REPRESENTATION AGREEMENTS IN BRITISH COLUMBIA: WHO IS USING THEM AND WHY?

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ABSTRACT

Despite the passage of BC's *Representation Agreement Act* in 2000, there have been no studies conducted to date to determine who is using these agreements and why. Three groups of individuals were interviewed: capable representation agreement holders (n=48), representatives of capable agreement holders (n=38), and representatives of agreement holders no longer capable (n=7). Study participants differed from the general population of seniors in BC in terms of income and education but were similar to those using advance care planning tools in the United States. The data revealed interesting gender differences suggesting that men and women may enter into agreements for different reasons and have dissimilar expectations of how their wishes are to be carried out. Overall, this sample of representation agreement holders felt the agreements are a good idea and a means of ensuring their wishes are followed should they become incapable of making their own health care decisions.

DEDICATION

I wish to dedicate this to my family, without whom I would never have had the courage and perseverance to complete this arduous journey. To Ed, who has always supported me whole-heartedly, even when I had given up on myself and was ready to throw in the towel. He has endured frustrations, self-doubt, really bad moods and a postponed wedding date all so I could concentrate on finishing what I started. I thank him from the bottom of my heart, because I never would have made it without his support.

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CHAPTER 1: INTRODUCTION

People today are living longer than they have in the past. Along with living to an older age comes the risk a person will suffer some sort of functional or cognitive decline. Given the possibility of cognitive decline and the chronic nature of many illnesses, there has been much interest in ways to direct the care one receives when one is no longer capable of consenting to health care. Advance directives in various forms have been touted as a means of selecting care options while one is still capable, to take effect when one is no longer capable. They are seen as a strategy used by individuals to gain control over their future (Dresser, 2003).

This idea is not new and literature from the United States has paid much attention to this topic over the past 30 years. Although the United States and Canada have had different experiences, it still remains an important area and research findings from the United States have the potential to teach Canadians valuable lessons in trying to implement policies and practices that will effectively guide end-of-life decision-making. It is clear from the research that older adults generally support the concept of advance directives but effective practices to ensure people's directives are implemented have met with substantial difficulties. There is also a great deal of debate about what form directives should take in order to be successful in directing care.

This is an important issue because of the demographic changes taking place in Canada. It is projected that by the year 2031, the number of people aged 65 and over will range between 8.9 and 9.4 million (Statistics Canada, 2005). Population aging is expected to accelerate in 2011 as the first group of baby boomers reaches the age of 65 (Statistics Canada, 2005). This rapid aging is projected to extend to 2031 when seniors will account for between 23-25% of the total population, which is almost double their current proportion (13%) of the population (Statistics Canada, 2005).

Approximately 64,000 people in British Columbia are living with Alzheimer's disease or a related dementia and it is estimated that every year, an additional 14,000 people will develop dementia (Alzheimer Society of BC, 2008). The prevalence of dementia increases with age in the 65+ population. In those aged 85 and over, the ratio of those with dementia may be as many as one in three (Havens, 1995). Given that the chances of developing Alzheimer's disease or a related dementia appears to be more pronounced in women than in men and the longer life expectancy of women, taken together with the declining birth rate, it is probable that in the future, women will outlive their spouse, not have as large a family network on which to rely and face an increased risk of incapacity due to cognitive decline. This suggests that methods of directing one's care at a time of incapacity may become more important as the population ages. This, together with a continuing trend away from institutional care to community care, means there should be effective means in place to help those who may need assistance in making decisions.

To date, there has been no research undertaken in British Columbia examining the use of representation agreements, a form of advance directive. This research investigates the socio-demographic and health characteristics of those using representation agreements and why they feel representation agreements are important to have in place.

CHAPTER 2: LITERATURE REVIEW

The term "advance directive" covers a variety of tools used by people to govern the care they receive when they are no longer capable of self-directing. One of the difficulties in interpreting research in this area is that not all researchers mean the same thing when they talk about advance directives so caution is required when comparing research findings. Much of the literature is from the United States and because of the differences between the Canadian and American health-care systems, caution must be taken in extrapolating research results from the United States to Canada.

There are two main categories of advance directives. One type consists of instructional documents, such as living wills and other directives that state what types of life-sustaining treatment would be acceptable and not acceptable to the person (Dresser, 2003). The other type is a proxy directive, where a person designates a specific individual as their preferred treatment decision-maker to act on their behalf when they become incapable (Dresser, 2003). Durable powers of attorney for health care, a health care proxy and representation agreements are examples of this latter type of directive.

A third category consists of a combination of both instructional and proxy directives. People may enact both types of directives, appointing a person to make decisions on their behalf while also formalizing their treatment wishes in order to instruct their proxy at a later date (Dresser, 2003). Instructional directives can be very specific in directing what kind of care is or is not wanted at a time of incapacity or they can be very general. The same is true of proxy directives. People may appoint a proxy and have no discussions with them as to what type of care they would or would not want while others may appoint a proxy and give very specific instructions as to the type of care they want or do not want. There is great variability across geographic jurisdictions in the types of advance directives available, as well as the quantity and quality of guidance given in directives.

2.1 The American Experience

The concept of pre-determining treatments while still capable for a time when one is no longer capable is based on the principles of self-determination and preservation of autonomy. Some argue that the concept of advance planning is a means of enhancing personal autonomy and serves as an antidote to the paternalistic nature of the relationship between health care provider and client, especially if the client is elderly (Clark, 1987). The move toward promoting greater use of instructional or proxy advance directives arose from an assumption that dying hospital patients receive unwanted and non-beneficial care and having an advance directive is an important means of avoiding intrusive care (Brock, 1994). Dying nursing home residents also frequently experience unwanted interventions, uncoordinated care and unnecessary suffering, largely as a result of the inability of nursing home staff to provide comprehensive end-of-life care, which may put them at high risk for hospitalization (Happ, Capezuti, Strumpf et al., 2002). Therefore, it was thought that pre-determining the types of treatment one would want at a time of incapacity would prevent needless suffering and allow for some measure of control over the care received.

There are those who are suspicious about the true motives behind advance care planning or advance directives, especially if individuals are encouraged to execute directives or authorize surrogates to limit treatments or medical interventions (Kapp, 2001). Rather than promoting autonomy and self-determination, there is fear that these documents will become a mechanism of health care rationing, especially among older adults who have higher probabilities of impaired cognitive functioning that may make them vulnerable to abuse or neglect.

There is evidence that de facto health care rationing by health care providers on the basis of age occurs among older adults in end-of-life situations (Kapp, 2001). A study by Hanson, Danis, Mutran and Kennan (1994) of the relationship between patient incompetence and the decision to withhold life-sustaining treatments found that after controlling for differences in severity of illness, diagnosis, race and insurance status, patient incompetence remained strongly associated with decisions to withhold CPR and other treatments. However, the majority of decisions to withhold treatment were found to have been made in accordance with ethical guidelines, based on collaborative decisions by physicians and the patient's family members and major conflicts very rarely occurred.

There has been speculation that in addition to promoting patient autonomy, a secondary benefit of advance directives (defined as any expression of patient wishes, verbal, written or otherwise) would be their potential to help reduce health care resource use by preventing unwanted medical interventions during end-of-life care (Taylor, Heyland, Taylor, 1999). It has not yet been determined if advance planning saves money, and if it does, how much money it saves or how money is saved (Kapp, 2001). However, studies have shown that if there are any savings to the health care system as a whole, they are relatively small (Miles, Koepp and Weber, 1996).

In an effort to shift to a less paternalistic medical care system, the United States passed the federal *Patient Self-Determination Act* (hereafter referred to as the *PSDA*) in 1990. According to Lo and Steinbrook (2004), the mandate of the *PSDA* was to make it a requirement for nursing homes that receive Medicare and Medicaid funding to advise patients of their right to complete an instructional advance directive at the time of admission. Nursing homes were also to inquire as to whether patients had completed an advance directive and were to follow the directive to the extent permitted under state law. The legislation left it to individual states to set the requirements for advance directives, which has resulted in requirement variations. The hope was that better education and information would result in more people completing an advance directive. Despite the passage of the *PSDA*, the number of people in the United States who have completed an advance directive still remains relatively small. Research shows that less than 25% of people have instructional directives although some studies have found higher rates of completion among groups of seriously ill patients (Dresser, 2003).

There is conflicting evidence as to the overall effectiveness of instructional and proxy directives. Evidence about both has shown that they are easily misunderstood or misinterpreted and would be more useful if they emphasized advance care planning, including discussions about end-of-life care with physicians, rather than merely completing a legal document that either sets out treatment wishes or appoints a proxy (Lo and Steinbrook, 2004).

Physician compliance with treatment preferences set out in advance directives has also had an impact on their effectiveness. Even when patient preferences about end-of-life care are obtained and included in a patient's chart, they may not be followed when treatment decisions are made (Doukas and Hardwig, 2003). This may be because physicians have difficulty honouring vaguely worded directives when faced with distressed, demanding and potentially litigious family members who request care different from that contained in a directive (Doukas and Hardwig, 2003).

Proxy directives are problematic as well. In order to make the treatment decisions that a patient would want, the surrogate decision-maker must know what the patient would or wouldn't want in any given scenario that may arise. However, a study by Suhl, Simons, Reedy and Garrick (1994) found that surrogates guessed patient's preferences for life support no better than could be expected from chance alone, even though the patients and their surrogates had generally had long and close relationships and there was a belief that the surrogates knew the patient's wishes. As well, surrogates tended to overestimate patient's wishes for life support. This study also found that the amount of discussion between patient and surrogate regarding life support was the only factor identified that correlated with accurate surrogate decision-making while relationship duration between patient and surrogate did not correlate with the surrogate's ability to predict patient response. Other studies have shown that knowing only a person's general values and goals for care, which are thought to guide surrogates when making specific treatment decisions, do not allow surrogates to accurately identify the patient's wishes (Phillips, Wenger, Teno, et al., Schneiderman, Pearlman, Kalpan, Anderson and Rosenberg as cited in Lo and Steinbrook, 2004). It is clear from the research that regardless of the form of directive, there are difficulties with them both in terms of theory and practice.

2.2 Who Uses Instructional and Proxy Advance Directives?

2.2.1 Socio-Demographic Characteristics of Users

In the case of both instructional and proxy directives, there are consistent findings from the United States with respect to race and education. A study by Suri, Egleston, Brody and Rudberg (1999) of nursing home residents found that older, Caucasian women were more likely to have an advance directive or Do-Not-Resuscitate order upon admission to the facility. People who are white, upper-middle class and well-educated are more likely to complete an advance directive than those who are non-white, less educated and have a lower income status (Forbes, Bern-Klug and Gessert, 2000). In a study of intervention strategies to increase use of instructional advance directives, High (1993) found that 21% of participants who had less than a high school education had completed a living will compared to 34% of those with a high school education or more. Other studies have found that when compared with other adults, those who possess advance directives are older, white, more highly educated, middle class and in poor health (Allen and Shuster, 2002).

With respect to age, a study of nursing home residents by Bradley, Wetle and Horwitz (1998) found that older residents (aged 75-90 years) were more likely to complete advance directives than were those 75 years old and younger. A study of non-hospitalized elderly adults by Ali (1999) found that those aged 70 and older signed more advance directives than those who were younger. Participants whose annual household income was $40,000 or higher (USD) signed more advance directives than those whose annual income was less than $40,000.

There are conflicting findings with regard to religion and ethnicity. Ejaz (2000) found religious affiliation was predictive of having implemented either a living will and/or a durable power of attorney for health care. Jewish nursing home residents were the most likely to have implemented advance directives and had more positive attitudes towards life-prolonging treatments at end-of-life compared to Catholics or Protestants. However, another study by Gordon and Shade (1999) found that completing a durable power of attorney for health care, a living will or a written advance directive, was not significantly associated with sex, race/ethnicity, marital status or self-rated health status.

2.2.2 Concordance between patient's and their surrogate's decision-making

As explained earlier, proxy directives consist of appointing a person to make treatment decisions on one's behalf if one is no longer capable of doing so. The concept of proxy consent was developed as a means of ensuring that people's wishes would be respected even when they were no longer able to make decisions for themselves (Ouslander, Tymchuk and Rahbar, 1989). Proxy consent extends the concept of informed consent and is based on the assumption that the proxy's decision would be identical or similar to that of the person who designated the proxy (Ouslander, Tymchuk and Rahbar, 1989). It has been recognized that merely appointing a proxy decision-maker is of questionable benefit (Culver, 1998). The appointment must be made in conjunction with both the person and his/her proxy becoming familiar with the range of potential choices that may need to be made in the future and the person's individual preferences about the choices (Culver, 1998).

There is some suggestion from the research that a substantial proportion of patients may not communicate to their surrogate decision-maker their basic assumptions and preferences about the final stages of decision-making (Hawkins, Ditto, Danks and Smucker, 2005). For example, only 33-68% of substituted judgments made by spouses or physicians are estimated to match the patient's actual prior wishes (Emanuel, 1995). Discrepancies between proxy and patient preferences arose with sufficient frequency in a study by Diamond, Jernigan, Moseley, Messina and McKeown (1989) to raise the researchers' concern. These findings imply that there is not always a clear understanding on the part of the proxy as to what the patient wanted. Or it may be that neither the patient nor the proxy contemplated the situation at the time the patient expressed his or her wishes.

There is also evidence suggesting that surrogate decision-makers rely on other factors such as their own personal beliefs about acceptable quality of life, or intend to rely on advice received from others in their family or social networks, even though this might result in decisions that did not match the patient's preferences (Vig, Taylor, Starks, Hopley and Fryer-Edwards, 2006). Although the researchers initially thought this could be a cause for concern, a deeper examination of surrogates' reasoning found that surrogates might find it difficult to isolate their own perspectives when making decisions. They may base decisions on their own needs because of their close relationship with the patient and anticipated difficulties this closeness would have on making life-and-death decisions.

There is also some evidence that suggests that elderly people would rather trust a proxy than express a treatment preference themselves (Miles, Koepp and Weber, 1996). This may suggest that the act of advance care planning stops at the appointment of a proxy rather than continuing on to include discussions of treatment preferences. In the case where the patient had a written directive as well as a surrogate decision-maker, explicit conversations about the patient's preferences were not held, but surrogates were confident that the written document would indicate what the right decision to make would be (Vig, Taylor, Starks, Hopley and Fryer-Edwards, 2006). Some argue that written advance directives, which may include the naming of surrogate decision-maker, needs to be recast from a formal, legal process of signing a document to a more dynamic process of communication and negotiation about care goals, referred to as advance care planning (Teno, Stevens, Spernak and Lynn, 1998).

One explanation for the lack of success in predicting wishes is that people are not talking with their proxy or if they are, the discussions are not ongoing over a period of time. Furthermore, instructional or proxy directives are unlikely to have an effect on care if a health care provider, proxy or family member does not support and advocate for following the person's wishes (Perrin, 1997). It is difficult to be an effective advocate if one does not know what the adult's wishes are, thus demonstrating the importance of discussions between those involved in the decision-making process i.e. health care provider, patient, proxy and/or family members.

2.2.3 Need for control

It has been suggested by Rodriguez and Young (2006) that decisions individuals make about their health and treatment options are affected by a wide range of psychosocial factors, including their beliefs about the extent to which they are able to control or have an influence over the outcomes of their decisions. These researchers found that of 14 participants who, in a qualitative study, had exhibited signs of having a tendency toward internal health locus of control, 11 had completed a written advance directive.

Other studies have shown similar findings. For example, LaPuma, Orentlicher and Moss (1991) report that among nursing home residents support of living wills was significantly correlated to a feeling of internal control. Similarly, Rosnick and Reynolds (2003) found that reporting a high sense of control over one's life was significantly related to having either a durable power of attorney, durable power of attorney for health care or living will. It has also been found that achieving an overall sense of control in the dying process is an important psychosocial outcome (Martin, Emanuel and Singer, 2000). Taken together, the evidence suggests that being in charge of one's own decision-making may be more appealing to those with a higher need for control compared to those who have a lower need for control.

2.3 Advance Directives in Canada

The development of legislation governing instructional and proxy directives in Canada has followed a different path than that in the United States. There is no federal legislation such as the *PSDA* in Canada governing the use of advance directives or guiding the use of advance directives in a uniform manner among the provinces and territories. This is due in part to the Canadian constitution, which puts the authority for health care primarily within the jurisdiction of the provinces rather than the federal government (Verma and Silberfeld, 1997). It has been left to the individual provinces and territories to develop policy and legislation as they see fit to address decision-making at a time of incapacity.

While there are differences among provinces and territories, all either provide for both proxy and instructional directives or expressly/implicitly allow for instructions (Browne and Sullivan, 2006). The lack of uniformity among the provinces is problematic in that not all provinces have signed reciprocity legislation, which means an advance directive signed in one province may not be recognized in another (Dalhousie Health Law Institute End of Life (EOL) Project, 2008). While there is evidence that Canadian doctors, patients and the public widely support the concept of life-sustaining treatments and advance directives (Choudhry, Ma, Rasooly and Singer, 1994), Canadians have not been overly eager to enter into advance directives to guide future care. It is suggested that only 10% of Canadians have completed an advance directive (Browne and Sullivan, 2006).

2.4 Current State of BC's Legislation

The common law right to specify treatment wishes prior to incapacity and have those wishes respected was established in Canada by *Malette v Shulman* [1990 67 D.L.R. 322 (Ont. C.A.)], a case involving blood transfusions being given to an objecting Jehovah's Witness. The plaintiff successfully sued the doctor and the Court ruled that a capable adult has a right to pre-determine and document refusal of certain treatments even if a decision could result in death. The Court said:

> the right to self-determination, which underlies the concept of informed consent, also obviously encompasses the right to refuse medical treatment...The doctrine of informed consent is plainly intended to ensure the freedom of individuals to make choices concerning their medical care. For this freedom to be meaningful, people must have the right to make choices that accord with their own values, regardless of how unwise or foolish those choices may appear to others.

The Court also said:

> The right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based.

BC's *Health Care (Consent) and Care Facility (Admission) Act* reflects this right in section 4:

> Every adult who is capable of giving or refusing consent to health care has
>
> a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even in the refusal will result in death,
> b) the right to select a particular form of available health care on any grounds, including moral or religious grounds,
> c) the right to revoke consent,
> d) the right to expect that a decision to give, refuse or revoke consent will be respected, and
> e) the right to be involved to the greatest degree possible in all case planning and decision making.

BC's legislation that allows for proxy directives is called the *Representation Agreement Act* (hereinafter referred to as the *RAA*) and came into force in 2000. The *RAA,* which was part of a larger package of legislation dealing with guardianship and assisted decision-making reform, had an interesting journey into passage. The history leading up to the current state of the law is quite complex, spanning a number of years and much discussion between interested parties. Due to its complexity, a full description of the history is better left to others and in any event, is beyond the scope of this project.

The purpose of the *RAA*, according to s. 2, is to provide a mechanism allowing adults to arrange in advance how, when and by whom, decisions about their health care, personal care or financial affairs or about other matters will be made if they become incapable of making decisions independently and to avoid the need for the court to appoint someone to help adults make decisions when they are no longer capable of doing so. Section 3 states that every adult is presumed to be capable until proven otherwise.

Under the *RAA*, one can have an agreement under s. 7, in which one appoints a representative to make decisions on their behalf to deal with such things as personal care, routine financial affairs, major and minor health care and obtaining legal services for certain proceedings. Section 7 does not include making decisions related to refusing life-supporting care or treatment. It is argued that there is minimal risk to an adult if their authorized representative fails to comply with their duties under s. 7 and what risk there is can be reduced with the appointment of a monitor to oversee the representative's actions (Gordon, 2005). Section 8 sets out the test of incapability, identifying that an adult can make a s. 7 agreement even if incapable of making a contract or managing his or her health care, personal care, legal matters, financial affairs, business or assets.

In order to authorize a representative to make decisions related to refusing life-supporting care or treatment, one must enact an agreement under s. 9 of the *RAA*. The types of provisions contained in s. 9(1) encompass those contained within pre-planning documents, such as living wills, advance medical directives and health care proxies, which although popular have not had a clear statutory or common law foundation (Gordon, 2005). Section 10 sets out the test of incapability for s. 9 agreements, stating that an adult may authorize a representative to do any or all of the things referred to in s. 9 unless the adult is incapable of understanding the nature of the authority and the effect of giving it to the representative. It is a more stringent test than that set out in s. 8 because these types of decisions are more controversial and complex (Gordon, 2005). A person must consult with a lawyer in order to enact a s. 9 representation agreement. The lawyer must sign a consultation certificate, stating that the lawyer saw the adult, explained the provisions of the agreement and the adult appeared to understand the authority and effect that was given to the representative. The consultation requirement makes implementing an agreement more costly and more of an effort than entering into a s. 7 agreement. However, if an appointed representative fails to carry out his/her duties, the risk of harm to the adult is much greater under a s. 9 agreement, thus the need for a higher standard (Gordon, 2005).

The duties of a representative are set out in Section 16 of the *RAA*. Section 16(2) says a representative must consult, to the extent reasonable, with the adult to determine his or her current wishes and comply with those wishes if it is reasonable to do so. Section 16(2) does not apply if a representative is acting within the authority given to him or her under s. 9 and the representation agreement provides that in exercising that authority the representative need only comply with instructions or wishes the adult made while capable. The *RAA* also provides that if the current wishes of an adult cannot be determined or it is not reasonable to comply with those wishes, the representative must comply with any instructions or wishes the adult expressed while capable. If the adult did not express any instructions or wishes, the representative must act on the basis of the adult's known beliefs and values or in the adult's best interest, if beliefs and values are not known. A representative can make application to the Supreme Court of British Columbia to be exempt from the duty to comply with any instructions or wishes the adult made while still capable but may not delegate any authority given under the representation agreement, except with regard to investment matters.

Section 12 of the *Health Care (Consent) and Care Facility (Admission) Act* (hereinafter referred to as the *HCC&CFA Act*) allows for pre-expressed wishes to be respected if at all possible in emergency situations (Gordon, 2005). Section 12.1 of the *HCC&CFA Act* states that a health care provider must not provide emergency or urgent care if they have reasonable grounds to believe that the person, while capable and having attained the age of majority, expressed an instruction or wish to refuse consent to that specific kind of health care. Section 19(1) of the *HCC&CFA Act* states that a temporary substitute decision-maker, who is someone appointed under s. 16 of the *HCC&CFA Act* to consent to major or minor health care of an incapable adult, must comply with any instructions or wishes the adult expressed while still capable. Other than these references to pre-expressed wishes in the above-mentioned *Acts,* instructional directives, such as a written advance directive do not have standing in British Columbia law as of this date.

2.5 Purposes and Research Questions of the study

There is not a great amount of research on the use of either instructional or proxy directives in Canada. There has been no research conducted about the characteristics, motivations and experiences of users of representation agreements in British Columbia, so it is difficult to say whether or not the findings from the United States and Canada are applicable to this province. There are greatly divergent opinions as to whether advance directives, regardless of their form, are effective tools for ensuring people's treatment wishes are followed. Therefore, this is an important area of study.

The purpose of this study was to determine what types of individuals are entering into representation agreements in British Columbia and to explore motivating factors for doing so. If one is to successfully argue that the United States experience with both instructional and proxy directives, i.e. limited usefulness, will be repeated if British Columbia proceeds along the same road, concrete findings are needed. If representation agreements, currently the only legally recognized form of proxy directives, are meeting the needs of only a limited subsection of society, then this is important to know as well, so efforts can be directed to implementing tools that will be useful to wider groups of people.

2.5.1 Research Question 1

Do individuals who enter into representation agreements have specific socio-demographic and personality characteristics? Are they predominantly white, upper-middle class, highly educated women with a high need for control as reflected in their scores on a standard locus of control measure?

Rationale: Research from the United States has consistently found these specific socio-demographic characteristics to be associated with a higher likelihood of entering into either instructional or proxy directives. Studies from the United States suggest a link between having either an instructional or proxy advance directive and internal locus of control.

2.5.2 Research Question 2

Is there a specific reason behind why a person has entered into a representation agreement?

Rationale: S. 16 of the *HCC&CFA Act* sets out a hierarchical list of people who are able to make health care decisions on behalf of someone else, on a temporary basis. The list starts with one's spouse and continues throughout the family. Therefore, if something were to happen to a person, and they had not appointed a representative, health care providers would have to consult with the prescribed people in that list prior to making any treatment decisions. If one were content to rely on the people in that list to make decisions on their behalf at a time of incapacity, they could rely on that legislation. However, a temporary decision maker's authority only lasts for 21 days and there are limitations placed on the authority to refuse consent to the provision of life supporting treatment (Gordon, 2005). The authority granted under s. 9 of the *RAA* is greater in scope than that of a temporary decision-maker.

It takes some effort and expense to enter into a representation agreement, under s. 9 of the *RAA*. Given the evidence that shows that older adults are generally supportive of advance directives yet relatively unlikely to enter into them, something significant must make people take the extra step to actually implement an agreement. That is, people with a representation agreement must have some reason why they are not satisfied to rely on a spouse and family members to make decisions for them in the event of incapacity or why they think they must formalize this arrangement. The most obvious explanation is that there is either a situation where there is family discord or distrust or no close family upon which to rely, but it may be related to the temporary nature of and limitations on the authority to make health care decisions without being formally appointed as a representative.

2.5.3 Research Question 3

How much discussion occurs between adults and their representatives as to what the adult's preferences for treatment are?

Rationale: There is evidence from the United States that there is a lack of discussion between patients and their proxies, so the expectation would be that the same is true of adults and their representatives in British Columbia.

2.5.4 Research Question 4

Do representatives encounter difficulties with respect to health care providers accepting the treatment decisions they make on behalf of the adult?

Rationale: The evidence from the literature indicates there may be difficulties ensuring health care providers follow a patient's previously stated wishes or the wishes of a patient's family and that proxy's decisions may not be readily accepted. The provisions of the *Health Care (Consent) and Care Facility (Admission) Act* give a certain amount of discretion for healthcare providers to override a representative's decision, under specific circumstances.

2.5.5 Research Question 5

Do people entering into representation agreements have some type of additional written document clearly setting out their treatment preferences in order to help guide their representative?

Rationale: Given the assumption that people entering representation agreements are highly motivated individuals with a tendency toward internal locus of control, an individual will want to ensure that their treatment preferences and wishes are clearly set out in order to avoid confusion and to help guide their representative at a time when they are not able to voice their preferences. People who enter into representation agreements will demonstrate a preference for their wishes to be acted on as set out, rather than allowing for much decision-making leeway on the part of their proxy. Setting out one's wishes may also be the individual's way of relieving the representative of any burden that may be associated with making treatment decisions.

CHAPTER 3: METHOD

3.1 Overview of the Research Design

As indicated previously, there are two types of representation agreements: s. 7 and s. 9. This study focused exclusively on persons involved in s. 9 agreements. Three groups of people constituted the sample: 48 capable representation agreement holders (CRAHs), 38 representatives of capable representation agreement holders (RCRAHs) and 7 representatives of incapable representation agreement holders (RIRAHs).

By interviewing a sample of CRAHs, the study attempted to gain a perspective on motivating factors behind their decision to enter into a representation agreement as well as their thoughts on the role their representative should play if ever those individuals had to make decisions on the CRAHs behalf. A sample of individuals who have been appointed as representatives was also included in the study in order to obtain their perspective on the process and what they saw their roles and responsibilities to the adult as being.

3.2 Participant Identification and Recruitment

Given that the number of people who have entered into any kind of advance directive was thought to be small, it was anticipated that obtaining an adequate sample would be challenging. Therefore, the assistance of the Representation Agreement Resource Centre (RARC) was enlisted. The Centre helps individuals develop representation agreement and maintains a database of the names and addresses of persons who have received information and/or assistance from the Centre and have entered into s.

9 agreements. The RARC advised that their database contained roughly 600 names, as of August 2007, when the study was initiated.

The RARC was asked to send a letter to everyone in the database. This letter, which was on the organization's letterhead, set out the nature of the study, and provided information as to why, from their perspective, they felt participation in the study was important. A separate letter from the researcher was enclosed, outlining the purposes of the research, the nature of the questions that would be asked, the time commitment required of those who chose to participate and contact information for the researcher. To maximize the number of respondents, no eligibility requirements were specified. The letter said only that persons of any age who had entered into a s. 9 agreement and were still capable of making decisions on their own or, who had been appointed as a representative of either a capable or an incapable representation agreement holder were invited to participate. In order to manage respondents in a timely manner, letters were sent out in batches of 200, with the first batch being sent out in the middle of October 2007, a second batch in the middle of November and the last 200 in January 2008. In order to ensure confidentiality, the researcher prepared envelopes containing the letter of introduction from the RARC and the letter of invitation from the researcher. The envelopes were then addressed and mailed by RARC staff. Copies of the recruitment material can be found in Appendix 1.

