Experiences and Perceptions of Unattached Older Adults in New Brunswick; A Qualitative Study on Primary Care Access and Health System Navigation

by

Kate Tucker

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Supervisor:	Pamela Durepos, PhD, Nursing
Examining Board:	Lisa Keeping-Burke, PhD, Nursing and Health Sciences, Chair
	Rose McCloskey, PhD, Nursing and Health Sciences
	Michelle Greason, PhD, Social Work, St. Thomas University

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Abstract

Primary care includes routine care and first point-of-contact services essential to healthy aging. However, we currently lack an understanding of the experiences of people who require primary care services and are without an "attached" care provider (PCP). This study explored experiences of unattachment through semi-structured interviews with 14 community-dwelling older adults. Interpretive description was the methodological approach used for this study. Findings indicate the importance of a sense of belonging in care navigation for older adults and the profound impact of a meaningful and consistent relationship with a PCP. Other themes included age-specific decision-making criteria, the impact of various privileges and experiences of unattachment, and innovative approaches to health services access/navigation. Adverse outcomes have been associated with unattached older adults elsewhere in Canada; however, minimal research explores their perceptions of this experience. This study provides critical insight into the circumstances of being unattached and highlights strategic direction for necessary reform.

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Chapter 1 - Literature Review

Canadians take great pride in an internationally renowned universal health care system that intends to allow for reasonable access to all health services without the fear of irrecoverable debt or a forced decision between feeding a family or obtaining critical medical services. Unfortunately, access to health services is becoming increasingly inaccessible for people across the country. Despite overall high levels of satisfaction with the care received, Canadians rate their access to health services quite poorly and are generally not seeing improvements in this domain (Canadian Institute for Health Information, 2022). Primary health care includes routine care for urgent but minor health problems. It is delivered by primary care providers, often family doctors and nurse practitioners (Canadian Institute for Health Information, 2022). Other health professionals, such as pharmacists, midwives, physiotherapists, and emergency physicians, also provide primary care services due to their potential for providing preventative care and their capacity to address minor health problems. Primary health services are critical in supporting peoples' wellness and overall health maintenance. Therefore, what happens when people do not have access to these services? Alternative options for access to primary care services in New Brunswick include emergency departments, after-hour clinics, telehealth, or forgoing the care they need (Government of New Brunswick, 2022).

Although these services exist, we currently do not understand the experiences of people who require health services and cannot access their primary care provider in a timely manner or who are without a primary care provider. Further, lack of access impacts specific populations, particularly marginalized groups, and those with access to

fewer social and socioeconomic resources, more acutely than others. Notably, older adults rely more on health services than any other demographic, and the population of older adults is rapidly increasing in the Atlantic region—the number of older adults aged 65 and older is growing six times faster than that of children aged 0–14 (Statistics Canada, 2022b). As the most prominent users of primary health care services, it is essential to understand the perceptions of community-dwelling older adults of alternate primary care services so that alternative resources may accommodate their needs and experiences navigating services without a primary care provider. Clinicians, stakeholders such as policymakers and administrators, government officials, and older adults alike will benefit from a further understanding of the experience of this group in using alternate care services. These services will undoubtedly continue to be developed and expanded to meet population needs in the future. In this master's thesis, I will explore older adults' experiences, journeys, perceptions, and perceived outcomes while accessing primary health care services without a primary care provider in New Brunswick.

Search Strategy- Literature Review

Three databases were searched to explore the published knowledge of access to primary care services in New Brunswick, consider what is known about older adults' experiences accessing primary health services without a primary care provider, and investigate the ideal models for primary care within the province and across the country. CINAHL, Medline, and Embase databases served as the primary repertoire for academic publications about community-dwelling older adults, primary care, and access to health services. Additionally, collecting grey literature was essential to understanding the current expectations, best practices, and policies related to primary care in New

Brunswick, and thus, Google Scholar and the Google search engine were utilized to access and investigate government policies, clinical, educational resources, and advocacy documentation from various non-for-profit groups in the province.

Primary Care

It has been known for over two decades that in high-income countries, health systems most oriented toward primary care have better outcomes, lower costs, and greater patient satisfaction (Hansen et al., 2015; Starfield, 1994). Primary health care services include routine care for urgent but minor health problems, chronic disease prevention and management, health promotion, and other first-point-of-contact services such as mental health care, maternity, and childcare, psychosocial services, liaison with home care, nutrition counseling, and end-of-life care. A robust primary care system is recognized as the cornerstone of health systems and is essential to the health system's success (Starfield et al., 2005). Primary health care is the most inclusive, equitable, cost-effective, and efficient approach to supporting the mental and physical health of the population (World Health Organization, 2021). As the first point of contact for the more extensive health system, primary health care has the unique opportunity to provide upstream care that can relieve the burden of care placed on acute care services. Robust primary care systems deliver improved access to health services, better coordination and integration of care, improved quality/appropriateness, and increased focus on prevention (Hutchison et al., 2011). Such systems focus on managing chronic and complex illnesses, promote greater engagement and self-management, and deliver improved experiences for persons seeking care and providers. In contrast, health systems with less emphasis on primary health care often see higher health costs, poorer population health, lower patient satisfaction, more

unnecessary hospital admissions, and lower success in addressing the needs of persons with multimorbidity (Starfield et al., 2005; van Weel &. Kidd, 2018). As mentioned, primary care is delivered by primary care providers, often family doctors and nurse practitioners; however, other health professionals, such as pharmacists, midwives, physiotherapists, and emergency room physicians, also play a role in delivering these services.

Trends in Primary Health Care Access

Approximately 85.5% of the Canadian population are attached to a designated primary care provider; however, just 38.7% report the capacity to access same-day or next-day appointments with their regular provider (Grant & Thanh Ha, 2023). New Brunswick reports above-average numbers of attachment with nearly 90% of the population assigned to a primary care provider (New Brunswick Health Council, 2021; Statistics Canada, 2019). However, it should also be noted that being assigned to a primary care provider does not assure timely access to primary care services. For primary care services, *timely access* is defined in New Brunswick as the ability to see your provider within five days (New Brunswick Health Council, 2021). Just fifty-one percent of New Brunswick residents report having timely access to their primary care provider, and only 57% of New Brunswickers with an attached provider record typically seeing them when in need of care (New Brunswick Health Council, 2021). This is particularly concerning given the demographic composition of New Brunswick, which is statistically older, more remote, and poorer compared to other Canadian provinces and thus more adversely impacted by lack of access to primary health services (Statistics Canada, 2022c). The most common reasons why Canadians do not have primary care providers

include feeling as though they do not need one or they access services elsewhere, there are no providers available in their area who are accepting new clients, or their previous provider recently retired or left their community (Statistics Canada, 2019).

Ideal Delivery of Primary Health Care in Canada

In 2002, the Canadian government released the Romanow Report, written by former Saskatchewan New Democratic Party Premier Roy Romanow. This report presented recommendations supporting the need for a coordinated national approach for health care planning and outlined best practices to promote the long-term sustainability of a universally accessible and publicly funded health system (Browne, 2004). This report has been used to inform the policies addressing the health care system's demands and set the groundwork for health care reform in Canada. The collaborative approach suggested in the Romanow report is now being taken quite seriously across Canada, particularly in primary care, to improve patients' outcomes and provider well-being. Provincial and territorial health policies are also in place to address the shortfalls of primary care and contribute to improving patient and provider experiences. In fact, in a summary of the primary care models prepared for the Canadian Foundation for Health care Improvement in 2018, it was found that British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, and Newfoundland and Labrador have had some model for collaborative health care in place for the past decade (Peckham et al., 2018).

The policies governing these jurisdictions contain common themes centered around high-quality, patient-centered care that provides the best health service at the most economical cost. However, despite these frameworks for care, the lack of legislative requirements for such an approach to primary care limits the impacts of these policies.

Team-based and community-centered care is a priority in provincial primary care frameworks, and emphasis on accessibility and sustainability is evident through the best practices outlined by health professional organizations, however, the practical impacts of these non-binding policies are limited.

Despite the apparent demand for primary care reform and well-researched directionality for an improved system, Canada does not have a national standard for primary care. The Canada Health Act (1984) is Canada's federal legislation for publicly funded health services. It dictates the requirements for the provision of health services delivered by the provinces and territories so that they may receive funding, in the form of the Canada Health Transfer, from the federal government to support health services delivered in their region (Olubanwo, 2014). The Canada Health Act is broad in its objectives. However, it generally requires that health systems in Canada serve to "protect, promote and restore the physical and mental wellbeing of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (The Canada Health Act, 1984, p.5). The Canada Health Act focuses primarily on insurance coverage and requires that medically necessary services be insured by provincial or territorial insurance and, therefore, available to residents. The exact services deemed essential are not clearly articulated in the Act. As a result, some health services that may be considered essential in maintaining good health and are often associated with primary care services, such as out-of-hospital prescription drugs and mental health services, are not required to be covered or adequately provided by the province or territory (Tiedemann, 2019). Thus, the provincial or territorial governments are responsible for determining which services and resources are included in their regional insurance

coverage. Additionally, the wide variation in services included in provincial/territorial health coverage varies dramatically between regions. Persons may have access to a service through provincial health insurance in one province but not in another.

Due to the provincial/territorial regulation of health services, it is up to each province to dictate what the future of primary care should look like for its residents. Research suggests that interprofessional teams of health professionals could dramatically improve access for persons seeking care, as could a remodeled payment model for primary care (Kiran, 2022). As with the current requirements of the Canada Health Act, Public Administration, the documentation of services delivered in the health system, is required to access the Canada Health Transfer (The Canada Health Act, 1984). The time to document these services is often unpaid in the current health model, particularly in primary care, and often acts as a barrier to efficient care. Remodeling this system could positively impact the accessibility of primary care services. Countries that have invested in their primary care services have succeeded in making their services accessible to their populations, seeing reduced hospital spending, and reporting greater satisfaction (Hutchison et al., 2011). Canada has identified on numerous occasions that primary care services should be positioned to align with these interdisciplinary models. However, a clear direction for primary care providers across the country is lacking. Across the provinces, leadership bodies such as professional groups, health-associated non-profits, and health authorities call for varying priorities ranging from physician payment to broader population health goals and infrastructure development (Aggarwal & Williams, 2019).

Patient's Medical Home

In 2011, the College of Family Physicians of Canada released its idealized model for primary care delivery in an attempt to develop national standards in response to the identified demand for revised primary care services in Canada, (Gutkin, 2011). The first version of the primary care best practices and guidelines policy document, titled 'Patients Medical Home', was released in 2011. This document is designed to support family physicians (and nurse practitioners) across the country in implementing essential practices to improve the quality of primary care across Canada. It provides clear expectations for governments, other health professionals, and patients on how a primary health care system could be structured to meet the needs of Canadians. Ten ideals emphasize the importance of accessible, interdisciplinary, person-centered practices. A revised version of the guiding document released in 2019 aims to reflect current national circumstances better and address current realities that primary care providers face in their practice (College of Family Physicians of Canada, 2019). The 2019 version reframed the 2011 ideals into three central themes: foundations, functions, and ongoing development.

The revised model maintained its focus on accessible, interdisciplinary, and continuous care with a renewed emphasis on person and family-centered care, community adaptiveness and social accountability, and continuing professional development. This framework intends to facilitate an ideal model of primary care in Canada, however, due to lack of provincial regulations requiring such a model is largely up to primary care providers to implement. Patients medical home is the “gold standard” for primary care though is largely implemented on an individual basis and thus has not significantly impacted care for most people in Canada. Despite these idealized models,

and the awareness that these stadards of care are not required to be upheld, there is little understand of the impact that the current system has on patients. Specifically, research is limited regarding the experiences of older adults accessing primary care without primary care providers.

Pillars of Primary Care

Primary care is identified in the literature and practice as an essential component in delivering equitable and integrated care services. Primary care provides an opportunity for community improvement and reduces inequalities between groups by providing accessible, affordable, and appropriate services (Behera & Prasad, 2022). The foundation of this objective is built upon four pillars of primary health care.

1. Community participation: a social approach involving community health service providers being active and attentive members of their communities who are attuned to their community's needs, circumstances, and experiences.
2. Intersectoral coordination: the collaborative efforts of a multi-disciplinary team of health care providers in the integrated delivery of care as is practiced in other aspects of health and various other industries to provide a holistic and team-based approach to the delivery of services.
3. Appropriate technologies: the availability of tools and health systems resources to support the delivery of primary health services and meet the needs of the community and providers.
4. Available support mechanisms: address the critical importance of support mechanisms that are instrumental in the personal, spiritual, mental, and physical

goals of primary care and the adequate distribution of human resources to deliver appropriate services to their communities (Behera & Prasad, 2022).

As noted by Behera and Prasad (2022), while these pillars exist in the literature and are among the identified core components of a successful primary health care network, they must be consistently represented in health policies or best practices. The general understanding of primary care as a cornerstone of the health system is apparent in the body of published research; however, the practical application of this message is varied across the health services landscape.

Current Realities in New Brunswick

New Brunswick is a small province situated in Atlantic Canada. Approximately 776,000 people live in New Brunswick; just over 23% of the population is above 65 (Statistics Canada, 2021). French and English are the two official languages of the province, with about 30% and 70% of the population identifying French and English as their primary languages, respectively. New Brunswick reports one of the highest rates of poverty in Canada, approximately 20% of older adults live in poverty, and a diversifying population with high rates of immigration (Canada, 2022). New Brunswick has critical urban centers (Moncton, Fredericton, Saint John), and according to the 2021 census data, approximately half of the population lives in rural communities (Canada, 2022). This is notable as many New Brunswick residents travel to one of the three larger urban centers to receive more specialized health services. Thus, primary care services are thus essential to New Brunswick in supporting accessible health services close to home.

Alternative Primary Care Services in New Brunswick

New Brunswick offers various alternate primary care services for those unable to see a primary care provider in a traditional clinical setting; much of the innovation on this front was catalyzed by the demand for change during the COVID-19 pandemic. These alternate options include expanded telehealth services, increased utilization of pharmacists in primary care delivery, walk-in and virtual clinics, and extended mental health and reproductive health services (Government of New Brunswick, 2022). Telehealth services developed to support COVID-19 needs have been maintained and are accessible via landline or cell phone. The capacity of pharmacists to renew existing prescriptions, prescribe for minor ailments, and deliver vaccinations has been increasingly promoted. These services prevent reliance on local emergency departments by persons seeking primary care services; however, emergency departments can also deliver these services if other options are limited. Further, longer-term solutions such as increased medical and residency seats and increased recruitment efforts are also in place to support primary care reform (Government of New Brunswick, 2022). However, these long-term solutions offer minimal relief for the current health services and will not have a significant effect for years to come.

Planning for the Future

In 2021, the New Brunswick Department of Health released "Stabilizing Health Care: An Urgent Call to Action," which outlined their commitment to stabilizing health care across the province by the fall of 2024 (New Brunswick Department of Health, 2021). This report lists calls to action, a timeline for provincial reform, and outlines the provincial direction for the primary care sector. The calls to action are based on their comprehensive public engagement initiative, held in the spring of 2021 when the health

system was under increased strain due to the pandemic. While the pandemic did not ignite the need for health system reform, it illuminated the gaps in the system and the ways that many populations were being 'let down' by the current health services delivery model. The report claims that by the end of 2024, the waitlist for primary care will be fully addressed.

The 2021 report also highlights upcoming digital personal health records through the MyHealthNB platform, improved services to older adults living at home, and a centralized referral process. These actions aim to deliver the right services to the right people at the right time. The expanded primary care services are intended to build upon the existing infrastructure, which includes telephone, virtual, and in-person care. Specifically, in April 2024, the New Brunswick Health Council reported that the Government of New Brunswick has launched a Provincial Primary Care Network, available by registration for people without primary care providers, and is beginning to accept appointments. However, the Patient Connect List is still in place (intended to be dismantled by fall 2024), Community Care Networks have not yet launched, and NB health link has not been integrated with Tele-Care 811 (New Brunswick Heath Council, 2023).

Further, a two-part report from the New Brunswick Child, Youth and Seniors' Advocate released in the spring of 2024 calls for immediate action in access to primary care services through urgent reform (New Brunswick Child, Youth and Seniors' Advocate, 2024). The reports are written in accessible language and intended to highlight the years of neglect and strain that have resulted in the current healthcare crisis in New Brunswick. In fact, the final recommendation from the overarching report on health care

addresses the need for accessible primary care and mental health services, as well as a functional emergency and alternate point of access system to prevent patients from being without appropriate care. The reports indicate a strong need for deeper understanding of the experiences of those without primary care access, and a strengthened body of research to support the urgency of primary care-centered reform in New Brunswick.

Older Adults

The impact of a lack of access, such as that experienced in New Brunswick, is profound for populations relying on primary care services more heavily and those more vulnerable. People of lower socioeconomic status, people with disabilities, and older adults are among this group. The literature recognizes community-dwelling older adults as people over 65 who reside in personal homes. This review focuses on community-dwelling older adults as opposed to persons in residential care settings such as long-term care homes, whose experiences are often unique.

In Atlantic Canada, the percentage of the population of older adults is the highest in the country and is steadily climbing (Statistics Canada, 2022a). In 2015, New Brunswick recorded more deaths than births for the first time. As mentioned, older adults depend on primary care and health care services more than any other age group (Health Council of Canada, 2005; McGeorge & Bateman, 2017). While they are more likely to have an attached primary care provider than other demographics, those who are without or who are unable to seek timely access are consequently subject to a more significant impact than other persons seeking care. Healthy aging constitutes maintaining the functional ability that allows for well-being in older age (McMaughan et al., 2020). Maintaining good health, disease and disability prevention and management, and a

healthy lifestyle are central to healthy aging. Efforts are in place to promote healthy aging in New Brunswick as is emphasized in the New Brunswick Provincial Health Plan (New Brunswick Department of Health, 2021). However, access to healthy aging depends on sufficient financial resources to engage in leisure and lifestyle activities and is directly correlated to the social determinants of health (McMaughan et al.).

