An assessment of the psychometric properties of a visual communication capacity aid

by

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Abstract

Decision-making is required for daily living. Specific decision-making ability in the area of finances is complex, and determining an individual's capacity requires an in-depth assessment. In the presence of communication disorders such as aphasia, such assessments can become challenging, and require the use of communication supports.

Unfortunately, no communication aid exists to help with the assessment of financial decision-making capacity (DMC) for persons with aphasia (PWA) (Carr, 2016). Therefore, this study sought to establish the validity, reliability and feasibility of a newly constructed visual communication aid designed to assist the assessment process of financial DMC for PWA.

We conducted a mixed methods study that was divided into three Phases. Phase one was aimed at capturing the current understanding by community dwelling seniors of DMC, which included financial DMC, and communication, through the use of focus groups. The goal of Phase two was to develop a new visual communication aid to assist with the assessment of financial DMC for PWA. The third Phase aimed to establish the psychometric properties and usability of this new visual communication aid using a combination of different techniques.

The preliminary results from this study are promising. Future research will involve testing and validating this aid in PWA to confirm its psychometric properties and how acceptable it is for use in this population.

Preface

This thesis is an original work by Frances Carr. The research project on which this thesis is based received research ethics approval from the University of Alberta Research Ethics Board, Project Name "An assessment of the psychometric properties of a visual communication capacity aid," ID: Pro00069318, on February 22, 2017, with the most recent amendment being created on December 23, 2019.

The published manuscript incorporated into this thesis is the original work of Frances Carr, who is the sole author of the manuscript. The manuscript was published on September 16, 2016, in the *Medical-Legal Journal*.

The research that was performed as part of this thesis involved collaboration with the following research team members: Frances Carr (Project Lead), Michelle Valpreda, Kristine Portlock and Andrew Mitchell, who are all employed by Alberta Health Services and based at the Royal Alexandra Hospital, Edmonton, Alberta. While the background of the thesis is my own work, all members of the research team were involved in conducting the study.

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List Of Abbreviations

ADL: Activities of daily living

ADM: Alternative Decision Maker

AGTA: Adult Guardianship and Trusteeship Act

AHS: Alberta Health Services

BADL: Basic activities of daily living

BNVR: Butt Non-Verbal Reasoning Test

DCA: Designated capacity assessors

DMC: Decision-making capacity

DMCA: Decision-making capacity assessment

DMCAM: Decision-making capacity assessment model

EPA: Enduring Power of Attorney

EPOA: Enduring Power of Attorney Act

GRH: Glenrose Rehabilitation Hospital

IADL: Instrumental activities of daily living

MCI: Mild cognitive impairment

MMSE: Mini-Mental Status Examination

PD: Personal directive

PDA: Personal Directive Act

POA: Power of Attorney

PWA: Persons with aphasia

RAH: Royal Alexandra Hospital

SCA: Supported Conversations for Adults with Aphasia

SLP: Speech and Language pathologists

UAH: University of Alberta Hospital

WAB: Western Aphasia Battery

Glossary Of Terms

Alternative Decision Maker (ADM): In Alberta, a person who is authorized to make decisions with or on behalf of the patient (Alberta Health Services, 2016).

Agent: In Alberta, a person designated in a personal directive to make personal decisions on behalf of the maker (term to be defined under 'maker') (Goverment of Alberta, 2017).

Assent: The assumption of agreement by an individual pertaining to consent for healthcare treatment.

Attorney: In Alberta, a person who is empowered to act on behalf of the donor (term to be defined under 'donor') under a power of attorney ("Powers Of Attorney Act - Revised Statutes of Alberta 2000," 2014).

Capacity assessment: An assessment conducted to determine an adult's capacity to make decisions regarding personal or financial matters (Goverment of Alberta, 2017).

Capacity assessor: A member of the health profession who is qualified to conduct decision-making capacity assessments and has been designated as a capacity assessor under the Personal Directive Act (Goverment of Alberta, 2017).

Consent: The act of giving permission or agreeing to do something, often to someone in authority.

Decision-making capacity (DMC): The "ability to understand information relevant to a decision [and] retain and integrate this information into the decision-making process, and communicate [the] decision" (Bellhouse, Holland, Clare, & Gunn, 2001).

Decision-making capacity assessment (DMCA): An assessment of an adult's DMC regarding personal matters or financial matters (Goverment of Alberta, 2017).

Designated capacity assessor (DCA): In Alberta, a regulated healthcare professional who has been appointed by the Government of Alberta to complete DMCA and make recommendations to the Office of the Public Guardian/Trustee (Covenant's Network of Excellence in Seniors' Health and Wellness (the Network), 2018).

Domain: Refers to a "specified sphere of activity or knowledge" (Lexico, 2020).

Donor: A person who gives power of attorney ("Powers Of Attorney Act - Revised Statutes of Alberta 2000," 2014).

Enduring Power of Attorney (EPA): In Alberta, this is a power of attorney under Section 2 of the Power of Attorney Act ("Powers Of Attorney Act - Revised Statutes of Alberta 2000," 2014), whose role continues after it has been determined that the donor lacks DMC for financial matters.

Financial matters: Money and property within the decision-making scope of an individual.

Maker: A person who makes a personal directive (Goverment of Alberta, 2017).

Personal decisions: Collective term for decision-making in the domains of healthcare, accommodation, people with whom to associate, participation in educational/vocational activities, participation in employment, and legal decision-making. This excludes financial decisions.

Personal directive (PD): In Alberta, this is “a directive made in accordance with Part 2” (Goverment of Alberta, 2017). It is a legal document that gives one person (or more than one person) the authority to make decisions around personal matters for the maker.

Personal matters: Refers to all matters within the decision-making scope of an individual, except financial matters.

Power of Attorney (POA): In Alberta, a legal document that gives one person (or more than one person) the authority to make decisions around financial matters for the donor.

Speech and Language Pathologist (SLP): A healthcare professional with training and expertise in the assessment and management of disorders pertaining to communication and swallowing.

Substitute Decision Maker (SDM): A person chosen by an individual to make personal decisions for that individual (the SDM may also be the agent).

Trustee: In Alberta, according to the Alberta Guardianship and Trustee Act ("Adult guardianship and trusteeship Act. Statutes of Alberta 2008," 2013), this is the person named by the courts to make decisions around financial matters for an individual.

Chapter One: An Introduction To Decision-Making Capacity (DMC)

1.1 An Introduction to DMC

Decision-making capacity (DMC) is an important and highly complex medical-legal topic that is often misunderstood. DMC should not be considered as being generally present or absent but should be assessed with reference to a specific decision and domain. Although not formally defined, the term general DMC refers to DMC that incorporates any number of the domains specified below. Specific DMC refers to decision-making pertaining to a specific domain–for instance, decision-making around accommodation.

Within Alberta (our home province), eight domains have been identified in which DMC can be assessed (Alberta, 2013). These domains fall under the two broad categories of personal and financial decision-making. Personal decision-making includes the domains of healthcare and treatment, accommodation, choice of associates, participation in social/leisure activities, participation in education/vocational training, employment, and legal decisions. Financial decision-making pertains solely to decisions about financial matters (Alberta, 2013; Goverment of Alberta, 2013).

The complexity of the DMC assessment (DMCA) process is likely influenced by many factors, including the specific domain(s) being assessed. Given the current absence of literature available on the topic, it is unclear if DMCAs for certain domains are more complex than others. Rather, factors such as the nature of the decision in question (with different decisions requiring different skills), context, and patient and assessor characteristics are all likely to have a greater influence on the complexity of the DMCA process than those associated with the domain being assessed.

A large proportion of current research in DMC has been within healthcare DMC, with a predominant focus on patient consent (Dunn, Nowrangi, Palmer, Jeste, & Saks, 2006; Grisso & Appelbaum, 1995; T. Grisso & P.S. Appelbaum, 1998; Grisso, Appelbaum, & Hill-Fotouhi, 1997), and considerably less in other, equally important domains, such as financial decision-making. This imbalance within the research is a problem, given the expansion in the aging

population, and the fact that aging has been associated with an increased risk of developing impairment in DMC and, in particular, financial DMC (Gardiner, Byrne, Mitchell, & Pachana, 2015). Aging is associated with a higher likelihood of developing comorbidities that can impact decision-making ability (Gardiner et al., 2015), such as mild cognitive impairment (Okonkwo et al., 2008), stroke (Diener, 2004), and aphasia (Diener, 2004). In addition, older adults usually undergo changes in their social-economic status, which often result in the need for significant financial decisions to be made in later life (Gardiner et al., 2015). All of these considerations justify the need for further research in this area.

There has been a greater awareness of the impact that certain medical conditions (e.g., aphasia) (Diener, 2004) can have on the ability to make decisions. This has resulted in an increase in the demand for physicians (and Designated Capacity Assessors (DCAs)) to assess DMC within individuals with these conditions. Due to a lack of confidence, or to inexperience and/or minimal training in this area, many physicians are uncomfortable performing any DMCA, and are reticent to do so in the presence of aphasia and other conditions (Young, Douglass, & Davison, 2018). This is particularly the case when any communication barriers are present, and such barriers are always present in persons with aphasia (PWA). Such barriers do not exist for healthy individuals without such impairments, but in the presence of any language disorder, such as aphasia, the assessment process can become extremely difficult or impossible. As a consequence, such assessments may be either poorly conducted or not performed (Kagan, 1995). The result is that PWA and similar communication problems are labelled as lacking DMC, but without fair process.

Establishing specific DMC in PWA is particularly challenging. For people with communication deficits, the primary impairment in decision-making ability is difficulties with information processing, which likely stems from problems in language and in the cognitive-communication process. Consequently, the DMCA process becomes challenging, particularly for financial decision-making. Financial decision-making has arguably higher stakes, and thus the need for communication supports is greater than in other areas of decision-making. However, despite these recognized challenges, there is a lack of current literature regarding financial DMC in PWA.

People with cognitive or communication disorders often need DMCAs when significant decisions are required in the area of financial matters. Although the complexity of financial decisions can vary, they typically involve a higher level of independence in daily living, and require a wider range of cognitive and language abilities to perform (D. C. Marson et al., 2000a; Wollinsky & Johnson, 1991). The consequences that can arise from a loss of financial DMC are significant for both the individual and his/her family, and include loss of independence and loss of personal autonomy (Moye, 1996), which are basic human rights and essential for establishing the individual's role in society. The loss of financial DMC may leave the individual vulnerable to financial exploitation or abuse, and likely affects other aspects of decision-making, e.g., legal matters (Grisso, 1986). This, in turn, can result in lengthy and costly legal proceedings for the individual and family members. Given the significance of the ramifications that can occur following a declaration of lack of financial DMC, such assessments should only ever be done when absolutely required.

Almost all financial DMC research to date has focused on understanding the financial decision-making process and how this becomes impaired in the context of neurodegenerative and psychiatric conditions, e.g., mild cognitive impairment (Sherod et al., 2009), dementia (Martin et al., 2008), and schizophrenia (Moye, Marson, & Edelstein, 2013; Pinsker, Pachana, Wilson, Tilse, & Byrne, 2010). There is no current research on financial DMC in PWA, making for a significant knowledge gap (Carr, 2016).

The process for assessing DMC requires clear communication between the individual being assessed, and the assessor. The British 2005 Mental Capacity Act notes that "a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success" (United Kingdom Law Commission, 1995), a recommendation that is also supported by both Alberta's Personal Directive Act (Goverment of Alberta, 2017) and Alberta's Adult Guardianship and Trustee Act (Alberta, 2013).

Using specifically designed communication aids in the DMCA process can help with communication and enable participation in the assessment process. A communication aid is a tool, strategy or device that helps an individual to communicate. For PWA, providing a bespoke communication aid to assist with assessments is necessary to ensure that these individuals have

the opportunity to participate in a fair and accurate assessment. Such communication aids can also help assessors demonstrate objective evidence of an individual's DMC.

Only one communication aid currently exists to support DMCAs for PWA (Carling-Rowland, Black, McDonald, & Kagan, 2014), and it is specific to personal decision-making for accommodation decisions only. No similar communication aids exist to support other areas of personal decision-making, or for financial decision-making. This finding is surprising, given the numerous challenges that PWA face during the assessment of DMC due to their communication impairment, as they are the people who most need communication support. Given this significant knowledge-practice gap, there is a great need to develop and validate a communication aid that has been specifically designed to support assessments of financial DMC for PWA.

To be clear, the initial objective of the research in this thesis was to develop a visual communication aid that would support assessments of both legal and financial DMC to address the knowledge-practice gap within these areas that was identified in the literature review (Chapter two). However, after the research study had commenced and following the completion of the first Phase, it became evident that developing a single communication aid with these dual purposes was neither practical nor feasible. Therefore, the decision was made to change the research objective and focus of the new communication aid to support assessments of financial DMC only for post-stroke PWA. As this decision was made during the second Phase of the study, the focus of the initial literature review, the published manuscript (Chapter two) and first Phase of the study was still on developing a communication aid to support assessments of both legal and financial decision-making. The remainder of the research study and thesis is focused only on financial DMC.

A brief outline of the structure of this thesis follows. An introduction to DMC is provided, which includes a discussion about financial DMC. This is followed by a detailed discussion about the DMCA process, which includes the results from a scoping review about DMC that the author conducted across Canada. The next section focuses on aphasia, the use of communication supports, and DMC within aphasia. After that is a review of the currently available DMCA tools. Chapter two contains the published manuscript, which is a narrative review performed by the author on financial and legal DMC in PWA. Chapter three presents an

overview of the research study, while Chapter four discusses the findings. Chapter five contains the summary and conclusion.

a) Terminology and definitions

DMC refers to an individual's ability to "understand information relevant to a decision" and "to retain and integrate this information into the decision making process, and communicate a decision" (Bellhouse et al., 2001), which includes "manipulating that information in a deliberative process" and "appreciating the consequences of making or not making a decision." (Appelbaum & Grisso, 1988)

There is no universal or standardized definition for capacity. Instead, the precise definition used tends to be jurisdictional, with variations described between different governing bodies at both the international (e.g., Canada and Austria) (Carling-Rowland & Wahl, 2010) and provincial level. For example, the province of Alberta has defined capacity as "the ability to understand the information that is relevant to the decision and to appreciate the reasonably foreseeable consequences of a decision, and a failure to make a decision." (Goverment of Alberta, 2013) In spite of these variations, most societies reference the key elements as reported above, which are required to establish the presence of capacity.

To avoid controversy, it is important to distinguish between the terms "capacity" and "competence." Although these terms are often used interchangeably, they have also been defined as separate entities. "Capacity" has been described as referring to general decision-making ability, while "competence" has been referred to as being an absolute term, referring to specific decision-making (Black, 1979; Leo, 1999). However, this is not the case everywhere. In many places, including Alberta, the term "capacity" is also considered absolute.

Other controversies surrounding these definitions are that "competence" has been considered a legal rather than clinical term. Competency means that an individual has the "mental ability and cognitive capabilities required to execute a legally recognized act rationally." (Bisbing, 1998) The result of this is that making the determination of incompetence becomes a judicial decision. By comparison, SLPs have viewed "capacity" as the theoretical ability for decision-making, while "competence" refers to the individual's actual functional ability. For the purpose of this thesis, and for consistency in terminology, "DMC" will be the term used from

here onward, which encompasses the terms competence and capacity, as well as both theoretical ability and demonstrated function.

The decision-making process is complex, and cannot be accurately categorized into distinct processes. It is most likely that a complex interaction occurs between higher level cognitive processes and communication abilities which, together, allow for the registration, manipulation and communication of information required for decision-making. One proposed model for specific DMC identified three essential elements required for DMC to be present. These include an ability to understand communication, activation of necessary cognitive processes to make a decision, and subsequent implementation (communication) of the result (i.e., action, explanation) (Alexander, 1988). An impairment in any one area will inherently complicate and may even prevent assessments of DMC.

b) Cognition and DMC

Decision-making involves complex interactions between various cognitive domains. These interactions lead to "a deliberative process that results in the commitment to a categorical proposition act." (Gold & Shadlen, 2007) The decision-making process involves a number of different cognitive domains that include attention, memory, and executive functioning (Suleman & Kim, 2015). Language is also required, both to comprehend and communicate the decision options.

During the process of decision-making, interactions occur between these cognitive domains which allow the selection of one choice or action over other, i.e., alternative possibilities. The range of options identified and selected depended on the decision-maker's values, preferences, and beliefs.

c) DMC models

Blum proposed three conceptual models for DMC. These include a philosophical-legal model, a medical model, and a functional model (Blum, 2005; O'Connor, 2009). Each is described below.

The philosophical-legal model is the one most commonly employed, and forms the basis for most of the existing DMCA tools. This model proposes that DMC is based on an individual having the appropriate cognitive processes to be able to understand and use information to make a rational decision and express his/her desires.

The medical model (Blum, 2005) is based on the concept that certain medical and/or psychiatric symptoms can influence an individual's decision-making ability through the impairment of or interaction with necessary cognitive processes required for DMC. Although this model can help to identify the underlying etiology for impaired DMC and to develop an appropriate management plan, its use has been limited by two factors: it is only applicable in healthcare settings, and it relies on the need to assess and establish an association between clinical symptoms and DMC through a formal medical/neuropsychiatric assessment.

Despite its infrequent use, the functional model (Blum, 2005) may be the most practical and accurate approach for conceptualizing DMC, as it focuses on the demonstration of observable behaviour to identify the presence of both decisional and executive capacity, both of which are key components of DMC.

DMC refers to the *process* of making a decision, while executive capacity pertains to an individual's *ability* to execute a decision (O'Connor, 2009). The importance of executive functioning (defined as the "ability to orchestrate relatively simple ideas, movements or actions into complex, goal-directed behavior") (Royall, Mahurin, & Gray, 1992) within the decision-making process is being increasingly recognized, and involves the domains of intellect (information handling and processing system), emotionality (pertaining to an individual's feelings and emotions), and control (physical expression of behavior.) (White, 1994). It is important to remember that all of these separate domains can influence decision-making; emotionality, for example, reflects the individual's values, which will directly influence a person's ability to make competent decisions.

In summary, three separate models for DMC have been clearly described, with each model targeting different components of decision-making. It is most likely that no single model can fully explain and encompass the DMC process. Rather, components from each model likely interact with one another during the DMC process and, thus, all three models should be considered and incorporated into any explanation of DMC.

d) DMC Domains

Individuals are often labelled as generally "lacking DMC". This is an incorrect assumption; instead, all discussions regarding an individual's decision-making ability should pertain to a

specific decision, and a certain "domain." In Alberta (our home province), eight different domains exist pertaining to decision-making, as defined by both the Adult Guardianship and Trusteeship Act (Goverment of Alberta, 2013), the Personal Directive Act (Goverment of Alberta, 2017), and Alberta Health Services (AHS), as described earlier. These domains are incorporated into the locally developed Capacity Interview Worksheet (Alberta Health Services, 2018) and Decision-Making Capacity Assessment Model (DMCAM) (Parmar, Bremault-Phillips, & Charles, 2015), both of which are currently used by AHS (our provincial health authority). These eight domains have been grouped into two categories: 1. personal decisions and 2. financial decisions.

1. Personal decisions.

As defined in Alberta, personal decision-making refers to decision-making in the following domains: healthcare, accommodation, persons with whom to associate, participation in social activities, participation in educational/vocational activities, participation in employment, and legal affairs (Alberta Health Services, 2018; Goverment of Alberta, 2013, 2017). While assessments in the domains of healthcare and accommodation are often required in healthcare settings, the assessment of other domains-such as whom to associate with, and participation in educational/vocational activities and employment-are less frequently required, especially in older adults.

2. Financial decisions.

Assessments of financial DMC pertain solely to financial decision-making ability. Decisions in this domain refer to property and financial matters, and exclude any other domain. Although often mistakenly included with this domain, decisions pertaining to legal matters (e.g., personal directive (PD) or power of attorney (POA)) are included under the category of personal decision-making.

Given the limited amount of research in the area of financial DMC, and the potential challenges of assessing financial DMC in PWA, an in-depth review of financial DMC is required, which is provided below.

e) Financial DMC

Financial DMC refers to "the ability to satisfactorily manage one's financial affairs in a manner consistent with personal self-interest and values." (D.C. Marson & Herbert, 2008) Financial DMC has been described as comprising two components: financial capacity and financial performance. Financial capacity refers to the presence of necessary financial skills, which are demonstrated by financial knowledge and financial judgement (Beneficiaries, 2016). Financial performance is shown by the degree of success seen in managing financial demands (Beneficiaries, 2016). These two conceptual components of financial DMC are important to keep in mind, as impairment in either will likely impact financial DMC.

Marson and colleagues have conceptualized a model for financial DMC that is based on the ability to complete three increasingly complex aspects of financial functioning. These include having specific financial abilities (i.e., the ability to perform single tasks), being able to perform more broad financial activities, and overall financial DMC (Griffith et al., 2003; D. Marson, 2016).

Nine separate domains of financial DMC have been recognized (Gardiner et al., 2015; Martin et al., 2008). These cover 18 abilities required for financial DMC, and are based on the financial conceptual model proposed by Martin et al (Martin et al., 2008). These domains include an evaluation of basic monetary skills, financial conceptual knowledge, cash transaction, chequebook management, bank statement management, financial judgement, bill payment, knowledge of assets, investment decision-making, and overall financial capacity (Martin et al., 2008). The complexity of these abilities ranges from simple tasks to higher level complex task performance. Although this classification system has not been standardized, it does provide guidance to a physician when considering the key knowledge and abilities that require assessment when determining financial DMC.

Overall financial DMC is thought to reflect functioning in different areas: cognitive, affective, instrumental, and social (Pinsker et al., 2010). The interaction between these different areas of functioning supports the high degree of complexity involved in financial decision-making. It has been recognized that certain groups of individuals may be at higher risk of developing problems with financial decision-making. These groups range from individuals with even mild cognitive changes (Griffith et al., 2003) to those with established dementia (Gardiner

et al., 2015) (e.g., Alzheimer's (D. C. Marson, 2013)) and frontotemporal dementia (D. C. Marson, 2013), and other neurological and psychiatric comorbidities (Pinsker et al., 2010). Although advancing age is a risk factor for diminished financial decision-making, the aforementioned cognitive areas are not significantly impacted with healthy aging. However, older adults are at a higher risk for developing either one or more of these comorbidities (Fowles, 1983) or for developing difficulties in one or more of the core components required for financial DMC.

Notwithstanding the importance of determining an individual's financial DMC, an assessment of an individual's financial DMC would be incomplete without evaluating and anticipating his or her real-life financial functioning. An evaluation of (or anticipating for) an individual's real life financial functioning is crucial, given the consequences that can result from impaired financial DMC. These consequences include an inability to manage financial affairs, the risks of financial exploitation from undue influence (Gardiner et al., 2015) or consumer fraud, and financial abuse (Moye et al., 2013). Financial abuse is a concerning problem, and was identified in an Australian study (Boldy, Horner, Crouchley, Davey, & Boylen, 2005). Additionally, the loss of financial abilities has been described as a "litmus for declining capacity to live independently and care for oneself" (D. C. Marson et al., 2000a).

There is no standardized approach to the overall assessment of financial DMC; instead, it has been suggested that the best approach may be a multi-pronged strategy that incorporates a clinical interview, neuropsychological assessment, and performance-based assessment (D. C. Marson, Triebel, & Knight, 2012; Pinsker et al., 2010). Within the clinical interview, recommended areas for assessment should include, at a minimum, an assessment of basic monetary skills, financial conceptual knowledge, cash transactions, cheque book management, bank statement management, and financial judgement (D. C. Marson et al., 2009; D. C. Marson et al., 2000b). The use of objective testing to identify cognitive and psychiatric co-morbidities is important, and can be achieved using recognized instruments. There has been a recent trend towards incorporating a performance-based definition within the model for financial DMC to be able to highlight where and when deficits occur. The use of a pragmatic approach may aid the assessment process and assist with determining when and where assistance and/or interventions may be needed (Van Wielingen, Tuokko, Cramer, Mateer, & Hultsch, 2004).

f) Scoping review on DMC across Canada

A preliminary scoping review that looked at DMC, the assessment process, and the use of advance documentation across Canada was performed by the author for the purpose of this thesis. A summary of these findings is provided below.

Across Canada, the general principles used for guiding and conducting DMCA are similar between provinces, and are guided by common law (and civil law in Quebec) (Wahl, 2007). The general presumption is that all individuals have general DMC and it is up to the assessor to prove otherwise. Capacity assessors can only provide a judgement regarding the presence or absence of specific DMC. Formal decisions regarding DMC are made by the courts. However, the judgements made by capacity assessors in certain provinces are binding under certain acts (e.g., the Personal Directive Act (PDA) and Enduring Power Of Attorney Act (EPOA)). In other jurisdictions, these judgements are considered advice only, with the final judgement being made by courts (e.g., the Adult Guardianship and Trusteeship Act (AGTA)).

There is no single DMCA tool that has been universally recognized for supporting the DMCA process; instead, provinces (and territories) have recommended using a number of different tools to support the assessment process, but the use of such tools should not be a substitute for the DMCA process itself.

A number of differences were identified between the provinces and territories in the areas of domain classification, eligibility of capacity assessors, and the type of documentation used within the DMCA process. Variation was also observed in the age of majority for individuals to be able to provide DMC; however, recognition was made that people under the age of majority could be considered as mature minors who are capable of providing consent. In Manitoba, for instance, individuals 16 years or older are deemed to have DMC and can make a healthcare directive. Saskatchewan and Alberta define the age of majority as 18 (although interestingly, in Saskatchewan, children 16 years or older can create their own healthcare directives). In Newfoundland, the age of majority is 19, although similar to Saskatchewan, children 16 and older can create their own healthcare directives. The Northwest Territories, Nunavut, the Yukon, Nova Scotia, and New Brunswick also list 19 as the age of majority.

The other most noticeable finding in the scoping review was a lack of standardization around advance care documentation. The term "advance care documentation" was used in the review to refer to a broad category of documentation that includes PD's, POA's, EPA's etc., and was used due to the lack of naming standardization seen across all provinces and territories. In the absence of a national standard, individual provinces and territories have developed their own approach towards advance care documentation, which is governed by local legislation. This lack of standardization across jurisdictions in the type, mobility and validity of advanced care documentation is an interesting finding, and is surprising to the author, considering the ease and availability of travel across Canada.

1.2 Decision-Making Capacity Assessment (DMCA) process

a) DMCA process

General Considerations.

Before proceeding with any DMCA, a number of considerations need to be taken into account, the details of which are described in the sections below. These include recognizing which domain and decision is of interest, the need to obtain prior consent, and a consideration of an individual's beliefs/values and context, all of which can significantly influence the DMCA process.

i. Domains need to be specified for DMCAs.

Prior to any assessment, it is vital that the assessor, commonly a physician, clearly defines the specific decision and domain for which DMC is to be assessed. Although no universal classification system for these domains currently exists, commonly recognized domains used within Alberta include personal decision-making (which includes decisions around healthcare, accommodation, legal. etc.,) and financial decision-making, as mentioned earlier. The domain(s) of greatest interest to the assessor are those based on any identified themes relating to suspected poor decision-making, and those relating to a concern that poor decisions are not otherwise mitigated, and by the anticipated consequences of inaction on DMC.

ii. DMC is decision-specific.

While DMC is judged according to the specific domain involved in the process, it is important to remember that it is inherently decision-specific - i.e., related to the ability to make specific decisions. One of the most common examples of this has to with DMC for healthcare decisions, specifically concerning consent for medical treatment. Therefore, recognizing the decision about which DMC has been questioned is crucial, as this will determine the domain involved.

iii. Need for consent/assent.

Consent should always be sought from the participating individual. This includes providing the individual with sufficient information about the assessment process, the reason for the assessment, the purpose of the assessment and its process, the significance of the results, and all potential outcomes. Because an individual may prove to lack DMC to consent, it is acceptable to proceed based on assent alone, when indicated. Despite all individuals having the right to refuse testing, depending on the clinical scenario, a DMCA may still be pursued, often with a court order as necessary.

When evaluating for DMC, relevant information must be provided to ensure that the individual is fully informed (Bellhouse et al., 2001) and is in possession of information in a format that is easily understandable (Bellhouse et al., 2001). Sufficient information should be provided to ensure that the individual understands all options available and the consequences of each option. Specifically, as pertains to discussions around obtaining consent for healthcare treatment, information should be given about the changes to expect with or without treatment and the possibility of serious outcomes (Bellhouse et al., 2001).

iv. Understanding beliefs and values is essential.

The patient's beliefs and values (religious and non-religious) and cultural perspectives should be taken into consideration during the assessment process, as these will likely influence the answers and decisions made (Waldfogel & Meadows, 1996); without such consideration, the assessment could result in unfair assumptions about the individual (Waldfogel & Meadows, 1996). This also ensures protection for those who have established beliefs or values that are not commonly held, but are nonetheless acceptable and reasonable within a pluralistic society.

v. Context of the DMCA is essential.

The context in which a DMCA is conducted is important. DMCAs should always be conducted in a quiet and private environment. Usually, only the individual and the assessor are present, unless the individual requests otherwise, or if clinically indicated. In the instance of a communication barrier, such as language impairment or a language barrier, appropriate assistance should be sought to conduct the assessment. This may involve seeking assistance from a SLP, using additional or alternative forms of communication such as visual communication aids (Grisso & Appelbaum, 1995) or use of a formal translator.

vi. Is the DMCA a gold standard?

Despite the legal importance of DMC, no gold standard approach has been developed to conducting DMCAs, which contributes to the variations observed in clinical practice, and strengthens the need for research within this area. Current DMC literature requires the assessor to evaluate four key criterion standards (also referred to as abilities) during the assessment process. These standards are integral to conducting any DMCA. They include the ability to express a choice, an understanding of the information required for a decision, an appreciation of how the information being given pertains to the person's own life and circumstances, and logical reasoning (T. Grisso & P.S. Appelbaum, 1998). The importance of each individual standard is hierarchal and depends on the individual, the situation, and the decision at hand.

The use of these standards is most important when within legal tests of DMC; however, such use is subject to judicial variations which are dependent on local regulations. There is no standard implementation, which likely contributes to the variations observed in clinical practice. Despite this, there is general consensus that to demonstrate DMC an individual must have the ability to demonstrate, understand, appreciate, reason and choose.

Assessment process.

There is no single standardized method for how DMCAs should be conducted; instead, assessments are typically dictated by local and provincial health authority regulations. Within Edmonton, DMCAs are guided by the DMCAM, and involve the use of a Capacity Assessment Care Map (Parmar et al., 2015), as discussed earlier. A good DMCA should be complete and contextual and incorporate evaluations of psychosocial, cognitive, functional, medical, emotional, and social-cultural factors (American Bar Association Commission on Law and

Aging, American Psychological Association, & National College of Probate Judges, 2006). While in theory, all DMCAs should be multidimensional as mentioned above, most of the current research in DMC has been focused DMCAs assessing single domains (e.g.. healthcare, accommodation etc.) or on using a single domain model of DMC (usually the cognitive or medical model) (Blum, 2005; O'Connor, 2009).

The general process for assessing DMC is typically divided into two stages. The first involves gathering background data from multiple sources, which is crucial to the assessment process. This also involves collecting collateral information from a variety of sources, such as a reliable informants, objective records, and other healthcare providers. This process also provides the opportunity to screen for the presence of any reversible factor(s) that may influence the results (Pachet, Allan, & Erskine, 2012), such as reversible medical conditions (e.g., delirium) or the presence of medications or toxic substances that can impair decision-making ability. Although specific details may vary, the second stage of the assessment process usually starts by conducting a clinical interview, sometimes referred to as a functional inquiry (Carling-Rowland & Wahl, 2010). Unlike a physical assessment, this explores the individual's insight into his/her functional and cognitive abilities.

Following completion of the assessment, the assessor has a duty to report the findings to the individual, which will then trigger further action as appropriate. The assessor must report the findings verbally and document them in writing. Due to the medical-legal issues associated with DMC and its assessment, it is essential that clear and accurate documentation is provided in the patient's medical record, detailing the justifications for doing the assessment, the assessment process, and the outcome. This documentation should include the rationale behind the decision (Bellhouse et al., 2001). The assessment results are presented as the assessor's judgement as to whether or not the individual should receive a declaration of incapacity.

Lai and Karlawish (Lai & Karlawish, 2007) suggest using a multipronged approach to assess general decision-making ability. This includes data collection, a clinical interview, and a performance-based assessment of the individual's cognitive and functional abilities. An alternative but infrequently used approach recommends that such decisions should not be based on whether an individual lacks capacity, but should be based on a sliding scale threshold of

competency taking into consideration the decision being made and the nature and severity of possible consequences that could ensue (T. Grisso & P.S. Appelbaum, 1998).

Regardless of the approach used, any assessment that is undertaken should be accurate and complete, with the emphasis on using the assessment to evaluate the decision-making process and not the decision itself, a recommendation supported by almost all authorities (including the Canadian Courts) (Law Commission of Ontario).

b) Valid and Invalid triggers

There is a global consensus that all individuals are presumed to have DMC. Therefore, undertaking an assessment of DMC should not be done lightly, and should only be considered when there is an element of risk or interference (undue influence) within decision-making that has occurred in the setting of potentially impaired DMC. Recognized situations that suggest the presence of impaired DMC include changes in the individual's level of consciousness, or temporary or permanent medical problems (predominantly psychiatric or neuro-cognitive in origin, such as delirium or dementia, or aphasia) that could impact the individual's ability to make decisions.

There are a number of acute changes that may suggest the presence of risk to or interference with an individual's DMC. This includes changes within the individual's medical status, care provider concerns that the individual may not have made a balanced decision, and instances where the individual has at least one or more known risk factors for impaired decision making. Other concerns suggesting risk or interference include the individuals refusal at treatment (especially when they will not or cannot discuss reasons for their refusal), and when the individual makes quick decisions made about risky interventions or treatments (Tunzi, 2001).

i. Triggers and their validation.

A trigger refers to a particular event, circumstance, or behaviour that leads the observer to question the individual's DMC (Attorney General's Department of New South Wales, 2008). Examples include when an individual fails to pay bills, resulting in the accumulation of debt; or fails to attend to critical house maintenance issues resulting in putting himself/herself at significant risk of harm (Attorney General's Department of New South Wales, 2008). Possible behavioural triggers include decision-making that is out of character for the person or repeatedly

making decisions that could put him/her at significant risk of harm (Attorney General's Department of New South Wales, 2008). However, although necessary, the presence of a trigger alone is insufficient for initiating a DMCA. Thus, triggers form only part of the DMCA.