Since not all people who enter into representation agreements have enlisted the help of the RARC, the assistance of two lawyers who work in this area of the law was sought as well. Lawyer A, practicing in Vancouver, agreed to forward letters of invitation to participate in the study to 39 of his clients that had entered into s.9

representation agreements. Lawyer B, practicing in Richmond, also agreed to forward letters of invitation to his clients. The same procedure used to mail out letters to RARC clients was followed to ensure the lawyers' client's identities were protected.

Recruiting letters were sent to the address of the person who entered the agreement and not to their representatives, unless the representative had also completed a representation agreement, as the RARC does not keep track of contact information of a person's representative. For the purposes of a possible sub study designed to test concordance between CRAHs and their representatives, CRAHs were asked during the interview if their representative would be willing to participate in the study and if so, to pass along the researcher's contact information to their representative in the hope of recruiting a sizeable number of CRAH/RCRAH dyads.

3.3 Procedure

After the letters of invitation to participate were sent out, the researcher received phone calls and e-mail from 110 people expressing a willingness to participate. The researcher responded, typically within one day, and eligibility to participate was determined i.e. did the person have a representation agreement under s. 9 of the *Act* or were they a representative of a capable or incapable adult. One individual had a s. 7 agreement and was deemed ineligible. The researcher was unable to make contact or set up interviews with 14 persons. Interviews were set up with the remaining 95, for times based on the parties' mutual convenience. In order to ensure that no one was excluded from participating due to geographic location, the option of conducting the interview by telephone was offered. The vast majority (n=88) chose this option; only seven interviews were conducted in person. By conducting interviews by telephone, participants from the

British Columbia Interior, Vancouver Island and Fraser Valley as well as the Lower Mainland were able to participate in the study. The final sample consisted of 93 individuals as one CRAH who was interviewed later withdrew from the study and another was the alternate representative of a CRAH whose main representative was also interviewed.

The interviews took place over a seven-month period, from the end of August 2007 to February 2008. Informed consent was obtained by having the participant read the informed consent form and sign it, if the interview was conducted in person, or in the case of those interviewed by telephone, by reading the informed consent form to the participant over the telephone and obtaining verbal consent. Participants were then asked if they would like to receive a copy of the informed consent form by email, and if it was requested, a copy was sent. A copy of the informed consent form can be found in Appendix 2.

3.4 Content and Design of questionnaire

The researcher developed separate interview guides for each of the three groups of participants: CRAHs, RCRAHs and RIRAHs. All were asked the same questions concerning socio-demographic and health characteristics. These included: age, gender, educational attainment, country of origin, immigration status, marital status, religious affiliation, number of children, geographic proximity of children, relationship with children, common health problems and income. The health problems question was modeled on one used in two Statistics Canada reports: S*eniors: A Diverse Group Aging Well* (Lindsay, 1999) and *Seniors in Canada* (Statistics Canada, 2001). Both of these reports describe common chronic health problems of seniors as well as leading causes of death among seniors.

The question about marital status used the same categories as surveys by Statistics Canada. The question about income used the income categories found in the Statistics Canada publication entitled *Portrait of Seniors in Canada, 2006* (Turcotte and Schellenberg (2007). The question related to religion draws on the findings of Clark and Schellenberg (2006). Locus of control was measured by administering Rotter's (1966) Locus of Control scale, which is a 29 item, forced choice test that includes 6 filler items, intended to make the purpose of the test more ambiguous. The score a person receives on the scale is the total number of external control choices. The scale items deal with the subjects' belief about the nature of the world and is considered to be a measure of a generalized expectancy, which may correlate with the value a subject places on internal control but none of the items directly addresses the preference for internal or external control (Rotter, 1966). The scale has been tested for consistency and reliability and appears to be relatively stable and consistent, with test-retest correlations of .55 and .72 for two samples of students (Rotter, 1966). Harrow and Ferrante (1969) used Rotter's scale on a group of hospitalized psychiatric patients and reported a test-retest reliability of .75 (df = 86) over a six-week interval. The scale has been shown to have construct validity in laboratory and field situations (Strickland & Haley, 1980).

The questions asked of each of the three groups concerning representation agreements were somewhat different. The focus in the case of the CRAHs was on their motivations in entering into the agreement and their expectations of their representatives. For the RCRAHs, the focus was on their understanding of what the person they represented expected of them should they ever have to make treatment decisions and how they would proceed in the circumstances. The focus for the RIRAHs group was on their experiences with actually making decisions on the incapable adults' behalf. The questionnaire was pilot tested on two people very knowledgeable about representation agreements (one a volunteer at RARC and the other a RARC board member) and no significant potential problems were identified with the way the questions were worded. It is recognized however, that there could be problems with the reliability and validity of these questions, which in turn may affect how much weight can be placed on the findings. Caution should therefore be used in interpretation of results. The interview guides used for all three groups can be found in Appendix 3.

3.5 The Sample

Of the 639 people who received letters of invitation, 48 adults with agreements, 38 representatives of capable adults and 7 representatives of incapable adults participated in the study. Of the 48 CRAHs and 38 RCRAHs, 13 were dyads. The remainder were CRAHs and RCRAHs who were not connected to each other. As indicated previously, of the 93 people interviewed, only two responded as a result of the letters of invitation sent by lawyers.

When the CRAHs (n=48) were asked how they had found out about the study, 97.9% reported receiving a letter of invitation from the RARC; 2.1% had received a letter from a lawyer. When RCRAHs were asked the same question, 76.3% advised they had received a letter from the RARC, while 23.7% said the person they represent told them about the study. In 50% of the cases, the person with the agreement was the one who had first found out about representation agreements, in 34.2% of cases the representatives found out about them first. In 13.2% of cases both found out at the same time and 2.6% weren't sure who had heard about representation agreements first.

When asked how they had found out about the study, six of the seven RIRAHs (85.7%) reported that they had received a letter from the RARC; one person (14.3%) received a letter from a lawyer.

CHAPTER 4: RESULTS

Since research question 1 was concerned with the characteristics of individuals who entered into representation agreements (CRAHs), the presentation of findings begins (Section 4.1) with a description of their socio-demographic and health characteristics and their need for control. Data are disaggregated by gender in order to ascertain if there are significant differences between males who enter into representation agreements and the typically greater number of women who do so. Next in section 4.1, the socio-demographic and health characteristics of representatives are described and compared to the CRAHs.[1] Section 4.2 of the results describes how people found out about representation agreements; Section 4.3 describes motivating factors for entering into an agreement; 4.4 describes the relationship between the agreement holder and the representative and why that individual was chosen as a representative; 4.5 explores the discussions regarding treatment wishes the CRAHs and their representatives had; 4.6 examines discussions held between RAHs and their health-care providers as well as exploring the experiences of those representatives who have had to use their powers under a representation agreement; 4.7 describes written instructions that RAHs had with their representative; 4.8 sets out the expectations CRAHs have of how their representative is to make treatment decisions and the representatives interpretations of these expectations; and 4.9 summarizes the experiences of CRAHs and representatives and their feelings on being involved with representation agreements.

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[1] Socio-demographic and health characteristics of CRAHs and RAHs not interviewed but provided by their representatives are included in Appendixes 4 and 5 respectively, but are not discussed.

4.1 Characteristics of Study Participants

4.1.1 Capable representation agreement holders (CRAHs)

Table 1 shows the socio-demographic and health characteristics of CRAHs by gender. In answer to research question 1, there were more females than males among the CRAHs who volunteered and participated in the study: of the 48 adults who had agreements, 18 were male (37.5%) and 30 were female (62.5%). Men ranged in age from 48-95 (mean age=76 years, sd=10), while women ranged in age from 60-87 (mean age=71 years, sd=8). While the women were younger than the men, an independent t-test revealed no statistically significant difference between the mean age of men and women (t=1.76, df =46, p = .08).

There was a noticeable gender difference in marital status: 7 or 23.3% of the women reported that they were widows. Of the women who were widows, one had been widowed less than 5 years, four had been widowed 5-10 years and two had been widowed 11-15 years. In contrast, none of the men in the sample were widowed and the men were more likely than the women to be married (61.1% vs. 33.3% married). However, the observed gender difference in marital status was not statistically significant. ($\chi^2 = 6.25$, df = 3, p = .10).

Overall, the group was well-educated, with 60% of the women and 55.5% of the men having graduated from university with either an undergraduate or post-graduate degree, or having taken some post-graduate courses. Of the 14 people with post-graduate degrees, five hold PhDs, four MAs, one an MBA, one an MSc, two hold an MSW and one a DDS. Of those holding either an undergraduate or graduate degree (n=27), the highest concentrations were nursing (n=5) and education (n=7). Slightly more men than women held graduate degrees, with more men having a PhD than women but gender differences in education were not significant.

Chi-square analysis did not show any statistically significant differences between the gender groups as to their place of origin. More than half (62.5%) of the sample had been born in Canada, 12.5% were born in England and 6.2% were born in Germany. Slightly more men than women had been born in Canada. The rest of the sample originated from other parts of Europe, with the exception of one person from Panama and one person from Jamaica. Of those not born in Canada, 12.5% had been in Canada for 35-45 years, 14.6% for 46-55 years and 8.3% for 56 years or more. Although men and women differed in terms of the length of time they had been in Canada, they had all been in Canada for at least 35 years.

The group was fairly evenly split in their level of religiousity with 45.8% reporting some religious affiliation and 54.2% saying they did not have an affiliation with a religion. Of those reporting a religious affiliation, 44.4% were men and 46.7% were women. When asked about their level of activity within their religion, 19.0% of the group said they were extremely active in their religion; 28.6% said they were very active and 52.4% rated their activity as somewhat to not at all active. Chi-square analyses did not show any statistically significant differences between men and women on religiousity, religious affiliation or activity in their religion.

Most of the sample (81.2%) had natural children with slightly more women than men having children. Men were more likely than women to have step-children or to have natural and step-children. Slightly more than one-third of the group (38.5%) had at least one child living within 60 minutes car travel with women being more likely than men to have no children within 60 minutes car travel. When asked the frequency with which they spoke to at least one child, 15.4% of the sample spoke with at least one child on a daily basis, 20.5% spoke once a week, 20.5% spoke several times a week and 30.8% spoke several times a month. Men were more likely than women to report speaking with at least one child once a week or several times a month, but chi-square analysis did not reveal any statistically significant differences. Relationships with children were rated as excellent by 25.6% of the sample and 46.2% rated them as very good/good. Women were slightly more likely than men to report that their relationship with their children was excellent. No statistically significant differences between men and women on any of the questions regarding their children were uncovered by chi-square analyses.

The sample was relatively well off financially, with 32.6% having a gross household annual income of $40,000-59,999 and 37.0% having an income of over $60,000. Slightly more women than men had incomes under $30,000 (14.3% and 5.6% respectively). Chi square analysis did not reveal any significant differences between men and women on levels of income.

Overall, the health of the sample was good with 16.7% having no chronic health conditions, 33.3% reported having one, 25% had two and 25.0% had three or more. Women had more chronic conditions than the men with 26.6% of women reporting three or more chronic conditions compared to 17.6% of men. The most common chronic conditions were high blood pressure, heart disease and arthritis. Chi square analysis performed on all chronic conditions as well as the total number of conditions did not reveal any statistically significant differences between the two groups.

Table 1: Socio-Demographic and Health Characteristics of Capable Representation Agreement Holders (CRAHs), by Gender* **

Characteristic	Male (n=18)		Female (n=30)		Total %
	n	%	n	%	
Age					
48-64	1	5.6	8	26.7	18.8
65-74	6	33.3	13	43.3	39.6
75-84	9	50.0	6	20.0	31.2
85+	2	11.1	3	10.0	10.4
Marital status					
Married	11	61.1	10	33.3	43.8
Divorced/separated	5	27.8	9	30.0	29.2
Widowed	0	0	7	23.3	14.3
Never married	2	11.1	4	13.3	12.5
Education					
Less than high school	1	5.6	2	6.7	6.2
Some high school	1	5.6	2	6.7	6.2
High school graduation	2	11.1	2	6.7	8.3
Some college or university	4	22.2	6	20.0	20.8
University graduation	4	22.2	9	30.0	27.1
Some post-graduate education	0	0	1	3.3	2.1
Graduate degree	6	33.3	8	26.7	29.2
Type of degree					
BA	1	10.0	4	25.0	19.2
BSc	1	10.0	4	25.0	19.2
BASc	1	10.0	0	0	3.8
MA	2	20.0	2	12.5	15.4
MSc	1	10.0	0	0	3.8
MSW	0	0	2	12.5	7.7
MBA	0	0	1	6.2	3.8
PhD	3	30.0	2	12.5	19.2
DDS	1	10.0	0	0	3.8
Other	0	0	1	6.2	3.8
Degree Concentration					
Engineering	1	11.1	0	0	3.7
Oral Surgery	1	11.1	0	0	3.7
Sociology	1	11.1	0	0	3.7
Education	3	33.3	4	22.2	25.9
Agriculture	1	11.1	0	0	3.7
Nuclear Physics	1	11.1	0	0	3.7
Nursing	1	0	5	27.8	18.5
Theology	0	0	1	11.1	3.7
Business	0	0	2	22.2	7.4
Political Science	0	0	1	11.1	3.7
Home Economics	0	0	2	22.2	7.4
Social Work	0	0	2	22.2	7.4
Physical Education	0	0	1	11.1	3.7
Not specified	0	11.1	0	0	3.7

Characteristic	Male (n=18)		Female (n=30)		Total %
	n	%	n	%	
Country of Origin					
Canada	14	77.8	16	53.3	62.5
England	1	5.6	5	16.7	12.5
Germany	1	5.6	2	6.7	6.2
Scotland	1	5.6	0	0	2.1
Slovakia	1	5.6	0	0	2.1
Northern Ireland	0	0	1	3.3	2.1
Italy	0	0	1	3.3	2.1
Netherlands	0	0	1	3.3	2.1
Czechslovakia	0	0	1	3.3	2.1
Panama	0	0	1	3.3	2.1
Jamaica	0	0	1	3.3	2.1
USA	0	0	1	3.3	2.1
Length of time in Canada (yrs)					
35-45	1	25.0	6	42.9	12.5
46-55	2	50.0	5	35.7	14.6
56-65	0	0	3	21.4	6.3
66-75	1	25.0	0	0	2.1
Religiousity					
Have a religious affiliation	8	44.4	14	46.7	45.8
Religion affiliated with					
Catholic	4	50.0	0	0	18.2
Anglican	1	12.5	4	28.6	22.7
Christian	1	12.5	2	14.3	13.6
Protestant	1	12.5	4	28.6	22.7
Jewish	1	12.5	0	0	4.5
Baptist	0	0	1	7.1	4.5
Unitarian	0	0	1	7.1	4.5
United	0	0	2	14.3	9.1
Level of activity					
Extremely active	1	12.5	3	23.1	19.0
Very active	2	25.0	4	30.8	28.6
Somewhat active	1	12.5	1	7.7	9.5
Not very active	3	37.5	0	0	14.3
Not at all active	1	12.5	5	38.5	28.6

Characteristic	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Children					
Have children	14	77.8	25	83.3	81.2
How many					
1	0	0	4	16.0	10.3
2	6	42.9	10	40.0	41.0
3	2	14.3	6	24.0	20.5
4	5	35.7	4	16.0	23.1
5	1	7.1	1	4.0	5.1
Natural	12	85.7	24	96.0	92.3
Step	1	7.1	0	0	2.6
Both	1	7.1	4	4.0	5.1
# within 60 minutes car travel					
0	1	7.1	9	36.0	25.6
1	6	42.9	9	36.0	38.5
2	3	21.4	4	16.0	17.9
3	3	21.4	2	8.0	12.8
4	1	7.1	1	4.0	5.1
Frequency of communication					
Daily	2	14.3	4	16.0	15.4
Once a week	4	28.6	4	16.0	20.5
Once every 2 weeks	0	0	1	4.0	2.6
Several times a week	3	21.4	5	20.0	20.5
Once a month	0	0	3	12.0	7.7
Several times a month	5	35.7	3	28.0	30.8
Several times a year	0	0	7	4.0	2.6
Strength of relationship					
Excellent	3	21.4	7	28.0	25.6
Very good/Good	8	57.1	10	40.0	46.2
Good/Fairly Good	3	21.4	6	24.0	23.1
Distant/Strained	0	0	2	8.0	5.1
Income					
Less than $20,000	0	0	3	10.7	6.5
$20,001-$29,999	1	5.6	1	3.6	4.3
$30,000-$39,999	3	16.7	4	14.3	15.2
$40,000-$59,999	6	33.3	9	32.1	32.6
$60,000+	8	44.4	9	32.1	37.0

Characteristic	Male (n=18) n	 %	Female (n=30) n	 %	Total %
Health problems suffered from					
Cancer	0	0	2	6.7	4.2
Heart disease	5	27.8	7	23.3	25.0
High blood pressure	7	38.9	12	40.0	39.6
Breathing problems	3	16.7	3	10.0	12.5
Cerebrovascular disease	2	11.1	3	10.0	10.4
Congestive heart failure	0	0	1	3.3	2.1
Arthritis	6	33.3	13	43.3	39.6
Diabetes	3	16.7	3	10.0	12.5
Neurological disease	2	11.1	1	3.3	6.2
Alzheimer's or other dementia	1	5.6	0	0	2.1
Depression	2	11.1	6	20.0	16.7
# of chronic conditions					
0	5	27.8	3	10.0	16.7
1	3	16.7	13	43.3	33.3
2	6	33.3	6	20.0	25.0
3	1	5.6	3	10.0	8.3
4	2	11.1	3	10.0	10.4
5	0	0	1	3.3	2.1
6	1	5.6	1	3.3	4.2

* Multiple responses permitted when reporting health problems

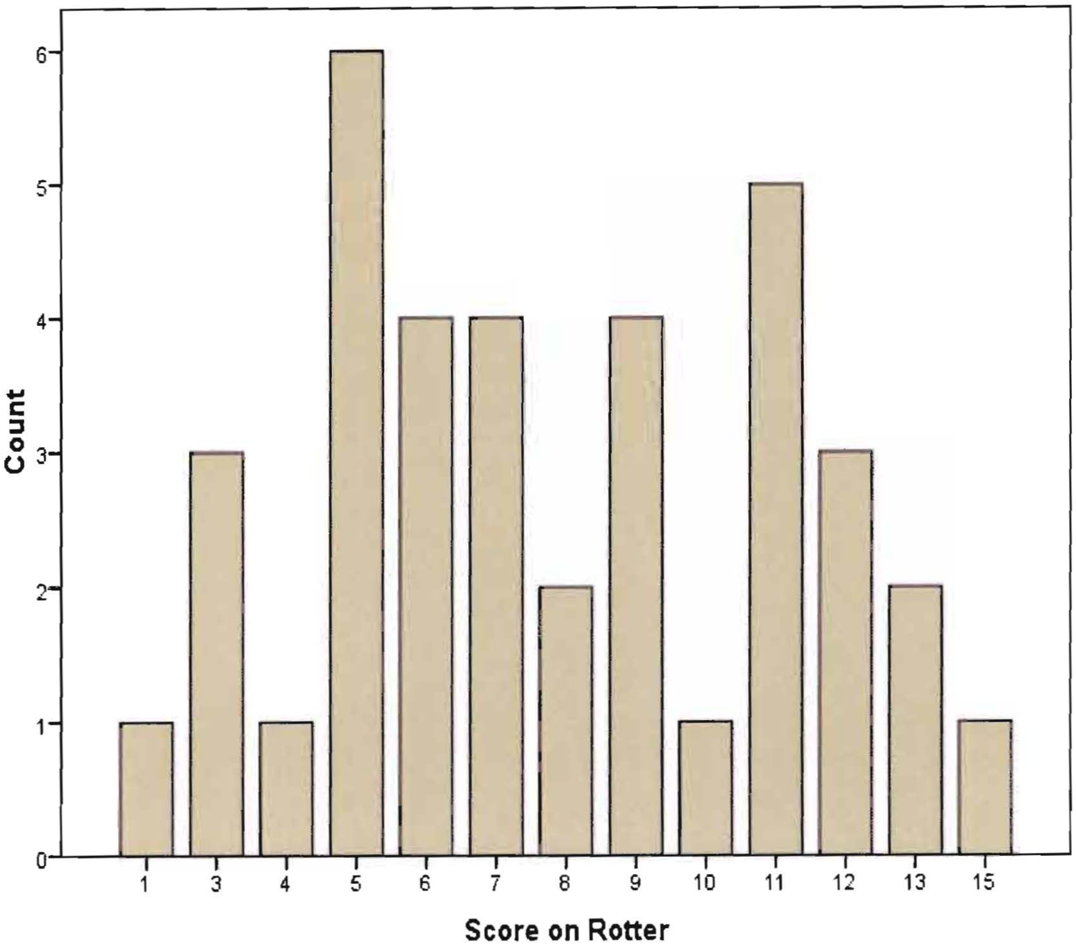
**Not all people answered all questions

4.1.1.1 Locus of Control

It was thought that women with representation agreements would demonstrate a high need for control. If a person scores more towards the internal (i.e. low) end of the spectrum on Rotter's Locus of Control scale, this can indicate that they have a higher level of internal control. This means that they are more inclined to believe that events are contingent upon their own behaviour or their own relatively permanent characteristics (Rotter, 1966). That is, they believe they can control the outcomes of situations they go through. Those exhibiting a belief in external control believe that it is not their own actions but the actions of others or unpredictable events that affect what happens to them (Rotter, 1966). As Rotter (1975) points out, one's score on the scale does not put people into an internal or external typology, nor was it designed to be an instrument that would allow for high levels of predictability in a particular, specific situation. It is an indicator, which must take other situational factors into account and was intended to allow for a low degree of predictability of behaviour across a wide range of situations.

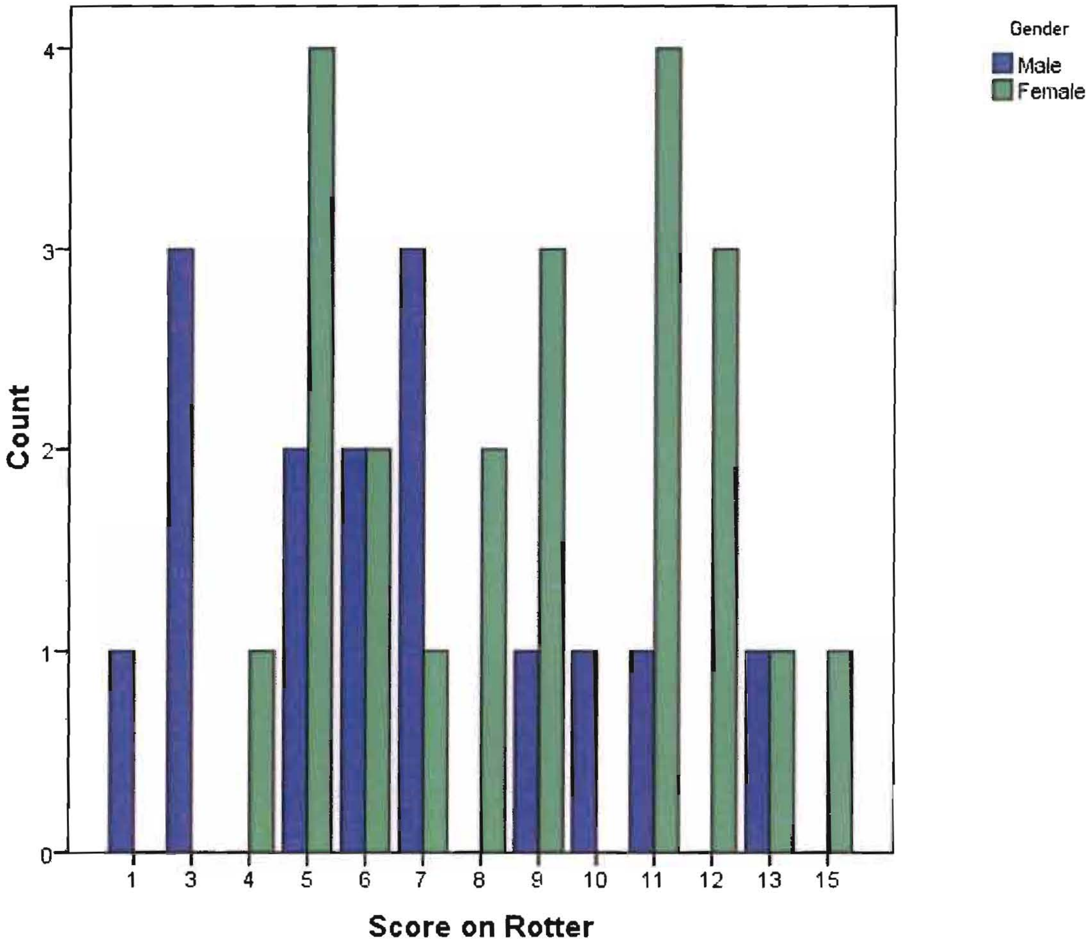
At the end of the interview, the Rotter scale was administered to all CRAHs. Of the 48, 37 completed all items. Of those, the mean score was 8 (s.d. = 3) out of a possible 23. The higher the score, the more external a person is, so a score of 8 is interpreted as demonstrating that the group tended toward internal control. Figure 1 shows the frequency distribution. As can be seen, it is bimodal.

Figure 1: Bar Graph of Scores on Rotter's Locus of Control Scale



An independent samples t-test was performed to compare scores on the Rotter scale for males and females. There was a significant difference between the mean score for males (mean score=6.40, s.d. 3.31) and females (mean score=8.82, s.d. 3.14); t=-2.25, df=35, p=.03. Some 12.6% of variance on the sample's score on the Rotter scale is explained by gender. Figure 2 shows the scores by gender.

Figure 2: Bar Graph of Scores on Rotter's Locus of Control Scale, by Gender



To further investigate locus of control, participants were asked to rate on a scale of 1 to 5, with 1 being not at all important and 5 being extremely important, how important it was for them to be involved in decisions about their health care. In total, 89.6% said it was extremely important, 6.2% said it was very important and 4.2% said it was somewhat important. Table 2 shows the response disaggregated by gender. Somewhat surprising given the direction of the Rotter scores, whereas 77.8% of men (n=14) said it was extremely important and 16.7% very important, 96.7% (n=29) of women rated it as extremely important. However, chi square analysis did not determine this to be a statistically significant difference.

Table 2: Importance of Being Involved in Health-Care Decision-Making, by Gender

Importance Scale	**Men (n=18)**		**Women (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Extremely Important	14	77.8	29	93.3	89.6
Very important	3	16.7	0	0	6.2
Somewhat important	1	5.6	1	3.3	4.2

Participants were then asked if completing a representation agreement made them feel like they had achieved a sense of control over their future. Of the total sample, 89.6% said it had. However, men were slightly less likely than women to say so (83.3% vs. 93.3% respectively). When asked in what way it had done so, 38.6% of the sample responded that any decisions to be made would be done by trusted people they had chosen; 31.8% said it made their wishes known and made it easier for others; 18.2% said it gave them peace of mind and was like an insurance policy which one may not ever need, but is glad to have if the need arises; 6.8% felt completing an agreement would prevent receiving treatments against their wishes; 2.3% were skeptical and hoped having an agreement would help them control their future, but they weren't sure it would; 2.3% wanted the agreement to stop any problems before they started. Table 3 shows the responses by gender. Chi square analysis failed to reveal any statistically significant gender differences.

Table 3: Reasons Why Completing a Representation Agreement was Associated with Sense of Control, by Gender

Reason	Male (n=16)*		Female (n=18)*		Total (n=44)*	
	n	%	n	%	N	%
Decisions made by people chosen by CRAH	4	25.0	13	46.4	17	38.6
Made wishes known/makes it easier for others	5	31.2	9	32.1	14	31.8
Peace of mind/insurance policy	4	25.0	4	14.3	8	18.2
Prevent treatment against wishes	2	12.5	1	3.6	3	6.8
Not sure it will but hope it does	0	0	1	3.6	1	2.3
Stop problems before they start	1	6.2	0	0	1	2.3

* 4 people (2 male, 2 female) missing from analysis

4.1.1.2 Incapable Representation Agreement Holders

Representatives of representation agreement holders no longer capable (RIRAHs) were asked to rate how they thought their representation agreement holder (RAHs) had felt about their involvement in making health care decisions, prior to their incapacity. A majority (66.7%) felt that the RAH had thought it was extremely important to be involved in making decisions about their health care and 33.3% felt the RAH had thought it very important.

An even stronger majority (83.3%) of the RIRAHs thought their RAH had felt he or she had control over his/her health and subsequent health care decision-making. When asked if they thought their RAH had felt their health or treatment outcomes were more in the hands of others, such as health-care providers rather than their own control, as shown in Table 4, 33.3% indicated their RAH thought he or she was in control; 33.3% thought their RAH felt control was in the hands of others; 16.7% thought their RAH felt in control until they started to get sicker, at which point they relied more on medical professionals; and 16.7% weren't sure.

