

# Inclusive Design

Exploring Accessible Informed Consent for People with Aphasia

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**Geena Stanley**

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# Abstract

## Abstract

This research explores how information design and typographic approaches can help create accessible participant information sheets for people with aphasia to ensure they can be included in research. There are worrying statistics that individuals with communication impairments post-stroke are often excluded from research due to perceptions of vulnerability, and that they do not have the decision-making capacity to provide informed consent. These exclusions have the potential to create health disparities for people with aphasia and contribute to existing generalisations in stroke research that can have a negative impact on the care they receive.

Participant information sheets were prototyped using a human-centred design approach by adhering to the information design principles of accessibility and inclusiveness. The prototypes were presented to people with aphasia for feedback to ensure the readability, comprehension, and design preferences were appropriate and accessible to the targeted audience.

The outcome of the research was a refined set of prototype participant information sheets that ensure greater accessibility to research for people with aphasia. This research found that implementing information design and typographic principles to participant information sheets for people with aphasia can facilitate their inclusion in research through their readability.



# Introduction

## Positioning the Researcher

As a young child, I engaged with a speech-language therapist to help with a stammer that affected my speech. This stammer has persisted to a lesser extent, but it is still something I struggle with in my everyday life. My stammer is barely noticeable, but it does come through in conversation, and I notice it even when others don't. I've come up with strategies to help me when my stammer occurs. I completely stop mid-sentence and start all over again, even if I'm at the end of a sentence. Although distant, my stammer connects me to the topic of communication impairments and the everyday struggles of producing words. Having a stammer has helped me gain empathy for anyone living with a communication impairment, including those with aphasia. I understand how frustrating it can be when you cannot translate your thoughts into words or when you fumble with your words or sentences.

While I began this research with no prior knowledge or experience with aphasia or stroke, I felt connected to the topic. My initial approach to the research was from an empathetic perspective, driven by my personal experiences, views and values of fairness and equality. My approach was also informed by human-centred design and my experience working on design for health projects. During my communication design undergraduate studies, I had the opportunity to work on two healthcare-related projects that involved the design and

structure of information for targeted audiences. I worked on these projects through Good Health Design, a design studio located within AUT as a student intern. From interning at Good Health Design, I have gained experience working collaboratively with healthcare experts while also using human-centred design approaches. The internship opportunities with Good Health Design led to an interest in how communication design can help people understand complex information in an easily digestible way. From this interest, an opportunity arose to work on creating accessible participant information sheets for people with aphasia. Participant information sheets adapted for people with aphasia exist in research, but very few, if any, participant information sheets have been created by a communication designer with knowledge of information design and typographic principles.

Although, as a designer, I lack expertise in aphasia or stroke-related communication difficulties, my previous experience working on healthcare-related communication design projects has enabled me to understand the potential complexities of navigating healthcare spaces. My experience has given me the knowledge of how to work through the process of designing information for the specific communication needs of the intended audience.

## COVID-19

This research took place during New Zealand's nationwide COVID-19 lockdown that went from August 2021 until December 2021. During this time, the research was conducted remotely with no access to the university campus or its relevant facilities. This affected various aspects of my research such as access to studio workspaces, workshop facilities, and my ability to print designed prototypes. Many design outcomes had to be reconsidered or postponed as a result. Additionally, data collection was affected by the shift to a remote workspace. Data gathering was postponed until there was more certainty around the duration of the lockdown, and I experienced communication breakdowns in the initial recruitment stages. Data gathering had to be reconsidered and switched to digital data gathering methods, and other avenues of recruitment had to be sought.

# Contextual Review

## Introduction

Aphasia is a common communication impairment that occurs in one-third of individuals after experiencing a stroke (Flowers et al., 2016). Aphasia affects an individual's ability to understand and produce language in written and/or spoken forms, including people's ability to read and write. Aphasia can be a chronic condition, with effects that can persist for years after the stroke has taken place. Because aphasia can be chronic, a person's verbal communication and reading comprehension may not return to the level it was before a stroke occurred (Knollman-Porter et al., 2015). Fortunately, language difficulties and everyday life for people with aphasia can improve with time, rehabilitation, and successful adaptation to their new way of living (Grohn et al., 2014). Many people with aphasia go on to live meaningful lives after their stroke by continuing to live in the community, engaging in social activities, and actively moving forward in their life while living with aphasia and navigating the complexities that go along with it (Grohn et al., 2014).

Despite one-third of the post-stroke population having aphasia, multiple reviews of post-stroke research (Brady et al., 2013; Wray et al., 2018) show that people with aphasia and others with similar communication impairments are being excluded from research. People with communication impairments make up around 60% of the stroke population (Mitchell et al., 2020). This population includes people with aphasia among others. Excluding these people means that research does not accurately reflect the stroke population. These exclusions can lead to generalisations in research findings, care, and rehabilitation for people with communication impairments resulting from having a stroke (Brady et al., 2013; Shepherd, 2020).

A common issue that arises when recruiting people with aphasia or populations with similar communication impairments in research is the informed consent process. There is a common misconception that people with aphasia do not have the capacity to consent to research and make an informed decision for themselves based on the information given to them about a study (Brady et al., 2013; Kagan & Kimelman, 1995). This view is inaccurate in many circumstances and can be stigmatising to the whole population by branding everyone with aphasia as vulnerable (Douglass & Ballantyne, 2019). The capacity to make informed decisions is often masked by language barriers (Kagan & Kimelman, 1995). Sufficient adaptation of informed consent materials, presented in ways that are appropriate for their communication needs can help enable people with aphasia to participate in stroke research that affects their wellbeing (Kagan & Kimelman, 1995; National Ethics Advisory Committee, 2020).

It is relatively common for researchers in the aphasia field to modify and adapt standard consent forms and participant information sheet templates provided by research ethics

committees to facilitate a greater understanding of the information provided for people with aphasia. Numerous studies have looked into the best design and characteristics for written materials to allow a greater comprehension and understanding of information for people with aphasia (Brennan et al., 2005; Herbert et al., 2019; Rose et al., 2003, 2011; Wilson & Read, 2016). Within these studies, there is little evidence as to who designed these written materials in question or what design expertise or knowledge they had other than being an aphasia researcher. One study (Herbert et al., 2019) mentions that the written materials were ‘professionally designed’; another stated that they used existing stroke education materials to test comprehension (Rose et al., 2011). The remaining studies did not indicate who designed the written materials used to analyse reading comprehension and understanding in people with aphasia (Brennan et al., 2005; Rose et al., 2003; Wilson & Read, 2016). After cross-referencing the authors of each of the mentioned studies, all authors appeared to work in the fields of speech-language therapy or health and rehabilitation. It can be safe to assume that these researchers may have designed these remaining materials with minimal or no knowledge of information design and typographic principles.

An opportunity emerged to use a design-led approach to address the issue of presenting and obtaining informed consent for people with aphasia to participate in research in a way that is inclusive and accommodating to their communication needs. Information design approaches are used extensively to organise, structure, and interpret information to improve the overall readability<sup>1</sup> of a design to make it easier to use for a particular audience (Bonsiepe, 1999; Visocky O'Grady & Visocky O'Grady, 2008). Information design has the potential to simplify complex concepts (Naar et al., 2018) and make information more accessible to particular populations.

The literature suggests that people with aphasia who want to participate in research would benefit from the application of information design principles and typographic considerations to the design of participant information sheets intended for them. The design features detailed in the literature around accessible information for people with aphasia are a foundation for building and expanding upon what is already known.

Consequently, through this research, I aimed to address the following research question:

***How can information design positively impact people with aphasia's rights to fair and ethical consent processes when considering taking part in research through the design of participant information materials?***

<sup>1</sup> Readability in this thesis is defined by O'Grady and O'Grady (2008) and only refers to the typographic treatment of text. Readability in this context can affect comprehension but not vice versa.

## Aphasia

Aphasia is a common communication impairment that can occur after a stroke that affects an individual's ability to understand spoken and written language. Aphasia can also affect a person's ability to write, read, speak and recall words (Mayo Clinic, 2020). The severity of an individual's aphasia can vary from mild to severe, but the communication abilities of many people with aphasia can improve with time and speech-language therapy. About one-third of all individuals will experience aphasia after a stroke, making it a common communication impairment in the stroke population (Brady et al., 2013; Flowers et al., 2016; Mitchell et al., 2020).

The history of aphasia as a medical condition dates back to the first accounts of speechlessness<sup>2</sup> that surfaced in medical fragments<sup>3</sup> (Eling & Whitaker, 2009). The symptom of speechlessness was often a sign that a person's prognosis was not good (Eling & Whitaker, 2009). Speechless became an umbrella term for several conditions where one may lose their voice. A breakthrough discovery in the 16th

century by Giovanni De Vigo's and his account of 'traumatic speechlessness' led to speechlessness being correlated to the mental functions of the brain (Eling & Whitaker, 2009).

Johann Gesner's (1770) book *Sammlung von Beobachtungen aus der Arzneygelahrtheit* included a case description that is considered the first major work in what we now know to be the subject of aphasia (Eling & Whitaker, 2009). Gesner concluded that this particular disorder is not related to a lack of intelligence, nor is it a memory disorder. Rather, it is due to what he described as a 'verbal memory impairment' (Eling & Whitaker, 2009). From this point forward, the most notable names in the study of aphasia have been Paul Broca and Carl Wernicke, both of whom made breakthroughs in the field of aphasia in the 19th century that have led us to what we know about aphasia today.

<sup>2</sup> Speechlessness in the ancient texts refers to the inability to speak, presumably because of a medical event such as a stroke or aphasia.

<sup>3</sup> Medical fragments refer to ancient medical texts created before and during the middle ages. Examples include the Edwin Smith Surgical Papyrus and the Hippocratic Corpus.



The understanding of written language can often be a struggle for many individuals with aphasia as aphasia can affect their reading, writing, and general communication. The reading comprehension of people with aphasia can vary from:

**Little to no impairment**

There is either no change in reading comprehension or reading may be slower than before aphasia (Lingraphica, n.d.; Webster et al., 2022).

**Mild impairment**

Lengthy text and complex sentences will most likely be difficult (Lingraphica, n.d.; Webster et al., 2022).

**Moderate impairment**

Only short phrases or sentences can be read, with simple sentences being the easiest to read (Lingraphica, n.d.; Webster et al., 2022).

**Severe impairment**

Only simple or familiar words can be read, or there is no reading ability at all (Lingraphica, n.d.; Webster et al., 2022).

Written language is all around us and present in everyday activities. We interact with written language when we send and receive emails when we read a book, a newspaper or a webpage, and even when we are out ordering food from a menu. People with aphasia may find what we perceive as simple everyday tasks to be challenging and often difficult to navigate efficiently (Knollman-Porter et al., 2015). In the face of these difficulties, people with aphasia are resilient. Many people with aphasia develop strategies to navigate these daily tasks where reading or written communication is involved and can live meaningful lives with simple adaptations to the way they engage with people, items, and written information (Grohn et al., 2012; Wray et al., 2019). People with aphasia who live in the community engage and function in society just as any other person would without a communication impairment.

Many people with aphasia have expressed they would like to regain their literacy skills, as well as a desire to be able to read (Knollman-Porter et al., 2015). The desire to be able to read for people with aphasia comes from wanting to stay connected with family and friends through digital technology, keeping up-to-date with current events, assisting with their shopping experience, and to gather information about their friends and acquaintances (Knollman-Porter et al., 2015). This continued expression of motivation and desire to be able to read again among people with aphasia shows that there is a need for accessibly written information in all aspects of everyday life and beyond.

# Ethics

## History of Ethical Practices

Ethical practices were first established in the aftermath of World War II, with the discovery that Nazi German physicians were using concentration camp prisoners as human subjects for medical experiments without consent. As a result of the American military tribunal opening a criminal case against the German physicians, the Nuremberg Code was established in 1947. The Nuremberg Code states that “the voluntary consent of the human subject is absolutely essential” and goes on to say that researchers should avoid unnecessary harm, both physically and mentally (The Nuremberg Code, 1947).

The most notable guidelines for ethical principles and practices come from the Belmont Report in 1979. The Belmont Report outlines the basic ethical principles to follow when involving human subjects, which include *respect for persons*, *beneficence*, and *justice*. The Belmont Report also outlines the need for informed consent, and that sufficient information must be disclosed to participants, including the research procedures, purpose, risks, benefits, and the opportunity to ask further questions or withdraw from the research at any

time (United States, 1978). The Belmont Report also highlights the need to “adapt the presentation of the information to the subject’s capacities” so that participants can comprehend the information given to them (United States, 1978).

In Aotearoa, New Zealand, researchers wanting to conduct research with human participants must follow the National Ethical Standards (National Ethics Advisory Committee, 2021). The National Ethical Standards contain a chapter on the *Ethical Management of Vulnerability* that has a section about how to balance access to research while avoiding exploitation of participants<sup>4</sup>. The section talks about how researchers should not exclude participants because they *may* be vulnerable and how “Researchers should provide all potentially vulnerable participants with appropriate support to help them make informed decisions about participating in a study” (National Ethics Advisory Committee, 2021, 6.3). These guidelines exist to promote the inclusion of vulnerable populations such as the aphasia population; yet people with aphasia are still largely excluded from stroke research, despite support resources being available to help people with aphasia communicate an informed decision (Brady et al., 2013).

<sup>4</sup> National Ethical Standards, Part 2, 6. Ethical Management of Vulnerability

### **Informed Consent, Vulnerability, and Excluding People with Aphasia from Research**

Informed consent is defined in this research as the process of obtaining knowledge and understanding the information sufficiently enough to make an informed decision to partake in research (Dunn, 2001; Ryan et al., 2020; Simpson, 2010). A fundamental aspect of taking part in research is providing informed consent, yet, it is hard for people with aphasia to provide informed consent when relevant information is presented in a way that they are unable to access it due to their communication impairments.

People with aphasia are commonly considered to be vulnerable in the context of research. This is due to there being a perception that they lack the decision-making capacity to make an informed decision to participate in research (Brady et al., 2013). To take part in research, one must be able to communicate genuine informed consent, which involves voluntary participation, understanding and appreciating the information given, and communicating a choice (Dunn, 2001; Pearl & Cruice, 2017; Ryan et al., 2020; Simpson, 2010). For

many people with aphasia, their decision-making capacity is often masked by their language difficulties; therefore, a choice cannot be communicated without sufficient support to allow their decision-making capacity to be revealed (Brady et al., 2013; Kagan & Kimelman, 1995). The assumption that all people with aphasia are vulnerable and do not have the decision-making capacity to consent to research is a flawed assumption that disregards the complexities of having a communication impairment or language difficulties. Being part of a vulnerable group of people does not inherently make someone vulnerable, and people who are interested in taking part in research should be treated as individuals with various needs and capabilities rather than being defined by their condition (Grady et al., 2017; Pieper & Thomson, 2020). People with aphasia need to be treated as individuals with unique language needs that can provide informed consent with appropriate support, rather than being unjustly excluded because they are part of a population that is considered vulnerable (Kagan & Kimelman, 1995; Pieper & Thomson, 2020; Stein & Brady Wagner, 2006).

What is needed to help uncover an individual's decision-making capacity is the appropriate support to reveal this capacity (Brady et al., 2013; Kagan & Kimelman, 1995). For individuals with aphasia, this can take the form of accessible participant information sheets and written consent materials that are simplified and delivered in an appropriate and accessible way using written and verbal language adaptations (Kagan & Kimelman, 1995).

There have been growing concerns among practitioners in the aphasia field due to the exclusions of this population from participant-based research (Brady et al., 2013; Wray et al., 2018). The exclusion of people with aphasia and other populations with communication impairments post-stroke may be due to several reasons. These reasons include the perception that people with aphasia do not have the decision-making capacity to consent to research or make informed decisions for themselves, researcher bias in the participant selection process, or that there is not enough implementation of adapted participant information sheets and consent forms to aid comprehension in the informed consent process (Brady et al., 2013). A recent New Zealand based review that looked

into the exclusion of people with communication impairments post-stroke found that the problem lies in the reluctance or inability to meet the communication needs of people with aphasia and has nothing to do with people with aphasia being unwilling to participate in research (Adviento & George, 2020).

Regardless of the reasoning behind excluding people with aphasia from research, the act of excluding a population from research can be seen as unjust, especially for populations where their exclusion can contribute to inequities in care and rehabilitation (Brady et al., 2013; Douglass & Ballantyne, 2019). There is a need for vulnerable populations to receive high-quality, evidence-based care, and a high frequency of exclusions may mean that this population misses out on potential healthcare innovations (Douglass & Ballantyne, 2019). In the case of people with aphasia, exclusions from research may hinder the quality of care provided and increase the risk of care not being suitable or accessible for people with aphasia (Brady et al., 2013). Exclusions also cause generalisations across stroke research that may not apply to people with aphasia and do not take into account the specific needs of this population (Brady et al., 2013).

Excluding people with aphasia from research, who make up a third of the post-stroke population, is unacceptable, is a disservice to people with aphasia, and breaches the National Ethical Standards here in New Zealand. These exclusions trigger an unethical cycle where populations consisting of potentially vulnerable individuals needing research attention are continually excluded (Brady et al., 2013). More needs to be made to ensure people with aphasia are included in research and their communication and language needs are met to allow their participation.

## Design in Healthcare

Healthcare systems are strict, rigid organisations that rely on metrics and quantitative insights to gauge efficiency and success. However, quantitative data and insights fail to acknowledge the patient experience and the impact it has on their health outcomes (Robert et al., 2015).

Design in healthcare establishes a trans-disciplinary approach ‘infused’ with the knowledge and experience of trained designers equipped with their own unique set of problem-solving skills to support innovation in healthcare (Langley et al., 2018). Design is starting to play a more critical role in establishing increasingly human-centred healthcare practices and has helped solve complex problems in the healthcare sector. A human-centred approach to design in healthcare is based on collaboration and inclusivity. This is often achieved by acknowledging people and patients navigating health systems as experts of their own lived experiences and challenges (Ku & Lupton, 2020). Addressing health issues with a human-centred design approach emphasises the power of sharing, listening and empathising with the experiences of patients and users. Patient and user collaboration with researchers and designers play an integral

role in determining how best to design for the intended user – often users may see, perceive, and interact with information and artefacts in ways that differ from what designers and healthcare professionals might expect (Krippendorff, 2006). Such findings show the value of human-centred design and collaborative end-user outcomes in providing healthcare solutions.

Empathy is an essential aspect of human-centred design practices due to its nature of recognising, understanding and connecting with the emotions and struggles of other people (Jones & Halamka, 2012; Ku & Lupton, 2020). Empathy allows designers in a healthcare setting to better understand a specific audience to design targeted outcomes that draw from the audience’s own experiences living and navigating their healthcare needs. An empathetic approach to designing for people with aphasia involves listening, engaging, and responding to their everyday experiences while navigating their communication impairment.

## Information in Healthcare

In New Zealand, the Ministry of Social Development (2016) defines 'prose literacy' as the ability to understand continuous texts<sup>5</sup>, with a prose literacy sitting at level 3 or above. Data from 2006 shows that 56% of the population between the ages of 16-65 years had a high prose literacy. This means just under half of New Zealander's may encounter difficulties understanding continuous texts such as health information in the form of pamphlets, brochures, or participant information sheets. This brings into question the health literacy of New Zealanders and if more can be done to make health information more accessible.

Health literacy is a form of literacy that describes an individual's capacity to make decisions about their healthcare and other clinical needs (Kidd et al., 2018; Nutbeam, 2008). Health literacy can affect an individual's access to health care, the care provided to them by their healthcare professionals, their own engagement with self-care, and their ability to use health information (Batterham et al., 2016; Nutbeam, 2008). Good health literacy enables a person to access, understand,

and use health information and services to maintain their health and wellbeing (Nutbeam, 2008). Meanwhile, poor health literacy can mean that individuals may not have access to healthcare services and may not understand the health information provided to them, resulting in poor health outcomes (Nutbeam, 2008). Health literacy has been linked to poor literacy, but its effects can be mitigated through the improvement of health communications, both through health service providers and written health information (Batterham et al., 2016; Nutbeam, 2008). A New Zealand study that looked into health literacy for Māori in palliative care shows that whānau want to know about relevant health information, but health professionals do not communicate sufficiently to allow access to such information (Kidd et al., 2018). Instead, whānau were shown to use complex health literacy strategies in finding the information they seek independently to compensate for poor communication by health professionals (Kidd et al., 2018). Increasing health literacy at a systemic level has the potential to improve the health outcomes of Māori as well as the general population.

<sup>5</sup> Continuous texts include examples such as brochures, editorials, and instruction manuals.



Improving health literacy can help improve the understanding of written health information. A crucial element to consider in the creation of health materials is the readability of the information presented to an individual. The readability of health information can be affected by the type of language used (using Plain English vs jargon), the formatting of information on a page, the accuracy of the information, and the legibility of the text (Davis et al., 1994).

In healthcare, patients and ‘health seekers’ often find themselves overwhelmed by the sheer amount of medical information and how it is conveyed to them. Medical jargon is often used across various forms of patient information, causing the average reader to be overwhelmed with unknown medical terms with little explanation of their relevance or meaning. Similarly, for healthcare products being sold in the consumer market, information to the healthcare consumer is provided for legal and commercial reasons rather than to inform and help patients make appropriate decisions about their own health (van der Waarde, 2017). This is often true for participant information sheets and informed consent procedures for participation in health research. For example,

a study on the function of informed consent documents for cancer trials showed that these documents did not facilitate decision-making in over half the patients [54%] (Armstrong et al., 2012). Furthermore, a few patients commented on how the participant information sheets served the interests of the institutions, staff and researchers more than the patients (Armstrong et al., 2012). Using human-centred design strategies to improve the information output in both the consumer health market and participant information sheets can improve an individual’s decision-making process about their health and wellbeing. This is especially relevant when designing information outputs for health consumers with communication difficulties.

## Information Design for Aphasia

The Society for Experiential Graphics (n.d.) defines information design as “the practice of presenting information in a way that makes it most accessible and easily understood by users”. Information design is primarily used to deliver knowledge accurately to a specific audience for their unique information requirements (Visocky O’Grady & Visocky O’Grady, 2008). Information design, at its core, is a human-centred practice that concerns itself with making sure the needs of the end-user are met through creating appropriate content and presenting that content in an accessible way (Visocky O’Grady & Visocky O’Grady, 2008). Using information design principles to convey written information to people with aphasia addresses how information is designed and presented on the page in a way that improves the readability and comprehension<sup>6</sup> of the information given. This is essential when designing for a population with unique communication needs.

Comprehension of a text can be made easier by language choice, sentence length, and the structure of the body of the text. The use of Plain English is a common enabler of comprehension for all audiences (The Office for Disability Issues, 2011; Readability Guidelines, 2020) and is used in many studies (Brady et al., 2013; Rose et al., 2003; Rose et al., 2011) for the design of aphasia friendly<sup>7</sup> information or reading materials. Plain English aims to use the simplest words and sentence structure possible when constructing a body of text (Readability Guidelines, 2020). This includes avoiding the use of jargon and any other words or phrases that might be unfamiliar or unknown to the target audience. Short and simple sentence structures where the text is broken up into shorter paragraphs enable easier comprehension alongside Plain English. Sentences are the most comprehensible when they contain around 15 words and are limited to one subject per paragraph (Cutts, 2020; The Office for Disability Issues, 2011). An example of this can be found in Figure 1.

<sup>6</sup> Comprehension refers to the understanding of the content of the text. In the instance of participant information materials, comprehension would involve understanding the content given to enable a person with aphasia to make an informed decision.

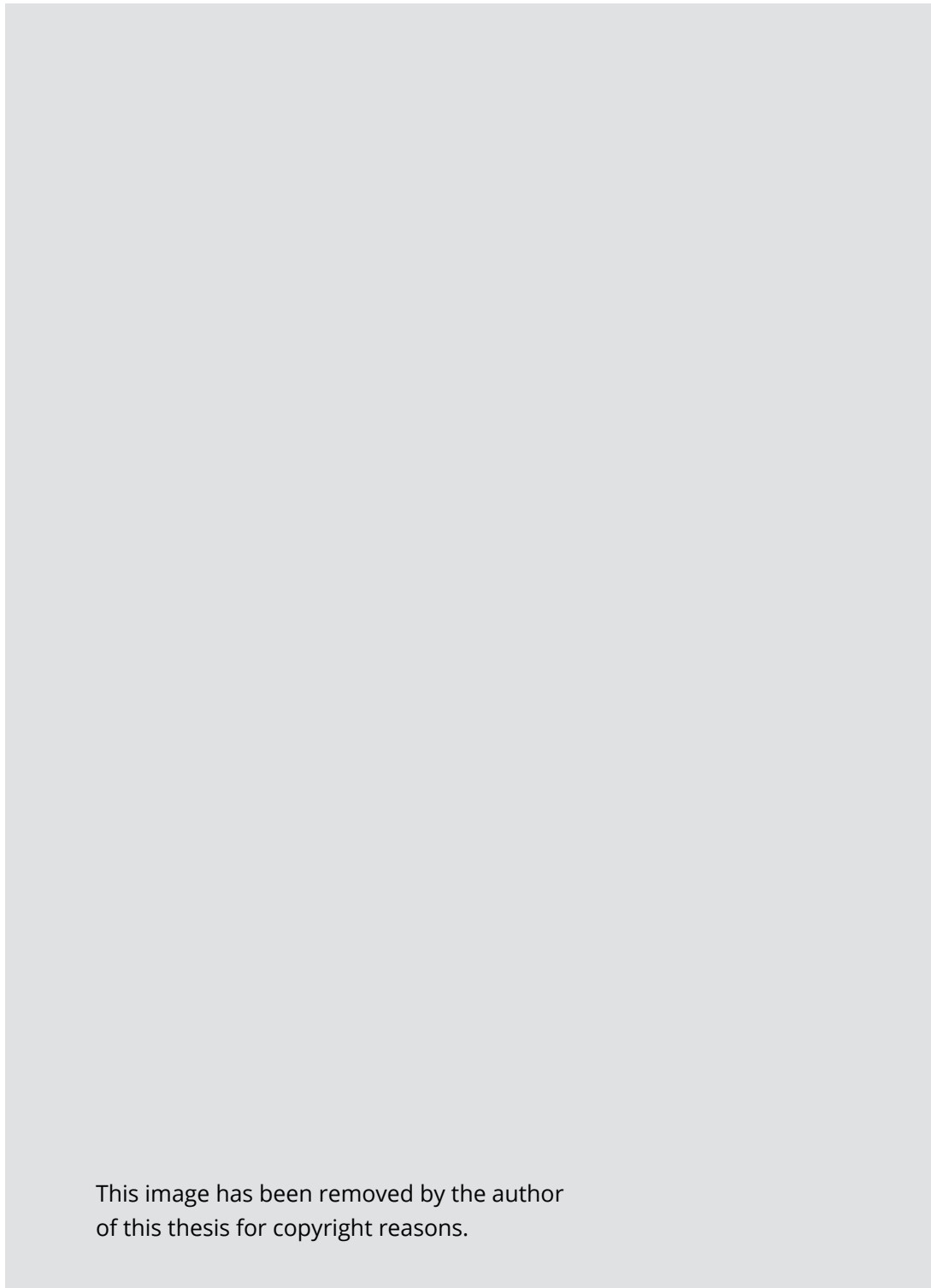
<sup>7</sup> Aphasia-friendly is used to describe “verbal and visual materials that are presented clearly, simply, and in plain English” (Luck & Rose, 2007 p. 212).

Typography can be improved by introducing a hierarchy of elements through contrast and layout decisions. This can help with the readability of a document or piece of text. A well-laid-out typographic piece that uses information design techniques can simplify complex information and data, and orientate and guide the reader through information (Bonsiepe, 1999; Spyridakis, 2000). Good principles of typography which can be implemented into the design of information include having clear and appropriate headings, relevant and ordered sectioning of type, and relevant placement of composite typographic elements. On the other hand, typography can be manipulated to make a document or text illegible. The consequences of bad typography in the design of information can lead to misinformation, confusion, and in the most extreme circumstances, injury or death (Sless, 2018). Caution is required to make sure the typographic treatment of text is made accessible and appropriate to the target audience.

**This sentence is about 15 words long and is easy to understand.**

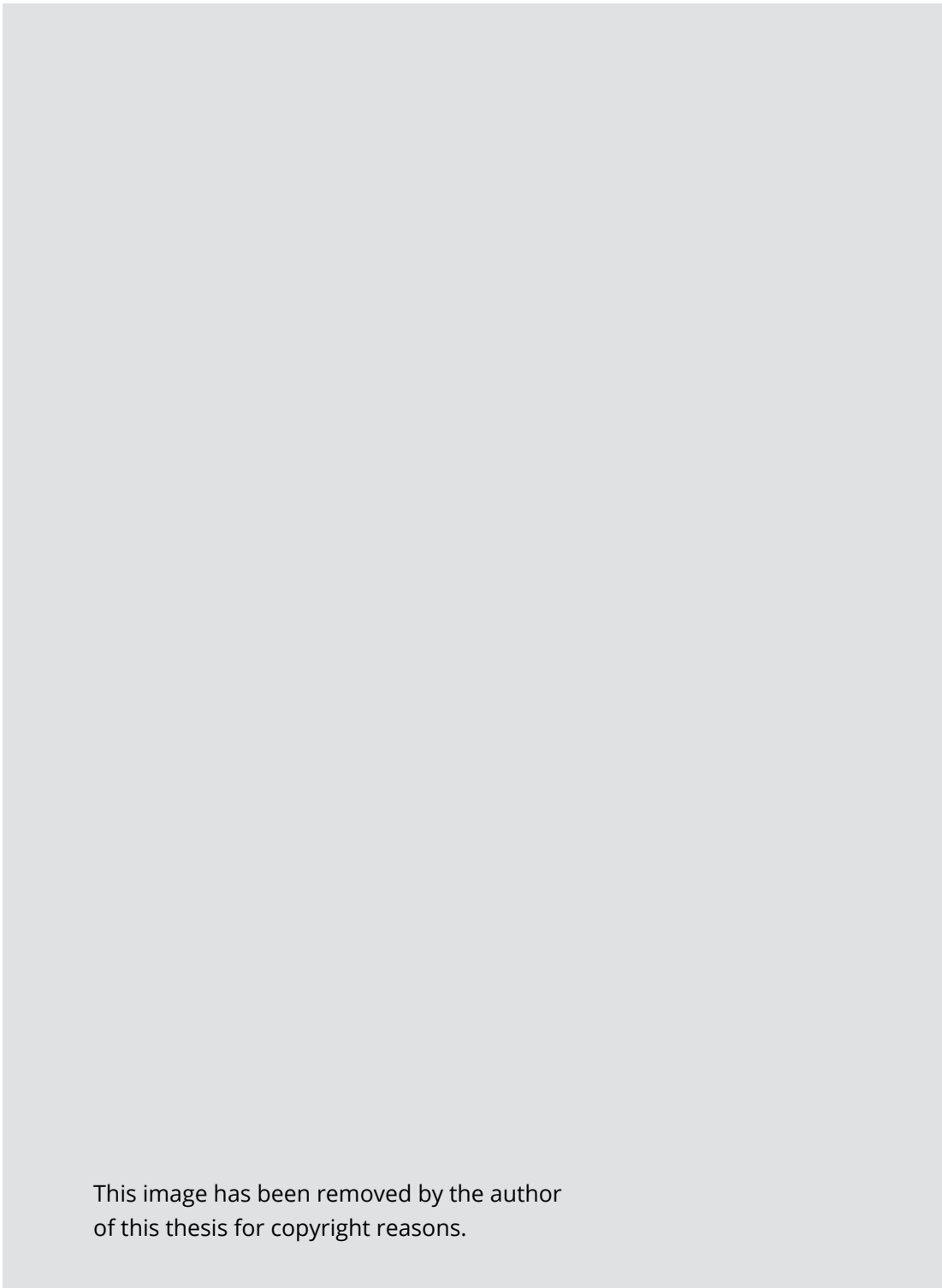
**This sentence is a lot longer than 15 words and will end up being a lot harder to understand what is being said due to there being approximately 40 words to read, think about, and comprehend continuously before there is a pause.**

*Figure 1. Sentence length comparison.*



**Figure 2.** Black, A., Bravo Burnier, J., Brook, M., Carey, C., Goonasekera, M., Meredith, D., Olsson-Brown, A., & Rosenorn-Laang, D. (2017). Designing care bundle documentation to support the recognition and treatment of acute kidney injury: A route to quality improvement. In *Design for Health* (pp. 174). Taylor & Francis Group.

*Note.* The existing hospital AKI bundle documentation



**Figure 3.** Black, A., Bravo Burnier, J., Brook, M., Carey, C., Goonasekera, M., Meredith, D., Olsson-Brown, A., & Rosenorn-Laang, D. (2017). Designing care bundle documentation to support the recognition and treatment of acute kidney injury: A route to quality improvement. In *Design for Health* (pp. 181). Taylor & Francis Group.

*Note.* The near final version of the bundle documentation used for simulation testing

Figure 2 (left) shows the acute kidney injury (AKI) care bundle before, and Figure 3 (right) shows the near final version of the acute injury care bundle. The results after applying information design and typographic principles was a refined and user-friendly bundle made to ensure the right treatment was given to patients with AKI by implementing a step-by-step easy to follow checklist.

### **Modifying Informed Consent for People with Aphasia**

A recent New Zealand review on the involvement of people with a communication impairment after a stroke in research concluded that out of 28 studies, only 9 (32%) reported any modifications to the recruitment process for people with communication impairments (Adviento & George, 2020). The rates of modified recruitment processes being this low in stroke research represent a barrier to the inclusion of people with aphasia and individuals with similar communication impairments in meaningful research that can benefit these groups.

It is common practice for researchers and clinicians in the aphasia field to modify consent forms and participant information sheets for their participants. Researchers in this field have an excellent idea of how to navigate communication impairments present in people with aphasia and understand the need for modified consent procedures to obtain informed consent. What they do lack, however, is design expertise. The help of a communication designer equipped with the expertise

to effectively apply typographic principles and information design strategies to participant information sheets will benefit both researchers and participants. A communication designer can aid in the structure, organisation and readability of participant information sheets for people with aphasia by presenting information that is clear, accessible, and readable (Bonsiepe, 1999; Visocky O'Grady & Visocky O'Grady, 2008).

Recommendations for the design of written health information for people with aphasia are widely documented in the literature (Aleligay et al., 2008; Dalemans et al., 2009; Eames et al., 2003; Herbert et al., 2019; Knollman-Porter et al., 2015; Rose et al., 2003, 2011, 2012; Wilson & Read, 2016). The recurring design characteristics mentioned in the literature are the use of simple language, short sentences, the use of white space, highlighting key information, having images alongside the text, the use of a sans-serif typeface, and large text (Aleligay et al., 2008; Dalemans et al., 2009; Eames et al., 2003; Knollman-Porter et al., 2015; Rose et al., 2003, 2011, 2012; Wilson & Read, 2016). The challenge for a health researcher without design expertise and experience, however, is how to consolidate and implement

these recommendations practically. Information design principles for universal accessibility and inclusivity refer to all of the above design characteristics when producing written information in its many forms (RGD Ontario, 2010; Visocky O'Grady & Visocky O'Grady, 2008). Taking an information design approach to the design of participant information sheets with a focus on typography will improve and refine what has already been recommended for the design of written information for people with aphasia.

The literature suggests there is an opportunity to apply information design principles and typographic considerations to the design of participant information sheets for people with aphasia to improve upon the informed consent process and facilitate participation. The design features detailed in the literature around accessible information for people with aphasia are a foundation for building and expanding upon what is already known. The expertise of a communication designer can fill the gaps in how to design information for people with aphasia that health researchers can benefit from when designing similar resources in the future.

Alongside this research facilitating the inclusion of people with aphasia in research, health researchers are anticipated to benefit from the outcomes when recruiting participants with aphasia. Design considerations and recommendations are identified to aid in the creation of accessible participant information sheets. By providing this design expertise, researchers may be less hesitant to include people with aphasia in stroke research that will improve their health outcomes.

The overall aim of this research was to facilitate the involvement of people with aphasia in research through the implementation of information design principles. Additional aims were to:

- Create accessible participant information sheets for people with aphasia that facilitate their understanding of the outlined research.
- Explore how typographic principles used alongside information design can improve the understanding of written information.

# Methodology

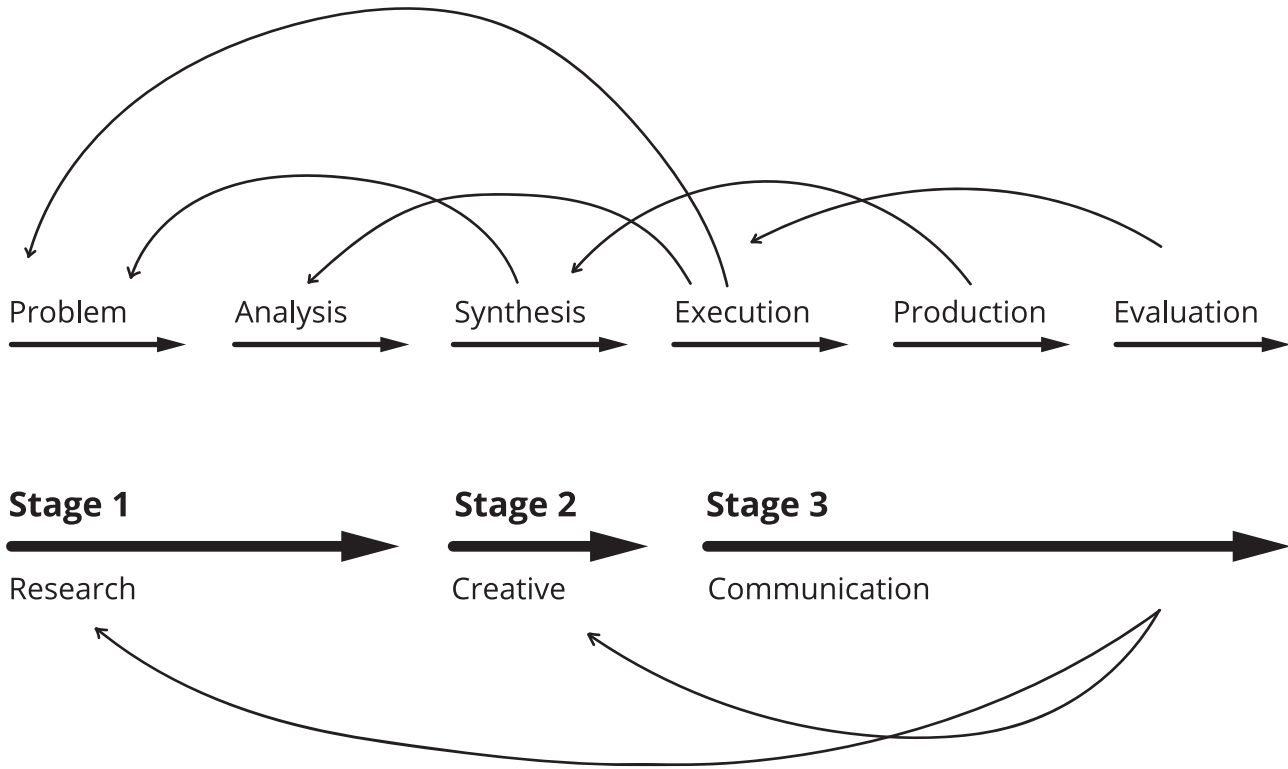
## Introduction

This research was a practice-led project that contributed to the knowledge and understanding of how information design and typography can improve the accessibility of health research. The research employed a human-centred framework alongside a participatory action research (PAR) methodology to work alongside the aphasia community to whom this research may benefit. Qualitative methods, such as expert interviews, interviews with people with aphasia, and questionnaires, were primarily used to gain a deeper understanding of the experiences of people with aphasia (Luck & Rose, 2007). Qualitative methods allowed differing views and perspectives to be heard and considered equally. Having a wide range of perspectives is important to discover common themes and provide a solution that considers these perspectives (Gray, 2018).



