



The
University
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Accessible information: collaborating with people with
aphasia to develop an evidence-based template for health
information.

Caroline Haw

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Potential conflict of interest. R. Herbert, C. Haw and E. Gregory co-authored Accessible Information Guidelines (2012) (<http://www.stroke.org.uk/professionals/accessible-information-guidelines>), which are based partially on the work reported here.

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Abstract

People with aphasia require information about their health. Guidelines highlight the importance of providing information to this population in an accessible format to support their health literacy. Studies suggest, however, that people continue to feel under-informed after stroke, a particularly distressing predicament in the presence of language impairment.

This study aimed to develop a template for accessible information for people with aphasia. In Phase 1, literature regarding modified formatting for people with aphasia, facilitating language processing in aphasia, and information topics needed after stroke was reviewed, and principles for design extracted. These principles informed the prototype template, developed in collaboration with graphic designers.

In Phase 2, fourteen people with a range of aphasia types and severity collaborated in an iterative design process. Participants attended two facilitated focus groups, using Talking Mats® to give their views on the template, and on specific issues relating to modified formatting. Discussions were recorded, transcribed, and analysed using Framework analysis (Richie & Spencer, 1994). After each focus group, modifications to the template were made following feedback.

The collaborative, iterative design process resulted in the development of a template for conveying health information for people with aphasia. Analysis of the discussion data generated four themes: 'Visual access', 'The look of it', and 'Understanding', reflected the issues surrounding information access from the perspective of people with aphasia. The overarching theme, 'Everyone's different', captured the varied experience of aphasia for individuals.

The findings informed the final version of the template, including relevant topics, language structures to maximise comprehension of text, optimum number of concepts per page, facilitative features of typography, use of images, and layout of information.

In Phase 3, the template principles were translated into accessible information guidelines, which were user-tested, modified, and subsequently published by The Stroke Association.

Designing for people with aphasia requires attention to the visual, cognitive, conceptual, and language processing demands, and consideration of the experience of aphasia. Further implications for practice and research are outlined.

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Chapter 1 Introduction and literature review

The availability of accessible information for people with aphasia is an essential component of healthcare provision after a stroke (Intercollegiate Stroke Working Party, 2016). This chapter introduces background and contemporary literature and developments pertinent to the field of accessible information for people with aphasia, with the aim of setting the context for the thesis.

1.1 Introduction to stroke and aphasia

Stroke is a complex medical condition with multiple psychological, cognitive, language, and social consequences. The total incidence of stroke in the UK is over 100,000 new cases per year (Stroke Association, 2017). In the general population, the prevalence of stroke is reported as 1.5 - 1.75% (Mant, Wade, & Winner, 2004), translated by the Stroke Association as representing 1.2 million people who have survived a stroke. Of these people, approximately 50% live with ongoing physical, cognitive, and linguistic disabilities, and approximately 33% experience post-stroke depression (Stroke Association, 2017).

Aphasia is an acquired communication disorder caused by focal damage to the language-dominant hemisphere of the brain, affecting approximately one third of people following a stroke. Aphasia occurs in 52% of all stroke cases at the acute stage, 29% at three months, and persists beyond six months after stroke in 15% of cases (Mant et al., 2004). Currently in the UK, approximately 350,000 people are estimated to have aphasia resulting from stroke (Stroke Association, 2017).

Aphasia can affect all modalities of language function, including auditory comprehension, spoken language output, reading, writing, and gesture, with implications for people's ability to communicate functionally, and to participate in their family and social environments. Despite the use of a single diagnostic term, aphasia varies widely, reflecting overall stroke and aphasia severity, individual patterns of language impairment, and related stroke consequences such as cognitive impairment.

The impact of aphasia is extensive and enduring, both for those directly affected, and for their families and friends (Avent et al., 2005). It is associated with reduced independence (Cruise, Worrall, & Hickson, 2011), and, overall, impacts more severely on people's quality of life than stroke without aphasia (Hilari, 2011). People with aphasia are more likely to be depressed than their non-aphasic peers (Hilari, Needle, & Harrison, 2012), and have higher levels of stress

(Stroke Association, 2013). Aphasia can also lead to a reduction in quantity and quality of social activity, including loss of friendships (Northcott & Hilari, 2011), and this is worse for those with severe aphasia (Parr, 2007).

Recent research has endeavoured to show positive approaches taken by individuals with aphasia, revealing acceptance and resilience to the challenges of living with aphasia (e.g. Bright, Kayes, McCann, & McPherson, 2013; Brown, Worrall, Davidson, & Howe, 2010; Cruice, Hill, Worrall, & Hickson, 2010; Worrall et al., 2010). The reciprocal benefits to both individuals and services have been demonstrated by studies reporting a partnership approach with people with aphasia, in which the expertise of those living with the condition to inform and educate is valued (e.g. Swart & Horton, 2015).

1.2 Health literacy

Health literacy refers to the understanding a person has of their health, through a process of obtaining, understanding, and using health information (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). It is based on a body of evidence that has demonstrated that people who are informed are better able to make wise decisions about their health, and to develop resilience in the face of ill-health or disability (Nutbeam, 2000).

Access to health information has been demonstrated to benefit patients' ability to understand their condition (Coulter & Ellins, 2006; McPherson, Higginson, & Hearn, 2001) and their ability to interact with staff who provide health services (Coulter, Entwistle, & Gilbert, 1999). Better-informed patients have been found to follow treatment plans more assiduously (Mansoor & Dowse, 2003), to be more productively involved in decisions about their care (Stacey, Légaré, Col, et al., 2014), and to be more autonomous and able to engage in self-management (Murray, Burns, See, Lai, & Nazareth, 2005). Reduced anxiety (Humphris, Ireland, & Field, 2001) and increased satisfaction with services (Tomkins, Siyambalapitiya, & Worrall, 2013) are also associated with access to health information. Involving service users in developing health information relevant to their condition has resulted in better uptake, with information more appropriately targeted in terms of both content and format (Bunge, Muehlhauser, & Steckelberg, 2010).

Nutbeam (2000) identified three levels of health literacy, representing the skills needed to engage with health information and services, a model which has been adopted in the UK by the Royal College of General Practitioners (Rowlands, Protheroe, Price, Gann, & Rafi, 2014). The first level, functional health literacy, refers to understanding basic health information; the second, interactive health literacy, entails being able to discuss the information in order to ask

questions and make decisions. The third level, critical health literacy, involves self-management, taking control of one's own health. Inherent in this definition is a reciprocal responsibility between individuals and service providers: individuals to engage with their health, with information and services, and service providers to make information and services accessible to all service users, for example through the provision of accessible information (Paasche-Orlow, McCaffery, & Wolf, 2009).

Access to health information to support all levels of health literacy is vital, since research identifies that poorer health outcomes are associated with low health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Magasi, Durkin, Wolf, & Deutsch, 2009; Serper et al., 2014; Wolf, Gazmararian, & Baker, 2005). Interventions to improve health literacy are described at the level of countries, communities and individuals, addressing the needs of both whole populations and groups, and individuals within their specific contexts. However, as Pleasant, McKinney, and Rikard (2011) note, measuring health literacy poses significant challenges, since it is a broad concept, which may vary within and between individuals, dependent on context. They propose that measurement should include objective assessment of the different aspects of accessing, understanding, appraising, and using health information, as well as literacy and numeracy.

The growing evidence for the impact of health literacy on healthcare outcomes is represented by a significant body of literature and guidance for healthcare staff regarding effective communication with patients (e.g. Ley, 1988; Street, 2009) and the production of written information for patients (e.g. Duman, 2003; Hoffmann & Worrall, 2004). Research has addressed the information formatting needs of specific groups, for example people with low literacy (e.g. Doak, Doak, & Root, 1996), adults with learning disabilities (e.g. Rodgers & Namaganda, 2005), and people with aphasia (e.g. Rose, Worrall, & McKenna, 2003).

Coulter, Entwistle, and Gilbert (1998) identified the need to include people affected by a health condition in developing information, and this principle is carried forward in guidance aimed at health care professionals producing information for their patient groups (e.g. Duman, 2003; Department of Health, 2003). Within these guidance documents, readers are advised to consider the needs of those with intellectual or sensory disabilities, such as people with a learning disability, hearing impairment, or low vision, but the specific disabling effects of acquired language disorders are not represented.

1.2.1 Systems to support accessibility of health information

Health literacy is a moral imperative, underpinned by concepts of human rights, accessibility, inclusion, empowerment, and equality of opportunity. Such principles are embedded in the

aims of the United Nations, which provides guidance to member states on their legal obligations in relation to the rights of citizens, including those with disabilities (Convention on the Rights of Persons with Disabilities, 2008). The World Health Organisation (2011) identifies the right to health as a basic human right, with accessibility, including information accessibility, as one of its core principles.

As a human right and as a prerequisite to health literacy, accessibility of health information forms part of public health strategy and is included within wider policies in the USA and the UK. In the United States, the U.S. National Action Plan to Improve Health Literacy (2010) includes the target of providing health information which can be understood by all people.

In the United Kingdom, several legal and policy systems are now in place to support individuals, regardless of disability, to take an active role in their own health. Firstly, the Equality Act (2010) provides a legal framework to protect the rights of people with so-called “protected characteristics” (p.4) including those with communication disabilities. Secondly, the UK government’s strategic white paper “Equity and excellence: Liberating the NHS” (DOH, 2010) articulates an aim for all patients to have access to information and be involved in all decisions about their care in order to take responsibility for their health. Finally, the recently launched NHS England Accessible Information Standard (2015) supports this aim, requiring health and social care organisations to provide communication support and appropriately accessible information to any adult with a communication disability. Compliance with this standard requires services systematically to identify, record, highlight, and share the communication needs of their individual service users. The standard primarily aims to support individuals with long-term communication disability arising from a sensory loss, such as hearing or visual impairment, or a learning disability, but those with or other, less prevalent impairments, such as aphasia, are included. The scope of the standard does not extend to people with low literacy, dyslexia or English as a Second Language. Nor does it encompass support for decision-making, which falls within the scope of the Mental Capacity Act (Office of Public Sector Information, 2005), or aspects of the physical environment, such as signage in public buildings.

As Bunning and Horton (2007) propose, there are commonalities in the experience of having a communication disability, which this standard now recognises. However, to address specific needs appropriately, modifications to information must be suitable for individuals, with specific alterations to communication and information tailored to the needs of each group. Currently the standard mandates the provision of accessible information, but no evidence-based guidance for the different groups within its scope is provided. As noted by Rafi, Sullivan, and Mathers (2016), specific resources to support the diverse needs of different groups of

people affected by a wide range of communication impairments, including, for example, those with learning disabilities, sensory impairments, dementia, or aphasia, will need to be made available to organisations providing health and social care to achieve the requirements of the Accessible Information Standard.

1.3 Information after stroke

In this section, the information needs of people after a stroke will be outlined, in terms of information required, optimal timing of information provision, and the range of formats used. The research literature on this topic relates to the population of people after a stroke in broad terms without specifying the nature of their impairments. For example, some studies have included people with aphasia, but their specific contributions are not separated out in the reporting of findings.

1.3.1 Topics and timing of information after stroke

In the United Kingdom, the period following a stroke may involve emergency admission to hospital for diagnosis and hyper-acute medical care, ongoing acute medical treatment, and early hospital rehabilitation. Hospital care is usually followed by transfer home, with community rehabilitation services (Intercollegiate Stroke Working Party, 2012). Progression through these different phases of care in hospital and at home will vary, determined by individual needs and local service provision. The disabling consequences of stroke are life-long in many cases, persisting well beyond the time allocated by care providers. Throughout the aftermath of a stroke, people need information. The importance of information is recognised in UK national Stroke guidelines, which specify that all patients and their families should receive information tailored to their individual needs and formatted in a way they can understand at each stage of the stroke care pathway (Intercollegiate Stroke Working Party, 2012:62; National Institute for Health and Care Excellence (NICE), 2013:26).

1.3.1.1 *Information topics*

Specific information needs following a stroke are wide-ranging, since the consequences of stroke can be both varied and long-lasting. A systematic review of the education needs reported by patients and carers after stroke by Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans (2011) reflects the findings of 21 selected studies, identifying a range of topics. These include medical concerns such as the cause of stroke, its diagnosis, prognosis, and treatment, and how to prevent further strokes. Information is also needed to address practical concerns, such as dealing with medication and supporting rehabilitation. The need to be informed about what to expect and how to help with psychological and emotional issues, such

as fatigue and depression, and cognitive issues such as memory and concentration, are identified. Finally, information is required relating to finance and benefits, access to services and social activities, driving after stroke, and return to work.

1.3.1.2 *Timing of information*

People report a need for different types of information at different stages after a stroke, and this has been found to be of most value when it is individualised, personally relevant information, rather than generic (Wiles, Pain, Buckland, & McLellan, 1998). Linked with this, the timing of such information has been found to be an important factor, with people reporting that they want to receive information at a time when they are able to process it (Eames, Hoffmann, Worrall, & Read, 2010). The need for information to be repeated is also highlighted in the literature, to provide multiple opportunities for people to apply the information to their current circumstances (Danzl et al., 2016).

Whilst the literature reports preferences for information to be provided responsively and individually, some studies also report participants expressing dissatisfaction with services where information was not provided systematically (e.g. Danzl et al., 2016; Eames et al., 2010). As Eames et al. observe, this reflects a tension in the expectations of patients and family members, and provides a challenge for healthcare providers seeking to answer the questions that patients and families ask, as well as educating them in the areas where they do not yet have awareness.

1.3.2 Information formats after stroke

In clinical practice in the developed world, information after stroke is provided by healthcare services in a range of different ways, and the literature in this area reflects its multi-faceted nature. The formats described in the literature include those which are provided as an intervention, such as written information packages (e.g. Mant, Carter, Wade, & Winner, 1998) or education sessions covering predetermined topics (e.g. Forster et al., 2012b). The format of such provision may include, for example, stroke information leaflets, posters, or web-based information, and the use of individual and group teaching methods.

Verbal provision of information also arises within the context of service provision, during, for example, consultations, daily care, or rehabilitation sessions. Such interactive information provision may be conceptualised as part of communication, and is not generally reflected in the information as intervention studies, but is captured by studies recording the experiences of people after stroke. For example, as Eames et al. (2010) found, the reported experience of patients and family members reflects the whole, rather than separate elements of their care.

And as Anderson and Marlett (2004) argue, the skilful use of communication during stroke rehabilitation can serve to inform patients and family members in a positive way.

Effectiveness of information provision depends on individual preferences and needs. Forster, Smith, and Young (2012a) found that an active style, in which people could check their understanding by asking questions, was more effective when aiming to increase knowledge about stroke. This echoes the findings of preference surveys (e.g. Eames, Hoffmann, Worrall, & Read, 2011; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005) which showed that people valued time and attention to their personal concerns.

To accommodate individual preferences, research has explored the use of information packages which provide a bespoke combination of different formats. For example, Eames, Hoffmann, Worrall, Read, & Wong (2013) found increased satisfaction with information provision and greater ability to seek information independently among people who received a tailored package of computer-generated written information and the opportunity for verbal follow-up.

Across the literature, people express a preference for a combination of verbal information, backed up with written resources, which they may keep for reference (Eames et al., 2011). Written information is also valued as a support for talking things through during face-to-face consultations (Wachters-Kaufmann et al., 2005). This written information is essential, since as participants in the study by Eames et al. (2011) reported, memory for verbal information alone is vulnerable: “[They] may have told me but [the information has] gone in and out...didn’t register.” (p.75).

Despite the reported need to provide written information, however, the literature suggests that there may be a tendency for healthcare providers to give only verbal information (Eames, Hoffmann, McKenna, & Worrall, 2008; Hoffmann, McKenna, Herd, & Wearing, 2007). This may relate to a lack of suitable materials for healthcare staff to provide. In addition, patients and families may discard written materials that they find unsuitable for them.

1.3.3 Summary

Information provision after stroke has been the focus of a growing volume of research, providing valuable evidence regarding the topics, timing, and formats of information needed by patients and their families. The literature tells, however, of longstanding concerns expressed by both healthcare providers and stroke survivors and their families, that information provision remains inadequate (Hanger, Walker, Paterson, McBride, & Sainsbury, 1998; Hanger & Wilkinson, 2001; Rodgers, Bond, & Curless, 2001). The Stroke Association

(McKevitt et al., 2011) report that 54% of people were dissatisfied with the amount of information they received after their stroke. The needs of people post-stroke with retained language and communication skills are therefore not being fully met. People with aphasia after stroke are likely to be further disadvantaged with regard to information provision, and indeed Brady, Fredrick, and Williams (2013) report that few studies have attended to the specific needs of those with language impairment after stroke.

1.4 Aphasia and information after stroke

People with aphasia after a stroke have the same need for information as those with stroke without aphasia, and in addition need information about aphasia. Impairments to language processing, including reading, present significant barriers to access to information for those with aphasia, their families, and healthcare providers. In this section, language processing in aphasia will first be described, then related to the issue of health information, including health literacy.

1.4.1 Aphasia

Aphasia is an acquired disorder of language processing which may affect speaking, understanding, reading, and writing. It affects individuals differently in terms of language modalities impaired and functional communication ability, and it varies in severity. Improvements can occur over time, but it is viewed as a chronic condition, with enduring effects on language and communication. The characteristics of aphasia are manifold, and a detailed description is beyond the scope of this thesis. The following section is provided to orientate the reader to the range of difficulties faced by people with aphasia when accessing spoken or written information.

1.4.1.1 *Comprehension of language*

Aphasia may affect comprehension of spoken and written language, and may vary between individuals depending on the type of stroke and extent of the lesion (Damasio, 1981).

1.4.1.1.1 Auditory comprehension

Auditory comprehension deficits are common in aphasia and these are manifested in terms of lexical comprehension, semantic impairments, and sentence processing. Syndromes such as Wernicke's aphasia are particularly associated with impairments in auditory comprehension, in which individuals may have difficulty processing the sounds in words or accessing the word meaning.

In healthcare, people with aphasia may have difficulty understanding information due to lexical, semantic, and sentence comprehension impairments. For example, the vocabulary used to explain the details of stroke and its treatment may be particularly challenging in the presence of aphasia, since medical terms are frequently long and unfamiliar. Technical medical terms, describing specialist procedures or medication, for example, may be difficult to comprehend. Medical vocabulary may also be new to someone who has no previous experience of stroke; for example, terms such as 'aphasia' or 'dysphagia' may have no meaning for them. Terms may be used to convey uncertain or previously unknown concepts, such as possible recovery, future care needs, or services. Terms such as 'rehabilitation' may have different semantic associations, presenting a difficulty in comprehending what such a term might mean in the person's current situation. Within stroke care, metaphorical language is used, for example 'stroke journey', 'stroke pathway', 'goals', presenting possible problems for people with aphasia, who may interpret these terms literally (Ianni, Cardillo, McQuire, & Chatterjee, 2014).

Impairments to sentence comprehension can result in difficulties understanding health information, since healthcare staff may explain complex concepts using correspondingly complex language structures. Overall, sentence complexity is a predictor of difficulty, with more non-canonical and complex structures being harder to understand (Caplan, Waters, DeDe, Michaud, & Reddy, 2007). Trying to comprehend information presented verbally may be challenging for someone with aphasia, particularly if no accommodation is made for their syntactic impairment.

1.4.1.1.2 Acquired dyslexia in aphasia

Of particular importance to people's access to information in healthcare settings is the fact that most people with aphasia present with acquired deficit in reading. According to theories of reading comprehension (e.g. Marshall & Newcombe, 1973) there are several stages in access to written word meaning, with damage to any stage resulting in reading comprehension difficulties.

Sentence reading requires an ability to understand the individual words, as outlined above. In addition, use of syntactic rules and the assignation of semantic roles to the different parts of the sentence is needed to derive the propositional meaning (Ellis, 1984, reprinted 1989), with challenges mirroring those of spoken sentence comprehension. Text reading has recently attracted more interest within aphasiology, found to require additional cognitive skills such as working memory and making inferences (e.g. Chesneau & Ska, 2015; Meteyard, Bruce, Edmundson, & Oakhill, 2015).

Impairments in visual orthographic analysis result in peripheral dyslexias. For example, neglect dyslexia and attentional dyslexia result in errors due to visual processing of letters at the initial or final position, or due to intrusion of letters from neighbouring words. Letter-by-letter reading involves sequential single letter reading, without these being integrated and recognised as a whole word unit. In visual dyslexia, words are mistaken for visually similar word forms. Peripheral dyslexias may or may not co-occur with aphasia; in contrast, central dyslexias which arise from lexical and semantic levels of processing are more usually associated with aphasia (Riley & Kendall, 2013).

Written information materials may present difficulties for reading at any of the levels outlined above. As with spoken information, the vocabulary choices may be challenging for people with aphasia if medical terminology is used without explanation. Similarly, use of syntactically complex forms, such as passive forms or long sentences, may be difficult to read. Challenges to memory and visual processing may be presented if materials are lengthy or poorly reproduced. Since written language is used in a variety of information media, difficulties with reading can affect people's ability to understand such formats as patient information leaflets, public posters and displays, and web-based information.

1.4.1.2 *Language output in aphasia*

1.4.1.2.1 Spoken language output

Word finding difficulties are one of the most prevalent features of aphasia (Hickin, Best, Herbert, Howard, & Osborne, 2002) and range in severity and type from non-retrieval to occasional delays to overt errors. Such errors may be related to the target in terms of form (e.g. word length), sound, or meaning.

Sentence production requires the conceptualisation of an event, the creation of an argument structure, and the selection of the correct syntactic frame (e.g. Garrett, 1980). Individuals with aphasia may have specific difficulties generating syntactic structures, or mapping the argument structure to the sentence form (Marshall, 2013), resulting in reduced fluency and a reduced range of structures available to them.

In the context of information exchanges, individuals may therefore have difficulty retrieving the vocabulary and sentence structures necessary to identify their concerns or to ask specific questions about their health. Communication partners may also fail to interpret the intended meaning of the speaker with aphasia, due to errors in production by the person with aphasia.

1.4.1.2.2 Written language output

In addition to impaired motor skills resulting from stroke, difficulties with writing may mirror impairments in spoken language output. At the single word level, difficulties arise with word retrieval and spelling; beyond single words, people might experience problems with syntax and text level writing. Such difficulties affect people's ability to operate independently in the realm of written language, for example writing letters, using email, texting, or completing forms.

1.4.1.3 *Other cognitive deficits and aphasia*

Cognitive changes after stroke are widely reported, with impairments to individual or multiple cognitive domains including attention, memory, visuospatial processing, language, and executive function (Helm-Estabrooks, 2002), any or all of which may affect individual's ability to interact with information. Cognitive impairment after stroke is not limited to the acute stages, suggesting that ongoing specific difficulties may combine with language impairments to hinder access to information (Cumming, Marshall, & Lazar, 2013). As stated above, visual processing deficits, including hemianopia and peripheral dyslexias, can affect ability to process written information formats.

Traditional accounts of aphasia have emphasised the linguistic nature of the condition (e.g. Edelman & Greenwood, 1992). Recent investigations, however, indicate that aphasia can co-occur with impairments to other cognitive functions such as attention (Heuer & Hallowell, 2015; Murray, 2012), executive function (Frankel, Penn, & Ormond-Brown, 2007), and short-term memory (Kalbe, Reinhold, Brand, Markowitsch, & Kessler, 2005). The presence of such cognitive deficits, combined with the purely linguistic impairments evidenced in acquired dyslexia, can be seen to present additional challenges to accessing written information formats in healthcare.

Reading is a cognitively challenging activity, requiring a combination of visual skills and selective and sustained attention, to focus on the text; working and short-term memory, to link sections of text and draw inferences; and self-monitoring, to ensure continued focus on the task (Rayner & Pollatsek, 1989). Memory of the text, both in the short and long term, is needed in order to retain information content. According to Alvarez and Emory (2006), these basic cognitive skills underpin higher order cognitive processes involved with planning and problem solving, encompassed by the term executive function, skills which are also used when approaching a task such as reading in a strategic manner. Strategic approaches to reading employed by people with aphasia have been found to influence reading comprehension and enjoyment (Lynch, Damico, Abendroth, & Nelson, 2013). For example, self-pacing (Caplan et

al., 2007) results in better comprehension than fast reading, but depends on an individual having adequate executive function control to use the strategy.

Given the above potential language and other cognitive processing difficulties which may present in aphasia, it is unsurprising that people with aphasia have difficulties accessing written and spoken information. The specific difficulties faced by people with aphasia will be further considered below.

1.4.2 The challenges for people with aphasia and health information

Information is provided in different formats in stroke care, as discussed in section 1.3.2 above, but all depend on spoken and written language, and hence are inherently demanding for people with aphasia. These are lasting challenges in many cases, as aphasia is often a lifelong condition.

An early challenge for understanding information relates to the sudden onset of stroke, after which people may find themselves unable to understand others, speak, read, or write, a situation which people have reported as finding frightening (Parr, Byng, Gilpin, & Ireland, 1997). In such stressful and unwanted situations, unfamiliar and conceptually difficult information can be particularly challenging, and studies have reported people feeling too overwhelmed to be able to absorb new information (Eames et al., 2010).

Public awareness of aphasia is low (McCann, Tunnicliffe, & Anderson, 2013; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002), therefore developing an understanding of aphasia in itself presents a challenge to new patients and families, who may well have had no previous knowledge of the condition.

The skills of healthcare staff play an important role in supporting people with aphasia to access information during such interactions. National guidelines (Intercollegiate Stroke Working Party, 2012) indicate the need for all staff to be aware of aphasia, and trained in the practical strategies to support interactions. Such training has been demonstrated to have a positive influence, for example Carling-Rowland, Black, McDonald, & Kagan (2014) report the increased reliability of social workers when assessing the mental capacity of people with aphasia after practical training.

Guidelines produced for the general population are not always appropriate for the needs of people with aphasia. For example, Duman (2003) proposes the use of question forms, to encourage engagement with the materials. This technique may, however, be a barrier to understanding for people with aphasia, given that non-canonical forms are known to be more difficult to comprehend.

In sum, information may be inaccessible due to a combination of the constellation of impairments associated with aphasia, the nature, formats, and timing of the information, and the environment, including the communication skills of those around the individual.

1.4.3 Historical background to research into information access for people with aphasia

The social model of disability understands disability as it is constructed within wider society (Oliver, 1996). Applied to aphasia, it removes the focus of the impairment from the individual, and relocates it within the interactions that the individual has in the society they live in, including with other people and in the wider environment (Byng & Duchan, 2005). With regard to access to health information, the skills and knowledge of healthcare providers, and the materials used to provide information, are critical factors in enabling people with aphasia to access information, and so they are the focus of the research in this field.

Developed principally in the USA, Canada, and the UK from the early 1990s, the social model of disability informed developmental work into communication environments and communication access. The literature surrounding accessible information for people with aphasia has its origins in this important body of work.

Within the area of everyday conversation, Kagan and Gailey (1993) introduced the concept of “communicative accessibility” (p.204). They developed the idea of training conversation partners to adopt specific communication strategies to assist people with aphasia to participate in conversational interactions. Kagan and Kimelman’s (1995) investigation of aphasia and informed consent introduced the concept of communication access, posing the question “do we provide subjects with information in an accessible format?” (p.67). Through this work, they identified that written information could be modified to maximise the reading comprehension of participants with aphasia.

Further research into the lived experience of aphasia took place subsequently. In the UK, Parr et al. (1997) investigated the experience of aphasia from the perspective of those living with the condition through in-depth interviews with fifty people with chronic aphasia. Eight overarching themes identified through Framework analysis characterised the complexity of the individual and shared experience of aphasia. One of these themes, “*Everything seems a secret*’: information and aphasia” (p.87) highlights the difficulties experienced by people with aphasia in accessing information after their stroke. In health literacy terms, the study found that both obtaining and understanding information were problematic for people with aphasia, demonstrating powerfully the need for healthcare providers to provide accessible information

to people with aphasia after stroke. These findings provided a categorically negative response to the question posed by Kagan and Kimelman two years previously.

As a result of Parr et al.'s (1997) findings, subsequent work involved people with aphasia in developing information resources. Parr, Pound, Byng, & Long (1999) involved people with aphasia in the development of an information resource about aphasia. This was a ground-breaking achievement due to both the involvement of people with aphasia in its production and the novel presentation, which included images as well as text, use of bold font, and colour-coding to delineate different topics. Rose et al. (2003) later described this formatting as "aphasia-friendly principles: (1) use of simple words and short sentences; (2) use of large and standard font; (3) use of white space; and (4) use of relevant pictures." (p.950).

Later work at the charity Connect, in the UK, continued to use these principles whilst developing a model for including people with aphasia in the operational management of the organisation (Parr, Pound, & Hewitt, 2006; Pound, Duchan, Penman, Hewitt, & Parr, 2007). Working in collaboration with people with aphasia, these authors also produced guidance for good practice in involving people with aphasia in research (e.g. Swinburn, Parr, & Pound, 2007) and training resources to educate organisations about aphasia (e.g. Parr, Wimborne, Hewitt, & Pound, 2008). 'Aphasia-friendly' principles are promoted in these resources as part of the overall aim of maximising communication access for people with aphasia. The principles underlying aphasia-accessible formatting are stated in very broad terms only, however, raising a risk of mis-interpretation by consumers in their use of the guidance to produce new information materials for people with aphasia.

The broadening scope of aphasia researchers and clinicians working within a social rather than a medical model of disability (e.g. Kagan & LeBlanc, 2002; Pound, Parr, Lindsay, & Woolf, 2000) is consistent with the World Health Organisation ICF (2001) model, which seeks to provide a means of describing the health of individuals within their personal context. Of particular importance in this discussion is the concept of the environment, which can be classed as either enabling or disabling, due to the presence of either facilitators (factors which improve functioning) or barriers (which limit functioning). According to the ICF (2001) classification, the environment includes any aspect of the physical environment, people (including their skills and attitudes), and the services (including systems and policies) which an individual may access.

Using this ICF (2001) model, Howe, Worrall, & Hickson (2004) identified the concept of an "aphasia-friendly environment" (p.1015), in which facilitators to participation are maximised and barriers minimised, and they reviewed research which addressed the different aspects of the environment listed by the ICF (2001). They found limited specific evidence about how to

modify environments for people with aphasia, calling for further research to both understand the issues from the perspective of those with aphasia, and to specify the barriers and facilitators across all areas, including the modification of written information. A later review using the same framework, with reference to the acute hospital environment, by O'Halloran, Hickson, & Worrall (2008), found evidence that the knowledge, skills and attitudes of healthcare staff significantly affected the experience of people with aphasia whilst in hospital, and this was generally reported from a negative perspective.

Within the field of written information, Worrall, Rose, Howe, McKenna, & Hickson (2007) discuss accessibility of written information, calling for further research into the ways of formatting written information for people with aphasia. Since the integration of the social model and the ICF into aphasia care, however, and the conceptualisation of aphasia-friendly environments and formatting, relatively little research has been conducted to examine the impact of this approach on people with aphasia.

A number of studies have investigated the impact of modifying written information for people with aphasia (Brennan, Worrall, & McKenna, 2005; Dietz, Hux, McKelvey, Beukelman, & Weissling, 2009; Ghidella, Murray, Smart, McKenna, & Worrall, 2005; McKelvey, Hux, Dietz, & Beukelman, 2010; Rose, Worrall, Hickson, & Hoffmann, 2011a, 2011b, 2012; Wilson & Read, 2016). Such research has taken a largely positivist approach, seeking to establish clear evidence for specific aspects of formatting which are either preferred by people with aphasia, or beneficial to comprehension. Only one study (Rose et al., 2003) has demonstrated that the use of combined modified formatting of written information can facilitate the comprehension of health information in people with aphasia.

The body of work surrounding communication access to written information by people with aphasia has led to an apparent perception amongst healthcare staff in the UK and elsewhere that effective and evidence-based principles have now been established. Guidelines have now been produced for making information accessible to people with aphasia (Herbert, Haw, Brown, Gregory, & Brumfitt, 2012), representing an increasing resource available to healthcare staff. These were produced in collaboration with people with aphasia, but their effectiveness has not been rigorously tested.

Materials are now being published, using methods of formatting described in the literature, which have been assumed effective in ensuring accessibility to people with aphasia (e.g. Carling-Rowland et al., 2014; Jayes & Palmer, 2014; Pearl, 2014). The term 'aphasia-friendly' is widely used in both research and clinical practice, suggesting that there is agreement about what this means and how it may be delivered. It is not the case, however, that effective

methods for providing access to information for people with aphasia have been firmly established.

1.4.4 The current status of accessible health information for people with aphasia

Recent research into access to information suggests that people with aphasia want information (Rose, Worrall, Hickson, & Hoffmann, 2010; Worrall et al., 2010; Worrall et al., 2011) and report higher levels of satisfaction and support when they feel informed (Hilari & Northcott, 2006; Tomkins et al., 2013). A recent survey into how people with aphasia obtain information (Hinckley, Hasselkus, & Ganzfried, 2013) found, however, that people with aphasia continue to report that they do not receive the information they need after a stroke, suggesting that there has been little improvement since Parr et al.'s (1997) study.

The research suggests that people with aphasia experience greater difficulties obtaining and understanding information (Cottrell & Davies, 2004; Eames et al., 2010) and are less likely to receive written information than other stroke patients (Eames, McKenna, Worrall, & Read, 2003; Knight, Worrall, & Rose, 2006). When information is provided, it is frequently written in ways which are not accessible (Aleligay, Worrall, & Rose, 2008; Eames et al., 2003; Rose, Worrall, McKenna, Hickson, & Hoffmann, 2009). There is some evidence that people with aphasia are not treated as independent consumers of health care. For example, Knight et al. (2006) observed that in an acute stroke setting, people with aphasia were given information only when a family member was present.

The provision of information accessible to individuals is needed from the outset of their stroke and into the longer term (Parr et al., 1997). However, as Eames et al. (2008) found, less than half the 119 community stroke services they surveyed in Australia considered the specific information needs of people with aphasia, suggesting that there remains a continuing lack of awareness and skill in this area. There are also several reports of a lack of supported or accessible information to facilitate people living independently (Brown et al., 2010; Hilari & Northcott, 2006; Hinckley et al., 2013; Parr, 2007). This means that people are less likely to receive information about services or activities, fuelling a cycle of social isolation and poor health-related quality of life outcomes, as described by Hilari et al. (2012).

Kagan and Kimelman (1995) first asked: "do we provide subjects with information in an accessible format?" (p.67). Parr et al.'s (1997) account suggested that the answer was no. Following their findings, significant developments in the concept of communication access were made, and from this an accumulation of work has led to an acceptance of the concept of

'aphasia-friendly' information. However, this work has not yet had a significant impact on enabling people with aphasia to feel informed.

1.4.5 Aphasia and health literacy

Aphasia can be viewed as a barrier to health literacy, since it has a direct and negative effect on obtaining, understanding, and using health information. UK Stroke guidelines and wider policies include consideration of those affected by aphasia, specifying that information should be provided in accessible formats, attending to individual communication needs (NHS England, 2015; Intercollegiate Stroke Working Party, 2012; NICE, 2013). Guidance has now been provided (e.g. Herbert et al., 2012), but the reported experiences of people with aphasia do not yet suggest there has been an impact on the health information they receive. Two factors may account for this. Firstly, research into the social consequences of aphasia reports the low public awareness of aphasia (McCann et al., 2013; Simmons-Mackie et al., 2002), with a consequence that there is a lack of awareness of the needs of those with aphasia. As Parr (2007) noted, the Disability Discrimination Act (1995) made provision for people with a communication disability, but lack of awareness of the condition remained a barrier to its proper implementation. Secondly, translating guidance into good practice is a complex process, requiring both time and resources to ensure successful implementation (e.g. Graham et al., 2006). It is likely that making published guidelines (e.g. Herbert et al., 2012) available in isolation not sufficient, and that service providers require training to increase both their awareness of aphasia, and their knowledge of accessible formatting for this population.

1.4.6 Iterative design involving people with aphasia

Supporting the health literacy of people with aphasia is complex. In order to address the concerns outlined, further details of both accessible formatting modifications and the responses of people with aphasia to modified materials is needed. To achieve this aim, one possible option is to involve people with aphasia as collaborators in the design of materials in which their views determine the resulting design. Such an approach is consistent with the concept of "inclusive design" (Cruice, 2007:6), whereby people affected by a condition contribute to the design of products or environments which they are likely to use.

Previous work in the area of accessible information has involved people with aphasia either as active collaborators in an organisational context in developing new information resources (e.g. Parr et al., 1999, 2004; Cottrell & Davies, 2006), or as research participants responding either to controlled stimuli (e.g. Brennan et al., 2005), to surveys (e.g. Ghidella et al., 2005), or to interviews (e.g. Rose et al., 2011a). None of these approaches has resulted in the dissemination of clear findings which can be used when producing new accessible information.

An iterative design process provides clarity in the steps taken towards the final design output. As described by Sears and Lund (1997), this process follows several stages, depending on the complexity of the target design. In the first stages, a prototype design is developed, based on the needs of, and tested with, the target users. In later stages, the design is refined and re-tested in a cyclical process.

In recent years, several studies have reported the process of co-design and participatory design with people with aphasia, towards a variety of aims. Such studies include the development of novel therapy tools (Galliers et al., 2012; Wilson et al., 2015), modified social networking and email platforms (Al Mahmud & Martens, 2013; Miller, Buhr, Johnson, & Hoepner, 2013), and devices to support communication (Al Mahmud, Limpens, & Martens, 2013; Moffatt, McGrenere, Purves, & Klawe, 2004).

Whilst these studies vary in their aims, they all seek to create new designs through genuine collaboration between the “end-users” of the product (Wilson et al., 2015:21), design professionals, and clinical researchers. The sharing of expertise between collaborators is viewed as central to this process. The meaningful involvement of people with aphasia in such a process necessitates consideration of how to engage people so that they can understand the aims and objectives and contribute their opinions.

1.5 Overview of the study

This thesis reports the methods and findings of a project which took place between October 2010 and July 2011.

1.5.1 Study aims

The overarching aim of this study was to design a means of formatting health and related information within a template which is maximally accessible to people with aphasia.

Further aims identified to achieve this included:

1. Identification of the knowledge base in three critical domains to inform the initial design of a prototype template for presenting information to people with aphasia.

These three domains are:

- a. Evidence regarding the impact of formatting modifications on people with aphasia.
- b. Evidence concerning the lexical and syntactic means of facilitating comprehension of the written word for people with aphasia.

- c. Evidence surrounding the priorities for health information topics required by people with aphasia.
2. Collaborating with people with aphasia and graphic designers in an iterative design process, seeking the views of people with aphasia to develop the prototype template and attempting to understand the issues of accessible formatting from the perspective of people with aphasia.
3. Developing practical guidelines for use by health professionals, researchers, family members or others working with people with aphasia producing new information materials.

1.5.2 Study design

The study was conducted in three phases.

Phase 1 included scrutiny of the literature and subsequent development of the prototype template in collaboration with graphic designers and healthcare professionals, and is described in Chapters 2 and 3.

Phase 2 involved a collaboration with people with aphasia and the graphic designers in an iterative design process, culminating in the final version of the template, and is described in Chapters 4 - 8.

Phase 3 involved the translation of the findings of Phase 2 into practical guidelines, user-testing and further development of the guidelines. This phase, which resulted in the publication of accessible information guidelines, is outlined in Chapter 9.

1.5.2.1 *Phase 1*

Phase 1 involved two stages. Stage 1 involved scrutiny of the existing evidence in the research literature in order to extract evidence based principles from three bodies of evidence to inform the development of the prototype template. The three areas investigated were:

1. Existing published evidence concerning the effectiveness of formatting modifications used to facilitate the access of people with aphasia to written health and related materials. This includes what has been investigated in terms of both the impact on people with aphasia's comprehension and the preferences of people with aphasia for written information and modified formatting.
2. Evidence from research into language processing in aphasia regarding the lexical and syntactic parameters that enable people with aphasia to access the meaning of written language.

3. Evidence about the health information topics required by people with aphasia.

In Stage 2, the principles extracted from the three reviews were carried forward into the design of the prototype Template 1, devised in collaboration with a graphic design team, and with advice from relevant healthcare professionals.

1.5.2.2 Phase 2

Phase 2 involved a collaboration with people with aphasia and the graphic designers in an iterative design process. A focus group design was selected, bringing people with aphasia together to review the template and to gather their views on accessible formatting. For this collaboration, suitable methods for maximising the involvement of all participants in the design process were developed through consideration of previous literature described in Chapter 4.

The same people participated consistently throughout the iterative design process, each participant attending two focus group meetings. During each focus group meeting, qualitative and rating scale data were collected.

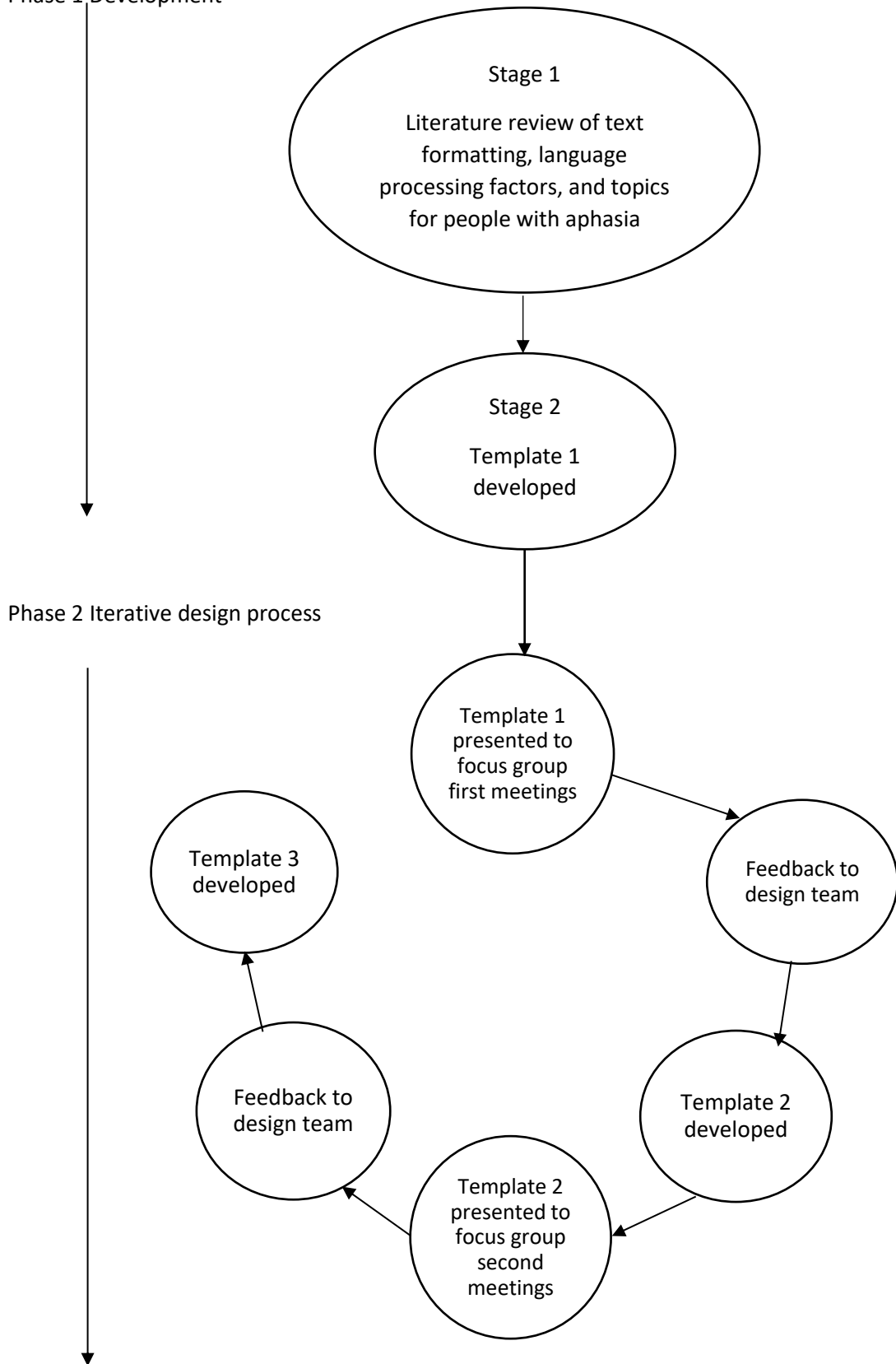
In the first focus group meeting, people with aphasia provided structured feedback on Template 1. Following this meeting, feedback provided to the graphic design team informed the development of the second version of the prototype, Template 2. In the second focus group meeting, people with aphasia provided feedback on Template 2, after which feedback to the graphic design team informed the third and final template, Template 3. Figure 2.1 below summarises the study design.

1.5.2.3 Phase 3

In Phase 3, the design team collaborated to translate the principles embodied in the final Template into practical guidelines for use by anyone making accessible information for people with aphasia. The draft guidelines were then user-tested by a mixed group of participants, who gave their views on the draft guideline via an online survey. The data collected from the survey was used to inform modifications to the guidelines, which were subsequently submitted for publication.

Figure 1.1 Summary of Phase 1 and 2 study design

Phase 1 Development



Phase 3 Development, user-testing, and completion of accessible information guidelines, submitted for publication.

1.6 Summary

Current literature highlights the need for information for people after a stroke, showing that access to appropriate and timely health information has a positive impact on their recovery, their engagement and motivation with rehabilitation, and ultimately on their psychological adjustment to stroke and wellbeing (Forster et al., 2012a). However, it is acknowledged that patients and their families remain dissatisfied with the amount of information they receive (e.g. McKeivitt et al., 2010). This is a recurring theme in the literature, and strongly stated for people with aphasia, who reportedly do not feel adequately informed about their health (Parr et al., 1997, Tomkins et al., 2013).

Research has been conducted in healthcare settings to address patient information needs, resulting in guidance for professionals producing information (e.g. Duman, 2003). There are two strands to this guidance. Firstly, advice regarding design and production is provided, and secondly, it is recommended that people affected by a health condition should be involved in producing information. Within this literature, however, the challenges of designing for or collaborating with people with aphasia are not addressed.

The need to adapt information for people with aphasia falls within the scope of the Equality Act (2010) and the Accessible Information Standard (2015), but a lack of evidence-based guidelines means that implementing such legislation is left to the interpretation of local services.

Further literature addresses the information needs of patients and their families after a stroke (e.g. Forster et al., 2012a; Hafsteinsdottir et al., 2011; Hanger et al., 1998), and this has contributed to national guidance (e.g. NICE, 2013). Within this literature, it is acknowledged that people with aphasia require adapted information. There is, however, an implicit assumption about the ability of speech and language therapists to provide appropriately modified information, with no clear evidence-based guidance for how to produce accessible information for people with aphasia. Whilst there is a body of research into accessible information (e.g. Rose et al., 2003, Brennan et al., 2005), different methodologies and research aims mean that findings are not always consistent, and cannot be easily translated. Despite this, the concept of 'aphasia-friendly' information is currently widely used, and new materials are being published which follow the broad principles modelled by Parr et al. (1999) and further specified by Rose et al. (2003). There remains, however, limited evidence into the impact of these formatting modifications on the experience of information or comprehension by people with aphasia.

Chapter 2 Phase 1: Extraction of principles for accessible formatting from the existing research

The research outlined in Chapter 1 demonstrates the need people with aphasia have for accessible health and related information, but highlights an ongoing dissatisfaction with current provision of information materials. This study therefore aimed to work with people with aphasia to develop more accessible formats within a novel template. Three strands of knowledge were considered necessary to the task of generating such a template. The purpose of this chapter is to review the existing literature in each of the three areas identified in Section 1.5: the effectiveness of formatting modifications, factors to facilitate written language processing, and health information topics needed by people with aphasia.

2.1 Introduction

The aim of these reviews is to identify principles of best practice for designing new health information for people with aphasia, including accessible formatting and language, and relevant topics. These three reviews form the first part of Phase 1 of this investigation, the outcome of which is destined to inform the design and formatting of a prototype template for health information, to trial with participants with aphasia in Phase 2 of this study. These initial literature reviews were conducted between October 2010 and January 2011.

2.2 Review of text formatting modifications

The first literature review is concerned with the research evidence for modifications to features of formatting which have been explored with a view to increasing the accessibility of information materials to people with aphasia.

2.2.1 Aims of literature review into text formatting modifications

This review has two related aims. The first is to identify the existing research literature on the impact of formatting modifications to written health materials on people with aphasia. The second aim is to establish the current evidence base regarding the effectiveness of specific modifications on access to information for people with aphasia, in order to extract principles to be applied in the development of the prototype template.

2.2.2 Literature search methods

2.2.2.1 *Databases and search terms*

Two electronic databases, Web of Science and Scopus, were searched, using a range of different search terms, reflecting the requirements of the review.

The following search terms, visible in any or all of title, key words, abstract: aphasia OR dysphasia AND accessib* OR read* OR prefer* AND information OR print* OR writ* OR internet OR web OR comput*.

A second search combining the term 'aphasia-friendly' with aphasia OR dysphasia was conducted to ensure coverage.

2.2.2.2 *Study inclusion and exclusion criteria*

To be included in this review studies had to meet the following criteria. Studies had to report novel empirical data gathered from participants who were adults with acquired aphasia, with no other neurological conditions. If studies included other sub-groups such as people with dementia or healthcare professionals, the data from the stroke aphasia sub-group had to be clearly differentiated and only those data were considered for the review. The studies had to examine participants' comprehension of or their views of functionally relevant, written information materials, either printed or computer-mediated, which had been modified to include clearly described formatting changes hypothesised to facilitate access for people with aphasia. Studies had to report clear outcomes of providing such information to people with aphasia. These included the impact on participants' comprehension of the formatting modifications, and/or participants' reported preferences for specific formatting features. Studies reporting only the views of proxies such as family members, or only the views of healthcare professionals, were excluded. There was no restriction on study design, publication date or geographical location, but publications not in English were excluded. Review articles were retained for citation checks but were not included.

2.2.2.3 *Results of literature search and selection process*

The initial search yielded 10,406 and 5,731,009 results on Scopus and Web of Science respectively. The search was therefore refined using a sequence of the terms aphasia AND accessib*, and 'aphasia-friendly'. This resulted in the retrieval of 110 articles.

Articles were selected for review based on an initial reading of the title, the abstract, and where necessary, the full article.

Articles were discarded if they were duplicates or did not meet the inclusion and exclusion criteria outlined above. For example, articles were discarded which did not report materials specifically designed to explore accessibility or readability, failed to provide novel data, or which reported outcomes which were not related to comprehension, recall or preference of modified materials. Several studies were retrieved which reported the use of aphasia-friendly principles, but did not specifically examine the effect of the modifications on the participants (e.g Egan, Worrall, & Oxenham, 2004; Kerr, Hilari, & Litosseliti, 2010) and therefore were not included. Two review articles were also found (Howe et al., 2004 and Worrall et al., 2007), reflecting the studies previously undertaken, but were excluded since they did not provide new data.

The literature search resulted in the retrieval of three studies which provided new empirical or qualitative data on either comprehension or acceptability of modified information. These were: Rose et al. (2003); Ghidella et al. (2005); Brennan et al. (2005). A further two articles were retrieved following scrutiny of the citations of the selected articles: Dietz et al. (2009) and McKelvey et al. (2010).

2.2.3 Reviews of selected studies

Using the criteria identified above, five studies were selected for this review. See Table 2.1 below for a summary of the studies.

Table 2.1 Studies included in the literature review of modified formatting

<i>Authors</i>	<i>Number of participants</i>	<i>Participant characteristics</i>	<i>Study design</i>	<i>Procedures</i>	<i>Findings</i>
1 Rose et al. (2003)	12	Mild - moderate aphasia, 1;10 - 9;5 years post onset.	Comprehension/knowledge testing of two matched groups. Health information. Preference ratings.	Participants answered knowledge questions after reading 'aphasia-friendly' and unmodified health leaflets. Rated different leaflets.	AF format resulted in 11.2% increase in comprehension over control format. Over 50% preferred control format.
2 Ghidella et al. (2005)	6 PWA 18 SLT	Mild - moderate aphasia, 1 - 12 years post onset.	Survey. Quantitative rankings of websites.	Participants rated five aphasia websites for quality and perceived accessibility.	PWA ratings of accessibility agreed with those of researchers, but their overall preferences did not completely reflect this.
3 Brennan et al. (2005)	9	Mild - moderate aphasia, 3 - 11 years post onset.	Comprehension testing of individual participants. Non-health topics.	Cloze task in six different conditions and across reading grades 5, 6 and 7: Control (no modifications); simple words and short sentences; large print; increased white space; with pictures; combined AF features.	At Grade 6, significant effect of all separate (except pictures) and combined modifications.

<i>Authors</i>	<i>Number of participants</i>	<i>Participant characteristics</i>	<i>Study design</i>	<i>Procedures</i>	<i>Findings</i>
4 Dietz et al. (2009)	7	Moderate - severe Broca's aphasia, 2 - 6 years post onset.	Comprehension testing of individual participants. Non-health topics.	Comparison of high context versus low context photographs versus control (no picture).	Significant increase in comprehension with high context over low context photographs. No difference between high context photographs and control. Faster response times in control.
			Preference ratings.	Participant ratings of picture type.	Preference for high context over low context photographs.
5 McKelvey et al. (2010)	8	Severe aphasia, 0;4 - 19;6 years post onset.	Comprehension testing of individual participants. Non-health topics.	Spoken and written single word to picture matching task: personally relevant contextualised vs non-personally relevant contextualised photographs vs non-personally relevant iconic images.	Significant increase in comprehension with personally relevant contextualised photographs.
			Preference ratings.	Participant ratings of picture type.	Preference for personally-relevant contextualised photographs.

AF = Aphasia Friendly; SLT = Speech and language therapists

2.2.3.1 *Rose, Worrall, & McKenna (2003)*

Rose et al. (2003) were the first research team to define and test the impact of modified health information on people with aphasia. Building on previous work by Parr et al. (1999) and others, they defined “aphasia-friendly principles” as “(1) use of simple words and short sentences; (2) use of large and standard font; (3) use of white space; and (4) use of relevant pictures.” (p.950). The study aimed to examine both the impact of these combined factors on participants’ comprehension of health information materials, and participants’ preferences for modified or original formats.

Twelve participants with mild to moderate chronic aphasia were asked to read health information on four different topics. These were presented in original and modified formats, the latter produced following the above-defined principles. To determine gain in knowledge, which would imply comprehension of the materials, the authors developed twelve reversed pairs of yes/no questions about the health topics covered; these were posed one month before the test session and immediately after reading all the information. Participants were also asked to rate whether they were highly certain (3), mildly certain (2), or uncertain (1) of their responses. After looking at all the leaflets, participants were asked to state their preferred type of leaflet for each of the topics.

Group data showed that participants’ knowledge increased significantly after reading any type of information. However, this was significantly greater after reading the adapted materials, with participants expressing more confidence in their responses. Whilst this is an encouraging finding, it may be that caution is required. Whether participants did indeed understand more is questionable, given the use of a yes/no question format, with both spoken and key written word input. Arguably, features of the aphasia-friendly materials, such as large font and short sentences, might facilitate the participants to utilise visual recognition of key words to select correct responses, rather than deeper processing of the information. And whilst the authors reasoned that providing information on topics not directly relevant to the participants would reduce interference of prior knowledge, it is possible that providing novel, possibly emotionally distressing information might in itself heighten attention, reinforcing recognition memory.

Despite the positive impact on comprehension of the modified materials, over half of the participants preferred the original leaflets. A quarter of participants varied in their preferences between the modified and original materials, but it is not reported whether there was any pattern for preferences between the different topics; that is, whether people with aphasia preferred modified information on the topics of personal relevance, compared with other

health topics. As the authors note, this finding reveals a level of complexity in this area requiring further qualitative research to understand in greater detail the perspectives of people with aphasia.

2.2.3.2 *Ghidella, Murray, Smart, McKenna, & Worrall (2005)*

Websites about aphasia designed for people with aphasia were examined in this study for their overall quality, readability, and accessibility. Six people with mild to moderate chronic aphasia and eighteen speech and language therapists (SLTs) participated.