Table 4: Who Was In Control of RAH's Health or Treatment Outcomes, as Reported by RIRAHs*

Whose Control	**Total %**	
	n	**%**
RAHs control	2	33.3
Other's control	2	33.3
Not sure	1	16.7
RAHs control until illness worsened, then relied more on medical profession	1	16.7

* 1 person missing from analysis

RIRAHs were then asked if they felt their RAH's health and treatment outcomes were more in the representative's control or the control of others, such as health-care providers to which 50% said they felt they were in control; 33.3% said others were in control; and 16.7% said it was difficult to say. In explaining why they felt as they did, 25% of the representatives said they felt the health-care providers were the experts and the representative was only there to provide input, whereas 75% said they felt the doctors were more in control until the point at which the RIRAHs stepped in and told the doctor to stop treating the RAH.

In summary, in answer to research question 1, the majority of the CRAHs in the sample were highly educated women; 58.4% having at least one university degree. They also fell within the upper-middle class in terms of income, as 69.6% reported a household, gross income of $40,000 or greater per annum. Also as predicted, women showed a high need for control as demonstrated in their Rotter scale scores and in their responses to questions about the importance of being involved in health-care decision-making and their motivations for entering into a representation agreement. While male and female CRAHs were similar in terms of place of origin, level of education, religiousity, having children with whom they enjoy a good relationship and being financially well-off, the data also showed some interesting gender differences. These included a statistically significant difference in locus of control scores with men showing, on the Rotter scale, an even greater need for control than women did. Women were more likely than men to report feeling like they had a sense of control over their future because they had chosen who would make treatment decisions on their behalf, whereas men were more likely than women to report feeling in control because they saw their representation agreement as an insurance policy, which gave them peace of mind and they felt having an agreement would stop unwanted treatments.

Data from the RIRAHs was interesting in suggesting that perceived and actual control may change as illness progresses.

4.1.2 Representative's interviewed

Two types of representatives were interviewed: 38 whose representation agreement holder (RAH) was competent and 7 whose RAH was not. The characteristics of the representatives of competent individuals are described first.

4.1.2.1 Representatives of Competent Agreement Holders (RCRAHs)

Table 5 shows the socio-demographic and health characteristics of the representatives that were interviewed. Of the 38 representatives of capable adults interviewed, 18 (47.4%) were male and 20 (52.6%) were female. They ranged in age from 36-84 (mean age = 65 years, sd=11). Just under half (18 or 47.4%) were less than 65 years of age; the remainder were seniors. Men ranged in age from 50-84 (mean age=67 years, sd = 9), while women ranged in age from 36-78 (mean age=62 years, sd=12). While on average the women were younger than the men, an independent t-test revealed no statistically significant age difference between men and women (t=1.24, df=36, p=.22). The majority (81.6%) of the sample was married, 5.3% were divorced or separated, and 13.2% have never married or were single and unlike the CRAH's group, no one was widowed. Although slightly more men than women were divorced or separated, there was no noticeable difference between men and women as to marital status.

This group of representatives was even more educated than the CRAHs with 68.5% having graduated from university. Men and women did not differ significantly on this characteristic. Graduate degrees were held by 8 (21.1%) of the sample, which was slightly less than the CRAHs or RIRAHs. Of the eight, five held MAs, two a MSc and one a PhD. Of those having either an undergraduate or graduate degree (n=24), six were in education, three were in sociology, two were in law and two were in nursing. Women were more likely than men to hold degrees in education, sociology or nursing, whereas men were more likely than women to hold law degrees.

Well over half (68.4%) of the sample was born in Canada with men being slightly more likely than women to have been born in Canada. Those not born in Canada immigrated from England, Germany, Scotland, USA and East Africa; 7.9% had been here for less than 35 years, the remainder had been here 35-65 years.

The sample was not strongly religious, with 81.6% of the sample reporting no affiliation with religion. [2] Men and women did not differ noticeably on religiousity. Of those reporting an affiliation with religion, women were more likely than men to report being Catholic or Presbyterian, whereas men were equally split between Anglican, Christian, United or Unitarian religions.

The representatives were relatively well-off, with 73% of the sample having an annual household gross income of over $60,000. Only 2.7% had an annual income under $30,000. Women were more likely than men to have an income below $30,000 and above $60,000 whereas men were more likely than women to have an income between $30,000-$39,999 or $40,000-$59,999. Chi-square analyses on all socio-demographic and health characteristics did not reveal any statistically significant differences between male and female RCRAHs.

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[2] Of the 15.8% who did report an affiliation, there was not one particular religion that was more popular than another. The other questions pertaining to socio-demographic characteristics that were asked of RAHs were not asked of the representatives.

Overall, the representatives were in good health. The most common health conditions were: high blood pressure, arthritis and heart disease. Men were more likely than women to report having cancer, heart disease, high blood pressure, cerebrovascular disease, neurological disorder or depression. Women were more likely than men to report having breathing problems and arthritis. None of the sample reported having Alzheimer's disease or other dementia. Only 13.1% of the sample reported having more than three chronic conditions; 28.9% reported having no chronic conditions. On average, women reported fewer chronic conditions than men (1.15 v 1.55).

Table 5: Socio-Demographic and Health Characteristics of Representatives (RCRAHs), by Gender* **

Characteristic	**Male (n=18)**		**Female (n=20)**		**Total %**
	n	**%**	**n**	**%**	
Age					
Less than 65	7	38.9	11	55.0	47.4
65-74	7	38.9	6	30.0	34.2
75-84	4	22.2	3	15.0	18.4
Marital status					
Married	14	77.8	17	85.0	81.6
Divorced/separated	2	11.1	0	0	5.3
Widowed	0	0	0	0	0
Never married	2	11.1	3	15.0	13.2

Characteristic	**Male (n=18)**		**Female (n=20)**		**Total %**
	n	**%**	**n**	**%**	
Education					
Some high school	0	0	2	10.0	5.3
High school graduation	1	5.6	2	10.0	7.9
Some college or university	4	22.2	3	15.0	18.4
University graduation	8	44.4	8	40.0	42.1
Some post-graduate education	1	5.6	1	5.0	5.3
Graduate degree	4	22.2	4	20.0	21.1
Type of degree					
BA	5	41.7	4	30.8	37.5
BSc	2	16.7	2	15.4	16.7
MA	3	25.0	2	15.4	20.8
PhD	1	8.3	0	0	4.2
MSc	0	0	2	15.4	4.2
BEd	0	0	2	15.4	8.3
PBD	0	0	1	7.7	4.2
BFA	1	8.3	0	0	4.2
Degree Concentration					
Engineering	1	10.0	0	0	4.5
Education	1	10.0	5	38.5	27.3
Architecture	1	10.0	0	0	4.5
Accounting	1	10.0	0	0	4.5
History	1	10.0	0	0	4.5
Law	2	20.0	0	0	9.1
Philosophy	1	10.0	0	0	4.5
Nursing	0	0	2	15.4	9.1
Sociology	1	0	2	15.4	13.6
Library Science	0	0	1	7.7	4.5
Public Health	0	0	1	7.7	4.5
Psychology	0	0	1	7.7	4.5
Math/Chemistry	0	0	1	7.7	4.5
Country of Origin					
Canada	14	77.8	12	60.0	68.4
England	1	5.6	3	15.0	10.5
Germany	1	5.6	0	0	2.6
Scotland	0	0	1	5.0	2.6
France	0	0	1	5.0	2.6
East Africa	1	5.6	0	0	2.6
USA	1	5.6	3	15.0	10.5
Years in Canada (yrs)					
Less than 35	1	20.0	2	28.6	25.0
35-45	3	60.0	2	28.6	41.7
46-55	0	0	3	42.9	25.0
56-65	1	20.0	0	0	8.3

Characteristic	**Male (n=18)**		**Female (n=20)**		**Total %**
	n	**%**	**n**	**%**	
Religiousity					
Have a religious affiliation	4	22.2	2	10.0	18.4
Religion affiliated with					
Catholic	0	0	2	66.7	28.6
Anglican	2	40.0	0	0	14.3
Christian	1	20.0	0	0	14.3
Presbyterian	0	0	1	33.3	14.3
Unitarian	1	20.0	0	0	14.3
United	1	20.0	0	0	14.3
Level of activity					
Extremely active	1	25.0	0	0	14.3
Very active	0	0	1	33.3	14.3
Somewhat active	2	11.1	2	66.7	57.1
Not very active	0	0	0	0	14.3
Not at all active	0	0	0	0	0
Income					
Less than $20,000	0	0	0	0	0
$20,001-$29,999	0	0	1	5.3	2.7
$30,000-$39,999	3	16.7	0	0	8.1
$40,000-$59,999	5	27.8	1	5.3	16.2
$60,000+	10	55.6	17	89.5	73.0
Health problems suffered from					
Cancer	3	16.7	0	0	7.9
Heart disease	5	27.8	1	5.0	15.8
High blood pressure	9	50.0	6	30.0	39.5
Breathing problems	1	5.6	2	10.0	7.9
Cerebrovascular disease	1	5.6	0	0	2.6
Congestive heart failure	0	0	0	0	0
Arthritis	4	22.2	7	35.0	28.9
Diabetes	2	11.1	2	10.0	10.5
Neurological disease	1	5.6	0	0	2.6
Alzheimer's or other dementia	0	0	0	0	0
Depression	2	11.1	3	15.0	13.2
# of chronic conditions					
0	4	22.2	7	35.0	28.9
1	7	38.9	4	20.0	28.9
2	4	22.2	7	35.0	28.9
3	2	11.1	2	10.0	10.5
5	1	5.6	0	0	2.6

* Multiple responses permitted when reporting health problems

**Not all people answered all questions

4.1.2.2 Representatives of incapable adults (RIRAHs)

Table 6 shows the socio-demographic and health characteristics of the representatives of incapable adults. Of the seven, three (43%) were male and four (57%) were female. They ranged in age from 63-84 (mean age=72 years, sd = 8). The majority (57.1%) were married, and 28.6% were widowed and had been for less than 5 years.

This group of representatives was even more educated than the RCRAH group with 57% holding a graduate degree, 29% an undergraduate degree and 14% some college or university. The majority (71.4%) had been born in Canada with the remainder coming from England and Scotland. Those not born in Canada had been here for 46-55 years.

This group was also not very religious, with 28.6% claiming an affiliation with a religion but rating their level of activity as somewhat active and not at all active. The sample also fell into the higher spectrum in terms of income with 14.3% having an annual, household gross income of $40,000-59,999 and 85.7% having an income of $60,000 or greater. On the whole, their health was good, with only 14.3% having cerebrovascular disease and 57.1% having arthritis. No other chronic conditions were reported.

Table 6: Socio-Demographic and Health Characteristics of Representatives of Incapable Adults (RIRAHs), by Gender*

Characteristic	Male (n=3)		Female (n=4)		Total %
	n	%	n	%	
Age					
Less than 65	0	0	1	25.0	14.3
65-74	2	66.7	2	50.0	71.9
75-84	1	33.3	1	25.0	28.9
85+	0	0	0	0	0

Characteristic	Male (n=3)		Female (n=4)		Total %
	n	%	n	%	
Marital status					
Married	3	100.0	1	25.0	57.1
Divorced/separated	0	0	0	0	0
Widowed	0	0	2	50.0	28.6
Never married	0	0	1	25.0	14.3
Education					
Some college or university	0	0	1	25.0	14.3
University graduation	0	0	2	50.0	28.6
Graduate degree	3	100.0	1	25.0	57.1
Type of degree					
BA	0	0	1	25.0	16.6
BSc	0	0	2	50.0	33.3
PhD	2	66.7	0	0	33.3
MBA	1	33.3	0	0	16.6
Degree Concentration					
Business	1	33.3	0	0	16.7
Mining/Geology	1	33.3	0	0	16.7
IS Management	1	33.3	0	0	16.7
Nursing	0	0	1	33.3	16.7
Dentistry	0	0	1	33.3	16.7
Philosophy	0	0	1	33.3	16.7
Country of Origin					
Canada	2	66.7	3	75.0	71.4
England	1	33.3	0	0	14.3
Scotland	0	0	1	25.0	14.3
Religiousity					
Have a religious affiliation	0	0	2	50.0	28.6
Religion affiliated with					
Catholic	0	0	1	50.0	50.0
Presbyterian	0	0	1	50.0	50.0
Level of activity					
Somewhat active	0	0	1	50.0	50.0
Not at all active	0	0	1	50.0	50.0
Income					
$40,000-$59,999	0	0	1	25.0	14.3
$60,000+	3	100.0	3	75.0	85.7
Health problems suffered from					
Cerebrovascular disease	1	33.3	0	0	14.3
Arthritis	1	33.3	3	75.0	57.1

Characteristic	**Male (n=3)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
# of chronic conditions					
0	2	66.7	1	25.0	42.9
1	0	0	3	75.0	42.9
2	1	33.3	0	0	14.3

* Multiple responses permitted when reporting health problems
**Not all people answered all questions

Table 7 compares the groups on specific socio-demographic characteristics. In summary, the majority of representatives, whether RCRAHs or RIRAHs tended to be married, born in Canada, have low levels of religiousity and incomes over $60,000. There were slightly more females than males in both groups. While both groups were highly educated, the RIRAHs had slightly higher levels of education with more holding a graduate degree, compared to the RCRAHs. The RCRAHs were slightly younger than RIRAHs although, surprisingly, they reported more chronic health conditions than RIRAHs. The representatives differed most from the CRAHs in gender, marital status and religiousity: the majority of CRAHs were women, and they were less likely to be married that the representatives. The CRAHs had higher levels of religiousity than either of the representative groups. Slightly fewer of the CRAHs had been born in Canada. While all the groups were highly educated, only 29.2% of CRAHs held a graduate degree making them slightly less educated than the RIRAHs but slightly more educated than RCRAHs.[3] Similarly, the CRAHs were in slightly better health than the RCRAHs.

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[3] CRAHs, RCRAHs and RIRAHs were compared to the general population of those aged 65+ in the province of BC on selected characteristics (See Appendix 6). The samples were representative of the population of seniors in BC except in terms of education and income, with the samples being more highly educated and having higher incomes.

Table 7: Comparison of Socio-Demographic Characteristics between CRAHs, RCRAHs and RIRAHs

Characteristic	CRAHs (n=48)		RCRAHs (n=38)		RIRAHs (n=7)	
	n	%	n	%	n	%
Married	21	43.8	31	81.6	4	57.1
Have religious affiliation	22	45.8	7	18.4	2	28.6
Born in Canada	30	62.5	26	68.4	5	71.4
University degree	13	27.1	16	42.1	2	28.6
Graduate degree	14	29.2	8	21.1	4	57.1
Income over $60,000	17	37.0	27	73.0	6	85.7
# of Chronic conditions						
0	8	16.7	11	28.9	3	42.9
1	16	33.3	11	28.9	3	42.9
2	12	25.0	11	28.9	1	14.3
3	4	8.3	4	10.5	0	0
Males	18	37.5	18	47.4	3	42.9
Females	30	62.5	20	52.6	4	57.1
Mean age	73	-	65	-	72	-

4.2 Sources of Information about Representation Agreements

Both the CRAHs and the representatives were asked when and where they had heard about representation agreements and what types of information or assistance they had received in completing an agreement.

4.2.1 Capable representation agreement holders

Of the 48 CRAHs interviewed, 11.1% had entered into their agreement in 2007, 33.3% in 2006, 28.9% in 2005, 15.6% in 2004 and 11.1% prior to 2004. This suggests a lag between the passage of the legislation in 2000 and the time at which people entered into their agreements, with numbers increasing markedly from 2005 onwards.

As shown in Table 8, the most common source of information among both men and women was from someone else. Senior centre presentations or newsletters were also an important source, with 19% of the sample citing this source. Health care providers and legal advisors were not reported as being important sources of information about representation agreements by any of the females, but financial advisors were by 10.4% of the sample. Other sources included doing research on their own, the topic being covered on the radio or television or seeing a pamphlet in the hospital. A small portion of the sample (8.3%) couldn't remember how they first heard about the agreements.

Table 8: CRAHs Sources of Information About Representation Agreements, by Gender*

Source of information	Males (n=18)		Females (n=30)		Total %
	n	%	n	%	
Health care providers	2	11.1	-	-	4.2
Legal advisor	1	5.6	-	-	2.1
Newspaper article	3	16.7	4	13.3	14.6
RARC website	-		1	3.3	2.1
Attend RARC presentation	2	11.1	3	10.0	10.4
Seniors centre presentation/newsletter	3	16.7	6	20.0	18.8
Support group	3	16.7	2	6.7	10.4
Retirement association	2	11.1	4	13.3	12.5
From someone else	3	16.7	9	30.0	25.0
Financial advisor	2	11.1	3	10.0	10.4
Can't remember	2	11.1	2	6.7	8.3
Topic in media	2	11.1	1	3.3	6.2
Doing research on their own	-	-	2	6.7	4.2
Have supported RA from beginning	-	-	1	3.3	2.1
Saw pamphlet in hospital	1	5.6	-	-	2.1

* Multiple responses permitted

In order to make an agreement, 44 (91.7%) of the CRAHS in the sample had sought information and/or assistance and of those, 93.8% sought it from the

Representation Agreement Resource Centre (RARC). Since the sample was recruited through letters sent out from the RARC to people in their database, this is hardly surprising. As shown in Table 9, the types of information and/or assistance received included handouts or written material or attending a presentation prior to attending the RARC legal clinic to complete their agreements and attending the clinic itself.[4]

Table 9: Types of Information Received by CRAHs from RARC, by Gender*

Types of information	**Males (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Handouts	16	88.9	27	90.0	89.6
Attend RARC presentation	12	66.7	11	36.7	47.9
RARC legal clinic	18	100.0	28	93.3	95.8

* Multiple responses permitted

4.2.2 RCRAHs

The representatives reported that only 2.6% of the persons they represented (RAHs) had found out about representation agreements through their health-care provider, 10.5% from a presentation put on by the RARC, 26.3% from their representative and 60.5% from another source. Of the other possible sources, 20.8% heard about representation agreements through work, 25.0% from their financial advisor, 20.8% from someone else, 8.3% through a seniors centre, 8.3% on the radio, 8.3% couldn't remember or didn't know, 4.2% from a retirement association meeting and 4.2% through research on the Internet.

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[4] One of the services offered by the RARC is a legal clinic, in which people can complete their agreements. A lawyer is on site to sign the agreements and answer questions. This service is provided at a much lower cost than if a person was to consult a lawyer independently. The information or assistance received from the RARC was rated by 97.8% of the sample as being extremely or very helpful and 90.6% were extremely or very satisfied with the information or assistance received from the legal clinic lawyer.

With respect to themselves, Table 10 shows that of the 38 representatives interviewed, 5.3% found out about representation agreements through their health-care provider, 5.3% through a RARC presentation, 50% through the person whom they represent and 42.1% through another source. As can be seen, the pattern was similar for both male and female RCRAHs.

Table 10: Source of information for RCRAHs, by Gender*

Source of information	**Male (n=18)**		**Female (n=20)**		**Total %**
	n	**%**	**n**	**%**	
Health Provider	1	5.6	1	5.0	5.3
RARC presentation	1	5.6	1	5.0	5.3
From CRAHs	8	44.4	11	55.0	50.0
Other source	8	44.4	8	40.0	21.1

*Multiple responses permitted

Table 11 shows other sources of information accessed by RCRAHs, which included: from someone else (33.3%), a support group (16.7%), a retirement association (11.1%) and at a meeting (11.1%). A small percentage (5.6%) could not remember how they found out about representation agreements. Women were slightly more likely than men to have found out about representation agreements from the person they represent and through support groups, a financial advisor or a seniors centre, whereas men were slightly more likely to find out about representation agreements at a meeting, from someone besides their RAH, through a retirement association or by doing research on their own.

Table 11: Other Sources of Information Accessed by RCRAHs, by Gender*

Other source of information	**Male (n=9)**		**Female (n=9)**		**Total %**
	n	**%**	**n**	**%**	
Meeting	2	22.2	-	-	11.1
From someone else	3	33.3	3	33.3	33.3
Retirement association	2	22.2	-	-	11.1
Support group	1	11.1	2	22.2	16.7
Financial advisor	-	-	1	11.1	5.6
Seniors centre	-	-	1	11.1	5.6
Research	1	11.1	-	-	5.6
Got a brochure on them	-	-	1	11.1	5.6
Can't remember	-	-	1	11.1	5.6

* Multiple responses permitted

When asked if they had participated with their RAH in the actual completion of the representation agreement (i.e. had been present and involved as compared, for example, with offspring living in another country), 86.8% said yes. When asked to describe their participation, 72.7% of RCRAHs said they and the person they represent (as will be seen in Section 4.4 commonly their spouse) completed their agreements at the same time; 18.2% of RCRAHs had discussions with their RAH about their wishes as the RAH went through the process of completing their agreement; 3.0% said the RAH had given them material to review and they then attended the legal clinic together; 3.0% said their participation consisted of attending a presentation about representation agreements together and 3.0% said they obtain the necessary forms for the RAH and accompanied the RAH to the lawyer to complete the documents. As shown in Table 12, the pattern was similar for male and female RCRAHs.

Table 12: Description of Participation with RAHs by RCRAHs, by Gender of RCRAHs

Method of participation	**Male (n=16)**		**Female (n=17)**		**Total %**
	n	**%**	**n**	**%**	
Did agreements together at same time	12	75.0	12	70.6	72.6
Discussed wishes as went through process	3	18.8	3	17.6	18.2
Attended presentation together	1	6.2	-	-	3.0
RAH gave rep materials to review; went to legal clinic together	-	-	1	5.9	3.0
Obtained forms for RAH, went to lawyer together	-	-	1	5.9	3.0

* 5 people (2 male, 3 female) missing from analysis

4.2.3 Representatives of Incapable adults (RIRAHs)

When the RIRAHs were asked if they knew how the person they represent (RAH) (n=7) had found out about representation agreements, 14.3% stated that it was from their legal advisor, 14.3% said from the newspaper and 85.7% said from another source. Other sources consisted of themselves in five (71.4%) of the cases with the remaining two RAHs (28.6%) having found out about them from the Right to Die Society. Assistance with entering into their agreement was reported to have been sought by six (85.7%) of the RAHs and six (85.7%) received assistance from the RARC while one person (14.3%) sought assistance from a family member and a lawyer not associated with the RARC's legal clinic. The RAHs had received handouts in 85.7% of the cases, 28.6% attended a presentation put on by the RARC and 71.4% attended the RARC legal clinic. All of the RIRAHs felt their RAH would rate the information and/or assistance received as being extremely or very helpful.

With respect to themselves, three RIRAHs, (42.9%) had found out about representation agreements from the newspaper and two (28.6%) from their RAHs. Additionally, (multiple responses were permitted), five mentioned other sources: three

(60%) found out about them at a senior's centre, one (20.0%) from their own business dealings and one (20.0%) from research done on the Internet.

When asked if they had participated with their RAH at the time the representation agreement was entered into, all RIRAHs answered yes. When asked to describe their participation, RIRAHs and their RAH had done the agreement together in 42.9% of the cases; 14.3% went to the lawyer with the agreement holder; 14.3% had explained the document and got the agreement holder to sign it and 28.6% went to the legal clinic with the then competent RAH.

4.3 Motivating Factors

In order to determine what motivated people to enter into representation agreements, a number of questions were asked about why a representation agreement had been entered into and what affect having an agreement would have. Questions were open-ended, responses were examined for themes and each theme was coded.

4.3.1 CRAHs

When asked to describe, in their own words, why they entered into a representation agreement, a large majority of CRAHs (68.8%) said they felt it was a good idea to have one. The second most popular reason to have an agreement was to ensure that their wishes were followed (39.6%). The third most common reason was to make things easier for one's family (33.3%). Another factor identified by more than one-quarter of the group was to have control over one's future (27.1%). As shown in Table 13, men and women did not differ dramatically on these top four motivating factors, although the women were slightly more likely than the men to cite making it easier for family and having control over the future as a motivating factor. Women also seemed to be more concerned than the men about a representation agreement being the only legally binding document that would ensure their wishes were followed and in citing past experiences with the health care system as motivating factors behind getting an agreement.

Table 13: CRAHs Motivating Factors for Entering Representation Agreement, by Gender*

Motivating Factor	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Good idea to have one	12	66.7	21	70.0	68.8
Ensure wishes followed	7	38.9	12	40.0	39.6
Make it easier for family	5	27.8	11	36.7	33.3
Have control over one's future	4	22.2	9	30.0	27.1
Choose who makes decisions for you	4	22.2	5	16.7	18.8
Wanted a legally binding document to ensure wishes followed	3	16.7	8	26.7	22.9
Past experiences of loved one	2	11.1	5	16.7	14.6
On one's own/no family to trust	2	11.1	5	16.7	14.6
Past experience with health care system	1	5.6	5	16.7	12.5
Suggestion of health care provider	2	11.1	-	-	4.2
Terry Schiavo influence	2	11.1	-	-	4.2
Avoid family disputes	1	5.6	-	-	2.1

* Multiple responses permitted

CRAHs were then asked what effect they hoped having an agreement would have. In response to this question, 56.2% said they hoped it would ensure that their wishes were followed or known, 54.2% saw their representation agreement as an insurance policy against future incapacity, which gave them peace of mind, 41.7% hoped it would give their family the power to instruct health care providers, 29.2% said it would maintain their control, 25% said it would ensure that the person who knows them best would be making decisions on their behalf, 18.8% mentioned that they hoped it would preserve their autonomy and dignity and 4.2% said it would avoid family disputes and ill-feelings or prevent misunderstandings. When asked what was meant by feeling their agreement was like an insurance policy, respondents said that it was something that one hoped would never be used, but it was comforting to know that it was there if it was needed. As shown in Table 14, there were no major differences between men and women on the effects they hoped the agreement would have, except men were more likely than women to see the agreement as an insurance policy against future incapacity, which gave them peace of mind. Women, on the other hand, were slightly more likely than men to cite maintaining control as an important effect they hoped having an agreement would have and as ensuring their wishes were followed.

Table 14: Expected Effects of Having a Representation Agreement, by Gender*

What effect will having agreement have	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Ensure wishes followed	9	50.0	18	60.0	56.2
Peace of mind/insurance policy	12	66.7	14	46.7	54.2
Give family power to instruct health care providers	8	44.4	12	40.0	41.7
Maintain control	4	22.2	10	33.3	29.2
Decision-maker knows CRAH best	4	22.2	8	26.7	25.0
Preserve autonomy/dignity	3	16.7	6	20.0	18.8
Avoid family disputes	1	5.6	1	3.3	4.2

* Multiple responses permitted

In order to test research question 2, that representation agreement holders would have a very specific reason for having entered into an agreement, this group was also asked what event, if any, led up to their decision to put a representation agreement into place. As shown in Table 15, there was no specific event that led up to the decision to obtain a representation agreement in 31.2% of the cases. Finding out about representation agreements accounted for 20.8% of CRAHs deciding to get one, as did getting older or having a previous medical condition or health scare. Past experiences with family accounted for 18.8%'s decision and 14.6% cited their knowledge of the health care system as the event that spurred them into action. Other less frequently mentioned events were the Terry Schiavo case in the United States and not wanting to end up in a similar situation (6.2%), family influencing them to get one (6.2%), having invalid documents from another jurisdiction (4.2%) and pre-surgery discussions with a health care provider (2.1%).

As can also be seen in Table 16, men were more likely than women to say that there had been no significant event influencing their decision whereas women were more likely than men to have entered an agreement based on finding out about them, to have had a previous health condition or health scare, to have been influenced by past experiences with family members and they were also more likely to be influenced by their knowledge of the health care system than men.

Table 15: Event Leading Up to Obtaining a Representation Agreement, by Gender*

Event	Male (n=18)		Female (n=30)		Total %
	n	%	n	%	
Nothing significant	7	38.9	8	26.7	31.2
Finding out about representation agreements	2	11.1	8	26.7	20.8
Getting older	4	22.2	6	20.0	20.8
Previous medical condition/health scare	3	16.7	7	23.3	20.8
Past experience with family	2	11.1	7	23.3	18.8
Knowledge of health care system	1	5.6	6	20.0	14.6
Schiavo case	2	11.1	1	3.3	6.2
Family influence to get one	1	5.6	2	6.7	6.2
Invalid documents from another jurisdiction	-	-	2	6.7	4.2
Pre-surgery discussions with Dr	1	5.6	-	-	2.1

* Multiple responses were permitted

4.3.2 RCRAHs

RCRAHs were asked if they knew of any event that led up to their RAH's decision to enter into a representation agreement. Table 16 shows that in total, 23.7% said there was nothing specific; 34.2% reported that their RAH was getting older, so had thought it seemed like a good idea – it was a way to be prepared for the future; 21.1% mentioned that someone close to their RAH had passed away recently or that there had been a bad past experience with a loved one who passed away, which they felt precipitated the move to put an agreement in place. Health concerns, like a health scare or upcoming surgery accounted for 10.5% of the responses, while 2.6% cited the diagnosis of a life-threatening illness and Alzheimer's as reasons for putting an agreement in place. A further 2.6% were concerned about something happening to their spouse or representative and 2.6% got an agreement at the suggestion of their representative. Male RAHs were slightly more often perceived by their representative to have had no specific reason, felt it was a good idea since they were getting older or based on their past experience with a loved one whereas female RAHs were more often perceived as having had health concerns affecting their decision.