It is necessary to validate all triggers to ensure their accuracy and minimize confounding issues surrounding the trigger. As triggers may be identified by an observer, external party or the individual himself/herself, they can be highly subjective, which is why they must be validated. For a trigger to be valid, it should fulfill five requirements, as suggested by Malloy et al. (Malloy, Darzins, & Strang, 1999). These include demonstration of behaviour that puts the individual or others at risk for significant harm, known or suspected impairment in decision-making, choices that are inconsistent with previously held values, failure on the part of others to resolve the problem, and the need to perform a DMCA with an appointment of alternative decision makers as the only possible way to resolve the problem (Malloy et al., 1999).

ii. Risks by choice.

It is important to clearly distinguish triggers from risky decision-making. All decisions comprise five components (Anderson, Dillon, & Hardaker, 1977; Dijkhuizen, Huirne, & Hardaker): acts, states, probabilities, consequences, and a choice criterion (Anderson et al., 1977). Acts refers to the relevant actions that can be made by the decision maker. States refers to the possible events or states of nature pertaining to the decision (i.e., anything that is outside of the control of the decision maker). Probabilities refers to the process of weighing available options according to the decision-maker's prior beliefs and knowledge of the probability of each option. Consequences are the outcomes possible for that decision. Choice criterion refers to the process of comparing the possible outcome of any act to that from other acts.

All decisions include these five components. The main difference between non-risky decision-making and risky decision-making is that, in the former, the states and consequence components are usually not known. By comparison, for risky decisions, the state or event may not be known for certain, but using a balance of probability against beliefs, the decision maker has confidence in the states available, and is aware of the consequences that the decision can have. It is thought that the process of risky decisions may involve greater executive functioning than decisions made in the presence of uncertainty (Groot & Thurik, 2018).

Every individual is allowed to make risky decisions, provided his/her decision is reasonably informed regarding states and consequences, and he/she can comprehend the options and risks involved. The importance of this is evident in the subjectivity seen in decision-making– what one individual may see as a 'bad' decision may not appear so to another. For example, despite the objections of others, a person with declining health and function may choose to continue living in his/her home without assistance, provided that he/she understands his/her health and living state, existing options, and the reasonably foreseeable consequences of the decision.

c) Factors influencing the DMCA process

The assessment of an individual's DMC can be influenced by many factors which may fluctuate over time, contributing to the dynamic nature of DMC. These include (but are not limited to) the presence of one or more medical conditions, disease activity, psychodynamic factors, medication effects, and inter-current illness or treatment effects. Consideration of these influencing factors is crucial when there is a need to determine an individual's DMC and risk factor mitigation should occur where possible. Although DMC is dynamic, the ability to make a logical, well thought out decision consistently over time supports the presence of DMC, assuming that there has not been a significant change in the individual's circumstances.

d) Legislation around the use of DMCA tools

There is currently no specific legislation at either the provincial or federal level governing the use of DMCA tools within the DMCA process. However, most provincial and territorial legislation indirectly or directly specifies that all accommodations should be made to ensure the individual can participate in the DMCA process. The Yukon Adult Protection and Decision Making Act reports that "an adult's way of communicating with others is not grounds for deciding that they are incapable of managing their affairs" (Goverment of Yukon, 2003), while Saskatchewan's Adult Guardianship and Co-Decision-making Act reports that "adults who have difficulty communicating because of physical or mental disabilities are entitled to communicate by any means that enables them to be understood" (Goverment of Saskatchewan, 2000). These recommendations are also supported by the 2005 Mental Capacity Act (UK) which reports that a "person is not to be treated as unable to make a decision unless all practicable steps to help him

to do so have been taken without success" and that a lack of DMC cannot be established based on "a condition of his, or an aspect of his behavior, which might lead others to make unjustified assumptions about his capacity" (Office of Public Sector Information, 2005).

To summarize, although no formal legislation exists dictating the role of DMCA tools in the DMCA process, the general consensus across Canada, and internationally, is that all efforts should be made to ensure that an individual can fully participate in the process, which should include the use of DMCA tools where necessary. For our purpose, there is particular relevance to providing accommodation for the communication barriers that arise from aphasia.

1.3 Aphasia

a) Introduction to aphasia

Aphasia is a recognized condition representing a broad array of communication difficulties. The American Speech-Language-Hearing Association has defined aphasia as being "an acquired neurogenic language disorder resulting from an injury to the brain, most typically the left hemisphere, that affects all language modalities" (Birchfield et al., 2016). This broad definition reflects the fact that aphasia refers to any disorder involving any degree of impairment in either verbal or written communication, and is supported by the absence of a universally recognized definition, perhaps because of its broad and various presentations (Birchfield et al., 2016). Disorders of articulation, reading, and writing are also usually considered within this broad definition of aphasia (O. Spreen & Risser, 2002). While the incidence of aphasia is thought to be low within the general population (Code & Petheram, 2011), it may be up to 30% in high-risk populations, e.g., post stroke patients (Dickey et al., 2010).

Aphasia classification.

Aphasia can be classified using either a clinical-neuroanatomical or a psycholinguistic model. Each of these models has its own benefits and limitations, and the decision around which model to adopt is probably only relevant for researchers or aphasia specialists, rather than the practicing clinician.

For clinical practice, the clinical–neuroanatomical model is by far the most commonly used model. This is likely because it relies on clinical observation and the validation of the

clinical deficits based on anatomical location. Using this model, aphasia can be classified according to speech fluency (i.e., "the rhythm of speech") (American Speech-Language-Hearing Association, 2017) into either fluent or non-fluent aphasia. In fluent aphasia, speech production and articulation are preserved, but there are difficulties with comprehension and, often, with repetition. With non-fluent aphasia, there are observable difficulties in the verbal expression of language, often with relative preservation of comprehension.

Four fluent and four non-fluent aphasic syndromes have been recognized. The fluent aphasic syndromes includes Wernicke's aphasia (fluent speech with impaired comprehension and repetition), conductive aphasia (fluent speech with multiple paraphasias, self-corrections and impaired repetition), transcortical sensory aphasia (fluent speech with impaired comprehension, mixed-up speech but preserved repetition), and anomic aphasia (fluent speech, good auditory comprehension, word-finding difficulties). The four non-fluent syndromes are: global aphasia (impaired comprehension and speech), Broca's aphasia (non-fluent speech, impaired grammar and naming, preservation of comprehension), transcortical motor aphasia (non-fluent speech, comprehension and repetition preserved) and mixed transcortical aphasia (non-fluent speech, impaired auditory comprehension, preserved repetition, impaired naming/word finding). For a more in-depth discussion around aphasia, its syndromes, and related assessment, please refer to the many detailed reviews available elsewhere, such as "Assessment of Aphasia" by Spreen and Risser (O. Spreen & Risser, 2003a).

b) Aphasia assessment

The purpose of the aphasia assessment is to detect the presence (or absence) of aphasia, which includes first ruling out related conditions. The assessment encompasses a comprehensive evaluation of the individual, which involves initial screening for aphasia, which is then followed by a detailed evaluation of the type and severity of deficits. The focus of the next section is to provide the reader with a brief, high-level overview of the assessment process, with the main focus on two commonly used tests

Assessment overview.

The specific details regarding the aphasia assessment for PWA is dependent on the clinical situation, the aphasic individual, and the assessor. However, using the clinical-neuroanatomical

approach, the general assessment typically begins with data-gathering, followed by a clinical assessment, which will usually involve one or more specific tests or a battery of tests. The assessment and test results are then used to identify and classify the type and severity of deficits.

The purpose of the assessment should be clarified at the beginning, as this will dictate the type of assessment required. Four main reasons for conducting aphasia assessments have been recognised: (1) screening or for diagnosis, (2) testing for rehabilitative purposes, (3) progress assessment, and (4) as part of an evaluation of the use of functional communication (O. Spreen & Risser, 2003a).

For the purpose of this thesis, only two tests will be discussed: the Western Aphasia Battery (WAB) (Kertesz, 1982) and the Butt Non-Verbal Reasoning test (BNVR) (Butt & Bucks, 2004).

i. Western Aphasia Battery (WAB).

The WAB is probably one of the most commonly utilized comprehensive aphasia assessment batteries currently available (Kertesz, 1982). The WAB is designed to diagnose, classify and assess aphasia severity. The WAB evaluates four language domains and three performance domains. The weighted responses in the language domains measure aphasia severity in the form of the Aphasia Quotient, while an overall measure of performance ability is calculated from the performance domains to yield the Performance Quotient. The sum of these two measures is combined to form the Cortical Quotient (O. Spreen & Risser, 2003b). Classification of aphasia type is determined from the language response.

The WAB has good internal and external validity and is reliable, which explains its frequent use. The main drawback is the time constraints required for its administration. For this reason, a bedside screener based on the WAB has been developed, which takes considerably less time and provides sufficient information to make a diagnosis and classify the type of aphasia present.

ii. Butt Non-Verbal Reasoning (BVNR) Test.

The BNVR (Butt & Bucks, 2004) is another in-depth test that evaluates problem-solving ability for patients with post-stroke aphasia. It is thought to be most useful in the acute stage, defined as up to six months. There is an initial screening component to ensure that sufficient perceptual

skills are present to conduct the test. After the screening, the individual is asked to solve 10 everyday problems. The final score is based on the 10 responses. Strengths of this tool include its good test-retest reliability, high sensitivity to changes, and rapid administration time. Limitations include the lack of research about its use.

c) Enhancing the communication process

All PWA experience communication difficulties. Each of these individuals require support, by any method possible, to enhance the communication process between themselves and the assessor. This can be achieved by any number of communication supports. The use of communication supports in any interaction with PWA is strongly recommended by all authorities (Aphasia Institute, 2015). A wide range of communication supports is available. These are discussed in more detail below. The section also covers the use of Augmentative and Alternative Communication (AAC), and aphasia-friendly material.

Strategies.

i. Communication supports.

The inherent nature of aphasia makes the process of communication difficult for PWA. To overcome this, it is recommended that PWA should be provided with the necessary support to enable them to participate in the communication process. This support should be in the form of communication supports.

"Communication supports" refers to "anything that supplements residual language to improve access to or participation in communication, events or activities for people with aphasia." (King, 2013) Given this broad definition, communication supports can range from tools and aids to the use of particular strategies, techniques, and even environmental changes or adaptions, all with the goal of enhancing and improving communication. Utilizing available communication supports for any intervention or intervention program is critical to aid understanding and enable communication between both parties.

ii. Categories of communication supports.

Four main categories of communication supports have been recognised: personally relevant intervention stimuli, contextual supports, supplemental supports and environmental supports. A

broad overview of these categories follows, with a focus on their use for supplementing the DMCA process. Since these methods all provide ways to assist communication with PWA, consideration should be given to their routine incorporation for all interactions with PWA, a recommendation supported by all national aphasia societies.

1. **Personally relevant stimuli.** Personally relevant communication supports involves the use of personally relevant stimuli to help engage the individual and support understanding and appreciation of the proposed intervention and its usefulness. An example of this includes the use of personally relevant photographs. A personally relevant photograph provides a connection with either the person showing it or for the viewer, and contains an image of the viewer or shows a setting which with the viewer is familiar (McKelvey, Hux, Dietz, & Beukelman, 2010).
2. **Contextual supports.** Contextual supports highlight the circumstances or setting around the message being communicated by putting the communication exchange in a relevant context. An example is using props such utensils or photographs of people eating when communicating about eating. Another form of contextual support is using visual-graphics, such as a "high context photograph," which portrays people interacting with each other in a specific environment. The main action of the scene is designed to independently reveal any relations among people and the objects, e.g., a photo of a football game with fans cheering as they watch the event (Dietz, Hux, McKelvey, Beukelman, & Weissling, 2009).
3. **Supplemental supports.** Supplemental supports are used to supplement the communication process. An example is a communication board.
4. **Environmental supports.** Environmental supports are changes or adaptations made within the environment to support the communication process for PWA. These may include the use of aphasia-friendly signage and documents, as well as improved educational awareness of aphasia. Perhaps one of the most important forms of environmental support is specialized communication training (such as Supported Conversation for Adults with Aphasia (SCA)) for all (potential) communication partners of persons with aphasia (Aphasia Institute). SCA involves a combination of different

techniques and methods to aid communication, such as spoken/key words, body language, hand drawing, and pictographs.

Augmentative and Alternative Communication (AAC) refers to a type of communication support that is designed to enhance residual communication ability and compensate for any communication deficits present. AAC is a broad term that covers a wide range of assisted and unassisted communication strategies and devices (American Speech-Language-Hearing Association), with the exception of speech.

The specific type of AAC required is dependent on the nature of the communication impairment, the encounter, and the individual involved (Sevcik & Romski, 2000). One potential AAC method of AAC involves an augmentative aid containing pictures or symbols, such as a communication board (Sevcik & Romski, 2000). Prior to using any form of communication support, a needs assessment is required to tailor the supports to the person's individual communication needs, as what works for one person may not for another.

iii. ***Aphasia-friendly material.***

There is a general consensus that any document, tool, or material available to PWA should be aphasia-friendly. Use of an aphasia-friendly format can help with the comprehension of written information (Brennan, Worrall, & McKenna, 2005) while improving PWA access to appropriately formatted patient material.

Certain formatting features have been recognized as being aphasia-friendly. These include clear wording, larger font size, white space between written information, including colour and graphics (T. A. Rose, L. Worrall, L. Hickson, & T. Hoffmann, 2011a). The use of short and simple sentences has also been shown to be helpful, as have highlighting or bolding important information, organizing the information in a logical manner, and including relevant graphics (Rose, Worrall, Hickson, & Hoffmann, 2012). One study looked at the specific text and formatting style preferences from a group of 40 adults with post-stroke aphasia. This group preferred larger font sizes (i.e., 14), certain font types (San serif), and line spacing of 1.5 to double (T. A. Rose, L. E. Worrall, L. M. Hickson, & T. C. Hoffmann, 2011b).

While visual graphics can be useful for augmenting and understanding communication, consideration must be given to the specific type of graphic to be employed. For instance, clipart

(and even internet pictures) may generate more harm than good (Brennan et al., 2005). Studies have shown that PWA prefer photographs and pictographic communication symbols compared to other sources. No particular preferences were identified about the presentation of numbers except for fractions, where orthographic representation was preferred (Rose et al., 2011a).

Aphasia-friendly material can benefit the communication process. However, some individuals find such modifications unacceptable and prefer unformatted documents. This highlights the importance of tailoring such material to individual preferences.

d) DMC in the setting of aphasia

i. History of DMCA for PWA.

The topic of assessing specific DMC in PWA was first described in 1970 in the context of testamentary capacity. The authors identified the need to assess and incorporate the evaluation of both verbal and non-verbal language (Critchley, 1970) into the DMCA process. Further studies, with the most comprehensive by Enderby in 1994, stated that elements of the language assessment that should be incorporated into DMCA for PWA should include identifying disparity between comprehension and expression, presence of paraphasias, whether yes/no confusions occur, and level of reading, writing and calculation ability (Enderby, 1994). A case study based on a legal hearing emphasized the influence of SLPs (who presented as an expert witness); the case study made clear that SLPs aid and facilitate communication, identify significant environmental factors, focus on functional assessment, and provide and describe strategies affecting communication (McKelvey et al., 2010).

ii. Challenges of conducting DMCAs for PWA.

Essential components of the DMCA process include the transfer, understanding, and communication of appropriate information between parties, which highlight some of the problems that can arise for individuals with language difficulties (Ferguson et al., 2003). During the usual DMCA process, shared decision-making occurs. This involves the active engagement and participation of both the person being assessed and the assessor, and the communication of decision-making information. This kind of engagement provides some evidence of informed decision-making ability. For PWA, however, due to the communication impairment, applying the DMCA process becomes difficult (Freedman, Stuss, & Gordon, 1991) and the process of

shared decision-making between the patient and clinician is disrupted (Brady & Kirschner, 1995; Kagan, 1995).

All individuals should be provided with all means necessary to assist with communication during these assessments. For PWA, this should involve the use of communication supports. However, despite general consensus, this does not always occur and, as a consequence, an assessor who does not manipulate and present information in a way that optimizes communication may falsely conclude that the individual being assessed lacks DMC (Kagan, 1995). Even though all individuals have the right to engage in such discussions, in the presence of any communication deficit, this right is often forgotten or forsaken.

Establishing specific DMC for PWA is particularly challenging. For people with communication deficits, the primary impairment in decision-making ability is information processing, which likely stems from problems in language and in the cognitive-communication process (Brady & Kirschner, 1995). Clinically, it is possible to observe difficulties in two areas: the way in which an individual registers pertinent information and the way he/she subsequently transfers it back to the assessor (Freedman et al., 1991). Although the deficits in aphasia may be primarily related to an isolated language impairment, more commonly they are due to the presence of combined deficits in information processing. As stated earlier, this makes it difficult to apply the DMCA process (Freedman et al., 1991). It may also complicate the usual process of shared decision-making between the patient and clinician (Brady & Kirschner, 1995). This is particularly so for complex domains of decision-making, such as financial decision-making. However, despite these difficulties, financial DMC has been an understudied area with minimal research conducted in the non-aphasic population, let alone in this unique, vulnerable population.

e) Communication support during DMCA process for PWA

The process for assessing DMC requires clear communication between the individual being assessed and the assessor, as previously discussed. In order to allow as fair and accurate an assessment as possible in PWA, all provisions should be made to enhance communication. This should include, as a minimum, incorporation of AAC (commonly in the form of aids) to improve communication techniques and strategies. However, incorporation of such basic measures to improve these critically important assessments is not routine. In contrast, in some countries, providing accessible information is a legal requirement.

To enhance the communication process, the Aphasia Institute recommends that all individuals working with PWA receive training in the use of SCA (Aphasia Institute, 2015), and other forms of communication support. The specific type of communication support needed for assessment of DMC has not been studied, as far as the author is aware. Visual communication is important for PWA, as evidenced by the use of graphics and colour in aphasia-friendly documents. This supports a role for supplemental visual communication support to assist with the financial DMCA process for PWA. Probably one of the simplest and most practical forms of visual communication support for such persons would be a specifically designed visual communication aid.

1.4. Role of DMCA tools in the assessment process

a) Introduction to the use of DMCA tools

Incorporating DMCA tools, aids, or tests in the DMCA process has the potential to significantly enhance the process. The term "tool" will be used herein to represent any instrument (including both tools and aids) used to assist the assessment process. The use of a standardized tool can help to support the decisions made and improve consistency and reliability between assessors. However, at present, in the absence of a single, standardized DMCA tool, the assessor's role in the DMCA process is purely supportive.

Currently available DMCA tools are all focused on either assessing decision-making abilities within a certain domain, or are designed to collect and provide information to inform the assessment decision. The term "DMCA instrument" (O'Connor, 2009) refers to those tools that evaluate decision-making abilities, while "DMCA screening tools" pertains to the assessment tools designed to evaluate the various processes required for decision-making capacity – e.g., cognition and function, to name a few (O'Connor, 2009).

Often these tools have been developed for purposes other than assessing DMC, but may provide additional and useful information to supplement the assessment decision. An example of a DMCA instrument is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (which will be discussed later), while examples of screening tools for cognition include the Mini Mental Status Examination (MMSE) and, for functioning, the Independent Living Scale (ILS). One essential consideration when using any DMCA instrument or screening tool is that

they must be used in with knowledge of what is being measured and the appropriate legal standards.

There is a plethora of DMCA instruments in the literature addressing healthcare decision-making regarding patient consent to treatment, which has been addressed in detail elsewhere (Dunn et al., 2006). An analysis of the available DMCA instruments identified the use of four main approaches, including a structured interview, hypothetical vignette with a structured interview, a structured interview guide, or a semi-structured interview technique (O'Connor, 2009).

To date, the predominant focus of research in this area has been on the development of DMCA instruments for healthcare decision-making: chiefly, patient consent and research participation. Considerably less research has been invested in the development of instruments designed to address other areas of decision-making. For the purpose of this thesis, the following discussion will be limited to only the most commonly utilized assessment instruments (the Aid to Competency Evaluation (ACE), MaCCAT tools, Assessment of Capacity for Everyday Decision-Making (ACED)) used for healthcare and personal care decisions.

i. DMCA instruments.

The Aid to Competency Evaluation (ACE).

The ACE (Etchells et al., 1995; Etchells & Joint Center for Bioethics) is a decisional tool that was developed in Canada to assist with the assessment of specific DMC for healthcare consent for inpatient treatment (Etchells et al., 1995). Although a useful tool, it is limited to just one area of DMC, and thus should not be used for other purposes.

The MacArthur Competence Assessment Tools (MacCAT).

The MacArthur Competence Assessment Tools (T. Grisso & P.S. Appelbaum, 1998) comprise three DMCA instruments, with each instrument designed for use within a specific setting. These include the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (Grisso et al., 1997), the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) (Dunn et al., 2006; Schaefer, 2013), and the MacArthur Competence Assessment Tool-Criminal Adjudication (MacCAT-CA) (Schaefer, 2013) (Dunn et al., 2006). Each of these instruments evaluates different areas of decisional capacity.

i. ***MacCAT-T.*** The MacCAT-T (Grisso et al., 1997) is one of the most commonly utilized instruments for DMCA. It provides the capacity assessor with a structured approach and can guide him/her through the evaluation of DMC for consenting to medical treatment. This instrument was designed specifically to evaluate DMC for consenting to treatment and should not be used for assessment of other areas of decision-making. The MacCAT-T is comprised of several parts, including a chart review and a semi-structured interview. The time required to use the MacCAT-T is around 15 to 20 minutes. The scores are derived from an evaluation of the decision-making ability in the four domains of choice: understanding, reasoning around risks and benefits, appreciation of consequences, and expression of choice. The MacCAT-T has been validated in three patient populations (dementia, schizophrenia, and depression) (T. Grisso & P.S. Appelbaum, 1998). Limitations include the training requirement for using the tool and interpreting the results (Grisso et al., 1997).

ii. ***MacCAT-CR.*** The MacCAT-CR (Dunn et al., 2006; Schaefer) assesses DMC to consent to research participation. The questions are tailored to the research study for which participation is being sought. The same four domains are assessed as in the MacCAT-T. Application of this instrument requires 20-25 minutes. However, it is possible to tailor the MacCAT-CR to assess competence for specific decisions.

iii. ***MacCAT-CA.*** The final MacCAT instrument is the MacCAT-CA (T. Grisso & P.S. Appelbaum, 1998), which evaluates an individual's competency to stand trial. Since this is beyond the scope of this thesis, this instrument will not be discussed further.

The Assessment of Capacity for Everyday Decision-Making (ACED).

For personal care decision-making, the most frequently employed instrument is the Assessment of Capacity for Everyday Decision-Making (ACED) (Lai et al., 2008). This instrument addresses and evaluates DMC for problem solving and/or decision-making around functional problems. Its primary aim is to evaluate an individual's ability to function at home. The ACED uses a semi-structured interview format to address the four key elements required for decision-making ability (understanding, appreciation, reasoning, and expression of a choice). This instrument has only been studied in individuals with mild-to-moderate dementia; however, within this population, the scores correlated well with the MMSE (Lai et al., 2008). There are several notable limitations to

using the ACED however, which include its inability to measure all domains of DMC and its limited target population.

One group has developed an "articulate-demonstrate" approach to evaluate decisional and executive DMC. This approach poses a set of screening questions to the individual, to assess his/her functional ability for self-care and protection (Naik, Lai, Kunik, & Dyer, 2008). It has not been generally applied because there is no formal instrument for application, nor has it been externally validated.

A review of the available DMCA instruments for assessing DMC for consent to healthcare treatment and research supports the use of the MacCAT-T and MacCAT-CR respectively. This support is based on the fact that they are the most frequently adopted and studied assessment instruments (Dunn et al., 2006). However, as with all other assessment instruments, there are considerable limitations associated with their use, and thus no single tool has been recognized as the "gold standard" for DMCA.

ii. DMCA screening tools.

Most screening tools that have been studied for use in DMCAs are designed to assess the individual's cognitive or functional abilities. The most commonly employed cognitive screening tools include the Mini-Mental Status Exam (MMSE) and Trail Making Tests A & B. One of the most frequently employed functional screening tools is the ILS. These screening tools are discussed in more depth in the section below.

The role of screening tools in the DMCA is to provide supplementary information to support the results from the DMCA; the screening tools are not diagnostic in and of themselves, and should not be used in isolation, nor do they play a role in the DMCA process. This is in contrast to DMCA instruments; they are directly incorporated into the DMCA process, and the results directly impact the assessment results.

1. Cognitive screening tools. Cognitive screening tools are tools used to screen for the presence of any underlying cognitive dysfunction, the presence of which could influence DMC. The results obtained are used to *supplement* the DMCA process. Table 1 highlights the most commonly recognized cognitive screening tools, and includes a summary of their use.

Table 1

Cognitive screening tools

Instrument	Function	Population	Benefits	Limitations
MMSE (Folstein, Folstein, & McHugh, 1975)	Brief screening tool that assesses cognition in the domains of orientation, attention, visuospatial, language and memory.	Older adults with dementia (Alzheimer's), Stroke	Simple to apply and quick to administer. Certain scores correlate with DMC ability (Tombaugh & McIntyre, 1992). Available in many languages.	Does not evaluate domains required for DMC. Results are influenced by many factors (age, education, language) (Tombaugh & McIntyre, 1992).
Trail Making Tests (A&B) (O. Spreen & Strauss, 1998)	Screening tool that assesses attention, cognitive processing speed, task switching/mental flexibility.	Dementia	Simple to use. Results linked to financial ability via Financial Capacity Index (Sherod et al., 2009).	Use of outside financial DMC assessments not well validated.
Clock Drawing Test (Agrell & Dehlin, 1998)	Assesses executive functioning, visuospatial domain, and memory. Several different methods available (free-drawn, pre-drawn).	Dementia (Alzheimer's)	Results have been shown to correlate to DMC. Good test/retest reliability. Most useful when used in conjunction with other tools (Royall et al., 1992).	Wide diversity of scoring methods. Can be influenced by education, age and mood.
EXIT 25 (Royall et al., 1992)	More comprehensive screening tool of multiple cognitive domains.	Dementia (Alzheimer's, vascular), depression, schizophrenia	Diverse range of cognitive domains assessed. Scores linked to function in dementia population.	Lack of score standardization (Royall et al., 1992). Lengthy to administer.

Table 1 provides an overview of cognitive screening tools that are currently available

2. Functional screening tools. Evaluating the functional ability of an individual is important for providing an objective assessment of his/her current performance on a day-to-day basis. The focus of these functional evaluations should be on determining an "overall level of adaptive functioning" (i.e., activities of daily living (ADL) and/or instrumental activities of daily living functioning (IADL's)) (Stebnicki, 1997), which takes into consideration the specifics of behaviors used, environmental demands, and available resources (Stebnicki, 1997). The two main requirements for any functional screening tool are that the tool is performance-based and situation- or decision-specific (O'Connor, 2009). A sample of the more commonly used and recognized functional screening tools currently available is summarized below, in Table 2.

Table 2

Functional screening tools

Instrument	Function	Population	Benefits	Limitations
Direct Assessment of Functional Abilities (DAFS) tool (Loewenstein et al., 1989; Napier et al., 2007)	Evaluates the individual's ability to perform IADLs and ADLS, and incorporates a multidimensional approach in its assessment.	Dementia, elderly	Multidimensional assessment. Excellent inter-rater reliability.	Does not address all areas of ADLS. Limited to use in clinical setting.
Independent Living Scale (Loeb, 1996)	Evaluates 5 cognitive domains (memory/orientation, money management, managing home and transportation, health and safety, and social adjustment).	Elderly	Reliable tool.	Does not assess functional ability for basic ADL Unclear correlation between DMC and ILS scores (Baird, Podell, Lovell, & McGinty, 2001).
University of California Performance-based Skills Assessment Brief (UPSA – Brief) (Mausbach, Harvey, Goldman, Jeste, & Patterson, 2007)	Abbreviated version of the University of California Performance-based Skills Assessment (UPSA)	Schizophrenia	High correlation for areas of specific decision-making (e.g., accommodation)	Limited research in use of this tool for assessing financial decision-making capacity
Kohlman Evaluation of Living Skills (KELS) tool (Mausbach et al., 2007)	Assesses 5 subscales evaluating 17 different areas, including ADLs, IADLs, money management, safety, and health. Includes self report, observation, and performance-based components.	Self-neglect	Evidence supporting its use with people in cases of self-neglect.	Limited evidence for its use in other situations.
Instrumental Activities of Daily Living (Lawton & Brody, 1969)	Self-report and/or proxy completed scale.	General population	Most frequently used scale for evaluating IADLs.	No research into its role with DMC.

Table 2 provides an overview of the functional screening tools that are currently available

iii. Financial DMCA tools.

At present, no single tool has been recognized as being the gold standard for aiding assessments of financial DMC. A wide range of tools have been developed and proposed. These are summarised in Table 3, which provides information about their purpose, target population, advantages, and limitations.

Table 3

Financial DMCA tools

Instrument	Purpose	Population	Advantages	Limitations
Financial Capacity Instrument (FCI) (D. C. Marson et al., 2000a)	Assess financial knowledge, judgement, and executive ability required for performing financial transactions. Revised several times, with addition of 3 domains (Criminal Justice Research, 2017).	Dementia	Comprehensive tool. Excellent reliability. Well validated.	Reliability is limited to specific task level (D. C. Marson, 2001). Takes 45-60 mins to administer.
Measure of Awareness of Financial Skills (MAFS) (Cramer, Tuokko, Mateer, & Hultsch, 2004)	Uses information collected from both the participant and informant using a standardized questionnaire, in addition to objectively assessing performance in 6 areas.	Dementia	Recommended for clinical and research use. Good reliability and validity. Quick to use.	Limited evidence supporting its use.
Direct Assessment Functional Status Scale (DAFS) (Loewenstein et al., 1989)	21-item tool that measures 5 different functional abilities.	Dementia, schizophrenia.	High inter-rater and test-retest reliability	Does not address all three key knowledge components required for evaluating financial capacity.
Self-Reported Financial Skills Scale (SRFS) (Napier et al., 2007)	6-item participant-completed scale, which asks about financial ability. Domain assessed is similar to that assessed by the DAFS.	Schizophrenia	Brief to administer (5 mins)	Has not been formally validated
Prior Financial Capacity Form (PFCF) (Wadley, Harrell, & Marson, 2003)	Elicits self-reports of financial judgements about a patient's financial functioning prior to developing dementia. Used in conjunction with CFCF to determine prior and current financial functioning.	Dementia (Alzheimer's)	Unique in that it compares the individual's pre-morbid functioning to his/her current functional ability	Limited use in persons unable to self-report
Current Financial	Assesses global financial judgement, along with judgement about current financial			Limited use in persons unable to self-report.

Capacity Form (CFCF) (Wadley et al., 2003)	functioning in 8 financial domains and on 20 associated tasks. Used in conjunction with CFCF to determine prior and current financial functioning.	Dementia (Alzheimer's)	Unique. Compares the individual's pre-morbid functioning to his/her current functional ability	Requires collateral source. Assessment does not include performance measures.
Semi-Structured Clinical Interview for Financial Capacity (SSCIFC) (D. C. Marson et al., 2009)	Assesses financial knowledge and performance using an interview format which examines the individual's competency in 8 of the domains from Marsons financial conceptual model.	Dementia (Alzheimer's), MCI	Includes assessment of financial knowledge and performance testing	Great variability in assessment outcomes because clinician assessments of competency are incorporated into results.
Hopemont Capacity Assessment Interview (HCAI)-Financial (Edelstein, 1999; Edelstein, Nygren, Northrop, Staats, & Poole, 1993; Moye, 2003)	Semi-structured format involving three theoretical scenarios for the participant to solve. Addresses judgement, knowledge, and appreciation of consequences.	Cognitively impaired individuals	Good reliability. Test-retest reliability is moderate. HCAI-financial has been moderately correlated with MMSE scores amongst LTC residents.	Use is mostly for medical decision-making Limited research about its use
Financial Competence Assessment Inventory (FCAI) (Kershaw & Webber, 2008)	Structured interview format that evaluates 38 items and includes assessment of 6 tasks.	Acute brain injury, dementia, Huntington's Disease and schizophrenia	Good reliability and validity. Correlates with the ILS Money Management scale and HCAI financial component	Requires training before its use. Requires administrative skill for administration. Lengthy to administer.
ILS - Money Management subtest (Loeb, 1996)	Subcomponent of the ILS assessing 17 items divided into problem-solving and performance/information.	Dementia, schizophrenia	Assesses financial knowledge and includes performance task	Although ILS scale has been validated, money management sub test has not. Lacks assessment of the multi-dimensional concept of financial capacity

Table 3 provides an overview of the financial DMCA tools that are currently available.

A large number of cognitive and functional screening tools are available to use in the DMCA process; however, there is no single tool that has been recognized as the gold standard for use within its category. For assessments of financial DMC, the most commonly used and studied is

the Financial Capacity Instrument (FCI), but again, the exact tool chosen depends on the aforementioned factors.

Given the lack of a gold standard DMCA tool to support the assessment of personal and financial DMC, the exact type and number of tools will depend on the decision being made, the individual's characteristics and requirements, and the assessor's needs. However, it is advisable that a combination of both a cognitive and functional screening tool be employed for any DMCA. The results obtained are then used by the assessor to identify for the presence of cognitive impairment impacting on the decision making ability, while also providing an overview of functional capacity.

e) Role of DMCA tools in the assessment process

Although not routinely employed, there is growing support for incorporating formal DMCA tools within the DMCA process. While the use of such assessment tools may provide additional information to support the assessment results, they are not a substitute for conducting a formal DMCA, and no single DMCA tool has been recognised as being the standard to use for these assessments. Please refer to the sections above, which describe in detail the roles and type of tools available.

1.5. The assessment of DMC in PWA

a) Background

Current problem.

