Exploring the role of digital technologies for social connectedness, outcomes and experiences with the chronic obstructive pulmonary disease (COPD) community: A transformative mixed methods research study

by

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Bachelor of Science, Simon Fraser University, 1994
Master of Public Health, University of Victoria, 2013
Graduate Certificate in Learning & Teaching in Higher Education (LATHE), University of Victoria, 2018

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We acknowledge with respect the Lekwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

Supervisory Committee

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Dr. Laurene Sheilds, (School of Nursing)
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Dr. Francis Lau, (School of Health Information Science)
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Abstract

Prior to the coronavirus disease-2019 (COVID-19) pandemic people with chronic obstructive pulmonary disease (COPD) were already experiencing social isolation due to the complex intersection of symptoms, and perceptions towards the illness. COPD is a chronic lung illness characterized by progressive shortness of breath, and decreasing lung function, with influenza and other respiratory illnesses more likely to have fatal consequences for this population. Societal beliefs and assumptions around behavioural risk factors, and in particular smoking, contribute to perceptions that COPD diagnosis, outcomes and experiences are self-inflicted and an individual responsibility. This is a perspective that fails to take into the account the complex contextual factors of the social determinants of health, where structural inequities result in higher smoking rates among populations with lower socioeconomic status. Further, these underlying societal values may compound the isolation experienced with COPD in which ongoing stigma towards the illness discourages people from identifying with a COPD diagnosis. The lack of identity may discourage developing a community where people can share experiences and strategies in living with COPD, and form a collective group that can advocate for change.

Digital technologies (DTs), such as Facebook and Zoom offer new avenues to support social connectedness. However, little focus has been given on how people with COPD may (or may not) be using DTs to support their illness. This study explored the role DTs could serve in addressing social connectedness and experiences and outcomes for the COPD community. The study was informed by Mertens (2003, 2007) transformative approach where the knowledge of people living with COPD was prioritized in finding out what DTs they may be using to maintain social connectedness and to support their illness.

The three stage mixed methods research design consisted of interviews, patient-reported outcome measures, patient-reported experience measures and a DT survey. Bazeley's (2018) approach was used to guide the integrative mixed analysis on data collected across the three stages.

The overall findings were:

1) Participants' experiences in living with COPD had uniquely prepared them for the COVID-19 pandemic, and it was the community that lacked capacity;

2) Dominant discourse around technology may be creating further harms to the COPD population that extend beyond the digital world;

3) Current digital health monitoring strategies for other chronic illnesses do not fully translate to the interests and needs for people living with COPD;

4) People living with COPD are using DTs, but prefer to keep their virtual world separate from their illness world; and

5) Considerations for DTs for COPD should move beyond managing outcomes, and include supporting experiences of living.

Conducted between December 2018 and July 2020, and concurrent with the COVID-19 pandemic, the study demonstrated even greater importance with the onset of the pandemic in understanding how DTs may support social connectedness for people living with life-limiting chronic lung conditions.

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Acknowledgement

When I began this PhD journey, I never imagined all opportunities that would become available. I have been so grateful for the privilege that has been given to me during my doctoral journey, in being given the space to think, travel, and carve my own path.

I first wanted to express my deep gratitude to all the people who participated in the study. The knowledge you shared translated into my approach to the pandemic, in being reminded of the importance of music and laughter. I hope to continue to give back to a community that has so graciously shared their knowledge during such changing times.

I have also been blessed to have an amazing committee in supporting me in circling around and within complexity. You have been instrumental in achieving my PhD goal in being able to think and see the world differently. Thank-you Dr. Laurene Sheilds for providing ongoing insights and encouragement that gave me the confidence to become a scholar. Thank-you Dr. Francis Lau for the multiple opportunities you created in bringing health equity perspectives into health informatics that allowed me to go far beyond your handful of five criteria for my dissertation. Thank-you Dr. Anne Bruce for the collegial support as we explored multiple interpretations during our many walks and discussions.

I also want to thank the people along the way who reviewed and provided their expertise on the different stages of my mixed research study: Robyn Wiebe for reviewing my codebook, Dr. Helena Kadlec for the multiple times you advised me on my statistical analysis, the Community Health Equity Research group and Dr. Denise Cloutier for reviewing my survey, and Nathan Kelerstein for all your support with RedCap. As well, I would like to thank the BC SUPPORT Unit Vancouver Island Centre and University of Victoria for the funding provided for this dissertation research.

With my dissertation focused on social connectedness, I am especially grateful for my friends, mentors and colleagues who I have met during my graduate studies. To Dr. Anita Molzahn for ongoing mentorship during the Liminality study and to Dr. Karen Courtney for the research and teaching opportunities provided that extended far beyond my dissertation research. Shannon Tracey, who made me think deeper about my methodological approach, while also keeping me entertained through her amazing skills in story-telling. Lesley Scott for our bi-monthly virtual discussions during the pandemic that helped me think through the different ideas which had been not quite formulated in my mind. Jen Van de Pol I am so grateful for our ongoing friendship, which began so long ago when we cheered each other through our Master degrees. Dr. Olga Petrovskaya, our shared passion in reading and discussing the philosophy of science helped me think through my ideas around technology. To Dr. Kara Schick-Makaroff, who first introduced me to mixed methods research and gave me the confidence to pursue my PhD. Her advice to me was to try out the PhD and if I didn't like it, I could always leave. Although there were bumps, I can honestly say that there wasn't a single day when I thought it was time to leave.

Dedication

To Kelly who rebuilt my strength and confidence one Supta Padangusthasana at time,
My miniature schnauzers who made sure that I did not become glued to my desk,
And most of all...

David my partner, best friend and strongest advocate.

Chapter One: Overview

Background and Context

Chronic obstructive pulmonary disease (COPD) is a chronic illness characterized by progressive difficulties in breathing and acute events (exacerbations) that can contribute to increased pain, fear, anxiety and depression, and is ultimately fatal (Benady, 2010; Bourbeau et al., 2017, p. 6; Vestbo et al., 2013). The number of people with COPD who are living alone is increasing, and thus exacerbations are more likely to be solitary experiences (Ek et al., 2011; Gore et al., 2000; Lee et al., 2018). People living with COPD may experience social and existential loneliness as the illness progresses, expressing fears of pain, suffering and dying alone (Ek & Ternestedt, 2008).

The importance of addressing this illness is further evident through the increasing rates of COPD, as by 2030 it is estimated that COPD will move from the fourth to third leading cause of death worldwide (World Health Organization (WHO), 2017a). Yet, COPD is an illness which receives fewer fiscal and human resources when compared to other chronic fatal conditions (Au & Feemster, 2014; Gardiner et al., 2010; Gore et al., 2000; Sadatsafavi, 2017). Studies that have examined social determinants and health outcomes for COPD individuals have reported a demonstrable link between COPD, gender, race, low socioeconomic status, and increased likelihood of late diagnosis and rates of hospitalization (Canadian Institute for Health Information, 2008b; Disano et al., 2010; Mamary et al., 2018; Trachtenberg et al., 2014). Since smoking is viewed as the most common risk factor for COPD, the resulting shame and victim-blaming may further discourage self-identification and sharing of illness experiences (Barnes, 2007; Berger et al., 2010; Halding et al., 2011; Harrison et al., 2015).

Self-management interventions introduced through the formal healthcare system are a common strategy aimed at improving health outcomes and experiences for COPD individuals (Bourbeau et al., 2004; Zwerink et al., 2014). Yet, clinically-based self-management interventions have limited evidence of success, (Zwerink et al., 2014), and may overlook the delivery of care outside the healthcare system and a patient's unique context and experience (Greenhalgh, 2009). Further, the predominant focus on self-management interventions has failed to take into account the complex intersection of the 'the social' on overall health, including socioeconomic status, quality of social networks and social cohesion (Ek & Ternestedt, 2008). People who have social supports that extend from the macro (structural, political and societal) to the micro (family, friends and community) are more likely to have an improved quality of life and live longer (Berkman & Syme, 1979; Holt-Lunstad et al., 2010; Steptoe et al., 2013). The complex intersection of symptomology, co-morbidities, socioeconomic status, and societal perceptions introduces distinct challenges in addressing the social isolation experienced with COPD. To improve the overall quality of life for people living with COPD necessitates moving beyond self-management strategies and exploring how to support social connectedness for people living with COPD. To date, in examining the relationship between 'the social' and COPD, research has focused on the negative health outcomes of social isolation, and few studies have examined the characteristics of social networks and interventions for enhancing social support (Barton et al., 2015).

The emerging digital technologies (DTs) such as Facebook and Zoom hold great potential for encouraging social connectedness for people living with COPD. DTs may improve people's outcomes of living with COPD by providing a place for anonymity, communication, community building, engagement, education, identity, narration of experience, peer and emotional support and policy influence (Allen et al., 2016; Merolli et al., 2013; Moorhead et al., 2013). Although there has been some research on how these technologies can support other chronic illnesses, there has been minimal research specific to COPD. Furthermore, many of the studies on DTs and chronic illness have focused on clinical health measures, and few studies have examined social connectedness and patients' perceived outcomes and experiences.

Research Question and Dissertation Design

With a goal of targeting the social isolation and inequitable outcomes and experiences of living with COPD, the research question for this dissertation was: *'what is the role of digital technologies in social connectedness and illness outcomes and experiences for people living with chronic obstructive pulmonary disease'*. The following sections in this chapter will introduce the dissertation foundations for the development of the research question (summarized in Table 1.1). This will include an overview of: 1) foundational concepts of health equity, digital technologies, social connectedness and illness outcomes and experiences; 2) transformative paradigm; 3) Berkman and Krishna (2014) conceptual model on "*How social networks impact health*"; and 4) Mertens' (2003, 2007) transformative methodology in designing a mixed methods research study.

Table 1. 1 *Dissertation Foundations*

Foundational concepts	Health equity, digital technologies, illness outcomes and experiences, social connectedness
Paradigm	Transformative
Conceptual model	How Social Network Impact Health
Methodology	Mertens' transformative approach
Study design	Transformative mixed methods research; sequential, exploratory
Methods	Interviews, surveys and integrative analysis
Techniques	Semi-structured interviews, closed-ended survey questions, open-ended survey questions, patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs), and thematic analysis, descriptive and inferential statistics

Development of the Dissertation Focus

This dissertation required bringing together multiple disciplines in order to understand how to address the complexity of inequities experienced by a population that historically has been underserved. I viewed myself as a research "bricoleur", who used multiple methods, methodologies and theories within a single study, where each stage unfolded and I did not finalize the study focus during study design (Kincheloe, 2001). It involved drawing from the disciplines of public health, health informatics, nursing, education, and sociology.

As an interdisciplinary[1] student, I became distinctly aware of the tensions between disciplines' differing identities, beliefs and principles. From this exploration *values*

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[1] Two of these disciplines, health informatics and public health are already identified with being *interdisciplinary disciplines*. They often pull from across other disciplines of sociology, medicine, computer

emerged as the foundation to these tensions, as values underlie the implicit assumptions within a discipline that determine not only what to research, but how to conduct research. These values are also apparent within healthcare and broader society in how different illness groups get prioritized or marginalized. My substantive focus made me consider the different observational approaches that are considered of merit across my disciplines, and the broader socio-political values that impact overall supports for the COPD population. In a society where value is placed on the empirical evidence-based practice, illnesses that have better prediction and control (e.g., cancer and diabetes) may receive greater research and health resources than COPD (Bourbeau et al., 2017; Curtis, 2008; Curtis et al., 2002; Gardiner et al., 2010; Henoch et al., 2016; Vermylen et al., 2015). More significantly, value judgments around smoking may influence healthcare decisions that impact access to healthcare services, and overall health outcomes and experiences for people living with COPD (Gore et al., 2000; Halding et al., 2011; Harrison et al., 2015). People living with COPD may not only be marginalized due to their illness and past 'behaviours', but are impacted by the influence of the social determinants of health. Disability due to illness, socioeconomic status gender have influenced the social capital for this population[2], resulting in diminished social cohesion for the COPD community and limited resources dedicated to addressing the compounding social isolation experienced with COPD (Eisner et al., 2011; Liu et al., 2014; Prescott et al., 2003).

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[2] Throughout the dissertation, I have been selective as to how I used 'COPD population' and 'COPD community'. Population is referenced when I speak more broadly about COPD statistics and ongoing inequities. Community is used to bring particular attention to the importance of building and supporting a community for people living with COPD.

Transformative Paradigm

My recognition of how values negatively impact supports for COPD drew me to ground my dissertation in a transformative paradigm that placed axiology above ontology, epistemology and methodology. Specifically it was the values of social justice and health equity that I prioritized in challenging the structural barriers that perpetuate stigma and discrimination towards people living with COPD (Greenhalgh, 2009; Mertens, 2007). A transformative lens permeated all the decisions within the study, including the conceptualization of the research question in challenging the underlying assumptions and the larger health and social structures that determine how things were defined, what was identified as problems and what questions were asked (Mertens, 2007). Being an interdisciplinary student, I found that even the words used across disciplines can mean very different things, thus Appendix A provides definitions of foundational concepts used within this dissertation. For example, my transformative lens took a different value perspective from the formal healthcare system's perception of care. ‘Care’ was not defined as an individual endeavour, whereby the healthcare provider introduced self-management strategies to the 'expert patient', that aim to control behaviour (Greenhalgh, 2009). Rather, I viewed 'care′ as a collective support structure for populations that have experienced inequities in health (Greenhalgh, 2009;Hancock, T., personal communication, July 13, 2017). ‘Good care’ offers a place of common understanding so that people living with COPD can "overcome the sense of alienation, loss of self-understanding, and loss of social integration that accompany illness" (Benner & Wrubel, 1989, p. 9).

This connection between care and social integration, brings awareness to the contextual factors that are impacting the outcomes and experiences for people living with

COPD: the societal perceptions of illness, the political structures that determine resource allocation and an individual's social capital (Greenhalgh, 2009; Solar & Irwin, 2010). The prioritization of COPD resources to smoking cessation programs overlooks other 'problems' that needs to be addressed for people living with a diagnosis of COPD. In fact, this approach may reinforce the 'wicked problem' of inequities that have been experienced by people with COPD across their life course. People with COPD are living with a fatal diagnosis, and yet the emphasis on addressing a person's individual behaviour may result in stigmatizing and isolating care experiences, rather than supportive care near end of life. Focusing on larger contextual factors removes victim-blaming perspectives, where people are viewed as being solely responsible for their behaviours, and recognizes that when people living with COPD have sufficient social and societal supports, symptom management and overall health outcomes and experiences are improved (Barton et al., 2015; Gardiner et al., 2010; Harris, 2007).

Health Equity, Digital Technologies and Social Connectedness

My exploration of the way values influence care and social integration within different illness populations led me to develop a research question that was specifically focused on addressing the health inequities that were experienced by people living with COPD. The study design prioritized the value of health equity in addressing the social, political and cultural structures that were impacting the illness experience and outcomes for people living with COPD. Health equity recognizes the implicit value judgments that compound avoidable, long-standing injustices (Braveman, 2006), and attends to "the systematic differences in health that occur for different groups of people [that] are avoidable by reasonable action, their existence is, quite simply, unfair" (Marmot et al., 2008, p. 1661).

The focus of this dissertation was not on *measuring* inequities for the COPD population, but rather explored the strategies in *addressing* the outcomes of these inequities, namely social isolation. The emergence of DTs offers new possibilities for addressing the social isolation uniquely experienced by the COPD population. DTs can provide a venue to connect with others living with illness and who are at risk of being socially isolated (Chen & Schulz, 2016; Khosravi et al., 2016; Merolli et al., 2015). DTs' immediate impact can be to support social connectedness by address the compounding impact of social isolation that contributes to decreased quality of life and an increased risk of early mortality (Chen & Schulz, 2016; Khosravi et al., 2016; Smith & Christakis, 2008; Steptoe et al., 2013). Over the long term, the development of these social networks can offer a place for "democratization" by providing a place where people with shared experiences can come together and build a community that can advocate for change (Lopez et al., 2011).

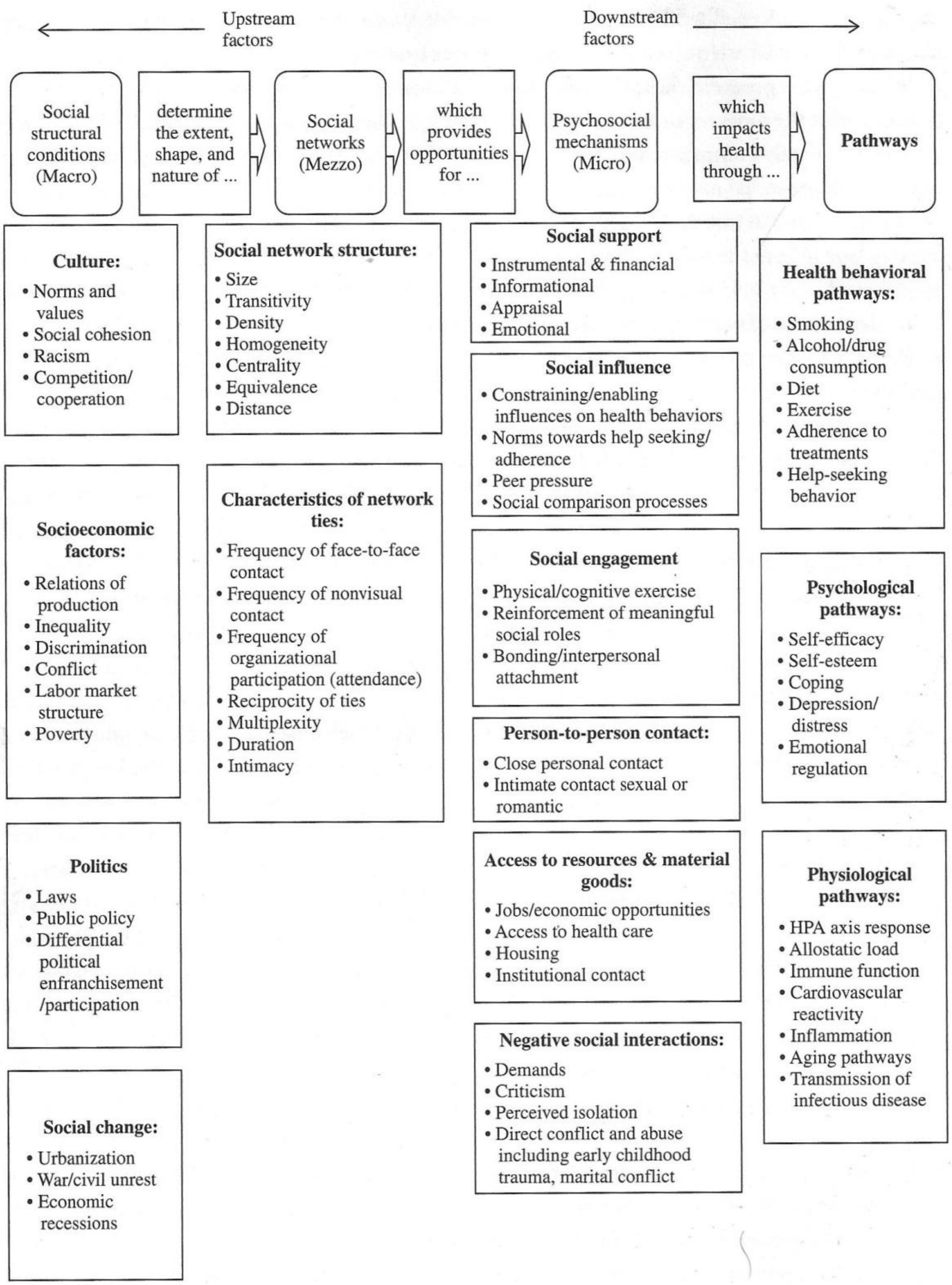
Within the context of this study, the definition of DTs intentionally remained quite broad, so that the technologies that were of value to COPD individuals were not unintentionally eliminated. People living with COPD were asked about what technologies they have used outside the formal healthcare system to support social connectedness and illness outcomes and experiences. Consideration for DTs was informed by Merolli's et al. (2013) systematic review of social media and included 1) video conferencing (e.g., Zoom and Face Time); 2) mobile devices (e.g., text messaging, apps and wearable devices); 3) social networks sites (e.g., Facebook, Instagram, Dailystrength, and Twitter); 4) online support groups (e.g., forums, discussion boards, chatrooms and blogs); and 5) virtual worlds (e.g., Second Life). Specific focus was on the DTs that support social connectedness, and provide a place for anonymity, communication, community building, engagement, education, identity, narration of experience, peer and emotional support and policy influence (Allen et al., 2016; Merolli et al., 2015; Moorhead et al., 2013). The definition encompassed the multiple layers of 'the social' in considering social cohesion, social support, social influence, social engagement, personal contact, negative social interactions and resource access (Berkman & Krishna, 2014).

Conceptual Model: How Social Networks Impact Health

The reappearance of 'the social' throughout my methodological and substantive focus, lead me to Berkman and Krishna's (2014) conceptual modal of how social networks impact health as the theoretical framework that informed the research question (see Figure 1.1). This conceptual model has particular relevance to people living with COPD, since it considers the complex relationships between social factors, behaviour and health. It also connects conceptual pieces across my disciplines in incorporating social structural conditions (i.e., social determinants of health) and pathways to health (i.e., biomedical parameters). Berkman and Krishna's (2014) model brings together multiple lenses that are

Figure 1. 1 *Conceptual Model of How Social Networks Impact Health*

(Berkman & Krishna, 2014) (Reproduced with permission of the Licensor through PLSclear)



often viewed as distinct models: there are the *upstream* social structures identified within public health, and the *downstream* clinical/biomedical pathways commonly identified with health informatics and nursing. The *midstream* measures unite these factors through the social networks and psychosocial mechanisms, the specific focus for the proposed research study. A more thorough review of the model and how it relates to this dissertation is presented in chapter three.

Methodological Design: Mertens' Transformative Approach

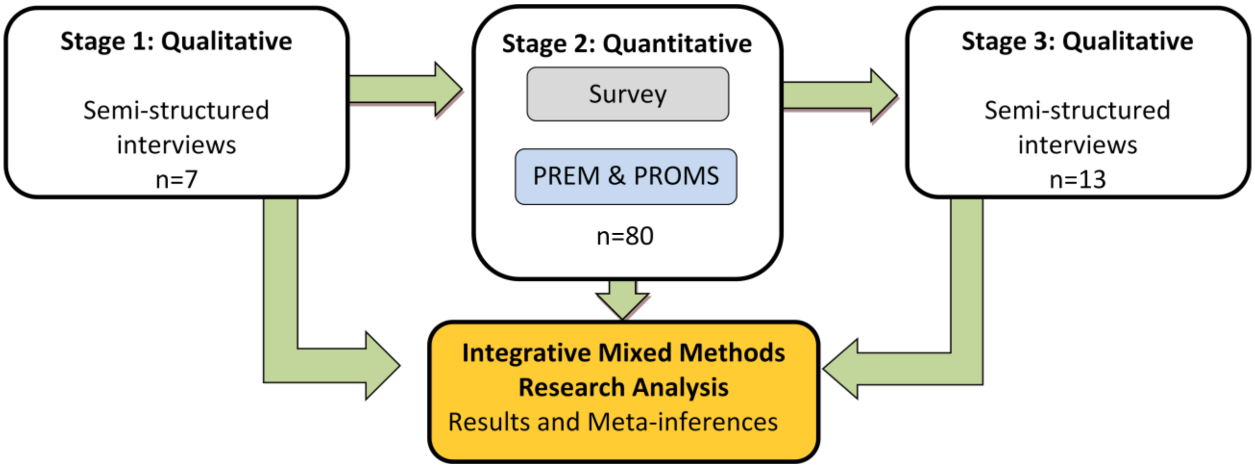
Mertens’ (2003, 2007, 2008, 2013) transformative approach was selected for the research study for its focus on social justice and equity. Mertens' (2003, 2007) placement of axiology as the foundation of the approach emphasizes the implicit values and beliefs that result in the privileging of realities. Within this approach, questioning of the power relations in research is encouraged, and the researcher is invited to be reflective on their underlying assumptions, while ensuring that it is the values of the participants that are represented in the research question. In reflecting on my own values, I identify with Mertens' (2007) description of the role of the researcher: in "recogniz[ing] the inequalities and injustices in society, [I] striv[e] to challenge the status quo,... [and be] a bit of a provocateur with overtones of humility, and...possess a shared sense of responsibility (p.212). The development of the research question was strongly informed by my involvement with the COPD community during my doctoral fellowship on the narrative inquiry study: *'Living-and-Dying with Life-limiting Chronic Conditions: Understanding Narratives of Liminality'* (Sheilds et al., 2020). The shared narratives of social isolation for people living with COPD specifically led me to explore how DTs could support social connectedness and illness outcomes and experiences for people living with COPD (Antonio et al., 2017; Molzahn et al., 2021).

This narrative project matched with the transformative approach in privileging the knowledge gained from individuals whose voice had been diminished (Mertens, 2007), rather than prioritizing the perspectives within the formal structures of healthcare and the academy. Mertens (2003, 2007) acknowledges the complexity in addressing health and social inequities, and recommends mixed methods research (MMR) in examining the multiple layers that underlie these injustices. As such, a MMR study consisting of three sequential stages was conducted for this dissertation (see Figure 1.2). The first and third stage involved semi-structured interviews, and the second stage was informed by data from the first stage and consisted of a DT survey (grey box in Figure 1.2) and a patient-reported experience (PREM) and two patient-reported outcome measures (PROM)s (blue box in Figure 1.2). Bazeley's (2018) integrative mixed methods approach guided the analysis, in which mixing occurs between each sequential stage and at the end of data collection (green arrows in Figure 1.2). The end goal of the study was the development of a series of meta-inferences (orange box in Figure 1.2) that have been iteratively developed through integrative analysis of the data (Bazeley, 2018).

Outline of Dissertation

In the upcoming chapters, the background, methodology, results and overall findings are presented. Figure 1.3 serves as a graphical table of contents which can be used as a visual roadmap for the different chapters presented in this dissertation. Chapter two applies a transformative lens in examining the background literature on the prognosis, symptomology and current supports specific to COPD in relation to DTs and

Figure 1. 2 *Mixed Methods Research Design for Dissertation Study*

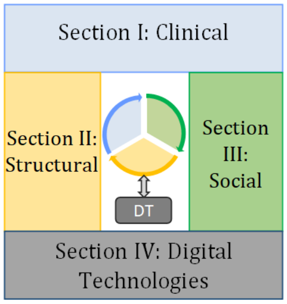


The study involved a total of 83 participants across three different stages.

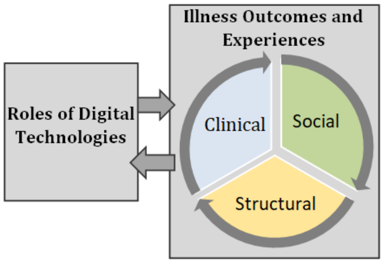
social connectedness. Chapter three details the transformation of Berkman and Krishna's (2014) model and how it was used to inform the study design. Chapter four outlines the methodology and transformative mixed methods study design in exploring the research question. Chapters five, six and seven present the study results. Chapter five reports the applied results in detailing the context and types and frequency of DT activities reported by participants. Chapter six focuses on the first half of the research question in detailing the roles of DTs for people living with COPD. Chapter seven addresses the second half of the question by exploring the relationship between DTs, and illness outcomes and experiences and social connectedness. Chapter eight pulls together the overall findings by presenting a set of meta-inferences, as well as interesting areas that warrant further exploration.

Figure 1. 3 *Graphical Table of Contents*

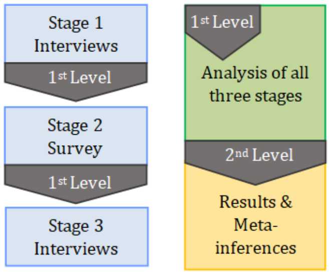
PART I: Background and Study Design



Chapter 2: Literature Review

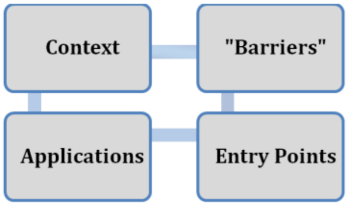


Chapter 3: Theoretical Foundations

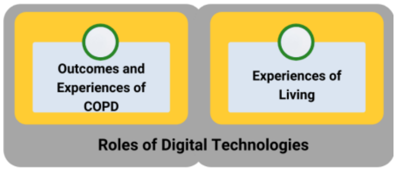


Chapter 4: Methodology

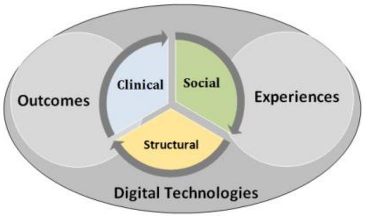
PART II: Results



Chapter 5: Current Landscape



Chapter 6: Roles of Digital Technologies



Chapter 7: Digital Technologies and Outcomes and Experiences for COPD

PART III: Conclusion

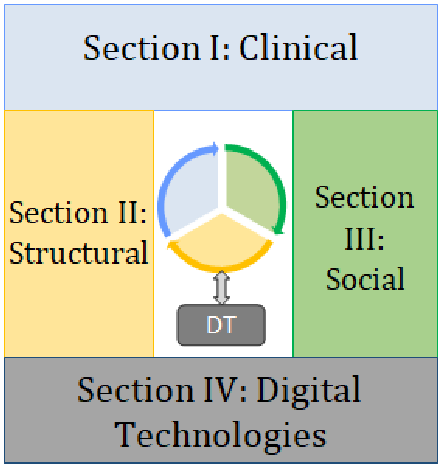
Chapter 8: Meta-inferences Areas of Further Exploration Limitations

Scholarly Contribution

Through a transformative MMR study, I explored *the role of digital technologies for social connectedness and illness outcomes and experiences for people living with chronic obstructive pulmonary disease.* By addressing this question, I aim to make the following scholarly contribution:

1) Provide an initial mapping on how DTs are being used by people with COPD.
2) Enhance knowledge on how the use of DTs intersects with the social isolation experienced by people living with COPD.
3) Conceptualize how health and social inequities experienced by people living with COPD may be addressed through DTs.
4) Provide an interdisciplinary example as to how value-based approaches (i.e., health equity, transformative mixed methods research, and patient reported measures) could be used for community-based, patient-driven interventions.
5) Analyze how current dominant discourse around DTs is impacting people living with COPD.
6) Recommend the role DTs could serve in social connectedness, and illness outcomes and experiences for people living with COPD.

Chapter Two: Literature Review

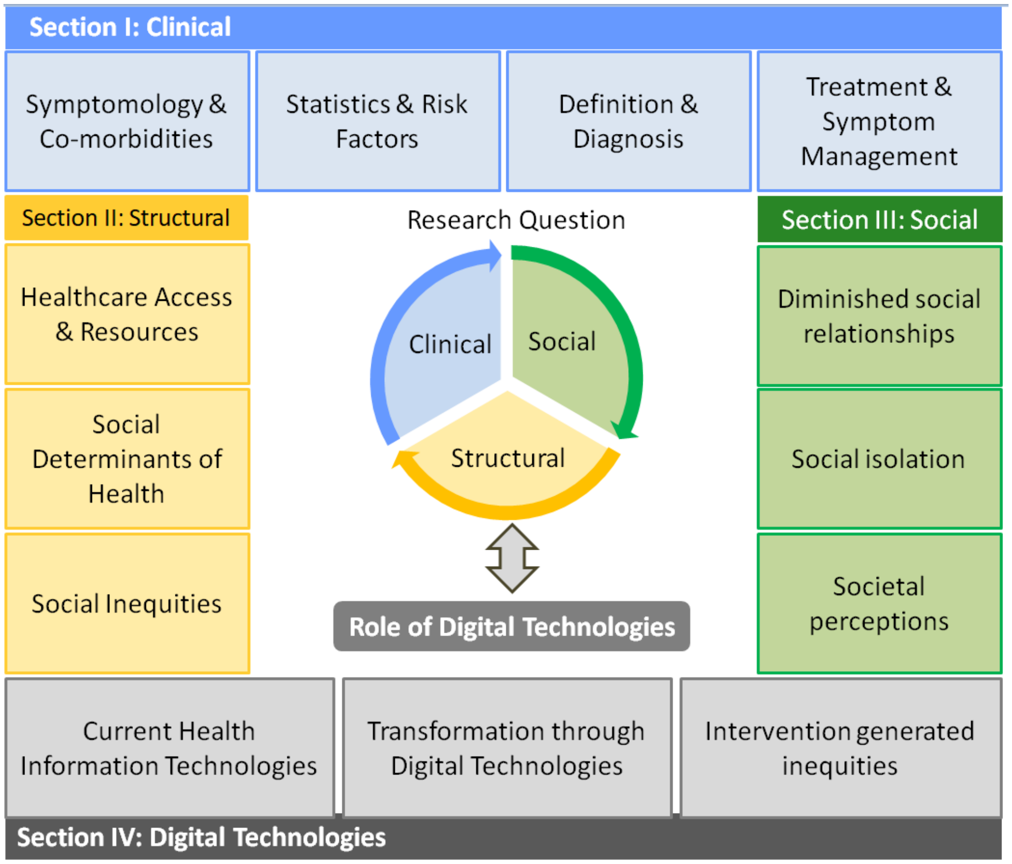


Introduction

This chapter will provide a background on the evidence, supports and current gaps specific to chronic obstructive pulmonary disease (COPD). The health equity lens guiding this review is based on a transformative paradigm that prioritizes challenging the status quo and questioning how knowledge is prioritized (Mertens, 2007). Thus, this review will be accompanied by a critique on how the dominant discourse in the academic literature may be reinforcing inequities and negative perceptions for the COPD population. The chapter will begin by examining symptoms, risk factors, diagnosis and treatments related to COPD and how this knowledge may be impacting perceptions towards the illness. Two health informatics strategies, patient-centered care systems and consumer health informatics will be explored for their potential in empowering the COPD population. This will be followed by an examination of how current prioritization of self-management interventions for chronic illness fail to recognize the contextual and societal structures that are impacting the overall outcomes and experiences for people living with COPD. In response to the dominance of self-management strategies that are overlooking the social and health inequities experienced, digital technologies (DTs) will be introduced for their potential in supporting social connectedness.

There are multiple concepts presented in this chapter, which on their own are considered complex: the factors that influence diagnosis, progression, treatments and outcomes of COPD, health inequities, the role of 'the social' on illness, and the mediating effects of technology (Latour, 2005; Solar & Irwin, 2010; Vestbo et al., 2013). Figure 2.1 provides a map of the concepts within this chapter, as an aid in navigating through this complexity. A transformative lens is applied throughout in presenting clinical.

Figure 2.1 *Conceptual Map of Chapter Two*



considerations for COPD, structural health and social inequities, considerations for 'the social' aspect of COPD, and the roles of DTs.

Addendum: The literature review was conducted in 2017-2018, prior to the coronavirus disease-2019 (COVID-19) pandemic. The additional contextual piece of COVID-19 was not brought into this literature review for two main reasons: 1) data collection began prior to the pandemic, so COVID-19 was only part of the current context of the stages within the study; and 2) the literature review provides a step back in time just prior to COVID-19, when inequities, technological solutions for maintaining social connectedness, living with uncertainty, and risk of a viral infection were not yet part of the dominant discourse. While the literature review section will maintain the context for where the study was originally situated, the significance of the pandemic will be brought into the results and discussion.

Clinical Overview of COPD

Symptomology and Co-morbidities

COPD is an umbrella term that serves to capture a range of chronic lung diseases, and is most commonly identified with emphysema and bronchitis (Bourbeau et al., 2017; Evans et al., 2014; Vestbo et al., 2013). It is an illness characterized by decreased breathing function and repeated "scary" breathing events (i.e., exacerbations) that can be fatal (Bourbeau et al., 2017; Gore et al., 2000; Hoogendoorn et al., 2011; Molzahn et al., 2021; O'Donnell et al., 2007). Exacerbations experienced with COPD involve increased coughing, wheezing and sputum production that is often painful and can have long term impact on overall lung function, resulting in diminished quality of life (Bourbeau et al., 2017; Vestbo et al., 2013). As COPD progresses, people can have increased muscle and weight loss, as well as fatigue that can contribute to decreased physical ability and increased risk of falls and hospitalization (Agustí et al., 2002; Lahousse et al., 2016; Marengoni et al., 2018).

The factors impacting quality of life for people living with COPD are further complicated by multiple co-morbidities (Decramer et al., 2008). On average an individual living with COPD has 3.7 co-morbidities, with common conditions being cardiovascular disease, diabetes, osteoporosis, anemia, and anxiety/depression (Decramer et al., 2008; Mapel et al., 2000; O'Donnell et al., 2007). Depression and anxiety can become more severe, as symptoms worsen and exacerbations become more frequent (Gore et al., 2000; Kim et al., 2000; Quint et al., 2008). After receiving a diagnosis of COPD, people's physical activity may quickly reduce, which may hasten the progression of COPD and other associated co-morbidities (Decramer et al., 2008). Regular physical activity reduces the risk of mortality and hospitalization for people with COPD (Garcia-Aymerich et al., 2006; Waschki et al., 2011). Sachdev et al. (2006) found a relationship between lung function and overall level of physical activity, and physical activity may impact overall cognition. Although the specific relationship between COPD, lung function and cognition remains unclear, the cognitive decline distinct to COPD may contribute to increase mortality and disability (Dodd et al., 2010).

Statistics and Risk Factors

COPD is a fatal chronic illness which is estimated to become the third leading cause of death worldwide by 2030 (Vestbo et al., 2013; World Health Organization, 2017a). In Canada, COPD is the leading cause of hospitalization and re-hospitalization (Benady, 2010; Canadian Institute for Health Information, 2008a; Public Health Agency of Canada, 2007). People who smoke have a 12 to 13 times higher chance of dying from COPD than people who have not smoked (Vestbo et al., 2013). The impact of smoking is often delayed and symptoms of COPD can appear decades after beginning smoking (Sørheim et al., 2010). What is less clear is the influence of risk factors that are genetic and those introduced over the life course (Vestbo et al., 2013). These may include having prenatal influences, a history of childhood respiratory infections or asthma, and overall air quality resulting from outdoor air pollution, home cooking environment and occupational hazards (Bourbeau et al., 2017; Martinez, 2016; Soriano et al., 2009; Vestbo et al., 2013; World Health Organization, 2017a). However, aging can also be viewed as a risk factor for COPD, since the deterioration of organs, including the lungs, is an anticipated natural symptom of aging

(Sadatsafavi, 2017; Soriano et al., 2017). It is estimated that 25.4% of Canadians over the age of 80 may be living with COPD, compared to 19% between the age of 60 to 79 and 11% of Canadians between the age of 40 to 59 (Public Health Agency of Canada, 2016; Statistics Canada. Health Statistics, 2013).

I am cautious in presenting these statistics on healthcare utilization and risks, as they only illustrate the endpoint of a complex intersection of factors that have resulted in different outcomes for different populations. Presenting these numbers without recognizing this complexity may reinforce narratives of healthcare utilization that continue to stigmatize particular populations. Dominant discourses on the economic costs of illnesses (Ehteshami-Afshar et al., 2016) are evident through labels such as 'frequent flyers of the healthcare system' (Bieler et al., 2012; Byrne et al., 2003; George et al., 2016; Michelen et al., 2006). People within lower socioeconomic status groups are more likely to live with a chronic condition, and thus may have greater need for the healthcare system. Yet, stigmatizing views towards poverty and certain illnesses persist, in which individuals are viewed as not 'paying' for this service, and being a 'burden' to the broader society. However, these perspectives fail to recognize the policies, organizational structures and material circumstances that result in different health outcomes based on one's position in society (Bieler et al., 2012; Byrne et al., 2003; Marmot et al., 2008; Michelen et al., 2006). Thus, rather than look at statistics, risk factors, and costs as simple cause and effect, there needs to be recognition of the complex factors across the life course that determine healthcare utilization and illness outcomes. This next section will further examine how reducing COPD to a single risk factor may result in further harm to this population.

Defining and Diagnosing COPD

The concept of COPD began to emerge in the mid twentieth century, when healthcare practitioners and researchers were moving away from promoting smoking as a safe behaviour (Briscoe & Nash, 1965; Petty, 2006; Smith & Leggat, 2008). Bronchitis and emphysema were incorporated into the COPD umbrella term for respiratory illnesses that were commonly linked to smoking, and many of the definitions for COPD began by focusing on individual health behaviour, followed by the pathology. As recently as 2007, the Canadian Thoracic Society defined COPD as a respiratory disease that is "*largely caused by smoking* and is characterized by progressive, partially, reversible airway obstruction and lung hyperinflation, systematic manifestations, and increasing frequency and severity of exacerbations" (O'Donnell et al., 2007, p. 6B)[3].

Since smoking is often conveyed as the greatest risk factor for COPD, the illness is often portrayed as preventable (GOLD national leaders, 2020; O'Donnell et al., 2007; Vestbo et al., 2013). As a result, people living with COPD may feel stigmatization, shame, guilt and responsibility for an illness that is 'preventable' (Berger et al., 2010; Halding et al., 2011; Harrison et al., 2015). In a qualitative study examining people living with COPD who spoke about their experiences of feeling "underprivileged, sometimes exploited, and discredited because of value judgments regarding their diagnosis" due to the perceptions of being responsible for their illness (Halding et al., 2011, p. 102). These judgments have

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[3] Since I began my research there here has been a notable, encouraging shift as to how COPD is being defined. The Mayo Clinic's (2020) definition begins with etiology that recognizes the impact of "long-term exposure to irritating gases, or particulate matter". Similarly, the Canadian Thoracic Society (2019) introduces COPD by recognizing the complex interplay of factors across the life course that go beyond smoking (e.g., childhood asthma, biomass exposure) Bourbeau, et al. (2019) .

filtered down throughout all aspects of society including healthcare, and thus, COPD patients may not receive the same level of research, care and supports as other illness groups (Barnes, 2007; Berger et al., 2010; Gardiner et al., 2010; Halding et al., 2011). Barnes (2007) finds that in spite of the growing global epidemic of COPD, the perceptions around smoking has resulted in COPD being viewed as a "less worthy" disease and is "relatively neglected among common diseases" (p. e112-e113). The impact of attitudes toward COPD is evident in the limited research on the cellular, genetic and environmental causes of COPD, and development of successful interventions that can slow the progression of illness (Barnes, 2007). There is evidence that when COPD is properly supported, it can lead to decrease fear, pain, anxiety and improve overall quality of life (Benady, 2010; O'Donnell et al., 2007). Access to receiving therapies and medications to support quality of life has its own barriers, as perceptions and beliefs around respiratory illnesses can delay a diagnosis of COPD.

Four percent of Canadians have been diagnosed with COPD, yet, it is an illness that often goes under-diagnosed, and it is estimated that the prevalence rate is two to six times higher than the self-reported diagnosis rates (Evans et al., 2014)[4]. Spirometry testing is recommended to accurately diagnose and distinguish COPD from other respiratory illness (Vestbo et al., 2013). This is a ten minute test that can be completed in a primary care setting and involves breathing into a hand-held device (The Lung Association, 2015; Vestbo

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[4] Throughout this dissertation I refer to 'people living with COPD', however, a more accurate description is 'people living with a diagnosis of COPD'. 'People living with COPD' fails to capture the individuals who may be unaware that they are living with a chronic illness where early treatment can improve outcomes and experiences over the illness trajectory. The under-diagnosis of COPD may be contributing to another avoidable and unjust outcome.

et al., 2013). Yet, spirometry testing continues to be underutilized; in BC, only 37% of newly diagnosed COPD patients had undergone a spirometry test (Camp & Levy, 2008). The reasons for this are unclear, physicians state discomfort with the test and a lack of access to testing facilities, and question the need for spirometry testing for COPD patients (Camp & Levy, 2008).

Another factor that should also be taken into consideration is how societal perceptions towards stigmatized illnesses may influence testing practices and diagnosis. A study examining physicians' perceptions of COPD found that 79% (n=145) of physicians agreed that "current smokers with COPD were most at fault for their condition" and 80% of physicians placed more blame on smokers with COPD when compared to other illnesses associated with substance-use (Winstanley et al., 2008). Klimathianaki (2006) challenges the resulting inequities and discrimination within healthcare by views that suggest "that since smokers voluntarily expose themselves to smoking, despite being intensively warned against it, they are responsible for their disease burden and society is not obliged to pay for their health care expenses" (p.443). The prioritization of healthcare and research resources may also be contributing to COPD misdiagnosis due to low quality spirometry testing and training, lack of a standard definition for COPD and limited knowledge of COPD amongst healthcare providers (Hangaard et al., 2017).

Patients may also avoid seeking a diagnosis. It is not uncommon for a person to first become aware of their diagnosis after hospitalization due to breathing difficulties, and 40% of people are first diagnosed with COPD after experiencing a severe exacerbation (Sadatsafavi, 2017). Soriano et al. (2009) refer to the "historical nihilism" that involves both patients and doctors "establishing blame and blatantly denying a medical problem exists" (p. 725). When people were asked about their experiences of being diagnosed with COPD they stated that they "no longer felt like being full members of the 'world of the healthy' nor did they receive the anticipated support of their social circles... [and they] often felt discredited because society judged their diagnosis to be smoking-related and self-inflicted" (Halding et al., 2011, p. 102). The importance of early diagnosis of COPD has been compared to successful early cardiac interventions that have resulted in significant reductions in morbidity and mortality rates (Soriano et al., 2009). When COPD is properly treated there is a reduction in the severity and incidence of exacerbations and overall illness progression (Benady, 2010; Bourbeau et al., 2017).

Treatment and Symptom Management

After diagnosis the continuing perceptions towards illness can influence COPD patients to not seek healthcare treatment. To date there is no conclusive evidence that pharmacological treatments can change the long-term progression of COPD (Global initiative for chronic obstructive lung disease, 2019). However, medications can be used to treat and reduce the severity of exacerbations, and improve symptoms, physical activity tolerance and overall health status (Global initiative for chronic obstructive lung disease, 2019). In a Canadian study, it was estimated that 67% of exacerbations go unreported to healthcare providers (Wilkinson, Donaldson, Hurst & Seemungal, 2004 in (Seemungal et al., 2009). This is a statistic that is even more alarming when considering that exacerbations speed disease progression and a severe event can be fatal (Benady, 2010; Seemungal et al., 2009).

Stigma towards COPD may also impact decisions around symptom management, as demonstrated through the limited adoption of pulmonary rehabilitation and oxygen therapy. Pulmonary rehabilitation is a self-management strategy that can increase quality of life and reduce hospitalization rates for people living with COPD. Yet, only 1.2% of Canadians living with COPD have participated in a pulmonary rehabilitation program (Brooks et al., 2007). A study examining pulmonary rehabilitation programs after an acute exacerbation found that people may not participate due to guilt, self-worth, societal perceptions and a desire to limit burden on others (Harrison et al., 2015).

Oxygen therapy is another intervention for COPD and has been found to reduce mortality rates and improve cognition skills, motor ability and quality of sleep (No Author, 1980, Block, Castle & Keitt, 1974, Leggett & Flenley, 1977, Stewart, Hood & Block, 1975, and Vergeret, Brambilla & Mounier, 1989 in (Earnest, 2002). However, people with COPD may avoid adopting oxygen therapy as the tank can serve as an "advertisement" for their illness (Earnest, 2002). The benefits of oxygen therapy may not outweigh the additional suffering of stigma and embarrassment introduced through the increased visibility of COPD (Arnold et al., 2011; Earnest, 2002).

There are also specific strategies within health informatics for symptom management of chronic diseases that will be visited later in this chapter when looking specifically at how information technology interventions can support people living with COPD. Up until this point, the transformative approach has been to examine how perceptions towards smoking and the resulting stigma and discrimination can impact outcomes and experiences for people living with COPD. In this next section, the transformative paradigm will be applied to examine the relationship between the social determinants of health and how socioeconomic status, cultural identity and gender impact experiences and outcomes of people living with COPD.

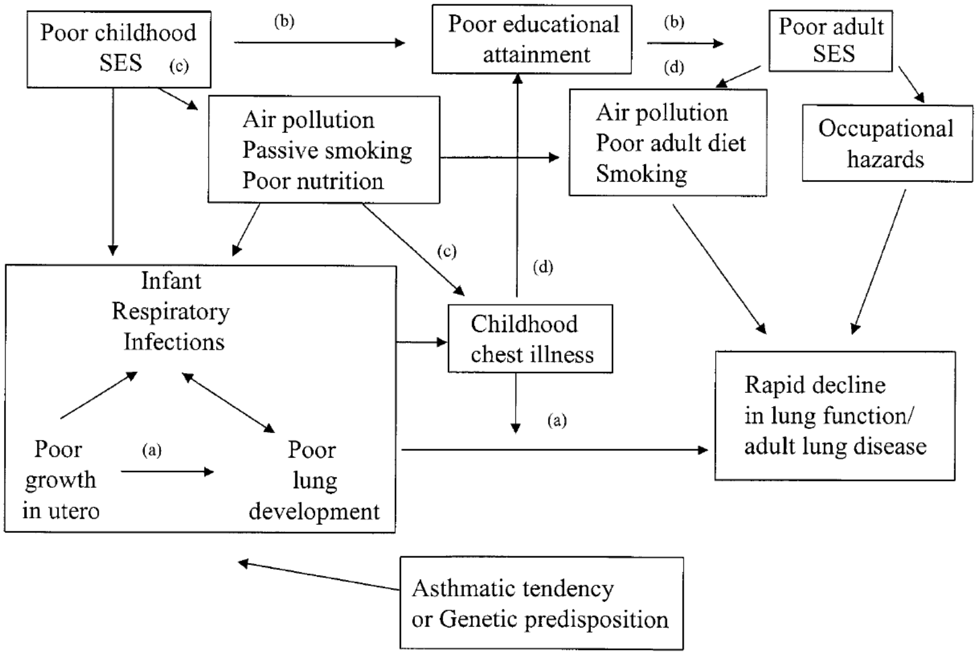
Structural Inequities

Health equity acknowledges the avoidable inequalities that are introduced through system, social and economic structures (Marmot et al., 2008; Povall et al., 2014; Whitehead, 1991). To address inequities, a transformative approach prioritizes the "structural preconditions" and the "powerful vested interests" that may result in poorer health outcomes and experiences (Greenhalgh, 2009; Mertens, 2007). For COPD, there are multiple levels of inequities occurring that are directly impacting the care people seek and their overall quality of life. As described in the previous section, there is societal inequity, wherein the societal perceptions towards smoking may result in self-blame and stigma that may be contributing to the under diagnosis and utilization of treatments for people living with COPD. There are also the inequities that are introduced at the healthcare system level, in the recognition that COPD is viewed as "the poor cousin" to other chronic illnesses (Barnes, 2007; Sadatsafavi, 2017). Although COPD is viewed as an epidemic, with the highest rates of hospitalization and re-hospitalizations when compared to other chronic illnesses, it continues to receive fewer dedicated healthcare, community and research resources (both human and fiscal) (Barnes, 2007; Bourbeau et al., 2017; Gardiner et al., 2010; Gore et al., 2000).

There are also the inequitable outcomes related to COPD that are reinforced across the life course based on where people are born, live, work and play (Ben-Shlomo & Kuh, 2002). Figure 2.2 illustrates the complexity involved in the multiple structural and social factors that influence rates of respiratory illnesses over the life course. Social determinants

Figure 2. 2 *A Life Course Approach to Chronic Disease Epidemiology: Conceptual Models, Empirical Challenges and Interdisciplinary Perspectives*

(Ben-Shlomo & Kuh, 2002) Reproduced with permission from the International Journal of Epidemiology



The figure demonstrates different pathways across the life course that influence incidence of chronic respiratory disease. The biological pathway is represented by (a). The social model is represented by (b). A socio-biological pathway that acknowledges the impact of low childhood socioeconomic status (SES) on incidence of respiratory illness is represented by (c). A bio-social pathway that reflects how repeated childhood illnesses can impact socio-economic status and educational level is represented by pathway (d).

such as income, geographic location, education, gender, culture, race and ethnicity can impact incidence, hospitalization rates, mortality rates and quality of life for people living with COPD (Brennan Ramirez et al., 2008; Disano et al., 2010; Jackson et al., 2013; Prescott et al., 2003). Social determinants are broader than material circumstances and individual characteristics and extend to social norms, healthcare structures and social policies that influence access to healthcare, illness perceptions and who receives care (Metzl & Hansen, 2014; Solar & Irwin, 2010; World Health Organization, 2017b). Through a social determinants perspective, COPD (and other chronic illnesses) are not viewed as self-inflicted, rather there is recognition of the socioeconomic conditions, and societal norms that influence health behaviours and outcomes of specific populations; where one is 'born, grows, lives and ages' is the strongest predictors for health outcomes (Solar & Irwin, 2010; Wesche et al., 2010; World Health Organization, 2017b).

People who fall within lower socio-economic groups are more likely to smoke due to the intersection of complex factors, which includes tobacco industries targeting selective populations, social norms, and the increased stress and anxiety that can come from living in poverty (David et al., 2010; Mentis, 2017). A demonstrable link has been found between COPD, low socioeconomic status (SES), gender, race, social isolation and increased rates of hospitalization (Canadian Institute for Health Information, 2008b; Disano et al., 2010; Mamary et al., 2018; Trachtenberg et al., 2014). Similarly, a Canadian systematic review found that people with COPD that fall within the lowest SES group had double the likelihood of experiencing poorer health outcomes compared to those within the highest income group (Gershon et al., 2012).

Compared to the overall Canadian population, there are significantly higher rates of COPD amongst First Nations (2.3-2.4 times higher), Inuit (1.86 to 2.10 times higher) and Métis (1.59-1.67 times higher) that are the result of the complex intersection of the social determinants of health (Ospina et al., 2015). In Canada, social and economic policies, colonialism, social exclusion and hidden racism towards Indigenous populations have been responsible for creating extreme health disparities amongst First Nations, Inuit and Métis (Loppie Reading & Wien, 2015). Continuing colonialist practices continue to impact Indigenous populations in Canada, where federal-provincial jurisdictional challenges, limited control over resources capacity, and lack of funding can exacerbate lung conditions and overall health (Wesche et al., 2010;Czyzewski, 2011). There are also the shared disparities between Indigenous populations and low and poor income countries, where epidemiological and housing factors influence incidence of respiratory illness (Ospina et al., 2015; Wesche et al., 2010). This may include cooking with biomass fuel, poorly ventilated homes, remote locations, prenatal and childhood exposure to smoking, as well the additional stressors of lack of employment, poverty and overcrowded housing that does not offer a place of respite (Loppie Reading & Wien, 2015; Ospina et al., 2015). A social determinants of health approach aims to address these health disparities by focusing in on the "distal, intermediate and proximal determinants of health [that] are associated with increased stress though lack of control, diminished immunity and resiliency to disease and social problems" (Loppie Reading & Wien, 2015, p. 24).

