Top ten research priorities relating to long-term aphasia following stroke – research gathered from people with aphasia, caregivers and speech and language therapists.
Abstract

Aim: The purpose of this research project was to determine the top ten research priorities relating to long-term aphasia following stroke.

Background: This project is a follow up study to Pollock and colleagues (2012) paper, which used the James Lind Alliance (JLA) methodology to attain the top ten research priorities to life after stroke. The JLA is a UK health initiative which ensures meaningful client and clinician involvement in research priority setting.

Method: A questionnaire was developed comprising of thirty four research uncertainties relating to aphasia, derived from the Pollock study. Data was gathered from forty six participants, comprising of people with aphasia (PWA), carers and speech and language therapists (SLT). The questionnaire was administered using face-to-face meetings, mail and e-mail. Participants were asked to identify and rank their personal top ten research uncertainties. The overall combined top ten priorities were identified.

Results: The top four research priorities related to determining ‘specific treatments’ and ‘service delivery’ including the best treatment ‘time’, ‘amount’ and ‘intensity’ for aphasia. A further three questions related to enhancing communication with someone with aphasia, with the rest falling under headings such as ‘carers and families’, and ‘aphasia and cognition’. The top two research priorities were identified in each participating groups top ten. The overall SLT group’s research priorities differed considerably from those of the PWA group. An extensive research of the literature highlighted a lack of relevant literature associated with these top ten research questions.

Conclusion: The top ten research priorities relating to life with aphasia have been identified using a systematic and person-centred approach. It is hoped that these findings will allow for greater funding for future research relating to life with aphasia following a stroke.
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Introduction

Every year fifteen million people suffer a stroke worldwide, making it the third most common cause of death, leaving one third of victims with a permanent disability (Schabitz & Reinecke 2011). The risk of stroke doubles with each decade of life over the age of fifty five, however with advances in medical intervention, increased public awareness, specialist acute teams and medication, death rates are reduced and life expectancy is significantly extended (Laska and colleagues 2001). It is estimated that one hundred and seventy six thousand new individuals across Ireland and the United Kingdom (UK) are diagnosed with a stroke every year, with one third of individuals who survive experience aphasia (McMenamin et al 2015; Palmer et al 2015).

Aphasia Post Stroke

Aphasia is a major life-changing event impacting significantly on the individual involved and those around them (Dalemans 2010). It is an acquired communication disorder caused by damage to parts of the brain controlling language, and is associated with impairments in understanding and/or expression of speech, reading and writing (Grawburg et al 2013). Aphasia can have debilitating and profound effects on a person’s life (RCSLT 2009). These include a loss of independence, relationships and social participation, a decreased quality of life leading to isolation, and an increase in distress and depression (Bakheit et al 2007). It is one of the most disabling consequences of an acquired brain injury (ABI), and the condition can range from mild to severe (Grawburg et al 2013). The severity of aphasia is identified as a valuable prognostic feature for recovery (Plowman et al 2012), however due to the heterogeneity of the condition, recovery from aphasia after stroke is highly variable (Koenig-Bruhin et al 2013; Hillis and Heidler 2002). In the acute phase, twenty one to thirty eight per cent of stroke patients are aphasic, with thirty five per cent said to be chronically aphasic upon discharge from hospital (Berthier 2005; Dickey et al 2010). Consequently, the rehabilitation process is an essential component in the recovery process for people with aphasia (PWA) (Barthel and colleagues 2008).

Traditional Research Setting

Health treatments and research priority settings are traditionally based on research planning set by academics and industry, without consultation or shared contribution from patients, carers and clinicians (Stakeholders). The National Institute for Health and Care Excellence (NICE) Guidelines (2014), state that individuals’ with communication difficulties after a stroke are to be facilitated in contributing to everyday
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and major life decisions. However, data consistently reflects exclusion of PWA in research, particularly if investigations are outside the area of the communication impairment (Andersson & Fridlund, 2002; Cruice et al 2005). Furthermore, due to this lack of recognition, PWA are challenged with problems that remain unknown (Daleman et al 2009). Therefore, without acknowledgment, people affected by aphasia become marginalised and hidden by the label of their condition, having their opinions overlooked on the basis of presumption of an inability to communicate (Daleman et al 2009). Best practice needs to be relevant and reflect the concerns of all stakeholders to direct and enhance aphasia research (Kagan et al 2010).

The speech and language therapists (SLT) primary focus when working with individuals with aphasia is to deliver a high quality service (Code and Petheram 2011). However, research has demonstrated that PWA have been excluded from research, particularly those who fall within the severe range. If researchers have failed to ask PWA what problematic areas and questions they would like researched, how can healthcare professionals provide this service efficiently? Moreover, the SLT’s priorities for recovery may be significantly different to those with aphasia. SLT’s play a fundamental role throughout all stages of the care pathway, with involvement in the immediate phase post stroke and the long-term rehabilitation phase in community settings (RCSLT 2007). This gap in the research suggests that those involved in their care are missing vital information which may enhance recovery and rehabilitation.

Current Study

The current quantitative research project involves three participant groups; PWA, carers, and SLT’s, with the researcher seeking to determine their combined future research uncertainties in the area of aphasia. By adopting a holistic and client-centred approach in future research planning, the perspectives from the three participant groups provide an invaluable and unique contribution to best practice, and shape the future health research agenda. Research needs to address important questions that would make a difference in the lives of individuals with this communication impairment.

The purpose of this study was to work in partnership with all stakeholders to determine research priorities in order to offer guidance and direction for future research setting, and to continue to improve clinical practice and services for those affected by aphasia. A study by Pollock and colleagues (2012) examining the top ten research priorities to life after stroke, developed a questionnaire of two hundred and twenty six treatment uncertainties. Although their study was not aimed specifically at people with
aphasia, Pollock’s findings revealed aphasia to be the third highest research priority as a consequence of stroke. For this research project, thirty four uncertainties specific to aphasia were derived from Pollock’s study. Before commencing this project, the researcher conducted an extensive review of the literature examining PWA participation in research and setting of future research priorities.

**Literature Review**

An examination of relevant aphasia related literature was conducted. Research was carried out primarily online via the University of Limerick’s library, and included the following databases; Cochrane Collaboration, Database of Research in Stoke (DORIS), Pubmed, Web of Science, and journals including; Aphasiology, Clinical Rehabilitation, Stroke, and International Journal of Stroke. It became evident from reviewing the literature that there is limited public awareness relating to aphasia, and barriers may be present inhibiting individuals from participating in society. The analysis also highlighted the exclusion of PWA in previous studies, including stroke research. However, strategies employed by researchers to enhance inclusion of PWA, have proven to be successful in previous research studies. This literature review will discuss these issues in closer detail.