There is currently limited research about DMC in PWA, with no literature addressing financial DMC in PWA. This is evident in the narrative review performed on legal and financial DMC in PWA (Chapter two). Given the communication difficulties experienced by PWA and the requirement that "all communication methods be made available" when performing any DMCA, it is very surprising that there is only one communication aid currently available to support the DMCA process. This communication aid is for accommodation decision-making only, with no similar communication aids available to support assessments of financial DMC. Despite being a relatively specific and unique population, given the considerable difficulties that are currently experienced by PWA during the DMCA process, and especially for financial DMCAs, there is a dire need to develop a communication aid to support financial DMCA for PWA.

b) Study overview

We employed a mixed-methods design that was divided into three separate Phases. A flow diagram highlighting each Phase is shown below in Figure 1, which helps provide a clear and easy-to-understand overview of the study design. Chapter three provides a comprehensive description of the study method, and a detailed outline of each of the three Phases.

Figure 1:

Schema of the study design

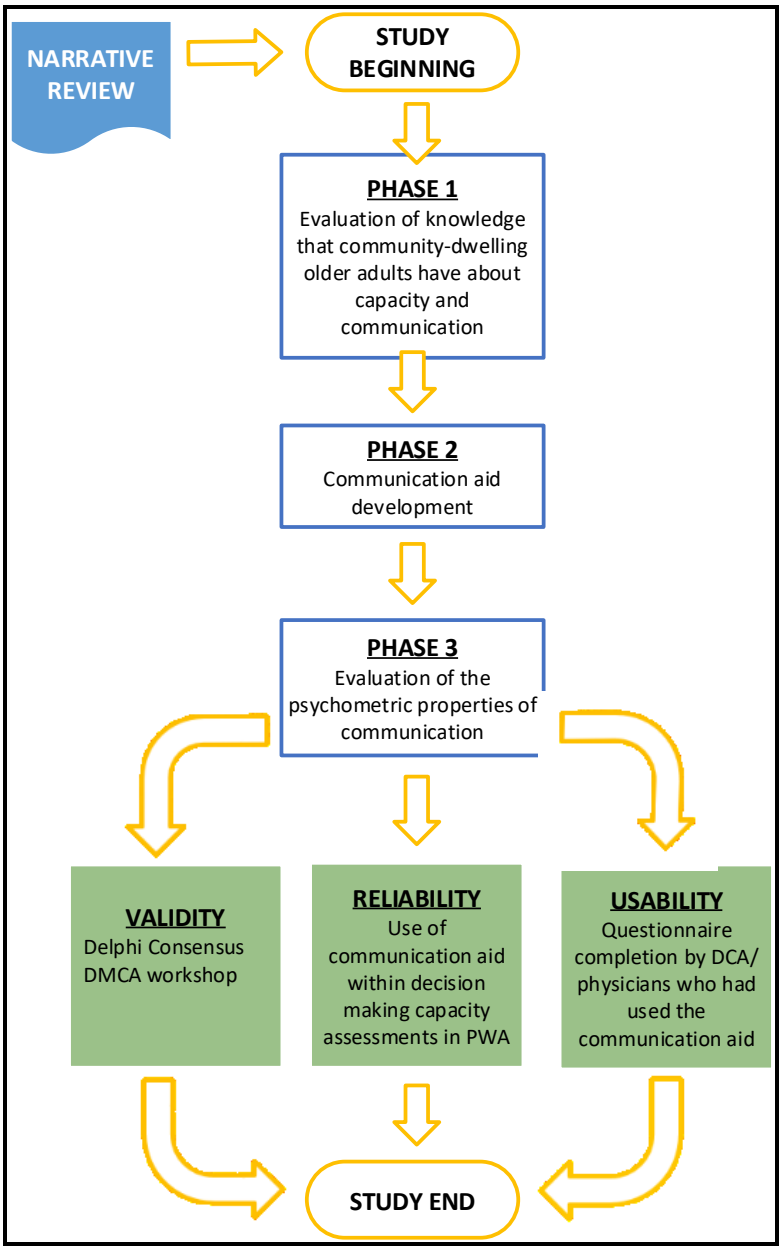

Figure 1 shows a schema showing study design

1. Narrative review (Chapter two).

The initial step prior to commencing the study was to perform a narrative review of current literature about financial and legal DMC in PWA. The literature review is in Chapter two.

2. Phase one (Chapter three).

The first Phase of the study involved exploring the awareness and understanding that community-dwelling older adults have about DMC (including financial and legal decision-making), and communication and its disorders, including aphasia. This was achieved through the use of focus groups.

3. Phase two (Chapter three).

Phase two focused on the development of a new visual communication aid to support assessments of financial DMC in post-stroke PWA. Focus group feedback, along with guidance obtained from the DMCA worksheets and SLPs, were used to guide the content of the communication aid.

4. Phase three (Chapter three).

The final Phase of the study involved evaluating the psychometric properties of the communication aid using a combination of methods. The validity of the communication aid was assessed using Delphi Consensus, while reliability of the communication aid was determined using the communication aid in 30 financial DMCAs. The usability of the communication aid was determined through an ease-of-use questionnaire.

Chapter Two: Financial And Legal Decision-Making Capacity In The Aphasic Population – A Narrative Review

2.1. Abstract

a) Introduction

Capacity is assumed to be present unless proven otherwise. Assessments of specific decision-making capacity (DMC) for financial and legal decisions, although challenging in the general population, becomes almost impossible for individuals with language disorders (i.e. aphasia) in the absence of appropriate communication aids. Several capacity aids exist for the general population; however, it is unclear whether any communication aids exist specifically for the aphasic population to assist assessment of financial and legal DMC.

b) Method

A literature review was conducted of 6 databases with the assistance of a research librarian. From 171 articles screened, 12 were included in the final review.

c) Results

The literature focus was on medical DMC, and in particular, patient consent. Few articles addressed legal or financial DMC. Several articles identified the presence of general and specific capacity aids for the general population; however, there was a clear absence of similar communication aids available for the aphasic population, with only one communication aid identified to assist with DMC assessment for healthcare and accommodation decisions only.

d) Conclusion

Whilst a significant amount of research has been done on DMC, it is mostly focused on healthcare; in particular, on patient consent for treatment for the non-aphasic population. Although a communication aid exists to aid assessment of DMC for healthcare for aphasic individuals, no similar tools exist to aid financial and legal DMC assessments. This paper highlights an important problem encountered during clinical practice which requires further research.

2.2. Financial and Legal Decision-Making Capacity in the Aphasic Population – A Narrative Review

a) Introduction

Capacity is an important and complex medico-legal topic which is often misunderstood. For a variety of reasons, many physicians are not comfortable with conducting assessments of an individual's decision making capacity (DMC). Research in this area has been focused mainly on medical decision making, specifically patient consent, with little directed on DMC assessment of financial and legal affairs.

However, there has been a significant growth in the demand for physicians and other eligible individuals to perform DMC assessments. DMC assessments of people with communication problems (i.e. aphasia) are difficult if not impossible, indicating a need for communication aids.

This paper's main objectives are to review the current literature dealing with financial and legal DMC assessments in aphasic individuals and to identify communication aids needed to help these assessments.

b) Methods

A literature search was conducted using the following databases: CINAHL, Medline, Academic Search Complete, Embase, Psychinfo and ComDisDOME; assistance was obtained from a research librarian to identify all appropriate key terms, words and MeSH headings. As a small number of articles were retrieved no time frame limits were used for conducting the searches. Search keywords included: aphasia, capacity, ability, competency, legal, finance, money, decision making and make decisions. Additional articles were also identified by hand searching the references of selected articles and in grey literature using recognized search techniques. Articles whose topic focus did not include one or more of the following were excluded: aphasic individuals, decision-making ability / capacity and / or financial or legal making capacity. From 171 articles initially screened, 12 articles were included in the review.

Table 4

Results from the primary literature search

SEARCH DATE	DATABASE	KEYWORDS	STRING OF TERMS USED	HITS
June 20, 2016	CINAHL (EBSCOHost)	aphasia, capacity, ability, competent, legal, finances, money, decision making, make decisions	aphasia* AND ((capacity or ability or competen*) n10 (legal* or financ* or money or decision making or make decisions))	19
June 20, 2016	Medline (ESBCOHost)	Aphasia, capacity, ability, competent, legal, finances, money, decision making, make decisions	aphasi* AND ((capacity or ability or competen*) n10 (legal* or financ* or money or decision making or make decisions))	21
June 20, 2016	Academic Search Complete (EBSCOHost)	Aphasia, capacity, ability, competent, legal, finances, money, decision making, make decisions	aphasi* AND ((capacity or ability or competen*) n10 (legal* or financ* or money or decision making or make decisions))	14
June 20, 2016	Embase (OVID interface) 1974 to 2016 June 17	Aphasia, capacity, ability, competent, legal, finances, money, decision making, make decisions	1. aphasi*.mp. 2. ((capacity or ability or competen*) adj10 (legal* or financ* or money or decision making or make decisions)).mp. 3. 1 and	35
June 20, 2016	Psycinfo (OVID interface) 1806 to June Week 3 2016	Aphasia, capacity, ability, competent, legal, finances, money, decision making, make decisions	1.aphasi*.mp. 2. ((capacity or ability or competen*) adj10 (legal* or financ* or money or decision making or make decisions)).mp. 3. 1 and 2	35
June 20, 2016	ComDisDome (Proquest interface)	Aphasia, capacity, ability, competent, legal, finances, money,	aphasi* AND (capacity or ability or competen*) AND (legal* or	31

		decision making, make decisions	financ* or money or decision making or make decisions)	

Table 4 shows the results from the primary literature search

Table 5

Number of hand-picked references

DATE	HITS
June 27	7
June 28	3

Table 5 shows the number of hand-picked references, per date

Table 6

Results from a grey literature search

DATE	DATEBASE / SOURCES	SEARCH TERMS	HITS
June 28	Google	aphasia communication tools	1
June 28	Google	assessment legal capacity aphasia	4
June 29	American Speech, language and hearing association	Augmentative and Alterative communication	1

Table 6 shows the results obtained from a search of grey literature

c) Results

Much of the literature retrieved related to capacity and/or competence and focused on issues arising when performing DMC assessments in the general population. Many articles discussed medical DMC regarding patient consent and only a small number addressed legal or financial DMC. No formal guidelines or regulations were identified addressing financial or legal decision-

making. Several articles focused on the potential role of speech and language pathologists (SLPs) in DMC assessments for aphasic individuals.

There are several aids available to help DMC assessments in the general population but none were designed to help (specific) DMC assessments of aphasic individuals.

d) Discussion

1. Decision-making capacity.

The term 'capacity' is frequently used interchangeably with competence. In the medical community, DMC refers to the ability of the patient to understand, register the information and use this information to come to an informed decision whilst competence is considered to be the legal equivalent of capacity. By comparison, SLPs have viewed capacity as the theoretical ability for decision-making, while competence is seen as the individual's actual functional ability. For ease of reading, the two terms will be used interchangeably unless stated otherwise.

Decision-making capacity requires 'multiple cognitive-linguistic abilities, including understanding information relevant to a decision, manipulating that information in a deliberative process, appreciating the consequences of making or not making a decision, and communicating a choice.' (Appelbaum, P. S., & Grisso, T. 1988) No standardised definition exists for capacity; instead, the precise definition will depend upon the quoting source. The province of Alberta has defined capacity as 'the ability to understand the information that is relevant to the decision and to appreciate the reasonably foreseeable consequences of a decision, and a failure to make a decision.' Despite variations, most will reference the key elements required for establishing the presence of DMC.

2. What does DMC involve?

When commenting on an individual's decision-making ability, this should always be relating to a specific decision or decisions within a certain 'domain'. The most commonly recognized domains requiring testing include healthcare, accommodation, finances and legal affairs; additional domains infrequently assessed includes choice of associates, leisure or social activities, education and employment (Alberta Health Services, 2018). The aforementioned domains are those recognized by the author's local health authority in their standardized capacity worksheet (Alberta Health Services, 2018). Whilst the assessment of healthcare and

accommodation domains is self-explanatory, the assessment of the domains for financial and legal affairs are more complex. Recommended areas which require assessment for financial DMC include an assessment of their basic monetary skills, financial conceptual knowledge, cash transactions, check book management, bank statement management and financial judgement (Marson et al., 2000).

The specific DMC assessment for legal decision-making is less clear, but should, at a minimum, assess their ability to make a will; additional areas include personal directives, power of attorney and legal rights.

Before assessing DMC, it is vital that the assessor, usually a physician, clearly defines the specific decision or domain for which DMC is to be assessed. Also, the individuals being assessed may have specific DMC for one task but not another. DMC can fluctuate over time, especially when the impairment is related to the presence of one or more active medical condition or from the effects of medication.

3. Conducting DMC assessments.

Capacity is assumed to be present unless proven otherwise; therefore, an assessment of an individual's DMC is only indicated when there has been a clear trigger (i.e. fluctuating decisions made out of context for the individual) or in the presence of a medical condition which may affect DMC (i.e. cognitive decline, language disorders). Currently, there are no formal guidelines or protocols available detailing the specific requirements for conducting DMC assessments; instead, assessments are usually dictated by local health authority standards / requirements. For example, Alberta Health Services (AHS) has created a capacity worksheet to guide DMC assessments for any of the domains aforementioned (Alberta Health Services, 2018). The basic assessment process will usually involve conducting a semi-structured clinical interview between the assessor and individual being assessed. Since an essential component of the interview is adequate communication by both parties, any deficits in the production, communication or understanding of this information will affect the assessment results. This highlights some of the problems that can arise for individuals experiencing language difficulties.

4. Who can assess capacity?

In Alberta, provincial regulation dictates that all physicians, surgeons and psychologists, by way of their professions, are legally able to conduct capacity assessments when indicated (Government of Alberta, 2000). Other eligible individuals (such as registered nurses, occupational therapists) can also perform DMC assessments provided they undergo specialized training.

5. DMC in aphasic individuals.

DMC assessments are a commonly required part of clinical practice, where decisions are required of individuals who may lack competence. Although the assessment may be relatively straight forward in the general population, in the presence of communication deficits the assessment process becomes difficult or impossible. Thus, aphasic individuals are usually unable to meet all the required criteria for confirming capacity despite potentially having sufficient skills present.

6. Aphasic population.

Aphasia is a recognised condition representing a broad array of communication difficulties but it has no universally accepted definitions perhaps because of its broad and various presentations (American Speech, Language and Hearing Association, 2016). The American College of Speech, Language and Hearing Association has defined aphasia as being ‘an acquired neurogenic language disorder resulting from an injury to the brain, most typically the left hemisphere that affects all language modalities’. This proposed definition is broad in nature; hence, the term aphasia refers to any disorder involving varying degrees of impairment in either verbal or written language, or reading comprehension. Although the incidence of aphasia is thought to be low within the general population, its incidence may be up to 30% (Dickey, L. et al, 2010) in high risk populations, e.g. post stroke patients.

Establishing specific DMC in aphasic patients is particularly challenging. Ethical conduct dictates that any individual being assessed should be provided with all means necessary to enable them to participate fully within these assessments. For aphasic individuals, this should include integration of ‘Augmentative and Alternative Communication (AAC)’ to enhance and compensate for communication deficits present. AAC is a broad term used to refer to a wide range of (assisted and unassisted) communication strategies and devices (American Speech,

Language and Hearing Association). The specific type of AAC used is dependent on the type of communication impairment present, the nature of the encounter and the individuals involved but most commonly involves the use of communication aids.

Assessing DMC in aphasic individuals is not new and was first described in 1970 in relation to testimony capacity. Further studies, importantly by Enderby in 1994, stated that elements of the language assessment should be incorporated into capacity assessments for aphasic individuals, which should include: identifying disparity between comprehension and expression, presence of paraphasias, whether yes / no confusions occur, level of reading, writing and calculation ability (Enderby, P., 1994) A case study based on a legal hearing emphasised the important influence of an SLP (who presented as an expert witness) for aiding and facilitating communication, and provision of a description of positive and negative strategies affecting communication (Ferguson et al, 2003)

In England and Wales, the Mental Health Act (2005) states that 'every effort should be made to support individuals to make an informed decision, and that information should be provided in different formats for those who have difficulty understanding information in traditional written or spoken forms' (Mental Capacity Act, 2005). This should include incorporation of AAC (often in the form of aids) to improve communication techniques and strategies; the provision of accessible information forms is a legal standard in certain countries. Although several aids are available to help with capacity assessments (Mental Capacity Act., 2005), there are only a limited number of tools in existence to aid capacity assessments with aphasic individuals for any domains, let alone legal or financial affairs.

7. DMC aids for the aphasic population.

Several aids exist to assist general DMC assessments for the general population (i.e. Aid to Capacity Evaluation (ACE)) (Bioethics) and a single aid exists to assist with financial decision making capacity, but none have been designed specifically for the aphasic population.

A specifically designed communication aid to help specific DMC assessments involving healthcare and accommodation for the aphasic population is currently available. The CACE (Carling-Rowland A et al., 2014) communication aid was validated in a population of individuals with aphasia, and was shown to be effective in improving communication and information transfer by demonstrating a better appreciation of the aphasic individual's decision-making

understanding and ability. This is the only tool of its kind available that the author is aware of; whilst it has been shown to be effective, its use is restricted to support decision making for healthcare and accommodation.

e) Conclusion

DMC is an important and growing area of medicine encountered by many physicians; capacity is assumed for all, and is only assessed when clinically indicated. The assessment of an aphasic person should be conducted with the provision of appropriate aids or strategies deemed necessary to enhance the communication process. However, there are no communication aids currently available to assist assessment of financial and legal decision-making capacity for aphasic individuals.

Accordingly, this literature review has identified a lack of research in the area of specific DMC for legal and financial affairs for the aphasic population and an associated absence of communication aids to assist with these difficult and complex assessments. This is an important finding given the high number of people who are aphasic or likely to develop aphasia and the need to assess their DMC in financial and legal matters. There is an urgent need for further research and development of aids to deal with these difficult issues.

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Chapter Three: The Validity and Reliability Of a New Visual Communication Aid to Assess Financial DMC in PWA

The primary objective for this study was to develop and establish the psychometric properties of a new visual communication aid to assist with the assessment of financial DMC for post-stroke PWA. In order to do this, it was important to first determine how a new instrument is validated. This is described in Section 3.1. The background of the study is discussed in Section 3.2, followed by a comprehensive description of the study method (Section 3,3), ethics approval (Section 3.4) and finally, the results (Section 3.5).

3.1. Validation of a new research instrument

The utility of any proposed research measure or instrument should be established prior to its use. This requires "the assessment of its reliability and validity as a form of measurement." (Ginty, 2013) Reliability of an instrument refers to its "ability to produce consistent, stable results over time" (Salmond, 2008), while validity is "the extent to which the measurement instrument measures what it says it measures." (Salmond, 2008) The usability of an instrument is equally important, and will influence how well it is taken up by the target population. Each of these properties will be discussed in more depth in the following sections.

a) Reliability

Reliability is an important psychometric property used to ensure that consistent results are obtained from a target population in a standardized setting. Establishing the reliability of any assessment instrument requires an objective assessment of its inter-rater reliability (the agreement of results between two different observers); by comparison, establishing the reliability of subjectively administered instruments is demonstrated by test-retest reliability (obtaining similar results with repeated use of the instrument by the same individual on separate occasions) (Streiner, 2011), and measuring the correlation between these scores. Inter-rater agreement can be evaluated by calculating the kappa statistic, with agreement being conventionally described using the following criteria: 0-0.19 is slight, 0.20-0.39 is fair, 0.40-0.59 is moderate, 0.60-0.79 is substantial, and 0.8-1.0 is almost perfect (Landis & Koch, 1977).

The other important construct of reliability to consider is its internal consistency ("the degree to which the instrument items are correlated to one another" (Streiner, 2011)); however, depending on the type and purpose of the instrument, this may not always be required. Internal consistency can be calculated using Cronbach's α statistic (an index measure of reliability).

b) Validity

Validity is a comprehensive area of study, and different classifications of validity have been proposed. Internal validity shows that the instrument is representative and measures what it is intended to measure, and can be demonstrated by establishing content validity (defined as "the extent to which the instrument is representative of the content of the property being measured") (Kerlinger, 2000). Content validity is confirmed by comparing the instrument's content with known reference standards, current literature and/or through its assessment by experts in the field.

External validity, defined as "the extent to which a study's results can be generalized/applied to other people or settings," (Huitt, Hummel, & Kaeck, 1999) ensures that the tool is generalizable to the target population outside research conditions. Construct validity reflects the "degree to which an instrument measures the construct it is intended to measure," (Cronbach & Meehl, 1955) and is used to establish external validity. Construct validity can be operationalized using face validity (defined as "an estimate of the degree to which a measure is clearly and unambiguously tapping the construct it purports to assess") (Bornstein, 2007), and is assessed by asking participants to identify the purpose of the tool or instrument (Bornstein, 2007). While the use of face validity as a measure of construct validity may only be relevant in certain situations, for the purpose of establishing the psychometric properties of this proposed communication aid, both face validity and content validity can be established.

c) Usability

The final psychometric property to establish for a new research instrument is its usability (in other words, "how feasible is it for you to use in your setting") (Streiner, 2011). This requires consideration of the educational level of the recipient and user, the time required to administer the instrument, and the need for prior training. This can be assessed by obtaining feedback from those who use the instrument in its intended setting.

3.2 Study background

a) Problem statement

All individuals are presumed to have DMC unless otherwise proven. Although this presumption is normally of no concern in the general population, people with communication difficulties who cannot express themselves clearly will often perform poorly during the DMCA, or have difficulty participating in the process. Consequently, they may be labelled as "lacking capacity" (Sharp & Mills, 2002; Wagner, 2003). Although demoralizing for individuals who truly lack specific DMC, it is of even greater concern for those individuals who have not been provided with the necessary means to facilitate a full assessment. A specially designed communication aid to assist and provide a voice for these patients can only help (and ideally allow) an accurate assessment to proceed.

The process for assessing DMC requires clear communication between the individual being assessed and the assessor. Given the difficulties experienced by PWA and the previously described recommendations (Goverment of Alberta, 2013; Office of Public Sector Information, 2005) to provide accommodations for these individuals to support the DMCA process, the use of a bespoke communication aid to assist with such assessments is a crucial component to allow these individuals with the opportunity to participate in a fair and accurate assessment.

People with cognitive or language disorders often need DMCAs in situations requiring significant decisions about financial matters. Even though the complexity of financial decisions can vary, they typically involve higher (or advanced) levels of functioning required for independent daily living, and require a wide range of cognitive and language abilities to perform (D. C. Marson et al., 2000a; Wollinsky & Johnson, 1991). The consequences that can arise from a loss of financial DMC are significant for both the individual and family, as described in Chapter one. The assessment of financial DMC, therefore, is an important and complex process, which should not be undertaken lightly.

A narrative review was performed, which identified an absence of communication aids for assisting with, specifically, DMCAs around legal or financial matters in PWA (Carr, 2016) (Chapter two). Although DMCA tools exist to help with the DMCA as a whole (i.e., Capacity Interview Worksheet) (Alberta Health Services, 2018) or for decision-making in specific

domains (MacCAT), there is only one communication capacity aid for DMCA for PWA. It addresses personal-care decision-making for accommodation only. No similar communication aids exist to help assess financial or legal DMC.

b) Research question

1. Can the validity and reliability be established for a newly constructed visual communication aid designed for assisting the assessment process of financial and legal DMC for PWA?
2. Is this communication aid feasible for capacity assessors to use?

3.3 Method

A quasi-experimental mixed methods study design was chosen for this study. This type of study design is commonly utilized for validation studies as it provides the opportunity to combine qualitative and quantitative research within a single study, which is important when the focus of the research is the development and validation of a new instrument. It also provides an opportunity to control the intervention while allowing some control of other confounding factors, and can help to enhance the generalizability of the results, which is critical for this research. Another advantage to this approach is that it allows for the use of data triangulation. This was important when developing the communication aid.

The study was conducted in three Phases, over four years. Due to difficulties achieving the required sample size for participant recruitment, the study is ongoing. Phase one involved exploring community-dwelling seniors' knowledge about general and specific DMC, and about communication and communication disorders. This was done using focus groups. Phase two involved the development of the visual communication aid and supporting documents. The final Phase involved establishing the psychometric properties of the communication aid- e.g., validity, reliability and usability—through a variety of methods, which included conducting two Delphi Consensuses, using the communication aid in DMCAs, and distributing and collecting questionnaires for post-study feedback.

a) Phase one

The first Phase involved exploring general community-dwelling older adults' understanding of general and specific (financial and legal) DMC and communication. This included methods of

communication and its disorders. The best way to collect this data was through focus groups, using participants selected from the intended population. The number of focus group sessions required was determined by how much information was needed to achieve data theme saturation.

i. Focus groups.

The focus group population comprised community-dwelling adults 65 years or older, who were recruited from local community centers and two of the local hospital volunteer programs (University of Alberta (UAH) and Glenrose Rehabilitation Hospital (GRH)). A purposeful sampling technique was used for recruitment. Formal selection criteria were used to identify a homogenous group of appropriate participants who would be able to provide the information required.

Recruitment strategies included poster adverts, which provided information about the study and the planned focus groups. These were displayed in the community center and hospital volunteer department. Other strategies included in-person presentations about the study at the local community center, and by electronic communication, with email. The planned focus group size ranged from five to eight participants, which was thought to be appropriate to allow the sufficient data diversity but not large enough to be unmanageable (Saldana & Omasta, 2017).

The group sessions were conducted at one of the local community centers and in one of the hospitals (UAH). Each focus group session was facilitated by two or more members of the research team and basic refreshments were provided. Prior to their sessions, all focus groups participants were required to sign a consent form, which guaranteed confidentiality of the data obtained and included permission to audio record each session. The discussions from each session were documented using a handheld digital recorder.

The topic of these sessions was guided by a set of standardized questions that covered the following areas: general and specific (financial and legal) DMC, and communication and its underlying disorders, and methods of communications. Each session was divided into two discussions: the first included 15 questions, which covered the topic of general and specific (financial and legal) DMC. The second included 13 questions, which asked about communication, its disorders, and methods of communication (Appendix 1). Each group was also shown an initial draft of the communication aid, and feedback was encouraged.

ii. Data analysis.

After completion of all the focus groups, the session recordings were transcribed by an independent party. Any personally identifying information was removed during this process. Transcribed data was thematically analyzed, with NVIVO software (Version 12)(QSR International) used to support data analysis. The generated themes were used to inform and guide the development of the new visual communication capacity aid.

b) Phase two

Phase two involved the development of the new visual communication aid to assist with the assessment of financial and legal DMC. Content for the communication aid was obtained using a triangulation of data sources, which included focus group feedback and the generated themes, images purchased from the Aphasia Institute, SLP feedback, and content from the Capacity Interview Worksheets (Alberta Health Services, 2018). The questions included on the communication aid were guided by those in the Capacity Interview Worksheets (Alberta Health Services, 2018). The themes identified from the focus group sessions were transformed into pictographic representation for each question, and were incorporated into the visual communication aid.

During this time, and after several meetings with the research team and the thesis committee, it was recognized that it would be extremely difficult to develop a single comprehensive communication aid that would adequately cover the assessment of these two separate domains of decision-making; assessing financial and legal decision-making together is simply too complex. Therefore, the decision was made to change the research question and focus of the study to the development and establishment of the psychometric properties of a visual communication aid to assist with the assessment of financial DMC only. As this was a significant change to the study protocol, a new ethics application was required, which was submitted and approved. However, given this change and the sensitive nature of the study, the new ethics application took longer than anticipated to be approved, which resulted in prolonging the study duration.

Following ethical approval, an initial draft of the revised communication aid was developed, and presented to the research team. The feedback was used to revise the

communication aid accordingly. General consensus was obtained from the research team about the appearance and content of the communication aid before the study progressed to its last Phase.

c) Phase three

The final Phase of the study involved evaluating the psychometric properties of the communication aid - specifically, its validity (content and face), reliability, and usability.

i. Validity.

Content validity was established by presenting the proposed communication aid to a group of Designated Capacity Assessors (DCAs). DCAs are "regulated healthcare professionals who have been appointed by the Government of Alberta to complete capacity interviews and make recommendations to the Office of the Public Guardian/Trustee" (Covenant's Network of Excellence in Seniors' Health and Wellness (the Network), 2018). These DCAs compared the information content of the communication aid to that included in the Capacity Interview Worksheet to ensure that all essential information was captured and that the communication aid was representative. Face validity was determined by presenting the communication aid to a group of DCAs external to the study. The DCAs evaluated all of the areas required to assess financial DMC.

Consensus agreement on the validity of the communication aid was achieved using a predetermined modified Delphi protocol, as reported below. The Delphi method, using a modified Delphi Protocol, was selected as the most appropriate format to evaluate validity. While this technique is more commonly used to obtaining agreement around guidelines, it can act as an important tool to gain consensus agreement amongst a diverse group of content-matter experts on content validity and representativeness of the communication aid.

1. Modified Delphi Protocol.

Scientific rigor. To ensure scientific rigor, prior to conducting the second Delphi consensus, a priori decisions were made regarding participant group size, number of iterations to be conducted, definitions of "partial and full agreements," criteria for dropping and adding assessment items, and defined levels of acceptable and unacceptable dropout. The Delphi group

evaluated the communication aid in two categories: 1. content and design (seven questions) and 2. intended purpose (five questions).

Size of the Delphi group. Given the absence of guidance or standards around an appropriate Delphi group size for this purpose and the limited number of eligible participants available, a group size of 10-16 participants was selected.

Delphi participants. A diverse range of participants were considered for the Delphi group. These included known content-matter experts in the field of interest (DCAs, lawyers, physicians (e.g., geriatricians and psychiatrists) who commonly perform DMCAs) and individuals representing the target population. Once selected for the Delphi group, participants were required to commit to three iterations of the Delphi protocol.

A dropout rate of 20-35% was allowed per round, providing the dropout could be justified. If the dropout rate exceeded this, additional participants would [will be] recruited to reach the required group number. If the dropout rate were to exceed 40%, a new Delphi group would be established.

Delphi process. To account for the relatively small group size, three iterations of Delphi were considered sufficient to reach an agreement on all items. To complete a single iteration of the Delphi consensus, feedback was required from all participants, with the exception of extenuating circumstances, e.g., participant illness.

A set of criteria and rules was developed before the Delphi protocol was initiated, as previously described. Complete agreement on a question was defined by a mean score of four or greater, while partial agreement was defined by a mean score of three or more, but less than four. Disagreement was defined by a score less than three. Questions achieving a mean score of three or less were removed, per iteration.

Three iterations were planned, with the goal to achieve general consensus on the content validity of the communication aid. Consensus was defined as achieving a mean score of four or more on 80% of the questions. However, if agreement on the tool was reached at an earlier stage, the Delphi method was stopped and no further rounds held. If the agreement criteria was not achieved by the third iteration, further rounds would be held until agreement was reached. If,

after five iterations, agreement was still not reached, a focus group would be arranged to reassess the communication aid.

2. Initial Delphi Consensus.

An initial round of Delphi Consensus was conducted from June to August 2017 using a group of seven DMC experts. Each Delphi group member was sent an electronic package, which contained a cover letter explaining the study and request for feedback, a copy of the visual communication aid, and an evaluation questionnaire used to collect feedback about the aid. The questionnaire asked how well the aid addressed all areas necessary for assessing financial DMC, and whether it was representative of its primary purpose

After receiving the groups' feedback, a summary was presented to the research group. Based on that feedback, the research team discussed and came to an agreement about what changes needed to be made to the aid. Once agreement had been reached, appropriate modifications were made. The modified aid was then redistributed to this same expert group using the same method.

A high dropout rate occurred during the second iteration, with five DMC not providing feedback. Therefore, a decision was made to repeat the Delphi Consensus with a completely different and larger group of DMC experts.

3. Second Delphi process.

A second Delphi consensus was conducted over three months. All participants received an electronic copy of the communication aid via REDCap, and were requested to complete an online electronic survey within two weeks. The results were tallied, and a mean score calculated for each question. At the end of each iteration, feedback was provided to each participant in the form of a summary score, which was electronically distributed amongst the group over a one-week period.

A total of three iterations of Delphi were planned, with the goal of achieving general consensus for all questions. This was to confirm that the content and design reflected the purpose of the aid, and represented a communication aid for assisting with financial DMC, and evaluated whether the aid measured what it was intended to measure.

ii. Reliability of the communication aid.

Reliability of the communication aid was evaluated based on its use by different assessors in the DMCA process for PWA. Participants who met the study criteria (described below) underwent two separate DMCAs on different days with two different assessors (either a DCA or physician (geriatrician)). The results from each DMCA were documented on the data record form (Appendix 2), and entered into an excel database. Due to the variety in the number of responses obtained, this data was transformed into numbers, with each correlating to a specific response to a question, with no significance given to the number selected. After an initial exploration of the data, frequency tables and bar charts were generated for each question.

The results from these DMCAs were used to evaluate the reliability of the communication aid. Inter-rater agreement was calculated using Gwet's AC1 kappa. Gwet's AC1 kappa was chosen over Cohen's as it has been shown to be a more stable inter-rater reliability coefficient than Cohens, and is less affected by sample size than Cohen (Wongpakaran, Wongpakaran, Wedding, & Gwet, 2013). The decision to use kappa rather than a correlation coefficient to determine inter-rater agreement was due to the type of data collected, which was nominal and, thus, prohibited the use of any correlation coefficients.

An assessment of test-retest reliability was not possible, as each assessor only used the communication once for each patient, nor was it feasible, as it would involve the assessor repeating the capacity assessment with the communication aid again on the same patient, which would likely be unacceptable to patients. However, an indirect evaluation of test-retest reliability was performed using the communication aid by the same assessor for multiple patients.

The most ideal measure of internal consistency of the communication aid was through the use of Cronbach's alpha. However, application of Cronbach's alpha in this setting is not ideal, due to the variable responses expected from each patient and the absence of a final score. However, the covariance of the communication aid, which can indicate variation between answers, was possible, and therefore was used to determine the aid's internal consistency.

1. Study population.

The target population for the DMCAs included hospitalized patients at the Royal Alexandra Hospital (RAH) (one of two Acute Care Teaching Hospitals in Edmonton, Canada) who were 65

years or older and had been diagnosed with post-stroke aphasia using the WAB. The additional inclusion criteria were that they had to be native English speakers, have no enacted EPA, no previous financial DMCA, no previous assessment of lacking financial DMC, and no current triggers requiring a DMCA. Justification for using participants who had no indication for requiring a DMCA was due to an ethics requirement for obtaining ethical approval for the study. Participants whose auditory or visual deficits were correctable with hearing aids and glasses were eligible for inclusion.