Table 16: Events Leading Up to RAHs Entering Agreement, as Reported by their Representative, by RAHs Gender

Event	**Male (n=13)**		**Female (n=25)**		**Total %**
	n	**%**	**n**	**%**	**(n=38)**
Getting older/good idea to be prepared for future	5	38.5	8	32.0	34.2
Nothing specific	4	30.8	5	20.0	23.7
Past experience with loved one passing away	4	30.8	4	16.0	21.1
Health scare/upcoming surgery	-	-	4	16.0	10.5
Concern about something happening to rep/spouse	-	-	1	4.0	2.6
Diagnosis of life-threatening illness	-	-	1	4.0	2.6
Diagnosis of Alzheimer's	-	-	1	4.0	2.6
RCRAH's suggestion	-	-	1	4.0	2.6

Table 17 shows the reasons given by RAHs to their representatives as to why they felt the need to enter into a representation agreement. As can be seen, 36.8% of RCRAHs said it eased the agreement holder's mind, was a way of protecting themselves and part of the process of getting one's affairs in order; 18.4% said their RAH was getting older so it seemed like a good idea and 18.4% said it was the only legal means of ensuring their wishes were carried out. Other reasons mentioned were: the RAH didn't want decisions made by strangers, their children or other family members were far away, they felt the need to have an agreement to protect them from the health care system, they didn't want a specific family member involved in their care and it was a matter of common sense in case of incompetency.

Table 17: RAH's Reasons for Entering Agreement, as Reported by their Representative, by RAH's Gender

Reason	**Male (n=13)**		**Female (n=25)**		**Total %**
	n	**%**	**n**	**%**	
Ease one's mind/protect oneself/get affairs in order	4	30.8	10	40.0	36.8
Getting older/good idea	5	38.5	2	8.0	18.4
Only legal means of ensuring wishes carried out	2	15.4	5	20.0	18.4
Matter of common sense	-	-	3	12.0	7.9
Didn't want decisions made by strangers	-	-	2	8.0	5.3
Children/family far away	-	-	2	8.0	5.3
Didn't want particular family member involved in care	2	15.4	-	-	5.3
Protection from health care system	-	-	1	4.0	2.6

Representatives were also asked if their RAH gave them any reason as to why they were asked to be the person's representative. The most common response, given by 63.2%, was that the representative knew the RAH well, felt he/she would know what the RAH would want, was the logical choice and a person trusted by the RAH. Other reasons, as shown in Table 18, were: the representative was knowledgeable about representation agreements, lived close by, or there were family difficulties with children. Male RAHs were noticeably more likely than female RAHs to have felt that the RCRAH knew them well and was a logical choice, and slightly more likely than women to have no particular reason for asking who they did to represent them and to have felt that the RCRAH was the closest person that the RAH could trust whereas women were more likely than men to cite other reasons.

Table 18: Reasons Given by RAHs for Asking Person to Represent Them, as Reported by RCRAHs, by RAHs Gender

Reason	Male (n=13)		Female (n=25)		Total %
	n	%	n	%	
Rep knows RAH well/logical choice	10	76.9	15	60.0	63.2
No particular reason given	2	15.4	3	12.0	13.2
Closest person RAH could trust	1	7.7	1	4.0	5.3
Rep knowledgeable about representation agreements	-	-	1	4.0	2.6
Rep lives close by	-	-	1	4.0	2.6
Family difficulties with children	-	-	1	4.0	2.6
Rep more likely than spouse/children to do what RAH wants	-	-	1	4.0	2.6
Concerned for each other	-	-	1	4.0	2.6
Eldest child/takes interest in RAH's health	-	-	1	4.0	2.6

A majority (68.4%) of the representatives said they agreed to be the RAH's representative because they were the logical person or that it was a natural choice; 10.5% said they agreed because there was no one else or no family available; 10.5% said they agreed out of a sense of duty or feeling of responsibility to take care of the RAH. Other reasons were: that the representative couldn't see anything wrong with acting as representative (2.6%), thought it was a good idea (2.6%), knew the RAH fairly well (2.6%) or was honoured to be asked (2.6%).

4.3.3 RIRAHs

Representatives of representation agreement holders who were no longer capable were asked if there was a particular event that had led up to their RAH's decision to enter into a representation agreement. As shown in Table 19, 42.9% said it was the RAH's declining health over time that precipitated the decision to have an agreement; 14.3% said that it was brought to their attention that the RAH should have one, given their advancing

Alzheimer's disease; 14.3% said that while dealing with the RAH's power of attorney documentation, it was realized that it could not authorize the attorney to make any health care decisions; 14.3% said an investment advisor had told the RAH and the representative to have an agreement in place; and 14.3% said there was nothing specific.

Table 19: Event Leading Up to RAH's Decision to Enter into Representation Agreement, as Reported by RIRAHs, by RAH's Gender

Event	**Male (n=4)**		**Female (n=3)**		**Total**
	n	**%**	**n**	**%**	**%**
Declining health	2	50.0	1	33.3	42.9
Advancing Alzheimer's disease	-	-	1	33.3	14.3
POA not sufficient to make health-care decisions	-	-	1	33.3	14.3
Advised to get one by financial advisor	1	25.0	-	-	14.3
Nothing specific	1	25.0	-	-	14.3

Representatives were asked if their RAH had ever told them why they had wanted a representation agreement. As seen in Table 20, one third (33.3%) of the representatives said the RAH had told them they wanted the representative to look out for them and ensure that their wishes were carried out; 16.7% had a mutual agreement that it made sense to have one; 16.7% of the representatives had told the RAH that they should have a representation agreement; 16.7% said they did not want to end up in long-term care and having a representation agreement would ensure that wouldn't happen and 16.7% of the RAHs recognized that it made sense to have an agreement.

Table 20: Reasons Given by RAHs for Wanting a Representation Agreement, as Reported by RIRAHs, by RAH's Gender*

Reason	Male (n=4)		Female (n=2)		Total %
	n	%	n	%	
RAH wanted rep to look out for them and ensure wishes followed	1	25.0	1	50.0	33.3
Rep told RAH they should have agreement	1	25.0	-	-	16.7
RAH didn't want to end up in LTC	1	25.0	-	-	16.7
RAH recognized sensibility of having agreement	1	25.0	-	-	16.7
Mutual agreement between RAH and rep that made sense to have one	-	-	1	50.0	16.7

*1 person (1 female) missing from analysis

Just over half (57.1%) of the RAHs told their representatives what effect they hoped having a representation agreement would have. Of these, 75% said it would ensure that their wishes were carried out; 25% said they trusted their representative to take care of matters if they were unable to do so themselves.

In summary, in answer to research question 2, for most people there was not a specific event that preceded entering into an agreement. A variety of reasons for getting an agreement were given, but more often than not, RAHs merely felt it was a good idea to have one and had no specific reason behind their decision to get one. Some interesting themes were alluded to, such as past experiences with loved one's passing away and health scares or diagnoses of illness. While not wanting particular family members involved and family difficulties were mentioned, they were not cited by large numbers of the sample, and were not statistically significant in any way, refuting the assumption that family discord or unavailability of family members may be a possible explanation why people appointed representatives. RAHs no longer capable seemed to have had more specific reasons, according to their RIRAHs.

4.4 Who was Appointed and Why?

A number of questions were asked to determine who was acting as representative for the representation agreement holders interviewed and to ascertain the nature of the relationship between them. Questions were also asked to determine how many people had appointed more than one representative or had appointed alternates.

4.4.1 CRAHs

Under s. 9 of the *Representation Agreement Act*, people can authorize their representative to make a number of decisions on their behalf and can also restrict their representative's authority. Of the CRAHs interviewed, 97.9% had not restricted their representative's authority in any way; only 2.1% had imposed some restrictions.

Under the *Act*, a person can appoint one representative, or may name more than one representative, who are equally ranked and can act jointly if assigned to the same area of authority as the other representative or they can be assigned different areas of authority under the agreement. One can also appoint an alternate representative, which as the name suggests, is someone who is authorized to act as representative if something happens to the primary representative(s) or if the primary representative(s) does not want to act. The agreement must specify under what circumstances the alternate is authorized to act in place of the representative.

Overall, the sample of 48 was split evenly as to whether or not they had appointed more than one primary representative. Although chi-square analysis did not reveal a statistically significant difference, men and women differed noticeably in their response to this question. Just over half (56.7%) of women had appointed more than one representative compared to 38.9% of men. When asked what their representative's relationship was to them, as shown in Table 21, 29.2% of the sample had appointed their spouse; 54.2% had appointed a family member, other than a spouse and 16.7% had appointed a friend. Men were more likely than women to have appointed their spouse as one of their representatives whereas women were slightly more likely than men to appoint a family member other than a spouse as their first representative. While at first it seems unusual that a low number of CRAHs appointed their spouse to be their representative, it must be remembered that only 43.8% of the CRAH's sample were married.

Table 21: Nature of Relationship Between CRAHs and their First Representative, by Gender

Nature of Relationship	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Spouse	7	38.9	7	23.3	29.2
Family member	8	44.4	18	60.0	54.2
Friend	3	16.7	5	16.7	16.7

As shown in Table 22, where a family member other than a spouse was appointed, 40% were sons; 28% were daughters. Men were more likely than women to appoint a son as a representative.

Table 22: Family Members Appointed as Representatives (n=25), by Gender of CRAHs*

Family member appointed	Male (n=8) n	 %	Female (n=17) n	 %	Total %
Son	5	62.5	5	29.4	65.8
Daughter	2	25.0	5	29.4	13.2
Niece	1	12.5	2	11.8	5.3
Step-daughter	-	-	1	5.9	2.6
Brother	-	-	1	5.9	2.6
Sister	-	-	1	5.9	2.6
Son-in-law	-	-	1	5.9	2.6
Cousin	-	-	1	5.9	2.6

*23 people (10 males and 13 females) missing from analysis

When those who had appointed a second primary representative were asked what the second representative's relationship was to them, 81% advised they had appointed a family member other than a spouse, while 19% appointed a friend. As shown in Table 23, all the men appointed a family member as their second representative, whereas 75% of women appointed a family member and the remaining 25% appointed a friend.

Table 23: Relationship of Second Representative, by Gender*

Nature of Relationship	Male (n=5) n	 %	Female (n=16) n	 %	Total %
Family member	5	100.0	12	75.0	81.0
Friend	-	-	4	25.0	19.0

* 27 people (13 male and 14 female) missing from analysis

As shown in Table 24, of those family members, 12.5% were sons, 75% were daughters, and 12.5% were nieces. Both men and women were more likely to select daughters as their second representative than any other family member.

Table 24: Family Members Appointed as Second Representatives (n=21), by Gender of CRAHs*

Family member appointed	Male (n=5)		Female (n=16)		Total %
	n	%	n	%	
Son	1	20.0	1	9.1	12.5
Daughter	3	60.0	9	81.8	75.0
Niece	1	20.0	1	9.1	12.5

*13 men and 16 men missing from analysis

The vast majority of CRAHs had known their representatives for long periods of time. Only 4.2% of the group had known their representative for less than twenty years; 12.5% had known their representative between 21-30 years; 22.9% between 31-40 years; 25% between 41-50 years; 20.8% between 51-60 years; 14.6% had known their representative more than 60 years.

CRAHs and their representatives lived within close proximity of each other in the majority of cases; 89.6% living within 60 minutes by car. As shown in Table 25, they also speak to each other regularly - 45.8% daily; 14.6% at least once a week. There is no sizeable difference in communication patterns between males and females in the sample.

Table 25: Frequency of Communication Between CRAHs and their Representatives, by Gender of CRAHs

Frequency of communication	Male (n=18)		Female (n =30)		Total %
	n	%	n	%	
Daily	8	44.4	14	46.7	45.8
Several times a month	3	16.7	5	16.7	16.7
Once a week	3	16.7	4	13.3	14.6
Several times a week	1	5.6	3	10.0	8.3
Several times a year	1	5.6	1	3.3	4.2
Once a year	1	5.6	1	3.3	4.2
Once every 2 weeks	-	-	1	3.3	2.1
Once every 2-3 months	1	5.6	-	-	2.1

Just over half (54.2%) of CRAHs had appointed an alternate representative with men being slightly more likely than women to do so. When asked why they did, 91.7% of CRAHs said they were advised to do so, in case something happened to their main representative(s); 4.2% wanted the representative to have someone to consult with and 4.2% wanted both their children to feel involved with decision-making. Of the alternates, 45.5% were the CRAH's son; 31.8% were the daughter; 9.1% appointed a friend; 4.5% appointed a brother; 4.5% appointed a sister and 4.5% appointed a sister-in-law.

When asked why they chose who they did to be their primary representative, 75% said it was because they were the closest person to them who knew them best and was someone they trusted; 10.4% said they were the best person for the job; 4.2% said it was because he/she was the eldest child; 4.2% said it was because of physical proximity; 2.1% said it was because their representative got along with the entire family; and 2.1% said the representative had forced them to get an agreement and appoint him/her as representative.

When asked the same question about the other primary representative, 60% said it was because they were the closest person to them; 16% said that person was the best one for the job; 12% said because the representative was the second eldest child; 4% said it was because they had the same beliefs; 4% cited the representative's close physical proximity; and 4% said the representative was closest to them emotionally.

4.4.2 RCRAHs

The 38 representatives reported that they had been given all the powers they could be authorized to have under s. 9 of the *Act.* A majority (63.2%) of the representatives were their RAH's spouse; 23.7% were some other family member and 13.2% were friends of the RAH. Of those who were family members, 50.0% were daughters; 20.0% sons; 10.0% a step-son; 10.0% a brother; and 10.0% an ex-spouse. It should be noted that RCRAHs were more likely to report being their RAH's spouse than would be expected based on the data provided by the CRAHs sample, only 29% of whom identified their spouse as being their representative. This apparent over-sampling of spousal RCRAHs explains the high proportion of married RCRAHs in this study, as well as other data.

The RCRAHs interviewed had known their RAH for a long time, with only 13.1% knowing their RAH for less than 20 years; 10.5% had known the RAH for 21-30 years; 21.1% 31-40 years; 26.3% for 41-50 years; 26.3% for 51-60 years; and 2.6% for more than 60 years. The vast majority of representatives (92.1%) lived within 60 minutes car travel of the person they represent and to their knowledge, in 84.2% of the cases, were the only main representative appointed. However, 84.2% reported that their RAH had appointed an alternate. As shown in Table 26, family members were most likely to be appointed as alternates, with 23.5% being children; 23.5% sons and 20.6% daughters. Others who were appointed were: niece (5.9%) nephew (2.9%); a brother (2.9%); a sister (5.9%); a son-in-law (2.9%) and a daughter-in-law (2.9%).

Table 26: Family Members Appointed as Alternate Representatives by RAHs, as Reported by RCRAHs, by RAH's Gender*

Family member appointed	Male (n=12)		Female (n=22)		Total % (n=34)
	n	%	n	%	(%)
Children (combination son/daughter)	3	25.0	5	22.7	23.5
Son	3	25.0	5	22.7	23.5
Daughter	2	16.7	5	22.7	20.6
Niece	-	-	2	9.1	5.9
Nephew	-	-	1	4.5	2.9
Brother	-	-	1	4.5	2.9
Sister	2	16.7	-	-	5.9
Son-in-law	-	-	1	4.5	2.9
Daughter-in-law	1	8.3	-	-	2.9
Cousin	-	-	1	4.5	2.9
Friend	1	8.3	1	4.5	5.9

*4 people (1 male and 3 female) missing from analysis

As seen in Table 27, when asked if they knew why their RAH had appointed another representative or an alternate, 64.5% of RCRAHs said it was in case the representative was not available; and 12.9% said it was so it would make it easier for the representative if they had to make a decision or that the alternate would help the representative.

Table 27: Reasons Given by Representatives as to why RAHs had Appointed an Alternate Representative, as Reported by RCRAHs, by RAH's Gender*

Reason given	Male (n=12)		Female (n=19)		Total %
	n	%	n	%	
In case rep not available	7	58.3	13	68.4	64.5
Make it easier for rep/someone to help rep	2	16.7	2	10.5	12.9
No reason specified	1	8.3	-	-	3.2
Wanted the whole family involved	-	-	1	5.3	3.2
Logical	-	-	1	5.3	3.2
Closest in physical proximity	-	-	1	5.3	3.2
Is a nurse	1	8.3	-	-	3.2
Alternate is younger, someone trusted who would do a good job	1	8.3	-	-	3.2
Only relative on speaking terms with	-	-	1	5.3	3.2

*7 people (1 male, 6 female) missing from analysis

4.4.3 RIRAHs

All RIRAHs interviewed had been given the full powers allowed under s. 9 of the *Act.* A majority (71.4%) were the RAH's spouse. Of the two who were not spouses, one was the RAH's son and one was the RAH's niece. A majority (71.4%) had been chosen to be the RAH's representative because they were the spouse, so they were "the logical choice"; 14.3% were chosen as the representative because they were the RAH's eldest son and already acted as their business advisor; and 14.3% were chosen as the representative because they were already looking after the RAH.

Over one-quarter (28.6%) of the representatives agreed to act for the RAH because of their love and concern for their spouse; 28.6% because they were acting reciprocally with their spouse; 14.3% wanted to make sure the RAH was well looked after and their wishes carried through; 14.3% because they were the natural choice; and

14.3% because they wanted to spare their children for as long as the representative was able to act on the RAH's behalf.

All but one (85.7%) of the RAH had appointed one representative and an alternate. In half of the cases, the alternates were children; 33.3% appointed their spouses and 16.7% a nephew.

4.5 Discussions Between RAHs and their Representatives

Research question 3 predicted that there would be minimal discussions between representation agreement holders and their representatives as to what the RAH's preferences for treatment were. A number of questions were asked to determine what types of discussions went on between representatives and those they represent in terms of how they should make decisions and what types of decisions they should be making, if called upon to do so.

4.5.1 CRAHs

CRAHs were asked if they had discussed with their representative how the representative was to proceed in the event the CRAH became incapable; 81.2% said they had. If there had been discussions, they were then asked what types of situations had been discussed and 39.6% said they did not want life support if there was no hope of a meaningful recovery; 22.9% had discussed Do Not Resuscitate orders and not wanting "heroic measures"; 16.7% said they had discussed quality of life vs. quantity of life (length of life); 16.7% had discussed going into a nursing home; 10.4% said they had discussed time frames for remaining in a coma; 6.2% discussed what types of decisions to make if they developed dementia; 6.2% talked about their wishes on organ donation;

4.2% had left very specific written instructions and 2.1% talked about pain control. However, 52.1% said they had only had very general discussions about situations that may arise in the future.

As shown in Table 28, there were no major differences between men and women as to the types of discussions they had with their representatives as to their treatment wishes. Men were only slightly more likely than women to have had only general discussions, to have discussed not wanting life support and to have discussed organ donation and pain control. Women were only slightly more likely than men to have discussed nursing home placement and what to do if they were to develop dementia.

In summary, research question 3, which predicted minimal discussion of *specific* treatment preferences, was supported because just over half of CRAHs reported having had only very general discussions about their treatment preferences. As indicated below however, greater proportions discussed feelings and values.

Table 28: CRAH's Treatment Wishes and Scenarios Discussed with Representatives, by Gender*

Types of scenarios	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
General discussions only	10	55.6	15	50.0	52.1
No life support	8	44.4	11	36.7	39.6
Do not resuscitate/no heroic measures	4	22.2	7	23.2	22.9
Quality of life vs. quantity	3	16.7	5	16.7	16.7
Nursing home placement	1	5.6	7	23.3	16.7
Time frame for remaining in coma	2	11.1	3	10.0	10.4
What to do if get dementia	-	-	3	10.0	6.2
Organ donation	2	11.1	1	3.3	6.2
Very specific written instructions	-	-	1	3.3	2.1
Pain control	1	5.6	-	-	2.1

*Multiple responses permitted

Of those interviewed, 89.6% said they had discussed with their representative their feelings and values about the types of situations that could arise and what impact that should have on how their representative made treatment decisions; 65.2% said they had ongoing discussions over time or discussed situations periodically; 19.6% said they had discussions at the time the representation agreement was entered into; 8.7% said they had about 2-3 discussions; and 6.5% said there had been no discussions between themselves and their representative. There was no appreciable difference between men and women about whether or not they had discussions with their representatives.

As shown in Table 29, of the 10.4% of CRAHs who had not had any discussions with their representative, 76.9% said their representative would know what the CRAH would want; 12.5% had included wishes or instructions in their representation agreement; 7.7% didn't want to burden their representative; 7.7% said it was a hard topic to discuss and 7.7% felt their wishes were adequately expressed in their representation agreement. Men were slightly more confident than women that their representative would know what the CRAH would want done, whereas women had slightly more reasons for feeling that discussions with their representatives were unnecessary.

Table 29: Why CRAHs had not Discussed Treatment Wishes with their Representative, by Gender*

Why no discussions	**Male (n=5)**		**Female (n=8)**		**Total %**
	n	**%**	**n**	**%**	
Rep knows what CRAH would want	5	100.0	5	62.5	76.9
Didn't want to burden rep	-	-	1	12.5	7.7
Hard topic to discuss	-	-	1	12.5	7.7
Wishes adequately described in agreement	-	-	1	12.5	7.7

*13 males and 12 females missing from analysis

4.5.2 RCRAHs

Representatives were asked if they had discussed with their RAH what treatments and care the RAH would and would not want if they were incapable of making their own decisions. Their pattern of answers was similar to that of the CRAHs. A majority (81.6%) reported these discussions had taken place. However, 44.7% had only had general discussions, with no specific scenarios discussed. Where specific topics were discussed, as shown in Table 30, life support was the topic most commonly discussed. The next most common topic was that they wanted no heroic measures taken. Also in similarity to the CRAHs, but more pronounced in terms of proportion, men were reported more likely than women to have had only general discussions about their treatment wishes with their representative. Women were more likely than men to want life-supporting treatments but also more likely than men to not want heroic measures.

Table 30: Treatment Wishes Discussed by RAHs and their Representatives, as Reported by RCRAHs, by Gender of RAHs*

Treatment wishes	**Male (n=13)**		**Female (n=25)**		**Total %**
	n	**%**	**n**	**%**	
General discussions only	8	61.5	9	36.0	44.7
Life-supporting treatments	4	30.8	12	48.0	42.1
No heroic measures	1	7.7	7	28.0	21.1
Do not resuscitate	3	23.1	6	24.0	21.1
No nursing home	-	-	2	8.0	5.3
Put in nursing home	-	-	2	8.0	5.3
No meds to control behaviour	1	7.7	1	4.0	5.3

* Multiple responses permitted

Also in similarity to the CRAHs, a high proportion (71.1%) of representatives had discussed the RAH's feelings and values about their treatment wishes and what impact that should have on how treatment decisions would be made on the RAH's behalf. When asked how many discussions the RAH and their representative had, 64.9% said that discussions were ongoing over time; 16.2% said they had discussed it at the time the representation agreement was entered into; 13.5% said that they had no discussions with the person they represent and 5.4% said they had 2 or 3 discussions.

As shown in Table 31, when asked why they thought they hadn't had discussions, 25% of representatives said that they didn't know how to talk about it or didn't want to talk about it with their RAH; 25% said they didn't need to talk about it yet because the RAH was still in good health and there had been no health crisis as yet; 16.7% said they knew the RAH well enough to know what would be wanted; 8.3% said it was hard to get information from the RAH; 8.3% said they had not had the time when the agreement was entered into; 8.3% said the RAH does not answer questions even when specifically asked; and 8.3% said they have a general idea of what would be wanted, but would rely on the alternate who would know more of the details. Men were more likely than women to say they didn't know how or didn't want to talk about it.

Table 31: Why No Discussions with RAH About Treatment Wishes as Reported by RCRAHs, by Gender of RAHs*

Reasons	Male (n=5)		Female (n=7)		Total %
	n	%	n	%	
Don't know how to talk about/don't want to talk about it	2	40.0	1	14.3	25.0
RAH still in good health/no health crisis yet	2	40.0	1	14.3	25.0
Knows RAH well enough to know what would be wanted	1	20.0	1	14.3	16.7
Hard to come up with general strategy/get information from RAH	-	-	1	14.3	8.3
Didn't have time when agreement entered into	-	-	1	14.3	8.3
RAH doesn't answer questions when asked	-	-	1	14.3	8.3
Has general idea but would rely on alternate, who knows more about wishes, if had to make decisions	-	-	1	14.3	8.3

*8 males and 18 females missing from analysis

When asked how they planned on making treatment decisions on behalf of the RAH, since there had been no discussions about treatment wishes, 38.5% were confident they had a good idea of what the RAH would want; 38.5% said they would discuss it with other family members; 15.4% said they didn't know; and 7.7% would rely on their limited knowledge to make any necessary decisions.

4.5.3 RIRAHs

When asked if they had discussions with the RAH, prior to their incapacity, about their treatment wishes, 85.7% of RIRAHs said they had. In terms of what they had talked about with the RAH (see Table 32), 28.6% had discussed quality of life versus quantity; 57.1% wanted no heroic measures or did not wish to be resuscitated; 28.6% discussed their feelings about going into a nursing home; 71.4% said they did not want life support if there was no chance for a meaningful life; 28.6% had discussions about pain control. While 14.3% had only general discussions, with no specific scenarios being discussed, 42.9% left very specific instructions. Most of the representatives (85.7%) said that their RAH's wishes did not change over time. This group differs from the CRAHs and RCRAHs in having a much small proportion engaging in only general discussions about treatment wishes (14.3%).

Table 32: Treatment Wishes Discussed by RIRAHs and RAHs, Prior to Incapacity as Reported by RIRAHs *

Treatment wishes	**n (n=7)**	**Total %**
Life-supporting treatments	5	71.4
No heroic measures/DNR	4	57.1
Very specific instructions	3	42.9
Nursing home admittance	2	28.6
Quality of life vs. quantity	2	28.6
Pain control	2	28.6
General discussions	1	14.3

*Multiple responses permitted

Over half (57.1%) of the RAHs had discussed their feelings and values about these types of situations prior to their incapacity and what impact that should have on how representatives made decisions about their treatment. While 14.3% of the representatives said they hadn't had specific discussions, they felt they knew what the RAHs feelings and values would be based on previous discussions. More than one-third (42.9%) said the discussions they had were ongoing over time; 28.6% said they had discussions periodically over the years, while 14.3% said they had discussions in the context of things happening to other people over the years.

When the two RIRAHs who had said there had been no discussions were asked why there hadn't been, one said they knew what the RAH would and wouldn't want; the other said it had been a hard topic to discuss before the RAH's incapacity and now, due to Alzheimer's disease, it was too late to have these discussions (when the RAH says something about their treatment preferences, the representative doesn't know if that's what the RAH would really want). When asked how they would make decisions, having not had any discussions, one of the RIRAHs said they had an idea of what was wanted and would make decisions based on that, while the other said they would have to discuss the situation with other family members.

4.6 Discussions with Health-Care Providers

The CRAHs and RCRAHs were asked a series of questions designed to determine what kinds of discussions, if any, were taking place between people with representation agreements and their health care providers. The RIRAHs were asked questions designed to test research question 4, which predicted that representatives may encounter difficulties in ensuring that health-care providers accepted the treatment decisions made on behalf of RAHs.

4.6.1 CRAHs

CRAHs were asked if they had discussed their treatment wishes with their health-care providers. Only 14 (29.2%) said they had these types of discussions but 42.6% had told their health-care provider that they had authorized a representative to make treatment decisions on their behalf. When the 17 who had not done so were asked why they had not told their doctor about authorizing a representative, as shown in Table 33, 29.4% said they hadn't thought of it; 17.6% hadn't gotten around to it yet; 11.8% said they didn't think it was important; 11.8% said they don't have a steady doctor; 11.8% said the doctor is too busy, 11.8% said it hasn't come up yet and 5.9% said it was none of the doctor's business. Men were noticeably more likely than women to have not thought about telling their health-care provider or hadn't brought up the topic with their health-care provider, thinking it wasn't important. Women were more likely than men to have just not gotten around to doing so yet or to cite concerns about their relationship or lack thereof with their health-care provider.

