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Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study

Patricia Nistor, *The University of Western Ontario*

Supervisor: Ryan, Bridget L., *The University of Western Ontario*
Co-Supervisor: Terry, Amanda L., *The University of Western Ontario*
A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Epidemiology and Biostatistics
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Abstract

Introduction. Social restrictions preventing the spread of COVID-19 possibly increased social isolation and loneliness. The validity and reliability of a questionnaire assessing the COVID-19 pandemic's impact on social isolation and loneliness in community dwelling older adults with multimorbidity was investigated.

Methods. A conceptual framework was developed to guide questionnaire construction. Participants were recruited through professional networks, comprising a convenience sample. Feedback interviews assessed usability and face validity. Content validity was assessed using a Content Validity Matrix, and construct validity through tests of association. Reliability of validated scales was assessed using Cronbach's α. Descriptive statistics and logistic regression were computed.

Results. This questionnaire was found to have strong content validity and validated scale reliability in this population and setting. Construct validity could not be fully ascertained.

Conclusions. The current thesis found the questionnaire to be valid and reliable in this setting and population.

Keywords

Keywords: multimorbidity, COVID-19, social isolation, loneliness, resilience

Summary for Lay Audience

This study was a pilot study, in preparation for a larger Canadian Institutes of Health Research-funded study, called “Exploring the Untold Story of COVID-19: Understanding the Wider and Future Impacts of the Pandemic and Finding Solutions to Improve Population Health, Resiliency, and Preparedness” (hereafter referred to as the Untold Story of COVID-19). The Untold Story of COVID-19 is investigating the COVID-19 pandemic’s effect on people aged 50 years and older with multiple chronic diseases in terms of their feelings of social isolation and loneliness as we emerge from the pandemic. The current thesis project was the pilot study portion of The Untold Story of COVID-19 and was conducted to test the methodology of the larger study. This thesis project involved constructing the questionnaire and testing its feasibility, validity and reliability. This study informs the questionnaire for The Untold Story of COVID-19, in terms of clarity of questions and ease of understanding of them. It is important to do this trial run of the larger study to be sure that the most accurate information is gathered to meet the larger study objectives. This study found that the questionnaire was well made, and participants found it easy to complete and illustrated that the Untold Story of COVID-19 project can progress forward.

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Chapter 1

1 Introduction

The current thesis project forms the pilot study for the "Exploring the Untold Story of COVID-19: Understanding the Wider and Future Impacts of the Pandemic and Finding Solutions to Improve Population Health, Resiliency, and Preparedness" project. This chapter focuses on a broad overview of the components of the current thesis project and offers an introduction to the processes used in this study.

1.1 Overview of Larger Untold Story Study Design

The current thesis project was part of a larger Canadian Institutes of Health Research (CIHR)-funded study called "Exploring the Untold Story of COVID-19: Understanding the Wider and Future Impacts of the Pandemic and Finding Solutions to Improve Population Health, Resiliency, and Preparedness" (hereafter referred to as The Untold Story of COVID-19, or Untold Story project).

This larger Untold Story of COVID-19 project has three major research objectives:

"1) To qualitatively and quantitatively identify and describe the differential direct and indirect impacts of the COVID-19 pandemic on older adults with multimorbidity, including social isolation, resilience, and health behaviours;

2) To identify the characteristics of older adults with multimorbidity associated with social isolation during the pandemic and to develop a scoring rule to identify those most likely to experience social isolation; and

3) To develop and internally validate a model of care intervention informed by the first two objectives, called COVID-19 Patient-Provider Exchange in Primary Care (COPE_PC) to provide tailored support for older patients with multimorbidity and their family physicians when discussing social isolation and its role in resilience and health behaviour outcomes."[1]

In order to meet objectives 1 and 2, the larger Untold Story project will employ an online questionnaire; this thesis project involved the design of the conceptual model for the Untold Story project, the questionnaire construction, and the pilot study design and its execution, including a test of the statistical code that will be used to analyze the data from the full-scale questionnaire.

1.2 Study Rationale

The physical distancing public health measures that were employed to reduce the risk of COVID-19 have exacerbated social isolation and loneliness.[2] This is of concern because both social isolation and loneliness are generally associated with adverse health outcomes,[3,4] especially for individuals who were at greater risk of contracting COVID-19 who had to be especially cautious. These at-risk individuals for adverse outcomes of COVID-19 infection, both in the short and long term, were older and had increasing numbers of chronic conditions.[5,6,7,8,9] Therefore, it is important to gather more information about the experiences of these individuals to identify ways to help reduce social isolation and loneliness for them as we emerge from the COVID-19 pandemic.

Multimorbidity is defined as the co-occurrence of two or more chronic diseases in the same individual[10,11,12] and has become a major health concern as the global population ages.[13] While more prevalent in older individuals, age is not the sole driver of multimorbidity,[11,14] with younger age groups starting to be affected,[15,16,17] and multimorbidity occurring in people as young as 35 years old.[14] Stratification by income also exists, where lower income levels,[18] higher economic deprivation[19,20,21,22] and lower education levels[18,19] are associated with higher levels of multimorbidity. Being female is another risk factor for multimorbidity.[13,17,23] Modifiable risk factors such as physical activity may be targets for interventions to prevent the progression and development of multimorbidity.[24]

Social isolation and loneliness are distinct concepts that are closely related, with resilience seemingly related to the relationship of social isolation and loneliness and

adverse health outcomes.[25] Social isolation is a more objective measure of one's social network[26] and can be defined as little or no social interaction.[27] On the other hand, loneliness is a subjective measure of one's social network[26] and can be defined as a disconnect between a person's desired and actual social network.[27] Similar to multimorbidity, risk factors for social isolation include age,[28,29] being female[29] and poorer health.[30,31] Social isolation and loneliness are also associated with an increased risk of mortality and morbidity,[3,4] cardiovascular disease,[32,33] dementia,[34,35] and overall poor health.

The outbreak of SARS-CoV-2-β-coronavirus (COVID-19) rapidly spread across the world and by March 13, 2020, the World Health Organization (WHO) declared it a global pandemic.[36] During the course of the COVID-19 pandemic, a number of variants arose with their most prominent features including increased transmissibility.[37] Early adoption of public health measures, including closing schools[38] and all services apart from essential ones,[39] and restricting gatherings[40] showed efficacy in reducing case numbers in most Canadian provinces.[41]

Risk profiles for COVID-19 infection and adverse outcomes overlapped with increasing numbers of chronic conditions[5,7,32,42,43] and age[42,43,44,45] being the most strongly associated. During the COVID-19 pandemic, it was found that higher levels of multimorbidity were associated with higher risk of severe COVID-19 infection[46] and those with severe COVID-19 infection had over two times the prevalence of multimorbidity.[47] Due to healthcare systems being overloaded by those infected with COVID-19,[48] health care utilization decreased among those with chronic diseases,[49] and caused health declines in those individuals with multimorbidity.[50]

In addition to the health effects of COVID-19 infection, the pandemic itself led to social isolation especially for those with multimorbidity.[3] Even prior to the COVID-19 pandemic, social isolation and loneliness were associated with mortality and morbidity.[3,4] Following the start of the COVID-19 pandemic, public health lockdowns were most strongly associated with social isolation and loneliness in younger and older individuals.[3]

In the United States, high levels of individual resilience helped buffer the relationship between pandemic related stressors and depressive symptoms.[51] Older Canadians living alone or in smaller spaces appeared to have been more negatively affected by the pandemic, while the reverse was true for those living in larger spaces with others.[52] Potential negative effects of mental health for older adults arose from the COVID-19 pandemic due to social isolation as a consequence of public health measures.[53] Therefore, it is important to study the impact of the COVID-19 pandemic on social isolation and loneliness in older adults as we emerge from the pandemic.

When conducting large questionnaire studies, it is best practice to conduct a pilot study with a smaller sample before the full-scale studies.[54] Conducting a pilot study before launching the full project can help identify possible problems with methodology,[55,56,57,58] lead to improvements in a full-scale study's methodology,[57] determine variables for analysis, and identify ethical considerations.[55] Pilot studies can also help to assess the validity and reliability of a questionnaire when the pilot study is conducted within the context of a survey study. Due to these important methodological considerations when conducting large-scale studies, the current thesis forms the pilot study for the questionnaire to be used in the larger Untold Story project.

1.3 Description of the Current Study

The current thesis project comprises the design and construction of the questionnaire that will be used in the larger Untold Story project, the pilot study to test the questionnaire and methodology of the larger Untold Story project, and analysis of the pilot sample data. The validity, reliability, feasibility, and usability of the questionnaire for the larger Untold Story project was assessed during this thesis project. To be able to construct the questionnaire in such a way as to capture the variables of interest, a conceptual model for the study had to be developed as a satisfactory existing one could not be found. This conceptual model was designed around the relationship of interest for the Untold Story project, which was the impact of social isolation and loneliness on health outcomes in

individuals with multiple chronic diseases in the context of the post-COVID-19 pandemic world.

Using the conceptual model as a guide, the questionnaire was constructed using questions and response categories from previously validated scales or questions from large, population-based surveys like the Canadian Community Health Survey, Canadian Housing Study and Canadian Census when available. When this was not possible, the research team constructed questions. As the main goal of the larger Untold Story project was to have a questionnaire no longer than 80 questions in length and one that took no longer than 30 minutes to complete to reduce respondent burden, an iterative item reduction process was employed to reduce the number of questions from 116 to 80. This process involved many discussions within the research team and conducting literature searches to gather information about the key concepts in the model. The questionnaire was administered online through Qualtrics XM software and was programmed and tested during the course of the current thesis project.

The sample used for this pilot study was a convenience sample, though, for the larger Untold Story project, the University of Waterloo Survey Research Centre[59] was contracted to conduct the data collection. Therefore, the Survey Research Centre's panels will be used to recruit potential participants for the larger Untold Story project. The current thesis project also comprised writing and testing the statistical code that will be used for the larger Untold Story project.

The main objective of the current thesis project was to assess the properties of the questionnaire to be administered during the full Untold Story study. In order to assess the validity, reliability, feasibility and usability of the questionnaire, a mixed-methods approach was used with a quantitative emphasis. Content validity was assessed through the Content Validity Matrix and targeted questions about participant interpretations of questionnaire questions during feedback interviews. Construct validity was assessed through testing of six hypothesized relationships between variables representing questionnaire constructs. Face validity was also assessed during the feedback interviews.

Reliability was assessed by computing a Cronbach's α coefficient for the previously validated scales utilized in the questionnaire, the 11-item Duke Social Support Index and 10-item Connor-Davidson Resilience Scale. Feedback interview questions about participant experiences with completing the questionnaire were used to assess usability and feasibility.

1.4 Current Study Objectives and Question

1.4.1 Study Objectives

1. Design a questionnaire to assess the direct and indirect impacts of the COVID-19 pandemic on older adults with multimorbidity, as these impacts relate to social isolation, loneliness, and health behaviours.

2. Pilot test the questionnaire to assess its properties with respect to validity, reliability, and its feasibility and usability.

3. Conduct an analysis of the pilot sample data.

1.4.2 Study Question

What is the validity, reliability, feasibility, and usability of a questionnaire designed to assess the impacts of the COVID-19 pandemic on the social isolation, loneliness, and resiliency of community dwelling older adults (aged 50+ years) with multimorbidity?

1.5 Conclusion

The current thesis project comprised the pilot study for the larger Untold Story of COVID-19 project. The steps to construct and test the online questionnaire included the design of the conceptual model, questionnaire construction and programing into Qualtrics XM software, and testing questionnaire properties and the statistical code to inform the analysis of the larger Untold Story project. The following chapters will outline in detail the processes of the current thesis, starting with Chapter 2: Literature Review, followed by Chapter 3: Methods, Chapter 4: Results, and Chapter 5: Discussion.

Chapter 2

2 Literature Review

This literature review begins with setting the context for this thesis by describing the COVID-19 pandemic. The epidemiology and sequence of events of the COVID-19 pandemic, along with public health measures are summarized. Next, the population of interest; that is, people with multimorbidity is described. The impact of the COVID-19 pandemic on people with multimorbidity is then summarized through a description of the epidemiology and burden of multimorbidity, and the impact of multimorbidity on survival of infection by COVID-19. Then the concepts of social isolation, loneliness and resilience are discussed, particularly as they relate to people with multimorbidity in the context of the pandemic. Lastly, this literature review will frame the information about individuals with multimorbidity during the COVID-19 pandemic in relation to social isolation, loneliness and resilience within the context of primary care. The review finishes with highlighting the general structure of healthcare in Canada, how individuals with multimorbidity navigate the healthcare system, the impact of the COVID-19 pandemic on care for this population, and previous primary care interventions aimed at reducing social isolation and loneliness among older adults with multimorbidity.

2.1 Epidemiology of the COVID-19 Pandemic

2.1.1 Global Outbreak

The outbreak of SARS-CoV-2-β-coronavirus (COVID-19) rapidly became a global pandemic within a few months. The COVID-19 virus was first identified in Wuhan China on December 8, 2019, causing symptoms similar to pneumonia.[60] Since the first identification of the COVID-19 outbreak in China, cases began to be detected around the world quickly.[36] The first cases were reported in Japan on January 15, 2020, followed by the United States on January 21, 2020, three days later in Europe, another five days later in the United Arab Emirates[36], in Canada on January 25, 2020,[61] and Africa on February 25, 2020.[36] On March 13, 2020, the World Health Organization (WHO) declared a global

pandemic, and by April 4, 2020, there were over 1 million confirmed cases of COVID-19 globally.[36] SARS-CoV-2-β-coronavirus is primarily transmitted through aerosols dispersed in the air when an infected individual sneezes, exhales, or coughs.[62] Initially, the biggest risk of infection was from contact with international travelers; however, by March 24, 2020, the biggest risk was through community transmission.[63]

As variants of the COVID-19 virus emerged, differences to the pandemic's epidemiology were seen in tandem. The incidence of COVID-19 during the first wave was correlated with the incidence during the second wave, where low first wave incidence was positively correlated with second wave incidence.[64] As a consequence of natural selection, viruses undergo selection for mutations that confer a survival advantage for the virus; thus, variants of the SARS-CoV-2-β-coronavirus began to arise.[37] The Alpha variant (B.1.1.7) was first identified in the United Kingdom in September 2020 and was declared a variant of concern by WHO on December 18, 2020; simultaneously, the Beta variant (B1.357) was declared a variant of concern, first identified in South Africa in May 2020.[65] The Gamma (P.1) variant was soon declared a variant of concern on January 11, 2021, after it was first identified in Brazil in May 2020.[65] The Delta (B.1.617.2) variant was first identified in India in October 2020 and declared a variant of concern on May 11, 2021.[65] The most recent variant of concern was the Omicron variant (B.1.1.529), first identified in multiple countries in November 2021 and declared a variant of concern November 26, 2021.[65] These variants differed in their exact mutations, though most mutations involved increased transmissibility, and some dampening of the immune response or vaccine efficacy, or differences in age groups affected.[37] Generally, the duration of acute symptoms was longer for individuals infected with the Delta variant compared to those infected with Omicron, with this difference being less noticeable in individuals with two vaccine doses.[66] Individuals who were infected with the Omicron variant were also two times as likely to recover within a week of infection than those infected by the Delta variant.[66] COVID-19 prevalence determined through serological testing (seroprevalence), was found to vary greatly between Global Burden of Disease regions after correction of study characteristics and sensitivity and specificity analysis for

imperfect COVID-19 test specificity.[67] Marginalized and high-risk groups were found to have a disproportionately higher seroprevalence of COVID-19.[67]

2.1.2 Epidemiology of the COVID-19 Pandemic in Canada

Within two days of the WHO declaration of the pandemic, on March 15, 2020 there was already a public health directive in place in Canada for individuals to only go out if necessary.[68] By March 21, 2020 there were already 300 confirmed cases in Ontario[69] and over 1400 confirmed cases in Canada.[70] Within a week of the presentation of these data, the total number of deaths in Ontario had exceeded 20,[69] and 65 in all of Canada.[70] Within one month of WHO's declaration of a global pandemic, the total number of deaths in Ontario exceeded 600,[69] and 1900 in all of Canada.[70] During the first wave of the COVID-19 pandemic there was an exponential increase in the number of cumulative deaths, reaching 717 deaths out of 25,000 infections by April 12, 2020, partway through the first wave.[63] Over the course of the second wave of the pandemic, the case fatality rate for COVID-19 significantly decreased, in part because of a larger proportion of young people being infected.[71] In long-term care homes, the case fatality ratio was 18.4% during Delta variant predominance, compared to the lower 3.7% case fatality ratio for Omicron variant predominance.[72] During the first wave of the COVID-19 pandemic, from January 15, 2020 to August 2, 2020, 15% of confirmed cases were in individuals from long-term care homes, with 32.6% of deaths being from this population.[73] In comparison to long term care homes, retirement homes experienced a similar pattern of COVID-19 outbreaks, though these similarities depended on a number of factors.[74] When looking at retirement homes, it was found that the adjusted hazard of COVID-19 outbreak was associated with retirement homes that had large resident capacity, were part of a large chain of homes, shared a location with a long-term care home, had many services onsite, and were located in areas with greater numbers of people of the same ethnicity.[74]

2.1.3 Effect of Vaccines on COVID-19 Pandemic Epidemiology Globally and In Canada

The introduction of COVID-19 vaccines helped reduce transmission, risk of reinfection and provided protection against severe COVID-19 outcomes. By August 2021 over 100 individual vaccines were developed that can be classified into one of three types, messenger RNA (mRNA), viral vector, and inactivated and protein subunit.[75] While vaccines appear efficacious and well tolerated at the population level, neither fully vaccinated individuals nor those infected by SARS-CoV-2-β-coronavirus maintain long term immunity.[76] Based on expert guidance, in Canada the first populations who received vaccinations were the most vulnerable to illness, including those in congregate living settings for seniors, individuals aged 70 and older, health care workers, and individuals at risk in Indigenous communities.[77] Once these individuals received vaccines, the next group vaccinated were healthcare workers not previously included, those working in all other congregate living settings, and essential workers.[77] Vaccine uptake in Canada was high with 83.2% of Canadians vaccinated with at least one dose of a COVID-19 vaccine by December 4, 2022.[78]

As more individuals were vaccinated and different variants of concern appeared, it was observed that vaccines remained efficacious, though to varying degrees. After the initial wave of infections, case numbers decreased with the introduction of COVID-19 vaccines and these vaccines were pivotal in reducing the outbreak of the Alpha variant in Nunavut.[79] However, cases increased again with the emergence of the Omicron variant in December 2021 and waned again around March 2022.[80] Vaccinated individuals,[81,82] with either partial or full vaccination,[82] had lower risk of hospital admission and of death than those who were unvaccinated.[81,82] Compared to partially vaccinated or unvaccinated individuals, those who were fully vaccinated had lower rates of secondary transmission and shorter duration of viable viral shedding,[83] and had lower risk of re-infection.[44] When comparing individuals who were vaccinated and those who were infected with COVID-19 and had symptoms, the vaccinated groups had less decline in efficacy of protection against COVID-19 than infected groups.[84] The effectiveness of COVID-19 vaccines was

lower in individuals with comorbidities and individuals who were over the age of 70.[82] Overall, vaccine effectiveness was consistently high across SARS-CoV-2-β-coronavirus lineage, age, sex, comorbidity presence, epidemic wave, and vaccine product subgroups for individuals who were fully vaccinated and for older individuals with 14 days or more having elapsed following vaccination with the first dose.[82]

2.1.4 Effect of Public Health Measures on the Epidemiology of the COVID-19 Pandemic

Early in the pandemic, Ontario instated a number of public health measures, including closing schools[38] and all services apart from essential ones,[39] and restricting gatherings.[40] These public health measures, limiting contact between individuals, showed efficacy as the number of cases gradually decreased in most provinces.[41] In Canada, as in many other countries worldwide, after the first wave of the COVID-19 pandemic a testing strategy was developed.[85] Plans for lifting public health restrictions in Ontario were slow[86] and at times halting[87] with restrictions being re-introduced after their removal.[88,89] Eventually, with the declaration of the fourth wave of the pandemic being over on March 9, 2022[90] plans to lift public health restrictions and not reintroduce them continued and remained.[91]

Social or physical distancing was introduced to reduce the number of infections, and to prevent strain on health care services in Canada.[63] Additional public health measures implemented in Canada included education about hand hygiene, mask wearing mandates, physical distancing, increased ventilation in buildings, staying at home when sick, and vaccination once vaccines became available.[92] In Canada, different areas of the country have different access to resources.[63] For example, there are some areas of the country that lack access to clean drinking water, which increased difficulty in practicing hand hygiene during the pandemic, and areas that had different COVID-19 testing capacities.[63]

While public health measures helped reduce COVID-19 infections, some of these measures increased the complexity of providing care for people with non-COVID-19 illnesses, such as people with multiple chronic conditions. In Canada, to increase health care system capacity to care for those with COVID-19 infection, elective surgeries were

reduced or in some instances cancelled entirely.[63] As a result, there was a reduction in referrals for needed procedures and an increase in wait list times.[93] This led to further disease progression before patients received interventions.[93]

2.1.5 COVID-19 Risk Profiles and Outcomes

Risk profiles for COVID-19 infection and outcomes were rapidly elucidated and compiled in systematic reviews.[5,6] Risk factors for contracting COVID-19 included increased age and increasing numbers of chronic conditions.[5,6,7] As well, age and severity of first infection were predictors of severe reinfection.[44] Patients with multiple organ dysfunctions or damage, including immune system damage, comprised a significant amount of severe COVID-19 cases,[6] while being male and/or obese led to more severe COVID-19 outcomes,[6,7] and having cardiometabolic[5,6,7] and respiratory[5,7] comorbidities and infectious disease like symptoms[7] were associated with more severe course of illness. Factors increasing risk of death from COVID-19 included older age,[42,45,43] male gender[42,45] and pre-existing comorbidities,[42,43] in particular cardiovascular disease, chronic obstructive pulmonary disease,[45,43] hypertension, diabetes, and cancer.[45]

COVID-19 symptoms have been found to range from asymptomatic to severe.[60] Overall, strong associations between age[94] and chronic diseases,[5,95] and COVID-19 outcomes were seen, with COVID-19-associated pulmonary aspergillosis (CAPA) development significantly associated with people aged over 60 years.[95] As the age of patients increased, so did the percentage with underlying disorders and the percentage with severe COVID-19 infection, with this group comprising the majority of severe cases.[96] Patients with chronic diseases were more likely to be admitted to the intensive care unit and/or need mechanical ventilation.[94] Gender was identified as another predisposing factor, specifically, women were more at risk of contracting COVID-19 and men were more at risk of intensive care unit admission with COVID-19,[46] with male gender and presence of respiratory disease having been associated with mortality in the intensive care unit.[94]

The risk profile for long-term adverse outcomes for those who had severe initial infection or were reinfected with COVID-19 is similar to the risk profile for adverse outcomes at initial infection. Patients who were reinfected with COVID-19 usually experienced symptoms and reinfection could occur shortly after initial infection or long after.[97] Factors associated with readmission to hospitals for COVID-19 included advanced age, morbid obesity,[8] male gender, being Caucasian,[9] and underlying comorbidities,[8,9] with many of these comorbidities being common with reinfected individuals.[97] As well, since high risk patients tended not to survive COVID-19 during the initial admission, mortality was found to be lower among patients who were readmitted.[9] There were patients who experienced multiple organ complications after the acute phase of COVID-19, lasting for weeks or months,[98,99] which can be defined as Post-COVID-19 Syndrome[99] or Long COVID-19.[98] Risk factors for developing Long COVID-19 include being female,[98,99] clinical status during hospitalization[99] and the acute phase of the illness, older age, high number of comorbidities, hospital admission, and acute phase oxygen supplementation.[98] The most prevalent symptoms of Long COVID-19 include chest pain, dyspnea, cough and sputum production, arthralgia, myalgia, functional impairment, memory[98] and cognitive impairment, sleep disturbances, and fatigue.[98,100] Following COVID-19 infection, a number of psychological sequelae were found in patients, including anxiety, depression, and post-traumatic stress disorder.[100]

There was variation in the adverse outcomes of COVID-19 depending on the variant with which people were infected. Individuals infected with the Omicron variant of SARS-CoV-2-β-coronavirus had a lower risk of severe infection when quantified using risk of severe hospital events[101] and individuals with two or three vaccines had lower risk of hospitalization,[66] while mortality rates were higher during Delta variant predominant emergence periods.[102] On the other hand, the highest incidence of infection in both vaccinated and unvaccinated individuals was during the time when the Omicron variant was predominant.[102]

2.2 Multimorbidity

2.2.1 Definitions of Multimorbidity

Multimorbidity has become a major health concern as the global population ages.[13] While studies focusing on single chronic conditions are important, multimorbidity is emerging as an important field of research as many individuals have multiple chronic diseases concurrently.[103] Despite the increase in multimorbidity research, there is not a generally accepted definition of multimorbidity; studies focused on multimorbidity have been conducted in a variety of populations and settings.[13,10,104] Comorbidity is generally defined as multiple chronic diseases occurring simultaneously with an index disease, though a broader definition includes these diseases occurring simultaneously, which is a characteristic shared with definitions of multimorbidity.[10] While definitions of multimorbidity vary from patient to patient and clinician to clinician, they generally include a minimum number of chronic conditions and a list of conditions to be included, tending to be restricted to long-term or chronic conditions.[12] For ease of classification, related chronic conditions may be grouped and only counted once; for example, the cardiovascular disease category may include angina, myocardial infraction, atrial fibrillation, and other heart diseases.[105] Cut-off points[13] for the number of conditions a person has in order to be classified as having multimorbidity vary, with two or more chronic conditions being the most common but the count can range from two to five or more.[12] As well, the number of conditions included in the list of conditions that comprise multimorbidity varies and variation in condition severity[106] is not always accounted for.[13] While chronic conditions can differ in their severity and impact on a person's life, this severity is not uniformly evaluated in clinical practice and therefore not available for research purposes.[12] This lack of consensus leads to challenges in the treatment and study of multimorbidity, making it difficult to reconcile or address necessary factors related to complex multimorbidity during clinical decision making.[11] Without an accurate and comprehensive definition, multimorbidity may be overestimated in general practice because of possible misclassification, possibly reducing the accuracy of research results, such as prevalence estimates.[107]

2.2.2 Epidemiology of Multimorbidity

2.2.2.1 Multimorbidity Prevalence

In order to accurately assess the public health impact of multimorbidity and to project medical needs for this patient population, accurate prevalence estimation is necessary.[13] However, differences in methodology and definitions of multimorbidity in prevalence estimating studies may lead to differences in prevalence estimates.[106] Prevalence estimates of multimorbidity differ between definitions; for example, a multimorbidity definition of three or more co-occurring chronic conditions yielded a weighted difference between prevalence estimates of 12.9 percentage points lower than the definition of two or more co-occurring chronic conditions when looking at global prevalence of multimorbidity.[13] In Ontario, Canada the absolute number of patients with two or more and three or more conditions increased by 12.2% and 13.5%, respectively, between 2008 and 2017, while, age- and sex-standardized prevalence estimates of individuals with 7 or less chronic conditions decreased slightly, and prevalence of individuals with 8 to 13 chronic conditions increased slightly.[15] In the United Kingdom prevalence estimates for middle aged and older adults in 2018 were 91.0% and 81.1% for those with two or more and three or more chronic conditions, respectively.[23] Regarding the component chronic conditions contributing to multimorbidity, a study conducted in Canada[16] found that the most prevalent diagnoses of chronic conditions were obesity, hypertension, musculoskeletal problems, and anxiety or depression and the least prevalent were stroke or transient ischaemic attack, liver disease, and kidney disease or failure. Among adult primary care patients, approximately one in two had two or more concurrent chronic conditions and one in three had three or more concurrent chronic conditions.[16]

2.2.2.2 Risk Factors Associated with Multimorbidity

Risk factors for multimorbidity are complex and still emerging; however, common risk factors for developing multimorbidity include age,[11,15,16,14,17] being female,[13,23,17] socioeconomic deprivation[23,108] and lifestyle factors.[14,24] Aging processes are complex and include both the number of morbidities an individual has and their physical

functioning.[17] While the prevalence of multimorbidity is higher in older people, age is not the sole driver of multimorbidity[11,14] as it is starting to be seen in younger age groups[15,16,17] and can occur in people as young as 35.[14] Generally, multimorbidity increases with increasing age in men and women, with prevalence being higher in women,[13,23,17,108] with older age not completely accounting for the higher prevalence in older women.[23] The prevalence of complex multimorbidity is higher in men than women living in England.[17] Individuals with multimorbidity are at higher risk of developing additional conditions,[11] and having more chronic conditions was associated with more physician consultations.[108] Specific chronic conditions that people have differ based on age group.[23]

Social, economic, and demographic factors play an important role in multimorbidity incidence, prevalence, and mortality. Among individuals living in urban areas, those with post-secondary education and in the highest income quintile are less likely to develop multimorbidity compared to those with secondary or less education and those in lower income quintiles, respectively.[18] Generally, when the prevalence of multimorbidity, complex multimorbidity and multiple functional limitations were stratified based on income quintiles, the highest prevalence was seen in the lowest income quintile and lower education levels,[19,21,20] and lowest prevalence in the highest income quintile.[23,17,108] In Canada, the proportion of people with three or more chronic conditions increased successively with each quintile of urban material deprivation, and is highest in rural areas, though mortality rates for these individuals did not vary across quintiles once the model was adjusted for age and health region.[22] Recent and established immigrants are less likely to have multimorbidity compared to individuals born in Canada.[18] Individuals from African, East/South-east Asian, and other ethno-cultural groups have lower odds of developing multimorbidity, while individuals of Indigenous descent have higher odds than those of Caucasian descent.[18]

Modifiable risk factors could help to prevent multimorbidity or make it more manageable for patients. Prevention in younger age groups may have merit as targeting younger ages

may reduce the rate of multimorbidity and subsequently excess mortality associated with younger age.[22] While not all diseases can be prevented, there are many diseases that contribute to multimorbidity that can be prevented or ameliorated through healthy lifestyle choices.[14] Physical activity is an example of a risk factor which plays a vital role in overall health and the development of chronic diseases and so may be an appropriate target for prevention efforts.[24] Complex multimorbidity has been inversely associated with physical activity level, with the highest proportion of participants with complex multimorbidity being in the least active group.[24] While modifiable risk factors may play a role in prevention of multimorbidity, further research on their contribution to multimorbidity is needed.[21]

2.2.3 Chronic Condition Combinations in Multimorbidity

In a sample of individuals aged 65 and older, 291 unique multimorbidity combinations were found with the arthritis and hypertension combination being most prevalent, and the arthritis, hypertension, and cardiovascular disease combination being second most prevalent.[109] Of all the combinations, the one associated with the most disability scores for activities of daily living and instrumental activities of daily living was arthritis and hypertension with high depressive symptoms.[109] Among individuals who were admitted to long term care, a significantly larger proportion of this group had three, four, five, or more concurrent chronic diseases than those not admitted.[104] Dementia, mood and neurological disorders were associated with high risk of admission to long term care, along with having five or more chronic conditions.[104] Individuals with two or more chronic diseases had greater cognitive decline than those with one chronic condition or none.[110] Among these individuals, greater cognitive decline was associated with older age, lower income, not being married, and living alone at baseline.[110] Multimorbidity patient profiles depend on specific chronic disease combinations, and these play a role in multimorbidity burden.