Exclusion criteria were a diagnosis of global aphasia or other non-aphasic communication disorders, did not speak English, no past medical history of pre-existing mild-to-severe stage of dementia (Mini Mental Status Examination (MMSE) score less than 20 if available), significant visual or hearing impairment that not correctable by glasses/visual aids or hearing aids, legal blindness, pre-existing learning disabilities or an enacted EPA, or previous assessment as lacking financial DMC.

2. Consent process.

Potentially eligible participants fitting the inclusion criteria were initially identified and flagged by a member of their respective healthcare team. They were then approached by a member of their healthcare team external to the study, and asked to provide written consent to release their contact details to the research team. This consent could come from either the patient or alternate decision maker (ADM) (such as family member). The form used was a specially designed "Aphasia Friendly Participant Consent Form - Release Of Contact Details" (see Appendix 3).

All consenting patients were approached by a member of the research team and provided with detailed information about the purpose of the study, the process, confidentiality of the data obtained, and all possible benefits and risks associated with being enrolled. The aforementioned Aphasia Friendly Participant Consent Form was used to assist with the consent process (see Appendix 4). In cases where it was not possible to obtain direct patient consent, consent was sought from the patient's ADM. A more comprehensive participant information form was also provided to the patient and/or ADM (see Appendix 5).

The target sample size for the capacity study population was 30, as mentioned earlier. This sample size was chosen to ensure reliability of the communication aid. Justification was based on literature about prior validation studies supporting a similar sample size (Glaser &

Strauss, 1998). This was because formal sample size and power calculations were not possible due to the absence of prior literature and research in this area involved identifying potential study participants by members of their healthcare teams. Despite the intended sample size, due to difficulty enrolling participants and for the purpose of completing this thesis, preliminary results were obtained after enrolling eight patients. The results are reported below.

3. DMCA process.

Once consent had been obtained from each participant, a financial DMCA was conducted, which incorporated the use of the communication aid. These assessments were conducted by either one of the two DCAs who were members of the research team or by the geriatric physician. The DCAs included a nurse practitioner and occupational therapist. Both the DCAs and physician had received additional training in the form of a two-hour face-to-face workshop on the use of SCA (Aphasia Institute, 2015) by a trained instructor from the Aphasia Institute. This SCA training is recommended for all individuals working with persons with aphasia.

Each DMCA took place with only the individual (and ADM where requested) and the assessor present. The assessment process followed that as recommended by the Capacity Interview Worksheet, as discussed earlier. The duration of the assessment was variable and depended on the individual being assessed, the assessor, and aphasia severity. The communication aid was used to support the assessment process as much as necessary. Additional communication supports were provided as deemed necessary by the participant's aphasia deficits, as per the SLP recommendations.

The results from each assessment were kept confidential from the healthcare team and patient, were available only to the research team, and used primarily for the purposes of instrument validation.

iii. Usability of the communication aid.

The feasibility of using the communication aid was evaluated from feedback obtained from the Visual Communication Aid User-Experience Questionnaire (see Appendix 6). This questionnaire was designed to determine whether training was adequate, how easy the aid was to use in the assessment process, and what were its strengths and limitations. It also asked for general

feedback about the aid. The feedback was intended to be used to modify the aid and its training as necessary.

3.4. Ethics Approval

Ethical approval was obtained prior to initiating the study. After the decision was made to change the research question and to focus the communication aid on financial decision-making, a second ethics application was submitted.

Since the research topic was sensitive in nature, and a vulnerable population was to be sampled for the quantitative Phase of the study, it was critical to obtain ethical approval to ensure that participants were not put at excessive risk. To mitigate risks in the third Phase of the project when DMCAs were to be conducted, DMCAs were only done to validate the communication aid. To that end, assessments were done only for patients with post-stroke aphasia who had no clinical indications for financial DMC assessments. DMCA results were not disclosed to the patient, family, or healthcare team, nor were they documented in the chart. This was done to ensure that the results would not influence future care. Consent was obtained from the patient directly, where possible (using the aforementioned Aphasia Friendly Participant Consent Form), or from a substitute decision maker or guardian.

3.4. Results

a) Focus groups

The focus group sessions were held over a period of nine months (April 2015 to January 2016). Of the 19 participants initially recruited, 17 were included in the focus group sessions. Two participants dropped out for personal reasons. Three focus groups were held, with group size ranging from four to nine participants. Not surprisingly, the results from these focus groups indicated a lack of understanding around general and specific DMC for financial and legal matters. However, there appeared to be a clear understanding around communication and its methods, and, in particular, the participants appeared to understand well how impairments in communication can impact decision-making ability and the assessment thereof.

The feedback about the communication aid (Appendix 7) revealed a need for picture consistency regarding type of pictures used (e.g. photographs) and the use of color. It also

showed how sensitive pictures are to individual interpretation. However, with modification, the aid has the potential to help with the assessment of financial and legal DMC for PWA.

b) Development of the communication aid

As discussed earlier, during the process of developing a visual communication aid for legal and financial decision making, it was recognized that a single tool would be unable to adequately assess both of these complex areas of DMC. Therefore, a decision was made to change the research objective and focus of the study towards the development of a visual communication aid to support DMCA for financial decisions only. The change in focus required a new ethics application. Because it took so long for the application to be approved, the study was delayed until 2017.

After receiving ethics approval for the revised study, an initial draft of the communication aid was finalized. The questions incorporated into the communication aid were guided by those included in the Capacity Interview Worksheet (Alberta Health Services). The feedback and themes generated from the focus group discussions were also used to guide content and assist with decisions about how content should be formatted within the communication aid. As images had been identified as the best way to help communicate the different concepts needing to be assessed, the Aphasia Institute was approached, and a set of 40 images was purchased to use in the aid. Additional images were also downloaded from the internet. These included a combination of purchased and rights-free images while several images were created by the research team for the sole purpose of the study. Any potential copyright issues were discussed with a copyright lawyer. A list of these images was created and is included in the appendix in the communication aid.

The final visual communication aid is a 37-page paper-based document comprised of 34 picture-based questions (containing black-and-white pictures) along with a set of user instructions (which detail additional equipment requirements) and an appendix listing the image sources. The instructions contain no clear guidelines about the duration of time required to use the aid, as this will depend heavily on aphasia severity, the individual, and the assessor. Images of bank logos and/or pamphlets are also recommended for use in conjunction with the aid, to support the assessment process. Please see Appendix 8 for a copy of the communication aid.

There were challenges with how to visually portray several of the more difficult financial concepts, among them "What is an enduring power of attorney" and "What is a Trustee." Neither term leads itself to a concrete image, nor are there suitable images of either. Therefore, the decision was used to use a photograph of the heading of the Government of Alberta's Enduring Power of Attorney form to represent question 33. However, for question 34, no suitable images were identified or could be made. To prevent confusion by using an unrelated image, the decision was made to not use any images and leave the question in word form. Additionally, although the initial goal and preference from the focus groups had been to use colour images, the decision was made to change to black-and-white images to ensure better consistency during printing.

As mentioned earlier, in conjunction with the communication aid, an Aphasia Friendly Participant Consent Form was developed using a format similar to that of the communication aid (Appendix 4). The 22-page consent form addresses all the necessary aspects for obtaining consent, including providing information about the study, participant involvement, confidentiality and the risk and benefits of study participation. It uses a variety of picture-based questions. The final page is a Yes/No consent form for the participant or ADM to sign.

c) Evaluation of the psychometric properties of the communication aid

i. Content and face validity.

The next phase involved determining the content and face validity of the communication aid. This was achieved using the Delphi Consensus with a group of content-matter experts.

An initial Delphi Consensus was conducted from June to August 2017 using a group of seven DMC experts contacted via email. The Delphi group comprised five DCAs external to the study, a representative from the Office of Public Guardian and Trusteeship, and a psychologist with experience in assessing DMC in aphasic individuals. After receiving the electronic package, feedback was obtained from all seven participants. A summary was presented to the research team. After the team agreed on changes to the communication aid based on the feedback, the appropriate modifications were made, and the modified communication aid was re-distributed amongst the Delphi group using the same method described previously.

Unfortunately, feedback on the modified communication aid was only provided by two participants (one DCA and the psychologist), despite multiple attempts to contact all of the Delphi group participants. One of the DCAs had left during the second iteration of Delphi and was not available for further contact, which complicated matters. Due to the high dropout rate during the second round and the inadequate amount of feedback, the decision was made to form a second, larger and different group of 15 DMC experts and conduct a second iteration of the Delphi Consensus.

The second Delphi group was established in August 2018. This comprised 15 individuals, including included three physicians (two Care of the Elderly, Geriatric Psychiatry), a lawyer, and 11 DCAs from a variety of backgrounds (nursing, social work, occupational therapy). The Delphi Consensus was conducted over three months, using the same format as previously described. The results from each question were tallied, and a mean score calculated for each. At the end of each iteration, feedback was provided to each participant in the form of a summary score which was electronically distributed amongst the group over a one-week period. Three iterations of Delphi were conducted, with 15 participants in the first iteration, 12 in the second, and 10 in the third.

By the end of the third iteration, feedback from four people suggested the need for minor changes (which were subsequently performed), and a 90% consensus had been achieved, which allowed confirmation of the content and face validity of the communication aid. The Delphi Consensus results showed that the aid is well designed and has content appropriate for its purpose.

ii. Reliability.

The final stage involved using the communication aid with a sample group of eight participants to confirm reliability in the assessment process. Please see the previous section for more detailed information about the inclusion criteria.

Once the process of identifying participants had begun, it became clear that the number of potentially eligible participants was extremely small. Therefore, following discussions with the research team and the thesis committee, the decision was made to expand recruitment to inpatients on the stroke and geriatric rehabilitation units at the GRH, and to lower the age criteria to over 18 years of age, rather than 65. It was also identified early on that many SLPs at the RAH

and other units do not routinely use the WAB to conduct their language assessments, but used a variety of other screening tools (e.g., the BTNV) often in combination. A decision was made to change the study population inclusion criteria around the diagnosis of aphasia to "formal assessment by SLP which has confirmed aphasia."

After the required modifications were made to the inclusion criteria, the study was again presented to physicians and members of the multidisciplinary team (including SLPs) from these units. They were given information and asked to help with recruitment. The SLP leads at both sites were also actively approached and they assisted with the project.

After a potentially eligible participant was identified, consent was obtained as described in the methods section. Each participant underwent two separate DMCAs, which were performed by two separate assessors (either two DCAs or a DCA and geriatrician).

Over a period of a year, eight participants were recruited, with the eventual goal to recruit 30. A preliminary analysis of the results obtained from these eight participants was performed, which is described below.

Three raters were involved in conducting the DMCAS (two DCAs and one physician). Rater A (MV) assessed eight patients, Rater B (FC) assessed six and Rater C (KP) assessed two. All patients had their two assessments conducted on different days, with the mean duration between assessments being 14 days (SD 24.3), with the range varying from one day to 66 days (one patient). Most patients (n=7) had the second assessment done within one week.

In total, 544 observations were made: 272 by Rater A, 204 by Rater B, and 68 by Rater C. The communication aid was used in all DMCAs (n=16). In all DMCAs which were attempted were completed, with all questions being answered by each participant during each assessment. The assessment results for each question across all participants are shown in Figures 1-34, and in the frequency tables in Appendix 8.

Figure 2

Participant answers to question 1

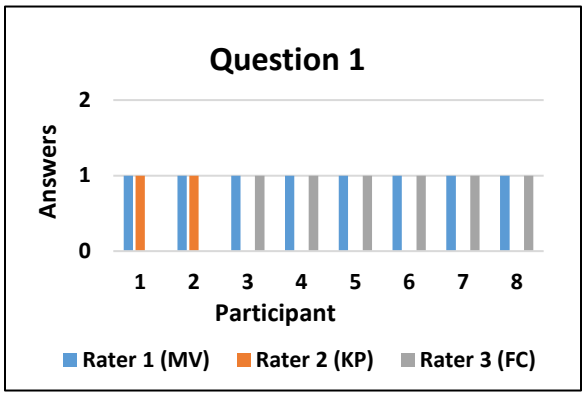


Figure 3

Participant answers to question 2

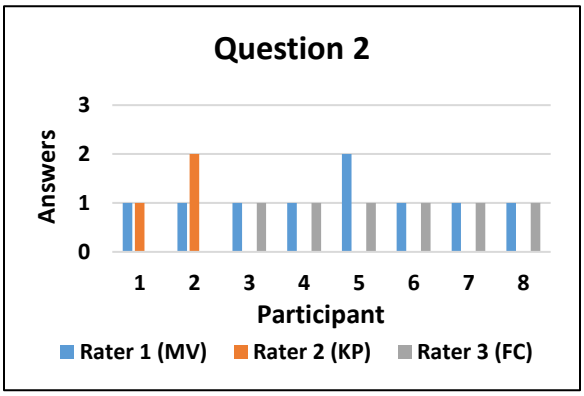


Figure 4

Participant answers to question 3

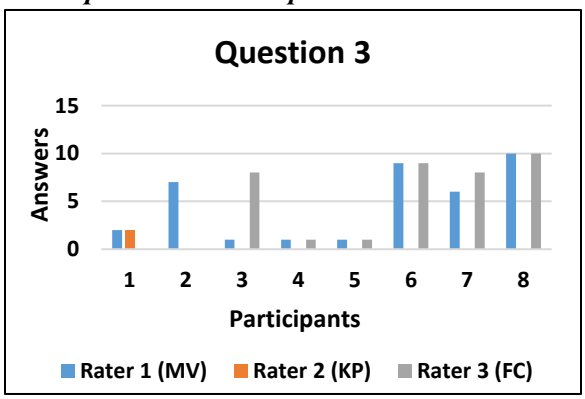


Figure 5

Participant answers to question 4

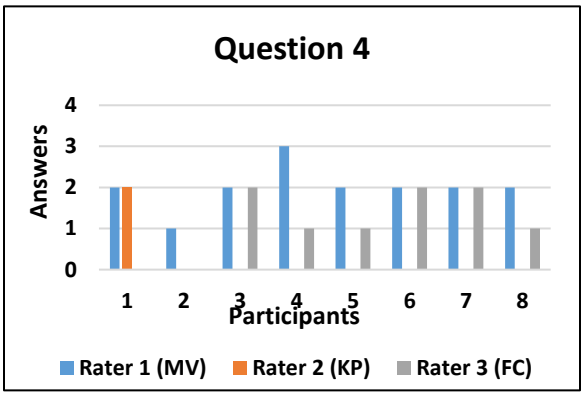


Figure 6

Participant answers to question 5

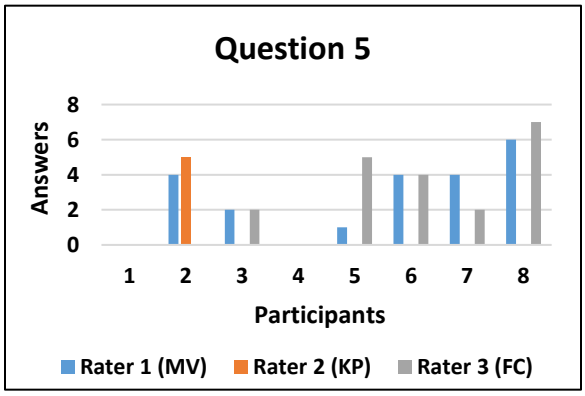


Figure 7

Participant answers to question 6

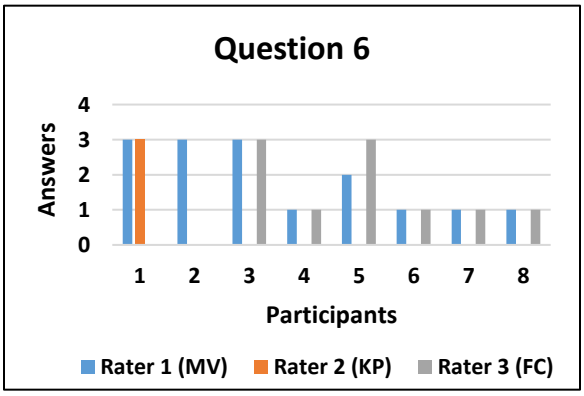


Figure 8

Participant answers to question 7

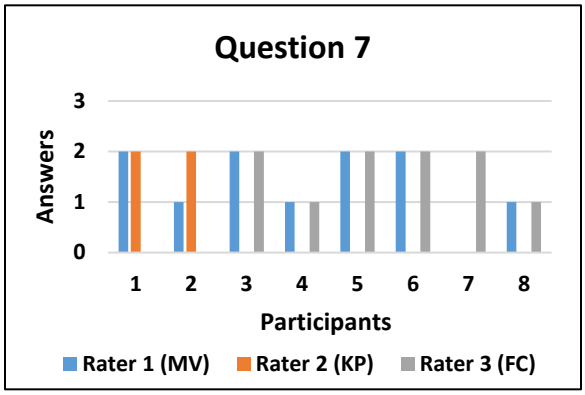


Figure 9

Participant answers to question 8

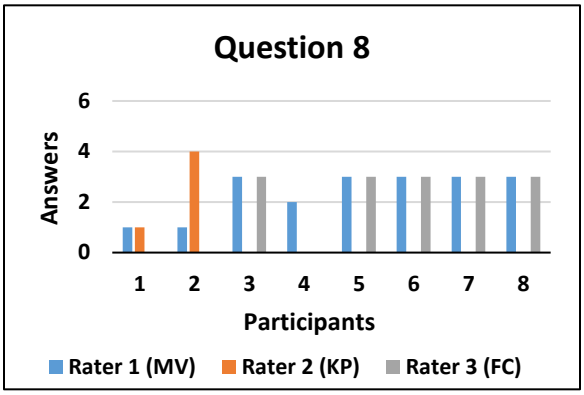


Figure 10

Participant answers to question 9

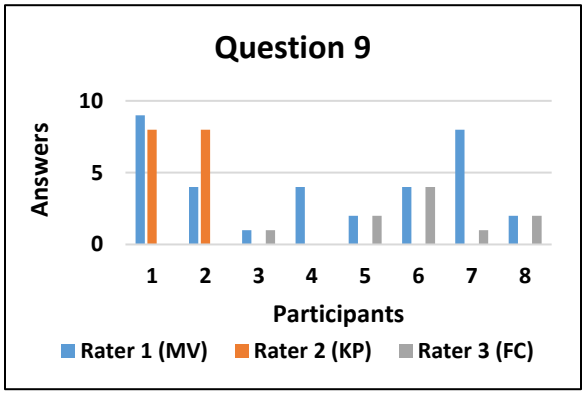


Figure 11

Participant answers to question 10

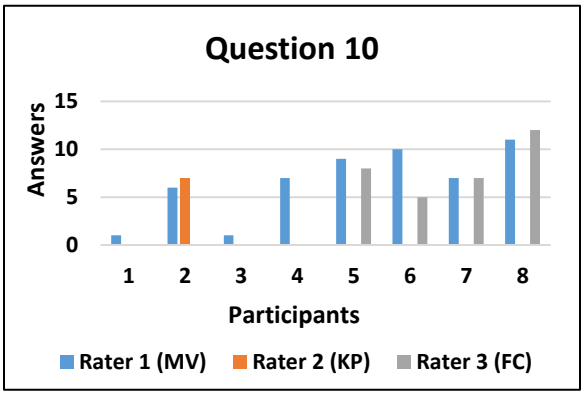


Figure 12

Participant answers to question 11

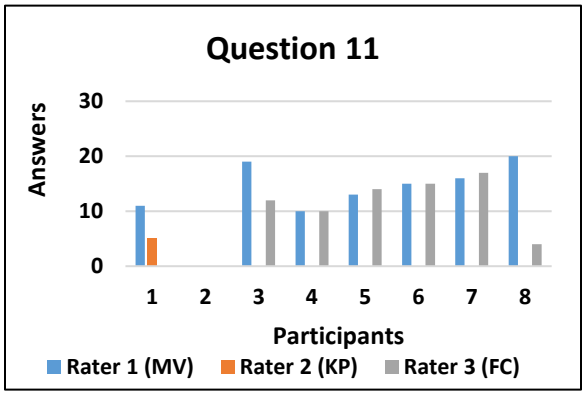


Figure 13

Participant answers to question 12

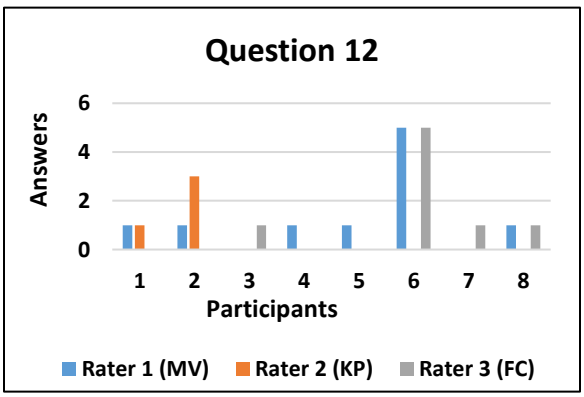


Figure 14

Participant answers to question 13

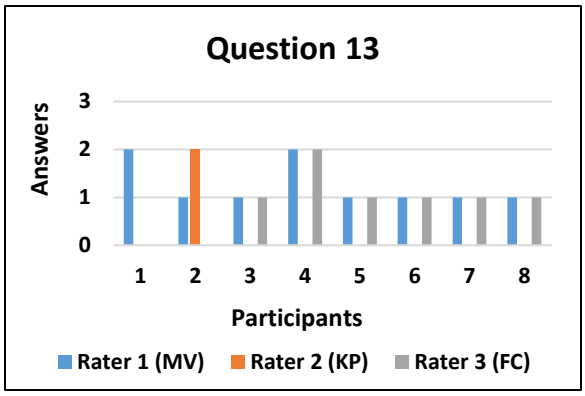


Figure 15

Participant answers to question 14

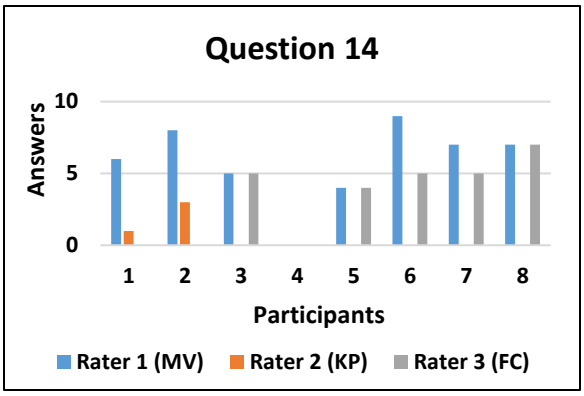


Figure 16

Participant answers to question 15

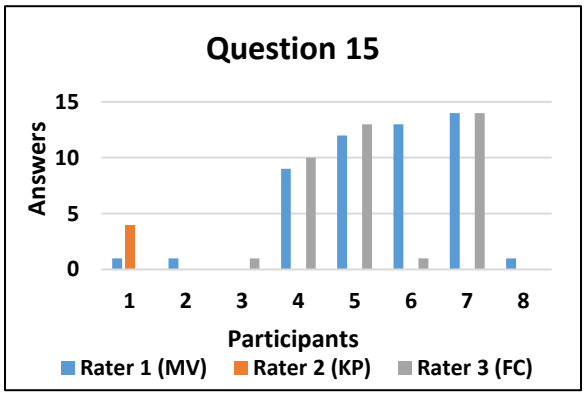


Figure 17

Participant answers to question 16

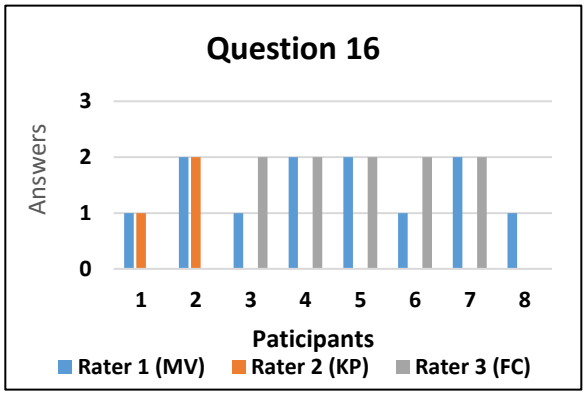


Figure 18

Participant answers to question 17

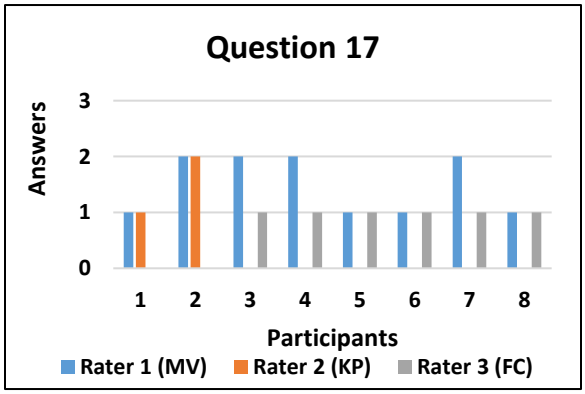


Figure 19

Participant answers to question 18

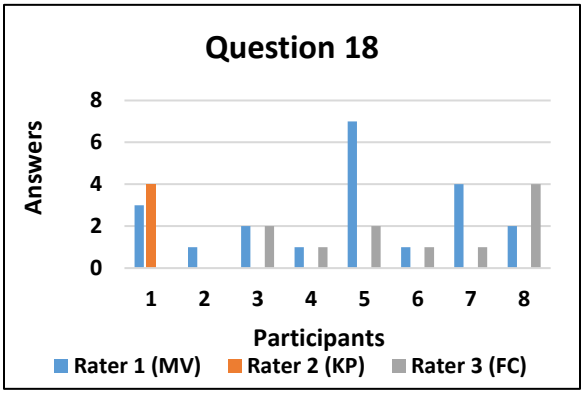


Figure 20

Participant answers to question 19

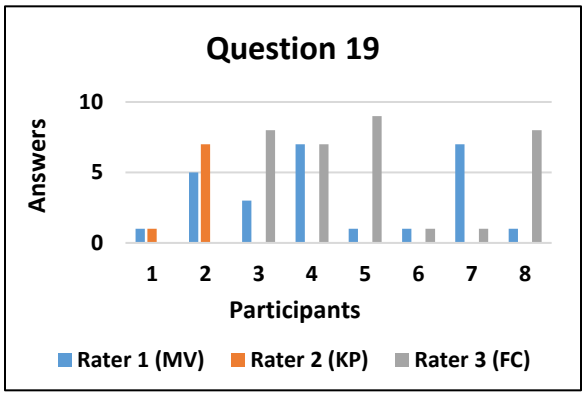


Figure 20

Participant answers to question 20

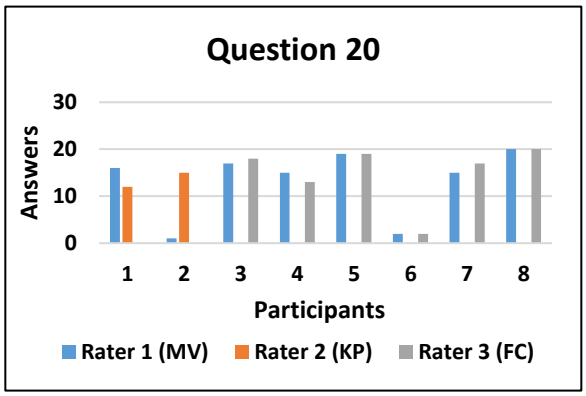


Figure 22

Participant answers to question 21

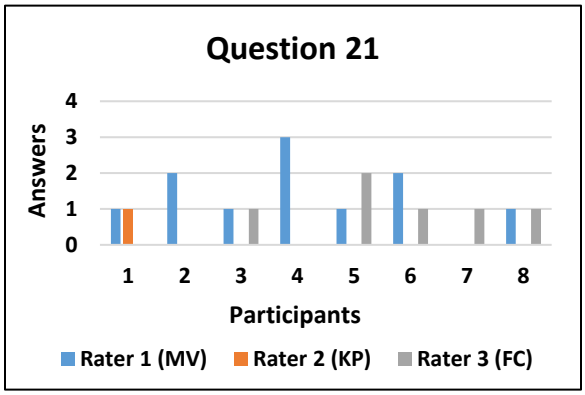


Figure 23

Participant answers to question 22

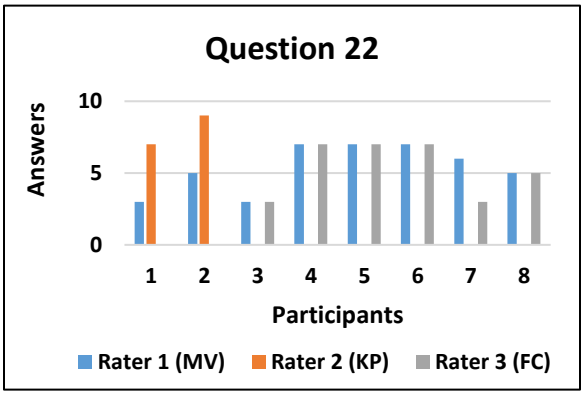


Figure 24

Participant answers to question 23

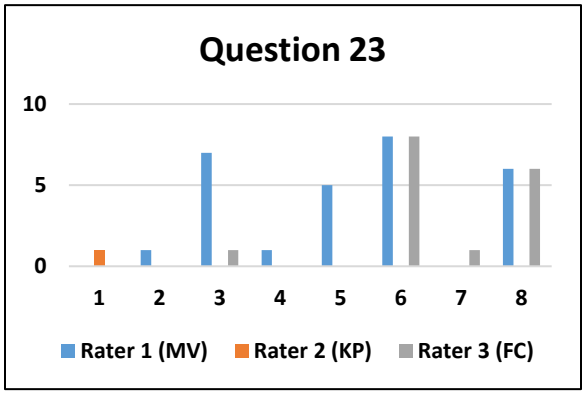


Figure 25

Participant answers to question 24

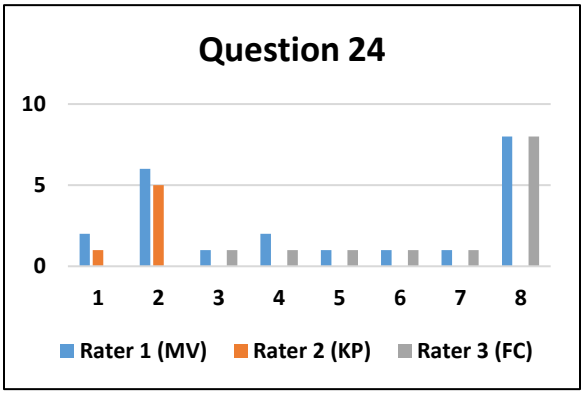


Figure 26

Participant answers to question 25

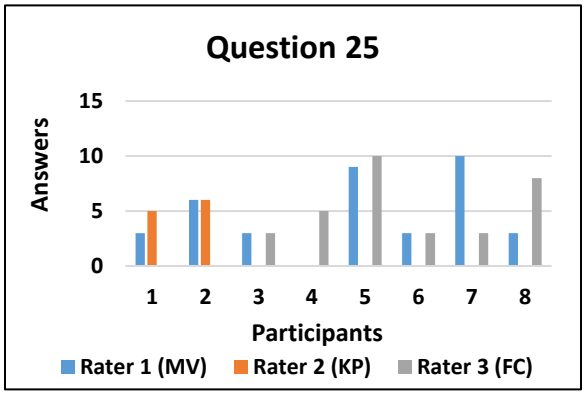


Figure 27

Participant answers to question 26

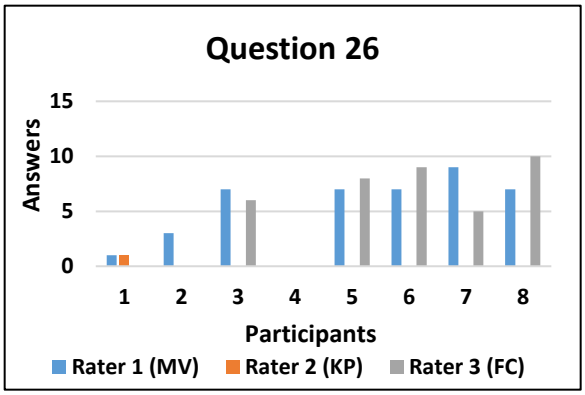


Figure 28

Participant answers to question 27

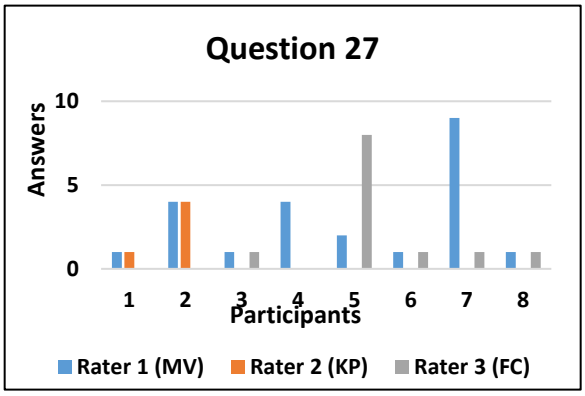


Figure 29

Participant answers to question 28

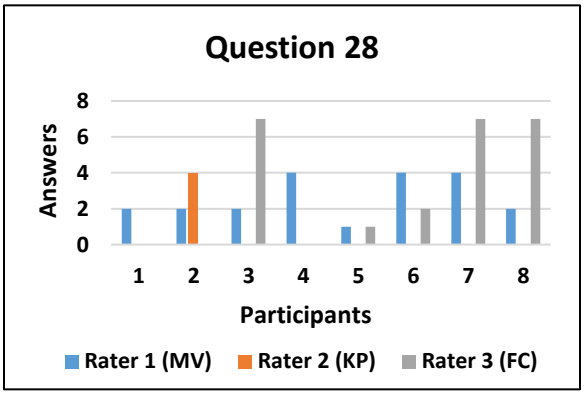


Figure 30

Participant answers to question 29

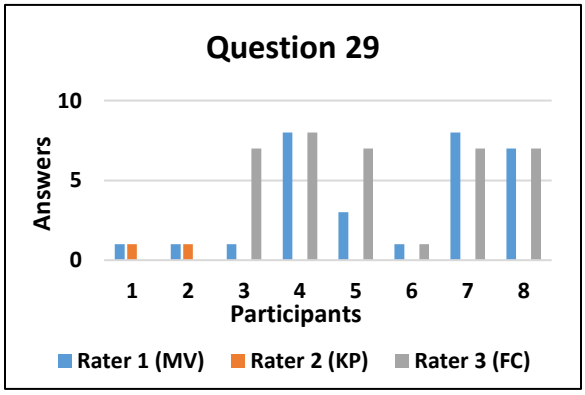


Figure 31

Participant answers to question 30

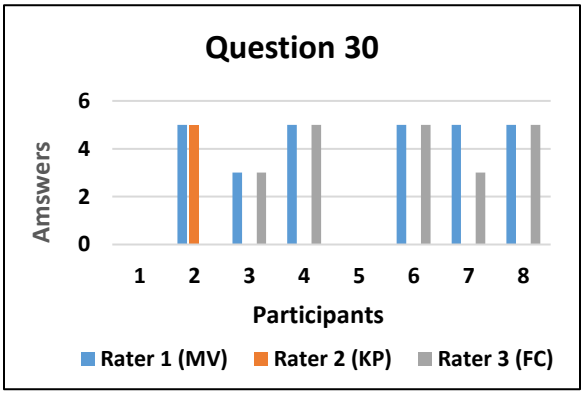


Figure 32

Participant answers to question 31

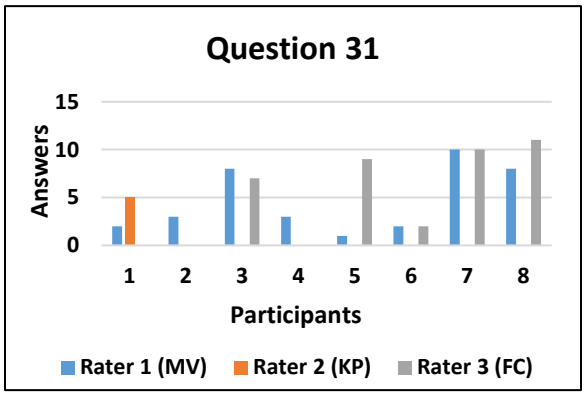


Figure 33

Participant answers to question 32

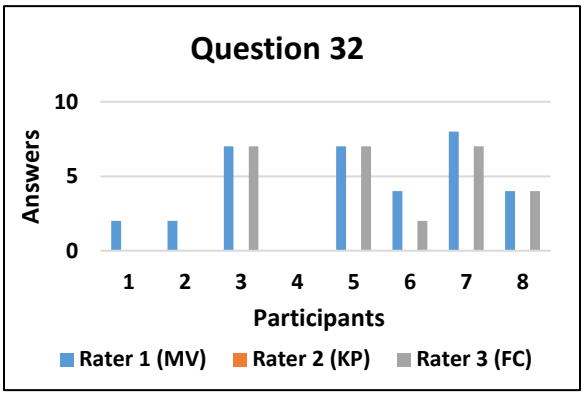


Figure 34

Participant answers to question 33

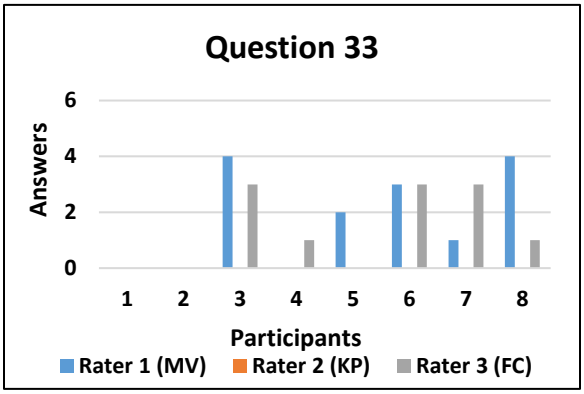
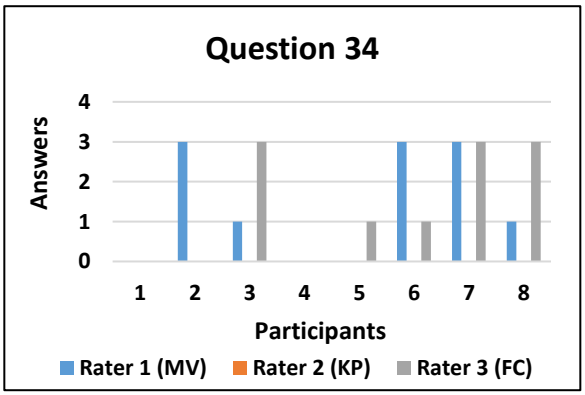


Figure 35

Participant answers to question 34



1. Inter-rater assessment.

The data collected was categorical and, thus, an assessment of its normality was not required. As three different raters were involved in conducting the assessments, each seeing a different number of patients, inter-rater reliability was assessed within two groups, according to the number of patients seen. The first group (Rater A vs Rater B) included six patients, while the second group (Rater A vs Rater C) included two. Due to the extremely small sample size of the second group (Rater A vs C), the significance of the results obtained between these latter two raters was difficult to interpret.

a. Group one: Rater A vs Rater B.