Table 33: Reasons Why CRAHs Had Not Told Health Care Provider About Appointing a Representative, by Gender*

Reasons for not telling health care provider	**Male (n=6)**		**Female (n=11)**		**Total %**
	n	**%**	**n**	**%**	
Hadn't thought of it	3	50.0	2	18.2	29.4
Hasn't come up	2	33.3		-	11.8
Didn't think it was important	1	16.7	1	9.1	11.8
Hasn't gotten around to it	-	-	3	27.3	17.6
Doesn't have steady GP	-	-	2	18.2	11.8
Doctor too busy	-	-	2	18.2	11.8
None of Dr.'s business	-	-	1	9.1	5.9

*31 people (12 males and 19 females) missing from analysis

Only 12.8% of CRAHs had given their doctor a copy of their representation agreement and asked that it be included in their medical file. Table 34 shows that of those who hadn't, 67.6% are relying on having their agreement available on NIDUS, a database to which representatives and health-care providers have access to the CRAH's agreement; 17.6% hadn't thought about giving a copy to go on their file; 5.9% hadn't had their representatives sign off on it yet; 5.9% hadn't done it yet; and 2.9% were reluctant to do so because they don't feel their doctor keeps his files in very good order. Men were slightly more likely than women to rely on NIDUS, whereas women were slightly more likely than men to have not thought of giving a copy of their agreement to their health-care provider.

Table 34: Reasons why CRAHs Had Not Given a Copy of their Representation Agreement to their Health-Care Provider, By Gender*

Reason	**Male (n=11)**		**Female (n=23)**		**Total %**
	n	**%**	**n**	**%**	
Relying on NIDUS	9	81.8	14	60.9	67.6
Didn't think of it	1	9.1	5	21.7	17.6
Haven't done it yet	1	9.1	1	4.3	5.9
Dr. doesn't keep files very well	-	-	1	4.3	2.9
Reps haven't signed off yet	-	-	2	8.7	5.

*14 people (7 males and 7 females) missing from analysis

Of those who answered the question about whether or not their health care provider was receptive to discussions about having a representative and a representation agreement, 92.9% said they were and none of the providers had expressed concerns about having a representation agreement.

4.6.2 RIRAHs

A majority (71.4%) of RIRAHs had made decisions on their RAH's behalf, as authorized by the representation agreement. These decisions included: medications (40%), end of life decisions (80%), care home placement (20%), life support (60%), and decisions to stop treatment (80%). Multiple responses were permitted.

Due to the person's illness, 40% of the representatives were unable to consult with the RAH when making these decisions and had to take into account the RAH's previously expressed wishes; 20% made the decisions in consultation with the doctor and their family; 40% asked the RAH if they wanted more treatments prior to making any treatment decisions. Representatives were more likely to consult others, including the RAH, prior to making treatment decisions than they were to act independently. The majority of RIRAHs (85.7%) reported that their RAH's treatment wishes did not change over time. There were no appreciable differences between men and women on these questions.

All of the five RIRAHs who had made decisions felt that the decisions they made reflected their RAH's wishes and slightly more than half (60%) did not find making decisions stressful or burdensome. Of the three (40%) who did find decision-making stressful or burdensome, one (25%) found it difficult because the person was close to them, but they knew they were doing what the RAH wanted; one (25%) found it hard when a medical specialist went against the representative's decision to stop treatment; one (25%) found it hard because of family problems. One of the RIRAHs, who did not find decision-making stressful, explained that decisions were made as a family, which made it easier. Men and women did not differ noticeably in their feelings on the decision-making process.

All five of the RIRAHs who had made treatment decisions found health-care professionals to be receptive to them as the RAH's representative, although one representative had an experience with a doctor who re-instated treatment after being told to stop it. However, this doctor was new to the case, and did not know either the representative or the RAH. Upon finding out that the RIRAHs was the RAH's representative, medical treatment was stopped again. All five RIRAHs found that having the authority given to them by their RAH under the agreement was helpful in discussions or decision-making. For 33.3%, it was helpful in that they had better discussions with the RAH having gone through the process of doing up the agreement than they would have if they had not done the agreement; 33.3% said it was good to have learned what one could legally do as a person's representative and 33.3% hadn't consciously thought about it.

Six of the seven RIRAHs considered having a representative and a representation agreement a benefit to those who were incapable; one found it was very important and didn't know what would have happened to the RAH if there hadn't had been someone to speak on their behalf; one felt it would be good as a lever if necessary because family and doctors would be bound by it; one said it was a benefit because it was required by law and one said a person doesn't necessarily have the authority if they aren't the representative and would then be forced to rely on medical professionals who didn't know the RAH as well as a representative would.

In summary, research question 4 was not supported. Rather, it appears that on the whole, health-care providers were receptive to representatives and representation agreements, with only one person reporting having had a difficulty with a doctor who was not familiar with the RAH's case. Interestingly, in spite of evidence that health-care providers appeared to be receptive to themselves as representatives, RIRAHs felt that having a formal agreement was a good thing for the RAH and they all felt that having the authority of a representative was helpful.

4.7 Written Instructions

Research question 5 predicted that people entering into representation agreements would have some type of written document that clearly set out their treatment preferences in order to guide their representative in addition to their representation agreement.

4.7.1 CRAHs

Contrary to the prediction, only a very small number of CRAHs (n=6) were found to have expressed their wishes in written format, either within the representation agreement, or in a separate document. For those who did have written instructions or wishes, they ranged from instructions pertaining to specific treatments (33.3%), to not allowing certain family members to make treatment decisions (16.7%), to telling their representative to discuss care options with the doctors and then go along with their recommendations (16.7%). As shown in Table 35, men cited the importance to them of staying with their spouse for as long as it was possible, and also for their representative to discuss care options with the CRAH's doctor, and then follow the doctor's advice, whereas women were more likely to set out specific treatments or write a letter setting out their wishes and also to restrict family members from making decisions on their behalf. It could be argued that the women's wishes were more in keeping with efforts at controlling their health outcomes compared to the reasons given by the men.

Table 35: Wishes Contained Within Representation Agreement, by Gender*

Wishes/Instructions	**Male (n=3)**		**Female (n=3)**		**Total %**
	n	**%**	**n**	**%**	
Stay together with spouse as long as possible	1	33.3	-	-	16.7
Discuss care options with Dr. and follow recommendations made	1	33.3	-	-	16.7
Specific treatments	1	33.3	1	33.3	33.3
Letter	-	-	1	33.3	16.7
Restrict certain family members from making decisions on CRAHs behalf	-	-	1	33.3	16.7

*42 people (15 males and 27 females) missing from analysis

Slightly less than one-third (31.2%) of the group had made reference in their representation agreement to other written instructions, such as a living will, with the intention that the document would help guide the representative in decision-making. As can be seen in Table 36, women were noticeably more likely than men to make reference to other written instructions.

Table 36: Did the CRAH Make Reference to Written Instructions in their Representation Agreement, by Gender

Reference made to written instructions	**Male (n=18)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Yes	3	16.7	12	40.0	31.2
No	15	83.3	18	60.0	68.8

As shown in Table 37, eight people offered further clarification with regard to written instructions of which 50% said they had a living will but didn't make reference to it in the representation agreement; 25% said they had written letters or sent email to the representative, but these were not mentioned in the representation agreement; and 25%

had a separate handwritten document setting out specific instructions. Again, women were more likely than men to have some form of written instruction or communication in place.

Table 37: Clarifications Made Via Written Instructions, by Gender*

Other explanations	**Male (n=3)**		**Female (n=5)**		**Total %**
	n	**%**	**n**	**%**	
Has a living will but didn't refer to it in the agreement	3	100.0	1	20.0	50.0
Letters/email written but not mentioned in agreement	-	-	2	40.0	25.0
Separate document setting out specific instructions	-	-	2	40.0	25.0

*40 people (15 males and 25 females) missing from analysis

When the group was asked when these written documents were completed, as set out in Table 38, 58.8% said they were completed prior to entering into the representation agreement; 35.3% completed them at the same time as the representation agreement and 5.9% said they were done after. Men were slightly more likely to have completed written instructions after they entered into their agreement than women were, while women were slightly more likely to have completed written instructions at the same time as they did their agreement. Both men and women were more likely to have completed written instructions prior to entering into an agreement than at any other time.

Table 38: When Written Documents Were Completed, by Gender

When completed	**Male (n=5)**		**Female (n=12)**		**Total %**
	n	**%**	**n**	**%**	
Before agreement	3	60.0	5	58.3	58.8
After agreement	1	20.0	-	-	5.9
Same time as agreement	1	20.0	5	41.7	35.3

When asked why the CRAH felt it necessary to have a representation agreement even though they had previously completed written instructions, 30% said living wills were not legally binding, whereas the representation agreement was; 20% said the representation agreement had sounded like a good idea; 20% said their living will was more precise as to their wishes; 10% said they wanted to ensure that family members couldn't interfere; a further 10% said that it was better to have someone who could speak for them, rather than relying "on a piece of paper"; 10% said they entered into a representation agreement so as to be an example to others. As set out in Table 39, both men and women had proceeded with a representation agreement because it was legal, whereas the living will was not a legally recognized document. Women had slightly more reasons than men for proceeding with an agreement but most of the reasons given by both men and women seem to be related to the legality of the representation agreement compared to the living will.

Table 39: Reasons why Representation Agreement Necessary Despite Written Instructions, by Gender*

Reason	**Male (n=3)**		**Female (n=7)**		**Total %**
	n	**%**	**n**	**%**	
Living will not legal document	1	33.3	2	28.6	30.0
Sounded like a good idea	1	33.3	1	14.3	20.0
Living will more precise as to wishes	1	33.3	1	14.3	20.0
Wanted to ensure family couldn't interfere	-	-	1	14.3	10.0
Better to have someone to speak on one's behalf, rather than rely on piece of paper	-	-	1	14.3	10.0
Set an example to others	-	-	1	14.3	10.0

*38 people (15 males and 23 females) missing from analysis

Responses to the question of why written instructions had not been completed, set out in Table 40, show that 62.1% said they trusted their representative to follow their instructions or the representative would know what the CRAH would want; 13.8% said they didn't want to tie their representative's hands and that it was best for the representative to use their judgment; 6.9% pointed out that living wills or other written instructions weren't legally binding, whereas the representation agreement is and was therefore a better thing to rely on; 6.9% hadn't thought about it; 3.4% had been advised against it, in case they ever changed their mind; 3.4% didn't know you could; and 3.4% were procrastinating. There was no noticeable difference between men and women in that the majority of both trusted their representative to either follow their instructions or already knew what the CRAH would want done. Women were slightly more likely than men to not want to tie their representatives hands by setting out instructions in writing, thinking it best for the representative to rely on their judgment if decisions regarding treatment needed to be made.

Table 40: Why CRAHs Did Not Complete Written Instructions, by Gender*

Why Written Instructions not Completed	**Male (n=12)**		**Female (n=17)**		**Total %**
	n	**%**	**n**	**%**	
Trust rep to follow instructions/rep knows what CRAH wants	7	58.3	11	64.7	62.1
Advised against it	1	8.3	-	-	3.4
Didn't know you could	1	8.3	-	-	3.4
Didn't want to tie reps hands/best for rep to use their judgment	1	8.3	3	17.6	13.8
Not legally binding/better to rely on agreement	1	8.3	1	5.9	6.9
Didn't think of it	1	8.3	1	5.9	6.9
Procrastination	-	-	1	5.9	3.4

*19 people (6 males and 13 females) missing from analysis

4.7.2 RCRAHs

RCRAHs reported that only 34.2% of their RAHs had a written document that they were aware of and 30.8% of RCRAHs didn't know or couldn't remember what types of instructions were included in them. Of those who could specify the content, 15.4% said the written instructions included the RAH's feelings about life support; 15.4% said the document stated the representative was not to feel guilty if they had to make the decision to stop or forego life supporting treatment; 7.7% said the document contained the RAH's philosophy on life or death; 7.7% said it contained specific instructions on hospitalization, not being kept alive heroically and organ donation; 7.7% said the document outlined the parameters of care wanted; and 7.7% said it outlined in general what the RAH wanted.

Of those RAHs with written instructions, 57.1% were reported to have completed them prior to entering into their representation agreement; 21.4% of the RCRAHs said the document was completed at the same time as the representation agreement; 14.3% said it was worked on both before and after the agreement; and 7.1% didn't know when the instructions had been completed.

4.7.3 RIRAHs

Of the seven RAHs, four (57.1%) had a written document that outlined their wishes, values or specific instructions to guide the representative. Two of the RIRAHs (50.0%) said the written document contained instructions stating the RAH wanted no heroic measures taken and did not want to be resuscitated; one (25%) had the same instructions, but also included a statement that they wanted assisted suicide if necessary; one (25%) had a written document, but destroyed it when they entered into the representation agreement, because the document was not legally enforceable. Three (75%) of those with written documents had completed them prior to entering into the representation agreement; 25% composed the document at the same time as their agreement. Two of the RIRAHs (28.6%) were involved with the completion of written instructions.

In summary, the research question that CRAHs would also have written instructions setting out their wishes was not supported. Slightly less than one-third of CRAHs had completed written instructions along with their representation agreement; 62.1% of CRAHs said they had not completed written instructions because they were content to rely upon their representative to follow their instructions and 74.5% were extremely confident that their representative would make treatment decisions the CRAH would want.

4.8 Expectations and Interpretation of Expectations

All groups were asked a number of questions that were designed to shed light on what RAHs expected of their representatives, and how representatives interpreted their responsibility. It was hoped that these questions would allow insight into the nature of the relationship between RAHs and their representative.

4.8.1 CRAH's Expectations of Representatives

When CRAHs were asked if they expected their representative to carry out their wishes exactly as they had been stated or expressed, 70.8% said they did. As shown in Table 41, proportions were slightly higher for women than for men.

Table 41: Did CRAHs Expect their Representatives to Carry Out Wishes As Stated, by Gender

Carry out wishes as stated	Male (n=18) n	Male (n=18) %	Female (n=30) n	Female (n=30) %	Total %
Yes	12	66.7	22	73.3	70.8
No	4	22.2	5	16.7	18.8
Wishes not stated per se	2	11.1	3	10.0	10.4

When asked why their representative should carry out their wishes as stated or why they shouldn't, as shown in Table 42, the most common explanations were that CRAHs expected their representative to carry out their wishes and they had faith in their representative to do what the CRAH wanted. Men were slightly more likely than women to say that they had faith that their representative would do what they wanted, whereas women were slightly more likely than men to expect their representative to carry out the CRAH's wishes. Women were also slightly more likely than men to acknowledge that it may not be possible for their representative to carry out their wishes in all circumstances.

Table 42: Explanations Offered as to why Representative Should Carry Out CRAH's Wishes, by Gender*

Explanation	Male (n=15)		Female (n=27)		Total %
	n	%	n	%	
Has faith rep will do what CRAH wants	5	33.3	5	18.5	23.8
Expects wishes as understood by rep to be carried out appropriately	3	20.0	7	25.9	23.8
Willing to let rep use discretion, rep agreement a good guide	3	20.0	5	18.5	19.0
If possible, but sometimes other factors at play	1	6.7	5	18.5	14.3
Pointless if rep doesn't follow instructions	2	13.3	3	11.1	11.9
Has more faith in rep's judgment than has in own	1	6.7	2	7.4	7.1

*6 people (3 males and 3 females) missing from analysis

When asked if their representative should be allowed to use their discretion in making treatment decisions on the representation agreement holder's behalf, almost the entire group (97.9%) said they should; only 2.1% weren't sure if they should or not. When asked if there were any circumstances under which their representative should go against any previously stated wishes, 66.7% of CRAHs said no, however as set out in Table 43, men were slightly more likely than women to say there were circumstances under which their representative should go against the CRAH's wishes.

Table 43: Any Circumstances that Representative Be Permitted to Go Against CRAH's Wishes, by Gender

Are there circumstances under which rep can go against wishes	Male (n=18)		Female (n=30)		Total %
	n	%	n	%	
Yes	7	38.9	8	26.7	31.2
No	11	61.1	21	70.0	66.7
Not sure/can't think of any	-	-	1	3.3	2.1

When asked under what circumstances, 63.2% of CRAHs said that the whole point of having a representative was for them to evaluate the situation and make decisions accordingly, even if it went against previously expressed wishes of the CRAH; 26.3% said that if something unforeseen had happened, they wouldn't expect their representative to make inappropriate decisions; 10.5% said their representative could go against their wishes if in doing so there was hope that the CRAH would make a full recovery. As shown in Table 44, men were noticeably more likely than women to feel that their representative should evaluate any situation and act accordingly, even if it went against their previously expressed wishes. Women were more likely than men to feel that their representative could go against their wishes if something unforeseen occurred, but they wouldn't expect their representative to make inappropriate decisions. Women were also more likely than men to allow their representative to go against their wishes if there had been advances in medical technology that could not have been anticipated at the time the agreement was entered into that would mean the CRAH could make a full recovery.

Table 44: Circumstances Under Which Representatives Could Go Against CRAH's wishes, by Gender*

Circumstance	**Male (n=8)**		**Female (n=11)**		**Total %**
	n	**%**	**n**	**%**	
Rep to evaluate situation and act accordingly, even if goes against CRAH's wishes	7	87.5	5	45.5	63.2
If something unforeseen happens/wouldn't expect rep to make inappropriate decision	1	12.5	4	36.4	26.3
Advances in medical technology that would allow for full recovery	-	-	2	18.2	10.5

* 29 people (10 males and 19 females) missing from analysis

CRAHs were asked if their representatives should be allowed to consider the impact making treatment decisions may have on them to which 56.2% said yes; 41.7% said no and 2.1% weren't sure. There was no noticeable difference between men and women on this point.

With regard to any emotional burden decision-making may have on their representative, 60.4% said they were not worried about it; 39.6% said they had some concerns. Men were slightly more likely than women to have concerns about the emotional burden decision-making might have on their representative, as shown in Table 45.

Table 45: CRAH's Concerns about Emotional Burden of Decision-Making on Representatives, by Gender

Worry about emotional burden on rep	Male (n=18) n	%	Female (n=30) n	%	Total %
Yes	8	44.4	11	36.7	39.6
No	10	55.6	19	63.3	60.4

The majority (74.5%) of the sample was extremely confident that their representatives would make the treatment decisions that they wanted. As shown in Table 46, there were no sizeable differences between men and women with respect to levels of confidence regarding their treatment wishes being carried out by their representatives.

Table 46: Levels of Confidence Regarding Decisions Made by Representatives, by Gender*

Level of Confidence	**Males (n=17)**		**Female (n=30)**		**Total %**
	n	**%**	**n**	**%**	
Extremely confident	13	76.5	22	73.3	74.5
Very Confident	3	17.6	6	20.0	19.1
Somewhat confident	1	5.9	2	6.7	6.4
Not very confident	-	-	-	-	-
Not at all confident	-	-	-	-	-

*1 person (male) missing from analysis

When asked to rate on a scale of 1-5, with 1 being not at all important and 5 being extremely important, how important it was to them that their representative follow directions exactly as they had been set out by the CRAH, 43.5% felt it was extremely important; 34.8% felt it was very important; 13.0% thought it was somewhat important while 8.7% didn't think it was important at all. There was no significant difference between men and women on this point, as shown in Table 47.

Table 47: Level of Importance that Representatives Follow CRAH's Directions, by Gender*

Level of importance	**Male (n=18)**		**Female (n=28)**		**Total %**
	n	**%**	**n**	**%**	
Extremely important	8	44.4	12	42.9	43.5
Very important	6	33.3	10	35.7	34.8
Somewhat important	2	11.1	4	14.3	13.0
Not very important	-	-	-	-	-
Not at all important	2	11.1	2	7.1	8.7

*2 people (females) missing from analysis

4.8.2 RCRAHs Understanding of CRAHs Expectations

In order to gain insight into what the representative's interpretation of what the person they represent expected them to do when making treatment decisions, a number of questions similar to those asked of the representation agreement holders were posed. Representatives were asked if the CRAH had ever told them to carry out their treatment wishes exactly as they had orally stated them to the representative. Of the 38, 42.1% said yes; 26.3% said no; 10.5% weren't sure and 21.1% hadn't been told orally what the CRAH's wishes were. Women were slightly more likely than men to state that they had been told to carry out wishes exactly as stated and also slightly more likely than men to report that their CRAH had not expressed their wishes orally, as shown in Table 48. Men were slightly more likely than women to state that they had not been told to carry out wishes exactly as the CRAH had stated them. This is noticeably lower than when CRAHs were asked the same question – 70.8% of CRAHs said they had told their representative to carry out their treatment wishes exactly as they had stated them.

Table 48: Is Representative to Carry Out CRAH's Wishes as Orally Stated, by Gender

Carry out wishes as orally stated	Male (n=18) n	%	Female (n=20) n	%	Total %
Yes	7	38.9	9	45.0	42.1
No	6	33.3	4	20.0	26.3
Don't know/not sure	2	11.1	2	10.0	10.5
Wishes haven't been stated exactly	3	16.7	5	25.0	21.1

When asked if the representative had been told to follow any written instructions from the CRAH, 65.8% said there were no written instructions; 23.7% said yes; 5.3% said no; 2.6% weren't sure or didn't know; 2.6% said the CRAH had not exactly stated their expectation in this way. There were no noticeable differences between men and women as to their understanding of whether or not to follow written instructions, as set out in Table 49.

Table 49: Representative to Follow CRAHs Written Instructions, by Gender

Told to follow Written Instructions	Male (n=18)		Female (n=20)		Total %
	n	%	n	%	
No written instructions	12	66.7	13	65.0	65.8
Yes	5	27.8	4	20.0	23.7
No	-	-	2	10.0	5.3
Don't know/not sure	-	-	1	5.0	2.6
Not exactly	1	5.6	-	-	2.6

When asked what their understanding was of how to proceed in making treatment decisions, 28.6% of representatives said they would do what was in the CRAH's best interests; 23.8% said they would have to discuss the situation with the family and then make a decision; 19.0% said they would do what the CRAH wanted; 19.0% had general discussions with the CRAH and there was an assumption that the representative knew what the CRAH wanted, but hadn't been explicitly told what to do; 4.8% said they hadn't discussed anything in great detail with the CRAH and 4.8% said one couldn't predict everything. As set out in Table 50, women were slightly more likely than men to say they would do what was in the CRAH's best interest or do the right thing and were also more likely to discuss the situation with the family before making any decisions. Men were more likely than women to say they would do what the CRAH wanted and also were more likely than women to have had only general discussions with their CRAH, with an assumption that the representative knew what the CRAH would want.

Table 50: Representatives Understanding as to How to Proceed, by Gender*

Understanding of how to proceed	Male (n=12)		Female (n=9)		Total %
	n	%	n	%	
Do what's in the CRAH's best interest/do the right thing	3	25.0	3	33.3	28.6
Discuss with family and then make decision	2	16.7	3	33.3	23.8
Do what the CRAH wanted	3	25.0	1	11.1	19.0
General discussions/assumption rep knows what CRAH would want	3	25.0	1	11.1	19.0
Not discussed in great detail	1	8.3	-	-	4.8
Can't predict everything	-	-	1	11.1	4.8

*15 people (6 males and 9 females) missing from analysis

When asked if the CRAH had told their representative to use their discretion in making treatment decisions, despite any oral or written instructions they may have given, 47.4% said yes, 21.1% said that it hadn't been explicitly stated, but it was understood that the representative could use it; 21.1% said there had been no discussions regarding the use of discretion; 5.3% said no; 2.6% said it was not explicitly stated so they believed they should carry out the CRAH's wishes exactly as they had been stated; 2.6% believed they couldn't override every scenario but they could use their common sense when making decisions. Women were more likely than men to report having been told by the CRAH to use their discretion but otherwise there were no sizeable differences between the two groups, as set out in Table 51. This is noticeably different from what CRAHs said they had told their representatives – 97.7% of CRAHs said they had told their representative to use their discretion when making treatment decisions.

Table 51: Did CRAHs Tell Representatives to Use their Discretion, by Gender

Told to use discretion	Male (n=18)		Female (n=20)		Total
	n	%	n	%	%
Yes	7	38.9	11	55.0	47.4
No	1	5.6	1	5.0	5.3
Not explicitly stated, but understood can use it	4	22.2	4	20.0	21.1
Not explicitly stated so rep believes CRAH's wishes to be carried out as stated	1	5.6	-	-	2.6
No discussions	4	22.2	4	20.0	21.1
Can't override every scenario but expected to use common sense	1	5.6	-	-	2.6

When asked if they felt they should be allowed to use their discretion when making treatment decisions, 71.1% of representatives answered yes; 10.5% said no and 18.4% felt it depended. As shown in Table 52, women were slightly more likely than men to feel that they should be able to use their discretion and men were slightly more likely to feel that they should not be able to use their discretion. The two groups did not differ noticeably on whether or not they felt the use of discretion depended on other factors.

Table 52: Does Representative Feel They Should Use Their Discretion, by RCRAH's Gender

Ok for rep to use discretion	Male (n=18)		Female (n=20)		Total %
	n	%	n	%	
Yes	12	66.7	15	75.0	71.1
No	3	16.7	1	5.0	10.5
It depends	3	16.7	4	20.0	18.4

When asked why they should be allowed to use discretion or why they shouldn't, almost three-quarters (70.0%) said that situations needed to be interpreted, and since one can't predict everything, that was part of the point of having a representative – they could take the CRAH's wishes into consideration, depending on the situation that arose; 10% felt that discretion could not be used if the CRAH's wishes were known, they would try to follow them as closely as possible. Other reasons are set out in Table 53. As can be seen, there are no sizeable differences between men and women although women were more likely than men to cite concerns about having to live with the decisions they made or going against medical advice if they thought that is what the CRAH would want, whereas men were more inclined than women to not be in favor of the use of discretion if the CRAH's wishes were known, feeling that the CRAH had the right to have their wishes carried out.

Table 53: Why Representatives Should or Should Not be Allowed to Use Discretion, by Gender

Why or why not use discretion	**Male (n=14)**		**Female (n=16)**		**Total**
	n	**%**	**n**	**%**	**%**
Situations need to be interpreted	10	71.4	11	68.8	70.0
Not if wishes known	2	14.3	1	6.2	10.0
If wishes not explicit/gray area	1	7.1	1	6.2	6.7
Would go against medical advice if thought that's what CRAH would want	-	-	2	12.5	6.7
Has to live with decisions made	-	-	1	6.2	3.3
CRAH has right to have wishes carried out	1	7.1	-	-	3.3

*8 people (4 males and 4 females) missing from analysis

For those who felt the use of discretion was dependent, when asked what it depended on, 87.5% said the situation, while 12.5% said if the CRAH's wishes were known, one couldn't digress from them. As set out in Table 54, women were slightly more likely than men to say it depended on the situation and men were more likely than women to feel that they could not go against known wishes.

Table 54: What Does Use of Discretion Depend on, by Gender*

What does use of discretion depend on	Male (n=7) n	%	Female (n=9) n	%	Total %
The situation	5	71.4	9	45.0	87.5
If wishes known, can't digress	2	28.6	-	-	12.5

*20 people (11 males and 9 females) missing from analysis

A large majority (78.9%) of representatives could not think of any circumstances in which they would go against the CRAH's previously expressed wishes; 18.4% would and 2.6% said they might. As seen in Table 55, women were slightly more likely than men to say there were no circumstances under which they would go against the CRAH's wishes, while men were slightly more likely than women to say there were circumstances under which they would go against the CRAH's wishes.

Table 55: Would Representative Go Against CRAH's Previously Expressed Wishes, by RCRAHs Gender

Circumstances under which rep go against CRAHs wishes	Male (n=18) n	%	Female (n=20) n	%	Total %
Yes	4	22.2	3	15.0	18.4
No	13	72.2	17	85.0	78.9
Maybe	1	5.6	-	-	2.6

When asked under what circumstances they would go against the CRAH's wishes, 40% of RCRAHs said they would if they were not sure the decision was what the CRAH would really want if they were capable of making decisions; 40.0% felt they would if unforeseen circumstances had arisen; 10% said if the CRAH expressed that he or she did not want to live anymore, but there was clear evidence or a chance of medical hope they would; 10% couldn't imagine the situation coming up. Men and women did not differ noticeably.

When asked what they would do if called upon to make a decision where the CRAH had made clear what they wanted, but it was contrary to the decision the representative would make or required the representative to make a decision they did not want to make, half (50.0%) said they would carry out the CRAH's wishes, that being the whole purpose of being a representative; 13.2% said they would consult with family and medical professionals and then make a decision. Other reasons are set out in Table 56. While men and women equally agreed that they would carry out the CRAH's wishes, women were more likely than men to say they would consult with family and medical professionals before making any decisions. Men were slightly more likely than women to say they might override the CRAH's wishes in order to do what the representative thought was in their best interest. Women had more explanations of what they would do in a situation than men did.