In 2014, it was reported that 39% of older adults in New Brunswick had three or more chronic health conditions (Jeffery et al., 2018; Province of New Brunswick, 2017). Overwhelmingly, older adults in New Brunswick want to be able to age in place (New Brunswick Child, Youth and Seniors' Advocate, 2024). Aging in place encompasses remaining at home in their communities, surrounded by the people that are important to them, and in places that they love. Keeping older adults at home is a priority in the New Brunswick strategy for aging and would provide some relief for the long-term care homes of the province, which are at total capacity (MacKinnon, 2022). Access to adequate primary care services is critical for aging in place. If older adults cannot efficiently address their health needs in their communities, they may be required to make lengthy and expensive trips to larger population centers or relocate to communities that can serve them well. Alternatively, if they forgo the services that they require due to an inability to access primary care services, older adults can experience adverse health outcomes. Being without primary care access can lead to premature and costly long-term care or more frequent and severe hospital services (Menec et al., 2006). In Northern Ontario, it was found that the risk of in-hospital mortality drastically increased by 56% for older adults without primary care providers (Peel et al., 2019). This alarming statistic is the result of a lack of access to continuous and preventative primary care services, resulting in poorer

health outcomes and a dramatic increase in the likelihood of hospitalization and death.

In the literature, people without primary care providers are occasionally referred to as 'unattached'. Elsewhere in Canada, adverse outcomes have been reported amongst older adults who fall into this group (Marshall, White, et al., 2022). In 2021, the consequences of being *unattached* were studied in Nova Scotia and provided insight into what may be expected in New Brunswick based on similar contexts. The authors found that people who were unattached experienced a 'burden of care' and felt a negative impact of navigating care independently and taking personal responsibility for navigating the health system (Marshall, Wuite, et al., 2022). These findings apply to the experiences of New Brunswickers due to similar geographical, demographic, and political circumstances. The study also found that this burden was likely amplified for persons with more significant health needs, such as people with chronic illnesses and older adults (Marshall, Wuite, et al., 2022).

Perceived Health Outcomes

Despite the recognition of the importance of primary care in supporting the health outcomes of older adults, minimal research has been undertaken to explore the experiences and perceptions those accessing or relying on alternate primary care options (e.g., benefits, challenges) or their perceived health outcomes, specifically in New Brunswick. In 2009, in Eastern Canada, Gould et al. studied the perceived functions or purpose of alternative primary health care options (e.g., telehealth and walk-in clinics) (Gould et al., 2009). They found that younger, middle-aged, and older adults shared similar perspectives and used similar criteria for deciding when to seek alternate options. This is important to consider when scaling up existing services, as it contradicts the

common (and often ageist) assumption that older adults cannot use technology-based resources or have different understandings of health services. However, experiences of service utilization and related health outcomes were not explored in this work. Studies exploring health system users' perceptions help better understand the patient experience and provide insight into the personal barriers, facilitators, and recommendations for health system improvements, rather than solely relying on clinical data (Lafortune et al., 2015). For example, Ontario-based researchers conducted focus groups to explore perceptions of community-based primary health care for older adults (Lafortune et al., 2015). They found that poor system integration and limited access to services were barriers to accessing health services through a program designed to support older adults. Participants generated recommendations for future system improvement, including expansion and integration of care teams and modifications to support system navigation and standardized pathways. While these findings can lend some insight into the direction New Brunswick may take to support older adults in accessing primary care services, ultimately, these findings highlight the need to make changes and support services that are informed by and benefit the people who use them. The results from the Ontario study have the potential to inform the direction of primary care at multiple levels to ultimately deliver better care to older adults in their region (Lafortune et al., 2015).

Similarly, when a large sample of 533 older adults from Saskatchewan responded to a survey asking, "What suggestions can you make to engage someone in their health and health care?" it was determined that older adults want to be included in conversations about primary care reform and in advocating for services that suit their unique needs (Tzeng et al., 2019). Exploring the perceptions, perceived outcomes, and unique

experiences of older adults in New Brunswick is needed to improve understanding of the barriers, facilitators, and experiences that impact their ability to access primary care services. This understanding is essential in a time of reform.

Consideration for Socioeconomic Status

Socioeconomic conditions also contribute to inequitable access to primary health care services. Across the country, approximately one in five Canadians over 65 live in poverty (MacAfee, 2022). These numbers vary significantly depending on gender, race, marital status, caregiver status, and ability. Approximately one-fifth of older adults in New Brunswick are considered low-income (Beaudin, 2018; L'Association francophone des aînés du Nouveau-Brunswick et al., 2019). This is comparable to other Atlantic provinces where poverty rates and percentages of the population above 65 are the highest (MacAfee, 2022). It is well known that despite universal health coverage in Canada, low-income is directly correlated with poorer health (Shimmin, 2022). For example, the incidence of cardiovascular disease, diabetes, cancer, and mental illness is higher among low-income populations in Canada. People reporting low-income are more likely to report not receiving needed care in the past 12 months and are 40% more likely to report waiting more than five days for a doctor appointment. Additionally, compliance with medical treatment tends to be lower among individuals living in poverty, which results in more frequent use of emergency departments for treatment. These rates of compliance can be attributed to low-income groups being less likely to fill prescriptions and access services such as physiotherapy or occupational therapy and some mental health services due to additional costs that are not covered under provincial health plans.

When considering access to health services, particularly alternative forms of care,

the impact of socioeconomic status and life experience cannot be overlooked. Access to education, financial and social capital, and the ability to navigate new means of access are all associated with carrying the burden of care associated with accessing primary health care services without a primary care provider (Marshall, Wuite, et al., 2022). In 2020, McMaughan et al. developed a framework for considering socioeconomic status, the Theory of Socioeconomic Status and Access to Health Care, which reflects the role of intersectionality in examining older adults' access to health care. According to the framework, when considering access to health services, it is critical to account for the availability of relevant and effective services and providers, physical accessibility and affordability, how accommodating services and service providers are, and the acceptability of the services and service providers to the patient (McMaughan et al., 2020). The Theory of Socioeconomic Status and Access to Health Care supports a holistic view of the experiences of older adults. It offers an opportunity to guide the exploration of the social contexts that impact older adults' access to primary health care services in New Brunswick. In a time of ongoing primary care reform and alternate service development, it is critical to understand the experiences of the most frequent users of primary healthcare to ensure the health system is making strategic changes that support its users. Having a clear understanding of what is working and what is not, from a patient perspective, promotes systemic person-centered care, saves precious resources, and drastically impacts the health outcomes of residents.

Availability

Availability of health services refers to the opportunities to seek care based on adequate community resources, for example, sufficient providers to serve a population or

readily available alternate care services (McMaughan et al., 2020). Alternate care services exist to improve the availability of primary health care services and alleviate the demand for resources that are not best suited to support primary care services. In New Brunswick, 10% of the population utilizes the emergency room of their local hospital when they require primary health care services (New Brunswick Heath Council, 2023). In most urban regions of the province, emergency departments offer 24-hour services, thus are continually available as an option to people seeking care who may otherwise wait weeks to see their primary care provider or may be unaware of alternate means of accessing care. If other services are available to the same extent, the demand for emergency departments may be diminished, and care can be delivered in the community.

Alternatively, many rural communities in New Brunswick experience reduced hours in their emergency departments, sometimes unexpectedly, due to staffing shortages (Lothian, 2023). In these instances, persons accessing emergency medical attention must travel to larger centers for care, and they have diminished access to alternate pathways to meet their primary care needs. While New Brunswick is increasing the availability of walk-in clinics, and many pharmacies are open 'after hours' late into the evening, the traditional availability of daytime hours for primary care providers is a potential barrier for persons seeking care. People who work long hours, shift work, or non-traditional schedules cannot utilize daytime services (McMaughan et al., 2020).

Further, these services are not episodic and thus do not offer the continuous and follow-up care that is the cornerstone of most successful primary care. A further understanding of the perceived availability of alternate primary care services for older

adults would support an improved understanding of barriers and facilitators to primary health care access.

Accessibility

Accessible care refers to health services that can be appropriately utilized by the population they serve and that address their needs with as few complications as possible (McMaughan et al., 2020). The New Brunswick Health Council emphasizes a "right person, right provider, right care, right time, right venue" model when considering accessible care (New Brunswick Heath Council, 2023). This model intends to match persons seeking care with a health care professional with an appropriate scope of practice who can provide evidence-based care promptly at a safe and efficient location. According to the New Brunswick Heath Council, access to a health care provider within five days or less constitutes timely access to primary health care services.

Team-based approaches, appropriate use of scope, and virtual services support accessible primary care services. However, the ability to deliver a team-based approach, rely on other health professionals and access virtual care services depends on adequate staffing, sufficient resources, and reliable internet connections, all of which are only present in some communities in New Brunswick. A 2023 study of primary care access in New Brunswick found that primary care services are more accessible when the provider spends most of their working time at their primary care clinic rather than rotating between hospital and clinic roles (Manuel et al., 2023). In rural communities, many primary care providers must cover clinic-based (private practice) and hospital-based duties due to the limited number of physicians or nurse practitioners. Further, the study

found inconsistent policies and regulations for consult expectations (numbers, length, etc.) for primary care providers between regional health authorities. This inconsistency could prompt further disparities in access between English and French-speaking regions of the province. The sole existence of two regional health authorities in New Brunswick, one English-speaking and one French-speaking, with unique policies and regulations, may contribute to variations in access to care, from a primary care provider or otherwise, in one's preferred language. This will not be explored in the proposed master's thesis; however, it offers potential for further exploration in the field.

Affordability

The cost of health services, particularly those delivered via primary care services, can accumulate quickly despite universal access to some level of health coverage granted to residents of New Brunswick. In addition to the cost of medications (prescription and over the counter), access to health services in New Brunswick can require substantial financial output from persons seeking care. Specialist care is often only available in larger city centers; thus, rural residents must travel for appointments and procedures. Even persons who live in the larger city centers are often required to travel for health services due to the distribution of specialist care across the province due to the small size of the population (Government of New Brunswick, 2022). The cost of transportation and accommodations (if required) for the person seeking care and their support team can be a barrier to access to care. While primary care cannot provide all necessary services for older adults, access to a community-based or virtually accessible provider lessens the travel demand. It thus reduces some of the burden of accessing health services in New Brunswick. Outpatient medications, such as those prescribed by primary care providers

and administered through community pharmacies, are subject to payment if insurance is insufficient or unavailable or the drug is not covered under provincial or private drug coverage plans. Additional medical equipment and devices, such as walkers or railings, and non-essential medical services, such as physiotherapy and mental health services, fall under the same umbrella (The Canada Health Act, 1984).

Limitations in Current Knowledge

There are limitations to the current body of research about the experiences of older adults in accessing primary care services without attachment to a primary care provider in New Brunswick. The increased reliance on alternate primary care services to meet the population's needs is a recent demand characterized by the aging workforce and shift in human resource availability to meet the population's needs (Li et al., 2023). Comprehensive research anticipating perceived outcomes for patients in the foreseeable shift of primary health services is lacking across the country, as is the focus on perceived health outcomes/experiences of older adults' interactions with primary health services. While some recent publications address the state of primary health services and the use of alternate primary care in the Atlantic provinces and other comparable regions of Canada, such as Northern Ontario, the literature is limited in this domain and the region of interest. Atlantic Canada, while unique in demographics and circumstances, often relies on the best practices and experiences of other Canadian provinces, which are also currently lacking in this field of study, particularly pertaining to older adult’s experiences with independent health management, perceived health outcomes related to primary care access, and health system navigation. Extensive further research is required, however qualitative studies are particularly needed to explore the perceived outcomes of older

adults seeking care from other alternate primary health care services in various regions and further consider older adults navigating primary health care services with limited access to regular primary care providers. Specifically, the aging population, such as those in more rural communities, has not been explored. However, their experiences would support the reform of primary health services in a way that best serves the population who relies most heavily on their services.

Chapter 2 - Researcher Positionality

As a product of my environment and background, I present my work as a community/people-oriented problem solver in almost every facet of my life. As a cis-gender, white, heterosexual, able-bodied settler from an educated middle-class family, I recognized the privileges that I experienced in my interactions with my community and with the world. I have been taught to value others and their unique experiences in the same way I do my own, to ask thoughtful and inquisitive questions to expose the root causes of challenges in question, and to ensure that my work contributes to positive change in some capacity. These values and intentions are reflected in my actions and research. I enjoy spending my time and energy on activities and commitments that support others. I value the opportunity to do this in a way that contributes to a greater understanding of the question at hand. I firmly believe that to do better, we must know better, and I aim to uphold this principle in my academic and personal endeavors. As a researcher, it is valuable to consider the views and beliefs that I bring to my work concerning the nature of the world, knowledge, and truth. In this section, I will reflect on my ontological, epistemological, and axial perspectives to further understand my position as a researcher.

Ontology is an individual's beliefs about the nature of social reality and what is knowable about the world (Holmes, 2020). My current ontological stance most aligns with a relativist perspective. A relativist ontology prompts learners to consider the subjective experiences of reality and the multiple truths therein (Levers, 2013). It suggests that reality is a finite subjective experience, and everything exists within our thoughts. In short, the world is only as we experience it. I see the world as a product of

one's experience, which is compiled to create a subjective human experience unique to everyone. As a learner and researcher, there are as many perspectives as there are people- each person experiences their subjective reality in the world we share.

Epistemology is an individual's belief about the nature of knowledge and how knowledge is acquired (Holmes, 2020). In exploring my positionality as a researcher, I understand that my current epistemology aligns most with that of constructivism. The constructivist view is underpinned by the values of sociocultural influences in the learning process (Peters, 2000). It validates building knowledge on previous learning, rather than knowledge discovered or brought to light from the unconscious. I see knowledge as a product of our creation and human decisions. I understand learning as the capacity to expand on what we already know through the collective construction of ideas and theories. I also resonate with knowledge being both limited and expanded by our capacity to create knowledge from the world around us—we are limited by what we can generate but are also enabled by our capacity to develop further thinking.

After thoughtful consideration and explanation of my relevant experiences, views, values, and philosophical stance, I can further consider how my perspective relates to and impacts my research. I have been interested in health for many years, but my personal experiences propelled me to do this work with older adults and primary care. When I was beginning university, all four of my grandparents experienced health complications that amplified their complex realities as older adults and their dependency on the health system. I saw that the experience of each older adult in my life was unique, and their interpretation of their health and health-related realities was subjective. I watched as they struggled to navigate accessing care, advocating for their needs, interpreting their

environment, and managing their health. I volunteered at my local hospital in high school. I had spent significant time with older adults receiving acute care treatments, so I knew enough about their experience to have many questions but not enough to have very many answers or provide advice for navigation.

In summary, my past educational curiosities, my interest in health, and my personal background prompt me to consider the experiences of older adults in the hope that researchers, health care providers, and key stakeholders alike can use this knowledge to provide more accessible and well-received care. This understanding of experience reflects my philosophical stances and encourages my work. In alignment with my philosophical views, I am interested in the role of intersectional systemic factors (such as socioeconomic status, education, gender, income, etc.) on older adults and their access to care.

Chapter 3 - Methods and Methodology

This chapter outlines the research questions, methodological approach, and methods. Considerations for ethics are included, as is a description of the sample and recruitment process. The analytical framework and process for analysis are described and are followed by a validation of the trustworthiness of the study.

Research Questions

1. What are English-speaking community-dwelling older adults' experiences, perceptions, and perceived outcomes of accessing health care to meet their health needs without a primary care provider in New Brunswick?

2. How does socioeconomic status impact older adults' perceptions of navigating primary health care services without a primary care provider in New Brunswick?

Methodological Approach

This study utilized the methodological approach of interpretive description. Interpretive description offers a qualitative naturalistic approach to inquiry closely aligned with constructivism. Interpretive description was developed by nursing researcher Sally Thorne and was created to provide a credible method to develop clinical knowledge with significant health science applications (Thorne et al., 1997). The methodological approach of interpretive description suggests there is value in clinical knowledge, relevance, and formal and published research. This means researchers need to conduct relevant research that can be effectively translated to address a gap or support practice. In maintaining this philosophy through the study, interpretive description provided an

approach that emphasized the importance of a person's experience and health services realities, and considered pre-existing d literature on experiences of health and illness. This methodologic approach fit well with the questions for this study and the goal of interpreting personal circumstances may influence experiences, in order to ensure future reforms to healthcare system can reflect the needs of those it serves. Participant recruitment was intended to encourage diverse perspectives to articulate applicable findings.

Further, data analysis was rooted in critical deliberation rather than simply sorting and compiling the data. Reflective questions such as "What am I learning about this?" and "What is happening here?" are strongly encouraged within this framework and were utilized in the data analysis. Interpretive description encouraged holistic incorporation of person-centered perspectives and epistemology ideally suited for this study.

Interpretive description suggests the use of an analytic framework, whereby the researcher uses existing theory/literature as scaffolding to help guide aspects of the study, for example, participant recruitment, interview guide creation and preliminary coding. In this study, McMaughan et al.'s Theory of Socioeconomic Status and Access to Health Care (2020) was used as an analytic framework which assisted with the consideration of social contexts in exploring perceptions of primary care access. Overall, the use of interpretive description as the methodological approach and McMaughan et al.'s Theory of Socioeconomic Status and Access to Health Care for analysis ensured a holistic perspective and a consistent foundation for practical applications for the work.

Methods

The following section details the methods for this study including consideration for ethics, sampling and recruitment, data collection and data analysis.

