Receiving Aphasia Intervention in a Virtual Environment:

The Participants’ Perspective

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Abstract

Background: Digital technology is making an increasing contribution to aphasia therapy. However applications of virtual reality are rare. EVA Park is a virtual island developed with and for people with aphasia. It is a multi-user environment, which enables people with aphasia to interact with support workers, therapists and each other. The first study to use EVA Park in aphasia rehabilitation demonstrated significant gains in functional communication. This paper augments the findings of that study, by reporting results from qualitative interviews conducted with the 20 study participants.

Aims: This study aimed to determine the views of participants about the intervention that they received in EVA Park, and the impacts of that intervention. Long-term retrospective views were also explored.

Methods & Procedures: Participants took part in 1:1, semi-structured interviews two weeks before (Entry) and to weeks after (Exit) the intervention. Questions focussed on activities undertaken by participants, communication, changes since the stroke and uses of technology. Exit interviews additionally explored participants’ views and experiences of EVA Park and any perceived impacts of the intervention. A sub-set of 5 participants was interviewed at least one year later, to explore long term recollections of the EVA Park intervention and any perceived long term impacts. Interview data were transcribed and subject to framework analysis.

Outcomes & Results: The thematic framework comprised 10 parent themes and 33 sub-themes. Following ‘affect’, the largest single theme related to EVA Park, with 636 coded references. Comments were overwhelmingly positive. EVA Park intervention was strongly
associated with fun and enjoyment. Participants particularly valued their relationship with the support workers who delivered the intervention. The virtual locations and activities in EVA Park were also appreciated, together with the contact with other participants. Perceived impacts related to communication, activity, computer use and confidence. Most (4) participants in the long term interviews described maintained impacts.

Conclusions: These interview results indicate that the first intervention delivered in EVA Park was highly acceptable to participants and perceived as beneficial. They augment the findings of our experimental study and suggest that EVA Park could be a valuable addition to the resources available to practising clinicians.

Key words: aphasia, therapy, participant perspectives, virtual reality

Introduction

Evaluations of new aphasia interventions should do more than simply explore change on outcome measures. They should also examine the views of those who receive the intervention, e.g. to ensure that the treatment is acceptable and perceived as valuable (Tomkins, Siyambalapitiya & Worrall, 2013). Recipients’ opinions are particularly relevant when new modes of delivery, such as computer interventions, are being tested. Evidence is needed that computer tools are easy to use and, ideally, enjoyable. Minimal adverse side effects, e.g. in the form of fatigue, should also be demonstrated. Studies that have interviewed people with aphasia about previous computer interventions have largely produced such findings (Cherney, Halper & Kaye, 2011; Kelly, Kennedy, Britton, McGuire & Law, 2016; Wade, Mortley & Enderby, 2003; True, Bartlett, Fink, Linebarger, & Schwartz, 2010; Palmer, Enderby & Paterson, 2013), although a range of views, e.g. about
the comparative merits of computer vs face to face therapy, are also represented (Palmer et al, 2013).

User opinion should not just demonstrate acceptability, but also validate any changes identified in testing. For example, if formal testing shows that the intervention brought about significant gains in communication, this should be reflected in the comments of users. Changes in test scores that are not so validated may be of questionable clinical relevance. Areas that are difficult to test may also be illuminated by user opinion. For example, stroke survivors often report negative emotional consequences of aphasia, such as loss of confidence (Lynch, Butt, Heinemann, Victorson, Nowinski, Perez, et al, 2008) and feelings of social isolation (Parr, 2007). While there are tools to measure these constructs (Babbitt, Heinemann, Semik, & Cherney, 2011; Hawthorne, 2006), they may not fully capture an individual’s experience. Exploring user views may reveal changes that are perceived by participants, even if those changes are undetected by the measures used to assess them.

EVA Park, is a new computer tool that was designed with and for people with aphasia (Wilson, Roper, Marshall, Galliers, Devane, Booth, et al., 2015). It is a multi-user virtual island in which people with aphasia can interact in real time with therapists, support workers, and/or each other. EVA Park contains a number of locations, designed to stimulate conversation, including a town square, houses, a café, a bar, a health centre, a hair salon and a disco. There are green spaces, water features, examples of wild life and elements of fantasy. For example, users who dive into the lake encounter a mermaid, a pearl oyster and a turtle; and those who click on the turtle are taken for a ride. Users of EVA Park are represented in the virtual world by personalised avatars and communicate mainly through speech, using a headset and microphone. They can also, optionally, type into a messaging facility. Thus, EVA Park offers a safe environment for language practice, which mimics but is set apart from some of the demands of real world communication.
The first intervention study using EVA Park involved 20 people with aphasia (Marshall, Booth, Devane, Galliers, Greenwood, Talbot, Wilson, & Woolf, 2016). They received 25 sessions of language stimulation over 5 weeks, delivered by support workers. Participants set individual communication goals, such as asking questions, making requests and initiating conversations. Sessions with the support workers addressed these goals, through targeted activities that used the simulated settings available in EVA Park. For example, making requests could be practised in the health centre or hair salon with the support worker playing relevant roles. The other key activity was conversation, conducted with the support workers and through weekly group sessions, in which up to 5 participants met together. It was hypothesised that the situated language practice provided in EVA Park would improve functional communication. Gains in confidence were also anticipated, given that virtual applications had successfully treated communication anxieties in other groups (e.g. Anderson, Zimand, Hodges & Rothbaum, 2005; Wallach, Saffir, & Bar-Zvi M. 2009). Benefits with respect to feelings of isolation were also hypothesised, given that participants were meeting others in EVA Park.

The EVA Park intervention was evaluated through a quasi-randomised experimental design, comparing a group that received immediate therapy with a waitlist control group. A range of measures assessed functional communication, language, feelings of communicative confidence and social isolation. Results showed significant gains in functional communication, as assessed by the CADL-2 (Holland, Frattali, & Fromm, 1999). These were not only achieved by the immediate group, but also by the waitlist control group, once they received the EVA Park intervention. Other measures, however, showed no change.