**Aphasia Awareness**

In light of the global incidences of aphasia post stroke, public awareness and knowledge of aphasia and its effects are limited in comparison to other disorders with similar or lower prevalence (Sherratt 2011). A survey conducted by Simmons-Mackie *et al* (2010) in the UK, aimed to determine the general public’s level of knowledge of aphasia. The results of the study comprising of (N=978) individuals, indicated that 13.6 per cent had heard of aphasia, yet just 5.4 per cent met the criterion of having “basic knowledge of aphasia”. This lack of public awareness raises concerns potentially affecting the quality of services, public acceptance, and research funding for this disorder (Simmons-Mackie *et al* 2010).

PWA experience communication limitations leading to a decreased ability to participate and contribute in everyday activities. Due to the heterogeneity of the impairment, PWA may or may not experience co-occurring cognitive deficits, fatigue and a physical disability which may directly affect social involvement, and create barriers within society (Sherratt 2011). Worrall and colleagues (2011) administered a qualitative study involving semi-structured in-depth interviews to determine the needs of people with aphasia according to the International Classification of Functioning
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(ICF). A total of (N=50) participates with aphasia one year post stroke, with mild to moderate aphasia (severity was classified using the Western Aphasia Battery Aphasia Quotient) were included. A limitation to this study was that people with severe aphasia were excluded. Nine broad categories were identified including topics such as ‘wanting to participate in social and leisure activities’, and ‘having more control and independence’. The eighth theme was that of altruism and contribution to society. PWA expressed that they wanted to improve the lives of others (including those who had just had strokes), contribute to educating society about issues relating to aphasia (teaching students), and increasing public awareness of aphasia.

Exclusion of People with Aphasia in Research

Brady et al (2007) completed a Cochrane review comprising of fourteen randomized controlled trials (RCT) relating to information provision post-stroke. Their findings indicated that just one RCA included PWA, with ten out of the fourteen trials excluding this patients category, and the remaining three failing to reports their exclusion criteria altogether.

Dismissal of PWA in stroke research is problematic as it questions the reliability of research findings. Additionally, a large area of research is left unexplored by systematically excluding PWA. Evaluation of stroke studies has highlighted researcher bias, with a selective process of either including or excluding PWA evident, depending on their communication impairment, particularly relating to aphasia severity (Clarke et al 1999; Lynch et al 2008). Lazar et al (2010) suggests that one reason for excluding patients with severe aphasia from acute therapy studies is because of the challenge to obtain consent. However, aphasia must not be confused with inability to give informed consent (Brady et al 2007). A deficiency in research data reflects some researchers approach to exclude PWA, viewing therapy and recovery from severe aphasia to be poor, regardless of several reports of patients’ retrieval of language function beyond expectation (Berthier 2005; Lazar et al 2010). Another study conducted by Townsend (2007), highlighted early identification of mood disorders in post stroke patients to improve stroke outcomes, in turn leading to reduced length of stay in hospital. This study initially involved (N=151) stroke patients however, twenty two were automatically excluded due to reduced levels of consciousness, cognitive impairment and having aphasia. Automatic exclusion of individuals from research could be seen as an act of discrimination.
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**Supporting Inclusion and Participation in Research**

Since the early 1990’s there has been a gradual shift away from researchers’ interpretations and towards setting research priorities in discussion with stakeholders (Oliver and Gray 2006). Barham (2011) highlighted the different stages research should take including; identification of research priorities and goal setting, development of patient information and consent, data collection, analysis, intervention and outcomes, and informing policy and practice. Gooberman-Hill and colleagues (2013) conducted a small study comprising of a qualitative questionnaire involving patients with musculoskeletal disease (N=8) and researchers (N=14) reflecting the impact of the Patient Experience Partnership in Research group (PEP-R). Results provided information for twenty one studies, and led to the development of project ideas, with their findings suggesting that patients were keen and curious to learn about topics and research in general. Researchers recognised the importance of early patient involvement, valuing their opinions and the relevance to projects. This can act as a catalyst for better research designs and the delivering of higher quality health services.

A systematic search strategy conducted by Stewart and colleagues (2010) highlighted patients and clinicians views when developing research priorities. Out of the two hundred and fifty eight papers (involving patients with twenty health topics), only nine addressed the issue of collaboration between client and clinician when identifying research questions. These nine studies varied in health topics with patients’ ailments including metabolic and endocrine disorders, respiratory disease, nutritional, urology and genital disorders, infection, kidney disease and mental health issues. As policy supports stakeholder contribution, client and clinician priority setting may be seen to be a largely academic exercise. However, Stewart et al (2010) findings indicated that researchers were being made aware of patients and clinicians experiences regarding their health and their opinions relating to future research. This in turn aided in the development of new ideas for methods such as consent and recruitment, and contributed to the development of assessment tools for clinical practice (Stewart and colleagues 2010). Despite this approach by contributing stakeholders to shape research agenda’s, PWA continue to experience exclusion which prohibits their involvement in research priority setting and participation from research in general.

The process of consent is interlinked with complex spoken and written language (Brady et al 2007). However, modification of documentation to aid communication can be made by using pictures, symbols, aphasia friendly text, larger font size, and
simplified sentence structures. PWA regardless of severity levels can participate successfully in research using these communication tools, and this has been demonstrated in qualitative research conducted by Hinckley et al (2013) and Worrall et al (2010). Both studies incorporated maximum variation sampling in order to obtain diverse sampling from participants, allowing for the inclusion of those with severe aphasia. The use of communication tools, semi-structured interviews, and supported conversation techniques allowed for the interview to be accessible to those with aphasia. Hinckley and colleagues (2013) implemented the use of a communication partner to assist in completing their study.

*James Lind Alliance (JLA) and Future Research Priority Setting*

The JLA works in collaboration with multiple stakeholders to address systematic identification and prioritization of the most critical needs (Petit-Zeman et al 2010). The methodology involved four stages including; establishing a collaborative working partnership, collecting treatment uncertainties using patient survey, the analysis of existing systematic reviews and categorising of uncertainties, and finally the convening of a workshop. Elwyn et al (2010) conducted a survey utilising the James Lind Alliance (JLA) methodology to ascertain the top ten research uncertainties involving stakeholder suffering from or working with those with respiratory disease. Their findings highlighted treatment uncertainties that had not previously been identified in the literature (Elwyn et al 2010). The results from this study give weight to the argument that greater PWA involvement would benefit future research. This questions the research priorities of funding bodies and how they may not be completely in the best interests of patients and their clinicians. Pollock et al (2012) conducted a study in collaboration with the JLA and the priority setting partnership (PSP) to establish the top ten research priorities for life after stroke. A steering group ensured that submission to the procedure was not constrained, enabling participants to use their own interpretation of the phrase ‘life after stroke’ and insuring the exclusion of PWA did not occur. The information was presented using a presentation graphics software programme (PowerPoint), with an audio version of the questionnaire implemented for those with visual or reading problems. Aphasia friendly text and information sheets, both written in plain English, were used in gathering treatment uncertainties across electronic, mail and visual formats. Face to face interviews were also held and the use of communicative partners was sourced. Ten research uncertainties were established as priority by stakeholders, with the intention for this information to help further research and inform
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decisions about healthcare (Pollock et al 2012). Communication was the third research uncertainty highlighted by the stakeholders, warranting further investigation to determine the top ten research priorities relating to life with aphasia.

