# Decisional Needs of African, Caribbean, and Black Patients Diagnosed with Brain-Heart Conditions

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## Thesis Abstract

Equity-deserving groups, including African, Caribbean, and Black (ACB) populations, face barriers to equitable brain-heart healthcare. These barriers contribute to unmet decisional needs and challenges in making informed health decisions. For my master's thesis, I aimed to investigate the decisional needs of ACB patients with brain-heart conditions and the unique challenges they encounter during decision-making using an explanatory sequential mixed-methods design. We included participants from equity-deserving groups who participated in an ongoing parent study. We administered surveys and conducted semi-structured interviews with adult patients from the Ottawa Hospital, the University of Ottawa Heart Institute, and community organizations. Our work was guided by the Ottawa Decision Support Framework, PROGRESS-Plus framework, and intersectionality theory. Survey results from 23 participants facing a variety of brain-heart health decisions in the past 12 months revealed that seven (30.4%) participants experienced clinically significant decisional conflict and six (30.0%) experienced clinically significant decision regret. The common challenges that participants experienced during decision-making included worrying about choosing the wrong option (n=10, 50%) and feeling that brain implications were never part of the conversation for their heart condition (n=9, 45%). The interviews further demonstrated complex barriers contributing to their unmet decisional needs, such as difficulties in accessing health information, strong emotions, challenges with patient-clinician communication, mistrust, and barriers to healthcare access. We integrated these findings using joint displays. The insights gained from this study can inform the development of equitable decision-support interventions to effectively address the decisional needs of ACB patients with brain-heart conditions.

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To Dawn, I sincerely thank you for sharing your expertise and providing excellent feedback throughout my thesis. Your thoughtful insights and constructive suggestions have significantly strengthened my work, pushing me to think more critically and deepen my understanding of decisional needs and the Ottawa Decision Support Framework. I truly appreciate the time and effort that both you and Krystina have dedicated to supporting my growth throughout my master's education, always being available to answer my many questions. I am deeply grateful for all of your guidance and support.

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A heartfelt thank you to the University of Ottawa Heart Institute and the University of Ottawa for providing me with an environment to grow and learn as a Registered Nurse and graduate student trainee.

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## Contribution of Collaborators

The research team supporting this master's thesis brings together individuals with diverse backgrounds and expertise, all united by a shared commitment to advancing health equity in health decision-making. Collectively, we aim to address systemic barriers to brain-heart health decision-making while amplifying the voices of the ACB community throughout this work.

Rosalyn Blackett served as patient partner in the study, bringing a valuable perspective from her personal experiences as a member of the ACB community seeking healthcare services. Her intersecting identities as a Black woman, patient, and advocate for equitable healthcare offer insights to the systemic barriers that shape health outcomes for ACB people. Rosalyn has been instrumental in ensuring the study remained patient-centered and culturally relevant by advising on inclusive language, contributing to the development of a culturally appropriate recruitment poster, and guiding the interpretation of the study findings. Her involvement has amplified the voices of ACB individuals often overlooked in health research, while highlighting the challenges they face in accessing and navigating healthcare systems. Rosalyn enhanced this study's cultural responsiveness and its potential to inform equitable healthcare practices for the ACB community.

Dr. Dawn Stacey is a Distinguished Professor at the School of Nursing within the Faculty of Health Sciences at the University of Ottawa. Dr. Stacey is the Vice-Dean of Research at the Faculty of Health Sciences, a Senior Scientist at the Ottawa Hospital Research Institute, held a Research Chair in Knowledge Translation to Patients (2012-2024), a member of the Centre for Implementation Research, and co-leads the Patient Decision Aids Research Group. Her research focuses on decision support, decision coaching, shared decision-making, oncology nursing, and implementation science. Dr. Stacey's positionality as a Registered Nurse, researcher, and educator shaped this study. Dr. Dawn Stacey has been actively involved throughout the development of this thesis, providing valuable guidance and expertise. She was actively involved and provided detailed feedback on every component of this work, ensuring that the decisional needs of ACB patients were accurately captured and represented. With her expertise in the Ottawa Decision Support Framework, decision support, and knowledge translation, Dr. Stacey had an essential role in ensuring the use of rigorous research methodologies and evidence-based approaches to identifying and exploring the decisional needs of ACB patients making decisions regarding their brain-heart health.

Dr. Josephine Etowa is a Full Professor at the School of Nursing within the University of Ottawa and holds the Canada Research Chair Tier 1 in Advancing Black Women's Health. Dr. Etowa is the Senior Investigator at the Centre for Research on Health and Nursing and founder of the Collaborative Critical Research for Equity and Transformation in Heath (CO-CREATH) Lab. Her research focuses on health inequities and includes studies on ACB health, health equity, HIV and AIDS, and perinatal health. Dr. Etowa's expertise brought a thorough understanding of the systemic barriers that marginalized groups face in accessing equitable healthcare. Dr. Etowa's contributions ensured that the study accurately addressed the social determinants of health that disproportionately impact ACB populations with brain-heart conditions and the role of intersectionality. As a member of the ACB community, researcher, educator, and advocate for racialized communities, her positionality supported this study's efforts to promote inclusive and culturally competent brain-heart healthcare among ACB populations.

Dr. Krystina B. Lewis (KBL) is an Associate Professor at the School of Nursing within the Faculty of Health Sciences at the University of Ottawa and was the supervisor for this thesis. Dr. Lewis is an Affiliate Researcher at the University of Ottawa Heart Institute (UOHI), leads the Knowledge Mobilization stream of the Brain-Heart Interconnectome (BHI), co-leads the

Patient Decision Aids Research Group, is a New Investigator Award recipient of the Heart and Stroke Foundation (2024-2027), and holds a Canadian Nurses' Association certification in cardiovascular nursing. Dr. Lewis' positionality as a Registered Nurse, researcher, and educator with expertise in shared decision-making and the Ottawa Decision Support Framework guided this study's focus on identifying the decisional needs of ACB patients with brain-heart conditions. Her understanding of the brain-heart connection and the challenges patients face when managing complex health decisions provided critical insight throughout the research process. Dr. Lewis had a pivotal role from the study's inception, overseeing each step of the research process and development of this thesis. Her leadership in knowledge mobilization ensured the study findings translate into actionable strategies to support equitable healthcare.

In addition to my thesis committee members, several individuals have contributed to the success of this study. Victoria Cole, a librarian at the University of Ottawa, provided valuable support in developing the search strategy for the literature review in Chapter Two of this thesis. Meg E. Carley (MC), a research coordinator at the Ottawa Hospital Research Institute and primary research coordinator for the parent study, had an important role in the study management, ethics submission, and data collection. She graciously shared her expertise in quantitative data analysis using SPSS and helped verify data. Meghan Masztalar (MM), a master's student in the School of Nursing at the University of Ottawa, was responsible for transcribing the interviews from the parent study. Together, we collaborated on the qualitative data analysis.

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# Chapter One

## Introduction

# Introduction

The brain and heart are two organs in the body that have important roles in maintaining overall health. Conditions affecting these organs include mental illnesses and neurological disorders for the brain, and cardiovascular diseases (CVDs) for the heart. Mental illnesses are the leading cause of disability worldwide and are defined as conditions that impair one's thought process, mood, and behaviour (Lang et al., 2018; World Health Organization [WHO], 2022). In Canada, mental illnesses affect approximately 1 in 5 people and include conditions such as schizophrenia, mood and anxiety disorders, and substance use disorders (Canadian Institute for Health Information [CIHI], 2024; Smetanin et al., 2011). Neurological conditions affect approximately 3.6 million Canadians and encompass conditions affecting the brain or spinal cord, such as dementia, stroke, and multiple sclerosis (Public Health Agency of Canada [PHAC], 2014). CVDs remain the leading cause of death globally, including conditions such as arrhythmias, heart failure, congenital heart diseases, and valve diseases, impacting 2.6 million Canadians (Lindstrom et al., 2022; WHO, 2024; PHAC, 2018).

Although traditionally viewed as separate organs, the brain and heart are closely connected, with dysfunction in one leading to changes in the other (Heart and Stroke Foundation of Canada [HSFC], 2019). Mental illnesses and neurological conditions increase the likelihood of developing CVDs (Zhao et al., 2023). For example, individuals diagnosed with depression are at an increased risk of developing CVDs compared to those without depression (Goldstein et al., 2015; Lichtman et al., 2014; Liu et al., 2022). Similarly, CVDs are linked to conditions impacting the brain (Zhao et al., 2023). For instance, heart failure is associated with twice the risk for ischemic stroke (Haeusler et al., 2011). In Canada, nearly 90% of the population have one or more risk factors for conditions affecting both the brain and heart, including diabetes, coronary artery disease, atrial fibrillation, and hypertension

(HSFC, 2019; Rossi et al., 2021). These conditions lead to higher morbidity and mortality rates and reduced quality of life (Fan et al., 2023; Leto & Feola, 2014).

Despite the interconnectedness of brain-heart health, the current Canadian healthcare system is structured to manage brain and heart conditions separately (Doessing & Bureau, 2015; Lau et al., 2024). This fragmented approach leads to poor interdisciplinary communication, as clinicians with expertise in one organ work independently and focus solely on their respective specialty, while overlooking the holistic impact of the brain-heart connection on the patient's health and wellbeing (Doessing & Bureau, 2015; HSFC, 2019; Lau et al., 2024). Consequently, patients and their families may not fully understand the interplay between brain and heart health, requiring consultations with multiple clinicians who are not collaborating with one another (Bell et al., 2022; HSFC, 2019). This results in difficulties navigating the healthcare system and patients experiencing increased stress, delays in treatment, and confusing treatment plans which further contribute to negative health outcomes and poor quality of care (Bell et al., 2022; HSFC, 2019; Nissen et al., 2022).

Equity-deserving groups experience disparities in brain-heart healthcare (HSFC, 2019). Equity-deserving groups are populations that face greater challenges in accessing equitable healthcare due to systemic barriers, discrimination, and prejudice, which limit their access to the resources, opportunities, and services needed to achieve optimal health outcomes (CIHR, 2024). Among these groups, African, Caribbean, and Black (ACB) populations face a disproportionate burden of brain-heart conditions and their associated risk factors compared to White patients (Morency et al., 2017). According to Statistics Canada (2024), there are over 1.5 million Canadians who self-identify as ACB, accounting for 4.3% of the population. ACB populations experience a higher prevalence and earlier onset of brain-heart risk factors, such as hypertension, chronic stress, diabetes, and obesity compared to their White counterparts (Carnethon et al., 2017; HSFC, 2019; Tjepkema et al., 2023). For example, hypertension is recognized as a notable risk factor that disproportionately impacts the ACB population and increases their risk for heart failure, stroke, and coronary artery disease (Carnethon et al., 2017). These disparities in brain-heart healthcare are intricately linked to the social determinants of health, encompassing the "social, economic, and political factors that shape the conditions in which individuals grow, live, work, and age" (PHAC, 2020, p.4). Anti-Black racism is a determinant of health that impacts ACB individuals, leading to inequitable healthcare and adverse health outcomes (Beagan et al., 2022; Paradies et al., 2015). Interpersonal, institutional, and structural forms of anti-Black racism are prevalent in healthcare. Clinicians' racial bias exacerbate health inequities, limit access to care, and compromise health outcomes (Beagan et al., 2022; Ray, 2022). Experiences of racism and discrimination are also influenced by intersecting social identities, such as disability, gender, language, age, and religion (Williams et al., 2024). In the context of brain-heart health, these disparities and the impact of the determinants of health on ACB populations contribute to declining mental health, increased risk for neurological conditions, and higher rates of CVDs (Morency et al., 2017; Paradies et al., 2015).

Health equity is essential for ensuring that ACB patients have access to quality healthcare (Beagan et al., 2022; Morency et al., 2017). Health equity refers to the principle that all individuals should have the opportunity and access to resources necessary to achieve optimal health outcomes (PHAC, 2024). Barriers that hinder access to healthcare services and resources create health inequities, which can lead to systematic disparities in health outcomes (PHAC, 2024). The Institute for Healthcare Improvement's (IHI) *Quintuple Aim* identifies health equity as a factor to achieving optimal health outcomes (Itchhaporia et al., 2021). The Quintuple Aim builds on the *Quadruple Aim* framework introduced in 2014, which focused on enhancing population health, improving patient experiences, reducing healthcare costs, and improving the work life and health of clinicians (Itchhaporia et al., 2021). The recent expansion now includes advancing health equity, acknowledging that systemic inequities rooted in the social determinants of health must be addressed to achieve optimal health outcomes (Itchhaporia et al., 2021). Similarly, the United Nation's *2030 Agenda for Sustainable Development* identifies 17 sustainable development goals that are "a universal call to action to end poverty, protect the planet, and ensure that by 2030 all people enjoy peace and prosperity" (United Nations, 2024, para. 1). Goal 10 specifically targets reducing inequalities, advocating for global efforts to address disparities driven by the social determinants of health (United Nations, 2024). Together, the Quintuple Aim and the tenth Sustainable Development Goal underscore the crucial role of health equity in improving outcomes for marginalized communities (Itchhaporia et al., 2021; United Nations, 2024).

Achieving health equity requires integrating cultural competency into clinical practice (Beattie et al., 2024). In the context of healthcare, cultural competency is defined as the knowledge and ability of clinicians to provide appropriate care that aligns with the cultural needs of patients from diverse backgrounds (Campinha-Bacote, 1999; Hooper et al., 2018). This process begins with engaging in meaningful conversations with patients by asking thoughtful questions and actively listening (Carnethon et al., 2017). This allows clinicians to understand the patient's cultural needs, perspectives, lived experiences, and values to be integrated into care delivery (Carnethon et al., 2017). Clinicians must also recognize the impact of how the social determinants of health impact individuals, families, and populations (Alden et al., 2014). Cultural competency fosters an environment that respects cultural differences while promoting an inclusive, patient-centered environment (Alden et al., 2014). Additionally, clinicians need to reflect on how their own biases and assumptions, such as stereotypes or preconceived notions, may influence their interactions with patients (Alden et al., 2014; Campinha-Bacote, 2024). The effective implementation of culturally competent healthcare is essential for improving access to healthcare services, fostering trust, enhancing patient-clinician communication, and promoting health equity (Campinha-Bacote, 2024; Cooper et al., 2013). By incorporating cultural competency into clinical practice, clinicians can better meet the needs of ACB patients, enhancing both the quality of care and patient engagement (Beattie et al., 2024; Cooper et al., 2013; Mhaimeed et al., 2023).

Failure to address barriers to equitable healthcare and lack of cultural competency presents significant challenges for ACB patients with brain-heart conditions, particularly when making decisions about their health (Carnethon et al., 2017; Doessing & Bureau, 2015; HSFC, 2019; Lau et al., 2024). Throughout the course of treatment, patients often face complex decisions regarding medications, procedures, lifestyle changes, diet, and finances, amongst others (Stacey et al., 2020). These challenges are compounded by decisional needs, defined as the factors that can negatively impact the quality of an individual's decision (Hoefel et al., 2020). The Ottawa Decision Support Framework (ODSF) outlines seven key decisional needs: Decisional conflict, inadequate knowledge, unrealistic expectations, unclear values, inadequate support and resources, complex decision characteristics, and personal or clinical needs (Stacey et al., 2020). Identifying an individual's decisional needs and offering tailored decision support can result in quality decisions that are defined as informed and aligned with the patient's values (Bujold et al., 2017; Hoefel et al., 2020; Stacey et al., 2020). This approach also enhances shared decision-making (SDM), a collaborative process where clinicians and patients work together to make informed, patient-centered, and values-based decisions (Hoefel et al., 2020; Stacey et al., 2020). A systematic review by Makoul and Clayman (2006) of 161 articles defining SDM identified its key components. The SDM process begins with the patient and clinician identifying the health issue to address, followed by exploring available options and discussing the advantages and disadvantages of each. During these discussions, the patient's concerns, preferences, and values are considered. Next, the clinician and patient explore the patient's *ability* to act on the decision, with the clinician providing relevant information and recommendations. Throughout this process, both the patient and clinician need to express mutual understanding of what is being discussed. The final step involves either making a decision or scheduling a follow-up discussion to finalize the choice.

Existing SDM practices often do not demonstrate cultural competency, failing to acknowledge and integrate the cultural values and preferences of the patient into the decision-making process (Mhaimeed et al., 2023). Anti-Black racism and the lack of culturally competent healthcare further impedes equitable SDM practices, leading to unmet decisional needs and preventing quality decision-making (Bujold et al., 2017; Mhaimeed et al., 2023). Unmet decisional needs can result in decision regret, decreased involvement in the decision-making process, and deter individuals from seeking necessary healthcare services (Bujold et al., 2017; Hoefel et al., 2020; Mhaimeed et al., 2023). A scoping review by Mhaimeed et al. (2023), which analyzed 30 studies on SDM practices among Black patients, identified ineffective communication between patients and clinicians as the most frequent barrier. This communication gap contributes to the suboptimal implementation of SDM for Black patients compared to non-Black patients. Despite these recognized challenges, research exploring the decisional needs and decision-making experiences of ACB individuals remains limited, and no studies in this scoping review explore the decisional needs and decision-making experiences of ACB patients with brain-heart conditions (Mhaimeed et al., 2023).

The overall purpose of this master's thesis is to investigate the decisional needs of ACB patients with brain-heart conditions and the challenges they encounter during the decision-making process. The study aims to address four key questions: (1) What are the decisional needs of ACB patients with brain-heart conditions? (2) How do ACB patients with brain-heart conditions experience and express their decisional needs? (3) What challenges do ACB patients face throughout the decision-making process? (4) How do the decisional needs identified among ACB patients align with the challenges they report during the decision-making process?

## Positionality Statement

Positionality involves researchers reflecting on their own perspective, assumptions, and beliefs in relation to their work (Holmes, 2020). This awareness influences all aspects of a study, from how the research is conducted to how the findings are interpreted and presented (Holmes, 2020). Positionality also signifies that a researcher's "social-historical-political location ... influences their orientations, i.e., that they are not separate from the social processes they study" (Holmes, 2020, p.3). This reflection enhances transparency, addresses potential biases, and promotes objectivity in research (Holmes, 2020).

I self-identify as a woman of African descent and a member of Ottawa's ACB community. As a master's student at the University of Ottawa and a cardiac surgery Registered Nurse, I bring professional experience in conducting research on this topic as I provide cardiovascular care to patients from diverse racial and ethnic backgrounds. Additionally, I have lived experience as a caregiver to a family member who is part of the ACB community and is currently receiving healthcare services. These intersecting identities as a Black woman, graduate student, clinician, and caregiver provide me with a multifaceted perspective on healthcare delivery and the challenges faced by ACB populations. Throughout my career, I have encountered and witnessed instances of implicit and explicit racism from both patients and fellow clinicians. These experiences have driven my commitment to researching healthcare inequities, particularly within the context of interpersonal exchanges and experiences such as SDM. My research aims to address barriers to equitable healthcare, promote cultural competency, and develop tailored SDM strategies for ACB communities. I recognize that my positionality influences how I conducted research and how I interpreted research findings. As such, I am committed to maintaining reflexivity and transparency throughout the research process. My thesis committee has been actively involved in supporting this commitment. The feedback from my thesis committee has been instrumental in minimizing personal biases, ensuring the study design aligns with its objectives, and maintaining rigor. Additionally, a patient partner contributed to the study through a co-production approach, offering valuable insights to ensure the research is culturally relevant and appropriate. Their guidance has helped uphold ethical considerations and ensure the principles of equity, diversity, and inclusion are integrated throughout this study.

## Thesis Outline

This master's thesis is organized into five chapters. Chapter One introduces the research problem, the rationale for the study, the purpose and objectives for this thesis, a positionality statement, and the thesis outline. Chapter Two presents a review of the literature to investigate what is known regarding the decisional needs of ACB patients with brain-heart conditions. Chapter Three outlines the three theoretical frameworks that guide this thesis: The Ottawa Decision Support Framework, the PROGRESS-Plus framework, and intersectionality theory, and explains their complementarity. It then details the research objectives and methodology, including the study design, setting, sample, participant recruitment procedures, methods for data collection, data analysis approach, data integration, measures to ensure confidentiality and privacy, and criteria for establishing research rigor. Chapter Four consists of a manuscript formatted for submission to the *Journal of Cardiovascular Nursing*, presenting the key features and findings of the study. As participant recruitment for ACB participants was slow, we expanded the study’s eligibility criteria to include participants from equity-deserving groups more broadly. Chapter Five provides an integrated discussion, which situates the study’s findings within the existing literature, the study’s theoretical underpinnings, and explores their implications for nursing clinical practice, education, policy, and research in brain-heart healthcare.

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# Chapter Two

## Literature Review

# Literature Review

The purpose of the literature review was to investigate what is known regarding the decisional needs and experiences of African, Caribbean, and Black (ACB) patients with brain-heart conditions, a brain condition with risk factors for heart conditions, or a heart condition with risk factors for brain conditions. The specific objectives of this literature review were to: (1) investigate the experiences of ACB patients with brain-heart conditions during shared decision-making (SDM), (2) examine the barriers to cultural competency, (3) identify challenges in patient-clinician communication, (4) investigate the impact of racial bias among clinicians, and (5) assess the factors contributing to healthcare mistrust.

## Search

I conducted a literature review search on July 2024 using the CINAHL, Medline (Ovid), PsycInfo, and Embase databases. The search strategy was carefully developed in collaboration with a University of Ottawa librarian (see Table 2.1). This literature search was conducted using two separate search strategies within each database. The first focused on the decision-making experiences and decisional needs of ACB patients with brain conditions, and the second centered on those with heart conditions.

**Table 2.1.** Database search terms for literature review

| **Search** | **Title and Abstract Search Terms** | | |
|---|---|---|---|
| | **Concept 1:** Decisions | **Concept 2:** ACB Population | **Concept 3:** Condition |
| **Search 1:**<br>Decisional Needs of ACB Patients with *Brain* Conditions | “Decision making” OR “decisional needs” OR “making decisions” OR “decisional conflict” OR “decision support” OR | “african*” OR “caribbean*” OR “black*” OR “afro*” OR “racialized*” | “psychiatr*” OR “brain*” OR “mental*” OR “neuro*” OR “stroke” OR “dementia” OR “depression” OR |

| | | | |
|---|---|---|---|
| | "preferred decision" OR "information needs" OR "decisional regret" | | "anxiety" OR "psycholog*" |
| **Search 2:**<br>Decisional Needs of ACB Patients with *Heart* Conditions | "Decision making" OR "decisional needs" OR "making decisions" OR "decisional conflict" OR "decision support" OR "preferred decision" OR "information needs" OR "decisional regret" | "african*" OR "caribbean*" OR "black*" OR "afro*" OR "racialized*" | "cardio*" OR "cardiac" OR "heart*" OR "arrhythmia" OR "dysrhythmia" OR "atrial fibrillation" OR "coronary artery disease" OR "hypertension" |

## Eligibility Criteria

Eligible articles had to focus on adults 18 years and older who self-identify as ACB and are diagnosed with combined brain-heart conditions, a brain condition with risk factors for heart conditions, or a heart condition with risk factors for brain conditions (see Table 2.2). The inclusion of these conditions was informed by a comprehensive review of the literature and my clinical understanding of the interconnected risk factors between brain and heart conditions. The selected studies needed to address patient engagement in care decisions, decisional needs, or decision-making experiences specific to the ACB population. Studies using quantitative, qualitative, or mixed-methods designs that were published in the English language were included. To ensure the inclusion of the most current research, only studies published from 2010 onwards were considered, as this period marks a growing recognition of health disparities and the critical role of culturally competent care (Like, 2011). Exclusion criteria encompassed studies in pediatric populations, those lacking ACB participants, research focusing on conditions other than brain-heart conditions or associated risk factors, studies not available in English, studies published before 2010, and research that did not centre on decision-making. I also excluded knowledge syntheses, editorials, protocols, conference abstracts, dissertations, discussion papers, and commentaries (see Table 2.2).

**Table 2.2.** Inclusion and Exclusion Criteria for the Literature Review

| **Eligibility Criteria** | **Inclusion** | **Exclusion** |
|---|---|---|
| **S** (Sample) | • Adults aged 18 or older<br>• Self-identify as African, Caribbean, or Black<br>• Making decisions for themselves or for a cognitively impaired individual<br>• Making decisions related to a combined brain-heart condition, a brain condition with risk factors for heart conditions, or a heart condition with risk factors for brain conditions | • Pediatric participants<br>• People who self-identify within a racial/ethnic group other than African, Caribbean, or Black<br>• People with health conditions that do not involve the brain or the heart |
| **PI** (Phenomenon of Interest) | • Patient engagement in care decisions, decisional needs, or decision-making experiences from the perspectives of patients, family members, caregivers, or clinicians. | • Clinician-controlled decision-making<br>• Experiences of living with a health condition<br>• Patient engagement in care decisions, decisional needs, or decision-making experiences are not addressed. |
| **DE** (Design Evaluation) | • Quantitative, qualitative, or mixed-methods designs | • Knowledge syntheses |
| **R** (Research Type) | • Peer-reviewed articles | • Editorials, conference abstracts, protocols, discussion papers, commentaries, and dissertations |
| Year of Publication | • Published 2010 and onwards | • Published before 2010 |

### Screening and Extraction

I screened the articles identified through the literature search at two levels using the Covidence systematic review software (Covidence, 2024). The screening process began with a review of the titles and abstracts to identify potentially relevant studies. Following this, I examined full-text articles to confirm that they met the inclusion criteria. I performed data extraction using a Microsoft Word document to systematically collect pertinent information from the included studies. The extracted information included whether the study focused on brain conditions, heart conditions, or both, as well as the first author, year of publication, study setting, methodology, aim, number of participants, data collection methods, main findings, and limitations.

## Analysis and Synthesis

I conducted a directed content analysis to systematically examine the data extracted from the included studies (Hseih & Shannon, 2005). First, I reviewed each article to develop a thorough understanding of its content. I then categorized the studies based on key concepts aligned with the objectives of this literature review: SDM, cultural competency, patient-clinician communication, racial bias, and healthcare mistrust. I analyzed how the study findings aligned with these concepts, extracting descriptive characteristics and identifying patterns across studies that addressed similar themes. This process allowed for a comprehensive and systematic synthesis of the study findings to investigate key concepts regarding the decision-making experiences of ACB patients diagnosed with brain-heart conditions (Hseih & Shannon, 2005).

## Literature Review Results

The initial search across the selected databases produced 1,680 results (see Figure 1). After adding three sources found through a search done for a parent study exploring the decisional needs of patients with brain-heart conditions, removing 453 duplicates, and excluding 1,211 sources that did not meet the inclusion criteria, 19 studies remained. The characteristics of the included studies are summarized in Table 2.3, and a description of the findings and identified concepts for each study are presented in Appendix A. There are ten quantitative studies (Boursiquot et al., 2024; Chang et al., 2021; Chen et al., 2023; Cooper et al., 2013; Cuevas et al., 2019; Hines et al., 2018; Hooper et al., 2018; Jimenez et al., 2012;

Ratanawongsa et al., 2010; Saha & Beach, 2020), seven qualitative studies (Breathett et al., 2020; Hopp et al., 2014; Jackson et al., 2024; Mann et al., 2023; Marshall et al., 2021; Mayers & Gordon, 2024; Peek et al., 2010), and two mixed-methods studies (Breathett et al., 2019; Progovac et al., 2020). These include six sources focused on heart conditions, seven sources focusing on brain conditions, one source focusing on combined brain-heart conditions, and five sources focusing on risk factors impacting both the brain and the heart.

**Figure 1.** PRISMA diagram for the literature review via Covidence

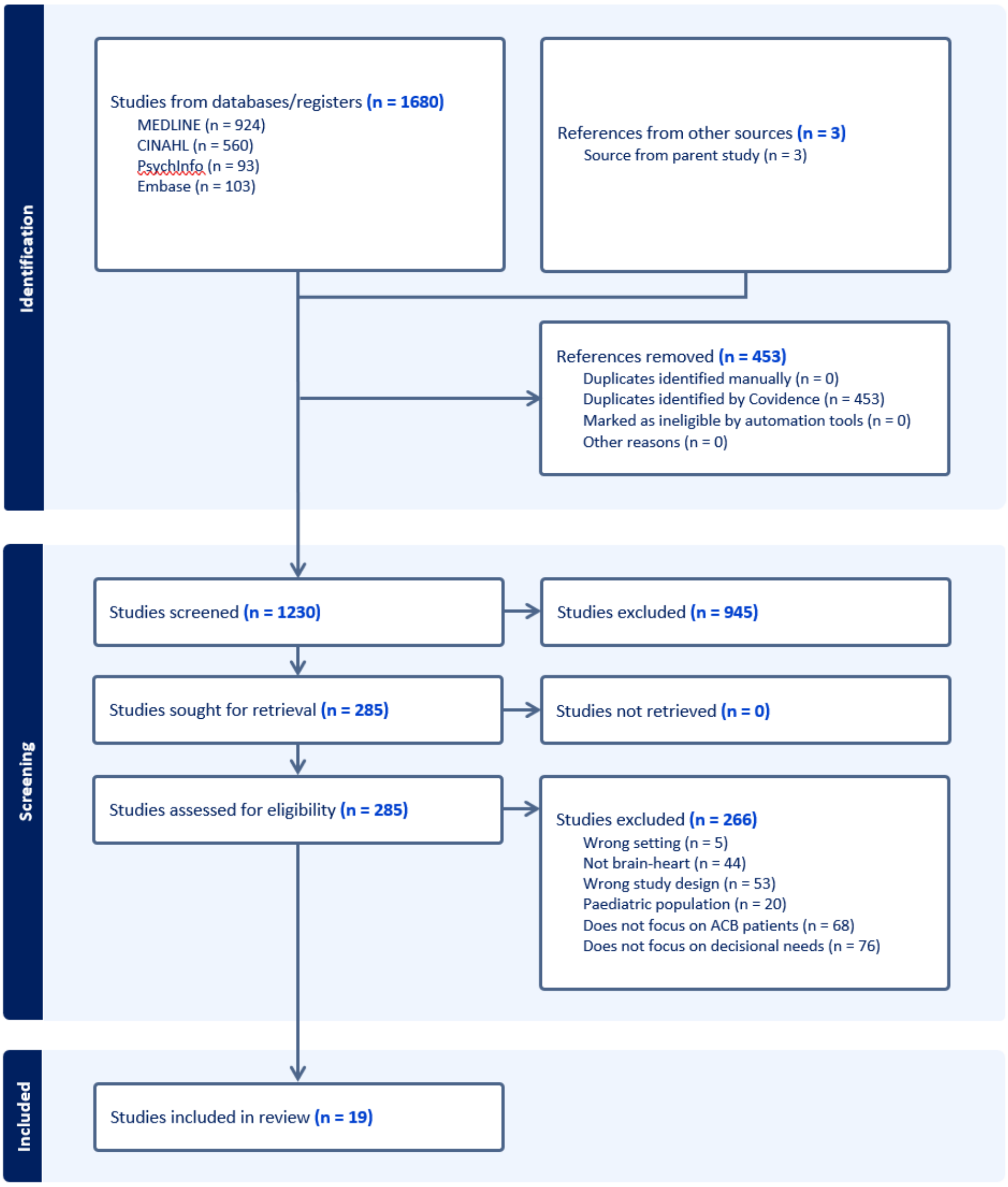

**Table 2.3.** Characteristics of included studies and their alignment with the study objectives

| First Author, Year, and Country | Study Design | Participants | Study Objectives |
|---|---|---|---|
| **Heart** | | | |
| **Breathett**, 2019, USA | Explanatory sequential mixed-methods | 1432 clinicians involved in decision making | • Racial bias |
| **Breathett**, 2020, USA | Qualitative - Phenomenology | 46 clinicians involved in decision making | • Racial bias |
| **Cuevas**, 2019, USA | Quantitative – Randomized Trial | 101 Black participants with a history of coronary artery disease or a coronary artery bypass graft. | • Shared decision-making<br>• Patient-clinician communication<br>• Healthcare mistrust |
| **Hopp**, 2014, USA | Qualitative - Phenomenology | 35 African American adults | • Shared decision-making<br>• Patient-clinician communication<br>• Healthcare mistrust |
| **Jackson,** 2024, USA | Qualitative description | 59 Black participants | • Shared decision-making |
| **Mann,** 2023, USA | Qualitative description | 15 Black participants | • Patient-clinician communication<br>• Healthcare mistrust |
| **Brain** | | | |
| **Chen**, 2023, USA | Quantitative - Cross-sectional | Data from the 2017 to 2020 Health Information National Trends Survey were used, with (N=4893) American adults with hypertension | • Shared decision-making<br>• Patient-clinician communication |
| **Cooper**, 2013, USA | Quantitative - Cluster randomized trial | 27 clinicians and 132 African American patients with depression | • Cultural competency<br>• Patient-clinician communication<br>• Healthcare mistrust |
| **Hines**, 2017, USA | Quantitative - Cross-sectional | 76 patients diagnosed with depression and 21 primary care clinicians. | • Patient-clinician communication<br>• Healthcare mistrust |
| **Hooper**, 2018, USA | Quantitative - Cross-sectional | 38 Black American participants, 38 White American participants, 4 biracial participants, and 7 Hispanic or Latino participants. | • Cultural competency |
| **Jimenez**, 2012, USA | Quantitative – cross-sectional | 1,257 White participants, 536 Black participants, 112 Asian Americans, and 303 Latino participants. | • Racial bias<br>• Healthcare mistrust |
| **Mayers**, 2024, United Kingdom | Qualitative idiographic | Five Black men who had been hospitalized for mental health issues. | • Shared decision-making<br>• Cultural competency |

| | | | |
|---|---|---|---|
| | | | • Patient-clinician communication<br>• Racial bias<br>• Healthcare mistrust |
| **Progovac,** 2020, USA | Explanatory sequential mixed-methods | 21 adults diagnosed with depression | • Shared decision-making<br>• Patient-clinician Communication<br>• Healthcare mistrust |
| **Combined Brain-Heart** | | | |
| **Boursiquot,** 2024, USA | Quantitative – Secondary analysis of a prospective randomized trial | 306 Black participants diagnosed with chronic systolic heart failure. | • Shared decision-making<br>• Patient-clinician communication<br>• Racial bias |
| **Brain-Heart Risk Factors** | | | |
| **Chang,** 2021, USA | Quantitative - Retrospective cohort study design | 2571 patients diagnosed with hypertension and self-identify as Black | • Shared decision-making<br>• Patient-clinician communication |
| **Marshall**, 2021, USA | Qualitative - Phenomenology | 318,720 patients | • Shared decision-making |
| **Peek**, 2010, USA | Qualitative - Phenomenology | 51 patients who self-identify as African American. | • Shared decision-making<br>• Patient-clinician communication<br>• Racial bias<br>• Healthcare mistrust |
| **Ratanawongsa,** 2010, USA | Quantitative – Cross-sectional | 3010 participants were recruited from the National Survey of Medical Decisions. | • Shared decision-making<br>• Patient-clinician communication |
| **Saha,** 2020, USA | Quantitative – Randomized experimental study | 238 participants (107 who identify as African American and 131 who identify as White) diagnosed with coronary artery disease or coronary risk factors seeking primary care services. | • Cultural competency<br>• Patient-clinician communication<br>• Healthcare mistrust |

### *Shared Decision-Making*

Of the 19 studies, 11 discussed SDM (Boursiquot et al., 2024; Chang et al., 2021; Chen et al., 2023; Cuevas et al., 2019; Hopp et al., 2014; Jackson et al., 2024; Marshall et al., 2021; Mayers & Gordon, 2024; Peek et al., 2010; Progovac et al., 2020; Ratanawongsa et al., 2010), with six clearly defining the process of SDM (Chen et al., 2023; Cuevas et al., 2019; Hopp et al., 2014; Mayers & Gordon, 2024; Peek et al., 2010; Ratanawongsa et al., 2010). The included studies described SDM as a collaborative approach where patients and clinicians jointly make healthcare decisions by integrating the best available evidence with the patient's preferences and needs (Cuevas et al., 2019; Marshall, 2021; Progovac et al., 2020). As a key component of patient-centered care, SDM emphasizes mutual respect and effective communication between patients and clinicians throughout the decision-making process (Cuevas et al., 2019; Mayers & Gordon, 2024; Peek et al., 2010). Effective communication between patients and clinicians enhances the patient's trust towards clinicians, understanding of available options, and overall satisfaction with care (Chang et al, 2021; Cuevas et al., 2019; Progovac et al., 2020). This contributes to quality healthcare decisions, adherence to treatment plans, and improved health outcomes (Cuevas et al., 2019; Hopp et al., 2014; Ratanawongsa et al., 2010).

A cross-sectional study by Chen et al. (2023) revealed that ACB patients living in the United States often face reduced participation in SDM compared to White patients. This disparity is exacerbated by factors such as systemic racism, discrimination, and medical mistrust, which create obstacles to fully engage in healthcare decisions (Chen et al., 2023; Progovac et al., 2020). Chen et al. (2023) discussed how the United States' national guidelines for managing chronic conditions, such as hypertension, highlight the importance of SDM for improving health outcomes and equitable healthcare delivery. Equitable SDM promotes an inclusive approach to decision-making, integrating evidence-based practice, patient preferences, and the impact of the social determinants of health. Collaboration and communication between patients and clinicians are vital for effective SDM as it leads to more personalized care and patient-centered decisions (Boursiquot et al., 2024; Jackson et al., 2024; Progovac et al., 2020).

### ***Cultural Competency***

Four studies describe cultural competency as an ability to acknowledge the diverse values, cultural backgrounds, and needs of patients (Cooper et al., 2013; Hooper et al., 2018;

Mayers & Gordon, 2024; Saha & Beach, 2020). This approach involves clinicians building strong relationships with patients to effectively understand their culture and tailor treatment that reflect their individual preferences (Cooper et al., 2013). Cultural competency, which equips clinicians to recognize and address the diverse cultural backgrounds of patients, is essential for delivering equitable care (Hooper et al., 2018). The included studies suggest that engaging in culturally tailored SDM can enhance the patient's satisfaction with their care, adherence to the treatment plan, and overall mental health (Cooper et al., 2013; Hooper et al., 2018). Additionally, cultural competency contributes to greater patient understanding and reduced barriers to care, resulting in higher quality of care (Cooper et al., 2013).

Despite these advantages, barriers to implementing cultural competency remain prevalent in brain-heart healthcare. Current approaches to care tend to prioritize clinical guidelines while overlooking the cultural needs and preferences of patients (Cooper et al., 2013). ACB patients have reported experiencing impersonal and non-holistic care during medical encounters (Cooper et al., 2013; Cuevas et al., 2019). For instance, a qualitative study by Mayers and Gordon (2024) found that ACB patients in mental health facilities in the United Kingdom often felt isolated and that their needs were unmet due to the absence of culturally diverse clinicians and a lack of culturally appropriate food options. This absence of considerations for the cultural needs of ACB patients and feeling excluded discourages them from seeking healthcare services (Hooper et al., 2018).

The consequences of inadequate cultural competency include treatment nonadherence and exacerbated health disparities (Cuevas et al., 2019; Hooper et al., 2018). Hooper et al.'s (2018) quantitative study found an inverse relationship ($r = -0.295$) between the patients' perceptions of their clinicians' cultural competence and treatment adherence. This finding suggests that patients who perceive their clinicians as culturally competent are more likely to follow their treatment plans. Conversely, patients who feel that their clinicians fail to respect or understand their cultural values are less likely to follow treatment plans or participate actively in decision-making (Hooper et al., 2018). Feelings of exclusion and doubt regarding their clinician's ability to address their holistic needs further reduce adherence (Hooper et al., 2018; Mayers and Gordon, 2024). However, enhancing cultural competency among clinicians correlates with increased trust in the healthcare system, greater patient involvement, improved adherence rates, and better health outcomes (Hooper et al., 2018). By promoting cultural competency and integrating SDM, clinicians can foster more equitable and higher-quality care for ACB patients (Hooper et al., 2018).

### ***Patient-Clinician Communication***

Effective communication between patients and clinicians is essential for fostering trust, increasing patient understanding, and improving healthcare outcomes among ACB populations (Cuevas, 2019; Hopp et al., 2014). However, ACB patients often face significant barriers in these interactions (Peek et al., 2010; Saha & Beach, 2020). For example, Peek et al.'s (2010) qualitative study found that ACB patients in the United States with diabetes frequently report limited clinician engagement, inadequate explanations of treatment options, and a lack of consideration from clinicians for the patient's values and preferences. This ineffective communication leaves patients feeling unheard and discouraged, hindering their ability to express needs and engage in SDM. Consequently, they struggle to manage their conditions effectively, which increases their risk for uncontrolled diabetes and associated complications, such as amputation and renal failure. ACB individuals are twice as likely to be diagnosed with diabetes compared to White individuals (Peek et al., 2010). Furthermore, ACB individuals also frequently experience co-existing conditions such as hypertension and hyperlipidemia, which further complicate the management of brain-heart conditions (Peek et al., 2010). Ultimately, effective diabetes management is linked to positive clinician-patient interactions and SDM, which can enhance self-efficacy, treatment adherence, and overall quality of life (Peek et al., 2010).