2.2.4 Burden of Multimorbidity

The existing burden of multimorbidity has only increased during the course of the COVID-19 pandemic. The association between mental health disorders and worse physical health has gained recognition in recent years.[103] The presence of multimorbidity is linked to higher odds of anxiety symptoms; higher odds of these symptoms have been linked with increasing numbers of chronic diseases, suggesting that anxiety symptoms may be related to dysregulation of physiological systems, with similar trends seen across countries.[103] A dose-response relationship was observed between age and risk of multimorbidity; women were at higher risk of developing multimorbidity during social distancing during the pandemic period than men, with about one in four people developing multimorbidity.[111] Lower levels of physical activity is associated with higher levels of healthcare utilization and complex multimorbidity.[24] Having multimorbidity likely increases complexity of care because the clustering of these chronic diseases differs across individuals, resulting in differences in adverse outcomes and frequency of healthcare utilization.[24]

2.2.5 Multimorbidity During the COVID-19 Pandemic

2.2.5.1 Higher Risk of Adverse COVID-19 Outcomes

In older adults, having chronic conditions was strongly associated with adverse COVID-19 outcomes.[46,112,113] Of a group of patients admitted to hospital for COVID-19 infection most had multimorbidity, almost half had complex multimorbidity, and over three-quarters of individuals who died from COVID-19 had multimorbidity.[114] Individuals of South Asian and African, compared to those of Caucasian descent were found to be more at risk of all-cause mortality independent of cardiometabolic multimorbidity status at hospital admission.[115] More men who died of COVID-19 appeared to have higher levels of multimorbidity than women.[113] Individuals with severe COVID-19 infection had over two times the prevalence of multimorbidity than those without, and the risk of severe COVID-19 infection increased with growing numbers of concurrent chronic conditions,[47] such that patients with three, four, and five co-occurrent chronic conditions had the

highest percentages of mortality when compared to patients with zero to two chronic diseases, with five chronic diseases being the highest count included.[116] This association is so strong, that multimorbidity may be considered an independent risk factor for adverse COVID-19 outcomes.[114] Across differing rates of income-poverty, there was a differential effect of multimorbidity on COVID-19 severity, such that there were increased odds[117] and prevalence[114] of multimorbidity in more economically deprived areas.[114,117] A related concept is multimorbidity resilience, which Wister et al., (2022)[118] defined as how well individuals adapt to illness-related adversity and the ability to regain wellness in their lives. While older adults with multimorbidity are an at-risk group for COVID-19, some exhibited multimorbidity resilience, as they were less negatively affected by the pandemic, which may in part be due to not living alone.[118]

2.2.5.2 The Effects of Vaccination

There is generally a higher risk of adverse events associated with COVID-19 vaccination in individuals with well-controlled, stable multiple chronic conditions compared to only one condition.[119] The authors of this study cautioned that these results may not be generalizable to those with poorly controlled chronic conditions.[119] Individuals with multimorbidity have been impacted by the COVID-19 pandemic because they are both more likely to have severe COVID-19 disease and experience more care disruptions.[120] Vaccination in older individuals with multimorbidity conferred some protection against the most severe outcomes of COVID-19 during both the Delta and Omicron outbreak periods.[121] During both of these outbreak periods hospitalized individuals still consisted more of older individuals with multiple chronic diseases (121). Older age and having more co-occurrent chronic diseases were among the independent predictors of hospital inpatient mortality.[121]

2.3 Social Isolation and Resilience

This section of the literature review will discuss social isolation, and the closely related concepts of loneliness, and resilience. This section begins with definitions for key terms, followed by the roles of social isolation, loneliness, and resilience in the health of older

adults, particularly in the context of chronic conditions. Lastly, the impact of the COVID-19 pandemic on health within the context of social isolation, loneliness, and resilience will be discussed.

2.3.1 Definitions of Social Isolation, Loneliness, Resilience and Related Terms

Social isolation and loneliness are closely related, yet distinct concepts, and resilience is a complex concept related to adversity. Generally, social isolation can be defined as a small amount or even lack of social interaction.[27] Loneliness can be defined as a discrepancy between the actual and desired network of relationships a person has.[26] Social isolation and loneliness are closely related, though distinct[26,28] as a person may experience one, but not the other, or both together.[26] Both loneliness and social isolation have been found to be associated with adverse health outcomes.[25] Since they are closely related, loneliness being a subjective measure of one's social network, and social isolation an objective measure of the same concept,[26] they will both be considered in the literature review in this section. Resilience is a multifaceted and dynamic concept that is manifested through the adaptive attitudes and behaviours of individuals and the capacity to positively adapt.[122] Psychological resilience can be defined as the ability to recover from adverse life events while simultaneously developing one's ability to, and resources for, adapting to stressful events and conditions.[122] Terms closely related to resilience are positive and negative emotions, as positive emotions have been found to be associated with good physical health and psychological outcomes and to be beneficial to health throughout the life-course.[123]

2.3.2 Loneliness in Older Adults

Overall, an increase in loneliness levels was observed during the pandemic, with higher levels of loneliness seen in younger and older individuals, and lower levels in middle-aged individuals.[124] During the COVID-19 pandemic older women were more likely than older men to report feelings of loneliness,[124,125] though men reported less frequent communication with family, friends and neighbours, and had lower likelihood of

reducing loneliness by seeking out social connection.[125] Those living alone and those who were/are single were more likely to report loneliness.[124] Higher levels of loneliness were associated with mental disorders.[124] Also, the perceptions of older adults about the pandemic and their experiences during this time, effected the odds of loneliness[125]; for example, changes to routine, finding positives in difficulties, offers of support received, and communication with people close to them.[125]

2.3.3 Factors Associated with Social Isolation

2.3.3.1 Risk Factors for Social Isolation

Complex factors lead to social isolation, and are at times contradictory, though age,[28,29] being female[29] and poorer health[30,31] are common risk factors. Social isolation can be defined as a lack of, or limited social contact, with loneliness being a separate yet related concept.[28] As individuals age, their chances of living with chronic diseases, living alone, and becoming housebound increases.[28] Age has been found to be positively associated with loneliness and social isolation, with higher levels in women compared to men, and in individuals with diagnosed cardiovascular disease (CVD),[29] though another study did not find a statistically significant relationship between age, and social isolation and loneliness.[126] Social isolation is also associated with younger age, lower income, not working 30 hours or more per week, living alone, personal vulnerability, being female,[126,127] and experiencing loneliness when health and mental health characteristics are added.[126] When comparing men and women, men are less likely to be lonely but are more likely to be socially isolated and lack social support.[32] Social isolation is more common in older women, with low levels of education or who are unemployed, and who lived in urban areas and in richer countries.[127] There is a paucity of evidence about the effects of social isolation on frailty.[30] The available evidence shows that frail individuals are less socially active, have fewer social networks and receive less social support, are less educated, less likely to drink alcohol, and more likely to have sleep disturbances.[31] As well, greater frailty scores at baseline of the English Longitudinal Study of Ageing were associated with increased risk of higher levels of loneliness at follow-up.[30]

2.3.3.2 Outcomes of Social Isolation

Loneliness and social isolation are associated with an increased risk of mortality and morbidity,[3,4] and overall poor health. Social isolation is independently associated with mortality in all clinical and community settings,[127,128,129] regardless of subjective or objective measures of social isolation,[128] though the most consistent effects of social isolation and loneliness on mortality are seen with measures of loneliness.[129] In a recent systematic review, there was strong evidence for the association between social isolation, loneliness and cardiovascular disease, and moderate evidence for a relationship between social isolation, loneliness and mental health variables, such as dementia.[129] Evidence in this review for the relationship between social isolation, loneliness and other physical conditions including cancer, low back pain and chronic obstructive pulmonary disease was poor.[129]

2.3.3.2.1 Cardiovascular Disease and Dementia

Cardiovascular disease (CVD) and dementia are common outcomes of social isolation**.** Loneliness,[32] social isolation,[32,33] and poor social relationships[33] are associated with a greater risk of CVD.[32,33] Both poor social relationships[33] and living in social isolation[130] were associated with increased risk of stroke.[33,130] Older community dwelling adults with poor composite social health, comprised of measures of social isolation and support, and loneliness, were more likely to develop CVD and twice as likely to die from it, while social isolation and low social support are strong predictors of incident CVD, and loneliness a strong predictor of fatal CVD.[131] Among individuals who smoked, lived in a major city, or were between 70 and 75 years old, poor composite social health was a stronger predictor of incident CVD.[131] Loneliness and social isolation can influence a wide variety of emotional and cognitive processes, and a devastating effect of feelings of social isolation is cognitive decline and dementia.[4] Evidence about the association of loneliness and dementia risk has been mixed.[34] Loneliness is associated with increased risk of dementia, and is independent of social isolation, behavioral, clinical, and genetic risk factors for dementia, and depressive symptoms, with this association holding across

demographic groups.[34] Among community dwelling older adults, those aged 75 years or older, women, racial and ethnic minority groups, and those who have lower socioeconomic status have the highest risk of dementia and highest social isolation burden.[35]

2.3.3.3 Social Support and Feelings of Loneliness

Social support appears to be an important factor for a variety of outcomes of social isolation, including mental health and health behaviours. Social support can be defined as people who are available and on whom one can rely for care, value, and love.[132] Social support is thought to vary later in life and seems to have a mediating role in the relationship between loneliness and depression,[132] with age, depression, and loneliness being the most strongly associated with poor health status.[133] While loneliness can exacerbate depressive symptoms, social support can weaken this relationship.[132] A greater risk of depression, comorbidity, and cognitive decline is seen for those who perceived they had inadequate social support from their children and intimate partner.[31] Larger social networks and older age have been associated with less loneliness.[2] A contrasting study found that loneliness and size of social network have low correlation, while loneliness and network quality, and loneliness and frequency of contact are moderately correlated.[133] Frequency of contact is associated with better health status, and as age increased, the relationship between loneliness and health becomes less strong.[133] Feelings of loneliness can also negatively impact health behaviours, for example reducing physical activity.[4,134] As well, increasing loneliness is associated with increased difficulties with activities of daily living, while isolation is not.[29]

2.3.4 Social Isolation During the COVID-19 Pandemic

Social restrictions employed to reduce the spread of COVID-19 may have increased social isolation and loneliness.[2] Numerous kinds of technology emerged to help people stay connected despite public health measures, but those with less access to technology were more likely to experience lockdown-associated loneliness.[3] Loneliness associated with lockdowns increased in younger and older individuals, while those of middle-age

were less likely to be affected.[3] Specific ethnic groups such as Black, Asian, and minority ethnic groups were at increased risk of loneliness associated with lockdowns.[3] Interestingly, a longitudinal study found higher virtual social contact at baseline was associated with more loneliness at follow-up.[2] In the same study, in-person contact with people outside the household had no association with loneliness at follow-up.[2] In older adults, the structural and functional characteristics of social networks, including network size, number of social interactions before and during the pandemic, not living alone and availability of support were associated with lower levels of loneliness.[135] Individuals who were more satisfied with communication during the pandemic experienced less decline in positive affect and less increase in loneliness,[135] while those who lived alone, were female, and had four or more chronic conditions were more likely to have higher levels of loneliness.[136] Also, living alone and in small spaces seemed to have a negative effect on managing the pandemic for older Canadians, while living in large spaces with others had the opposite effect.[52] Many older Canadians were upset by the loss of social interaction and the disruption of their routines.[52] Social isolation during the COVID-19 pandemic generally had a negative impact on mental health, with prevalence of anxiety and depression varying greatly across studies and social distancing during the pandemic potentially leading to negative physical health consequences in older adults.[53]

2.3.5 Factors Associated with Resilience

Factors associated with resilience range from socioeconomic characteristics such as income to coping behaviours to social support. Resilience can generally be defined as the ability to recover or adjust to change and adversity, though while the definition is agreed upon, it is usually treated as a theoretical, hypothetical concept, making empirical research difficult.[137] In order to best conceptualize resilience, it needs to be linked to adversity, as it arises in the face of adversity; for example, the adversity arising from the COVID-19 pandemic.[138] Resilience seems to be related to an individual's psychological resources and personal efficacy.[137] Resilience has also been proposed to change within an individual depending on context and time frame, though there are also differences between individuals such as self-beliefs and self-regulation that are less subject to context

and time.[139] Self-regulation and resilience are related yet distinct concepts, with self-regulation being predictive of resilience and resilience encompassing a wider range of factors related to mental health.[139] Individuals with greater psychological resilience are younger, have less cumulative socioeconomic disadvantage, live in urban areas, are married, have higher levels of physical activity, healthier diet, less prevalence of hypertension, lower BMI, and fewer psychological diseases.[140] Exposure to one or more adverse childhood events has a dose-response association with lower perceived coping ability and perceived psychological resilience.[141] While this association is present across all levels of social support, it is higher in those with low social support.[141]

To achieve both optimal physical and mental health, resilience is key across the human lifespan, and has been found to be important across many settings and in different populations.[138] The importance of resilience to people's health is highlighted by the experience of migrant populations.[142] In older Chinese migrant adults, psychological resilience partially mediated the positive relationship between social support and physical and mental health-related quality of life.[142] In older adults, resilience is directly associated with life satisfaction, and higher socioeconomic status is related to psychological well-being, helping explain the relationship between resilience, quality of life and health.[143] Higher psychological resilience is associated with lower risk of both all-cause and CVD related mortality.[140] Higher resilience scores are associated with greater participation in Advanced Activities of Daily Living, being male, better self-perceived health, absence of depressive symptoms, and having between zero and four self-reported morbidities.[144] Individuals who are more resilient to difficulties in life usually have better health outcomes, and this observation was strengthened during the COVID-19 pandemic.

2.3.6 Resilience During the COVID-19 Pandemic

The pandemic brought about much uncertainty and resulted in high psychological and emotional burdens for the general population.[145] Psychological burden is paramount to consider during pandemics as negative emotions, such as panic, can readily arise in

citizens which can make control of disease spread difficult as it can result in less adherence to public health guidelines.[146] Individuals with high psychological resilience were less likely to develop negative emotional symptoms during the COVID-19 pandemic.[146] Resiliency can help individuals cope with crises by potentially acting as a form of self-protection.[146] Resilience levels among Australian adults did not change during the pandemic.[147] Higher resilience scores among Australian adults have been associated with achieving at least 150 minutes of moderate and vigorous physical activities per week, and having normal scores on measures of depression, anxiety, and stress.[147] While exercise alone does not necessarily produce positive mental health status, it is thought to play a role in the mediating effect that mental health plays on resilience with individuals who increased their physical activity levels also reporting increased resilience.[148] While under normal circumstances this relationship appears to be independent of sleep levels and mental health status, this was not the case during the COVID-19 pandemic.[148]

Perceived social support is a key factor in reducing psychological burden[145]. Sources of social support, such as family, friends, romantic partners, the community and workplace, and psychological resilience can be protective for an individual's mental health during stressful life events.[145] Levels of social support differ between age groups as older individuals tend to spend more time in close emotional relationships.[145] Self-reported loneliness increased by 14% in community dwelling older adults during the COVID-19 pandemic, though no additional increase in loneliness attributable to quarantine introduction was observed in this population.[149] Pandemic-related stressors such as physical distancing, COVID-19 symptoms in self or family, and employment-related factors, were associated with more mental health symptoms among individuals living in both Minnesota and Hong Kong.[51] Higher levels of individual resilience was associated with fewer mental health symptoms in individuals living in both Minnesota and Hong Kong and during the pandemic; family behaviours, like communication, and country of residence moderated this relationship.[51] In Minnesota, strong family communication and problem solving was associated with less impact of pandemic-related stressors, while in

Hong Kong those with positive family outlook experienced more anxiety and pandemic-related stressors.[51]

2.4 The Role of Primary Health Care

Since primary care is usually the first contact of a patient with the healthcare system, it is a key component of healthcare.[150] Primary care should reflect and evolve with a country's social and economic context.[150] It should also address the main health concerns of the community, provide education and preventative measures, and should promote community self-reliance and participation in care.[150] Primary care should also be interdisciplinary and be sustained by referral processes and a wide range of professionals who make referrals.[150] While the Alma Ata Declaration became a call to action to improve healthcare for all and raised concerns about health equity, its implementation was difficult, particularly regarding definitions of equity and financing of programs.[151] When investigating the determinants of health and healthcare related topics, it is important to consider a wide range of variables as the causes of poor health are varied and, in most cases, external to the formal healthcare system.[152]

2.4.1 General Structure in Canada

Generally, the Canadian healthcare system aims to provide universal coverage for all citizens.[63,153] Primary care is delivered in a variety of ways, ranging from a single professional practitioner to interprofessional team models.[154] During the early 2000s there was a shift from the traditional fee-for-service model[155,156] to a rostering model requiring physicians to work in a group, of at a minimum three, where they rotated taking patients after-hours and allowing for patients to receive care more immediately.[156] One approach when reforming the healthcare system was to integrate nurses into family medicine clinics, and this was generally well-received by patients.[157] Primary healthcare services in Canada focus on first-contact health services and ensuring continuity of care, with an emphasis on tailoring services to the needs of each community.[158] Primary healthcare services generally encompass prevention and treatment of common diseases and injuries, basic emergency services, referrals or coordination with hospitals and

specialists, primary mental health care, palliative and end-of-life care, health promotion, healthy child development, primary maternity care, and rehabilitation services.[158] Health and social sectors have begun to consider alternative approaches to improving care delivery and health outcomes as the global population ages and chronic disease burden grows.[159]

2.4.2 Healthcare for Individuals with Multimorbidity

Healthcare services need to be tailored to meet the specific needs of people with multimorbidity.[104] Especially for older individuals, services need to be flexible and include comprehensive assessment of patient needs[104] as this population has difficulties navigating the healthcare system and managing their health,[52] and experience fragmentation of care.[160] Prevention approaches targeted to individuals with mental health disorders may also be beneficial in preventing development of further physical chronic conditions.[103] A more holistic approach, treating the patient as a whole, not just their diseases, is needed for treating individuals with multimorbidity as multimorbidity is becoming the norm.[19] Health systems designs need to take into consideration that multimorbidity is multiple chronic conditions co-occurring, without a specific index condition.[11] When looking for effective ways to improve care for patients with multimorbidity, it is vital to include input from patients and their caregivers.[160] Healthcare for individuals with multimorbidity is complex because these patients experience difficulties with the healthcare system[52,160] and clinical definitions are inconsistent across primary care practice.[13,12,106]

2.4.3 COVID-19 Pandemic Impact on Healthcare for Individuals with Multimorbidity

The COVID-19 pandemic has made care more difficult for individuals with multimorbidity. The healthcare systems of many countries were overloaded with the most severe cases of COVID-19, therefore rapid and effective identification of individuals most at risk of death was needed to help with clinical decision making.[48] Individuals with higher frailty scores and multimorbidity were more likely to die during hospitalization for

COVID-19 infection than individuals with one chronic condition.[48] Individuals with one chronic condition were more likely to die than individuals with neither frailty nor multimorbidity.[48] When patients with multimorbidity have fewer overall numbers of physician visits, as was the case during the COVID-19 pandemic, their overall health declined, with this being especially drastic for those with psychiatric disorders.[50] Patients with four or more occurrences of delayed or missed care had overall higher mortality during the pandemic.[49] Individuals with multimorbidity were found to have greater disruptions to care and daily routine, and more challenges related to accessing routine and emergency care during the COVID-19 pandemic than individuals with only one chronic disease.[161] Challenges in accessing routine and emergency care were reported among women, individuals less than 45 years old, living in urban areas, having more education, individuals who were retired or homemakers, and those living alone or away from family.[161]

Differential trends in adverse COVID-19 outcomes reflected inequalities in chronic disease experiences and social determinants of health.[162] In more disadvantaged and marginalized communities, reduced access to healthcare generally both before and during the pandemic contributed to inequalities in care and possibly increased the likelihood of more adverse COVID-19 outcomes in these communities.[162] Drops in care utilization were seen in all types of primary health care services except for virtual care during the first wave of the COVID-19 pandemic,[49,163,164] with in-person visits returning to pre-pandemic levels by later stages of the pandemic.[163,164] Many primary healthcare practices shifted to a virtual care model during the first part of the pandemic, and problems related to equity came to the forefront as the pandemic shed light on inequalities related to technology access and utilization, and exacerbated socioeconomic and racial disparities in healthcare.[165] The effects of virtual care were mixed as it provided a way to continue to manage chronic diseases during the early part of the pandemic,[163,164,165] though difficulties arose with internet connection,[165] especially in rural communities,[164] and need for home-based monitoring devices that not all patients had access to.[165] This is particularly concerning for individuals with multimorbidity, as socioeconomic

deprivation is a risk factor for developing multimorbidity,[23,108] potentially making care for these individuals even more challenging during the pandemic. For individuals with multimorbidity, inequalities in care were seen during the pandemic. For example, in more disadvantaged communities a magnification of existing social and economic inequalities led to exacerbations of existing chronic diseases and more severe impacts of the COVID-19 pandemic in individuals.[162]

2.4.4 Primary Care Interventions to Mitigate Social Isolation and Loneliness

In Section 2.3.3 *Factors Associated with Social Isolation*, the adverse outcomes of social isolation were explored. Additionally, there are health system effects because social isolation predicts increased primary care services delivery utilization.[166] The COVID-19 pandemic resulted in an increase in individuals who were vulnerable to social isolation and loneliness, necessitating effective interventions to mitigate this.[167] Various interventions were found effective in mitigating social isolation and loneliness, including psychological therapy, educational programmes, and social facilitation.[167] Social group connectedness, self-defined by membership in groups such as recreational groups, appears to be protective of health and partially attributable to improvements in subjective health.[166] Success of community interventions generally depends on tailoring interventions to the community where they will be implemented.[168] Successful implementation of interventions can be increased by leveraging local resources, recognizing and integrating tangible aspects of those living in the community; for example, resources of local businesses and including key stakeholders in the process.[168] Social prescribing is one way that primary care doctors refer their patients who suffer from social isolation to community-based interventions.[169] Social prescribing may not be effective for older individuals as some have expressed negative views about services such as befriending programs or activities that were purely social, and a preference for activities with a purpose apart from socializing.[169] Some older individuals also feel that primary care is not necessarily a place to discuss loneliness.[169] However, given the higher use of primary care among those with social isolation and the effect of social isolation on

health, further work is needed to explore potential primary care interventions that address social isolation in older adults with multimorbidity.

2.5 Conclusion

Multimorbidity, or most commonly defined as the presence of two or more chronic conditions in the same individual,[12] has become of increasing concern as global populations age.[13] Differences in definitions of multimorbidity, related to cut-off points[13] and the clusters of chronic conditions included[105] results in differences in prevalence estimates across studies, making data difficult to interpret.[106] Despite these difficulties, some common risk factors for multimorbidity have been identified, including age,[11,15,16,14,17] being female,[13,23,17] socioeconomic deprivation[23,108] and lifestyle factors.[14,24] The COVID-19 pandemic, while fast-spreading, was successfully contained through public health measures[63] and effective vaccination planning[78] in Canada. Risk profiles for adverse outcomes of COVID-19 infection, both in the short and long term, were similar and included age and increasing numbers of chronic conditions.[5,6,7,8,9] Social isolation and loneliness are distinct, yet related concepts[26,28] that are generally associated with adverse health outcomes,[3,4] and the COVID-19 pandemic has only exacerbated social isolation and loneliness through physical distancing public health measures.[2] Primary healthcare plays an important role in care for individuals with multimorbidity, though during the pandemic delays in care led to worsening of existing conditions[49] and highlighted healthcare inequalities for these individuals.[162]

Despite the above-mentioned difficulties that arose during the COVID-19 pandemic, there is still a paucity of primary care interventions targeted to reduce social isolation in older adults with multimorbidity as we emerge from the pandemic. Some previously explored strategies include psychological therapy, educational programmes, and social facilitation.[167] The current study was the pilot study for a larger project titled "Exploring the Untold Story of COVID-19: Understanding the Wider and Future Impacts of the Pandemic and Finding Solutions to Improve Population Health, Resiliency, and Preparedness". This is a Canadian Institutes of Health Research (CIHR)-funded study

whose overall objective is to create a tool for primary care physicians to help identify among their older patients with multimorbidity, those who are most at risk of social isolation and loneliness, allowing for timely intervention. The next chapter, Chapter 3 Methods, will describe the design and execution of the pilot study for this project, one of the key steps in developing the above-mentioned tool. This will be done through an online questionnaire, the focus of this thesis project, and qualitative interviews.

Chapter 3

3 Methods

This chapter will describe the study design and methods for this thesis. This thesis comprises a pilot study for a larger research project - "Exploring the Untold Story of COVID-19: Understanding the Wider and Future Impacts of the Pandemic and Finding Solutions to Improve Population Health, Resiliency, and Preparedness" (hereafter referred to as The Untold Story of COVID-19, or Untold Story project). The larger Untold Story of COVID-19 is a Canadian Institutes of Health Research (CIHR)-funded study whose overarching objectives are:

"1) To qualitatively and quantitatively identify and describe the differential direct and indirect impacts of the COVID-19 pandemic on older adults with multimorbidity, including social isolation, resilience, and health behaviours;

2) To identify the characteristics of older adults with multimorbidity associated with social isolation during the pandemic and to develop a scoring rule to identify those most likely to experience social isolation; and

3) To develop and internally validate a model of care intervention informed by the first two objectives, called COVID-19 Patient-Provider Exchange in Primary Care (COPE_PC) to provide tailored support for older patients with multimorbidity and their family physicians when discussing social isolation and its role in resilience and health behaviour outcomes."[1]

A conceptual model was developed for this thesis to inform the construction and design of the questionnaire that will be used for data collection for addressing the quantitative component of Objective 1 (listed above) for the Untold Story project. This chapter describes the steps taken to develop the conceptual model, to design, construct, and pilot test the questionnaire, to develop the ethics submission for the pilot study, and to create an interview guide, which was used as part of the pilot test to gain insight about the

validity and usability of the questionnaire from participants. The pilot study assessed the validity, reliability, feasibility, and usability of the Untold Story project questionnaire.

3.1 Designing and Conducting Pilot Studies

The main goal of a pilot study is to inform the design of a larger study.[54] Pilot studies can be conducted for quantitative and qualitative research,[54] and are typically exploratory in nature.[170] The purpose of pilot studies is to identify possible problems with methodology,[56,55,57,58] determine variables for analysis,[55] and identify any ethical considerations.[55] Since pilot studies can identify potential methodological problems, they can lead to improvements in a full-scale study's methodology[57] and in the case of a survey, improvements to the questionnaire through the conduct of cognitive interviews and other assessment methods.[171,172] Cognitive interviews are completed during the pretest phase of questionnaire development[173] and involve a researcher sitting with a participant and going through the questionnaire question by question, asking them why they answered the way that they did.[171] Cognitive interviews can help identify if: 1) the questionnaire is measuring what it was designed for; 2) the questionnaire is clear or not; 3) all response options possible have been included[171]; and 4) that participants' interpretation of questions align with the researchers' intentions when they wrote the questions.[172]

Pilot studies should be conducted with the same rigour as a full-scale study[56]; their design should be as close to the corresponding full-scale study's design as possible.[174] To make assessments of questionnaire length and interpretation more effective, questionnaire pilot testing should be conducted with participant samples that are similar to the target population of the larger study.[171] Though a smaller version of a larger study, the sample for the pilot study is not included in the larger study's sample.[55,174] Pilot study samples are usually large enough to have enough data that can be cleaned and analyzed[174] to accurately test all aspects of the study design. Along with assessing how a questionnaire is conducted in the context of a survey study, pilot studies can also be useful in conducting validity and reliability assessment of questionnaires. The overall process for

the current pilot study included designing all study procedures for the full Untold Story project questionnaire and scaling down the design to be appropriate for a pilot study (e.g., recruiting a smaller convenience sample). The process of recruitment, participant inclusion and exclusion criteria, and data collection were the same as for the Untold Story project.

