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DONATION AFTER CARDIOCIRCULATORY DEATH IN THE CONTEXT OF MEDICAL ASSISTANCE IN DYING

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Submitted by

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In partial fulfillment of the requirements for the degree of

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Abstract

Owing to the wide gap between the number of patients who would benefit from transplantation and the availability of organs, there is a pressing need to explore intentions of healthcare providers to enable controlled donation after cardiocirculatory death (cDCD) in the context of medical assistance in dying (MAiD). This is a major change in end-of-life practices and poses significant ethical and procedural challenges for care providers. Impetus is drawn from reconciling the discord surrounding autonomy for eligible MAiD patients who have capacity to be involved in shared decision-making. The Theory of Planned Behaviour was used to examine attitudinal, normative, and perceived behavioural control beliefs on these intentions in 132 MAiD service providers from multiple Canadian health jurisdictions. Regression analysis showed that the overall model significantly predicted 45% of variance in intention to enable cDCD. Of the theoretical constructs, moral norm and perceived behavioural control emerged as the key predictors.

Keywords: controlled donation after cardiocirculatory death, end-of-life care, hospice, medical assistance in dying, medical ethics, organ donation, palliative care, tissue donation, theory of planned behaviour

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Acronyms and Key Terms

AA	Affective Attitude
CA	Cognitive Attitude
CBS	Canadian Blood Services
cDCD	Controlled Donation after Cardiocirculatory Death
CAMAP	Canadian Association of MAiD Assessors and Providers
CIHI	Canadian Institute for Health Information
CMA	Canadian Medical Association
CNA	Canadian Nurses Association
CSPCP	Canadian Society of Palliative Care Physicians
ICU	Intensive Care Unit
IN	Intention
MAiD	Medical Assistance in Dying
MN	Moral Norm
NDD	Neurological Determination of Death
NP	Nurse Practitioner
OTD	Organ and Tissue Donation
PBC	Perceived Behavioral Control

PN	Professional Norm
RN	Registered Nurse
TPB	Theory of Planned Behavior
WHO	World Health Organization

Chapter 1. Introduction

Deceased organ donation and transplantation is a well-established clinical practice that greatly improves quality of life and survival of recipients with end-stage organ system failure (Hong et al., 2006; Lien et al., 2010; Rabbat et al., 2000; Sela et al., 2013). Organ donation alleviates pressure facing healthcare systems to increase the number of donors providing substantial cost-saving advantages (Barnieh et al., 2011; Bollen et al., 2017; Canadian Blood Services [CBS], 2012; Shaw, 2014). Organ donation provides psychological and emotional benefits for families (Dicks et al., 2017). Not least of all, an individual's choice to be an organ and/or tissue donor promotes quality patient-centred care that values autonomy in end-of-life decision-making (Cerutti, 2012).

There is a wide gap between the number of patients who would benefit from transplantation and the availability of organs in Canada (CBS, 2016; Shemie et al., 2011). In 2020, there were approximately 2,600 organ transplants in Canada (Canadian Institute for Health Information [CIHI], 2021). While approximately 4,100 patients remained on the waitlist for transplants, almost 300 Canadians died while waiting for an organ transplant (CIHI, 2021). The greatest need in Canada is for kidney transplantation and approximately ¾ of the waitlist is comprised of people awaiting kidney transplants (CIHI, 2021; CBS, 2016; Shemie et al., 2011). The ten-year outcome data for end-stage kidney disease showed that 16% of Canadians on dialysis survive past 10 years, whereas up to 74% of Canadians with a kidney transplant still have a functioning kidney after 10 years (CIHI, 2018). At the end of 2017, there were 38,833 Canadians (excluding Quebec) living with end-stage kidney disease (CIHI, 2018). The median wait time after being listed for kidney transplantation in Canada is 2.5-5 years per annum (CIHI, 2018). Kidney transplantation (as opposed to transplantation of other major organs) by far yields the most cost-savings to health systems, with a significantly lower financial burden over time as compared with costly standard dialysis treatment (Barnieh et al., 2011; Bollen et al., 2017).

Research supports added value that donation offers in terms of the positive psychological and emotional benefits for bereaved families of organ donors (Dicks et al., 2017). Families of deceased organ donors generally maintain positive enduring outlooks towards donation when interviewed following the donation; [and] when given the opportunity to voice positive and negative experiences, 50% reported that "something good and/or useful came out of a tragic event" (Merchant et al., 2008, p. 345). This is also true for the public who maintain that organ donation promotes the values of patient autonomy, dignity, and self-determination that underpin patient-centred care (Casey et al., 2020; Cerutti, 2012; Downar et al., 2020).

Deceased organ donation routinely occurs following neurological determination of death in an intensive care unit (ICU). More recently, controlled donation after cardiocirculatory death (cDCD), the more complex donation practice model in ICU, accounts for the largest global increments in deceased organ donation (CIHI, 2018; Scientific Registry of Transplant Recipients, 2011; Squires et al., 2014; World Health Organization [WHO], 2011). Widely used complex healthcare interventions (such as cDCD) involve: (a) several interacting professional groups; (b) difficult and unfamiliar behaviours; (c) variability of outcomes; and (d) limited degrees of flexibility (Craig et al., 2008). Controlled DCD, that is available in the context of medical assistance in dying (MAiD), further escalates the level of complexity representing significant paradigm shifts in *both* contemporary organ donation *and* in standard MAiD processes. MAiD is a healthcare option that deliberately ends the life of a terminal patient at their explicit request (Government of Canada, 2021). Offering cDCD as an end-of-life care option for patients who have requested MAiD is at the center of intense international debate; [and] while sanctioned by Canadian society and legislation, cDCD in the MAiD setting remains under deliberation in prominent jurisdictions (Buote et al., 2022; Kirby, 2016).

Canadian organ donation researchers emphasized that Canada performs sub optimally in organ donation as compared to other developed countries (Squires et al., 2014). According to the WHO, every country must strive for self-sufficiency in meeting its population's healthcare needs and "opportunities for donation should be provided in as many circumstances of death as possible that begin with resources obtained locally" (2011, p. S31). In 2015, an estimated 10% of the 2,023 patients who underwent voluntary euthanasia in Belgium could have potentially donated at least one organ (Bollen et al., 2017). Because of the importance of optimizing the donor pool, it may be helpful to have a better understanding of MAiD service providers' beliefs around their intentions to enable organ and tissue donation. By better understanding of intentions of this unique group of healthcare providers, we may be able to identify points of intervention and design future research to help address the discord that prevents patients, who have requested MAiD, from the opportunity to donate organs and tissues. The Theory of Planned Behaviour (TPB) methodology is widely used in health research and was applied as the guiding framework for this study (Ajzen, 1991; Lavoie et al., 2015).

Contextual Background in MAiD and cDCD

There are two types of MAiD available to Canadians, including where a physician or nurse practitioner: (1) directly injects medication that causes death at the explicit request of the patient (commonly called voluntary euthanasia); or (2) prescribes medication that is self-administered to cause death [commonly called medically-assisted or physician-assisted suicide] (Government of Canada, 2021). In order to be eligible for MAiD, the patient must meet all of the following conditions: (a) be 18 years of age or older and have decision-making capacity; (b) be eligible for publicly funded healthcare services; (c) make a voluntary request that is not the result of external pressure; (d) give informed consent to receive MAiD, meaning that the person has consented to receiving MAiD after they have received all information needed to make this decision; (e) have a serious and incurable illness, disease or disability; (f) be in an advanced state of irreversible decline in capability; and (g) have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable (Government of Canada, 2021).

Superimposed on Canadian legislation allowing eligible adults to access MAiD is the lawful provision of cDCD for these patients. In contemporary cDCD, life-support is withdrawn from a patient in ICU for whom there is no hope of a meaningful recovery, and once declared deceased, organ procurement can begin.

Medically speaking, cDCD is only available to those patients who access MAiD via voluntary euthanasia in a hospital setting. Compounding issues faced by the contentious practice of MAiD, are healthcare organizations striving to develop and/or sustain protocols that reconcile the rights of MAiD patients to access organ and tissue donation services, and the resistance of some healthcare providers.

Transformative Worldview.

The transformative paradigm is accepted as the broad worldview that seeks to utilize the results of this study to inform future solutions for leading healthcare change that reconcile competing values. These values can pit patient autonomy in end-of-life decisions against healthcare personnel resistance. The transformative theoretical framework is a lens for looking at a problem recognizing the: (a) bias of knowledge; (b) pervasive influence of human interests; and (c) issues concerning power and social relationships – especially applicable to groups in the margins (Creswell, 2014). The epistemological assumptions inherent in the transformative paradigm: "rely on ethical stances of inclusion and challenge oppressive social structures; build trust and make goals and strategies transparent; and encourage the use of study results to enhance social justice and human rights" (Creswell, 2014, p. 70). Transformative research has the potential to enhance the knowledge base, promote paradigm shifts, change cultural values, and even transform a society (Trevors et al., 2012**).**

Positionality Statement. The research vision in more effectively linking MAiD patients (who choose, or who *would* choose donation) to cDCD lies in the optimization of end-of-life care provision for patients and families; improvement in morbidity and mortality (for patients needing transplants); and recovery of health region capital. The vision cornerstone involves ethical tenets underpinning both the mediators and barriers to healthcare change within this context. However, as Scharp and Thomas (2019) argued, scholars engaged in critical social science research should assess how their positions and experiences might contribute to their interpretations of people's lived experiences. Thus, deeply rooted in my 14-year professional role as a Donor Coordinator with the Southern Alberta Organ and Tissue Donation Program, I acknowledge my positionality as an *advocate for individual choice* as a vital part of high quality care within the end-of-life landscape. I believe that end-of-life care providers should champion informed and shared decision-making by establishing this as a widely accepted professional norm. I believe that discussing the option of organ and tissue donation for eligible patients should be a routine part of professional practice, and that behavioral obstacles impeding this in MAiD settings should ideally be mitigated. My over-arching attitude surrounding the importance of optimizing end-of-life care is based on the moral belief that one’s duty of care is to provide timely and reasonable access to *all information* about end-of-life options for patients approved for MAiD, including organ and tissue donation. However, because I am not a MAiD service provider, I of course lack understanding of what it is like to engage in donation conversations through their lens and how they might experience these discussions differently.

Chapter 2. Literature Review

An exploratory review of medical, nursing, ethical and psychosocial literature spanning 1988 to 2022, which bridge historical concepts of cDCD in intensive care to a contemporary paradigm in a non-acute, end-of-life care setting is presented. The following databases were searched: CINAHL, MEDLINE, PubMed, Science Direct, OVID, PsycINFO, Sage and Springer. The following key search words were used: end-of-life care, palliative care, hospice care, medical assistance in dying, euthanasia, physician-assisted suicide, organ donation, tissue donation, donation after cardiocirculatory death, medical ethics, and the theory of planned behaviour. Because of the paucity of literature surrounding professional organ and tissue donation behaviour in the context of MAiD, research was largely extrapolated from three key sources: (1) TPB analysis of professional behaviours of wide-ranging healthcare providers; (2) organ and tissue donation services in intensive care; and (3) MAiD services in end-of-life care. Over 300 peer-reviewed articles were found of which 95 were deemed applicable to this study. While 35 of the 95 studies were conducted in Canada, most investigations were conducted in jurisdictions with markedly different healthcare systems and patient demographics as compared to Canada. Specifically, 30 in the United States, 25 in Europe, three in Australia, one in Africa, and one in Asia. In addition, Canadian grey online literature was searched yielding 15 germane documents.

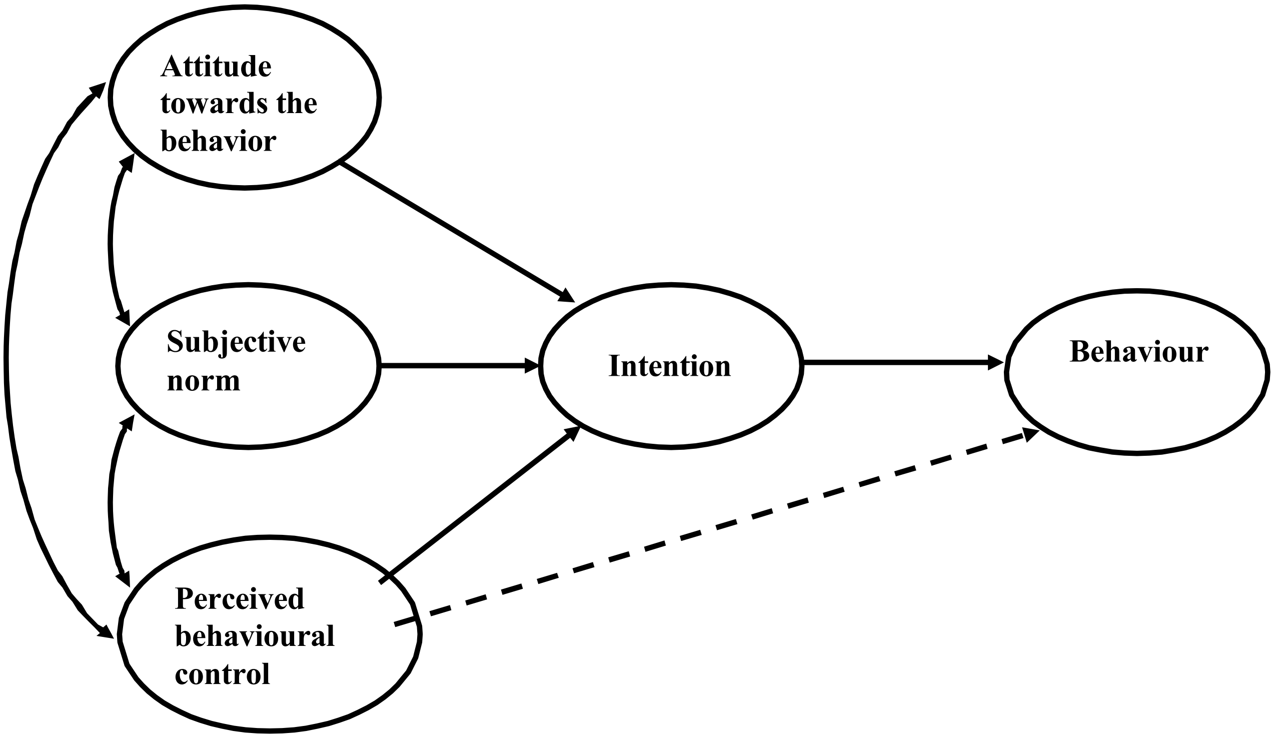
Approximately half of articles related to organ and tissue donation were published between 2011 and 2021. Six of the older studies were valuable in providing historical context. In general, much of the organ and tissue donation literature has explored the process of how critical care and organ donation professionals engage families of potential organ donors in ICU. The primary emphasis has been on strategies aimed at maximizing consent rates of surrogate decision-makers. Twenty studies largely published in 2016 were important to illuminate emergent issues in MAiD research. Fifteen studies looked specifically at cDCD in the context of MAiD. While the TPB has served as the theoretical basis for thousands of health-related studies, most of the research is related to investigating patient behaviours. However, ten studies were valuable in looking at how the theory was applied to healthcare provider intentions toward, or actual, professional behaviours. None of the research reviewed the theoretical determinants of the TPB to explain MAiD service providers' intentions to engage in, and take up, cDCD in any end-of-life situation.

Theory of Planned Behaviour (TPB)

Nevertheless, because literature has shown the importance of attitude, subjective norm, and perceived behavioural control beliefs in understanding the confluence of cDCD and MAiD, the TPB is regarded as a useful and relevant model by which these constructs can be studied together within a single theoretical framework. The hallmark of the theory is that intention is the key predictor of behaviour (Ajzen, 1991). Individuals with stronger intentions to act are more likely to engage in that behaviour (Ajzen, 1991). The TPB can be applied to any behaviour under an individual's volition [including enabling organ and tissue donation] (Ajzen, 1991). Behaviour is a function of salient information, or beliefs, relevant to the behaviour (Ajzen, 1991). In other words, each theoretical construct (i.e., attitude, subjective norm, perceived behavioural control) is related to a specific set of beliefs that include the opinions or ideas that we believe to be true – and we can hold a great many subjective beliefs about any given behaviour (Ajzen, 1991). "Whether based on direct observation, outside information, or inference processes, we assume that once beliefs related to a particular behaviour have been formed, they provide the basis for attitudes, subjective norms, and perceptions of control which in turn lead to intentions and actions" (Fishbein & Ajzen, 2010, p. 223).

Figure 1

Theory of Planned Behaviour (Ajzen, 1991, p. 182)



According to Ajzen (1991), one of the key constructs in the TPB is attitude, which is an evaluation, either positive or negative, of the acceptance of a behaviour. Krech and Crutchfield (1948) who described attitude as "an enduring organization of motivational, emotional, perceptual, and cognitive processes" influenced this definition (as cited by Fishbein & Ajzen, 2010, p. 76). Thus, attitudes are evaluated by considering both cognitive and affective factors (Ajzen, 1991; Lavoie et al., 2015). Cognitive attitude refers to objective consequences of the acceptance of a behaviour (e.g., *Organ and tissue donation is a valuable end-of-life care option for MAiD patients*); while affective attitude is concerned with emotional consequences [e.g., *I feel that organ and tissue donation discussions are damaging to my patients*] (Ajzen, 1991; Lavoie et al., 2015). Attitudes are expressed by a set of beliefs that "refer to the perceived positive and negative consequences of the adoption of a behaviour" (Lavoie, et al., 2015, p. 2). Thus, we can assume that a healthcare provider's commitment to organ and tissue donation is influenced by their positive or negative attitudes regarding donation and transplantation (Ajzen, 1991; Kent, 1997; Rumsey et al., 2003).

Subjective norm is another important concept within the TPB and is likewise considered to directly predict behavioural intention (Ajzen, 1991). Subjective norms relate to perceived social support or pressure to adopt a behaviour (Ajzen, 1991; Lavoie et al., 2015). Subjective norms are expressed through a set of normative beliefs (Ajzen, 1991, Lavoie et al., 2015). "Normative beliefs represent how individuals believe people who are important to them would react if they adopted a given behaviour" [i.e., approve/disapprove] (Lavoie et al., 2015, p. 2). Normative beliefs have also been expanded to include professional and moral norms (Lavoie et al., 2015). Professional norm refers to the "appropriateness of adopting a behaviour given one's profession" (Lavoie et al., 2015, p. 3). For example, *my colleagues* *would accept that I support cDCD for my patients who desire organ donation*. While moral norm refers to the "appropriateness of adopting a behaviour according to one's personal and moral values" (Lavoie et al., 2015, p. 3). For example, *facilitating organ and tissue donation in a MAiD patient would be acting in accordance with my principles.* Given the context and topic area of this study, examining both professional and moral norms may offer important information. For example, a healthcare provider may hold an overall positive attitude toward organ donation, however, they may feel that their colleagues would not approve of them enabling organ donation in the context of MAiD. If they value those collegial relationships (i.e., if they care what their peers think and how they are perceived), then they may not wish to challenge the status quo and opt not to enable organ donation at a particular time.

Perceived behavioural control is another key construct in the TPB and previous research has shown that it can influence intention and behaviour. For example, Ajzen (1991) and Lavoie et al (2015) found that perceived behavioural control reflects one's felt capability to perform a behaviour, including self-efficacy (i.e., self-belief), and external conditions (e.g., resources, time, knowledge, skills, and organizational support). The set of beliefs surrounding volitional control is characterized by perceived factors that may foster or impede performance of a behaviour (Ajzen, 1991; Lavoie et al., 2015). For example, *there are sufficient staffing resources available in facilitating organ and tissue donation for eligible MAiD patients*. In other words, control beliefs refer to elements that can hinder [i.e., barriers], or enable [i.e., facilitators], the adoption of a behaviour (Ajzen, 1991;

Lavoie et al., 2015). Thus, given a sufficient degree of actual control over the behaviour, individuals are expected to carry out their intentions when the opportunity arises (Fishbein & Ajzen, 2010).

Behavioural intention, the final TPB construct, is "an indication of how hard individuals are willing to try, and how much of an effort they are planning to exert in executing the behaviour" (Ajzen, 1991, p. 181). In the context of this study for example, intentions may look like, *I intend to discuss organ and tissue donation with all eligible patients who have requested MAiD*. Fishbein and Ajzen asserted, "as long as measures of attitude, subjective norm, and perceived control are fully compatible with the intention under consideration, these measures should provide accurate prediction of the behavioural intention" (2010, p. 179). In addition, external factors such as socio-demographic variables (e.g., age, gender, profession) can likewise influence intention to adopt behaviour through the other constructs (Ajzen, 1991). Attitudes, normative beliefs, and perceived behavioural controls are all theorized to be potential predictors of intention, and the extent to which they are important may vary by situation (Fishbein & Ajzen, 2010). Mostly one, two or all three of the *determinants of intention* may affect behavioral intention for some people (Fishbein & Ajzen, 2010). This may result in one or two of the determinants to carry a statistically insignificant measure in the prediction of intentions; suggesting that for some individuals or groups, one or another of the three potential determinants of intentions may be largely irrelevant (Fishbein & Ajzen, 2010).

TPB and Healthcare Provider Behaviour. The efficacy in predicting intentions to adopt a wide range of health-related behaviours across a variety of populations (including among healthcare providers), have been shown in several meta-analyses (Conner & Sparks, 2005; Fishbein & Ajzen, 2010; Lavoie, et al., 2015; Godin et al., 2008, Perkins et al., 2007). While the following studies do not address organ or tissue donation specifically, they may nevertheless be important to understand diverse motivations, experiences, and perceptions that influence healthcare provider intentions to engage in, and take up new practice models. For example, there is a burgeoning interest in improving healthcare professionals' compliance with clinical pathways, and adherence to protocols for standards of care in many areas of healthcare. In a cross-sectional study exploring family presence during resuscitation for example, researchers examined physicians' and nurses' intentions, attitudes (cognitive and affective), subjective norms, and perceived behavioural controls related to allowing family presence during resuscitation (Meng-Kuan et al., 2017). The results of this study showed that intention to allow family presence during resuscitation was predicted by positive attitudes (both cognitive and affective), subjective norms, and practiced clinical experience, while negative attitudes, perceived behavioural controls, and other socio-demographic variables were not statistically significant. The researchers reported that positive attitudes might have had the strongest effect on intention because the benefits of family presence during resuscitation may play a more important role in decision-making, as compared to the related fear, anxiety, and capacity felt by the care providers.

A systematic review examining the TPB to evaluate shared decision-making behaviours in healthcare professionals was conducted (Thompson-Leduc et al., 2014). Healthcare professionals were defined as physicians, nurses, chiropractors, dentists, dietitians, kinesiologists, pharmacists, physical therapists and mental health professionals. Studies included research conducted in Canada, The Netherlands, United Kingdom, Australia, and the United States. The concept of shared decision-making was defined as "a decisional process undertaken jointly by a patient and their clinician in which best clinical evidence is considered in light of patient-specific characteristics and values" (Thompson-Leduc et al., 2014, p. 755). This systematic review found that the construct most frequently and significantly associated with intention was subjective norm, which referred to the influence of the immediate professional environment, or the opinions of people deemed important (Thompson-Leduc et al., 2014). This was followed by perceived behavioural control and then by attitude. This result was believed to have been influenced by the very interpersonal nature of shared-decision-making behaviours in general, but also by the importance of the belief that patient-centred care is an important foundation guiding contemporary health policy.