The experimental findings were supplemented with two nested investigations. One employed user experience techniques from the field of Human Computer Interaction, to explore participants’ experiences of EVA Park (Galliers, Wilson, Marshall, Talbot, Devane, et al,
Structured observations of EVA Park sessions and participant rating responses showed that EVA Park sessions were highly enjoyed by participants, stimulated a wide range of conversational exchanges and were strongly associated with positive affect, such as playfulness, joking and laughter.

The other nested investigation used semi-structured interviews to explore user views about the EVA Park intervention. This is reported here. Study participants took part in entry and exit interviews before and after intervention. A subset was also interviewed at least 12 months later, to explore their longer term responses to the intervention. The study addressed the following questions:

What were participants’ views about the EVA Park intervention?

What, if any, were the perceived impacts of the EVA Park intervention?

For those involved in follow up interviews, what were participants’ long term retrospective views of the EVA Park intervention and did these participants perceive any long lasting impacts of the intervention?

Method

Ethical approval for the study was granted by the School of Health Ethics Committee, City University of London. Written consent was obtained from all participants using materials designed to be accessible for people with aphasia (Rose, Worrall, Hickson & Hoffmann, 2011).

Participants were 20 people with aphasia (9 women, 11 men) who took part in the main study (see Marshall et al, 2016). Their mean age was 57.8 years (s.d. 11.58). All were at least one year post stroke (mean number of months post stroke: 62.10; s.d. 53.56). Most had mild or moderate aphasia (determined by their picture naming score and clinical observation). In line
with the study selection criteria they scored at least 20% correct in spoken picture naming, above 70% correct on spoken word to picture matching and above chance on sentence to picture matching (all testing from the Comprehensive Aphasia Test (Swinburn, Porter & Howard, 2016). Further participant details are in table 1. None of the participants had returned to employment post stroke, although two were volunteering and one was a child minder for a family member.

Insert Table 1 about here

**Intervention**

Each participant had five weeks’ access to EVA Park. In that time, they received four, one-hour, individual therapy sessions each week with their support worker, and one group session, involving four other participants and their support workers. They also had unlimited independent access to EVA Park. Individual sessions addressed personalised communication goals. These goals were set at the start of intervention, during the early individual sessions, and were various. Examples included: asking questions, initiating conversation, improving word finding, ordering food in a restaurant, and making a doctor’s appointment. Support workers were met in world (not face to face). Most were qualified speech and language therapists (SLTs), although two were experienced stroke group volunteers. All support workers received four hours of training prior to the intervention and weekly supervision from the SLT project managers (ND and RT). Intervention activities included role plays, which exploited the various EVA Park settings, conversation and group discussions. Features were built into EVA Park to enhance communication opportunities. For example, a news board in the town centre played topical videos when clicked. We also staged an EVA Park election, with four fictional candidates for Mayor. These candidates released manifestos which could be discussed and were the subject of often scandalous news stories.
Interviews (see Appendices I, II, III for topic guides)

The entry interviews took place two weeks before EVA Park intervention. Questions focussed on activities undertaken by participants, communication issues, life satisfaction, changes since the stroke and uses of technology. Exit interviews took place two weeks after intervention. In addition to the topics explored in the entry interviews, questions asked about participants’ views and experiences of EVA Park and any perceived impacts of the intervention. Entry and exit interviews were conducted by researchers from the main study (ND and RT), who had not directly delivered intervention; i.e. neither had acted as support workers in EVA Park. Nineteen participants undertook entry interviews, and 20 undertook exit interviews.

Long term interviews were conducted at least 12 months post intervention with a random selection of 5 participants. The topic guide for long-term Interviews focussed on recollections of the EVA Park intervention; any impacts on communication, daily life activities, technology use and social activities; suggestions for how the intervention may support other people with aphasia in future. Participants were reminded of previous interview responses and invited to reflect on these. Long term interviews were conducted by the first author (AA). She had acted as a support worker in the main study, but not with any of the interviewees. Her role as support worker was concealed from respondents.

All interviews were conducted in participants’ homes and were video recorded. The average time for entry interviews was 17.05 minutes (range 9 – 25 minutes). The average time for exit interviews was 21.6 minutes (range 10 – 46 minutes). The average time for follow-up interviews was 22.8 minutes (range 15 - 42 minutes). The briefest interviews involved participants with the least output. Where necessary communication techniques were adapted for people with aphasia, e.g. by using gesture and other visual supports, simplifying language
and checking back responses. Such techniques have been advocated and deployed in previous qualitative studies involving people with aphasia (e.g. Luck and Rose, 2007; Simmons Mackie & Lynch, 2013). Most interviews were conducted with participants alone. Four interviews (across all time points), were also attended by a family member, in one case very briefly. Only one family member contributed coded comments (four in total), which were about activity and communication changes post EVA Park intervention.

Data were transcribed verbatim, by an independent transcription service. The transcriptions of 6 interviews (13.6%) were checked against the recording to confirm accuracy. To ensure a systematic approach, Framework Analysis was conducted (Pope, Ziebland, & Mays, 2000; Spencer, Ritchie, Ormston, O’Connor & Barnard, 2014), using NVivo 10 Software. Following familiarisation with the data (reading and re-reading) an initial coding index was created by ND, RT and CW. This index reflected the research and interview questions as well as the themes and sub-themes emerging from the data during the familiarisation stage. The scripts were then coded according to this index. The process was iterative, i.e. the coding index was augmented if new themes were identified during analysis. Charting followed, in which data were grouped into matrices, representing each theme. This involved abstraction and synthesis, in an attempt to extract the key meanings being expressed. The final stage involved mapping and interpretation. This sought patterns in the data, e.g. reflecting associations between themes or commonly expressed opinions, and possible explanatory contexts.

Coding was undertaken by three authors (AA, ND and RT). A random sample of 8 transcripts (just under 20% of the data) was double coded in blind conditions. Agreement between coders was very high (97.94%). Coding comparisons for each code in the thematic framework ranged from 76.27% - 100%. The few discrepancies occurred mainly because one
coder included more words or phrases into the coded segment than the other. Discrepancies between coded themes were very rare.