Accessibility and quality of the websites were determined by the authors based on previous research evidence, for example Rose et al. (2003). Readability scores were calculated by the authors using a 500-word sample from each website.

Participants with aphasia were asked to rate the accessibility of the websites via an eight question survey addressing broad issues of content, language, design, navigation and overall usefulness. Having completed the surveys for all five websites, participants were then asked to place them in order of overall preference. The SLTs completed a “similar” (p.1139) accessibility survey and answered questions about quality of the websites.

Contrary to their hypotheses, the authors found that websites designed for users with aphasia were not necessarily accessible or of high quality, based on their evaluation. Aphasia Help, designed with input from people with aphasia, scored highest for both quality and accessibility. All other websites varied between their quality and accessibility scores. For example, Speakability scored highly for accessibility, but low for quality. SLTs’ ratings of quality and accessibility were similar to those of the researchers.

Ratings of accessibility between the researchers, the SLTs and people with aphasia showed some agreement about the most and least accessible websites, but the people with aphasia expressed some different opinions. For example, Aphasia Help, rated highest for accessibility by researchers and SLTs, was rated third most accessible by people with aphasia. The Aphasia Center of California, rated second most accessible by people with aphasia was, in contrast, rated poorly for accessibility by SLTs and researchers.

There were also slight differences between the people with aphasia’s accessibility ratings and their ranked preferences, similar to the findings of Rose et al. (2003). Issues of tone or childishness are considered by the authors to account for this, although this is speculative, since, as they acknowledge, the fixed response format did not allow participants to elaborate on their responses. It is noteworthy that accessibility, the factor considered most important by researchers, may not be of primary interest to users when rating websites. The authors note

that most of the participants were daily users of the internet, so it may be that the participants' familiarity with internet sites for general use influenced their preferences.

2.2.3.3 *Brennan, Worrall, & McKenna (2005)*

The positive findings of Rose et al. (2003) prompted Brennan et al. (2005) to test the impact of the same four aphasia-friendly principles identified in the preceding study on the comprehension of people with aphasia. They hypothesised that people with aphasia would understand more content where any or all of the aphasia-friendly principles were used. Nine people with chronic mild to moderate aphasia from a university aphasia group took part in the study.

The authors devised materials based on a published reading assessment tool (Thurstone, 1990). Subjects were required to read a paragraph and complete the final sentence with a multiple choice word or phrase (cloze task), where correctly completing the sentence indicates comprehension of the preceding paragraph. These materials were divided into sets of stimuli at reading grades 5, 6, and 7, as defined by the published assessment tool. The authors then formed each of these into six further subsets, modifying the original materials into the following conditions: control, simple language and vocabulary, large font size, increased white space, addition of pictures, and all four principles combined. A total of 90 paragraphs were presented to participants over a two-session testing period, starting with the Grade 5 set. The application of a discontinue rule meant that if participants failed either all five Grade 5 paragraphs, or four consecutive paragraphs in any of the subsets of Grades 6 or 7, no further paragraphs in that subset were shown.

Results at Grade 5 were discounted due to a ceiling effect found for these materials, which, the authors propose, left little room for any effect of the modifications. Grade 7 prompted the discontinue rule for several participants, meaning that the data is skewed towards the more able readers rather than the whole sample. Reporting of the results is focused on the Grade 6 group findings. At Grade 6, the group data showed a significant positive impact on comprehension of all modifications except the addition of images. The four principles applied together, however, did not produce any significantly greater benefit to comprehension than the separately applied principles of simplified language and large font, which had the greatest impact.

Contrary to their hypothesis, the authors found that adding images to unmodified text did not aid comprehension. Participants were observed to persist with looking at the materials with added pictures, leading the authors to question whether there may be cognitive (distracting), engagement (irritating), stylistic, or design (pictures not attached to cloze answers) issues

affecting their utility. They do not question why images appeared to have no negative impact in the aphasia-friendly condition, in which they would have been equally distracting, irritating, of the wrong style, or badly placed. An alternative explanation could be that the addition of images to unmodified text places a processing load on participants as they attempt to integrate linguistic and visual stimuli at different levels of complexity. This increased processing could also account for the longer looking time observed.

2.2.3.4 *Dietz, Hux, McKelvey, Beukelman, & Weissling (2009)*

In the previous studies, the images presented in the information materials were reported as a single entity, without consideration of image style as a sub-factor of accessibility. Dietz and colleagues argued that the line drawings used in the study by Brennan et al. (2005) could have presented a processing challenge for people with aphasia, thus accounting for the finding that pictures did not support comprehension of unmodified text.

Seven people with moderate to severe chronic aphasia participated in the study. The authors devised materials to reflect the study aims of comparing comprehension, response times and preferences of three conditions: high context photographs, low context photographs, and a “no context” (p.1057) text only control.

To develop the materials, the researchers first selected photographs, then composed reading passages to accompany these for testing in the three conditions. The reading passages were all controlled for linguistic variables and ease of reading, none exceeding Flesch-Kincaid Grade level 2.5. Participants were shown each reading passage in turn, along with either two high context photographs, two low context photographs, or no photographs. Following each passage, participants were asked nine fixed-response questions, each of which was recorded for accuracy and response time. Preferences for the materials were gathered via a 1-5 Likert scale, recording the degree to which the participants considered that the photographs either were or would have been helpful for understanding the passages.

This study found that the high context photographs conferred a significant benefit to comprehension over the low context photographs and a non-significant benefit over the control condition. Response times were longest in the condition associated with greatest comprehension, and shortest in the control condition. Participants reported a preference for the high over the low context photographs, and reported they would have preferred to see photographs where none were shown.

2.2.3.5 *McKelvey, Hux, Dietz, & Beukelman (2010)*

In a further exploration of image style, McKelvey et al. set out to compare responses to personally relevant, non-personally relevant and pictographic symbols. The aim of the study was to identify picture materials for alternative and augmentative communication (AAC). The potential transferability of findings to health information is perhaps questionable; however, it is of interest to this review as it deals with picture processing and the preferences of people with aphasia. This study examined accuracy of responses to photographs in a single word to picture matching task. The authors hypothesised that participants would both prefer and be more accurate in matching single words to “personally relevant, contextualised photographs over non-personally relevant, contextualised photographs and non-contextualised, iconic images.” (p.24). Participants’ preferences for the different image styles were also explored.

Participants were eight adult AAC users with severe chronic aphasia. In keeping with the AAC context, materials were created by the researchers and individualised to each participant. Each participant was shown sixteen individual concepts in three conditions: personally-relevant, contextualised photographs; non-personally relevant, contextualised photographs; and non-contextualised symbols. Participants were asked to select the best picture for the concept. Comprehension of the concept word was maximised via use of both spoken and written input.

As a group, response accuracy was highest with personally relevant items, and lowest with symbols, although the variation in responses was wide. In addition, participants expressed a strong preference for personally relevant, contextualised photographs, particularly for nouns and proper nouns.

2.2.4 Summary of findings

The current evidence includes preference and comprehension data, and congruence between these varies.

2.2.4.1 *Language*

A positive impact of simple vocabulary and syntax on comprehension was found by Brennan et al. (2005), but methodological difficulties mean that the findings are difficult to interpret. Overall, it was found that the language component of information materials was underspecified in relation to the complexity of aphasic language processing impairments.

2.2.4.2 *Typography*

The use of larger font size is supported by studies exploring comprehension of people with aphasia, both as an isolated formatting feature (Brennan et al., 2005), and as part of combined

aphasia-friendly formatting (Rose et al., 2003). No studies have examined different methods for emphasising key words in text.

2.2.4.3 Images

Images have been demonstrated to aid comprehension only in the context of other combined features including reduced complexity of vocabulary and syntax (Brennan et al., 2005; Dietz et al., 2009). Mixed findings concerning study participants' preferences for use of images has been reported, with variation between studies addressing images specifically (Dietz et al., 2009; McKelvey et al., 2010) and those addressing combined formatting features (Rose et al., 2003; Ghidella et al., 2005).

2.2.4.4 Layout

No studies have empirically explored variations in the layout of text and images, and no clear evidence supports the provision of single or multiple images with text.

2.2.4.5 Combined formatting features

Only one study, Rose et al. (2003), explored the impact on comprehension in relation to health information, reporting that the use of aphasia-friendly formatting increased knowledge by 11.2% over traditional leaflets. The studies reviewed varied in focus, addressing health related information (Rose et al., 2003; Ghidella et al., 2005), general interest topics (Brennan et al., 2005; Dietz et al., 2009), or personally relevant information (McKelvey et al., 2010). The question of whether health information should be differently formatted from other reading materials was not addressed in these studies. As discussed, the inherent difficulty of health concepts may be an additional consideration compared to other types of information. Although researchers noted that modified formatting resulted in longer documents, no studies addressed the formatting of a set of related information concepts.

The findings of preference surveys and rankings suggest that although some people with aphasia may acknowledge the utility of modified formatting to facilitate their comprehension of written material, many do not wish to receive adapted written information materials. None of the studies reviewed incorporated a qualitative element to explore the issue of accessibility and acceptability of materials in greater depth.

2.2.4.6 Appraisal of the selected studies

The five studies reviewed here represent the published literature into the specifics of formatting information accessibly for people with aphasia. The small number of studies retrieved demonstrates that, although accepted within clinical practice, the research evidence base is not extensive.

The studies have varying aims and methods, but are all exploratory in nature. A desire to achieve consensus with respect to formatting features is visible, despite displaying individual differences amongst participants. Studies are therefore also linked by a will to understand the preferences of readers, showing sensitivity to their changed abilities since onset of aphasia. All studies adopted quantitative methods to explore pre-determined questions, testing comprehension or seeking preferences.

All the studies have small sample sizes ($n = 6 - 12$), with only forty-two people with aphasia represented in the studies in total. A wide range of ages are represented (28 - 86 years), but participants' other characteristics are more limited. Fewer women (17) than men (25) were involved, and average educational level is high (13 years). Although it is recognised that people have different information needs at different stages after stroke, these studies do not capture this aspect, with the time since onset being over three years. The range of aphasia severity represents largely those with mild-moderate impairments. Only McKelvey et al. (2010) sought those with severe expressive aphasia, since the study focussed on AAC, which is likely to be more used by those with severe aphasia.

Most studies used the Aphasia Quotient (AQ) to provide profiles of participants' aphasia. In the context of addressing participants' responses to written materials however, this may not be the most useful measure, since it is calculated from scores of the oral language subtests of the Western Aphasia Battery (WAB) (Kertesz, 2007). Similarly, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Murphy et al., 1993) used by Rose et al. (2003) is of debatable value with a sample with aphasia, since it produces a reading grade based on a person's ability to read aloud medical terms. It is standardised on a non-aphasic population, and since any errors in output are scored as incorrect, reading grades may appear lower for people with aphasia than actual reading ability. Dietz et al. (2009) used supplementary reading assessments such as the Reading Comprehension Battery for Aphasia (RCBA) (LaPointe & Horner, 1998). Where participants are described only in averages, these are, however, of limited value, particularly since little reference is then made to any correlation between reading ability and responses. As Dietz et al. propose, wider profiling of participants with increased detail on cognitive functioning would allow greater opportunity to link findings with individual formatting needs.

Across all studies, a variety of materials were used, including relevant and non-relevant health leaflets, topics of general interest, and personally relevant information. The limited description of materials in several of the studies means that credibility and replicability are limited. All researchers developed new measures to test comprehension, comparing variables of interest to their research aims. Such a range of individual approaches raises challenges when comparing findings across the studies. The use of surveys and rankings has produced

quantifiable data. This may, however, have resulted in a narrow reporting of the views of people with aphasia, since such methods do not allow participants to elaborate on their responses (e.g. Ghidella et al., 2005).

Finally, none of the studies reported providing feedback to participants on how their input may have influenced the design of information materials.

This is a multifaceted area of research, and the variety of methods attempted bear witness to this. In the following section, the implications for the development of a new template for health information for people with aphasia will be considered.

2.2.5 Implications for the development of novel materials

The literature review undertaken aimed to identify principles to be used to create a new, evidence-based template for presenting information in the most accessible format for people with aphasia.

There is some evidence for the impact of modified formatting on comprehension of materials and some evidence that people with aphasia perceive modified formatting as both beneficial to their comprehension and an acceptable format for the provision of written information. The range of study designs, research aims, and methods used, however, limit the strength of the evidence for both the acceptability of modified formatting and some specific aspects of the modifications to information. In this section, the implications of the literature review findings to devise the prototype template will be discussed in relation to five key areas: language, typography, images, layout, and combined features.

2.2.5.1 *Language*

Despite the large amount of research into language processing in aphasia, the language modifications within the literature on accessible information are described in broad terms only. For example, Rose et al. (2003) specify “simple words and short sentences” (p.950). Whilst both Brennan et al. (2005) and Ghidella et al. (2005) identify background information about aphasia, neither provides any detail on the processes involved in the linguistic modifications to materials.

The Flesch-Kincaid Reading Grade level (Flesch, 1948) was used as a measure of text reading difficulty in all the quantitative studies, with the exception of McKelvey et al.’s (2010) single word study. This formula is based on the length of words and sentences used in the text and provides a guide to the North American school grade level which would be required to read text. Whilst this is an established tool, it accounts for quantitative features of sentence length

and word letter length only. Psycholinguistic variables such as word frequency, word imageability, or syntax are not accounted for in this measure. Since aphasic language impairment is subject to other factors than non-impaired language, such a measure cannot address the reading requirements of people with aphasia.

Only one study (Brennan et al., 2005) isolated simple language and vocabulary as a condition in their investigation, but demonstrated its positive impact on comprehension at reading grade 6 only.

2.2.5.2 Typography

Explorations of typographical features suggest there is evidence for the use of larger font sizes. Brennan et al. (2005) found that a large font size resulted in greater comprehension of written material presented at reading grade 6.

There is, however, no evidence about the impact on comprehension of either different font styles, or of different methods of emphasis in font, and further investigation is warranted into how these features can be used in accessible design.

2.2.5.3 Images

Research into the use of images has dominated this field of study, but widely varying study aims and methods and findings make it difficult to synthesise the evidence.

Rose et al. (2003) found varied responses to the use of images in modified health information materials, with some participants reportedly perceiving images as helpful and others finding them unacceptable.

Overall, the effectiveness of images in facilitating comprehension remains inconclusive. Images do not support comprehension when added to unmodified text (Brennan et al., 2005), but do appear to add value where the text and images were composed together (Dietz et al., 2009). For people with more severe language impairment, a greater impact on comprehension is shown when personally relevant, high context photographs are used (Dietz et al., 2009; McKelvey et al., 2010).

Overall, the evidence to date points to a need for further clarification of the use of images. Exploration of responses to images in general and to different image styles is needed to determine their acceptability and perceived usefulness for people with aphasia when accessing written information materials.

2.2.5.4 *Layout*

The literature review yielded limited evidence about specific layout of information. This may in part be due to the different terms used to describe this aspect of formatting. For example Rose et al. (2003) discuss the impact of modified formatting on document length, but others, for example Brennan et al. (2005), do not refer to this, focusing instead on individual features such as line spacing, rather than the layout. The question of amount of information per page was not addressed specifically by any studies.

The use of increased white space has been shown to be effective in supporting comprehension at Reading Grade 6 (Brennan et al., 2005), but no other evidence about the impact on comprehension of layout was retrieved from the literature. The findings of studies focusing on images signal the need to consider more carefully how images are presented with text in the context of the overall layout.

Specific features of layout remain underspecified for the purposes of producing a new template. Further exploration of people with aphasia's response to the layout of modified information is needed, particularly concerning the number of images in relation to the text.

2.2.5.5 *Combined formatting features*

The reported preferences of people with aphasia suggest an ambivalence towards the use of combined formatting features, with a tension reported in the literature between the perceptions of people with aphasia in relation to accessibility versus acceptability of combined features of modified information.

A positive impact on comprehension of these combined features was demonstrated initially in relation to health information (Rose et al., 2003), but no subsequent studies have provided categorical support for combining larger fonts, increased white space, and images accompanying text. For example, Brennan et al. (2005) found that the combined features did not produce any significantly greater benefit to comprehension than providing simplified text or large font sizes. This lack of support stems largely from the study aims, which have focussed attention on individual formatting features, rather than exploring the impact of combined features. Study findings regarding the impact of images point to the benefit of a considered pairing of text and images (Brennan et al., 2005; Dietz et al., 2009) where images are linked with simplified text. Table 2.2 below provides a summary of the findings of the literature review regarding facilitative formatting features.

Table 2.2 Summary of findings of facilitative formatting features identified in literature review

Language	Beneficial impact of simple words and short sentences at RG6* (Brennan et al., 2005).
Typography	
Font size	Positive impact of 24pt font compared with unspecified control (Brennan et al., 2005).
Font style	No studies of font style and comprehension.
Emphasis	No studies of emphasis and comprehension.
Images	<p>Line drawings beneficial as part of combined AF format at RG6 only (Brennan et al., 2005).</p> <p>Significant impact of high context, personally relevant photographs over low context photographs at max RG2.5, but non-significantly better than control (Dietz et al., 2009).</p> <p>Significant impact of personally relevant contextualised photographs over non-personally relevant photographs or iconic images in accuracy of single word to picture matching in people with severe aphasia (McKelvey et al., 2010).</p> <p>Preference expressed for use of contextualised photographs (Dietz et al., 2009) and of personally relevant, contextualised photographs (McKelvey et al., 2010).</p>
Layout	Increased line spacing in text improved comprehension at RG6 (Brennan et al., 2005).
Combined factors	Combined AF features result in 11.2% increase in comprehension of health information (Rose et al., 2003). However, Rose et al. (2003) found that over 50% preferred unmodified format and Ghidella et al. (2005) report that participants' perceptions of accessibility of websites differed from their preferences.

*RG = Reading Grade

2.2.6 Summary

This review found a small evidence base. There is very limited evidence regarding effects on comprehension, with only one study showing a clear advantage for health information materials presented in a modified format (Rose et al., 2003). Reported preferences for

pecially formatted materials remain varied, with differences reported between participants' perceptions of accessibility and their preferred written and web-based formats.

Principles for some aspects of typography, use of images, layout, and combined features have been identified, and there is evidence to support the provision of short sentences. As highlighted, however, the studies reviewed did not provide evidence concerning linguistic factors known to affect language comprehension in aphasia. In order to derive principles of language use for the proposed template, therefore, the following review will address the knowledge base regarding language processing in aphasia.

2.3 Review of factors affecting language processing in aphasia

The second literature review addressed research literature on factors affecting language processing in aphasia. Given the large scale of this literature, and the confines of the thesis, the review will focus on established knowledge, aiming to identify factors which facilitate lexical and syntactic aspects of language processing, and which can be translated into principles for the template.

Two previous reviews of facilitating reading in aphasia were retrieved, which aimed to identify language processing characteristics of aphasia, and to apply these to the provision of simplified text (Singh, Gedeon, & Rho, 1998; Devlin & Tait, 1998). Whilst these reviews provide useful syntheses of language in aphasia and its possible impact on the reading of web-based text (Singh et al., 1998) and newspapers (Devlin & Tait, 1998), these do not appear to have been translated into tangible materials for people with aphasia. Further investigation of factors to facilitate language processes is therefore required, which can be applied to written health information for people with aphasia.

2.3.1 Aim of literature review into language processing in aphasia

The aim of this review is to identify relevant literature, which can be used to specify lexical and syntactic aspects of written language which are known to facilitate the language processing of people with aphasia.

2.3.1.1 *Methods*

Due to the volume of possible research literature, this review does not attempt to be comprehensive, but aims rather to provide an overview based on key texts and seminal research findings. Relevant literature was retrieved based on clinical expertise, with a view to possible applications of the knowledge base to the development of text for the proposed template. Clinical expertise is acknowledged to form one facet of the evidence base for an

area, such as aphasia, and is considered when formulating clinical guidelines (e.g. Simmons-Mackie et al., 2017).

Three areas of the evidence base for language processing were considered important to this review: factors affecting single word processing, sentence processing factors, and evidence into the utility of priming to facilitate processing in people with aphasia.

2.3.2 Findings 1: Lexical factors affecting processing in aphasia

At the single word level of language processing, two factors were considered highly significant in terms of identifying facilitators to processing: psycholinguistic variables and grammatical class.

2.3.2.1 *Psycholinguistic properties of single words*

According to cognitive neuropsychological models of language processing (e.g. Ellis & Young, 1988), factors known to affect lexical processing relate to the different levels of processing, namely semantic and phonological processing. The psycholinguistic properties of lexical items have been found to affect processing speed and accuracy of processing in people with aphasia. Lexical processing pertaining to the semantic system is affected by the imageability or concreteness of lexical items, whereas phonological processing is affected by features such as frequency, familiarity, and word length (e.g. Cole-Virtue & Nickels, 2004; Coltheart, 1981; Nickels & Howard, 1995, Kay et al., 1997).

2.3.2.1.1 Imageability

Imageability effects are linked with semantic processing, with higher imageability words more likely to be understood than lower imageability items (Coltheart, 1981; Franklin, 1989). In reading, imageability is associated with access to the semantic system via orthography, with higher imageability items more easily processed (Ellis & Young, 1988).

2.3.2.1.2 Concreteness

There is a link between imageability and the degree to which words are considered concrete or abstract, since concrete terms are inherently more easily imageable than abstract terms (Bird, Howard, & Franklin, 2003). Franklin, Howard, & Patterson (1994) report a significant deterioration in comprehension of abstract terms amongst some people with aphasia. Metaphors and idioms use words in their non-literal meanings to convey meanings which are established through shared understanding within a population. In healthcare, metaphors are considered a useful means of conveying concepts such as a patient's 'stroke journey', however, research demonstrates that such non-literal use of lexical terms is more difficult to process in aphasia (Papagno & Caporali, 2007).

2.3.2.1.3 Frequency and familiarity

The effects on comprehension of word frequency are well-documented in aphasia, with more frequently accessed terms found to be understood more rapidly and accurately than their less frequently used counterparts (Coltheart, 1981; Laiacona, Luzzatti, Zonca, Guarnaschelli, & Capitani, 2001).

In reading, word frequency is associated with access to the orthographic input lexicon, with higher frequency items more likely to be recognised as real words (Ellis & Young, 1988).

There is a known link between the concepts of personal word frequency and familiarity (e.g. Gernsbacher, 1984), since words which are more familiar are likely to be more frequently accessed. In the realm of healthcare information, this aspect of frequency is important, since terms which are highly familiar and frequently accessed by healthcare professionals may be either unfamiliar or novel to patients. This links with lexicality, the variable determining whether a term is a real word or a non-word. In healthcare, people may be encountering medical terminology for the first time. For example, the term 'Warfarin' will be frequently accessed by a pharmacist, but may be a new term for a person experiencing stroke care for the first time. For a person with acquired dyslexia, this term may have no representation within their orthographic input lexicon, rendering it incomprehensible to them through the expected reading channels (Ellis 1984).

2.3.2.1.4 Word length

Increasing word length in nouns is associated with greater processing difficulty, with shorter words typically processed with greater ease (Nickels & Howard, 2004).

In reading, effects of word length are associated with a deficit at the level of visual orthographic analysis, which may in turn impact on a person's ability to perform any reading task (Marshall & Newcombe, 1973). Providing short words in text can therefore be seen to maximise a person's access to the meaning of the text.

2.3.2.1.5 Individual variation in aphasia

The outline above reports findings from the literature which are applicable to the broad population with aphasia, but it is important to note that individual differences in aphasia presentation are widely reported, due to factors including the overall severity of stroke and aphasia, and the range and specific patterns of impairments (Franklin, 1989; Lesser & Milroy, 1993; Nickels & Howard, 1995). In relation to processing the written word, variability occurs due to deficits at different levels of processing in terms of visual, lexical and semantic processing (Coltheart, Rastle, Perry, Langdon, & Ziegler, 2001). Cases of individuals with

aphasia presenting with reverse effects of the above psycholinguistic variables have been reported by researchers, for example, for frequency (Marshall, Pring, Chiat, & Robson, 2001) and word length (Best, 1995).

2.3.2.1.6 Effects of grammatical class on processing in aphasia

Evidence from the aphasia literature suggests that content words such as nouns and verbs are more easily processed than grammatical function words, such as pronouns (Berndt & Caramazza, 1981). Difficulties processing nouns and verbs can arise due to the lexical factors discussed above, but difficulties with verbs may be more pronounced, since the exact meaning of a verb is dependent on the syntactic and semantic context in which it is used, an issue discussed further below.

Difficulties processing function words arise for different reasons, depending on aphasia type. For people with Broca's aphasia, grammatical function words are considered to be more difficult to process because they are governed by syntactic rules (Berndt & Caramazza, 1981). For people with semantic impairments, comprehension is compromised by the low imageability of function words (Bird, Franklin, & Howard, 2002).

Proforms can present specific difficulties in processing since their comprehension is dependent on identification of the previous referent, a different lexical item. The meaning of the proform must therefore be inferred by the reader (Raynor & Pollatsek, 1989). Proforms such as pronouns are inherently of low imageability, since their meaning relates to a different lexical term, which must be tracked in the sentence.

2.3.3 Findings 2: Sentence processing in aphasia

Research into sentence comprehension in aphasia has established that deficits in syntactic processing are more likely to disrupt comprehension of sentence forms which do not conform to highly frequently occurring canonical structures (Caramazza & Zurif, 1976). As discussed by Schwartz, Saffran and Marin (1980), this is viewed as a "... dissociation between lexical and syntactic aspects of comprehension..." (p.249). In such cases, people with agrammatism parse sentences using the expected, canonical structure, processing the individual lexical items in the order in which they appear. This can also result in difficulties in mapping the surface structure of the sentence to the meaning, particularly where the semantic roles of nouns are ambiguous, for example in passive sentences (Caramazza & Zurif, 1976).

Resulting difficulties arise for people with aphasia when attempting to process reversible sentences, in which the subject and object of the sentence can appear in opposing positions in a sentence, but have semantically different roles. Sentence structures which incur a change in

canonical word order, such as question forms and passive constructions, have also been found to present processing challenges (Caplan et al., 2007). Such difficulties are pertinent to accessing health information, since formatting guidelines promote the use of a question and answer format, whereby information topics are introduced via the interrogative form (e.g. Duman, 2003).

Syntactically complex sentences involving more than one clause are more difficult to process with aphasia, since they place demands on both syntactic processing and working memory. Longer sentences are not necessarily more challenging in aphasia, since it is the syntactic complexity, rather than the sentence length per se, which has the greatest impact on processing (Marshall, 1995; Marshall, 2002). However, extra sentence length adds to the overall cognitive load experienced by a reader with aphasia, who may have additional impairments to non-linguistic cognitive domains, such as attention and working memory (Helm-Estabrooks, 2002).

2.3.4 Findings 3: Priming

A body of literature regarding the effects of structural and semantic priming on language processing supports the idea that targeted repetition of input may be utilised to enhance the reduced capacity for language processing found in aphasia (e.g. Hartsuiker & Kolk, 1998; Pickering & Ferreira, 2008).

Structural priming refers to the facilitation of processing of specific sentence structures following exposure to that same or similar sentence structure (Pickering & Ferreira, 2008). Lexical boost is associated with structural priming, but refers specifically to the additional priming that occurs due to the repetition of content words within the sentence frame. This has been demonstrated strongly in relation to verbs but applies also to nouns (Pickering & Branigan, 1998).

Repetition priming refers to the same effect, but in this case the prime is the target word itself. This is based on the finding that a stimulus is easier to process if it has recently been experienced (Cave, 1997).

These priming techniques are distinct from semantic priming, which refers to the greater ease in processing a lexical term when this has been preceded by a semantically related term, performed under experimental conditions (McNamara, 2005).

Studies of priming with people with aphasia report that subjects were found to have increased access to syntactic forms which they were exposed to repeatedly. Hartsuiker and Kolk (1998) propose that the use of repeated syntactic structures and lexical items has a facilitative effect

by reducing the processing effort needed by an individual when processing language. Saffran and Martin (1997) found that participants with aphasia were more able to produce passive structures after being exposed to such structures repeatedly. Hartsuiker and Kolk (1998) found, in addition, that priming exerted a stronger effect on study participants with aphasia than on participants without aphasia. In both studies, priming had some lasting effects, leading the authors to postulate that priming facilitates access to language structures, which had previously been restricted by the presence of aphasia.

Studies into facilitating word finding in aphasia have shown the value of repetition priming as a means of improving study participants' ability to retrieve stimulus items (Best, Herbert, Hickin, Osborne, & Howard, 2002; Hickin et al., 2002; Nickels, 2002).

Research into priming with people with aphasia has focused on the impact of structural priming on spoken word production. It is, however, possible to argue that facilitating production affects comprehension, due to increased language processing activity, and, as proposed by Pickering and Ferreira (2008:453), "Priming occurs between comprehension and production, and so it is reasonable to hypothesize that comprehension and production involve the same representations."

In the following section, the principles taken forward from this knowledge for application to the development of the template will be outlined.

2.3.5 Implications for the development of novel materials

It was argued in Section 2.2 that within the literature relating to the formatting of information for people with aphasia, the optimal means of modifying written language was underspecified. The preceding overview of knowledge regarding language processing in aphasia provides evidence that aspects of lexical-semantic and syntactic processing may be used to specify the written language input on the Template developed in this study.

In this section, the principles which determine the choice of lexical terms and sentence forms, and the use of structural and semantic priming to maximise reading comprehension, will be described.

2.3.5.1 *Lexical terms*

The choice of lexical terms in the template will be governed by the evidence from the literature which shows that lexical processing is in general easier in aphasia when words are of high imageability, concrete rather than abstract, high frequency and familiarity, and short in length. Factors known to aid processing include the selection of content, rather than function words. Avoiding idioms and metaphors is also known to aid processing. The specific

processing difficulties associated with pronouns will be avoided by repetition of nouns. It must be acknowledged that in the context of providing accurate health information, novel or unfamiliar terms which are highly pertinent to the condition are required. For example, to explain adequately the presence of aphasia, the term 'aphasia' must be used, but this requires explanation.

2.3.5.2 *Sentence forms*

Evidence from syntactic processing in aphasia supports the provision of single clause, canonical sentence forms. This principle implies that passive, interrogative, or other moved structures will not be included. Other complex structures, such as embedded clauses, will be avoided. Sentences will be short, thereby minimising the impact of working memory deficits on text reading.

2.3.5.3 *Priming*

Evidence regarding the beneficial impact of structural and lexical priming can be translated into principles for devising maximally accessible written text. With regard to structural priming, the use of repeated, canonical structures is adopted to minimise the processing load and maximise syntactic comprehension. The concept of lexical boost is adopted, with content words (nouns and verbs) repeated across sentences. An advantage of repeating content words within sentences is that it means that proforms are not required.

With regard to repetition priming, the use of the same content words repeatedly in the template materials maximises opportunities for readers to process their meaning. For example, repetition of the same lexical term in a heading and within the subsequent sentences.

The example below shows the use of the repeated canonical subject – verb – object sentence structure, with repetition of the term 'brain' through the heading and the sentences.

<i>Heading</i>	The brain
<i>Sentence 1</i>	Your brain controls your body.
<i>Sentence 2</i>	Your brain controls your speech

Finally, semantically related words will be included in the materials in order to maximise any semantic priming.

2.3.6 Summary

The overview of the language processing literature in aphasia has demonstrated its application to the development of maximally accessible text for people with aphasia within the proposed template. This is summarised in Table 2.3 below.

Table 2.3 Summary of facilitative features of language derived from language processing literature

	<i>Use</i>	<i>Avoid</i>
Lexical terms	Content words (Berndt & Caramazza, 1981) High imageability, concrete, high frequency, familiar, short words. (e.g. Coltheart, 1981; Nickels & Howard, 2004)	Proforms (Berndt & Caramazza, 1981; Bird, Franklin, & Howard, 2002) Abstract terms (Franklin et al., 1994) Metaphors and idioms (Papagno & Caporali, 2007)
Sentence forms	Single clause, frequently-occurring canonical structures Short sentences (Caramazza & Zurif, 1976)	Non-canonical structures, such as passive or interrogative forms (Caplan et al., 2007) Embedded clauses (Marshall, 2002)
Structural priming	Repeated canonical forms (Saffran & Martin, 1997; Hartsuiker & Kolk, 1998)	
Lexical boost	Repeat content words, specifically verbs and nouns (Pickering & Ferreira, 2008)	
Repetition priming	Repeat terms throughout template	
Semantic priming	Present information within semantic categories (McNamara, 2005)	

Note that in the context of health information, certain terms which do not conform to the ideal in terms of their psycholinguistic properties are unavoidable, in order to convey accurate information, as discussed in Section 2.3.5.1.

Principles for the formatting and language components of the template have been established through the scrutiny of relevant literature. The final strand of knowledge required to inform the template development concerns the information content.

2.4 Review of health information topics pertinent to people with aphasia

In order to develop the proposed template, details of the information content of relevance to the intended audience were required. As noted in Section 2.2, previous studies in this area have incorporated a variety of relevant and non-relevant health information topics, general

interest, or personally relevant information. As Rose et al. (2011a) observed, participants with aphasia displayed greater engagement with information materials which were of direct, personal interest.

2.4.1 Aims of literature review into health information topics for people with aphasia

This review aimed to examine the literature to identify health information required by people with aphasia arising from stroke for the proposed template.

2.4.2 Literature search methods

Two electronic databases, Web of Science and Scopus, were searched, using the following two search terms, visible in any or all of title, key words, abstract: stroke AND aphasia AND information, and “information OR questions OR topics”. Due to the large number of articles generated (over 17,000), the search was refined to include the following search terms: “stroke education” OR “stroke information” AND aphasia.

Articles were selected based on an initial reading of the title, and where necessary, the abstract. In addition to a library search, articles cited by others were examined for potential relevance. This review was conducted between December, 2010 and January, 2011.

2.4.2.1 *Criteria for inclusion and exclusion of studies.*

To be included in this review studies had to meet the following criteria. Studies had to report novel empirical data gathered from participants who were adults who had sustained a stroke and who presented with acquired aphasia, with no other neurological conditions.

The studies had to examine participants’ views on which topics of information they thought should be provided to people who had sustained a stroke.

Studies had to report clear outcomes including details of the topics and sub-topics participants requested information about. Studies which referred to patient education and information, but which did not specifically seek the outcomes described above were excluded. Examples of studies which were excluded from this review included those which examined the process of information provision in healthcare settings, those which reported participants’ responses to their own experiences of receiving information, and studies investigating the impact of information on patient and carer outcomes.

Due to the paucity of studies retrieved regarding the specific information topics required by people with aphasia, studies which sought the views of the stroke population as a whole were included.

There was no restriction on study design, publication date or geographical location, but publications not in English were excluded.

2.4.3 Findings of the literature search

2.4.3.1 *Studies identified*

Nine studies were identified through the search strategy, the main characteristics of which are shown in Table 2.4 below.

Table 2.4 Summary of studies included in the literature overview of topics relevant to people with aphasia

<i>Authors</i>	<i>Participants</i>	<i>Data collection methods</i>
Hanger & Mulley (1993)	Any person making information enquiry. 1,397 people asked 1,908 questions.	18-week record of all enquiries made to 8 Stroke Association UK advice centres. Quantitative, descriptive results reported.
van Veenendaal et al. (1996)	n = 35 stroke patients, 39 family members and 43 health professionals. Mean 18 months post onset.	Questionnaires sent out to stroke survivors, family members and health professionals. Received and desired information topics. Quantitative, descriptive analysis.
Parr et al. (1997)	n = 50 people with aphasia, 1/3 with severe aphasia, all between 5 – 18 years post onset.	Individual interviews, Framework analysis of interview data. Information formed one major theme.
Hanger et al. (1998)	n = any stroke patient: 60 at 2 weeks, 111 at 6 months, 72 at 2 years	Prospective recruitment of all patients attending one hospital in four-month period. Individual interviews at 2 weeks, 6 months, and 2 years post stroke.
Wiles et al. (1998)	n = 31 stroke patients and their carers.	Interviews with patients, carers or jointly at three stages: in hospital; up to 1 month after going home; 2-12 months post-discharge.
Wachters-Kaufmann et al. (2005)	n = 33 patients, 27 carers. 15 months post onset.	Telephone survey as part of a larger study. Quantitative data, descriptive analysis.
Avent et al. (2005)	n = 16 family members of people with aphasia, mean 5.5 years post onset.	Focus groups. Asked to discuss their experiences at three stages after stroke: at stroke onset – during rehabilitation – in chronic phase. Framework analysis.
Hare et al. (2006)	n = 27, recruited via primary care, 9 months – 22 years post onset.	Focus groups, home visits to severely disabled participants. Participants were asked what they want from community services. Thematic analysis. Information was one of three main themes.
Kerr et al. (2010)	n = 12 people living with stroke, 5 with aphasia, 7 without aphasia, 6 – 15 months post onset.	Focus groups. Participants asked what stroke information they would like to see on a website, and to identify information needs at different stages after stroke. Content analysis.

2.4.3.2 *Methods used in the studies*

Different methods were used to gather data, including questionnaires (van Veenendaal, Grinspun, & Adriaanse, 1996), face-to-face interviews (Hanger et al., 1998; Parr et al., 1997; Wachters-Kaufmann et al., 2005; Wiles et al., 1998), telephone interviews (Wachters-Kaufmann et al., 2005), and focus groups (Avent et al., 2005; Hare, Rogers, Lester, McManus, & Mant, 2006; Kerr et al., 2010). One study (Hanger & Mulley, 1993) asked UK Stroke Association information centres to record all requests for information during a set period. Studies varied in whether they recruited only service users, family members, or a combination.

Participants were questioned about their information needs at different stages post stroke, depending on the study aims. Data collection time points included during acute hospital admission, on transfer home, and in the longer term post stroke. Overall, studies found that although the focus of information needs changed somewhat with passing time and changing circumstances, people continued to have information needs for many years after a stroke, and these included both unresolved questions and new information requirements.

2.4.3.3 *Topics identified in the studies*

The studies revealed both the wide range of information needs and a considerable overlap in findings between studies regarding the desired topics, suggesting some consistency for people experiencing stroke, with and without aphasia. In order to synthesise the findings, the types of information people need are presented here categorised according to the ICF (2001) domains of impairment, activity, participation, and well-being.

Regarding impairment information, all studies reported that people expressed a need for basic knowledge about their stroke, citing a lack of understanding about the physical causes and manifestations of a stroke. People wanted to know what to expect in terms of medical treatment, rehabilitation, and overall recovery, and their need to understand risk factors to prevent future strokes was reflected across several studies. People also wanted information about associated impairments specific to themselves, such as headaches, pain, abnormal sensation, and vision. Information was required repeatedly at different stages, reflecting that stroke can have lasting consequences, and that information needs change with individual patterns of recovery and circumstance. Avent et al. (2005) report the need for the term aphasia to be used to name the condition and for this to be shared to increase local and public awareness.

Information needs relating to activity tended to focus on rehabilitation, going home from hospital, and the longer term. People wanted information to help them to go home and be safe there, with advice about practical caring and coping, equipment, and services to support

this. They wanted to understand and engage with rehabilitation to help regain functions such as communication within families. A desire for information about issues such as memory, concentration, communication in aphasia, and sex suggests that people prefer to be prepared for potential difficulties, reinforcing the importance of information in helping people to be in control of their own lives.

In the longer term, information needed to facilitate social participation was wide-ranging, reflecting the breadth of daily life. People required information which would enable them to regain and then maintain their independence as members of society, including information about finances, and assistance with claiming benefits and entitlements, self-help, managing health, and resources to enable planning for the future. Information was needed to allow people to continue to live in their own homes, for example information about help with shopping, and adaptations to property. People wanted to know about services in the community, such as health and voluntary services which could support their independent living. In terms of participating in social activities, people needed information about getting out, including information about accessing public transport and returning to driving, including the Blue Badge scheme. They wanted information about social and support groups in the community, with people with aphasia particularly expressing a wish to meet others with the same condition. People wanted to pursue leisure activities and take holidays, and sought advice about how to achieve this. Information about return to work or future employment was desired by some people.

Within the domain of well-being, people wanted information about the psychological and emotional impact of stroke, including direct consequences such as emotionalism, and reactions such as depression, anxiety and panic. Support to understand issues such as frustration, fatigue, loss of initiative, and decreased confidence was sought, together with information about specific problems, such as personality changes. People wanted information about how to cope with stress after a stroke, and how to deal with family tensions in the light of changed circumstances. Overall, such information was sought in order to enable people to adjust and cope with the changes brought about by stroke. Throughout all stages, but most particularly in the longer term, people wanted to know how to access psychosocial support and counselling. Table 2.5 below summarises the information topics required, classified using the ICF (2001) domains.

Table 2.5 Information topics required after stroke, classified by ICF (2001) domains

<i>ICF (2001) domain</i>	<i>Information topics required</i>
Impairment	What is a stroke/TIA, causes of stroke How to prevent strokes Risk of recurrence Headaches, pain, abnormal sensation, vision Aphasia information, generic and specific to individuals
Activity	Memory and concentration Communication difficulties Sex Balance Going home from hospital Equipment Exercise
Participation	Driving, dealing with DVLA and Blue Badge criteria Finances, benefits and entitlements, and help with completing claim forms Employment Awareness raising for public Accessing local health, voluntary services Bus passes Shopping and help with shopping
Well-being	Depression, anxiety, panic Fatigue Personality changes Emotionalism Frustration, decreased confidence Family tension Coping with stress Psychosocial support and counselling Positive expectations and need to retain hope Long term emotional and psychological support

Table 2.6 below provides a summary of the research studies which contributed evidence on topics within each of the four domains of the ICF (2001).

Table 2.6 Studies contributing to the evidence for topics in each of the four ICF (2001) domains.

<i>ICF (2001) domains</i>	<i>Studies contributing to findings</i>
Findings relating to impairment , activity, participation, and wellbeing	Hanger & Mulley (1993) Parr et al. (1997) Hanger et al. (1998) Wiles et al. (1998) Hare et al. (2005) Kerr et al. (2010)
Findings relating to impairment , activity, and participation	Wachters-Kaufman et al. (2005)
Findings relating to impairment , activity, and wellbeing	van Veenendaal et al. (1996) Avent et al. (2005)

As shown, six of the nine studies contributed evidence to all four ICF domains, with the remaining three studies contributing to three of the four domains. As discussed above, the information topics required after stroke are both broad and detailed in scope, relating to both general and personally relevant issues.

2.4.3.4 *Topics selected for the template*

For the purpose of the current study, topics were selected from the above for their relevance to all potential participants, and their likelihood of engaging people in focus group discussions. Topics were selected which would be applicable to participants who were no longer in receipt of local stroke services, and who were already living successfully with aphasia in their local communities. Topics applicable to people still requiring services, or containing specific local information, were not considered appropriate for these materials.

Three broad topics were selected for the template. Basic information about what a stroke is and how it is caused in the body was the most frequently cited area where people expressed a need for information, yet continued to report a lack of understanding. The topic of aphasia was highly relevant, since it affected all participants. Finally, information about emotional consequences of stroke was frequently reported as a high information need in the longer term, a stage after stroke currently applicable to the study participants.

2.4.4 **Formatting features requiring further evidence**

The literature review into formatting modifications presented in Section 2.2 revealed areas for which the evidence base is not yet clearly established.

With regard to typography, research has shown the value of large fonts. However, evidence remains incomplete regarding font size in relation to page size, and no evidence supports the use of specific font styles, or specific styles of emphasis of key words in text. A lack of evidence about optimum image styles emerged from the research literature, indicating a need for further exploration of this area. The literature review highlighted that the specific layout of text and images within the design of information materials was not a focus for study. Clear evidence could therefore not be retrieved to specify the optimum number and positioning of images in relation to text. Finally, no evidence emerged to identify how to present a set of related information concepts.

2.5 **Principles for the design of Template 1**

Principles to be applied to the design of the prototype Template 1 were derived from the three literature reviews, as detailed above. These principles are presented in Table 2.7 below, and show the features of language, formatting and topics to be operationalised in the template.

Table 2.7 Principles derived from the literature for the design of Template 1

Language	
<i>Lexical terms</i>	<p>Use content words (e.g. Berndt & Caramazza, 1981). Use high frequency, high imageability short words (e.g. Coltheart, 1981; Nickels & Howard, 2004).</p> <p>Avoid abstract terms (Franklin et al., 2004). Avoid metaphors and idioms (Papagno & Caporali, 2007). Avoid proforms (e.g. Berndt & Caramazza, 1981).</p>
<i>Sentence forms</i>	<p>Use single clause, frequently-occurring canonical structures (Caramazza & Zurif, 1976). Avoid non-canonical structures, such as passive or interrogative forms (Caplan et al., 2007). Avoid embedded clauses (Marshall, 2002).</p>
<i>Priming</i>	<p>Use repeated canonical forms (Saffran & Martin, 1997; Hartsuiker & Kolk, 1998). Repeat content words, specifically verbs and nouns (Pickering & Ferreira, 2008). Use the same terms repeatedly. Present information within semantic categories (McNamara, 2005).</p>
<i>Readability</i>	<p>Reading Grade 5 or lower (Aleligay et al., 2008).</p>
Typography	
<i>Font size</i>	<p>Large and very large font sizes (Brennan et al., 2005).</p>
<i>Font style</i>	<p>No evidence – needs further exploration.</p>
<i>Emphasis</i>	<p>No evidence – needs further exploration.</p>
Images	<p>Contextualised photographs preferred (Dietz et al., 2009). Personally relevant, contextualised photographs preferred (McKelvey et al., 2010).</p>
Layout	<p>Increased spacing between lines of text (Brennan et al., 2005).</p> <p>Increased comprehension of health information via combined formatting features of large font sizes, use of images, increased white space and simple language (Rose et al., 2003). People with aphasia perceive combined formatting features as more accessible than unmodified formats (Ghidella et al., 2005).</p>
Topics	<p>Information about stroke and the causes of stroke (see Table 2.5). Aphasia (see Table 2.5). Emotional consequences of stroke (see Table 2.5).</p>

2.6 Summary of chapter

This chapter has provided reviews of the literature across three separate areas of knowledge: accessible formatting for people with aphasia, the knowledge base concerning language processing in aphasia, and the information topics required by people with aphasia after stroke. These areas were selected for scrutiny, because each was considered to contribute to defining the principles for a new template to convey health information for people with aphasia.

Through this process of review, principles for formatting, use of language, and relevant topics have been identified for the proposed template, and areas identified as requiring further evidence highlighted.

The following chapter comprises the second part of the template development, in which the details of how these principles were carried forward into the template design will be outlined.

Chapter 3 Phase 1: Development of the template

This chapter describes how the strands of evidence identified in Chapter 2 were integrated into the prototype template (Template 1), in a collaborative design process with the graphic designers.

3.1 Establishment of Phase 1 collaborative design team

The design team in Phase 1 of the study included the author, who is an experienced speech and language therapist (SLT), a research SLT, a family member of a person with aphasia who is also an experienced teacher of English, and a team of professional graphic designers. Healthcare professionals, including a stroke physician, an occupational therapist, physiotherapist, stroke nurse, and clinical psychologist were involved on a consultative basis.

3.1.1 Identification of graphic designers

The author and research SLT selected the graphic designer by viewing the work of local designers via their websites, rating their work for clarity and simplicity of design, and gauging their interest through discussion of the project.

3.1.2 Discussion of principles with the graphic designers

A first meeting of the design team was arranged in order to discuss the design brief. The agenda included background discussion of aphasia and access to information, an introduction to the work required, and specific issues of designing information for people with aphasia. To facilitate this discussion, current, freely available information materials used in stroke care settings were collected. These included published materials (e.g. Parr et al, 1999, 2004; Cottrell & Davies, 2006); web-based information produced for people with aphasia (e.g. Aphasia Now www.aphasianow.org ; Aphasia Help www.aphasiahelp.org; Speakability www.speakability.org.uk ; Connect www.ukconnect.org, and general stroke information resources (e.g. Stroke Association leaflets).

Principles for the design of the prototype template were agreed at this meeting. These principles were based on the evidence extracted from the literature review, and are summarised in Table 2.7. The lead graphic designer provided professional opinions on best practice in graphic design.

It was agreed that the researchers would provide the key concepts for the template to the graphic designers as a series of short sentences, composed according to the principles

identified from the review of factors affecting language processing in aphasia, and categorised within topic areas identified in the literature review reported in Sections 2.3 and 2.4 (see Tables 2.3 and 2.5).

The graphic designers were asked to use their professional skills to create engaging, well-designed materials, suitable for adults, taking into account the nature of language processing in aphasia and possible visual and cognitive difficulties arising from stroke (Helm-Estabrooks, 2002).

3.2 Generation of text for the template

Text for the template was devised by the researchers in line with the principles derived from the reviews of formatting modifications, factors affecting language processing in aphasia, and information topics required. Initial drafts of the text were refined with input from health professionals to ensure the accuracy of all concepts.

3.2.1 Topics

Topics selected for Template 1 included information about stroke and the causes of stroke, and information about what aphasia is. Further sentences were composed on the topics of emotional consequences of stroke.

Accuracy of information was checked using current, publicly available information resources (e.g. Stroke Association factsheets) and with healthcare professionals. The researchers then considered ways of conveying information to maximise comprehension of fundamental concepts. Through discussion, the researchers agreed to present background concepts first, with new concepts following on from this basic explanation. For example, the concept of stroke illness was explained by first outlining the role of the brain in relation to body functions.

Secondly, it was agreed to present information within three broad categories, representing background explanation, facts about the specific limitation to function (e.g. aphasia, emotions after stroke), and information to support readers, titled 'what helps'.

An example of each of these type of statements in the set of information concepts about aphasia included the following (see Appendix A for further examples):

<i>background information:</i>	language is talking and understanding
<i>fact:</i>	it is difficult to say words
<i>what helps:</i>	practising the words again and again helps

3.2.2 Text content

Principles derived from the literature reviews into modified formatting and language processing in aphasia were followed throughout the development of the text for the template. In this section, the process for selecting lexical terms, constructing sentences and the application of evidence regarding priming in aphasia is described.

3.2.2.1 *Lexical terms*

Selection of vocabulary items took account of the psycholinguistic variables of length, frequency and imageability. For each concept, a range of possible terms was identified, and these were each considered in terms of their imageability, concreteness, frequency, and likely familiarity. Abstract, metaphorical, or technical terms were avoided where possible. The British National Corpus (Leech, 2001) was consulted to ensure choice of high frequency items, for example 'makes' rather than 'produces', 'talking' rather than 'speech'. Ideally, the shortest terms were selected, although this was not always possible, due to the specific nature of the vocabulary involved. For example, the word 'haemorrhage' is specific to the explanation of one type of stroke, and cannot therefore be substituted, but needs to be explained.

Given that the possible choice of terms was limited by the topic areas, this was a pragmatic process, and the researchers discussed vocabulary choices to ensure that all variables had been considered, and that the choices were consistent with the context of the information topics.

Within each topic, subtopics were identified and a superordinate term selected for each subtopic. Repeated forms were used through the repetition of key content words in both the banner heading and the sentence (see example provided below).

3.2.2.2 *Sentence forms*

Sentences were constructed which consisted of single clause, canonical structures within the identified topics and subtopics. As with the lexical terms, the researchers discussed the construction of sentences to ensure that they both adhered to the principles identified in the literature and were pragmatically meaningful. Once the sentences had been agreed, the researcher used Flesch-Kincaid readability software to generate a reading grade for each set of sentences within a subtopic. These were then checked to ensure that all sentences used had a Reading Grade of five or lower, the level advised for text aimed at people with aphasia (Aleligay et al., 2008).

3.2.2.3 Use of priming

The principle of repeating key words and sentence structures was followed throughout the text development. The following two examples show how the principles of priming were used to convey key concepts about the brain and blood flow. Example 1 shows the use of structural and lexical priming for a subject – verb – object sentence, with repetition of the initial subject noun and the verb. In the second example, the first sentence introduces the concept; the initial noun is then repeated throughout the sequence, with structural repetition seen in the second and third sentences. In both examples, the heading identifies the superordinate term, which is repeated in the sentences.

	<i>Example 1</i>	<i>Example 2</i>
<i>Heading</i>	The brain	Your blood
<i>Sentence 1</i>	Your brain controls your body.	Arteries are blood vessels.
<i>Sentence 2</i>	Your brain controls your arms and legs.	Arteries carry blood.
<i>Sentence 3</i>	Your brain controls your speech.	Arteries carry blood to the brain.

Construction of the sentences maximised the chances of structural and lexical priming occurring. See Appendix A for further examples of information sentences generated for Template 1. Examples showing how the text was incorporated into the overall template design are provided below and in Appendices B and C.

3.3 Agreement with graphic designers on Template 1 design

Decisions taken by the design team were based on the principles generated from the literature review and in discussions regarding the optimum means of incorporating these principles into a physical template, which could be presented to people with aphasia in the focus groups.

3.3.1 Overall layout

In the light of the evidence concerning language processing in aphasia (see Section 2.3), the researchers identified the idea of presenting only one concept per page. As a result, the design team agreed to present each concept within a single white space, which was printed onto single cards measuring 170mm by 110mm.

The overall design of this white space included a coloured banner with heading text printed in bold black reversed into white and aligned to the left side. Below this banner, the information was conveyed in a single sentence, printed in black and aligned to the left side. Below the sentence, one, two, or three images were placed centrally. Evidence regarding line spacing was not required, due to the decision to present single sentences per page.

3.3.2 Typography

Large font sizes were selected to reflect research findings which suggest that people with aphasia comprehend more easily when presented with material printed in large or very large fonts (see Section 2.2.5). Thus, for the banner headline, font size 24pt was selected, and for the content sentence below this, 14pt was selected. The substantial difference in font sizes was selected to ensure that the difference between them could be easily perceived. Since no research evidence provided guidance on the use of serif or sans serif fonts, the professional opinion of the lead graphic designer's regarding current graphic design principles was sought. He advised the use of a sans serif font, and in addition he proposed the use of Vectora font style. Given that the literature review yielded no clear evidence for preference or effectiveness of emphasising key words, the design team agreed to present the Template 1 information without emphasis.

3.3.3 Images

Images were used throughout to illustrate the written information. Photographs and line drawings were both selected as suitable illustrative styles for the information content, since no consensus for the superiority of line drawings or photographs had emerged from the literature (see Section 2.2.5.3).

For people with severe aphasia, personally relevant photographs were found to be both easier to process and more highly rated (McKelvey et al., 2010), but the applicability of this finding to generic health information is limited, and for the purposes of the template design, this was not carried forward. It was agreed that the graphic designers would select images from a professional photographic library. Line drawings were then produced by the graphic designers from the photographs selected.

3.3.4 Number of images per concept

Evidence regarding number of images to present is unclear, but the mixed results of comprehension studies highlight the need for coherence between appropriately modified text and meaningful images (Brennan et al., 2005, Dietz et al., 2009).

