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**Title: Collaborative design of accessible information with people with aphasia**

Running head: Collaborative design of aphasia information

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Potential conflict of interest
R Herbert, C Haw and E Gregory co-authored with S Brumfitt and C Brown 'Accessible Information Guidelines' via the Stroke Association website in 2012, which were devised from the work carried out here.
https://www.stroke.org.uk/sites/default/.../accessible_information_guidelines.pdf1_.pd..
R Herbert C Haw and E Gregory developed the Communicate Stroke resource, based on the work described here, which was commissioned by the Stroke Association. Materials from that resource are integrated into the Stroke Association's new online information resource 'My Stroke Guide'. https://mystrokeguide.com/user

Disclosure statement
The authors are in receipt of no financial gain from the publication of this work or from any products emanating from this research.

**Abstract**

Background
People with aphasia report preferences for specially formatted health information materials, but there is little evidence that modified materials result in improved comprehension. Potential explanations for this include language included not taking account of aphasic processing difficulties, topics unrelated to aphasia, lack of clarity regarding the use of images, and the lack of end-user involvement in the design. Additionally, no definitive criteria for production of accessible information have been identified.

Aims
The first aim of this study was to collaborate with people with aphasia in an iterative design process to develop and finalise accessible information materials. The second aim was to identify definitive criteria for use in the future production of information materials for people with aphasia.

Methods and procedure
Prototype materials were developed for the study, based on criteria identified from the existing research into aphasia-accessible information, and on the evidence base concerning language processing in aphasia. Fourteen people with aphasia took part in two rounds of consensus group meetings and viewed information about aphasia presented within the prototype materials. Consensus points were identified within the groups through discussion and through ratings using Likert scales. The set of consensus points and ratings were adapted into criteria for graphic designers to incorporate into subsequent designs of the materials, in order to generate a final version, and related criteria.

Outcomes and results
The group discussions and the ratings of materials led to the identification of an agreed layout within which to present information, and specific criteria for the following: information consisting of one proposition expressed via everyday words and canonical syntactic forms; one or two images relating directly to keywords; sans serif typography with keyword emphasis. Individual preferences with regard to image types were identified. Novel criteria were identified in the study, relating to layout, language, images and typography. These were added to the original set of criteria to form definitive criteria for use in the development of accessible aphasia materials.

Conclusions
This study successfully involved people with aphasia in the design process to produce novel materials, and related design criteria. The resulting materials and criteria differ from those previously proposed, by reflecting directly people with aphasia's views and preferences, and by incorporating language and images suitable for people with aphasia, based on the existing research evidence and the outcomes of this study. The materials and criteria have the potential to improve people with aphasia's understanding of health information.

## Introduction

There exist no user-designed evidence-based materials for provision of information for people with aphasia, and no definitive criteria for use in adapting information materials for people with aphasia. In this study we aimed to rectify these gaps in the knowledge base. The study incorporated the main findings from research into language processing difficulties in aphasia, and the existing evidence concerning formatting factors people with aphasia state as preferred, to make novel materials. People with aphasia then collaborated in an iterative design process to produce a final version of the materials, and related criteria were identified from the points raised by the participants. The resulting materials represent the first user-designed information materials in the field of aphasia, and the criteria represent the first set of fully evidenced criteria for use with this population.

### *Health information*

There is growing evidence of the importance of effective accessible health information in enabling people to recover from and live with medical conditions. Information can aid in the understanding of one's medical condition (Coulter, Entwistle & Gilbert, 1999; Coulter & Ellins, 2006; McPherson, Higginson & Hearn, 2001), increase the uptake of and adherence to interventions (Myers & Calvert, 1984), positively affect people's involvement in decisions about their care (Stacey, Légaré, Col, et al., 2014), reduce anxiety (Humphris, Ireland, & Field, 2001), and increase autonomy and self-management (Murray, Burns, See-Tai et al., 2005). The above positive effects culminate in a potential reduction in people accessing health services, with consequent cost reductions (Johnson, Sandford, & Tyndall, 2003). This has also been found in the specific context of stroke (e.g. Smith, Forster & Young, 2009).

Most health information is provided in written form however, which presents barriers to anyone with difficulties processing written language, including those with acquired aphasia. Recent relevant initiatives aim to address this inequality, such as the World Health Organisation's (2011) stated global ambition to increase access for all, elucidated in their Health Literacy document. In the UK the NHS Accessible Information Standard provides advice regarding special formatting of information for a number of patient groups, using criteria developed by organisations such as the Plain English campaign. There is no agreed set of evidence-based criteria however for the specific needs of people with aphasia, and this study set out to rectify that situation.

In the specific context of stroke, respondents to McKevitt, Fudge, Redfern, et al.'s (2010) survey expressed a need for more information about stroke, and Sharma, Tridimas and Fitzsimmons (2014) found that information on stroke websites is too complex for people to process. Within acquired aphasia a number of studies report difficulties for people trying to access information. There is a reported need for information (e.g. Wallace, Worrall, Rose et al., 2017), but insufficient information is provided (Avent, Glista, Wallace et al., 2005; Rose, Worrall, McKenna et al., 2009; Rose, Worrall, Hickson, & Hoffmann, 2010). There is a risk that people with aphasia receive less information than those without aphasia (Eames, McKenna, Worrall & Read, 2003; Parr, Byng, Gilpin & Ireland, 1997). The actual written information has been found to be inaccessible to people with aphasia (Rose et al., 2010), the written

language shown to be too difficult to understand (Aleligay, Worrall & Rose, 2008), and the subsequent lack of information has been associated with reduced satisfaction with health services (Tomkins, Siyambalapitiya, & Worrall, 2013).

### *Accessible health information in aphasia*

Given the above findings, there is a need for more effective methods of making information about aphasia accessible. In this context the concept of aphasia-friendly or aphasia-accessible information was introduced by Parr, Pound and Hewitt (2006), which refers to the presentation of written information in such a format as to facilitate comprehension for people with aphasia. The organisation Connect developed information resources with people with aphasia (e.g. Parr, Pound Byng & Long, 1999), and methods for increasing inclusion (Parr, Wimborne, Hewitt & Pound, 2008; Pound, Duchan, Penman et al., 2007), including particular formatting modifications which people with aphasia reported as preferred. This includes simpler language, images to support text, and bold text to highlight keywords, all of which have been included in subsequent studies examining the effects of modified materials on people with aphasia. The Connect documents do not prescribe specific formatting methods however, and as a result research studies investigating the impact of modifying text for people with aphasia have interpreted this early work in different ways.

Studies investigating the impact of modified text on people with aphasia have used the broad principles identified by Connect to explore two factors: people with aphasia's comprehension of written information, or people's reported preferences for formatting modifications. The modifications investigated include: the layout; the type of language, termed as 'simple words and short sentences' (e.g. Rose, Worrall & McKenna, 2003: 950); the inclusion of images; and the typography. Some studies have looked at factors in isolation (e.g. Brennan et al., 2005) and others have looked at combined factors (e.g. Rose et al., 2003).

The existing research provides limited evidence of a positive effect of modified formatting on people with aphasia's comprehension of modified written information materials. The most positive outcomes were reported by Rose et al. (2003) who compared people with aphasia's comprehension of health information in its usual format, with an aphasia-accessible modified format, and found people gleaned 11.2% more knowledge from the modified condition. Other studies are less positive (e.g. Brennan et al., 2005). There is stronger evidence regarding people with aphasia's preferences for specially formatted materials. People prefer white space and design features such as headings (Rose et al., 2011a), relevant and contextualised photographs (Dietz et al., 2009; McKelvey et al., 2010), and line drawings (Rose et al, 2011b), and sans serif fonts (Rose et al., 2011a). In recent studies looking at combined formatting modifications people reported a preference for the modified materials (Ghidella, Murray, Smart, McKenna & Worrall, 2005; Rose et al., 2011a). Thus people with aphasia want to engage with the modified materials, but are still struggling to understand the content.

Possible reasons for the lack of evidence of a positive impact of formatting on comprehension include: the type of language used in the modified materials, the topics covered, the ways in which images have been included, and the fact that

materials to date have not been user-designed. Each of these factors were addressed in the current study and details of each follow below.

### *Modified language for people with aphasia*

Previous studies investigating the impact of modified materials on comprehension have used what is called simpler language and vocabulary, without explicitly defining this, and without recourse to the evidence base regarding language processing in aphasia. Rose et al. (2003), Brennan et al. (2005) and Wilson and Read (2016) modified the language by incorporating lower than usual Flesch-Kincaid Reading Grade levels (Kincaid et al., 1975). The Flesch-Kincaid method was developed for use in US high schools, and computes a grade level from a formula involving the numbers of words, sentences and syllables. It therefore fails to take account of factors specific to aphasia, and hence may well not be sufficiently sensitive to the needs of this population.

