### ORIGINAL RESEARCH

# A Preliminary Assessment of the Psychometric Properties of a New Communication Aid to Support Assessments of Financial Decision-Making Capacity in People with Aphasia<sup>a</sup>



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### **ABSTRACT**

### **Background**

Financial decision-making is complex and requires an in-depth assessment. In the presence of communication disorders, like aphasia, such assessments become challenging and require the use of a dedicated communication aid. No communication aid currently exists to support financial decision-making capacity (DMC) assessments for persons with aphasia (PWA).<sup>(1)</sup> We sought to establish the validity, reliability, and feasibility of a newly constructed communication aid designed for this purpose.

### Methods

A mixed methods study was performed, divided into three phases. Phase one was aimed at capturing current understanding of DMC and communication by community-dwelling seniors, using focus groups. The second phase involved the development of a new communication aid to assist with the assessment of financial DMC for PWA. The third phase aimed to establish the psychometric properties of this new visual communication aid.

### Results

The new communication aid is a 37-page, paper-based document, with 34 picture-based questions. Due to unforeseen difficulties in participant recruitment for evaluating the communication aid, a preliminary evaluation was performed on the results from eight participants. These indicated the communication aid had moderate inter-rater reliability (Gwet's AC1 kappa of 0.51 [CI 0.4362 to 0.5816, p < .000]), good internal consistency (0.76), and was usable.

### **Conclusions**

This newly developed communication aid is one of a kind, and provides essential support for PWA requiring a financial DMC assessment, which was not previously available. Preliminary evaluation of its psychometric properties is promising; however, further validation is required to confirm its validity and reliability in the proposed sample size.

**Key words:** aphasia, decision-making capacity, communication aid, financial decision-making

### INTRODUCTION

Decision-making capacity (DMC) refers to the "ability to understand information that is relevant to making a personal decision, and to appreciate the reasonably foreseeable consequences of that decision". Within Alberta, eight domains have been identified in which DMC can be assessed, which fall under the categories of either personal and financial decision-making. Personal decision-making includes the domains of health care 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. (4)

The complexity of any DMC assessment (DMCA) process is influenced by many factors, including the specific domain(s) being assessed. Given the current absence of literature on the topic, it is unclear if the assessment of certain domains is more complex than others. Rather, factors such as the decision in question, context, and patient and assessor characteristics all likely have a greater influence on DMCA complexity.

Most of the current research in DMC has been within health-care DMC, predominantly focusing on patient consent, (5-8) with considerably less research in other, equally

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<sup>&</sup>lt;sup>a</sup>The content of this manuscript is based on a Master's Thesis, which was completed and published in 2020 by the author.

important domains, like financial decision-making. This is concerning, given the aging population and that aging has been associated with an increased risk of developing impairment in DMC and, in particular, financial DMC.<sup>(9)</sup> The incidence of communication disorders, like aphasia, also increases with age, which also impacts significantly on DMC and DMCAs.<sup>(10)</sup>

Due to lack of confidence, inexperience and/or minimal training in this area, many physicians are uncomfortable performing any DMCA, and especially in the setting of any communication barrier, present in all persons with aphasia (PWA). Therefore, the assessment process becomes either extremely difficult or impossible, and is often not performed. This is particularly the case for financial DMCAs, which have, arguably, higher stakes.

Communication aids should be used to support all DMCAs in PWA. However, only one communication aid exists, which is designed only to support assessments of personal DMC for accommodation decisions. No communication aids exists to support DMCAs for either legal and/or financial DMC.<sup>(1)</sup> Therefore, the primary objectives for this study were to develop and establish the psychometric properties of a new communication aid to assist with financial DMCAs for PWA.

### **METHODS**

A mixed-methods, quasi-experimental study design was used, which is a study design commonly used for validation studies such as this. The study was divided into three phases, and was conducted over four years. Due to difficulties in participant recruitment and extensive restrictions on clinical research due to the prolonged COVID-19 epidemic, the study is still ongoing. Due to importance of this research, this paper presents our preliminary results from the initial evaluation of the new communication aid.

### **Phase One**

The first phase involved exploring community-dwelling older adults' (65 years or older) current understanding of general and specific (financial and legal) DMC, and about communication and communication disorders, using focus groups the number of which was determine by data theme saturation. Focus group participants were recruited from local community centres and two of the local hospital volunteer programs (University of Alberta (UAH) and Glenrose Rehabilitation Hospital (GRH)) using a purposeful sampling technique. Focus group discussions were recorded, and transcribed by an independent party, with personally identifying information being removed during this process. Transcribed data were thematically analyzed using NVIVO software (Version 12) (QSR International, Burlington, MA). The generated themes were used to inform and guide the development of the new visual communication capacity aid.

### **Phase Two**

The second phase involved the development of a new communication aid. During this time, it was quickly recognized

that it would be too difficult to develop a single communication aid that could adequately cover the assessment of both financial and legal domains of decision-making. Therefore, the research question was changed to develop a communication aid to support financial DMCAs only. Due to the change in study protocol, a new ethics application was submitted, with granting of approval being delayed, resulting in delaying the study.

Content for the communication aid was obtained using a triangulation of data sources, which included focus group feedback, purchased images, speech-language pathologist (SLP) feedback, and content from the Capacity Interview Worksheets. (3) Common themes from the focus group feedback where identified and transformed into pictographic representation for each question in the communication aid. Potential copyright issues were discussed with a copyright lawyer. Each draft of the communication aid was presented to the research team and revised accordingly until consensus was reached on the appearance and content of the communication aid. Please refer to Appendix A for a copy of the communication aid.

### **Phase Three**

The final phase of the study involved evaluating the validity, reliability, and usability of the communication aid. Content validity was assessed through the presentation of the communication aid to a group of Designated Capacity Assessors (DCAs) who compared its content with that of the Capacity Interview Worksheet to ensure that the communication aid was representative. DCAs are "regulated health-care 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". [2] Face validity was determined through the presentation of the communication aid to a group of DCAs external to the study.

Consensus agreement on the validity of the communication aid was evaluated using a predetermined modified Delphi protocol. 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. Due to a high dropout rate during the second iteration, a second Delphi group was formed, comprising of 15 different DMC experts.

Reliability was evaluated from the use of the communication aid within financial DMCAs for PWA. The proposed sample size was 30, which was based on prior validation study literature, (13) as formal power and sample size calculations were not possible due to the absence of prior literature. The target population for the DMCAs were 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). Each participant underwent two financial DMCAs

using the communication aid, with each DMCA done on different days and by different assessors from the research team (DCA or geriatric physician). All assessors had received additional training in the use of 'Supported Conversation for Adults with Aphasia' (SCA), (14) which is recommended for all individuals working with PWA. DMCA results were kept confidential from the care team.

Feasibility was determined from the feedback received from assessors, using a specifically designed 'Visual Communication Aid User-Experience Questionnaire'. This feedback would then be used to modify the aid (and training), if necessary.

Data analysis involved initial data exploration, followed by the generation of frequency tables and bar charts for each question. Reliability was determined from the DMCA results. Inter-rater agreement was calculated using Gwet's AC1 kappa. Assessment of test/retest reliability was not possible as each assessor only used the communication aid once for each participant; instead, an indirect evaluation of test/retest reliability was performed, using the communication aid by the same assessor for multiple patients. The Cronbach alpha was chosen to provide an assessment of the average covariance.

Ethical approval was obtained both prior to study initiation, and after the research objective of the communication aid was changed.

### RESULTS

Three focus groups were held over nine months (April 2015 to January 2016). The results revealed a lack of understanding about general, and specific, DMC for financial and legal matters, but a clear understanding about communication, communication disorders, and how communication impairments can impact DMC and DMCA. Feedback about the communication aid indicated a need for picture consistency, the importance of color, and subjectivity in picture interpretation.

The new 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 that details the additional equipment required, and an appendix listing the image sources (Appendix A). Although the initial plan had been to use color images, due to concerns about degradation and reproducibility of images, black-and-white images were used instead. In addition, a unique 'Aphasia Friendly Participant Consent Form' was also developed, using a similar format (Appendix B). This is a 22-page paper consent form that covers all the necessary aspects required for obtaining consent, using a variety of picture-based questions.

Content and face validity of the communication aid was established using Delphi Consensus with a group of content-matter experts. An initial Delphi protocol was conducted from June to August 2017 with a group of seven DMC experts. Due to high dropout (n=5), a second Delphi group was formed in August 2018, comprising 15 DMC experts. These included three physicians (two Care of the Elderly, Geriatric Psychiatry), a lawyer, and 11 DCAs from a variety of backgrounds. The Delphi protocol was conducted over

three months electronically, through three iterations, with 15 participants in the first iteration, 12 in the second, and 10 in the third. By the end of the third iteration, 90% consensus was reached, thus confirming the content and face validity of the communication aid.

During the recruitment process for the DMCAs, it quickly became clear that the pool of potentially eligible participants was extremely small, and so several changes were made to increase the number of available eligible participants. Recruitment was expanded to include the stroke and geriatric rehabilitation units at the Glenrose Rehabilitation Hospital, and age of inclusion lowered to 18 years or older. It was also identified that many SLPs at the RAH do not routinely use the Western Aphasia Battery (WAB) for language assessments, but instead use a variety of other screening tools (e.g., the BTNV), and so the aphasia diagnostic criteria was broadened to requiring only a formal SLP assessment to confirm an aphasia diagnosis.

Over one year, only eight participants were recruited despite the changes described above. A preliminary analysis of the results from these eight participants 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. The mean duration between assessments was 14 days (SD 24.3, 1–66 days). 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). All attempted DMCAs were completed. All questions were answered by all participants. The assessment results for each question across all participants are shown in Figures 1–68 (in Appendix C), and in Table D1 (of Appendix D).

### **Inter-rater Assessment**

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.

### Group One: Rater A vs. Rater B

Group one had six participants. Each participant underwent two assessments, one by Rater A and one by Rater B, resulting in 12 assessments and 408 observations (see Tables E1 to E6 of Appendix E). Gwet's kappa was 0.5089 (CI 0.436-0.581, p < .000) (see Table F1 in Appendix F).

### **Group Two: Rater A vs. Rater C**

Group two had two participants, resulting in four assessments and a total of 136 observations (see Tables E7 & E8 in Appendix E). Gwen's kappa of 0.3719 (CI 0.248-0.5010, *p* < .00) (see Table F1 of Appendix F).

### **Internal Consistency**

Cronbach alpha 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 < .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.

### **Usability**

Feedback from two out of three assessors reported that the communication aid was simple to use and incorporate into the assessment process, and that the SCA training provided was sufficient. The only negative feedback reported was concern that PWA may have difficulties understanding the last question.

### **DISCUSSION**

Financial DMC is a complex process, and its assessment can be challenging, especially for PWA. The absence of prior literature in this area combined with the lack of communication aids to support such assessments justifies the importance of this study and this new communication aid.

Although the original objective had been to develop a communication aid to support DMCAs for both legal and financial matters, the length and complexity of such a communication aid would make it impractical for use. Therefore, this new communication aid was designed to support financial DMCAs only, and is the first of its type. Due to an insufficient number of eligible participants being available to meet our intended sample size, a preliminary evaluation was done on the results from the eight participants recruited, the results of which are promising and justify the need to continue the study to fully validate the communication aid.

The results obtained from the focus groups identified an overall lack of understanding amongst older adults about DMC and, specifically, legal and financial DMC. This supports the need for public education along with future research in this area. Interestingly, they appear to have a good understanding about communication and its disorders, and of communication methodsused to inform communication aid development.

The other new product from this study is the "Aphasia Friendly Participant Consent Form" (Appendix B). As this consent form was not the study focus, it requires formal evaluation, which is a future goal of the authors following completion of this study.