There are currently a number of studies utilising communication tools that have been successfully applied in assisting PWA to contribute to research (Hinckley et al 2013; Pollock et al 2012; Worrall et al 2010). Presently there is insufficient research being conducted involving PWA, particularly pertaining to their future research priorities. It has been shown that it is of the utmost importance that both researching bodies and aphasia organisations need to facilitate public awareness, promote inclusion and accessibility in research, and address the issues that are most important to PWA and other stakeholders (Pollock et al 2012; WHO and The World Bank, 2011).

Utilising the JLA methodology approach in aphasia research is essential as the literature has demonstrated that PWA’s are less empowered and their opinions regarding future research treatments have not been previously sought. Furthermore, by devising this partnership, the stakeholders can identify important research that they would like future researchers to address. In order to determine future aphasia research priorities, a research project was carried out from November 2014 to March 2015. The outcomes obtained from this project aim to influence and develop future direction in aphasia research.

**Objectives**

The objectives of this research project are:

- To identify the top ten research priorities relating to long-term aphasia following stroke.
- To insure the data sample comprises of PWA (including all severity types following stroke), caregivers, and SLT’s (working in acute, rehabilitation and community settings).
- To increase relevance of research by involving PWA in identifying research priorities.
- To evaluate the combined research priority findings from all participants.
- To use the study’s findings to influence future direction in aphasia research.
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Methodology

Ethical Consideration

Ethical approval was sought and authorised by the Faculty of Education and Health Sciences Research Ethics Committee at the University of Limerick. The criteria for inclusion consisted of the following:

- All participants needed to be over eighteen years
- Can be any gender and ethnicity
- The aphasia must have been as a result of a stroke
- No restriction relating to the length of time since the stroke
- PWA could experience a mild, moderate or a severe level of aphasia
- Caregivers needed to be the principal carer for the PWA
- The SLT’s needed to work in the acute, community or rehabilitation setting with PWA

Potential risks to the participant were identified such as emotional distress, with the researcher allowing the participant to withdraw from the questionnaire at any time if this occurred. All questionnaires were anonymous and confidentiality rules were strictly adhered to.

Project Design

The project is a quantitative questionnaire based research design, which comprised of four phases:

First Phase - The current research project is a follow up study to Pollock’s research, which determined aphasia to be the third highest research priority to life following stroke. The postgraduate researcher received training for one day in the James Lind Alliance (JLA) methodology taught by Dr Alex Pollack at Glasgow Caledonian University, Scotland. The JLA methodology is a UK health initiative, funded by the National Institute for Health Research (NIHR), which ensures meaningful client and clinician involvement in research priority setting. The current project adopted the JLA methodology which is designed to highlight what is most important to the stakeholders involved to ensure correct focus for those conducting research in the specialist area. For this current project, thirty four research uncertainties identified in the Pollock study that related to aphasia were utilized.

Second Phase - A questionnaire comprising of the thirty four research uncertainties was developed and delivered through four different formats. Firstly, to
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ensure accessibility across all severity levels experienced by PWA, the questionnaire was designed to be administered in one of two methods, an aphasia friendly text questionnaire and a picture based questionnaire (see Appendix A and B). A paper based questionnaire was created to be used by carers, with the fourth design taking the form of an online survey development cloud based programme “SurveyMonkey”, aimed to be completed by SLT’s. Additionally, during this phase, a pilot study was completed prior to distribution of the questionnaire. Three speech and language therapists reviewed the research uncertainties, with two having a high level of experience working with this client group. Questions and materials were then modified following their advice.

Third Phase - Data collection was carried out during the third phase. The questionnaire was administered in the following ways;

1. Face-to-face meetings - The researcher attended four aphasia support groups associated with the Irish Heart Foundation. An information pack, consent forms and a paper questionnaire (see Appendix C, D and E) were sent to the stroke club organiser (an SLT) detailing our research four weeks prior to our attendance. Discussions about the project were conducted between the stroke club organiser and PWA prior to the researcher attending the aphasia group. The researcher delivered a short presentation using simple English, prompts, gestures and images, to facilitate all severity levels of aphasia. The PWA and their carer were offered the opportunity to participate. The questionnaire was also administered to stroke club organisers during this time. An information sheet and consent form was given to each participant with consent obtained prior to distribution of the questionnaire.

2. Mail - Project information, response forms (see Appendix F), and prepaid return envelopes were posted to speech and language therapists associated with the Irish Heart Foundation who are responsible for organizing monthly aphasia and stroke club meetings. Apart from completing the questionnaires with PWA in the aphasia club, the researcher wished to visit the PWA in their home environment maximizing the amount of data collected. The aphasia club organisers and PWA consented to this procedure, which also facilitated PWA who were unable to attend stroke club meetings. Researchers visited participants in pairs to administer the questionnaire (garda vetting had been previously completed, and departmental health and safety procedures were adhered to).
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3. E-mail - The questionnaire was emailed to SLT’s working with aphasic’s in acute, community and rehabilitation settings. The health professional was emailed the project information and asked to submit their personalised top ten via “SurveyMonkey”. The completed and returned questionnaire via survey monkey was taken as evidence of consent.

Fourth Phase: Unfortunately the fourth phase could not be completed during the timeframe of this project. A plenary meeting will be held reviewing the top twenty research uncertainties identified from this study which are outlined in appendix G of this paper. This meeting will take place in the University of Limerick and attended by PWA, carers and SLT’s. During this meeting, a consensus will be reached on the final top ten research priorities.

Considerations when communicating with someone with aphasia

The researcher aimed to engage with the individual with aphasia prior to administering the questionnaire. The questionnaire was administered away from the group in order allow for maximum focus on the task at hand. During this time an explanation and the rationale behind the study were given, with the researcher emphasizing the importance of determining the research uncertainty questions the PWA would like future research to investigate. The questionnaire was administered depending on the clients’ preference, needs and level of severity. The researcher spoke in clear English, using simple language and gesture to convey meaning. Questionnaires were delivered on a one-to-one basis, with the researcher reading the uncertainty slowly and aloud. No time constraints were implemented so as to ensure the participant did not feel hurried, with the research questions being repeated if required. To minimize any research bias, the questionnaire was always given in the same format. Each research question/picture was printed and laminated individually. Once the PWA made their decision, their chosen question was placed into one of three different piles; very important, quite important and not important (aphasia friendly font theme and size on three different coloured paper). The research uncertainties were then taken from the ‘very important’ pile and the PWA ranked each uncertainty from one to ten. The individual personal top ten priorities were then transcribed onto a scoring sheet.