TPB and Organ and Tissue Donation. Perkins et al (2007) performed a meta-analysis of all studies describing the use of the TPB to predict healthcare provider behaviour, noting that the studies largely correlated the theory's constructs with behavioural intention. There are relatively few studies using the TPB in relation to healthcare provider behaviour surrounding organ or tissue donation. There is one study however, in which the TPB was used to evaluate healthcare provider adherence to espoused professional standards in the organ and tissue donation context (Kent, 2002; Perkins et al., 2007). The cross-sectional study assessed the factors that were most significant in determining when registered nurses engaged in, or disengaged from, donation-related behaviour in the United Kingdom (Kent, 2002). Knowledge in this study reflected awareness of donation processes and donation related issues such as medical ethics and legislation. Subjective norms were defined as factors that influence perceptions of social pressure to ask about donation. Perceived behavioural controls were operationalized by the level of ease or difficulty in asking about donation based on beliefs about resources, opportunities, and experiences. The researchers identified that the factors significantly influencing the perception of ability to approach and discuss donation potential with families included knowledge and previous experience. Knowledge appeared to be the key statistical factor in determining nurses' perceptions of ability to discuss donation, while attitudinal factors had a limited effect. The results suggested that nurses found donation discussions difficult and that their willingness to raise this topic may have been influenced by their clinical area of work and/or prior clinical experience.

TPB and MAiD. TPB framed research has also examined Canadian physicians' intentions to practice voluntary euthanasia or physician-assisted suicide within palliative care. The objectives of one study were to identify the psychosocial determinants of physicians' intentions to practice euthanasia and to verify whether respect for patient autonomy was important in decision-making (Lavoie et al., 2015). Lavoie et al (2015) cross-sectionally examined theoretical determinants of intention using attitudes; subjective, moral, and professional norms; and perceived behavioural control. Attitudes were assessed in terms of being cognitive (e.g., "For me, practicing euthanasia would be *useless/useful*"), or affective (e.g., "For me, practicing euthanasia would be *uncomfortable/comfortable*") in nature (Lavoie et al., 2015, p. 4). Subjective norm was defined as the sensed social pressure to adopt euthanasia. Moral norm referred to the ethical suitability of adopting euthanasia looking specifically at the principles of beneficence and justice (e.g., "Practicing an act of euthanasia would be acting in accordance with my principles"). While professional norm referred to the aptness of adopting euthanasia given one's profession [e.g., "Practicing an act of euthanasia would be compatible with my role as a physician"] (Lavoie et al., 2015, p. 4). Perceived behavioural control in this study was defined as physicians' evaluations of their ability to adopt the practice of euthanasia [e.g., "I would be capable of practicing euthanasia"] (Lavoie et al., 2015, p. 4). Intention was assessed with the following single item, "My intention would be to practice an act of euthanasia" (Lavoie et al., 2015, p. 4). Overall, this study determined that physicians have weak intentions to practice euthanasia in palliative care. Results showed that among physicians, perceived behavioural control was the key determinant of intention to practice euthanasia in palliative care, followed closely by moral norm, cognitive attitude, and autonomy (which was entered into the model separately). First, this result indicates that physicians would be more inclined to practice euthanasia if they thought that they had the ability or the medical skills necessary. Second, the fact that cognitive attitude significantly contributed to physician intention to perform euthanasia (while affective attitude did not) suggested to the researchers that physicians rely mainly on the factual consequences rather than on the emotional consequences that practicing euthanasia would have on them.

Third, the ethical principle that emerged as significant within the construct of moral norm was beneficence, while justice was not a significant predictor of intention. This suggested to the researchers that physicians would be motivated to practice euthanasia if they perceived that this act agreed with their personal values and principles [and] if they believed that this would be in the best interests of a terminal patient. However, the significance of the ethical principle of autonomy also indicated to the researchers that knowing patients' wishes significantly motivated physicians' willingness to practice euthanasia (Lavoie et al., 2015).

The TPB is well suited as a framework in my study because it focuses on the factors that potentially predict professional engagement in the cDCD practice model in the MAiD setting, and it emphasizes that there are several variables theorized to explain behavioural intention. Although not directly based on the TPB, attitudinal, normative, and perceived behavioural control beliefs surrounding cDCD in MAiD have been elicited from the following summary of the literature that turns to the psychosocial, organizational, and societal factors that directly, or indirectly, influence healthcare provider behaviour and consequential organ and tissue donation potential. Given the relative lack of TPB framed research within organ and tissue donation, the preceding summary of the TPB research, together with the following review of other forms of literature generated by organ and tissue donation and MAiD researchers, will clarify key issues that were explored in my study.

Attitudes in MAiD

Voluntary euthanasia and physician-assisted suicide are highly controversial practices among healthcare professionals worldwide, and the number of countries that have legalized them remains low [i.e., The Netherlands, Belgium, Ireland, Luxembourg, Columbia, India, Japan, Canada, and United States] (Allard & Fortin, 2017; Baines & Jindal, 2016; Bollen et al., 2016a; Chen & Ko, 2011; De Castro et al., 2016; Government of Canada, 2016c). In Western Europe, increasing public support for voluntary euthanasia and physician-assisted suicide had been reported in 2016, while in Central and Eastern Europe, support was decreasing (Emanuel et al., 2016). At that time in the United States, less than 20% of physicians reported having received requests for euthanasia or physician-assisted suicide, and 5% or less had complied (Emanuel et al., 2016). European studies have shown that positive attitudes in favour of voluntary euthanasia and physician-assisted suicide related to beliefs such as valuing patient rights to decide about their own life and death, respecting patient desires to die with dignity, and acknowledging that these are appropriate solutions to avoid futile treatment (Gielen et al., 2008). Other European studies have established negative attitudes impeding voluntary euthanasia and physician-assisted suicide characterized with beliefs such as fear of pressure on vulnerable patients, unwillingness to decide about life and death, and uncertainty about a patient's prognosis (Gielen et al., 2008). Not surprisingly, physicians in Belgium and The Netherlands were more in favour of voluntary euthanasia and physician-assisted suicide as compared to those from other countries (Gielen et al., 2008). International disparity of attitudes regarding the relationship between assisted dying and palliative care ranges from synergistic and cooperative to conflicted and opposed (Gerson et al., 2019).

With respect to the Canadian experience, palliative care physicians were overwhelmingly not supportive of assisted death in a 2015 survey (Eggertson, 2015). In a second survey conducted by the Canadian Society of Palliative Care Physicians [CSPCP] (2015), 74% of physicians were opposed to assisted death. Likewise shown in a third survey of 1,407 physicians conducted by the Canadian Medical Association [CMA] (2016) that while 29% of physicians reported that they would participate in assisted dying, 63% reported that they would not and 8% were undecided. Two major concerns that have emerged in Canada include: (1) whether patients might request MAiD because of poor access to palliative care, or because of social or economic vulnerabilities; and (2) that potential barriers exist to MAiD access due to geographic location, administrative obstacles, or provider and institutional conscientious objection (CSPCP, 2019; Downar at al., 2019; Wright & Shaw, 2019). Other palliative care providers in Canada believe that MAiD is an important part of their clinical practice and integrate it into the care they provide (Downar et al., 2019).

Despite the dissention, involvement of palliative care providers in the facilitation of MAiD is significant (Downar et al., 2019). While Canadian physicians have been described to have “weak intentions” to practice euthanasia in palliative care, respecting patients' final wishes concerning euthanasia was nevertheless of particular importance to them (Lavoie, et al., 2015). In studies on attitudes toward euthanasia among palliative care providers, religious predilection and tenure in caring for terminally ill patients were generally associated with negative attitudes toward euthanasia (Francke et al., 2016; Lavoie et al., 2015). While age, medical specialty, and gender were more conflicting with no, clear correlation to positive or negative attitudes toward euthanasia (Lavoie, et al., 2015). In a qualitative study exploring Canadian physicians' experiences providing MAiD, many of the respondents expressed "deep dissatisfaction with the current state of affairs [and] concerns about whether they would be able to sustain this service over time" (Khoshnood et al., 2018, p. 226). Now, established attitudes held by palliative and hospice care providers regarding MAiD may be further influenced by the integration of cDCD as an end-of-life care option in the same setting – thereby potentially compounding the issues inherent in both practice models.

Attitudes in Organ and Tissue Donation

In Canada, varying attitudes have been identified as barriers to cDCD in a few studies (Hernadez-Alejandro et al., 2011; Robertson, 1999; Dhanani et al., 2012; Dhanani et al., 2012b). In early research, Prottas and Batten (1988) characterized a positive attitude as having a favourable disposition towards accepting organ donation. Positive attitudes were expressed by accepting donation as a professional responsibility, supporting patients in the pursuit of organ donation, and demonstrating a commitment to cooperate with peers in donation efforts (Prottas & Batten, 1988). Healthcare providers, who hold strongly positive attitudes, may act as promoters or enablers of organ donation, while healthcare providers who hold negative attitudes may impede patient access to donation services (Prottas & Batten, 1988).

More studies have also shown that positive or negative attitudes of healthcare providers influenced the likelihood of a potential donor becoming an actual donor; [and] the more positive the attitude, the greater their efforts in supporting the practice of donation (Flodén & Forsberg, 2009; Fujioka et al., 2018). Sanner (2007) classified differing organ donation attitudes among physicians as pro-donation, neutral, or ambivalent; and attitude is manifested in their behaviour by how, *or even if,* the question of organ donation was raised with families (as cited in Flodén & Forsberg, 2009). In a study assessing attitudes of physicians toward organ donation, the following general beliefs were reported: (a) organ donation can save lives; (b) organ donation can help the family cope with grief; and (c) there is trust in the donation system that allocates organs fairly (Marck & Weiland, 2012). Attitudinal beliefs were again closely linked to behaviours, and those physicians with positive general beliefs were also more likely to report willingness to donate, give family consent, and register their personal donation intents (Marck & Weiland, 2012).

Attitudes, evident in the beliefs and subsequent behaviours of individuals and groups, are often influenced by the behaviours of leaders (Daft, 2015). For example, physician support for organ donation is the strongest predictor of nurses' attitudes toward acceptance of donation practices (Prottas & Batten, 1988). Some studies indicated that a fundamental factor to clinical uptake of organ and tissue donation included the attitude among nurses and other allied health professionals [e.g., social workers, respiratory therapists] (Flodén & Forsberg, 2009; Fujioka et al., 2018; Kent, 1997; Marck & Weiland, 2012; Ploeg et al., 2003; Siminoff, & Traino, 2009; Spencer, 2012; Watkinson, 1995; Weiland et al., 2013). Nurses are acknowledged in the research as the professionals who have the most contact with the patient in the clinical environment and are therefore key in identifying potential donors. Organ and tissue donation attitudes of nurses were measured in a quantitative study using positive and negative belief-items valued on a Likert scale ranging from strongly agree to strongly disagree (Kent & Owens, 1995). Positive beliefs focused on the "humanitarian benefits of donation" (i.e., cognitive attitude), for example, "Organ donation endows death with more meaning" (Kent & Owens, 1995, p. 487). While negative beliefs focused on "fears of mutilation and fatalism" (i.e., affective attitude), for example, "The body is sacred – organ donation should not be considered" (Kent & Owens, 1995, p. 487).

Flodén and Forsberg (2009) conducted a qualitative study that described nurses' attitudes surrounding organ donation. This study established that a colleague's attitude could be discerned from their actions, highlighting the importance that: (a) it was considered necessary to be aware of one's own attitude and the influence it could have on family; and (b) that an ethical conflict could arise from a colleague who holds a negative attitude (Flodén & Forsberg, 2009). Positive attitudes were characterized with three main beliefs: (1) there is professional responsibility in providing the preferred care for the donor and family; (2) there is accountability in making donation discussions a routine part of practice; and (3) there is comfort in knowing that suffering will be alleviated for the recipient[s] (Flodén & Forsberg, 2009). Two beliefs characterizing negative attitudes of nurses in this study include: (1) that the duty is to care for the living and not the dead; and (2) that the whole donation process is deemed "unpleasant" – where care of the donor was provided only out of a sense of duty emphasized in nursing culture (Flodén & Forsberg, 2009).

Subjective Norms in cDCD and MAiD

Subjective norms, reflecting the ethos of healthcare culture, are embedded in a network of practices that are visible in the way that work gets done on a day-to-day basis (Johansson et al., 2016). Specifically, it is the professional and moral norms that incorporate rules, myths, stories, behaviours, thoughts, and beliefs that members of healthcare groups have in common. Normative beliefs may become evident through the evolution of donation practices from the prevailing paradigms in acute care settings to a contemporary donation paradigm in non-acute end-of-life care settings including, but not limited to, palliative or hospice care.

Understanding Normative Beliefs Through the Evolution of Organ Donation. Pioneer organ donation was performed with organ procurement following cardiocirculatory death in the 1960s (Brink & Hassoulas, 2009; DeVita et al., 1993). Following publication of the Harvard Criteria (1968), ethical concerns about inappropriate practices in the procurement of organs were reported (Doig, 2006, Joffe et al., 2011). Since then, organ recovery in the context of neurological determination of death (NDD) in ICU has been the prevailing donation paradigm for deceased donation. Neurological determination of death is complete and permanent cessation of all cerebral functions, a state referred to as “brain death”, which at the time of diagnosis is considered the legal time of death in Canada. Organ donation is not discussed with surrogate decision makers in ICU *until a patient is legally dead*. In contrast, controlled donation after cardiocirculatory death (cDCD) in ICU must be discussed with surrogate decision makers *prior to patient death*. Following the re-emergence of donation after cardiocirculatory death in the early 1990s, the Canadian Critical Care Society called for a moratorium on the practice in 2001 because physicians believed that ethical and procedural issues were not adequately addressed (Doig, 2006; Joffe et al., 2011). Canadian discord underpinning resistance to cDCD implementation was based on lack of agreement, including but not limited to: (1) the *Dead Donor Rule* which establishes that the act of organ procurement should not be responsible for, or a contributing factor in, a patient's death; and (2) that the primary benefits of cDCD are to others, and not to the critically ill patient (Dhanani et al., 2012a; Dhanani et al., 2012b; Doig, 2006; Hernadez-Alejandro et al., 2011; Joffe et al., 2011; Robertson, 1999; Shemie et al., 2006; Squires et al., 2014). cDCD had not gained acceptance throughout all Canadian jurisdictions until 2016 – 10 years after its re-establishment in leading provinces.

However, Canadian research has identified momentum towards a cultural shift in favour of cDCD in ICU whereby decoupling optimal patient care from the process of donation is emphasized, well thought out protocols fostering safe and consistent practices are offered, and a strong sense of teamwork is promoted (D'Alessandro et al., 2008; Dhanani et al., 2012a; Squires et al., 2014). Nevertheless, conflict persists between the need to supply organs to the largest number of individuals who would benefit, and healthcare provider beliefs surrounding how care for those who are dying should otherwise be provided. An even more radical practice change within the realm of organ donation is to consider the contentious practice of cDCD in the MAiD setting. cDCD in the context of MAiD is only available to patients in Belgium, The Netherlands, and Canada

(Allard & Fortin, 2017). While it is recognized by Belgium, The Netherlands, and Switzerland that the potential for an increase in the pool of donors is substantial, limited acceptance of organ donation in the context of voluntary euthanasia prevails in those jurisdictions (Bollen et al., 2016a; Bollen et al., 2017; Shaw, 2014; Ysebaert et al., 2009). Current disapproval of cDCD in the setting of voluntary euthanasia is again largely considered the result of ethical and/or legal considerations not yet reconciled towards accepting it as a donation norm (Bollen et al., 2016b; Van Wijngaardena et al., 2016; Downar et al., 2019).

Understanding Professional Norms Through the Evolution of End-of-life Care. As the tenets of end-of-life care evolve, many physicians worldwide may be influenced by persistent tensions when making cDCD, a complex acute care practice model, available in non-acute care settings. Prevailing conflicts surrounding organ donation in acute care that may potentially influence normative beliefs in other end-of-life care settings include: (a) the extensively debated Dead Donor Rule; (b) the lack of consensus regarding pre-mortem interventions (that benefit the organs rather than the patient); c) the optics or public perception regarding potential risk for conflicts of interest; and (d) the concerns regarding interference with quality and diversity in end-of-life care (Chen & Ko, 2011; Doig, 2006; Joffe et al., 2011; Potts, 2007; Truog & Robinson, 2003).

In a systematic review, Hui et al (2014) examined the concept of end-of-life care. One definition that resonates is that end-of-life care represents that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown (as cited by Hui et al., 2014). Thus, for the purpose of a definition in this study, end-of-life suggests the final phase of life after a terminal patient has been approved for MAiD – when the individual has only days, weeks, or months to live. Their end-of-life care reflects the *care plan* that is tailored to reflect personal goals of care based on their needs and desires.

It is often misunderstood to represent end-of-life care as palliative or hospice care in general. With a life-threatening condition or a serious illness, the objectives of traditional palliative care can improve quality of life; reduce, or relieve physical and psychological symptoms; enable a more peaceful and dignified death; and support family and friends during the dying process and afterward (Government of Canada, 2016c). Chochinov emphasizes that "the goal of palliative care may be summarized as helping patients to die with dignity" (2002, p. 2253). Using dignity as a framework, the patient, family, and palliative care team are guided in defining the goals of end-of-life care that should prioritize the right of the patient to decide what would be beneficial (Chochinov, 2002). Important research has shown that considerations of dignity increasingly influence medical decision-making in end-of-life care (as cited by Chochinov, 2002). Underpinning tenets of palliative care, that have traditionally focused on the right to refuse treatment, have evolved to include the right to demand treatment (e.g., euthanasia and physician-assisted death) – particularly when the preservation of dignity is prioritized (Landry et al., 2015).

Systematically including all end-of-life care options within discussions could foster more choice [and] opportunity regarding issues of life closure (Chochinov, 2002). However, loss of dignity is one of the most common responses given by physicians in studies examining why patients select euthanasia or assisted suicide in the first place (Chochinov, 2002). In a study that looked at Canadian physicians' experiences providing MAiD, physicians felt that MAiD both strained, and enhanced, relationships with colleagues depending on each of their perspectives (Khoshnood et al., 2018). Many Canadian palliative care physicians believe there is a philosophical misalignment between MAiD legislation and the traditional mission and purpose of palliative care (Brindley & Kerrie, 2016).

Nurses too are divided in terms of reporting on the certainty that MAiD is an important part of the palliative care or hospice culture (Pesut et al., 2020a). The Canadian Nurses Association [CNA] (2016) forecasted that palliative care nurses would face several ethical, legal, and psychological risks in dealing with MAiD that need to be acknowledged. Literature has examined the implications of nursing socialization surrounding MAiD participation that focused on the personal beliefs of nurses within the context of their professional obligations (Elmore et al., 2018; Pesut et al., 2019). Their colleagues, families, prior clinical experiences, and commitments to personal and professional values, influenced nursing participation in MAiD services (Pesut et al., 2020a). Some nurses believe that the choice of MAiD provides terminal patients with desired control in an often-presumptive healthcare system that makes moral judgements on their behalf (Pesut, et al., 2020a). In contrast, other nurses believe that the option of MAiD should not be explicitly based on patient autonomy, but rather alongside the considerations of community, society, optimal palliative care, and confidence in patient capacity for decision-making (Pesut et al., 2020a).

Alongside participation in MAiD is the opportunity for organ and tissue donation, and palliative care nurses are often better situated to initiate discussions about donation than are physicians (Kirby, 2016). Yet, many nurses feel hesitancy in raising the subject of donation with patients and families, a conversation that is often described as a daunting task in the literature (Fujioka et al., 2018; Kirby, 2016; Marck & Weiland, 2012; Prous & Ponto, 2015). For example, there are inconsistencies in nursing practice that relate to approaching patients or families with the option of tissue donation. In general, this issue may be compounded by ethical conflicts regarding shared control over decision-making, creating a situation of power imbalance with little patient and/or family input (Joseph-Williams et al., 2014). It has thereby been shown in the literature that nursing involvement in MAiD and donation services is contingent on how nurses believe that personal values should influence their professional practice – and their behaviour relies on interpretation of the ethical tenets implicated (Elmore et al., 2018; Pesut et al., 2019; Pesut et al., 2020).

Understanding Moral Norms Surrounding cDCD in MAiD. Some research examining moral norms in donation are grounded on ethical tenets that have emerged through the confluence of cDCD and MAiD. Prevalent in the literature is the opposing tenet of *justice* when considering the consequence of *selectively* discussing the option of organ and tissue donation with MAiD patients. If the practice is not consistent, the principles of *equity and fairness* may be violated, because some patients are informed, while others are not (Allard & Fortin, 2017). While organ donation is largely the focus of the literature, tissue donation has garnered much less attention, but is also important when considering that the prevailing tissue donation paradigm relies on families being made aware that the option of donating tissues is even available post-mortem. In this case, the surrogate decision-maker has final authority for tissue donation (*if* they were informed) following the death of a MAiD donor – rather than the patient themself prior to death. Related to the ethical principle of justice within the cDCD practice model, and at the core of consent, is *respect for persons*, in which first-person authorization is a major component in this novel deceased donation paradigm (Bollen et al., 2016; Marker, 2011; Rodriquez-Prat, 2016; Verheijde et al., 2007). Given that MAiD is becoming a more popular end-of-life care option, Casey et al (2020) also contend that growing consent may rely on directed donation for cDCD.

In response to increasing patient requests in Canada, CBS partnered with the Canadian Neurological Sciences Federation, the Canadian Critical Care Society, the Canadian Society of Transplantation, and the Canadian Association of Critical Care Nurses to develop ethical, legal, and clinical guidance in managing deceased organ donation in conscious, competent donors (Downar et al., 2020). The first key point resulting from this collaboration stressed that first-person consent for eligible organ donation in the MAiD setting should be available (Downar et al., 2020). The second key point asserted that the ethical concern regarding the decision for cDCD in MAiD should be mitigated by ensuring that any discussion about organ donation takes place only *after* the decision for MAiD is first determined (Downar et al., 2019). Mulder (2019) explains that the desire for cDCD in the MAiD setting originates from Canadian patients because it offers a welcome possibility to *do good* with the diseased body. However, to preserve the confidence and trust of the public and society as a whole, the priority in dealing with cDCD in the context of MAiD must be on preserving patient autonomy [and] avoiding doing harm (Mulder, 2019). *Respect for donor autonomy* surrounding cDCD in the MAiD setting was emphasized in a study exploring perspectives of Québec intensivists, nurses, and organ donation coordinators working in ICU (Allard et al., 2021). Other literature has shown that the general principle promoting a patient's right to choose donation is operationalized in The Netherlands by the strategy that the healthcare provider who carries out voluntary euthanasia is responsible for guaranteeing that potential for organ donation was discussed with the patient (Mulder et al., 2017). However, superimposed on the ethical principle of autonomy, is the tenet that preserves healthcare provider well-being. While some oppose restrictions on *freedom of conscience* because it violates the fundamental right to act in accordance with deeply held convictions, others believe that when duty of care for patient autonomy is true, *conscientious objection* is wrong and immoral (Lamb, 2016; Savulescu, 2006).

The cDCD practice model imposes a major change to MAiD practices in which end-of-life processes for care providers are markedly altered. Irrespective of being real or perceived, overarching *conflicts of interest,* predominant in the literature, are damaging to public and professional trust, and should be recognized to safeguard the donation system (Shemie & Young, 2005). Specifically highlighted are the ethical principles of *beneficence*, or the duty to promote the best interest of the patient, and *non-maleficence*, in which protection of vulnerable groups must be safeguarded (Doig & Rocker, 2003; DuBois, 1999; Kirby, 2016; Robertson, 1999; Shemie & Young, 2005; Shemie et al., 2006). While beneficence denotes the moral obligation that healthcare providers have to benefit their patients, non-maleficence captures the Hippocratic injunction to, *first of all, do no harm* (McMillan, 2019). For example, one concern is that a MAiD patient has been seemingly influenced to access MAiD by their desire to donate organs, either by feeling coerced by healthcare organizations framing MAiD as a means to donate, or believing that these organizations make MAiD more accessible to potential donors (Kirby, 2016). In another example, organ and tissue donation could potentially burden those who qualify for MAiD to choose death; in other words, the terminally ill may feel pressure to serve society through MAiD, and to sacrifice themselves to save other people's lives (Kirby, 2016). Moreover, the capacity to change one's mind about accessing MAiD in general, and/or pursuing organ donation may, be called into question because there may be pressure to follow through – particularly knowing that a significant amount of time and resources have been invested, and/or that recipients have been chosen (Kirby, 2016).