## Participatory Action Research (PAR)

Participatory Action Research (PAR) is a cyclical form of inquiry derived from Action Research (AR) (MacDonald, 2012; Rowe, 2020) which takes place over a sequence of cyclical phases consisting of planning, action, observing, and evaluating the results of action (Rowe, 2020). The PAR process is identical to Action Research with the addition of the intended audience included in this cyclical process of inquiry. PAR steps away from the traditional role of truth-seeking seen in Action Research and looks to work with its intended audience to facilitate changes to problems identified within the community (Rowe, 2020). For this research, the problem identified was the exclusion of people with aphasia from research due to the lack of well-designed and accessible participant information sheets to facilitate inclusion.



**Figure 4.** Swann (2002). *Non Linear Design Process*.

Participatory Action Research measures its success through the enactment of change (Rowe, 2020). Change can be seen as “the development of critical consciousness of the researcher and the participants, improvement in the lives of those participating in the research process, and transformation of societal structures and relationships” (MacDonald, 2012, p. 38-39). This research strived to facilitate change in all three areas MacDonald (2012) spoke about:

- Having the researcher be an active participant and learner in the research process.
- Facilitating the inclusion of people with aphasia in research.
- Digging into the deeper systemic issues of vulnerability and the uncertainty of people with aphasia’s capacity to consent.

Using PAR as a research methodology allows constant change, iteration, and adaptation based on the needs, feedback and involvement of participants in the research process through reflection and evaluation. PAR steps away from the quantifiable certainties many scientific methodologies

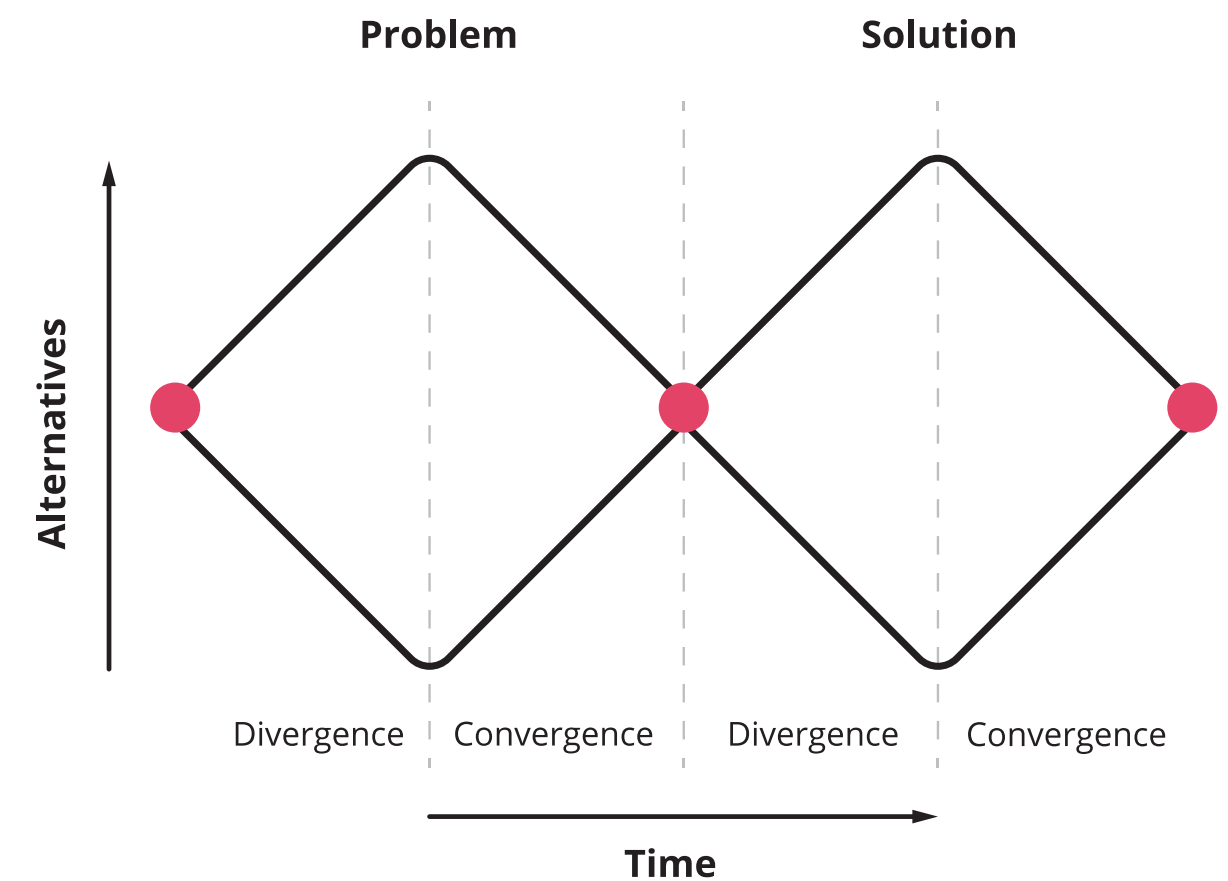
endeavour to find (Swann, 2002). It offers an alternative approach with no predetermined and obvious solution to the problem (Swann, 2002). Through my own practice as a designer, I have the design expertise to be able to facilitate accessible changes. However, I do not have aphasia myself, nor am I an aphasia researcher or clinician. Therefore, I have little knowledge about the language needs of those who do have aphasia and may struggle with reading. Therefore, it was crucial people with aphasia were included in this research to help identify challenges when reading and interacting with a participant information sheet and how design can aid in overcoming these challenges. This required an iterative cycle involving participants with aphasia who are experts in their lived experiences.

Participatory Action Research shares many commonalities with design practices, making it a viable methodological process for interdisciplinary research (Swann, 2002) – in this case, a collaboration between design and health. PAR and design practices have roots in collaboration, working with target audiences, utilising an iterative and reflective practice, and measuring success through the implementation of change (Rowe, 2020).

## Human-centred Framework

Alongside Participatory Action Research, this research employed a human-centred design approach. Human-centred design is an approach to design that looks at the needs, desires, and wellbeing of the intended users over the business and artistic preferences (Giacomin, 2014; IDEO, 2015; Ku & Lupton, 2020). Similar to PAR, human-centred design involves working alongside its intended audience, treating people as experts in their own experiences, and keeping people and their needs as the focus of the design outcome by observing and engaging in meaningful conversations throughout the process (IDEO, 2015; Ku & Lupton, 2020). These processes ensure that outcomes are guided by first-hand perspectives rather than external bias or assumptions on what people might need, want or desire (IDEO, 2015; MacDonald, 2012).

Human-centred design allows designers the chance to interact with their audience to dismantle barriers, find the right problem and produce solutions that meet their needs and capabilities as users (Fletcher, 2006; Norman, 2013). Meanwhile, ideas are rethought continually, and backtracking is normalised as part of the iterative design process (Norman, 2013).



**Figure 5.** Norman (2013). *The Double-Diamond Model of Design* by the British Design Council, 2007.

Human-centred design relies on empathy. The designer engages with the audience to create an empathetic solution to the problem by understanding the audience's perspectives (IDEO, 2015). Empathy allows the designer and researcher to take a walk in another person's shoes to understand the experiences, everyday life, and hidden complexities of the audience they are designing for (IDEO, 2015; Ku & Lupton, 2020). When engaging and working with people with aphasia, empathy is essential. Designers and researchers often have little lived experience of the contexts they design and research in. They may have a general idea of their wants, needs, and experiences through secondary sources, but each person may have different goals, desires, wants and needs. Most designers and researchers will not know what it is like living with aphasia, unless they themselves have aphasia or are impacted by aphasia. For example, we might only know generalisations about what living successfully with aphasia looks like e.g. (Brown et al., 2012; Grohn et al., 2012, 2014), but each person may have different goals and objectives that can be made visible to others only through interacting directly with them. When it comes to understanding written information and reading, there seems to be a strong desire to

regain literacy skills amongst people with aphasia (Knollman-Porter et al., 2015). This is where an empathetic approach is essential to understanding the needs of people with aphasia regarding their process of understanding written information and what design can do to help facilitate this reading process.

A human-centred design framework for designing participant information sheets for people with aphasia is essential to understanding the design, readability, and comprehension preferences of people with aphasia. In this project, the human-centred design process paired with participatory research enabled an exploration of how design could create a better reading and decision-making experience for those with aphasia interested in taking part in the research.

# Project Timeline

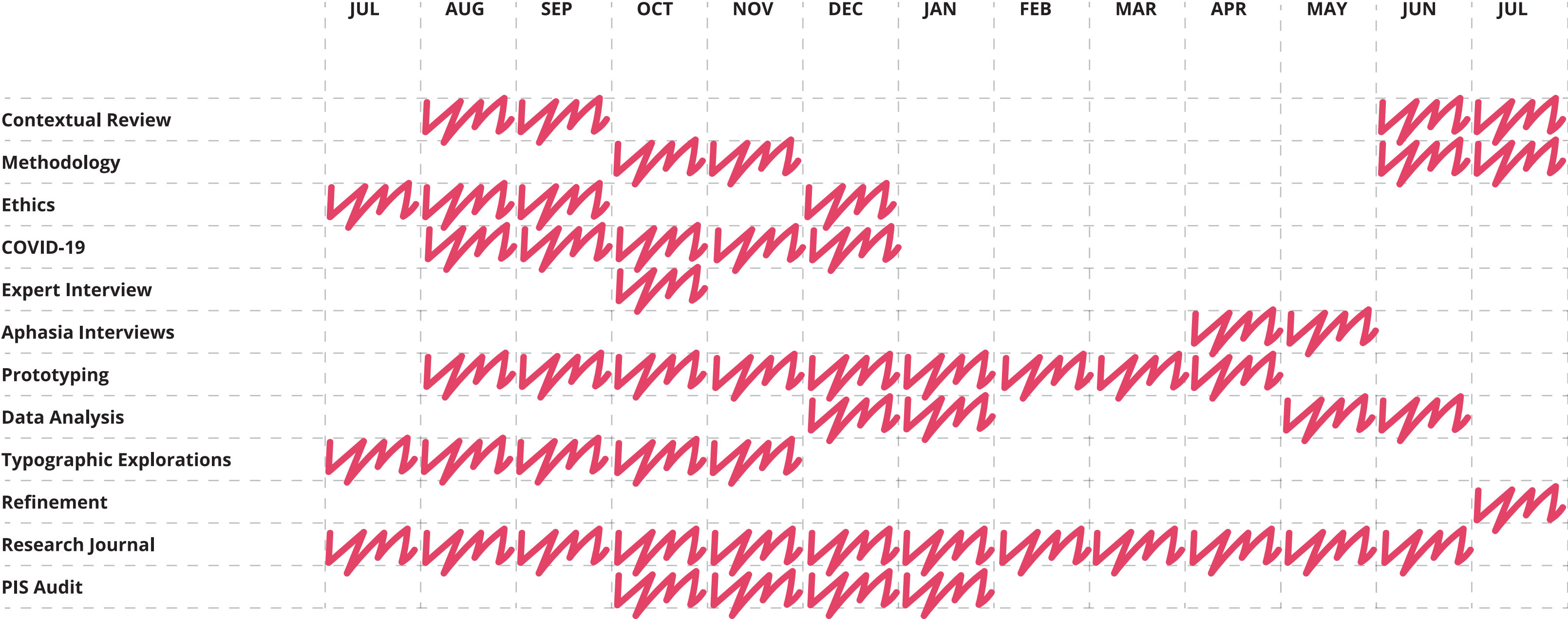


Figure 6. Research Project Timeline.

# Research Methods

## Contextual Review

A contextual review is a critical evaluation that helps to define the scope of the research and the extent of the relevant knowledge on a particular research topic or field of inquiry (Gray & Malins, 2004). A contextual review helps the researcher establish their research project in relation to relevant contexts and make sure the project's scope is feasible and appropriate in connection to past research and knowledge (Gray & Malins, 2004). It aims to equip the researcher with multiple perspectives to critically analyse, discuss, and consider when situating their research (Gray & Malins, 2004). This process allows the researcher to uncover gaps in knowledge and explore new approaches to add to existing knowledge (Gray & Malins, 2004; Gray, 2018).

A contextual review was conducted at the start and throughout this research project. It was used initially to help gain a comprehensive understanding of aphasia as a communication impairment, the experiences of people with aphasia managing everyday life, their exclusion from stroke research, and the ethical implications of these exclusions. Secondly, the contextual review confirmed there is a need for accessible and well-designed participant information sheets

to facilitate the inclusion of people with aphasia in research through a design-led approach using information design strategies.

Additional areas of inquiry were conducted as the research developed and included the use of written health information for people with aphasia, design in a healthcare context, health literacy, informed consent, and vulnerability of research participants. Identifying literature in these contexts guided the research process.

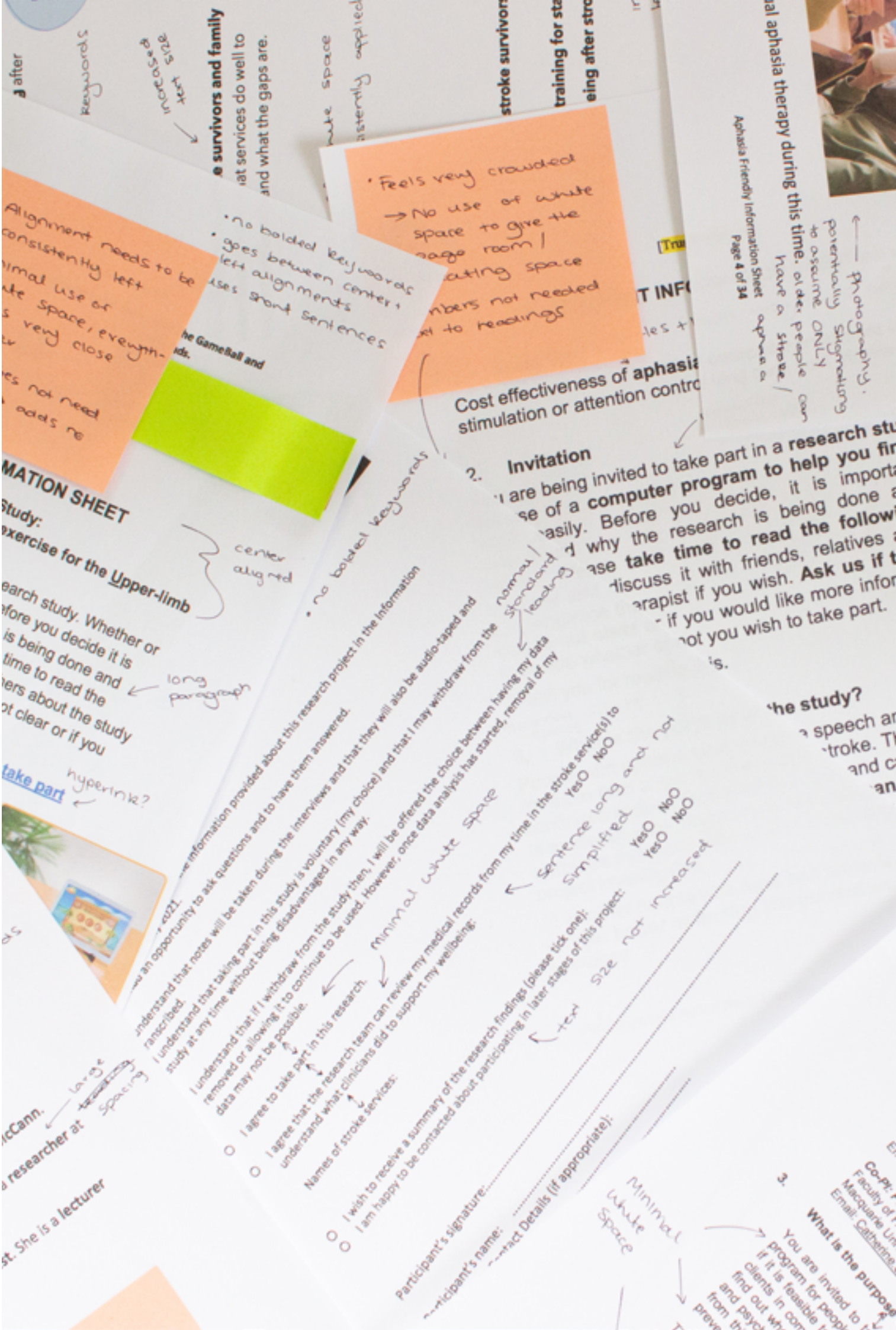


# Audit of Participant Information Sheets

An audit is a process of evaluation of an item or service to ensure its quality and effectiveness (Schwandt & Halpern, 2022). An audit of existing participant information sheets and consent forms previously used for recruiting people with aphasia in research was undertaken. The purpose was to gain an understanding of the design, format and readability of information sheets currently being used by researchers in the recruitment and consent processes for people with aphasia. Alongside aphasia-specific information sheets, stroke research participant information sheets and institutional participant information sheet templates were analysed to compare and contrast their accessibility to people with aphasia.

Existing participant information materials were obtained through search engines, institutional websites that were publicly available, and through my supervision team. The participant information sheets, along with consent forms, where relevant, were printed in their intended size and format, and notes and comparisons were taken on their readability, format, and design. As a designer and researcher undertaking this process, I reviewed these documents from a design perspective backed by the knowledge and understanding of

Figure 7. PIS audit pile with notes.





successful accounts of aphasia-friendly techniques used in the design of written information (Dalemans et al., 2009; Eames et al., 2003; Herbert et al., 2019; Pearl & Cruice, 2017; Rose et al., 2003, 2011; Wilson & Read, 2016). Analysing and reviewing participant information materials was a starting point in designing accessible participant information materials before engaging, prototyping and testing alongside people with aphasia who will be the end-users.



Figure 8. PIS audit papers with notes.

## Expert Interviews

Expert interviews were conducted to engage with people knowledgeable in aphasia research. It was vital to interview someone who had an understanding of the language difficulties that follow a stroke and was familiar with aphasia as a condition. Alongside this, a health researcher and clinician's understanding of the experiences people with aphasia go through when engaging in the informed consent process, was equally as valuable for the design of participant information materials. With this research being focused on informed consent, it was valuable to engage with an expert who had experience gaining ethical approvals for an audience with communication impairments or had sat on an ethics committee. Having expert knowledge of the ethics process helped to gain an understanding of the considerations and frameworks that need to be put in place when engaging people with communication or language difficulties in research.

## Interviews with People with Aphasia

Interviewing the target audience and end-users of a design solution allows participants to share their lived experiences and give insights about a topic or area of interest that is often not spoken about without engaging directly with the audience (IDEO, 2015). For this research, participants with aphasia were interviewed as experts in their own experiences and their insights heard. It was important to build an understanding of their experiences living with aphasia; understanding how people with aphasia navigate written information with their communication impairment became an invaluable source of knowledge and information (IDEO, 2015; Ku & Lupton, 2020).

Each participant with aphasia underwent two interviews. The first interview explored questions about getting to know the participant, managing their life with aphasia, and their experiences now with the process of reading. The second interview was a time for participants to give feedback on the prototype participant information sheets and talk about their preferences when designing information. Both interviews were conducted in a semi-structured format to allow for additional questions to be asked, the structure of questions to be changed based on the participant's answers

and communication abilities, and other lines of inquiry to be explored that came up during the questioning.

When conducting interviews with people with aphasia, considerations and adaptations to the interview process were needed to enable effective communication and connection between the participant and researcher. Appropriate adaptations ensured participants' communication and language difficulties were not a barrier to their ability to contribute insights about their own lived experiences meaningfully. Additional communication formats were discussed and offered to the participants upon the first meeting to support the interviewing process. These additional communication formats suggested included using a pen and paper to write or draw, typing out words or sentences when in an online environment, and encouraging the use of gestures to communicate a word or idea (Dalemans et al., 2009; Kagan, 1995). Alongside these formats, there was a need to pay closer attention to body language cues to help identify and interpret words, meanings and ideas in the interview (IDEO, 2015; Kagan, 1995).

Interviews are seen as a qualitative research method where questions are encouraged to be broad, open-ended and the meaning is interpreted based on the participant's perspectives and experiences (Rubin & Rubin, 2005). Engaging in broad and open-ended questioning when conducting interviews with people with aphasia can sometimes lead to participants having difficulty responding to the questions received (Luck & Rose, 2007). To enable people with aphasia to adequately express themselves, probing questions were sometimes employed to gather further information alongside word offerings and closed-ended questions when clarification was needed (Dalemans et al., 2009; Grohn et al., 2012; Luck & Rose, 2007; Pearl & Cruice, 2017). An example of a yes or no probing question that was utilised: *"Is it helpful to have each sentence as a new paragraph?"*

Additional time was offered for answering questions to allow the participants to understand, ponder and communicate their responses without the added stress and time pressure (Dalemans et al., 2009, 2010; Grohn et al., 2012). Further, I adapted my speech to be slower, use simple grammar, short sentences, and have long pauses after each sentence to allow participants with aphasia to comprehend as much of what I said as possible (Dalemans et al., 2009; Gray, 2018; Kagan, 1995; Topping et al., 2021).

## User Testing

User testing gives insights into how an audience uses and navigates a product or system and if any barriers or challenges arise through the process of testing the prototype (Nielsen, 1993). In this research, user testing was conducted in the form of an interview with people with aphasia. The participants with aphasia navigated prototype participant information sheets to test whether the design features enhance the accessibility and readability of the information presented about a study. Participants with aphasia were given two physical prototype participant information sheets that focused on a specific set of design variables (to be discussed in the documentation chapter). All other design features and elements were fixed throughout both prototypes. Participants were sent a package containing the prototypes and other materials that aided in the discussion of the design variables in an accessible and user-friendly format. Participants were asked to choose what prototype they liked the most and were invited to comment on each design variable to determine which variable was most helpful and if any of the variables aided in a participant's ability to read and access the information about the study.



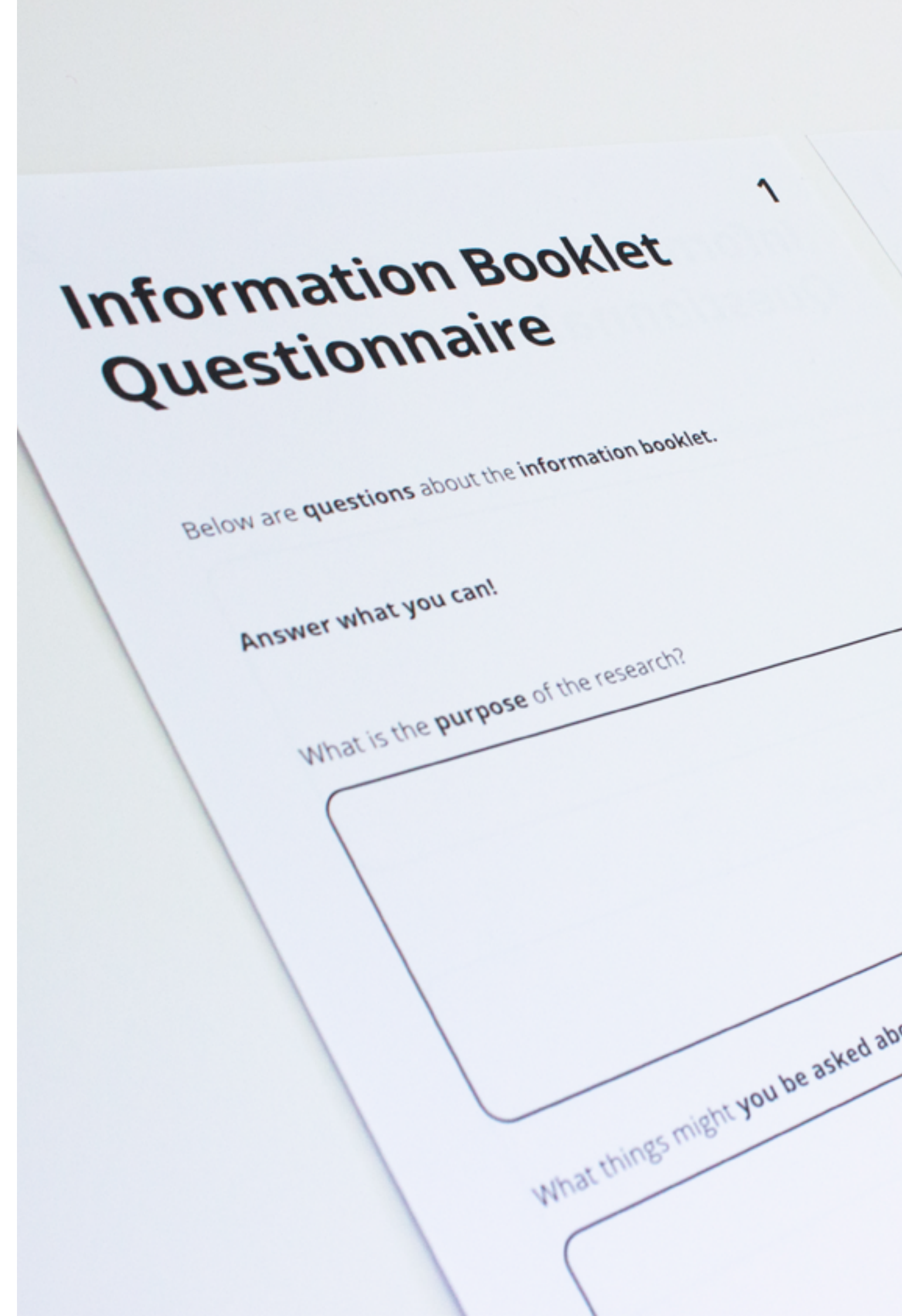
Figure 9. User testing of prototype PIS.



## Questionnaire

A questionnaire was created for use during the interview process with people with aphasia while feedback on prototype participant information sheets was gathered. An alternative approach was taken where questionnaire was not intended to gather new insights into their lives or feedback on prototypes. It was instead created to ensure that when participants with aphasia read the prototype participant information sheets, they understood the contents and information being given to them well enough to be able to provide genuine informed consent. The questions are derived from Smith et al.'s (2009) Older Adults' Capacity to Consent to Research (OACCR) scale that has been adapted for participants with aphasia. The questionnaire was given to participants in the package with the prototype participant information sheets that were mailed to them.

**Figure 10.** *Information booklet questionnaire.*



# Research Journal & Note-Taking

The research journal details the researchers’ complex experience navigating unseen details such as inspiration, successes, failures, roadblocks, emotions, revelations, hunches, assumptions, and disappointments (Gray, 2018). A physical research journal was kept on me at all times that detailed insights, ideas and thoughts on each aspect of my research journey as they occurred or when an idea came to mind. Every two weeks, a digital journal entry was made alongside my physical research journal to summarise and reflect on all the important aspects of the research regularly. The physical research journal helped me to express my thoughts and ideas in writing in a way that was non-linear and open to scrutiny and exploration. It allowed me to openly explore problems, map out, link, and play with ideas fluidly before committing to any one concept or solution. I also used post-it notes stuck to a wall as a variation to the typical note-taking format to write down any ideas, thoughts, or tasks that needed attention. The post-it notes were taken down once an idea or task was explored or completed.



Figure 11. Research journal.



Figure 12. Post-it note taking.

## Data Analysis

Qualitative data analysis is a process where data is given meaning (Gray, 2018). It is intended to break data down into smaller parts to find connections and discover new meanings (Gray, 2018).

Content analysis is a qualitative method of data analysis that analyses text that focuses on language features as communication in regards to the content or context of the text (Hsieh & Shannon, 2005). Text data can come in many forms including verbal, print, or digital formats that can be obtained from qualitative data gathering methods such as interviews and questionnaires, but also printed media such as books, or in this instance, information sheets and consent forms (Hsieh & Shannon, 2005). Content analysis examines language closely to organise text into categories or themes that show similar meanings (Hsieh & Shannon, 2005). These categories or themes can represent both explicit or inferred communication (Hsieh & Shannon, 2005).

Analysis of data was conducted at three main stages of the research process: the expert interviews, the audit of participant information sheets, and the interviews with participants with aphasia. The data analysis was kept simple throughout each stage of the process as key themes had already been identified prior to the data being analysed.



# Design Methods


## Typographic Explorations

Typographic explorations are a form of visual research that critically looks at how typography can affect people's lives (Muratovski, 2016). Typographic explorations were used in this research to experiment, test and understand how typography can be used in multiple ways and to give voice to various contexts and issues that have informed my line of inquiry for this research. The experiments aimed to explore how typography can grant or deny the reader access to information, and how it can visually represent a feeling, emotion, or experience through its visual characteristics and forms.


Three types of typographic explorations were carried out. The first exploration looked into the documentary *My Beautiful Broken Brain* which explores the recovery of a woman who had a stroke and acquired aphasia as a result (Robinson & Sodderland, 2016). Quotes taken from the documentary about her life and experiences of recovery were used to create typographic experiments that played with how typography can visually portray her experiences and emotions. The second exploration looked at the word 'inaccessibility' and how it applied to the exclusion of people

with aphasia from research. Statements from the National Ethics Advisory Committee (2020) about the exclusion of vulnerable populations were typographically manipulated to be difficult or inaccessible to read. The last typographic exploration looked into accessible typefaces that can aid in literacy and enhance the reading experience. The exploration dove into the anatomy of multiple typefaces and investigated how the design of letterforms can make reading easier for people who may find it difficult.

Lowercase letters 'r' and 'n'  
placed next to each other.

The image shows two lowercase letters, 'r' and 'n', in a bold, white, sans-serif font. They are positioned side-by-side on a black background. The 'r' has a curved shoulder and a short vertical stem. The 'n' has a similar curved shoulder and a taller vertical stem.

Lowercase letters 'r' and 'n'  
placed next to each other  
overlapping a lowercase  
letter 'm'.

The image shows three lowercase letters, 'r', 'n', and 'm', in a bold, white, sans-serif font. They are positioned side-by-side on a black background. The 'r' and 'n' are overlapping the 'm'. The 'r' is on the left, the 'n' is in the middle, and the 'm' is on the right. The 'r' and 'n' are slightly offset to the left and right of the 'm' respectively, creating a layered effect.

**Figure 13.** *Sample of typographic exploration.*

## Mind-mapping

Mind-mapping is a process of generating, structuring and organising thoughts and ideas (Rustler & Buzan, 2012). Mind-maps can be thought of as branches or keywords that come out of a central theme or idea that needs exploring (Rustler & Buzan, 2012). It can help provide an overview of the subject or topic, make connections, generate ideas and can help to define the scope of a project or research (IDEO, 2015; Norman, 2013; Rustler & Buzan, 2012).

Mind-mapping was used extensively throughout this research as a tool for establishing the contexts and the scope of inquiry by drawing connections between participant information sheets, ethics, information design and aphasia. It helped to situate the contexts within the research and also helped to organise methods and approaches that aligned with participatory action research and human-centred design. Mind-mapping also helped with collating and organising design characteristics to use or avoid when creating participant information sheets for people with aphasia. The mind-mapping process helped me to understand and develop prototypes that can help people with aphasia to understand, comprehend and read written information in participant information sheets and other supplementary resources. Mind-mapping helped to fluidly generate and organise ideas to make accessible and human-centred decisions about the implementation, approach and design of all aspects of this research project.



Figure 14. Mind-mapping of the questionnaire.

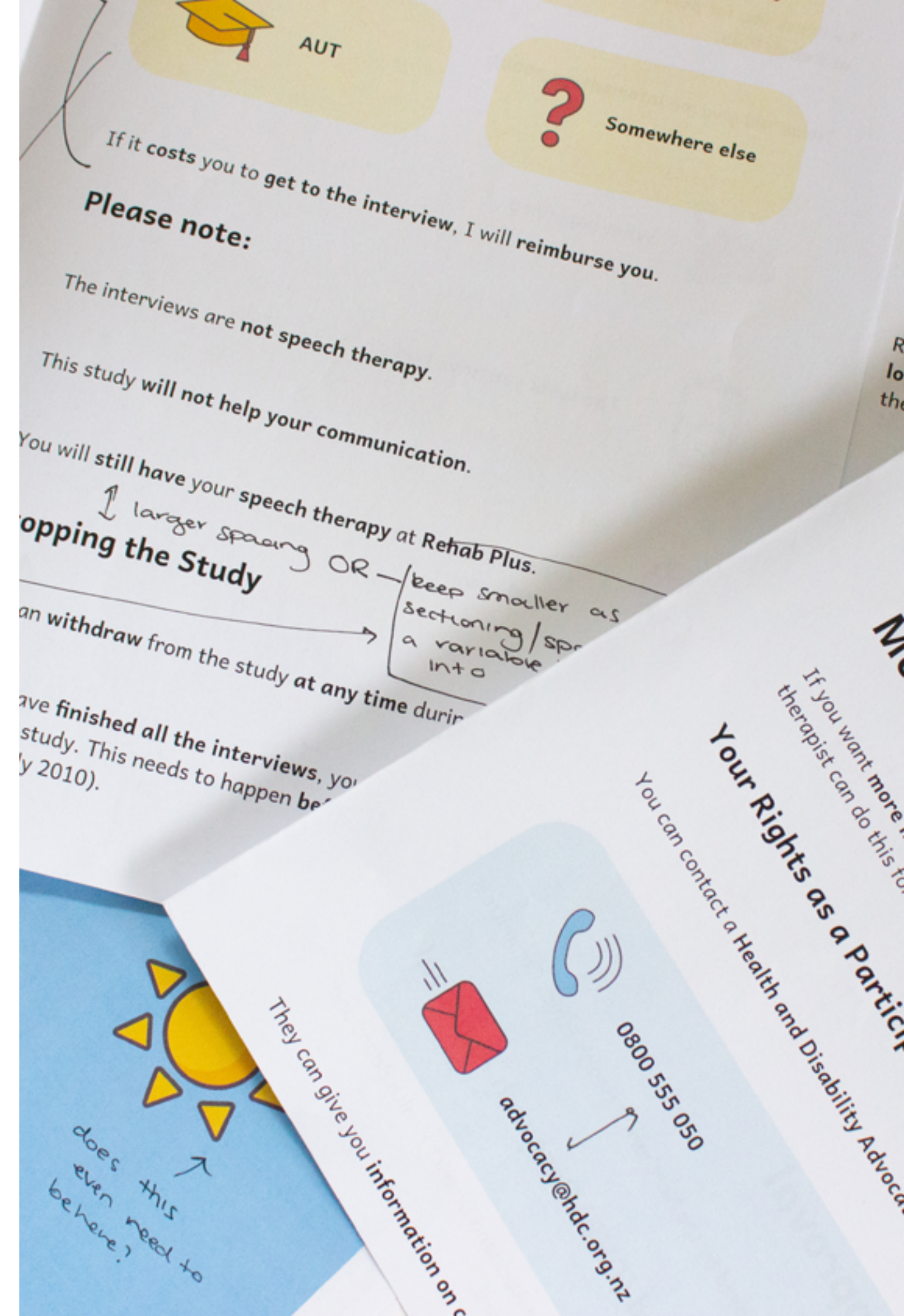


## Prototyping

Prototyping is defined as the iterative process of rapidly developing and testing ideas in a tangible form (IDEO, 2015; Naar et al., 2018). The rapidness of prototyping is key in the early stages to ensure all ideas have been tested before committing to a final design. In the prototyping process, end-user feedback is essential to quickly assess which ideas have potential and which do not, so as to ensure that the unique wants and needs of the intended audience are considered (IDEO, 2015); this informs further development and iterations of prototypes (IDEO, 2015; Naar et al., 2018). Through constant iteration developed from feedback, learning is fostered and built back into further prototypes and the final outcome through the making process (IDEO, 2015).

Prototyping was used throughout this research to create multiple iterations of all three of the typographic explorations, communication aids, as well as the participant information sheets for participation in this study, and the participant information sheets designed as part of the research outcome. The participant information sheets, consent form, and questionnaire required for participation in this research went through multiple prototyping stages before being finalised and

**Figure 15.** *Prototyping of the PIS.*





sent through for ethical approval. The participant information sheet prototypes designed as part of the research process and designed outcome were presented to people with aphasia for end-user feedback during the second participant interviews. Having the voices of people with aphasia involved in prototype feedback assisted in understanding what worked well and what needed further refinement.

All prototyping went through multiple stages that ranged from ideation, creation, feedback, and refinement in a continuous cycle until a final outcome was produced (Norman, 2013). Additional refinement on the prototype participant information sheets presented to people with aphasia took place after feedback was gathered.

**Figure 16.** Card sort prototyping.



# Ethical Considerations

This research aligns itself within a human-centred framework to ensure the inclusion of people with aphasia and aphasia researchers throughout the research process. This was necessary to ensure the design solution aligned with the reading capabilities of people with aphasia (end-users) while also taking into account aphasia researchers' experiences and knowledge by ensuring the outcome is able to be implemented into their own participant information sheets.

Formal ethical approval for this research was given by AUTECH on 8 September 2021 (number 21/279) for expert interviews with people with aphasia who are experts in their own experiences, and the questionnaire (see Appendix 1).



### **Ethics Amendment**

As the research progressed, it was becoming more and more evident that changes would have to be made to data gathering due to the ongoing uncertainty around COVID-19. Data gathering needed to be conducted online while COVID restrictions were in place.

Approval for an ethical amendment was given by AUTECH on 14 December 2021 for online interviews with people with aphasia who are experts in their own experience (see Appendix 1).

To enable my research to proceed despite the uncertainty and restrictions, I made the following amendments to my ethics application:

### **Recruitment Changes**

During this time, it became difficult to get in contact with the aphasia community group I intended to recruit from, and attempts to facilitate recruitment ceased. With no other avenues available, recruitment was extended from community groups to include rehabilitation providers and professional contacts of the research team. This allowed a wider range of recruitment possibilities in the event where there are further communication breakdowns or no participant interest.

#### **Option for Online Participation in Interviews.**

With the uncertainty of when in-person data collection would re-commence, an option for online data collection was needed for people with aphasia. This option was to be used as a last resort due to some communication limitations when conducting interviews with people with aphasia in an online environment. However, these limitations could be worked around with prior planning and assessment of the participants with aphasia.

### **Designing Participant Information Sheets for the Ethics Application**

A review of research ethics forms used in previous studies with people with aphasia informed the design of participant information sheets (PIS) and consent forms for participation in this research. The design characteristics described below have been found to facilitate the understanding of health information when tested with people with aphasia (Rose et al., 2011) and have informed the design of the PIS for participation in this research:

- Language
- Sectioning
- Relevant headings
- Emphasis using bold text
- Graphics alongside text
- Large text size

When re-designing the consent form for this research from the university template provided, many sentences were simplified, and complex words were substituted for simpler words and phrasing where appropriate. Special attention was made not to oversimplify key concepts where the meaning may shift if certain words or phrases were simplified too much.