There are a number of significant limitations to this study. The inclusion criteria and sensitive nature surrounding DMCA resulted in an extremely limited pool of potential participants, which persisted despite revising the recruitment location and

the inclusion criteria, resulting in not meeting the intended sample size. The other major limitation was the need to change the study protocol after study initiation. Although not ideal, the challenges encountered were both unforeseeable and unpredictable, given the lack of prior studies, and the changes were deemed necessary to allow continuation of the research. While modifications were made to limit the impact from these changes, they will have likely impacted on the accuracy and interpretation of the results.

Other limitations include the diversity observed in the results from these DMCAs, and in 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; this was not possible due to restrictions from patient and DMCA assessor commitments and availability.

The use of a mixed methods design allows for the combination of qualitative and quantitative research within a single study, which is required for validation of a new instrument. However, this can lead to the development of complex and resource intense studies, such as ours.

Additional limitations include the focus group participants, who may not be representative of community-dwelling older adults, thus limiting the generalizability of the results.

### **CONCLUSION**

The assessment of financial DMC in PWA is challenging, and there are no communication aids to support such assessments. Therefore, through this study, we have developed a communication aid to support DMCAs in PWA. Due to a number of significant challenges encountered during the study, we have only been able to recruit eight participants for the study. The preliminary results from this small sample size revealed the communication aid to be possibly reliable (with moderate inter-rater reliability), valid, and usable. However, further evaluation is required once the sample size is reached, to fully establish the psychometric properties of the communication aid.

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### CONFLICT OF INTEREST DISCLOSURES

I have read and understood the *Canadian Geriatrics Jour-nal*'s policy on conflicts of interest disclosure and declare there are none.

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**APPENDIX A** 

# 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.

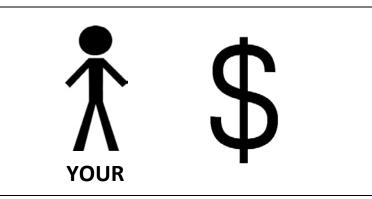
All potential users of this communication capacity aid should have the necessary training required to conduct capacity assessments either by nature of their qualifications (physicians, surgeons and psychologists) or have undergo specialized training to become a designated capacity assessor (DCA). In addition, all users are required to have undergone training in the use of Supported Conversation for Adults with Aphasia' which is available online at <a href="http://www.aphasia.ca/home-page/health-care-professionals/knowledge-exchange/">http://www.aphasia.ca/home-page/health-care-professionals/knowledge-exchange/</a> 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.

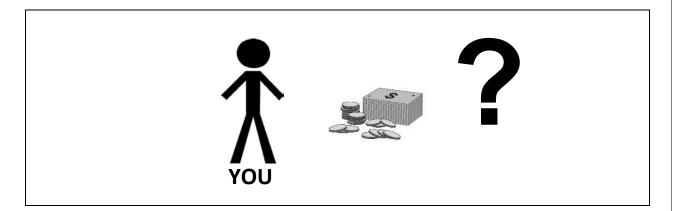
The communication aid is free to use by registered professionals who are (licensed) to perform capacity assessments within the population for which it has been validated. The communication aid can be obtained at no extra cost by emailing the author (contact details included in the appendix).

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?



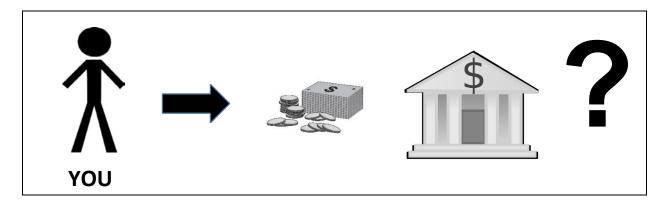
# 3. Where does your **money** come **from**?



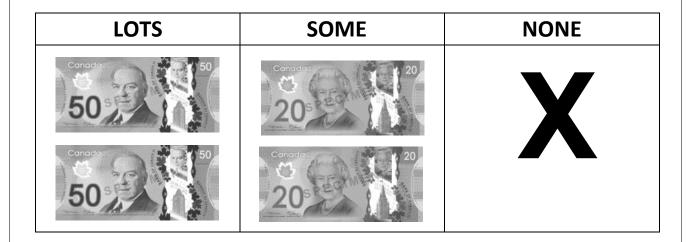


PENSION PLAN	DISABILITY		1	WOI	RK		
	ALLOWANCE						
		Pay Statem				My Compa	ny Ltd
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GIS	<b>BENEFITS</b>				1100000	Earn For NI Nat Ins ER Nat Ins EE	62,500,00 6284,32 6227,15
				Total Deductions	6649.72		
		Total Pay Produced By PAYEsoft is	62,600.00 nc Copyright 2008 w	10021010	£1,810.28	RECEVABLE	E1,810.28
BANK SAVINGS	DOG	ID	ON	'T K	NO	W	
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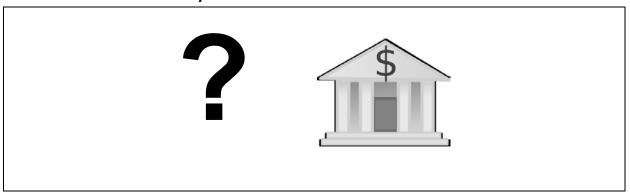
### 4. Do you have money in the bank?



### If yes, how much?

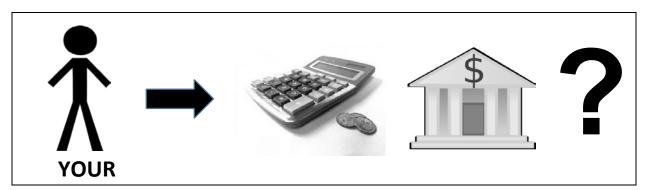


# 5. Which bank do you use?



(Offer examples of financial institutions)

# 6. Do you manage your own accounts?



# If **no**, who does?

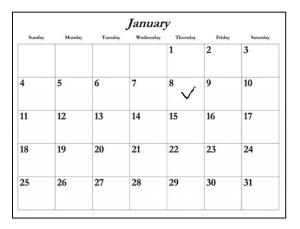
SPOUSE	FAMILY MEMBER
FRIEND	OFFICE OF THE PUBLIC
	GUARDIAN & TRUSTEE
	Your Personal and Financial Decisions Matter
DOG	NO-ONE
	X

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

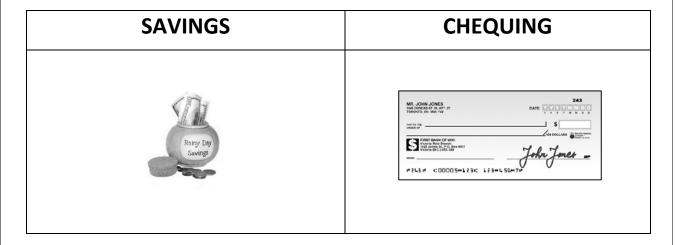
# Weekly?

Mon	<b>T</b> ue	<b>W</b> ed	<b>T</b> hur	<b>F</b> ri	<b>S</b> at	<b>S</b> un
					<b>✓</b>	

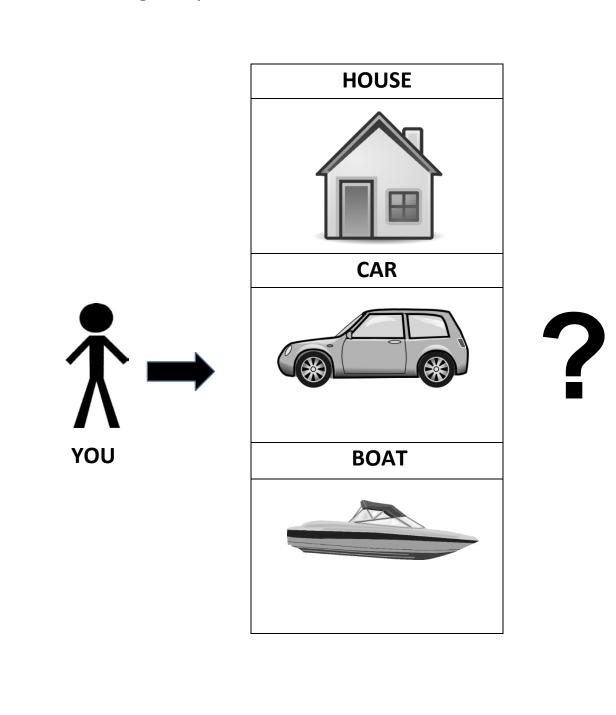
# Monthly?



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



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



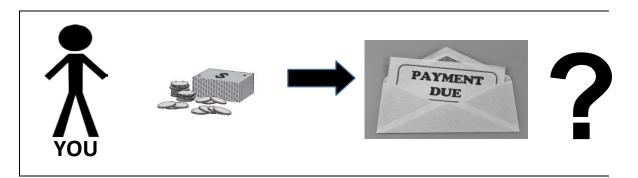
# 10. Do you have any money invested?



# If so, where?

RRSP	SAVINGS BOND	STOCKS
RRSP	BOND	STOCKS
REAL ESTATE	MUTUAL FUNDS	NONE
HOUSE FOR SALE	MUTUAL FUNDS	

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



# If so, what for?

WATER	HEATING	ELECTRICITY
PHONE / TV	TAXES	DOG
	Government Gouvernement du Canada	
INTERNET	RENT / MORTGAGE	I DON'T KNOW
@		X

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

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

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

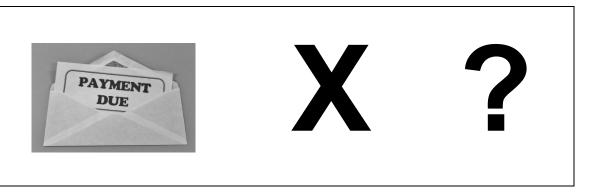








# 14. What happens if you cannot pay your bills?



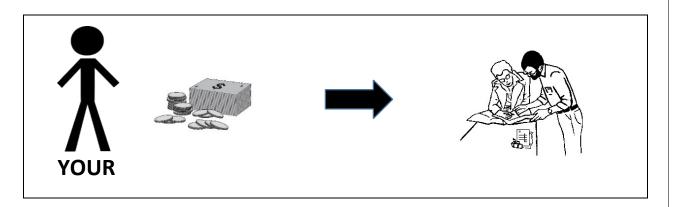


NOTHING	HEAT SWITCHED OFF	WATER SWITCHED OFF
X		
I DON'T KNOW	ELECTRICITY SWITCHED OFF	EVICTION
?		

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

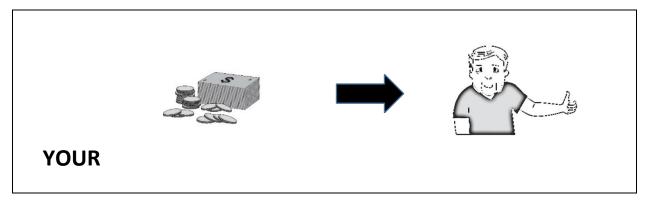
BANK	DOG		DEBIT / CREDIT CARD
\$			myBANK  SEES SEES SEES SEES  WasterCord  WasterCord
CHEQUE	IN PE	RSON	ATM
MR. JOHN JONES UNIC DARRIE OF WAT JY TORONTO OR MAY 19 J TORONTO O			ATM
COMPUTER		I D	ON'T KNOW
			?

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

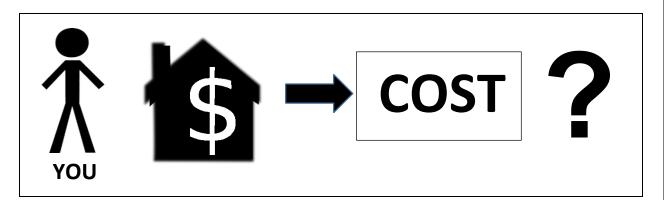


Or...