Moral tensions in healthcare involve contradictory ethical obligations, such as conflict between what a patient desires and what a healthcare worker decides is "good for them" (McMillan, 2019). These tensions are described as instances where autonomy, beneficence, and justice appear to imply that opposing things are *all true* (McMillan, 2019). Moral support of cDCD in the context of voluntary euthanasia requires: (1) preservation of an individual's *autonomy* or voluntary nature of decision-making; and (2) accountability to duty of care, and to the transforming *do no harm* principle (Bollen et al., 2016b; Cerutti, 2012; Kirby, 2016; Mulder et al., 2017; Verheijde et al., 2007; Wilkinson & Savulescu, 2012). Patients who request MAiD may perceive their harm as whatever prohibits them from the ability to choose a "good death" which supports their well-being (Petropanagos, 2019). Casey et al (2020) emphasized that in balancing autonomy and vulnerability, they object to paternalism that involves further marginalization of vulnerable groups. There is a risk of infantilizing MAiD patients to mitigate risks to society (Casey et al., 2020). Casey et al (2020) further assert that, "Being vulnerable does not mean a person cannot be autonomous" (p. 808).

Proponents emphasize that the choice of MAiD respects the right to security for patients who want to end their suffering, [and] cDCD further respects the autonomy surrounding their personal choices that are vital to patient-centred end-of-life care. Opponents of cDCD in MAiD are concerned about societal pressures on vulnerable patients. Nevertheless, medical ethics committees have agreed that the request for organ donation, after approval for voluntary euthanasia, should not be waived, and that every effort can be made to mitigate conflicts of interest for patients and healthcare providers (Bollen et al., 2016b; Casey et al., 2020; Downar et al., 2019; Downar et al., 2020; Mulder et al., 2017; Ysebaert et al., 2009). MAiD has only been legal in Canada since the latter half of 2016, so researchers now need to explore how healthcare providers reflect on the ethical and practical ways in which their limited experience in working with patients who have requested MAiD, can be applied to care of those same patients *who would choose* organ and tissue donation.

Perceived Behavioural Control

Perceived Behavioural Control in cDCD. While there is no research based on the TPB looking at perceived behavioural control in the context of cDCD, some research has examined the practical capacity of intensive care providers to support cDCD in general. Time limits and other logistical constraints have been identified as perceived barriers impeding cDCD acceptance in ICU (Dhanani et al., 2012a; Dhanani et al., 2012b; Hernadez-Alejandro et al., 2011; Robertson, 1999; Squires et al., 2014). In a three-year comprehensive study undertaken across the United States, different healthcare providers' (i.e., nurses, physicians, social workers, clergy, administrators, organ donation professionals) perceptions of barriers and enablers to clinical uptake of cDCD were identified (D'Alessandro et al., 2008). This study found several key barriers to cDCD acceptance including knowledge deficits, psychological difficulties, lack of consensus regarding recognition of death, lack of trust in the organ donation organization, and misgivings surrounding the shift in goals of care from life-saving to organ optimization (D'Alessandro et al., 2008). Conversely, perceived enablers to the acceptance of cDCD included efficacious education initiatives, well-trained personnel, and consistent cDCD protocols (D'Alessandro et al., 2008). The researchers concluded that better understanding of healthcare providers' knowledge, attitudes, and behaviours is critical to the implementation of strategic plans for implementing cDCD programs (D'Alessandro et al., 2008). They also resolved that "one of the biggest barriers to overcome is a lack of knowledge of cDCD, which leads to misperceptions, which in turn contribute to negative attitudes and/or discomfort by healthcare professionals" (D'Alessandro et al., 2008, p.1075). In a similar Canadian study conducted by Squires et al (2014), researchers interviewed intensivists, nurses, and organ donation coordinators that determined parallel barriers and enablers to cDCD approval in ICU.

Perceived Behavioural Control in MAiD. While there is no research looking at perceived behavioural control in the context of cDCD in MAiD for palliative or hospice care providers, there is research examining the clinical and practical challenges identified in the practice of MAiD itself. In a scoping review, researchers consolidated evidence exploring the involvement of diverse healthcare professionals that included physicians, nurses, mental health providers, pharmacists, social workers, and medical examiners (Fujioka et al., 2018). Challenges confronted by these multidisciplinary healthcare providers in facilitating MAiD [that may influence cDCD facilitation in the same setting] include "perceived absence of clear, professional and legal guidelines, role ambiguity, lack of inter-professional collaboration, conscientious objection, lack of knowledge or training, emotional impact, and limits of confidentiality" (Fujioka et al., 2018, p. 1568). In one study, physicians believed that MAiD negatively impacted their professional practices through inadequate financial compensation for time and increased workload (Khoshnood et al., 2018). In another study, Canadian physicians who believe MAiD has negatively affected access to, or delivery of, palliative care in their communities, noted concern about the risk of inadequate palliative care being made available to patients (CSPCP, 2018). Perceived barriers included lack of resources for palliative care (affected by resources being diverted to MAiD), onerousness of the MAiD process (which takes time that could have been devoted to providing care), and refusal of patients to accept effective palliative care [for fear they will not be sufficiently lucid to make a decision on MAiD] (CSPCP, 2018). In addition, physicians reported that there is a level of stress felt by healthcare providers because of MAiD, and that differing beliefs have negatively affected the atmosphere within treatment centres (CSPCP, 2018). They maintained that the focus is now more on MAiD and less on palliative care, that there is a lack of support for conscientious objectors, and that a degree of professional respect is now lacking among team members (CSPCP, 2018).

There are additional studies in which nurses' perceived capacity have impeded their behaviour of offering tissue donation to families of deceased loved ones. These barriers include lack of support for donation that relies solely on physician leads, and ambivalence or even refusal to engage in donation conversations based on personal and/or logistical reasons [e.g., workload management] (Fujioka et al., 2018; Marck & Weiland, 2012; Prous & Ponto, 2015). It is conceivable that missed donation opportunities may be due to poor knowledge of nurses regarding donor suitability criteria, or performance issues in failing to comply with offering families the option of donation (Kruijff et al., 2014). While some of the barriers for not initiating donation conversations include lack of training, anxiety about the possible impact of the discussion on patients, families, and even on themselves was also reported (Prous & Ponto, 2015).

Summary of Literature Review

Overall, research shows that the TPB may be a useful model for describing and explaining predictors of individuals' intentions and behaviours in the provision of healthcare. Research varies as to what theoretical construct (i.e., attitude, subjective norm or perceived behavioural control) is the key predictor of intention. This may be a function of the behaviour under question, the population being studied, or broader contextual factors. The importance of understanding diverse motivations, experiences, and perceptions that influence intentions of healthcare provider behaviours have also been shown. The concomitant beliefs are assumed, not to be innate, but to be acquired in daily encounters with the real world (Fishbein & Ajzen, 2010). Differences in beliefs suggest the importance of the role of background factors such as individual motivations, as well as social and organizational contexts (Fishbein & Ajzen, 2010). If there is reason to believe that people who vary have likely been exposed to different experiences, then they may consequently form different behaviour-relevant beliefs (Fishbein & Ajzen, 2010). Thus, salient beliefs [surrounding the cDCD practice model in the MAiD context] should be identified (Ajzen et al., 2011; Fishbein & Ajzen, 2010). Explanations for the behavioural determinants of healthcare professionals are complex; and although influenced to some degree by environmental, organizational, and societal factors, determinants of behaviour are psychosocial in nature. There may be instances where organ and tissue donation activities may be incongruent with personal beliefs or norms of healthcare providers. Then again, supporting organ and tissue donation services may be considered unreasonable by some providers, given inordinate demands on time or emotional energy; particularly for those who find that this is not a regular occurrence in their primary day-to-day functions.

cDCD and MAiD are two separate clinical processes, each with its own policies and procedures to ensure the safety and protection of patients. This is important because the confluence of these two practice models into one clinical pathway is multifaceted, and we cannot assume that the variables that influence or explain either cDCD or MAiD alone can explain the behavioural consequences when combined. Given the complexity underpinning cDCD in MAiD, it may be practical for researchers to examine which beliefs, using the TPB as a framework, seem to be key in understanding the mix of professional experiences, knowledge, skills, fears, beliefs, organizational, and/or other factors that correlate with, and possibly shape, MAiD professionals' intentions. Specifically, it is essential to examine cognitive and affective attitudes toward donation among MAiD service providers, together with their professional and/or moral norms in the end-of-life care environment, their perceived behavioural control over the organ and tissue donation process, and their intentions to participate in organ and tissue donation services.

Chapter 3. Methods

Statement of Problem

When the traditional deceased organ donation model shifts from an intensive care setting to an end-of-life care setting with the confluence of MAiD and cDCD, conflicting determinants of intention (i.e., attitudes, subjective norms, perceived behavioural controls) are posited in decision-making for MAiD service providers. In jurisdictions where MAiD has been made available, the body of research that conveys healthcare providers' intentions to engage in, and take up, cDCD in the context of MAiD is very limited.

Research Questions. Framed by the TPB, the overarching aim of this study was to examine MAiD service providers' attitudes (cognitive and affective), normative beliefs (professional and moral), perceived behavioural controls, and intentions surrounding cDCD up-take, and to determine which of the constructs are the key correlate(s) of this intention. The a priori hypothesis was that cognitive and affective attitude, professional and moral norm, and perceived behavioural control would each predict intention to engage in, and take up cDCD in MAiD. Corresponding research questions included:

1. Which of the socio-demographic variables are significantly associated with intention to enable cDCD in MAiD?
2. What are the relationships among attitude, subjective norm, and perceived behavioural control to intentions to enable cDCD in MAiD?
3. Which of the constructs (e.g., attitudes, normative beliefs,

perceived behavioural control) will be the key statistical predictor of intention to enable cDCD in MAiD?

Participants

One hundred and sixty healthcare professionals replied to a cross sectional survey assessing their beliefs surrounding cDCD in MAiD. Twenty-eight respondents were excluded from the analysis because they were either ineligible in terms of not being directly involved in MAiD services, or they had large sections (i.e., one or more variables with an entire incomplete belief-set) of incomplete data. Complete data were available for the sample that included 132 healthcare providers directly involved in MAiD services from across Canada. Of the three groups of healthcare professionals, the physician group was the largest (*n* = 60), followed by the registered nurse MAiD Coordinator group (*n* = 57), and the nurse practitioner group (*n* = 15) was the smallest. The median participating age group was 41-50 years, and the mean number of practice years was 20.3. While there were 20% more physicians over the age of 50 as compared to nurses, 7% more nurses were under the age of 40. While 60% of the participants identified as female and 24% identified as male, 16% declined to answer the question of gender identification. The most frequently “skipped” question was the query surrounding religious or spiritual affiliation for which almost half of the cohort declined to answer.

Table 1

Frequencies and Percentages of Healthcare Provider Sample (N = 132)

	Physician		Nurse Practitioner		RN MAiD Coordinator	
	n = 60		*n* = 15		*n* = 57	
Percentage (*N* = 132)	46 %		11 %		43 %	
Variable	*n*	%	*n*	%	*n*	%
Age Group						
20-30	2	3.3	0	0	8	14
31-40	13	21.7	3	20	16	28.1
41-50	12	20	9	60	16	28.1
51-60	12	20	3	20	7	12.3
60+	21	35	0	0	10	17.5
Gender						
Male	24	40	1	6.7	4	7
Female	27	45	12	80	43	75.5
Unknown	9	15	2	13.3	10	17.5
Religious Affiliation						
Christian	13	21.7	1	6.7	15	26.3
Jewish	2	3.3	2	13.3	0	0
Buddhist	1	1.7	0	0	0	0
Hindu	1	1.7	0	0	0	0
None	26	43.3	7	46.7	17	29.8
Unknown	17	28.3	5	33.3	25	43.9
Worksite						
Hospital	23	38.3	4	26.7	23	40.4
Community	18	30	10	66.7	30	52.6
Both	19	31.7	1	6.6	4	7
Prior Organ and Tissue Donation Conversation Experience						
Yes	41	68.3	11	73.3	44	77.2
No	19	31.7	4	26.7	13	22.8

Sampling Procedures

Inclusion criteria for the cohort of participants included physicians, nurse practitioners, and registered nurse MAiD Coordinators or *Navigators* who were directly involved in the assessment, coordination, and/or provision of MAiD within Canadian health jurisdictions. While registered nurses in general are not providers or assessors of MAiD in Canada (as are the physician and nurse practitioner leads), it is nevertheless recognized that they do have important supportive roles in coordinating and/or facilitating the MAiD process for patients, and they are often present during the procedure. This study included registered nurses in the sample along with physicians and nurse practitioners, as all three professional groups have access to terminal patients and may take part in, and/or initiate donation conversations in the context of MAiD.

The following organizations helped to support this research by providing access to their members: Alberta Health Services (AHS); Canadian Association of MAiD Assessors and Providers (CAMAP); British Columbia College of Nurses and Midwives (BCCNM); College and Association of Registered Nurses of Alberta (CARNA); Vitalité New Brunswick Health Network; Canadian Society of Palliative Care Physicians [CSPCP]; College of Physicians and Surgeons of Alberta (CPSA); and Ontario Medical Association (OMA). For the desired statistical power level, the minimum required sample size for this multiple regression study was 97 participants – given 5% probability, six predictors, and medium anticipated effect size ($f^2 = 0.15$) to detect relative risk.

Following ethics approval from the Health Research Ethics Board (HREB) at the University of Alberta and Athabasca University, operational approval was obtained from the above Canadian health regions, and medical and nursing organizations who provide end-of-life care, and whose membership or staffing roster included healthcare providers who deliver MAiD services. Permission to conduct the study was obtained at two levels: (1) organization and institution leadership approval; and (2) informed consent from participants. Leadership and research participants were assured that the questionnaire was anonymous, that the data was strictly confidential, and that participation was voluntary. Informed consent was embedded in the survey and was obtained from participants by having them check the consent boxes (outlined in Appendix E). All electronic data including, but not limited to, the questionnaire and participant traceability were maintained on the researcher's password protected personal computer, in an encrypted transmission cloud back-up system. Data were shared with the study supervisor. Digitally stored information will be destroyed (by electronic shredding) within five years following publication of the research. No data relating to this study that includes names or other identifying features will be released or published.

Measures

The questionnaire consisted of two defined sections: (1) consent and socio-demographics; and (2) measures of TPB constructs (i.e., cognitive attitude, affective attitude, professional norm, moral norm, perceived behavioural control and intention). Using the TPB as a framework, each construct's belief-set was measured by placing value on individual belief items using a 5-point forced-choice Likert-type scale – with response options ranging between "strongly agree", "agree", "neutral", "disagree" and "strongly disagree”. Supported in the literature, each group of questions that related to a specific theoretical construct was then calculated as a total or mean score for the belief-set of scale items (Sullivan & Artino, 2014).

Demographics. Socio-demographic items consisted of the following eight variables: age group; professional practice group; gender; religious affiliation; practice setting; practice years; prior experience with organ and/or tissue donation conversations; and confirmation of involvement in the assessment, coordination, and/or provision of MAiD.

Theory of Planned Behaviour. The TPB section was categorized into distinct groups for each of the theoretical constructs. The survey questions were adapted from existing validated tools that had been utilized in a variety of professional healthcare settings. All questions were tailored to the context of organ and tissue donation in the end-of-life care setting.

Attitudes. Six belief items assessed cognitive attitude, and six belief items assessed affective attitude. An example of a belief item that represented cognitive attitude was, *Organ and tissue donation is a valuable end-of-life care option for MAiD patients* (Kent, 2002; Lavoie et al., 2015; Ogle et al., 2002; Prottas & Batten, 1988). Likewise, an example of a belief-item that represented affective attitude was, *I feel comfortable introducing the subject of organ and tissue donation with MAiD patients and families* (Ogle et al., 2002; Prottas & Batten, 1988). Items representing cognitive and affective attitudes were each meaned to represent overall cognitive and affective attitude scores, with higher scores indicating more positive attitudes. Cronbach’s alpha was .78 for cognitive attitude, and .75 for affective attitude.

Normative Beliefs. Five items were used to assess professional normative beliefs and seven items were used to assess moral normative beliefs (Kent, 2002; Lavoie et al., 2016; Meng-Kuan et al., 2017; Ogle et al., 2002; Prottas & Batten, 1988; Rousseau et al., 2017). An example of a professional normative belief was, *I do not feel that consideration of organ and tissue donation is a professional responsibility in end-of-life care* (Lavoie et al., 2016). Similarly, an example of a moral normative belief was, *Organ and tissue donation promotes patient autonomy* (Kent, 2002). The means of the two sets of normative items were each used to represent overall professional and moral norm scores, with higher scores indicating more favourable or positive normative outlooks. Cronbach's alpha was .65 for professional norm, and .77 for moral norm.

Perceived Behavioural Controls. Seven items were used to assess perceived control beliefs that related to time, logistics, compensation, legislation, and staffing resources (Khoshnood et al., 2018; Lavoie et al., 2015; Meng-Kuan et al., 2017; Ogle et al., 2002 Prottas & Batten, 1988). An example of a perceived behavioural control item was, *There are sufficient staffing resources available in facilitating cDCD for eligible MAiD patients* (Meng-Kuan et al., 2017). Based on findings of the reliability analysis, two items assessing role suitability were deleted to improve the internal consistency of measure (initial internal consistency was at .40). The mean of five remaining items was used to represent an overall perceived behavioural control score, with a higher score representing greater perceived behavioural control in facilitating cDCD in the MAiD setting. Cronbach's alpha was

.60 for perceived behavioural control.

Intentions. Intention to engage in, and take up, cDCD in the context of MAiD was assessed using three items, two were related to organ and tissue donation in the context of MAiD, and one item related to intention to support donation in general (Lavoie et al., 2015). For example, one MAiD-specific item posed, *I intend to offer cDCD to eligible patients who have requested MAiD* (Lavoie et al., 2015). The mean of the three items was used to represent an overall intention score, with a higher score signifying greater intention to take up organ and tissue donation services in MAiD situations. Cronbach's alpha was .75 for intention.

Procedure

A cross-sectional-survey research design was used to provide a one-time assessment of cognitive attitude, affective attitude, professional norm, moral norm, perceived behavioural control, and intention of physicians and nurses, involved in the assessment, coordination, and/or provision of MAiD, to engage in, and take up organ and tissue donation services in end-of-life care. Data were collected via electronic survey questions administered by the primary researcher. Following the specification of participant parameters, each organization identified enumeration from their Listerv, and then sent the invitation to participate directly to their members. Targeting MAiD professionals from multiple Canadian provinces and organizations was aimed to help ensure a more representative sample of each healthcare discipline, and to mitigate a possible low response rate. The survey (see Appendix A) link was made available electronically via SurveyMonkey® software.

Embedded in the on-line survey was an information section (see Appendix C) detailing the purpose, method, intent, and risks of the study, followed by a radio-button for electronic consent. The survey consisted of 50 items in total with eight items relating to consent. On average, the survey took respondents approximately 5-10 minutes to complete.

Ethics and Permissions

Information letters were sent via email to each level of leadership (e.g., executive directors, medical directors, and/or administrative managers), detailing the purpose, method, intent, and risks of the study and requesting operational support and approval (see Appendix C). Ethics approval was obtained from the Health Research Ethics Board of Alberta (HREBA) and Athabasca University. The research proposal, ethics approval certificate, estimated timelines, survey, budget, and supporting documents were provided to each organization and institution.

Data Analysis

All analyses were conducted using the Statistical Package for the Social Sciences 25 (SPSS) software. Preliminary analyses were performed to examine potential violations of assumptions surrounding regression. The assumption of normality of the dependent variable was not met when interpreting the Kolmogorov-Smirnov test as shown by $p < .001$. However, the dependent variable was only slightly positively skewed with a statistical value of .09, which is less than one, and significantly lower than double the Standard Error [$SE = .42$] (Field, 2008; UCLA, 2016). The independent variables were all somewhat positively skewed, but they were still normally distributed overall. The assumption of linearity was met with relatively normal *probability – probability* plots, showing linear relationships between the predictors and the dependent variable. To rule out influential outliers, the maximum value of Cook's distance was normal at a minimum value of .000 and a maximum value of .189. Using the correlations output, the assumptions of multicollinearity were satisfied between the independent variables, where all the values fell below .70 and above -.70; meaning that none of the independent variables were multi-collinear (Field, 2008; UCLA, 2016).

The sample size ($N = 132$) met the expected medium effect size required to test the overall regression model with six predictors [$R^2 = 6/ (132-1) = .04$] (Field, 2018). Descriptive statistics and correlations were first computed to examine associations among the conceptual variables. Then to assess what factors were statistically predictive of healthcare providers' intentions, a hierarchical linear regression analysis was performed. The dependent variable entered into the model was intention and the independent variables entered were cognitive attitude, affective attitude, professional norm, moral norm, and perceived behavioural control. The model controlled for prior organ and tissue donation conversation experience (i.e., OTD Experience). Statistical significance was established at the $p < .05$ level.

Chapter 4. Results

Data were collected from July to October 2021. Of note, data were collected in the midst of the fourth wave of the COVID-19 pandemic in Canada. Many provincial health regions and professional organizations elected not to participate to safeguard staff and health resources from additional stressors.

Correlations Among Conceptual Variables

To examine associations among study variables, correlation analysis was conducted. In general, results showed significant, positive correlations among study variables (see Table 2). The results indicated that the conceptual variables were all positively correlated with each other, and with intention. This is consistent with both theory (Fishbein & Ajzen, 2010) and previous research (Kent, 2002, Perkins et al., 2007). Inspection of the correlation matrix shows that all the conceptual variables were very similar in magnitude overall to each other, with cognitive attitude and professional norm sharing the strongest relationship. In terms of intention and the conceptual variables, all correlations were again similar in magnitude, with the strongest correlation coefficient being between professional norm and intention. Correlation of prior experience with organ and tissue donation conversations with intention was also statistically significant (OTD experience $r = .30$, $p < .001$). All socio-demographic variables were not statistically significant and were thus not included in the regression model.

Table 2

Means and Standard Deviations for, and Correlations Between, Intention and Predictor Variables

	M (*SD*)	2	3	4	5	6	7
1. Intention	2.27 (.73)	.50**	.48**	.53**	.51**	.50**	.30**
2. Moral Norm	1.74 (.50)		.30**	.52**	.48**	.53**	.06
3. Perceived Behavioural Control	2.86 (.64)			.41**	.51**	.36**	.33**
4. Professional Norm	2.06 (.56)				.59**	.61**	.17*
5. Affective Attitude	2.11 (.59)					.53**	.20*
6. Cognitive Attitude	1.72 (.52)						.23*
7. OTD Experience	1.27 (.45)						

Note. * $p < .05$
* * $p < .001$

Intention

Since the TPB hypothesizes that intention is a precursor of actual behaviour, it is important to discuss the results of the direct measures of intention. First, over half of all participants responded that they do not intend to bring up and discuss the option of organ and tissue donation with eligible patients who have requested MAiD. Of those participants, 18% absolutely do not intend to discuss organ and tissue donation in this situation, and 34% are undecided. Second, while approximately 82% of all participants intend to discuss the option of cDCD with MAiD patients who bring up the subject, 18% are largely undecided. Last, while over half of all participants intend to discuss donation options in end-of-life with all eligible patients in their care, the other half of participants are either undecided or do not intend to discuss donation potential in any circumstance.

