THE SOCIAL HEALTH PROJECT

Bree Galbraith | Emily Carr University of Art + Design

THE SOCIAL HEALTH PROJECT

by

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RAY GALBRAITH, Caregiver

I advocated on my wife’s behalf as she had neither the psychological nor physical strength to do so.

1.0 **PREFACE**

Six years ago I received an early morning phone call from my dad. It was 7:40 am. Back then my dad called like clockwork every day at 8 am. He'd be checking in to see if I needed anything for the day ahead. This morning I knew instinctively something had happened. My dad is a clockwork man, and nothing would be so important *but an emergency* when a clockwork man calls 20 minutes early.

It was my mom, he told me. She had fallen down the stairs in the middle of the night and had broken her neck and back. We were told she was going to die within 24 hours.

My mom lived. She is now a quadriplegic, unable to use her arms or legs, and confined to a wheelchair, pushed everywhere by my dad. For the past six years I have watched him navigate the health system, grow into the role of patient advocate and care provider, and work through the inherent emotional struggles these conditions bring along with them. When I undertook this design thesis, I realized it was by no mistake I had embarked on a path to design for health initiatives. For years I have witnessed people – healthcare professionals and workers, families and friends – devote their lives to the betterment of others.

I realized after I enrolled in Emily Carr's Master of Design program, that I should play to my life experience to connect and support people who provide care to those facing serious health challenges. I know from my experience as a designer that I am equipped with the tools, skill-set and motivation needed to make a difference in the lives of caregivers, and, that part of the challenge would come from understanding and explaining what design could do to help.

It became clear to me that in order to ***support the caregiver***, I would need to design a system that would meet their needs *as well as* illustrate and demonstrate the potential values of design-thinking to health professionals and workers. Without their confidence in a designer, the reasoning behind any system I design would not resonate with this dedicated, articulate, and well-educated group.

Design has not yet revealed it's potential to impact health services (JONES, 2013, P.310), due to both an antiquated understanding of design in the health professions, and to a lack of awareness among designers (ASSADBEIGI, 2012, P.14). My focus for The Social Health Project was to ***use design methods to learn from people*** who are actively engaged with the health system, and discuss the current view of the role of a designer in a health initiative with health professionals. In this way, I was able to illustrate where design methods could aid in the development of a system that was user/patient-centred.

The Caregiver Access Network (CAN) is this system. What follows in this thesis is the research and reasoning – the ***What, Why*** and ***How*** – behind The Social Health Project. It's a project that started as one thing and grew into something different altogether when people began to tell me what they needed, and I began to listen.

Welcome to The Social Health Project.

the What section

ABSTRACT

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RESEARCH OBJECTIVES

DESIGN OBJECTIVES

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1.1 **ABSTRACT**

As concerns in public healthcare come forward as priorities in British Columbia through observation of data, literature reviews, critical incident or political will (A.KING, PERSONAL COMMUNICATION, FEBRUARY 2015) a designer/design researcher is rarely involved at the forefront of a proposal phase, or early stages of strategy. Instead, design interventions take place when the findings have concluded, and results in visual form need to be communicated to stakeholders (reports, brochures, posters, websites, etc.).

This Master of Design Thesis, the Social Health Project (SHP), challenges the traditional health-industry/design relationship, and explores the potential of design-oriented research methods to aid in the development of healthcare services and initiatives. The SHP Draws on research that pinpoints design innovation to be in the centre of three realms: **feasibility, viability and desirability** (STANFORD D.SCHOOL).

Through consultation with healthcare professionals, literature reviews and ethnographic research ***(feasibility)***, interviews with caregivers, health professionals and co-creative activities ***(desirability)***, the Social Health Project describes a model for designers to use when working within multidisciplinary teams in the field of healthcare.

This multidisciplinary approach is vital to the project's goal of a socially innovative system. In prototyping for this project, successful design interventions in healthcare are explained and illustrated, and a framework has been developed for designers to adopt when working in health-service design. A health network that aims to meet the needs of unpaid family caregivers, **The Caregiver Access Network** (CAN), has been developed using the framework described. A working prototype of the CAN system has been demonstrated with significant detail so it can be easily adopted and adapted by a health authority or other governing body ***(viability)***.