The literature on language processing in aphasia identifies three potential broad factors that need to be considered in written information materials: lexical factors, sentence processing factors, and effects of priming through prior exposure. Lexical processing is easier in general when stimuli are high imageability (Franklin et al., 1994; Nickels & Howard, 1995; Coltheart, 1980; Crisp & Lambon Ralph, 2006; Marshall & Newcombe, 1973), acquired earlier in life (Nickels & Howard, 1995; Hirsh & Ellis, 1994), of higher lexical frequency (Schuell, Jenkins & Landis, 1961; Patterson & Behrmann, 1997; Kittredge, Dell, Verkuilen, & Schwartz, 2008), and shorter in length (Nickels & Howard, 1995). In addition people with aphasia process content words more easily than function words (Bird, Franklin & Howard, 2002; Biassou et al., 1997; Coltheart, 1980). Sentence processing is easier when sentences maintain canonical form, with no moved arguments or embedded elements (Caramazza & Zurif, 1976; Grodzinsky, 2000; Meyer, Mack & Thompson, 2012; Thompson et al., 1999)[1]. Finally priming, which refers to quicker and more efficient processing following prior exposure. Priming effects have been found with people with aphasia from lexical primes (Blumstein et al., 2000), syntactic primes (Cho-Reyes et al., 2016), or combined lexical and syntactic primes (Hartsuiker & Kolk, 1998). This has particular relevance for the selection of vocabulary and sentence types used in information materials, with the potential that repeated use of the same words and sentences across materials will facilitate comprehension. In none of the studies investigating comprehension of modified materials have the above three factors been systematically incorporated.

Related to this are recent studies investigating the strategies people with aphasia adopt to assist with reading difficulties. Lynch et al. (2013) found that people with aphasia used a variety of strategies, including ignoring function words, and reading text partially. This indicates that longer and more linguistically complex text is problematic, so reducing sentence length and amount of text, and eliminating function words as far as possible may be beneficial. Knollman-Porter, Wallace, Hux et al.,

[1] There are reports in the literature of reverse effects in frequency (e.g. Marshall, Pring, Chiat & Robson, 2001), imageability (e.g. Breedin, Saffran, & Coslett, 1994) word length (e.g. Howard & Gatehouse, 2006), and of better processing of passives than actives in primary progressive aphasia (Zimmerer et al., 2014) but these are infrequent findings

(2015) provide further insights into reading strategies used by people with aphasia, finding they were drawn to shorter texts supported by images, which provided information familiar to them. They also scanned text for keywords, and recruited partner support.

### *Topics covered in accessible materials*

Relevance of the information is a second critical factor which has not been fully considered in previous studies. A number of studies including Brennan et al. (2005) and Wilson & Read (2016) examined comprehension using Thurstone's (1978) US Grade School reading sets, which cover general knowledge topics appropriate for school students. Rose et al. (2003) asked people to read health information about conditions such as arthritis. According to the work by Knollman-Porter et al. (2015) this type of content is unlikely to engage people with aphasia. Given that reading is challenging, access to the content needs to be worth the effort. Studies exploring what people with aphasia want information about such as those by Parr et al. (1997) and Kerr et al. (2010) found a need for information about what a stroke is and what aphasia is. Studies investigating the impact of modified formatting on comprehension would engage people with aphasia more readily therefore by focusing the content directly on these topics.

### *Use of images to support comprehension*

The third factor introduced by the Connect work is the inclusion of images. None of the studies published to date provide details of principles guiding the relationship between their written content and images. Brennan et al. (2005) provide an example where 'Before they learned to make weapons people killed animals with their bare hands or with sticks and stones' is supported by one image of a person using a tool on another object (Brennan et al., 2005, page 711). This study found no evidence of an impact of inclusion of images on sentence comprehension. One possible reason for this, apart from the complex language and obscure topic, is that the image's relationship to the overall sentence meaning is opaque. The image depicts one proposition, whereas the text relates a set of related propositions, and hence there is little transparency between text and image. Moreover the image does not depict a proposition related in the text but rather provides a sense of the topic. The exact degree to which images should relate to text remains uncertain.

### *User-design*

Finally and critically, the materials that people with aphasia viewed have usually been designed by the researchers (e.g. Rose et al., 2003; Brennan et al., 2005; Rose et al., 2011a), without input from the end-users. An exception in aphasia is the work of Parr et al. (1999) who collaborated with people with aphasia to develop new information resources. Information designers such as Frascara (2015: 5-9) assert that users are critical to design, and that the aims of design are to develop a solution that is not only understandable but relevant and engaging to users. User involvement ensures these properties emerge. Such research usually follows an iterative design process, which involves development of a prototype based on the needs of the users, which is then tested by users, and subsequently refined in a cyclical process until an acceptable version emerges (Sears & Lund, 1997). This approach states that the initial design

should be based on a ‘deep understanding’ (p21) of the users, and that users’ concerns be incorporated into subsequent and final designs. Some examples include development of novel therapy resources for people with aphasia (e.g. Galliers, Wilson, Roper et al., 2012), modifying social network and email platforms for people with aphasia (e.g. Miller, Buhr, Johnson, & Hoepner, 2013; Al Mahmud & Martens, 2013), developing communication devices (Al Mahmud, Limpens & Martens, 2013; Moffatt et al., 2004) and a range of products for people with dementia (e.g. Orpwood, Chadd, Howcroft, et al. 2010).

### *Aims of the study*

The main aims of this study were: i) to co-design accessible acceptable information materials with people with aphasia from prototype materials designed specifically for this study; and ii) to generate a definitive set of related design criteria for use in developing effective accessible materials. Some aspects of formatting were not defined clearly by existing research so a subsidiary aim was to explore these aspects. The literature had not provided definitive information about preferred types of images, i.e. line-drawings or photographs (see e.g. Rose et al., 2011b), and so a subsidiary aim was to explore people with aphasia’s preferences for the type of images used. In addition, evidence of preferred typography and emphasis portrayed via typography was lacking. For this study this was explored within the specific context of the information materials used here. Finally the amount of information people with aphasia can process at a time was investigated, via the amount of information people preferred to view on a page.

## Methods

### *Participant details*

Fourteen people with aphasia took part details of whom are in table 1. Inclusion criteria were: adults aged 18 or over; acquired aphasia arising at least one year before participation; participant report of difficulty with reading comprehension; adequate hearing and vision to enable participation; normal literacy development and normal pre-morbid literacy function; English speaker with normal pre-morbid language function; educated to age 16 or over; able to attend group sessions. Exclusion criteria were: a history of other neurological or psychiatric illness or of developmental or other acquired speech or language difficulties. Thirteen participants had used UK English from birth, and one (TM) was a balanced German-English bilingual. Age, gender and severity of aphasia informed the sample selection to ensure a range of ages, equal numbers of female and male, and range of written language comprehension.

Table 1 here

*Ethical approval, recruitment and consent*

Ethical approval was obtained from the Departmental Research Ethics Committee at the University of Sheffield. Participants were approached through local voluntary groups, or contacted via a local database of research participants with aphasia. Informed consent was obtained via accessible information materials.

*Aphasia profiling*

Language assessment was undertaken over the course of the study. Standardised assessments were used, including subtests from the Comprehensive Aphasia Test (CAT: Swinburn, Porter & Howard, 2005) and the Psycholinguistic Assessment of Language Processing in Aphasia (PALPA: Kay, Coltheart & Lesser, 1992) (see table 2). Table 3 provides z scores for the assessments of written comprehension. All of the participants were able to complete all the tasks, apart from MB, who was unable to complete any written task. Nine of the participants were within normal range on CAT 8 Written word to picture matching, and five showed a moderate to severe impairment. Five participants were impaired in sentence comprehension, three of whom were also impaired at single word level. All participants with valid scores showed an advantage for higher imageability words, apart from MH who showed a reverse effect. These data show a range of reading comprehension ability, from assessment scores within normal limits, to severe impairments.

Table 2 here

Table 3 here

*Constitution of the groups*

The participants formed three groups. Allocation was based on participants' availability and preferences, ensuring a maximum five per group, which the team felt

was the maximum number to include, while still ensuring full participation of all PWA members.

### *Study design*

The study involved a consensus building approach (Suskind, McKearnan & Thomas-Lamar, 1999) in group meetings, to achieve a collaborative co-designed solution. To achieve a single solution the 'single text procedure' was used (Fisher, Ury & Patton, 1991), in which group members view a single version of a possible solution rather than each generating a solution. Hence all three groups viewed the same prototype materials and the two revisions thereof. This method was used to ensure that the final version of the prototype constituted one agreed format that is acceptable to all group members.

### *Group methodology*

The consensus-building approach involved the following elements, designed to ensure: equal participation of members, full representation of their views, and clarity on what has been agreed. The key components identified for this study were based on definitions in Suskind et al. (1999: pp 5-11) and include:

- convening of meetings by a facilitator;
- facilitation of meetings by an external participant i.e. someone without aphasia, who would guide the group in a non-partisan fashion;
- mediation to ensure that disputes were resolved to all parties' satisfaction;
- recording of the key points, and for this study this was via multi-media formats to support what Suskind et al. refer to as the 'group memory';
- 'single-text procedure' (Fisher et al., 1991).

The 'single-text procedure' involved providing prototype materials as the single possible solution to which amendments could be added, and then ensuring that all issues raised by the groups and agreed upon within groups were implemented in subsequent and final designs.

### *Materials*

#### *Information materials*

Prototype materials were designed from which to develop the end-product. The materials were designed in line with the existing literatures concerning language processing in aphasia, and accessible formatting for people with aphasia. These latter had been reviewed by the researchers for the purposes of designing the prototype, and are summarised in Table 4. A sample of the prototype design developed for the study is shown in appendix A.