Ethics

Approval from the University of New Brunswick ethics board was obtained prior to the data collection process and the Tri-Council Policy Statement guided all aspects of the study. The Tri-Council Policy Statement 2: Course on Research Ethics was completed in January 2023 prior to starting this study. There was minimal risk for participants involved in the study and there was no deception or partial disclosure involved in the study. Recruitment is described in further detail below and allowed for participants to contact researcher to express interest or inquire about the study. Potential participants who reached out to the researcher were provided with a detailed study information sheet (Appendix E) and offered to have a phone call with the researcher to discuss their involvement in the study. It was emphasized in all communications with potential participants that participation in the study was confidential, that participation would have no impact on their relationship with future or current primary care providers, and that they could withdraw their consent to participate at any time prior to the completion of analysis.

Once admitted to the study, participants shared oral consent which was recorded (audio only) and saved to a password protected file. Interviews were recorded and transcribed verbatim, they were saved on a password protected file on a password protected computer. All identifying data was removed from transcripts and participants were identified by participant ID only. Participants were provided with a $20 gift card for groceries as an appreciation of their time, though the amount is small enough to

incentivise participation. Additionally, participants were provided with a list of mental health resources and a list of alternate primary care services (Appendix F) available in New Brunswick as well as respective contact information for alternate primary care services to supported future navigation of health services.

The study was reviewed and approved by the UNB research ethics board (REB 2023-143) as included in Appendix J.

Sampling and Recruitment

Purposive convenience sampling was used in this study. Purposive convenience sampling involves the recruitment of participants who are easily accessible to the researchers through connections or partners (Sedgwick, 2013). Interpretive description suggests a purposive selection of research participants whose accounts reveal elements that are shared with others in the sample to some degree (Thorne, 1997). It was estimated that 10-15 participants would be adequate to develop an understanding of the experiences in question and determine some sense of data saturation through the articulation of common experiences. An iterative approach was planned to account for the unpredictable nature of the process. Persons were eligible to participate if they were English-speaking adults over 65 who resided in New Brunswick and had either been without a primary care provider for more than twelve months prior to participation or were peer advocates for those without primary care providers. Participants without primary care providers were invited to express their interest in participating in the study via a recruitment poster (Appendix G), which was shared on social media (Facebook and LinkedIn) on various community pages and personal accounts, as was also shared with multiple pharmacies in New Brunswick to post for a one-month period in their locations.

Additionally, snowball sampling was identified as an alternate recruitment strategy if needed and involved utilizing the connections of existing participants to recruit future participants (Parker et al., 2019). Participants could express their interest in the study via email or telephone call and were asked a series of screening questions prior to their invitation to participate (See Appendix C and Appendix D).

Data Collection

Data for this study was collected via virtual semi-structured interviews. The interview guide (see Appendix A) was developed in alignment with the concepts of the interpretive description and McMaughan et al.'s (2020) Theory of Socioeconomic Status and Access to Health Care. Questions considered thorough understanding of personal experiences and consideration of socioeconomic status to create practical knowledge of the experience of being an unattached older adult in New Brunswick. All interviews were conducted by the primary researcher. Due to the desire to engage participants from across New Brunswick and the cost and time associated with traveling across the province, interviews were held via Microsoft Teams and telephone, as per the preference of the participant. Participants were asked a series of demographic questions (Appendix I), and the interview guide (Appendix H) contained a series of eight questions to guide the interview. Due to the semi-structured and iterative nature of the interviews, each conversation was determined by the responses and experiences of those involved. Interviews were recorded and transcribed using the transcription software available with Microsoft Teams and were approximately one hour in duration. The transcripts were then reviewed with the recording to ensure readability and accurate capture of the conversations. Any identifying data was removed.

Data Analysis

The process for analysis of the data included immersion in the data, coding of transcripts, memoing, constant comparative analysis, and intentional reflection of findings/data. Due to the iterative nature of interpretive description, preliminary analysis was concurrent with interviews to allow for modifications to interview questions as needed. Thematic analysis began with immersion in the data which includes thorough review and reflection of the transcripts, followed by the development of an initial coding template and organization of the data based on the template. Coding is the process of analyzing data by deconstructing the data and reconstructing prominent and meaningful themes; Dedoose Software was used to support the coding process for this study (Creswell & Báez, 2020). Preliminary codes were developed based on early interview transcripts; then through constant comparative analysis, a consistent codebook was solidified and used for analysis. Reflexivity was ongoing during this process and following the first round of surface-level coding reflective thematic analysis was used to develop the deeper meaning and impact of the data which is presented in the findings chapter. Each transcript was reviewed a minimum of three times during this process which ensured researcher immersion in the data and profound understanding of the experiences of participants. Reflexive thematic analysis and a bottom-up approach aligned well with interpretive description, which suggests that researchers employ inductive reasoning to produce practically applicable findings and interpret the deeper meaning of the data (Thompson Burdine et al., 2021; Thorne et al., 1997).

Throughout the analysis process, I reviewed interview transcripts, used constant comparative analysis, remained immersed in the data, critically reflected on the data and

on my personal interpretations and sentiments. This ensures a close following with the interpretive description approach that allowed for an in-depth description and interpretation of a phenomenon which is trustworthy, rooted in data, and useful in practice. Ongoing, intentional reflection occurred through conversations with the research supervisor and the use of memos and was followed by constant comparative analysis (i.e., comparing, and contrasting data within similar participant categories and comparing and contrasting data with different participant categories). Themes were identified based on the application and meaning of surface-level codes and sought to describe the broad experiences. Lastly, member-checking interviews were conducted with three participants to confirm the findings and allow for a collaborative deduction of meaning with participants; the three participants supported the findings and maintained that they felt their experiences were reflected in the findings. They also anticipated that their peers in similar situations would see themselves reflected in the findings in some capacity given the breadth of the themes.

Trustworthiness of Data

Strategies for rigor and trustworthiness are critical to the creation of credible, dependable, confirmable, and transferable findings in qualitative research (Lincoln & Guba, 1986).

- Credibility aims to establish that the results are true and believable (Lincoln & Guba, 1986). Credibility was established in this study through an iterative interview guide which allowed for adaptation to new circumstances, as well as in

debriefing with my supervisor consistently throughout the data collection and analysis processes.

- Dependability intends to ensure that the findings of the study could be reasonably repeated with the same participants and a researcher who holds comparable perspectives (Lincoln & Guba, 1986). In this study, dependability was established through thick description of methods and findings and the maintenance of an audit trail which depicts the reflexive process throughout the study.
- Confirmability promoted that findings can be confirmed by another researcher and was established through triangulation with my supervisor and committee member during analysis of the findings, as well as through member checking interviews (Lincoln & Guba, 1986). Data triangulation is the process of using multiple methods or data sources to develop a comprehensive understanding of the phenomena and support rigor in the co-creation of knowledge (Patton, 1999).
- Transferability denotes the extent to which the results can be transferred to other contexts or settings (Lincoln & Guba, 1986). While individual contexts will vary, the achievement of hypothetical data saturation through the consistent homogenous experiences of participants ensure that these findings can be transferred to other older adults, similarly privileged people in Atlantic Canada, and broadly to persons who are without primary care providers in Canada.

Further, interpretive description emphasizes that researchers intentionally reflect on the potential impact of bias in the study to ensure trustworthiness. I have done this in forming my positionality statement and through reflexive journaling. Reflexive journaling was practiced both in preparation for and following each interview with

consideration for researcher expectations and assumptions, the emotional impact of the interview, notable/surprising comments/experiences discussed, and how I might change my approach for future interviews. This active reflexivity was maintained throughout data collection and analysis to support transparency, demonstrate critical reflection, and encourage reproducibility (Williams, 2018).

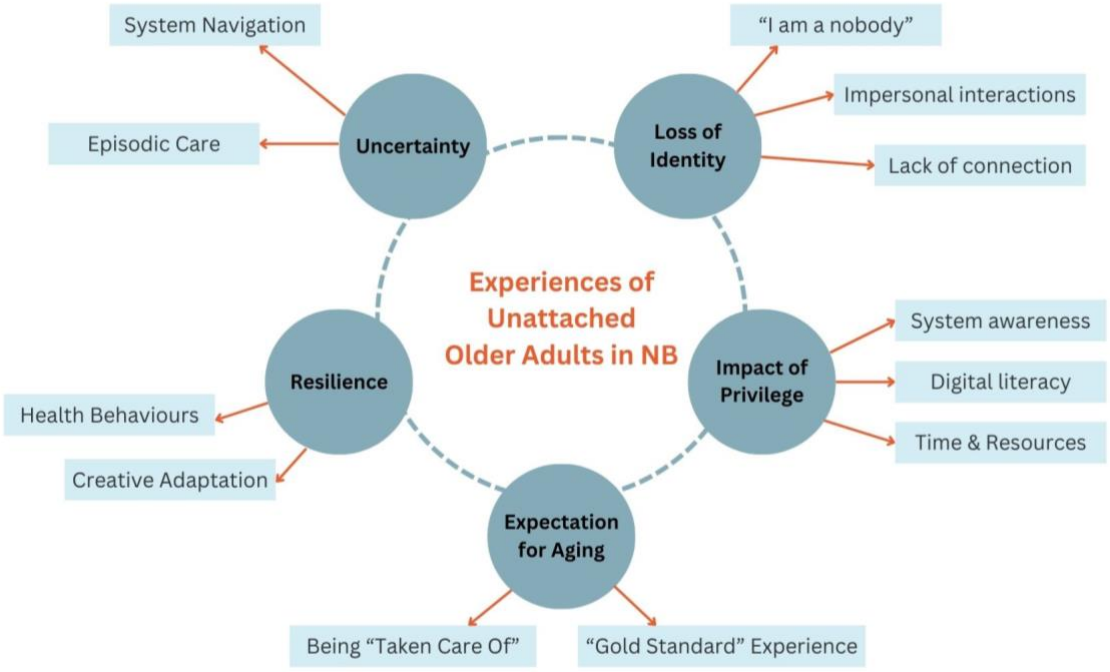
Chapter 4 - Findings

This chapter addresses the findings from this study which explored the experiences and perceptions of older adults accessing primary care services without a primary care provider in New Brunswick. A description of participants and contextual background is provided, followed by five primary themes. These five themes are:

1. "You don't know what you don't know"—Uncertainty is Certain, insecurity in the healthcare system,
2. "I'm a nobody"—Left Behind, loss of identity without a primary care provider,
3. "Rob Peter to Pay Paul"—Privilege in our Health care System, the impact of privilege on health system success,
4. "The Gold Standard"—Product of their Times, impact of age on participant's experiences, and
5. "I want to be healthy"—Resilience and Strength, recognition of the hope that the participants manage to create in a challenging circumstance.

An overview of the themes and their central tenants is displayed in Image 1. An expanded thematic visual of the themes is also included in Appendix A. A table of supplementary participant quotes has also been included in Appendix B to further support the participant quotes included in this chapter.

Figure 1 - Thematic Visual of Themes



Participants

This study included 14 participants, which allowed for both diversity in perspectives and similar experiences with the phenomenon of interest. Two participants were identified as peer advocates and worked to support older adults without primary care providers, and 12 were without primary care providers. Further participant descriptors are outlined in Table 1.

Table 1 - Participant Demographics and Descriptive Statistics

Participants (n=14)	Role	Unattached older adult = 12 (86%)
		Peer Advocate = 2 (14%)
	Gender	Woman = 9 (64%)
		Man = 5 (36%)

	Education	Trade / Community / Vocational College = 3 (21%)
		Undergraduate University = 6 (43%)
		Graduate Degree = 4 (29%)
		Professional Degree (Nurse Practitioner, Doctor, Lawyer, etc.) = 1 (7%)
	Self-Identification (multiple may apply)	White = 13 (93%)
		Acadian = 2 (14%)
	Location	Rural (population less than 10,000) = 4 (29%)
		Urban (population more than 10,000) = 10 (71%)
Participants-Unattached Older Adults (n=12)	Age	Average = 70.1
		Minimum = 63*
		Maximum = 85
	Income	Less than $20,000 = 1
		$20,000 - $49,999 = 2
		$50,000 - $79,999 = 2
		$80,000 - $109,999 = 4
		$110,000 - $199,999 = 3
	Time without primary care provider	1-2 years = 5
		2-5 years = 5
		5+ years = 2
	Living Arrangements	Living with spouse/partner = 8
		Living alone = 4

*One participant below 65 was included in the study- they were 63 during the interview. This participant had previously experienced precarious housing. It was suggested that due to their age and past precarious housing circumstances, those younger than 65 may relate to the experiences of older adults who have not experienced precarious housing. Thus, this participant was included in the study as an exception to the inclusion criteria.

Context—Building Blocks for Current Experiences

All participants for this study had been without a primary care provider for longer than one year during the interview. Reasons for being without a primary care provider included the recent retirement of a provider, providers leaving their roles to pursue other opportunities in acute or virtual care, and recent relocation to or within New Brunswick. Participants described their experiences using various services such as pharmacists, emergency departments, walk-in clinics, virtual health care platforms, and other healthcare professionals (such as specialist physicians) to access health care when needed. They received episodic care most often, a one-time encounter with a health care professional to address an immediate need, and, therefore, no opportunity for follow-up care.

Concepts of trust, sense of control, and connection were prevalent throughout all themes. Trust, or lack of trust, in the health care system, the government, or care providers was discussed in multiple ways by many participants. Trust was often mentioned when participants were describing their relationships with the health care system. Sense of control, or a lack of control, was also prominent for each participant in discussing what they missed from their time with a primary care provider and as a

notable consequence of being without a primary care provider in the current context. Finally, connection to the health care system, support systems, and many others was discussed extensively in all interviews. Participants expressed their gratitude for the opportunity to share their experiences and highlight their perceptions of health services without a primary care provider.

Theme 1: "You don't know what you don't know"—Uncertainty is Certain

Multiple participants used the phrase "you don't know what you don't know" when describing their experiences without a primary care provider. Uncertainty referred to a lack of awareness of how to navigate the healthcare system, as well as unknowingness about their health since being without a primary care provider. When asked to describe how they felt being without a primary care provider had impacted their health outcomes so far, most participants found it challenging to articulate the impact of the experience on their health due to uncertainty about their health status. Further, recognition of many unknowns in this experience was shared when discussing service navigation and accessing health care services through the available alternative models. Participants shared uncertainty about which services were available to them and how to use services they may be aware of but have not yet interacted with; however, they were hopeful about their ability to learn about navigation once they were made aware of the options. Finally, participants expressed frustration about being unaware of changes in health system structure. For example, as the ongoing shift to primary care hubs in NB, and shared experiences of being unsure of who to ask for help, what to ask about in times of need, or interactions with health care providers. This theme explores the uncertainty of

being an unattached older adult in New Brunswick and the impacts of not knowing what you don't know.

Health Outcomes

Participants shared concern about their lack of awareness of their current health status since being without a primary care provider. When asked to describe their health before and after being without a primary care provider (better outcomes, worse outcomes, no changes, etc.), it was evident in their thoughtfulness and quick responses that the participants had previously considered this. Participants who described themselves in good health when they lost their primary care provider articulated that early detection is critical, especially as an older adult. They were mindful of actively monitoring any changes they noticed in themselves. A few participants shared that they had become more diligent about practicing positive health behaviors like regular physical activity and eating a well-balanced diet. When asked if they thought that their health had changed since being without a primary care provider, one participant described the following:

> Well, I don't know what I don't know. So, I don't know if something is going on that I should be having paid attention to. In the sense of the mental side, there's a certain amount of anxiety associated with all of this that I wouldn't have if I had access to primary care. (P12)

Other participants shared a similar sentiment about the negative mental health impact of being without a primary care provider. A participant said that they find themselves, "worrying about underlying conditions that you don't know you have… or conditions that you [do]… you're just not sure if they're getting worse or not" (P16).

Some participants had been regularly followed by a primary care provider for specific conditions in the past and were notably concerned by a lack of sustained information on any changes in their conditions. For example, multiple participants shared stories of being prescribed a new medication shortly before losing their primary care provider and not receiving any follow-up after beginning the medication. These participants were grateful for pharmacy services, which can refill prescriptions and monitor some side effects for attached and unattached patients. However, participants expressed frustration that pharmacists could not order appropriate diagnostic tests to monitor the impacts of these medications.

Participants shared concern for the impacts of predictable health outcomes associated with family history and a lack of control in monitoring or preventing future conditions. A participant shared their perception when they said:

> It's not a question of whether I will [become sick], I know because of [my family] history, but when is the thing? But what worries me is that there's nobody has a pulse [on this]. (P09)

A reoccurring theme in the finding is the lack of a connection with a health care provider who knows participants' experiences and has a holistic view of their health is a recurring theme in the findings. It speaks to participants' desire for continuous care in the alternate care system to maintain some control. Further, participants who had longstanding concerns that had developed since being without a primary care provider were alarmed by their inability to devise answers to their questions with the available resources in the system. Multiple participants shared experiences of knowing that something was not

quite right and being unable to find a conclusive explanation through the episodic care available through alternative services.

Service Navigation and Sources of Alternative Care

A second use of the phrase "you don't know what you don't know" meant the availability and accessibility of alternate care services. When participants shared their stories about finding out they would not have a primary care provider; they recalled an overwhelming uncertainty regarding what they should do next. Most participants were on their own to find new ways to access health services and utilized whatever resources were available to find a solution that could support them. Participants were primarily reliant on one service they had found to work well for them including pharmacists, virtual care, or walk-in clinics; however, this ranged depending on digital literacy, time availability, and pre-existing knowledge of the health care system. It is essential to note that increased access to a well-connected social network was a central factor in exploring available service options. This factor and the impact of socio-economic status and privilege is further expanded in Theme 3: "Rob Peter to pay Paul". Despite a wide range of time spent without a primary care provider, many participants were in the process of finding new services or available options within a known service that may work for them and their unique needs.

Pharmacists.

The discovery of the role pharmacists could play in providing service was a newly discovered treasure for many participants, mainly due to their accessibility in the community and expanded scope of practice. Participants shared a new reliance on their

pharmacists since being without a primary care provider; many were grateful for the continued friendly face, awareness of their health history, and access to consolidated prescription records. Since being without a primary care provider, participants began to utilize their pharmacists for health needs such as vaccinations. They shared that they had asked them more questions since becoming unattached. They also expressed trust in their pharmacists as people who had known them for a "long time and see [them] regularly out and about [in the community]" (P16), which emphasizes the person-first (as opposed to patient-first) experience that participants described seeking. Pharmacists were highly regarded for their connection, accessibility, and scope throughout the study and substantially reduced uncertainty for many participants.