Historically, COPD has been reported as a chronic illness affecting older white men. However, over the past two decades the prevalence rates of this illness have shifted (Ohar et al., 2011). In Canada, starting in 1950 there was a steady increase in mortality rates among men living with COPD, which then began to decrease in 1998 and then reached a plateau in 2011 and have started to decline (Bryan & Navaneelan, 2015). For women the death rates from COPD have been on a steady rise and they have not yet reached a plateau (Bryan & Navaneelan, 2015). As a result in Canada, gender difference in the mortality rates of COPD no longer exists (Bryan & Navaneelan, 2015).

It has been hypothesized that although smoking rates amongst women are not as high as for men (both in terms of overall numbers of individuals and packs/year), women may be experiencing higher mortality rates, due to biological differences in how smoking compromises lung function for women (Aryal et al., 2013; Gan et al., 2006; Hardin et al., 2016; Prescott et al., 1997; Sørheim et al., 2010). Although it may initially appear that this difference in health outcomes is due to the biological differences, a further examination of the supports women with COPD receive reveals further gender related inequities. Compared to men, women living with COPD are more likely to report poorer quality of life and experience higher rates of misdiagnosis, late diagnosis, and delayed hospitalization (Aryal et al., 2013; Centers for Disease Control Prevention, 2008; Hangaard et al., 2017; Martinez et al., 2012; Ohar et al., 2011), and younger women are at greater risk of exacerbation and experiencing severe dyspnoea (DeMeo et al., 2018). The perceptions of COPD as still being viewed as an illness predominantly affecting men may be impacting the care women are receiving (Ohar et al., 2011).

Gender-related health inequities also exist among sexual and gender minorities who are living with lung disease. Most apparent is the limited research available on COPD rates for sexual and gender minorities (Cabrera-Serrano et al., 2019; Clausen & Morris, 2017). One of the few studies on gender-related inequities and COPD, found transgender individuals within Canada had higher rates of COPD (2.4% versus 1.5%) compared to cisgender individuals. While a study in Puerto Rico, found a lack of targeted health promotion strategies to address the higher prevalence of smoking amongst the LGBTT community may be contributing to increased incidence of COPD (Cabrera-Serrano et al., 2019).

'The Social'

There are also the social inequities that may be introduced with increased social isolation experienced with COPD progression (Antonio et al., 2017; Ek et al., 2011; Ek &

Ternestedt, 2008; Gardiner et al., 2010; Molzahn et al., 2021). In a US retrospective study, when compared to other older adults over the age of 70, people with COPD were less likely to engage in social activities (32.6% vs 26.3%), and more likely to die (70.7% vs 60.4%; adjusted risk ratio 1.15, <,0.05) (Liu et al., 2014). There are an increasing number of people with COPD who are living alone, with exacerbations more likely to be solitary and unsupported (Ek et al., 2011; Statistics Canada, 2015). Repeated, untreated exacerbations can lead to poorer overall quality of life and an increased burden of disease (Seemungal et al., 2009).

Overall research on the context factors that impact 'the social' has found that health outcomes are improved through social networks, whereas social isolation leads to greater rates of depression, anxiety and mortality (Berkman, 1995; Hill et al., 2008). Symptom management, quality of life and overall mental and emotional health are improved when people living with COPD have family and community support (Barton et al., 2015; Gardiner et al., 2010; Greenhalgh, 2009; Harris, 2007). Social support has been found to be a critical component for people with COPD to maintain physical activity after participating in pulmonary rehab programs (Robinson et al., 2018), and to benefit mental health and self-efficacy (Barton et al., 2015). The significance of addressing 'the social' aspect is exemplified in a phenomenological study when a participant spoke about their experiences of COPD near end of life: "some of it is the medical aspect…(taking medicine, etc.), but that's the smallest part…the big problem is the social aspect…but no one takes that into account…the healthcare staff never ask about this…but it's the social aspect that's important" (Ek & Ternestedt, 2008, p. 475).

Being part of a community is an integral part of being human, as we are social beings. However, the complex relationship between social determinants of health, smoking rates and progression of COPD may actually compromise this sense of belonging. People's social group may consist of other people around them who smoke, where smoking cessation programs may diminish a person's social network by discouraging people to be around others who smoke (Antonio et al., 2017). Relationships may be impacted by the stigma and judgment people feel in living with a debilitating illness, and family members' changes in responsibility (Gabriel et al., 2014). As COPD progresses, people may not want to share experiences that focus on their illness (Gabriel et al., 2014). Social class not only influences smoking rates, but the ability for one to feel connected and empowered to make change within broader society in addressing inequitable experiences of (Mentis, 2017).

Stigma and blame towards COPD that discourage people from engaging with their community is only one form of social isolation that is experienced by the COPD population (Berger et al., 2010). There is also the social isolation that is the result of co-morbidities, and illness progression and the external environment. The progression of COPD results in a reduction in physical function, which can result in becoming more home-bound and making it more challenging to maintain relationships and engage with one's community (Ek & Ternestedt, 2008; Gardiner et al., 2010). People living with COPD may be hesitant to engage with their community for fear of experiencing an exacerbation due to the added risk of influenza or overall air quality and the added strain on social and physical activities (Antonio et al., 2017; Ek & Ternestedt, 2008). Oxygen therapy also introduces physical barriers that may result in people having reduce access to their community (Antonio et al., 2017; Arnold et al., 2011; Cullen, 2006).

These forms of social isolation historically have not been considered inequitable, as until recently there have been few viable strategies that could address the social isolation experienced with increased severity of COPD. A scoping review focused on social support and social networks for people living with COPD found limited understanding on the characteristics of social networks, and interventions that allow for social supports to be maintained (Barton et al., 2015). As will be proposed later in this chapter, the emergence of DTs offer a novel social environment, in which existing social networks are not lost and new ones can be created. The *social connectedness* afforded through DTs could be of greatest benefit to people living with COPD, and yet there is the risk that our current technological systems may be generating new inequities. Social inequities may be perpetuated while the overall population is gaining new ways to support social networks, the progression of COPD leads people with this illness to diminished social networks. The digital divide may be introducing health inequities, in which the impact of the social determinants of health may further limit access and utilization of these technologies in supporting COPD individuals' illness outcomes and experiences (Fox, 2010; Merolli et al., 2015). These "intervention generated inequities" (Lorenc et al., 2013) go beyond technology access related to social determinants of health, but are being reinforced through the lack of research dedicated to examining the potential of DTs in addressing the social isolation experienced with COPD.

Up until this point in the chapter the focus has been on the current gaps in addressing the social and health inequities, and outcomes and experiences for people living with COPD. In this next section, I critique current health informatics strategies in their ability to achieve their aim of empowering patients, addressing inequities and improving patient outcomes. I then propose DTs as a possible strategy to support social connectedness and illness outcomes and experiences for people living with COPD.

Current Health Information Technology Strategies

Health information technologies (HITs) are information technologies that have been designed and implemented within the formal healthcare system to improve efficiency and resource use, and patient care, safety and satisfaction (Wallask, 2021). Within Canada, there has been increased interest in patient-centred technologies, such as patient portals. These HITs aim to improve outcomes for people living with chronic illness by empowering patients in self-management, care coordinating of their "problem list", and encouraging "adherence″ and "compliance″ of their medications and treatments (Ammenwerth et al., 2012; Demiris & Kneale, 2015; Gee et al., 2015; Ozbolt et al., 2014).

In applying my transformative approach, I have questioned the dominant narratives represented within patient-centred technologies, whereby these technologies may not be empowering, but rather may be reinforcing power differentials (Antonio et al., 2019). Terms such as 'management', 'adherence' and 'compliance' are terms that identify with 'the good patient', as one who is willing to adhere to interventions in addressing their 'problems′. Weust (1993) questioned whether terms such as "compliance" empower the patient, but rather reinforce a paternalistic system that serves to inhibit client's autonomy (Crespo-Fierro, 1997). The perception of 'non-compliance' in regards to healthcare system that values adherence has particular significance in considering the underlying stigma experienced by people living with lung disease: the non-compliant patient is one who continues to smoke, and thus this characterization of non-compliance may result in unspoken, entrenched beliefs as to whether people are deserving of treatment (Björk et al., 2015). Similarly, Lupton (2014b) collation on the critiques on digitized health strategies found that these interventions often "represent individuals or social groups as ignorant, morally deficient and lacking self-control and the capacity to take appropriate responsibility for their health if they fail to take up health promotion imperatives" (p. 178).

In addition, patient-centred technologies are often developed to represent the values of the healthcare system, with patients' input and values as an afterthought (Klecun, 2016). Botin (2015) suggests that current health informatics strategies that are centred on 'the patient' may aim to incorporate values of "empathy, empowerment and emancipation", however, the reality is that "the opponent to the autonomy of the citizen [can be the] ... paternalistic and commanding attitude of medical staff and of the health care system" continue to be perpetuated through these health informatics platforms (p. 155). In a study examining communication between providers and patients with chronic conditions, the authors discussed how existing technologies are failing to "elicit and capture information about what is most important to people's lives, especially more abstract aspects such as values and beliefs" (Lim et al., 2016, p. 1179). In a systematic review that examined how human values are represented in patient portals, Simons et al. (2017) suggests that the lack of control in the design and support for patient values may deter people from using these technologies to manage their health. This is further evident in the low adoption rates of patient portals for populations where there is distrust of the healthcare system, due to past experiences of marginalization (Antonio et al., 2019) . Consumer health informatics have been proposed as a pathway for overcoming these power differentials in current HITs by incorporating consumers' information needs into the use of technologies to manage their health (American Medical Informatics Association, 2017).

Consumer health informatics has cross-over with patient-centred care technologies, but extends to HITs that may be selected by the patient without involvement of the formal healthcare system. However, the design and development of these technologies are informed by the dominant populations within the current healthcare structures and systems. Technology examples within consumer health informatics include social networking sites, electronic support groups and personal health records (Johnson et al., 2014). Consumer health informatics strategies are often focused on health education, literacy and information that support patient decision aids" and serve to "empower" the patient (American Medical Informatics Association, 2017). This perspective suggests that when patients are more educated on their health, they are more engaged in their health, have better health outcomes, and most significantly are less costly to the healthcare system (DeWalt et al., 2004). Yet this view may fail to take into the complex intersection of the social determinants of health. Rather, a transformative approach acknowledges that instead of the central focus being on how to improve patients' health literacy, we should also be considering how the healthcare system can be adapted to patients' context and skills (Heijmans et al., 2015). This highlights a key element of as to why I selected DTs as the focus of my dissertation: I wanted to understand how *patients are selecting* the technologies that match with what they *value* in managing their overall health.

Parameters that may be of value to patients may be quite different to what is of value to the healthcare system. Current consumer health informatics initiatives have focus on how technologies can support the healthcare system goals in communicating, monitoring and recording patient data (Gibbons et al., 2011). Contrastingly, people living with COPD stress the importance of the social, emotional and peer support offered through

DTs to address depressive symptoms (McCabe et al., 2014). Thus, my approach for this dissertation is focused on how DTs that support social connectedness, and are outside of the formal healthcare system, can impact the outcomes and experiences in living with COPD[5]. It is a position that aligns with a transformative approach, in challenging the socio-political power structures that result in social injustices and health inequities (Greenhalgh, 2009; Mertens, 2007). Most significantly DTs can offer a different approach to patient-centred technology and consumer health informatics, by taking *care* outside of the formal healthcare system and enabling *patients* to truly be at the *centre* by encouraging them to select technologies that match with their values and perspectives.

Transformation through Digital Technologies

There is great diversity in the types of DTs that are available and examples may include social media, SMS-text messaging, online forums, and Smartphone applications. Informed by Merolli's et al. (2013)_systematic review examples of social media include: 1) video conferencing (e.g., Zoom and Face Time); 2) mobile (e.g., text messaging, apps and wearable devices); 3) social media (e.g., Facebook, Instagram, Dailystrength and Twitter); 4) online support groups (e.g., forums, discussion boards, chatrooms and blogs); and 5) virtual worlds (e.g., Second Life). At the beginning of the research study, the definition of DTs was intentionally left quite broad, to limit my own preconceptions as to what technologies people with COPD may be using. The definition was not based on the *types* of

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[5] This chapter was initially written in 2018, when eHealth equity was an emerging term. Conceptually, ehealth equity has been focused on targeting industry, policies and the structures introduced through the formal healthcare system (Siminerio, 2013). I viewed ehealth from a broader lens by exploring how technologies outside of formal healthcare structures can address health inequities (Antonio et al., 2019). Over the past three year ehealth equity has gained more recognition, and there has also been an expansion of using digital health in applications that consider technologies outside of the healthcare system.

current technologies available. Rather, the definition of DTs was based on the *role* these technologies could serve, with examples being anonymity, communication, community building, engagement, education, identity, narration of experience, peer and emotional support, policy influence, self-management and tracking (Allen et al., 2016; Merolli et al., 2013; Moorhead et al., 2013). This next section applies this definition of DTs in examining how these different roles have been applied to supporting COPD and other chronic conditions.

Self-Management

Studies specific to COPD and DTs have focused on self-management through education tools, dyspnoea management and peer-based health promoting videos (Kaptein et al., 2014; McCabe et al., 2017; Nguyen et al., 2013; Sobnath et al., 2017; Stellefson et al., 2014; Talboom-Kamp et al., 2017). Self-management strategies have been critiqued for being governed by the healthcare structures that adopt the language of risk, and making people obligated to take on particular social roles in controlling and living with the uncertainty of a chronic illness (Morden et al., 2012). In addition, the evidence on self-management tools for chronic illnesses has been debated, where overall success for managing COPD is impacted by socioeconomic factors, overall health status, illness beliefs and level of social supports (Bos-Touwen et al., 2015; Dowson et al., 2004; Greenhalgh, 2009; Jonsdottir, 2013).

A Cochrane review on '*Computer and mobile technology interventions for self-management in COPD*' found limited evidence that self management through DTs may improve quality of life over the short-term, and more research was needed to evaluate their impact when utilized over the long-term (McCabe et al., 2017). A similar finding was found by Nguyen et al. (2013) when examining internet-based self-management tool for COPD: in a randomized control trial of 124 participants, no difference was found between interventions that focused on standard education, face-to-face self-management and web-based self-management. A more recent randomized time series study (n=702) had similar findings: when compared to usual care, a web-based self-management tool resulted in no difference in overall quality of life and health status for people living COPD (Talboom-Kamp et al., 2017). The Cochrane review by McCabe et al. (2017) shared similar conclusions as other systematic reviews and meta-analysis focused on chronic disease and DTs; there is a current knowledge gap in understanding the underlying mechanisms, and enablers and barriers that influence the success of these technologies (Khosravi et al., 2016; Merolli et al., 2015). This gap has particular relevance to the overall research question of this dissertation in examining the underlying role of DTs that are utilized by people living with COPD.

Psychosocial Factors.

Recent literature reviews on DTs that have looked beyond self-management have been considering how they can support psychosocial factors such as communication and peer and emotional support. Moorhead et al. (2013) found that social media has the potential to support health communication between the public, patients and healthcare providers. Benefits in using social media included increased interactions, greater availability to tailored health information, and peer, emotional and social support (Moorhead et al., 2013). This study also had findings specific to social change: social media could provide a channel for formation of groups who are impacted by the social determinants of health and historically have had limited access to health information and influence on health policy (Moorhead et al., 2013). Two literature reviews on social media and chronic disease reported benefits for psychosocial management, narration and social connectedness (Merolli et al., 2013; Patel et al., 2015). Virtual worlds are an emerging DT that may have particular significance for COPD, as they may address the psychosocial components, emotional health and limited face-to-face interactions (Hoch et al., 2012; Merolli et al., 2013). In examining various forms of DTs that addressed social isolation experienced by older adults, a systematic review found improved well-being through online supports that promote social connectivity (Khosravi et al., 2016). Through an examination of limited studies focused on COPD and DTs, a systematic review/meta-analysis of three studies suggested that Smartphones could be useful in reducing the frequency of COPD exacerbations (Alwashmi et al., 2016).

Socio-Structural and Community Building.

A distinct consideration for DTs is their potential for social transformations by providing a venue for people with similar experiences to meet and form a community (Berkman & Glass, 2000; Kanter et al., 2012; Minkler, 2005). Satariano and Wong (2012) refer to several publications in suggesting that DTs, such as social media, support "community organizing principles, such as listening to and assessing the community, ... developing a long-term action strategy, starting where people are, building community capacity and social capital and... promot[ing] community identity" (in Alinsky, 1971; Chávez, et al., 2010; Amsden & van Wynsberghe, 2005).

In spite of this recognition, minimal studies could be found that were focused on utilizing DTs to support community building for the COPD population. A systematic review of online communities for chronic disease found that DTs can provide a place for knowledge exchange through lived experience, modeling behaviour from others, peer engagement for validation and negate frustration, community building, narrative expression, and anonymity. Allen et al. (2016) and Himes and Weitzman (2016) examinations of online communities that provide people with similar illness experiences to connect (e.g., PatientsLikeMe) found no large studies that focused on the COPD population. One case study focused on the introduction of a web-site that specifically supported social connectedness for people with COPD, in connecting them to education resources and events in their community (Osborne & Patel, 2013). The main recommendation from this study was to consider how DTs may be impacting health equity: "populations that are already socially and economically disadvantaged are likely to further miss out on the benefits to be gained from online information and services because the 'digital gradient' overlays the social gradient" (Osborne & Patel, 2013, p. 329).

Possible Intervention Generated Inequalities

Before ending this chapter, there are some important precautions in considering the use of DTs as a strategy to support the COPD population. As previously referenced, DTs have the potential for creating "intervention generated inequalities" (Lorenc et al., 2013). The potential for DTs has yet to be fully realized, rather their introduction may be supporting a widening digital divide that is increasing health inequities (Lopez et al., 2011; Sarkar et al., 2011). People who are healthier and wealthier have greater utilization of DTs, which translates to having enhanced social and health supports (Hsu et al., 2005; Sarkar et al., 2010; Yamin et al., 2011). DTs are often viewed as the individualization of health, where the influence of the social determinants of health are not being recognized (Lupton, 2014a). Himes and Weitzman's (2016) examination of HITs specific to people with COPD raised the concern of widening disparities in health, as "most HIT tools have not been designed to address the concerns and barriers faced by racial/ethnic minority groups or those of low SES [socio-economic status] who are disproportionately affected by asthmas and/or COPD" (p. 5). Furthermore, the different literacy levels of individuals may be compounded through the introduction of DTs, since people with low literacy levels and limited social networks, may not have the resources to evaluate the vast amount of online health information (Osborne & Patel, 2013).

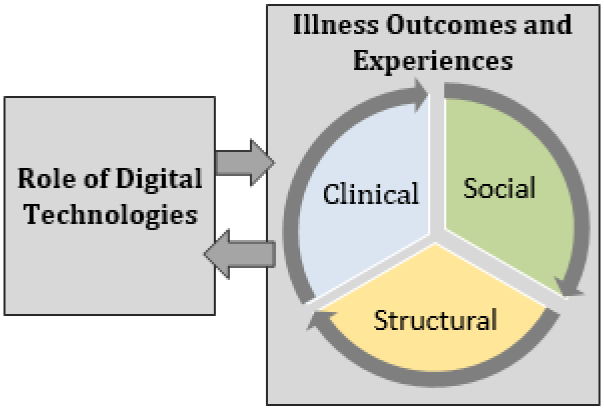
Another potential harm is the reinforcement of negative, stigmatizing experiences. DTs uniquely provide a venue for social engagement where people can remain anonymous, and thus, not be labeled or stigmatized due to their illness. Yet, this same anonymity may allow for cyber-bullying, resulting in the creation of online stigmatized places that may lead to further oppression of populations. Keene and Padilla's (2014) concept of *spatial stigma* acknowledges that stigmatized places may result in "both symbolic and physical distancing [that] may weaken the social fabric of marginalized [populations] and limit... access to health promoting, community-based social-support resources, social capital and opportunities for collective action" (p. 399). The authors however, also recognize that social integration, social support resources, community advocacy and strengthening social networks are necessary for the social transformation for groups that have experienced oppression (Keene & Padilla, 2014). Thus, although there are risks involved with DTs, the larger harm may come by not examining these technologies for how they can narrow the digital divide and support community building for the COPD population.

Summary

Current values within healthcare and broader society are compounding the inequities experienced by the COPD population. It is an illness that does not fit within our healthcare system's values in prioritizing self-management. As it is a fatal chronic illness, the long term outcome is known. However, the complex intersection of co-morbidities, environmental factors and social determinants of health makes it impossible to predict the specific progression for an individual. The perceptions of risks related to COPD characterization as a 'smoking disease' continue to deny people access to diagnosis, treatments and non-stigmatizing care. The 'risk' factors for experiencing a COPD exacerbation, which include influenza, air quality, and increased frailty due to limited physical activity, can compound experiences of social isolation.

DTs may be one avenue to address this social isolation, and improve overall outcomes and experiences of COPD. Although research on DTs to support chronic illness has predominantly focused on the self-management (Greenhalgh, 2009; McCabe et al., 2017), recent efforts have expanded to examining the psychosocial mechanisms of DTs, specifically peer, emotional and social support, and communication. There are limited examples as to how DTs can support illness experience and outcomes and social connectedness for the COPD population. To further understand how to approach this research gap, in the next chapter I will examine foundational theoretical and conceptual models specific to chronic disease, health equity, social determinants of health and social networks.

Chapter Three: Theoretical Foundations



Introduction

Chapter two examined foundational concepts that are being addressed within this dissertation: chronic obstructive pulmonary disease (COPD) and the relationship to outcomes experience and social connectedness, and digital technologies (DTs). A transformative approach was applied to expose how perceptions towards COPD prevent equitable access to care, resulting in delay diagnosis of COPD and treatment of symptoms. There are also the social inequities, which include people with COPD experiencing stigmatization within their community, and the lack of dedicated resources to addressing social isolation. DTs were then introduced as a possible strategy to transform these inequitable outcomes, by providing a venue where the values of people living with COPD can be supported. Chapter three presents common conceptual models referenced within literature related to these foundational concepts. I then examine how addressing the complexity of these inequities can be understood through Berkman and Krishna's (2014) conceptual model of how social networks impact health. Through this exploration, I introduce a core shift in how illness outcomes, illness experiences and social connectedness have been conceptualized within the research question.

The Search for a Methodological/ Theoretical/ Conceptual Framework

Illness-centric Models

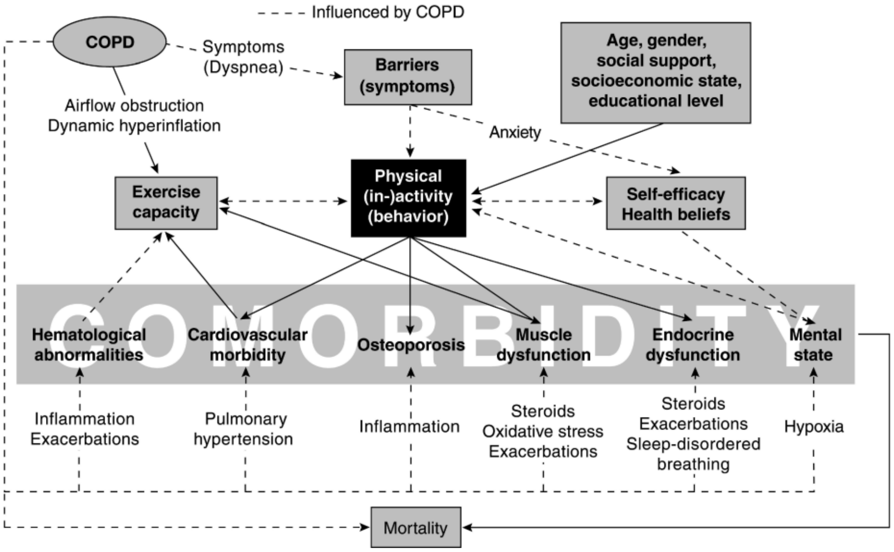
In understanding the complex factors impacting the physical, emotional and social health for the COPD population different theoretical/conceptual models were considered for this dissertation. The Chronic Care Model is commonly cited within COPD literature, and it has been extended to specific concepts within public health (e.g., health promotion, health equity and prevention) and health informatics (e.g., ehealth) (Barr et al., 2003;

Gammon et al., 2015; Gee et al., 2015; Glasgow et al., 2001; Kaptein et al., 2014; Stephens, 2008). The Chronic Care Model has a strong focus on the healthcare system in prioritizing self-management, decision support, clinical information systems, and delivery system design. It is a model based on the values of the healthcare system, in viewing self-management as an effective strategy for improved outcomes (Kaptein et al., 2014).

Decramer et al. (2008) provides a conceptualization of the relationship between symptoms of COPD, physical activity, social determinants of health, self-efficacy, and co-morbidities. The illustration in Figure 3.1 serves as a good foundation for explaining the complex factors intersecting with COPD, co-morbidities was the primary concept, physical (in)activity was identified as the emergent factor (as indicated by the central black box), and social support had a minor reference (as indicated in the top right box). This made me look to models that focused on health inequities to see if there was a better fit for the research question.

Figure 3. 1 *Systematic Consequences and Co-morbidities Related to COPD*

Decramer et al. (2008) ©Reproduced with permission by Taylor & Francis



Public Health Foundations

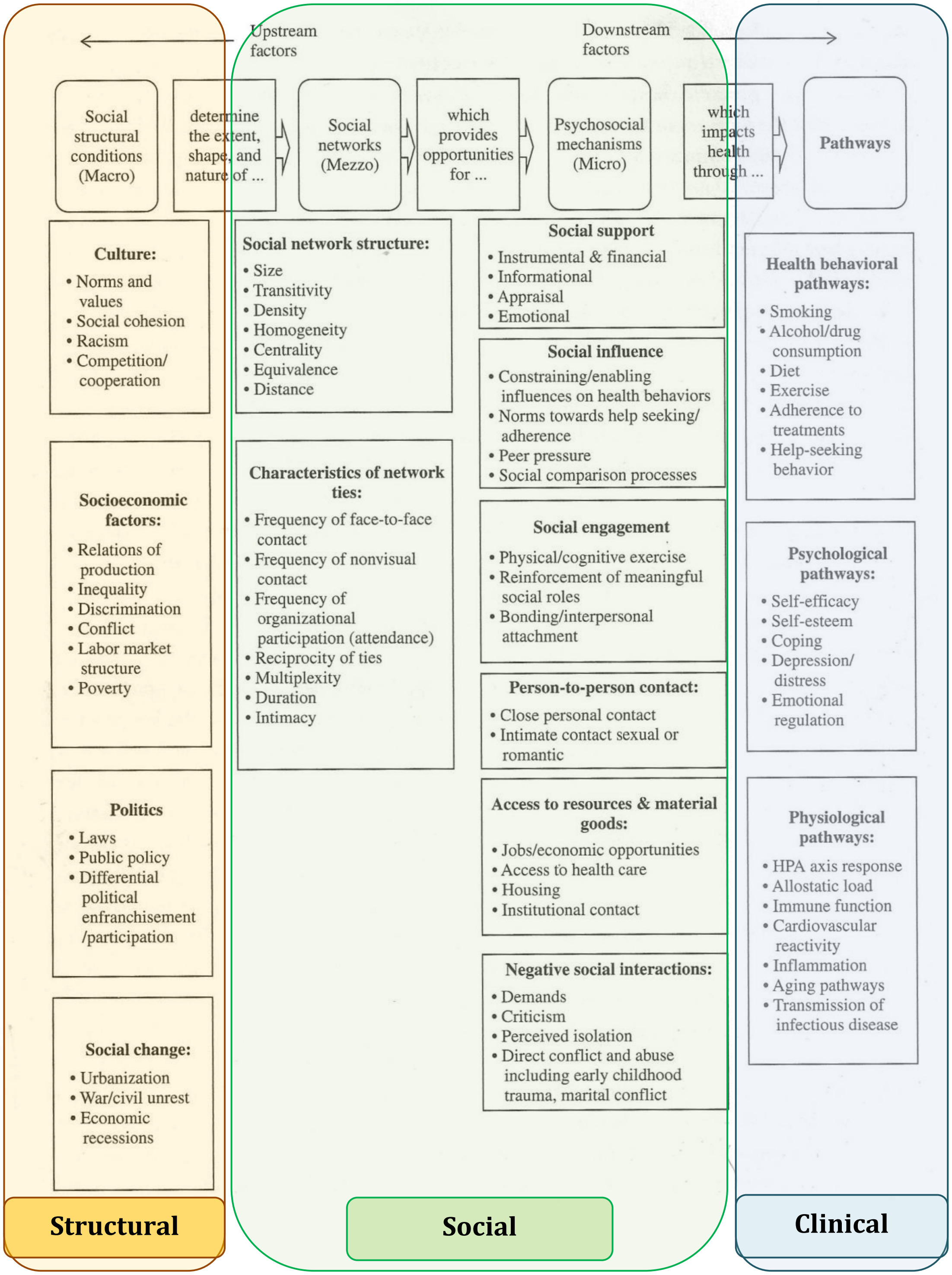
Although health equity is a key concept of this dissertation, I found that most theoretical models focus on mapping the *presence* of health inequities, rather than how to *address* inequities (Pauly et al., 2016). Similarly theoretical/conceptual models on the social determinants of health often are focused on distribution of illness and do not provide a strong conceptual focus on how to address the experiences and outcomes for people who were already diagnosed and living with a chronic illness (Marmot et al., 2008; Solar & Irwin, 2010). I found myself not fully identifying with these explanatory approaches in examining the inequities experienced with COPD. An explanatory approach often offers suggestions as to *why* inequities are happening, but provide little insights into *how to address* the impact of these ongoing inequities across the life course, or *why we should*. Explanatory theories may also reinforce power differentials in relying on knowledge valued within healthcare and the academy, and not recognizing the knowledge and voice of populations that experience marginalization. Further, the label of 'theory' prioritizes knowledge created through the academy and fails to recognize the implicit value judgments that occur in prioritizing healthcare and research goals. In order to address health inequities, it requires moving beyond the theoretical and recognizing the value judgments that lead to unjust health outcomes. Thus, for this dissertation health equity was not viewed from a theoretical perspective in *evaluating* whether health inequities existed. Rather, in applying Mertens' (2003, 2007) transformative approach, my aim was to explore how to address the inequities experienced by underserved populations by directly representing the knowledge and values of people living with COPD.

Through an examination of the different models that focused on chronic disease, health equity and social determinants of health, there emerged a shared conceptual parameter of 'the social' (e.g., community, social networks, social cohesion and social position), however, none of these models provided satisfactory details in examining 'the social'. The social isolation experienced by COPD highlights the significance in prioritizing how social connectedness can impact overall outcomes and experience. There has been great promise that the emerging DTs will lead to the "democratization" of populations who historically have had their voice diminished (Carroll & Hackett, 2006; Kaplan & Haenlein, 2010). I found myself navigating to Latour's concept of "reassembling the social", where rather than focusing on the pre-established, engrained social theories to explain health inequities, I looked to ways to encourage the interaction of the human and non-human objects (Latour, 2005). The emergence of DTs offered a new way to support emancipation, as their disruption may open up the "black box" of the complex structures reinforcing inequities (Latour, 2005).

Further consideration of 'the social', values and creation of social networks through digital technologies, lead me to Berkman and Krishna's (2014) conceptual model of how social networks impact health (see Figure 3.2). This model brings together multiple approaches in recognizing "the psychobiological processes that are dynamically linked together to form the processes by which social integration affects health to the macrosocial context in which network forms and are sustained" (Berkman & Krishna, 2014, p. 241-3). With foundations in social epidemiology, I initially identified with this model for its similar presentation as the WHO's model on *social determinants of inequities in health* (Solar & Irwin, 2010), however, the focus shifts to how *social networks impact health*. In this model,

Figure 3.2 *Conceptual Model of How Social Networks Impact Health*

(Berkman & Krishna, 2014) ©Reproduced with permission of the Licensor through PLSclear



social networks are not in reference to a methodology (i.e., social network analysis), or specific to a technological concept (i.e., computer networks). Rather the emphasis of the model is on the structural conditions, mechanisms, and pathways that impact *how* a person's social network can be enabling or constraining within health, and thus, offers a way to conceptualize how social networks may address inequities.

This highlights an important decision point in selecting the concept of 'social connectedness' within the research question. There is much theoretical and philosophical debate about the different social concepts (e.g., social networks, social capital, social connections, social connectivity and social isolation) (Berkman & Krishna, 2014; Chappell & Badger, 1989; Solar & Irwin, 2010). Similarly, to not wanting a formal definition of digital technologies, I did not want to select a specific aspect of 'the social' that would restrict how people with COPD may conceptualize 'the social'. As the study was designed to prioritize the knowledge of people with COPD, I did not want to get distracted by academic conceptual debates and theories that reinforce dominant conceptualizations of 'the social' (Latour, 2005). I landed upon social connectedness as it is often conveyed at the opposite end of the continuum to social isolation (Gardiner et al., 2016; Poscia et al., 2018) , and "connecting" was a word that resonated during first stage interviews.

Social Networks Impact on Health

To aid in examining this model further, the italicized words in this section highlight key concepts in relation to COPD. The *midstream* factors that are on the left side and highlighted in orange are most significant to the identified research gap in addressing the social *isolation* for COPD, and the potential of DTs to support developing and maintaining *social networks.* In chapter 2, specific focus was given on the *physiological pathways* that can contribute to an exacerbation (*immune function, inflammation, aging, transmission of infectious disease). Behavioural pathways* represent the discussion in chapter 2 on self-management tools and the rhetoric around *adherence* and *smoking*.

The *upstream, socio-structural conditions* represent the multiple factors that need to be considered in addressing health inequities for the COPD population: *norms and values*, *social cohesion*, *inequality*, *discrimination*, *poverty*, *public policy*, and *participation*. The transformative paradigm acknowledges the impact of labelling COPD as a *behavioural* disease, and the resulting societal and healthcare *norms and values* that are leading to *inequalities* and *discrimination*. The multiple levels of inequities that are experienced within the COPD population are compounding the social *isolation* that is already inherent with this illness. The recent emergence of DTs that support *social networks* puts these inequities at a cross-road, whereby these technologies have the potential to encourage *social engagement* and *social support* and most significantly *social change*. The model also represents many of the benefits of DTs identified within systematic reviews on chronic disease: *psychosocial management*, *social connectedness*, *emotional health* and support for those with limited *face-to-face interactions* (Hoch et al., 2012; Merolli et al., 2013; Patel et al., 2015). However, there must also be caution in only viewing these emerging DTs for their promise in addressing the social isolation. There are the potential harms that may emerge, which have been captured in the concept of *negative social interactions.*

How this Model was Applied

The structures of social networks that impact health are commonly examined through social supports. Berkman and Krishna's (2014) model provides additional mechanisms of "social influence, levels of social engagement and participation, regulation of contact with infectious disease, access to material goods and resources, and negative interactions" (p. 247). Applications of these mechanisms specific to COPD reveals how social networks can be impacted by stigma and discrimination, the fears in contracting an illness that may lead to exacerbation, and limited resources due to low socioeconomic status. However, DTs have the potential to address some of the historical barriers people with COPD experience in sustaining social networks. The model was used throughout the research study to explore the complex factors within 'the social' related to COPD individuals' utilization of DTs. This included returning to the model to a) determine questions for the stage-2 survey and stage-3 interviews; b) develop concepts for coding; and c) inform analysis as to how people were referring to use of DTs, social connectedness, and outcomes and experiences.

Possible Limitations of the Model

The reference to *face-to-face interactions* demonstrates one of the possible limitations of this model. The introduction of social media has introduced new forms of social connections that are no longer in-person. This model was created prior to the disruptive innovation of social media, so it may not have fully captured the unique considerations that are being introduced with the introduction of technologies that are offering novel methods of socialization. Latour's (2005) discussion on the role of objects and actors draws attention to a possible limitation of the model in considering the social as human interactions. Historically, only humans have been delegated the role of actors: "objects [not having] the chance to play any role before was not only due to the definition of the social used by sociologists, but also to the very definition of actors and agencies" (p.71). The line between humans and technologies are now becoming blurred. Humans are no longer "the subject" and technology are "the object", but there have emerged "quasi-objects" and "quasi-subjects" which may have their own agency (Latour, 1993). DTs such as social media are not only moving face-to-face (subject-to-subject) online social interactions, but also to face-to-virtual face (subject-to-object)[6] social interactions. Thus, in considering the role of DTs, it may not be enough to consider the traditional subject-object and subject-subject interactions, but the resulting actions that emerge through the blurring of boundaries between object and subject. The novel outcomes and experiences were explored by looking for the unexpected actions and creation of things that emerged through the interactions between DTs and people with COPD (Latour, 2005).

Berkman and Krishna (2014) point out that their conceptual model serves to pin-point specific areas of assessing social relationships. Applying this model in the design of an intervention should involve targeting specific mechanisms, such as social support, social networks and social integration (Berkman & Krishna, 2014). Due to the limited knowledge in both countering the social isolation experienced with COPD and the recent emergence of DTs, the MMR study was not focused on a specific mechanism within this model. Rather the exploratory study focused on areas across the model that were identified as current or novel roles for DTs for the COPD community.

The linear presentation of the model of *upstream* and *downstream* pathways reinforces some of the challenges experienced in locating a model that best serves the COPD population. In public health the emphasis on addressing the social determinants of health commonly involves targeting the structural forces that result in health inequities

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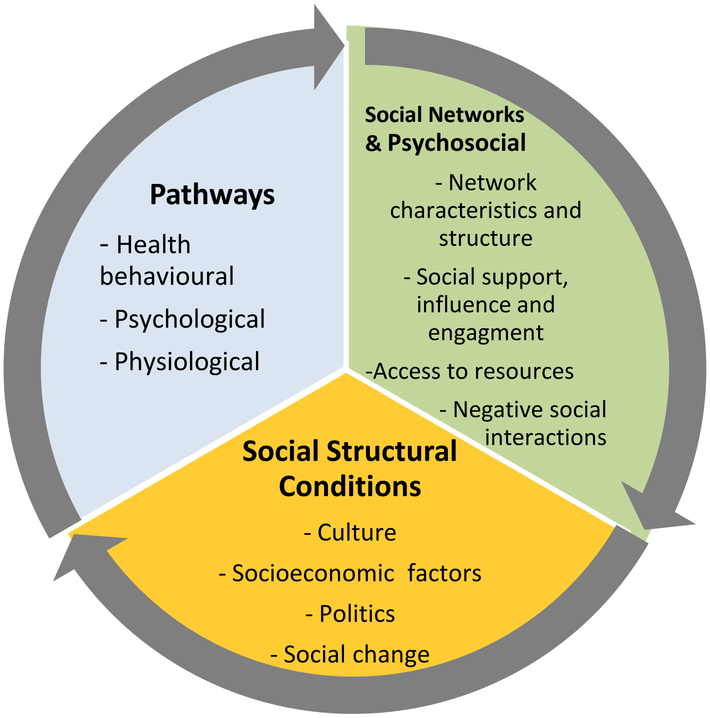
[6] I wrote this section in 2018. Now reading it at the end of 2020, these face-to-face virtual connections became even more significant during the pandemic.

and early childhood interventions to prevent chronic illness (Marmot & Wilkinson, 2005; Thornton et al., 2016). Through this lens, individuals are often moved out of public health's focus (and into primary care) once they develop a chronic illness or disability. However, people who are living with chronic conditions continue to be impacted by the social and structural conditions into which they were born. Thus, rather than taking an upstream/downstream view, where people with COPD are moved out of the public health lens, I sought to reconceptualise the model to emphasize the ongoing inequities that have been compounded over one's life course.

Transformation of the Model

Figure 3.3 represents the first stage of my re-conceptualization of Berkman and Krishna's (2014) model. The revised model contains the most pertinent concepts to this dissertation, while also recognizing that other concepts within the original model are intersecting with these primary concepts. The upstream, midstream and downstream factors are no longer linear, but are holistically represented to reflect the interconnection of social structural conditions, pathways and social networks across the life-course, and their combined impact on social connectedness, illness outcomes and experiences. For example, the norms and values around smoking, may result in negative interactions for someone living with COPD (social structural), that impacts their decision to access healthcare resources (social networks & psychosocial), and thus they may experience a more severe exacerbation (pathways). This holistic representation, serves to capture how the concepts of pathways, social networks and social structural conditions overlap and influence each other.

Figure 3. 3 *Stage One Transformation of Original Model*



Defining Experiences and Outcomes

A critical consideration in applying the revised model to the research question was how to interpret illness outcomes and experiences. These have not been separated out, but rather are seen as interconnected, as the encounters one has in life (experiences) impacts the end result (outcomes). Traditionally within clinical practice, outcomes have been described under symptomology (e.g., incidence of shortness of breath, number of exacerbations) and quantitative terms (e.g., hospitalization, morbidity and mortality rates). Crucially, these measures have not focused on the irreducibly qualitative nature of the *experiences* of dying from a stigmatized, incurable disease. This qualitative experience constitutes a significant outcome for this population, where people have poorer quality of life, late diagnosis, and higher mortality rates that are interconnected with societal and structural perceptions. As a reminder of this intersection between outcomes and experiences of COPD, there are specific sections in this dissertation where I have elected to use phrases such as 'living with a life-limiting illness' or 'fatal chronic condition'. In using these phrases I aim to illuminate the inequitable experiences that can lead to fatal outcomes for individuals with COPD.

The language around outcomes and experiences is further complicated by patient-reported measures[7], one of the tools that will be used within this study. These measures serve to represent patient voices and perceptions of living with illness, and recent focus has specifically been on patient-reported *outcome* measures (PROMs) and patient-reported *experience* measures (PREMs) (Canadian Institute for Health Information, 2015). For COPD specific 'PROMs', the focus is often on symptomology, physical function and psycho-social, and quality of life, and not the broader outcomes in living with a stigmatized illness symptoms (Cazzola et al., 2015). The experiences that are evaluated within PREMs often pertain to the formal healthcare system, and are not defined as the broader experiences of living with COPD.

To capture the inequities in living with COPD, in this study illness experiences and outcomes are not viewed as separate, rather the division occurs between clinical, structural and social (see Figure 3.4). The blue section represents clinical concepts that are commonly

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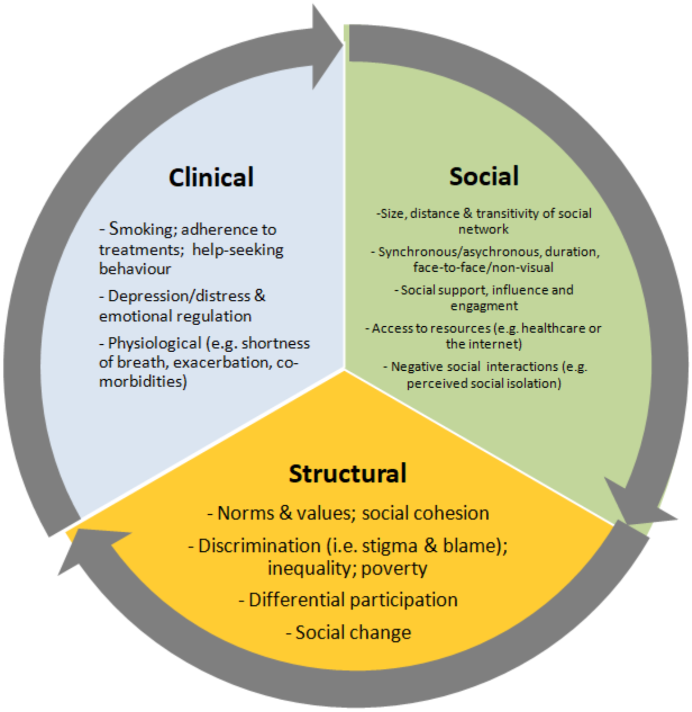
[7] Patient-reported outcomes (PROs) are "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (Deshpande, 2011). Historically, PROs emerged to support patient-centred care within clinical trials (Deshpande, 2011). Their application has since broadened across healthcare interventions. Patient-reported outcome measures and patient-reported experience measures are specific forms of PROs that have undergone psychometric testing.

considered within a biomedical model such illness symptoms, diagnosis and prognosis. Orange represents the structural in considering equity concepts, such as norms and values and social change. Green represents social represents concepts such as social isolation and social connectedness.

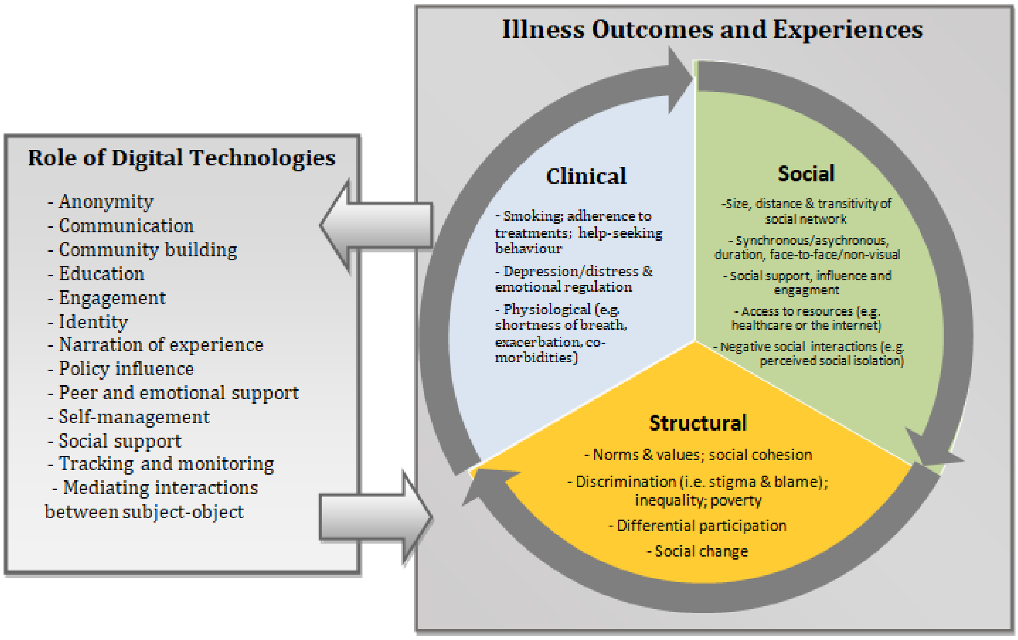
Figure 3. 4 *Stage Two Application of the Holistic Model to the Research Domains*



The Role of Digital Technologies

The final stage of transformation of the model is represented in Figure 3.5 and involves bringing in the role of DTs. The roles that are represented include the ones identified within my literature review (Allen, et al., 2016; Berkman & Krishna, 2014; Merolli et al., 2015; Moorhead et al., 2013), as well considerations for the new roles that may be identified by looking at the mediating interactions between the subject (i.e., the person living with COPD) and object (i.e., technology) (Latour, 2005). Grounding all of this is my transformative lens in examining the research question: *'what is the role of digital* *technologies in social connectedness and illness outcomes and experiences for people living with chronic obstructive pulmonary disease'*.

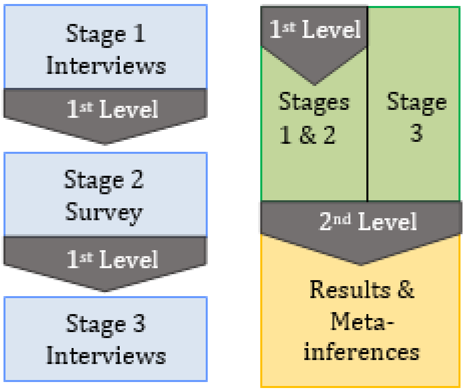
Figure 3. 5 *Stage Three Final Transformation of the Model in Bringing in the Role of Digital Technologies*



Summary

People living with COPD often experience compounding social isolation that can diminish their overall quality of life. When the illness is unsupported there is an increase likelihood of exacerbations that can contribute to increased risk of hospitalization and a shortened life expectancy. A primary aim for this dissertation was to address the ongoing health and social inequities experienced by the COPD population, by examining the role DTs play in supporting illness outcomes and experiences. Transformation of Berkman and Krishna's (2014) model allowed illness outcomes and experiences to be considered in three key ways: 1) through 'the clinical' in considering how DTs can support symptoms, such as shortness of breath and exacerbations and in improving overall quality of life experiences; 2) through 'the social' in exploring how DTs can support social connectedness; and 3) through 'the structural' perspective in considering how DT utilization can support social cohesion in addressing the discrimination experienced with COPD. Through this exploration I sought to understand how DTs may be used in future applications for supporting social change in addressing the ongoing inequities experienced amongst the COPD population.

Chapter Four: Methodology



Introduction

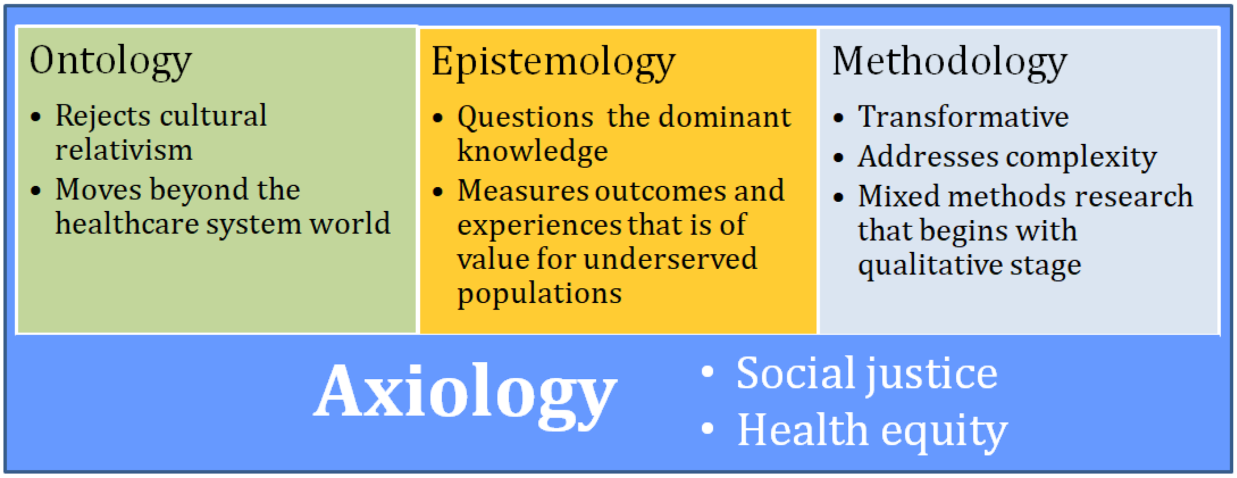
The values of social justice and equity that are identified within a critical public health lens (Greenhalgh, 2009; Solar & Irwin, 2010) informed the selection of Mertens' (2003, 2007) transformative approach for this study. This chapter will begin in applying Mertens' (2007) four assumptions related to axiology, ontology, epistemology and methodology to the overall research question *'the role of digital technologies (DTs) in social connectedness and illness outcomes and experiences for people living with chronic obstructive pulmonary disease (COPD)'*. The final section of this chapter will then provide justification and details on the methods, data collection and analysis methods I used in conducting this transformative mixed methods research (MMR) study.

Methodology

Introduction to Mertens' Transformative Paradigm

The value judgments that are impacting the experiences and outcomes of living with COPD led me to select Mertens' (2007, 2008, 2013) transformative paradigm as the methodology for this dissertation. It acknowledges "power issues, social justice and cultural complexity" (Mertens, 2007, p. 213) and provides direction in addressing my specific dissertation question how health equity can inform the conceptualization of digital technologies in supporting people living with COPD. Mertens' (2003, 2007) transformative paradigm also translates down to the specific research study question in asking people with COPD how they utilize DTs to support social networks and illness outcomes and experiences. In these next sections, Mertens' (2003, 2007) transformative approach will be further explored by applying the four assumptions of axiology, epistemology, ontology and methodology to the research focus (see Figure 4.1).

Figure 4. 1 *Mertens' (2003, 2007)Transformative Approach*



Axiological Assumption

With axiology at its foundation, the transformative paradigm takes an ethical position in prioritizing equity and social justice and challenging the status quo when populations are being marginalized (Mertens, 2007). Axiology reveals how different groups' beliefs and values are prioritized through ontology (which group has the dominant reality), epistemology (whose knowledge is privileged) and methodology (how participants' voices are represented) (Mertens, 2007). I navigated toward Mertens'(2003, 2007) transformative paradigm, as it encourages confronting the rhetoric and perceptions that are reinforced through dominant structures. In applying this to the COPD population, it means questioning how the current formal healthcare system may be furthering inequities for this population, and exploring how to address these social injustices.

Health equity recognizes how social capital is critical for encouraging the voice of marginalized populations in overcoming inequities (Solar & Irwin, 2010). The unique characteristics of COPD result in multiple contributors to social isolation. Some of the sources of this social isolation are the result of the progressive frailty and fatigue experienced with COPD, while others are the result of stigmatization towards the COPD population, which may cause people to become more disconnected from their community. In addition, our current healthcare structures focus on models of care that aim for cures and measuring clinical outcomes may result in limited strategies for people living with a fatal, incurable illness. Thus, the overall aim in addressing these health and social inequities was to bring a social justice perspective to this research by exploring how the DTs that people with COPD were using could be used as a strategy in enhancing social connectedness for this community. For example, addressing inequities could begin by offering an online place for people with shared experience to meet, which could lead to a community with a collective voice that could advocate for change.

Ontological Assumption

Mertens' et al. (2010) ontological assumption rejects cultural relativism, in which all realities are equally valid. Rather, recognizes the different power levels that exist in determining whose socially constructed reality is privileged. This is exemplified through the relationship between smoking, the social determinants of health and COPD. The predominant biomedical perspective would view smoking as the greatest risk factor for COPD. The impact of this accepted reality is oppression, whereby people living with COPD blame themselves for their illness. A health equity lens would view one of the greatest risk factors for COPD as being raised in an area with limited socio-economic opportunities. This less accepted healthcare model would support Mertens' ontological assumption in looking to the complexities in addressing the "oppressive social conditions... that result in lack of access to services" (Mertens et al., 2010, p. 471). The ontological assumption in my dissertation aimed to move away from the common patient-centered/consumer health strategies within health informatics that were delivered by the formal healthcare system (Ozbolt et al., 2014) and ask COPD individuals about the DTs they were using to support their social connectedness. The focus was not on the technologies that monitor clinical measures, such as patient portals and personal health records, as these technologies represent what was considered of value for the formal healthcare system. Patient portals and personal health records were explored if participants referenced them as of value in supporting their social connectedness and illness outcomes and experience.

Epistemological Assumption

Mertens' (2007) epistemological assumption draws awareness to the knowledge that is privileged in data collection and evaluation. This assumption has particular relevance for this study, as it brings awareness to the different outcome measures and strategies that have been historically evaluated and implemented within the formalized healthcare system. For example, a patient-centered care strategy may emphasize the importance of collecting, analyzing comparing and normalizing data so that it can be used by healthcare providers (Ozbolt et al., 2014). Patients and families then become involved in the shared decision-making around this data. The methods and outcome measures that were used for this research study moved beyond this conception of patient-centered care and incorporated measures that represented patients′ perspectives in evaluating their overall social connectedness and illness outcomes and experiences.