Participants

A large original sample size (n=117) of potential participants were identified to insure optimal levels of inclusion across all stakeholders. Initially, during phase three, it was intended that a total of fifty SLT’s were to be emailed (assuming a response rate of
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less than fifty per cent). However, this number increased to a total of one hundred and three, as response rates were low. It was hoped that twenty PWA, ten caregivers and three stroke club organizers would be recruited. During phase four, it was hoped that ten SLT’s, eight PWA, six caregivers and one coordinator would be recruited, however phase four is to be completed at a later date. PWA and their carers were sourced through stroke and aphasia group gatekeepers associated with the Irish Heart Foundation. SLT’s were sourced from the clinical therapies database in the University of Limerick.

Scoring System

A questionnaire asked participants to identify their top ten research uncertainty. They were then asked to rank their selected top ten, with one being the highest priority, through to ten being the lowest priority. Each question ranked resulted in a scoring system as follows; one (10 points), two (9 points), three (8 points), four (7 points), five (6 points), six (5 points), seven (4 points), eight (3 point), nine (2 points) and ten (1 point).

Results

Total Number of Participants

A total number of participants (n=49) completed the questionnaire. Three contributors were excluded due to not fitting the research criteria, with one individual experiencing aphasia as a result of a traumatic brain injury (TBI), and the other PWA and her carer excluded due to a primary progressive aphasia (PPA). The final number of participants included was forty six; PWA (n=21; seventeen males and four females), with all twenty one participants experiencing chronic aphasia (> one year post onset). The level of aphasia severity was assessed by the researcher, and the stroke club organisers confirmed each participant’s level. This included participants with mild (n=4), moderate (n= 11), and severe (n= 6) aphasia. The overall number of SLT’s (n=16; one male and fifteen females), Stroke Club Organisers (n=2; zero males and two females), and carers (n=7; one male and six females).

Calculating the Results

Each completed questionnaire containing the participants top ten and priority ranked order was entered into an excel spreadsheet and categorised into four groups; PWA group, Carer’s group, SLT’s group, and the overall combined group (including the PWA, carer’s and SLT’s). The three participating groups and combined group findings were determined using two approaches. Firstly, each personalised ranked top ten was entered into the database which contained the thirty four research uncertainties.
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This gave the total combined score for each research uncertainty. Secondly, the number of times each question was selected was then entered into the system. When findings revealed the same outcome for two or more research questions, the question ranked by more stakeholders had a greater shared priority offering a higher ranking status. Results from the three participant groups were combined to determine the overall top ten future research priority questions. These results were analysed by three independent researchers and then checked for reliability.

Results can be considered under five categories; ‘Service Delivery’ (x3), ‘Communicating with someone with aphasia’ (x3), ‘Aphasia-carers and families’ (x 1), ‘Aphasia and cognition’ (x 1), and ‘Type of treatments’ (x 2). The top four overall findings highlighted research uncertainties that directly correlate to type of speech and language therapy, and three service delivery issues. Two research priorities were associated with communicating with someone with aphasia, focusing on communication strategies, and wanting to determine whether social groups increase confidence in PWA. The remaining four priorities fell under the headings ‘Aphasia – Carer’s and Family’, ‘Aphasia and Cognition’, and two further treatment issues; to determine which therapy treatment works best for aphasia, and the use of structured sentence therapy. Overall combined result demonstrated interesting findings, with the first two research priorities selected being present in all three participant groups. The combined stakeholders’ top ten research priorities can be viewed in table one.
Table 1: The Top Ten Overall Combined Results

<table>
<thead>
<tr>
<th>Top 10</th>
<th>Top 10 Research Priority</th>
<th>PWA</th>
<th>SLT</th>
<th>Carer</th>
<th>Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When is the best time after stroke to deliver speech and language therapy? (Service Delivery)</td>
<td>82</td>
<td>67</td>
<td>27</td>
<td>176</td>
</tr>
<tr>
<td>2</td>
<td>Which speech and language therapy treatments work best for aphasia? (Specific treatment)</td>
<td>92</td>
<td>50</td>
<td>16</td>
<td>158</td>
</tr>
<tr>
<td>3</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia? (Service Delivery)</td>
<td>24</td>
<td>81</td>
<td>15</td>
<td>120</td>
</tr>
<tr>
<td>4</td>
<td>Is speech and language therapy helpful for patients more than 1 year after a stroke? (Service Delivery)</td>
<td>74</td>
<td>29</td>
<td>15</td>
<td>118</td>
</tr>
<tr>
<td>5</td>
<td>Do communication aids and software packages improve communication in patients with aphasia? (Communicating with someone with aphasia)</td>
<td>25</td>
<td>76</td>
<td>11</td>
<td>112</td>
</tr>
<tr>
<td>6</td>
<td>How can carers be helped to communicate with someone with aphasia? (Aphasia – Carers &amp; Families)</td>
<td>50</td>
<td>28</td>
<td>29</td>
<td>108</td>
</tr>
<tr>
<td>7</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia? (Communicating with someone with aphasia)</td>
<td>49</td>
<td>7</td>
<td>37</td>
<td>93</td>
</tr>
<tr>
<td>8</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke? (Communicating with someone with aphasia)</td>
<td>27</td>
<td>47</td>
<td>18</td>
<td>92</td>
</tr>
<tr>
<td>9</td>
<td>What is the best way to improve understanding (cognition) after stroke? (Aphasia &amp; Cognition)</td>
<td>42</td>
<td>32</td>
<td>14</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>(Selected 21 times)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to improve the production of structured sentences in people with aphasia? (Specific treatment)</td>
<td>46</td>
<td>32</td>
<td>10</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>(Selected 15 times)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

*Literature Surrounding the Top Ten Research Priorities*

An evaluation of the literature representing the combined top ten research uncertainties was investigated. An analysis was conducted using database searches including; Web of Science, Database of Research in Stroke (DORIS) and PubMed. The selection criteria incorporated standard search words including ‘aphasia’, initially however specific phrases were then inserted including ‘aphasia following stroke’. The
Top ten research priorities relating to long-term aphasia following stroke

researcher then entered key words from each of the top ten research questions e.g., ‘best time for speech and language treatment’, ‘improve structured sentences’ ‘carers be helped’ into the database search. The overall combined research uncertainties entered resulted in less than twelve per cent of the current literature search representing these uncertainties. This highlighted the lack of relevant literature associated with these top ten research questions relating to life with aphasia following stroke. The graph below represents the dearth of research available.