Six patients were included in Group one, with each patient undergoing two assessments, one by Rater A and one by Rater B, resulting in a total of 12 assessments. In total, 408 observations were collected. The results from Rater A and Rater B are shown in the figures above and the frequency tables in Appendix 9. An assessment of inter-rater reliability between Rater A and Rater B revealed a (Gwen's) kappa of 0.5089 (CI 0.436-0.581, P < 0.000).

b. Group two: Rater A vs Rater C.

Two patients were included in Group two, with each patient undergoing two assessments-one by Rater A and one by Rater C-resulting in four assessments. In total, 136 observations were collected. Again, as above, the results from these assessments are shown in Figures 1-34 and the frequency tables in Appendix 9. The inter-rater reliability between Rater A and Rater C had a kappa of 0.3719 (CI 0.248-0.5010, p < 0.00).

2. Internal consistency.

The Cronbach alpha was used to provide an assessment of the average covariance. The average covariance was 0.76, with an (overall) Cronbach alpha greater than 0.7 (0.7283). Although several items had small item-rest and item-test correlations, given the large number of items evaluated (n=34), these values support the communication aid having overall quite good internal consistency.

The agreement between Rater A and Rater B revealed a Gwet's AC kappa of 0.51 (CI 0.4362 to 0.5816, P < 0.000), indicating a moderate inter-rater agreement. A slightly lower kappa was found between Rater A and Rater C, but given the sample size, interpretation is not possible. These results are promising, especially given the limited sample size and the diversity of possible responses.

iii. Usability.

Feedback was received from two out of three communication aid users. They reported that the communication aid was simple to use and incorporate into the assessment process, and that they experienced no difficulties. The required training to use the aid (the SCA) was reported to be sufficient. The only negative feedback was a concern that PWA could potentially have difficulties understanding the last question.

Chapter Four: Discussion

There is variation in the terminology used for "capacity," with the definition depending on the defining authority. The term decision-making capacity (DMC) was used in this thesis as an umbrella term for these variations in terminology. General DMC refers to decision-making involving one or more of the previously identified domains, for example, including personal decision-making in the areas of healthcare consent and accommodation. By comparison, specific decision-making pertains to DMC within a single domain, such as financial DMC. However, all DMC is specific to a decision and domain; the decision being identified dictates which domain requires assessment.

DMC research to date has mostly focused on personal and financial decision-making in the general population, and especially healthcare decisions (e.g., consent for treatment), and around the use of DMC assessment (DMCA) tools in the assessment process. There is considerably less research on aphasia and DMC, and no research on financial DMC in the aphasic population (Carr, 2016).

A considerable number of DMCA tools exist to support DMCAs for personal and financial matters; however, almost all have been designed for and validated in the general population. Only one tool (the CACE) (Carling-Rowland et al., 2014) was designed specifically for people with aphasia (PWA). Developed in Ontario, it is limited to personal decision-making around accommodation decisions only. No tools exist to support assessments of financial DMC in PWA, and in particular, post-stroke aphasia populations (Carr, 2016).

The results from the literature review in this thesis highlighted a critical knowledge gap in current aphasia and DMC research. The importance of addressing this knowledge gap is evident by the potential complexity of this decision-making domain, the vulnerability of the target population, and the serious consequences that can arise following improper assessment supports, which all justify this research. This knowledge gap was addressed through the development and evaluation of a new visual communication aid to support financial DMCAs in post-stroke PWA.

4.1 What this thesis has added

a) New products

1. Visual communication aid.

A number of new products were created from this study. The most important product, which was the primary objective of this study, was a new visual communication aid to support assessments of financial DMC for post-stroke PWA. A copy of this visual communication aid is available in Appendix 8.

The initial plan had been to create a visual communication aid to support specific DMCAs for legal and financial matters. However, the topic complexity and length of a communication aid required to achieve this would make the aid impractical. Thus, the study objective was changed to develop a visual communication aid targeted to support assessments of financial DMC assessments only. This new and (preliminary) validated communication aid is, as far as we are aware, the first of its type to support specific financial DMCAs in PWA (Carr, 2016).

2. Aphasia Friendly Participant Consent Form.

The second new product created from this study was an Aphasia Friendly Participant Consent Form (Appendix 4), which was designed specifically for this study. A description was provided in Chapter three. Because the consent form was not the focus of the study, it has not been formally evaluated. Future validation of form is one of the author's goals following completion of this study.

Due to the absence of current literature (and tools) available for financial DMC in post-stroke PWA, there is nothing with which to compare these two new products. Therefore, as far as the author is aware, these two new products are the first of their kind and have the potential to set the standard for financial DMCA in post-stroke PWA.

b) Lack of knowledge about DMC within the community

The results obtained from the focus groups identified an overall, general lack of understanding amongst older adults regarding DMC and, specifically, legal and financial DMC. This

knowledge gap is an important finding. Although it has been identified in other studies, there is still limited research available about this topic. However, this finding should not be surprising to the reader, given the complexity of DMC, especially within these two domains. Indeed, many healthcare professionals also lack a similar understanding of DMC.

These findings are significant, given the general absence of literature in this area, and the increased frequency of medical and psychiatric co-morbidities observed in older adults that can impact DMC (Boettger, Bergman, Jenewein, & Boettger, 2015; Moye et al., 2013). Older adults are also more likely to encounter high-risk situations which can result in the need for a DMCA, especially within healthcare (Fowles, 1983).

c) Understanding about communication and disorders

The other important finding identified from focus group feedback pertains to the general understanding about communication and its disorders, an understanding that appeared to be surprisingly good. This feedback also revealed a good understanding about communication, how it occurs and potential problems. The focus group members were able to identify a wide variety of methods available to assist with the communication process. They appeared to have a general understanding of aphasia, and how communication disorders like aphasia can impact a DMCA. Their level of understanding made it possible to generate useful feedback, which was used to guide and inform the development of the communication aid.

d) Other additional findings

An observed deficit was identified in the general public's knowledge (and that of healthcare professionals (HCP's)) about general and specific DMC. This finding supports the need to educate the public in this area, and also justifies the need for further research and interventions. Although important for HCPs, it is likely most important for vulnerable populations (like older adults), who will likely have the most need for such assessments, while also having the most at stake.

Another important consideration in the context of this finding is that older adults are routinely advised to create advance care documents, such as personal directives (PDs) and enduring power of attorney (EPAs), as part of future planning. Since both documents pertain to use in future situations in which the person creating them lacks DMC, it is important that these

people (who are often older adults, but could be anyone) have a basic understanding of the documents and their importance. For this to happen, a general understanding of DMC is required. This supports the need for public education along with future research in this area.

e) Existing Controversies

Given the absence of literature in this area, it is not possible to compare our results and findings to current literature. The only exception to this is our finding about the high level of understanding observed in older adults about communication and its disorders, which is discussed below.

Previous literature about this issue has been limited to the use of population-based surveys, which have identified the general public's awareness and understanding of the communication disorder of aphasia as low (Elman, Ogar, & Elman, 2000). There are likely several reasons for the observed discrepancy between our findings and those reported in the literature, with the most obvious the different populations that were included in the different studies. In addition, earlier studies were observational in nature, in the form of surveys. By comparison, our study was qualitative and used focus groups to collect data. These differences in study designs, will also likely have influenced the results.

This disagreement between our study and the literature poses an interesting question about whether certain populations have a greater awareness of aphasia than others, and supports the need for further exploratory research in this area, especially given that so few studies have explored this issue specifically in older adults. This observation is important, as future research (and funding) for aphasia may be predicted by society's awareness of aphasia (Elman et al., 2000).

4.2. Challenges encountered in this study

After starting the study and during the process, we encountered several significant issues which required revisions to the design. These revisions are highlighted in the section below.

a) Communication aid development

The development of the communication aid was prolonged for a number of reasons. The first time delay occurred because when we changed the focus of the aid to assessments of financial

DMC only, we had to resubmit a new ethics application. This took far more time than we expected. Due to this change and the need to submit a new ethics application, there was a significant prolongation in the study duration. The other challenges encountered while the developing the aid are described below.

The research team needed several rounds of feedback before it could prepare a final draft of the communication aid to distribute to the Delphi groups. This was due to the differences in opinion about the images to be used for a number of questions in the aid. In addition, due to a lack of available images for a number of the questions, and despite purchasing a set of aphasia-friendly images, the research team had to create several photograph specifically for this project.

Another significant hurdle during the development of the aid was how to translate some of the more challenging and complex concepts of financial DMC into a visual, which was described in depth in the Results chapter.

b) Evaluation of the psychometric properties of the communication aid

i. Delphi Consensus.

The visual communication aid was validated through the use of a Delphi Consensus, as described previously. Due to a limited number of DMC in this area, the pool size for possible Delphi participants was small, which made recruitment difficult. Following the high dropout amongst the first Delphi group, a decision was made to repeat the Delphi process with a larger group of experts. The second group had a wider diversity of content experts, which helped improve the likelihood of validation of the communication aid. After three rounds with the Delphi group, the higher-than-ideal dropout rate was offset by positive feedback and a 90% consensus. As a result, it was decided that content validation had been achieved.

ii. Changes to the Inclusion criteria.

The other, most challenging aspect of this study pertained to recruiting an adequate number of participants for Phase three. This may have been related to the restrictive inclusion criteria used for the target population to evaluate the reliability of the aid. The criteria were restrictive to ensure that the appropriate participants were recruited, and that the aid was appropriately validated in the target population. However, there was an extremely limited pool of eligible participants. After multiple discussions with SLPs outside the study, the research team decided to

change the age criteria to include adults 18 years or older, and expand the study to an additional hospital (three units at the Glenrose Rehabilitation Hospital (GRH)).

The method for diagnosing aphasia also had to be changed when the research team learned that the SLPs at target hospitals were not using the WAB, but were using other equivalent assessments to confirm the presence and type of aphasia. The new method criteria required an aphasia assessment by SLP using whatever method he/she deemed suitable.

Although far from ideal, the revisions made to the study design were felt to be necessary to provide a considerably larger population for recruitment purposes, without adversely impacting the study validity. However, even after one year of actively recruiting participants, only 15 patients had been identified for the study, with only eight eligible and subsequently enrolled. The other seven were either found to be ineligible or refused to participate due to the sensitivity of the topic.

4.3. Study limitations

There are a number of limitations to this study, which have been categorized into those relating to the study design, those related to the study process, and those pertaining to the communication aid itself.

a) Study design

A mixed methods research design was selected for this study. This makes it possible to use qualitative and quantitative research methods and to interpret the data from both. There are limitations with this approach, however. Mixed methods can often result in the development of very complex research (such as ours), which can make the study less feasible and the research more difficult to implement. Additionally, mixed method studies can take a prolonged period of time, making them more resource-intensive than studies using more simple designs. This was observed in this study, which took four years to reach this point, and will require yet more time to achieve its overall aim. Finally, although the design was ideal for the purpose of this study, it can be difficult to assess the quality of date generated from mixed method studies, and that has been the case here.

b) Study process

A number of limitations were identified relating to the different data methods used in the study. These are listed below.

i. Focus groups.

The focus group participants were self-identified, and voluntarily participated in the focus groups. Given the complex topic of discussion in the focus groups, it is likely that the individuals who agreed to participate are those with a higher socio-economic standing, and would likely have achieved higher levels of education than their peers. Therefore, this small and specific population may not be very representative of all community-dwelling older adults. Also, despite having a broad plan to recruit focus group members (from both local community centers and several hospital volunteer programs), the plan excluded any older adult with physical, cognitive or mobility issues that would have negatively affected their ability to attend these programs or centres. Because of these factors, the focus group may not have been an accurate representation of community dwelling older adults, thus limiting the generalizability of the results.

Overall, there were three focus group sessions, comprising a total of 17 participants. While this is a sufficient number of participants for obtaining the information required, ideally more focus group sessions would have been held to ensure data saturation. In addition, a greater number of participants would have been recruited per session. However, finding appropriate and willing participants for these focus groups was challenging, with one of the limitations being the complexity (and potentially sensitive nature) of the discussion topic. To help improve recruitment and participation in the focus group sessions, the sessions were held at lunchtime (which was thought to be the most convenient time for participants) in several different locations.

ii. Delphi Consensus.

The initial Delphi Consensus had a small number of DMC experts, with the size limited by the number of available experts. Despite several attempts to recruit a wide variety of content experts, due to lack of availability of content experts in certain areas (e.g. law), it was not possible to achieve the range in diversity of the group that had been hoped for. However, despite this limitation, we were able to include a diversity of content experts within that second group.

Although some experts dropped out of the second Delphi group, we were able to achieve general consensus about the communication aid.

iii. Participant recruitment.

As described in more depth earlier on, we encountered significant difficulties while recruiting participants for the DMCAs, primarily due to an extremely limited number of potentially eligible participants who met the inclusion criteria. To overcome this barrier, the aforementioned changes were made to the inclusion criteria, but in spite of these changes, we were only able to recruit eight participants.

Another limiting factor to participant recruitment pertained to the sensitive nature of the research topic. While 15 people had been identified as being eligible for the study, seven refused to participate, as they were uncomfortable with the topic. Unfortunately, this observation is not surprising; any discussion about personal finances and how they are managed can be challenging in the general population. Such discussions become even more sensitive in the presence of a communication disorder such as aphasia, despite there being a greater need to have such discussions in these situations.

Cultural and personal beliefs and expectations, as well as religious beliefs, can all influence how much an individual will engage in such conversations. This certainly affected our study in terms of limiting the number of people willing to participate. All attempts were made to explain the purposes for having these discussions; we made clear that we were asking the questions we did only to validate the communication aid, and that the information collected would be kept completely confidential. However, apart from employing these strategies, and providing sufficient education about the need for this discussion, there was little we could do to overcome people's discomfort with examining such a personal topic for the purpose of an academic study.

iv. DMCAs.

A DMCA is a significant event for patients, and fears and worries are often associated with such assessments. While the ideal situation would be to not perform such assessments, this is not possible with our study, as DMCAs that incorporated the use of the new communication aid were needed to allow us to complete our evaluation. Given that the purpose of these assessments was

to validate the aid, it was decided (and required by ethics) to only enroll patients who did not need a DMCA, and that the results of any assessment would not be formally documented within their chart but would be documented only within the research study notes and kept confidential. To minimize patient discomfort, patients were selected based on meeting the inclusion criteria, which included an absence of any clinical indication for conducting a DMCA. As the purpose of these assessments was to determine the reliability of the communication, and not to determine the individual's financial DMC, the assessment results were not documented within the chart nor shared with the patient, but were restricted to the research team. Strategies to help improve and engage individuals in such discussions included conversations to establish rapport before initiating financial discussions, ensuring that sensitive discussions were held in a private and quiet area, establishing understanding about the confidentiality of the information disclosed, and incorporating the individual's cultural and other beliefs into the discussion. However, while all these strategies were incorporated into the DMCA process, not all were successful due the presence of the language disorder.

Not surprisingly, diversity was observed in the results from these DMCAs, but also within the consistency of the answers provided. Possible explanations for this are the timing of the capacity assessment, fluctuation within the participant's aphasia, fatigue and medications. Ideally, the assessments would have been done at the same time on different days, but due to patient commitments and availability, and availability of the raters, this was often not possible.

v. Changes in the study.

Due to unforeseen circumstances during the study duration, it was necessary to make a number of changes. Clearly this is not ideal, as potential changes should be incorporated into the protocol before the study commences. Given the complexity of the study design and the lack of prior research in this area, the challenges were not predictable (although will likely not be surprising to the reader)

The most significant change to the study was in the research question and the focus of the communication aid. The reason for changing the focus to financial DMCA was discussed in depth earlier, and will not be repeated here, except to say that while not ideal, it could not have been foreseen prior to the study, and was necessary to allow the development of a valid and practical communication aid.

The other changes that were required (e.g., to the inclusion criteria) were unforeseen. Had they been predictable, wider inclusion criteria would have been developed. However, despite these changes to the study design, none had a significant impact on the accuracy of the results.

c) Visual Communication aid

This new visual communication aid is the first of its type, as far as we are aware of, to support assessments of financial DMC in post-stroke PWA. Thus, there is no gold standard to compare to. Although there is nothing to compare it to, it does have three main limitations for this communication aid which should be pointed out: the specific population in which the aid was validated, limitations about the aid itself, and the fact the evaluation performed was only preliminary because of the small sample size.

i. Study population.

The visual communication aid was developed for and validated within a very specific population (hospitalized adults with a diagnosis of post-stroke aphasia). There were many reasons for using this specific population in this setting. By being in hospital, this population would have easy access to SLPs to formalize an aphasia diagnoses, which may not have been the case in a community setting. Patients are often required to undergo formal assessments of their capacity because of their communication barriers. Finally, a hospital setting facilitates accessibility to eligible participants, which would be considerably more difficult in the community. All of this helped with validation of the communication aid.

However, the use of a narrow and specific population does limit the external validity of the communication aid and its generalizability. For instance, it may be that community-dwelling post-stroke aphasic individuals have a greater need for such a communication aid. To overcome this limitation, future plans include the validation of the aid within a wider, non-hospital based population.

ii. Psychometric evaluation of the communication aid.

The preliminary results obtained from the eight participants were analysed within two separate groups: Group One (Rater A and Rater B), and Group Two (Rater A and Rater C). Rater A is a nurse practitioner, Rater B is a physician, and Rater C is an occupational therapist. All three underwent dedicated Supported Conversations for Adults with Aphasia (SCA) training.

However, although Rater A and Rater C also received Designated Capacity Assessors (DCA) training, Rater B, being a physician, did not. This difference in training (and also differences in underlying professions and experiences) will likely influence how each individual approaches and interacts with the aphasic patient. For this reason, although the number of patients seen by Rater C was too small to draw any conclusions, it was felt that Raters B and C should not be combined, and thus, the data was analyzed in two clusters.

There was noticeable diversity in the answers for many of the questions in the communication aid, which can be seen in Figures 2-35, and Tables 9-43. For example, there was a limited number of potential answers to questions 1 and 2, which likely reduced the possibility of disagreement between raters and consistency in patient responses. By comparison, there were eight different answers to question 15, which increased the likelihood that the raters would hear contradictory answers, and may have reduced the internal consistency of the communication aid. On a practical basis, it may reflect that some questions (especially those that received a diverse range of responses) were more challenging for aphasic individuals to answer, and may require editing.

Another important factor that we had to consider when assessing the reliability of the communication aid was the consistency of responses. While this may not be an issue within the general population, it is for PWA, in whom the severity and nature of aphasia may fluctuate. The DMCAs were done on separate days to avoid the risk of bias that could arise from repeating the assessment on the same day. Also, doing the assessment on different days prevented participant fatigue and likely reduced the risk of participant refusal or withdrawal from the study.

iii. Preliminary status of validation of the communication aid.

The initial goal of the study was to validate the communication aid in 30 hospitalized adults with post-stroke aphasia. However, as mentioned earlier, it became clear during the recruitment Phase that there were few eligible participants. For the purposes of this thesis, a decision was made to perform a preliminary evaluation based on eight participants. While these results are promising, and certainly support extending this study, the sample size is insufficient to accurately determine the psychometric properties of the communication aid.

As there is no research done in this area, it was not possible to determine an appropriate sample size for validation of this communication aid. As previous literature addressing

instrument validation has reported a sample size of 30 as being sufficient for this purpose.(Glaser & Strauss, 1998), this sample size was used for the study. Future iterations of this study will continue until this sample size has been met. If, after continued recruitment, we still have difficulty achieving this sample size, it may be feasible to lower the number to 20. Although this would be far from ideal, given the lack of prior research (and, thus, the need for more) this would be acceptable.

4.4. Future plans

Preliminary evaluation has shown that this new visual communication aid is reliable (with moderate inter-rater reliability and good internal consistency), valid, and usable. Although these results are promising, because they were generated from a smaller-than-expected sample size, the accuracy and interpretation are limited. The plan is to continue the study until a sufficient number of participants (n=30) have been enrolled to meet the required sample size. This will allow an accurate evaluation of the psychometric properties of the communication aid and confirmation of its validity, reliability, and usability within this population.

After establishing the psychometric properties within the post-stroke PWA population, future plans include validating its use in the general aphasic population and other settings (e.g., community-dwelling PWA). Evaluation in a wider population would help to establish external validity and improve generalizability of its use.

Another future goal is the validation of the other new product created from this study, the Aphasia-Friendly Participant Consent Form. Initial validation of this consent form should come from the population for which it was developed (similar to the communication aid). Following that, the plan is to evaluate its use in a wider population.

Chapter Five: Conclusion

5.1. Study summary

The initial research objective was to develop a new visual communication aid to support assessments of financial and legal decision-making capacity (DMC) in people with post-stroke aphasia. However, after completing Phase one of the study, it was determined that it would not have been feasible to develop a single instrument to adequately assess both domains. Consequently, the research objective was changed to developing a visual communication aid to support decision-making capacity assessments (DMCA) for financial decision-making ability only.

The study design was quite complex, and was divided into three Phases. Phase one involved using focus groups to learn what (community-dwelling) older adults' knew about DMC and communication and its disorders. Phase two involved developing the visual communication aid to support DMC for financial matters. The third Phase involved evaluating the psychometric properties of the new aid.

Due to a number of unexpected barriers encountered during the study, several changes were made to the inclusion criteria, details of which can be found in Chapter four. The changes were related to difficulties with recruitment, specifically, that were not enough eligible participants. As a result, the duration of the study was significantly prolonged.

Despite the challenges, the main research objective was achieved. To evaluate the psychometric properties of the visual communication aid, a sample size of 30 participants was required. However, given that after one year we had only recruited eight participants, for the sake of this thesis a decision was made to perform a preliminary evaluation of the communication aid using the data from the eight patients, with a future goal to continue the study after I completed writing the thesis. These preliminary results revealed the communication aid to be reliable (with moderate inter-rater reliability), valid, and usable. However, further evaluation is required once the sample size has been reached, to confirm this.

5.2 Discussion of results

There is very limited research about financial DMC in PWA, and no communication tool exists to support assessments. Given this clear gap in current knowledge, this study developed a new visual communication aid to support assessments of financial DMC for PWA.

An analysis of these preliminary results from eight patients revealed the visual communication aid to be valid and usable, and to have moderate inter-rater reliability, with good internal consistency. Although preliminary, these result are promising, and certainly warrant continuation of the study until a sufficient number of participants have been recruited to meet our intended sample size of 30. Only then can the psychometric properties of the aid be fully established.

The aid was validated by a relatively small and unique population (hospitalized patients with post-stroke aphasia), which, at present, limits its generalizability for use within a broader population and other settings. However, there is great potential for the aid to support financial DMC within a wider population, such as individuals with any form of aphasia (or other language disorders) who require assessment of their financial DMC. Thus, once the psychometric properties of the aid have been fully established in this particular setting, the next step will be validate its use within a wider population.

Two other new products were developed from this research: the Aphasia Friendly Participant Consent Form – Release of Contact Details form and the Aphasia Friendly Participant Consent Form. Both are based on standard participant consent forms that have been adapted for PWA using an aphasia-friendly format. Although forms were developed for this study and have not yet been validated, they have the potential to serve as valid consent forms with PWA prior to conducting (financial) DMCA. Future plans include looking at the validation of each of these consent forms.

This thesis has also identified an important gap in the current literature about the general lack of understanding of DMC and, specifically, financial and legal matters. This is an important finding that should prompt further investigation, given the importance that DMC plays in everyday life. Another important aspect of this is that older adults (and adults in general) are routinely asked to create legal documents, such as a personal directive and enduring power of

attorney, as part of advance care planning. These documents are important in case the individual is deemed to lack capacity in the future. Given this identified lack of awareness about DMC, it is concerning that individuals are potentially creating such documents without understanding the context and relevance. This highlights a need for greater public awareness and education about these topics.

One of the other interesting finding had to do with the general understanding among community-dwelling older adults about communication and its disorders, and the impact that communication impairment can have on the DMCA process. This was an unexpected but enlightening finding, which requires further exploration.

In summary, the objective of this research was to develop and evaluate a new visual communication aid to assist with financial DMC for PWA, which has been achieved. Although the research is not complete at this time, the preliminary results show the communication aid to be valid, have moderate inter-rater reliability, and be usable. The final step is to complete enrollment of 30 participants, which will allow us to fully establish the psychometric properties of the communication aid.

5.3 Contribution to current research

This study and thesis have made a number of important contributions to current research. The first contribution was the recognition of the knowledge gap in the literature about financial and legal DMC in the aphasic population, as described in Chapter two. This is an important finding, which provided the basis for this research, and strengthens the need for future research about this vulnerable population.

The second, and most important contribution, is the development and (preliminary) validation of a visual communication aid to support financial DMCAs for post-stroke PWA. The development and validation of this new aid is extremely important, as the aid the only one of its kind. Prior to this research, DMCAs for financial matters would probably not have been completed or even attempted. Now, using this communication aid, PWA can at least participate in such assessments, and the aid can also help assessors to demonstrate an individual's financial DMC.

The third contribution was the development of a new Aphasia Friendly Participant Consent Form (Appendix 4), to obtain consent before conducting financial DMCAs on aphasic individuals. While this consent form was specifically designed for this study and has not yet been validated as it was not the focus for the study, it has potential importance, as it is the only document of its type currently available, and should undergo evaluation and validation of its role within these assessments.

The final contribution is the recognition (from the focus group feedback) of the general lack of awareness and understanding among community-dwelling older adults in the areas of DMC and, in particular, the domains of legal and financial decision-making. This is another important knowledge gap existing in the current literature, which requires further exploration.

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APPENDIX 1

Focus Group Questions

First discussion:

1. What is capacity or decision making?
    a. When you think of the term capacity, what comes to your mind?
    b. Why would someone's capacity or decision making be assessed?
2. What is a capacity assessment?
    a. What is the process involved?
    b. Who can assess capacity or decision making?
3. What are the areas of capacity or decision making?
    a. Why is it important for you to be able to demonstrate understanding or initiation?
4. What does legal decision making mean?
    a. What legal matters do you need to understand in order to be "capable"?
    b. At what point do you think you would be concerned about someone's ability to manage their legal affairs?
5. What does financial decision making mean?
    a. What financial matters do you need to understand in order to be "capable"?
    b. At what point do you think you would be concerned about someone's ability to manage their finances?
6. What is the result or end outcome of being found to lack capacity?

Second discussion:

1. When you hear the term "communication", what does that mean to you?
    a. What are different types of communication techniques (i.e. communication board)
2. What are some common problems with communication?

3. What does the term aphasia mean to you?
4. Why would a communication problem/disorder affect the assessment of someone's capacity or decision making?
5. In what ways do you think communication can be performed without using speech?
    a. Someone without speech?
    b. Someone who can not hear?
    c. Someone who is blind?
6. How would pictures help with communication?
7. How do you think pictures could help communicate questions about finances?
8. How do you think pictures could help communicate questions about legal matters?
9. What other communication methods could be used?

APPENDIX 2

Data Record Form

Patient ID (e.g. 1, 2, 3):_____

Date of capacity assessment:_____

Time of capacity assessment:_____

Duration of capacity assessment (mins):_____

Was the capacity assessment completed? (Yes/No):_____

If not, why not? (explain): _____

Diagnosis of Aphasia by SLP (yes / no):_____

Type of aphasia present if known (expressive (non-fluent / motor), receptive (fluent / sensory), conductive aphasia, unknown, other):_____

Assessor (MV / KP / FC): _____

Was any addition communication support provided / used? (Yes / No): _____

If yes, what type of support was used: _____

Is there any hearing / visual impairment present? :_____

If so, was this corrected for the assessment with appropriate supportive aids?_____

Question	Answer	Unable to answer / refused
F1		
F2		
F3		
F4		
F5		
F6		

F7		
F8		
F9		
F10		
F11		
F12		
F13		
F14		
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F29		
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F32		
F33		
F34		

APPENDIX 3

APHASIA FRIENDLY PARTICIPANT CONSENT FORM – RELEASE OF CONTACT DETAILS

We are developing a **communication aid** to help with capacity assessments for people with aphasia.

You have been selected as you have been diagnosed with aphasia and are over the age of 65.

If you agree, your contact details will be given to the study team. The study team will then contact you about the study information.

Your medical care will not be affected by your choice.

Do you **agree** to **release your contact information**?

Signature of Research Participant / Agent / Guardian: _____

(Printed Name); _____

Date: _____

Signature of Witness (when required):_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to the release of their contact information.

Signature of Investigator or Designee: _____

Date: _____

APPENDIX 4

APHASIA FRIENDLY PARTICIPANT CONSENT FORM

STUDY ID:

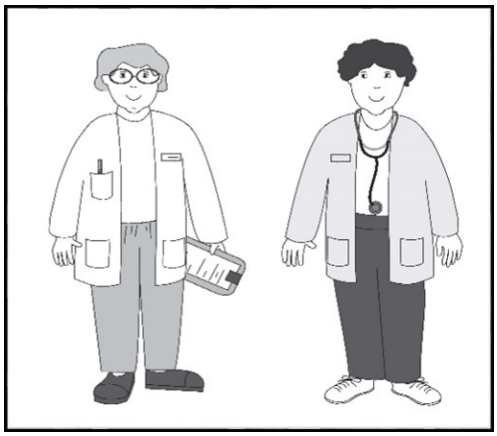
PARTICIPANT ID:

PRINCIPLE INVESTIGATOR:

CONTENTS PAGE

1. INTRODUCTION

You are being asked to participate in a research study about capacity assessment.