Methodological Assumption

In this dissertation concepts that were individually recognized as being complex were brought together: the social determinants of health, DTs and chronic illnesses. Outcomes and experiences provided the conceptual link between social determinants of health, DTs and COPD, as well as within my methodological approach. To assist in dissecting the complexity of the study, Table 4.1 summarizes the multiple ways that outcomes and experiences were conceptualized within the methodological approach.

Table 4. 1 *Methodological Approach to Outcomes and Experiences*

Level	Description
Axiology	Grounded in a transformative lens, *outcomes* and *experiences* were used throughout the study to explore the knowledge, values and preferences of people living with COPD.
Research Question	Concepts within the research question included reference to *outcomes and experiences* of living with COPD.
Study Design	Involved a sequential mixed methods approach, which brought together objective *outcomes* (i.e., quantitative) and subjective *experiences* (i.e., qualitative).
Data Collection Techniques	Encompassed two patient-reported *outcome* measures, a patient-reported *experience* measure and a DT survey for the comparing *outcomes*, and interviews for gathering subjective *experiences*.
Analytical Guide	As the research question should be the guide in MMR, o*utcomes and experiences* were part of the conceptual foundations for the analysis. The integrative component of the analyses involved mixing and contrasting the results from the first level (statistical) analysis of the quantitative data with the first level analysis of the qualitative data.
Reporting of Integrated Results	The reporting of the mixed results was organized into three chapters. Chapter five reports the applied mixed results in providing a description of participant demographics, context and DT use. Chapter six specifically focuses on the research question, in looking at the relationship between the role of DTs and *outcomes* and *experiences*. Chapter seven takes a paradigmatic approach, by reporting the mixed results under what is commonly identified within quantitative paradigm (i.e., *outcomes*) and qualitative paradigm (i.e., *experiences*).
Development of Meta-inferences	In the final chapter five meta-inferences are presented on current limitations, and ways forward in conceptualizing how DTs can support transformative *outcomes* and *experiences* for people living with COPD.

Mertens' (2007) transformative approach aligns with complex research studies, and MMR is the study design commonly identified with this approach. Studies focused on addressing inequities and the social determinants of health matches with a MMR approach, as it is a design that supports understanding lived experiences and looking beyond the boundaries of macro or micro level (Mason, 2006). In addition, there has been a call for MMR studies that can examine the successful components of DTs and address the complexity of chronic health conditions (Alwashmi et al., 2016; Klassen et al., 2012).

In considering the suggested guide for MMR, there are the traditional approaches in looking to theory (Morse, 2010), the research question (Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2010) and pragmatism (Biesta, 2010; Greene & Hall, 2010; Morgan, 2007, 2014). Mertens (2003, 2007) recognizes the role that each of these serve within MMR design, however, within the transformative paradigm axiology is at the forefront. With a social justice lens as the guide, a transformative MMR study forces an examination of the philosophical assumptions as to how reality is perceived, what knowledge is privileged and how inquiry is conducted (Mertens, 2007) .

One of the challenges in deciding on a methodology for this dissertation is that approaches that have social change, emancipation, social justice or equity require participation with *the community* (Mertens, 2007). However, what if the first step to social change is focusing on the lack of social cohesion for people who have a common interest, but do not view themselves as part of a community? Perceptions towards COPD has resulted in many people living with COPD not wanting to identify with their illness, thus they may not connect with others living with COPD (Harrison et al., 2015). The formation of community for the COPD population is additionally discouraged by the illness being a fatal chronic condition that is characterized by progressive social isolation and fatigue that may prohibit people from being active community members. Further, the compounding impact of the social determinants across the life course diminishes the political power and social capital of this population. Mertens' (2007) transformative approach recognizes the importance of involvement with "community members", but the "central tenet is that power is an issue that must be addressed at each stage of the research process" (p.213). Thus, my decision to go with the transformative MMR design was based on the emphasis on responding to the power differentials that result in that lack of community cohesion. In recognizing that there may be limited social connections between members within this community, for this study community was initially defined as people living with COPD, however, as will be discussed in the results section, I ended up broadening this community to people living with a fatal chronic lung disease.

Mixed Methods Research Study Design

Research Question and Objectives

This MMR study specifically examined *the role of digital technologies (DTs) in social connectedness and illness outcomes and experiences for people living with chronic obstructive pulmonary disease (COPD).* Figure 4.2 provides a further conceptualization of the research question and objectives. The main objectives were to explore:

1) how DTs are being used by people with COPD;
2) the role DTs could serve in social connectedness, and illness outcomes and experiences for people living with COPD;
3) the relationship between DTs use, and clinical, social and structural outcomes and experiences for people with COPD[8]; and

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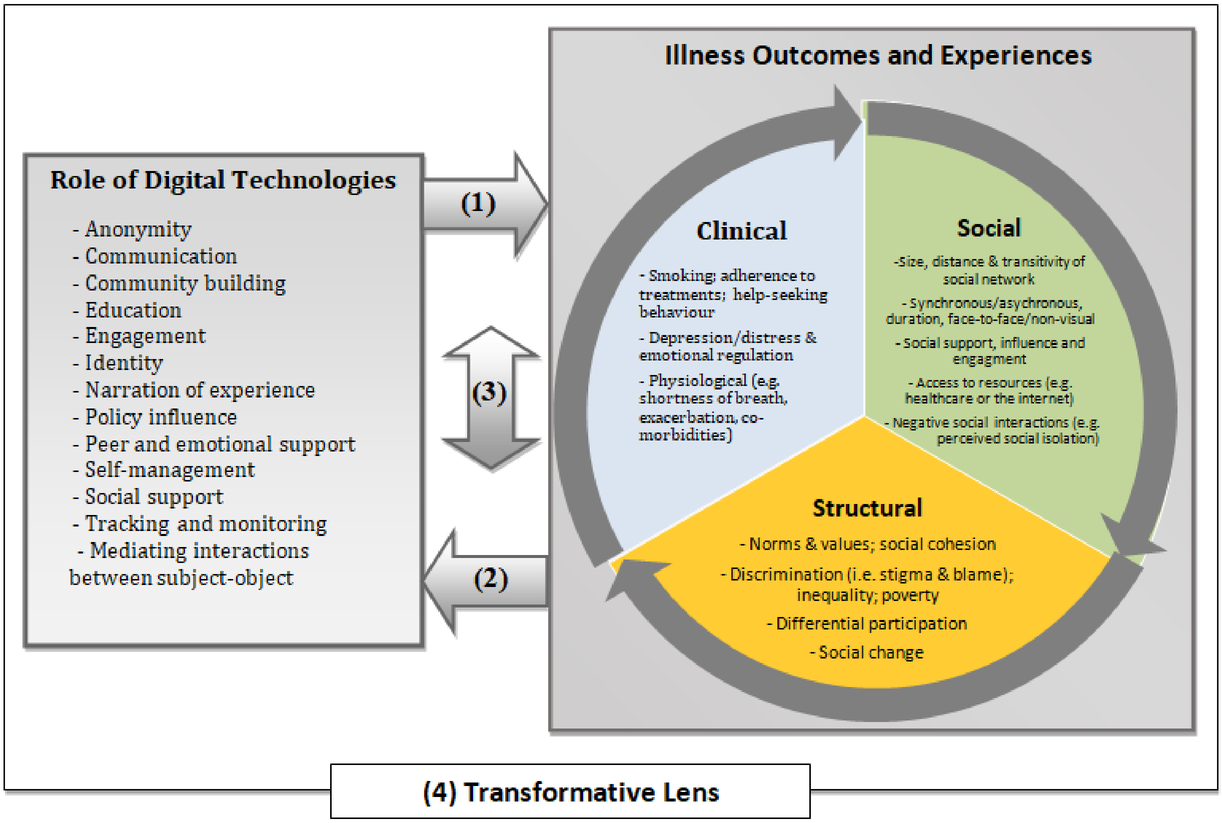
[8] The following example was in the original proposal to illustrate these objectives. A participant references their regular use of Skype with their friend, and specifically speaks to how the face-to-face contact allows them a close connection to talk about their doctor visits and daily life events. As the participant's illness has

4) how health and social inequities experienced by people living with COPD may be transformed through DTs.

Figure 4. 2 *Conceptualization of the Research Question and Study Objectives*



Overview of the MMR Stages and Study Design

The transformative MMR study design consisted of three stages (Qual →Quant → Qual) with equal weight and priority. Figure 4.3 provides a summary on each of these stages and how they were integrated to develop the overall findings. The two qualitative

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progressed, they have become more restricted to their home. They share a specific experience of being in the community and the negative perception they faced from being on portable oxygen. In addressing the first objective, the DT roles may include narration of experience, social support, engagement and communication. The relationships that exist in this example include: a) the role that the DT plays in supporting narration of healthcare experiences. b) the individual's utilization of the DT to avoiding stigmatizing experiences. c) the face-to-face virtual connection is a social network characteristic that supports pre-existing social connections.

stages were critical to the transformative approach in bringing awareness to the socio-cultural context and needs of marginalized population (Mertens, 2008). The quantitative stage explored DT frequency of use, types, activities, and assumptions around utilization of DTs for people living with COPD.

To aid in the initial development of questions for all three stages, proposed questions were mapped to concepts within the research question (see Appendix C). In addition to having each stage inform the next stage, the results were analyzed together to synthesize overall findings. To track methodological decisions and insights field notes were recorded through audio, online and paper-based journals and using the comment feature in the coding software. Knowledge translation strategies included sharing findings with the community across the duration of the study and developing infographics that were shared with participants, the COPD community, researchers, and healthcare providers (see Appendix U for example). In addition, findings were integrated into the successful application of a federally-funded community grant that could further support virtual connections for the COPD community.

Figure 4. 3 *Transformative Mixed Methods Study Design*

Stage 1: Qualitative (n = 7)
Technique: Semi-structured interviews conducted in-person, or over the phone or video.

Participants: People living with a life-limiting chronic lung disease

Sampling: Mixed, purposeful

Overall Purpose: To gain participant insights that could inform the development of stage 2 and contribute to overall study findings.

First-Stage Qualitative Analysis: Supported through coding through AtlasTi, writing summary narratives, reading across transcripts, presenting preliminary results.

First level integration into stage two
Purpose: Modification to original survey draft

Stage 2: Quantitative (n=80)
Technique: Paper-based survey with DT questions, demographic questions and one PREM and two PROMs

Participants: People living with a life-limiting chronic lung disease

Sampling: Mixed, purposeful

Overall Purpose: To examine the relationship between DTs types and use and how these relate to social connectedness and COPD outcomes and experiences.

First-Stage Quantitative Analysis: Descriptive statistics and correlational analysis (Pearson two-tailed)

First level integration into stage three
Purpose: Identify heterogeneous group of people to interview

Stage 3: Qualitative (n =13)
Technique: Semi-structured interviews conducted over the phone or video platforms.

Participants: People living with a life-limiting chronic lung disease

Sampling: Heterogeneity, maximum variation, purposeful sampling based on DT use, PREMs and PROMs and demographics

Overall Purpose: To further understand contextual factors and experiences of COPD individuals' use of DTs that could contribute to overall findings.

Research Question: *What is the role of digital technologies in social connectedness and illness outcomes and experience for people living with chronic obstructive pulmonary disease?*

First level integration of stages one and three
Combined interview transcripts

Combined Qualitative Data: Supported through coding all interviews together through AtlasTi, writing summary narratives and reading across transcripts

Further statistical analysis and creation of graphs to illustrate the following:
1) The relationship between DTs and patient-reported measures specific to satisfaction with social connectedness and illness outcomes and experiences.
2) Current frequency, types and activities of DTs amongst individuals with COPD.

Second level integration of all three stages
Analysis: Supported through an iterative approach of moving narratives and graphs within PowerPoint

Creation of meta-inferences based on analyzing the following:

1) The DT types and activities reported by participants;
2) DT roles in supporting social connectedness, and illness outcomes and experiences;
3) The characteristics of social, clinical and structural outcomes and experiences supported through DTs; and
4) Transformative considerations for people living with COPD on DT use.

The MMR study design (n=83) consisted of three sequential stages (grey boxes). The colour of the boxes indicate the following: blue represent individual stages, dark grey is when sequential mixing occurred, green outlines how data were integrated as final combined set and orange is the deliverable for the overall analysis.

To ensure the voice of people living with COPD were represented throughout the study, people participated in multiple stages so that they could inform the development of subsequent stages and patient-reported measures (PRO) were used in the second stage. PROs are measures that ask patients directly about how their perceptions on illness symptoms, health and functional status, quality of care supports and quality of life (Black, 2013; Hodson, 2014; Hodson et al., 2013). PROs can be conducted over a single interval in gaining patients' insights on whether an intervention has been effective in addressing physical, social and mental health and quality of life (Black, 2013; Canadian Institute for Health Information, 2015). They have also been used to evaluate the equity of health services (Neuburger et al., 2012). PREMs and PROMs are specific types of validated PROs, where PREMs evaluate patient's experiences with the care they receive through the formal healthcare system, and PROMs ask questions about patient's perceptions on their overall social, cognitive, emotional and physical health status.

Below is a summary of each stage, followed by details on the development of the techniques used throughout the study. Due to the sequential design of this study, in this chapter the narratives shared during stage one interviews are introduced as way to illustrate how they informed my survey design.

Stage One: Qualitative

The initial qualitative (qual) stage (n=7) matched with Mertens' (2003, 2007) transformative approach, in beginning with a qualitative stage to gain participants' perspectives and knowledge prior to implementing the quantitative stage. During semi-structured interviews people were asked about how they used different DTs for social connectedness and to support their illness. People who were within travel distance were given the choice whether to have the interview in-person, or using their preferred technology, and all decided to meet in-person (n=3). The remaining participants had their interviews over the phone (n=3) and Skype (n=1). The participant data collected from this first stage was used to further develop the survey in the second stage, which included considerations for the types and roles of DTs that were being utilized by people with COPD, and whether the proposed patient-reported measures were still a good fit for developing the second stage or whether these needed to be modified. (See Appendix H for the interview script).

Stage Two: Quantitative

The quantitative (quant) stage (n=80) was a survey that consisted of the following sections: a) Two patient-reported outcome measures (PROMs) that specifically focused on social activities and COPD health status; b) one patient reported experience measure (PREM) specific to COPD experiences; c) assumptions around DTs; and d) A *DT survey* on frequency, types and activities; and e) demographic questions. (See Appendix D for the first iteration and Appendix M final iteration of the survey). An initial draft of the survey was created at the onset of the study and the first stage interviews were used to build in additional considerations. As a result of the first stage interviews, changes were made to particular terms and language, DT activities, and selection of PROs. To further understand how people identified with the COPD, the survey began with two questions about diagnosis with COPD and being "a good fit for this study". The survey was only offered in a paper-based format. The original plan was to also offer the survey online, however, as one PRO company would only grant permission to use their platform for online data collection, this made it not possible to offer an integrated survey [9].

Stage Three: Qualitative

The final qualitative stage (n=13) involved 12 people who had completed the second stage survey and one person who had participated in both stages one and two. The survey results were used to achieve heterogeneity for the stage three interviews, while also striving for a group that represented the overall survey results. Individual surveys were evaluated for PREM and PROM scores, use of DTs, and demographics. I then compared these rankings to overall survey results in evaluating for heterogeneity and representation of the study population. This was an iterative process as some people did not respond or were not interested in participated as their condition had changed. Of the 24 participants asked to participate in stage 3 interviews, 13 consented to participate.

Ethics Approval and Recruitment

Harmonized ethics approval (UBC REB# H18-01530) across five health authorities and two universities in BC was obtained (see Appendices N and O), and an amendment was submitted with the changes to the survey questions in stage two. Participants completed a signed informed consent either online or paper-based prior to each interview (See Appendices K and L), and completion of the survey indicated consent.

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[9] This was a lengthy process of emails and using REDCap to the design the measure to the organizations' specifications. Upon consultation with my committee I opted to use the right measure for my question rather than the right mode of delivery. This experience further highlighted how inequities can be introduced through research, where organizations may privilege their ownership of patient-oriented measures even though the questions were developed by patients to represent their own perspective of their health status.

Given that this study was focused on exploring supports for population that experiences progressive social isolation, multiple recruitment strategies were used to connect with potential participants. Flyers to introduce the first stage (see Appendix I) and surveys for the second stage (see Appendices L and M) were distributed broadly across multiple organizations involved with supporting people living with COPD. Respiratory therapists at multiple health authorities across BC were introduced to the study through a brief presentation and asked to distribute the flyers and surveys to people living with COPD. Additionally, I met and connected with community support groups to introduce the study and distribute flyers and surveys. As part of building community capacity, at these community meetings I also provided a presentation on 'what is patient-oriented research' and a resource document that contained a preliminary list of COPD and technological resources that had been identified during the study (see Appendix K). A survey was mailed to everyone who were members of a provincial COPD support group (~340 people), and a batch of 300 surveys was provided to one health authority to distribute to COPD patients.

Detailed Description of Data Collection Techniques

Participants

When the study began 'having COPD' was the only inclusion criteria. During both recruitment stages, individuals also came forward who were living with a life-limiting chronic lung condition but did identify as being under the COPD umbrella. It was decided to have these people participate, as they shared how they often felt excluded from accessing services and treatments because they did not fit under the medical definitions. I wanted to understand how the healthcare's system categorization of fatal chronic lung diseases may possibly be introducing another form of an inequity where different programs and services may only be accessible to particular illness groups. The inclusion criteria as '*diagnosed* with COPD' was intentionally not specified, as the literature review demonstrated how people may be told they have COPD without being formerly tested.

Sampling Strategy

Informed by Collins (2010) and Onwuegbuzie and Collins (2007) sampling strategy, a two-dimensional sampling model consisting of multilevel, mixed purposeful, convenience and nested sampling was used. For purposeful sampling, the recommendations for 6-12 participants for interviews and 65-70 participants for correlational analysis were followed. For the first qualitative stage, the aim was to have 8-12 participants, but after eight months of recruitment the decision was made to end this stage with seven participants, and interview more people during the third stage (n=13). The aim for final interview was to have nested samples consisting of three to four participants per four subgroups. As a way of striving for heterogeneity within the final interviews, these subgroups were created that were based on technology use (i.e., non-adopter, low use, high use), technology activities (i.e., emails, social media, distinct technology), PREM and PROM scores (i.e., low, medium and high) and demographics (i.e., age, gender, education-level, income stress and living situation).

Development of Questions and Measures

Interview and survey questions were developed by mapping them out to the concepts within the research question (see Appendix C). To capture the contextual details that impact the health inequities experienced by people living with COPD, demographic questions developed for stages one and two were based on the PROGRESS health equity framework. PROGRESS has been utilized in interventions to recognize the complex interaction of the social determinants, and specifically incorporates the concepts of housing, culture, race, ethnicity, gender, religion, education, occupation, socioeconomic status, and social capital (O'Neill et al., 2014).

In addition to the demographic questions the survey in stage two consisted of questions on DT use and activities, three PROs (i.e., one PREM and two PROMs) and a section to explore assumptions on DT use. The questions on DT activities and roles were informed by existing surveys on DTs (Educause Center for Analysis and Research, 2019; Merolli et al., 2015) and publications found during the literature review (Allen et al., 2016; Merolli et al., 2013; Moorhead et al., 2013; Patel et al., 2015). The specific application of applying questions from PROs was informed by Merolli's et al. (2015) study on therapeutic affordances of social media to manage chronic illness. In looking to social media, this study design expanded beyond the formal healthcare system and involved applying PROs during a single time interval in having people living with chronic pain evaluate their overall health needs and outcomes (Merolli et al., 2015). My study built off of this design in using multiple PROs to explore how DTs were used by COPD individuals to support illness experiences and outcomes and social connectedness. The PROs in my study were specifically used in the following ways: a) to provide further context on the study participants b) support identification of people to interview in stage three; c) as part of the proposed hypotheses; and d) to inform the development of the stage three codebook.

The selection of the PREM and PROMs for the study were guided by four literature reviews (Cazzola et al., 2015; Jahagirdar et al., 2013; Paap et al., 2014; Reeve et al., 2013). Paap et al. (2014) examined the key domains within PROMs specific to COPD and identified similar concepts within this proposed research study; these include physical health, social health, ability to participate in social roles and coping with COPD. Similarly, a review of the PROMs applied to COPD determined that symptoms, physical function and psycho-social well-being were the most common focus (Cazzola et al., 2015). Two critical limitations of PROMs specific to COPD are that they may fail to fully represent experiences of living with a stigmatized illness (as referenced in chapter 2) and provide a sufficient range of patient context. In a literature review on PROMs specific to COPD, Jahagirdar et al. (2013) found that the patient recruitment strategies for studies developing the PROMs often eliminated people with limited literacy and developmental disabilities, and thus are introducing an inequity in the tool development and evaluation. This translates to the level of validity of PROMs in connecting with a population where literacy, clinical outcomes and social connectedness intersect with the social determinants.

In determining PROs that best match with the research question and study population and question a three step-process was utilized. First, the proposed PREM and PROMs were initially screened for meeting the following inclusion criteria: concepts match with the research question, involvement of COPD individuals in the development of the measure, and a measurement scale that captures the daily variation of living with COPD[10] (see Appendix F for a review of the patient-reported measures that were reviewed and excluded). The second step involved evaluating the remaining PROMs informed by the guidelines developed by Reeve et al. (2013), which included: documentation of the conceptual and measurement model, evidence for reliability and validity, interpretability of

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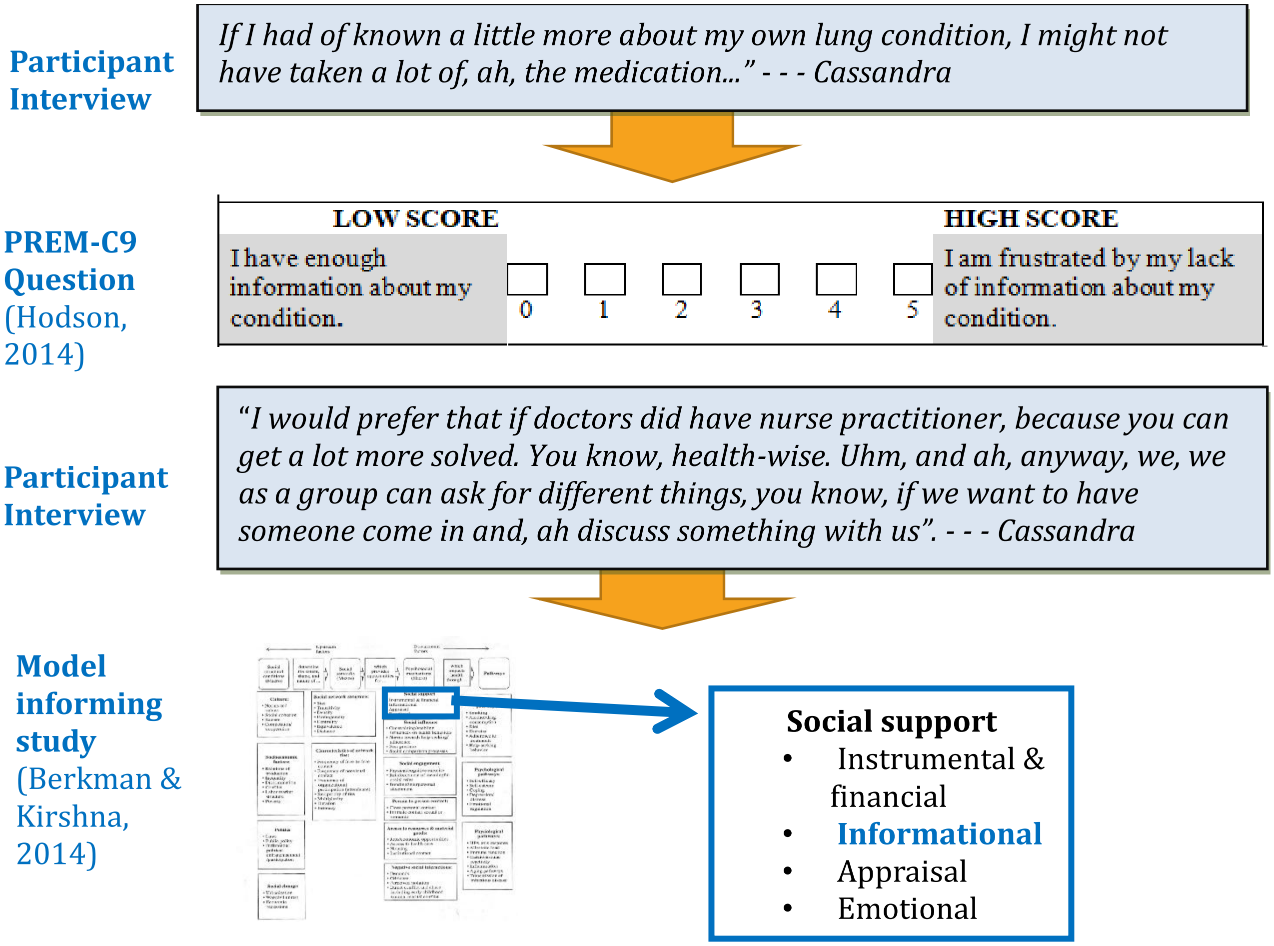
[10] PROMs that were based on a dichotomous (yes or no) measure were not included. People living with COPD may have a range of outcomes based on their daily experiences. Thus, it was decided that PROMs should consist of a range of choices that can capture the daily variations in living with COPD.

scores, quality translation and acceptable patient and investigator burden (see Appendix E).

The third evaluation step occurred between the first and second stage of the study, when the initial selected PROs were re-evaluated for how they aligned with the research question, conceptual model, and with what participants shared during the interviews. This evaluation was part of the analysis of stage-1 interviews, when the coding reports were used to compare the concepts within the proposed PROs. Figure 4.4 provides an example of this evaluation, where during the interviews a participant shared experiences related to

Figure 4. 4 *Confirming Selection of PROs through Comparison of Interview Passages to PREM and Study Model*



Participant Interview

If I had of known a little more about my own lung condition, I might not have taken a lot of, ah, the medication..." - - - Cassandra

PREM-C9 Question (Hodson, 2014)

LOW SCORE							HIGH SCORE
I have enough information about my condition.	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	I am frustrated by my lack of information about my condition.

Participant Interview

"I would prefer that if doctors did have nurse practitioner, because you can get a lot more solved. You know, health-wise. Uhm, and ah, anyway, we, we as a group can ask for different things, you know, if we want to have someone come in and, ah discuss something with us". - - - Cassandra

Model informing study (Berkman & Kirshna, 2014)

Social support

- Instrumental & financial
- **Informational**
- Appraisal
- Emotional

information and understanding condition made me revisit the questions in the PREM-C9. Selection of PREM-C9 was further confirmed when I returned to Berkman and Krishna's (2014) model and was reminded of the reference to social support and information.

In the initial proposal, three PROMs were proposed for matching with the inclusion criteria and key domains within the research study: *McGill COPD Quality of Life Questionnaire, PROMIS-Social Isolation* and the *Chronic Illness Anticipated Stigma Scale*. The first stage interviews provided a much better understanding as to how people were referring to experiences and outcomes of COPD, which resulted in switching the selection of PROs to *PREM-C9*, and *COPD assessment test (CAT)* and *PROMIS-Satisfaction with Social Activities (short form)*. PREM-C9 was selected after multiple participants discussed concepts related to this PREM. The language used by participants during the interviews, and overall structure of CAT made it a better fit for the survey design and purpose. PROMIS-Satisfaction with Social Activities matched with the research focus in exploring how DTs support social connectedness (and not social isolation and stigma).

Developing Questions to Explore Assumptions of Digital Technology Use

It was during analysis in stage two that I was reminded not to be swayed by the merits of quantitative analysis that looks for commonality, but rather as this is a MMR study, I should pay particular attention to the divergent findings. In mixed methods it is the cases that go against the trends that can offer unique insights into new areas or ones that are only partially understood (Bazeley, 2018). These divergent cases can be in the form of a narrative that is quite different to what would be expected within a demographic group, an outlier during quantative analysis, or differences between data gathered from a single participant (Bazeley, 2018). An example of this divergence first appeared during the initial stage of interviews when two participants spoke very differently about how DTs had connected them. A participant in stage one represented my exemplar as to why I was doing this study. In spite of having experienced "*broken links*" during his childhood, he spoke about how he had made connections all over the world through his use of DTs:

> *I play pool against people from all over the wooooorld [sic]... I have a person who has befriended me and we have become friends on Facebook... I have two lady friends who live in Nairobi and another lady lives in Greece and another fellow lives in Israel, one in France, England, uhm - the United Kingdom, I know people that play there from the United Kingdom, all over Canada.*

In contrast, Darla[11] who had introduced this phrase of "*broken links*" stated:

> *Our society is in a new stage of broken links... I find that with all this technology, that people are busier than ever. They are more overwhelmed, by the world. Whereas before we all had some degree of control, over that which we had awareness of, and how we fit into that small little section of the world. And now I know I feel that I'm adrift amongst so much stuff. But it, it detracts from my ability to be with other people, so I can only assume other people are feeling the same way.*

These contrasting narratives lead me to change the survey questions that focused on the social isolation and social connectedness. Initially, I had selected a social isolation PROM to understand the social isolation associated with COPD and the the isolating affects of technology. I separated out these two ideas out by selecting a PROM that focused on

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[11] Pseudonyms have been used in place of participants' names. .

social roles and activities, and added a question that asked about people's perceptions on the isolating effects of technology. This 'technology as isolating' question was added to a section in the survey that are referred to 'assumption questions'. These questions were added into the survey as part of the transformative lens and served to explore how dominant discourses may be influencing people's use of DTs. The questions emerged from the first stage interviews and the extensive literature focused on barriers to technology use. The six questions can be found in question 7 of the survey (see Appendix M). They focused on privacy and security concerns, costs as a barrier, encouragement from providers and family members, staying up-to-date on technology, and technology as isolating.

Further Techniques for Qualitative and Quantitative Stages

The length of interviews in both qualitative stages was approximately one hour, with the shortest being 25 minutes, and the longest lasting 151 minutes. Interviews in stages one and three were recorded. I transcribed all of the interviews in the first stage and one interview in stage three, while the remaining stage three interviews were transcribed by a research assistant. Cleaning of all of the transcripts allowed me another opportunity to listen and become more familiar with the interviews. Familiarity with the first stage interviews was further supported and verified by writing condensed narratives from memory. Transcripts for first stage and third stage were read multiple times before I moved them to coding through AtlasTi. The first stage interviews were coded prior to stage two. After the final stage of data collection, stage one transcripts were re-coded as part of a combined batch with stage three transcripts.

A codebook was created for each of the two coding stages (see Appendix S). Slight changes to the first stage codebook were made after consulting with a researcher with expertise in coding qualitative interviews. Guided by Saldaña's (2016) approach to coding, the codebook was structured under "eclectic coding" that involved initial coding, concept coding, versus coding, attribute coding and in vivo coding. Versus coding aided in exploring the power differentials perpetuated within current structures, and attribute coding was used to track socio-demographic context (Saldaña, 2016). In vivo coding was added for the third stage transcripts, as ongoing analysis throughout the study made me more familiar with terms and phrases that were appearing across all stages. AtlasTi was also used to code concepts within the open-ended responses provided in the survey.

Before implementing the survey, I met with one participant from the first stage, where he was observed and timed as he walked through the survey. Although I had reached out to four participants, after not hearing back from two and delays in hearing back from two others, I opted to have a community of doctoral students and academics with experience in survey development do further reviews of my survey. The majority of questions were developed from pre-existing measures. The face-validity of the questions within the survey were further verified during stage three interviews, when people commented on how I understood their use of DTs. The stage three interviews also revealed questions on the survey that may have been unclear, and thus indicated the need to place less weight on the overall results to these questions.

Prior to analysis of the survey results, a statistician was consulted to confirm the types of statistical analysis and tests to complete. A protocol for the statistical analysis was developed prior to beginning analysis of the survey results (see Appendix T). The statistician was consulted throughout the analysis stages to verify use and interpretation of statistical tests. SPSS was used as the software tool to further support the statistical analysis. Descriptive analysis was done to: 1) identify people to interview in stage 3 (for further details see section on sampling strategy); 2) verify heterogeneity of the study population; and 3) evaluate frequency distribution for types and activities of DTs. Pearson's Correlation tests were completed to explore patterns of DT use, roles and activities, and test three proposed hypotheses: a) people who use DTs to support their COPD report stronger satisfaction with social roles and activities; b) people who use DTs for social connectedness report stronger satisfaction with their social roles and activities; and c) people who use DTs to support their COPD report stronger experiences of COPD.

Integrative Mixed Methods Research Analysis

Bazeley (2018) was used as the overarching guide for the mixed methods analysis across the three stages. My overall analysis and interpretations were further assisted through conference presentations and writing field notes throughout the duration of my study. A process of first level and second level of mixed methods research integration was followed, where the first level helped to inform each subsequent stage, and the second level process involved mixing and analyzing data across all three stages (Bazeley, 2018). Although Figure 4.1 shows these stages as very distinct, in reality my second level of integration was occurring throughout the duration of my study, where I moved backward and forward within my data as my interpretations developed (Bazeley, 2018).

Each stage began with non-integrated analysis. For stages one and three, this involved looking within an interview before moving across multiple participants' data. Stage two began with descriptive statistics to get an overall sense of the data within the study population. Individual participant's data were compared to evaluate for heterogeneity and to find examples of unique applications of DT use. Pearson's correlation tests were then used to test the hypotheses and for comparative analysis.

The process for the first level mixing involved creating linkages within individual cases so that context could be retained, and moving out into the broader study data so that relationships and associations could emerge (Bazeley, 2018). Mixing between the first and second stages occurred as an iterative process of reading the transcripts and coding reports, writing, and cross-referencing interview data with each successive version of the survey. Excel was used at the initial stages of survey development to link narratives to proposed PREM and PROMs, and AtlasTi was used at the final stage of survey development to track the source of each survey question (i.e., whether the question emerged from interview data, the literature review, transformed model, central focus of research question and objectives, or existing DT surveys).

Mixing between the second and third stages involved the development of interview questions that were informed by looking at trends in the close-ended and open-ended survey questions, and coded interview data in stage one. Global questions for the third stage were developed based on the overall results from the survey. With the changing context due to the onset of the pandemic one question was added: 'what has changed for you since you completed the survey'. Prior to each interview, the participant's survey was reviewed in order to develop more specific questions based on their individual responses. (Appendix N provides for the interview script for stage three).

As part of the second level analyses, the combined batch of coded interview data and graphs developed from the quantitative stage were transferred into PowerPoint. Saving the

PowerPoint file under each analysis date allowed tracking of the ongoing evolution of my thinking. I transitioned over to PowerPoint for this final stage of integrative analysis, as I was finding the hierarchical/linear structure of AtlasTi was making my analysis cumbersome, and didn't match with my holistic approach in moving within the complexity of the research study. The diagrams and figures created in PowerPoint allowed for visual tools which were an important aid during MMR analysis (Bazeley, 2018). PowerPoint provided a novel way to follow the principles of a joint display in mixing the qualitative and quantitative data (Guetterman et al., 2015). It also allowed me to look at data through multiple views: a) the slide sorter page allowed move out and see the data as a whole; b) the title slides were used for grouping slides in the development of the key findings; c) the single slide view supporting moving deeply into the data; and d) the notes feature was used to create field notes during the mixed analysis. This weaving and mixing supported my role as bricoleur in following and reflecting on the conceptual links across data and in bringing the results together as whole (Bazeley, 2018).

The data was analyzed through a transformative lens by considering how different worldviews were being privileged. Examples of how this lens was applied during analysis include: a) looking at discourse markers (Fraser, 1988) that referenced a person's identity; b) using value coding (Saldaña, 2016) as a way to record when people reference difference groups; c) applying correlation analysis so see if any patterns emerged in the PREM and PROM scores and different sub populations within the study; and d) contrasting participant's narratives that focused on similar concepts.

Meta-inferences were the final output of my study, and were the "best explanations" I had that could describe my overall inferences and knowledge claims (Bazeley, 2018).

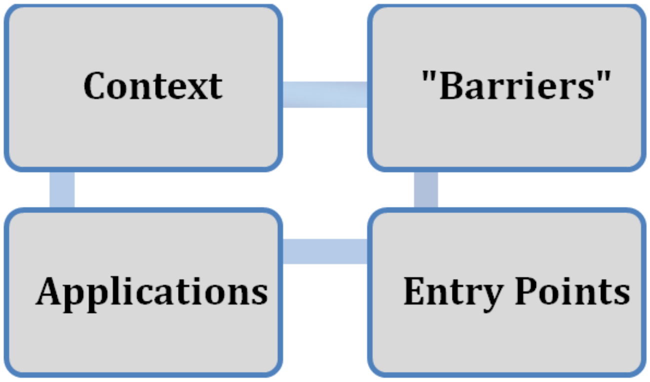
Bazeley (2018) refers to these inferences as "warranted assertions". I opted to use the language of meta-inferences, to convey less conclusive language that was a better match for being an exploratory study (Poth, C., personal communication April 29, 2019). Following Bazeley's (2018) guide, fundamental strategies I undertook to ensure the validity of the meta-inferences included being transparent in the quality and management of the data, demonstrating enriched integration of the data, and developing inferences that were consistent with the data.

Reporting of Results

The next three chapters present the results from the research study. Rather than present the results from each stage, I followed Bazeley's (2018) recommendation for presenting integrative mixed analysis where quantitative and qualitative results are reported together. The results chapters are based on the first three objectives. Chapter five reports the applied findings in detailing the context and types and frequency of DT activities reported by participants. The applied findings involved bringing in narrative text to further situate the aggregated descriptive results. Chapter six focuses on the first half of the research question in detailing the roles of DTs for people living with COPD. Chapter seven addresses the second half of the question in exploring the relationship between DTs, and illness outcomes and experiences and social connectedness. It begins by looking at outcomes by reporting on the hypothesis results, and then is followed by experiences in exploring the narratives shared by participants. Chapter 8 pulls together the overall findings in presenting five meta-inferences from the results from chapters five, six and seven. The development of this chapter involved a thematic approach where I looked across the chapters, and returned to the data for verification and to see if any new areas emerged.

In an effort to maintain the transparency of these meta-inferences, in this chapter I have laid out the methodological decisions points of the transformative mixed methods study. Steps undertaken to ensure quality of the inferences, while also honouring the assumptions within the transformative paradigm included: 1) considering how the study would build capacity and voice for the COPD population; 2) basing sample size requirements and integrative analysis on recommendations from foundational MMR methodologists; 3) consulting with experts at different stages of my study to confirm development of questions and choice of analytical tools and processes; and 4) and selecting analytical software tools that aligned with each stage of the integrative approach. In these upcoming chapters, I aim to further establish transparency by using visual and narrative presentations to communicate my interpretations of the data. Thus, by the final chapter, when I conclude with my meta-inferences, the reader will be able judge whether these inferences were warranted (Bazeley, 2018).

Chapter Five: Results - Context and Applications of Digital Technologies



Introduction

This chapter is one of three that focuses on results. In this chapter the more applied, practical findings are presented on examining overall use of digital technologies (DTs) by the people who participated in the study. The chapter does not specifically focus on DTs to support chronic obstructive pulmonary disease (COPD), but rather serves to set the landscape in examining participants' use and perceptions around DTs. Chapters six and seven brings in greater focus on COPD by examining the roles and relationships between DTs use and the experiences and outcomes of living with COPD. This current chapter is divided into four sections: a) overall context in considering the timeline the different stages of the study and demographics for the people who participated across the different stages; b) the frequency of use and activities with DTs that people reported in the study; c) commonly perceived 'barriers'[12] of security and privacy concerns, costs and technical skills; and d) people's introduction to DTs; (see Figure 5.1 for an overview of the chapter).

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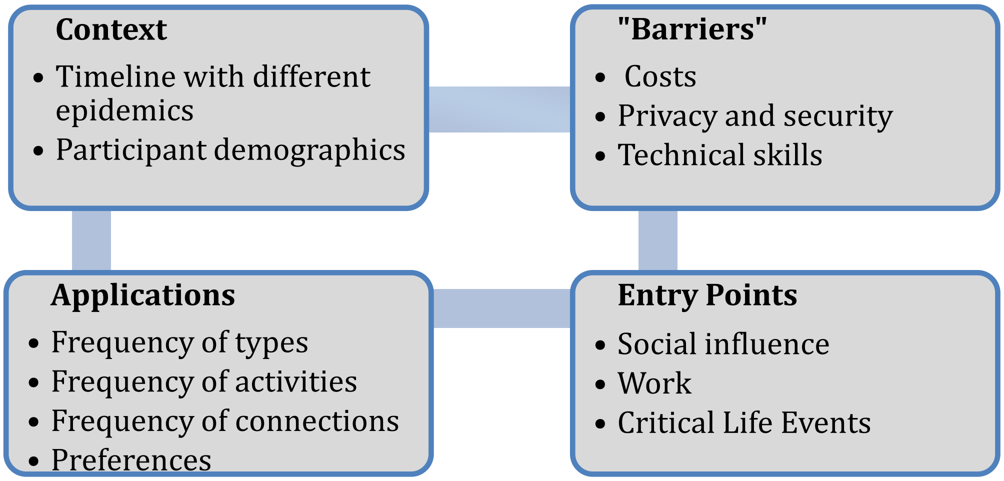
[12] Barriers and facilitators have become a common term in the discipline of Health Informatics, as evident by the number of publications which often present a list of common patient barriers as being costs, privacy and security, and technical skills (Antonio, 2019). The quotes around barriers serve to indicate how the language of barriers and facilitators has become a prominent discourse within the discipline. This reduction to a simple list fails to acknowledge the complexity of technology being applied across varying patient context. In addition, the meta-narrative of "patient-barriers" has been taken up to the point where responsibility of using (or not using) a technology falls on the responsibility of the individual patient, instead of recognition of the complex structural inequities that impact adoption (Antonio, 2019).

Figure 5. 1 *Overview of the Context and Landscape for the Study*



Setting the Context

Data collection for the study began in December 2018 and ended in July 2020 (see Figure 5.2 for timeline)[13]. Over this time, there were three epidemics occurring that had great significance on the experiences and outcomes that were shared. The first was COPD, where more than a decade ago was identified as global epidemic (Camp & Levy, 2008). The second was the increased rate of opioid overdoses, which in 2015 the Public Health Officer of BC declared a public health crisis (BC Emergency Health Services, 2020). The third was the pandemic in which the first cases of COVID-19 were being recognized during the month the survey was mailed out, and third stage interviews began a week after the first lockdown pandemic measures in the province were lifted.

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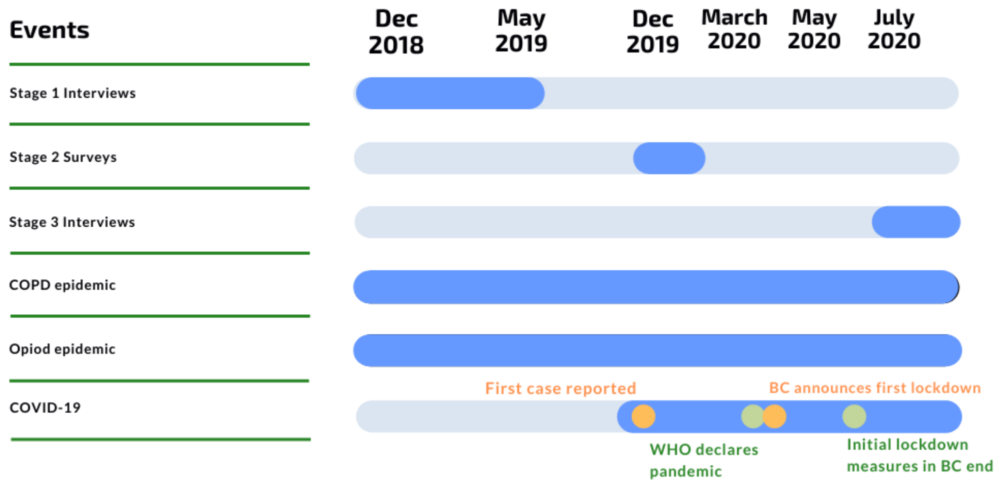
[13] In addition to socio-demographics, there are two contextual pieces that were considered in interpreting the results. The first was the changing context with the COVID-19 pandemic beginning in 2020. The second was that the study represented perspectives that were broader than people diagnosed with COPD. When presenting the results, the pandemic or a diagnosis will be referenced when it has been interpreted that these details add context that is relevant to interpreting the data presented.

Figure 5. 2 *Timeline of Stages of the Study and Key Events Related to the Epidemics*



The changing context with COVID-19 added another element to the mixing of the results, as people's social world and use of technology was in the midst of a world-wide disruption between the stages of the study. As the research study was focused on social connectedness, fatal chronic lung disease, and technology, I could see the immediate links to the pandemic with social distancing measures, societal shifts in adopting new technology, and COVID-19 being a respiratory virus. However, what I did not anticipate was the significance the opioid epidemic would have on people living with COPD. Participants now saw a potential new treatment for COPD through transplants, as organ donations were on the rise with the increasing numbers of people dying from overdoses. My social justice lens was in conflict: both illness groups were experiencing ongoing stigmatization and inequities within the healthcare system, yet one group was now introducing the possibility of improving outcomes for the other. This was a new phenomenon, which has not been represented in previous studies that have explored the experiences of living with COPD. With the study focused on social justice, my analysis involved looking at how people talked about these new experiences of living with a transplant, or seeing the possibility of a cure, while grounding these experiences to the research question.

Socio-demographics

Heterogeneity of Participants

Eighty-three people participated over the course of the study, with seven people interviewed in stage one, 80 people returned the survey in the second stage, and 13 people interviewed for stage three. One participant was involved in all three stages, four participated in the first two stages, and twelve participated in both stages two and three. Participants represented a range of demographics in terms of age, gender, education level, living situation and geographic location (see Table 5.1). People ranged in age from 49 to 93, and the majority were retired (79.5%, 66/83). Of the 19 participants who reported having a university or professional degree (19/83; 22.9%), 14 were women. The 32 women that reported some difficulties making ends meet had a mix of educational backgrounds, whereas all of the 15 men who reported difficulties making ends meet did not have a university or professional degree. Although 31 men participated in the study, only one lived alone (3.2%). In comparison, 33 of the 51 (64.7%) women who participated lived alone.

There were demographics that were not represented that may have limited the range of experiences within the study. In particular, there was limited diversity in cultural backgrounds, as the majority of participants identified as white or European descent (68/83, 81.9%), followed by Canadian (12/83, 14.5%), or Indigenous (2/83, 2.4%), and some identified with multiple categories. There was also high representation of

Table 5. 1 *Participant Demographics*

		All Stages	Interviews
Age			
	Under 50	1 (1.2%)	0
	55-59	3 (3.7%)	1 (5.6%)
	60-64	4 (7.2%)	1 (5.6%)
	65-69	12 (14.5%)	4 (22.2%)
	70-74	20 (24.1%)	5 (27.8%)
	75-79	21 (25.3%)	4 (22.2%)
	80-84	15 (18.1%)	3 (16.7%)
	85-89	4 (4.8%)	0
	Over 90	1 (1.2%)	0
	Not provided	1	
Gender			
	Man	31 (37.3%)	7 (38.9%)
	Woman	51 (61.4 %)	11 (61.1%)
	Cisgender	82 (100%)	18 (100%)
	Not provided	1	
Cultural background[1]			
	White or European Descent	68 (81.9%)	17 (85%)
	Canadian	12 (14.5%)	1 (5%)
	Indigenous	2 (2.4%)	2 (10%)
	Preferred not to answer	9 (10.8%)	0
	Not provided	1	
Employment status			
	Retired	66 (79.5%)	12 (66.7%)
	Long-term disability	9 (10.8%)	3 (16.7%)
	Home-maker	1 (1.2%)	0
	Self-employed	2 (2.4%)	1 (5.6%)
	Work full-time	3 (3.6%)	0
	Semi-retired	1 (1.2%)	0
	Employment insurance	1 (1.2%)	1 (5.6%)

		All Stages	Interviews
Employment status			
	Another option not listed	1	1 (5.6%)
Difficulties making ends meet			
	Never	27 (32.5%)	9 (50.0%)
	Rarely	22 (26.5%)	2 (11.1%)
	Sometimes	16 (19.3%)	4 (22.2%)
	Very often	6 (7.2%)	0
	Always	3 (3.6%)	0
	Prefer not to answer	5 (6.0%)	1 (5.6%)
	Not provided	4 (4.8%)	2 (11.1%)
Education			
	Some elementary or high school	12 (14.5%)	1 (5.6%)
	High school graduate	16 (19.3%)	2 (11.1%)
	Some college or trade school	14 (16.9%)	5 (27.8%)
	College or trade graduate	20 (24.0%)	3 (16.7%)
	Bachelor degree	9 (10.8%)	1(5.6%)
	Graduate degree	7 (8.4%)	3 (16.7%)
	Professional degree	3 (3.6%)	2 (11.1%)
	Prefer not to answer	1 (1.2%)	1 (5.6%)
	Not provided	1	0
Location			
	Metropolitan (over 1 million)	9 (10.8%)	2 (10.5%)
	Large urban population (two island communities over 100,000)	32 (38.6%)	8 (42.1%)
	Medium population centres (3 island and 1 northern community between 30,000 and 99,999)	31 (37.3%)	5 (26.3%)
	Small population centre (4 island communities between 1,000 and 29,999)	6 (7.2%)	4 (21.1%)
	Not provided	5	0

		All Stages	Interviews
Living situation			
	Alone	34 (41.0%)	9 (50.0%)
	Spouse or partner	42 (50.6%)	7 (38.9%)
	Parent	2 (2.4%)	0
	Child	1 (1.2%)	0
	Grandchild(ren)	2 (2.4%)	2 (11.1%)
	Another option not listed	2 (2.4%)	0
	Not provided	0	0
Marital status			
	Single	9 (10.8%)	2 (11.1%)
	Married or common-law	43 (51.8%)	8 (44.4%)
	Separated	2 (2.4%)	0
	Divorced	9 (10.8%)	4 (22.2%)
	Previous common-law relationship	2 (2.4%)	0
	Widowed	15 (18.1%)	3 (16.7%)
	Another option not listed	1 (1.2%)	0
	Not provided	2	0
Religious practice			
	Never	25 (30.1%)	6 (33.3%)
	Rarely	18 (21.7%)	2 (11.1%)
	Sometimes	11 (13.3%)	3 (16.7%)
	Very often	8 (9.6%)	3 (16.7%)
	Always	10 (12.0%)	1 (5.6%)
	Prefer not to answer	1 (8.4%)	1 (5.6%)
	Not provided	4 (4.8%)	0

[1] Note: Some people referenced multiple cultural identities

participants who attended COPD support groups[14]. Thus, it is recognized that the experiences of people represented outside these groups may have quite different strategies for staying socially connected and supporting their COPD that may be represented within this study.

Everyone under the age of 77 (54/83, 65%) reported using DTs, while people over 77 reported a mix of technology use: within this latter age group some had previously owned DTs, but no longer used them, and others were interested but had never owned any DTs. In addition, out of the 29 people who were identified as being high adopters of DT (as determined by self-reported frequency of use), 18 were 77 or older (62%), and 11 were under the age of 77 (38%). The difference in use between age groups was further discussed by one participant in her late fifties and whose work involved teaching older adults about technology: "*there's a whole generation there, with a fear of technology, and they are, for your sake and my sake, they're seventy-five to ninety-five. There's a huge gap, right there. The fifty-five to seventy-five, they know this technology stuff* ". This view seemed to also be reflected in the participants in the study. Although some people over the age of 75 expressed interest in learning about DTs, others commented on how it was not worth their time or energy. This aspect of "interest" will be revisited later in this chapter when discussing people's different preferences for types and use of DTs.

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[14] The question about whether or not people were attending a COPD support group was not asked within the survey. However, due the way that recruitment evolved between the different organizations, resulted in most participants being involved with a COPD support group.

Identifying with a Life-Limiting Lung Condition

Across the three stages, the majority of participants identified with COPD (88%, 73/83), and within this group three participants reported not being formally diagnosed. Five participants were uncertain about their diagnosis, but had been told at some point they had COPD (6%, 5/83) (see Table 5.2). This uncertainty about their diagnosis was demonstrated by two participants who had written into the survey "don't know COPD diagnosis, since there has been no follow-up" and "yes and no - problem for me as my MD says I will always have COPD, but respirologist says no, so I will fill in as much as I can with 12+ years COPD". Two participants in stage 1 (3.6%, 3/83) did not fall under the COPD umbrella, but had a diagnosis of idiopathic pulmonary fibrosis (IPF), or sarcoidosis. Within the second stage survey, four participants identified as not currently having COPD, but found that they were a good fit for the study as they had a lung condition that was similar to COPD (i.e., hypersensitive pneumonitis, bronchiectasis, connection tissue disease/pulmonary fibrosis, and acute respiratory distress syndrome (ARDS)). One of these four participants was interviewed in stage 3 due to his unique response to the technology is isolating question. In addition, four participants were interviewed that were at different stages of being on the lung transplant list, one of whom received a lung transplant over the course of the study and he was not sure if still identified with having COPD. Although not everyone identified with currently having COPD, the results from the PREM and PROM scores demonstrated that people were identifying with similar illness outcomes and experiences of living with a life-limiting chronic lung condition. The relationship between how someone identifies with their lung condition, and their illness outcomes and experiences will be further examined later in this chapter when reporting the PREM and PROM results.

Table 5. 2 *Participants' Identification with a Life-limiting Chronic Lung Condition*

Currently identified with having COPD	73 (88%)[1]	15 (79%)
Other life-limiting chronic lung condition	6 (7.2%)	3 (15.7%)[2]
No longer living with COPD (lung transplant)	1 (1.2%)	1 (5.2%)
Did not answer	3 (3.6%)	0

[1] Five of these people were not sure whether they still had COPD, and three had not received a formal diagnosis of COPD.
[2] Two of these people were interviewed in stage 1 and did not participate in the survey. The other participant completed the survey and an interview in stage 3.

Having inclusion criterion broader than a 'diagnosis of COPD', opened up opportunities for people who had not received a formal diagnosis to identify with COPD in several different ways. Not everyone identified as living with a *fatal* chronic illness. During interviews, participants with more severe COPD spoke about "*fatalism*" and "*having died once*", while other participants with less severe COPD tended to use words such as "*life-limiting*", or "*lack of a cure*". People talked about being "*in denial*" or "*didn't buy into it*", but were now more accepting of the illness after being tested again.

Asthma frequently came up in the interviews when people questioned whether they had COPD or asthma. This was demonstrated by Ruth when she said "*It was the doctor's kind of assumption that that's what I had, but when I went to the respirologist and went through their little tests and stuff he felt that it was more asthma. But they call it COPD anyway I guess, but I find it confusing*". Some people spoke about the undesirable label of COPD, and how this impacted receiving a diagnosis. Pamela mentioned how "*they don't come right out and say emphysema. They're not allowed to, because I hadn't had a scan, and* *then they've labeled you. Which is what COPD is like giving you a label*". A few people talked about the stigma associated with COPD and how it may have impacted diagnosis. Sarah acknowledged how:

> "*a lot of people were passing it off as asthma and I think a lot of the reason why is because of the connection between COPD and smoking. I mean everybody knew smoking was bad for you. So when you come down with COPD, you don't want to tell people – oh yea, well you caused it yourself, you should have not smoked. But I think that stigma's being overcome*".