A visual representation of the study design of the current pilot study can be seen below in Figure 1.

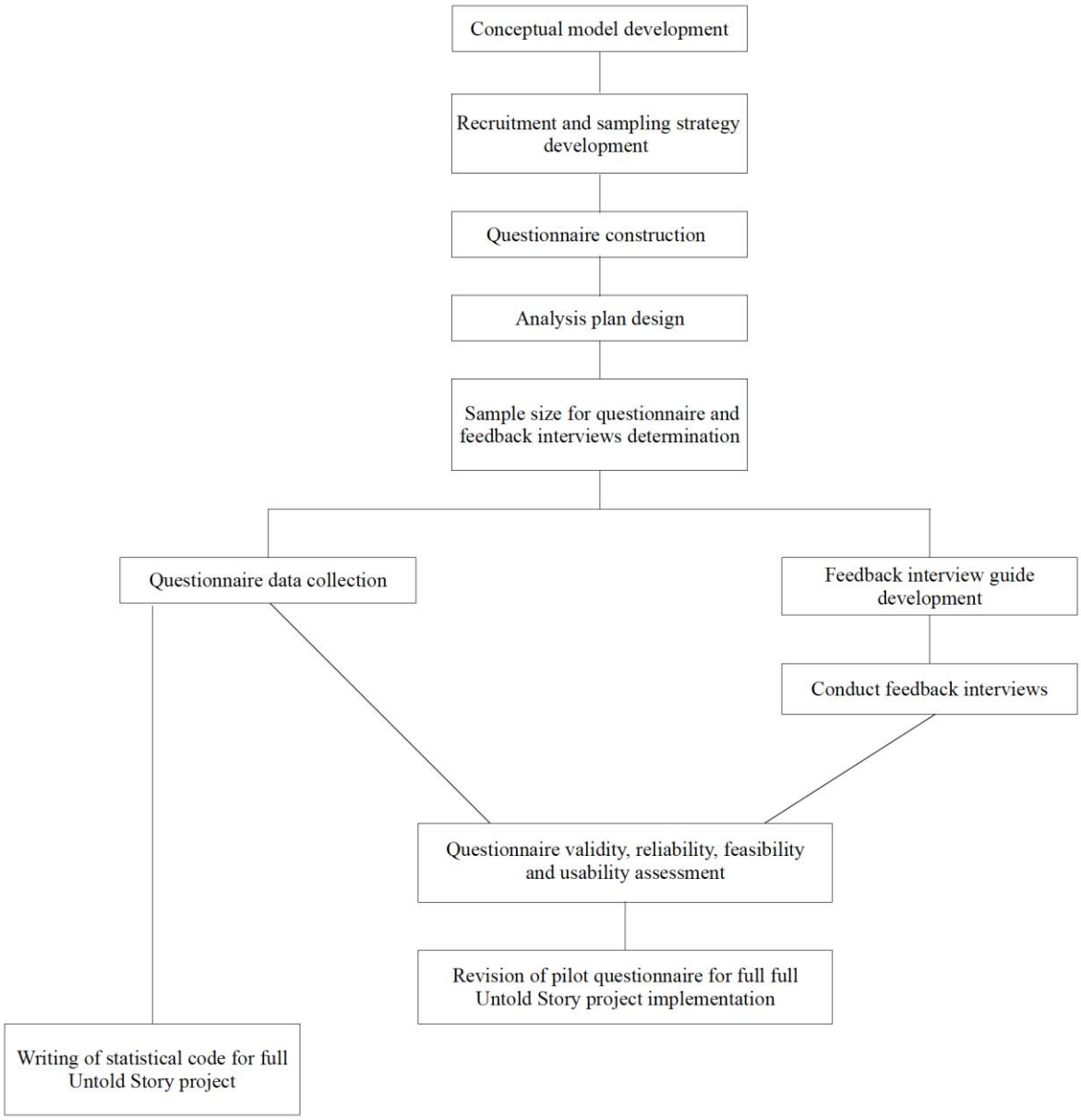

Figure 1. Pilot study design and steps to completion.

3.2 Sampling and Recruitment

The pilot study employed a convenience sample of individuals similar in composition to the sample for the larger Untold Story project, as this was the most feasible sampling procedure. Convenience samples have been used previously in similar

studies.[175,176,177,178,179] Information about the study and the team's contact information was displayed in physical and digital locations as posters. Potential participants meeting the inclusion criteria were then able to contact the study team if they were interested in participating in this study. Calculation of the sample size will be discussed later in this chapter, in Section 3.5.2 *Sample Size*.

3.2.1 Inclusion/Exclusion Criteria

The inclusion and exclusion criteria were:

Inclusion Criteria:

- Reside in Ontario
- 50 years of age or older.
- Self-report as having two or more chronic health conditions.
- Able to understand English well enough to complete an online questionnaire in English.
- Able to understand the letter of information and provide informed consent.

Exclusion Criteria:

- Not able to conduct the questionnaire in English.
- Have a cognitive impairment that prevents them from participating in a questionnaire and/or providing informed consent.

3.3 Conceptual Model Development

A conceptual model was developed to inform the construction and design of the questionnaire for the Untold Story project. Existing related conceptual models predated the COVID-19 pandemic or did not contain elements regarding social isolation and

loneliness and their related factors; therefore, it was necessary to develop a new model. The framework from The National Academies Press Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System (2020)[180] (hereafter referred to as the National Academies Press report), was used to guide the development of the conceptual model used in this study (see Figure 2).

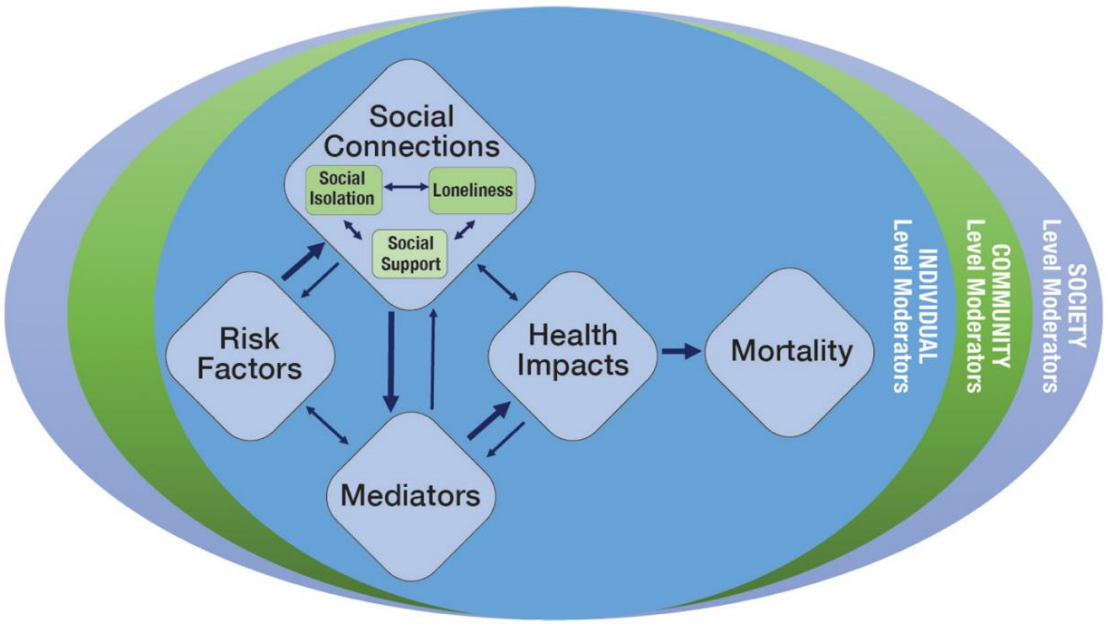

Figure 2. Framework from The National Academies Press Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System (2020).[180] (Republished with permission from The National Academies Press)

The National Academies Press report (2020)[180] contextualized their guiding framework in terms of clinical care settings because the authors of this report found that these settings offer many opportunities for identifying problems and possible solutions for social isolation. This guiding framework was developed in the context of an ecological model of health, whereby individual factors contributing to social isolation and loneliness are affected by contextual factors related to the community and society at large.[180] The relationships depicted in Figure 2 above, are potentially bidirectional, though the thicker arrows are meant to show stronger hypothesized relationships.[180] These relationships are

complex and at times it is difficult to disentangle health impacts from risk or protective factors related to social isolation and loneliness.[180]

The conceptual framework developed for this thesis and the Untold Story project (see Figure 3 below) was broadly based on the study objectives of the Untold Story project and includes the key study outcomes or dependent variables - social isolation and loneliness, and the key variables that were found to be related to the dependent variables in the literature. [124,180,181] This model includes variables that are risk factors for developing social isolation and loneliness, and variables that mediate or possibly mediate the relationship between social isolation, loneliness and health outcomes. The conceptual framework also includes COVID-19 related variables that may be linked with social isolation and loneliness; these variables had less consistent associations in the literature, as this research is still emerging.

The key variables associated with the dependent variables of social isolation and loneliness in the literature were classified in the model as falling under: Physical Health Factors; Health Related Behaviours - Lifestyle Factors; Psychological, Psychiatric, and Cognitive Factors; Socio-demographic Factors; Societal/Cultural Factors; and Social Environmental Factors. Variables from each of these factors were included in the model. Variables for the COVID-19 Related Factors were added as COVID-19 is one of the main areas of focus of the larger Untold Story project. Variables that have a strong association with social isolation and loneliness in the literature are identified with a double asterisk in Figure 3. Variables that were identified as mediators or possible mediators were treated as risk factors in the analysis. The cross-sectional nature of this study precludes mediation analysis because cross-sectional studies do not allow for determination of the direction of the relationship of interest, and hence where the possible mediator variables would be in the relationship.[182]

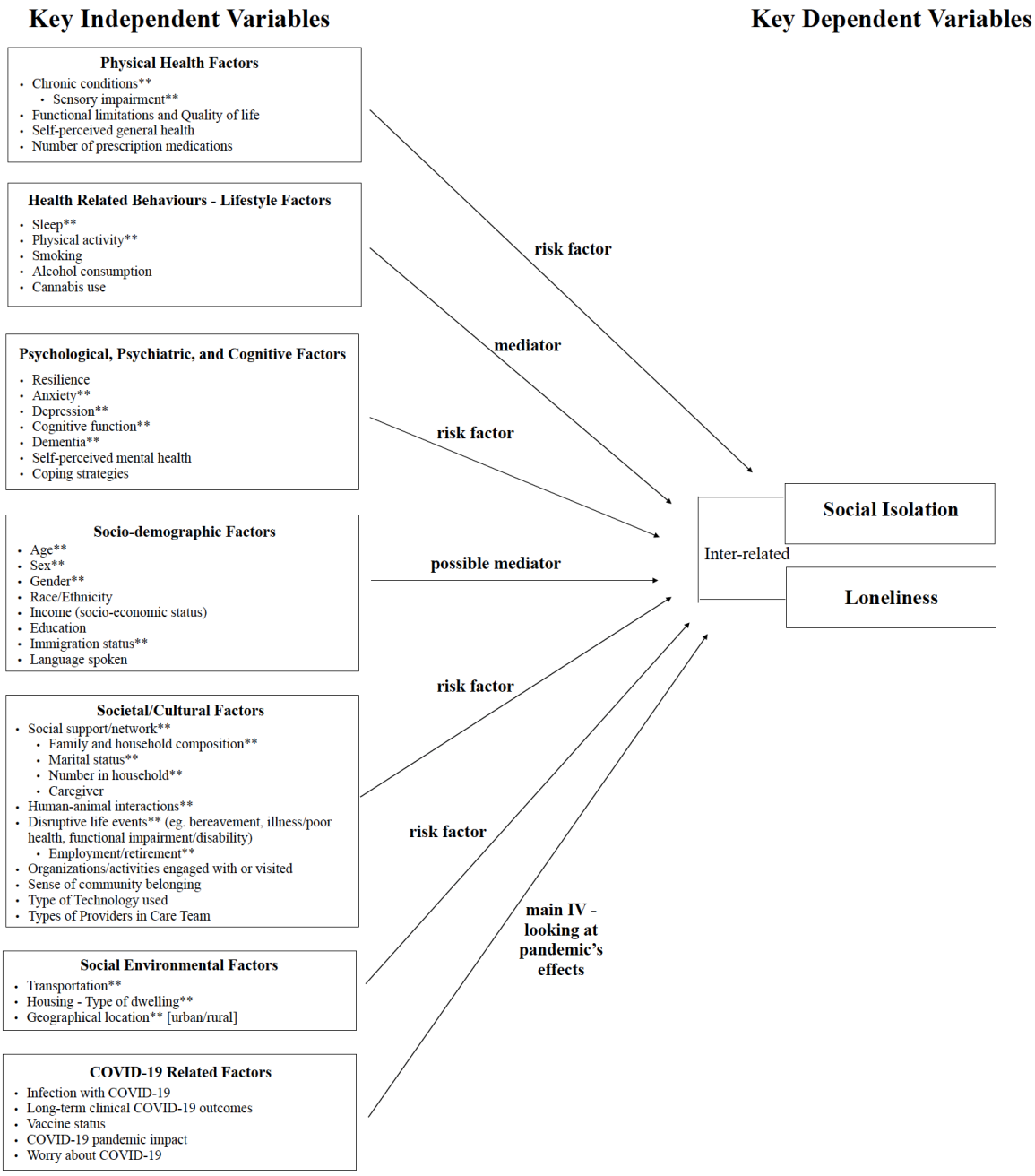

Figure 3. The conceptual model illustrating the key variables for the Untold Story of COVID-19 project.

** = variables that have a strong association with social isolation and loneliness

Indented points = these variables that were found to be important to the relationship of interest but were also related to other key variables are presented as indented under the key variable they are related to or compose.

3.4 Questionnaire Development

3.4.1 Questionnaire Construction

Generally, constructing a questionnaire involves the following steps: decide the data you want to collect (based on your research question), select the items to include, design the individual questions, formulate wording, design the layout, determine the coding, draft the questionnaire and pretest the draft, conduct the pilot study and evaluate, perform the full-scale survey, and repeat to achieve replication of results.[183] Questionnaire reliability and validity is important because self-reported data in general can be very unreliable.[172] Designing questionnaires to minimize this problem involves a few key steps. These steps include making sure that participants understand what is being asked in the question and that their interpretation of the question aligns with the researcher's intent, with cognitive interviews playing a key role in the researcher's assessment of participant comprehension and interpretation of the questions.[172] Another important consideration is that participants need to remember what the question is asking them to convey; recall can be aided by time and recall cues in the questions.[172] Participant recall may be incomplete, even with proper recall cues, therefore, the questionnaire response format needs to allow for easy mapping of the respondent's answer from their mind to the paper.[172]

One of the main objectives for the Untold Story project was to have a questionnaire that was no longer than 80 questions and took no longer than 30 minutes to complete to reduce respondent burden. An Excel document was created detailing the concepts of interest from the conceptual model. Question stems and response categories were added to the table for each concept, using previously validated scales or questions from large, population-based surveys like the Canadian Community Health Survey, Canadian Housing Study and Canadian Census when available. When this was not possible, questions were constructed *de novo*. Table 1 below lists the questionnaire concepts, the source for the question, the actual questions, and their response categories. Each question is listed under their appropriate heading in the questionnaire and appear in the order they were in for the pilot questionnaire. While there are questions for each of the concepts in

the conceptual model, to improve participant ease when moving through the questionnaire, the order of questions in the questionnaire itself does not completely map to the conceptual model.

Questionnaire items were included to reflect the key independent and dependent variables from the conceptual model (see Figure 3). Items were grouped within the questionnaire under the following headings: Health and Healthcare, Health Related Behaviours - Lifestyle Factors, Resilience, Societal/Cultural Factors, Social Isolation, Loneliness, Technology Use, and Socio-demographic Factors. The items included to measure Physical Health Factors and Psychological, Psychiatric, and Cognitive Factors from the model were mostly grouped together and named Health and Healthcare in the questionnaire, and the items included to measure Societal/Cultural Factors and Social Environmental Factors from the model were mostly grouped together and named Societal/Cultural Factors in the questionnaire. The individual items' response category types range from choosing the best descriptor, which was the most common kind of question, to choosing multiple descriptors, to writing numbers as the response.

An iterative item reduction process was used to reduce the number of items in the questionnaire to make the length manageable for respondents. This process started with reviewing the concepts of interest in the Excel table and evaluating each item multiple times. This table underwent constant refinement. This evaluation was informed through numerous Untold Story research team discussions and with returning to the literature at multiple points to clarify the relationships between the potential independent variables and the dependent variables, social isolation and loneliness. For example, the physical activity item was an important concept, but when further investigation could not elucidate a satisfactory short scale, it was decided to use a single item because this was not one of the main predictor variables for the relationship being investigated in the larger study.

3.4.2 Choice of Included Previously Validated Scales

In order to best capture information for the variables of interest, a number of previously validated scales for the questionnaire were chosen based on their use in the literature. However, for social isolation, loneliness, resilience, and quality of life equally good scales were found in the literature; in this section the process used to choose these scales is described.

Two social isolation scales were considered - the Duke Social Support Index (DSSI)[184] and the Lubben Social Network Scale.[185] These two scales were compared item for item and there was significant overlap in the questions; therefore, it was determined that the DSSI alone sufficiently captured the concept of social isolation for the purposes of this study. A further decision was taken to use the short 11-item DSSI scale instead of the full 35-item version. The 11-item scale has been found to demonstrate good construct validity,[186,187] is often used in studies with older individuals[186,187,188,189,190,191] and has the advantage of reducing respondent burden. Table A.1 provides the specific comparisons between the long and short version of the DSSI (see Appendix A).

During the conceptual model construction process, loneliness was identified as a key dependent variable, along with social isolation, therefore, an adequate scale had to be identified to measure this variable. To balance the burden on respondents with obtaining an accurate measurement of loneliness, the two-item loneliness scale from Elovanio et al. (2022)[192] utilized in the UK Biobank was decided upon.

The Connor-Davidson Resilience Scale (CD-RISC)[193] was similarly examined and the short 10-item CD-RISC scale instead of the full 25-item version was selected. The CD-RISC 10-item scale has good validity[194,195] and internal consistency,[194,195,196] and the same advantage as the 11-item DSSI of reducing respondent burden. Table A.2 provides the specific comparisons between the long and short version of the CD-RISC (see Appendix A).

Other key independent variables associated with social isolation and loneliness were quality of life and functional limitations. Multiple literature searches were conducted to find scales that minimized respondent burden and accurately captured these concepts. Ultimately the EuroQol 5-level EQ-5D version (EQ-5D-5L) scale[197] was included because it is a quality of life scale that asks about functional limitations, like mobility or ability to perform activities of daily living.

Table 1. Questions for the Untold Story questionnaire according to concepts measured

Concept	Source	Question and Response Categories
Health and Healthcare		
Self-perceived general health	Canadian Community Health Survey (CCHS)[198] 2023	In general, how is your health? • Excellent • Very good • Good • Fair • Poor
Self-perceived mental health	CCHS 2023[198]	In general, how is your mental health? • Excellent • Very good • Good • Fair • Poor
Chronic conditions	/pmc/articles/ PMC5636032 /table/tb003/ ?report=objectonly [199]	The following is a list of chronic conditions. Chronic conditions are defined as those that you have had for at least 6 months and that have been diagnosed by a health care professional. Please check all chronic conditions that you have. • Anxiety and/or depression • Any cancer in the previous 5 years (including melanoma, but excluding other skin cancers) • Asthma • Cardiovascular disease (examples: angina, myocardial infarction, atrial fibrillation, poor circulation in the lower limbs) • Chronic liver disease including chronic hepatitis • Chronic kidney disease or failure • Chronic musculoskeletal conditions • Chronic obstructive pulmonary disease (COPD) (including chronic bronchitis) • Chronic urinary problem including urinary incontinence • Colon problem (examples: Irritable Bowel Syndrome, Crohn's disease, ulcerative colitis, diverticulosis) • Dementia (including) Alzheimer's disease • Diabetes • Heart failure (including valve problems or replacement) • Hyperlipidemia (high cholesterol)

Concept	Source	Question and Response Categories
		• Hypertension (high blood pressure) • Obesity • Osteoarthritis and/or rheumatoid arthritis • Osteoporosis • Stomach problem (examples: reflux, heartburn, or gastric ulcer) • Stroke and/or transient ischemic attack (TIA) • Thyroid disorder • Others, Please specify:
Number of prescription medications	Question adapted from AARP[200]; response options for this survey	Approximately how many prescription medications do you take on a regular basis? • 0 • 1 • 2 • 3 • 4 • 5+
Sensory impairment	Developed specific question for this survey	If you normally wear corrective glasses and/or contact lenses, please assume you are wearing your corrective glasses and/or contact lenses when answering the following question. Would you consider yourself to have a visual impairment? • Yes • No
	Developed specific question for this survey	If you normally use hearing aids/devices, please assume you are using your hearing aids/devices when answering the following question. Would you consider yourself to have a hearing impairment? • Yes • No
Functional limitations and Quality of Life	EuroQol 5D-5L (EQ-5D-5L)[197]	For the following questions, please select the statement that best describes your health TODAY. Your mobility TODAY • I have no problems in walking about • I have slight problems in walking about • I have moderate problems in walking about • I have severe problems in walking about • I am unable to walk about
		Your self-care TODAY • I have no problems washing or dressing myself • I have slight problems washing or dressing myself • I have moderate problems washing or dressing myself • I have severe problems washing or dressing myself • I am unable to wash or dress myself
		Your usual activities TODAY (example: work, study, housework, family or leisure activities) • I have no problems doing my usual activities • I have slight problems doing my usual activities

Concept	Source	Question and Response Categories
		• I have moderate problems doing my usual activities • I have severe problems doing my usual activities • I am unable to do my usual activities
		Your pain/discomfort TODAY • I have no pain or discomfort • I have slight pain or discomfort • I have moderate pain or discomfort • I have severe pain or discomfort • I have extreme pain or discomfort
		Your anxiety/depression TODAY • I am not anxious or depressed • I am slightly anxious or depressed • I am moderately anxious or depressed • I am severely anxious or depressed • I am extremely anxious or depressed
		We would like to know how good or bad your health is TODAY. On the next screen, you will see a scale numbered 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine.
Infection with COVID-19	Adapted from Hughes et al., 2022[201]	Have you had COVID-19? Please indicate "yes" if you were either formally diagnosed with COVID-19 or if you believe you had COVID-19 but were not formally diagnosed. • Yes • No
Long-term clinical COVID-19 outcomes	Developed specific question for this survey	If you had COVID-19, have you experienced any long COVID symptoms? Please select any Long COVID symptoms that apply: • Cognitive symptoms (example: brain fog, memory issues) • Sleep disruption • Mobility symptoms (example: issues with movement) • Pain (in muscles or joints) • Skin and hair symptoms (including hair loss) • Mental health symptoms (example: anxiety) • Fast beating heart, fatigue, chest pain, shortness of breath • Other symptoms, please specify:
Vaccine status	Developed specific question for this survey	Have you received any COVID-19 vaccines? • Yes • No
	Developed specific question for this survey	If yes, to the best of your recollection, how many doses have you received? • Type in number of doses
Caregiver	Savage et al., 2021[125]	Do you provide assistance to another person because of a health condition or limitation? By assistance we mean personal care, medical treatments, scheduling or coordinating care-related tasks, meal preparation, house maintenance, transportation, social or emotional support, mobility, or financial assistance or management. Please exclude any assistance you provided as part of a volunteer organization or paid job.

Concept	Source	Question and Response Categories
		• Yes • No
	Savage et al., 2021[125]	Do you receive assistance from family, friends, or neighbours because of a health condition or limitation that affects your daily activities? By assistance we mean personal care, medical treatments, scheduling or coordinating care-related tasks, meal preparation, house maintenance, transportation, social or emotional support, mobility, or financial assistance or management. • Yes • No
Death of a loved one	Developed specific question for this survey	Have you experienced the death of a loved one (examples: family, friend) or a pet in the past three years? • Yes • No
Types of Providers in Care Team [contact with physician]	CCHS 2021[202]	Do you have a regular health care provider? By this, we mean one health professional that you regularly see or talk to when you need care or advice for your health. • Yes • No
	CCHS 2021[202]	If yes, please choose the best answer. Is that regular health care provider a...? • Family doctor (general practitioner) • Medical specialist (example: cardiologist or a pediatrician) • Nurse practitioner • Other; please specify:
	Developed specific question for this survey	Approximately how many times have you seen this provider in the past year? • Type in number of visits
COVID-19 pandemic impact	Wister et al., 2022[118] wrote the questions in context of COVID-19 pandemic, based on Cao-Lei et al., 2016	Taking everything about COVID-19 into account, how would you describe the consequences of COVID-19 on you? • Very negative • Negative • No effect • Positive • Very positive
Worry about COVID-19	Adapted from Wister et al., 2022[118]	How worried are you personally about COVID-19 at present? • Not at all worried • A little worried • Moderately worried • Very worried • Extremely worried
Health-Related Behaviours-Lifestyle Factors		
Sleep	Questions stem from Rodrigues et al., 2022[203], based on the Canadian Longitudinal Study on Aging (CLSA) questions;	On average, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed.) • Less than 6 hours • 6–8 hours • More than 8 hours

Concept	Source	Question and Response Categories
	with response options based on - Hirshkowitz et al., 2015[204]	
	Rodrigues et al., 2022, based on the CLSA questions [203]	How satisfied or dissatisfied are you with your current sleep pattern? • Very dissatisfied • Dissatisfied • Neutral • Satisfied • Very satisfied
Physical activity	For question and adapted responses: Musich et al., 2022[205] For examples of activities: Musich et al., 2022[205] (walking, gardening, golfing); Zimmer and McDonough, 2022[206] (walking, light or moderate recreational activities, muscle strength/endurance activities)	How many days per week do you get 30 minutes or more of light-to-moderate physical activity? Examples: walking, gardening, golfing, light or moderate recreational activities, muscle strength/endurance activities • 0-2 days per week • 3-4 days per week • more than 5 days per week
Smoking	CCHS 2023[198]	Currently, which of the following best describes your smoking habits? • Currently daily • Occasional smoker • Former smoker who quit • Non-Smoker
Alcohol Consumption	Health Awareness and Behaviour Tool (HABiT)[207]; response categories adapted to reflect latest Canada's Low-Risk Alcohol Drinking Guideline[208]	How many drinks of alcohol do you drink in an average week? (1 standard drink = 12 oz. Beer, 5 oz wine, 1.5 oz alcohol) • None • 1-5 • 6-10 • 11-15 • More than 15
	HABiT[207]; response categories adapted to reflect latest Canada's Low-Risk Alcohol Drinking Guideline[208]	How often in the past 12 months have you had four (4) or more drinks of alcohol on one occasion? • Never or less than once a month • Once a month • 2 to 3 times a month • Once a week • More than once a week
Cannabis use	Adapted from CCHS 2023[198]	Currently, which of the following best describes your cannabis use? (smoking cannabis, vaping cannabis, cannabis edibles etc.) • Currently daily use of cannabis • Occasional use of cannabis • Used cannabis formerly but not currently • Do not use cannabis

Concept	Source	Question and Response Categories
Resilience		
Resilience	Connor-Davidson Resilience Scale 10 (CD-RISC-10) ©[193]	Please indicate how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt.
		I am able to adapt when changes occur. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I can deal with whatever comes my way. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I try to see the humorous side of things when I am faced with problems. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		Having to cope with stress can make me stronger. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I tend to bounce back after illness, injury, or other hardships. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I believe I can achieve my goals, even if there are obstacles. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		Under pressure, I stay focused and think clearly. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I am not easily discouraged by failure.

Concept	Source	Question and Response Categories
		• Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I think of myself as a strong person when dealing with life's challenges and difficulties. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
		I am able to handle unpleasant or painful feelings like sadness, fear, and anger. • Not true at all • Rarely true • Sometimes true • Often true • True nearly all the time
Societal/Cultural Factors		
Housing - Type of dwelling	Developed question stem for this survey; response options adapted from Canadian Census[209]	Which of the following best describes the dwelling in which you live? • Single-detached house • Semi-detached house • Row house/town house • Apartment building • Mobile home or other movable dwelling • Other, please specify:
Number in household	Adapted from Investigating Novel Predictions of Hypoglycemia Occurrence using Real-world Models (iNPHORM)[210]	How many people live in your household including yourself? • Type in number of people
Family and household composition	iNPHORM[210]	What is your current living arrangement? Please select all that apply • I live alone • I live with a spouse or partner • I live with minor children • I live with other adult family members • I live with other people (example: roommates) • I live with pet(s)
Transportation	Adapted from Transport, Housing and Wellbeing in Glasgow[211]	How do you usually travel locally; for example, to go to appointments, grocery shopping or meeting with friends? • I don't usually go out • My own car or van • Public transportation such as bus • Taxi (including other ride services like Uber) • Walk

Concept	Source	Question and Response Categories
		• Cycle • With a friend/family member
Safety of neighbourhood	Adapted from Canadian Housing Survey 2022[212]	How safe do you feel in your neighbourhood? • Very safe • Reasonably safe • Somewhat unsafe • Very unsafe
Sense of community belonging	CCHS 2023[198]	How would you describe your sense of belonging to your local community? • Very strong • Somewhat strong • Somewhat weak • Very weak
Engagement with organizations or activities	Developed specific question for this survey	Please check the organizations and/or activities in which you participate or visit. • Appointments for professional services (example: health care, lawyer) • Clubs (example: book club, car club) • Community centres/service organizations (example: Kiwanis) • Exercise facilities • Food and beverage establishments • Local markets • Open spaces (including playgrounds) • Parks • Places of worship • Senior centres • Stores (including shopping malls) • Other, please specify:
Social Isolation (OUTCOME)		
Social Isolation	Duke Social Support Index social interaction scale (DSSI) 11-item scale[213]	Other than members of your family how many persons in your local area do you feel you can depend on or feel very close to? • None • 1-2 people • More than 2 people
		How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together? • Not at all • Once • Twice • Three times • Four times • Five times • Six times • Seven times or more
		How many times did you talk to someone (friends, relatives or others) on the telephone or another communication platform like Zoom, Skype, or Facebook in the past week? That is they either contacted you, or you contacted them?