Table 56: What Would Representative Do if Didn't Want to Make Decision, by Gender

What would rep do	Male (n=18)		Female (n=20)		Total %
	n	%	n	%	
Carry out CRAH's wishes	9	50.0	10	50.0	50.0
Consult with family/medical before making decision	1	5.6	4	20.0	13.2
Can't see situation arising	3	16.7	-	-	7.9
Might override CRAH's wishes in order to do what rep thinks is best for CRAH	2	11.1	1	5.0	7.9
Hopes would do what CRAH wanted	2	11.1	-	-	5.3
Go along with CRAH decisions, as long as they are reasonable	1	5.6	1	5.0	5.3
Don't know	-	-	1	5.0	2.6
Depends on situation	-	-	1	5.0	2.6
If wishes clear, would follow them	-	-	1	5.0	2.6
Take medical advise but promote CRAH's wishes	-	-	1	5.0	2.6

A large majority (60.5%) of representatives were not apprehensive about the possibility of being called upon to make treatment decisions on the CRAH's behalf with 42.9% commenting that it was a concern, but that they would do it; 14.3% said they were more apprehensive about their health holding up over time rather than any apprehension over making treatment decisions and 14.3% said they weren't at this point in time, but they might be when and if the actual time came to make decisions. Other reasons, as set out in Table 57, included that nothing was ever black and white and it was a great responsibility that required much thought. There were no sizeable differences between men and women on this point.

Table 57: Reasons for Being Apprehensive about Making Treatment Decisions, by Gender*

Reasons for Apprehension	**Male (n=5)**		**Female (n=2)**		**Total**
	n	**%**	**n**	**%**	**%**
It's a concern, but would do it	2	40.0	1	50.0	42.9
Great responsibility requiring much thought	-	-	1	50.0	14.3
Nothing is ever black and white	1	20.0	-	-	14.3
Not concerned about making decisions, but with health holding up	1	20.0	-	-	14.3
Not now, maybe when time comes	1	20.0			14.3

*31 people (13 males and 18 females) missing from analysis

When asked if they had any worries about the potential emotional burden making treatment decisions may have on them, 68.4% of the representatives said they weren't worried; 28.9% did have some concerns and 4% weren't sure. Men and women did not differ appreciably on this.

When asked to comment on what some of their concerns or worries about the potential emotional burden of decision-making, 27.3% felt there would be some degree of emotional burden and that they were not looking forward to having to make decisions and 18.2% were unsure how they would act, since they hadn't been in the situation yet. Table 58 sets out other concerns expressed. Men and women did not differ noticeably in their concerns.

Table 58: Representatives Comments About Emotional Burden of Decision-Making, by Gender*

Comment	Male (n=5)		Female (n=6)		Total %
	n	%	n	%	
Thinks there will be emotional burden/not looking forward to it	2	40.0	1	16.7	27.3
Hasn't happened so not sure how will act	1	20.0	1	16.7	18.2
Decisions made with best of intentions	1	20.0	-	-	9.1
Balancing risks of treatment against CRAH's wishes	-	-	1	16.7	9.1
Doesn't want CRAH to die, will do best they can	1	20.0	-	-	9.1
Depends on circumstances	-	-	1	16.7	9.1
Second guessing, wondering if made right decision	-	-	1	16.7	9.1
CRAH is aging, needs increasing	-	-	1	16.7	9.1

*27 people (13 males and 14 females) missing from analysis

When asked how confident they were that they would be able to make the treatment decisions the CRAH would want, 52.6% of representatives said they were extremely confident; 42.1% were very confident and 5.3% were only somewhat confident they would. As shown in Table 59, women were more likely than men to be extremely confident that they would make the treatment decisions that the CRAH would want.

Table 59: Levels of Confidence Regarding Treatment Decision-Making, by Gender

Confidence Level	Male (n=18)		Female (n=20)		Total %
	n	%	n	%	
Extremely confident	7	38.9	13	65.0	52.6
Very confident	10	55.6	6	30.0	42.1
Somewhat confident	1	5.6	1	5.0	5.3
Not very confident	-	-	-	-	-
Not at all confident	-	-	-	-	-

4.8.3 RIRAHs Understanding of RAHs Expectations

When asked if the RAH had ever told them to carry out their wishes exactly as they had orally stated them, 28.6% of RIRAHs said yes, 42.9% said no; 14.3% said their RAH had never explicitly stated so; 14.3% said the RAH never orally stated their wishes. As shown in Table 60, women were more likely than men to report that they had been told to carry out the RAH's wishes as stated. This is interesting when one considers that 70.8% of CRAHs said they had told their representatives to carry out their wishes exactly as stated.

Table 60: RIRAHs to Carry Out RAH's Wishes as Stated, by Gender

Carry out wishes as stated	**Male (n=3)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
Yes	-	-	2	50.0	28.6
No	1	33.3	2	50.0	42.9
Not explicitly stated	1	33.3	-	-	14.3
Wishes never expressed orally	1	33.3	-	-	14.3

When asked to explain their understanding of how to proceed, 50% of RIRAHs said they were to do the right thing or do what was in their RAH's best interests and 50% said they would take into account the RAH's feeling and values. As shown in Table 61, women were more likely than men to say they would do what was in the RAH's best interests or would do the right thing whereas men were more likely than women to say they would take the RAH's wishes or values into account when making treatment decisions.

Table 61: RIRAHs Understanding of How to Make Treatment Decisions, by Gender*

How to make treatment decisions	Male (n=2)		Female (n=2)		Total %
	n	%	n	%	
Take into account RAHs values and wishes	2	100.0	-	-	50.0
Do what is in RAHs best interest/do the right thing	-	-	2	100.0	50.0

*3 people (1 male and 2 females) missing from analysis

Half (50%) of the RIRAHs reported that they had been told to follow exactly any written instructions the RAH had provided; 25% said this was never discussed and 25% said their RAH had given them no written instructions. There were no noticeable differences between men and women on this point.

Almost three-quarters (71.4%) of RIRAHs said they had been told to use their discretion when making treatment decisions for the RAH; 14.3% had never had any discussions about the use of discretion; 14.3% had not been told to use their discretion. As shown in Table 62, women were slightly more likely than men to report being told to use their discretion when making treatment decisions. This again is interesting given that 97.4% of CRAHs said they had told their representatives to use their discretion in making treatment decisions and slightly less than half (47.4%) of RCRAHs said they had been told to use their discretion.

Table 62: Were RIRAHs Told to Use Discretion, by Gender

Told to use discretion	Male (n=3)		Female (n=4)		Total %
	n	%	n	%	
Yes	2	66.7	3	75.0	71.4
No	-	-	1	25.0	14.3
Never discussed	1	33.3	-	-	14.3

When asked if they should be allowed to use their discretion when making treatment decisions on behalf of the person they represent, 85.7% of RIRAHs felt they should while 14.3% said it depended on the situation. When asked to explain why they should be permitted to use discretion or why not, 57.1% said it was hard to define all situations, so they needed some latitude in order to make decisions; 28.6% said they would make decisions that were best for their RAH and 14.3% said they know the RAH well enough to know what they would want. As shown in Table 63, men and women did not differ noticeably in their explanations about the use of discretion.

Table 63: RIRAH's Explanations About Use of Discretion, by Gender

Explanation	**Male (n=3)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
Hard to define all situations, need some latitude to make decisions	2	66.7	2	50.0	57.1
Would make decisions that were best for RAH	1	33.3	1	25.0	28.6
If rep knows RAH well enough and knows what RAH would want	-	-	1	25.0	14.3

When asked if they would go against the previously expressed wishes of their RAH, 85.7% of the representatives said no. For the one representative whose RAH had not previously expressed any treatment wishes, they said they would make decisions that were in the RAH's best interests regardless of what the RAH now said they wanted. When asked what they would do if they had to make a decision the RAHs had made clear they wanted but required the RIRAH to make a decision they did not want to make, 66.7% would do what the RAH wanted and 33.3% said they would do what was in the RAH's best interests. Men and women did not differ noticeably on any of these points but RIRAHs differed slightly from RCRAHs on this point, as 78.9% of RCRAHs said they wouldn't go against previously expressed wishes of the CRAHs.

When asked if they were apprehensive about making treatment decisions on their RAH's behalf, 71.4% of RIRAHs said they were not and there were no appreciable differences between men and women. When asked to explain why they were apprehensive or why they were not, 42.9% said they were confident they knew what their RAH wanted; 14.3% said they were honoured to make decisions on the RAH's behalf; 14.3% felt apprehensive because they had no experience or background in making these types of decisions; 14.3% said they didn't want to be in the position of representative but it had to be done and 14.3% hadn't been apprehensive until they actually had to make decisions on the RAH's behalf. Aside from expressing confidence that they knew what had to be done, men and women had different apprehensions, as shown in Table 64.

Table 64: Explanations Regarding Apprehension Over Making Treatment Decisions, by Gender

Why or why not apprehensive	**Male (n=3)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
RIRAH confident knows what has to be done	1	33.3	2	50.0	42.9
Honored to be selected to make decisions for RAH	1	33.3	-	-	14.3
No experience or background	1	33.3	-	-	14.3
Doesn't want to be in that position but has to be done	-	-	1	25.0	14.3
Wasn't until had to make decisions	-	-	1	25.0	14.3

When asked about concerns over the emotional burden making treatment decisions may have on them, 85.7% of the representatives said they had none, commenting that they had to handle it, it was all part of their marriage vows or said they had to put their personal feelings in the background and be strong enough to carry out the RAH's wishes. There were no sizeable differences between men and women about their concerns with emotional burden.

Of those representatives who answered, all were extremely or very confident that they would be able to carry out the person's wishes, with no noticeable differences between men and women in terms of their level of confidence in decision-making. Nobody expressed any reservations with their confidence to carry out the RAH's wishes.

All of the representatives were extremely or very confident that they had or would make the treatment decisions that the RAH wanted or would want. As can be seen in Table 65, women were more likely than men to be extremely confident that they would make the treatment decisions the RAH would want, whereas men were more likely than women to be very confident about making the correct treatment decisions.

Table 65: Level of Confidence Had or Would Make Proper Treatment Decisions, by Gender

Level of Confidence	**Male (n=3)** n	%	**Female (n=4)** n	%	**Total %**
Extremely confident	1	33.3	3	75.0	57.1
Very confident	2	66.7	1	25.0	42.9

4.9 Comments on having an agreement or being a representative

All groups were asked to comment on the process of entering into a representation agreement, the experience of being appointed as a representative or the experience of having to act as a representative.

4.9.1 CRAHs Experiences with Representation Agreements

CRAHs were asked if there was anything they wished to add about their experience with entering into a representation agreement; 15.2% had no further comments. However, 43.5% said that it is a good idea and they were happy to have it; 13% felt representation agreements are not used enough and need to be better promoted; 10.9% commented that everyone at the RARC was very helpful and completing it with their assistance was an inexpensive option. Other comments are set out in Table 66. Men and women did not differ substantially in their comments, although each brought up different points.

Table 66: Comments by CRAHs on their experience with entering into an agreement

Comments made	Male (n=18)		Female (n=28)		Total %
	n	%	n	%	
Good idea/happy to have it	8	44.4	12	42.9	43.5
No further comments	3	16.7	4	14.3	15.2
Not used enough/need to be better promoted	2	11.1	4	14.3	13.0
RARC staff very helpful/inexpensive option	2	11.1	3	10.7	10.9
No problems with process	-	-	2	7.1	4.3
Should be reviewed by CRAH and representative yearly	1	5.6	1	3.6	4.3
Complicated process/confusion among legal profession	1	5.6	-	-	2.2
Only did it to keep peace in the family	1	5.6	-	-	2.2
Useful vehicle for bringing topic forward for discussion	-	-	1	3.6	2.2
Fearful that some people aren't entering into them of their own free will	-	-	1	3.6	2.2

4.9.2 RCRAHs Comments on Being a Representative

RCRAHs were asked if there was anything they wanted to say about their experience of being appointed as a representative or their feelings on being a representative and although 26.3% had no further comments to make, 15.8% said it was the right thing to do; 10.5% felt they would be able to make thoughtful decisions, having gone through the process and that it makes it easier to talk about; 7.9% expressed reluctance about acting alone. Other comments are included in Table 67. While men and women generally had different comments, men were slightly more likely than women to see acting as a representative as being the right thing to do whereas women were more likely than men to feel that the process had made it easier to make decisions on behalf of their CRAH.

Table 67: Comments made by representatives about being a representative, by Gender

Comments made	Male (n=18)		Female (n=20)		Total %
	n	%	n	%	
No further comments	5	27.8	6	30.0	26.3
Right thing to do	5	27.8	1	5.0	15.8
Easier to make thoughtful decisions	1	5.6	4	20.0	10.5
Reluctant to act alone	2	11.1	-	-	7.9
Thing you have to face as you get older	1	5.6	-	-	5.3
Enormous responsibility but also an honour	-	-	2	10.0	5.3
Strongly recommend to others/insurance policy	1	5.6	1	5.0	5.3
Need to be clear on what RAH wants	1	5.6	1	5.0	5.3
Good idea that needs to be better promoted	-	-	2	10.0	5.3
Position of trust	1	5.6	-	-	2.6
Have to be in contact with RAH so know if something changes	-	-	1	5.0	2.6
Concern about burden being representative has on rep's health	1	5.6	-	-	2.6
Essential in ensuring other's don't try to interfere with RAH's wishes/keeps decision-making in the family	-	-	1	5.0	2.6

The vast majority (84.2%) of representatives had no concerns about acting as a representative; 13.2% did have concerns and 2.6% said it depended as to whether or not they would have concerns. There were no sizeable differences between men and women as to whether or not they had concerns about acting as a representative.

Of those who did have concerns, as shown in Table 68, concerns were: not doing the right thing or not knowing what the CRAH would have wanted (25%); it being an emotionally difficult process (16.7%); the representative's own health and ability to cope over the long term (16.7%); the magnitude of responsibility was not to be taken lightly (16.7%); 8.3% said it would be difficult to act alone and they were glad other representatives had been appointed; 8.3% expressed concerns about the family and were glad to have the authority of a representation agreement; 8.3% were concerned about how they would carry out the CRAH's wishes. Men were slightly more concerned than women were about doing the right thing, or knowing for sure what the CRAH wanted, whereas women were slightly more likely than men to cite concerns about acting alone or having problems with the CRAH's family.

Table 68: Concerns Expressed by Representatives, by Gender*

Concerns	**Male (n=6)**		**Female (n=6)**		**Total %**
	n	**%**	**n**	**%**	
Doing the right thing/knowing for sure what the CRAH wanted	2	33.3	1	16.7	25.0
Emotionally difficult	1	16.7	1	16.7	16.7
Rep's own health and being well enough to carry out duties	1	16.7	1	16.7	16.7
Great responsibility/not taken lightly	1	16.7	1	16.7	16.7
How to carry out CRAH's wishes	1	16.7	-	-	8.3
Would have concerns if had to act alone, feels better other reps appointed	-	-	1	16.7	8.3
Glad to have authority of agreement, due to concerns about CRAH's family	-	-	1	16.7	8.3

*26 people (12 males and 14 females) missing from analysis

The majority (81.6%) of representatives felt they had enough information about the scope of their authority and what their legal responsibilities as a representative are, with no noticeable differences between men and women in terms of their level of understanding as to the scope of their authority or responsibilities. Of those who did not feel they had enough information about the scope of their authority or their responsibilities, 25% said they would find out when the time came; 12.5% said they would need to review the document; 12.5% said they wanted more information about what the CRAH wanted. Other explanations are set out in Table 69 and as can be seen, men and women had different requirements in terms of what they felt they needed in order to more fully understand what was expected of them as representatives.

Table 69: What Further Information Required by Representatives, by Gender*

Further Information required	**Male (n=4)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
Don't want the law getting in the way of carrying out CRAH's wishes	2	50.0	-	-	25.0
More information on what CRAH wants	1	25.0	-	-	12.5
Not comfortable situation but someone has to do it	1	25.0	-	-	12.5
Will find out when time comes	-	-	2	50.0	25.0
Need to review document	-	-	1	25.0	12.5
Don't know	-	-	1	25.0	12.5

*30 people (14 males and 16 females) missing from analysis

4.9.3 RIRAHs Comments on Representation Agreements

Most (60%) of the RIRAHs couldn't think of any improvements to make to the process and thought it was a sound way to proceed. However, 40% stressed the need for the representative to know the RAH's wishes, otherwise they felt too much pressure was put on the representative. There were no sizeable differences between men and women.

When asked about their experience with the process, two RIRAHs (33.3%) wished the RAH's doctor had told them about representation agreements earlier, because they felt they could have been better prepared if they had found out earlier; one (16.7%) was happy with the process; one (16.7%) were glad the RAH had an agreement; one (16.7%) commented that the family's reluctance to accept the inevitability of death made it difficult to carry out the RAH's wishes and one (16.7%) said it was a good thing to have if a person had family that was going to be problematic. As set out in Table 70, women were more likely than men to mention difficulties with family as reasons why they felt it was a good thing to have had the authority of a representation agreement. Men were more likely than women to express regret about not finding out about representation agreements earlier.

Table 70: RIRAHs Experiences with Representation Agreements, by Gender*

Comments on Experiences	**Male (n=3)**		**Female (n=3)**		**Total**
	n	**%**	**n**	**%**	**%**
Happy with process	1	33.3	-	-	16.7
Wished Dr. had told RIRAH about agreements earlier	2	66.7	-	-	33.3
Glad RAH had it	-	-	1	33.3	16.7
Family's reluctance to accept inevitability of death made it difficult to carry out RAH's wishes	-		1	33.3	16.7
Good thing to have if family going to be problematic	-	-	1	33.3	16.7

*1 person (female) missing from analysis

When asked if there was anything the representative would like to say about their experience of being appointed as a representative or their feelings on being a representative, 42.9% responded that it was a good thing for the RAH and the representative; 14.3% said the RARC did "a hell of a good job" with the information;

14.3% found it helpful knowing exactly what their RAH wanted; 14.3% said they wouldn't be a representative again and 14.3% said they would be okay as long as they had the support of their family. While men and women agreed that having an agreement was beneficial for both the representative as well as the RAH, their comments about their experiences differed slightly, as shown in Table 71.

Table 71: RIRAH's Experience with Representation Agreements, by Gender

Comments on RIRAHs experience	**Male (n=3)**		**Female (n=4)**		**Total %**
	n	**%**	**n**	**%**	
Good thing for RAH and RIRAH	2	66.7	1	25.0	42.9
RARC did good job with information	1	33.3	-	-	14.3
RIRAH will be ok as long as has family support	-	-	1	25.0	14.3
Wouldn't do it again	-	-	1	25.0	14.3
Helpful knowing what RAH wanted	-	-	1	25.0	14.3

All of the RIRAHs felt that they had enough information about the scope of their authority and what their legal responsibilities were and 85.7% had no concerns about acting as a representative; one person (14.3%) said they had no concerns when they were appointed, but when it came time to act, they had problems with the family. There were no appreciable differences between men and women.

CHAPTER 5: DISCUSSION

5.1 Socio-demographic characteristics

The first research question dealt with the socio-demographic characteristics of those who have representation agreements. Based on the literature from the United States, conflicting findings regarding socio-demographic characteristics and uncertainty about whether or not different groups of people were using instructional in contrast to proxy directives, it was important to include questions about socio-demographics of users in the study to see if the same groups of people in Canada or more specifically British Columbia are attracted to proxy directives as seem to be in the United States. There has been some concern expressed that the usefulness of advance directives may be linked to a "middle class" approach to health care and for this reason, may only appeal to a specific subset of the population, which limits the usefulness of advance care planning documents (Murphy, Palmer, Azen, Frank, Michel and Blackhall, 1996). There has also been concern that advance directives are a North American or Western European concept, because of their emphasis on individual autonomy, which may not be a concept shared by other ethnicities (Martin, Emanuel and Singer, 2000). If effective advance care planning tools are to be developed and successfully implemented, it must first be determined who is using the tools that are currently in place.

As expected, the sample of CRAHs who volunteered to participate in the study was predominantly white, upper-middle class, highly educated females. The study also revealed that while a majority were seniors, 18.8% were under age 65. It also showed that less than half were married. CRAHs were in generally good health and showed a health profile similar to that of the general population of seniors in BC. Where they differed most was in having higher incomes and in being more highly educated. Generally, it appears that users of representation agreements in British Columbia have similar socio-demographic characteristics to users of advance care planning tools in the United States. Further, studies from the United States have yielded conflicting evidence with regard to whether or not having a religious affiliation is predictive of having an advance directive. In this study, 45.8% of CRAHs reported a religious affiliation.

No predictions were made regarding the socio-demographic characteristics of representatives. However, it was determined that RCRAHs were younger than either the CRAHs or RIRAHs but similar in health to CRAHs. This group was also not representative of BC senior's population in that the majority reported having incomes over $40,000 and had completed a university degree, although they were less likely than the other two groups to have obtained a post-graduate degree.

RIRAHs were more likely than CRAHs but less likely than RCRAHs to be married. They were less likely than CRAHs but more likely than RCRAHs to report having a religious affiliation (28.6% compared to 18.4% of RCRAHs). They were in better health than either CRAHs or RCRAHs . They were also not representative of the senior population in BC in terms of education and income, reporting higher incomes and levels of education than the average senior.

5.1.1 Locus of Control

Based on studies that found internal control associated with having an advance directive, it was expected that CRAHs would have a low score on Rotter's Locus of Control scale, indicating a propensity towards internal control, meaning they are more likely to feel that their health outcomes are in their own hands or control rather than someone else's. The mean score for the 37 people who completed the scale was 8 out of a possible 23, supporting the hypothesis. The finding of male CRAHs having significantly lower Rotter scores (and higher internal locus of control) than female CRAHs was unexpected in light of findings from general locus of control studies. It should be noted however, that while many studies using the scale have reported similar means and standard deviations for males and females, there has also been suggestion of a sex role bias in the scale, with significant sex differences found on 8 of the 23 items when individual item analysis was performed (Strickland and Haley, 1980). However, Strickland and Haley's hypothesis that males would be more internal in response to personal control items in the scale was not supported, but sex differences were most prominent on the personal control factor within the scale. Regardless, what is most important with respect to the present study is that both male and female CRAHs tended to be persons with a high need for control.

5.2 Communication between agreement holders and representatives

Caution also needs to be exercised with respect to assumptions made about the extent and nature of communication between RAHs and their representatives. It was hypothesized that there would be minimal discussions between RAHs and their representatives as to treatment preferences. While technically this was not found to be the case, since 81.2% of CRAHs and 81.6% of RCRAHs reported having had discussions about treatment wishes, whether or not these discussions had been detailed enough to provide representatives with clear guidelines as to what treatments were wanted or not is a different question. There appears to be a reliance on unspoken knowledge of what RAHs would want, and confidence among the CRAHs that their representative would know what to do, despite a lack of specific discussion or specific written instructions. A common response on the part of CRAHs as to why they had not had discussions with their representative, who in most cases was either their spouse or a family member, was because "they know me, they know what I would want" or "when you've been together as long as we have, you just know what the other person would want". In fact, 74.5% of the CRAHs were extremely confident that their representatives would make the treatment decisions that the CRAHs would want. However, only 52.6% of RCRAHs shared that same level of confidence.

As the evidence from the United States has shown, cursory discussions or faith in the judgment of the representative may not be sufficient to ensure that a CRAH's wishes are carried out. Interestingly, fewer RIRAHs (14.3%) than RCRAHs reported having only general discussions with their RAH. It may be that because the RAHs in this group were in poorer health and a decline in health over a period of time was cited as a precipitating reason for having entered an agreement, the necessity of discussing treatment wishes was more urgent than it was felt to be for those RAHs still in relatively good health. Also, the majority of RAHs had written instructions outlining their wishes or instructions to guide the representative.

5.3 Motivating Factors

Another assumption the findings from this research challenges concerns the triggering event for entering into a representation agreement. It was thought that there would be a very specific situation or event that precipitated entering into an agreement, given the time and expense it takes to do so. One explanation was thought to be family discord or distrust or having no family on which to rely upon. While the majority of CRAHs interviewed (68.8%) did not provide much reason beyond "it seemed like a good idea", when asked to describe in their own words why they had entered into a representation agreement, evidence of what most commonly spurred them into obtaining an agreement can be broken into situational and conceptual scenarios. In the situational context, CRAHs mentioned such things as their past experiences with loved ones and ensuring that the same things didn't happen to them, past experiences with the health care system or the case of Terry Schiavo in the United States. Only 14.6% said they were on their own or had no family to trust and 2.1% cited avoiding family disputes as reasons for having an agreement. Therefore, there is no evidence to support the assumption that family discord would be a reason cited for entering into an agreement.

In the conceptual context, control over their future was a key, underlying theme that was apparent in answers to many questions. In answer to why they had appointed a representative, 39.6% said it was to ensure their wishes were followed; 27.1% said to have control over their future; 18.8% wanted to choose who would make decisions on their behalf and 22.9% referred to the legality of the agreement in ensuring their wishes would be followed. Women were slightly more likely than men to mention control. When asked what effect they hoped having an agreement would have, 56.2% said they hoped it would ensure that their wishes were followed or known; 54.2% saw the agreement as an insurance policy against future incapacity, which gave them peace of mind; 29.2% felt it would maintain their control and 18.8% hoped it would preserve their autonomy and dignity. Again, slightly more women than men used the word "control". Overall, the CRAHs scored towards the internal end of Rotter's Locus of Control scale, yet an independent t-test showed that men scored significantly lower on the scale than women. However, when asked how important it was to be involved in health-care decision-making, women were noticeably more likely than men to say it was extremely important. In response to the question of whether or not having a representation agreement made them feel like they had achieved a sense of control over their future, men were slightly more likely than women to say it had, and men were more likely than women to say that having a representation agreement was like having an insurance policy, which gave them peace of mind. It may be that the concept of control is more important for women than men because, due to their longer life expectancy, they anticipate being alone at a time of incapacity and at the mercy of strangers, compared to men, who will likely still be married and have their spouse to rely on. Since response to the two other questions relating to control were not found to differ significantly between men and women however, it is difficult to explain why they differed on Rotter's scale but not on the other measures of control. Another problematic area is that when asked what their understanding was of how to proceed when making treatment decisions on the CRAH's behalf, while 78% of CRAHs said it was extremely or very important to them that their representative follow their instructions, only 19% of RCRAHs said they would do what the CRAHs wanted. Another 28.6% said they would do what was in the CRAH's best interests, which may not be what the CRAH would want.

Another conceptual theme that was evident was that of making things easier for one's family, with 33.3% of CRAHs citing that as a reason to have an agreement, which has been found in other studies to be a key factor behind advance care planning (Singer, Martin, Lavery, Thiel, Kelner and Mendelssohn, 1998). Women were slightly more likely than men to mention this reason.

5.4 Written Instructions

It was predicted that people entering into representation agreements would have some type of written document setting out their treatment preferences, whether it be to ensure their wishes were known and followed or whether it was to ease any potential burden on their representative. However, only six of the 48 CRAHs (12.5%) reported having expressed their wishes in written format, either within the representation agreement or in a separate document. Interestingly, when RCRAHs were asked if their RAH had written instructions, 34.2% said yes. The RIRAHs reported that four of their seven RAHs had written instructions. However, when asked how they had made decisions on the RAH's behalf, none of the RIRAHs mentioned referring to the written document to help guide their decision-making. They did mention taking into account the RAH's wishes, but it is not clear if that included wishes expressed within a written document.

When CRAHs were asked why those who had written instructions completed a representation agreement as well, they cited several reasons, none of which related to ensuring their treatment wishes were known or easing the burden on one's family. Further, from the evidence regarding discussions between CRAHs and their health-care providers, it is clear that the majority of CRAHs had not discussed their treatment wishes with their providers, although 42.6% had told their health-care provider that they had appointed a representative. One would think that if CRAHs were concerned with ensuring their wishes were known or easing the burden on their family, they would have told their health-care provider about their treatment preferences and wishes, so as to avoid any uncertainty at a time when it might be necessary to make treatment decisions. Therefore, written instructions do not seem to have had the attraction that it was thought they would, which is somewhat surprising for a group that seems to be concerned with control and ensuring their wishes are followed.

5.5 Discussions with health-care providers

When asked why they hadn't given a copy of their representation agreement to their health-care provider, 67.6% of CRAHs said they were content to rely on having their agreement available on NIDUS, a database to which representatives and health-care providers have access. While this may be a good idea if one were to require emergency care and a copy of one's representation agreement could not be located and one were receiving treatment in a hospital by someone other than their usual health-care provider, not telling one's health care providers about the agreement's existence assumes that health-care providers will take the initiative to consult the database, yet there has been anecdotal evidence to suggest that this may not occur.