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



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

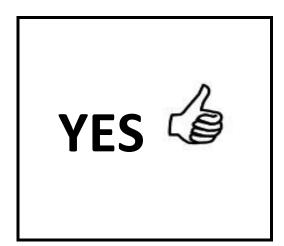


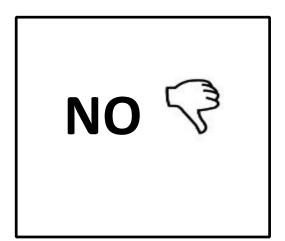


MORE THAN \$3000 \$3000

LESS THAN \$40 NOTHING

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

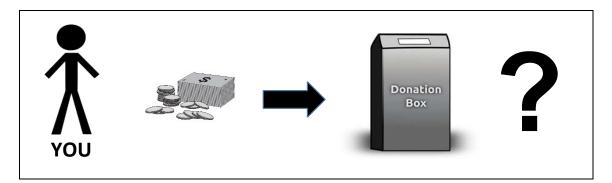




# If yes, to whom?

FAMILY	DOG	CHARITY
		Donation Box
BANK	ACCOUNTANT	I DON'T KNOW
\$		?

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



# If so, which ones?

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

# 21. How much money do you donate?

MORE THAN 100 DOLLARS	LESS THAN 40 DOLLARS	NONE
50 50 50 50	Canada 20  Canada 20  Canada 20  20	X

# 22. Who does your income tax return?



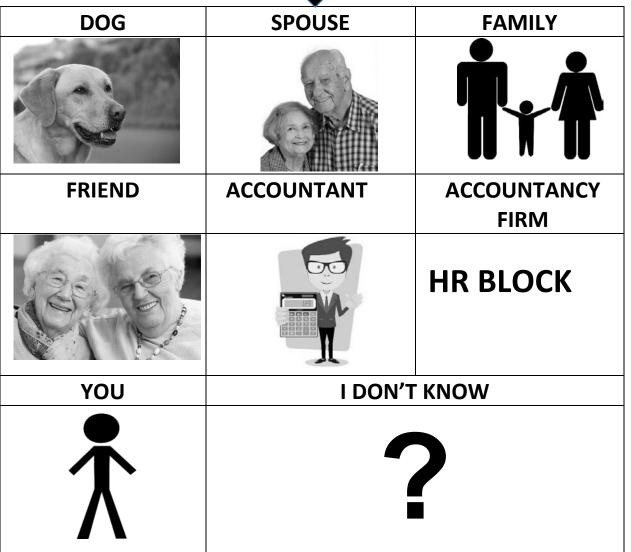


Government of Canada

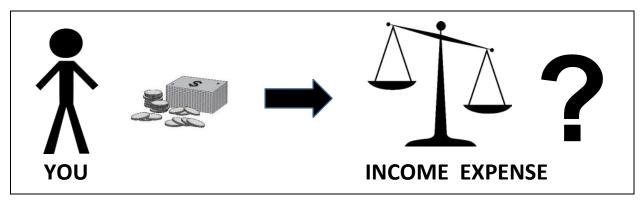
Gouvernement du Canada







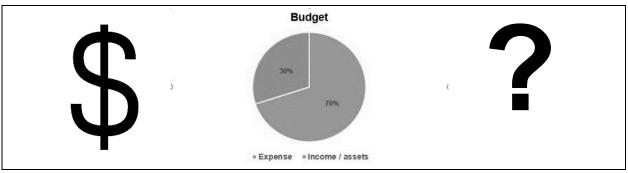
# 23. What will happen if you spend more money than you have?





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

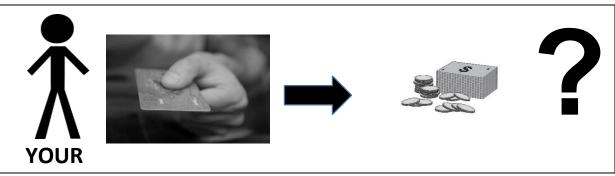
# 24. Who keeps track of your budget?





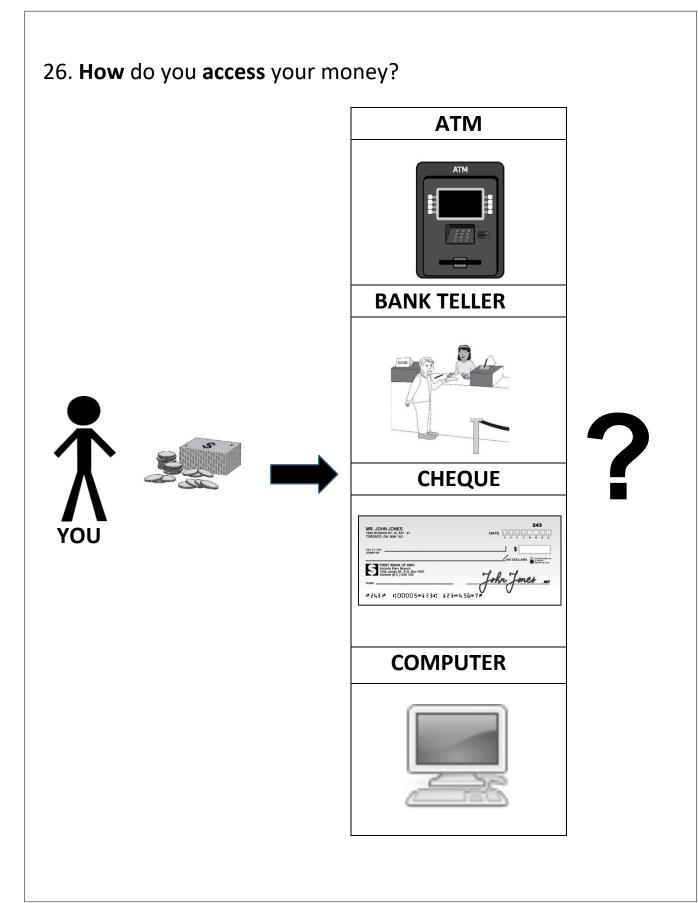
YOU	FAMILY
ACCOUNTANT	DOG
NO ONE	OFFICE OF THE PUBLIC
	GUARDIAN & TRUSTEE
X	Your Personal and Financial Decisions Matter

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

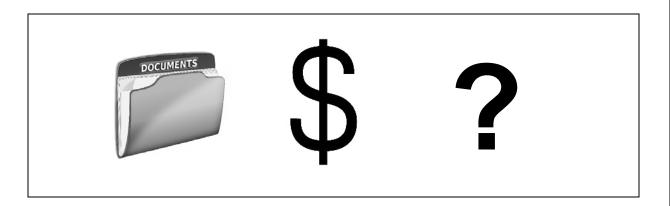




FRIENDS	DOG
FAMILY	ACCOUNTANT
NO ONE	OFFICE OF THE PUBLIC
	GUARDIAN & TRUSTEE
X	Your Personal and Financial Decisions Matter



# 27. Where do you keep your financial documents?





FILING CABINET	SAFE	COMPUTER
DESK	вох	NOWHERE
		X

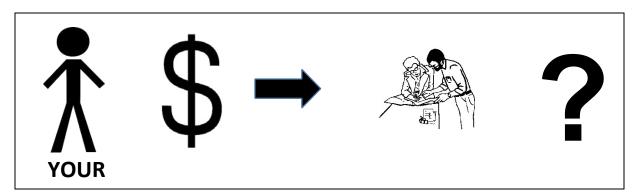
# 28. How do you protect financial documents?





SAFE	FILING CABINET
DOG	NO METHOD
	X

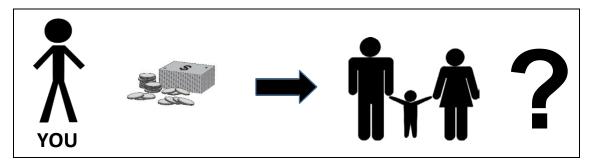
# 29. If you needed **help** with your finances....



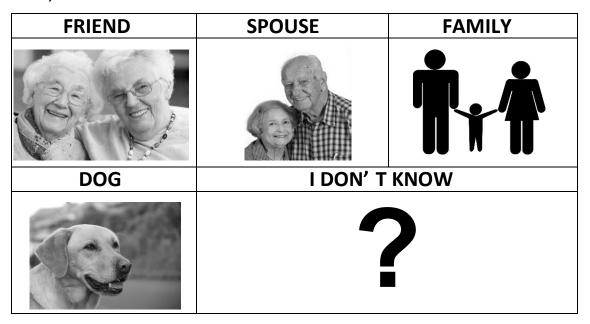
# ....who would you ask?

FAMILY	FRIEND
BANK	ACCOUNTANT
\$	
ACCOUNTANCY FIRM	I DON'T KNOW
HR BLOCK	2

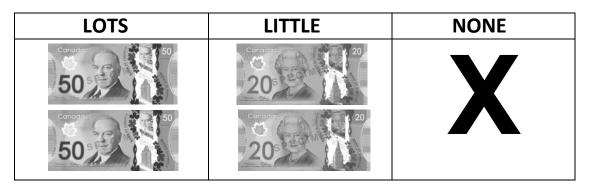
### 30. Is there anyone who depends on you for money?



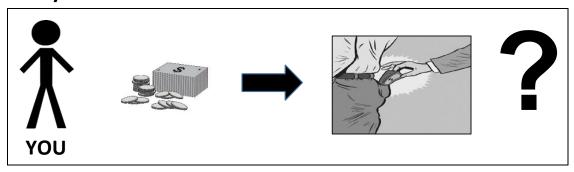
# If so, who?



### And how much?



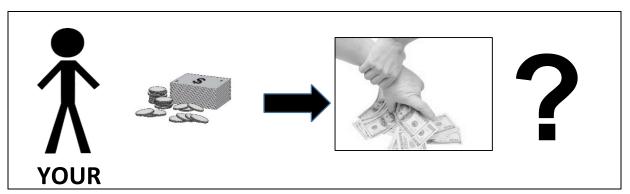
# 31. If **you thought** someone was trying to **take money** from **you**...



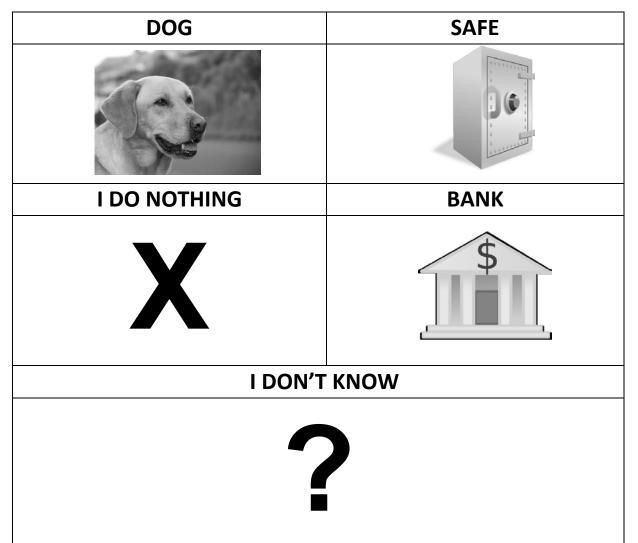
# What would you do?

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?







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

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 B

# APHASIA FRIENDLY PARTICIPANT CONSENT FORM

PARTICIPANT ID:	

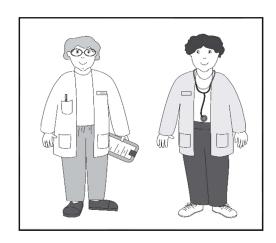
STUDY ID:

# PRINCIPLE INVESTIGATOR: CONTENTS PAGE

TOPIC CONTENT	PAGE
1. Introduction	
Study background including the aims for this research study.	
3. Participant information	
4. Participant involvement:  Location  Duration  Frequency  Data usage	
5. Data privacy	
6. Risks and benefits from study participation.	
7. Decision about study participation.	
8. Questions?	
9. Participant consent form	

#### 1. INTRODUCTION

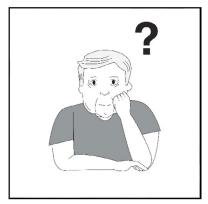
You are being asked to participate in a research study about capacity assessment.