Concept	Source	Question and Response Categories
		• Not at all • Once • Twice • Three times • Four times • Five times • Six times • Seven times or more
		About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week? • Not at all • Once • Twice • Three times • Four times • Five times • Six times • Seven times or more
		Does it seem that your family and friends (people who are important to you) understand you? • Hardly ever • Some of the time • Most of the time
		Do you feel useful to your family and friends (people important to you)? • Hardly ever • Some of the time • Most of the time
		Do you know what is going on with your family and friends? • Hardly ever • Some of the time • Most of the time
		When you are talking with your family and friends, do you feel you are being listened to? • Hardly ever • Some of the time • Most of the time
		Do you feel you have a definite role (place) in your family and among your friends? • Hardly ever • Some of the time • Most of the time
		Can you talk about your deepest problems with at least some of your family and friends? • Hardly ever • Some of the time • Most of the time

Concept	Source	Question and Response Categories
		How satisfied are you with the kinds of relationships you have with your family and friends? • Very dissatisfied • Somewhat dissatisfied • Satisfied
Loneliness (OUTCOME)		
Loneliness	UK Biobank - Elovainio et al., 2022[192]	Do you often feel lonely? • Yes • No
		How often are you able to confide in someone close to you? • Almost daily • Once every few months • Never/almost never
Coping strategies	Adapted from Savage et al., 2021[125]	What steps do you take to avoid feeling lonely? Please select up to three strategies you use most often. • Connect with a friend or family member • Get fresh air • Get active • Stay busy with work or projects • Engage in a hobby • Try to get proper rest and sleep • Spend time with my pet • Other, please share any strategies:
	Adapted from Savage et al., 2021[125]	Please share with us any specific resources you use to avoid feeling lonely (e.g., participating in a virtual book club): • Type in answer
Technology Use		
Type of Technology used	Savage et al., 2021[125]	Do you have access to the Internet at home? • Yes • No • Don't Know
		How would you rate the internet connection in your home? • Very good • Good • Moderate • Poor • Don't know
		Do you have a smartphone that you use for personal use? A smartphone is a mobile phone that performs many of the functions of a computer, typically having a touchscreen interface, Internet access, and an operating system capable of running downloaded applications, e.g. Apple iPhone and Samsung Galaxy • Yes • No
		Do you use any social networking websites (e.g. Facebook) or apps (e.g. Zoom or FaceTime) to communicate with friends and family? • Yes

Concept	Source	Question and Response Categories
		• No • Don't Know
Socio-demographic Factors		
Age	CCHS 2023[198]	In what year were you born? • Choose year from drop-down menu – 1923-1973
Sex	Bauer et al., 2017 - Figure 4 Creative Commons with attribution[214]	What sex were you assigned at birth, meaning on your original birth certificate? • Male • Female
Gender		Which best describes your current gender identity? • Male • Female • Indigenous or other cultural minority identity (example: two-spirit) • Something else (example: gender fluid, non-binary) - Please specify if you wish:
Marital status	Adapted from iNPHORM[215]	Currently, which of the following best describes you? • Never married or single • Married or common-law • Separated or divorced • Widowed
Race/Ethnicity	University of Waterloo Survey Research Centre[59]	Please select the racial category or categories with which you primarily identify. (Select all that apply) • Black (e.g., African, Afro-Caribbean, Black Canadian, Afro-Latine, African American, or other African descent) • East Asian (e.g., Chinese, Korean, Japanese, or other East Asian descent) • Latine (e.g., Latin American, Indigenous, Afro-Latine or European) • Middle Eastern (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, or other Arab or Persian descent) • South Asian (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, or other South Asian descent) • Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, Malaysian, or other Southeast Asian descent) • White (e.g., British, German, Ukrainian, or other European descent) • Another racial category (please specify): • I prefer not to answer
Immigration Status	CCHS 2023[198]	Where were you born? • Born in Canada • Born outside Canada
	CCHS 2023[198]	In what year did you first come to Canada to live? • Type in year
Language spoken	CCHS 2023[198]	Can you speak English or French well enough to conduct a conversation?

Concept	Source	Question and Response Categories
		• English only • French only • Both English and French • Neither English nor French
Education	Adapted from (1) Elections Canada [216] /content.aspx?section=res&dir=rec/part/genz&document=p13&lang=e (2) University of Waterloo Survey Research Centre[59]	What is the highest level of education that you have completed? • Less than secondary/high school graduation • Secondary/high school graduation diploma or equivalent • Trade certificate or diploma from a vocational school or apprenticeship training. • Some postsecondary education (example: college or university courses) • Postsecondary certificate or diploma (example: from community college) • Bachelor's degree (example: BA, BSc) • Graduate or professional degree (example: MA, PhD, LLB, MD)
Employment	iNPHORM[215]	What is your current employment situation? • Working full-time including self-employment (25 hours per week or more) • Working part-time including self-employment (less than 25 hours a week) Temporarily laid off • Temporarily unemployed due to a health-related reason • Unemployed and looking for work • Unemployed and not looking for work • Unable to work due to health • Going to school • Looking after house/family • Retired
Income	Question stem from CCHS 2023[198]; response categories adapted from Statistics Canada 2019 categories[217]	Which of the following categories best represents your total household income for the year ending December 31, 2022? • Under $20,000 • $20,000 to $39,999 • $40,000 to $59,999 • $60,000 to $79,999 • $80,000 to $99,999 • $100,000 to $149,999 • $150,000 and over
Geographical location [urban/rural]	Developed specific question for this survey	Please provide us with the first three digits of your postal code: • Type in first three digits of postal code

3.4.3 Data Management

3.4.3.1 Data Preparation for Analysis

Data were downloaded from Qualtrics XM in the form of a .csv file for analysis in Stata/SE 18 software and cleaned in Excel. Of the 27 participants who were completed the questionnaire, two were excluded from the final analysis as they did not meet eligibility criteria and one participant withdrew their consent partway through completion of the survey, leaving data from 25 participants for analysis.

3.4.3.2 Recoding of Variables

The main dependent and independent variables were derived from the questionnaire items and transformed into variables that could be used for statistical analysis. The variable names align with the key variables in the conceptual model, though they are truncated, and most of the response categories were recoded into numerical values. Full information of recoded variables can be seen in Appendix B, which contains the codebook for recoded variables used for analysis in this thesis.

3.4.3.3 Scoring of Scales

The previously validated scales used, the DSSI, CD-RISC, EQ-5D-5L, and UK Biobank Loneliness scale were all coded according to their specific manuals. All four of these scales produce one value each for the overall score, and these were used in the analysis. Below the specific scoring of the DSSI, CD-RISC, EQ-5D-5L, and UK Biobank Loneliness scale is discussed.

Duke Social Support Index

While the DSSI is subdivided into four subscales, individual items can also be used on their own.[213] The 11-item DSSI only contains the Subjective Social Support and Social Interaction Scales.[184] The scale scores are summed after a recoding process, with higher scores indicating higher levels of social support and lower social isolation levels.[213] The process of recoding values is based on administration of the full 35-item DSSI and the

recode values are written under each question by the person administering the scale, where they are relevant in the instrument.[213] The recode numbers are based on the number of people the respondent interacted with, the number of activities they participated in and how often certain situations apply to the respondent. The DSSI working paper,[213] describing scoring of the scale and sub scales, focuses on scoring of the subscales as individual scales and does not give a formula for a summary value for the whole scale. However, the values can be summed across subscales to give an overall number, as in the 10-item version of the DSSI.[218] In the 35-item DSSI, and applicable to the 11-item DSSI, the Subjective Social Support Scale can be dichotomized with assigning the value of one to those with scores 23 and under, indicating "impairment" [213,p5] (meaning lacking in social network), and zero to those with value of 24 and over, indicating no impairment. [213] For the Social Interaction Scale, those with values of three or less are considered "impaired" [213], and this scale was used in the dichotomous categorization of participants as socially isolated or not in the current study because it appears in its entirety in the 11-item DSSI and this classification can be accurately applied.

Connor-Davidson Resilience Scale

For the CD-RISC 10, each item score ranges from zero to four, with zero indicating the resilience statement is not true at all and four indicating that it is almost always true.[219] The scores for each of the individual items are summed, and for the CD-RISC 10, scores range from zero to 40, the higher the score, the more resilient the person.[219] For the CD-RISC 10, the quartiles, in increasing order, for the scores are 0-29, 30-32, 33-36, and 37-40.[219] The current study constructed the resilience variable based on the CD-RISC 10 score, not the quartiles. CD-RISC scores have been found to be affected by geographical location and characteristics of the sample.[220] The CD-RISC is a self-administered scale where individuals answer the questions based on experiences in the past month.[220] Also, it is not recommended to use any subscales on their own, apart from the validated reduced versions of the CD-RISC.[219,220]

UK Biobank Loneliness Scale

The loneliness scale used was from Elovanio et al., 2022,[192] and are the questions asked in the UK Biobank. These two questions are scored dichotomously and together, with the dichotomization being zero or one.[192] Taken together, if participants respond positively to both questions (receiving the score of two), they are defined as lonely, and if they respond negatively to one or both questions, with scores of one and zero, respectively, they are defined as not lonely[192] and was used in the dichotomous categorization of participants as lonely or not.

EuroQol 5-level EQ-5D version

The 5-level EQ-5D version (EQ-5D-5L)[197] is a quality of life scale and can be scored in two ways, the first is by scoring the five items by number and the visual analogue scale separately, and the second is to compute a single index value for the whole scale using the value set for the region where the study is being conducted.[221] The value set for Canada was obtained for the current thesis and Untold Story project.[221] For the current pilot study and larger Untold Story project, the index value was and will be computed because a single number is more convenient for data analysis with such a large number of variables.

3.5 Questionnaire Assessment

This section describes the steps taken to assess the validity, reliability, feasibility, and usability of the questionnaire in the current pilot study. This was done to inform questionnaire implementation, study design and analysis plan for the larger Untold Story project.

3.5.1 Analysis Plan

Data analysis included multiple steps, starting with a descriptive analysis of the pilot study questionnaire data (hereafter, referred to as pilot data) to ascertain sample characteristics.[210,222] This was followed by the validity and reliability analysis of the pilot data. Feedback interviews were conducted to collect information about various aspects of the questionnaire from survey respondents, and data from these feedback interviews was used for two purposes. The first purpose was to ascertain face and content validity. The second purpose of the interviews was related to usability of the questionnaire. In preparation for the feedback interview, the data were assessed to see if any participants had chosen not to answer a large number of questions, and to prioritize speaking with these individuals for feedback interviews. This pilot data check was done to ascertain if there were major problems with questionnaire clarity or difficulties in completing it in the online format. As there were no major problems identified, participants were contacted in order they had completed the questionnaire if they indicated interest in the feedback interview. The feedback interviews served to determine if the lack of completion of questions was a result of the questionnaire construction, or the participants' choice not to answer the questions.

The pilot study data were analyzed by first conducting a bivariate analysis. The results of this analysis were used to determine which variables to include in the multivariable model; i.e., a logistic regression model. These steps were undertaken to create the statistical code for analysis of the larger study data and to test this code using the pilot data. The data analysis was conducted using Stata/SE 18 software. The full statistical code is included in Appendix C.

3.5.1.1 Descriptive Statistics

Descriptive statistics were used to describe the characteristics of the sample and included frequencies and percentages for key sample characteristic variables, with the mean calculated for age. Age, sex and gender, marital status, family and household composition, race/ethnicity, immigration status, language spoken, education,

employment, income, geographical location, and the number of chronic diseases an individual had were described.

3.5.1.2 Validity and Reliability

Validity refers to the measurement accuracy of a questionnaire or instrument, and reliability refers to the measurement consistency of a questionnaire or instrument.[223] Instruments can be neither, either, or both valid and reliable, and the degree of each is most important.[223] Validity is the most important component, and should be assessed before reliability.[223] When assessing the validity of a questionnaire, the main objective is to determine the extent to which the answers correspond to the truth.[224] Content validity refers to the extent to which the instrument measures what it was designed to measure,[223]. In this study, content validity was assessed using the Content Validity Matrix developed by Streiner (1993)[225] and through questions in the feedback interview related to if participants found questions to be asking what they were expecting them to ask. Construct validity refers to the degree to which the instrument is related to theoretical expectations of the concept being measured[223,226]; these hypothetical constructs cannot be directly measured, only inferred from behaviours, and usually involve several assessments of validity.[223] Defining the theoretical ways the variables in this study were thought to be related was key to assessing construct validity.[227] Construct validity was assessed by calculating correlation coefficients, independent sample t-tests, and Fisher's Exact tests between items from the questionnaire that were hypothesized to be related in specific ways.[228] Face validity refers to the extent that the instrument appears to be measuring what it says it measures,[226] and was assessed through the feedback interviews through questions targeted towards how respondents answered questions. Validity is a multifaceted concept that refers to the extent to which observed associations are real and how closely conclusions align with data.[229] In this study, validity was assessed using the Content Validity Matrix approach, between-item tests of association, and questions in the feedback interview related to if participants found questions to be asking what they thought was being asked.

Reliability refers to the internal consistency of an instrument[223] and measures of reliability are a way to reflect the amount of error in measurement.[230] Reliability can be assessed by calculating an interclass correlation coefficient for continuous variables and using Cohen's Kappa coefficient for categorical variables with higher reliability seen when within subjects variation is small.[229] The Cronbach's α coefficient computes internal consistency for non-dichotomous responses,[223] and is the most widely used objective measure of reliability.[231] Internal consistency is a measure of the extent to which items in the questionnaire tap into the same concept.[231] In this study, reliability was assessed by calculating the Cronbach's α coefficient for the DSSI and CD-RISC scales used in the questionnaire.

Content Validity

Content validity was assessed using the Content Validity Matrix outlined in Streiner (1993)[225] and through the feedback interview questions that asked about removing or adding questions, and if participants found the questions to be asking what they were expecting them to ask. As described in Section 3.5.4 *Feedback Interview*, during the feedback interviews participants were asked if, for each of the main sections of the questionnaire, there was anything missing that they thought should have been asked. In order to populate the Content Validity Matrix, the study team utilized multiple discussions and questionnaire iterations to ascertain if each question was asking what was intended, and incorporated participant feedback where appropriate. The Content Validity Matrix consisted of the overarching concepts from the conceptual models, the main groupings of independent and dependent variables from the conceptual model across the top, and the items going down the side.[225] Below is part of the matrix constructed for this questionnaire for illustrative purposes; the full matrix is found in the Results section, Section 4.2.2.1 *Content Validity*. This matrix should have one "X" per item and multiple "X"s per domain or concept.[225]

Table 2. Illustration of the set-up of the Content Validity Matrix for the pilot study questionnaire

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
1. In general, how is your health?	**X**								
2. In general, how is your mental health?			**X**						
. . .									
41.Other than members of your family, how many people in your local area do you feel you can depend on or feel very close to?								**X**	

Construct Validity

Construct validity was assessed using correlations, independent sample t-tests, and Fisher's Exact tests to test hypotheses about relationships between items in the questionnaire based on existing findings in the literature. A correlation matrix, a method suggested by Cronbach and Meehl (1955)[228] for assessing construct validity, was used to ascertain if the measurements from the questionnaire were related as expected based upon empirical evidence from the literature.[228,223] Fisher's Exact tests were used because in the Chi squared tables, all the pairings had at least one expected cell count under five. For each Fisher's Exact test *post hoc* Cramér's V tests were also conducted to test the strength of these associations. Significance level of p=0.05 was chosen for significant association. The method outlined by Cronbach and Meehl (1955)[228] included three steps for assessing

construct validity: 1) define the theoretical constructs and their relationships; 2) develop the measurement tool for these constructs; 3) empirically test the relationships between constructs using the observations collected from the measurement tool. The first step was completed with the conceptual model (see Section 3.3 and Figure 3), the second step was completed with the design and creation of the questionnaire (see Section 3.4 and Table 1), and the third step is outlined in this section, *Construct Validity*.

Construct Validity Hypotheses Tested

To assess construct validity, the following hypotheses were tested by calculating correlation coefficients, independent sample t-tests, or Fisher's Exact tests between items in the questionnaire, based on information from the literature review about the pre-existing relationships between key variables of interest.

- *Social isolation and loneliness:* A positive association was hypothesized to exist between these variables because they are closely linked, yet distinct concepts[26,28] and individuals may experience both, either, or neither.[26]

- *Multimorbidity level and social isolation:* A positive association was hypothesized to exist between these variables because social isolation has been found to be associated with chronic diseases such as cardiovascular disease[32,33] and dementia,[4,34,35] and social isolation has been found to be associated with increased morbidity risk.[4,3]

- *General health and social isolation:* A common risk factor for social isolation is poor health[30,31]; thus, a negative association was hypothesized for these variables.

- *General mental health and loneliness:* Since higher loneliness levels are associated with psychological disorders,[124] a negative association was hypothesized for these variables.

- *Resilience and loneliness:* Perceived social support has been found to reduce psychological burden, with social support having been found to be protective during stressful life events, increasing resilience.[145] Therefore, a negative association between these variables was hypothesized.

- *Resilience and multimorbidity level:* A negative correlation was hypothesized for these variables because individuals with higher levels of resilience tend to have less prevalence of hypertension, lower BMI, and fewer psychological diseases,[140] and resilience has been linked to optimal physical and mental health.[138]

Reliability

The Cronbach's α coefficient for internal consistency was computed to assess the reliability of the previously validated outcome scales included in the questionnaire in this population and setting. For the DSSI, the Cronbach's α coefficient value used for the comparison from the literature was 0.71[184] and for the CD-RISC the Cronbach's α coefficient value used for the comparison from the literature was between 0.86[194] and 0.88.[196]

The following formula from Cronbach (1951)[232] was used to compute the Cronbach's α coefficient values for the DSSI and CD-RISC, though the value was computed using Stata/SE 18 software:

$$\alpha = \frac{n}{n-1}\frac{\sum\sum_{i\ j} C_{ij}}{V_t};\ (i, j = 1, 2, \cdots n; i \neq j).$$

Where $\frac{\sum\sum_{i\ j} C_{ij}}{V_t}$ is the ratio of inter-item covariance, *C*, to total variance, *V*, and $\frac{n}{n-1}$ is the multiplier constructed of the number of items, *n*.[232]

3.5.1.3 Bivariate Analysis and Logistic Regression

Bivariate analysis and multivariable logistic regression were run with the pilot data as a test of the code for the larger study. This code will be used in the larger Untold Story project. First, a bivariate analysis was run to test the dichotomous dependent variables of social isolation and loneliness with each of the independent variables from column one (Concepts) from Table 1, using p=0.05 significance level. For continuous independent variables, t-test were conducted and for categorical variables, Fisher's Exact tests were conducted. Fisher's Exact tests were used because the in the tables, all the pairings had at least one expected cell count under five. The bivariate analysis was followed by a multivariable logistic regression where the independent variables that were found to be statistically significantly associated with the dependent variables in the bivariate analyses were used as the predictor variables in the multivariable logistic regression with p=0.05 significance level. The reference categories for the logistic regression models were not being socially isolated and not being lonely.

3.5.2 Sample Size

There is a paucity of evidence about calculating sample sizes for pilot studies, though guidelines have been developed.[233] Pilot study samples need to be representative of the larger study's target population and the inclusion and exclusion criteria need to align with the larger study's.[54] Calculating sample sizes for pilot studies is more difficult than for full-scale studies and is influenced by a multitude of factors, with the final number depending on the type of analysis, desired significance level and power.[234] An important consideration for pilot study sample sizes is having a sufficient number of participants to accurately represent the target population.[234] Johanson and Brooks (2010)[234] advise a minimum of 30 representative participants for pilot studies of scale development or preliminary surveys. This was their suggestion because when they conducted simulations of correlation studies they found that the size of the confidence intervals around the correlation coefficients became smaller and remained constant around N=24 to 30 and N=30 to 36.[234] Hertzog (2008)[233] recommends sample sizes of 20 to 40 in pilot studies as

samples of more than 40 participants may not be possible, and this range provides sufficient power for most pilot study analyses. While sample sizes of 10 may be sufficient for assessing clarity of a questionnaire, estimations of internal consistency and test-retest reliability require larger sample sizes.[233] Hertzog (2008)[233] suggests sample sizes ranging from 25 to 40 if researchers want to estimate internal consistency using Cronbach's α coefficient. Since the current pilot study used Cronbach's α coefficient to assess the internal consistency of the DSSI and CD-RISC scales in the questionnaire, Bujang's (2018)[235] formula was used to calculate the sample size.

Bujang's (2018)[235] formula uses the Cronbach's α coefficient as the measure of effect, with the hypothesis test being conducted for the difference between the Cronbach's α coefficient found in the literature for the scale used and the Cronbach's α coefficient value computed from the pilot study. The formula also requires the significance level, two-tailed α equal to 5% for this study, and power, β equal to 80% for this study, and the number of items in the validated scale being used in the questionnaire.[235] The two previously validated scales used in the questionnaire for this thesis are the 11-item DSSI and 10-item CD-RISC, and the sample size calculation was conducted for the 11-item DSSI scale because social isolation was one of the main outcomes of interest. Using Bujang's (2018)[235] formula yielded a sample size of 17 (see calculation below. For the current pilot study, this number was rounded up 25 participants to be consistent with the general recommendation of between 20 and 40 participants for a pilot study sample sizes..[233,234]

Formula from Bujang et al., 2018[235]:

$$n = \left[\frac{\left\{\left(\frac{2k}{k-1}\right)\left(Z_{\alpha/2} + Z_{\beta}\right)^2\right\}}{ln\left(\frac{1-CA_0}{1-CA_1}\right)^2}\right] + 2$$

2-tailed test of Cronbach's α coefficient

n = number in sample

k = number of items in scale

$Z_{\alpha/2}$ = Z value for α

Z_{β} = Z value for β

CA_0 = Cronbach's α coefficient at the null hypothesis

CA_1 = Cronbach's α coefficient for scale from literature

For the 11-item DSSI:

$$n = \left[\frac{\left\{\left(\frac{2k}{k-1}\right)\left(Z_{\alpha/2} + Z_{\beta}\right)^2\right\}}{ln\left(\frac{1-CA_0}{1-CA_1}\right)^2}\right] + 2$$

$$= \left[\frac{\left\{\left(\frac{2k}{k-1}\right)\left(Z_{0.025} + Z_{0.20}\right)^2\right\}}{ln\left(\frac{1-CA_0}{1-CA_1}\right)^2}\right] + 2$$

$$= \left[\frac{\left\{\left(\frac{2(11)}{11-1}\right)(1.96 + 2.051)^2\right\}}{ln\left(\frac{1-0}{1-0.71}\right)^2}\right] + 2$$

$$= 16.296, approx\ 17$$

3.5.3 Recruitment and Questionnaire Administration

Potential participants for this pilot study were recruited as a convenience sample through poster advertisements and the professional and personal networks of the larger study team. Posters were hung in public places such as libraries and community centres, and contained information about the study and the pilot study-specific email address participants could contact if they were interested. Investigators on the larger study team also approached potential participants with a pre-set script asking if they would be

interested in participating; the script included the pilot study-specific email address and asked participants to contact this email address if they were interested. Once participants expressed interest via the pilot study-specific email address, they were provided with the link to the questionnaire. This link included the Letter of Information on the first page because implied consent was obtained for the online questionnaire.

The questionnaire developed for this study was administered online through Qualtrics XM software. After the questionnaire was constructed and finalized, it was coded into Qualtrics XM, as part of the current thesis project. Unique, trackable links were generated in Qualtrics for each email address of participants who agreed to participate in order to be able to identify participants for email follow-up about questionnaire completion. This trackable link was also used to reach out to those participants who indicated that they would be interested in the feedback interviews after they completed the questionnaire. For the feedback interviews, it was necessary to be able to link the participant to their completed questionnaire because this allowed them to review their questionnaire during the interview and allowed the interviewer to ask specific questions about the participant's responses.

3.5.4 Feedback Interview

In order to assess the feasibility and usability of the questionnaire, a feedback interview was included in the design. When conducting only a pilot test of a questionnaire, it is difficult to obtain information on respondent understanding of questions in a consistent way and how the researcher intended, without interviewing participants to specifically ask their thoughts while completing the questionnaire.[173] This feedback interview was similar to a cognitive interview, in that it helped inform the quantitative questionnaire's design, and face and content validity,[171,172,236] and helped assess possible problems with question clarity.[237] This feedback interview differed from a cognitive interview in that the interviewer did not go through every question with the respondent, only generally each section, questions participants did not answer, and questions that the participants or the interviewer identified as being of concern.

3.5.4.1 Audio Transcripts

All the feedback interviews were audio recorded, without video and sent to Transcript Heroes[238] for verbatim transcription. The feedback interviews were conducted through Western University Zoom or via phone with the participants having access to their completed questionnaire either through a password protected PDF document or secure screen sharing on the Western University Zoom account. The feedback provided by participants was used to provide recommendations to the study team on further refinement of the questionnaire prior to the larger study being conducted.

3.5.4.2 Interview Guide

The interview guide (see Appendix D) was written to include general questions for each of the questionnaire sections with the wording adjusted to fit each section of the questionnaire, along with specific questions written to ask about questions of possible concern, or wording that may have caused variation in responses, or participants indicated they had difficulties answering. The general questions for each of the sections were:

- When we ask about your, the Factor (e.g., physical health) were the questions we asked consistent with what, the Factor (e.g., physical health) means to you?
- Was there anything that you did not understand and would have liked further clarification on? This could include instructions, questions, and options for your responses.
- Was the language easy to understand?
- Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
- Thinking about the questions asking you to “choose all that apply” – these are questions where you could choose more than one response – did you find at least

one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

There were also probing questions for questions that were not answered, including:

- Did you find the question unclear?
- Did you find the question to be worded awkwardly?

Questions about specific items of concern, or those expected to cause variation among responses, or those that may be unclear or difficult to answer were also created. These were similar in specificity to the following example:

Thinking about the question asking you to type in the number of times you visited your healthcare provider in the past year, did you find this question easy to answer or would it be easier to choose from a list of options?

3.6 HSREB Submission

In order to obtain approval from the Western University's Health Sciences Research Ethics Board (Western HSREB), I, with guidance from my supervisors and the larger team, wrote the required materials and online application for submission. Approval from Western HSREB was received on June 2, 2023, for project number 122300 (see Appendix E for the final approval letter). The process of completing the application included writing the study rationale and protocol, Letter of Information/Consent forms (see Appendix F) for both the questionnaire and feedback interview, developing the feedback interview guide, constructing the questionnaire, and writing the email and telephone scripts. After finalization, the consent forms and questionnaire were coded in Qualtrics XM software. All of these components underwent several rounds of revisions prior to submission to ensure they met all of Western HSREB's requirements to the fullest.

3.7 Conclusion

The current thesis project was a pilot study to test the methodology of the larger Untold Story project and to assess the validity, reliability and usability of a questionnaire designed to assess the effect of the COVID-19 pandemic on social isolation and loneliness in older adults with multimorbidity. The data from this pilot study were used to identify any problems with data collection, help inform improvements to the questionnaire itself, and help guide the statistical models to be used in the larger Untold Story project. A conceptual model was developed to align with study objectives, for both the pilot study and Untold Story project, and guide development of the questionnaire. The current study employed a convenience sample, having been most efficient for the current pilot study, and sample size aimed at least 25 participants for the questionnaire and five to ten participants for the feedback interviews. Feedback interviews were conducted to ask participants about their experiences while completing the questionnaire. The questionnaire was administered online through Qualtrics XM software, and feedback interviews were conducted over Zoom conferencing software or telephone. Different techniques were employed for assessing validity, reliability and usability of the questionnaire. Validity was assessed with a combination of the Content Validity Matrix, relevant questions in the feedback interview, research team discussions, and testing specific hypothesis about relationships between constructs. Reliability was assessed using the Cronbach's α coefficient for internal reliability of the DSSI and CD-RISC scales. Usability was assessed through the feedback interviews. The results of these assessments, described in the next chapter, were used to test and inform the methodology and questionnaire construction in preparation for the larger Untold Story project.

Chapter 4

4 Results

This chapter will include the results from the current pilot study. The chapter will begin with a description of the sample. This will be followed by a description of the questionnaire's properties, the results of the validity and reliability assessments, and the results of the feedback interviews. This chapter will also include the results of testing the statistical models; that is, the bivariate and logistic regression models, which will be employed in the larger Untold Story of COVID-19 project. The full codebook for the recoded variables can be found in Appendix B.