Table 3

Means and Standard Deviations for, and Correlations Between, Sociodemographic Variables and Intention

	M (*SD*)	2	3	4	5	6	7	8
1. Intention	2.27 (.73)	.03	-.02	.08	.07	.02	-.05	.30**
2. Age Group	3.24 (1.27)		-.23*	-.70	-.16	-.02	.83**	-.15
3. Practice Group	1.66 (.68)			.24*	.05	-.12	-.18*	-.07
4. Gender	1.94 (.62)				.29*	-.04	-.12	.06
5. Religious Affiliation	3.64 (1.54)					.06	.16	.09
6. Worksite	1.80 (.73)						-.01	.12
7. Practice Years	20.17 (13.01)							-.25*
8. OTD Experience	1.27 (.45)							

Note. * $p < .05$
* * $p < .001$

Regression Analysis

To examine which of the independent variables (i.e., cognitive and affective attitude, professional and moral norm, and perceived behavioural control) were a statistical predictor of intention, a hierarchical multiple regression analysis was performed (see Table 4). The overall regression model predicted approximately 45% of variance in the dependent variable (i.e., intention), $R^2 = .45$, F (1, 125) = 5.57, $p = .02$ (see Table 4). On the first step, OTD experience was added and was found to be a significant statistical predictor of behavioural intention, accounting for 9% of the variance. On the second step, cognitive and affective attitudes were added and accounted for 27% of variance. On the third step, professional and moral norms were added and explained an additional 7% of variance; however, cognitive attitude was no longer a significant predictor of intention.

On the fourth step, perceived behavioural control was added and explained an additional 2% of the variance in intention; however, affective attitude and professional norm were no longer significant after perceived behavioural control was entered. As shown in Table 4, once all independent variables were entered into the model, the significant predictors of intention were moral norm, perceived behavioural control, and OTD experience. Inspection of the beta coefficients showed that moral norm appeared to be the key conceptual variable, followed by perceived behavioural control, and then OTD experience.

Table 4

Regression Analysis Using the Exploratory Variables as Predictors of Intention

Variable	Continuous		Simultaneous		
Model	ΔR^2	ΔF	*B*	*p*	pr^2
Step 1					
OTD Experience	.09	*F* (1, 130) = 13.11**	.30	.000	.09
Step 2	.27	Δ*F* (2 ,128) = 26.79**			
OTD Experience			.17	.020	.04
Cognitive Attitude (CA)			.29	.001	.09
Affective Attitude (AA)			.32	.000	.10
Step 3	.07	Δ*F* (2, 126) = 7.93*			
OTD Experience			.20	.006	.06
Cognitive Attitude			.11	.221	.01
Affective Attitude			.18	.047	.03
Professional Norm (PN)			.19	.043	.03
Moral Norm (MN)			.25	.004	.06
Step 4	.02	ΔF (1, 125) = 5.57*			
OTD Experience			.15	.034	.03
Cognitive Attitude			.11	.234	.01
Affective Attitude			.11	.246	.01
Professional Norm			.17	.072	.03
Moral Norm			.24	.004	.06
Perceived Behavioural Control (PBC)			.19	.020	.04

Note. * $p < .05$
* * $p < .001$

Chapter 5. Discussion

The overall purpose of the study was to examine attendant healthcare providers' beliefs surrounding the cDCD practice model in the context of MAiD. More specifically, I examined attitudinal, normative, and control beliefs of MAiD service providers regarding their intentions to engage in the cDCD practice model on behalf of their patients. The study explored the a priori hypothesis that cognitive and affective attitude, professional and moral norm, and perceived behavioural control would each be a significant predictor of this intention. It was hypothesized that MAiD service providers who hold positive attitudes, favourable normative beliefs, and who perceive more control over cDCD in MAiD would be more likely to *intend* to engage in this practice model. Overall correlation results supported the hypothesis showing that all the theoretical constructs were significantly associated with intention to enable cDCD for MAiD patients. However, moral norm and perceived behavioural control emerged as the significant conceptual predictors of intention in the regression model. In some contexts and groups for example, intentions may be affected mostly by subjective norms and perceived behavioral controls, and less so by attitudes (Fishbein & Ajzen, 2010). Theoretically, the relative weight of the three predictors of intention is expected to vary across behaviours and across populations being studied, and dependent on the conditions under which the behaviours are being performed (Fishbein & Ajzen, 2010; Reinecke et al., 1996). Thus, the analyses support that the TPB may be a useful framework for evaluating beliefs regarding the cDCD practice model within MAiD settings.

Study results were like findings in previous applications of the TPB in which *all* the theoretical constructs emerged as significant correlates of healthcare professional intention, including attitude (Perkins et al., 2007). Where other studies differed include that attitude had in certain circumstances emerged as the *key* predictor of healthcare professional intention. One reason posited is that some constructs may conceptually overlap (Godin et al., 2008; Perkins et al., 2007; Rivis et al., 2009; Thompson-Leduc et al., 2014). In one study for example, the concepts of *fatalism* and the *sacred body* were tied to negative affective attitudes, yet these constructs may conceptually overlap with moral norm in other studies. In another study, positive and negative attitudes were delineated into stand-alone variables; and while positive attitude was found to have a significant effect on intention; negative attitude was not (Meng-Kuan et al., 2017). In the systematic review done by Thompson-Leduc et al (2014), attitude was also found to be an important predictor of provider intention; however, subjective norms (in which moral and professional norms were combined), and perceived behavioural control were similarly more statistically significant in the regression models. Likewise in the Lavoie et al (2015) study in which moral norm and perceived behavioural control emerged with greater importance as compared to attitude, which nevertheless also remained significant in the regression as compared to our study. Last, while some results showed particular socio-demographic variables as important correlates to intention, they were far less frequently reported as significant predictors of intention (Godin et al., 2008). The explanations posited in the meta-analyses conclude that important variations in results depend on the specific behaviours being studied, the specialized groups of healthcare professionals involved, and the fundamental beliefs attached to each theoretical construct (Godin et al., 2008; Perkins et al., 2007; Rivis et al., 2009).

Findings support previous research that reported the most consistent factors explaining healthcare provider behaviour in multiple healthcare environments included beliefs about pragmatic capabilities [i.e., perceived behavioural control] (Godin et al., 2008). Other studies have also emphasized the importance of perceived behavioural control as a key predictor of healthcare provider intention towards behaviour (Godin, et al., 2008, Kent, 2002, Perkins et al., 2007, Thompson-Leduc et al., 2014). Like other studies, perceived behavioural control in my study was defined by a set of beliefs that included time, knowledge, financial compensation, and sufficient resources (Godin et al., 2008, Khoshnood et al., 2008, Lavoie et al., 2015). Perceived behavioural control reflects participants' felt capability to perform cDCD in MAiD because of both self-efficacy and external conditions. These beliefs have been identified as elements that can hinder (i.e., barriers), or enable (i.e., facilitators), the adoption of cDCD in the MAiD context depending on healthcare provider viewpoint. Therefore, we can surmise that given a sufficient degree of actual control over behaviour, MAiD service providers would be expected to carry out their intentions to discuss cDCD with MAiD patients when the opportunity arises (Fishbein & Ajzen, 2010).

Research in health and healthcare settings has shown that *previous experience with a specific behaviour* (i.e., past behaviour) has emerged as a strong predictor of intention to engage in that behaviour in the future (Godin et al., 2008, Meng-Kuan et al., 2017). In my study, prior experience with organ and tissue donation conversations was assessed, and it may be that this is a marker of past behaviour or previous experience. Findings show that healthcare providers' intentions were significantly correlated with previous experience in organ and tissue donation conversations. Donation experience remained a consistent and strong predictor of intention in the regression model. Given more experience with organ and tissue donation, we can infer that MAiD professionals would be more likely to discuss cDCD with eligible MAiD patients who might desire this opportunity.

Findings also showed that participants who had favourable normative beliefs were more likely to intend to engage in donation-related behaviours in end-of-life situations. Specifically, moral norms were found to be the most important predictor of intention – and while professional norm was not found to be significant in the regression model, it did have the strongest correlation with intention. This extends previous research, emphasizing the potential importance of examining normative beliefs in terms of differentiating professional from moral norms. While some studies have not shown differences between moral and professional norms (Kent, 2002, Perkins et al., 2007, Thompson-Leduc et al., 2014), other studies have found that these two variables may be distinct (Godin et al., 2008, Lavoie et al., 2015, Rivis et al., 2009).

Research has largely supported the predictive utility of moral norms. Data from meta-analyses suggest that the relationship between moral norm and intention was found to be stronger among behaviours with an obvious moral dimension (Godin et al., 2008; Perkins et al., 2007; Rivis et al., 2009). Findings in the Rivis et al (2009) meta-analysis for example, likewise showed that moral norm explained significant variance in behavioural intention after controlling for attitude, subjective norm and perceived behavioural control. Differences in results when compared to other studies may be related to important contextual factors. In my study for example, the topic is cDCD in the context of MAiD, which is a major change in end-of-life practices and poses significant ethical challenges in clinical decision-making for care providers. Applying the TPB model to topics such as ethical decision-making in healthcare environments may be well served by the inclusion of moral norm as an independent variable. Moral norms were defined, in my study, by a set of beliefs that included religious affiliation, the ethical tenets of autonomy, justice, conscientious objection, and conflict of interest (in which the principles of beneficence and non-maleficence were entangled).

Organ donation conversations in the setting of MAiD (or voluntary euthanasia) are recognized as potential conflicts of interest in end-of-life care (Bollen et al., 2016a, Bollen et al., 2016b; Casey et al., 2020; Downar et al., 2019; Downar et al., 2020; Mulder et al., 2017; Ysebaert et al., 2009). Perhaps beneficence, non-maleficence, and autonomy in particular have similarly emerged as the coveted principles in my study as compared to other studies (e.g., Godin et al., 2008, Lavoie et al., 2017). The importance of recognizing these competing principles in clinical settings is reinforced by the discord in the literature surrounding the nature of patient autonomy in MAiD – and thus the basic concept of *how autonomy should be respected* is invigorated through a new donation lens. While patient autonomy is seemingly valued by healthcare professionals, it is not always prioritized in clinical decision-making (Allard et al., 2019, Bollen et al., 2016a, Bollen et al., 2016b, Casey et al., 2020, Joseph-Williams et al., 2014, Lavoie et al., 2015, Mulder, 2019). Arguably, while offering the option of cDCD to MAiD patients could be seen as coercion, not offering the option could prevent patients from the opportunity to donate organs as a consequence of disregarding their latent choice (Allard & Fortin, 2017; Bollen et al., 2016a; Bollen et al., 2016b; Casey et al., 2020). If prioritizing patient autonomy is an important professional objective in end-of-life care settings, then cDCD may be more widely available to MAiD patients who would choose donation (Casey et al., 2020; Downar et al., 2020). Given the significant predictability of moral norm, we can infer that our cohort's intention strongly reflects their shared values and principles regarding cDCD in MAiD. The data support the inference that reconciling the principles of MAiD service providers with those of their patients who choose donation, would help sustain the adoption of cDCD in MAiD settings.

Conclusion

Given the inexorable need for organ transplants in Canada, MAiD becoming a more widely accepted end-of-life care practice, the burgeoning interest in patient autonomy, and the ever-evolving Hippocratic injunction to *do no harm,* it may be important to better link cDCD to MAiD patients who *choose, or who would choose,* organ donation. It is acknowledged that organ donation adds an ethically charged layer of complexity in the setting of MAiD where the interests of the organ recipient(s) inherently implicate the autonomous act of donation for the terminal patient. It is recognized that deeply held principles and values can conflict with practices of organ donation because of the ethical concerns about vulnerability in MAiD patients that can arise in several ways. It is for this reason in particular, that moral norm may have emerged as a dominant predictor of intention to engage in this unique and novel donation practice.

Suitably framed by the TPB, the importance of moral norm, perceived behavioural control, and prior organ and tissue donation experience emerged as key correlates that significantly predicted intention of MAiD personnel to engage in, and take up, the cDCD practice model. Results of my study have shown that moral norms and perceived behavioural controls have emerged as potential latent mediators of the cDCD practice model in the context of MAiD. First, it is unknown at this time which of the ethical principles wielded the most influence on healthcare providers' intentions to engage in organ and tissue donation behaviours. Future direction could potentially involve rich qualitative research to not only unravel the key ethical tenets implicated for individuals, but to determine how to mitigate the potential risk of healthcare professionals from making moral judgements on behalf of their MAiD patients. Second, it is unknown whether results occurred as a consequence of self-efficacy and/or external conditions. It might be important, perhaps, for future research to disentangle these two factors from perceived behavioural control. A wide range of factors exist for perceived behavioural control that can influence access to complex donation practice models, including individual motivational predispositions to change as well as economic, political, and organizational contexts. Thus, even more research is needed to evaluate the degree of *actual control* over cDCD behaviour, and to determine whether these health professionals would, in reality, carry out their intentions when the opportunity arises in end-of-life care settings.

Despite this, overall many Canadian MAiD service providers showed positive attitudes, favourable subjective norms, and efficacious perceptions of behavioural controls towards cDCD in MAiD. Given the transformative worldview of my study from the outset, it is expected that through validation of professional beliefs and perceptions of the multi-level factors surrounding cDCD in MAiD, appropriate professional education and training can be designed to best support those professionals otherwise not engaged in donation services for their patients favouring donation. For example, healthcare organizations could potentially develop a training module that drills into reflecting on one’s beliefs toward cDCD and MAiD, and demonstrates the importance of cDCD as an end-of-life option for patients, families, and health systems. The findings gleaned from this research may be used to inform donation-related goals and objectives for implementing efficacious strategies necessary to link the opportunity for organ and tissue donation to MAiD patients. Strategies linking cDCD to MAiD should ideally focus on normalizing cDCD culture, reconciling opposing values between MAiD patients and their caregivers, and identifying and removing perceived barriers to the cDCD practice model in end-of-life care settings.

Finally, this study surveyed known proponents of MAiD and did not include other healthcare providers who work with terminal patients, including palliative or hospice care providers, who are opposed to MAiD and/or cDCD in the context of MAiD. Given the complexity of the moral norm construct, further work could be done to include the entire end-of-life care landscape to bring about inclusive change to practice and policy.

Strengths and Limitations

An interprovincial quantitative survey design had the distinct advantage of identifying attributes of a large population from a smaller cohort of individuals. All healthcare providers within each respective group invited to participate had opportunity to provide data. An added strength in this study was a clear theoretical focus for the research from the outset ensuring greater opportunity to retain control of the research process and to define the research method. Health-related behaviours are complex and multifaceted, so the design of a study can be daunting, but one made easier by the use of a framework that effectively supported the researcher in categorizing, validating, and challenging theoretical assumptions. Moreover, the structure connected the researcher to the existing knowledge through guidance in identifying the research problem, providing the basis of the hypotheses, specifying the key variables, and critically analyzing the data.

The theoretical framework also helped elucidate study limitations. While comparing and contrasting studies was useful in providing insight as to which of the theoretical constructs might be important to motivate the target cohort toward intention. The issue of how theoretical components were otherwise operationalized within the context of different behavioural goals must be acknowledged. Some of the same-name predictor variables in comparable studies differed or overlapped in concept, while others that were similar in concept, contrasted in name. Consequently, it appeared that the variables had different relationships with the outcomes in a few studies. Thus, it is important to acknowledge the conceptual and operational pitfalls of this cross-study analysis based on the TPB.

Not specifically related to the TPB, it is recognized that conducting research on a sensitive topic is challenging, especially since the researcher is a novice and has limited expertise in developing a questionnaire about topics of a complex nature. In addition, the survey combined and modified seven existing tools that were not all explicitly based on the TPB. As a potential consequence, two of the key variables (i.e., professional norm and perceived behavioural control) had sub-optimal internal consistency. An additional disadvantage of this study design includes the recognition of a possible response bias. This raises the potential concern where beliefs either for or against cDCD in the context of MAiD are disproportionally represented. Last, while the cohort was sufficient in terms of the required sample size, it is assumed that the target sample may have been impacted by restricted access to prospective respondents in the setting of a pandemic.

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Appendix A[1]

Survey

Table 1a

Participant Demographic Information

Participant Demographic Information

- I have read the information letter for consent that was sent via email and is embedded in this survey:
  - o yes
  - o no
- Age:
  - o 20-30
  - o 31-40
  - o 41-50
  - o 51-60
  - o 61+
- Professional Practice Group:
  - o Physician
  - o Registered Nurse
  - o Nurse Practitioner

- Gender (optional): __________
- Religious Affiliation (optional): __________
- Worksite (e.g., hospital/unit, homecare, family medicine): __________
- In my professional role, I am involved in the assessment and/or provision of Medical Assistance in Dying (MAiD):

  o yes

  o no

- Years of practice: _________
- Previous experience in discussing organ and/or tissue donation with patients or families:

  o yes

  o no

Table 2a

Behavioural Belief Set That Relates to Attitudes

Beliefs That relate to cognitive attitudes
• Organ and/or tissue donation is a valuable end-of-life care option for all my eligible patients (Kent, 2002; Lavoie et al., 2015; Ogle et al., 2002). • Organ and tissue donation is a valuable end-of-life care option for MAiD patients (Kent, 2002; Lavoie et al., 2015; Ogle et al., 2002). • Organ and tissue donation helps families in the grieving process (Kent, 2002; Prottas & Batten, 1988). • Organ and tissue donation increase the survival and quality of life for people who have received transplants (Kent, 2002). • Organ donation is cost effective in management of patients with end-stage organ failure (Kent, 2002).
• I would consider donating my own organs and tissues (Prottas & Batten, 1988; Symvoulakis et al., 2012). • I feel that tissue donation discussions are emotionally demanding for me (Prottas & Batten, 1988).
Beliefs That Relate to Affective Attitudes
• I feel that organ and/or tissue donation discussions are damaging to my patients (Meng-Kuan et al., 2017; Ogle et al., 2002). • I feel comfortable introducing the subject of tissue donation with patients and families (Ogle et al., 2002; Prottas & Batten, 1988). • I feel comfortable introducing the subject of organ donation that entails controlled donation after cardiocirculatory death (cDCD) with MAiD patients. • I feel that organ and tissue discussions are damaging to MAiD patients (Meng-Kuan et al., 2017; Ogle et al., 2002).

Note. All items are rated on a 5-point Likert scale where: 1 = strongly agree; 2 = agree; 3 = not sure; 4 = disagree; 5 = strongly disagree

Table 3a

Normative Belief Set That Relates to Subjective Norms

Professional Normative Beliefs
• I have discussed my feelings about organ and tissue donation with my family (Prottas & Batten, 1988) • I feel that consideration of organ and tissue donation is a professional responsibility in end-of-life care (Lavoie et al., 2015) • My colleagues would accept that I support controlled donation after cardiocirculatory death (cDCD) for my patients who desire MAiD (Lavoie et al., 2015; Meng-Kuan et al., 2017) • Patients or families are often unwilling to choose organ and tissue donation as an end-of-life care option (Ogle et al., 2002) • Helping to facilitate controlled donation after cardiocirculatory death (cDCD) for MAiD patients would be compatible with my role as a physician/nurse (Lavoie et al., 2015)
Moral Normative Beliefs
• Discussion of organ and tissue donation is a conflict of interest within the realm of end-of-life care (Lavoie et al., 2015) • Discussion of controlled donation after cardiocirculatory death (cDCD) is a conflict of interest within the realm of MAiD (Lavoie et al., 2015) • Organ and tissue donation is unacceptable because of my religious and/or spiritual beliefs (Rousseau et al., 2017; Symvoulakis et al., 2012) • Controlled donation after cardiocirculatory death (cDCD) in the setting of MAiD is unacceptable because of my religious and/or spiritual beliefs (Rousseau et al., 2017; Symvoulakis et al., 2012) • Facilitating controlled donation after cardiocirculatory death (cDCD) for a MAiD patient would be acting in accordance with my principles (Lavoie et al., 2015) • The ethical principle of justice is compromised when healthcare providers do not offer an eligible MAiD patient the opportunity for organ and tissue donation (Kent, 2002) • Organ and tissue donation promotes patient autonomy (Kent, 2002)

Note. All items are rated on a 5-point Likert scale where: 1 = strongly agree; 2 = agree; 3 = not sure; 4 = disagree; 5 = strongly disagree

Table 4a

Control Belief Set That Relates to Perceived Behavioural Controls

Control Beliefs
• I do not have the time to support organ and tissue donation together with my routine end-of-life care and/or MAiD services (Ogle et al., 2002) • I am uncertain of the types of organ and tissue donation services for which my patients are eligible (Ogle et al., 2002) • I am not adequately compensated for my time when organ and tissue donation services are used (Khoshnood et al., 2018) • I (as the physician or nurse) am the most appropriate person to introduce the concept of donation to the patient and family (Ogle et al., 2002) • The organ and tissue donation program coordinator is the most appropriate person to introduce the concept of donation to the patient and family (Ogle et al., 2002) • There are sufficient staffing resources available in facilitating organ and tissue donation (cDCD) for eligible MAiD patients (Lavoie et al., 2015; Meng-Kuan et al., 2017; Prottas & Batten, 1988) • I believe there are legal liabilities in organ and tissue donation in the context of MAiD that prevent me from supporting same (Prottas & Batten, 1988)

Note. All items are rated on a 5-point Likert scale where: 1 = strongly agree; 2 = agree; 3 = not sure; 4 = disagree; 5 = strongly disagree

Table 5a

Determinants of Intention

Direct Determinants of Intention
• I intend to discuss controlled donation after cardiocirculatory death (cDCD) with MAiD patients who bring up the subject of organ and tissue donation (Lavoie et al., 2015) • I intend to discuss organ and tissue donation with <u>all eligible patients</u> who have requested MAiD (Lavoie et al., 2015) • I intend to always discuss organ and/or tissue donation in end-of-life care conversations with my patients (Lavoie et al., 2015)

Note. All items are rated on a 5-point Likert scale where: 1 = strongly agree; 2 = agree; 3 = not sure; 4 = disagree; 5 = strongly disagree

Appendix A^2

Survey (French)

Table 1b

Information démographique du participant

Information

- J’ai lu la lettre de consentement envoyée par courriel et incluse avec le sondage:

  o oui

  o non
- Âge:

  o 20-30

  o 31-40

  o 41-50

  o 51-60

  o 61+
- Groupe professionel:

  o Médecin

  o Infirmière

  o Infirmière-clinicienne
- Genre (optionnel): _________
- Affiliation religieuse (optionnel): __________
- Lieu de travail (hôpital, soins à domicile, médecin de famille): __________

- Dan mon cadre professionnel, je participe à l'évaluation ou à la provision de l'aide médicale à mourir (AMM):

  o oui

  o non

- Années d'expériences: __________

- Expérience pour discuter le don d'organe avec les patients ou les familles:

  o oui

  o non

Table 2b

Croyances associées aux attitudes

Croyances associées aux attitudes cognitives
• L'option du don d'organe est une option de fin de vie importante pour tous les patients éligibles (Kent, 2002; Lavoie et al., 2015; Ogle et al., 2002). • L'option du don d'organe est une option de fin de vie importante pour les patients ayant recours à l'aide médicale à mourir (AMM) (Kent, 2002; Lavoie et al., 2015; Ogle et al., 2002). • Le don d'organe aide le deuil des familles (Kent, 2002; Prottas & Batten, 1988). • Le don d'organe améliore la durée et la qualité de vie des greffés (Kent, 2002). • Le don d'organe est un traitement rentable pour les patients avec défaillance d'organes sévères (Kent, 2002).
Croyances associées aux attitudes affectives
• Je pense au don de mes propres organes. (Prottas & Batten, 1988; Symvoulakis et al., 2012) • Je trouve les discussions à propos du don exigeantes au niveau émotionnel. (Prottas & Batten, 1988) • Je crois que les conversations à propos du don sont néfastes pour mes patients. (Meng-Kuan et al., 2017; Ogle et al., 2002) • Je me sens confortable d'amener le sujet du don d'organe auprès des patients et des familles. (Ogle et al., 2002; Prottas & Batten, 1988) • Je me sens confortable de discuter du don d'organe dans le contexte de l'aide médicale à mourir. • Je crois que les conversations à propos du don sont néfastes pour les patients ayant recours à l'aide médicale à mourir. Meng-Kuan et al., 2017; Ogle et al., 2002)