**Results**

The thematic framework comprised 10 overarching (parent) themes and 33 sub-themes (see figure 1 a & b). Figure 2 shows the total number of comments contributed under each of these parent themes. Themes were not mutually exclusive; i.e. many comments were coded under several themes. This report draws mainly from the themes that are most relevant to the research questions. They are: Change, Confidence, Affect, Communication, Virtual Worlds and EVA.

Insert Figure 1 a & b and Figure 2 about here

*What were participants’ views about the EVA Park intervention?*

This section will report data from the EVA and Virtual World themes. Data are reported from all time points, although most comments are drawn from the exit interviews.

All participants contributed comments within the EVA theme. There were 636 coded references under this theme, 498 made at exit and 138 at long term. As reflected in table 2, comments were overwhelmingly positive. Nineteen respondents talked positively about EVA activities, such as exploring the different locations and performing role play. Twelve flagged particular places that were enjoyed. Associations with play (fun, laughter, playfulness or relaxation) were expressed by 9 of the participants. Indeed 255 of the comments under the EVA theme were also coded for positive affect, compared to just 58 that were coded for negative affect. The experience of being represented by avatars was discussed by 5 participants, in all cases positively. Danny commented appreciatively about the avatar having ‘two arms’, suggesting that he enjoyed losing his hemiplegia in the virtual world.
All the participants commented on and particularly valued their interactions with support workers. They were seen as encouraging and supportive, with skills in providing opportunities for conversation and confidence-building. Most people worked with just one support worker throughout their intervention, but this was not the case for Stanley and Ash. While they were positive about their workers, they found the changes unsettling, for example Ash said ‘changing my helper was a bit disconcerting’ (exit). All participants also spoke about their interactions with other users, in most cases positively. Here the social contact and, often, humour was appreciated. One person commented that interactions were fatiguing and four found interacting in groups challenging.

Fourteen participants contributed to the theme about virtual world communication. Eight participants highlighted factors that they valued and which supported communication, such as the encouragement of support workers and the opportunities to practise in the various EVA Park contexts. Two comments suggested that elements of communication in a virtual world were facilitatory. Ash found communication over the microphone easier than ‘face-to-face’ (long term); and Liz suggested that being in a virtual world bestowed a sense of freedom: ‘It’s nice to think that you can pretend to be you and, er, maybe even something silly and get away with it’ (exit). Five participants commented on communication barriers (all at exit). These included the experience of word finding difficulties, problems with group communication and fatigue. One comment made the point that non-verbal cues were reduced in the virtual environment.

Turning to recommendations all participants said that they would recommend EVA Park intervention to other people with aphasia. When asked if there was anything that they would change about EVA Park, 7 indicated that no improvements were necessary. When changes were suggested, most related to increasing the opportunities available in EVA Park, e.g. by including more locations, increasing the activities that can be performed or the interactivity
with objects. Two comments related to increasing the number of participants or holding more
groups in EVA Park. Ten participants expressed a desire for EVA Park to continue beyond
the duration of the research and to be available to other users.

A few aspects of EVA Park elicited more equivocal views (all at exit). A virtual election
campaign was held in EVA Park, in which participants had the opportunity to vote for
fictional mayoral candidates. Eleven participants enjoyed the campaign and said they
participated in the voting, but 4 were not interested. The news boards, which carried fictional
news stories, were another feature that elicited mixed views. Eleven participants spoke
positively about these, while 3 were more negative. EVA Park also contained a video screen
that showed Youtube clips, aiming to stimulate conversation. These were enjoyed by 12
participants; but 4 reported that they did not watch them or had technical difficulties using the
screens.

Half of the sample commented on the user interface. Three made positive comments, about
ease of navigation, the ability to manipulate view point and the fact that the headset and
microphone helped communication. Seven participants made mixed or negative comments.
Limitations included the fact that some objects were not interactive, problems with sound, the
positioning of some keys on the switchpad and the possibility of navigation errors. One
participant (Gregory) found the interface generally complicated. This participant also felt
that there was too much going on in EVA Park: Gregory: [Pause] ‘there’s too much to it’.
Interviewer: ‘Too much going on was it?’ Gregory: [Nods] ‘yeah’. Interviewer: ‘You didn’t,
um... Too many games’. Gregory: ‘The elephants, the kangaroos... Giraffes’ [shakes head].

In addition to EVA Park, participants were asked about their prior experience with and
general attitude to virtual worlds. Although only 5 had any prior experience, most (14)
expressed a positive attitude even at the entry interview, e.g. wanting to find out more. Four
were more sceptical, for example expressing a dislike of ‘computer games’. At the exit interviews 18 expressed positive views about virtual worlds, while the other two (Gregory and Mia) said they found them complicated.

Insert Table 2 about here

*What, if any, were the perceived impacts of the EVA Park intervention?*

Data in this section are derived from all time points. Most impacts were reported under the themes of Change, and Confidence (see table 3). All participants contributed to these themes. The Change theme was divided into two sub-themes: ‘Change post stroke’ and ‘Change post EVA’. Perhaps unsurprisingly, most comments coded under ‘Change post stroke’ identified negative impacts. Respondents identified physical and communicative barriers and losses in their professional or social lives. These themes were represented at all time points, but were particularly evident in the entry interviews. Out of 56 comments coded under ‘change post stroke’, 50 were derived from the entry interviews, 4 from the exit and 2 from the follow up.

‘Change post EVA’ comprised three sub-themes: ‘Change in communication’, ‘Change in activity’ and ‘Change in computer use’. All participants contributed to the ‘Change in communication’ theme. Two felt that their communication was unaffected by the intervention, while the remaining 18 reported gains. Participants described talking more to family and friends, finding speech easier and feeling more able to talk. Gregory felt that the intervention gave him a new strategy, in that he now thought more before he spoke. Two reported positive feedback from friends or relatives about their communication following intervention.