In Alberta, a formal capacity assessment is done...



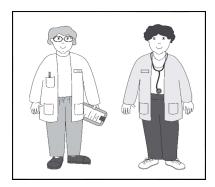
... to **see** if a person is **able to understand** important **information** for making **decisions**...



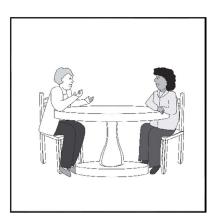
... and is able to **understand** the possible **results** of making a decision or of not making a decision.



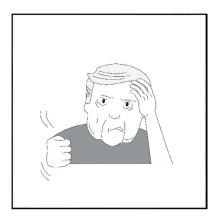
A formal **capacity assessment is done by** a trained capacity assessor or doctor.



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



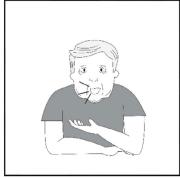
We know it can be very difficult for a person with aphasia to communicate their thoughts.

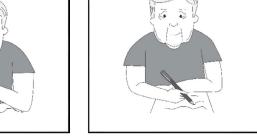


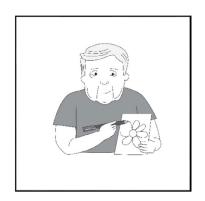
#### Therefore, capacity is ...

'A person's ability to make decisions they understand'.

#### A person is entitled to communicate however they can.



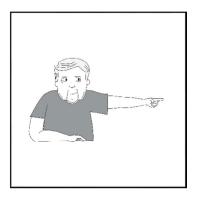


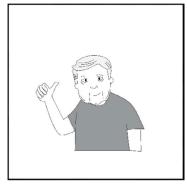


Speaking

Writing

Drawing



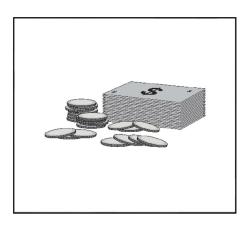


**Pointing** 

Gesturing

#### 2. STUDY BACKGROUND

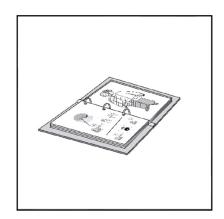
There is a communication aid that can be used to **help** assess capacity with persons with aphasia **but** it does **not** look at **financial issues**.





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?







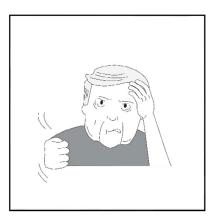
#### 3. PARTICIPANT INFORMATION

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

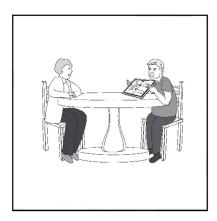
#### and

2. You have been diagnosed with Aphasia.



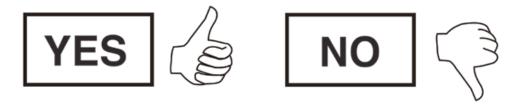
#### The study will involve...

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



#### And...

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

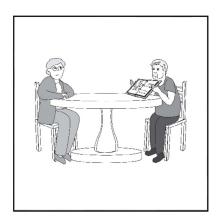


#### If you agree...

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



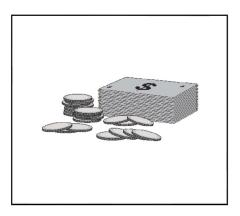
4. A second person will assess the same domains using the same tool.



#### 4. PARTICIPANT INVOLVEMENT

#### What is Your Role?

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

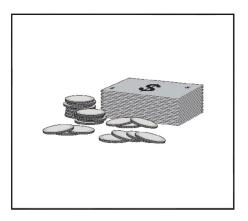


**Finances** 

#### 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.









#### Where will this take place?

At the Hospital.

#### When will this take place?

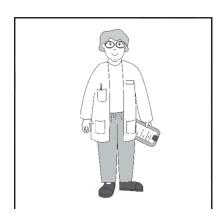
During the daytime.

Any day of the week.

Sun Mon Tues	Wed Thurs	Fri	<b>S</b> at	ì
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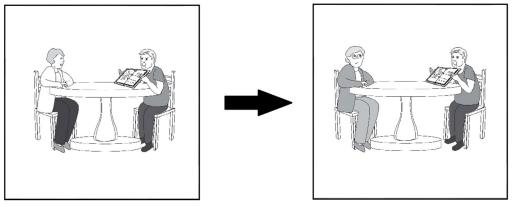
#### Who will do the capacity assessments?

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



#### How often will I be assessed?

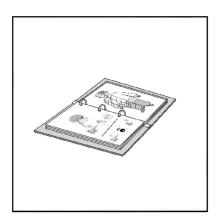
2 sessions, and more if needed.



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

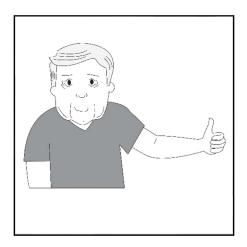
Session 2 A second designated on another day.

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

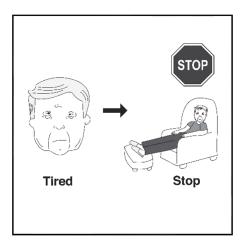


# How long will the assessment take?

It will depend on how it goes.



If you get tired, we can stop...

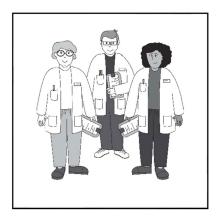


And start again another day.

#### 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.

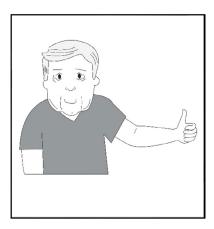
#### 6. RISKS AND BENEFITS



There is no physical danger in participating in this study.

#### Are there any benefits?

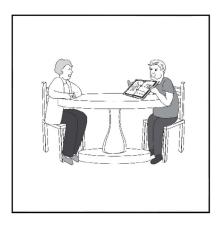
You may find the tool helpful with the assessment.



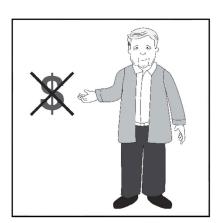
We hope to create a tool that is helpful for assessing capacity with people with aphasia.

#### 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.





I agree to participate in this research project.



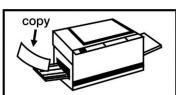








I have been given a copy of this form.











Signature of Participant	Date	
orginataro or rantiorparit	Date	

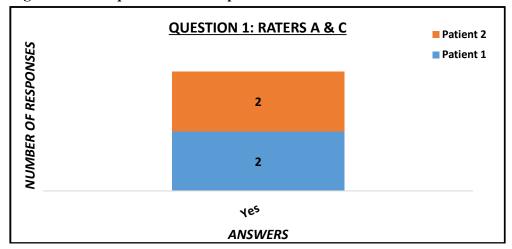
Signature of Witness Date

© copyright 1996 Aphasia Centre - North York

#### APPENDIX C

#### Participant responses from the decision-making capacity assessment

Figure 1: Participant answers to question 1 between raters A & C



The stacked bar chart shows each participant response to question 1, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

QUESTION 1: RATERS A & B

| Patient 8 |
| Patient 7 |
| Patient 6 |
| Patient 5 |
| Patient 4 |
| Patient 3 |
| Patient 3 |
| Patient 5 |
| Patient 3 |
| Patient 5 |
| Patient 5 |
| Patient 3 |
| Patient 5 |
| Patient 5 |
| Patient 5 |
| Patient 3 |
| Patient 5 |
| Patient 6 |
| Patient 6 |
| Patient 6 |
| Patient 7 |
| Patient 8 |
| Patient 5 |
| Patient 8 |
| Patient 5 |
| Patient 9 |
| Pa

Figure 2: Participant answers to question 1 between raters A & B

The stacked bar chart shows each participant response to question 1, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

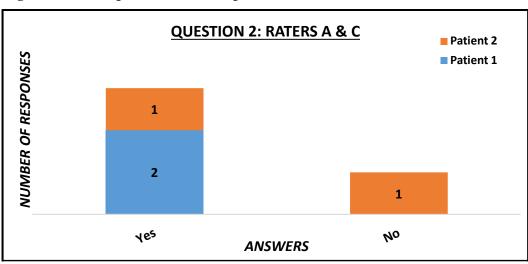


Figure 3: Participant answers to question 2 between raters A & C

The stacked bar chart shows each participant response to question 2, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

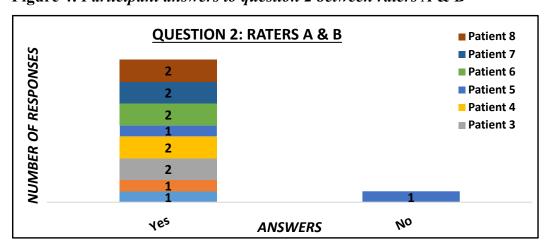


Figure 4: Participant answers to question 2 between raters A & B

The stacked bar chart shows each participant response to question 2, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

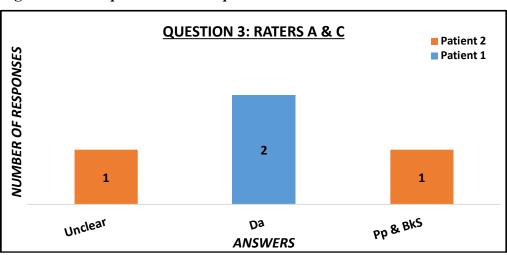


Figure 5: Participant answers to question 3 between raters A & C

The stacked bar chart shows each participant response to question 3, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Pp – pension plan; Da – disability allowance; BkS – bank savings.

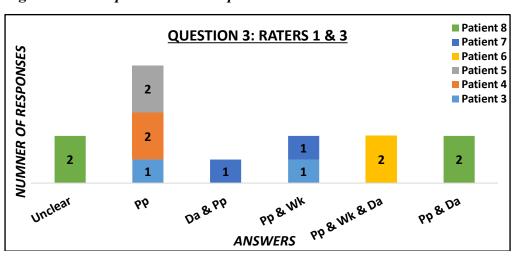


Figure 6: Participant answers to question 3 between raters A & B

The stacked bar chart shows each participant response to question 3, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: Pp – pension plan; Da – disability allowance; Wk – work; BkS – bank savings.

