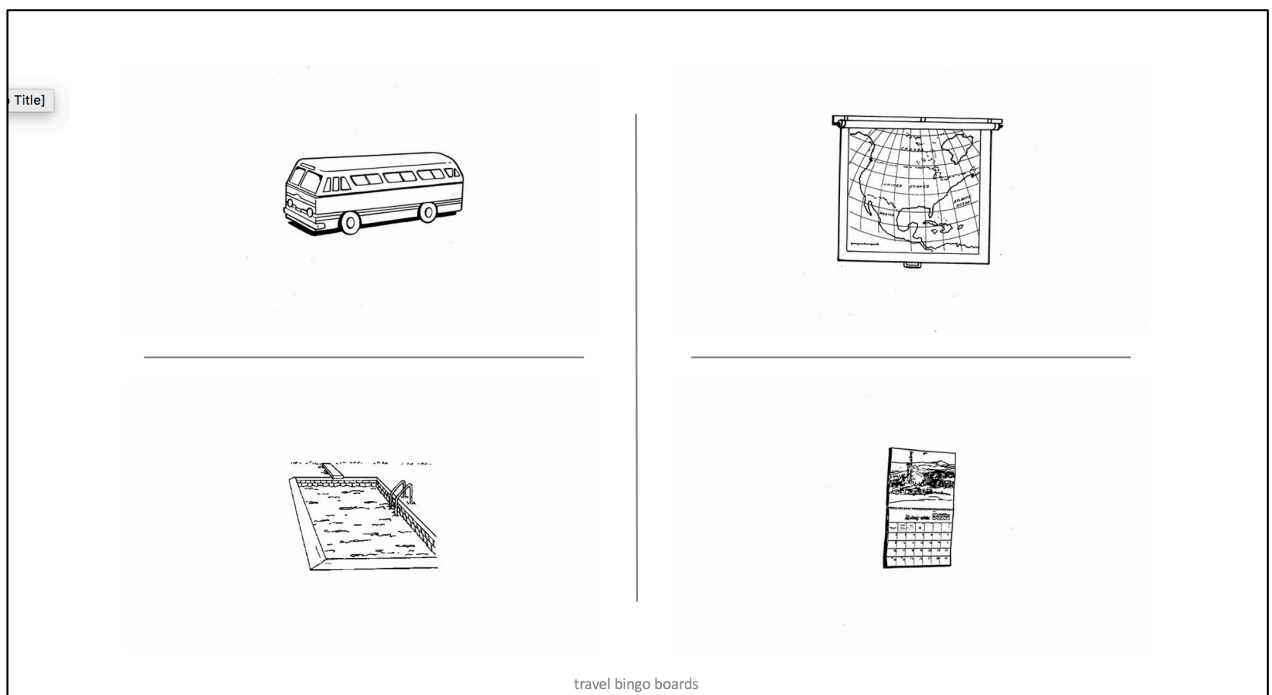


5.