Patients reported that barriers to effective atrial fibrillation (AF) management include insufficient social support, the perception that managing AF is difficult, concerns about the effectiveness of prescribed medications, and high levels of stress (Mann et al., 2023). Poor patient-clinician communication exacerbates these challenges, leading to a lack of understanding of the condition and limited awareness of treatment options and resources for decision-making (Mann et al., 2023). Given that AF is a significant risk factor for both brain and heart conditions, these barriers are particularly alarming, especially considering the pronounced disparities in management and outcomes among ACB individuals (HSFC, 2019; Mann et al., 2023). ACB patients with AF are at an increased risk for developing heart failure and stroke compared to their White counterparts, and they also experience higher rates of hospital readmission, reduced quality of life, and significant mental health challenges related to their diagnosis (Mann et al., 2023). This underscores the urgent need for improved communication strategies to enhance patient engagement and care outcomes, noting that successful AF management relies on increased educational resources, strong social support, and effective communication with clinicians (Mann et al., 2023).

While effective communication and SDM are vital for successful hypertension management, ACB patients frequently encounter barriers that limit their involvement in treatment decisions (Chen et al., 2023). Studies show that ACB patients often receive less information and have less influence over their hypertension management compared to White patients (Chen et al., 2023; Ratanawongsa et al., 2010). Communication gaps between patients and clinicians contribute to reduced patient engagement in managing these conditions, ultimately leading to poorer health outcomes for ACB patients (Chen et al., 2023; Mann et al., 2023). For instance, Chang et al.'s (2021) quantitative study found that effective communication during health decision-making significantly improved adherence to antihypertensive medications among ACB patients in the United States. Their findings revealed that patients who reported that their clinicians consistently explained information clearly (OR 1.40; 95% CI, 1.15–1.72) and listened carefully to their concerns (OR 1.38; 95% CI, 1.13–1.69) were more likely to adhere to treatment. By actively listening and respecting the patient's cultural values and perspectives, clinicians can tailor their care to address specific concerns, such as medication preferences and side effects (Chang et al., 2023; Cooper et al., 2013). Patient-clinician communication during SDM facilitates mutual trust, an important predictor for treatment adherence in hypertension management. Increasing the involvement of ACB individuals in decision-making processes is crucial to ensuring that their needs are addressed and to reducing disparities impacting their care (Cooper et al., 2013)

Barriers to patient-clinician communication during SDM are also evident when caring for ACB patients with depression (Hines et al., 2018). Many ACB individuals in the United States and United Kingdom report feeling excluded from important decisions regarding their treatment (Cooper et al., 2013; Hines et al., 2018; Mayers & Gordon, 2024). This leads to a sense of powerlessness, challenges in participating in decision-making, and experiencing power imbalances with clinicians (Cooper et al., 2013; Hines et al., 2018; Mayers & Gordon, 2024). This dynamic often results in patients feeling pressured to accept clinician decisions, experiencing restrictive care practices, and facing the over-prescription of sedative medications (Hines et al., 2018; Mayers & Gordon, 2024). As a result, ACB patients are disproportionately affected by depression, facing an elevated risk for severe forms of the condition while being less likely to receive appropriate healthcare (Hines et al., 2018; Mayers & Gordon, 2024). This is particularly concerning in the context of brain-heart health, where depression is linked to an increased risk of heart disease (Dhar & Barton, 2016; Hines et al., 2018). For example, Boursiquot et al. (2024) explored the brain-heart connection in a study of 306 Black patients in the United States with chronic systolic heart failure who were considering implantable cardioverter-defibrillators. Among the participants, 66% reported experiencing both depressive symptoms and anhedonia. Additionally, a mixed-methods study by Progovac et al., (2020) discussed how only 25% of ACB patients in the United States are receiving mental healthcare services (Progovac et al., 2020). These barriers need to be addressed to promote mutual trust between patients and clinicians and enhance equitable SDM.

### ***Racial Bias***

Racial bias among clinicians poses a significant barrier to equitable healthcare for ACB patients, resulting in disparities in treatment quality and health outcomes (Breathett et al., 2019; Peek et al., 2010). While SDM aims to engage patients in care and informed and values-based choices, unconscious biases can negatively impact this process, leading to disparities in the quality of care (Breathett et al., 2019). For example, a mixed-methods study by Breathett et al. (2019) found that Black men in the United States are often perceived as less compliant with heart failure treatment compared to White men. Consequently, ACB patients with heart failure received fewer medications and advanced therapies, exacerbating disparities in treatment outcomes (Breathett et al., 2019). This population faces earlier onset, higher incidence rates, greater mortality, and longer hospital stays associated with heart failure compared to White patients (Breathett et al., 2019). Moreover, ACB individuals are at increased risk for ischemic stroke and other brain conditions due to shared risk factors such as hypertension, diabetes, and coronary artery disease (HSFC, 2019; Jimenez et al., 2012). Barriers to accessing effective heart failure care, including racial biases within the healthcare system, further hinder the equitable distribution of therapies like ventricular assist devices and heart transplants (Breathett et al., 2020). Similarly, implicit bias is also evident in mental healthcare, particularly in the treatment of depression (Mayers & Gordon, 2024). Many ACB patients in the United Kingdom report experiencing harmful stereotypes, such as the perception that Black men are inherently "dangerous," which further affects clinician-patient interactions (Mayers & Gordon, 2024). Additionally, racial bias contributes to disparities in recognizing and addressing depression among racialized groups, including ACB communities (Boursiquot et al., 2024). Ultimately, discriminatory practices further contribute to inadequate care and stigmas that adversely impact ACB patients (Jimenez et al., 2012; Mayers & Gordon, 2024). Addressing racial bias is essential to reducing these disparities and improving SDM for ACB patients.

### ***Healthcare Mistrust***

Mistrust in healthcare services is a significant issue for ACB patients seeking healthcare services (Peek et al., 2010). This mistrust is often driven by experiences of stereotyping, racism, discrimination, and mistreatment by clinicians, which can profoundly affect ACB patients' willingness to engage with the healthcare system (Progovac et al., 2020). Progovac et al. (2020) discussed in their paper how historical and ongoing negative interactions contribute to a pervasive sense of exclusion and marginalization among ACB individuals in the United States, leading to delays in seeking care and a reluctance to pursue further treatment (Progovac et al., 2020; Jimenez et al., 2012; Mayers & Gordon, 2024). For example, in mental health care, ACB patients frequently report being misdiagnosed or subjected to inadequate treatment plans, which exacerbate their feelings of powerlessness and distrust (Hines et al., 2018; Mayers & Gordon, 2024). In the context of heart failure care, research has identified racial bias as a critical factor that further undermines trust and significantly impacts ACB patients’ engagement in SDM (Cuevas et al., 2019; Hopp et al., 2014). Cuevas et al.’s (2019) quantitative study with 101 African American participants in the United States found that participants had statistically significant levels of medical mistrust towards their clinicians compared to their White counterparts ($B = 0.26$, $SE = 0.08$, $p < 0.01$, 95% CI [0.10, 0.42]). This lack of trust not only affects their participation in SDM but also influences overall treatment outcomes, as patients may avoid necessary healthcare interventions out of fear of discriminatory practices (Hopp et al., 2014). As a result, these disparities influence ACB patients' healthcare decisions and often cause hesitation in seeking care due to fears of mistreatment or having their concerns dismissed (Hopp et al., 2014; Mann et al., 2023). Addressing these issues are crucial for building trust, enhancing health outcomes, and ensuring equitable access to care for ACB patients (Mann et al., 2023).

Mistrust in healthcare is often exacerbated by cultural and racial discordance between patients and clinicians (Cooper et al., 2013). ACB patients often perceive that clinicians from different racial or cultural backgrounds do not fully understand their lived experience, leading to a disconnect (Cooper et al., 2013). Research shows that race concordance between patients and clinicians is a key facilitator to fostering trust and strengthening patient-clinician communication (Cooper et al., 2013). Saha and Beach’s (2020) quantitative study discussed how race and cultural concordance between primary care patients and their clinicians in the United States lead to enhanced patient-clinician communication, mutual understanding, reduced implicit bias, and increased trust. In their study with 107 African American participants, the participants who had experienced racial bias from clinicians were more likely to have favorable perceptions of race concordance (2.61 vs. 2.10, $p = 0.003$). Peek et al. (2010) found that White physicians in the United States may dismiss cultural factors, such as dietary practices common in the ACB community, which can result in ACB patients feeling judged or misunderstood. This disconnect often leads ACB patients to feel that physicians are not truly listening to them, leaving their needs unmet and concerns dismissed. These communication challenges further erode trust and hinder effective SDM. Addressing these barriers is essential for building trust, enhancing SDM, and ensuring equitable care for

ACB patients, as patients often place greater trust in clinicians who share their racial or cultural background.

## Strengths and Limitations

This literature review regarding the decisional needs and experiences of ACB patients with brain-heart conditions has several strengths. The included studies employed a range of methodologies, including quantitative, qualitative, and mixed-methods, providing a comprehensive view of the issues at hand. They explored various barriers and the unique challenges faced by ACB patients in the decision-making process. These identified challenges in the literature can be viewed as factors that influence the decisional needs of the study participants. Furthermore, the identification of decisional needs and the barriers to health decision-making offers valuable insights that can inform future interventions. Importantly, the literature includes patients who self-identify as ACB, ensuring that the findings are relevant and reflective of their specific identities and experiences.

An important limitation among the articles in this literature review involves the limited number of identified articles on combined brain-heart health conditions. The studies focused on either brain conditions with potential risks for the heart, heart conditions with risks for the brain, or simply on shared risk factors for both. Only one of the included studies specifically address the decision-making experiences of ACB patients who have both brain and heart conditions, highlighting a significant gap. While key variables such as racial concordance between patients and clinicians and cultural competency are discussed in some studies, they are not consistently examined, thereby missing opportunities to enhance understanding of how these factors influence decision-making. Additionally, while SDM is frequently discussed, there is a lack of research exploring SDM from the perspective of ACB patients. Most studies focused on barriers to SDM, rather than providing a comprehensive view of how ACB patients engage in and perceive the decision-making process. There is an absence of discussion on how intersecting social identities, such as gender and age, alongside the self-identification of race such as ACB, can shape and contextualize patients' healthcare experiences. Another limitation is that the majority of the studies were conducted in the United States, with only Mayers and Gordon's (2024) study originating from the United Kingdom. This highlights a notable gap in research exploring this topic within the Canadian context. Lastly, among the included qualitative and mixed-methods studies, only Mayers and Gordon (2024) disclosed a researcher positionality statement. The absence of a positionality statement limits understanding of the researchers' assumptions and beliefs, which may influence the interpretation of the findings.

## Conclusion

In this literature review, I identified what has been addressed in the existing literature regarding the decisional needs and experiences of ACB patients with brain-heart conditions, a brain condition with risk factors for heart conditions, or a heart condition with risk factors for brain conditions. Overall, studies revealed that racism and discrimination reduce ACB patients' participation in SDM, leading to communication breakdowns and gaps in care (Chen et al., 2023; Progovac et al., 2020). Without extending an invitation to participate or establishing a bidirectional exchange of information, clinicians are challenged to learn about their patients' values and preferences for the options they face. Although cultural competency is acknowledged as vital for facilitating SDM and delivering equitable healthcare to diverse populations, current practices often prioritize clinical guidelines over culturally tailored approaches, thereby compromising patient-centered care (Cooper et al., 2013; Cuevas et al., 2019). Additionally, barriers to effective patient-clinician communication exacerbate health disparities, limiting ACB patients' ability to express their cultural values, needs, and preferences, and contributing to their sense of exclusion from important healthcare decisions (Breathett et al., 2019; Hines et al., 2018). Racial bias is identified as a significant barrier that limits SDM and patient-clinician communication (Hopp et al., 2014). This bias also contributes to healthcare mistrust, deterring ACB patients from seeking medical services and further straining SDM (Progovac et al., 2020). Overall, this literature review provides insights into the barriers and facilitators to decision-making for ACB patients with brain or heart conditions, a brain condition with risk factors for heart conditions, or a heart condition with risk factors for brain conditions. More research is needed, particularly within the Canadian context, to understand the decisional needs and experiences of ACB patients with both brain and heart conditions, explore their self-reported experiences and perspectives, and understand how intersecting social identities contribute to these experiences. I aim to address this research gap through my master’s thesis.

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# Chapter Three

## Theoretical Frameworks and Methodology

This chapter outlines the theoretical frameworks and methodology used in this master’s thesis. It provides a detailed description of the three guiding theoretical frameworks, research objectives, study design, positionality of the research team, setting, sample, data collection, recruitment procedures, data analysis, confidentiality and privacy, and criteria for establishing research rigor. Due to challenges in recruitment of African, Caribbean, and Black participants, the eligibility criteria for this study broadened to include all participants who self-identified as a member of an equity-deserving group.

## Theoretical Frameworks

This thesis is guided by three complementary theoretical underpinnings: The Ottawa Decision Support Framework (ODSF), the PROGRESS-Plus Framework, and intersectionality theory (Crenshaw, 1991; O’Neill et al., 2014; Stacey et al., 2020). Together, these frameworks provide a comprehensive understanding of both individual decisional needs and the broader social context, which is essential for addressing the unique challenges faced by equity-deserving groups (O’Neill et al., 2014; Stacey et al., 2020).

### The Ottawa Decision Support Framework

Introduced by O’Connor et al. in 1998 and updated by Stacey et al. (2020), the ODSF is an empirically validated framework widely cited in academic literature, designed to assist clinicians and researchers in supporting individuals and their families during the decision-making process (see Appendix B). The ODSF is based on three core components: (1) decisional needs, (2) decision support, and (3) decisional outcomes. When decisional needs, such as unclear values or inadequate knowledge, exist, they can lead to decisional conflict, decision regret, delays in seeking treatment, or poor-quality decisions. The ODSF emphasizes identifying and addressing patients' specific decisional needs through tailored decision support interventions such as decision coaching, clinical counseling, and decision aids. These interventions aim to help patients make high-quality decisions that are informed and aligned with their values and preferences. The limitations of the ODSF include the absence of consideration of contextual and systemic factors, focusing primarily on individual factors. Despite these limitations, the ODSF remains an evidence-based resource for addressing the decisional needs of patients making health decisions with their clinicians. The ODSF was selected for this study because in reviews of shared decision-making (SDM) theories, the ODSF was the only decision-making framework that specifically conceptualizes decisional needs (Stacey et al., 2020, Lewis et al., 2016).

The ODSF was used in this thesis to guide quantitative and qualitative data collection and analysis that focused on the decisional needs of equity-deserving patients with brain-heart conditions. The ODSF informed the development of the quantitative survey questions aimed at identifying the specific decisional needs participants encounter when making brain-heart health decisions. For example, questions elicited participants' knowledge about their brain-heart diagnosis, their understanding of the available treatment options, their level of involvement in decision making, and satisfaction with the decision-making process. In the qualitative interview, the interview guide consists of questions and prompts informed by the ODSF to further examine the decisional needs identified in the surveys. During the data analysis phase, a coding manual was utilized to systematically map the findings onto the decisional needs categories outlined in the ODSF, ensuring a structured and comprehensive analysis (Hoefel et al., 2020). By integrating the ODSF into these phases of the study, the decisional needs of equity-deserving patients with brain-heart conditions were identified and thoroughly examined

## PROGRESS-Plus Framework

The PROGRESS-Plus Framework is another theoretical framework guiding this thesis. O’Neill et al. (2014) describe this equity-focused framework as a tool used to address the social determinants of health that contribute to inequities in health. The acronym

*PROGRESS* encompasses: (1) Place of residence, (2) Race, ethnicity, culture, and language, (3) Occupation, (4) Gender or sex, (5) Religion, (6) Education, (7) Socioeconomic status, and (8) Social capital. The *Plus* component broadens the framework to include: (1) Characteristics associated with discrimination (e.g. age, disability), (2) Relationship dynamics, and (3) Time-dependent relationships. The PROGRESS-Plus Framework serves as a valuable tool for researchers, guiding them to account for health determinants throughout the study, as these factors can lead to inequities in health outcomes (O'Neill et al., 2014). It is a well-established, equity-focused framework widely recognized in the literature, including by the Campbell and Cochrane Equity Methods Group (O'Neill et al., 2024). It has been validated and widely applied in systematic reviews and methodological studies, making it a robust resource for analyzing health inequities (O'Neill et al., 2014). This framework was chosen for its comprehensive, evidence-based approach to allow the identification of which social determinants of health influence the decisional needs of equity-deserving brain-heart patients, making it suitable for integration into survey questions (O'Neill et al., 2014). A limitation of the PROGRESS-Plus Framework is the lack of recognition of contextual factors that contribute to health inequities (Hollands et al., 2024). Additionally, while the framework accounts for multiple determinants, it does not examine how these factors interact and shape an individual's experiences, overlooking the complexity of intersecting inequities (Hollands et al., 2024). Despite these limitations, the framework remains a valuable tool for researchers, offering a measurable approach to explicitly addressing the determinants of health (O'Neill et al., 2014).

The PROGRESS-Plus Framework informed the participant recruitment process to ensure diversity among study participants. This framework was also used in the survey to collect participants' demographic information, such as ethnicity, age, relationship dynamics, religion, income, and education. This framework guided data analysis by providing a lens to examine which social determinants of health impact the decisional needs of the study participants, as identified through ODSF-informed surveys and interviews. This consideration of the PROGRESS-Plus framework ensures that the research captured the full spectrum of factors affecting equity-deserving patients, providing a more nuanced and equity-centered analysis of their health experiences (O'Neill et al., 2014).

## Intersectionality

The Intersectionality theory was another theoretical approach chosen to guide the thesis (Crenshaw, 1991). Kimberlé Crenshaw's (1991) concept of intersectionality emerged as a response to the social injustices and discrimination faced by African American women. Inspired by the work of Black feminist scholars and activists, Crenshaw emphasized that traditional approaches often overlook the lived experiences of marginalized groups facing multiple forms of discrimination. Intersectionality recognizes that identities such as race, gender, socioeconomic status, age, sexuality, and religion do not exist in isolation. Rather, they intersect and collectively shape unique experiences. This theory focuses on equity-deserving groups, emphasizing the ways in which power structures, including racism, sexism, and colonialism, combine with these intersecting identities, resulting in complex dynamics impacting individuals. By calling for social justice and activism, intersectionality seeks to bring attention to these dynamics and advocate for systemic change to address the needs of those most affected by compounded discrimination and oppression.

This theory was selected for its ability to capture the nuanced and multifaceted experiences of equity-deserving patients as it relates to brain-heart health decision-making (Crenshaw, 1991). While the PROGRESS-Plus framework considers individual characteristics through an equity lens, intersectionality enhances this by examining how these characteristics intersect with broader systems of power, influencing personal and societal identities. Intersectionality provides a framework for understanding the structural barriers faced by equity-deserving groups, offering a comprehensive understanding of the context within which the decisional needs of equity-deserving groups with brain-heart conditions are experienced.

In summary, the ODSF guided the recognition of the decisional needs of the patients, while the PROGRESS-Plus framework identified determinants known to impact one’s health. Intersectionality bridged the remaining gaps by revealing how contextual barriers overlap and uniquely affect equity-deserving patients, emphasizing the importance of clinician-patient interactions that acknowledge the challenges faced during decision-making. This integrated approach deepened insights into the specific decisional needs of equity-deserving patients with brain-heart conditions.

## Objectives

The purpose of this master’s thesis was to investigate the decisional needs of equity-deserving groups diagnosed with brain-heart conditions and identify the unique challenges they encounter during the decision-making process. The four study objectives include:

1) Identifying the decisional needs of equity-deserving groups with brain-heart conditions.

2) Investigating how equity-deserving groups with brain-heart conditions experience and express their decisional needs.

3) Identifying the challenges equity-deserving patients face throughout the decision-making process.

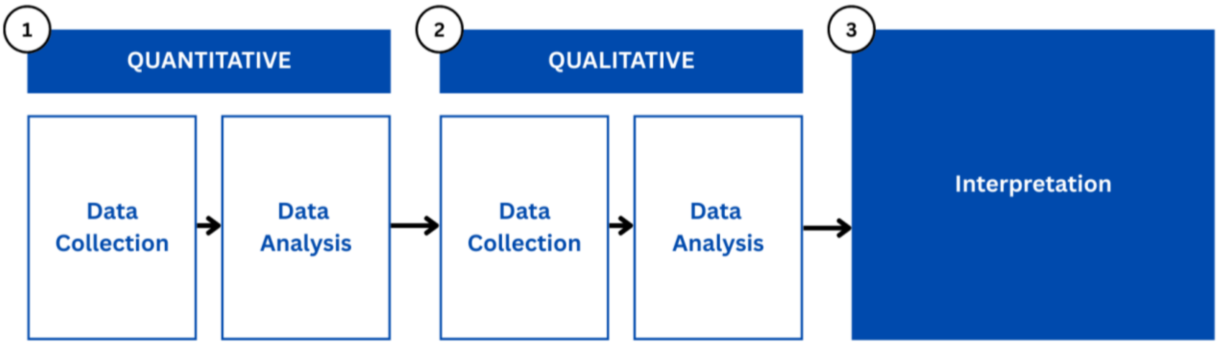
4) Determining how the decisional needs identified among equity-deserving patients align with the challenges they report during the decision-making process.

## Study Design

This study used an explanatory sequential mixed-methods design, beginning with the collection and analysis of quantitative data followed by collection and analysis of qualitative data (Shiyanbola et al., 2021; see figure 2). Initially, quantitative data was gathered through a cross-sectional survey to capture data from multiple participants at a single point in time. Subsequently, qualitative data was collected through semi-structured interviews (Polit & Beck, 2021). This mixed-methods approach allows for the integration of both types of data, facilitating a deeper, more comprehensive understanding of the influence of the determinants of health and intersecting social identities on the decisional needs experienced by equity-deserving patients with brain-heart conditions (Shiyanbola et al., 2021). To ensure adequate reporting of the survey component of the study, the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines were used (see Appendix C; Eysenbach, 2004).

The qualitative component of this study followed Thorne's (2016) *interpretive description*, an approach developed by nursing researchers to examine complex health phenomena and generate practical insights to inform clinical practice. This approach allows researchers to analyze participants' subjective accounts to uncover patterns and themes. In this study, interpretive description enabled an in-depth examination of the experiences of equity-deserving patients with brain-heart conditions, providing context for the decisional needs identified from the survey data. This ensured the results were meaningful and relevant, while thoroughly addressing the specific decisional needs and barriers equity-deserving patients face during SDM. The reporting for the qualitative portion of this study adhered to the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (see Appendix D; Tong et al., 2007). To ensure a systematic integration of the quantitative and qualitative components, the Good Reporting of a Mixed Methods Study (GRAMMS) guidelines were also applied (see Appendix E; O'Cathain et al., 2008). Reporting guidelines were applied as previous research shows that when used, studies are transparent and effectively reported for readers (Arundel et al., 2019).

**Figure 2.** Explanatory-sequential mixed methods study design



## Integrated Knowledge Translation

This study utilized an integrated knowledge translation (IKT) approach, with the involvement of patient partners and clinicians as active members on the research team. IKT is an approach in which researchers collaborate with knowledge users as equal partners throughout the research process (Canadian Institutes of Health Research [CIHR], 2015). Knowledge users are individuals who are expected to benefit from and apply the research findings, including patients, clinicians, and other stakeholders (CIHR, 2015). Engaging knowledge users throughout the research process ensures that the findings are both meaningful and directly applicable to those who will ultimately implement and benefit from them (CIHR, 2015). In this master's thesis, a patient partner was actively involved as a key member of the research team, contributing their valuable lived experience to ensure that the perspectives of equity-deserving individuals were considered during study design, conduct, and interpretation. This IKT approach reflects the commitment to including the perspectives of patients throughout the research process, enhancing its relevance and impact (CIHR, 2015).

## Setting

This study recruited participants from acute and community care healthcare facilities where patients receive brain-heart healthcare services in Eastern Ontario, Canada. Eastern

Ontario has a population of 2.06 million people (Government of Ontario, 2023). Participants were recruited from two large academic teaching hospitals serving Eastern Ontario and community-based groups. One facility was the University of Ottawa Heart Institute (UOHI), the largest multidisciplinary cardiac health center in Canada, located in Ottawa, Ontario (UOHI, 2024). The UOHI provides care to over 200,000 patients each year (UOHI, 2024). Eligible patients were recruited from outpatient clinics, including the heart function, heart transplant, cardiology, palliative care, and cardiac rehabilitation intake clinics. Another facility was the Ottawa Hospital (TOH, 2024). This study recruited patients from the psychiatric and stroke clinics at TOH. Aiming for diverse representation of equity-deserving participants, recruitment efforts extended into the community. This study collaborated with the following community organizations: Ottawa Public Health, Somerset West Community Health Centre, ACB Wellness Resource Centre, Restore Medical Clinic, Ottawa Black Mental Health Coalition, and Myrtha Counselling Services. These organizations shared the study poster on social media and displayed it within their facilities.

## Eligibility

For this study, all participants from an ongoing parent study who self-identified as a member of an equity-deserving group in the demographic section of the survey were included. This study focused on the responses of participants from an equity-deserving group to understand their specific decisional needs and experiences. Other eligibility criteria included being adults aged 18 and older that either have a diagnosed brain-heart condition or have one (e.g., brain condition) and are at risk of developing the other one (e.g., heart condition). Participants must have made a health decision regarding a brain-heart condition for themselves in the past year.

## Sample Size

For the survey, this study aimed to recruit all participants that self-identified as a member of an equity-deserving group from an ongoing parent study. Due to the exploratory nature of this mixed-methods study, a formal sample size calculation was not required. The sample size for the interviews was chosen to align with Thorne's (2016) approach, which prioritizes gaining deep, meaningful insights from a small sample. This ensured that the data collected supports a comprehensive and nuanced understanding of each participant's unique experiences.

## Recruitment Procedures

The recruitment process involved identifying eligible participants through multiple strategies. First, members of the research team (SG, MC) screened and contacted potential participants receiving care from select UOHI and TOH clinics to let them know about this study. At the UOHI, physician administrative assistants provided a patient list with the names and medical record numbers of patients attending each clinic. The research assistant (SG) screened potential participants from these lists using the EPIC platform to confirm if they have consented to be contacted for research and have a brain-heart condition or are at risk for developing one. The research assistant approached eligible patients either in-person during their clinic visit or spoke to them by phone to invite them to participate in the study. Patients who agreed to participate in this study were presented with the choice to complete the survey by phone, in-person, or online via email. At TOH, team members screened the clinic and unit lists, identified potential participants, and provided the names and contact information of eligible participants who consented to being contacted for research purposes to the research team (SG, MC) for initial contact. Second, snowball sampling was utilized by inviting participants to share the study information with others in their networks and inviting interested people to contact the research team for more information. This was achieved through an invitation at the end of the completed survey. Third, posters with study details and contact information were placed within community organizations that have agreed to assist with recruitment, including Somerset West Community Health Centre, Ottawa Public Health, ACB Wellness Resource Centre, Restore Medical Clinic, Ottawa Black Mental Health Coalition, and Myrtha Counselling Services (see Appendix H). Four, social media posts on open and closed social media groups and an announcement on the Faculty of Health Sciences website aimed to reach potential participants.

Patients who agreed to participate in the study were contacted by the research assistant (SG) via email to arrange a time to complete the informed consent process over the phone. The verbal consent process included discussing the purpose of the study, information on the 20-25 minutes electronic survey, information on the optional 30- to 60-minute follow-up interview, data being either anonymous or coded, methods for data protection, the name of the primary investigator, and who to contact if they had any questions or concerns.

## Data Collection

With informed consent received, participants could begin the survey according to their preference: a) independently through a virtual link sent to each participant via email, b) over the phone with the research assistant (SG), or c) in-person with the research assistant (see Appendix F). The survey was available in both English and French. Participants who received the survey link, but did not complete the survey, received a reminder email at the one- and two-week mark. In the survey, one question appeared on each screen. Any duplicate surveys were detected by the research coordinator (MC) by monitoring participants' IP address and keeping track of these duplicates on a Microsoft Excel sheet accessible only to the research team. Participants could go back to modify their responses, and a return code was available for participants to stop the survey and come back at a later time. Each question allowed participants to indicate that they "prefer not to say." Participants who completed the survey were offered a $10 gift card as recognition for their time and contributions. Gift cards were sent through email or postal mail, according to their preference.

Once consented individuals completed the survey, purposive sampling was used to invite patients to participate in semi-structured interview. Interviews were conducted either in-person, virtually, or over the phone as per their preference. To ensure a comprehensive account of the experiences of equity-deserving groups, maximum variation sampling was used to include equity-deserving participants from diverse backgrounds, ages, genders, socioeconomic statuses, health experiences, etc. related to brain-heart conditions. A moderator (SG, KBL) led the 30- to 60-minute discussion, starting with an explanation of the study's objectives and offering an opportunity for participants to ask questions before moving into the semi-structured interview questions. Participants who completed the interview were offered an additional $20 gift card either through email or postal mail. The interviews were audio or video recorded. A research assistant (MM) transcribed each recording using the Microsoft Teams platform.

## Survey and Interview Guide

Quantitative data were collected using a cross-sectional electronic open survey with questions informed by the ODSF and delivered through the REDCap platform (REDCap, 2024). The survey was pilot tested with 15 patients and caregivers with a brain-heart condition or were at risk of developing a brain-heart condition. Minor revisions were made for language and clarity. The survey was divided into three sections: (1) six questions regarding the type of health condition, (2) 24 questions to assess decisional needs, and (3) 15 questions regarding the participants' socio-demographic information. The second section consisted of the decisional conflict scale (DCS) and the decision regret scale (DRS), both of which are validated and reliable tools based on the ODSF (Brehaut et al., 2003; O'Connor, 1995). The DCS demonstrates construct validity, meaning it effectively reflects data that are related to decisional conflict (Heale & Twycross, 2015; O’Connor, 1995). The DCS also shows strong reliability, with Cronbach's alpha values ranging from 0.78 to 0.89 and test-retest correlations above 0.80 (O'Connor, 1995). Similarly, the DRS has been validated, demonstrates strong reliability, and exhibits good internal consistency with Cronbach's alpha values between 0.81 and 0.92 (Brehaut et al., 2003). Together, these psychometric properties show that the DCS and DRS instruments provided robust and reliable measurements for this study. The third section of the survey adhered to the PROGRESS-Plus framework to collect the socio-demographic information. No questions in the survey were randomized.

An interview guide was developed to guide the discussions, incorporating probes that emphasize equity, diversity, and inclusion to ensure comprehensive exploration of participants' experiences and perspectives. The research team, including myself, and patient partners collaboratively developed an interview guide, informed by the ODSF, PROGRESS-Plus framework, intersectionality theory, literature review, and research objectives (see Appendix G).The interview guide was pilot tested with two patient partners and a research team member who had lived experience as a patient with a brain-heart condition or as a caregiver. The interview guide was revised to improve language and clarity based on feedback. The purpose of the interview guide was to provide a structured set of questions while also allowing participants the freedom to openly share their experiences.

**Data Analysis**

All collected data was securely stored on password-protected documents in the University of Ottawa’s OneDrive. Quantitative data was transferred from the REDCap platform to IBM SPSS Statistics for analysis using descriptive statistics (IBM SPSS, 2024). The research team (SG, MC, KBL) reviewed the data to identify and address any incomplete or missing data. Incomplete or missing data were left blank, and the number of responses received for each item was reported as *N*. Descriptive statistics were used to analyze patient demographics and decisional needs. Decisional conflict was measured using the DCS, a 16-tem instrument designed to assess uncertainty and difficulty in making informed and values-based decisions (O'Connor, 1995). Scores above 37.5 out of 100 indicated that participants experienced decisional conflict (see Appendix I; O'Connor, 1995). Decision regret, referring to feelings of remorse after a health decision has been made, was measured using the 5-item DRS. Scores above 25 signified that participants experienced moderate to severe decision regret (see Appendix J; Brehaut et al., 2003). Normally distributed data were reported using the mean and standard deviation, whereas data that were not normally distributed were reported using the median and interquartile range. Completion and submission of the survey was considered as the participant's consent to be included in the study.

Qualitative data from the semi-structured interviews was analyzed using Braun and Clarke's (2006) six-phase approach to thematic analysis to identify and organize themes related to the decisional needs of equity-deserving patients when making decisions about their brain-heart health. This approach was chosen for its systematic approach to conducting a thematic analysis while providing flexibility to adapt to the nuances of the data. The first step involved familiarizing oneself with the data, which includes transcribing the audio recordings of each patient interview and thoroughly reading through each transcript to gain a deep understanding of the content. In the second step, initial codes were generated by identifying key concepts and quotes, which were labeled with descriptive terms and compiled into a codebook. The third step involved systematically organizing the identified codes into relevant themes that reflect the overarching patterns in the data. In the fourth step, the research team (SG, MM, KBL) met to review the emerging themes, ensuring they accurately represent the data. The fifth step focused on clearly defining each theme. Finally, the sixth step involved documenting the findings from this thematic analysis.

### Data Integration

In this mixed-methods study, data integration occurred at two key levels: At the sample and interview level, as well as during data interpretation. First, at the sample level and interview level, the participants selected through purposive and snowball sampling for the qualitative interviews were a subset of those who completed the quantitative survey. At the interpretation level, the quantitative and qualitative data were analyzed separately and then synthesized through side-by-side joint displays, which aligned the quantitative results with their corresponding qualitative insights in a single table (Guetterman et al., 2015; McCrudden et al, 2021). This approach facilitated clear comparisons, allowing qualitative data to deepen and contextualize the quantitative findings (Guetterman et al., 2015). This study involved presenting the quantitative findings as a summary and the qualitative data as a thematic synthesis, facilitating triangulation of the synthesized findings. By triangulating both data sources, the analysis provides a more nuanced understanding of how various factors, such as the social determinants of health, shape the decisional needs of equity-deserving groups with brain-heart conditions.

## Confidentiality and Privacy

Ethics approval was obtained from the Ottawa Health Science Network Research Ethics Board (OHSN-REB; # File # 20240227-01H) and administrative approval from the University of Ottawa (# H-05-24-10471) shown in Appendix K. Participants provided verbal consent by reviewing one verbal consent form with a member of the research team (SG, KBL) before beginning the survey and participating in the interviews (see Appendix L). A privacy statement preceded each survey, assuring participants of data confidentiality. Participation was voluntary, and participants could skip any question they did not feel comfortable answering and could withdraw at any time by stopping the survey. The survey and interview data for each participant were coded by replacing the participant's identifying information with an alphanumeric code. Data was stored securely on password-protected computers that were accessible only to the research team. Recordings from the audio-recorded interviews were discarded once transcribed by a member of the research team (MM).

## Rigor

Rigor involves the structured and systematic implementation of research methods to uphold the quality, accuracy, and integrity of the study (Heale & Twycross, 2015). Rigor for the quantitative data was achieved by using questions from valid and reliable instruments (Heale & Twycross, 2015). Furthermore, we established rigor for the qualitative data by following four criteria established by Lincoln and Guba (1985) for evaluating qualitative research: Credibility, transferability, dependability, and confirmability. Rigor was maintained for the integration of both the quantitative and qualitative data, which were analyzed separately and then integrated, by adhering to Harrison et al.'s (2020) Rigorous Mixed Methods Framework (see Table 3.1). Establishing the trustworthiness of the research is essential for demonstrating its relevance and significance. By applying these criteria, our study aimed to ensure that the findings accurately represented participants' experiences and could be reliably interpreted and applied in various contexts.

### Validity and Reliability

Validity in quantitative research refers to how accurately an instrument captures the data it intended to measure (Heale & Twycross, 2015). Reliability refers to the consistency of a measurement and its ability to be reproduced when using the same study design and methodology (Heale & Twycross, 2015). Both the DCS and the DRS instruments used for data collection exhibit satisfactory psychometric properties as presented earlier strong validity and reliability (Brehaut et al., 2003; O'Connor, 1995). The other items were validated in Canadian surveys of decisional needs, including the sociodemographic questions (Haesebaert et al., 2019; Stacey et al., 2023).

### Credibility

To establish credibility in this thesis, multiple strategies were employed. Credibility in qualitative research ensures that the findings accurately represent the participants' experiences (Lincoln & Guba, 1985). First, data triangulation was used by collecting information from different sources, including patient interviews and surveys, to construct a comprehensive understanding of participants' decisional needs and experiences. This approach helped highlight both consistencies and variations, thereby increasing the trustworthiness of the study findings (Lincoln & Guba, 1985). Second, member checking was carried out after the interviews, where participants had the opportunity to review the moderator's interpretations and interview transcript to confirm that their experiences have been captured accurately. This process ensures that the participants' perspectives remain at the core of the findings (Lincoln & Guba, 1985). Third, peer debriefing involved working closely with another research team member during the interview process to cross-check and discuss interpretations, adding depth and reducing bias (Lincoln & Guba, 1985). Transcripts were thoroughly reviewed, and audio recordings were listened to at least twice to ensure accuracy.

### Transferability

In this thesis, thick description of the setting supported transferability by providing detailed accounts of the participants' experiences during decision making (Lincoln & Guba, 1985). These rich descriptions enable readers to determine the relevance of the findings for other contexts (Lincoln & Guba, 1985).

### Dependability and Confirmability

In qualitative research, dependability involves demonstrating the consistency of the findings, ensuring that the research process is logical, traceable, and well-documented

(Lincoln & Guba, 1985). Confirmability emphasizes objectivity, showing that the results are based on participants' perspectives and experiences rather than being influenced by the researcher's personal biases or motivations (Lincoln & Guba, 1985). To address both criteria, this study maintained clear and detailed documentation of the research process (Lincoln & Guba, 1985). An audit trail was kept, including interview transcripts, the interview guide, and the codebook used for analysis. This documentation allows for external review and verification, reinforcing the study's reliability and objectivity (Lincoln & Guba, 1985).

## Rigorous Mixed Methods

Harrison et al.'s (2020) Rigorous Mixed Methods Framework, shown in Table 3.1, categorizes the rigor of mixed-methods research as high, medium, or low based on specific criteria. In this explanatory sequential mixed-methods study, a high level of rigor was maintained throughout the research process. This study, which examines the decisional needs of equity-deserving patients with brain-heart conditions, provides a clear rationale for using a mixed-methods approach. This design allows the quantitative survey findings on decisional needs to be further explored through qualitative interviews, offering a more comprehensive and nuanced understanding of participants' decisional needs and experiences. Among the four research questions guiding this study, the fourth question (outlined in Chapter One) specifically addressed data integration: *How do the decisional needs identified among equity-deserving patients align with the challenges they report during the decision-making process?* Data collection methods for both quantitative and qualitative components were clearly described. Similarly, data analysis was systematically reported, and data integration was conducted through side-by-side joint displays. Reporting guidelines for quantitative, qualitative, and mixed-methods components for this study were adhered to, ensuring alignment with established academic standards.