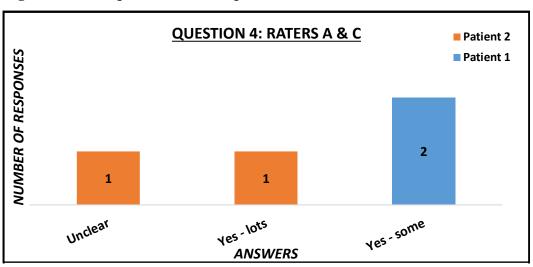


Figure 7: Participant answers to question 4 between raters A & C

The stacked bar chart shows each participant response to question 4, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

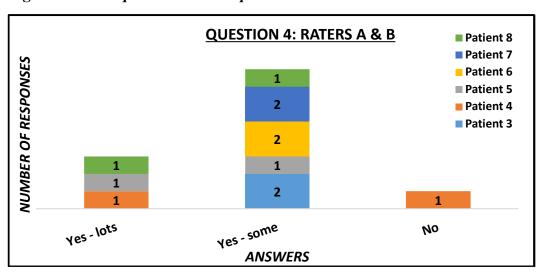


Figure 8: Participant answers to question 4 between raters A & B

The stacked bar chart shows each participant response to question 4, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

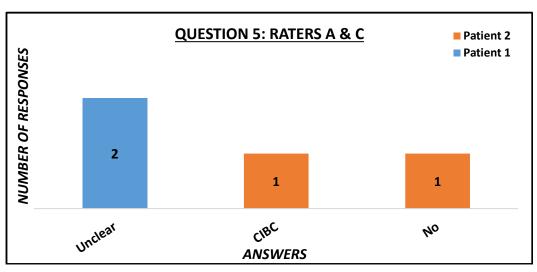


Figure 9: Participant answers to question 5 between raters A & C

The stacked bar chart shows each participant response to question 5, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

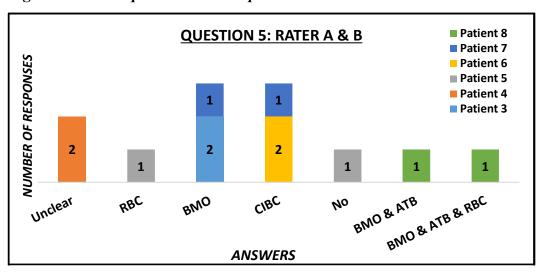


Figure 10: Participant answers to question 5 between raters A & B

The stacked bar chart shows each participant response to question 5, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

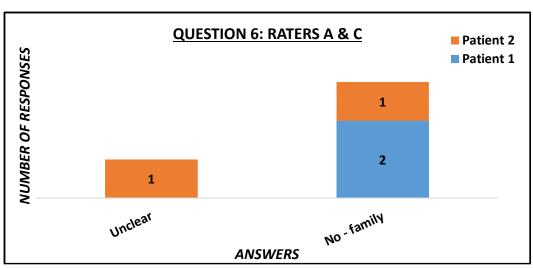


Figure 11: Participant answers to question 6 between raters A & C

The stacked bar chart shows each participant response to question 6, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

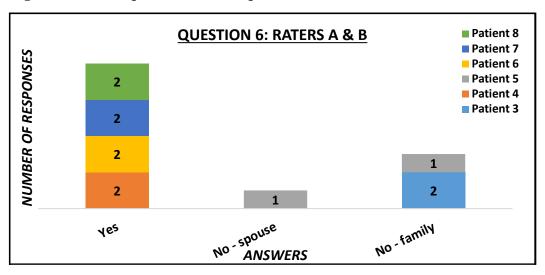


Figure 12: Participant answers to question 6 between raters A & B

The stacked bar chart shows each participant response to question 6, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

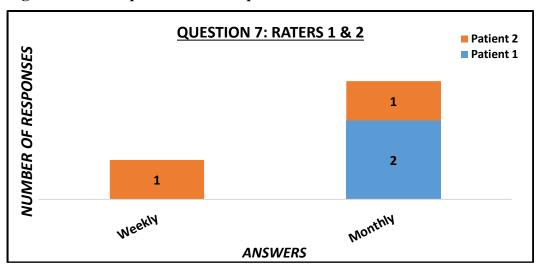


Figure 13: Participant answers to question 7 between raters 1 & 2

The stacked bar chart shows each participant response to question 7, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

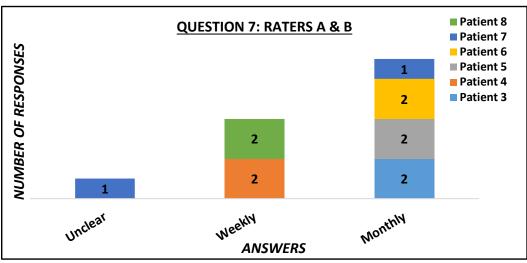


Figure 14: Participant answers to question 7 between raters A & B

The stacked bar chart shows each participant response to question 7, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

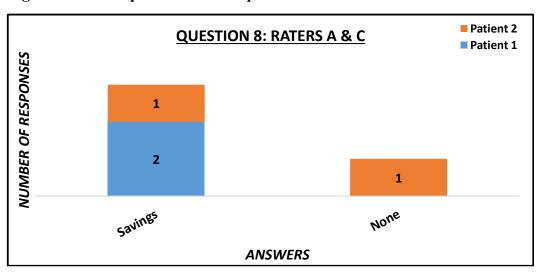


Figure 15: Participant answers to question 8 between raters A & C

The stacked bar chart shows each participant response to question 8, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

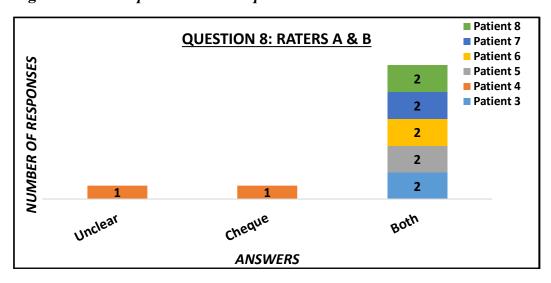


Figure 16: Participant answers to question 8 between raters A & B

The stacked bar chart shows each participant response to question 8, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

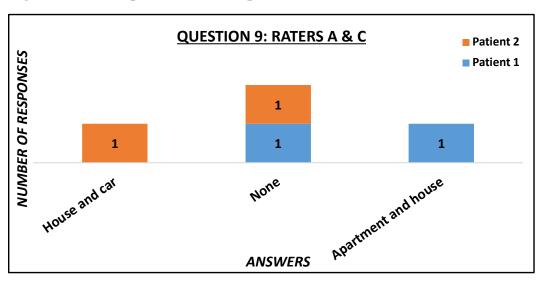


Figure 17: Participant answers to question 9 between raters A & C

The stacked bar chart shows each participant response to question 9, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

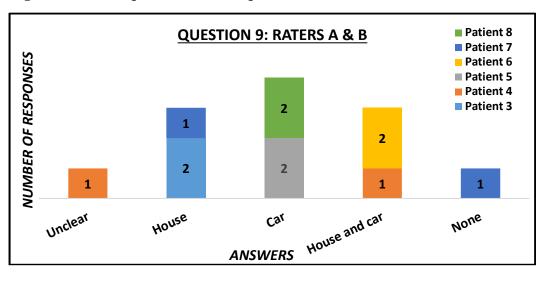


Figure 18: Participant answers to question 9 between raters A & B

The stacked bar chart shows each participant response to question 9, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

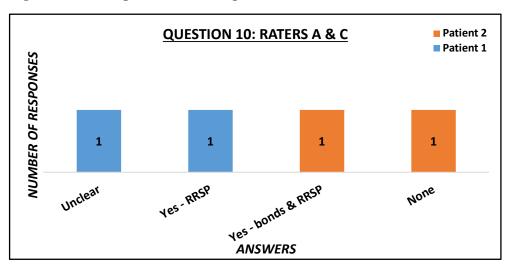


Figure 19: Participant answers to question 10 between raters A & C

The stacked bar chart shows each participant response to question 10, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: RRSP – registered retirement savings plan.

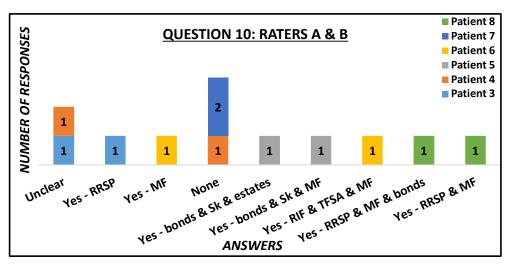


Figure 20: Participant answers to question 10 between raters A & B

The stacked bar chart shows each participant response to question 10, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: RRSP – registered retirement savings plan; Sk – stocks; MF – mutual funds; RIF – retirement income fund; TFSA – tax free savings account.

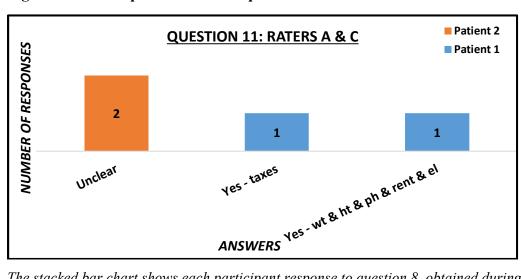


Figure 21: Participant answers to question 11 between raters A & C

The stacked bar chart shows each participant response to question 8, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: wt-water; ht-heat; ph-phone; el-electricity.

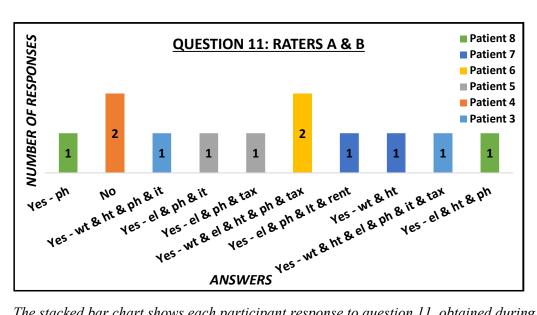


Figure 22: Participant answers to question 11 between raters A & B

The stacked bar chart shows each participant response to question 11, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: wt-water; ht-heat, ph-phone/TV, el-electricity, it-internet; rent-rent/mortgage.

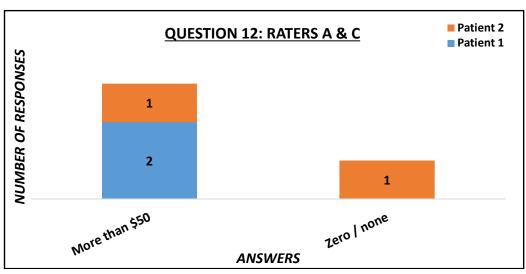


Figure 23: Participant answers to question 12 between raters A & C

The stacked bar chart shows each participant response to question 12, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

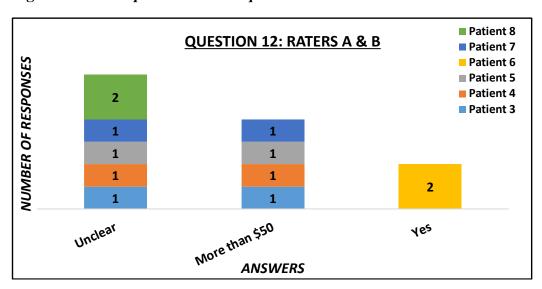


Figure 24: Participant answers to question 12 between raters A & B

The stacked bar chart shows each participant response to question 12, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

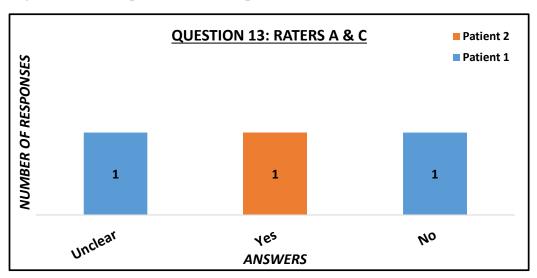


Figure 25: Participant answers to question 13 between raters A & C

The stacked bar chart shows each participant response to question 13, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

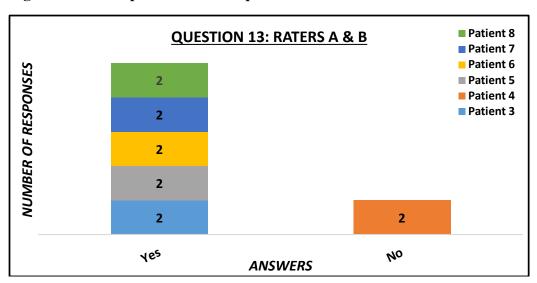


Figure 26: Participant answers to question 13 between raters A & B

The stacked bar chart shows each participant response to question 13, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

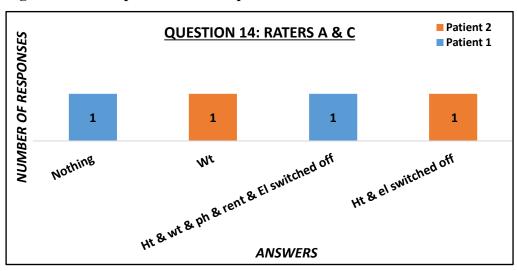


Figure 27: Participant answers to question 14 between raters A & C

The stacked bar chart shows each participant response to question 14, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Wt-water; ht-heat, ph-phone, el-electricity.