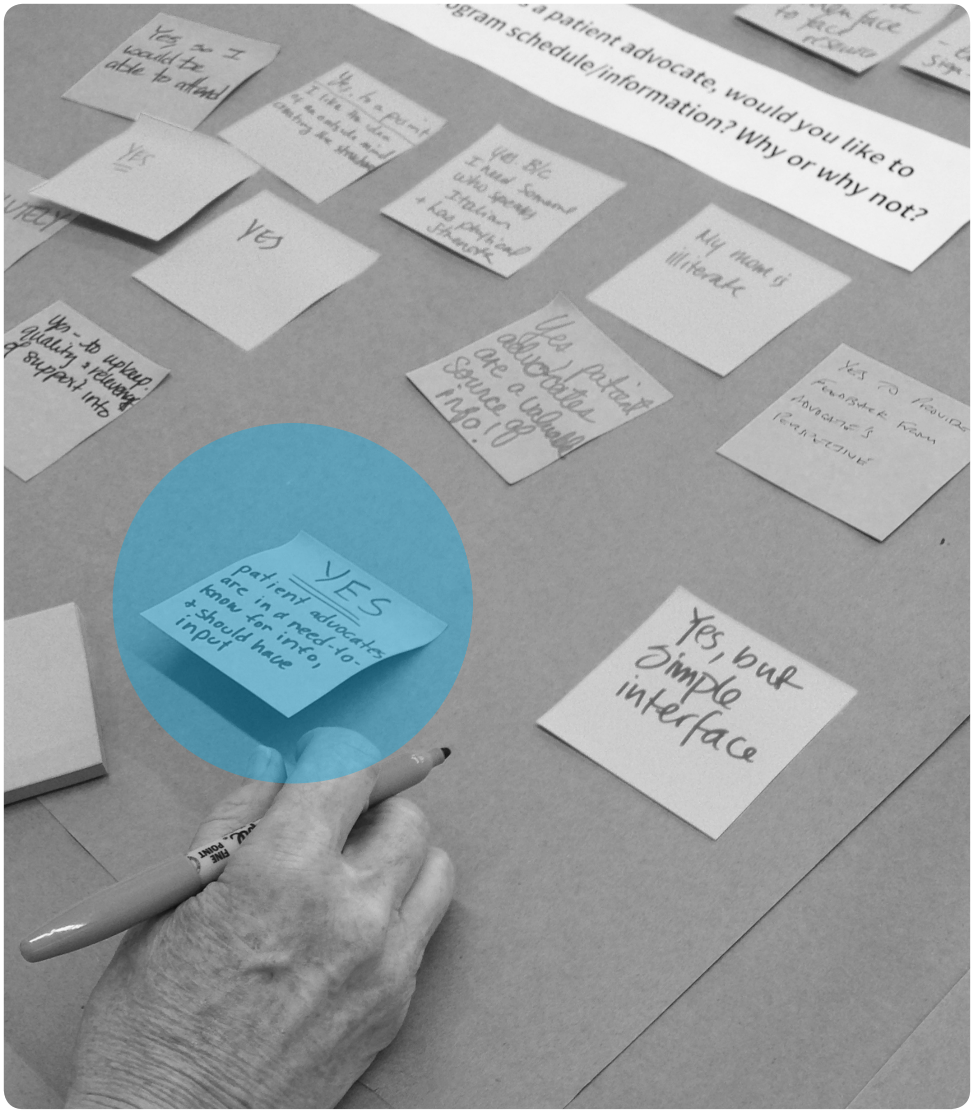


FIGURE 1.0: A co-creation participant responding to one of the tasks in the session.

1.2 KEY WORDS

Design, Caregiver, Chronic Condition, Design Thinking, Human-Centred Design, Narrative, Self-Management, Strategic Design

CAREGIVER: Family caregivers provide unpaid care and assistance to loved ones who need support – at their home, in supportive housing, assisted living or a residential care facility – because of age, injury, long-term chronic illness or disability. – CAREGIVERS DIRECTORY 2013

(Please note family caregiver or caregiver are the terms used in this paper to denote the family and friends who provide care to individuals wherever they reside, be that in their own home or an institution. The term “patient advocate” was used in the project prior to participant research, and evolved to caregiver as research developed).

CHRONIC CONDITION: A human health condition or disease that is constant or ongoing in its effects. Some common chronic diseases include arthritis, cancer, diabetes, depression, heart disease, asthma, AIDS, or chronic obstructive pulmonary disease.

DESIGN: Design is the act of deliberately moving from an existing situation to a preferred one by professional designers or others applying design knowingly or unknowingly. – FUAD-LUKE, DESIGN ACTIVISM

DESIGN THINKING: A methodology for innovation that combines creative and analytical approaches, and requires collaboration across disciplines. – STANFORD D.SCHOOL (HTTP://DSCHOOL.STANFORD.EDU/OUR-POINT-OF-VIEW/)

HUMAN-CENTERED DESIGN (HCD): HCD considers the question: “how do public agencies change when people are considered part of the solution—i.e., when people become main actors in the process of conceiving and delivering public services?” – MANZINI AND STASZOWSKI, 2013, P.II

NARRATIVE: The narrative is a collection of events that tells a story, which may be true or not, placed in particular order and recounted through either telling, representing or writing. A narrative has a sequence in which the events are told and has a narrator telling the story.

– SERVICE DESIGN TOOLS (HTTP://WWW.SERVICEDESIGNTOOLS.ORG/TAXONOMY/TERM/10)

SELF-MANAGEMENT: Self-management relates to the tasks an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management.

- ADAMS, GREINER, AND CORRIGAN, SELF MANAGEMENT SUPPORT: A HEALTH CARE INTERVENTION, BC MINISTRY OF HEALTH

STRATEGIC DESIGN: Strategic design applies some of the principles of traditional design to “big picture” systemic challenges like health care, education, and climate change. It redefines how problems are approached, identifies opportunities for action, and helps deliver more complete and resilient solutions. – HELSINKI DESIGN LAB (HTTP://WWW.HELSINKIDESIGNLAB.ORG/PAGES/WHAT-IS-STRATEGIC-DESIGN)

1.3 ACRONYM GLOSSARY

CAN, CCC, CIHR, HCC, PHC, PHC RCFM, PHSA, REB, SHP, THINK PHC, VCH

CAN | CAREGIVER ACCESS NETWORK: The Caregiver Access Network is the system designed for the Social Health Project.

CCC | CANADIAN CAREGIVER COALITION: Established in 2000, the Canadian Caregiver Coalition is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada. – HTTP://WWW.CCC-CCAN.CA

CIHR | CANADIAN INSTITUTE OF HEALTH RESEARCH: The Canadian Institute of Health Research is Canada's federal funding agency for health research. Composed of 13 Institutes, CIHR provides leadership and support to more than 13,700 health researchers and trainees across Canada. – HTTP://CIHR-IRSC.GC.CA/E/193.HTML

I was awarded the 2014 CIHR Graduate Studies Research Grant for the Social Health Project.