4.1 Description of Sample

The final sample for the current pilot study included 25 participants who completed the questionnaire; two participants were excluded because it was determined after they completed the questionnaire that they were not eligible. The mean age of participants was 70.3 years (SD=8.9), and 48% were men. The majority of participants self-identified as White (n=23). Most participants were married or in common-law relationships (n=20) and the most common family and household composition was living with a spouse or partner (n=18). Being born in Canada (n=14), speaking only English (n=22), and living in urban areas (n=20) were most common in this sample. Most participants had completed at least some postsecondary education or higher (n=19), with most being retired (n=17) and having annual household income of $60,000 and higher (n=16). About half of participants chose the response of having two chronic diseases (n=12); the remainder had 3 or more chronic conditions. The full description of the sample can be seen below in Table 3.

Of the 25 participants who completed the questionnaire, six completed the feedback interview; one participant with only one chronic condition was included in this sub-sample because it was through the feedback interview that it was discerned that they did not meet eligibility criteria. The mean age of the feedback interview participants was 66

years (SD=4.3), and 50% were men. All participants self-identified as White, spoke English only and were retired. Most participants were married or in common-law relationships, were born in Canada, lived in urban areas, had a bachelor's degree or higher, and had between two and five chronic diseases. Participant responses about annual income varied greatly, with responses chosen ranging across less than $20,000 to over $150,000 annual income.

Table 3. Socio-demographic characteristics of the participants included in the pilot study.

	Completed the Questionnaire (N = 25)[a] N (%)
Age, years, mean (SD)[a]	70.3 (SD 8.9)
Sex	
Male	12 (48%)
Female	13 (52%)
Gender	
Male	12 (48%)
Female	13 (52%)
Indigenous or other cultural minority identity (example: two-spirit)	0% [b]
Something else	0%
Marital Status	
Never married or single	1 (4%)
Married or common-law	20 (80%)
Separated or divorced	3 (12%)
Widowed	1 (4%)
Family and Household Composition[c]	
Living alone	3 (8.6%)
Living with a spouse or partner	18 (51.4%)
Living with minor children	1 (2.9%)
Living with other adult family members	5 (14.2%)
Living with other people	1 (2.9%)
Living with pet(s)	7 (20%)
Race/Ethnicity[a]	
Black	0%
East Asian	0%
Latine	0%
Middle Eastern	1 (4.2%)
South Asian	0%
Southeast Asian	0%
White	23 (95.8%)
Another racial category	0%
Immigration Status	

	Completed the Questionnaire (N = 25)[a] N (%)
Born in Canada	14 (56%)
Born Outside Canada	11 (44%)
Language Spoken	
English only	22 (88%)
French only	0%
Both English and French	2 (8%)
Neither English nor French	1 (4%)
Education	
Less than secondary/high school graduation	0%
Secondary/high school graduation diploma or equivalent	5 (20%)
Trade certificate or diploma from a vocational school or apprenticeship training	1 (4%)
Some postsecondary education (example: college or university courses)	4 (16%)
Postsecondary certificate or diploma (example: from community college)	3 (12%)
Bachelor's degree (example: BA, BSc)	7 (28%)
Graduate or professional degree (example: MA, PhD, LLB, MD)	5 (20%)
Employment	
Working full-time including self-employment (25 hours per week or more)	4 (16%)
Working part-time including self-employment (less than 25 hours a week)	4 (16%)
Temporarily laid off	0%
Temporarily unemployed due to a health-related reason	0%
Unemployed and looking for work	0%
Unemployed and not looking for work	0%
Unable to work due to health	0%
Going to school	0%
Looking after house/family	0%
Retired	17 (68%)
Income[a]	
Under $20,000	1 (4.2%)
$20,000 to $39,999	5 (20.8%)
$40,000 to $59,999	2 (8.3%)
$60,000 to $79,999	3 (12.5%)
$80,000 to $99,999	3 (12.5%)
$100,000 to $149,999	7 (29.2)
$150,000 and over	3 (12.5%)
Geographical Location[a]	
Urban	20 (83.3%)
Rural	4 (16.7%)

	Completed the Questionnaire (N = 25)[a] N (%)
Number of Chronic Diseases	
2	12 (48%)
3	4 (16%)
4	4 (16%)
5	2 (8%)
6	3 (12%)

[a] For variables Age, Family and Household Composition, Race/Ethnicity, Income, and Geographical Location, totals do not add up to 25 as these questions were not answered by all participants.
[b] For response categories that had no responses, 0% was used to indicate this.
[c] For the question asking about family and household composition, participants were allowed to choose more than one response, all that applied to their situation. Therefore, the frequency of responses does not sum to 25, though the percentage of each response from all six possible responses that is included after the frequency sums to 100%.

4.2 Properties of the Questionnaire

4.2.1 Summary of Questionnaire Metrics

Of the 30 personalized links sent to people who expressed interest in the study, 27 participants completed the questionnaire. Two participants were excluded from the final data analysis as they did not meet eligibility criteria (determined post-questionnaire completion), one person chose not to complete it after receiving the link and three follow-up emails, and one person chose to withdraw consent partway through completion of the questionnaire. The participant's data who chose to withdraw consent partway through was not included in the analysis. Nineteen participants completed the questionnaire within a week of receiving the link, or shortly after the first follow-up email was sent one week after the initial invitation.

Time to complete questionnaire: Nineteen participants took 30 minutes or less to complete the questionnaire, two participants took between 31 and 60 minutes, and two participants took over an hour to complete. The personalized links allowed for participants to open the questionnaire, begin completing it, leave and then return at a later time. This was the case for two participants; they appeared to have completed the questionnaire over the course of a few days because time stamps showed that they started

it one day and finished it several days later, and the number of minutes computed to completion sums to over 24 hours.

Missing Data: Overall, there was not much missing data, though there were a few places where participants chose not to answer the questions or accidentally skipped them. For the CD-RISC scale, three participants were excluded from the scale score variable due to missing data points. Two participants only had one missing response, which were for different questions, and one participant chose not to answer the whole scale. The age variable had two missing data points, as two people chose not to answer question 70 asking the year they were born. One person chose not to answer question 42 asking about family and household composition. One person chose not to answer question 74 asking about race/ethnicity. Of the 11 individuals who responded that they were not born in Canada, only three indicated the year they first came to Canada in question 76. Question 81, asking about geographical location, was answered by all participants apart from two. Question 80, asking about income, was answered by all participants, except for three, who skipped the question, but completed all other questions.

4.2.2 Validity of the Questionnaire

4.2.2.1 Content Validity

Content validity was assessed using the Content Validity Matrix, and through questions from the feedback interview asking about adding or removing questions, and asking if the questionnaire questions aligned with what participants were expecting to be asked. Specific results of the Content Validity Matrix can be seen in Table 4 below. The team employed multiple discussions and questionnaire iterations to ascertain if each question was asking what was intended. The results of these discussions were captured in the Content Validity Matrix. The domains for this Content Validity Matrix refer to the concepts from the conceptual model and are labelled as the concepts from Figure 3 shown in Section 3.2 *Conceptual Model Development*. A review of the matrix indicates that each question or item corresponded to only one concept from the conceptual model, as is the goal in questionnaire construction.[225] As the questions appear in the order of the

questionnaire in the matrix below, when reviewing the concepts each question corresponds to, it can be seen that section groupings of the questions are consistent with the conceptual model. Evidence for consistency across these groupings is seen through the clustering of X's across the overarching concepts of health and healthcare, lifestyle factors, social and cultural factors, socio-demographic factors, resilience, social isolation and loneliness.

Table 4. Content Validity Matrix for Untold Story Pilot Questionnaire.

Item	**Concept**								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
1. In general, how is your health?	**X**								
2. In general, how is your mental health?			**X**						
3. The following is a list of chronic conditions. Chronic conditions are defined as those that you have had for at least 6 months and that have been diagnosed by a health care professional. Please check all chronic conditions that you have.	**X**								
4. Approximately how many prescription medications do you take on a regular basis?	**X**								
5. If you normally wear corrective glasses and/or contact lenses, please assume you are wearing your corrective glasses and/or contact lenses when answering the following question. Would you consider yourself to have a visual impairment?	**X**								
6. If you normally use hearing aids/devices, please assume you are using your hearing aids/devices when answering the following question. Would you consider yourself to have a hearing impairment?	**X**								
7. Your mobility TODAY	**X**								
8. Your self-care TODAY	**X**								
9. Your usual activities TODAY (example: work, study, housework, family or leisure activities)	**X**								
10. Your pain/discomfort TODAY	**X**								

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
11. Your anxiety/depression TODAY			**X**						
12. Click on the scale to indicate how your health is TODAY.	**X**								
13. Have you had COVID-19? Please indicate "yes" if you were either formally diagnosed with COVID-19 or if you believe you had COVID-19 but were not formally diagnosed.							**X**		
14. If you had COVID-19, have you experienced any long COVID symptoms? Please select any Long COVID symptoms that apply:							**X**		
15. Have you received any COVID-19 vaccines?	**X**								
16. If yes, to the best of your recollection, how many doses have you received?	**X**								
17. Do you provide assistance to another person because of a health condition or limitation?	**X**								
18. Do you receive assistance from family, friends, or neighbours because of a health condition or limitation that affects your daily activities?	**X**								
19. Have you experienced the death of a loved one (examples: family, friend) or a pet in the past three years?					**X**				
20. Do you have a regular health care provider? By this, we mean one health professional that you regularly see or talk to when you need care or advice for your health.	**X**								
21. If yes, please choose the best answer. Is that regular health care provider a...?	**X**								
22. Approximately how many times have you seen this provider in the past year?	**X**								
23. Taking everything about COVID-19 into account, how would you describe the consequences of COVID-19 on you?							**X**		
24. How worried are you personally about COVID-19 at present?							**X**		
25. On average, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed.)		**X**							
26. How satisfied or dissatisfied are you with your current sleep pattern?		**X**							

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
27. How many days per week do you get 30 minutes or more of light-to-moderate physical activity? Examples: walking, gardening, golfing, light or moderate recreational activities, muscle strength/endurance activities		**X**							
28. Currently, which of the following best describes your smoking habits?		**X**							
29. How many drinks of alcohol do you drink in an average week? (1 standard drink = 12 oz. Beer, 5 oz wine, 1.5 oz alcohol)		**X**							
30. How often in the past 12 months have you had four (4) or more drinks of alcohol on one occasion?		**X**							
31. Currently, which of the following best describes your cannabis use? (smoking cannabis, vaping cannabis, cannabis edibles etc.)		**X**							
32. Please indicate how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt. I am able to adapt when changes occur.			**X**						
33. I can deal with whatever comes my way.			**X**						
34. I try to see the humorous side of things when I am faced with problems.			**X**						
35. Having to cope with stress can make me stronger.			**X**						
36. I tend to bounce back after illness, injury, or other hardships.			**X**						
37. I believe I can achieve my goals, even if there are obstacles.			**X**						
38. Under pressure, I stay focused and think clearly.			**X**						
39. I am not easily discouraged by failure.			**X**						
40. I think of myself as a strong person when dealing with life's challenges and difficulties.			**X**						
41. I am able to handle unpleasant or painful feelings like sadness, fear, and anger.			**X**						

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
42. Which of the following best describes the dwelling in which you live?						**X**			
43. How many people live in your household including yourself?					**X**				
44. What is your current living arrangement? Please select all that apply					**X**				
45. How do you usually travel locally; for example, to go to appointments, grocery shopping or meeting with friends?						**X**			
46. How safe do you feel in your neighbourhood?					**X**				
47. How would you describe your sense of belonging to your local community?					**X**				
48. Please check the organizations and/or activities in which you participate or visit.					**X**				
49. Other than members of your family, how many people in your local area do you feel you can depend on or feel very close to?								**X**	
50. How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?								**X**	
51. How many times did you talk to someone (friends, relatives or others) on the telephone or another communication platform like Zoom, Skype, or Facebook in the past week? That is they either contacted you, or you contacted them?								**X**	
52. About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?								**X**	
53. Does it seem that your family and friends (people who are important to you) understand you?								**X**	
54. Do you feel useful to your family and friends (people important to you)?								**X**	
55. Do you know what is going on with your family and friends?								**X**	
56. When you are talking with your family and friends, do you feel you are being listened to?								**X**	

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
57. Do you feel you have a definite role (place) in your family and among your friends?								**X**	
58. Can you talk about your deepest problems with at least some of your family and friends?								**X**	
59. How satisfied are you with the kinds of relationships you have with your family and friends?								**X**	
60. Do you often feel lonely?									**X**
61. How often are you able to confide in someone close to you?									**X**
62. What steps do you take to avoid feeling lonely? Please select up to three strategies you use most often.									**X**
63. Please share with us any specific resources you use to avoid feeling lonely (e.g., participating in a virtual book club):									**X**
64. Do you have access to the Internet at home?					**X**				
65. How would you rate the internet connection in your home?					**X**				
66. Do you have a smartphone that you use for personal use? A smartphone is a mobile phone that performs many of the functions of a computer, typically having a touchscreen interface, Internet access, and an operating system capable of running downloaded applications, e.g. Apple iPhone and Samsung Galaxy					**X**				
67. Do you use any social networking websites (e.g. Facebook) or apps (e.g. Zoom or FaceTime) to communicate with friends and family?					**X**				
68. In what year were you born?				**X**					
69. What sex were you assigned at birth, meaning on your original birth certificate?				**X**					
70. Which best describes your current gender identity?				**X**					
71. Currently, which of the following best describes you?				**X**					
72. Please select the racial category or categories with which you primarily identify. (Select all that apply)				**X**					
73. Where were you born?				**X**					

Item	Concept								
	Physical Health Factors	Health Related Behaviours - Lifestyle Factors	Psychological, Psychiatric, and Cognitive Factors	Socio-demographic Factors	Societal/ Cultural Factors	Social Environmental Factors	COVID-19 Related Factors	Social Isolation	Loneliness
74. In what year did you first come to Canada to live?				**X**					
75. Can you speak English or French well enough to conduct a conversation?				**X**					
76. What is the highest level of education that you have completed?				**X**					
77. What is your current employment situation?				**X**					
78. Which of the following categories best represents your total household income for the year ending December 31, 2022?				**X**					
79. Please provide us with the first three digits of your postal code:						**X**			

4.2.2.2 Construct Validity

Six hypotheses were tested to assess the construct validity of the questionnaire, as described in Section 3.5.1.2, subsection *Construct Validity Hypotheses Tested*. These hypotheses were tested using correlations, independent sample t-test, and Fisher's exact tests as appropriate, using a minimum value of p=0.05 chosen *a priori* for a significant association between the variables. Table 5 presents the results from the hypotheses testing. None of the results were statistically significant. The direction of the association between resilience and loneliness was in the expected direction, while not statistically significant. The correlation between resilience and multimorbidity was not in the expected direction. The directions of the other associations could not be ascertained due to the small sample size and distribution of variables in this sample. For each Fisher's Exact test pair *post hoc* Cramér's V tests were conducted.

Table 5. Construct validity testing through correlation of construct pairs chosen a priori.

Construct Pair	Correlation Coefficient (p-value)	T-test T-value (df, p-value)	Fisher's Exact p-value (Cramér's V)
Social isolation and loneliness			0.470 (0.1561)
Multimorbidity level and social isolation			0.735 (0.3819)
General health and social isolation			0.436 (0.4645)
General mental health and loneliness			0.709 (0.2758)
Resilience and loneliness		0.6946 (18, 0.2481)	
Resilience and multimorbidity level	0.0155 (p=0.9453)		

4.2.3 Reliability of the Questionnaire

Questionnaire reliability was assessed using the Cronbach's α coefficient for internal reliability and was computed for the DSSI and CD-RISC scales. This was done because these were the two previously validated scales included in the current questionnaire that had Cronbach' α coefficient values in the literature that could be used for comparison. The Cronbach's α coefficient for the DSSI in this questionnaire was 0.86. The Cronbach's α coefficient for the CD-RISC in this questionnaire was 0.93. These values were both close to the ones from the literature of 0.71[184] for the DSSI and between 0.86[194] and 0.88[196] for the CD-RISC.

4.2.4 Qualitative Results from Feedback Interviews

Of the 27 participants who completed the questionnaire, 20 expressed interest in the feedback interview portion of the study, and six interviews were conducted as saturation was quickly reached, with participants having similar feedback about the questionnaire.

Generally, participant feedback was positive about the questionnaire, consisting of positive remarks about the construction and clarity of language. Participants found the questions to align with their expectations of what was being asked, the flow of the questionnaire to be easy to follow, and the language clear. Participants also found the

response options to be appropriate and were able to find at least one response option that fit their situations for each question. Additionally, participants found the questions where they were asked to type in numbers to be easy to manage, apart from having to look up information such as the number of COVID-19 vaccinations they had received. Though, for the question asking about the number of doctor's visits in the past year, three participants typed in words, instead of numbers, precluding inclusion of their responses to these questions in the analysis.

Participants identified some areas of improvement for the questionnaire. These included adding a "prefer not to answer" option for question 80 asking about household income in case someone would choose not to disclose this information. There were also suggestions of making language clearer in some instructions or response options, though most of these were for the validated EQ-5D-5L and DSSI scales meaning that making changes could affect the scales' validity. The specific suggestions and corresponding responses can be seen in summary Table 6 below. Detailed changes for improving the questionnaire before launch of the full study will be discussed in Section 5.3 *Suggested Questionnaire and Methodology Changes* in the following chapter, Chapter 5 Discussion.

Table 6. Suggestions from six feedback interviews and responses.

Section	Question # and Summary of Feedback	Response
Health and Healthcare	Q15e: Possibly unclear to what the word "depression" was referring; i.e., clinical depression or just sadness	Cannot add clarification or change as part of EQ-5D-5L scale.
	Q16: *We would like to know how good or bad your health is TODAY. On the next screen, you will see a scale numbered 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine*. Possibly unclear instructions because position of scale was not on next screen.	Correct by saying: "Below, you will see a scale numbered 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine."

Section	Question # and Summary of Feedback	Response
	Additional suggested question: Ask about diet.	After consultation with nutritionist, determined no valid short scale for diet; insufficient space within questionnaire to add longer diet scale.
	Additional suggested question: More COVID-19 related questions generally; for example, if family members had COVID-19, or how impacted financial situation, or had a loved one in long-term care during pandemic.	Add additional specific question following Q27: "Thinking about different impacts mentioned above, could you please indicate the impacts that have been the most lasting. Please select all that apply." Response options may include: a family member was infected with COVID-19; financial situation impacted; had a loved one in long-term care during pandemic; worry about family members' safety and health; other: please specify
	Ask about spiritually as part of health, beyond organizations attended.	Add the following questions from (https://www.questionpro.com/blog/religion-survey-questions/)[239] "To what level, do you consider yourself to be religious?" Response options: Not religious Slightly religious Moderately religious Very religious Don't know "To what level, do you consider yourself to be spiritual?" Response options: Not spiritual Slightly spiritual Moderately spiritual Very spiritual Don't know Adapted: "How often do you turn to your religion or spirituality to help you deal with problems in your life?" Response options: Never

Section	Question # and Summary of Feedback	Response
		Rarely Sometimes Often Always
Health-Related Behaviours-Lifestyle Factors	No concerns were raised by participants in this section of questions.	Nothing to address
Resilience	No concerns were raised by participants in this section of questions.	Nothing to address
Societal/Cultural/ Environmental Factors	Q42: *What is your current living arrangement? Please select all that apply* Include response option about renters living with respondent	Add "renter" as a second example under response option: "I live with other unrelated people".
	Additional suggested question: Q45: *How would you describe your sense of belonging to your local community?* Offer two versions of Q45, one about community belonging pre-COVID and one post COVID-19	Divide this question into two and ask the following instead: "How would you describe your sense of belonging to your local community **before** the COVID-19 pandemic (before March 2020)?" followed by: "How would you describe your sense of belonging to your local community **now** (**after** the COVID-19 pandemic)?" The response options will remain the same for both questions as before: Very strong; Somewhat strong; Somewhat weak; Very weak
Social Isolation	Q50: *How many times did you talk to someone (friends, relatives or others) on the telephone or another communication platform like Zoom, Skype, or Facebook in the past week? That is they either contacted you, or you contacted them?* Separate out the response option that refers to friends, family and relatives into	Cannot add clarification or change it as part of DSSI scale.

Section	Question # and Summary of Feedback	Response
	three separate response options.	
	Q51: *About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?* Maybe ask for time period longer than 1 week as during the summer may be less social activities than other parts of year.	Cannot add clarification or change it as part of DSSI scale.
Loneliness	Remove duplicate option of "once very few months" from question 61: *How often are you able to confide in someone close to you?*	Corrected for full study questionnaire
Technology Use	Q68: *Do you use any social networking websites (e.g. Facebook) or apps (e.g. Zoom or FaceTime) to communicate with friends and family?* Maybe parse out strictly social media and communication software like Zoom	After consultation with study team, determined no separate question as it was deemed unnecessarily repetitive.
	Additional suggested questions: More technology related questions; for example, if people feel they have the skills required to communicate using technology, or if they used novel technology not previously used during the pandemic or their feelings about technology like Zoom generally.	From the Computer Literacy Test[240], include the question: "On a scale from one to seven, one being extremely comfortable and 7 being extremely uncomfortable, how comfortable do you feel with **technology in general**? Response options: 1(Extremely Comfortable) 2(Very Comfortable) 3(Comfortable) 4(Mixed) 5(Uncomfortable) 6(Very Uncomfortable) 7(Extremely Uncomfortable)

Section	Question # and Summary of Feedback	Response
Socio-demographic Factors	Q 79: *What is your current employment situation?* Maybe parse out retired to partly retired and fully retired in case person retired but still does some work.	Remove response option "retired". Add response options, "partly retired" and "fully retired".
	Q 80: *Which of the following categories best represents your total household income for the year ending December 31, 2022*? Consider adding "prefer not to answer" category.	Will not add the "prefer not to answer" category as it is clear that participants can choose not to answer any question.
Questionnaire Flow and General Suggestions	Consider adding a comment box at the end of each section or the entire questionnaire for participant clarification.	Will add a comment box, only at the end of the entire questionnaire, with the question: "If you would like to provide any additional information, please feel free to type in the box below."

4.3 Testing Statistical Models for the Larger Untold Story of COVID-19 Study

The statistical code for the current pilot study and the models tested from it will be used in the statistical analysis of the larger Untold Story project.

4.3.1 Bivariate Analysis

Bivariate analysis was conducted to determine which independent variables to include in the logistic regression models for each of the outcomes of social isolation and loneliness. T-tests were conducted for numeric variables and Fisher's exact tests were conducted for categorical variables. The full results can be seen in Table 7 for the t-tests and Table 8 for the Fisher's exact tests below. For constructing the model with social isolation as the dependent variable, the variables that reached statistical significant from the t-tests were MM (number of chronic conditions) (p=0.0415), CD_RISC_tot (resilience) (p=0.0265), and places (number of places or activities attended) (p=0.0186) and from the Fisher's exact tests were q17 (diagnosis with COVID-19) (p=0.039), q44 (neighbourhood safety)

(p=0.019), and q45 (community belonging) (p=0.026). For constructing the model with loneliness as the dependent variable, the variables that reached statistically significant from the t-tests were places (number visited) (p=0.0024) and from the Fisher's exact tests were q8 (visual impairment) (p=0.010) and q80 (income) (p=0.033).

Table 7. Results of the t-tests from the bivariate analysis.

Social Isolation			
	t value	Degrees of Freedom	*p*
MM (number of chronic conditions)	1.813	23	0.0415*
EQ5D_index (quality of life summary index value)	0.874	23	0.2957
sumlCV19 (number of long COVID_19 symptoms)	-0.362	11	0.6379
num_dr (number of doctor visits in past year)	0.522	18	0.3040
CD_RISC_tot (resilience)	2.058	20	0.0265*
q41_1 (number of people in household)	-3.777	23	0.9995
places (number of places or activities attended)	2.213	23	0.0186*
age	1.425	21	0.0845
yrsCan (number of years in Canada)	This t-test did not run as not enough variation in the yrsCan variable; therefore, could not make two testable groups		
Loneliness			
	t value	Degrees of Freedom	*p*
MM (number of chronic conditions)	1.575	20	0.0655
EQ5D_index (quality of life summary index value)	0.826	20	0.2094
sumlCV19 (number of long COVID_19 symptoms)	-0.549	8	0.701
num_dr (number of doctor visits in past year)	-0.389	16	0.6487
CD_RISC_tot (resilience)	0.695	18	0.2481
q41_1 (number of people in household)	1.036	20	0.1563
places (number of places or activities attended)	3.167	20	0.0024*
age	0.069	19	0.4729
yrsCan (number of years in Canada)	This t-test did not run as not enough variation in the yrsCan variable; therefore, could not make two testable groups		

*denotes statistical significance, minimum p=0.05, chosen *a priori*

Table 8. Results of the Fisher's Exact p-values from the bivariate analysis.

Social Isolation	
	Fisher's Exact p-value
q4 (general health)	0.436
q5 (general mental health)	0.426
q8 (visual impairment)	1.000
q9 (auditory impairment)	1.000
q17 (diagnosis with COVID-19)	0.039*
q21 (if participant provides care to someone)	0.544
q22 (if participant receives care from someone)	1.000
q23 (death of loved one)	1.000
q24 (having a regular healthcare provider)	1.000
q27 (overall COVID-19 consequences)	0.424
q28 (COVID-19 worry)	0.323
q30 (sleep duration)	0.301
q31 (sleep quality)	0.596
q32 (exercise)	1.000
smoke_status_fq (former smoker who quit)	0.560
smoke_status_os (occasional smoker)	1.000
smoke_status_cds (current daily smoker)	1.000
q34 (average drinking)	0.756
q35 (binge drinking)	0.410
cann_status_fu (former use of cannabis)	This Fisher's Exact tests did not run as not enough variation in the cannabis status variable; therefore, could not make two testable groups for this dummy variable
cann_status_ou (occasional use of cannabis)	1.000
cann_status_cdu (current daily use of cannabis)	This Fisher's Exact tests did not run as not enough variation in the cannabis status variable; therefore, could not make two testable groups for this dummy variable
q44 (neighbourhood safety)	0.019*
q45 (community belonging)	0.026*
q80 (income)	1.000
Loneliness	
	Fisher's Exact p-value
q4 (general health)	0.308
q5 (general mental health)	0.709
q8 (visual impairment)	0.010*
q9 (auditory impairment)	1.000
q17 (diagnosis with COVID-19)	0.293
q21 (if participant provides care to someone)	0.535
q22 (if participant receives care from someone)	0.210
q23 (death of loved one)	1.000
q24 (having a regular healthcare provider)	0.182

q27 (overall COVID-19 consequences)	0.627
q28 (COVID-19 worry)	0.105
q30 (sleep duration)	0.292
q31 (sleep quality)	0.264
q32 (exercise)	1.000
smoke_status_fq (former smoker who quit)	1.000
smoke_status_os (occasional smoker)	1.000
smoke_status_cds (current daily smoker)	1.000
q34 (average drinking)	0.709
q35 (binge drinking)	0.701
cann_status_fu (former use of cannabis)	This Fisher's Exact tests did not run as not enough variation in the cannabis status variable; therefore, could not make two testable groups for this dummy variable
cann_status_ou (occasional use of cannabis)	1.000
cann_status_cdu (current daily use of cannabis)	This Fisher's Exact tests did not run as not enough variation in the cannabis status variable; therefore, could not make two testable groups for this dummy variable
q44 (neighbourhood safety)	0.204
q45 (community belonging)	0.301
q80 (income)	0.033*

*denotes statistical significance, minimum p=0.05, chosen *a priori*

4.3.2 Logistic Regression

Two logistic regression models were conducted, one with social isolation as the dependent variable, and the other with loneliness as the dependent variable. The reference categories for the logistic regression models were: for social isolation, 0 as not being socially isolated (with 1 being socially isolated), and for loneliness, 0 as not being lonely (with 1 being lonely). The full tabulation of the results can be seen in Table 9 below. Of note, for the social isolation model the q17 variable, diagnosis of COVID-19, was omitted because of the small sample size leaving one cell on the Fisher's Exact test empty. For the loneliness model, q8, visual impairment, was omitted because of the small sample size leaving one cell on the Fisher's Exact test empty, and the places variable was also omitted because there was not enough variation in the responses. Though these variables did not run in this pilot study, any variable may prove significant in the full Untold Story study.

The model for the social isolation dependent variable was:

$$\log\left[\frac{P\left(MM + \mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}} + places + q44 + q45\right)}{1 - P\left(MM + \mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}} + places + q44 + q45\right)}\right]$$
$$= -2.056 - 0.736_{MM} - 0.128_{\mathrm{CD_RISC_tot}} - 0.007_{places} + 2.064_{q44} + 1.098_{q45}$$

The transformation to get from the log odds to the odds ratio estimates.

$$P\left(MM + \mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}} + places + q44 + q45\right)$$
$$= \frac{e^{(-2.056 - 0.736_{MM} - 0.128_{\mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}}} - 0.007_{places} + 2.064_{q44} + 1.098_{q45})}}{1 - e^{(-2.056 - 0.736_{MM} - 0.128_{\mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}}} - 0.007_{places} + 2.064_{q44} + 1.098_{q45})}}$$

$$P\left(MM + \mathrm{CD}_{\mathrm{RISC}_{\mathrm{tot}}} + places + q44 + q45\right) = 0.128$$
$$+ 0.479_{MM} + 0.879_{\mathrm{CD_RISC_tot}} + 0.993_{places} + 7.881_{q44} + 3.000_{q45}$$

The model for the loneliness dependent variable was:

$$\log\left[\frac{P(q80)}{1 - P(q805)}\right] = 1.928 - 0.986_{q80}$$

The transformation to get from the log odds to the odds ratio estimates.

$$P(q80) = \frac{e^{(6.876 + 0.373_{q80})}}{1 - e^{(6.876 + 0.373_{q80})}}$$

$$P(q80) = 6.876 + 0.373_{q80}$$

Typically, the results for these logistic regression models would be interpreted, though, because the 95% confidence intervals cross one for all odds ratio estimates, none can be interpreted as statistically significant, and no further interpretation will be provided.