Virtual Care.

Many participants described their experiences using New Brunswick's free virtual health care platform. Participants had mixed reviews about the system and its ability to suit their needs. Those who typically only required a regular prescription refill were content to use the platform for a quick service. However, they highlighted the lack of connection with a provider due to the sole use of the chat function available. Additionally, they expressed concern for a lack of a holistic understanding of their perspective and frustration with an inability to confirm when a provider would be available to assist them. Participants expressed further frustration with the complexity of accessing the website. While they recognized that the platform was not equipped for preventative care, they were disappointed with the limited range of services.

Specialist Care.

Some participants described a unique privilege in being associated with a specialist for complex medical conditions which reduced their levels of uncertainty in light of having some form of attachment, even if not to a primary care provider. These participants found that they could access additional health services from their specialist that they had previously accessed through a primary care provider. One participant described their cancer diagnosis as a facilitator in some regards, as it had allowed them to stay connected to a health care provider- their oncologist. In telling their story, they said:

> Well, I have been lucky because, now this will sound odd because I have a cancer diagnosis… I got through to the cancer clinic [when I moved here from another province] … [My oncologist has] referred me to another specialist, [for something] which I know doesn't need to go to a specialist. If I had a doctor, I would go to the doctor for it, and they could deal with it. (P12).

Other participants shared similar experiences, and while appreciative of their specialists, they recognized that this was not a sustainable solution to being without a primary care provider.

Communication

A third notable category included a sense of unknown relating to communication—Participants described a profound lack of communication about the status of health services and opportunities for access from the government in particular. For example, The NB Health Link program is a new program that began in Moncton in 2022 and contacts people who are on the Patient Connect NB list (the list of people waiting for a primary care provider) to offer access to a network of family doctors and

nurse practitioners (New Brunswick Health Council, 2022b). The program was being expanded to the Fredericton region in Fall 2023. During the interviews, many participants were situated in this region of the province. Participants described information about NB Health Link as the first update they have heard from the government regarding their status on the wait list for a primary care provider; however, many shared that this increased confusion in many ways. One participant described providing a caller with their medical identification number, mailing address, and other personal information in early October of 2023 and had not heard back at the time of their interview in mid-December 2023. This lack of follow-up concerned the participant and therefore they took initiative to contact NB Health Link themselves and confirm that the call was not a dishonest scheme to obtain their private information. The participant felt this incident reduced their trust in the healthcare system, which could have been avoided with timely communication.

In summary, being unaware of their personal health outcomes and status, strategies for navigating the system and accessing care, and a lack of communication contributed to uncertainty for those without a primary care provider. As older adults, they were increasingly aware of the potential cost of being without preventative care, and thus, they fear poorer health outcomes because of uncertainty. Unfortunately, uncertainty was a constant for participants during their time without primary care providers in a time of faltering and unsteadiness.

Theme 2: "I'm a nobody"—Left Behind

A constant theme outlined by participants was the sentiment of being forgotten, unimportant to the health system, and alone which meant being ‘left behind’. One participant provided a powerful description of losing a primary care provider, stating, "I'm a nobody; I don't matter." (P09). Participants expressed that without a consistent provider to monitor their health, maintain a pulse on their wellbeing, and follow through on concerns, they were left to their own devices in multiple ways. This feeling of being ‘left behind’ was apparent in participant’s experiences when navigating the health system, especially when feeling as though they should be receiving care as they age and being forgotten as a priority group. It was also evident when participants described their study motivation and experience with the interview. "I'm a nobody" profoundly describes the experience of being an unattached older adult in the New Brunswick health care system. As P09 adeptly described this theme "There's nobody who has a pulse on who I am. I don't even exist. I'm a nobody."

Unknown to the Health Care System

When describing their experiences of navigating the healthcare system independently, participants emphasized an overwhelming feeling of being alone in managing their health and accessing services. Many participants shared a sentiment that no one knew their health status or knew them within the health care system. Some felt left behind when they had to explain their medical history to a new care provider each time they sought care; others were actively grieving a longstanding relationship with a care provider that they had trusted with some of the most intimate details of their life. In all cases, they maintained an awareness that no one understands them as people with a story, a history, and a future that matters.

A significant point of frustration for many participants and a constant reminder that they were unattached in the health system was the nearly exclusive availability of episodic care in the alternate care system. Participants had found creative ways to share their histories and give as much context to their situation as possible in their short appointments; however, the disconnection was undeniable. Feeling seen, heard, and valued was described as incredibly challenging because the participants were acutely aware that the provider knew nothing about them. While participants were mindful that the available services were intended to provide episodic care, overwhelmingly, it was not what these participants were looking for. They described wanting to feel like they mattered to their provider, a task becoming increasingly difficult in a time of digital reliance and 5-minute appointments. Participants acknowledged that this gap in care was not often the care provider's fault but simply a product of the system they are working in. They were clear in their appreciation for the available services that allowed them to fill prescriptions or receive a vaccination; however, they were painfully lacking a connection to the system.

The Last Resort- Primary Care Access Through Emergency Departments.

Some services were described as more isolating than others. For example, participants were incredibly reluctant to visit an emergency department out of certainty that they would face excruciating wait times and would not have anyone to empathize with them for hours. They described stories of sitting in various emergency departments for upward of 10 hours with no resolution for their concerns, and thus, most had lost trust in their regional emergency departments. For all participants, emergency departments were perceived as a last resort for care.

Perceptions of Primary Care in Walk-in/by-appointment Clinics.

Clinics that operated by walk-in/by-appointment clinics were perceived slightly better than emergency departments and virtual care by those who could access appointments there. Participants described the value of being able to “look their provider in the eyes” (P01) and have someone see them in person; however, they still experienced battles in booking appointments in an overcrowded system. One participant shared a grueling experience calling a clinic 234 times before being connected with someone who could schedule them in for an appointment. The inaccessibility of the available services was perceived as contributing to a disconnect in the health care system. The previously discussed complexity of navigating virtual services, excessive phone calls required to access an in-person clinic, and the certainty of an unfathomable wait time at an emergency department was perceived as creating a hostile system that did not provide comfort or reassurance to those who are sick or in need in of health services.

In some instances, participants felt they were ‘left behind’ because they were older adults. Participants described their symptoms being dismissed because they were older and that they were not being considered in system design since they were not actively advocating for their needs with the working population. P16 shared their feelings about being treated differently as an older adult in the healthcare system and said, "you get treated a little bit like that when you're older, and that is pretty disgusting". Some participants spoke about being active in their communities and knowing that if they did not advocate for their needs, they would often be overlooked because systems would be designed to suit the needs of the younger population (often with increased reliance on digital/technological delivery). Being left out of considerations for system design was

confusing for many, though unfortunately unsurprising to them, as participants were aware that older adults use the health care system more than any other demographic; however, participants felt that they were fighting the system more than anyone else in the current context. P09 was concerned with the lack of consideration for unattached older adults as per their experience since being without a family doctor and said “as part of the aging process things start to fall apart […] Who is going to look after me as I'm getting older? I don't know". This describes both an unpredictable future in the healthcare system and a feeling of abandonment due to the knowledge that care will be required but possibly not available.

Finally, it is essential to note that the sentiment of being "nobody" was more pronounced for some than others. Particularly those who lived alone, who were not well-connected to the health care system through their social networks, belong to a historically underserved community, and were without a unique point of entry to care (such as those a specialist is following). Participants who lived with partners appeared to be comforted by the fact that even if not a health professional, someone in their life knew their health history and could support them in navigating the health care system. Those who lived alone and participated in the study expressed gratitude for close friends and nearby family who could support them in shouldering the burden of being unattached. However, it was not perceived as the same as having someone who lived with them and would be able to detect small changes in them as quickly as a partner may. One participant explained that being alone (without a primary care provider and a partner) when navigating the health system, "[is an] uncomfortable feeling that you have because you

don't have anybody. And when you're alone, you can't even talk to anybody. And that's even worse." (P16).

One participant explained that they chose to participate in the study so that the Francophone community in New Brunswick would be represented, and they described the challenges that some of their peers who needed French providers faced. The participants were bilingual and often accessed services in English; however, they had only become attached to a French primary care provider in their older age and felt that being Francophone added significant complexity to their experience, even in Canada's only officially bilingual province. They noted that other historically underserved populations may face similar challenges, such as accessing culturally appropriate care. These experiences and privileges, or lack thereof, significantly impacted participants' sense of belonging in the health care system and are further explored in theme 3, "Rob Peter to pay Paul"- Privilege in our Health care System.

In summary, the participants appreciated the opportunity to feel valued, meaningful, and heard when addressing a system that has left so many of them behind. Despite having spent the past hour discussing an incredibly complex and emotional experience, each participant closed their interview with gratitude and enthusiastically looked forward to hearing more as the research progressed. The participants were articulate in advocating for a sense of belonging and interpersonal connection/recognition in future and existing health services for those without primary care providers.

Theme 3: “Rob Peter to pay Paul” —Privilege in our Healthcare System

This theme considers the impact of privilege and explores the sacrifices that are frequently required to access appropriate services for those without primary care providers. In a conversation discussing relative privilege, one participant described having to "rob Peter to pay Paul" (P19) meaning that they were often forced to choose which health priorities matter most to them and what they can reasonably give up in accommodating those needs. In this participant's specific situation, this meant finding transportation to an appointment while on a tight budget. The $30 taxi fare would mean that something else in their life would have to be cut. However, it was applicable to other privileges as well. Many participants described choosing between giving up their time to be "held hostage by the telephone" (P06) while waiting to receive a medical call or asking for favours from family or friends and drawing on social resources to "use any resources you have to make things work" (P12) within the health care context. This theme describes the give and take in between resources required to navigate alternate care services and examines a variety of privileges that influence participants experience without a primary care provider.

Privilege

Privileges in the health care system were presented and discussed in many ways. When considering cost-related barriers for accessing primary care services, most participants immediately considered transportation. New Brunswick distributes various health care services between the tri-city municipalities (Fredericton, Moncton, and Saint John) and so people seeking care may be required to travel to another region of the province to access specialist care. Primary care is ideally delivered close to home, however, for those without a primary care provider, accessing services in another region

of the province may be a reasonable alternative to forgoing care. One participant described moving within New Brunswick in the past decade and despite living close to an hour's drive away from their primary care provider, the participant and their partner decided to keep seeing their primary care provider in fear that they would be without a primary care provider for an extended period if they gave up their position in their former community. They said, "it was a long drive to get back to [urban location], but it was better than not having our doctor" (P01). As someone with a chronic illness and complex family history who relied deeply on their primary care provider, this was not a risk they were willing to take.

Rural Experience.

Participants who were intimately aware of the rural experience, were particularly vulnerable to longer travel to access most health services and found this reality amplified since being without a primary care provider. In some instances, participants described leaving urban centres to seek care in more suburban communities due to shorter wait times. Others questioned if in some places, rural residents appeared to have an advantage, with quicker access to in-person care in communities where an alternate care service was available due to lesser demand. In all cases, participants considered the cost of travel and accessibility of roads when choosing where to access services. They noted that for people on a fixed income, as most seniors are, unexpected transportation costs would be impactful, but participants were willing to make sacrifices if it meant that they would be able to access health services.

Private Healthcare.

Multiple participants discussed their willingness to access private care, though most expressed that they wished they could access the care they needed within the public system. To many, the prospect of being able to see a health care provider was perceived as worth the potential cost of a private health service and was an option that many had considered, though ultimately had not yet accessed. While paying for private care would certainly be more burdensome to those with lower socio-economic status, participants from all ranges of income had considered seeking private care elsewhere if it would result in an accessible option to meeting their healthcare needs. One participant noted that even though they did not intend to pay for private health care soon, they would appreciate knowing that this option existed if all their other options had been exhausted. Other participants described that they reached a point of exhaustion at the time of interview and were actively considering exploring private health care options.

Social Capital.

In addition to considering the financial cost, participants noted social connections and their respective social capital was an impactful privilege when accessing health care without a primary care provider. Most participants credited their social networks for their increased awareness of the health care system, occasional opportunities to connect with a health care provider in their circle, general direction for the types of questions to ask, knowledge of how much a care provider could be pushed to fulfill primary care services (such as asking specialists to conduct tests typically obtained through a primary care provider), and general emotional support. In this context, privilege meant having available resources. One participant explained that many of the question they ask during appointments with alternative primary care services are often informed by the

conversations they have with their social network. They said, “I have to go with knowledge, because they don't know me, so I have to be knowing what questions that I want to ask and should ask” (P12). People with these connections described being able to draw on this tool when needed, however those without these networks were without this option entirely. Therefore, there was no chance to rob Peter to pay Paul when Peter did not exist.

One participant described being able to ask friends for their opinion on where to access services or seek out an informed opinion regarding their latest ailment, however, this consistently required them to have conversations about their health. They went on to say, “I don’t want to talk about health all the time!” (P12). In the past, when they had a primary care provider, the participant described talking about their health occasionally. However, being without a primary care provider, as were many of their close friends, the participant shared that they find themselves talking about their health constantly. They share in the burden of worry and service navigation, which the participant appreciated, nonetheless they would enjoy the opportunity to talk about other things as well and occasionally forget about the critical state of their access to health services. Other participants shared this sentiment when expressing a desire to keep any part of their life separate from their health care contexts, though this is becoming increasingly challenging as these circumstances becomes all-consuming.

Time.

All participants considered the impact of time as a resource they carefully managed when describing their experiences without a primary care provider. As

previously discussed, participants articulated their frustration with wait times for various services and the experience of being “held hostage” when trying to access virtual care. Further, participants discussed time as a valuable resource and often being able to spend this currency generously while navigating health services. One participant said,

> Even though people are older and retired, they still have lives. And so back to the held hostage thing, you can't spend your whole day just trying to dial and well trying this clinic here and then that clinic there. It can get really tiresome. (P06)

At each turn in their journeys without a primary care provider, participants perceived that time was the resource that was asked of them the most. For example. one participant described following a three-month routine, where they dedicated approximately one week to finding a prescriber before their three-month prescription was depleted. They plan to continue giving up a week of their time to health systems navigation indefinitely, or until they receive a primary care provider. Other participants were actively managing an increasingly large binder of medical records, servings as the administrators of their health care and occasionally their partner’s as well. Without exception, each participant described countless experiences where they were required to devote time to navigate the system and access care. The time allocated to navigating the healthcare system was substantial for many participants and, similarly to re-budgeting finances to accommodate needs, they found themselves re-balance their time to allow for the efforts required for health system navigation.

Comfort.

Finally, participants described making a choice between comfort and discomfort regularly in their time without a primary care provider. Nearly all confidently declared that they waited longer to reach out for support from a health care provider than they would have waited to call their primary care provider. At the time of their interview, most participants had waited to reach out to alternate care providers on at least one occasion in hopes that their health concern would remedy itself on its own. Due to past negative experiences with care, participants described choosing physical and/or mental discomfort over the discomfort they anticipated in the health care system. The current health care system is costly to those without a primary care provider, these participants were aware of this long before their engagement with this study.

Two-Way Burden

The participants in this study described a unique two-way burden—a give and take relationship—between the health care system and those who are looking for care. Participants described feeling like a burden to the health care system each time they accessed care. They recognized that their ability to see a provider meant that someone else may not have that same opportunity that day. The challenges they faced reinforced the sentiment that they were taking up space in a system that they perceive to be incredibly strained. Participants carried this with them in the interviews and despite often describing complex situations where they required some form of care, they felt guilty for taking that opportunity from someone else. They felt as though they were robbing someone else of the chance to access care each time that they did.

Further, participants described that in addition to their own sentiments of being a burden on the health care system, the health care system was certainly burdensome on

them as well. Participants described their experience without a primary care provider as exhausting, frustrating, and overwhelming. They described hearing that health care providers are burning out in the system, as they are as well. Many of the participants were highly informed about health systems reform, some had taken a new interest to the topic since being without a primary care provider while others have had careers in the industry. Regardless of how they became interested in health systems advocacy, each participant made unprompted recommendations for change and expressed their perspectives on feasible changes that could significantly improve user experience. One participant eloquently said, “Solutions are not that far away. What is far away is informed leadership.” (P02). As outlined in Theme 2, battles with accessibility and loss of identity when without a primary care provider all highlight the way that the current health context in New Brunswick was perceived as burdensome to participants. As older adults, the participants described further consequences of an aged health system as they fear aging without access to health care. Without a seat at the table for conversations on change, and without access to the services they have expected for their entire lives, participants shared their grief in response to their current context. They are burdened by choices and are not rewarded for their sacrifices, there is a high price for older adults to pay in navigating the health care system without a primary care in NB.

Theme 4: "The Gold Standard"—Product of their Times

All participants identified as older adults, and their age certainly shaped their experiences of being without a primary care provider. This theme, "The Gold Standard"—Product of their Times, addresses how being an older adult influences the perception of the experience of being without health care. Many participants described a

time when they experienced a "gold standard" of care. The gold standard included being known to their primary care provider, they could easily access health services, and were confident that a medical professional could see them in or before a time of need. This previous experience allowed the participants to find some light in the health care system, as they could recall a time when things worked well for them and therefore seemed hopeful in many ways that the health care system could serve them well again. Tt should be made clear that the participants explained that they were not expecting the same experience of care that they had when their primary care provider did routine house calls and was available at all hours of the day; however, this foundation with the health care system reminded them of a time in which they were connected to a care provider, felt a sense of control over their health and wellbeing, and trusted that they system would look after them. They hope to experience this again someday.