**Table 3.1.** The Rigorous Mixed Methods Framework.

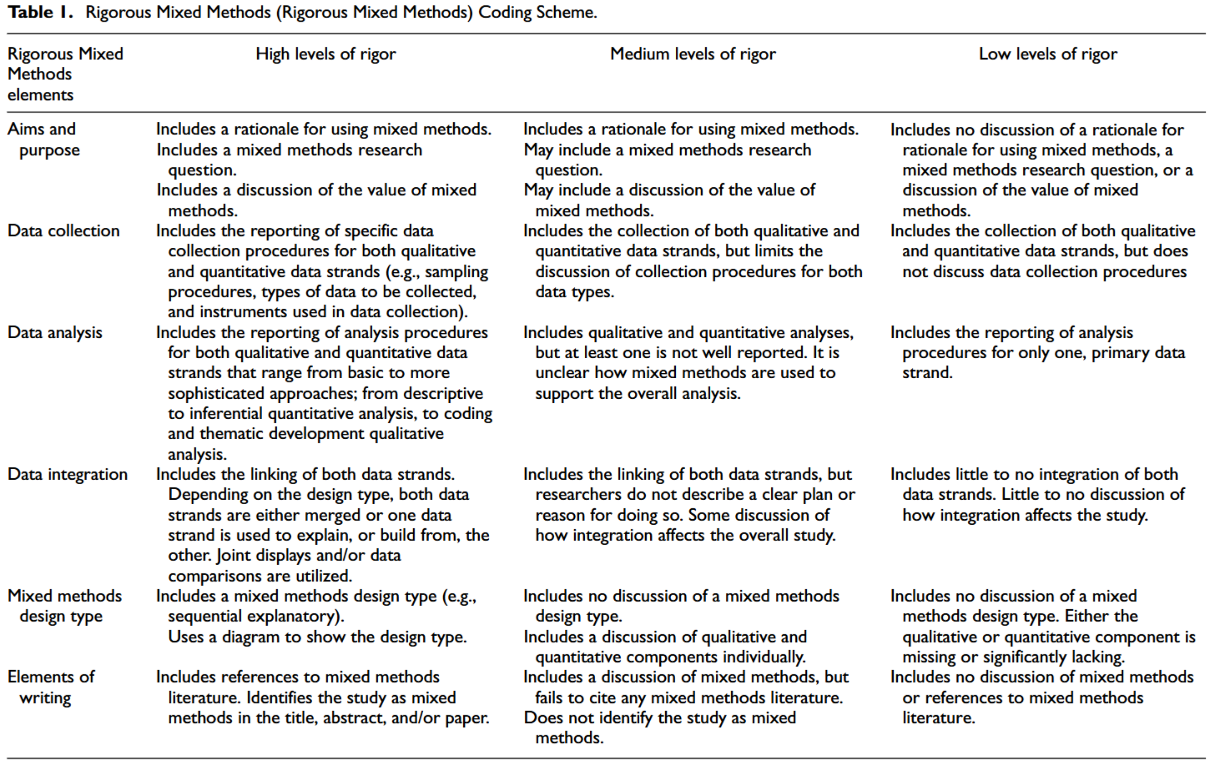


**Table 1.** Rigorous Mixed Methods (Rigorous Mixed Methods) Coding Scheme.

| Rigorous Mixed Methods elements | High levels of rigor | Medium levels of rigor | Low levels of rigor |
|---|---|---|---|
| Aims and purpose | Includes a rationale for using mixed methods.<br>Includes a mixed methods research question.<br>Includes a discussion of the value of mixed methods. | Includes a rationale for using mixed methods.<br>May include a mixed methods research question.<br>May include a discussion of the value of mixed methods. | Includes no discussion of a rationale for rationale for using mixed methods, a mixed methods research question, or a discussion of the value of mixed methods. |
| Data collection | Includes the reporting of specific data collection procedures for both qualitative and quantitative data strands (e.g., sampling procedures, types of data to be collected, and instruments used in data collection). | Includes the collection of both qualitative and quantitative data strands, but limits the discussion of collection procedures for both data types. | Includes the collection of both qualitative and quantitative data strands, but does not discuss data collection procedures |
| Data analysis | Includes the reporting of analysis procedures for both qualitative and quantitative data strands that range from basic to more sophisticated approaches; from descriptive to inferential quantitative analysis, to coding and thematic development qualitative analysis. | Includes qualitative and quantitative analyses, but at least one is not well reported. It is unclear how mixed methods are used to support the overall analysis. | Includes the reporting of analysis procedures for only one, primary data strand. |
| Data integration | Includes the linking of both data strands. Depending on the design type, both data strands are either merged or one data strand is used to explain, or build from, the other. Joint displays and/or data comparisons are utilized. | Includes the linking of both data strands, but researchers do not describe a clear plan or reason for doing so. Some discussion of how integration affects the overall study. | Includes little to no integration of both data strands. Little to no discussion of how integration affects the study. |
| Mixed methods design type | Includes a mixed methods design type (e.g., sequential explanatory).<br>Uses a diagram to show the design type. | Includes no discussion of a mixed methods design type.<br>Includes a discussion of qualitative and quantitative components individually. | Includes no discussion of a mixed methods design type. Either the qualitative or quantitative component is missing or significantly lacking. |
| Elements of writing | Includes references to mixed methods literature. Identifies the study as mixed methods in the title, abstract, and/or paper. | Includes a discussion of mixed methods, but fails to cite any mixed methods literature.<br>Does not identify the study as mixed methods. | Includes no discussion of mixed methods or references to mixed methods literature. |

*Note:* Adapted from “Methodological Rigor in Mixed Methods: An Application in Management Studies,” by R. L. Harrison, T. M. Reilly, & J.W. Creswell, 2020, *Journal of Mixed Methods Research, 14*(4), p.478. Copyright 2020 by Harrison.

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# Chapter Four

## Decisional Needs of Equity-Deserving Groups Diagnosed with Brain-Heart Conditions: A Mixed-Methods Study

*This chapter is formatted for submission to the Journal of Cardiovascular Nursing*

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Meghan Masztalar, Krystina B. Lewis

## Abstract

**Background:** Brain-heart conditions disproportionately affect equity-deserving groups. Barriers to equitable healthcare lead to unmet decisional needs and ineffective decision-making.

**Objectives:** To investigate the decisional needs of equity-deserving patients with brain-heart conditions and the barriers they encounter during the decision-making process.

**Methods:** An explanatory sequential mixed-methods study was conducted. Eligible participants were adults (≥ 18 years) who self-identified as a member of an equity-deserving group, with a brain-heart condition, and having faced a brain-heart health decision in the past 12 months. Quantitative survey data were analyzed using descriptive statistics and qualitative interviews were analyzed thematically. Data integration occurred at various levels with results represented through joint displays.

**Results:** Twenty-three participants that participated in an ongoing parent study between June 2024 to March 2025 were included. Thirteen (56.5%) had a concurrent brain-heart condition, nine (39.1%) had a heart condition with risk factors for a brain condition, and one (4.3%) had a brain condition with risk factors for a heart condition. Common decisions included lifestyle changes (n=22, 95.7%), medication (n=21, 91.3%), and diagnostic tests (n=14, 60.9%). Participants experienced clinically significant decisional conflict (n=7, 30.4%) and decision regret (n=6, 30.0%). Challenges included worrying about choosing the wrong option (n=12, 52.2%) and feeling that brain implications were never part of the conversation (n=10, 43.5%). Barriers to decision-making included complex emotions, communication barriers, and healthcare mistrust.

**Conclusion:** Unmet decisional needs among equity-deserving patients making brain-heart decisions were decisional conflict, decision regret, and other factors. Decision support interventions could address patients unmet decisional needs.

## Background

Cardiovascular diseases are the top cause of mortality in the world, accounting for 20.5 million deaths in 2021.[1,2] Research indicates that neurological and mental conditions in the brain are contributing factors to the prevalence of cardiovascular diseases.[3] For instance, ischemic stroke increases the likelihood of developing heart conditions, including myocardial infarction, arrhythmias, and heart failure.[4] Conversely, conditions in the heart, such as coronary artery disease, increases the risk for vascular dementia.[5] Shared risk factors, such as dyslipidemia and hypertension, further contribute to the prevalence and severity of brain-heart conditions.[6]

Managing brain-heart conditions requires patients to navigate complex decisions related to screening, diagnosis, prevention, and treatment with clinicians.[7-9] Shared decision-making (SDM) is a patient-centered approach where patients and clinicians work together to make health decisions guided by evidence-based information while integrating the patient's values and preferences.[10] A systematic review revealed that more than half of patients prefer to share decisions with their clinicians.[11] SDM enhances patient engagement, improves patient-clinician communication, and supports informed decisions for individuals with brain-heart conditions.[7-9]

Brain and heart health conditions are treated as separate entities by clinicians across various specialties, with limited coordination and communication between them.[3,12] This siloed structure results in increased medical errors, treatment delays, barriers to accessing services, communication breakdowns, increased costs, and inconsistent treatment plans.[12,13] These systemic barriers lead to patients having decisional needs, defined as "deficits that can adversely affect the quality of a decision."[14(p1)] An ongoing parent study is investigating the decisional needs of patients with brain-heart conditions using the Ottawa Decision Support Framework (ODSF).[14,15] The ODSF conceptualizes 22 decisional needs, including decisional conflict, inadequate knowledge, unrealistic expectations, unclear values, inadequate support/resources, complex decision characteristics, and personal and clinical needs.[14] Decisional conflict occurs when individuals experience uncertainty about how to proceed with a decision when presented with various options.[14] Unmet decisional needs compromise the quality of decisions and lead to negative outcomes, particularly decision regret and failure to proceed with a selected option.[16]

Barriers to SDM and brain-heart healthcare disproportionately affect equity-deserving groups.[3] These inequities are influenced by the social determinants of health, which include factors that impact health outcomes, such as education and employment.[17,18] Equity-deserving groups are more likely to have earlier onset of brain-heart conditions, higher prevalence, greater complications, and increased mortality.[18,19] For instance, African, Caribbean, and Black (ACB) communities have a higher risk for hypertension and are twice as likely to experience a stroke compared to White patients.[19,20] Disparities extend to health decision-making.[21] A systematic review of 18 studies revealed that equity-deserving groups experience more barriers to SDM compared to White patients.[21] In fact, patients from equity-deserving groups experienced limited time with clinicians, lack of access to healthcare services, and paternalistic care; which hindered communication and trust.[21] However, no known studies have explored the decisional needs of equity-deserving patients with brain-heart conditions to determine how best to support them to participate in SDM.

This study investigated the decisional needs of people belonging to equity-deserving groups with brain-heart conditions and barriers they encounter to achieve SDM. The objectives were to: (1) identify their decisional needs; (2) explore how they experience and express their decisional needs; (3) identify the barriers they face during decision-making; and (4) investigate how decisional needs align with the barriers they reported during decision-making.

# Methods

## Study Design

This study follows an explanatory sequential mixed-methods study and is guided by the ODSF. The methods included collecting quantitative data through a cross-sectional survey, followed by semi-structured interviews to provide a comprehensive investigation of participants' decisional needs.[22] The interviews followed Thorne's interpretive description methods.[23] This study used integrated knowledge translation by including patient partners and clinicians throughout the lifecycle of the project, from proposal development to the interpretation of the findings. [24] This collaboration ensured that the findings are culturally appropriate.[24] Ethics approval was obtained from the Ottawa Health Science Network (OHSN-REB; # File # 20240227-01H) and the University of Ottawa Research Ethics Board (# H-05-24-10471). The study was reported using the Checklist for Reporting Results of Internet E-Surveys (CHERRIES), the Consolidated Criteria for Reporting Qualitative Research (COREQ), and the Good Reporting of a Mixed Methods Study (GRAMMS) guidelines. [25-27]

## Setting

The parent study was conducted at two Canadian academic teaching hospitals and within Ottawa-based community organizations serving Eastern Ontario, which has a population of 2.06 million people. [28] At the University of Ottawa Heart Institute (UOHI), eligible participants were recruited from the heart function, cardiology, palliative care, cardiac rehabilitation, and heart transplant outpatient clinics. At the Ottawa Hospital (TOH), participants were recruited from the psychiatry and stroke units. Recruitment occurred in six community organizations serving people from equity-deserving groups.

### Eligibility and Sample Size

Identified from an ongoing parent study,[15] participants included adults (≥18 years) diagnosed with a combined brain-heart condition or pre-specified risk factors for developing a brain-heart condition (i.e. hypertension, diabetes, atrial fibrillation, and coronary artery disease), who made or were in the process of making brain-heart decisions within the past 12 months, were able to read and understand English/French, and provided verbal informed consent. This study included all participants who completed the survey and interview in the parent study and self-identified as a member of an equity-deserving group (e.g, a person living with a disability, a caregiver to a person with a disability, racialized, Indigenous, LGTBQIA+, and/or gender-diverse). For the quantitative portion, all participants were included. For the qualitative portion, the sample size aligned with Thorne's prioritization of gaining deep, meaningful insights from fewer participants.[23]

### Recruitment Procedures

The parent study used purposive and snowball sampling methods to recruit participants using multiple strategies: 1) screening of outpatient clinic lists, 2) clinician team members identifying potentially eligible patients within their clinics, and their names and contact details were forwarded to the research coordinator (MC) to learn more about the study, 3) study posters, 4) social media posts (e.g., uOttawa Faculty of Health Sciences, Brain-Heart Interconnectome), 5) asking participants at the end of the survey to refer eligible people they know to participate in this study. Once connected to the research team, interested patients were screened for eligibility.

Eligible participants were invited by a member of the research team to participate in this study either in-person, through email, or by phone. Upon agreeing to participate, the research assistant (SG) scheduled a brief meeting with each participant to review the verbal informed consent process. During this process, participants were informed about the purpose of the study, the estimated survey duration (20-25 minutes), the option for a follow-up interview (30-60 minutes), data storage on password-protected computers, and the name of the primary investigator. Participants were assured of their right to withdraw at any time. Personal data remained anonymous for survey-only participants. A research assistant (MM) transcribed interviews in Microsoft Word and removed identifiers.

Participants who provided consent were able to complete the electronic survey through a method of choice: 1) independently with a link emailed by the research coordinator, 2) in-person with a research assistant, or 3) over the phone with a research assistant. The research coordinator (MC) sent reminder emails one and two weeks after the initial invitation email. The research coordinator identified and monitored duplicate survey responses, IP addresses, participation, and completion rates. Survey items were not randomized. One item appeared on the screen per page. Adaptive questioning occurred depending on whether participants described that they are currently making or have already made a decision. Participants who completed the survey were offered a $10 gift card, which was distributed via email or postal mail. At the end of the survey, participants were asked if they were interested in participating in an optional interview. If interested in the interview, the research assistant contacted participants to arrange for the interview. Interviews, on the telephone or through Microsoft Teams, were audio or video recorded and transcribed by a member of the research team. No field notes were taken and none required repeat interviews. Participants who completed the interview were offered an additional $20 gift card, which was distributed via email or postal mail.

### Survey and Interview Guide

In the parent study, participants were asked to complete a electronic survey administered via REDCap in either English or French.[29] The survey was pilot tested in English with 15 participants with brain-heart conditions and minor changes to the questions were made. The survey was then translated into French. The survey consisted of three sections. The first section with six questions gathered details about the participants' diagnosed health condition(s) and risk for developing another condition. The second section with 24 questions evaluated decisional needs using validated instruments based on the ODSF, including the decisional conflict scale (DCS) and decision regret scale (DRS).[30,31] This section was guided by the ODSF Decisional Needs Assessment in Populations workbook.[32] The third section with 15 questions gathered socio-demographic characteristics using the PROGRESS-Plus framework (e.g., participant's place of residence, race, ethnicity, culture, language, occupation, gender or sex, religion, education, socioeconomic status, social capital, experience of discrimination, relationship dynamics, and time-dependent relationships).[33] This framework facilitated the identification of participants eligible for this sub-study of equity deserving populations. The PROGRESS-Plus framework guided data collection to consider which determinants of health may influence participants' experiences and decisional needs while also assessing the representation of various sociodemographic groups within the study sample. The survey questions were adapted from previous Canadian surveys .[34-38] Finally, participants were asked to describe their preferred level of involvement in decision-making and rate their quality of life on a 7-point scale. Participants could not pass to the next page unless all questions were answered, which always included an *other* or *prefer not to say* option for each survey item. Participants were given the option to return to modify their responses.

The interview guide in the parent study was designed to explore participants' survey responses in more detail.[15] The open-ended questions and probes were informed by the ODSF[39] and PROGRESS-Plus framework.[33] Intersectionality theory also guided the development of the interview guide.[40] Intersectionality recognizes that individuals possess multiple social identities, such as race, ethnicity, occupation, religion, and age.[40] These intersecting identities shape a person's experiences and are influenced by systemic power structures, which can lead to inequities in access to opportunities, access to resources, and health outcomes.[40] Intersectionality was used to inform the questions in the interview guide to reflect how social and structural factors shaped the decisional needs of patients with brain-heart conditions.[40] The topics discussed in the interviews included participants' experiences during decision-making, their understanding of the connection between brain-heart conditions, their perspectives on barriers to care, and their need for resources that would have been helpful in making informed decisions. It was pilot tested with two patient partners, with revisions made to adjust the order of questions and include additional prompts.

### Data Analysis

The quantitative survey data from REDCap was transferred to IBM SPSS Statistics for analysis.[29,41] Descriptive statistics were used to summarize participants' sociodemographic characteristics according to the PROGRESS-Plus framework, brain-heart health conditions, types of health decisions made, and factors influencing those decisions. DCS scores greater than 37.5 of 100 indicated clinically significant decisional conflict given it is associated with decision delay and feeling unsure about the decision.[30] DRS scores greater than or equal to 25 indicated moderate to severe decision regret.[31]

We analyzed qualitative data using Braun and Clarke's 6-step approach for thematic analysis.[42] First, the research team (SG, MM, KBL) read each transcript to become familiarized with the content. Second, descriptive codes were developed and listed into a codebook by the research team on an excel spreadsheet based on key features identified in the transcripts. Third, these codes were grouped into themes based on similarities and differences. Fourth, the research team reviewed each theme to ensure alignment with the study data. Fifth, each theme was clearly defined and mapped onto the ODSF decisional needs coding manual.[14] Sixth, the findings were documented. Participants did not provide feedback on the qualitative results.

Data integration occurred at the interpretation levels to provide a deeper understanding of participants' decision-making processes and barriers to care that contribute to decisional needs. Quantitative and qualitative data were analyzed separately, and then integrated using side-by-side joint displays to visually compare and integrate quantitative and qualitative results.[43,44]

## Results

### Survey

#### *Participant Characteristics*

Between June 2024 and March 2025, 23 adult participants from an equity-deserving group completed the survey in the parent study and were eligible to be included (Table 4.1). Among them, 13 (56.5%) were diagnosed with a concurrent brain-heart condition, nine (39.1%) had a heart condition with risk factors for a brain condition, and one (4.3%) had a brain condition with risk factors for a heart condition (Table 4.2). All participants were from an equity-deserving group and 16 participants self-identified as having lived experience as a member of the following equity-deserving groups: Living with a disability (n=12, 52.2%), LGTBQIA+ (n=5, 21.7%), caregiver to a person with a disability (n=3, 13.0%), racialized (n=2, 8.7%), and/or gender-diverse (n=1, 4.3%). Five (21.7%) participants identified as belonging to more than one equity-deserving group and 11 participants (47.8%) identified with a single equity-deserving group. Of 23 participants, 11 (47.8%) were assigned male at birth and self-identified as a man. Twelve (52.2%) were assigned female at birth and self-identified as a woman. Among them, one participant (4.3%) also identified as both a woman and *other*. Participants' ages ranged from 18 to 79 years with different cultures, religions, education, marital statuses, and household incomes.

### *Decisions and Decisional Needs*

Twenty participants had made a decision and three were making a decision. The most common brain-heart decisions made within the past 12 months were about lifestyle changes (n=22, 95.7%), medication (n=21, 91.3%), and diagnostic tests (n=14, 60.9%) (Table 4.3). Of the 23 participants, seven (30.4%) experienced clinically significant decisional conflict (see table 4.4). The mean total DCS score was 28.53 (standard deviation [SD] 18.14). DCS subscales revealed that participants felt unsupported in decisions (mean 33.7, SD 22.8), uncertain about the best choice (mean 29.7, SD 25.4), unclear about personal values (mean 29.7, SD 25.4), uninformed on their options (mean 27.90, SD 20.50), and experienced an ineffective decision (mean 23.4, SD 19.1). The most common factors that made decision making more difficult were worrying about choosing the wrong option (n=12, 52.2%), brain implications were never part of the conversation for their diagnosed heart condition (n=10, 43.5%), difficulty discussing the decision with important others (n=9, 39.1%), having no/limited access to information on the decision (n=6, 26.1%), and difficulty discussing the decision with clinicians (n=6, 26.1%). Sixteen (69.6%) reported that they felt able to make this brain-heart decision, and seven (30.4%) reported feeling unsure. Of 20 who made a decision, six (30.0%) participants had clinically significant decision regret, 10 (50.0%) had low decision regret, and four (20.0%) had no decision regret (see Table 4.5).

### *Involvement in Decision-Making*

Eleven participants reported that they preferred to share health decisions with their clinicians (47.8%) and eight (34.8%) made a decision equally with their clinicians (Table 4.3). Ten (43.5%) participants indicated that they preferred to make the decision alone. When making their decision, seven (30.4%) made the decision alone while considering the opinion of their clinicians and three (13.0%) made the decision alone. One (4.3%) preferred their clinicians to make the decisions and five (21.7%) had clinicians that made the decision while considering their opinion. No participant reported that their clinicians made the decision alone. Eighteen (78.3%) reported that the decision aligned with their preferred option. Eight (34.8%) indicated that their clinicians never asked for their ideas/preferences regarding options. Ten (43.5%) reported that their clinicians always involved them in decisions as much as they wanted to.

### *Helpful Resources for Decision-Making*

When asked what participants would find helpful if they had to make another brain-heart health decision, the top preferences were to receive reliable information about the options in a language that they could understand (n=14, 60.9%), discuss available options and their advantages/disadvantages with a clinician (n=14, 60.9%), speak with someone who has made the same decision recently (n=13, 56.5%), and have access to a patient decision aid (n=13, 56.5%).

## Interviews

### *Participant Characteristics*

The five interviewed participants were part of the following equity-deserving groups: Living with a disability, racialized, LGTBQIA+, and/or a caregiver to a person with a disability. Four (80%) participants were diagnosed with a concurrent brain-heart condition and one (20%) had a heart condition with risk factors for developing a brain condition. Four (80%) participants were assigned female at birth and self-identified as women. One (20%) participant was assigned male at birth and self-identified as a man.

### *Decision-Making Experiences*

The overarching theme was *complexity.* Participants identified nine subthemes indicating complexity about factors that impacted brain-heart health decision-making (Table 4.6). These subthemes included the complexity of 1) finding and understanding health information, 2) emotions, 3) the decision, 4) external influences, 5) accessing healthcare services, 6) patient-clinician communication, 7) brain-heart health, 8) trust dynamics in care, and 9) personal characteristics.

### ***1) Complexities in Finding and Understanding Health Information***

All participants reported barriers in *finding and understanding information* related to their decision (see Table 4.6). They lacked information and understanding of their brain-heart diagnosis, medications, options, and medical terminology. For example, participants reported that despite seeking out scholarly articles for more information, they experienced challenges in understanding the terminology used. Another challenge was receiving inadequate information on the advantages and disadvantages of each option and needing to seek information online through websites, scholarly articles, patient groups, and by consulting clinicians. Others described receiving too much information and needing time to process it. Participants expressed the need for decision support in the form of a decision model, aid, or tree.

### ***2) Complex Emotions***

Participants described experiencing a range of *complex emotions* during the decision-making process, including frustration, anxiousness, fear, sadness, exhaustion, and anger. Participants reported experiencing multiple emotions with inadequate emotional support from clinicians or family. Participants also noted that their emotions affected their thought processes, ability to retain information, readiness to make decisions, and communication with clinicians. They reported being diagnosed or at risk for a mental health condition, particularly anxiety and/or depression.

### ***3) Complexity of the Decision***

Participants described decisions as *complex* and, in some cases, urgent, contributing to limited time to making them. Participants reported that the decision itself was uncommon due to being diagnosed with a rare condition, having concerning risks associated with it, and were afraid of making the wrong decision. Some participants felt that they had no options and others were concerned about the impact of the decision on their personal life.

### ***4) Complexity of Influences from Others***

The *influence of others* was described as both a facilitator and barrier to decision making. Some participants reported that they had support from friends and family during decision-making as they helped advocate for them, exchange information with clinicians, and provide instrumental support by facilitating transportation to appointments. Other participants shared that they experienced pressure from family and friends to choose a particular option. For example, a participant with a cognitive impairment relied on their spouse for communicating with clinicians, transportation, and financial support. While this support was helpful, the participant felt pressured by their spouse to follow the doctors' recommendation to stop working. Their family believed this would help preserve the participant's cognitive function and allow them to be more present as they neared retirement. This dilemma impacted the participant, as they felt torn between their personal preferences and their family's wishes. Some participants also reported experiencing pressure from clinicians to accept the clinician's recommendation for treatment.

### ***5) Complexity in Accessing Healthcare Services***

Participants faced barriers in *accessing healthcare* for their brain-heart conditions, including difficulties navigating the healthcare system. Participants expressed concerns with finding a specialist and difficulties getting transportation to and from their appointments. Some noted that they reached out to neurologists themselves or asked their clinicians to send a referral to receive the specialized care they needed.

### ***6) Complexity of Patient-Clinician Communication***

*Communication* with clinicians emerged as an important factor in decision-making. Barriers to communication included a lack interdisciplinary communication, participants being ignored by clinicians, and *language barriers*. A participant described barriers to care due to lack of coordination between two healthcare facilities that did not receive all of the participants' medical records when they were transferred. Participants expressed the importance of therapeutic communication and meeting communication preferences, including wanting doctors to sit down and talk to them as equals, and avoiding paternalistic communication or power imbalances. A participant that was unable to express their needs due to their brain diagnosis experienced barriers in retaining health information and advocating for themselves. Many described short appointment times as a barrier, limiting opportunities for patient-clinician communication and being unable to ask questions, seek clarification, or express concerns. This resulted in participants feeling rushed during appointments and unsupported. This was especially challenging for participants who perceived their decision as urgent, contributing to the sense of pressure and time constraints. Others noted positive experiences with clinicians who provided clear explanations and emotional support. Another participant was unreceptive to communication from the clinician and was not ready to communicate with their clinicians.

### *7) Complexity of the Brain-Heart Connection*

All participants reported that their clinicians did not clearly explain the *brain-heart connection* and its impact on their health. While some participants recognized or suspected that there was a connection between brain and heart health either during or after the decision was made, others were unaware or only learned about stroke as a potential risk factor from their clinicians briefly during their appointment. All participants with heart conditions or combined brain-heart condition expressed a desire to learn more about the brain and identified the need for more integrated brain-heart healthcare services.

### *8) Complex Trust Dynamics in Care*

*Trust in clinicians* was influenced by past negative healthcare experiences. For example, one participant discovered they had been prescribed contraindicated medications for an extended period, leading them to seek second opinions and conduct independent research to verify their medications. Another participant described mistrust during transitions in care when transferred from one healthcare facility to a new one with missing health documents. As a result, they took it upon themselves to print and manage their own medical records to bring to each appointment. One participant reported feeling ignored by their clinicians, as well as their clinicians not taking their health concerns seriously. One participant had difficulty trusting people in general due to previous personal experiences and another participant emphasized the importance of trust during decision-making.

#### *9) Complex Impact of Personal Characteristics*

Participants reported the impact of *personal characteristics* on the decision. Two participants noted the role of religion, with one who sought guidance and support from a chaplain, and another mentioned the role of Islam in their decision-making process. Some participants noted that their level of education may have impacted decision-making, as some participants felt it enhanced their ability to seek information independently and ask clinicians questions. Participants noted that their advanced age was a factor in the clinicians' recommendation for treatment. Others recalled instances where clinicians dismissed their health concerns, including one who felt disregarded due to their sexual orientation. Other characteristics that participants identified as having influenced their decisions included finances, family history, cognition, and whether they have a disability.

### Data Integration

Differences were noted between the survey and interview findings. In the survey, few participants reported having no or limited access to information on their health decision or available options (n=6, 26.1%) and few participants experienced difficulty understanding or believing the scientific evidence related to their decision (n=2, 8.7%). In the interviews, all participants discussed the difficulties they encountered in accessing the information that they needed to make a decision. These experiences are reflected in the reported *complexities in finding and understanding health information* subtheme, with participants describing insufficient information and understanding of their medication or the advantages/ disadvantages of their options. Few survey participants reported difficulty discussing the decision with their clinicians (n=6, 26.1%). In the interviews, all participants discussed barriers to communicating with their clinicians. These barriers were captured under the *complexity of patient-clinician communication* subtheme, with participants describing experiences where they felt ignored by clinicians, encountering unreceptive clinicians, had limited time during appointments, were unable to ask questions, and experienced gaps in interdisciplinary communication.

Similarities between the survey and interview responses emerged when participants reflected on helpful resources for decision-making. In the survey, participants identified strategies they believed would be helpful if they were to make their decision again, including receiving reliable information in a language they could understand, discussing the advantages and disadvantages with clinicians, and having access to a decision aid. Similar strategies were discussed in the interviews, where participants emphasized the importance of seeking information through reliable online sources, patient groups, and clinicians. Participants also mentioned the need for a decision model to guide and support the decision-making process.

## Discussion

The findings provided insights into the decisional needs and decision-making experiences of patients from equity-deserving groups diagnosed with brain-heart conditions. Through an explanatory sequential mixed-methods design with 23 participants from equity-deserving groups that have made/were making a brain-heart health decision, the findings revealed that participants experienced clinically significant decisional conflict (n=7, 30.4%) and decision regret (n=6, 30.0%). Common decisions were related to lifestyle modification (n=22, 95.7%), medication (n=21, 91.3%), and diagnostics (n=14, 60.9%). Factors that impacted decisions were in regard to concerns about choosing the wrong option (n=12, 52.2%) and the absence of brain implications being discussed by clinicians among patients with a diagnosed heart condition (n=10, 43.5%). Interviews further revealed nine complex factors that contribute to decisional conflict and impede SDM: Complexity of finding and understanding health information, emotions, the decision, external influences, accessing healthcare services, patient-clinician communication, brain-heart health, trust dynamics in care, and personal characteristics. The integrated findings are consistent with other decisional needs studies and lead to three points of discussion.[14]

## Need for Integrated and Accessible Brain-Heart Information to Enhance Health Literacy

Clinicians need to provide integrated and accessible information about brain-heart health in plain language that aligns with each patient's health literacy level. In this study, the findings revealed that participants felt uninformed about their diagnoses, medications, and their options. Feeling uninformed is a modifiable factor influenced by health literacy.[14] Health literacy is a determinant of health that reflects an individual's understanding of health information and ability to use this information to make decisions.[18,45] Health literacy can impact SDM and one's ability to make informed decisions based on scientific evidence.[45,46] Existing literature shows that individuals with a high level of health literacy are twice as likely to prefer involvement in decisions, whereas those with low health literacy levels preferred to let clinicians make the decision, encountered difficulties understanding health information, and experienced decisional conflict.[46,47] In this study, 43.5% of surveyed participants reported that brain-related implications were never discussed, and all interview participants revealed that they did not receive clear information on the brain-heart connection from their clinicians. The absence of clear information on the brain-heart connection can contribute to decisional conflict by increasing uncertainty about how one condition affects the other.[14] Many interviewed participants sought reliable information online, but struggled with medical terminology, highlighting how low health literacy can influence understanding of information. Health literacy is also influenced by other determinants of health such as education, language, gender, ethnicity, and race.[46-48]A study found that among marginalized groups, health literacy was statistically significant predictor of decision-making preferences.[46] These findings reveal that clinicians need to clearly explain the brain-heart connection when discussing treatment options, using language that aligns with each patient's health literacy level and individual needs.

### Need for Improved Patient-Clinician Communication

Barriers to patient-clinician communication contribute to mistrust and reduced participation in SDM. While few surveys reported difficulty discussing decisions with clinicians (n=6, 26.1%), interviews revealed the complexity of patient-clinician communication as a prominent concern. Participants described the need to avoid paternalistic communication and power imbalances impacting SDM. Ineffective patient-clinician communication can lead to decisional conflict by leaving patients feeling uncertain, unclear about their values, uninformed, and unsupported.[14] Multiple studies underscore the role of trust impacting patient-clinician communication and SDM, particularly among marginalized groups. Zisman-Ilani and colleagues found that ACB patients with diabetes commonly experienced impersonal care and paternalistic communication, which hindered SDM and contributed to mistrust of clinicians.[49] Furthermore, participants described negative experiences that diminished their trust in clinicians, prompting participants to seek second opinions, conduct independent research, or manage their own medical records. The importance of trust was also emphasized in a study by Morris and colleagues, which explored SDM among LGBTQIA+ individuals from racial and ethnic minority groups and highlighted how trust is needed for engagement in SDM.[50] Similarly, Peek and colleagues identified communication barriers such as power imbalances, physician bias, and lack of information exchange as factors contributing to healthcare mistrust among ACB patients.[51] Short appointments limited time for questions and rapport-building, leaving patients feeling rushed, unsupported, or pressured. Studies also discussed how education and health literacy influence patients' involvement in SDM, and rapport with clinicians fosters effective patient-clinician communication.[46,52] Together, these findings demonstrate the need for addressing barriers to patient-clinician communication and fostering trust in SDM.

### Need for Support from Important Others During Decision-Making

Clinicians need to respect patients' preferences for involving important others in SDM, while also being mindful to the potential influence of social pressure. In this study, interviews revealed that the influence of important others could both facilitate and hinder SDM. Evidence shows that the involvement of important others can enhance patients' confidence and ability to engage in care.[53] The role of family in healthcare decisions is influenced by several determinants of health such as income, gender, and age.[16,17,53] It is often deeply shaped by culture.[54,55] For example, some ethnic/racial groups value the inclusion of family in their care and collective decision-making.[54,55] A systematic review found that among racialized adults with breast or prostate cancer, family and friends were actively involved in SDM and managing their condition.[55] However, unlike the systematic review, some interview participants described feeling pressured by family to choose a particular option. Participants reported difficulty discussing the decision with important others, (i.e. family, caregivers, and/or friends), which emerged as the third commonly reported barrier to decision-making in the surveys. This can lead to feeling unsupported when making decisions or encountering challenges in making decisions when their own preferences varied with those of their family. Hence contributing to decisional conflict, as social pressure contributes to uncertainty.[14,53] These findings demonstrate the need for clinicians to recognize the role of family in healthcare decisions while addressing external pressure that may undermine patient autonomy, values, and engagement in decision-making.

## Strengths and Limitations

This study has several strengths and limitations to be considered. Survey participants were either diagnosed with or at risk for a wide range of brain-heart conditions and they had a range of socio-demographic characteristics; providing diverse experiences and perspectives regarding decision-making. The research team included clinicians with experience in brain-heart care and members from equity-deserving groups, including a patient partner with lived experience as a member of the ACB community seeking brain-heart healthcare. The mixed-methods study design provided a comprehensive understanding of participants' experiences by integrating quantitative data with qualitative insights. One limitation was that the survey uses a cross-sectional design, which captures responses at a single point in time. It does not account for potential changes in decisional needs over time. Another limitation is that participants were required to retrospectively recall a decision made within the last year, potentially contributing to recall bias.

## Conclusion

In summary, equity-deserving groups with brain-heart conditions experienced clinically significant decisional conflict and decision regret during the decision-making process. Interviews further revealed the complexities participants experienced with decision-making about their brain-heart conditions. The integrated data revealed that the barriers identified through the interviews contributed to the unmet decisional needs reported in the survey, making it challenging for participants to make informed and values-based decisions with their clinicians. Future research should prioritize the development of decision support interventions to address these decisional needs and enhance equitable SDM among equity-deserving groups with brain-heart conditions.

**Table 4.1.** Socio-demographic characteristics of participants.

| **Variable** [a] | **Patients (N= 23)** |
|---|---|
| **Age (years), n(%)** | |
| 18-39 | 2 (8.7%) |
| 40-59 | 11 (47.8%) |
| 60-79 | 10 (43.5%) |
| **Sex at birth, n(%)** | |
| Male | 11 (47.8%) |
| Female | 12 (52.2%) |
| Intersex | 0 (0.0%) |
| **Gender identity,** [b] **n(%)** | |
| Man | 11 (47.8%) |
| Woman | 12 (52.2%) |
| Other[c] | 1 (4.3%) |
| **Language(s) spoken fluently or with near fluency,**[b] **n(%)** | |
| English | 23 (100.0%) |
| French | 8 (34.8%) |
| Other (Arabic, Portuguese, Italian) | 3 (13.0%) |
| **Highest level of education earned or completed, n(%)** | |
| Highschool diploma or equivalency certificate | 3 (13.0%) |
| College, CEGEP, or other non-university certificate or diploma | 12 (52.2%) |
| University certificate or diploma below a bachelor's level | 1 (4.3%) |
| Bachelor's degree | 2 (8.7%) |
| University certificate or diploma/degree above a bachelor's level | 5 (21.7%) |
| **Province/ Territory, n(%)** | |
| Ontario | 22 (95.7%) |
| Other | 1 (4.3%) |
| **Urban or Rural, n (%)** | |
| Urban | 20 (87.0%) |
| Rural | 3 (13.0%) |

| | |
|---|---|
| **Cultural background,[b] n(%)** | |
| Indigenous (Métis) | 1 (4.3%) |
| Arab, Middle Eastern, or North African | 2 (8.7%) |
| Asian or Asian Canadian | 1 (4.3%) |
| Black or African Canadian | 1 (4.3%) |
| White (Caucasian) or European Canadian | 19 (82.6%) |
| **Religion,[b] n(%)** | |
| Agnostic or nothing in particular | 7 (30.4%) |
| Atheist | 3 (13.0%) |
| Christian | 10 (43.5%) |
| Other (Buddhist, Muslim, Wiccan, or Pagan) | 3 (13.0%) |
| **Lived experience as member of an equity-seeking or equity-deserving group,[b] n(%)** | |
| Gender-diverse (e.g., agender, non-binary, and other gender identities) | 1 (4.3%) |
| LGBTQIA+[d] | 5 (21.7%) |
| Racialized (i.e., person of colour) | 2 (8.7%) |
| A person living with a disability | 12 (52.2%) |
| A caregiver to a person with a disability | 3 (13.0%) |
| Prefer not to say | 4 (17.4%) |
| None of the above | 3 (13.0%) |
| **Marital Status, n(%)** | |
| Single or separated (but still legally married/ divorced | 11 (47.8%) |
| Legally married/ living common law | 12 (52.2%) |
| **How many people living in household, n(%)** | |
| One (I live alone) | 6 (26.1%) |
| Two | 8 (34.8%) |
| Three | 5 (21.7%) |
| Four or more | 4 (17.4%) |
| **Annual Household Income, n(%)** | |
| Less than $24,999 | 3 (13.0%) |
| $25,000 to less than $49,999 | 2 (8.7%) |
| $50,000 to less than $74,999 | 2 (8.7%) |

| | |
|---|---|
| $75,000 to less than $99,999 | 2 (8.7%) |
| $100,000 or more | 12 (52.2%) |
| Prefer not to say | 2 (8.7%) |
| **Quality of life** [e] | |
| Mean (SD), [Range] | 4.30, 1.428 [1-7] |
| Median [25th /75th Quartiles] | 4.00 [4.00/5.00] |

[a] The question had a *prefer not to say* option. However, none of the participants selected this option.

[b] Some participants selected more than one option.

[c] For the *other* option, examples of gender identities include non-binary, transgender, bisexual, 2-spirited, and gender fluid.

[d] LGBTQIA+ refers to lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations.

[e] Quality of life was measured on a 7-point scale. 1 indicates that life is very distressing and difficult to imagine how it could get much worse. 4 indicates that life is so-so, neither good nor bad. 7 indicates that life is great, and difficult to imagine how it could get much better.

**Table 4.2.** Participants' brain-heart condition(s)

| Heart Condition | At Risk for a Brain Condition[a] | Diagnosed with a Brain Condition[a] |
|---|---|---|
| Atrial flutter or atrial fibrillation (n=14, 60.9%) | • Anxiety: n=4 (17.4%)<br>• Dementia: n=1 (4.3%)<br>• Depression: n=5 (21.7%)<br>• Eating disorder: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=2 (8.7%)<br>• Stroke: n=4 (17.4%) | • Anxiety: n=5 (21.7%)<br>• Depression: n=4 (17.4%)<br>• Eating disorder: n=2 (8.7%)<br>• Post-traumatic stress disorder: n=2 (8.7%) |
| Cardiomyopathy (n=7, 30.4%) | • Anxiety: n=4 (17.4%)<br>• Depression: n=5 (21.7%)<br>• Eating disorder: n=2 (8.7%)<br>• Post-traumatic stress disorder: n=1 (4.3%)<br>• Stroke: n=2 (8.7%) | • Anxiety: n=5 (21.7%)<br>• Depression: n=3 (13.0%)<br>• Eating disorder: n=3 (13.0%)<br>• Post-traumatic stress disorder: n=1 (4.3%)<br>• Stroke: n=1 (4.3%) |
| Congenital heart (n=5, 21.7%) | • Anxiety: n=2 (8.7%)<br>• Post-traumatic stress disorder: n=2 (8.7%) | • Anxiety: n=2 (8.7%)<br>• Depression: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=1 (4.3%) |
| Coronary artery disease (n=14 (60.9%) | • Anxiety: n=7 (30.4%)<br>• Depression: n=5 (21.7%)<br>• Epilepsy: n=2 (8.7%)<br>• Eating disorder: n=2 (8.7%)<br>• Post-traumatic stress disorder: n=1 (4.3%)<br>• Stroke: n=3 (13.0%) | • Anxiety: n=6 (26.1%)<br>• Depression: n=6 (26.1%)<br>• Eating disorder: n=2 (8.7%)<br>• Post-traumatic stress disorder: n=3 (13.0%) |
| Heart failure (n=12, 52.2%) | • Anxiety: n=4 (17.4%)<br>• Depression: n=4 (17.4%)<br>• Post-traumatic stress disorder: n=3 (13.0%)<br>• Stroke: n=3 (4.3%) | • Anxiety: n=5 (21.7%)<br>• Depression: n=3 (13.0%)<br>• Eating disorder: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=2 (8.7%)<br>• Stroke: n=1 (4.3%) |
| Hypertension and high cholesterol (n=13, 56.5%) | • Anxiety: n=5 (21.7%)<br>• Depression: n=8 (34.8%)<br>• Epilepsy: n=2 (8.7%)<br>• Eating disorder: n=2 (8.7%)<br>• Stroke: n=6 (26.1%) | • Anxiety: n=4 (17.4%)<br>• Depression: n=4 (17.4%)<br>• Eating disorder: n=2 (8.7%)<br>• Stroke: n=1 (4.3%) |
| Pericarditis (n=1, 4.3%) | • Epilepsy: n=1 (4.3%) | • Depression: n=1 (4.3%) |
| Valvular heart disease (n=3, 13.0%) | • Anxiety: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=2 (8.7%) | • Anxiety: n=2 (8.7%)<br>• Depression: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=1 (4.3%) |
| Other arrhythmias[b] (n=7, 30.4%) | • Anxiety: n=3 (13.0%)<br>• Depression: n=3 (13.0%)<br>• Eating disorder: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=1 (4.3%)<br>• Stroke: n=2 (8.7%) | • Anxiety: n=2 (8.7%)<br>• Depression: n=2 (8.7%)<br>• Eating disorder: n=1 (4.3%)<br>• Post-traumatic stress disorder: n=2 (8.7%) |

[a] Some participants selected more than one option.