HCC | HEALTH COUNCIL OF CANADA: Canada's Prime Minister and the provincial and territorial premiers established the Health Council of Canada and later enhanced their role through two agreements referred to as "the Accords" - the 2003 First Ministers' Accord on Health Care Renewal, and the 2004 10-Year Plan to Strengthen Health Care.
– HTTP://WWW.HEALTHCOUNCILCANADA.CA

PHC | PROVIDENCE HEALTH CARE: Providence Health Care was formed through the consolidation of CHARA Health Care Society, Holy Family Hospital and St. Paul's Hospital on April 1st, 1997. Providence Health Care became a single legal entity on March 31st, 2000, providing health-care services on eight sites in Vancouver, BC.; There are now almost 9,000 people working at 16 sites, with 6,000 staff, 1,000 medical staff/physicians, 200 researchers and 1,600 volunteers. – HTTP://WWW.PROVIDENCEHEALTHCARE.ORG

PHC RCFM | PROVIDENCE HEALTH CARE RESIDENTIAL CARE FOR ME: The Providence Health Care Residential Care for Me project is an initiative run by the Research & Development Team at PHC to re-imagine residential care. The project team has spent hours watching, listening to and talking to residents, families and staff, as well as doing research on care homes around the world.

PHSA | PROVINCIAL HEALTH SERVICES AUTHORITY: The PHSA has a unique role in BC's health authority system: to ensure that BC residents have access to a coordinated provincial network of high-quality specialized health-care services. – HTTP://WWW.PHSA.CA

REB | RESEARCH ETHICS BOARD: Emily Carr University promotes a high standard of ethics and integrity in research and scholarship. All university-affiliated research and scholarship involving human participants requires review and approval of the University's Research Ethics Board.
– HTTPS://WWW.ECUAD.CA/RESEARCH/REB

SHP | THE SOCIAL HEALTH PROJECT

THINK PHC | TRANSFORMING HEALTH, INNOVATION AND NEW KNOWLEDGE: Services that provide performance reporting, measurement and improvement services to PHC. Specifically, these services include – decision support (data and analytics), and quality and change management – CATHERINE HELLIWELL, CORPORATE DIRECTOR, THINK PHC

VCH | VANCOUVER COASTAL HEALTH: Vancouver Coastal Health delivers health services to more than one million BC residents living in Vancouver, Vancouver's North Shore, Richmond, the Sea-to-Sky Highway, Sunshine Coast, Bella Bella, Bella Coola, the Central Coast and the surrounding areas – HTTP://WWW.VCH.CA

“

ADAM KING, Provincial Lead, Health Promotion & Prevention, Perinatal Services BC

‘Patient-centered care’ is identified as the highest priority across all health institutions in BC, and yet there is a clear knowledge and skills gap among health planners and managers to achieve this. Design thinking and designers can add enormous value to the health system planning process by providing the framework and methods required to make real progress toward being ‘patient-centered.’

2.0 RESEARCH OBJECTIVES

OBJECTIVE 1:

Highlight the value of a designer's perspective in shaping and developing a health service through the design of a working prototype – a visualization of a community-driven program centred around the needs of the caregiver navigating the healthcare system on behalf of a loved one (family, friend and acquaintance, etc.) with a chronic condition.

Method:

Central to the success of the program is the integration of the designer in the process. The Social Health Project underscores the benefit of a reflective design practitioner in designing health initiatives by detailing the open-ended research observations and conclusions that lead to the design(ed) outcomes.

OBJECTIVE 2:

To contribute to the discussion on design for health that has been initiated by research institutions worldwide (such as the Royal College of Art, and the Massachusetts Institute of Technology).

Method:

Primary research through the use of surveys, interviews, ethnography, and co-creation sessions was used to gain insight and frame the potential for design-oriented research in the development and delivery of health services.

Secondary research, including a literature review of both existing case studies and conceptual models of health delivery and practice, supported an evaluation of the needs of the modern health consumer through precedents in the field of patient advocacy and unpaid caregiving.

OBJECTIVE 3:

Lay the groundwork for the creation of a framework for designing for health services, with potential for further research.

Method: (For Designers)

Detail key points where the project evolved and the design-action that initiated/precipitated that evolution.

Method: (For Health Authorities):

Develop the Caregiver Access Network system effectively so it serves as a tool to educate health administrators and planners about how designers and design-thinking can add value throughout the many phases of a health project.

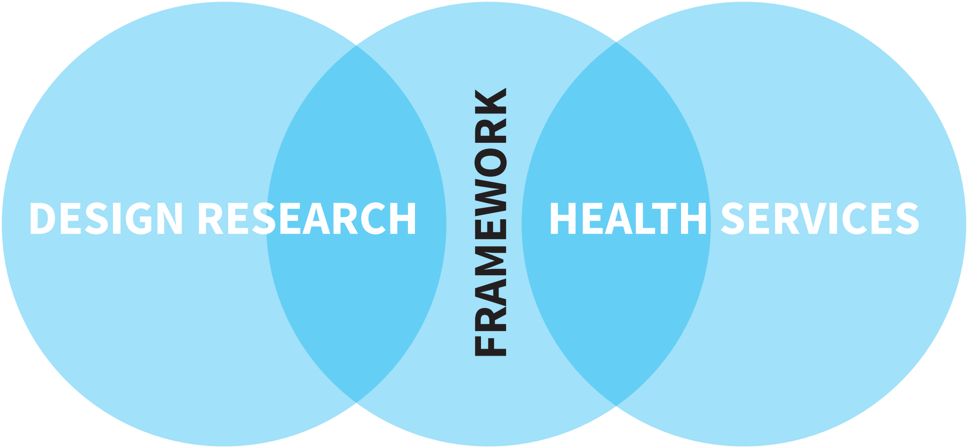


FIGURE 2.0: Graphic representation of the relationship between the research and design framework.