1.1 Graph representing the current literature
Top ten research priorities relating to long-term aphasia following stroke

*Individual Group Results*

The individual groups top ten research uncertainties were identified and are demonstrated in table two (PWA), table three (SLT’s), and table four (carer’s).

**Table 2: PWA’s Results**

<table>
<thead>
<tr>
<th>Top 10</th>
<th>Top 10 Research Priority</th>
<th>PWA Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Which speech and language therapy treatments work best for aphasia? (Specific Treatment)</td>
<td>92</td>
</tr>
<tr>
<td>2</td>
<td>When is the best time after stroke to deliver speech and language therapy? (Service Delivery)</td>
<td>82</td>
</tr>
<tr>
<td>3</td>
<td>Is speech and language therapy helpful for patients more than 1 year after a stroke? (Service Delivery)</td>
<td>74</td>
</tr>
<tr>
<td>4</td>
<td>How can carers be helped to communicate with someone with aphasia? (Aphasia-Carers &amp; Families)</td>
<td>50</td>
</tr>
<tr>
<td>5</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia? (Communicating with someone with aphasia)</td>
<td>49</td>
</tr>
<tr>
<td>6</td>
<td>What is the best way to improve the production of structured sentences in people with aphasia? (Specific Treatments)</td>
<td>46</td>
</tr>
<tr>
<td>7</td>
<td>Can trained volunteers and carers help improve communication after stroke? (Aphasia-Carers &amp; Families)</td>
<td>45</td>
</tr>
<tr>
<td>8</td>
<td>What is the best way to manage feelings of panic due to aphasia? (Aphasia &amp; Depression)</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>(Selected 9 times)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>What is the best way to help people with aphasia return to driving after stroke? (Service Delivery)</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>(Selected 8 times)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to treat depression in people with aphasia following a stroke? (Aphasia &amp; Depression)</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>(Selected 8 times)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to improve understanding (cognition) after stroke? (Aphasia &amp; Cognition)</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>(Selected 8 times)</td>
<td></td>
</tr>
</tbody>
</table>
Top ten research priorities relating to long-term aphasia following stroke

Table 3: Carer’s Results

<table>
<thead>
<tr>
<th>Top 10</th>
<th>Top 10 Research Priority</th>
<th>Carer Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia? (Communicating with someone with aphasia)</td>
<td>37</td>
</tr>
<tr>
<td>2</td>
<td>How can carers be helped to communicate with someone with aphasia? (Aphasia- Carers &amp; Families)</td>
<td>29</td>
</tr>
<tr>
<td>3</td>
<td>When is the best time after stroke to deliver speech and language therapy? (Service Delivery)</td>
<td>27</td>
</tr>
<tr>
<td>4</td>
<td>What is the best way to help people recover from aphasia? (Service Delivery)</td>
<td>24</td>
</tr>
<tr>
<td>5</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke? (Communicating with someone with aphasia)</td>
<td>18</td>
</tr>
<tr>
<td>6</td>
<td>Which speech and language therapy treatments work best for aphasia? (Specific treatment)</td>
<td>16 (Selected 3 times)</td>
</tr>
<tr>
<td>7</td>
<td>What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairments? (Aphasia &amp; Cognition)</td>
<td>16 (Selected 2 times)</td>
</tr>
<tr>
<td>8</td>
<td>Can trained volunteers and carers help improve communication after stroke? (Aphasia- Carers &amp; Families)</td>
<td>15 (Selected 4 times)</td>
</tr>
<tr>
<td>9</td>
<td>Can transcranial magnetic stimulation help people with aphasia? (Specific Treatment)</td>
<td>15 (Selected 2 times)</td>
</tr>
<tr>
<td>9</td>
<td>Is speech and language therapy helpful for patients more than 1 year after a stroke? (Service Delivery)</td>
<td>15 (Selected 2 times)</td>
</tr>
<tr>
<td>9</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia? (Service Delivery)</td>
<td>15 (Selected 2 times)</td>
</tr>
<tr>
<td>10</td>
<td>What is the best way of giving information about stroke to someone with aphasia? (Communicating with someone with aphasia)</td>
<td>14</td>
</tr>
</tbody>
</table>
Table 4: SLT’s Results

<table>
<thead>
<tr>
<th>Top 10</th>
<th>Top 10 Research Priority</th>
<th>SLT Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia? (Service Delivery)</td>
<td>81</td>
</tr>
<tr>
<td>2</td>
<td>Do communication aids and software packages improve communication in patients with aphasia? (Communicating with someone with aphasia)</td>
<td>76</td>
</tr>
<tr>
<td>3</td>
<td>When is the best time after stroke to deliver speech and language therapy? (Service Delivery)</td>
<td>67</td>
</tr>
<tr>
<td>4</td>
<td>Has the HSE National Clinical Programme for Stroke impacted on the provision of services for patients with long term communication problems following stroke? (Service Delivery)</td>
<td>57</td>
</tr>
<tr>
<td>5</td>
<td>Which speech and language therapy treatments work best for aphasia? (Specific treatment)</td>
<td>50</td>
</tr>
<tr>
<td>6</td>
<td>What is the best way to help people with aphasia return to work? (Service Delivery)</td>
<td>48</td>
</tr>
<tr>
<td>7</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke? (Communicating with someone with aphasia)</td>
<td>47</td>
</tr>
<tr>
<td>8</td>
<td>Can cognitive behavioural therapy (CBT) help recovery of speech? (Specific Treatment)</td>
<td>37</td>
</tr>
<tr>
<td>9</td>
<td>Can Adult Education improve stroke acquired literacy/numeracy problems? (Aphasia &amp; Cognition)</td>
<td>36</td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to diagnose and assess depression in people with aphasia following a stroke? (Aphasia &amp; Depression)</td>
<td>35</td>
</tr>
</tbody>
</table>

Comparison of the PWA, Carer and SLT Groups

All three participating groups prioritised service delivery and treatment issues, focusing on ‘best treatments’ and ‘best time’ to deliver speech and language therapy in order to enhance recovery from aphasia. As expected, the research priorities selected by the PWA and the carer groups correlated significantly, with six priorities in common. The PWA and carer groups’ future research questions were centred on how to
communicate with someone with aphasia, family and carers, and approaches to enhance communication through training and the development of strategies. Findings indicated that PWA in particular focused on psychological well-being such as ‘managing feelings of panic’ and finding out the ‘best way to treat depression’. A further future research question expressed explicitly by PWA related to a ‘specific treatment’, particularly, how to improve the production of structured sentences in aphasics, a question not selected by either carer or SLT participating groups. The carers alone selected future research uncertainties including; the investigation of a different specific treatments (transcranial magnetic stimulation), how best to give information to PWA, improving carer techniques, and improving recovery for those living with aphasia.