Table 4 here

The prototype information materials consisted of sets of professionally-designed, colour-printed cards measuring 170mm by 110mm, with a matt white background. A coloured banner was printed across the top in 24pt Vectora Black font reversed into white. A number on the right indicated the card's position in the set of information. Below the banner a sentence conveying the concept was printed in 14pt black Vectora

Roman. The banner and written sentence were left-aligned. Below the sentence were one or two colour images, either photographs or line drawings, depicting the concept/s portrayed in the sentence. Vocabulary consisted of high frequency, high imageability, early acquired, short words, and lay terms were used as far as possible. Sentences contained one proposition, were short, and used canonical syntactic structures. No proforms were used in sentences. Key words were repeated across cards depicting related concepts, and the same sentence structure was used across sets of related cards. All cards in a topic set had the same colour in the layout and text, and the same text and image style. The information depicted concerns stroke and aphasia. Two versions were provided: one version included colour photographs, and the second line drawings.

*Additional materials*

Text-based materials were devised to explore key word emphasis. One short phrase was produced with emphasis shown either in bold, larger font size 18, or bold and font size 18. All text was printed in black on white card. Each exemplar was presented on a laminated card. Each participant was supplied with an example of each phrase in each condition.

To explore the amount of information people were able to process at one time three sheets of A4 paper depicting a different number of cards were produced. These consisted of a single card, two cards, or three cards, arranged vertically. The options with two and three cards involved related concepts.

*Communication support materials*

Purpose-made Talking Mats© (Murphy, 2000; Murphy & Boa, 2012) were used to support communication. Each participant had one mat, with a five-point visual-rating scale (Appendix B). The principles and techniques of Supported Conversation (Kagan, 1998), and Total Communication (Lawson & Fawcus, 1999) were used in individual interactions and group discussions.

*Communication partners*

Each participant with aphasia was paired with a communication partner, who were either members of the research team (n=4), qualified speech and language therapists (n=2), a volunteer with experience of aphasia (n=1), and a paid researcher on the project (n=1). All the communication partners had received prior training in, and had experience of supported communication techniques, apart from the additional researcher, who received training. They were all additionally trained in the procedure for the groups. This included: one to one interactions with the person with aphasia to elicit their views; noting down key points, agreeing these with the person and writing these in field notes; supporting the person to communicate views to the group; alerting the group to any other points with the person's agreement; supporting them to complete the rating tasks.

## *Procedure*

*Overview*

The overall procedure involved: first viewing of prototype information materials by groups; design revision; second viewing by groups; design finalisation[2]. The groups therefore met twice to view the information materials. The graphic designers produced three versions of the materials: initial design, first design revision, and final design revision. The information that informed each design stage was gathered from the PWA group meetings, and summarised as a set of design instructions. All design instructions identified via the group meetings were added to the set of formatting criteria which underlay the original design, to form the final set of criteria.

*Participant involvement*

Each PWA attended two meetings, approximately two hours, one month apart, and one final meeting a month later to view the final design. The membership of the groups was the same on both occasions. Each group contained one group facilitator, four or five participants with aphasia, and a communication partner for each person with aphasia.

*Group procedure*

At the start of each meeting the group facilitator outlined the aims of the meeting and the project, the schedule, and the activities, using aphasia accessible materials. The facilitator also outlined the ground-rules: that each participant's views were important; that each point raised would be recorded; that the views raised would inform each stage of the project. In each group meeting the participants viewed samples of the information materials (see Appendix A), then had one-to-one discussions with their communication partner. They also expressed their views of the materials by placing them on the visual rating scale. After 20 minutes of individual discussion the facilitator convened a group discussion. The PWA fed back their views, using the rating scale to support their meaning. At the end of each discussion point the facilitator summarised the point, and confirmed what had been agreed. A visual record was kept of the consensus points reached, and of alternative views, such as preferences for photos or line drawings. Participants also viewed the materials showing emphasised keywords, and the different amounts of information, and rated these.

Where one person raised an issue with which no others identified, people were asked to comment on the issue. Where there were no dissenting views, but a sole proponent of that view, the resulting point was noted as an individual modification but was not included in the final set of points. This was in order to develop the user-led design, and identify individual needs. After each round of meetings the researchers compiled the complete set of consensus points identified by the groups. They then met with the graphic designers to clarify integration of each point into the materials. The designers then produced a modified version of the materials for discussion at the next round of meetings, and similarly for production of the final design.

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[2] Participants viewed the final version at an informal meeting one month after the last group but no further data were collected.

***Data recording and checking***

*Data recording*
All group discussion in the meetings was audio-recorded using a Marantz recorder with a microphone in the centre of the table. Discussion between each person with aphasia and their communication partner was not audio-recorded due to practical considerations, but communication facilitators noted all points raised and noted other field notes such as gestures to convey a meaning.

*Verification of consensus points*
The consensus points collected during the group discussions were checked for accuracy and completeness by reviewing audio-recordings relating to discussions, accompanying notes from the communication partners, and field notes. These were checked against the points agreed upon and any difficulties were resolved by the research team, one of whom would have facilitated that group.

*Ratings*
There were 14 values for each of the additional materials provided, one from each group member. This generated frequency tables, showing the number of times a given rating on the scale was assigned to an option by the group members. This form of data was produced for: the type of image (line drawing or photograph); emphasis via font; amount of information. Chi square analyses were used to examine these ratings.

## Results

### *Analysis of consensus points*

*First iteration*
The consensus points were compiled and are shown in Table 5. These include agreement regarding the positive aspects of the design, and proposals for changes. They are categorised under the overall design and layout, the language used, the images, and the typography. The outcomes of the ratings data are incorporated into the table.

Table 5 here

Layout
There was consensus regarding the layout in which the information was presented. Consistency of design, layout, image style, and representations of key concepts was considered important. Use of colour was considered helpful by many people, in particular where colour was meaningful and reflected real life, such as blue for a particular healthcare worker's uniform. Participants agreed that the visual attractiveness of the design was important in encouraging further engagement with materials. The amount of information ie one heading, one sentence, and one or two images depicted in each card was considered appropriate.

Language
Most participants reported that they found the heading phrase helpful, and the written content acceptable. The groups agreed that the heading phrase was useful in terms of identifying the overall topic clearly to them.

Images
Participants commented that the images used should be absolutely clear in meaning, and should relate directly to the text. Participants reacted negatively to images involving inference or metaphorical interpretation, such as an image of a TV control used for the verb 'control'. Participants noticed inconsistencies between images and words readily, and reported their dissatisfaction (see for example appendix A). Some people preferred one image for each sentence, two images being too demanding, others preferred two images. Several people expressed a strong preference for line drawings, and several others for photographs. One property of images was identified as preferred by a sole participant: GG wanted images that portrayed him in person, not stock photographs.

The ratings for the two image types are shown in table 6. The line drawings were rated more positively although Chi square comparisons showed neither was significant (sample 1: Chi square=2.51, df=4, p=0.473; sample 2: Chi square=3.01, df=4, p=0.556). For line drawing 1 the differences between categories of ratings were significant (Chi square=13.14, df=4,p=0.0106). There were no significant differences between categories of ratings for the other samples (photograph 1: Chi square=7.43, df=4,p=0.1149; photograph 2: Chi square=2.43,df=4,p=0.6575; line drawing 2: Chi square=5.29, df=4, p=0.2592). The data show more people prefer line drawings, but strong individual differences pertain, with some participants strongly preferring photographs.

Table 6 here

Typography

Participants reported that the largest appropriate font size, relative to page size, was preferred, although they cautioned against a too large font, which some healthcare leaflets for people with aphasia adopt, as this could be difficult to read. The ratings for emphasis shown through typography are shown in table 7. There are more positive ratings for the large and bold font than for the other fonts (Chi square=44.59, df=12, $p<0.001$). Chi square and p values for each font are - normal font: Chi square=18.14, df=4, p=0.0012; bold font: Chi square=3.86, df=4, p=0.4257; large font: Chi square=6.71, df=4, p=0.1518; large and bold font: Chi square =25.29, df=4, $p<0.001$). The data show low ratings for normal font, and highest ratings for emphasised words in large and bold font.

Table 7 here

The consensus points shown in table 5 were discussed with the graphic designers. The latter then amended the design in line with these findings, and produced the revised design for group members to view at their second round of meetings.

*Second iteration*

The discussions led to the identification of further consensus points summarised in Table 8. The main issues included the overall design of sets of cards to depict related concepts, the number of cards that people could process at one time, and further information about the kinds of images.

Table 8 here

Overall design of card sets and amount of information

Participants approved of the system of a set of cards with a consistent design to depict related concepts. Most people preferred one concept at a time, with only two participants reporting that they wanted to view two concepts on one page, and all participants finding three per page very difficult to process. People's comments related to language processing difficulties, but also to problems with memory and attention. Participants reported that they might forget information processed at the top of a page by the time they reached the bottom.

The ratings for the three amounts of information on one page are shown in table 9. Chi square showed a significant overall difference between the ratings (Chi square =30.70, df=8, $p<0.001$). Most participants were positive about viewing one concept at a time, and negative about viewing three at a time, and both were statistically significant differences (one concept: Chi square=21.00, df=4, p=0.0003; three concepts: Chi square=11.00, df=4, p=0.0266). Some participants reacted positively to viewing two concepts at a time but this was not significant (Chi square=3.86, df=4, p=0.4257).

Table 9 here

Images

Participants emphasised the need for images to display positive information, which gives hope to people with aphasia. They also stressed that images needed to portray realistic information, for example in reflecting realistic timescales for recovery, and not depicting complete recovery. Several participants were distracted by extraneous details within images. The need for a consistent image-concept relationship was also identified across cards.

Participants preferred concrete images, an example being recovery depicted via images of people (Appendix C).