Experience with the System

When reflecting on past interactions with the health care system, it appeared that interactions with the system had likely influenced participants' expectations for health care as seniors. Some participants had lived in the same communities for most of their lives and had never been without primary care providers; others had moved multiple times and had consistently been able to access a primary care provider shortly after moving. Most participants described that for the first time in their lives that they were unsure when or if they would ever have consistent access to a primary care provider again. One participant described this sentiment when they said “in all my years, I have never, ever been without a family physician. [And now] I have really no hope of getting a family doctor before I die” (P21). This highlights the unexpected circumstance that

people have now found themselves in without a primary care provider and emphasizes the lack of trust that the healthcare system will be able to care for the people who need it.

Overwhelmingly, participants described experiencing loss and grief regarding the future they had imagined for themselves in older age. Many felt that their plans for aging have been shifted due to an inability to access a primary care provider and the dramatic actions they are required to take to manage their health. Others fear that they will become unhealthy without the continuous and preventative care they are currently lacking; their plans for aging are looking very different than they had hoped.

These experiences align with the concept of loss of control, highlighted throughout multiple themes. In addition to being unable to control their access to health services, participants felt that, in many ways, the way that they will age is out of their control due to the lack of access to a consistent primary care provider. The participants described experiencing much more than the loss of a primary care provider; they are experiencing the loss of the future they expected.

> I think it's uncomfortable and disturbing just knowing that [primary healthcare is] not available. You don't go every day to see the doctor, but there was always [access]. Like you always looked forward to having an assessment once a year. I mean, that's all gone. And that was one of the best things that we ever had in our system that there was somebody at least seeing you once a year. And that's not happening now. (P16)

Despite the negative experiences they described, for many participants, the knowledge that the health system has been able to help them in the past allowed them to maintain a sense of trust that their health needs would be met, even with the knowledge that the health climate is incredibly different than when it worked well for them. Further, they were incredibly realistic about the increasing pressure to access consistent care as they age. Participants described understanding that health services are delivered in a triage system. However, they also felt that as older adults they should be considered a higher priority than they were experiencing at the time of interview.

Participants also realized that health complications could become increasingly complex as they age and that the consequences of poor health are climbing. While most people without primary care providers may experience frustrated for various reasons, the participants described the knowledge that they might not have as much time left as others who are younger and that this time could be spent in poorer health if they are without a primary care provider than if they are with a primary care provider increases their urgency for action. Many participants shared perceptions of the health care system, noting that the government of New Brunswick emphasized the need for care for the aging population. However, they were confident that their situation did not promote the outlined vision for health aging for New Brunswick seniors. Others expressed frustration with the government and as shared many times in these conversations, expressed a sentiment of being left behind or not heard by an institution in place to support them. Participants wanted to emphasize that they were grateful for the current programs that allow them to access some health services; however, they urged those in positions of power to act quickly and do better to protect and support the older adults of NB.

Senior Specific Facilitators and Barriers

The specific experiences of older adults have been highlighted throughout all themes in this study; however, considerations for the unique experiences associated with age are notable and thus deserve to be highlighted independently. In addition to the previously mentioned foundational trust in the health care system and a history of primarily positive experiences, a second factor that participants emphasized was the age-related reliance on others and prioritization of connections to other older adults. Participants described being resilient in a challenging system as a credit to the social support they work hard to maintain. Reliance on these relationships established creative means of navigating the system and was strongly emphasized as an age-specific priority.

Senior-specific barriers included flexibility of resources and variability in accessibility needs. Participants described limitations related to fixed income and limited ability to increase or change monthly finances in times of need. A consistent comment from participants was the importance of considering varying abilities and avoiding ageist assumptions about older adults. The participants were articulate and informed activists who took the time to consider many people who have similar or varied personal contexts from their own. Ageist sentiments perpetuate harmful ideas about older adults and limit the influence of their advocacy; this needs to change. The participants in this study wanted to ensure that the health system supports everyone who may require accessible considerations, but they are not unique to older adults. The development of a socially inclusive health system was a top priority for the participants of this study.

Theme 5: "I want to be healthy"—Resilience and Strength

This study's fifth theme carves a narrative of resilience despite overwhelming challenges. Consistently, participants were honest about their struggles, frustrations, and fears yet, they each addressed some points of hope in this experience. This speaks highly of the strength of these people and those who find themselves in similar situations. The quote, "I want to be healthy," was shared when a participant discussed their plan and personal actions to do as much as they can maintain and follow their health without a primary care provider. It speaks to the efforts taken to stay afloat in the health care system. It should be made clear that this hardiness does not indicate a lack of required action or success. However, it does indicate the hope that has persisted.

Community-Centered Advocacy

While describing experiences without a primary care provider, most participants engaged in some form of advocacy. It was clear from the beginning of the interviews that participants were not volunteering for the study simply to share their experiences; they were adding this to the long list of actions that they were taking to try and make things better for themselves and others. They described political engagement, regularly writing letters to provincial and federal health ministers to share their stories and demand reform. Most have actively followed multiple sources of health-related media for quite some time and have taken it upon themselves to learn more about the system they are operating within and how other places have been able to flip a dire situation. One participant was keen to read articles used to inform the literature review for this study, and all participants were eager to receive progress updates and summaries of the findings.

It should be noted that involvement in action-oriented groups and work as advocates brought about opportunities for many participants and those who are members of many of these community groups; however, it is a privilege in many ways to spend the time and energy doing this work. Participants described thinking about those who were frail, sick, or disconnected and the ways that their perspectives may be lost because they may not be able to be involved in these conversations. One participant spoke about the lack of seniors in full-time work, often limiting strategic direction involving seniors, so they were leveraging community groups, many of which were primarily volunteer based, to advocate for change. The participant said that they want to be involved but the system needs to advocate for people who are not part of the full-time work force and making these decisions. They said, “I retired for a reason. You know, I didn't want to work my whole life, […] I think it's a little unrealistic to expect me at my age to take that role on as well. But I still want a say [in what happens]” (P01). This speaks to a desire to participate but also requires a trust that others will advocate for the priority items of people who are not immediately present in conversations of healthcare reform.

The same participant shared the impact of a community program that focused on increasing older adults' access to general information about services in their community. The program brought in guest speakers every week to address the inquiries of the seniors who attended, and social workers, researchers, and government representatives were included. This program addressed a significant need for knowledge mobilization surrounding primary care access and was described as an ongoing success for the community. Others shared ways to leverage opportunities and empower others to do the same in similar situations.

Individually, participants creatively made the system work for their circumstances. Multiple participants described creating their own medical records systems through thorough record keeping of health records and updates, including new clinics, phone numbers to call, and notes about past experiences with certain available alternative services. One participant proudly declared that they had recently taken the time to type a complete record of their notable health history that they could hand to a health care provider or administrator and thus be sure they are not forgetting something important during an appointment; it was working well for them so far. Two participants, a married couple, had each been trying different services (they had almost tried everything they were aware of at the time of the interview) and were going to decide what worked best for them collectively. Other participants described a similar system with family or close friends. A few participants discussed resourcefulness by finding new ways to connect with their community through Facebook pages or email-based newsletters. Through this, they became community experts who helped connect their peers with various events, services, and resources separate from primary care. Participants described becoming increasingly resourceful in this situation because they had been forced to. P12 said, “So I mean, I am pretty resourceful. It's all about trying to work out all of the different systems that are out there”. In many ways, if participants had successfully found a suitable option for them, they have become more connected to their community without a primary care provider.

Gratitude, Despite it All

Without exceptions, participants expressed gratitude. They appreciated the opportunity to share their stories and were thankful that someone cared about their

experience. In addition to their gratitude for the interview, participants wanted others who were working to shed light on the system to know that they appreciated the efforts being taken. They recognized that system reform is slow and that many people were putting in time and effort to make things as best they could in a challenging climate. Once they could see a care provider in any available alternate care services, most participants were met with a kind care provider who did their best to deal with the problem in front of them. They were mindful that providers were asked to deliver care in impossible situations and respected the reasons why some have left the system or moved to other places. Participants expressed thankfulness for the opportunity to connect with community pharmacists and emergency room practitioners who acknowledged the discomfort they were experiencing and were grateful that there was still an expression of compassion on occasion.

As noted above, gratitude does not indicate a lack of urgency for these people. However, it highlights the fact that there is still patience and understanding from those being left behind, which should not be taken advantage of. Older adults in New Brunswick deserve access to high-quality care—the experiences of these participants do not detail a story of which the health system is proud of, but there is still room to regain their trust. The participants shared a deep concern for others in similar situations, often more concern than they expressed for themselves, and were eager to see a change. They appreciated the work being done for health system reform and shared a strong hope that the system would listen to their stories and act quickly.

Chapter 5 - Discussion

This study sought to explore the experiences, perceptions, and perceived outcomes of English-speaking, community-dwelling, older adults accessing health care to meet their health needs without a primary care provider in New Brunswick. Additionally, the study considered the influence of socioeconomic status on older adults' perceptions. Key findings included experiences of uncertainty, loss of identity, consideration for the cost of being unattached, recognition of the impact of age on this phenomenon, and the development of resilience in the face of unattachment. This chapter will further explore the perceived emotional impacts of being without a primary care provider such as social isolation and loss of identity, considerations for the variable impact of being unattached for those with or without numerous privileges, and offer comparisons with ideal models for primary care in New Brunswick and elsewhere.

As noted early in the findings, it is worth addressing that participant generally affirmed the positive benefits of previously studied alternative primary care services, such as the vital role of community pharmacists in supporting unattached patients to access health services and the increased, though reluctant, use of emergency departments for circumstances previously addressed by a primary care provider (Isenor et al., 2024; Marshall, Stock, et al., 2022). Further, participants expressed concern for unmonitored or potential missed diagnoses due to being unattached, which is a consistent consequence of a lack of attached primary care providers in other comparable contexts (Peel et al., 2019). While the findings of this study go beyond these experiences, they are important to

consider when examining the context in which participants are experiencing the healthcare system.

Social Isolation and Loss of Identity

A prominent finding in this study was isolation and loss of identity for older adults without primary care providers in New Brunswick. The theme “I'm a nobody," addressed varying experiences of loss of control, lack of connection, and the mental health impacts of being without a primary care provider as an older adult. This experience of being without a primary care provider is notable as it was not articulated in the preliminary literature review. While there are numerous documented experiences of loss of control or identity for people seeking care in other facets of the health care system, such as those with cancer, this experience is not widely documented for those who are unattached (Mischel, 1990).

Loss of Control

Participants described experiencing a loss of control as unattached older adults in New Brunswick. This experience of a lack of control is consistent with experiences described in other medical contexts, and notably is described in Mishel's Theory of Uncertainty in Illness, which aims to explain how uncertainty is generated and its psychological impact on the experience of cancer (Mishel, 1990). The Theory of Uncertainty in Illness recognizes multiple negative physical and psychological consequences of living with uncertainty, including fear, emotional distress, a sense of losing control, and diminished quality of life. In a systematic review of literature relating to the Theory of Uncertainty in Illness, it was found that lack of medical information,

incomplete understanding of health outcomes or treatment choices, and difficulty coping with the precariousness of daily life increased instances of uncertainty; the same was unarguably true for participants of this study (Zumstein-Shaha et al., 2017). Mishel's theory defines uncertainty as "the inability to determine the meaning of illness-related events and accurately anticipate or predict health outcomes " (p.256),.Participants in the current study similarly described feeling uncertain and concerned about their current health status (e.g., potential illnesses), the trajectory of their health and their future without a primary care provider (Zhang, 2017; Mishel, 1990). The findings from this study support that many participants are experiencing similar reasons for uncertainty described in the review and nearly identical outcomes as identified in the Theory of Uncertainty in Illness since being without a primary care provider including a circumstance-induced sense of disorganization and instability, a new view of life and re-defined expectations for the future, and a re-prioritization of resources to accommodate the context (Mishel, 1990).

Lack of Connection

In addition to experiencing a lack of control due to unattachment, participants described a loss of identity due to the lack of connection with a primary care provider, and notable mental health impacts. Participants discussed the mental health impacts of being without a primary care provider and the literature supports these sentiments in that loss of power, and lack of social connection is strongly correlated to poor mental health (Marshall, Wuite, et al., 2022). However, a discussion of the mental health impacts of being without a primary care provider has not been previously identified in the current literature on the experiences of people without primary care providers. Participants noted

the positive impacts of pharmacists in providing connection, which is directly related to improved mental health for older adults (Isenor et al., 2024).

Relationships with primary care providers are certainly not the only way most people seek connection; however, positive therapeutic relationships with patients are rooted in trust, safety, knowledge, and loyalty which promote connection and acceptance (Ramachandran et al., 2023; Bova et al., 2012). It is well documented that the physician/provider-patient relationship impacts health outcomes and treatment adherence in medical settings, particularly in primary care, due to continuity and being the first point-of-contact care (Hooper et al., 2012). However, knowledge surrounding the consequences of being without a care provider is lacking. This is particularly concerning for the health of older adults as the benefits of being with a consistent primary care provider are substantial.

Participants described the loss of connection to their primary care provider as a loss of identity in many ways. Perceived changes in identity are documented in the changing health of older adults. Older adults who have faced significant losses (e.g., loss of a spouse, the onset of a limiting disability, etc.) are frequently understood to experience a loss of identity (Langer, 2010). Correlations between loss of identity, central tenants of self, and loss of significant relationships are prevalent in literature (Langer, 2010). However, to my knowledge, descriptions of an experience of loss because of being without a primary care provider are absent in literature, particularly in considering that perceived changes in identity are common in older adults and there is an identified

correlation between changes in identity, wellness, longevity, and other indicators of positive health (Weinberger & Whitbourne, 2010).

Research on loneliness, isolation, and aging is prominent in the literature and while the participants did not specifically describe an experience of loneliness due to a lack of connection to a primary care provider, many of the current findings on the importance of connection are directly applicable. Social connection broadly includes feeling cared about by others, a sentiment that a positive relationship with a primary care provider can fulfill (Seppala et al., 2013). Increased focus on social connection to improve health outcomes supports the perceived health outcomes described by participants and encourages specific and critical attention to connection for unattached older adults.

Privilege and Primary Care Access

The findings of this study suggest that various privileges, such as socioeconomic status, social connectedness, and education, impact the experiences of older adults without primary care providers. The participants of this study were primarily well-educated and well-informed older adults as per their strong understanding of the healthcare system and consideration for the impact of their privilege as unattached people. Notably, participants who reported higher income, strong digital literacy, and a supportive network perceived that they were better equipped to navigate the health care system and manage their health independently than they would expect their peers without access to such resources to find themselves if without a primary care provider. The literature supports these findings and maintains that increased privilege is strongly tied to

better health outcomes (Kwate & Goodman, 2014). Notably, those who have experienced privilege throughout their lives may find themselves in better health in older age and thus suffer fewer consequences of being unattached as an older adult. While this study did not seek to explore racial or geographic differences between older adults without primary care providers, it was strongly suggested by participants that they feel some older adults struggle more without a primary care provider than others as a result of social connectedness, existing health conditions, geographic location, and many other individualized factors such as digital literacy and awareness of community resources.

In New Brunswick, residing in an urban geographic location and speaking the majority language (English) appeared to be a privilege for health and access to services. With nearly 49% of the New Brunswick population residing in rural communities, it is essential to consider how older adults in rural New Brunswick may experience health system navigation without a primary care provider differently than those in urban centers (Canada, 2022). Participants of this study were almost exclusively residents of urban or suburban communities, and all shared their experiences accessing services in one of the three major cities in the province since they had been without a care provider. Existing research indicates that older adults, people in rural communities, people of low socioeconomic status, and especially those who intersect these groups, are at particular risk of poor access to health services and often have higher health needs (Ford et al., 2018; Sheridan et al., 2015). As alternate primary care services are diminished in rural communities with closure or reduced hours of emergency departments and amplified staffing shortages, it is reasonable to assume that the participants of this study experienced a lesser burden of unattachment due to their geographic location (i.e., close

to an urban centre). In New Brunswick, there are no significant differences between rural and urban reports of chronic health conditions, except in the Miramichi region of the province, which reports elevated numbers; however, the four major hospitals of the province are all located within the three urban centers, and thus the availability of specialized services may be more readily available to populations in those communities (Breneol et al., 2022). Further consideration for older adults who reside in rural New Brunswick is critical, given the likelihood of the variability of their experiences when compared with those in urban and suburban communities, particularly for those who experience an intersection of multiple underprivileged circumstances.

Participants in this study were all English-speaking and primarily found that the services they accessed were culturally appropriate. However, accessing health services in French or English is essential for accessible services in New Brunswick. In 2021, New Brunswick's languages watchdog reported complaints from Francophones who could not access care in their preferred language within the province, primarily attributed to staffing shortages (Leger, 2021). Accessibility of other culturally appropriate services, such as those for Indigenous people or newcomers, were also not explored in this study; however, they may present further barriers and needs for accessible care without a primary care provider. Further, unique experiences as a cultural or linguistic minority may reasonably impact the perceptions of experiences without a primary care provider for members of these groups (Collin et al., 2023).

Considerations for socioeconomic status and the potential impact of access to financial support on the experiences of older adults without primary care providers were

explored in this study; surprisingly however, the secondary resources that become accessible with financial privileges, such as education, social capital, or digital literacy, were perceived as even more important to participants. The costs of accessing services or treatment adherence were limited in the discussion, and most participants indicated that, despite a wide range of gross annual income in participants, they would be able to access financial resources to do what was needed to maintain good health or address new challenges. A further consideration for older adults who lack this privilege should be considered as the current literature strongly indicates that there is a persistent negative correlation between low-income and chronic illnesses and decreased life expectancy (Raphael, 2020). Access to essential out-of-pocket health care services such as vision, rehabilitation services, or mental health care largely remains the onus of the patient. Thus, health challenges may arise for those unable to access out-of-pocket services or a consistent primary care provider (Tiagi, 2016). The financial burden of being without a primary care provider was limited for participants of this study; however, it was strongly indicated that the costs associated with maintaining health in older age should continue to be explored. It is critical to co-create an understanding of the experiences of those who may experience a lack of a primary care provider with different privileges than those included in this study to avoid perpetuating harmful biases and collaboratively express their needs.