Eighteen respondents contributed to the ‘Change in activity’ theme. Eleven reported increased participation in activities post treatment. These activities included ordering a drink, swimming, attending a pottery class, going to the gym, taking part in sport, attending church,
playing music, using the telephone, shopping, texting, giving talks and helping others with aphasia. Four participants reported no change in activity and 3 said that they reduced their activities while taking part in the intervention. This was because the daily EVA sessions gave them less time for other things. Some participants commented on whether or not they felt satisfied by their social activities. At entry, most comments (3/4) were negative. At exit, 10 comments related to satisfaction. At this stage, 4 were satisfied, one felt ‘fifty fifty’ and 5 were still unsatisfied. At follow up, four participants commented on satisfaction, all negatively.

Eighteen participants made comments under the ‘Change in computer use’ theme. Eight felt this had not changed. For example, Marc still found writing emails difficult because of spelling problems. However, 10 people reported positive changes. These included increased confidence, more proficient use of computers, increased use of the internet, setting up online accounts and increased use of social media.

The theme of ‘Confidence’ featured in both the entry and exit interviews. At entry 8 participants contributed to this theme. Although four comments were positive, e.g. about retained feelings of confidence, four participants experienced reduced confidence or were hoping to increase this through the intervention. At exit, 12 participants contributed to the theme and all reported increases in confidence as a result on the intervention. Most examples related to increased feelings of communicative confidence. For example, participants felt able to talk in a wider range of situations, described feeling less shy or having less anxiety about communication. Others felt more socially confident or more confident with computers.

What were participants’ long term retrospective views of the EVA Park intervention and did these participants perceive any long lasting impacts of the intervention?
Data for this section were derived only from the follow up interviews.

Participants’ long term recollections of EVA Park intervention were very positive (see Table 4). The association with fun and enjoyment was still strong. For example, there were 90 comments that were coded for positive affect, compared to just 15 negatively coded comments. Valued features included EVA Park activities, such as role play and dancing, the attractive locations, the contribution of support workers and communication with other people with aphasia. Interestingly, some themes that elicited equivocal views at the exit interviews, such as the election narrative and user interface, were not commented on at follow up. When asked about their predominant memory, four flagged enjoyment, with Ash adding ‘a sense of well-being’. Other enduring features were the EVA environment and contacts with others.

All five participants expressed the wish that EVA Park could continue. Those who commented under the theme of ‘Recommendations’ (3) all said that they would still recommend EVA Park for other people with aphasia. One person suggested things to change, advocating more groups and a less intensive regime.

All five participants commented on the long term impacts from the EVA Park intervention, with four citing positive changes. Three (Amy, Ash and Susan) cited changes in communication. Indeed Amy and Ash described specific communication skills that they practised in EVA Park that they still employed in their everyday lives, such as ordering a latte in a café. Liz and Danny indicated that they had maintained communication gains, but were unsure whether these could be attributed to EVA Park intervention.

Views about long term impacts on activity and computer use were mixed. Amy was able to describe specific changes to her weekly regime, such as going shopping on her scooter, which
drew on skills developed in EVA Park. Three others were able to cite maintained or increased activity, such as going to the church and using the gym, although Danny was doubtful about whether this was due to EVA Park. Turning to computer use, 3 maintained computer skills acquired during EVA Park intervention. Susan had expressed dislike of computers on entry, but modified her opinion after intervention, when she considered buying a computer. This ambition was not maintained at the follow up interview.

Other long term impacts were expressed under the theme of Confidence, with three participants attributing increased communicative and social confidence to their EVA Park experiences. Danny did not perceive a change in confidence for himself, but felt that EVA Pak could help others to increase their confidence in future.

Insert Table 5 about here

**Discussion**

20 people with aphasia took part in entry and exit interviews flanking a novel intervention delivered in a virtual island called EVA Park. Five of the original sample were also interviewed at least 12 months later. Interviews aimed to determine the acceptability of the intervention and the perceived impacts, both immediate and long term.

Findings with respect to acceptability were extremely positive. Many aspects of EVA Park were singled out for praise and participants were unanimous in thinking that the intervention should be recommended for other people with aphasia. Feelings of fun and enjoyment were a particularly strong theme. This was consistent with the results of the study’s other nested investigation, which conducted User Experience (Ux) observations during intervention (Galliers et al, 2017). These Ux observations showed that a very high proportion of activities undertaken in EVA Park were associated with positive affect, for example marked by laughter, playfulness or joke making. It is, perhaps, not surprising therefore that feelings of
enjoyment were so strongly expressed in the interviews, even 12 months after intervention had ceased.

The fact that EVA Park intervention was so enjoyable may have important implications. Rates of depression are high post stroke (Hackett & Pickles, 2014), particularly for those with aphasia (Kauhanen, Korpelainen, Hiltunen, et al. 2000); and depressive feelings can reduce participation in rehabilitation (van Dijk, de Man-van Ginkel, Hafsteinsdóttir & Schuurmans, 2016). A highly enjoyable intervention like EVA Park may sustain motivation and even impact on mood. Indeed, a study of other disability groups found that participation in virtual worlds significantly improved a range of affective state measures (Gilbert, Murphy, Krueger, Ludwig & Efron, 2013). Mood was not assessed in the current study, which was perhaps an omission. Some comments, like Ash’s belief that EVA Park engendered a ‘sense of well-being’, may point to changes.

Participants’ comments illuminate which components of the intervention were particularly valued. A key factor was the contribution of support workers, with all respondents commenting very positively on their skills. Contacts with other people with aphasia were also appreciated. Thus, as in conventional, face-to-face therapy, human relationships were crucial (Fourie, 2009; Lawton, Haddock, Conroy & Sage, 2016). It is striking that the human dimension was not undermined by the virtual context, e.g. strong therapeutic relationships could be forged despite the fact that support workers were met remotely and were themselves represented as avatars. The consistency of these relationships seemed important. Two participants experienced changes in their support workers during intervention and were unsettled by this.