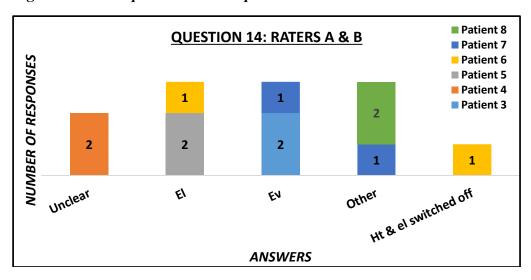


Figure 28: Participant answers to question 14 between raters A & B

The stacked bar chart shows each participant response to question 8, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: ht-heat; el-electricity; ev-eviction.

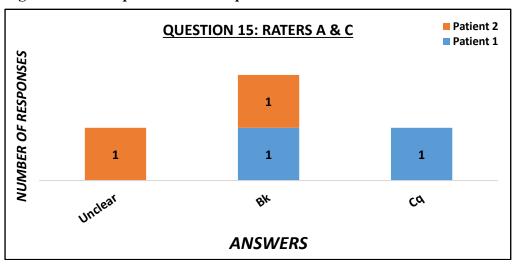


Figure 29: Participant answers to question 15 between raters A & C

The stacked bar chart shows each participant response to question 15, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Bk – bank; Cq – cheque.

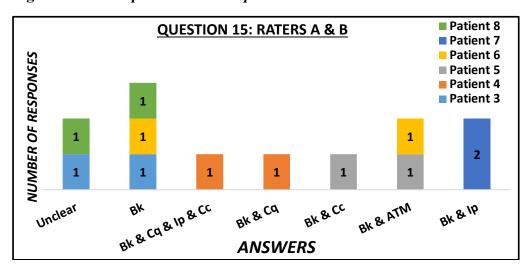


Figure 30: Participant answers to question 15 between raters A & B

The stacked bar chart shows each participant response to question 15, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: Bk - bank; Cq - cheque; Cc - debit / credit card; Ip - In person.

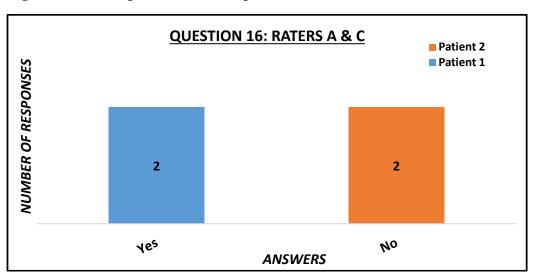


Figure 31: Participant answers to question 16 between raters A & C

The stacked bar chart shows each participant response to question 16, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

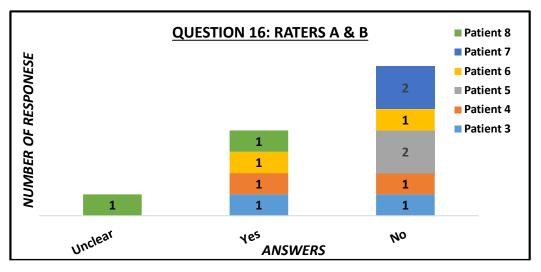


Figure 32: Participant answers to question 16 between raters A & B

The stacked bar chart shows each participant response to question 16, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

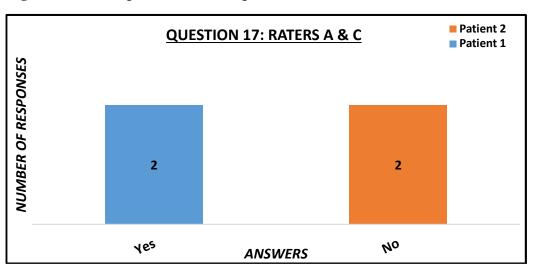


Figure 33: Participant answers to question 17 between raters A & C

The stacked bar chart shows each participant response to question 17, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

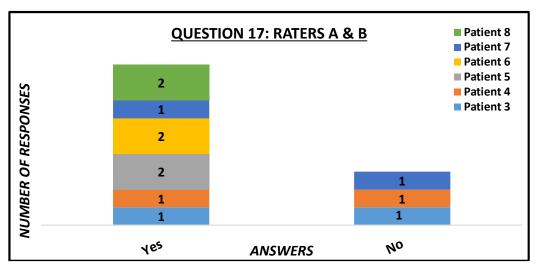


Figure 34: Participant answers to question 17 between raters A & B

The stacked bar chart shows each participant response to question 17, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

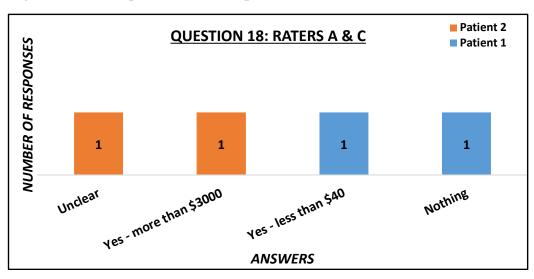


Figure 35: Participant answers to question 18 between raters A & C

The stacked bar chart shows each participant response to question 18, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

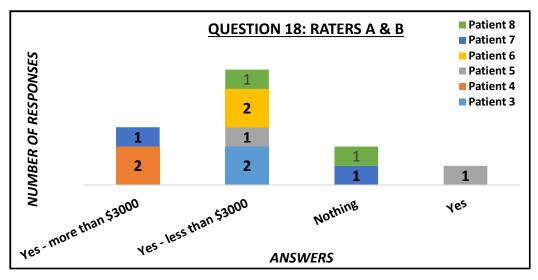


Figure 36: Participant answers to question 18 between raters A & B

The stacked bar chart shows each participant response to question 18, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

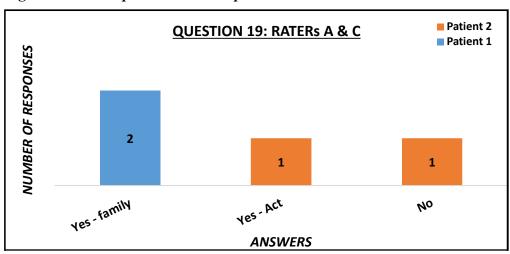


Figure 37: Participant answers to question 19 between raters A & C

The stacked bar chart shows each participant response to question 19, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Act – accountant.

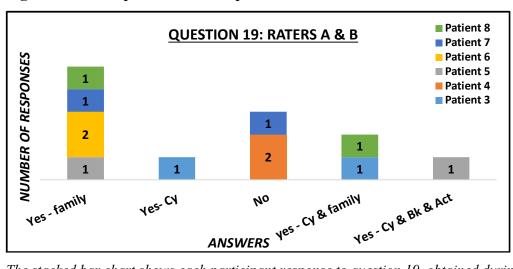


Figure 38: Participant answers to question 19 between raters A & B

The stacked bar chart shows each participant response to question 19, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: Cy – charity; Bk – bank; Act – accountant.

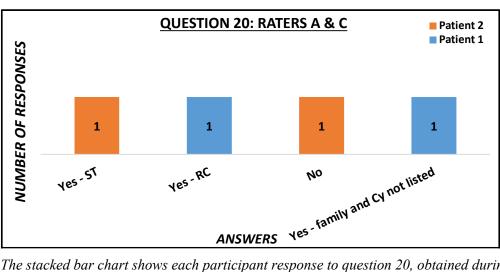


Figure 39: Participant answers to question 20 between raters A & C

The stacked bar chart shows each participant response to question 20, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: ST – Stollery children's hospital foundation; RC – Red Cross; Cy – charity.

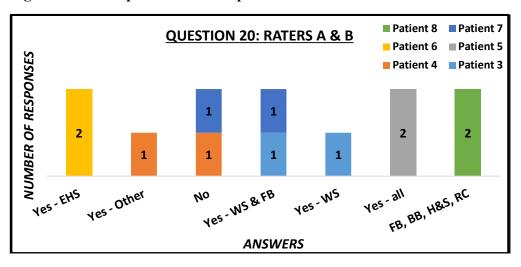


Figure 40: Participant answers to question 20 between raters A & B

The stacked bar chart shows each participant response to question 20, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: EHS – Edmonton Humane Society; WS – Women's shelter; FB – foodbank; BB – Big Brother Big Sisters of Edmonton and area; H&S – Heart & Stroke Foundation; RC – Red Cross.



Figure 41: Participant answers to question 21 between raters A & C

The stacked bar chart shows each participant response to question 21, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

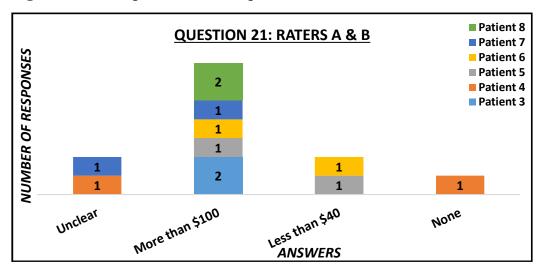


Figure 42: Participant answers to question 21 between raters A & B

The stacked bar chart shows each participant response to question 21, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

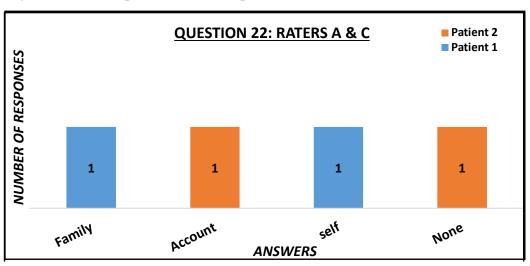


Figure 43: Participant answers to question 22 between raters A & C

The stacked bar chart shows each participant response to question 22, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

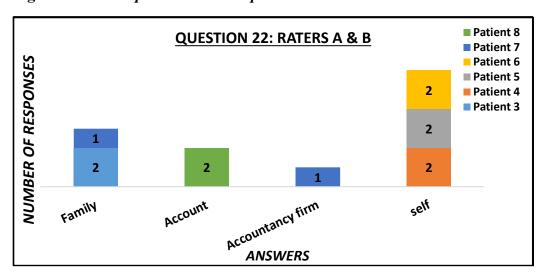


Figure 44: Participant answers to question 22 between raters A & B

The stacked bar chart shows each participant response to question 22, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

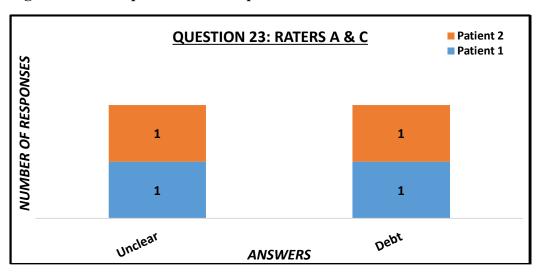


Figure 45: Participant answers to question 23 between raters A & C

The stacked bar chart shows each participant response to question 23, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

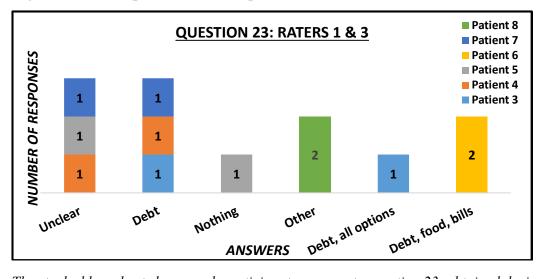


Figure 46: Participant answers to question 23 between raters A & B

The stacked bar chart shows each participant response to question 23, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

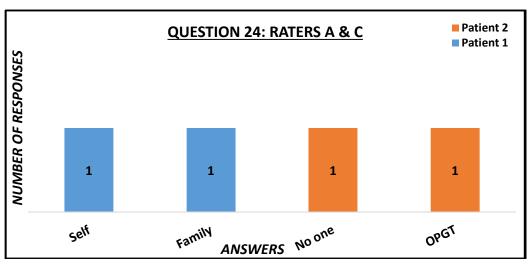


Figure 47: Participant answers to question 24 between raters A & C

The stacked bar chart shows each participant response to question 24, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