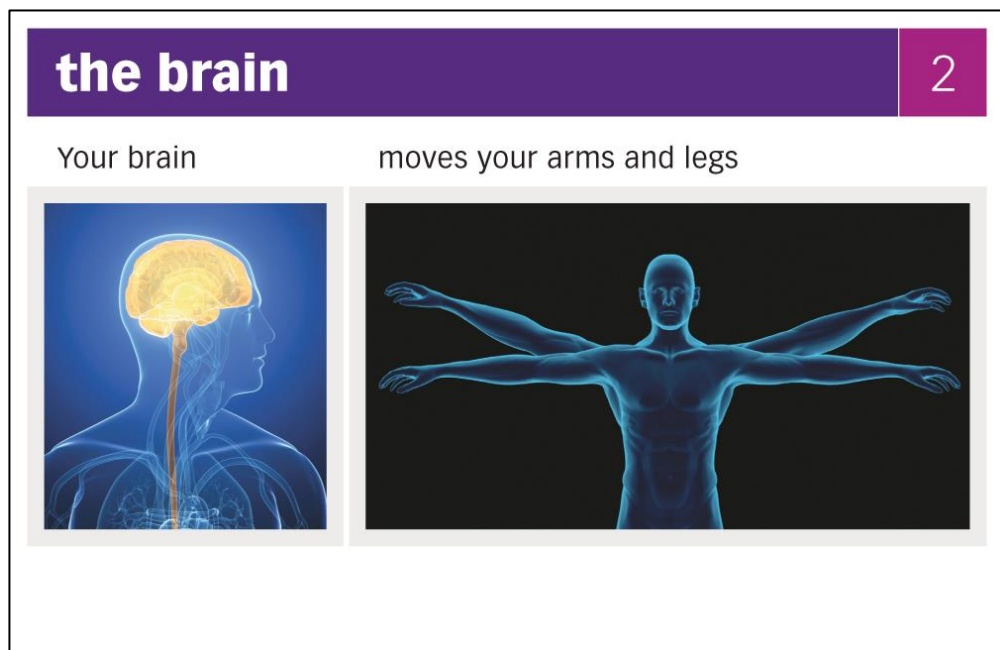
3.3.5 Language content

As described above, the text to be included in the template design was devised by the research team, and each card included a single word or short phrase banner heading, to orientate readers to the topic. It was agreed that precise placement of the written sentence would be decided at point of design by the graphic designers, taking into consideration other aspects of the design, such as the placement of the images.

3.4 Summary of design principles for the prototype template

The final principles identifying the design criteria for Template 1 were agreed through the process described above and are summarised in Table 3.2 below. Figure 3.1 below shows an example of how the design principles described in this chapter were applied to produce a single card (shown actual size) conveying one information concept about the function of the brain. Further examples of the template are provided in Appendices B, C, and D.

Figure 3.1 Example showing application of the agreed design principles into Template 1



© The Stroke Association.

Table 3.3.1 Design principles for Template 1

<i>Language</i>	Banner headings – single word or short phrase to orient to the topic covered by the sentence.
<i>Lexical terms</i>	Use content words. Use high imageability, high frequency, short words. Use familiar words. Avoid abstract terms. Avoid metaphors and idioms. Avoid proforms.
<i>Sentence forms</i>	Use single clause, frequently-occurring canonical structures. Use short sentences. Avoid non-canonical structures, such as passive or interrogative forms. Avoid embedded clauses.
<i>Priming</i>	Use repeated canonical forms. Repeat content words, specifically verbs and nouns. Use the same terms repeatedly. Present information within semantic categories.
<i>Readability</i>	Flesch Kincaid readability software to be used to monitor reading grades, ensuring RG5 or lower throughout.
<i>Typography</i>	
<i>Font size</i>	Banner heading - very large font (24). Information content sentence - large font (14).
<i>Font style</i>	Banner heading - Vectora Black. Information content sentence - Vectora Roman.
<i>Emphasis</i>	Not used in Template 1.
<i>Images</i>	Each sentence to be accompanied by one, two or three images to illustrate meaning. Photographs to be selected by graphic designer from professional photo libraries. Line drawings to be produced by designers from photographs.
<i>Layout</i>	A white space measuring 170mm by 110mm to contain the content. White background to the overall space. Coloured banner with heading text printed in bold black reversed into white and aligned to the left side. Single sentence below banner to convey information content, printed in black and aligned to the left side. One, two, or three images placed centrally, below sentence. Borders to separate areas of text and related images. Consistent use of colour used in headings and images within specific topics.
<i>Topics</i>	Basic information about stroke and the causes of stroke. Background information to aphasia. Emotional consequences of stroke.

3.5 Provision of content to the graphic design team and Template 1 delivery

The researchers provided the content to the graphic designers in the form of a sequence of written sentences, categorised within the topic areas of ‘What a stroke is’ and ‘What aphasia is’. The graphic designers were encouraged to seek clarification for any concepts which might be unclear or present design difficulties.

The graphic designers delivered a full set of Template 1 prototype materials in advance of the first focus group meeting.

3.6 Development of materials for exploration of factors identified in the literature review lacking clear evidence.

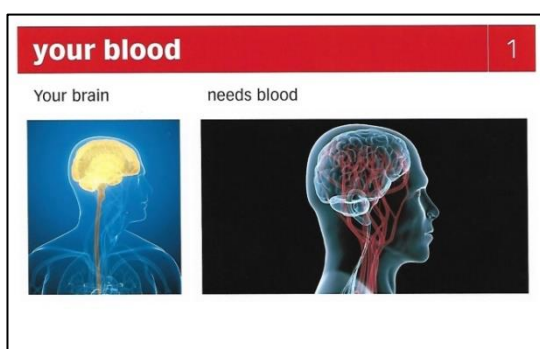
In Section 2.4.4, factors relevant to the design of Template 1, about which there was little clear agreement in the research literature, were highlighted. In this section, the methods and materials selected by the researcher for further exploration of these factors are outlined. The graphic designers were asked to provide variations in design to allow for further focus group exploration of two issues identified in the literature review as requiring further evidence: image style and number of images per sentence.

3.6.1 Further evidence for image style

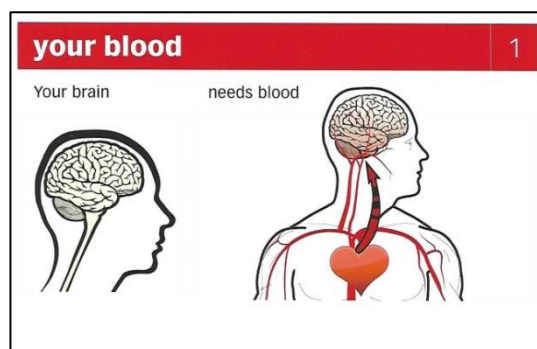
To explore participants’ responses to different image styles, the graphic designers were asked to provide two different versions of Template 1, one version including photographs, the other including line drawings.

Examples of Template 1 showing variations in image style are shown below. Images © The Stroke Association.

Photographic style

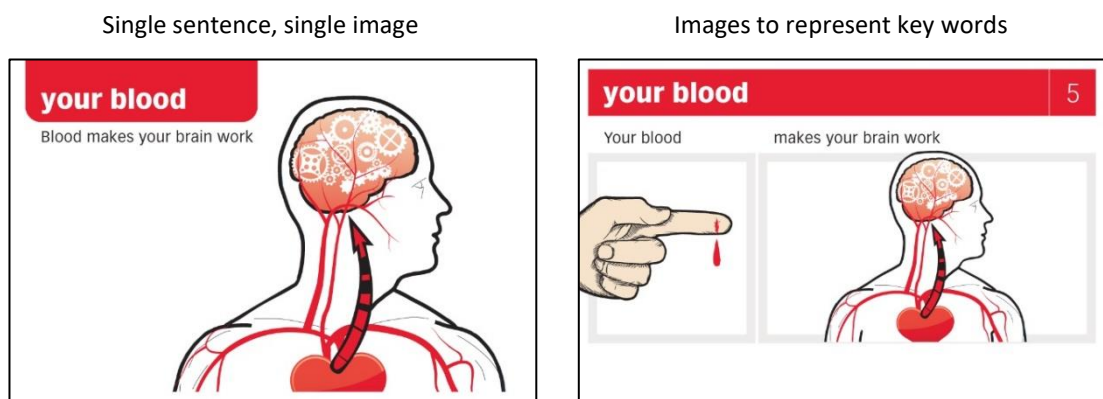


Line drawing style



3.6.2 Further evidence for number of images per concept

To explore participants' responses to variations in the number of images per concept, the graphic designers were asked to provide two versions of Template 1. In the first version, the sentence was illustrated with a single image. In the second version, the sentence was illustrated by up to three images, to illustrate each key word in the sentence. To accommodate the separate images, the sentence was separated out, with space between each of the key concepts. Examples of Template 1 showing variations in number of images per concept are shown below. Images © The Stroke Association.



3.6.3 Further evidence for font sizes, font styles, and emphasis of key words

The literature review revealed a lack of clarity regarding optimum font sizes, font styles, and means of emphasising key words in text. The researcher therefore prepared materials to present to participants. These are described in Chapter 5, and examples are shown in Appendix E.

3.7 Summary of template development

In this chapter, the collaborative design of the Template 1 prototype has been described. This has demonstrated how three strands of knowledge, namely the findings of the literature review concerning the effectiveness of formatting modifications on people with aphasia's access to written information; the specific research evidence concerning factors which facilitate people with aphasia's processing of lexis and syntax; and the evidence from the literature review regarding the topics about which people with aphasia state they require information, were synthesised in the formulation of a new template for accessible information. The development of Template 1 materials to explore factors identified as needing further clarification from the research literature has also been described.

In the following chapter, consideration is given to suitable methods for collaborating with people with aphasia in a further, iterative design process.

Chapter 4 Phase 2: Methodological issues

The previous two chapters have detailed Phase 1 of the current study, including a review of the evidence and the process of designing an initial prototype Template 1 according to research evidence. Phase 2 of this study involves people with aphasia in a collaborative iterative design process to develop and refine this template. In this phase, people with aphasia will be involved in reviewing current best practice, and providing new insights into areas identified without robust research evidence.

As identified in Chapter 1, health literacy research identifies that patients should be involved in the development of new health information to ensure that it meets the needs of the target population in content, design, and accessibility (Bunge et al., 2010; Coulter et al., 1998).

The purpose of this chapter is to consider suitable methods for involving people with aphasia in the iterative design process. A brief review of previous methods used to involve people with aphasia in accessible information will be outlined. The rationale for the choice of data collection methods will then be described, including the techniques for facilitating the participation of people with aphasia. Lastly, issues relating to data analysis will be considered.

4.1 Involvement of people with aphasia in the development of information

The literature concerning the development of information aimed at people with aphasia has involved the target population in a range of ways. At the charity Connect in the UK, people with aphasia participated in focus groups to develop the Aphasia Handbook (Parr et al., 1999). Since the aim of the project was to develop information resources which would be accessible to people with aphasia, it is not reported as a research project in the usual sense. As a result, it is difficult to evaluate the involvement of people with aphasia in this work, since no published account is available.

As identified in Chapter 2, people with aphasia have participated in research studies addressing the impact of modified formatting on the comprehension of written information materials (e.g. Brennan et al., 2005; Dietz et al., 2009; Rose et al., 2003). Of these, only one study examined the impact of modified formatting on health information (Rose et al., 2003).

The opinions of people with aphasia have also been gathered in studies which aimed to understand their views of modified formatting (e.g. Ghidella et al., 2005; Rose et al., 2003) or their preferences with regard to images (Dietz et al., 2009; McKelvey et al., 2010).

These studies have added to the evidence regarding accessible formatting, but none described a process of incorporating the findings in the design of new materials. The present study seeks to close the gap between research and design, by involving participants in a collaborative process. One means of achieving this is to employ methods developed in organisations such as Connect, and apply these in a research context, with the methods and analysis clearly described.

4.2 Focus groups

4.2.1 Introduction to focus groups as a research method

Focus groups are a form of group discussion, in which the views of people are expressed and collected within a natural human context, that is, a group. Morgan (1997) provides the following definition:

“...a research technique that collects data through group interaction on a topic determined by the researcher. In essence, it is the researcher’s interest that provides the focus, whereas the data themselves come from the group interaction.” (p.6).

As Stewart, Shamdasani, and Rook (2007) emphasise, the purpose of focus groups is to both canvass participants’ opinions and seek more detailed reasons for these, through group discussion. In health care research, focus groups have been used extensively. As Kitinger (2006) notes, such groups can be naturally supportive to participants who have health conditions in common, producing an environment in which people say more, and are often more critical than they would be in interviews. Through this process, focus groups generate data which are rich and varied (McLafferty, 2004).

As described by Merton, Fiske and Kendall (1990), effective focus groups should meet four criteria: firstly, they should address all the researcher’s questions, but raise more issues; secondly, they should be focused on the issues; thirdly, they should involve all participants in a thorough discussion, addressing the issues in depth; finally, the researcher should be able to understand participants’ responses through the sharing of individual opinions.

The challenge in conducting a group with people with communication disability is to ensure that the participants can follow the discussion and express their views. Finch and Lewis (2003) report that the use of techniques to enable participation is perceived as more acceptable in groups, in which looking at information together, or sharing experiences, is more natural and enjoyable, and less forced, than on one’s own with a researcher. They highlight the need for “co-moderation” (p.196) when using such techniques; that is, allocating one leading

moderator and other supporting facilitators. Such a structure allows the group moderator to retain their leadership of the group overall, and to preserve the flow of the group topic, while the facilitators provide support to the participants in doing the activities. Relevant techniques for participants with aphasia include the use of flipcharts to list issues, and providing visual materials.

4.2.2 Focus groups and people with aphasia

In this section, the methods used to involve people with aphasia in focus groups will be reviewed, to determine the feasibility of using focus groups methodology in an iterative design process with people with aphasia for the present study.

Few studies report strategies for including people with aphasia in focus groups. Four studies were reviewed for the methods used to support the specific language and communication needs of participants with aphasia (Dalemans, Wade, van den Heuvel, & de Witte, 2009; Garcia, Barrette, & Laroche, 2000; Kerr et al., 2010; Murphy, 2006). Of these, three studies conducted focus groups as a primary method for collecting qualitative data. Garcia et al. (2000) included people with aphasia, speech and language therapists, and local employers in focus groups to seek opinions about return to employment after stroke by people with aphasia. Murphy (2006) gathered the views of different stakeholders regarding communication between people with aphasia and General Practice staff. Kerr et al. (2010) involved people with and without aphasia in focus groups to decide on topics for stroke information for a local website.

Garcia et al. (2000) recruited fourteen people with mild or mild to moderate aphasia from an aphasia centre and via local speech and language therapists. It is unclear whether separate focus groups were conducted for the participants with aphasia. People with aphasia were accommodated in smaller groups of between two and six participants, in which the group facilitator is reported to provide communication support. In the case of the group of six people with aphasia, additional communication support was provided by a social worker. The authors state that "Participants were encouraged to use all methods of communication at their disposal" (p.275), but no detail is provided of the skills of the facilitators, or of the specific facilitation or communication techniques employed.

Murphy (2006) recruited two groups of people with aphasia from local support groups. No detail is provided on the numbers per group, or the participants, except that they are said to have three key word level comprehension. Talking Mats® were used to provide structure and symbols for participants to refer to. Although the exact method for this is not made clear, the reader can infer from the presentation of results that a single group Talking Mat® was used,

with all participants using the same mat and its accompanying symbols as a point of reference. In this study, the discussion data were then analysed, rather than the Talking Mat® itself, which functioned as a prop for group communication.

Kerr et al. (2010) report a focus group of five people with aphasia. Facilitation of the focus group in this study was undertaken by the researcher, with no other support staff reported. Kerr et al. refer to the use of pictures to illustrate key points in the group discussions between participants with and without aphasia, but no further detail is provided on how people with aphasia were supported to participate.

In these three studies, clinical interpersonal skills and techniques (e.g. encouraging all means of communication, provision of pictures and written words to support comprehension, use of Talking Mats®) were reported as means of supporting the participation of people with aphasia in focus groups addressing varied research aims. The reporting of such measures appears to assume that they increased the accessibility of the process to participants with aphasia, with research findings forming the focus of interest for the researchers. It can be argued, however, that a lack of clarity in reporting the means of ensuring access to the research for the participants is to the detriment of the rigour, and thus to the reliability and validity, of the findings.

One further study examined methods for involving people with aphasia in focus groups, within the context of an existing research project. Dalemans et al. (2009) used focus groups as a means of verifying results obtained from two other methods of data collection, namely structured diaries kept by participants with aphasia and family members, and semi-structured interviews addressing social participation. The participants in the focus group study are described as ten people with aphasia and nine family members, a subgroup of the larger study. The authors do not report the staffing involved in conducting a focus group of nineteen people with mixed communication abilities, implying that there was one interviewer for this large group. In keeping with the study aims, the authors identify four strategies used to ensure the participation of people with aphasia: firstly, a report from the previous stage of the research was sent to all participants in an 'aphasia-friendly' style, following principles identified by Brennan et al. (2005); secondly, PowerPoint was used to present these findings to the group; thirdly, during the subsequent discussion, pictures and written words from the presentation were again shown on the PowerPoint screen; finally, the group agreed ground rules regarding taking turns to talk, listening, and pace. These measures show an attempt to address the generic language processing needs of the participants, focusing particularly on supporting comprehension. Support to express views in the focus group discussion is, however, limited to the statement, "The interviewer tried to encourage each person with aphasia to express

themselves, by addressing them personally.” (p.952). In a group of nineteen people with one facilitator, it is difficult for the critical reader to imagine that this provided sufficient support to people with aphasia to communicate their views.

Murphy (2006) comments on the usefulness of Talking Mats® in helping participants to understand the questions asked and in promoting a group discussion. The study aimed to record the group response, with the purpose of achieving consensus, therefore no commentary on the quality of participants’ individual responses is provided. The use of a single Talking Mat® provides structure to the discussion, and, as with the use of pictures and written words made by Kerr et al. (2010) and Dalemans et al. (2009), can be seen to provide generic language processing support to the whole group. The communication needs of individuals within the group, however, are not attended to. It is possible that in these three studies (Dalemans et al., 2009; Kerr et al., 2010; Murphy, 2006) the researchers have overestimated the power of pictures to aid comprehension, and underestimated the need for communication support to individuals in a group. In Garcia et al.’s (2000) study, individual communication strengths were emphasised by facilitators, and valuable data was generated, however, the lack of detail in the reporting compromises the transferability of the methods to other studies. Dalemans et al. report on the success of their measures to facilitate participation. Whilst their researcher-centred report is positive, a more convincing claim would have been made had the experience been reported from the viewpoint of the participants.

4.2.3 Consideration of alternative data collection methods

Other possible methods for data collection are interviews and observation, and each will be briefly considered here. Structured interviews provide an opportunity to gather detailed opinions from individuals. In the aphasia literature, some researchers have suggested that such interviews are more suitable as a data collection method for participants with aphasia (e.g. Howe et al., 2004). In an individual interview, Morgan (1997) suggests that sharing the burden for developing the topic with one interviewee encourages participants to say more, generating more data for the researcher. People with aphasia may, however, find such a situation uncomfortable, placing undue pressure on them to speak. Since people with aphasia report that increased pressure to speak reduces their ability to speak (Edelman & Greenwood, 1992), there may in fact be a negative impact on the data collection. As Finch & Lewis (2003) state, “Social context creates spontaneity” (p.171) in which a greater opportunity for the exchange of ideas is fostered within a focus group. They provide an example of a study on attitudes towards disability amongst members of the public. A “layered” (p.186) discussion through the skilled facilitation of the group emerged, based on the skill of the moderator in picking up

themes within the group as it unfolded, and offering these for further discussion. They argue that these rich data would not have emerged in the course of individual interviews.

A further consideration concerning the choice of methods relates to the aims and nature of the research. Northcott & Hilari (2011) conducted individual interviews with people with aphasia to explore issues around loss of friends after a stroke, a personal and sensitive issue which people might be reluctant to discuss in a group. In contrast, the focus group studies discussed in Section 4.2.2 gathered opinions, drawing on the insights and expertise of people with aphasia, without asking participants to share their personal experiences in any detail. Such an approach is relevant here, since the current study does not seek in-depth personal information or experiences, but opinions based on the experience of having aphasia.

An alternative method, participant observation, could be used to collect data on how people interact with information. However, since the aim is to seek opinions, natural observation of participants is less informative to the research aims than hearing what participants have to say on the topic. In addition, the planned iteration of feedback to the graphic designer for this project needs to be prompt and clear, which would not be possible if detailed observation over time were recorded (Morgan, 1997).

4.2.4 Summary

The previous discussion supports the feasibility of involving people with aphasia in focus groups, but further consideration is needed to identify methods for maximising the inclusion of all participants. Specific issues include the use of evidence-based techniques to support communication, the numbers of participants per focus group, and how best to staff a focus group, including the potential roles of a lead moderator and the availability of trained communication facilitators within the group.

4.3 Methods to facilitate the participation of people with aphasia in focus groups

The review of literature reporting strategies to involve people with aphasia in focus group research showed that, whilst researchers have made efforts to facilitate participation, a lack of clarity surrounded the methods used to achieve this. In some cases, there was an apparent mismatch between the methods reported and the outcomes achieved. For example, Dalemans et al. (2009) report as successful a focus group involving nineteen people with aphasia, with minimal language support.

For the purposes of collaborating with people with aphasia in an iterative design process, greater clarity regarding communication support for participants with aphasia is needed, both

in terms of individual participant facilitation and the use of visual materials. In this section, findings from the literature which inform the development of principles for facilitating the participation of people with aphasia in focus groups will be outlined.

4.3.1 Supported communication techniques

The application of the social model of disability to aphasia provides a useful context to this study, which seeks to collaborate with participants with aphasia as partners in an iterative design process rather than as recipients of a procedure or intervention (Kagan & LeBlanc, 2002). In order to build a successful partnership, the communication between participants and researchers needs to function as a two-way interaction, in which the communication challenge is shared. According to the social model of disability, the person with the impairment (aphasia) is disabled by a society, which lacks both the awareness and the communication skills to include people with aphasia (Pound et al., 2007).

In the domain of communication disability, “supported conversation for adults with aphasia” (Kagan, 1998: 817) refers to a set of techniques which can be used when interacting with people with aphasia. Such techniques are described as “communication ramps” (Kagan and Gailey, 1993:206), since they mirror the notion of a physical ramp for a person who may otherwise be excluded by a physical disability from, for example, a building. Supported conversation techniques were developed through observation and analysis of people attending an Aphasia Centre in Ontario, Canada. The approach is underpinned by the philosophy that aphasia masks the valid thoughts and ideas of people with the condition. The skilful use by conversation partners of techniques to support conversations with people with aphasia reveals the underlying competence of the person with aphasia, who is then able to express their opinions.

Supported Conversation, as described by Kagan and Gailey (1993), is chiefly concerned with what they term “maintaining the feel and flow of conversation” (p.214), achieved through the use of techniques to facilitate both understanding and expression. Conversation partners of people with aphasia are trained in a range of techniques including pragmatic, communication, language, and practical skills. Pragmatic skills include, for example, giving a clear indication of a new topic, attending to comprehension difficulties, and giving time to process. Communication skills incorporate the ability to use, for example, gesture and pantomime, communicative drawing, and using these simultaneously if necessary. Language skills include, for example using closed questions, re-capping or verifying, and suggesting possible word choices to the person with aphasia. Lastly, practical skills for example, finding physical resources such as images to use within conversations, are needed.

Most of the techniques can be used to facilitate either comprehension or expression. For example, gesture, drawings, or visual resources may be used by the communication partner to illustrate a concept, or by the person with aphasia to convey an idea. Conversation partners maximise comprehension by routinely using other modalities (e.g. writing single words, drawing, gesture) whilst talking in conversation, and seek ways to allow an individual to finish what they are trying to express. In Supported Conversation, communication partners are trained to take account of the skills that the person with aphasia brings to the conversation.

There is an obvious overlap between Supported Conversation and Total Communication (Lawson & Fawcus, 1999), an approach in which communication by any means is encouraged to maximise communicative effectiveness. As Lawson and Fawcus describe, Total Communication was developed in aphasia clinics to enable an individual to express their thoughts and ideas, based on the idea that all channels of communication are equally valid. In this approach, the emphasis lies with the person with aphasia developing their communication skills to compensate for their language impairment.

These approaches do not only serve to improve communication between people with aphasia and others. By participating in genuine social interaction, people can express themselves as a whole person. In research to explore a partnership approach to communication participation, Lyon et al. (1997) paired ten people with aphasia and their caregivers with volunteers to support their communication in community activities. In the first phase, people with aphasia and their communication partners established their relationship and developed communication strategies; in the second, they jointly planned and undertook community-based activities. As well as finding the expected benefits to communication and psychological well-being, the authors also noted qualitative changes which emerged through analysis of diary entries kept by the participants. This led the authors to propose that when people with aphasia were able to participate in activities in a fully absorbed fashion, they "... appeared to temporarily suspend any awareness that there were communicatively disabled." (p.703). This finding was striking, and supports the idea that communication can still feel natural for people with aphasia if it is well facilitated.

The benefits of specific strategies to support communication of people with aphasia within a research context are further supported by the findings of a pilot study carried out by Luck and Rose (2007), who found that when participants were appropriately supported to communicate in individual interviews, they provided more data than when an open-ended interview questioning style was used. The four strategies used were identified from thematic analysis of interview data with four participants. Firstly, there was an overt recognition of the possible impact of aphasia at the outset of the interview; secondly, the interviewer checked with the

participant that they had understood correctly, termed “interviewer clarification” (p.214); thirdly, they supported participants with encouragement, time to think, and suggestions of possible words to use; finally, they used “interviewer-generated ideas” (p.214) as a way of giving the person with aphasia something to respond to, rather than participants having to generate their own ideas.

Supported Conversation techniques validate the expertise of a person with aphasia, suggesting that data collected using such techniques is likely to reflect participants’ genuine, individual opinions. The approach also provides an evidence-based approach to facilitating individuals with aphasia to participate, adding rigour to the research study. Since Supported Conversation techniques have been developed in the context of individual interactions, it is important to consider the provision of individual communication facilitators within the group.

In the following section, the use of visual materials to support individuals to participate will be discussed, principally with reference to Talking Mats®.

4.3.2 Talking Mats®

The concept of Talking Mats® was developed at the University of Stirling by speech and language therapy researchers, and was initially developed for people with communication disability due to cerebral palsy, and later for people with motor neurone disease (Murphy, 1998, 1999). It has since been used in clinical and research contexts with adults and children with a wide range of communication impairments, including people with aphasia (Gillespie, Murphy, & Place, 2010; Murphy, 2000), intellectual impairment (Murphy & Cameron, 2008), and dementia (Murphy, Gray, van Achterberg, Wyke, & Cox, 2010)

The Talking Mat® concept consists of a structured approach to communication, in which the placement of symbols or pictures on a mat allows people with communication disabilities to express their views. The three main components to the materials needed are a topic or question, represented by an appropriate image, a rating scale representing positive, neutral or negative responses, and a set of options, also represented by appropriate images. The options images are then placed on the scale by the person with the communication disability, to indicate their response to each option. For example, in a discussion about food preferences, the topic would be represented via a picture of a meal; the rating scale would reflect likes or dislikes, and the options would include images of a range of possible food choices for that meal. The person would then place the options cards on the mat according to their like or dislike for each one. A more complex discussion could involve a topic of life decisions after a stroke, with options reflecting where a person might choose to live, and what care they might require. Following the interaction, the healthcare professional takes a photographic record of

the completed mat. This record can then be used for further conversations, for sharing with others, or for recording for research purposes.

Talking Mats® have been used in individual interactions (e.g. Murphy et al., 2010) and in groups (Murphy, 2006) to achieve a variety of aims involving the expression of views and preferences. It is important to note that Talking Mats® are a tool for conversations which can be thoroughly pre-planned by the researcher or healthcare professional. They are designed to enhance communication of choices and opinions, but are not a tool for spontaneous conversation, since the framework relies on the use of prepared materials. The utility and effectiveness of Talking Mats® has been reported in the research literature.

Murphy (2000) trialled the use of Talking Mats® with twelve participants with receptive and expressive aphasia, ranging from mild to severe, using the framework to explore participants' opinions about their quality of life. She found that in participants with stable neurological symptoms, all were able to participate in the interactions and express their views, and concluded that this is a suitable approach for use with people with aphasia in clinical and research interactions.

A later study by Murphy, Tester, Hubbard, Downs, and MacDonald (2005), involved ten frail, older care home residents in Talking Mats® interviews about their current life. Similar to Murphy's earlier (2000) findings, they report that the participants enjoyed using this framework, and that it enhanced their ability to give their personal views. The authors comment that the use of a scale provided a means of asking questions in a neutral way, resulting in authentic responses.

Murphy and Cameron (2008) studied the interactions of forty-eight young adults with intellectual disabilities in separate individual interviews, communicating via their usual means versus Talking Mats®. The findings suggest that the use of Talking Mats® improved both the person's understanding of the issues discussed as well as the researcher's understanding of the person's views, and the apparent confidence, engagement, and satisfaction of the person with intellectual disability. They also found that the interaction lasted longer, with sustained attention and more topics discussed than in the usual communication condition.

Murphy et al. (2010) report a similar finding, in a study of conversations with people at different stages of dementia. Thirty-one people with dementia were recruited from local services and grouped according to carer description into early, moderate, and late stage dementia. Each person was interviewed by a researcher in three separate conditions at different times: Talking Mats®, structured, and unstructured conversations on the topics of activities, people, environment, and self. They found that the use of Talking Mats® resulted in

a reduction in perseveration and more sustained attention to the topic than either structured or unstructured approaches, particularly in those individuals with moderate or late stage dementia.

In summary, Talking Mats® have been found to provide effective support to people with a range of communication disabilities for communicating opinions and choices within a structured context. The applicability to the current study suggests that Talking Mats® may provide both a means of supporting communication, and collecting individual data during the focus groups. As noted by Murphy et al. (2005), this approach should be used together with other methods for facilitating communication with people with specific communication disabilities. It is notable that in all the above studies, Talking Mats® have supported individual interactions, therefore the application of an individual Talking Mat® framework to a group context requires consideration.

4.3.3 Identification of principles for facilitating people with aphasia to participate in focus groups

The above discussion has demonstrated how people with communication disabilities, including aphasia, can participate in a range of activities, including informal conversations and more structured research, to give their opinions. In this section, the principles for the full participation of people with aphasia in focus groups will be identified, with reference to this literature.

4.3.3.1 *Feeling comfortable in the group*

In order for people with aphasia to share their opinions, it is important for them to feel comfortable and supported within an environment which recognises the presence of aphasia. Evidence from the literature supports that an overt recognition of aphasia within the group from the outset is important (Kagan & Gailey, 1993; Luck & Rose, 2007; Lyon et al., 1997).

The principles of Supported Conversation also include the assumption that a person with aphasia is a competent adult, with their own expertise on the subject of aphasia.

4.3.3.2 *Supporting comprehension*

In order to participate fully, people with aphasia need to understand the aims of the focus groups and the proposed overall plan for the meeting. In addition, they need to understand the purpose and procedure for each of the activities within the focus group to ensure that their responses are cogent. Finally, they need to be able to follow the ensuing discussion so that they can hear the views of other members of the group.

Supported Conversation techniques encompass a range of verbal and non-verbal strategies. A key factor in the implementation of such techniques is that the communication partner should be able to deploy the various techniques flexibly, responding to the needs of the person with aphasia both proactively and reactively. That is, resources such as visual materials must be prepared ahead, and be available for use in the interaction as necessary in order to achieve the aim of “maintaining the feel and flow of conversation” (Kagan & Gailey, 1993:214).

Two studies reviewed above reported that visual materials were used to provide support to the participants’ understanding of the objectives and procedures (Dalemans et al., 2009; Kerr et al., 2010). Dalemans et al. (2009) report the presentation of a PowerPoint summary of the issues to the whole group for discussion, but neither study specifies exactly how the visual resources were used in the course of the focus group discussions. The presence of only one facilitator in these studies may have reduced the potential for flexible deployment of the resources.

4.3.3.3 *Supporting expression of individual views*

The purpose of focus groups is to collect individual views, therefore establishing the means for people with aphasia to communicate their opinions is critical. People with aphasia need time to think and time to formulate their own opinions in response to the focus group topics. They may also need support to contribute to the discussion, possibly reviewing their opinions in the light of what others say.

Talking Mats® have been shown to be an effective tool in supporting people with communication disabilities, including aphasia, to express their views (Murphy, 2000; Murphy et al., 2005; Murphy, 2006; Murphy & Cameron, 2008; Murphy et al., 2010). The framework provides a means for people to consider the issues and options on an individual basis, interacting physically with the materials in a defined physical space.

In the case of the study by Murphy (2006), all participants in the group were facilitated to interact with a single Talking Mat®, with the aim of gaining consensus. Where individual opinions are sought, the presence of the physical mat and its contents then provide a point of reference for further discussion. The Talking Mats® approach is consistent with the strategy proposed by Luck and Rose (2007) of providing materials for participant to respond to, rather than expecting participants to generate ideas. In this context, therefore, the provision of an individual Talking Mat® for each participant, and an individual facilitator to support the use of this, is indicated.

Evidence suggests that techniques to facilitate individual expression of views in one-to-one interaction are now well established (Kagan & Gailey, 1993; Lawson & Fawcus, 1999; Luck & Rose, 2007; Lyon et al, 1997). Although none of the reviewed studies, aside from Garcia et al. (2000), provided additional communication support, this principle is proposed by Finch and Lewis (2003), who advocate the allocation of a lead moderator and additional facilitators to support individuals in the group. A summary of the principles for facilitating communication, and the means to achieve these in the focus groups, is shown in Table 4.1 below.

Table 4.1 Principles for facilitating participation of people in focus groups

Principle	Means	Evidence
All participants to feel comfortable and supported, empowered to express their views freely.	Acknowledgement of aphasia. Overt acknowledgement of competence and expertise as people living with aphasia. Communication support provided throughout group process.	Kagan & Gailey (1993), Lyon et al. (1997), Luck & Rose (2007).
All participants to understand the aims and overall plan of the groups.	Use of visual resources.	Dalemans et al. (2010).
All participants to understand the aims and procedures for each activity.	Use of Talking Mats® framework.	Murphy (2000), Murphy et al. (2005), Murphy (2006), Murphy et al. (2010).
	Use of Supported conversation techniques and Total Communication.	Kagan & Gailey (1993), Lawson & Fawcus (1999).
All participants to be able to express their individual opinion.	Use of Talking Mats® framework.	Murphy (2000), Murphy et al. (2005), Murphy (2006), Murphy et al. (2010).
	Use of Supported Conversation Techniques and Total Communication.	Kagan & Gailey (1993), Lawson & Fawcus (1999).
All participants to be able to respond in the discussion.	Additional facilitation provided for individuals.	Garcia et al.(2000), Finch & Lewis (2003).

4.4 Discussion of suitable methods for the analysis of focus group data

The previous section identified methods to support the communication of participants in the iterative design process. This was done to ensure that the methods used are maximally productive in generating useful data for subsequent analysis, contributing to the overall trustworthiness of the findings.

In this section, the issues relating to the analysis of focus group data will be discussed, firstly with regard to the qualitative discussion data, and secondly for the data which will arise from the use of Talking Mats®.

4.4.1 Background literature and discussion of data analysis methods

It is anticipated that focus group methods will yield qualitative data in the form of transcripts of discussions in the focus groups alongside ratings data generated by the use of the Talking Mats® framework with individuals within the groups. The topics for these discussions will be guided by the research aims, and participants will be encouraged to contribute their personal opinions. It is hoped that this approach will result in a rich understanding of the topics from the perspective of people with aphasia, consistent with the aims of qualitative research (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999; Denzin & Lincoln, 1998). The choice of specific methods is made on consideration of issues including the nature of the data and the purpose of the analysis (Richie, Spencer, & O'Connor, 2003).

This section will address methods for analysing the data arising from group discussions and the individual opinions expressed via Talking Mats®.

4.4.1.1 *Analysis of discussion data*

Options for analysis of qualitative data range from inductive approaches, relying on interpretation of the data on the part of the researcher to deductive approaches such as Content Analysis, which quantifies participant responses to pre-determined criteria (Bryman, 2008).

Phase 2 of the current study explores participants' views about accessibility of health information and specifically about the presentation of health information on a novel template. The analysis seeks to capture the responses of participants to the template materials presented during the focus groups and to understand the reasons for their responses. It does not aim to provide an account of people's phenomenological experience in relating to information.

Previous research into accessible information for people with aphasia has, as discussed, pursued a positivist research tradition, and no studies have yet explored the issues in depth from the perspective of people with aphasia. Since this study aims to explore individual responses within a group context, it needs to allow for different perspectives on the issues discussed. A risk of using a deductive approach, such as Content Analysis, which quantifies the responses given by participants according to the researchers' predetermined knowledge or interest (Bryman, 2008), is that new insights from the data may be missed.

An inductive approach to data analysis relies on the interpretation of the data by the researcher, in a reflexive, more intuitive process (Patton, 2002), the degree of interpretation depending on the nature of the data collected. Methods such as Interpretive Phenomenological Analysis (Smith, Jarman, & Osborn, 1999) are used to analyse data which may be concerned with highly individual experiences or perspectives; for example, families' perceptions of follow-up care of children who had survived cancer (Earle, Davies, Greenfield, Ross, & Eiser, 2005). Whilst attention to the individual perspective is a clear strength of such an approach, it is arguable that the data in this study are unlikely to be sufficiently complex to require a high degree of interpretation.

Framework analysis (Richie & Spencer, 1994; Richie, Spencer, & O'Connor, 2003) is a form of thematic analysis which follows a systematic process, from the data, via the analysis, to the presentation of the findings. It was developed in the area of applied policy research, and was designed to meet the requirement of being accountable to commissioners of research. A principle of Framework analysis is that the data analysis should be transparent, and Richie, Spencer, and O'Connor (2003) emphasise the importance of being able to return directly to the data to show how the analysis has been conducted. The use of such a method answers the potential criticism levelled by Braun and Clarke (2006) at studies using thematic analysis "...of themes 'emerging' from the data..." (p.80) without a clear rationale.

Framework analysis can generate a novel thematic framework, through systematic inductive analysis. Alternatively, data may be applied to an existing "typology" (Ritchie, Spencer and O'Connor, 2003: 248). As Pope, Ziebland, and Mays (2006) note, "... although framework is heavily based in the original accounts and observations of the people studied (i.e. it is 'grounded' and inductive), it starts deductively from the aims and objectives already set up for the study." (p.72). Thus, Framework analysis is typically a more deductive process, seeking answers to the research question rather than, as might occur in a more inductive study, developing new questions on the basis of initial inductive analysis.

According to Richie, Spencer, and O'Connor (2003), two broad stages are followed when conducting Framework analysis. The first, data management, involves a methodical process of familiarisation with the data, identification of an initial thematic framework, and the indexing and sorting of the data using this framework. The second stage of analysis involves abstracting the data from the transcripts, collating extracts within identified themes in a process termed "charting" (Richie & Spencer, 1994:182), and starting to develop explanations of the concepts represented in the data. Whilst the specific processes undertaken will depend on the aims of the research, the priority in Framework analysis is the ability to return directly to the data to show how the associations and interpretations are made. In keeping with other qualitative methods of data analysis, Richie, Spencer, and O'Connor (2003) note that the process of analysing the data continues throughout each stage.

4.4.1.2 *Analysis of the Talking Mats® scale*

As discussed above, Talking Mats® provides a framework for participants to express their individual views. With the mat in front of each person, participants also retain a tangible means of referring to their opinions within the group discussion, with the support of a communication facilitator.

In the context of research, Talking Mats® can function both as a framework to support participants' communication and as a tool to record participants' views. In considering the issues for the analysis of such data, the reliability and trustworthiness of the scale presented to participants is important.

A Likert scale is widely used in research to gather views (Bryman, 2008). A statement is presented, and the points on the scale represent a continuum relating to the intensity with which a study participant agrees or disagrees with the statement. Scales are constructed to reflect the research aims and then frequently converted to a numerical scale for the purposes of data analysis. The Talking Mats® scale, in contrast, represents categorical options including negative, positive, and 'unsure' and participants respond by placing an image on their chosen option.

A number of studies which used Talking Mats® to collect data were discussed in Section 4.3.2. Of these, two studies report the data generated from the use of the framework.

Methodologically, these two studies report varying treatment of the scale used. Murphy et al. (2005) interviewed ten older people on four topics related to their everyday lives using a three-point Talking Mats® scale, representing whether the person felt "unhappy", "not sure" or "happy" (p. 97). The results were reported descriptively, using these terms.

Gillespie et al. (2010) explored the views of people with aphasia and their carers regarding their communication using a three-point pictographic scale, indicating positive, negative or unsure (midpoint) responses. For the purposes of data analysis and reporting, the researchers then inferred a five-point numerical scale from the original visual three-point scale.

Murphy et al.'s (2005) data analysis reports directly the choices which participants made during the activity. In contrast, the approach taken by Gillespie et al. (2010) might be criticised for introducing a level of interpretation which could subtly change the meaning of the scale. Firstly, participants did not respond to a five-point scale, so the data reported may not reliably reflect the participants' opinions. Secondly, the conversion to a numerical scale might imply a continuous scale rather than the categorical scale to which participants responded. Finally, the mid-point of the scale as presented to participants can be used to indicate either uncertainty or the mid-point of a continuum. By inferring a numerical scale, the analysis removes the option for participants to express uncertainty.

To ensure the trustworthiness of the Talking Mats® data, the meaning of the scale needs to be shared by participants and researchers. Subsequent analysis and reporting of the data will thus reflect the intended meaning of the participants, rather than a researcher-led interpretation.

4.5 Summary of chapter

This chapter has considered the methodology required to ensure a rigorous and trustworthy study. A review of the relevant literature has identified suitable methods for generating and analysing qualitative data to address the study aims.

4.5.1 Aims of Phase 2

In Phase 1 of the study, three literature reviews addressing modified formatting, factors affecting language processing in aphasia, and health information topics required by people with aphasia, were integrated into the methods used in the design phase of the project. The aim of this first phase was to extract principles from the evidence base in each of the three areas to inform the design of the prototype Template 1.

The main aim of Phase 2 is to collaborate with people with aphasia and graphic designers in an iterative, collaborative design process. The aims for the focus group were:

- For people with aphasia to provide qualitative feedback on the accessibility of the template materials in the form of individual supported discussions of preferences for specific aspects of Templates 1 and 2, and related group discussion (see Appendices B, C, and D for examples of template materials).

Further aims for Phase 2 were identified as a result of the Phase 1 literature review, reflecting the lack of clear evidence in specific areas, detailed below.

Typography:

- For people with aphasia to denote their preferences for accessibility for specific variations of font size (see Appendix E).
- For people with aphasia to denote their preferences for accessibility for specific variations of font style (see Appendix E).
- For people with aphasia to denote their preferences for accessibility for specific variations of emphasis in font such as bold and italics (see Appendix E).

Image type:

- For people with aphasia to denote their preferences for accessibility for specific variations of image type including photographs and line drawings (see Appendix B).

Number of images per concept:

- For people with aphasia to denote their preferences for accessibility for specific variations of number of images per concept, including one image per concept, versus separate images for each key word up to a maximum of three (see Appendix C).

Set of related concepts:

- For people with aphasia to provide qualitative feedback on the accessibility of a set of cards conveying related concepts in the form of individual supported discussions and related group discussion (see Appendix D).

Within the proposed study design, issues arising from participants will be incorporated into the iterative design process, with identification of further specific aims based on the discussions generated in the first focus groups. In the following chapter, the methods undertaken within the iterative design study will be described.

Chapter 5 Phase 2: Methods

This chapter provides a detailed account of the methods followed in the second phase of the study, which took place between January and April, 2011.

5.1 Participant details

5.1.1 Sampling

Purposive sampling was undertaken for the Phase 2 study, aiming to achieve representation of the population with aphasia, and maximum diversity within that population (Bryman, 2008; Patton, 2002). Such representation of the population is important to ensure the transferability of study findings and concepts (Richie, Lewis, & Elam, 2003). The researcher identified three factors as critical to purposive sampling: age, gender, and severity of aphasia.

The number of participants sampled reflected the aim of achieving data saturation, the point when participants have generated all possible ideas for the subsequent analysis (Corbin & Strauss, 2008). Three focus groups were planned in order to achieve data saturation (Teddlie & Tashakkori, 2009). Each focus group was limited to a maximum of five participants, due to the need for individual communication support within the groups (Finch & Lewis, 2003). Given the need for small groups, a target number of between twelve and fifteen people with aphasia was identified for recruitment, allowing for a maximum of five in each group.

Initial recruitment led to seven men and three women agreeing to take part. To ensure a balance of men and women, four more women were recruited, who were willing to take part but wanted the security of premises known to them.

A possible source of bias within the sample was that some of the participants were known to the researcher, due to previous clinical contact.

5.1.2 Inclusion and exclusion criteria

People were considered eligible to participate in the study if they had acquired aphasia following one or more strokes, or other aetiology, in adulthood. Participants were over 18 years of age, and had acquired their aphasia at least one year before participating in the study. They had no known history of other neurological or psychiatric illness, and had adequate hearing and vision (corrected with aids in some cases) to be able to participate in verbal and visual focus group activities. They presented with normal premorbid language function and level of literacy, and spoke English as their main language to a high level of functionality.

People with severe cognitive deficits, such that they were not able to grasp the purpose of the activities, or participate in a group, were excluded. Finally, potential participants needed to have an interest in the topic under discussion, and to live close enough to be able to travel to the focus group meetings.

Ability to participate in a supported focus group was judged by the researcher, an experienced speech and language therapist. This was based on observations of interactions in the Communication Support Groups.

5.1.3 Recruitment

Participants for the study were identified by one of two methods. They were approached either through local voluntary sector Communication Support Groups for people with aphasia, or they were contacted via a database of previous research participants with aphasia held in the university department supporting this study.

At an initial meeting between the researcher and the local Communication Support Group organisers, the aims and the methods of investigation were outlined. The researcher and another member of the research team then visited the two groups on consecutive weeks. Basic information about the background to the project was presented, with pictures and illustrations used to support the information. People who expressed an initial interest in taking part were given an accessible project information sheet to take home (Appendix K). They could discuss this with a family member if they chose, and take time to think about the project.

One week after visiting the groups, the researcher telephoned those people who had expressed an interest in the project and asked if they still wished to be involved. Those who were eligible to participate and said they would like to be involved at this stage were invited to attend a first focus group meeting.

The second form of recruitment involved the researcher contacting previous research participants by email or telephone according to previously expressed preferences. These are people who live independently with aphasia. The aims and methods of investigation for the project were outlined, and those who were interested in taking part expressed their interest and availability via a return telephone call or email.

Following the researcher's visits to the Communication Support Groups, a total of eight people with aphasia expressed an interest in participating. One man was excluded due to severe cognitive impairment, as judged by the researcher following informal discussion. Two further people with aphasia were identified via the database of participants. At this stage, seven men

and three women had been identified as eligible and had each expressed an interest in participating.

To ensure a balance between male and female participants, four more women were recruited, who were willing to take part but wanted to meet in premises known to them. Exercising care to avoid coercion in recruitment, the researcher negotiated with this group of four women to participate in the project. As a result, seven men and seven women were identified as eligible and interested participants for the study.

5.1.4 Ethical approval for the study

Ethical approval for the study was granted by the Departmental Research Ethics Committee at the Department of Human Communication Sciences at the University of Sheffield on 17th December, 2010. A copy of the approval form can be found in Appendix J.

5.1.5 Constitution of the focus groups

The participants formed three separate groups. On meeting participants at the recruitment stage, the researcher conversed with each person to form a judgement of the degree of communication support they would need in the focus groups.

In allocating people to groups, various factors were considered, including participants' expressed preferences regarding the day of the meeting and their wish to attend with a friend. Groups were formed to ensure that people with a range of communication support needs were included. The three groups were named Group A, Group B, and Group C to ensure accuracy and consistency in recording the data.

Group A consisted of four men who attended one Communication Support Group and one woman who had previously taken part in research projects at the University. Group B consisted of two men and two women from two different Communication Support Groups and one man who had previously taken part in research projects at the University. Group C consisted of the group of four women from one Communication Support Group, who asked to work together at their regular venue. Each group met on two occasions, four weeks apart.

5.1.6 Informed consent to participate

Informed consent to take part in the study was sought at the start of the first meeting for each of Groups A, B, and C (Kruger & Casey, 2009). Researchers interviewed participants individually, using the project information sheet (Appendix K) as a guide to explain the elements of the project again, and completed an accessible consent form (Appendix N). All were reminded of all elements of the consent process, including the ability to stop their

participation at any stage without the need to give a reason. Fourteen people with aphasia gave their independent, informed, written consent to participate.

5.1.7 Aphasia profiling of participants

Standardised assessments of language processing were used to assess the type and severity of aphasia in each participant. In addition, further detail about participants' reading comprehension was sought, due to the focus on reading written information in this study.

Selected subtests from the Comprehensive Aphasia Test (CAT) (Swinburn, Porter, & Howard, 2005) were used to provide an aphasia profile of each participant. Additional reading comprehension data were collected using subtests from the Psycholinguistic Assessment of Language Processing in Aphasia (PALPA) (Kay, Coltheart, & Lesser, 1992). The results for each participant are displayed in Table 6.1.

The assessment of the participants' aphasia was undertaken in their own home at a time agreed with them. An experienced speech and language therapist was employed to contact the participants and conduct the assessments. Each participant underwent one or two assessment sessions. The data were gathered during a single visit between the first and second focus group meetings, and up to six weeks after the second focus group meetings. All responses were noted on the published score sheets of the relevant tests, transcribed phonemically, and scored according to the protocols of the assessments used. Data for three participants were collected after the second focus group meeting, due to difficulties in arranging the visits. In these cases, the data were collected by the researcher and a research colleague, both experienced speech and language therapists. The detailed results of the aphasia testing, together with further details of the participants involved, are presented in Chapter 6.

5.1.8 Overview of the participants

All participants live in a large city in Yorkshire. They are all retired from employment, either prior to or subsequent to their stroke. Participants varied in their independence in terms of both their home lives and their participation in wider activities.

All except one are British nationals, with English as their first language. One woman is a German national who has lived in the UK since 1964. She is a bilingual speaker of German and English.

All had suffered one stroke apart from TM (who had suffered three strokes in the course of ten years), BT (who had suffered three strokes within nine months), and MB, who developed

aphasia as a result of viral encephalitis. All were eligible for inclusion according to the criteria described in Section 5.1.2.

Table 5.1 below summarises the participants by group. Information is given about gender, age, time since stroke, aphasia type, and home circumstances. Diagnosis of aphasia type was achieved by applying scores gained on formal language testing to the Western Aphasia Battery Aphasia Classification (Kertesz, 1979), following the algorithm provided by Davis (1993). The information provided is contemporaneous with the focus group meetings.

Table 5.1 Overview of the participants

Group	Person	Gender	Age	Time since stroke	Aphasia type	Home situation
Group A						
	EC	Male	68	6 years	Broca's	Lives at home with wife
	BT	Male	77	9 years	Broca's	Lives at home with wife
	RW	Male	66	11 years	Broca's	Lives at home with wife
	TM	Female	75	6 years	Broca's	Lives at home with husband
	GG	Male	65	13 years	Global	Lives at home with wife
Group B						
	RP	Male	58	5 years	Anomia	Lives at home with wife
	SE	Male	67	1.5 years	Transcortical Motor	Lives at home with wife
	NH	Male	68	4 years	Anomia	Lives at home with wife
	OS	Female	67	4 years	Wernicke's	Lives at home with husband
	JB	Female	80	3 years	Transcortical Sensory	Lives alone, supported by family locally
Group C						
	SG	Female	71	5 years	Broca's	Lives alone, independently
	MM	Female	82	15 years	Broca's	Lives alone, supported by family
	MH	Female	76	11 years	Global	Lives alone, supported by family
	MB	Female	80	10 years (viral encephalitis)	Wernicke's	Lives alone, supported by family

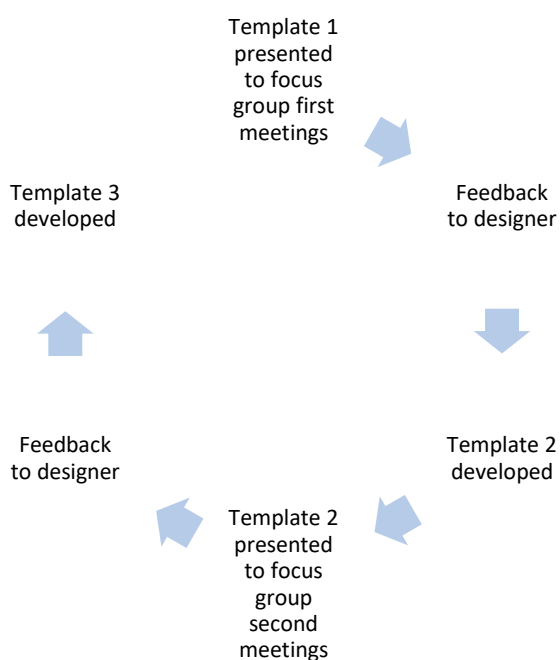
5.2 Study design

Phase 2 involved collaborating with people with aphasia and the graphic designers in an iterative design process. The same people participated throughout, each participant attending two focus group meetings. During each focus group meeting, qualitative discussion data and Talking Mats® ratings were collected.

In the first focus group meeting, people with aphasia provided structured feedback on the prototype Template 1 materials. Following this meeting, feedback provided to the graphic design team informed the development of the second version of the prototype, Template 2.

In the second focus group meeting, people with aphasia provided feedback on Template 2, after which feedback to the graphic design team informed the third and final template, Template 3. Table 5.2 summarises the iterative design process followed in Phase 2.

Table 5.2 Phase 2 Iterative design process



5.3 Materials and resources

5.3.1 Communication Support for participants with aphasia

The principles for facilitating communication in the focus groups identified in Chapter 4 were followed, and the techniques identified were employed to provide a maximally accessible communication environment for all participants.

5.3.1.1 *Focus group leadership*

For each topic, one member of the research team was allocated the role of Group Leader. The Group Leader took responsibility for introducing the topic and the associated activity, allocating time for individuals to complete the Talking Mats®, and leading the subsequent group discussion.

All other staff took the role of communication facilitators. Further duties, for example operating the audio-recorder, were allocated before each focus group meeting.

5.3.1.2 *Communication Facilitators*

A Communication Facilitator was allocated to each participant, regardless of the type or severity of aphasia. This ensured communication support for all participants, and promoted the principle of equality in the group, since no individual was identified as having a greater need for support than others.

The eight facilitators included three members of the research team (the researcher, a research speech and language therapist, and a family member of a person with aphasia), two speech and language therapists, a Communication Support Group volunteer, a psychology graduate with experience of people with aphasia, and a linguistics MSc graduate with an interest in aphasia research.

All facilitators received training from the researcher in Supported Conversation techniques (Kagan & Gailey, 1993; Kagan, 1998) and Total Communication (Lawson & Fawcus, 1999) prior to participating in the project.

As it was expected that participants might have difficulty reporting back to the larger group in open discussions, it was agreed beforehand that facilitators could report back following the paired discussions between participants and their Communication Facilitators. In these cases, facilitators checked with participants to ensure that they were accurately reflecting the views expressed, and that the interpretation offered to the group discussion was correct. Time was allowed in the group discussion for this collaboration between participants and their communication facilitators, and, when needed, further explanation or re-capping of ideas.

Where the meaning of participants' output was unclear, the facilitator provided a range of possible meanings for them to reject or accept. When reporting back to the large group, the facilitator suggested the meaning, and the participant was invited to confirm or deny the meaning (Luck & Rose, 2007). Communication facilitators were asked to keep brief field notes of issues raised by participants.

5.3.1.3 *Communication resources*

The researcher prepared accessible written materials to support participants' understanding of the study aims and focus group plans. Several copies of the focus group schedule were printed out on A3 and pasted on the wall; copies of the schedule were printed out on A4 and left on the table top. This information was also provided in poster form on the wall at several points around the room.

Further communication resources were provided on the group table: pens and paper, alphabet charts, and a paper copy of the Talking Mat's® visual rating scale. A flip chart and pens were available to record key words from discussions. Participants were asked to bring any specific communication resources to the focus groups.

5.3.2 Talking Mats® materials

5.3.2.1 *The Talking Mat® and visual rating scales*

The Talking Mats® used in the focus groups were designed specifically for the project, with one mat and associated materials provided for each participant to use at the table. Mats were made of thick card in standard A2 (59cm x 42cm) covered with thick dark green felt fabric. The dark background allowed for the materials to be seen clearly. The dimensions allowed for each participant to have their own work space of a comfortable size. For clarity in recording the data, each participant's mat was identified using a printed and laminated card with the participant's name attached at the top left corner.