In addition to the human dimension, participants valued many of the virtual aspects of intervention. The environment of EVA Park, with its different locations and amusing content,
was the focus of frequent positive comments. Some individuals particularly enjoyed the
experience of ‘otherness’ possible in EVA Park. Danny valued the fact that his avatar, unlike
him, did not have a hemiplegic arm, and Liz appreciated the opportunity for make believe
and the fact that she could do ‘something silly and get away with it’. The opportunity for
virtual, situated practice, such as ordering a drink or making a doctor’s appointment, was
recalled by several respondents. Less positively, a number of barriers to virtual
communication were identified. Some of these reflected common aphasic and/or stroke
symptoms, such as word finding problems (Martin, 2017), fatigue (Ingles, Eskes & Phillips,
1999; Lerdal, Bakken, Kouwenhoven, Pedersen, Kirkevold, et al., 2009) and increased
problems communicating in groups. One was more specific to the virtual environment, which
was the reduction in non-verbal cues. This comment was salutary, and suggests that
individuals with severe aphasia, who are highly dependent on such cues, might struggle to
use EVA Park. This could be the focus for further research. For example, follow up studies
might explore the degree of auditory comprehension impairment that can be compensated for
during communication in EVA Park.

Elements of EVA Park were criticised, at least by some participants. Augmentations to the
world, in the form of the election narrative, news boards and video screens, were the focus of
some negative comments. However, opinions differed and participants could build a
successful experience in EVA Park while ignoring the augmentations. Criticisms of the user
interface were perhaps more concerning. Some of these reflect the prototype status of the
technology, which has since been strengthened. In one case, that of Gregory, further training
in using EVA Park might have helped. Importantly, only 7 participants provided negative or
mixed comments about the interface, and their problems did not undermine their overall
enjoyment or the perceived value of the intervention.
There were very few indications of adverse side effects. Two participants flagged fatigue. It is difficult to know whether this was due to the virtual nature of the intervention, or might have been equally induced by a conventional programme of therapy. Certainly fatigue is commonly observed in aphasia therapy sessions (Riley, 2016). Ash suggested that a less intensive schedule would allow for recovery between sessions, which suggested that the regime, rather than the format, was critical. In line with this, three other participants commented that the daily EVA Park sessions reduced time for other, real world activities. Adjustments to the regime in any future study might therefore be considered. Interestingly, one possible adverse consequence of therapy intensity, that of drop out (Brady, Kelly, Godwin, Enderby & Campbell P. (2016), did not occur here.

Perceived impacts of intervention related to 4 themes: communication, activity, computer use and confidence. All bar two participants in the exit interviews felt that the EVA Park intervention benefited their communication. This is an important finding as it validates the significant change on a formal measure of functional communication found in the host study (Marshall et al, 2016). Maintenance of gain was demonstrated in the host study, but only after a follow up period of 6 weeks. The fact that three participants (60%) in the long term interviews felt that improvements were maintained one year later is, therefore, very encouraging. Improvements in functional communication have been flagged as a key objective for aphasia therapy (Brady et al, 2016). Such improvements were demonstrated in this study, not only on a formal measure but also in participants’ reports.

Increased participation in everyday activities was identified as a further impact by 11 participants, and they cited an impressive array of pursuits in relation to this claim. In the long term, 4 participants described maintained activities, although not all attributed these to EVA Park. Given that aphasia is known to reduce social participation (Cruice, Worrall & Hickson, 2006) the change in activity is another important finding. However, it is tempered
by the fact that only just over half the participants reported this change, and by the fact that, at all time points, the majority of participants expressed dissatisfaction with their activity levels.

Activity was not assessed in the host study. However, feelings of social isolation were measured by the Friendship Scale (Hawthorne, 2006), with no significant findings (Marshall et al., 2016). It is interesting that the increased activity reported by at least some participants did not impact on this measure. Changes might also have been predicted from the social contacts in EVA Park that were so highly valued. Here the reported satisfaction levels may be illuminating. It may be that these arise from comparisons with the person’s pre-stroke status; and it may be this comparison that similarly drives feelings of isolation. A further consideration is the brief duration of the intervention, which took place over just 5 weeks. It may be that a longer period of intervention is needed to effect change on the Friendship Scale. The novelty of this study makes it difficult to draw comparisons with previous research. Gilbert and colleagues (Gilbert et al., 2013) examined the psychological benefits of involvement in a virtual world (Second Life®) for people with a range of real world disabilities. Here, three months use of Second Life brought about significant changes on a measure of Loneliness (Russell, 1996), but not Social Connectedness (Lee & Robbins, 2001). The authors speculate that further benefits might have been observed after a longer period of involvement.

Half the participants in the exit interviews indicated that intervention brought about changes in their computer use, with some very specific examples of how these were being applied. In the long term, 3 participants (60%) indicated that these changes were maintained. Computer access is very widespread in the general population (Department for Business Innovation and Skills, 2012), and an increasing range of everyday activities is now conducted on line. In this context, there are concerns that people with aphasia face digital exclusion, and that such
exclusion is as disadvantaging as the barriers faced in the real world (Menger, Morris & Sallis, 2016). Digital applications in therapy have the potential benefit of (re)introducing participants to computer use. If applications are designed to be aphasia friendly, as was the case here (see Wilson et al, 2016) this will hopefully stimulate a sense of mastery and a willingness to try other things. This seems to have occurred in the current study, at least for some participants.

The final impact related to confidence. This was cited by 12 participants at the exit interviews, with maintenance indicated by 3 (60%) in the long term. The measure of communicative confidence employed in the host study did not demonstrate an effect of intervention, partly because scores increased irrespective of whether or not intervention had been received (Marshall et al, 2016). The participants’ reports therefore bring treatments effect to light that were not evident in the quantitative data. It is difficult to speculate about why confidence increased. For some, this seemed related to the positive therapeutic relationships formed with support workers. Others may have profited from practice in a safe environment that was at one remove from reality. Increased confidence has been reported from previous, very different, computer interventions (Palmer et al, 2013; Wade et al, 2003). It may be that the autonomous use of a computer, albeit for varying purposes, contributes to the effect.