The consensus points summarised in table 8 were discussed with the graphic designers. The latter then amended the design for the second time and produced the final design, a sample of which is shown in appendix D. This includes most of the original features, plus emphasis in font, plus accuracy and relevance in images used. The criteria identified through the two iterations of the design of the template were then added to the original set, and this combined set forms the final definitive set of criteria for use in the development of information materials for people with aphasia. These are shown in table 10.

Table 10 here

## Discussion

In this study people with aphasia collaborated with researchers to co-design a novel set of information materials for people with aphasia, from which related criteria emerged. The materials represent the first fully evidence-based user-designed information materials and are suitable for electronic formats, and individualized versions. The criteria for use in the production of information for people with aphasia combine previous seminal work in this area and novel findings from this study. The study thus contributes new evidence to support effective provision of health information in aphasia rehabilitation. The study is timely in its coherence with the World Health Organisation's (2011) Health Literacy principles, the UK's NHS Accessible Information Standard, and the growing awareness of the need for individualised interventions.

### *Design and criteria*

Numerous sets of guidelines exist for producing accessible information, mainly directed at the general population, and there is considerable overlap between these and the criteria described here for people with aphasia. These include advice on layout, language and typography (e.g. Plain English Campaign (http://www.plainenglish.co.uk/); medical information leaflets guidance from Young, Tordoff & Smith, 2017; Young, Tordoff and Smith, 2018). Where criteria for aphasia part company from these general criteria is in the extent of the modifications required, the language required, the type and number of images people need in order to support textual understanding, the amount of information people can process, and the need for individualized solutions. For example, with regard to the layout, Young et al. (2018) recommend white space, headings, spacing, line breaks, and page breaks, without specific instructions on each. Similar findings are reported from people with aphasia (e.g. Rose et al. 2011a), again with insufficient clarity. The card system used in the materials here represents a set of explicit layout recommendations. By encapsulating the space within a card, within which are held the various elements (header, text, images) which are critical to understanding, the layout promotes unity according to Gestalt principles, clarifies the relationships between the elements, and renders their relationships to each other completely transparent. This explicit demonstration of layout serves to elucidate a previously opaque aspect of accessible design for aphasia.

With regard to reading strategies used by people with aphasia, Knollman-Porter et al. (2015) found that people with aphasia report having to actively seek out key words, scanning texts to find these, which necessitates considerable cognitive resource. The layout provided here obviates the need for this extra activity, arguably decreasing the cognitive burden involved in gathering meaning from text, and thereby easing engagement with and understanding of text.

### *Language for aphasia*

The language criteria described in this study are more detailed and intricate than those provided in previous aphasia studies, or in general non-aphasic guidelines. General guidelines refer to e.g. 'user-friendly language', and 'short sentences' (Young et al. (2018: 198), and the Plain English Campaign recommends no jargon, and active not passive verbs. Previous studies of accessible information have not defined what is

meant by terms such as simple language, apart from recommending Reading Grades from Flesch-Kincaid values. To our knowledge the criteria for lexical, syntactic, and repeated lexical and syntactic terms thereby harnessing priming have not been integrated into aphasia accessible materials before.

Participants responded positively to the language content, and to the repetition of content across the materials, and did not recommend any changes. By using one short sentence our materials provide the person with aphasia with maximal opportunity to process the written content. What remains to be seen is whether access to information i.e. comprehension of the content is indeed facilitated by using written content at this language level. By repeating lexical content instead of using proforms such as pronouns, meaning is again more accessible (see Knollman-Porter et al., 2015 regarding function words).

As noted in the introduction, not all people with aphasia show the same effects of psycholinguistic variables, or difficulties with particular syntactic structures, (e.g. reverse frequency effects were reported by Marshall et al., 2001). Assessment of reading comprehension could feasibly include identification of critical variables, which would enable individualized language content to be developed in future electronic versions of the materials.

***Images***

Some of the findings in this study concerning images echo those previously reported. Previous studies have found that people with aphasia show a preference for the inclusion of images to support meaning (e.g. Rose et al., 2011a) and this was the case here as well. Studies have also found little agreement regarding the type of image to include (e.g. Rose et al., 2011b), with people preferring either line drawings or photographs, and that was so here.
The novel findings concerning images which this study provide us with much more detail about the particular properties people with aphasia require in the images used, and the specific ways in which images should be combined with text.

The participants generated novel insights into the types of images and image-text relationships. Participants reported high clarity of meaning when the image conveyed the concept unambiguously, and when the same image was used consistently to depict a given concept. Difficulties with processing the meaning of images is not a hallmark of aphasia, although many people with aphasia make errors in picture association tasks such as Pyramids and Palm Trees (Howard & Patterson, 1992). One recent account proposes that people with aphasia may present with difficulties in semantic control (e.g. Noonan, Jefferies, Corbett & Lambon Ralph, 2010). This could manifest itself in the kind of rigid processing that was found here, with some participants unable to accept slight anomalies in text-image relationships. These hypothesized difficulties with semantic control would account for the need for complete consistency, and complete accuracy and coherence, and related difficulties in coping with extraneous details in images.

Image acceptability was valued, in terms of the accuracy of the images in portraying facts, and the emotional valence. Participants reacted strongly to two images in particular, one showing recovery over six months, and one showing perfect recovery

of language. Participants agreed that information needs to depict the facts accurately, and not give false or unrealistic information. They also agreed that the messages portrayed about aphasia need to be positive and provide people with hope. The issue of hope has been investigated by Bright, Kayes, McCann and McPherson (2013) who found that this construct was significant for people in terms of coping with aphasia and the future. Ensuring that information provides a balance, being realistic but not fatalistic, appears to be central here.

GG expressed an individual preference for image type, requiring the images to depict him and his experience directly. This is similar to the findings of McKelvey et al. (2010) who used contextualized relevant images of photographs of people and places known to the participant, and those of Knollman-Porter, Brown, Hux, et al. (2016) where PWA preferred high context images to support reading. Again, the individualised version would be possible to achieve with electronic formats.

### *Typography*

Some previous studies have focused on larger font sizes as facilitators (e.g. Rose et al., 2003; Brennan et al., 2005; Rose et al., 2011a) without always clarifying exactly how large (see Rose et al. 2012 for an exception). Noel (2015) notes this lack of clarity in her study of word recognition in text by PWA, concluding that context will determine size. The participants in our study reported no 'correct' font size, and that the context is critical and should ensure words are visible and clear, but not so large that visual parsing becomes arduous. With regard to emphasis of keywords Rose et al. (2011a: 341) reported comments from participants who wanted emphasis in the text but no details regarding how. The finding here of a preference for words that stand out by being larger and in bold provides some clarity to this issue.

### *Amount of information*

Participants preferred to be faced with a limited amount of information, and their comments regarding memory and attention deficits impacting on reading and retaining information explain this. Many health information leaflets and websites include large amounts of information, with complex layouts involving columns of text and images. Even materials formatted for aphasia include much more information than one of the cards shown here. This important finding has implications for the way in which information is presented by healthcare services, with alternatives to the standard sized paper-based leaflets needing to be considered. An app with swipe-through 'cards' depicting one proposition at a time in a logical order is one such solution which would enable people to access as much information as they are able to process.

### *Collaborative iterative design*

Studies using co-design methods have been reported with health service users (e.g. Scheltema, Reay & Piper, 2018), complex communication needs (e.g. Owens, 2006), dementia (e.g. Orpwood et al., 2010), and aphasia (e.g. Galliers et al., 2012). The importance of end-user involvement in design is encapsulated in Scheltema et al's (2018) study of co-design of medical illustrations. They found that lay-users of health

services preferred more complex images than did health professionals, who favoured simplicity. These findings clearly highlight the need for users to be designers.

The participants in this study contributed readily to the design process, and the outcomes are evidence that, even with severe aphasia people can make their views clear. For these purposes the communication partners formed an essential part of the process. This type of research is therefore labour-intensive, and necessitates skilled practice which is only achievable with sufficient training.

### *Electronic individualized formats*

The materials were specifically designed to enable their translation into electronic formats if required. Dietz et al. (2014: 314) report on the positive impact of electronic media on AAC use by PWA, and similar impact can be anticipated with electronic forms of information. The other advantage to electronic systems is that individualized formats with personally relevant data are possible from a standard template. This would enable layout, language, images and fonts to be adapted to suit individual processing requirements, in line with the paradigm of precision medicine, which involves 'prevention and treatment strategies that take individual variability into account' (Collins & Varmus, 2015: 793). People with aphasia have shown improved linguistic performance in the context of personally relevant materials (e.g. Wallace & Canter, 1985; McKelvey et al., 2010) and have expressed a preference for these (McKelvey et al., 2010). This is particularly the case with those with severe aphasia. In the field of AAC this approach is increasingly used (e.g. Dietz et al. 2014; Wallace & Hux, 2014), but to our knowledge there are no apps providing health information for people with aphasia and no facility for individual information systems.

### *Limitations of this study*

The study included 14 participants with aphasia, who, whilst representing extremes in terms of processing of language, constitute a small sample. Evidence concerning factors identified here should be explored with a wider range of people, as different demographic groups might experience information differently. The method of collecting data also warrants some consideration. The dyad discussions ensured that the participants were primed by the time they entered group discussions. Some of the data from those dyads may have been lost however as this depended somewhat on the communication partner, in particular for people with severe aphasia. The use of consensus groups in aphasia is relatively uncommon, and methods need to be developed to ensure that all participants are content with all outcomes. There is a risk of people not providing their view to counter an argument because of the stress involved.