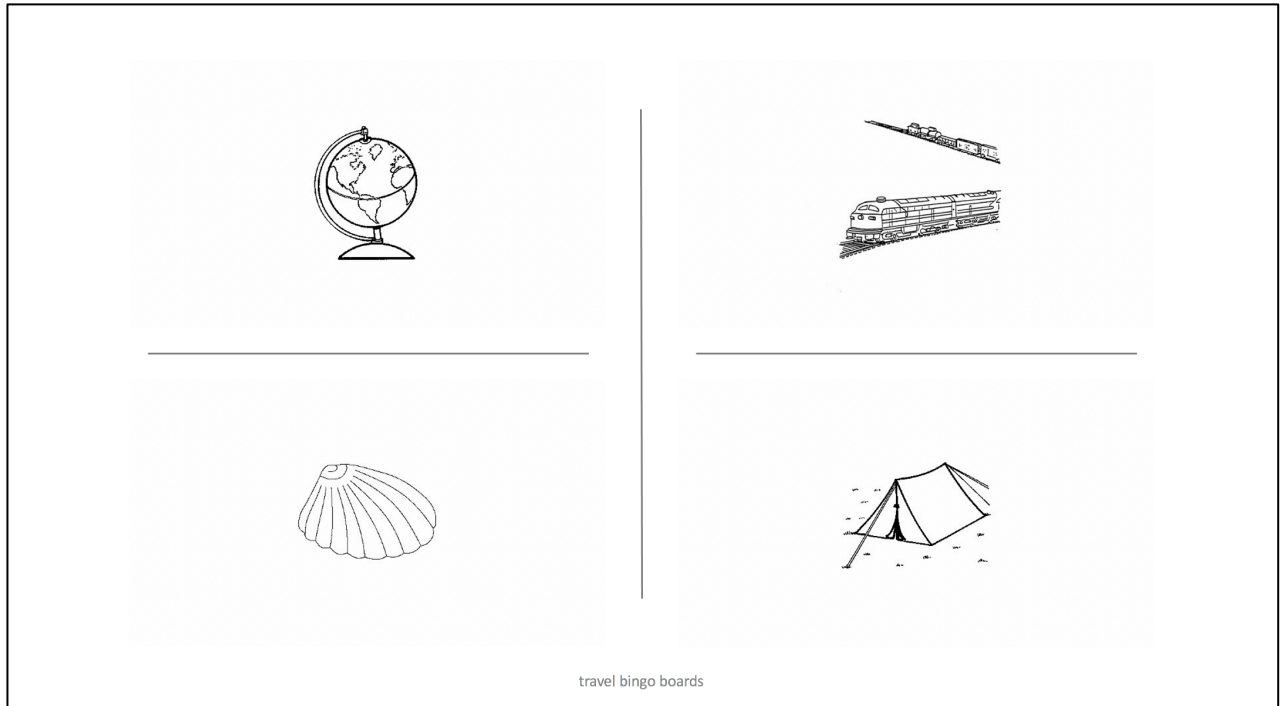


Travel

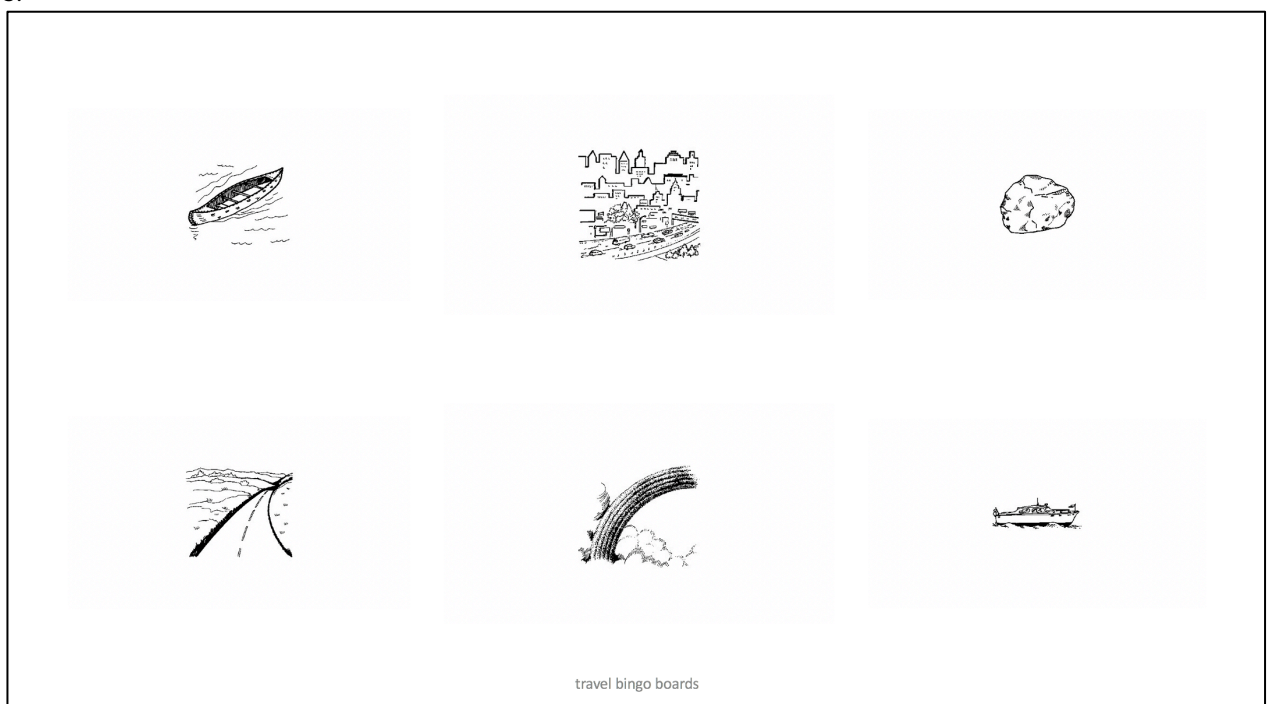
1.



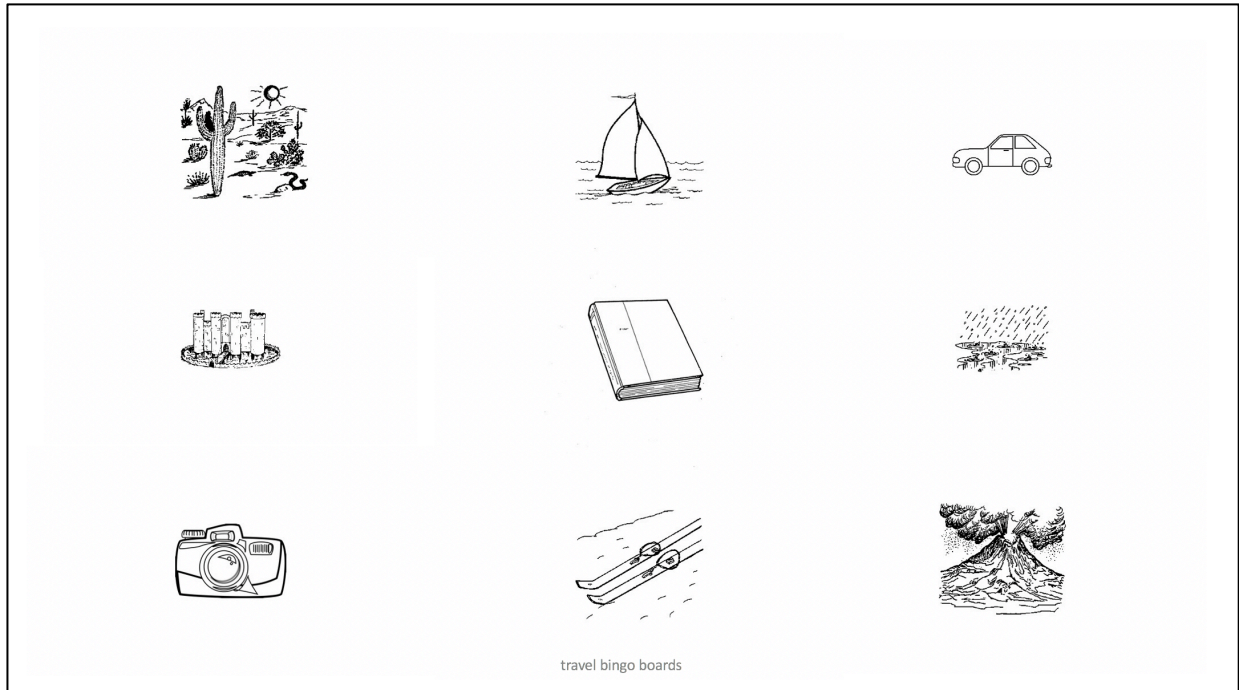
2.