Limitations of the study

This paper reports data from a small group of participants who may not be typical of the wider aphasic population. With a mean age of 57.8 they were younger than most stroke survivors (Lee, Shafe & Cowie, 2011) and all bar two had prior computer experience. Even at entry most were receptive to the idea of virtual worlds. It is possible that their positive responses to intervention would not be replicated in an older, or less computer literate sample.
Two interviewers in this study had not directly delivered intervention (ND, RT), but were part of the host study research team. The third had acted as a support worker, although this was concealed from respondents. The risk of interview bias would be reduced by involving an independent qualitative researcher, with no other role in the wider study. Related to this, interviews were structured around topic guides that were developed by the investigators, again introducing a risk of bias. However, the guides were determined by the research questions and the interviewing was designed to be as non-leading as possible. It is also reassuring that participants were not simply providing positive responses, which they might have imagined that the researchers wanted to hear. For example, there were critiques of EVA Park, and qualifications to some positive remarks. To illustrate the latter, Liz and Danny identified communication gains in their follow up interviews, but made the point that these may not be attributable to EVA Park. The interviews ended with an entirely open invitation to say anything more. There were 15 coded responses to this invitation. Fourteen of these were coded for positive affect, but one highlighted a feature that could be changed.

**Conclusions and clinical implications**

The tested EVA Park intervention was highly acceptable to users, with perceived benefits for communication, activity levels, computer use and confidence. Together with the experimental results (Marshall et al, 2016) these findings suggest that EVA Park could be a valuable addition to the resources available to aphasia therapists. Further research by our team is currently investigating alternative models of therapy delivery in EVA Park, including programmes of individual language intervention and social group support.
Acknowledgements: This work was funded by The Stroke Association, Grant Number: TSA 2011/10. We thank all our participants with aphasia who generously gave their time to this project.

References


<table>
<thead>
<tr>
<th>Participant</th>
<th>Age Group</th>
<th>CAT Picture Naming Score</th>
<th>Aphasia type</th>
<th>Education</th>
<th>Gender</th>
<th>Hemiplegia</th>
<th>Motor speech difficulty</th>
<th>Pre-Stroke Occupation</th>
<th>Time post Stroke</th>
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<tbody>
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<td>Stanley (M)*</td>
<td>66+</td>
<td>97.9%</td>
<td>Fluent</td>
<td>Degree</td>
<td>Male</td>
<td>Yes</td>
<td>No</td>
<td>Musician</td>
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<td>Ash (I)</td>
<td>51-65</td>
<td>100%</td>
<td>Fluent</td>
<td>18</td>
<td>Male</td>
<td>No</td>
<td>Yes</td>
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<td>Philip (MK)</td>
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<td>Fluent</td>
<td>18</td>
<td>Male</td>
<td>No</td>
<td>No</td>
<td>Business travel agent</td>
<td>2-5 years</td>
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<tr>
<td>Ahmed (J)</td>
<td>51-65</td>
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<td>Non-fluent</td>
<td>Degree</td>
<td>Male</td>
<td>Yes</td>
<td>Yes</td>
<td>Engineering project manager</td>
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<tr>
<td>Lyra (R)</td>
<td>36-50</td>
<td>85%</td>
<td>Fluent</td>
<td>18</td>
<td>Female</td>
<td>Yes</td>
<td>No</td>
<td>Small business owner</td>
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<td>Gregory (S)</td>
<td>51-65</td>
<td>85%</td>
<td>Fluent</td>
<td>16</td>
<td>Male</td>
<td>Yes</td>
<td>Yes</td>
<td>Publican</td>
<td>&lt; 1 year</td>
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<tr>
<td>Kevin (Y)</td>
<td>51-65</td>
<td>79%</td>
<td>Non-fluent</td>
<td>Degree</td>
<td>Male</td>
<td>Yes</td>
<td>No</td>
<td>Computer repairer</td>
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<td>Mia (D)</td>
<td>36-50</td>
<td>72%</td>
<td>Non-fluent</td>
<td>Degree</td>
<td>Female</td>
<td>Yes</td>
<td>No</td>
<td>Maths teacher</td>
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<td>Margaret (O)</td>
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<td>43.75%</td>
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<td>Female</td>
<td>Yes</td>
<td>No</td>
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<td>Annie (P)</td>
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<td>Fluent</td>
<td>18</td>
<td>Female</td>
<td>No</td>
<td>No</td>
<td>Office administrator</td>
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<td>Marc (Pe)</td>
<td>51-65</td>
<td>81%</td>
<td>Fluent</td>
<td>18</td>
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<td>No</td>
<td>No</td>
<td>Telecoms engineer</td>
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<td>Amy (Lo)</td>
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<td>16</td>
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<td>Yes</td>
<td>Yes</td>
<td>Dry cleaning operator</td>
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<tr>
<td>Frank (T)</td>
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<td>27%</td>
<td>Non-fluent</td>
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<td>Male</td>
<td>Yes</td>
<td>Yes</td>
<td>Military</td>
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<td>Susan (Sa)</td>
<td>36-50</td>
<td>85.41%</td>
<td>Fluent</td>
<td>16</td>
<td>Female</td>
<td>No</td>
<td>No</td>
<td>Music artiste and repertoire manager</td>
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<td>Liz (W)</td>
<td>66+</td>
<td>68.75%</td>
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<td>Female</td>
<td>No</td>
<td>No</td>
<td>Estate agent</td>
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<tr>
<td>Jessica (L)</td>
<td>51-65</td>
<td>79%</td>
<td>Fluent</td>
<td>16</td>
<td>Female</td>
<td>No</td>
<td>No</td>
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<tr>
<td>James (Di)</td>
<td>66+</td>
<td>84%</td>
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<td>Male</td>
<td>No</td>
<td>Yes</td>
<td>Carpenter</td>
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<td>Joshua (A)</td>
<td>51-65</td>
<td>64.6%</td>
<td>Fluent</td>
<td>18</td>
<td>Male</td>
<td>Yes</td>
<td>No</td>
<td>Health care assistant</td>
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<tr>
<td>Fenella (V)</td>
<td>66+</td>
<td>79%</td>
<td>Fluent</td>
<td>Degree</td>
<td>Female</td>
<td>No</td>
<td>No</td>
<td>Office administrator</td>
<td>&gt; 5 years</td>
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<tr>
<td>Danny (B)</td>
<td>36-50</td>
<td>79%</td>
<td>Fluent</td>
<td>Degree</td>
<td>Male</td>
<td>Yes</td>
<td>Yes</td>
<td>Video editor</td>
<td>1-2 years</td>
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</tbody>
</table>