For example, the phrase:

*I may withdraw from the study at any time without being disadvantaged in any way*

was replaced with:

*I may stop taking part in the study at any time.  
There will be no problems if you do not take part.*

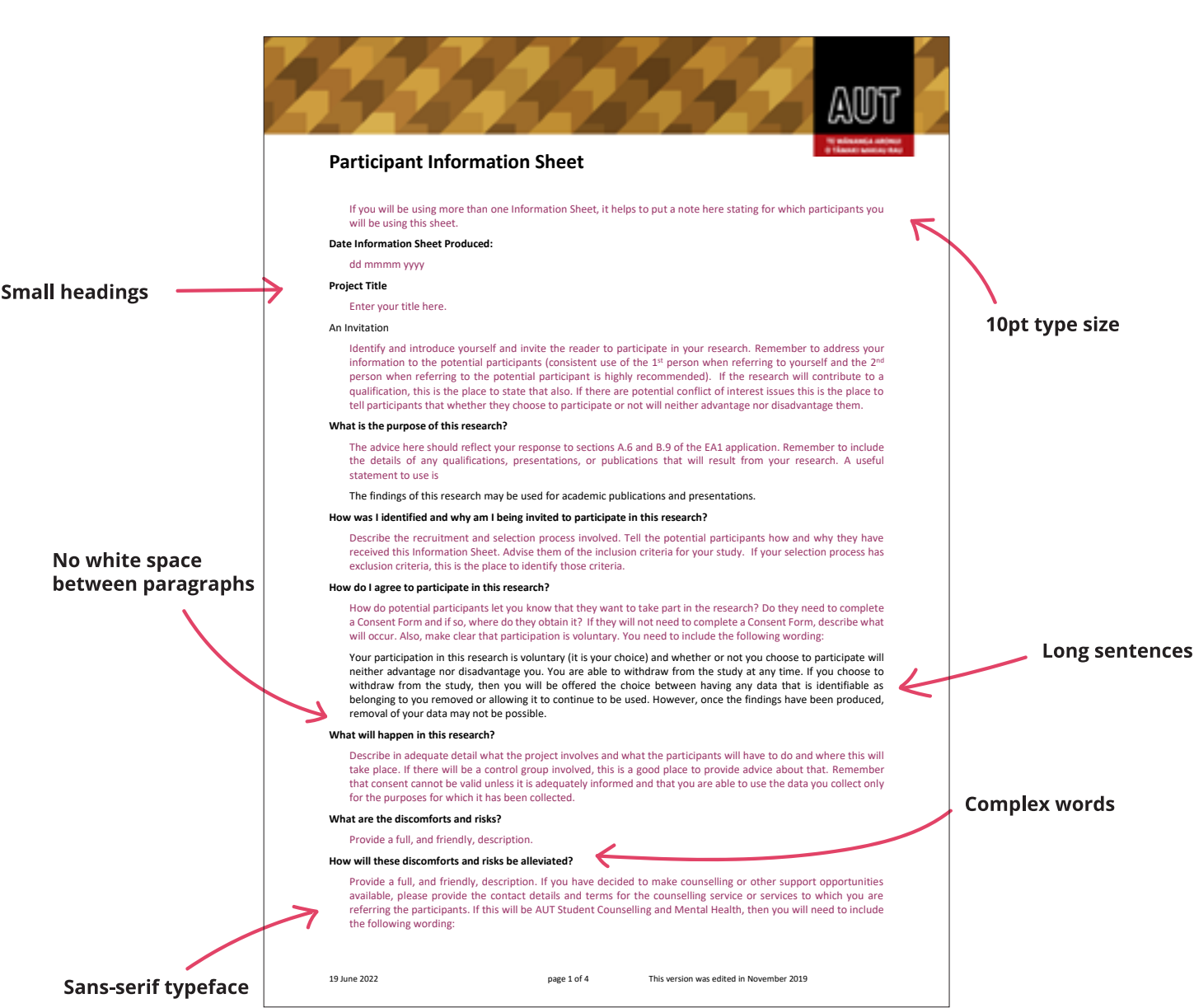


Figure 17. AUTEc participant information sheet template with annotated features.

Note. This AUTEc participant information sheet is publicly available at:  
<https://www.aut.ac.nz/research/researchethics/forms>

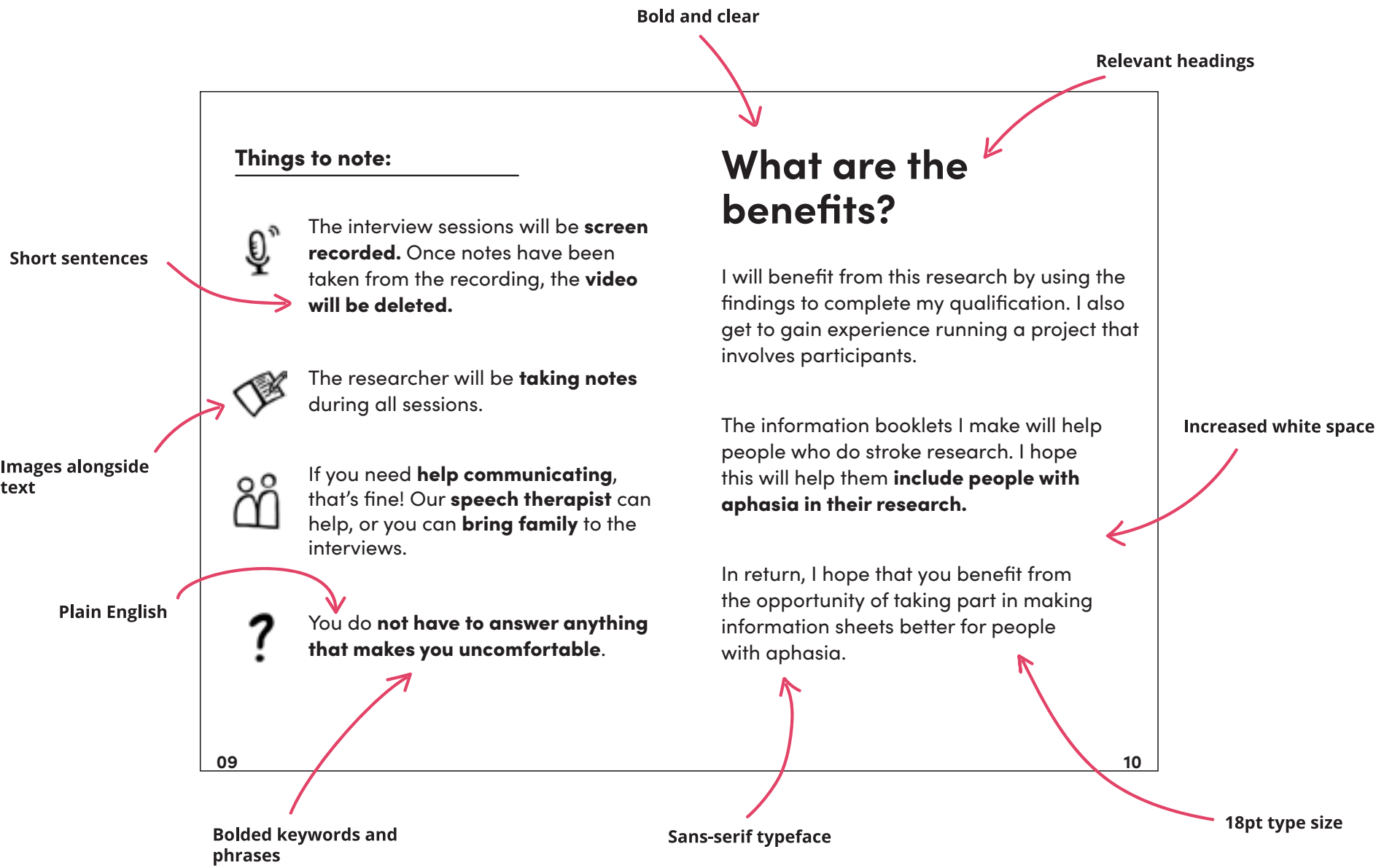


Figure 18. Participant information sheet designed for participants with aphasia for this study with annotated features.

Note. Comparison of the AUTEc participant information sheet template (left) with the participant information sheet designed for participants with aphasia for this study (right). The comparison shows the aphasia-friendly features utilised in the re-designed version against the featured currently utilised in the AUTEc template.





Figure 19. PIS for people with aphasia about the research.

# Documentation of Research

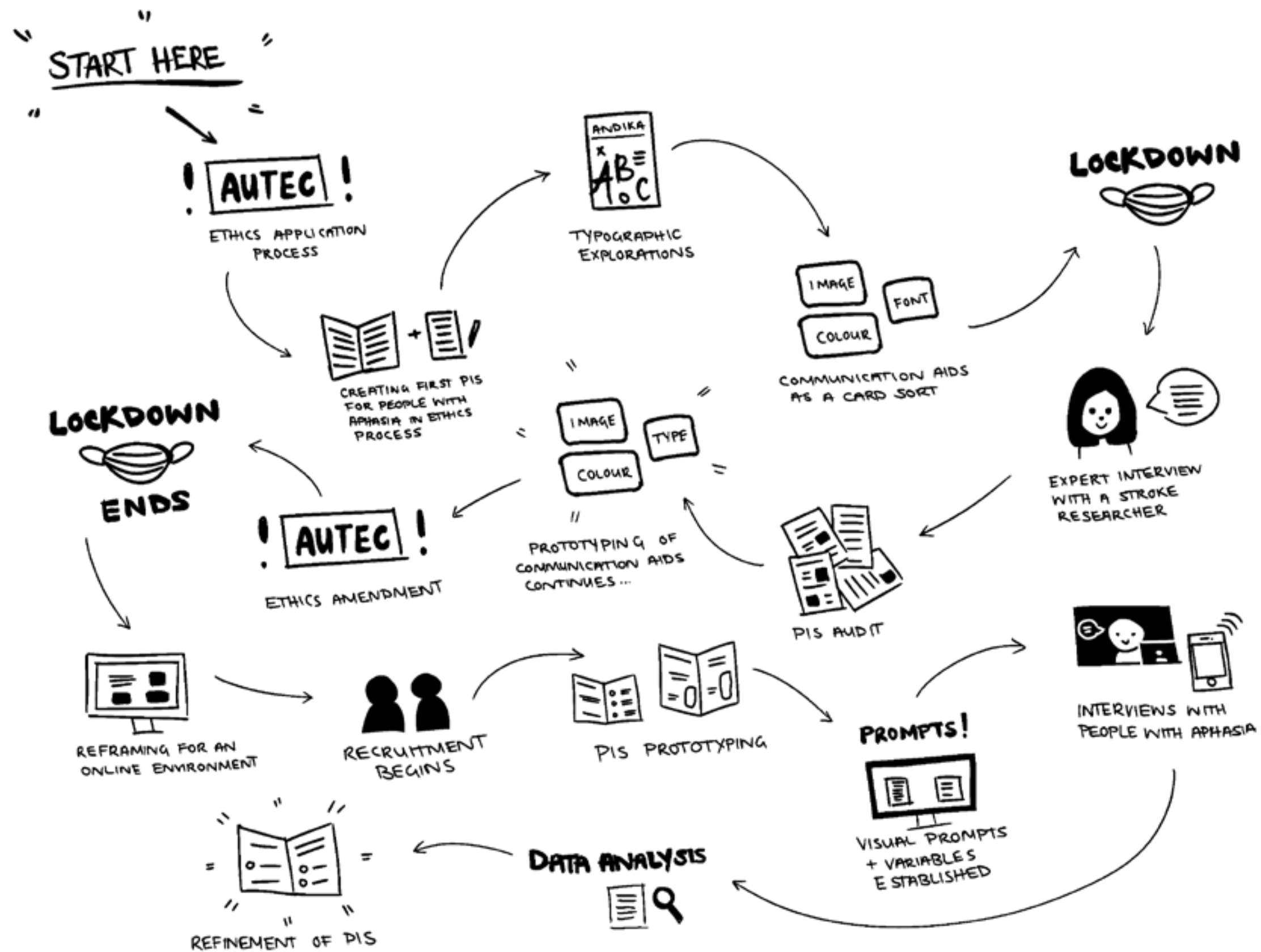


Figure 20. The research journey.



## Introduction

This research began with the need to facilitate the inclusion of people with aphasia in research opportunities. Often, people with aphasia are excluded from research due to their communication needs and accompanying language difficulties (Brady et al., 2013; Wray et al., 2018). With one-third of all individuals experiencing aphasia after having a stroke (Flowers et al., 2016), excluding people with aphasia from stroke-related research can lead to generalisations in research findings (Brady et al., 2013; Shepherd, 2020). Through the use of typographic and information design principles in this research, participant information sheets were re-designed to be readable and accessible to facilitate the inclusion of people with aphasia.

The research process is shown visually in Figure 20. The process started by obtaining ethical approval to work with people with aphasia to allow their voices and feedback to shape the research outcome. Typographic experiments were then produced to explore the concept of accessibility and to visually portray experiences and emotions through type. The typographic experiments made way for the construction of a card sort activity to aid participants with aphasia in communicating their feedback about the eventual prototype participant information

sheets. An analysis of participant information sheets was then conducted to determine what is being done to improve the accessibility for people with aphasia and what can be done for to their design to facilitate further inclusion. An expert was approached to share their experiences on inclusion, vulnerability, navigating ethics, and creating participant information sheets for people with aphasia. At this stage, data collection was reconsidered for an online environment and changes were made to accommodate this shift. While further progress was being made on the card sort, prototyping of participant information sheets commenced. While iterative prototypes were being produced, a breakthrough came in the form utilising visual prompts that included variables to analysed. Data collection commenced, and prototypes were presented to participants with aphasia for feedback. Feedback was gathered and analysed which lead to the prototypes being refined and a set of best-practice guidelines for researchers and clinicians was created to help them design their own aphasia-friendly information sheets.

## Exploring the Post-Stroke Experience Through Typography

As part of understanding aphasia and what it is like to live and navigate life with aphasia, I watched the documentary *My Beautiful Broken Brain* on Netflix (Robinson & Sodderland, 2016). The documentary is about Lotje Sodderland, a 34-year-old filmmaker who acquired aphasia as a result of a stroke. The documentary follows Lotje's journey of recovery from the first moments after she wakes up in hospital to one year post-stroke. Much of the footage is filmed by Lotje herself on her phone camera as a way of documenting, remembering, and piecing together her own post-stroke journey.

The use of Lotje's phone camera to document her journey shows a raw depiction of her road to recovery as she talks about the thoughts and feelings she is experiencing in the moment she experiences them. It was very confronting watching a young woman who wrote and produced films for a living lose the ability to communicate as articulately as she used to. Despite her aphasia, Lotje has a beautiful way with spoken words and despite her aphasia, speaks very expressively about her feelings and experiences. Lotje's way

with words inspired me to use some quotes from her recovery journey to typographically express the feelings, emotions and experiences she went through.

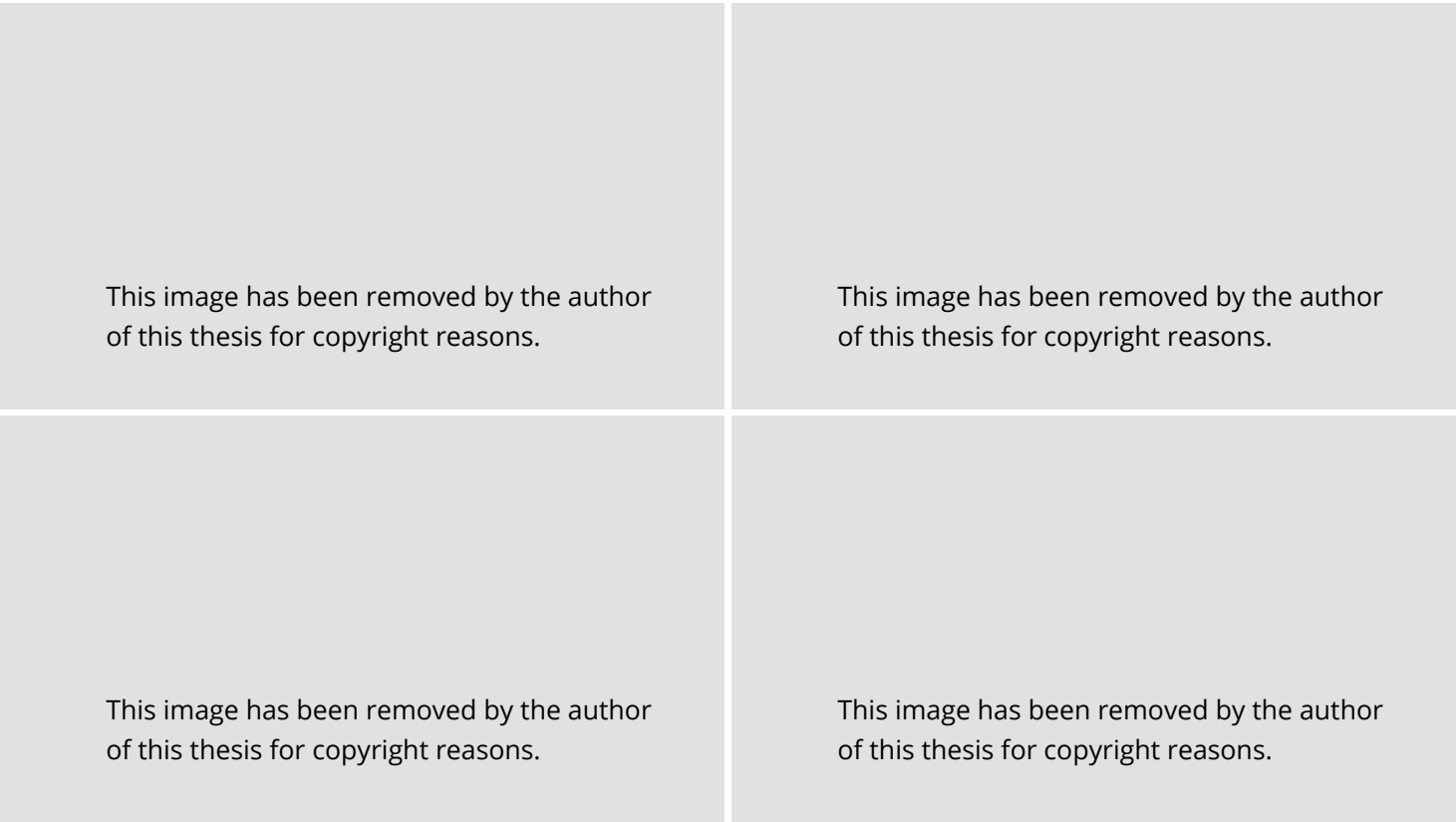
Using the documentary transcript, I pulled quotes from Lotje where she expressed her experience of having a stroke and living with aphasia. Some of the quotes that I found particularly impactful or intriguing are represented in Figures 23 and 24 (page 69).



After watching the documentary for the first time and learning of Lotje’s story, I re-watched the documentary once more and took more time to look into the visual storytelling that was used to portray the sense of loss and confusion she felt after having a stroke and not being able to read or write. The word distortion came to mind which went on to inform the direction I took with these typographic explorations. Many scenes were edited to visualise how Lotje saw the world in her recovery and how having a stroke has distorted her reality.

In addition to these techniques, one visual technique used in the film was a source of inspiration for me. In the documentary, Lotje mentions something has happened to her vision on the right side. She describes it as:

*“If I go on the right side, it’s like a whole another dimension. Vision to an internal space, an inner world. It’s a heightened sense of reality. I don’t know, it becomes a sort of euphoric notion. Whether it’s my brain or reality, I can experience colours and sounds like I wasn’t able to before. It sounds like a very loud sound. So intensified, so exaggerated.”* (Robinson & Sodderland, 2016)



**Figure 21.** Robinson & Sodderland (2016). *My Beautiful Broken Brain right side distortion collage.*

*Note.* The frames in Figure 21 depict the right side distortion Lotje describes quoted to the left. The right side of the images taken from *My Beautiful Broke Brain* use saturated colours, blur, and warping to represent the ‘other dimension’ she experiences.

Another thing I noticed after watching the documentary again was when Lotje used her phone as a camera, the video quality was poor which left her videos looking slightly pixelated and grainy. This, along with the visual inspiration from My Beautiful Broken Brain such as colour distortion and the use of blurred, indiscernible and distorted scenes was used to explore how typography visualises the experience and recovery after having a stroke in the typographic explorations.

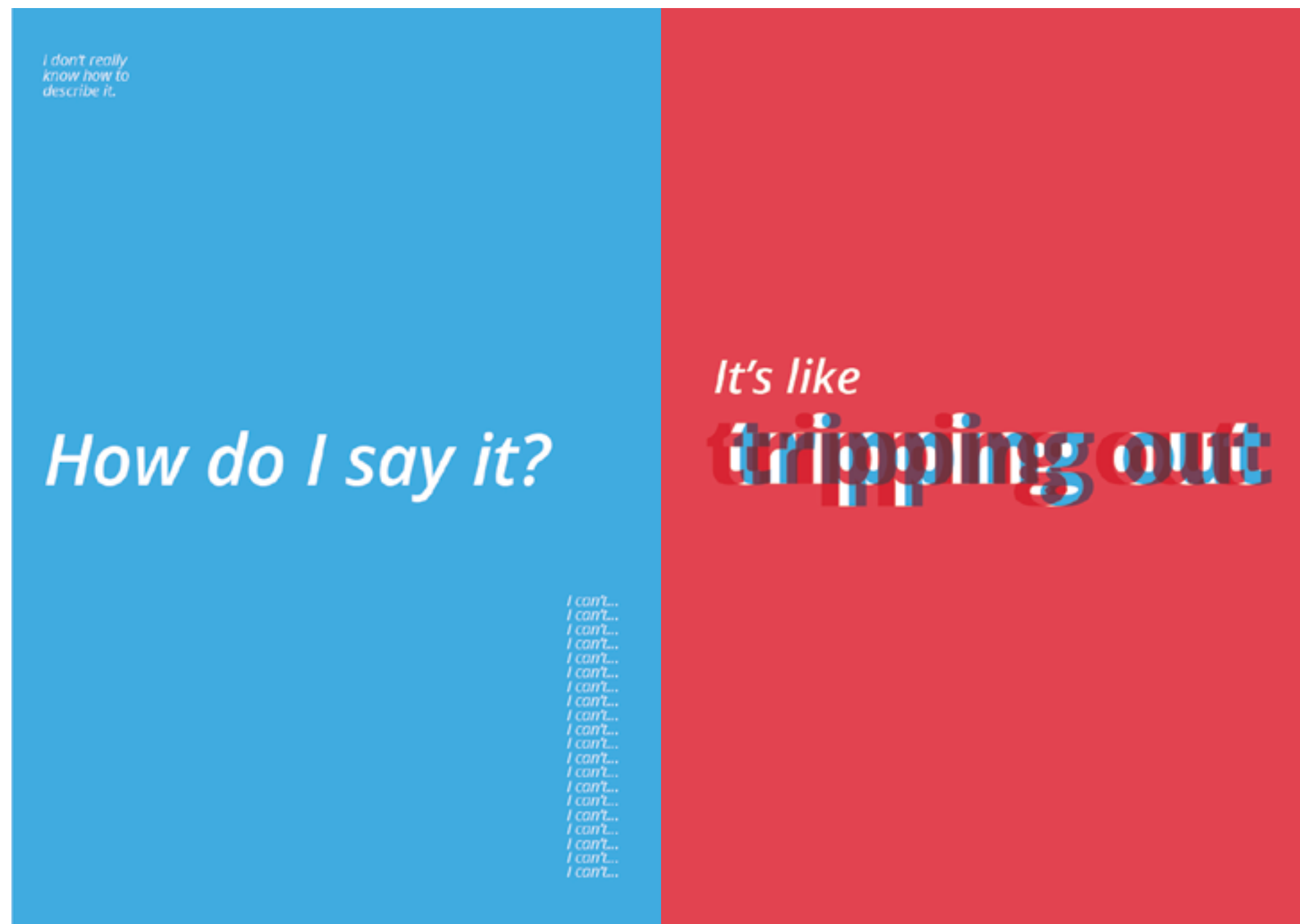
This documentary helped me to understand more about aphasia and how it presents in a persons speech and reading abilities. Watching Lotje navigate her spoken and written language difficulties helped me consider the steps I would need to make to ensure I am communicating effectively and appropriately with people with aphasia.

**Figure 22.** Robinson & Sodderland (2016). *My Beautiful Broken Brain* distortion collage.

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**Figure 23.** Initial typographic explorations of Lotje's post-stroke experience.

*Note.* The initial typographic explorations drew from my perspective of 'distortion'. This was a very early exploration. After learning more and re-watching the documentary, I felt that these posters did not capture how distortion was portrayed in the film. This led me to re-visit these explorations later in my research journey.



**Figure 24.** Typographic exploration using distortion to represent Lotje's post-stroke experience.

*Note.* The updated version of the typographic explorations after making note of the visual effects present in the documentary. This exploration specifically shows the distortion on the right side of Lotje's vision.

## Letterform Exploration

### Inaccessibility Zine

In preparation for my research journey, I did a typographic exploration in a format of a zine that centred around the theme of 'inaccessibility'. The inspiration to use the word 'inaccessibility' came from studies that showed people with aphasia were deliberately left out or excluded from research efforts (Brady et al., 2013; Dalemans et al., 2009; Pearl & Cruice, 2017) that may benefit their quality of life or improve their health (Brady et al., 2013). The zine used statements from the National Ethical Standards about vulnerability and the inclusion of vulnerable populations in research (National Ethics Advisory Committee, 2020). These statements were manipulated typographically to be difficult to read and therefore 'inaccessible'. The zine was also stitched shut to emphasise that the zine itself is inaccessible, and additional 'tools', i.e. scissors, are needed to access the contents inside. This is in reference to the fact that people with aphasia need additional modifications to the informed consent process and adapted information sheets to be able to 'access' or take part in stroke research (Brady et al., 2013; Kagan & Kimelman,

1995; Pearl & Cruice, 2017). As a continuation of the idea of demonstrating inaccessibility using typography, I saw the need to explore the concept of accessibility in typography through exploring different typefaces and what makes them easy to read or 'accessible'.





should noted  
at almost  
any person,  
with the  
support, is  
capable of  
providing

informed  
consent.

inequity

**Figure 25.** *Inaccessibility Zine.*

*Note.* The zine can be viewed in Appendix 7.

Accessible Typefaces

While reading The Information Design Handbook, one of the case studies presented was a typeface called Read Regular by Natascha Frensch (Visocky O’Grady & Visocky O’Grady, 2008). This typeface was made specifically for people with dyslexia to help differentiate between the individual letters inside a word (Visocky O’Grady & Visocky O’Grady, 2008). One example of the subtle design differences in Read Regular was the shape of the stem and counter in the lowercase letters ‘b’ and ‘d’ (Figure 26). Often, the lowercase letters ‘b’ and ‘d’ are mirrored, and there is not much shape differentiation (Visocky O’Grady & Visocky O’Grady, 2008). My initial thoughts were that if a typeface is created to help people with dyslexia identify individual letters within words when reading, then this should be a typeface that can aid in the reading process for everyone.

**Figure 26.** Natascha Frensch. (2003). *Read Regular*. <http://www.readregular.com/english/regular.html>

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I found the Read Regular typeface only to discover that it was copyrighted by a children's publishing house under a different name and was, ironically, not accessible. It was disappointing to see a typeface that has the potential to help many people who struggle with language disorders being inaccessible to the general population. From here I searched for other accessible typefaces and found Andika. Andika is a typeface designed to help with literacy and accommodate new readers (SIL International, n.d.). Andika focuses on clear and easy-to-read letterforms that are not easily confused with one another (SIL International, n.d.).

To explore how Andika as a typeface functioned at different sizes and weights, large-scale typographic posters were created. These typographic posters showcased Andika by using large type in the form of headers, small type as body copy paragraphs, and individual glyphs at a large scale to explore the shape of the letterforms. This typographic exploration offered visual insight into whether Andika would be suitable as a typeface for people with aphasia to read in everyday life.



Figure 27. Andika type specimen poster.





Figure 28. Andika poster testing headings, paragraphs, and glyphs.



# Andika\*

Created by SIL International

Andika is a sans serif, Unicode-compliant font designed especially for literacy use, taking into account the needs of beginning readers. The focus is on clear, easy-to-perceive letterforms that will not be readily confused with one another.

A sans serif font is preferred by some literacy personnel for teaching people to read. Its forms are simpler and less cluttered than those of most serif fonts. For years, literacy workers have had to make do with fonts that were not really suitable for beginning readers and writers. In some cases, literacy specialists have had to tediously assemble letters from a variety of fonts in order to get all of the characters they need for their particular language project, resulting in confusing and unattractive publications. Andika addresses those issues.

Andika Regular  
*Andika Italic*  
Andika Bold  
***Andika Bold Italic***

ABCDEFGHIJKLMNOPQRSTUVWXYZ

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abcdefghijklmnopqrstuvwxyz  
0123456789;“?!@/%\$!#(

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0123456789;“?!”@/%\$)#(

Dd Pp Bb

**Figure 29.** *Andika final type specimen poster showcasing the fonts.*

# ndika

Andika's design takes into account the needs of beginning readers. The focus is on clear, easy-to-perceive letterforms that will not be readily confused with one another.

Andika provides clear, simply designed letters. This facilitates letter recognition, a skill second only to distinguishing sounds in learning to read. Some fonts have letters that look like mirror images of each other, which for a new reader can be confusing. Andika gives those similar letters distinct characteristics to reduce confusion.

or more information, please visit <https://software.sil.org/ondak>

**Figure 30.** *Andika final type specimen poster showcasing typeface as various sizes.*

After exploring typefaces such as Andika and Read Regular and their focus on clear and distinguishable letterforms, I was inspired to conduct a typeface audit. The purpose of the typeface audit was to break down, compare and contrast multiple typefaces based on their legibility, readability and letterforms. Various typefaces were chosen for the audit – this included the typeface Andika along with other popular serif and sans-serif typefaces that were frequently found in digital spaces and printed materials such as Arial, Calibri, Baskerville, and Times New Roman. The typeface Verdana was chosen as it appears frequently in the aphasia literature as a recommended typeface (Dalemans et al., 2009; Rose et al., 2012; Wilson & Read, 2016).

The typeface audit focused on analysing the letterforms of similar glyphs in each individual typeface. This showed how similar glyphs can potentially be misread without clear distinctions in their individual letterforms (Beier, 2016). The chosen letterforms were broken down into their anatomical parts and diagrams were used to compare, contrast, and explain the differences in the letterforms of the glyphs.

This typeface audit helped me to consider what the features of an accessible typeface are, and how to best implement a typeface that exhibits these features into the creation of participant information sheets for people with aphasia.



Figure 31. Verdana introduction page in the typeface audit.

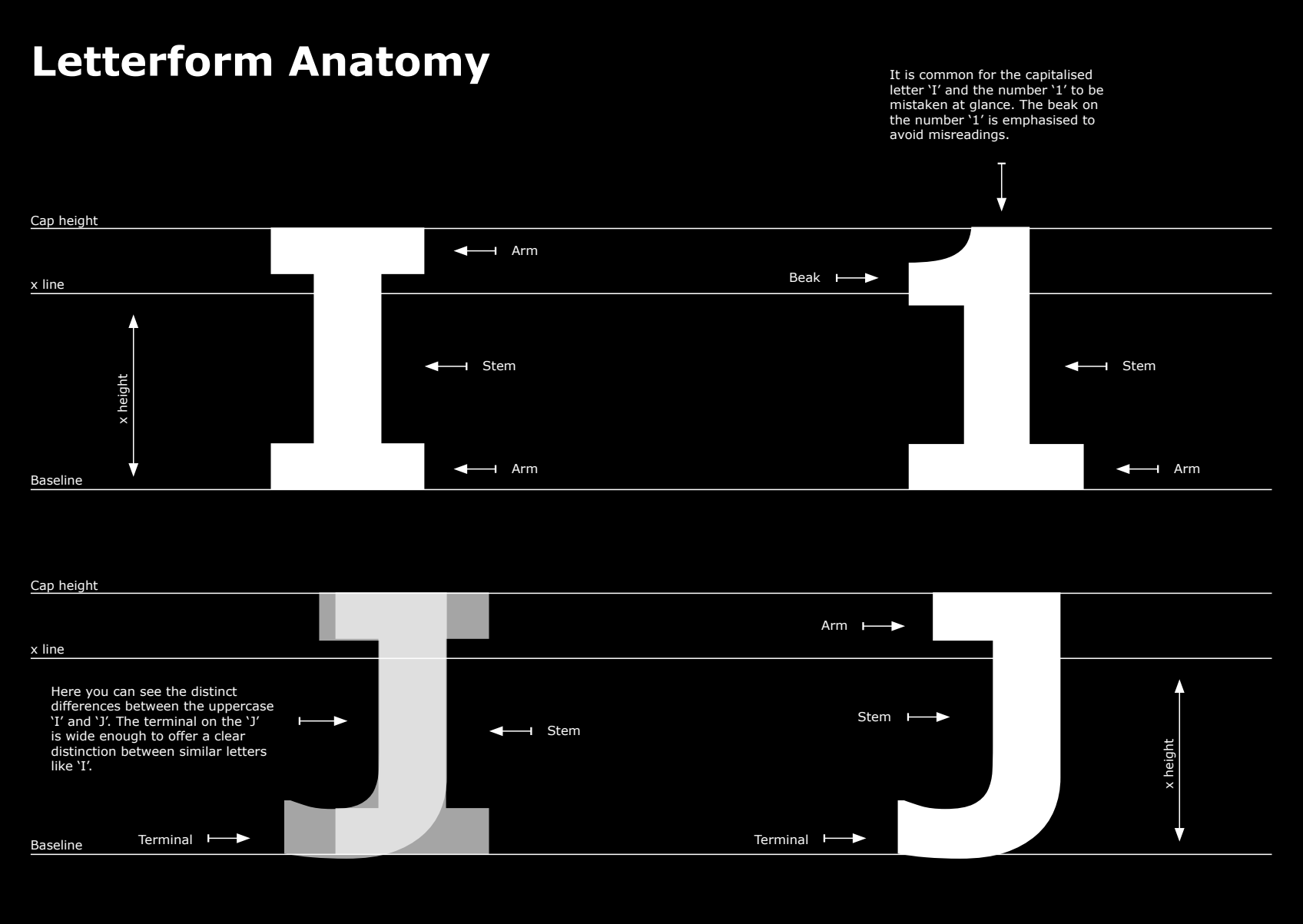


Figure 32. Verdana letterform anatomy of the lowercase letters 'i', 'j' and 'l' in the typeface audit.

Note. The typeface audit can be viewed in Appendix 8.

# Participant Information Sheet Audit

An audit/review of existing research materials for people with aphasia was explored from an information design perspective. Participant information sheets used in previous research with people with aphasia by a stroke researcher (the speech and language therapist supervisor) were looked at initially and reviewed. A wider review was then conducted of participant information sheets for participants in aphasia research and stroke research. This was followed by a review of institutional participant information sheets to analyse the overall design and language used for a typical information sheet used for research in New Zealand. These allowed for insights to be made into how aphasia information sheets were adapted compared to stroke information sheets, as well as how accessible institution’s information sheets are not just for people with aphasia but the general public.

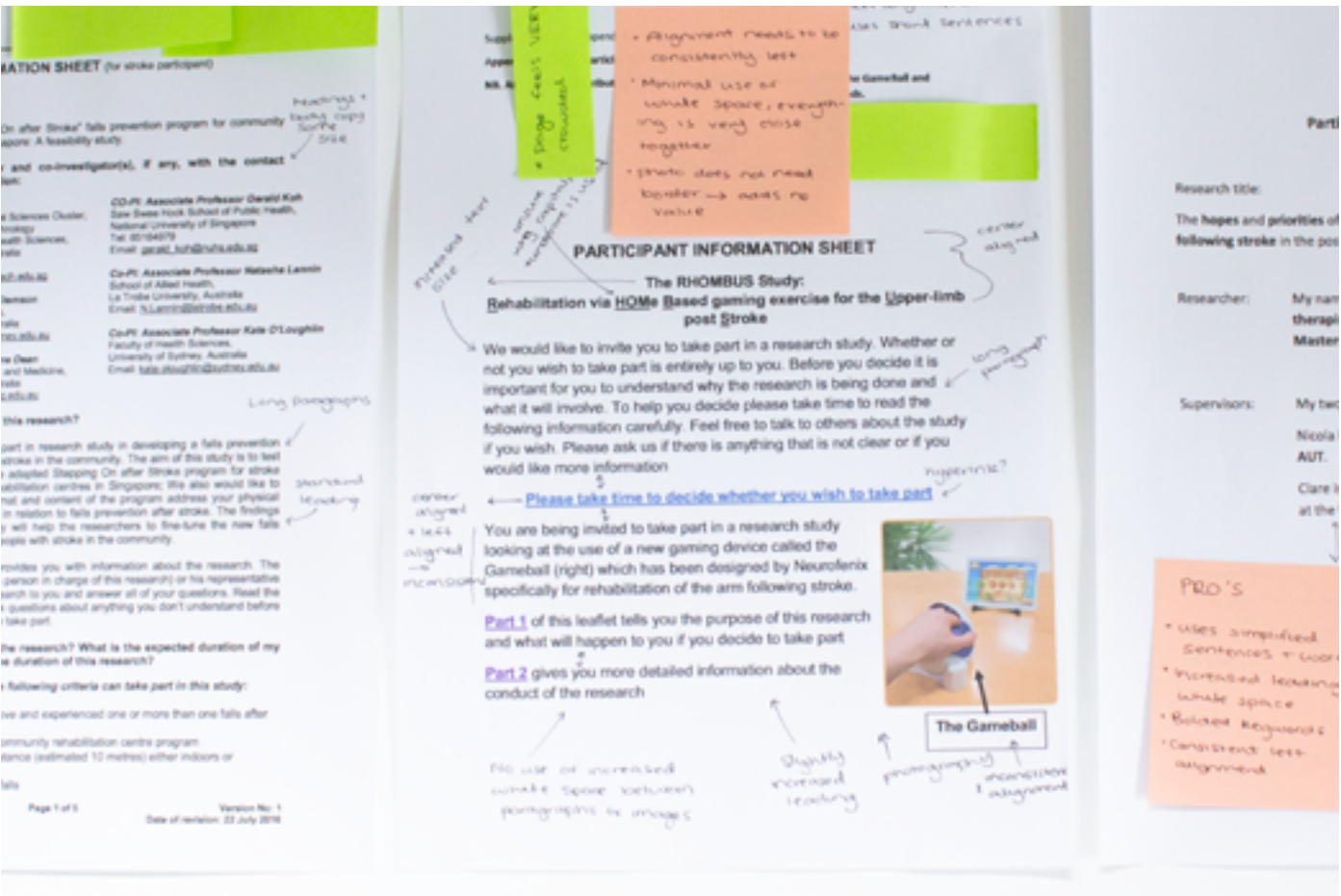


Figure 33. PIS audit and notes from multiple stroke and aphasia studies.

A small number of participant information sheets and consent forms were found for each of the three categories of participant information sheets described above. All stroke and aphasia-related material were found using the Google search engine by searching the terms ‘stroke participant information sheet’ or ‘aphasia participant information sheet’ and their similar variants. The institutional information sheets and consent forms were found by directly accessing six New Zealand tertiary institutions’ websites. Of the participant information sheets found, only those studies that were qualitative were selected to be analysed. This allowed studies to be included in the analysis that used similar data collection methods to those used in this research. This reasoning was also applied to the institutional materials, and only interview or focus group templates or exemplars were chosen to be analysed. All together, 36 participant information sheets and consent forms were analysed as outlined in Table 1.

	PIS	Consent Forms	Total
Aphasia Studies	11	3	14
Stroke Studies	8	2	10
Institutional Templates	6	6	12
Total	25	11	36

**Table 1.** Participant information sheet studies used.

*Note.* Each institution had a matching participant information sheet and consent form, but only a few of the aphasia and stroke participant information sheets had a matching consent form.

For the review and analysis of the participant information sheets and consent forms, analysis points to focus on were developed from the literature that provided recommendations for the design of information for people with aphasia (Rose et al., 2003, 2011; Wilson & Read, 2016), and following information design principles (Lipton, 2007; RGD Ontario, 2010). I critically examined the materials from an information design perspective, backed by the knowledge from the aphasia literature. The analysis points focused on were:

- The typefaces used in the document with notes taken on the typeface family, weights, and point sizes used for titles, subtitles, headers, and body copy<sup>8</sup> text.
- The use of leading<sup>9</sup> (line spacing) is used throughout the body text of the document. Notes were made on the consistency of the leading and if the leading fluctuated throughout the document.
- White space was subjectively judged based on the space between each paragraph or section in the document and the proximity between images and other elements on the page.