Participants PREM and PROM Scores

The scores for the PREM and PROMs provide further contextual information on the overall study population, the subset of people who participated in the third stage interviews, and the subset of people who did not identify with currently having COPD. As determined by COPD assessment test (CAT), the mean severity of COPD (mean 19.67) was evaluated high, and five participants evaluated their severity as very high (>30), while two people had very low (<10) (GlaxoSmithKline, 2018). Participants who were interviewed in stage three represented a slightly lower overall CAT average (18.71). The CAT questions with the highest scores were in 'completely limited in doing any activities at home'' and 'have no energy at all' (see Table 5.3). When compared to all participants who had completed the CAT: a) four participants who identified with a similar illness to COPD reported more severe illness outcomes (as indicated by an average CAT score of 24.5); and b) the three people who had not been formally diagnosed with COPD reported more severe illness outcomes (as indicated by an average CAT score of 21.7).

Table 5. 3 *Participant Scores on COPD-Assessment Test (CAT)*

Individual Questions	Overall Mean	Stage 3 Mean
Limited in doing any activities at home (0=not at all; 5=completely)	3.66	3.43
Having energy (0=lots of energy; 5=no energy)	3.15	3.00
Tightness of chest (0=not at all; 5=very tight)	2.58	2.40
Confidence in leaving my home despite lung condition (0=confident; 5=not at all confident)	1.61	1.20
Coughing frequency (0=not at all; 5=all the time)	2.27	2.13
Phlegm and mucus in chest (0=none; 5=full)	2.21	2.07
Out of breath after exertion (0=not at all; 5=completely)	2.09	1.93
Quality of sleep (0=soundly; 5=not soundly because of lung condition)	2.55	2.60
Overall Score	19.67[1]	18.71

[1] A high severity score (>20) is interpreted as COPD is impacting the lives of people to the point where the symptoms prevent people from doing most their activities and having a restful sleep, and people may have fear and anxiety in not feeling in control of their illness (GlaxoSmithKline, 2018).

Overall people rated their overall satisfaction with social roles and activities as 'quite a bit', as evaluated by the PROMIS Satisfaction with Social Roles and Activities. The mean of the study population was 7.66, which was slightly higher than the people interviewed in stage 3 (Mean=7.07), and the average scores across the four questions had very similar means (ranged from 1.88-1.95) (See Table 5.4). When compared to all participants who completed the PROMIS measure: a) the four people who identified with a similar illness to COPD averaged less satisfaction in their social roles and activities (as indicated by an average PROMIS Satisfaction in Social Roles and Activities score of 5.4); and b) the three people who reported not being formally diagnosed with COPD averaged similar satisfaction in their social roles and activities (as indicated by an average PROMIS Satisfaction in Social Roles and Activities score of 7.0).

Table 5. 4 *Participant Scores of PROMIS Satisfaction in Social Roles and Activities*

Individual Questions	Overall Mean	Stage 3 Mean
Satisfied with ability to do things for my family (0=not at all; 1=a little bit; 2=somewhat; 3= quite a bit; 5=very much)	1.94	1.79
Satisfied with ability to do things for fun with others (0=not at all; 1=a little bit; 2=somewhat; 3= quite a bit; 5=very much)	1.88	1.80
Feel good about ability to do things for friends (0=not at all; 1=a little bit; 2=somewhat; 3= quite a bit; 5=very much)	1.90	1.73
Satisfied with ability to perform daily routine (0=not at all; 1=a little bit; 2=somewhat; 3= quite a bit; 5=very much)	1.95	1.80
Satisfied with ability to do things for my family (0=not at all; 1=a little bit; 2=somewhat; 3= quite a bit; 5=very much)	1.94	1.79
Overall Score (0=positive experiences; 45=negative experiences)	7.66[1]	7.07

[1] Unlike the other patient-reported measure, PROMIS Satisfaction with Social Roles and Activities, has positive wording such that the overall score is in opposite direction to the PREM-C9 and CAT (i.e., a higher score indicates a stronger overall satisfaction with social roles and activities). The range for the individual questions was 0 to 4, and the range for the overall was 0 to 16

PREM-C9 was used to inform people's perceptions of their experiences everyday life and care in living with COPD. In the survey, the average PREM score was 16.08, resulting in an average score of 2.01 (range of 0 to 5) across the nine questions. People interviewed represented a similar overall mean, where six had a PREM-C9 score higher than 20. Across the nine questions, the highest values reported were focused on 'not accepting their lifestyle limitations', 'not feeling in control of their illness' and 'not having enough information out their condition' (see Table 5.5). When compared to all participants who had completed the PREM-C9: a) the four people who identified with a similar illness to COPD averaged similar everyday illness experiences (as indicated by an average PREM-C9 score of 14.2); and b) the three people who reported not being formally diagnosed with

COPD averaged similar everyday illness experiences (as indicated by an average PREM-C9 score of 18.0).

Table 5. 5 *Participant Scores on PREM-C9*

Individual Questions	**Overall Mean**	**Stage 3 Mean**
Lifestyle limitations (0=acceptance; 5=frustration)	2.55	2.93
Feel in control of condition (0=in control; 5=not any control)	2.29	2.33
Information about my condition (0=have enough; 5=frustrated by lack of)	2.09	2.60
Have access to care in case of flare-up (0=confident; 5=worried)	1.99	1.79
Care from health professionals (0=not worried; 5=worried)	1.95	1.67
Talking about future (0=happy to; 5=makes me feel depressed)	1.94	1.87
How my COPD treatments work (0=understand; 5=confused)	1.83	2.07
Support from others (0=feel good; 5=do not have)	1.78	1.67
Doctor will listen to my point of view (0=confident; 5=concerned)	1.73	1.93
Overall Score (0=positive experiences; 45=negative experiences)	16.08[1]	16.36

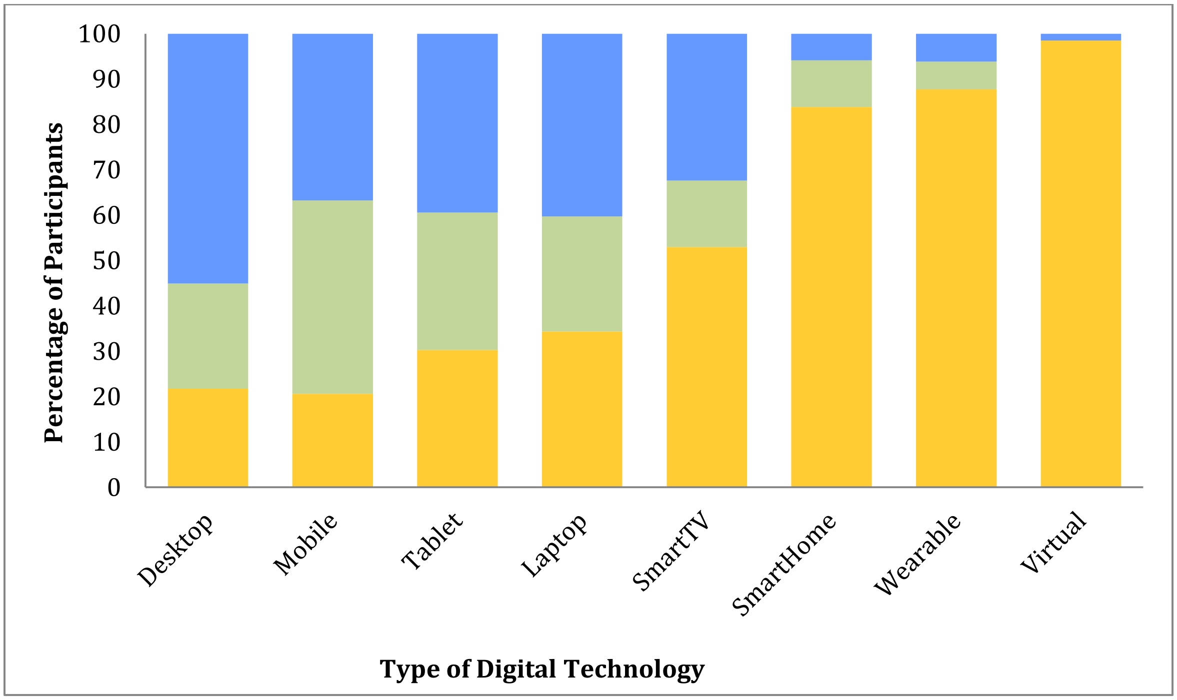
[1] There currently is not a validated guide for how to interpret these results. '0' on a question indicates a good experience and '5' indicates a bad experience. A score of 45 indicates highest overall score, and poorest experience of living with COPD.

Use of Digital Technologies

Types of Digital Technologies

The survey asked people to report their frequency of use of DTs as 'not at all', 'a little bit', 'somewhat', 'quite a bit', or 'very much'. To aid in identifying people for the third stage interviews and interpreting results, categories for technology were created as 'non-use', 'low use', 'moderate use' and 'high use'. *Non-use* was for people who did not report any use of technology, *'low use'* represented people who reported 'a little bit of use', *moderate use/frequency* people who reported frequency fell within 'somewhat', and *high use/frequency* was for people who reported frequencies as 'quite a bit' or 'very much'. There were nine people (11.3%; 9/80) categorized in the 'non-use' group who did not use any DTs. The groups categorized within 'low use' (13.8%; 11/80) or 'moderate use' (38.8%; 31/80) tended to use one or two devices, while people categorized within the 'high use' group (36.3%; 29/80) often used three or more devices. The graphs that follow on frequency represent all of the participants who reported some use of DTs on the survey in stage two. Figure 5.3 details the frequency in use of the types of technology for people who

Figure 5. 3 *Frequency of Types of Digital Technologies*



The graph represents participants who reported some use of DTs (n= 66 to 69). Yellow demonstrates the percentage of participants who reported not using this type of DT. Moderate represents the percentage of participants who reported moderate frequency in using this type of DT. High represents the percentage of participants who reported high frequency of use of this type of DT.

reported using DTs. The main devices used across the groups were mobile phones (79.4%; 54/68), desktops (78.3%; 54/69), tablets (69.7%; 46/66) and laptops (65.7%, 44/67). Out of these four devices mobile phones had the lowest percentage of high use (36.8 %; 25/68).

Other than age, no patterns were found in comparing DT use to demographics that are commonly identified with the digital divide. The impact of the social determinants of health was also not as simplistic as to whether or not someone had access to the internet or DTs. Rather the interviews revealed how a person's social context over the life course can impact how people choose to connect through DTs. For example, the person who spoke about using DTs to make new connections with people all of the world had experienced extensive loss of connections since early childhood. As a First Nations man he shared his experience of being part of "*the sixty's scoop*", when as a young child he was removed from his family and raised in foster care. He also shared how upon his diagnosis of COPD he again felt a loss of connection, as he had to retire early from an occupation where he had been potentially exposed to harmful chemicals. In contrast, one of the few women who was in her late seventies and had a graduate degree had elected not to use any DTs after previously using them in her personal life and throughout her career. She spoke about her rich social connections with her son and friends, and thus didn't see the need to use DTs. She demonstrated how one can be empowered in making very conscious decisions about when to use DTs, and even after using them she found it was "*not something [she] was inclined to do*".

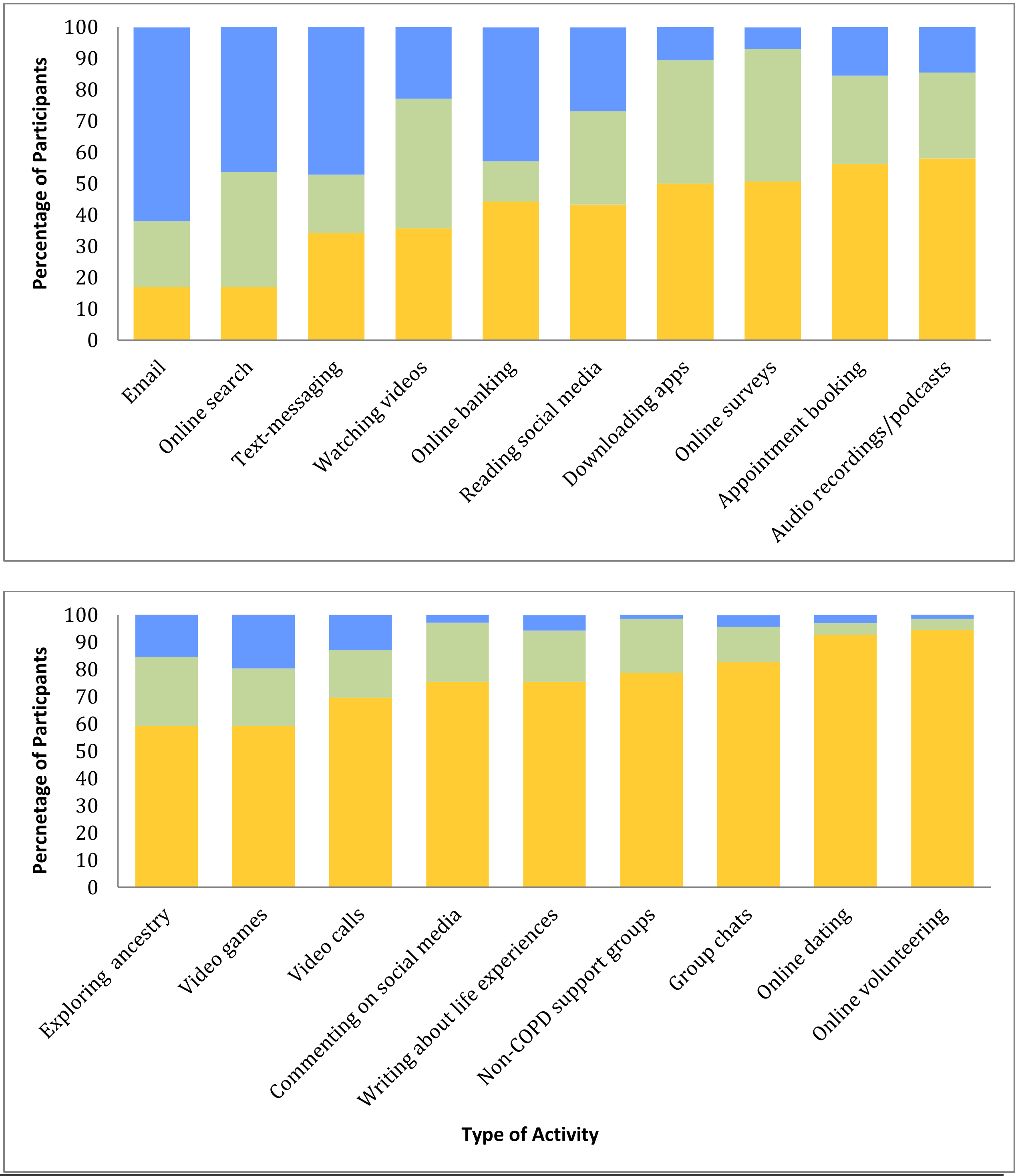
Types of Activities through Digital Technologies

When examining the activities being done by people who had used DTs, the most common were emailing (83.1%; 59/71) and internet searches (83.1%; 59/71), followed by text messaging (65.7%; 46/70) and watching videos (64.3%; 45/70). Further details on the frequency of these different activities are provided in Figure 5.4. "*Canada Post*" or "*mailing letters*" was an additional preferred way for communication that was referenced through open-ended section of the survey and during interviews.

Although many people read forum or blog posts (56.7%; 38/67), only two people reported high frequency in commenting on forums, blogs or social media (2.9%; 2/67). Vicki's perspective on social media were similar to many other participants: "*some people text or make comments, it's just not something I do. I'm interested in reading. I'm interested in what they're doing*". Henry's experiences with social media demonstrated why people may have been hesitant to post comments. Although he still made comments in the app that connected him to his Bible study group, he no longer posted in more public forums "*I commented a couple of times articles on Facebook but the reaction that I got back, I thought I wasn't going to do that anymore. I sometimes surf through to see what's going on but I don't comment anymore*".

The majority of people who reported using DTs had not downloaded any type of app: 50% (33/66) reported not at all, 39.4% (26/66) were categorized as limited frequency and 10.6% (7/66) reported high frequency. During the first stage interviews when people were asked about apps, one participant picked up her phone and scrolled through the apps she was using. It led me to ask other participants to go through a similar exercise. One participant who regularly used DTs commented how she didn't even know what an app was, so didn't know if she used them, and was unclear what she had on her phone. For people who had downloaded apps, the ones they selected were either related to finances or news, with one person using a dating app. No one reported

Figure 5. 4 *Frequency of Digital Technology Activities*



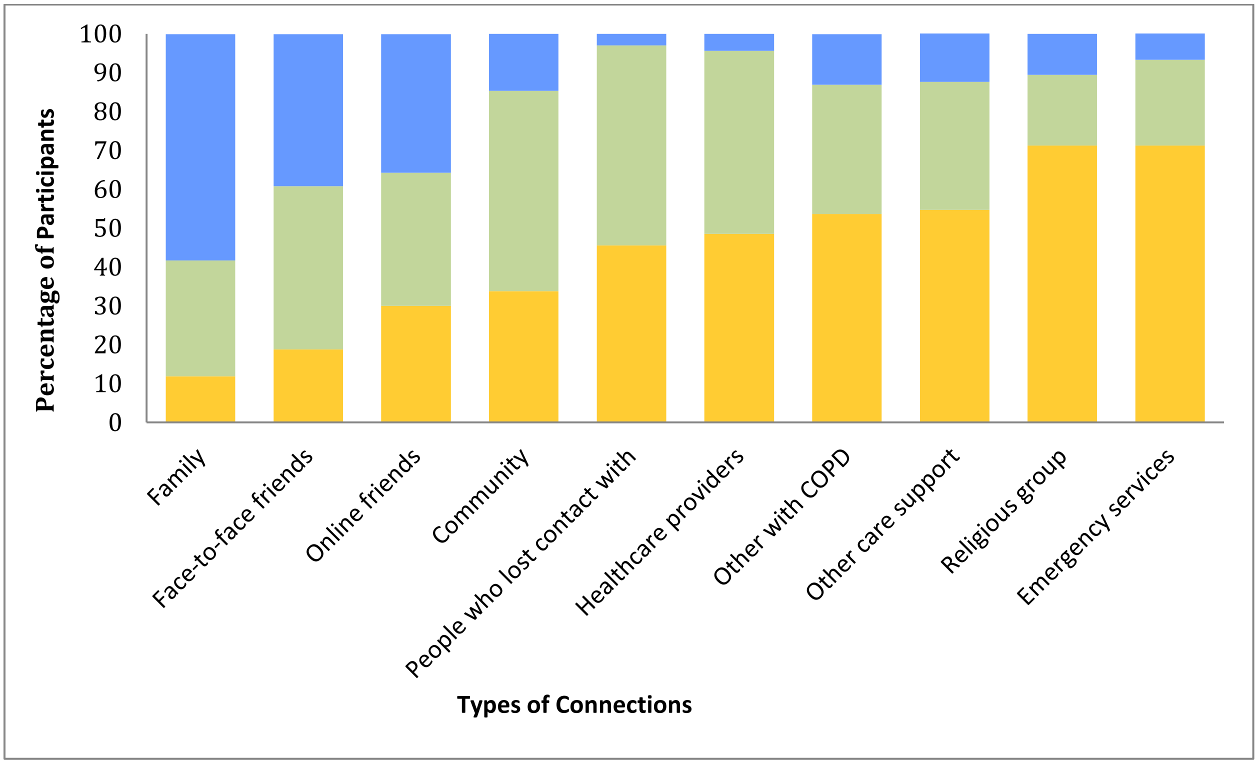
The graph represents participants who reported some use of DTs (n=66 to 69). Yellow demonstrates the percentage of participants who reported not doing this DT activity. Moderate represents the percentage of participants who reported moderate frequency of the DT activity. High represents the percentage of participants who reported high frequency of the DT activity.

downloading or using a health app, rather people were often surprised to discover that they had a health app already on their phone. This lack of use of healthcare apps was represented by Vicki's reaction when she scrolled through her phone: "*There's one here that says health! Welcome to the new health app. But I've never – I haven't got it set up. I don't know what it could do for me, if it could do anything*". This aspect of what the technology could do and what can be done for COPD is one that will be revisited in chapter 6 in considering the roles of DTs for COPD.

Types of Connections through Digital Technologies

The types and frequencies of connections people were making through DTs are detailed in Figure 5.5. Of particular note, is that people most often used DTs to connect with their family (88%; 59/67 of people who used DTs), with 58.2% (39/67) reporting high use. What had changed since the onset of the pandemic was the type of virtual connections that were being made with family: instead of individual video calls, people were now meeting in large virtual groups. This was demonstrated by Adam, who had regularly used Face Time prior the pandemic to connect one-on-one, but found that since the pandemic his use of video calls had changed. He said: "*My wife did something recently on a platform called Zoom because there were quite a few people involved, and even that is better than nothing you know? Your talk time now gets divided amongst say 20 or 30 other people, and of course we all like to talk right*"?

Figure 5. 5 *Frequency of Types of Connections through Digital Technologies*



The graph represents participants who reported some use of DTs (n=66 to 69). Yellow demonstrates the percentage of participants who reported not using DT for this type of connection. Moderate represents the percentage of participants who reported moderate frequency in using DT for this type of connection. High represents the percentage of participants who reported high frequency in using DTs for this type of connection.

People also frequently used DTs to connect with their face-to-face friends (81.2%; 56/69 of people who used DTs). Many people had already established ways to connect remotely with friends, and thus did not find that the pandemic had significantly changed as to how they were using technology for one-on-one interactions. Some people spoke about how they had retired in a different city than their friend, so had already established ways to stay connected through DTs. For their local friends, most had turned to using the phone as replacement for their in-person visits. Preference for a landline was repeatedly mentioned both within the open-ended section of the survey, and during the interviews. One person whose memory had declined after a stroke, found that a wired phone connection enabled her to always find the device, while other people preferred the sound quality offered through a landline.

People also reported using DTs to stay connected with their community (66.2%; 45/68 of people who used DTs) and religious associations (28.8 %, 19/66). One participant provided a more novel way by using an app to stay in touch with his church community. As "*a snowbird*" he had been set-up to stay in touch with his church in the United States throughout the year by using a Bible app, which allowed him to connect with "*other people that are from our church are on and then there's a place for commenting so we do commenting, and make your comments on what you've read and everybody else can read it*".

Although the survey demonstrated that people were using DTs to connect with family, friends and their community, there were limited examples of people using DTs to connect with people to support their COPD. As illustrated on the right side of Figure 5.4 few people used DTs to connect with their healthcare providers and other people who supported their care. In the interviews that were conducted early into the pandemic, this appeared to still remain the case, as only one person referenced a doctor's appointment over video, and everyone else had their appointments conducted over the phone. In addition, some participants mentioned how they no longer had contact with home support as they had cancelled all of their home visits. During both interview stages, people most often referenced how they used DTs to stay connected to their local COPD through the emails they received from different mailing lists, such as the BC Lung Association. Some participants recognized how few COPD supports were offered through DTs. This was demonstrated by Adam when he spoke about the difference he noticed in online supports for his other health conditions: "*there are online support groups, for congestive heart failure* *and I also have atrial fibrillation and ventricular fibrillation, so there is online support through that, but not for COPD. I've had a much harder time finding anything like that for COPD and I have a lot of questions about COPD that I haven't really found anything yet*".

One participant provided one of the few examples of using DTs related to his COPD that went beyond email. He had become quite active on lung transplant groups, as he wanted to "*see how other people had faired through this*". His strategy in evaluating forums was to read the "*long list of comments with every bit of information*" to see how people replied. He also recognized when it was time to leave a group, if responses were offensive. He spoke about visiting a site where his comments were criticized: "*I said that's ridiculous, I said, do you really have to go there, we're talking about lung transplants and you have to – well good luck, I'm out of here, and I did, I moved off there*".

These first two sections served to set the landscape by providing an overview of the participants within the study, and the types of DTs they used for different activities and connections. This next section builds off of the above quote by this participant, by exploring different values. It begins with presenting different preferences for using DTs and then follows with an exploration as to how dominant discourse around barriers and facilitators of DT use appeared throughout the study.

Preferences on Use of Digital Technologies

Not a One-Size-Fits-All

Participants recognized that there wasn't a "*one-size-fit-all*" for technology, as everyone had personal preferences, which often was based on familiarity and convenience. Penny spoke about her preference for using her phone: "*it's right there in front of me, handy, where as uhm I need to come into my spare bedroom, turn on the computer, and do all* *of those things. I don't have to do that, the phone's right there*. While Lily selected activities "*because I'm unfamiliar with what else is out there, it [is what] works for me*". In contrast Michelle was "*always like looking for the tools - looking for efficiency*". What became very apparent during the interviews is that these individual preferences were also greatly influenced by the DTs that were being used by participants' social groups. For example, one participant had joined LinkedIn to stay in touch with a missionary, used Skype to see her son, followed Facebook for her granddaughter's online business, and used text message to connect with me in my role as a researcher.

The preference of technology was further evident during the third stage, where the pandemic meant that all interviews had to be conducted remotely. Four out of thirteen people opted to have their interviews conducted over video because they liked the face-to-face connection. Gary commented on how it was "*nice to put a face to someone you are talking to*". Adam expanded on this by saying: "*Telephone conversations are fine, email conversations are fine, Facebook's fine, all that stuff is fine, it's better than what we had 30-years ago but I personally like – if it's gonna be through technology I'd personally like this [messenger]*".

Yet the majority of people elected to have their interviews over the phone. During a few of these phone interviews people would mention that the next time they would like to connect with me over video, but didn't set it up this time as they weren't too comfortable with it. This preference may have been due not only to a person's comfort with the technology, but with meeting a new person and doing an unfamiliar activity such as a research interview.

During the interviews people also spoke about their visual, auditory and tactile preferences in selecting the way they to receive information. For example, Henry preferred watching videos as the visual was how he learned: "*If I'm gonna be speaking or anything I practice it out loud because what I hear I remember better. So, so you know I need the hearing and the visual*". Whereas Sarah found the opposite: "*Oh no, I don't do audio books, no, no. And even my son was gonna get me a kindle and I said no… I like the tactile feel of a book in my lap and turning pages and stuff like that... I get a lot of my information is from reading stuff. I retain it better I think than listening to it*".

Co-morbidities and Changing Abilities

The preferences for the DTs people used were also impacted by other health conditions. Common co-morbidities that people wrote in the open-ended survey question were heart disease (13/80), asthma (11/80) and arthritis (10/80) (see Table 5.6). Edith reflected other participants' experiences in referencing how pain or degenerative condition discouraged DT use. She had been living with fibromyalgia for several decades and found:"*when I had the computer, it aggravated the neck and then I got neck spasm and then it radiated to the other areas and so it was totally tiring for me to even use a computer. So that's a major thing... I can't use the more modern things which one might think would help me*". One participant also spoke about how changes to her memory due to a possible stroke had made her hesitant to go online.

Table 5. 6 *List of Co-morbidities Self-Reported by Participants* *(n=83)*

Condition[1]	**Number of Participants**
Heart or vascular disease	13
Arthritis	11
Asthma	6
Cancer	7
High blood pressure	5
Neurodegenerative or muscular degenerative	7
Pain	4
HIV or Hep C	3
Irregular heart beat	3
Kidney disease	3
Diabetes	2
Digestive condition	3
Allergies	1
Broken hip	1
Sleep apnea	1
Sinusitis	1

[1] Notably, no one reported mental health conditions, such as depression or anxiety. How the question was asked in the survey, or people's comfort in providing this information on a survey may be two possible reasons why no participants reported having depression or anxiety.

Face-to-Face Versus Remote Visits

The pandemic had significantly changed how care was being delivered. With people now being introduced options for virtual care, they talked about their preferences for remote versus in-person appointments. These preferences were dependent on the nature of the visit, the distance required to travel and time involved in waiting for an appointment. For example, Ruth spoke about her recent appointment to check on a spot on her leg. She emailed a photo to her doctor and the visit was conducted over the video, but found that "*I definitely prefer in-house, like I'd rather go and see him personally. I mean he can't burn that* *thing off over technology, you know, there's certain things you need to show him or whatever*".

In contrast, one participant who was in the midst of going through the series of tests in preparing for his lung transplant, commented on how things had changed since COVID-19:

> *It's a lot easier to talk to people... since the survey, I've received calls from the hospital and they're going to be setting up video calls so you can talk to the doctor. So what a huge relief that is, I don't have to travel to [large city] every time I need to talk to somebody for five-minutes…. So I would say yea, it's a great positive to have the technology that we have today. Can you imagine in the old days, it would take eight-months to get back and forth. So this way you get instant responses.*

Prior to the pandemic, people who did not drive spoke about the time required to get to a face-to-face visit. It could involve a full day of transportation on public accessible transit to attend a short doctor's visit. Yet there was also recognition of the importance of face-to-face visits. Although Richard had to spend three hours travelling every three months to see his respirologist, he shared a story on how he was immediately hospitalized after a visit with his respirologist: "*And he said I'm going to book you into [the hospital]. I said, "what, why?" He goes because you're looking really, really off. And I had superbug! It took me a long time to get rid of that. But he knew as soon as he looked at me that there was something wrong*".

Exploring Dominant Discourse of Digital Technology Use

To understand how people's preferences may have been impacted by current discourse around technology, this section focuses on what is commonly conveyed in the literature as 'barriers and facilitators'. The section begins with 'privacy and security', ‘costs' and 'technical skill', as areas that are often conveyed as barriers to DT use. The question on ‘technology as isolating’ is explored in chapter 7, as part of examining how DTs translate to the experiences for people living with COPD. It is then followed by an exploration as to how people are encouraged and introduced to use DTs in considering 'facilitators' of DT use.

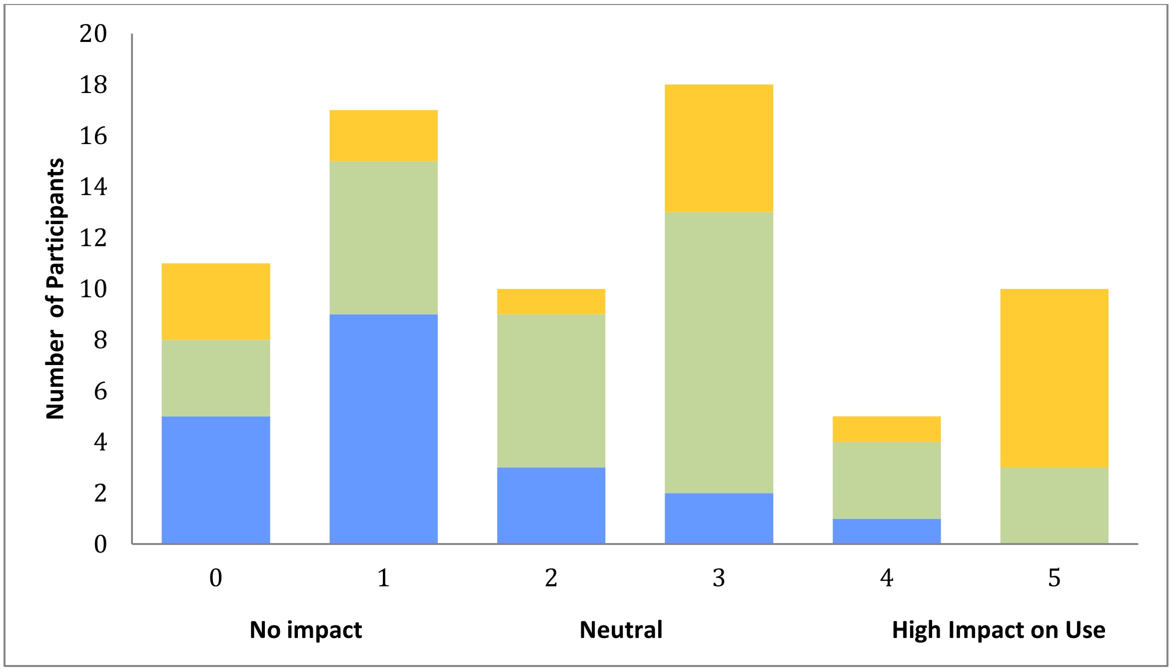
Different to previous graphs in this chapter, the graphs in this section represent all of the people who completed the survey, including people who reported not using any DTs. The 'high' represents people who were identified as high users of DTs, mid represents moderate use of DTs, and non-use or low represents people who reported little or no use of DTs. Pearson's two-tailed test of correlation was also used to determine if there was any relationship between responses to survey questions and reported frequency of use of DT. The stage one and three interviews were used to add more context as to how meta-narratives around perceived barriers may be taken up by people living with COPD.

Costs as a Perceived Barrier to Use

As illustrated in Figure 5.6, people who did not use, or had low use of DTs were more likely to report that costs influenced their use of technology (right side of figure), yet overall cost did not impact use for the majority of participants. A relationship was found between people who were more likely to report financial cost as preventing them from using technology, and the frequency of use of DTs (r=.360; p(two-tailed) p<.001; n=77).

However, when looking at the demographics as to which participants were some of the greatest adopters of DTs, income security did not appear to impact DT use. Out of all the participants who completed the income security question, 33.8%, (25/74) reported having difficulties making ends-meet as sometimes, very often or always. Within this group of 25,

Figure 5.6 *Cost as a Perceived Barrier to Use*



The graph represents all participants who completed the survey (n=80). Yellow represents participants who reported no or low use of DTs. Green represents the number of participants who reported middle-level adoption of DTs. Blue represents number of participants who reported high level adoption of DTs.

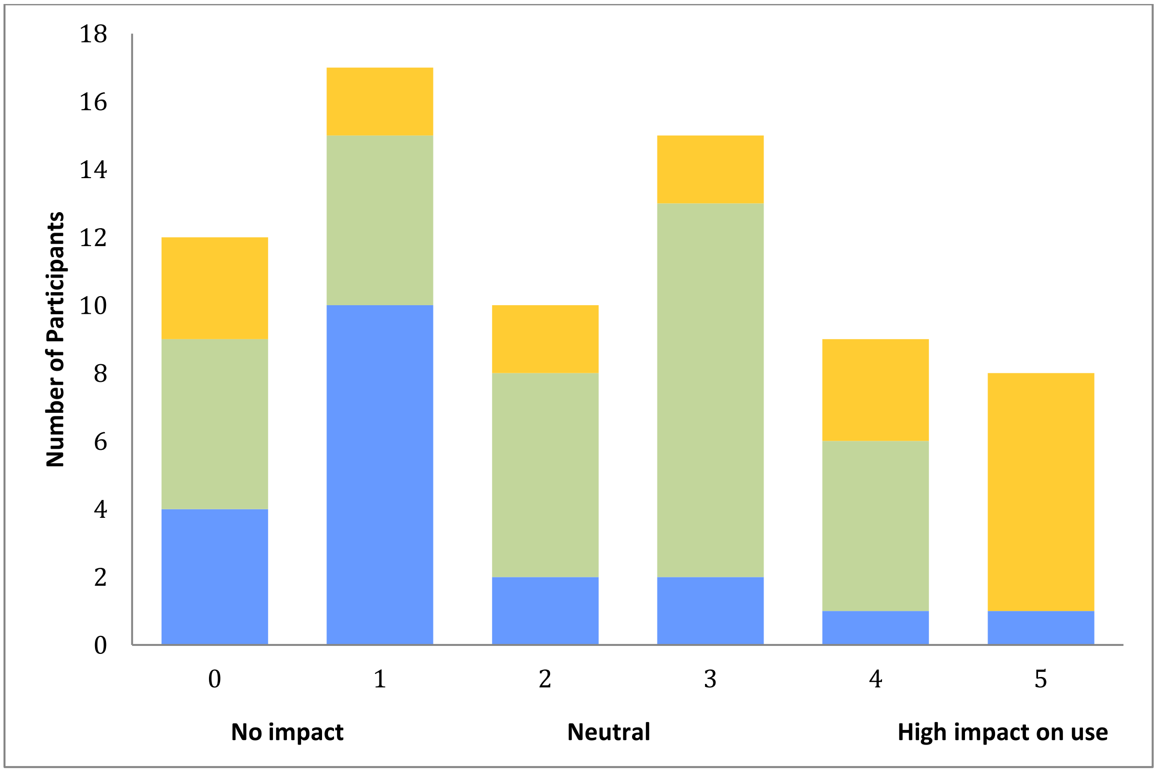
only two out had not adopted any DTs, and 22 people identified within the high adopter category (22/29, 75.9%).

The interviews further demonstrated that cost itself was not a barrier to overall DT use, rather people would weigh purchasing a device against other expenses. Norah mentioned how she had cancelled her cell phone to save money, as she already was using a tablet. When asked further about how costs had stopped Sarah from using any DTs she replied "*The cost is actually a poor excuse because I mean, I could afford to get it, cost isn't a major factor, it's just not something I really am inclined to do... It's just not something that I feel I need, you know and it's not something I want*". This lack of need appeared throughout the study stages. Eighteen people had written in a "*lack of interest* or *need*" into the open-ended responses, where one person's response reflects similar comments: "*not needed, have more than enough technology, [and] will not be driven by it".*

Privacy and Security Concerns as a Barrier to Use

Figure 5.7 illustrates that people who did not use, or had low use of DTs were more likely to report that privacy and security concerns influenced their use of technology (right side of Figures 5.7). A relationship was found between people who were more likely to report privacy and security concerns as preventing them from using technology, and the frequency of use of DTs (*r*=.260; (two-tailed) p<.01; n=77).

Figure 5. 7 *Security and Privacy Concerns as a Perceived Barrier to Use*



The graph represents all participants who completed the survey (n=80). Yellow represents participants who reported no or low use of DTs. Green represents the number of participants who reported middle-level adoption of DTs. Blue represents number of participants who reported high level adoption of DTs.

During the interviews it became apparent that 'privacy and security' concerns were much more nuanced in discouraging people from going online. Cassandra, who did not use technology, was not discouraged even when her friend told her not to go online. She recognized that "*bad things*" can happen and DTs can be an "*invasion of your own life... but really, there are more plusses with the computer than there is the negative, and you know you have to sort of, ah, work through that. You see how much of your information is protected, really*"? She then went on to say that she wanted to learn about DTs, but first wanted to take a course to understand these privacy and security concerns. Owen who relied more on his wife's use of DTs, talked about being hacked a couple of times. This experience did not deter him, but rather he had weighed the risk of what could be lost and continued to use his computer after getting it repaired: "*You know, so I don't, why would they hack us, we've got nothing*"*?*

Gary provided an example of being a highly active adopter who had only began to use technology over the past decade. He remembers asking his wife about the security of her online banking: *"I'm not too sure about that, are you sure about that?" And she'd go, "it's safe." And then I found out later too that these are – I mean if you buy and something goes wrong they cover it, VISA covers it, you're covered that way*. Seeing his wife do this activity and not having negative repercussions gave him assurance in later adopting DTs, and one of his first online activities had been online banking to settle his wife's estate.

Strategies to Address Privacy and Security Concerns

It was the way "risk" was referred in the interviews that further demonstrated how people were weighing different decisions. No one used risk in reference to online privacy and security, but rather risk was used around the uncertainty related to their overall health. There was the risk related to COVID-19 where people said: "*COPD people are more at risk*" or "*we are all at risk*" or "*we don't want to take any unnecessary risk*". Others spoke about risk in terms of "risk factors". This included going for a transplant where "*it's a risk, but it's a risk worth taking*", in reference to COVID-19 where it put people in a "*precarious position... you know you're kind of at risk*", or in relation to cause of COPD "*I fought forest fires... that's a risk factor*".

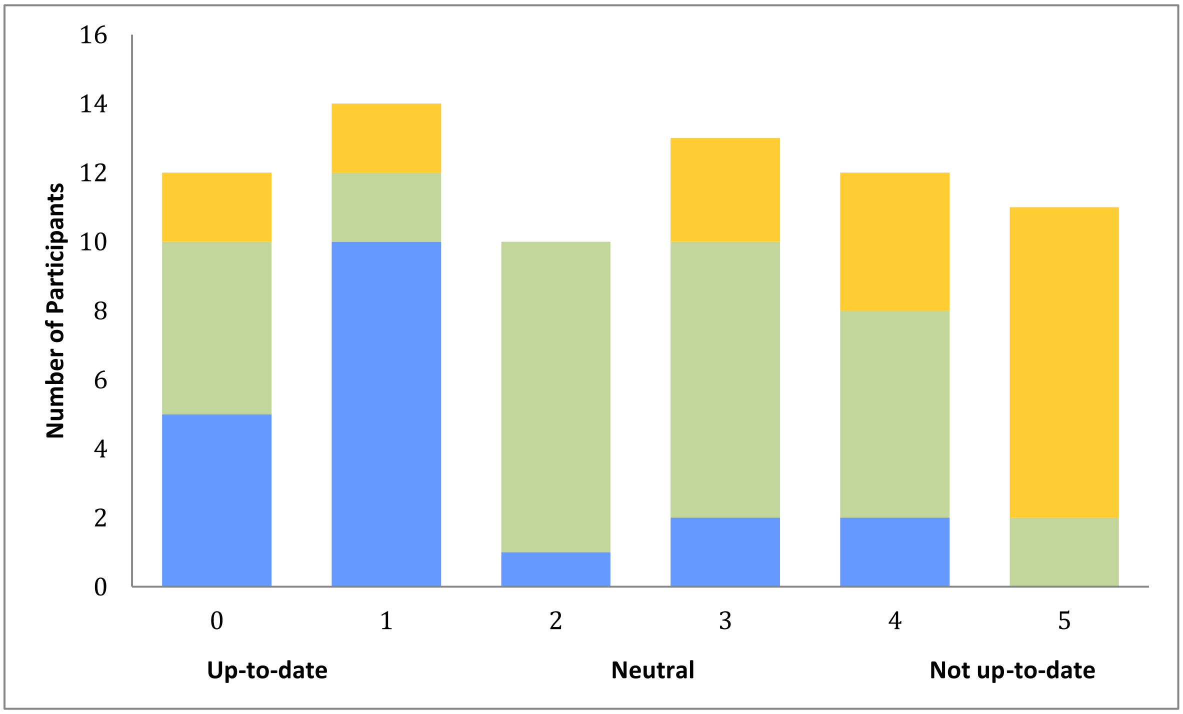
What was found instead is that people had developed strategies to mitigate the online risk by addressing the varying levels of security offered through different sites. There were the repeated concerns about "*clicking on the wrong button*", where people inadvertently clicked on an advertisement that took them outside the web site they were viewing. In contrast, You-tube was often used as a safe space for spontaneity, where people could do a search and get swept away into new areas. The people who did their banking online felt reassured in knowing that the sites were secure and encrypted, and the added security in being able to view instant updates on bank records so that errors on recent purchases could be caught. People also separated out their devices for different activities. For example, they would use their computer for online searches, and their tablet for online banking. One participant mentioned how purchasing identity theft insurance under his home insurance plan had given him more comfort in going online.

When people faced security or technical hurdles, they would return to the vendor they had purchased the device or source a local computer store for ongoing in-home technical support. Having family members purchase the same device or pass on an older version of their phone enabled remote training or troubleshooting on a familiar device. Technical support was not one way: although friends and family may have been a source for technical support questions, and participants had also served as technical support or introduced their peers to new technology. People would also listen to podcasts, watch videos or do online searches as way of becoming more familiar with their current or emerging DTs.

Technical Skills as a Barrier to Use

In the survey, the people who used DTS most often were most likely to report feeling up-to-date with technology (see Figure 5.8). Yet, in spite of these perceptions of feeling up-to-date with technology, I heard opposite perspectives during the interviews.

Figure 5. 8 *Feeling Up-to-date with Technology*



The graph represents all participants who completed the survey (n=80). Yellow represents participants who reported no or low use of DTs. Green represents the number of participants who reported middle-level adoption of DTs. Blue represents number of participants who reported high level adoption of DTs.

People who identified as being very active adopters of DTs, would often bring in their age when talking about technology. They would situate themselves by beginning with terms like "*technophobe*" or "*tech-savvy*", and often compare themselves to younger generations. This was illustrated by Lily when she began with "*sometimes it's hard to teach an old dog new tricks*", before referencing her frustration at how quickly things evolve: "*my own children, or my grandchildren they'll say "why don't you get such and such" and I'll say "I don't even know what that is", well " I don't know what you are talking about*".

Darla who began her interview by talking about how she started using a computer in 1970, quickly moved to talking about feeling out of date: "*yay, uhm, when you talk about all the modern whatevers, uhm, you are talking about features that people up to thirty or forty are very familiar with, but if you are fifty / sixty / seventy you're not, okay*". Similarly, Adam who had used technology for thirty years still did not think that he had the skills:

> *And of course you have to remember guys like me, I'm 75 now, when we went through school we didn't have these toys to play with, we didn't grow up with these things. These were introduced into my life probably back in the… well you know, probably back in the early 90's. For me that's not that long ago!*

Gary provided a slightly different perspective to this intergenerational comparison. He had only recently adopted DTs and talked about being in awe of his nine-year-old granddaughter: "*They're savvy. Like they play these things… there's this one thing they're playing right now called Minecraft. I don't know if you've ever seen it. But they build their own worlds and how they navigate around in this stuff I have no idea. It's just amazing. I'm just in awe of how they get around in the electronic world. Their brain is put together different than mine was when I was that age, that's for sure*". Yet, he wasn't comparing his current skills to his granddaughter, but to where he was at when he was a child. His reference to the different world he grew up and his granddaughter's online world illuminated how the generational differences may be more to do with our creation of different social worlds, rather than technical aptitude.

Entry Points to Using Digital Technologies

Social Influence

Often when introducing the study to healthcare providers or researchers, I would hear how older adults weren't using technology, and particularly how low income older adults would be even more deterred. I wanted to find out how these beliefs and assumptions may be filtering down and whether people felt encouraged to use DTs. Most people responded in the survey that they felt encouraged by friends and providers, and there was no significant difference found as to whether or not people were already using DTs (see Figures 5.9 and 5.10). During the interviews people would talk about how they were first introduced to using a new technology. What I found was that it wasn't necessarily the *encouragement* from other people but the *influence* of other people, in people's adoption of DTs. Often, it was through "*word of mouth*" or in observing other people using technology that made people want to learn a new DT.

Gary, who had only recently adopted DTs, mentioned how he got "*hooked up to Twitter and I did it because I started seeing all this stuff about Trump and it said he was on Twitter all the time and I'm going, well let me see what this Twitter is all about*". Michelle talked about how watching her teenage sons text made her realize "*I'm either gonna learn about this stuff, or I'll never know what they're doing*". Similarly, Penny shared how she decided to purchase a computer in the early 2000s after seeing that "*everybody else is*

Figure 5. 9 *Friends Encouragement in Using Technology*

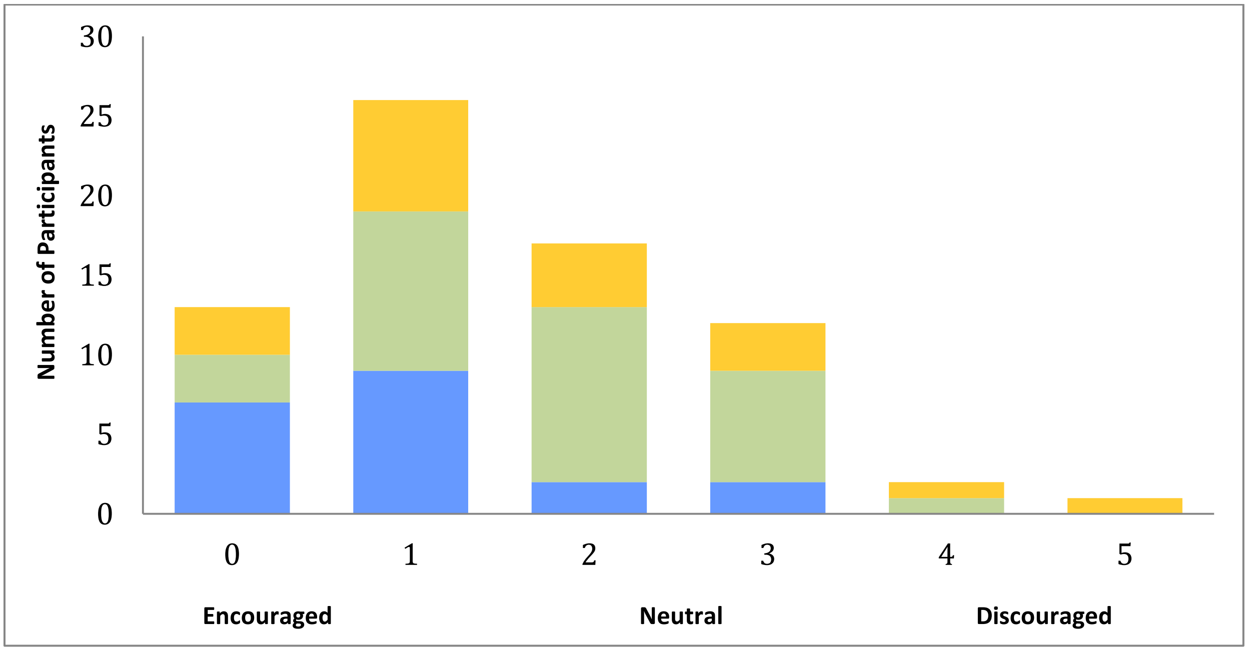
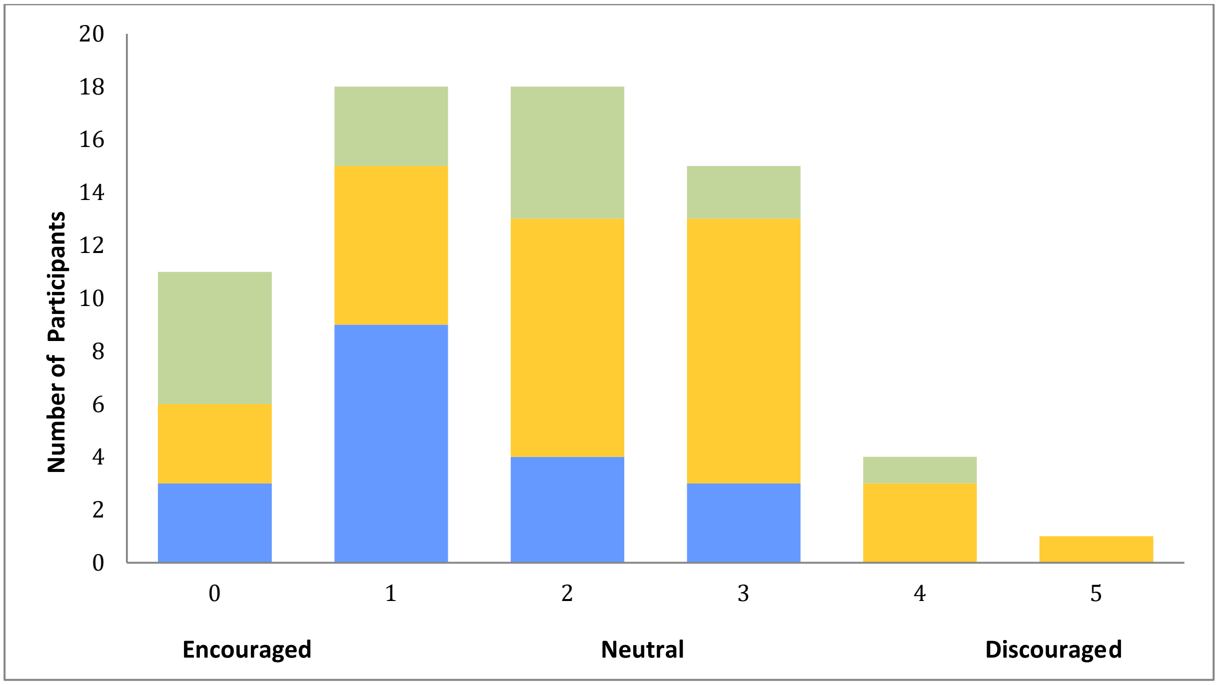


Figure 5. 10 *Healthcare Providers' Encouragement in Using Technology*



The graphs represent all participants who completed the survey (n=80). Yellow represents participants who reported no or low use of DTs. Green represents the number of participants who reported middle-level adoption of DTs. Blue represents number of participants who reported high level adoption of DTs.

communicating by computer and I wanted to do that too". Through Michelle's work in teaching older adults about technology she recognized that not everyone may be curious and especially people over the age of 75 may need a nudge by showing how DTs can overcome their "*pain points... [to] help them make a connection and then unveil all of these possibilities*". She then goes onto introduce the term “*entry points*” as way to introduce people to DTs, by starting off with a single, simple task, such as sending a text message, to overcome apprehensions.

Workplace

The workplace was where most people had been introduced to technology, and these work experiences continued to influence use of DTs. Two women who were over the age of 77 shared very different experiences about how their workplace had influenced their use of DTs. Penny who had worked in administration talked about how she overcame her initial trepidation in using computers: "*I think if you have the fear of it, my opinion is it's all in your mind, and you just have to start doing it... The fear wasn't so great, that was my job. I wouldn't be careful for too long, because I had to do the job*". In contrast, a retired nurse spoke about her experience in using the technologies at her work in the hospital: "*I was locking things or refusing to accept things that were on the computer and it became an issue so I had to stop... I’ve kept that fear. It’s not through lack of wanting to do it*".

Gerald found that his work experiences had given him confidence in using current DTs: "*I was the first guy ever to have a computer at work…So technology wise I’ve always been… so anything new with computers, I’m on top of pretty much*". Yet others who had worked with computers throughout their life spoke about the challenge in having DTs always evolving. This was demonstrated by Adam when he reflected on being part of the digital age:

> *The first introduction to digitization and then eventually, word processor[s], and that evolved into platforms like excel where you could do financial stuff, and then somebody introduced email... and then all of a sudden, little telephones came out... And things have evolved from there.*

And yet, in spite of these experiences he found that when he came across new platforms he had to "*fumble my way through*".