Participants interviewed at long term are in highlighted cells

*Initials in parenthesis are identifiers used in Galliers et al (under review)
<table>
<thead>
<tr>
<th>Parent/Sub-theme (number of respondents contributing comments)</th>
<th>Illustrative quotes*</th>
</tr>
</thead>
<tbody>
<tr>
<td>EVA/Activities (19)</td>
<td>‘Every day we went somewhere new, I love that’ (Fenella)</td>
</tr>
<tr>
<td>EVA/Play (9)</td>
<td>‘I’m sitting right on the …… on a decking up the top .. of the houses.. and I’m thinking oh God I’m on holiday here’ (Jessica)</td>
</tr>
<tr>
<td>EVA/Avatars (5)</td>
<td>‘it’s pretty good because you get to be a character with two arms [raises own arms and laughs]’ (Danny)</td>
</tr>
</tbody>
</table>
| EVA/Support workers (15) | ‘She said “Don’t worry … carry on” and she wonderful’ (James)  
‘help me with the .. the words.. couldn’t say and she found /f/ /l/ me feel free’ interviewer: ‘she let you feel free?’ Annie: ‘yeah, to talk’ (Annie)  
‘My helper was very good.. So helped me talk better and I got my confidence back again [smiles]’ (Fenella) |
| EVA/Interaction with other people with aphasia (20) | ‘and we could … have um … take the mickey out of one another .. and it’s wonderful’ (James)  
Interviewer: ‘What did you enjoy about it?’ Liz: ‘Everything. Go around the .. the .. island and from place to place and er, talking to other people when they were there’ (Liz)  
‘I don’t like doing the group.’ Interviewer: ‘Why not?’ Jessica: ‘Um, the noise is unbelievable. It is literally pounding in my head. I can’t bear it.’ (Jessica) |
| Communication/Virtual worlds (11) | ‘In fact it was easier on the microphone than seeing someone face to face’ (Ash, long term)  
‘If I look at [gesture] your mouth, like you. I can look at yours, one like that….But if… [hand gesture] if I haven’t got someone’s mouth or anything I find sometimes [turns head away] myself the words...’ (Jessica) |
| EVA/Recommendations (20) | ‘The idea of [points] avatar and communicating with other people is by and large brilliant and I want to see many more of this, um, many more of this avatar with other people, with communicating news and music’ (Stanley)  
‘I’d just tell everyone to do it, if they could. Go there and do it again. I wish it was a real world’ (Jessica) |
<p>| EVA/Things to change (18) | ‘I’m the wrong person to ask because I liked everything’ (Liz) |</p>
<table>
<thead>
<tr>
<th>EVA/User interface (10)</th>
<th>‘Claps. Open and [hand gesture] closing and closing.’ Interviewer: ‘you’d like to be able to open and close the windows?’ Ahmed: ‘yeah’ (Ahmed)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘When there was more than one participant there .. the noise was cracking up. I didn’t like that’ (Gregory)</td>
</tr>
<tr>
<td></td>
<td>‘sometimes I’d .. I’d get lost. I’m going into the water instead of carrying on to the [laughs] to the thing and we were going up the hill’ (Liz)</td>
</tr>
<tr>
<td></td>
<td>‘It’s easy to learn’ (James)</td>
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</table>

* Unless marked, all comments were made at exit
<table>
<thead>
<tr>
<th>Parent/Sub-theme (number of respondents contributing comments)</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change/Change post stroke (17) (at entry)</td>
<td>‘Very slow and er, not even slow. Some of the things, I just stopped doing things’ (Marc)</td>
</tr>
<tr>
<td>Change/Change post EVA/Change in communication (20) (at exit)</td>
<td>‘I’m more … more free or more able to talk’ (Annie)</td>
</tr>
<tr>
<td></td>
<td>‘It made a difference. It made me, um, made me think before I speak, um, which, um, I never used to before. Yeah, I think it did make me think before I speak’ (Gregory)</td>
</tr>
<tr>
<td></td>
<td>‘My wife’s and daughter said I hadn’t spoken so much for ages [laughs]’ (Ash)</td>
</tr>
<tr>
<td>Change/Change post EVA/Change in activity (18) (at exit)</td>
<td>‘Long back [hand gesture] glued in the TV… Now you’d either [hand gesture] and going shopping’ (Marc)</td>
</tr>
<tr>
<td></td>
<td>Interviewer: ‘How satisfied are you with your social activities now?’ Gregory: ‘erm well still upset’ (Gregory)</td>
</tr>
<tr>
<td>Change/Change post EVA/Change in computer use (18) (at exit)</td>
<td>‘I’m doing things I never thought I’d do again’</td>
</tr>
<tr>
<td></td>
<td>Interviewer: ‘Such as?’ Fenella: ‘Going to the computer and ordering my freedom pass .. yes and logged in with ah British Gas’ (Fenella)</td>
</tr>
<tr>
<td></td>
<td>Interviewer: ‘Has it changed the way you use your computer?’ … Susan: ‘No, because I, I still don’t know how to email so …yeah’ (Susan)</td>
</tr>
<tr>
<td>Confidence (12) (at exit)</td>
<td>‘I’m more fluent and more confident in outside situations’ (Ash)</td>
</tr>
<tr>
<td></td>
<td>‘was a bit shy and [hand gesture] watching TV only but now [hand gesture] I’ve improved’ (Lyra)</td>
</tr>
<tr>
<td></td>
<td>‘I’m not afraid now of saying what I want to say, so the words come out. So the confidence has come back now. Cos before I was full of it but now, after the stroke, it all disappears’ (Fenella)</td>
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### Table 4: Long term recollections of EVA Park Intervention: Illustrative quotes