<sup>8</sup> Body copy refers to the main body of text in a document or publication.

- The use of bolded keywords and phrases. This was not a point of analysis for institutional materials as this technique is primarily used for people with aphasia in the literature.
- Image type (e.g., icon, illustration, photography), their position in relation to the text, how frequently images were used, and their relevance to the text.
- The sentence length and word choices used to describe information in the document and their simplicity.
- The number of pages in the document.
- The alignment of text and graphic elements to each other and on the page.

Comments were also made on the typographic hierarchy used in the documents and any other design elements that were of interest that either enhanced or diminished the design of the documents.

<sup>9</sup> Leading or line spacing is the space between lines of text in a paragraph. Line spacing is often referred to in numbers, where a 1.2 is equivalent to the leading being a 120% of the type size. For example, 10pt type with a line spacing of 1.2 equates to the leading being 12pt.



PIS Analysis												
File Edit View Insert Format Data Tools Extensions Help												
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	A	B	C	D	E	F	G	H	I	J	K	L
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3	Institution PIS & Consent form exemplars											
4		#1	#2	#3	#4	#5	#6	#7	#8	#9	#10	#11
5	PIS or Consent Form	Consent Form	PIS	Consent form	PIS	PIS	Consent form	PIS	Consent form	PIS	Consent form	PIS
6	Typeface	Calibri	Calibri	Calibri	Calibri	Arial	Arial	Calibri	Calibri	Calibri	Calibri	Arial
7	Header Text Size	11pt bold	11pt bold	18pt bold for title,	18pt bold for title, 10pt bold for subtitles	18pt bold for title, 10pt bold for subtitles	10pt bold	16pt bold for title, 12pt bold for subtitles	16pt bold for title, 12pt bold for subtitles	16pt bold for subtitles	20pt bold for title, 14pt uppercase, 18pt regular	16pt bold for title, 12pt bold for research title, 12pt bold for regular under for some sub 9.5 bold (white blue) smallca main subtitle
8	Body Text Size	11pt reg	11pt reg	10pt reg, 12pt reg for study details	10pt reg, 8pt reg for footer details	10pt reg	10pt reg	12pt reg	12pt reg	11pt reg	11pt reg	11pt reg
9	Leading/Line Spacing	1.18	1.22	1.23	1.2	1.15	2.3	1.2	1.2	1.4	1.40, 1.80	
10	White Space	No	No	Yes but inconsistent	No	No	Yes increased	No	Yes	Yes but inconsistent	No	No
11	Shorter Sentences	No	Yes but not consistent	No	No	N/A	No	Yes	No	N/A	No	No
12	Simpler Sentences	No	No	No	No	N/A	No	Yes	No	N/A	No	No
13	Number of Pages	1	3	1	2-3	3	1	3	2	3	2	
14	Alignment	Title centered, everything else left aligned	Title centered, everything else left aligned	Consistnetly left aligned	Body text is indented to the titles, other than that, everything is left aligned	Title is centered, everything else consistently left aligned	Consistently left aligned	Consistently left aligned	Mostly left aligned, introductory titles centered, some text not consistently aligned	Consistently left aligned	Center alignment for first three titles/sentences, then consistently left alignment for the body copy	Consistently aligned
15												
16												
17												
18												
19												
20												
21												

Figure 34. Spreadsheet of PIS variables analysed.

### **Analysis of Design Variables**

Based on this review, a set of design characteristics and features were compiled to aid in the design of the prototype participant information sheets for people with aphasia. These characteristics and features are:

#### **Using a sans-serif typeface.**

All participant information sheets and consent forms but one used a sans-serif typeface. The one document that used a serif typeface was a stroke document.

#### **Having larger body copy.**

Only one aphasia participant information sheet did not include larger body copy, with the text size sitting at 12pt. Point size of 14 or larger is recommended (Rose et al., 2012).

#### **Increasing the leading (line spacing) to 1.4 or 140% of the type size for the body copy.**

The most common leading size in the aphasia information sheets was 1.4 with the stroke and institutional information sheets leading averaging 1.2 which is recommended for optimal reading (RGD Ontario, 2010).

#### **Increasing the amount of white space between paragraphs and sections of the participant information sheets and keeping the spacing consistent throughout the document.**

Many aphasia documents and a few stroke documents increased the amount of white space used but failed to consistently utilise increased white space.

#### **Bolding keywords and phrases.**

All but one aphasia document used this form of emphasis within the text to highlight important aspects of the participant information sheet.

#### **Using images to support the understanding of the text.**

Just over two-thirds of the aphasia documents had images to support the text and only two stroke documents used images. Images ranged from the use of photography and illustrations to icons. One image type is not proven to be preferred over another but aphasia literature states the use of simple line drawings as illustrations receive positive feedback (Rose et al., 2011). This was something to explore further in the prototypes.



**Using short and simple sentences.**

Most of the aphasia documents used short and simple sentences when conveying information about the study while only a few stroke documents utilised this.

**Keeping the number of pages to 10 or below.**

Keeping the number of pages in participant information sheets below 10 A4 sized single pages or 20 A5 sized pages in a double-paged spread. Pages used in the analysed documents ranged from 1 to 34 A4-sized single pages.

**Having a consistent alignment of elements throughout the document.**

This includes having the text aligned to a margin, and images consistently placed near its relevant text. There was only one aphasia document that had a consistent alignment of elements on a page and most documents had formatting errors that prevented consistent alignment.

**Utilising a strong typographic hierarchy.**

None of the documents in this review showed a strong typographic hierarchy of the elements on the page. Typographic hierarchy is important to emphasise the most important information in a document and to structure the information in a way that makes sense to the reader (Lipton, 2007).

A list was also compiled of design features and characteristics that were seen throughout the review to avoid when designing participant information sheets:

**Having the information too close to the bottom of the page or right next to page markers.**

Having many different types of information in close proximity can confuse the reader.

**Using multiple different types of styles of images.**

The documents look more cohesive and easy to follow when the images are all consistent.

**Using one continuous table for all the information and images in the document.**

The table takes up a lot of space on the page and is unnecessary to use for the main body of the text.

**Using extremely large leading (line spacing).**

One document had leading of 2.4 which is over 200% larger than the optimal size. Having a very large space between each line can make it harder for people with aphasia to read (Rose et al., 2012).

**Having the headings the same size as the body copy.**

The heading need to be proportionally larger and bolder than the body copy so readers can easily find the information they are looking for and establish typographic hierarchy (Lipton, 2007).

## Expert Interview

As part of understanding the ethical process that clinicians and health researchers have to go through when working with participants with aphasia, I interviewed an expert that conducts research with people with aphasia and was a member of an ethics committee. Specifically, I wanted to gain an understanding of what the process of navigating an ethical approval to involve participants with aphasia in research was like from a researcher's and a committee member's perspective and gain insight into the challenges and potential barriers to the involvement of people with aphasia in research. This interview was also to ensure that, when designing participant information sheets, I strike the right balance between my ethical obligations with the information that must be provided, and the way information is presented to people with aphasia.

The expert I interviewed was a stroke researcher that has been working with people with aphasia for over twenty years. They are a speech-language therapist, an academic and have spent 4 years on a NZ ethics committee. The stroke researcher spends a lot of time interacting with people with aphasia and teaching about aphasia in undergraduate and postgraduate education.

**"The work we do in research as a clinician is really complex as I know what I need to do to support someone's understanding and to give them the information they need to be involved in a study, but sometimes that sits in contrast with ethical requirements and legal expectations."**

Stroke researcher

### **Interview Process**

There were two areas of inquiry for the expert interview. One area looked into the stroke researcher's personal experience navigating a formal ethical process for research involving participants with aphasia. This topic included questions surrounding the inclusion of people with aphasia in research from a researcher's and ethics committee member's perspective. The other area of inquiry looked into the adaption of participant information sheets. Questions around the adaption of participant information sheets were asked to understand what is already being done to include people with aphasia in research, and what more can be done to create more accessible information.

This interview was conducted via Zoom, recorded and transcribed. The full list of questions asked can be found in Appendix 6.

There were 4 themes explored through these areas of inquiry:

- Ethics
- Vulnerability
- Inclusion
- Participant Information Sheets & Accessibility

The findings around these themes are described on the following pages.

## Findings

### Ethics

The stroke researcher had many unpleasant experiences with ethics committees, with one experience, in particular, leaving them in tears. Despite having applied the findings from Rose et al., (2003) and Rose et al., (2011) on creating accessible information for people with aphasia to the design of their own research and supporting materials, the feedback from the ethics committee was that:

- The stroke researcher was being patronising, insulting, and rude towards people with aphasia.
- Just because they have aphasia, it does not mean that participants cannot read.
- They (the researcher) did not know what aphasia was, that aphasia is a speech impediment, not a visual impediment and there is no need to bold the words and have the text so big .

**"A misconception by ethics committees about aphasia is a real understanding of what language is. I explained to them that actually, it isn't speech, it is language, and I tried to explain the difference between speech and language."**

Stroke researcher

Following a response to the ethics committee that cited academic articles as examples, the stroke researcher received a letter of apology from the chair of the ethics committee, acknowledging that the ethics committee's response to the situation was completely inappropriate.

These findings raise a question of where the boundaries within which research ethics committees should operate lie, and what should and should not be in their decision-making scope. The demonstrated lack of knowledge and understanding of populations traditionally underrepresented in research due to their impairments – in this instance, aphasia – also raises the question of the suitability of the existing written materials to support research provided and dictated by institutional ethics committees themselves (e.g. templates for participant information sheets and consent forms).

**" Ethics committee is a representation of society, there is no reason why they would know about it (aphasia)."**

Stroke researcher

### **Vulnerability**

Reflecting on the meaning and interpretation of the term ‘vulnerability’ or being ‘vulnerable’ as it is being used to define people with aphasia in ethical applications, the stroke researcher stated that having an altered verbal expression or difficulty expressing oneself does not make a person automatically vulnerable; having impaired comprehension is what makes someone vulnerable. For people with aphasia, comprehension can sometimes be masked; no one can see that they have not understood.

### **Inclusion**

When asked about the inclusion of people with aphasia in stroke research, the stroke researcher replied that more needed to be done to include people with aphasia. They seek out people with aphasia for research because *“they are an under served group, and they deserve a voice in research”*. The stroke researcher also believed that more could be done to adapt participant information sheets to include people with aphasia in research. Adapting participant information sheets makes the ethics process longer and can cause a disincentive for some researchers because of the time and effort it takes to create the information sheets.



### Participant Information Sheets & Accessibility

The stroke researcher talked about their experiences adapting information sheets and their thoughts on the features used in accessible information sheets for people with aphasia. They commented that:

- To get accessibly designed information sheets for participants with aphasia approved by ethics committees requires constantly revising and sending them back to ethics.
- People with aphasia just want to know what the study is about. They do not care about how the information is stored or how they got recruited – the information ethics committees require to be included in a participant information sheet.
- It might be a good idea to separate out what *has* to be in the participant information sheets from what *needs* to be there.
- They would like to see a good flow in the participant information sheets for people with aphasia. The information needs to be presented well so people do not have to go looking for it.

**" Really, there is a disconnect between supporting the potential participants and meeting the needs of an ethics committee that doesn't necessarily understand."**

Stroke researcher

### Summary of Findings

The interview with the stroke researcher offered first-hand insights into the experience of navigating ethics to enable people with aphasia to participate in research. Their experience highlights the absence of knowledge ethics committees have on what aphasia actually is, and a misunderstanding of how aphasia can affect a person. The stroke researchers experience is similar to that of Pearl & Cruice (2017) where an ethics committee rejected the adapted materials for people with aphasia and labeled them as inappropriate. These experiences show the struggle many researchers have to go through to create participant information sheets that facilitate the inclusion of people with aphasia.

The interviewee's views on vulnerability are similar to those of Kagan & Kimelman (1995), who state that many people with aphasia's comprehension or 'competence' may be masked by their communication difficulties. It seems that comprehension being masked can be viewed as a person either understanding or not understanding due to their

communication difficulties. Alternative approaches may be needed to 'unmask' comprehension. The stroke researcher's insights on vulnerability confirmed that branding a population as vulnerable can be stigmatising and lead to barriers in their perception by ethics committees (Luck & Rose, 2007; Pieper & Thomson, 2020).

The stated belief that more can be done to include people with aphasia in research through the adaptation of participant information sheets mirrors other opinions that the lack of inclusion of people with aphasia in research can partly come down to there not being adapted versions of information sheets that are readable for this population (Brady et al., 2013; Pearl & Cruice, 2017). It seems that resources to adapt information sheets are readily available in the aphasia literature (designing written information), yet people with aphasia are continually excluded from research

The one thing the stroke researcher would like to see improved in the design of participant information sheets was the flow and hierarchy of information. The hierarchy of information is an important part of how information is conveyed to an audience and can emphasise what is most important and what is not as important to know in a document (Lipton, 2007; RGD Ontario, 2010; Spyridakis, 2000). Finding out what information is most important for people with aphasia when wanting to take part in a study could be a first step to establishing a hierarchy and flow of information that will be clear, engaging, and useful for people with aphasia.

## Prototyping the Participant Information Sheets: Phase One

Prototyping of the participant information sheets started after the decision to move the interviews with people with aphasia online. Platforms exist and software and applications have been created in an attempt to streamline the informed consent process and improve comprehension through the use of digital multimedia methods (Abujarad et al., 2021; Chen et al., 2020; Gesualdo et al., 2021; Lunt et al., 2019; Ramos, 2017). Although these studies have shown that implementing digital-based multimedia techniques can improve the comprehension and overall informed consent experience, this however was outside the scope of this study where the focus was on designing participant information sheets as they are commonly used in research – in their paper format.

Prototyping of the participant information sheets commenced in the traditional paper format with two individual prototypes designed. The content for each prototype was taken from participant information sheets previously used in two aphasia studies conducted by my speech-language therapist supervisor. This was done to ensure the prototypes felt genuine, and the participant information sheet contents reflected information that would typically be included. Going forward I refer to the two prototype participant information sheets from hereon referred to as the *hope prototype* and the *rehabilitation prototype* (named after their respective studies).

The list of design features identified from the review of the aphasia and information design literature (as described on page 80) was further expanded on to inform the design of the prototypes. A full breakdown of the initial concept design features and differences between the design features manipulated in the two prototypes are shown in Figure 33. One prototype contained all of the aphasia-friendly features identified, while the other prototype included only a few features recommended for people with aphasia, namely:

- Increased text size
- Short sentences and simplified language
- Increased use of white space
- Bolded keywords

The idea of only including a few recommended design features in the prototypes was to compare and contrast the effects these features would have on the reading ability and comprehension of the information for participants with aphasia. This idea changed not long after its conception, and both prototypes were conceptualised to be appropriate and accessible to people with aphasia. Instead, both prototypes implemented the recommended design features, but to varying extents of their emphasis. A comparison is shown in Figure 34 and 35.

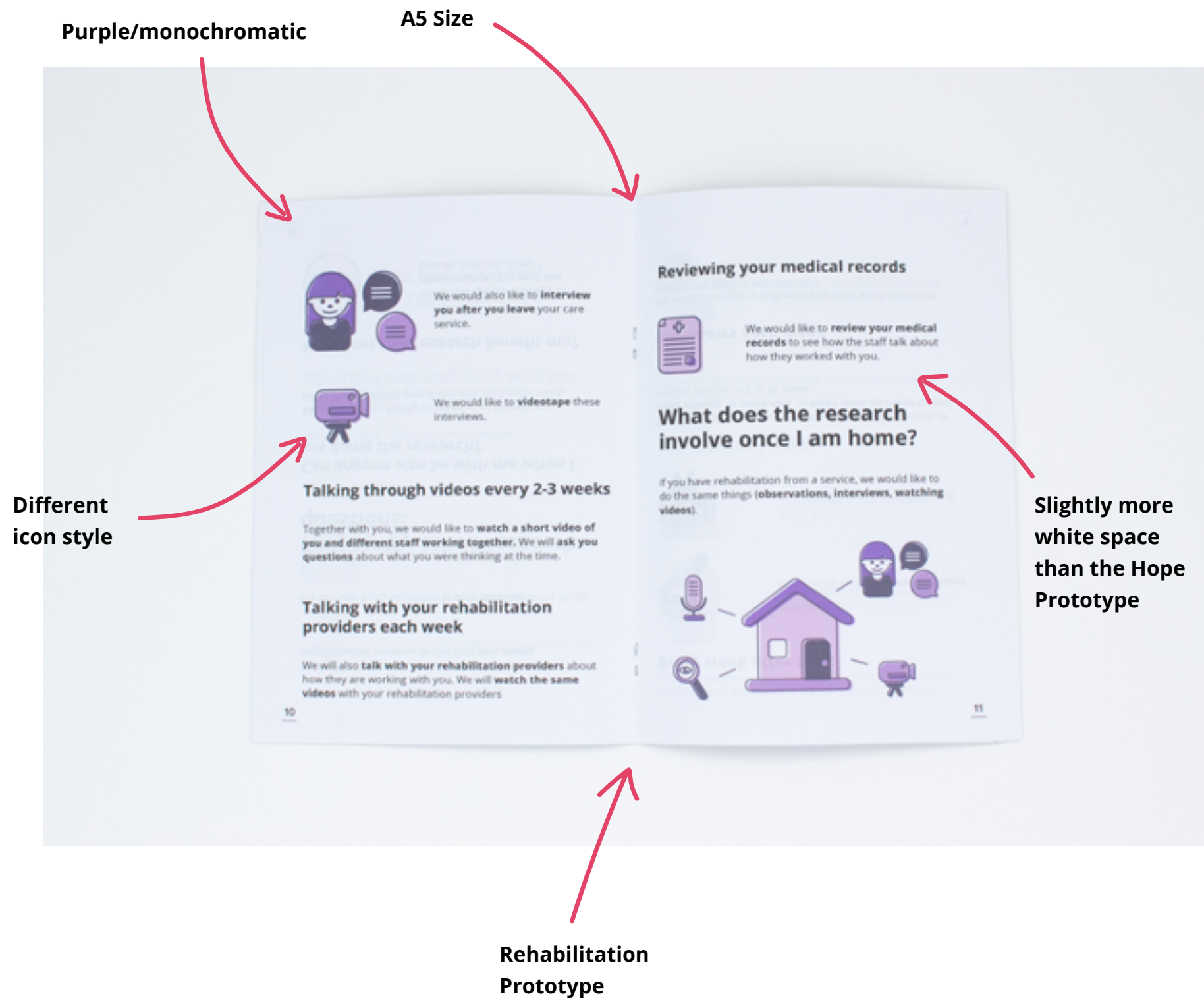
## PROTOTYPE 1

- A4 Booklet size
- 18pt body copy
- 24pt headers (or what seems big enough / appropriate for body copy size)
- Sans-serif typeface (maybe one with a smaller x-height?)
- Doesn't use images??
- Doesn't use colour (or monochromatic?)
- Bolded keywords
- Normal line spacing / leading
- Increased amount of white space
- Good structure of information / sectioning (but could be better)

## PROTOTYPE 2

- A5 booklet size
- 14pt or 16pt body copy
- 18pt or larger headers (whatever is appropriate for type size)
- Sans-serif typeface (larger x-height or even test Andira?)
- Uses images
- Uses colour
- Bolded keywords
- Slightly increased line-spacing
- Increased amount of white space (more than in prototype 1)
- Very well thought out structure of information

Figure 35. Initial brainstorm of the design feature differences.



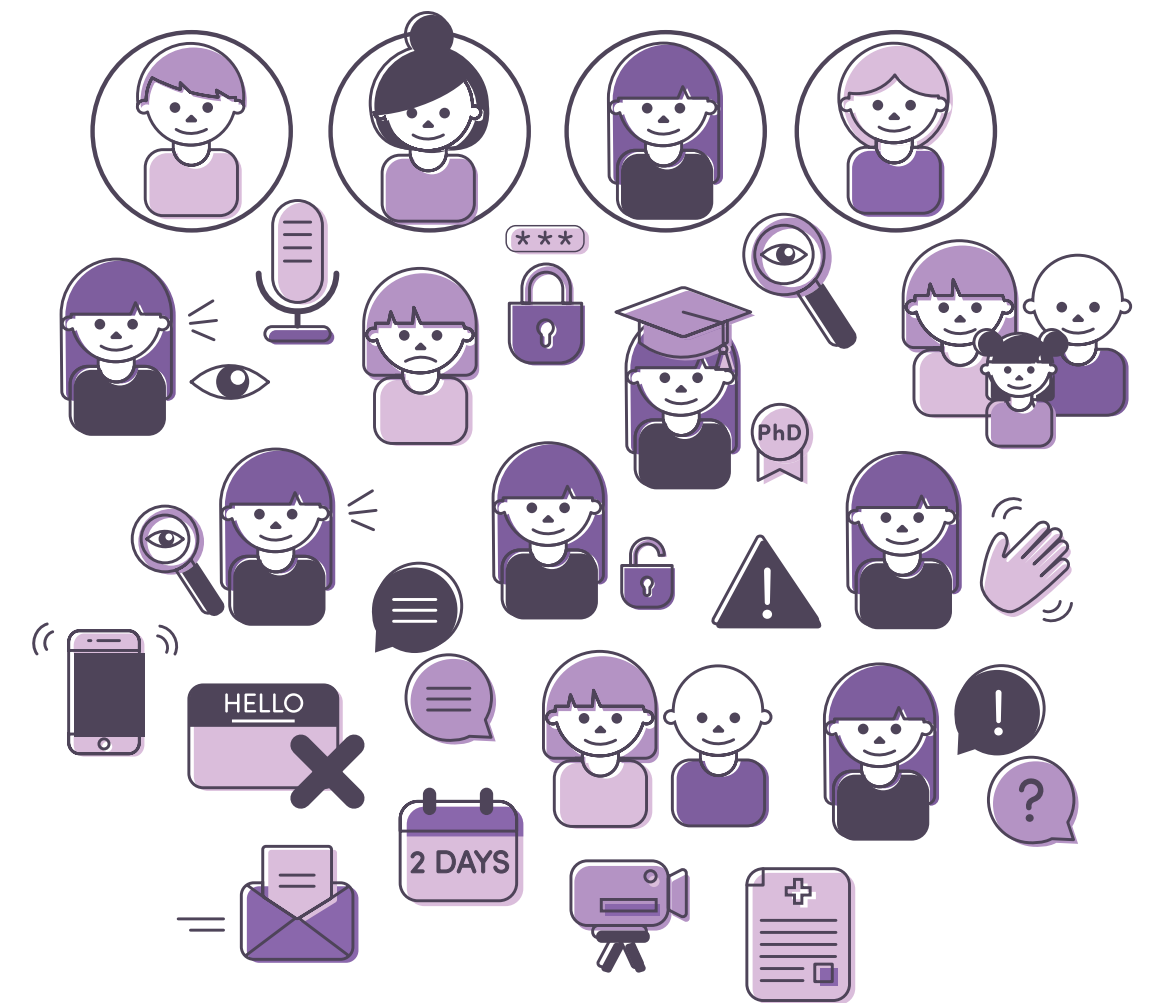
**Figure 36.** A5 rehabilitation prototype with annotated design features.



**Figure 37.** A4 hope prototype with annotated design features.



For each prototype, a different illustration style was used to visually depict details within. The Hope prototype used simple iconic illustrations in various bright colours similar to what was also explored in the card sort prototypes (page 116) to draw the reader's eye to the page (O'Connor, 2015). The Rehabilitation prototype used more detailed iconic illustrations stylised differently, with monochromatic purple as the only colour. The differing colour choices were done to see if participants' perceptions of the participant information sheet differed depending on the use of colourful illustrations versus monochromatic illustrations.



**Figure 39.** Initial purple monochromatic icons in the rehabilitation prototype (bottom right).



### **Additional design considerations**

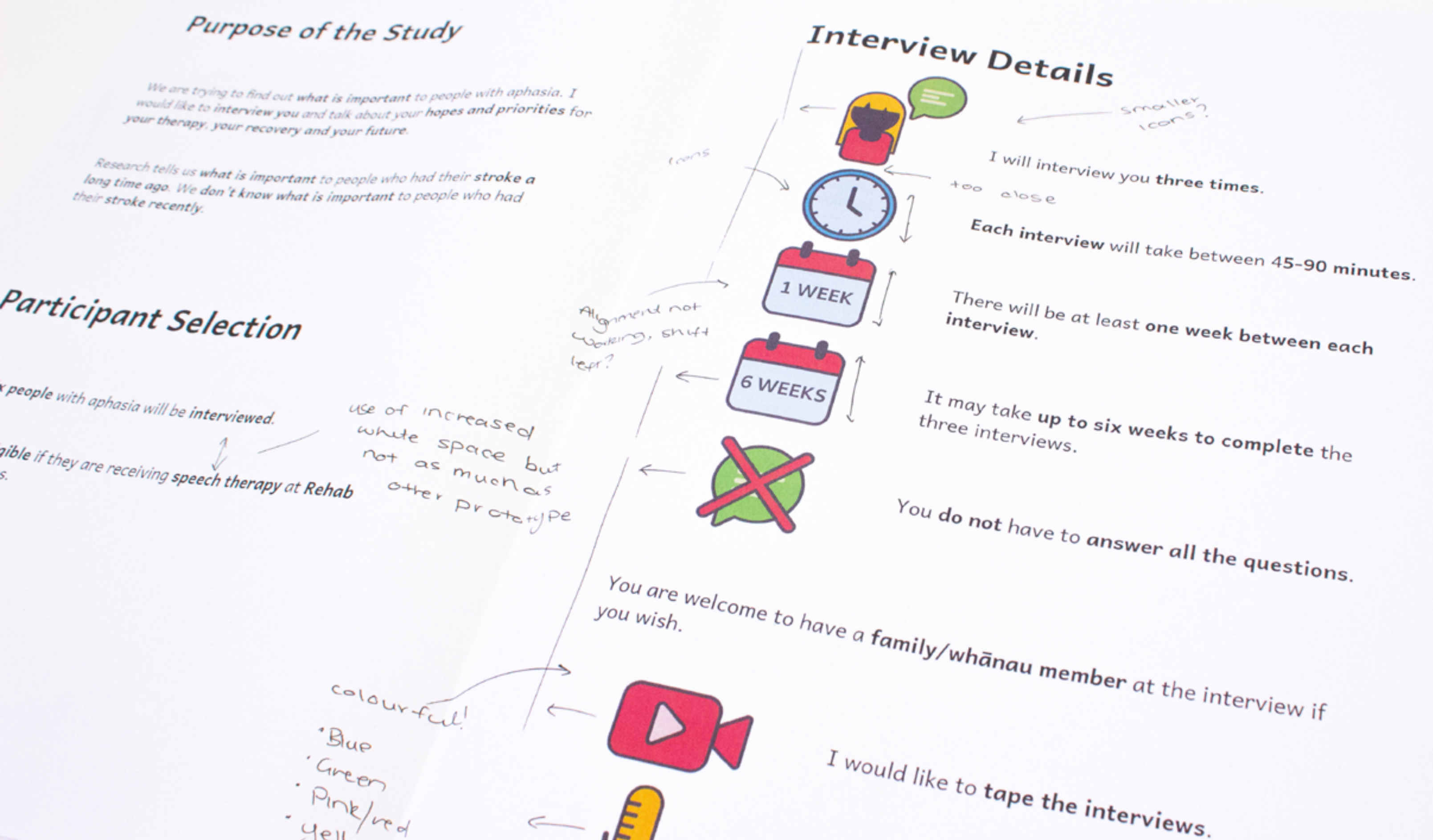
Throughout the prototyping phase, additional design considerations arose as multiple iterations of each prototype participant information sheet were produced. Some changes and considerations to the design were:

- Ensuring the formatting of the text in both prototypes did not cut sentences off in awkward places. For example, ensuring there were no orphans<sup>10</sup>, and that sentences could be read easily by not starting them at the end of a line.
- The positioning of the images. For the hope prototype, I experimented and iterated with positioning of the icons alongside the text, being mindful of the feedback that people tend to look from icon to icon rather than from the icon to the accompanying text when viewing presented information. To solve this, the size of the icons was reduced, and the proximity to the text was reduced so participants with aphasia could relate the icon to the text due to its positioning and proximity.

- Sectioning was experimented with in the form of coloured background and boxes used for information held important information or details as added emphasis.

<sup>10</sup> An orphan is very short line, usually one word, at the end of a paragraph of text.

Figure 40. Notes on icon alignment in hope prototype.



## Prototyping the Participant Information Sheets: Phase Two

At this stage in the prototyping phase, a shift occurred in the design variables that would be analysed by participants with aphasia in the prototypes. Details on this shift is explained in the *Interviewing People with Aphasia* section (page 125).

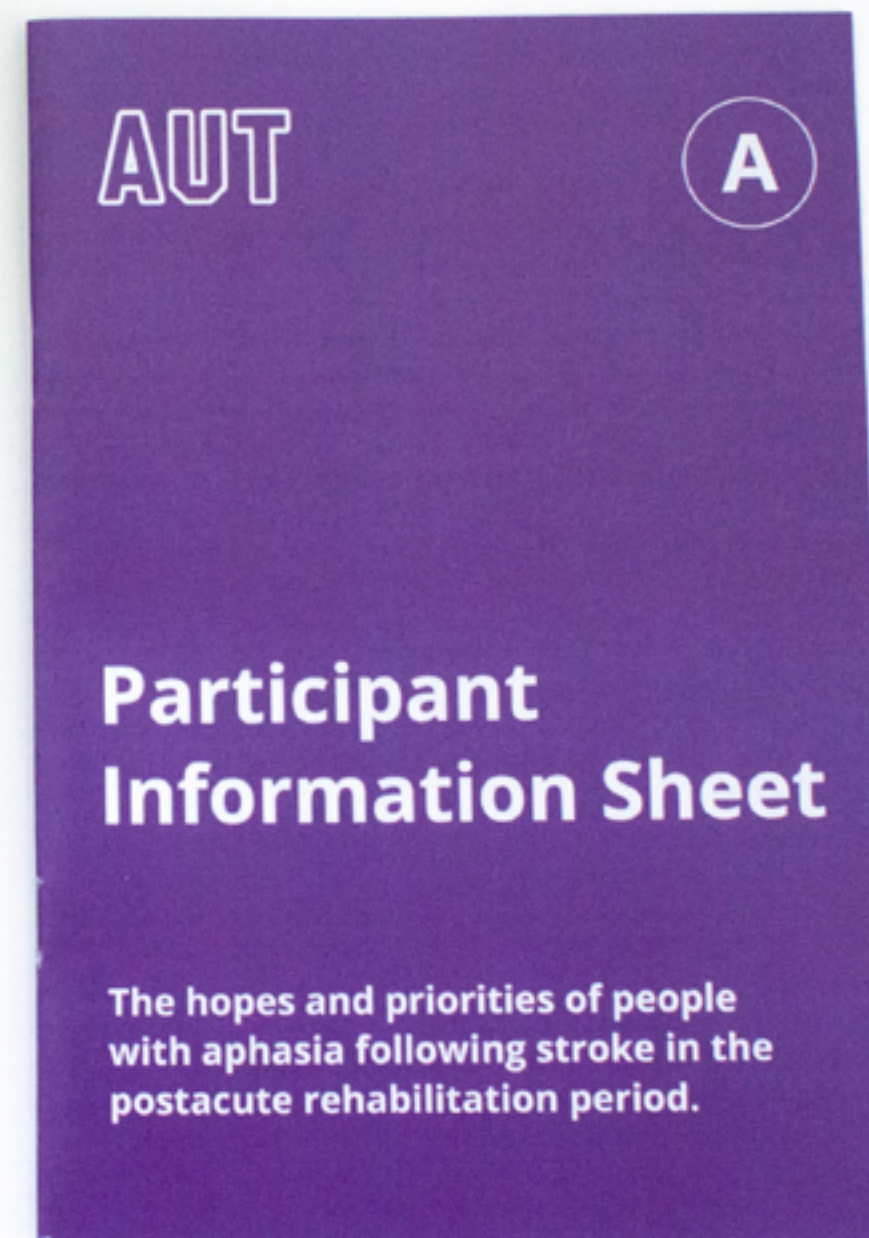
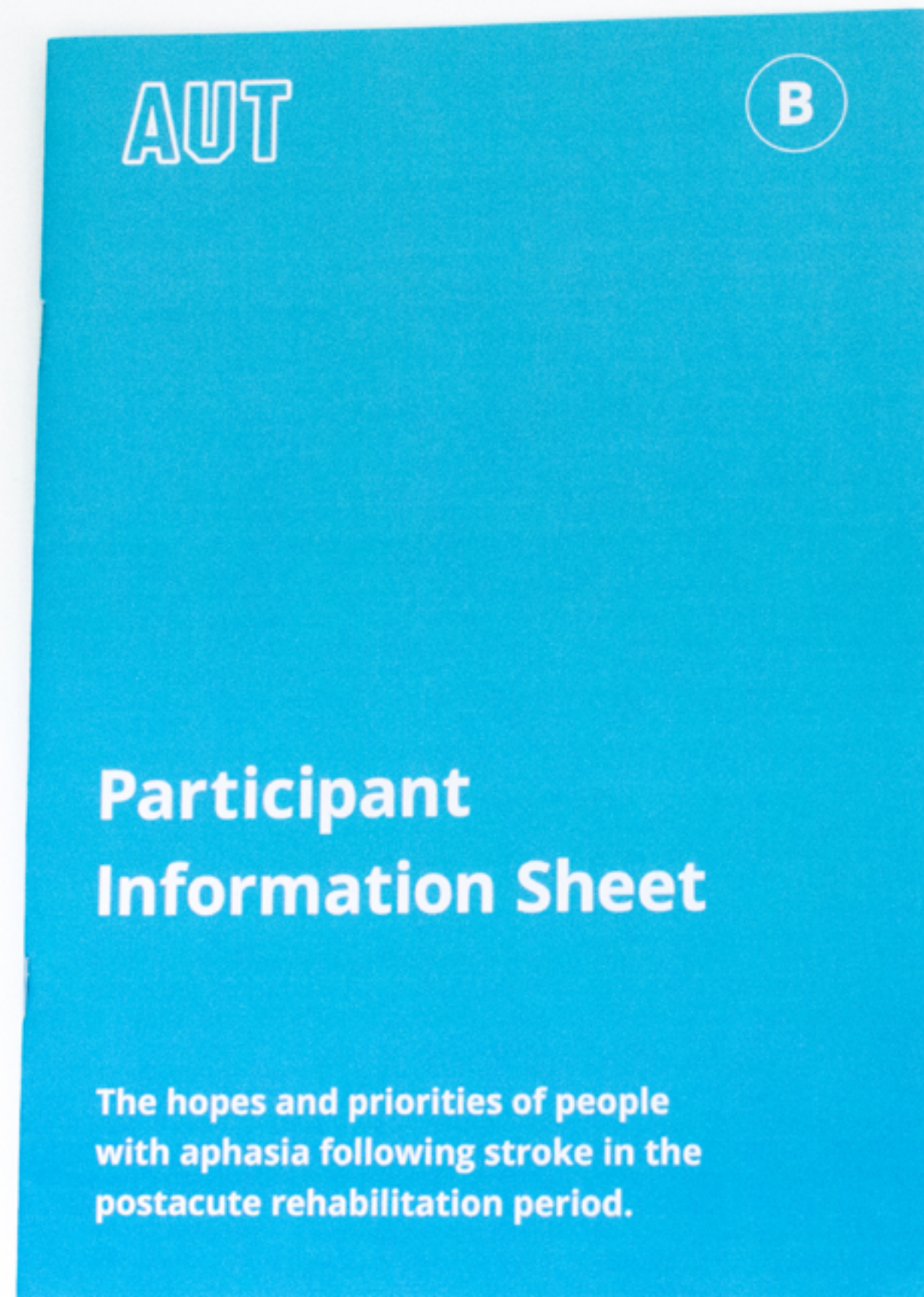
A set of variables was established to be implemented in each prototype to various extents. These variables were:

- Booklet size
- Images
- Colour
- Arrangement

For these variables to be compared, one study of the two currently in use for the prototypes had to be chosen. The study that was chosen to be used in both prototypes was the *hope* study due to its simplicity in its research design. The *rehabilitation* study was more involved and described multiple stages of involvement. It was important to keep the prototype's contents as simple as possible so the design variables can be analysed rather than the contents.

With both prototypes using the same study, their current names were no longer valid to identify each prototype. The prototype's main colour was implemented to differentiate between each prototype, giving them the names of the *blue prototype/booklet* and the *purple prototype/booklet*. In addition to colour, a distinguishable letter was placed on the cover of each prototype as a secondary indicator for the prototypes. This would be used in the instance where a participant may be colour blind and could not distinguish each prototype based on its colour.





**Figure 41.** *Front cover of blue and purple prototypes.*

Each newly established variables was implemented to varying degrees into each prototype. Many features stayed the same in the prototype, such as the amount of white space already allocated (the purple booklet had more white space) and the size of each booklet. Because the purple booklet already has a larger amount of white space, more attention was spent on the new arrangement variable in this prototype. In summary, the purple prototype put more consideration into:

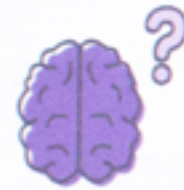
- The amount of white space used between each paragraph of text and section of information. There was an increased amount of white space used in the purple prototype that distinguished between the paragraphs and sections better
- The sectioning. Each new section or header in the information sheet started on a new page, while in the blue prototype, the new sections continued below each other regardless of where they sat on the page.



## Medical Records

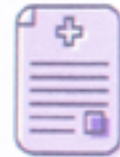
I will ask you for **permission** to review your **medical records** that are at **Rehab Plus**.

These will give me **information about**:



What happened

increased white space



The **tests you have had** since your stroke



The **treatment you are having** with your therapists

\* A5 sized

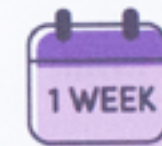
## Interview Details



I will interview you **three times**.



Each **interview** will take between **45-90 minutes**.



There will be at least **one week** between each **interview**.



It may take **up to six weeks** to **complete** the three interviews.

monochromatic purple colour

icons as the images beside text

Figure 42. Variables annotated in purple prototype.

The static features in the prototype participant information sheets were:

#### **Information**

The same study in both participant information sheets. This was to ensure the same information was given and the rest of the static design features would be consistent throughout each prototype to ensure comparable variables. The *hope* study already utilised short and simplified sentences.

#### **The Typeface**

Open Sans was used. This was chosen as a clear sans-serif typeface that worked well in body text and headers.

#### **Type Size**

14pt type size was used. This type size was taken from the participant information sheet analysis as a recommended size for people with aphasia.

#### **Leading (line spacing)**

Line spacing of 1.40 was used. The line spacing is slightly increased from the default format to give more space between the sentences to make following a sentence easier without causing too much separation and getting lost.

#### **Order of Information**

The sections were ordered the same in each prototype.

#### **Bolding of Keywords**

Each prototype used bold type to emphasise keywords and phrases.



Alongside the implementation of the selected variables, the prototypes were additionally considered from the perspective of Gestalt psychology where all elements are structured, ordered, and simplified to work harmoniously together on a page as a whole (Jackson, 2008; Moore & Fitz, 1993; Moszkowicz, 2011). Five of the six Gestalt principles were considered when designing both prototypes (Moore & Fitz, 1993; Moszkowicz, 2011; O'Connor, 2015):

**Figure-ground Segregation**

Having ample white space to ensure the readability of the information.

**Symmetry (Equilibrium)**

Making sure the elements are symmetrical and balanced on each page.

**Closure**

Having clearly defined spaces at the end of paragraphs and sections so the reader can see where each section starts and ends. Closure is considered more closely in the purple booklet by separating sections by page.

**Proximity**

Placing images near the information they represent and having an appropriate amount of space between elements so the reader is aware of sections of information.