[b] Examples of arrhythmias include bradycardia, ventricular tachycardia, and ventricular fibrillation

**Table 4.3.** Types of decisions and factors influencing decision-making of patients making brain-heart health decisions.

| Survey data | Patients (N= 23) | Interview data – Illustrative examples and quotes (N=5) |
|---|---|---|
| **Types of Brain-Heart Decisions,[a] n(%)** | | **Decisions made among interviewed participants included the following:**<br>• Deciding whether to continue taking medications microvascular dysfunction or stop taking the medication so they can start medication for migraines.<br>• Deciding whether to stop working post-stroke to preserve brain function or continue working but risk deteriorating brain function.<br>• Deciding what the next steps for treatment for heart condition would be.<br>• Deciding whether to an ablation for atrial fibrillation or not have an ablation. |
| Lifestyle changes to reduce risk | 22 (95.7%) | |
| Medications (starting, changing, stopping, or continuing) | 21 (91.3%) | |
| Diagnostic tests (e.g. computed tomography scan) | 14 (60.9%) | |
| Participating in rehabilitation | 10 (43.5%) | |
| Surgery | 7 (30.4%) | |
| Participating in a research study or clinical trial | 7 (30.4%) | |
| Other treatments (starting/changing/stopping/continuing) | 5 (21.7%) | |
| Screening (e.g. stress test) | 4 (17.4%) | |
| Setting out my advanced care planning | 1 (4.3%) | |
| Moving to palliative, supportive, or end of life care | 1 (4.3%) | |
| Other | 1 (4.3%) | |
| **Has the brain and/or heart health decision been made?, n(%)** | | |
| Yes (decision has been implemented or I will be following through with it) | 20 (87.0%) | |
| No (I am still thinking about what to do) | 3 (13.0%) | |

| | | |
|---|---|---|
| **Preferred level of involvement in health decisions,**[b] **n(%)** | | “I believe that people should have autonomy over their own health and their decision.” – *8C, self-identified as a person living with a disability.*<br>“It's a collaborative rather than an authoritarian approach to health care. It’s like here's my expert advice, what would you like to do?” – *28A, self-identified as a person living with a disability.* |
| I prefer to make the decision | 10 (43.5%) | |
| I prefer to share the decision with my health care professional | 11 (47.8%) | |
| I prefer the health care professional makes the decision | 1 (4.3%) | |
| Other (I would prefer to make the decision with family) | 1 (4.3%) | |
| **Was it your preferred option,** [b] **n(%)** | | “I feel like [my healthcare professionals] gave me all the help I need, all the information I need and I'm happy with that …[and] at the time to decision, yes, yeah, I was ready to do it " – *16C, self-identified as a member of a racialized group.*<br>“I think I was so scared and so desperate for a solution [that] I would have grabbed onto anything” – 28A<br>“Am I happy with the outcome? Absolutely not … [but] that's a better alternative than where I was six months ago." – 8C |
| Yes (I preferred the option) | 18 (78.3%) | |
| No (I did not prefer the option) | 5 (21.7%) | |
| **Were there financial costs associated with the options?** [b] **n(%)** | | “Those were really hard decisions to make … from a health perspective, it was deemed the best choice for me [to stop working]. So I mean, there's a lot of things that went into that financially … because my career is essentially going to be over.” – 8C |
| Yes | 12 (52.2%) | |
| No | 11 (47.8%) | |
| **Factors that made decision-making difficult,** [a,b] **n(%)** | | |
| Worry about choosing the 'wrong' option? | 12 (52.2%) | |

| | | |
|---|---|---|
| Feel that brain implications were never part of the conversation for my diagnosed heart condition? | 10 (43.5%) | “So I always worry [that] my heart [will] like to stop or if I have something wrong happened or if I die like... This is the risk always from having to make the decision." – 16C<br>“I didn't get as much information as I would like and I fully appreciate they have, you know, 15 minutes to talk to me. I get that. But that doesn't change the fact that I would have liked more information.” – 28A<br>“In the beginning … They sent me emails and I wasn't ... Like I didn't have enough information … I was like I don't know and she was explaining to me." – 16C<br>"When do you want to do this? Like are you trying to shoot me down there to the EP team now? Like I’m not ready for this kind of thing." [c] *– 22A, self-identified as a member of a racialized group and a person living with a disability.*<br>"When you talk to the doctors, you're stressed out, right? You only have like 15 minutes. Sometimes it might take me longer to just process things ... I think it would been easier if I was allowed to spend more time and talk and get my questions, because that will make me less stressful." *– 11C, self-identified as a member of the LGTBQIA+ community and a caregiver to a person living with a disability.*<br>“That lack of interdisciplinary collaboration and provision of information and solution … I don't really have anybody to talk to say okay well, I can't do this. So what do I do?" – 28A<br>“You know, actually, I never thought that [the brain and heart are] related between like the physical or for like heart issues and brain issues. I never thought about this before I had my heart issues" – 16C |
| Have difficulty discussing the decision with important others (e.g., spouse, family, friends)? | 9 (39.1%) | |
| Have no or limited access to information on the decision or options? | 6 (26.1%) | |
| Have difficulty discussing the decision with health care professionals? | 6 (26.1%) | |
| Feel overloaded with information? | 5 (21.7%) | |
| Feel you did not have the skills to make this type of decision? | 5 (21.7%) | |
| Feel that you did not have access to members of the brain and/or heart health care team to help support you in making the decision? | 5 (21.7%) | |
| Not know there was a brain-heart related decision to be made? | 3 (13.0%) | |
| Have difficulty in believing scientific evidence on the decision or options? | 2 (8.7%) | |
| Have difficulty understanding the scientific evidence on the decision or options? | 2 (8.7%) | |
| Have difficulty separating fake information from real scientific evidence on the decision or options? | 2 (8.7%) | |
| Feel that heart implications were never part of the conversation for my diagnosed brain condition? | 1 (4.3%) | |

| | | |
|---|---|---|
| Other experiences (unsure of the next steps for treatment, worried about diagnostic results,<br>None of the above | 4 (17.4%)<br>4 (17.4%) | "I actually said to [my physiotherapist] I wish the doctors or whoever the nurses, whoever would talk more about the brain." – 11C<br>"I would like there to be a mechanism for integrated conversations. Like I get the fact that a cardiologist can't understand a neurologist's world and vice versa. But there is value in those two people having a conversation, and I suspect that there are common pairings of brain and heart issues that it would be good if those were being addressed." – 28A<br>"We're in a health care system that we don't know how to navigate often, right? … Don't expect people to tell you what's wrong with them 'cause they don't understand it." – 8C |
| **During decision making, how often did health care professionals do the following:** | | |
| **Mention you had a choice of different possible options?** | | |
| Always | 3 (13.0%) | "I'm kind of going through it now where like I have to kind of figure out what to do with my heart situation 'cause I'm supposed to be having heart surgery and that never happened. Then I'm supposed to have a heart transplant and we're not sure what's going to happen there. So I guess the decision would be you know what's the next steps" – 11C<br>"I really still don't think there's a lot of options, right So understanding the options is not like surgery like you can do A or you can do B … So it didn't feel like a choice it felt like." – 8C |
| Often | 7 (30.4%) | |
| Sometimes | 7 (30.4%) | |
| Rarely | 3 (13.0%) | |
| Never | 3 (13.0%) | |
| I don't know / I prefer not to answer | 0 (0.0%) | |
| **Present the advantages of the different possible options?** | | |
| Always | 4 (17.4%) | |

| | | |
|---|---|---|
| Often | 6 (26.1%) | "[The cardiologist] is kind of like give me lots of time. Explained to me how benefit to do it and then I have to do it. I did it and I was glad to get more information from my doctor to reduce the fear I have right."– 16C |
| Sometimes | 7 (30.4%) | |
| Rarely | 1 (4.3%) | "I didn't have the kind of information that I would normally want to make this kind of decision both on the pro side and on the con side." – 28A |
| Never | 5 (21.7%) | |
| I don't know / I prefer not to answer | 0 (0.0%) | |
| **Present disadvantages of the different possible options?** | | |
| Always | 4 (17.4%) | "I asked [the doctor] that I met...what's your take? Should I do this or should I not do that? And he was like well that's completely up to you… like all I can tell you is that these are the benefits if you do it and it works and these are the risk if you don't do it … all I can do is give you all of the information and then so you can make the best decision." – 22A |
| Often | 4 (17.4%) | |
| Sometimes | 6 (26.1%) | |
| Rarely | 1 (4.3%) | |
| Never | 6 (26.1%) | "There wasn't an alternative option other than make yourself worse. It was you can [either] stop or you can continue to damage your brain. So I didn't feel like– I wasn't in a space where I felt like I had options." – 8C |
| I don't know / I prefer not to answer | 2 (8.7%) | |
| **Ask for your ideas/preferences regarding the options?** | | "They definitely gave me time and you know, they kept checking on me and asked me if is there any other information I want or is there anything to specify about it. And I was like yeah I want to speak to this person, I want to speak to the psychiatrist … I want to speak to my cardiologist and I spoke to everybody about it...And weighed everything. " – 22A |
| Always | 1 (4.3%) | |
| Often | 6 (26.1%) | |
| Sometimes | 6 (26.1%) | "I think because what we have with like short of doctors and short of nurses and all what we have-like too many problems. So you go to see, they don't give you enough time. You trying to ask [questions, but] they don't answer everything you need and I don't know. I didn't really like it. I lost that trust." – 16C |
| Rarely | 1 (4.3%) | |
| Never | 8 (34.8%) | |

| | | |
|---|---|---|
| I don't know / I prefer not to answer | 1 (4.3%) | |
| **Ask whether you preferred one option or another?** | 4 (17.4%) | “[The electrophysiologist] told me like, okay here's the reality.<br>Either we can send you home or we keep you until you have the ICD done. If you decide to go home, we still think you can come back and have the ICD done, but it'll take about a week … you can go home if you want. But in terms of your condition and your state, we really think you should stay. So I agreed [to stay]” – 22A |
| Always | 4 (17.4%) | |
| Often | 2 (8.7%) | |
| Sometimes | 4 (17.4%) | |
| Rarely | 8 (34.8%) | “When I went to see [my family doctor], they don't give you the care … you can't go see [the family doctor] easily … When I saw him and talked with him like... they kind of like, ignore what you have … He's treating me like its nothing like … I didn't feel like there is enough care at the family clinic to support patients. – 16C |
| Never | 1 (4.3%) | |
| I don't know / I prefer not to answer | | |
| **Involve you as much as you wanted in the decision?** | 10 (43.5%) | |
| Always | 5 (21.7%) | “The doctor in [my previous healthcare facility] called me from home to give me the decision-making process while [the doctors in my current facility had] shorter time … I'm the type of patient that likes to talk about future and just to know like the whole kind of roundabout decision tree plan.” – 11C |
| Often | 3 (13.0%) | |
| Sometimes | 0 (0.0%) | |
| Rarely | 4 (17.4%) | |
| Never | 1 (4.3%) | |
| I don't know / I prefer not to answer | | |
| **How decision was reached,** [b] **n(%)** | | |
| I made the decision alone | 3 (13.0%) | |

| | | |
|---|---|---|
| I made the decision alone, but considered the opinion of my healthcare professional(s) | 7 (30.4%) | “So to me as a patient … I always have a choice, but I don't have a choice in a way because if [the cardiologist] feels that this is important to me, I will do it. But if she says you know what, I don't think you're ready yet, let's not do it until whenever you need to do it. Then I will believe that too.” – 11C<br>"In retrospect, I can look back at it and think was there a decision? The decision was to accept the doctors, you know, ultimate direction, which was you're not going to get better unless you stop doing everything." – 8C |
| My healthcare professional(s) and I decided together equally | 8 (34.8%) | |
| My healthcare professional(s) made the decision but considered my opinion | 5 (21.7%) | |
| My healthcare professional(s) made the decision alone | 0 (0.0%) | |
| **Did you feel able to make this brain-heart decision,[b] n(%)** | | “So it was very difficult for me to kind of like, you know, when your brain is telling you, okay, the decision is this but now might be that, but Nope now might be this- now we don't know what's going to happen, so it was very stressful.” – 11C |
| Yes | 16 (69.6%) | |
| No | 0 (0.0%) | |
| Unsure | 7 (30.4%) | |
| **If you had to make this decision again, what would you find helpful,[a,b] n(%)** | | "If there was some sort of a human or not human, non-academic friendly, and plain English access to research … that would have been, and still would be, super helpful.” – 28A<br>“I had a chance to reach out to a couple people, as well as talking to my friend’s mom. My friend's mom had various heart procedures and is also in heart failure.” – 22A<br>"More information, more integrated information. Research. Advice from both a neurologist and the cardiologist in this case. And really understanding both the risks and the benefits of the medication." – 28A<br>“I had a chance to reach out to a couple people there, as well as talking to my friend and her mom who had various heart procedures and is also in heart failure |
| Reliable information about the options in a language I and my loved ones can understand | 14 (60.9%) | |
| Speaking with someone who has made the same decision recently | 13 (56.5%) | |
| Discussing options and their advantages/disadvantages with my healthcare professional | 14 (60.9%) | |
| Discussing options with important others (e.g., spouse, family, friends) | 8 (34.8%) | |

| | | |
|---|---|---|
| Having someone guide me through the decision-making process | 7 (30.4%) | … So she's got more know you knowledge on the procedures and that than I do … It helps to know a couple people in your life that's been through it" – 16C |
| Access to a patient decision aid, a tool that is explicit about the decision, the options to consider, and their features (e.g. benefits/harms) | 13 (56.5%) | "So I do use decision trees and also in the big picture the hospital is wonderful for doing the decision tree because they say to you, you have to see the psychiatrist, you have to do rehab, you have to do this you have to go coordinator. So that in itself in a way is kind of decision thing because you go through the steps." – 11C<br>"It would be lovely if there was like a road map to say, you know you have some sort of rubric that says, you know, when this happens, then you know, can you do A-B-C right?" – 8C<br>"Some sort of directory ... almost like a Wikipedia for medical research. Like just some way of accessing it, because … there is a lot of research happening but it's happening in little pockets all over the world … And I have no easy way of finding it" – 28A |

[a] Some participants selected more than one option

[b] The question had a *prefer not to say* option. However, none of the participants selected this option.

[c] The abbreviation EP refers to an electrophysiologist.

**Table 4.4.** Decisional conflict among participants.

| Variables | Patients (N= 23) | Example Quotes |
|---|---|---|
| **Decisional conflict < 25 out of 100 on the DCS** [a,b], n(%) | 11 (47.8) | “I’d say right now, at this moment, like 80/20. Like 80% yes, 20% no. Like I know I need to do it, but I don't want to do anymore procedures.” – 22A<br>"We don't know if we're gonna do the heart transplant or not. And that's a big decision to make, and that's a bigger implication. If we don't do it, what's gonna happen?” – 11C<br>“It was scary for me. And that evening, I said no, I'm not gonna do [the ablation]. In the morning, I think again and I want to do it because I don't wanna have any issues. It was very hard for me to decide." – 16C |
| **Clinically significant decisional conflict > 37.5 out of 100 on the DCS**[a,b], n(%) | 7 (30.4%) | |
| **DCS Total score** [c], Mean (SD) | 28.53 (18.14) | |
| **DCS Subscales**[c]**:** | | |
| **Uncertainty,** Mean (SD) | 29.7 (25.4) | |
| **Uninformed,** Mean (SD) | 27.9 (20.5) | |
| **Unclear values,** Mean (SD) | 29.7 (20.7) | |
| **Unsupported,** Mean (SD) | 33.7 (22.8) | |
| **Ineffective decision,** Mean (SD) | 23.4 (19.1) | |

[a] DCS: Decisional Conflict Scale.

[b] Scores >37.5/100 are associated with decision delay and feeling unsure about proceeding with a decision.

[c] The data was normally distributed. Therefore, we report the mean and standard deviation (SD).

**Table 4.5.** Decision regret among participants.

| **Variables** | **Patients**[b] **(N= 20)** |
|---|---|
| **DRS**[a,b] **Total Score,** Median (Q1, Q3)[c,d] | 15.0 (5.0, 15.0) |
| **No decision regret** [e]**,** n(%) | 4 (20.0%) |
| **Low decision regret** [f]**,** n (%) | 10 (50%) |
| **Clinically significant decision regret (moderate to severe)**[g]**,** n (%) | 6 (30.0%) |

[a] DRS: Decision Regret Scale.

[b] Three participants were not included as they reported that they are still in the process of making a decision.

[c] Q1 is quartile 1. Q3 is quartile 3.

[d] The data was not normally distributed. Therefore, we report the median and interquartile range.

[e] DRS Score of 0

[f] DRS Score of 1 to 25

[g] DRS score of >25

**Table 4.6.** Codes and illustrative quotes from five participants interviewed.

| **High-Level Themes** | **Sub-Level Codes** | **Illustrative Quotes** | **Ottawa Decision Support Framework Decisional Needs** |
|---|---|---|---|
| Complexities in finding and understanding health information | Lack of understanding on diagnosis or medication | “Don't expect people to tell you what's wrong with them 'cause they don't understand it.” – 8C | Inadequate knowledge |
| | Lack of understanding of medical terminology | "If there was some sort of a human or not human, non-academic friendly, and plain English access to research … that would have been, and still would be, super helpful.” – 28A | |
| | Need time to process | “The one thing that didn't happen was to kind of have time to process [the information].” – 28A | Difficult decision timing |
| | Too much information | “[The doctors] are throwing like a million things at me." – 11C | Information overload |
| | Lack of information on advantages/disadvantages | “I didn't have the kind of information that I would normally want to make this kind of decision. Both on the pro side and on the con side." – 28A | Inadequate Information |
| | Seeking information online | “[I used] Google Scholar and followed up into reputable journals and reputable sites like, you know, Mayo Clinic, Cleveland Clinic." – 8C | |
| | Seeking information from clinicians | “[The cardiologist] talked with me and then he told me that the psychologist put a requisition in for me to see a psychiatrist." – 16C | |
| | Need for decision support | “If there had been some sort of decision model that would be really helpful.” – 8C | Inadequate support/resources |
| Complex emotions | Frustration | “[I feel] really frustrated at the lack of anybody to talk to about both sides of the coin." – 28A | Inadequate emotional support |
| | Anxious | “I was getting anxious, and [I] still am" – 16C | |
| | Fear | “Yeah, fear of the unknown to the 10 million degrees.” – 22A | |
| | Sadness | “Saying it out loud brought me to tears initially.” – 8C | |
| | Exhaustion | “I was just exhausted, and I couldn't figure out why … I couldn't think clearly.” – 8C | |
| | Anger | “I noticed my behaviour started to be not normal … I got angry.” – 16C | |

| | | | |
|---|---|---|---|
| | Emotions and mental health | “From the anxiety side of things … there's a certain level of fear. Some of it is irrational. Like anytime I have to have any kind of procedure that's gonna require me to be under general anaesthetic, I’m [thinking that] I’m not going to wake up.” – 22A | |
| Complexity of the decision | Uncommon decision | “When you're dealing with rare diseases ... that becomes much more complicated” – 28A | Difficult Decision Type |
| | No options | “I didn't feel like I had options.” – 8C | |
| | Risk with the decision | “Did I have enough time to make a choice? Not really … The longer I wait, the more scarred my heart [will be] and there are less chances that an ablation will actually work.” – 22A | Difficult Decision Timing |
| | Uncertainty | “Because the issue is [that] we don't know what we're doing yet, right?” – 11C | Decisional Conflict |
| | Impact on personal life | “Like pause everything, pause life, pause driving, pause work, pause social stuff, pause committees, pause board work. Like it was a massive stoppage.” – 8C | |
| | Afraid of making the wrong decision | “Did I have enough time to make a choice? Not really.” The first con would be obviously making the wrong decision.” – 11C | |
| Complexity of influence from others | Pressure from family | “And my oldest daughter was pregnant with her first baby ... She [said to me] ‘mom, I just really need you to be alive. Right?’ ... So there's a lot of pressure from other people." – 8C | Social Pressure |
| | Pressure from clinicians | “The decision was to accept the doctors, you know, ultimate direction, which was you're not going to get better unless you stop doing everything." – 8C | |
| | Family/Friend Support | “And my son was the [only] one in the whole [process] supporting me.” – 16C | Inadequate support and resources |
| Complexity in accessing healthcare services | Difficulty navigating the healthcare system | “We're in a health care system that we don't know how to navigate often, right?” – 8C | Inadequate health and social services |
| | No neurologist | “I've had a number of one-off visits with various neurologists, and the one that I found who was fantastic moved on me. I have not found one since then.” – 28A | |
| | Transportation concerns | “I can't drive myself to appointments. So then I'm coming back out to the waiting room and getting a drive home from one of my daughters.”– 8C | Inadequate instrumental help |
| Complexity of patient-clinician communication | Therapeutic communication | “So when you feel that communication, when you feel that connection with someone … You're going to feel like you're a person and not a number.” – 11C | Personal needs |
| | No interdisciplinary conversation | “There isn't that interdisciplinary conversation ... [there is a] lack of interdisciplinary collaboration and provision of information and solutions.” – 28A | Inadequate health and social services |
| | Coordination gaps between facilities | “Like they receive things in [City 1], and [City 2] doesn't. And then [City 1] does not receive things in [City 2].” – 11C | |

| | | | |
|---|---|---|---|
| | Ignored by clinicians | "When I saw [my family doctor] and talked with him like... they kind of like, ignore what you have … He's treating me like its nothing." – 16C | |
| | Language barrier | "Since [my chart is] not translated, how are [my clinicians] gonna know? [If] I go somewhere that [doesn't speak] French. That's the issue … So I print everything off my chart." – 11C | |
| | Lack of time impedes communication | "I can talk to my doctor for like 2 hours in [my previous hospital]. But here, they're more pressed for time." – 11C | |
| | Unable to ask questions | "Sometimes you can't ask the questions you want to here. Like let's say I have 50 questions, well I'll be lucky if I [ask] 5." – 11C | |
| | Difficulty with expressing needs | "It's really hard to understand and advocate for what it is you want because it feels like you're trying to put a puzzle together with oven mitts and a blindfold on." – 8C | Clinical needs |
| | Unreceptive | "In the beginning, [the doctors] used to talk with me about the ablation … in the middle of the visit, I just switched my brain to think about something else. I didn't listen to this." – 16C | Unreceptive Decisional Stage |
| | Communication preferences | "There were some doctors who would talk to me from the edge of the bed and I would say, 'can you please sit down? You're making me nervous'" – 22A | Personal needs |
| | Effective communication | "[the doctor] gave me lots of time, explained how it would benefit me, and I was glad to get more information to reduce my fear" – 16C | |
| Complexity of Brain-Heart Health | Recognition of the brain-heart connection | "[The brain and heart] are two of the most, in my view, critical organs in my body, and I can't live without either of them." – 28A | Inadequate knowledge |
| | Unaware of the brain-heart connection | "I never saw that [the brain and heart] are related. Between like the physical or for like heart issues and brain issues. I never thought about this." – 16C | |
| | Information on the brain | "I actually said I wish the doctors … would talk more about the brain." – 11C | Inadequate information |
| | Need for integrated brain-heart healthcare | "Advice from both a neurologist and the cardiologist in this case ... And really understanding both the risks and the benefits of the medication." – 28A | Inadequate health and social services |
| Complex trust dynamics in care | Impact of a negative prior experience | "I discovered months after the fact that the cardiac medication I'm on was actually contraindicated to [a different] med that I used to take … and so since then, I've been really diligent about checking contraindications and talking to pharmacists" – 28A | Inadequate health and social services |
| | Feeling ignored | "[I] feel like the family doctor deny [what] you talk about. They don't believe you." – 16C | |

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|---|---|---|---|
| | Mistrust during transitions in care | “If you've been going to some place that you know for 16 years, and then all of a sudden, they're telling you should do it back in [City 1] … it just kinda creates anxiety for me”– 11C | Personal needs |
| | Losing trust | “They don't give you enough time .... I didn't really like it. I lost that trust.” – 16C | |
| | Difficulty trusting others | “I've got mad trust issues … I’ve been wronged by too many people too many times …” – 22A | |
| | Importance of trust | “If [the doctor] feels I need to do this heart transplant, I will say yes because I have confidence in her.” – 16C | |
| Complex impact of personal characteristics | Religion | “I'm from like Muslim religion ... I believe that good thing will happen and bad things will happen. So why my concern was I just wanted to have a normal life again." –16C | Personal and clinical needs |
| | Age | “It's not like I'm 30 and choosing not to continue with my professional career … we're not talking about like 20 years of career growth that we shelving … we're nearing the end.” – 8C | |
| | Disability | “I'm on disability.... I'm not really 100% [sure] how this could negatively affect me.” – 22A | |
| | Finances | “It's a hit financially, right? In terms of this is the end [of my career]. So no big, huge annual bonuses for me anymore because I just can't deliver those results.” – 8C | |
| | Education | “I’m very aware [of] how lucky I am that I am as educated as I am … so I can get this information. I really feel for people out there who don't have those advantages in life.” – 28A | |
| | Family history | “We have a long family history of early death through a heart attack ... this decision was made fairly close to when I turned 60. That's when my father had a second fatal heart attack.” – 28A | |
| | Cognition | “You're not thinking clearly because you have a brain injury." – 8C | |
| | Sexual orientation | “I had a doctor like years ago who did not believe in me. Like they thought that something happened, and it wasn't true. So because of my, you know, because I was gay, right?” – 11C | |

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# Chapter Five

## Integrated Discussion

The purpose of an integrated discussion is to synthesize and connect the chapters presented in my thesis and offer a unified interpretation of the findings (Lewis et al., 2021). Following Lewis' et al.'s (2021) method to writing an integrated discussion, I begin this chapter by summarizing the purpose of my master's thesis, as well as the key findings from the literature review (Chapter Two) and the mixed-methods study (Chapter Four). Second, I present the main points of the integrated discussion, a culmination of integrating the findings from the mixed-methods study with the literature review (Chapter Two), theoretical approaches (Chapter Three), and broader literature. Third, I outline the implications for the nursing discipline, particularly in the areas of nursing practice, education, policy, and research. Fourth, I identify the overall strengths and limitations of my thesis as a whole. Lastly, I offer a concluding summary.

## Thesis Summary

The aim of my master's thesis was to determine the decisional needs of African, Caribbean, and Black (ACB) patients with brain-heart conditions and the barriers they encountered during decision-making. The four questions that guided my thesis were: (1) What are the decisional needs of ACB patients with brain-heart conditions? (2) How do ACB patients with brain-heart conditions experience and express their decisional needs? (3) What barriers do ACB patients face throughout the decision-making process? (4) How do the decisional needs identified among ACB patients align with the barriers they report during the decision-making process?

I conducted a literature review (Chapter Two) on July 2024 to examine the existing evidence regarding the decision-making experiences and decisional needs of ACB patients diagnosed with a brain-heart condition, brain condition with risk factors for a heart condition, or a heart condition with risk factors for a brain condition. A total of 19 studies were included, specifically ten quantitative studies (Boursiquot et al., 2024; Chang et al., 2021; Chen et al., 2023; Cooper et al., 2013; Cuevas et al., 2019; Hines et al., 2018; Hooper et al., 2018; Jimenez et al., 2012; Ratanawongsa et al., 2010; Saha & Beach, 2020), seven qualitative studies (Breathett et al., 2020; Hopp et al., 2014; Jackson et al., 2024; Mann et al., 2023; Marshall et al., 2021; Mayers & Gordon, 2024; Peek et al., 2010), and two mixed-methods studies (Breathett et al., 2019; Progovac et al., 2020). We categorized the findings from these studies to reflect the five concepts we aimed to investigate: 1) shared decision-making (SDM), 2) cultural competency, 3) patient-clinician communication, 4) racial bias, and 5) healthcare mistrust. Our findings offered insights into the facilitators and barriers to decision-making experienced by ACB populations diagnosed with or at risk for brain-heart conditions, highlighting the need for further research to better understand their decisional needs.

We used an explanatory sequential mixed-methods design guided by the Ottawa Decision Support Framework (ODSF), PROGRESS-Plus framework, and intersectionality theory to investigate the decisional needs and decision-making experiences of equity-deserving groups diagnosed with brain-heart conditions (Chapter Four). We included all eligible participants from a parent study that self-identified as a member of an equity-deserving group between June 2024 to March 2025. The 23 included participants self-identified as a member of a racialized group (including ACB), LGTBQIA+, gender-diverse, living with a disability, and/or a caregiver to a person living with a disability. Of 23 participants who completed an electronic cross-sectional survey, seven (30.4%) participants experienced clinically significant decisional conflict and six (26.1%) participants experienced clinically significant decision regret. Our results revealed that the participants most often reported making or having made the following decisions in the past year: lifestyle changes (n=22, 95.7%), medication (n=21, 91.3%), and diagnostic tests (n=14, 60.9%). Of five (21.7%) who also completed semi-structured interviews, findings revealed the complexity of nine specific factors that impacted their decision-making process, which all map onto the ODSF: 1) finding and understanding health information, 2) emotions, 3) the decision, 4) external influences, 5) accessing healthcare services, 6) patient-clinician communication, 7) brain-heart health, 8) trust dynamics in care, and 9) personal characteristics. We integrated both sets of quantitative and qualitative data, revealing areas of convergence around barriers to decision-making that contributed to participants' experiences of decisional conflict. Participants experienced barriers to therapeutic patient-clinician communication, influenced by factors such as healthcare mistrust and lack of involvement in SDM. Participants also felt uninformed due to gaps in communication about the risks and benefits of treatment options and the brain-heart connection. Finally, many participants felt unsupported by important others during the decision-making process.

## Integrated Discussion

Three important considerations emerged from my thesis. First, the evolution of our recruitment strategies to achieve a diverse sample enabled us to deliberately engage with equity-deserving groups. Second, we observed similarities and some differences in the decisional needs and decision-making experiences reported by ACB populations compared to equity-deserving groups more broadly. Third, we found that individual and intersecting social determinants of health shaped participants' decisional needs and experiences.

### Evolution of Participant Recruitment Towards a Diverse Sample

Initially, our mixed-methods study aimed to recruit ACB patients and caregivers who participated in a parent study examining the decisions and decisional needs of patients with brain-heart conditions (Lewis et al., 2025). Recruitment for the parent study began in June 2024 through multiple strategies. At the University of Ottawa Heart Institute, we recruited eligible participants from outpatient clinics, including the heart function, cardiology, palliative care, cardiac rehabilitation, and heart transplant outpatient clinics. At the Ottawa Hospital, we recruited participants from the psychiatry and stroke units. At the end of the survey, we invited participants to refer others who may be eligible and interested in the study. Despite these efforts, we encountered challenges in recruiting enough participants who self-identified as ACB and were diagnosed with or had a pre-determined risk factor (e.g., hypertension, coronary artery disease, diabetes, and atrial fibrillation) for a brain-heart condition. By August 2024, most participants recruited for the parent study identified as White, raising concerns about my thesis' focus on ACB patients. Although the parent study was not exclusively focused on ACB individuals, ensuring a diverse sample remained important to our team, and deemed essential to reflect the voices, needs, and lived experiences of all groups. The lack of diversity also risked reinforcing existing inequities in health research. As reflected in the Canadian Institutes of Health Research's (CIHR) Research Excellence Framework, the Equity, Diversity, and Inclusion (EDI) principles asserts that excellent research must be "inclusive, equitable, diverse, anti-racist, anti-ableist, and anti-colonial in approach and impact" (CIHR, 2024, paragraph 7). Our team recognized that we needed to better reach and engage diverse populations in alignment with EDI principles.

To better reach ACB populations, we expanded our recruitment strategy by partnering with community organizations in Ottawa that primarily support ACB populations. As described in Chapter Three, we partnered with six community-based organizations: Somerset West Community Health Centre, Ottawa Public Health, ACB Wellness Resource Centre, Restore Medical Clinic, Ottawa Black Mental Health Coalition, and Myrtha Counselling Services. These community organizations agreed to promote the study within their networks and refer eligible patients to our research team. We included these organizations in an ethics amendment submitted in September 2024 and approved in November 2024. This strategy to expand our recruitment locations also aligns with the recommendations by Still et al. (2023), who emphasized building partnerships and collaborating with community organizations to promote health equity in nursing research and recruit diverse knowledge users. Similarly, Prichard et al. (2024) discussed that directing recruitment efforts toward community organizations serving diverse populations is an effective approach to enhancing the diversity of the study sample. Overall, collaborating with community organizations supported our recruitment efforts with a goal of reaching ACB populations and demonstrated our commitment in upholding EDI principles in research.

Another strategy we implemented was evolving our recruitment materials. Although participation in the study was originally offered in both English and French, we recognized the need to create recruitment materials that were also inclusive. We developed English and French recruitment posters that were displayed at the University of Ottawa Heart Institute, distributed to representatives from each community organization, and shared on social media. This bilingual approach helped mitigate language barriers, a barrier discussed in an umbrella review of 11 studies that identified language as a key factor preventing equity-deserving groups from fully understanding study objectives, providing informed consent, and engaging in research (Pardhan et al., 2025). In addition to our focus on language, I developed a recruitment poster specifically targeted for patients with brain-heart conditions that self-identified as ACB to try to increase representation of ACB participants in our study (Appendix H). Prichard et al. (2024) noted that the use of recruitment materials that prioritize diverse populations, clearly outline the objectives of study, and leveraging social media to increase visibility are effective strategies for reaching and engaging a diverse sample. By developing inclusive recruitment materials, we proactively tried to address barriers to recruiting diverse participants and uphold the EDI principles of CIHR's Research Excellence Framework (CIHR, 2024; Pardhan et al., 2025).

By March 2025, results showed that there were two participants who self-identified as ACB, which included one caregiver who completed the survey and one patient who completed both the survey and interview. Given the limited number of caregivers and the study's focus on gathering rich, in-depth insights through a mixed-methods approach, our team collectively decided to focus on patients only for my thesis research. We acknowledged that including just one ACB patient would not adequately represent the decisional needs of ACB populations. ACB communities are considered a racialized group within the broader category of equity-deserving groups (CIHR, 2024). We decided to expand our inclusion criteria for my thesis research study to include any participant from the parent study that were part of the following equity-deserving groups: a person who self-identifies as living with a disability (including a caregiver to a person living with a disability), racialized, Indigenous, LGTBQIA+, and/or gender-diverse. Using the PROGRESS-Plus framework allowed us to remain mindful of these sociodemographic characteristics and collect this information from our sample. While these groups are considered under the umbrella term of equity-deserving populations, we acknowledge that each group holds distinct lived experiences, histories, and needs that shape their experiences with and access to healthcare services (Government of Canada, 2025). At the same time, these groups share a disproportionate exposure to discrimination, underrepresentation, and systemic barriers that "prevent them from having the same access to the resources and opportunities that are available to other members of society, and that are necessary for them to attain just outcomes" (Government of Canada, 2025, para. 2). Our intention to broaden our inclusion criteria to include multiple equity-deserving groups aligns with Prichard et al.'s (2024) recommendation to carefully modify the eligibility criteria to effectively promote the participation of equity-deserving populations in research. This approach allowed us to recruit more participants and provided a deeper understanding of how disparities in brain-heart healthcare, decision-making, and decisional needs affect a range of multiple diverse equity-deserving groups. This also allowed us to align with principles of EDI by including the lived experiences and perspectives of multiple groups who are underrepresented in research. Between June 2024 and March 2025, 23 eligible participants met our eligibility criteria. We agreed that this sample was sufficient to meet the exploratory aims of this study and aligned with Thorne's (2016) interpretive description approach that prioritizes in-depth information from a smaller sample.

### Decisional Needs of ACB Populations Versus Equity-Deserving Groups

We found that many of the decisional needs and experiences with SDM of ACB patients with brain-heart conditions revealed in the literature review (Chapter Two) closely aligned with those of equity-deserving groups revealed in our mixed-methods study (Chapter Four). The ODSF was a valuable theoretical framework to guide our exploration of the decisional needs of equity-deserving groups with brain-heart conditions. Furthermore, all the decisional needs we identified in the mixed-methods study mapped onto the ODSF, demonstrating that the framework is useful when examining the decisional needs of equity-deserving groups. Of the five concepts examined in our literature review, the following three concepts were strongly reflected in Chapter Four: Barriers to patient-clinician communication, healthcare mistrust, and engagement in SDM. These factors are deeply connected, as poor communication contributes to healthcare mistrust, which in turn reduces engagement in SDM (Tian et al., 2024). For example, our literature review revealed that ACB patients with brain-heart conditions experienced poor patient-clinician communication due to limited clinician engagement, discrimination, lack of information, power imbalances, exclusion from decision-making, and disregard for patients' values and preferences (Chen et al., 2023; Cooper et al., 2013; Hines et al., 2018; Mayers & Gordon, 2024; Peek et al., 2010; Ratanawongsa et al., 2010). These barriers left patients feeling unheard, uniformed, powerless, excluded, and pressured (Cooper et al., 2013; Hines et al., 2018; Jimenez et al., 2012; Mann et al., 2023; Mayers & Gordon, 2024; Progovac et al., 2020). Similarly, in our mixed-methods study, participants from other equity-deserving groups described negative experiences such as being ignored, rushed through appointments, and subjected to paternalistic communication, leading them to seek out information alone and manage their care without their clinician's support. In both examples, breakdowns in communication led to mistrust and left patients feeling unsupported, unclear about their values, and uncertain about how to proceed, contributing to unmet decisional needs.

A fourth concept prioritized in our literature review was cultural competency. Cultural competency is essential in healthcare, requiring clinicians to respect cultural differences while understanding and incorporating patients' cultural needs into their care (Alden et al., 2014; Cooper et al., 2013; Falatah et al., 2022; Saha & Beach, 2020). Our review identified barriers to achieving cultural competency, such as clinicians neglecting patients' cultural needs and providing impersonal care (Cooper et al., 2013; Cuevas et al., 2019). Although our findings in Chapter Four did not explicitly reveal an absence of culturally competent care, underlying indicators of this issue were evident. For example, barriers such as paternalistic communication, negative past healthcare experiences, feeling ignored, and having one's values dismissed contributed to poor patient-clinician communication and mistrust (Chapter Four). These barriers to patient-clinician communication and patient-centered care can directly impair the delivery of culturally competent healthcare services (Cooper et al., 2013; Cuevas et al., 2019; Saha et al., 2008). As discussed by Falatah et al. (2022), effective patient-clinician communication is a predictor of cultural competence. When patients feel that they cannot communicate their values and preferences to clinicians, they may disengage from decision-making or avoid future care altogether (Mhaimeed et al., 2023). Brown et al. (2016) discussed the need for clinicians to develop both cultural competence and therapeutic communication skills to provide responsive and respectful care. This includes engaging bidirectional communication, exploring patients' cultural backgrounds, understanding their decision-making preferences and decisional needs, and reflecting on one's own biases and assumptions, which can be achieved through SDM (Brown et al., 2016). Furthermore, trust is needed for this effective and culturally competent communication to occur (De Peralta et al., 2019). These findings demonstrate the importance of therapeutic communication as a key component of culturally competent care, particularly during decision-making with patients from equity-deserving groups.

Racial bias is another concept discussed in our literature review that greatly impacts SDM. Racial bias refers to prejudices that negatively affect the care of racialized groups (Breathett et al., 2019). While racial bias was not a major focus in participants' responses, this may partly reflect the demographic composition of our sample. Of the 23 equity-deserving participants that completed our survey, five (21.7%) participants self-identified as members of a racial or ethnic minority group. This includes two (8.7%) Arab/Middle Eastern/North African participants, one (4.3%) Indigenous (Métis) participant, one (4.3%) Asian participant, and one (4.3%) ACB participant. However, when specifically asked whether they identified as having lived experience as a member of an equity-deserving group, only two participants (8.7%) selected the racialized group option. This discrepancy may reflect differences in how participants perceive and interpret their racial identity. It is also possible that some participants have not experienced being racialized, perhaps due to differences in socioeconomic status, environment, or personal experiences that shape their lived experiences. Alternatively, it may be due to a lack of understanding of the term or an oversight when completing the survey. This small representation of racialized participants may have limited the extent to which explicit experiences of racial bias and barriers to cultural competency were captured. Nevertheless, these barriers remain important to consider when involving racialized groups in decisions about their brain-heart health.

### Intersections of the Social Determinants of Health and Decisional Needs

The social determinants of health greatly influence health decisions (Alden et al., 2014). Equity-deserving groups are particularly impacted by social determinants of health in regard to systemic inequities that impact access to care, health outcome, and health decisions (Baah et al., 2018). The PROGRESS-Plus framework helped us acknowledge the diversity within our sample and identify the social determinants of health that influence the health outcomes, decision-making experiences, and decisional needs of equity-deserving groups with brain-heart conditions (O’Neill et al., 2014). Intersectionality theory helped us recognize how intersecting social determinants, such as sex/gender, sexual orientation, socioeconomic status, occupation, education, religion, language, disability, and age, can collectively shape participants’ lived experiences during decision-making (Crenshaw, 1991). These intersections reflect and are shaped by systems of power and marginalization (Crenshaw, 1991).