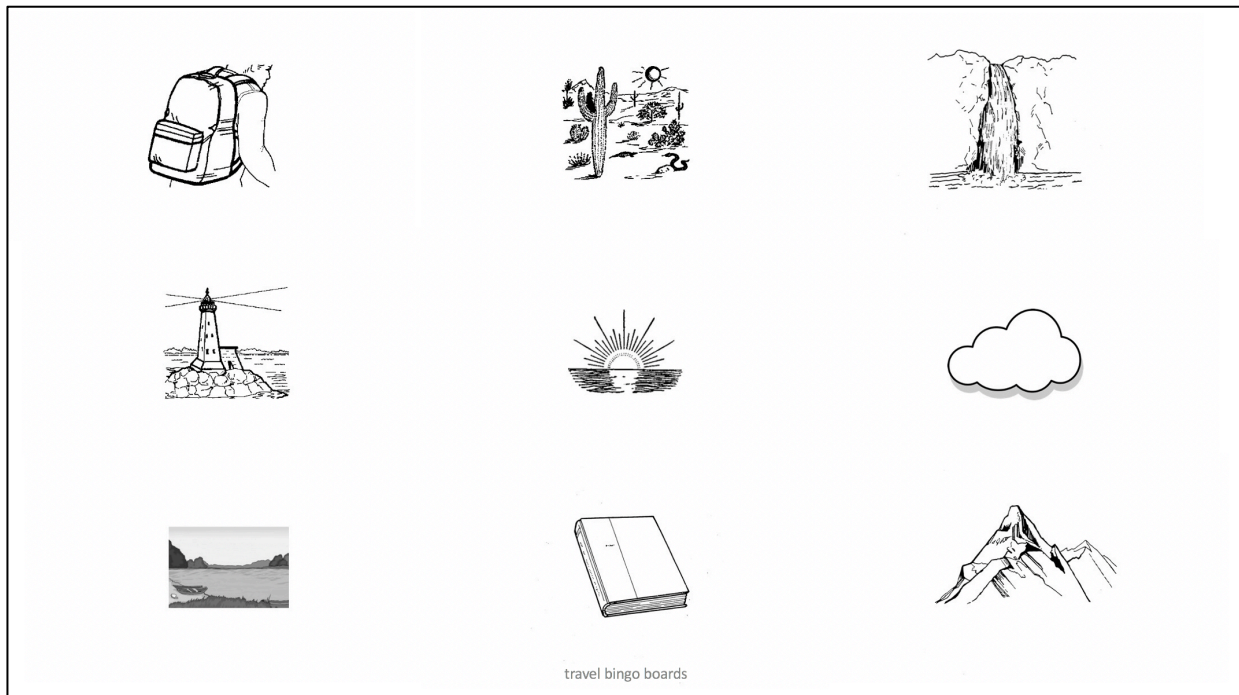
3.



4.



5.



NAVIGATION

You access EVA Park from a laptop or a computer. Niamh will set up the software.

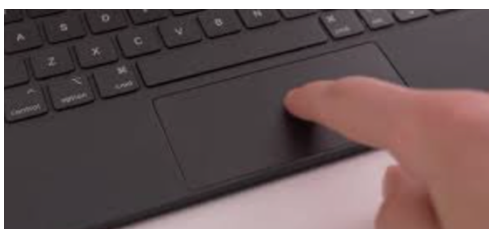


You will use the **mouse** or **trackpad** to move the **cursor** to click on the screen to navigate

Mouse



Trackpad



Cursor



Walk



To move around EVA Park click on the **walk** button

This opens the **move menu** onto your screen



Place your cursor on an arrow and hold down to navigate

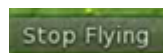
Press **↑** to walk **forward**,
← to turn **left**,
and **→** to turn **right**

Click on the man image to select **walk** , **run**  or **fly** 



Use these broken arrows to
Fly **up**
Fly **down**

To stop flying you can also press **stop flying**



View



To change your view, click on the **eye** button

This opens up the **view menu** on your screen



The arrows will change your viewpoint
left circle = swivel
middle control = zoom
right square = directional

If you want to **return** to the normal view just behind your avatars head press **escape**



You can change the direction your avatar faces by clicking on the top left icons



Facing you Side view Facing away

Sit

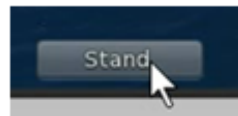


To **sit down** hover your cursor  over the sit ball

until you see a **chair image**

Then **press** to sit

Click **stand** to stand up



Teleporting



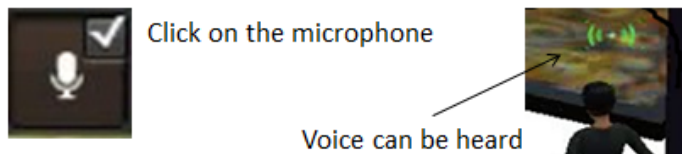
- Click on a picture on the teleport board and it takes you there
- You can also double click using the mouse on a piece of land to teleport there.
- You can also click on an area of [the map](#) to teleport there.
- You can also find a person in the [person list](#) and click their name to teleport to them (see below).