Table 9. Results of the logistic regression.

Social Isolation Outcome[a]			
Predictor/Independent Variables	**OR**	**SE OR**	**95% CI**
MM (number of chronic conditions)	0.48	0.38	0.10 - 2.29
CD_RISC_tot (resilience)	0. 88	0.16	0.62 - 1.26
places (number of places or activities attended)	0.99	0.71	0.24 - 4.06
q44 (neighbourhood safety)	7.88	21.81	0.03 - 1785.02
q45 (community belonging)	3.00	5.51	0.08 - 109.88
_cons	0.13	0.84	3.20×10^{-7} - 51051.98
Loneliness Outcome[b]			
Predictor/Independent Variables	**OR**	**SE OR**	**95% CI**
q80 (income)	0.37	0.21	0.12 - 1.14
_cons	6.88	12.59	0.19 – 249.26

[a] Refence category for social isolation outcome variable was “not social isolated”.
[b] Refence category for loneliness outcome variable was “not lonely”.

4.3.3 Assessment of Model Fit

In order to assess the fit of the logistic regression models, collinearity and binned residual plot assessments were conducted. The collinearity assessment showed that the variance inflation factor (VIF) values were all under five for both the social isolation and loneliness models. The VIF values for the social isolation were 1.07 for MM (number of chronic conditions), 1.78 for CD_RISC_tot (resilience), 1.43 for places (number of places or activities attended), 1.60 for q44 (neighbourhood safety), and 2.38 for q45 (community belonging) independent variables, respectively. The VIF value for the q80 (income) independent variable in the loneliness model was 1.00. As these values are under 10, this indicates that there is not high correlation or collinearity between the independent variables of either model, leading to the conclusion that both models are well-fitted. Binned residual plots could not be generated for either model, with the Stata/SE 18 software having given specification errors for the number of bins. This may be due to a

small sample size causing instability of the generated bins.[241] The code for this assessment is written and can be seen in Appendix C and will be used for analysis of model fit in the larger Untold Story project.

4.4 Conclusion

The results of this pilot study indicate that the questionnaire developed for the larger Untold Story project is valid and reliable in the population of interest for the study. The average age of respondents was around 70 years of age, with the number of chronic diseases ranging from two to six, and most lived in urban areas. The questionnaire was found to have content validity through assessment with the Content Validity Matrix Construct validity assessments of pairwise correlations, independent sample t-tests, and Fisher's Exact tests were inconclusive. Participants from the feedback interviews generally had positive feedback about the questions asked and how they flowed throughout the questionnaire. In order to test statistical models for the larger Untold Story project, first bivariate analysis was conducted to ascertain which independent variables to include in the logistic regression models. In the final social isolation model, the MM (number of chronic conditions), CD_RISC_tot (resilience), places (number of places or activities attended), q44 (neighbourhood safety), and q45 (community belonging) independent variables were included. In the loneliness the q80 (income) independent variable were included. In the tests of collinearity for model fit, both models had no VIF value above 10, indicating good model fit.

Chapter 5

5 Discussion

This chapter discusses the results of the pilot study and the implications of the pilot study results for the larger Untold Story. The chapter will conclude with the strengths and weaknesses of this study and recommended future directions.

5.1 Summary of Findings

The current thesis employed quantitative and qualitative methods to assess the validity and reliability of the questionnaire constructed for the larger Untold Story project. Content validity was evaluated using the Content Validity Matrix and feedback interviews. Construct validity was assessed through testing hypotheses about expected relationships among study variables. Questionnaire reliability was assessed through computation of the Cronbach's α coefficient for the DSSI and CD-RISC scales. Feedback interviews were used to assess the usability and feasibility of the questionnaire.

Review of feedback interview responses and the Content Validity Matrix showed strong content validity of the questionnaire. Cronbach's α coefficients demonstrated the reliability of the DSSI and CD-RISC scales in this questionnaire. In feedback interviews, participants indicated that the questionnaire elements fit with what they expected to be asked and that they found the questionnaire easy to understand and complete. These findings indicate that the administration of this online questionnaire is both usable and feasible in an older population.

The statistical code for the regression models that will be used in the larger Untold Story project was also tested. While none of the independent variables reached statistical significance in either model, the results do indicate relationships between the independent variables included in the models and the dependent variables, social isolation and loneliness. Regression modelling results indicate that the overall odds of being social isolated increased with greater numbers of chronic diseases, being less resilient, attending

less activities, and feeling less safe in or connected to local communities. The overall odds of being lonely decreased with each additional increment of $10,000 of annual income.

5.2 Questionnaire Properties

5.2.1 Questionnaire Validity

The questionnaire was found to have strong content and face validity. Results from construct validity assessments were inconclusive. This was assessed through a combination of quantitative and qualitative methods. Content validity was assessed through the Content Validity Matrix and showed that each item in the questionnaire only corresponded to one concept from the conceptual model, which Streiner (1993)[225] described as an ideal outcome of utilizing this matrix. As good quality questionnaires are rooted in theoretical concepts, the Content Validity Matrix helps to check that the questions chosen for the questionnaire map to the theoretical concepts the researcher wants to measure.[225] Construction of this matrix also helps researchers find and remove redundant questions and change or clarify ambiguous ones to reduce participant confusion.[225] The mapping of each question to the concept illustrates content validity, and the ability to easily identify which concept each question corresponds to demonstrates face validity.[225] The construct validity assessments, comprised of correlations, independent sample t-tests, and Fisher's Exact tests, were not statistically significant. This lack of statistical significance is likely due to the current study's convenience sample not having enough variation across the variables.

A positive association was hypothesized between social isolation and loneliness because they are closely linked, yet distinct concepts.[26,28] There was not a statistically significant association, and the Cramér's V value was 0.16, which is interpreted as a weak association.[242] There is evidence that individuals may experience both, either, or neither social isolation nor loneliness suggesting social isolation and loneliness are distinct concepts, which appears to be the case in this pilot study.[26] As well, upon visual inspection of the data, in this sample, there was little variation in these two variables,

with most individuals being neither lonely nor socially isolated. This small variation would explain the lack of an association.

A positive association was hypothesized between the count of chronic diseases and social isolation because social isolation has been found to be associated with increased morbidity risk[3,4] and chronic diseases such as cardiovascular disease[32,33] and dementia.[4,34,35] The Cramér's V value was 0.38, which is interpreted as a moderate association between variables.[242] Cardiovascular disease[32,33] and dementia [4,34,35] are most specifically cited in the literature as being associated with social isolation, though in the current study having a cognitive impairment that prevented someone from responding to the questionnaire was an exclusion criteria. Therefore, the relationship between number of chronic diseases and social isolation may not have been as strong as anticipated because only one of these two specific chronic diseases was represented in the current sample.

Since a common risk factor for social isolation is poor health,[30, 31] a negative association was hypothesized between these variables. This relationship had a Cramér's V value of 0.46, which is moderately strong[242]; however it did not reach statistical significance. This may be because most of this sample rated their general heath as being good and were not classified as socially isolated with the DSSI scale. Therefore, there was not much variation in the distribution of responses.

Since higher loneliness levels are associated with psychological disorders,[124] a negative association was hypothesized to exist between these variables. This relationship and had a Cramér's V value 0.28, just falling into the moderately strong association classification;[242] however it did not reach statistical significance. This may be because most of this sample rated their general mental health as being fair or good and were not classified as lonely with the loneliness measure from the UK Biobank. Therefore, there was not much variation in the distribution of responses.

A negative association was hypothesized between resilience and loneliness because perceived social support has been found to reduce psychological burden, and to be protective during stressful life events, increasing resilience.[145] The difference in mean CD-RISC scores between those who were lonely and not, while not statically significant, showed that individuals who were not lonely had a higher mean CD-RISC score, indicating that this relationship was in the expected direction. This relationship may not have reached statistical significance in the pilot study because most of this sample were not classified as lonely according to the loneliness measure from the UK Biobank. Therefore, there was not much variation in the distribution of responses.

While the correlation coefficient for resilience and multimorbidity level was not statistically significant, it was positive, instead of the hypothesized negative. A negative correlation was hypothesized because more resilient individuals tend to have less prevalence of hypertension, lower BMI, and fewer psychological diseases,[140] and higher levels of resiliency have been associated with optimal physical and mental health.[138] The results of the current correlation may be weakly positive because of multimorbidity resilience, where individuals adapt to illness-related adversity and are able to regain wellness in their lives.[118] This phenomenon was observed during the COIVD-19 pandemic in older individuals,[118] who were the population of interest for this pilot study.

The feedback interviews contributed to assessing content and face validity through asking participants if the questions from the questionnaire asked them what they were expecting to be asked. Overall, participants indicated that the questions they were asked in each section corresponded with what they were expecting to be asked based on the title and introduction of each section. There were a couple of comments regarding the Health and Healthcare section indicating that more questions about COVID-19 should be asked, as should a question about spiritual health.

These feedback interviews were designed based on cognitive interviews, which help assess face and content validity[171,172,236] though asking participants about their thoughts while completing questionnaires.[173] The only difference between the approach taken in

this study and that of cognitive interviews was that the feedback interviews did not go through each individual question with participants. These types of interviews can assess if the questionnaire is measuring what it was meant to measure[171] and if participant interpretations of questions aligned with researcher intent when constructing them.[172] Based on the suggestions offered by participants the feedback interviews met this purpose as they offered insight into how participants perceived and answered questions.

5.2.2 Questionnaire Reliability

Reliability was assessed using the Cronbach's α coefficient, the most often used objective measure of reliability.[231] Study results showed reliability of both the DSSI and CD-RISC scales in the population of interest. The values for the DSSI and CD-RISC fell within the recommended range of 0.70 to 0.95 for values of Cronbach's α coefficient, indicating strong reliability.[231] The value of 0.86 for the DSSI was higher than 0.71[183] from the literature and the value of 0.93 for the CD-RISC scale was larger than the range of 0.86[194] and 0.88[196] found in the literature. The values found in this study may be higher than those in the literature because the questionnaire contained many items,[231,233] and the value of Cronbach's α coefficient decreases with shorter questionnaires.[231,233] The high values of the Cronbach's α coefficient in the current study are not of concern because the previously validated scales themselves are 11 and 10 items in length, for the DSSI and CD-RISC, respectively. Therefore, the length of the overall questionnaire should have had little impact on the computed Cronbach's α coefficients. As well, based on the variance inflation factor analysis described in Section 5.4.2.1 *Model Fit Assessments*, the questionnaire items do not appear to have high correlations with each other, reducing the possibility of this being a reason for high Cronbach's α coefficient values.[231]

5.2.3 Usability – Results from Feedback Interview

Overall, feedback about questionnaire clarity and flow from all six participants who participated in the feedback interviews assessing questionnaire usability and feasibility

was positive. Participants said the questions were well written and easy to understand, including one participant whose first language is not English; this participant found reading and completing the questionnaire to be easier than the spoken interview. The one participant who chose not to complete the survey and asked to withdraw their data did not provide a reason for this decision. Apart from minor suggestions during the feedback interviews, there were no major changes suggested, indicating that the questionnaire was well constructed. Generally, cognitive interviews are used to assess questionnaire validity, usability, and feasibility because they can help identify questionnaire content and construct validity,[171] questionnaire clarity,[171] inclusion of diverse response options,[171] and if participants' interpretation of questions align with the researchers' intent for those questions.[172] The feedback interviews conducted during the current pilot study were in line with these recommendations and found valuable information about usability, feasibility and clarity of this questionnaire.

5.3 Suggested Questionnaire and Methodology Changes

Table 6 in Chapter 4 *Results* summarizes the changes that are discussed below.

5.3.1 Questionnaire Related Suggestions

One of the key inclusion criteria was for participants to have at least two chronic conditions; many potential participants who were eligible for study participation thought they would not qualify but realized they would have been eligible after they were given a list of common chronic diseases. This is particularly important for common diseases such as hypertension and diabetes where many patients may not know about their disease status due to low public awareness[243] or may discount these conditions if they do not find them troublesome. To reduce this confusion during the full study, a list of common chronic diseases will be provided to potential participants during recruitment.

There were a couple of minor problems with online questionnaire administration that will be addressed in the full study through the University of Waterloo Survey Research Centre[59] who are contracted for the full Untold Story project questionnaire

administration. A couple of the participants experienced technical difficulties, though these were quickly resolved. These types of challenges should be further reduced as the University of Waterloo Survey Research Centre[59] will provide technical support for Qualtrics XM as part of their contract. Most of the questions that were not answered were by accident. The Survey Research Centre[59] will provide a note to participants when they miss a question which may help reduce accidentally missed questions. This note would remind participants that there are questions they have not answered but specify that if they chose not to answer those questions, they can still submit the questionnaire and their responses will be included in the analysis. This message would be tied to flags at each unanswered question and together be displayed at the end of the questionnaire, before the submit page.

The one question from the EQ-5D-5L that was not answered because of confusing wording was clarified. The confusion was in the instructions, not the actual question, thus the wording will be modified to be clearer. Apart from the instructions for one of the EQ-5D-5L questions, there were a few other places where clarity was suggested, for example in the response options for the questions asking about living arrangements and employment. These small, suggested clarifications that were unrelated to validated scales were added. Though, most of the suggestions had to do with previously validated scales, and therefore, cannot be implemented out of concern for changing the properties of these validated scales. For example, one participant suggested clarifying what was meant by "depressed" in one of the EQ-5D-5L questions, and there were mentions of changing the timeframe in the DSSI questions from one week to longer or further clarifying family and friend groups in the DSSI. There was one common suggestion from a few of the participants, which involved asking more questions about COVID-19, which will be implemented in the full study by adding one additional question. This question will be a follow-up to the one asking about negative COVID-19 impacts and will have a list participants can choose from to clarify the actual impacts if they answer as COVID-19 having a "negative" or "very negative" impact on them.

5.3.2 Data Management and Variable Coding Related Suggestions

Overall, there were little missing data, indicating interest in completing the questionnaire on behalf of the participants, despite its length. There was only one participant who had multiple missing data points, likely from questions they chose not to answer, as the questionnaire was programed to allow for this. As there were few overall missing data points, data analysis was not strongly affected. Of note was the difference in calculating DSSI and CD-RISC scores. The Working Paper for the DSSI[213] gives recode values for missing values that are included in the calculation of the scale score, therefore data from all participants can be included. There are no corresponding recode values for the CD-RISC,[219] therefore, if even one question in the scale is not answered, all resilience data from that participant will be excluded. There were only three scores that could not be calculated, two only had one missing question, with no discernible pattern between them, and one person appeared to have chosen not to answer the entire scale. This may be a problem in the full study, as the sample size for this variable would decrease greatly if the same proportion of people miss or not answer questions from this section. A possible solution to this problem will be to include the previously mentioned flagging of unanswered questions because the single missing data points may have been accidental. This may be the case because the CD-RISC questions are coded to appear as a table in the online questionnaire, and in going through all 10 statements it is possible to miss one.

In the current analysis, the variable corresponding to Long COVID-19 symptoms was treated as a sum of the symptoms chosen by participants who responded as having had COVID-19. The question asking about symptoms followed the question asking about diagnosis through a skip pattern, thus, answers were only recorded for those who had COVID-19. This may be a problem for data analysis of the full study, as the sample size of this variable may be greatly reduced. A way to mitigate this problem would be to treat this variable as categorical with three levels, no COVID-19, COVID-19 with no Long COVID-19 symptoms and COVID-19 with one or more Long COVID-19 symptoms,

with the no COVID-19 category being the reference. This way the whole study sample's responses can be included.

As well, three data points for the number of doctor visits in the past year variable had to be excluded from the current analysis because these participants typed in values that were not easily transformed into numeric characters. One participant of the three also typed three to four visits, making it difficult to choose which number to include. To resolve this problem for the full study, the type-in field will be kept, though the University of Waterloo Survey Research Centre[59] will be asked if they can translate the word version of numbers into their numeric counterparts. Also, the following scoring rule will be applied in the case a range is given: take the mean of the range and if necessary, round down to the nearest whole number.

Another variable that was difficult to construct was the multimorbidity or number of chronic diseases variable. This is because of the "other" option allowing for participants to type in more than one chronic disease in this field. For example, one participant had one chronic disease counted less as they wrote two in the "other" field and there was no effective way to count the additional one. The coding of the variable counts each option selected and cannot count typed in options. A possible solution to this problem will be to ask the University of Waterloo Survey Research Centre[59] to count the conditions in the other category. If not possible, the research team will be responsible for recoding the "Other" category into separate conditions and creating the multimorbidity count variable.

5.4 Model Testing for Larger Untold Story of COVID-19 Study

This section discusses the results of model building, running, and evaluation conducted in the current thesis project. While the main objectives of the current pilot study were to assess the validity, reliability and usability of the questionnaire, these models were constructed to test the statistical code for the larger Untold Story project. The methodology employed will be used in the full study. The relationships that were found

between variables align with expectations from the literature review discussed in Chapter 2, though definitive conclusions cannot be drawn from these results about what models should be used in the full Untold Story study.

5.4.1 Bivariate Analysis

As part of the statistical model building process, bivariate analysis was conducted. Relationships that were found to be statistically significant are reported here, recognizing that the relationships found in the full study may differ. In the interest of being comprehensive for the purposes of this thesis, the statistically significant results are discussed below with incorporation of findings from the literature. Bivariate analyses in the form of t-tests for numeric variables and Fisher's exact tests for categorical variables were conducted to assess which variables should be included in the logistic regression models. A significance level of p=0.05 was chosen *a priori* for all tests. The variables that were found to be statistically significant are in line with what was expected from existing study findings discussed in the literature review in Chapter 2. These variables should not be the only ones included in the models for the full Untold Story study because any variable tested here has the potential to be statistically significant in the full study as they were all chosen based on evidence from the literature, except for the COVID-19 related variables, and the full study will be powered to detect differences.

The variables from the bivariate analysis that were statistically significant for inclusion in the social isolation logistic regression model were MM (number of chronic conditions), q17 (COVID-19 diagnosis), CD_RISC_tot (resilience), places (number of places or activities attended), q44 (community safety), and q45 (community belonging). The association of the aforementioned variables with social isolation align with previous literature on social isolation. Increasing numbers of chronic diseases,[30,31] and morbidity and mortality[3,4] are associated with increased levels of social isolation.[3,4,30,31] Lower levels of resilience[145] and community safety and belonging[180] are both associated with higher levels of social isolation and loneliness, through a person's social support network which is connected to their community.[145,180,244] Fewer places visited has been found to

be associated with both social isolation and loneliness,[244] which is why the Fisher's Exact tests being statistically significant for both models for the places (number of places or activities attended) variable is in line with previous findings. Social isolation and loneliness are closely related concepts yet distinct,[26,28] therefore the variables related to social isolation and loneliness are expected to be similar and, in some cases, overlap in the results of the bivariate analysis.

The variables from the bivariate analysis that were statistically significant for inclusion in the loneliness logistic regression model were q8 (visual impairment), places (number of places or activities attended), and q80 (income). Multiple studies have found an association between lower income levels and higher levels of multimorbidity,[17,18,19,20,21,23,108] and multimorbidity is associated with higher levels of social isolation and loneliness.[3,4] This may possibly reflect the mediating role of multimorbidity in the association between income and loneliness. As well, sensory impairment, particularly visual impairment, has been associated with higher levels of loneliness and has to do with lower quality of life.[180]

5.4.2 Logistic Regression

Logistic regression analyses were conducted for both of the dependent variables, social isolation and loneliness. Three variables that were statistically significant in the bivariate analyses were removed across the two models because the regression did not run properly when included. This was because there was not enough variation in these variables due to the small sample size. Therefore, the variables included in the social isolation model were MM (multimorbidity), CD_RISC_tot (resilience), places (number of places or activities attended), q44 (community safety), q45 (community belonging) and the variable included in the loneliness model was q80 (income). Neither of the logistic regression models had significant results, as all the 95% confidence intervals for the odds ratio estimates crossed one, therefore, no further interpretation will be provided.

5.4.2.1 Model Fit Assessments

Testing of model fit for both logistic regression models was completed. Collinearity assessments showed good model fit for both, as there was no variance inflation factor value above five, and above ten are the values that become concerning. There is little between item correlation between the independent variables included in the two logistic regression models. Binned residual plots were another test of model fit to be employed, though this could not be done in the current study because the sample size was too small, possibly making the bins unstable, and precluding graphing of the residuals.[241] If the models are well fitted, the binned residual plots should show residuals clustered around zero, having no discernible pattern to the residuals.[245] This code has been included for use in the larger study to assess model fit, seen in Appendix C.

5.5 Strengths and Limitations

5.5.1 Limitations

A limitation of the recruitment strategy was participant confusion regarding chronic conditions. Thus, individuals who would have qualified for the pilot study may have self-excluded because they did not think they had chronic conditions. As mentioned in Section 5.3 *Suggested Questionnaire and Methodology Changes*, this will be mitigated in the full study by providing potential participants with a list of common chronic diseases during recruitment. Another limitation was related to the convenience sample as participants were limited in geographical location to mainly Southwestern Ontario. However, this pilot study provided the basis for the larger Ontario-wide full study, and the full study will recruit from Ontario-wide panels through the University of Waterloo Survey Research Centre.[59] The sample size of 25 exceeded the sample size calculation of 17, which was calculated to meet the main objectives of the current thesis and was robust enough for assessing questionnaire properties. The bivariate analysis and logistic regression models were meant to test the statistical code to be used for data analysis for the larger Untold Story project, and sample size of the current pilot study precludes definitive conclusions from being drawn from these specific analyses.

5.5.2 Strengths

Strengths include the systematic approach used for all aspects of the study. The conceptual model and questionnaire were each developed from rigorous appraisals of the literature. As the pilot study was testing the data collection processes as well, it closely resembled the study procedures developed for the larger Untold Story project. Another strength of the current study was that all three key study objectives were achieved. The first was to design a questionnaire assessing the impact of the COVID-19 pandemic on older adults with multimorbidity, related to their social isolation and loneliness. This was done through development of the conceptual model used to guide questionnaire construction, and the iterative process to have the final questionnaire be 80 questions long and take 30 minutes to complete. The second objective was to pilot test the questionnaire to assess its properties. The current pilot study employed mixed methods techniques that are best practice for assessing questionnaire validity, reliability, usability, and feasibility. The questionnaire was found to be valid, reliable, usable, and feasible through a combination of validity and reliability analyses and participant feedback. The third objective was to analyze the pilot sample data, which was done to test the statistical code for the larger Untold Story project.

5.6 Implications of Findings

Pilot studies need to be conducted with the same vigour as corresponding full-scale studies.[56] Best practice is for pilot studies to have the same methodology[174] and sample[171] as the full-scale study, but at a reduced scale.[174] Effective pilot studies assess validity and reliability of the questionnaire and can provide insight into study methodology through smaller scale testing[55,56,57, 58] and variables for analysis.[55] Participant experiences completing the questionnaire,[171,172] and identification of participant understanding of questionnaire items can be assessed through cognitive interviews,[171,172] usually conducted during the pilot or pre-test phase of a study.[173] The current pilot study included all these components to evaluate and test the questionnaire in preparation for the larger Untold Story project. The sample recruited for the current study, while a convenience sample,

was chosen based on the same inclusion and exclusion criteria as will be used for the larger Untold Story project. Questionnaire validity was assessed through a mixed methods approach, incorporating correlations, independent sample t-tests, and Fisher's Exact tests to assess construct validity, the Content Validity Matrix for assessing content validity and feedback interviews to help assess face and content validity. Questionnaire reliability was assessed through computation of the Cronbach's α coefficient for the DSSI and CD-RISC scales. Feedback interviews also helped with refining the questionnaire for the large-scale study and understating participant experiences completing the questionnaire. The models tested in the current study were prepared for analysis of the larger Untold Story project.

5.7 Future Directions

Moving forward, the questionnaire will be further refined in preparation for the full study. This includes clarifying where possible, both instructions and response options, and including more specific questions about COVID-19. With validity and reliability demonstrated for a sample of community dwelling adults aged 50 years and over with multimorbidity, the Untold Story project can confidently move on to the next phase, the full questionnaire study. With the statistical code written and tested for model building and assessment for the larger Untold Story project, data analysis of the full study data can proceed shortly after data collection. This will help with rapid development of the COVID-19 Patient-Provider Exchange in Primary Care (COPE_PC) tool for primary care physicians to better identify older adults at risk of social isolation and loneliness as we emerge from the COVID-19 pandemic. With this tool, physicians will be better able to recommend tools and practices to patients to hopefully help them reduce their social isolation and loneliness.

5.8 Conclusions

The questionnaire designed and pilot tested for the Untold Story project illustrated strong content and face validity, and reliability for a sample of community dwelling adults aged

50 years and over with multimorbidity. Results from construct validity assessments were inconclusive. Feedback interviews conducted with participants also provided positive feedback about the construction and language used in the questionnaire, with some suggestions that will be applied to the questionnaire when it will be administered during the full Untold Story study. The current pilot study was designed with rigour and best practice techniques for assessing questionnaire properties, leading to confidence in the conclusions drawn from these assessments. Suggestions for improving recruitment, clarifying questions and instruction, and including a couple new questions to the questionnaire that arose from the current pilot study will be implemented in the coming full scale Untold Story study. In preparation for this larger Untold Story project, bivariate analysis for model building, logistic regression, and model fit analyses were conducted to test the statistical code that will be used for these analyses with the full study dataset. With development of the COPE_PC tool, hopefully physicians will be better able to make recommendations for patients to help them reduce their social isolation and loneliness.