These findings demonstrate the importance of recognizing that individuals may hold multiple, overlapping social identities. In our study, participants represented a range of intersecting identities and lived experiences. Of the 23 survey participants, 16 (69.6%) provided a response to the survey question, *do you have lived/living experience as a member of any of the following equity-seeking or equity-deserving groups?* Five (21.7%) participants identified as belonging to more than one equity-deserving group, demonstrating the complexity of intersecting identities that must be acknowledged when examining health decision-making. Eleven participants (47.8%) identified with a single equity-deserving group, although intersections with other social determinants of health were apparent. Among the four participants (17.4%) who preferred not to disclose and the three participants (13.0%) who selected *none of the above*, their other sociodemographic responses, particularly related to cultural and ethnic identity, suggested they could be at risk of being affected by systemic inequities and barriers to care. These findings demonstrate the need for clinicians to understand the intersections of multiple social identities and determinants of health that interact to shape patients' health experiences.

Several social determinants of health emerged in our sample that may influence how decisions were made/are being made. Education and health literacy are determinants of health that are known to greatly influence SDM (Smith et al., 2009; Stacey et al., 2017). In our mixed-methods study, the majority of participants (n=20, 87.0%) reported having some form of post-secondary education and three participants (13.0%) indicated that their highest education degree/level they have completed was a high school diploma or equivalent. As described in our discussion and supported by the existing literature, an individual's level of education and health literacy can influence their understanding of health information, ability to seek resources to support their understanding, and expectations regarding their involvement in the decision-making process (Smith et al., 2009). A qualitative study by Keij et al. (2021) revealed that one's readiness and involvement in SDM are influenced by their ability to understand their diagnosis, treatment options, and associated risks. These skills are often associated with higher levels of education (Keij et al., 2021). Individuals with lower levels of education may have limited access to the resources and support necessary to understand and apply health information, further limiting their ability to fully engage in health-related decisions (Keij et al., 2021; Smith et al., 2009). This was discussed by a participant during an interview in our mixed-methods study (Chapter Four), who stated "I'm very aware [of] how lucky I am that I am as educated as I am … so I can get this information. I really feel for people out there who don't have those advantages in life." (participant 28A). Smith et al. (2009) found that lower education is linked to low involvement in decisions, and Lent et al. (2022) revealed that decisional conflict was higher among participants with low health literacy levels. Recognizing the impact education and health literacy on SDM among patients from equity-deserving groups is necessary, as these factors directly shape how individuals interpret health information, deliberate on their options, and make informed brain-heart health decisions.

Language is a determinant of health that impacts patient-clinician communication during the decision-making process. In our sample, all participants reported speaking English fluently or with near fluency. Some participants were also fluent in another language (i.e., Arabic, French, Portuguese, and/or Italian). While language was not revealed as a prominent barrier in our mixed-methods study, existing research demonstrates that language barriers between patients and their clinicians can impede SDM (Al Shamsi et al., 2020; Keij et al., 2021). Language barriers impact patients' understanding of healthcare options pertaining to the decision, ability to express their values and preferences, and compromise overall patient-clinician communication (Anaya et al., 2025). For instance, the absence of professional interpreter services has been identified as a barrier that prevents effective patient-clinician communication (Anaya et al., 2025). It is important to recognize the impact of language and to find effective strategies to address barriers to patient-clinician communication during SDM.

Culture, ethnicity, and religion are important social determinants of health that can shape how equity-deserving groups make decisions about their brain-heart health and engage in SDM. In our mixed-methods study, five (21.7%) participants self-identified as members of an ethnic or racial minority group. Literature shows that cultural and ethnic backgrounds can influence expectations for participating in health decisions, communication styles, and trust in the healthcare system (Anaya et al., 2025; Keij et al., 2021; Mhaimeed et al., 2023). Cultural discordance between patients and clinicians can limit understanding of patients' cultural needs and lived experiences as well as hinder trust, communication, and engagement in SDM (Anaya et al., 2025). Keij et al. (2021) noted that patients from diverse cultural and ethnic backgrounds were often less actively involved in SDM and Breathett et al. (2019) discussed how discrimination and implicit bias can further limit participation. Our sample was also diverse in terms of religious beliefs, with ten participants (43.5%) identified as Christian, while others identified as Agnostic (n=7, 30.4%), Atheist (n=3, 13.0%), or other (Buddhist, Muslim, Wiccan, or Pagan; n=3; 13.0%). Religion can shape one's values, understanding of their health, lifestyle, consideration of options, and implementation of decisions (Borges et al., 2021). For example, Gendler et al. (2025) found that religious and communal beliefs among Jewish Ultra-Orthodox families influenced vaccine hesitancy and immunization decisions. Overall, recognizing the influence of culture, ethnic background, and religious beliefs is essential to fully engage patients in SDM and ensure that their values, preferences, and needs are integrated in health decisions.

Household composition and income are determinants of health that are also important to consider during the decision-making process. In our mixed-methods study, six participants

(26.1%) reported living alone, while the rest lived with at least one other person. In the interviews, participants shared the role of household members including spouses or partners, children, or close friends that were frequently described as key sources of emotional, informational, and instrumental support throughout the decision-making process. Participants shared how these relationships supported them in reflecting on treatment options, attending appointments, and communicating with clinicians. Existing literature acknowledges the role of family and close social networks in SDM, which is valued among certain cultural and ethnic groups (Keij et al., 2021; Scherr et al., 2022). Keij et al. (2021) discussed how close relationships with important others can enhance patient involvement in SDM by helping them prepare for consultations and retain health information. However, these relationships can sometimes hinder patient participation, particularly when individuals defer decision-making or overlook their own preferences or values in favor of those of an important other (Keij et al., 2021). This duality was reflected in our findings, where participants described both feeling supported and experiencing social pressure during decision-making, revealing the complex and sometimes conflicting influence of important others living in the same household when making health decisions. Individual and household income can also shape decisions (Campbell et al., 2017; Lu et al., 2022). Our mixed-methods study included participants with a range of annual household incomes. When asked whether there were financial costs associated with their healthcare options in the survey, the responses were split with 12 (52.2%) participants that reported there were no financial costs associated with their options, and 11 (47.8%) that reported there were none. During our interviews (Chapter Four), participants described the financial implications of their decision, such as the decision requiring them to stop working and leading to reduced income. Existing evidence indicates that financial constraints can limit access to care options, medications, and follow-up services, directly shaping patient decisions and contributing to poorer health outcomes (Campbell et al., 2017; Lu et al., 2022). Overall, it is essential to recognize how income and other individual social determinants of health shape participants' decision-making experiences, with their intersections further contributing to unmet decisional needs.

## Implications for Nursing

The findings from my master's thesis have important implications for nursing practice, education, health policy, and future research.

### *Nursing Practice*

Nurses can support ACB patients and more broadly patients from equity-deserving groups as they navigate complex decisions related to their brain-heart health. They can do so by recognizing and responding to patients' decisional needs using decision support interventions, including nurse-led decision coaching and/or patient decision aids (Stacey et al., 2012; Stacey et al., 2024). According to the ODSF, the effective implementation of decision support interventions improves the quality of a decision and leads to following through with the selected option (Stacey et al., 2020). Decision coaching is a patient-centered and non-directive decision support intervention implemented by trained clinicians to help patients prepare for and engage in health decisions (Jull et al., 2021; Rahn et al., 2024; Stacey et al., 2012). Decision coaching can occur with a patient through a phone call, face-to-face, or online such as through video chatting (Jull et al., 2021; Stacey et al., 2012). Components of decision coaching include identifying an individual's decisional needs, supporting them in understanding available options and related information, eliciting their personal values and preferences, empowering them to collaborate with clinicians and important others (e.g., family and friends), and providing support as their option is followed through (Zhao et al., 2022). Jull et al.'s (2021) Cochrane review of 28 randomized controlled trials found that the implementation of decision coaching as a decision support intervention improved patient knowledge on available options and their associated risks and benefits. By integrating decision coaching into nursing practice, nurses can better support informed and values-congruent decisions.

Decision coaching can also be implemented alongside decision support tools. Patient decision aids are a resource that present available options and help patients evaluate which choices best align with their values, preferences, and needs (Stacey et al., 2024). Similarly, decision guides assist patients in clarifying the decision at hand, exploring available options, identifying their decisional needs, and planning the next steps (O'Connor et al., 2015). These tools can be culturally adapted to reflect the cultural values, preferences, and decisional needs of equity-deserving groups. For example, a qualitative study by Jull et al. (2015) culturally adapted the Ottawa Person Decision Guide to support Aboriginal women during SDM. The adapted tool, combined with decision coaching, provided effective decision support by addressing patients' decisional needs, improving accessibility, tailoring information to health literacy levels, and ensuring a more patient-centered approach. The study also highlighted the importance of decision coaching in facilitating meaningful engagement and effective use of the Ottawa Personal Decision Guide. Together, both decision coaching and decision aids/guides are decision support interventions that can further support patients in being informed and make value-congruent decisions, as well as engage in SDM with their family and healthcare team (Hoefel et al., 2020; Stacey et al., 2012).

### *Nursing Education*

To address the decisional needs of patients from equity-deserving groups making brain-heart decisions identified in my master's thesis, nurses must be equipped with the skills to provide effective and tailored decision support interventions. An evidence-based approach to achieving this is through the Ottawa Decision Support Tutorial (ODST). The ODST was established by O'Connor and Jacobsen in 1998, and later updated in 2021 (O'Connor et al., 2021). Informed by the ODSF, the ODST was developed to build clinicians' capacity to support patients and families facing complex health decisions (O'Connor et al., 2021). It aims to strengthen clinicians' understanding of SDM and the application of decision support interventions in clinical practice (O'Connor et al., 2021). The tutorial includes nine sections providing an overview of SDM, decision support, patient engagement in decisions, the ODSF, decisional needs, decision tools, and decision coaching (O'Connor et al., 2021). Importantly, the ODST can be integrated into nursing education as early as the undergraduate level (Boland et al., 2019). An implementation project by Stacey et al. (2009) demonstrated that when undergraduate nursing students completed the ODST as a self-directed learning activity, they reported high satisfaction with the tutorial and knowledge of decision support concepts. The ODST is also accessible to practicing nurses at any stage in their career. The ODST was recently evaluated by Boland et al. (2019), who reported high user acceptability and knowledge test scores following the completion of the ODST. Incorporating the ODST into nursing education is a practical step toward equipping nurses with the knowledge needed to provide decision support, recognize and address barriers to decision-making, and address decisional needs experienced among equity-deserving groups navigating challenging brain-heart health decisions.

Nurses and nursing students should be trained in culturally competent approaches to SDM to address health inequities that lead to unmet decisional needs. Cultural competency training is needed to ensure that individuals from equity-deserving groups, particularly those from diverse cultural and ethnic backgrounds, have their values embedded in care decisions and can communicate effectively with their clinicians (Osmancevic et al., 2025). Such training can help address cultural and language differences, promote mutual understanding of patient-specific values and preferences, foster trust, and enhance patient engagement in decision-making (Brown et al., 2016; De Peralta et al., 2019; Falatah et al., 2022; Osmancevic et al., 2025). A systematic review of seven studies evaluating cultural competence training for clinicians found that six studies reported a significant improvement in clinicians' knowledge and skills related to cultural competence (Govere & Govere, 2016). Additionally, five studies showed that such training was associated with increased patient satisfaction related to their care (Govere & Govere, 2016). These findings demonstrate the need for effective cultural competency training to be included in nursing education.

### ***Nursing Policy***

Nursing organization policies must prioritize addressing the decisional needs and barriers to SDM experienced among equity-deserving groups. This requires the development of policies that promote EDI principles, accessible healthcare, patient–clinician communication, and tailored decision support interventions. Brain-heart healthcare services must also consider the broader impacts of social determinants of health and aim to meaningfully engage patients and their families in care decisions to ensure choices are aligned with their values, preferences, and lived experiences. The College of Nurses of Ontario's (CNO) *Code of Conduct* outlines the professional expectations for all nurses in Ontario and explicitly states that the code "puts clients at the center of nursing care and includes principles of diversity, equity and inclusion to ensure client care is safe, compassionate, equitable and discrimination free" (CNO, 2025, p. 3). To uphold these principles in practice, nursing leadership must embed EDI into organizational policies (CNO, 2025). This includes developing policies that ensure patients from equity-deserving groups are heard, valued, and supported in making health decisions (CNO, 2024). In alignment with these objectives, the CNO's 2024–2027 EDI Strategy, *Inclusion for All: Nothing About Us, Without Us*, offers a systematic plan for implementing system-level change (CNO, 2024). This strategy aims to address discrimination in Ontario's healthcare while promoting cultural competency (CNO, 2024). Policies can mandate clinician training to build skills in brain–heart health, cultural competency, effective communication, understanding social determinants of health, addressing discrimination, and providing decision support.

### *Future Research*

To date, there are no known decision support interventions developed with and tailored for equity-deserving populations diagnosed with brain-heart conditions. Co-developing a culturally tailored patient decision aid represents a valuable opportunity to support individuals from equity-deserving groups in making informed, values-based decisions about their brain-heart health. Such decision aids have the potential to facilitate culturally tailored SDM. It also has the potential to address the decisional needs and barriers to decision making identified in our mixed-methods study. This supports positive brain-heart health outcomes, improves engagement in SDM, and reduces disparities. Future nursing research should prioritize the development of culturally tailored patient decision aids, that may be used alongside decision coaching, to better support the decisional needs of patients from equity-deserving populations with brain-heart conditions and their caregivers.

Future research needs to align with the EDI principles of the CIHR's (2024) Research Excellence Framework. Prichard et al.'s (2024) methodological paper, which outlines strategies to embed EDI at every stage of cardiovascular research, is a useful resource for researchers. During the planning phase, researchers are encouraged to collaborate with community organizations, co-produce the research, and engage diverse patient/community partners as part of the research team. In the conduct phase, recommendations include ensuring that eligibility criteria are inclusive of equity-deserving groups. Recruitment should involve the development of culturally appropriate recruitment materials that can be shared with community partners and distributed through social media platforms to broaden outreach. Participation in research should be accessible, such as how we offered flexible options for participants to complete the survey and interviews in our mixed-methods study. During data collection and analysis, it is essential to use culturally appropriate language and report socio-demographic characteristics. Finally, dissemination of the study findings can be achieved by engaging with community partners and fostering ongoing dialogue with knowledge users.

## Strengths and Limitations

My thesis addressed a gap in the literature by investigating the decisional needs and decision-making experiences of equity-deserving groups with brain-heart conditions. This is an under-researched area and represents a novel contribution to nursing. By centering the voices of individuals who are often underrepresented in research, our study provides insights into their decision-making experiences. Specifically, these insights reveal barriers and facilitators to care that contribute to decisional needs and impacts SDM. Another key strength is the use of an intersectional lens to contextualize and examine the impact of various social determinants of health, as identified through the PROGRESS-Plus framework. Intersectionality supported the interpretation of the data and understand the interplay between intersecting social determinants of health and decision-making experiences. This approach allowed for us to demonstrate a deeper understanding of how overlapping factors, such as race/ethnicity, gender identity, socioeconomic status, and disability, interact and influence patients' decision-making.

There are limitations that should be considered. While a patient partner with lived experience as a member of an equity-deserving group was involved in our team from the start, the involvement of our broader community partners was focused only on recruitment. The involvement of our community partners in the design and conduct of the study was limited. A community-based participatory approach could have strengthened the study by bringing in community-level insights, shaping the research in more meaningful ways, and fostering stronger engagement with community partners throughout each phase. This approach would ensure that the findings are representative of the needs of equity-deserving communities broadly. Such an approach would bring immense value to the process and could be considered for future studies. Caregivers were not included in the analysis due to insufficient sample. The absence of caregiver perspectives is a limitation, as they could offer a more holistic perspective into the decision-making experiences impacting patients with brain-heart conditions, especially among equity-deserving groups where family involvement is valued. Additionally, the representation of certain equity-deserving groups, particularly gender-diverse and racialized groups, were lower compared to other groups. Despite these limitations, our findings offer valuable insights into the decisional needs of equity-deserving groups and support the findings from the literature review.

## Thesis Conclusion

In my master’s thesis, I examined the decisional needs and decision-making experiences of patients from equity-deserving groups (including ACB) who are diagnosed with or at risk for brain-heart conditions. Through surveys, we found that decisional conflict was a prominent decisional need driven by a lack of support, insufficient information, and communication barriers. In the interviews, we gained deeper insight into the lived experiences of participants and identified nine complex factors that shaped their decision-making experience, each of which could be mapped to the ODSF. They included complexities in finding and understanding health information, emotions, the nature of the decision itself, external influences, access to healthcare services, patient-clinician communication, brain-heart health, trust in care, and personal characteristics. Our findings from both the quantitative and qualitative data revealed a clear need for more integrated brain-heart information and tailored decision support for equity-deserving groups. Research needs to continue to seek ways to promote equitable and tailored approaches brain-heart healthcare. Future research also needs to develop and implement decision support interventions that meets the decisional need of patients from equity-deserving groups.

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## Appendix A

### Data Extraction for Studies Included in the Literature Review

| First Author, Year, Country | Study design | Aim | Participants | Data Collection | Results | Limitations |
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| **Heart** | | | | | | |
| **Breathett**, 2019, USA | Explanatory sequential mixed-methods | Evaluate the impact of race on decisions regarding advanced heart failure treatments. | 1432 clinicians involved in decision making | Quantitative - Participants would rate how much each listed factor impacted their decision using a 10-item Likert scale<br>Qualitative - think aloud Interviews where participants shared the decision-making process and considered a vignette. | Participants raised concerns about social determinants of health and the risk of caregiver burnout, particularly highlighting greater worries about medication adherence. Although there was hesitation in offering a transplant in each scenario, the final recommendations differed depending on the patient's race. | • Survey response rate was low at 29%, which limits the study's generalizability.<br>• Interviewers knew the study's purpose, potentially leading to unintentional emphasis on certain topics during interviews. |
| **Breathett**, 2020, USA | Qualitative - Phenomenology | Investigate whether gender and race influences decision-making for advanced heart failure treatment. | 46 clinicians involved in decision making | Participants were presented with a vignette and were asked to verbalize their thought process using the think-aloud method and completed additional surveys for further insights. | The study uncovered bias based on both gender and race in the decision-making process for offering advanced heart failure therapies. African American women, in particular, were subject to harsher judgments related to their appearance and perceived adequacy of social support | • The use of a single clinical vignette did not capture all possible clinical situations.<br>• Small sample size.<br>• Some participants had previously taken part in a similar study, which may have led to potential Hawthorne effect. |
| **Cuevas**, 2019, USA | Quantitative – Randomized Trial | Examine how medical mistrust and physician mistrust influence patient decision-making and the role of patient- | 231 primary care patients: 101 Black participants with a history of coronary artery disease or a coronary artery bypass graft, or a | Participants initially completed a brief survey assessing medical mistrust. They were then randomly assigned to watch one of 32 standardized video vignettes in which a cardiologist recommends coronary bypass surgery to a patient with angina and three- | Higher medical mistrust was linked to increased physician mistrust and lower support for bypass surgery. In patients exposed to high levels of patient-centered communication, the impact of medical mistrust on physician mistrust and surgery endorsement was less | • The study did not include other influential variables, such as clinician age and patient-perceived social status, which can impact trust.<br>• Study findings did not show a three-way interaction between race, mistrust, and patient centered care levels, potentially due to a small sample size. |

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| | | centered care | close family member or friend with such a history, and 130 White participants | vessel coronary artery disease. | pronounced compared to those exposed to lower levels of patient-centered communication. Black patients reported higher levels of medical mistrust compared to White patients. | |
| **Hopp**, 2014, USA | Qualitative - Phenomenology | Investigates how African Americans with heart failure and their caregivers view hospitalization experiences. | 35 adult participants and caregivers who self-identify as African American | Participants filled out a questionnaire about their heart health using the Kansas City Cardiomyopathy Questionnaire. Caregivers provided demographic details and their self-reported health status. | African Americans with heart failure often use hospital services to monitor their condition, seek medical guidance, and avoid severe outcomes, despite the difficulties of hospitalization. Additionally, the study highlights the significant role of family involvement in their decision-making process. | • Small sample size<br>• Researchers did not directly evaluate the decision-making capacity of heart failure participants involved in the study. |
| **Jackson,** 2024, USA | Qualitative Description | Explore the factors influencing decision making among Black patients that were deciding to receive an implantable cardioverter defibrillator. | 59 Black participants | Participants from a randomized control trial were invited to participate in in-depth interviews. | The key factors influencing decision making among Black patients considering implantable cardioverter defibrillator implantation include clinician recommendations, perceptions of their health, and desire to prolong their life. | • Small sample size<br>• Perspectives from participants might be influenced by their involvement in the randomized control trial |
| **Mann,** 2023, USA | Qualitative description | Uncover the challenges faced by Black patients with atrial fibrillation. | 15 Black participants | Transcripts from four focus group discussions were examined through an inductive coding process to identify recurring themes. | The themes identified include 1) physical and mental burdens associated with their diagnosis, 2) difficulty in atrial fibrillation management, and 3) components required for self-management. | • Small sample size<br>• Participants were recruited from a single-center trial.<br>• Perspectives from participants might be influenced by their involvement in the randomized control trial |
| **Brain** | | | | | | |

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| **Chen**, 2023, USA | Quantitative - Cross-sectional | Explore the level of participation in shared decision-making and the use of mobile health technology in managing health-related activities among American adults with hypertension | This study utilized data from the 2017 to 2020 Health Information National Trends Survey, which surveyed American adults (N=4893) who self-reported having hypertension and provided information on their race and ethnicity. | Shared decision-making was evaluated through the following survey item: “In the past 12 months, how often did your health professional involve you in decisions about your healthcare as much as you wanted?” | Non-Hispanic Black adults were 1.38 times more likely to use mHealth for discussing health decisions (95% CI 1.38-1.87), 1.70 times more likely for making health decisions (95% CI 1.23-2.34), and 1.62 times more likely for engaging in health activities (95% CI 1.13-2.32). They were also 1.90 times more likely to use mHealth for decision-making (95% CI 1.18-3.05) and 1.61 times more likely for health-related decisions (95% CI 1.04-2.49). | • Used a single item to measure shared decision-making<br>• The analysis did not explicitly consider factors like cultural safety, which affect individuals' trust and comfort<br>• As a cross-sectional study, it cannot establish temporal relationships.<br>• The outcomes rely on self-reported hypertension diagnoses, which may have been influenced by participants' understanding of their health status. |
| **Cooper**, 2013, USA | Quantitative - Cluster randomized trial | Assess impact of standard care vs patient-centered, culturally tailored collaborative care interventions for African American patients with depression. | 27 clinicians and 132 African American patients with depression | Patients participated in evaluations at baseline, as well as at 6, 12, and 18 months. These assessments measured depression severity, mental health status, healthcare usage, and patient satisfaction with care. | Patients in the patient-centered collaborative care group showed similar improvements in depression and mental health scores as those in the standard collaborative care group. While treatment rates rose for the standard collaborative care group, only the patient-centered collaborative care group found their care managers more effective in addressing concerns and supporting adherence. | • The cluster design introduces specific challenges related to group comparability<br>• The findings may not generalize to all primary care practices. |
| **Hines**, 2017, USA | Quantitative - Cross-sectional | Assessed the efficacy of informed decision-making during primary care visits for Black | 76 patients diagnosed with depression and 21 primary care clinicians. | Analyzed 76 audiotaped primary care visits and post-visit surveys using the Roter Interaction Analysis System to assess patient-centeredness, informed decision-making, and | About 25% of decisions involved core informed decision-making elements, and 40% included patient-centered decision-making aspects. High patient-centeredness linked informed decision-making to | • Small sample size<br>• Clinicians and patients who opted to participate may differ significantly from those who chose not to participate, potentially introducing bias into the findings.<br>• This study was conducted in a single |

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| | | patients with depression. | | patient-centered decision-making | patients feeling respected and liking clinicians, but informed decision-making did not affect clinician ratings. In lower patient-centered visits, patient-centered decision-making was associated with patients feeling respected and clinicians showing respect. | geographic area in the United States<br>• Patient evaluations of clinicians may be impacted by recall bias, as patients were interviewed two weeks later |
| **Hooper**, 2018, USA | Quantitative - Cross-sectional | Investigated predictors of treatment nonadherence among racially diverse patients | 38 Black American participants, 38 White American participants, 4 biracial participants, and 7 Hispanic or Latino participants. | Participants completed a written survey covering physical and mental health, cultural factors, and experiences with their healthcare providers | The results showed a statistically significant link between treatment nonadherence and two of the study variables: depressive symptoms and the perceived cultural competence of the provider. | • The cross-sectional study design limits the ability to draw conclusions.<br>• Data collection relied on self-reported information<br>• The small sample size. |
| **Jimenez**, 2012, USA | Quantitative – cross-sectional | Explore cultural beliefs regarding the causes of mental illness and treatment preferences across different racial groups. | 1,257 White participants, 536 Black participants, 112 Asian Americans, and 303 Latinos. | Data was collected through the healthcare and mental illness questionnaire, | Differences in beliefs regarding decision-making treatment preferences and desired traits in healthcare providers were noted. | • May not be generalizable to primary care patients with different mental health conditions not described in this study<br>• Latino and Asian American participants were considered as one group<br>• The analysis included multiple comparisons, which raises the risk of Type II errors. |
| **Mayers**, 2024, United Kingdom | Qualitative idiographic | Examine the experiences of Black men regarding decision-making processes in mental health | Five Black men who had been hospitalized for mental health issues. | Data was collected using semi-structured interviews with each participant. | Themes that were found include the importance of medication, family support, and alignment with treatment. Furthermore, participants noted their limited involvement in decisions about their care. | • The COVID-19 pandemic hindered the researchers' ability to gather up-to-date insights regarding the experiences of Black men in inpatient settings. |

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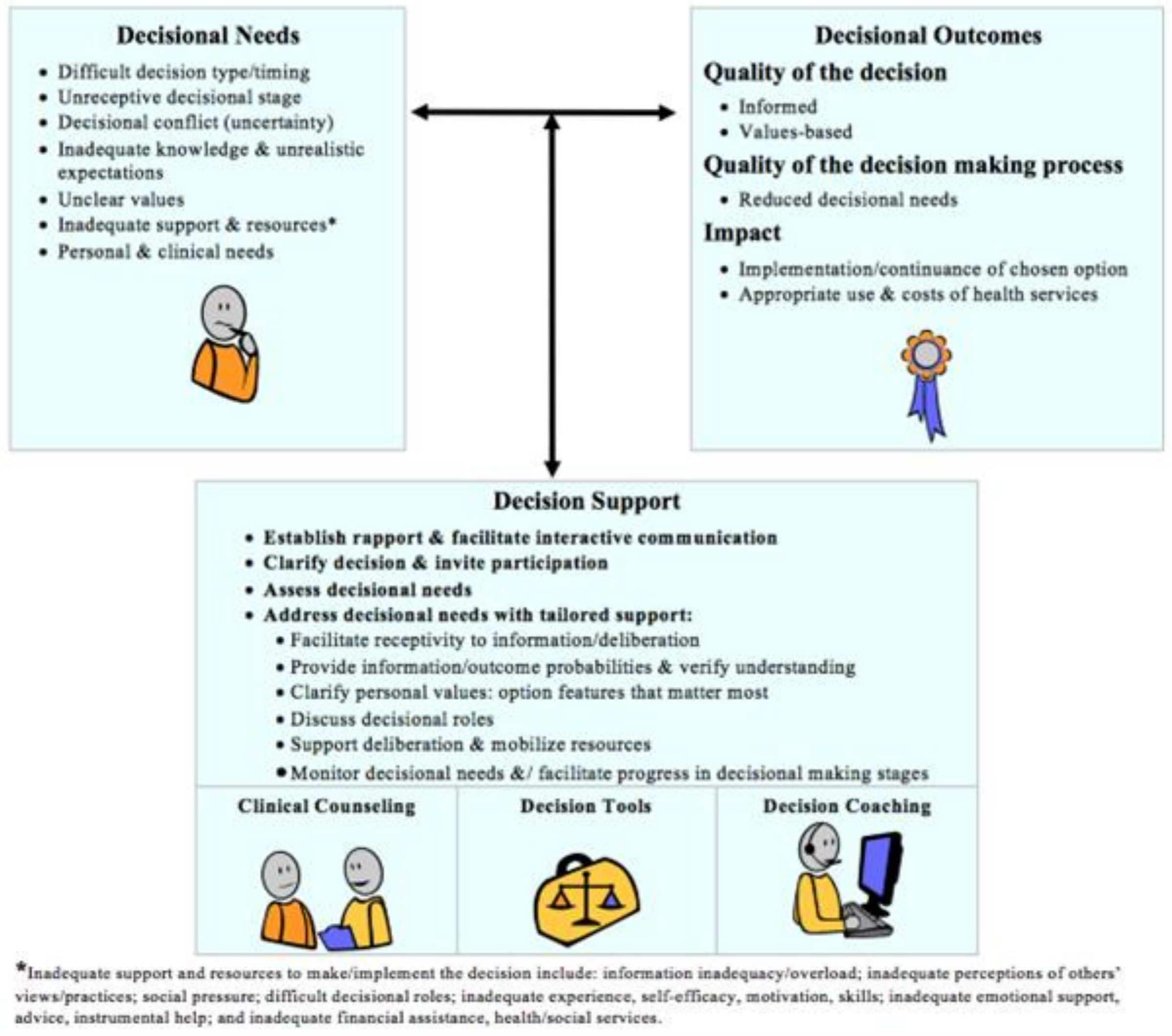
| **Progovac,** 2020, USA | Explanatory sequential mixed-methods | Investigate how past experiences of racism and discrimination in healthcare affect patients with depression in their pursuit of additional care. | 21 adults diagnosed with depression | Data was collected using semi-structured interviews | Twelve participants reported experiencing discrimination in healthcare related to their race/ethnicity, language, social class, or mental health diagnosis. This discrimination intensified obstacles to starting and maintaining treatment for depression. | • Small sample size<br>• The sample was predominantly female<br>• No Black men were interviewed<br>• Implicit biases may have impacted style of communication |
| **Combined Brain-Heart** | | | | | | |
| **Boursiquot,** 2024, USA | Quantitative – Secondary analysis of a prospective randomized trial | Explore the impact of mental health on the decision-making experiences of Black patients eligible for an implantable cardioverter-defibrillator. | 306 adult participants that self-identify as Black and are diagnosed with chronic systolic heart failure (with a left ventricular ejection fraction equal to or less than 35%). | Data was collected through questionnaire to collect baseline data to assess for symptoms of depression prior to their initial appointment, a survey to assess their physical and mental health, and a second questionnaire evaluating decisional conflict one-week post-intervention. | 60 study participants reported experiencing depressed mood and 142 participants reported anhedonia. Those with lower scores on the 12-Item Short-Form Health Survey, indicating poorer mental health and increased risk of depression, experienced greater decisional conflict in regard to the choice to receive an implantable cardioverter-defibrillator. | • The two-item Patient Health Questionnaire used in this study exhibits poor specificity.<br>• The use of antidepressant drugs was not evaluated.<br>• Findings may not be generalizable to other locations. |
| **Brain-Heart Risk Factors** | | | | | | |
| **Chang,** 2021, USA | Quantitative - Retrospective cohort study design | Evaluate the impact of communication and shared decision making between patients diagnosed with | 2571 patients diagnosed with hypertension and self-identify as Black | Participants were given a questionnaire regarding their satisfaction with care. Medication adherence was evaluated by confirming the patient’s antihypertensive medication refill information. | The study findings demonstrated that patient-clinician communication and effective shared decision making are linked to medication adherence among Black patients receiving antihypertensive medications. | • There may be potential confounding variables that were not accounted for<br>• Recall bias may interfere with accuracy of the reported data.<br>• The clinician's perspective regarding the level of shared decision making and communication with their patients were not evaluated. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | hypertension and clinicians on medication adherence. | | | | |
| **Marshall**, 2021, USA | Qualitative - Phenomenology | Determine the efficacy of shared decision-making practices in promoting uptake of thiazides. | 318,720 patients | Participants were interviewed to determine the use of thiazide medication among demographics after receiving the tool. | The analysis showed no change in thiazide usage or blood pressure control for either racial group after the tool was implemented. However, after the tool was removed, there was a slight, statistically significant decrease. Challenges to the tool's implementation included resistance from physicians and pharmacists regarding thiazide use | • Patients may have received their prescriptions from sources outside this healthcare system.<br>• Other racial and ethnic disparities may exist that were not addressed in this analysis. |
| **Peek**, 2010, USA | Qualitative - Phenomenology | Investigated how race might affect patient-clinician shared decision-making in regard to diabetes care. | 51 patients that self-identify as African American were randomly assigned into focus groups. | Recordings from the patient interviews and focus groups were transcribed and coded. | Results demonstrate that barriers to shared decision-making include physician bias, discrimination, and cultural mismatch. Participants also highlighted that mistrust of white physicians, negative attitudes, and internalized racism could impact this process as well. | • This study occurred in only one setting with mainly female participants that were retired.<br>• The findings may not apply to all African Americans with diabetes.<br>• The research relied on a purposeful sample<br>• Additionally, the study did not examine factors such as gender, income, age, diabetes severity, or education. |
| **Ratanawongsa**, 2010, USA | Quantitative – Cross-sectional | Examine impact of race ethnicity on patients' discussions regarding cardiac risk-reduction therapy | 3010 participants were recruited from the National Survey of Medical Decisions. | Data was collected using a survey. | Differences were observed regarding knowledge scores for hyperlipidemia across racial groups in this study. | • Potential response bias<br>• The small representation of minority groups, particularly Hispanic individuals<br>• The research relied on self-reported data<br>• Potential selection bias |
| **Saha,** 2020, USA | Quantitative – Randomized | Explore the impact of | 238 participants | Participants were presented with vignettes involving | Results demonstrate that the African American participants | • Participants were recruited from one setting. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | experimental study | physician-patient race concordance impacts decision making and quality of care | (107 that identify as African American and 131 that -identify as White) diagnosed with coronary artery disease or coronary risk factors | physicians of different ethno-racial backgrounds describing the coronary artery bypass grafting procedure. Participants were then asked to provide a rating on communication, performance, likeability, and decision making. | provided positive ratings for the vignette depicting African American physicians compared to vignettes depicting White physicians. | • Decision making was limited to only one procedure (i.e. the coronary artery bypass procedure), thus limiting the generalizability of the findings. |

# Appendix B

The Ottawa Decision Support Framework (ODSF)



**Decisional Needs**

- Difficult decision type/timing
- Unreceptive decisional stage
- Decisional conflict (uncertainty)
- Inadequate knowledge & unrealistic expectations
- Unclear values
- Inadequate support & resources*
- Personal & clinical needs

**Decisional Outcomes**

**Quality of the decision**

- Informed
- Values-based

**Quality of the decision making process**

- Reduced decisional needs

**Impact**

- Implementation/continuance of chosen option
- Appropriate use & costs of health services

**Decision Support**

- **Establish rapport & facilitate interactive communication**
- **Clarify decision & invite participation**
- **Assess decisional needs**
- **Address decisional needs with tailored support:**
  - Facilitate receptivity to information/deliberation
  - Provide information/outcome probabilities & verify understanding
  - Clarify personal values: option features that matter most
  - Discuss decisional roles
  - Support deliberation & mobilize resources
  - Monitor decisional needs &/ facilitate progress in decisional making stages

*Inadequate support and resources to make/implement the decision include: information inadequacy/overload; inadequate perceptions of others' views/practices; social pressure; difficult decisional roles; inadequate experience, self-efficacy, motivation, skills; inadequate emotional support, advice, instrumental help; and inadequate financial assistance, health/social services.

*Note:* Adapted from "Ottawa Decision Support Framework (ODSF)," by the Patient Decision Aids Research Group, 2020, *The Ottawa Hospital Research Institute* (https://decisionaid-ohri-ca.proxy.bib.uottawa.ca/odsf.html).

# Appendix C

## The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) Guidelines

| Item Category | Checklist Item | Explanation | Have Items Been Met |
|---|---|---|---|
| **Design** | Describe survey design | Describe target population, sample frame. Is the sample a convenience sample? (In "open" surveys this is most likely.) | ☑<br>In chapters three and four, the sample was described under *eligibility*, and the survey design was described under *survey and interview guide* |
| **Institutional Review Board approval and informed consent process** | Institutional Review Board approval | Mention whether the study has been approved by an Institutional Review Board. | ☑<br>In chapter three, ethics approval is described under *confidentiality and privacy.* In chapter 4, it is described under *study design.* |
| | Informed consent | Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study? | ☑<br>In chapters three and four, both informed consent and data protection were described under *recruitment procedures.* |
| | Data protection | If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access. | |
| **Development and pre-testing** | Development and testing | State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire. | ☑<br>In chapters three and four, the development and testing of the open survey were described under *survey and interview guide.* |
| **Recruitment process and description of the sample having access to the questionnaire** | Open survey versus closed survey | An "open survey" is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey). | |
| | Contact mode | Indicate whether or not the initial contact with the potential participants was made on the Internet. | ☑<br>In chapters three and four, how participants were contacted were described under *recruitment procedures.* |
| | Advertising the survey | How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner Advertising the survey ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. The survey announcement should be published as an appendix | ☑<br>In chapters three and four, how the surveys were described under *recruitment procedures.* |
| **Survey administration** | Web/E-mail | State the type of e-survey. If it is an e-mail survey, were the responses entered manually into | ☑ |

| | | | |
|---|---|---|---|
| | | a database, or was there an automatic method for capturing responses? | In chapters three and four, survey administration via REDCap were described under *survey and interview guide.* |
| | Context | Describe the Web site in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally Context looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site | |
| | Mandatory/ voluntary | Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey? | ☑<br>In chapter three, the voluntary nature of the study was described under *confidentiality and privacy.* In chapter four, it was described under *survey and interview guide.* |
| | Incentives | Were any incentives offered (e.g, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)? | ☑<br>In chapters three and four, survey administration via REDCap were described under *recruitment procedures.* |
| | Time/Date | In what timeframe were the data collected? | ☑<br>This is described in the results section in chapter four, under *results.* |
| | Randomization of items | To prevent biases items can be randomized or alternated. | n/a |
| | Adaptive questioning | Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions | ☑<br>In chapter four, adaptive questioning, the number of items per page, and the number of items were described under *survey and interview guide.* |
| | Number of Items | What was the number of questionnaire items per page? The number of items is an important factor for the completion rate. | |
| | Number of screens (pages) | Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate. | |
| | Completeness check | It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if "yes", how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as "not applicable" or "rather not say", and selection of one response option should be enforced. | ☑<br>In chapters three and four, the non-response options, ability for participants to review/change answers, and verifying IP addresses/duplicates were described under *recruitment procedures.* |
| | Review step | State whether respondents were able to review and change their answers | |
| **Response rates** | Unique site visitor | If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both. | |

| | | | |
|---|---|---|---|
| | View rate (Ratio of unique survey visitors/unique site visitors) | Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary. | n/a |
| | Participation rate | Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called “recruitment” rate. | ☑<br>In chapter four, participation and completion rates were described under *recruitment procedures.* |
| | Completion rate | The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate. This is only relevant if there is a separate “informed consent” page or if the survey goes over several pages. This is a measure for attrition. Note that “completion” can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. | |
| **Preventing multiple entries from the same individual** | Cookies used | Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)? | n/a |
| | IP check | Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)? | ☑<br>In chapters three and four, IP address verification and duplicates were described under *recruitment procedures.* |
| | Log file analysis | Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe. | n/a |
| | Registration | In “closed” (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, | n/a |

| | | | |
|---|---|---|---|
| | | which entries were kept for analysis (eg, the first entry or the most recent)? | |
| **Analysis** | Handling of incomplete questionnaires | Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed? | ☑<br>In chapters three and four, handling of missing data were described under *data analysis.* |
| | Questionnaires submitted with an atypical timestamp | Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined. | n/a |
| | Statistical correction | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; please describe the methods. | n/a |

*Note:* Adapted from "Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES)," by G. Eysenbach, 2004, *Journal of Medical Internet Research, 6*(3), p.3. Copyright 2004 by Eysenbach.