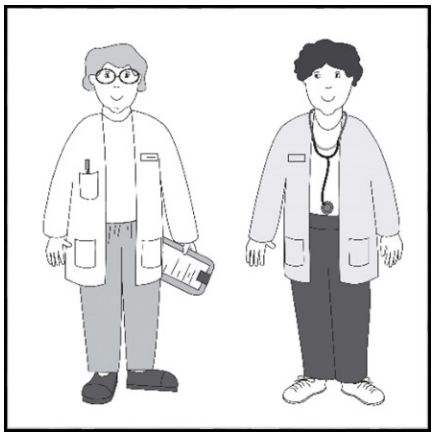


In Alberta, a formal **capacity assessment is done**…

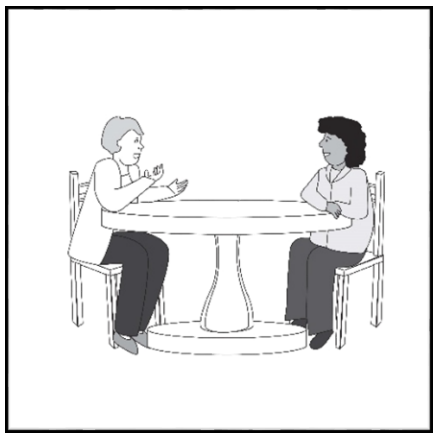
… to **see** if a person is **able to understand** important **information** for making **decisions**…

… and is able to **understand** the possible **results** of making a decision or of not making a decision.

A formal **capacity assessment is done by** a trained capacity assessor or doctor.



For this **capacity assessment …** a capacity assessor or doctor will talk with the person.

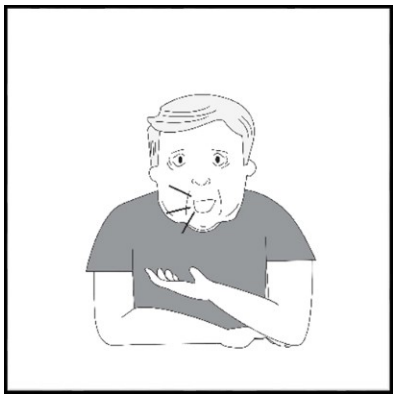


We know it can be very difficult for a person with aphasia to communicate their thoughts.

Therefore, capacity is …

‘A person’s ability to make decisions they understand’.

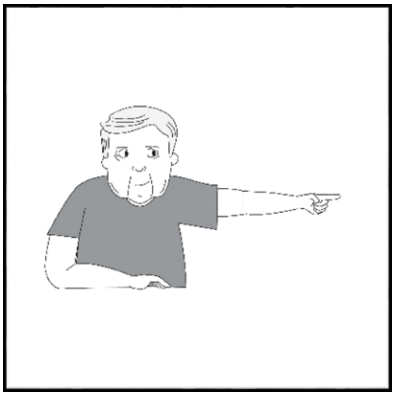
A person is entitled to communicate however they can.



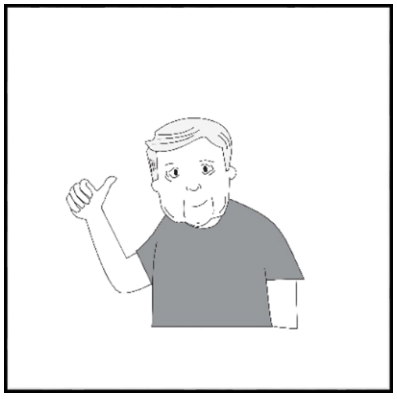
Speaking

Writing

Drawing



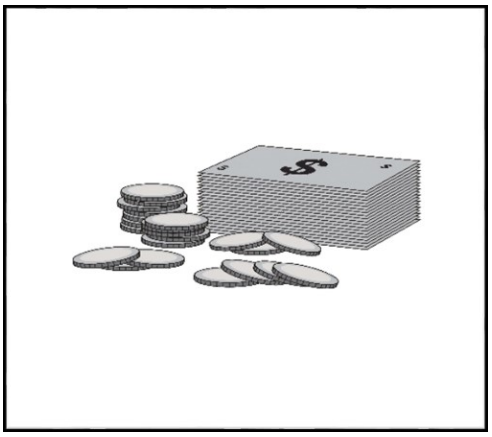
Pointing



Gesturing

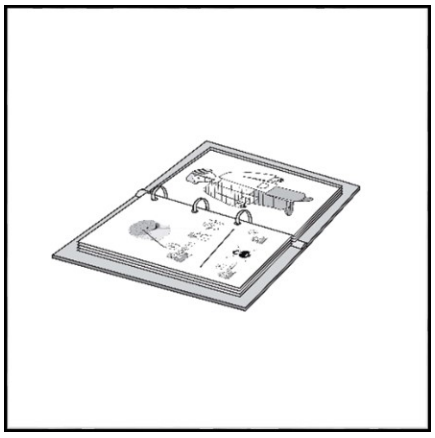
2. STUDY BACKGROUND

There is a communication aid that can be used to **help assess capacity** with persons with aphasia **but** it does **not** look at **financial issues.**



Therefore…

We are **developing a communication aid to help with capacity assessments in people with aphasia.**



We want to know …

1. **Can this communication aid produce consistent results?**

And

2. **Does it help?**

3. PARTICIPANT INFORMATION

You have been chosen to take part in this study because …

1. You have been admitted to the hospital and have had a recent stroke

and

2. You have been diagnosed with Aphasia.

The study will involve…

1. A research member will talk with you about the study.

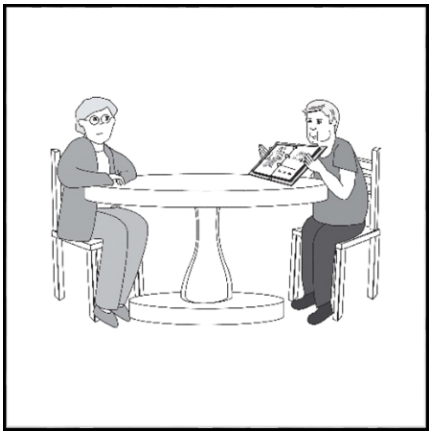
And…

2. Asking you for your consent to take part in the study.

If you **agree…**

3. A capacity assessor will perform a capacity assessment with you using the **communication aid**.

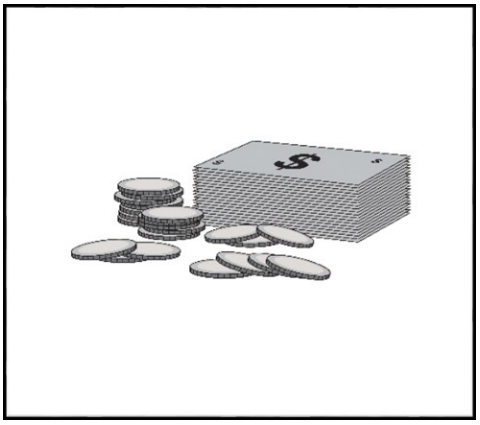
4. A second person will assess the same domains using the same tool.



4. PARTICIPANT INVOLVEMENT

What is Your Role?

You will be asked to have a capacity assessment done in the areas of **financial matters.**

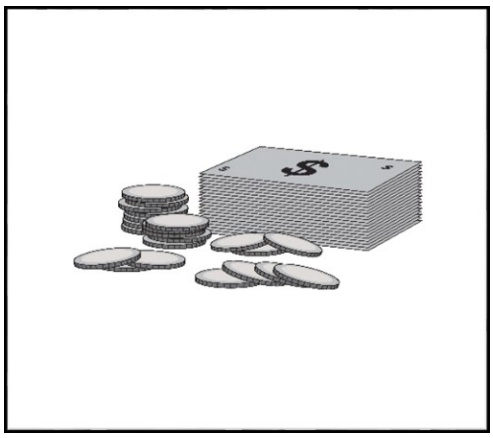


Finances

Why is this important?

Aphasia can make it hard for you to communicate and be understood.

The purpose of this study is to ensure the newly created communication aid helps with the assessment of financial decision making ability.



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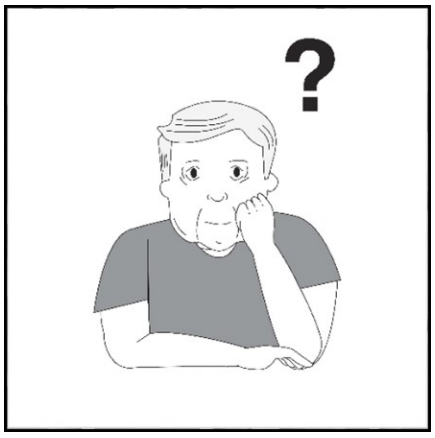


?

Where will this take place?

At the Hospital.

When will this take place?

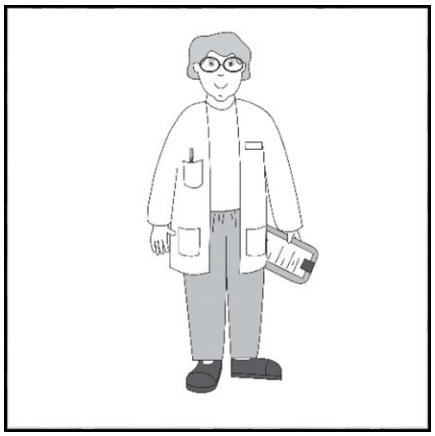
During the **daytime.**

Any day of the week.

Sun	**M**on	**T**ues	**W**ed	**T**hurs	**F**ri	**S**at

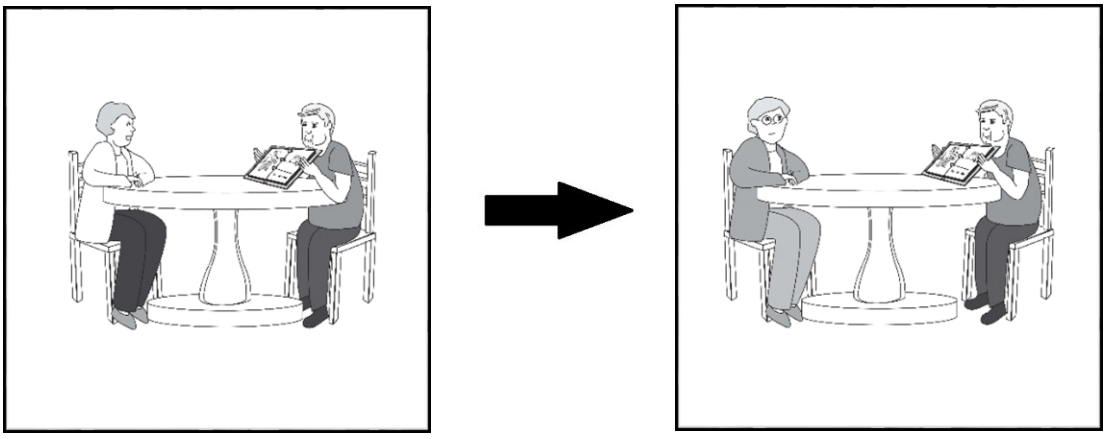
Who will do the capacity assessments?

A **trained designated capacity assessor** will come to do the capacity assessment with you.



How often will I be assessed?

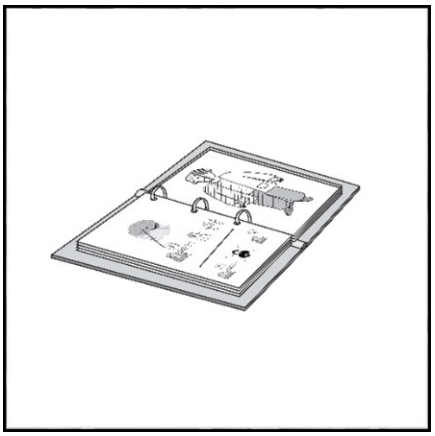
2 sessions, and more if needed.



Session 1
One designated capacity assessor will come **one** day.

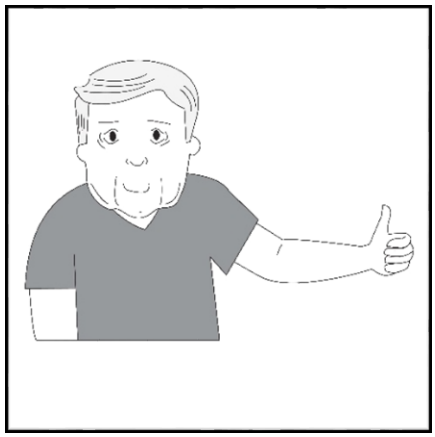
Session 2
A **second** designated capacity assessor will come on **another** day.

Both people will ask you questions about the same areas using the **same communication aid**.

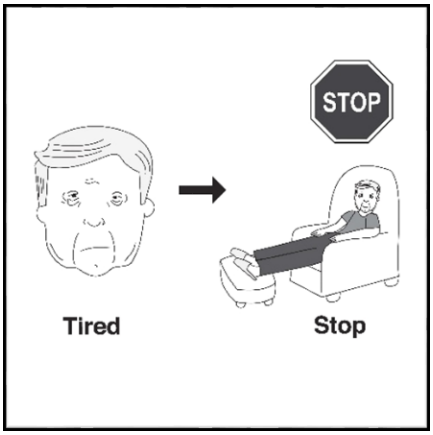


How long will the assessment take?

It will depend on how it goes.



If you get tired, we can stop…

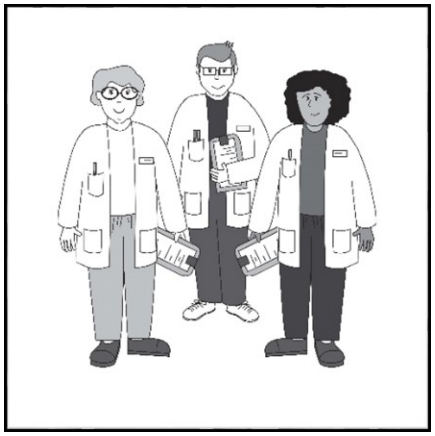


And start again another day

5. DATA PRIVACY

What personal information might be used?

Your **information** will be held by the research group.



Example:

Your **name, diagnoses, capacity decision.**

Your **information** will be kept confidential.

We might have to share your **information** with a judge or the Health Research Ethics Board.

They review information to protect you.

How will the study data be used?

Your information will only be used to answer the research question.

How will the capacity assessment results be used?

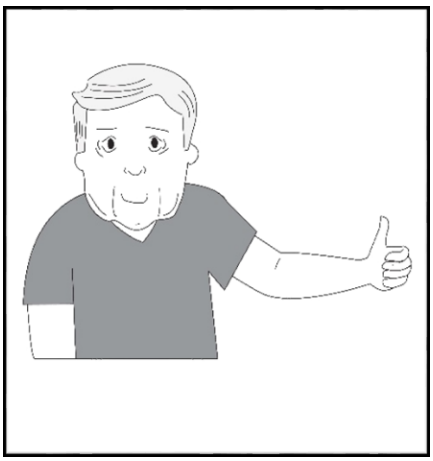
The results will be kept confidential, and will only be used to determine if the communication aid helps the assessment process.

6. RISKS AND BENEFITS

There is no physical danger in participating in this study.

Are there any benefits?

You may find the tool helpful with the assessment.

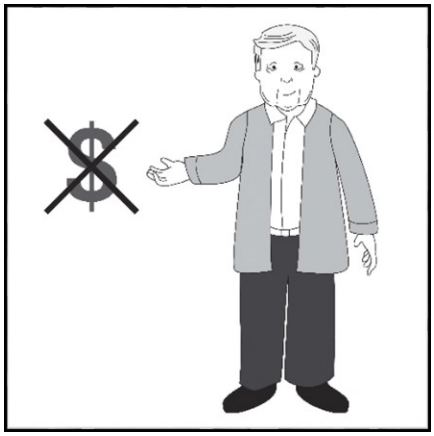


We hope to create a tool that is helpful for assessing capacity with people with aphasia.

7. JOINING THE STUDY

Your can choose whether you take part in the study or not.

Will I be paid to be in the research?



No

Do I have to take part in the study?

No - it is your choice to take part in the study. Your decision will not affect your medical care.

You can stop at any time.

QUESTIONS?

If you have any questions or concerns about participating in this study, please speak with any member of the:

Research team

Or

Dr Frances Carr:

Telephone: 780 394 8596
Email: fcarr@ualberta.ca

IC-10

Project Consent:

The information presented on the previous pages has been **explained** to me.

YES 

_____

I **agree** to participate in this research project.

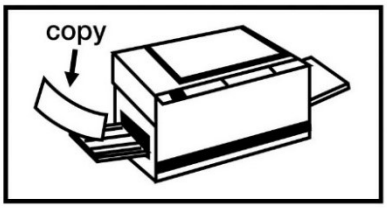
YES 

_____

NO 

_____

I have been given a **copy** of this form.



YES 

_____

NO 

_____

_____ _____

Signature of Participant Date

_____ _____

Signature of Witness Date

APPENDIX 5

Participant Information Form

Title of Study: An assessment of the psychometric properties of a visual communication capacity aid.

Principal Investigator: **Frances Carr** (phone number: 780 394 8596)

Research/Study Coordinator: **Frances Carr (**phone number: 780 394 8596)

Why am I being asked to take part in this research study?

You are being asked to take part in this study because you have been admitted to hospital, and have been diagnosed with aphasia after a stroke.

Everybody is assumed to have decision-making ability unless confirmed otherwise through a formal capacity assessment. The assessment process that is used by your doctor or capacity assessor for determining whether decision making ability is present requires your assessor to determine your ability to understand the information that you have been given regarding a specific decision. This will involve looking at your ability to understand the risks and benefits from making that decision and your ability to weigh up and remember the information in order to make a fully informed decision, which you are able to communicate to your assessor.

The complexity of this assessment process makes this assessment very difficult or impossible for participants with communication or language difficulties similar to yourself. Unfortunately, we do not have any communication aids or tools that can help with the assessment of decision-making capacity for financial matters, which supports the reason for our study.

Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

The purpose of this study is to determine if a specifically designed visual communication aid can help with the assessment of specific decision making capacity for financial matters for people with language difficulties similar to yourself. The results from this study will determine the need for further research

and, if this communication aid is shown to be successful, then our intention would be for the visual communication aid to be used routinely for all similar capacity assessments of financial decision making ability for people with communication difficulties.

The study will be conducted at the Royal Alexander hospital. We are aiming to enroll thirty participants similar to yourself over the course of one year.

What will I be asked to do?

As a participant, you will be asked to consent to undergo a capacity assessment to assess your decision making capacity in the areas of financial matters. These capacity assessments will take place on two separate days using two separate assessors (called designated capacity assessors (DCA's)) who have received specialized training for this purpose.

By consenting to participate in this study, you are consenting to allow the research team access to your medical records in order to obtain necessary information required for performing the capacity assessment (which includes but is not limited to active medical conditions, communication difficulties, social circumstances and background). The assessment results, and other information collected, will be kept confidential to the research team, and will only be used to determine if the communication aid is effective.

Study process

The first step will involve a member of the healthcare team asking you or a substitute decision maker (a named representative) for consent to release your details to the research team. If you consent, they will ask you or your named representative to sign a consent form, allowing the research team to make contact with you. If you are unable to provide consent, then we will approach your named representative for consent to participate.

The second step will involve a member of the research team contacting you / your named representative, to discuss the study in more depth. You will also have the opportunity to ask and have questions answered, and any concerns addressed.

The third step involves one of two DCAs meeting with you on a pre-arranged date to perform the capacity assessment using the communication aid. The assessment will assess your decision making capacity for financial matters only.

The final step will involve performing a seperate capacity assessment by a second DCA on a consecutive day. The results from these assessments will only be available to the research team.

What are the risks and discomforts?

Due to the sensitive nature of the data collected and results obtained from the capacity assessments, there is potential for you to experience psychological distress, embarressment or frustration both during the assessment process or from the results. Additional stressors and / or frustration may be experienced due to difficulties experienced in communicating your thoughts or ideas sufficiently.

To minimize these aforementioned risks, we will provide you and / or named representative with full information about the study, what it involves and how the results are handled. All capacity assessments will be performed by DCAs who have undergone additional specialized training for this role in the form (in the form of 'Supported Conversation for Adults with Aphasia'). This is to ensure that the assessments are done accurately and fairly. Both the DCA's and members of the research team will be available throughout the study duration and at its completion to provide additional support to you as needed. You will also be given the opportunity to have someone present during the assessment to ease anxiety.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant. Should any risk/s develop, then your research team will endeavour to provided with the appropriate support and guidance required to overcome these risk/s.

If we find out anything new during the course of this research which may change your willingness to be in the study, we will inform you about these findings.

What are the benefits to me?

Currently, there are no similar communication aids available to help with these assessments. Therefore, any improvements which arise from using this communication aid will be a benefit. Even if no clear benefit is obvious following your participation in this research study, we hope that the results from this study will both provide evidence supporting the role of this communication aid for supporting capacity assessments of financial decision making ability for peoples with communication difficulties in the future.

Do I have to take part in the study?

Participating in this study is your choice. If you decide to participate in the study, you can change your mind and withdraw from the study at any time. Should you choose to withdraw, this will in no way affect the medical care or treatment that you are entitled to now or in the future.

The capacity assessments will be performed on a one to one basis between yourself and the capacity assessor. Due to the sensitive nature of the assessment and questions, the capacity assessors will perform these assessments in a culturally sensitive manner to avoid exerting any undue distress. However, if at any point you wish for your assessment to be terminated or are unable to answer the questions asked then your decision will be respected.

Should you choose to stop and withdraw from a capacity assessment you are free to do so. If this occurs, you will be approached by a member of the research team who will discuss with you the reasons for your actions, and you will be given the option of withdrawing from the study altogether or to re-arrange another capacity assessment. If you are unable to provide consent yourselves, we would then approach your alternative decision maker regarding this matter. An exception to this will be if, at any point during your participation in our study, we observe or believe that you may be experiencing distress then we will stop any current assessment and we would discuss and re-evaluate your further participation in the study.

Will I be paid to be in the research?

You will not receive any financial or other monetary incentive for participation into this study.

Will my information be kept private?

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The investigator or their study staff may need to look at your personal health records or at those kept by other health care providers that you may have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will be only what is needed for the study.

During research studies it is important that the data we get is accurate. For this reason your health data, including your name, may be looked at by people from the University of Alberta and the Human Research Ethics Board.

By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

What if I have questions?

If you have any questions about the research now or later, please contact Frances Carr at 780 394 8596.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

There are no actual or potential conflicts of interest to declare with respect to remuneration received from the funding agency for conducting or being involved with any part of the study and/or the possibility of commercialization of research findings.

CONSENT

Title of Study: An assessment of the psychometric properties of a visual communication capacity aid.

Principal Investigator(s): Frances Carr Phone Number(s): 780 394 8596

Study Coordinator: Frances Carr Phone Number(s): 780 394 8596

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care, or without penalty?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records, including personally identifiable health information?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are Participating in this research study? If so, give his / her name: _____	☐	☐

Who explained this study to you? _____

I agree to take part in this study: ☐ ☐

Signature of Research Participant / alternative decision maker: _____

(Printed Name) _____

Date:_____

Signature of Witness:_____

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e. not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e. not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)

Signature of Investigator or Designee_____

Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

APPENDIX 6

Visual Communication Aid

User Experience Questionnaire

Please answer the following questions regarding your experiences with using the communication aid by checking the appropriate boxes. Feel free to expand on any answers in the boxes provided.

Q1. Did you feel adequately prepared to use the communication aid*?*

Yes ☐ Maybe ☐ No ☐

If you answered no or maybe, proceed to Q1b. If not, proceed to Q2.

Q1b. Is training required prior to its use?

Yes ☐ Maybe ☐ No ☐

If you feel training is required, please provide details below regarding the amount and / or type of training required**:**

Q2. Were the instructions provided easy to understand?

Yes ☐ Maybe ☐ No ☐

If you answered no or maybe, please provide more details below:

Q3. Did you require additional time for using the communication aid?

Yes ☐ Maybe ☐ No ☐

If you answered yes or maybe, please provide more details below:

Q4. How easy was the aid to use? (1 = impossible to use; 10 = simple to use)

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐

If you answered between 1 and 5, please provide more details below:

Q5. How easy was it to incorporate into the assessment? (1 = impossible; 10 = easy).

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐

If you answered between 1 and 5, please provide more details below:

Q6. What are the strengths of using the communication aid? Please provide details below:

Q7. Did you face any difficulties with using the communication aid?

Yes ☐ No ☐

If you answered yes, please provide more details below:

Q8. In your opinion, did the communication aid improve the assessment process?

Yes ☐ Maybe ☐ No ☐

If you answered no or maybe, please provide more details below:

Q9. Would you be willing to use it again?

Yes ☐ Maybe ☐ No ☐

If you answered no or maybe, please provide more details below:

Q10. Is there anything you feel should be changed to improve how the communication aid is used?

Yes ☐ Maybe ☐ No ☐

If you answered yes or maybe, please provide more details below:

Thank you for taking the time to complete this questionnaire. Once you have completed this questionnaire, please email it to Frances Carr at fcarr@ualberta.ca / Frances.Carr@albertahealthservices.ca. Alternatively, you can hand it in person to myself or send it by post using the mailing address included in the cover letter

APPENDIX 7

Summary of Focus Group Feedback of the Visual Communication Aid

Table 7: Summary of focus group participant's feedback of the communication aid. Italics have been used to highlight quoted suggestions and examples from the participants.

Question	Summary of transcription results from all focus groups
1	Dollar sign is ok, add bank picture or personal cheque. Include a question mark as you want to question the finances with the symbol. Use large print and remove the shadow. *'These are not good pictures'.* Use Canadian funds i.e. dollar bills / coins. If you use a dollar sign, use a clearer and simple picture sign, and keep it plain and big as this is too fuzzy and shadow is too confusing. Reword the question - use money instead of finances.
2	Misleading picture re: the source of the money. Use more specific pictures relating to the source of money (? i.e. stocks). Include a dollar sign, a question mark and / or picture of you with dollars or something. +/- an arrow pointing right at you. Rephrase 'where do you get your money?' or 'where does your money come from?', or simplify even further and stating 'do you have any money?
3	Reword the question- how much money you have in your bank account. Get rid of the piggy bank. Include pictures of a bank book /account / bank/ cheque book. Need to include a picture of a person, dollars and a question mark. Need to convey a sense of volume – e.g. a bank building with money hanging out the windows and another of a bank / financial institution with no money. The calculator picture is confusing. Have a picture of piggy bank (this is universal meaning of money that you are saving' and of a bank with a picture of a bank.

4	Include a Credit Union like Servus, RBC, CIBC, TD. Could use picture of an ATM / Dollar sign. Good idea using leaflets to represent different banks.
5	Pictures are confusing. Suggestion -'*To represent an account there should be some kind of a bank slot or a bank teller or something like that. And then the person should have the bank info or cheque in the hand'.* Use a computer for idea of online banking, or a picture of a screen that says something to do with accounts, or use a pie diagrams divided into different accounts. Include a picture of an ATM. Include a scale and justice picture with assets on it to represent balancing accounts. Use a picture of a financial advisor and use combined with a universal sign for don't do it, no or yes. Need to demonstrate the concept of cash flow - a calculator is good. Rephrase the question - change wording to 'review' rather than manage. Suggestion – '*picture of a teller or you could have an ATM. That is ways to manage. You could have a picture of a person. So that way the person could just point to the person and then you would know someone else is taking care of your money'.*
6	Expand the question 'how often' to 'how often do you…". Include a picture of a calendar that shows the months and the days and the individual can tick of days (daily) or months (monthly). Use a calendar, but include the term daily and have days of the weeks on it. Leave out weeks of the months.
7	Use pictures of a bank, ATM, or bank teller and not piggy bank. Cheques are fine for chequing account. Pictures are good and are fine by themselves.
	Use pictures e.g. car, house, boat and put a question mark at the end and line up the pictures.

8	Have a picture with arms wrapped around assets. Rephrase the question to 'what do you own?' The pictures are ok, but need to adjust the wording of the question.
9	Include the Stocks and shares pictures, Bonds, Artwork. The current pictures for stocks and shares are good, but not for Mutual funds. For the Savings bond, use a picture with a bond on. Don't use a piggy bank for RRSP picture. Mutual funds could be represented by a picture of a sheet with stock on / bonds.
10	Correct interpretation by one candidate of picture. Could also include picture of total monthly bills i.e. condo fees. Picture is understandable. Could also include pictures of house / dwelling and use a pie chart to represent bills. Other pictures could include food, utilities, car / bus, insurance, travel. Combine the two questions into one. Rephrase the question 'What bills do you have to pay each month?'. Suggestion - '*The calendar relates to the monthly word and the other two drawings relate to the expense. It is fine'.*
11	Suggestion - *'use pictures of property tax, income, three dollar bills going out, five dollar bills. To indicate problems with income'*. Use a picture of a Credit card cut in half The current picture is not that clear. Could include pictures of a face with tears or a sad picture. Using a combination of words and pictures is good. Suggestion - '*I like the money. And arrows to figure out where to get it from. It is a good picture'.* Rephrase the question 'Do you have enough money to pay your bills?'. Suggestion - *'Use the current pictures, and then have a picture of a balance of zero. Like bills have been looked after and paid in full'.*
	Use a universal picture – e.g. picture of someone drowning so it conveys that you need help, or use another help picture

12	*Example –' The money picture. All this money in someone's hand. And arrows to things you have to pay. One hand can have the money and the other so that they can choose whether they are happy. . For managing could you have hands laying out money for that bill. In both cases you have money, do you have money and you are writing a cheque. And the next picture you have money but you have someone else with you. Include a real bill'*
13	See above question.
14	Include a picture of an envelope Picture is good. Could add word property tax
15	Include a picture of a cheque book, ATM, computer and telephone. Include a picture of cash and a chequebook. Include a picture of automatic payment methods.
16	Change colour of man from black and use a different picture. Include a logo of heart and stroke foundation. Use different pictures of charitable organizations. The current picture is a poor representation of a guy - remove it. Use instead recognized logos /charity symbols, i.e. jumpstart, Salvation army, Food bank, heart and stroke foundation, Breast cancer, salvation army, Bissell center Use of colour is important.
17	Use a list of common charities, with their logo's.
18	Use a dollar sign and include % sign. Looks good.
19	Change the friend's picture to a picture of two friends sat down at a table. Include a picture of H&R block /business and accountant. Include a picture of tax return or T4 or even CRA. Include pictures of a calculator, H&R block picture and tax preparers / someone sitting at a desk, one person there and person behind the tax (accountant). Suggestion – '*For the family picture, use mom and dad and two children. Age of children not important but they should be shown as being small. Proper picture better than silhouette. Picture of baby walking is ok'*

20	Include a positive picture followed by a negative picture – e.g. use pictures of a house and food for a positive picture, and prison (indicating going into debt) as a negative picture. Suggestion - *'If you are going to have a picture then you should have somebody with their pockets inside out and they are like empty. How about two pictures; one of a person with money in their hands and one of a person with no money in their hands and a sad look on their face. So, they have a choice between two things. Include people who would have received are happy and the people who have no money have sad faces.*' Picture of plate of food and empty plate. Include a picture of a Jail. Include a picture of an Eviction notice
21	The picture is fine but include an arrow and a dollar sign. Could include pictures of accommodation, transport, a person going hungry. Include pictures of family members, lawyer, or financial organization. Have a number of different pictures to represent different possibilities for 'WHO' and include picture of 'YOUR'. Use the word 'ME' to represent 'you'. Include an accountant (which is represented by this picture) and pictures of various family members. A picture of 'me' and family members is suffice, although the current picture is good.
22	Need a different picture of a padlock – replace with a real padlock. Include a picture of a person with a face with that padlock and the key. Include picture of self, family and a computer. Have a picture of a bank institution and the question and include the symbol for money as being just a dollar sign. Remove the calculator. Suggestion – *'You might show a bunch of money and whether someone can dip into the fund. Whether it is a picture of a family and bills'.* Have a picture of a court / court chamber, family (mum, dad, child), lawyer / agent, social worker, AISH, Alberta works.
	Picture of someone going into the bank.

23	Use same pictures but include pictures of a Bank, bank teller and a person at bank teller.
24	Use a picture of desk with a drawer e.g. filing cabinet type of thing, as part of a desk. Include pictures of a Filing cabinet, safety deposit box and picture of home. Suggestion – '*Use a picture of the documents. I like the file folders. Possibly include a dollar sign. +/- picture of a stock certificate, a will or anything like that. File folders and computers. Instead of the picture of a box, use a file cabinet with a file folder going into it*'. Computer picture is useful. Make pictures bigger. Include pictures of family. Maybe also include a picture of drawing an actual bank statement or tax return assessment.
25	Similar to other question. Use pictures of Family, bank, Lawyer, Friend. Redundant question, or combine with Q12.
26	Use a picture of a Safety deposit box. Suggestion - '*dollar sign represents money'*. Use pictures of a Safe, Safety deposit box, vault, bank, filing cabinet. The safe and file pictures are ok. Rephrase question - 'how do you protect your financial documents?' Also include a picture of lawyer and family.
27	Include a picture of family and children. Include a question mark with a $20 bill. Suggestion – 'If they have no-one, have a picture of person with a cross and picture of coins, dollar signs or both.' Suggestion – '*Need to convey the concept of needs'*. Suggestion – '*A picture of you. Again you can have you and a bunch of different pictures with question marks going towards the various people. You can have family, friends, etc. You need a hand-out and people.'*

	Suggestion – '*use a speech bubble. Using an arrow and having a dollar bill floating through the air. Put him on his knees as well with his hand out. Because I think if he is on his knee, he is begging'.* Can also use pictures of a disabled / handicapped person, charities, children etc. Use the same stick figures / other pictures for consistency. Use more lifelike pictures, like use sunset and sunrise to depict days, and a calendar (like that used before) for how often.
28	Picture of salesman, possibly knocking at the door. Could include a picture of a family member. Could include a picture of a computer screen. Use pictures of gambling, alcohol, and smoking. Use a picture of money falling away - as if someone is trying to take money from you. Picture of somebody with something standing outside your front door.
29	Use a bank account or picture of bank rather than piggy bank. Maybe combine this question with the one above (Q28) Use a picture of a pocket and a hand going into the pocket and money somewhere.
30	Conflicting thoughts about picture of thieves. Include a policeman picture Combine this question with q26. Take away piggy bank and put in a bank picture. Include a picture of money going into a bank / safe and next to this just have a picture of money sitting on the kitchen table and it is not protected at all. *'Add police officers, a ticket writer, EMT, a neighbor. You are getting help to protect yourself. To understand that, that is really important'.*
31	Use pictures of: Power of Attorney. Documents, Will, legal proceedings, Judge or courtroom. Use a picture of someone speaking – freedom of speech. Could rephrase to 'do you need legal advice'. This could be represented by a picture or word of 'you' with a question mark maybe, with the stick person.