The SLT group determined that future research should include the best way to improve the assessment and diagnosis of depression in PWA. Four identical research uncertainties were noted between the SLT and carers groups, with two research uncertainties corresponding to social communication groups and treatments that work best for aphasia. The SLT group focused on treatments issues such as, determining if Cognitive Behavioural Therapy (CBT) improves recovery of speech, and the evidence and efficacy of communication aids and software packages. The SLT group focused on PWA returning to work. When this was further examined, over half of the SLT group selected this priority compared to just four PWA and one carer. SLT’s who selected this priority worked in an acute setting. Most PWA in the study were of retirement age. It is hoped our findings will enhance investigations in the area of aphasia, determining what is important to those affected by and living with aphasia.

Discussion

The purpose of this study was to determine the top ten research priorities relating to life with aphasia following stroke, with data collected from PWA, carers and SLT’s. The top ten future research uncertainties have been identified, and the findings have been analysed. Each participating group’s top ten research uncertainties have also been identified. As expected, research uncertainties determined by PWA and their carer’s were different to the SLT’s. The projects findings highlighted four research priorities from the combined top ten related to service delivery and speech and language treatments. This section will review service delivery and the evidence regarding speech and language treatments specific to aphasia, as well as psychiatric concerns experienced by PWA.
Top ten research priorities relating to long-term aphasia following stroke

Service Delivery

The guidelines and literature relating to the effectiveness of models of intervention to service delivery in aphasia remain limited (RCSLT 2009). Evidence suggests the need for highly individualised therapy tailored to the individuals’ needs and capabilities (Kelly et al 2010). A Cochrane review reported by Kelly and colleagues (2010), suggested that improved treatment outcomes result from intensive one-to-one therapy (very intense treatment over a short period), rather than conventional therapy. However these intensive treatments led to a higher withdrawal rate in patients. Basso (2005) recommended that treatment for aphasia works better if it is of high intensity and of a longer duration. PWA report not being informed about the nature and implications of aphasia, and are unaware of services they can receive (NHS 2007). There is disparity in what is considered to be the optimum number of therapy sessions, which these including assessment, diagnosis, counselling, and specific therapy treatments (Code and Heron 2003; Verna et al 2009). One-to-one services provided by the clinician may be problematic due to the SLT’s duties extending beyond the remit of one-to-one therapy. These additional duties include liaising and training family members and carers, in turn leading to a reduced amount of time allocated to being spent with the individual with aphasia (NHS 2007). Lanyon and colleagues (2013) suggest that group therapy may improve specific linguistic processes and social participation, however there is limited evidence showing improvements in functional communication as a result of group therapy. There is inadequate and conflicting research relating to the effectiveness of service delivery in the area of aphasia (Raymer et al 2008).

Speech and Language Therapy Treatments

Maximising the individual with aphasia’s ability to communicate is the principal goal for speech and language therapy in aphasia management (Brady et al 2010). Rehabilitation outcomes vary from person to person, with recovery depending on age of the individual, and the severity of the stroke (Croquelois and Bogousslavsky 2011; Kyrozis et al 2009). The most severe form of aphasia is associated with poorer recovery rates (Laska et al 2001; Pedersen et al 2004). The most effective means of treating aphasia has yet to be decided (Sanjit 2002), and studies investigating the efficacy of treatments have yielded conflicting findings (Salter et al 2013). A Cochrane review by Greener et al (2008) emphasises the importance of functional therapy approaches, indicating that rehabilitation must aim to maximise successful communication in everyday interactions. Reviewing specific therapy treatments can be difficult due to the
extensive amount of heterogeneous studies, which have demonstrated to be of poor design, low quality, and contain small sample sizes (Salter et al 2013).

**Depression, Anxiety and Panic Attacks**

Research has shown that sixty to eighty per cent of patients with aphasia will experience depression, well above general population rates (Cocchini *et al* 2013; Hackett *et al* 2005; NHS 2012; Paolucci 2008). Depression is a major pathological condition frequently observed in PWA that significantly impacts on quality of life leading to infrequent participation and social isolation (Thomas and Lincoln 2008). The findings from this study demonstrated PWA selected two future research healthcare priorities pertaining to depression and how to manage feelings of panic. Anxiety disorders are the most common mental health problems worldwide (Kessler *et al* 2012). Therefore, depending on the individual’s level of anxiety prior to the stroke, and due to the multiple co-morbidities associated with the disorder such as pain, fatigue, hemiplegia etc., as well as a communication deficit, feelings of panic may increase and be intensified. The Diagnostic and Statistical Manual of Mental Disorders – 5 (DSM-V) classify anxiety disorders as a collection of individual syndromes. As a result, anxiety disorders observed in PWA may be classified under the DSM-V as being associated with a medical condition (Asmundson *et al* 2014). A case report by Caixeta and Caixeta (2011), reported that panic attacks manifest as an early symptom in people with PPA. Although the biological correlation between PPA and aphasia post stroke are vastly different, the experience of panic may be similar in PWA following stroke, which warrants future investigation. A meta-analysis and a systematic review conducted by Campbell-Burton *et al* (2012) reported a large number of studies examining the frequency of depression and anxiety post stroke. However, very little research into anxiety impairments has been conducted with PWA. A study conducted by De Wit *et al* (2008) cited in Brumfitt (2010, p 2) examined the prevalence of depression as well as anxiety in five hundred people six months post-stroke. The study was not specifically aimed at people with an acquired communication disorder. Their findings revealed that twenty four to thirty percent of participants experienced depression, with twenty two to twenty five percent experiencing anxiety (De Wit *et al* 2008). These results may offer guidance and direction into understanding the prevalence of anxiety in individuals post stroke, with the incidence of anxiety predicted to be even greater in those with communication impairments (Brumfit 2012, p2). Future research needs to provide
Top ten research priorities relating to long-term aphasia following stroke

inclusion of PWA into research and further investigate the prevalence of anxiety disorders, specifically panic attacks associated with the communication impairment.

Limitations

A limitation to this study was the difficulty accessing PWA and their carer’s. This was due to the irregularity of when group meetings occurred, with some conducted monthly, and others bi-monthly. Depending on geographical area, better services were provided within a particular county, with some having just one area to conduct the group meetings with no services being provided for the rest of the county. Some counties were noted to have limited resources with no service provided to conduct group meetings. Additionally, due to time constraints, it was not possible to attend specific meeting dates.

Strengths to the research project & implications and future research

The inclusion of all severity levels of PWA (mild (n=4), moderate (n= 11), and severe (n= 6) aphasia) strengthened this research. This was accomplished through a rigorous approach using aphasia friendly tools and communication ramps, allowing for the participation of all PWA in this study. This project has demonstrated that PWA can successfully participate in research once specific tools and strategies are in place to assist them. It is hoped that future aphasia research can adopt the methods used in this project including explanation tools, gaining consent, and allowing for inclusion and full participation regardless of severity level. Further investigations are warranted to explore the research priorities determined in this project, with particular attention to service delivery, speech and language therapy treatments, communicating with someone with aphasia, depression and addressing the feelings of panic in PWA.