## Appendix D

The 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) Guidelines

| Number and Item | Guide question/description | Have Items Been Met |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | ☑<br>In chapters three and four, the research assistant's role in the interviews was described under *recruitment procedures.* The role, credentials, occupation, gender, and experience of the research team are described in the *contribution of collaborators* section of this thesis. |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | |
| 3. Occupation | What was their occupation at the time of the study? | |
| 4. Gender | Was the researcher male or female? | |
| 5. Experience and training | What experience or training did the researcher have? | |
| 6. Relationship established | Was a relationship established prior to study commencement? | n/a |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | ☑<br>In chapters three and four, the purpose of the research and providing participants with the name of the research assistant and PI are described under *recruitment procedures.* |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | ☑<br>The positionality of the research team are discussed under the *contribution of collaborators* section of this thesis. |
| **Domain 2: Study design** | | |
| 9. Methodological orientation and theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | ☑<br>In chapter three, the theoretical underpinnings are described under *theoretical frameworks*. In chapter four, it is discussed under *survey and interview guide.* |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | ☑<br>In chapters three and four, sampling and method of approach are |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | |

| | | |
|---|---|---|
| | | described under *recruitment procedures.* |
| 12. Sample size | How many participants were in the study? | ☑<br>In chapters three and four, sample size is discussed under *sample size.* |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | n/a |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | ☑<br>In chapters three and four, the setting for data collection were described under *recruitment procedures.* |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | n/a |
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | ☑<br>In chapters three and four, the description of the sample is described under *eligibility.* |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | ☑<br>In chapters three and four, the description of the interview guide was described in *surveys and interview guide.* |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | n/a |
| 19. Audio/visual recordings | Did the research use audio or visual recording to collect the data? | ☑<br>In chapters three and four, the description of the interview recordings, absence of field notes, and duration of the interviews are described in *recruitment procedures.* |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | |
| 21. Duration | What was the duration of the interviews or focus group? | |
| 22. Data saturation | Was data saturation discussed? | ☑<br>In chapters three and four, data saturation was discussed under *sample size.* |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | n/a |
| **Domain 3: Analysis and findings** | | |
| 24. Number of data coders | How many data coders coded the data? | ☑ |

| | | |
|---|---|---|
| | | In chapters three and four, the number of coders is described under *data analysis.* |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | ☑<br>In chapter four, the codes and themes are described in the results section under *semi-structured interviews.* |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | |
| 27. Software | What software, if applicable, was used to manage the data? | ☑<br>In chapter four, the software used to manage the data was described under *data analysis.* |
| 28. Participant checking | Did participants provide feedback on the findings? | n/a |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number | ☑<br>In chapter four, the quotations and participant numbers are provided under *semi-structured interviews.* |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | ☑<br>In chapter four, all codes and themes are presented and integrated to the quantitative findings in the results section. |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | |

*Note:* Adapted from “Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups,” by A. Tong, P. Sainsbury, & J.Craig, 2007, *International Journal for Quality in Health Care*, *19*(6), p.4. Copyright 2007 by Tong.

## Appendix E

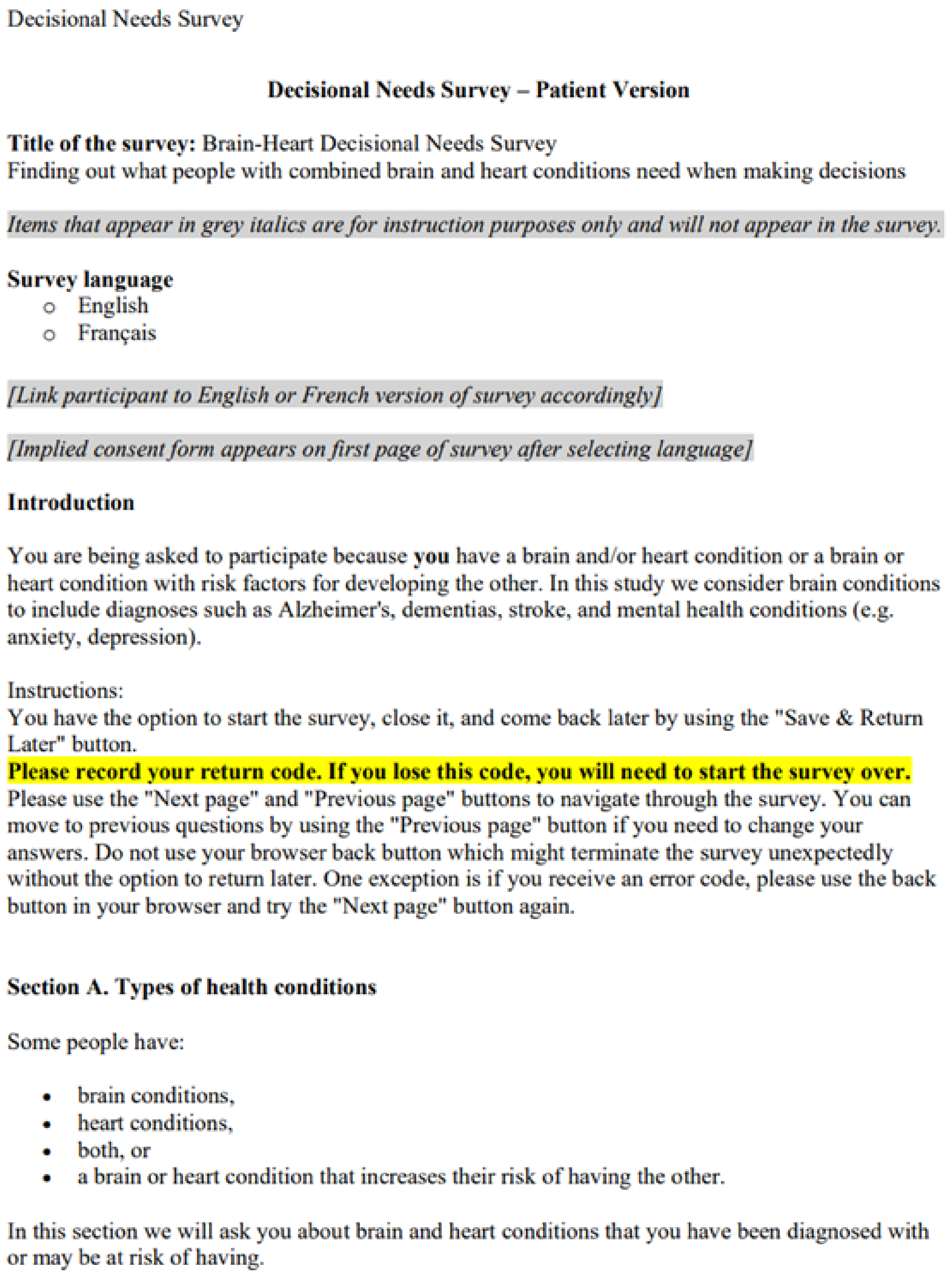
The Good Reporting of a Mixed Methods Study (GRAMMS) Guidelines

| Checklist Item | Have Items Been Met |
|---|---|
| 1. Describe the justification for using a mixed methods approach to the research question | ☑<br>In chapters three and four, the justification for using an explanatory sequential mixed methods design and its description is discussed under *study design.* |
| 2. Describe the design in terms of the purpose, priority and sequence of methods | |
| 3. Describe each method in terms of sampling, data collection and analysis | ☑<br>In chapters three and four, the sampling, data collection, and analysis are described in the *methods* section. |
| 4. Describe where integration has occurred, how it has occurred and who has participated in it | ☑<br>In chapter three , data integration was described under the *data integration* section. In chapter four, it was discussed under *data analysis.* |
| 5. Describe any limitation of one method associated with the presence of the other method | ☑<br>In chapter four, the limitations for this mixed-methods study and the insights gained are described in the *discussion* section. |
| 6. Describe any insights gained from mixing or integrating methods | |

*Note:* Adapted from “The quality of mixed methods studies in health services research,” by A. O’Cathain, E. Murphy, & J. Nicholl, 2008, *Journal of Health Services Research & Policy*, *13*(2), p.92-98. Copyright 2008 by O’Cathain.

# Appendix F

## Decisional Needs Survey



Decisional Needs Survey

### Decisional Needs Survey – Patient Version

**Title of the survey:** Brain-Heart Decisional Needs Survey
Finding out what people with combined brain and heart conditions need when making decisions

*Items that appear in grey italics are for instruction purposes only and will not appear in the survey.*

**Survey language**

- ○ English
- ○ Français

*[Link participant to English or French version of survey accordingly]*

*[Implied consent form appears on first page of survey after selecting language]*

**Introduction**

You are being asked to participate because **you** have a brain and/or heart condition or a brain or heart condition with risk factors for developing the other. In this study we consider brain conditions to include diagnoses such as Alzheimer's, dementias, stroke, and mental health conditions (e.g. anxiety, depression).

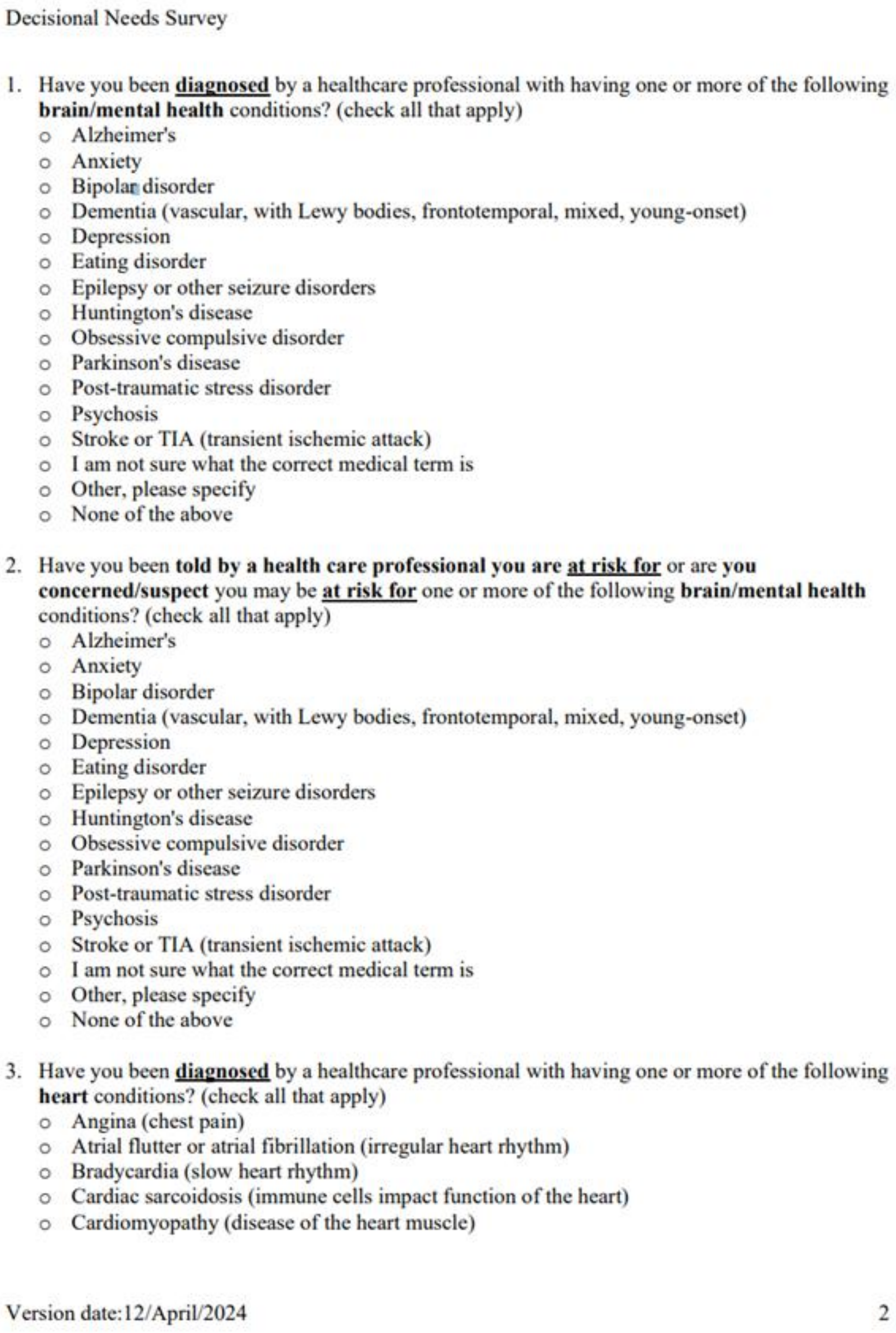
Instructions:
You have the option to start the survey, close it, and come back later by using the "Save & Return Later" button.
**Please record your return code. If you lose this code, you will need to start the survey over.**
Please use the "Next page" and "Previous page" buttons to navigate through the survey. You can move to previous questions by using the "Previous page" button if you need to change your answers. Do not use your browser back button which might terminate the survey unexpectedly without the option to return later. One exception is if you receive an error code, please use the back button in your browser and try the "Next page" button again.

**Section A. Types of health conditions**

Some people have:

- brain conditions,
- heart conditions,
- both, or
- a brain or heart condition that increases their risk of having the other.

In this section we will ask you about brain and heart conditions that you have been diagnosed with or may be at risk of having.



Decisional Needs Survey

1. Have you been **<u>diagnosed</u>** by a healthcare professional with having one or more of the following **brain/mental health** conditions? (check all that apply)
   - ○ Alzheimer's
   - ○ Anxiety
   - ○ Bipolar disorder
   - ○ Dementia (vascular, with Lewy bodies, frontotemporal, mixed, young-onset)
   - ○ Depression
   - ○ Eating disorder
   - ○ Epilepsy or other seizure disorders
   - ○ Huntington's disease
   - ○ Obsessive compulsive disorder
   - ○ Parkinson's disease
   - ○ Post-traumatic stress disorder
   - ○ Psychosis
   - ○ Stroke or TIA (transient ischemic attack)
   - ○ I am not sure what the correct medical term is
   - ○ Other, please specify
   - ○ None of the above

2. Have you been **told by a health care professional you are <u>at risk for</u>** or are **you concerned/suspect** you may be **<u>at risk for</u>** one or more of the following **brain/mental health** conditions? (check all that apply)
   - ○ Alzheimer's
   - ○ Anxiety
   - ○ Bipolar disorder
   - ○ Dementia (vascular, with Lewy bodies, frontotemporal, mixed, young-onset)
   - ○ Depression
   - ○ Eating disorder
   - ○ Epilepsy or other seizure disorders
   - ○ Huntington's disease
   - ○ Obsessive compulsive disorder
   - ○ Parkinson's disease
   - ○ Post-traumatic stress disorder
   - ○ Psychosis
   - ○ Stroke or TIA (transient ischemic attack)
   - ○ I am not sure what the correct medical term is
   - ○ Other, please specify
   - ○ None of the above

3. Have you been **<u>diagnosed</u>** by a healthcare professional with having one or more of the following **heart** conditions? (check all that apply)
   - ○ Angina (chest pain)
   - ○ Atrial flutter or atrial fibrillation (irregular heart rhythm)
   - ○ Bradycardia (slow heart rhythm)
   - ○ Cardiac sarcoidosis (immune cells impact function of the heart)
   - ○ Cardiomyopathy (disease of the heart muscle)

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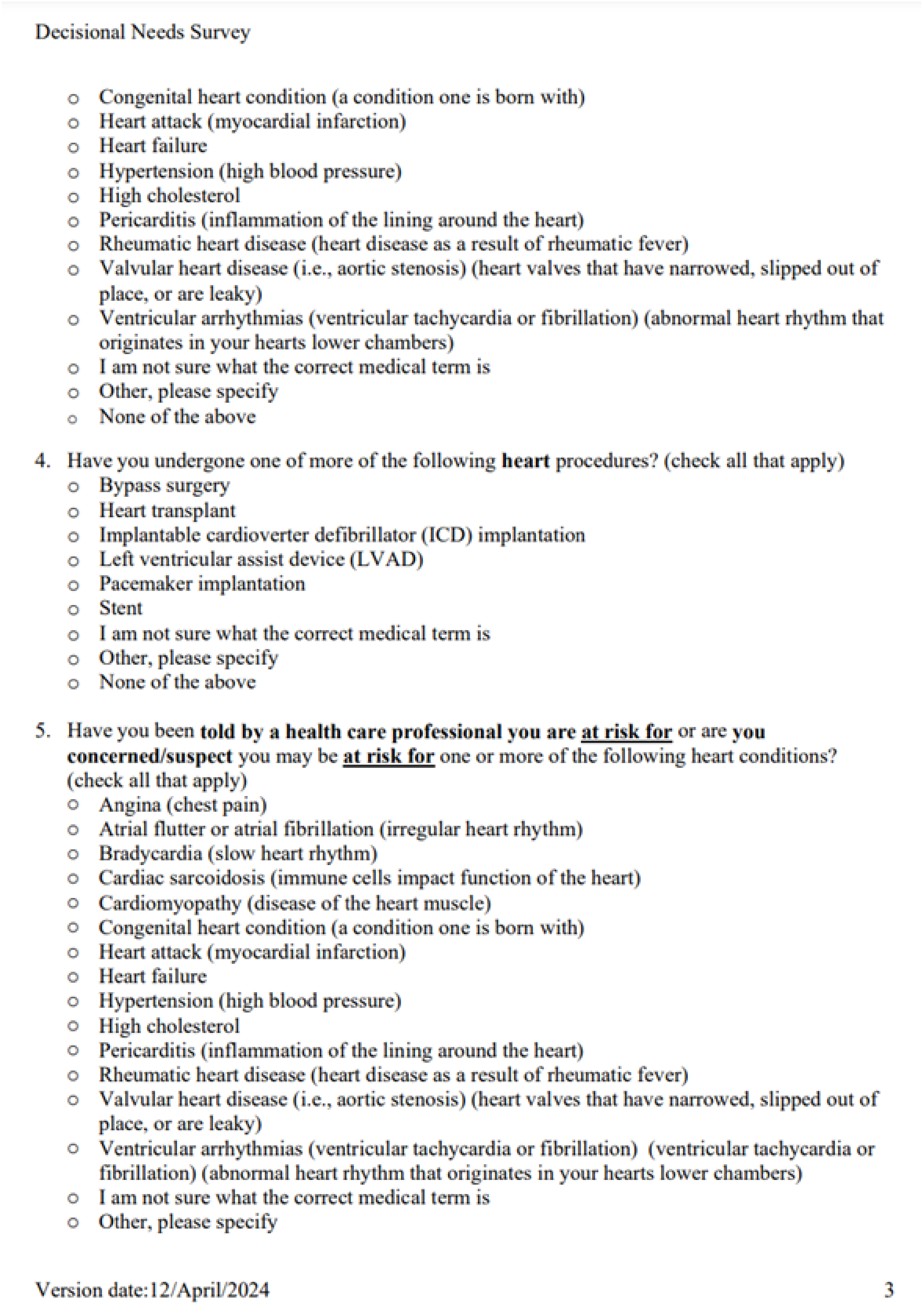


Decisional Needs Survey

- ○ Congenital heart condition (a condition one is born with)
- ○ Heart attack (myocardial infarction)
- ○ Heart failure
- ○ Hypertension (high blood pressure)
- ○ High cholesterol
- ○ Pericarditis (inflammation of the lining around the heart)
- ○ Rheumatic heart disease (heart disease as a result of rheumatic fever)
- ○ Valvular heart disease (i.e., aortic stenosis) (heart valves that have narrowed, slipped out of place, or are leaky)
- ○ Ventricular arrhythmias (ventricular tachycardia or fibrillation) (abnormal heart rhythm that originates in your hearts lower chambers)
- ○ I am not sure what the correct medical term is
- ○ Other, please specify
- ○ None of the above

4. Have you undergone one of more of the following **heart** procedures? (check all that apply)
    - ○ Bypass surgery
    - ○ Heart transplant
    - ○ Implantable cardioverter defibrillator (ICD) implantation
    - ○ Left ventricular assist device (LVAD)
    - ○ Pacemaker implantation
    - ○ Stent
    - ○ I am not sure what the correct medical term is
    - ○ Other, please specify
    - ○ None of the above

5. Have you been **told by a health care professional you are <u>at risk for</u>** or are **you concerned/suspect** you may be **<u>at risk for</u>** one or more of the following heart conditions? (check all that apply)
    - ○ Angina (chest pain)
    - ○ Atrial flutter or atrial fibrillation (irregular heart rhythm)
    - ○ Bradycardia (slow heart rhythm)
    - ○ Cardiac sarcoidosis (immune cells impact function of the heart)
    - ○ Cardiomyopathy (disease of the heart muscle)
    - ○ Congenital heart condition (a condition one is born with)
    - ○ Heart attack (myocardial infarction)
    - ○ Heart failure
    - ○ Hypertension (high blood pressure)
    - ○ High cholesterol
    - ○ Pericarditis (inflammation of the lining around the heart)
    - ○ Rheumatic heart disease (heart disease as a result of rheumatic fever)
    - ○ Valvular heart disease (i.e., aortic stenosis) (heart valves that have narrowed, slipped out of place, or are leaky)
    - ○ Ventricular arrhythmias (ventricular tachycardia or fibrillation) (ventricular tachycardia or fibrillation) (abnormal heart rhythm that originates in your hearts lower chambers)
    - ○ I am not sure what the correct medical term is
    - ○ Other, please specify

Version date:12/April/2024 3

- ○ None of the above

6. Have you been **told by a health care professional you are eligible for** or **do you think you may be eligible** for one or more of the following **heart** procedures? (check all that apply)
   - ○ Bypass surgery
   - ○ Heart transplant
   - ○ Implantable cardioverter defibrillator (ICD) implantation
   - ○ Left ventricular assist device (LVAD)
   - ○ Pacemaker implantation
   - ○ Stent
   - ○ I am not sure what the correct medical term is
   - ○ Other, please specify
   - ○ None of the above

**Section B. Decisional needs assessment**

In this section, we will ask you about tough health decisions that you are facing or have made in the last year about your brain and/or heart health.

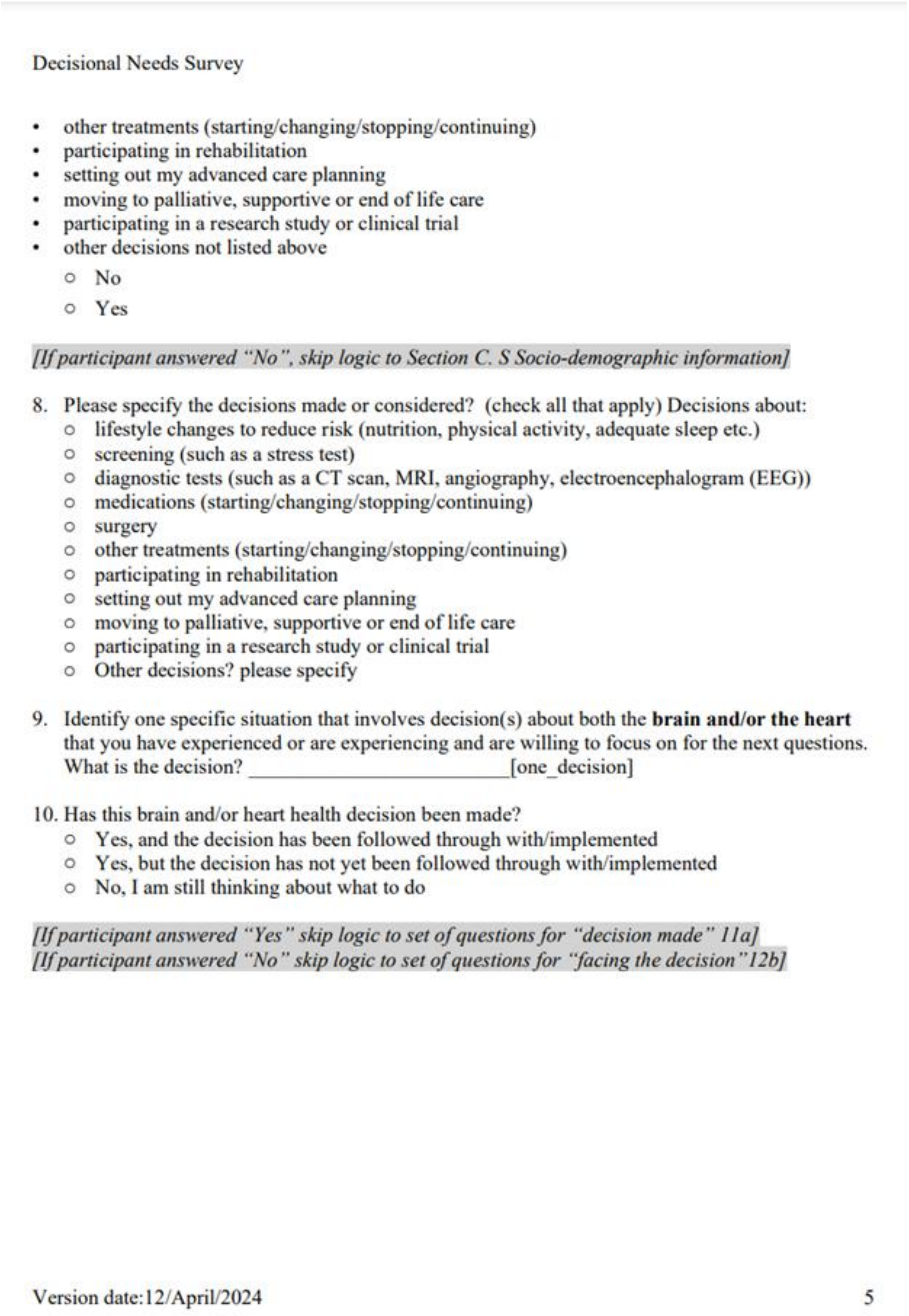
Definition of a tough decision:
A decision is tough when there is more than one option and there is no clear best option. For this type of decision, your chosen option will depend on your personal situation and the pros and the cons of the possible options. When faced with a tough decision, people often discuss it with a healthcare professional (e.g. doctor, nurse, social worker), family member, or a friend. Brain and heart-related decisions can be tough, and even further complicated by many interrelated decisions that follow over time, often involving different people and health care teams.

**Box 1. Examples of tough brain and heart health decisions**

- Deciding to undergo a catheter ablation to minimize atrial fibrillation episodes given the increased risk of stroke and dementia of that condition
- Deciding to start a new course of medications for my brain condition that may not be compatible with my medications for my heart condition
- Deciding to start cardiac rehabilitation while undergoing treatment for depression and heart failure

7. In the last year, have any decisions been made or considered about your brain and/or heart health?

For example:
- lifestyle changes to reduce risk (nutrition, physical activity, adequate sleep etc.)
- screening (such as a stress test)
- diagnostic tests (such as a CT scan, MRI, angiography, electroencephalogram (EEG))
- medications (starting/changing/stopping/continuing)
- surgery



- other treatments (starting/changing/stopping/continuing)
- participating in rehabilitation
- setting out my advanced care planning
- moving to palliative, supportive or end of life care
- participating in a research study or clinical trial
- other decisions not listed above
  - ○ No
  - ○ Yes

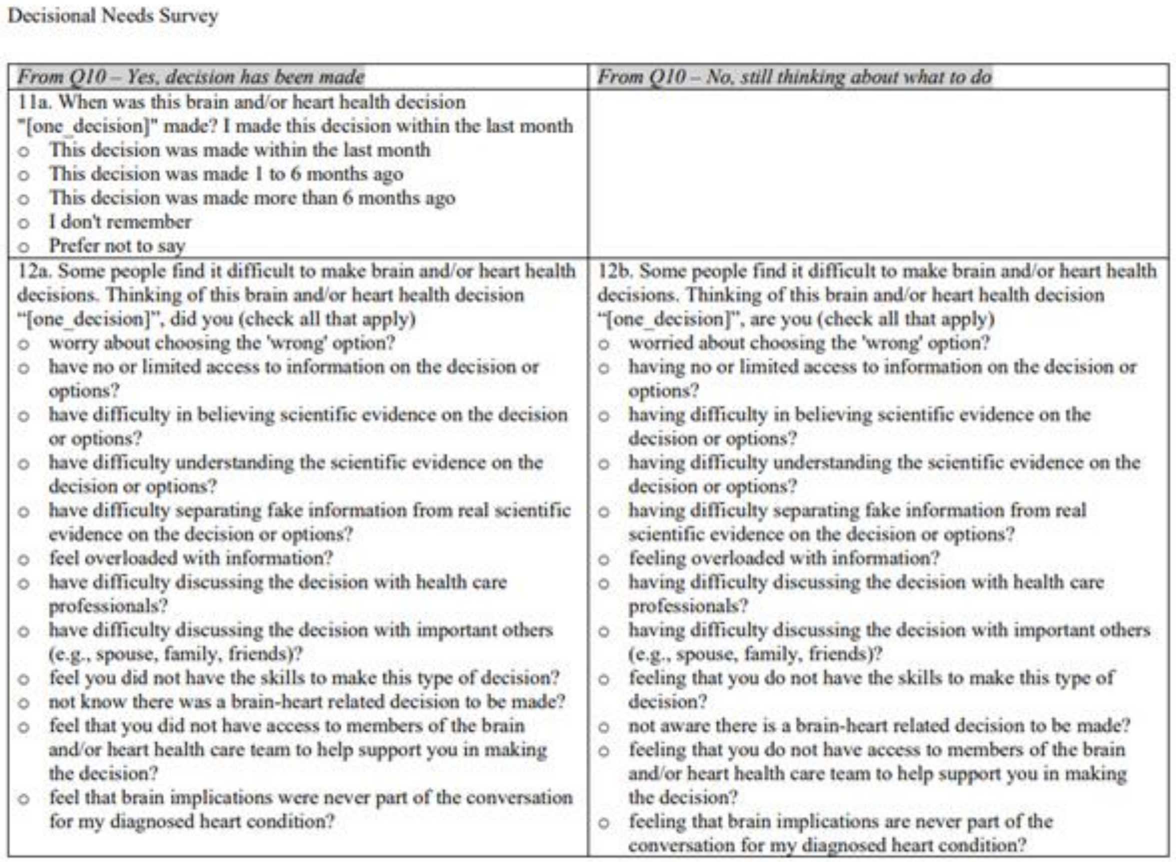
*[If participant answered "No", skip logic to Section C. S Socio-demographic information]*

8. Please specify the decisions made or considered? (check all that apply) Decisions about:
   - ○ lifestyle changes to reduce risk (nutrition, physical activity, adequate sleep etc.)
   - ○ screening (such as a stress test)
   - ○ diagnostic tests (such as a CT scan, MRI, angiography, electroencephalogram (EEG))
   - ○ medications (starting/changing/stopping/continuing)
   - ○ surgery
   - ○ other treatments (starting/changing/stopping/continuing)
   - ○ participating in rehabilitation
   - ○ setting out my advanced care planning
   - ○ moving to palliative, supportive or end of life care
   - ○ participating in a research study or clinical trial
   - ○ Other decisions? please specify

9. Identify one specific situation that involves decision(s) about both the **brain and/or the heart** that you have experienced or are experiencing and are willing to focus on for the next questions. What is the decision? _________________________[one_decision]

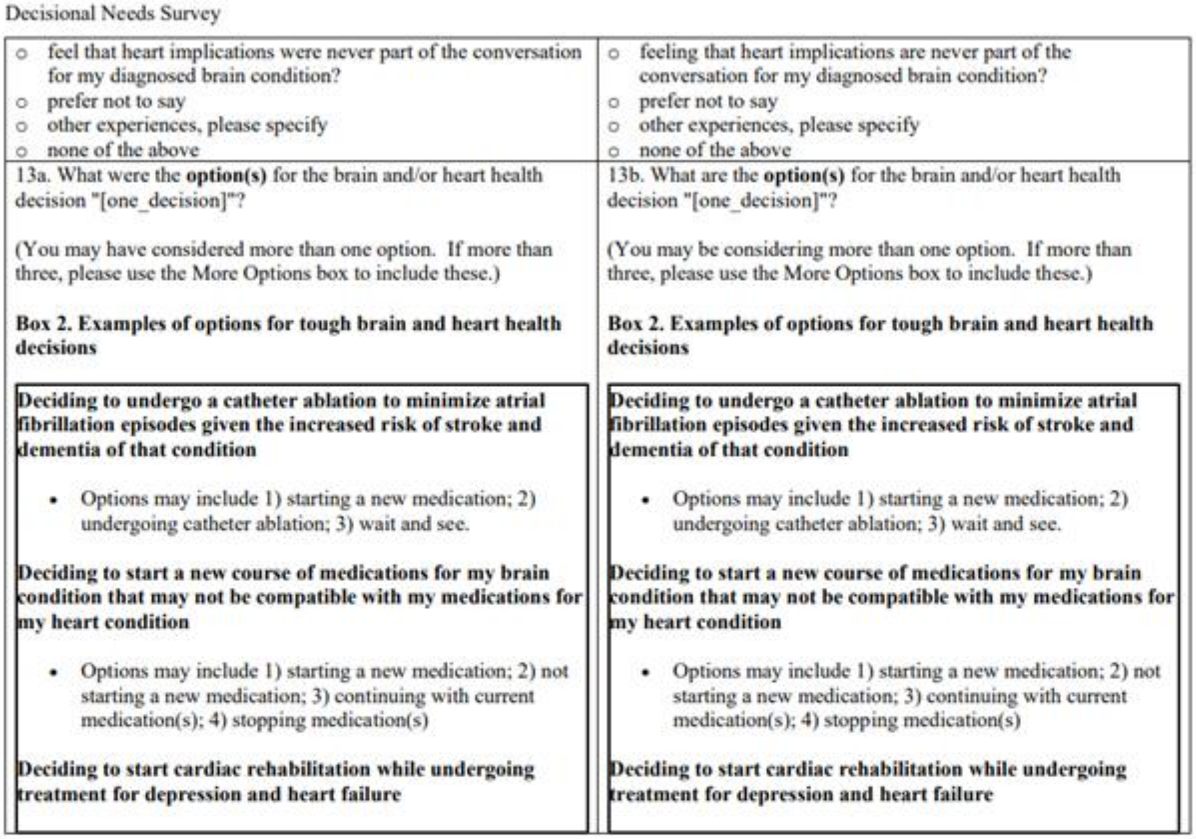
10. Has this brain and/or heart health decision been made?
    - ○ Yes, and the decision has been followed through with/implemented
    - ○ Yes, but the decision has not yet been followed through with/implemented
    - ○ No, I am still thinking about what to do

*[If participant answered "Yes" skip logic to set of questions for "decision made" 11a]*
*[If participant answered "No" skip logic to set of questions for "facing the decision" 12b]*



Decisional Needs Survey

| *From Q10 – Yes, decision has been made* | *From Q10 – No, still thinking about what to do* |
|---|---|
| 11a. When was this brain and/or heart health decision "[one_decision]" made? I made this decision within the last month<br>○ This decision was made within the last month<br>○ This decision was made 1 to 6 months ago<br>○ This decision was made more than 6 months ago<br>○ I don't remember<br>○ Prefer not to say | |
| 12a. Some people find it difficult to make brain and/or heart health decisions. Thinking of this brain and/or heart health decision "[one_decision]", did you (check all that apply)<br>○ worry about choosing the 'wrong' option?<br>○ have no or limited access to information on the decision or options?<br>○ have difficulty in believing scientific evidence on the decision or options?<br>○ have difficulty understanding the scientific evidence on the decision or options?<br>○ have difficulty separating fake information from real scientific evidence on the decision or options?<br>○ feel overloaded with information?<br>○ have difficulty discussing the decision with health care professionals?<br>○ have difficulty discussing the decision with important others (e.g., spouse, family, friends)?<br>○ feel you did not have the skills to make this type of decision?<br>○ not know there was a brain-heart related decision to be made?<br>○ feel that you did not have access to members of the brain and/or heart health care team to help support you in making the decision?<br>○ feel that brain implications were never part of the conversation for my diagnosed heart condition? | 12b. Some people find it difficult to make brain and/or heart health decisions. Thinking of this brain and/or heart health decision "[one_decision]", are you (check all that apply)<br>○ worried about choosing the 'wrong' option?<br>○ having no or limited access to information on the decision or options?<br>○ having difficulty in believing scientific evidence on the decision or options?<br>○ having difficulty understanding the scientific evidence on the decision or options?<br>○ having difficulty separating fake information from real scientific evidence on the decision or options?<br>○ feeling overloaded with information?<br>○ having difficulty discussing the decision with health care professionals?<br>○ having difficulty discussing the decision with important others (e.g., spouse, family, friends)?<br>○ feeling that you do not have the skills to make this type of decision?<br>○ not aware there is a brain-heart related decision to be made?<br>○ feeling that you do not have access to members of the brain and/or heart health care team to help support you in making the decision?<br>○ feeling that brain implications are never part of the conversation for my diagnosed heart condition? |



Decisional Needs Survey

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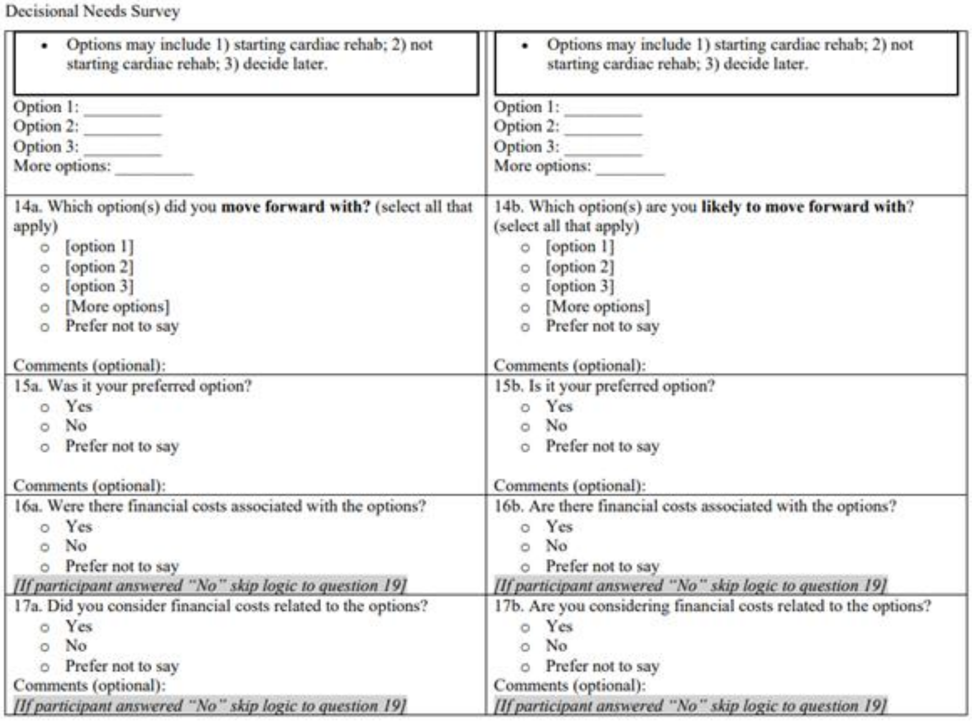
| ○ feel that heart implications were never part of the conversation for my diagnosed brain condition?<br>○ prefer not to say<br>○ other experiences, please specify<br>○ none of the above | ○ feeling that heart implications are never part of the conversation for my diagnosed brain condition?<br>○ prefer not to say<br>○ other experiences, please specify<br>○ none of the above |
| 13a. What were the **option(s)** for the brain and/or heart health decision "[one_decision]"?<br>(You may have considered more than one option. If more than three, please use the More Options box to include these.)<br>**Box 2. Examples of options for tough brain and heart health decisions**<br>**Deciding to undergo a catheter ablation to minimize atrial fibrillation episodes given the increased risk of stroke and dementia of that condition**<br>• Options may include 1) starting a new medication; 2) undergoing catheter ablation; 3) wait and see.<br>**Deciding to start a new course of medications for my brain condition that may not be compatible with my medications for my heart condition**<br>• Options may include 1) starting a new medication; 2) not starting a new medication; 3) continuing with current medication(s); 4) stopping medication(s)<br>**Deciding to start cardiac rehabilitation while undergoing treatment for depression and heart failure** | 13b. What are the **option(s)** for the brain and/or heart health decision "[one_decision]"?<br>(You may be considering more than one option. If more than three, please use the More Options box to include these.)<br>**Box 2. Examples of options for tough brain and heart health decisions**<br>**Deciding to undergo a catheter ablation to minimize atrial fibrillation episodes given the increased risk of stroke and dementia of that condition**<br>• Options may include 1) starting a new medication; 2) undergoing catheter ablation; 3) wait and see.<br>**Deciding to start a new course of medications for my brain condition that may not be compatible with my medications for my heart condition**<br>• Options may include 1) starting a new medication; 2) not starting a new medication; 3) continuing with current medication(s); 4) stopping medication(s)<br>**Deciding to start cardiac rehabilitation while undergoing treatment for depression and heart failure** |