Sudden Life Events

There were also the sudden life events that could introduce people who had never used DTs to rapidly becoming high adopters. Two men who didn't adopt DTs until their mid fifties spoke about their entry point when they became very active users after their wives had died. Gary said:

> *I lost my wife to cancer in 2005 and before then I just relied on her. I knew nothing about this. I relied on her to contact the rest of the world... I had to deal with lawyers, I had to deal with real estate agents, I had to deal with banks, I had to deal with money and I did everything on my iPad. I even transferred the money myself from [country] to my Canadian bank account, on the iPad. It's amazing what you can do with an iPad"*

Henry shared a similar experience:

> *She did all the paperwork and stuff like that but when she passed away I sort of had to do it because there was nobody else to do it. So I sort of learned. In the beginning I was*

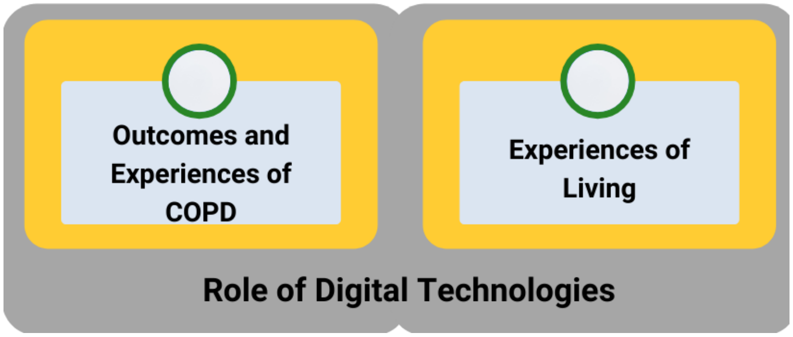
> *a little bit sluggish with getting computers, like I wasn't really overly drawn to the computer.*

These men illustrated how critical events that cause disruptions in social roles and responsibilities can encourage people to adopt DTs. In context of the pandemic, the global social disruptions through current social distancing measures may be providing the possibility of an entry point for people who have never used DTs.

Summary

People with COPD are using DTs in multiple ways. However, the study demonstrated that people in the oldest demographic continue to have lower adoption rates. As many people talked about their introduction to DTs was through their work, it may have been that older adults in their eighties did not have the same opportunities to use DTs in their workplace. The assumptions around who are using DTs and the barriers to using DTs did not appear to have as strong of an impact on the people who participated in the study. Most notably, everyone in the study under the age of 77 was using DTs, suggesting that the capacity to use DTs is already being established by people living with COPD. In chapter six, I continue to explore how people are using DTs by examining the different roles of DT to support people living with COPD.

Chapter Six: Results -The Role of Digital Technologies for COPD



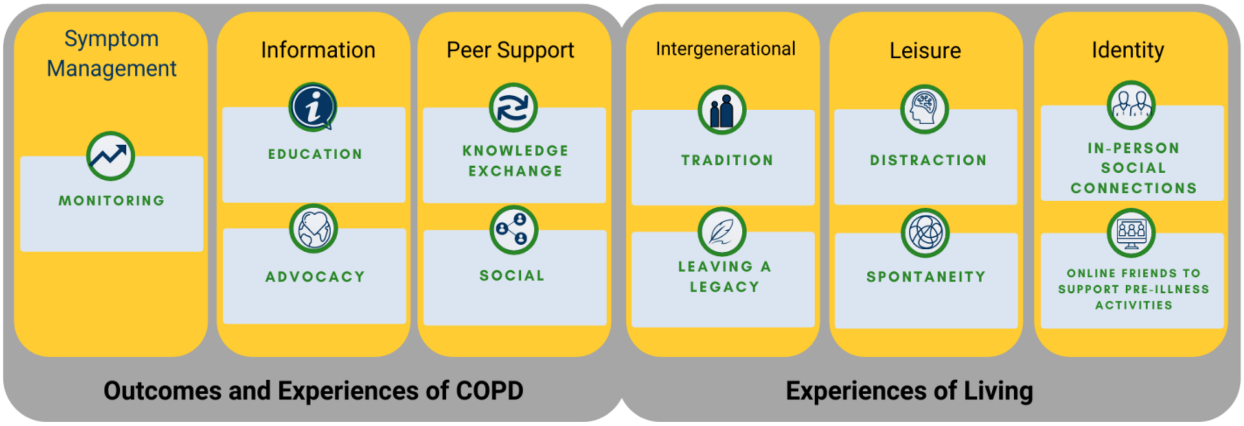
Introduction

The previous chapter detailed the *landscape* for how participants in the study were using digital technologies (DTs) that may not have been related to their chronic obstructive pulmonary disease (COPD). Chapter six focuses on the *roles* DTs may distinctly serve for people living with COPD. The roles that have been identified through this study are summarized in Figure 6.1. It begins with the roles of monitoring for symptom-management, information for education and advocacy, and peer support for sharing of illness knowledge and advocacy as *current* roles in supporting outcomes and experiences of COPD (left-side of Figure 6.1). The chapter concludes with possible <u>new</u> roles of DTs that focus on supporting experiences of *living* with a fatal chronic illness (right-side of Figure 6.1). Through this exploration, examples are offered on how DTs are currently being used by people with COPD to support these roles. The chapter also includes examples of how people referred to these roles where they may not have reference DTs or COPD in order to illuminate the possibility of new roles of DTs for people living with COPD.

Overview of Types of Digital Technology Activities for COPD

Across all stages of the study, the most common activities that people reporting doing through DTs to support their COPD were related to accessing information on symptoms or treatments. Although people reported using DTs for tracking and monitoring, this was most often for tracking other health measures that were not related to their COPD. People were using technology to stay connected to their COPD support group, however, this was commonly done through asynchronous one-way communication such as monthly

Figure 6. 1 *The Role of Digital Technologies for Supporting COPD*



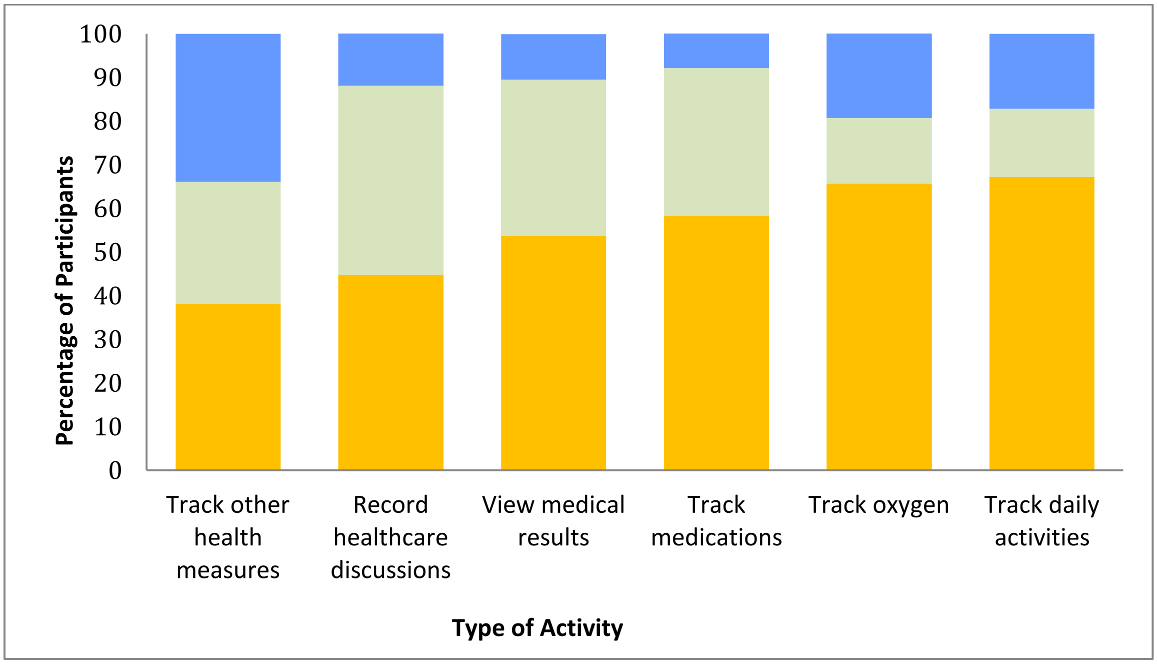
e-newsletters. Few people provided examples of using technology for what is often considered under self-management (e.g., breathing exercises and tracking medications). It was not that people were not doing these activities, but that they did not use DTs for these activities. To understand the roles of DTs to support COPD, the next section explores examples of how DTs are currently be used for monitoring symptoms, information for education and advocacy, and peer support for knowledge exchange and social connectedness. The figures that are included in this section represent survey results from people who reported some use of DTs.

Current Roles of Digital Technologies for COPD

Monitoring and Tracking

Although people used DTs for tracking other health measures, a minority of participants had used DTs for tracking oxygen levels, medications and daily activities. See Figure 6.2 for the frequencies of the different ways that people used DTs for monitoring and tracking. Throughout all stages, people referenced their use of blood pressure monitors for tracking their overall health.

Figure 6. 2 *Health-related Tracking and Monitoring through Digital Technologies*



The graph represents participants who reported some use of DTs (n=66 to 69). Yellow represents the percentage of participants who reported not using DTs for the monitoring activity. Green represents the percentage of participants who reported limited frequency in using DTs for the monitoring activity. Blue represents the percentage of participants who reported high frequency of using DTs for the monitoring activity.

As illustrated by the green sections in Figure 6.1, over one-third (33.8%; 23/67) of participants who used DTs reported high frequency for tracking other health measures. Yet, far fewer people reported using DTs to track their oxygen levels (19.4%; 13/67). Sarah provided further insights as to why more people may not use an oximeter: "*I take my blood pressure every now and then because that's something you can't tell. But with my breathing I know when it's problematic and when it's not*". Similarly, the majority of people didn't use DTs for tracking medications (17.9%; 12/67). During the interviews people would often mention how they kept a paper journal or used blister packs for tracking their medications, so did not find the need to use DTs for medication tracking.

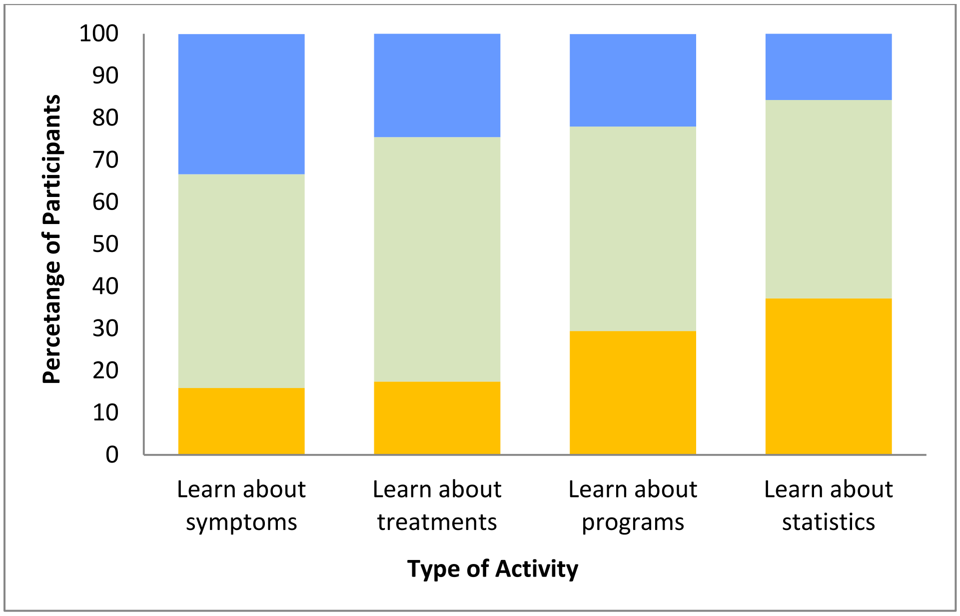
During both stages of interviews, a few people had mentioned how they had tried oximeters for monitoring symptoms of COPD, but few continued using them over the long-term. The person who had participated across all three stages had recently ordered an oximeter due to the onset of the pandemic. Vicki spoke about how she had used an oximeter during particular times when her COPD was more severe, and as a way of reassurance in evaluating where she was in her overall severity of COPD: "*I was checking it when I wasn't doing well and it would go down but come back up when I stopped and did my breathing exercises so I don't think I'll ever be on oxygen because it doesn't go… my oxygen level doesn't go low enough*". Samuel provided a rare example of daily tracking of his breathing, where he viewed his oximeter as his "saviour".

> *I was dead! for fifteen minutes!... My doctor was basically explaining that the $C0_2$ can build up when you're breathing shallow. So what I had been doing [takes a few shallow breathes] in trying to catch-up. But what I have to do is [breathes a deep long breath and then a lengthy exhale with a slight roar, breathes again with a deep long breath and then exhales with a long ahhhhh]. And that way I get rid of the stale air that sits at the bottom of the lungs, which is full of $C0_2$. So now I know if I get a good oxygen level [on my oximeter], but I'm out of breath, I have to do the extra job of extra inhale exhalation. And this [points to oximeter] has been my saviour.*

Educational Role of Online Information

Online searches were the second most common activity people did through their DTs (see Figure 5.4 in the previous chapter), and this was also reflected in the online activities people identified specific to supporting their COPD. Figure 6.3 illustrates the frequencies of the different types of information people search for online, with the most common activity being to look up information about symptoms.

Figure 6. 3 *Online Searches for COPD-related Information and Education*



The graph represents participants who reported some use of DTs (n=66 to 69). Yellow demonstrates the percentage of participants who reported not using DT for the type of information. Green represents the percentage of participants who reported limited frequency in using DT for the type of information. Blue represents the percentage of participants who reported high frequency of using DTs for the type of information.

During the interviews, people also talked about how they did online searches for information after their doctor's visit as way of better understanding their COPD. Although many people talked about not understanding the progression of their illness, some were hesitant to look up this information online.[15] This was demonstrated during the first stage of interviews when Lily spoke about noticing a recent change in her COPD progression, and so "*needed to dig in and search because mentally it can be quite uhm, upsetting to know that*

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[15] Note: There was not a specific question on that asked people about whether they use do online searches to find out about progression of COPD. This would be one question I would have like to have added.

you have a terminal disease, right? And that you don't know what's going to happen in the future". Her quote also helped to illuminate why people may be were more likely to use DTs to look up information on symptoms (84%; 58/69) and medications and treatments (82.6%; 57/69), rather than statistics on COPD (62.9%; 44/70).

Other people talked about how they initially looked up information on COPD, but no longer needed to search for this information. This was illustrated by Sarah's comment: "*Yea and I mean this is it, you know, I mean so you're gonna do the research and access it once or twice and by that point you've pretty much got all the information you need, you know, so why keep delving into it every day*". Similarly, Norah said "*I've looked at it, to read up on what it says and there's so many different sites that you can go to, Mayo Clinic, but it's all pretty routine, it's all the same as to when I was nursing*".

Advocating Through Online Information

What emerged during the interviews was how online searches could be a form of self-advocacy in filling in the health information gaps. This was demonstrated by Lily when she said: "*So I started to take on my own, looking for resources for persons' with disabilities... and then, there's no advocate that's readily available for persons' with disabilities, as to what's out there for you*". Pamela referenced this advocacy role when she talked about having to be on her "*toes in this world of doctors*" and the positive role of technology for "*filling in the blanks of lack of information shared by doctors and people that should know... research, and advocating for myself when I decide there's a need for more information*".

A third woman talked about the research she had done prior to being diagnosed with sarcoidosis: "*I didn't know what I had. I did a lot of research. Of course, I googled everything, you know what could be causing everything, and you know I had everything in my* *head* ". When asked about how she used this information she replied: "*You go to your doctor, your specialist, with lots of knowledge, you know, but you still want them to be the specialist.... There is a lot of good information out there as much as there's a lot of not so good information out there. And I think the whole healthcare profession is like really frustrated with people who come in going I think I have lump here, it's cancer, you know, like, let them do their job".*

Information as a form of advocacy contrasted to other participants' reference to how power differentials were being reinforced within healthcare settings. One woman had written in "*doctor knows best*" beside the PREM-C9 question that asked people about rating that 'my doctor listens to my point'. One man who had served in the military questioned the hierarchy between patient, doctor, and specialist:

> *Some of that is tied into practicality, there's probably not that many respirologists in the world, but secondly it's also tied in, partly, to this medical mystique that they try to maintain to keep certain elements of medical practice out of the public eye, or out of public contact. For some reason that seems to have evolved, I don't understand it completely but you know, it's like they still want to maintain – oh we're some kind of magical people. "You really shouldn't know what we do".*

Type of Information

Although the study questions focused on asking people about the types of technologies they were using outside of the formal healthcare system, I found they would often lead participants to question the information and technological strategies they had been offered from the healthcare system in the diagnosis and prognosis of COPD. When I first introduced the study to Adam he immediately made the connection between the differences in healthcare supports offered for his COPD and heart failure. At his subsequent interview, he could not make sense of the differences in technologies used and procedures conducted before reaching certainty of a fatal diagnosis:

> *You know where you take a puffer and they wait a few minutes, and then you take another puffer and blah, blah, blah, blah, and I just couldn't fathom how that little bit of information could make such a serious diagnosis. Now with heart disease there were so many tests done to determine what damage my heart has undergone, but they have imaging, they have blood tests, they have angiograms...they have echocardiograms– so they have a number of diagnostic tools.*
>
> *But with COPD the diagnostic tools seem to me… I mean I'm sure they're very well based in science and experience, but it just seems pretty minimal compared to another organ's disease and yet COPD or chronic lung disease is such a common problem.*

People also couldn't understand how they could be given a fatal diagnosis, and then receive no follow-up testing or discussions by their providers. Norah wanted more detailed follow-up testing to know how her COPD was progressing: "*They give you the testing for the amount of air, or oxygen you're not getting and they in the lungs… and uh, so, they can tell you, well, you are getting worse each year and they can't tell you exactly where [you are at]".* This lack of follow-up was further demonstrated by the people in the study who had been told at some point that they may have COPD, but had never been formerly tested and diagnosed.

Multiple participants linked the lack of *information* to lack of a *cure,* lack of *treatments* and lack of information about *prognosis.* Ruth spoke about how "*there's no like* *cure or anything but if they can give you an idea of what might relieve symptoms that would be something that [I] would be interested in".* Adam shared very similar sentiments when he said *"oh there's no cure, there's really no treatment – but nobody says ok, here's what you're going to go through, here's what the progression of it is like".* A similar sentiment was shared in the survey when a participant wrote in "*what treatments*?" beside the question on 'understanding their treatments'.

These perceptions of "*lack of*" was quite different from two participants who lived in a region with a pulmonary rehab program, where being on a "*maintenance program*" for several years had given them regular connections to a targeted treatment program for their COPD. Norah who lived in a region that did not offer any ongoing programs had initiated her own form of a pulmonary program, but had no idea if she was being successful:

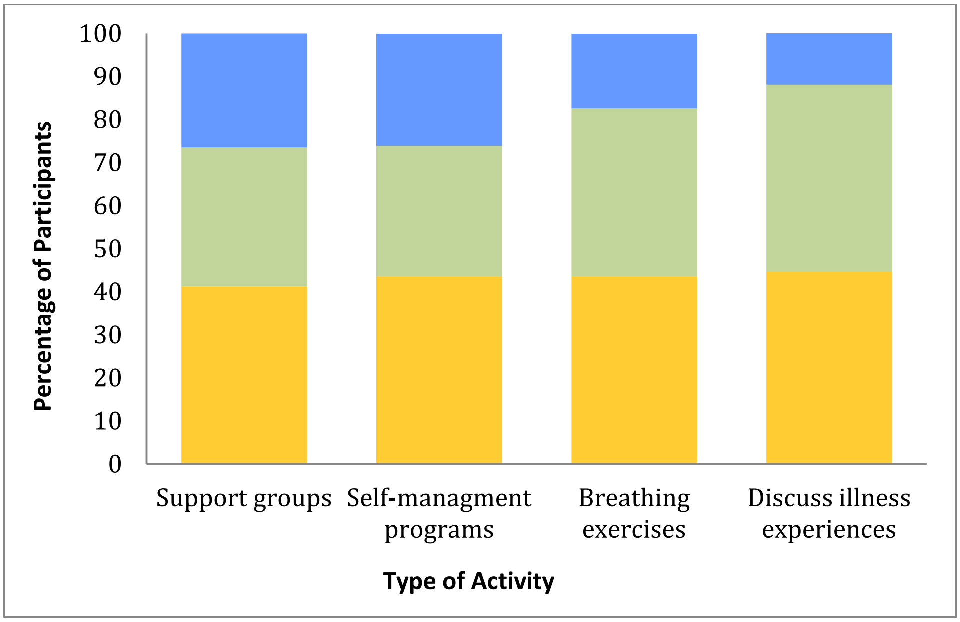
> *I started a program of constantly breathing through my nose and out through my mouth and pushing the air out? If I do that more every day is that going to help? I don't know. I can only go from my experience and try to live with it.*

These differences in supports revealed how it may not be a *lack of information* but the *lack of ongoing care* where people are part of regular programs to better understand and treat symptoms for of an illness in which there is no cure. This isn't information that can be found through an online search, but requires personalized information that tells people where they are with their lung function, and whether their current treatments are being effective in managing their COPD.

Peer Support for Knowledge Exchanges and Social Connectedness

As most of the participants were recruited from various COPD support groups, people often talked about the role these support groups served in being a place to practice breathing exercises, share experiences of living with COPD, and to socialize. Figure 6.4 details the frequency of use, and number or participants who used DTs for peer support, as well the type of activities that were supported within these groups. The graphs demonstrate that more than 40% of participants had not used DTs for activities that could be supported by peers.

Figure 6. 4 *Activities that may be supported through Peer Support Groups*



The graph represents participants who reported some use of DTs (n=66 to 68). Yellow represents the percentage of participants who reported not using DT for this type of activity. Green represents the percentage of participants who reported limited frequency in using DT for this type of activity. Blue represents the percentage of participants who reported high frequency of using DTs for this type of activity.

Asynchronous Peer Support

When people were asked further about these peer-supported activities the examples shared were most often about connecting in-person, and there were very few examples of where people had used online peer support. One participant who was in the final process of being added to the lung transplant list provided a rare example of regularly logging onto and commenting in forums to connect with other people with COPD. However, this was all with the intent of finding out about people's experiences of a lung transplant, and not COPD.

People had visited Facebook page or forums of COPD groups, but no one mentioned posting comments on these sites. Pamela had gone to the American-based COPD online support group, but found the type and tone of the discussion didn't resonate, as she found "*they're too whiney,, they're too "I" directed, you know. "I did this" and "I did that", and blah, blah, blah. And they're too, it's not encouraging, they're very heavy I guess because [they] are using it to vent about how unwell they are*". Others found that the type of experiences they wanted to share would not match with an online forum, as demonstrated by Sarah:

> *"Yea I'm not sure that I'd be prepared to have the type of discussion that you and I are having...with a large group online. I'm a little bit more of a private person than exposing, you know, to the world at large when I don't know who these people are. But yea, I've got no problem discussing with you and with my friends and neighbours, we talk about it".*

Learning From Existing In-person Peer Support

Although use of DTs for online peer support were not often mentioned, I asked people about their in-person support groups in an effort to better understand how these groups may translate to an online environment. Some groups were set-up with a monthly newsletter and Facebook page, and often one member was often seen as the hub in connecting through email or phone, or making visits to the hospital.

Many participants emphasized the importance of the social aspect. Pamela talked about her group being "*a community of people that you can talk to so that you find people and connect with them… [and] make friends*". Another person reflected similar views as other participants when he said they went beyond "*a social outing and [that] you get helpful information out of it as well*". People also found the group as a means of social comparison in evaluating their severity of COPD, as demonstrated by statements such as: "*Mines's a funny shortness of breath*", or "*Mine's not THAT bad yet*" or "*there's a few people there that have got worse conditions than I'm in*". One participant talked about his COPD group being his "*nuclear family*", which involved inviting members' children to play the keyboard or guitar, so that people could sing along and "*exercise those lungs*", and encouraging storytelling as "*some of the old cards in the group could spin a tale*". Although the linking factor for this group was COPD, discussions would sometimes go beyond this, as spouses who were attending the group were also living with a chronic disease.

Most often people commented on the information on medications and treatments that was shared through in-person meetings. People valued having respirologists being brought in as guest speakers in order to learn more about treatments. There was a desire for more intimate conversations within some of the groups. Samuel who had "*died for 15 minutes*" expressed that "*I do ask questions of other people there with COPD, if they've experienced the kind of things that I've experienced. But more often, it's that - does this medication have this side effect?"* Whereas, Owen found the sharing of existential experiences of living with a fatal illness was a critical component of his COPD support group: "*the one thing that we all know that none of us are gonna escape... perhaps there is a wee bit of fatalism in our group. But I guess it's a whole lot easier, even with this sorrow, to know that we have other people that we could care about rather than go through it alone*".

Roles of DTs that are Focused on Experiences of Living

Up until this point, the roles that DTs could possibly serve for COPD have specifically focused on supporting illness outcomes and experiences. There was a third category of roles that emerged when many people talked about the way they used DTs that were outside of their COPD. These included references to using DTs for intergenerational connections and leisure activities. In this next section I explore the different ways that people talked about these roles as a way to introduce a new possible overarching category for DTs in considering how to support experiences of living.

Intergenerational Connections: The Role of Carrying on Traditions and Leaving a Legacy

The survey demonstrated that nearly 40% (29/71) of people had used DTs to explore their ancestry, and during the interviews several participants mentioned how they had made new online connections with relatives they people had never met. When people were asked about the connections they made online, people would often reference the connections they had with their grandchildren. The phone was the common way to stay in touch with friends. Facebook, Instagram, Skype and YouTube were used to stay updated on their grandchildren, and often it was the participants' children who were posting photos of participants' grandchildren.

In the survey 25% of participants (17/69) people had used technology to write about their life experiences, and during the interviews one participant mentioned her aspiration to write the "*great Canadian novel*" so that she could share it with her daughter. Some would go onto ancestry platforms to share photos and documents, while others found ways to carry on a tradition. People had moved their in-person games on online, and even when it was a solitary endeavour people felt connected to their family:

> *My grandmother taught me how to play solitaire when I was just a little kid and I've just kind of, you know, I've played it with cards over the years but I can play it online, [laughs] I just… it's something to do. My whole family does the same thing with solitaire so I don't feel so alone* (Ruth).

People also stressed the importance of writing letters, as a way to stay connected outside of the digital world. In the open-ended responses, many people wrote in "*Canada Post*" as a common way to stay connected. During the third stage interviews, Adam mentioned his practice of writing letters as a way of maintaining a legacy:

> *I write my grandchildren a letter every month, I write my daughters every month and send letters to them, through the old way. Just because I think it's kind of neat to keep a little tradition there. I mean I can email them in the flash of a… the wink of an eye, but writing a letter, taking the time to think about it, do it, to me it has something more to it.*

Adam then goes on to say "*My first granddaughter still has all the original cards and letters I sent to her. She's nine now so she's got – and she goes through them every once in a while. Sometimes I'll include old photographs of my ancestors, of our ancestors, or little stories about our ancestors*".

The intergenerational connections were further encouraged during the pandemic. Multiple people who had experience with using video conferencing tools were now using it to connect with their family in groups, rather than individually. Some participants were being called upon to set up the video calls for these virtual family reunions. Henry talked about how "*I just started using WhatsApp here maybe, not even two months ago. One of my step son's set it – well he didn't set it up, I set it up but he wanted to do it so that was… so we get the whole family on there*". Penny, who had used Skype during both interview stages, shared how she had made a zoom call with multiple family members: *"my daughter organized it and I just went down to her condo and talked to mostly family members. And it's… it's really cool to be able to do that.*

DTs were introducing new possibilities for establishing meaningful connections with their grandchildren, that allowed for carrying on tradition and leaving a legacy for the next generation. These intergenerational references were different to the way generations were referenced in chapter five where people were making comparisons to their technical aptitude. Rather these were examples of proud, positive social interactions between generations.

Leisure Activities: The Role of Distraction and Spontaneity

During the first and third stage interviews many people referenced the leisure activities they did through DTs, which included listening to music and watching videos, movies and the news. These activities not only allowed a way for people to feel connected, but offered a place for reminiscing, distraction and spontaneity. Several people talked about how they watched multiple news channels on their television or through DTs as a way of staying connected to the world. Penny shared a story of spontaneity by being swept away and a larger connection afforded through music:

> *They were just having a wonderful time. They were in Scotland - they were entertaining Scottish people. And Johnny Cash stopped his playing and he just looks*

> *out at everyone, I mean it was enormous! I don't know what type of building they were in but it was huge. I've never seen such a huge building with so many people in it. Yea, but he just told them how much he enjoyed visiting Scotland and visiting all you people and coming and entertaining all of you people and then he went back to his playing. They all just sang songs that they had made famous in the past and then sang new ones, and sang as a quartet. It was fun. And another night I was connected to … what was it? I'd have to think about it. But it was just basically starting with Celtic Thunder and then going forward and getting connected with these other [concerts].*

DTs also allowed people to return to past events or activities that people used to be able to do. Henry had used a movie production program as a way of documenting his travels, and YouTube to watch nature documents as it brought him back to his passions: "*I love nature, I love outdoors. I spend a lot of time outdoors".*

People also appreciated the distracting role of DTs. This was demonstrated by Pamela's "*addiction*" to a stand-up comedy app, which helped her fall to sleep: *"I put the headset on and I get into bed and I will fall asleep, but who cares. But I will wake up laughing... And I think that is one of the best thing I do for myself... Some days I don't like what's in my head, but listening to these people and the things that they tell you, you get a whole different slant on life*". Similarly, the participant who was waiting for a lung transplant said "*Well I've got time on my hands right, I've got nothing else to do so…*". Vicki also talked about the positive aspect of DTs being a form of distraction and connection: "*It gives you something else to do. It's not great sitting all the time, but it is... and you learn a little something here and there. Yeah, it's sort of like when I watch Netflix, it's sort of like having company, you know? So I find it positive*".

The Role in Supporting Multiple Social Identities

The way that people spoke about their different identities also revealed a new possible role for DTs, in allowing people to support multiple online identities in their multiple social worlds. There was one's social identity as to whether or not someone saw themselves as a "*social butterfly*" or a "*joiner*". People recognized that this social identity had been influenced through their familial background where a series of broken links was due to having a "*mother who was orange and a father who was green*", or being part of a family that moved around extensively during childhood. The perceptions around age revealed particular identities as to who was considered "*tech-savvy*". In contrast, many spoke with pride in their identity of being a grandparent, and how DTs had supported their intergenerational connections.

People also referenced the different identities related to COPD. There was questioning about one's illness identity after receiving a transplant, and whether they would still have COPD. Healthcare provider's perceptions of one's identity was revealed when participant read the documents that their healthcare providers had written, where people were offended by the word "*obese*" appearing in her record, or chuckled at being described as "*a frail old lady*". Societal assumptions that created different acceptance of identity that was evident during COVID-19, when people would say "*don't worry, I have COPD*" after coughing out in public, or refrain from wearing an N-95 mask in the community. Risk identity was most often linked to COVID-19, and the identity of "*an addict*" was used in reference to smoking.

There were also examples of changing identities. This was most evident when people talked about receiving a diagnosis with COPD, and resistance to taking on the "*COPD* *label*". Quite often it meant that their diagnosis had resulted in no longer being able to work, and thus they were being forced to swap their work identity with their illness identity. This change in identity was also demonstrated when one participant spoke about using videos as a way to reminisce on his past identity in being an avid hiker.

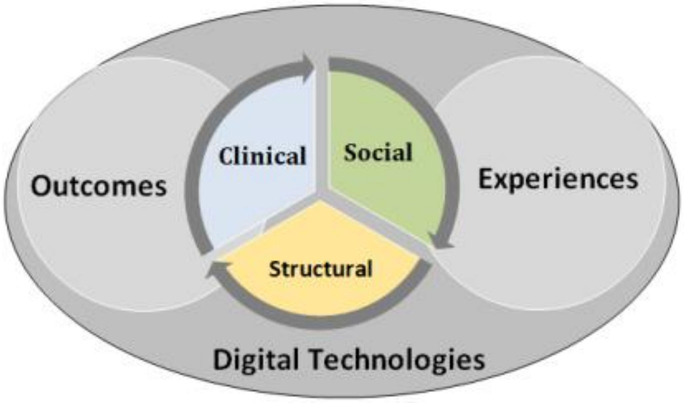
However, what was distinctly missing within these identities was an online identity for COPD. Only one person spoke about posting to forums that were related to his COPD, but this all to gain information about lung transplants. Although people had visited forums and Facebook pages dedicated to COPD, no examples were found where people had posted comments to these sites.

Summary

Few examples were found of DTs serving a role in supporting clinical *outcomes,* and a limited number of people had used oximeters for ongoing use. Although information seeking was the most frequently reported DT role, multiple people reported being frustrated by the lack of information about *their* COPD. Further exploration of this lack of information revealed that the "*lack of*" had more to do with the lack of individualized information that could help people understand their current treatments, severity and prognosis of living with COPD. The forms of online asynchronous peer support that were being offered to the COPD population had little interest for most participants. Rather it was the way that DTs supported experiences outside of COPD that most often was of greatest significant for participants.

The proposed roles of DTs that focus on experience, and the lack of an online identity for COPD will be revisited in chapter eight when a series of meta-inferences are proposed. . Before going onto this concluding chapter, chapter seven presents the results that are focused on the second half of the research question, as to how social connectedness, and COPD outcomes and experiences can be supported through DTs.

Chapter Seven: Results - Clinical, Social and Structural Outcomes and Experiences

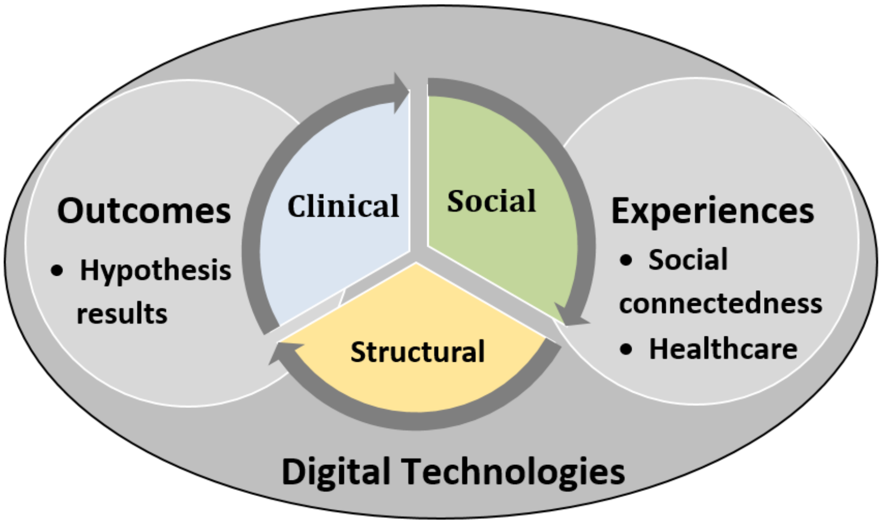


Introduction

This final results chapter focuses on how digital technologies (DTs) support *social connectedness and illness outcomes and experiences* for people living with chronic obstructive pulmonary disease (COPD). Section one focuses on outcomes in presenting the results for the proposed hypotheses which focused on how DTs may or may not impact social connectedness, and illness outcomes and experiences for people living with COPD. Section two focuses on experiences of social connectedness through DTs by exploring social isolation, and the changing context with the onset of the pandemic. The chapter concludes with an exploration of the experiences shared by people with COPD that were beyond DT use, but which offered further understanding on possible DT roles for people with COPD. (See Figure 7.0 for an overview of the chapter).

The sections integrate a foundational methodological element to support the interpretation. The application of PREM and PROM scores is used to evaluate the overall 'outcomes' of DTs, where outcomes is being used in the traditional sense to measure the effectiveness of an intervention. The areas of divergence inherent to mixed methods design is then used to explore the complex relationship between DTs and social connectedness and isolation. A transformative approach that questions the dominant worldview introduces considerations for the current healthcare experiences shared by people with COPD and how these may or may not be addressed through DTs.

Figure 7. 1 *Exploring Outcomes and Experiences of DT Use for People with COPD*



Outcomes of Using Digital Technologies

Hypotheses Results

The overall 'outcomes' for DT use were evaluated through the proposed hypotheses, which focused on the relationship between frequency of use of DTs and PREM and PROM scores. The blue cells highlighted in Table 7.1 indicate the correlations for the proposed hypotheses. Using Pearson's correlation test, the results from the proposed hypotheses include:

1) Higher frequency of use of DTs was significantly related to less negative (i.e., more positive) experiences of COPD, *r*=.24, *p* (two-tailed) <.01.

2) Higher frequency of use of DTs for COPD activities was significantly related with increased satisfaction in social roles and responsibilities, *r*=.28, *p* (two-tailed) <.01.

3) The frequency of using DTs for social connectedness demonstrated no statistically significant relationship between COPD severity, experiences of COPD, and satisfaction in social roles and activities.

Table 7. 1 *Pearson's Correlation Coefficients for Frequency of DTs and PREM and PROM Scores*

Variable	1	2	3	4	5
1. COPD severity	1	-	-	-	-
2. Experiences of COPD	.45**	-	-	-	-
3. Satisfaction in social roles and responsibilities	-.57**	-.37**	-	-	-
4. Frequency of DTs	-.01	-.24*	.12	-	-
5. Frequency of DTs for social connectedness	.08	-.02	.04	.59**	-
6. Frequency of DTs for COPD	-.09	-.061	.28*	.47**	.54**

Note: The high scores for the PREM and PROM used for 1 and 2 represent more negative experiences or severe COPD. A higher score for the third measure represents greater satisfaction in social roles and activities.

Sample size n= 75-79

* p<.05; **p<.01

Pearson's correlation test was also used to examine the relationships between the different DT activities and PREM and PROM scores. Table 7.2 details the correlations of the five most frequently reported activities and PREM and PROM scores. Through Pearson's correlation coefficient the following were found: ok

1) Higher frequency of sending and receiving emails was significantly related to less negative (i.e., more positive) experiences of COPD, r=-.32, p (two-tailed) <.01.

2) Higher frequency of sending and receiving emails was significantly related to greater satisfaction in social roles and responsibilities, r=.31, p (two-tailed) <.01.

3) Higher frequency of searching for online information was significantly related to less negative (i.e., more positive) experiences of COPD, r=-.32, p (two-tailed) <.01.

4) Higher frequency of watching videos online was significantly correlated to more positive experiences of COPD, *r*=-.24, *p* (two-tailed) <.01.

5) No statistically significant relationships were found for text messaging and PREM and PROM scores.

Table 7. 2 *Pearson's Correlation Coefficients for Technology Activities and PREM and PROM Scores*

Variable	1	2	3	4	5	6	7
1. COPD severity	1	-	-	-	-	-	-
2. Experiences of COPD	.45**	-	-	-	-	-	-
3. Satisfaction in social roles and responsibilities	-.58**	-.38**	-	-	-	-	-
4. Sending and receiving emails	-.11	-32**	.31**	-	-	-	-
5. Online information searches	-.07	-.22*	.07	.72**	-	-	-
6. Sending and receiving text-messages	.01	-.22	.02	.642**	.652**	-	-
7. Watching online videos	-.08	-.24*	.042	.512**	.632**	.47**	
8. Readings post on social media sites	-.08	-.09	.02	.38**	.57**	.45**	.44**

Note: The high scores for the PREM and PROM used for 1 and 2 represent more negatives experiences or severe COPD. A higher score for the third measure represents greater satisfaction in social roles and activities.

Sample size n= 75-79

**p<.01

Tables 7.1 and 7.2 also illustrate statistically significant relationships that were beyond the proposed hypotheses, but were anticipated for being inter-related variables. This includes finding statistically significant relationships between COPD severity (as determined by the CAT), negative experiences of COPD (as determined by PREM-C9) and satisfaction in social roles and activities (as determined by PROMIS measure). In addition, statistically significance relationships between the frequency of use of DT types, DTs for social connectedness and use of DTs to support COPD were found.

Social Isolation - Digital Technologies - Social Connectedness

The complexity as to how DTs can address social isolation by promoting social connectedness became apparent through the divergence in overall results across the stages, and also within individual participant data. In the survey, it was found that people who had never used technology were more likely to report 'technology as isolating'. When correlation tests were conducted to further understand how technology may address isolation and connectedness it was found that (see Table 7.3):

1) People who were more satisfied with their social activities were less likely to report that technology isolated them, *r*= -. 23; *p* (two-tailed) <.05.
2) People who reported more frequent use of DTs were less likely to feel that technology isolated them, *r*= -.40; *p* (two-tailed) <.001.
3) People who reported more frequent use of DTs for social connectedness were less likely to feel that technology isolated them, *r*= -.32; *p* (two-tailed) <.001.
4) People who reported more frequent use of DTs for supporting their COPD were less likely to feel that technology isolated them, r= -.27; *p* (two-tailed) <.05.

Table 7. 3 *Pearson's Correlation Coefficients for Technology is Isolating*

Variable	1	2	3	4
1. Technology isolates me	1	-	-	-
2. Satisfaction in social roles and activities	-.23*	-	-	-
2. Frequency of DTs	-.40**	.122	-	-
3. Frequency of DTs for social connectedness	-.32**	.044	.594**	-
4. Frequency of DTs for COPD	-.27*	.278*	.467**	.594**

Sample size n= 76-78

* p<.05; **p<.01

The 'technology as isolating' survey question was inspired from a first stage interview, when a participant who was frequently user of technology talked about the isolating effects of technology. In addition, when the only one "outlier" was interviewed in stage three, he shared how his perspective on the isolating effects of technology had evolved since completing the survey. Both of these participants identified as being one of the earliest adopters of computers, and both were living with a fatal chronic lung condition that was not COPD. What I heard from them was that it was the intersection of their illness with the use of DTs that potentially introduced increased feelings of isolation, and that this could be further magnified through limited social capital. The following section explores the narratives of these two participants to illustrate the complex intersection between social isolation, technology and a person's broader social world. This is then followed by how the pandemic has impacted experiences of social isolation and social connectedness for the people interviewed in stage three.

The Isolating Effect of Being an Oddball

I first met Gerald at the COPD support group in fall 2019, where he discussed his frustrations with an illness that had no treatment. When he had initially used DTs for his acute respiratory distress syndrome (ARDS), he had found it to be an isolating experience, as there was no information or connections out there that could help him. Eight months later when he was interviewed, he was more accepting of this lack of information: "*Well I haven't really found anything to support because I haven't really looked in a while, I must admit. I did look and there wasn't very much on at all available so I just uh, basically said "ok", you know, uh, I don't need to keep looking for it*". He said he "*didn't mind being an oddball*" in his COPD support group and not knowing anyone else who was living with ARDS. During this interview when he as was asked about his 'outlier' survey response in finding technology as isolating he talked about how he no longer felt this form of isolation. Rather he spoke about how the pandemic had introduced new ways to connect through technology: "*Well, I shouldn't say I find it isolating in a sense, it's mostly with my kids and my grandkids... so we do a lot of that and we've actually gotten into doing some Zoom work... we use Duo quite a bit, which is through Google*". Now when he turned to DTs, everyone was experiencing the threat of COVID-19, and DTs were enabling to stay connected to his family. However, he was now experiencing a new form of disconnection due to the loss of his community groups who were not connecting through DTs: "*I go to my events like the [COPD support group] and my [hobby] club, and a few other things, but … and it doesn't bother me. I shouldn't say it doesn't bother me, it bothers me but … I didn't recognize the COVID as a component of that*".

The Effects of Digital Technologies in Compounding Social Isolation

In contrast, Darla was finding limited connections in multiple aspects of her life. As she lived alone, she was in the midst of developing her "*recovery plan*" which involved finding people who could commit to caring for her after receiving a lung transplant:

I have to have somebody with me full-time, all the time. And while I've got some family members that are going to do it, ah, most people, can't do a whole month at a time. And, when I wrote my recovery plan, uhm, I actually had twenty people that were willing to do for a week. Yay, but then transplant clinic came back and said "no, you can't do that. We have to train you, at the most we are willing to have you have three people, one month at a time".

She shared how in spite of growing up in a family of "*broken links*", she was "*a good person when I was in my working years and I sacrificed to save money for my retirement*". And yet in spite of this hard work she "*felt victimized*", where the healthcare system was now placing responsibility on her to find social connections that could save her life. In addition, she was being asked to take on new "*work*" in maintaining meaningful social connections while living with a fatal illness:

> *But what I find really surprising is we know lots of people when we are younger, but when we are older, [breath] our good friends really come down to one hand... I've really noticed that my friends do not call me as often. And [breath] I don't think it is because I have turned into a nasty person, or anything. Ah [breath], as somebody explained to me, they are afraid to be around me in case something happens... So I just find that I don't hear from them [friends] as much, so I have to work really hard at it".*

When she was talking about technology as being isolating, it is with this entire context in mind - it was the loss of social connections throughout her world, and technology was just another venue to amplify this isolation. This was illustrated when she said:

> *I do find that current technology is more isolating, People wanna text. No, 'A' I wanna to talk to you, if I can't actually see you. It's like my daughter, if I can't see her and give her a big hug and smell her skin and feel her hair, okay, know that it's her, then at least I want to talk to her.*

DTs were not the sole cause of this social isolation, but was another mediator in compounding this isolation. This is further demonstrated through the hypotheses results presented earlier in this chapter, where people who did not feel satisfied with their social roles and activities also identified with the isolating effects of DTs.

Isolation and Connectedness During a Pandemic

Already Familiar with Self-Isolation

The pandemic shifted how isolation was being recognized across the broader world. Being a researcher focused on COPD and social isolation and in the midst of global lockdowns and social distancing measures due to a respiratory virus, I was acutely aware how language had shifted. The isolation, uncertainty and existential fear that the world was now experiencing was an experience all too familiar for people with COPD, and thus they found that the pandemic did not have significant changes to some aspects of their lives.

People spoke about being prepared during the pandemic, as illustrated by Pamela when she talked about "*all these life experiences... you know everybody that's sixty-plus, we've all got something and we all know how to live with it*". Richard, who was interviewed prior to the pandemic, talked about some of the measures he undertook to address the risks introduced through being around other people:

> *"I get the pneumonia shot every five years, and the flu shot every year. So, the flu shot helps. And ah, well, I don't take uhm, I hardly ever take buses. I take taxis.... The buses, uhm, I took the bus for many years, but a lot of sick people on the buses. So, I'm fine with taking cabs, it's a little more faster and a little more cleaner. Well it's much cleaner so and, I, well you get to know all of the cab drivers too eh. It works for me".*

Gerald had masks in his home for his hobby, although he did not feel that he should be using them in public:

> *"Although the unfortunate thing is of all the masks that I have in the house, because I use them for doing my carving when I can, are the N-95s. I had them already because … and I bought them at the local store, this was well before that because I needed them for … but I don't want to walk around with an N-95 mask on because people [p] [wheezing chuckle] you know, those are supposed to be just for the professionals only. So we have purchased some just regular ones".*

People had been living for years with the diagnosis of a progressive fatal lung conditions, and thus had experiences with self-isolating when they noticed changes in their environment that could affect their respiratory health. This was illustrated by Pamela during the third interview when she said talked about the how "*there may be days when you are a little breathless, and the air is still, and you just have to identify the problem. Oh it's my COPD. Well, what can I do? Well I think I'll sit in my car with air conditioning on and drive around*". Similarly, Sarah recognized the risk and the importance of self-monitoring: "*I'm pretty self-aware so I know when I'm getting…I know when the heat and humidity get up I just close the house down, I don't go out because that's deadly – it's not deadly but I mean it's* *very, very difficult".* She opted not to have social distancing meeting with her friends: "*Yea, we're doing a lot more phone calls, so there's a group of us, we keep in touch almost weekly and stuff like that... we're all sort of hunkering down, we're all sort of that age and stage I guess where we don't wanna to take any unnecessary risks*".

What had changed during the pandemic was another avenue for compounding the social isolation already being experienced by participants. One participant had quarantined himself the previous year in preparation for a lung transplant, and was about to start visiting friends again. He spoke about the challenge in being at the end of his recovery plan when pandemic began:

> *It's made everything difficult because this COVID is making it that much more isolated. I was isolated before COVID come along and you would think it would make that easier but security is tighter, let's put it that way… Like making sure that I don't have access to people coming willy-nilly, they like to visit eh? You know, it's sad that you gotta tell your friends that, "no, no, I'm sorry, we're not having visitors at this time."*

Loss of Community Connections

Although the survey demonstrated that few people reported regularly participating in video calls or group chats, I was expecting people would be developing new connections with DTs as a way to stay connected during lockdown and social distancing. Although video conferencing tools were being used to stay connected with family members, these tools had not been set-up to connect people to their local community groups. Rather, people were told all senior and recreation centres "*were shutting down*" and no alternatives were offered for staying connected. As a result, people had lost all their connections. Pamela discussed how her groups had *"seemed to have stopped. The Scrabble group was through a* *seniors' organization. Now I never got a newsletter from them. I read the paper and I'm pretty up to with what's happening in town and I'm not seeing, not seeing sort of places, that you know things for seniors, other than I could probably get phone calls and stuff*". She also shared other participants' views of the impact of no longer being able to access services that could keep them physically active: "*I just totally stopped going to the gym. Sooooo... the refit of my life is, I'm afraid to start back to the gym. I'm afraid to go to the hairdresser. I'm afraid to go.... you know*". People recognized the significance of this, as when Gerald stated "*There's not much I can do about it. Exercising does help. Unfortunately, you know, right now we can't get out, frankly there are no exercises, so I don't do as much exercising*".

The possibility of new forms of isolation was further evident by how people's COPD support groups had responded to the pandemic. When Adam was asked about significant changes since the pandemic, he replied: "*the major thing is that I don't get to go to [my COPD group] anymore, all of those kinds of support groups are cancelled of course. And uhh, although it only meets once a month or so it is a little bit of extra support and education, and you pick up a little bit of knowledge here and there*". The one example of social connections being maintained in the community was in a closely knit group, where members were relying on individual phone calls and were not using any DTs that could connect multiple members:

> *We are almost like, it's like nuclear family to say the least, so we help each other, you know. And when COVID came along that actually limited us quite a bit, you know, where you know I actually make it my business to turn around and bug people on the phone now and again just to see how they're doing, you know? And so we try not to annoy anyone, but you know, just do a little health check" (Owen).*

People also recognized the significance of the long-term effects of social distancing on their support groups not staying connected, and that they may not see many of these people again. Owen was grieving for the couple of members who had died during the previous month and wondered how the group would be able to carry on without these mentors:"*Many of them are deceased, I don't know, quite a few are, you know. Hopefully, I don't know when we will resume or if we will resume, ok, because we'll have to start from fresh and that's gonna be difficult*".

Stigmatizing Healthcare Experiences

During interviews many people would navigate to sharing negative healthcare experiences that went beyond DT use. When I initially examined these narratives, I found that they demonstrated why my study was important, but did not seem to be focused enough on the research question. As I delved further into analysis, I found that these narratives provided insights as to how DTs may address or reinforce the negative social interactions experienced with COPD. In paying particular attention to these healthcare experiences, I started to notice how a person's context may impact the type of narratives that are shared. In examining these different ways of sharing, I aim to demonstrate the contextual considerations in the role DTs may serve in transforming these experiences.

Most often it was the women participants who would reference negative healthcare interactions by directly using the term stigma, or by sharing personal stories[16]. Two women were forthright in referencing the stigma that had been associated with COPD. Pamela shared her "*COPD stories*" in demonstrating how "*the stigma... within the medical*

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[16] I recognize that as a woman my gender may have impacted how people shared these experiences, whereby men may have presented these experiences to me in very different ways.

community [where] oh you've got COPD. Oh there's not much we can do for you". Sarah suggested that the "*stigma is being overcome*", and then goes on to share how "*I have nobody to blame but myself. This isn't something that came out of the blue. This is something I caused and so I'm quite prepared to you know own up to my part in getting it. But there is… yea, I think just in the broader community, there might have been, maybe not so much now but there might have been stigma attached to being diagnosed with COPD*".

Women also shared experiences where their concerns were dismissed by their healthcare provider. For two women their COPD diagnosis was delayed when their symptoms were confused with anxiety or asthma. Cassandra said: "*I was suffering with anxiety, say and this is what they called it, you see. But I knew it wasn't quite anxiety- like I wasn't feeling anxious, but it was a shortness of breath and things that I wasn't aware, like you know, you have shortness of breath, but you don't know whether it is your lungs or not*". Pamela also shared her experience in not being diagnosed:

> *So I have extreme shortness of breath. It's all I can do to walk around it's like, less than half a block. I walk into his office. And I get in there, and I'm out of breath [gasping], and I'm thinking it's anxiety. I'm thinking I'm having a panic attack. And maybe a bit I am. But, anyway, I said to him, uhm, okay, so I'm coughing quite a bit, blah, blah. Well he says "it's just your asthma"*".

While two other women spoke about their perspectives not being heard during visits with a specialist. This was demonstrated by Penny's healthcare interaction with her specialist: "*He wasn't any better than I was and I made the mistake of issuing him an order and so he did exactly the opposite and I thought, ok, now if this had been a different circumstance*". Similarly, upon reflecting on a specialist's visit, Edith recommended to "*acknowledge that* *there's a problem, even if they can't help it, and be supportive but this guy, I mean, he barely said hello and ... So that's off putting, people don't understand something and they won't listen*".

Men in the study would discuss these negative healthcare interactions by noting the power differentials and comparing themselves to other groups. Adam implicitly acknowledged the stigma, when he compared the language around his prognosis of COPD to his wife's cancer prognosis: "*Nobody has ever said to me, "oh Adam, COPD is a <u>terminal illness</u>." Physicians have said to me, "oh Adam, COPD is going to <u>kill you</u>*". Another man discussed the relationship between patient and providers when he said: "*sometimes they get caught off in their own little position in their organization and they forget the patient and throw them out in the water*". Later in the interview, this participant spoke about healthcare's role in his use of pain killers where he talked about how "*the doctors habituated me on purpose*". One participant who was on limited income was quite concerned about the cost associated with a transplant said "*if you put them all into one pool, all transplantees, whether it's heart or lung or kidney or livers, why discriminate between the different ones? I just don't see, I don't see what gives them the right? They shouldn't be able to say… they might as well say, you're Black, you're not getting a transplant, you know? I know that's far fetched but …*"

What I found to be surprising is that it was the women who lived alone who were referencing stigma and sharing of stories being unheard by their doctors. These stigmatizing experiences made me return to my survey data to see how living situation (i.e., living alone or with someone) may be related to COPD experiences may be represented in the PREM and PROMs. There was no statistically significant differences found between living situation and overall COPD experiences (r-.043; p<.352, two-tailed, n =73). The questions that focused on usual care in COPD that asks about healthcare experiences also did not demonstrated in statistically significant relationships. Three of the four questions from the PREM-C9 that were with everyday life with COPD were found to have a statistically significant relationship (see Table 7.4):

> Living alone was positively related to acceptance of the limitations of lifestyle caused by COPD, *r*=.21; p<.05, two-tailed.
>
> Living alone was negatively related to feeling like there are good support from others like family/friends and carer, *r*=-.20; p<.05, two-tailed.
>
> Living alone was positively related to accepting feeling in control of one's condition, *r*=.21; p<.05, two-tailed.