AUDIO SETTINGS

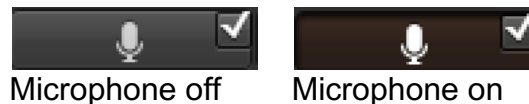
Turn your microphone on

Every time you log into EVA Park you need to turn your microphone on:

VOICE



- The check box in the corner has to be selected **AND** the button must be pressed.
- The button turns *from grey to brown* when switched on. It's a very small difference:

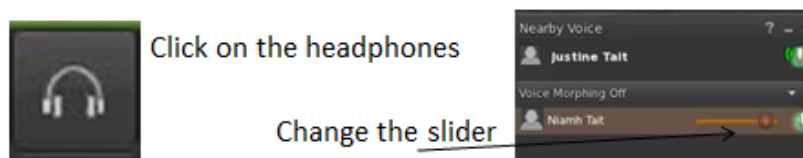


Volume

Use the **volume button** to see who in-world has their microphones on (flashing green).

You can then modify their volume using the slider. Up if you cannot hear them. Down if you are getting feedback, crackle or clipping noises.

VOLUME



If you continue to experience sound problems, try logging out, then logging back into EVA Park.

If all else fails, try turning both computers off, then on again and log back into EVA Park.

USEFUL TIPS

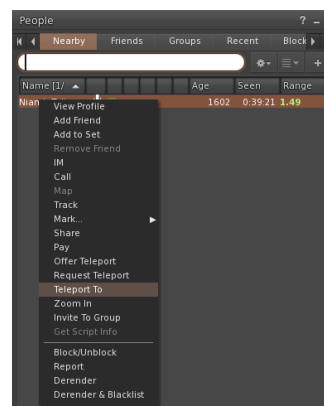
Finding people easily and teleporting to them

- Press the 'People' button, this will give you a list of the people who are in EVA Park.



- It shows basic information like whether the person has their microphone on (green halo)

- Right click on the avatar's name and a drop down menu will appear. Click on 'teleport to' to be taken to them.



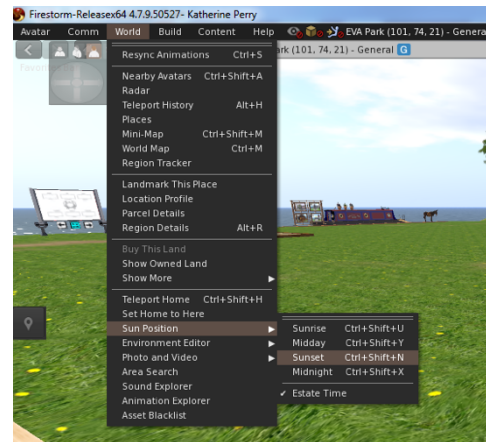
Using the mini-map

- Press the 'Mini-map' button.
- This will show you a simple map of the island
- Green dots represent **other** avatars
- The purple dot is **your** avatar.
- Double click on an area of the map to Teleport directly there.



Changing the sun position

- Click on the 'World' menu
- Click on 'Sun position'
- Choose from:
 - Sunrise
 - Midday
 - Sunset
 - Midnight



CONTACT DETAILS



Niamh Devane ☎ 020 70408821 | 07771 896662

Appendix 19 | The VESFA Naming Test record form

VESFA NAMING TEST

Participant: _____

Date: _____

Tester: _____

ITEM	WORD	RESPONSE	SCORE
<i>Practice</i>			
P1	peas		
P2	waitress		
P3	candle		
<i>Test</i>			
1	tent		
2	rug		
3	washing machine		
4	priest		
5	mountain		
6	potato		
7	boot (accept welly)		
8	tree		
9	mirror		
10	stairs		
11	scale		
12	fly		
13	sink		
14	backpack (accept rucksack)		
15	mop		
16	cup		
17	cherry		
18	can opener		
19	cheese		
20	globe		
21	bowl		
22	curtains		
23	calendar		
24	cabbage		
25	pencil		
26	peach		

27	frog		
28	fence		
29	canoe		
30	bathtub		
31	tomato		
32	toilet		
33	watering can		
34	walnut		
35	salt		
36	fish		
37	squirrel		
38	chair		
39	doctor		
40	table		
41	kettle		
42	caterpillar		
43	castle		
44	skis		
45	fire		
46	rain		
47	butterfly		
48	carrot		
49	fox		
50	pie		
51	ant		
52	flower		
53	volcano		
54	pineapple		
55	key		
56	picture (accept painting)		
57	fan		
58	train		
59	owl		
60	rainbow		
61	lake		
62	pumpkin		
63	asparagus		
64	iron		
65	city		
66	basket		
67	swing		
68	floor		

69	spoon		
70	frying pan		
71	church		
72	bee		
73	can (accept tin)		
74	boat		
75	window		
76	fork		
77	pepper		
78	bus		
79	bench		
80	corn		
81	egg		
82	spider		
83	bucket (accept pail)		
84	shell		
85	plant		
86	road		
87	vacuum (accept Hoover)		
88	bird		
89	butter		
90	wheat		
91	hose		
92	waiter		
93	glass		
94	car		
95	sunset		
96	desert		
97	pen		
98	pool		
99	leaf		
100	lamp		
101	mixer		
102	cloud		
103	camera		
104	sailboat (accept yacht)		
105	rake		
106	snail		
107	waterfall		
108	rock		
109	plate		

110	mousetrap		
111	sandwich		
112	sun		
113	roof		
114	dustpan		
115	octopus		
116	pot (accept saucepan)		
117	lighthouse		
118	book		
119	map		
120	daffodil		

KEY: ✓=correct, SC=self correction, S=semantic, M=mixed/phonological & semantic, U=unrelated,

N=nonwords related phonologically, F=real words related phonologically

P=perseveration*, D=description, NR=no response, Misc= miscellaneous

Misc=miscellaneous (blends, nonwords that are unrelated phonologically, picture parts)

SCORE: 2= ✓, 1= SC, 0=all others

Guidance notes:

Perseveration: If the participant has produced the same production for 3 items pause the test. Stop and chat about something unrelated for a few minutes and then return to the test.