Decisional Needs Survey

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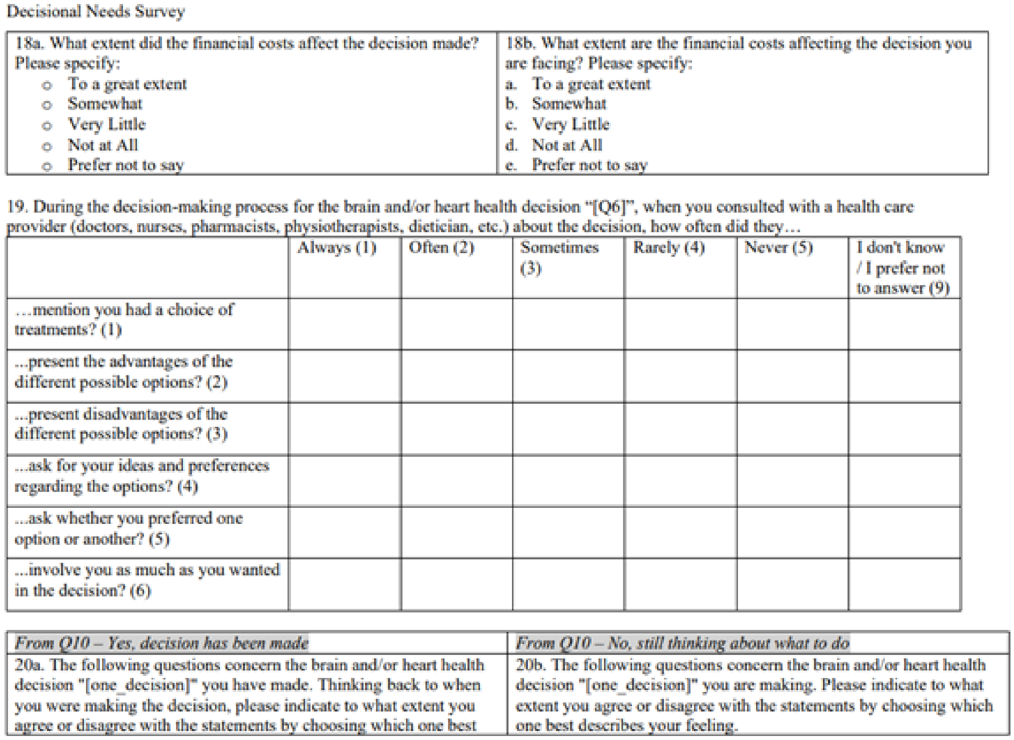
| • Options may include 1) starting cardiac rehab; 2) not starting cardiac rehab; 3) decide later. | • Options may include 1) starting cardiac rehab; 2) not starting cardiac rehab; 3) decide later. |
| Option 1: ________<br>Option 2: ________<br>Option 3: ________<br>More options: ________ | Option 1: ________<br>Option 2: ________<br>Option 3: ________<br>More options: ________ |
| 14a. Which option(s) did you **move forward with?** (select all that apply)<br>○ [option 1]<br>○ [option 2]<br>○ [option 3]<br>○ [More options]<br>○ Prefer not to say<br>Comments (optional): | 14b. Which option(s) are you **likely to move forward with**? (select all that apply)<br>○ [option 1]<br>○ [option 2]<br>○ [option 3]<br>○ [More options]<br>○ Prefer not to say<br>Comments (optional): |
| 15a. Was it your preferred option?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>Comments (optional): | 15b. Is it your preferred option?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>Comments (optional): |
| 16a. Were there financial costs associated with the options?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>*[If participant answered "No" skip logic to question 19]* | 16b. Are there financial costs associated with the options?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>*[If participant answered "No" skip logic to question 19]* |
| 17a. Did you consider financial costs related to the options?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>Comments (optional):<br>*[If participant answered "No" skip logic to question 19]* | 17b. Are you considering financial costs related to the options?<br>○ Yes<br>○ No<br>○ Prefer not to say<br>Comments (optional):<br>*[If participant answered "No" skip logic to question 19]* |



Decisional Needs Survey

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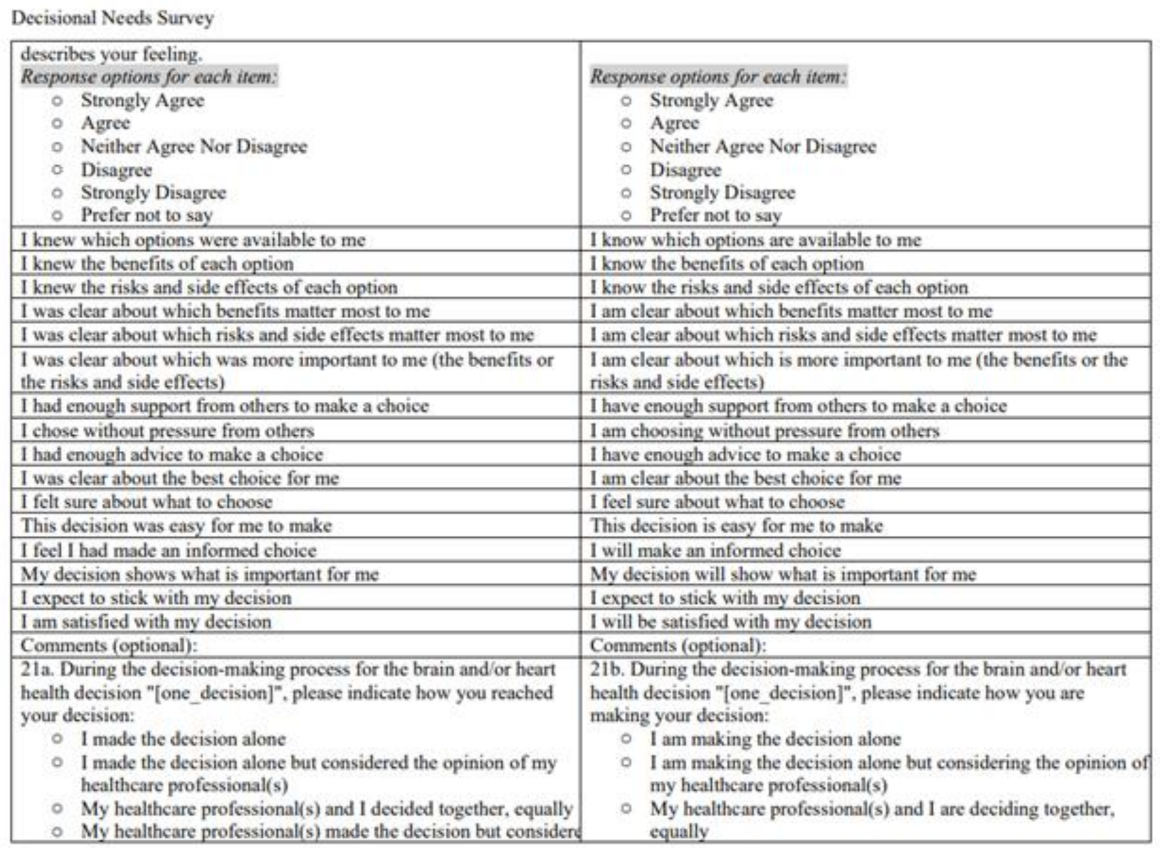
| 18a. What extent did the financial costs affect the decision made? Please specify:<br>○ To a great extent<br>○ Somewhat<br>○ Very Little<br>○ Not at All<br>○ Prefer not to say | 18b. What extent are the financial costs affecting the decision you are facing? Please specify:<br>a. To a great extent<br>b. Somewhat<br>c. Very Little<br>d. Not at All<br>e. Prefer not to say |

19. During the decision-making process for the brain and/or heart health decision "[Q6]", when you consulted with a health care provider (doctors, nurses, pharmacists, physiotherapists, dietician, etc.) about the decision, how often did they…

| | Always (1) | Often (2) | Sometimes (3) | Rarely (4) | Never (5) | I don't know / I prefer not to answer (9) |
|---|---|---|---|---|---|---|
| …mention you had a choice of treatments? (1) | | | | | | |
| ...present the advantages of the different possible options? (2) | | | | | | |
| ...present disadvantages of the different possible options? (3) | | | | | | |
| ...ask for your ideas and preferences regarding the options? (4) | | | | | | |
| ...ask whether you preferred one option or another? (5) | | | | | | |
| ...involve you as much as you wanted in the decision? (6) | | | | | | |

| *From Q10 – Yes, decision has been made* | *From Q10 – No, still thinking about what to do* |
|---|---|
| 20a. The following questions concern the brain and/or heart health decision "[one_decision]" you have made. Thinking back to when you were making the decision, please indicate to what extent you agree or disagree with the statements by choosing which one best | 20b. The following questions concern the brain and/or heart health decision "[one_decision]" you are making. Please indicate to what extent you agree or disagree with the statements by choosing which one best describes your feeling. |



Decisional Needs Survey

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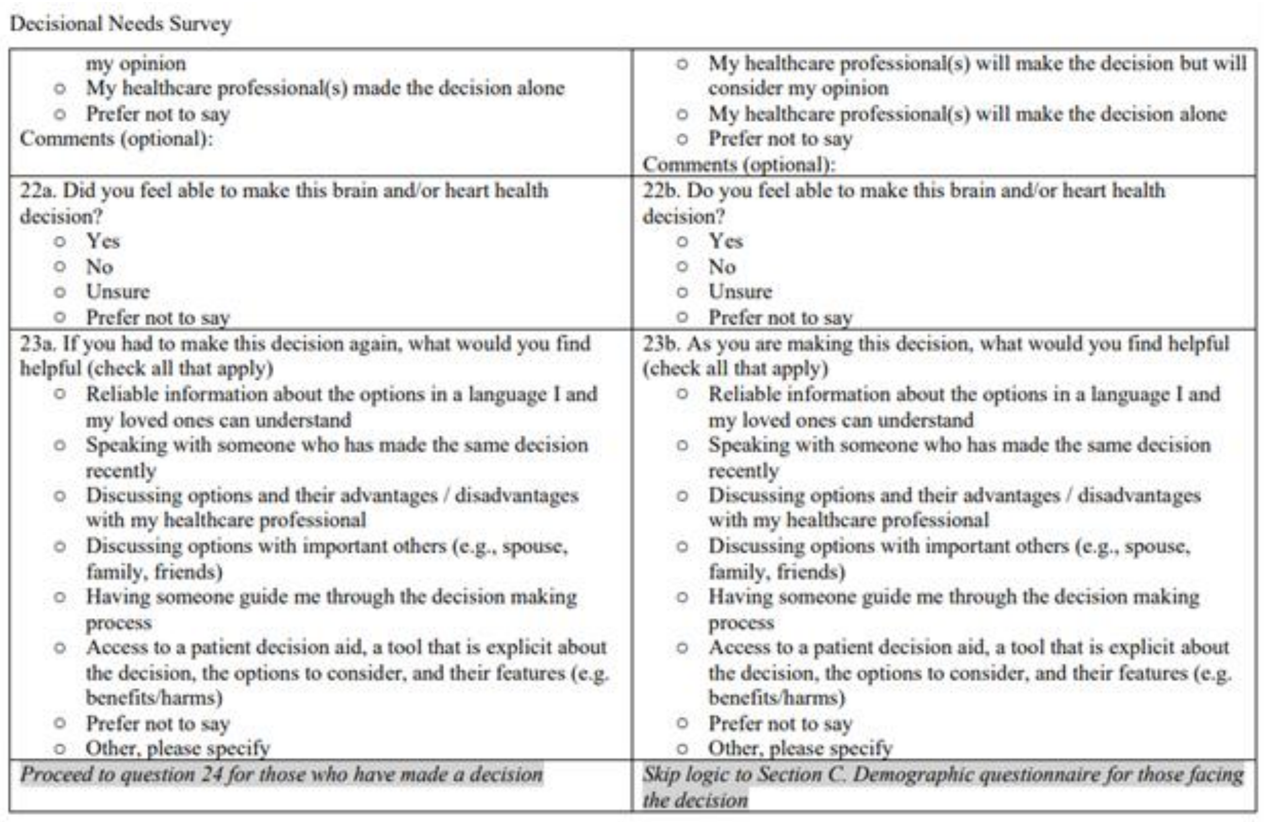
| describes your feeling.<br>*Response options for each item:*<br>○ Strongly Agree<br>○ Agree<br>○ Neither Agree Nor Disagree<br>○ Disagree<br>○ Strongly Disagree<br>○ Prefer not to say | *Response options for each item:*<br>○ Strongly Agree<br>○ Agree<br>○ Neither Agree Nor Disagree<br>○ Disagree<br>○ Strongly Disagree<br>○ Prefer not to say |
| I knew which options were available to me | I know which options are available to me |
| I knew the benefits of each option | I know the benefits of each option |
| I knew the risks and side effects of each option | I know the risks and side effects of each option |
| I was clear about which benefits matter most to me | I am clear about which benefits matter most to me |
| I was clear about which risks and side effects matter most to me | I am clear about which risks and side effects matter most to me |
| I was clear about which was more important to me (the benefits or the risks and side effects) | I am clear about which is more important to me (the benefits or the risks and side effects) |
| I had enough support from others to make a choice | I have enough support from others to make a choice |
| I chose without pressure from others | I am choosing without pressure from others |
| I had enough advice to make a choice | I have enough advice to make a choice |
| I was clear about the best choice for me | I am clear about the best choice for me |
| I felt sure about what to choose | I feel sure about what to choose |
| This decision was easy for me to make | This decision is easy for me to make |
| I feel I had made an informed choice | I will make an informed choice |
| My decision shows what is important for me | My decision will show what is important for me |
| I expect to stick with my decision | I expect to stick with my decision |
| I am satisfied with my decision | I will be satisfied with my decision |
| Comments (optional): | Comments (optional): |
| 21a. During the decision-making process for the brain and/or heart health decision "[one_decision]", please indicate how you reached your decision:<br>○ I made the decision alone<br>○ I made the decision alone but considered the opinion of my healthcare professional(s)<br>○ My healthcare professional(s) and I decided together, equally<br>○ My healthcare professional(s) made the decision but considere | 21b. During the decision-making process for the brain and/or heart health decision "[one_decision]", please indicate how you are making your decision:<br>○ I am making the decision alone<br>○ I am making the decision alone but considering the opinion of my healthcare professional(s)<br>○ My healthcare professional(s) and I are deciding together, equally |



Decisional Needs Survey

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|---|---|
| my opinion<br>○ My healthcare professional(s) made the decision alone<br>○ Prefer not to say<br>Comments (optional): | ○ My healthcare professional(s) will make the decision but will consider my opinion<br>○ My healthcare professional(s) will make the decision alone<br>○ Prefer not to say<br>Comments (optional): |
| 22a. Did you feel able to make this brain and/or heart health decision?<br>○ Yes<br>○ No<br>○ Unsure<br>○ Prefer not to say | 22b. Do you feel able to make this brain and/or heart health decision?<br>○ Yes<br>○ No<br>○ Unsure<br>○ Prefer not to say |
| 23a. If you had to make this decision again, what would you find helpful (check all that apply)<br>○ Reliable information about the options in a language I and my loved ones can understand<br>○ Speaking with someone who has made the same decision recently<br>○ Discussing options and their advantages / disadvantages with my healthcare professional<br>○ Discussing options with important others (e.g., spouse, family, friends)<br>○ Having someone guide me through the decision making process<br>○ Access to a patient decision aid, a tool that is explicit about the decision, the options to consider, and their features (e.g. benefits/harms)<br>○ Prefer not to say<br>○ Other, please specify | 23b. As you are making this decision, what would you find helpful (check all that apply)<br>○ Reliable information about the options in a language I and my loved ones can understand<br>○ Speaking with someone who has made the same decision recently<br>○ Discussing options and their advantages / disadvantages with my healthcare professional<br>○ Discussing options with important others (e.g., spouse, family, friends)<br>○ Having someone guide me through the decision making process<br>○ Access to a patient decision aid, a tool that is explicit about the decision, the options to consider, and their features (e.g. benefits/harms)<br>○ Prefer not to say<br>○ Other, please specify |
| *Proceed to question 24 for those who have made a decision* | *Skip logic to Section C. Demographic questionnaire for those facing the decision* |

Decisional Needs Survey

24. Now please think about the brain and/or heart health decision "[one_decision]" you made. Indicate whether you agree or disagree with the following statements by choosing which one that best represents your opinion about this decision.

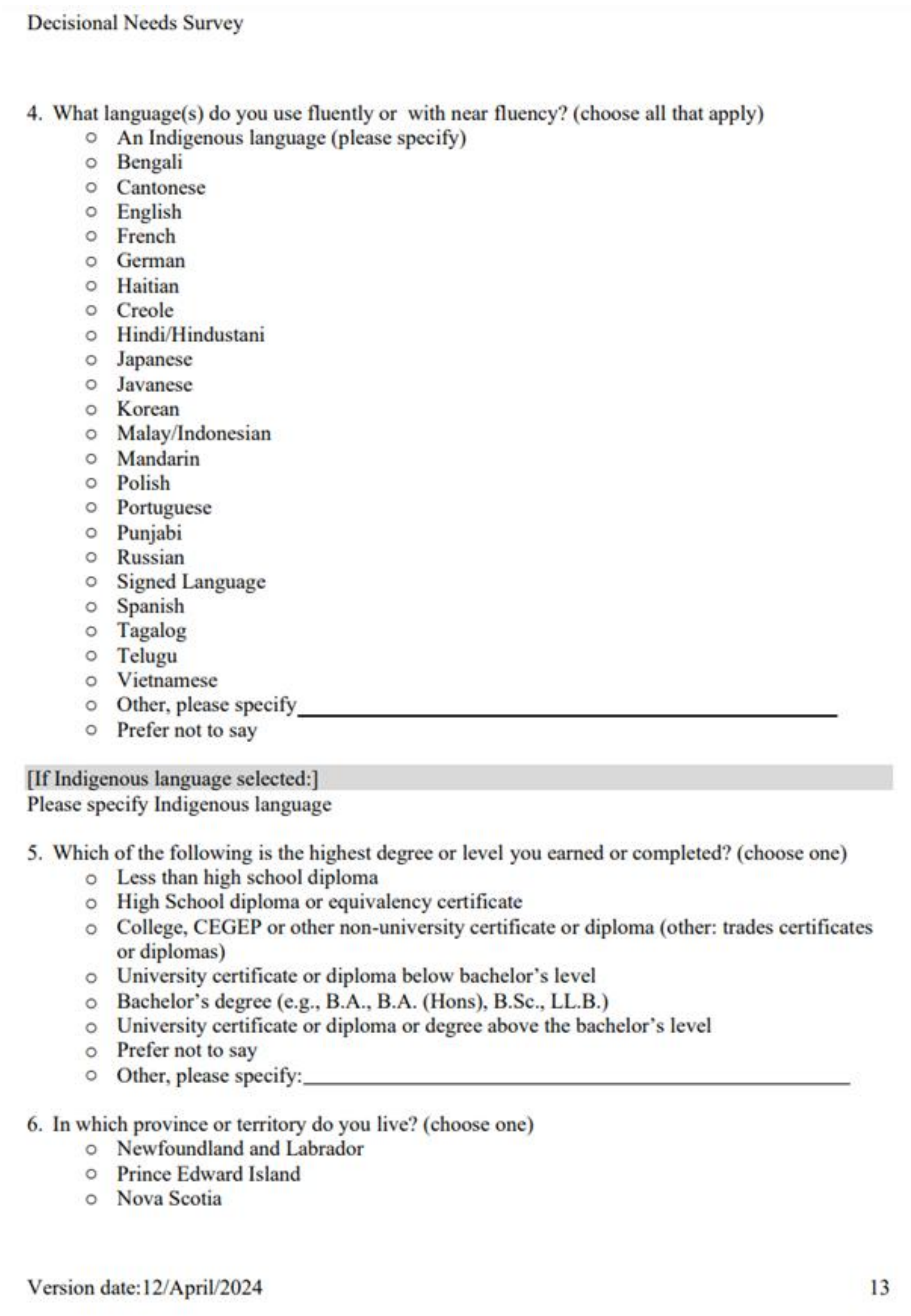
| | Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| a. It was the right decision | | | | | |
| b. I regret the choice that was made | | | | | |
| c. I would go for the same choice if I had to do it over again | | | | | |
| d. The choice did me a lot of harm | | | | | |
| e. The decision was a wise one | | | | | |

**Section C. Socio-demographic information on participants**
To complete the survey, we would like to know more about you. This information will be used to help us describe the group of people who filled out the survey and help us analyze the findings..

1. What is your age range? (choose one)
   - ○ 18-29 years
   - ○ 30-39 years
   - ○ 40-49 years
   - ○ 50-59 years
   - ○ 60-69 years
   - ○ 70-79 years
   - ○ 80-89 years
   - ○ 90+ years
   - ○ Prefer not to say

2. What was your sex at birth? Sex refers to sex assigned at birth. (choose one)
   - ○ Male
   - ○ Female
   - ○ Intersex
   - ○ Prefer not to say

3. Which of the following best describes your gender identity? Refers to current gender which may be different from sex assigned at birth and may be different from what is indicated on legal documents. (select all that apply)
   - ○ Man
   - ○ Woman
   - ○ Trans
   - ○ Non-Binary
   - ○ Prefer not to say
   - ○ Other, please specify: ______________________________



Decisional Needs Survey

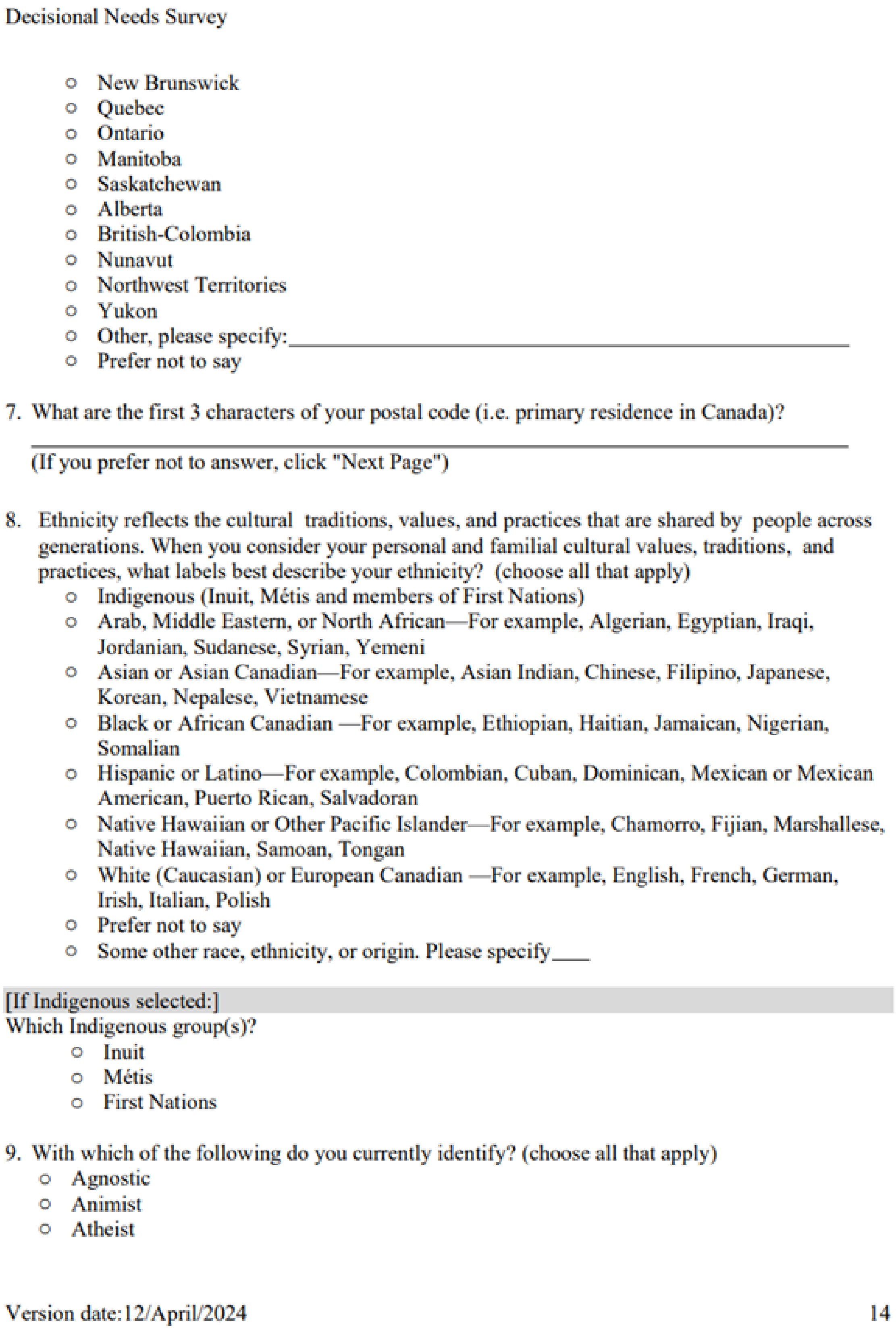
4. What language(s) do you use fluently or with near fluency? (choose all that apply)
   - ○ An Indigenous language (please specify)
   - ○ Bengali
   - ○ Cantonese
   - ○ English
   - ○ French
   - ○ German
   - ○ Haitian
   - ○ Creole
   - ○ Hindi/Hindustani
   - ○ Japanese
   - ○ Javanese
   - ○ Korean
   - ○ Malay/Indonesian
   - ○ Mandarin
   - ○ Polish
   - ○ Portuguese
   - ○ Punjabi
   - ○ Russian
   - ○ Signed Language
   - ○ Spanish
   - ○ Tagalog
   - ○ Telugu
   - ○ Vietnamese
   - ○ Other, please specify________________________________________
   - ○ Prefer not to say

[If Indigenous language selected:]

Please specify Indigenous language

5. Which of the following is the highest degree or level you earned or completed? (choose one)
   - ○ Less than high school diploma
   - ○ High School diploma or equivalency certificate
   - ○ College, CEGEP or other non-university certificate or diploma (other: trades certificates or diplomas)
   - ○ University certificate or diploma below bachelor's level
   - ○ Bachelor's degree (e.g., B.A., B.A. (Hons), B.Sc., LL.B.)
   - ○ University certificate or diploma or degree above the bachelor's level
   - ○ Prefer not to say
   - ○ Other, please specify:________________________________________

6. In which province or territory do you live? (choose one)
   - ○ Newfoundland and Labrador
   - ○ Prince Edward Island
   - ○ Nova Scotia



Decisional Needs Survey

- ○ New Brunswick
- ○ Quebec
- ○ Ontario
- ○ Manitoba
- ○ Saskatchewan
- ○ Alberta
- ○ British-Colombia
- ○ Nunavut
- ○ Northwest Territories
- ○ Yukon
- ○ Other, please specify:____________________________________________
- ○ Prefer not to say

7. What are the first 3 characters of your postal code (i.e. primary residence in Canada)?

   ______________________________________________________________

   (If you prefer not to answer, click "Next Page")

8. Ethnicity reflects the cultural traditions, values, and practices that are shared by people across generations. When you consider your personal and familial cultural values, traditions, and practices, what labels best describe your ethnicity? (choose all that apply)
   - ○ Indigenous (Inuit, Métis and members of First Nations)
   - ○ Arab, Middle Eastern, or North African—For example, Algerian, Egyptian, Iraqi, Jordanian, Sudanese, Syrian, Yemeni
   - ○ Asian or Asian Canadian—For example, Asian Indian, Chinese, Filipino, Japanese, Korean, Nepalese, Vietnamese
   - ○ Black or African Canadian —For example, Ethiopian, Haitian, Jamaican, Nigerian, Somalian
   - ○ Hispanic or Latino—For example, Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran
   - ○ Native Hawaiian or Other Pacific Islander—For example, Chamorro, Fijian, Marshallese, Native Hawaiian, Samoan, Tongan
   - ○ White (Caucasian) or European Canadian —For example, English, French, German, Irish, Italian, Polish
   - ○ Prefer not to say
   - ○ Some other race, ethnicity, or origin. Please specify____

[If Indigenous selected:]

Which Indigenous group(s)?

- ○ Inuit
- ○ Métis
- ○ First Nations

9. With which of the following do you currently identify? (choose all that apply)
   - ○ Agnostic
   - ○ Animist
   - ○ Atheist

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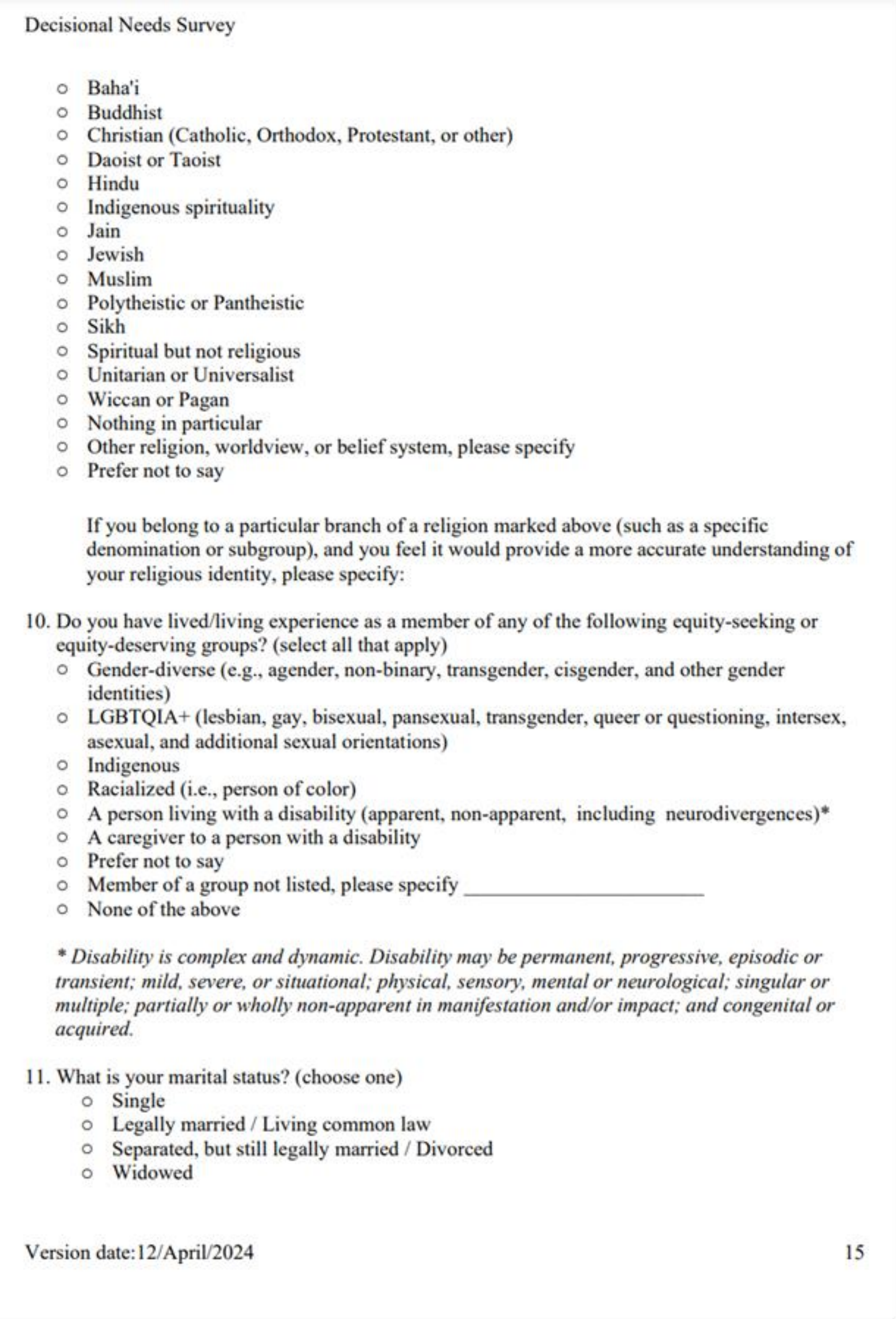


- ○ Baha'i
- ○ Buddhist
- ○ Christian (Catholic, Orthodox, Protestant, or other)
- ○ Daoist or Taoist
- ○ Hindu
- ○ Indigenous spirituality
- ○ Jain
- ○ Jewish
- ○ Muslim
- ○ Polytheistic or Pantheistic
- ○ Sikh
- ○ Spiritual but not religious
- ○ Unitarian or Universalist
- ○ Wiccan or Pagan
- ○ Nothing in particular
- ○ Other religion, worldview, or belief system, please specify
- ○ Prefer not to say

If you belong to a particular branch of a religion marked above (such as a specific denomination or subgroup), and you feel it would provide a more accurate understanding of your religious identity, please specify:

10. Do you have lived/living experience as a member of any of the following equity-seeking or equity-deserving groups? (select all that apply)
    - ○ Gender-diverse (e.g., agender, non-binary, transgender, cisgender, and other gender identities)
    - ○ LGBTQIA+ (lesbian, gay, bisexual, pansexual, transgender, queer or questioning, intersex, asexual, and additional sexual orientations)
    - ○ Indigenous
    - ○ Racialized (i.e., person of color)
    - ○ A person living with a disability (apparent, non-apparent, including neurodivergences)*
    - ○ A caregiver to a person with a disability
    - ○ Prefer not to say
    - ○ Member of a group not listed, please specify ________________________
    - ○ None of the above

** Disability is complex and dynamic. Disability may be permanent, progressive, episodic or transient; mild, severe, or situational; physical, sensory, mental or neurological; singular or multiple; partially or wholly non-apparent in manifestation and/or impact; and congenital or acquired.*

11. What is your marital status? (choose one)
    - ○ Single
    - ○ Legally married / Living common law
    - ○ Separated, but still legally married / Divorced
    - ○ Widowed

- ○ Prefer not to say
- ○ Other, please specify:____________________________________________

12. How many people are currently living in your household, **including yourself**? (choose one)
    - ○ One (I live alone)
    - ○ Two
    - ○ Three
    - ○ Four
    - ○ Five
    - ○ Six or more
    - ○ Prefer not to say

13. Which of the following categories best describes your household income, before taxes and other deductions, for the last 12 months? (choose one)
    - ○ Less than $24,999
    - ○ $25,000 to less than $49,999
    - ○ $50,000 to less than $74,999
    - ○ $75,000 to less than $99,999
    - ○ $100,000 or more
    - ○ Prefer not to say

14. What is your usual preferred level of involvement in decisions regarding your health? (choose one)
    - ○ I prefer to make the decision
    - ○ I prefer to share the decision with my health care provider
    - ○ I prefer the health care provider makes the decision
    - ○ Prefer not to say
    - ○ Other, please specify

15. Taking everything in your life into account, please rate your overall Quality of life on the following 7 points scale. (choose one)

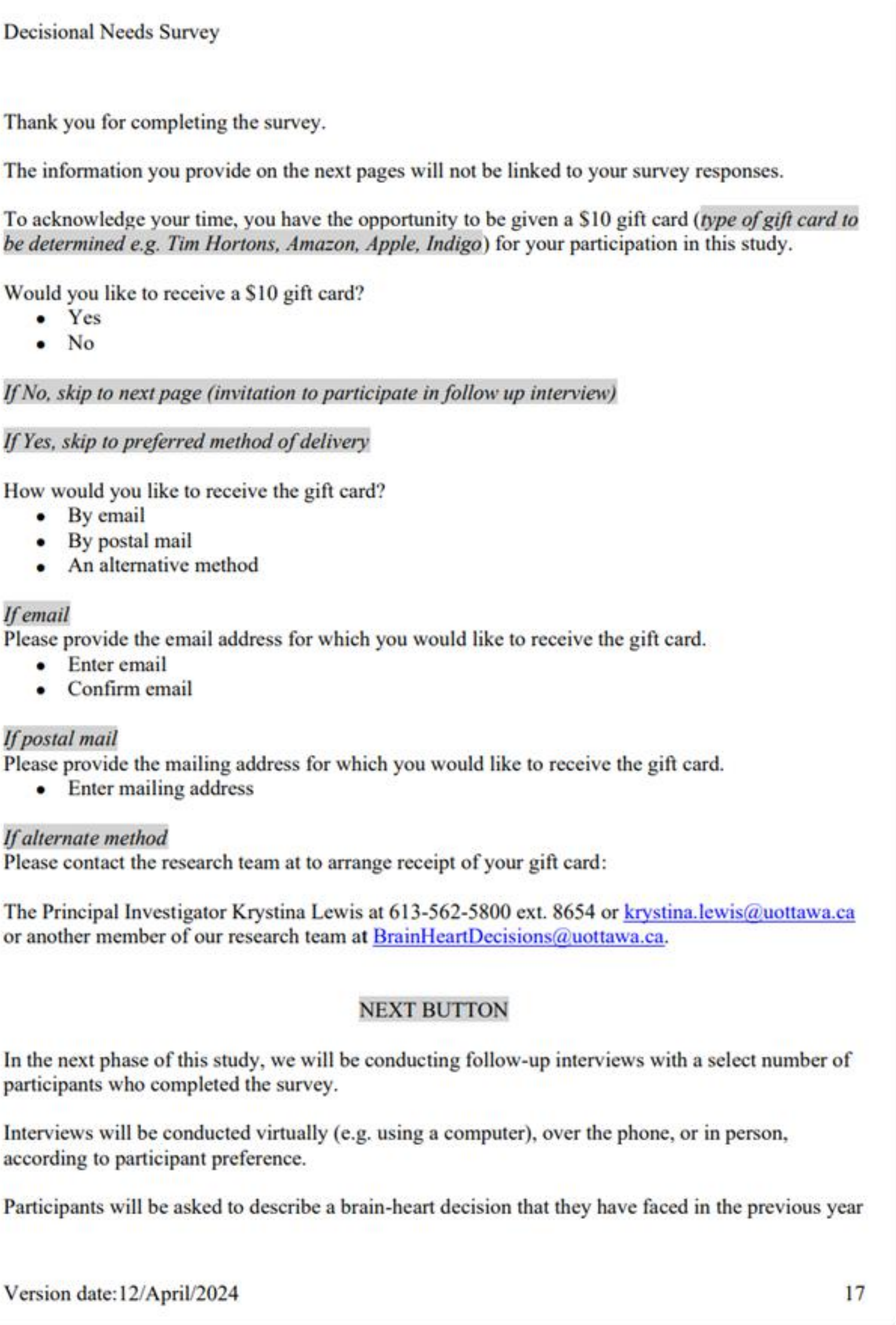
One (1) means life is very distressing; it's hard to imagine how it could get much worse.
Four (4) means life is so-so, neither good nor bad.
Seven (7) means life is great; it's hard to imagine how it could get much better.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Life is very distressing | | | Life is so-so | | | Life is great |

Prefer not to say

NEW SURVEY BUTTON

*After clicking the "Submit survey" button, respondents will be taken to a new survey that is not linked to their survey data.*



Decisional Needs Survey

Thank you for completing the survey.

The information you provide on the next pages will not be linked to your survey responses.

To acknowledge your time, you have the opportunity to be given a $10 gift card (*type of gift card to be determined e.g. Tim Hortons, Amazon, Apple, Indigo*) for your participation in this study.

Would you like to receive a $10 gift card?
- Yes
- No

*If No, skip to next page (invitation to participate in follow up interview)*

*If Yes, skip to preferred method of delivery*

How would you like to receive the gift card?
- By email
- By postal mail
- An alternative method

*If email*
Please provide the email address for which you would like to receive the gift card.
- Enter email
- Confirm email

*If postal mail*
Please provide the mailing address for which you would like to receive the gift card.
- Enter mailing address

*If alternate method*
Please contact the research team at to arrange receipt of your gift card:

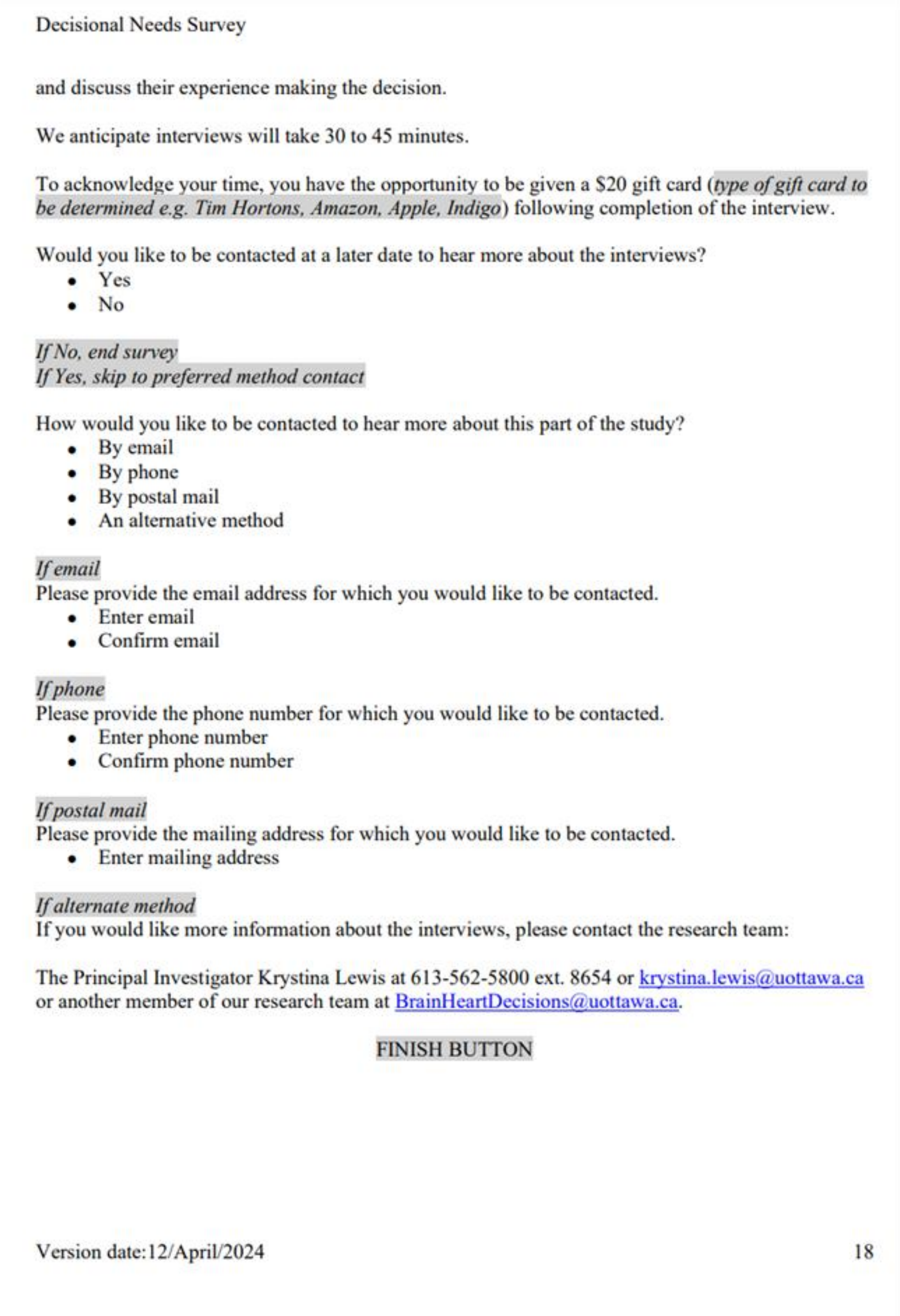
The Principal Investigator Krystina Lewis at 613-562-5800 ext. 8654 or krystina.lewis@uottawa.ca or another member of our research team at BrainHeartDecisions@uottawa.ca.