Table 7. 4 *Pearson's Correlation Coefficients for Living Situation and Experiences of Living with COPD*

Variable	1	2	3	4	5	6	7	8	9
1. Living situation	1	-	-	-	-	-	-	-	-
2. Acceptance of lifestyle	.21*	-	-	-	-	-	-	-	-
3. Support from others	-.20*	.40**	-	-	-	-	-	-	-
4. In control of condition	.21*	.50**	.47**	-	-	-	-	-	-
5. Happy to talk about the future	.05	.51**	.47**	.51**	-	-	-	-	-
6. Doctors listen to my point of view	-.15	.01	.41**	.27**	.27**	-	-	-	-
7. Enough information about my condition	.01	.26**	.35**	.37**	.30**	.55**	-	-	-
8. Understand COPD treatments	-.04	.17	.27**	.35**	.25*	.62**	.64**	-	-
9. Confidence in access to rescue pack	-.06	.12	.32**	.20*	.26*	.59**	.40**	.54**	-
10. Worried about care	-.03	.27**	.36**	.20*	.35**	.58**	.42**	.59**	.76**

Sample size n= 79-80

* p<.05; **p<.01

As only one man in the study lived alone and with the small sample size, these findings cannot be generalized to *people* who live alone, or *women* who live alone. However, it does raise areas for further exploration as to whether people with COPD who live alone (and in particular women) may not have an advocate to limit or make sense of these stigmatizing experiences, and as such these experiences of everyday life with COPD may compound feelings of isolation.

The different ways that women and men spoke about the negative experiences also raises questions about how the perceptions of different social roles and positions may be or reinforced through DTs. This was pointedly demonstrated by one participant when he spoke about the gender differences in how people share and respond online: "*There was another group I was in and I told them to go and suck it because they turned it into a female group only... I said that's ridiculous, do you really have to go there, we're talking about lung transplants and you have to – well good luck, I'm out of here, and I did, I moved off there*".

Summary

The statistically significant results for the proposed hypotheses included finding that frequency of use of DTs was related to more positive experiences of COPD, and frequency of use of DTs was related to increased satisfaction in social roles and responsibilities. The relationship between DTs, social connectedness and social isolation are further demonstrated by the relationship that was found where people who did not use DTs were more likely to report technology as isolating. The repeated narratives of discrimination and stigmatization that were shared by participants demonstrate the need to further understand how DTs could transform these negative experiences. The narratives shared by women who lived alone in particular demonstrated a further need to understand how DTs can address the gender inequities experienced by women living with COPD.

Chapter Eight: Meta-inferences and Conclusion

Introduction

In this final chapter of this dissertation I present a series of inferences that are supported by the results presented across the previous three chapters. These meta-inferences include: 1) people with COPD have the individual capacity and it was the healthcare system and local community that lacks the technological capacity; 2) dominant discourse about technology may be creating further harms that extend beyond the digital world; 3) current digital health strategies for chronic illness do not align with the preferences of the COPD population; 4) the separation of worlds may provide an additional role for DTs in providing respite from living with a fatal chronic illness; and 5) digital technologies considerations for COPD should expand to supporting experiences of living. Transformative considerations of these assertions are further explored by bringing in relevant literature. The presentation of these assertions is then followed by study limitations and further areas of exploration before concluding with an overall discussion. Figure 8.1 provides a visual of these meta-inferences. Further examples for these meta-inferences are summarized in a joint display which is presented later in the chapter (Table 8.1).

Participants Demonstrated Individual Capacity but Lacked Community Capacity

Throughout all stages of the study, it became apparent that people were using DTs in multiple ways and had developed successful preventive strategies in living with a respiratory illness. The stressor of the COVID-19 pandemic illuminated how the specialized knowledge that participants had gained in living with COPD may have uniquely prepared them in adapting to the preventive strategies. This individual capacity was evident when people spoke about previous uncertain events in their lives and how their COPD-specific

Figure 8. 1 *Meta-inferences on the Role of Digital Technologies for COPD*

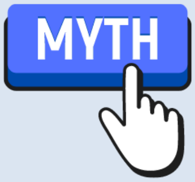
ROLE OF DIGITAL TECHNOLOGIES FOR CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

INDIVIDUAL CAPACITY VERSUS COMMUNITY CAPACTIY

Participants daily use of digital technologies demonstrated the individual capacity

It was the community and healthcare system that lacked technological resources to support social connectedness at the beginning of the pandemic.

DOMINANT DISCOURSE MAY DISCOURAGE TECHNOLOGY USE



Participants across all income levels had developed multiple strategies to address online privacy and security concerns.

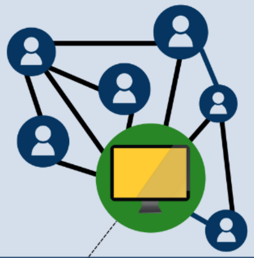
The ongoing myths that "seniors do not use technology" may be reinforcing ageist myths as to who is "savvy" and "competent".

MISALIGNMENT IN HAVING CURRENT TECHNOLOGICAL STRATEGIES FOCUSED ON TRACKING

Few participants used a technology to track health measures.

Many found that the information provided from these technologies did not connect directly with daily life of COPD.

INTENTIONAL SEPARATION OF DIFFFERENT WORLDS



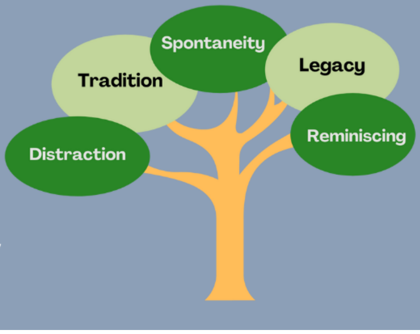
People with COPD may prefer to have their online world separate to their illness.

Having this separation may provide a place of respite in thinking about one's illness.

ENCOURAGING EXPERIENCES FOCUSED ON LIVING

Digital technologies can provide opportunities for reminiscing, distraction and spontaneity that can support emotional and mental health.

Intergenerational online connections that are supported online can provide opportunities to carry on tradition and create a legacy.



strategies they had in place prior to the pandemic had prepared them for the current social distancing measures.

Individual capacity was also demonstrated by the high number of participants who were using DTs prior to the pandemic. Although there were limited examples of using virtual conferencing tools, such as Zoom, people talked about how they commonly adopted new DTs based on the influence of their social group. With the exponential increase of video calls over the past year, I anticipate that many participants have experienced these emerging technologies since the study ended.

Boyce's et al. (2020) study that examined people with COPD use of telemedicine during COVID-19 demonstrated similar capacity of the COPD community, when only few participants (15%) reported that they would like assistance with technology. Rather than individual technical skills, it was the organizational capacity that was of concern, where "the quality, consistency, technological accessibility, and affordability of the telemedicine options available to the COPD community at large and accelerating the development of better digital tools remains a key focus" (Boyce et al., 2020, p. 7). It further supports findings in my study in that people with COPD had the technological capacity for virtual visits, but it was the healthcare community that was playing catch-up in becoming "*tech-savvy*". Healthcare was not only scrambling to find virtual solutions for *all* populations (Bokolo, 2020; Mehrotra et al., 2020; Wosik et al., 2020), but also for people living with COPD who were at greater risk of experiencing more severe outcomes from COVID-19 (Leung et al., 2020; Pleguezuelos et al., 2020).

Transformative Considerations

The pandemic may have temporarily narrowed respiratory health inequalities for people living with COPD and the broader population. The narrowing of the gap was not due to increased resources for COPD, but as a result of everyone experiencing the existential threat of a fatal lung disease. The measures that people with COPD commonly undertook were now being done on a global scale: people were wearing masks, more likely to stay at home when ill, improving air quality by driving and flying less, getting influenza vaccinations, and practicing social distancing. These were actions that potentially could have a direct effect on the outcomes of COPD, and illustrate the motivation for change when the dominant population experiences similar threats to underserved populations.

To-Miles (2020) had a similar finding in their Canadian study during the pandemic, where people who were living with a chronic illness (i.e., rheumatoid arthritis) prior to the pandemic demonstrated stronger resilience than people who identified with no illness. Similarly, a qualitative study (n=100) that asked about people's experiences in living with COPD during the pandemic found that little had changed after three months of lockdown (Pleguezuelos et al., 2020).

There has also been focus as how the pandemic has reduced the number of emergency room visits for people living with COPD, suggesting that people with COPD may be experiencing fewer serious exacerbations (Chan et al., 2020; Pleguezuelos et al., 2020). Reasons given for this decrease include how mask-wearing and social distancing measures may have decreased risk of infection, how a pandemic that involves a respiratory illness may have heightened awareness in monitoring symptoms related to COPD, and improved air quality due to less pollution (Chan et al., 2020; Pleguezuelos et al., 2020). In British

Columbia, as of January 2021, only seven cases (compared to 1005 the previous year) of the influenza virus were detected and there was no evidence of it spreading into communities (BC Centre for Disease Control, 2021). There also has been recognition that people with COPD may have been hesitant to go to the hospital for fear of contracting COVID-19, and may have treated their exacerbations at home (Pleguezuelos et al., 2020). What is unclear is if people are reaching out to healthcare services through virtual visits, or if they are trying to manage their exacerbations on their own. As such, we do not fully know how COVID-19 may be impacting the social, emotional and mental health for people living with COPD, and overall progression of the illness.

I do not want to diminish the impact the pandemic has had on illuminating health inequities of different cultural and socioeconomic backgrounds. Nor do I want to diminish the health, structural and social inequities that were already being experienced by people with COPD. Injustices are still present for the COPD population, and will persist after the pandemic ends. In addition, this study ended four months after COVID-19 was declared a pandemic. As the pandemic and continues into its second year, the impacts of limited online community capacity, decreased physical activity and social distancing measures may have significant consequences for people living with COPD. We need to be vigilant in monitoring the ongoing impact of COVID-19 for people living with a fatal lung condition who were already experiencing social isolation prior to the pandemic.

I am also aware that current virtual care strategies may be a short-term measure and that we need to take the lessons from the pandemic in sustaining these technological strategies for our more vulnerable, and underserved populations. The virtual strategies that the healthcare system is currently implementing were recognized strategies for COPD but were in limited scope prior to the pandemic. There needs to be commitment in continuing to pursue these technological strategies long after the pandemic in order to prevent re-widening of the health equity gap for people living with COPD.

Negative Impact of the Dominant Technological Discourse

The current discourse around technology may be introducing inequities by perpetuating beliefs that discourage people with COPD from accessing DTs, and reinforce ageist and stigmatizing assumptions. The effect of meta-narratives about technology was most apparent from the survey question that asked people whether they found technology isolating. People who did not use any DTs were more likely to report on the isolating effects of technology, and during interviews it was found that technology was just a component of this isolation. I suggest that the *ongoing messages* about the isolating effect of technology may actually be perpetuating the isolation. People who have never used DTs may not see the potential in providing a place for connection rather than disconnection. The repeated message of technological isolation, may discourage adoption of DTs, and thus may be further disconnect people from strategies that could address the isolation experienced with the progression of COPD.

The impact of dominant beliefs was also evident through the ageist discourse around who is capable within a digital world. During interviews participants would commonly reference how they were not tech-savvy, and this included people who were some of the highest adopters of DTs. I did not find that this discourse necessarily discouraged people from using DTs, but the greater harm may have been how these perceptions have filtered outside of the digital world. This may be in the form of reinforcing ageist views about who is and is not capable, whereby individuals take on an identity that can lead to further marginalization.

Ageist views may also be appearing around discourse regarding privacy and security. In this study, these concerns were not as prominent as has been reported in other research on patient-oriented tools (Alwashmi et al., 2019; Antonio et al., 2019, 2020). Rather, I found much more nuance in responses to these concerns, whereby people had evaluated and taken measures for their online security. I suggest that not only does emphasis on privacy and security give an oversimplification of DT use, but may be promoting ageist views where older adults are viewed as not competent in evaluating safe use of DTs.

A third assumption that I heard when I was introducing my study to researchers and healthcare providers is that people with COPD would not use DTs because of the influence of the social determinants of health, and most specifically around the associated costs of DTs. Cost had a minimal impact of influencing use, rather what became apparent through all stages of the study was the lack of interest in current DTs for COPD.

Transformative Considerations

A 2020 Canadian study found that 65% of people over the age of 65 owned a Smartphone, and 72% felt confident in using technology (AGE-WELL Network of Centres of Excellence (NCE), 2020). Yet, myths about older adults not using technology persist, and may be reinforced by providers. This is demonstrated through a recent Canadian study on healthcare providers' views of people with COPD use of mHealth[17]. A physician participant said: "*I suppose I would assume that the elderly and the more frail would not be tech-savvy, though, I know smartphone use is increasing with the ageing population"* (Alwashmi et al., 2019, p. 8). This provider belief is one I also heard when presenting my research study to healthcare providers and researchers. I found these larger societal narratives are transferring over into patient narratives, as evident during many interviews when people would commonly reference their age before stating that they were not skilled in using DTs.

There are real harms that may come when these beliefs of who is tech-savvy determines who gets access to DT strategies. Mariano's et al. (2021) study on how these ageist views influence older adults, found that "stereotype threat" was a barrier where people may not use technology for fear of being judged and reinforcing negative stereotypes. It can lead to further marginalization of a population who is already experiencing stigmatization and isolation, and be denied access to care. In a study that examined patient portal enrollment, it was found that disparities in portal use for older adults disappeared when a universal policy was introduced rather than having providers oversee portal enrollment (Ancker et al., 2011). The authors concluded that it was the providers' perceptions as to who they viewed as tech-savvy may have influenced who they approach for an intervention. There may be similar implications for people with COPD during the pandemic. The underlying societal belief that older adults are not tech-savvy may have discouraged communities from developing virtual strategies for the COPD population. I contrast the community response to my own experience, where all of my

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[17] mHealth are mobile and wireless technologies that are designed to improve health outcomes (WHO, 2011). Examples include apps and wearable devices for tracking health indicators and supporting beheavior change.

communities quickly transitioned to a virtual environment within a month of the pandemic. Whereas, when I spoke to people with COPD all of them spoke about how connections with their community organizations had disappeared, and no alternatives had been provided.

There are also the harms that can come in viewing the social determinants of health through an individual lens. The assumption that people within lower income groups may not own devices, may deny them opportunities to access DT strategies for COPD. This can translate into reinforcing individual responsibility that continues to be placed on populations that are already experiencing marginalization. This is demonstrated through study that asked providers about mhealth strategies for COPD (Alwashmi et al., 2019). A pharmacist suggested COPD patients lack of motivation in using self-management tools was related to education-level and lifestyle choices:

> *The biggest challenge I find with COPD patients, now that's the population that I deal with, is that they are smokers and continue to smoke, the majority of them. Their education level is probably a little bit on the lower side and that's related to the whole smoking, right, that kind of thing, the socio-economic status of the patient. So they're not necessarily invested in improving their health with a lot of effort, right. They'll take an inhaler, take a pill to help them get better, but really changing their lifestyle and their smoking is not high on their list* (Alwashmi et al., 2019).

The above provider quote reflects similar views I have heard in interpreting the social determinants of health at an individualistic level, where responsibility is place on the person with COPD for not being invested in their health. In order for inequities experienced by COPD to be fully addressed, requires recognition of the responsibility of system-level structures that have failed to develop successful strategies for illnesses that continue to be marginalized.

The Misalignment of Current Digital Chronic Health Strategies

The overall aim for this dissertation research was to explore how people with COPD were using DTs to support their illness. Yet, few examples were found of people using DTs related to their COPD. People in the study were actively using DTs in other aspects of their lives, but were not invested in using DTs for their COPD. Throughout all stages, participants repeatedly demonstrated that they were not interested in using DTs for their COPD. I propose that this lack of interest is because current DTs do not address the aspects that are of interest and could be of benefit for people living with COPD. This is illustrated by examining information and tracking, as they were the two health-related activities that had the highest frequency in the survey.

The most common DT activities people reported doing related to their COPD was around seeking information about symptoms and treatments. Yet people responded differently to this information: some had more than enough information, while others limited their searches due to the existential challenge in reading information about their fatal illness. Several participants talked about the "lack of information" as synonym for "no cure" and "no treatment". The different ways that people were referencing information first alerted me as to how current illness-centric models of care may not align for people living with a fatal chronic illness, as it reinforces the perception that if people only had the right information they would be able to *treat* and *cure* their illness. This may be reflective of other illnesses, and even for some reversible chronic illnesses; however, COPD is a progressive, fatal illness. The type of information that people want cannot be found by "*googling it*". For some participants there was acceptance that "*is all there is*" and that there was no other information online that could be of benefit. For others it was not the online information that they wanted, but specialized healthcare knowledge that could tell them about their individual progression.

The way that people used technology for tracking also highlights the unique consideration for COPD. People were using DTs for other health conditions, but not for their COPD. Part of these differences in low rate may have been due to the fact that the majority of participants did not identify with severe COPD. Yet some participants did not yet see the benefits in using an oximeter as they could sense their changes to the breathing. In addition, there is also the applied challenge of oximeters only being able to track oxygen levels, and carbon dioxide levels are also an important indicator for understanding shortness of breath distinct to COPD.

Transformative Considerations

The few technologies available for COPD brought me back to the beginning in considering context and self-management (Greenhalgh, 2009). For COPD, it is not only the context of the social determinants of health to consider, but the very nature of COPD. COPD has not seen the same techno-scientific advancements as other chronic conditions. Diabetes is often used as the example for how technology can be used to change outcomes, where glucose is monitored for glycemic control. There is not an equivalent indicator for COPD, and yet tracking and monitoring continue to be promoted for COPD. The responsibility for the lack of interest in using these technologies falls on the person with COPD. Rather than recognition that COPD is different to other illnesses, and thus the information that is available for changing outcomes for other illnesses may not translate to COPD.

Aas (2006) warned about our technological drive towards more accuracy and precision, and how these forms of biometric identification can be used as a further source of exclusion. With the increased focus on precision medicine and wearable devices this warning has even more significant for people with COPD, as currently there are not biometrics for COPD that can be widely used for prediction. This deficiency in having technologies that can actually be of benefit parallels the deficiency in the type of information that is desired by people with COPD. People with COPD are being pushed into the role of using DTs in order to become an informed patient, yet currently there are limited technological solutions out there to assist them in this role. It is understandable that people with COPD feel even more isolated when they see the multiple investments into technological strategies for other illnesses that are not offered to COPD.

The Role of Digital Technologies for COPD may be to Create a Separation of Worlds

Few people shared examples of making new connections that were fully online, and the majority of these were in support of pre-existing in-person social worlds. Only one person spoke about his online identity in being able to virtually travel and meet with his online friends all over the world. These connections allowed him to continue on playing pool, which was an activity he had done throughout this life. The only participant who spoke about making new online connections with people living with COPD, was in order to connect with people who could share experiences about lung transplants. One participant's observation on how his granddaughter used DTs that demonstrated the possibility of using DTs to create intricate worlds that support different virtual identities.

What became apparent is that people are going online to support their multiple in-person social identities, but few currently merge their virtual social identity with their COPD identity. Rather than consider this a failing of current technological strategies it may actually indicate that people explicitly elected not to bring their illness identity into a virtual world. The next section on transformative considerations offers three possibilities as to why the COPD population may not want more of an online identity.

Transformative Considerations

Firstly, identities can threaten other existing identities, so people may be hesitant to take on a more public online identity that focuses on their illness. Steele et al. (2002) hypothesized that the cultural knowledge and situational cues that indicate a group's status can threaten one's self identity when they have membership within groups that are devalued. This change in identity from being seen as a contributing member of society, to being viewed as being responsible for their illness reveals the ways that different identities can be threatened. People with COPD have picked up on healthcare's social cues and the type of knowledge that is shared for supporting COPD. In addition, the identity threat related to stigma may make people hesitant to share COPD experiences in an online public forum and proclaim membership in a group that can threaten other social identities.

A second possibility for less of an online presence specific to COPD may be related to DT strategies focused on information and control may not align with living with COPD. Sulik (2011) talks about a new identity that patients are being encouraged to take on in the form of the "techno-scientific illness identity". This "illness identity centered on biomedical, techno-scientific information encourages people to take ownership for understanding information, assessing their risk and making medical decisions" (Sulik, 2011, p. 473). Yet this requires having technological solutions in order to access biomedical information that can give people a greater sense of control and understanding when faced with an uncertain illness trajectory (Sulik, 2011). Not only is this information not available for COPD, but there is no amount of information that can give a person control or cure their disease, and thus people are left frustrated in being pushed to take on an identity that does not align with their illness experiences.

A third possibility for limited examples of using DTs for COPD, is that people may be using their online world as place of respite from their illness world. Algorithms that track and make recommendations based on information searches and posts are forcing a merging of worlds, which may not be desired. People may not want to mix their social media presence with their illness world, but rather prefer to use it for their intergenerational connections. By encouraging the merging of illness identities into people's digital identities, more reminders about one's illness may be introduced, rather than allowing a separate place for respite.

The Importance of Focusing on Experiences of Living

I began this study with a strong conviction that the strategy for the COPD was to build online presence, so that ongoing stigmatizing identities could be transformed. However, after listening to the values and preferences of the participants, I have come to realize this is only one possible avenue for DTs in transforming supports for COPD. What appeared to be more important for people was the need for supportive experiences of living, rather than managing illness outcomes. Participants offered promising DT strategies for COPD that move beyond prioritizing information for monitoring outcomes. The intergenerational connections and leisure activities people were doing online revealed how the experiences of COPD may not be completely separated from these virtual worlds, as they supported the existential aspect of living with a fatal illness.

People with COPD are often living between "the dual kingdoms of the well and the sick" (Donnelly, 1993, p. 6 in Paterson, 2001, p. 23). Yet current strategies for DTs for COPD commonly foreground illness, where people are required to be vigilant in monitoring symptoms and making self-management plans. In contrast to this illness model, wellness models recognizes that to live life as normally requires being able to be spontaneous in daily life (Paterson, 2001). This need for spontaneity was evident through the stories participants shared in the study where watching You-tube videos allowed them to be swept away into a new world.

Music and watching travel videos also offered opportunities to reminiscence about past events and previous identities and experiences. Pinquart and Forstmeier's (2012) meta-analysis on the effects of interventions that offered opportunities to reminiscence found modest improvements to depression, and small improvement on purpose of life, death preparation, mental health symptoms, well-being and social integration.

The distracting role that is often promoted as a negative aspect of DTs may also provide an important role for people with COPD, due to the associated high rates of depression and anxiety. Fulford's et al. (2019) study with people living with depression found that mhealth may serve as a self-care tool in distancing from negative thoughts and keeping people in the moment. Huffziger and Kuehner's (2009) study that explored effects after experiencing negative moods found that distraction had a positive effect on mental health for people with depression. The importance of spontaneity, reminiscing and distraction again point to the need to move away from viewing DTs mainly as a self-management tool for COPD. DTs can serve an important role for overall social, mental and emotional health by offering a separation between illness and wellness worlds.

Transformative Considerations

The recognition that current healthcare strategies for DTs are often focused on illness self-management that may not align with the context of people living with COPD was a foundational justification for exploring the DTs that people with COPD were selecting on their own. However, what I did not anticipate at the study outset was how the dominant discourse around self-management had translated to online environments that are outside of the formal healthcare system. As such, people were still being influenced by the types of activities and information that were available for their COPD. I heard an overall frustration from people in noting how few options were available in DT strategies that could change their outcomes.

The many leisure activities that people spoke about suggests the need to move DTs focus away from outcomes and consider the experiences that could be supported by DTs. The activities that participants were doing online, paralleled many of the ones that have been identified as common leisure activities in supporting social connectedness for older adults: cultural activities, holidays, hobbies and sports (Toepoel, 2013). The authors of this study also found that passive activities such as watching the television, or using the computer were not associated with close social connections (Toepoel, 2013). Toepoel (2013) goes on to confirm Putnam's (2000) conclusion that it is the *doing* of things, rather than the *watching* or *listening* that accumulates social contacts. However, I suggest that this focus on *doing* may actually overlook the role of online leisure activities for people living with a fatal chronic condition who have decreased physical ability to *do.* Although the number of social contacts and doing activities for managing outcomes is important, the *passive* activities that people emphasized throughout the study demonstrated the need for recognition of the emotional support that people gained through *watching* and *listening* the broader social world.

Table 8.1 provides further support for these five meta-inferences. The table provides links to the sections of the dissertation for further verification of these inferences. The qualitative and quantitative examples further demonstrate how data was integrated in reaching these final meta-inferences. Grounding all of these inferences are considerations for transforming illness outcomes and experiences for people with COPD.

Areas of Further Exploration

As the nature of being an exploratory study, participants revealed areas that were beyond the research question but require further exploration. The increased rate of lung transplants since the opioid epidemic was announced has introduced experiences of COPD that are not being addressed within current research. Participants were trying to reconcile how to live with the possibility of *a treatment/cure* that would result in the death of another person who was also living with an "*addiction*", and the inspirational role that was assumed after a person received a lung transplant.

The intersection between living alone and gender revealed areas for possible research in understanding how DTs could be used to target isolating, stigmatizing experiences for people who may not have daily in-person social supports. O'Neill (2002) qualitative study with 21 women with COPD where more than 50% of lived alone also found that participants also referenced the bias they felt by their doctors and in not being heard. Johnson's et al. (2007) examination of gender, stigma and COPD and found that little

Table 8. 1 *Joint Display of Meta-inferences*

Dissertation Section	Example of Qualitative Data	Example of Quantitative Data	Transformative Considerations
People with COPD had individual capacity that had uniquely prepared them for the pandemic, it was the community that lacked capacity			
Chapter 5: Use of Digital Technologies Chapter 7: Isolation and Connectedness During a Pandemic	*"you know everybody that's sixty-plus, we've all got something and we all know how to live with it"* *"But you know, you've got to adapt to what's going on.... I go to my events like the [COPD support group] and my [hobby] club, and a few other things, but ... and it doesn't bother me. I shouldn't say it doesn't bother me, it bothers me but ... I didn't recognize the COVID as a component of that".*	Close to 90% of participants (72/83) reported some use of DTs.	The inequities gaps may have temporarily narrowed, as the worldwide measures for COVID-19 were of benefit to living with a respiratory condition. It was the community that did not have the capacity to support ongoing connections for COPD support groups.
Dominant discourse around technology may be creating further harms for the COPD population that extend beyond the digital world			
Chapter 5: Exploring Dominant Discourse on Digital Technology Use Chapter 7: Social Isolation - DTs - Social Connectedness	Ageist phrases appeared throughout the interviews when people started talking about technology they used phrases such as " "*it's hard to teach an old dog new tricks*", "*technophobe*", "*not tech-savvy*" "*maybe I'm just old school*".	People who did not use digital technologies were more likely to report technology as isolating, even though they did not use any DTs. People who used DTs more frequently were less likely to feel that technology isolated them (r= -0.40; *p* (two-tailed) <.001; n=78. Similarly, people who used technology less often were more likely to report that costs, and privacy and security concerns prevented them from using technology.	The ageist discourse around technical skills can be disempowering by reinforcing beliefs around who is capable. Further demonstrates the importance of considering the heterogeneity of the COPD population in developing multiple DT strategies that extend beyond categorizing people under one age group.

Dissertation Section	Example of Qualitative Data	Example of Quantitative Data	Transformative Considerations
Current digital health monitoring strategies for other chronic illnesses do not align with COPD			
Chapter 5: Costs as Perceived Barrier to Use Chapter 6: Current Roles of Digital Technologies for COPD	*"as far as myself tracking it, uhm, I don't really have anything. Nothing concrete."* *"No, no I can tell when I'm out of breath, and I can tell when I've sort of forgot to take my inhaler at the time I'm supposed to because I burn over time and I go, oh God now I know why I'm out of breath but to monitor on it on a real regular basis, I don't know if I would find any value in that. I don't know. I can tell pretty much what's going on".*	See Figure 6.2 for health-related tracking and monitoring. Tracking other health measures was the most frequent activity reported by people who use DTs (high use: 33.8%, 23/67; limited use: 14.9%; 10/67; non-use: 51.3%, 34/67) had never done this activity. In comparison tracking oxygen levels was the second least frequent activity (high use: 19.4%; 13/67; medium use: 9.0%, 6/67; non-use 71.6%, 48/67).	Need to move beyond applying strategies that are based on other chronic illnesses that are more suitable for tracking and monitoring outcomes.
A foundational role of digital technologies for COPD may be to create a separation of virtual and illness worlds			
Chapter 5: Types of Connections Through Digital Technologies Chapter 6: The Role in Supporting Multiple Social Identities	"*Yea I'm not sure that I'd be prepared to have the type of discussion that you and I are having...with a large group online. I'm a little bit more of a private person than exposing, you know, to the world at large when I don't know who these people are. But yea, I've got no problem discussing with you and with my friends and neighbours, we talk about it".*	See Figure 5.5 for the Frequency of Types of Connections Through Digital Technologies and Figures 6.4 for activities related to peer supports for COPD. Of the people who used DTs, 88% (59/67) reported that they most frequently connected with family, and 58.2% (39/67) reported high frequency. In contrast, 46.4% (32/69) reported not connecting with other people living with COPD, and only 13% reported high frequency (9/69).	This separation of worlds may prevent identity threats to other identities, and give a person with COPD respite from their illness world.

Dissertation Section	Example of Qualitative Data	Example of Quantitative Data	Transformative Considerations
Digital technologies considerations for COPD should expand to supporting experiences of living			
Chapter 6: Intergenerational Connections: The Roles of Carrying on Traditions and Leaving a Legacy Chapter 6: Leisure Activities: The Roles of Distraction and Spontaneity Chapter 6: The Role in Supporting Multiple Social Identities	*"I have an app I'm addicted to. I put in stand-up comic ... it's so interesting to me sitting there are sunny day. You've got your headset on and the next thing you know you are laughing. And I think that is one of the best thing I do for myself*".	This meta-inference was grounded in the differences between qualitative and quantitative data. The quantitative results illustrated in the following figures demonstrated the limited examples of people using DTs for COPD: Figure 6.1 'DTs for COPD; Figure 6.2 'Health-related Tracking and Monitoring'; and Figure 6.4 'Activities for Peer Support'.	The role of DTs for supporting experiences of living could potentially support the mental and emotional health of people living with COPD.

research has been done to understand how gender may impact care for COPD. A retrospective study (N=6476) that examined socio-demographic variables with use of DTs found that there was greater use by men (89.8% versus 85.7%, p=0.001) but suggested that this gap was narrowing (Kim et al., 2017). They also found that women were more likely to not have a partner or be unmarried (53.2% versus 23.6%) and have limitations in physical and daily activities (Kim et al., 2017). The study recommended the need to develop strategies to reduce gender inequalities in targeting social isolation for women (Kim et al., 2017).

Current studies involving technology for older adults, or focused on COPD, are often viewed as a homogenous population. When I looked to the literature, most studies were examining the type of DTs and online activities of older adults as homogenous group, and Kim et al. (2017) provided a rare example of examining how the different gender roles of older adults are enacted online. With most research viewing older adults as a homogenous group, it points to areas for further research in examining how DTs can address the different social roles that are reinforced through societal assumptions around gender, age, and living with a stigmatized chronic illness. Future research should focus on applying an intersectional lens (Misra et al., 2021) to unpack the complexity in understanding how DTs may be specifically used to address the different forms of social isolation and the inequities that are experienced by people living with COPD. In addition, as the rates of DT adoption increases, it requires reconceptualising the digital divide beyond ownership of a device, or internet access, and understanding the different online activities that may narrow this divide. This study only began to unpack the diverse ways that DTs are being used by looking at the varying preferences, use of multiple devices, range of activities, and how people may be socially influenced.

I also do not want to diminish the role oximeters play, as highlighted by the one participant who found it his "*saviour*" in deciphering his symptoms between his co-morbidities. His example highlights a limitation in current technological strategies for COPD, where technological strategies continue to focus on each illness, rather than the reality that most people living with COPD are living with co-morbidities. The symptoms and side effects are often difficult to separate for people. Thus, future research should explore how to create DTs that address co-morbidities rather than different technology for each illness.

The importance of in-person support group indicates a current deficiency in current DT strategies for COPD. Although online support groups for COPD exist, they did not match with what people were gaining from their in-person support groups. I recognize the characteristics of these in-person interactions can never be replaced by technology; however, there are also the aspects of synchronous communication that allow for meaningful connections that are currently not being offered through online peer supports. The global disruption of Zoom introduces new possibilities to address the social isolation experienced living with COPD, where the synchronous, face-to-face interactions may open up new opportunities for sharing deeply personal and existential experiences of living with a fatal chronic illness. With limited examples of transitioning in-person COPD support groups online, there is the need for evaluating how these groups can sustain connections during future events that continue to isolate these populations.

Given evidence that pulmonary rehabilitation is one of the limited interventions known to improve outcomes of COPD, the differences in respiratory programs being offered throughout the province was quite surprising. Some health authorities offered these programs as ongoing maintenance for all of their COPD patients, while others offered a six-week program to introduce people to managing their illness. The onset of the pandemic has resulted in renewed focus on how pulmonary rehab programs could be offered online in order to reach under resourced and hard to reach populations.

Limitations

Although I strove for heterogeneity, there were critical areas identified as limiting this heterogeneity. Firstly, the majority of participants were attending a COPD support group, so may have represented a particular group of individuals who are interested in peer support strategies. Secondly, I was not able to recruit people with severe COPD who may be more impacted by their use of DTs. Thirdly, there were socio-demographics that limited the diversity of the study population: most people identified with European descent, everyone identified as cisgender, and the majority of people who lived alone were women.

One of the questions that was not possible to be fully explored was how DTs are used as by people who identify with more severe COPD. For the final interviews people who identified in stage two as having more severe COPD were contacted. However, people either did not reply back, did not have the energy to participate, or were already busy with many healthcare appointments. Their comment contrasted to participants who identified with less severe COPD and found that technology "*kills an awful lot of time*" and "*passes the time*". The reference to time raised questions about when is the ideal time to promote learning a new activity such as use of DTs: when someone who has never used DTs, and is at the end stages of COPD, it is understandable that their priority may not be focused on learning a new skill that takes up their limited time and brings them into an unfamiliar virtual world.

As this was an independent research study, no one was asked to cross-check my coding. I recognize that qualitative research has different levels of researcher interpretation; however, I tried to stay close to participant data by reading and sorting in multiple ways. In presenting the three chapters as an integration of the qualitative and quantitative data, rather than a separation, I aimed to provide an audit trail for my interpretation and how I reached the final five meta-inferences.

Other than the PREM and PROMs, the questions in the survey did not undergo formal testing for validity. To address this limitation, existing surveys were reviewed and multiple people evaluated the survey before it was launched. Face validity was further achieved when people would comment during interviews that I really understood how they were using DTs.

Some of the assumption questions in the survey had equal distribution of responses across all of the categories, which made me question whether they were getting to the concept that was being evaluated. In these instances, less emphasis was placed on the quantitative data and the qualitative data was used to further understand these areas. However, the design of the questions opened up opportunities for a more nuanced understanding around the discourse of barriers to technology use, and thus future research could focus on refining and validating these questions so that they can be used to unpack dominants discourse and assumptions.

With the sudden event of the pandemic the data from the first two stages were collected under a very different context than the third stage. Whenever possible I reported my findings based on the mixing of my quantitative and qualitative results. Not wanting to lose the particular context the pandemic was referenced when I interpreted it as having relevance to the data.

Not everyone in the study was living with a formal diagnosis of COPD. In some instances participants were unclear about their own condition after receiving conflicting information about having COPD. The strength in having inclusion criteria using fixed categorizations of illness is that it allows a quick interpretation in transferring studies to other similar context and populations. However, by its very nature, it also excludes individuals who do not fit within formal healthcare and research definitions, and thus may remain hidden, marginalized and unsupported within our current structures. Requiring participants to have a formal diagnosis of COPD suggests there is more clarity regarding illness criteria than people living with the illness may actually perceive or accept.

In addition, early in the study people wanted to participate who were living with a life limiting lung condition, but did not meet the formal definition of COPD. I made the decision to include them in order to prioritize the knowledge of the community. These decisions also created limitations; however, I sought to minimize these by being explicit about participant's diagnosis throughout the result chapters.

The three 'cases' of people who did not identify with COPD that were interviewed matched with my transformative MMR approach in achieving heterogeneity, understanding range of experiences and representing the voice of the community (Bazeley, 2018; Mertens, 2007). In this study, people shared very similar experiences and outcomes of living with a life-limiting lung condition (as indicated by the PREM and PROM scores and interviews), but it was their diagnosis that was creating another source of exclusion. It highlights the need for further research across these different illness groups (e.g., COPD, IPF, ARDS, bronchiectasis, sarcoidosis) to understand how these clinical categorizations of lung conditions impact structural and social experiences and outcomes.

Conclusion

The strategies that have been developed have been based on illness models that may not fully translate to COPD. Through this study, participants shared a new way of conceptualizing how to support COPD through DTs. Most significantly, this involves shifting considerations to supporting experiences which are not only focused on illness, but focused on living. The examples that people shared illustrate new possibilities of using DTs to support experiences of COPD, by looking to virtual synchronous peer support that offers a separation of virtual worlds, and encouraging people to go online for activities that are outside of their illness. To fully realize the possibilities of these new strategies requires challenging discriminatory discourse that discourages individual access, and development of system level strategies that represent the values of the COPD community.

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Appendices

Appendix A: Key Definitions and Terms

chronic obstructive pulmonary disease (COPD): COPD is an umbrella term that serves to capture a range of chronic lung diseases, and is most commonly identified with emphysema and bronchitis (Bourbeau et al., 2017; Evans et al., 2014; Vestbo et al., 2013). It is an illness characterized by decreased breathing function and repeated scary breathing events (i.e., exacerbations) that can be fatal (Bourbeau et al., 2017; Gore et al., 2000; Hoogendoorn et al., 2011; Molzahn et al., 2021; O'Donnell et al., 2007).

clinical outcomes: Represent outcomes that historically have been quantitatively measured in order to improve healthcare analytics (e.g., hospitalization, morbidity and mortality rates), clinical practice and patient symptoms (e.g., incidence of shortness of breath, number of exacerbations).

digital technologies (DTs): Considerations for DTs is informed by Merolli's et al. (2013) categorization of social media and will include 1) video conferencing (e.g., Skype, Face Time; 2) mobile (e.g., text messaging, apps and wearable devices); 3) social media (e.g., Facebook, Instagram, Dailystrength Twitter); 4) online support groups (e.g., forums, discussion boards, chatrooms and blogs); and 5) virtual worlds (e.g., Second Life). DTs may be utilized for information/education, emotional support, peer support, engagement/participation, narration, and personal contact.

health equity: "A difference in which disadvantaged social groups (such as the poor, racial/ethnic minorities, women, or other groups that have persistently experienced social disadvantage or discrimination) systematically experience worse health or greater health risks that more advantaged groups" (Braveman, 2006, p.180).

illness experiences and outcomes: In this dissertation illness outcomes and experiences are considered within one concept that cannot be fully separated out, but rather are seen as interconnected, as the encounters one has across the life course (experiences) impacts the end result (outcomes). With a potential outcome of COPD being death, it highlights the importance of preventing experiences of severe exacerbations that can impact daily activities of living with COPD (experience) and life expectancy (outcome).

patient-reported experience measures (PREMs): Are a form of patient-reported outcomes that evaluate patient's experiences with the care they receive through the formal healthcare system (Black, 2013; Canadian Institute for Health Information, 2015).

patient-reported outcomes (PROs): PROs are measures that ask patients directly about how their perceptions on illness symptoms, health and functional status, quality of care supports and quality of life (Black, 2013; Hodson, 2014; Hodson et al., 2013). PROs can be conducted over a single interval in gaining patients' insights on whether an intervention has been effective in addressing physical, social and mental health and quality of life (Black, 2013; Canadian Institute for Health Information, 2015). They have also been used to evaluate the equity of health services (Neuburger et al., 2012). PREMs and PROMs are specific types of validated PROs, where PREMs and PROMs ask questions about patient's perceptions on their overall social, cognitive, emotional and physical health status.

patient-reported outcome measures (PROMs): Are a form of patient-reported outcomes ask questions about patient's perceptions on their overall social, cognitive, emotional and physical health status (Black, 2013; Canadian Institute for Health Information, 2015).

social connectedness: The sense of belonging one has with their peers, community, family and friends (Van Bel et al., 2009). In this dissertation, it was in juxtaposition to social isolation.

social determinants of health: "The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels" (World Health Organization, 2017).

social isolation: A sense of lack of integration within a community, which may limit a person from accessing resources necessary for overall well-being (Chappell & Badger, 1989).

self-management: Developed from Lorig's work on having health practitioners train patients on management of their illness to become experts in their own care (Greenhalgh, 2009).

technology: Represents more lay language than digital technologies. The word 'technology' was used during interviews and in the survey to ask what participants about the types of online and mobile devices they used in their daily life.

Key Terms Referenced within Mertens' (2003, 2007) Transformative Approach

axiology: the foundation for the transformative paradigm and takes an ethical position in prioritizing equity and social justice and encourages challenging the status quo when populations are being marginalized

ontology: 'what exists'; Mertens' ontological assumption rejects cultural relativism, whereby all realities are equally valid. Rather, recognizes the different power levels that exist in determining who's socially constructed reality is privileged

epistemology: 'how we know what we know'; Mertens' epistemological assumption brings awareness to the knowledge that is privileged in data collection and evaluation. This brings considerations to the different outcome measures and strategies that have been historically evaluated and implemented within health informatics.

methodology: the framework that guides the overall research; in Mertens' transformative approach, axiology is emphasized as the overall guide.

transformative: perspective that represents the need for social change in addressing continuing inequities of underserved populations. It particularly stresses the importance of engaging with community members in understanding how to counter the power differentials reinforced by dominant populations.

Key Social Terms Referenced in Conceptual Model Social Networks Impact on Health (Berkman & Krishna, 2014)

social engagement: results from the ability to enact and participate with social ties and real-life activities; social roles are reinforced through the opportunities of engagement

social influence: within a social network it is the set of values and norms within a group that impact person's behavior

social networks: consists of social engagement, social influence and social support that contribute to physical, mental and emotional health

social support: encompasses the emotional (assistance provided through close personal ties), instrumental (assistance in daily tasks) , appraisal (assistance in decision-making) and informational (provision of advice) support (Berkman & Krishna, 2014)

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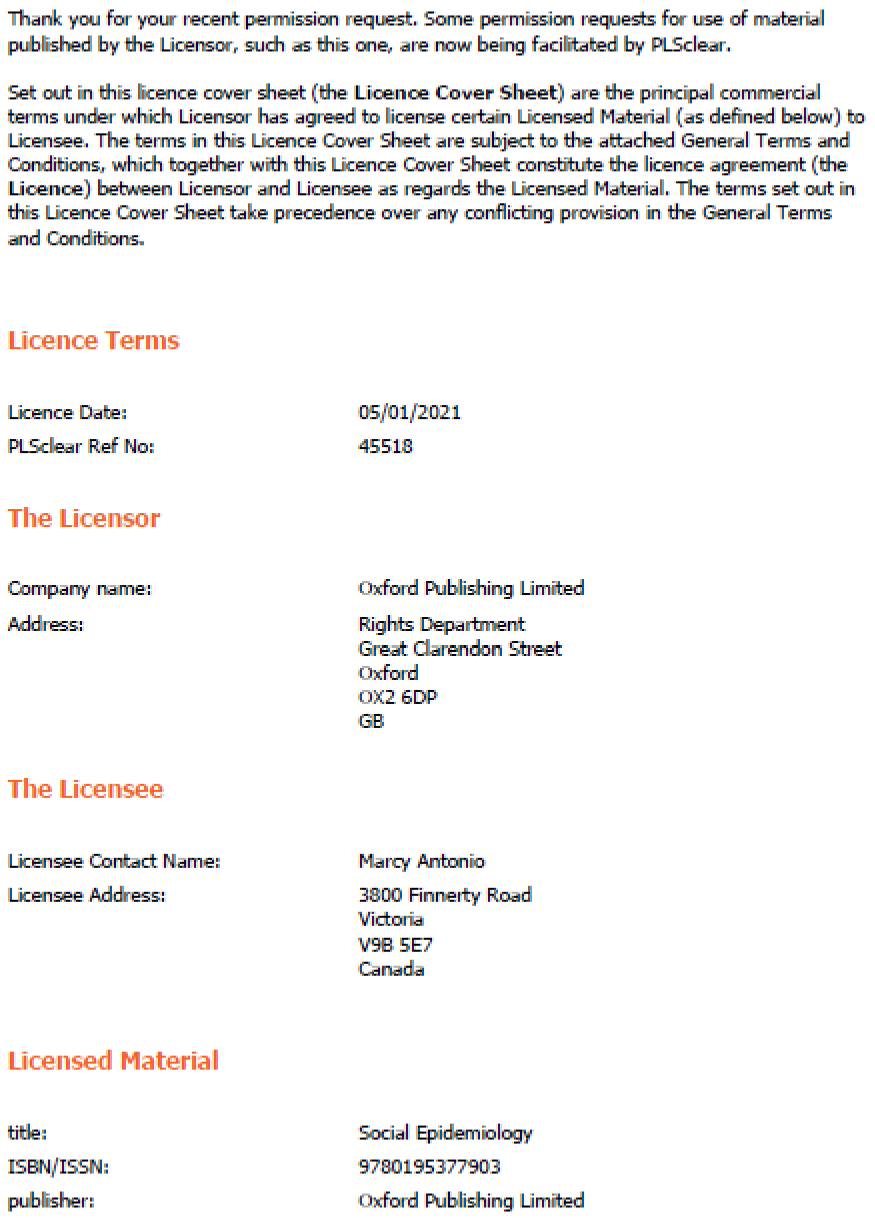

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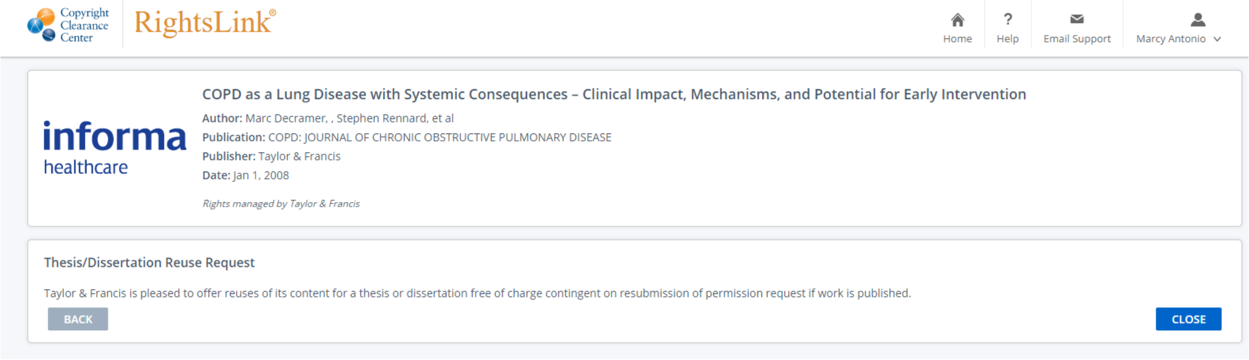

COPD as a Lung Disease with Systemic Consequences – Clinical Impact, Mechanisms, and Potential for Early Intervention

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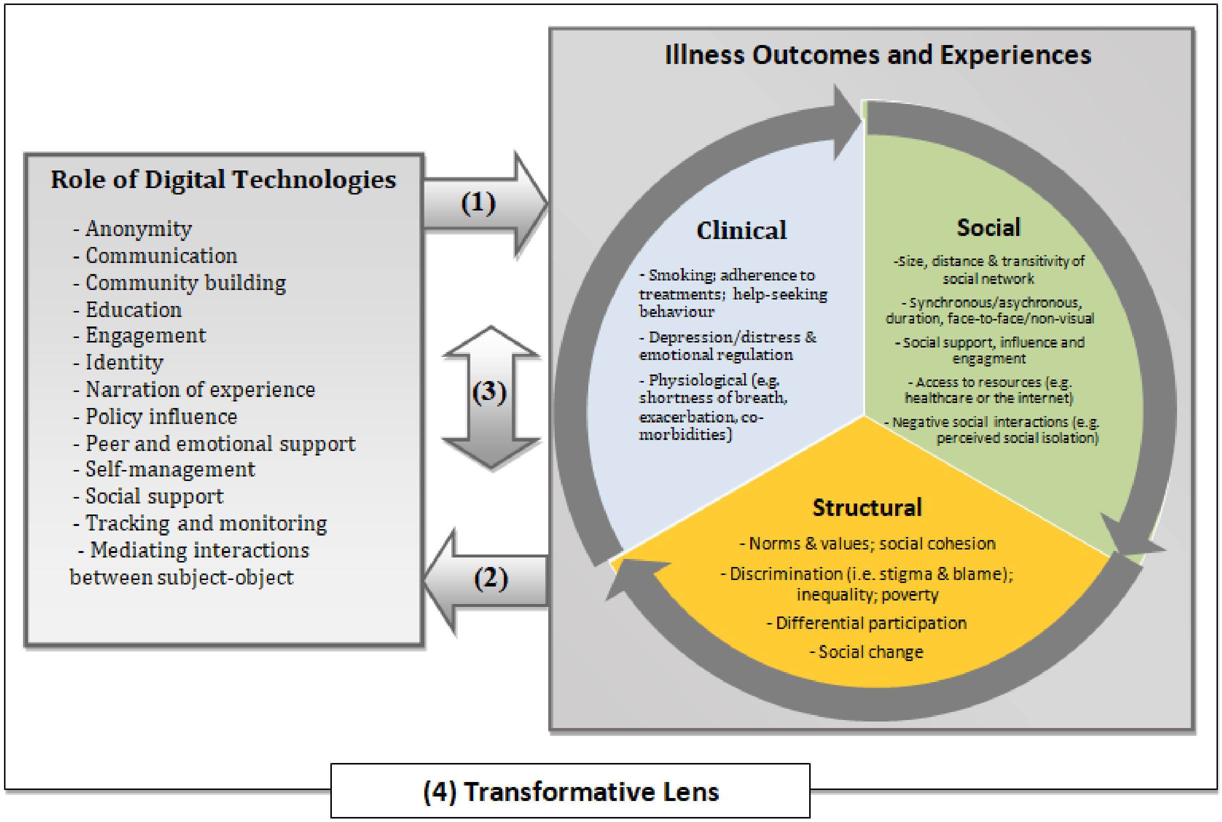
Appendix C: Initial Mapping of Interview and Survey Questions

This mapping exercise was conducted prior to beginning stage one. A similar mapping exercise was done prior to beginning each successive stage. The transformed model and research was used as a guide to determine how the questions within each stage focused on equity, role of DTs, social connectedness and illness outcomes and experiences (both clinical and structural).