**Similarity**

Keeping design features consistently throughout each prototype such as colour, typeface, type size, illustration style, spacing of elements, headers etc.

Figure 43. Purple prototype with variables and Gestalt principles applied.

## Confidentiality

What you say is **anonymous**.

**I will not tell anyone** what you say. You will not be identified in research findings.

**I will give you a summary** of our discussions. You can **choose** if you want to give this to anyone. You don't have to.

securely locked.  
recordings will be

I can give you a **copy** of the results.  
These will be **available** in 2011.

## Benefits & Risks

Benefits for you:



You may find it helpful to talk about what is important to you.

This may help you identify goals to work on in or by yourself.



Rethinking illustration and colour

After reviewing the images used in both prototypes, it was observed that both illustrations were too similar to each other and could both be classified as simple icons. It was decided to change one set of icons to more detailed character illustrations to have two completely different styles of illustrations to compare. The more detailed illustrations were chosen to be included in the blue prototype. This was decided as the larger A4 size of the blue booklet accommodated larger and more detailed images without making the text feel crammed onto the page.

Sketches of illustrations were made to represent various sections of information in the participant information sheets. The concept was to create a recurring character as the ‘researcher’ that appears throughout the booklet doing various actions that represent the information in a particular section. A recurring character creates a sense of familiarity when navigating the booklet that can be identified as a warm and approachable figure in the research journey.



Figure 44. Brainstorm of detailed illustrations.



Figure 45. Illustration sketches for blue prototype.

At the same time, the colour palette of both prototypes was reconsidered. I wanted the colour to elicit a sense of trust and calmness. Participant information sheets are documents that intend to inform and reassure the reader of their involvement in research. A degree of trust and authority needs to be formed at the time of reading and reviewing a participant information sheet for this to occur. These feelings of trust can be influenced not only by a document's design but by colour (Sless, 2004; Su et al., 2019). Blue was the best colour choice to elicit these feelings of trust and calmness.

Blue was incorporated into the 'researcher's' clothing along with pinks and purples. These analogous colours were chosen for their proximity to each other on the colour wheel. Analogous colours have similar wavelengths resulting in less strain on the eyes when being viewed (Stone et al., 2006). In addition to these detailed illustrations, stock photos were used alongside the researcher's contact details in the blue prototype to compare against the illustrated versions in the purple prototype.

Once the character illustrations were complete, they were placed in the blue prototype. Due to their increased size, the booklet had to be re-formatted to allow the illustrations to sit alongside the appropriate text. Less time was spent on the sectioning and arrangement aspect as the purple booklet considered this variable more.



Figure 46. Coloured illustrations for the blue prototype.



Figure 47. Blue prototype spread showing illustrations.

## What is this research about?

Kia Ora,

You are invited to **take part** in a **research project**. We are doing research into **what is important** to people with **aphasia**.

You can **choose** if you want to take part in the research. **It is your choice**. If you decide to not take part, this **will not affect your therapy** at Rehab Plus.

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet will give you **information about the study**. It may **help you decide** if you would like to take part. Please **tell us** if it is **difficult to understand**, or if you have any **questions**.



## Purpose of the Study

We are trying to find out **what is important** to people with aphasia. I would like to **interview you** and talk about your **hopes and priorities** for **your therapy, your recovery and your future**.

Research tells us **what is important** to people who had their **stroke a long time ago**. We **don't know what is important** to people who had their **stroke recently**.

## Interview Details



I will interview you **three times**.

Each interview will take between **45-90 minutes**.

There will be at least **one week** between each interview.



## Interviewing People with Aphasia

Interviews were conducted with participants with aphasia. They were a way to:

- Connect with people with aphasia to gain an understanding of their everyday lives and what it is like living with a communication impairment (interview 1).
- Learn more about what makes reading harder or easier for people with aphasia (interview 1).
- Gather feedback from people with aphasia on the design features that facilitate their understanding of the information presented in the prototype participant information sheets (interview 2).

Participants provided feedback on the two prototype participant information sheets that were re-designed for people with aphasia. The questions for this interview were established from four visual prompts that were created to aid the participants when talking about the design of the participant information sheets. The prompts were colour, images, page size, and arrangement (see page 125 for the

details on the communication aids used to present these to participants). Questions were also asked about the participant's responses to the information ordering activity that was included in the prototype package (see page 114).

The full list of questions asked in the first and second interviews can be found in Appendices 4 & 5.

## Interview Process

To ensure that potential participants with aphasia were suitable to engage in this research, it was required that they had to be living from home and not in an acute care facility. This was taken as a sign that all participants were living within the wider community setting and were engaged in regular everyday activities.

Participants with aphasia were recruited through professional contacts of the research team who practised in rehabilitation centres. Recruitment flyers were emailed out to these contacts to be distributed to their clients with aphasia who expressed interest in taking part in the research. Recruitment was a lengthy process and was delayed due to the COVID lockdown. Eventually, two people with aphasia expressed interest in participating. A friendly introduction along with the information sheet for the research was sent to the participant who provided an email address (see Appendix 2).

Two people with aphasia under the pseudonyms Janet and Katherine took part in two interviews each. Janet was interviewed over Zoom, and Katherine was interviewed over

the phone. One of my supervisors who is a speech-language therapist was present alongside me during both interviews with Janet, and during the first interview with Katherine. Her presence was to ensure the participants were properly introduced to the research and could provide verbal consent. She assisted with the flow of conversation her presence was a precautionary measure to:

- Ensure that the participants and I could communicate together effectively.
- Get an informal understanding of the participant's language and communication abilities.
- Use her professional skills to ensure the participant can communicate effectively in the interviews.

Additionally, efforts were made to support conversation with participants with aphasia using communication techniques such as utilising longer pauses, speaking slower, and confirming their understanding (Dalemans et al., 2009; Gray, 2018; Kagan, 1995; Luck & Rose, 2007; Pearl & Cruice, 2017).

### **Communication Aids to Facilitate Feedback**

In preparation for interviews with people with aphasia, a package was put together along with the prototype participant information sheets that was mailed out to participants. Additional materials were needed to help explain the contents of the package and provide information on what to expect in the second interview.

A set of visual prompts and an ‘information ordering’ activity were used to aid the participants in giving feedback on design features in the participant information sheets. These aids were developed through an exploration that started by looking into the use of prompt cards that participants could sort/arrange into categories. The exploration progressed and shifted to consider how these communication aids could be used in an online environment in the wake of the pandemic, until they led to the creation of the visual prompts and information ordering activity.

The review of the literature showed the difficulties researchers and health practitioners often face in communicating

effectively with people with aphasia, especially when it comes to eliciting responses during an interview process. It has been shown that when some people with aphasia are asked about a certain topic they may not be familiar with, or when asked an open-ended question, their responses can sometimes be minimal, or they will only reply with ‘yes’ or ‘no’ answers (Dalemans et al., 2009; Luck & Rose, 2007). This may be due to how aphasia has affected a person's verbal communication, the imposed time pressures to answer questions (Dalemans et al., 2009), or their communication partner's lack of knowledge or resources to effectively communicate with them (Pearl & Cruice, 2017).

These findings led me to explore some strategies I could develop to help enhance my communication with people with aphasia during our upcoming interviews.

Figure 48. Participant package contents.

Package guide

1

What is in this package?

This package has some things for you to look at!

You will need to look at everything before the second interview.

In this package there is:

Two information sheets for you to look at. You will be giving feedback on them in the second interview.

A page of visual prompts. This page will help you talk about information sheets in the interview.

A questionnaire. Please fill this out after reading the information sheets.

An activity about ordering information. This activity has a fold out page and cards. You will order the cards.

Turn over page →

Visual prompts

2

Question Prompts

I will ask questions about:

Paper Size

Colour

Image Style

Which layout do you like better?

Questionnaire

1

Information Booklet Questionnaire

Below are questions about the information booklet.

Answer what you can!

What is the purpose of the research?

What things might you be asked about?

Turn over page →

Order of Information activity

Order of Information

Place the cards in the order you want to see them in the information sheets:

1.

6.

2.

7.

3.

8.

4.

9.

5.

Prototype participant information sheets

AUT

A

Participant Information Sheet

The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.

AUT

B

Participant Information Sheet

The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.



Prompt Cards

Some common techniques to facilitate communication and elicit more informative answers from people with aphasia include the use of probing<sup>11</sup> (Luck & Rose, 2007), prompts or interviewer-generated ideas (Luck & Rose, 2007), word offerings<sup>12</sup> (Luck & Rose, 2007), and the use of closed-ended questions in situations where clarification and understanding of an answer are needed (Dalemans et al., 2009).

Guided by IDEO’s resource The Field Guide to Human-centred Design (IDEO, 2015) I adopted the idea to use a card sort to aid participants with aphasia to communicate their thoughts during our subsequent interviews to gain feedback on the design of prototypes. The idea of using pre-made cards to start a conversation is similar to the technique of using interviewer-generated ideas or prompts to facilitate a conversation with people with aphasia (Luck & Rose, 2007). Generating cards with prompt words would eliminate the struggle of asking participants with aphasia (who most likely have little to no knowledge of graphic design and typography) their thoughts on the prototypes in a way that is simple and easy to understand.

<sup>11</sup> Probing is where an interviewer or researcher asks a follow-up question about a specific topic or open-ended questions to ‘probe’ for specific information related to that area that may not have been given in the initial answer to the question.

The prompt cards used words to do with design features of the prototype information sheets, such as colour, images, word choice, font etc. Blank cards were also provided so participants could write their own words for anything else they wanted to comment on about the prototype. Participants were then tasked with sorting the cards into three categories: *like*, *neutral*, and *dislike* for each of the displayed design features.

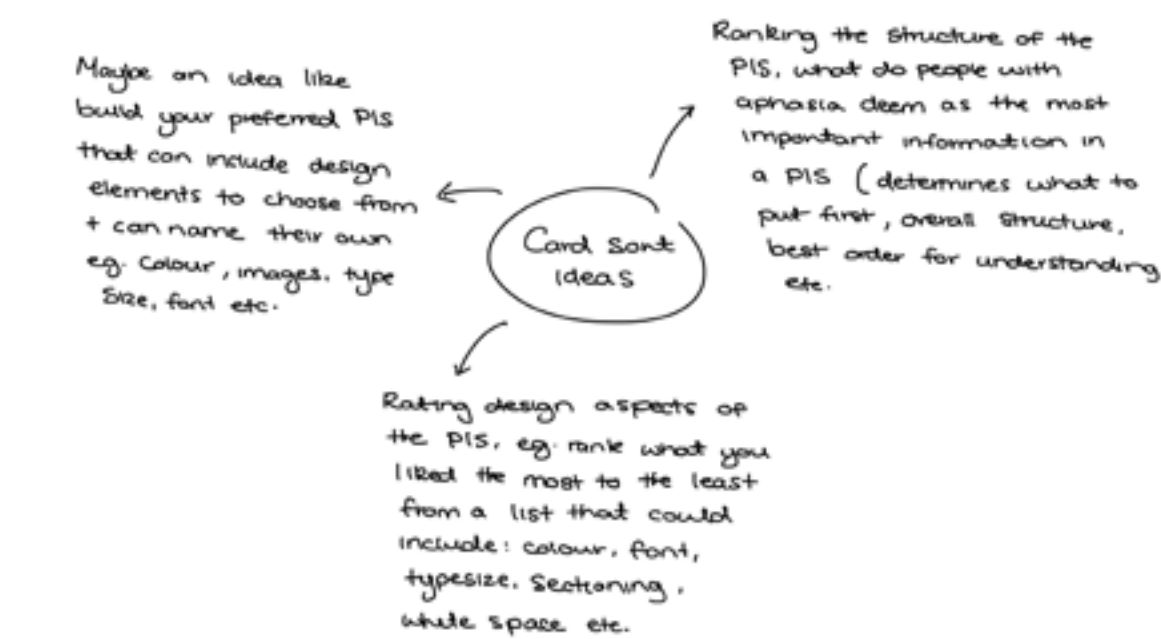


Figure 49. Card sort ideation brainstorm.

<sup>12</sup> Word offerings are often given when a person with aphasia may be struggling to communicate a word, idea, or emotion to the given question.

To create a set of design features that would be relevant to the design of a participant information sheet for people with aphasia, I took inspiration from the aphasia literature that discussed design features that were used to create accessible information (Aleligay et al., 2008; Dalemans et al., 2009; Knollman-Porter et al., 2015; Rose et al., 2003, 2011, 2012; Wilson & Read, 2016), as well as typographic features used in information design practice that improve readability and accessibility of information (Lipton, 2007; *Readability Guidelines*, 2020; RGD Ontario, 2010; Spyridakis, 2000; Visocky O’Grady & Visocky O’Grady, 2008). A list of 10 design features was created that would be relevant to the design of prototype information sheets:

- Colour
- Pictures
- Size of the font
- Font choice
- Word Choices
- Sentence Length
- Layout
- White Space
- Number of Pages
- Booklet Size

A lot of thought and consideration went into the best way to word each design feature so that it is simple and easily understood by a non-designer (e.g., ‘fonts’, ‘layout’, ‘white space’). This was an ongoing challenge throughout this project.

Experimenting with typography and readability of the prompt cards provided an opportunity to test typefaces such as Andika to explore whether the typeface had any effect on the readability of the prompts, as its letterforms were created to be distinguishable from similarly displayed characters or glyph forms. The typeface was tested in its various fonts that included regular, italic and bold, as well as in lowercase, uppercase, and colour.

When designing the back of the prompt cards, considerations were made to avoid confusing participants who were handling the cards, such as keeping the colours on each card consistent and choosing a strong, visible colour. I choose to use a line illustration of a brain due to the brain often symbolising stroke-related written materials.

Card Sort: Design elements ideas

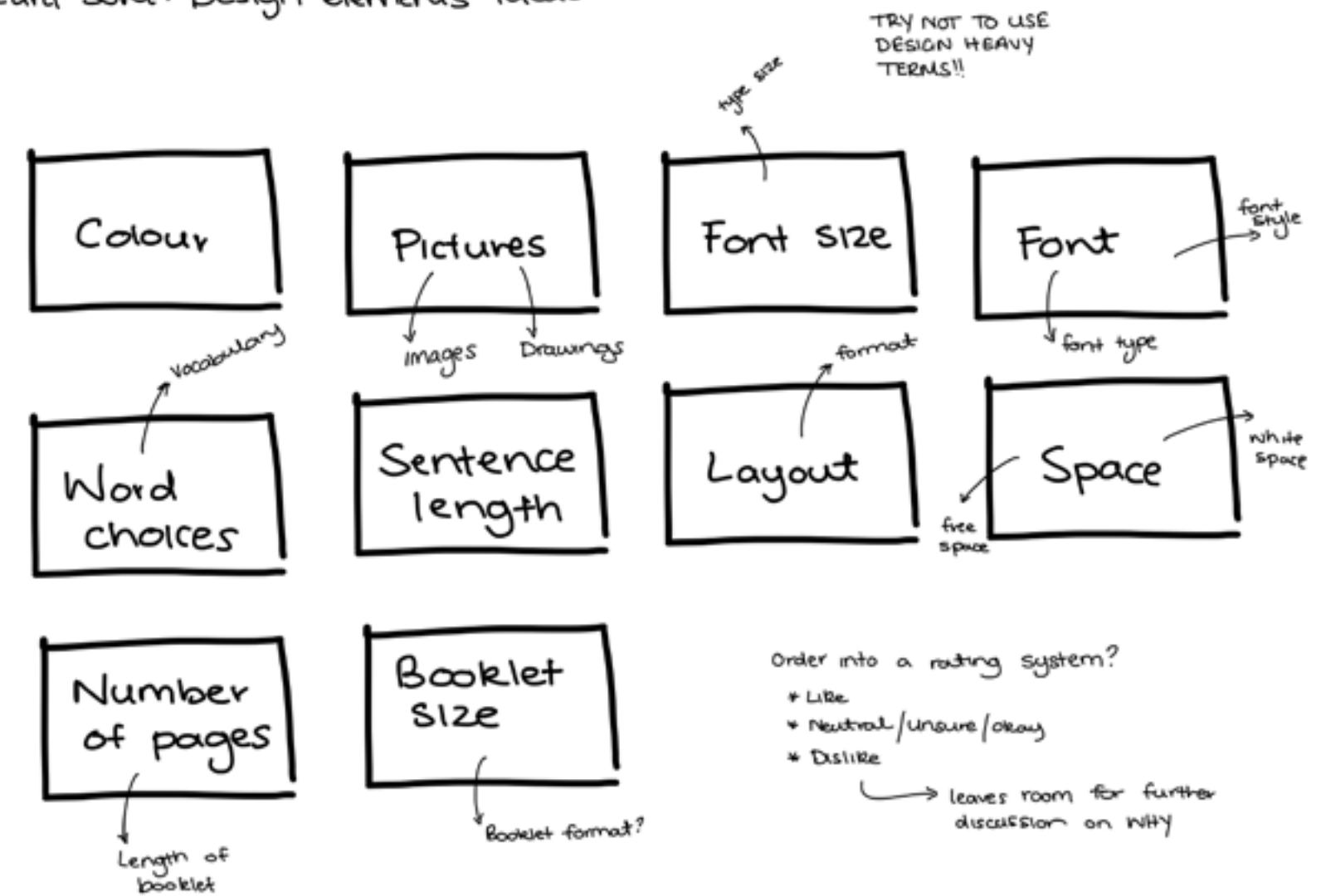


Figure 50. Word choice brainstorm for card sort.

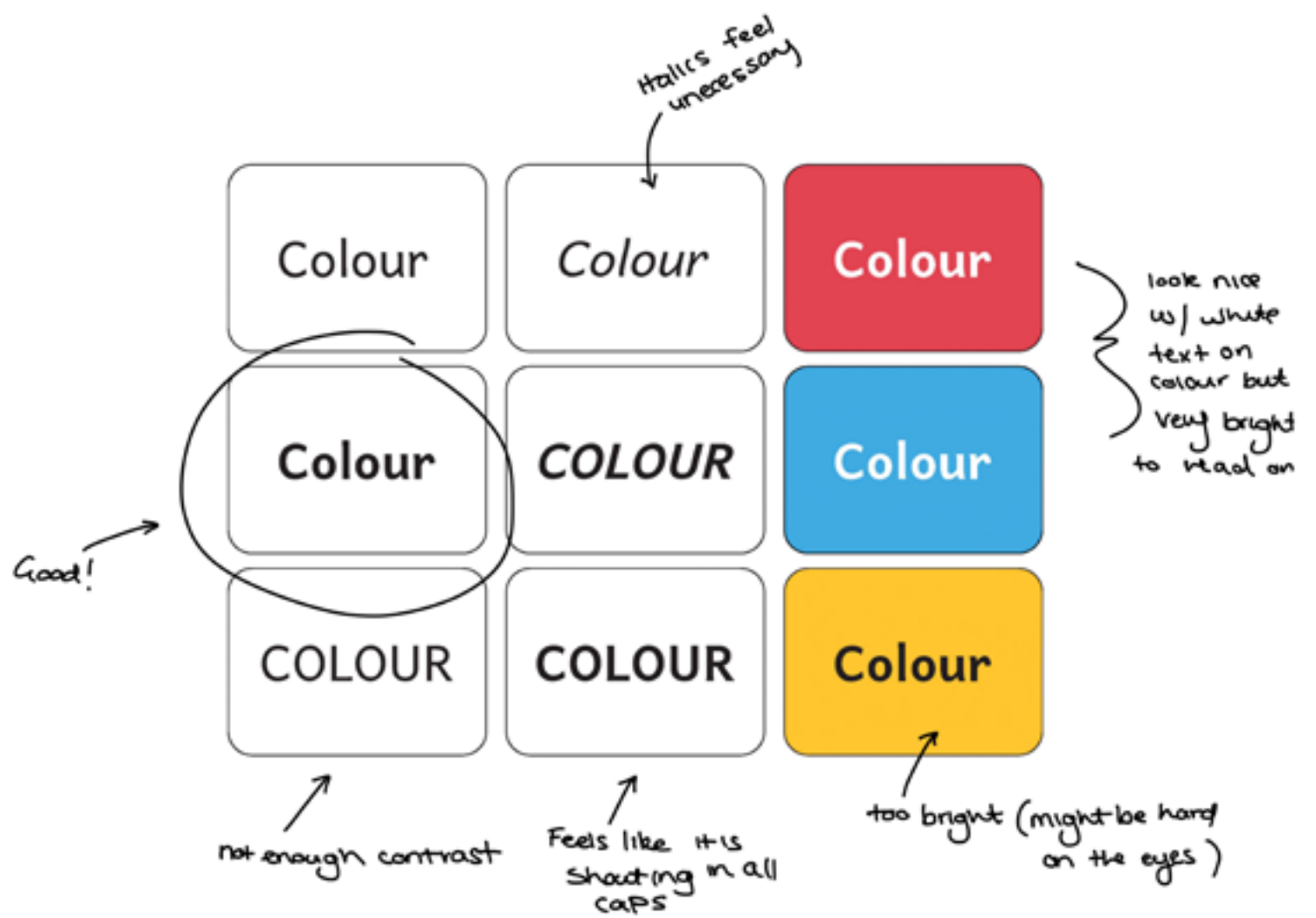


Figure 51. Testing type combinations for the cards.

Note. The circled card was considered good because it was bold, clear and neutral with only the first letter capitalised.

### Revisiting the Prompt Cards

Terminology was revisited for the prompt cards as I felt that using single words as prompts may be difficult for anyone who has little knowledge of design to answer confidently without asking additional questions about each word prompt. In particular, the cards: word choices, sentence length, layout, and white space are difficult design concepts to understand for non-designers and needed further explanation. To avoid the use of design terminology, a new set of prompts was created as statements. The statements were created to be answered as yes or no questions and to allow follow-up questions to be asked. The prompts used for the alternate version of the card sort were:

- Nice to look at
- Lots of information
- Easy to read
- Not too long
- Simple sentences
- Looks professional
- Images next to the text
- Easy to find information
- Made for people like me

Having prompt cards as general statements about the prototypes do not allow for direct questioning about a specific design features; however, this type of questioning does allow for an interpretation of what design features make up these statements. For example, the statement *nice to look at* could be answered with a simple yes, or an explanation of what is nice to look. This answer may not directly talk about design features such as the typeface or amount of white space, but that may be implied by what is said in the answer.

Single word or phrases set

Font	Font size	Number of pages	
Images	Sentence length	Word choices	
Space	Layout	Colour	Paper size

General statement set

Nice to look at	Lots of information	Easy to read
Not too long	Simple sentences	Looks professional
Images alongside text	Easy to find information	Made for people with aphasia

Figure 52. Card sort word sets.

Note. The single word or phrase design features set (left) and the general statement set (right). Both sets of cards refer to or imply the specific design features that appear in the prototype participant information sheets.



### Feedback on the Prompt Cards

I gathered Informal feedback from my peers on the prompt cards to test the usability of the activity and to see if the design terminology on the cards was understandable to someone who may not know much about design. I explained the card sort and presented the cards along with a piece of designed text in place of a participant information sheet. They were asked to comment on the prompts in relation to the designed text in front of them. I found that:

- People found it easier to talk about the prompts when they were phrased as statements about the information (e.g. 'easy to read' or 'nice to look at').
- The single-word prompts about the design features were harder to answer because they were not explained in the context of the information the person was viewing (e.g. 'font' or 'colour' were hard to understand unless re-phrasing to 'the font used on this page' etc.).
- Using the word space in place of white space was confusing to people. They understood what white space was and preferred the use of the correct terminology.
- People were confused with the term paper size. The paper size was interpreted in different ways depending on the size of the booklet or publication when it is closed, and the size when it was open showing the double-paged spreads.
- The prompts phrased as statements were hard to rank on a like, neutral, and dislike scale. To fix this issue, a question was formulated to rank the prompts on their importance to the participant when reading on a scale of very important, kind of important, and not important. The question was changed to: *What is important to you when reading information?*

Getting feedback from my peers showed me that a set of instructions needed to be created to explain how to do the card sort activity for people with aphasia. Instructions needed to explain the premise of the activity simply and concisely in an accessible format. Additional changes were needed for the terminology used on prompt cards. Certain prompt cards such as *layout* and *sentence length* did not make sense on their own or were too ambiguous of a concept to answer.

Changes to the prompt cards were made following insights from the expert interview with an stroke researcher. They mentioned they would like to see improvement in the flow and hierarchy of information presented in participant information sheets for people with aphasia. Additional prompt cards such as *order of information* and *headings* were therefore created to reflect this.

**Figure 53.** *Prototype card sort with prompts and card back testing.*



### **Reframing for an Online Environment**

In light of the amendments to ethics, data collection tools and protocols had to be redesigned for an online environment. These included changes to:

1. The interview questions recognised the shift to a digital space. A few interview questions were re-framed that recognised the shift to a digital space and asked the participants about their thoughts on receiving a digital participant information sheet rather than a printed version.
2. The way prototype feedback was gathered by using a card sort as a prompt for conversation. The card sort, originally designed for in-person use and the process adapted for online use is described in more detail in the section below.
3. How potential participants would receive and interact with the participant information sheet for this research. The mode of delivery was decided on a person-by-person basis, with individual participants.
4. How participants would receive and interact with the prototype participant information sheets. After deliberating if digital versions would be appropriate, it was decided to instead mail out the information sheets as their design, size, and features were intended for feedback in their printed versions.

**Digital Card Sort**

The prompt cards were originally designed to be an in-person activity. The activity needed to be recreated for an online environment that considered:

- How both the participant and researcher could access the activity simultaneously.
- Strategies for how the activity would be navigated in an online environment.
- The participant's familiarity with digital technology and how to work around navigating an unfamiliar environment
- The language needs of people with aphasia.

A website called MIRO that uses digital 'whiteboards' as collaborative spaces was explored to digitise the card sort. A prototype was created using MIRO to enable the sort to be completed in the digital space, with both sets of prompt cards, blank cards, and the importance scale for the cards to be sorted onto.

As navigating MIRO takes some practice, the online card sort activity was designed to be researcher controlled during the interview and visible to interview participants through screen-sharing in the video conference call where the interview took place.

After testing the digital card sort activity, I explored the options of condensing the prompts into one set of cards to sort, and for participants to only do the card sort for their favourite prototype and not both participant information sheet prototypes. This came from observations that the number of prompts, together with having to do the activity twice, would be too time-consuming and potentially stressful for people with aphasia.



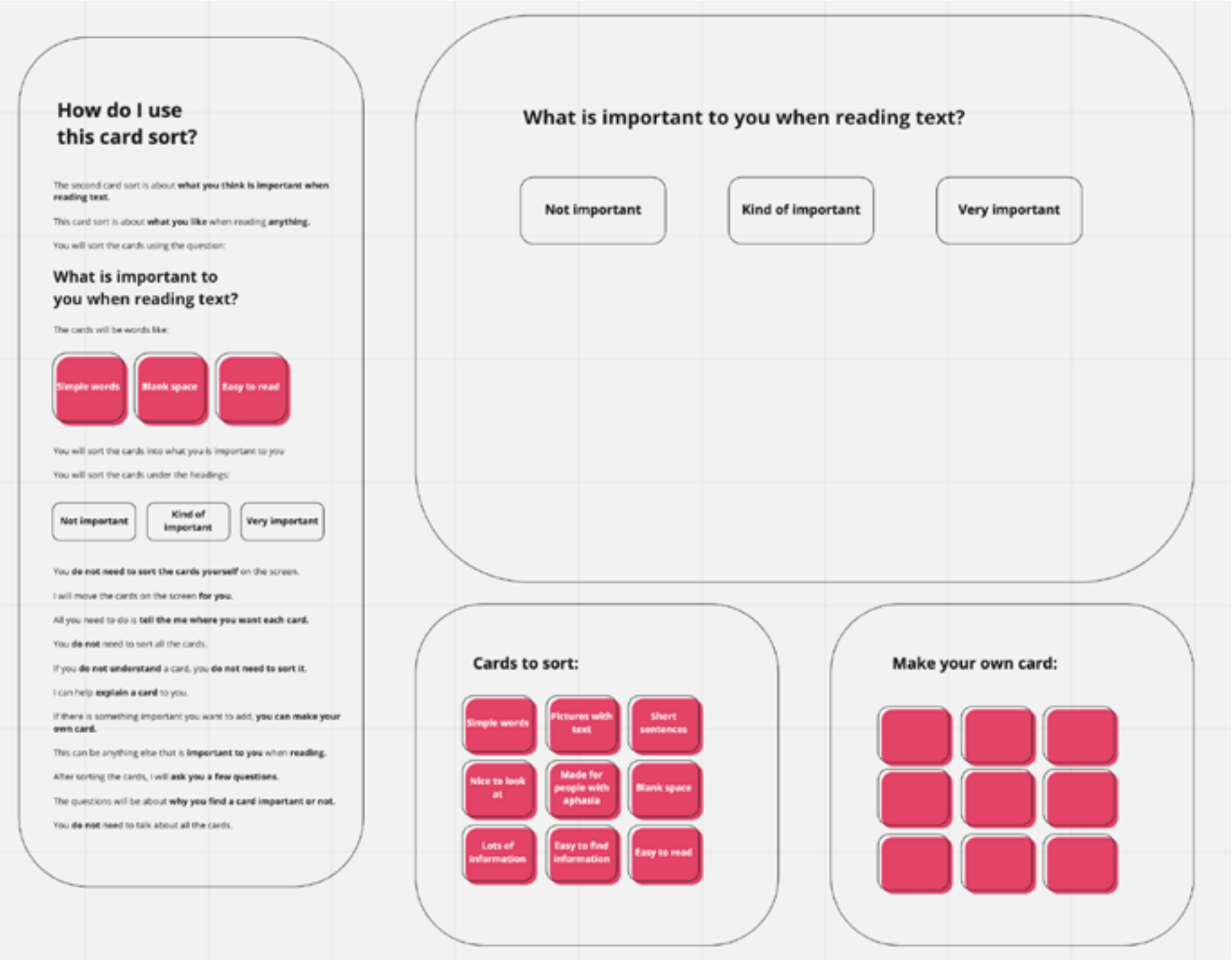


Figure 54. Card sort in Miro with statement cards.

*Note.* Instructions were mocked up in the Miro version of the card sort. This set of instructions was the base for the creation of both the ordering information activity instructions and the package instructions.

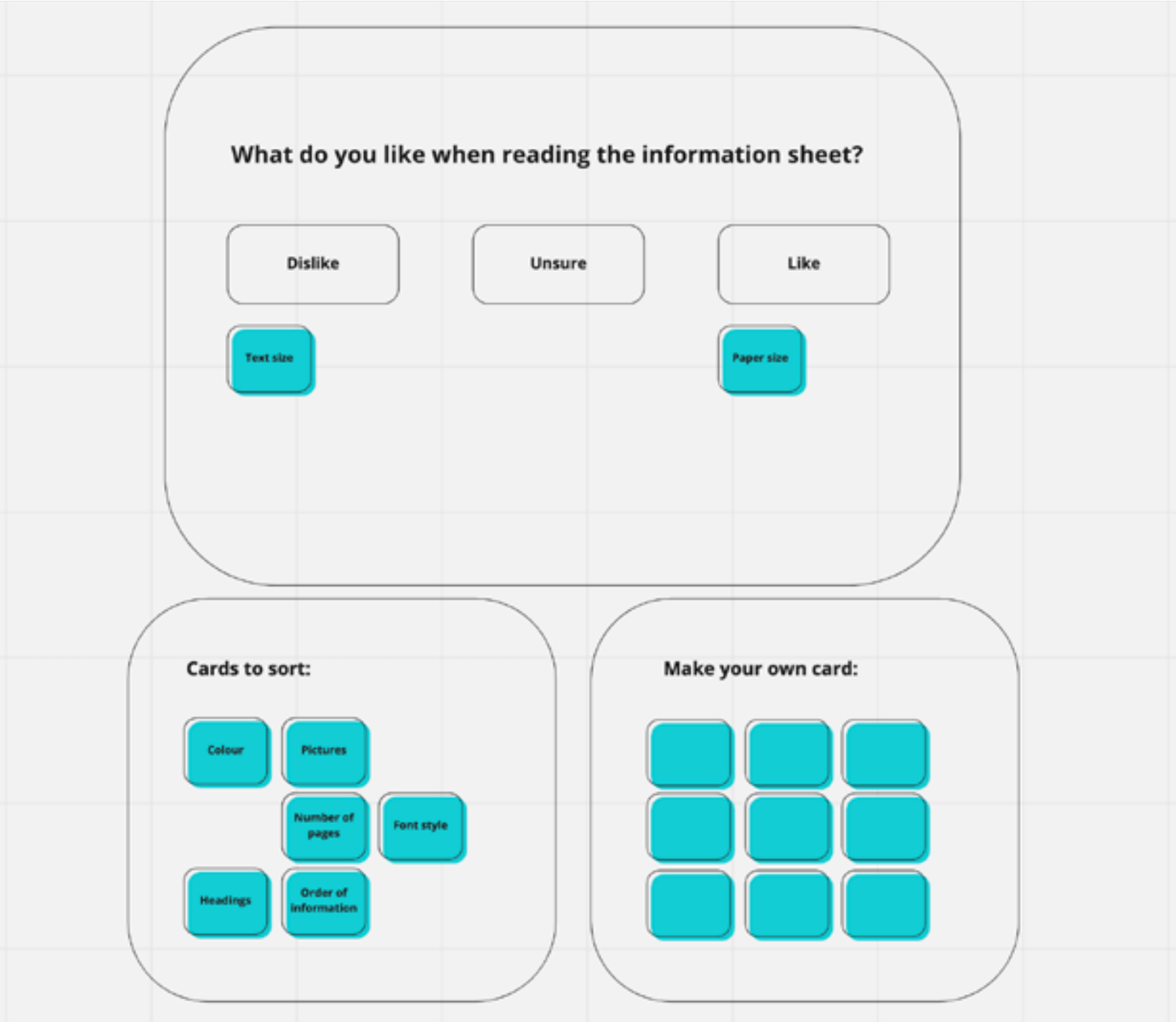


Figure 55. Card sort in Miro with single word/phrase design feature cards.



### **Re-evaluating the Design Variables**

A change was needed to focus the conversation to be about the comparison of both prototypes, rather than focusing on each participant's information sheet separately. The solution was to instead create a set of visual aids that act as prompts to talk about the design features of the prototype participant information sheets.

The prompt cards were narrowed down to 11 design features that were considered when designing the prototype participant information sheets. Sketches were made from each design feature and concepts were drawn on how to best visualise each design variable. The design features were:

- Booklet Size
- Colour
- Images
- Word Size
- Font Style
- Number of Pages
- Words
- Blank Space

Some features were best described as questions and they were:

- What do you think about the headings?
- Are the sentences easy to read?
- Is there enough information?

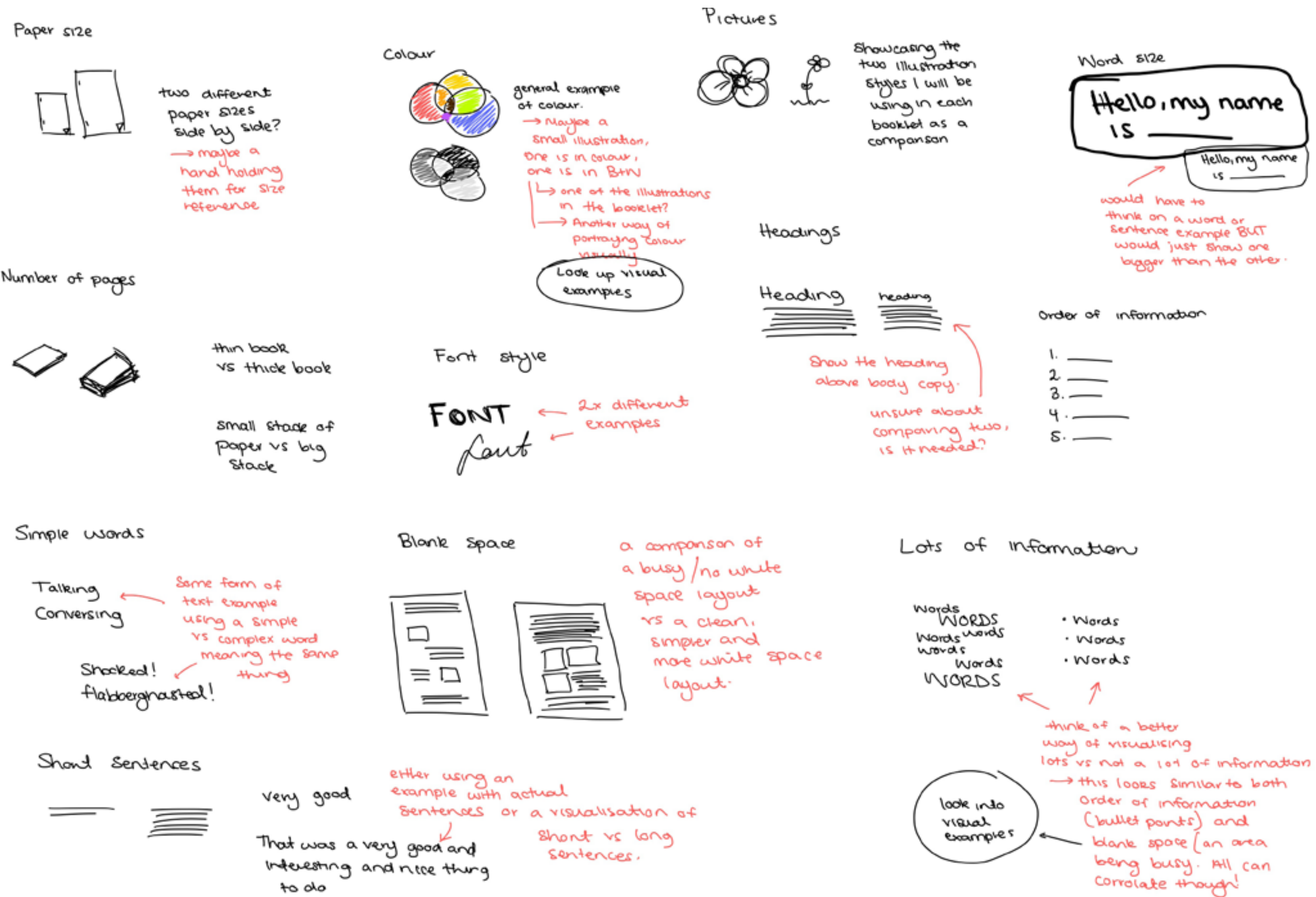


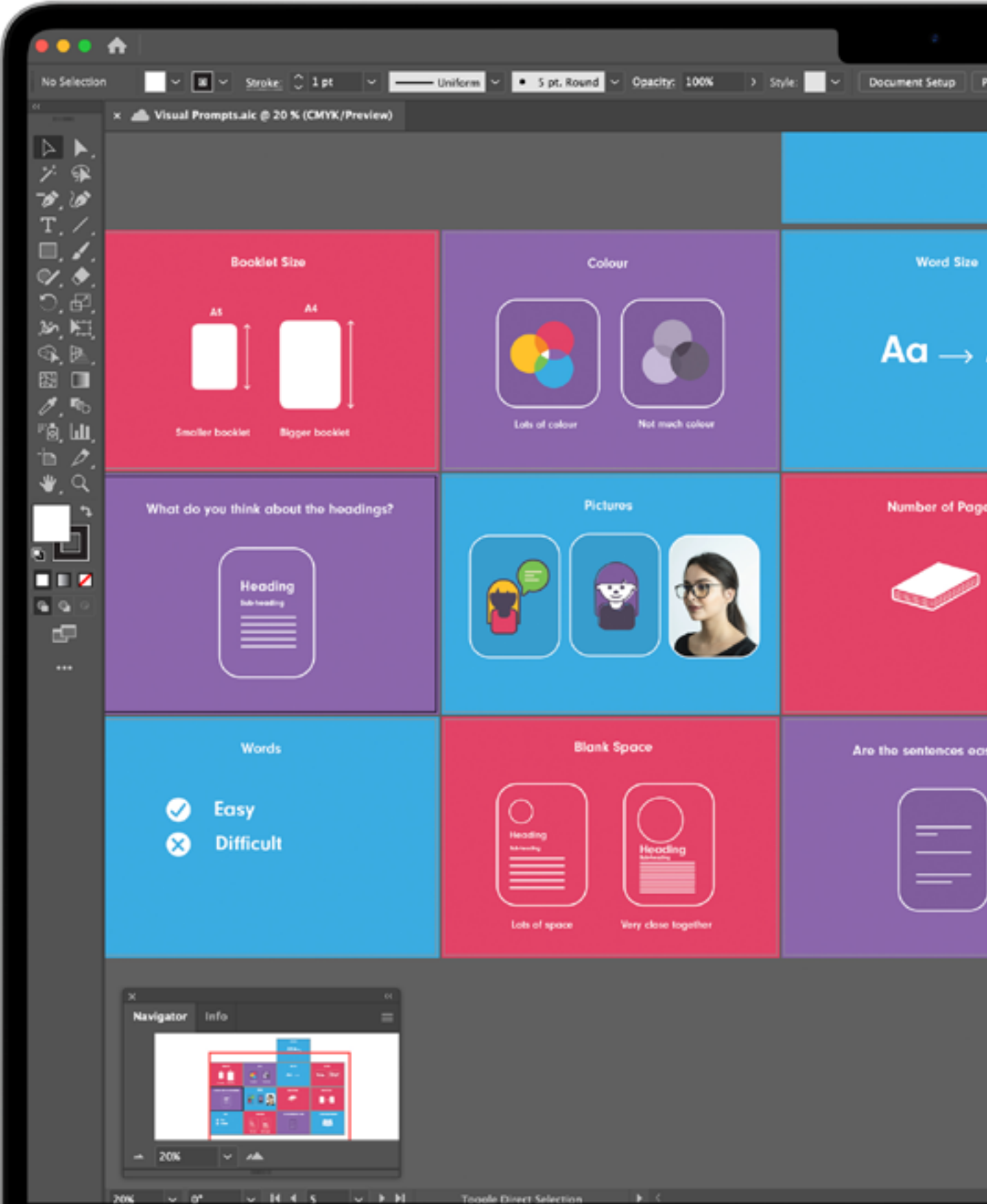
Figure 56. Visualising the prompt cards brainstorm.