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Appendices

Appendix A: Version validation comparison tables for the Duke Social Support Index and Connor-Davidson Resilience Scale

Table A.1. Version validation comparison for the Duke Social Support Index

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
Goodger et al., 1999 Australia	11 item	Cross-sectional	Reliability/ internal consistency; test-retest reliability; construct validity; concurrent validity	Community-dwelling adults, aged 70 and over	Interview	Cronbach's a; intraclass correlation and Pearson Product moment correlations (test-retest reliability); Pearson correlations (construct validity); Spearman correlations (concurrent validity); factor analysis with varimax rotation; one-way ANOVA; multiple regression model	"In comparison to other scales, the 11-item DSSl has the advantages of brevity, ease of administration and was well received and accepted by older people in this study." "Construct validity of the DSSI is supported by theoretically consistent correlations obtained between the DSSI and measures of health, quality of life and loneliness and significant independent associations between social support and quality of life in the stepwise regression model. Loneliness was not significantly associated with social interaction but was related to satisfaction and the total score."
Hou et al., 2018 China	23 item	Cross-sectional	Construct validity	Rural community-dwelling women, aged 16 and over	Interview	Confirmatory factor analysis	intimate partner violence prevalence rate - 29.05%; "results supported our a priori hypotheses that (1) social support had direct effects on

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
							physical, psychological and sexual violence; (2) objective economic status had indirect effects on physical, psychological and sexual violence through social support; and (3) education had indirect effect on psychological violence through social support and objective economic status";
Jia and Zhang 2012 China	23 item	Case-control	Reliability/ internal consistency; construct validity	Individuals who died of suicide and community living controls from the same counties; both groups aged 15–34 years	Interview	Cronbach's a; Confirmatory factor analysis; Multiple linear regression	"In the suicide sample, the DSSI alpha was .84. In the control sample, alpha was .79"; "In both groups, personal annual income and low anxiety related to social support."; "In the suicide sample, lack of education and hopelessness related to low social support. In controls, in contrast, gender, marriage, and party affiliation related to social support."
Koenig et al., 1993 United States	35 to develop the 11 item	Validation Cross-sectional	Reliability/ internal consistency; construct validity; convergent validity	Community-dwelling adults, aged 60 and over	Questionnaire	Factor analysis with orthogonal rotations; followed by factor analysis with orthogonal and oblique rotations for the 23 and 11 item scales; (for factor structure); Cronbach's a;	"Although reliability for the 7-item scale was lower in the sick elderly group than in any other group, this was also true for the original 10-item scale." Cronbach's a for the 2 above scales was 0.71. "Factor analysis of the 23-item index ... using

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
						Correlations between subscales	orthogonal rotation, revealed 4 major factors." "Performing the same analysis for the 11- item index in both chronically ill elderly individuals and the entire population revealed only a single factor."
Pan et al., 2020 China	23 item	Case-control	Reliability/ internal consistency; criterion validity; construct validity	Individuals who died of suicide and community living controls from the same neighbourhood both groups aged 60 years or older	Face-to face interview	t-tests or Kolmogorov–Smirnov Z tests -continuous variables; $\chi 2$-tests - categorical variables; Cronbach's a - DSSI; Spearman correlations between ULS-6 and three dimensions of DSSI and the whole DSSI; Confirmatory factor analysis	"corrected Cronbach's a of the DSSI was .89 in completed suicides and .90 in controls"; "total DSSI and three subscales were all negatively related to loneliness in male, female, and total suicide and control samples, which verified satisfactory criterion validity"; "confirmatory factor analysis was conducted to confirm the three-factor model"; "DSSI had satisfactory reliability and acceptable validity in Chinese culture"
Powers et al., 2004 Australia	11 item	Cross-sectional	Reliability/ internal consistency; construct validity	Women randomly selected from national health insurance database; aged 70 to 75 years	Questionnaire	Exploratory factor analyses with principal components method with orthogonal (varimax) and oblique rotations (promax) - DSSI; Kaiser's measure of sampling adequacy;	DSSI and its factors, measuring satisfaction with social support and social interaction, showed good reliability and construct validity"; "high completion rates observed in this study support the choice of the DSSI and indicate that it was easy to complete

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
						Cronbach's alpha; correlations; multiple linear regression	and acceptable to older women, the majority of whom had no post-school qualifications"
Wardian et al., 2013 United States	10 item	Cross-sectional	Reliability/ internal consistency; construct validity	Community-dwelling adults, aged 18 and over	Telephone interview	Secondary analysis of 2010 AHS data; exploratory factor analysis; confirmatory factor analysis; multiple linear regression; Cronbach's alpha	"robustness of the results across subgroups provides confidence in the reliability of the results. The subscales are not to be independently used as reliable measurements for each dimension of social support; however, combined, they provide a valid measurement of two important constructs related to social support"
Steinman et al., 2020 United States	10 item	Pre-post evaluation study	Construct validity, convergent validity, internal consistency	Community-dwelling adults, aged 50 to 96 years	Telephone interview	Correlations; paired t tests; Cohen's d effect sizes; regression models; Bonferroni correction	Cronbach's alpha - 0.76 for DSSI; "PEARLS participants were more socially connected at 6-month follow-up than at baseline"; "PEARLS participants reported receiving encouragement and social support from their PEARLS providers, and appreciated having someone to talk to about issues they were experiencing."
Zhang et al., 2012 China	23 item	Case-control	Criterion validity	Individuals who died of suicide and living controls, aged 15 to 34 years	Proxy interview	Descriptive statistics; correlations; scale score comparisons	"Social Support scale had moderate negative correlations with both hopelessness (r =

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
							−0.41, p < 0.001) and anxiety (r = −0.38, p < 0.001)." " Social Support scales and their factor components were found to be significantly lower in suicide sample than they were for controls"

Table A.2. Version validation comparison for the Connor-Davidson Resilience Scale

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
Blanco et al., 2019 Spain	10 item	Cross-sectional	Reliability/ internal consistency; construct validity; convergent validity	Caregivers of dependents, mean age of 55.3	Questionnaire	Descriptive statistics; Cronbach's alpha; exploratory factor analysis; confirmatory factor analysis; Pearson's bivariate correlations	Cronbach' a = 0.86; "Kaiser–Meyer–Olkin (KMO = 0.876) sample adequacy measure, and Bartlett's sphericity index ($x2(45) = 975.999$; $p < .001$) indicated a good fit to the data"; "Regarding convergent validity, we found significant and direct correlations of the resilience score in the CD-RISC 10 with the self-esteem score ($r = .416$, $p < .001$) and the social support score ($r = .228$, $p < .001$), and a significant and inverse correlation between the CD-RISC 10 score and the emotional distress score ($r = –.311$, $p < .001$)."
Bruwer et al., 2008 South Africa	25 item	Cross-sectional	Reliability/ internal consistency; divergent/	High school attending youth, no specific age	Questionnaire	Confirmatory factor analysis; descriptive	"Positive correlation between [perceived

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
			discriminant validity of Multidimensional Scale of Perceived Social Support	information given		statistics; Cronbach α; Missing value analysis	social support] and resilience, and a negative correlation between [perceived social support] and depression, exposure to community violence, and other potentially life-threatening trauma." "MSPSS has divergent/discriminant validity (as supported by a negative correlation between MSPSS and BDI scores)."
Burns et al., 2010 Australia	25 item	Longitudinal population-based cohorts	Construct validity - looked at the correlation of CD-RISC Positive and Negative Affect Schedule (PANAS) and Personal Mastery Scale (PMS)	Young and middle-aged cohorts (aged 20 to 24 and 40 to 44)	Questionnaire	Exploratory factor analysis (principal axis factoring)	Discrimination between the four constructs at the item level is present; moderate factor correlations - Moderate to strong associations with measures of prior and current symptoms of depression and anxiety and prior affect
Campbell-Sills et al., 2006 United States	25 item	Validation Cross-sectional	Construct validity - looked at the correlation of CD-RISC and the Big Five	Undergraduate students (mean age 18.87 yrs, SD = 1.55)	Questionnaire	Hypothesis testing via correlational and multiple regression methods; Hierarchical	CD-RISC scores were statistically significantly related to three of the five factor model

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
			personality traits			multiple regression for testing a model of personality, coping, and resilience	personality constructs (r>0.30)
Genet & Siemer 2011 United States	25 item	Case-control	Convergent validity between instruments	Introductory Psychology students, mean age of 19	Questionnaire	Correlations	"Cognitive flexibility, as measured by a conventional task-switching paradigm, predicted level of trait resilience is one of the first demonstrations of a positive relation between executive control and measures of trait resilience in an adult population."
He et al., 2013 China	25 item	Cross-sectional	Model validity	Burn patients from five general hospitals in Xi'an, aged 17 to 35	Questionnaire	Confirmatory factor analysis for assessing structural model validity; Maximum likelihood estimation to test the structural model	Positive relationship between optimism and subjective well-being
Kuiper et al 2019 Netherlands	Comp of 25, 10, 2 item versions	Cross-sectional psychometric study of prospectively collected data	Convergent and divergent validity between instruments	Individuals with SCI, at authors' rehab clinic, aged 18 and older	Questionnaire	Cronbach's α for internal consistency; "Spearman's correlation coefficients between these versions and	"Scores on the CD-RISC 2 were somewhat higher compared to the other versions and showed a skewness

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
						four convergent reference measures, and five divergent reference measures"; Intraclass correlation coefficients	outside the acceptable range. Cronbach's α value was highest (0.90) for the CD-RISC 25 and lowest (0.66) for the CD- RISC 2. For the CD-RISC 10 and CD-RISC 2, all questions showed a correlated item-total correlation value of >0.30.CD-RISC 10 scored most positively on the validity test with 89% of the expectations confirmed; three out of four convergent validity tests and all five divergent validity tests. CD-RISC 25 and CD-RISC 10 model accounts for the highest explained variance (81.5%) as confirmed by the correlation between those scale"
Liu DWY et al., 2015 Australia	25 item	Longitudinal	Factorial invariance	Community dwelling participants from - PATH	Questionnaire	Multiple group analysis; Confirmatory	"Unconstrained unidimensional CD-RISC factor structure fit

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
				Through Life Project; aged 20–24, 40–44, 60–64 at baseline		Factor Analysis; chi-square test; Root mean square error of approximation	comparatively well between gender across the lifespan. Constraining factor loadings between groups indicated no significant decrement in fit between gender or age cohorts. This is an important finding since it suggests that the items reflect a consistent underlying latent construct. However, we also found that constraining item means and residuals to be equivalent between gender for each age cohort indicated a significant decrement in fit in comparison with the freely estimated model."
Ni MY et al., 2016 Hong Kong, China	25 item, 2 item	Longitudinal	Reliability/ internal consistency; convergent validity, discriminant validity	Participants from - FAMILY Cohort, a prospective population-based cohort study; aged 20 and older	Questionnaire	Mixed model; Spearman correlations; Cronbach's a	"Cronbach's a for the full scale (CD-RISC) was 0.97. For young adults, middle-aged adults, and older adults, a's was 0.96, 0.97 and 0.98, respectively. Cronbach's a for the

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
							abbreviated scale (CD-RISC2) was 0.79, and a's for young adults, middle-aged adults, and older adults was 0.73, 0.76, and 0.86, respectively." "The CD-RISC and CD-RISC2 were significantly correlated in the direction expected with depressive symptoms, family harmony, and family functioning (Table 2), with comparable correlation coefficients. ... [C]orrelations of CD-RISC and CD-RISC2 with alcohol consumption were <0.1."
Noghan et al., 2018 Iran	25 item	Cross-sectional	Reliability/ internal consistency	Hemodialysis patients referred to Besat and Shahid Beheshti Hospitals of Hamedan, aged 18 and older	Questionnaire	Two-tailed independent t-test; Chi-square test to compare qualitative variables between the patients; Logistic regression with conditional backward method	Cronbach's a = 0.76. "Resilience is related to the therapeutic regimen compliance and in patients with greater resilience scores; the chance of therapeutic regimen

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
							compliance is increase."
Pietrzak et al., 2014 United States	10 item	Cross-sectional	Model validity	Participants from National Health and Resilience in Veterans Study (NHRVS) aged 60 to 96	Questionnaire	Structural equation modeling; Confirmatory factor analysis for assessing structural model validity; "Multiple regression analysis of correlates of successful aging"; "Bivariate correlations between latent and observed indicator variables associated with scores on the latent factor of successful aging"	82.1% of veterans in the study rated themselves aging successfully. Found several variables related to successful aging in this population
Scali et al., 2012 France	10 item	Retrospective cohort	Reliability/ internal consistency	Women from a previous comparative study of breast cancer survivors and women without previous history of cancer by the authors, aged 18 to 75	Questionnaire	Chi-square test for categorical variables and Wilcoxon's test for quantitative variables to compare socio-demographic variables between the two groups; multinomial logistic regression model as non-	"Level of resilience measured with the CD-RISC-10 was negatively associated with the presence of current psychiatric disorder and positively and independently associated with previous history of trauma."; Cronbach's a = 0.88 for internal

Article citation	Version of the scale used	Study Type	Type of Validity	Population	Measures	Analysis used	Results
						normal distribution	consistency in study sample.
Wingo et al., 2010 United States	10 item	Cross-sectional	Model validity	Urban community-dwelling, low-income, highly traumatized, predominantly African American individuals, aged 18 to 75 years	Questionnaire	Descriptive statistics; Multiple linear regression; SAS regression diagnostics for checking model fit	Childhood abuse and other trauma exposures significantly contributed to depressive symptom severity; resilience significantly mitigated it. Resilience moderated depression severity both as main effect and interaction with other trauma exposures.

Appendix B: Codebook for recoded variables

Dependent Variables

Social isolation: soc_isol (binary) – 0 is NO, 1 is YES

Loneliness: lone (binary) – 0 is NO, 1 is YES

Independent Variables

Multimorbidity: MM (count, continuous) – ranges from 2 to 6 in this study

Quality of Life: EQ5D_index (continuous) – EQ5D responses calculated as a single index value

Number of doctor visits in past year: num_dr (count, continuous) – needed recoding as appears as a string variable in Stata and needs to be modified by "destring" command to be able to use the number

*Number of Long COVID-19 symptom*s: sumlCV19 (count, continuous) – sum how many long COVID-19 symptoms, restricted to individuals who responded that they had COVID-19, ranges from 0 to 3 in this study

Smoking status: smoke_status (categorical) – dummy variables made with non-smoker as reference category; smoke_status_fq (former smoker who quit), smoke_status_os (occasional smoker); smoke_status_cds (current daily smoker)

*Cannabis us*e: cann_status (categorical) – dummy variables made with no cannabis use as reference category; cann_status_fu (former use of cannabis), cann_status_ou (occasional use of cannabis), cann_status_cdu (current daily use of cannabis)

Resilience: CD_RISC_tot (count, continuous) – ranges from 9 to 33 in this study

Number of places or activities attended: places (count, continuous) – sum of responses chosen, ranges from 1 to 10 in this study

Age: age (continuous) – variable calculated from responses to what year born, 2023 subtract response to question 70

Number of years in Canada: yrsCan (continuous) – variable calculated from responses to what year came to Canada, 2023 subtract response to question 76

Postal Code/urbanicity: Q81 (dichotomous) – based on: if 0 in FSA, then rural, in rest urban in this study

Appendix C: Full Stata/SE 18 Statistical Code

```
log using Thesis Code_230818

**UNTOLD STORY OF COVID-19 PILOT STUDY CODE**
**UNTOLD STORY OF COVID-19 – ANALYSIS DESCRIPTION**
/* This code is written to describe the variables from the questionnaire, they are treated as the question number but have the corresponding label ahead of the code itself.
        Then the variables are generated that need to be modifications of the values from the questionnaire, for example, age is calculated from the year participants indicate being born in.
        This is followed by the computation of the EQ-5D index, and scoring of the CD-RISC, DSSI, and loneliness scales.
        The Cronbach's alpha coefficient and construct validity assessments were used to assess questionnaire properties.
        The last part of the code is the model building, running, and testing for the full study. This starts with the bivariate analysis that will be used to determine the independent/predictor variables to be included in the logistic regression models. The variables that will be included are the ones that have statistically significant test results at p=0.05. The logistic regression models will be run, and then to assess model fit collinearity assessment will be run and binned residual plots constructed.*/

/*NOTE: the entire code is ordered by increasing complexity of analysis
        it starts with simple descriptive statistics, then moves into generating the variables needed for further computations, in the order they appear in the questionnaire, followed by the commands for model building and model fit assessment*/

**NOTE: within each section, creation of variables follows the order of the questionnaire**

/*NOTE: need to use mrtab for the questions with multiple response options to display, in the descriptive statistics and for any additional tabulations of the questions in the questionnaire that ask participants to "check all that apply"
        cannot mix numeric and string variables, cannot tabulate with this command the written "other" options*/

*****************************************************************
**FREQUENCY TABLES - DESCRIPTIVE STATS**
**table by variable, so by question or group of questions in a scale, they are listed in the order of the questions of the questionnaire**

**general health**
table q4
**general mental health**
table q5
```

Multimorbidity (MM)
mrtab q6_1 q6_2 q6_3 q6_4 q6_5 q6_6 q6_7 q6_8 q6_9 q6_10 q6_11 q6_12 q6_13 q6_14 q6_15 q6_16 q6_17 q6_18 q6_19 q6_20 q6_21 q6_22
** # prescription meds**
table q7
visual and auditory impairment
table q8
table q9
EQ-5D-5L
table q11 q12 q13 q14 q15 q16_1
COVID-19 diagnosis
table q17
long COVID-19 symptoms
mrtab q18_1 q18_2 q18_3 q18_4 q18_5 q18_6 q18_7 q18_8
COVID-19 vaccines
table q19 q20_1
care providing
table q21 q22
death of loved one
table q23
regular healthcare provider
table q24 q25 q26_1
COVID-19 effects
table q27 q28
sleep
table q30 q31
exercise
table q32
smoking status
table q33
drinking
table q34 q35
cannabis use
table q36
resilience
mrtab q38_*
dwelling type
table q40
** # in household**
table q41_1
living arrangement/household composition
mrtab q42_*
transportation
table q43

```
**neighbourhood safety**
table q44
**community belonging**
table q45
**activities participate in**
mrtab q46_1 q46_2 q46_3 q46_4 q46_5 q46_6 q46_7 q46_8 q46_9 q46_10 q46_11
q46_12
**DSSI**
table q48 q49 q50 q51
table q52 q53 q54 q55 q56 q57 q58
**loneliness**
table q60 q61
**steps to avoid loneliness**
mrtab q62_1 q62_2 q62_3 q62_4 q62_5 q62_6 q62_7 q62_8
**technology use**
table q65 q66 q67 q68
**year born, used for age variable**
table q70_1
**sex assigned at birth**
table q71
**gender**
table q72
**marital status**
table q73
**race**
mrtab q74_1 q74_2 q74_3 q74_4 q74_5 q74_6 q74_7 q74_8 q74_9
**where born**
table q75
**year come to Canada**
table q76
**conversation language**
table q77
**education**
table q78
**employment**
table q79
**income**
table q80
**forward sortation area**
table q81

*************************************************************************
**RECODING/GENERATING VARIABLES ***
```

```
**correlations - just all the questions, or if get an error message saying too many variables then make those variables that can be, into dichotomous or dummy variables**

**GENERATED VARIABLES**
/* the “generate” command creates a new variable as an expression of an existing variable
        allows for manipulation of information into a form that is more convenient for analysis*/

**TIME TO COMPLETION**
generate time = durationinseconds/60
table time
summarize time

**AGE**
generate age = 2023-q70_1
mean age
summarize age

**YEARS IN CANADA**
generate yrsCan = 2023-q76
mean yrsCan
summarize yrsCan

/*these 2 variables were created because smoking status and cannabis use are variables that should be treated as nominal, categorical
        this is because their categories cannot be ordered*/

**SMOKING STATUS**
generate smoke_status_fq = 0 if q33==4
replace smoke_status_fq = 1 if q33==3

generate smoke_status_os = 0 if q33==4
replace smoke_status_os = 1 if q33==2

generate smoke_status_cds = 0 if q33==4
replace smoke_status_cds = 1 if q33==1

table smoke_status_fq
table smoke_status_os
table smoke_status_cds

**CANNABIS USE STATUS**
generate cann_status_fu = 0 if q36==4
```

```
replace cann_status_fu = 1 if q36==3

generate cann_status_ou = 0 if q36==4
replace cann_status_ou = 1 if q36==2

generate cann_status_cdu = 0 if q36==4
replace cann_status_cdu = 1 if q36==1

table cann_status_fu
table cann_status_ou
table cann_status_cdu

**EGEN VARIBALES**
/* the “egen” command creates a new variable as a sum across the rows of a variable that has multiple response options
        allows for manipulation of information into a form that is more convenient for analysis from questions that allow participants to “choose all that apply”
        does not count response options that are string variables, for example the written portion of an “other” category*/

**the rownomiss command gives a sum of not-missing values**

**MULTIOMORBIDITY COUNT**
**sum across the instances of q6**

egen MM = rownonmiss(q6_1 q6_2 q6_3 q6_4 q6_5 q6_6 q6_7 q6_8 q6_9 q6_10 q6_11 q6_12 q6_13 q6_14 q6_15 q6_16 q6_17 q6_18 q6_19 q6_20 q6_21 q6_22)

table MM
summarize MM

**LONG COVID-19 SYMPTOMS**
**sum across instances of q18**
egen sumlCV19 = rownonmiss(q18_1 q18_2 q18_3 q18_4 q18_5 q18_6 q18_7 q18_8) if q17==1
table sumlCV19
summarize sumlCV19

summarize q18_1 q18_2 q18_3 q18_4 q18_5 q18_6 q18_7 q18_8

**ACTIVITIES PARTICIPATE IN - RELATED TO 1st, 2nd, 3rd PLACES**
**places - sum across instances of q46**
egen places = rownonmiss(q46_1 q46_2 q46_3 q46_4 q46_5 q46_6 q46_7 q46_8 q46_9 q46_10 q46_11 q46_12)
```

```
table places
summarize place

**SUMMARIZED VARIABLES**
** the “summarize” command shows additional information about a variable like the quartiles of responses**

**HOUSEHOLD COMPOSITION**

mrtab q42_1 q42_2 q42_3 q42_4 q42_5 q42_6
summarize q42_1 q42_2 q42_3 q42_4 q42_5 q42_6

**STRATEGIES FOR REDUCING LONELINESS**
mrtab q62_1 q62_2 q62_3 q62_4 q62_5 q62_6 q62_7 q62_8
summarize q62_1 q62_2 q62_3 q62_4 q62_5 q62_6 q62_7 q62_8

**RACE**
mrtab q74_1 q74_2 q74_3 q74_4 q74_5 q74_6 q74_7 q74_8 q74_9
**summarize seems to give frequency info for each category**
summarize q74_1 q74_2 q74_3 q74_4 q74_5 q74_6 q74_7 q74_8 q74_9

**********************************************************************
**EQ-5D-5L**
**EQ5D_index is the variable that will be input into the regression model**
**This is now the code from the APERSU website, a creation of the University of Alberta**
**includes APERSU's instructions and comments**

**Canadian EQ-5D-5L Time Tread-off-derived value set**
**This program computes the Canadian preference-weighted index score using self-reported EQ-5D data**

**It is presumed that the data set includes the following five variables**
**will need to rename with our dataset from question numbers to actual var names, included below**
```

*Dimension	Variable Name	Range
*Mobility	MO	1-5
*Self-care	SC	1-5
*Usual activities	UA	1-5
*Pain/discomfort	PD	1-5
*Anxiety/depression	AD	1-5

```
/*where 1 indicates no problems, 2 indicates slight problems, 3 indicates moderate
problems, 4 indicates severe problems, and 5 indicates inability to perform.
The variables containing responses for the five dimensions must be named as above (in
capital letters).
Missing values should be left blank (ie., a "." should not be substituted for a missing
value)
The index score will not be generated when responses are missing for 1 or more of the
five dimensions.*/

**STATA SYNTAX CODE FOR COMPUTATION OF INDEX**
**VALUES WITH CANADIAN VALUE SET**

**rename question numbers to match variable names in above table**
rename q11 MO
rename q12 SC
rename q13 UA
rename q14 PD
rename q15 AD

generate MO45=1 if MO>3
replace MO45=0 if MO<=3
replace MO45=. if MO==.

generate SC45=1 if SC>3
replace SC45=0 if SC<=3
replace SC45=. if SC==.3

generate UA45=1 if UA>3
replace UA45=0 if UA<=3
replace UA45=. if UA==.

generate PD45=1 if PD>3
replace PD45=0 if PD<=3
replace PD45=. if PD==.

generate AD45=1 if AD>3
replace AD45=0 if AD<=3
replace AD45=. if AD==.

generate count1=1 if MO>3
replace count1=0 if MO<=3
replace count1=. if MO==.
```

```
generate count2=1 if SC>3
replace count2=0 if SC<=3
replace count2=. if SC==.3

generate count3=1 if UA>3
replace count3=0 if UA<=3
replace count3=. if UA==.

generate count4=1 if PD>3
replace count4=0 if PD<=3
replace count4=. if PD==.

generate count5=1 if AD>3
replace count5=0 if AD<=3
replace count5=. if AD==.

generate Num45=0 if count1+count2+count3+count4+count5<1
replace Num45=count1+count2+count3+count4+count5-1 if
count1+count2+count3+count4+count5>=1
replace Num45=. if count1+count2+count3+count4+count5==.

generate Num45sq=Num45*Num45

generate EQ5D_index=1.1351-0.0389*MO-0.0458*SC-0.0195*UA-0.0444*PD-
0.0376*AD-0.0510*(MO45)-0.0584*(SC45)-0.1103*(UA45)-0.1409*(PD45)-
0.1277*(AD45)+0.0085*Num45sq

display EQ5D_index

table EQ5D_index

**********************************************************************
**SCORING OF CD-RISC**

recode q38_1(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_1)

recode q38_2(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_2)

recode q38_3(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_3)

recode q38_4(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_4)

recode q38_5(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_5)
```

```
recode q38_6(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_6)

recode q38_7(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_7)

recode q38_8(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_8)

recode q38_9(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_9)

recode q38_10(1=0)(2=1)(3=2)(4=3)(5=4),generate (newq38_10)

generate CD_RISC_tot =
newq38_1+newq38_2+newq38_3+newq38_4+newq38_5+newq38_6+newq38_7+newq3
8_8+newq38_9+newq38_10

**get quartiles with the summarize command**
summarize CD_RISC_tot, detail
table CD_RISC_tot

**********************************************************************
**SCORING OF DSSI**

**need line for "if missing" code as need to tell Stata this**
**recoded directly the values the Duke Social Support Index (DSSI): A Working Paper
(Revised) said to recode the second time to**

recode q48(1=0)(2=1)(3=2)(.=4),generate (newq48)
**if look at working paper - recoded for consistency**

recode q49(1=0)(2=1)(3=1)(4=2)(5=2)(6=3)(7=3)(8=3)(.=3),generate (newq49)

recode q50(1=0)(2=1)(3=1)(4=2)(5=2)(6=3)(7=3)(8=3)(.=3),generate (newq50)

recode q51(1=0)(2=1)(3=2)(4=3)(5=3)(6=3)(7=3)(8=3)(.=3),generate (newq51)

**based on DSSI working paper, no need to recode q52 q53 q54 q55 q56 q57 q58 as
numbers correspond except for the missing values**

recode q52(1=1)(2=2)(3=3)(.=7), generate (newq52)

recode q53(1=1)(2=2)(3=3)(.=7), generate (newq53)

recode q54(1=1)(2=2)(3=3)(.=7), generate (newq54)

recode q55(1=1)(2=2)(3=3)(.=7), generate (newq55)
```

```
recode q56(1=1)(2=2)(3=3)(.=7), generate (newq56)

recode q57(1=1)(2=2)(3=3)(.=7), generate (newq57)

recode q58(1=1)(2=2)(3=3)(.=7), generate (newq58)

generate
DSSI_tot=newq48+newq49+newq50+newq51+newq52+newq53+newq54+newq55+new
q56+newq57+newq58
summarize DSSI_tot, detail
table DSSI_tot

/*will base the dichotomization off of the social interaction scale because it exists in its
entirety in the 11-item DSSI, therefore seems the best way to classify participants
        participants are classified as impaired, or socially isolated if they score 3 or less
on this section, corresponding to "1"*/

generate DSSI_SIS = newq48+newq49+newq50+newq51

generate soc_isol=0 if DSSI_SIS>3
replace soc_isol=1 if DSSI_SIS<=3

table soc_isol
summarize soc_isol

**********************************************************************
**SCORING OF LONELINESS SCALE**
**need to recode q59 and q60 to fit with what UK Biobank says**
recode q60(1=0)(2=1),generate (q60_1)
recode q61(1=0)(2=1)(3=1),generate (q61_1)
generate sumlone = q60_1+q61_1
display sumlone
table sumlone

generate lone=0 if sumlone<=1
replace lone=1 if sumlone==2
table lone

**********************************************************************
**CRONBACH'S ALPHA COEFFICIENT **

alpha [var list for DSSI],std
alpha q48 q49 q50 q51 q52 q53 q54 q55 q56 q57 q58, std
```

```
alpha [var list for CD-RISC],std
alpha q38_1 q38_2 q38_3 q38_4 q38_5 q38_6 q38_7 q38_8 q38_9 q38_10, std
**********************************************************************
**CONSTRUCT VALIDITY ASSESSMENT**
**NOTE: gen_health = q4; gen_ment_health = q5; social isolation = soc_isol; resilience
= CD_RISC_tot; loneliness = lone**

**Use correlation for score (CD_RISC) and count (MM) continuous variables**
scatter CD_RISC_tot MM
pwcorr CD_RISC_tot MM, star(.05) bonferroni sig

**Use independent sample t-test for continuous independent variables and dichotomous
dependent variables soc_isol and lone**
ttest CD_RISC_tot, by(lone)

**Use Chi square for categorical independent variables and dichotomous dependent
variables soc_isol and lone**
tabulate soc_isol lone, chi2 exact expected
tabulate soc_isol MM, chi2 exact expected
tabulate soc_isol q4, chi2 exact expected
tabulate lone q5, chi2 exact expected
tabulate lone CD_RISC_tot, chi2 exact expected
**********************************************************************
**BIVARIATE ANALYSIS**

**independent sample t-tests**

/*q_26_1 asks for the number to be typed in; therefore, Stata imports it as a string
variable, which does not allow for numeric manipulations
        due to this, the “destring” command is needed to make this variable numeric*/

destring q26_1, generate (num_dr) force
table num_dr

**use independent sample t-tests because continuous independent variables and
dichotomous dependent variables soc_isol and lone **

**t-tests**
ttest MM, by(soc_isol)
ttest EQ5D_index, by(soc_isol)
ttest sumlCV19, by(soc_isol)
ttest num_dr, by(soc_isol)
ttest CD_RISC_tot, by(soc_isol)
```

```
ttest q41_1, by(soc_isol)
ttest places, by(soc_isol)
ttest age, by(soc_isol)
ttest yrsCan, by(soc_isol)

ttest MM, by(lone)
ttest EQ5D_index, by(lone)
ttest sumlCV19, by(lone)
ttest num_dr, by(lone)
ttest CD_RISC_tot, by(lone)
ttest q41_1, by(lone)
ttest places, by(lone)
ttest age, by(lone)
ttest yrsCan, by(lone)
```

if the t-test does not run, can use the “table” command like in the example below to see the distribution of the responses for the variable and if there is enough variation to make two groups that can be tested

```
table yrsCan lone
```

**use Chi square tests because categorical independent variables and dichotomous dependent variables soc_isol and lone **

chi^2 tests
does not allow string variables

```
tabulate soc_isol q4, chi2 exact expected
tabulate soc_isol q5, chi2 exact expected
tabulate soc_isol q8, chi2 exact expected
tabulate soc_isol q9, chi2 exact expected
tabulate soc_isol q17, chi2 exact expected
tabulate soc_isol q21, chi2 exact expected
tabulate soc_isol q22, chi2 exact expected
tabulate soc_isol q23, chi2 exact expected
tabulate soc_isol q24, chi2 exact expected
tabulate soc_isol q27, chi2 exact expected
tabulate soc_isol q28, chi2 exact expected
tabulate soc_isol q30, chi2 exact expected
tabulate soc_isol q31, chi2 exact expected
tabulate soc_isol q32, chi2 exact expected
tabulate soc_isol smoke_status_fq, chi2 exact expected
tabulate soc_isol smoke_status_os, chi2 exact expected
tabulate soc_isol smoke_status_cds, chi2 exact expected
```

```
tabulate soc_isol q34, chi2 exact expected
tabulate soc_isol q35, chi2 exact expected
tabulate soc_isol cann_status_fu, chi2 exact expected
tabulate soc_isol cann_status_ou, chi2 exact expected
tabulate soc_isol cann_status_cdu, chi2 exact expected
tabulate soc_isol q44, chi2 exact expected
tabulate soc_isol q45, chi2 exact expected
tabulate soc_isol q80, chi2 exact expected


tabulate lone q4, chi2 exact expected
tabulate lone q5, chi2 exact expected
tabulate lone q8, chi2 exact expected
tabulate lone q9, chi2 exact expected
tabulate lone q17, chi2 exact expected
tabulate lone q21, chi2 exact expected
tabulate lone q22, chi2 exact expected
tabulate lone q23, chi2 exact expected
tabulate lone q24, chi2 exact expected
tabulate lone q27, chi2 exact expected
tabulate lone q28, chi2 exact expected
tabulate lone q30, chi2 exact expected
tabulate lone q31, chi2 exact expected
tabulate lone q32, chi2 exact expected
tabulate lone smoke_status_fq, chi2 exact expected
tabulate lone smoke_status_os, chi2 exact expected
tabulate lone smoke_status_cds, chi2 exact expected
tabulate lone q34, chi2 exact expected
tabulate lone q35, chi2 exact expected
tabulate lone cann_status_fu, chi2 exact expected
tabulate lone cann_status_ou, chi2 exact expected
tabulate lone cann_status_cdu, chi2 exact expected
tabulate lone q44, chi2 exact expected
tabulate lone q45, chi2 exact expected
tabulate lone q80, chi2 exact expected

**********************************************************************
**LOGISTIC REGRESSION**
**syntax: logistic depvar indepvars [if] [in] [weight] [, options]**

**full model**

logistic soc_isol MM CD_RISC_tot places q17 q44 q45
logistic soc_isol MM CD_RISC_tot places q17 q44 q45, coef
```

```
logistic lone places q8 q80
logistic lone places q8 q80, coef

**model that runs in pilot study**
logistic soc_isol MM CD_RISC_tot places q44 q45
logistic soc_isol MM CD_RISC_tot places q44 q45, coef

logistic lone q80
logistic lone q80, coef

*************************************************************************
**COLLINEARITY ASSESSMENT OF LOGISTIC REGRESSION MODELS**
**do this after running the regression model to see if independent variables correlated**

**now command is estat vif**

predict phat
generate w=phat*(1-phat)

regress soc_isol MM CD_RISC_tot places q44 q45
estat vif

regress lone q80
estat vif

*************************************************************************
**CHECKING MODEL FIT**
**Binned Residual Plots**

**social isolation model**

qui logit soc_isol CD_RISC_tot places q44 q45, nolog

predict pred_y, pr
generate resid = soc_isol - pred_y
sort pred_y
generate myids = _n if pred_y <.
local nbins = floor(sqrt(_N))
egen binno = cut(myids) if pred_y <., group(nbins) icodes
egen avefit = mean(pred_y), by(binno)
egen myaveres = mean(resid), by(binno)
egen mysd = sd(resid), by(binno)
bysort binno: egen binsize = count(pred_y)
```

```
gen uplim = 2*mysd/sqrt(binsize)
gen dwlim = -2*mysd/sqrt(binsize)

graph twoway (scatter myaveres avefit) ///
> (line uplim avefit) ///
> (line dwlim avefit), legend(off)

**loneliness model**

qui logistic lone q80, nolog

predict pred_y, pr
generate resid = lone - pred_y
sort pred_y
generate myids = _n if pred_y <.
local nbins=floor(sqrt(_N))
egen binno = cut(myids) if pred_y <., group(  nbins  ) icodes
egen avefit = mean(pred_y), by(binno)
egen myaveres = mean(resid), by(binno)
egen mysd = sd(resid), by(binno)
bysort binno: egen binsize = count(pred_y)
gen uplim = 2*mysd/sqrt(binsize)
gen dwlim = -2*mysd/sqrt(binsize)

graph twoway (scatter myaveres avefit) ///
> (line uplim avefit) ///
> (line dwlim avefit), legend(off)

log close
```

****

References

EQ-5D-5L Code: EQ-5D scoring algorithms. APERSU. May 10, 2020. Accessed August 16, 2023. https://apersu.ca/eq-5d-scoring-algorithms/.