Conclusion

This project set out and successfully worked in partnership with all stakeholders affected by aphasia to determine future research priorities. By attaining fundamental information never sought before, it now offers direction for future research setting, by continuing to improve clinical practice and service. The top ten research priorities relating to life with aphasia following stoke have been identified using a systematic and person-centred approach. To date, there is limited research addressing the top ten research priorities determined in this project. Conflicting research exists concerning how to successfully obtain positive outcomes within service delivery and from speech and language therapy treatments. Future research needs to be conducted to address these research priorities determined in this study to enhance inclusion, promote recovery and
Top ten research priorities relating to long-term aphasia following stroke

participation within society. The World Report on Disability (WHO and The World Bank 2011) called for an increase in research relating to disability that occurs in collaboration with the consumer, to strengthen and support disability research. This project has shown that PWA, regardless of severity level, can successfully participate in research once communication strategies are implemented. It is hoped that the findings from this research project should allow for greater funding for future research relating to life with aphasia following stroke.
References


Databases

Database of research in stroke (DORIS), [online], available: http://www.askdoris.org/tcd_t1.asp?opt=2709


The Cochrane Collaboration, [online], available: http://www.cochrane.org/

Web of Science, [online], available: http://www.cochrane.org/

Websites


www.aphasia United, [online], available: http://www.aphasiaunited.org
1. Which **speech and language therapy** treatments **work best** for aphasia?

4. What is the best way to **improve understanding** (cognition) after stroke?
1. Best Treatments

2. Slowing down

Providing written material

Allowing time for questions

conversation partners help?
3. How can carers be helped to communicate?

HUSBAND  WIFE

4. Best way to improve understanding?

5. Instrument help?

6. Can trained volunteers and carers help improve communication after stroke?
7. What **stimulation techniques** are **useful** for enhancing the engagement of stroke patients with severe **understanding** and **communication impairments**?

8. Group speech therapy

Or

Individual Therapy

Cost less?
9. Music therapy & art therapy help?

10. How can carers to manage depression?
11. Communication aids and software packages

12. Cognitive behavioural therapy

Good?
13. How much therapy?

14. When is the best time for Speech and language therapy?

15. Is speech and language therapy helpful more than 1 year after a stroke?
17. Diary

Good?

18. Where to get therapy?

Community Or Hospital
19. Return to work?

20. Best way
Treat depression?
21. Can education help?
   Reading & number problems?

22. Return to driving?
   How?
23. Can supported communication training for carers help prevent relationship breakdown?

24. What is the best way to improve the production of structured sentences in people with aphasia?

25. Recover from aphasia How?
26. Diagnose depression

How?

27. Manage pain

How?

28. Is conversation partner training good?

![Thumbs up emoji]
29. Do social communication groups improve confidence in people with communication problems after stroke?

30. Stop panic?

How?
31. How can stroke survivors and families be helped to cope with speech problems?

32. Transcranial magnetic stimulation

Good?

33. Is non-linguistic cognitive training effective for aphasia?
34. HSE National Clinical Programme for Stroke

Helped?
Top 10 research priorities relating to long-term aphasia following stroke - consensus from people with aphasia, caregivers and health professionals
This is a student project. The student researchers are:

Dearbhla Harhen
Michelle Hayes
Sasha McManus

They are Speech and Language Therapy MSc students at the University of Limerick
And are supervised by Professor Sue Franklin

This information booklet tells you about the research and how you can help
Why is this study being done?

The students will **write reports**

They will **give** them to the **University of Limerick**

This is part of their **Masters of Science**

This report will go into a **journal** for other SLTs to **read**

---

Why I am being asked to take part?

You have an interest in deciding what are the important areas for aphasia research
What is the research project about?

The research asks people what kind of aphasia research should be carried out.

What will happen?

You will be asked to fill in a questionnaire.

It will take 20 minutes.

You will:

Look at all the research priorities suggested.

You will rate your top 10.

Where will the research take place?

At your stroke club
At a time to suit you

Confidentiality and Privacy

All information is kept private and safe

Your name will not be used

We will NOT look at your medical records

What are the benefits?

We hope to influence research funding

What are the risks?

You will be giving 20 minutes of your time.
**Taking part in the research**

You are **free** to decide if you want to **take part**

Filling in the questionnaire signifies you consent

You are **free** to **stop** at any time

You **do not** have to give a **reason** for stopping

**Other Information**

You can contact:

Sue Franklin, Professor of Speech and Language Therapy

061 234274

**Thank you for reading this!**

If you have any concerns about this study and want to contact someone independent you may contact:

Chairman Education and Health Sciences Research Committee

EHS Faculty Office, University of Limerick

Tel 061 234101 Email: [ehsresearchethics@ul.ie](mailto:ehsresearchethics@ul.ie)
I _________________________ of ____________________ hereby,

*consent* to *participate* in a research project:

**Top 10 research priorities relating to long-term aphasia following stroke - consensus from people with aphasia, caregivers and health professionals**

Date ____________________________

The *purpose* of the *research* was explained to me by

________________________________
I read the information leaflet

I had an opportunity to ask questions

I was satisfied with the answers to my questions.

I understand the reason for the research

I understand what is involved

I understand that information is kept safe and private

**Testing:**

I agree to be tested

I know I can STOP doing the research at any time

| Date:_____________ Signature:__________________ | YES NO |
Life with Aphasia in Ireland: Research priorities

Thank you for taking part in our project to determine the top 10 priorities for future research relating to life with aphasia in Ireland.

We have 34 questions about treatment uncertainties which need further research. These questions have been gathered from the James Lind Alliance, established specifically to help involve patients in research priority setting.

These 34 questions have been developed as a result from interviews with stroke survivors, carers and health professionals. The questions are listed in this booklet.

We now want you to choose 10 questions, which you feel are highest priority for future research.

What is important is that they are your personal top 10.

- We know that this is a challenging task, however your top 10 is very important to us, and could change future stroke research in the area of aphasia.
- Your top 10 will be used in combination with those of other people with aphasia, carers and health professionals. They will then be discussed at a final consensus meeting where the final top 10 research priorities will be agreed on. It is our aim that these will be used to influence what future research is carried out.
INSTRUCTIONS:

1. Read through each question and make a tick next to the questions most important to you.
2. Go back to the start, reading the questions you have marked as important. Now rate the top 10 which are most important to you for future research in aphasia.
3. Rank your ten using 1 = most important, working through to 10 = least important, and enter the rank order in the second column.
4. Return the completed form to us.