A visual five-point rating scale was designed for use with participants with aphasia (see Appendix H). A five-point scale was selected as optimal for participants to express a range of views. The scale was made maximally accessible through the use of familiar symbols and colour on each point of the scale. The scale was colour-printed on white paper in Calibri font with the ticks, crosses and question mark in 90pt, and the symbols in 36pt. The scale was laminated, cut into sections, and placed using Velcro® across the width of the top of the Talking Mat®.

5.3.2.2 *Talking Mats® practice items*

Materials were devised to introduce participants to the use of Talking Mats®, in preparation for their use in reviewing Template 1, with an emphasis on judging clarity of meaning rather than personal preferences. Picture materials were devised around the concept of an imagined three-course menu. Items were selected on the basis of likely familiarity for all participants, to maximise comprehension of the activity. Three different photographs for each course were selected to represent high, medium, and low degrees of clarity of picture meaning, based on

the researcher's subjective judgement. Pictures were colour-printed and presented on individual laminated cards of approximately 8cm x 6cm, and a set of pictures provided for each participant.

5.3.3 Template 1 for focus group meeting 1

The information materials for review in the first focus group meetings were made up of a set of concepts providing background information about stroke and the function and working of the brain, the design of which was described in Chapter 3. The term Template 1 is used here to refer to the design of the materials at this stage of the study. (See Appendices B, C, and D for examples). The materials for Template 1 were professionally colour printed on mid-weight cards measuring 170mm by 110mm. Each card had a white background, and a matt finish.

There were three elements to the information content of each card. Firstly, a coloured banner was printed across the top of the card. A single word or phrase header to identify the topic was printed in Vectora Black at 24 pt, reversed into white font on this banner. Black weight refers to a heavier font than bold rather than describing the font colour. It has the appearance of bold font to the reader, but retains clarity when printed in white on a coloured background. Secondly, below the header, a sentence to convey the information was printed in Vectora Roman at 14pt in black. Thirdly, below the sentence, one, two, or three images which supported the written information were printed. Variations in image style and number of images were provided for review by the participants, as detailed below.

5.3.3.1 *Variations in Template 1 presented to participants*

As described in Section 3.6, pairs of cards were produced to explore participants' preferences for variations in image style and number of images per sentence. To investigate preferences for image style, cards were presented which conveyed identical concepts, but which were illustrated either by colour photographs or by coloured line drawings.

To investigate participants' preferences for variations in number of images per sentence, pairs of cards were presented which conveyed identical concepts, but which were illustrated either by a single image for the sentence, or by a separate image for each key word in the sentence, up to a maximum of three images.

5.3.3.2 *Materials for exploration of text preferences*

Text-based materials were devised to explore participants' preferences for a range of font sizes, a range of font styles, and different methods of emphasising keywords in the written text.

These variations were not included in the template but were presented in separate written materials. All text was printed in black ink on white card. Each exemplar was presented on a separate laminated card of 6cm x 4.5cm. Materials were provided for each participant in the focus groups. Examples of these materials are provided in Appendix E.

To investigate font size, a short phrase was printed in Arial font in four different sizes: 10pt, 12pt, 18pt, and 26pt, each presented on a separate card.

To investigate font style, the same phrase was printed in two font styles to contrast serif versus sans serif fonts: serif Times New Roman 12pt and sans serif Arial 12pt. Again this involved separate cards, one with each style.

To investigate emphasis of keywords, the same phrase was printed in Arial 12pt using four different styles of emphasis applied to the final single key word of the phrase: bold, italic, underlined, and large, each style presented on a separate card.

5.3.4 Template 2 for the second focus group meetings

Template 2 was developed from Template 1, with modifications based on the feedback from the first focus group meetings, and were professionally produced in the same way as Template 1.

The information materials for review in the second focus group meetings involved a set of concepts providing information about aphasia and emotions after stroke, depicted using Template 2. The choice of these topics was determined through the literature review (see Section 2.4).

5.4 Procedure

Each participant was invited to attend two separate focus groups, of approximately two hours in duration and one month apart. They underwent language assessment at home in between attending the first and second focus groups.

5.4.1 Preparation for the focus groups

A letter of confirmation was sent to all prospective participants, which was written in an accessible format, giving information about the venue, the transport arrangements, and the start and finish times of the focus group meeting (see Appendix L). Information about the date and time of the second focus group meeting was given to participants at the close of the first session. This was followed up by the transport arrangements and a letter of confirmation one week before the focus group meeting.

The fourteen participants were allocated to one of three groups. As each person was allocated to a specific group, they attended with the same people for both meetings. The focus groups met in the same place on each occasion. The meetings took place in purpose-built facilities, with easy physical access and a quiet environment which ensured uninterrupted discussions.

A structured protocol was developed for each focus group meeting to ensure clarity of purpose and consistency in addressing the research aims across each of the three participant groups (see Appendix O). This specified the focus group topics and activities and their timings, and named the Group Leader for each. Specific equipment and audio recording requirements for each activity were also detailed.

Facilitators were briefed by the researcher before each group to ensure that all were familiar with the research questions and aims, and received a copy of the protocol for their reference during the focus group. For each activity, a designated facilitator was assigned the role of Group Leader, with all others acting as Communication Facilitators, each paired with one person with aphasia.

5.4.2 Communication support within the focus groups

To ensure appropriate communication support for individuals, each Communication Facilitator was allocated to a participant and briefed on their aphasia and likely individual communication needs. At the start of each session, each participant was partnered with their Communication Facilitator, who supported them throughout the focus group meeting using Supported Conversation techniques and Total Communication, where needed. For each activity, these pairs worked together initially. Talking Mats® were used as directed by the Group Leader, depending on the aims of the activity. Feedback to the larger group discussion was then given by the participants, where possible, supported by their Communication Facilitators.

Frequently, the Communication Facilitator offered detailed feedback from their individual discussions, on behalf of the participant; in these instances, the group leader sought clarification from individual participants that their views were being clearly expressed. Where non-verbal communication was used, the Group Leader reported this verbally for the audio recording, to provide clarity for data analysis. Communication Facilitators also noted any significant non-verbal communication.

5.4.3 Focus group meetings

5.4.3.1 *Introductions and settling in*

At the start of each focus group meeting, participants were welcomed to the venue and shown the facilities. The process of obtaining final informed consent to participate in the study was completed at the venue, immediately before the first focus group meetings.

Introductions of all participants and facilitators were undertaken by the group leader. Participants were thanked for coming, and all were encouraged to share their opinions as experts in stroke and aphasia. The group aims were explained and an overview of the schedule given in a structured form, to ensure that all were familiar with the plan. Participants were invited to ask questions at any time, and to leave the room for any reason if they needed to. Following their consent to audio recording of the discussions, the recording equipment was pointed out to all members of the groups, with information about when recording would take place.

5.4.3.2 *Introduction to the Talking Mats® framework*

An introductory activity was carried out, to familiarise participants with Talking Mats® and to practise using this framework to rate accessibility of picture materials. The Group Leader directed the Communication Facilitators to present each participant with the three pictures of the same item. Participants could seek clarification of the task and discuss the pictures with their Communication Facilitators if they wished. Participants then placed each picture on the Talking Mat®, underneath the visual scale, to indicate how well each picture conveyed the meaning of the item. The Communication Facilitators reminded participants, if necessary, to focus on the strength of the pictures for conveying menu information, rather than personal preferences for the food. Three pictures were presented at a time for participants to consider, with items from each menu course remaining on the Talking Mat®. Once all pictures had been rated, each participant's Talking Mat® was photographed by the Group Leader. The Group Leader then clarified that all participants were comfortable with the use of the Talking Mats® format, and initiated a brief discussion about the individual responses.

5.4.3.3 *Presentation of samples of Template 1 for discussion*

Participants' responses to specific aspects of Template 1 were sought using the materials devised for the purpose, within a Talking Mats® framework. To address each of the aims of the focus group, the same procedure was used in two separate activities, as follows.

In each activity, participants were shown six examples of Template 1. These were presented in the form of three pairs of cards, in which each pair conveyed the same concept, but varied in one dimension, namely image type or number of images per concept.

Participants were shown one pair of cards at a time. They were invited to place the cards on their Talking Mat®, closest to the point on the visual rating scale which represented their opinion of each card. Time was allowed for participants to complete the rating of each pair of cards, and to discuss this with their Communication Facilitator if they wished. The Group Leader waited for each participant to place each pair of cards before asking Communication Facilitators to present the next pair.

Participants could seek clarification if they were unsure of the task, and Communication Facilitators offered assistance if they thought that their partner might be having difficulty with the task. Time and space was allowed for participants to consider their own views and to talk about the issues with their Communication Facilitator. The importance of participants expressing their own opinion was emphasised.

The Talking Mats® were photographed by the Group Leader once all the cards in each activity had been rated. The Group Leader then initiated a whole group discussion, asking participants and their Communication Facilitators to feed back their comments from the Talking Mats® activity. Participants were invited to use their Talking Mats® as a point of reference, and to comment on the reasons for their preferences. At all times, the Group Leader and Communication Facilitators emphasised the researchers' interest in gaining the individual opinions of the participants, and emphasised that there were 'no right or wrong answers'. Time was allowed for the discussion to develop and it concluded when all who wanted to contribute had done so.

This procedure guided the following activities:

- 1) Seeking participants' preferences for the specific variations of image type of photographs and line drawings. For this, three pairs of cards, each pair conveying the same concept, but using either photographic or line drawing images, were presented (see Appendix B).
- 2) Seeking participants' preferences for specific variations of number of images per concept. For this, three pairs of cards were presented. In one set, the information was presented with a single sentence above a single image. In the other set, the sentence was separated out with space between each of two or three key concepts, and

separate images to represent each key concept were presented below the sentence (see Appendix C).

5.4.3.4 *Presentation of materials comparing font size, style and emphasis*

Participants' responses to specific variations in font size, style and emphasis were sought using the materials devised for the purpose (see Section 5.3.4) within a Talking Mats® framework. A similar procedure to the presentation of Template 1 was used, but here, the full set of materials addressing each issue of font size, font style and emphasis in font were presented to the participants by the Communication Facilitators together, in three separate activities.

For each activity, the same short phrase was used. To support participants' understanding of this phrase, the Communication Facilitators placed a picture to illustrate it at the top of each participant's Talking Mat, above the visual scale.

The participants were invited to compare and rate the accessibility of the written information on the cards using the Talking Mats®. The Talking Mats® were then photographed by the Group Leader once all the cards in each activity had been rated. As previously, a whole group discussion was then led by the Group Leader.

5.4.4 *Compilation of feedback to the graphic designer 1 (first iteration)*

After the first focus group meetings, the researcher compiled key information from the data collected (see Section 1.5) to feed back to the designer. This iteration informed the development of Template 2. The qualitative data, Talking Mats® ratings, and field notes were summarised.

The researcher met with the designer to provide the feedback. Specific feedback about individual examples of Template 1 was presented in a table showing all examples of the template, with participants' comments and requests for alterations recorded. Any comments applying to the whole set of materials were recorded outside the table, on the same document. Examples of Template 1 were used to illustrate the participants' feedback.

The designer then worked through the written feedback, applying changes to Template 1, to produce Template 2.

5.4.5 *Second focus group meetings*

5.4.5.1 *Preparation for the second focus group meetings*

At the end of the first focus group meetings, participants were thanked for their contributions. Each participant was given a written sheet with information about the date and venue of their next focus group meeting (see Appendix M). A letter of confirmation was sent to all

participants one week before each of the second focus group meetings, and arrangements made for those people requiring transport.

Planning of the second focus group meetings was undertaken by the research team following the first focus group meetings. This allowed flexibility to explore further any significant issues arising from the first focus group meetings, which might be issues highlighted by participants, or noted by the researchers.

Feedback to the graphic designer resulted in the production of a set of Template 2 materials (see Appendix D). The researchers agreed that these materials should be reviewed as a set by the participants, firstly in discussion with Communication Facilitators and subsequently in the larger group, facilitated by the Group Leader.

5.4.5.2 Identification of further aims for the second focus group meetings

Two issues requiring further attention were identified in the preparatory stage for the second focus group meetings. In the first focus group meetings, the Template 1 materials were presented as single concepts on one card. As a result of participant comments and reflection by the researcher, it was agreed that further views on the accessibility of different amounts of information should be sought in the second focus group meetings. The second issue related to the materials used to examine typography preferences. The materials used in the first focus groups to examine preferences of font size, style and emphasis were devised by the researcher and were unrelated to the Template 1 information materials under review. In the light of information gathered in the first focus groups regarding typography preferences, the research team agreed that a re-examination of emphasis in font preferences, presented on the template, was required. The following aims were agreed by the research team:

- a) To seek participants' preferences for the specific variations in amount of information conveyed at one time, using materials showing one, two or three concepts per page (see Appendix G).
- b) To seek participants' preferences for specific variations of emphasis in font, using materials showing emphasis in bold, large font and large bold font (see Appendix F).

A structured protocol was then devised for the second focus group meetings (Appendix P). As with the first focus groups, all Communication Facilitators were briefed beforehand and received a copy of the protocol for their reference.

5.4.5.3 *Materials for the investigation of amount of information and emphasis in font preferences*

To investigate participants' preferences for the amount of information conveyed at one time, materials were devised which presented one, two, or three concepts. To present one concept, the researcher selected one information card; to present two and three related concepts on one page, the researcher selected two or three related cards. These were then photocopied in high quality colour onto A4 paper showing two or three concepts on each page (see Appendix G).

To investigate participants' preferences for different methods of emphasis in font within the template, the graphic designer was asked to produce four versions of Template 2 materials, in which the design differed only in the means of emphasis of key words, selected by the researcher, as follows: normal (14pt), bold font (14pt), large font (18pt), and large bold font (18pt) (see Appendix F for examples).

5.4.5.4 *Presentation of samples of Template 2 for discussion*

Three topics were discussed in the second focus group meetings: participant responses to a set of cards conveying information about aphasia, amount of information per page, and emphasis in font.

5.4.5.4.1 *Review of Template 2 presented as a set of cards*

As identified in Chapter 2, no previous research has examined concepts presented as a set of related concepts. The evidence concerning language processing in aphasia and effective formatting methods suggests that concepts should be presented singly. Explanations of more complex topics therefore require a set of related concepts.

Participants were shown a series of eight cards, which formed a set of information about aphasia. These were formatted in the Template 2 design (Appendix D).

The Group Leader directed the Communication Facilitators to show the examples to the participants in sequential order 1 - 8. Once all eight cards had been presented, Communication Facilitators asked participants for their opinions on the accessibility of the set of cards. Talking Mats® were not employed for this topic, since participants were asked to review the set rather than individual examples.

Once all participants had expressed their views in paired conversations, the Group Leader invited participants and Communication Facilitators to feed back to a whole group discussion. The Group Leader firstly asked for feedback about the concept of a set of cards to convey information. She then invited participants' comments on each card. In each case, feedback was

given by both participants and Communication Facilitators and the Group Leader endeavoured to ensure that the discussion encompassed all opinions.

5.4.5.4.2 Amount of information and emphasis in font

A similar, shorter procedure to that followed in the first focus groups was followed to orientate participants to using Talking Mats® again. Participants then rated the materials using Talking Mats® framework following the same procedure as in the first focus groups for the following two activities.

- 1) Seeking participants' preferences for the specific variations in amount of information per page, materials featuring one, two, and three concepts per page (Appendix G).
- 2) Seeking participants' preferences for specific variations of emphasis in font, including Template 2 materials showing emphasis in bold font, large font, large bold font, and normal font control (Appendix F).

Again, Talking Mats® were photographed, and a group discussion was initiated by the group leader. The focus groups were closed with thanks to the participants for their contributions and expertise.

5.4.6 Compilation of feedback to the graphic designer (second iteration)

The same process conducted after the first focus group was completed by the researcher, as outlined in Section 5.4.4.

5.4.7 Production of Template 3

The two iterations described resulted in the production of the final version of the template, Template 3. Full feedback from focus group participants was incorporated in the collaboration between the researcher and the designer, ensuring a completion of the iterative cycle, from the first focus groups to the final template.

5.5 Data recording, preparation and analysis

5.5.1 Overview

The data for the study consist of audio recordings of focus group discussions, associated field notes from facilitators, and digital photographs of Talking Mats® completed by individual participants. The audio recordings include the spoken contributions in the groups of all project participants and facilitators. The photographs comprise a record of participants' responses to research questions regarding aspects of information materials, such as image type and number

of images per concept, using a visual rating scale (see Appendix I for examples of the completed Talking Mats®).

5.5.2 Audio recordings of discussions

Focus group discussions were recorded using a digital audio recorder. A microphone was placed in the centre of the table, around which group members sat. The recording equipment was placed to one side, operated by an allocated member of the research team, and out of the immediate view of the participants. The recordings took place according to the protocol, capturing the whole group discussions. Periods in the focus groups when participants were completing their individual Talking Mats® were not recorded, due to the number of people talking simultaneously. Immediately after the focus group meetings, the recordings were transferred to MP3 files. These files were stored digitally in a password-protected folder. Recordings were stored in separate folders representing each of the focus group meetings, and the different activities within the meetings.

5.5.2.1 Audio-recorded material

As shown in table 5.3, a total of three hours and thirty three minutes of focus group discussion was recorded. The total amount of discussion recorded in the first and second focus groups was similar overall; however, it is notable that in Group C, less data was recorded. This may be a reflection that the participants in Group C required more time to process the information and consider their responses, or had less to say in the discussions.

Table 5.3 Amount of audio data from each group at each meeting in hours, minutes, and seconds

	Meeting 1	Meeting 2	TOTAL
Group A	35' 57	40' 03	1 hr 16 min
Group B	48' 08	34' 30	1 hr 22 min
Group C	31' 29	23' 47	55 min
TOTAL	1 hr 47 min	1 hr 37 min	3 hrs 33 min

Groups A and B, as shown in Table 5.4 below, generated similar amounts of discussion data. The exception to this is the discussion of font size, style and emphasis, which Group B discussed for twice as long as the other two groups. As can be seen, Group C did not attempt discussions of the topics amount of information or emphasis in font. This group also had less whole group discussion time across all topics, except font size, style, and emphasis.

Table 5.4 Amount of audio data from each topic in each group, in minutes and seconds

	Meeting 1 discussion topics			Meeting 2 discussion topics		
	Template 1 Image type	Template 1 Number of images	Font size, style, and emphasis	Template 2 Aphasia set	Amount of information	Emphasis in font set
Group A	11' 32	17' 20	07' 05	31' 23	03' 25	05' 15
Group B	13' 00	19' 14	15' 54	27' 56	03' 33	02' 01
Group C	09' 24	14' 50	07' 15	23' 47	nil	nil
TOTAL	33' 56	51' 24	30' 16	83' 06	06' 58	07' 15

5.5.2.2 Transcription of audio recordings

The MP3 files of each topic were transcribed by members of the research team, including the Communication Facilitators. This was done to ensure a timely record of the focus group meetings by staff who had been present, with knowledge of the context and different speakers' voices (Poland, 1995). All transcribers received instructions from the researcher regarding the aims, approach, and conventions of the transcription.

All turns of all participants, the group leader, and facilitators were transcribed. In the transcriptions, each turn was labelled with the participant's or facilitator's initials, and a code to indicate whether the speaker was a person with aphasia or a facilitator.

The transcription conventions used were as follows (Atkinson & Heritage, 1984):

- Transcription was orthographic; non-words were transcribed with broad phonemic transcription. Unintelligible content was recorded in round brackets.
- Non-verbal communication was noted in square brackets, e.g. [laughs]
- Brief pauses were recorded with a hyphen, and longer pauses denoted by a sequence of three full stops. No measure of longer delays was undertaken.
- Overlaps between speakers were recorded with both speakers' turns marked in round brackets, on separate lines of transcription. Prosody is not recorded, but obvious questions are denoted by a question mark. Other standard punctuation is used at times in the transcription to add context and meaning; for example, an exclamation mark denotes tone of voice.

To ensure rigour, the researcher reviewed all transcripts whilst listening to the original sound recordings, and corrected all errors (Poland, 1995). A sample of the transcriptions is included in Appendix Q.

5.5.2.3 *Data preparation*

The researcher prepared the transcribed data for analysis to ensure that the data were complete and accurate. The data were formatted appropriately for ease of initial management and indexing, as well as later retrieval. Transcriptions were stored in Excel workbooks and labelled for each group, each meeting, and each activity within the meeting. The digital photographs of all participants' Talking Mats® were inserted at the end of each transcription to add context during the reading and analysis.

5.5.2.4 *Data analysis*

Framework analysis was selected for this phase of the study due to nature of the data and the research aims, as discussed in Chapter 4. Following Spencer, Richie, & O'Connor (2003), the analysis followed a hierarchical approach, moving from management of the raw data towards a description of the framework and themes, and later, an attempt to interpret the findings. The methods used in each of these stages are described below.

5.5.2.4.1 *Familiarisation*

The researcher read through the transcriptions of each topic addressed in the focus groups, and listened to all the recorded group discussions, in order to enhance her understanding of individual speakers in context. Notes were made in a 'comments' box within the transcripts.

5.5.2.4.2 *Identifying a thematic framework*

After several readings of the discussions for each group, notes were made on all emerging issues. This was done to ensure consistency and internal reliability, and to keep any emerging themes close to the data. Overarching themes were avoided, to ensure capture of all data within themes close to their original meaning, and to prevent over-interpretation. Examples were noted of issues in the discussion which fitted within each theme. Constant comparison (Pope, Ziebland & Mays, 2006) was used to ensure that turns allocated to a theme were consistent in meaning within the theme. At this stage, the point of "saturation" (Pope, Ziebland & Mays, 2006:71) was reached as the themes identified in the index covered all issues arising in the data.

The index developed from this list was condensed to a manageable number of headings and subordinate categories (Spencer, Richie, & O'Connor, 2003). A numerical code was then

assigned to the index. All the key issues were represented in this draft of the index, and the process of labelling the data using this index then started.

5.5.2.4.3 Indexing

The researcher applied the numerical index to a section of the data using the prepared transcriptions. This was completed directly into the Excel workbooks saved for this purpose. The index was then applied to all the discussion data covering all focus group meetings.

The transcriptions of different discussions in each focus group were stored as separate worksheets as described above in Section 5.5.2.3. The assigned theme was marked in a separate column on the transcript, adjacent to the relevant sequence of turns. Where a turn was indexed with more than one theme, this cell was copied and inserted.

After indexing each discussion, the researcher sorted the data within each worksheet by theme. Indexed segments were then copied and inserted separately at the end of the worksheet for storage. The text of each indexed turn was copied and re-inserted in red font into the body of the transcription to highlight it. Following this, indexed data from each worksheet were copied into a new worksheet, where it was then sorted again as part of the whole focus group discussion. The merged and sorted data were also retained in the separate focus groups discussions.

During the indexing process, the researcher kept notes both in the comments column of the transcription and in a research journal.

5.5.2.4.3.1 [Methods for handling collaborative discussion data](#)

Due to the presence of aphasia, in many instances the meaning an individual wished to convey emerged over a series of turns, rather than in a single turn. This reflects both the collaborative nature of participants with aphasia working with Communication Facilitators to express opinions, and the dynamics of group interactions in which several people contributed to a discussion topic at once. In order to capture authentic and contextualised data, segments of the transcript were indexed together.

5.5.2.4.4 Charting

Initial sorting of data within themes was completed by the researcher as described above. Following this, the researcher created a chart for each theme and each group. Sub-themes were represented in separate columns within the table. At this stage, the researcher recorded themes and primary sub-themes only, so that all segments were visible on the charts, with participants recorded in a consistent order on each chart.

Where segments were indexed in more than one theme, this was noted within the table, via a numerical reference underneath the text. As the process of analysis was continuous, this allowed the researcher to reconsider the meanings of the segments. In some cases, segments were then allocated to a single theme rather than multiple themes.

The individual group charts were then collated into whole data set charts. During this process, the data were examined further, particularly any data which were cross-referenced or in the category 'Other'. This completed the initial management of the data, and provided the researcher with a summary of the data for the purpose of a descriptive analysis.

5.5.2.4.4.1 Methods for handling collaborative discussion data in the analytic process

As described above, collaborative turns were indexed together. Retaining the context and meaning of turns into the charting was more problematic, however, since lifting turns out of indexed material into charts resulted initially in a loss of context, requiring the researcher to return frequently to the original transcript for interpretation. To resolve this, the researcher included a description of the collaborative context in the charts.

5.5.2.4.5 Mapping and interpretation

The next phase of the analysis aims to understand the meaning of the themes, abstracted from the raw data, and involves a descriptive analysis of the summarised data (Spencer, Richie, & O'Connor, 2003).

The whole data set charts were examined by the researcher. Working through each chart in turn, an interpretation of the meaning of each segment was noted directly onto the chart.

The descriptions of each segment were then collated and analysed by the researcher to determine overlaps and differences in meaning, then categorised. These categories informed the final version of the framework.

5.5.2.5 *Rigour in the data analysis*

All stages of the Framework analysis were completed by the researcher, who kept a research journal with notes and comments throughout for later discussion and to ensure a reflexive and transparent process.

To ensure rigour in the analysis of the data, the researcher and supervisor met to talk through this process, with the notes made open to discussion. To test out the framework, a segment of the data was selected for the supervisor to index independently using the thematic framework. Informal training in the framework was given as follows:

1. A description of the process undertaken to date.

2. A description of the way the data were handled, capturing collaborative turns between participants with aphasia and facilitators.
3. A description of the themes and the emerging framework.

The segment chosen was rich in a variety of themes to allow for the supervisor to use the full framework. This was done in a face-to-face meeting, allowing for discussion and debate where necessary. The researcher had some expectation that this meeting would result in a change to the framework. In fact, there was little need for debate, with this experienced by both researcher and supervisor as a positive and affirmative process, in which the supervisor was readily able to assign indexing codes to the data.

5.5.3 Talking Mats® data

The Talking Mats® data for this study consist of participants' ratings of materials using the scale incorporated into the Talking Mats® framework. A full record of these ratings was produced in the form of digital photographs of each Talking Mat® completed by the participants in the focus group meetings. Participants' initial ratings only were recorded for this purpose.

5.5.3.1 *Photographic material generated in the focus groups*

This data set consists of 62 digital photographs. As shown in Table 5.5 below, all participants completed a Talking Mat® for each of the topics presented. Note that in Meeting 2, Focus group C participants completed a Talking Mat® for the topics of Amount of information and Emphasis in font, however as noted above these topics were not followed up with full group discussions.

Table 5.5 Number of Talking Mats® data from each group at each meeting

	Meeting 1 data			Meeting 2 data	
	Template 1 Image type	Template 1 Number of images	Font size, style and emphasis	Amount of information	Template 2 Emphasis in font
Group A	5	5	5	5	5
Group B	5	5	5	5	5
Group C	4	4	4	4	4
TOTAL	14	14	14	14	14

5.5.3.2 *Data preparation*

The researcher downloaded the digital photographs and stored them in files labelled for each group, each meeting, and each activity. In addition, all photographs were inserted at the end of each section of transcription, so that the two types of data could be viewed together. Each participant's data was identified during the focus group via a card with the participant's name attached at the top left corner of the Talking Mat®.

5.5.3.3 *Data analysis*

The photographic material was analysed descriptively. Frequency of responses was noted for each condition presented, to identify trends in the data.

5.5.3.4 *Rigour*

All photographs were of sufficient quality to be interpreted with ease. Rigour was maintained by completing the analysis directly from the photographic materials. Keeping the photographs with the transcripts also supported the researcher's understanding of both discussion and photographic data.

5.6 Chapter summary

This chapter has provided an account of the methods used in Phase 2 of the study. In the following chapter, the results of this phase of the study are presented.

Chapter 6 Participants

The purpose of this chapter is to describe the people with aphasia who participated in the study, in order to provide context to the qualitative data and the subsequent data analysis.

6.1 Introduction

As described in Chapter 5, three separate groups were formed from the fourteen participants. Some people were already acquainted through the stroke support groups. Some were known to the research team due to previous clinical or research involvement, and this is acknowledged as a possible source of bias in the sample.

In the next section, details of the participants' language and communication will be provided. Reference will be made to language assessment profiles, as well as observations of participants' communication within the focus groups, in order to demonstrate the range of aphasia types and severities represented by the participants in the study.

6.2 Language and communication profiles of participants

Language profiles were constructed from the findings of standardised assessments (described in Section 5.1.7). Subtests from the Comprehensive Aphasia Test (CAT) (Swinburn et al., 2005) and additional subtests from the Psycholinguistic Assessment of Language Processing in Aphasia (PALPA) (Kay et al., 1992) to assess reading comprehension were used. Details of these are provided in Table 6.1 below.

A summary of participants' expressive language ability and communicative effectiveness was made, based on observations during language testing and in the focus group meetings. A judgement regarding the severity of aphasia overall was made by the author using clinical experience, based on a combination of the formal testing and communication performance in the focus groups.

Reading ability was determined with reference to the CAT comprehension of written single words and sentences subtests and the PALPA subtests, as noted above. The language assessment data are summarised in Table 6.1 below.

Table 6.1 Language assessment data for all participants

	Auditory comprehension		Written comprehension				Spoken naming	Repetition		Reading aloud	
Test name	CAT Comprehension of spoken words	CAT Comprehension of spoken sentences	CAT Comprehension of written words	CAT Comprehension of written sentences	PALPA 51 High Imag.	PALPA 51 Low Imag.	CAT Naming objects	CAT Repetition of words	CAT Repetition of nonwords	CAT Reading words	CAT Reading nonwords
n	30	32	30	32	15	15	48	32	10	48	10
Mean	0.97	0.94	0.99	0.93	0.90	0.82	0.97	0.99	0.92	0.99	0.94
SD	0.046	0.061	0.027	0.084	0.094	0.149	0.035	0.021	0.160	0.022	0.120
Range	0.83 - 1.00	0.81 - 1.00	0.90 - 1.00	0.75 - 1.00			0.87 - 1.00	0.94 - 1.00	0.40 - 1.00	0.92 - 1.00	0.60 - 1.00
Group A											
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	Missing *	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	-	-	-	-	-
Group B											
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	Missing *	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
Group C											
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	-	-	-

Note: Scores marked in bold show where performance is below the published normal range, or fall two or more standard deviations below the mean.

In this section, the language and communication of the participants in each of the three groups will be described. Each group is described in brief. Following this, a vignette for each participant provides an overview of their age, any additional impairments and aphasia type, language and communication performance, and reading ability.

6.2.1 Group A participants

Four participants in Group A were recruited from the weekly Communication Support group, and therefore were familiar with each other prior to the focus groups. One further woman was recruited from the research database, having been previously involved with research projects in the department. All were retired, with ages ranging from 65 to 77, and between six and thirteen years post stroke.

EC is a 68-year-old man with minimal residual physical disability. He has mild Broca's aphasia, with no residual auditory comprehension impairments. His spoken language showed reduced fluency, and slow rate of speech, with reduced syntax and some loss of function words. In connected speech, EC made articulation errors, suggesting a degree of motor speech impairment.

EC's reading comprehension was within normal range on single word and sentence tasks, and for written semantic association tasks.

BT is a 77-year-old man. He uses a wheelchair due to a right-sided hemiplegia. BT has mild Conduction aphasia, with auditory comprehension within the normal range at both single word and sentence levels. He scored at ceiling for object naming, but in connected speech his output was hesitant, with occasional phonological errors in production, and a degree of motor speech impairment.

BT performed within normal range on all measures of single word and sentence level reading, albeit slightly reduced for low imageability words.

RW is a 66-year-old man. He has Transcortical Motor aphasia. Auditory comprehension is within normal range at both single word and sentence levels. His spoken output was effortful, and was restricted to single words and short phrases, displaying reduced syntactic complexity. Although on formal testing, naming performance was within the normal range, he experienced significant word retrieval difficulties in connected speech, representing a moderate level of impairment. RW frequently relied on listeners to interpret his intended meaning. He then repeated their words in confirmation.

RW's reading ability was within normal range for single word to picture matching and semantic association of high imageability words. However, he had marked impairment for reading sentences and low imageability words.

TM is a 75-year-old woman. Although she is a native German speaker, she has been a UK resident for over fifty years, and communicates in English, the main language of her household. She has left-sided visual field difficulties. TM has Wernicke's aphasia, with impaired auditory comprehension at sentence level. Her naming ability is significantly impaired, with her spoken output characterised by the use of short, stereotypical phrases, appropriately used in context. Overall, she has moderate aphasia.

Her reading ability is within normal range for a single word to picture matching task. However, she was severely impaired on word semantic association tasks, performing below chance for high and low imageability words. There is no data on her written sentence comprehension but her performance on the CAT spoken sentence comprehension subtest is suggestive of syntactic processing impairment which is likely to be mirrored in written sentence comprehension.

GG is a 65-year-old man. He has right sided hemiplegia, mainly affecting his upper limb, and walks with a stick. GG has severe global aphasia affecting all modalities. On formal language testing, he attempted spoken and written comprehension tasks, but no expressive language tasks.

Auditory comprehension is significantly impaired, scoring at chance at single word level, and nil at sentence level. GG's spoken output was limited to open vowels or single bilabial (m/b/w) consonant and open vowel combinations. GG is able to communicate non-verbally. In focus group discussions he used facial expression, tone of voice, pointing and gesture to convey his responses.

GG's single word to picture matching was severely impaired, and he was unable to attempt either sentence to picture matching or single word semantic association tasks. Despite the severity of his aphasia, he expressed a determined interest in participating in the project, and contributed to all discussions with the support of a Communication Facilitator.

6.2.2 Group B participants

In this group, four participants were recruited from two different support groups and one from the research database. Whilst some were acquainted, they had not worked together as a group before the focus group meetings. Their ages ranged from 58 to 80 years, with all now

retired from employment, either prior to stroke or as a consequence. Time since stroke ranged from eighteen months to five years.

RP is a man of 58, with no physical disability. His aphasia profile is consistent with Anomic aphasia, with no auditory comprehension deficits. He experiences word finding difficulties with semantic errors in production, but overall his expressive language is characterised by fluent, phonologically and syntactically intact spoken output representing a mild language impairment.

Although RP's reading comprehension was in normal range for all tasks, he performed less well on written than spoken sentence comprehension, and reported difficulty with reading text level materials, suggesting a level of residual reading difficulty that the assessment tools may not have been sufficiently sensitive to detect.

SE is a man of 67. He has right-sided hemiplegia and walks with the aid of a stick. His aphasia profile is consistent with residual Transcortical Motor aphasia. Auditory comprehension of single words and sentences is within the normal range. His performance on spoken language tasks in formal testing was within normal range. In conversation, SE is a quiet man who tends to respond to questions posed rather than offering his opinion spontaneously. Whilst he appeared fully engaged in the focus groups, it was difficult to gauge whether his taciturnity stemmed from mild aphasia, his natural personality, or a combination of the two.

Although SE's reading comprehension was within normal range at sentence level, he had difficulty with all single word reading tasks. Word association tasks, particularly involving low imageability words, showed marked impairment, suggestive of acquired deep dyslexia.

NH is a man of 68. He has right-sided hemiplegia, and uses a wheelchair. He has Anomia. His auditory sentence comprehension is on the borderline of normal range, whereas single spoken word comprehension is at ceiling. On formal testing, his naming ability is impaired, and in connected speech, his output is fluent but hesitant, representing a moderate impairment.

He performed within the normal range on reading comprehension tasks involving word to picture matching or semantic association of high imageability words, but low imageability written words presented a difficulty for single word reading. Written sentence comprehension data is missing, but is likely to mirror his spoken comprehension.

OS is a woman of 67 with no physical disability. She has Wernicke's aphasia, with marked auditory comprehension impairment, particularly at single word level. She experienced

occasional word finding difficulties, but in general her spoken output was fluent. Overall, her language impairment is moderate, but her communication in the focus groups masks this.

OS's reading comprehension is just within normal range for both single words and sentence picture matching tasks. However, on semantic association tasks for both high and low imageability written words with no picture support, her reading performance was below the level of chance.

JB is an 80-year-old woman. She has mild physical disability and cognitive changes affecting her short term memory. JB's profile is consistent with Transcortical Sensory aphasia, characterised by impaired auditory lexical comprehension, with relatively spared auditory sentence comprehension. Her spoken language output is fluent, with impaired naming, but relatively preserved repetition. In connected speech, JB's fluent output is frequently difficult to understand due to paraphasic errors, and her communication is more impaired than her language assessment data suggest, resulting in a moderate impairment.

Her reading comprehension is just below normal range for single words, and just within normal range for sentences. She had greater difficulty however with semantic association tasks, particularly involving low imageability words, suggesting the presence of semantic impairment in reading.

6.2.3 Group C participants

In this group, all the participants were known to each other as they regularly attended the same support group. They had expressed a wish to work together for this study, and asked that the focus groups be conducted at their regular meeting venue. Their ages ranged from 71 to 80 years. All had been retired prior to the onset of aphasia, with time since stroke ranging from five to fifteen years.

SG is a woman of 71 with a mild right-sided weakness. She has Broca's aphasia. Her auditory comprehension was within normal range at both single word and sentence level, but with a slight disadvantage for sentences, consistent with a pattern of resolving syntactic impairment. Although she scored just within normal range for picture naming, she experienced significant word finding difficulties in connected speech, hindering her ability to express her opinions verbally in group discussions, and suggesting a moderate aphasia.

SG's reading comprehension mirrored her spoken language comprehension on word and sentence picture matching. However, her ability to perform word semantic associations was impaired, and she scored below the level of chance with low imageability words.

MM is a woman of 82 with mild residual right-sided hemiplegia. On language testing, her profile is consistent with moderate Broca's aphasia, with impaired auditory comprehension at sentence, but not single word level. Formal testing showed marked difficulties with naming and repetition. In conversation, however, MM was more able to use her expressive language than formal assessment suggests.

MM's reading comprehension was unimpaired for single word to picture matching and within normal range for word semantic association of high imageability words. However, she had difficulty understanding more complex written sentences, and her semantic association of low imageability words was at the level of chance.

MH is a 76-year-old woman with mild residual right-sided hemiplegia. She has global aphasia, with marked auditory comprehension impairments at single word and sentence level. She showed impairments for all aspects of spoken language processing. In the focus groups, she did not express her opinions spontaneously, but responded to choices provided through facilitated communication. Overall her impairment was severe.

MH has impaired reading comprehension at both single word and sentence level; her performance on word semantic association was at or below chance for low and high imageability words respectively.

MB is an 80-year-old woman who has aphasia resulting from viral encephalitis ten years prior to the project. Although her aphasia results from cerebral infection rather than stroke, she was keen to participate in the project and indicated that she felt the issues under discussion were relevant to her as a member of the Communication Support Group. MB has severe Wernicke's aphasia, characterised by severely compromised auditory comprehension in the presence of fluent spoken output. She attempted spoken single word and sentence to picture matching assessments, scoring below chance, but was otherwise unable to complete any other subtests of the formal test battery. In conversation, MB demonstrates evidence of pure word deafness. She uses lip-reading and requests repetitions and paraphrasing to assist her comprehension of auditory language. She was unable to complete any of the reading comprehension assessment tasks.

6.3 Summary

This study aimed to involve people with a range of aphasia severities, and this chapter has described the breadth of participants' language processing, including the varying degrees of severity and the different aphasia subtypes represented in the sample.

The study included participants with a range of mild, moderate, and severe aphasia. Although the individual profiles varied, four had mild (EC, BT, RP, SE), seven had moderate (RW, TM, NH, OS, JB, SG, MM), and three had severe aphasia (GG, MH, MB).

Seven different aphasia subtypes were represented by participants in the study. Those with non-fluent aphasia subtypes included two participants with Global, three with Broca's, and two with Transcortical Motor aphasia. Of the participants with fluent aphasia, three had Wernicke's, one had Transcortical Sensory, one had residual Conduction aphasia, and two had Anomia.

All participants had some degree of impairment in reading comprehension, even though in some cases this was residual (EC, RP), or mild, affecting only low imageability words (BT). For most participants, sentence and single word comprehension was affected to varying degrees (RW, TM, SE, NH, OS, SG, MM) and some showed severe impairment on the reading comprehension tasks (GG, MH, MB). Several participants reported difficulties reading beyond the sentence level, including those who showed no reading impairments on the tasks for single word and sentence reading (EC, RP). Since the formal testing battery included only single word and sentence level tasks, impairments at the text level were not identified.

In the following chapter, the results of the analysis of the focus group data will be presented.

Chapter 7 Thematic framework

This chapter presents the results of the Framework analysis undertaken of the data generated in the focus group meetings. The focus group discussions generated qualitative data, yielding insights into the experience of people with aphasia in their interaction with written health-related information. The qualitative data consist of the transcribed data, described in Section 5.5. All data analysed here are from the three group discussions in both sets of focus group meetings, and are primarily the comments or assisted comments of the participants. Participants' ratings of the accessibility of specific elements of the information were also generated by asking participants to place cards showing Template 1, Template 2, and variations in typography on a Talking Mats® rating scale.

The results of the qualitative and ratings data are presented here in an integrated form, in order to avoid repetition, to "tell the main story" (White, Woodfield & Richie, 2003:300), and to provide "hybrid vigor" (Miles & Huberman, 2002:396). The results of the qualitative data analysis provide the themes and narrative, with the ratings data presented at the end of the theme considered to best accommodate this data. Congruence and tension between the qualitative and ratings results are addressed in the discussion.

7.1 Thematic framework

This section provides a description of the themes and sub-themes which were generated from the qualitative data, and their conceptualisation into an understanding of the focus group discussions. The methods used to analyse the qualitative data were derived from Richie, Spencer, and O'Connor (2003), and follow the process outlined in Framework analysis, as described in Section 5.5.2.4. Results from the Talking Mats® data were then integrated into the framework.

7.1.1 Development of the framework 1 - Data management

In this section, the results of the initial stages of the process of Framework analysis are reported, to demonstrate how the framework was developed.

7.1.1.1 *Identifying a thematic framework*

Following the phase of familiarisation with the data, the initial thematic framework was developed by noting recurring themes in the data which were pertinent to the aims of the research. This process was completed methodically, working through the discussion topics

within each focus group meeting. The researcher generated six themes from the first discussion topic, and a further seven themes from the subsequent discussions. In total thirteen themes were identified for the initial framework. These are summarised in Table 7.1 below.

Table 7.7.1 Initial thematic framework

Themes generated from first discussions	Themes generated from subsequent discussions
1. See clearly	7. Acceptability
2. Size of text	8. Pictures
3. Words	9. Words and pictures together
4. Personal meaning	10. Approach to information
5. Timing after stroke	11. Amount of information
6. Aesthetics	12. Personal experience
	13. Individuals

7.1.1.2 Indexing

The index developed from the above initial list was condensed to a manageable number of headings and subordinate categories. To do this, the researcher assigned the thirteen original themes to one of seven categories, for example three themes: 'See clearly', 'Size of text', and 'Approach to information' were merged to form Theme 2 'Looking at the information', with sub-themes to retain the detail of the discussion. The complete index resulting from this process is shown in Table 7.2 below.

Table 7.7.2 Initial thematic framework for indexing the data

-
- 1. Everyone's different**
 - 1.1 Personal experience of stroke
 - 1.2 Personal experience of aphasia
 - 1.3 Personal style
 - 1.4 Personal preferences
 - 1.5 Individual differences
 - 2. Looking at the information**
 - 2.1 'see clearly'
 - 2.2 Size of picture
 - 2.3 Size of text
 - 2.4 Approach to information
 - 2.5 Presentation of information
 - 3. The meaning**
 - 3.1 Single words
 - 3.2 Phrases
 - 3.3 Sentences
 - 3.4 Single picture
 - 3.5 Picture meaning
 - 3.6 Picture style
 - 3.7 Picture detail
 - 3.8 Word and picture meaning matches ("cos you can see your arms and legs)
 - 3.9 Chunking
 - 3.10 Picture per word
 - 4. The look of it**
 - 4.1 Adult style
 - 4.2 Picture meaning
 - 4.3 Picture style preference
 - 4.4 Colour
 - 4.5 Font
 - 4.6 Consistency in the set
 - 5. Amount of information**
 - 5.1 Single concept
 - 5.2 Linked concepts
 - 5.3 Sequence of concepts
 - 5.4 'too much'
 - 6. Timing**
 - 6.1 Early days
 - 6.2 Now
 - 7. Other**
 - 7.1 Family
 - 7.2 Emotional responses
-

Two further sub-themes were added to the final index during this process: 6.3 'Recovery' and 7.3 'Suggestions for changes'.

7.1.1.3 *Charting*

All indexed data were inserted into the charts representing the seven main themes derived from the process of indexing:

1. Everyone's different
2. Looking at the information
3. The meaning
4. The look of it
5. Amount of information
6. Timing
7. Other

The meanings applied to the data at this stage resulted in the development of the final framework, forming the descriptive account provided in the following section. As noted by Spencer, Richie, and O'Connor (2003), the analysis is an ongoing process, continuing throughout the period of description and reporting of the data. This allows the researcher to continue to understand the data, making links, and developing new insights.

7.1.2 Development of the framework 2 – Descriptive account

The process of analysis included a consideration of the meaning of the issues arising in the working framework. This resulted in the identification of four overarching themes, which were ordered to reflect the process individuals may typically follow when interacting with information; thus, the first theme, 'Visual access', reflects individuals' initial visual processing of the information materials. In the second theme, 'The look of it', individuals' engagement with information follows from whether it looks right for them. The third theme, 'Understanding the information', addresses how people approach the different elements of the information to understand the overall meaning. The fourth and overarching theme, 'Everyone's different', captures the impact of the individual experience of stroke and aphasia, as well as individual responses and visual styles. The thematic framework is presented in Table 7.3 below.

Table 7.7.3 Thematic Framework of the qualitative data

Themes	Sub-themes	Issues within sub-themes
Visual access	Seeing clearly	Size Clarity Emphasis
	Amount of information	Single concepts Linked concepts
The look of it	Acceptable	To adults with aphasia To individuals
	Design	Image style Colour and font Consistent design
Understanding the information	The words	Aphasia and reading Understanding the words
	The images	Processing images/visual impact Interpreting image meaning
	Words and images together	Words and images work together Layout of words and images
Everyone's different	Experience of stroke and aphasia	Knowledge of aphasia Aphasia is individual
	Individual responses	Identifying with the information Reacting to the information
	Individual visual style	Looking at information Making sense with support

Extracts from the qualitative data are presented to exemplify issues from the discussion. For maximum clarity to the reader, these are presented orthographically, with broad phonemic transcription used to represent incomplete or unintelligible output. Where appropriate, sequences or interactions rather than individual turns are included, to provide a clear sense of the discussion, rather than decontextualized comments. These are provided particularly where a person with aphasia has been supported to develop their contributions by facilitators or other participants. Turns are presented in speaker order, but overlaps are not recorded as they do not add to the meaning of the data. Pauses in spoken turns were not measured for precise length, but were recorded and are represented here orthographically, according to the transcription conventions outlined in Section 5.5.2.2. Extracts follow a consistent format, with the speaker's initials at the beginning of the turn: participants are referred to by their initials,

Group Leaders as GL and the communication facilitators as F1, F2 etc. to represent individual facilitators.

Where appropriate, reference is made to individual participant's language impairment, where this may clarify the form or content of their contributions. In addition, context of the discussion is provided.

7.2 Theme 1 - Visual access

This theme relates to ease of visual access rather than seeing per se. Although many of the participants wore glasses, and clearly sensory access was an issue for some people, this theme is more about the ease with which materials can be visually processed.

The data contributing to this theme are from group discussions in all three groups across both sets of focus group meetings. The materials discussed include Template 1, Template 2, and the cards designed to elicit ratings of font size, font style and emphasis. All participants contributed in some way, although the amount differed across groups and within groups.

The two main sub-themes within this theme were 'seeing clearly' and 'amount of information,' both of which address people's perceptions of how easy it is to take information in visually. Within 'seeing clearly' the size of materials was important, along with the emphasis of particular elements, and the ways in which that emphasis is made. The theme 'amount of information' related specifically to how many concepts people were being asked to process at one time, and the links between these concepts.

7.2.1 Sub-theme 1 Seeing clearly

Size, clarity, and emphasis were identified as important issues within this sub-theme. Data relating to each of these issues are presented below.

7.2.1.1 *Size*

The size of text was an important issue for participants. In all discussions about font size, participants expressed the need to be able to see the materials clearly and easily. Several issues arose in the discussions of size of text and images in the materials.

The first of these is that participants talk about larger font sizes as being easier to process. In the extracts below, two participants in separate discussions described how size helped them to make sense of the content. OS's words suggest that the larger font size is more readily understandable to her.

OS: like bigger can you see it - explains

NH's comment adds an impression that larger fonts are also easier for him to process.

NH: if it's ease of choosing I would choose large

Conversely, the smaller fonts were not liked, as expressed by SG.

F2: so if the slightly bigger ones are easier to see - what did people think about the small ones?

SG: oh no!

The interaction between size of font and speed of processing was raised by NH, who articulated that larger fonts were more accessible to him. Here, he was referring to the phrase 'cup of coffee' which was presented to participants in varying font sizes.

NH: if it was the big - if it was coffee that said coffee - it - I would - coffee - I would get it - sooner than these that are - smaller

On a similar theme of ease of visual processing, BT raised the issue of font size and motivation to read information. The extract below follows on from a wider group discussion in which individuals gave their opinions on font size. Here, BT has rated a large font size as optimum for him, and went on to contrast this with the much smaller font sizes in newspaper articles, which he reported as difficult to read. He explained that reading smaller font size would require greater effort and motivation on his part.

BT: I can't read all the newspapers I want to, unless I'm really interested and then I'll concentrate on the column - but /ə/ that's a size /ə/ like

The issue of font size, visual processing and acute stroke was raised by EC. After the Group Leader opened the discussion and asked for general comments about what makes it easier or harder to read text, EC commented that he could now see the larger font clearly, but reflected on his experience soon after his stroke saying:

EC: but when I had first had stroke - I couldn't see that at all

He indicated that he would have found it impossible to process any text at all, regardless of size, and described that he had, in the immediate aftermath of the stroke, required visual information via pictures only.

Finally, the font size needs to be appropriate and look right in the context. In this final extract in this section, JB had selected the second largest font as her preferred size; this was remarked upon by her facilitator, and JB commented that the size is "sensible", contrasting it with the largest size.

JB: I think if you see it - that's what you - that seems sensible [points to size 18 font] ... that [points to size 26 font] makes it - shout out
F2: it's too big - it's shouting
JB: yeah

The size of images as a factor in ease of processing also emerged in one of the group discussions. This was introduced to the group discussion by a facilitator, as the issue had arisen in the preceding discussion between SG and her facilitator.

F2: with this picture - the one that you went for the double tick - am I right in thinking - it was because it was bigger?
SG: yeah

Overall, participants agreed that larger materials are generally easier for them to access visually. As JB's extract illustrates however, the font size needs to be in keeping with the overall materials so that there is a balance between visual access and acceptability, an issue which will be addressed in greater detail in Theme Two 'The look of it'.

7.2.1.2 *Clarity*

Related to size of text and images, participants also expressed that the visual clarity of information materials was important for them to start processing the content. This is summed up in an exchange reported by BT's facilitator from their individual discussion.

F1: the word that BT keeps saying is simple
BT: yeah
F1: simple and clear

In the meetings, participants commented freely on the images in the materials under discussion. In the extract below, when BT articulated his reason for preferring one of the images of a brain, he revealed his preference for an image which is easy to access visually.

BT: I like its simplicity

This was echoed by another participant, who, when the Group Leader asked him to say why he preferred line drawings to photographs said:

SE: I just think they're - lot - plainer to see

EC reported a preference for the line drawing style. He indicated that he might favour photographs, but that this was difficult for him to judge because, to him, the photographs presented here were not sufficiently clear.

EC: /ə/ - better photographs might be good in place of that - but it can't see because - /ə/

Clarity in text emerged as an important factor in the discussions around serif versus sans serif fonts. For the participants who had a strong preference, there appeared to be a difference in visual perception of the two font styles. For BT, the perceived darker appearance of the sans serif font appeared to make it accessible.

F1: there was another point that you noted wasn't there - that number 6 [serif] - you liked number 5 [sans serif] better than 6 - you said it was clearer - easier

BT: it's clearer - it's er - it's darker isn't it?

Similarly, darkness as an aspect of clarity was repeated in a comment reported back by a facilitator on behalf of GG. In this discussion, the Group Leader had asked the participants directly whether they preferred to see the text printed in black on a white background, or in white on a coloured background, as on the Template 1 materials. GG expressed to his communication facilitator that he found the text in black font easier to see than the white coloured font.

F2: GG was talking about the black writing and preferring it to the white

The meaning of clarity to individuals may vary, as demonstrated above. Analysis of the data suggested, however, that participants wanted information which was 'simple' and 'plain'. The discussions of the different font styles indicate the importance of material which is straightforward and uncluttered.

7.2.1.3 *Emphasis*

Overall, participants expressed their preference for key words to be emphasised, as in the extract below. Here, TM, together with the facilitator, explained how the emphasis helped her to process the text, highlighting the visual impact of the bold emphasis.

F2: so you like some sort of emphasis - something to

TM: to see

F2: draw it out - to see

The bold and large fonts were liked by participants. BT explained that the bold succeeds in making the key word stand out from the rest of the short phrase.

BT: that one is er is - I like it [bold font]

F2: the one with the bold

BT: /bə/ /bə/ - it comes out

Opinion varied among participants: some people preferred to see bold emphasis in normal font size; others preferred to see the key word in both large and bold font. Overall, there was agreement that emphasis is helpful, and that the larger and bolder fonts were most beneficial to visual access.

7.2.2 Sub-theme 2 Amount of information

This sub-theme comes under the overarching theme of 'Visual access', because the issue relates to how much people can look at when interacting with information. Participants described their different responses to the amount of information presented on a page before any attempt to process it began.

Two issues were extracted within this sub-theme, reflecting participants' preferences for the amount of information they find accessible. Firstly, when given the choice, most participants preferred to see only one concept on a page at a time. Secondly, for some participants, the presentation of linked concepts on one page was perceived as useful. Data relating to each of these are presented below.

7.2.2.1 *Single concepts*

Participants provided several different reasons why information presented as single concepts helped them. One benefit was that single concepts helped people to focus their attention and read information more slowly, and thus understand it more fully. The extract below is an interaction between BT and his communication facilitator in which BT has described that he generally attempts to read information at the same speed as he would have done prior to his stroke. After the stroke, however, he found that he frequently did not fully understand the information. Looking at materials showing information about the brain, BT identified that single concepts helped him to slow down his reading pace and focus his attention on the concepts as they are presented.

BT: my trouble is - I start reading I see - I go brain oh yeah - I - I - before I've - before my brain has absorbed that information - I'm on this one - that's the reason one card's better - because I didn't read properly

F2: that's interesting

BT: yeah

F2: so you're quite quick

BT: yeah

F2: in how you look

BT: yeah

F2: but you're a bit quick for absorbing it

BT: yes - yeah - at one time I could do it

JB commented that she preferred to look at information with a family member. The provision of single concepts was seen as helpful in pacing a shared engagement with information, as described by the facilitator in the extract below. JB explains that having the information read aloud, one concept at a time, helped her to understand, when she cannot understand by reading information on her own.

F2: we talked about each one of them didn't we and that was good wasn't it - so one at a time I kind of read it to you and we talked about it and then you linked it with your experience

JB: yes - when I couldn't do it and when I didn't - yes I can see it

The benefit of looking at information as single concepts together with someone else was also stated by RP, who contrasted the presentation of information on single cards with traditional leaflets. Here, he articulated how single cards help both the person who has had a stroke and the other person to attend to the concepts "one at a time". He added that he thought this especially useful in the early stage after a stroke.

RP: whereas I mean if you've got someone with you - you know family or whatever you can just you know - one at a time go through it all I think particularly the end of when you have your stroke I think they are good

In the extract below, TM commented that if information was presented as single concepts, she was more able to remember information. This would allow her to process each piece of information without the visual distraction of other concepts.

TM: well if you see one that's a lot better than because you then you go to the other one and then you by the time you have forgotten the other one but so you don't really want two what you want is one is first is good better

In summary, participants were positive in their view of single concepts, revealing that information presented in this way helped with engagement with the information, pacing their reading, and accessing and retaining the information. The issue of information which is easy to look at together with a family member was highlighted in these discussions as an important consideration for some people, and is considered further in Theme 4 'Everyone's different', sub-theme 3 'Individual visual style'.