	Could use a picture of symbols of justice and a picture of yourself. Use picture of two hands shaking otherwise the pictures are good.
32	Suggestion to '*Have 2 or three different document pictures shown (i.e. AD, will). This looks like a will. Have them sealed, delivered so it is official*'. Rephrase the question – 'Do you know how to sign a legal document?'. Use a picture of something to indicate binding – e.g. tying a knot. Include a picture of a contract that is binding?. Good picture.
33	Use a picture of a courtroom, stick figures (some sitting down, some standing up) with the judge is up there, or a judge with a gavel, or a courtroom thing and a jury. The question is too vague – make it more specific i.e. picture of a trial with evidence and call. Courtroom picture is good but include a judge.
34	Include a picture of someone calling them (? Telephone?). Include a picture of Yellow pages. Picture of someone looking on the internet. Picture of a law society, or law society logo / legal aid logo
35	Possible pictures could include licenses, passport, fishing license, identification card, Alberta health card, parking pass, Handicap permit, pet license, annual bus pass or birth certificate. Can use a calendar with a day circled. Could also use a picture of registry / driving school.
36	There was a general lack of awareness and understanding about what a personal directive was. Personal directive can be represented by a picture of a hospital bed and tubes, and another picture with no tubes and going to a coffin. Picture of a bed and some monitors and a person standing beside the bed Maybe a picture of a hospital with a witness. Picture of a person lying in a bed with lines and tubes and all that good stuff and a picture of a document with words, 'these are my wishes'.

37	Need a picture of a lawyer. Include a picture of money going to a house. *Good pictures.*

Other suggestions included:

1. Use color pictures in the communication aid.
2. Look at pictures in sign language book for ideas for different concepts.
3. Consistency with the pictures appeared to also be really important, and to use the same pictures throughout the communication aid.
4. Use of YES / NO tool whilst doing the assessment.

APPENDIX 8

VISUAL COMMUNICATION CAPACITY AID

INTRODUCTION

INSTRUCTIONS FOR USING THE VISUAL COMMUNICATION CAPACITY AID

This visual communication capacity aid has been designed and validated to assist with the evaluation of financial decision making capacity specifically for individuals with post stroke (expressive) aphasia. It should not be used to assist with capacity assessments for other domains or individuals without aphasia. The target population in which this communication aid has been validated are individuals over the age of 65 who have been diagnosed with post-stroke expressive aphasia and are native english speakers. Using this communication aid in other populations or outside its recommended use will limit the accuracy (and may invalidate) the results obtained, in addition to violating individual copyright use of the instrument.

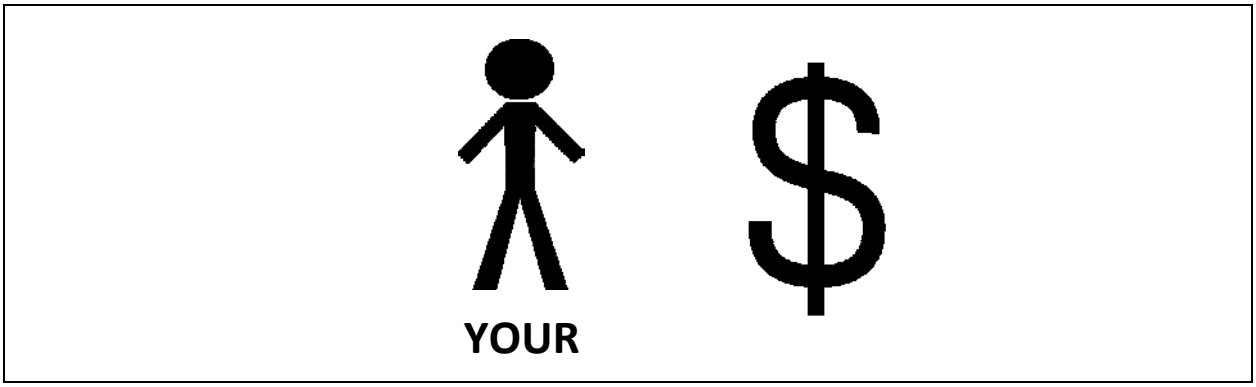
All potential users of this communication capacity aid should have the necessary training required to conduct capacity assessments either by nature of their qualifications (physicians, surgeons and psychologists) or have undergo specialized training to become a designated capacity assessor (DCA). In addition, all users are required to have undergone training in the use of Supported Conversation for Adults with Aphasia' which is available online at http://www.aphasia.ca/home-page/health-care-professionals/knowledge-exchange/ and provides information regarding the appropriate use of communication techniques to use when working with aphasic individuals. There are no recommended time constraints for using the visual communication aid, as the amount of time required will depend on individual needs.

An appendix is located at the end of the communication aid. The appendix includes an answer sheet document which should be used in conjunction with the communication aid for answering the questions, a list of the materials and equipment required for using the visual communication aid in the manner intended, a reference credit list for the purchased images that have been incorporated into the aid and a reference list of local and national charitable organizations for use with question 18. All potential users are required to obtain a collection of their financial institution logos for use with the communication aid specifically for question 5.

Given the comprehensive nature of the communication capacity aid, only small pictures could be accommodated within its scope. Should visual access be an issue, then it is recommended that larger versions of the pictures included in the aid be used for the assessment.

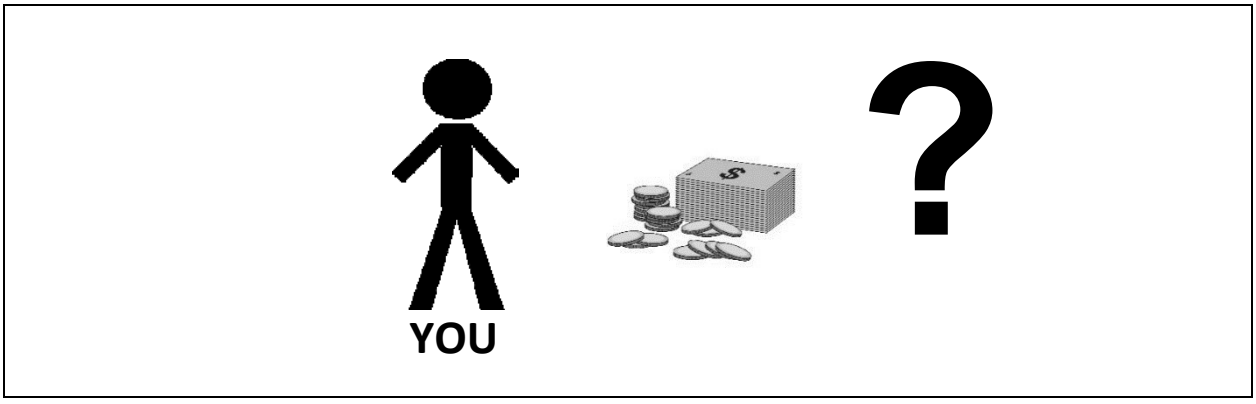
The communication aid is free to use by registered professionals who are (licensed) to perform capacity assessments within the population for which it has been validated. The communication aid can be obtained at no extra cost by emailing the author (contact details included in the appendix).

1. I would like to ask you about your **finances**.



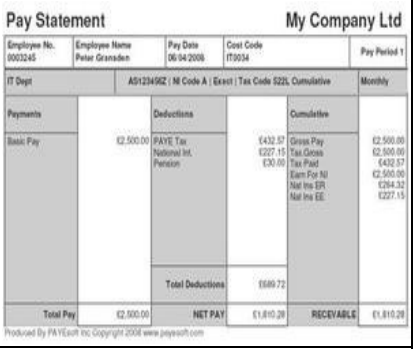
Would that be ok? (use answer sheet, appendix A)

2. Do you have any **money**?



3. Where does your **money** come **from**?

YOUR

PENSION PLAN	**DISABILITY ALLOWANCE**	**WORK**
CPP **OAS** **GIS**	**ALBERTA** **SENIORS** **BENEFITS**	
BANK SAVINGS	**DOG**	**I DON'T KNOW**
		**X**

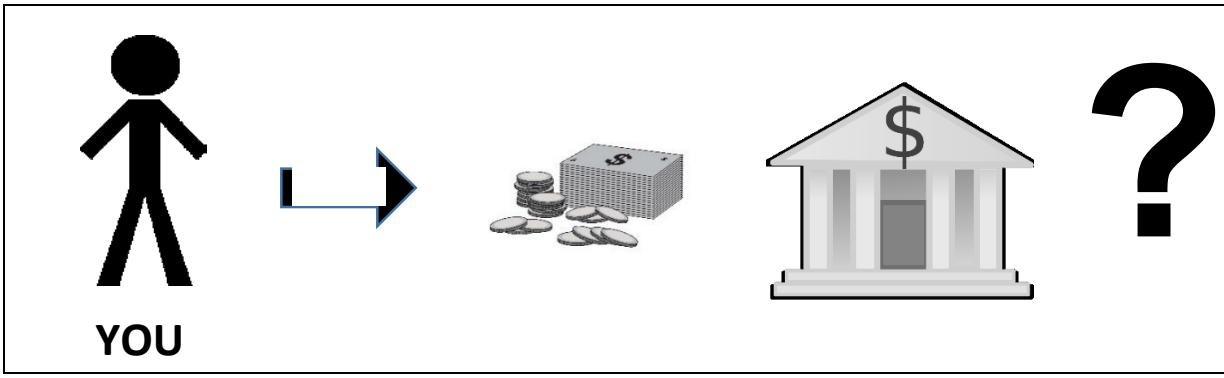
Pay Statement — My Company Ltd

Employee No. 0003245	Employee Name Peter Granaden	Pay Date 06/04/2006	Cost Code IT0034	Pay Period 1
IT Dept	AS123456Z | NI Code A | Exact | Tax Code 522L Cumulative			Monthly

Payments		Deductions		Cumulative	
Basic Pay	£2,500.00	PAYE Tax	£432.57	Gross Pay	£2,500.00
		National Ins.	£227.15	Tax Gross	£2,500.00
		Pension	£30.00	Tax Paid	£432.57
				Earn For NI	£2,500.00
				Nat Ins ER	£264.32
				Nat Ins EE	£227.15
		Total Deductions	£689.72		
Total Pay	£2,500.00	NET PAY	£1,810.28	RECEIVABLE	£1,810.28

Produced By PAYEsoft Inc Copyright 2006 www.payesoft.com

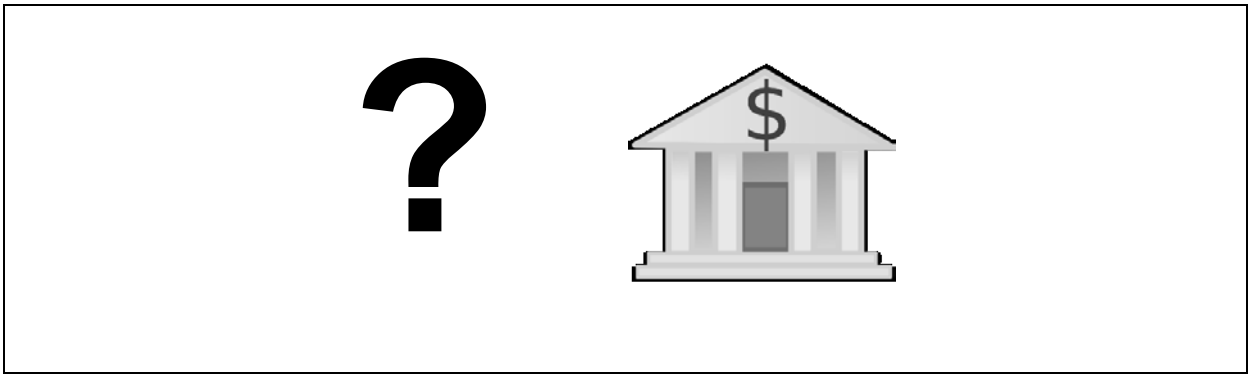
4. Do you **have money** in the **bank**?



If yes, **how much**?

LOTS	SOME	NONE
		X

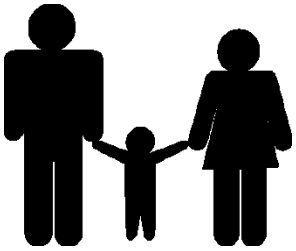
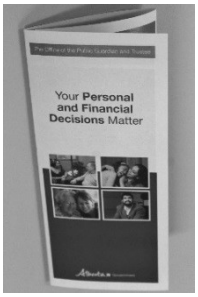
5. Which **bank** do you use?



(Offer examples of financial institutions)

6. Do you **manage your own accounts**?

If **no,** who does?

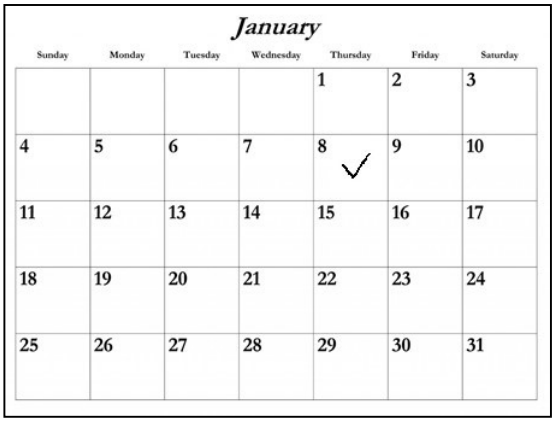
SPOUSE	FAMILY MEMBER
	
FRIEND	**OFFICE OF THE PUBLIC GUARDIAN & TRUSTEE**
	
DOG	**NO-ONE**
	X

7. **How often** do you **manage** your accounts?

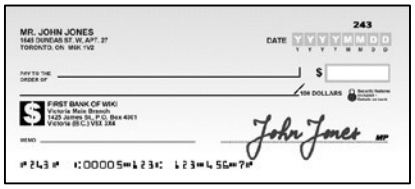
Weekly?

Mon	**T**ue	**W**ed	**T**hur	**F**ri	**S**at	**S**un
					✓	

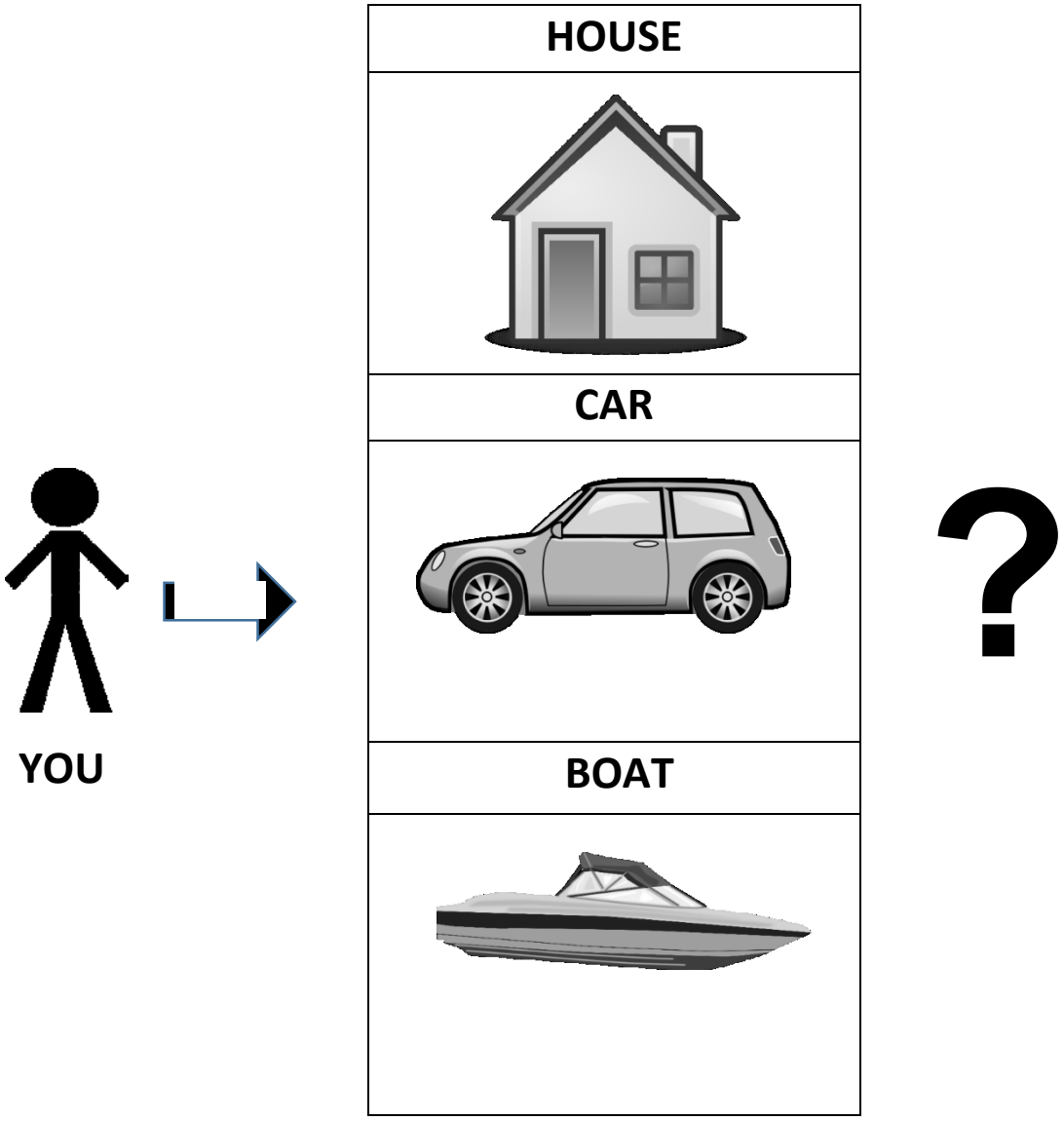
Monthly ?



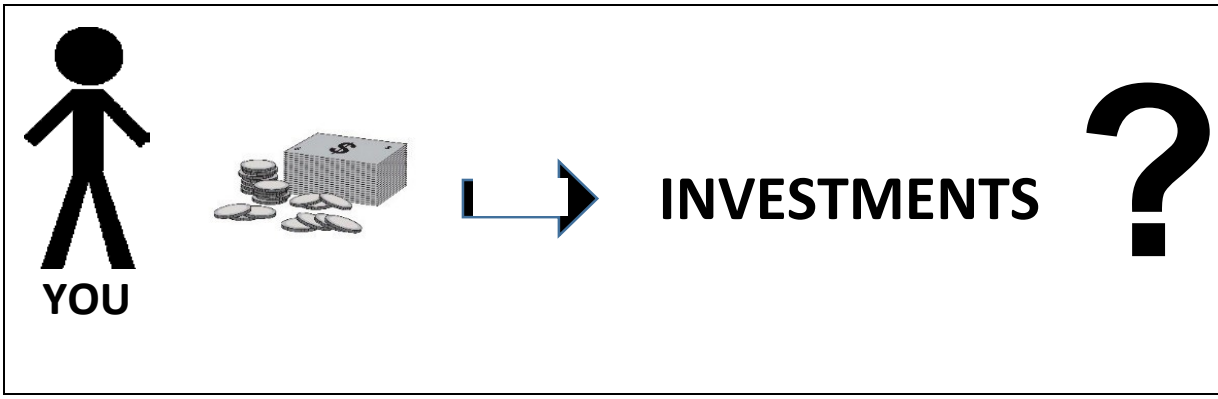
8. What **type** of **accounts** do you have?

SAVINGS	**CHEQUING**
	

9. What **things** do you **own**?



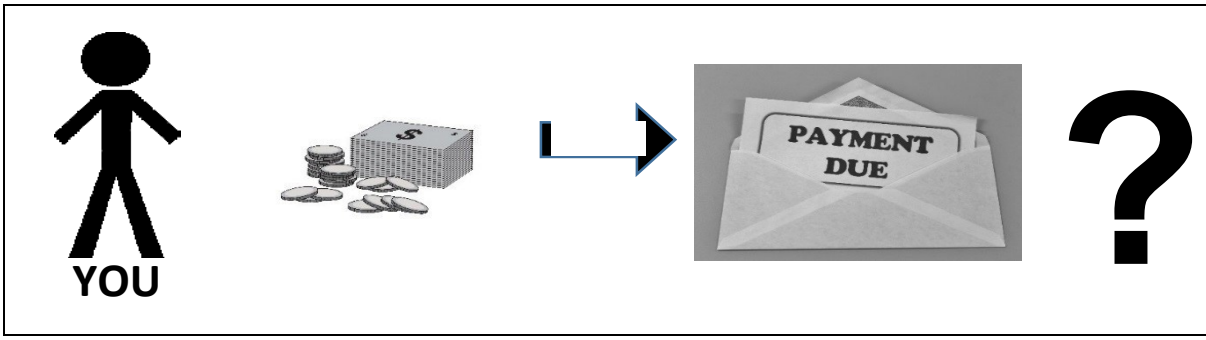
10. Do you have any **money invested**?



If so, **where?**

RRSP	SAVINGS BOND	STOCKS
		**STOCKS**
REAL ESTATE	**MUTUAL FUNDS**	**NONE**
	**MUTUAL FUNDS**	**X**

11. Do you have **bills** to **pay**?



If so, **what for?**

WATER	HEATING	ELECTRICITY
		
PHONE / TV	**TAXES**	**DOG**
		
INTERNET	**RENT / MORTGAGE**	**I DON'T KNOW**
@		X

12. How **much** are your **bills**?

MORE THAN 50 DOLLARS	LESS THAN 20 DOLLARS	ZERO / I DON'T KNOW
		X

13. Do you **have** enough **money** to pay your **bills**?

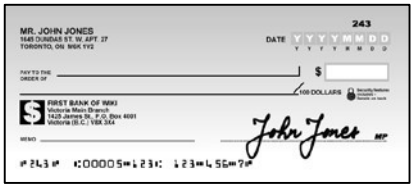
YOU

14. What happens if **you cannot pay** your **bills**?

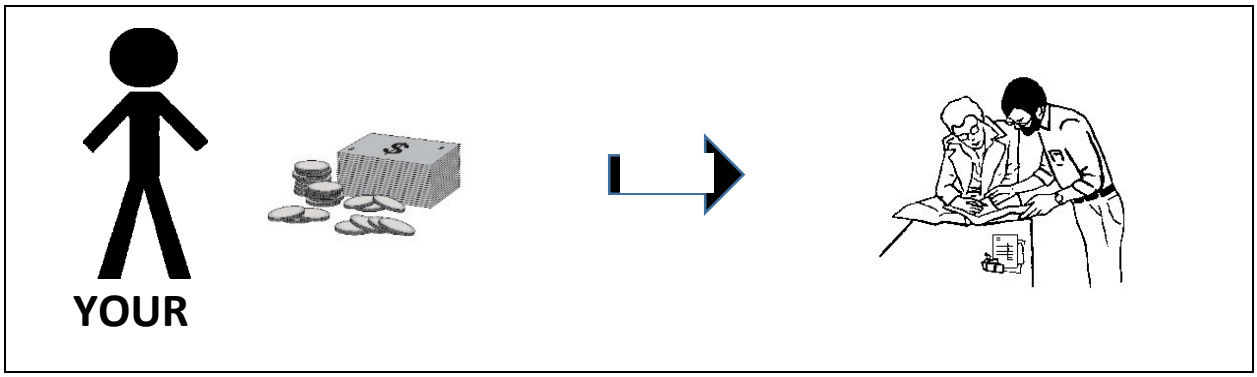
X ?

NOTHING	HEAT SWITCHED OFF	WATER SWITCHED OFF
X		
I DON'T KNOW	ELECTRICITY SWITCHED OFF	EVICTION
?		

15. **How** do you **pay** your bills?

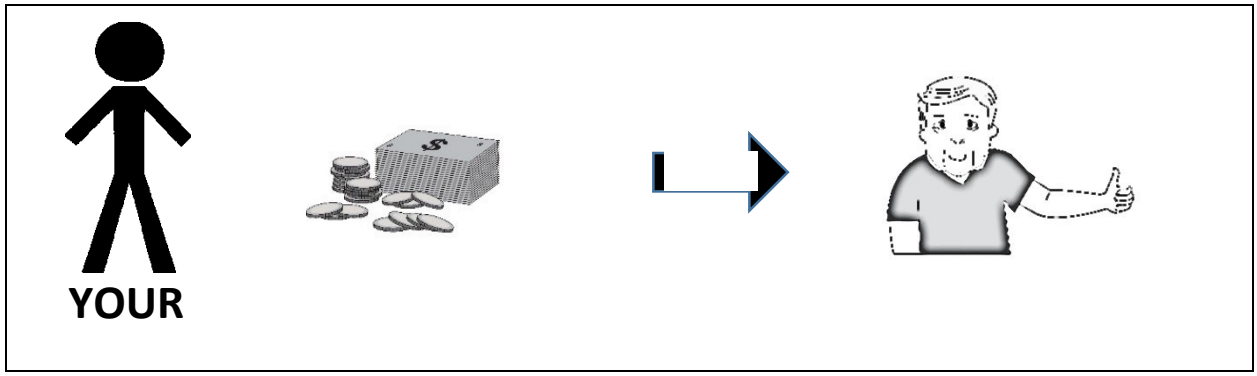
BANK	DOG	DEBIT / CREDIT CARD
		
CHEQUE	**IN PERSON**	**ATM**
		
COMPUTER	**I DON'T KNOW**	
	?	

16. Do you **need help** to manage your money**?**

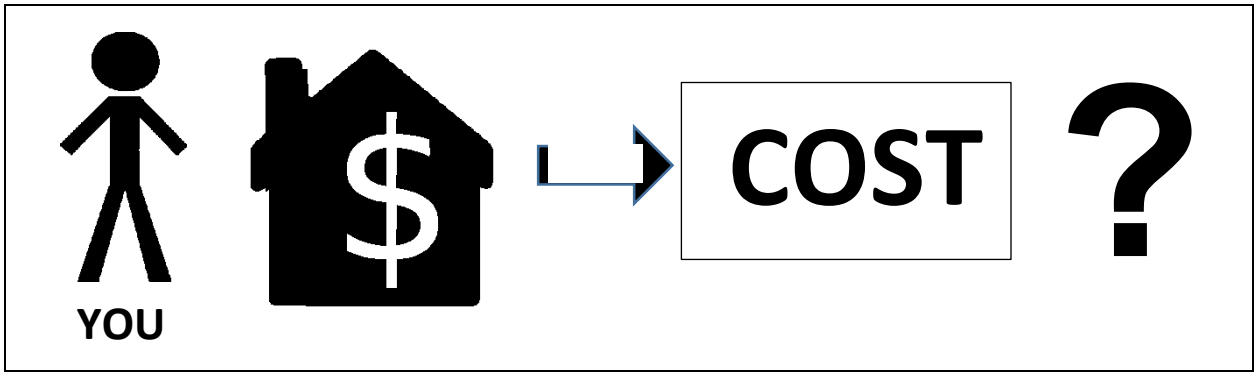


Or…

17. Could you **do it yourself** without any help**?**



18. Do you know **how much** your **property tax** would be for your home?

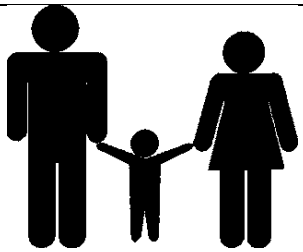


MORE THAN **$3000**	**LESS** THAN **$3000**
LESS THAN **$40**	**NOTHING**

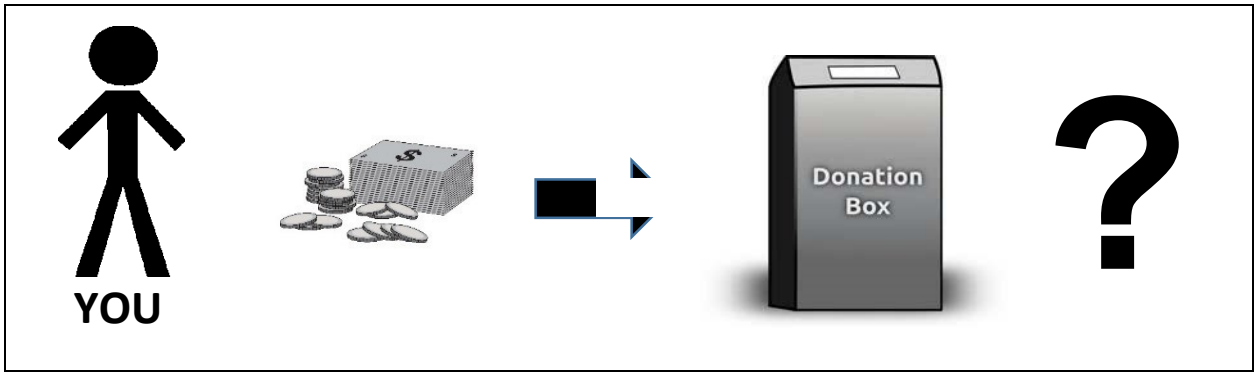
19. Do you **give** / **donate your** money to **anyone**?

YES 	NO 

If **yes**, to **whom**?

FAMILY	DOG	CHARITY
		
BANK	**ACCOUNTANT**	**I DON'T KNOW**
		?

20. Do you **donate** money to charity?



If so, **which** ones?

STOLLERY CHILDRENS HOSPITAL FOUNDATION	**EDMONTON HUMANE SOCIETY**	**FOOD BANK**
BISSELL CENTRE	**PARKINSON ALBERTA SOCIETY**	**BIG BROTHERS BIG SISTERS OF EDMONTON & AREA**
ALZHEIMER SOCIETY CANADA	**THE BREAST CANCER RESEARCH FOUNDATION**	**PROSTRATE CANCER FOUNDATION**
HEART & STROKE FOUNDATION	**WORLD VISION**	**RED CROSS**

(see appendix E)

21. How **much money** do you **donate**?

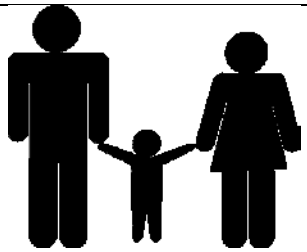
MORE THAN 100 DOLLARS	LESS THAN 40 DOLLARS	NONE
		X

22. **Who** does your **income tax return**?

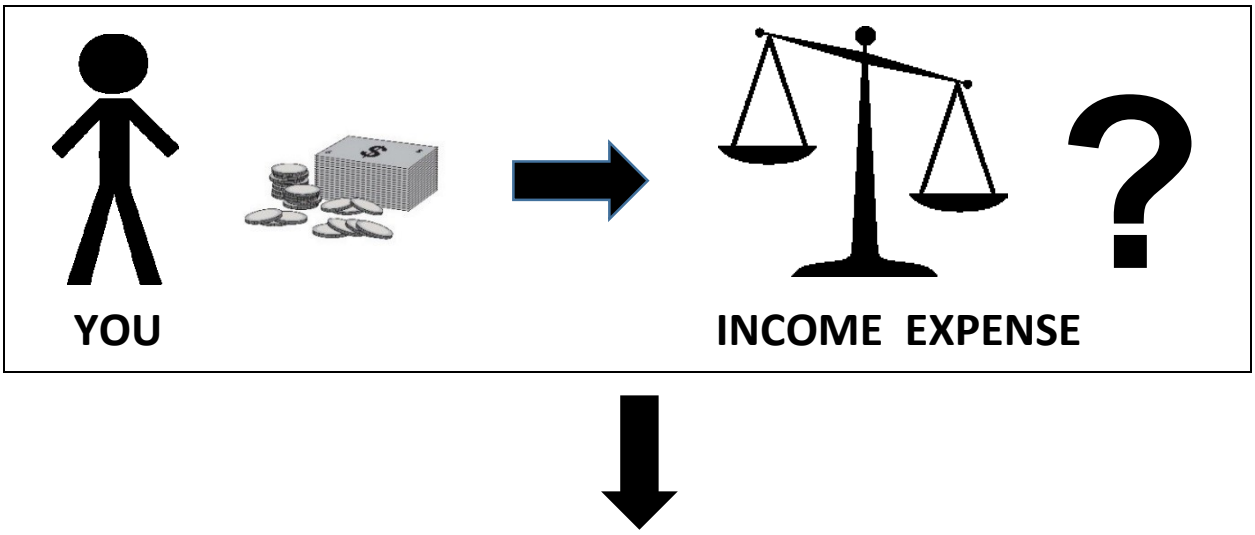
YOUR

Government of Canada | Gouvernement du Canada

TAX

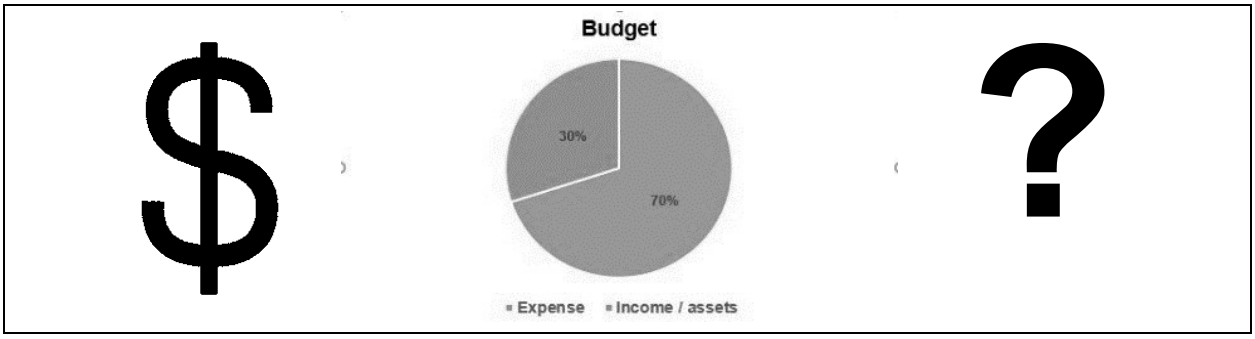
DOG	SPOUSE	FAMILY
		
FRIEND	**ACCOUNTANT**	**ACCOUNTANCY FIRM**
		**HR BLOCK**
YOU	**I DON'T KNOW**	
		

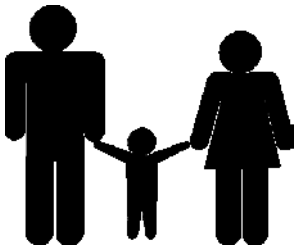
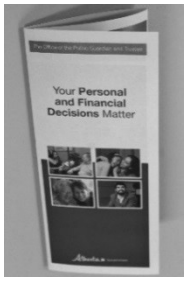
23. **What will happen if** you **spend more** money than you have?