2.1 **DESIGN OBJECTIVES**

This design thesis researches and practices a design for health framework. It follows this model to develop an evidence-based system (the Caregiver Access Network) based on the combination of both systematic and innovative approcahes to problem solving. With multidisciplinary partnerships, the CAN system recognizes, supports and informs unpaid family caregivers of chronically ill patients.

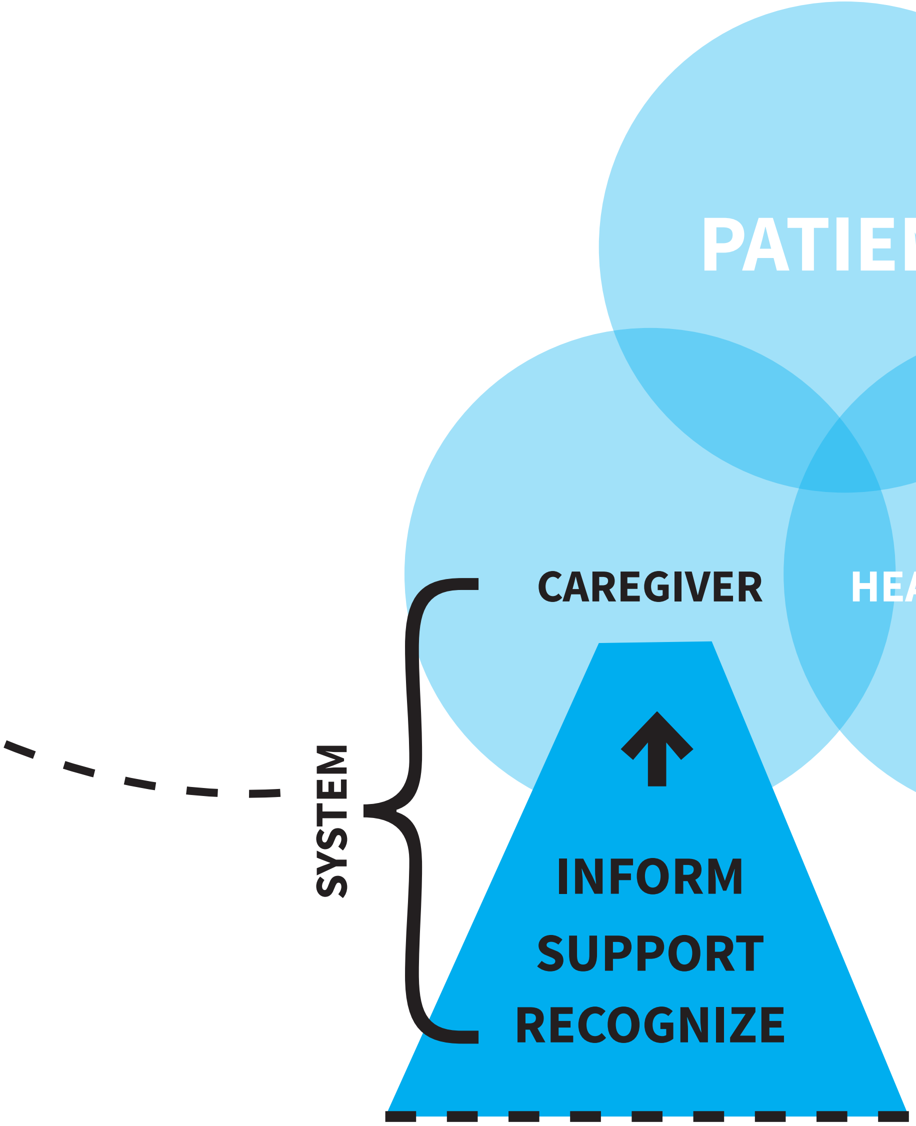


FIGURE 3.0: Graphic interpretation of system intentions.

2.2 RESEARCH QUESTIONS

How can empathetic design methods contribute to the emotional and psychological well-being of the caregiver?

How might I explain the value of a designer’s perspective in shaping and developing a health service to health professionals?

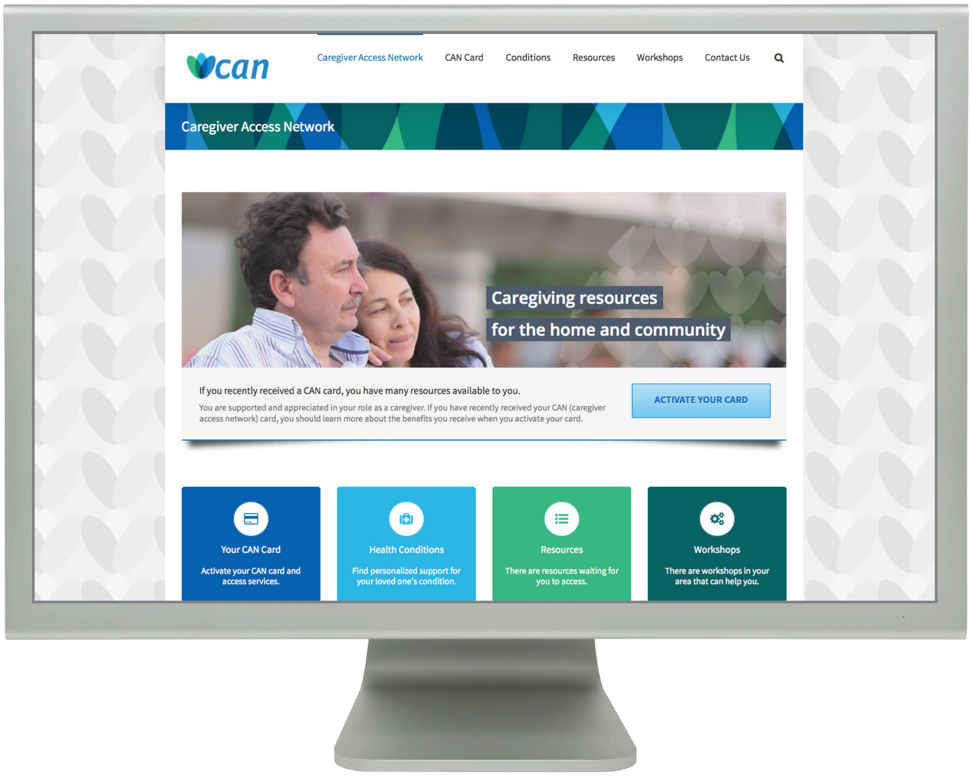
How might I employ and explain human-centred design principles to identify opportunities for intervention?