7.2.2.2 *Linked concepts*

For some participants, the presentation of two concepts on one page was rated as helpful to their processing of information. SE's comment serves to illustrate that it was difficult for him to articulate why, but that he perceived this amount of information positively.

SE: I thought that were good that

The benefit of two concepts was identified more clearly by RP, who responded to the Group Leader's suggestion that there was a link between the concepts.

GL: are the two things related on there?

RP: for me, yes, 'your brain does maths' - it doesn't now of course - and 'your brain concentrates for you' - makes you think about - oh yeah - it's to do with that stroke

OS agreed with RP, that presenting related concepts together helped her to understand the information.

OS: similar - similar - things you know - to me

A facilitator reported to the group that two participants had found the linking of concepts useful.

F3: MM and SG said that they go together - they follow - that's what they said

Within the theme of 'Visual access', it is important to note that, even where individuals found two linked concepts on a page helpful, they still preferred to see a limited amount of information at a time. In the extract below, NH explained that with too much to attend to visually, he was forced to disengage from the information.

NH: yes - well - I was looking at the brain - at number three - and looking at the - I think the brain is so much different in the one - it says it quite spontaneously - and that is that - and the - it ... [looking at the three concepts on one page] I'm sorry if I can't get it over - but it - when I saw three [three concepts on one page] - I just have to switch off

This opinion was supported by RP, who agreed with NH's comment.

RP: I can't do that - it's too much - what NH was saying [three concepts on one page]

Later in the discussion, RP summarised his view of the different number of concepts per page, and he identified that two concepts per page is optimum for him in conveying the content.

RP: I can manage with the two - but it - there's two things just bring the things out - whereas the one - not quite enough - but the three is too much

The most frequently expressed comment in relation to amount of information was that information that participants encountered in everyday life was generally inaccessible because there was too much to look at on one page. For some participants, this was expressed with some emotion, for example in the extract below, RP talked about internet-based information.

RP: far too many things ... millions - and it just gets annoying

RP, reflecting on what he thinks about information on single cards, commented in a similar way to NH's earlier turn, expressing the risk of disengaging with information when too much is presented at once.



RP: better than leaflets because you've got twenty things to look at - I think a lot of people are fazed -you think oh I can't look at that - what's that mean? - chuck it

These extracts sum up the importance of this issue for people with aphasia who expressed that their visual access was assisted by the presentation of one single or two linked concepts. In contrast, trying to visually process multiple concepts per page was perceived as a significant barrier to accessing information.

7.2.3 Presentation of Talking Mats® data

The fourteen participants completed Talking Mats® ratings for a subset of factors which were consistent with the theme of 'Visual Access'. These factors were font size, font style, emphasis in font, and amount of information per page. Each of the participants rated each condition within a given factor on the rating scale (see Appendix E).

7.2.3.1 Size

Each participant was given four cards. The text on each card was printed in one of four font sizes, 10pt, 12pt, 18pt, and 26pt. Participants placed the cards on the Talking Mat® underneath the visual scale, according to their opinion of the font size presented. For example, seven participants placed the 10pt card under the  symbol, and ten participants placed the 26pt card under the  symbol. Table 7.4 shows the participants' ratings of each font size.

There was a tendency for participants to rate the larger font sizes more highly, with the smaller font sizes less favoured. The smallest font size (10pt) was overall least favoured. One participant rated the two smaller font sizes more highly than the other participants. In the discussions, however, he expressed a preference for a larger font size.

Table 7.7.4 Frequency of font size ratings

	😊✓✓	✓	? 😞	✗	✗✗😞	
Font size						Total participants
10	0	0	1	6	7	14
12	1	0	5	6	2	14
18	9	5	0	0	0	14
26	10	3	1	0	0	14

7.2.3.2 Font style

Each participant was asked to rate two cards. Each card had text printed in either sans serif font or serif font. Table 7.5 shows the participants' ratings for each font style. As shown in the table, participants showed a trend towards preferring sans serif font, with no participants rating the serif font as 😊✓✓. The large number of mid-scale ratings, however, suggests that participants did not hold strong opinions about font style.

Table 7.7.5 Frequency of font style ratings

	😊✓✓	✓	? 😞	✗	✗✗😞	
Font style						Total participants
Sans serif	1	7	4	2	0	14
Serif	0	6	4	3	1	14

7.2.3.3 Emphasis

Ratings of different methods for emphasising font in text were collected in the first and second focus group meetings. In the first meetings, participants were given four cards, each one with a key word in the text printed using one of four styles of emphasis: large font, bold font, italic font, and underlined.

The results show a trend towards large font emphasis, as shown in Table 8.6, but the spread of ratings across emphasis types, and the high frequency of mid-range ratings, suggested that further clarity on this issue was required.

Table 7.7.6 Frequency of emphasis style ratings 1

	😊✓✓	✓	? 😊	✗	✗✗ 😞	
Emphasis style						Total participants
Large	6	3	4	1	0	14
Bold	3	2	5	2	2	14
Italic	2	2	4	3	3	14
Underlined	1	2	5	6	0	14

In the second focus group meetings, participants were given four cards, each with a key word in the text printed using one of three styles of emphasis, bold font, large font, large bold font, and a normal font control. As shown in Table 7.7 below, this activity demonstrated more clearly that participants favoured emphasis over no emphasis. The font which was both large and bold was highly rated against all other styles.

Table 7.7.7 Frequency of emphasis style ratings 2

	😊✓✓	✓	? 😊	✗	✗✗ 😞	
Emphasis style						Total participants
Normal	0	1	0	8	5	14
Bold	3	3	4	4	0	14
Large	4	6	2	1	1	14
Large + bold	10	3	1	0	0	14

7.2.3.4 Amount

Participants were asked to rate the accessibility of information presented with one, two, or three concepts on one page.

The data presented in table 7.8 below show that participants tended to favour materials which contained one or two concepts, and rated more poorly the materials which contained three concepts.

Table 7.7.8 Frequency of number of concepts per page ratings.

	😊✓✓	✓	? 😐	✘	✘✘ 😞	
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

7.2.4 Summary of Theme 1

Analysis of the data within this theme demonstrates the importance of initial visual access for people with aphasia. Participants responded more positively to large, clear text and images, using large and bold emphasis in font to highlight key words in the text, with concepts presented either singly, or showing two linked concepts.

The group discussions revealed how these factors contribute to individuals' ease of visual access, and the subsequent impact on their speed and ease of processing information as well as their engagement and motivation to persevere with the information materials. This links with the next theme, in which aspects of the appearance of the information were seen to affect the likelihood of participants engaging with it.

7.3 Theme 2 – The look of it

This second theme reflects participants' views on the appearance of the information. Overall, this theme is not specifically about processing or understanding information, but is concerned with whether it looks right. This subsequently has an impact on participants' engagement with the information.

The data contributing to this theme are from group discussions in all three groups across both sets of focus group meetings. The materials discussed include Template 1 and Template 2, and include ratings of Template 1 materials designed to elicit opinions regarding image style. All participants contributed in some way, although the amount differed across groups and within groups.

Two sub-themes are described in the following sections. The first sub-theme, 'Acceptable', relates to participants' views on whether the information looks appropriate for adults with aphasia, taking into consideration their personal experience of stroke and aphasia. The second sub-theme, 'Design', relates to the way in which aspects of the design, for example, image

style and colour, are used to create information which is attractive to and engaging for people with aphasia. Extracts from the data relating to these themes are presented below.

7.3.1 Sub-theme 1 Acceptable

In this sub-theme, participants expressed the importance of the information appearing appropriate for the intended adult reader. This is based on their experience of aphasia and their personal views concerning the types of images used. The emotional element to the responses seen in some of the extracts indicates the importance to individuals of this aspect of the information.

7.3.1.1 *Acceptable to adults with aphasia*

The issue of modified materials still maintaining an appropriate adult style emerged in one discussion. The Group Leader summarised this discussion, using the word “simple” to reflect that some participants were indicating that they preferred information with single images and sentences. Following a further discussion about what “simple” information meant to individuals, BT made the point that whilst stroke and aphasia can result in difficulties with understanding, simplified information still needs to reflect an adult style.

BT: yes - it's - when you have a stroke it makes things very simple - got be careful with not making fools out of them [sounds of agreement] ... yet /ə/ I think that's good

In the second part of this extract, BT's words suggest that he considered these materials “good”. This view was echoed by others when, in subsequent discussion, the Group Leader asked the group whether they thought the modified materials they were looking at were appropriate for adults. Whilst none considered the materials inappropriate, BT identified the risk of producing information which, although accessible, may look inappropriate for adult readers. BT's comment, in the extract below, highlights the risk of stigmatising people with aphasia, if a modified design is interpreted in a childish way.

BT: where do you draw the line? but you can't, /n/ normal person will think, well, that's childish

The tone of materials also influenced whether people viewed them as acceptable or not. Some participants demonstrated that if the information contained a positive message about recovery, their engagement with it would be greater. In the extract below, MM and her facilitator have been looking at a card depicting the concept of aphasia recovery, showing a sentence ‘aphasia can get better over time’ above a three-part illustration of improving speech (see Appendix D).

F2: what did you like about it MM?

MM: because they're getting better

MB, MM and SG also referred to this issue.

MB: I said it's going back a long time - but - right from beginning

MM: yeah

MB: I suppose it must have got better

MM: yeah

MB: going back

F2: yeah - and what he's trying to show in the picture is progress - so that you do have progress

MB: yeah - it must have done

SG: done and speak - /ba/ / ba/ / ba/ - /ə/, fifth time - speak a lot better

SG's concluding comment confirms that there is hope for recovery, but that for her, this followed repeated practice of her speech.

Within this sub-theme, the data indicate that information needs to be acceptable to adults and designed with them in mind, and that it should be positive in tone, conveying hope to the reader.

7.3.1.2 *Acceptable to individuals*

Several participants reacted strongly to the images used in the materials. One example of this concerned the depiction of blood in the context of information about brain, blood and stroke illness, with the sentence 'blood makes your brain work'. In these materials, blood was conveyed in two different ways: one illustration showed a drop of blood falling from a cut finger; another showed blood vessels between the heart and the brain. In discussions in which the Group Leader invited general comments about the images, some participants did not like the blood pictured in the context of a cut on a finger. For example, in the extract below, MM's facilitator reminded her how she had reacted adversely to this image.

F3: MM - do you mind if I just say - when you - when you looked at that one compared with that one - you said something straight away ... do you remember? When you saw it?

MM: /wɛ:/ - blood! [facial expression conveying horror] [laughter]

MM's response suggested that the image of blood was too graphic for her, and this impeded her desire to engage with the information. Similarly, in the extract below, MB indicated a neutral response to the depiction of blood flowing from the heart to the brain, but was evidently distracted by the image of dripping blood.

GL: do you like the red?

MB: yeah - well it goes in and out [laughter] ... but If I saw something like that

GL: that's the dripping finger

MB: I'd be thinking - you know - you know [facial expression conveying disgust]

This image of blood was unacceptable to many of the participants, and all, including those with more severe aphasia, were able to express their distaste in verbal or nonverbal terms. At other times, participants experienced a strong emotional reaction to the materials, appearing to have an unpleasant association with the images, but found it difficult to explain their feelings. In the extract below, SG reacted to a photographic image of 'listening', depicting a man cupping his ear in an exaggerated posture.

SG: made me be stupid - yeah - angry

F2: really? So that picture made you feel angry?

F1: really? so that's the 'listens to speech' man again - this man - do you know why?

SG: erm - go on - no tried no [laughs]

F1: just brought out that reaction in you

SG: I don't know - I know what I want to say - getting it out doesn't come easily

In the discussion, there followed a fairly lengthy exchange, initiated by MM with SG about the experience of having aphasia and the difficulties of participating in conversations involving those without aphasia, due to topics moving forward too quickly. SG's comment "don't listen" and her immediate engagement with this topic suggests that this is important to her, and may help to explain her response to the image discussed above.

MM: you know when I said talking - erm - talking place today - and they said it about - people they going to ask an - you should have time to listen to them - and they don't - that haven't people - um

SG: yeah - yeah

MM: that's

SG: I notice what you mean

MM: yeah

SG: don't listen

MM: yeah - they can't be bothered

SG: yeah yeah yeah

MM: they ant - oth - other people say leave it and let em tell ya

SG: yeah yeah

MM: and you can't 'cos they'll not - they'll not listen to you

SG: yeah yeah - they gone onto something else

MM: yeah

SG: done

As can be seen in the extract, SG was unable to articulate the exact reasons for her reaction to the image, but the discussion provided some insight into the importance and sensitivity of this topic to her personally. Her negative perception of this image distracted her attention and affected her motivation to engage with the information.

Within this discussion, participants expressed how they found some images in the materials to be unacceptable to them, either through being too graphic (as in the 'blood' image example), or through triggering an unpleasant association (as in the 'listening' image example). These examples demonstrate the importance of providing neutral images which allow the reader to remain engaged positively with the intended message of the information.

7.3.2 Sub-theme 2 Design

In this sub-theme, participants raised issues related to the style of images, the use of colour, font, and the consistency in the design of the materials.

7.3.2.1 *Image style*

In the focus groups, participants' opinions were sought on their preferences for image style in information materials. It was anticipated that people would express a consistent preference for one style of image over another, and that this would be elicited through the comparison of the two different image styles. Participants were therefore asked to comment on materials showing either photographs or line drawings. Whilst they did express preferences, their reasons varied. For some, the visual appeal of the images seemed most important, whereas for others, the clarity of the image in conveying its intended meaning was more pertinent.

In general, participants appeared to be attracted towards either the line drawing style or the photographic style. For example, responses to the Group Leader's open questioning indicated a simple preference for one style over the other. In the extract below, NH commented that he preferred the line drawing style.

NH: no - I - I - I prefer the - the other photo - not the realistic one but the - the other one

BT's facilitator reported back to the group discussion that he had suggested that he found the photographs more visually appealing, as captured in the extract below.

F2: BT you made a really good point about the photographs as opposed to the line drawings - about ... it was to do with pleasingness

BT noted that both he and GG favoured a photographic image of the brain, and commented on their shared interest in art.

BT: it was funny that we both have art and like that one

For these two participants, the visual appeal of the images seemed to be a key factor in their engagement with the materials. For others, the visual appeal seemed secondary to the clarity in meaning of the image. For example, EC explained that, even though he found photographs more visually appealing, he preferred the clear meaning conveyed in the line drawings.

Some participants made comments which suggested that their preferences changed over time, with recovering language processing. In a discussion about stroke information booklets BT explained that in the early days after a stroke, he would have preferred to look at a limited number of line drawings. Now, he is able to enjoy looking at photographic images in a book.

BT: if I was going to book - at first I wouldn't - but I might go through one or two pages and er - I think this is what I would look at and understand [indicates line drawings] - it's got better - I like that

His final comment conveys that he feels positive that he is once again able to enjoy looking at information in this way.

7.3.2.2 *Colour and font*

Colour and font were two aspects of design which prompted discussion. Some participants considered the use of colour in the design of information important, whereas others seemed to barely notice it. In the extract below, the issue of colour was initiated by JB's facilitator, reporting back to the group following their individual discussion of materials on which the header word was printed in white on a coloured background. The same colours were repeated sparingly in the images (see Appendices B and C).

F2: we had a little discussion about the colours didn't we?

JB: yes I didn't notice at all [the colours]

Once prompted to consider this aspect of the materials, others, such as NH, expressed a strong preference for colour to be used in information materials.

NH: I would say that you must always try to have colours

In a development of this discussion, RP suggested that a colour-coded index was useful to him when navigating through a set of information.

RP: if it came a book, or a leaflet or something - I wouldn't know anyway - I want to know something about - I would know which bit to look at

GL: hmm

RP: it's it's in the red bit

GL: hmm

F4: yeah

RP: you know - a bit - for most people with aphasia - it's awful put /əm/- an index

GL: yes

RP: that's - I would look - I would look for that [colour coded index]

As with the use of colour discussed above, the different colours of fonts used in the materials did not elicit any spontaneous comments from the participants. Again, the Group Leader asked participants to comment on their preferences. In the extract below, TM indicated that she liked to see the header text in white against a coloured background, but this appeared to relate more to the visual appeal of the coloured banner than the colour of the font.

TM: I like the red one

GL: and you like the white writing?

TM: yes that's fine

Many of the participants did not appear to notice the colours and fonts used in the design of the materials. Having had their attention drawn to these aspects, some participants recognised them as an important element of visual appeal and accessibility, but for others, they remained a side issue.

7.3.2.3 *Consistent design*

Consistency in design was raised by participants, in relation to both individual concepts and across a set of concepts. In the first focus group meetings, the participants were asked for their opinions on materials in which the sentence was separated into two parts, with an image presented below each part of the sentence.

OS referred to the materials in which the sentence 'your brain needs blood' is illustrated by two different images of a brain. OS described that she was distracted by the use of different images, and she wanted the image for the concept to be consistent.

OS: it's all the brain like - it's all in the blue - and then when you move it across like - then you get the other diagr-...

The same issue arose in a discussion in which participants were asked to comment on a set of eight cards conveying information about aphasia. The sentence 'stroke can damage language' was illustrated by an image of a brain in the first part of the sentence, and by a speaker with a mark in the brain in the second. BT voiced a similar opinion to OS.

BT: in this one ... why is the brain different for aphasia?

The extract below shows BT's response to the Group Leader's request for a solution to this: that the brain image should be the same for stroke as for aphasia.

BT: just the same brain as on the other side

NH's preference for line drawings emerged from his viewing them as a set of cards together, and experiencing the greater consistency in visual properties, in comparison to photographs which were visually more varied.

GL: so it's interesting that at first you liked the photograph - but when you saw more of them together

NH: together - it - it - it went completely the other way - and went out of the room that one - something - something acceptable to being - I don't know

As discussed in relation to the issue of image style in Section 7.4.2.1, participants expressed preferences for different image styles. These do not appear to be rigid, but are affected by other aspects of the design. In NH's case, the need for consistency outweighed the initial preferred image style presented.

Two aspects of consistent design emerged in this sub-theme: a repeated image to illustrate a repeated concept, and the use of the same style of images to illustrate information materials within a set of materials.






7.3.3 Presentation of Talking Mats® data

7.3.3.1 *Image style*

Participants compared materials which conveyed concepts using either photographs or line drawings. Participants in Group A rated four cards, of which two contained photographs and two contained line drawings. Participants in Groups B and C rated six cards, of which three contained photographs and three contained line drawings.

A summary of the ratings is provided in Table 7.9 below.

Table 7.7.9 Frequency of image style ratings

						
Photographs						Total participants
Photo 1	5	1	5	3	0	14
Photo 2	2	1	4	4	3	14
Photo 3	3	1	2	3	0	9
Line drawings (LD)						
LD 1	8	2	2	2	0	14
LD 2	6	1	3	2	2	14
LD 3	5	1	3	0	0	9

The data show that for each of the three concepts, more participants gave highly positive ratings to the line drawings, and more gave negative ratings to the photographs. However, many rated the images at the mid-point of the scale, suggesting uncertainty or indifference. Whilst these results appear to show a tentative trend for participants to prefer the line drawings over the photographs, it is not a clear finding.

7.3.4 Summary of Theme 2

The data show how participants' initial impressions of the materials influenced their motivation to persevere with attending to the information. Analysis highlights the importance of information which is acceptable to adults, and designed with people with aphasia in mind. One aspect of this is that information should present a positive view of stroke recovery which conveys hope to the reader.

Visual aspects of design, such as the use of colour, consistency in the overall design style, and the repetition of specific elements such as images, were found to affect participants' engagement with materials. It is noteworthy, however, that not all participants responded in the same way to these elements of the design, suggesting that they are more important for some participants than for others.

Individuals varied in how sensitively they responded to the images used in the materials, but overall it was found that images which were neutral in tone were more likely to retain participants' engagement than those which prompted emotional reactions.

Discussions of image style revealed that this is not a straightforward issue. Whilst individuals may tend to prefer one image style over another, their opinions of specific images were complicated by unpredicted features of the images shown, such as their acceptability, visual appeal, and clarity of meaning. The analysis demonstrates how these factors affected participants differently and influenced their opinions of the materials.

7.4 Theme 3 – Understanding the information

This theme captures the data relating to how participants talk about their understanding of the information presented. Whilst the participants were not specifically asked whether they understood the information, they did comment at times on this, expressing variously full, partial, or no understanding of the content.

The data contributing to this theme are from group discussions in all three groups across both sets of focus group meetings. The materials discussed include Template 1 and Template 2, and include ratings of Template 1 materials designed to elicit opinions regarding the number of images per concept. All participants contributed in some way, although the amount differed across groups and within groups.

The sub-themes for this theme related to the words, the images, and the interaction between words and images.

7.4.1 Sub-theme 1 - The words

The issues discussed within this sub-theme were found to link with aspects of other themes, reflecting that reading comprehension is a common experience in people with aphasia, connecting visual access, aspects of design, and individual visual approaches to information.

7.4.1.1 *Aphasia and reading*

When looking at the template materials, participants made general comments about aphasia and reading, remarking on whether they could understand the written words on the cards. The wide range of reading ability across participants was reflected in their comments.

In the following extracts, a range of participant responses are recorded. In a discussion introduced by the Group Leader about whether people looked at both the text and the images in the materials, MM commented that she looked first at the text because she could make sense of it.

MM: I can read that

MB expressed that she was able to read part, but not all of the information. She used the word “clicking” to denote comprehension of the single word heading, but suggested that the sentence was difficult for her to understand.

MB: we're clicking a bit different on top - in middle

For GG, the severity of his aphasia meant that the written words were beyond his comprehension, as summarised by his facilitator in the extract below. GG expressed that he found the illustration helpful because, as noted by his facilitator, he was not able to make sense of the written text.

F2: you were saying that the word doesn't help you

EC raised this issue of changes to reading over time, commenting that in the early days after his stroke he would have found it impossible to read at all, and would have preferred picture material only.

EC: because when I had a stroke in the first place I can't think about words

The comments in this sub-theme show how aphasia can vary in its effect on individuals' ability to read, and that this can change over time following a stroke.

7.4.1.2 *Understanding the words*

The second issue within this sub-theme relates to factors which affect participants' comprehension of written text in information materials. The factors included font size and emphasis, and the layout of the text. In addition, one participant suggested modifications to the number of words used and the specific choice of vocabulary.

Participants agreed that their reading was helped by fonts which are large in size and include bold font for emphasis of key words. In Theme 1 'Visual access', this was identified as part of the process of visually processing the information. Here, in contrast, participants commented on the impact of typography on their reading comprehension. As previously described in Theme 1, participants consistently favoured larger font sizes for ease of visual access. Here, NH commented that a larger font helped him to understand the text faster. He related this to the experience of feeling under pressure to read and make a choice from a menu.

NH: if it was the big ... if it was coffee that said coffee - I would - coffee ... I would get it sooner than these that are smaller

In a discussion of materials contrasting different styles of emphasis in font, TM noted that the large and bold font was helpful to her reading.

TM: to help - yeah - to read it

Features of the design of the templates were identified in discussions as helpful to reading the materials. Firstly, the use of a header phrase above a concept sentence was initiated in discussion by the Group Leader, who asked participants to give their opinion on this layout. In the discussions, most participants agreed that they found this layout helpful in guiding their reading. In the extract below, SE expressed that this top-down approach helped him to understand the information in stages.

SE: read that and then you - can move down - settle in - your head

In contrast, BT expressed that he had not really noticed the header phrase, or did not consider that it was within his scope for comment.

BT: I thought that was only for you

In one discussion, participants debated whether it was helpful to include words as well as images in the information. RP suggested that the image was primary, and that the sentence could be placed at the bottom of the card. NH argued that he wanted to see the written word at the top of the design, to catch his attention. Here he described a card conveying the concept 'your brain makes your speech' in which the image shows a line drawing of a person and a speech bubble with the word 'hello' inside.

NH: I start at the top - and if it - down at the bottom ... and if it was down at the bottom - I wouldn't bother about it - it's up there where it the brain says hello and - and that's important to you

Two further issues relating to easing the reading demands were discussed in the groups. In the discussion comparing a short phrase contrasting different styles of emphasis, RP expressed a preference for a single word rather than a phrase.

RP: bold's better - but if it's for me I would personally find it a lot easier if it just said 'coffee'

RP raised the issue of suitable vocabulary used in information for people with aphasia on several occasions. He made suggestions for words that seemed more meaningful to him, for example 'communication' rather than 'language'. An example of this is shown below, in which he expressed difficulty making sense of the specific words used in some of the materials. The sentence read 'your brain makes your speech', but RP suggested that the word 'makes' did not fit well in this context. He provided an alternative, as in the extract below, in which he also acknowledged individual variation and preferences.

RP: I preferred 'produces' - but it's - it's very difficult - because we are all - I'm not sure you can find the best word for everybody

This sub-theme reflects the varied experience of people with aphasia when reading after a stroke. Participants reported that this ability may change over time, with resulting changing needs for how information is presented.

Participants mentioned various factors which helped them to deal with the written words on the information materials. These included an increased font size and emphasis of key words, as noted in Theme 1. The layout of the information, with a header phrase and concept sentence helped to guide people in their reading, building their comprehension in stages. There were variations in the extent to which people attended to the different elements of the design, and their preferences for specific layout of the sentence.

7.4.2 Sub-theme 2 The images

This sub-theme records participants' comments regarding the images used in the information materials, and the impact of these on their comprehension of the concepts presented.

Two issues arose from the data in this theme, reflecting firstly participants' responses to different image styles, and secondly how well the meaning of the concepts was conveyed in the images used.

7.4.2.1 *Impact of image style*

This issue is concerned with the impact of different image styles on participants' understanding, and what they said about processing different styles of line drawings.

Participants' responses to different image styles suggested that individuals generally found one style easier to interpret. Several participants favoured the line drawing style, expressing that they were easier to understand than the photographs. In the extracts below, SE explained why he rated the line drawings more highly.

SE: yeah - I do see the - the - the drawings are much clearer

RP, in contrast, found the photographic style easier to understand, as in the extract below, in which he referred to an image of a man listening.

RP: right - start from the bottom one - 'your brain listens to speech' - the guy doing that to me is just - /komp/- tells me completely what that means

The extract below shows that the same image can be easy for one individual to process and more difficult for another. Here, MB's facilitator supported her to express that this image was difficult for her to process.

F4: MB you didn't like this one - did you? - where it says 'your brain - listens to speech'

MB: I put that because I wouldn't - wouldn't be able to

F4: this guy - you said that this - this man didn't click - didn't you - you said that you couldn't understand why

MB: yeah - I wouldn't - for me - I wouldn't be able to - it wouldn't click

The group discussions revealed that participants' image style preferences were not only based on whether these were line drawings or photographs. Differences in style within the line drawings or photographs affected the ease with which the concepts illustrated were understood. Among the line drawings, participants showed preferences for images which could be described as either representational, that is realistic, or figurative, that is less realistic, in style. The designer illustrated the concept of the brain using two styles of line drawings. The first showed a simplified but realistic representation of the brain; the second included an image of cogs and wheels inside the brain in a more figurative illustration. The Group Leader asked participants to comment on which of these styles made more sense to them. Some participants expressed that they found the representational style more accessible. OS's comment suggests that this style fitted more closely with her understanding of the concept.

OS: to me it explains /əm/ - it explains the brain

BT's comment about the representational image of a brain reflects the importance to him of a clear image style, linking with 'Clarity' in Theme 1, and 'Image Style' in Theme 2.

BT: I like its simplicity

MM expressed that she preferred the figurative illustration of the brain. Her comment in the extract below suggests that she found it helpful to see an illustration of activity in the brain via the cogs and wheels pictured, and applied this as a way of understanding the workings of the brain after stroke.

F2: you said something really interesting about that - when you looked at that brain MM - when you were looking at the cogs and the wheels ... it made you think - do you remember ... you said /u:/ - do you remember?

MM: well - I know somebody's died [referring to the brain] - I mean - /əm/ - your brain - it's gone ... you know - and - and and others not got as going - some going on [meaning that activity in the brain after a stroke varies]

Not everyone had strong opinions about the image style. In relation to the illustration of the brain, RW indicated that the style of the pictures did not affect his understanding, interpretation, or experience of the information, as his comment illustrates.

RW: I'm not bothered

The presentation of abstract visual material was problematic for some. MB expressed difficulty understanding an image which was intended to convey the concept 'a lot of people', in which stylised human figures were drawn close to each other in varying colours. Her response to her facilitator's comment suggests that she may experience some difficulty with visual processing in addition to having aphasia.

F4: we struggled with that didn't we? You thought this looked a little bit like a pattern or -

MB: I wake up in morning - I usually - when I wake up - I get that bit of light - on this side - not long - only a sec - but a bit of darkey

Others, however, also reported difficulty interpreting this image. JB's facilitator reported on their paired discussion about the same card.

F2: the word that you said JB was "it's a bit of a nothing"

In response to this discussion, RP suggested an alternative way of illustrating the concept in a more concrete way, relating to the numbers of people affected by aphasia in the UK, and using words, rather than an image.

RP: you could put there something like 450 thousand people in the UK have aphasia - something - after a stroke - maybe

Additional detail in the images also affected participants' understanding. The impact of illustrative detail was reported in both positive and negative terms, with individuals reporting aspects of the details in the images which seemed to help or to distract them, or interrupt their understanding.

A general problem with use of detail in images may be linked with the issue of amount of information, and having too much to look at, as described in Theme 1. This was expressed by RP, talking about his preference for photographs over line drawings.

RP: there's there's too many different things to look at - got that and that and that

BT expressed that the detail of arrows to indicate movement of arms and legs in an illustration of a body was unnecessary.

BT: those arrows - th – the - take them off - it's the same - can't he move that arm that way

Other participants did not comment that there was too much to look at, but spent time trying to process the details in the images. BT, describing the detail of an eye, drawn in profile, reported that this detail did not make sense to him.

BT: it may be very personal but on the first one - I were ages - I couldn't work out what that 'p' was

In the extract below, NH described materials illustrating stroke and aphasia, in which the first image of the brain was clear to him, whilst the second image of the brain had been faded out by the designer, and the previously clearly drawn cerebellum overlaid with an ear and 'mouthpiece' image, to represent communication.

NH: left me a bit confused as to where they was with the that one - I put it on one side and came back to it and it ... stroke - it he's got the stroke and it something at the back is quite clear there and it goes onto here and it gets an ear in it! [expressing surprise]

NH's facilitator reported further comments from their individual discussion, which illustrates how his attempt to process the detail in the images hindered his understanding. They were looking at a red shape overlaid on the brain to depict the area of stroke damage.

F3: just in relation to that but slightly different you mentioned NH about - /əm/ - you didn't really understand why there was a difference between the two red blobs - /ə/ - you said the first blob was more brilliant in colour

NH: yes

F3: and the second one was a bit different and

NH: yes

F3: you spent quite a bit of time wondering about what the difference meant

NH: yes

Whilst the above example shows NH trying to interpret the image, misinterpretations of images were reported by some participants. BT's comment about the same image suggested that he also tried, unsuccessfully, to interpret the red detail in the brain illustration.

BT: looks like a poppy

Here, both NH and BT attended to details in the images which distracted them from the intended meaning, and BT was distracted further by misinterpreting the image. The details in question were included by the graphic designer with the intention of assisting readers to

interpret the written information, but for these two individuals, the details were counter-productive.

In some cases, participants found it helpful to see extra detail in the images, as in the extract below. A line drawing of the concept 'your brain moves your arms and legs' included arrows drawn near the limbs to denote movement. In the extract below, RW's facilitator supported him to express an opinion he had previously made in an individual discussion.

F5: do you think they make it easier to understand movement with arrows?

RW: yeah

F5: is it the arrows that you liked?

RW: yeah - the arrows is - good

SE clarified that, for him, this detail helped to convey the sense of movement in the image.

SE: well - yes - it is the movement and everything there

Overall, participants demonstrated a preference for the image style which they felt best conveyed the meaning of the concept in the information materials. However, this was more complex than a choice between photographic and line drawing images, and further issues arose in discussion. These included different responses to representative or figurative styles and more abstract images. The presence of additional illustrative detail served to help some participants understand the images better, but distracted others, who struggled to make sense of the extra visual information, and some misinterpretations of images occurred.

7.4.2.2 *Interpreting image meaning*

This sub-theme reflects what participants said about how well or poorly the images conveyed their intended meaning. Comments included both positive and negative responses to this issue, the reasons for which were explored further in the discussions.

Participants agreed that the image needs to be right for the meaning, and they acknowledged that this is not always easy to achieve. The depiction of some concepts such as stroke and aphasia were discussed in the groups as presenting a challenge for illustration. In the extract below, the Group Leader raised the issue, responding to participants' comments regarding the materials showing that aphasia is different for different people.

GL: OK - so that's a difficult one isn't it - because it's very personal - look at the five of you and it's so different for each of you isn't it - but how do we get that across in a picture?

This issue was acknowledged, but left unresolved. It was summarised by NH, who said, in relation to the issue of picturing stroke:

NH: it's really a big question mark in there - a big question mark with stroke

Participants' contributions to the discussions provided interesting insights into the different aspects of the images which affected their interpretation. In some cases, the comments suggested that the images were ambiguous and this hindered participants' comprehension. For example, OS's response to photographic material showing an image of a human body with arms and legs extended, implied that she attributed to the image a connotation of fitness over and above the intended meaning of 'body'.

OS: I don't - yeah - well - it looks as though you're doing - just a keep fit there - to me - you know

Literal representations of concepts evoked differing responses, as the extract below shows. In a discussion about a card on which the verb 'control' was illustrated by an image of a remote control device, MM explained that the image was confusing to her, since it was unrelated to the sense of controlling one's body. SG clarified to her that the meaning was about 'control', but MM's response suggested that this still did not make sense to her.

F2: yeah - MM wants to say something about the remote control

MM: I don't know what's it doing there? [laughter]

SG: controls your body

MM: but that [pointing to remote control] don't - that don't do that for you - it's your brain

This discussion suggests that for MM, the literal meaning of the image distracted her from the overall meaning of the sentence. For SG, in contrast, the comprehension of the individual word was supported by an image, regardless of its literal meaning.

One aspect of the images which affected participants' interpretation was the context of the image in relation to the intended meaning. For example, participants discussed how best to illustrate the concept of blood in some of the materials. In one version, drops of blood were shown falling from a cut finger. In another version, blood was illustrated by showing vessels between the heart and the brain. RW expressed that, since the sentence was 'your brain needs blood', the cut finger illustration conveyed the wrong meaning.

RW: it's the blood of finger

BT defended this illustration, however, suggesting that this was a recognised way to illustrate the concept of blood.

BT: You couldn't put it any other place could you? - you couldn't put it on the toe or the arm - the finger is the most popular way

In addition, an exchange between BT and his facilitator revealed that the alternative image had not elicited the meaning of 'blood' to BT.

F2: the um - this one - of the brain and the heart ... it didn't really make you think of 'blood'

BT: no

F2: but when you looked at the finger with the blood dripping off it ...

BT: yes

F2: that made you think 'blood'

RW's comment suggests that the bleeding finger was a misleading image, because the context was not within the blood supply to the brain. For BT, the context was less important than a clear visual depiction of the word's meaning.

For MB, who has severe aphasia, the context of the image itself was important in helping her to understand the image, as shown in the following extract. When discussing materials showing line drawings of the brain (discussed in relation to their different styles, above) MB's facilitator reported to the group how MB found it easier to understand the image of a brain when it was presented in the context of a head, rather than in isolation.

F4: it helped you to understand it didn't it? whereas in the other one - where it's one - it's just sort of floating in the air - I think MB you said that you liked

MB: you what?

F4: you liked the brain being inside the head?

MB: them - yeah

When processing images showing people, some participants seemed more likely to relate images of people to themselves. For example, an image of a woman shrugging her shoulders with her hands outstretched illustrated a card which conveyed the concept 'most people have never heard of aphasia'. OS commented that she liked the image as it showed the value of gesture in communication. She confirmed, following a request for clarification from a facilitator, that she interpreted the image as showing herself, when unable to express herself verbally. She did not recognise that this was not the intended meaning of the image.

OS: I liked the one there 'cos it explains - your hands are tee - your hands are speaking for you

F2: OS can I just ask you then - what do you - how do you interpret that picture of the woman? Is that you thinking of something to say?

OS: yes - that's how I go - if I can't get the words out - I go [shrugs] and you - you know

In contrast, later in the same discussion, the Group Leader asked NH for his interpretation of this image. His response suggests a negative identification with the image of shrugging, which seemed to convey to him a lack of care on the part of the person pictured.

GL: what did it mean to you NH?

NH: it - so what - I've never heard of aphasic - so what?

GG indicated to his facilitator that a card showing an image of a woman after a stroke did not convey the right meaning for him, as the image was not sufficiently like him. This suggests that the image was too abstract for GG, who would find it easier to process an image which more closely resembled himself in the context of the information.

Overall, participants agreed that it is important for images to provide a clear representation of the concepts in information materials. They acknowledged that this can be difficult to achieve, particularly when the meaning of a concept may vary for individuals, for example 'stroke'. Aspects of the images which were seen to affect comprehension included the degree to which images were open to interpretation, whether participants were likely to be helped or distracted by literal interpretations, and, linked with this, the degree to which the image provided is suitable within the overall context of the topic. Finally, a tendency to see oneself in the image appeared to influence participants' ability to correctly interpret images. Some participants were more literal in their interpretation of images, leading to misunderstandings or distraction from the meaning. Others were able to override the literal meaning of the images, using them to support their interpretation of the information provided.

7.4.3 Sub-theme 3 Words and images together

The descriptive analysis of items indexed within the category of words and images together yielded extensive data. This sub-theme relates to the impact of selection and placement of words and images together on the accessibility of information. Two issues arose: the interaction between words and images and the impact of this on participants' understanding of the information, and the participants' preferences relating to the layout of the words and images.

7.4.3.1 *Words and images work together*

Participants commented on how their understanding of the information was influenced by the interaction between the text and images. Their observations show that, in general, text and images work together to convey meaning.

Participants agreed on the importance of an exact match between text and images. In a discussion about a card which showed the sentence 'your brain moves your arms and legs'

above a photographic image of a torso with extended arms, participants commented that the absence of legs caused them to respond negatively to this card. As the extract below shows, RW's facilitator supported him to report back to the group a comment that he had made in their paired discussion.

F5: so - what was it you said ... there were no legs?

RW: yeah

Similarly, EC explained why he rated the image poorly.

EC: yeah - no legs or owt

JB also pointed out that she found this same card inaccessible. In the following extract, JB's facilitator supported her initially unintelligible comment by referring back to their individual discussion, reporting what she said about the card when she first looked at it. In her final comment, JB indicated that the line drawing, which showed all limbs, was a better example of an illustration for the text.

JB: I think it's - it's very /ɛk/ - it's /ɛkə/ /kə/ - that throws it all off the page

GL: right - so that's the one with the photograph of the moving the arms

F2: it's only the arms - there's no toes is what you said - where are my toes?

JB: yes - it's - it should be more like that [pointing to line drawing showing arms and legs]

RP was the exception, commenting that the image was adequate for him to understand the information, and it was the overall photographic style which he found more accessible than the contrasting line drawing style.

RP: brilliant - and 'your brain moves your arms and legs' - yeah I think great - /prə/ - perhaps some legs down there but ... [laughter] - it's - whereas - incredibly simple

It is not suggested here that an imprecise match between word and image necessarily results in non-comprehension, but that some participants found it distracting and thus detrimental to their ease of processing. For example, EC responded negatively to an image of 'your brain listens to speech' because he thought the image did not convey the concept of listening to speech. In the discussion, he gave several interpretations of the image, and identified that it was "too vague". The extract below shows his response when the Group Leader summed up the issue that the images needed to match the words more closely. RW agreed initially, with EC developing his suggestion for a better image to match the text.

EC: same here ... /əm/ - better photograph ... speaking - you know - like an arrow across - might be better than that

EC understood the meaning of the words, and was able to infer the meaning of the image. His comment suggests that the image was a distraction rather than a barrier to understanding.

In the group discussions, participants made comments which showed that there was a variation in the extent to which they needed words and images to work together. RP commented that, since the meaning could be inferred from the image, the written words were not needed. In the extract below, he suggested that the image of a stethoscope to mark the meaning 'medical' rendered the sentence 'aphasia is a medical word' redundant.

RP: I would suggest that where it says aphasia is a medical word could go because it's obviously the doctor 'cos he's got that thing [pointing to stethoscope] - it says 'you have aphasia' so it means that doctor is saying 'you've got aphasia' that's straight

For a person with more severe processing difficulties, working out the implied meaning of the images without textual support may be more problematic. JB reported that for her, it is useful to have the written word to refer to, even if it is difficult to read. In the extract below, she expressed that she preferred to see both words and images together on the information so that she could relate the two to each other.

JB: and - and if definite things that - that - as separate and - and erm that - that what's helps out more and it doesn't - it gets it even more broken that way - but it was right that way

It is worth noting here that JB's access to information relies on having another person to talk it through with her. Thus, given her degree of aphasia, she acknowledged that she was unlikely to understand new information without support.

In summary, participants expected to see both words and images, and these needed to relate exactly to each other to convey the overall meaning. Whilst there were different preferences and abilities among individuals, the perceived match between text and images strongly influenced participants' understanding of the information.

7.4.3.2 *Number of images per concept*

Participants gave their views on information materials which showed either a single image per sentence, or separate images to illustrate each key word in the sentence (Appendix C). Most participants expressed a preference for a single image per sentence, the reasons for which are explored below.

One aspect of participants' preference for this layout appeared to be related to a perception that this required less processing. For example, EC expressed that the presentation of a single image was "simpler". This was followed up later in the discussion by the Group Leader, who asked participants to say more about this issue. In the extract below, EC had offered the opinion that providing separate images per key word was not simple.

EC: too much information

GL: too much information when you've got two pictures to worry about?

EC: yeah

Further evidence for this was provided by an exchange between SE and his facilitator, who reported their individual discussion to the group. In the extract below, SE expressed the opinion that there was less for him to have to attend to when processing a single sentence and image.

F5: and you said to me earlier - you liked the ones where it's all together because you didn't have to - think so hard

SE: /ə:/ ... I didn't have to learn anything

These extracts show that layout with one image appears to relate to the issue of amount of information presented at one time, as discussed in Theme 1.

Some participants, in contrast, expressed a consistent preference for the provision of a separate image for each key word. In the extract below, RP identified that an image placed underneath the first key word helped him to orientate to the topic. In contrast, he reported that he found the single sentence difficult to comprehend.

RP: I got the three that are broken down because to me the words is much much better - your brain - see the picture - know what I'm talking about - produces your speech - fantastic - this one - just explained to - [name of facilitator] that the next bit was sort of five letters - your brain makes your speech - doesn't go in

The data revealed differences between participants. Most perceived that a single short sentence, accompanied by a single image, was easier to understand. For a small number of participants however, there was a consistent preference for information with separate images for each key word in the sentence, and this applied where the image was either a direct match for the meaning of the word, or a more distant representation of the word, as in the discussion described above in Section 7.5.3.1, relating to the remote control image.

7.4.4 Presentation of Talking Mats® data

7.4.4.1 Number of images per concept

Template 1 materials, which varied in the number of images per concept, were presented for review by participants. On three cards, the information was presented with a single sentence above a single image. On a further three cards, the sentence was separated out with space between each of two or three key concepts. Separate images to represent each key concept, were presented below the sentence. All fourteen participants rated each card.

The data show that the single image style received the largest number of highly favourable ratings, and was rated very poorly only once. In contrast, the multiple image style was rated across all points of the scale, with the highest number responses at the mid-point. Although ratings of individual cards showed some variation, participants tended to respond consistently in this task, with most participants rating the single image style highly and a smaller group consistently rating the multiple image style more highly. Table 7.10 shows the ratings by frequency.

Table 7.7.10 Frequency of ratings for single or multiple images per concept

	😊✓✓	✓	? 😐	✗	✗✗ 😞	
Single image per sentence						Total participants
Card 1	8	0	4	2	0	14
Card 2	7	1	3	3	0	14
Card 3	10	1	1	1	1	14
Image per key word in sentence						
Card 1	3	2	5	2	2	14
Card 2	4	2	4	2	2	14
Card 3	2	3	4	2	3	14

7.4.5 Summary of Theme 3

This theme brings together all data relating to participants' understanding of the information presented to them during the focus groups.

Overall, participants indicated that they expected to see written words in the materials, even though individual reading ability varied widely. The analysis links with the findings of Themes 1

and 2, suggesting that reading was facilitated by visual presentation, including increased font size, large and bold emphasis of key words, and consistent layout.

The impact of different image styles on participants' perceived comprehension was found to be more complex than a straight choice between two types of image. Variation was found in their preferences for figurative versus representational line drawings, and in their ability to process additional detail or abstract images.

Although participants agreed that images should correctly represent concepts, they varied in their opinions on how best this could be achieved. For some participants, this was complicated by their tendency to process visual information literally. A key issue for some was whether the image was correct in the context of the meaning of the information presented; others seemed to use the images to support their reading more directly, whether their context was congruent or not.

Different processing abilities and approaches, along with varied preferences for image style, contributed to individual responses to the images presented. Whilst the variety of responses makes it difficult to draw conclusions, the breadth of discussion in this theme highlights the complexity of this issue for information design.

Finally, the interaction between text and images was an important element for all participants, a finding which emerged spontaneously in the focus group discussions. To varying degrees, participants expressed that their processing was either distracted or disabled by images which did not exactly match the text. Only one participant expressed that a precise match was not necessary to support his reading.

Alongside this, both discussions and ratings of the provision of single or multiple images per concept showed that most participants favoured the style in which a single image was placed below a short sentence. A smaller group consistently selected the style in which two or three separate images representing the key words were placed below spaced-out text.

The individual ways in which participants responded to the materials is described in the final, overarching theme, 'Everyone's different'.

7.5 Theme 4 - Everyone's different

This theme captures the different responses and individuality of the participants who brought their own life experience, as well as their own experience of stroke and aphasia, to the discussions. The acknowledgement that 'everyone's different' was frequently expressed in all the groups, by both participants and facilitators.

The data contributing to this theme are from group discussions in all three groups across both sets of focus group meetings. The materials discussed include Template 1 and Template 2. All participants contributed in some way, although the amount differed across groups and within groups. Three separate sub-themes were identified in the data, representing individual experience of stroke and aphasia, individual responses, and individual visual style.

7.5.1 Sub-theme 1 Experience of stroke and aphasia

The shared experience of stroke and aphasia was the common point of reference for the participants in the focus groups. When looking at the materials, participants drew on their own experiences, both of early days in hospital, and the continuing challenges of living with aphasia.

During the course of the discussions, there was an expressed acknowledgment that stroke is different for everyone, including how people are affected by stroke, the experiences they have, and the recovery they make. Almost all participants commented on their stroke recovery, both in relation to their ability to deal with information, and in a more general sense.

7.5.1.1 *Knowledge of aphasia*

Whilst there was recognition amongst group members that aphasia is different for individuals, there was a shared understanding of the concept of aphasia. This discussion was largely generated in response to the set of cards about aphasia, in which participants agreed with facts, identified with the information, or expressed opinions about how the information was depicted.

Participants agreed that information must be accurate, reflecting individuals' own experiences, and fitting with their broader knowledge about stroke and aphasia. This was most evident when discussing information about recovery, which was a common but different experience for everyone. One discussion centred on the timescale of recovery shown on one card. The sentence 'aphasia can get better over time' was illustrated by a line drawing of a person in triplicate. Each of these images was accompanied by an image of a calendar page showing three different dates from the months of February, July, and October, and a speech bubble showing the word 'hello', in which the font was initially very fragmented and, in the final image, perfectly formed (Appendix D). Participants in all focus groups indicated that this was inaccurate, and as EC's comment below suggested, potentially misleading to readers.

EC: it takes years for you to get better - but that looks like it's a month

Participants also agreed that the depiction of recovery from stroke had to represent realistically that people rarely recover completely from aphasia. In the extract below, the facilitator reported back to the group on behalf of GG, a man with no expressive language. The facilitator described his nonverbal response to the card described above, in which he expressed that a representation of complete recovery was incorrect. The facilitator's report of GG putting his hand over the perfectly formed font in the final image communicated clearly that this did not represent GG's experience of aphasia recovery.

F2: can GG and I say about - when you looked at card number 8 - you very clearly put your hand over the final one

RP, in the extract below, commented that the timescale for recovery should be represented in years not months, and that the image should show an incomplete recovery which, to him, conveyed the possibility of further recovery over a longer time.

RP: what about if - February to October you're doing incredibly well to get better in that time ... I would say year one - year two - year three ... and it shows it carrying on

BT expressed a preoccupation with the word 'aphasia' and its meaning, remembering that he had not encountered it before his own stroke, and then did not hear the word until he had been in hospital for several weeks. He talked about the importance of knowing the word aphasia for himself, and for others to know it as well, for there to be greater public awareness of aphasia.

BT: people don't know what aphasia is

Whilst all participants had personal experience of stroke and aphasia, two participants also drew on previous professional experience in healthcare in their interpretation and opinions of the information. For example, in the extract below, OS was responding to the Group Leader asking if the red mark on the image of the brain conveyed the idea of a stroke to her.

OS: no - because I'm a medical person - that doesn't say it to me - I know different things from them

Participants' expectations of information about stroke and aphasia were guided largely by their own experiences and by those of others with aphasia whom they had met since their stroke. They were intolerant of information content which they felt did not reflect this knowledge, and made suggestions for improvements in accuracy.

7.5.1.2 *Aphasia is individual*

The recognition that the experience of aphasia is different for everyone was a recurring theme in discussions. Language processing difficulties, including reading, understanding, and word finding, were described by individuals during the group discussions. These were all mentioned as factors in their everyday lives, including their interaction with information. For example, OS described her difficulty in finding the words:

OS: it's getting the words round

Participants also recognised other sensory and cognitive problems, such as visual processing difficulties, difficulties dealing with numbers, and poor memory. For example, in the extract below, JB described how she was aware that she could not always remember what she had read, even if she felt she had understood it at the time of reading.

JB: I can read it and I'm reading it well - but when I shut it up it's gone - and I can't get it back - maybe I can bring it back - but I can't always be sure

In the discussion, participants talked about the realities of having aphasia, sharing the different feelings such as depression, embarrassment, and the loss of confidence they had experienced. They talked about their recovery, comparing their experiences, both acutely after stroke and in their current lives. In the extract below, RW reflected that, ten years after his stroke, he still found it difficult to speak.

RW: I - ten years ago I had a stroke ... I can't - I can't ... speech is - years - ten years ... yeah

Participants also shared a sense of acceptance of aphasia as part of their lives. For example, BT expressed an acceptance of his aphasia and physical limitations.

BT: I don't think I've altered in my speech since the first month in hospital - walking about - I got a little bit better - I'm going downhill now [laughs] - well I don't try now

The concept of hope emerged in discussions and participants expressed a desire that information should be positive in tone, conveying a sense of hope to people new to the experience of aphasia. In a discussion about aphasia recovery, MM drew on her own experience in response to the facilitator asking her if she felt that the template materials conveyed hope for recovery. Her words suggest that she was reflecting back on her experience, and perhaps reappraising her progress, referring to a recent interaction in which her sister had commented that her speech was still improving.

MM: I do - yeah - if you couldn't talk before - like us ... I said you've done well - even my sister too - yesterday - you've been really good - you know - for some time

Overall, this issue reflects that whilst aphasia is different for individuals, participants identified with each other's experiences of aphasia as a group. The shared feelings and experiences in the discussion highlighted the value of informing people about aphasia in a realistic but positive way. Individuals' responses to the information content also demonstrated that the materials functioned as a resource for talking about the experience of aphasia, assisting some participants to reflect on and talk about their own experiences.

7.5.2 Sub-theme 2 Individual responses

In this sub-theme, the data reflects the variety of ways in which participants responded to the materials. This is less about accuracy of information and more about the individuals' responses to the materials.

Two issues informed this sub-theme: firstly, some participants' identification to varying degrees, with the words and images in the materials. The second issue relates to the strength of reaction among some individuals to the materials.

7.5.2.1 *Identifying with the information*

Sometimes, participants showed that they identified personally with the information on the cards. In the extract below, OS commented that she liked the card which showed the concept of reading and writing because this is something that she still liked to do, despite it being difficult for her now.

OS: I like reading and writing - I thought the reading - the person was quite happy 'cos he he looked to me as happy because he's reading the book and the writing you know /ə:/ you try and write so you put it down on paper and pen - which I do try

F1: you do try - so that's still part of your life

OS: that's part of my life

In a similar way, OS also expressed a positive response to a card which conveyed the concept of listening by depicting an interaction between two people. She commented that for her, language is about communicating with others, and that this is an important part of her life.

OS: it's nice to speak to someone isn't it

For some, there was a sense that the information had to convey the world as they see and understand it. This was most evident in discussions about how to depict language and

communication. TM expressed that, for her, the meaning of listening was only conveyed where a two-way interaction was shown, with both a speaker and a listener.

TM: well - because you listen as well what the other one saying

Similarly, in the following extract, JB described that an image to convey the concept of understanding language corresponded with her view of how understanding works in real communication exchanges, with both a speaker and a listener depicted. For her, the interaction shows the listener, the “aim person”, and the speaker “the one”, with the speech moving between them “it bubbles in”.

JB: noticing that - had this because - because I feel that's - there you've got the aim person - there you've got the one - and you've got that there - this one - and it bubbles it in

Participants varied in the extent to which they identified personally with the materials. In the example below, MB appeared to be integrating the information with her own experience and that of others in the group.

MB: it must be something like that that's done what we are now - what's happened to us

As discussed above, this phenomenon was most marked for GG, a man with global aphasia, who expressed nonverbally that the information needed to be ‘about me’ in order for him to be able to regard it as relevant. A close personal interpretation of the materials resulted at times, however, in participants misunderstanding the intended meaning of the images, as discussed in relation to Theme 3 in Section 7.5.2.2.

The data presented in this section demonstrate how the materials resonated to varying degrees with the participants. Some identified closely with the images and words, almost appearing to see themselves in the information. These individuals valued a portrayal of concepts which closely matched their perceptions. Others needed a stronger personal representation in the materials in order to identify it to themselves. This issue links closely with the issue of interpreting picture meaning in Theme 3, but highlights the degree of variation between individuals.

7.5.2.2 *Emotional reactions to the materials*

On some occasions during the focus groups, participants reacted with emotion to the materials or the topic under discussion. The researcher identified this issue within this sub-theme, since the responses were individual to different participants. In addition, it was considered

noteworthy in the context of health information, which may be intended to be factual and unemotional.

In a discussion comparing different image styles, described in Theme 2 above, NH expressed a strong dislike of one photograph. In the extract below, his response demonstrates his strength of feeling, which resulted in his overall poor rating of the photographic images.

NH: and when number three came along - I couldn't stand that one

SG articulated her negative reaction to the same image. Although she was unable to find the words to explain exactly why, this appeared to be related to the way in which the concept was depicted, by a photograph of a man cupping his ear in an exaggerated pose.

SG: made me be stupid - yeah - angry

In a discussion about the number of concepts conveyed at one time, RP recounted his involvement with a previous research project which involved using the internet. He expressed his irritation at the design of webpages, which displayed large numbers of different elements simultaneously. He acknowledged that this is different for different people, but for him, that this was a barrier to accessing web-based information.

RP: far too many things - millions - and it just - get annoying - but that's me I just - it's whether some people can read some people can't - some people can look - different basically

The above examples demonstrate that information about stroke and aphasia is not an emotionally neutral topic, and that the format of information impacts on individuals personally. Emotional responses were seen to hinder individuals' access to information. For example, when participants perceived that materials were presented with insufficient sensitivity to the challenges of aphasia, they were more likely to disengage from the information. This issue underlines the significance of aphasia as a life-changing experience, and highlights the need for information materials to be designed with awareness of the impact aphasia has on people.