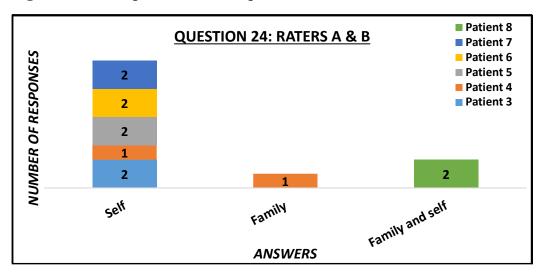


Figure 48: Participant answers to question 24 between raters A & B

The stacked bar chart shows each participant response to question 24, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

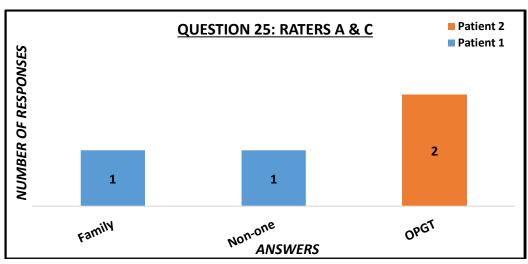


Figure 49: Participant answers to question 25 between raters A & C

The stacked bar chart shows each participant response to question 25, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

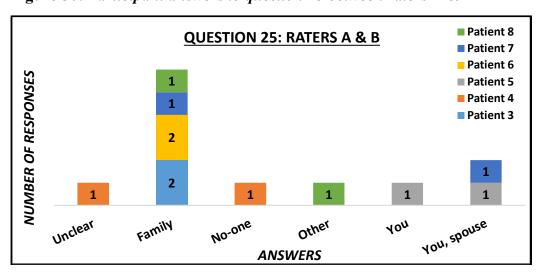


Figure 50: Participant answers to question 25 between raters A & B

The stacked bar chart shows each participant response to question 25, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

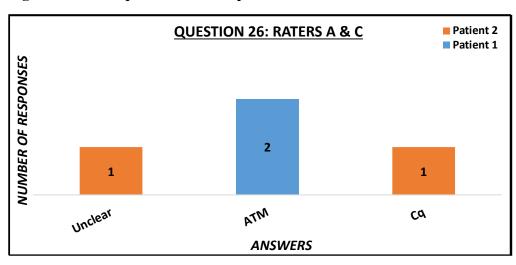


Figure 51: Participant answers to question 26 between raters A & C

The stacked bar chart shows each participant response to question 26, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Cq – cheque.

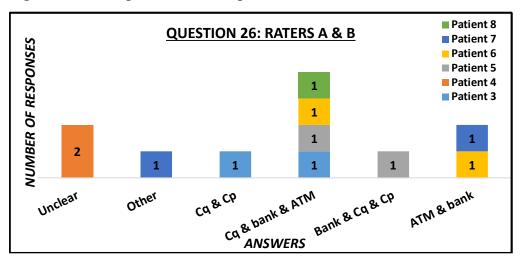


Figure 52: Participant answers to question 26 between raters A & B

The stacked bar chart shows each participant response to question 26, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: Bt-bank teller; Cq-cheque; Cp-computer.

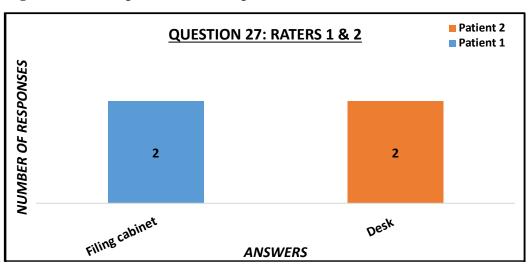


Figure 53: Participant answers to question 27 between raters A & C

The stacked bar chart shows each participant response to question 27, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

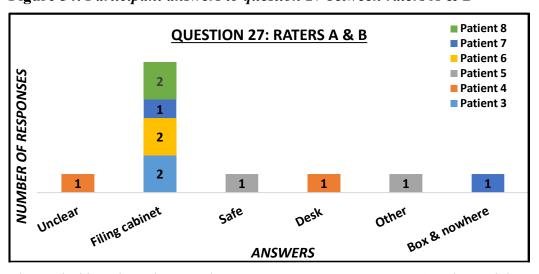


Figure 54: Participant answers to question 27 between raters A & B

The stacked bar chart shows each participant response to question 27, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

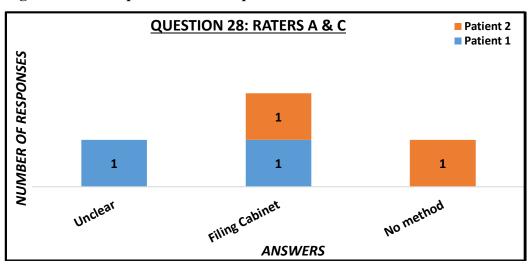


Figure 55: Participant answers to question 28 between raters A & C

The stacked bar chart shows each participant response to question 28, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

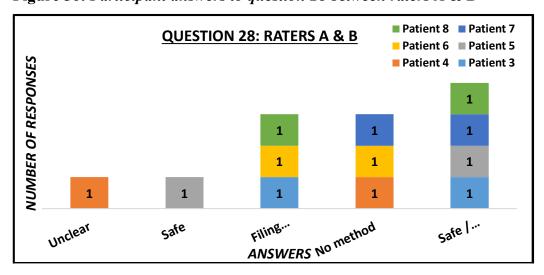


Figure 56: Participant answers to question 28 between raters A & B

The stacked bar chart shows each participant response to question 28, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

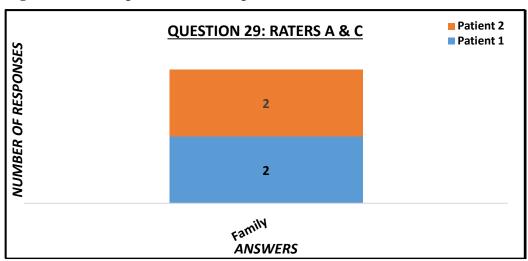


Figure 57: Participant answers to question 29 between raters A & C

The stacked bar chart shows each participant response to question 29, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

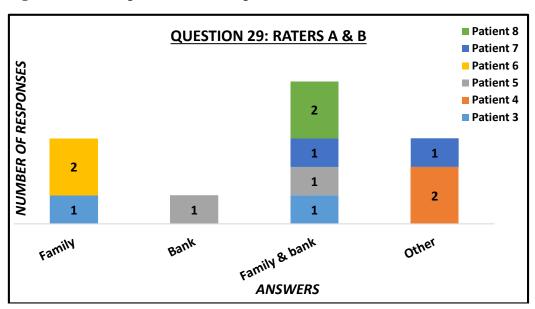


Figure 58: Participant answers to question 29 between raters A & B

The stacked bar chart shows each participant response to question 29, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

QUESTION 30: RATERS A & C

Patient 2
Patient 1

2

Unclear
ANSWERS

Figure 59: Participant answers to question 30 between raters A & C

The stacked bar chart shows each participant response to question 30, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

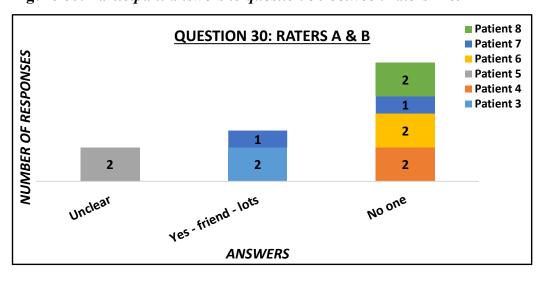


Figure 60: Participant answers to question 30 between raters A & B

The stacked bar chart shows each participant response to question 30, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

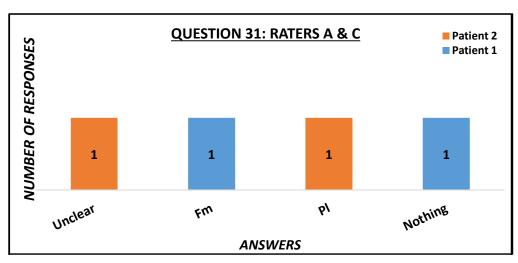


Figure 61: Participant answers to question 31 between raters A & C

The stacked bar chart shows each participant response to question 31, obtained during the decision-making capacity assessments done with the communication aid by raters A and C. Abbreviations: Fm - family; Pl - police; Bk - bank.

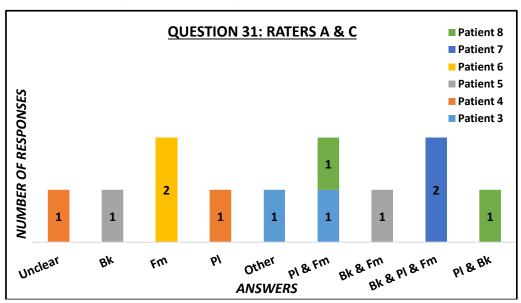


Figure 62: Participant answers to question 31 between raters A & B

The stacked bar chart shows each participant response to question 31, obtained during the decision-making capacity assessments done with the communication aid by raters A and B. Abbreviations: Fm - family; Pl - police; Bk - bank.

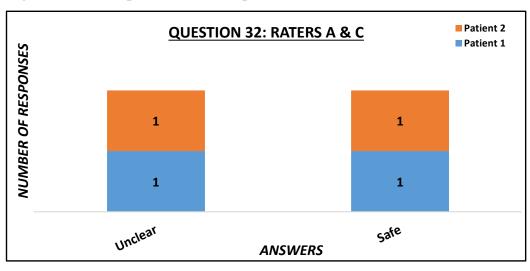


Figure 63: Participant answers to question 32 between raters A & C

The stacked bar chart shows each participant response to question 31, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

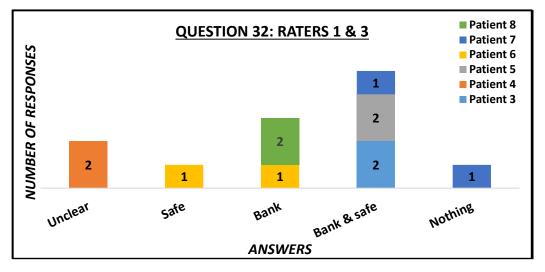


Figure 64: Participant answers to question 32 between raters A & B

The stacked bar chart shows each participant response to question 32, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

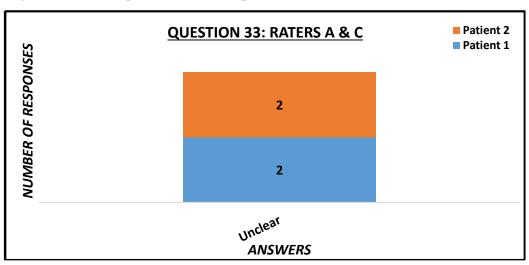


Figure 65: Participant answers to question 33 between raters A & C

The stacked bar chart shows each participant response to question 33, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

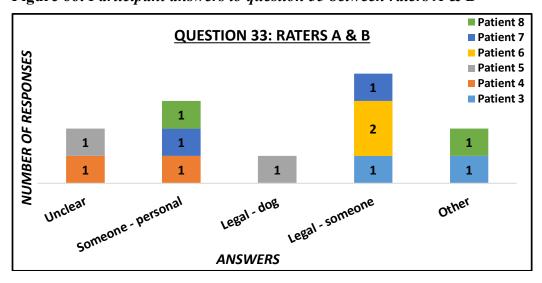


Figure 66: Participant answers to question 33 between raters A & B

The stacked bar chart shows each participant response to question 33, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

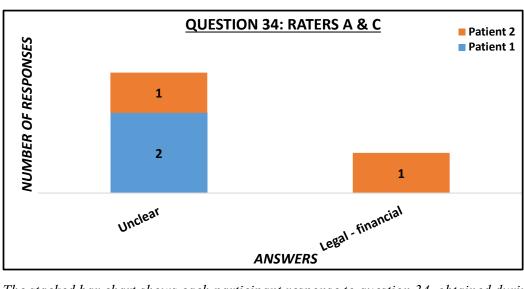


Figure 67: Participant answers to question 34 between raters A & C

The stacked bar chart shows each participant response to question 34, obtained during the decision-making capacity assessments done with the communication aid by raters A and C.