### *Clinical implications*

The above novel findings add to our understanding of the best methods to use to convey information about aphasia to people with aphasia. The data add to the existing knowledge base, identifying further characteristics of layout, language, images, typography, and amount of information, that are critical to engaging the person and enabling their understanding, which can be used to develop better information materials for people. The findings regarding differences across participants indicate

that assessment of visual and language processing prior to the introduction of particular formats for information is needed, and that individual preferences need to be addressed in making materials for people.

### *Future directions*

Early investigations into accessible materials sought to identify a consensus for preferred format, and from this to derive guidelines and checklists. These have met with some success, with healthcare staff more aware of the need for modified materials, and some knowledge of how to modify text. People with aphasia continue however to report a lack of access to information, so more evidence is needed regarding individual preferences. The degree to which the modifications recommended here aid comprehension of written content needs examining. More people with severe aphasia need to be involved in this research, and different methodologies are needed to explore the potential solutions. With electronic media there is the possibility of tailoring materials to suit individuals, which would ensure that people with aphasia have the maximum chance of opening the door to the knowledge which others take for granted.

**References**


Accessible Information Standard (NHS England) https://www.england.nhs.uk/ourwork/accessibleinfo/ (last accessed 20/07/2018)

Al Mahmud, A., Limpens, Y., & Martens, J.-B. (2013). Expressing through digital photographs: an assistive tool for persons with aphasia. Universal Access in the Information Society, 12(3), 309-326.

Al Mahmud, A., & Martens, J.-B. (2013). Amail: Design and Evaluation of an Accessible Email Tool for Persons with Aphasia. *Interacting with Computers, 25*(5), 351-374.

Aleligay, A., Worrall, L.E., & Rose, T.A. (2008). Readability of written health information provided to people with aphasia. *Aphasiology*, 22, 4, 383-407.

Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family information needs about aphasia. *Aphasiology*, *19*(3/4/5), 365–375.

Biassou, N, Obler, LK, Nespoulous, JL Dordain, M Harris, KS. (1997). Dual processing of open- and closed-class words. *Brain and Language*, 57, 3, 360-373

Bird, H., Franklin, S., & Howard, D. (2002). 'Little words'—not really: function and content words in normal and aphasic speech. *Journal of Neurolinguistics*, *15*(3), 209-237.

Blumstein, S. E., Milberg, W., Brown, T., Hutchinson, A., Kurowski, K., & Burton, M. W. (2000). The mapping from sound structure to the lexicon in aphasia: Evidence from rhyme and repetition priming. *Brain and language*, *72*(2), 75-99.

Brennan, A., Worrall, L. & McKenna, K. (2005) The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: An exploratory study. *Aphasiology 19 (8)* 693-711

Bright, F.A.S., Kayes, N.M., McCann, C.M. & McPherson, K.M. (2013) Hope in people with aphasia. *Aphasiology, 27 (1)* 41-58.

Caramazza, A. & Zurif, E.B. (1976). Dissociation of Algorithmic and Heuristic Processes in Language Comprehension: Evidence from Aphasia. *Brain and Language 3*, 572-582.

Chinn, D., & Homeyard, C. (2017). Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta□narrative literature review. *Health Expectations*, *20*(6), 1189-1200.

Cho-Reyes, S., Mack, J. E., & Thompson, C. K. (2016). Grammatical encoding and learning in agrammatic aphasia: Evidence from structural priming. *Journal of Memory and Language*, *91*, 202-218.

Coltheart, M. (1980). Deep dyslexia: A review of the syndrome. In M. Coltheart, K. Patterson & J. C. Marshall (Eds.), Deep dyslexia (pp. 22–47). London, UK:Routledge.

Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. *New England Journal of Medicine*, *372*(9), 793-795.

Coulter, A. & Ellins, J. (2006). Patient-focused interventions – A review of the evidence. *Quest for Quality and Improved Performance Programme*. London: The Health Foundation.

Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: Is the information good enough? *British Medical Journal, 318*(7179), 318-322.

Crisp, J., & Lambon Ralph, M. A. (2006). Unlocking the nature of the phonological–deep dyslexia continuum: The keys to reading aloud are in phonology and semantics. *Journal of Cognitive Neuroscience. doi: 10.1162/jocn.2006.18.3.348*

Dietz, A., Hux, K., McKelvey, M., Beukelman, D., & Weissling, K. (2009). Reading comprehension by people with chronic aphasia: A comparison of three levels of visuo-graphic contextual support. *Aphasiology* 23, 1053–1064.
Dietz, A., Weissling, K., Griffith, J., McKelvey, M., & Macke, D. (2014). The impact of interface design during an initial high-technology AAC experience: A collective case study of people with aphasia. *Augmentative and Alternative Communication, 30*(4), 314-328.
Eames, S., McKenna, K., Worrall, L., & Read, S. (2003). The suitability of written education materials for stroke survivors and their carers. *Topics in Stroke Rehabilitation, 10*, 70–83.
Fisher, R., Ury, W., & Patton, B. (1991). Getting to yes: Negotiating agreement without giving in (2nd ed.). New York: Penguin.
Franklin, S., Howard, D. Patterson, K. (1994). Abstract word meaning deafness. *Cognitive neuropsychology, 11(1),* 1-34.
Frascara, J. (2015). What is information design? Chapter 1 pp 5-56 in Jorge Frascara (Ed.) *Information Design as Principled Action*. Common Ground Publishing.
Galliers, J., Wilson, S., Roper, A., Cocks, N., Marshall, J., Muscroft, S., & Pring, T. (2012). *Words are not Enough: Empowering People with Aphasia in the Design Process.* Paper presented at the Participatory Design Conference, Roskilde, Denmark.
Ghidella, C., Murray, S., Smart, M., McKenna, K., & Worrall, L. (2005). Aphasia websites: an examination of their quality and communicative accessibility. *Aphasiology*, 19, 1134-1146.
Grodzinsky, Y. (2000). The neurology of syntax: Language use without Broca's area. *Behavioral and brain sciences*, *23*(01), 1-21.
Hartsuiker, R. J., & Kolk, H. H. (1998). Syntactic facilitation in agrammatic sentence production. *Brain and language*, *62*(2), 221-254.
Herbert, R., Haw, C., & Gregory, E. (2012). Communicate Stroke. Stroke Association Publications. Integrated into online resources: https://mystrokeguide.com/user
Herbert, R., Haw, C., Brown, C,. Gregory, E. (2012). *Accessible Information Guidelines*. Stroke Association, May 2012. ISBN 978-0-901548-66-5. https://www.stroke.org.uk/sites/default/.../accessible_information_guidelines.pdf1_.pd..
Hirsh, K. W., & Ellis, A. W. (1994). Age of acquisition and lexical processing in aphasia: A case study. *Cognitive Neuropsychology*, *11*(4), 435-458.
Howard, D., & Patterson, K. E. (1992). *The Pyramids and Palm Trees Test: A test of semantic access from words and pictures*. Thames Valley Test Company.
Humphris, G.M., Ireland, R.S., Field, E.A. (2001). Randomised trial of the psychological effect of information about oral cancer in primary care settings. *Oral Oncol*, *37* (7): 548-552.
Johnson, A., Sandford, J., & Tyndall, J. (2003). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database Systematic Review*, CD003716 (4).
Kagan, A. (1998). Supported conversation for adults with aphasia: methods and resources for training conversation partners. *Aphasiology, 12*(9), 816-830.
Kay, J., Lesser, R & Coltheart, M. (1992). *PALPA: Psycholinguistic Assessment of Language Processing in Aphasia*. Psychology Press: Hove UK
Kittredge, A. K., Dell, G. S., Verkuilen, J., & Schwartz, M. F. (2008). Where is the effect of frequency in word production? Insights from aphasic picture-naming errors. *Cognitive Neuropsychology*, 25(4), 463–492.