Cronbach's Alpha Coefficient code: Weesie, J. alpha—Compute interitem correlations (covariances) and Cronbach's alpha, Accessed August 16, 2023. https://www.stata.com/manuals/mvalpha.pdf.

Collinearity Assessment Code: Zou, G.Y. (2022, January). Ch.4 Linear Regression. Biostatistics 9521B Lecture. Presented at Western University, London, Canada.

Binned Residual Plots Code: Zou, G.Y. (2022, February). Ch.5 Linear Regression. Biostatistics 9521B Lecture. Presented at Western University, London, Canada.

Appendix D: Feedback Interview Guide

Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.

Feedback Interview Guide

Thank you for agreeing to participate in this feedback interview. My name is [NAME]. I am a [POSITION] and I am part of the research team for this study.

In our study, we are exploring the direct and indirect impacts of the pandemic on your life, through the questionnaire you completed. We want to learn about your experience completing the questionnaire and ask you for feedback on the questionnaire.

[If sharing screen on Zoom] Can I verify that you can see the screen that display the questionnaire you completed?

[If emailed in PDF format to participant beforehand] Can I verify that you have the questionnaire you completed in front of you?

Do you have any questions before we begin?

Just a reminder that I am recording this interview as mentioned in the letter of information. I will now start the recording. I also would like to remind you that you can choose not to answer any of the questions I ask.

I have started the recorders. I will go through the questionnaire starting at the beginning with the first section called Health and Healthcare. Then I will move through each of the sections in order.

Health and Healthcare

[If sharing screen on Zoom] We are going to now go to the section called "Health and Healthcare."

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Health and Healthcare."

This is the section that asked about your physical health, healthcare and COVID-19 experiences. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your physical health, were the questions we asked consistent with what physical health means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response – did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?
6. Thinking about the question asking you to type in the number of times you visited your healthcare provider in the past year, did you find this question easy to answer or would it be easier to choose from a list of options?
7. When you were deciding your answer to question 15, what did you consider when choosing your answer? For example, the effect on work, family, health.

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:
    1. Did you find the question unclear?
    2. Did you find the question to be worded awkwardly?

Health Related Behaviours - Lifestyle Factors

[If sharing screen on Zoom] We are going to now go to the section called "Health Related Behaviours - Lifestyle Factors".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Health Related Behaviours - Lifestyle Factors".

This is the section that asked about your lifestyle. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your lifestyle, were the questions we asked consistent with what lifestyle means to you?

2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?
6. I want to now ask you about the physical activity question. Can you tell me if you would say you do vigorous physical activity? [If they reply "YES"] the questionnaire only has choices for mild and moderate physical activity. Did you find this question confusing when there was no choice for vigorous?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:
  1. Did you find the question unclear?
  2. Did you find the question to be worded awkwardly?

Resilience

[If sharing screen on Zoom] We are going to now go to the section called "Resilience".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Resilience".

This is the section that asked about how you feel you can adapt to adverse life situations. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your resilience, were the questions we asked consistent with what resilience means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?

5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

Societal/Cultural/Environmental Factors

[If sharing screen on Zoom] We are going to now go to the section called "Societal/Cultural/Environmental Factors".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Societal/Cultural/Environmental Factors".

This is the section that asked about your community and how you feel living there. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your societal activities, were the questions we asked consistent with what societal activities means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?
6. Thinking about the question asking you to type in the number of people in your household, did you find this question easy to answer or would it be easier to choose from a list of options?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question? For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

Social Isolation

[If sharing screen on Zoom] We are going to now go to the section called "Social Isolation".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Social Isolation".

This is the section that asked about the people you interact with and you satisfaction with these relationships. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about social isolation, were the questions we asked consistent with what social isolation means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

Loneliness

[If sharing screen on Zoom] We are going to now go to the section called "Loneliness".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Loneliness".

This is the section that asked about your experiences with loneliness. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about loneliness, were the questions we asked consistent with what loneliness means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

Technology Use

[If sharing screen on Zoom] We are going to now go to the section called "Technology Use".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Technology Use".

This is the section that asked about the technology you use. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear

or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your technology use, were the questions we asked consistent with what technology use means to you?
2. Was there anything that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

*If there are any questions the participant answered with **"Don't know"**, ask for each of the questions:* I see you chose to answer question [NUMBER AND STEM] with "Don't know". May I ask the reason that you chose this response option - perhaps there was something we could do to improve the question?

Socio-demographic Factors

[If sharing screen on Zoom] We are going to now go to the section called "Socio-demographic Factors".

[If emailed in PDF format to participant beforehand] Could you please go to the section called "Socio-demographic Factors".

This is the section that asked about your background. Let me know when you have found it. *Pause…*Verify they have found the right section. Please take a couple of minutes to review this section. Please look through it for any questions you found unclear or difficult to answer. Once you have looked through the section, I will ask you a few questions about this section.

General questions for the section:

1. When we ask about your background information, were the questions we asked consistent with what background information means to you?
2. Was there anything, that you did not understand and would have like further clarification on? This could include instructions, questions, and options for your responses.
3. Was the language easy to understand?
4. Thinking about the questions in this section, did you find responses that applied to your situation? Or was it hard to find a response that fit your situation?
5. Thinking about the questions asking you to "choose all that apply" – these are questions where you could choose more than one response –, did you find at least one response option that applied to your situation? Or was it hard to find even one response that fit your situation?

If there are any questions the participant did not answer, ask for each of the questions: I see you chose not to answer question [NUMBER AND STEM]. May I ask if you simply chose not to answer this question (certainly your choice). Or was there a reason that you did not answer - perhaps there was something we could do to improve the question?

- For example *(suggest to the participant)*:

1. Did you find the question unclear?
2. Did you find the question to be worded awkwardly?

Questionnaire Generally

Now I'm going to ask a couple of questions about the survey as a whole.

1. How did the survey flow, was it easy to follow from section to section and question to question?
2. Would you change anything about the survey, like adding or deleting any questions, changing the order of the questions?

At the end: Do you have any other comments about the questions or sections that I didn't ask yet and you wanted to share?

Thank you for taking the time to speak with me today.

Appendix E: Western HSREB Acceptance Letter

Western Research

Date: 2 June 2023

To: Dr. Bridget Ryan

Project ID: 122300

Review Reference: 2023-122300-80255

Study Title: Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 20/June/2023

Date Approval Issued: 02/Jun/2023 09:03

REB Approval Expiry Date: 02/Jun/2024

Dear Dr. Bridget Ryan

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study**.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Untold Story Pilot Study Protocol_230501	Protocol	01/May/2023	01/May/2023
Feedback Interview Guide_230421	Interview Guide	21/Apr/2023	21/Apr/2023
Untold Story Pilot Poster 24MAR2023	Recruitment Materials	24/Mar/2023	24/Mar/2023
Telephone script_Pilot Study_230418	Telephone Script	18/Apr/2023	18/Apr/2023
Telephone script_Pilot Study Feedback Interview_230418	Telephone Script	18/Apr/2023	18/Apr/2023
Email script_Pilot Study_220420	Email Script	20/Apr/2023	20/Apr/2023
Email script reminder_Pilot Study_220502	Email Script	02/May/2023	02/May/2023
Consent Email script reminder_Pilot Study_230504	Email Script	04/May/2023	04/May/2023
Questionnaire Completion Email script reminder_Pilot Study_230420	Email Script	20/Apr/2023	20/Apr/2023
Email script_Pilot Study Feedback Interview_220418	Email Script	18/Apr/2023	18/Apr/2023
Email script reminder_Pilot Study Feedback Interview_220502	Email Script	02/May/2023	02/May/2023
Untold Story Pilot Study Social media posts 230418	Recruitment Materials	18/Apr/2023	18/Apr/2023
Untold Story Invesitigator List- 230518	Protocol	18/May/2023	18/May/2023
Untold Story Questionnaire_230524	Online Survey	24/May/2023	24/May/2023
LOIC_Pilot Study_230524	Written Consent/Assent	24/May/2023	24/May/2023
LOI_C_Pilot Study Feedback Interview_230529	Written Consent/Assent	29/May/2023	29/May/2023

Document Name	Document Type	Document Date	Document Version

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
Transcription Services Recommendation Document	Technology Review document	29/Mar/2023	29/Mar/2023
TRAC Response Template - Transcript Heroes	Technology Review document	29/Mar/2023	29/Mar/2023
Exploring Untold Story of COVID-19 CIHR budget pages Fall 2021	Study budget	02/May/2023	02/May/2023

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Electronically signed by:

Nicola Geoghegan-Morphet , Ethics Officer on behalf of Dr. Naveen Poonai, HSREB Chair, 02/Jun/2023 09:03

Reason: I am approving this document

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations, See Electronic System Compliance Review)

Appendix F: Pilot Study and Feedback Interview Letter of Information/Consent forms

Letter of Information and Informed Consent for Study Participants
Pilot Study Questionnaire

Project Title:	Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.
Document Title:	Letter of Information and Informed Consent for Study Participants
Nominated Principal Investigator:	Dr. Bridget Ryan, Departments of Family Medicine, Epidemiology and Biostatistics, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.
Co-Principal Investigator:	Dr. Amanda Terry, Departments of Family Medicine, Epidemiology and Biostatistics, Schulich Interfaculty Program in Public Health, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.
Study Funded through:	Canadian Institutes for Health Research (https://cihr-irsc.gc.ca/)
Research Staff:	Patricia Nistor, Department of Epidemiology and Biostatistics, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.

1. Invitation to Participate

You are being invited to participate in this research study about the direct and indirect impacts of the pandemic on your life. This study will pay special attention to social isolation and how family physicians can help to minimize the impact of social isolation for their patients.

This letter provides you with the information necessary to help you make an informed decision about whether to participate in this study. If you have any questions, please do not hesitate to contact our research team.

2. Why is this study being done?

The pandemic has impacted the lives of many whether they have had COVID-19 or not. This research aims to understand the wider impacts of the pandemic and find solutions to help people be healthy and prepare for the future. The goal is to describe the direct (for people who had COVID-19) and indirect (for everyone whether they had COVID-19 or not) impacts of the pandemic. The pandemic increased rates of social isolation, which can impact other areas of people's health. Reducing social isolation as we enter later stages of the pandemic can reduce long-term negative impacts of the pandemic.

The specific objective of this study is to test a questionnaire. Results from this study will inform the development of the final questionnaire that will be used to identify and describe the direct and indirect impacts of the COVID-19 pandemic on older adults with multimorbidity associated with social isolation, resilience and health behaviours.

3. How long will you be in this study?

You will be asked to participate in an online survey that will take you approximately 30 minutes to complete.

4. How do I know if I am eligible to participate in this study?

In order to participate in this study, you must:

1. Be 50 years of age or older;
2. Have at least two chronic health conditions;
3. Be an Ontario resident;
4. Be able to understand English well enough to complete an online questionnaire in English; and
5. Be able to understand this letter of information and consent form;

5. What are the study procedures?

If you agree to participate you will be asked to complete an online questionnaire that will take approximately 30 minutes to share your experiences during the COVID-19 pandemic. This questionnaire will be confidential. We will be recruiting up to 50 participants for this study.

The survey will take place through Western Qualtrics. The survey will immediately follow this Letter of Information. By submitting the survey, you are providing your

consent to participate in this study. This link will be unique to your email address and help in following up with you to remind you about the completing the questionnaire and if you agree to be contacted about the second part of the pilot study, the feedback interview. Only your email address will be connected with this link. Navigation through the survey is not restricted, you can answer the questions in any order you wish, and only the questions you feel comfortable answering.

6. What are the risks and harms of participating in this study?

All personal information will be handled with the utmost privacy and care; however, one cannot guarantee that there will never be a privacy breach. We will be asking some questions about social isolation, which may cause emotional distress. You can choose to not answer any questions in this questionnaire.

7. What are the benefits of participating in this study?

There are no known direct benefits to your participation in this study.

8. Can participants choose to leave the study?

Participation in this study is voluntary. If you decide to withdraw from the study, you have the right to request (e.g., written, calling, etc.) withdrawal of information collected about you. If you wish to have your information removed please let the researcher know. It is important to note that a record of your participation must remain with the study; as such, the researchers may not be able to destroy your signed letter of information and consent, or your name on the master list; however, any data may be withdrawn. **NOTE:** Once your data (information from the questionnaire) has been combined with other participants for analysis, we will not be able to withdraw your information.

9. How will participants' information be kept confidential?

Access to Information: All data collected will remain confidential and accessible only to the study's Western University Research Team members. The survey responses will be downloaded to, and saved by the Research Team through Western's OneDrive.

Representatives of Western University and its Health Sciences Research Ethics Board that oversees the ethical conduct of this study may contact you or require access to your study-related records to monitor the conduct of this study.

Identifiable Information Collected: All data collected will remain confidential and accessible only to the study's Western University Research Team members. Your full

name, email address, and phone number will be used to contact you and send you the link for the survey, and will not be used as part of the data in the study. Your demographic information such as gender, age, and education will be collected during the actual survey.

Retaining identifiable information: The Western University Research Team will keep any personal information about you in a secure and confidential location for seven years. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file.

Storage of information: All data collected will be stored on the secure servers of the Schulich T-drive and/or the locked cabinet in the locked office of the PIs. The survey responses will be downloaded to the T-drive and then immediately removed from the Qualtrics servers. While Qualtrics servers host their data in Ireland, they are compliant with European and American data protection regulation. This is the link to their Privacy Policy: https://www.qualtrics.com/privacy-statement/

Publication of Results: If the results are published, your name will not be used.

10. Are participants compensated to be in this study?

Participants will not be compensated for this study.

11. What are the rights of participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right not to answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time, it will have no effect on your health care.

You do not waive any legal right by consenting to this study.

12. Whom do participants contact for questions?

If you have questions about this research study, please contact Dr. Bridget Ryan by (Included in original study LOI/C, removed for thesis submission).

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (Included in original study LOI/C, removed for thesis submission). The HSREB (Health Sciences Research Ethics Board) is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss with the HSREB will be kept confidential.

Consent

Submitting the online survey serves as consent.

Feedback Interview

At the end of the questionnaire, please indicate if you would be willing to be contacted about possibly participating in a feedback interview where we would ask about your experience completing this questionnaire.

This letter can be downloaded and is yours to keep for future reference.

****

Letter of Information and Informed Consent for Study Participants
Pilot Study Feedback Interview

Project Title:	Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.
Document Title:	Letter of Information and Informed Consent for Study Participants
Nominated Principal Investigator:	Dr. Bridget Ryan, Departments of Family Medicine, Epidemiology and Biostatistics, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.
Co-Principal Investigator:	Dr. Amanda Terry, Departments of Family Medicine, Epidemiology and Biostatistics, Schulich Interfaculty Program in Public Health, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.
Study Funded through:	Canadian Institutes for Health Research (https://cihr-irsc.gc.ca/)
Research Staff:	Patricia Nistor, Department of Epidemiology and Biostatistics, Western University
Contact Information:	Included in original study LOI/C, removed for thesis submission.

1. Invitation to Participate

You are being invited to participate in this research study about the direct and indirect impacts of the pandemic on your life. This study will pay special attention to social isolation and how family physicians can help to minimize the impact of social isolation for their patients. As you have previously indicated interest in being contacted for the feedback interview for this questionnaire this document outlines the feedback portion of the study.

This letter provides you with the information necessary to help you make an informed decision about whether to participate in this study. If you have any questions, please do not hesitate to contact our research team.

2. Why is this study being done?

The pandemic has impacted the lives of many whether they have directly had COVID-19 or not. This research aims to understand the wider impacts of the pandemic and find solutions to help people be healthy and prepare for the future. The goal is to describe the direct (for people who had COVID-19) and indirect (for everyone whether they had COVID-19 or not) impacts of the pandemic. The pandemic increased rates of social isolation, which can impact other areas of people's health. Reducing social isolation as we enter later stages of the pandemic can mitigate long-term negative impacts of the pandemic.

As you may recall, from completing the questionnaire, the specific objective of this study is to identify and describe the direct and indirect impacts of the COVID-19 pandemic on older adults with multimorbidity associated with social isolation, resilience and health behaviours. The purpose of this feedback interview is to ask about your experience completing the questionnaire.

Additionally, this interview will help us to better understand how participants find the experience of taking of this survey. If you agree to participate, you will have an opportunity to share your feedback on the survey.

3. How long will you be in this study?

You will be asked to participate in an interview that will be approximately 30 to 45 minutes long.

4. How do I know if I am eligible to participate in this study?

In order to participate in this study, you must:

1. Be 50 years of age or older;
2. Have at least two chronic health conditions;
3. Be an Ontario resident;
4. Be able to understand English well enough to complete an interview in English;
5. Be able to understand this letter of information and consent form; and
6. Have completed the online questionnaire for this same pilot study.

5. What are the study procedures?

If you agree to participate you will be asked to complete an online interview that will be approximately 30 to 45 minutes long to share your experiences completing the questionnaire about the impacts of COVID-19 on social isolation and loneliness. This interview will be confidential. We will be recruiting between 5 and 10 participants for this study.

The interview will take place by videoconferencing technology (example Zoom) or telephone. Once you agree to participate, a Western University research team member will collect informed consent and arrange a time that is convenient for you.

If you would prefer Zoom for the interview, we will use a Western University research team member's Western Zoom account to schedule the interview and the invitation will be sent to the email that you have provided to us and you are not to share this with anyone. If you would prefer Zoom, your questionnaire results will be shared with you using the share screen function to help with the discussion.

If you would prefer the interview by telephone, we will ask you to provide your preferred phone number. At the scheduled time, the Western University researcher will call you for the interview. If you would prefer telephone, your questionnaire results will be shared with you through email as a password protected PDF document to help with the discussion.

6. What are the risks and harms of participating in this study?

All personal information will be handled with the utmost privacy and care; however, one cannot guarantee that there will never be a privacy breach.

7. What are the benefits of participating in this study?

There are no known direct benefits to your participation in this study.

8. Can participants choose to leave the study?

Participation in this study is voluntary. If you decide to withdraw from the study, you have the right to request (e.g., written, calling, etc.) withdrawal of information collected about you. If you wish to have your information removed please let the researcher know. It is important to note that a record of your participation must remain with the study; as such, the researchers may not be able to destroy your signed letter of information and consent, or your name on the master list; however, any data may be withdrawn. **NOTE:**

Once your data (information from the interview) has been combined with other participants for analysis, we will not be able to withdraw your information.

9. How will participants' information be kept confidential?

Access to Information: All data collected will remain confidential and accessible only to the study's Western University Research Team members with the exception of transcription service. Interviews will be audio-recorded and this will be mandatory. These audio-recordings will be sent to a transcription service called Transcript Heroes Transcriptions Services where the audio-recordings will be transcribed. The audio-recordings will be sent by, and the transcriptions returned to, the Research Team through Western's OneDrive. Additionally, external Research Team members may review de-identified quotes via Western's OneDrive.
Representatives of Western University and its Health Sciences Research Ethics Board that oversees the ethical conduct of this study may contact you or require access to your study-related records to monitor the conduct of this study

Identifiable Information Collected: All data collected will remain confidential and accessible only to the study's Western University Research Team members. Your full name, email address, and phone number will be used to contact you and coordinate the interview, and will not be used as part of the data in the study.

Location of interview: The interview will take place by telephone or videoconferencing technology (example Zoom) which has some privacy and security risks. It is possible that information could be intercepted by unauthorized people (hacked) or otherwise shared by accident. This risk cannot be completely eliminated. We want to make you aware of this.

Retaining identifiable information: All data collected will be stored on the secure servers of the Schulich T-drive and/or the locked cabinet in the locked office of the PIs. The voice recordings will be copied to the T-drive and then immediately removed from the external audio recorder. The voice recordings are also temporarily stored on the Western OneDrive belonging to one of the Western University Research Team members to transfer the recording to the transcription service.

Storage of information: All data collected will be stored on the secure servers of the Schulich T-drive and/or the locked cabinet in the locked office of the PIs. The survey responses will be downloaded to the T-drive and then immediately removed from the Qualtrics servers.

Publication of Results: If the results are published, your name will not be used.

10. Are participants compensated to be in this study?

Participants will be compensated with a $25 e-gift card for President's Choice, through the email address we have been corresponding through, or if they wish, they can indicate a different email address at the end of the interview session.

11. What are the rights of participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right not to answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time, it will have no effect on your health care.

You do not waive any legal right by consenting to this study.

12. Whom do participants contact for questions?

If you have questions about this research study, please contact Dr. Bridget Ryan by (Included in original study LOI/C, removed for thesis submission).

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (Included in original study LOI/C, removed for thesis submission). The HSREB (Health Sciences Research Ethics Board) is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss with the HSREB will be kept confidential.

Consent

Signing and returning this form serves as consent.

_____	_____	_____
Print Name of Participant	Signature	Date *(DD-MMM- YYYY)*

My signature means that I have explained the study to the participant named above. I have answered all questions.

_____	_____	_____
Print Name of Person Obtaining Consent	Signature	Date (*DD-MMM- YYYY)*

This letter is yours to keep for future reference.

Curriculum Vitae

Name:	Patricia Nistor
Post-secondary Education and Degrees:	The University of Western Ontario London, Ontario, Canada 2016-2020 BSc. The University of Western Ontario London, Ontario, Canada 2021-2023 MSc. Candidate
Honours and Awards:	UWO In-Course Scholarships Year III 2018
Related Work Experience:	Teaching Assistant The University of Western Ontario Jan. 2023-April 2023 Graduate Research Assistant The University of Western Ontario Sept. 2022-Present Graduate Student Assistant The University of Western Ontario May 2022-Aug.2022 Research Assistant Centre for Family Medicine Mobility Clinic Oct. 2020-Dec. 2021
Related Research Experience:	Student Researcher The University of Western Ontario April 2018-Present Undergraduate Honours Thesis The University of Western Ontario Sept. 2019-April 2020 Research Volunteer The University of Western Ontario Sept. 2018-March 2019

Publications:
Published Articles:
Nistor, P.*, Chang-Kit, B.*, Nicholson, K., Anderson, K.K., Stranges, S., (2022). The Relationship Between Sleep and Multimorbidity in Community Dwelling Populations: A Global Perspective. Sleep Medicine. 2023; 109:270-284. doi:10.1016/j.sleep.2023.07.002
*These authors contributed equally to this work and are Co-Primary Authors

Published Abstracts:
Nistor, P.*, Chang-Kit, B.*, Nicholson, K., Anderson, K.K., Stranges, S., (2022). The Relationship Between Sleep and Multimorbidity in Community Dwelling Populations: A Global Perspective. Sleep Medicine. 2022; 44(Supplement 1); December 2022.
*These authors contributed equally to this work and are Co-Primary Authors

Milligan, J., Lee, J., Nistor, P., Parikh, R., Beuermann, L., (2021). Development of a collaborative primary care spinal cord injury network. The Journal of Spinal Cord Medicine. 2021; 44(Supplement 1); November 2021.

Presentations:
London Health Research Day
June 2023
The University of Western Ontario (Western), London, Ontario
Nistor, P. (presenter), Ryan B., Terry A.L., daSilva M., Ali S., Bayliss L., Black J., Brown J.B., Cejic S, Cipriano L., Freeman T., Jan S.H., Keuper J., Lizotte D., Mathews M., Meyer M., Nicholson K., Ranade S., Rayner J., Sedig K, Silverman M., Speechley M., Stranges S., Summers A., Thind A., Vingilis E., Wetmore S.
Title: Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.
Poster presentation

EpiBio Research Day
April 2023
The University of Western Ontario (Western), London, Ontario
Nistor, P. (presenter), Ryan B., Terry A.L., daSilva M., Ali S., Bayliss L., Black J., Brown J.B., Cejic S, Cipriano L., Freeman T., Jan S.H., Keuper J., Lizotte D., Mathews M., Meyer M., Nicholson K., Ranade S., Rayner J., Sedig K, Silverman M., Speechley M., Stranges S., Summers A., Thind A., Vingilis E., Wetmore S.
Title: Developing an Online Questionnaire to Investigate the COVID-19 Pandemic's Impacts on Social Isolation and Health in Older Adults Living with Multimorbidity: A Pilot Study.
Poster presentation

16th World Sleep Congress
March 2022
Rome, Italy
Nistor, P.*, Chang-Kit, B.*, Nicholson, K., Anderson, K.K., Stranges, S. (presenter)
*These authors contributed equally to this work and are Co-Primary Authors
Title: The Relationship Between Sleep and Multimorbidity in Community Dwelling Populations: A Global Perspective.
Poster presentation

Canadian Spinal Cord Injury Rehabilitation Association 9th National Spinal Cord Injury Conference
Nov. 2021
Virtual
Milligan, J. (presenter), Lee, J., Nistor, P., Parikh, R., Beuermann, L.,
Title: Development of a collaborative primary care spinal cord injury network.
Poster presentation

Academy of Spinal Cord Injury Professionals, Inc. Conference and Expo
Sept. 2021
Virtual, Reno, United States
Milligan, J. (presenter), Lee, J., Nistor, P., Parikh, R., Beuermann, L.,
Title: Development of a collaborative primary care spinal cord injury network.
Oral presentation

The International Spinal Cord Society Annual Scientific Meeting
Sept. 2021
Virtual
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Poster presentation

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