7.5.3 Sub-theme 3 Individual visual style

In the same way that the data showed how individuals responded differently to the format and content of the information, so it emerged that participants approached information with varying visual styles. The first issue reflects the differences in how people approach looking at information independently. A second issue relates to the fact that some participants benefit from support when making sense of information.

7.5.3.1 *Looking at information*

Participants made comments about how they approached the information. It emerged that whilst many start reading information at the top left and work downwards, this did not apply to all, and different styles were revealed. In one discussion about the layout of Template 1, the Group Leader attended to RP's comment about the amount of information presented together on the internet, and asked whether the information in the template format was easier to manage.

GL: coming back to your point RP about internet and things - all over the place - with taking this in you've got to go brain-sentence-picture-hello - so it's going down and going across - did that work as a kind of following it through logically taking each piece of information in?

Two participants agreed with this description immediately, and following a discussion, most participants identified with the facilitator's description of a step-by-step approach to understanding the words and images. This was summed up by SE, who expressed that he found it helpful to process each element of the information in turn.

SE: read that and then you - can move down - settle in your head

NH agreed with this approach in principle, but qualified this with a comment that he may restrict his focus to the top of the card. In the extract below, he appeared to acknowledge that whilst he was able to read the first part of the information, he could no longer process a larger amount of writing, and wanted the key written information to be presented first.

NH: I start at the top - and if it - down at the bottom - and if it was down at the bottom - I wouldn't bother about it - it's up there where it the brain says hello

Following on from these discussions, participants were asked whether they looked at the words or the images first when engaging with information. They differed in their responses, with some expressing that they wanted to see the image first, whilst others read the header sentence first, and then worked downwards towards the image. When discussing approaches to looking at the cards, most participants agreed that the header sentence helped them to understand the information. One participant's comment, however, suggested that he disregarded the header and focused his attention on the sentence and image only, as captured in the extract below.

BT: yes but I wasn't looking at the title

Another difference emerged during the discussion, when a facilitator asked whether participants were looking at the whole template or at the separate elements. JB replied that she preferred to look at the text and images together.

JB: no - I put them all together - I can manage that together - but I can't get much more than that

This preference for a single view of the information meant that, if two different images were presented, she found it difficult to see the link between them, as in the example below. This comment relates to the photographic style, in which the information content was conveyed using two separate images.

JB: I don't see what that [pointing to first image] has got to do with that [pointing to second image]

In a later discussion, JB acknowledged that although she has looked at the whole card, she has not fully perceived or understood it.

F2: you didn't look at that bit

JB: no I just - I looked at it but I couldn't see it

Speed of approaching information emerged as an issue for BT, who identified that he scanned too quickly from one element of the information to the next. He found that he was helped by the presentation of one piece of information at a time, as a strategy to slow down his quick visual scanning.

BT: my trouble is I start reading I see - I go brain oh yeah - I - I - before I've - before my brain has absorbed that information - I'm on this one - that's the reason one card's better because I didn't read properly

Here, individual ways of looking at the information were described by participants, perhaps reflecting previous styles of engaging with information. Overall, discussions revealed differences in how individuals approached the materials. Whilst most identified with the description of reading from the top left of the page, working downwards, some variation emerged. Rather than looking at each element in turn, some participants attempted to process the words and images as a single unit and others processed only part of the content presented.

7.5.3.2 *Making sense with support*

In the focus groups, discussions centred on factors which contribute to independent access to information for people with aphasia. Alongside this, when looking at the set of cards about stroke and aphasia, some participants raised the issue of support in accessing information.

In the extract below, RP explained that the set of cards could be used for talking through information with a family member, and this was particularly important in the early stages after a stroke.

RP: whereas I mean if you've got someone with you - you know family or whatever you can just you know - one at a time go through it all I think particularly the end of when you have your stroke

He identified the role of families in filtering information to people with aphasia, recalling that he had been unable to take on new information during this time, as reported in the extract below.

RP: it's a blank - the first six months is a blank

For those with more severe language impairment, the enduring difficulty of making sense of information independently was articulated by JB. In the extract below she described how difficult it was for her to understand information fully on her own. The second part of her turn suggested that she was likely to misunderstand an element of the information, and then lose the full sense of it, with her understanding "a further difference", that is, more distant from the original meaning.

JB: maybe if it was that I didn't know what it was what it what when it was there at the time I was being told something now I look back and I know what this is either because I got the other side of it so it's got into a further difference for me

She then agreed with her facilitator's explanation of their collaborative approach to the materials. F2 identified that she had read the information aloud to JB, and they then related this to JB's own experience to ensure that it made sense to her personally.

F2: we talked about each one of them didn't we and that was good wasn't it - so one at a time I kind of read it to you and we talked about it - and then you linked it with your experience
JB: yes when I couldn't do it and when I didn't - yes I can see it

This section reports data showing that some participants needed support to access information, despite being designed to be maximally accessible. This was identified as a likely

need in the acute stages after stroke, and also needs to be considered for some people in the long term.

7.5.4 Summary of Theme 4

The data analysed within this theme relate to individuality, capturing differences in participants' responses to, and interaction with, the form and content of the materials. Despite varied experiences of aphasia, there was agreement on the importance of providing accurate and realistic but encouraging information about aphasia. This was found to be important for both accuracy of information, and to allow people to identify with the information, using it as a resource to tell others about their personal experience.

Participants varied in the degree to which they identified closely with the information. Whilst most participants related the information to their own situation, others needed the images to be a clearer mirror of them personally for them to feel meaningful. The emotional reactions displayed in response to the materials underlines the impact of aphasia on individuals, and the need for sensitivity when designing information for this population.

Finally, participants varied in their visual approach to information. When reading independently, participants varied in where they looked, how much they looked at, and how quickly they attempted to process the information. It emerged also that for some participants, independent access was not possible. For some, this related to the experience of acute stage aphasia; for others, this was highlighted as an enduring difficulty, with ongoing support needs identified.

In sum, the individuals and their differences interact with the other three themes, affecting their visual access, what they judge to be appropriate or acceptable, and their understanding of the information materials.

7.6 Chapter summary

This chapter has presented the development of the thematic framework and the results of the analysis of the data within this framework, showing the four overarching themes which reflect how individuals responded to the materials in focus group discussions. This qualitative analysis adds insights to the Talking Mats® data, revealing links and interactions between the themes. In the next chapter, the results of the iterative design process will be outlined.

Chapter 8 Outcomes of Phase 2 and design of Template 3

In the previous chapter, the analysis of qualitative and ratings data was presented in a thematic framework reflecting the concerns and opinions of the participants. In this chapter, the key points requiring feedback to the graphic designer are summarised to show how aspects of the template were changed in response to user feedback.

8.1 Results of focus groups: feedback to graphic designer

As introduced in Section 1.5, this study followed an iterative, collaborative design process. In Phase 1, the initial prototype, Template 1, was devised using the findings of three literature reviews into the impact on people with aphasia of the implementation of features of accessible formatting, language processing in aphasia, and health information topics required by people with aphasia.

In Phase 2, participants with aphasia reviewed the prototype templates over two separate focus group meetings. Following the first focus group meetings, the researcher compiled feedback for the graphic designer, the results of which were incorporated into the second version of the prototype, Template 2. These materials were then reviewed by participants in the second focus group meetings, after which the researcher again provided feedback to the graphic designer. The resulting final Template 3 was then produced, incorporating all the feedback from the focus groups.

8.1.1 First iteration

The main issues discussed in the first focus groups concerned variations in typography, image style, and number of images per concept. Overall, comments about the design included that participants valued the adult style in which the information was presented, and found the materials acceptable and pleasing. Few comments were made about the language in Template 1, but most participants found the use of a single word heading helpful, and the written content acceptable. The points raised in the first groups were summarised as follows:

- **Typography:** the largest appropriate font size relative to page size was welcomed, although participants cautioned against a too large font. A sans serif font style appeared slightly more popular than serif font. Participants favoured both large and bold fonts for emphasis.

- Images: clarity of meaning was of primary importance to participants. The selection of images demanded sensitivity to the experience of aphasia, and required increased consideration of possible misperceptions and negative connotations conveyed by images. Images needed to be completely coherent with text. Participants advised consideration of how to add meaning to images, via detail such as arrows to convey movement, for example. Some participants found that personally relevant images were helpful.
- Layout: a limited amount of information per page was perceived as helpful. The layout of Template 1 helped to focus people's attention, and participants responded positively to the use of a header sentence, as well as a concept sentence, above an image. Most preferred a style of layout in which the sentence was illustrated by a single image, but some participants consistently preferred sentences which provided separate images for each key word or concept. Consistency of design, layout, image style, and representations of key concepts was considered important. Use of colour was considered helpful, although some people did not notice it initially. Participants agreed that visual appeal was important in promoting engagement with materials.

8.1.2 Second iteration

The designer incorporated this feedback, applying changes to the prototype, to produce Template 2. Specific and new issues arising from the discussions in the second focus groups were then summarised and reported back to the graphic designer to inform changes to Template 2.

The second focus group meetings established that participants welcomed the concept of a set of cards as a means of presenting a sequence of single-information concepts. Discussions also concerned the amount of information per page and further details about emphasis in font. The review of Template 2 materials provided specific feedback to the designer, as follows:

- Language: participants advised specific changes to language; for example, the phrase 'Most people have never heard of aphasia' was changed to 'Most people don't know about aphasia' to make it more concrete in meaning.
- Amount of information per page: a key finding from the second focus groups was the almost unanimous preference for the presentation of one single concept at a time.

- **Typography:** further exploration of font size and emphasis concluded that participants found key words which were emphasised with a combination of larger and bold font more helpful than those with either bold or large font in isolation.
- **Images:** participants emphasised that images needed to depict positive but realistic information, for example reflecting realistic timescales for recovery. Details within images were sometimes distracting; the graphic designer was advised to simplify illustrations as much as possible, and to be aware of the distracting nature of extraneous details. Some types of image were considered difficult to understand, such as abstract graphic images. Participants advised using more obviously recognisable images relating to concrete nouns.

8.2 The final template

Following the feedback, the designer produced the final template. A checklist containing the criteria for the final template was developed, incorporating all participant feedback, and is presented in Table 8.1 below.

The two iterations described resulted in the final version of a template for accessible information. Template 3 functions as a design template for the production of information for people with aphasia. Its design incorporates key principles for accessible information, derived from the analysis of focus group data.

Table.8.1 Final checklist of template design criteria

Language
Banner headings to be single words or short phrases to orient to the topic.
Vocabulary to be short, highest frequency, familiar words.
Sentences to be short, and in canonical forms.
Proforms to be avoided, and, where possible, replaced with content words.
Content words to be repeated within sets of related concepts
Flesch Kincaid readability software to be used to monitor reading grades, ensuring RG5 or lower.
Typography
Banner headings to be printed in Vectora Black in 24pt.
Sentences to be printed in Vectora Roman 18pt in black.
Keywords to be emphasised using bold and font two pt sizes larger than surrounding text.
Images
Each sentence to be accompanied by one or two images to illustrate the meaning clearly.
Images to be professionally-produced line drawings or photographs, suitable for adults.
Images to be fully coherent with the text.
Images to be consistent in style, and to depict concepts in the same way throughout.
Images to depict realistic expectations of recovery.
Images to be sensitive to the experience of stroke.
Images to depict realistic experiences of stroke.
Images to be unambiguous, with attention paid to possible visual misperceptions.
Layout
A white space measuring 170mm by 110mm to contain the content.
White background to the overall space.
Coloured banner with heading text printed in bold black reversed into white and aligned to the left side.
Single sentence below the banner to convey information content, printed in black and aligned to the left side.
One or two images placed centrally, below the sentence.
Borders to separate areas of text and related images.
Consistent use of colour in headings and images within specific topics.

8.3 Chapter summary

This chapter has outlined the iterative design process, in which the participants' feedback was relayed to the graphic design team after the first and second focus group meetings. This took account of both immediate feedback and the results of the data analysis, and thus represents the full collaboration of people with aphasia in the design process.

The following chapter outlines Phase 3 of this study, involving the development of guidelines for making information accessible derived from the template principles, and the user-testing and further refinement of these guidelines.

Chapter 9 Phase three: Development of accessible information guidelines

9.1 Introduction

As identified in Chapter 1, prior to this research no published guidelines previously existed which were evidence-based, user-tested, and made available to clinicians, researchers, and others who produce information for people with aphasia. Chapter 1 highlighted the tensions between national guidelines for Stroke which suggest that information should be accessible to all, and the lack of published guidelines to support such provision. Phase 3 of this study aimed to use the template generated in Phases 1 and 2 to develop such guidelines to enable others outside of this project to integrate the knowledge gained during this project into the production of their own materials.

In this chapter, the process for developing the guidelines from the template, and the subsequent user-testing of these guidelines is outlined.

9.2 Development of the draft guidelines

Phases 1 and 2 of this study resulted in the final version of a template for accessible information. Its design incorporates key principles, summarised in Table 8.1. In this section, the process by which these principles were extracted and organised into a set of draft guidelines for accessible information for people with aphasia is outlined.

9.2.1 Aims

The aim of this phase of the study was to develop concise, practical, and accessible written guidelines which could be used by any health professional, researcher, family member or others working with people with aphasia producing new information materials. Objectives set by the research team in pursuit of this aim included:

- To convey the principles of the final template through clear explanation and modelling of the template criteria.
- To promote a practical approach to enable guideline users to produce accessible information materials.
- To user test the draft guidelines with stroke healthcare professionals.

- To derive the final version of the guidelines incorporating the feedback from the user-testing.

9.2.2 Methods for translating the template criteria into guidelines

A collaborative approach within the research team was taken in the development of the draft guidelines. All members of the team contributed, and consensus on the final draft guidelines was reached through a process of discussion.

In line with the aims and objectives, the research team firstly discussed possible methods for communicating the template design criteria. It was agreed that the criteria should be translated into a series of steps which individuals could follow. It was acknowledged that the criteria, as presented in Table 8.1 do not follow on from each other in a sequence. The guidelines however, aimed to provide a practical method, and therefore required translation into logical, active steps which would reflect the order of work an individual might undertake when producing accessible information.

For each of the design criteria, the research team agreed that the presentation of examples of good practice would support users. Hence for aspects of language, typography, images, and layout, examples were provided throughout the guideline.

It was also agreed that, as far as possible, the formatting of the guideline document should use the template principles. It was reasoned that this approach would perform a dual function, in that it would ensure that the guidelines are accessible and easy to use by a range of different users. Such a presentation style would also provide users of the guidelines with a model of good practice.

The following section will outline the five steps which the research team proposed for the draft guideline, and will indicate how the template criteria are incorporated into these steps.

9.2.2.1 *Development of the five step approach*

Step 1 A short message

The principles of the template which are summarised in Table 8.1 stand on the assumption that the information content to be conveyed has already been agreed. Step 1 therefore concerns the development of the information content to be conveyed.

A key aspect of the template is the presentation of single concepts, which is based on the need for people with aphasia to be faced with one proposition only at one time (see e.g. Caplan et al., 2007). This step directs users to be aware of how many separate concepts may be inadvertently included in their information content. To ensure that the guidelines themselves were accessible to users, the research team agreed to use the term “message” rather than “concept”, since this was considered to be more likely to be understood by all users.

The identification of single concepts within an overall larger set of concepts, leads users towards developing sets of sentences which might be used to explain the various concepts. The research team agreed that the development of sentences should therefore form the next logical step when producing information materials.

Step 2 Simple sentences

The research team agreed that the guidelines should provide clear specification regarding accessible sentence forms, and that these should be explained in lay terms to ensure access to all users. For example, lay users were not expected to understand the term “canonical” in relation to sentence forms. The principle of avoiding passive, compound, and complex sentence forms was therefore addressed by providing examples of each of these sentence forms. In each case, examples of the best practice version were also provided, such as active rather than passive sentences. For compound and complex sentences, examples were provided of how to simplify these sentences, or to separate them into two short sentences. Similarly, the issue of avoiding proforms was explained by the provision of examples of pronouns and examples of sentences showing how they can be avoided. The table below shows how the template criteria were translated into the content for the guideline. The template design criteria are presented in the left hand column, with the content for the draft guideline shown in the right hand column.

Table 9.1 Template criteria to guideline – sentences

Template design criteria	Draft guideline content
Language	Make your sentence simple Think about your sentence Simple sentences work best Check the sentence
Sentences to be short, and in canonical forms.	
Proforms to be avoided, and, where possible, replaced with content words.	

In the draft guidelines, information about the Flesch-Kincaid readability software was provided within this step, since the research team reasoned that this would be a convenient means of checking the complexity of sentences for users as they worked their way through the steps.

Step 3 Easy words

The research team agreed that the guidelines should prompt users to consider vocabulary choices at an early stage in developing information materials. As with the sentence criteria, users were not expected to have knowledge of terms such as “high frequency” in relation to vocabulary, therefore these criteria are translated into vocabulary considered more accessible to lay users, and examples of “easier” and “harder” words provided, both as single words and within sentences. The table below shows how the template criteria were translated into the content for the guideline.

Table 9.2 Template criteria to guideline – vocabulary

Template design criteria	Draft guideline content
Language Vocabulary to be short, highest frequency, familiar words.	Choose your words carefully Choose words people use often Choose words most people use

Step 4 Good layout

The research team considered that following steps 1 to 3 would result in users producing a set of related written sentences. The next step is to start to prepare the frame within which the sentences would be presented: this stage would direct users to start to produce information within a document. The step therefore draws on criteria specified within the areas of layout, typography, and images, as shown in the table below. The table below shows how the template criteria were translated into the content for the guidelines.

Note that the template criteria for images that relate specifically to stroke recovery, such as “Images to depict realistic expectations of recovery” were not carried through into the guidelines, due to the wider scope of application of the guidelines beyond just this one topic.

Table 9.3 Template criteria to guideline - layout, typography, images

Template design criteria	Draft guideline content
<p>Layout</p> <p>A white space measuring 170mm by 110mm to contain the content.</p> <p>White background to the overall space.</p>	<p>Space</p> <p>Postcard size is good</p> <p>Half of A4 is good</p> <p>A5 is good</p> <p>Make a border around this space</p> <p>Choose a border you like</p>
<p>Typography</p> <p>Sentences to be printed in Vectora Roman 18pt in black.</p> <p>Keywords to be emphasised using bold and font two pt sizes larger than surrounding text.</p>	<p>Typing</p> <p>Type the sentence top left</p> <p>Font size 14 – 18</p> <p>Use sans serif font Arial or Calibri</p> <p>Make important information bold</p> <p>Make important information two font sizes bigger</p>
<p>Images</p> <p>Each sentence to be accompanied by one or two images to illustrate the meaning clearly.</p> <p>Images to be professionally-produced line drawings or photographs, suitable for adults.</p> <p>Images to be consistent in style, and to depict concepts in the same way throughout.</p>	<p>Pictures</p> <p>Choose one or two pictures</p> <p>Use pictures that match the important information</p> <p>Choose good quality pictures</p> <p>Use line drawings or photos</p> <p>Pictures made for adults work best</p> <p>Colour can add meaning</p>
<p>Layout</p> <p>One or two images placed centrally, below the sentence</p> <p>Images</p> <p>Images to be fully coherent with the text.</p>	<p>Writing and pictures</p> <p>Put the picture under the sentence</p> <p>Check the pictures match the important information exactly</p>
<p>Layout</p> <p>White background to the overall space.</p> <p>Consistent use of colour used in headings and images within specific topics.</p> <p>Typography</p> <p>Sentences to be printed in black</p>	<p>Colour</p> <p>Use white paper</p> <p>Use dark writing</p> <p>Use colour in pictures to help</p>

Step 5 Make a set

This step directs users beyond the single template when producing a set of information on one topic. It directs users to return to Step 1, and to select a second concept, or message, instantiated in their second sentence, to repeat the design process with. The research team agreed that this step would support a methodical approach to developing information, which would assist users to comply with the recommendations.

The design criteria of consistency and repetition are emphasised in this step. The table below shows how the template criteria were translated into the content for the guideline.

Table 9.4 Template criteria to guideline - making a set

Template design criteria	Draft guideline content
Consistency Emphasised throughout across language, typography, images and layout of design template.	Keep it the same Use the same layout for each message Use the same style of writing Use the same type of pictures
Language Content words to be repeated within sets of related concepts	Repetition helps Repetition helps people with aphasia Your sentences can be similar Important words can be repeated
Layout Borders to separate areas of text and related images Consistent use of colour used in headings and images within specific topics	Clear sets Use one border colour for all messages in one set Or use one writing colour for all messages in one set

9.2.3 Production of the draft guidelines

Using the content identified in tables 9.1 to 9.4 above, the draft guidelines were subsequently produced as a 19 page document, printed on white A4 paper. They included a brief introduction, and the five steps described above, including the examples and checklists. The body of the text was printed in Calibri 14pt font, with font sizes 16pt and 20pt for the subheadings and main headings respectively. Images were selected from copyright free internet resources and printed in colour. As stated, the principles of the template that governed the design, outlined in Table 8.1, were used to develop the guideline document itself to maximise accessibility and to demonstrate the principles in the context of an authentic information booklet.

9.3 User-testing of the draft guidelines

9.3.1 Introduction

As previously discussed in Phase 2 of the study, user-testing is essential to ensuring that novel products are required, accessible and usable, as judged by their target users. In this context, potential users of accessible information guidelines were identified as any person working with people with aphasia. A user-testing study was therefore identified as a suitable means of gathering data on potential users' responses to the guidelines.

The data gathered were analysed qualitatively to develop an understanding of the responses of the participants. Secondly, feedback informed the research team regarding specific changes required to the content and design of the guidelines. In this section, the methods and results of the user-testing study are outlined.

9.3.2 Methods

9.3.2.1 *Participants*

Sampling for this phase of the study was opportunistic. Participants were sought who worked routinely with adults with aphasia at any stage after a stroke and who produced information for people with aphasia as part of their professional role. Two groups were identified for this preliminary user-testing: speech and language therapists and staff employed in a national UK voluntary sector organisation.

9.3.2.2 *Recruitment*

Potential participants were approached in two ways. Speech and language therapists were contacted via local professional networks and voluntary sector staff were contacted nationally via their regional coordinators. Initial interest in the project was sought via an email with the project information sheet attached. Those people with an interest in the study were invited to respond to the research team by email. Nine speech and language therapists and fourteen voluntary staff expressed an interest in the project.

9.3.2.3 *Ethics and Consent*

Ethical approval for the study was granted by the Department of Human Communication Sciences at the University of Sheffield.

Staff who responded by email expressing their interest in the project were sent a consent form by Royal Mail. They were asked to complete this and return it to the researcher.

Using this strategy, seven speech and language therapists and eleven voluntary sector staff gave their written consent to participate.

9.3.2.4 *Study design*

Staff who responded by email expressing their interest in the project were sent a copy of the draft guidelines together with the consent form by Royal Mail.

A survey was selected as the most appropriate design for the purpose of collecting user feedback on the draft guidelines. The research team reasoned that participants would be able to respond at their convenience, having had the opportunity to read and use the guidelines within their own work settings. It was anticipated that the data would accurately reflect participants' individual responses to the guidelines.

9.3.2.5 *Materials*

The materials for this phase of the study included the draft guidelines described in Section 9.2 above and a ten-item survey (see Appendix S). The survey was developed by the researcher and piloted with three colleagues in the research team using an online survey platform. Following the pilot, minor changes were made to the survey, the questions finalised, and the survey questions uploaded onto the online platform.

For each of the ten survey questions, participants were invited to respond with comments in the text boxes provided, in order to maximise responses and to allow for qualitative analysis of the data. No rating scales were used. No minimum or maximum word limit was imposed, and participants were free to respond as they wished.

Participants were asked to comment on their initial responses to the draft guidelines, on which aspects of the content they found easy or difficult to follow and to use, and whether the content was sufficient or not. Participants were asked if they had used the draft guidelines to produce new information, and for their reflections on how the guidelines supported them to do so. Further questions about access to current guidelines about accessible information production, evidence, and resources used by participants sought to probe what people were currently using to support their practice. This information was gathered for qualitative context, rather than anticipating any impact on the development of the draft guidelines per se.

9.3.2.6 *Procedure*

Participants received a copy of the draft guidelines and their consent form for completion in the Royal Mail once they had expressed an interest in taking part in the project. They were asked to return their signed consent form.

Once the consent form had been received by the research team, the researcher emailed each participant to explain the activity and provided a link to the online survey for them to complete. Participants were asked to read the guidelines and to use them to produce some information in the recommended format. Information topics were chosen by participants to ensure relevance to their usual practice. Information materials generated by participants were not reviewed as part of this process, since it was their views on the usability of the draft guidelines which were sought. Following this, participants were asked to give their views on the draft guidelines via the online survey. Responses were received anonymously.

9.3.2.7 *Data management and analysis*

All responses from all participants were retrieved by the researcher from the online survey platform and were collated within a single Word document. Framework analysis (Richie & Spencer, 1994) was then conducted on the data, following the stages outlined in Section 7.1, and applied to the whole data set.

9.3.3 *Results*

Completed surveys were received from seven speech and language therapists and eleven voluntary sector staff. Across both groups of participants, responses were collected for all the survey questions. This section reports the qualitative analysis of the survey data and the subsequent modifications made to the guidelines.

9.3.3.1 *Thematic Framework*

Framework analysis resulted in the identification of four overarching themes: the need for the guidelines, content, accessibility, and usability, and associated subthemes, all of which are presented in Table 9.5 below.

In this section, each of the four themes will be outlined, with extracts from the data provided to exemplify the issues. Participants are identified by participant group (SLT or VS) and their participant number. Comments are recorded as they were written by participants on the online survey platform, with no amendments to spelling or grammar.

Table 9.5 Thematic framework of the survey data

Theme	Subthemes
The need for guidelines	Current practice New information Perceived quality
Content	Amount and relevance of information What works/is easy to do What doesn't work/is hard to do
Accessibility	Overall clarity and comprehensibility Language and terminology Instructions and examples Presentation/layout Accessibility for different users
Usability	Overall ease of use Time demands/efficiency Usability for and with different users Attempts at applying the guidelines Perceived usefulness Resources

Theme 1 - Need for guidelines

All respondents welcomed the guidelines and indicated that they were a valuable resource for those producing accessible information, both for people with previous experience and those new to the task. As the comment below suggests, respondents were supportive of the guidelines being made available to a wide audience.

VS 2 – Clear, logical, concise. Useful. Good that they are evidence based. Would like to see a published booklet be made available for wider distribution to a huge range of organisations who want to make their information more accessible to comply with the Disability Discrimination Act, including both the private and public sector.

Comments regarding current practice suggest that both SLTs and VS respondents have built up their experience through working with people with aphasia, and gathering ideas from a variety of sources. All identified a lack of, and a need for published guidance in this area.

SLT 6 – Knowledge from SLT training or word-of-mouth from research. I feel like it is not explicitly taught in relation to accessible information. And I feel that awareness of accessible information necessary for people with Stroke aphasia is poor, or if present not actively followed.

VS 7 – I don't have any formal guidelines that I refer to. I have generally produced accessible information on the basis of my own knowledge, the knowledge of others who work very closely with people with aphasia and feedback from people with aphasia.

Many respondents felt that the guidelines provided them with new information which they could now implement.

VS 9 – some aspects of the guidelines were really useful and suggested new ways of presenting information that I hadn't considered using before.

SLT 2 – I didn't know that people with aphasia like the key word to be bigger than the other text - this is something new that I'm doing.

Many respondents commented on the quality of the guidelines. Generally respondents felt the guidelines were sound, high-quality, and evidence-based.

SLT 2 – I feel confident using the guidelines as I know they are devised from what people with aphasia have said they want.

Respondents also reported that the perceived credibility of the guidelines made them feel more confident using them with others.

SLT 3 – I feel that having read this guide I will now need to re-evaluate the information I had previously felt to be accessible and that having a clear guide based on evidence rather than my own opinion and brief training gives me more inclination and more support to do this with colleagues.

VS 2 – Having a published set of evidence based guidelines also gives credibility to the content and is therefore useful in influencing the wider teams.

Overall, all respondents perceived the guidelines to be useful and agreed that they would use them in the future, both for their own work, and to support others.

VS 8 – Will use them in the future. They should form part of our training/induction!

VS 5 – I have also been to stroke groups that produce information for members that is not aphasia accessible. I then advise people on how to improve it but having guidelines that people can see would be fantastic, much better than me trying to explain and just giving examples.

Many respondents highlighted areas in which the guidelines would be particularly useful. Specific suggestions included patient and family information leaflets (e.g., health information and advice, explanations of medical procedures, details of service provision, communication strategies), goal setting, letters, emails, meeting minutes, signs, PowerPoint presentations, notices, websites, training materials, advertising and campaigning leaflets, resources for

communication groups. Some respondents felt that more information would be needed to adapt certain information, e.g., surveys, evaluation/feedback forms.

Theme 2 - Content

Respondents commented that all of the information contained in the guidelines was required and relevant. While the majority of respondents thought the amount of information included in the guideline was manageable, two respondents felt that document length was an issue. However, this was mainly related to a 'first glance' impression.

VS 10 – Quite daunting at first - it looks like a lot of pages to get through! But once you start reading it, it becomes clear that it's very spread out, and therefore, quick to read. I don't know if there's any way of condensing it at all, I know the examples have to be a certain size, but the rest of the text maybe? It should also be printed front and back, to condense it into more of a 'handy guide'.

Respondents commented on the potential difficulty of providing word processing instructions for software which is used in different versions, but others reported a need for more detailed instructions, reflecting, perhaps, different levels of word processing experience. The issue of further training raised by some respondents is key here.

Suggestions for additional content included background information about aphasia and why it impacts on reading ability, further details on picture resources, and on formatting.

VS 10- Something more about developing the A5 sets of messages. As I want to create newsletters, I want a bit more information about how many pages is too long, the best layout.

Several respondents commented that information about the study which produced the guidelines should be included, to lend authority to the recommendations.

VS 9 - It might be nice to include a bit more about the study...so people realise that the guide hasn't just been produced using guesswork, but with sound scientific backing behind it.

Respondents commented on specific aspects of the guidelines which worked particularly well. The majority of respondents liked the inclusion of a contents page and the five steps approach. Many respondents liked the use of Flesch Kincaid for establishing readability. This was a new tool for all respondents and they reported it could be implemented in a range of communications, such as email, letters, and newsletters.

VS 8 – Have never used Flesch Kincaid before and I believe it should be defaulted (if that is possible) on all our PCs in the Stroke Association. This will enable us to practice what we are preaching.

Some respondents commented on aspects of creating information that was particularly useful, e.g., use of borders to surround information, use of larger font, using active language, avoiding pronouns.

Theme 3 – Accessibility

The majority of respondents reported that the guidelines were very clear and easy to follow and understand. It was apparent that the overall sense of clarity was aided by layout, with comments on specific design features.

SLT 5 – Clearly set out, written in an accessible format. Good examples clearly separated from the instructions by block of colour or border. I like them!

VS 8 – Very simple to follow. I like the way in which they are laid out - it makes it much easier to understand.

Two respondents identified specific terminology used within the text that was ambiguous or unfamiliar. Another respondent commented on the usefulness of word definitions, e.g., pronouns. Some specific suggestions were made, for example,

SLT 5 – There was some terminology that I had to google e.g., Flesch-Kincaid, sans-serif, could there be a footnote relating to these or a glossary at the end?

The majority of respondents felt that the guidelines were written in an accessible format which demonstrated the principles of accessibility clearly.

SLT 1 – ...the guidelines themselves also followed many of the principles you set out for producing easily accessible info for PWA.

Some respondents perceived the accessible format as a positive feature, acknowledging that the guidelines would be accessible to a range of users. However, for some respondents, attempts to make the document accessible, e.g., by using simple language and short simple phrases, were viewed more negatively.

SLT 6 – I found the short sentences used more difficult to follow than typical sentences. I realise that the document itself is likely to be set up as a model for accessible information, however wonder whether if the guidelines are intended for people who do not have aphasia, they would be easier to read in longer, more typical sentence/paragraph explanations. I found the reduced complexity of the language almost off-putting.

Comments relating to instructions and examples indicated that there were clear associations between accessibility and usability. Respondents generally agreed that instructions were clear

and consequently easy to follow. The “5 steps” aided clarity and helped respondents to follow the instructions. SLT respondents liked the use of examples, particularly those relating to the use of pictures to supported written text. Two SLTs commented that the examples made the guidelines easier to use. VS comments relating to examples were more variable. Some VS respondents agreed with SLT respondents commenting that examples were well presented and useful. Others felt that more examples were needed, particularly those demonstrating good examples of adapted information. Some VS respondents also thought the scope of the examples used was limited and did not relate closely to their own role.

VS 6 – Most of the picture examples show statements (e.g., Physiotherapists help with walking). It would be good to have more picture examples of how to adapt practical information (e.g., a letter, details of an out-patient appointment, or asking for views on something).

VS 9 – The examples given seem to concentrate on producing very formal material such as medical information, information about rehabilitation, information about services etc.

Theme 4 - Usability

Most respondents felt that the guidelines were easy to apply. However, not all respondents agreed, particularly on the first attempt to implement the guidelines.

SLT 4 – Generally I found the activity very useful and much harder and more time consuming than I had anticipated. I really had to think through the points and refer back to the guidelines. When doing this I found I had to keep flicking forward and back through the guideline.

Others agreed that time available was a barrier to implementing the guidelines. One SLT commented that making time for adapting information was challenging in the context of their current workload.

SLT 1 – It is hard to make time for this kind of thing when we are constantly faced with so many patients to see on the wards. I know that this is important though and we should organise our time better. However the reality is that other staff, and patients themselves want to be seen by us face to face and we are spread very thinly.

Another SLT suggested that they would be more likely to allocate such a task to an assistant. SA respondents agreed that time was an influencing factor. One VS respondent commented that time demands as well as potential cost would influence the type of document they would attempt to adapt.

VS 1 – There are cost and time implications involved when we produce information for a large audience about, for example, stroke policy and survivors getting involved in campaigning. We

use guidelines to make info more accessible generally but probably will never be able to make most of it accessible for people with aphasia.

Others agreed that particular types of document were more challenging, and consequently more time consuming, to adapt. This was particularly apparent in the responses of VS respondents who were interested in adapting a greater range of information. Some found specific aspects of the process more time consuming, particularly finding appropriate images.

VS 6 – I was able to apply the guidelines to statements of fact but struggled to adapt questionnaires.

VS 10 – I had to stop when I realised translating a newsletter wasn't going to work, and needed more thinking about!

Respondents commented on specific aspects of the guidelines which they found easy or more difficult to use, for example some identified the issue of increasing length of documents if separated out into individual messages.

VS 9 – The accessible information I produce has a lot of space around the text and images but each message does not take up half a page of A4. A simple volunteer role description being produced in this way would stretch to a dozen pages or more!

Most reported that finding pictures was hard and time consuming, and were daunted by the prospect of seeking suitable images in consistent styles to support all concepts. The issue of copyright was also raised.

SLT 10 - It says 'use the same style pictures', but finding good, relevant, simple, adult images which were either all photos, or all line drawings was really difficult / impossible.

VS 6 - It was also impossible to find images for every message - what can I do when I have no picture? Can I just use the text?

Some reported taking their own photographs and using photoshop programmes or picture symbols, and one had had specialist material made. A few commented on how good the pictures section was e.g.

VS 7 - I thought these resources were so useful and have given me extra tools to use in my current role, which is really helpful, and I found the section on good pictures very useful.

Word processing issues relating to guideline use appeared to vary according to individual skill level. Some found the word processing demands reasonable, but others thought the demands were high:

SLT 7 – I think that people producing these guidelines will need medium to high computer skills and this needs to be taken into consideration when thinking about who will produce the information.

Respondents identified that word processing knowledge should not be assumed.

SLT 2 – ...it was difficult to know how to put ideas into a box, how to add a picture. Maybe attach a simple 'how to' for putting pictures and text into Word.

Whilst all agreed on the usefulness of Flesch-Kincaid, participants varied in how easy they found it to set up. This seemed to be linked to the version of Word being used.

Overall, there was disagreement about the ease with which different users might be able to apply the guidelines. Some felt that any health professional would be able to use the guidelines.

SLT 3 – I feel that until a lead is given in how to make info more accessible people will continue to think of it as a 'speech therapists job' and yet guidelines like these make it easy for any member of the team.

VS 2 – Easy to follow and to apply, even for people who do not have much experience of working with people with aphasia.

Other respondents felt that the guidelines in their current format could not easily be used by all. One respondent felt that the guidelines could not be used by a person with aphasia. Specific suggestions for improvement were made including development of cue cards and training packages for non SLT users.

SLT 7 – May be more difficult for someone other than speech and language therapist to use. The guidelines may need to come alongside some further training on aphasia and supported conversation if being used by other AHP's.

Summary

Overall, participants expressed strong support for the guidelines. They identified clearly the need for published guidelines to be made available as a resource for individual use and for staff training. Content of the guidelines was identified as appropriate, with constructive comments received on content which respondents felt would improve the guidelines. Accessibility of the guidelines was rated highly overall, and most participants appreciated the design of the guidelines in modelling good practice in accessible information.

Comments regarding the usability of the guidelines were generally positive, but were honest regarding the challenges participants had faced, including those of time, resources, and individual skills and knowledge. The issue of further training to support the implementation of the guidelines was raised repeatedly.

9.3.3.2 Results of the qualitative analysis and modifications to the guidelines

As outlined above, the survey responses provided support for the publication of the guidelines and for aspects of the draft presentation, particularly in terms of its content, accessibility and usability. In this section, the specific modifications to the guidelines made by the research team on the basis of the user-testing feedback are described.

Participants' comments suggested that guideline users may require more introduction to the document. Therefore an introductory section was inserted, including basic background information about aphasia, and the rationale and purpose of the guidelines.

Participants' comments (see Theme 1 above) suggested that the credibility of the guidelines rested on both the use of the evidence base in developing the template (Phase 1 of this study) and the involvement of people with aphasia in the development of the template (described in Phase 2 of this study). Participants commented that the guidelines should include information about the research underpinning the guidelines, in terms of both the current study and the wider literature. Brief background to the project was provided therefore in a section entitled 'Development of these Guidelines'. In addition, a 'Further Reading' section was inserted at the end of the document.

Participants varied in how much word processing advice they required, therefore all word processing information additional to the basic formatting of the template was collated in a section at the end of the document. Additionally, a web-link for Microsoft Word Help was provided.

The five steps approach was well-received and this was therefore retained. Small changes to ensure consistency and clarity were made to the final version, for example the inclusion of sub-headings within each Step, for example Step 1 – A short message – Make sure you have a clear message; Step 2 Clear sentences – Make your sentence simple; Step 3 Easy words – Use everyday words; Step 4 Good layout – Create a space for your message; Step 5 Make a set – Make a set of messages.

In the draft Guidelines, each of the five steps concluded with a small checklist. For the final version of the Guidelines, these small checklists were replaced by a single final checklist, tick-box in style to encourage user interaction, after the final Step.

Table 9.6 summarises the differences between the draft and final versions of the guidelines in order of presentation in the final document. The left hand column shows the draft Guidelines content, the right hand column shows the content of the final version of the Guidelines. For example, the draft Guideline contained a brief introductory paragraph; in the final version, the Introduction was expanded significantly to include further background about aphasia, the need for the Guidelines and instructions for their use.

Table 9.6 Changes to the Guidelines document following user-testing

Draft Guidelines	Final version of Guidelines
No authors or acknowledgements included in draft version.	Authors listed and statement of acknowledgements
Brief, single paragraph introduction.	Introduction Background What is aphasia? The need for Guidelines Development of these Guidelines Who are these Guidelines for? What are these Guidelines for? How to use these Guidelines
The Five Steps – different coloured fonts for each step	Black font. Orientation to final checklist, Word advice.
Short checklist for each step Variable use of headers within each step Use of language Use of images	Final checklist with interactive tick boxes. Checklist points subsumed into instructional bullet points within each step. Each step has a header instruction e.g. “Use everyday words” “Create a space for your message” Increased specification to instructional language e.g. “logical order” rather than “sensible order”; “choose a simple border” rather than “choose a border you like”. Examples taken from template materials developed in Phase 2, to demonstrate the principles in practice.
Step 1: A short message Step 2: Clear sentences Step 3: Easy words Step 4: Good layout Step 5: Make a set	Steps remain the same, identified as helpful in user-testing. Slight differences as above to increase clarity, to demonstrate principles.
Using the materials	Included in the Introduction
	Additions to final version: Interactive checklist for all formatting features. Word processing advice for: Flesch-Kincaid in Microsoft Word 2003/2007/2010 How to: make a box; put a border around a box; add a picture; edit a picture. Web link to Microsoft Word help site. Further reading section

The modifications made following the user-testing resulted in the final version of the Guidelines. These were agreed by the research team and submitted for publication. The Guidelines were subsequently published by the Stroke Association (Herbert et al., 2012) as a 30-page booklet, available to purchase in print or to download without charge, via the Stroke Association website (see Appendix T).

9.4 Interpretation of main findings

This phase of the study aimed to develop concise, practical, written guidelines, accessible to any user. To achieve this aim, the research team set out to firstly convey the principles of the final template through clear explanation and modelling of the template criteria, and secondly to develop a practical and methodical approach to enable guideline users to produce accessible information materials.

In this phase of the study, the principles for accessible information, embodied in the template developed in Phases 1 and 2, were translated into draft guidelines. The template design criteria provided the basis for the research team to develop a step-by-step approach to creating accessible information. The draft guidelines were then subjected to testing by potential users, who gave their feedback via an on-line survey.

The results of the user-testing survey resulted in an understanding of the key issues for users of the guidelines, such as the need for guidelines, the content, accessibility and usability of guidelines. The results of the qualitative analysis were then used to further refine the guidelines, by generating amendments and additions to the draft document, to produce the final version.

The user-testing findings were largely positive, supporting the need for published, high-quality, evidence-based guidelines in the area of accessible formatting. Overall, participants found the draft guidelines easy to use and they commented favourably on the step by step approach and the use of examples to explain aspects of language and formatting. Results of the qualitative analysis suggest, however, that further training to users on how to use the guidelines may be indicated.

It is interesting to note that, in the guidelines, three separate steps were used to guide users in their composition of accessible language which adheres to the template criteria. In contrast, the criteria relating to typography, images, and layout were managed within two steps. This finding is important, since it highlights the complexity of language impairments in aphasia and the importance of a clear specification for the language used in information materials. As

argued in Chapter 2, previous studies (e.g. Brennan et al., 2005; Rose et al., 2003; Rose et al., 2012) have underspecified the language component of accessible information materials for people with aphasia, with greater research focus emphasis placed on issues such as font size and the use of images. Further, whilst the Flesch-Kincaid reading tool can be a useful adjunct, it is insufficient in itself in guiding composition, since it does not reflect the complexity of factors which facilitate comprehension in aphasia. The facilitative features relating to lexical terms, sentence forms, and structural priming introduced in Section 2.3, which were incorporated in the template, and subsequently specified in Steps 1, 2, and 3 of the guidelines clearly demonstrate these complexities. This represents an important contribution to this field.

The template developed in Phases 1 and 2 of this study was designed to convey health information to people with aphasia. User-testing highlighted challenges when extending the scope of the types of information materials, such as questionnaires and newsletters, suggesting a need for further developmental work in formatting different types of documents using the principles of the template.

Interestingly, several of the areas which participants identified as potentially problematic in adhering to the guidelines involved accessing skills and resources beyond the scope of the guidelines themselves, such as word processing skills and access to suitable image resources. As suggested by several survey respondents, supplementary training is indicated, to ensure that users have resources to support their use of the guidelines.

The changes made to the draft guidelines and carried through to the final version reflected the user-testing process. The main changes to the document included the addition of content to orientate users to the guidelines, to support understanding of the principles, and to provide additional word processing instruction. Some content was moved, and in the case of the checklist, consolidated at the end of the document.

As identified in Chapter 1, no user-tested guidelines to support accessible formatting of information for people with aphasia had been published prior to this study. Previous studies in the area of accessible information have presented findings which authors suggest could be used to inform the design of information materials (e.g. Rose et al., 2011a), but none have translated such findings into practical, accessible guidelines. Previous guidance documents have been produced (e.g. Parr et al., 2008), but no studies have undertaken user-testing of these to evaluate either their usability or their impact on information materials. The development and user-testing of draft guidelines described in this phase of the study is therefore a novel contribution to the field of accessible information for people with aphasia.

The publication of the guidelines represents significant progress towards enabling healthcare providers and others to provide information to people with aphasia which meets both the standards required by national policy (NHS England, 2015) and Stroke guidelines (Intercollegiate Stroke Working Party, 2016; NICE, 2013) and the preferences of people with aphasia (e.g. Rose et al., 2011a). Further training to support the implementation of the guidelines is indicated, as identified through the user-testing process outlined above.

The impact of these guidelines on the outcomes of people with aphasia remains unknown, however, and further research will be required to evaluate their effectiveness. Firstly, the quality of information produced by healthcare staff and others will need to be evaluated to determine whether the guidelines are sufficiently well specified for their purpose. Secondly, research needs to explore the responses of people with aphasia to information materials produced according to the guidelines. Finally, responses of people with aphasia to a broader range of types of information produced using the guidelines, including formats such as newsletters and questionnaires are needed. This is particularly important, given that the principles carried into the development of the guidelines were based on health information only.

9.5 Chapter summary

This chapter has outlined the stages involved in the translation of the template principles into draft guidelines and the subsequent user-testing of the draft guidelines. A focused discussion of the findings of this phase of the study has highlighted issues for practice and further research.

The following chapter presents a full discussion of the study in relation to previous and more recent literature.

Chapter 10 Discussion of findings

The purpose of this chapter is to consider the findings of this study, with the aim of developing an “explanatory account” (Spencer, Ritchie, & O’Connor, 2003: 212) of the issues pertinent to designing health information for people with aphasia. It is important to acknowledge here that the methods reported in Phase 1 and Phase 2 of this study were conducted between October, 2010 and April, 2011. Since the original literature reviews to inform the materials and methods for the study were conducted, further research has been published. In this chapter, the more recent research findings will be introduced into the discussion.

A further aim of this chapter is to address issues surrounding the quality of the study, including validity and transferability of the findings, and to reflect on the strengths and limitations of the study. Finally, implications for practice and future research will be considered.

10.1 Aims of the study

The overarching aim of this study was to collaborate with people with aphasia to develop a novel template for conveying health information in an accessible format for people with aphasia. Within the concept of health literacy, such a template may be viewed as an intervention, since it supports access to health information (Coulter & Ellins, 2006).

The aim of Phase 1 was to generate a prototype template based on relevant research evidence. The design of the initial prototype template was informed by reviews of the literature in three areas: evidence about the impact of modified formatting on people with aphasia; evidence regarding the facilitation of language processing in people with aphasia; and evidence about the health information topics required by people with aphasia. The principles derived from the research evidence were instantiated into a physical template through a collaborative design process with a graphic design team and a network of relevant health professionals.

Phase 2 followed a collaborative, iterative design process with the graphic designers and people with aphasia, with two main aims: to explore the views of people with aphasia regarding aspects of the template, and hence to generate the final Template 3. In facilitated focus groups, participants gave their opinions of Template 1, and subsequently of Template 2, via individual supported discussions and group discussion, providing qualitative data and rating scales data.

In the first focus group meetings, participants were also asked to give their preferences for aspects of the template, for which clear evidence had not been identified in the literature, namely: image type, including photographs and line drawings; number of images per concept; font size; font style; and emphasis in font.

In the second focus group meetings, participants gave feedback on the revised template. New issues which emerged during the first focus group meetings, including the ideal amount of information presented on one page, and further clarification of emphasis of key words, were also explored.

In Phase 3, the research team aimed to translate the principles instantiated in the final Template into practical guidelines which could be used by anyone working with people with aphasia and producing accessible information for this population. Draft guidelines were developed through a process of collaboration between the members of the research team. Following this, participants working in speech and language therapy and the voluntary sector were recruited to user test the guidelines and to give their opinions via an online survey. Data generated in this phase were used in qualitative analysis and to inform modifications to the draft guidelines.

10.2 Summary of main findings

As discussed in Chapter 2, research into modifications to formatting to increase the accessibility of written information suggests that individual or combined formatting features can facilitate comprehension (Brennan et al., 2005; Rose et al., 2003). Some evidence was, however, unclear, such as the use of images (Brennan et al., 2005; Dietz et al., 2009), and some evidence was missing, such as evidence for emphasis in font. The literature regarding language facilitation in aphasia provided the specification required to identify principles for the template in terms of the choice of lexical terms (e.g. Coltheart, 1981), sentence forms (e.g. Caramazza & Zurif, 1976), and the use of priming to maximise reading comprehension (e.g. Hartsuiker and Kolk, 1998). Finally, examination of the literature into information topics required after stroke found a consistent need for basic information about stroke and aphasia, and information about the emotional consequences of stroke (e.g. Avent et al., 2005; Hanger et al., 1998; van Veenendaal et al., 1996). Thus, although the evidence for aspects of formatting was limited, the findings of the three literature reviews together generated sufficient evidence to identify principles for the design of the prototype Template 1 (summarised in Table 3.1). The Template 1 materials for review in Phase 2 were then produced in collaboration with the graphic designers.

Phase 2 of the study resulted in a successful collaboration with people with aphasia in an iterative design process (Sears & Lund, 1997). People with mild, moderate, and severe aphasia participated in facilitated focus groups to give their views on the prototype design template derived from the current evidence base. The feedback to the designer, collected after each focus group, and the qualitative analysis of the focus group discussion data, resulted in the development of a checklist for the final Template 3 design (Table 8.1).

Phase 3 resulted in the successful collaboration between members of the research team to develop draft guidelines derived from the accessible information principles instantiated in the final Template generated in Phase 2. Following user-testing by speech and language therapists and voluntary sector staff, the guidelines were modified and finalised by the research team. These guidelines were subsequently published by the Stroke Association, and made freely available via the Stroke Association website. They are the first evidence-based, user-tested aphasia-accessible information guidelines to be published, and thus represent a novel contribution to the field of accessible information and aphasia.

In the following three sections, the findings of this study will be analysed in relation to the current research evidence in three main areas. In Section 10.3, the findings of the Phase 2 study which relate to the optimum design of health information for people with aphasia will be considered with reference to contemporary research findings, with the aim of explaining the results within a broader theoretical context. Section 10.4 discusses issues of individual variation, both in relation to the methodology and the findings of this study. In Section 10.5, the methods used for involving people with aphasia in the development of accessible information will be discussed.

10.3 Designing health information for people with aphasia

The evidence reported in Chapter 2 resulted in the development of principles for the design of Template 1. As noted in Section 2.2, the evidence base for specific features of accessible formatting was small, reflecting that little research had at that time been published in this area. Previous studies have explored variations in design in terms of the impact on comprehension and the preferences of people with aphasia, measured by responses to testing, surveys, and interviews.

In the following discussion, issues related to designing health information for people with aphasia will be considered, in order to embed the findings of this study into the current evidence base. This discussion will be structured to reflect aspects of content and formatting

incorporated into the template design: topics, language, amount of information per page, typography, use of images, layout, and issues of acceptability.

10.3.1 Topics

Research into the information needs of people after stroke forms a large body of work, addressing issues such as education needs (e.g. Hafsteinsdottir et al., 2011; Kerr et al., 2010), information formats (e.g. Eames et al., 2010; Hoffmann et al., 2007), and the experiences of patients and family members obtaining and using stroke information (e.g. Danzl et al., 2016; Eames et al., 2003). Some of the studies cited above included people with aphasia in their sample, but since the characteristics and needs of this sub-group were not specified, such studies offer limited additional insights into their information requirements. Studies into the experiences and information needs of people with aphasia are limited in number (e.g. Parr et al., 1997; Rose et al., 2010), but provide clarity on specific information needs and powerful evidence of the ways in which people with aphasia are disadvantaged in terms of information provision after stroke.

In the field of accessible information, the materials presented to research participants have varied according to the research aims, including information both related and unrelated to participants' health needs, general knowledge materials, and personally relevant information.

In the current study, topics for the template materials were identified through the literature review reported in Section 2.4. The review found a high level of consistency of findings between the studies, with identified information needs relating to early, rehabilitation and chronic phases, and stroke impairments, activity, participation and psychological well-being. Similar findings have also been reported in studies published subsequently (e.g. Hafsteinsdottir et al., 2011; Danzl et al., 2016).

Only two of the studies reviewed, however, were solely concerned with either the needs of people with aphasia (Parr et al., 1997) or of family members of people with aphasia (Avent et al., 2005). Based on an assumption that people with aphasia share the same information needs as any other person after a stroke, the findings of the other studies reviewed were included to inform the possible topics for the template materials. Topics were selected for the template on the basis of their likely relevance to the focus group participants.

During the focus group discussions, participants were not asked for structured feedback about the topics, but all responded readily to the content, suggesting that they considered the topics relevant and pertinent. This finding was in keeping with the findings of Rose et al. (2011a), who report that participants engaged more with information they perceived as relevant to their

own situation. Focus group participants reflected on the difficulties they had experienced obtaining basic information, for example one man reported that he did not find out for several weeks that he had suffered a stroke. Such experiences are in keeping with the literature (e.g. Hanger & Mulley, 1993; Hanger et al., 1998), which reports a fundamental lack of understanding among study participants of basic concepts about stroke, such as the causes of stroke. As well as causing dissatisfaction with services (Hinckley et al., 2013; Tomkins et al., 2013), this also has implications for people's subsequent understanding of risk factors associated with possible future strokes, and their ability to engage in self-management (Coulter & Ellins, 2006). Whilst several authors (e.g. Danzl et al., 2016) report the need for repetition of information over time, an ongoing lack of understanding suggests in addition that the concepts associated with stroke may be inherently complex, requiring carefully modified explanation.

10.3.2 Language

Aphasia is an impairment of language processing, and consideration of the language used in information for this population is therefore vital. Research in the area of accessible formatting for people with aphasia has focused on the use of readability formulae (e.g. Flesch, 1948) and terms such as "simple words and short sentences" (Rose et al., 2003:950) to describe and evaluate linguistic complexity. Research findings indicate the need for simple and straightforward language (e.g. Brennan et al., 2005; Rose et al., 2011a). In the field of applied aphasiology, more specific description of language processing in aphasia has been conducted, with the aim of providing simplified text in newspapers (Devlin & Tait, 1998) and on websites (Singh et al., 1998).

Such work has not carried over into the field of health information, however. Aleligay et al. (2008), in their analysis of the lexical and syntactic aspects of health information materials given to people with aphasia, identified high proportions of low frequency, low imageability words and complex sentences. Information for people with aphasia also continues to be evaluated at reading grade levels in excess of the recommended levels (Surman & Bath, 2013), suggesting that healthcare professionals need more specific guidance on how to write information for readers with aphasia.

The literature review conducted for this study, reported in Section 2.3, resulted in the identification of principles for generating text in ways known to facilitate language processing in people with aphasia (summarised in Table 2.3). These principles were then applied to develop the sentences for the template materials. Concepts were presented singly. Vocabulary choices were guided by evidence of lexical characteristics known to affect single word

processing, including imageability, frequency, and length (e.g. Coltheart, 1981), abstractness (Franklin et al., 1994) and use of non-literal language (Papagno & Caporali, 2007). Sentences were of single clause, canonical structure, avoiding complex structures, non-canonical forms, and reversible sentences, to maximise ease of reading (Caramazza & Zurif, 1976). Proforms were avoided, and replaced by repeated content words (Berndt & Caramazza, 1981). The concepts of structural priming, lexical boost and repetition priming were then applied, by repeating structures and key words (Hartsuiker & Kolk, 1998; Pickering & Ferreira, 2008). The sentences were assessed using the Flesch-Kincaid Reading Grade level tool (Flesch, 1948) to ensure that none exceeded Reading Grade 5.

In this study, participants were not asked to rate the language content on the template, but points for discussion were welcomed. Individuals commented on their own reading ability, with some referring to their comprehension of the template text, and some participants reflected on their early experience of aphasia, when they were unable to read.