Knollman-Porter, K., Brown, J., Hux, K., Wallace, S. E., & Uchtman, E. (2016). Preferred visuographic images to support reading by people with chronic aphasia. *Topics in stroke rehabilitation*, *23*(4), 269-275.
Knollman-Porter, K., Wallace, S. E., Hux, K., Brown, J., & Long, C. (2015). Reading experiences and use of supports by people with chronic aphasia. *Aphasiology*, *29*(12), 1448-1472.
Lawson, R. & Fawcus, M. (1999) Increasing effective communication using a total communication approach. In Byng, S., Swinburn, K. and Pound, C. (Eds) *The Aphasia Therapy File*. Psychology Press, Hove UK.
Lynch, K. E., Damico, J. S., Abendroth, K. J., & Nelson, R. L. (2013). Reading performance subsequent to aphasia: Strategies applied during authentic reading. Aphasiology, 27, 723–739.
Marshall, J. C., & Newcombe, F. (1973). Patterns of paralexia: A psycholinguistic approach. *Journal of psycholinguistic research*, *2*(3), 175-199.
Mayer Johnson Picture Communication Symbols™ http://www.mayer-johnson.com/category/symbols-and-photos
McKelvey, M., Hux, K., Dietz, A., & Beukelman, D. (2010). Impact of personal relevance and contextualization of word-picture matching by people with aphasia. *American Journal of Speech Language Pathology*, 19, 22–33.
McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., & Wolfe, C. (2010). *The Stroke Association UK Stroke Survivor Needs Survey.* Stroke Association, London.
McPherson, C.J., Higginson, I.J. & Hearn, J. (2001). Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials'. *Journal of Public Health Medicine*, *23*(3), 227-234.
Meyer, A. M., Mack, J.E., Thompson, C.K. (2012) Tracking passive sentence comprehension in agrammatic aphasia. *Journal of Neurolinguistics, 25*, 31–4.
Miller, H., Buhr, H., Johnson, C., & Hoepner, J. (2013). *AphasiaWeb: A Social Network for Individuals with Aphasia.* Paper presented at the ASSETS '13 October 21 - 23 2013, Bellevue, WA, USA
Moffatt, K., McGrenere, J., Purves, B., & Klawe, M. (2004). *The Participator Design of a Sound and Image Enhanced Daily Planner for People with Aphasia.*
In Proceedings of the SIGCHI conference on Human factors in computing systems (pp. 407-414). ACM.
Murphy, J. (2000). Enabling people with aphasia to discuss quality of life. *British Journal of Therapy and Rehabilitation*, 7 (11), 454 – 457.
Murphy, J., & Boa, S. (2012). Using the WHO-ICF with Talking Mats to Enable Adults with Long-term Communication Difficulties to Participate in Goal Setting. *Augmentative and Alternative Communication, 28*(1), 52-60.
Murray, E., Burns, J., See Tai, S., Lai, R., & Nazareth, I. (2004). Interactive health communication applications for people with chronic disease [Cochrane Review]. *Cochrane Library*, 4.
Myers, E.D. & Calvert, E.J. (1984). Information, compliance and side effects a study of patients on anti-depressant medication *British Journal of Clinical Pharmacology, 17*, 221-225.
Nickels, L. & Howard, D. (1995). Aphasic naming: What matters. *Neuropsychologia*, 33, 1281-1303.
Noel, G. (2015). Typography for people with aphasia: An exploratory study. Chapter 16 pp 236-248 in Jorge Frascara (Ed.) *Information Design as Principled Action*. Common Ground Publishing.

Noonan, K. A., Jefferies, E., Corbett, F. & Lambon Ralph, M. A. Elucidating the nature of deregulated semantic cognition in semantic aphasia: evidence for the roles of prefrontal and temporo-parietal cortices. *J. Cogn. Neurosci.* **22**, 1597–1613 (2010).
Orpwood, R., Chadd, J., Howcroft, D., Sixsmith, A., Torrington, J., Gibson, G., & Chalfont, G. (2010). Designing technology to improve quality of life for people with dementia: user-led approaches. *Universal Access in the Information Society, 9*(3), 249-259.
Parr, S. (2007). Living with severe aphasia: Tracking social exclusion, *Aphasiology*, 21:1, 98-123
Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with loss of language after stroke*. Buckingham, UK: Open University Press.
Parr, S., Pound, C., Byng, S. & Long, B. (1999) *The Aphasia Handbook.* Connect Press, London.
Parr, S., Pound, C., & Hewitt, A. (2006). Communication access to health and social services. *Topics in Language Disorders*, 26(3), 189-198.
Parr, S., Wimborne, N., Hewitt, A. & Pound, C. (2008, reprinted 2011). *The Communication Access Toolkit.* Connect, London.
Patterson, K., & Behrmann, M. (1997). Frequency and consistency effects in a pure surface dyslexic patient. *Journal of Experimental Psychology: Human Perception and Performance*, *23*(4), 1217.
Plain English Campaign (http://www.plainenglish.co.uk/)
Pound, C., Duchan, J., Penman, T., Hewitt, A., & Parr, S. (2007). Communication access to organisations: Inclusionary practices for people with aphasia. *Aphasiology, 21*(1), 23-38.
Rose, T. A., Balse, A., Osmond, S., Poon, A., Simons, N., & Wallace, S. J. (2018). Aphasia education: speech-language pathologists' perspectives regarding current and optimal practice. *Aphasiology*, *32*(8), 967-988.
Rose, T., Worrall, L., Hickson, L., Hoffmann, T. (2010) Do people with aphasia want written stroke and aphasia information? A verbal survey exploring preferences for when and how to provide stroke and aphasia information. *Topics in stroke rehabilitation 17 (2)*, 79-98
Rose, T.A., Worrall, L.E., Hickson, L.M., & Hoffmann, T.C. (2011a). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, 13, 335-347.
Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2011b). Exploring the use of graphics in written health information for people with aphasia. *Aphasiology*, *25*(12), 1579–1599.
Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2012). Guiding principles for printed education materials: Design preferences of people with aphasia. *International Journal of Speech-Language Pathology, 14*(1), 11-23. doi: 10.3109/17549507.2011.631583
Rose, T., Worrall, L., McKenna, K. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology*, 17, 947-963.
Rose, T., Worrall, L., McKenna, K., Hickson, L., Hoffmann, T. (2009) Do people with aphasia receive written stroke and aphasia information? *Aphasiology, 23 (3),* 364-392
Scheltema, E., Reay, S., & Piper, G. (2018). Visual representation of medical information: the importance of considering the end-user in the design of medical illustrations. *Journal of visual communication in medicine, 41*(1), 9-17.

Schuell, H., Jenkins, J., & Landis, L. (1961). Relationship between auditory comprehension and word frequency in aphasia. *Journal of Speech and Hearing Research*, 4, 30-36.
Sears, A & Lund, A.M. (1997). Creating effective user interfaces. *IEEE Software*, 14, 21-24.
Sharma, N., Tridimas, A., & Fitzsimmons, P. R. (2014). A readability assessment of online stroke information. *Journal of Stroke and Cerebrovascular Diseases*, *23*(6), 1362-1367.
Smith, J., Forster, A., & Young, J. (2009). Cochrane Review: Information provision for stroke patients and their caregivers.*Clinical Rehabilitation, 23, 195-206.*
Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., Wu, J. H. C. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*(1). doi: 10.1002/14651858.CD001431.pub4
Suskind, L. E., McKearnen, S., & Thomas-Lamar, J. (1999). *The consensus building handbook: A comprehensive guide to reaching agreement*. Sage Publications.
Swinburn, K., Howard, D., & Porter, G. (2005). *CAT: Comprehensive Aphasia Test*. Psychology Press: Hove UK.
Thompson, C. K., Tait, M. E., Ballard, K. J., & Fix, S. C. (1999). Agrammatic aphasic subjects' comprehension of subject and object extracted wh questions. *Brain and Language*, *67*(3), 169-187.
Thurstone, T. (1978) *Reading for understanding 2.* Chicago, IL: Science Research Associates.
Tomkins, B., Siyambalapitiya, S., Worrall, L. (2013) What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology 27* (8) 972-991.
Wallace, G. L., & Canter, G. J. (1985). Effects of personally relevant lan- guage materials on the performance of severely aphasic individuals. *Journal of Speech and Hearing Disorders, 50,* 385–390.
Wallace, S. E., & Hux, K. (2013). Effect of two layouts on high technol- ogy AAC navigation and content location by people with aphasia. *Disability and Rehabilitation: Assistive Technology, 9,* 173–182.
Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Hin Kong, A.P., Simmons-Mackie, N., Scarinci, N. & Gauvreau, C. A. (2017). Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF. *Disability and Rehabilitation*, *39*(14), 1364-1379.
Wilson, L. & Read, J. (2016). Do particular design features assist people with aphasia to comprehend text? An exploratory study. *International Journal of Language and Communication Disorders*, 51, 3, 346–354
World Health Organisation: Health Literacy http://www.who.int/healthpromotion/conferences/7gchp/track2/en/
Young, A., Tordoff, J., & Smith, A. (2018). Regulatory agencies' recommendations for medicine information leaflets: Are they in line with research findings?. *Research in Social and Administrative Pharmacy*, *14*(2), 196-202.
Young, A., Tordoff, J., & Smith, A. (2017). 'What do patients want?'Tailoring medicines information to meet patients' needs. *Research in Social and Administrative Pharmacy*, *13*(6), 1186-1190.

Table 1 Background details of participants

| **Group** | **Initials** | **Gender** | **Age** | **Time post onset in years** | **Aphasia type** |
|---|---|---|---|---|---|
| 1 | EC | Male | 68 | 6 | Broca's |
| 1 | BT | Male | 77 | 9 | Broca's |
| 1 | RW | Male | 66 | 11 | Broca's |
| 1 | TM | Female | 75 | 6 | Broca's |
| 1 | GG | Male | 65 | 13 | Global |
| 2 | RP | Male | 58 | 5 | Anomia |
| 2 | SE | Male | 67 | 1 | Transcortical Motor |
| 2 | NH | Male | 68 | 4 | Anomia |
| 2 | OS | Female | 67 | 4 | Wernicke's |
| 2 | JB | Female | 80 | 3 | Transcortical Sensory |
| 3 | SG | Female | 71 | 5 | Broca's |
| 3 | MM | Female | 82 | 15 | Broca's |
| 3 | MH | Female | 76 | 11 | Global |
| 3 | MB | Female | 80 | 10 | Wernicke's |