Discontinue: If the participant has failed to produce either the target or a close error for 15 consecutive items you can discontinue.

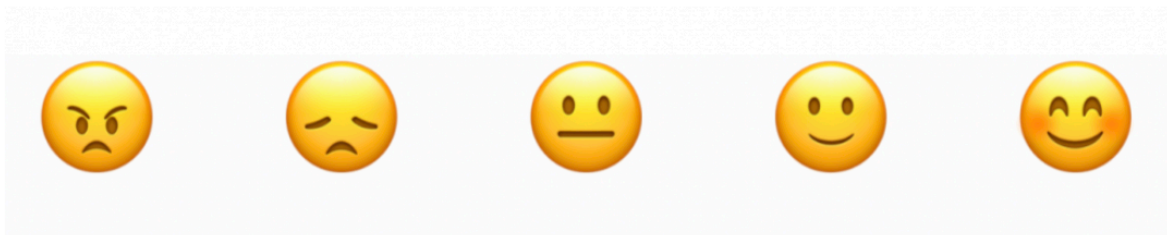
Appendix 20 | Post Therapy Interview

VESFA | After Therapy Interview

Participant number:

The first set of questions ask about **setting things up** in EVA Park

Q1. How did you find **setting up** EVA Park on your computer?



Very difficult

☐

Difficult

☐

So-so

☐

Easy

☐

Very easy

☐

Comments about set up:

Q2. How did you find **logging in** to EVA Park?

				
Very difficult ☐	Difficult ☐	So-so ☐	Easy ☐	Very easy ☐

Comments about logging in:

Q3. How did you find **moving your avatar** around the EVA Park island?

				
Very difficult ☐	Difficult ☐	So-so ☐	Easy ☐	Very easy ☐

Did you move your avatar without help?

	
Yes ☐	No ☐

Comments about moving your avatar:

The next set of questions are about the **therapy**

Q4. How did you find the **number of sessions per week**?











Very dissatisfied

Dissatisfied

So-so

Satisfied

Very satisfied

☐

☐

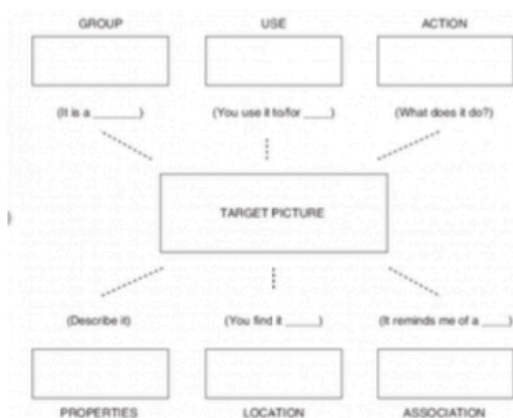
☐

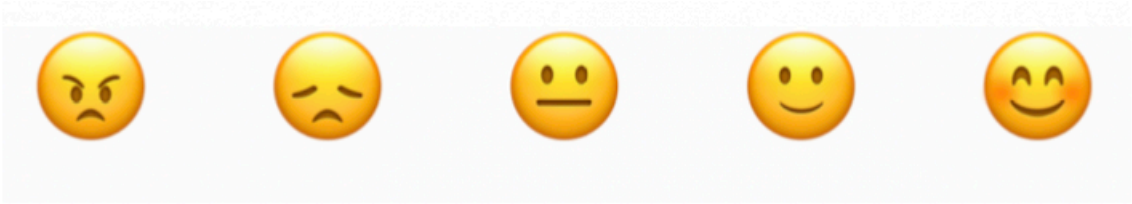
☐

☐

Comments on number of sessions:

Q5. How did you find the **1:1 sessions** at the boards?





Very dissatisfied
☐

Dissatisfied
☐

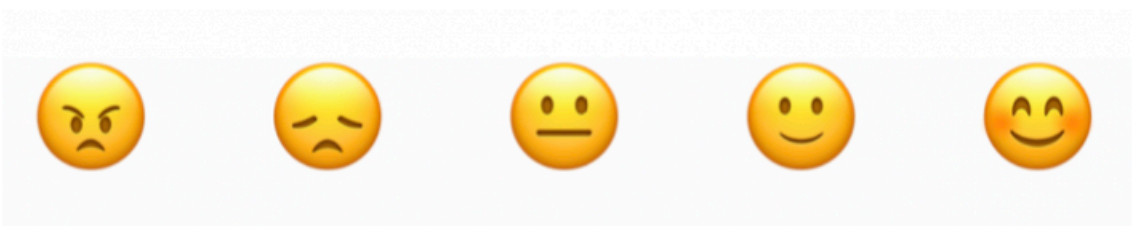
So-so
☐

Satisfied
☐

Very satisfied
☐

Comments about 1:1 sessions:

Q6. How did you find the **groups**?