What role can design play in supporting unpaid family and friend caregivers in sustaining the provision of care for a loved one with a chronic condition?

How might I design a physical tool that recognizes and raises the awareness of the caregiver in the community?

2.3 THE DESIGN OUTCOME

The Caregiver Access Network is a system that gives caregivers access to information from reputable sources, provides face-to-face contact with other caregivers and professionals trained to provide support, and raises awareness of the caregiver in the community.



If you recently received a CAN card, you have many resources available to you.

You are supported and appreciated in your role as a caregiver. If you have recently received your CAN (caregiver access network) card, you should learn more about the benefits you receive when you activate your card.

Activate your CAN card and access services.

Find personalized support for your loved one's condition.

There are resources waiting for you to access.

There are workshops in your area that can help you.

FIGURE 3.0: The Caregiver Access Network website

2.4 **THE CAN SYSTEM**

A

The caregiveraccessnetwork.ca online website – curated caregiver content available 24/7

B

The CAN card – once activated through the online site, it offers discounts at local retailers for the caregiver

Activate your CAN card and access services.

Find personalized support for your loved one's condition.

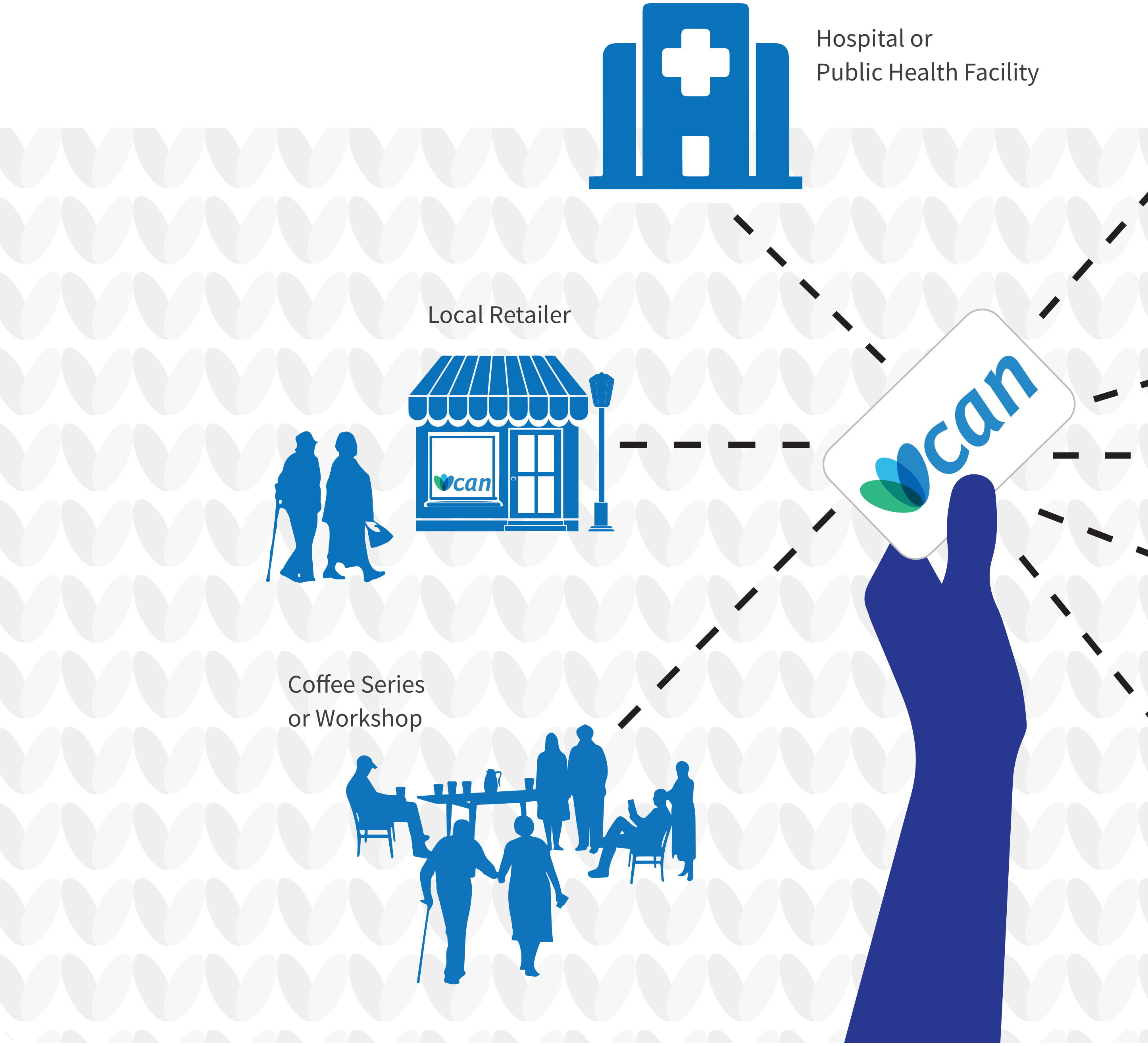
There are resources waiting for you to access.