As the prototype visual aids progressed, the wording of the prompts continually changed based on peer and supervisor feedback and critical evaluation. There was still indecision on the best words to use for:

- Describing the size of the text on the page. The prompt continually changed from *word size* to *text size* to *font size*.
- If using the word *images* or *pictures* would be best. The word *image* is broader and all-encompassing, *pictures* often refer to photographs.
- Describing the size of the participant information sheet changed very often between *paper size* and *booklet size*.
- The phrasing of *blank space* was used to describe the concept of white space.

I got further feedback that the visualisation of white space on the prompt card could be misinterpreted to mean the circle graphic element, rather than referring to the proximity of all the elements and the space between them. This was due to the circle being white, and the prompt name at the time being white space.

**Figure 57.** Visual prompt prototypes as presentation slides.



One prompt I struggled to visualise but was an important feature to explore in the design of participant information sheets for people with aphasia was the prompt question *is there enough information?* The idea behind the prompt was to understand if the information was too simple or too complex, if more information needed to be added, and for there to be follow-up questions on what information is the most important for people with aphasia to know in the participant information sheets. It proved too difficult to succinctly and accurately visualise this prompt, and instead, a stand-alone activity was considered that looked deeper into how people with aphasia wanted the information to be ordered.

Upon creating the concept of an activity that looked into the order of information, the remaining visual aids went through the second round of critical evaluation. Many of the features represented in the visual prompts had already been explored in the aphasia literature when designing written information and were shown to improve readability. Four design variables were kept as visual prompts that had not been explored in-depth before in the aphasia literature. These variables were:

#### **Booklet size**

Little has been explored on the size page size or booklet size of information presented to people with aphasia.

#### **Images**

The use of images has been shown to facilitate understanding of information for people with aphasia (Knollman-Porter et al., 2015; Rose et al., 2003, 2012). There is however no conclusive recommendation for what type of imagery works the best for people with aphasia.

#### **Colour**

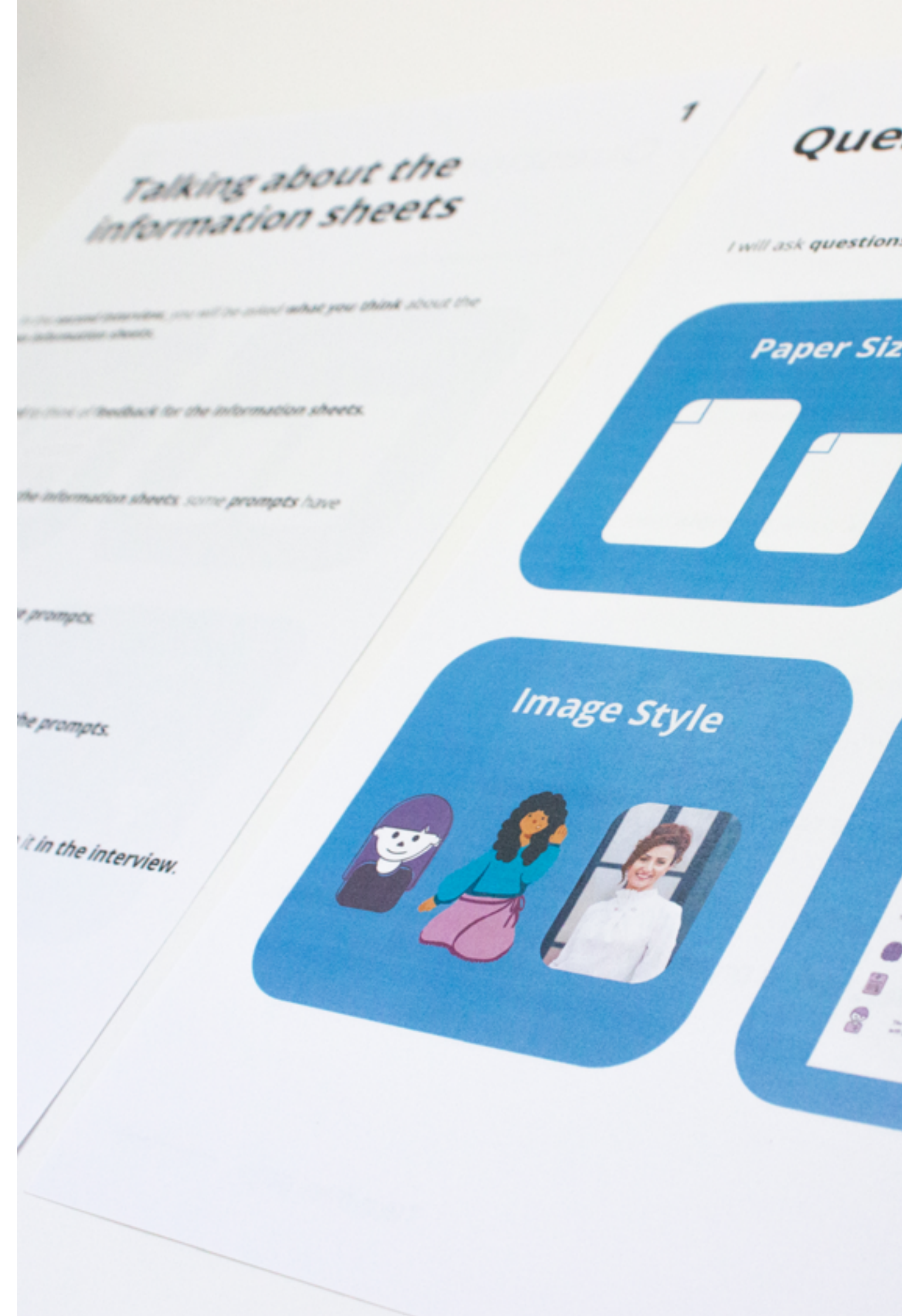
There is little about the use of colour in written information for people with aphasia. Colour psychology was investigated to ensure the information sheets elicit a sense of trust and calmness.

#### **Arrangement**

The term arrangement was used as an umbrella term for the use of typographic features such as sectioning and white space and the effects these have on the number of pages needed in prototypes.



These visual aids would take the form of slides in a PDF presentation that would be given to participants in the second interview via Zoom. To ensure participants were prepared to give feedback, a printed version of the visual prompts was made to send to the participants with the prototype participant information sheets to be viewed before the second interview.



**Figure 58.** Printed version of the visual prompts.



### **Information Ordering Activity**

The concept of the information ordering activity was prototyped as a replacement for the card sort activity. Prompt cards with the headings of each section of the study used in the prototype participant information sheets were made into cards. The activity required participants to order the headings from 1 to 9 on how they would like the information to be ordered in the participant information sheet. This determined what was important for participants to know and see first when they engage with an information sheet.

When designing the cards small descriptions were placed below each section header. This was to ensure participants knew what information is in each section so they can order them accordingly. Varying shades of soft light blue were used on each side of the card. The colour choice was drawn from my exploration into colour psychology and the calming and trustworthy effect blue can have on a person (Su et al., 2019).

A printed information ordering activity and a MIRO board version were created. The printed activity was sent with the prototype participant information sheets to the participants, while the MIRO version was used as a backup in the instance where the participant was unable to complete the activity themselves. Written instructions were created with both versions to ensure participants understood the activity.

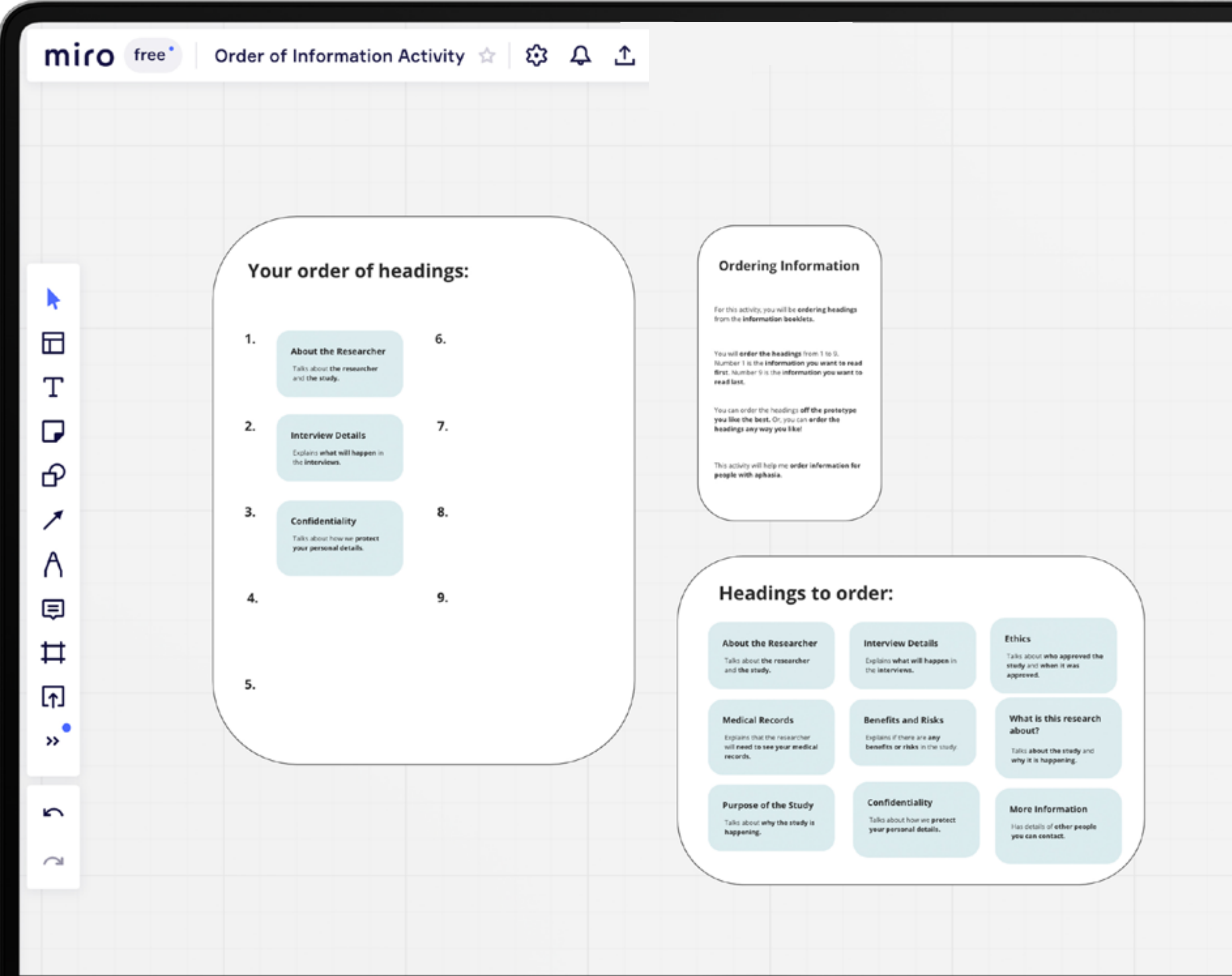


Figure 59. Order of information activity developed in MIRO for online interviews.



# Order of Information

Place the cards in the order you want to see them in the information sheets:

1.

**What is this research about?**

*Talks about the study and why it is happening.*

2.

**Purpose of the Study**

*Talks about why the study is happening.*

3.

6.

7.

**Medical Records**

*Explains that the researcher will need to see your medical records.*

8.

9.

**Ethics**

*Talks*

**Interview Details**  
*Explains what will happen in the interviews.*

**Figure 60.** Printed version of the order of information activity with cards.

## Interview Findings

### Living with Aphasia

Both participants actively engaged in the community with their aphasia. Katherine spends their time volunteering in the community while Janet juggles working a part-time job and raising a young family. Janet is a health professional and still practices in a non-clinical role at a high level despite her aphasia. Katherine went into great detail about her post-stroke journey and got emotional re-telling her experience.

### Reading

Both Janet and Katherine were active readers before having aphasia. Janet still loves to read and continues to read a lot despite her aphasia. While aphasia has not affected Janet's reading at all; Katherine finds reading hard and needs large print to be able to read. Katherine has a reading technique she uses called 'tracking'. Tracking is where another person sits to Katherine's left and uses their finger to follow the sentence they are reading from the left side of the page, and Katherine uses her finger to follow the same sentence on the right side of the page. This process is continued down to the next line in the sentence. Tracking helps Katherine keep 'track' of what line she is on when reading so she does not get lost in the text. Katherine can read really slowly but often she does not understand the words.

**" I am like a child but I am not. I have seen my words. I have remembered my words. They will come upon me."**

Katherine

**" Large print is very good; however, the world doesn't work this way, and I'll meet the world."**

Katherine



After learning that Katherine struggled with reading, changes were made to the approach of her second interview and what materials in the package she would engage with. The changes were as follows:

- Only one prototype participant information sheet was looked at from the package. The A5 purple booklet (Figure 59) was chosen as the design variables regarding the layout and sectioning were considered more carefully here than in the blue booklet.
- A plan was made to only read a small selection of pages from the participant information sheet together over the phone. I read the pages aloud while Katherine followed along.
- The order of information activity was adapted into interview questions about what information is the most important to know when wanting to participate in research.
- All other contents of the prototype package were disregarded.

**Figure 61.** *Front of purple prototype.*





## Speech

Verbal communication and speech with aphasia came a lot easier to Katherine than to Janet. Katherine spoke in sentences and had a large vocabulary, while Janet had trouble with word production and spoke in disjointed sentences due to apraxia of speech <sup>13</sup>. In Janet's situation, alternative methods of communication were offered such as writing words down and typing out words or sentences (Dalemans et al., 2009; Kagan, 1995).

Because of Janet's speech difficulties, special attention was made to pick up on any non-verbal cues she was making by observing her reaction to questions and their expressions when answering (Kagan, 1995). To aid with picking up on non-verbal cues, two screens were set up to aid in observation. Fewer notes were taken for the online Zoom interview with the participant due to their communication ability and the need to engage more intently with them to interpret their gestures and non-verbal cues.

## Design Features

When asked about the design of the participant information sheet they read for this study, Janet commented that it covered the basics and she felt neutral about it. Katherine misplaced her information sheet and had no comment. Janet suggested these changes to the participant information sheet:

- Shorten to around 10 pages instead of 20.
- Make the word size smaller.

Of the two prototype participant information sheets, Janet preferred the blue A4 size booklet over the smaller purple A5 size booklet. Janet's comments are presented in Figure 60 on the following page.

Additionally, Janet liked the use of photography to show the researchers. It was important for Janet to see photographs of the researchers to familiarise herself with them.

<sup>13</sup> Apraxia of speech is a speech sound disorder where the person has trouble saying what they want to correctly and consistently.

Did not like the large text size. She would have liked it smaller.

Liked the blue background to distinguish important information.

Did not like the use of bolded keywords for emphasis.

Preferred the illustrations but she did not like this one of the person talking on the phone as it was not relevant to her experience.

Liked it had fewer pages than the purple booklet.

Would like a phone number and SMS/email option as she cannot talk on the phone.

Liked that the booklet was colourful.

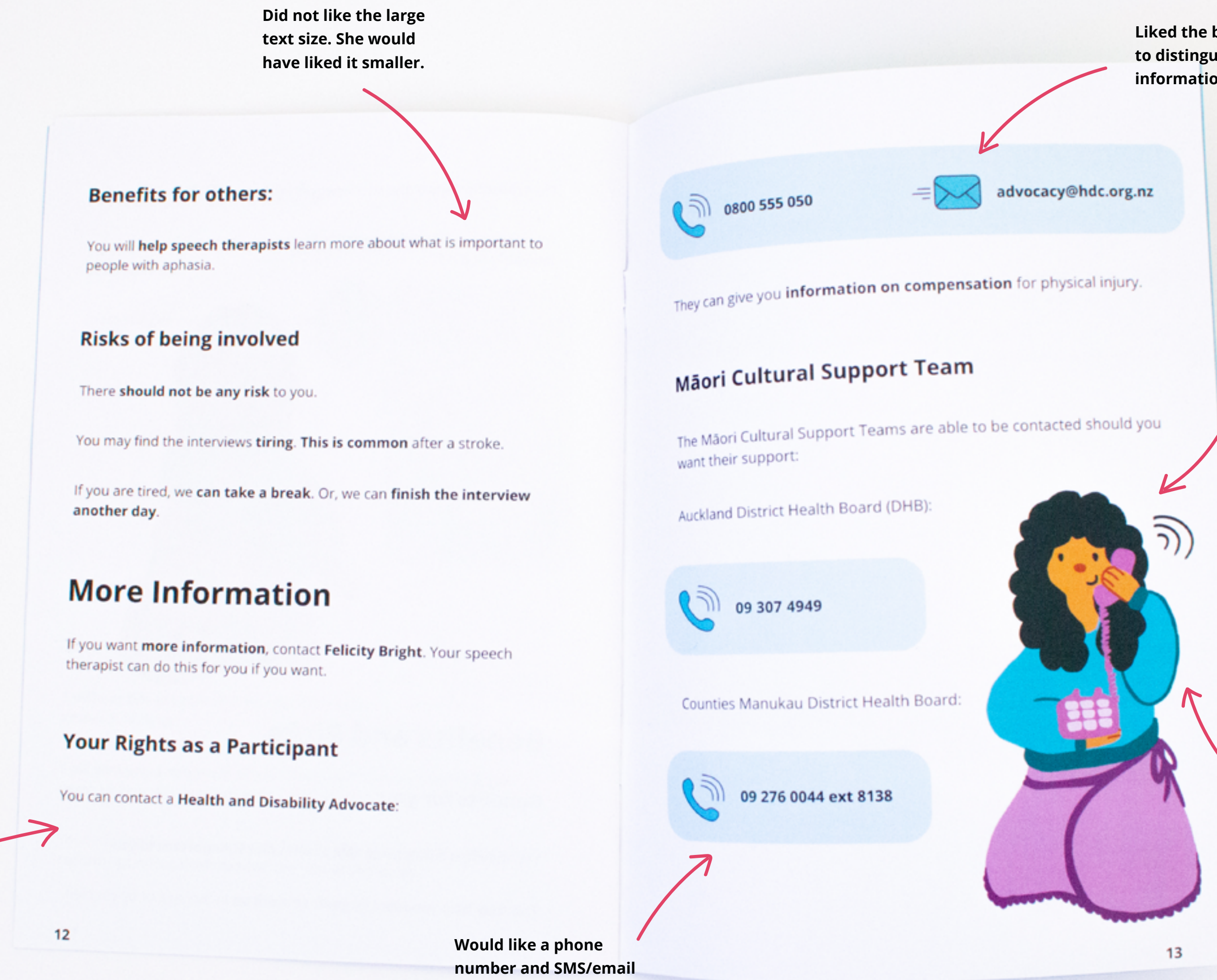


Figure 62. Janet's feedback on the blue prototype (annotated).

Katherine was only given the purple booklet to give feedback on as detailed previously. She was able to read and follow along while I read the pages aloud. This was the first time she was able to read without using her tracking strategy. Katherine's comments are presented in Figure 61. Additionally, she commented that:

- She liked the size of the booklet but questioned if it could be smaller to carry around in her pocket, but later reconsidered the idea of having a smaller pocket-sized booklet by saying *"The font will be compromised"*.
- She questioned the Ethics section, stating that she would like to have all the information about ethics in one separate document with the consent form. She did not like that it was repeated in more than one place and said: *"You just want to do the meat of the book, it just gives us again and again."*

**"I've never done a book like it, and it was easy peasy!"**

Katherine

**"I take it (the pictures) to be a blessing for me. It is not condescending. No, it is a blessing, and I will take it... it is a blessing, and I thank you."**

Katherine



Liked the purple colour used.

## Interview Details



I will interview you **three times**.



**Each interview** will take between 45-90 minutes.



There will be at least **one week between each interview**.



It may take **up to six weeks to complete** the three interviews.

You are welcome to have a **family/whānau member** at the interview if you wish.

8

The icons helped her understand the text better.



You **do not** have to **answer all the questions**.



I would like to **tape the interviews**.



During the **first interview**, I will just use a **tape recorder**.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional**.

Liked the text size, she didn't have to take her glasses off to read.

9

Figure 63. Katherine's feedback on the purple prototype (annotated).

### Ordering Information

Janet completed the order of information activity sent in the prototypes package, while Katherine was asked questions about what information is most important to know in a participant information sheet. The findings were as follows:

- Both wanted to know the details of the research more than who the researchers are, although knowing about the researchers is still important.

*"I am going to get into the (researchers) brain and see what they are thinking. I will flesh them out."* - Katherine

- Both found the confidentiality section not as important to know. This was because they both had previously taken part in studies and knew the details of these sections well.
- Janet found the 'benefits and risks' section not as important, while Katherine found it important as risks and benefits will directly affect her.

- Janet likes to have the more information section on the last pages. She prefers to have this at the end of the booklet because of familiarity. It is common to have phone numbers and further information last. Janet added that having this information last is easy to access as you can just flip to the back of the booklet.
- Katherine likes to know the small details of the study and appreciates it when information sheets are transparent in the information they give to participants.



### Digital Technology

An unexpected insight that came out of the data collection was the use of digital technology. The effect of a global pandemic brought into question how digital technology can aid in the informed consent process. The entire informed consent and data collection process occurred digitally for Janet, while none occurred digitally with Katherine. Janet was initially contacted by email where a PDF version of the participant information sheet was sent. It was found that:

- Janet had no issues with receiving a digital version of the participant information sheet and preferred this over a paper version.
- Katherine spoke about a talking box in her local library where she listens to words being spoken through earphones and can slow down the talking pace.
- Katherine has an iPhone that is set up to enable text-to-speech. She can read along with the text while it is being spoken to her and can slow down the pace and rewind the speech.

**"It reads with me. I can see the words... they will read with me... Technology is wonderful!"**

**Katherine**

### **Summary of Findings**

Because of Janet and Katherine's different reading abilities, the feedback varied. What both participants did agree on was:

- The most important information to know is the details of the study.
- The use of colour. Katherine liked the purple colour, but Janet wanted the participant information sheets to be colourful, not just one colour.
- The use of images alongside text. Because Katherine only looked at one prototype, there is no feedback on if she would have preferred icons or illustrations. Janet preferred the illustrations because they were colourful, not necessarily because of their illustrative style.
- They both did not find the confidentiality section of the participant information sheets as important as other sections.

## Reflection

### Additional obstacles in the recruitment process

All recruitment and associated correspondence with participants in this research had been conducted via email communications, so I was surprised when I was given a phone number as the only point of contact for one participant with aphasia. With this being the case, I had to re-think how I would communicate with the participant and change and tweak the flow of conversation to best suit phone call interviews rather than Zoom interviews. A phone interview was the only option as the participant did not live in Auckland where the research was taking place and did not have a computer.

The initial challenge in recruitment was talking through the contents of the participant information sheet over the phone rather than sending a copy through email. I did this by following the format of the participant information sheet for this study and explained the research as simply and concisely as possible over the phone. I added the participant information sheet to the prototype package sent to this participant to ensure they were given all relevant details about the study.

With the switch to a phone call interview, there were additional challenges. These challenges included:

- How informed consent would be obtained.
- Re-structuring the interview questions to remove any prompts involving visual materials that would have been presented on a screen.
- The participant and researcher not being able to see the prototypes simultaneously and visually address aspects of the design.
- Not being able to pick up on any non-verbal cues, gestures, or facial expressions that may aid in communication.

Navigating communication solely over the phone made me aware that not everyone has access to, or wants access to computers and technology we take for granted. Online video conference calls, meetings and interviews have become standard for most of us in the past few years due to the ongoing effects of the COVID-19 pandemic. We forget that there are still people who cannot access or choose not to access these computer-based technologies.

### **Participants**

I was fortunate enough to interview two people whose aphasia presented completely differently from each other. Janet had no difficulties with reading, but struggled with word production and could only say a few words at a time. Katherine could not read a lot by herself but could communicate in full sentences. Because Janet had no reading difficulties, many interview questions and changes to the prototype participant information sheets were redundant to her. This experience showed me that there is no one-size-fits-all approach to engaging with participants with aphasia, and continual adaptation is needed to best meet the needs of each individual's language ability.

## Refining the Prototype

From the interview findings, one prototype participant information sheet (the purple prototype, Figure 59) was refined to reflect the shared feedback of both participants. Because of the starkly different reading abilities of the participants with aphasia, a third prototype participant information sheet was developed.

The purple prototype was selected to refine as this prototype showed potential for reading improvement in the participant who had reading difficulties. The purple prototype was the version that had more careful consideration put into the arrangement variable than what was done for the blue prototype, which may have been a contributing factor to the participants' ease of reading. The participant commented that the space between each paragraph meant they didn't need to use their 'tracking' strategy to read. Other factors may have contributed to her ease of reading such as the increased leading and shorter paragraphs alongside the increased amount of white space, but these adapted feature cannot be confirmed. In light of these findings, refinement of the selected purple prototype involved:

Changing the order of the information to reflect that participants wanted to know details of the study before being introduced to the researcher.

- Adding more than one colour to the icons and overall design to reflect the participant's enjoyment of colour.
- Adding additional email addresses or phone numbers in areas where only one was given to reflect the various individual capabilities of people with aphasia.
- Adding colour behind contact information to emphasise its importance.
- Moving the 'more information' section to the back for ease of access by flipping to the last page(s).



## Interview Details



I will interview you **three times**.



**Each interview** will take between 45-90 minutes.



There will be at least **one week** between each interview.



It may take **up to six weeks** to complete the three interviews.

You are welcome to have a **family/whānau member** with you for the interview if you wish.



You **do not** have to answer all the questions.



I would like to **tape** the interviews.



During the **first interview**, I will just use a **tape recorder**.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional.**

Figure 64. Refined aphasia PIS prototype.

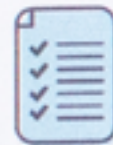


## Benefits & Risks

### Benefits for you:



You **may** find it **helpful to talk about what is important** to you.



This **may help** you **identify goals to work on** in therapy, or by yourself.

### Benefits for others:



You will **help speech therapists** learn more about what is important to people with aphasia.

### Risks of being involved:



You may find the interviews **tiring**.  
**This is common** after a stroke.

## Confidentiality

What you say is **anonymous**.

**I will not tell anyone** what you say. You **will not be identified** in research findings.

I will **give you a summary** of our discussions. You can **choose if you want to give this to anyone**. You don't have to.

Figure 65. Benefits and Risks section in the refined aphasia PIS prototype.



The third and newly designed prototype was created to reflect the need for a well-designed information sheet that does not have the added aphasia-friendly features. Bolded keywords and larger type size that are key features in information design for people with aphasia were removed. This additional prototype was designed with information design and typographic principles in mind to allow for universal accessibility. Features such as shorter sentences and simple language were kept to promote universal access and health literacy (Batterham et al., 2016; Nutbeam, 2008). A study by Paasche-Orlow et al. (2003) shows that ethics committees and Institutional Review Boards' (IRB's) own information provided for the informed consent process do not pass their own readability standards. Designing an accessible participant information sheet with information design features that promote health literacy is the best option for people with aphasia who may not find reading difficult, along with everyone in our society who may want to participate in research.



## Medical Records

I will ask you for permission to review your medical records that are at Rehab Plus.

These will give me information about:

- What happened
- The tests you have had since your stroke
- The treatment you are having with your therapists.



## Benefits and Risks

### Benefits for you:

You may find it helpful to talk about what is important to you.

This may help you identify goals to work on in therapy, or by yourself.

### Benefits for others:

You will help speech therapists learn more about what is important to people with aphasia.

### Risks of being involved:

You may find the interviews tiring. This is common after a stroke.

**Figure 66.** Universally accessible PIS prototype.





Figure 67. About the Research page in the Universally accessible PIS prototype.



## Guide to Designing Participant Information Sheets

After conducting the participant information sheet audit along with gathering feedback from participants with aphasia on the prototype participant information sheets created, it felt necessary to create a guide for designing participant information sheets for health and stroke researchers.

A big part of facilitating the involvement of people with aphasia in research is to enable researchers to create their own participant information sheets that are accessible and readable. A guide was created that outlines design recommendations to enhance the readability and accessibility for people with aphasia. These design recommendations were the design features and variables that were used in the design of the prototype participant information sheets, along with the features participants with aphasia found helpful or preferred.

Designers use a range of different programmes and software that is not easily accessible to the general public to create our design work. It was important that these design recommendations could be implemented in a programme that is easily accessible to researchers wanting to create participant information sheets. Consideration was put into the capabilities of the word processing software Microsoft Word and how

these design recommendations could be implemented into this program. Recommendations were created and re-phrased to best represent the corresponding tools or functions in Microsoft Word that would create the same or similar suggested effect.

● Contents

Typographic Hierarchy  
Page 6

Images  
Page 10

A4 Sheets or  
A5 Booklet size  
Page 7

Colour  
Page 9

White Space  
Page 8

## Interview Details



I will interview you **three times**.



Each interview will take between  
**45-90 minutes**.



There will be at least **one week**  
**between each interview**.



It may take **up to six weeks** to  
**complete** the three interviews.

You are welcome to have a **family/whānau member** at the interview if you wish.



You **do not** have to answer **all**  
**the questions**.



I would like to **tape** the interviews.



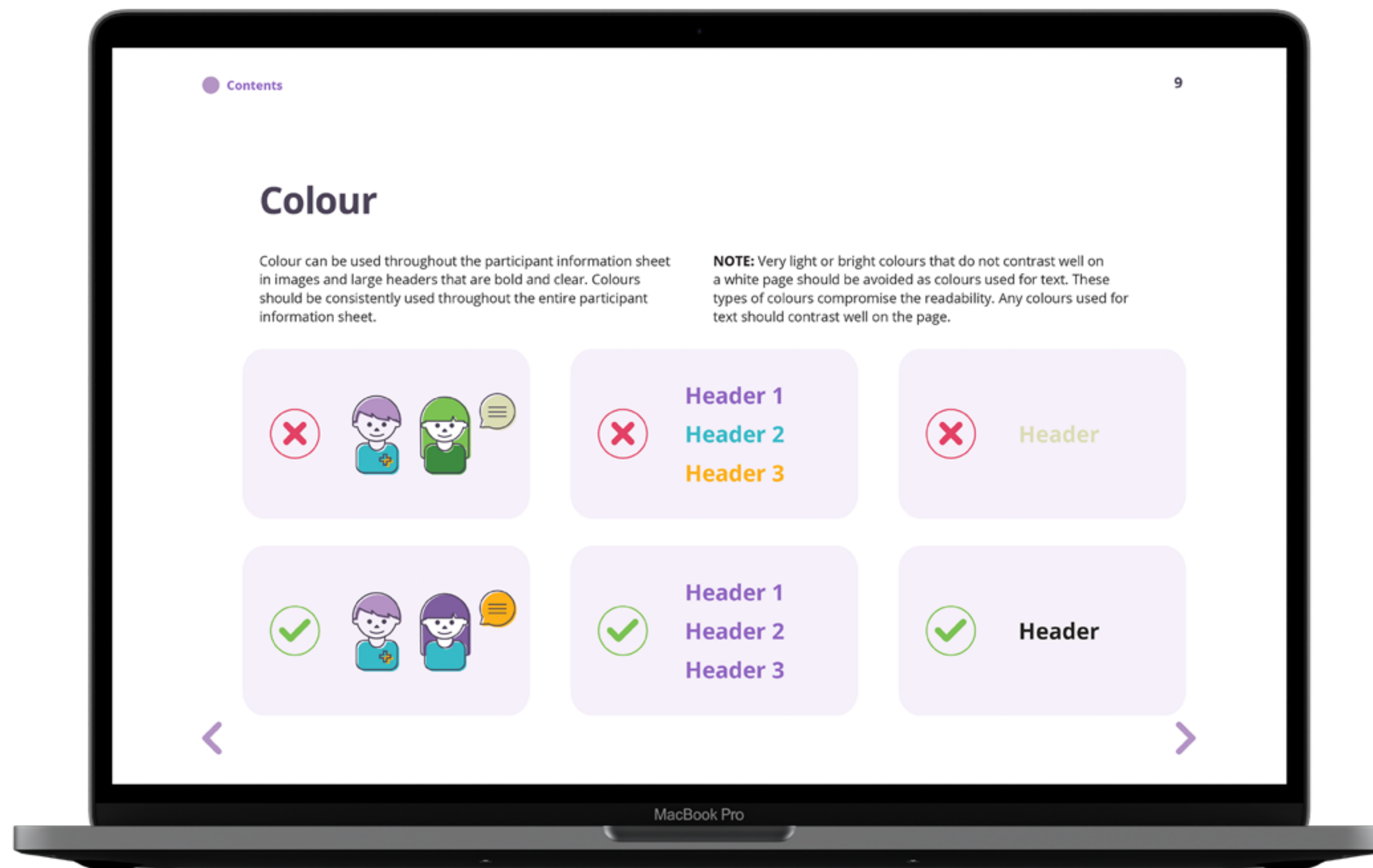
During the **first interview**, I will  
just use a **tape recorder**.

In the **second and third interviews**, I would like to  
use a **video recorder**. This is so I can record gesture  
and writing, as well as our voices.

I would like to **talk with you at the end of my**  
**study** to make sure my findings are correct. This  
would take about an hour. **This is optional**.

Short and  
Simplified Se  
Page 7

Figure 68. Contents page in the guide to assist researchers in creating participant information sheets.



**Figure 69.** Section on colour in the guide to assist researchers in creating participant information sheets.

# Discussion



## Key Insights

I set out on this research journey to explore how information design principles and typographic techniques could be used to create accessible participant information sheets for people with aphasia. Applying typographic principles from an information design perspective has not been explored deeply in the design of written information for people with aphasia. This perspective allows for participant information sheets to be designed alongside people with aphasia and to have their voices and feedback valued in the design process. This research evolved from simply designing participant information sheets to exploring how every instance of communication with participants with aphasia throughout the research process can be made more accommodating and accessible to their individual communication needs through design.

The literature showed that people with aphasia are often excluded from post-stroke research opportunities for reasons such as researcher perceptions of the language impairment, and the research not being designed to include those people with aphasia (Brady et al., 2013; Wray et al., 2018). These exclusions create generalisations in stroke research,

in addition to perpetuating health care and rehabilitation inequities for people with aphasia (Brady et al., 2013; Douglass & Ballantyne, 2019). There is an ongoing misconception that people with aphasia do not have the decision-making capacity to consent to take part in research (Brady et al., 2013; Kagan & Kimelman, 1995). This misconception can lead to stigmatisation and exclusions of an entire population which leads to barriers being perpetuated regarding their inclusion in research opportunities (Douglass & Ballantyne, 2019).

One of the first considerations I explored in this research was trying to find ways to communicate and gain useful feedback on the prototypes. This exploration evolved from the initial idea of sorting cards about the prototypes design features into creating visual prompts for the design variables that were being tested in the prototype participant information sheets. I ended up putting more time and consideration into these communication aids than the actual prototype participant information sheets. It was imperative I could communicate with participants with aphasia about a subject that they may have little knowledge about and could adequately take part in the conversation about a potentially unfamiliar topic.

Although I came into this research wanting to design accessible participant information sheets, all aspects of communication with participants with aphasia were explored, not just written communication.

The goal of re-designing participant information sheets was to facilitate the inclusion of people with aphasia in research through accessible well-designed adaptations that aid in the readability of written information. The interviews with people with aphasia revealed that when participant information sheets were modified according to suggestions in aphasia literature, including the use of large type sizes (Brady et al., 2013; Dalemans et al., 2009) and bolded keywords (Dalemans et al., 2009; Rose et al., 2011), they were not always preferred by people with aphasia. These adaptations were not seen as helpful by one of the participants in this study because their reading abilities and comprehension were not affected by them having aphasia. On the opposite end of the spectrum, the other participant found the participant information sheet easy to read compared to other reading materials she had tried, and did not have to use her 'tracking' strategy to read.

The first two participant information sheets presented to the participants with aphasia in this study (blue and purple prototypes) employed specific features that were shown in the aphasia literature to improve the comprehension of the content among people with aphasia. This was paired with information design and typographic principles. The third participant information sheet (information design prototype) was designed for increased accessibility and readability among the general population by implementing information design principles alone. Having two versions allowed participants whose aphasia presents differently to have the option of choosing which participant information sheet best fits their individual language needs.

There was no conclusive agreement on what type and style of images would work best in the participant information sheets for people with aphasia. Katherine was only exposed to the prototype that used icons as images, while Janet preferred the more detailed illustrations purely because they were colourful. Janet offered that she did not like the icons because they were all one colour, not because they were icons.

It has been shown that images are helpful and contribute to the understanding of the text for people with aphasia, no matter the style of the image used (Knollman-Porter et al., 2015; Rose et al., 2012; Wilson & Read, 2016). However, it has been discussed that icons do not work as well as illustrations or photographs when it comes to aiding the understanding of the text for people with aphasia as they often symbolise something other than what they are depicting (Dalemans et al., 2009; Herbert et al., 2019; Rose et al., 2012). In contrast, icons have been shown to be preferred by some with aphasia due to the familiarity of icons in everyday interface use, such as mobile and computer interfaces (Moys et al., 2018). It will remain uncertain without further research which image style is preferred by people with aphasia. What is clear is that images, even for someone who has no difficulty with reading like Janet, were not disregarded as a helpful feature of the participant information sheets.

These findings showed that there was a need for aphasia-friendly participant information sheets for those who may struggle with reading. They also showed that those with no reading difficulties did not necessarily appreciate some

aphasia-friendly modifications. This resulted in an additional designed information sheet that did not include some aphasia-friendly features, such as large type size and bolded keywords. A participant information sheet of this nature would additionally be of benefit to the general population.