Models of Ideal Primary Care

In exploring the literature related to unattached older adults, the implications of various frameworks and policies such as McMaughan et al's Theory of Socioeconomic Status and Access to Health Care and the Pillars of Primary Care (2020), as well as

considerations for the College of Family Physicians of Canada's Patients Medical Home model and New Brunswick visions for health system reform can help to address the impact and urgency of primary care access for older adults Behera & Prasad, 2022; College of Family Physicians of Canada, 2019).

McMaughan's Theory of Socioeconomic Status and Access to Health Care acknowledges the complexity of aging and socioeconomic status and the intersections of these considerations through access to health services. The theory considers how wealth impacts the accessibility, availability, affordability, acceptability, and accommodation of the health care system and their relationship to healthy aging, as defined by those seeking care (McMaughan et al., 2020). In addition to socioeconomic status-associated barriers, utilizing appropriate services at the proper time and in the appropriate manner is a capacity for perceived healthy aging. Accessibility, availability, and affordability were particularly prominent for participants of this study and may speak to the gaps in the Canadian health care system compared to the United States for which this model was first developed.

From a public and global health perspective, access to primary care has been a central tenant of positive community health for nearly four decades. The pillars of primary care include community participation, inter-sectoral coordination, appropriate technology, and available support mechanisms and aim to reduce inequities in communities (Behera & Prasad, 2022). These pillars strongly relate to the expectations of study participants for a robust primary care system and have been consistently proven to serve as the foundation of a successful health care system. In particular, the social

approach to care, integrated service delivery, support mechanisms for personal, physical, mental, and spiritual care, and the use of appropriate technologies align strongly with the findings of this study. Many participant experiences highlight a lack of such sub-criteria from each essential pillar. Thus, according to the pillars of the primary care framework, it is reasonable to justify participants' frustration with the primary care services they use. The pillars of the primary care model are recognized in the United Nations' Sustainable Development Goals, particularly in Sustainable Development Goal Three (SDG3), which aims to ensure healthy lives and promote well-being for all ages (Tangcharoensathien et al., 2015). Building a health care system on the four pillars of primary care steers the whole of health care in a more sustainable and equitable direction, urgently required to support the aging population in Canada and worldwide. The pillars of primary care, as well as the identified need for their support in addressing SDG3, amplify the findings of this study and the experiences of older adults in New Brunswick without primary care providers.

Patient's Medical Home- Revisited

In Canada, the College of Family Physicians of Canada has created a vision for primary care called the Patients Medical Home model. This vision is intended to support primary care providers in developing a model that allows the people they care for to receive the highest quality of care (College of Family Physicians of Canada, 2019). This standard is determined by those who deliver primary care and thus speaks to a feasible system that is sustainable for providers and people accessing care. The model was created in 2011 and revised to reflect current contexts in 2019. It emphasizes accessible, interdisciplinary, and person-centered needs and sets the expectation for primary care

delivery in Canada. The participants of this study mirrored the priorities of this model for their care; however, their experiences do not fit with the expectations of an ideal primary care model for people in Canada. The Patient's Medical Home model/framework for care is intended to function in a system where patients are attached to a provider or interdisciplinary team, and thus, an exact version of the framework is not reasonably expected for unattached people; however, the core values of accessible, person-centered, and interdisciplinary care set an ideal for alternate primary care access points as well as attached care practices. Currently, older adults in New Brunswick are seeking such values in a system. However, due to a loss of identity, inaccessible care hours, and scattered services, they are not receiving expected/ideal primary care services.

Further, it is worth noting that the typical pay model for primary care providers in Canada is the Fee for Service model, which provides a fixed fee for each unit of health care service provided and thus encourages physicians to treat patients with more significant needs and provide more services to maximize their income (Hong et al., 2024). Unfortunately, this model may not incentivize primary care providers working in alternative services to focus on preventative care and thus further consideration for the impact of current incentives in maintaining the current status quo in alternative primary care services, as well as the impact of other compensation models such as capitation or blended models, should be explored in future research.

New Brunswick

In New Brunswick, the most recent policy guiding health services is the Government of New Brunswick's Provincial Health Plan, "Stabilizing Health Care: An

Urgent Call to Action," which was released in November of 2021 (New Brunswick Department of Health, 2021). This strategic plan contains five Action Areas: Access to Primary Health Care, Surgery, Create a Connected System, Access to Additions and Mental Health Services, and Support Seniors to Age in Place, with 35 deliverables distributed between Action Areas. Three of these five priority areas relate strongly to the experiences of older adults without primary care providers who participated in this study. Access to primary care was identified as a priority in the 2021 plan; however, as per the experiences of participants, it still requires notable work. Creating a connected system is a priority area that intersects accessible primary care due to the need for communication between health care providers and people seeking care, the government and system users, and interdisciplinary providers/leaders. Building a collaborative system that can deliver accessible primary health care will support the fifth priority area, supporting seniors to age in place. Older adults without primary care providers find themselves at the intersection of the strategic priorities, many of whom may require improved services from all five.

While the provincial plan to address these action areas is critical to support unattached older adults, it is worth noting that the current circumstance in which unattached older adults find themselves is a result of a lack of preparatory action for the current health climate. The increase in older adults across Canada, specifically in New Brunswick, has been anticipated for decades. However, the system now finds itself in a point of crisis, and older adults without primary care providers are suffering because of this lack of action. Urgent and sustainable solutions are required to support the current

population, and early consideration for anticipated population changes is essential to future health systems' success.

Chapter 6 - Limitations

Notable limitations of this study include the transferability of findings due to sample composition and the evolving definitions of primary care services with ongoing reform and public discourse. The sample for this study consisted primarily of well-educated, urban/suburban, able-bodied, white people. Thus, their experiences are rooted in characteristics typically associated with privilege in this context. Participants in the sample expressed similar experiences to one another, however, their experiences may not be transferable to various other demographic groups as explored in the discussion chapter. At the time of the interview, most participants perceived their health to be stable and relatively good. In New Brunswick, nearly 68% of the population is estimated to have one or more chronic health conditions, and almost 25% have three or more chronic health conditions (New Brunswick Health Council, 2022a). In New Brunswick, approximately 30% of the population report French as their first language (Statistics Canada, 2021). This demographic group was not included in this study due to the scope of the project and researcher limitations. However, the specific experience of Francophones in New Brunswick is essential to explore further.

A second limitation in this study is the evolution of perception of primary care due to ongoing changes in expectations surrounding who delivers primary health care and how primary care is accessed. Participants may have held a current or traditional perspective of primary health care services wherein family doctors provide primary care from their offices; however, with advancing reform and expanded scope of practice for many health professionals, primary health care services are increasingly understood to encompass community pharmacists and nurse practitioners. As such, perceptions of what

constitutes primary care are being actively reshaped. Thus, perceptions of primary care access may vary in future research due to ongoing renewed understanding of primary care. The current and up-to-date language was used in this study. However, that language may quickly become understood differently by participants or readers based on ongoing reform and language used in the media. This may serve as a limitation in confirmability and thus should be considered in future discussions of primary health care that build on this work (Forero et al., 2018; Lincoln & Guba, 1986).

Chapter 7 - Implications

The implications for this study are broad and span practice, education, research, and policy. Building on the co-creation of understanding between the researcher and participants, applications of this work support an older-adult-informed and inclusive approach to health system reform.

Practice

A greater understanding of the personal experiences of older adults without primary care providers implies the need for relationship-driven practice amongst health care providers of attached and unattached patients. Episodic care encourages strict, timely visits with care providers; however, it is apparent in the findings of this study that relationship-driven care is required to support unattached older adults adequately. Health care providers need to become aware of the critical role of relationality and aim to provide connection-minded person-centered care, even in alternate and episodic care contexts. Further, continued efforts to expand the scope of practice for alternative primary care providers, such as pharmacists, nurse practitioners, registered nurses, and social workers, should be maintained to increase the availability of in-person and accessible services that facilitate connection with people seeking care. Alternative models of delivery that have been enhanced in response to the COVID-19 pandemic should be maintained as they allow for accessible care in certain circumstances; however, they should also be supported by connection-driven options.

To support relationship-driven care, practitioners can advocate for the prioritization of connection in their practices to better support their patients, and people

seeking care must advocate for the holistic and person-centered care that they deserve, even in episodic care settings. For example, participants in the study described using strategies to facilitate connection and reinforce their identity, including comprehensive medical histories prepared and printed for episodic care providers and actively questioning the impact of their circumstances when interacting with care providers. Ideally, health care providers should create opportunities to connect and build relationships with patients so that they can better support their health, even in very short/episodic appointments. However, patients can also play a role in this shift through advocacy and preparedness. Connection/relationship-driven primary care is essential for the success of unattached older adults and can be implemented in practice by both people seeking care and health care providers.

Education

To support a connection-driven alternate primary care system, education on the importance of relationality as health care providers should be emphasized in professional health education programs and has been shown to increase patient connectedness to healthcare providers, and healthcare providers compassionate and altruistic behaviours (Harden & Laidlaw, 2020). This objective may be achieved through both theoretical and experiential learning; both play an important role in understanding the context of this work and future actions based on an enhanced understanding of unattachment (Dolev, 2021). Consideration for theoretical applications to contexts beyond that of which the theory has been developed, such as the application of the theory of uncertainty in illness (developed based on experiences of people with cancer) for people without primary care providers. Additionally, experiential learning, such as clinical practicums, which are

often required in professional health education, may emphasize relationship building/connection as a key competency for success and underscore the importance of this skill in clinical settings. Encouraging the prioritization of connection and curiosity about patient experiences/navigation in education could support an impactful change that better supports unattached older adults and many others seeking care. Further, interdisciplinary care providers who are increasingly aware of the experiences of unattached older adults may reflect on and act to address the potential physical and mental health outcomes of people without primary care providers and the additional stressors/burdens impacting their health.

Educational health training programs and professional development initiatives may consider further exploring health care provider's roles in health system navigation. For many providers, navigation may not be an expected or traditional role within their scope of practice; however, navigating the current health care system is challenging for many, and an inability to access care due to navigation can have negative repercussions. Further education on health care navigation, interdisciplinary approaches to health services navigation, and how to best support people seeking care to access the appropriate services is form of preventative health care. Navigation resources and inclusion in supplementary education for primary care providers and students in professional health programs could substantially impact the experiences of unattachment for older adults and many others.

Finally, education relating to accessible resources for health system navigation and support for those who are unattached is required to allow equitable opportunity for

success without a primary care provider. Lack of consistent communication from health systems, care providers, and other supports has created a siloed experience for many without care providers. Some can access resources through social networks, however, a lack of trusted and reliable direction limits those who are unable to find decipher accurate information. Educational resources surrounding opportunities for care and information about health concerns should be made available for those who are unattached through practical, policy, and educational means.

Research

Future research should explore the experience of being without a primary care provider in additional populations, particularly groups identified as having more complex living situations, such as older adults who live alone or with a chronic illness. Variable access to care, urgency of their circumstances, or perceptions of their health may impact their experiences and indicate further gaps in the system. Additionally, considerations for other age groups and geographic locations should be considered. Access to primary care services can vary drastically between rural and urban contexts. For example, some rural communities in New Brunswick and across Canada face limited emergency department hours, and thus, there is a possibility of accessing alternative primary care services. In contrast, rural communities with well-established alternative primary care services, such as pharmacist-run primary care clinics or evening walk-in clinics, are much less crowded than those in urban settings. Additionally, age may impact experiences without a primary care provider due to individual concern for health, accessibility of available alternate primary care services, or past experiences within the health care system.

Research surrounding experiences being unattached is limited. While this study seeks to describe the experiences of unattached older adults in New Brunswick, future studies with varied methodologies would be impactful in broadening the understanding of experiences. For example, a quantitative study that reaches a large sample could support the findings from this study, as would future mixed-methods research. Further investigations regarding the impact of unattached on the health outcomes of those without primary care providers, both physical and mental, would enhance understanding of the unattached experience. The findings from this study indicate that this is a complex and unique experience that needs to be better understood so that reform may suit the needs of those without adequate access to health services.

Policy

Based on the findings of this study, further policy is needed to improve the experiences of unattached older adults in New Brunswick accessing and navigating health care. The policy should incorporate community-centered approaches to care that emphasize connection and accessible points of access to continuous care wherever possible. For example, a policy-directed collaboration between the health care system and various community organizations that assist with health services navigation and health system communication would allow for a bottom-up approach to accessible and appropriate care. As is detailed in the New Brunswick Child, Youth and Seniors' Advocate's recent reports on the healthcare system, policy changes are essential to ensure older adults are able to access primary health care that meets their needs to maintain good health without being attached primary care provider (New Brunswick Child, Youth and Seniors' Advocate, 2024)

Policymakers should continue encouraging meaningful engagement of older adults in decisions about system reform. As per participants' experiences in this study, persons with lived experience should be engaged to inform the strategic reform of primary care. The policy should build on the findings of this study in collaboration with those they aim to support to develop practically applicable and necessary solutions to address prominent challenges and maintain critical solutions for people without primary care providers.

Chapter 8 - Conclusion

The findings from this study demonstrate that unattached older adults in New Brunswick are experiencing complex and challenging circumstances without primary care providers. In alignment with the experiences shared, themes produced, and connections with related research, I present three recommendations to address the findings of this study.

Recommendation #1: Facilitate connection in the alternate care system.

- Those offering alternative primary care services such as nurse practitioners, pharmacists, and emergency physicians should be skilled at guiding health services navigation.
- Utilize interdisciplinary providers to facilitate access to various health promotion, self-management services, and mental health services (Tadic et al., 2020).

Recommendation #2: Prioritize accurate and accessible health systems information through clear and consistent communication.

- Consistent and reliable information should be provided from the government and health authorities to inform them of changes to the primary health care system and available resources.
- Increase access to reliable health information and navigation resources.

Recommendation #3: Participatory involvement in reform.

- Encourage the participatory involvement of older adults in health system reform to design a system that suits their needs, with or without a primary care provider.

- Consult with and co-create sustainable solutions that will be useful to those they are intended for.

Finally, it has been an immense privilege to share these stories and highlight the experiences of unattached older adults in New Brunswick while drawing connections to existing understandings of various experiences in the health care system. The experiences of loss of identity, impacts of privilege imbalances, and uncertainty describe a unique and painful burden of unattachment; however, it exists alongside a narrative of resilience and hopefulness that situations? may improve. Older adults in New Brunswick deserve a health care system that addresses their needs and makes them feel visible; they are capable of meaningful engagement in reform and need sustainable health systems that benefit both their health and the collective well-being of the system. The hope of both participants and researchers is that this work may highlight the experience of unattached older adults and inform impactful and sustainable change.

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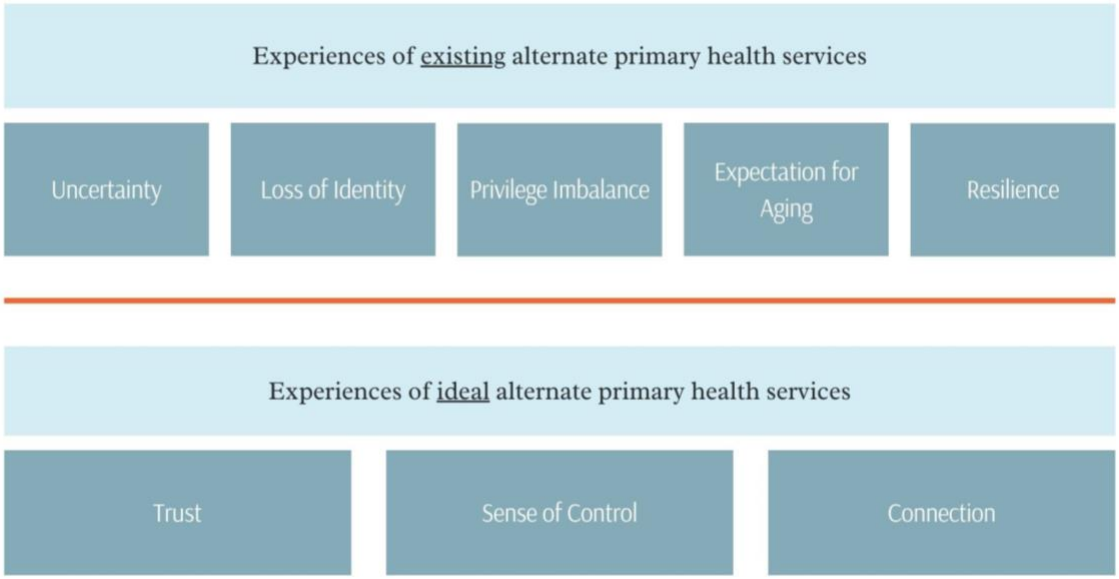
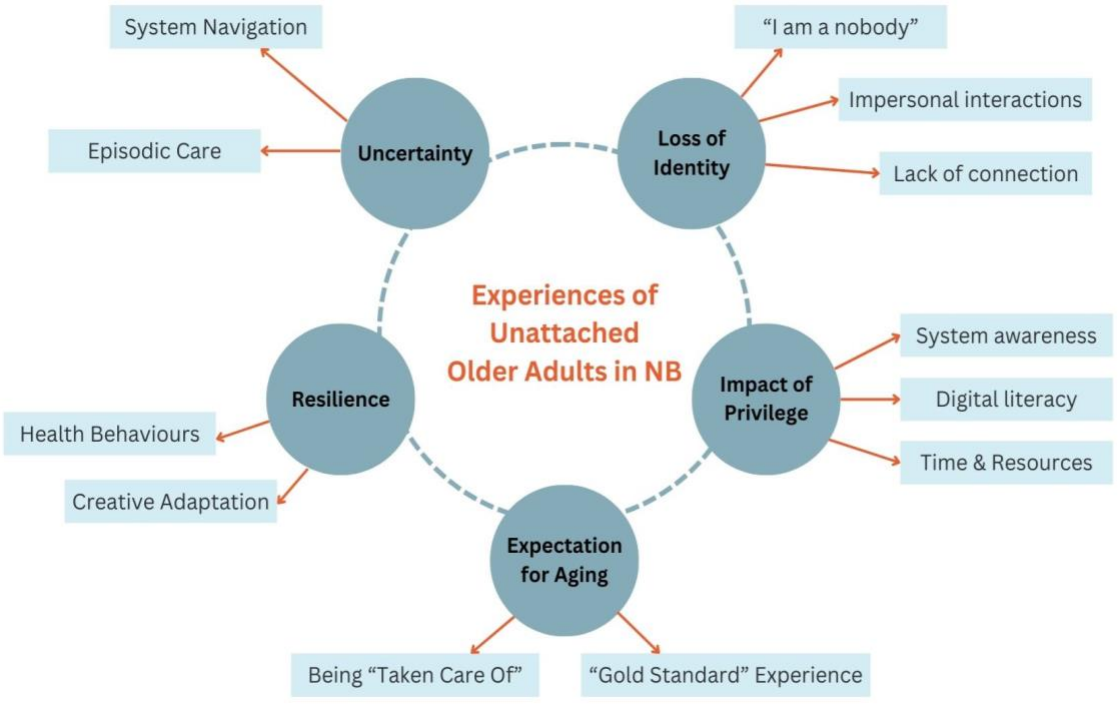
Appendix A: Thematic Visuals