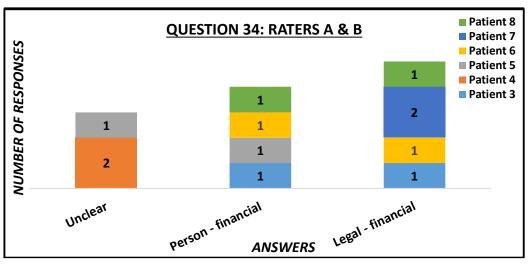


Figure 68: Participant answers to question 34 between raters A & B

The stacked bar chart shows each participant response to question 34, obtained during the decision-making capacity assessments done with the communication aid by raters A and B.

#### **APPENDIX D**

### Tables showing the outcomes from DMCA

Table 1. Outcomes from the decision-making capacity assessments by patient

<b>PATIENT</b>	RATER A	RATER B	RATER C
1	Lacks financial decision-		Lacks financial decision-
	making capacity		making capacity
2	Lacks financial decision-		Lacks financial decision-
	making capacity		making capacity
3	Lacks financial decision-	Lacks financial decision-	
	making capacity	making capacity	
4	Lacks financial decision-	Lacks financial decision-	
	making capacity	making capacity	
5	Lacks financial decision-	Lacks financial decision-	
	making capacity	making capacity	
6	Has financial decision-	Has financial decision-	
	making capacity	making capacity	
7	Lacks financial decision-	Lacks financial decision-	
	making capacity	making capacity	
8	Lacks financial decision-	Lacks financial decision-	
	making capacity	making capacity	

#### **APPENDIX E**

## List of tables showing participant responses to each question

Table 2: Participant 1 responses

QUESTION	RATER A	RATER C
1	Yes	Yes
2	Yes	Yes
3	Disability allowance	Disability allowance
4	Some	Some
5	Unclear	Unclear
6	Family	Family
7	Monthly	Monthly
8	Savings	Savings
9	Apartment, house	No
10	RRSP	Don't know
11	Yes – water & heat ☎ & rent &	Yes - tax
	electricity	
12	More than \$50	More than \$50
13	No	Unclear
14	Turn off water, heat, phone, rent,	Nothing
	electricity	
15	Bank	Cheque
16	Yes	Yes
17	Yes	Yes
18	<\$40	Nothing
19	Yes - family	Yes - family
20	Yes – family & charity not listed	Yes - Red Cross
21	More than \$100	More than \$100
22	Family	You / self
23	Unclear	Debt - owe money
24	Family	You / self
25	Family	No one
26	ATM	ATM
27	Filing cabinet	Filing cabinet
28	Filing cabinet	Unclear
29	Family	Family
30	Unclear	Unclear
31	Family	Do nothing
32	Safe	Unclear
33	Unclear	Unclear
34	Unclear	Unclear

 Table 3: Participant 2 responses

QUESTION	RATER A	RATER C
1	Yes	Yes - ok
2	Yes	No
3	Pension & bank saving	Don't know
4	Yes - Lots	Don't know
5	CIBC	No
6	Family	Unclear
7	Weekly	Monthly
8	Savings	None
9	Yes – House & car	Nothing
10	Bond & RRSP	No
11	Unclear	Unclear
12	More than 50	No
13	Yes	No
14	Heat & electricity switched off	Water turned off
15	Bank	Unclear
16	No	No
17	No	No
18	More than \$3000	Unclear
19	Accountant	No
20	Yes - Stollery	No
21	Less than \$40	Unclear
22	Accountant	You / self
23	Debt - owe money	Unclear
24	OPGT	No one
25	OPGT	OPGT
26	Cheque	Unclear
27	No where	No where
28	File cabinet	No where
29	Family	Family
30	Nobody	Nobody
31	Police	Unclear
32	Safe	Unclear
33	Unclear	Unclear
34	Legal document naming someone to	Unclear
	make financial decisions for you	

Table 4: Participant 3 responses

QUESTION	RATER A	RATER B
1	Yes	Yes
2	Yes	Yes
3	Pension	Pension / work
4	Yes - some	Yes - some
5	BMO	BMO
6	Yes - talk to brother	Yes - then talk with brother
7	Monthly	Monthly
8	Both	Both
9	House	House
10	Yes - RRSP	Yes - unsure where
11	Yes – water & heating & electricity & phone & internet & taxes	Yes – water & heating & phone & internet
12	Unclear	More than \$50
13	Yes	Yes
14	Things get switched off, eviction	Eviction
15	Unclear	Bank
16	Yes	No
17	No	Yes
18	Less than \$3000	Less than 3000
19	Yes - charity	Yes - family & charity
20	Yes – Woman's shelter, food bank	Yes – Woman's charity in Edmonton
21	More than \$100	More than \$100
22	Family	Family
23	Debt, all options	Debt
24	You	You
25	Family	Family
26	Cheque & bank, ATM	Cheque & computer
27	Filing cabinet	Filing cabinet
28	File cabinet	Safe / filing cabinet
29	Family	Bank & family
30	Family - lots	Family - lots (\$1200/month)
31	Everyone whoever	Police & family
32	Bank & safe	Bank & safe
33	Both	Legal document naming someone to make financial decisions
34	Person appointed by courts to make	Legal document naming someone to make
	financial decisions	financial decisions

**Table 5:** *Participant 4 responses* 

QUESTION	RATER A	RATER B
1	Yes	Yes
2	Yes	Yes
3	Pension plan	Pension plan
4	None	Yes - lots
5	Unclear	Unclear
6	Yes	Yes
7	Weekly	Weekly
8		Not included in list / I don't know (hard to
	Chequing	determine specific answer)
9	House, car	Unclear
10	No	Unclear
11	No	No
12	More than \$50	Unclear
13	No	No
14	Unclear	Unclear
15	Bank	Unclear
16	No	No
17	No	Yes
18	More than \$3000	More than \$3000
19	No	No
20	No	Yes - none of the answers
21	None	Unclear
22	You	You
23	Debt	Unclear
24	Family	You
25	Unclear	No one
26	Unclear	Unclear
27	Desk	Unclear
28	No method	Unclear
29	No one	None
30	No	No
31	No	Unclear
32	Unclear	Unclear
33	Unclear	Someone to make personal decisions
34	Unclear	Unclear

Table 6: Participant 5 responses

QUESTION	RATER A	RATER B
1	Yes	Yes
2	No	Yes
3	Pension plan	Pension plan
4	Yes - some	Yes - lots
5	RBC	None of these answers
6	Yes - spouse & myself	Yes - family
7	Monthly	Monthly
8	Both	Both
9	Car	Car
10	Yes – bonds & stocks & mutual	Yes – bonds & stocks & real estate
11	Yes – electricity & phone & TV &	Yes –electricity & phone & taxes
	internet	
12	More than \$50	Unclear
13	Yes	Yes
14	Electricity switched off	Electricity switched off
15	Bank & cheque & in person & card	Bank & cheque
16	Yes	No
17	Yes	Yes
18	Yes	Less than \$3000
19	Yes - family	Yes – charity & bank & accountant
20	Yes - all	Yes - all
21	More than 100	Less than \$40
22	You	You
23	Nothing	Unclear
24	You	You
25	You, spouse	You
26	Bank teller & ATM & cheque	Bank teller & cheque & computer
27	Safe	None of these answers
28	Safe	Safe
29	Bank	Family, bank
30	Unclear	Unclear
31	Call bank & family	Call bank
32	Safe & bank	Safe & bank
33	Legal document - financial decisions	Unclear
34	Unclear	Person who makes financial decisions

Table 7: Participant 6 responses

QUESTION	RATER A	RATER B
1	Yes	Yes
2	Yes	Yes
3	Pension & disability & work & savings	Pension & disability & work & bank savings
4	Yes - some	Yes - some
5	CIBC	CIBC
6	Yes	Yes
7	Monthly	Monthly
8	Both	Both
9	House, car	Car, house
10	Yes - MF	RIF, TFSA & Mutual funds
11	Water & heating & electricity & phone & tax	Water & heating & electricity & phone & tax
12	More than \$50	More than \$50
13	Yes	Yes
14	Heat & water & electricity switched off	? Eviction
15	Bank & credit card & ATM	Bank & credit card
16	No	No
17	Yes	Yes
18	More than \$3000	More than \$3000
19	Yes – Charity	Yes charity
20	Edmonton humane society	Edmonton humane society
21	More than \$100	Less than \$40
22	Self	Self
23	Debt & food & bills	Debt & food & bills
24	You	You
25	Family	Family
26	ATM & bank teller	ATM & bank teller & cheque
27	Filing cabinet	Filing cabinet
28	File cabinet	No method
29	Family	family
30	No	No
31	Call bank & police & tell family	Call bank & police & tell family
32	Safe	Bank
33	Legal document	Legal document
34	Person appointed by courts to make financial decisions for you	Legal document

Table 8: Participant 7 responses

QUESTION	RATER A	RATER V
1	Yes	Yes
2	Yes	Yes
3	Pension & disability allowance	Pension & work
4	Yes - some	Yes - some
5	CIBC	ВМО
6	Yes	Yes
7	Unclear	Monthly
8	Both	Both
9	Nothing	House (husband had a car)
10	None	None
11	Electricity & phone & internet & rent	Water & heating
12	Unclear	More than \$50
13	Yes	Υ
14	Loan & phone & personal care	Unable - ?eviction
15	Bank & ATM	Bank
16	No	No
17	No	Yes
18	Not have property tax	More than \$3000
19	No	Yes
20	No	Yes – Woman's charity
21	Unclear	More than \$100
22	HM block	Family
23	Unclear /not sure	Debt
24	Self	You
25	Self	Family
26	Bank & ATM	Cheque & computer
27	Box & nowhere	Filing cabinet
28	Nowhere	Safe & filing cabinet
29	None	Bank & family
30	No	Family - lots
31	Bank & police	Police & family
32	Nothing	Bank & safe
33	Someone who will make person decisions for	Legal document naming someone make
	your	financial decisions
34	Legal document naming someone to make	Legal document naming someone make
	financial decisions for you	financial decisions

Table 9: Participant 8 responses

QUESTION	RATE A	RATER B
1	Yes	Yes
2	Yes	Yes
3	Pension & disability allowance & bank	Pension & disability allowance & bank
	savings	savings
4	Yes - some	Yes - lots
5	ATB & BMO	BMO & ATB & RBC
6	Yes	Yes
7	Weekly & sometimes monthly	Weekly
8	Both	Both
9	Car	Car
10	RRSP, MF, Bonds	RRSP & mutual funds
11	Phone & electricity & heating	Phone
12	More than \$50	More than \$50
13	Yes	Yes
14	Other	Other
15	Bank & in person	Bank & in person
16	Yes	No
17	Yes	Yes
18	Less than \$3000	Nothing as I don't have any
19	Yes - Family	Charity & family
20	Foodbank, Big Brothers Big Sisters & Heart	Foodbank & Big Brothers Big Sisters &
	and Stroke Foundation & Red Cross	Heart and Stroke Foundation & Red cross
21	More than \$100	More than \$100
22	Accountant	Accountant
23	Don't do that	Don't do that
24	Family & self	Family, self
25	Family	Family, self
26	ATM & bank & cheque	Bank & cheque
27	Safe	Safe
28	Safe & filing cabinet	Safe
29	Bank & family	Family & bank I guess
30	No	No
31	Police	Police & family
32	Bank	Bank
33	Both	Someone making personal decisions for
		you
34	Someone who will make financial decisions	Legal document of someone making
	for your	financial decisions for you

# APPENDIX F <u>Tables showing Inter-rater agreement</u>

#### Table 2: Inter rater assessment

	Gwets AC Kappa
Raters A & B	0.5089 (CI 0.4362 to 0.5816, P < 0.000)
Raters A & C	0.3719 (CI 0.248-0.5010, p < 0.00)