Very dissatisfied
☐

Dissatisfied
☐

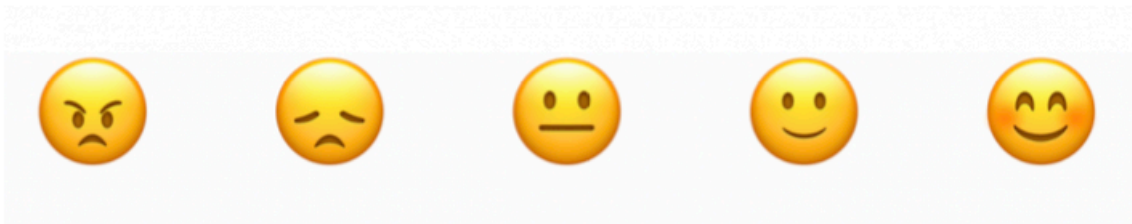
So-so
☐

Satisfied
☐

Very satisfied
☐

Comments about the groups:

Q7. Was the therapy a good **challenge**?



Too easy or too
difficult

☐☐

Some tasks at the
right level

☐☐

At the right level

☐

Comments:

What elements were challenging - word finding, speaking in conversations, role play?

What supported you to achieve the challenge?

Q8. How did you find the **therapy** overall?

				
Hated it	Didn't like	So-so	Liked	Really liked
☐	☐	☐	☐	☐

Comments about the therapy:

What things did you particularly **like**?

What things did you particularly **dislike**?

Q9. How did you find receiving therapy **online in EVA Park**?

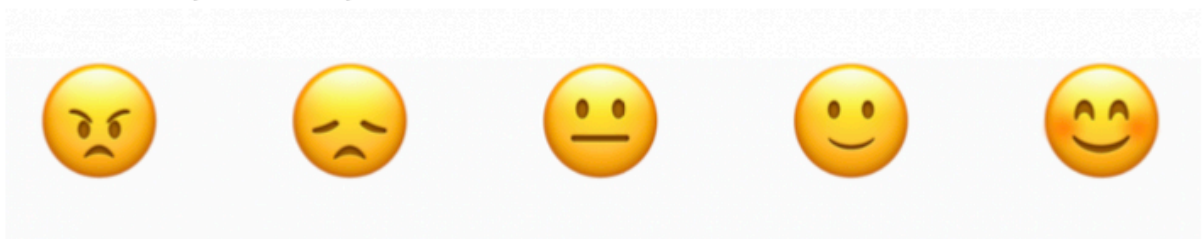
				
Hated it	Didn't like	So-so	Liked	Really liked
☐	☐	☐	☐	☐

Comments about online delivery:

What things did you particularly **liked** about EVA Park?

What things did you particularly **dislike** about EVA Park?

Q10. What did you think of your **avatar**?



Hated it
☐

Didn't like
☐

So-so
☐

Liked
☐

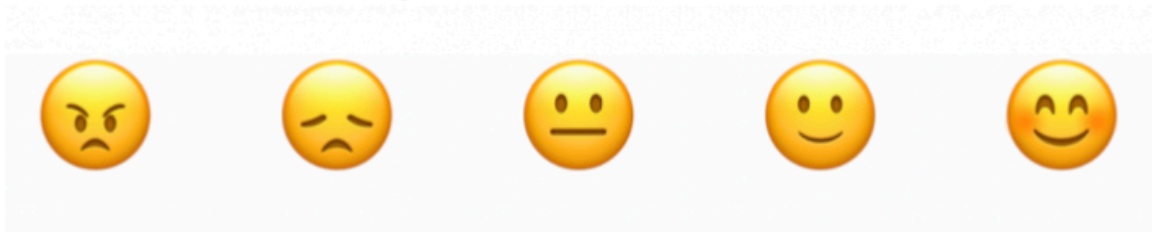
Really liked
☐

Comments about the avatar:

Testing

The next set of questions are about the **testing sessions**

Q11. How did you find the **testing sessions**?



Hated them
☐

Didn't like
☐

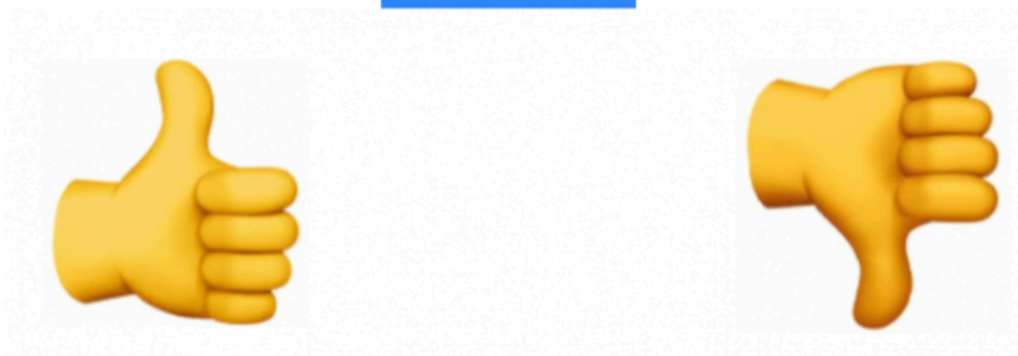
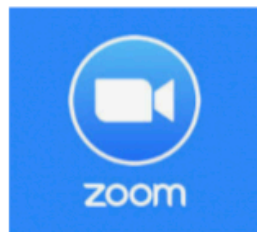
So-so
☐

Liked
☐

Really liked
☐

Comments on testing sessions:

Q12. Did you **use zoom** *without* help?