Remargue. Échelle de Likert à 5 points: 1= Tout à fait d'accord; 2= Plutôt d'accord; 3= Ni d'accord, ni pas d'accord; 4= Plutôt pas d'accord; 5=Pas du tout d'accord

Table 3b

Normes et croyances subjectives

Normes et croyances professionnelles
• J’ai discuté des préférences quant au don d’organe avec ma famille. (Prottas & Batten, 1988) • Je considère que le don d’organe est une responsabilité professionnelle est une responsabilité professionnelle en soins en fin de vie. (Lavoie et al., 2015) • Mes collègues acceptent mon support du don d’organe dans le contexte de l’aide médicale à mourir. (Lavoie et al., 2015; Meng-Kuan et al., 2017) • Les patients et les familles sont souvent réticentes à choisir le don d’organe en fin de vie. (Ogle et al., 2002) • Mon rôle d’infirmière / de médecin est compatible avec le don d’organe dans le contexte de l’AMM. (Lavoie et al., 2015)
Croyances morales et éthiques
• Un conflit d’intérêt existe entre les soins en fin de vie et la discussion au sujet du don d’organe. (Lavoie et al., 2015) • Il existe un conflit d’intérêt entre la discussion du don d’organe après la mort cardiaque et l’aide médicale à mourir. (Lavoie et al., 2015) • Le don d’organe est inacceptable à cause de mes croyances religieuses ou spirituelles. (Rousseau et al., 2017; Symvoulakis et al., 2012) • Le don d’organe après la mort cardiaque et l’aide médicale à mourir est inacceptable à cause de mes croyances religieuses ou spirituelles. (Rousseau et al., 2017; Symvoulakis et al., 2012) • Mes principes me permettent de participer au don d’organe dans le contexte de l’AMM. (Lavoie et al., 2015) • Le principe de justice est compromis lorsque l’on n’offre pas le don d’organe dans le contexte de l’AMM. (Kent, 2002) Le don d’organe supporte le respect de l’autonomie du patient. (Kent, 2002)

Remarque. Échelle de Likert à 5 points: 1= Tout à fait d’accord; 2= Plutôt d’accord; 3= Ni d’accord, ni pas d’accord; 4= Plutôt pas d’accord; 5=Pas du tout d’accord

Table 4b

Perception d'influence des comportements

Croyances liées au contrôle
• Je n'ai pas le temps nécessaire pour supporter le don d'organe dans ma pratique de soin en fin de vie. (Ogle et al., 2002) • Je ne suis pas certain de l'éligibilité de mes patients pour le don d'organe. (Ogle et al., 2002) • Je ne suis pas suffisamment compensé pour mon temps lors du processus de don d'organe. (Khoshnood et al., 2018) • En tant que médecin ou infirmière, je suis le mieux placé (la mieux placée) pour introduire le concept du don d'organe avec les patients et la famille. (Ogle et al., 2002) • Le coordinateur de l'agence de don d'organe est le mieux placé (la mieux placée) pour introduire le concept du don d'organe avec les patients et la famille. (Ogle et al., 2002) • Les ressources humaines sont suffisantes pour faciliter le don dans le contexte de l'AMM. (Lavoie et al., 2015; Meng-Kuan et al., 2017; Prottas & Batten, 1988) • Je crois être à risque de poursuite pour les dons d'organes dans le contexte de l'AMM. (Prottas & Batten, 1988)

Remarque. Échelle de Likert à 5 points : 1= Tout à fait d'accord; 2= Plutôt d'accord; 3= Ni d'accord, ni pas d'accord; 4= Plutôt pas d'accord; 5=Pas du tout d'accord

Table 5b

Déterminants des intentions

Déterminants directs *des intentions*
• Je compte discuter du don d'organe dans le contexte de l'AMM chez les patients intéressés. (Lavoie et al., 2015) • Je compte discuter du don d'organe dans le contexte de l'AMM avec tous les patients éligibles. (Lavoie et al., 2015) • Je compte discuter du don d'organe avec mes patients en contexte de fin de vie. (Lavoie et al., 2015)

Remarque. Échelle de Likert à 5 points : 1= Tout à fait d'accord; 2= Plutôt d'accord; 3= Ni d'accord, ni pas d'accord; 4= Plutôt pas d'accord; 5=Pas du tout d'accord

Appendix B[1]

Recruitment Poster

Controlled Donation after Cardiocirculatory Death

In the Context of Medical Assistance in Dying – The Link

We are looking for volunteer Physicians, Registered Nurses and Nurse Practitioners to take part in a study exploring your beliefs that may impact clinical uptake of the Controlled Donation after Cardiocirculatory Death (cDCD) practice model for terminal patients that have been accepted for Medical Assistance in Dying (MAiD)

Your one-time participation is entirely voluntary and would take approximately 15 minutes of your time. By participating in this study you will help us to better understand the intentions of End-of-Life Care Physicians and Nurses,
together with organizational supports and culture, that connect organ and tissue donation to patients accessing MAiD <u>and</u> value the personal consequences of healthcare providers

To learn more about this study, or to participate in this study, please contact:
Tina Shaver
Email tina.shaver@ahs.ca
Phone 403-404-8684

This study is supervised by Dr. Terra Murray.
This study has been reviewed by the
University of Alberta Health Research Ethics Board

Appendix B^2 (French)

Nous recruitons des participants

L’aide médicale à mourir et le don d’organe après un arrêt circulatoire – faire le pont

Nous recherchons des infirmières, infirmière-clinicienne et médecins volontaires pour un sondage au sujet des croyances liées au Don d’organes après un Arrêt Circulatoire (DAC) dans le contexte de l’Aide Médicale à Mourir (AMM).

Ce sondage nécessite environ 15 minutes. Il permettra de mieux comprendre les motivations, la culture et le support organisationnel chez les intervenants de soins en fin de vie. Il tente aussi de mieux comprendre l’impact du don d’organe dans le contexte de l’aide médicale à mourir pour les soignants.

Pour en apprendre davantage ou participer à l’étude,
veuillez contacter:

Tina Shaver
Courriel : tina.shaver@ahs.ca
Téléphone 403-404-8684

Cette étude est supervisée par Dr. Terra Murray

L’étude a été revue et approuvée par le comité d’éthique de l’Université de l’Alberta

Appendix C[1]

Information for Organizational Leadership

[Date]

[To Whom It May Concern],

My name is Tina Shaver and I am a Graduate Nursing Student at Athabasca University. As a requirement to complete my Master's degree, I am conducting research about a topical issue relevant to organ and tissue donation after cardiocirculatory death (DCD) for terminal patients receiving medical assistance in dying (MAiD). Enhanced understanding of what may be influencing intentions may help inform future interventions with well-conceived plans that safeguard optimal end-of-life care, designate respect for patient-centred care, and value the personal consequences of healthcare providers.

I am conducting this study under the supervision of Dr. Terra Murray. I have obtained ethics approval from the Health Research Ethics Board (HREB) of the University of Alberta. This research will utilize a one-time survey (completed online at a convenient time) that will take 10-20 minutes and will consist of two sections: (1) demographic information; (2) theoretical constructs that measure the value of behavioural, normative and control belief sets promoting or impeding organ and tissue donation in the context of MAiD.

I am seeking your assistance with recruiting end-of-life care Physicians, Registered Nurses and Nurse Practitioners involved in the assessment and/or provision of MAiD. Please review the information that I have enclosed in this letter. I will be available to answer any questions that you may have concerning my research.

At the conclusion of my research, I hope to publish the findings in relevant scholarly journals, in addition to submitting my findings as a presentation at the Canadian Society of Transplant (CST) meeting.

Please contact me if you would like any further information. I can be reached by email at Tina.Shaver@ahs.ca or phone at 403-818-2023.

I look forward to hearing from you soon.

Sincerely,

Tina Shaver, RN, BN, BA Enclosure

Appendix C^2 (French)

Information supplémentaire

[Date]

[À qui de droit],

Je me nomme Tina Shaver et je poursuis des études graduées en Sciences Infirmières à l'Université Athabasca. Mon projet de recherche a pour sujet le don d'organes dans le contexte de l'aide médicale à mourir. Je cherche à mieux comprendre les motivations et perceptions des soignants. Éventuellement, l'intention serait de développer des plans qui permettent une fin de vie digne, respectent les désirs des patients et tiennent en compte des valeurs et de la morale des soignants.

Cette étude est supervisée par Dre. Terra Murray. Le comité d'éthique de l'Université de l'Alberta l'a approuvée. Cette étude nécessite un sondage en ligne d'environ 15 minutes. Le sondage comprend deux parties : (1) de l'information démographique; (2) des questions théoriques à propos des attitudes, des croyances normatives et à propos du contrôle qui influencent de façon positive ou négative le don d'organe dans le contexte de l'aide médicale é mourir.

Je recruite des participants intéressés à ce projet de recherche parmi les médecins, infirmières et infirmières-cliniciennes oeuvrant en soins de fin de vie. Veuillez prendre le temps de lire l'information inclues avec cette lettre. Je suis disponible pour répondre à vois questions.

Je compte publier les résultats de ce sondage et les présenter lors de la conférence de la Société Canadienne de Transplantation. Vous pouvez me joindre par courriel

Tina.Shaver@ahs.ca ou par téléphone au 403-818-2023 pour toute question concernant l’étude.

Merci pour votre intérêt.

Sincérement,

Tina Shaver, RN, BN, BA

Appendix D[1]

Participant Information Letter

PARTICPANT INFORMATION LETTER FOR CONSENT

Title of Study: Controlled Donation after Cardiocirculatory Death In the Context of Medical Assistance in Dying: The Link

Principle Investigator

Name	Tina Shaver, BN, BA, RN
Department	Graduate Student in the Faculty of Health Disciplines
Institution	Athabasca University
Contact	Phone: 403-818-2023 / Email: tina.shaver@ahs.ca

Supervisor

Name	Dr. Terra Murray, Ph.D., Associate Dean Teaching & Learning, Assistant Professor
Department	Faculty of Health Disciplines
Institution	Athabasca University
Contact	Phone: 866-379-1127 / Email: tmurray@athabascau.ca

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

You are invited to participate in this study as part of a voluntary research initiative because you are employed as a Physician, Registered Nurse or Nurse Practitioner involved in the assessment and/or provision of medical assistance in dying (MAiD). In this study, we will be exploring your beliefs surrounding the facilitation of controlled organ and tissue donation after cardiocirculatory death (cDCD) for terminal patients that have requested MAiD.

What is the reason for doing this study?

Intention toward enabling this donation practice model for end-of-life care in Canada, to date has not been explored by researchers. In response, this study will examine beliefs of Physicians and Nurses that may impact clinical engagement and uptake of this novel practice model. Enhanced understanding of what may be influencing intentions, may help inform future interventions among healthcare providers with well-conceived plans that safeguard optimal end-of-life care, designate respect for patient centred care, and value the personal consequences of healthcare providers.

What will I be asked to do?
We are asking you to agree to complete a 42-question survey that I expect will take approximately 10-20 minutes. The survey is completed online at a time that is convenient to you. Informed consent, embedded within the survey is required by all participants in which the risks and benefits of participating are clearly outlined. At the beginning of the survey, you will check a box confirming that you have read this letter of consent and are a willing participant. Before you make a decision, you are encouraged to ask questions if you feel anything needs further clarification.

What are the risks and discomforts?
The sensitive nature of the topic may elicit some strong feelings. If this should occur, you may withdraw from the study at any time without any negative consequences. It is not possible to know all the risks that may happen in a study, but I have taken all reasonable safeguards to minimize any known risk to you.

What are the benefits to me?
You may find it rewarding to contribute to new clinical knowledge, and to proffer a voice that connects your values and beliefs to the organ and tissue donation system.

Do I have to take part in this study?
Being in this study is your choice. If you decide to be in the study, you can change your mind and stop participating in the study at any time, and it will in no way affect your employment. If at any time, you decide to withdraw from participating in my study, your survey data will be destroyed and will not be used. Please be aware however, that once I have analyzed the data and merged it with other participants' information, I will be unable to remove your data from my findings.

Will I be paid to be in the research?
You will not be compensated for participating in the online survey.

Will my information be kept private?
All your information will be kept confidential. All electronic data, including but not limited to, the questionnaire and participant traceability will be maintained on my password-protected personal computer, which will be maintained in an encrypted transmission cloud back-up system. Please note that the survey data may be initially collected and stored on a server in the United States (US) and is subject to access under the US Patriot Act until it is transferred from that server to my computer. Information may be shared with my study supervisor and the other members of my study committee. All electronic data will be electronically shredded once data analysis is complete. No data relating to this study that includes your name (or other identifiers) will be released outside of my office or published by me.

How will the study be disseminated?
Results of this study may be submitted as an article(s) to academic and professional journals. Study findings will be submitted as a presentation at the Canadian Transplant Society meeting. The final report will be distributed to the host institutions and to the participants (as requested).

What if I have questions?
If you have any questions about the research now or later please contact me, Tina Shaver at email: tina.shaver@ahs.ca or phone: 403-818-2023. This study has been reviewed by the University of Alberta Health Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the Office of Research Ethics at 1-800-788-9041, ext. 6718 or by e-mail to rebsec@athabascau.ca

Thank you.

Tina Shaver, RN, BN, BA
Faculty of Health Disciplines
Athabasca University

CONSENT:

The completion of the survey and its submission is viewed as your consent to participate.

BEGIN THE SURVEY

Appendix D^2 (French)

Formulaire de consentement

Titre de l'étude: L'aide médicale à mourir après l'arrêt circulatoire dans le contexte de l'aide médicale à mourir: faire le pont.

Investigatrice principale

Nom	Tina Shaver, BN, BA, RN
Départment	Études Graduées Faculté de la santé
Institution	Université Athabasca
Contact	Téléhone: 403-818-2023 Courriel: tina.shaver@ahs.ca

Superviseure

Nom	Dre.Terra Murray, Ph.D., Doyenne Associée à l'enseignement, Professeure agrégée
Départment	Faculté de la santé
Institution	Athabasca University
Contact	Téléphone: 866-379-1127 Courriel: tmurray@athabascau.ca

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Pourquoi je peux participer?
Vous êtes invités à participer à cette étude parce que vous travaillez avec les patients en fin de vie et que vous participez de près à l'aide médicale à mourir (AMM). Cette étude explore les croyances liées au don d'organes dans ce contexte d'arrêt circulatoire.

But de l'étude?
Des lacunes existent quant aux connaissances au niveau des perceptions du personnel soignant en soins de fin de vie par rapport au don dans le contexte de l'AMM au Canada. Pour accroître ces connaissances, nous proposons d'explorer les croyances et perceptions des intervenants pour mieux comprendre les déterminants favorables et défavorables à cette situation clinique.

La demande?
Il s'agit d'un sondage en deux parties qui demande environ 15 minutes. Il y a 42 questions en ligne ainsi qu'une section démographique afin de comprendre qui a répondu au sondage. Il faut aussi donner un consentement éclairé au sujet de l'étude. Au début du sondage en ligne, vous devrez indiquer avoir lu cette lettre et que vous participez en connaissance de cause. N'hésitez pas à me contacter si vous avez des questions ou besoin de clarification.

Quels sont les risques?
Il s'agit d'un sujet qui peut causer des émotions vives. Vous avez la possibilité de retirer votre consentement à l'étude en tout temps. Somme toute, les risques sont jugés bas et les questions choisies plutôt neutres.

Quels sont les avantages personels?
Il y en a peu, outre le fait de partager son opinion sur un sujet d'actualité important. Faire entendre sa voix à propos des croyances et valeurs entourant le don d'organe pourra permettre de faire avancer les connaissances à ce sujet.

Suis-je dans l'obligation de participer?
Pas du tout. Ce choix est tout-à-fait volontaire. Vous avez le droit de retirer votre consentement en tout temps. Les réponses au sondage seront traitées de façon confidentielle. Il sera possible d'éliminer vos réponses si vous le désirez, avant l'analyse des réponses mis en commun. À partir de cette étape, il sera impossible de les séparer

Vais-je recevoir une compensation financière?
Non

Mon information sera confidentielle?
Oui. Les données informatiques seront seront sécurisées par dé-identification, cryptage et protégées par mot de passe. La collecte et l'entreposage initial passera par un serveur américain asujetti au US Patriot Act. Une fois le transfert effectué, les données seront visibles par l'équipe de rechercher exclusivement. Les données seront détruites de manière confidentielle. Aucune information personnelle ne sera publiée.

Où pensez-vous disséminer vos trouvailles?
Je compte publier les résultats de ce sondage et les présenter lors de la conférence de la Société Canadienne de Transplantation. Il sera possible pour les participants de recevoir une copie du rapport final.

J'ai plus de questions?
Contactez-moi au besoin. Je me nomme Tina Shaver et mon courriel est: tina.shaver@ahs.ca. Mon numéro de téléphone est: 403-818-2023. Cette étude a été approuvée par le comité d'Éthique de l'Université de l'Alberta. Leur contact est ci-bas : Office of Research Ethics 1-800- 788-9041, ext. 6718; courriel rebsec@athabascau.ca

Merci grandement,

Tina Shaver, RN, BN, BA
Études GraduéesFaculté de la santé
Université Athabasca

CONSENTEMENT:

En remplissant le sondage et en le soumettant, je consens à la participation à l'étude.

Débuter le sondage

Appendix E[1]

Participant Survey Consent

PARTICIPANT SURVEY CONSENT

Title of Study: Controlled Donation after Cardiocirculatory Death
In the Context of Medical Assistance in Dying: The Link

Principle Investigator

Name	Tina Shaver, BN, BA, RN
Department	Graduate Student in the Faculty of Health Disciplines
Institution	Athabasca University
Contact	Phone: 403-818-2023 / Email: tina.shaver@ahs.ca

Supervisor

Name	Dr. Terra Murray, Ph.D., Associate Dean Teaching & Learning, Assistant Professor
Department	Faculty of Health Disciplines
Institution	Athabasca University
Contact	Phone: 866-379-1127 / Email: tmurray@athabascau.ca

	Yes/No
Do you understand that you have been asked to be in a research study?	
Have you received and read the Participant Information Letter for Consent?	
Do you understand the benefits and risks involved in taking part in this research?	
Have you had an opportunity to ask questions and discuss this study?	
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your employment?	
Has the issue of confidentiality been adequately explained to you?	
Do you understand who will have access to your information?	
I agree to take part in this study.	

Appendix E^2 (French)

Consentement des participants au sondage

Titre de l'étude: L'aide médicale à mourir après l'arrêt circulatoire dans le contexte de l'aide médicale à mourir : faire le pont.

Investigatrice principale	
Nom	Tina Shaver, BN, BA, RN
Départment	Études Graduées Faculté de la santé
Institution	Université Athabasca
Contact	Téléhone: 403-818-2023 Courriel: tina.shaver@ahs.ca

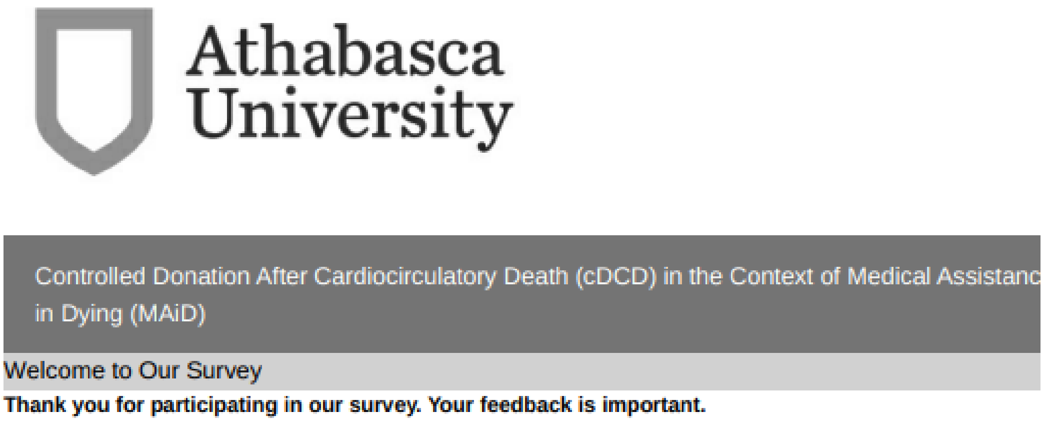
Superviseure	
Nom	Dre.Terra Murray, Ph.D., Doyenne Associée à l'enseignement, Professeure agrégée
Départment	Faculté de la santé
Institution	Athabasca University
Contact	Téléphone: 866-379-1127 Courriel: tmurray@athabascau.ca

---

	Oui/No
On m'a demandé de participer à ce projet de recherche?	
J'ai reçu et lu la lettre de consentement?	
Je comprends les riques et avantages liés à cette étude?	
On m'a offert de répondre à mes questions?	
Je suis libre de me retirer en tout temps sans conséquence néfastes?	
On m'a expliqué comment la confidentialité sera assurés?	
Je comprends qui aura accès aux données?	
J'accepte de participer à cette étude.	

Appendix F[1]

Survey Monkey Questionnaire

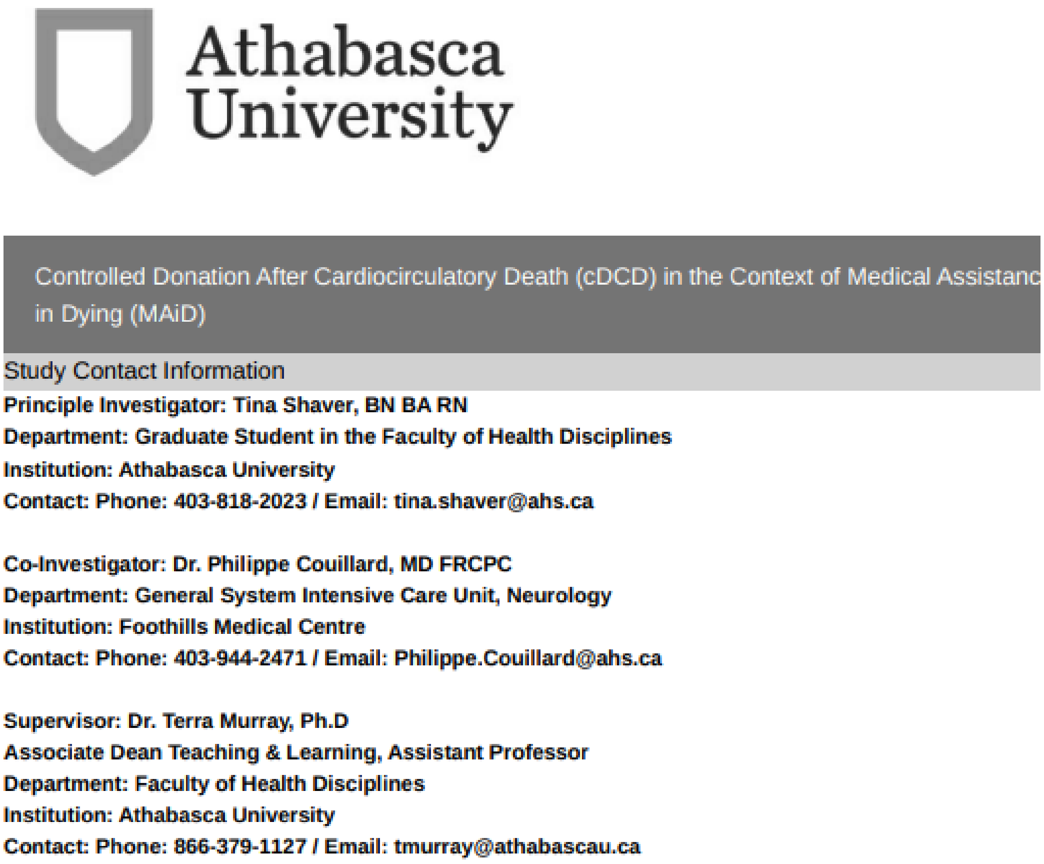


Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Welcome to Our Survey

Thank you for participating in our survey. Your feedback is important.