It was thought that representatives may encounter difficulties with respect to health-care providers accepting the treatment decisions they made on behalf of their

RAH, which would make the reliance on NIDUS perilous. Unfortunately, the sample of people participating in the study who had actually used their powers under a representation agreement was small. However, five (71.4%) of the seven representatives of no longer capable RAHs had made end-of-life decisions. On a positive note, all reported having found health-care professionals receptive to them in their role as a representative, and all found having the authority given to them by the RAH under the agreement helpful in discussions or decision-making.

5.6 Gender Differences

Although it was assumed that women would be more likely than men to use representation agreements, gender differences were not considered when formulating the research questions. However, upon reviewing the data, it became apparent that there were some differences between men and women on some of the variables under investigation. For example, while male and female CRAHs did not differ in the frequency with which they had discussions about their feelings and values regarding treatment decisions, when those who hadn't had discussions were asked why they had not, men were more likely than women to say that their representative would know what they wanted (100% compared to 62.5%).

With regard to written instructions, while only a small portion of the sample of CRAHs had written instructions contained either within the representation agreement or in a separate document, such as a living will, women were more likely than men to have made reference to this type of document.

Men and women did not differ dramatically in their expectations that their representative would carry out their wishes exactly as they had expressed them, although women were slightly more likely than men to expect this. Men were slightly more likely than women to say that they had faith that their representative would do what they wanted. Men were slightly more likely than women to feel there were circumstances under which their representative could go against their previously expressed wishes.

It is difficult to speculate as to what is behind the gender differences that became apparent. However, the possibility that men and women enter representation agreements for different reasons or have difference expectations should be considered in future studies. While the evidence showed that mainly women used representation agreements, men use them as well and their motivations would be an interesting area of investigation. The fact that representation agreements appear to appeal to both men and women with tendencies toward inner locus of control, as shown by their scores on Rotter's scale should be kept in mind in future efforts to educate and promote representation agreement use.

5.7 Limitations

A prospective study was undertaken. One difficulty with undertaking prospective research in this area is that the number of individuals in British Columbia who have representation agreements and have had to use them is limited. Another limitation of the study is that the majority of CRAHs and representatives were party to different agreements. The ideal study design would have been to interview people who entered into a representation agreement as well as their representative in order to explore and draw inferences about communication patterns between the two. However, response to the invitation to participate was far greater from people with agreements than it was from their representatives. This may be because in a number of cases, representatives were children of the CRAHs and when the CRAHs was asked if their representative would be interested in participating, the CRAHs stated their representative was too busy or wouldn't be interested and would not be able to participate. Therefore, in many cases, it was only possible to interview the CRAH's spouse if they were the CRAH's representative. This may explain the disproportionate number of RCRAHs who were married. This problem was exacerbated by the fact that the RARC only has addresses for those CRAHs who have agreements on file, not the addresses of their representatives. As a result, letters could only be sent to people who had actually entered the agreements. This may also explain the lack of response from representatives of RAHs who are deceased or no longer capable of making decisions – it is possible that letters of invitation to participate were not received. If letters of invitation could have been sent to representatives in addition to agreement holders, more representatives who were not spouses may have participated in the study.

Also, given the reliance in using the RARC to send out letters of invitation to their clients, people who have agreements that entered them through other means had no way of finding out about the study and may have had different characteristics than the pool of participants who did their representation agreement through the legal clinic held by the RARC and that responded to the RARC's letter. Efforts to recruit participants through two different lawyers were not successful in obtaining a meaningful number of respondents and since no methods of advertising in different venues were used, it is possible that respondents recruited through the RARC differ from other representation agreement users. It is unusual that although the participants were from a higher income bracket than the majority of BC's senior population, they entered their agreements through the RARC, a non-profit society that offers legal clinics at much lower prices than if one were to consult a lawyer independently.

Although it was beyond the scope of this report to provide a detailed description of the history of the development and implementation of the *Representation Agreement Act*, the context within which this occurred and the impact it has had on the legislation and how it is used is an important consideration that should be explored in future studies. It is clear from responses made by participants in this study that there is a certain amount of misinformation and confusion surrounding the use and utility of these agreements. Very few people in this study learned of representation agreements from their health-care provider or legal advisor. This in turn, has implications for the representativeness of the sample. The fact that the RARC provides education and specialized services in this area at an affordable price may be the reason that they have attracted more users than lawyers in private practice have. In other words, it is possible that of the very small number of people using agreements, the majority may have enlisted the services of the RARC to do so. If that is the case, there may not be a large number of users who were missed because of the recruitment method used in this study.

As mentioned earlier, the ideal study design would have been to interview dyads of RAHs and their representatives in order to determine levels of concordance between the groups. A limitation of this study is that since CRAHs and the RCRAHs were not necessarily related, concordance of views could not be tested. However, patterns between the two groups were identified and this information could be useful in designing future studies.

Overall, sample sizes are small and caution must be used in the weight that can be placed on the results and their interpretation. As mentioned earlier, caution must be used in extrapolating research findings from the United States to Canada, in light of the differences between the two countries. Given the dearth of Canadian research in this area, the researcher was forced to develop her own questionnaires based on literature mostly from the United States. There was insufficient time and opportunity to establish the reliability and validity of the questions asked thus limiting the weight that can be placed on the answers given. Also, questions were asked of representatives about their RAH's motivations for entering into representation agreements or their interpretation of what the RAH they represent might have thought or felt about certain situations. This is not ideal because in some cases the representative may not know, or the reason motivated the action may not be what the RAH would have said. On the other hand, it gives insight into what the representative thought was the RAH's motivating factors, and since in many cases, the representative was a close family member, it may be quite accurate. This approach was also important to see if any differences emerged between the CRAHs interviewed and those described by the two groups of representatives.

Another potential limitation of the study is in the way data were captured and in the coding of themes. During the interviews, the majority of which were by telephone and not tape-recorded, care was taken to ensure that respondent's answers were written down exactly as stated, with no paraphrasing or interpretation by the researcher.

However, it is always possible that responses were not accurately reported. In future studies all interviews, whether in person or on the telephone, should be tape-recorded.

In order to code data, all responses were read and themes identified, which requires a degree of interpretation. As another researcher did not review the responses, there is a possibility of bias or misinterpretation that may skew results. Ideally, two or more individuals should code the data and concordance rates should be calculated.

5.8 Recommendations for Future Research

It is hoped that this research will provide a starting point for future research in the area. One of the biggest disappointments was that inadequate numbers of representatives for people who have become incapable were recruited. It is crucial to further explore people's experiences with these agreements, in order to gauge what sort of impact they have and whether they do what the people who enter into them hope they will - i.e. to determine whether having a representation agreement ensures that one's wishes are followed at a time when one is no longer capable of making decisions on one's own behalf. As agreement holders get older, the numbers of those becoming incapable is likely to increase, therefore making it easier to obtain a sufficient sample of representatives who have had to use their authority under a representation agreement.

The RCRAHs sample provides us with some interesting data on representative's perceptions and understandings of how they are to make decisions on behalf of their RAH. It would be interesting to investigate dyads of CRAHs and their representatives to further explore communication patterns and concordance of expectations and understandings of how to proceed between the two groups and to compare and contrast spousal dyads and dyads who have relationships other than spousal. One way to examine this area would be to consider the argument of Maltby and Fins (2004) which is that the approach to advance care planning has relied too heavily on the concept of self-determination and has failed to recognize the nature of the relationship between patient and proxy. They suggest that rather than being an exercise in autonomy with a contractual notion of responsibility to the stated preferences of a proxy, a covenantal model of advance care planning more accurately explains how patients and their proxies make decisions. Maltby and Fins argue that patient-proxy relationships exist on a contractual-covenantal continuum and contain elements of both. The data from this study suggests this may be true, but requires further examination and analysis.

Another area of investigation would be to investigate why people feel these agreements are necessary. Evidence from this study indicates that some people have them because they sounded like a "good idea" or were part of the estate planning function. But the findings regarding ensuring wishes were followed or maintaining control didn't delve into why it is that people feel their wishes wouldn't be followed if they didn't have this kind of agreement. Getting at the reasons behind why they are considered a "good idea" would go a long way in furthering understanding in this area. Perhaps this is a tool that is only of interest to a particular subset of people but it also hints at a larger, systemic problem, perhaps with people's perceptions of how the health care system operates at a time of incapacity or fears of dying.

Some evidence emerged of gender differences surrounding the use of and expectations surrounding representation agreement use. Future studies should be cognizant of potential gender differences, attempt to flush them out and look for explanations behind them.

5.9 Conclusion

This study's purpose was to determine who in British Columbia is using representation agreements and why. Given the relatively low numbers of people using advance directives, either instructional or proxy, until it is understood why so few people actually implement a directive, or what they expect from having an advance directive, regardless of it's form, efforts to expand advance care planning options may not be effective. It is clear that having a representation agreement brings peace of mind and a sense of control over their future to some of those who have them, but there are still many more questions to be answered.

This is an area that continues to evolve. Although at present instructional directives have limited standing in British Columbia, changes to the legislation are coming. In November 2007, the *Adult Guardianship and Planning Statutes Amendment Act* received royal assent. Under the *Act*, instructional directives, i.e. advance directives, would receive legal standing. Changes to representation agreements are included in the legislation as well. In light of the relatively small number of people who have used representation agreements since the legislation allowing for their use was passed in 2000, and their apparent lack of promotion by health care providers and legal advisors, increased efforts to educate people concerning the potential benefits of advance directives will be important. There also needs to be more discussion of the advantages and disadvantages of both types of directives so that people can choose the one that best meets their particular needs. Also, although women were more prominently represented in this study than males, it may be that the appeal of advance directives is related more to desire for control than it is to gender. This possibility should be considered in both education and marketing efforts.

Since the *Act* is not yet in force, it is difficult to speculate on what impact the legislation will have. However, it is clear that this is an area that will continue to grow and change and will remain an important area of research in the future, in order to ensure that effective advance care planning tools are available to those who want them.

APPENDIX 1: INVITATION TO PARTICIPATE

To Whom It May Concern,

My name is Wendy Harrison and I am a graduate student in gerontology at Simon Fraser University. As part of my Master's degree requirements, I am working on a project regarding representation agreement use in BC. I am specifically trying to gather information on who uses these agreements and why, because although the *Representation Agreement Act* came into force in 2000, there has been no data gathered on the use of these agreements and people's experiences with them.

I am enlisting the help of organizations and lawyers who do work within this area. You are receiving this letter because you have been identified by one of these sources as a person who has completed a representation agreement.

The focus of my study is on people who have completed agreements under s. 9 of the *Act.* I wish to interview adults who have entered into a representation agreement, representatives appointed by an agreement and representatives of adults who are no longer capable. The interview will take about 45 minutes. It can be conducted in person or by telephone. All information gathered in the interviews will be kept strictly confidential.

If you are willing to participate or if you have any questions, please contact me at the number listed below or by email. You may also contact my academic supervisor, Dr. Gloria Gutman, at 604-291-5063.

Thank you very much for considering this request.

Sincerely,

Wendy Harrison
Tel: 778-782-5062
E-mail: wth@sfu.ca

APPENDIX 2: INFORMED CONSENT

Form 2- Informed Consent By Participants In a Research Study

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by email at hweinber@sfu.ca or phone at 778-782-6593.

Your signature on this form will signify that you have received a document which describes the procedures, whether there are possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

Title: Representation Agreements in British Columbia: Who is Using them and Why?

Investigator Name: Wendy Harrison

Investigator Department: Department of Gerontology

Having been asked to participate in the research study named above, I certify that I have read the procedures specified in the Study Information Document describing the study. I understand the procedures to be used in this study and the personal risks to me in taking part in the study as described below:

Purpose and goals of this study:

This study is designed to investigate the characteristics and experiences of capable and incapable adults who have entered into representation agreements as well as those who are appointed as representatives.

What the participants will be required to do:

Submit to an interview, administered either in-person or by telephone.

Risks to the participant, third parties or society:

There are no risks to participating in this study.

Benefits of study to the development of new knowledge:

The benefits of this study are there have been no other studies done that have examined the use of representation agreements in BC and given the changes underway in the area of adult guardianship, it would be useful to know what the characteristics and experiences of people who have these agreements are.

Statement of confidentiality: The data of this study will maintain confidentiality of your name and the contributions you have made to the extent allowed by the law.

Date will be kept in a locked file cabinet. After the study has been completed and reported, all raw data will be destroyed.

Interview of employees about their company or agency:

N/A

Inclusion of names of participants in reports of the study:

If it necessary to refer to participants, they will be referred to by their study ID number or a pseudonyms and not their own names.

Contact of participants at a future time or use of the data in other studies:

There is no intention to contact participants at a future time or use the data in other studies.

I understand that I may withdraw my participation at any time. I also understand that I may register any complaint with the Director of the Office of Research Ethics.

Director, Office of Research Ethics
8888 University Drive
Simon Fraser University
Burnaby, British Columbia
Canada V5A 1S6
+1 778 782 3447
email: dore@sfu.ca

I may obtain copies of the results of this study, upon its completion by contacting:

Wendy Harrison wth@sfu.ca

I understand the risks and contributions of my participation in this study and agree to participate:

The participant and witness shall fill in this area. Please print legibly

Participant Last Name:	Participant First Name:

Participant Contact Information:

Participant Signature (for adults):	Witness (if required by the Office of Research Ethics):
Date (use format MM/DD/YYYY)	Contact at a future time / use of data in other studies

APPENDIX 3A: INTERVIEW GUIDE FOR CRAHs

Introduction: Thank you for agreeing to participate in this research. I am going to start out by asking you some general questions about yourself. Please remember that you may refuse to answer any questions that you do not feel comfortable answering. Your responses will be kept in the strictest confidence and you will not be able to be identified in any way by your answers. You are free to terminate this interview at any time.

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. What was your age as of your last birthday: __________

2. Sex: ______ Male
______ Female

3. What is your highest level of educational attainment

________Some high school
________High school graduation
________Some college or university
________University graduation eg. B.A., BSc. (Specify)
________Some post-graduate education e.g. First year MSc. program in nursing (Specify)
________Graduate degree e.g. MA or PhD in Psychology (Specify Degree)

4. In what country were you born? _____________

If other than Canada, ask:

4A. What year did you come to Canada? __________

4B. What is your immigration status? __________

5. Marital Status

________Married/Common Law
________Widowed
________Divorced/Separated
________Never married
[If widowed, ask] About how many years is it since your partner passed away?

____

6. Do you have an affiliation with a religion?

__________Yes
__________No

[If yes, ask] What religion do you consider yourself to be affiliated with? ____________

7. On a scale of 1-5, with 1 being not at all active and 5 being very active, how active in your religion do you consider yourself to be? __________

8. Do you have any living children, either natural or step?

________Yes
________No

9. If yes, how many living children do you have and what is their relationship to you?

____

10. How many live within 60 minutes car travel of you? __________

11. In a typical month, how often do you speak with one or more of them? __________

12. How would you describe your relationship with your children? _________________

13. Are there any minor children or other persons who rely on you for care and/or support?

___________Yes
___________No

[If yes, ask] Please tell me who relies on you. (e.g. Minor child, adult child with disability, spouse, etc.)

14. I am going to mention some common health problems that people may suffer from. Please tell me if you have been diagnosed with any of these problems and the degree to which you feel you suffer from them (i.e. mild, moderate, severe). Please tell me about all that apply.

Health problems	**Suffers from**	**Mild**	**Moderate**	**Severe**
Cancer (Please specify type)				
Heart disease				

High blood pressure				
Breathing problems (e.g. Asthma, COPD, please specify)				
Cerebrovascular disease (e.g. stroke, other)				
Congestive heart failure				
Arthritis				
Rheumatism				
Diabetes				
Neurological disorders (e.g. Parkinson's disease, MS (Please specify)				
Alzheimer's disease or other dementia				
Depression or other mood disorder				
Other (Please specify)				

15. How did you find out about this study?

_______Received letter from Representation Agreement Resource Centre
_______Received letter from lawyer
_______Other

B. SOURCE OF INFORMATION/REASONS FOR ENTERING INTO REPRESENTATION AGREEMENTS

I am now going to ask you some questions related specifically to representation agreements.

16. What year did you enter into your representation agreement?

17. How did you find out about representation agreements? Did you:

Source of information	**Yes**	**No**
Discuss them with health care provider		
Discuss them with legal advisor		
See an article in a newspaper or community newsletter.		
Get referred by someone to the Representation Agreement Resource Centre website? [If yes, ask} Who told you about the website?		
Attend presentation by Representation Agreement Resource Centre		
Other source (Specify)		

18. Did you seek information and/or assistance with making a representation agreement from a group or individual?

___________Yes
___________No

[If yes, ask] Who did you seek information/assistance from?

19. What types of information/assistance did you receive? Did you:

Information/Assistance Received	**Yes**	**No**
Get handouts (brochure, written material, pamphlet		
Attend a presentation		
Meet with someone from the Representation Agreement Resource Centre or a lawyer		
Get a referral		
Other (Please specify)		

20. On a scale of 1-5, with 1 being not at all helpful and 5 being extremely helpful, how helpful did you find the information/assistance that you received? ___________

21. Did you go to a lawyer to complete your agreement?

___________Yes
___________No

[If yes, ask] What kind of information/assistance did you get from your lawyer?

On a scale of 1-5, with 1 being not at all satisfied and 5 being extremely satisfied, how satisfied are you with the information/assistance you received from your lawyer?

____

22. In your own words, why did you enter into a representation agreement?

23. In your own words, what affect do you hope having such an agreement will have?

24. S. 9 of the *Representation Agreement Act* says you can authorize your representative to do certain things on your behalf. What have you authorized your representative to do on your behalf? Please specify.

25. Did you restrict your representative's authority in any way?

__________Yes
__________No

[If yes, ask] Why did you restrict your representative's authority?

[If yes, ask] In what way did you restrict your representative's authority?

C. INSTRUCTIONS/DISCUSSIONS WITH YOUR REPRESENTATIVE

26. What events led up to you deciding to have a representative and a representation agreement?

27. Did you appoint more than one representative?

________Yes
________No

28. What is your representative(s) relationship to you?

Rep 1:
________Spouse (including common law partner)
________Same sex partner
________Family member (e.g. Son/daughter, niece/nephew, etc) Please specify.
________Friend
________Other (Please specify)

Rep 2:
________Spouse (including common law partner)
________Same sex partner
________Family member (e.g. Son/daughter, niece/nephew, etc) Please specify.
________Friend
________Other (Please specify)

29. How long have you known your representative(s)? ____________

30. Does your representative(s) live within 60 minutes car travel of you?

________Yes
________No

31. How often do you talk with your representative? __________

32. Did you appoint an alternate representative?

_______Yes
_______No

[If yes, ask] Why did you appoint an alternate?

33. Did you appoint a monitor?

________Yes
________No

[If yes, ask] Why did you appoint a monitor?

[If yes, ask] What is the relationship of the monitor to the adult?

34. Why did you choose the person you did to be your representative?

Rep 1:

Rep 2:

35. Have you had any discussions with your representative(s) about how to proceed in the event of your incapacity?

_______Yes
_______No (Skip to question 39)

36. If you have had discussions, what types of situations have you discussed? For example, in the event of a life-threatening illness or event, some people may want to receive all treatments available while others may only want certain treatments.

37. Have you discussed with your representative your feelings and values about these types of situations and what impact this should have on how your representative makes treatment decisions?

________Yes
________No

38. About how many discussions have you had?_________

39. If you have not had any discussions about your values or wishes with your representative, why not?

40. Did you include any wishes or instructions in your representation agreement?

_______Yes
_______No

[If yes, ask] What kind of wishes or instructions did you include?

41. Did you make reference in your representation agreement to any written instructions, such as a living will to help guide your representative's decision-making?

_______Yes
_______No [Skip to question 44]

42. Did you complete these written instructions before, after or at the same time as you drew up your representation agreement?

___________Before
___________After
___________At the same time

43. If you completed written instructions prior to entering into a representation agreement, why did you still feel it was necessary to appoint a representative and have a representation agreement?

44. If you haven't completed written instructions, why not?

45. On a scale of 1-5, with 1 being not at all confident and 5 being extremely confident, how confident are you that your representative will make the treatment decisions that you want? ___________

D. DISCUSSIONS WITH HEALTH CARE PROVIDERS

46. Have you had any discussions with your health care provider(s) about your treatment wishes at a time when you are not capable of consenting to treatment?

_________Yes
_________No

47. Did you tell your health care provider that you have authorized a representative to make decisions for you?

_________Yes
_________No [Ask: Why not?] ____________________________________

48. Have you given your health care provider(s) a copy of your representation agreement to go on your medical file?

________Yes
________No [Ask: Why not?] ________________________________

49. Did you find your health care provider receptive to discussions about having a representative and/or representation agreement?

________Yes
________No

50. Did your health care provider express any concerns about you having a representative and/or a representation agreement?

_______Yes [Ask: What kinds of concerns were they?] ____________________
_______No

51. Did your health care provider express any concerns about your wishes or instructions about treatment decisions?

______Yes [Ask: What kinds of concerns were they?]
______No

E. LOCUS OF CONTROL

52. On a scale of 1-5, with 1 being not at all important and 5 being extremely important, how important is it to you that you be involved in decisions about your health care?

____

53. Did completing a representation agreement make you feel like you achieved a sense of control over your future?

_______Yes
_______No

[If yes, ask] How?

F. PATIENT/PROXY CONTRACTUAL-COVENANTAL CONTINUUM

54. When making treatment decisions on your behalf, do you expect your representative to carry out your wishes exactly as you have stated them?

________Yes
________No

[If either yes or no, ask] Why?

55. Do you think your representative should be allowed to use his or her discretion when making treatment decisions on your behalf?

__________Yes
__________No

56. Are there any circumstances under which you would want your representative to go against your previously stated wishes?

_________Yes
_________No

[If yes, ask] Please explain what those circumstances would be.

57. When making treatment decisions on your behalf, should your representative be allowed to consider the impact making these decisions may have on him/her?

_________Yes
_________No

58. Do you worry about the emotional burden making treatment decisions may have on your representative?

_________Yes
_________No

59. On a scale of 1-5, with 1 being not at all important and 5 being extremely important, how important is it to you that your representative follows your directions exactly as you have set them out? ___________________

60. Is there anything else you would like to tell me about your experience with entering into a representation agreement?

Additional Socio-Demographic Questions

I have one more question about yourself that I need to ask.

61. What is your household yearly, gross income? Is it:

___________Less than $20000
___________$20001-$29999
___________$30000-$39999
___________$40000-$59999
___________$60000+

SCALE ADMINISTRATION

I am now going to give you a short questionnaire that asks general questions, not related to what we have discussed already. Your answers will give me some important information on the views of people who enter into representation agreements that were not captured in the questions I asked. There are no right or wrong answers to any of these questions.

Rotter's (1966) Locus of Control Scale

1. a. Children get into trouble because their parents punish them too much.
1. b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
2. b. People's misfortunes result from the mistakes they make.

3. a. One of the major reasons why we have wars is because people don't take enough interest in politics.
3. b. There will always be wars, no matter how hard people try to prevent them.

4. a. In the long run people get the respect they deserve in this world.
4. b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. a. The idea that teachers are unfair to students is nonsense.
5. b. Most students don't realize the extent to which their grades are influenced by accidental happenings.

6. a. Without the right breaks, one cannot be an effective leader.
6. b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a. No matter how hard you try, some people just don't like you.
7. b. People who can't get others to like them don't understand how to get along with others.

8. a. Heredity plays the major role in determining one's personality.
8. b. It is one's experiences in life which determine what they're like.

9. a. I have often found that what is going to happen will happen.
9. b. Trusting fate has never turned out as well for me as making a decision to take a definite course of action.

10. a. In the case of the well prepared student there is rarely, if ever, such a thing as an unfair test.
10. b. Many times, exam questions tend to be so unrelated to course work that studying in really useless.

11. a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.
11. b. Getting a good job depends mainly on being in the right place at the right time.

12. a. The average citizen can have an influence in government decisions.
12. b. This world is run by the few people in power, and there is not much the little guy can do about it.

13. a. When I make plans, I am almost certain that I can make them work.
13. b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

14. a. There are certain people who are just no good.
14. b. There is some good in everybody.

15. a. In my case getting what I want has little or nothing to do with luck.
15. b. Many times we might just as well decide what to do by flipping a coin.

16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
16. b. Getting people to do the right thing depends upon ability - luck has little or nothing to do with it.

17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
17. b. By taking an active part in political and social affairs the people can control world events.

18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
18. b. There really is no such thing as "luck."

19. a. One should always be willing to admit mistakes.
19. b. It is usually best to cover up one's mistakes.

20. a. It is hard to know whether or not a person really likes you.
20. b. How many friends you have depends upon how nice a person you are.

21. a. In the long run the bad things that happen to us are balanced by the good ones.
21. b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.

22. a. With enough effort we can wipe out political corruption.
22. b. It is difficult for people to have much control over the things politicians do in office.

23. a. Sometimes I can't understand how teachers arrive at the grades they give.
23. b. There is a direct connection between how hard I study and the grades I get.

24. a. A good leader expects people to decide for themselves what they should do.
24. b. A good leader makes it clear to everybody what their jobs are.

25. a. Many times I feel that I have little influence over the things that happen to me.
25. b. It is impossible for me to believe that chance or luck plays an important role in my life.

26. a. People are lonely because they don't try to be friendly.
26. b. There's not much use in trying too hard to please people, if they like you, they like you.

27. a. There is too much emphasis on athletics in high school.
27. b. Team sports are an excellent way to build character.

28. a. What happens to me is my own doing.
28. b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a. Most of the time I can't understand why politicians behave the way they do.
29. b. In the long run the people are responsible for bad government on a national as well as on a local level.

APPENDIX 3B: INTERVIEW GUIDE FOR REPRESENTATIVES OF CRAHs

Introduction: Thank you for agreeing to participate in this research. I am going to start out by asking you some general questions about yourself. Please remember that you may refuse to answer any questions that you do not feel comfortable answering. Your responses to questions will be kept in the strictest confidence and you will not be able to be identified in any way by your answers. You are free to terminate this interview at any time.

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. What was your age as of your last birthday: ___________

2. Sex: ______ Male
   ______ Female

3. What is your highest level of educational attainment?

   ________Some high school
   ________High school graduation
   ________Some college or university
   ________University graduation e.g. B.A., BSc. (Specify) _________________
   ________Some post-graduate education e.g. First year MA program in psychology (Specify)
   ________Graduate degree e.g. MA or PhD in Psychology (Specify Degree)

4. In what country were you born? ________________

   If other than Canada, ask:

   4A. What year did you come to Canada? ____________

   4B. What is your immigration status? _______________

5. Marital Status

   ________Married/Common law
   ________Widowed
   ________Divorced/Separated

________Never married

If widowed, ask: About how many years is it since your partner passed away?
____

6. Do you have an affiliation with a religion?

________Yes
________No

If yes, what religion do you consider yourself to be affiliated with?__________________

7. On a scale of 1-5, with 1 being not at all active and 5 being very active, how active in your religion do you consider yourself to be? ___________

8. What was the age of the adult at his/her last birthday: ___________

9. Sex: ______ Male
______ Female

10. What is the adult's highest level of educational attainment?

________Some high school
________High school graduation
________Some college or university
________University graduation e.g. B.A., BSc. (Specify) _________________
________Some post-graduate education e.g. First year MA program in psychology (Specify)
________Graduate degree e.g. MA or PhD in Psychology (Specify Degree)

11. In what country was the adult born? _________________

If other than Canada, ask:

4A. What year did the adult come to Canada? _____________

4B. What is the adult's immigration status? ________________

12. Marital Status

________Married/Common law
________Widowed
________Divorced/Separated
________Never married

If widowed, ask: About how many years is it since the adult's partner passed away?

____

13. Does the adult have an affiliation with a religion?

________Yes
________No

If yes, what religion does the adult consider him/herself to be affiliated with?__________________

14. On a scale of 1-5, with 1 being not at all active and 5 being very active, how active in their religion does the adult consider him/herself to be? __________

15. Does the adult have any living children, either natural or step?

________Yes
________No

16. If yes, how many living children does the adult have and what is their relationship to the adult? ________

17. How many live within 60 minutes car travel of the adult? __________

18. In a typical month, how often does the adult speak with one or more of them?

____

19. How would you describe the adult's relationship with their children?

____

20. Are there any minor children or other persons who rely on the adult for care and/or support?

___________Yes
___________No

[If yes, ask] Please tell me who relies on the adult. (e.g. Minor child, adult child with disability, spouse, etc.)

21. I am going to mention some common health problems that people may suffer from. Please tell me if the adult has been diagnosed with any of these problems and the degree to which you feel the adult suffers from them (i.e. mild, moderate, severe). Please tell me about all that apply.