Generally, participants commented more on the visual appearance of the text presented than on the language itself. Only one participant commented on the specific vocabulary used, and others did not extend these ideas. Findings from the third sub-theme demonstrate that a clear match between text and image was important, suggesting that participants did read the text, where possible, but did not comment.

As Krueger (1998) notes, the analysis of focus group data should include an account of what participants did not say, as well as reporting on what they did say. Several reasons could account for the paucity of comments in the current study. The application of the evidence base (see Table 2.3) and the systematic development of the sentences could mean that the language level was appropriate and therefore non-controversial. Had the materials incorporated language known to be more difficult to process, such as non-canonical or complex sentences, or low frequency, abstract vocabulary, participants may have responded negatively. Participants were encouraged to comment critically on the template, but the methods did not incorporate a structured way to respond to the language element, as was done with typography and images. Communication facilitators may have read aloud the content during individual discussions, ensuring that participants were able to understand, thus allowing them to focus their critical attention on more visual aspects of the template. Finally, since language is an abstract concept, aphasia itself is likely to limit people's ability to discuss it overtly.

Research findings (e.g. Aleligay et al., 2008) suggest that information about lexical and syntactic processing in aphasia constitutes established knowledge, but that this has been

inadequately applied to the production of health information. In addition, the inherent complexity of information about stroke suggests that explanations require a systematic way of reducing the cognitive load on readers (Wilson & Wolf, 2009). In this study, the application of principles from the literature on structural priming (Hartsuiker & Kolk, 1998; Pickering & Ferreira, 2008) resulted in a novel presentation of text within the template. Such principles have not been previously identified in the field of accessible health information. The potential impact of these principles on readers' comprehension of text, and on their perceptions of acceptability, therefore require further scrutiny.

Further work is now required on two fronts. Firstly, the factors to facilitate language processing in readers with aphasia need to be more clearly specified than in studies to date. The development of principles for generating text in this study contributes to this field.

Secondly, further work is needed to increase the knowledge of healthcare professionals regarding the specific nature of aphasia. Specifically, knowledge about facilitating features of language for readers with aphasia requires more structured explanation in order for professionals who write information for people with aphasia to understand and apply the knowledge. Without this shared understanding, it is likely that there will continue to be a gap between guidance and practice.

10.3.3 Amount of information per page

Although previous studies have aimed to gain consensus on aspects of accessible design, the literature remains underspecified in relation to the amount of information presented per page. Previous research has focused on the length of documents, and no studies have specifically defined the number of concepts per page.

In this study, participants raised the issue of amount of information during the first focus group discussions, identifying that health leaflets or webpages contained too many different ideas on one page. Subsequently, participants rated the accessibility of materials in which one, two, or three concepts were presented on one page at a time. They unanimously rated one or two concepts highly, perceiving any more than this as "too much". Apart from their initial visual reaction to the amount presented, participants preferred single concepts because this guided them to read more slowly than they might otherwise attempt; consequently, this more measured approach supported their understanding and memory of the concepts. In a similar way, where participants rated two concepts per page highly, the linked meaning helped readers to relate the concepts to each other. Presentation of single concepts was also perceived as a support for people early after stroke, or for some with chronic aphasia, as a tool to support looking at information together with a family member.

Previous research findings are mixed, perhaps due to a lack of definition of the concept of amount. Rose et al. (2003) report that some participants did not like the materials adapted along 'aphasia-friendly' principles, because they perceived them as "too long" (p.959) although, as the authors acknowledge, the meaning of this is not clear. Rose et al. (2011a) coded participants' comments on the issue as facilitators (small amounts of information) or barriers (large amounts), but again, these were not specified. Interestingly, in contrast to the earlier (Rose et al., 2003) study, comments were recorded from some participants who expressed a dislike of the "reduced amount of information" (p.339) in the adapted materials. This lack of definition in the research is also inherent in the study by Ghidella et al. (2005), who identified "a reasonable amount of information" (p.1138) as one element of an objective measure of quality of websites designed for users with aphasia. No further description of the concept is provided, however, and no specific findings of it are reported.

Rose et al. (2012) attempted to quantify the issue of document length by asking participants to state their preferences for five A4 documents, varying from 3, 8, 17, 26, and 38 pages. They found that 43.6% preferred the longest booklet, compared with 2.6% preferring the shortest. The remaining participants' ratings were spread evenly across the three other booklet lengths. Since, as the authors claim, the five booklets contained exactly the same information, it may be that the longest document spread the concepts out over the pages in a way that allowed readers to focus on a small number of concepts at a time. These findings help to clarify that a clearly delineated, sequential presentation of concepts is more important for accessibility than length per se for readers with aphasia. This is supported by the findings of more recent studies, for example Knollman-Porter, Wallace, Hux, Brown, and Long (2015) who found that people with aphasia preferred to read short paragraphs of one or two sentences rather than a full page, and Jayes and Palmer (2014), who report that participants preferred to see a limited amount of information per page.

When two people look at information together, the presentation of single concepts provides a means of slowing the rate of information and provides an opportunity for individuals to check their shared understanding as they proceed. This is in contrast to both traditional written leaflets and 'aphasia friendly' materials, where it would be difficult to hold a shared focus of attention on a page containing many concepts. Such presentation is consistent with the notion of supported reading proposed by Knollman-Porter et al. (2015).

It is notable that even the presentation of three concepts per page is less than is generally seen in health information, whether this is adapted for people with aphasia or not. This is therefore an important finding, which helps to define amount (as distinct from length), and has implications for design.

10.3.4 Typography

Following Rose et al.'s (2003) definition of the principles of "aphasia friendly formatting" (p.950), research into typography has sought to gain consensus on the optimum font size and styles to use in information for people with aphasia. Rose et al. (2012) explored the preferences of people for different font sizes and styles, whilst Brennan et al. (2005) investigated the impact of increased font size on comprehension of written material. Wilson and Read (2016) compared the impact on comprehension of serif versus sans serif fonts, and sentence case versus capitalised text. The emphasis of key words using bold font is routinely seen in patient information literature, and is accepted as standard practice (e.g. Stroke Association information leaflets, Cottrell & Davies, 2006). However, it is not included in Rose et al.'s (2003) definition, and has not been subject to empirical investigation with people with aphasia.

In this study, participants rated the accessibility of short phrases presented in four different font sizes: 10, 12, 18, and 26pt, of which the two largest sizes were equally and most positively rated. Although they generally found larger fonts to be more accessible, participants cautioned that font size should be in proportion to the materials. They commented on their changing needs over time, for example that a larger font size early post stroke was needed.

There were no marked differences in the ratings of serif versus sans serif font styles in this study. However, a limitation of the methods used was that a short phrase was presented in 12pt, a font size which participants rated less favourably than larger fonts. Had more text been presented, and in a more accessible font size, it is possible that a greater range in participants' ratings might have resulted.

Participants unanimously rated some form of emphasis of key words more highly than none, and the marked preference for emphasis that is both large and bold was a new finding for this study. Overall, participants repeatedly expressed the importance of clear information. On analysis, the breadth of meaning of this term emerged, including that materials should be simple (not complicated), clear (stated obviously) and uncluttered (without too much detail). Literal visual clarity, for example dark printing, also fell within this concept of clarity.

The findings presented here concur with previous studies in which larger font sizes were found to be preferred by people with aphasia (Rose et al., 2011a, 2012) and to impact positively on comprehension of materials (Brennan et al., 2005), but provide more detail on what it is about larger fonts that influenced participants' ratings. Firstly, people reported finding reading easier to attempt when they can see the text clearly. This is not only a visual preference; participants reported that they could read larger fonts more quickly and accurately, and that this allowed

them to read more text. Participants highlighted that this could be subject to change over time, remembering that in the early stage after stroke, larger fonts were needed more than at later stages.

The positive rating of small fonts by a man with severe aphasia is in keeping with the findings of Rose et al. (2003), who report that some of the most severely affected participants stated a preference for the information materials which were not adapted. It is possible that such participants are seeking familiarity rather than accessibility. As Rose et al. (2012) report, some people with aphasia acknowledge that whilst the largest font sizes may be easiest to read, they would not choose to look at information presented in this way. There may therefore be tension between individual preferences and formatting styles which support reading comprehension.

Two factors may influence why larger font sizes are preferred. Firstly, larger font sizes may result in increased engagement because people are not struggling to see, thus increasing motivation. Secondly, if page size remains stable, increased font size will reduce the number of words per line. Rayner and Pollatsek (1989) report that for readers without neurological impairment, "...reading appears to proceed at about the same rate if the type font, size and length of line employed are at all reasonable." (p.119). For readers with aphasia, a reduction in the number of words per line, together with a combination of large, clear font, is likely to benefit attention and comprehension.

In contrast to the equivocal responses to serif and sans serif font styles in the current study, Rose et al. (2012) found a preference for sans serif fonts. This has been recently supported by Wilson and Read (2016), who found a significant advantage to comprehension of the sans serif font Verdana over both Times New Roman and Harrington. It is interesting that the serif styles which were both least preferred and detrimental to comprehension in these two studies were of a light print quality, in comparison to the darker sans serif fonts. It may be, therefore, that serifs alone do not account for ease of processing of specific font styles, but that print darkness is also a factor.

The finding that emphasising key words increases accessibility concurs with those of previous studies such as Rose et al. (2011a), but adds detail about the nature of the emphasis used. The preference for larger and bolder emphasis may be a result of what Heuer and Hallowell (2007) describe as the "pop out effect" (p.884), in which the visual impact of darker font or larger font size causes readers to attend longer to selected words or segments of written materials. This could account for previous explanations of bold font interrupting the flow of reading, to the detriment of comprehension (Hoffman & Worrall, 2004). In fact, some interruption to the flow

of reading may be beneficial to readers with aphasia, to focus attention on words carrying the greatest meaning in a sentence. However, as recently found by Wilson and Read (2016), the use of upper case for emphasis is not suitable, since it is less readable than sentence case. This suggests that that judicious use of bold font is required, to ensure that readers' attention is directed usefully.

10.3.5 Images

Adding images to written text constitutes part of the "aphasia friendly" format, defined by Rose et al. (2003:950). Whilst early research into the effectiveness of such principles focused on whether images do indeed support people with aphasia's comprehension, subsequent studies explored whether different image styles may have a greater impact on reading comprehension. Alongside this, the subjective preferences of people with aphasia have been explored, with a view to obtaining a consensus on the optimum image style for supporting reading in people with aphasia.

In this study, participants commented on the images both in isolation, and in combination with written text on the template. Overall, the line drawings were rated more highly than the photographs, but there was no clear consensus for one style over the other. Although some participants expressed strong aesthetic preferences, participants' responses generally related more to the effectiveness of specific images to convey a particular meaning, rather than whether these were photographs or line drawings. Generally, participants expressed that simple, clear, and uncluttered representational images were easiest to process. Comments made about abstract designs, or images with extra detail, suggested that visual processing sometimes took more time and cognitive effort than was predicted by the design team, and this occurred regardless of aphasia severity.

The portrayal of concepts through images prompted varied responses, demonstrating variability in how participants used the images to support their comprehension of the concepts. The example of how to depict 'blood' showed that while for one person, the literal meaning of the concept was triggered by the image of a bleeding finger, for another, the same image was misleading, since the blood did not refer directly to the blood flow in the brain. Similarly, participants varied in their responses to images of people; one female participant appeared to relate all images of women to herself, resulting in idiosyncratic interpretations of the information. In contrast, a male participant indicated that he could not relate images of women to himself, since they literally did not look like him.

All template materials included both images and text, and whilst many comments focused on the images themselves, discussion also arose from the interaction between the two. All the

participants, with the exception of one man with mild aphasia, agreed on the importance of an exact match between words and images. The cards which prompted such discussion were those in which concrete wording was accompanied by images which did not match exactly. Arguably, the images therefore required some degree of interpretation, and it was this which some participants found distracting, and others a barrier to comprehension. Severity of aphasia might be a consideration here; however, participants with all levels of aphasia commented on this issue. Interestingly, where a sentence carried more abstract information, participants did not seem to expect the illustration to match the text precisely. No participants in the current study questioned the presence of images in the template; rather, all seemed to expect images to be used.

The study of aphasia suggests that images are a valuable resource, allowing people with aphasia to utilise preserved visual ability to support a range of communication and language activities. For example, in facilitative approaches to communicating with people with aphasia, pictures have been found to be useful to support interaction. This includes a range of image styles including photographs (Ho et al., 2005), line drawings (Kagan et al., 1998), picture symbols (Murphy, 2004), and drawing (Sacchet, 1999). Knollman-Porter et al. (2015) found that people with chronic aphasia were more likely to select readily-available reading materials which included pictures. They report that looking at the pictures assisted people to decide whether or not the text was of interest or relevance, and supported text comprehension.

Despite this endorsement for the inclusion of images alongside text, studies attempting to clarify the role of images to support reading comprehension have had mixed findings. Brennan et al. (2005), Rose et al. (2011b), and Wilson & Read (2016) found that images did not in themselves support written word comprehension, regardless of image style. Two further studies of reading with pictures in people without aphasia by Thompson et al. (2010) and Liu et al. (2009) were similarly inconclusive. One study by Dietz et al. (2009) demonstrated that the presence of high-context photographs did influence comprehension. As discussed in Chapter 2, the variation in findings may have resulted from differing methods; whereas Brennan et al., Rose et al., and Wilson and Read sourced images to support performance on a cloze task, Dietz et al. developed written paragraphs after identifying suitable images.

A further caution regarding the use of images is indicated by studies exploring visual perception. Multiple levels of visual processing are involved in the correct recognition of images (Warren, 1993) and impairments at any level may disrupt picture recognition, leading to difficulties in understanding the meanings of images. Beaufilet et al. (2014) and Liu et al. (2009) both report that older participants experienced greater difficulty understanding pictograms and illustrations than younger participants. This suggests that visual

comprehension is a cognitive process which is susceptible to individual variation, including amongst those with aphasia. In this study, some participants struggled to make sense of some images, but whether this was due to a stroke-related visual processing impairment, or a consequence of age, is unclear. A measure of the visuospatial processing abilities of the participants would have provided a means of analysing this in more depth in this study.

Identifying the optimum image style for people with aphasia has been the aim of several studies. Dietz et al. (2009) argued that Brennan et al.'s (2005) use of line drawings accounted for their finding that images do not support written word comprehension. Dietz et al. found that high-context photographs were more successfully matched with written sentences than low-context photographs, but since they did not include a line drawing condition in the experiment, the suggested inferiority of line drawings was not demonstrated.

In an eye tracking study examining a sequence of single word to multiple choice picture matching tasks, Heuer (2016) found that college students without neurological damage processed colour photographs more easily than line drawings. She suggests that increased complexity of photographs versus line drawings may account for this finding, but cautions that people with aphasia may perform differently. Although the current study did not explore the impact of images on comprehension, the data demonstrate that the participants' perceptions of the accessibility of images rests on a variety of factors, of which image style is only one. For example, several participants commented that they would prefer to look at photographs, but stated that the image must be correct for the concept. As Heuer (2016) argues, the type of image selected is determined by the communicative purpose it serves. As Ho et al. (2005) and McKelvey et al. (2010) found, personal photographs were of greater use in supporting communication than pictograms, line drawings, or low-context (non-personalised) photographs. However, such findings are not necessarily transferrable to the communication of printed information, in which concepts are relevant to a population or group rather than individuals, and therefore require less personal specification.

The choice of images in health information materials is therefore of paramount importance. There is agreement in the literature that the target population should be involved in the production of new health information materials (e.g. Coulter et al., 1998; Duman, 2003), and the response of participants in this study and others (e.g. Elman et al., 2003) supports this. Examples of engagement by people with aphasia in developing materials (e.g. Parr et al., 1999, 2004; Cottrell & Davies, 2006) do not, however, provide a clear account of how consensus was achieved in the choice of images. This is concerning, given that in the current study, selection of the correct image was identified as a challenge by participants, and was frequently a source of disagreement.

The finding that text and images must match exactly appears to be novel to this study, although Rose et al. (2011a) found a similar, but more general, response, reporting that “Participants also commented that it was helpful when graphics closely linked with the text...” (p.342), and that graphics should have captions. Griffin and Wright (2009) found that older subjects without aphasia read information more quickly when text and graphics were closely allied, but were distracted by decorative graphics which served no communicative purpose.

This discussion has suggested that people with aphasia make use of both text and images in written information. However, evidence for the simplification of language is stronger than the current evidence for use of images, which remains controversial. Whilst images are perceived by many people with aphasia as helpful, research evidence remains inconclusive. This suggests that further knowledge about how best to use images in health information is needed. In the following section, further consideration is given to the layout of written information incorporating both text and images.

10.3.6 Layout

Previous empirical studies have focussed attention on features of formatting, rather than overall layout of the content. Studies by Rose et al. (2011a; 2012) found that participants preferred clear layout and design, but the methods did not allow for an in-depth analysis. Rose et al. (2012) found that, when asked in the abstract, most participants reported white space to be helpful. When looking at information materials, wide line spacing was poorly rated, suggesting that extra white space is unhelpful within sections of text.

Two issues relating to how content is presented were discussed in the current study: overall layout of content, and the number of images per concept.

Overall, participants agreed that the template layout guided their reading, although individuals varied in how they approached the template, and how much of it they looked at consciously. In terms of number of images per concept, two distinct groups were identified. Whilst most participants preferred the presentation of a single image for the concept, a sub-group showed a consistent preference for an image of each key word in the sentence for the concept. Participants with a range of reading ability favoured each style of presentation, and no obvious link between aphasia severity and preference for number of images per concept was found.

Morrow et al. (2012) employed eye tracking technology to examine how older readers without aphasia look at health information containing both text and images. They observed differences in how participants with varying levels of knowledge about their health attended to the materials. Those with higher levels of knowledge attended first to the text, and then to the

relevant image, whereas less knowledgeable participants moved between text and both types of images in a less ordered way. The authors postulate that the comprehension strategy of the more knowledgeable was to use the relevant images to reinforce their initial reading of the text. They conclude that designing health information materials which facilitate this strategy could be beneficial, showing readers where to look next and providing materials which prompt different processing styles. Whilst caution is needed transferring findings to a population with aphasia, the observed reading styles of Morrow et al.'s (2012) participants have similarities to those in the current study.

As well as visual and linguistic processing, reading text and images together uses additional cognitive resources, such as allocation of attention and working memory, skills necessary for executive function (Alvarez & Emory, 2006), which is required when drawing inferences between, say, words and images. Since research has demonstrated that attention, working memory, and executive functions have all been found to be vulnerable in people with aphasia (Frankel et al., 2007; Kalbe et al., 2005; Murray, 2012), it is possible that presenting text and images in combination may actually add complexity to the task of reading for some people with aphasia.

In an eye-tracking study comparing participants with and without aphasia, Heuer and Hallowell (2015) found that participants with aphasia had more difficulty allocating attention, and this was exacerbated by increasing complexity in the stimuli. Further, there was no correlation between aphasia severity and ability to allocate attention, although as the authors note, their sample was skewed, with most participants having mild, and only two having severe, aphasia. Thus, although images are intended to support lexical access, they may add complexity to reading by increasing the cognitive load. This issue has been investigated by Hurtado, Jones, and Burniston (2014), who questioned the established 'Easy Read' format for people with intellectual disability. They propose that a "picture only" (p.824) leaflet, when presented with communication support, may enhance comprehension by minimising the cognitive load required to process both text and images.

Wilson and Wolf (2009) argue that design of printed information materials should take account of users' finite working memory capacity. Citing cognitive load theory (Sweller, 1994), they argue that reducing the burden on "extrinsic load" (p.319) (the form of information) releases cognitive resources to process the "intrinsic load" (p.319) (the content). Findings from the current study support this approach, since some participants had difficulty processing the images, which distracted their attention from the content. For example, participants sometimes persisted, despite not being able to draw a clear meaning from the images; or disengaged, either because they could not make any sense of the images, or because they took

too long to process. The concept of intrinsic load may also be useful in exploring issues such as how to convey abstract or unfamiliar concepts, and illustrating sentences versus single words in health information materials. How to achieve “germane cognitive load” (Wilson & Wolf, 2009:319), that is, the optimum presentation of text and images to promote learning, is also pertinent to this discussion.

The benefits to cognitive load of developing text content following the principles of structural and repetition priming, as in this study, are worth considering, since researchers into structural priming (e.g. Hartsuiker & Kolk, 1998; Pickering & Ferreira, 2008) argue that priming enhances language processing by reducing cognitive load.

In relation to people with aphasia, further research is needed to understand how people with acquired dyslexia read when images are present, and how the different modalities are integrated for comprehension of the information. It may be that people with aphasia, as demonstrated by Morrow et al. (2012), vary in how they process information when images and text are presented together. While most of the participants in this study seemed to refer to the image as a support for the overall concept, a smaller group preferred to see an image to support their reading of individual words, a finding which may suggest a desire to understand each word in the sentence.

Differences in reading behaviour as well as ability also need to be accounted for. For example, the model of reading proposed by Rayner and Pollatsek (1989) includes behaviours (saccades and eye fixation), processes (word processing), memory (working memory and long term memory), and world knowledge. The impairments to word processing in people with acquired dyslexia and aphasia are known through psycholinguistic assessments. Readers may, however, also display varied visual reading behaviours, cognitive function, and world (or prior) knowledge. Greater understanding of all these would provide a fuller account of individuals’ approach to information, and could potentially inform design of materials to maximise comprehension.

10.3.7 Acceptability

In the research literature, the issue of acceptability has been explored in two different ways. Firstly, researchers have sought opinions on whether information modified using ‘aphasia-friendly’ principles is acceptable to people with aphasia (e.g. Rose et al., 2003; Rose et al., 2011a). Secondly, preferences regarding the acceptability of specific aspects of the content and design of the information have been gathered (e.g. Rose et al, 2011b; Rose et al., 2012). The reported responses of study participants between 2003 and 2012 indicate an increasing acceptance of modified information over time, suggesting that generally, people with aphasia

welcome attempts to formulate accessible health information. The change in responses to adapted formats over time may indicate that people with aphasia have been increasingly exposed to aphasia-friendly information. Given that one research unit has a specialist focus on accessible information, this may be particularly relevant. Individual variation proliferates in the area of participant preferences, but appears to be frequently linked to severity of aphasia, with more severe aphasia associated with a lower acceptance.

In the present study, participants identified a need for modifications to design which they hoped would help them access relevant information. Focussing on the template materials, they discussed the importance of information which is simple in design and language but adult in style. Some sensitivity to images which were either too graphic, or were insensitive to aphasic difficulties, was highlighted during discussions. In the same way, participants responded positively to materials which they felt conveyed a sense of hope, both for themselves and for those new to stroke and aphasia.

Participants did not elaborate on what might constitute a childish style of information, since the issue was not raised as a criticism of the materials per se, but as a challenge to design. In previous studies, researchers have sought views based on their own assumptions of this concept. For example, Rose et al. (2102) surveyed participants' responses to information materials which included multiple images. Forty participants were asked to comment on information materials on the topics of stroke and aphasia via a structured questionnaire. These were designed for people with aphasia and included pictures, although no further description of the materials is provided. Participant responses to the open ended question "How do you feel receiving information that has several pictures?" (p.15) were largely positive (as categorised by the authors), suggesting that information which includes pictures does not in itself prompt negative feelings. Interestingly, however, when provided with a closed question format, 40% of the participants rated the materials as "childish" and 35% as "embarrassing" (p.18). It would be interesting to know whether the authors selected such words to force polarised responses. Here, the authors appear to assume that it is the provision of several images which may confer a childish look on information materials. Other aspects of the design, such as the presence of images, or questions of single or multiple image style, are not addressed.

Hope is recognised as an important factor in recovery for people with aphasia after a stroke (e.g. Bright et al., 2013), but no research has been found which specifically investigated the provision of information which provides hope. As Bright et al. (2013) found, "the experience of hope was fluid and changed in response to how people perceived their current situation and future" (p.48). As a highly individual phenomenon, it would be difficult to be confident in

providing hope per se. However, aspects of the literature about stroke and hope may serve to inform the content and tone of written information. Coulter et al. (1998) asked five people who had had a stroke (none with aphasia) to review patient information materials in a focus group. They found that whereas these people preferred information which conveyed a hopeful tone, stroke specialist clinicians and academics were more concerned with whether the information was accurate and evidence-based.

Anderson and Marlett (2004) also discuss the tensions between professionals wishing to provide accurate information about medical conditions, including possible negative prognoses, and the patient and family's need for hope to sustain them through a challenging experience. They advocate a problem-solving approach in contrast to "problem-centred communication" (p.60), acknowledging that "It is a challenge to communicate positively about uncertain recovery, disabilities and the real problems stroke creates." (p.60)

Bright et al. (2013) suggest that a clinical implication of their study is the provision of information "to reduce uncertainty" (p.54), presumably to inform people of services and pathways of care, or next steps in service provision. And whilst the authors also suggest that service providers have a role in developing hope with clients and families through interactive approaches, they do not explore the possible role of information materials in fostering hope.

Adverse reactions to the images of blood support the findings of Coulter et al. (1998), who reported that "gory" (p. 57) images were not welcomed. As reported by Houts et al.(2006), people did not appreciate cartoons which dealt with a serious topic in an inappropriately comic tone. Rose et al. (2012) report strong adverse reactions to some pictographic symbols shown to participants in the course of their study, but did not analyse this further.

The tone of information is carried in language and images, and as Elman et al. (2003) found, sensitivity to this may be heightened for people with aphasia. In a participatory action research project investigating access to the internet, twelve people with aphasia reviewed websites in focus groups over the period of one year. The authors report that some participants reacted strongly to some images, reporting that "The group has been very sensitive to the images of disability presented by websites, and even fleeting, seemingly innocuous images have provoked strong reactions" (p.113).

As Worrall et al. (2007) note, accessibility is an "emotive issue for people with aphasia" (p.135) since people have experienced the traumatic event of stroke and its life-changing consequences (e.g. Edelman & Greenwood, 1992; Parr et al., 1997). This finding suggests that the design of information aimed at people with aphasia requires knowledge of aphasia and sensitivity to the experience. It also lends support for the recommendation that potential

consumers of the information should be involved in developing materials to ensure their suitability and acceptability (Coulter et al., 1998, Duman, 2003). As discussed by Cruice (2007), such an approach is needed to ensure that people with aphasia are properly included in the design of products intended for their use.

10.3.8 Summary

The discussion has demonstrated the interacting issues surrounding the design of accessible information for people with aphasia, including content, amount per page, facilitative language, and formatting features such as typography, images, and layout. The guidelines developed in Phase 3 of the study incorporated all these issues, and propose practical steps towards fulfilling the design criteria of the Template developed in Phases 1 and 2.

Alongside this, it is important to distinguish between design and provision of health information.

Designing acceptable information materials for people with aphasia requires attention to the topics of information required, to visual, cognitive, conceptual, and language processing demands, and understanding of the experience of aphasia.

The provision of health information to individuals demands careful attention to each person's processing abilities, style, and preferences, tailored to their individual current needs.

10.4 Individual differences

Research involving human experience or perceptions must recognise individuality. Previous research in the area of accessible formatting has sought and recognised individual variation in responses to both the provision of information in modified formats (Rose et al., 2003; Rose et al., 2011a) and to specific aspects of formatting, such as image style, typography, or the length of information leaflets (Rose et al., 2011b; Rose et al., 2012). However, the use of surveys, rankings, and structured interviews in these studies has resulted in a tendency to report findings which reflect the majority view. Although this is consistent with the aim of identifying consensus for factors which facilitate access to information, there is a lack of accounting for the full range of individual responses. For example, studies have reported negative or unexpected responses to modified formatting, but did not include methods to explore the reasons for this (Ghidella et al., 2005; Rose et al., 2003). In their later study, Rose et al. (2012) comment that questionnaire methods limit the interpretation of responses.

In the current study, the data revealed individual variability in opinions about formatting and approaches to information, reflected in Theme 4 'Everyone's different'. Three key issues were

identified within this theme: firstly, the differences between participants in terms of their stroke and experience of aphasia; secondly, different ways in which individuals approached the template materials; and finally, the need for support in accessing information for some individuals.

10.4.1 Individuals with aphasia

Although it seems obvious to state that all participants brought their unique experience and character to the discussions, this is a key element of qualitative research, which aims to understand an issue from the perspective of those affected by it (Denzin & Lincoln, 1998; Simmons-Mackie & Lynch, 2013).

The participants in the Phase 2 study had a variety of types of aphasia, and their presentation ranged from mild to severe. They also differed in their pre-stroke lives and their approaches to living with aphasia. All the participants had had their stroke at least one year prior to the study, but this ranged from eighteen months to thirteen years. People varied in their physical recovery and the degree to which issues such as cognitive impairment affected their lives. Some lived with partners; others lived alone. Participants varied in how talkative they were. Whilst many of these differences resulted from the stroke and aphasia, some were integral to the individuals and their personal situations. It was striking that whilst they drew on their own experiences, participants also demonstrated a wider knowledge about what aphasia might mean for others. They agreed on key issues of accuracy about aphasia recovery, balancing the need for realistic and 'hopeful' information. During the focus group discussions, participants referred to the template content to reflect on their experiences of aphasia. Many issues arose from such discussions, including variations in aphasia, cognitive changes, distress, depression, and acceptance.

Previous research in this area (e.g. Rose et al., 2011a; 2012) has reported on factors of interest to the research question, such as time since onset, aphasia severity and specific language testing scores. The range of variation is highlighted, and some degree of individuality is recognised. However, these aspects of the findings are reported conceptually as relating only to fixed individual preferences. For example, Rose et al. (2011a) used Content Analysis to code interview data using researcher-defined categories, and Rose et al. (2012) used a questionnaire to gather views on aspects of formatting such as typography. Such methods reflect the stated aims of the research in attempting to identify the preferences of people with aphasia, but a possible limitation is that quantitative methods do not provide a means of interpreting the issue from the perspective of the person with aphasia. In addition, when results are analysed only in relation to the severity of participants' aphasia, there is a risk of

over stating the role of aphasia in how people respond. Consequently, and unintentionally, other aspects of individuals are under-represented in the analysis. One example of this is that participants with severe aphasia have been reported in the literature to give adverse responses to modified information. The authors explain this only in terms of comprehension (Rose et al., 2003, 2011a), noting that those who disliked adapted information tended to be people with severe aphasia, but that they could not say why. In the current study a man with severe global aphasia also disliked many of the images presented. He also expressed the importance to him of the visual appeal of images. It may be that such visual appeal becomes more significant to people for whom written language is inaccessible. An alternative explanation is that the visual aesthetic is more important for some people than others, regardless of aphasia type or severity. In this study, a man with mild aphasia also spontaneously expressed the importance of aesthetically pleasing images. This insight arose from the discussion, since participants were not asked directly about the importance of the aesthetic per se. This example demonstrates how appropriately facilitated individual and group discussion provided rich data which supported a thorough understanding of participants' responses. And whilst aphasia is common to the participants, it is not their sole defining characteristic, nor does it inform all their preferences.

10.4.2 Individual approaches to information content

In previous studies seeking the response of people with aphasia to health information, participants were asked to look at information materials with a view to reading (Rose et al., 2003), reviewing accessibility (Ghidella et al., 2005) or commenting on the content and format (Rose et al., 2011a). No observations are reported of how participants approached these activities.

A novel finding of this study concerns individual variation in approaches to information. In the course of the discussions, participants revealed differences in how they looked at the template. Most people were guided initially by the header sentence, and then looked at the sentence and images in turn. Some participants limited the number of elements they approached, focusing attention at the top of the page only. In contrast, others seemed to attempt to look at the template as a whole unit. The ensuing discussion suggested that such differences reflect whether participants persist with their pre-stroke visual style, or modify their approach to accommodate their aphasia. For example, whether a person tends read quickly, despite not being able to process the full meaning, or whether people have learnt through having aphasia to approach information more slowly and methodically. Such differences did not appear to have any relation to severity or type of aphasia, but seemed more idiosyncratic.

This suggests that factors, such as cognition and personal reading style, may play a larger role in how people interact with information, an idea supported by the wider literature in aphasia. For example, research into successful text level reading highlights the role of cognitive functions such as working memory and drawing inferences (Chesneau & Ska, 2015; Meteyard et al, 2015), and executive function for self-pacing to maximise comprehension (Caplan et al., 2007). As Caplan et al. note, using such cognitive resources may reduce the capacity available to an individual for other tasks, such as processing language or visual content.

The finding that participants varied in their approach to the template is consistent with the findings of Morrow et al. (2012), who identified variations in how people with and without aphasia look at stimuli containing words and images. Whether this is linked with specific cognitive profiles, or reflects a more general individual style, requires consideration. Further research is also indicated to determine whether readers' idiosyncratic approaches to modified formats have an impact on their comprehension of the content.

10.4.3 Support with accessing information content

Research into modified formatting has focused on individuals' responses to information via testing (e.g. Brennan et al., 2005; Wilson & Read, 2016), surveys (e.g. Rose et al, 2012), ranking materials (e.g. Ghidella et al., 2005), or commenting during individual interviews (Rose et al, 2011a).

Whilst the current study also aimed to explore individuals' views on their independent access to information, some participants identified the need for support in looking at information. This was highlighted as important for people early after a stroke and for some people with chronic aphasia. Participants commented that the template design could help family members or others talk through and explain information at a pace to suit the individual.

The comments made by participants about supported access to information echo what has been reported previously (e.g. Parr et al., 1997), that people with aphasia have different information needs at different times after a stroke.

For people with severe aphasia, or with concomitant cognitive impairments, independent access to information may be an unrealistic target. For such individuals, a more helpful approach may be to provide information in a format which enables their communication partners (family members, service providers) to support access. Knollman-Porter et al. (2015) discuss the concept of "partner assistance" (p.1461). This is described as reading aloud, but the authors propose that training for reading support could be provided in the same way as conversation partner training (Kagan, 1998; McVicker, Parr, Pound, & Duchan, 2009). The

template design described here could be used to support such a paired approach to reading, since single concepts are introduced and developed in a step-by-step progression.

10.5 Methods for involving people with aphasia in developing accessible information

As previously discussed in Section 4.1, people with aphasia have been involved in research and development of accessible information in different ways. Developmental work at aphasia centres such as Connect, UK has involved people with aphasia as partners in an approach based on a social model of disability, with the aim of developing information materials (e.g. Parr et al, 1999). Whilst such projects have resulted in widely-used resources, little detail has been provided by authors to display the evidence for the principles used or the methods followed.

Responding to the need to develop a more robust evidence base for accessible information and aphasia, subsequent empirical studies employed a positivist approach, involving people with aphasia as research participants. Such studies aimed to clarify issues, such as the impact of typography on comprehension of text (e.g. Brennan et al., 2005; Wilson & Read, 2016). Participants in these studies were individually tested, surveyed, or interviewed, but limited detail has been reported on the methods used to support their participation, and no studies have reported the impact of the findings on information resources developed in light of the research.

In this section, issues relating to the methodology adopted in this study for developing the evidence into accessible information with people with aphasia are discussed, with reference to the participants, the materials, the data collection methods, and the data analysis methods used in Phase 2 of this study.

10.5.1 Participants

Previous studies of modified formatting have tended to involve participants with mild or moderate aphasia (e.g. Rose et al, 2003; Wilson & Read, 2016), with a paucity of contribution to this field from those with more severe language impairments. Only McKelvey et al. (2010) sought participants with severe aphasia, and this sampling strategy can be attributed to the study aim of identifying optimum images for use in AAC.

The three studies reported by Rose et al. (2011a, 2011b, and 2012) were conducted at the same research centre, and involved the same participants. This can be said to reduce the numbers of people with aphasia who have contributed to the evidence. In addition, it can be

argued that these participants may not be representative of the population with aphasia, since they have been exposed to modified formatting through the studies.

In the current study, purposive sampling (Patton, 2002) was undertaken to ensure that people with mild, moderate, and severe aphasia were included, in order to capture the views of a wider segment of the population with aphasia than has previously been achieved. In common with other studies (Brennan et al., 2005; Dietz et al., 2009; Ghidella et al., 2005; Jayes & Palmer, 2014; Rose et al., 2003; Rose et al., 2011b), all Phase 2 participants had chronic aphasia and commented on their current and earlier information needs with the benefit of experience.

Participants' language was tested in some detail, as described in Chapter 6. On reflection, two aspects of this process would benefit from modification. Firstly, the CAT (Swinburn et al., 2005) reading subtests did not always reflect the participants' reported level of difficulty, suggesting that these tests lacked sensitivity. For example, participants reported greater difficulty with everyday reading activities than was predicted by the test scores. In addition, as noted by Dietz et al. (2009), broader testing across cognition would have provided useful background information, against which to understand individual responses and analyse the data. For example, participants reported difficulties with remembering information, despite no overt impairments to their cognition. Subtle changes to language and cognitive abilities appeared to have an impact on individuals, and therefore require a fuller account.

The current study has contributed the views of people with a broader range of types and severities of aphasia to the evidence for modified formatting. Consistent with the aims of qualitative methods, it is the inclusion of "information-rich cases" (Patton, 2002:230) which is important to the collection of rich and varied discussion data, rather than the numbers of participants included.

10.5.2 Materials

The materials presented to participants in previous research has varied widely, according to study aims and objectives. Published information resources (e.g. Parr et al., 1999, 2004; Cottrell & Davies, 2006) represent the output of collaborative work with people with aphasia. The purpose and practice of such collaborations, which may be described as action research (Patton, 2002), means that traditional research accounts of the development process have not been published.

Previous empirical research (Rose et al, 2003; Rose et al., 2011b; 2012) and one qualitative study (Rose et al., 2011a) sought the opinions of people with aphasia regarding modified

formatting, by showing materials produced according to 'aphasia-friendly' principles. In one study, however, Rose et al. (2011b) asked participants to state their preferences for image styles in health information without reference to any visual materials, suggesting that participants were able to understand the issue and visualise independently to consider their opinions. Topics included in study materials have varied widely, including relevant and non-relevant health information (e.g. Rose et al., 2003; Ghidella et al., 2005), general interest topics (Brennan et al., 2005; Dietz et al., 2009; Wilson & Read, 2016), and topics of personal relevance (McKelvey et al., 2010).

A novel aspect of this study is the systematic iterative design process described herein. In Phase 1, the prototype materials were developed from the findings of reviews in the literature concerning modified formatting, factors facilitating language processing in aphasia, and the health information topics required by people with aphasia. The materials were then refined through the collaboration with people with aphasia in the iterative design process, described in Phase 2. This approach has resulted in the design of a novel template for health information for people with aphasia, incorporating the principles of accessible language and formatting discussed in Section 10.3.

The production of this template is consistent with health literacy literature, which states that people affected by a health condition should be involved with producing information (e.g. Coulter et al., 1998), and with concepts of inclusion and user-centred design (Cruice, 2007; Wilson et al., 2015).

In realising the final template through the prototype design and iterative design process (Sears & Lund, 1997), the study achieved its overall aim of developing an evidence-based template for conveying health information for people with aphasia. Previous collaborations (e.g. Parr et al., 1999, 2004) have developed new information materials for people with aphasia and previous empirical studies have examined the impact of modified formatting on people with aphasia. This thesis describes a novel study which has combined a collaborative, user-centred approach, embedded within a rigorously designed and reported study.

10.5.3 Focus group methods

Previous studies into accessible formatting have conducted individual testing, surveys and interviews with people with aphasia (e.g. Brennan et al., 2005; Ghidella et al., 2005; Rose et al., 2011a). Focus groups have not previously been used to explore the impact of modified formatting on participants with aphasia and in this regard, this study attempted a novel method. Central to the decision to conduct focus groups for the data collection was the

consideration of methods to support the communication of the participants with aphasia, to ensure the comfort of all participants (World Medical Association, 2001) and the quality of the data collection (Finch & Lewis, 2003).

The literature reporting the involvement of people with aphasia in focus groups suggests that researchers utilise a range of strategies, including their clinical skills in interacting with participants (e.g. Kerr et al., 2010), the provision of visual materials to support generic language processing (e.g. Dalemans et al., 2009), and, in the case of Murphy (2006), a group Talking Mat®.

In the current study, principles for supporting participants' communication were derived from the literature (e.g. Kagan & Gailey, 1993; Lawson & Fawcus, 1999; Lyon et al., 1997; Luck & Rose, 2007) and were followed in the focus groups. Providing individual communication support to all participants, as well as a group leader (Finch & Lewis, 2003; Garcia et al., 2000) aimed to foster a sense of equality in the focus groups, but it was evident that the people with the most severe aphasia required more individual facilitation than those with milder language impairments. Despite the level of communication support, and participants' willingness to respond to the visual materials, there were times when researchers questioned whether some participants were fully able to understand the issues. There were also occasions when participants were unable, despite facilitation, to articulate or develop their opinions.

The use of individual Talking Mats® in a group of people with aphasia was a novel approach in this study. Previous research using Talking Mats® has been conducted on an individual basis (e.g. Murphy, 2000; Murphy et al., 2005; Murphy, 2006; Murphy et al., 2010). More recently, the use of individual Talking Mats® within a group context have been reported to support communicative effectiveness of people with Huntington's Disease (Hallberg, Mellgren, Hartelius, & Ferm, 2013).

The data generated during the focus groups indicate that the Talking Mats® framework was an effective means of providing both communication support and a tool for individual data collection. The subsequent group discussions were also richer since participants had time and space to develop their own views, with the mat still in place during the discussion as a point of reference. The Communication facilitators were key to this process, functioning both as a supporter for the Talking Mats® process and as a conversation partner. Throughout Phase 2, all participants contributed, remained engaged, and attended both focus group meetings, suggesting that they found the groups a supportive environment in which to exchange views. The transcriptions record a number of occasions when group members overtly support each

other to express their views, despite evident word finding difficulties, and the amount of laughter recorded testifies to the good humour shared in the groups. It is possible that hearing others' views encouraged participants to be more critical of the materials than they might have been in an individual interview, as suggested by Finch and Lewis (2003) and Kitzinger (2006). The combination of individual supported Talking Mats® conversations and facilitated group discussions in the focus groups allowed for different ways of interacting and expressing views.

In the field of co-design, whereby end users of products or services are involved in the design process, recent research has used focus group methods to involve people with aphasia in designing novel approaches to language therapy (Galliers et al., 2012; Wilson et al., 2015). This suggests that there is a growing confidence in this methodology for including people with aphasia in design projects. Suitable methods for providing linguistic and communication support need to be established, however, as discussed by Galliers et al. (2012), to ensure the credibility of the findings.

10.5.4 Data analysis methods

Decisions regarding data analysis methods follow from the aims and design of research (Bryman, 2008). Previous empirical research addressing the response of people with aphasia to modified formatting (e.g. Ghidella et al., 2005; Rose et al., 2003) or aspects of formatting (e.g. Brennan et al., 2005; Rose et al., 2012) have generated quantitative data. In keeping with the hypothesis-testing approach, the data have been analysed deductively, in response to the research questions. The sole qualitative study by Rose et al. (2011a) generated interview data. The data were analysed using Content Analysis, which records the incidence of participant responses according to the researchers' predetermined coding criteria. On a deductive - inductive continuum, Content Analysis is considered to represent a quantitative approach to the analysis of data derived through qualitative research methods (Silverman, 2006).

The analysis of the Phase 2 focus group discussions was conducted using Framework analysis (Richie, Spencer, & O'Connor, 2003), an approach which allows for the use of a deductive analysis, through the use of an existing framework, similar to Content analysis. In the current study, however, the researcher took a more inductive approach, seeking to capture new perspectives on the topic of accessible formatting, and the full range of individual views. The collection of both qualitative discussion data and rating scales data provided a means of triangulating different forms of data, both in the course of data collection and in the subsequent data analysis (Denzin & Lincoln, 1998).

The language processing impairments inherent to aphasia present a challenge to collecting qualitative data with this group, particularly with people who have more severe impairments. It may be partly for this reason that previous studies have used more quantitative methods, which allow participants to select from choices, rather than generating their own responses (e.g. Luck & Rose, 2007). However, as identified by previous researchers (e.g. Rose et al., 2003; Rose et al, 2012), study findings were limited by the lack of insights gained into the reasons for participants' responses. And as discussed in Section 10.5.1, a deductive approach to data analysis may potentially limit the development of new ideas or interpretations of the data.

Inductive methods are often selected to investigate areas of knowledge in which there is limited evidence, to build theories (Bryman, 2008). The use of deductive methods to test theories implies therefore that there is sufficient theoretical evidence in place to adopt empirical methods. The limited evidence base into accessible formatting identified in Chapter 2, however, suggests that this is an area in which further theoretical evidence is still required.

The analysis of the data in the current study has resulted in new findings, including the optimum amount of information per page, the optimum emphasis of key words, and the need for an exact match between text and images. New connections have been made between people with aphasia and aspects of formatting, such as individual approaches to looking at information and the importance of the personal aesthetic. Issues which require further clarification, such as the presentation of images and text together have been identified. Ultimately, the methods, including the approach to data analysis, resulted in the design of the novel template described in this thesis.

The implications for further research are outlined in Section 10.8.2. With a view to developing the theoretical framework for accessible formatting, further focus groups could be conducted and their data analysed using the framework devised in this study in a more deductive method (Pope, Ziebland, & Mays, 2006). Confirmation and building on this framework would then suggest further routes for empirical research, to test the theory (Bryman, 2008).

10.6 Quality, rigour and transferability of findings

The quality of research is judged by the credibility and transferability of the findings (Mays & Pope, 2006). This study has employed techniques from both qualitative and quantitative paradigms, in the pursuit of a well-crafted investigation (Sandelowski, 1995; Symonds & Gorard, 2010). Rigour has been addressed throughout the thesis, with attention given to providing a clear account of the methods of data collection and analysis, to enable readers to make their own judgement of the quality of the research (Seale, 1999; Spencer, Ritchie, Lewis,

& Dillon, 2003). In this section, two key issues, the validation and the transferability of the findings, will be considered.

10.6.1 Validation of findings

Several methods were used to ensure the credibility of the findings. Triangulation of discussion data and Talking Mats® ratings provided a means of checking different perspectives, providing a richer account than that afforded by a single perspective (Denzin & Lincoln, 1998). The subsequent presentation of the findings within a single thematic framework demonstrates this clearly, describing and accounting for similarities and differences in the two types of data.

Analysis by one researcher can be criticised as subjective. To validate the interpretation throughout the analysis, data were presented and discussed with supervisory colleagues, who were invited to challenge the researcher's interpretations of the data (Miles & Huberman, 2002).

Validation by participants, to ensure that their views were accurately reported, was incorporated into the study design, due to their involvement throughout the iterative process, in which issues could be discussed at the time they were raised (Seale, 1999). Following this, participants were not subsequently invited to review the results of the data analysis as a separate enterprise, since it was reasoned that such an approach could be problematic for people with aphasia, potentially challenging both people's memory of their contribution, and the linguistic abilities required to confirm or challenge the researcher's interpretations of the data. This position concurs with the caution against respondent validation proposed by Hammersley and Atkinson (1995), who highlight the potential difficulties for participants when asked to remember the details of their contributions to the research.

10.6.2 Transferability of findings

The topic addressed in this thesis is of significance to both people with aphasia and those who work with this population, therefore implicit in this discussion is the aim of what Damico et al. (1999) term "clinical utility" (p.660); that is, the transferability of the findings to wider contexts.

Addressing the issue of transferability of findings, Lewis and Richie (2003) identify two key issues for consideration. Firstly, the quality of the data collection and analysis, and secondly, whether the sample can be said to represent the target population.

This thesis has aimed to provide a transparent account of the research undertaken, including its theoretical context. Chapters 2 and 4 provide the theoretical context, with explanations of how the various literatures have informed both the objectives and design of the study. A

detailed description of the initial design and subsequent iterative development of the template materials has been documented, with the aim of enabling readers to both understand the process undertaken, and to gain a clear picture of the template materials reviewed by the participants. The procedures for collecting and analysing the data, and additional measures to ensure rigour in the conduct of the study, have been recorded transparently in the body of the thesis. Throughout, any difficulties or errors have been documented.

Whether the participants in this study can, or should be said to represent the aphasic population as a whole is a challenging question. No group of fourteen can be said to represent a whole population. In this context, purposive sampling (Patton, 2002) was conducted to ensure opinions could be collected from both women and men, from people of differing ages, and from people affected mildly, moderately, or severely by aphasia. This last was considered of primary importance, since previous research findings have largely represented those with mild and moderate aphasia. This raises a question of whether those most severely affected can genuinely contribute to the findings, due to potential difficulties understanding the aims and tasks, or expressing their thoughts. In this study, methods to maximise the participation of all were developed from the existing literature (e.g. Kagan, 1998; Murphy, 2000) and operationalised in the data collection methods. Participants with severe aphasia did contribute, but their responses showed a high level of individual variation, suggesting that aphasia severity is only one factor in their response to information materials. The analysis demonstrated that factors other than aphasia itself, such as cognition, confidence, and individual style all contributed to participants' views.

The methods used highlighted individuality in an attempt to understand the issues from the perspective of people with aphasia, consistent with the aims of qualitative research (Damico et al., 1999; Patton, 2002; Spencer et al., 2003). There was also an attempt to capture the commonality of responses, to derive implications for practice.

Future research could stratify the sample in greater detail, for example through seeking further detail on aphasia subtypes, cognition and vision, ethnicity and culture, and health literacy behaviours. Such segments would then provide greater opportunity for analysis and would potentially reveal further issues for the transfer of findings.

10.6.3 Reflection on strengths and limitations

One aspect of quality is the demonstrated reflexivity of the researcher (Seale, 1999). Throughout, the reporting of research methods and findings has aimed to provide a transparent account of the study, and reflections on the methods and findings have been

included throughout this thesis. Final reflections, based on the strengths and limitations of the whole study, are outlined in this section.

The strengths of this study lie in the methods used in both phases to generate valid and relevant findings. In Phase 1, the prototype template was developed following scrutiny of the evidence base in three areas. The application of research evidence concerning the facilitation of language processing to the principles for the template design provided greater specification than has previously been achieved. The inclusion of principles derived from evidence regarding priming and language processing was, in addition, a novel aspect of this study.

In Phase 2, the collaboration with people with severe, as well as mild and moderate, aphasia means that the perspectives of people with a wider range of aphasia types and severities have been added to the overall evidence base on accessible information. This was achieved in this study via careful consideration of facilitative and inclusive methods. Secondly, and alongside this, the materials developed in Phase 1, produced to a professional standard in collaboration with professional graphic designers, promoted participants' genuine engagement with them as relevant information. The clarity of description of the template aimed to enable readers to envisage the materials and evaluate the data analysis in relation to them more transparently than has been achieved in previous studies.

The methods selected for collecting and analysing the data, combining rating scales and facilitated group discussion, resulted in a clearer understanding of the perceptions and issues for participants. The use of the Talking Mats® framework by individuals in a group context, supported by communication facilitators, was a novel approach taken in this study, and the findings generated revealed insights not previously gathered in this topic. The study has therefore extended the evidence base, and generated implications for practice and further research.

There are, however, limitations to the study which require acknowledgement. The study was conducted as part of a larger commissioned project within a limited timescale. With more time, a user group could have been established to collaborate with the initial development of the project, for example, to identify the topics for the materials, and to develop the focus groups formats.

In line with previous studies, participants were profiled based on their linguistic processing abilities. Whilst this was conducted thoroughly, the data analysis would have benefitted from a greater understanding of participants' visual and cognitive processing abilities.

Finally, part-time study has lengthened the process of analysis and reporting, resulting in a time-lag between the data collection and the presentation of the thesis. Whilst not an inherent weakness of the study itself, this has resulted in a delay in disseminating the findings more widely, perpetuating a lack of published evidence in the area of accessible formatting for people with aphasia. In the final section, the implications for practice and for further research will be outlined.

10.7 Implications for practice and future research

People with aphasia both need and want to receive information after a stroke, but research demonstrates that they continue to feel under-informed (Hinckley et al., 2013; Rose et al., 2010). Whilst significant progress has been made in the area of interpersonal communication access (e.g. Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010), the evidence base for how to format accessible information remains limited. Alongside this, knowledge about the use of facilitative language for people with aphasia has been inconsistently applied in the area of health information. This may in part be due to the inherent difficulty of concepts to be communicated, or due to a lack of knowledge about how to use language to support readers with aphasia. These gaps in evidence, knowledge, and skill have resulted in a tension between what healthcare professionals should provide and what people with aphasia receive in practice.

This thesis has framed the issue of accessible information for people with aphasia within two broad concepts: health literacy and accessibility. A wealth of research relating to the improved outcomes for informed patients underpins the concept of health literacy (e.g. Kickbusch et al., 2013). In this context, the development of information which can be understood by service users with aphasia can be regarded as a health literacy intervention (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010).

Concurrently, the global ambition to increase access to all, articulated in the aims of the United Nations (2008) and the World Health Organisation (2011), includes the concepts of communication and information access. This ambition is now embedded within systematic processes to improve communication and information access to any person with a communication disability, both as a citizen (Equality Act, 2010), and as a user of health and social care services (NHS England, 2015). This thesis contributes to the evidence in both health literacy and information access, with implications for clinical and research practice.

10.7.1 Implications for practice

In health literacy terms, the template is an intervention, which serves a dual purpose. Its first function is to guide the design of information for people with aphasia. As such, it incorporates the key principles of language and formatting accessible information for people with aphasia. The second function of the template is to provide a physical means for conveying health information.

The guiding function of the template has reaching implications for improving the provision of information to people with aphasia, since it involves transferring the findings beyond the current context (Lewis & Richie, 2003). Since the design characteristics of the template serve to illustrate the language and formatting requirements of those affected by aphasia, it has the potential to increase service providers' awareness of aphasia and the needs of this population. The template could serve as a point of reference for adhering to guidelines and policies (e.g. NHS England, 2015), functioning as a means of ensuring good practice. The translation of the template principles into practical guidelines further supports good practice, by guiding the design of new information materials.

As a physical resource, the template has a range of flexible applications, supporting the three levels of health literacy (Nutbeam, 2000). Firstly, by conveying information in a maximally-accessible format, it contributes to people's understanding of basic health information. Secondly, it functions as a tool to support communication about health, with the template providing a shared point of reference in, say, an interaction between a person with aphasia and a health professional. Thirdly, to support critical health literacy, template materials could be used by people with aphasia as a resource to explain their health to others, thereby increasing awareness of the condition.

Many people with aphasia have language or cognitive impairments, which preclude their independent reading, and they may depend on family members or others to filter information for them. Howe et al. (2012) found that family members wanted to be better informed, to support their partners to understand information after a stroke. This template could be used to support shared reading with others, as well as providing a reference point for later looking. This may be a useful addition to the various ways of providing information after a stroke, which could be tailored to individual need.

This thesis has focused on the factors affecting accessibility of health information. There is, however, potential to use the template to convey other types of information in a range of contexts, and in different media, including electronic and web-based information.

Training healthcare professionals and others to produce accessible information is pivotal to the implementation of good practice (Graham et al., 2006). Such training needs to include knowledge of what aphasia is and its potential impact on individuals, as well as specific skills training in the appropriate use of language and accessible formatting. This could augment training already judged to improve interpersonal communication between people with aphasia and care providers (e.g. Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). The guidelines developed in this study support the development of good practice by individual healthcare professionals and others, and could be used as a basis for such training.

10.7.2 Implications for further research

As previously identified, research into accessible information for people with aphasia is at an early stage of its development and the evidence is limited. This study has contributed to the evolving evidence base, but inevitably raises further questions. Key areas for research are outlined below.

Whilst the study gained further insights into the perceptions of people with aphasia, participants' comprehension of the materials was not tested. Having developed a template which is acceptable to people with aphasia, further research should establish the impact of this format on the comprehension of health information when contrasted with traditional aphasia-friendly formatting. Within this aim, the development of methods to check comprehension of information remains a further challenge for future studies.

The guidelines developed in this study require further evaluation. Firstly, research is indicated to examine the quality of information materials produced by users of the guidelines, potentially informing the training needs of staff. Secondly, the responses of people with aphasia to information materials produced using the guidelines is needed, to ensure that the preferences of larger numbers of people with aphasia are included in future research and development in the area of accessible formatting.