Stage 1: Qualitative (Semi-Structured Interviews) **Sample Questions**	Equity / Context	Role of DTs	Clinical illness experience and outcomes	Structural Illness Experiences and Outcomes	Social Connectedness
Do you access the internet or utilize a mobile phone or smartphones? What do you access through these technologies? How do you use these technologies? learn about your illness? Who do you connect with through these technologies? online connections? friends? family? healthcare providers?		X	X		X
Can you tell me about your experiences in using these different technologies to learn about, support and manage your illness. [Will ask specific questions on timing, duration, roles that is specific to the referenced technology].		X	X		
How have you learned more about your illness? --> If mentioning a technology, how does this technology impact your social connections?		X			X
Can you tell me about the different technologies you use to interact with friends? healthcare providers? Where would you place these on the map? [Will ask specific questions on timing, duration, roles that is specific to the referenced technology].		X			X
Do you interact with others online? Do these online connections provide support for living with COPD? Where do see these fit on the map? [Will ask specific questions on timing, duration, roles that is specific to the referenced technology].		X		X	X
What connections do you have with others living with COPD?		X		X	X
What is it that you like about these technologies? What have you found successful in using this technology? How often do you use these technologies? Are there specific aspects of living with COPD that are supported through these technologies? Are there specific aspects of living with COPD that make it difficult to use these technologies? What advice would you give to others living with COPD in utilizing these technologies?		X	X		
How do you believe others perceive your illness and how does this impact the supports you receive? Have you had any negative experiences in using these technologies in relation to supporting your illness?		X		X	
Demographic Questions based on PROGRESS Framework: What is your preferred language?; What is your cultural background? Where were you born?; What is/was your occupation?;Are you currently working/retired/on disability?; What is your gender?; Do you identify with a specific religion? spirituality?; As a child how would you rate your socioeconomic status? and currently?; What is your level of education?;	X				

Are you married/common-law/partnership? How many people do you live with? Do you have any children? Additional demographic question: What other health conditions do you have?					
Stage II: Quantitative (Survey and PROMs)	Equity / Context	Role of DTs	Clinical illness experience and outcomes	Structural Illness Experiences and Outcomes	Social Connections
Digital Technology Survey that asks people about the digital technologies they utilize to support their illness experience and social connections. (Will be designed based on the findings from Stage One)		X	X	X	X
McGill COPD - Question one: How much fatigue have you experienced in the last four weeks?	X		X		
McGill COPD - Question two: On an average day during the past four weeks a) how often have your coughed? b) how often did you bring up phlegm?			X		
McGill COPD Question: On average over the past four weeks, how much shortness of breath di you have a) during normal activities, b) performed activities that required you to raise your arms overhead; c) walking on the level at your own pace.			X		
McGill COPD Question 4: During the past four weeks, how often did the fear of becoming short of breath limit you activities of daily life?			X		
McGill COPD Question 5: On average over the past four weeks, how often have you felt: a) frightened or worried about not being able to breathe; b) frustrated or impatient; c) that everything seems too much of an effort; d) unable to accept your pulmonary condition.			X		
McGill COPD Question 6: These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give only one answer that comes closest to the way you have been feeling. How much time during the past 4 weeks... a) did you feel full of life? b) have been very nervous? c) have you felt downhearted or depressed? d) did you feel warn out?			X		
McGill COPD - Question 7: How true or false is the following statement for you: My health is excellent.			X		
McGill COPD - Question 8: Compared to a person your own age, how much more time does it take you to perform your daily activities?			X		
McGill COPD - Question 9: The following items are about activities you might do during a typical day. To what extent do your breathing		X			X

problems now limit you in your ability to perform these activities? a) climbing a slope or hill b) getting outside the house c) getting outside on days which are hot/sunny, cold/damp or windy, or have elevated dust/pollution levels? d) being autonomous in your home i.e., not requiring any assistance; e) being able to function sexually (if sexual activity is not an issue for you, answer not limited at all).			
PROMIS Social Isolation- Question 1: I find that friends or relatives have difficulty talking with me about my health.	X		X
PROMIS Social Isolation- Question2: I feel isolated even when I am not alone.			X
PROMIS Social Isolation- Question 3: I feel that people avoid talking to me.			X
PROMIS Social Isolation- Question 4: I feel detached from other people.			X
PROMIS Social Isolation- Question 5: I feel like a stranger to those around me.			X
PROMIS Social Isolation- Question 6: People get the wrong idea about my situation.		X	
PROMIS Social Isolation- Question 7: I feel that some of my friends avoid me.		X	X
PROMIS Social Isolation- Question 8: I feel left out.			X
PROMIS Social Isolation- Question 9: I feel that people barely know me.		X	X
PROMIS Social Isolation- Question 10: I feel isolated from others.			X
PROMIS Social Isolation- Question 11: I feel that people are around me but not with me.			X
PROMIS Social Isolation- Question 12: I feel that I am no longer close to anyone.			X
PROMIS Social Isolation- Question 13: I feel that I am alone in my interests and ideas			X
CIASS - Question 1: A friend or family member will be angry with you.		X	
CIASS - Question 2: A friend or family member will blame you for not getting better.		X	
CIASS - Question 3: A friend or family member will think that your illness is your fault.		X	
CIASS - Question 4: A friend or family member will not think as highly of you.		X	
CIASS - Question 5: A healthcare worker will be frustrated with you.		X	

CIASS - Question 6: A healthcare worker will give you poor care.				X	
CIASS - Question 7: A healthcare worker will blame you for not getting better.				X	
CIASS - Question 8: A healthcare worker will think that you are a bad person.				X	
Demographic Questions based on PROGRESS Framework (formatted categorically): What is your preferred language?; What is your cultural background? Where were you born?; What is/was your occupation?;Are you currently working/retired/on disability?; What is your gender?; Do you identify with a specific religion? spirituality?; As a child how would you rate your socioeconomic status? and currently?; What is your level of education?; Are you married/common-law/partnership? How many people do you live with? Do you have any children? Additional demographic question: What other health conditions do you have?	X				X
Stage 3: Qualitative (Semi-Structured Interviews)	Equity / Context	Role of DTs	Clinical illness experience and outcomes	Structural Illness Experiences and Outcomes	Social Connections
You listed ____ as a technology that you utilize quite frequently. Can you tell me how you use this technology. [Will ask specific questions on timing, duration, roles that is specific to the referenced technology].		X			X
Are there technologies that you now use that you didn't use prior to your illness? Are there other technologies that you use that were not mentioned in the survey that you find beneficial for supporting COPD and your overall health? Can you tell me how you use this technology. [Will ask specific questions on timing, duration, roles that is specific to the referenced technology].		X	X		X
What technologies do you use to connect with friends, family? What is it that you talk about (e.g., your illness, events of the day, healthcare interactions, social conversations)? How often do you connect with these people/groups?		X			X
Do you interact with others online? Do these online connections provide support for living with COPD? What have these interactions been like? How often do you connect with these people/groups?					X
What technologies do you use to connect the healthcare system and people within healthcare? How often do you connect with these people/technology? What are these interactions like?		X		X	

What connections do you have with others living with COPD?				X	X
Have there been times in using any of these technologies/or interacting with people through these technologies that you have experienced negative perceptions in living with COPD?		X		X	
What is it that you like about these technologies? What have you found successful in using this technology? How often do you use these technologies? Are there specific aspects of living with COPD that are supported through these technologies? Are there specific aspects of living with COPD that make it difficult to use these technologies? What advice would you give to others living with COPD in utilizing these technologies?		X	X		
Demographic Questions based on PROGRESS Framework: What is your preferred language?; What is your cultural background? Where were you born?; What is/was your occupation?;Are you currently working/retired/on disability?; What is your gender?; Do you identify with a specific religion? spirituality?; As a child how would you rate your socioeconomic status? and currently?; What is your level of education?; Are you married/common-law/partnership? How many people do you live with? Do you have any children? Additional demographic question: What other health conditions do you have?	X				X

Appendix D: Preliminary Template of Survey Questions

(created prior to beginning stage one)

a) Technology Utilization - Initial Version

The DT survey will be developed upon analysis of the first stage. However, it is anticipated that this will be significantly modified based on interview data from stage 1. What technologies have you used (check all that apply):

Social network sites such as Facebook or Instagram	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Skype, FaceTime or other web conferencing tools	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Twitter	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Text Messaging	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Mobile Apps	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Wearable device	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Virtual platforms or computer games	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily
Blogs, chatrooms, forums, discussion boards	☐ Have never used	☐ Tried, but no longer use	☐ Use monthly	☐ Use weekly	☐ Use daily

Are there other online technologies that you regularly use to support your illness? Please list and indicate how often you use these:

Technology 1			☐ Use monthly	☐ Use weekly	☐ Use daily
Technology 2			☐ Use monthly	☐ Use weekly	☐ Use daily
Technology 3			☐ Use monthly	☐ Use weekly	☐ Use daily

In thinking about these technologies what have you used them for (check all that apply):

Social network sites such as Facebook or Instagram	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Skype, FaceTime or other web conferencing tools	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Twitter	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Text Messaging	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Mobile Apps	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Wearable Device	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: ________
Virtual	☐ Meeting	☐ Sharing	☐ To learn	☐ Emotional	☐ Connecting with my	☐ Connecting with	☐ Other:

platforms or computer games	with others living with illness	my story of living with illness	more about my illness	Support	health care providers	friends and family	__________
Blogs, chatrooms, forums, discussion boards	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: __________
Other online technologies: ______________ ___	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: __________
Other online technologies: ______________ ___	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: __________
Other online technologies: ______________ ___	☐ Meeting with others living with illness	☐ Sharing my story of living with illness	☐ To learn more about my illness	☐ Emotional Support	☐ Connecting with my health care providers	☐ Connecting with friends and family	☐ Other: __________

Appendix E: Summary of Patient-Reported Measures that were Reviewed

Patient-Reported Measure	Original Reason for Exclusion/Include	Decision at End of Stage One
LCOPD	Exclude: Unidimensional (yes or no) format does not allow for capturing range of experiences. Authors made this decision based on viewing "the overall impact of COPD on QoL" as a single construct.	Exclude
Clinical COPD	Exclude: Clinical focus, rather than patient-centered	Exclude
DIRECT	Exclude: Main focus on physical health and breathing and disability	Exclude
COPDSS	Exclude: Clinical focus; not focused on emotional health, but on COPD severity	Exclude
COPD-PS	Exclude: Screening tool for diagnosing COPD	
McGill COPD	Include: *McGill COPD Quality of Life Questionnaire* is based on parameters within a well-recognized, generic PROM (SF-36) and previous COPD specific modules McGill-COPD development occurred across four out-patient hospital settings in Quebec with people diagnosed with COPD (n=246). Although it has limited study applications, the measure demonstrated strong validity, reliability and consistency during psychometric testing (Cazzola et al., 2015; Pakhale et al., 2012; Pakhale et al., 2011). In comparing to other clinically-focused PROMs, McGill-COPD was determined to be the best fit for the research question, as it represented strong involvement of COPD individuals during development and evaluates how COPD symptom outcomes may impact experiences.	Exclude: Survey had many formats for question design which did not align with best practice for survey design, and translation to English may have resulted in spelling errors. Found the survey quite lengthy with 31 individual questions was concerned that the bulk of survey would prioritize COPD outcomes, rather than provide a balance with the other concepts within the study question and objectives (i.e., DT roles, use and activities, illness experiences and social connectedness).
SGRQ-C	Developed from a clinical	Exclude

	perspective, rather than patient centered.	
CIASS	In a search on patient-reported outcomes that evaluated stigma specific to COPD, no examples could be found, thus CIASS was selected to be the best match in specifically examining stigmatization experienced in living with a chronic illness. The development of this measure did not involve anyone living with COPD, introducing a possible limitation. However, the authors acknowledge this limitation as a justification for creating a generic measure for stigma: stigmatized illnesses often do not have dedicated resources to create illness-specific measures (Earnshaw et al., 2013). One change that I proposed in using this measure for the was the elimination of the work sub-category. At this stage, this decision is based on data from the Liminality study (Sheilds, et al., 2020), where no participants were employed full-time and many identified as falling within a low socioeconomic. Work-related question may reinforce societal values that being 'valuable contributors to society' requires employment, and may reinforce perceptions that this questionnaire is aiming to negate.	Exclude: Re-evaluation after stage1 made me realize that although it aligned with my transformative/social justice lens, it did not align with the concepts within my research question. Rather stigma may emerge during the interviews.
PROMIS Social Isolation	Include: This PROM was specifically selected to evaluate the distinct social isolation that can be experienced with COPD. This PROM is from the Patient-reported outcomes measurement information system (PROMIS), a data bank of PROMs developed specific to chronic illness and is managed by the US Department of Health	Exclude: Re-evaluation after stage 1 made me realize that this measure was the opposite to the social concept in my research question. My research question is focused on how DTs support social connectedness, and not how DTs create social isolation. Note: I did end up one question about social isolation in the survey, to understand this better,

	and Human Services. Two PROMIS measures specific to COPD were also considered for being validated PROMs specific to COPD: 'Satisfaction with Participation in Discretionary Social' and ‘Satisfaction with Participation in Social Roles’ (Cook et al., 2016). These two measures emphasize social connections with friends and families. PROMIS-Social Isolation was initially selected, as it goes beyond these relationships and "assesses perceptions of being avoided, excluded, detached, disconnected from, or unknown by, others". It is PROM that does not ask questions specific to a timeframe (e.g., over the past seven days have you...), rather aims to get at a person's overall experience of social isolation. Although no studies were found specific to COPD, *PROMIS-Social Isolation* has been validated in a study specific to social media utilization, (Primack et al., 2017). More broadly, the PROMIS domains of "pain, fatigue, anger, anxiety, depression and physical function... [have been] compared between people living with and without a chronic illness" (Rothrock et al., 2010).	but did not make social isolation the predominant focus.
CAT	Does not focus on emotional health, focus is on clinical measures – shortness of breath, fatigue and physical activity.	Move to include
PREM-C9	Evaluates the experiences with the intervention (i.e., the formal healthcare system), rather than the experiences of living with COPD.	Move to include

Appendix F: Review of Patient-reported Measures that were Originally Proposed

In my initial proposal, three PROMs were proposed for matching with the inclusion criteria and key domains within the research study: *PROMIS-Social Isolation*, *McGill COPD Quality of Life Questionnaire* and the *Chronic Illness Anticipated Stigma Scale*.

i) **Social Connectedness:** *PROMIS-Social Isolation* represents patients' perceptions of their relationships and social support. This PROM was specifically selected to evaluate the distinct social isolation that can be experienced with COPD. This PROM is from the Patient-reported outcomes measurement information system (PROMIS), a data bank of PROMs developed specific to chronic illness and is managed by the US Department of Health and Human Services. Two PROMIS measures specific to COPD were also considered for being validated PROMs specific to COPD: 'Satisfaction with Participation in Discretionary Social' and 'Satisfaction with Participation in Social Roles' (Cook et al., 2016). These two measures emphasize social connections with friends and families.

PROMIS-Social Isolation was initially selected, as it goes beyond these relationships and "assesses perceptions of being avoided, excluded, detached, disconnected from, or unknown by, others". It is PROM that does not ask questions specific to a timeframe (e.g., over the past seven days have you...), rather aims to get at a person's overall experience of social isolation. Although no studies were found specific to COPD, *PROMIS-Social Isolation* has been validated in a study specific to social media utilization, (Primack et al., 2017). More broadly, the PROMIS domains of "pain, fatigue, anger, anxiety, depression and physical function... [have been] compared between people living with and without a chronic illness" (Rothrock et al., 2010).

ii) **Clinical Outcomes and Experiences:** *McGill COPD Quality of Life Questionnaire* is based on parameters within a well-recognized, generic PROM (SF-36) and previous COPD specific modules. McGill-COPD development occurred across four out-patient hospital settings in Quebec with people diagnosed with COPD (n=246). Although it has limited study applications, the measure demonstrated strong validity, reliability and consistency during psychometric testing (Cazzola et al., 2015; Pakhale et al., 2012; Pakhale et al., 2011). In comparing to other clinically-focused PROMs, McGill-COPD was determined to be the best fit for the research question, as it represented strong involvement of COPD individuals during development and evaluates how COPD symptom outcomes may impact experiences.

iii) **Societal Illness Experiences and Outcomes**: *Chronic Illness Anticipated Stigma Scale (CIASS)* was developed to measure anticipated stigma experienced with friends and family, healthcare providers and work colleagues (Earnshaw et al., 2013). In a search on patient-reported outcomes that evaluated stigma specific to COPD, no examples could be found, thus CIASS was selected to be the best match in specifically examining stigmatization experienced in living with a chronic illness. The development of this measure did not involve anyone living with COPD, introducing a possible limitation. However, the authors acknowledge this limitation as a justification for creating a generic measure for stigma: stigmatized illnesses often do not have dedicated resources to create illness-specific measures (Earnshaw et al., 2013). One change that I proposed in using this measure was the elimination of the work sub-category. At this stage, this decision is based on data from the Liminality study (Sheilds, et al., 2020), where no participants were employed full-time and many identified as falling within a low socioeconomic. Work-related question may reinforce societal values that being 'valuable contributors to society' requires employment, and may reinforce perceptions that this questionnaire is aiming to negate.

	PROMIS-Social Isolation (Healthmeasures.net, 2015)	**Stigma** measures (Earnshaw et al., 2013).	**McGill COPD** (Cazzola et al., 2015; Pakhale et al., 2012; Pakhale et al., 2011).
Area of focus	Patients' perceptions of their relationships and social support.	Anticipated stigma experienced in with friends and family, healthcare providers and work colleagues in living with a chronic illness	Built off of the SF-36[18] and COPD-specific module (general PROM), but specific to COPD
Limitations	Not specifically designed for COPD.	Chronic illnesses considered did not include COPD: represented illnesses included lupus, asthma and heart failure. However, one of the two participant groups focused on older adults. Initial constructs were built from a literature review on existing measures on chronic illness, but did not include COPD. However, the review involved examining measures that are identified with COPD: internalized stigma, depression, anxiety, care access and illness symptoms	May not have the same level of testing as PROMIS, and requires further testing, but the initial development demonstrated strong validity and reliability with the study population.
Further considerations		The working category of the PROM may be eliminated, as it draws attention to SES and COPD individuals may not be working. Designed this to be a general PRO for stigma, as the authors recognized that stigmatized illnesses often do not have dedicated resources to create illness-specific measures.	Based off a general, well-recognized illness PROM (SF-36)

Target for research question	Social connectedness	Stigma (experiences of living with COPD)	Outcomes and experiences of living with COPD
Main constructs	Social isolation	Stigma of living with a chronic illness.	Symptoms, physical functioning and feelings
Population of focus	Chronic conditions	Chronic illness (one of the two populations in evaluation were older adults)	Developed in Canada, involved COPD individuals in the development (n=246)
Setting		Community, US	Out-patient COPD individuals participating in pulmonary rehab program in Canadian hospitals.
Timeline stated for reflection	None	None	'In the past four weeks'
Self-administered	Yes (computer version has been validated)	Yes	Yes
Literacy level	Evaluated through Word – Grade 4 level; Flesch Reading Ease: 82.6	Unknown.	Unclear
Length of time to complete PRO	Not stated (but estimate not more than 5 minutes)	Note specifically stated, however, authors note that it is a quick PRO to complete. Estimate not more than 5 minutes	Not stated (but estimate not more than 10 minutes)
Number of questions	14	8-12	17
Concepts that don't directly link to research question	none	Work (authors acknowledge that this may not have strong relevance to health behaviour and care access.	
Documentation of concepts and population	No	Yes	Yes
Documentation on organization of model	No	Yes	Yes - based off of SF-36
Reliability above 0.70 for group-level comparison	n/a	Yes, for both the 12-item scale and 4-item subscale.	
Testing (and justification of test) of reliability through internal consistency, reliability, rest-retest	Yes	Yes	"high internal consistency, reliability, convergent validity, and moderate responsiveness in COPD subjects".

reliability, or item response theory			
Evidence to support its content validity	Yes	Yes	Convergent and divergent validity
Justification for recall period	no	Yes	Based on SF-36
Justification for construct validity	Yes	Yes	Yes
Responsiveness - changes in scores depending on the hypotheses	Yes	Yes	Moderate responsiveness; needs further testing
Documentation to support interpretation of scores	Yes	No	Yes
Methods for language translation	n/a - originated in English	n/a - originated in English	n/a originated in English and French

Appendix G: Review of Final Selected Patient-reported Measures

Following the first stage interviews the following PREM and PROM were selected:

PROMIS-Satisfaction with Social Activities (Hahn et al., 2016);
PREM-C9 (Hodson, 2014; Hodson et al., 2019);
COPD Assessment Test (CAT)(GlaxoSmithKline, 2018; Jones et al., 2009)

	PROMIS-Satisfaction with Social Activities (Hahn et al., 2016)	**PREM-C9** (Hodson, 2014; Hodson et al., 2019)	**COPD Assessment Test** (CAT)(GlaxoSmithKline, 2018; Jones et al., 2009)
Area of focus	Patients' satisfaction with their participation in social roles and activities	Experiences of COPD	Quantifies how COPD impacts patient's health
Limitations		A way to evaluate the PREM scores has not yet been created beyond "good experience" as "0" and "bad experience" as "5". Initial sample size was 174 patients. However, relatively small sample size (n=36) in evaluating some of the validity criteria for first validation. Need for further validation.	One participant commented that the scale was not easy to understand. During development, all patients with severe or uncontrolled co-morbidities were not included
Further considerations	Relates to social roles rather than social connectedness, however it reflects the language that was being used during stage one interviews, where people talked about who they were connecting with and the activities they were able to do. Involved people who may have many of the co-morbidities associated with COPD.	Developed with a similar format to the CAT, so made it blend well in the survey format. Underwent extensive psychometric testing. Views experiences similar to the approach in my dissertation. That is, it isn't the experiences with the healthcare system, but experiences of living with COPD.	Would not grant permission to use an online version outside of the organization's platform. Validated in 2009 and continues to be one of the most common used PROM for COPD Large sample size in initial development (n=1503)
Target for research question	Social connectedness	clinical illness outcome experiences of COPD societal outcomes and experiences of COPD	clinical illness outcomes

Patient voice involved in the development	Yes, involved people with COPD in development of the measure	Yes, uses the language generated by patients	Yes
Main constructs	Social activities and roles	Experience of living with COPD Care received	health status for COPD
Population of focus	Chronic conditions (COPD, hear failure, chronic back pain and depression)	COPD	COPD
Setting		UK, everyone had a spirometry test, an were attending a respiratory group	USA
Timeline stated for reflection	None	None	None
Self-administered	Yes (computer version has been validated)	Yes	Yes
Literacy level		Recognized limitation: English only, may not be transferrable across linguistically diverse patient groups; although English was not the first language for every participants	Initially available in English, however, now has over 90 translations and that is it shown to translate across these different contexts.
Length of time to complete PRO	not stated (estimate 1 minute)	not stated (estimate 3 minutes)	not stated (estimate 3 minutes)
Number of questions	Four	Nine	Eight
Concepts that don't directly link to research question	none	none	none
Documentation of concepts and population	Yes	Yes	Yes
Documentation on organization of model	Yes	Yes	Yes
Reliability above 0.70 for group-level comparison	Yes	Yes	Yes
Testing (and	Yes	Yes (n=88)	Yes (n-1503)

justification of test) of reliability through internal consistency, reliability, rest-retest reliability, or item response theory			
Evidence to support its content validity	Yes	Yes	Yes
Justification for recall period (not applicable for my study design)	Yes	No	No
Justification for construct validity	Yes	Yes	Yes
Responsiveness - changes in scores depending on the hypotheses	Yes	Yes	Yes
Documentation to support interpretation of scores	Yes	No	Yes
Methods for language translation	Yes	n/a - originated in English	Yes - translated into over 90 languages

Appendix H: Stage One Interview Script

Questions for Stage 1 Semi-Structured Interviews

The following is set of questions that will be used as a guide. Matching with semi-structured interview format, questions may be reworded to match with participants.When we first spoke, you had mentioned you use [LIST THE TECHNOLOGIES THAT THE PERSON HAD MENTIONED]. Since we spoke last are there any other technologies you would like to add? How often do you use [TECHNOLOGY]? How long have you used [TECHNOLOGY]?

e.g., When we first spoke, you had mentioned you regularly use Facebook. How often do you use Facebook? What's the average amount of time you spend on Facebook at one time? How long have you used Facebook?

Can you tell me a bit about how you use [TECHNOLOGY] to help you with your COPD? In relation to your COPD, what is it that you like about [TECHNOLOGY]? In relation to your COPD, is there anything that limits you from using this [TECHNOLOGY]?

e.g., Can you tell me a bit more about how Facebook may help with your COPD? In relation to your COPD, what is that you like about Facebook? In relation to your COPD, is there anything that limits you in using Facebook?

Who do you connect with? How do you connect with them? Can you tell me a bit more about these interactions? How do these connections help you with your COPD? Who do you connect with through [TECHNOLOGY]?

e.g., If someone mentions that they do not use any of these technologies to connect with people → Are there things that are stopping you from using Facebook to connect with your friends or family?

What have you learned in using [TECHNOLOGY] that may be helpful to other people with COPD? Before we end this part, is there anything you would like to add? Any other technologies that you would like to mention?

This latter part of the interview ends with demographic questions.

Are there any other conditions you are receiving treatment for?

What is your age? Gender?

Are you married/common-law/partnership? How many people do you live with? Do you have any children? Grandchildren?

What is your preferred language? What is your cultural background? Where were you born?

What is your level of education? What is your occupation?

As a child how would you rate your socioeconomic status? and currently?

Do you identify with a specific religion? spirituality?

Would you like to receive updates on the study results? Would you like to be contacted to learn about participating in the next stage of the study?

Appendix I: Stage One Recruitment Flyer

Are you living with COPD?

Have you wanted to try or do you use the internet, social media, text-messaging, blogs, Smartphones, Skype^{TM}, video games, or other online technologies?

Have you used these technologies to connect?

Opportunity to take part in a study that explores how these technologies can support living with COPD.

What does the study involve?

- One interview 30 minutes in length.
- We can connect over the phone, or through Skype, Google Hangouts, FaceTime or Zoom.

To verify approval of this study contact Human Research Ethics Office at the

[redacted]

3800 Finnerty Rd, Victoria, BC V8P 5C2

To learn more about the study phone, text or email Marcy at:

Phone: [redacted] **email: mantonio@uvic.ca**

Ver2.0
14Aug2018

Appendix J: Informed Consent for Stage One

PARTICIPANT CONSENT FORM

Title of Study: Digital Technologies to Support Living with COPD

Principal Investigators: Dr. Francis Lau, Professor, University of Victoria

email: xxx@uvic.ca **phone:** xxx-xxx-xxxx

Dr. Anne Bruce (Providence Health Care),

Professor, University of Victoria

email: xxx@uvic.ca **phone:** xxx-xxx-xxxx

Co-investigator: Marcy Antonio, PhD Student, University of Victoria

email: xxx@uvic.ca **phone:** xxx-xxx-xxxx

Address: 3800 Finnerty Road, Victoria, BC V8P 5C2

Introduction

You are invited to participate in a study titled *Digital technologies to support living with COPD*. It is being conducted by Dr. Francis Lau and Marcy Antonio.

Dr. Lau is a faculty member in the School of Health Information Science at the University of Victoria. You may contact him if you have further questions.

As a graduate student, Ms. Antonio is required to conduct research as part of the requirements for a degree in Doctorate in Interdisciplinary Studies. Her study is being conducted under the supervision of Dr. Lau and Dr. Sheilds.

Purpose of the Study

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

You are invited to join this study because you have unique experiences to share in living with chronic obstructive pulmonary disease (COPD).

Before you decide, we will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing this study?

The purpose of this study is to learn about peoples' experiences of using digital technologies (e.g., social media, Skype™). We want to understand how these technologies can support living with COPD. We also want to find out what technologies people living with COPD may be using for social connection.

Location of Research

This study is being conducted across British Columbia.

Number of Participants

There will be about 100 people living with COPD participating across three different stages of this study. You are being asked to participate in the first stage, which will consist of 25-30 participants.

What is required if I Participate?

If you decide to take part in this study, you will:

- Give some information including your age, gender, education, and religious or spiritual affiliation.
- Take part in one interview:
    - It will be 45-60 minutes.
    - We will record the interview. After the interview, the recording will be transcribed into written form.
    - If you live in the Greater Victoria region, the interview can be done in-person and somewhere that is convenient for you.
    - The interview can also be done using your preferred communication technology (e.g., phone or video-conferencing).
    - You will be invited to share your experiences of using digital technologies to support your illness and social connections. You do not have to answer any questions that make you feel uncomfortable.
    - We will ask you about your social relationships. We will also ask you questions about how digital technologies may be supporting

these relationships.

What are the Possible Risks or Inconveniences of Participating?

Taking part in this study will take some of your time for the interview. We will make every effort to arrange times and place that is convenient for you.

We do not think there is anything in this study that could harm you or be bad for you. Some of the questions we ask might upset you. Please let one of the study staff know if you have any concerns.

Some of the questions we ask may seem sensitive or personal. You do not have to answer any question if you do not want to. If you need immediate, free, and confidential emotional support, you can contact the Fraser Health Crisis Line at 604-xxx-xxxx 24 hours a day – everyday.

What are the Possible Benefits of Participating?

You might find that talking with someone who is interested and educated in this area to be helpful. But you may not get any benefit from being in this study. However, in the future, others may benefit from what we learn in this study.

Do I have to take part in the study?

You are free to choose to participate or not. If you decide not to participate, your regular care or service will not be affected in any way. By consenting, you have not waived any rights to legal recourse connected to research-related harm. If you do decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you do withdraw from the study, we will ask you if we can still use your collected data.

Will I be Paid for Taking Part in the Study?

We will not pay you for the time you take to be in this study. As a way to thank you for your time and participation, you will be given a $10 grocery store gift card. This is not meant to influence your decision to participate.

On-Going Consent

If new information becomes available, or if this project takes place over a longer period of time, I will ask you to renew your consent to participate.

Sometimes a research project will recruit a subgroup of participants to perform other research activities. If this occurs, you will be provided with another consent form describing the new research activities and requesting your consent.

Confidentiality and How my Personal Information will be Used

For interviews that are not being done in person, we can use your preferred communication technology. There are some communication technologies that are based outside of Canada. US-based communication technologies are governed by US laws. Under the US Freedom Act, the US government may access information without your knowledge or consent.

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researcher.

Information that can identify you will be taken out of all written records. Recordings and written records will be kept in a locked metal cabinet in the researcher's office. Number codes will be used instead of your name. Only fictitious names will be used for reports, articles or presentations. Any person hired to work on the study will sign an agreement to keep everything private.

Future Use of Data

Your consent to collect your information for the purpose of this research project will expire when you complete the study. Data gathered from this study will not be used for other studies. However, if this changes I will provide a new consent form and ask you if you give permission for the data to be used in another study.

Disposal of Data

After the study is done, I will continue to safely store your information from this study in a secure, online data storage site that is housed within Canada. Data will be stored for at least 5 years after the end of the study. At the end of data storage, audio recordings will be erased and printed documents will be shredded.

Sharing of Study Results

The results will be shared with other people living with COPD, families, the community, health practitioners, policy-makers and researchers. The results of this study will be reported in a graduate thesis and may also be published in journal articles and books. The results may also be presented online through web sites, blogs or webinars.

Who Should I Contact if I Need More Information or Help?

If you have any questions or concerns about what we are asking of you, please contact the study leader or one of the study staff. The names and telephone numbers are listed at the top of the first page of this form.

In addition, you may verify the ethical approval of this study, or if you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact one of the following:

> Human Research Ethics Office at the University of Victoria by phone: 250-xxx-xxxx or email: xxxxx@uvic.ca.
>
> Research Participant Complaint Line at the University of British Columbia Office of Research Ethics by e-mail at XXXX@ors.ubc.ca or by phone at 604-xxx-xxxx (Toll Free: 1-877-xxx-xxxx.
>
> Fraser Health Research Ethics Board co-Chair by phone at 604-xxx-xxxx

Please reference the study number H18-01530 when calling so the staff can better assist you.

Consent

Your signature below indicates that:
1. You understand the above conditions of participation in this study,
2. You have had the opportunity to have your questions answered by the researchers.
3. You consent to participate in this research project.

____________________	____________________	____________
Name of Participant (print)	Signature	Date

I consent to be contacted in the event my data is requested for future research:

____________ (Participant to provide initials)

A copy of this consent form will be given to you, and a copy will be kept by the researcher.

Appendix K: Resource Document for the COPD Community

Resources: Digital Technologies to Support COPD

1. Want to learn about computers and the internet?

- The **Vancouver Island Regional Library** may offers 'e-help' or workshops to assist with your technology-related questions. Contact your local library, or cCheck out their calendar of events https://virl.bc.ca/calendar/?tribe_eventcategory%5B%5D=33 . The library also provides a listing of technology-related books on their website: https://virl.bc.ca/learn/skills/programming/
- Your **community centre** may also provide courses. Check out their seasonal program guides.

2. Looking for information on living with COPD?

- **HealthlinkBC** provides different health topics:
  - To search different health topics: https://www.healthlinkbc.ca/explore-health-topics
  - Information on living with COPD: https://www.healthlinkbc.ca/health-topics/hw32559#hw32561
  - Fran's story on going online to talk with others living with COPD: https://www.healthlinkbc.ca/health-topics/zx3804

- **Living well with COPD** is a website that offers videos and information on breathing exercises and managing COPD: https://www.livingwellwithcopd.com/

- Your **Local Health Unit** may also provide some additional resources on their web site. For example Island Health offers information on developing an action plan, how to use your inhaler and exercises: https://www.islandhealth.ca/our-services/home-care-services/home-health-monitoring

3. Looking for programs on living with COPD

- **Self-management BC** offers programs throughout BC. They are small group workshops that are held once a week for 2 to 2.5 hours over six weeks.

  Website: https://www.selfmanagementbc.ca/
  Phone number: 1-866-902-3767 **Email:** selfmgmt@uvic.ca

- **BC Lung Association** offers **Better Breathers** support groups where you can talk with other people living with COPD. The support groups are offered both:
  - Face-to-face: https://bc.lung.ca/how-we-can-help/patient-support-groups/better-breathers-support-groups or Online: https://www.lung.ca/lung-health/get-help/better-breathers-facing-copd-online-support-group

  Interested in learning more, or want to sign up for their newsletter? Contact Maureen:
  Phone number: 1-800-665-LUNG (5864) **Email:** betterbreathers@bc.lung.ca

- **Local Health Unit:** Check out what may be available through your local health unit. For example, Island Health offers a home health monitoring program to help people living with COPD manage their condition from the comfort of their home.
  Website: https://www.islandhealth.ca/hhm
  Phone: South Island: 1-888-533-2273 Centre Island: 1-877-734-4101
  Oceanside: 250-951-9550 North Island: 1-866-928-4988

4. Looking for services and program within your community?

- The **Seniors' Information Guide** by the BC Ministry of Health includes information on provincial and federal programs, with sections on benefits, health, lifestyle, housing, transportation, finances, safety and security, and other services https://www2.gov.bc.ca/assets/gov/people/seniors/about-seniorsbc/guide/bc-seniors-guide-11th-edition.pdf
- The **Seniors' Services Directory** contains over 500 listings of community resources.
  Website: http://seniorsservingseniors.bc.ca/service-directory/
  Phone number: 250-413-3211 **Email:** info@seniorsservingseniors.bc.ca

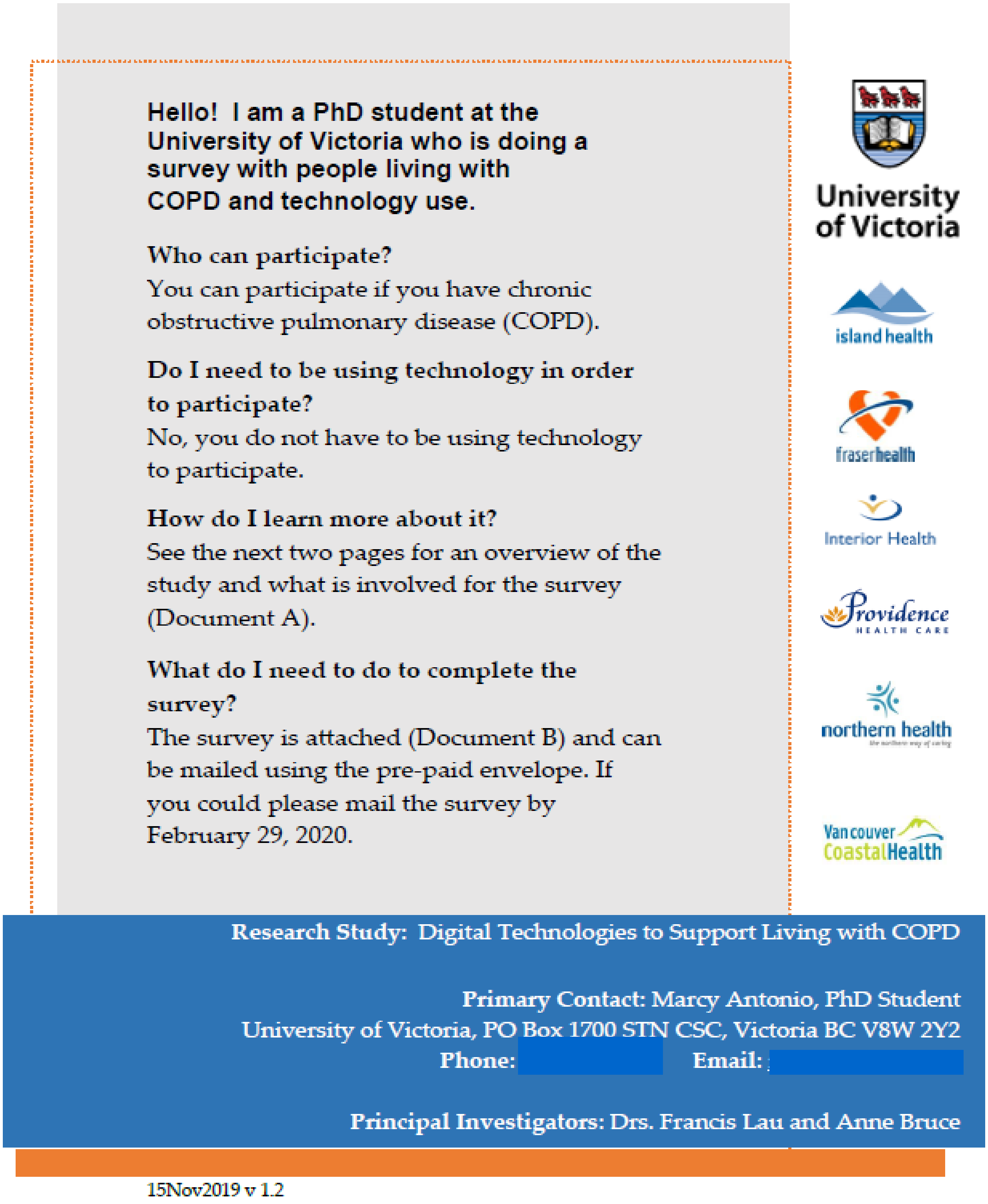
5. Interested in being involved in research and healthcare projects?

- **BC SUPPORT Centre** connects patients to ongoing research projects. The central idea behind this initiative is that patients move beyond the role of research "participant" or "subject". Instead, the focus is on bringing patients to the heart of health research by integrating them into the research team. Interested in learning more, or want to sign up for their newsletter?
  Website: https://bcsupportunit.ca/vancouver-island-centre
  Phone number: 250-370-8496
- **Patient Voices Network** brings together patients, families and health care partners in co-designing improvements to healthcare.

  Want to receive invitations to participate, updates on the Network's activities and notices on polls, surveys and learning updates?
  Website: https://patientvoicesbc.ca/patient-partners/sign-up-form/
  Phone number: 1-877-282-1919 **Email:** pvn.bcpsqc.ca
- **Canadian Institutes of Health Research**
  Health Research in Canada provides an overview of the types of research:
  http://www.cihr-irsc.gc.ca/e/documents/Health_Research_in_Canada_and_You_e.pdf
  Jargon Buster site provides definitions on common health research terms:
  http://www.cihr-irsc.gc.ca/e/48952.html

University of Victoria Providence HEALTH CARE UBC island health fraserhealth

Appendix L: Survey Introductory Letter



Hello! I am a PhD student at the University of Victoria who is doing a survey with people living with COPD and technology use.

Who can participate?
You can participate if you have chronic obstructive pulmonary disease (COPD).

Do I need to be using technology in order to participate?
No, you do not have to be using technology to participate.

How do I learn more about it?
See the next two pages for an overview of the study and what is involved for the survey (Document A).

What do I need to do to complete the survey?
The survey is attached (Document B) and can be mailed using the pre-paid envelope. If you could please mail the survey by February 29, 2020.

University of Victoria
island health
fraserhealth
Interior Health
Providence HEALTH CARE
northern health
Vancouver CoastalHealth

Research Study: Digital Technologies to Support Living with COPD

Primary Contact: Marcy Antonio, PhD Student
University of Victoria, PO Box 1700 STN CSC, Victoria BC V8W 2Y2
Phone: [redacted] **Email:** [redacted]

Principal Investigators: Drs. Francis Lau and Anne Bruce

15Nov2019 v 1.2

Appendix M: Survey Package

A) Overview of the Research Study

Digital Technologies to Support Living with COPD

What is the reason for doing this study?

The purpose of this study is to learn about peoples' experiences of using digital technologies (e.g., the internet or mobile phones) to support chronic obstructive pulmonary disease (COPD). We also want to find out what technologies people may be using to stay connected with friends and family. You do not have to have any experience in using these technologies.

What is required if I participate?

If you decide to take part in this stage of the study, you will be asked to complete a survey consisting of three parts. Any question on the survey that you do not want to answer can be left blank.

If you decide to participate, you will be asked to answer questions on:

- Your social activities and COPD (part 1)
- Whether or not you use online technologies for various activities (part 2)
- Demographic information including your age, gender, education, ethnicity and living situation (part 3)

After completing the survey, you will be asked if you would like to provide contact information and if it is okay to contact you at a later date to see if you would like to take part in an interview. If you are contacted, we will provide details as to what is involved. You can decide if you would like to participate in this next stage. If this occurs, you will be provided with a form describing the new research activities and requesting your consent to participate.

What are the possible risks or inconveniences of participating?

Taking part in this study will take some of your time to complete the survey. It is estimated that the survey will take 20-25 minutes to complete.

We do not think there is anything in this survey that could be bad for you. Some of the questions we ask might upset you. Please let one of the researchers/investigators know if you have any concerns.

What are the possible benefits of participating?

We will share what we learn from this study with patients and families, healthcare providers and researchers. You may not get any benefit from being in this study. However, in the future, others may benefit from what we learn in this study.

Do I have to take part in the study?

You are free to choose to participate or not. By completing the survey, you are consenting to participate in this research. If you do decide to participate and then change your mind later, you can withdraw from the study by contacting the researcher. There will not be any consequences or explanation needed to withdraw. If you do withdraw from the study, we will ask you if we can still use your collected data.

How will confidentiality be maintained and my personal information be used?

We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researcher.

Information that can identify you will be taken out of all written records. Written records will be kept in a locked metal cabinet in the researcher's office. Number codes will be used instead of your name. Only fictitious names will be used for reports, articles or presentations. Any person hired to work on the study will sign a legal agreement to keep everything private.

How will data be stored and disposed?

After the study is done, we will continue to store your information from this study in a secure, online data storage site that is housed within Canada. Data will be stored for at least 5 years after the end of the study. At the end of data storage, audio recordings will be erased and printed documents will be shredded.

Will I be paid for taking part in the study?

As a way to thank you for your time and participation, you will be given a $10 grocery store gift card. This is not meant to influence your decision to participate.

What is the timeline for the study?

The online survey will be available for two weeks after your initial login. We ask that you mail the surveys by February 29, 2020.

Who can I contact if I have any questions about the research, now or later?

Primary Contact, Co-investigator: Marcy Antonio, PhD Student, University of Victoria

email: xxxx@uvic.ca **phone:** xxx-xxx-xxxx

Principal Investigators: Dr. Francis Lau, Professor, University of Victoria
email: xxxxx@uvic.ca **phone:** 250-xxx-xxxx
Dr. Anne Bruce (Providence Health Care), Professor, University of Victoria
email: xxxxx@uvic.ca **phone:** 250-xxx-xxxx

Address: 3800 Finnerty Road, Victoria, BC V8P 5C2

In addition, you may verify the ethical approval of this study, or if you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact one of the following:

- Human Research Ethics Office at the University of Victoria by phone: 250-xxx-xxxx or email: xxxx@uvic.ca.
- Research Participant Complaint Line at the University of British Columbia Office of Research Ethics by e-mail at xxxx@ors.ubc.ca or by phone at 604-xxx-xxxx (Toll Free: 1-877-xxx-xxxx).
- Fraser Health Research Ethics Board co-Chair by phone at 604-xxx-xxxx

Please reference the study number H18-01530 when calling so the staff can better assist you.

B. SURVEY

Part 1: YOUR COPD EXPERIENCES

1. Do you have chronic obstructive pulmonary disease (COPD), emphysema, or chronic bronchitis? ☐ **Yes** ☐ **No** ⟶ **If no, what makes you a good fit for this study?**

____

2. Has your lung condition been formally diagnosed? ☐ **Yes** ☐ **No**

3. What other chronic conditions have you been diagnosed with? ______________________________

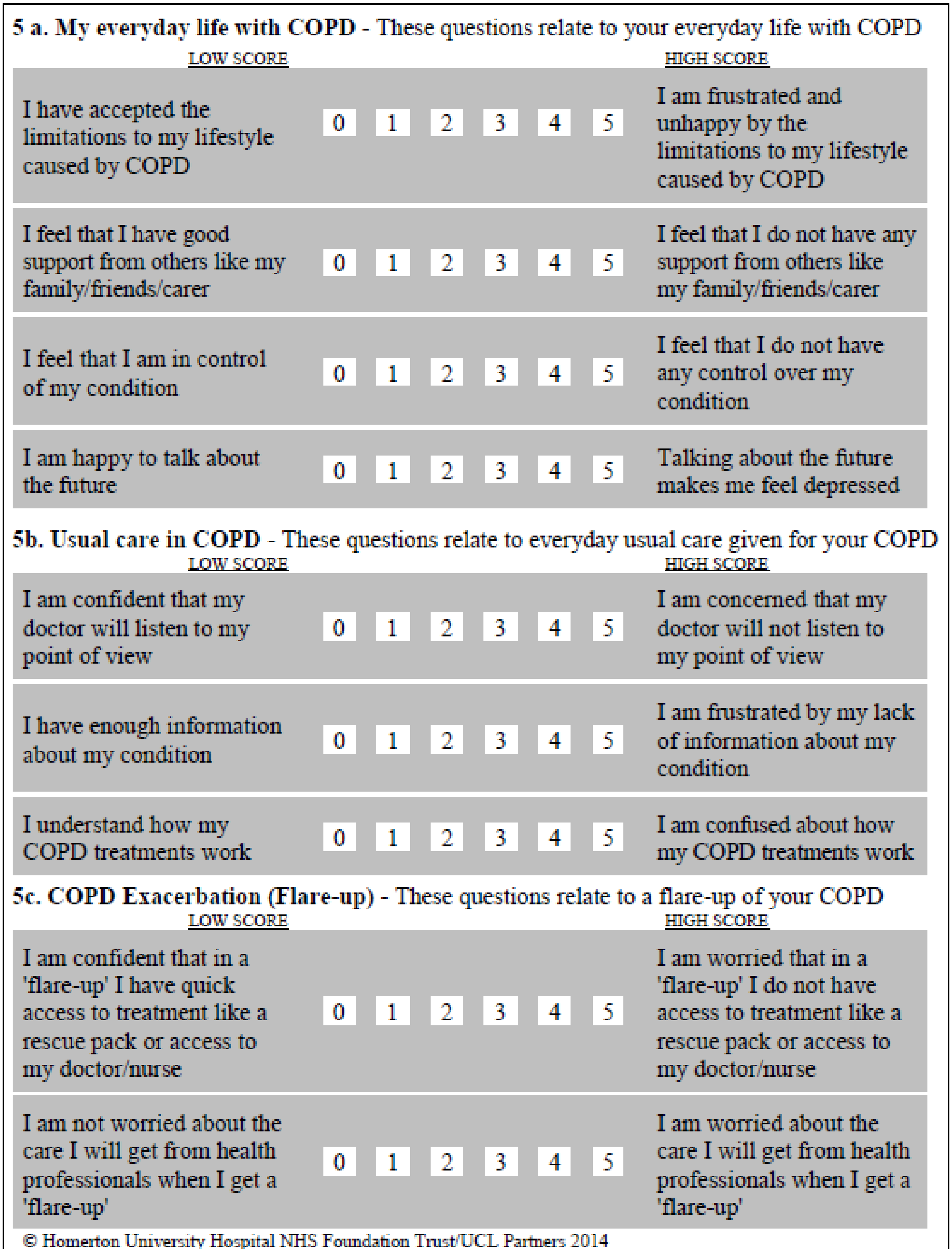
____

For each item below, place a mark (X) in the box that best describes your current situation. Please ensure that you only select one response for each question.

Example: I am very happy	0	1	X	3	4	5	I am very sad

4. How is your COPD?

I never cough	0	1	2	3	4	5	I cough all the time
I have no phlegm (mucus) on my chest at all	0	1	2	3	4	5	My chest is full of phlegm (mucus)
My chest does not feel tight at all	0	1	2	3	4	5	My chest feels very tight
When I walk up a hill or a flight of stairs I am not out of breath	0	1	2	3	4	5	When I walk up a hill or a flight of stairs I am completely out of breath
I am not limited to doing any activities at home	0	1	2	3	4	5	I am completely limited to doing all activities at home
I am confident leaving my home despite my lung condition	0	1	2	3	4	5	I am not confident leaving my home at all because of my lung condition
I sleep soundly	0	1	2	3	4	5	I do not sleep soundly because of my lung condition
I have lots of energy	0	1	2	3	4	5	I have no energy at all



5 a. My everyday life with COPD - These questions relate to your everyday life with COPD

LOW SCORE							HIGH SCORE
I have accepted the limitations to my lifestyle caused by COPD	0	1	2	3	4	5	I am frustrated and unhappy by the limitations to my lifestyle caused by COPD
I feel that I have good support from others like my family/friends/carer	0	1	2	3	4	5	I feel that I do not have any support from others like my family/friends/carer
I feel that I am in control of my condition	0	1	2	3	4	5	I feel that I do not have any control over my condition
I am happy to talk about the future	0	1	2	3	4	5	Talking about the future makes me feel depressed

5b. Usual care in COPD - These questions relate to everyday usual care given for your COPD

LOW SCORE							HIGH SCORE
I am confident that my doctor will listen to my point of view	0	1	2	3	4	5	I am concerned that my doctor will not listen to my point of view
I have enough information about my condition	0	1	2	3	4	5	I am frustrated by my lack of information about my condition
I understand how my COPD treatments work	0	1	2	3	4	5	I am confused about how my COPD treatments work

5c. COPD Exacerbation (Flare-up) - These questions relate to a flare-up of your COPD

LOW SCORE							HIGH SCORE
I am confident that in a 'flare-up' I have quick access to treatment like a rescue pack or access to my doctor/nurse	0	1	2	3	4	5	I am worried that in a 'flare-up' I do not have access to treatment like a rescue pack or access to my doctor/nurse
I am not worried about the care I will get from health professionals when I get a 'flare-up'	0	1	2	3	4	5	I am worried about the care I will get from health professionals when I get a 'flare-up'

Please respond to each item by marking one box per row.

6. These questions relate to your social activities.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am satisfied with my ability to do things for my family	☐	☐	☐	☐	☐
I am satisfied with my ability to do things for fun with others	☐	☐	☐	☐	☐
I feel good about my ability to do things for my friends	☐	☐	☐	☐	☐
I am satisfied with my ability to perform my daily routines	☐	☐	☐	☐	☐

Acknowledgment: PROMIS Health Organization and Assessment Center℠. View full acknowledgment at https://redcap.vanderbilt.edu/consortium/cite_promis.php

Part 2: TECHNOLOGY USE

7. For each item below, place a mark (X) in the box that best describes your experience with technology. Please ensure that you only select one response for each question.

I feel that technology does not isolate me	0	1	2	3	4	5	I feel that technology isolates me
I feel that my friends and family encourage me to use technology	0	1	2	3	4	5	I feel that my friends and family discourage me to use technology
I feel that my doctor encourages me to use technology to support my COPD	0	1	2	3	4	5	I feel that my doctor discourages me to use technology to support my COPD
I like to stay up-to-date with the latest technology	0	1	2	3	4	5	I feel like I am out-of-date with technology
Privacy and security concerns do not stop me from using technology	0	1	2	3	4	5	I do not use technology because of privacy and security concerns
The financial cost of technology does not stop me from using them	0	1	2	3	4	5	The financial cost of technology prevents me from using them

Please respond to each item by marking one box per row.

8a. I have used the following technologies:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Desktop computer	☐	☐	☐	☐	☐
Laptop	☐	☐	☐	☐	☐
Tablet or iPad	☐	☐	☐	☐	☐
Cell, Mobile or Smart phone	☐	☐	☐	☐	☐
Smartwatch	☐	☐	☐	☐	☐
SmartTV (e.g. TV with internet access)	☐	☐	☐	☐	☐
Smart Home, or Voice-controlled Speaker (e.g. Google Home, Amazon Echo, Alexa)	☐	☐	☐	☐	☐
Augmented / Virtual Headset (e.g. Google glasses, Samsung Gear VR)	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐

8b. If I checked 'not at all' or 'a little bit' for all the boxes in question 8a. ⟶ reasons I do not use these technologies are: ____

____

____

____

____

____

____

Please respond to each item by marking one box per row.

9a. I have used technologies to connect with:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Other people living with COPD	☐	☐	☐	☐	☐
My family	☐	☐	☐	☐	☐
My face-to-face friends	☐	☐	☐	☐	☐
My online friends	☐	☐	☐	☐	☐
My local community	☐	☐	☐	☐	☐
My religious/spiritual association	☐	☐	☐	☐	☐
People who I have lost contact with	☐	☐	☐	☐	☐
My health professionals (e.g. doctor, nurse, respiratory therapist).	☐	☐	☐	☐	☐
Other people who support my care	☐	☐	☐	☐	☐
Emergency services	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐
Other: ____________________	☐	☐	☐	☐	☐

9b. Other ways I stay connected with people that <u>does not involve technologies</u> are:

____

____

____

____

____

____

Please respond to each item by marking one box per row.

10a. In relation to my COPD, I have used technologies for the following activities:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Find out statistics	☐	☐	☐	☐	☐
Learn about symptoms	☐	☐	☐	☐	☐
Learn about medications and treatments	☐	☐	☐	☐	☐
Practice breathing exercises	☐	☐	☐	☐	☐
Search for programs and services	☐	☐	☐	☐	☐
Participate in programs to manage my illness	☐	☐	☐	☐	☐
Participate in support groups	☐	☐	☐	☐	☐
Discuss my illness experiences with others	☐	☐	☐	☐	☐
Record information discussed with my health professional (e.g. doctor, nurse, respiratory therapist)	☐	☐	☐	☐	☐
View my health records, such as lab results	☐	☐	☐	☐	☐
Track my medications	☐	☐	☐	☐	☐
Track my oxygen levels	☐	☐	☐	☐	☐
Track other health measures (e.g. heart rate, blood pressure)	☐	☐	☐	☐	☐
Track my daily activity (e.g. daily steps)	☐	☐	☐	☐	☐
Other: ______________________	☐	☐	☐	☐	☐
Other: ______________________	☐	☐	☐	☐	☐

10b. Ways I have done these activities without technologies are: ______________________

____

____

____

Please respond to each item by marking one box per row.

11. I have used technologies for:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Sending and receiving emails	☐	☐	☐	☐	☐
Sending and receiving text messages	☐	☐	☐	☐	☐
Participating in group text chats	☐	☐	☐	☐	☐
Participating in video conferences or video chats (e.g. Skype, Zoom, Facetime)	☐	☐	☐	☐	☐
Participating in online support groups that were not related to my COPD	☐	☐	☐	☐	☐
Downloading apps	☐	☐	☐	☐	☐
Searching on the internet / Googling for information	☐	☐	☐	☐	☐
Reading posts on social media sites (e.g. Facebook or Instagram)	☐	☐	☐	☐	☐
Commenting on social media sites, blogs or online forums	☐	☐	☐	☐	☐
Writing about my life experiences	☐	☐	☐	☐	☐
Exploring my ancestry	☐	☐	☐	☐	☐
Watching online videos (e.g. You-tube)	☐	☐	☐	☐	☐
Listening to audio recordings or podcasts	☐	☐	☐	☐	☐
Booking appointments online	☐	☐	☐	☐	☐
Playing video games online	☐	☐	☐	☐	☐
Completing surveys online	☐	☐	☐	☐	☐
Online banking	☐	☐	☐	☐	☐
Online dating	☐	☐	☐	☐	☐
Online volunteering	☐	☐	☐	☐	☐
Other: ______________________	☐	☐	☐	☐	☐
Other: ______________________	☐	☐	☐	☐	☐

Part 3: DEMOGRAPHICS

12. My age is: ____________________

13. My ethnic-racial background is: ____

14. I am currently living with (please select all that apply):

☐ No one ☐ Child ☐ Grandchild ☐ Great grandchild ☐ Friend

☐ Spouse or partner ☐ Parent ☐ Prefer not to answer ☐ Other: ____________________

15. My current employment status is:

☐ Retired ☐ Home-maker ☐ Long-term disability ☐ Income assistance ☐ Self-employed

☐ Work full-time ☐ Work part-time ☐ Prefer not to answer ☐ Other: ____________________

16. I have difficulty making ends meet at the end of the month:

☐ Never ☐ Rarely ☐ Sometimes ☐ Very often ☐ Always ☐ Prefer not to answer

17. I am currently involved in a religious or spiritual practice:

☐ Never ☐ Rarely ☐ Sometimes ☐ Very often ☐ Always ☐ Prefer not to answer

18. The maximum level of education I have completed is:

☐ Some elementary or high school ☐ High school graduate ☐ Some college or trade school ☐ College or trade graduate ☐ Bachelor's degree

☐ Graduate degree ☐ Professional degree ☐ Prefer not to answer ☐ Other: ____________________

19. My marital status is:

☐ Single ☐ Married, or common-law ☐ Separated ☐ Divorced ☐ Previous common-law relationship

☐ Widowed ☐ Prefer not to answer ☐ Other: ______________________________

20. My sex on my birth certificate is:

☐ Female ☐ Male ☐ Prefer not to answer

21. I identify as a:

☐ Woman ☐ Trans woman ☐ Gender queer/gender non-conforming ☐ Prefer not to answer

☐ Man ☐ Trans man ☐ Different identity (please specify):

Thank-you for taking the time to complete the survey.

Please mail the survey in the enclosed pre-paid envelope to:
University of Victoria
Learning and Teaching Support and Innovation - Harry Hickman Bldg. Room 120
Marcy Antonio, PhD Student
PO Box 1700 STN CSC
Victoria, BC V8W 2Y2

As a small thank-you, we would like to mail you a $10 gift card for your local grocery store. If you would like to receive this gift card, please fill out your address below.

We will not use this information to contact you at a later date, unless you would like to receive study updates or be contacted for a follow-up interview. Note that your survey responses will be saved in a file separate from your contact information.

Where would you like your gift card from?