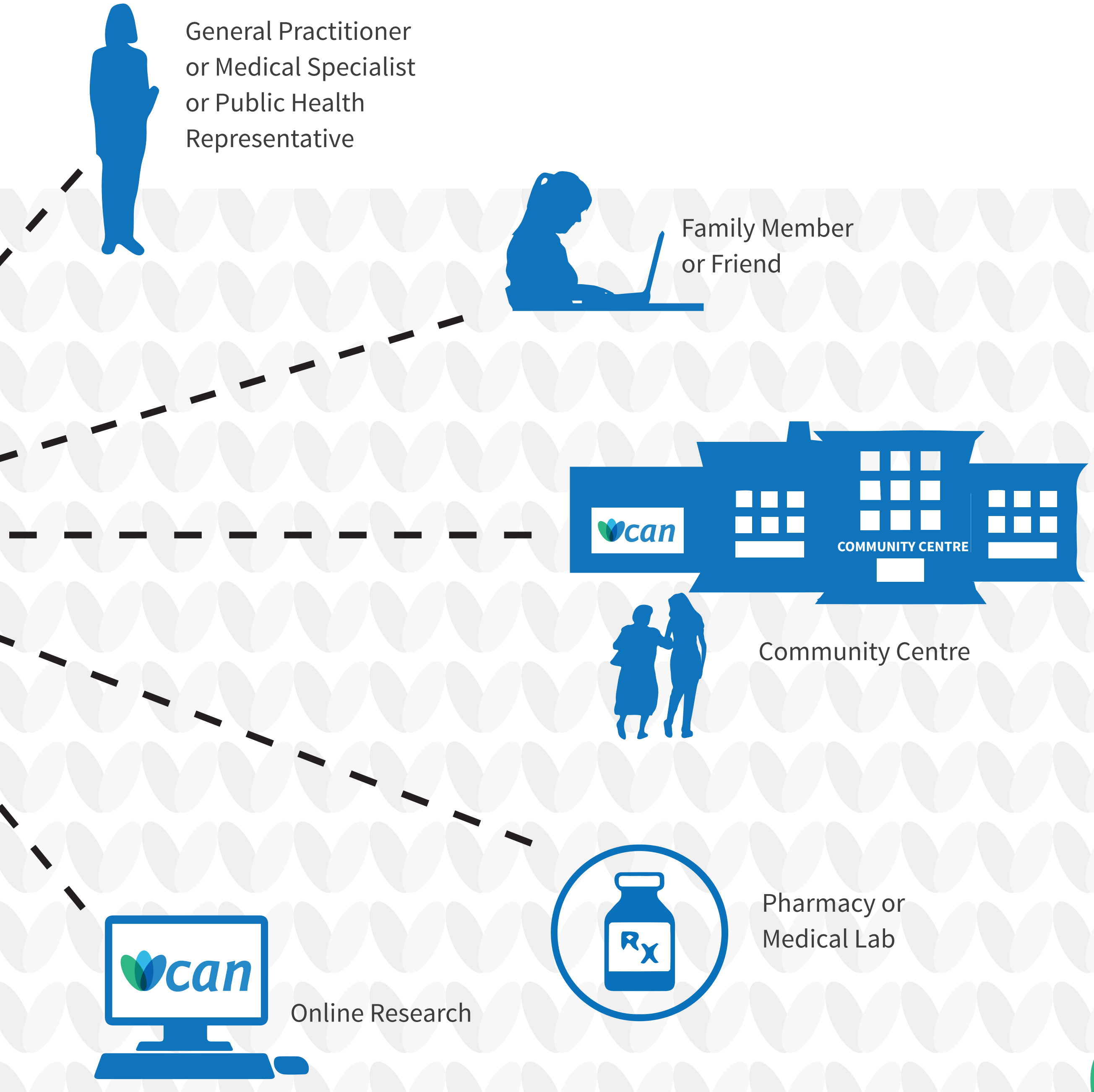
There are workshops in your area that can help you.

C

CAN drop-in weekly free Coffee Series and sign-up Workshops at local community centres

2.5 INITIAL POINTS OF CONTACT FOR THE CAN SYSTEM





General Practitioner
or Medical Specialist
or Public Health
Representative

Family Member
or Friend

Community Centre

Pharmacy or
Medical Lab

Online Research

2.6 INTENDED USER SCENARIOS

My aim is to produce user-group segments that represent actual people I consulted in my research, as well as elements from my survey and co-creation session. Three user-groups have been given an encapsulated set of characteristics, needs, and technological behaviours. This user-modeling documentation informs the design of the Caregiver Access System, and helps deliver resources that fit a variety of circumstances. This is by no means a definitive user-group.

We are all some version of Frank.