<table>
<thead>
<tr>
<th>Parent/Sub-theme (number of respondents contributing comments)</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>EVA/Activities (2)</td>
<td>‘We worked on various things well as in the, in the project like er.. doctor’s appointments and ordering food or drinks in a bar and gen-generally they were quite good [laughs]’ (Ash)</td>
</tr>
<tr>
<td>EVA/Play (3)</td>
<td>Interviewer: ‘You enjoyed the dancing?’ Amy: ‘yeah, really enjoy it. Boom [mimes singing and dancing] really enjoyed it. It really was exciting’ (Amy)</td>
</tr>
<tr>
<td>EVA/Avatars (1)</td>
<td>‘It’s quite fun cos you’d actually somebody different’ (Susan)</td>
</tr>
<tr>
<td>EVA/Support workers (4)</td>
<td>Interviewer (re support worker): ‘Harriet?’ Amy: ‘Yeah really gave me confidence’ Interviewer: ‘Harriet gave you confidence?’ Amy: ‘Yeah, really gave me confidence.’ (Amy)</td>
</tr>
<tr>
<td>EVA/Interaction with other people with aphasia (5)</td>
<td>‘We’d all get together and have a little talk about what, whatever would [hand gesture] talk we’d been given’ (Danny)</td>
</tr>
<tr>
<td>EVA/Things to change (1)</td>
<td>‘I think more group sessions would be beneficial’ (Ash) ‘Perhaps space it out a bit… Every other day or something’ (Ash)</td>
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</tbody>
</table>
### Table 5: Perceived long term impacts of EVA Park intervention: Illustrative quotes

<table>
<thead>
<tr>
<th>Parent/Sub-theme (number of respondents contributing comments)</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change/Change post EVA/Change in communication (5)</strong></td>
<td>‘I said it was a dream come true because I [points to self] I, I um get [gesture] on my scooter .. and go up [pointing] and say “A latte please” and I get one’ (Amy)</td>
</tr>
</tbody>
</table>
| **Change/Change post EVA/Change in activity (5)**             | ‘I’m, um, going … I, I go to [gesture] to um Windsor in [gestures, smiling] my scooter.. yeah and I, I um get stuff the shelf, er um Boots and um w.. what is it? Oh River Island’ (Amy)  
  Interviewer: ‘How satisfied are you with your social activities now?’ Danny: not as [gesture] okay. It’s not as wonderful as it could be’ (Danny) |
| **Change/Change post EVA/Change in computer use (5)**         | ‘I can find my way round a computer more quickly’ (Ash) |
| **Confidence (4)**                                            | Interviewer: ‘what would you say was the most important thing you got from EVA Park?’ Susan: ‘Um probably c, confi- [unclear] say confidence’ (Susan) |
Figure 1 a – Parent Themes and Subthemes (Excluding EVA)
Figure 1 b – EVA Parent Theme and Subthemes
Figure 2: Total number of comments contributed under each parent theme
Appendix I: Entry Interviews Topic Guide

1. Talk me through a typical week: What kinds of things do you do? (Prompt: social activities)

2. Any other activities you do now and then?

3. How do you find communicating in these activities?

4. How satisfied are you?

5. Has this changed since your stroke?

6. Are there things that make these activities difficult (e.g. finance, confidence, fatigue)

7. Are there things that make these activities easier? That help?

8. I see that you use ….. (email/facebook any social activity from tech screen)
   a) Are there things that make using this easy?
   b) Are there things that make using this difficult?

9. Have you used virtual worlds?
   a) What do you think of virtual worlds?

10. Are there any things you want to do but don’t feel you can?
    Why?

11. What advice would you give to other people with aphasia about anything that has really helped?
Appendix II: Exit Interviews Topic Guide

1. How did you find doing therapy in EVA?

2. Do you think EVA made a difference to your communication?
   *In what way?*

3. Have you used things you practiced in EVA in your daily life?
   *Can you give me an example?*

4. Did you interact with other people with aphasia in EVA?
   *How did you find that?*

5. Has the way you use your computer changed?
   *e.g. internet, email, Facebook*

6. What did you think of the news board and videos?
   *(in the town square, on a TV in the house and on a TV on a stall in the square)*

7. Should we change anything in EVA?

8. What do you think of virtual worlds now?

Now I’m going to ask you about your social activities:

9. Talk me through a typical week, what kinds of things did you do now?
   *Any new activities / anything you have cut out?*

10. How do you find communicating in these activities?

11. Has this changed since EVA?

12. How satisfied are you with your social activities now?

To finish:

13. Overall, what stood out from your experience in the project?
14. Would you recommend EVA to other people with aphasia?

15. Anything else you would like to tell us?
Appendix III: Long Term Interviews Topic Guide

- **EVA memories** - What can you remember about your experience of EVA Park?

- **Previous interviews** - Last time you were interviewed you said….

- **Communication** - Long-term, do you think your involvement in EVA Park has made a difference to your communication? *If so, in what way/s?*

- **Daily life activities** - Have you used things you practiced in EVA Park in your daily life? *Please can you give me an example? Any more?*

- **Technology use** - Has the way you use technology changed? e.g. Internet, email, Facebook. Do you think this has changed because of your involvement in EVA?

- **Social activities** - Talk me through a typical week, what kinds of things do you do now? Has this changed since EVA Park?
  
  o  *Any new activities since EVA Park / anything you have cut out?*
  o  *How is communication in these activities?*
  o  *How satisfied are you with your social activities now?*

- **Other people with aphasia** – Do you think EVA Park could help other people with aphasia? Can you think of another person with aphasia – how might they use/benefit from EVA Park? *e.g. in stroke groups?*

- **Other ways to support** – In EVA Park therapy you met up with a support worker every day. Are there any other ways in which EVA Park could be used to support people with aphasia?

- **Future involvement:** If you were offered EVA Park again, would you be interested?
• **Important thing** - What would you say was the most important thing you got from EVA Park?

• **Anything else** - Anything else you would like to tell us?