Table 2. Aphasia assessment data (- = unable to attempt * = missing data)

| Test name | **CAT 7 Spoken word comp.** | **CAT 9 Spoken Sentence Comp.** | **CAT 8 Written Word Comp.** | **CAT 10 Written Sentence Comp.** | **PALPA 51 Word semantic association (written) High Imag.** | **PALPA 51 Word semantic association (written) Low Imag.** | **CAT 17 Naming objects** | **CAT 12 Repetition words** | **CAT 14 Repetition nonwords** | **CAT 20 Reading words aloud** | **CAT 23 Reading nonwords** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| n | 30 | 32 | 30 | 32 | 15 | 15 | 48 | 32 | 10 | 48 | 10 |
| Values for normative data: | | | | | | | | | | | |
| Mean<br>SD<br>Range | 0.97<br>0.046<br>0.83 - 1.00 | 0.94<br>0.061<br>0.81 – 1.00 | 0.99<br>0.027<br>0.90 – 1.00 | 0.93<br>0.084<br>0.75 – 1.00 | 0.90<br>0.094 | 0.82<br>0.149 | 0.97<br>0.035<br>0.87 – 1.00 | 0.99<br>0.021<br>0.94 – 1.00 | 0.92<br>0.160<br>0.40 – 1.00 | 0.99<br>0.022<br>0.92 – 1.00 | 0.94<br>0.120<br>0.60 - 1.00 |
| EC | 0.97 | 1.00 | 1.00 | 0.94 | 0.87 | 0.80 | 0.96 | 0.88 | 0.20 | 0.73 | 0.20 |
| BT | 1.00 | 0.91 | 1.00 | 0.94 | 0.87 | 0.73 | 1.00 | 0.94 | 0.40 | 0.98 | 1.00 |
| RW | 1.00 | 0.84 | 1.00 | 0.63 | 0.80 | 0.27 | 0.92 | 1.00 | 0.70 | 0.88 | 0.20 |
| TM | 0.93 | 0.63 | 0.93 | * | 0.40 | 0.15 | 0.29 | 0.63 | 0.40 | 0.65 | 0.40 |
| GG | 0.43 | 0.00 | 0.23 | 0.06 | 0.00 | 0.00 | - | - | - | - | - |
| RP | 0.90 | 0.94 | 1.00 | 0.81 | 0.93 | 0.87 | 0.88 | 1.00 | 0.80 | 0.94 | 1.00 |
| SE | 0.93 | 0.94 | 0.87 | 0.88 | 0.67 | 0.46 | 0.98 | 0.94 | 1.00 | 1.00 | 0.80 |
| NH | 1.00 | 0.81 | 0.97 | * | 0.87 | 0.60 | 0.79 | 0.88 | 0.80 | 0.96 | 0.60 |
| OS | 0.73 | 0.88 | 0.90 | 0.78 | 0.47 | 0.47 | 0.92 | 0.38 | 0.40 | 0.92 | 0.60 |
| JB | 0.90 | 0.75 | 0.87 | 0.75 | 0.73 | 0.60 | 0.67 | 0.94 | 0.80 | 0.92 | 0.20 |
| SG | 0.93 | 0.81 | 1.00 | 0.81 | 0.53 | 0.40 | 0.88 | 0.75 | 1.00 | 0.83 | 0.60 |
| MM | 0.93 | 0.66 | 1.00 | 0.66 | 0.80 | 0.46 | 0.46 | 0.38 | 0.00 | 0.46 | 0.00 |
| MH | 0.63 | 0.06 | 0.30 | 0.34 | 0.33 | 0.47 | 0.38 | 0.84 | 0.70 | 0.23 | 0.70 |
| MB | 0.47 | 0.31 | - | - | - | - | - | 0.09 | - | - | - |

Table 3. Reading comprehension z-scores

| | CAT 8 Written word to picture matching | CAT 10 Written sentence comprehension | PALPA 51 Word semantic association – high imageability | PALPA 51 Word semantic association – low imageability |
|---|---|---|---|---|
| Impaired single word comprehension (CAT 8 score): | | | | |
| MB | - | - | - | - |
| GG | **-28.15** | **-10.36** | **-9.57** | **-5.50** |
| MH | **-25.56** | **-7.02** | **-6.06** | -2.35 |
| SE | **-4.44** | -0.60 | -2.45 | -2.42 |
| JB | **-4.44** | -2.14 | -1.81 | -1.48 |
| OS | -3.33 | -1.79 | **-4.57** | -2.35 |
| TM | -2.22 | * | **-5.32** | **-4.50** |
| Intact single word comprehension (CAT 8 score): | | | | |
| NH | -0.74 | * | -0.32 | -1.48 |
| RW | 0.37 | **-3.57** | -1.06 | **-3.69** |
| MM | 0.37 | **-3.21** | -1.06 | -2.42 |
| RP | 0.37 | -1.43 | 0.32 | 0.34 |
| SG | 0.37 | -1.43 | **-3.94** | -2.82 |
| EC | 0.37 | 0.12 | -0.32 | -0.13 |
| BT | 0.37 | 0.12 | -0.32 | -0.60 |

- task not completed. *missing data. Participants are split into two groups based on CAT 8 Written word to picture matching scores. Participants are sorted within the two groups by CAT 10 Written sentence comprehension scores. MB could not attempt any tasks. TM and NH's data for CAT 10 is missing. Bold scores are those outside the normal range. There is no normal range data for the PALPA assessment, and z-scores of -3 or greater are taken as outside norms.

Table 4. Criteria used in the prototype template

| |
|---|
| **Layout of content:** |
| White space measuring 170mm by 110mm produced via individual easy to hold cards |
| White background to the overall space |
| Coloured banner heading in white font on a coloured background, top left of the space, providing superordinate category for the concept |
| One sentence to convey the specific concept |
| Sentence printed below the banner, aligned to the left |
| Sentence printed in black font on white background |
| Consistent colour in headings and images, for concepts within a topic |
| Below and to right of the sentence one or two colour photographs or line drawings depicting the concept in the sentence |
| **Language:** |
| Banner headings to consist of single words or short phrases such as Aphasia |
| Keywords: frequently occurring, early acquired, high in imageability, and short in length |
| Content words replace proforms such as pronouns where possible |
| Sentences are short and in canonical forms |
| Lexical terms and syntactic structures repeated across cards where possible |
| Flesch-Kincaid readability software -> Reading Grades to ensure all sentences of Grade 5 or lower |
| **Images:** |
| Each sentence accompanied by one or two images depicting its core meaning |
| Photographs selected by the designers from professional photo libraries |
| Line-drawings produced from photographs by the designers |
| Line-drawings to include colour, matching the banner background |
| **Typography:** |
| The banner heading printed in Vectora Black in 24 pt |
| The sentences produced in Vectora Roman 14pt in black |
| **Content:** |
| Content covers stroke and aphasia |

Table 5. Summary of consensus points and rated preferences from first iteration

| **Factors** | ***Feedback to designers*** |
|---|---|
| **Overall design** | |
| Adult style approved | *No change* |
| Materials acceptable and pleasing | *No change* |
| Consistency of overall design important | *No change* |
| Colour helpful when conveying meaning clearly | *Include colour where this has meaning* |
| **Layout** | |
| Limited amount of information per card helpful | *No change* |
| Amount in card helped to focus attention | *No change* |
| **Language** | |
| Header phrase helpful | *No change* |
| Written content acceptable | *No change* |
| **Images** | |
| Clarity of meaning of primary importance | *Ensure images convey meaning of concept clearly* |
| Transparency (unambiguous meaning) of images important | *Ensure unambiguous images* |
| Images must be coherent with text | *Ensure clear relationship between text and image* |
| One or two images should support each sentence | *No change* |
| Images can be coloured line drawings or colour photographs | *Provide examples using both options* |
| **Typography** | |
| Largest appropriate font size helpful – relative to page size | *Implement a font size larger than usual (ie font 14 or above) but suitable for context* |
| Too large font not helpful | *Implement font size appropriate to context* |
| Emphasis of keywords preferred through a larger and bold font than the main font | *Apply font size 2 pt larger for key words and use bold* |
| **Individual preferences** | |
| Image to portray the individual via their own photographs (participant GG) | |

Table 6. Frequency of ratings of images

| | ☺✓✓ | ✓ | ? 😐 | ✖ | ✖✖☹ | **Total participants** |
|---|---|---|---|---|---|---|
| Photo 1 | 5 | 1 | 5 | 3 | 0 | 14 |
| LD 1 | 8 | 2 | 2 | 2 | 0 | 14 |
| Photo 2 | 2 | 1 | 4 | 4 | 3 | 14 |
| LD 2 | 6 | 1 | 3 | 2 | 2 | 14 |

LD=line drawing

Table 7. Frequency of ratings of emphasis in font

| | ☺✓✓ | ✓ | ? 😐 | ✖ | ✖✖☹ | |
|---|---|---|---|---|---|---|
| **Emphasis style** | | | | | | **Total participants** |
| **Normal 12pt** | 0 | 1 | 0 | 8 | 5 | 14 |
| **Bold 12pt** | 3 | 3 | 4 | 4 | 0 | 14 |
| **Large 18pt** | 4 | 6 | 2 | 1 | 1 | 14 |
| **Large 18pt + bold** | 10 | 3 | 1 | 0 | 0 | 14 |

Table 8. Summary of consensus points from second iteration

| **Factors** | ***Feedback to designers*** |
|---|---|
| **Overall design** | |
| Card system showing related concepts approved | *No change* |
| One concept depicted in each card approved | *No change* |
| **Images** | |
| Images should display positive information | *Use images with positive depiction of stroke and aphasia* |
| Images should display accurate and realistic information | *Use images which show accurate information of stroke and aphasia* |
| Images should not contain extraneous details | *Check images for extraneous materialand remove* |
| Images should depict each concept in a consistent way | *Ensure consistency in images displaying concepts* |
| Abstract terms depicted in images are difficult to decode | *Use concrete terms and concrete images* |
| **Presenting information to people** | |
| The number of concepts people can cope with is one or two concepts at a time | *Cards to continue to show one proposition* |