It is hard to know for certain if having two versions of the participant information sheets will be beneficial for people with aphasia due to only having two participants to collect data from. However, this research showed that a user-centred, information design approach to the design of participant information sheets for people with aphasia was needed to facilitate their inclusion in research.

## Navigating a Healthcare Space as a Communication Designer

I was fortunate enough to be accepted into the aphasia healthcare space as a designer and an outsider with open arms. The stroke researcher who was interviewed expressed that the aphasia research community needed the help of a designer to create accessible and functional participant information sheets that were also well designed. The participants with aphasia I worked with were happy to engage with a designer. Katherine in particular expressed her gratitude for what I was doing to help the aphasia community through this research.

Being a designer in a healthcare space was not without its challenges. Recruitment of participants with aphasia was a challenge, but would not have been possible without having a supervisor involved in aphasia research reaching out to their connections. Recruitment seems to be a recurring challenge for designers, along with finding the right people to collaborate with on design for health projects (Nakarada-Kordic et al., 2021). It is imperative to have end-users involved in the testing of prototypes in a design for health project as they are an invaluable source of insights that progress the development of a design (Groeneveld et al., 2018). It is rare nowadays to see a designer create things that are of benefit to others in isolation.

These participatory approaches are needed to ensure designers are designing with the end-user and not for them in isolation (Sanders & Stappers, 2008).

Implementing their design outputs (such as the re-designed participant information sheets for people with aphasia to participate in research) into real-world scenarios is another challenge designers face in the healthcare space (Nakarada-Kordic et al., 2021). Once the outcome of this research is finalised, it is up to stroke researchers and healthcare professionals to apply these recommendations and ‘champion’ the design work that has been done to facilitate the involvement of people with aphasia. Unfortunately, this aspect is outside of a designer's control.

It was also a humbling experience to be able to witness the participants with aphasia being comfortable enough during interviews to express themselves emotionally. During an interview, Katherine teared up while describing her experience after having a stroke. I knew when taking on aphasia research that many people living with aphasia have had to endure challenges on their road to recovery.



Hearing about her experience was heart-wrenching yet touching; it was a privilege they chose to share with a stranger what they have been through and how they have overcome these challenges. It also made me reflect on how the researcher-participant dynamic is the one where the power balance of 'giving' and 'taking' is delicate and how exploitative research can be if it does not ultimately benefit the participant.

Throughout the design of the prototype participant information sheets, there was a need to strike the right balance between how the prototype looked and how it functions. I experienced some tension with how to navigate designing the participant information sheets to meet the needs of people with aphasia while keeping the design looking pleasant and beautiful. Having a functional and accessible outcome in the healthcare space is important to allow the end-users to effectively engage in making decisions about their own healthcare (van der Waarde, 2017). It was important that the participant information sheets facilitated the participation of people with aphasia, meet their language needs, and empowered them to make an informed decision.

## Overcoming Challenges in Research

Although I was accepted into this healthcare space as a designer, there were many challenges that came with working in this space – as a designer and a researcher. These challenges provided valuable learnings about the importance of designers being advocates for the people whose needs are being addressed through design solutions and of being flexible and adaptable when working with end-users to make sure those needs are met.

### Misconceptions Around Aphasia

The ethical application for this research was my first experience navigating a formal ethical application and of the challenge this process presents for many researchers. The biggest hurdle encountered as part of this process was the ethics committee advisor, and subsequently, the ethics committee themselves, questioning the ability of people with aphasia to consent and the vulnerability of the aphasic population as a whole. I was advised to quantify the ‘severity’ of the participants with aphasia’s abilities to communicate as part of the consent process. One of the suggestions was that I work with people who do not have aphasia as participants providing feedback on aphasia-friendly

prototypes to get around this perceived issue of consent. These initial comments were in direct contradiction to the Participatory Action Research methodology and a Human-centred framework my research was based on, that value the voices, experiences, and autonomy of people with aphasia (Giacomin, 2014; Rowe, 2020; Simpson, 2010). The comments seem to mirror the generalisations that are often being made about the aphasic population and their inability to consent to research participation (Pieper & Thomson, 2020). Similar generalisations were also evident from the interview with the stroke researcher who described how an ethics committee completely misunderstood what it means to have aphasia and how it affects a person's language abilities.

As encountered by researchers in the past (Pearl & Cruice, 2017), I also received other feedback from the ethics committee that once again reinforced the generalisations and stereotypes that people with aphasia may not be capable of independently participating in research. I was met with questioning about people with aphasia’s ability to use a pen and paper to write, comments that the data gathering sessions may be too long, and that people with aphasia need

to have their journey to the interview location mapped out for them. These comments show the assumption that people with aphasia are incapable of doing many ordinary tasks simply because they have aphasia. Many people with aphasia are capable of managing their own lives and day-to-day activities, prefer to maintain independence, and where needed, create strategies to navigate any difficulties that arise (Brown et al., 2012; Grohn et al., 2012; Worrall et al., 2011; Wray et al., 2019).

It has been advised in a recent New Zealand study that both researchers and ethics committees needed to acknowledge vulnerability in populations, such as people with aphasia, as “contextual and layered” to avoid generalisations, stigmatisation, and inaccurate labeling (Douglass & Ballantyne, 2019, p. 387). The ‘vulnerability’ as defined here of each individual with aphasia should be taken into account and managed appropriately (Douglass & Ballantyne, 2019). The two participants' aphasia in this research presented completely differently, and two different communication and data gathering strategies were employed to meet their individual needs to allow effective and inclusive participation. As stated by Luck and Rose: “By excluding people with aphasia from research, we are reinforcing barriers” (Luck & Rose, 2007,

p. 221). The types of comments I received from the ethics committee play a big part in these barriers still existing and the cycle of exclusion continuing for people with aphasia; they also prompt a question of whether it is the ethical process itself that contributes to the exclusion of people with aphasia.

### **Verbal Communication**

Communicating with people with aphasia verbally throughout the data gathering process involved constantly adapting and simplifying my language. This included speaking slower, pausing more often, pausing longer between sentences and different conversational topics, not using jargon, and speaking clearly and concisely (Dalemans et al., 2009). This was a challenge for me because I talk fast and tend to mumble my words often. It took a lot of practice and learning to adjust my speech. I was lucky to have a participant that was vocal when she needed me to slow down or repeat myself which turned out to be an extremely helpful learning experience. Being coached by my speech-and-language specialist supervisor also played a role in adjusting to these modes of communication. Having to do a phone interview with a person with aphasia was an unexpected and initially daunting challenge. This scenario amplified the importance of good verbal communication in the absence of visual cues. To accommodate a phone call, the structure of both interviews was changed to remove any questions or prompts that asked about visual materials.

### **Non-verbal Cues**

An unforeseen challenge was adapting to the unique communication needs of a person with aphasia in an online environment. A challenge I had when interviewing Janet over Zoom was my screen viewing setup. When first meeting Janet to obtain consent, I was missing some non-verbal cues and gestures that indicated she wanted to ask questions or say something further. This occurred when I was moving my head to the left to view my notes. It was imperative I took notice of these non-verbal cues as Janet's speech and word production were impacted by her aphasia. To remedy this, I adapted my screen set up to have one screen above the other. This allowed my head to stay stationary, and my eyes to flick up and down so I did not miss any non-verbal cues in the subsequent interviews. The inability to use non-verbal cues in the phone interview with Katherine meant that I had to pay close attention to my verbal communication and try and impart the details of the designs using words only.



### **Reading Abilities**

Another unforeseen challenge was having a participant with aphasia who did not have any difficulty reading. During the first interview with Janet, it was discovered that aphasia had not affected her reading abilities, leaving me slightly flustered mid-interview on how to proceed. Questions were rephrased to focus on what features Janet thought others with aphasia may benefit from having in the participant information sheets along with what would have made reading easier for her in the first three months post-stroke. The adaption of these questions was met with uncertainty as Janet only had her experiences to draw from.

During the design of this research, I made the assumption that, while most people with aphasia would have various different reading abilities and comprehension, most, if not all people with aphasia would have some form of reading difficulty. The literature backed my assumption with the abundance of studies on the design of written information for people with aphasia. I did not have any exclusion criteria for people whose reading abilities were not affected by their

aphasia. This is a consideration that needs to be taken into account to ensure those with aphasia who do have difficulty with reading can be included in the research process.

Even with this oversight, having a participant whose reading ability was not affected provided valuable insight that not everyone with aphasia need or appreciate adapted participant information sheets, including the use of bolded keywords and larger type size, which are both design recommendations that feature heavily in aphasia literature (Brady et al., 2013; Dalemans et al., 2009; Knollman-Porter et al., 2015; Rose et al., 2003, 2011, 2012; Wilson & Read, 2016). Her insight showed that there needs to be an alternative option to the adapted participant information sheets for people with aphasia that takes into account only information design approaches to readability and accessibility.

By contrast, Katherine had trouble with reading and often could not read by herself. The challenge upon discovering Katherine's reading ability was how to re-structure the second interview to accommodate for Katherine potentially not being able to read the contents of the prototypes, given the number

of reading materials in the participant package. So as not to cause additional stress, the decision was made to discard all materials in the prototype package and have Katherine only look at the purple prototype for feedback. Consequently, the interview structure was also changed to focus solely on giving feedback on the visual features in the prototypes. This allowed for first-impression feedback on the overall design without focusing on the content.

This challenge is a good example of the extent of flexibility and adaptability that is often required of design researchers, especially in the area of health, in order to accommodate the needs of participants in their research, to be able to produce truly human-centred solutions that cater for the end-user.

### **Digital Technology**

An unforeseen topic that came out of this research was the conversation around digital technology and its effects on this research, the design of participant information sheets, and the lives of participants with aphasia. With the ongoing effects of the pandemic, a digital participant information sheet and informed consent process were considered when data gathering shifted to the online environment. This idea was not pursued further due to the uncertainty and feasibility of engaging people with aphasia along with their communication and language needs in a completely digital and potentially unfamiliar space. Prototyping participant information sheets in a digital environment would have needed more time and resources than what was available for this research.

An oversight with digital technology was assuming that data gathering in an online environment was accessible to people with aphasia who expressed interest in taking part in this research. Katherine's interview was conducted over the phone due to her not having a computer, and therefore not having access to an email address or online video conferencing

platforms. Instead of a computer, Katherine uses her iPhone which has been optimised for her communication and reading needs to engage with digital technology. Digital access should be considered when conducting research in an online environment. It should be acknowledged that some people may not have access to digital technology that we take for granted or may choose not to engage with it because it does not work for them. As a consequence, such people will unintentionally be excluded from this type of research without such considerations.

## **COVID-19**

The COVID-19 pandemic and the nationwide lockdown that took place from August to December of 2021 affected every aspect of this research and how it was conducted. Every element of this research was postponed to some extent. Nonetheless, the time in lockdown was beneficial to the exploration and refinement of concepts, ideas, and prototypes that would be developed once restrictions were lifted. The biggest challenges of conducting research during a pandemic were:

### **Working Remotely**

Researching from home was a struggle at times and many aspects of the design process got pushed back or postponed, including the development of the participant information sheet prototypes. Being confined to the home, paired with the uncertainty of the pandemic lead to additional stress and anxiety about the progress of the research and everyday life. This time at home allowed me to be creative with what resources I had available to me to test ideas and concepts.

### **Data Gathering**

An amendment to the ethical application was needed in light of the ongoing lockdown restrictions that limited in-person data gathering. Additional options were needed to engage participants with aphasia in an online environment in the event in-person data gathering could not go ahead. This was very much a last-resort option as it was not ideal to engage with people with aphasia in an online environment that they may be unfamiliar with, along with navigating their individual language and communication needs. For example, it would have been beneficial to have been able to interview Janet (who had difficulty with word production and spoken language) in person to be able to pick up on her gestures and non-verbal cues, along with giving her the option to have a pen and paper to write down anything she needed to say when words failed her. In the online interviews, we resorted to utilising Zoom's chat function when necessary. In this situation, it would have been more equitable to engage in face-to-face interaction.



**Recruitment**

COVID-19 was a contributing factor in the breakdown of communication in the preliminary stages of recruitment during the pandemic. Before lockdown commenced, I planned to recruit through a community organisation for people with aphasia. Once the nationwide lockdown commenced, all communication from the organisation's end ceased which resulted in pursuing other recruitment avenues, such as rehabilitation centres.

**Scope**

Recruitment took longer than expected and data gathering with participants with aphasia did not take place until April and concluded in May. Having data collection conclude so late in the research added a lot of time pressure to produce the final designed outcomes.

The arrival of COVID-19 made the world reconsider how we live, work, and carry out our everyday lives in a pandemic.

The challenges I faced in the wake of COVID such as navigating a remote workspace and the feeling of anxiety would have been present for everyone. Ultimately, researchers will have to adapt to new ways of conducting research and may have to make greater use of technology from the onset of their research to be able to have better access to research participants.

## Limitations and Future Research Opportunities

### Participant recruitment

Due to difficulties with finding suitable avenues for recruitment and the restrictions on research imposed by the pandemic, only one expert was interviewed and two people with aphasia expressed interest and participated in this study. Talking to more experts who engage in stroke research about their experiences facilitating the inclusion of people with aphasia could help identify areas that impede their inclusion, and how information design can remedy this. Additionally, there were doubts throughout the research process that there would be anyone with aphasia expressing interest to take part, and I was delighted that two people were found. Although two participants are not enough to have any conclusive findings, the feedback provided on the prototypes was positive and the ease of reading of one participant due to the design 'intervention' demonstrated the potential good information design can have in assisting people with aphasia. With so few participants and the number of changes needed to accommodate each participant and their communication needs, the findings are indicative only and further research is needed to establish a set of typographic adaptations.

Participant demographics were not recorded as part of the recruitment process. With only two participants with aphasia involved in the research, it was not possible to aim for gender and cultural diversity. Future research should consider a larger pool of participants with varying reading and language difficulties to uncover further preferences and challenges that could be addressed through information design and typography that may not have been uncovered with only two participants. There is also an opportunity to diversify the participant pool by facilitating the inclusion of Māori and Pasifika populations with aphasia in research. Further efforts to diversify may uncover whether different genders and cultures have different preferences in the design of information.

### **Communication**

Not having any in-person interaction with participants with aphasia limited to an extent the quality of researcher-participant communication, with certain aspects potentially being missed in an online environment. Hand gestures and other non-verbal cues are important when conducting research with people with aphasia, and these are harder to pick up on in an online environment where only a participant's face and facial expressions are visible to the researcher (and vice versa). Phone interviews present further challenges in communication between the participant and researcher, because this mode relies solely on verbal communication. While the participant in the phone interview in this study was comfortable communicating verbally and was very vocal if they did not understand something that was said, or if I was talking too fast for them, this might have been an exception.

While adjustments were made in this research to accommodate for both an online and phone interview, future research might consider the communication abilities and locality of each participant in the recruitment stage to ensure the right mode of data gathering is used to accommodate their communication needs as best as possible.

### **Comprehension**

Although information design can be used to simplify information into its most basic form for the intended audience, this research did not cover the comprehension aspect of the information presented in the participant information sheets from a linguistic perspective. Elements such as the use of short sentences, and simplified language were implemented throughout all communication and resources in this research, but their effects were not analysed. Whilst one person reported improved readability, it is uncertain which individual design (or linguistic) features contributed specifically to this improvement. There is an opportunity to pair an information design and linguistic approach to improve and assess the comprehensibility of participant information sheets.

### **Multiple Approaches to Accessible Information**

One of the final outcomes of this research was two accessibly designed participant information sheets for people with aphasia. Having two versions of a participant information sheet available for use in research with people with aphasia would involve an expert assessment of the individual to determine which version best suits their reading and language needs. A speech-language therapist would be equipped with the knowledge and expertise to assess the reading ability and comprehension of someone with aphasia. A limitation to this is who would determine who receives each participant information sheet when there is no access to a speech-language therapist. In theory, having two participant information sheets is ideal for the accessibility needs of people with aphasia. Realistically, there may not be an expert available who can accurately assess each individual with aphasia who expresses interest in taking part in a study to determine their reading capabilities. The 'not a one-size-fits-all' finding of this research could also indicate that research with a larger and more diverse group of participants with aphasia is needed in this context.

### **Digital Technology**

Digital technology was an unexpected theme that came up as this research progressed in the wake of the pandemic. Aspects of digital technology such as digital data collection and the use of MIRO to create additional interview materials was utilised throughout this research. I came across the concept of digital informed consent or 'e-consent' for participants with aphasia but chose not to explore this option. This was due to the complexity of implementing design features that improve readability alongside how people with aphasia would navigate an unfamiliar digital environment within the research time-frame. With the world becoming more digital and research being conducted remotely, there is an opportunity to explore an e-consent process for people with aphasia. Digital participant information sheets in particular have the ability to provide information in a multi-media format that offers multiple means of receiving and comprehending information to suit each individual's language needs.



## **Conclusion**

Information design has the ability to impact and facilitate the overall informed consent experience by considering how information is designed and presented to people with aphasia from the recruitment stage to the signing of the consent form. These information design considerations can also be applied to materials that participants may interact with in the data gathering stages. There is an opportunity to build upon how information design can improve all forms of communication when engaging with people with aphasia in not only research, but in the presentation of health information, and rehabilitation tools.

This research has revealed that information design principles can be applied to general health resources and participant information sheets to improve the accessibility and readability of information for the general public. There is an opportunity for the design features outlined in this research to be applied to all health information to facilitate decision-making about one's own health.

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# Appendices

Appendix 1 - Ethics Application 21/279

AUT

TE HĀKAREWA Kōwhiri  
O Tāmaki Makāau Rau

**Auckland University of Technology Ethics Committee (AUTEC)**

Auckland University of Technology  
D-88, Private Bag 92006, Auckland 1142, NZ  
T: +64 9 921 9999 ext. 8316  
E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

8 September 2021

Ivana Nakarada-Kordic  
Faculty of Design and Creative Technologies

Dear Ivana

Re Ethics Application:     **21/279 Inclusive Design: Exploring Informed Consent for People with Aphasia**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 8 September 2024.

**Non-Standard Conditions of Approval**

1. If the interviews with experts using video conferencing then a revised consent process needs to be provided to AUTEC.

**Standard Conditions of Approval**

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz). The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat  
**Auckland University of Technology Ethics Committee**

Cc:     geenastanley@hotmail.com; cassandra.khoo@aut.ac.nz; felicity.bright@aut.ac.nz

AUT

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17 September 2021

Ivana Nakarada-Kordic  
Faculty of Design and Creative Technologies

Dear Ivana

Re: Ethics Application:     **21/279 Inclusive Design: Exploring Informed Consent for People with Aphasia**

Thank you for your request for approval of amendments to your ethics application.

The option for the interviews with the experts to be conducted online has been approved.

**Standard Conditions of Approval.**

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
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8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz). The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

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[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

14 December 2021

Ivana Nakarada-Kordic  
Faculty of Design and Creative Technologies

Dear Ivana

Re: Ethics Application:     **21/279 Inclusive Design: Exploring Informed Consent for People with Aphasia**

Thank you for sending through your responses to AUTEC’s conditions.

The amendment to the data collection protocol has been approved.

**Standard Conditions of Approval.**

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
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6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
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Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz). The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat  
**Auckland University of Technology Ethics Committee**

Cc:     geenastanley@hotmail.com; cassandra.khoo@aut.ac.nz; felicity.bright@aut.ac.nz

Appendix 2 - Aphasia Participant Information Sheet (to take part in this study)

AUT

Inclusive Design:

Exploring Accessible Informed Consent for People with Aphasia




Participant Information Booklet

for online interviews

April 2022

Introduction




My name is **Geena Stanley**. I am a **graphic designer** currently studying a Master of Design at Auckland University of Technology (AUT)

I would like to ask for your help in this research project that looks into **designing participant information sheets** (like this one) **for people with aphasia**.


This research includes taking part in **two online interviews**. During these sessions, we will ask how you **manage life and reading** with aphasia. You will also be **giving feedback** on information booklets.

What is the purpose of the research?


The **aim of this research** is to:



Create **accessible participant information sheets** for people with aphasia.



Make it **easier for researchers** to include people with aphasia in research projects.



Understand **what people with aphasia find hard** when reading information.

01

02

181

## Why am I being invited to take part?

You are being invited to take part because **you have aphasia**. (Rehabilitation center) has asked if you want to take part.

Your lived experience with aphasia is important to the making of participant information booklets.

You can take part in this research if you:



You have had a **stroke** and have **aphasia**.



**Speak English** as a first language



Are **living at home**

03

## What will happen in this research?

If you take part, you will have to **show consent**. You will be asked to give consent **verbally**. We will **record your voice**.

You will take part in **two online interviews** in a video call.

04

### Interview #1

The researcher will make sure you **understand what this research is about** and what you **have to do**.

The researcher will also **answer any questions** you have. The researcher will also ask about **your experiences with reading with aphasia**. This interview will take **an hour**.

05

This **interview** will cover topics such as:



Managing life and reading with aphasia.



Accessing written information.



Feedback on the design of this information booklet.

At the **end of the interview**, you will be **given**:



Two information booklets to review



Some questions to think about before the next interview



Information for the next interview

06

**Interview #2**

In this online interview we will ask for your **feedback** on **information booklets** you read.

We will **share your answers** to the questionnaire you were given. You will be asked to **talk more about your answers**.

You will also be asked to **do a small activity**. This activity is about the **order you want to read information**. This activity will help me **best order information** for people with aphasia.

This feedback interview will take **an hour and a half**.

**Where will these sessions take place?**

You can take part in the interviews from **any location**. You will need **a computer** and an **Internet connection**.

We will use a **video call** program like Zoom.

We will **send you a link** to join the online interview. This link will be **emailed to you**. You can **choose the day and time** to have the interviews.

We are happy to help you set up for the interviews.

**Things to note:**



The interview sessions will be **screen recorded**. Once notes have been taken from the recording, the **video will be deleted**.



The researcher will be **taking notes** during all sessions.



If you need **help communicating**, that's fine! Our **speech therapist** can help, or you can **bring family** to the interviews.



You do **not have to answer anything** that makes you uncomfortable.

**What are the benefits?**

I will benefit from this research by using the findings to complete my qualification. I also get to gain experience running a project that involves participants.

The information booklets I make will help people who do stroke research. I hope this will help them **include people with aphasia in their research**.

In return, I hope that you benefit from the opportunity of taking part in making information sheets better for people with aphasia.



## Are there any risks involved?

There are **no expected risks**. However I am aware that you may be more comfortable communicating with someone who you know nearby.

## How will these risks be managed?

To make you feel as comfortable as possible, you are welcome to **bring a support person**.

11

## How will my privacy be protected?

**You will not be identified in the research.** Any identifying details will be removed. You may choose a pseudonym (fake name) to represent yourself in the published research.

12

## Are there any costs involved?

**There will not be any costs.** You will be only asked for **approximately 2 and a half hours** of your time.



**Interview #1** will take **an hour**.



**Interview #2** will take **an hour and a half**.

13

## How do I take part in this research?

If you are interested in taking part in this research, you can contact **the researcher**:

**Geena Stanley**  
**Email:** [thp8675@autuni.ac.nz](mailto:thp8675@autuni.ac.nz)

Taking part in this research is **your choice**. Taking part will not advantage or disadvantage you in any way.

**You are able to leave the study at any time.** If you leave the study, you can choose to have any data that is yours removed, or have it used. **Once the findings have been made, removing your data may not be possible.**

14

## How do I accept this invitation?

You have **two weeks** to accept this invitation. If you are interested you have until **(dd/mm/yyyy)** to contact the researcher.

## What if I want to know the research results?

You can choose to receive a summary of the results and a final prototype of the information booklet. You do not have to receive the results if you do not want to.

15

16

## What if I have any concerns?

If you are concerned about the research, please contact **Ivana Nakarada-Kordic**. She is supervising this research. Her details are:

**Dr Ivana Nakarada-Kordic**  
ivana.nakarada-kordic@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, ethics@aut.ac.nz , (+649) 921 9999 ext 6038.

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## Who do I contact for more information?

### Researcher Contact Details:

Geena Stanley  
thp8675@autuni.ac.nz

### Project Supervisor(s)

Dr Ivana Nakarada-Kordic  
ivana.nk@aut.ac.nz

Dr Felicity Bright  
felicity.bright@aut.ac.nz  
09 921 9999 ext 7097

Cassandra Khoo  
cassandra.khoo@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 8 September 2021, AUTC Reference number 21/279

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Consent Form

AUT

**Inclusive Design: *Exploring Accessible Informed Consent for People with Aphasia***

**Project Supervisors:**  
Ivana Nakarada-Kordic, Felicity Bright & Cassandra Khoo

**Researcher:**  
Geena Stanley

- I have **read and understand** the information given about this research project in the Information Booklet dated (dd/mm/yyyy.)
- I have **been able to ask questions** about the research. The researcher has answered my questions.
- I understand that **notes will be taken** during the interviews. I will also be **screen recorded** and the audio **transcribed**.
- I understand that **taking part in this study is voluntary** (my choice) and that I **may stop taking part in the study at any time**. There will be no problems if I do not take part.

Page 1 of 2

Consent Form

AUT

- I understand that if I stop taking part in the study, I can choose between:  
  
Having my data **removed**.  
  
Having my data **continue to be used**.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): ☐ **Yes** ☐ **No**
- I wish to receive the prototype information booklets by...  
(please tick one below):  
  
☐ **Email** (digital) \_\_\_\_\_  
  
☐ **Address** (physical) \_\_\_\_\_  
\_\_\_\_\_

**Participant's name:** \_\_\_\_\_

**Participant's signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Note:** The Participant should retain a copy of this form.

Approved by the Auckland University of Technology Ethics Committee on 8 September 2021.  
Reference number 21/279

Page 2 of 2

**Appendix 4 - Aphasia Interview #1 Questions**

What has changed in your life now that you have aphasia?

What do you do differently now with aphasia?

**Prompts:**

- Life at home
- Going out
- Socialising
- Community work
- Something small that you liked to do every day

Do you read much since having aphasia?

- Why/why not?

Could you tell me what it is like to read now?

Since your stroke, have you found your reading has changed?

**Prompts:**

- Topics
- Types of material
- Do anything differently when reading

Is there anything you cannot read anymore?

- What is it?
- What makes (the thing that they cannot read) difficult to read?

**Prompts:**

- Difficult words
- Too many words grouped together
- Too long
- Not enough breaks between words
- The size of the words etc.

Have you stopped doing anything you would usually do because of any changes in your reading?

**Prompts:**

- Order at restaurants
- Don't do a certain activity
- Something you have changed to be able to read

Can you think of an example of something you can read or like to read?

Is there anything that makes it easier for you to read?

**Prompts:**

- Larger word size
- Short sentences
- Lots of space between areas of text
- Easy to understand words etc,

**Appendix 4** - Aphasia Interview #1 Questions

**Information sheet**

How did you find reading the information sheet online for this study?

How was it looking at file to read the information?

Was there any part of the information sheet that was hard to read?

- Why was that hard to read?

Was there a feature about the information sheet you liked the most?

- Why is that?

If you could change one thing on the information sheet for this study, what would you change?



**Appendix 5** - Aphasia Interview #2 Questions

**Introductory questions**

Were there any problems with the items in the pack?

Was there anything in the package that you felt was not needed?

Was there anything that was confusing in the package?

Did you have any questions about anything in the package?

**Prototype Feedback**

Is there one booklet you like more than the other?

- Why is that?

**Paper Size**

What size booklet did you like the most?

- Why is that?

Would you like to see a different size used Instead? E.g. the in between size

**Arrangement**

Do you like how the information is placed on the pages in one booklet more than another?

- Why is that?

Is there anywhere in the booklets you would add more or less blank space?

Do you think others with aphasia would like a lot of space in the information booklets?

Is one booklet easier to find your way through than the other?

**Prompts:**

- Headings
- Starting a new section on a new page

Are there any sections that are hard to follow along with in booklets?

- Tell me about these area(s).

Do you think others with aphasia might find any sections hard to follow along?

Does the number of pages there matter to you? Why/why not?

How many pages would you like to see in the information booklets?

**Appendix 5** - Aphasia Interview #2 Questions

**Colour**

What did you think of the colour choices in each booklet?

Do you like the colour choices in one booklet more than another?

Is having colour on a page something you want when reading?

- Why/why not?

**Pictures**

Did you like one set of pictures or icons more than another?

- Why is that?

Do you think the pictures would help others with aphasia understand the text better?

- If so, do you think the pictures or the icons would help understanding more?

If you could choose any picture style to have in the booklets, what would it be?

**Prompts:**

- (It can be the ones in the booklets already or something like photographs, or more detailed drawings.)
- Or would you like to have no images?

**Order of Information**

Can you tell me about why you ordered the headings this way?

**Questions for Katherine**

Can you tell me which one of these is the most important to know about:

- What this research is about
- What will I be doing in the research
- What are the risks and benefits
- How is my privacy protected
- Who can I contact for more information

Which one of these titles is the least important to know about?

**Wrap up Questions**

Have one last look at the prompts on the sheet in front of you. Which prompt is the most important to have in an information booklet?

- Why is that?

Which prompt is not important to have in an information booklet?

- Why is that?

**Appendix 6** - Expert Interview Questions

**Inclusion of people with aphasia and ethics**

Tell me about what you do and what type of research you conduct with people with aphasia/ people with communication impairments?

What are the core principles you consider when designing research processes for people with aphasia? / What are the core principles that you consider when seeking informed consent with people with aphasia?

What is the overall process like obtaining ethical approvals when conducting research with people with aphasia?

Are there any misconceptions people have about aphasia or people with aphasia and do they arise when gaining ethical approvals?

Can you elaborate on what areas when gaining ethics approvals are, from your experience the hardest to navigate? Why do you think that is?

How different/what differences are there in gaining ethical approvals for other post-stroke populations that do not have a communication impairment compared to those that do?

What do you see as particular challenges that are unique to people with aphasia when engaging with ethics committees for research involving them?

In your expert opinion, do you think there needs to be change to allow further inclusion of people with aphasia in research and what change would you like to see happen?

What is your opinion on the term ‘vulnerability’ or ‘vulnerable’ and its use to define all people with aphasia in research and ethical considerations?

**Appendix 6** - Expert Interview Questions

**Adaptation of PIS**

Do you use information sheets and related materials that are adapted to be aphasia friendly when conducting aphasia or stroke research?

From your experience, do you find that aphasia friendly information sheets are routinely adapted in stroke research in general or could more be done? (do you have any suggestions on what could help make them more commonplace?)

What are the core features or changes that you use or think are important when creating participant information sheets that are aphasia friendly?

What other features or adaptations do you regularly use in the overall informed consent process when engaging with people with aphasia?

Have you run into any challenges addressing the needs of people with aphasia when creating participant information sheets?

Thinking of the adapted information sheets you use, do you have any reflections on the unintended consequences of these designs (and how do you balance these consequences?)

What feedback have you had from previous research participants with aphasia on the information sheets they received?

If you could recommend one important feature when creating aphasia friendly PIS to focus on, what would it be?

**Wrap up & final questions**

Was there anything you wanted to add or any questions for me?

Are there any other questions you think I should ask or any further insights and perspectives that you wish to share?



Appendix 7 - Inaccessibility Zine





**vulnerable.**

As a default position, researchers should take all people, regardless of disability, as having the capacity to provide informed consent.

Researchers  
should not  
exclude  
participants  
from research  
simply because  
they may be  
**vulnerable.**

People who have diminished capacity to make decisions about their participation in a study

are entitled to make informed decisions to the extent that their level of capacity allows.

***It should  
be noted  
that almost  
any person,  
with the  
right  
support, is  
capable of  
providing***

***informed  
consent.***

***inequity***





Researchers should ensure that  
people are *equally eligible to*  
*participate,*

**REGARDLESS**

of their disability or any other aspect of their identity.

if the individual is unable to read  
or write, using verbal or alternative  
methods of communication to  
convey information and record  
informed consent

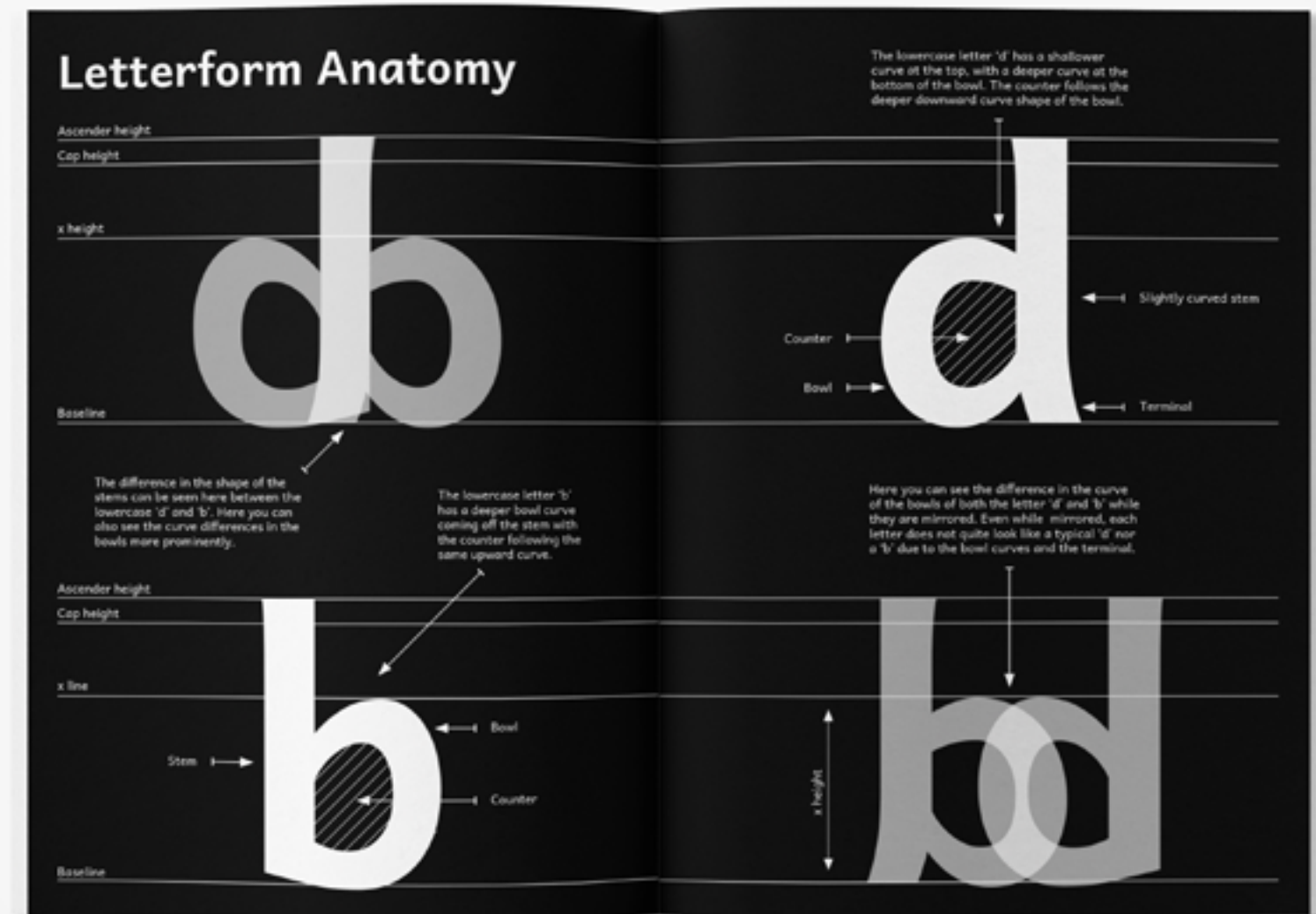


Appendix 8 - Typeface Audit



Selected spreads were chosen to showcase the typeface audit.





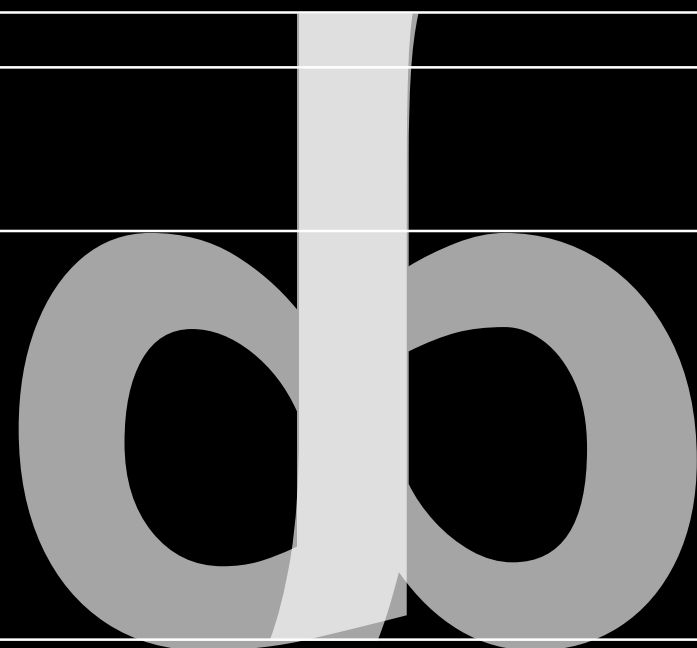
# Letterform Anatomy

Ascender height

Cap height

x height

Baseline



The difference in the shape of the stems can be seen here between the lowercase 'd' and 'b'. Here you can also see the curve differences in the bowls more prominently.

The lowercase letter 'b' has a deeper bowl curve coming off the stem with the counter following the same upward curve.

Ascender height

Cap height

x line

Baseline

Stem

Bowl

Counter



The lowercase letter 'd' has a shallower curve at the top, with a deeper curve at the bottom of the bowl. The counter follows the deeper downward curve shape of the bowl.

Counter

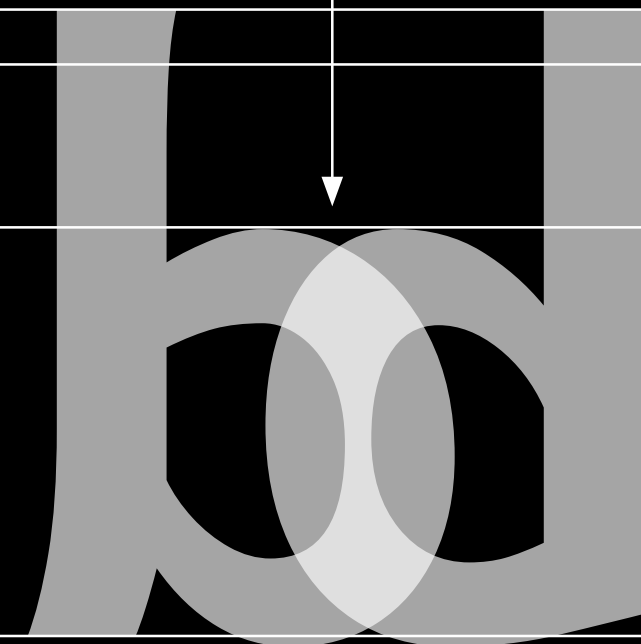
Bowl

Slightly curved stem

Terminal

Here you can see the difference in the curve of the bowls of both the letter 'd' and 'b' while they are mirrored. Even while mirrored, each letter does not quite look like a typical 'd' nor a 'b' due to the bowl curves and the terminal.

x height



# Verdana

Created for Microsoft Corporation by Matthew Carter

The Verdana typeface family was designed by Matthew Carter for Microsoft Corporation and published on July 8, 1996. The typeface consists of four TrueType fonts (digital font technology designed by Apple Computer) created specifically to address the challenges of on-screen display.