Athabasca University

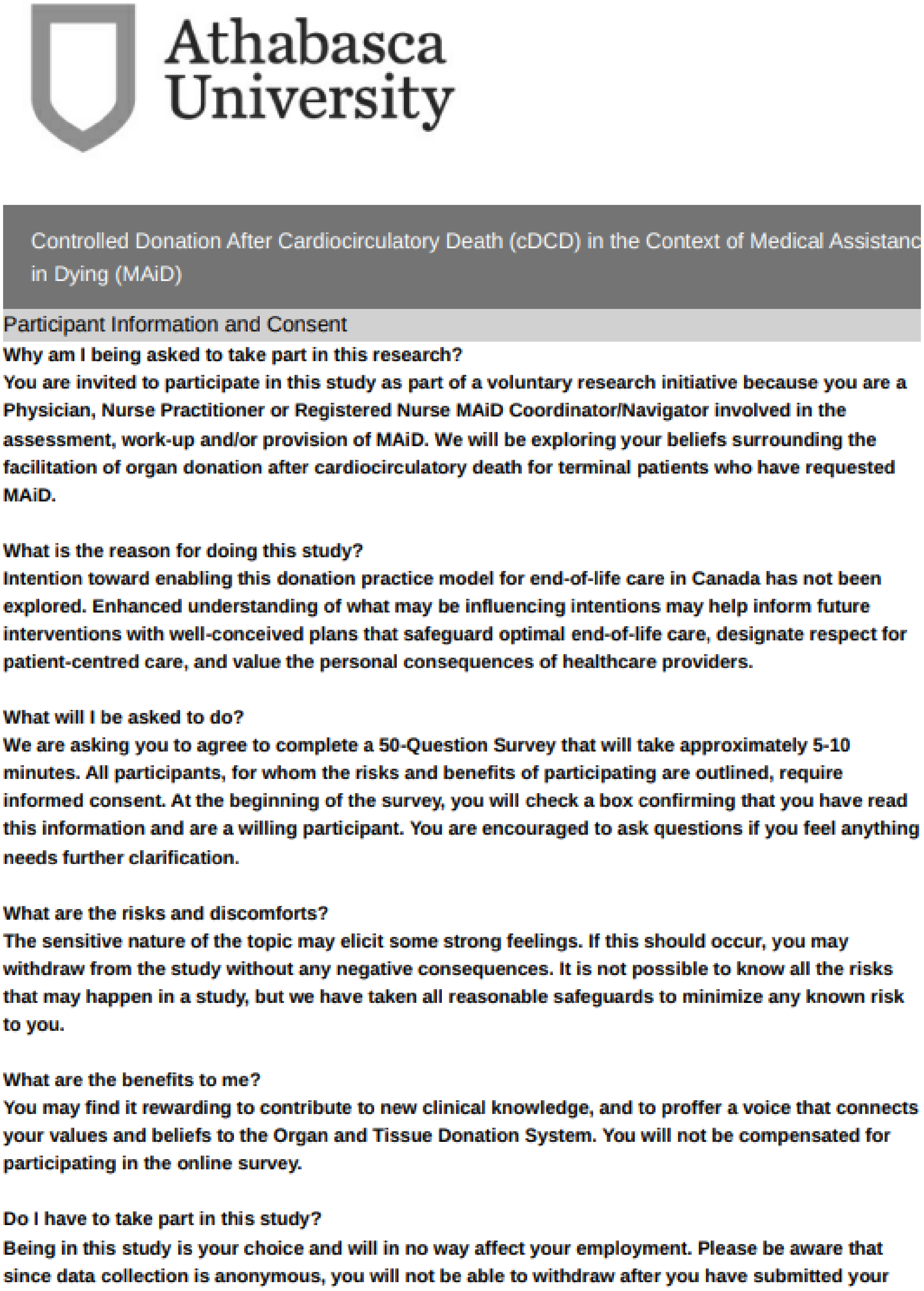
Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Study Contact Information

Principle Investigator: Tina Shaver, BN BA RN
Department: Graduate Student in the Faculty of Health Disciplines
Institution: Athabasca University
Contact: Phone: 403-818-2023 / Email: tina.shaver@ahs.ca

Co-Investigator: Dr. Philippe Couillard, MD FRCPC
Department: General System Intensive Care Unit, Neurology
Institution: Foothills Medical Centre
Contact: Phone: 403-944-2471 / Email: Philippe.Couillard@ahs.ca

Supervisor: Dr. Terra Murray, Ph.D
Associate Dean Teaching & Learning, Assistant Professor
Department: Faculty of Health Disciplines
Institution: Athabasca University
Contact: Phone: 866-379-1127 / Email: tmurray@athabascau.ca



Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Participant Information and Consent

Why am I being asked to take part in this research?
You are invited to participate in this study as part of a voluntary research initiative because you are a Physician, Nurse Practitioner or Registered Nurse MAiD Coordinator/Navigator involved in the assessment, work-up and/or provision of MAiD. We will be exploring your beliefs surrounding the facilitation of organ donation after cardiocirculatory death for terminal patients who have requested MAiD.

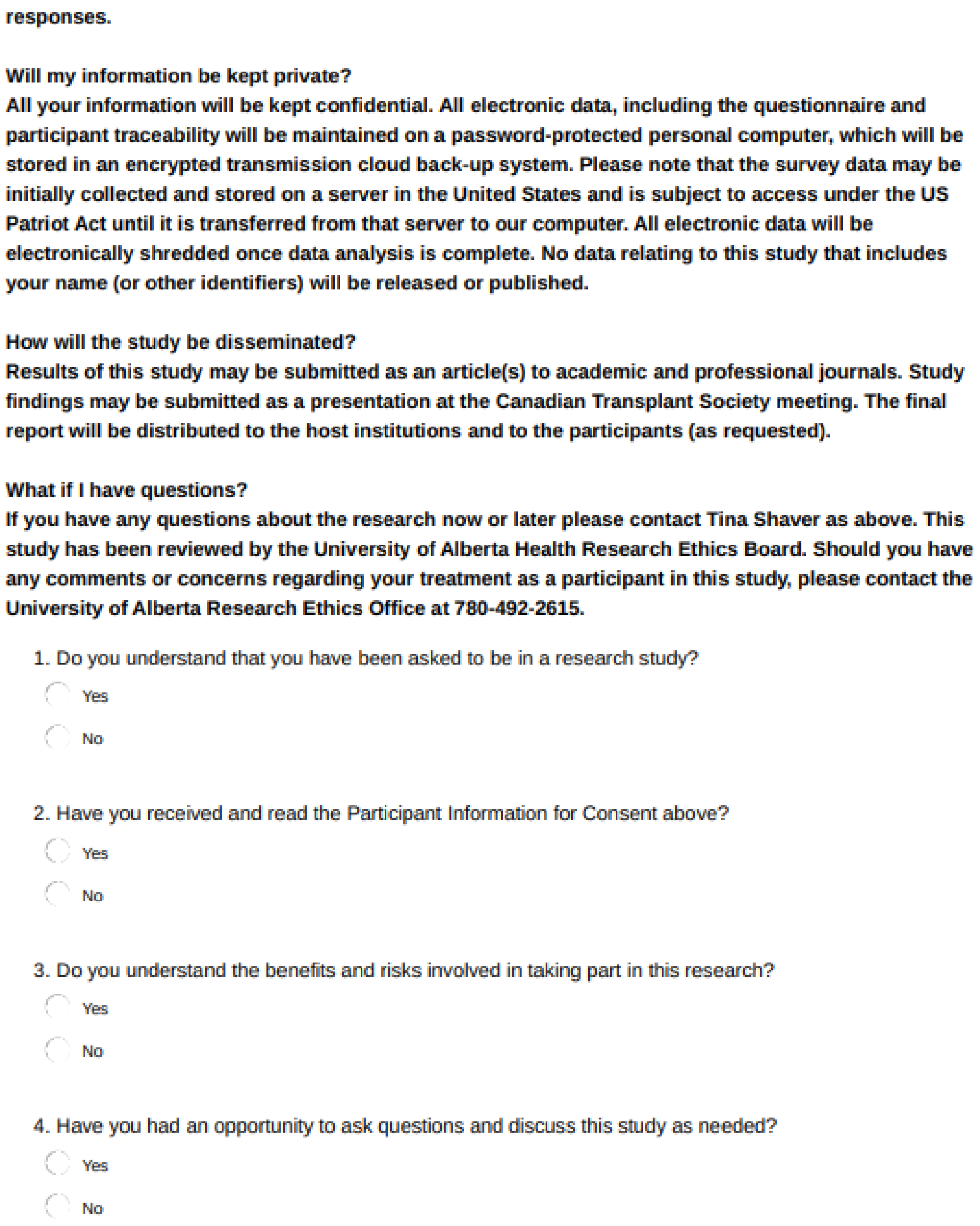
What is the reason for doing this study?
Intention toward enabling this donation practice model for end-of-life care in Canada has not been explored. Enhanced understanding of what may be influencing intentions may help inform future interventions with well-conceived plans that safeguard optimal end-of-life care, designate respect for patient-centred care, and value the personal consequences of healthcare providers.

What will I be asked to do?
We are asking you to agree to complete a 50-Question Survey that will take approximately 5-10 minutes. All participants, for whom the risks and benefits of participating are outlined, require informed consent. At the beginning of the survey, you will check a box confirming that you have read this information and are a willing participant. You are encouraged to ask questions if you feel anything needs further clarification.

What are the risks and discomforts?
The sensitive nature of the topic may elicit some strong feelings. If this should occur, you may withdraw from the study without any negative consequences. It is not possible to know all the risks that may happen in a study, but we have taken all reasonable safeguards to minimize any known risk to you.

What are the benefits to me?
You may find it rewarding to contribute to new clinical knowledge, and to proffer a voice that connects your values and beliefs to the Organ and Tissue Donation System. You will not be compensated for participating in the online survey.

Do I have to take part in this study?
Being in this study is your choice and will in no way affect your employment. Please be aware that since data collection is anonymous, you will not be able to withdraw after you have submitted your



responses.

Will my information be kept private?
All your information will be kept confidential. All electronic data, including the questionnaire and participant traceability will be maintained on a password-protected personal computer, which will be stored in an encrypted transmission cloud back-up system. Please note that the survey data may be initially collected and stored on a server in the United States and is subject to access under the US Patriot Act until it is transferred from that server to our computer. All electronic data will be electronically shredded once data analysis is complete. No data relating to this study that includes your name (or other identifiers) will be released or published.

How will the study be disseminated?
Results of this study may be submitted as an article(s) to academic and professional journals. Study findings may be submitted as a presentation at the Canadian Transplant Society meeting. The final report will be distributed to the host institutions and to the participants (as requested).

What if I have questions?
If you have any questions about the research now or later please contact Tina Shaver as above. This study has been reviewed by the University of Alberta Health Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this study, please contact the University of Alberta Research Ethics Office at 780-492-2615.

1. Do you understand that you have been asked to be in a research study?

○ Yes
○ No

2. Have you received and read the Participant Information for Consent above?

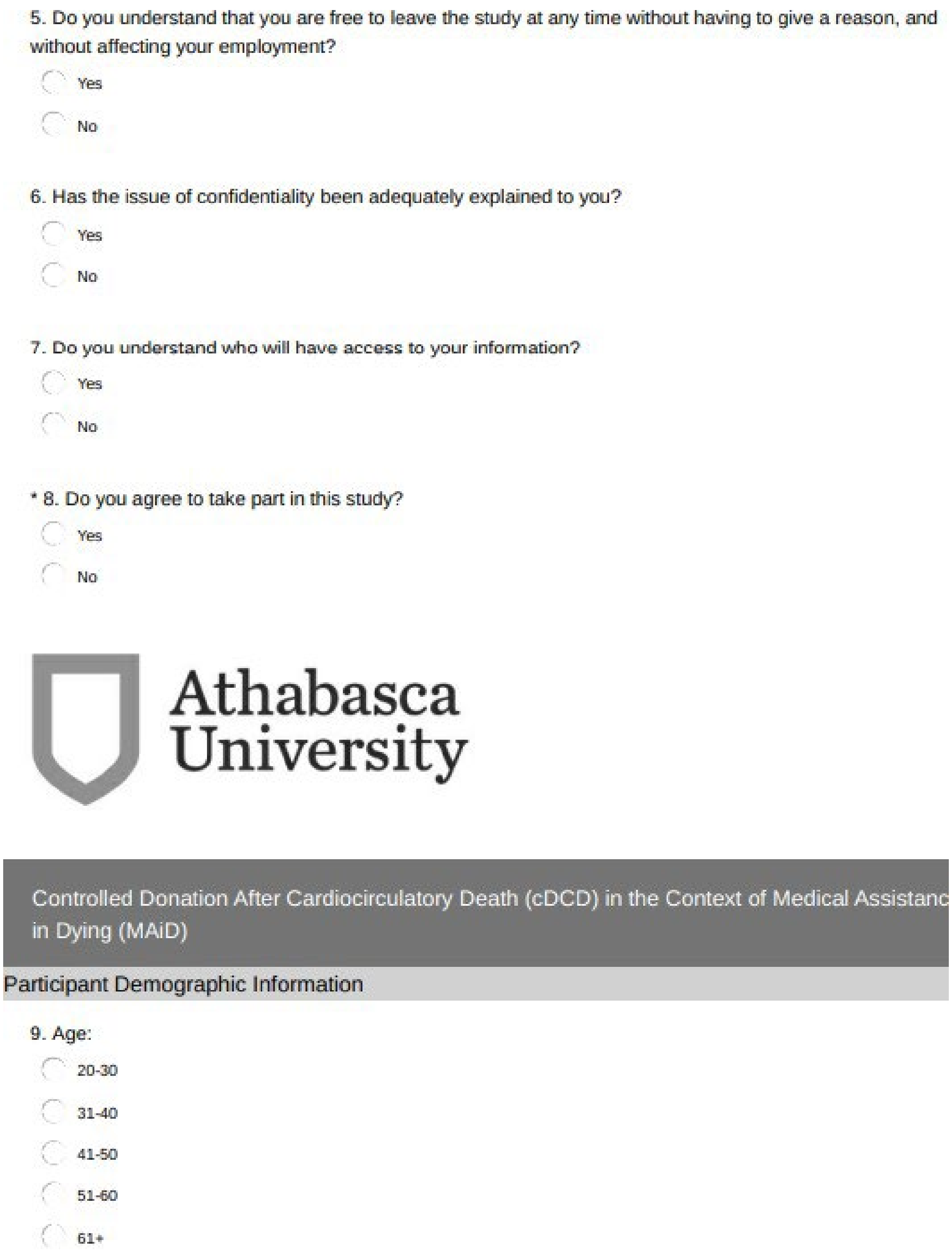
○ Yes
○ No

3. Do you understand the benefits and risks involved in taking part in this research?

○ Yes
○ No

4. Have you had an opportunity to ask questions and discuss this study as needed?

○ Yes
○ No



5. Do you understand that you are free to leave the study at any time without having to give a reason, and without affecting your employment?

○ Yes

○ No

6. Has the issue of confidentiality been adequately explained to you?

○ Yes

○ No

7. Do you understand who will have access to your information?

○ Yes

○ No

* 8. Do you agree to take part in this study?

○ Yes

○ No

Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Participant Demographic Information

9. Age:

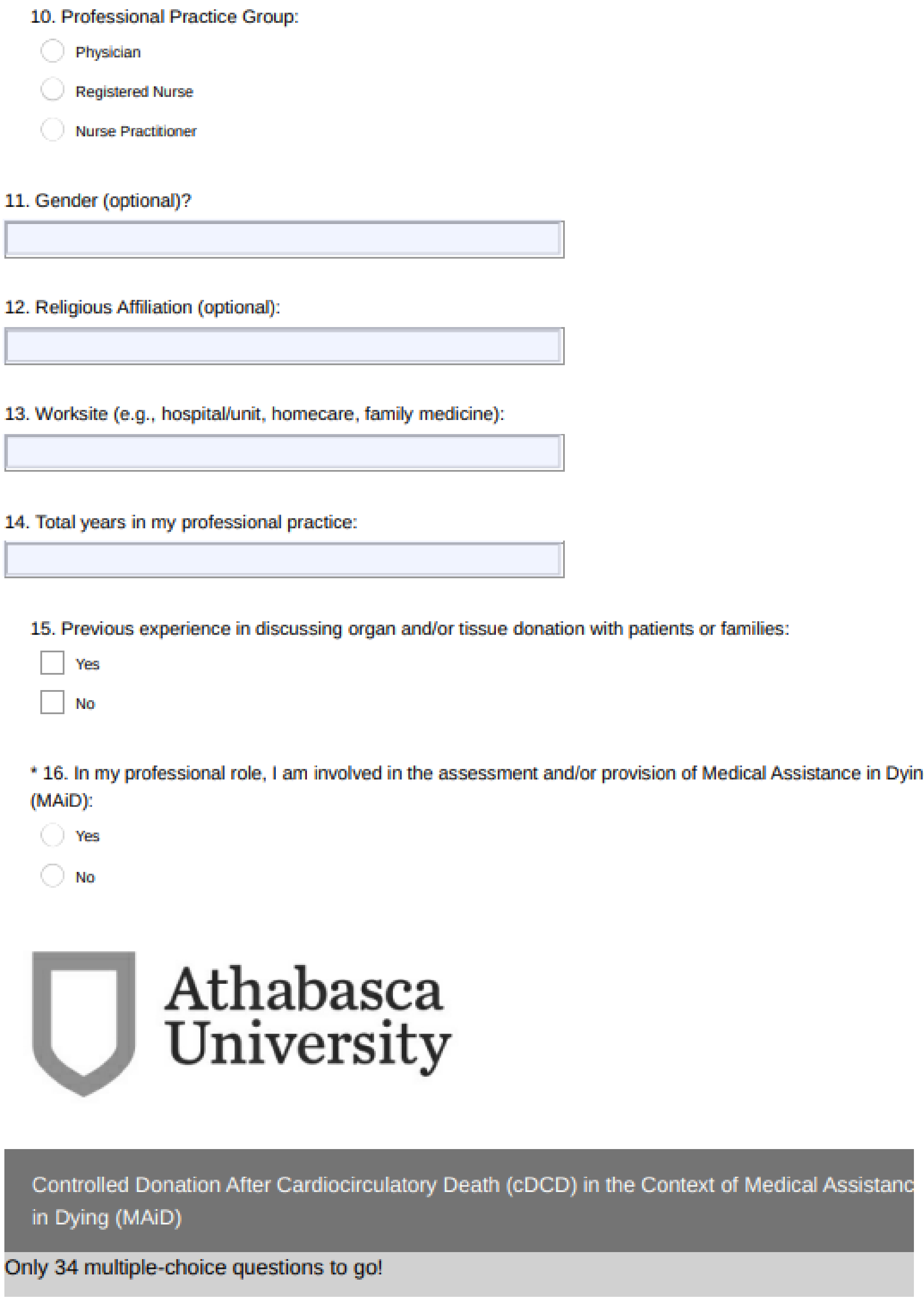
○ 20-30

○ 31-40

○ 41-50

○ 51-60

○ 61+



10. Professional Practice Group:

○ Physician
○ Registered Nurse
○ Nurse Practitioner

11. Gender (optional)?

12. Religious Affiliation (optional):

13. Worksite (e.g., hospital/unit, homecare, family medicine):

14. Total years in my professional practice:

15. Previous experience in discussing organ and/or tissue donation with patients or families:

☐ Yes
☐ No

* 16. In my professional role, I am involved in the assessment and/or provision of Medical Assistance in Dying (MAiD):

○ Yes
○ No

Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc in Dying (MAiD)

Only 34 multiple-choice questions to go!

Cognitive Attitude

Behavioral Belief-Set That Relates to Cognitive Attitude

17. Organ and/or tissue donation is a valuable end-of-life care option for all my eligible patients.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

18. *Tissue donation* is a valuable end-of-life care option for patients who will receive MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

19. *Organ donation* (via cDCD) is a valuable end-of-life care option for patients who will receive MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

20. Organ and/or tissue donation helps families in the grieving process.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

21. Organ donation and transplantation increases the survival and quality of life for people who have received transplants.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

22. Organ donation is cost effective in the management of patients with end-stage organ failure.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Affective Attitude

Behavioral Belief-set That Relates to Affective Attitude

23. I would consider donating my own organs.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

24. I feel that donation discussions are emotionally demanding for me.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

25. I feel that donation discussions are damaging to all my patients.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

26. I feel comfortable introducing the subject of *tissue donation* with patients and/or families.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

27. I feel comfortable introducing the subject of *organ donation* that entails controlled donation after cardiocirculatory death (cDCD) with eligible patients who will receive MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

28. I feel that donation discussions are damaging to patients who will receive MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

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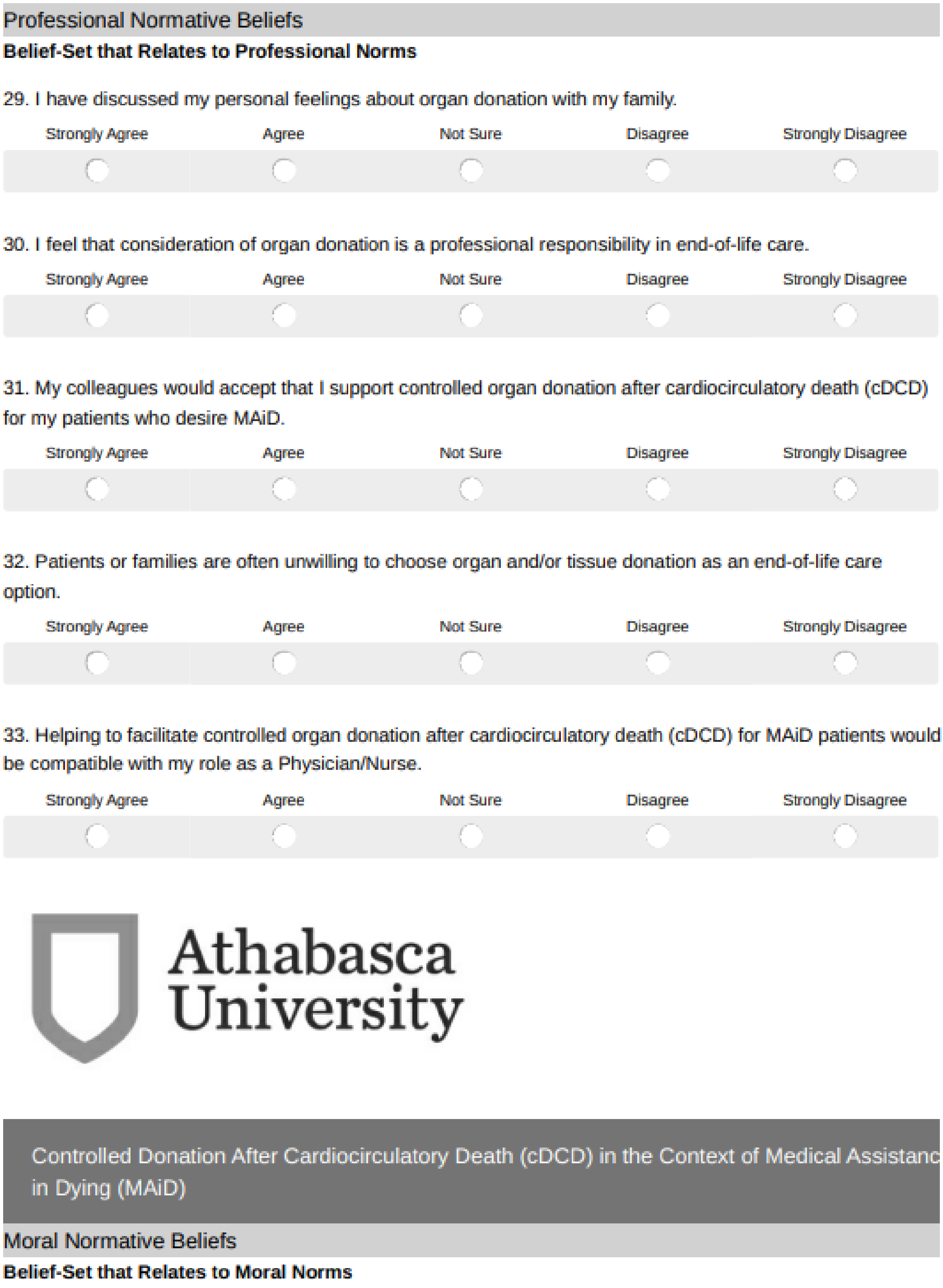
University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)



Professional Normative Beliefs

Belief-Set that Relates to Professional Norms

29. I have discussed my personal feelings about organ donation with my family.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

30. I feel that consideration of organ donation is a professional responsibility in end-of-life care.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

31. My colleagues would accept that I support controlled organ donation after cardiocirculatory death (cDCD) for my patients who desire MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

32. Patients or families are often unwilling to choose organ and/or tissue donation as an end-of-life care option.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

33. Helping to facilitate controlled organ donation after cardiocirculatory death (cDCD) for MAiD patients would be compatible with my role as a Physician/Nurse.