NEXT BUTTON

In the next phase of this study, we will be conducting follow-up interviews with a select number of participants who completed the survey.

Interviews will be conducted virtually (e.g. using a computer), over the phone, or in person, according to participant preference.

Participants will be asked to describe a brain-heart decision that they have faced in the previous year



and discuss their experience making the decision.

We anticipate interviews will take 30 to 45 minutes.

To acknowledge your time, you have the opportunity to be given a $20 gift card (*type of gift card to be determined e.g. Tim Hortons, Amazon, Apple, Indigo*) following completion of the interview.

Would you like to be contacted at a later date to hear more about the interviews?

- Yes
- No

*If No, end survey*
*If Yes, skip to preferred method contact*

How would you like to be contacted to hear more about this part of the study?

- By email
- By phone
- By postal mail
- An alternative method

*If email*
Please provide the email address for which you would like to be contacted.

- Enter email
- Confirm email

*If phone*
Please provide the phone number for which you would like to be contacted.

- Enter phone number
- Confirm phone number

*If postal mail*
Please provide the mailing address for which you would like to be contacted.

- Enter mailing address

*If alternate method*
If you would like more information about the interviews, please contact the research team:

The Principal Investigator Krystina Lewis at 613-562-5800 ext. 8654 or krystina.lewis@uottawa.ca or another member of our research team at BrainHeartDecisions@uottawa.ca.

FINISH BUTTON

# Appendix G

## Interview Guide for the Semi-Structured Interviews

**Supporting patients making health decisions about brain and heart conditions:**
**Determining decisional needs and interventions to support them**

### Interview guide – Patient version

**Before recording:**

Hello my name is _______________ and I am calling from the University of Ottawa as a graduate student/research assistant/patient partner member of Drs. Krystina Lewis research team. I am calling you about the research study that is exploring what people with brain-heart conditions need when making decisions about their care or managing their conditions. The interview should take about 30 to 45 minutes to complete.

Is now a good time to speak?

*[If no ...]*

When would be a good time to call you?

*[If yes:]*

The purpose of this research is to learn more about the needs of people who are making decisions about brain and heart conditions that are connected. In this study we consider **heart** conditions to include any conditions that involve the heart, such as abnormal heart rhythms, angina, prior heart attack, heart failure, valve problems for example. We consider **brain** conditions to include any conditions such as Alzheimer's, dementia, stroke, and mental health conditions such as anxiety and depression.

The information that you share with us today will help us to develop better materials and resources to support people facing brain-heart decisions.

I want to make sure you are comfortable answering the questions so if there are any questions that you would rather not answer, it is perfectly okay. As well, we can stop at any time and we can also take breaks. Please let me know how you feel as we go.

Are you ok if I audio-record this conversation so that we can write down what you said and review it later to make sure we fully captured your answers to the questions? We will remove any names or identifying information from these interviews so that your identity is protected. We erase the audio file of our interview once we have a written version prepared. It is only me and study staff who will have access to the written version.

Before we get started, do you have any questions for me?

In the survey that you completed, you were asked to identify a previous health decision. You noted this decision : ______________________, which had the following options: ______________________________.

Can we focus our conversation on this decision or would you like to talk about a different brain-heart decision you have made within the last year?

**Supporting patients making health decisions about brain and heart conditions:**
**Determining decisional needs and interventions to support them**

**Start recording:**

1. Please tell me the story about what happened when you heard that there was a decision to make?

**Probes**:

- how did you learn there was a decision to be made?
- what types of things were you thinking about?
- what was your response/reaction?

2. Can you describe how you felt about making this decision? [*Probe decisional needs*]

**Probes**: Did you:

- feel you had enough information about options, benefits, risks
- feel you had enough information on the chances of benefits and harms happening to you
- recognize and/or accept that there was a problem
- feel clear about what is most important to you
- feel supported in decision making
- feel pressure from others
- feel ready to make a decision
- feel you had the ability or skill to make a decision
- need to think about implications for both the brain and the heart
- need to think about implications the decision will have on other areas of your life, such as work, school, family, friends, community, etc.
- access information or support that was relevant or sensitive to your culture, religion, personal values?
- encounter language barriers that made it hard to understand or communicate with others
- experience any form of discrimination relating to your race, ethnicity, or background
- have financial barriers that impacted the decision or the options available to you

3a. Is there anything specific about this particular decision because it required you to think about both the brain and the heart?

3b. Did this make it more or less difficult than other health decisions you have faced in the past?

**Probes:**

- needing to think about other brain-heart related decisions that are related to this one
- the impact that this decision has on other aspects of your health care
- need to think about implications the decision will have on other areas of your life, such as work, school, family, friends, community, etc.

4a. During the decision making process, did you feel clear about what was personally important to you?

**Probes**:

- What benefits/advantages mattered most to you?
- Which risks/cons did you wish to avoid the most?
- Were there specific cultural, religious, or personal values that influenced what was important to you?

**Supporting patients making health decisions about brain and heart conditions:**
**Determining decisional needs and interventions to support them**

4b. Did you feel your health care team understood and respected what was important to you?

- Did you find it easy to communicate what was important to you to your healthcare team?
- Did you feel that what is important to you was considered in the decision-making process?

5. Who else was involved in making this decision with you? How were they involved?

**Probes**:

- Health care professionals (either heart-focused, brain/mind focused, or others) – *which ones?*
- If both brain/heart health care professionals, how did they work together?
- Important others – *family and/or friends, religious leaders, community elders*
- Did someone help you pull all of the information together, or did you do this on your own?

6. Do you think the discussions you had with health care professionals about this decision, were influenced at all by any of your personal characteristics, for example your age, your gender, your race, your culture, your religion, your occupation/profession?

7. Did the people involved in discussing your brain-heart condition provide you with any information and/or resources to help you make a decision?

**If yes**, which ones? If yes, were they useful?

**Probes**:

- What are the resources you would recommend to others making this decision?
- Why did you find those resources particularly useful?
- Are there other resources you think might have been useful?
- Is there someone else you would have liked to have talked to?
- How could the information or support provided be improved to better meet your needs and preferences?

**If not**, what resources do you think would have been helpful?

**Probes:**

- What would you have liked to have been told/heard about?
- Who would you have liked to have talked to?
- Were there any culturally specific resources or support systems that you felt were missing?
- How could the information or support provided be improved to better meet your needs and preferences?

8. Did you seek out any information on your own?

**Probes:**

- Did you look to the internet? If yes, where? Did you find that helpful?
- Did you look to social media? If yes, where? Did you find that helpful?
- Did you seek information from your family, friends, or community (e.g. cultural or religious groups)? If yes, where? Did you find that helpful?
- Did you feel that the information you found was accessible and tailored to your needs?

9. To what degree do/did you feel *ready* to make this decision and follow through with the chosen option?

**Supporting patients making health decisions about brain and heart conditions:**
**Determining decisional needs and interventions to support them**

**Probes:**
- How did your feelings of readiness change over time, if at all?
- Were there any factors that contributed to or hindered your readiness to make the decision?
- Did you feel you had enough support or resources to follow through with your choice?

10. To what degree did you feel you were able to participate in making the decision?

**Probes**
- Did you feel that your voice was heard and valued during the decision-making process?
- Were there anything that made it difficult for you to fully participate in the decision?
- Were there any personal, cultural, or logistical factors that affected how ready you felt to make the decision?

11. Was there anything else that made the decision more difficult or easier to make?

12. If you had to make another health decision about your brain-heart decision in the future, what would help you?

**Probes**:
- Information about the condition and options
- Explanation about how both the brain and the heart need to be considered in the decision
- Consider the personal importance that you place on the benefits and risks of the options
- Guidance in the steps of making a decision
- Information on what others decide or recommend
- Information that is tailored or sensitive to your culture, religion, or other aspects of you, as a person.
- Talking with someone about the decision, who could help pull all of the information together.

- Anything else?

13. Is there anything else you would like to add?

**Probes:**
- Do you have any suggestions for how health care professionals can better support patients in making ________[index decision] _______brain-heart related decisions?

# Appendix H

Social Media Recruitment Poster

UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

uOttawa

## VOLUNTEERS NEEDED!

Do you have a **brain-heart** condition?

**OR**

Do you have a **brain or heart** condition and are **at risk** of developing the other?

**We are looking for volunteers** (Patients or family members/caregivers of patients) faced with treatment decisions for brain-heart conditions or with one condition and at risk of developing the other to take part in a study.

We welcome participants from all racial and ethnic backgrounds, including people from **African, Caribbean, and Black (ACB) communities**.

### What is Involved?

You would be asked to complete a 20-25 minute survey.

This survey can be completed online, over the phone, by postal mail, or in-person according to your preference.

### Interested?

For more information, or to volunteer for this study, please call or email our research team:

**613-562-5800**
**(ext. 8654)**

BrainHeartDecisions@uottawa.ca

## Appendix I

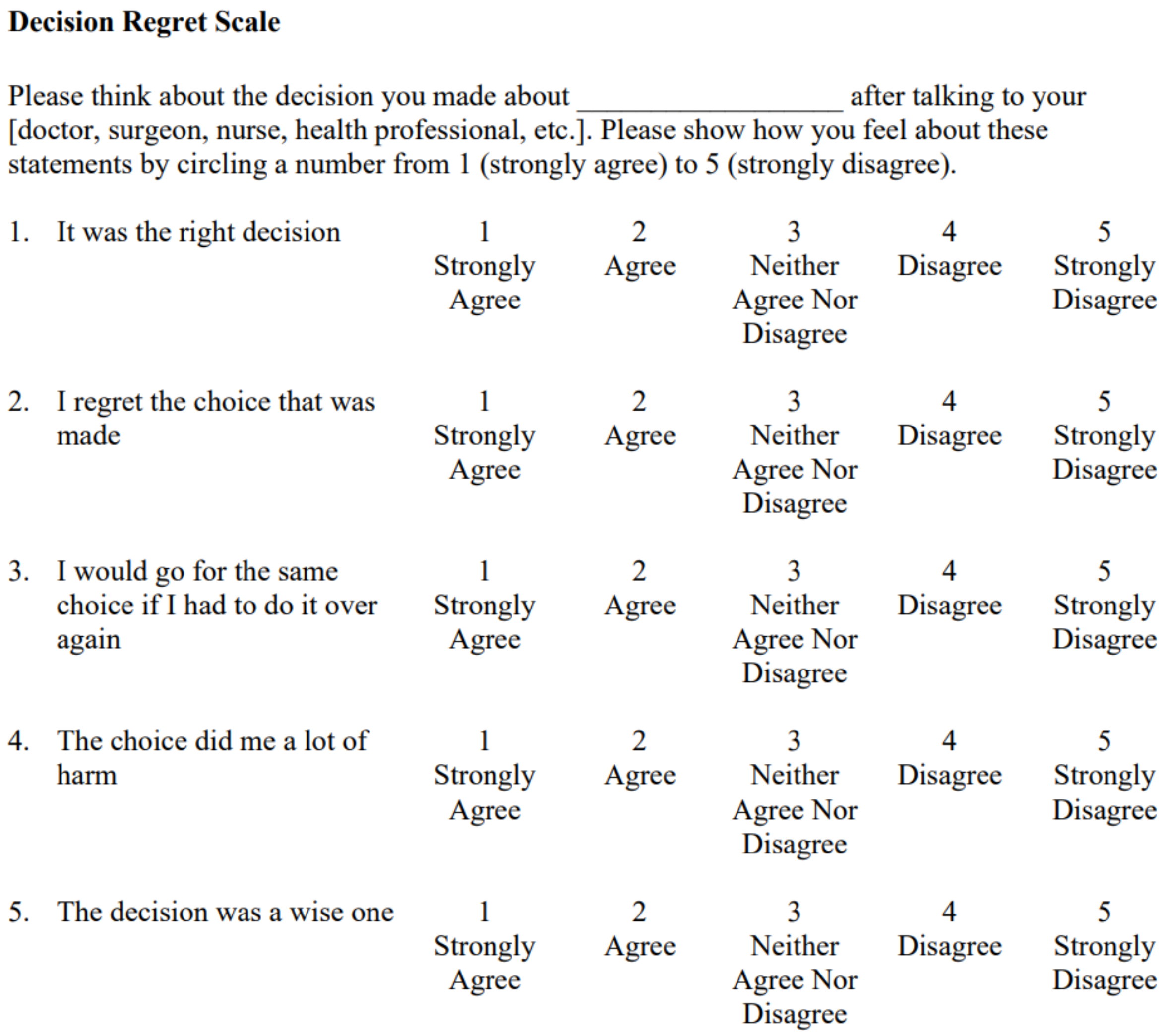
The Decisional Conflict Scale (DCS)

| | **Strongly Agree** [0] | **Agree** [1] | **Neither Agree Nor Disagree** [2] | **Disagree** [3] | **Strongly Disagree** [4] |
|---|---|---|---|---|---|
| 1. I know which options are available to me. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. I know the benefits of each option. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. I know the risks and side effects of each option. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. I am clear about which benefits matter most to me. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. I am clear about which risks and side effects matter most to me. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6. I am clear about which is more important to me (the benefits or the risks and side effects). | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. I have enough support from others to make a choice. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. I am choosing without pressure from others. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 9. I have enough advice to make a choice. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. I am clear about the best choice for me. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. I feel sure about what to choose. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12. This decision is easy for me to make. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. I feel I have made an informed choice. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14. My decision shows what is important to me. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15. I expect to stick with my decision. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16. I am satisfied with my decision. | ☐ | ☐ | ☐ | ☐ | ☐ |

*Note:* Adapted from “Decisional Conflict Scale,” by A.M. O’Connor. Copyright 1993 [updated 2005] by O’Connor.

# Appendix J

The Decision Regret Scale (DRS)



**Decision Regret Scale**

Please think about the decision you made about __________________ after talking to your [doctor, surgeon, nurse, health professional, etc.]. Please show how you feel about these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree).

| | | | | | |
|---|---|---|---|---|---|
| 1. It was the right decision | 1 Strongly Agree | 2 Agree | 3 Neither Agree Nor Disagree | 4 Disagree | 5 Strongly Disagree |
| 2. I regret the choice that was made | 1 Strongly Agree | 2 Agree | 3 Neither Agree Nor Disagree | 4 Disagree | 5 Strongly Disagree |
| 3. I would go for the same choice if I had to do it over again | 1 Strongly Agree | 2 Agree | 3 Neither Agree Nor Disagree | 4 Disagree | 5 Strongly Disagree |
| 4. The choice did me a lot of harm | 1 Strongly Agree | 2 Agree | 3 Neither Agree Nor Disagree | 4 Disagree | 5 Strongly Disagree |
| 5. The decision was a wise one | 1 Strongly Agree | 2 Agree | 3 Neither Agree Nor Disagree | 4 Disagree | 5 Strongly Disagree |

*Note:* Adapted from "Decision Regret Scale," by A.M. O'Connor. Copyright 1996 [updated 2005] by the University of Ottawa.

# Appendix K

## Ethics Approval Forms

UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

June 11, 2024

Dr. Krystina Lewis

University of Ottawa

**Re:** UOHI Institutional Approval for Ottawa Health Science Network Research Ethics Board (OHSN-REB) Submission

Local Protocol ID#: 20240227-01H;

**Supporting patients making health decisions about brain and heart conditions: Determining decisional needs and interventions to support them**

Dear Dr. Krystina Lewis,

This letter serves as **University of Ottawa Heart Institute (UOHI)** Institutional Approval for the above-referenced study. Please maintain this documentation in your investigator study file.

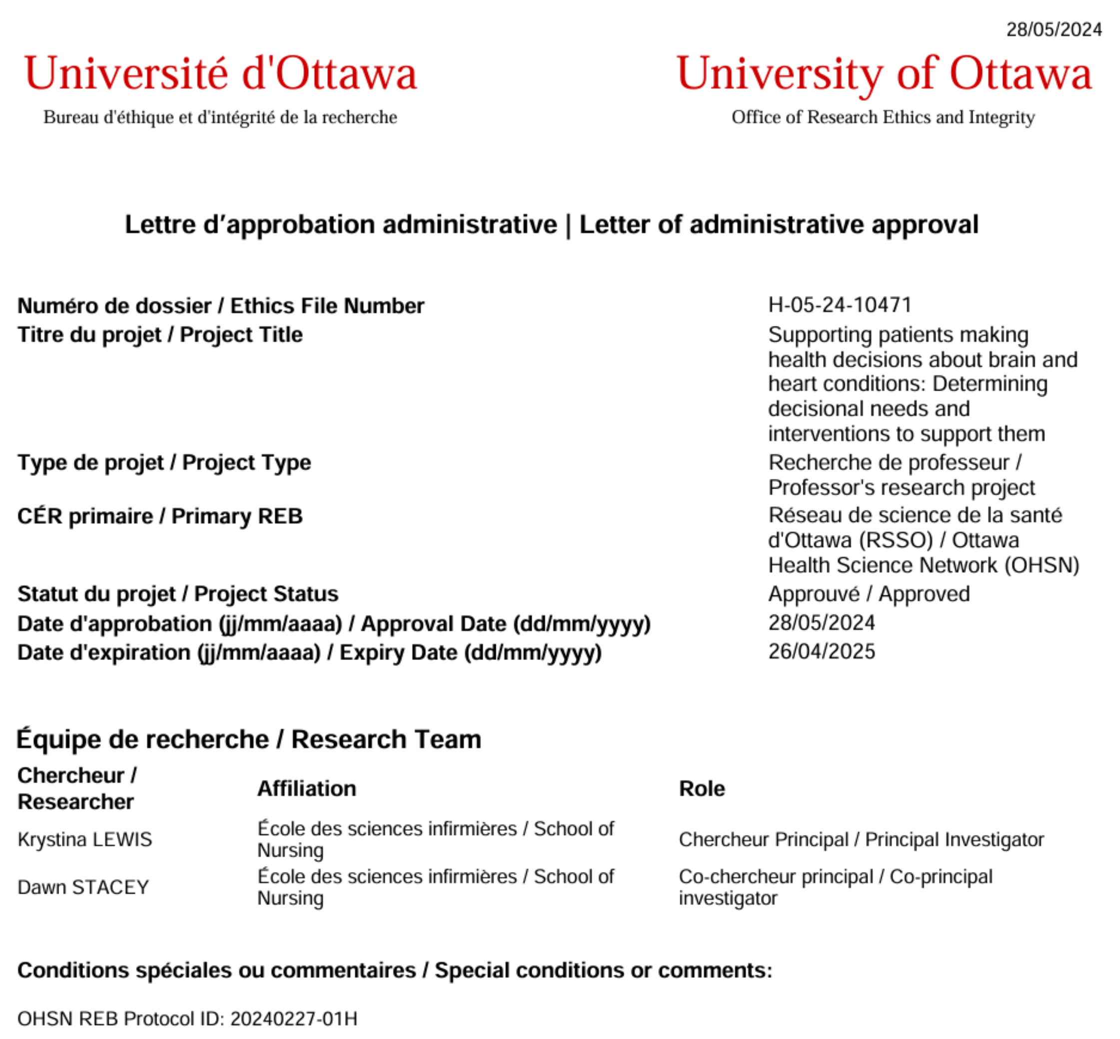
Based on the information you provided about this study through the Clinical Research Registration Form, you have satisfied the requirements for institutional (UOHI) approval. This includes initial research ethics approval by OHSN-REB, appropriate departmental/service area notifications and execution (fully signed versions) of all agreement(s) required to begin the study locally. Please note there may be additional agreement(s) pending execution that are required to send funds, samples, or data to external sites, but are not required for you to begin your study locally.

Changes and/or additions to your study that may require additional agreement(s) or revisions to existing agreement(s) must be communicated to the UOHI Legal Affairs. This should be undertaken simultaneously with any related OHSN-REB amendment submission.

Changes and/or additions to your study that affect various hospital/institution departments (e.g., pharmacy, Department of Medical Imaging, EORLA, EEG, etc.) must be communicated to the relevant departments.

As mentioned in the 'Response' tab of the Ethics application, you have 3 months from the date of initial OHSN-REB approval to submit French documents including the translation certificate to OHSN-REB through the Translated Documents section of the ethics application (if applicable).

Should you have any questions, please contact REBadministration@ohri.ca



28/05/2024

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

## Lettre d’approbation administrative | Letter of administrative approval

| | |
|---|---|
| **Numéro de dossier / Ethics File Number** | H-05-24-10471 |
| **Titre du projet / Project Title** | Supporting patients making health decisions about brain and heart conditions: Determining decisional needs and interventions to support them |
| **Type de projet / Project Type** | Recherche de professeur / Professor's research project |
| **CÉR primaire / Primary REB** | Réseau de science de la santé d'Ottawa (RSSO) / Ottawa Health Science Network (OHSN) |
| **Statut du projet / Project Status** | Approuvé / Approved |
| **Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)** | 28/05/2024 |
| **Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)** | 26/04/2025 |

### Équipe de recherche / Research Team

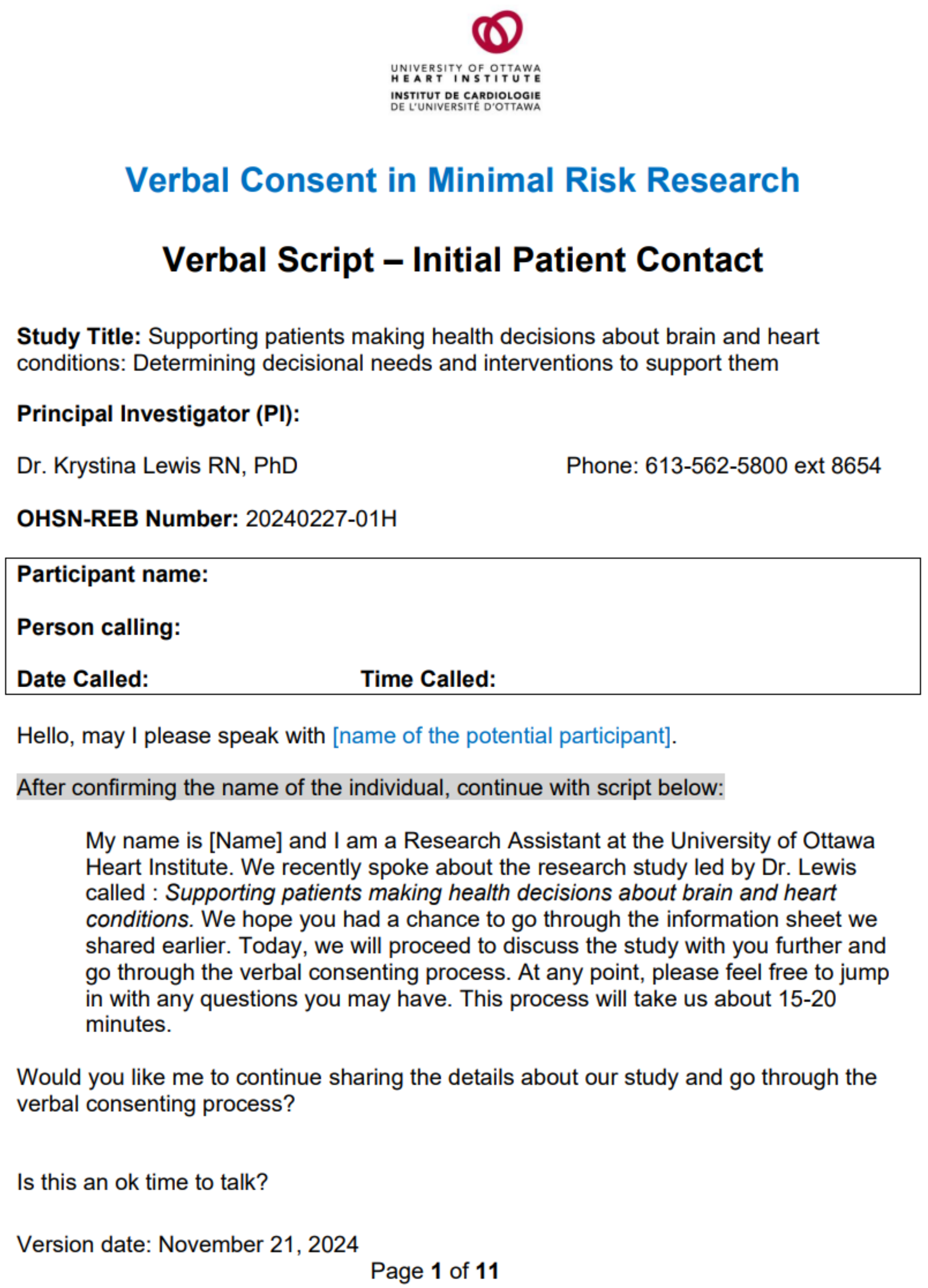
| Chercheur / Researcher | Affiliation | Role |
|---|---|---|
| Krystina LEWIS | École des sciences infirmières / School of Nursing | Chercheur Principal / Principal Investigator |
| Dawn STACEY | École des sciences infirmières / School of Nursing | Co-chercheur principal / Co-principal investigator |

**Conditions spéciales ou commentaires / Special conditions or comments:**

OHSN REB Protocol ID: 20240227-01H

# Appendix L

## Verbal Consent Script



UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

## Verbal Consent in Minimal Risk Research

## Verbal Script – Initial Patient Contact

**Study Title:** Supporting patients making health decisions about brain and heart conditions: Determining decisional needs and interventions to support them

**Principal Investigator (PI):**

Dr. Krystina Lewis RN, PhD Phone: 613-562-5800 ext 8654

**OHSN-REB Number:** 20240227-01H

**Participant name:**

**Person calling:**

**Date Called:** **Time Called:**

Hello, may I please speak with [name of the potential participant].

After confirming the name of the individual, continue with script below:

> My name is [Name] and I am a Research Assistant at the University of Ottawa Heart Institute. We recently spoke about the research study led by Dr. Lewis called : *Supporting patients making health decisions about brain and heart conditions.* We hope you had a chance to go through the information sheet we shared earlier. Today, we will proceed to discuss the study with you further and go through the verbal consenting process. At any point, please feel free to jump in with any questions you may have. This process will take us about 15-20 minutes.

Would you like me to continue sharing the details about our study and go through the verbal consenting process?

Is this an ok time to talk?

Version date: November 21, 2024

Page **1** of **11**

☐ No ***If no →** Is there a better time to speak? Date/time: or are you no longer interested in the study?

**If no:** Thank you for your time. Have a good day.

☒ Yes ***If yes →** *Continue with script below*

You are being asked to participate because you have or you are a family member/caregiver of someone who has a brain-heart condition or a brain or heart condition with risk factors for developing the other. In this study we consider brain conditions to include diagnoses such as Alzheimer's, dementias, stroke, and mental health conditions (e.g. anxiety, depression). This study examines the common decisions and decisional needs of people with brain-heart conditions and ways to address their needs.

Are you willing to hear more about the study?

☐ No ***If no →** Thank you for your time. Goodbye
☒ Yes ***If yes →** *Continue with script below*

## Conflicts of Interest:

There are no conflicts of interest to declare related to this study.

## Research Activities:

*All research activities must be described. What each activity entails, how long it will take, and the timing of the activities should be described. Descriptions may be brief and conversational in nature.*

There are two options for participation in this study: 1) to complete one survey only, or 2) to complete one survey with the option to participate in a follow-up interview.

Your participation in this study will require the completion of a survey. The survey asks questions about the decisions you have faced or are facing regarding your brain-heart condition or the brain-heart condition of the person you care for, factors that affected your decision making, how the decision was made, whether you have regret about your decision, your overall quality of life, and demographic questions. This should take approximately 20-25 minutes of your time.

The information you provide is for research purposes only. Some of the questions are personal. You can choose not to answer questions if you wish.

At the end of the survey, you will be asked if you would like to be contacted at a later date to be invited to participate in an optional interview. If you choose to provide your

contact information (e.g. email, phone number) it will be linked to your survey responses. Linking your contact information to your survey responses serves three purposes:
1) we will not need to re-ask you all of the demographic questions again during the interview;
2) the person doing the interview can delve deeper into your responses to the survey questions to gain a better understanding of the decision you are facing and your needs related to this decision; and
3) we want to conduct interviews with a diverse group of people and having access to your survey demographic information will allow us to do that.

If you choose to volunteer for a follow-up interview, you will be asked to attend one interview. During this interview, you will meet with a member of the research team. The interview will be about 30-45 minutes in length and will be conducted virtually (e.g. using a computer), over the phone, or in person according to your preference. You will be asked to describe a brain-heart decision that you have faced in the previous year and discuss your experience making the decision.

You will be audio/video recorded during the interview.

**What are the responsibilities of study participants?**
If you choose to participate in this study, you will be expected to:

- Complete one survey
- Participate in one interview if you are interested (optional)

**How long will participants be in the study?**

Completing the survey should take about 20-25 minutes of your time. If you choose to participate in an interview, it will take an additional 30-45 minutes.

Do you have questions about the activities this study involves?

☒ No ***If no →** *Continue with script below*
☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: _ Wishes to know whether he can receive the results of the study. He is interested in receiving the results.

Answers: I have indicated her interest in receiving study findings once the study is complete.

Other Comments: ______________________________________________

**Voluntary Participation and Withdrawal:**

You do not have to be in this study if you do not want to be. You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. The decision will not affect any healthcare services you are entitled to at the University of Ottawa Heart Institute.

1) If you would like to complete the survey only: The survey is anonymous. This means that you can withdraw from participating at any time while completing the survey/questionnaire simply by closing your browser or not returning the hardcopy document or if completing the survey by phone, by indicating to the study team you no longer wish to proceed; however, once the completed survey/questionnaire has been returned to the study team, it will not be possible to withdraw your information. Any information returned to the study team before your withdrawal will be used, but no information will be collected after you withdraw your permission.

2) If you would like to complete the survey with the option of to participate in a follow up interview: The survey is coded. "Coded" means that directly identifying information (such as your name) will be replaced by a randomly generated number, which will be applied to the study data.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know. However, this would also mean that you withdraw from the study.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

Do you have questions about the voluntary nature and ability to withdraw from this study?

☒ No ***If no →** *Continue with script below*
☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ________________________________________________

Answers: ________________________________________________

Other Comments: ____________________________________________

**Can participation in this study end early?**

Your participation in this study may be stopped early, and without your consent, for reasons such as:

- The research team decides to stop the study
- The Ottawa Health Science Network Research Ethics Board withdraws permission for this study to continue

If you are removed from this study, the research team will discuss the reasons with you.

## Potential Risks, Harms, Discomforts:

**What are the potential risks or harms of participating in this study?**

Participation involves minimal risk to you. Some of the questions may however make you feel uncomfortable.

If you choose to participate in the optional interview, you may become uncomfortable while discussing your experiences. You may choose not to answer questions or leave the interview at any time if you experience discomfort.

Do you have questions about the potential risks this study involves?

☒ No ***If no →** *Continue with script below*
☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ____________________________________________________________

Answers: ____________________________________________________________

Other Comments: ______________________________________________________

## Potential Benefits:

**What are the benefits of participating in this research study?**

You may not receive direct benefit from participating in this study. We hope the information learned from this study will help other people with brain and/or heart conditions in the future.

Do you have questions about the potential benefits this study involves?

☒ No ***If no →** *Continue with script below*
☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ____________________________________________________________

Answers: ____________________________________________________________

Other Comments: ______________________________________________________

## Privacy/Confidentiality:

If you decide to participate in this study, the research team will only collect the information they need for this study.

If you complete the anonymous survey only, it means that your answers will not be linked to you in any way,

If you choose to complete the survey and the optional interview, the survey and interview will be coded which means that directly identifying information (such as your name) will be replaced by a randomly generated number, which will be applied to the study data.

Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your original research records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study.
- Ottawa Heart Institute Research Corporation, the Sponsor for the study, and who oversees the conduct of research at this location.

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your sex/gender and age range.

This research study is collecting information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond. Providing information on your race or ethnic origin is voluntary.

Communication via e-mail is not absolutely secure. We do not recommend that you communicate sensitive personal information via e-mail.

During the interview discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and will be published/ presented to the scientific community at meetings and in journals.

Your coded or anonymous data from this study may be used for other research purposes. If your study data is shared with other researchers, no information that links your study data directly to you will be available.

**Will my research data be used in future research?**

Your coded or anonymous study data may be used or shared with other researchers (inside and outside of Canada) for future studies. “Coded” means that directly identifying information (such as your name) will be replaced by a randomly generated number, which will be applied to the study data. “Anonymous” means that the data never contained any directly identifying information (such as your name and date of birth). It will be assigned a randomly generated number instead This may include storing the coded or anonymous study data in controlled-access databases, for which access is limited to researcher(s) who submit a study plan and who sign an agreement to use the coded or anonymous study data only for that research. Very limited coded or anonymous study data may also be placed in an open access, publicly accessible database. The goal of sharing is to make more research possible. However, their will be no link kept to match your study data with your name.

You will not be asked if you agree to take part in future research studies using your study data. You nor the study researcher will be told what type of research will be done. You will not be given reports or other information about any research that is done with your study data.

Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

Do you have questions about how your privacy will be protected?

☒ No ***If no →** *Continue with script below*

☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ____________________________________________________

Answers: __________________________________________________________

Other Comments: _____________________________________________________

## Cost, Payment or Reimbursement:

To acknowledge your time, you will be offered a $10 gift card to (e.g. Tim Hortons, Amazon, Apple, Indigo) for your participation in this study. The gift card will be sent to you physically or electronically according to your preference after completion of the survey (you will be required to provide your email address to receive an electronic gift card; your email address will be collected separately from your survey data and the two will not be linked).

If you choose to participate in a follow-up interview, you will be offered a $20 gift card. The gift card will be sent to you physically or electronically according to your preference after completion of the interview (you will be required to provide your email address to receive an electronic gift card; your email address will be collected separately from your interview data and the two will not be linked).

Do you have questions about the costs of participation or payment/reimbursement?

☒ No ***If no →** *Continue with script below*

☐ Yes ***If yes →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ____________________________________________________________

Answers: ____________________________________________________________

Other Comments: ______________________________________________________

## Participant Rights:

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please let the research team know.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By providing your verbal consent, you do not give up any of your legal rights against the researcher, sponsor or involved institutions for compensation, nor does this form relieve the researcher, sponsor or their agents of their legal and professional responsibilities.

## Questions:

If you have any questions about taking part in this study, you may contact the Principal Investigator at 613-562-5800 ext. 8654 or a member of our research team at BrainHeartDecisions@uottawa.ca.

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

**Have all of your questions been answered?**

☐ No ***If no →** *Answer questions and document all questions and answers before continuing with script below*

Questions: ____________________________________________

Answers: ____________________________________________

Other Comments: _______________________________________

☐ Yes ***If yes →** *Continue with script below*

## Consent:

Based on the description of the study, would you like to participate? Or would you like some time to think about it?

☐ No ☐ X Yes ☐ More time to think about it

***If they do not want to participate:** Thank you for your time. Goodbye.

***If they do want to participate:** *Continue with script below*

***If they would like more time:** *Continue with script below*

What option of the study would you like to participate in:
☐ Anonymous one-time survey only, or
☐ One-time survey with the option to participate in an interview

***If they wanted more time:** When would be a good time for me to call you back to answer any further questions you may have and obtain your decision? Date/time:

*After the verbal consenting process is complete:*

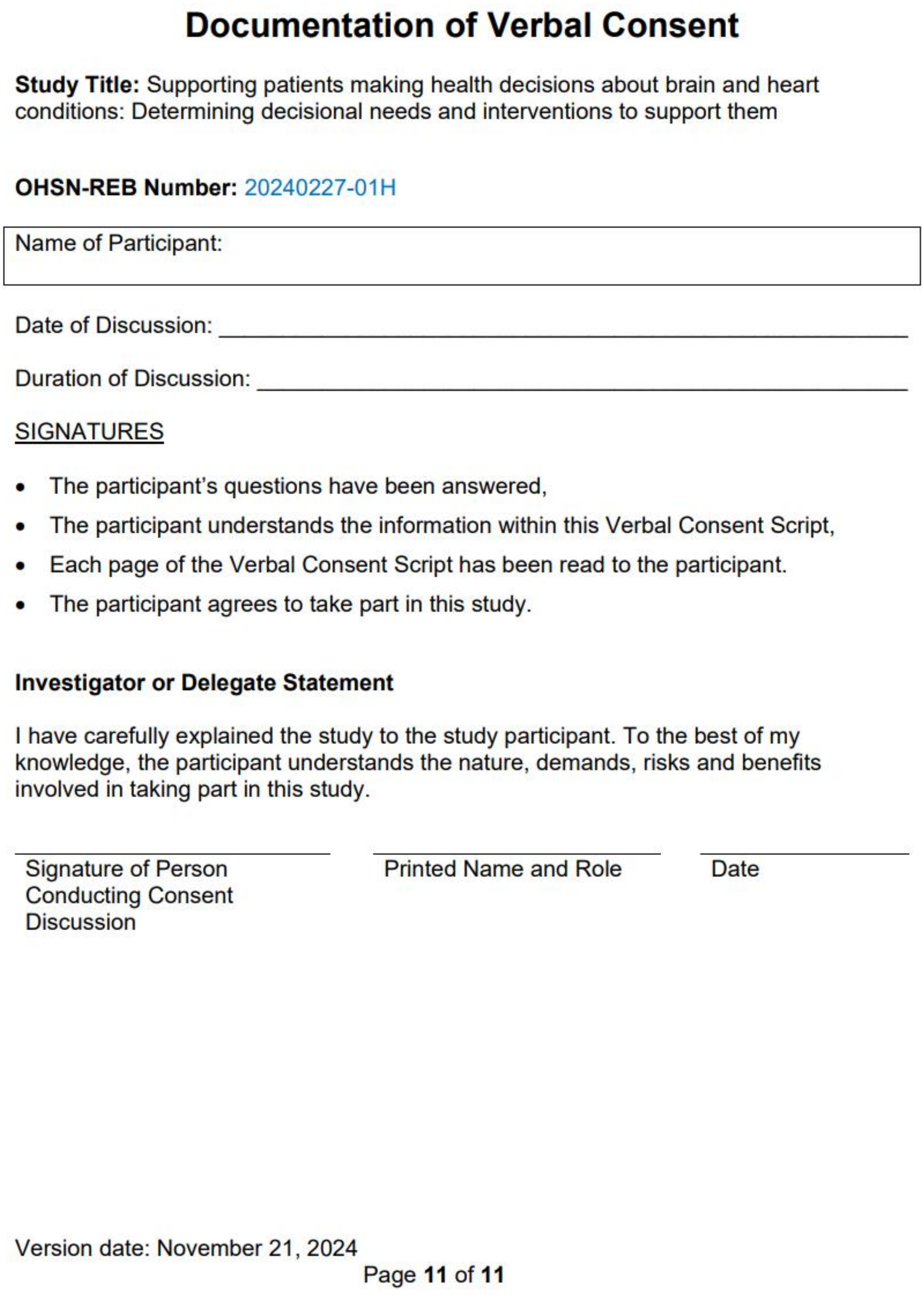
*****We have now completed the verbal consenting process. Thank you for consenting to participate in our study. Would you like to proceed with completing the survey today?

☐ No ***If no** → *Continue with script below*
☒ Yes ***If yes** → Thank you. (Move to Interview Guide)

*****Okay, what would be a good date/time for you to do the interview?

Date:_________________
Time:_________________

Platform:
MS Teams ________
Phone_________



# Documentation of Verbal Consent

**Study Title:** Supporting patients making health decisions about brain and heart conditions: Determining decisional needs and interventions to support them

**OHSN-REB Number:** 20240227-01H

| |
|---|
| Name of Participant: |

Date of Discussion: ____________________________________________

Duration of Discussion: _________________________________________

SIGNATURES

- The participant's questions have been answered,
- The participant understands the information within this Verbal Consent Script,
- Each page of the Verbal Consent Script has been read to the participant.
- The participant agrees to take part in this study.

**Investigator or Delegate Statement**

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

| | | |
|---|---|---|
| Signature of Person Conducting Consent Discussion | Printed Name and Role | Date |

Version date: November 21, 2024