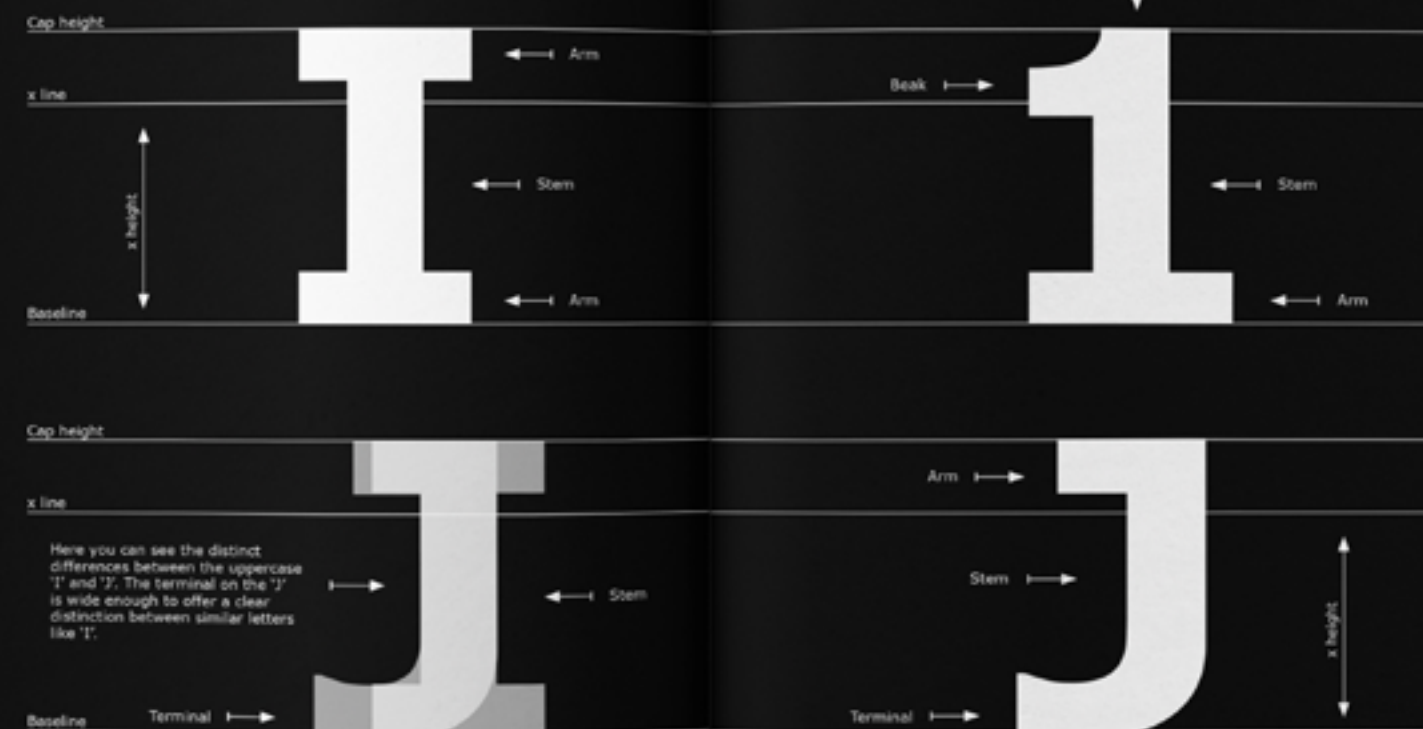
The Verdana typeface family exhibit characteristics derived from the pixel rather than the pen, the brush or the chisel. The relationship between straight, curved and diagonal strokes has been developed to ensure that the pixel patterns at small sizes are pleasing, clear and legible. Commonly confused characters such as the lowercase *i* *j* *l*, the uppercase *I* *K* *L* and the numeral *1* have been carefully drawn for maximum distinctiveness – an important characteristic of fonts designed for on-screen use. The various weights in the typeface family have been designed to create sufficient contrast from one another ensuring, for example, that the bold font is heavy enough even at sizes as small as 8 psem (pixels per em).

The generous width and spacing of Verdana's characters is key to the legibility of these fonts on the screen. The limited number of pixels available at low resolutions means that tightly set characters can easily clash; turning an *r* *n* into an *m*, or creating distracting black patches in a word. In on-screen typography, it's important to keep the characters distinct from one another, and research has shown that wider letterspacing significantly aids reading from the screen.

Text retrieved from:  
<https://docs.microsoft.com/en-us/Typography/Font-list/verdana#main>

## Letterform Anatomy

It is common for the capitalised letter 'I' and the number '1' to be mistaken at glance. The beak on the number '1' is emphasised to avoid misreadings.



# Adobe Garamond

Created for Adobe by Robert Slimbach

The Adobe Garamond™ font family is based upon the typefaces first created by the famed French printer Claude Garamond in the sixteenth century. This serif face was created by Robert Slimbach and released by Adobe in 1989; its italics are influenced by the designs of Garamond's assistant, Robert Granjon.

The renowned Parisian printer Claude Garamond was a driving force behind typeface creation during the Renaissance period in the sixteenth century. His most famous (and inspirational) typeface was cut early in his career for the French court – specifically King Francis I – and was based on the handwriting of the king's librarian, Angelo Vergcio. The earliest use of that font was in the production of a series of books by Robert Estienne.

The Adobe Garamond design is considered one of the most versatile fonts available today and certainly one of the most attractive and graceful in print. It is also one of the most eco friendly types to print because the letterforms use less ink than other similar faces. The Adobe Garamond font family has been widely used, including the instantly recognizable Google logo. Many very famous books have been set in Adobe Garamond; the Dr. Seuss range of books and the legendary Harry Potter volumes are just two examples.

Text retrieved from:  
<https://www.fonts.com/font/adobe/adobe-garamond/story>

Font Styles

Adobe Garamond Regular

*Adobe Garamond Italic*

Adobe Garamond Semibold

*Adobe Garamond Semibold Italic*

Adobe Garamond Bold

*Adobe Garamond Bold Italic*

Aa  
Aa  
Aa

Adobe Garamond Bold - Uppercase

ABCDEFGHIJKLM  
NOPQRSTUVWXYZ

ABCDEFGHIJKLMNOPQRSTUVWXYZ  
abcdefghijklmnopqrstuvwxyz  
0123456789;“?!”@/“%\$”#(

Adobe Garamond Bold Italic - Lowercase

*abcdefghijklmnop  
qrstuvwxyz*

ABCDEFGHIJKLMNOPQRSTUVWXYZ  
abcdefghijklmnopqrstuvwxyz  
0123456789;“?!”@/“%\$”#(

ABCDEFGHIJKLMNOPQRSTUVWXYZ  
abcdefghijklmnopqrstuvwxyz  
0123456789;“?!”@/“%\$”#(







AUT



## Participant Information Sheet

The hopes and priorities of people  
with aphasia following stroke in the  
postacute rehabilitation period.

The hopes and  
priorities of people  
with aphasia\* following  
stroke in the postacute\*  
rehabilitation period.

\* **Aphasia**  
Language difficulty

\* **Postacute**  
After hospital

## About the Researcher



My name is **Felicity Bright**. I am a **speech and language therapist**.

I work as a researcher at AUT. I am doing my **Masters degree** at AUT.

## My two supervisors are Jane Doe and Sarah Smith



**Jane** is a **health psychologist**. She works as a **researcher** at AUT.



**Sarah** is a **speech and language therapist**. She is a **lecturer** at the **University of Auckland**.

## Our Contact Details

### Felicity Bright



921-9999 ext 7097



**felicity.bright@aut.ac.nz**

### Jane Doe



912-3456 ext 7890



**janedoe@aut.ac.nz**

### Sarah Smith



987-6543 ext 2100



**sarahsmith@aut.ac.nz**

## What is this Research About?

Kia Ora,



You are invited to **take part** in a **research project**. We are doing research into **what is important to people with aphasia**.

**You can choose** if you want to take part in the research. **It is your choice**. If you decide to not take part, this **will not affect your therapy** at Rehab Plus.

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet will give you **information about the study**. It may **help you decide** if you would like to take part. Please **tell us** if it is **difficult to understand**, or if you have any **questions**.

## Purpose of the Study

We are trying to find out **what is important** to people with aphasia.

I would like to **interview you** and talk about your **hopes and priorities** for **your therapy, your recovery and your future**.

Research tells us **what is important** to people who had their **stroke a long time ago**.

We **don't know** what is important to people who had their **stroke recently**.

Interview Details



I will interview you **three times**.



Each interview will take between **45-90 minutes**.



There will be at least **one week** between each interview.



It may take **up to six weeks** to complete the three interviews.

You are welcome to have a **family/whānau member** at the interview if you wish.



You **do not** have to **answer all** the questions.



I would like to **tape the interviews**.



During the **first interview**, I will just use a **tape recorder**.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional**.

Participant Selection



Up to **six people** with aphasia will be **interviewed**.



People are **eligible** if they are receiving **speech therapy** at **Rehab Plus** Outpatients.

Interview Location

The **interview** can take place where you choose. It might be:



Your home



Rehab Plus



AUT

Or you can have the interview somewhere else.

If it **costs** you to **get to the interview**, I will **reimburse you**.

**Please note:**

The interviews are **not speech therapy**.

This study **will not help your communication**.

You will **still have your speech therapy at Rehab Plus**.

**Stopping the Study**

You can **withdraw** from the study **at any time** during the interviews.

If you have **finished all the interviews**, you can **completely withdraw** from the study. This needs to happen **before data analysis starts** (about July 2010).

**Medical Records**

I will ask you for **permission** to review your **medical records that are at Rehab Plus**.

These will give me **information about**:



What happened



The **tests you have had** since your stroke



The **treatment you are having** with your therapists

**Confidentiality**

What you say is **anonymous**.

I **will not tell anyone** what you say. You **will not be identified** in research findings.

I will **give you a summary** of our discussions. You can **choose if you want to give this to anyone**. You don't have to.

Your information will be **securely locked**. The audiotape and videotape **recordings** will be **destroyed at the end of the study**.

The **transcriptions** of the interviews will be **destroyed after 10 years**.

I can give you a **copy of the results** if you want. These will be **available in 2011**.

**Benefits & Risks**

**Benefits for you:**



You **may** find it **helpful to talk about what is important** to you.



This **may help** you **identify goals to work on** in therapy, or by yourself.



**Benefits for others:**



You will **help speech therapists** learn more about what is important to people with aphasia.

**Risks of being involved:**



You may find the interviews **tiring**. **This is common** after a stroke.

**More Information**

If you want **more information**, contact **Felicity Bright**. Your speech therapist can do this for you if you want.

**Your Rights as a Participant**

You can contact a **Health and Disability Advocate**:

 **0800 555 050**


 **advocacy@hdc.org.nz**

They can give you **information on compensation** for physical injury.

**Māori Cultural Support Team**

The Māori Cultural Support Teams are able to be contacted should you want their support:

Auckland District Health Board (DHB):

 **09 307 4949**

Counties Manukau District Health Board:

 **09 276 0044 ext 8138**

**Ethics Approval**

This study has been approved by the Northern Y Health Ethics Committee.

**District Health Board (DHB)  
Research Approval**

This study has been approved by the Auckland District Health Board and Counties Manukau District Health Board.

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ity Bright. I am a speech and  
pist.

archer at AUT. I am doing my  
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ane Doe and Sarah Smith

alth psychologist. She works as a  
r at AUT.

s a speech and language therapist. She is a  
er at the University of Auckland.

etails



felicity.bright@aut.ac.nz

Jane Doe



912 3456 ext 7890



janedoe@aut.ac.nz

Sarah Smith



987 6543 ext 2100



sarahsmith@aut.ac.nz



AUT

B

## Participant Information Sheet

The hopes and priorities of people  
with aphasia following stroke in the  
postacute rehabilitation period.

The hopes and  
priorities of people  
with aphasia<sup>\*</sup> following  
stroke in the postacute<sup>\*</sup>  
rehabilitation period.

<sup>\*</sup> **Aphasia**  
Language difficulty

<sup>\*</sup> **Postacute**  
After hospital

## About the Researcher



My name is **Felicity Bright**. I am a **speech and language therapist**.

I work as a researcher at AUT. I am doing my **Masters degree** at AUT.

My two **supervisors** are **Jane Doe** and **Sarah Smith**



Jane is a **health psychologist**. She works as a **researcher** at AUT.



Sarah is a **speech and language therapist**. She is a **lecturer** at the **University of Auckland**.

## Our Contact Details

### Felicity Bright



921 9999 ext 7097



felicity.bright@aut.ac.nz

### Jane Doe



912 3456 ext 7890



janedoe@aut.ac.nz

### Sarah Smith



987 6543 ext 2100



sarahsmith@aut.ac.nz



4

5

## What is this research about?

Kia Ora,

You are invited to **take part** in a research project. We are doing research into **what is important** to people with aphasia.

**You can choose** if you want to take part in the research. **It is your choice**. If you decide to not take part, this **will not affect your therapy** at Rehab Plus.

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet will give you **information about the study**. It may **help you decide** if you would like to take part. Please **tell us** if it is **difficult to understand**, or if you have any **questions**.



## Purpose of the Study

We are trying to find out **what is important** to people with aphasia. I would like to **interview you** and talk about your **hopes and priorities** for **your therapy, your recovery and your future**.

6

Research tells us **what is important** to people who had their **stroke a long time ago**. We **don't know what is important** to people who had their **stroke recently**.

## Interview Details



I will interview you **three times**.

**Each interview** will take between **45-90 minutes**.

There will be at least **one week** between each interview.

7



It may take **up to six weeks to complete** the three interviews.

You **do not** have to **answer all the questions**.

I would like to **tape the interviews**.

During the **first interview**, I will just use a **tape recorder**.

You are welcome to have a **family/whānau member** at the interview if you wish.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional**.

Participant Selection

Up to **six people** with aphasia will be **interviewed**.

People are **eligible** if they are receiving **speech therapy** at **Rehab Plus** Outpatients.

Interview Location

The **interview can take place where you choose**. It might be:



Or you can have the interview somewhere else.

If it **costs** you to **get to the interview**, I will **reimburse you**.

Please note:

The interviews are **not speech therapy**.

This study **will not help your communication**.

You will **still have** your **speech therapy** at **Rehab Plus**.

Stopping the Study

You can **withdraw** from the study **at any time** during the interviews.

If you have **finished all the interviews**, you can **completely withdraw** from the study. This needs to happen **before data analysis starts** (about July 2010).

Medical Records

I will ask you for **permission** to review your **medical records** that are at **Rehab Plus**.

These will give me **information about**:

What happened

The **tests you have had** since your stroke

The **treatment you are having** with your therapists.



Confidentiality

What you say is **anonymous**.

I **will not tell anyone** what you say. You **will not be identified** in research findings.

I will **give you a summary** of our discussions. You can **choose if you want to give this to anyone**. You don't have to.

Your information will be **securely locked**. The audiotape and videotape **recordings** will be **destroyed at the end of the study**.

The **transcriptions** of the interviews will be **destroyed after 10 years**.

I can give you a **copy of the results** if you want. These will be **available in 2011**.



Benefits and Risks

Benefits for you:

You **may** find it **helpful to talk about what is important** to you.

This **may help** you **identify goals to work on** in therapy, or by yourself.

**Benefits for others:**

You will **help speech therapists** learn more about what is important to people with aphasia.

**Risks of being involved**

There **should not be any risk** to you.

You may find the interviews **tiring. This is common** after a stroke.

If you are tired, we **can take a break**. Or, we can **finish the interview another day**.

**More Information**

If you want **more information**, contact **Felicity Bright**. Your speech therapist can do this for you if you want.

**Your Rights as a Participant**

You can contact a **Health and Disability Advocate**:



0800 555 050



advocacy@hdc.org.nz

They can give you **information on compensation** for physical injury.

**Māori Cultural Support Team**

The Māori Cultural Support Teams are able to be contacted should you want their support:

Auckland District Health Board (DHB):



09 307 4949

Counties Manukau District Health Board:



09 276 0044 ext 8138



**Ethics Approval**

This study has been approved by the Northern Y Health Ethics Committee.

**District Health Board (DHB) Research Approval**

This study has been approved by the Auckland District Health Board and Counties Manukau District Health Board.



ics

ks about **who** approved the  
**study** and **when** it was approved.

### About the Researcher

Talks about the researcher  
and the study.

What is this  
research about?

Talks about the study and  
why it is happening.

What is this  
research about?

Talks about the study and  
why it is happening.

## Medical Records

Explains that the researcher  
will **need to see your**  
**medical records.**

## More Information

Has details of other people  
you can contact.

Purpose of the  
study

Talks about  
the study and  
why it is happening.

## Benefits and Risks

Explains if there are any  
**benefits or risks** in the study.

## Interview Details

Explains what will happen  
in the interviews.



# Order of Information

Place the cards in the order you want to see them in the information sheets:

1.

**What is this research about?**  
Talks about the study and why it is happening.

2.

**Purpose of the Study**  
Talks about why the study is happening.

3.

4.

5.

6.

7.

8.

**Medical Records**  
Explains that the researcher will need to see your medical records.

9.

**Ethics**  
Talks about the study's ethical approval.



# Order of Information

For this activity, you will be **ordering headings**.

You will **order the headings** from 1 to 9. Number 1 is the **information you want first**. Number 9 is the **information you want last**.

You can order the headings **off the prototype you like the best**. Or, you can **order the headings in any way you like!**

This activity will help me **best order information** for people with aphasia.

Please **open** to do the activity.

## Ethics

Talks about **who approved the study** and **when it was approved**.

## What is this research about?

Talks **about the study** and **why it is happening**.

## Benefits and Risks

Explains if there are **any benefits or risks** in the study.

# Order of Information

Place the cards in **the order you want to see them** in the information sheets:

1.	<div></div>	6.	<div></div>
2.	<div></div>	7.	<div></div>
3.	<div></div>	8.	<div></div>
4.	<div></div>	9.	<div></div>
5.	<div></div>		

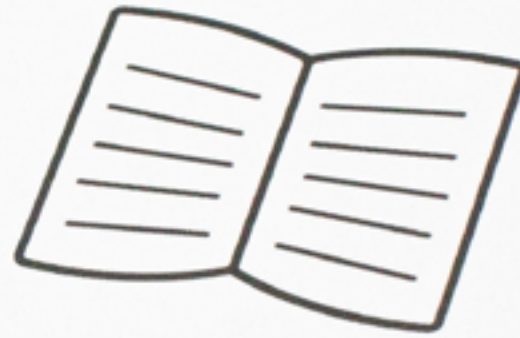
# What is in this package?

1

This package has **some things** for you to look

You will need to look at everything **before** the **se**

**In this package there is:**



**Two information sheets** for  
**giving feedback** on them in



A page of **visual prompts**. This  
**about information sheets** in



A **questionnaire**. Please

fill this out **after**

# What is in this package?<sup>1</sup>

This package has **some things for you to look at!**

You will need to look at everything **before** the **second interview**.

In this package there is:



**Two information sheets** for you to look at. You will be **giving feedback** on them in the **second interview**.



A page of **visual prompts**. This page will help you **talk about information sheets** in the interview.



A **questionnaire**. Please fill this out **after reading the information sheets**.



An activity about **ordering information**. This activity has a **fold out page** and **cards**. You will **order the cards**.

Turn over page →

# Contact Details<sup>2</sup>

If you have any **questions**, please **contact me**.

**Geena Stanley** (Researcher)



thp8675@autuni.ac.nz



**REDACTED**



# Talking about the information sheets

1

the second interview, you will be asked what you think about the information sheets.

may be **hard** to think of **feedback** for the information sheets.

**help** you talk about the information sheets, some **prompts** have been made.

will **ask** you **questions** about these prompts.

may ask **other questions** that are **not** about the prompts.

if you **do not** understand a prompt. We can explain it **in** the interview.

## Question Prompts

I will ask questions about:





1

# Talking about the information sheets

In the **second interview**, you will be asked **what you think** about the **two information sheets**.

It may be **hard** to think of **feedback for the information sheets**.

To **help you talk about the information sheets**, some **prompts** have been made.

We will ask you **questions about these prompts**.

We may ask **other questions** that are **not about the prompts**.

It is okay if you **do not understand a prompt**. We can explain it **in the interview**.

Turn over page →

2

# Question Prompts

I will ask **questions** about:

Paper Size



Colour



Image Style



Which layout do you like better?



# Information Booklet Questionnaire

Below are questions about the information booklet.  
Answer what you can!

What is the purpose of the research?

What things might you be asked about?

Turn over page →

## Information Booklet Questionnaire

What makes you eligible to take part?

What worries you about taking part?

1

# Information Booklet Questionnaire

Below are **questions** about the **information booklet**.

**Answer what you can!**

What is the **purpose** of the research?



What things might **you be asked about**?

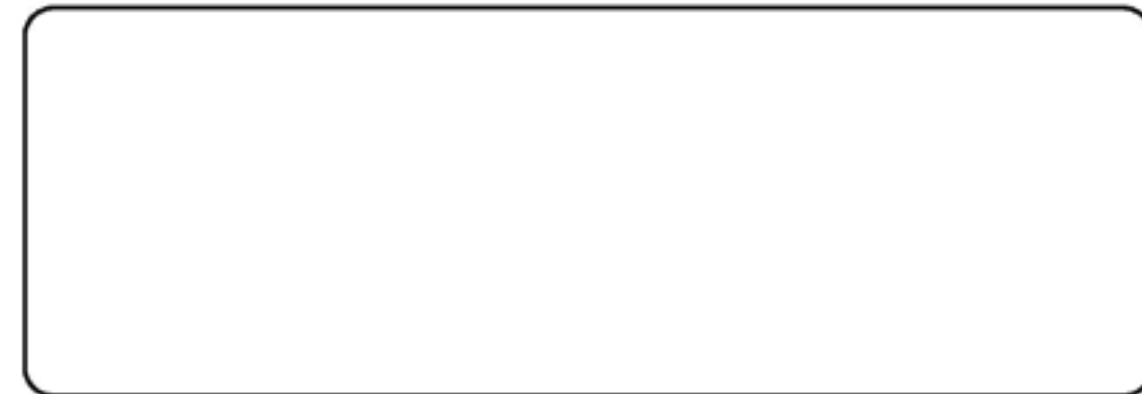


Turn over page →

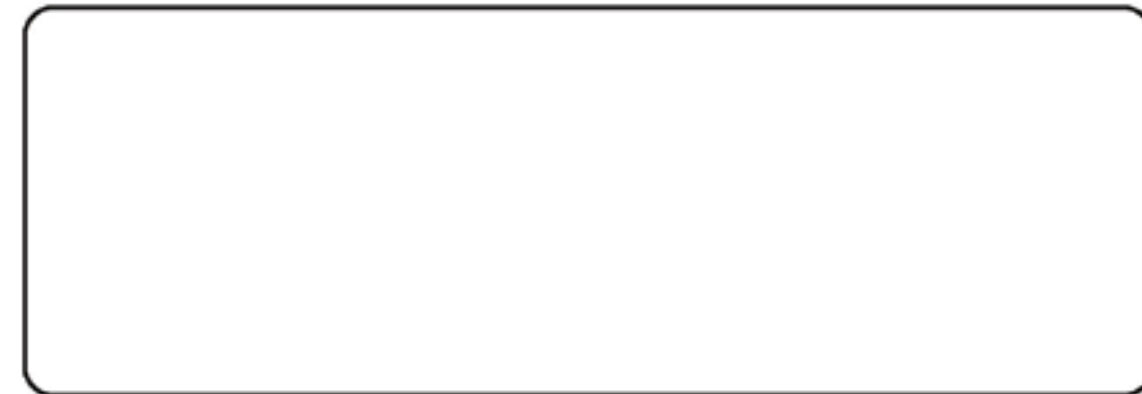
2

# Information Booklet Questionnaire

What makes you **eligible to take part**?



What **worries you** about taking part?



AUT

Participant Information Sheet

The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.

The hopes and priorities of people with aphasia\* following stroke in the postacute\* rehabilitation period.

\* Aphasia

Language difficulty

\* Postacute

After hospital

3



What is this Research About?



You are invited to **take part** in a **research project**. We are doing research into **what is important to people with aphasia**.

**You can choose** if you want to take part in the research. **It is your choice**. If you decide to not take part, this **will not affect your therapy** at Rehab Plus.

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet will give you **information about the study**. It may **help you decide** if you would like to take part. Please **tell us** if it is **difficult to understand**, or if you have any **questions**.

Purpose of the Study

We are trying to find out **what is important** to people with aphasia.

I would like to **interview you** and talk about your **hopes and priorities** for **your therapy, your recovery and your future**.

Research tells us **what is important** to people who had their **stroke a long time ago**.

We **don't know what is important** to people who had their **stroke recently**.

About the Researcher



My name is **Felicity Bright**. I am a **speech and language therapist**.

I work as a researcher at AUT. I am doing my **Masters degree** at AUT.

My two supervisors are Jane Doe and Sarah Smith



**Jane** is a **health psychologist**. She works as a **researcher** at **AUT**.



**Sarah** is a **speech and language therapist**. She is a **lecturer** at the **University of Auckland**.


Our Contact Details


Felicity Bright

 **921-9999 ext 7097**


 **felicity.bright@aut.ac.nz**


Jane Doe

 **912-3456 ext 7890**

 **janedoe@aut.ac.nz**

Sarah Smith

 **987-6543 ext 2100**

 **sarahsmith@aut.ac.nz**

Interview Details



I will interview you **three times**.



Each interview will take between **45-90 minutes**.



There will be at least **one week between each interview**.



It may take **up to six weeks to complete** the three interviews.

You are welcome to have a **family/whānau member** at the interview if you wish.



You **do not** have to **answer all the questions**.



I would like to **tape the interviews**.



During the **first interview**, I will just use a **tape recorder**.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional**.

Participant Selection



Up to **six people** with aphasia will be **interviewed**.



People are **eligible** if they are receiving **speech therapy** at **Rehab Plus** Outpatients.

Interview Location

The **interview** can take place where you choose. It might be:



**Your home**



**Rehab Plus**



**AUT**

Or you can have the interview somewhere else.

If it **costs** you to **get to the interview**, I will **reimburse you**.

**Please note:**

The interviews are **not speech therapy**.

This study **will not help your communication**.

You will **still have** your **speech therapy** at **Rehab Plus**.

**Stopping the Study**

You can **withdraw** from the study **at any time** during the interviews.

If you have **finished all the interviews**, you can **completely withdraw** from the study. This needs to happen **before data analysis starts** (about July 2010).

**Medical Records**

I will ask you for **permission** to review your **medical records that are at Rehab Plus**.

These will give me **information about**:



What happened



The **tests you have had** since your stroke



The **treatment you are having** with your therapists

**Benefits & Risks**

**Benefits for you:**



You **may** find it **helpful to talk about what is important** to you.



This **may help** you **identify goals to work on** in therapy, or by yourself.

**Benefits for others:**



You will **help speech therapists** learn more about what is important to people with aphasia.

**Risks of being involved:**



You may find the interviews **tiring**. **This is common** after a stroke.

**Confidentiality**

What you say is **anonymous**.

I **will not tell anyone** what you say. You **will not be identified** in research findings.

I will **give you a summary** of our discussions. You can **choose if you want to give this to anyone**. You don't have to.

Your information will be **securely locked**.  
The audiotape and videotape **recordings** will be  
**destroyed at the end of the study**.

The **transcriptions** of the interviews will be  
**destroyed after 10 years**.

I can give you a **copy of the results** if you want.  
These will be **available in 2011**.

Ethics Approval

This study has been approved by the Northern Y  
Health Ethics Committee.

District Health Board (DHB)  
Research Approval


This study has been approved by the Auckland  
District Health Board and Counties Manukau  
District Health Board.


More Information

If you want **more information**, contact **Felicity  
Bright**. Your speech therapist can do this for you  
if you want.

Your Rights as a Participant

You can contact a **Health and Disability Advocate**:

 **0800 555 050**


 **advocacy@hdc.org.nz**


They can give you **information on compensation**  
for physical injury.

Māori Cultural Support Team

The Māori Cultural Support Teams are able to be  
contacted should you want their support:

Auckland District Health Board (DHB):

 **09 307 4949**

 **email@aucklanddhb.nz**

Counties Manukau District Health Board:

 **09 276 0044 ext 8138**

 **email@manukaudbh.nz**



AUT

Participant  
Information Sheet

The hopes and priorities of people with aphasia following stroke in the postacute rehabilitation period.

What is this Research About?


Kia Ora,

You are invited to take part in a research project. We are doing research into what is important to people with aphasia.

You can choose if you want to take part in the research. It is your choice. If you decide to not take part, this will not affect your therapy at Rehab Plus.

If you do take part, you can change your mind at any time. You do not have to give a reason.

This information sheet will give you information about the study. It may help you decide if you would like to take part. Please tell us if it is difficult to understand, or if you have any questions.



Purpose of the Study

We are trying to find out what is important to people with aphasia.

I would like to interview you and talk about your hopes and priorities for your therapy, your recovery and your future.

Research tells us what is important to people who had their stroke a long time ago.

We don't know what is important to people who had their stroke recently.

2

3

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About the Researcher



My name is Felicity Bright. I am a speech and language therapist.

I work as a researcher at AUT.  
I am doing my Masters degree at AUT.

My two supervisors are Jane Doe and Sarah Smith



Jane is a health psychologist.  
She works as a researcher at AUT.



Sarah is a speech and language therapist.  
She is a lecturer at the University of Auckland.

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felicity.bright@aut.ac.nz

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janedoe@aut.ac.nz

Sarah Smith



987-6543 ext 2100



sarahsmith@aut.ac.nz



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I will interview you three times.

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There will be at least one week between each interview.

It may take up to six weeks to complete the three interviews.

You are welcome to have a family/whānau member at the interview if you wish.

You do not have to answer all the questions.

I would like to tape the interviews.

During the first interview, I will just use a tape recorder.

In the second and third interviews, I would like to use a video recorder. This is so I can record gesture and writing, as well as our voices.

I would like to talk with you at the end of my study to make sure my findings are correct. This would take about an hour. This is optional.



Participant Selection

Up to six people with aphasia will be interviewed.

People are eligible if they are receiving speech therapy at Rehab Plus Outpatients.

Interview Location

The interview can take place where you choose. It might be:



Your home



AUT



Rehab Plus

Or you can have the interview somewhere else.

If it costs you to get to the interview, I will reimburse you.

Please note:

The interviews are not speech therapy.

This study will not help your communication.

You will still have your speech therapy at Rehab Plus.

Stopping the Study

You can withdraw from the study at any time during the interviews.

If you have finished all the interviews, you can completely withdraw from the study. This needs to happen before data analysis starts (about July 2010).

Medical Records

I will ask you for permission to review your medical records that are at Rehab Plus.

These will give me information about:

- What happened
- The tests you have had since your stroke
- The treatment you are having with your therapists.



Benefits and Risks

Benefits for you:

You may find it helpful to talk about what is important to you.

This may help you identify goals to work on in therapy, or by yourself.

Benefits for others:

You will help speech therapists learn more about what is important to people with aphasia.

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You may find the interviews tiring. This is common after a stroke.

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More Information

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They can give you information on compensation for physical injury.

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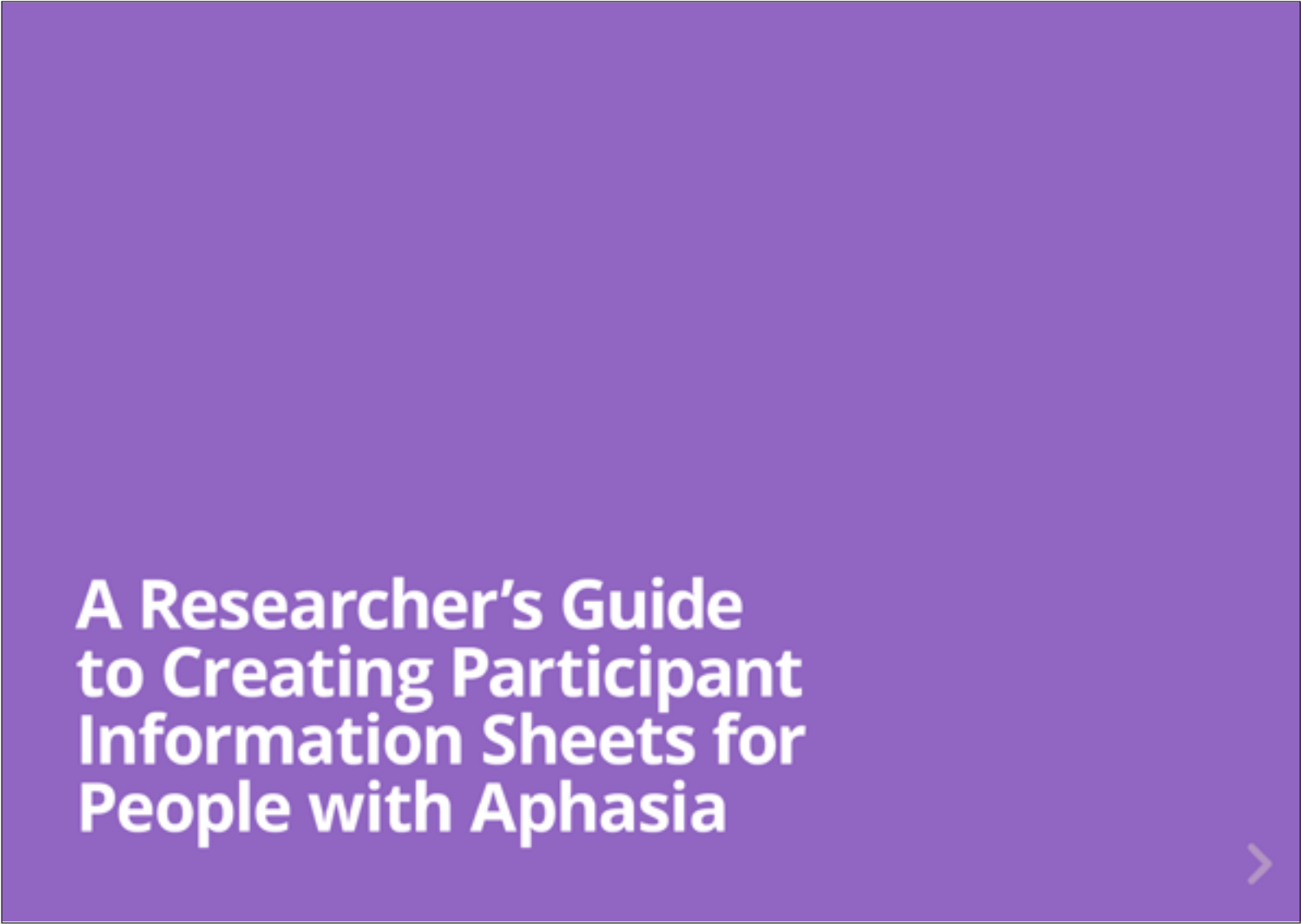
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 **email@aucklanddhb.nz**

Counties Manukau District Health Board:

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A4 Sheets or  
A5 Booklet size  
Page 7

Colour  
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Page 8

Leading (line spacing) at 1.4  
Page 5

Interview Details

 I will interview you **three times**.
  Each interview will take between 45-90 minutes.
  There will be at least **one week** between each interview.
  It may take up to **six weeks** to complete the three interviews.

You are welcome to have a **family/whānau member** at the interview if you wish.

 You do **not** have to **answer all the questions**.
  I would like to **tape the interviews**.
  During the **first interview**, I will just use a **tape recorder**.

In the **second and third interviews**, I would like to use a **video recorder**. This is so I can record gesture and writing, as well as our voices.

I would like to **talk with you at the end of my study** to make sure my findings are correct. This would take about an hour. **This is optional.**

Short and Simplified Sentences  
Page 7

Bold keywords  
Page 4

Sans-serif Typeface in 14pt  
Page 4

Contents

4

Bolding of Keywords and Phrases

Important keywords or phrases should be emphasised using bold type throughout the document. This allows the reader to pick up on the essential parts of the text.

✓ Using **bold type to emphasise keywords** is an important feature to have in participant information sheets for **people with aphasia**.

✗ Not using bold to emphasise keywords can mean that important keywords are not picked up when people with aphasia are reading.

Typeface

The typeface (font) used should be a sans-serif that is clear and readable. A good type size to use for the main body of text is 14pt.

✓ Arial, 14pt

✓ Verdana, 14pt

✗ Times New Roman, 14pt

✓ This is Arial 14pt

✗ This is Arial 10pt

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## Leading

Leading (most commonly referred to as line spacing) for the main body of text should be approximately 1.4. This increment ensures an increased amount of space between each line. This allows the reader to easily follow the text down to the next line.



This is 1.0 line spacing. This line spacing is very close to the line above which can sometimes make it hard for readers to follow.



This is 2.0 line spacing. This line spacing is very far from the line above which can sometimes make it hard for readers to follow.



This is 1.4 line spacing. This line spacing has a good amount of space between each line for readers with aphasia.



## Typographic Hierarchy

Typographic hierarchy helps to order information to ensure the contents of a participant information sheet is presented in a way that is logical to the reader. The most important information for the participants to know should go first, with the least important aspects appearing later on in the document.

To ensure readers can navigate the document efficiently, section headers should be emphasised to be the main focus on a page. This can be achieved through using a bold font and increasing the header size to be proportionally larger than the body text.



### Header at 24pt

#### Sub-header at 18pt

This body text is at 14pt and proportionally smaller than all the headers.



### Header at 16pt

#### Sub-header at 14pt

This body text is at 14pt and is the same size as the sub-header. This does not contrast sufficiently.



## Short and Simplified Sentences

Sentences should be as short, simple and concise as possible for the reader. Avoid using medical jargon and replace words that are difficult to read or understand with simpler or alternative phrasings or words.



This sentence is short and simple.



This sentence is long and relatively complex from the assortment of vocabulary utilised to show how long and potentially convoluted a sentence can be.

## Paper Size

For both physical and digital distribution, A4 single pages are an appropriate format to work with in MS Word and Google Docs. It is not advised make the participant information sheets larger than A4 or smaller than A5 when printing.



A4 Page



A5 Booklet



## White Space and Proximity

There should be an ample amount of white space between paragraphs and sections of information. Three sentence lengths is a good amount of white space between each paragraph in a section.

If you are starting a new section, ensure that it starts on a new page OR there is an increased amount of white space between the final paragraph of the previous section and the new sections headers. This ensures the sufficient separation of information.

**NOTE:** If you are starting a new section on the same page as the previous section, make sure there is enough room to fit the header and at least one or two paragraphs. If in doubt, move this section onto a new page.



### Confidentiality

What you say is anonymous.

I will not tell anyone what you say. You will not be identified in research findings.

### Risks and Benefits

You may find it helpful to talk



### Confidentiality

What you say is anonymous.

I will not tell anyone what you say. You will not be identified in research findings.


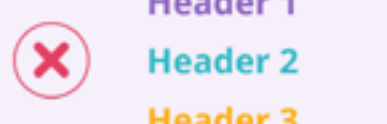


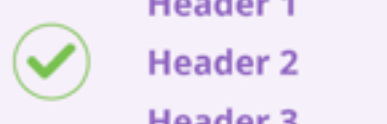





## Colour

Colour can be used throughout the participant information sheet in images and large headers that are bold and clear. Colours should be consistently used throughout the entire participant information sheet.

**NOTE:** Very light or bright colours that do not contrast well on a white page should be avoided as colours used for text. These types of colours compromise the readability. Any colours used for text should contrast well on the page.




		
		



## Images

Images alongside relevant text can help the reader understand appropriate information. To ensure the participant information sheets are consistent and cohesive, try to use one image style (photography, illustrations, icons, etc.) throughout the entire document.

Photographs and other image styles can be used sparingly. Photos are sometimes best used to represent a person or specific action or location, and icons are sometimes best used to represent areas of information like phone numbers and email addresses. Consistent use of colour ([Page 9](#)) should be considered when using different types of images together.

 <p>Different style, different colours</p>
 <p>Different style, same colours</p>
 <p>Same style, same colours</p>