The three speech and language therapy researchers (Dearbhla, Michelle and Sasha) will be present throughout this process. We will be there if you need any help.

Thank you!

Dearbhla, Michelle and Sasha.

For more information:

Dearbhla Harhen: 13012169@studentmail.ul.ie
Michelle Hayes: 13011952@studentmail.ul.ie
Sasha Mc Manus: 13011936@studentmail.ul.ie
### Important for Future Research in Aphasia

1. Which speech and language therapy treatments work best for aphasia?

2. Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia?

3. How can carers be helped to communicate with someone with aphasia?

4. What is the best way to improve understanding (cognition) after stroke?

5. Can playing an instrument help improve communication problems?

6. Can trained volunteers and carers help improve communication after stroke?

7. What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairments?

8. Is group speech and language therapy better and does it cost less than individual speech and language therapy?

9. Can music or art therapy help people with aphasia?

10. What is the best way for carers to manage depression in people with aphasia following stroke?

11. Do communication aids and software packages improve communication in patients with aphasia?

12. Can cognitive behavioural therapy (CBT) help recovery of speech?

13. What is the best amount and intensity of speech and language therapy for aphasia?

14. When is the best time after stroke to deliver speech and language therapy?

15. Is speech and language therapy helpful for patients more than 1 year after a stroke?

16. What is the best way of giving information about stroke to someone with aphasia?

17. Does a ‘day diary’ to record activities etc., completed by visitors, help people with communication problems share...
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What has been happening?</td>
<td></td>
</tr>
<tr>
<td>18. Where is the best place to receive speech and language therapy (community or hospital)?</td>
<td></td>
</tr>
<tr>
<td>19. What is the best way to help people with aphasia return to work?</td>
<td></td>
</tr>
<tr>
<td>20. What is the best way to treat depression in people with aphasia following a stroke?</td>
<td></td>
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<tr>
<td>21. Can Adult Education improve stroke acquired literacy/numeracy problems?</td>
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<tr>
<td>22. What is the best way to help people with aphasia return to driving after stroke?</td>
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<td>23. Can supported communication training for carers help prevent relationship breakdown?</td>
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<td>24. What is the best way to improve the production of structured sentences in people with aphasia?</td>
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<tr>
<td>25. What is the best way to help people recover from aphasia?</td>
<td></td>
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<tr>
<td>26. What is the best way to diagnose and assess depression in people with aphasia following a stroke?</td>
<td></td>
</tr>
<tr>
<td>27. What is the best way to manage pain in patients with communication problems?</td>
<td></td>
</tr>
<tr>
<td>28. Is conversation partner training useful in management of aphasia after stroke?</td>
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<tr>
<td>29. Do social communication groups improve confidence in people with communication problems after stroke?</td>
<td></td>
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<tr>
<td>30. What is the best way to manage feelings of panic due to aphasia?</td>
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</tr>
<tr>
<td>31. How can stroke survivors and families be helped to cope with speech problems?</td>
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<tr>
<td>32. Can transcranial magnetic stimulation help people with aphasia?</td>
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</tr>
<tr>
<td>33. Is non-linguistic cognitive training effective for aphasia?</td>
<td></td>
</tr>
<tr>
<td>34. Has the HSE National Clinical Programme for Stroke impacted on the provision of services for patients with long term communication problems following stroke?</td>
<td></td>
</tr>
</tbody>
</table>
## MY TOP 10 QUESTIONS

<table>
<thead>
<tr>
<th>Chosen 10 questions ID</th>
<th>Priority 1= most important 10= least important</th>
<th>Full text of question (optional) This may help you rank you 10.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Reference I.D:

- Individual with aphasia □  Individual carer □

Sex:  Male □  Female □

Severity of Aphasia:  Mild □  Moderate □  Severe □
APPENDIX: F

Please send us this form back with your answer in the enclosed stamped envelope provided.

By ticking ‘Yes’, this means that you are happy for us to come visit you, just don’t forget to provide us with your details so we can contact you.

By ticking ‘No’, this means that this is not convenient for you right now and there is no need to provide us with your details.

Thank you very much for your time!

I am happy for you to come visit me:  Yes               No

My name:__________________________________________________

My address: ________________________________________________
___________________________________________________________
___________________________________________________________
___________________________________________________________
My phone number: ___________________________________________
# APPENDIX: G

<table>
<thead>
<tr>
<th>Top 20</th>
<th>Score</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>176</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
</tr>
<tr>
<td>2</td>
<td>158</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
</tr>
<tr>
<td>3</td>
<td>120</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
</tr>
<tr>
<td>4</td>
<td>118</td>
<td>Is speech and language therapy helpful for patients more than 1 year after a stroke?</td>
</tr>
<tr>
<td>5</td>
<td>112</td>
<td>Do communication aids and software packages improve communication in patients with aphasia?</td>
</tr>
<tr>
<td>6</td>
<td>108</td>
<td>How can carers be helped to communicate with someone with aphasia?</td>
</tr>
<tr>
<td>7</td>
<td>93</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia?</td>
</tr>
<tr>
<td>8</td>
<td>92</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke?</td>
</tr>
<tr>
<td>9</td>
<td>88</td>
<td>What is the best way to improve understanding (cognition) after stroke?</td>
</tr>
<tr>
<td>10</td>
<td>88</td>
<td>What is the best way to improve the production of structured sentences in people with aphasia?</td>
</tr>
<tr>
<td>11</td>
<td>88</td>
<td>What is the best way to help people with aphasia return to work?</td>
</tr>
<tr>
<td>12</td>
<td>85</td>
<td>What is the best way to help people recover from aphasia?</td>
</tr>
<tr>
<td>13</td>
<td>83</td>
<td>Has the HSE National Clinical Programme for Stroke impacted on the provision of services for patients with long term communication problems following stroke?</td>
</tr>
<tr>
<td>14</td>
<td>79</td>
<td>Can Adult Education improve stroke acquired literacy/numeracy problems?</td>
</tr>
<tr>
<td>15</td>
<td>77</td>
<td>What is the best way to diagnose and assess depression in people with aphasia following a stroke?</td>
</tr>
<tr>
<td>16</td>
<td>73</td>
<td>What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairments?</td>
</tr>
<tr>
<td>17</td>
<td>69</td>
<td>Can trained volunteers and carers help improve communication after stroke?</td>
</tr>
<tr>
<td>18</td>
<td>69</td>
<td>How can stroke survivors and families be helped to cope with speech problems?</td>
</tr>
<tr>
<td>19</td>
<td>67</td>
<td>What is the best way to help people with aphasia return to driving after stroke?</td>
</tr>
<tr>
<td>20</td>
<td>66</td>
<td>What is the best way to treat depression in people with aphasia following a stroke?</td>
</tr>
</tbody>
</table>