☐ Real Canadian Supestore ☐ Save-on-Foods ☐ Thrifty's ☐ Wal-mart ☐ Do not want a gift card

First Name:____________________ **Last Name:** ________________________

Phone Number (home): ____

Phone Number (cell): ____

Email: ____

Mailing Address: ____

Town or City: _________________________ **Postal Code:** _______________

Preferred method of communication: ___________________________________

Would you like to receive updates on the study?

☐ Yes ☐ No

Is it okay to contact you to ask if you would like to participate in a follow-up interview?

☐ Yes ☐ No

Appendix N: Stage 3 Interview Questions

Part 1: Introduction

Thanks for connecting with me again. The interview should take about thirty minutes. The questions I will ask cover similar topics that you were asked in the survey. You are welcome to not answer any questions that may not be comfortable for you.

Part 2: Example of questions will be built from survey responses

<u>Participant who reported that they have not used any technology:</u> *You had mentioned in the survey that you are not tech-savvy. Can you tell me a bit more about not being tech-savvy.*

<u>Participant who reported using technology rarely:</u> *Have you used technology in the past? And if so, what have you used? And what has stopped you from using these technologies*

<u>Participant who reported that they regularly connect with online friends:</u> *You had mentioned that you connect regularly with your online friends? Can you tell me more about these interactions, such as the activities you might do with your online friends, and the support you provide to each other.*

<u>Participant who reported using for multiple activities, but not for supported their COPD:</u> *Can you share some of the reasons why you do not use technology in relation to your COPD?*

<u>Participant who reported using multiple technologies for multiple uses:</u> *Can you walk me through how you use the different technologies.*

Part 3: Examples of questions not linked to survey answers

<u>Participants who use technology:</u>
Can you share some of your experiences in how technology has impacted your life, either positively or negatively? Do you have some examples you can share as to how you used technology related to COPD?

<u>For all participants:</u>
Since you completed the survey, has anything changed in how your use of technology? Have there been changes in how you use technologies to stay connected other people? Have there been changes in how you use technologies to support your COPD? connect with your healthcare provider? Can you tell me a bit more about these interactions?

Part 4: Closing

What would you like others to know about supports for COPD? For example, this could be advice for a politician, doctor or nurse, friends and family, or other people living with COPD. Is there any advice would you give to other people with COPD in using these technologies?
Before we end, is there anything you would like to add?

Appendix O: Informed Consent for Stage Three

PARTICIPANT CONSENT FORM

Title of Study: Digital Technologies to Support Living with COPD

Principal Investigators: Dr. Francis Lau, Professor, University of Victoria

email: xxxxx@uvic.ca **phone:** 250-xxx-xxxx

Dr. Anne Bruce (Providence Health Care),

Professor, University of Victoria

email: xxxxx@uvic.ca **phone:** 250-xxx-xxxx

Co-investigator: Marcy Antonio, PhD Student, University of Victoria

email: xxxxx@uvic.ca **phone:** xxx-xxx-xxxx

Address: 3800 Finnerty Road, Harry Hickman, LTSI - Room 120
Victoria, BC V8P 5C2

Introduction

You are invited to participate in a study titled *Digital technologies to support living with COPD*. It is being conducted by Dr. Francis Lau and Marcy Antonio.

Dr. Lau is a faculty member in the School of Health Information Science at the University of Victoria. You may contact him if you have further questions.

As a graduate student, Ms. Antonio is required to conduct research as part of the requirements for a degree in Doctorate in Interdisciplinary Studies. Her study is being conducted under the supervision of Dr. Lau and Dr. Sheilds.

Purpose of the Study

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

You are invited to join this study because you have unique experiences to share in living with chronic obstructive pulmonary disease (COPD).

Before you decide, we will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing this study?

The purpose of this study is to learn about peoples' experiences of using digital technologies (e.g., social media, Skype™). We want to understand how these technologies can support living with COPD. We also want to find out what technologies people living with COPD may be using for social connections.

Location of Research

This study is being conducted across British Columbia.

Number of Participants

There will be about 100 people living with COPD participating across three different stages of this study. You are being asked to participate in the final stage, which will consist of 15-20 people.

What is required if I Participate?

If you decide to take part in this study, you will be asked to take part in one interview

- It will be approximately 45-60 minutes in length.
- We will record the interview. After the interview, the recording will be transcribed into written form.
- The interview can also be done using your preferred communication technology (e.g., phone, Skype, Face Time, Zoom).
- You do not have to answer any questions that make you feel uncomfortable.
- The survey on digital technologies will be used as a guide. We will ask you questions that are based on your responses in this earlier survey.

The questions will focus on:

- Your experiences of using digital technologies to support your illness.
- Your social relationships, and how digital technologies may be supporting these relationships.
- How your use of digital technologies has changed over the past few months.

What are the Possible Risks or Inconveniences of Participating?

Taking part in this study will take some of your time for the interview. We do not think there is anything in this study that could harm you or be bad for you. Some of the questions we ask might upset you. Please let one of the study staff know if you have any concerns.

Some of the questions we ask may seem sensitive or personal. You do not have to answer any question if you do not want to. If you need immediate, free, and confidential emotional support, you can contact the Fraser Health Crisis Line at 604-xxx-xxxx 24 hours a day – everyday.

What are the Possible Benefits of Participating?

You might find that talking with someone who is interested and educated in this area to be helpful. But you may not get any benefit from being in this study. However, in the future, others may benefit from what we learn in this study.

Do I have to take part in the study?

You are free to choose to participate or not. If you decide not to participate, your regular care or service will not be affected in any way. By consenting, you have not waived any rights to legal recourse connected to research-related harm. If you do decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you do withdraw from the study, we will ask you if we can still use your collected data.

Will I be Paid for Taking Part in the Study?

We will not pay you for the time you take to be in this study. As a way to thank you for your time and participation, you will be given a $10 grocery store gift card. This is not meant to influence your decision to participate.

On-Going Consent

If new information becomes available, or if this project takes place over a longer period of time, I will ask you to renew your consent to participate.

Sometimes a research project will recruit a subgroup of participants to perform other research activities. If this occurs, you will be provided with another consent form describing the new research activities and requesting your consent.

Confidentiality and How my Personal Information will be Used

If the interview is being conducted using a communication technology, there are some communication technologies that are based outside of Canada. US-based communication technologies are governed by US laws. Under the US Freedom Act, the US government may access information without your knowledge or consent.

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researcher.

Information that can identify you will be taken out of all written records. Recordings and written records will be kept in a locked metal cabinet in the researcher's office. Number codes will be used instead of your name. Only fictitious names will be used for reports, articles or presentations. Any person hired to work on the study will sign a legal agreement to keep everything private.

Future Use of Data

Your consent to collect your information for the purpose of this research project will expire when you complete the study. Data gathered from this study will not be used for other studies. However, if this changes I will provide a new consent form and ask you if you give permission for the data to be used in another study.

Disposal of Data

After the study is done, I will continue to safely store your information from this study in a secure, online data storage site that is housed within Canada. Data will be stored for at least 5 years after the end of the study. At the end of data storage, audio recordings will be erased and printed documents will be shredded.

Sharing of Study Results

The results will be shared with other people living with COPD, families, the community, health practitioners, policy-makers and researchers. The results of this study will be reported in a graduate thesis and may also be published in journal articles and books. The results may also be presented online through web sites, blogs or webinars.

Who Should I Contact if I Need More Information or Help?

In addition, you may verify the ethical approval of this study, or if you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact one of the following:

> Human Research Ethics Office at the University of Victoria by phone: 250-xxx-xxxx or email: xxxx@uvic.ca.
>
> Research Participant Complaint Line at the University of British Columbia Office of Research Ethics by e-mail at xxxx@ors.ubc.ca or by phone at 604-xxx-xxxx (Toll Free: 1-877-xxx-xxxx).
>
> Fraser Health Research Ethics Board Co-Chair by phone at 604-xxx-xxxx

Please reference the study number H18-01530 when calling so the staff can better assist you.

Consent

Your signature below indicates that:

1. You understand the above conditions of participation in this study,
2. You have had the opportunity to have your questions answered by the researchers
3. You consent to participate in this research project.

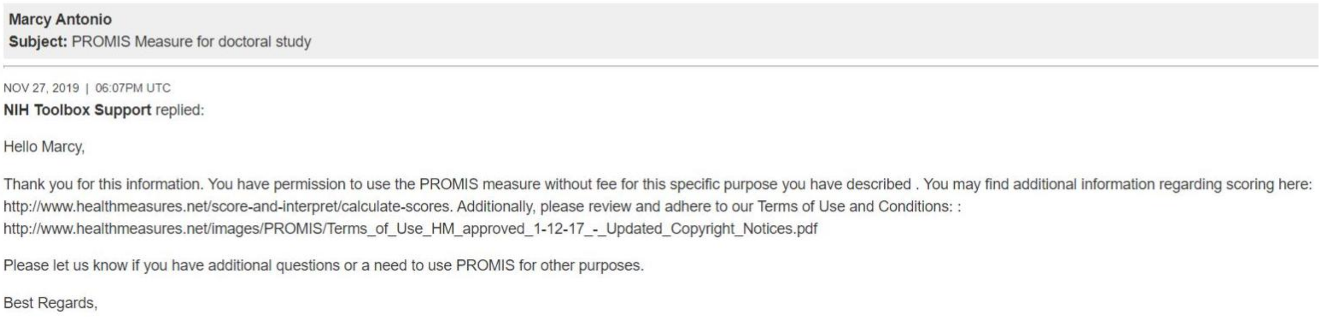
____________________	____________________	____________
Name (print)	Signature	Date

I consent to be contacted in the event my data is requested for future research:

____________ (Please provide initials)

A copy of this consent form will be given to you, and a copy will be kept by the researcher.

Appendix P: Permission Letters for Measures



Marcy Antonio
Subject: PROMIS Measure for doctoral study

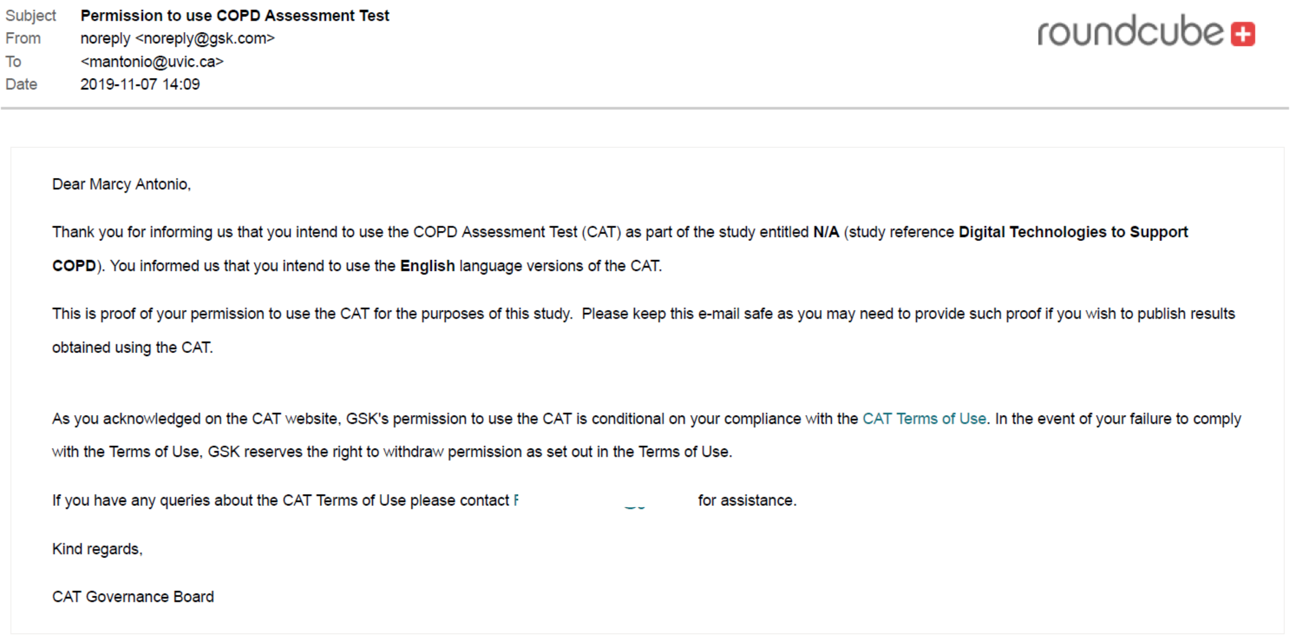
NOV 27, 2019 | 06:07PM UTC
NIH Toolbox Support replied:

Hello Marcy,

Thank you for this information. You have permission to use the PROMIS measure without fee for this specific purpose you have described . You may find additional information regarding scoring here: http://www.healthmeasures.net/score-and-interpret/calculate-scores. Additionally, please review and adhere to our Terms of Use and Conditions: : http://www.healthmeasures.net/images/PROMIS/Terms_of_Use_HM_approved_1-12-17_-_Updated_Copyright_Notices.pdf

Please let us know if you have additional questions or a need to use PROMIS for other purposes.

Best Regards,



Subject	**Permission to use COPD Assessment Test**
From	noreply <noreply@gsk.com>
To	<mantonio@uvic.ca>
Date	2019-11-07 14:09

Dear Marcy Antonio,

Thank you for informing us that you intend to use the COPD Assessment Test (CAT) as part of the study entitled **N/A** (study reference **Digital Technologies to Support COPD**). You informed us that you intend to use the **English** language versions of the CAT.

This is proof of your permission to use the CAT for the purposes of this study. Please keep this e-mail safe as you may need to provide such proof if you wish to publish results obtained using the CAT.

As you acknowledged on the CAT website, GSK's permission to use the CAT is conditional on your compliance with the CAT Terms of Use. In the event of your failure to comply with the Terms of Use, GSK reserves the right to withdraw permission as set out in the Terms of Use.

If you have any queries about the CAT Terms of Use please contact [redacted] for assistance.

Kind regards,

CAT Governance Board

PREM-C9 - Author proposed that the PREM-C9 would be free to use, and that it should be used in regular clinical practice (Hodson et al., 2013; Hodson et al., 2019). On December 3, 2019 and November 7, 2019 emailed Dr. Hodson to inform that PREM-C9 would be used as part of the research study, and referenced copyright in survey. As per instruction, made one slight change to questionnaire, used 'doctor' or 'nurse' in place of 'GP' as this was more common language that was used during phase one interviews.

Appendix Q: Institutional Approvals

island health

Research and Capacity Building
Memorial Pavilion – Main Floor | Royal Jubilee Hospital | 1952 Bay Street | Victoria, BC V8R 1J8

INSTITUTIONAL APPROVAL TO CONDUCT A RESEARCH PROJECT

Researcher: **Dr. Anne Bruce**

Study Title: **Digital Technologies to Support Living with COPD**

Island Health File Number: **H18-01530**

Institutional Approval Date: 12 September 2018
Certificate of Ethical Approval Date: 12 September 2018

This is to inform you that your amended research project may now be initiated as of the approval date above and is approved based on the following:

1. The Certificate of Approval dated above issued by the Health Research Ethics Board on behalf of Island Health.
2. All Island Health Operational Review approvals are received by Research and Capacity Building, including the following departments:
   Home Oxygen Program – [redacted],
   Sooke, West Shore, Esquimalt - [redacted]
   Home Health Monitoring Program – [redacted]
3. Satisfaction of all contract requirements and the final contract has been received by Research and Capacity Building.

The Institutional Approval to Conduct a Research Project will remain in effect as long as the Health Research Ethics Board approval is renewed annually and all amendments submitted are approved as required throughout the duration of this project. The Institutional Approval to Conduct a Research Project will expire upon the HREB receipt and acknowledgement of the study closure report.

This Institutional Approval to Conduct Research does not represent approval to use a new intervention or product within Island Health. Please discuss with the appropriate Director/Executive Director regarding making any changes to practice.

PROVIDENCE HEALTH CARE
Research Institute

UBC-Providence Health Care Research Institute
Office of Research Services
10th Floor Hornby Site - SPH
c/o 1081 Burrard St. Vancouver, BC V6Z 1Y6
Tel: (604) 806-8567 Fax: (604) 806-8568

Providence Health Care
Institutional Certificate of Final Approval

Principal Investigator: Anne Bruce	**Department:** Family Practice	**REB Number (UVic):** H18-01530

Sponsoring Agencies:

No funding

Project Title:

Digital Technologies to Support Living with COPD

Ethics Certificate Released: September 12, 2018

PHC Institutional Approval Date: September 24, 2018

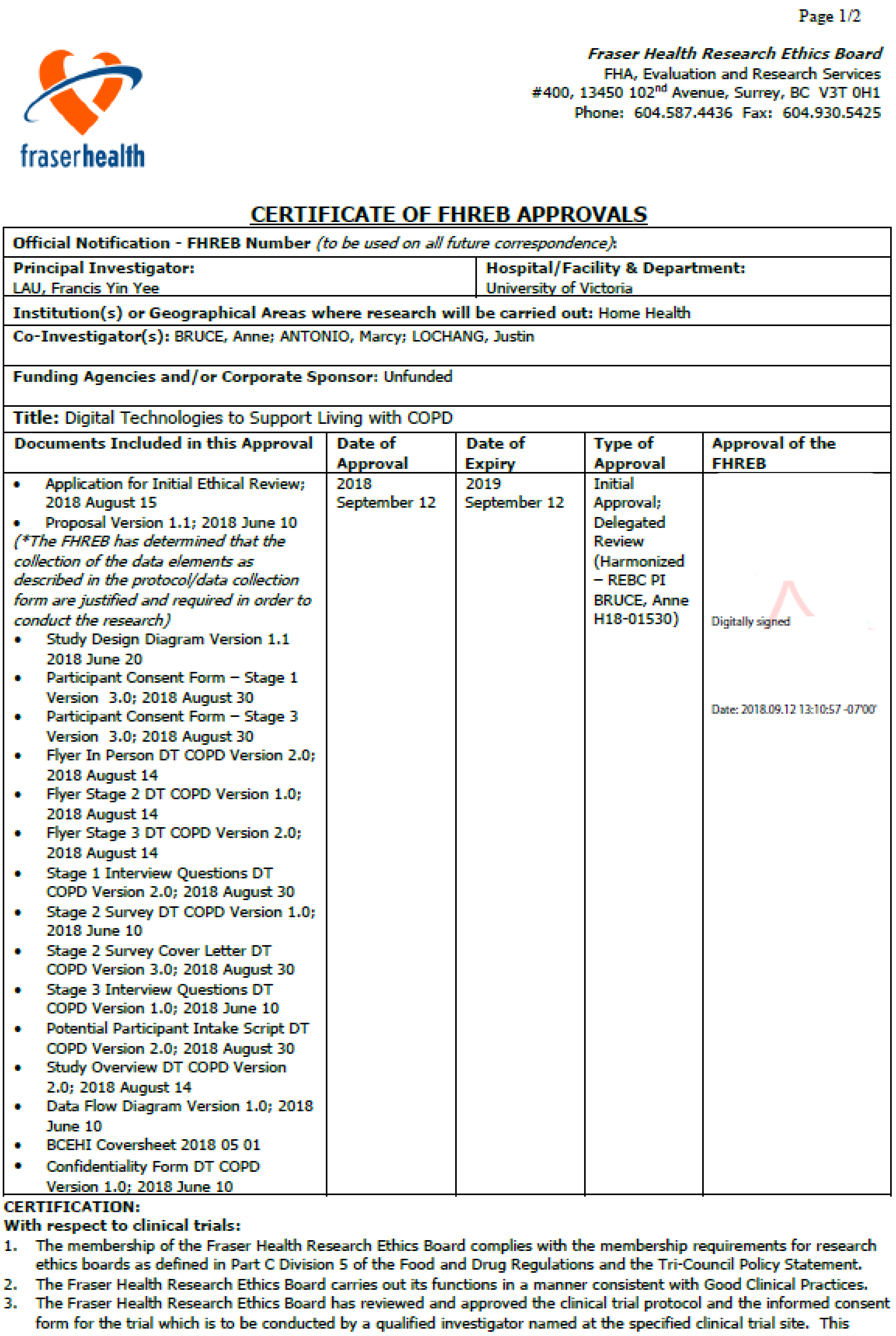
The UBC-PHC Research Ethics Board granted ethical approval for the above-referenced research project on the date stated above. All necessary hospital department/facilities approvals and institutional agreements/contracts are now in place and that you have permission to begin your research. *

VP Research & Academic Affairs, Providence Health Care
President, PHC Research Institute

* PHC Health Information Management requires a copy of this certificate prior to granting access to records.

St. Paul's Hospital
Holy Family Hospital
Mount St. Joseph's Hospital
St. Vincent's Hospital-Brock Fahrni Pavilion
St. Vincent's Hospital-Langara
Youville Residence

2016



Fraser Health Research Ethics Board
FHA, Evaluation and Research Services
#400, 13450 102nd Avenue, Surrey, BC V3T 0H1
Phone: 604.587.4436 Fax: 604.930.5425

CERTIFICATE OF FHREB APPROVALS

Official Notification - FHREB Number *(to be used on all future correspondence)*:

Principal Investigator: LAU, Francis Yin Yee

Hospital/Facility & Department: University of Victoria

Institution(s) or Geographical Areas where research will be carried out: Home Health

Co-Investigator(s): BRUCE, Anne; ANTONIO, Marcy; LOCHANG, Justin

Funding Agencies and/or Corporate Sponsor: Unfunded

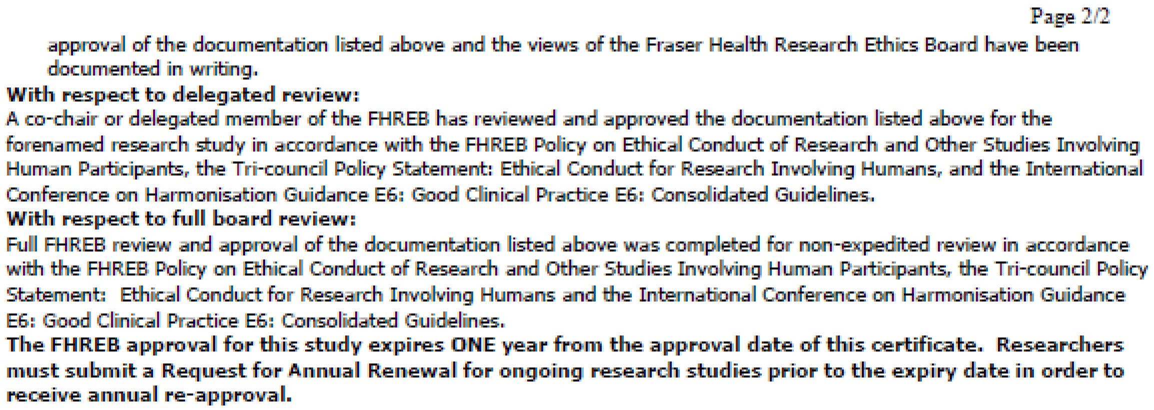
Title: Digital Technologies to Support Living with COPD

Documents Included in this Approval	**Date of Approval**	**Date of Expiry**	**Type of Approval**	**Approval of the FHREB**
• Application for Initial Ethical Review; 2018 August 15 • Proposal Version 1.1; 2018 June 10 *(*The FHREB has determined that the collection of the data elements as described in the protocol/data collection form are justified and required in order to conduct the research)* • Study Design Diagram Version 1.1 2018 June 20 • Participant Consent Form – Stage 1 Version 3.0; 2018 August 30 • Participant Consent Form – Stage 3 Version 3.0; 2018 August 30 • Flyer In Person DT COPD Version 2.0; 2018 August 14 • Flyer Stage 2 DT COPD Version 1.0; 2018 August 14 • Flyer Stage 3 DT COPD Version 2.0; 2018 August 14 • Stage 1 Interview Questions DT COPD Version 2.0; 2018 August 30 • Stage 2 Survey DT COPD Version 1.0; 2018 June 10 • Stage 2 Survey Cover Letter DT COPD Version 3.0; 2018 August 30 • Stage 3 Interview Questions DT COPD Version 1.0; 2018 June 10 • Potential Participant Intake Script DT COPD Version 2.0; 2018 August 30 • Study Overview DT COPD Version 2.0; 2018 August 14 • Data Flow Diagram Version 1.0; 2018 June 10 • BCEHI Coversheet 2018 05 01 • Confidentiality Form DT COPD Version 1.0; 2018 June 10	2018 September 12	2019 September 12	Initial Approval; Delegated Review (Harmonized – REBC PI BRUCE, Anne H18-01530)	Digitally signed Date: 2018.09.12 13:10:57 -07'00'

CERTIFICATION:

With respect to clinical trials:

1. The membership of the Fraser Health Research Ethics Board complies with the membership requirements for research ethics boards as defined in Part C Division 5 of the Food and Drug Regulations and the Tri-Council Policy Statement.
2. The Fraser Health Research Ethics Board carries out its functions in a manner consistent with Good Clinical Practices.
3. The Fraser Health Research Ethics Board has reviewed and approved the clinical trial protocol and the informed consent form for the trial which is to be conducted by a qualified investigator named at the specified clinical trial site. This



approval of the documentation listed above and the views of the Fraser Health Research Ethics Board have been documented in writing.

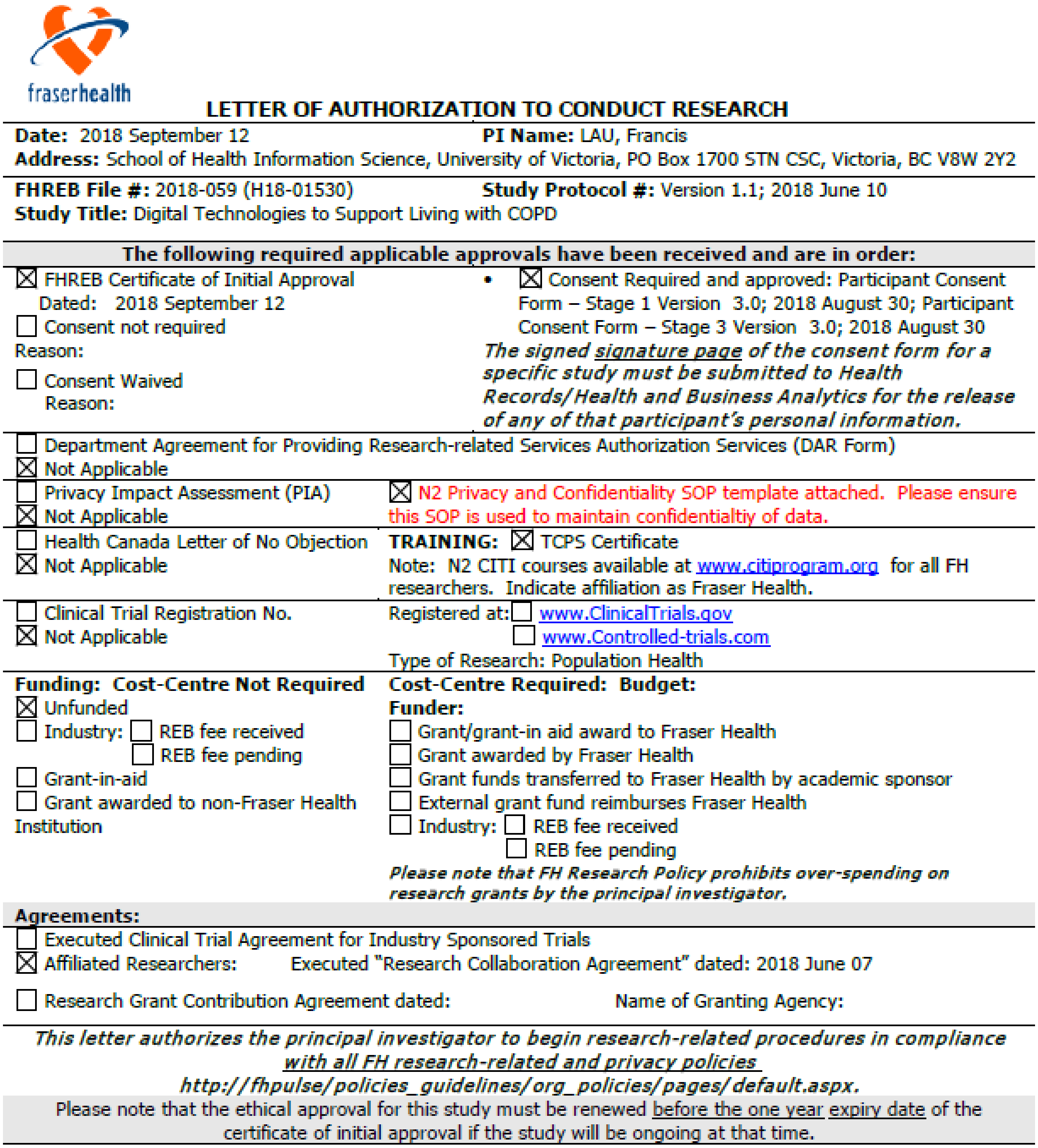
With respect to delegated review:

A co-chair or delegated member of the FHREB has reviewed and approved the documentation listed above for the forenamed research study in accordance with the FHREB Policy on Ethical Conduct of Research and Other Studies Involving Human Participants, the Tri-council Policy Statement: Ethical Conduct for Research Involving Humans, and the International Conference on Harmonisation Guidance E6: Good Clinical Practice E6: Consolidated Guidelines.

With respect to full board review:

Full FHREB review and approval of the documentation listed above was completed for non-expedited review in accordance with the FHREB Policy on Ethical Conduct of Research and Other Studies Involving Human Participants, the Tri-council Policy Statement: Ethical Conduct for Research Involving Humans and the International Conference on Harmonisation Guidance E6: Good Clinical Practice E6: Consolidated Guidelines.

The FHREB approval for this study expires ONE year from the approval date of this certificate. Researchers must submit a Request for Annual Renewal for ongoing research studies prior to the expiry date in order to receive annual re-approval.



fraserhealth

LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Date: 2018 September 12 **PI Name:** LAU, Francis

Address: School of Health Information Science, University of Victoria, PO Box 1700 STN CSC, Victoria, BC V8W 2Y2

FHREB File #: 2018-059 (H18-01530) **Study Protocol #:** Version 1.1; 2018 June 10

Study Title: Digital Technologies to Support Living with COPD

The following required applicable approvals have been received and are in order:

☒ FHREB Certificate of Initial Approval
Dated: 2018 September 12
☐ Consent not required
Reason:
☐ Consent Waived
Reason:

- ☒ Consent Required and approved: Participant Consent Form – Stage 1 Version 3.0; 2018 August 30; Participant Consent Form – Stage 3 Version 3.0; 2018 August 30

The signed signature page of the consent form for a specific study must be submitted to Health Records/Health and Business Analytics for the release of any of that participant's personal information.

☐ Department Agreement for Providing Research-related Services Authorization Services (DAR Form)
☒ Not Applicable

☐ Privacy Impact Assessment (PIA)
☒ Not Applicable

☒ N2 Privacy and Confidentiality SOP template attached. Please ensure this SOP is used to maintain confidentialtiy of data.

☐ Health Canada Letter of No Objection
☒ Not Applicable

TRAINING: ☒ TCPS Certificate
Note: N2 CITI courses available at www.citiprogram.org for all FH researchers. Indicate affiliation as Fraser Health.

☐ Clinical Trial Registration No.
☒ Not Applicable

Registered at: ☐ www.ClinicalTrials.gov
☐ www.Controlled-trials.com
Type of Research: Population Health

Funding: Cost-Centre Not Required
☒ Unfunded
☐ Industry: ☐ REB fee received
☐ REB fee pending
☐ Grant-in-aid
☐ Grant awarded to non-Fraser Health Institution

Cost-Centre Required: Budget:
Funder:
☐ Grant/grant-in aid award to Fraser Health
☐ Grant awarded by Fraser Health
☐ Grant funds transferred to Fraser Health by academic sponsor
☐ External grant fund reimburses Fraser Health
☐ Industry: ☐ REB fee received
☐ REB fee pending

Please note that FH Research Policy prohibits over-spending on research grants by the principal investigator.

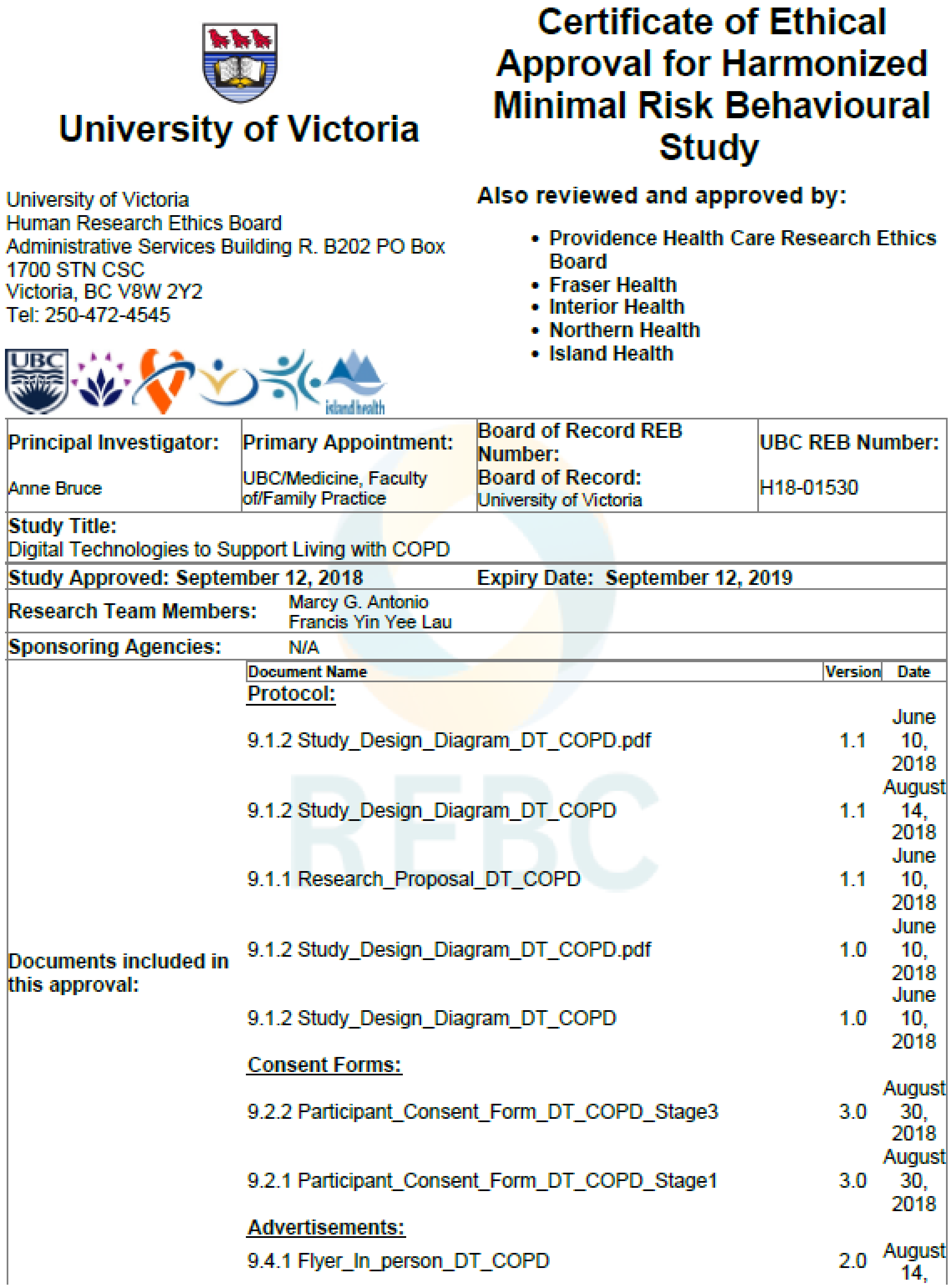
Agreements:
☐ Executed Clinical Trial Agreement for Industry Sponsored Trials
☒ Affiliated Researchers: Executed "Research Collaboration Agreement" dated: 2018 June 07

☐ Research Grant Contribution Agreement dated: Name of Granting Agency:

This letter authorizes the principal investigator to begin research-related procedures in compliance with all FH research-related and privacy policies http://fhpulse/policies_guidelines/org_policies/pages/default.aspx.

Please note that the ethical approval for this study must be renewed before the one year expiry date of the certificate of initial approval if the study will be ongoing at that time.

Appendix R: Harmonized Ethics Approval



University of Victoria

Certificate of Ethical Approval for Harmonized Minimal Risk Behavioural Study

University of Victoria
Human Research Ethics Board
Administrative Services Building R. B202 PO Box
1700 STN CSC
Victoria, BC V8W 2Y2
Tel: 250-472-4545

Also reviewed and approved by:

- **Providence Health Care Research Ethics Board**
- **Fraser Health**
- **Interior Health**
- **Northern Health**
- **Island Health**

Principal Investigator:	**Primary Appointment:**	**Board of Record REB Number:** **Board of Record:**	**UBC REB Number:**
Anne Bruce	UBC/Medicine, Faculty of/Family Practice	University of Victoria	H18-01530

Study Title:
Digital Technologies to Support Living with COPD

Study Approved: September 12, 2018 **Expiry Date: September 12, 2019**

Research Team Members: Marcy G. Antonio
Francis Yin Yee Lau

Sponsoring Agencies: N/A

Documents included in this approval:

Document Name	Version	Date
Protocol:		
9.1.2 Study_Design_Diagram_DT_COPD.pdf	1.1	June 10, 2018
9.1.2 Study_Design_Diagram_DT_COPD	1.1	August 14, 2018
9.1.1 Research_Proposal_DT_COPD	1.1	June 10, 2018
9.1.2 Study_Design_Diagram_DT_COPD.pdf	1.0	June 10, 2018
9.1.2 Study_Design_Diagram_DT_COPD	1.0	June 10, 2018
Consent Forms:		
9.2.2 Participant_Consent_Form_DT_COPD_Stage3	3.0	August 30, 2018
9.2.1 Participant_Consent_Form_DT_COPD_Stage1	3.0	August 30, 2018
Advertisements:		
9.4.1 Flyer_In_person_DT_COPD	2.0	August 14,

		2018
9.4.3 Flyer_Stage2_DT_COPD	1.0	August 14, 2018
9.4.2 Flyer_Remote_DT_COPD	2.0	August 14, 2018
<u>Questionnaire, Questionnaire Cover Letter, Tests:</u>		
9.5.3 Stage_ 2_Survey_Cover_Letter_DT_COPD	3.0	August 30, 2018
9.5.2 Stage_1_Interview_Questions_DT_COPD	2.0	August 30, 2018
9.5.5 Stage_3_Interview_Questions_DT_COPD	1.0	June 10, 2018
9.5.4 Stage_ 2_Survey_DT_COPD	1.0	June 10, 2018
9.5.1 Potential_Participant_Intake_Script_DT_COPD	2.0	August 30, 2018
<u>Other Documents:</u>		
9.7.3 Study_Overview_DT_COPD	2.0	August 14, 2018
9.7.5 FHREB_application_for_initial_review_privacy_for_RISe_studies	1.0	August 15, 2018
9.7.2 Data_Flow_Diagram_DT_COPD.pdf	1.0	June 10, 2018
9.7.3 Study_Overview_DT_COPD	1.0	June 10, 2018
9.7.4 BCEHI_Coversheet_DT_COPD	N/A	May 1, 2018
9.7.2 Data_Flow_Diagram_DT_COPD	1.0	June 10, 2018
9.7.1 Confidentiality_Form_DT_COPD	1.0	June 10, 2018

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2014).

The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

This study has been approved either by the Board of Record's full REB or by an authorized delegated reviewer.

Appendix S: Codebooks for Coding Interviews

Codebook for Stage One

Code1.0 Illness Outcomes and Experiences[19]

Symptoms and progression (e.g., breathing, pain, fear, anxiety, depression, physical activity level); events (e.g., exacerbations, hospitalization, death).
Reference to COPD, and relationship to smoking, oxygen, etc.

Code 2.0 Social Connections (general - broad reference to social isolation/connectedness)

2.1 Social network structure - who people connect with (e.g., friends, family, community, healthcare providers)
2.2 Social network characteristics - how people connect (e.g., synchronous/asynchronous, face-to-face, online; message length/duration)
2.3 Social interactions - negative and positive; constraining and enabling; "broken links"; reference to childhood social interactions

Code 3.0 Digital technologies (general)

3.1 Types
3.2 Knowledge, experience and background
3.3 Challenges and opportunities

Code 4.0 Potential role of digital technologies (participants may reference these codes in relation to how or how not they are being fulfilled by digital technologies)
For initial coding will not be separating this out to avoid having preconceptions as to what these roles may be.

Code 5.0 Societal Outcomes and Experiences

5.1 Equity
May include stories of inequities, contradictions dilemmas and references to change or status quo. Look for areas where participants reference other groups to see if they are representing this as "versus"[20] (e.g., other people with COPD, healthcare providers, tobacco companies, the government).

Code 6.0 Participant Context[21]

6.1 Diagnoses and overall health
6.2 Attributes - demographic/PROGRESS concepts; if referencing family, code under 2.1

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[19] *Codes 1-4 are structural coding -- appropriate for all qualitative studies, but particularly for those employing multiple participants, standardized or semi-structured data gathering [for]... exploratory investigations" (Saldana, 2016, p. 98).*

[20] *Versus coding: "patterns of social domination, hierarchy, and social privilege... examination of] the power that holds patterns in place, how people accept or struggle against them (Saldana, 2016, p. 136). "The focus is on patterns that reveal injustices"(Agar, 1996 in Saldana, 2016, p. 137).*

[21] Saldana refers to this as attribute coding that provides descriptive information about the participant.

6.3 Worldview - statements that people make about themselves or indicate how they view the world and what they value. May include reference to control, thinking positively, coping, etc.

7.0 Other

7.1 Survey development
7.2 No-code matches / interesting insight

Codebook for Stage Three

In developing the second codebook, I found that I was initially returning to similar ideas I had already developed in the first stage interviews. To help move my thinking forward, I changed my strategy for coding in the third stage. I generated far more codes and also tended to use multiple codes for one quote. In vivo codes were also used to helped see some of the larger pieces that people were referencing. My codebook was also more iterative, where I developed and renamed codes at the same time I was coding, rather than having a more structured code book at the onset.

Code 1 Clinical Outcomes and Experiences

01.0 COPD general: COPD is referred to generally, or as a broad concept
01.1 Symptoms: shortness of breath, exacerbations, changing symptoms
01.2 Medications and treatments
01.3 Diagnosis and testing: how COPD was diagnosed, first diagnosis
01.4 Co-morbidities: other illnesses that person is living with
01.5 Physical activity and frailty: ability to go to gym, change in daily activities and function
01.6 Care and supports: supports outside of the healthcare system, important role of spouses/ caregivers
01.7 Prognosis and outcomes: understanding prognosis and changes in health status

Code 2 Societal Outcomes and Experiences

02.0 Illness experiences: General reference to quality of life
02.1 Stigmatizing: experiences that have been alienating and isolating
02.2 Empowering: experiences of advocating or empowering care
02.3 Healthcare: interactions with the healthcare system (may also be dually coded under stigmatizing/empowering experiences)
02.4 Peers: experiences of COPD that are involved friends, family and other people with COPD
02.5 Life: life experiences that have informed how people respond to COPD or DT; may share similarity to concepts associated with coping and resiliency

Code 3 Social Connectedness

03.0 Social world: general - broad reference to social isolation/connectedness
03.1 List of connections: the list of connections that people give when asked how they use DTs to connect with other
03.2 All over the world: reference a "small world" or "all over the world" to indicate that we are all part of a larger world/community
03.3 Merging/separation of worlds: DT integrating (or not) with a person's in-person world
03.4 Broken links: sustaining, building or losing connections

Code 4 Digital technology

04.0 Technology: technology referred to as broad, general concept
04.1 List and types and use: people providing an overarching list of the DTs they use
04.2 Traditional technology: reference to technologies that are not typically considered as DTs (e.g., phone, television)
04.3 Takes me to another place: how DTs can serve as a distraction
04.4 Entry point: people's introduction to a DTs or a new technology
04.5 Technology coping strategies: what people have done to for privacy and security, limit their interactions, tec.
04.6 Technology frustrations: what people find challenging and frustrating with DTs
04.7 Online search: how people use DTs for online research
04.8 Leisure: how people use DTs for entertainment

Code 5 Framework Roles
05.1 Framework roles: roles that may not yet have a role with what I have identified in my literature review; note these passages do not necessarily link to DTs, but rather how people referenced these framework roles in their everyday life experiences
05.1 Information: role of DT for information seeking
05.2 Identity: "I am, I am not "how people talk about how they see their skills in using DTs; having a COPD diagnosis, aging, interactions with others. Worldview - statements that people make about themselves or indicate how they view the world and what they value. May include reference to control, thinking positively, coping, guilt, shame, fear, joy, etc.
05.3 Tracking: reference to tracking COPD symptoms, and may also be how people track other information they use day-to-day

Code 6 Preferences, interests, needs and awareness
06.0 Preferences, interests, needs and awareness: What people would like to see in supporting COPD and their use of DTs/

Code 7 Material Circumstances
07.0 Resources and material circumstances: general reference to lack of resources for people to access care / DTs
07.1 Financial: specific reference to costs for supporting COPD or DTs.
07.2 Food: reference to access to food

Code 8 Risk
08.0 Perceptions of risk: May include risk associated with smoking, risk in going online, security and privacy concerns.

Code 9 Epidemics
09.0 Epidemics: impact of COVID-19 and opioid crisis or lung transplants

Code 10 Individual responsibility

010.0 Individual responsibility: blame, shame, guilt addiction

Code 11 Versus

011.0 Versus coding: May include stories of inequities, contradictions dilemmas and references to change or status quo. Look for areas where participants reference other groups to see if they are representing this as "versus" (e.g., other people with COPD, healthcare providers, tobacco companies, the government).

Code 12 Demographics

012.0 Participant Context[22]: Attributes - demographic/PROGRESS concepts

Code 13 Other (No-code matches / interesting insight)

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[22] Saldana refers to this as attribute coding that provides descriptive information about the participant.

Appendix T: Protocol for Statistical Analysis of the Survey Results

Purpose, steps and statistical tests of the quantitative stage:

1) Data Entry

a) Set-up variables
b) Enter 0, 1, 2, 3, 4 for five point scales; 0, 1, 2, 3, 4, 5 for six point scales
c) Use 99 for missing variables
d) ‘Other’ and open-ended categories in demographic section will not be included in quantitative analysis. May categorize this at later date to ‘quantify’ the responses.
e) Open ended questions for questions 8,9, 10, 11 will not be included in quantitative analysis at this point, but will be used to inform overall mixed methods by recordings as part of qualitative data. May categorize this at later date to ‘quantify’ the responses.

2) Frequency distributions

a) Calculate frequency distributions of each sub-question.
b) Calculate overall score for each question (i.e., 4, 5, 6, 8, 9, 10, 11) by adding up the score for each sub-question.
c) Calculate frequency distributions for overall scores.
d) Include mean and standard deviation for a-c.

3) Hypothesis Testing

a) People who use digital technologies to support their COPD (#10) report better experiences of COPD (#5) and satisfaction with social roles and activities (#7). Using Pearson's Correlation, two-tailed.
b) People who use digital technologies for social connectedness (#9) report stronger satisfaction with their social roles and activities (#7). Using Pearson's Correlation, two-tailed.
c) People who use digital technologies to support their COPD (#10) report better experiences of COPD (#5). Using Pearson's Correlation, two-tailed.

4) Context of DT use

a) The relationship between severity of COPD (#4), demographics (section 3) and general DT use (#8).
b) The relationship between severity of COPD (#4), demographics (section 3) and DT use for social connectedness (#9).
c) The relationship between severity of COPD (#4), demographics (section 3) and DT use for COPD (#10).

5) Experiences of COPD

a) The relationship between experiences of COPD (#5), and DT use for social connectedness (#9) and DT use for COPD (#10).
b) The relationship between experiences of COPD (#5), and DT use for social connectedness (#9) and satisfaction with social roles & activities (#6).

6) The roles of DTs for COPD

a) Relationships within individual questions (#7), (#9), (#10).
b) DT use for general purposes (#8) and social connectedness and COPD support.
    - Relationship in overall score of question 8, 9, 10 → this is to see whether there is a relationship between people who are using DTs for general purpose (#8), DTs for social connectedness (#9) and DTs to support their COPD (#10).

- Relationship in overall score of question 10, 11 → this is to see if people who using DTs for multiple non-COPD activities also use them to support their COPD.

c) The relationship between experiences of COPD (#5) and experiences of DTs (#7).

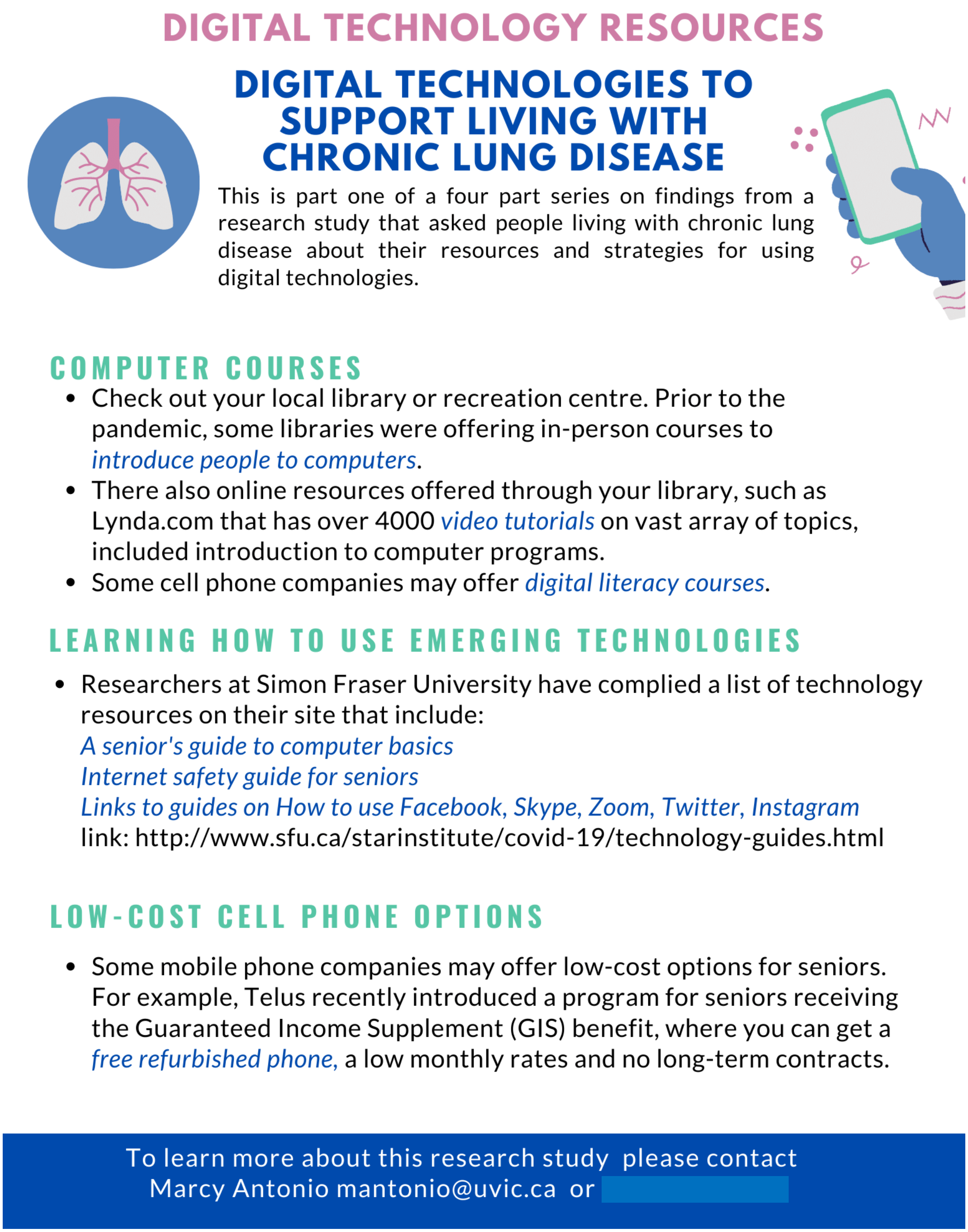
7) Categorization of different user groups

a) Categorize different categories of use of DTs by taking a sum of the overall frequency of DT types and divide by number of types of DTs.
b) Zero were people who reported no use of DTs. Average scores less than 1.8 were considered low use, 1.8 to 2.6 were considered moderate use, and greater than 2.6 were considered high use.

8) Inform third stage

a) Identify different groups of COPD and DT use: Categorize 4-5 groups to identify people to interview that represent each group.
b) AND/OR Possibly some exemplars (depending on the data) --- people who use DTs for social connectedness, and COPD and report strong experiences of COPD.
c) Questions to ask → will develop these later in the process after comparing the data in the first two stages.

Appendix U: Sample Infographic



DIGITAL TECHNOLOGY RESOURCES

DIGITAL TECHNOLOGIES TO SUPPORT LIVING WITH CHRONIC LUNG DISEASE

This is part one of a four part series on findings from a research study that asked people living with chronic lung disease about their resources and strategies for using digital technologies.

COMPUTER COURSES

- Check out your local library or recreation centre. Prior to the pandemic, some libraries were offering in-person courses to *introduce people to computers*.
- There also online resources offered through your library, such as Lynda.com that has over 4000 *video tutorials* on vast array of topics, included introduction to computer programs.
- Some cell phone companies may offer *digital literacy courses*.

LEARNING HOW TO USE EMERGING TECHNOLOGIES

- Researchers at Simon Fraser University have complied a list of technology resources on their site that include:
  A senior's guide to computer basics
  Internet safety guide for seniors
  Links to guides on How to use Facebook, Skype, Zoom, Twitter, Instagram
  link: http://www.sfu.ca/starinstitute/covid-19/technology-guides.html

LOW-COST CELL PHONE OPTIONS

- Some mobile phone companies may offer low-cost options for seniors. For example, Telus recently introduced a program for seniors receiving the Guaranteed Income Supplement (GIS) benefit, where you can get a *free refurbished phone,* a low monthly rates and no long-term contracts.

To learn more about this research study please contact
Marcy Antonio mantonio@uvic.ca or [redacted]

DIGITAL TECHNOLOGY RESOURCES

TECHNICAL STRATEGIES SHARED BY PARTICIPANTS

The following are some of the strategies people living with chronic lung disease shared about the how they use digital technologies.

The identity theft insurance I got through my home insurance give me a greater sense of security in being online.

Before signing up for a forum, I review the comments at the bottom to see if it is place I want to hang out in.

I went back to the store where I purchased the device. They gave pointers and helped me unlock my device.

I contacted my local computer store who could send out a technician to fix my computer.

If I don't know a technical answer, I can google it, or watch a You-tube video.

I listen to a weekly radio tech show that introduces me to new technologies.

University of Victoria

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BC SUPPORT Unit
Advancing Patient-Oriented Research

To learn more about this research study please contact
Marcy Antonio mantonio@uvic.ca or [redacted]