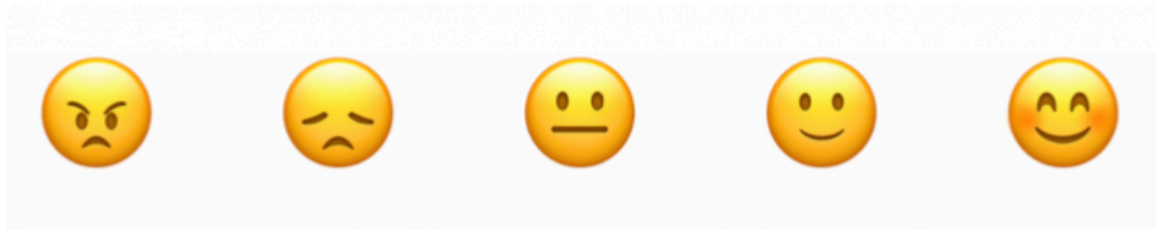


Yes
☐

No
☐

Comments on support needed:

Q13. How was the **amount** of testing?



Extremely
challenging
☐

Very challenging
☐

Challenging
☐

Slightly
challenging
☐

Not at all
☐

Comments on amount of testing:

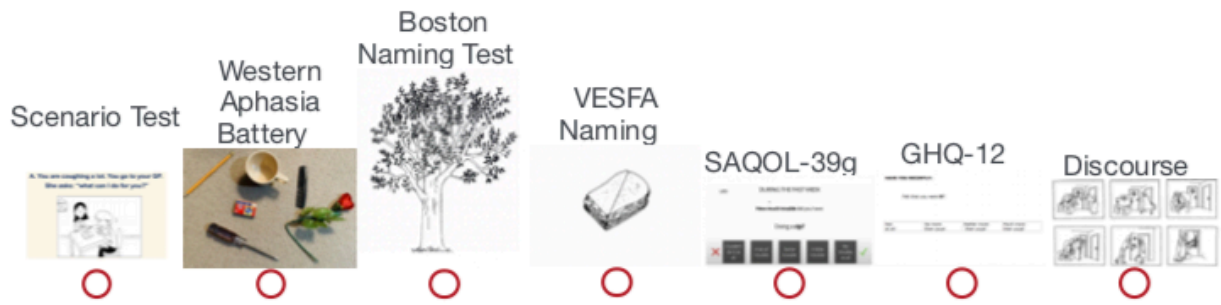
Q14. Were any of the tests problematic?



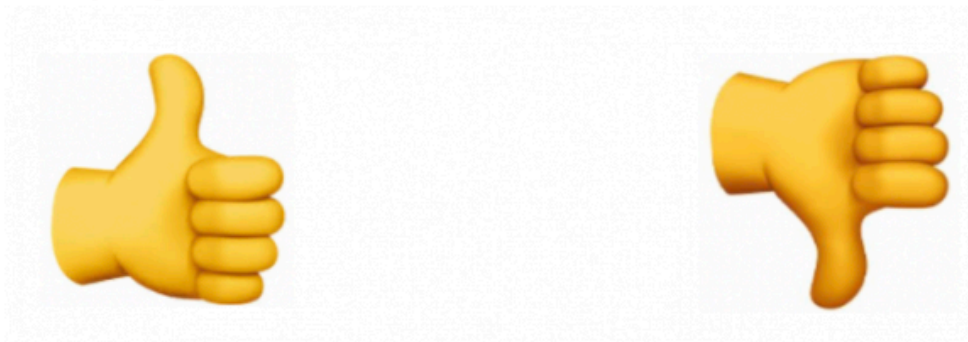
Yes
☐

No
☐

If yes, please tell us:



Q15. Is there anything the testers could do **differently**?



Yes
☐

No
☐

Comments:

For example, give more time, have more breaks, break up into more sessions.

Impact

The last set of questions are about the **outcomes** of the therapy

Q16. Was there anything you were **pleased to notice**?

Q17. Have you **used** the words and phrases practiced in EVA Park in **real world conversations**?

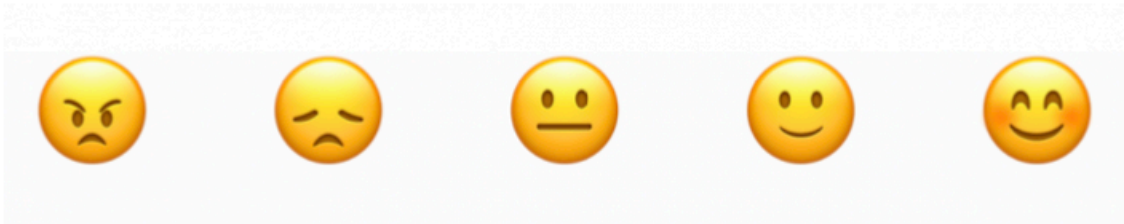


Yes
☐

No
☐

Comments about words practiced:

Q18. I noticed a change to my **talking in the real world**



Strongly disagree
☐

Disagree
☐

Neither agree nor disagree
☐

Agree
☐

Strongly agree
☐

What changes have you noticed in real world communication?

Q19. I noticed a change in how I **use technology**



Strongly disagree
☐

Disagree
☐

Neither agree nor
disagree
☐

Agree
☐

Strongly agree
☐

What changes have you noticed in technology use?

Q20. I noticed a change in my **mood**



Strongly disagree
☐

Disagree
☐

Neither agree nor
disagree
☐

Agree
☐

Strongly agree
☐

What changes have you noticed in mood?

Q21. Did your **family or friends notice** any change?



Yes
☐

No
☐

What changes did they notice?

close

Q22. Is there anything else you would like to tell us?

Q23. Would you **recommend** this project to other people with aphasia?