INTENDED USER SCENARIO 1

Frank

FRANK AT A GLANCE:

- Late 60’s
- Retired
- Urban setting
- Home computer
- Consults Internet before and after medical appointments

- Frank’s spouse has debilitating chronic condition
- Frank is retired and is the sole caregiver for his spouse
- Cares for his long-time spouse/life partner in their home
- Frank has no prior knowledge of caring for a person with this chronic condition and has been thrust into position of care provider
- Spouse has debilitating condition that leaves her unable to perform daily personal care tasks
- Spouse has debilitating condition that leaves her unable to perform daily home care tasks
- Frank and spouse have two adult children in the same city who have their own families
- Frank does not have a smart-phone, but does have a home computer
- Frank consults the Internet for medical information before and after meeting with specialists
- Frank is wary of the medical information on the Internet, does not always “trust” the sources
- Frank prints out and files his data for reference
- Frank prefers hard-copy resources
- Frank lives in an urban setting, belongs to a car co-op, but prefers to walk to appointments, meetings, grocery store, etc.
- Frank lives within a 10-30 minute walk of 4 community centres
- Frank is concerned about the issues of aging, both on himself as caregiver and on his spouse, and, about what options are available

INTENDED USER SCENARIO 2

Francine

- Francine has two school-aged children, a husband and one sibling
- Francine's father suffers from Alzheimer's
- Francine lives in an urban setting, while her senior parents live in a suburban setting several hours from her residence, and she can only visit them once a week due to career/family time constraints
- Francine is part of the "sandwich generation" - she has parents with medical needs, and also cares for her own young children
- Francine's mother requires assistance with care in the home and Francine is unaware of the resources available to her mother
- Francine's parents have a limited income, and she would like to know more about tax breaks and government benefits to caregivers
- Francine has determined that her mother will not be able to care for her father in the home for much longer alone, as her father has become agitated and occasionally combative on more than one occasion and has also begun to leave the stove on and fireplace unattended. Francine would like to start the process of finding a residential care facility "before it's too late"- she worries her mother will be socially isolated when this transition happens
- Francine is a proficient technology user, and readily consults the Internet for health information
- Francine's mother uses an iPad for email and Skype, but does not use it for much else
- Francine's parents live within a 10-minute drive/15-minute public transit ride of a community centre

FRANCINE AT A GLANCE:

- Mid 40's
- Working mother
- Urban setting
- Office and Home Computer
- Consults Internet
- Aging parent with chronic condition

INTENDED USER SCENARIO 3

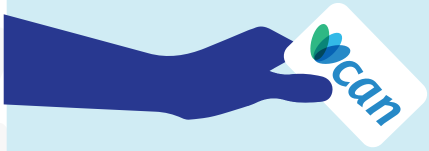
Dr. Francis

- Dr. Francis has been a general practitioner for over 30 years
- Dr. Francis' practice is located in an urban neighbourhood
- Some of Dr. Francis' patients are aging and developing chronic conditions, others are presenting with conditions such as diabetes and different stages of cancer
- Dr. Francis encourages the partners of patients to play an active role in their health journey
- Dr. Francis is aware of the many services available to her patients and their partners, yet her patients are very diverse in their age, incomes, education and chronic conditions
- Dr. Francis believes the caregiver burnout/overload and depression can and should be avoided at all costs for the betterment of her patients' recovery and overall well being
- Dr. Francis' practice requires a mix of hard-copy information and digital resources to meet the needs of her patients

DR. FRANCIS AT A GLANCE:

- Late 50's
- Working GP
- Community Health Practice
- Office and home Computer
- Refers patients to services

2.7 **CAN SYSTEM USAGE**



Uses the CAN Card to receive discounts at local retailers he and his wife frequent: home health product store, coffee shop, bakery, community centre, etc.

Uses CAN online for information about CAN coffee series and Workshops

Attends CAN Coffee Series and Workshops if they are related to his wife's condition and needs. Brings his wife along to both.

↓ FRANCINE	↓ DR. FRANCIS
Gave a CAN card to her mother and helped her to activate the card and understand the resources available to her	Gives patients CAN reading material and card during medical appointment
Uses CAN online for information about CAN coffee series and Workshops in her mother's area, tax information, respite resources for her mother and care facility info.	Urges patients to activate their CAN card on the system and refer to the CAN system for caregiving information
Encourages her mother to attend the CAN Coffee Series to have more community connections and avoid social isolation	Urges caregivers to attend Coffee Series and Workshops to avoid 'Caregiver Burnout'

the Why section

DESIGN OPPORTUNITY

PRIMARY RESEARCH

SECONDARY RESEARCH: METHODS & PRECEDENTS

3.0 **DESIGN OPPORTUNITY**

3.1 Support Self-Management of Chronic Conditions

As stated by the Health Council of Canada (HCC) in their *Self-Management Support for Canadians with Chronic Health Conditions Report (2012):*

> Approximately **half of all Canadians are living with at least one chronic health condition,** and more than one in four Canadians report having two or more chronic conditions. (HCC, P.3)