DEBT / OWE MONEY	I DON'T KNOW	CANNOT AFFORD FOOD
CREDIT CARDS LOANS	?	X
CANNOT PAY BILLS	CANNOT PAY RENT / MORTGAGE	NOTHING
X	X	X

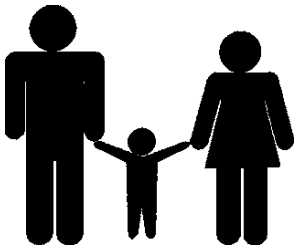
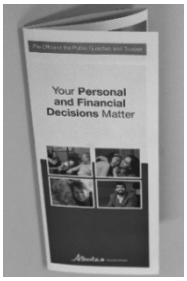
24. **Who keeps track** of your **budget**?



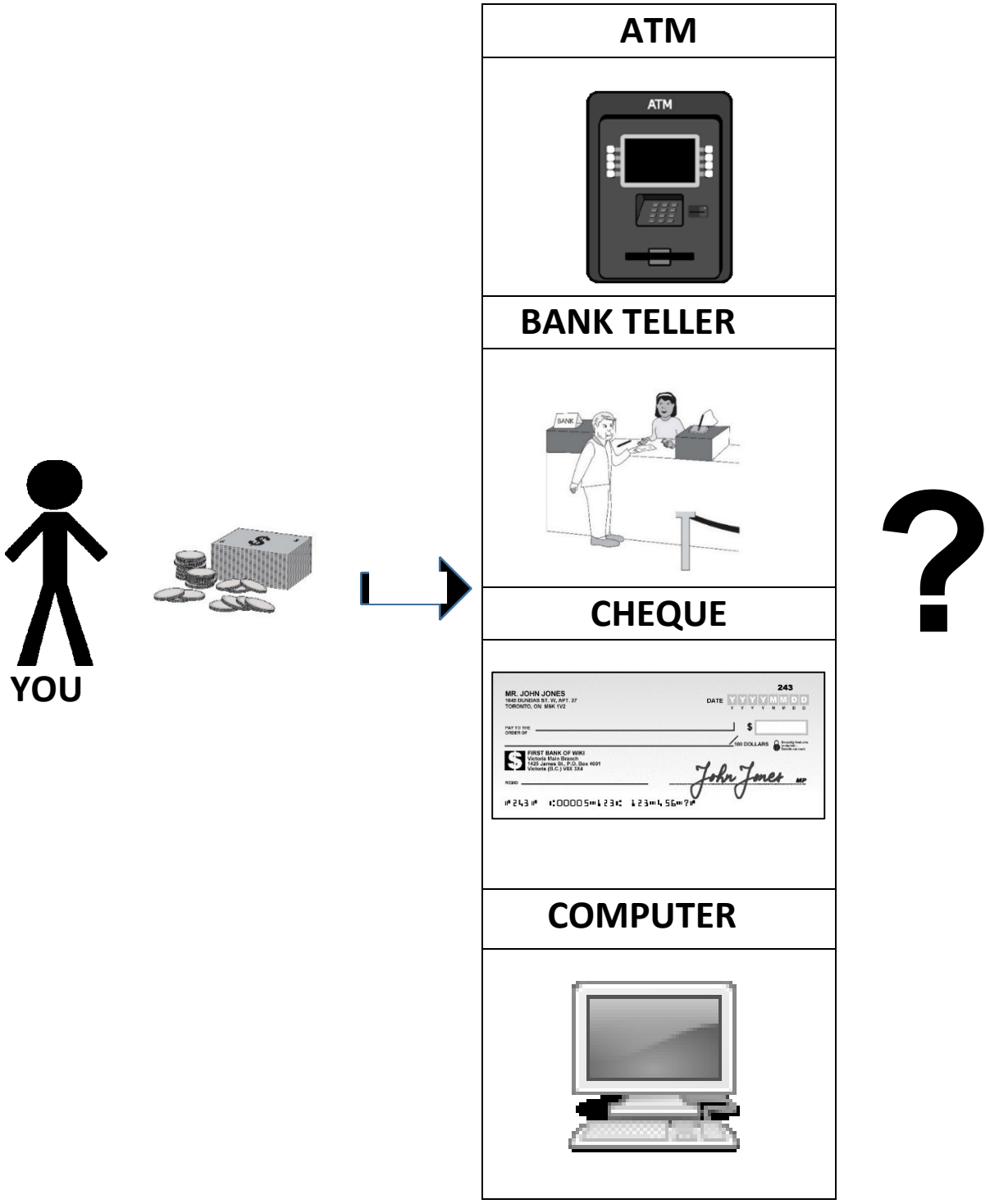
YOU	FAMILY
	
ACCOUNTANT	**DOG**
	
NO ONE	**OFFICE OF THE PUBLIC GUARDIAN & TRUSTEE**
X	

25. **Who** has **access** to your money?

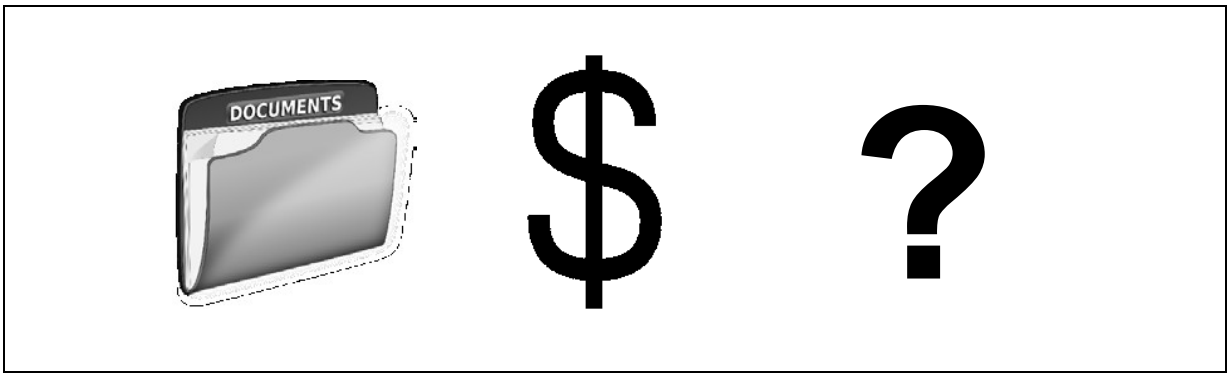
YOUR

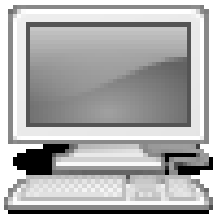
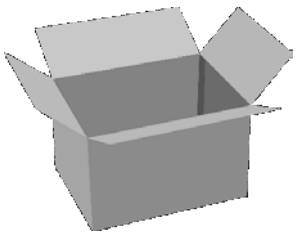
FRIENDS	DOG
	
FAMILY	**ACCOUNTANT**
	
NO ONE	**OFFICE OF THE PUBLIC GUARDIAN & TRUSTEE**
X	

26. **How** do you **access** your money?

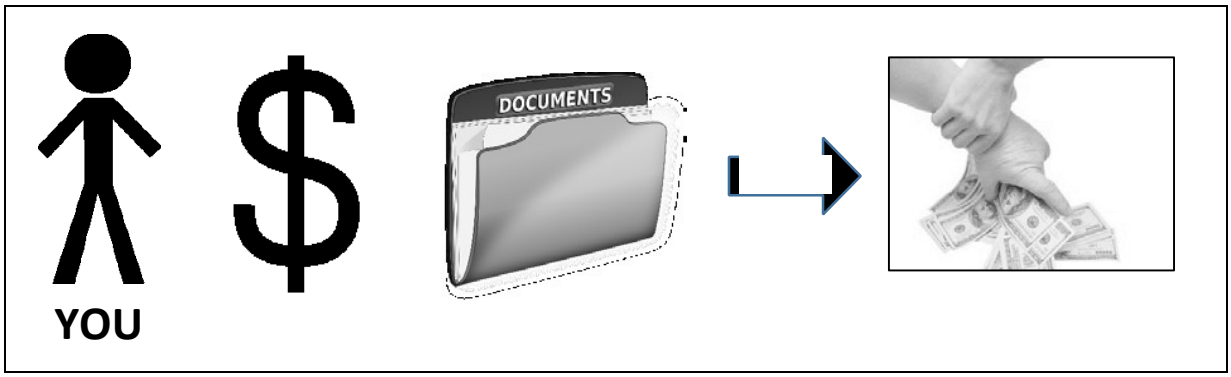


27. **Where** do you keep your **financial documents?**



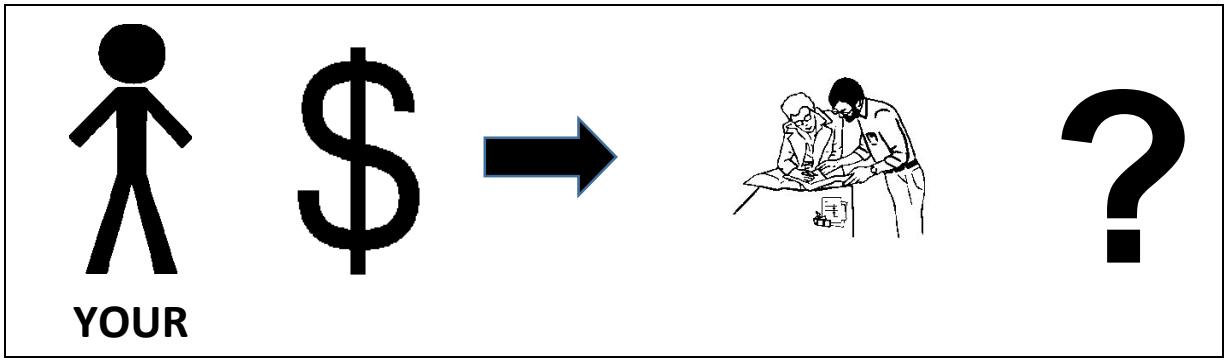
FILING CABINET	SAFE	COMPUTER
		
DESK	**BOX**	**NOWHERE**
		X

28. **How** do you **protect financial documents?**

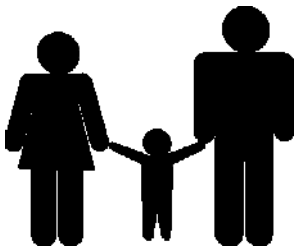


SAFE	FILING CABINET
	
DOG	**NO METHOD**
	X

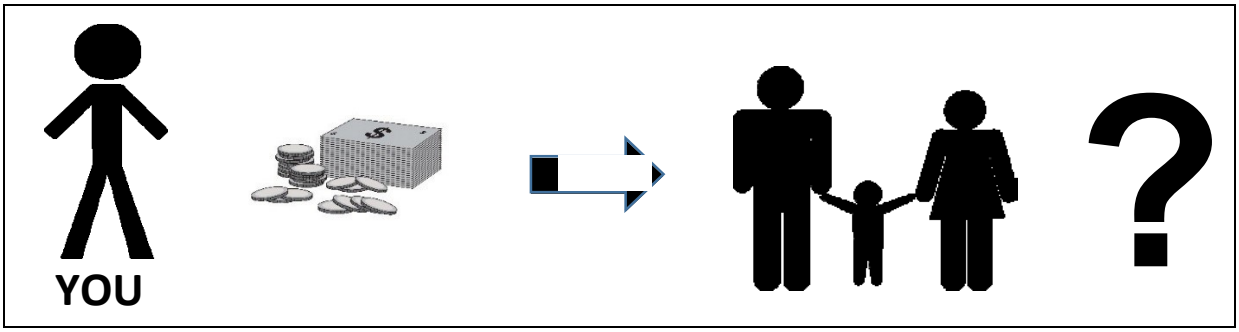
29. If you needed **help** with your finances….



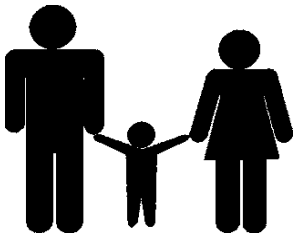
….**who** would you ask?

FAMILY	FRIEND
	
BANK	**ACCOUNTANT**
	
ACCOUNTANCY FIRM	**I DON'T KNOW**
HR BLOCK	

30. Is there anyone who **depends on you** for **money?**



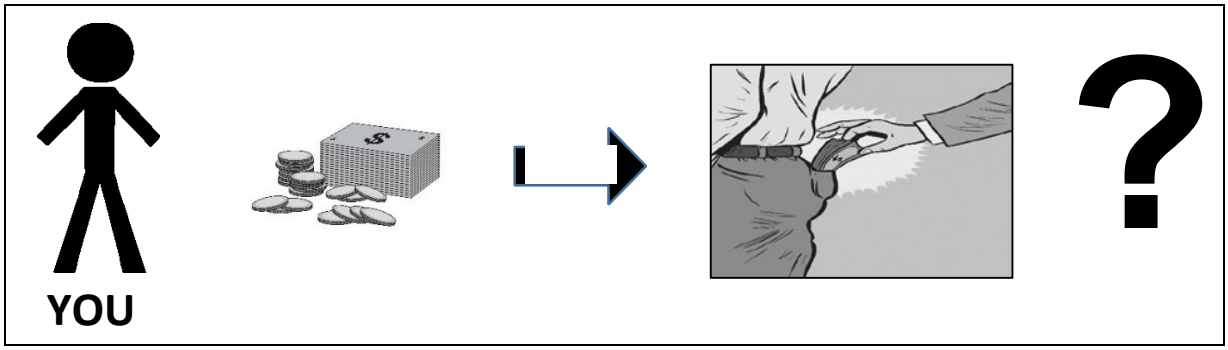
If so, **who?**

FRIEND	SPOUSE	FAMILY
		
DOG	**I DON' T KNOW**	
	?	

And **how much?**

LOTS	LITTLE	NONE
		X

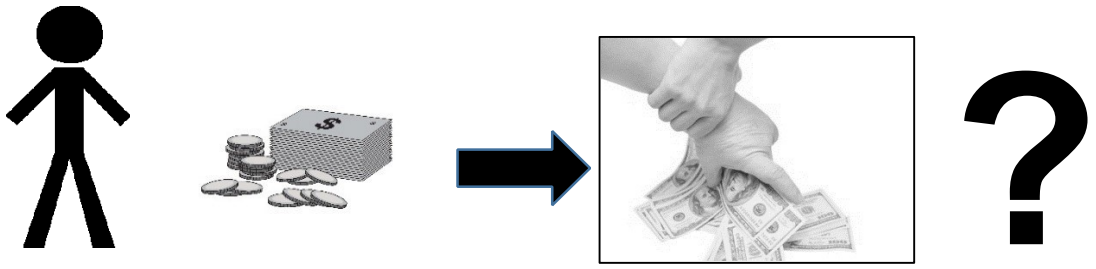
31. If **you thought** someone was trying to **take money** from **you**…

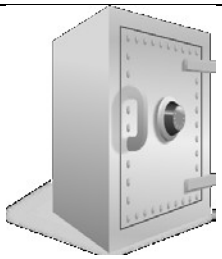


What would you **do**?

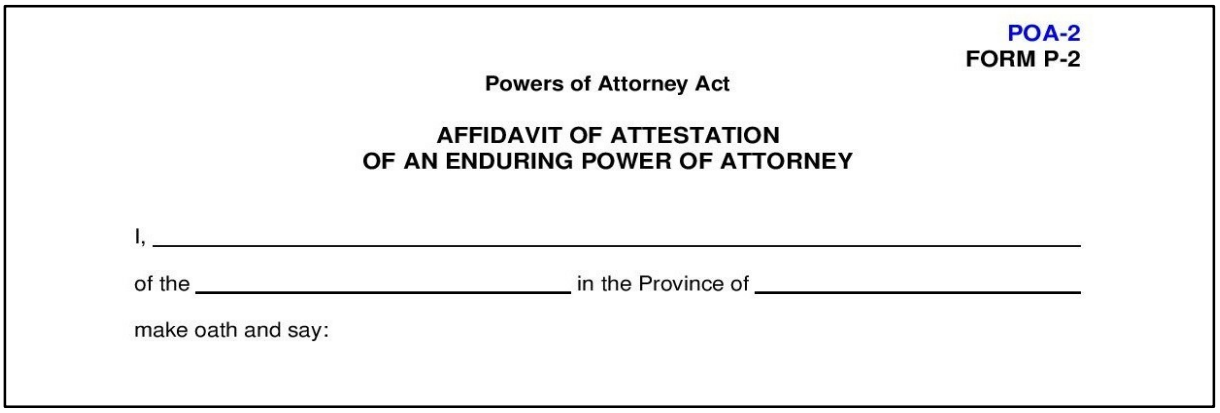
CALL THE BANK	TELL FAMILY / FRIENDS
	
CALL THE POLICE	**GIVE THEM YOUR MONEY**
POLICE	
DO NOTHING	**I DON'T KNOW**
X	**?**

32. **How** do you **protect** <u>your money</u> from others?



DOG	SAFE
	
I DO NOTHING	**BANK**
X	
I DON'T KNOW	
?	

33. What is an **Enduring power of attorney**?



POA-2
FORM P-2

Powers of Attorney Act

AFFIDAVIT OF ATTESTATION
OF AN ENDURING POWER OF ATTORNEY

I, _____

of the _____ in the Province of _____

make oath and say:

SOMEONE WHO WILL MAKE **PERSONAL DECISIONS** FOR YOU

LEGAL DOCUMENT NAMING **YOUR DOG** TO MAKE **DECISIONS** FOR YOU

I DON'T KNOW

LEGAL DOCUMENT NAMING **SOMEONE** TO MAKE **FINANCIAL DECISIONS** FOR YOU

34. **What** is a **Trustee?**

PERSON APPOINTED BY THE **COURTS** TO MAKE **FINANCIAL DECISIONS** FOR YOU	**DOG** APPOINTED BY THE **COURTS** TO MAKE **FINANCIAL DECISIONS** FOR YOU
LEGAL DOCUMENT NAMING **SOMEONE** TO MAKE **FINANCIAL DECISIONS** FOR YOU	I DON'T KNOW

APPENDIX

APPENDIX A

ANSWER SHEET

YES 

NO 

I DON'T KNOW ?

NONE OF THE ANSWERS X

APPENDIX B

ADDITIONAL RESOURCES / EQUIPMENT REQUIRED

1. Writing materials (pen, paper)
2. Blank paper
3. Pamphlets from local financial institutions. Recommended examples for Alberta include RBC, CIBC, TD, BMO and Scotiabank.

APPENDIX C

QUESTION NUMBER	*IMAGE DESCRIPTION*	*SOURCE*
8	Rainy day image	<ahref='http://www.123rf.com/profile_imagevillage'>imagevillage / 123RF Stock Photo
10	RRSP	karenr / 123RF Stock Photo
6,22,25,29, 30,32	Two Senior Women Friends At Day Care Centre	stockbroker / 123RF Stock Photo
19,22,24, 25,29	Accountant with a calculator	alekseiveprev / 123RF Stock Photo
32	Picturekpocket	<a href='http://www.123rf.com/profile_danomyte'>danomyte / 123RF Stock Photo</a

Additional copyright information is available from author on request regarding sources / copyright information for free image use.

APPENDIX D

Contact details

Author: Frances Carr

Address: Division of Geriatric Medicine

Department of Medicine

1-192 Clinical Science Building

11350 83 Ave

Edmonton

Alberta

Canada

T6G 2P4

Email: fcarr@ualberta.ca

APPENDIX E

REFERENCE LIST FOR QUESTION 20

APPENDIX 9

List of Frequency Tables for Each Question

Table 8.
Percentage frequency table for question 1

Answers	Rater A	Rater B	Rater C
1	100% (8)	100% (6)	100% (2)
	n= 8	**n=6**	**n=2**

Table 8: Percentage frequency table showing how participants answered question 1 (actual number shown in brackets)

Table 9.
Percentage frequency table for question 2

Answers	Rater A	Rater B	Rater C
1	87.5% (7)	100% (6)	50% (1)
2	12.5%(1)	0	50% (1)
	n=8	**n=6**	**n=2**

Table 9: Percentage frequency table showing how participants answered question 2 (actual number shown in brackets)

Table 10.
Percentage frequency table for question 3

Answers	Rater A	Rater B	Rater C
0	0	0	50% (1)
1	37.5% (3)	33.3% (2)	0
2	12.5% (1)	0	50% (1)
6	12.5% (1)	0	0
7	12.5% (1)	0	0
8	0	33.3% (2)	0
9	12.5% (1)	16.7% (1)	0
10	12.5% (1)	16.7% (1)	0
	n= 8	**n=6**	**n=2**

Table 10: Percentage frequency table showing how participants answered question 3 (actual number shown in brackets)

Table 11.
Percentage frequency table for question 4

Answers	Rater A	Rater B	Rater C
0	0	0	50 (1)
1	12.5 (1)	50 (3)	0
2	75 (6)	50 (3)	50 (1)
3	12.5 (1)	0	0
	n=8	n=6	n=2

Table 11: Percentage frequency table showing how participants answered question 4 (actual number shown in brackets)

Table 12.
Percentage frequency table for question 5

Answers	Rater A	Rater B	Rater C
0	25% (2)	16.75 (1)	50% (1)
1	12.5% (1)	0	0
2	12.5% (1)	33.3% (2)	0
4	37.5% (3)	16.75 (1)	0
5	0	16.7% (1)	50% (1)
6	12.5% (1)	0	0
7	0	16.7% (1)	0
	n=8	n=6	n=2

Table 12: Percentage frequency table showing how participants answered question 5 (actual number shown in brackets)

Table 13.
Percentage frequency table for question 6

Answers	Rater A	Rater B	Rater C
0	0	0	50% (1)
1	50% (4)	66.7% (4)	0
2	12.5% (1)	0	0
3	37.5% (3)	33.3% (2)	50% (1)
	n=8	**n=6**	**n=2**

Table 13: Percentage frequency table showing how participants answered question 6 (actual number shown in brackets)

Table 14.
Percentage frequency table for question 7

Answers	Rater A	Rater B	Rater C
0	12.5% (1)	0	0
1	37.5% (3)	33.3% (2)	0
2	50%(4)	66.7% (4)	100% (2)
	n=8	**n=6**	**n=2**

Table 14: Percentage frequency table showing how participants answered question 7 (actual number shown in brackets)

Table 15.
Percentage frequency table for question 8

Answer	Rater A	Rater B	Rater C
0	0	33.3% (2)	0
1	25% (2)	0	50% (1)
2	12.5% (1)	0	0
3	62.5% (5)	83.3% (5)	0
4	0	0	50% (1)
	n=8	**n=6**	**n=2**

Table 15: Percentage frequency table showing how participants answered question 8 (actual number shown in brackets)

Table 16.
Percentage frequency table for question 9

Answers	Rater A	Rater B	Rater C
0	0	16.7% (1)	0
1	12.5% (1)	33.3% (2)	0
2	25% (2)	33.3% (2)	0
4	27.5% (3)	16.7% (1)	0
8	12.5% (1)	0	100% (2)
9	12.5% (1)	0	0
	n=8	**n=6**	**n=2**

Table 16: Percentage frequency table showing how participants answered question 9 (actual number shown in brackets)

Table 17.
Percentage frequency table for question 10

Answers	Rater A	Rater B	Rater C
0	0	33.3% (2)	50% (1)
1	25% (2)	0	0
5	0	16.7 (1)	0
6	12.5% (1)	0	0
7	25% (2)	16.7% (1)	50% (1)
8	0	16.7% (1)	0
9	12.5% (1)	0	0
10	12.5% (1)	0	0
11	12.5% (1)	0	0
12	0	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 17: Percentage frequency table showing how participants answered question 10 (actual number shown in brackets)

Table 18.
Percentage frequency table for question 11

Answers	Rater A	Rater B	Rater C
0	12.5% (1)	0	50% (1)
4	0	16.7% (1)	0
5	0	0	50% (1)
10	12.5% (1)	16.7% (1)	0
11	12.5% (1)	0	0
12	0	16.7% (1)	0
13	12.5% (1)	0	0
14	0	16.7% (1)	0
15	12.5% (1)	16.7% (1)	0
16	12.5% (1)	0	0
17	0	16.7% (1)	0
19	12.5% (1)	0	0
20	12.5% (1)	0	0
	n=8	**n=6**	**n=2**

Table 18: Percentage frequency table showing how participants answered question 11 (actual number shown in brackets)

Table 19.
Percentage frequency table for question 12

Answers	Rater A	Rater B	Rater C
0	25% (2)	33.3% (2)	0
1	62.5% (5)	50% (3)	50% (1)
3	0	0	50% (1)
5	12.5% (1)	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 19: Percentage frequency table showing how participants answered question 12 (actual number shown in brackets)

Table 20.
Percentage frequency table for question 13

Answers	Rater A	Rater B	Rater C
0	0	0	50% (1)
1	75% (6)	83.3% (5)	0
2	25% (2)	16.7% (1)	50% (1)
	n=8	**n=6**	**n=2**

Table 20: Percentage frequency table showing how participants answered question 13 (actual number shown in brackets)

Table 21.
Percentage frequency table for question 14

Answers	Rater A	Rater B	Rater C
0	12.5% (1)	16.7% (1)	0
1	0	0	50% (1)
3	0	0	50% (1)
4	12.5% (1)	16.7% (1)	0
5	12.5% (1)	50% (3)	0
6	12.5% (1)	0	0
7	25% (2)	16.7% (1)	0
8	12.5% (1)	0	0
9	12.5% (1)	0	0
	n=8	**n=6**	**n=2**

Table 21: Percentage frequency table showing how participants answered question 14 (actual number shown in brackets)

Table 22.
Percentage frequency table for question 15

Answers	Rater A	Rater B	Rater C
0	12.5% (1)	16.7% (1)	50% (1)
1	37.5% (3)	33.3% (2)	0
4	0	0	50% (1)
9	12.5% (1)	0	0
10	0	16.7% (1)	0
12	12.5% (1)	0	0
13	12.5% (1)	16.7% (1)	0
14	12.5% (1)	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 22: Percentage frequency table showing how participants answered question 15 (actual number shown in brackets)

Table 23.
Percentage frequency table for question 16

Answers	Rater A		Rater B	Rater C
0	0		16.7% (1)	0
1	50% (4)		0	50% (1)
2	50% (4)		83.3% (5)	50% (1)
	n=8		**n=6**	**n=2**

Table 23: Percentage frequency table showing how participants answered question 16 (actual number shown in brackets)

Table 24.
Percentage frequency table for question 17

Answers	Rater A	Rater B	Rater C
1	50% (4)	100% (6)	50% (1)
2	50% (4)	0	50% (1)
	n=8	**n=6**	**n=2**

Table 24: Percentage frequency table showing how participants answered question 17 (actual number shown in brackets)

Table 25.
Percentage frequency table for question 18

Answers	Rater A	Rater B	Rater C
0	0	0	50% (1)
1	37.5% (3)	50% (3)	0
2	25% (2)	33.3% (2)	0
3	12.5% (1)	0	0
4	12.5% (1)	16.7% (1)	50% (1)
7	12.5% (1)	0	0
	n=8	**n=6**	**n=2**

Table 25: Percentage frequency table showing how participants answered question 18 (actual number shown in brackets)

Table 26.
Percentage frequency table for question 19

Answers	Rater A	Rater B	Rater C
1	50% (4)	33.3% (2)	50% (1)
3	12.5% (1)	0	0
5	12.5% (1)	0	0
7	25% (2)	16.7% (1)	50% (1)
8	0	33.3% (2)	0
9	0	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 26: Percentage frequency table showing how participants answered question 19 (actual number shown in brackets)

Table 27.
Percentage frequency table for question 20

Answers	Rater A	Rater B	Rater C
1	12.5% (1)	0	0
2	12.5% (1)	16.7% (1)	0
12	0	0	50% (1)
13	0	16.7% (1)	0
15	25% (2)	0	50% (1)
16	12.5% (1)	0	0
17	12.5% (1)	16.7% (1)	0
18	0	16.7% (1)	0
19	12.5% (1)	16.7% (1)	0
20	12.5% (1)	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 27: Percentage frequency table showing how participants answered question 20 (actual number shown in brackets)

Table 28.
Percentage frequency table for question 21

Answers	Rater A	Rater B	Rater C
0	12.5% (1)	16.7% (1)	50% (1)
1	50% (4)	66.7% (4)	50% (1)
2	25% (2)	16.7% (1)	0
3	12.5% (1)	0	0
	n=8	**n=6**	**n=2**

Table 28: Percentage frequency table showing how participants answered question 21 (actual number shown in brackets)

Table 29.
Percentage frequency table for question 22

Answers	Rater A	Rater B	Rater C
3	25% (2)	33.3% (2)	0
5	25% (2)	16.7% (1)	0
6	12.5% (1)	0	0
7	37.5% (3)	50% (3)	50% (1)
9	0	0	50% (1)
	n=8	**n=6**	**n=2**

Table 29: Percentage frequency table showing how participants answered question 22 (actual number shown in brackets)

Table 30.
Percentage frequency table for question 23

Answers	Rater A	Rater B	Rater C
0	25% (2)	33.3% (2)	50% (1)
1	25% (2)	33.3% (2)	50% (1)
5	12.5% (1)	0	0
6	12.5% (1)	16.7% (1)	0
7	12.5% (1)	0	0
8	12.5% (1)	16.7% (1)	0
	n=8	**n=6**	**n=2**

Table 30: Percentage frequency table showing how participants answered question 23 (actual number shown in brackets)

Table 31.
Percentage frequency table for question 24

Answers	Rater A	Rater B	Rater C
1	50 (4)	0	50 (1)
2	25 (2)	83.3 (5)	0
5	0	0	50 (1)
6	12.5 (1)	0	0
7	0	0	0
	12.5 (1)	16.7 (1)	0
	n=8	**n=6**	**n=2**

Table 31: Percentage frequency table showing how participants answered question 24 (actual number shown in brackets)

Table 32.
Percentage frequency table for question 25

Answers	Rater A	Rater B	Rater C
0	12.5 (1)	0	0
3	50 (4)	50 (3)	0
5	0	16.7 (1)	50 (1)
6	12.5 (1)	0	50 (1)
8	0	16.7 (1)	0
9	12.5 (1)	0	0
10	12.5 (1)	16.7 (1)	0
	n=8	**n=6**	**n=2**

Table 32: Percentage frequency table showing how participants answered question 25 (actual number shown in brackets)

Table 33.
Percentage frequency table for question 26

Answers	Rater A	Rater B	Rater C
0	12.5 (1)	16.7 (1)	50 (1)
1	12.5 (1)	0	50 (1)
3	12.5 (1)	0	0
5	0	16.7 (1)	0
6	0	16.7 (1)	0
7	50 (4)	0	0
8	0	16.7 (1)	0
9	12.5 (1)	16.7 (1)	0
10	0	16.7 (1)	0
	n=8	**n=6**	**n=2**

Table 33: Percentage frequency table showing how participants answered question 26 (actual number shown in brackets)

Table 34.
Percentage frequency table for question 27

Answers	Rater A	Rater B	Rater C
0	0	16.7 (1)	0
1	50 (4)	66.7 (4)	50 (1)
2	12.5 (1)	0	0
4	25 (2)	0	50 (1)
8	0	16.7 (1)	0
9	12.5 (1)	0	0
	n=8	**n=6**	**n=2**

Table 34: Percentage frequency table showing how participants answered question 27 (actual number shown in brackets)

Table 35.
Percentage frequency table for question 28

Answers	Rater A	Rater B	Rater C
0	0	16.7 (1)	50 (1)
1	12.5 (1)	16.7 (1)	0
2	50 (4)	16.7 (1)	0
4	37.5 (3)	0	50 (1)
7	0	50 (3)	0
	n=8	**n=6**	**n=2**

Table 35: Percentage frequency table showing how participants answered question 28 (actual number shown in brackets)

Table 36.
Percentage frequency table for question 29

Answers	Rater A	Rater B	Rater C
1	50 (4)	16.7 (1)	100 (2)
3	12.5 (1)	0	0
7	12.5 (1)	66.7 (4)	0
8	25 (2)	16.7 (1)	0
	n=8	**n=6**	**n=2**

Table 36: Percentage frequency table showing how participants answered question 29 (actual number shown in brackets)

Table 37.
Percentage frequency table for question 30

Answers	Rater A	Rater B	Rater C
0	25 (2)	16.7 (1)	50 (1)
3	12.5 (1)	33.3 (2)	0
5	62.5 (5)	50 (3)	50 (1)
	n=8	**n=6**	**n=2**

Table 37: Percentage frequency table showing how participants answered question 30 (actual number shown in brackets)

Table 38.
Percentage frequency table for question 31

Answers	Rater A	Rater B	Rater C
0	0	16.7 (1)	50 (1)
1	13 (1)	0	0
2	25 (2)	16.7 (1)	0
3	25 (2)	0	0
5	0	0	50 (1)
7	0	16.7 (1)	0
8	25 (2)	0	0
9	0	16.7 (1)	0
10	13 (1)	16.7 (1)	0
11	0	16.7 (1)	0
	n=8	**n=6**	**n=2**

Table 38: Percentage frequency table showing how participants answered question 31 (actual number shown in brackets)

Table 39.
Percentage frequency table for question 32

Answers	Rater A	Rater B	Rater C
0	12.5 (1)	16.7 (1)	100 (2)
2	25 (2)	16.7 (1)	0
4	25 (2)	16.7 (1)	0
7	25 (2)	50 (3)	0
8	12.5 (1)	0	0
	n=8	**n=6**	**n=2**

Table 39: Percentage frequency table showing how participants answered question 32 (actual number shown in brackets)

Table 40.
Percentage frequency table for question 33

Answers	Rater A	Rater	Rater C
0	37.5 (3)	16.7 (1)	100 (2)
1	12.5 (1)	33.3 (2)	0
2	12.5 (1)	0	0
3	12.5 (1)	50 (3)	0
4	25 (2)	0	0
	n=8	**n=6**	**n=2**

Table 40: Percentage frequency table showing how participants answered question 33 (actual number shown in brackets)

Table 41.
Percentage frequency table for question 34

Answers	Rater A	Rater B	Rater C
0	37.5 (3)	16.7 (1)	100 (2)
1	25 (2)	33.3 (2)	0
3	37.5 (3)	50 (3)	0
	n=8	**n=6**	**n=2**

Table 41: Percentage frequency table showing how participants answered question 34 (actual number shown in brackets)