Yes
☐

No
☐

Appendix 21 | Usual Care Questionnaire

Thank you for responding to this survey. It will take approx. 5mins-10mins

We will ask you about two things:

1. We would like to know how you **experienced the VESFA study**.
2. We would like to know what **services you received** during the VESFA study.

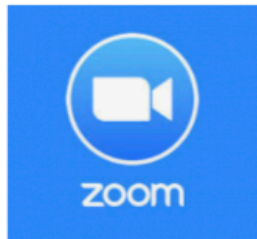
The next set of questions are about the **testing sessions**

Q1. How did you find the **testing sessions**?

				
Hated them	Didn't like	So-so	Liked	Really liked
☐	☐	☐	☐	☐

Comments on testing sessions:

Q2. Did you **use zoom** *without* help?



Yes
☐



No
☐

Comments on support needed:

Q3. How was the **amount** of testing?



Extremely

Very challenging

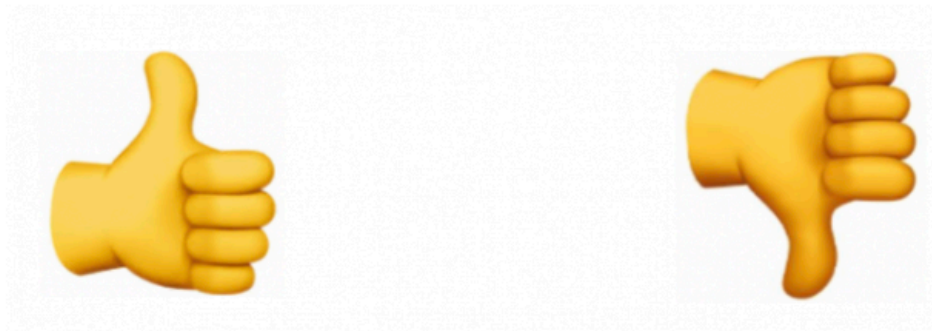
Challenging

Slightly

Not at all

Comments on amount of testing:

Q4. Were any of the tests problematic?



Yes
☐

No
☐

Please tell us which ones:

Scenario Test	Western Aphasia Battery	Boston Naming Test	VESFA Naming	SAQOL-39g	GHQ-12	Discourse
						
☐	☐	☐	☐	☐	☐	☐

Q5. Is there anything the testers could do **differently**?



Yes
☐

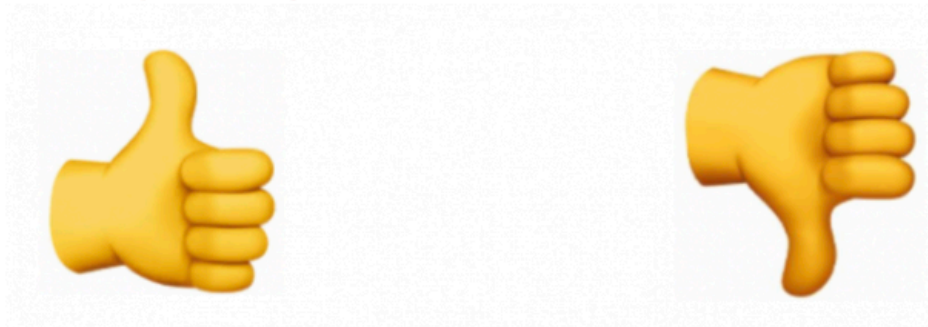
No
☐

Comments:

For example, give more time, have more breaks, break up into more sessions.

The next set of questions are about what **services you received** during the study

Q7. During the VESFA study,
did you spend any time living in a **residential or nursing care** home?



Yes
☐

No
☐

How many nights did you stay there?

Q8. During the VESFA study,
did you stay in **hospital overnight** because of any illness/injury?



Yes
☐



No
☐

Please tell us more about this

Reason for hospital stay

Number of nights

Q9. During the VESFA study,
did you have any **hospital treatment as a day patient** because of any illness/injury



Yes
☐



No
☐

Please tell us more about this

Reason

Speciality of ward

Full day or half day?

Q10. During the VESFA study
did you visit hospital for **outpatient appointments** (to see a doctor or for a test)
because of any illness/injury?



Yes
☐



No
☐

Please tell us more about this:

Reason

Department

Number of appointments

Q11. During the VESFA study,
did you visit **A&E** because of any illness/injury?



Yes
☐



No
☐

How many times?

Q12. During the VESFA study,
did you use:

- ☐ Speech therapy
- ☐ Physiotherapy
- ☐ Occupational therapy
- ☐ Your GP surgery
- ☐ Social services e.g. meals on wheels / carer

Q13. During the VESFA study,
did *anyone living with you* (e.g. spouse, partner, other relative or friend) give **more help than normal**?

Personal care	Shopping
Providing transport	Taking you for outings
Preparing meals	Socialising / companionship / emotional support
Housework / laundry	Help managing finances e.g. paying bills, collecting benefits
DIY	Technical support
Gardening	



Yes
☐



No
☐

Q14. During the VESFA study,
did any non-professional *who does not live with you* (e.g. other relative or friend) give **more help than normal**?

Personal care	Shopping
Providing transport	Taking you for outings
Preparing meals	Socialising / companionship / emotional support
Housework / laundry	Help managing finances e.g. paying bills, collecting benefits
DIY	Technical support
Gardening	



Yes
☐



No
☐

Q15. During the VESFA study,
did you attend any **voluntary services** or **stroke groups** or have **someone visit**
you regularly?



Yes
☐



No
☐

Please tell us more about this:

Stroke Group

Volunteering

Other

Would you recommend this study to other people with aphasia?

Comments:

Is there anything else you would like to tell us?