Table 9. Frequency of rating of number of concepts per page

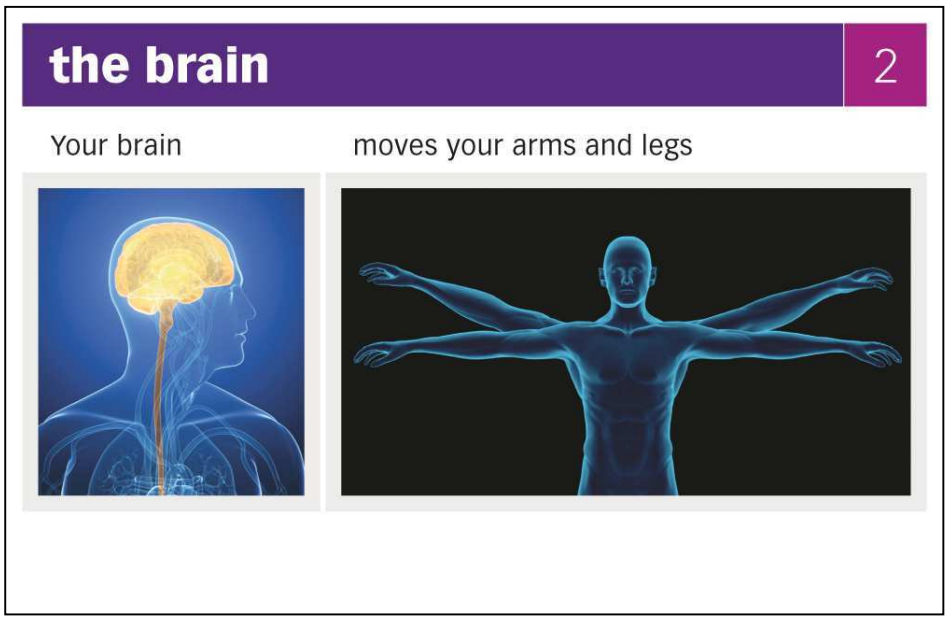
| | ☺✓✓ | ✓ | ? 😐 | ✖ | ✖✖☹ | |
|---|---|---|---|---|---|---|
| **Number of concepts** | | | | | | **Total participants** |
| **One concept** | 9 | 4 | 0 | 1 | 0 | 14 |
| **Two concepts** | 4 | 3 | 3 | 4 | 0 | 14 |
| **Three concepts** | 0 | 0 | 3 | 5 | 6 | 14 |

Table 10. Final criteria for production of materials

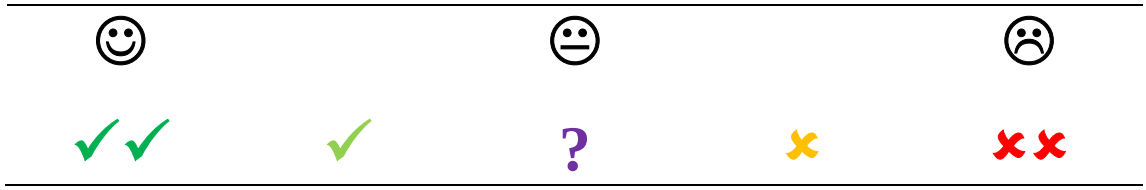
| |
|---|
| Layout of content: |
| White space measuring 170mm by 110mm produced via individual easy to hold cards |
| White background to the overall space |
| Coloured banner heading in white font on coloured background at top left of the space conveying the superordinate category for each concept |
| One sentence to convey the specific concept |
| **One concept depicted in each card** |
| Sentence printed below the banner and aligned to left |
| Sentence printed in black font on white background |
| Consistent colour used in headings and images, for a set of concepts |
| Below and to right of the sentence one or two colour photographs or line-drawings |
| **Colour to be included where this is meaningful for example blue to depict physiotherapy, green to depict occupational therapy (UK norms)** |
| Language: |
| Banner headings to consist of single words or short phrases such as Aphasia |
| Keywords: frequently occurring, early acquired, high in imageability, and short in length |
| Content words to replace proforms where possible |
| Sentences to be short and in canonical forms |
| Lexical terms and syntactic structures to be repeated across cards where possible |
| Flesch-Kincaid readability software derives Reading Grades to ensure that all sentences of Grade 5 or lower |
| Images: |
| Each sentence accompanied by one or two images depicting its meaning |
| Photographs selected from professional photo libraries |
| Line-drawings produced from photographs by the designers |
| Line-drawings include colour matching the banner background |
| **Images used should be unambiguous** |
| **Images used should convey the meaning of the concept clearly** |
| **One image should convey the sentence meaning** |
| **There should be coherence between the text and the images** |
| **Images should display positive information** |
| **Images should display accurate and realistic information** |
| **Images should not contain extraneous details** |
| **Images should depict each concept in a consistent way** |
| **Abstract or metaphorical extensions of meanings should not be used in images** |
| Text: |
| Banner heading printed in Vectora Black in 24 pt |
| Sentences produced in Vectora Roman 14pt in black |
| **Keywords produced in Vectora Roman 16pt in black and in bold** |
| Content: |
| Content refer to superordinate stroke and aphasia, |
| Specific content to be identified and organised within these categories |
| Presenting information: |
| **People with aphasia can process one and possibly two cards viewed together at one time. If two are viewed these should be related in meaning to each other.** |

*New criteria identified by the participants are shown in bold

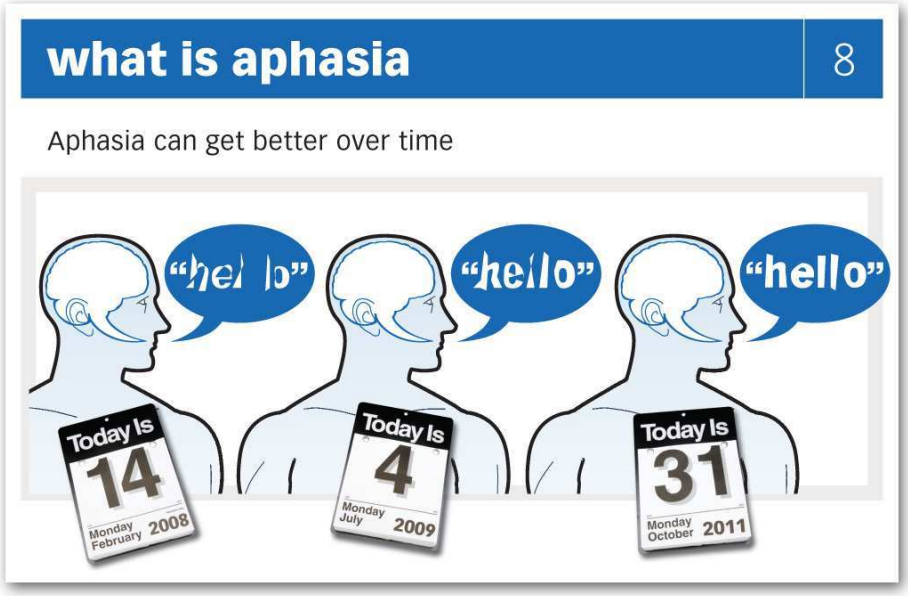
Appendix A. Sample of the initial design of the information materials



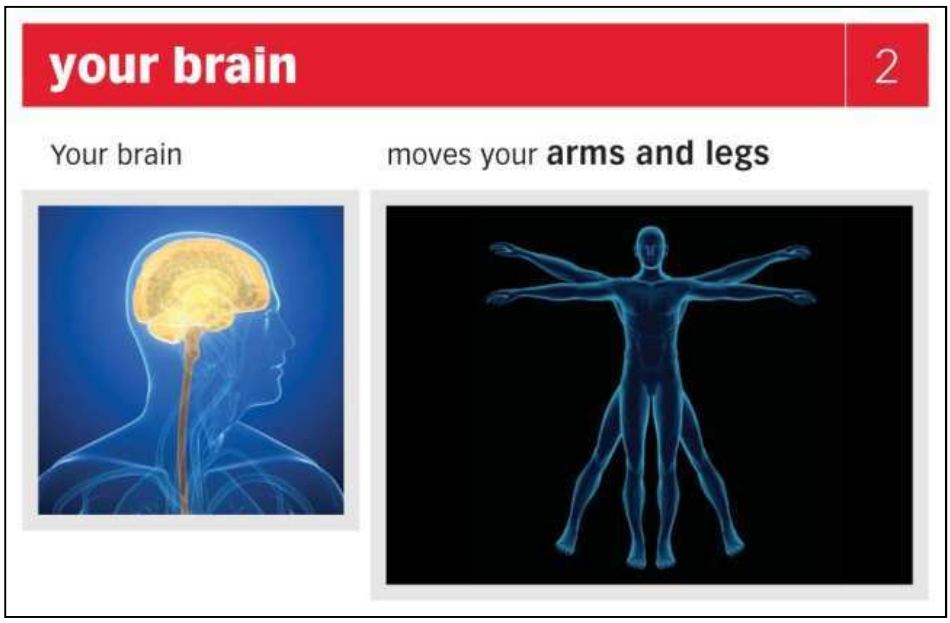
Appendix B. Visual rating scale



Appendix C. Concrete imagery approved by the groups



Appendix D:  Sample of final template






Amendments show an image which is coherent with the words in the sentence, and bold and large keywords