Appendix B: Supportive Participant Quotes

Theme	Additional Quotes from Participant
Theme 1: "You don't know what you don't know" – Uncertainty is Certain	"[When] people have someone who knows your history and is actually seeing you, they can deal with you more quickly and accurately. Then to enter the system isn't unknown." (P20a) "It's terrible once again knowing that you don't know what's going on with you. And all you want to do is just say like please see me so I can you can treat me. You're really lost. You're really lost and that's your health" (P16)
Theme 2: "I'm a nobody" – Left Behind	"So, you really don't have confidence in the system, and I feel that it's that the government, you know they're making you feel like you're being moved, you're being improved, but really, you're just what one waitlist list to another waitlist. I'm sort of really losing confidence thing in our system." (P20b) "But it's not even a conversation [with some alternate services]. There's no human contact, there's no eye contact, there's no voice intonation, there's no warmth. It's like I'm just a number, 1 down and 10 more to go." (P09)
Theme 3: "Rob Peter to pay Paul" – Privilege in our Health care System	"And at some point, you just give up I think, I'm sure lots of people just give up and do without I guess." (P06) "If things were better [financially], [my health] would be better. I'm on limited funding, every month my rent is high and so I only have some much to live on…" (P16) "Low-income seniors seem to struggle to figure out what some of the alternatives are, and the good alternatives. So, the folks with that are a little more well to do and connected, tend to be able to find solutions easier because they have a more informed, bigger social network. [It] plays a big role." (P02)

Theme 4: "The Gold Standard"- Product of their Time	“I know when I was providing care to people, sometimes folks who didn't have health insurance or basic health insurance or whatever, you would often be able to get access to samples or compassionate provision of certain medication. I certainly remember doing that for people on certain instances so if you don’t have a provider [who knows you] then that is gone for you, all those options are gone.” (P06) “I went back to thinking about what was it like [when I was younger], you know? Well, I say for instance, I'm from a small town [in New Brunswick]. There were always two doctors there, and there was always a doctor that would even come to your house [when you needed them to].” (P16)
Theme 5: "I want to be healthy"- Resilience and Strength	“I don't mess around. I always say I believe in preventative maintenance for my house, my car, and myself.” (P21) “I just monitor for symptoms, and you know, I know I don't have a family history or anything like that, but you just kind of hope that [nothing goes wrong].” (P06)

Appendix C: Recruitment Script for Interview Participants

Document: Email/Telephone Script

Target Audience: Community-Dwelling Older Adults without Primary Care Providers in New Brunswick

Purpose: Interview Invitation from Graduate Student Researcher to Potential Participants

Telephone Script

Good morning/afternoon/evening (name),

My name is Kate Tucker, and I am a graduate student at the University of New Brunswick. I am calling you today to invite you to participate in an interview for my master's thesis research study. I would like your help understanding older adults' experience without primary care providers in New Brunswick.

I am looking for older adults who have been without a designated primary care provider (Family Doctor or Nurse Practitioner) for the past year to talk about their perceptions and experiences accessing health services. I've received your contact information from [where contact information was received] and would like to know if you would be interested in participating in an interview at a later time.

Do you have a few minutes to discuss this with me now?

No: Can I call you back another time to describe the study and discuss further what it would mean to participate?

Yes: Would you have a few minutes now to go over the study and what it entails?

This study focuses on understanding the experiences of older adults in New Brunswick who don't have primary care providers and how that impacts them. I will conduct 10-15 virtual interviews and analyze the data to determine key themes and outcomes. I'm interested in hearing about your experiences navigating and accessing health services, how being without a primary care provider impacts you, and what other services you use to address your health needs.

Interview participants will be from all across New Brunswick and will be held online via MS Teams or on the phone, whichever is more comfortable for participants.

If you are interested in participating in an interview, I will email you the informed consent form to read. We'll then arrange a time to review it and conduct the interview by telephone or online. The interview will be scheduled at your convenience and will take approximately one hour. It will be recorded for transcription processes, but the recording will be deleted immediately after it is transcribed.

If you choose to participate, please note that your involvement is voluntary and confidential. You do not have to answer any questions you don't want to. You may also choose to withdraw from the study at any time by contacting me by phone or email with the information provided in the study description you received.

All information that is gathered in this study will be kept confidential. You will not be identified in any published results of the study. Only myself and my supervisory committee, who are established and respected researchers at UNB, will have access to the information.

This study has been reviewed by the University of New Brunswick Research Ethics Board (File #2023-143). If you have any questions about this study, please contact Kate Tucker at ktucker@unb.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca or Lisa Keeping-Burke, Coordinator for the Master of Applied Health Services Research (MAHSR) program,, at lkeeping@unb.ca.

Are you interested in participating in our study?

No: Thank you so much for your time today. If you change your mind or know of someone else who may be interested in participating, please feel free to email me at kate.tucker@unb.ca or nbprimarycarestudy@gmail.com. Have a wonderful rest of your day.

Yes: That sounds wonderful!

After this telephone call, I will email you the detailed consent sheet to review before the interview. Would you like to schedule the interview now? Or else I can follow up with you in a few days after you have read the consent sheet.

Yes: Deliberate meeting time and contact information

No: Thank you. I will follow up with you in 2-3 days to answer any questions you may have and schedule the interview. You are also welcome to contact me.

Thank you for your time. If you have any questions about the study going forward, don't hesitate to email me at any time at kate.tucker@unb.ca or nbprimarycarestudy@gmail.com. Have a wonderful rest of your day.

Email Script

Dear [Name],

How does being without a primary care provider (Family Doctor or Nurse Practitioner) affect you and your well-being?

My name is Kate Tucker, and I am a graduate student at the University of New Brunswick. I am reaching out to you today to invite you to participate in an interview for my master's thesis research study. I would like your help understanding older adults' experience without primary care providers in New Brunswick.

What's involved?

1. Participation in one hour-long interview with myself to discuss your experiences accessing health services without a primary care provider within the last year. Depending on your preference, the interview will be held virtually via MS Teams or phone.

The estimated total time to participate in this study is 1 hour.

What's In It for You?

· You will receive a $20 gift card (President's Choice) for your participation.

· Share your opinions and experiences accessing health services without a primary care provider in New Brunswick.

· Participate in a knowledge generation process.

For more information or to participate, please contact:

Kate Tucker, Graduate Student Researcher

Email: ktucker@unb.ca

Phone number: (506) 300-2675.

This study has been reviewed by the University of New Brunswick Research Ethics Board (File # 2023-143). If you have any questions about this study, please contact Kate Tucker at ktucker@unb.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca or Lisa Keeping-Burke, , at lkeeping@unb.ca.

Appendix D: Recruitment Email

Target Audience: Community-Dwelling Older Adults without Primary Care Providers in New Brunswick

Purpose: Interview Invitation from Graduate Student Researcher to Potential Participants

Dear [Name],

Thank you very much for your interest in participating in an interview to discuss your experiences and perceptions of navigating health services without a primary care provider in New Brunswick. My name is Kate Tucker, and I am a master's student in Applied Health Services Research at the University of New Brunswick. I am conducting this study.

I would love to meet with you on MS Teams or via phone to explain the study in more detail and answer any questions you may have. If you decide to participate, we will then complete a consent form. More detailed information about the study is attached to this email.

Are you able to meet on any of the following dates or times? [Kate to fill in availability]

_____

_____

Please respond to let me know when you are able to meet or suggest another time.

Thank you very much!

Sincerely,

Kate Tucker, Graduate Student Researcher

Email: ktucker@unb.ca

Phone number: (506) 300-2675.

This study has been reviewed by the University of New Brunswick Research Ethics Board (File # 2023-143). If you have any questions about this study, please contact Kate Tucker at ktucker@unb.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca or Lisa Keeping-Burke, Coordinator, Master of Applied Health Services Research (MAHSR) program, at lkeeping@unb.ca

Appendix E: Study Information Sheet and Informed Consent

Document: Study Information Sheet and Informed Consent

Study Information Sheet and Informed Consent

Title of the Study: Experiences and Perceived Outcomes of Community- Dwelling Older Adults Accessing and Navigating Primary Care in New Brunswick

Principal Investigators:

Kate Tucker, Graduate Student, Applied Health Services Research, UNB, Fredericton,

(506) 300-2675, ktucker@unb.ca

Supervisors:

Pam Durepos, Assistant Professor, Faculty of Nursing, UNB, Fredericton, p.durepos@unb.ca

Rose McCloskey, Faculty of Nursing, UNB, Saint John, rmmclosk@unb.ca

Funded by: Canadian Institute for Health Research, University of New Brunswick, New Brunswick Innovation Foundation

Summary

You are being invited to participate in this study because you are either an older adult, living in community, who has not had a primary care provider (family doctor or nurse practitioner) since, or before, September of 2022 OR are a peer advocate/service provider with significant experience working with older adults in NB who have been without a primary care provider. In this study, we aim to **explore older adults' experiences and understanding of using health services without a family doctor in New Brunswick and consider the impact of socioeconomic status on these experiences.** This study is voluntary. This form explains the study risks and benefits. This information will help you decide if you want to participate.

What is the purpose of the study?

The purpose of this study is to increase understanding of the experiences of older adults who use primary care services in NB without a primary care provider. These experiences highlight strengths and gaps in the health care system and may be used to consider future use of care options other than family doctors or emergency departments. They may also inform how health services can be adapted to sustainably support older adults from a range of socioeconomic backgrounds and communities.

What will my responsibilities be if I take part in the study?

If you decide to participate in the study, you will be asked to participate in 1-2 one-hour interview with Kate Tucker to discuss your experiences seeking health care without having your own Doctor or Nurse Practitioner within the last year. The interviews can be done by phone or by using a computer with internet (through MS Teams video conference).

What are the potential risks for me or society?

There are no major risks in this study. You may feel talking about your experiences with primary care. You can skip any question in the interview that you do not want to answer. If you choose to participate only the researchers will know. Your name and information will be kept private and confidential.

What are the possible benefits for me or society?

It may feel good to talk about your experiences with someone who wants to listen. This research may also be used to help improve primary health care in the province of New Brunswick.

What information will be kept confidential?

The information you provide will be kept private and confidential. Your name and information will be removed from surveys and interviews transcripts and replaced with a code. No one will know if you choose to participate or not except for the researcher. MS Teams will be used to record and transcribe the interview; MS word will be used to analyze the transcripts. The software platforms are secure, and all data is stored in Canada.

All electronic data will be kept on the researcher's password protected laptop in password protected files. The video recording of the interview will be deleted as soon as the transcript is created.

None of your information can be shared outside of the research team without your permission. All data will be destroyed five years after the completion of this study. When presenting at scientific conferences and publishing, the names of participants will not be shared or available to anyone.

How many people will participate in this study?

Approximately 10 people will participate in this study.

Will I be paid to participate?

You will be given a $20 gift card for President's Choice (can be used at Atlantic Superstore or Shoppers Drug Mart) after the interview.

Can participation end early?

Your participation is voluntary, and you are free to leave the study at any time, without explanation. You can withdraw by emailing Kate Tucker at ktucker@unb.ca. If you withdraw, you can decide if you want to keep what you say in the interview in the study, or have it removed. After the data (what you say in the interview) has been combined with data from other participants, your information will not be able to be removed from the analyzed findings.

How do I enroll?

To enroll in the study, please email your interest to Kate Tucker at ktucker@unb.ca. Kate will share the Study Information Sheet with you for your review. You will then be contacted via email to arrange a mutually acceptable time to meet virtually on MS Teams or by phone for the interview. During the interview, Kate will review the study and answer any questions that you have. If you decide to participate, she will record your verbal consent statement and sign the study consent form on your behalf. She will then start a new recording and begin the interview. You do not need to answer any questions that you are not comfortable with and are free to end the interview at any time. Following the interview, Kate will email you a copy of the consent form for your records and thank you for your participation.

How will I receive feedback about the study?

A summary of the study findings will be sent to you by email in Summer 2024. The results may also be published in an academic journal and presented at academic conferences. All participant information will be combined, and no identifying information can be shared without your permission.

What is informed consent?

Informed consent is the process by which you are given the information you need, including possible risks/benefits, to participate in a study. It means it is your choice whether you participate or not in this research.

If you have any questions about the study, please contact:

Kate Tucker, ktucker@unb.ca

Informed Consent Statement

I have read the information sheet and have been given the opportunity to have all my questions about the study answered.

As a participant I agree to:

1. Complete a one-hour interview to discuss my perceptions and experiences navigating primary care services without a primary care provider in NB.

I consent to participate in this study.

I understand that the information collected is kept strictly confidential. I understand that I am free to withdraw from this study at any time if I wish.

_____ _____

Signature of participant Date

_____

Name of participant (please print)

I certify that I have explained the study and my participation in this research to the person signing. I certify that I have answered the questions asked about the project and that I

have made it clear to this person that they are free to withdraw from this study if they wish. A copy of this signed consent will be provided to the individual.

_____ _____

Signature of graduate student researcher Date

_____

Name of graduate student researcher

This study has been reviewed by the University of New Brunswick Research Ethics Board (File # 2023-143). If you have any questions about this study, please contact Kate Tucker at ktucker@unb.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca or Lisa Keeping-Burke, Coordinator, Master of Applied Health Services Research (MAHSR) program at lkeeping@unb.ca.

Appendix F: Emotional Support Resources

Discussions of these experiences may be difficult and can bring up many emotions, they can be overwhelming at times. There are resources available to support you and your mental health, their availability and contact information is below.

CHIMO Helpline	Freely Available Online or by phone 24-7	1-800-667-5005 http://www.chimohelpline.ca/
Vitalite: Community Mental Health Centers	Free Counselling, Monday-Friday 8-4:30	Bathurst: 506-547-2110 Campbellton: 506-789-2440 Caraquet: 506-726-2030 Edmundston: 506-735-2070 Grand-Sault: 506-475-2440 Kedgwick: 506-284-3431 Moncton: 506-862-4144 Richibucto: 1-866-662-1166 Shippagan: 506-336-3367 Tracadie: 506-394-3760 https://www.vitalitenb.ca/en/points-service/mental-health/adults/community-mental-health-centres
Horizon Health Network: Emergency Mental Health Counselling	Free Counselling by phone 24-7	Fredericton: 506-452-5400 Mirimachi: 506-623-3333 Moncton: 506-857-5361 Saint John: 506-648-6479 Waterville: 506-375-5900 https://en.horizonnb.ca/home/facilities-and-services/services/addiction-and-mental-health-services/emergency-mental-health-services.aspx

Accessible Health Care Services

Additionally, if you are looking for more information on accessible primary care options available, resources and contact information for your region is as listed:

GNB Health Symptom Checker	Website available to help you determine: - How serious your symptoms are. - If a healthcare visit is needed - What steps you can take to relieve your symptoms at home	GNB Symptom Checker Link
Tele-Care 8-1-1	Telephone service available 24/7. - Support from a nurse with instructions for referral to additional community services	Phone number: 811
Pharmacists	Can provide refill for existing prescription and address questions about minor ailments (such as UTIs, eczema, shingles, cold sores, etc.).	Available at any local pharmacy across the province!
Virtual Clinics	Connect with a healthcare provider via phone, video, or chat messages. Registration is available from 8am-8pm, 7 days per week. Service is covered with a valid NB Medicare card.	https://www.evisitnb.ca/
Walk-in clinics	Walk-in clinics are available at some locations across the province. Patients are served on a first-come, first-serve basis.	Link to locations and hours of all NB walk-in clinics. https://www.nbms.nb.ca/walk-in-clinics/
Patient Connect NB	Looking to be matched with a primary care provider? Patient Connect NB allows you to register with a family doctor or	Link to Patient Connect NB

	nurse practitioner on a first come, first-serve basis. Once you are referred to a practice, you will be contacted directly by the Primary Care Provider's office. Your valid Medicare card will be required.	or call 8-1-1 and they will assist you.
NB Health Link	Patients who are registered with Patient Connect NB and waiting for an assigned healthcare provider can access a network of health professionals throughout the province, offering in-person, telephone, and online appointments in both official languages.	NB Health Link website You can also register for an appointment by calling 1-833-354-2300 (toll free) between 9am and 4pm, Monday to Friday.

Appendix G: Recruitment Poster

The below poster was used for distribution via email, in addition to the Study Information Sheet, to potential participants. Additionally, it was shared with primary care clinics in New Brunswick including walk-in clinics and various pharmacies. Additionally, the poster was circulated on social media.