Insights into the varied approaches to visual materials were revealed in this study, consistent with previous reports (e.g. Morrow et al., 2012). Further research is indicated to examine in more depth how people with aphasia look at information materials, using eye-tracking technology, for example, to inform optimum layout of concepts.

Given the equivocal findings of this study and others concerning the use of images (e.g. Brennan et al., 2005; Rose et al., 2012), there is also a need to investigate the effectiveness of materials which do not include images. Different groups may benefit from such investigation,

for example, people with mild reading impairment, or those for whom images present a significant distraction.

People with chronic aphasia participated in this study, but all acknowledged that their specific information needs had changed over time. Further research is needed to explore accessible formatting with people in the early stages after stroke, a sample which none of the current or previous literature has included.

This study involved only people with aphasia. The literature reports on the separate information needs of families (Avent et al., 2005; Hilton, Leenhouts, Webster, & Morris, 2014), but no studies have investigated how best to provide information to patients and families together, and none have explored the role of family members in mediating information for people with aphasia. Howe et al. (2012) report that some family members expressed the need to be better informed, in order to support their partners with aphasia to understand new information. Further research is therefore required into the ways in which accessible information can be provided to both patients and their family members.

The physical form of the template was developed as a set of cards, allowing participants to handle the materials. Further study into the application of the template into other media, including electronic and web-based information is now indicated. Caute et al. (2016) found that participants' reading confidence and enjoyment increased when using e-readers, on which they were able to adjust the text size and line spacing. The potential for technology to increase individual control in accessing information is vast, but practical solutions require robust investigation.

The template has provided principles for making information accessible, and guidelines are now freely available (Herbert et al., 2012). Issues of knowledge translation now need to be explored, and the training needs of providers identified, to ensure that the social and political will towards inclusive healthcare systems and the wider society is underpinned by adequate knowledge and skills.

The distress and sense of exclusion felt by people with aphasia when faced with inadequate and inaccessible information has been documented (e.g. Parr et al., 1997). Ultimately, the impact of accessible information on the outcomes of people with aphasia after stroke requires investigation, with the aim of improving both the experience of healthcare, and the health literacy of people with aphasia.

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Appendix A

Examples of information sentences generated for Template 1

Topic	Subtopic	Sentences
Stroke illness	Your brain	your brain controls your body your brain controls your arms and legs your brain makes your speech your brain understands speech
	your blood	your brain needs blood blood feeds your brain blood keeps the brain healthy arteries carry blood to the brain arteries need to be clean
	stroke illness - ischaemia	your arteries get blocked blocked arteries stop blood the brain can't work
Aphasia	background information	language is talking and understanding language is reading and writing stroke can damage language: this is aphasia
	facts	it is difficult to say words it is difficult to form sentences it is difficult to ask for things it is difficult to say yes or no
	what helps	practising the words again and again helps pointing helps using your face helps
Emotions after stroke	facts	stroke can cause depression stroke can cause anxiety stroke can cause frustration
	what helps	seeing a Clinical Psychologist will help telling people how you feel will help

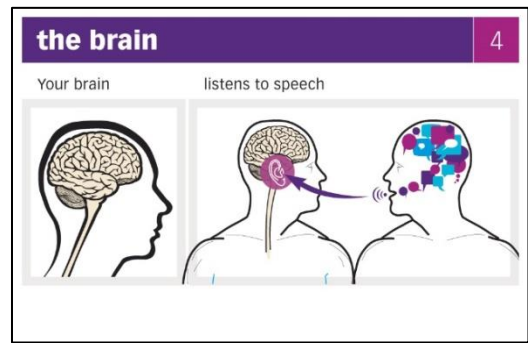
Appendix B

Examples of Template 1 – variations in image style

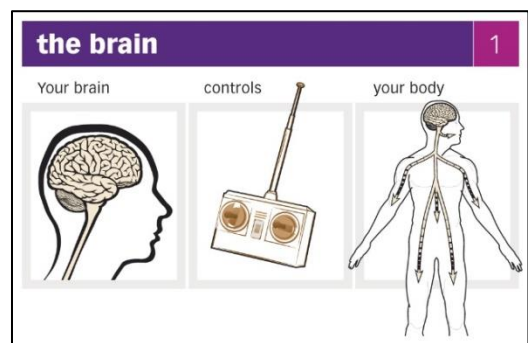
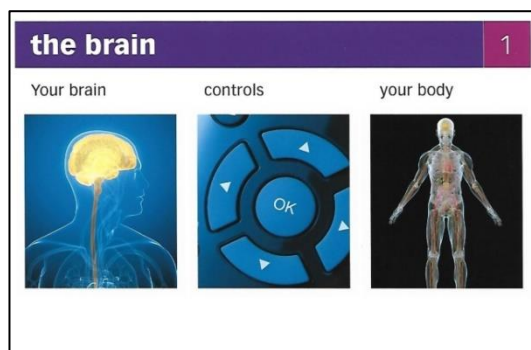
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(examples shown smaller than actual size)

Example 1: Your brain listens to speech



Example 2: Your brain controls your body



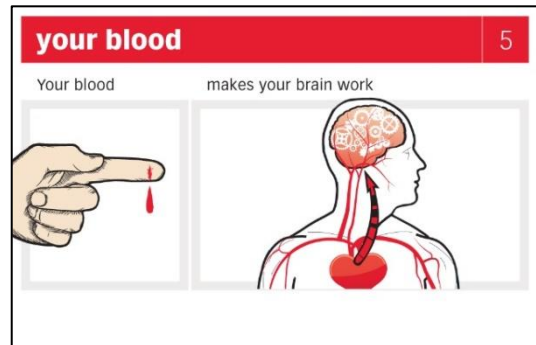
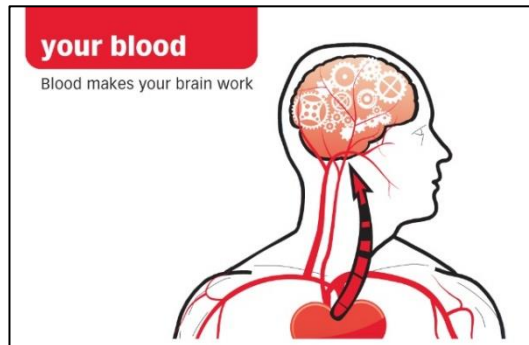
Appendix C

Examples of Template 1 – variations in number of images per concept

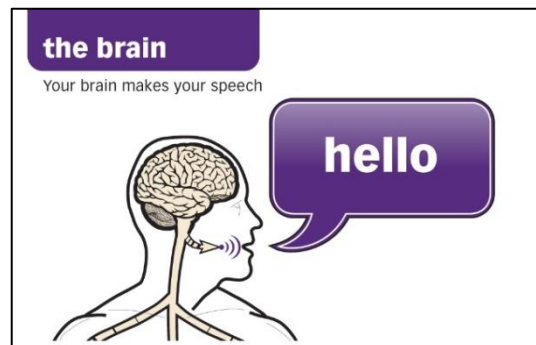
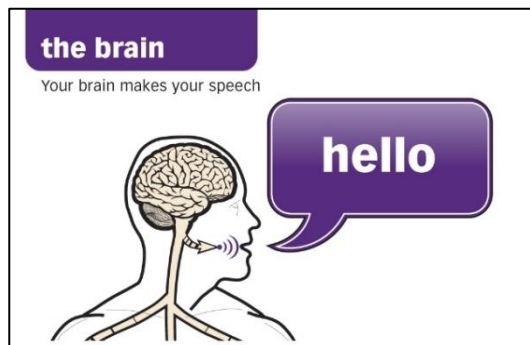
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(examples shown smaller than actual size)

Example 1: Blood makes your brain work



Example 2: Your brain produces your speech

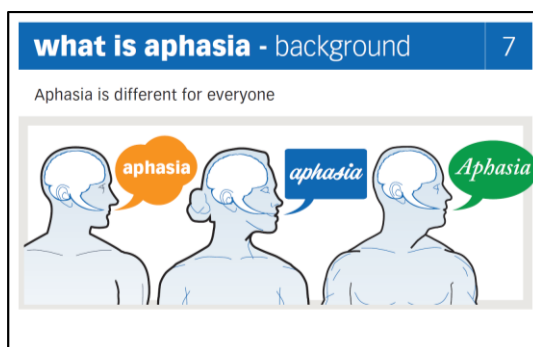
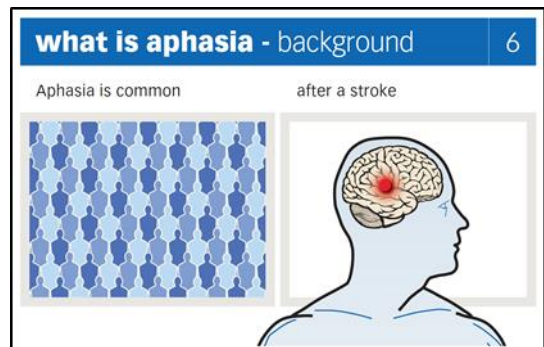
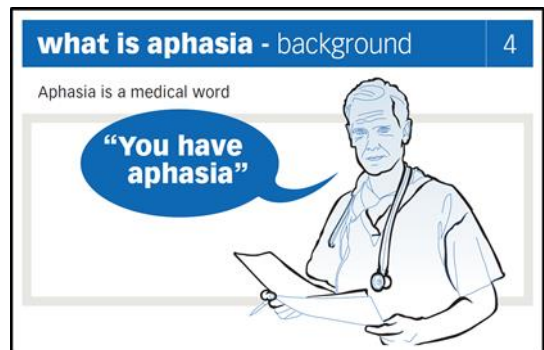
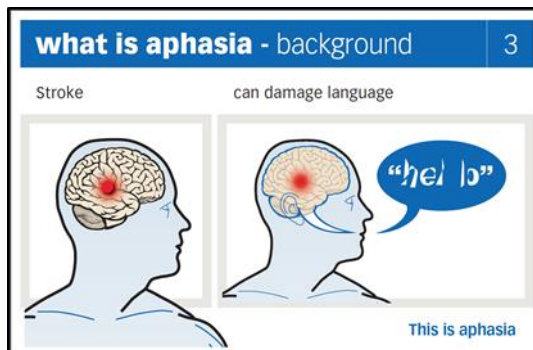
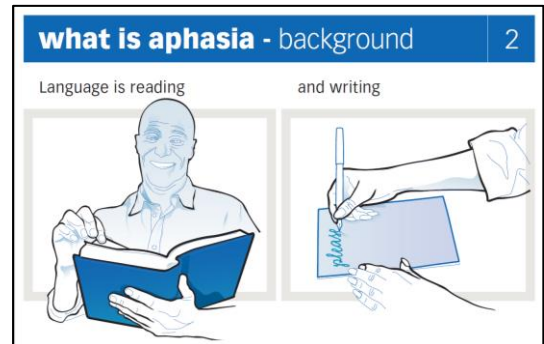
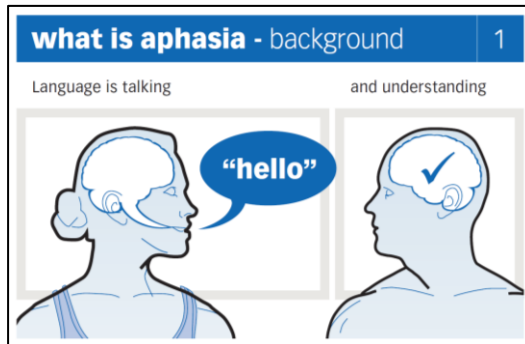


Appendix D

Set of Template 2 materials on the topic aphasia

All images © The Stroke Association

(examples shown smaller than actual size)



Appendix E

Focus group 1 - Typography materials, shown actual size.

1. Variations in font size

Arial 10	Cup of coffee
Arial 12	Cup of coffee
Arial 18	Cup of coffee
Arial 26	Cup of coffee

2. Variations in font style

Arial 12	Cup of coffee
Times New Roman 12	Cup of coffee

3. Variations in emphasis. Focus group 1 materials

Arial 12 + 16	Cup of coffee
Arial 12 + bold	Cup of coffee
Arial 12 + italics	Cup of <i>coffee</i>
Arial 12 + underline	Cup of <u>coffee</u>

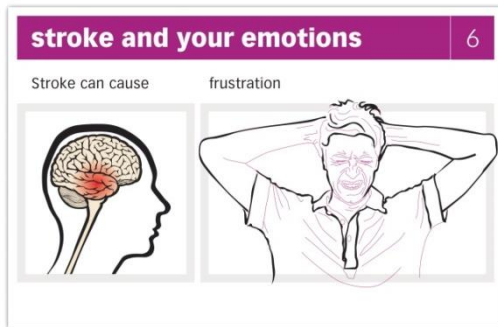
Appendix F

Focus group 2 – Template 2 materials to explore emphasis

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(examples shown smaller than actual size)

Normal font (control)



Bold font



Large font



Large and bold font



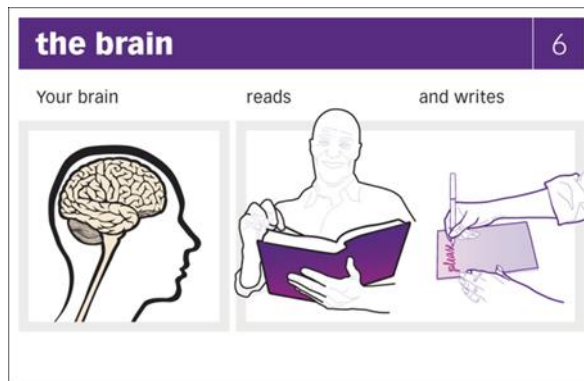
Appendix G

Focus group 2 – Template 2 materials to explore preferences for number of concepts per page

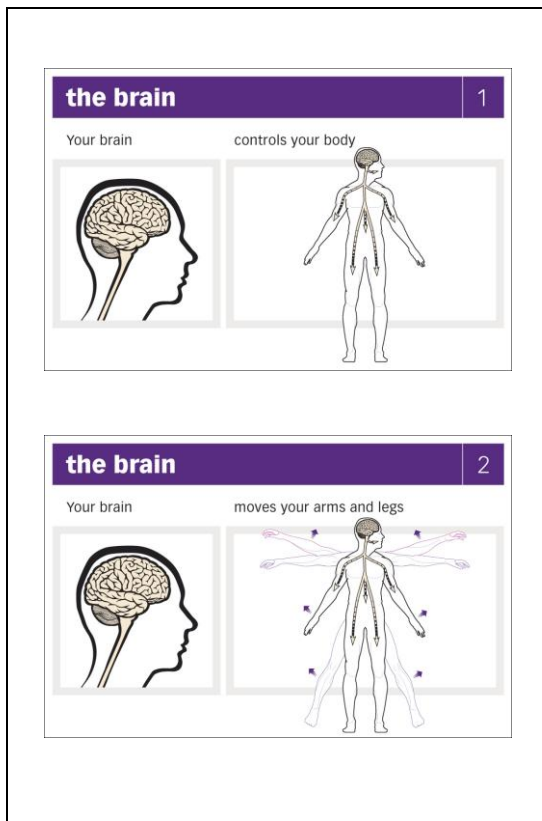
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(examples shown smaller than actual size)

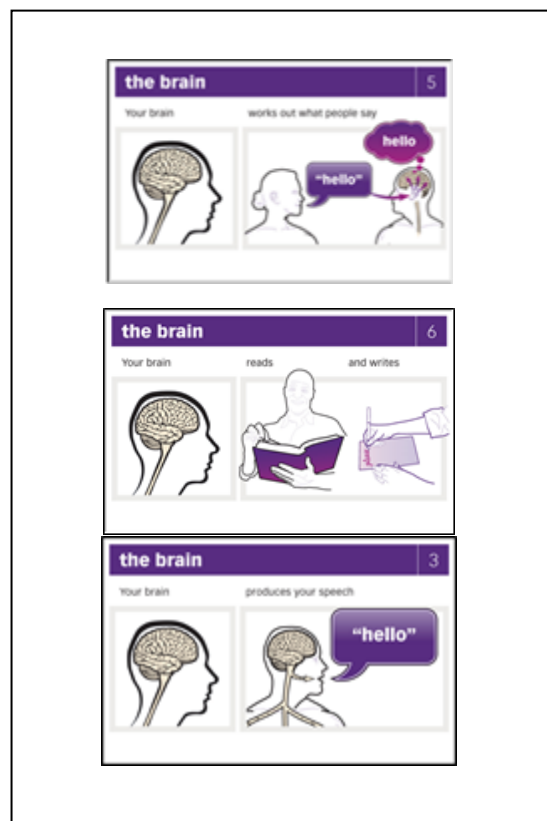
One concept per page



Two concepts per page



Three concepts per page



Appendix H

Visual rating scale provided on Talking Mats® framework

(shown smaller than actual size)



Appendix I

Examples of Talking Mats® data

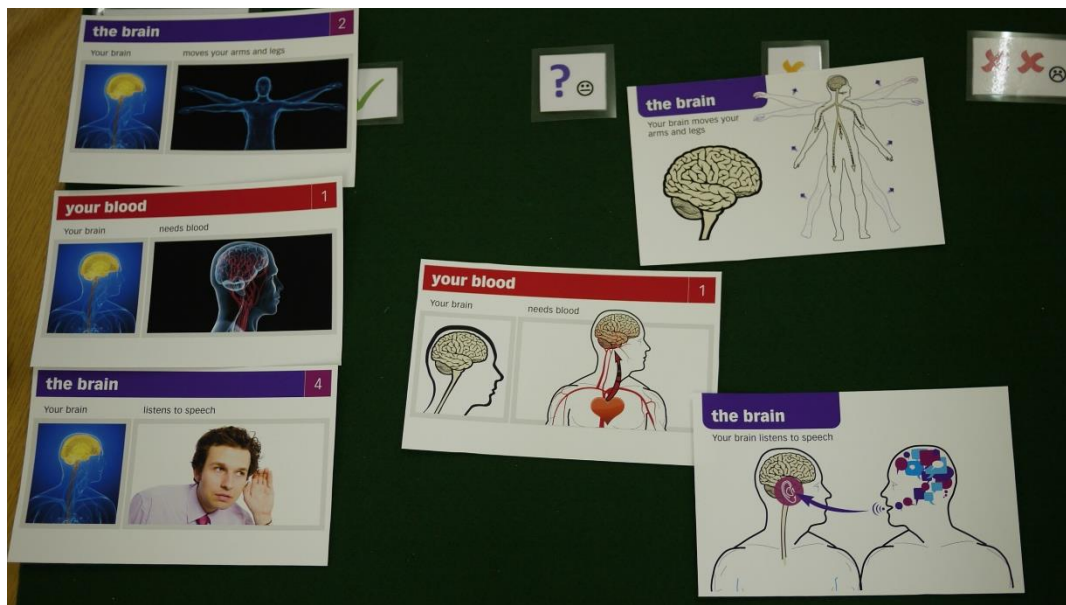
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Talking Mats® examples showing ratings for image style preferences

Example showing preference for line drawings

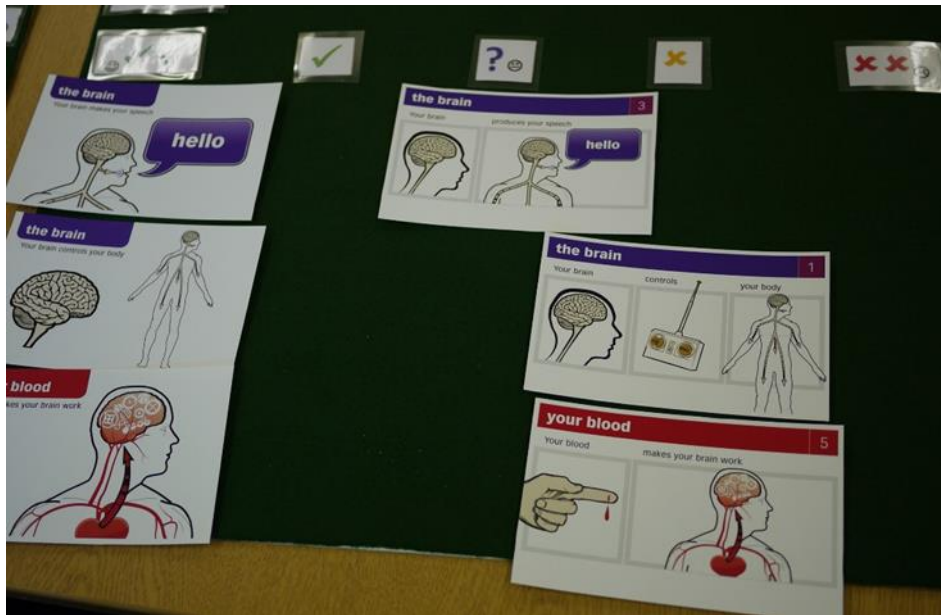


Example showing preference for photographs

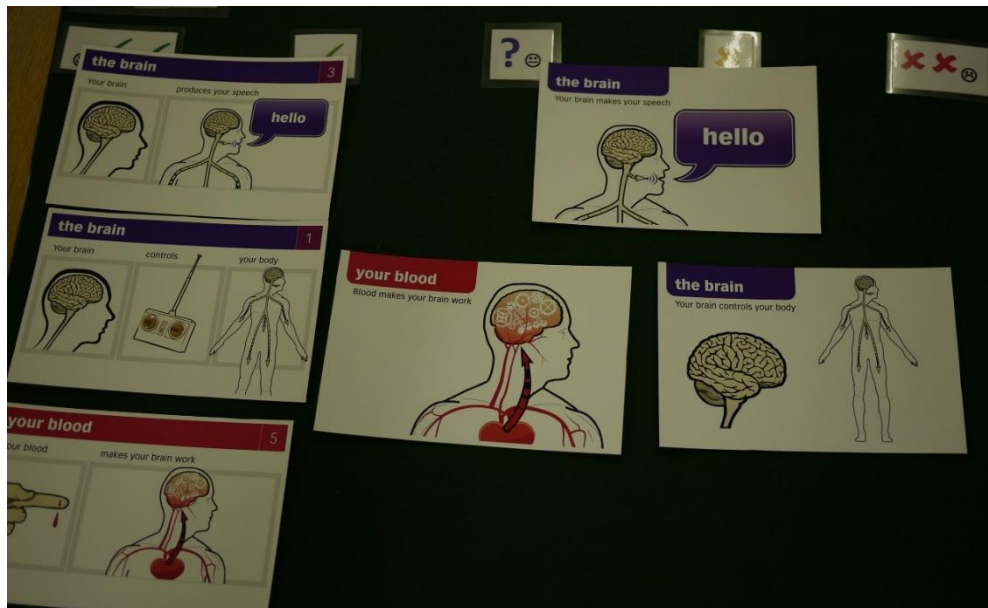


Talking Mats® examples showing ratings for number of images per sentence

Example showing preference for single image

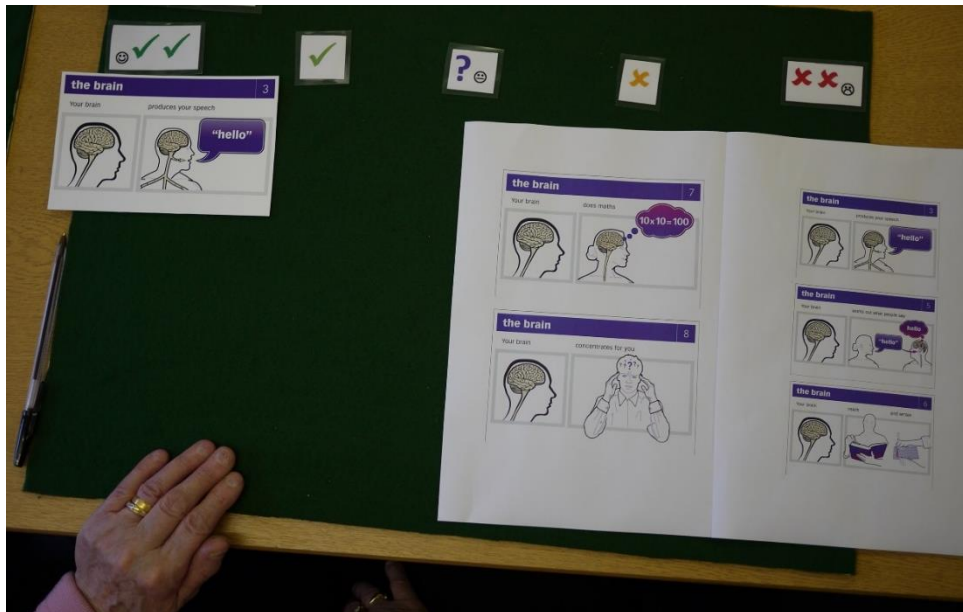


Example showing preference for multiple rather than single images

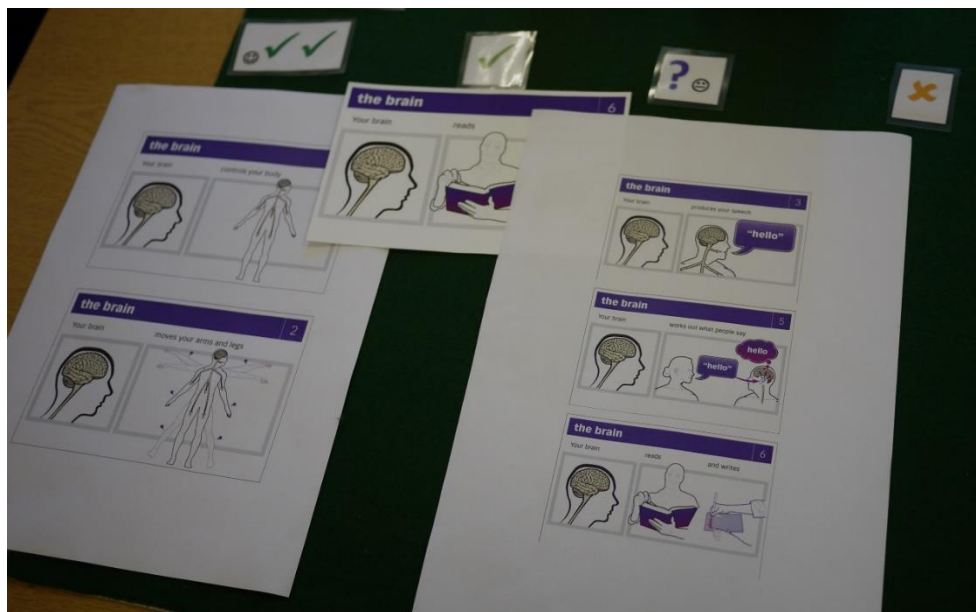


Talking Mats® examples showing ratings for number of concepts per page

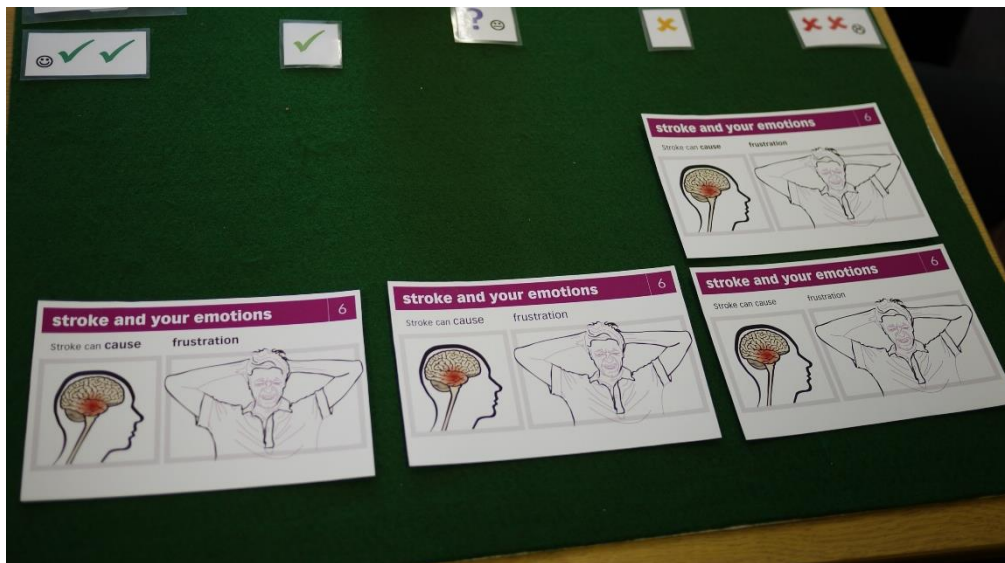
Example showing preference for one concept per page



Example showing preference for two related concepts per page



Talking Mats® examples showing ratings for emphasis of key words in Template 2



Appendix J

Ethical approval for the study form



Department of Human Communication Sciences
31 Claremont Crescent
Sheffield S10 2TA UK

Head of Department
Professor Joy Stackhouse, PhD., F.R.C.S.L.T., C.Psychol., A.F.B.Ps.S

Telephone: +44 (0) 114 222 2418/ 2402/ 2405
International: +44 (0) 114 222 2418
Fax: +44 (0) 114 273 0547
Email: hcs-support@sheffield.ac.uk
<http://www.shef.ac.uk/hcs>

17th December 2010

Dear Ruth

Title: Helping people with Aphasia to understand information

Thank you for your submission to the HCS Research Ethics Committee. The committee has reviewed your submission and supporting documents and grants you approval to commence the research.

We hope your project proceeds smoothly



Yours sincerely

A handwritten signature in black ink, appearing to read 'R Varley'.

Prof R Varley
Chair of HCS Ethics Committee

Appendix K

Accessible project information sheet

 <p>The University Of Sheffield.</p>	<p>Department Of Human Communication Sciences</p>	<p>The project has been approved by the Ethics Committee of the University of Sheffield in the Department of Human Communication Sciences.</p>
	<p>Head of Department Professor Shelagh Brumfit, PhD 31 Claremont Crescent Sheffield S10 2TA United Kingdom Telephone: +44 (0) 114 222 2418/ 2402/ 2405 International: +44 (0) 114 222 2418 Fax: +44 (0) 114 273 0547 Email: hcs-support@sheffield.ac.uk http://www.shef.ac.uk/hcs</p>	<p><u>Group discussion</u></p>
<p>Helping people with aphasia to understand information</p>		<p>We want to find out what you think. What does make it easier?</p>
<p>Researchers: Caroline Haw, Catherine Brown, Ruth Herbert</p>		<p>We will ask you to take part in a group.</p>
<p>Location: Department of Human Communication Sciences, University of Sheffield, 31, Claremont Crescent, Sheffield, S10 2TA.</p>		<p>The group will be five or six people with aphasia.</p> <p>The group will be at the University of Sheffield.</p>
<p> 0114 222 2416</p>		<p>The group will run twice, and afterwards we will meet once to talk about what we have done.</p>
<p>People with aphasia have problems understanding what they hear and what they read.</p> <p>Pictures, large type, or underlining words can make this easier. The Stroke Association has asked us to find out more about this.</p>		<p>The people running the group will be speech and language therapists or researchers used to working with people with aphasia.</p> <p>The group will last about two hours.</p> <p>There will be tea and coffee and biscuits to keep us going.</p> <p>If it is easier for you, we can talk to you on your own in your own home.</p> <p>If you do not want to take part, that is fine. This will have no effect on your Communication Support Group.</p> <p><u>Language tests</u></p>

They are funding this project.

Recordings

Everything that people **say** in the group is **important**.

We will **record** everything on a sound recorder, and on **video**.

We will **listen** to this afterwards to make sure that we **don't miss** anything.

Everything people say will help with the project.

The recordings will be stored in **computers** in the University.

The recordings will be **confidential**.

Only the researchers will be able to listen to them.

The recordings will be for this project only.

The recordings will be **destroyed five years** after the end of the project.

Getting there

The group will be held at the **University**.

We will arrange **a taxi** to collect you and take you home.

We will pay for the taxis.

We will need to know about your **language**.

We will **assess** your language

We can **visit your home** to do this,

or you can come to the **clinic**.

You can **choose**.

We will **pay for your taxi** to the clinic and back home.

It will take about **one hour**.

Stopping

You can **stop** whenever you want. You don't need to give a reason. Just let us know.

Interested?

If you are interested let us know, and tick the box here to find out more

I want to find out more

Appendix L

Pre-group participant confirmation letter
(shown smaller than actual size)



Department Of
Human
Communication
Sciences

Head of Department
Professor Shelagh Brumfitt, PhD
31 Claremont Crescent
Sheffield S10 2TA
United Kingdom

Telephone: +44 (0) 114 222 2418/ 2402/ 2405
International: +44 (0) 114 222 2418
Fax: +44 (0) 114 273 0547
Email: hcs-support@sheffield.ac.uk
<http://www.shef.ac.uk/hcs>

Helping people with aphasia to understand information

Dear

Thank you for agreeing to take part in our study.

You are going to come to the university on

The taxi is booked and paid for. It will call for you at pm. It will bring you to:

31, Claremont Crescent S10 2TA

The taxi will take you home again at 4:00.

We are looking forward to seeing you again.

Best wishes,

Ruth Herbert, Caroline Haw and Catherine Brown
(Researchers)

Tel 0114 222 2416

Appendix M

Participant post-group follow up letter
(shown smaller than actual size)



Department Of
Human
Communication
Sciences

Head of Department
Professor Shelagh Brumfit, PhD
31 Claremont Crescent
Sheffield S10 2TA
United Kingdom
Telephone: +44 (0) 114 222 2418/ 2402/ 2405
International: +44 (0) 114 222 2418
Fax: +44 (0) 114 273 0547
Email: hcs-support@sheffield.ac.uk
<http://www.shef.ac.uk/hcs>

Helping people with aphasia to understand information

Thank you for taking part in our study today.

Your next focus group will be on Friday 18th March at 1:30pm.

Your transport will be booked and paid for.

We will send you a letter about your pick up time.

We will also phone you.

We look forward to seeing you again then,

Best wishes,

Caroline Haw

Catherine Brown

Ruth Herbert

Tel: 0114 222 2416

Appendix N

Accessible consent form (shown smaller than actual size)



Department Of
Human
Communication
Sciences

Head of Department

Professor Shelagh Brumfit, PhD
31 Claremont Crescent
Sheffield S10 2TA
United Kingdom

Telephone: +44 (0) 114 222 2418/ 2402/
2405

International: +44 (0) 114 222 2418

Fax: +44 (0) 114 273 0547

Email: hcs-support@sheffield.ac.uk

<http://www.shef.ac.uk/hcs>

Helping people with aphasia to understand information

I understand what the project will involve.

_____ has explained what will happen

Disagree

Agree



I agree to involvement in the project



I understand I may stop at any time



I understand that my speaking will
be recorded



Signature.....Date.....

Name.....

Researcher name.....

Appendix O

Protocol for first focus group meetings (shown smaller than actual size)

PROTOCOL FOR FOCUS GROUPS FOR ACCESSIBLE INFORMATION PROJECT				
<p>All participants must sign the consent form before joining the focus group or participation in an interview concerning the accessible information.</p> <p>GROUP PROTOCOL</p> <p>All group discussion will be audio-recorded All people working with someone with aphasia on one to one basis to ensure that all comments are fed into the group discussion</p>				
NO	ACTIVITY	EQUIPMENT	AUDIO RECORDING?	WHO
1	Introduction: who we all are Convene group. Greetings Caroline to do introductions of everyone.	Name labels Pens	NO	CH
2	State aims of the group. Provide concrete examples of information given after stroke to demonstrate. Encourage all to express their opinions as experts in stroke Provide overview of the afternoon's schedule. Housekeeping.	Standard stroke leaflets A3 schedule x 2	YES	CH
3	Introduce Talking Mats and the Visual Scale as the means of communicating preferences which will be used in the group. All to be expressed openly for microphone to capture activity for transcription. Menu activity: Caroline to use 1 picture to introduce each course: <ul style="list-style-type: none"> - Like or dislike this food? - Place 3 pictures per course, rating how well each conveys what it is, i.e. its meaning. Focus on strength of picture in context of menu (ie information) rather than personal preference for the food item itself. - Photograph each TM once picture menu completed. - Group discussion Text activity: <ul style="list-style-type: none"> - Cup of coffee picture placed at top of each TM. - Participants to rate pairs of written phrases of "cup of coffee" for font preferences. - Photograph each TM once all fonts displayed. - Group discussion 	TM for each participant One set of food pictures for Caroline to demonstrate Set of food pictures ON VELCRO for each participant Cup of coffee picture x 8 Phrase 'cup of coffee' in range of fonts/sizes etc Visual scale for each participant, velcro'ed to the TM Digital camera Laptop to check photos on to	GROUP DISCUSSION	CH
4	Introduce some of Jon's pictures and word sets and select preferences using TM Compare and rate pairs of line drawings: Your brain makes your speech Your brain controls your body Blood makes your brain work Compare and rate pairs of line vs photo presentations: Your brain moves your arms and legs Your brain needs blood Your brain listens to speech Photograph of each TM Open discussion regarding why selections were made for both images and text	TM Visual scale Jon's pictures on Velcro Camera Laptop	GROUP DISCUSSION	RH

5	<p>Topic generation</p> <p>ASK PEOPLE to brainstorm what was most important for them after a stroke: "What does somebody need to know who is recovering after a stroke?"</p> <p>THEN PRESENT OUR LIST of topics</p> <p>Participants asked to rate these as very to not important</p> <p>Participants asked to think again of other topics</p>	<p>Flipchart to write the topics on</p> <p>Our list of possible top topics</p> <p>Visual scale to rate the topics</p> <p>Camera</p>	GROUP BRAINSTORM	CB
6	<p>Closing comments</p> <p>Reminder of date of next group</p>	<p>Written information sheet with date of next meeting on and information regarding taxis and that we will ring them beforehand</p> <p>One for each participant</p>		CB

SHOPPING / GET FROM GENERAL OFFICE

Name labels Pens suitable for people with stroke to use Blank paper – lots of .alphabet charts on A4
 Yes no on large piece of paper for people to point to
 Talking Mats x 10
 Number on each Mat so we know whose is whose when look at photos
 Tea bags
 Coffee
 Milk
 Water (jugs and tap water fine from kitchen)
 Good biscuits
 Other equipment:
 Flip chart Pens for flip chart Audio recording equipment
 Video recording: F1/ IT support to sort

Appendix P

Protocol for second focus group meetings (shown smaller than actual size)

PROTOCOL FOR FOCUS GROUPS FOR ACCESSIBLE INFORMATION PROJECT				
GROUP PROTOCOL				
All group discussion will be audio-recorded All people working with someone with aphasia on one to one basis to ensure that all comments are fed into the group discussion				
NO	ACTIVITY	EQUIPMENT	AUDIO RECORDING?	WHO
1	Introduction: Convene group. Greetings and thanks State aims of the group: <ul style="list-style-type: none"> - accessible information after stroke - a work in progress - designer worked based on your comments and opinions - today asking for your views on what we've done so far - plan for the afternoon 	Name labels Pens A3 schedule x2	NO	CB
2	Open the card boxes and take out one set (aphasia) Ask for individual response to the set and the box (one-on-one discussion) <ul style="list-style-type: none"> - Do you like the cards? Do you like the box? Do you like the name of the box? - Does the set make sense? - Can you follow all the cards? - Are there any that don't fit? - Which ones do you like best? 	Box Set of cards about aphasia for each participant Visual scale and yes/no card for each participant pen & paper	NO	RH
3	Open discussion and feedback regarding the set concept Offer options for name of box: Language Box Stroke Box Speech Box Information Box	Set of cards about aphasia for each participant Visual scale and yes/no card for each participant pen & paper	Yes	RH
TEA BREAK				
4	Place talking mats on the table. Reminder of visual scale as a way to express preference <ul style="list-style-type: none"> • Use TM to express preferences regarding 'Stroke and your Emotions' • Photograph mats and feedback • Use TM to express preferences regarding the amount of information per page • Photograph mats and feedback 	Emotions cards A4 pages with 3/2/ images from a set on each piece of paper and card with one image on it Talking mats camera		CH
5	What advice would you give to someone who's had a stroke? Group brainstorm	Flipchart Flipchart stand		CB
6	Final comments: <ul style="list-style-type: none"> - Thanks - Designer will keep working - We will be in touch when the initial set is ready (this is what it will be: 10 topics) - hope you can come back for a cup of tea and to see finished product 			CB

Appendix Q

Sample of transcriptions

Sample 1: Group A discussion relating to the set of cards about aphasia.

RW	Yeah	
F1	we talked about how different ideas work for some people - different pictures work for other people - so that one's ok for you [card no. 3] but not for TM?	
F4	it's the lettering	
TM	no - it just doesn't go in properly	
F1	no – ok - so we need to think again about that one	
F2	Can GG and I say about... picking up from card number 3 to card number 8. When you looked at card number 8, GG, you very clearly put you hand over the final one.[aphasia can get better over time card]	
GG	ah /mi mi/	
F2	which made me think - this card had really connected for you	
GG	ah /mi/	
F2	because what you're saying is – well - wasn't right [pointing to speech bubble with perfectly formed font 'hello']	
F1	so there's been progress so far.	
GG	Ah	
F1	but not back to...	
F2	but not back to normal	
GG	ah mi mi [nodding agreement]	
F2	so what I wonder - is when you looked at this card where there was that progression - that that lettering made sense but that card on its own didn't	
F4	yeah - that was the same for TM – actually - you said 'some days it's OK and other days...'	
TM	it's better - yeah -some days are better than others	
F2	all right so that's a good card – we like number 8	
F3	it's a good card [no.8] except	
F1	can we just hang on a sec because TM's brought up a different thing there about different days and this one's about progress	14'02
TM	Yes	
F1	but it's also applying to some days	
TM	are better than others	
F1	sorry EC	
EC	it takes years for you to get better - but that looks like it's a month	14'25
F1	a month - yeah so that's not doing it for you - is it? that's not the true story	
EC	Yeah	
F1	no - so we can change the dates - that's not a problem - I thought that as well - do people like having the dates there? you just need a different date? or could we get rid of the dates?	
TM	you don't need it	
F1	you don't need it - what about you RW?	
RW	I don't know	
F1	you don't know	

RW	I...ten years ago I had a stroke ... I can't...I can't ... speech is ...	15'17
F1	still difficult?	
RW	Yeah - ten years - yeah	
F1	yes - so this is a bit too optimistic	
RW	yeah	
F1	Maybe	
RW	I don't know	
EC	years and years	
F2	it's not realistic	
F1	years and years.	
EC	months or years - you don't know.	
F1	no - not months - it's over years -isn't it	
EC	Yeah	
RW	Yeah	
F1	what about having the perfect hello at the end? - which says 'back to normal' - doesn't it?	
BT	but they don't do they - you've always ... I don't think I've altered in my speech since the first month in hospital - walking about - I got a little bit better - I'm going downhill now [laughter] well - I don't try now	16'23
F1	you don't try now - you've got your wheels [mobility scooter]	
BT	I've had six years of doing this and having blood and I've not made any progress	
F1	no – right	
BT	so ... but with me I think it's ... you know - I accept it	17'12
TM	Yes	
BT	and I go on - I shave and I get around	
F3	Yes	
GG	ah /mi/	
F2	what we're saying is that we don't think that does make sense –GG - it doesn't - and actually when you first looked at that	
GG	ah /mi/	
F2	you didn't look at the calendar at all - it wasn't necessary - it made sense without the calendar	
GG	ah [indicating agreement]	

Sample 2: Group B discussion relating to the set of cards about aphasia: accuracy and illustration of concepts of recovery and prevalence of aphasia.

F1	it can get better - number 8 - what did you make of that one?	
OS	yes - I think that is – yes - it can - but it were the numbers - I'm not very good with numbers	
F1	Ok	
OS	clocks and numbers - first thing in the morning I cannot tell time [laughter] I can't no I can't	21'30
F1	Right	
F2	so was that a distraction for you?	
OS	that yeah - and numbers - numbers are numbers do	
F1	Ok	
OS	numbers are really difficult for me	
F1	Yep - anybody else	

RP	what about if - february to october you're doing incredibly well to get better in that time	
All	Laughter	
RP	I would say year one - year two - year three	
F2	well that would be very clear	
RP	and it shows it carrying on	
All	laughter and general agreement	
F1	does it need a time frame on it?	
OS	it doesn't for me	
NH	no because I think it is something that will get there in due course but it is not like the 14th of feb or the 31st of october - it's nowhere near that no	
All	[laughter]	
OS	I have to go with my finger january february what month it is - you know [laughs]	
F2	you didn't look at that bit [addressed to JB]	
JB	no I just - I looked at it but I couldn't see it	
F1	so we could cut off the dates at the bottom - if we cut off the dates at the bottom that would work - would - does the F2anging speeF2 work for you?	
NH	yes I think so - hallo hallo hallo - that is it getting better as the time goes in goes on	
F1	ok – okidoke - lovely thank you, any other comments anyone has to make about the	
All	[talking at once]	
F1	hang on - we'll have JB's thoughts on - [laughter] - on our favourite card – ok - number 6 [card 6 aphasia is common]	
JB	well she thought it was - she said it looked like [laughing] ... art form	
F1	looked like?	
JB	well I couldn't make that at all I hadn't worked out what it was - but I couldn't see it adding anything at all to anybody about anything	
F1	o - k	
F2	the word that you said was 'it's a bit of a nothing' and the word that I said was 'wallpaper'	
All	[laughter]	
F1	it's very nice wallpaper	
RP	I said a very similar thing to [name of communication facilitator] - same thing it's that /fuff/! - what if you did it in black? not too big - 'cos black's a good word sometimes - it is actually I don't know why - you could put there something like 450 thousand people in the UK have aphasia - something - after a stroke - maybe -	24'02
F1	it's a bit vague isn't it	
RP	dunno - there are about 450 thousand people - I've never met - we've met some of them [laughter]	
F1	you've met quite a lot of them	
RP	but do you know, those le - the numbers 450 thousand people have aphasia after a stroke - it's an idea	
F1	yeah - ok so very specific fact with a number - that might work - yeah	
RP	Yeah	
F1	yeah ok -anything else on that one?	
?	no –no	
F1	we've got the thumbs down for the wallpaper	
NH	Yes	

Sample 3: Group C discussion of number of images per sentence.

F1	Brilliant - anything else about the ones you didn't like?	
F2	Yeah - MM wants to say something about the remote control	
F1	Mm	
MM	I don't know what's it doing there [laughter]	07'48
F1	fair enough [laughter]	
F2	it's a fair point [laughter]	
F1	well –yes - so you could just get rid of it	
MM	Yeah	
F1	you'd be happy without it? but SG really liked that - didn't you? yeah?	
SG	controls your body	
F1	yeah, so each step of the (sentence)...	
SG	(yeah) – yeah	
F1	... controls body - that really...	
SG	(yeah)	
F1	(helped) - so again it's different for different people	
MM	what did you mean? how did you mean -anyway? I haven't got that	
SG	Erm –I - talking of erm – erm - oh my god [subvoc] - explain - erm - I don't know...	
MM	but that don't - that don't do that for you ... it's your brain	
unknown	Yeah	
F2	is it that there's a picture for each word?	
SG	Yeah	
F3	for SG it's better for her to have a picture for each word	

Appendix R

Samples of Template 1 and Template 3, to show changes made as result of the iterative process

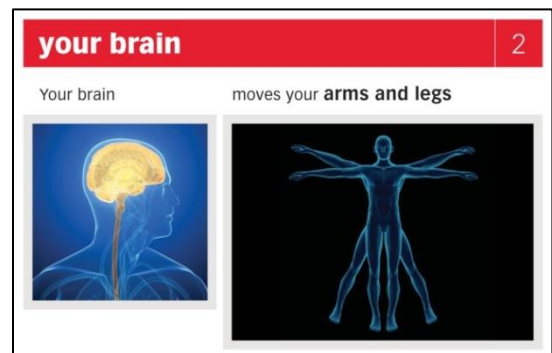
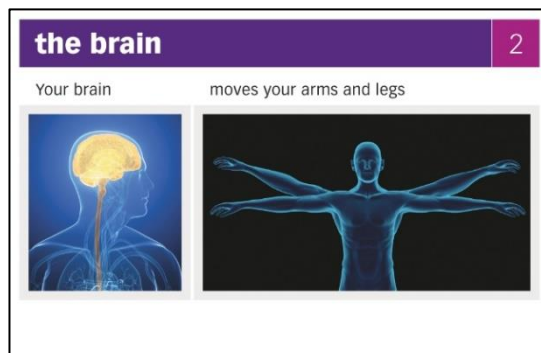
All images © The Stroke Association

(examples shown smaller than actual size)

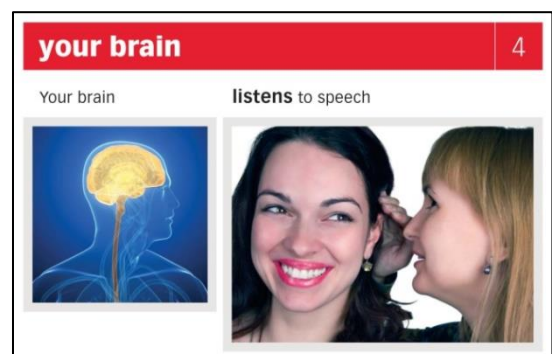
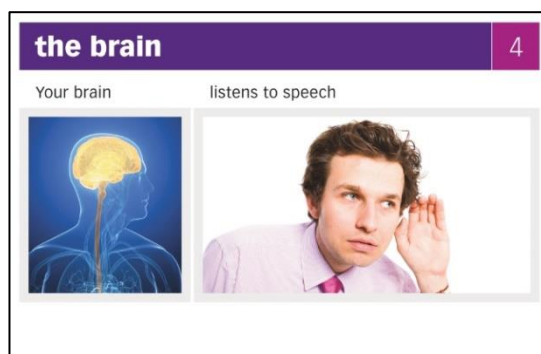
Template 1

Template 3

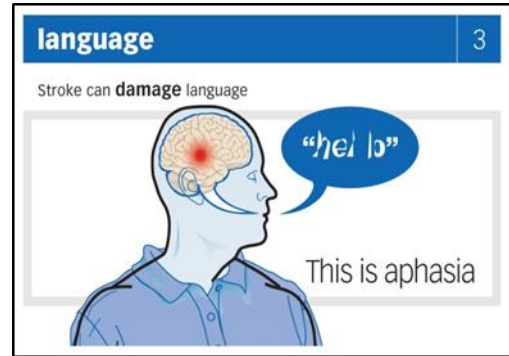
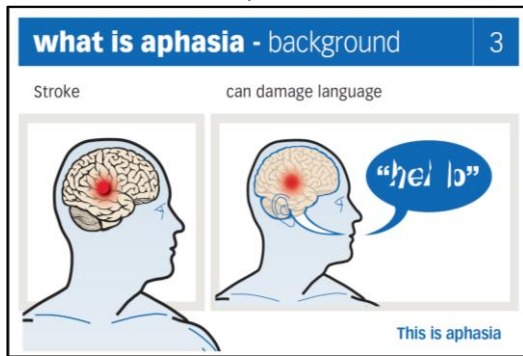
1. Example showing precise coherence between text and image. Note the inclusion of large and bold font in the Template 3 version.



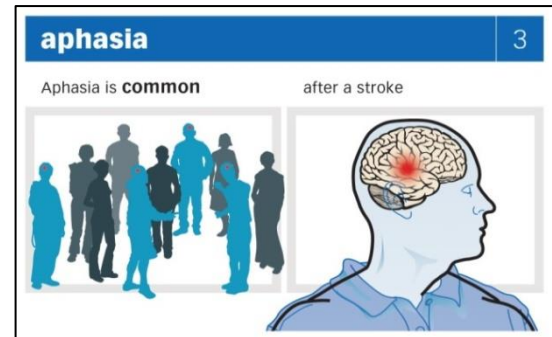
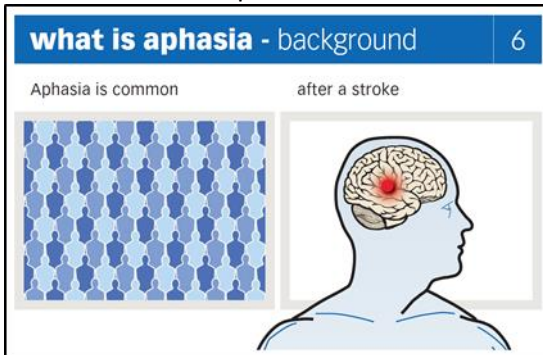
2. Example showing more acceptable photographic image of the concept 'listens to speech', including interaction between two people, both of whom appear comfortable.



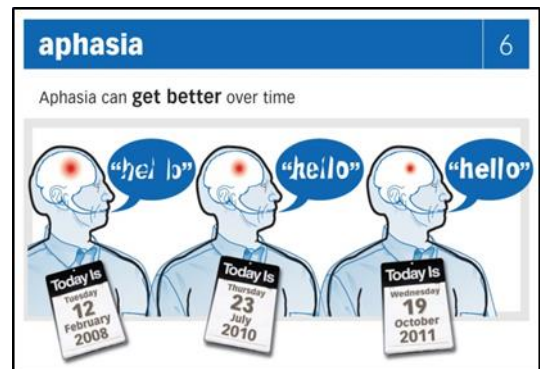
- Example to show change to single image layout, enlarged font for key message, large, bold font keyword



- Example showing progression from abstract representation towards a choice of more concrete representations. The first shows this in text form, the second in an image.



- Example to show realistic timescales for recovery from stroke

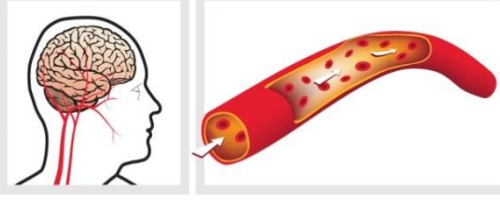


6. Example to show a sequence of Template 3 materials.

Each card presents a single concept. In sequence, the cards explain a complex concept.

stroke - haemorrhage 1

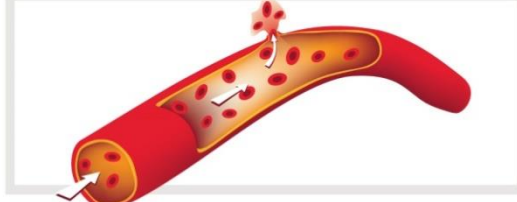
Your **artery walls** get thin



The diagram consists of two parts. On the left, a profile of a human head shows the brain and the neck with arteries. On the right, a cross-section of an artery is shown with a thinning of its walls, indicated by a white arrow pointing to the inner lining.

stroke - haemorrhage 2

The thin artery walls **burst**



The diagram shows a cross-section of an artery where the thinning wall has ruptured, with a small hole and a small amount of blood escaping from the lumen.

stroke - haemorrhage 3


Your blood **escapes**



The diagram shows a cross-section of an artery with a significant tear in the wall, and a large amount of red blood is shown escaping from the lumen.

stroke - haemorrhage 4

The escaping blood **injures** your brain



The diagram shows a profile of a human head with the brain and neck. A magnifying glass is focused on the brain, showing a cross-section of the artery from the previous card with a large amount of blood escaping and injuring the surrounding brain tissue.

Appendix S

User-testing survey for Phase 3

1. Tell us your first impressions of the guidelines.
2. Using the guidelines to produce information: what was **easy** to do? What worked well?
3. Using the guidelines: what was **hard** to do? What didn't work so well?
4. Is there **anything missing** from the guidelines? Is there any advice you need that we didn't include?
5. Was there anything we included which you felt you didn't need?
6. **Resources:** please tell us about your experience of finding and using the resources to make information. For example, using Word or Publisher, using Flesch-Kincaid, getting good pictures.
7. Were you able to produce some accessible information?
Did you produce a **set** of information?
8. What guidelines or information do you currently use (if any) to inform your production of aphasia friendly materials? Do you know of any resources for this?
9. Would you use these guidelines in future for making information accessible? If yes, please tell us what sort of materials you might use them for.
10. Is there anything else you'd like to mention?

Appendix T

Accessible Information Guidelines

Published by The Stroke Association, July, 2012

Please note these Accessible Information Guidelines are © The Stroke Association. They are available to download from:

https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf