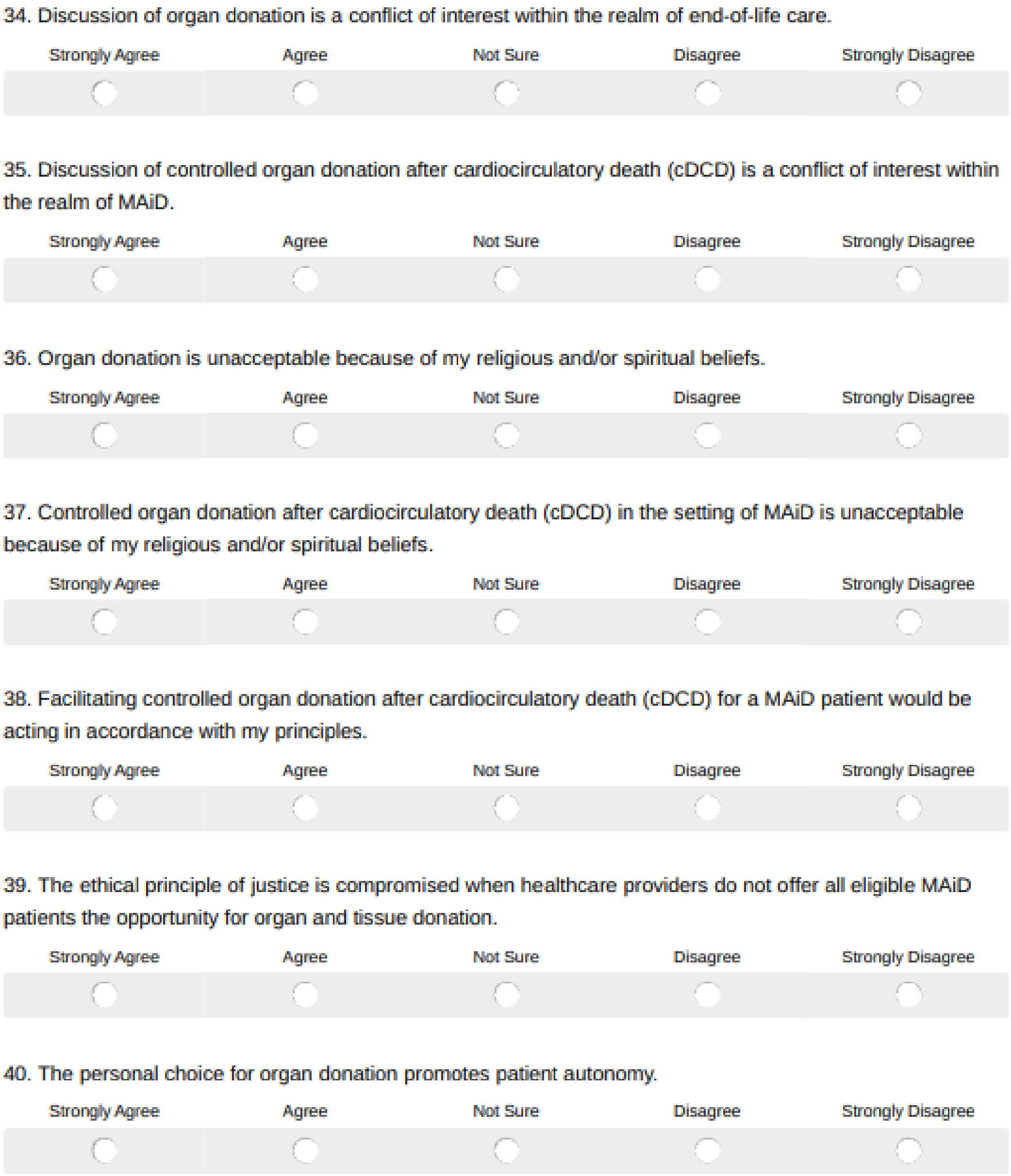
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Moral Normative Beliefs

Belief-Set that Relates to Moral Norms



34. Discussion of organ donation is a conflict of interest within the realm of end-of-life care.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

35. Discussion of controlled organ donation after cardiocirculatory death (cDCD) is a conflict of interest within the realm of MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

36. Organ donation is unacceptable because of my religious and/or spiritual beliefs.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

37. Controlled organ donation after cardiocirculatory death (cDCD) in the setting of MAiD is unacceptable because of my religious and/or spiritual beliefs.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

38. Facilitating controlled organ donation after cardiocirculatory death (cDCD) for a MAiD patient would be acting in accordance with my principles.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

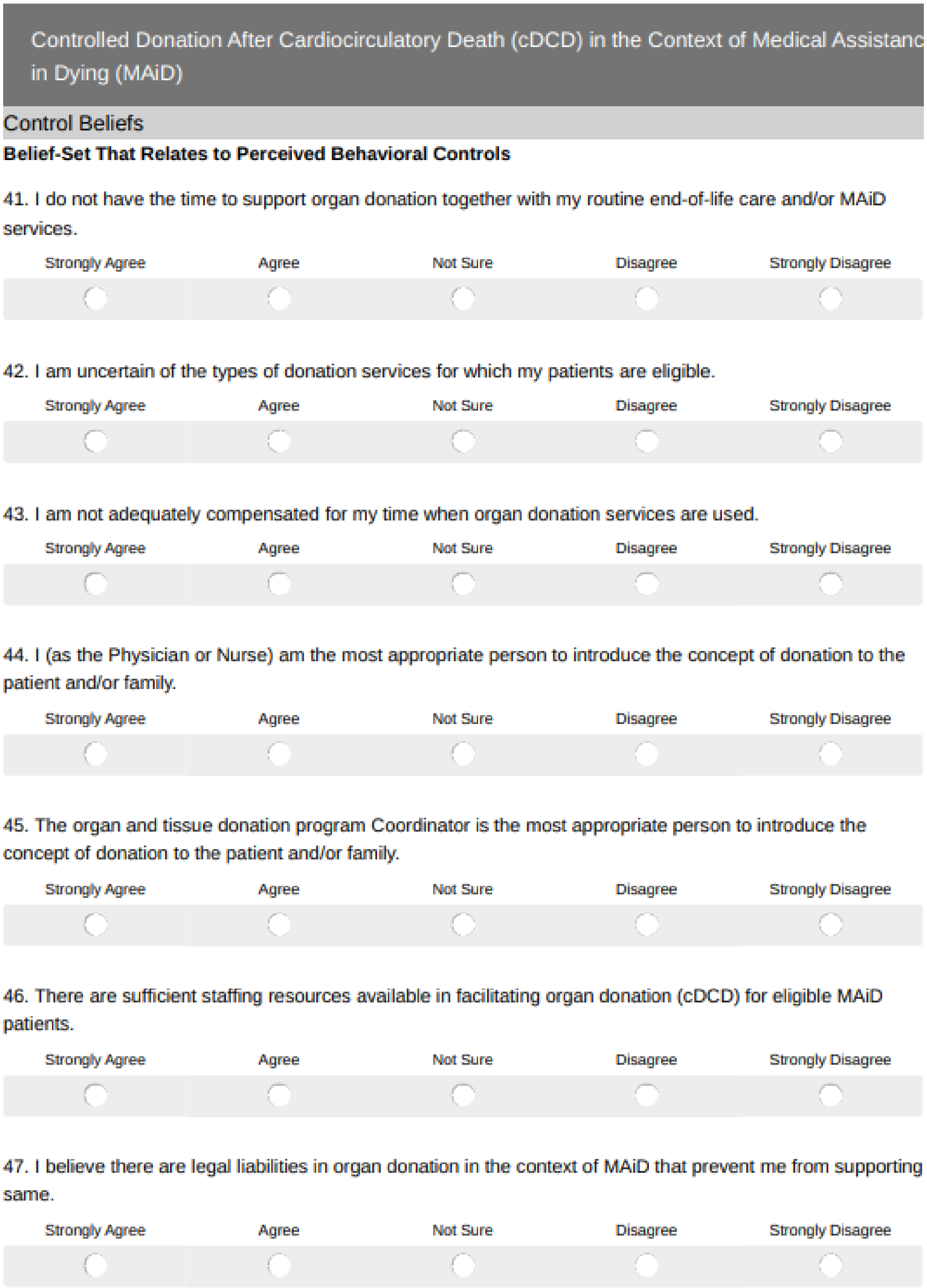
39. The ethical principle of justice is compromised when healthcare providers do not offer all eligible MAiD patients the opportunity for organ and tissue donation.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

40. The personal choice for organ donation promotes patient autonomy.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

Athabasca University



Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc in Dying (MAiD)

Control Beliefs

Belief-Set That Relates to Perceived Behavioral Controls

41. I do not have the time to support organ donation together with my routine end-of-life care and/or MAiD services.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

42. I am uncertain of the types of donation services for which my patients are eligible.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

43. I am not adequately compensated for my time when organ donation services are used.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

44. I (as the Physician or Nurse) am the most appropriate person to introduce the concept of donation to the patient and/or family.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

45. The organ and tissue donation program Coordinator is the most appropriate person to introduce the concept of donation to the patient and/or family.

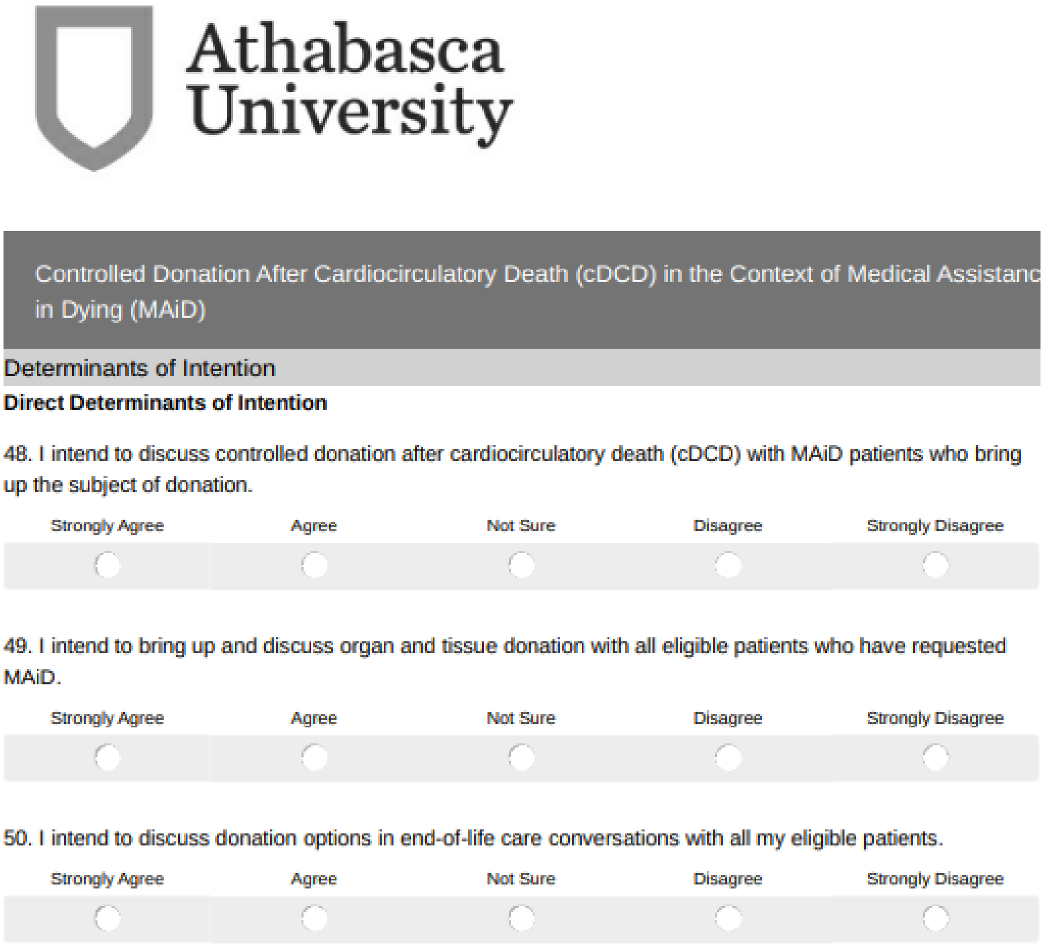
Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

46. There are sufficient staffing resources available in facilitating organ donation (cDCD) for eligible MAiD patients.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

47. I believe there are legal liabilities in organ donation in the context of MAiD that prevent me from supporting same.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○



Athabasca University

Controlled Donation After Cardiocirculatory Death (cDCD) in the Context of Medical Assistanc
in Dying (MAiD)

Determinants of Intention

Direct Determinants of Intention

48. I intend to discuss controlled donation after cardiocirculatory death (cDCD) with MAiD patients who bring up the subject of donation.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

49. I intend to bring up and discuss organ and tissue donation with all eligible patients who have requested MAiD.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

50. I intend to discuss donation options in end-of-life care conversations with all my eligible patients.

Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
○	○	○	○	○

Appendix F^2

Survey Monkey Questionnaire (French)

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Bienvenue au sondage

Merci pour votre participation à notre sondage. Vos commentaires sont importants.

Athabasca University

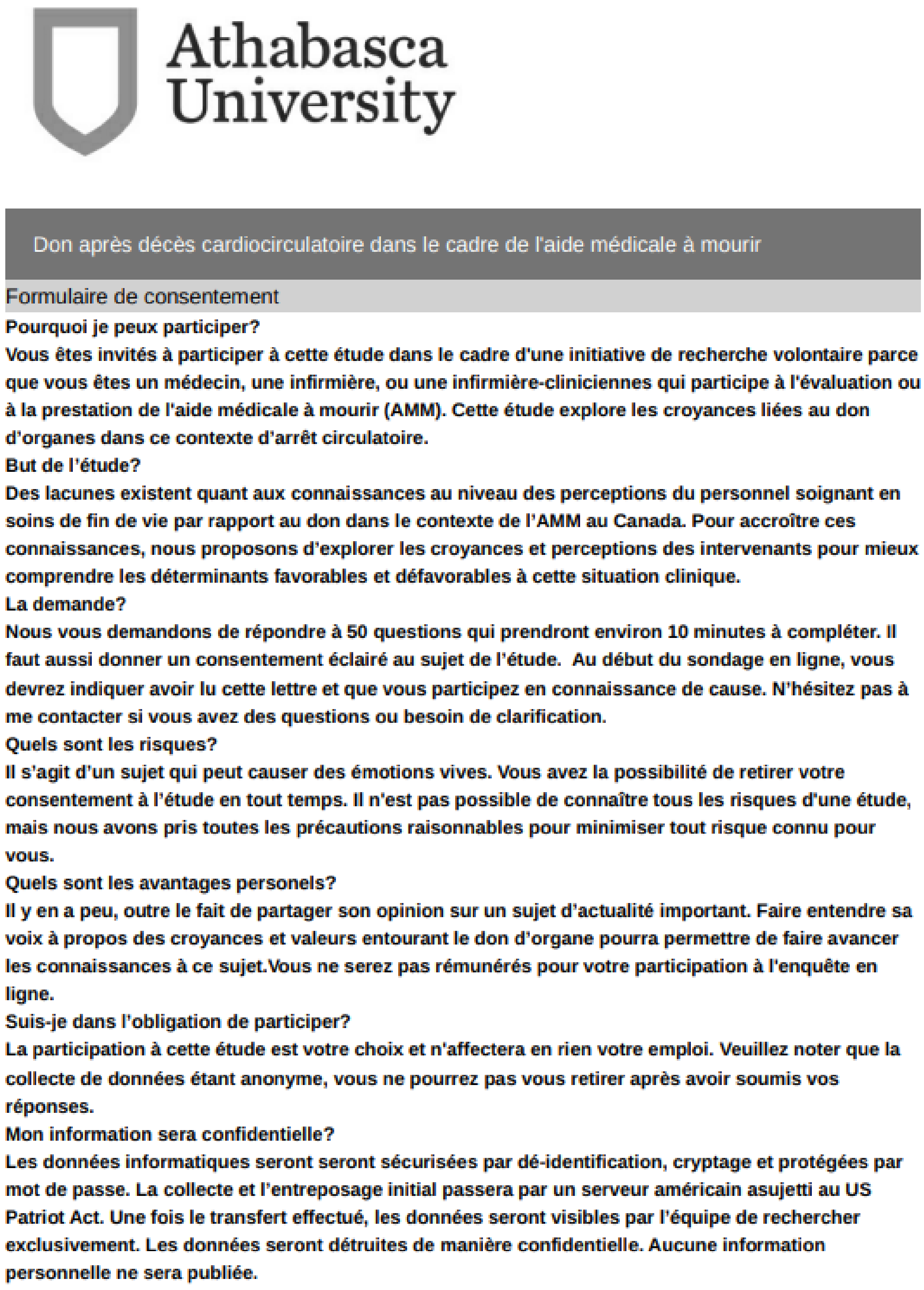
Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Coordonnées

Investigatrice principale: Tina Shaver, BN BA RN
Départment: Études Graduées Faculté de la santé
Institution: Université Athabasca
Contact: Téléhone: 403-818-2023 / Courriel: tina.shaver@ahs.ca

Co-Investigateur: Dr. Philippe Couillard, MD FRCPC
Départment: Soins intensifs, Neurologie
Institution: Foothills Medical Centre
Contact: Téléphone: 403-944-2471 / Courriel: philippe.couillard@ahs.ca

Superviseure: Dre. Terra Murray, Ph.D.
Départment:Faculté de la santé, Doyenne Associée à l'enseignement, Professeure agrégée
Institution: Athabasca University
Contact: Téléphone: 866-379-1127 / Courriel: tmurray@athabascau.ca



Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Formulaire de consentement

Pourquoi je peux participer?

Vous êtes invités à participer à cette étude dans le cadre d'une initiative de recherche volontaire parce que vous êtes un médecin, une infirmière, ou une infirmière-cliniciennes qui participe à l'évaluation ou à la prestation de l'aide médicale à mourir (AMM). Cette étude explore les croyances liées au don d'organes dans ce contexte d'arrêt circulatoire.

But de l'étude?

Des lacunes existent quant aux connaissances au niveau des perceptions du personnel soignant en soins de fin de vie par rapport au don dans le contexte de l'AMM au Canada. Pour accroître ces connaissances, nous proposons d'explorer les croyances et perceptions des intervenants pour mieux comprendre les déterminants favorables et défavorables à cette situation clinique.

La demande?

Nous vous demandons de répondre à 50 questions qui prendront environ 10 minutes à compléter. Il faut aussi donner un consentement éclairé au sujet de l'étude. Au début du sondage en ligne, vous devrez indiquer avoir lu cette lettre et que vous participez en connaissance de cause. N'hésitez pas à me contacter si vous avez des questions ou besoin de clarification.

Quels sont les risques?

Il s'agit d'un sujet qui peut causer des émotions vives. Vous avez la possibilité de retirer votre consentement à l'étude en tout temps. Il n'est pas possible de connaître tous les risques d'une étude, mais nous avons pris toutes les précautions raisonnables pour minimiser tout risque connu pour vous.

Quels sont les avantages personels?

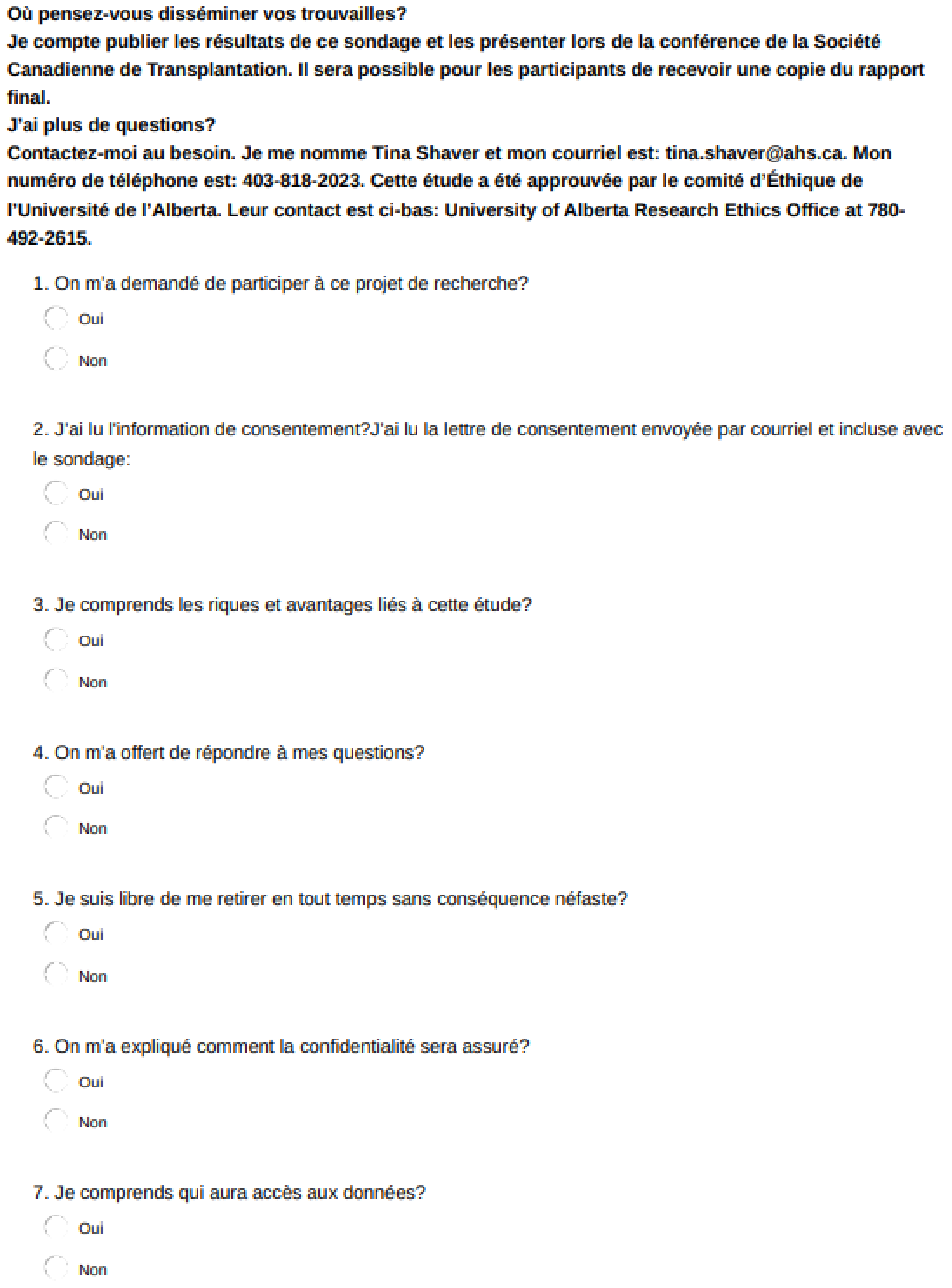
Il y en a peu, outre le fait de partager son opinion sur un sujet d'actualité important. Faire entendre sa voix à propos des croyances et valeurs entourant le don d'organe pourra permettre de faire avancer les connaissances à ce sujet.Vous ne serez pas rémunérés pour votre participation à l'enquête en ligne.

Suis-je dans l'obligation de participer?

La participation à cette étude est votre choix et n'affectera en rien votre emploi. Veuillez noter que la collecte de données étant anonyme, vous ne pourrez pas vous retirer après avoir soumis vos réponses.

Mon information sera confidentielle?

Les données informatiques seront seront sécurisées par dé-identification, cryptage et protégées par mot de passe. La collecte et l'entreposage initial passera par un serveur américain asujetti au US Patriot Act. Une fois le transfert effectué, les données seront visibles par l'équipe de rechercher exclusivement. Les données seront détruites de manière confidentielle. Aucune information personnelle ne sera publiée.



Où pensez-vous disséminer vos trouvailles?
Je compte publier les résultats de ce sondage et les présenter lors de la conférence de la Société Canadienne de Transplantation. Il sera possible pour les participants de recevoir une copie du rapport final.
J'ai plus de questions?
Contactez-moi au besoin. Je me nomme Tina Shaver et mon courriel est: tina.shaver@ahs.ca. Mon numéro de téléphone est: 403-818-2023. Cette étude a été approuvée par le comité d'Éthique de l'Université de l'Alberta. Leur contact est ci-bas: University of Alberta Research Ethics Office at 780-492-2615.

1. On m'a demandé de participer à ce projet de recherche?

○ Oui

○ Non

2. J'ai lu l'information de consentement?J'ai lu la lettre de consentement envoyée par courriel et incluse avec le sondage:

○ Oui

○ Non

3. Je comprends les riques et avantages liés à cette étude?

○ Oui

○ Non

4. On m'a offert de répondre à mes questions?

○ Oui

○ Non

5. Je suis libre de me retirer en tout temps sans conséquence néfaste?

○ Oui

○ Non

6. On m'a expliqué comment la confidentialité sera assuré?

○ Oui

○ Non

7. Je comprends qui aura accès aux données?

○ Oui

○ Non

* 8. J'accepte de participer à cette étude.

○ Oui

○ Non

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Information démographique

Information démographique du participant

9. Âge:

○ 20-30

○ 31-40

○ 41-50

○ 51-60

○ 61+

10. Groupe professionel:

○ Médecin

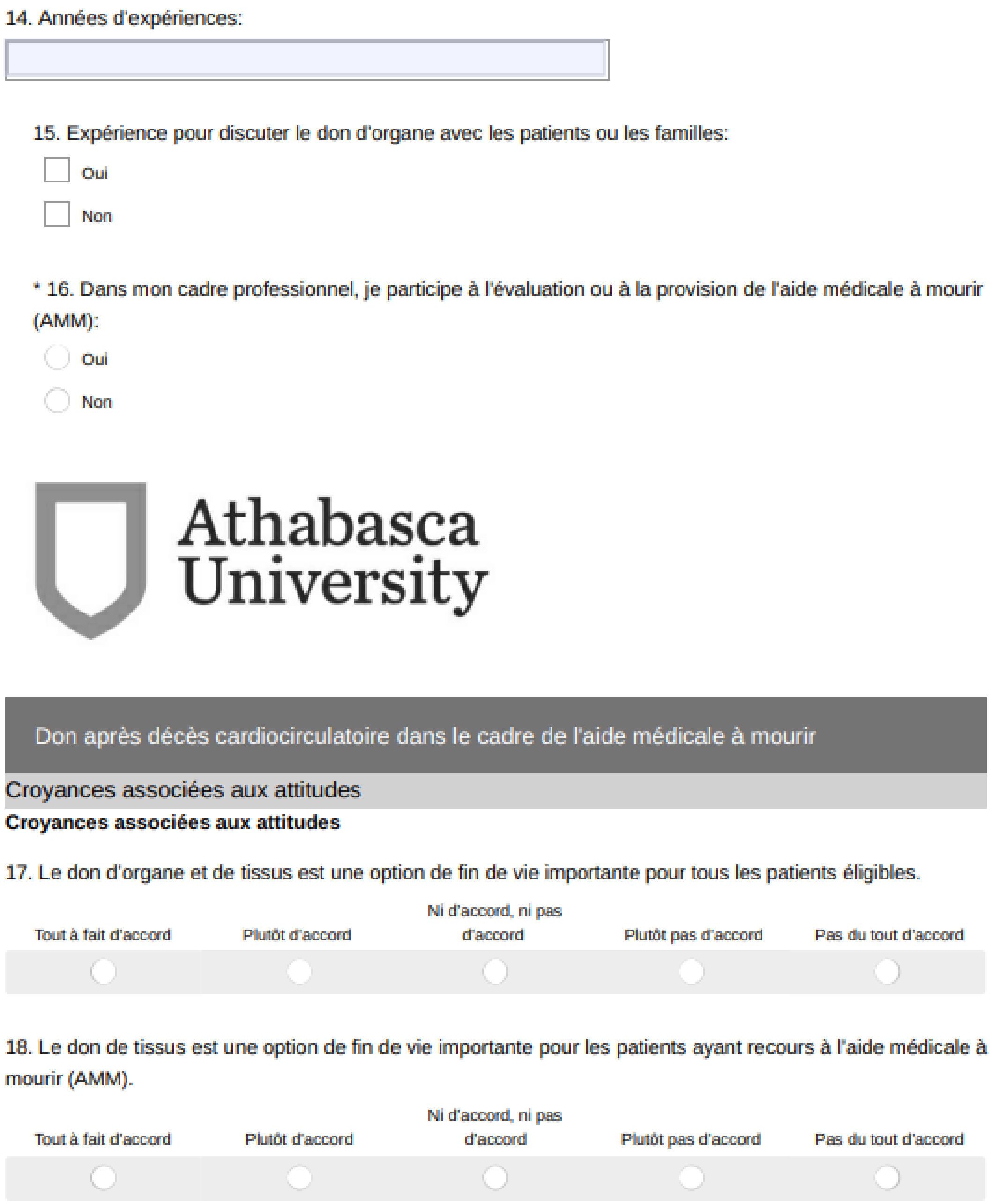
○ Infirmière

○ Infirmière-clinicienne

11. Genre (optionnel)

12. Affiliation religieuse (optionnel):

13. Lieu de travail (hôpital, soins à domicile, médecin de famille):



14. Années d'expériences:

15. Expérience pour discuter le don d'organe avec les patients ou les familles:

☐ Oui
☐ Non

* 16. Dans mon cadre professionnel, je participe à l'évaluation ou à la provision de l'aide médicale à mourir (AMM):

○ Oui
○ Non

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Croyances associées aux attitudes

Croyances associées aux attitudes

17. Le don d'organe et de tissus est une option de fin de vie importante pour tous les patients éligibles.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

18. Le don de tissus est une option de fin de vie importante pour les patients ayant recours à l'aide médicale à mourir (AMM).

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

19. L'option du don d'organe est une option de fin de vie importante pour les patients ayant recours à l'aide médicale à mourir (AMM).

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

20. Le don d'organe ou de tissus aide le deuil des familles.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

21. Le don d'organe améliore la durée et la qualité de vie des greffés.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

22. Le don d'organe est un traitement rentable pour les patients avec défaillance d'organes sévères.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Croyances associées aux attitudes affectives

Croyances associées aux attitudes affectives

23. Je pense au don de mes propres organes.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

24. Je trouve les discussions à propos du don exigeantes au niveau émotionnel.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

25. Je crois que les conversations à propos du don sont néfastes pour mes patients.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

26. Je me sens confortable de discuter du don de tissus auprès des patients et des familles.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

27. Je me sens confortable de discuter du don d'organe dans le contexte de l'aide médicale à mourir.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

28. Je crois que les conversations à propos du don sont néfastes pour les patients ayant recours à l'aide médicale à mourir.

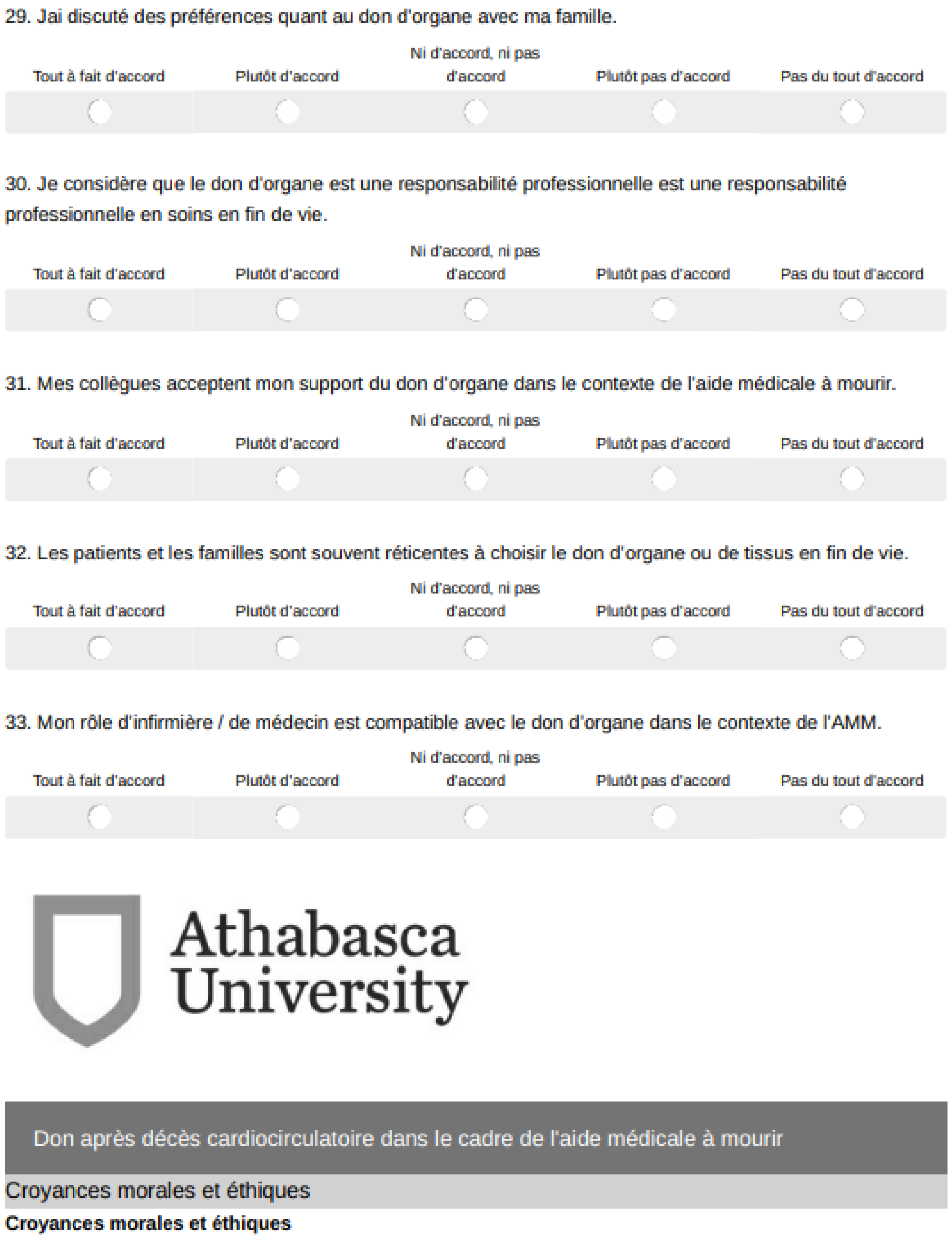
Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Normes et croyances subjectives

Normes et croyances professionnelles



29. Jai discuté des préférences quant au don d'organe avec ma famille.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

30. Je considère que le don d'organe est une responsabilité professionnelle est une responsabilité professionnelle en soins en fin de vie.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

31. Mes collègues acceptent mon support du don d'organe dans le contexte de l'aide médicale à mourir.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

32. Les patients et les familles sont souvent réticentes à choisir le don d'organe ou de tissus en fin de vie.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

33. Mon rôle d'infirmière / de médecin est compatible avec le don d'organe dans le contexte de l'AMM.

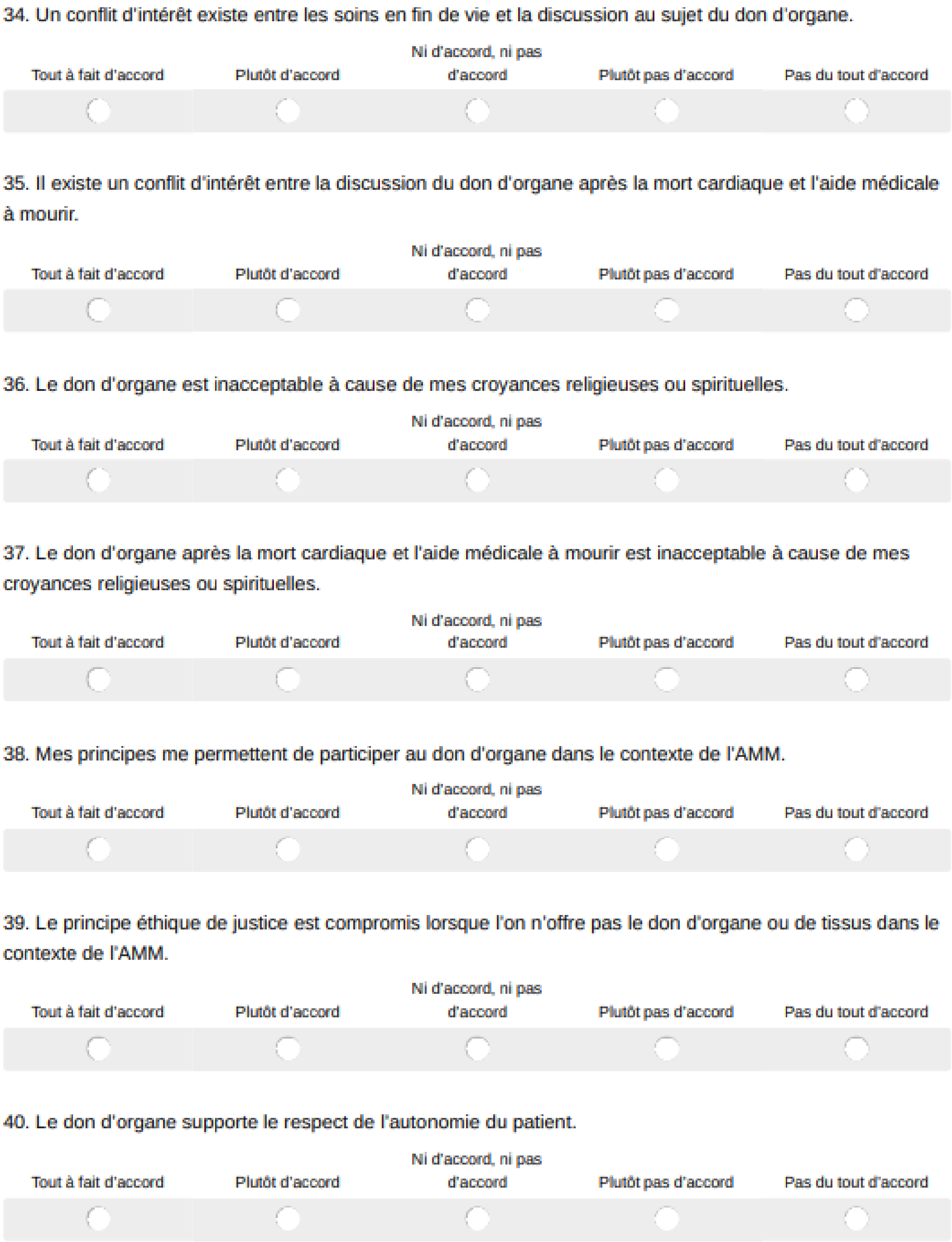
Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Croyances morales et éthiques

Croyances morales et éthiques



34. Un conflit d'intérêt existe entre les soins en fin de vie et la discussion au sujet du don d'organe.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

35. Il existe un conflit d'intérêt entre la discussion du don d'organe après la mort cardiaque et l'aide médicale à mourir.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

36. Le don d'organe est inacceptable à cause de mes croyances religieuses ou spirituelles.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

37. Le don d'organe après la mort cardiaque et l'aide médicale à mourir est inacceptable à cause de mes croyances religieuses ou spirituelles.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

38. Mes principes me permettent de participer au don d'organe dans le contexte de l'AMM.

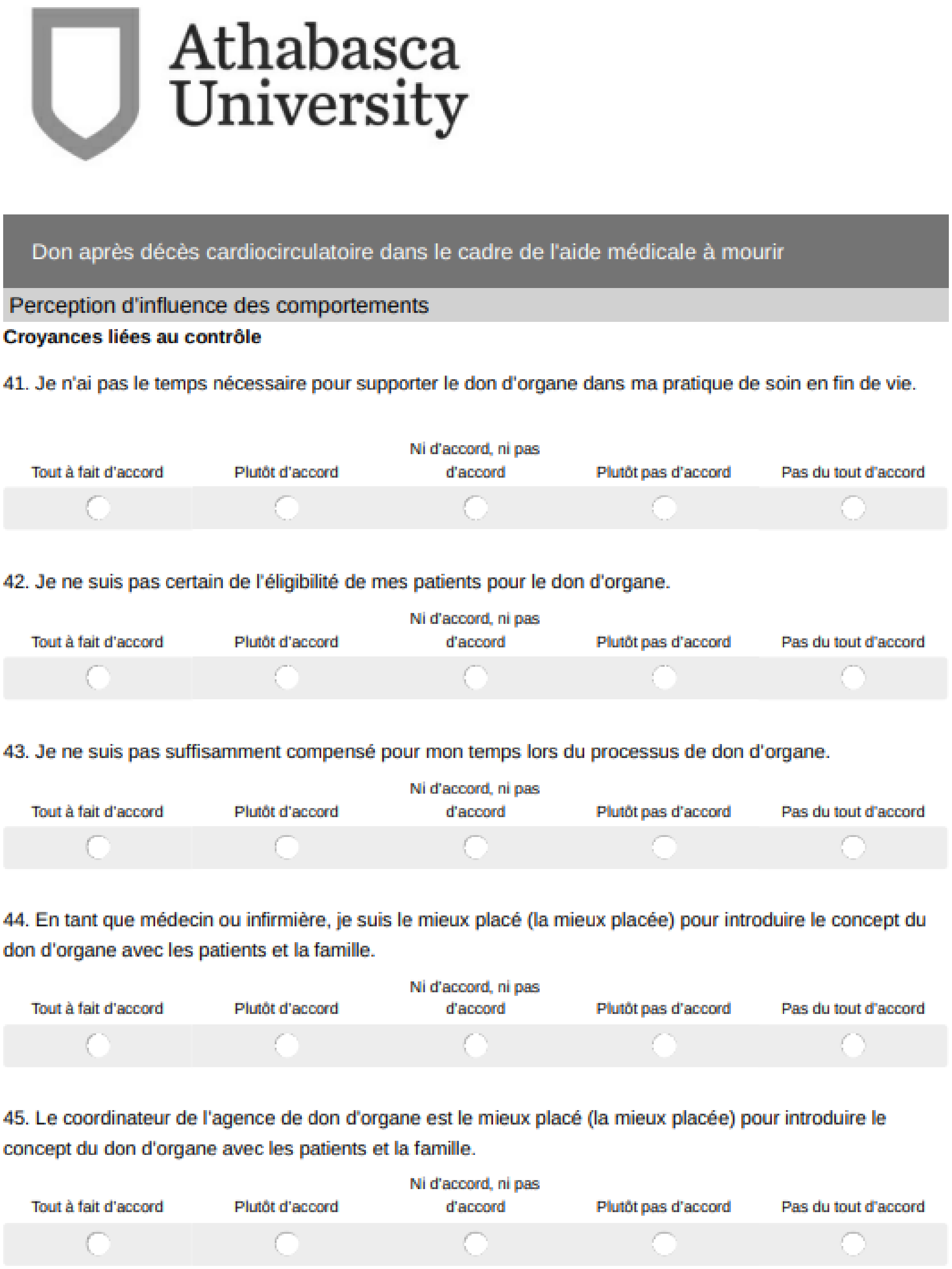
Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

39. Le principe éthique de justice est compromis lorsque l'on n'offre pas le don d'organe ou de tissus dans le contexte de l'AMM.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

40. Le don d'organe supporte le respect de l'autonomie du patient.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○



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Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Perception d'influence des comportements

Croyances liées au contrôle

41. Je n'ai pas le temps nécessaire pour supporter le don d'organe dans ma pratique de soin en fin de vie.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

42. Je ne suis pas certain de l'éligibilité de mes patients pour le don d'organe.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

43. Je ne suis pas suffisamment compensé pour mon temps lors du processus de don d'organe.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

44. En tant que médecin ou infirmière, je suis le mieux placé (la mieux placée) pour introduire le concept du don d'organe avec les patients et la famille.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

45. Le coordinateur de l'agence de don d'organe est le mieux placé (la mieux placée) pour introduire le concept du don d'organe avec les patients et la famille.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

46. Les ressources humaines sont suffisantes pour faciliter le don dans le contexte de l'AMM.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accor	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

47. Je crois être à risque de poursuite pour les dons d'organes dans le contexte de l'AMM.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

Athabasca University

Don après décès cardiocirculatoire dans le cadre de l'aide médicale à mourir

Déterminants des intentions

Déterminants des intentions

48. Je compte discuter du don d'organe après décès cardiocirculatoire (DDC) pour les patients ayant recours à l'AMM s'ils démontrent de l'intérêt pour le don d'organe.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

49. Je compte discuter du don d'organe et de tissus avec tous les patients éligibles ayant recours à l'aide médicale à mourir (AMM).

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

50. Je compte discuter du don d'organe et de tissus pour tous mes patients éligibles en fin de vie.

Tout à fait d'accord	Plutôt d'accord	Ni d'accord, ni pas d'accord	Plutôt pas d'accord	Pas du tout d'accord
○	○	○	○	○

Athabasca University
RESEARCH CENTRE

Appendix G

CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **24245**

Principal Investigator:
Ms. Tina Shaver, Graduate Student
Faculty of Health Disciplines\Centre for Nursing & Health Studies

Project Team:
Dr. Terra Murray (Supervisor),
General Program Director/Assistant Professor, Faculty of Health Disciplines, Athabasca University
Dr. Philippe Couillard (Co-Investigator),
Intensive Care, Medical Director General System ICU, Foothills Medical Centre

Project Title:
Controlled Donation After Cardiocirculatory Death in the Context of Medical Assistance in Dying: The Link

Effective Date: June 10, 2021 **Expiry Date**: June 09, 2022

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: June 15, 2021**

Carolyn Greene, Chair
Athabasca University Research Ethics Board

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