UNB
EST. 1785
UNIVERSITY OF NEW BRUNSWICK

How does being without a Primary Care Provider* impact you?

*Family Doctor or Nurse Practitioner

As part of a master's study at the University of New Brunswick, we want to know more about how being without a primary care provider impacts older adults in New Brunswick.

We are looking for older adults (65+) who have been without a Primary Care Provider for at least one year to participate in one hour-long virtual interview.

Participants will receive a $20 gift card in appreciation for their time. All participation is completely voluntary.

FOR MORE INFO PLEASE CONTACT KATE AT NBPrimaryCareStudy@gmail.com OR CALL (506) 300-2675.

This study has been reviewed by the University of New Brunswick Research Ethics Board (File # 2023-143). If you have any questions about this study, please contact Kate Tucker at ktucker@unb.ca. You may also contact Dr. David Coleman, Chair of the UNB Research Ethics Board, at ethics@unb.ca or Lisa Keeping-Burke, Associate Dean of Health Research, at lkeeping@unb.ca.

Appendix H: Interview Guides

Document: Interview Guide (Peer Advocates / Service Providers)

Experiences and Perceived Outcomes of Community-Dwelling Older Adults Accessing and Navigating Primary Care in New Brunswick

1. You are eligible for this study because you work closely with older adults who do not have a family doctor/nurse practitioner. Can you tell me about your role and the work that you do? *(prompt: How does being without a primary care provider come up in the work that you do)*

2. What are the different ways people try to access health care they would typically get from a family doctor when they need it? *(prompt: which do they use the most often?)*
    a. Are you aware of any other services available to you in New Brunswick that you don't often hear about them using? *(E.g. ED, 811, Telehealth)*
        i. (IF YES) Why do you think that they don't use those other services?

3. In your understanding of these alternate care services from the people you work with, what seems to work well?
    a. What does not work well for these services?
    b. What could make it better?

4. How do you think being without a family doctor/nurse practitioner impacts the people that you work with? (*prompt: How does it impact their access to health services? How do you perceive it to impact them emotionally/otherwise?)*

5. In your perspective, how accessible are the services to the people you work with? *(Prompt: Did you have to travel very far or learn to navigate a new website? Does access require assistance from family/friends?)*
    a. What tools support people in accessing these services?
    b. What are some barriers to accessing these services? How could those barriers be addressed?

6. On average, how long do you think that the people you work with wait after feeling unwell, to the point that you would go to a family doctor/nurse practitioner if you had one, before using any of the health services you mentioned?

a. How do you see these wait times impacting the people that you work with?

7. How do you feel that socioeconomic status impacts older adult's ability to use the services you mentioned? How? *(Prompt: access to transportation, ability to take time off work, access prescription medication/medical resources)*

8. How do you feel that using these services instead of having a family doctor/nurse practitioner, has affected the health of the older adults you work with?

    a. How is using these services different or similar to the care they would receive from a PCP? (*Same as outcomes as you would expect with a PCP, worse outcomes, better outcomes).*

9. What do you expect the unattached older adults you work with to do next time they need health services? *(Prompt: what services do you plan to access?)*
    a. How do you feel about your options for accessing health services?

10. Is there anything else you would like to share with me about your experience without a primary care provider?

Thank you for participating in this interview and sharing your experiences. The recording of this interview will be transcribed and then deleted. Would you like to be emailed a copy of the final findings from this study?

Document: Interview Guide (Community-Dwelling, Unattached Older Adults)

Experiences and Perceived Outcomes of Community-Dwelling Older Adults Accessing and Navigating Primary Care in New Brunswick

1. You are eligible for this study because you do not have a family doctor/nurse practitioner. What has contributed to you being without a care provider? *(prompt: the previous provider retired/moved, not available, you have come to NB recently, don't want one)*

2. How does being without a family doctor/nurse practitioner affect you? (*prompt: how does it make you feel, how does it impact your access to health services?)*

3. Since you have been without a family doctor/nurse practitioner, how have you accessed health services when you've needed them? *(prompt: which do you use the most often?)*
    a. Are you aware of any other services available to you in New Brunswick that you don't use? *(E.g. ED, 811, Telehealth)*
        i. (IF YES) Why don't you use those other services?

4. On average, how long do you typically wait after feeling unwell, to the point that you would go to a family doctor/nurse practitioner if you had one, before using any of the health services you mentioned?
    a. On average, how long do you wait to see a provider once you contact the service (e.g., walk into ER, call 811)?
    b. What are your thoughts about those wait times?

5. Please describe your general experiences with the services you access; what does a typical interaction look like?
    a. What do you like about this service?
    c. What don't you like about the service?
    d. What could make it better?

6. How accessible are the services to you? *(Prompt: Did you have to travel very far or learn to navigate a new website? Does access require assistance from family/friends?)*
    a. What tools support you to access these services?
    b. What are some barriers to accessing these services? How could those barriers be addressed?

7. Do you feel your socioeconomic status impacts your ability to use the services you mentioned? How? *(Prompt: access to transportation, ability to take time off work, access prescription medication/medical resources)*

8. How do you feel that using these services instead of having a family doctor/nurse practitioner, has affected your health? *(Same as outcomes as you would expect with a PCP, worse outcomes, better outcomes).*

9. What do you plan to do the next time you need health services? *(Prompt: what services do you plan to access?)*

    a. How do you feel about your options for accessing health services?

10. Is there anything else you would like to share with me about your experience without a primary care provider?

Thank you for participating in this interview and sharing your experiences. The recording of this interview will be transcribed and then deleted. Would you like to be emailed a copy of the final findings from this study?

Appendix I: Demographic Survey

Document: Demographic Survey for Interview Participants

Thank you for agreeing to participate in our study. Please answer the following questions about yourself. The purpose of collecting this information is so we will be able to describe, as a group, the participants for this study.

1.What is your gender?

- □ Man
- □ Woman
- □ Transgender
- □ Non-binary/non-conforming
- □ Self-Identify: _____
- □ Prefer not to say.

2.What is your age? _____

3.What is your highest level of education?

- □High School
- □ Trade / Community / Vocational College
- □Undergraduate University
- □Graduate School
- □ Professional Degree (Nurse Practitioner, Physician, Lawyer)
- □ Prefer not to say.

4.Do you self-identify as a person of minority sexual orientation, gender identity, or gender expression (2SLGBTQIA+)?

☐ Yes ☐ No ☐ Prefer not to answer.

5.Do you self-identify as a person living with a disability?

☐ Yes ☐ No ☐ Prefer not to answer.

6. How do you describe yourself? Select all that apply.

□ Indigenous

□ Asian

□ Black

□ Latino

□ Middle Eastern

□ White

□ Acadian

□ Self-identify _____

□ Prefer not to answer.

Comment: _____

7.What is your preferred language?

□ English

□ French

□ Another language _____

□ Prefer not to answer.

Comment: _____

8. What type of community do you live/work in?

□ Rural (Less than 10,000 people)

□ Urban (More than 10,000 people)

□ Prefer not to answer

9. Which participant group do you best identify with? Please select which applies best to you.

□ Older Adult

□ Healthcare/ service provider

□ Family member or friend of an older adult

□ Prefer not to answer

If older adult (question 5):

11. How long have you been without a primary care provider:

□ Less than one year

□ 1-2 years

□ 2-5 years

□ More than 5 years

□ Prefer not to answer

12. Who do you live with? Please select all that apply.

□ Spouse / Partner

□ Adult children

□ Friend/un-related older adult

□ Other (please describe)

□ Live alone

□ Prefer not to answer

13.Do you have any dependents?

Yes / No

If so, do they live with you?

13. What is the average yearly income in your household

□ Less than $20,000

□ $20,000 - $49,999

□ $50,000 - $79,000

□ $80,000 - $109,999

□ $110,00 - $199,999

□ $200,000+

□ Prefer not to answer

14. Do you ever struggle to afford your basic needs?

□ Yes, often (please explain) _____

□ Sometimes (please explain) _____

□ No

□ Unsure

□ Prefer not to answer

15. Do you feel that your income impacts your ability to access health services?

□ Yes (please explain) _____

□ No

□ Unsure

□ Prefer not to answer

If Healthcare/service provider (question 5):

16. What organization do you work with? _____

17.What is your role with your organization? _____

18. Optional: Is there anything else you would like to share on this survey about your experience without/working with people without a primary care provider?

_____

Appendix J: Research Ethics Board Approval

Wednesday, October 25, 2023 at 14:53:36 Eastern Daylight Time

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Subject: REB 2023-143
Date: Wednesday, October 25, 2023 at 1:49:44 PM Eastern Daylight Saving Time
From: David John Coleman
To: Kate Tucker
CC: Ethics, Department of, Elizabeth Harrison

Kate Tucker
Master of Applied Health Research Student
University of New Brunswick Fredericton

To Kate Tucker:

As Chair of the Research Ethics Board (REB) at UNB Fredericton, I have reviewed your ethics application for the project entitled "Experiences and Perceived Outcomes of Community-Dwelling Older Adults Accessing and Navigating Primary Care in New Brunswick" which has been assigned the file number **REB 2023-143**. On the basis of the review, I consider your project to be eligible for delegated review, since any risk to participants that might exist appears not to exceed the "minimal risk" outlined in the Tri-Council Policy Statement, 2nd edition (TCPS2). I am also pleased to inform you that, in my opinion, your project is in compliance with TCPS2 and the University Policy on Research Involving Humans (UPRIH). **Accordingly, please consider this E-mail to represent official notification of REB approval of your project. This REB approval is in effect from October 25, 2023 to October 25, 2026.**

NOTE 1: In the appropriate designated space in each of your relevant Appendix A, B, C and D documents, would you please insert the REB File Number assigned to this project (**REB 2023-143**)? Then, would you please email to me (cc to <ethics@unb.ca>) a copy of each of those modified documents for our records? There is no need to send a revised version of the whole application.

If you require an official hardcopy letter of this approval to satisfy a funding body, please inform the UNB Fredericton Research Ethics Board office <ethics@unb.ca> as soon as possible. If the funds for this research project are held until REB approval, then please inform UNB Fredericton's Office of Research Services of this approval in order to release your funds.

Please note that, in the future, if you find that you must make any changes to your protocol, those changes must be considered and approved by the REB before they are implemented. Please submit the REB Case Modification Request form, available online through the Research Ethics page of the Office of the VP (Research).

Also please note that you are obliged to advise the REB of any adverse event(s) that occur during this approval period. An adverse event includes — but is not limited to — a complaint, a change or unexpected event that alters the level of risk for the

1 of 2

researcher or participants, or a situation that requires a substantial change in approach to a participant or participants.

Finally, Annual Reports for this project are due on the 15th of January each year, provided that this date is at least six months after the date of this project approval. Final reports are due 90 days after project completion. Form templates for both of these reports can be found on our website at https://www.unb.ca/research/vp/ethics.html.

Best wishes for the successful completion of your research project.

— David

David Coleman
Chair • UNB Fredericton Research Ethics Board
Professor Emeritus • UNB Fredericton
T 506 453-5189 **E** dcoleman@unb.ca

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Friday, November 10, 2023 at 09:33:22 Atlantic Standard Time

Subject: REB 2023-143 Modification
Date: Friday, November 10, 2023 at 9:27:12 AM Atlantic Standard Time
From: David John Coleman
To: Kate Tucker
CC: Ethics, Department of, Elizabeth Harrison, Pam Durepos

Kate Tucker
Master of Applied Health Research Student
University of New Brunswick Fredericton

To Kate Tucker:

I have reviewed your request for a modification of your previously approved application to the UNB Fredericton Research Ethics Board ("Experiences and Perceived Outcomes of Community-Dwelling Older Adults Accessing and Navigating Primary Care in New Brunswick" -- REB #2023-143) for its compliance with Tri-Council Policy (TCP) and with UNB Policy (UPRIH). On the basis of the review, I am pleased to inform you that, in my opinion, your project appears to be still in compliance with TCP and UPRIH. Accordingly, please consider this E-mail to represent notification of the continuation of the previous REB approval of your project.

This approval is based on my understanding that the underlying nature of the research itself has not changed, and that your proposed modification involves the following:

1. Inclusion of demographics survey for interview participants; and
2. Inclusion of healthcare/service providers in interviews, with the Interview Guide updated to include appropriate questions for these participants.

If you require an official hardcopy letter of this approval to satisfy a funding body, please inform the UNB Fredericton Research Ethics Board office <ethics@unb.ca> as soon as possible. If the funds for this research project are held until REB approval, then please inform UNB Fredericton's Office of Research Services of this approval in order to release your funds.

Please note that, in the future, if you find that you must make any further changes to your protocol, those changes must be considered and approved by the REB before they are implemented. Please submit the REB Case Modification Request form, available online through the Research Ethics page of the Office of the VP (Research).

Also please note that you are obliged to advise the REB of any adverse event(s) that occur during this approval period. An adverse event includes — but is not limited to — a complaint, a change or unexpected event that alters the level of risk for the researcher or participants, or a situation that requires a substantial change in approach to a participant or participants.

Finally, Annual Reports for this project are due on the 15th of January each year, provided that this date is at least six months after the date of original project approval. Final reports are due 90 days after project completion. Form templates for both of these reports can be found on our website at https://www.unb.ca/research/vp/ethics.html.

Best wishes for the successful completion of your research project.

— David

David Coleman
Chair • UNB Fredericton Research Ethics Board
Professor Emeritus • UNB Fredericton
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Curriculum Vitae

Candidate's Full Name: Kate Marjorie Elizabeth Tucker

Universities Attended (with dates and degrees obtained):

University of New Brunswick, Bachelor of Philosophy- Interdisciplinary Leadership Studies (2019-2022)

Publications:

Durepos, P., MacLean, R., Cormier, N., Boamah, S.A., Witherspoon, R., Gould, O., Olthuis, J.A., Totton, K., Tucker, K., Boulay, I., Robitaille, A., Aquino- Russell, C., & Kaasalainen, S. (2024). Engaging care partners of persons living with dementia in Acceptance and Commitment Therapy (ACT) programs: A scoping review. *Aging & Mental Health*, 1–13. https://doi.org/10.1080/13607863.2023.2288864

Conference Presentations:

Gibbons, C., Durepos, P., Tucker, K., Brideau, S., Hamilton, S., Lanteigne, M., Savage, D., Elliott, J., Balcom, S., Busolo, D., Morris, P., McCloskey, R., & Kaasalainen, S. Palliative Programs in Long-Term Care Homes in New Brunswick, Canada: Findings and Lessons Learned from a Qualitative Analysis. Submitted to: *Canadian Association on Gerontology Annual Scientific Meeting,* October 26-28, 2024, Edmonton, AB.

Durepos, P., Gibbons, C., Balcom, S., Busolo, D., Morris, P., Elliott, J., Savage, D., Kaasalainen, S., Leger, M., Tucker, K., Lanteigne, M., Hamilton, S., Brideau, S., MacLean, R., & McCloskey, R. Building Capacity for Palliative Programs in Long-Term Care: Mixed Methods Evaluation of a Multi-Component Intervention. Submitted to: *Canadian Association on Gerontology Annual Scientific Meeting,* October 26-28, 2024, Edmonton, AB.

Tucker, K., Durepos, P., McCloskey, R. (2024). Perceptions of Primary Care Access for Unattached Older Adults in New Brunswick. Oral Presentation. *Canadian Healthcare Navigation Conference.* May 1-2, 2024, Virtual.

Tucker, K., Durepos, P., McCloskey, R. (2024). Left Behind: Experiences of Unattached Older Adults in New Brunswick. Oral Presentation. *Astra Zeneca Integrated Health Initiative Research Symposium.* April 11-12, 2024, Saint John, NB.

Tucker, K., Cormier, N., MacLean, R., Lanteigne, M., Totton, K., Gould, O., Olthuis, J., Pickford, K., Durepos, P. (2024). Acceptance and Commitment Therapy (ACT): feasibility of a tele-counseling program for caregivers of people with dementia. Poster

Presentation. *Astra Zeneca Integrated Health Initiative Research Symposium.* April 11-12, 2024, Saint John, NB.

Harley, M., Grey, L., Johnston, K., Tucker, K., Mancuso, R., Cho, M., Parrott, J. Frayme's Knowledge Mobilization Fellowship Showcase. Oral Presentation. *#FRAYME2024 Learning Institute*. February 21-22, 2024, Ottawa, ON.

Tucker, K., Cormier, N., MacLean, R., Lanteigne, M., Totton, K., Gould, O., Olthuis, J., Pickford, K., Durepos, P. (2023). Commitment Therapy (ACT): A Scoping Review of Program Factors. Poster Presentation. *Canadian Association on Gerontology, Annual Scientific Meeting.* October 26-28, 2023, Toronto, ON.

Tucker, K., Cormier, N., MacLean, R., Lanteigne, M., Totton, K., Gould, O., Olthuis, J., Pickford, K., Durepos, P. (2023). Qualitative Findings from a Pilot and Feasibility Study of Acceptance and Commitment Therapy with Caregivers of Persons with Dementia. Poster Presentation. *Canadian Association on Gerontology, Annual Scientific Meeting.* October 26-28, 2023, Toronto, ON.

Roitershtein, A., Tucker, K., Park, K., Ramirez, K., Mantor, V., Vandbakk Knudsen, M., Hammer Andersen, J., Pavri, F. (2023). Blueprints for the Arctic Blue Economy: International Graduate Student Research Cohort. Oral Presentation. *Arctic Circle Assembly*. October 19-21, 2023, Reykjavík, Iceland.

Tucker, K., Durepos, P. (2023). Experiences, Perceptions, and Perceived Outcomes of Unattached Older Adults Accessing Primary Care in New Brunswick- Proposed Master's Thesis. Oral Presentation. *28th Annual Nursing Research Day - Visions of Nursing: Insights, Innovations, and Impact.* August 31, 2023, University of New Brunswick (Virtual).