Health problems	**Suffers from**	**Mild**	**Moderate**	**Severe**
Cancer (Please specify type)				
Heart disease				
High blood pressure				
Breathing problems (e.g. Asthma, COPD, please specify)				
Cerebrovascular disease (e.g. stroke, other)				
Congestive heart failure				
Arthritis				
Rheumatism				
Diabetes				
Neurological disorders (e.g. Parkinson's disease, MS (Please specify)				
Alzheimer's disease or other dementia				
Depression or other mood disorder				
Other (Please specify)				

22. I am going to mention some common health problems that people may suffer from. Please tell me if you have been diagnosed with any of these problems and the degree to which you feel you suffer from them (i.e. mild, moderate, severe). Please tell me about all that apply.

Health problems	**Suffers from**	**Mild**	**Moderate**	**Severe**
Cancer (Please specify type)				
Heart disease				
High blood pressure				
Breathing problems (e.g. Asthma, COPD, please specify)				
Cerebrovascular disease (e.g. stroke, other)				
Congestive heart failure				
Arthritis				
Rheumatism				
Diabetes				
Neurological disorders (e.g. Parkinson's disease, MS (Please specify)				
Alzheimer's disease or other dementia				
Depression or other mood disorder				
Other (Please specify)				

23. How did you find out about this study?

_______Received letter from Representation Agreement Resource Centre
_______Received letter from lawyer
_______Was told about it by adult
_______Other

B. SOURCES OF INFORMATION/REASONS FOR ENTERING REPRESENTATION AGREEMENT

I am now going to ask you questions related specifically to representation agreements.

24. When did the adult enter his/her representation agreement?

25. Who was first to find out about representation agreements, you or the adult you represent?
_________Me
_________The adult

26. How did the adult find out about representation agreements? Did he/she:

Source of information	**Yes**	**No**
Discuss them with health care provider		
Discuss them with legal advisor		
See an article in a newspaper or community newsletter		
Attend presentation by the Representation Agreement Resource Centre		
Get referred by someone to the Representation Agreement Resource Centre website? [If yes, ask] Who told you about the website?		
Hear about them from you?		
Other source (Specify)		

27. How did you find out about representation agreements? Did you:

Source of information	**Yes**	**No**
Discuss them with health care provider		
Discuss them with legal advisor		
See an article in a newspaper or community newsletter		
Attend a presentation by the		

Representation Agreement
Resource Centre
Get referred by someone to the Representation Agreement Resource Centre website? [If yes, ask] Who told you about the website?
Other source (Specify)

28. Did you participate with the adult in the actual completion of the representation agreement?

__________Yes
__________No [Skip to question 23]

[If yes] Describe your participation.

29. Did the adult seek information and/or assistance with making a representation agreement from a group or individual?
___________Yes
___________No

[If yes, ask] Who did the adult seek information/assistance from?

30. What types of information/assistance did the adult receive? Did he/she:

Information/Assistance Received	**Yes**	**No**
Get handouts (brochure, written material, pamphlet		
Attend a presentation		
Meet with someone from the Representation Agreement Resource Centre or a lawyer		
Get a referral		
Other (Please specify)		

31. On a scale of 1-5, with 1 being not at all helpful and 5 being extremely helpful, how helpful did the adult find the information/assistance that he/she received?

____

32. Why did you agree to be the adult's representative?

33. Where does the person for whom you are a representative currently live?

_________Living independently in their own home
_________Living in an assisted living facility
_________Living in a long-term care facility
_________Other (Please specify)

34. If you know, what event(s) led up to the adult entering into a representation agreement?

35. What reason(s), if any, did the adult give for asking you to be their representative?

36. What reason(s), if any, did the adult give for feeling the need to enter into a representation agreement?

37. S. 9 of the *Representation Agreement Act* says an adult can authorize their representative to do certain things on their behalf. What have you been authorized by the adult you represent to do on their behalf? For example, has the adult given you the authority to refuse to consent to specific health care, such as life supporting care or treatment. Please specify.

C. INSTRUCTIONS/DISCUSSIONS WITH ADULT

38. What is your relationship to the person who appointed you as their representative?

________Spouse (including common law partner)
________Same sex partner
________Family member (e.g. Son/daughter, niece/nephew, etc) Please specify.
________Friend
________Other (Please specify)

39. How long have you known the adult?

____

40. Do you live within 60 minutes car travel of the adult you represent?

________Yes
________No

41. Are you the only person the adult appointed as a representative?

________Yes
________No

[If no] Who else is a representative? (i.e. what is their relationship to the adult)

[If no] What reason, if any, did the adult give you as to why they appointed an alternate representative?

42. Did the adult appoint a monitor?

_______Yes
_______No

[If yes, ask] What reason, if any, did the adult give you as to why they appointed a monitor?

[If yes, ask] What is the relationship of the monitor to the adult?

43. Have you had discussions with the person you represent about what treatments and care they want and do not want when they are incapable of making their own decisions?

_______Yes
_______No

If no, skip to question 47

44. If you have had discussions about the adult's treatment wishes, what types of situations have you discussed? For example, in the event of a life-threatening illness or event, some people may want to have all treatment available while others may only want certain treatment.

45. Have you discussed the adult's feelings and values about these types of situations and what impact this should have on how you make treatment decisions on behalf of the adult?

_______Yes
_______No

46. About how many of these discussions have you and the adult had?

47. If you have not had discussions with the adult about his/her wishes, feelings or values, why do you think you haven't?

48. If you have not had discussions with the adult about his/her treatment wishes, how do you plan on making decisions on the adult's behalf?

49. Does the adult have a written document outlining his or her wishes to guide you in the event they do become incapable?

50. If you know, what types of instructions does the written document contain?

51. Do you know if the adult completed these written instructions before, after or at the same time as the representation agreement was drawn up?

___________Before
___________After
___________At the same time

52. Do you have any concerns about acting as a representative?

[If yes, ask] What are the concerns that you have?

53. Do you feel that you have enough information about the scope of your authority and what your legal responsibilities as a representative are?

_________Yes
_________No

[If no, ask] What more do you feel you need?

54. On a scale of 1-5, with 1 being not at all confident and 5 being extremely confident, how confident are you will make the treatment decisions that the adult wants?

____

D. PATIENT/PROXY CONTRACTUAL-COVENENTAL CONTINUUM

55. When making treatment decisions on the adult's behalf, has the adult told you to carry out their wishes exactly as they have orally stated them?

____________Yes
____________No
____________Don't know/not sure

[If no or don't know, ask] Explain your understanding of how you are to proceed.

56. If the adult has written instructions, have you been told to follow the written instructions exactly as they are written when making treatment decisions?

____________Yes
____________No
____________Don't know/not sure

57. Has the adult told you to use your discretion in making treatment decisions, despite any oral or written instructions regarding treatment they may have?

58. Do you think you should be allowed any degree of discretion in making decisions?

___________Yes
___________No
___________Don't know/not sure
___________It depends

Why or why not?

[If it depends, ask] What does it depend upon?

59. Are there any circumstances under which you would go against the previously expressed wishes of the adult?

__________Yes
__________No

[f yes, ask] Please explain what those circumstances would be.

60. What would you do if you were called upon to make a decision where the adult had made clear what they wanted but which was contrary to the decision you would make or required you to make a decision that you did not want to make?

61. Are you apprehensive about being called upon to make treatment decisions on the adult's behalf?

____________Yes
____________No
____________It depends

62. Do you worry about the emotional burden making treatment decisions may have on you?

__________Yes
__________ No

[If yes, ask] What worries do you specifically have?

63. Is there anything more you would like to tell me about your experience of being appointed as a representative or your feelings on being a representative?

Additional Socio-Demographic Questions

I have one more question about yourself that I need to ask.

64. What is your household yearly, gross income? Is it:

___________Less than $20000
___________$20001-$29999
___________$30000-$39999
___________$40000-$59999
___________$60000+

APPENDIX 3C: INTERVIEW GUIDE FOR REPRESENTATIVES OF INCAPABLE ADULTS

Introduction: Thank you for agreeing to participate in this research. I am going to start out by asking you some general questions about the adult and yourself. Please remember that you may refuse to answer any questions that you do not feel comfortable answering. Your responses will be kept in the strictest confidence and you will not be able to be identified in any way by your answers. You are free to terminate this interview at any time.

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE ADULT

1. What was the age of the adult at their last birthday: ___________

2. Sex:
   ______ Male
   ______ Female

3. What is the adult's highest level of educational attainment?

   ________Some high school
   ________High school graduation
   ________Some college or university
   ________University graduation e.g. B.A., BSc. (Specify)
   ________Some post-graduate education e.g. First year MA in Psychology (Specify)
   ________Graduate degree e.g. MA in Psychology (Specify Degree)

4. In what country was the adult born? _______________

   If other than Canada, ask:

   4A. What year did the adult come to Canada? _______________

   4B. What is the adult's immigration status? _______________

5. Marital Status of adult at time of incapacity

   ________Married/Common Law
   ________Widowed
   ________Divorced/Separated
   ________Never married

[If widowed, ask] About how many years is it since the adult's partner passed away?

____

6. Does the adult have an affiliation with a religion?

_________Yes
_________No

If yes, what religion does the adult consider him/herself to be affiliated with?

____

7. On a scale of 1-5, with 1 being not at all active and 5 being very active, how active was the adult in their religion? ______________

8. Does the adult have any living children, either natural or step?

________Yes
________No

9. [If yes] How many living children does the adult have and what is their relationship to the adult? _________

10. How many children live within 60 minutes car travel of the adult? __________

11. In a typical month, how often does the adult speak with one or more of them?

____

12. How would you describe the adult's relationship with their children?

13. Were there any minor children or others who relied on the adult for care and/or support prior to the adult becoming incapable?

__________Yes
__________No

[If yes] Please tell me who was reliant on the adult (e.g. minor Child, adult child with disability, spouse, etc.)

14. I am going to mention some common health problems that people may suffer from. Please tell me, if you know, if the adult has been diagnosed with any of these problems and the degree to which the adult suffers from them (i.e. mild, moderate, severe). Please tell me about all that apply.

Health problems	**Suffers from**	**Mild**	**Moderate**	**Severe**
Cancer (Please specify type)				
Heart disease				
High blood pressure				
Breathing problems (e.g. Asthma, COPD, please specify)				
Cerebrovascular disease (e.g. stroke, other)				
Congestive heart failure				
Arthritis				
Rheumatism				
Diabetes				
Neurological disorders (e.g. Parkinson's disease, MS (Please specify)				
Alzheimer's disease or other dementia				
Depression or other mood disorder				
Other (Please specify)				

15. Is the person for whom you are a representative still living?

_________Yes
_________No

[If yes, ask] Where does the person for whom you are a representative currently live?

_________Living independently in their own home
_________Living in an assisted living facility
_________Living in a long-term care facility
_________Other (Please specify)

[If no, ask] How long ago did the adult pass away?

[If no, ask] Where was the adult living immediately prior to their death?

_________Living independently in their own home
_________Living in an assisted living facility
_________Living in a long-term care facility
_________Other (Please specify)

B. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF REPRESENTATIVE

16. What was your age at your last birthday: ___________

17. Sex:

______ Male
______ Female

18. What is your highest level of educational attainment?

________Some high school
________High school graduation
________Some college or university
________University graduation e.g. B.A., BSc, (Specify)
________Some post-graduate education e.g. First year MA program in psychology (Specify)___________________
________Graduate degree e.g. MA or PhD in Psychology (Specify Degree)

19. In what country were you born?

____

If other than Canada, ask:

19A. What year did you come to Canada? ______________

19B. What is your immigration status? _________________

20. Marital Status

________Married/Common Law
________Widowed
________Divorced/Separated
________Never married

[If widowed, ask] About how many years is it since your partner passed away?
____

21. Do you have an affiliation with a religion?

__________Yes
__________No

[If yes, ask] What religion do you consider yourself to be affiliated with? __________

22. On a scale of 1-5, with 1 being not at all active and 5 being very active, how active in your religion do you consider yourself to be? ______________

23. I am going to mention some common health problems that people may suffer from. Please tell me if you have been diagnosed with any of these problems and the degree to which you suffer from them (i.e. mild, moderate, severe). Please tell me about all that apply.

Health problems	**Suffers from**	**Mild**	**Moderate**	**Severe**
Cancer (Please specify type)				
Heart disease				
High blood pressure				
Breathing problems (e.g. Asthma, COPD, please specify)				
Cerebrovascular disease (e.g. stroke, other, please specify)				
Congestive heart failure				
Arthritis				
Rheumatism				
Diabetes				
Neurological				

disorders (e.g. Parkinson's disease, MS (Please specify)				
Alzheimer's disease or other dementia				
Depression or other mood disorder				
Other (Please specify)				

24. How did you find out about this study?

_______Received letter from Representation Agreement Resource Centre
_______Received letter from a lawyer
_______Other

C. SOURCE OF INFORMATION/REASONS FOR ENTERING INTO REPRESENTATION AGREEMENT

I am now going to ask you some questions related specifically to representation agreements.

25. What event led up to the adult being deemed incapable of making decisions on his or her own?

26. Did you participate with the adult in the actual completion of the representation agreement?
__________Yes
__________No [skip to question 31]

[If yes] Please describe your participation.

27. If you know, how did the adult find out about representation agreements? Did the adult:

Source of information	**Yes**	**No**
Discuss them with health care provider		
Discuss them with legal advisor		
See an article in a newspaper or community		

newsletter
Attend a presentation by the Representation Agreement Resource Centre
Get referred by someone to the Representation Agreement Resource Centre website? [If yes, ask] Who told you about the website?
Other source (Specify)

28. Did the adult seek assistance and/or information with making a representation agreement from a group or individual?

____________Yes
____________No
____________Don't know/unsure

[If yes, ask] Who did the adult seek information/assistance from?

29. What types of information/assistance did the adult receive? Did he/she:

Information/Assistance Received	**Yes**	**No**
Get handouts (brochure, written material, pamphlet		
Attend a presentation		
Meet with someone from the Representation Agreement Resource Centre or a lawyer		
Get a referral		
Other (Please specify)		

30. On a scale of 1-5, with 1 being not at all helpful and 5 being extremely helpful, how helpful did the adult find the information/assistance received? ___________

31. Did the adult make their representation agreement with a lawyer at a legal clinic put on by the Representation Agreement Resource Centre or did they go to a lawyer they selected independently?

____________Lawyer selected independently
____________Lawyer at a legal clinic
____________Don't know/unsure

32. What kind of information/assistance, if any, did the adult get from the lawyer?

33. How did you find out about representation agreements? Did you:

Source of information	**Yes**	**No**
Discuss them with health care provider		
Discuss them with legal advisor		
See an article in a newspaper or community newsletter		
Attend a presentation by the Representation Agreement Resource Centre		
Get referred by someone to the Representation Agreement Resource Centre website? [If yes, ask] Who told you about the website?		
Find out about them from the adult		
Other source (Specify)		

34. What event(s) led up to the adult entering into a representation agreement?

35. What is your relationship to the person who appointed you as their representative?

________Spouse (including common law partner)
________Same sex partner
________Family member (e.g. Son/daughter, niece/nephew, etc) Specify_________.
________Friend
________Other (Please specify)

36. What reason did the adult give for choosing you to be their representative?

37. Why did you agree to be the adult's representative?

38. Are you the adult's only representative or is there an alternate representative?

39. If there is an alternate representative, what is that person's relationship to the adult?

________Spouse (including common law partner)
________Same sex partner
________Family member (E.g. Son/daughter, niece/nephew, etc) Please specify.
________Friend
________Other (Please specify)

40. Did the adult appoint a monitor?

_______Yes
_______No

[If yes, ask] What reason, if any, did the adult give you as to why they appointed a monitor?

[If yes, ask] What is the relationship of the monitor to the adult?

41. Did the adult ever tell you why they had decided to enter into a representation agreement or why they felt they needed/wanted a representative?

__________Yes
__________No

[If yes, ask] What did they tell you?

42. Did the adult ever tell you what affect they hoped having a representative and a representation agreement would have on their future care?

__________Yes
__________No

[f yes, ask] What did they tell you?

43. s. 9 of the *Representation Agreement Act* says an adult can authorize their representative to do certain things on their behalf. What have you been authorized by the adult you represent to do on their behalf? For example, has the adult given you the authority to refuse to consent to specific health care, such as life supporting care or treatment? Please specify.

44. How did you find out what types of decisions the adult authorized you to make?

D. INSTRUCTIONS/DISCUSSIONS WITH ADULT

45. Prior to the adult becoming incapable, did you have any discussions with the adult about what treatments and care they want and do not want when they became incapable of making their own decisions?

_______Yes
_______No (skip to question 48)

[If yes, ask] What types of scenarios did you discuss? For example, in the event of a life-threatening illness or event, some people may want to receive all treatments available while others may only want certain treatments.

46. Did the adult discuss his/her feelings and values about these types of situations and what impact they should have on how your make your treatment decisions?

47. How many of these discussions do you think you and the adult had?

48. If you have not had discussions with the adult about his/her wishes, why do you think you haven't?

49. If you have not had discussions, how do you plan on making decisions on the adult's behalf?

50. Is the adult still able to express his/her preferences with respect to their current care?

________Yes
________No

[If yes, ask] How do they do so?

51. Have the adult's wishes or instructions changed over time?

_________Yes
_________No

[If yes, ask] How?

52. Does the adult have a written document, such as a living will or a personal values form, outlining his or her wishes, values or specific instructions to guide you?

_________Yes
_________No

[If yes, ask] What does the written document contain?

53. Do you know if the adult completed these written instructions before, after or at the same time as the representation agreement was drawn up?

___________Before
___________After
___________At the same time

54. Were you involved with the completion of any written instructions?

55. Do you feel that you have enough information about the scope of your authority and what your legal responsibilities are?

_________Yes
_________No

[If no, ask] What more do you feel you need?

56. Do you have any concerns about acting as a representative?

_______Yes
_______No

[If yes, ask] What are the concerns that you have?

57. On a scale of 1-5, with 1 being not at all confident and 5 being extremely confident, how confident are you will make the treatment decisions that the adult wants?

____

E. PATIENT/PROXY CONTRACTUAL-COVENENTAL CONTINUUM

58. When making treatment decisions on the adult's behalf, has the adult told you to carry out their wishes exactly as they have orally stated them?

____________Yes

____________No
____________Don't know/not sure

[If no or don't know, ask] Please explain your understanding of how you are to proceed.

59. If the adult has written instructions, have you been told to follow the written instructions exactly as they are written when making treatment decisions?

____________Yes
____________No
____________Don't know/not sure

60. Has the adult told you to use your discretion in making treatment decisions, despite any oral or written instructions regarding treatment they may have?

____________Yes
____________No

61. Do you think you should be allowed any degree of discretion in making decisions?

___________Yes
___________No
___________Don't know/not sure
___________It depends

Please explain.

62. Are there any circumstances under which you would go against the previously expressed wishes of the adult?

__________Yes
__________No

[If yes, ask] Please explain what those circumstances would be.

63. What would you do if you were called upon to make a decision that the adult had made clear they wanted but required you to make a decision that you did not want to make?

64. Are you apprehensive about being called upon to make treatment decisions on the adult's behalf?

___________Yes
___________No
___________It depends

Why or why not?

65. Do you worry about the emotional burden making treatment decisions may have on you?

_________Yes
_________ No

[If yes, ask] What worries do you specifically have?

66. On a scale of 1-5, with 1 being not at all confident and 5 being very confident, how confident are you that you will be able to carry out the person's wishes?

____

F. LOCUS OF CONTROL

67. On a scale of 1-5, with 1 being not at all important and 5 being extremely important, how important do you think it was to the adult that he/she was involved in decisions about their health care? _________

68. Did the adult feel he/she has much control over his/her health and subsequent health care decision-making?

69. Did the adult feel their health or treatment outcomes are more in the hands of others, such as health care providers rather than within their own control?

70. Do you feel that the adult's health or treatment outcomes are in your control, or more in the control of others, such as health care providers?

G. DECISION-MAKING ON BEHALF OF ADULT

71. Have you had to make any decisions for the adult as authorized by the representation agreement?

_________Yes
_________No (skip to question 81)

72. What kinds of decisions have you made?

73. Please describe the process you used to make those decisions? (e.g. Were you able to consult the adult?)

74. If yes, do you feel that the decisions you made reflected the wishes of the adult?

___________Yes
___________No

75. Did you find making decisions stressful or burdensome?

_________Yes
_________No

[If yes] Please explain.

76. Did you find health care professionals receptive to you as the person's representative?

_________Yes
_________No

[If no, ask] What types of difficulties did you experience?

77. If you had difficulties, who were they with?

78. Did you find that having the authority given to you by the adult under the agreement helpful in discussions or decision-making?

79. Given your experience, do you consider having a representative and representation agreement a benefit to those who are incapable?

80. If not, what improvements or changes would you make?

81. Is there anything else you would like to tell me about your experience with representation agreements?

82. Is there anything you would like to tell me about your experience of being appointed as a representative or your feelings on being a representative?

ADDITIONAL SOCIO-DEMOGRAPHIC QUESTIONS

I have two more questions about the adult and yourself that I need to ask.

83. If you know, what was the adult's gross yearly income, prior to their incapacity? Was it:

__________Less than $20000
__________$20001-$29999
__________$30000-$39999
__________$40000-$59999
__________$60000+

84. What is your gross yearly household income?

__________Less than $20000
__________$20001-$29999
__________$30000-$39999
__________$40000-$59999
__________$60000+

APPENDIX 4: CHARACTERISTICS OF CRAHS NOT INTERVIEWED

Characteristic	Male (n=8)		Female (n=17)	
	n	%	n	%
Age				
48-64	2	25.0	4	23.5
65-74	3	37.5	7	41.2
75-84	2	25,0	5	29.4
85+	1	12.5	1	5.9
Mean = 70.92, s.d.=9.367, range=50-89				
Marital status				
Married	6	75.0	9	52.9
Divorced/separated	0	0	1	5.9
Widowed	1	12.5	6	35.3
Never married	1	12.5	1	5.9
Education				
High school graduation	2	25.0	2	11.8
Some college or university	0	0	5	29.4
University graduation	2	25.0	6	35.3
Some post-graduate education	1	12.5	0	0
Graduate degree	3	37.5	4	23.5
Country of Origin				
Canada	6	75.0	9	52.9
England	0	0	2	11.8
Singapore	0	0	1	5.9
Scotland	0	0	1	5.9
East Africa	1	12.5	0	0
USA	1	12.5	4	23.5

Characteristic	**Male (n=8)**		**Female (n=17)**	
	n	**%**	**n**	**%**
Religiousity				
Have a religious affiliation	0	0	5	29.4
Religion affiliated with				
Anglican	0	0	1	20.0
Christian	0	0	1	20.0
Unitarian	0	0	1	20.0
Quaker	0	0	1	20.0
Presbyterian	0	0	1	20.0
Level of activity				
Extremely active	0	0	1	20.0
Very active	0	0	1	20.0
Somewhat active	0	0	0	0
Not very active	0	0	0	0
Not at all active	0	0	3	60.0

Characteristic	**Male (n=8)**		**Female (n=17)**	
	n	**%**	**n**	**%**
Children				
Have children	6	75.0	13	76.5
How many				
1	0	0	3	23.1
2	2	16.7	5	38.5
3	0	0	2	15.4
4	4	50.0	2	15.4
5	0	0	1	7.7
6 or more	1	16.7	0	0
Natural	4	66.7	11	84.6
Step	0	0	1	7.7
Both	1	16.7	1	7.7
Natural, Step, Adopted	1	16.7	0	0
# within 60 minutes car travel				
0	0	0	4	30.8
1	3	50.0	5	38.5
2	1	16.7	4	30.8
3	1	16.7	0	0
4	1	16.7	0	0
Frequency of communication				
Daily	1	12.5	2	15.4
Once a week	1	12.5	2	15.4
Once every 2 weeks	0	0	1	7.7
Several times a	1	12.5	1	7.7
week	1	12.5	1	7.7
Once a month	2	25.0	6	46.2
Several times a month				
	1	16.7	5	38.5
Strength of relationship	2	33.3	2	15.4
Excellent	3	50.0	5	38.5
Very good/Good	0	0	1	7.7
Good/Fairly Good				
Distant/Strained				

Characteristic	Male (n=8)		Female (n=17)	
	n	**%**	**n**	**%**
Health problems suffered from				
Cancer	1	12.5	3	17.6
Heart disease	0	0	3	17.6
High blood pressure	4	50.0	8	47.1
Breathing problems	1	12.5	0	0
Cerebrovascular disease	0	0	1	5.9
Congestive heart failure	0	0	0	0
Arthritis	0	0	6	35.3
Diabetes	0	0	1	5.9
Neurological disease	0	0	0	0
Alzheimer's or other dementia	0	0	1	5.9
Depression	0	0	4	23.5
# of chronic conditions				
0	4	50.0	2	11.8
1	2	25.0	7	41.2
2	2	25.0	4	23.5
3	0	0	4	23.5

APPENDIX 5: CHARACTERISTICS OF INCAPABLE ADULTS (RAHS)

Characteristic	**Male (n=4)**		**Female (n=3)**	
	n	**%**	**n**	**%**
Age				
48-64	0	0	0	0
65-74	0	0	1	33.3
75-84	3	75.0	2	66.7
85+	1	25.0	0	0
Mean = 79, sd=6, range 71-87				
Marital status				
Married	4	100.0	2	66.7
Widowed	0	0	1	33.3
Education				
Some high school	2	50.0	1	33.3
High school graduation	0	0	1	33.3
Some college or university	1	25.0	0	0
University graduation	1	25.0	1	33.3
Country of Origin				
Canada	2	50.0	1	33.3
England	1	25.0	2	66.7
Slovakia	1	25.0	0	0
Religiousity				
Have a religious affiliation	0	0	0	0

Characteristic	**Male (n=4)**		**Female (n=3)**	
	n	**%**	**n**	**%**
Children				
Have children	4	100.0	2	66.7
How many				
2	3	75.0	2	100.0
4	1	25.0	0	0
Natural	3	75.0	2	100.0
Step	1	25.0	0	0
Both	0	0	0	0
# within 60 minutes car travel				
0	1	25.0	0	0
1	3	75.0	1	50.0
2	0	0	1	50.0
Frequency of communication				
Daily	1	25.0	0	0
Once a week	3	75.0	1	50.0
Once every 2 weeks	0	0	1	50.0
Strength of relationship				
Excellent	0	0	1	50.0
Very good/Good	2	50.0	0	0
Good/Fairly Good	1	25.0	1	50.0
Like an uncle	1	25.0	0	0
Income				
$20,001-$29,999	1	25.0	0	0
$40,000-$59,999	1	25.0	0	0
$60,000+	2	50.0	3	100.0

Characteristic	**Male (n=4)**		**Female (n=3)**	
	n	**%**	**n**	**%**
Health problems suffered from				
Cancer	0	0	0	0
Heart disease	3	75	0	0
High blood pressure	2	50	1	33.3
Breathing problems	1	25	1	33.3
Cerebrovascular disease	2	50	1	33.3
Congestive heart failure	1	25	0	0
Arthritis	2	50	1	33.3
Diabetes	2	50	2	66.7
Neurological disease	0	0	0	0
Alzheimer's or other dementia	2	50	2	66.7
Depression	0	0	0	0
# of chronic conditions				
0	0	0	0	0
1	0	0	1	33.3
2	1	25	1	33.3
3	1	25	0	0
4	0	0	0	0
5	1	25	1	33.3
6	0	0	0	0

APPENDIX 6: COMPARISON OF CHARACTERISTIC'S OF STUDY SAMPLE WITH BC'S SENIOR POPULATION

Characteristics	BC's senior population (n=551,820) %	CRAHs (n=48) %	RCRAHs (n=38) %	RIRAHs (n=7) %
Age				
Less than 65	N/A	18.8	47.4	14.3
65-74	53	39.6	34.2	71.9
75-84	24	31.2	18.4	28.9
85+	12	10.4	0	0
Gender				
Male	44	37.5	47.3	42.9
Female	56	62.5	52.6	57.1
Health condition*				
Cancer	66	4.2	8.0	0
Cardiovascular disease	50	64.6	55.3	0
Cerebrovascular disease	17	10.4	2.6	14.2
Chronic lung disease	11	12.5	8.0	0
Diabetes	7	12.5	10.5	0
Alzheimer's or other dementia	N/A	2.1	0	0
Marital status				
Married	Most likely married or widowed	43.8	81.6	57.1
Divorced/separated		29.2	5.3	0
Widowed		14.3	0	28.6
Never married		12.5	13.2	14.3
Educational level				
No high school	33	6.2	0	0
University graduation	14	27.1	42.1	28.6
Income				
Less than $40,000	Majority	26.0	10.8	0
Greater than $40,000	11	69.6	89.2	100.0

* Multiple responses were permitted by CRAHs, RCRAHs and RIRAHs with regard to health problems

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