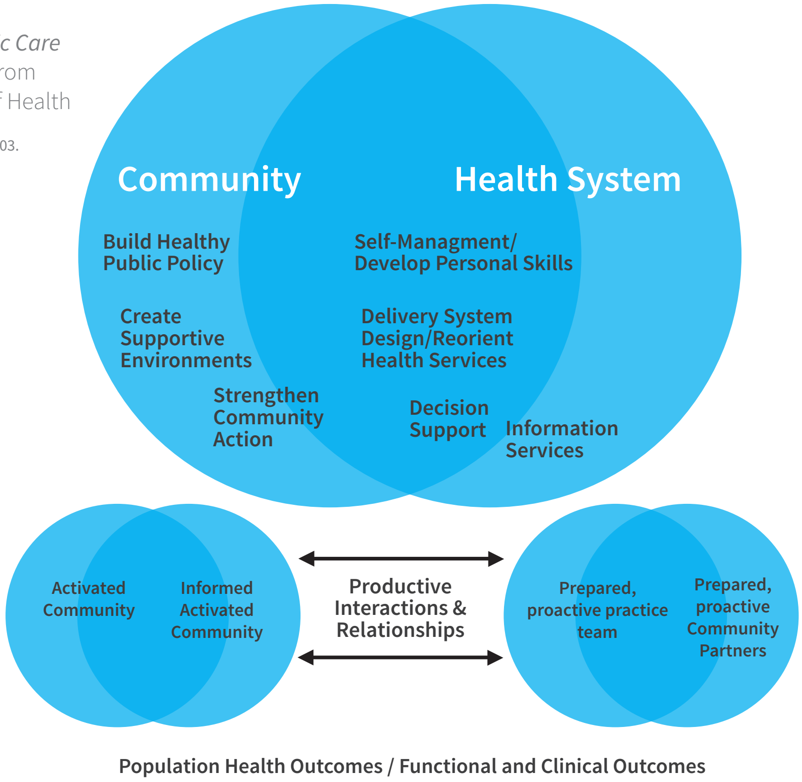
The fact that people with chronic conditions benefit physically, mentally and emotionally when actively involved in their own care has taken root and gained universal acceptance in Canada and internationally (HCC, P.4). This has become known as "self-management". Examples of self-management may include: the digital monitoring of glucose numbers and carbohydrates for a person with diabetes, sound and text reminders for prescription pill use, and digital devices that allow the transmission of blood pressure readings to a third-party resource.

Families and health care providers both benefit from patients engaged in self-care because of the more preferable patient outcomes associated with this practice. Another beneficiary of the chronically ill invested in self-management is the health system, as 'preferable outcomes' correspond to more sustainable use of the system (HCC, P.4) and allow people to manage their condition while remaining at home.

These societal benefits of self-management are widespread and can be realized by partnering health providers and patients in a systematic way (HCC, P.5). This has been depicted or defined as a model known as "The Expanded Chronic Care Model" (FIGURE 04, HCC, P.25). Support programs using this model that educate patients *and* their families on self-management have proven to reduce side effects related to chronic disease, as they often provide tools for behaviour change and monitoring of symptoms, which in turn prevents other health-related issues (HCC, P.8).

FIGURE 9.0:
Expanded Chronic Care Model, adapted from the BC Ministry of Health

SOURCE: BARR ET AL., 2003.



But there is a caveat in this process. There are factors that affect the self-management of health and make it difficult, if not impossible to seek out and join support programs. Some of these factors, or barriers, are described by the Health Council of Canada in their report to be the following:

- **Socioeconomic Inequities and Education –** It's been found by Statistics Canada "people with lower incomes and less education are more likely to have chronic conditions, and they are also less likely to have access to, and comfort with, using computers" (P.42). As well, those who do have access to a computer may not know how to find relevant online information.
- **Age –** "Cognitive decline and certain physical disabilities, such as chronic pain, can create barriers to using computers and engaging online." (P.42)

- **Disease-Related Obstacles –** “Disease-related challenges such as depression, pain, and mobility restrictions can make it difficult for some people to engage in self-management programs or summon the motivation to change health behaviours.” (P.42)

- **Technology –** While technology connects us, there is concern that smart phones and data plans that enable these connections may also present a barrier. As well, the importance of human contact remains, for how can we “ensure that the technology truly enhances communication between patients and primary health care providers, rather than creating a virtual world where health care interactions are dehumanized?” (P.43)

The goal of integrating design thinking and methods into health should be to articulate and address all aforementioned barriers to usability. As designers become present in the self-management conversation, they should **be aware of the barriers** described, and fill the void, rather than add more obstacles. It’s been identified through research that Canadians with chronic conditions and in general poor health are likely to face multiple barriers in succeeding to self-manage their condition. Therefore, designers should adopt the following Health Council of Canada message as their mantra, and continually during the design process, ask; “how can programs, services, and policies take these inequities into account so that more Canadians can benefit from self-management supports?” (HCC, P.2) Through my research, I’ve understood that designers would better serve healthcare by cautioning against a sweeping shift to technology-based solutions that will further isolate the already vulnerable, and should **think critically about designing digital-only services.** Peter Jones speaks to “a future driven by technological determinism" (JONES, 2013) in his *Design for Care: Innovating Healthcare Experience.* He asks us to bear in mind, “if patients are forced by economic changes to trust a technology instead of a physician, the ethics of 'brave new healthcare' scenarios become socially problematic.” (P.431)

3.2 Recognize Informal Caregivers

In order to maintain a consistent level of support for the person in their care, caregivers themselves need to be a part of a health system that acknowledges their own unique needs. This message emanates from and reverberates throughout my research and findings. In the recent *Canadian Caregiver Strategy Report* published by the Canadian Caregiver Coalition [CCC], a primary recommendation is that caregivers have their needs recognized and are provided with adequate "emotional, psychological and physical support" (CCC, 2013, P.7). Echoing this sentiment is the *Caregiver Roundtable* jointly sponsored by the Victoria Order of Nurses (VON) and Health Canada, both have called on the "federal government to recognize the importance of informal caregivers and provide the resources to support their efforts" (CAREGIVER ROUNDTABLE, 1999, P.7).

There are two related current trends in this sector of health care: the previously-mentioned shift towards self-management of chronic conditions in almost every attempted primary health reform initiative, and, the international inclusion of informal caregivers as an integral part of the self-management journey, a trend which is gaining momentum. This is in part due to the fact that caregivers are positioned to introduce effective behaviour change strategies into the lives of those they provide care for. In the British Columbia Ministry of Health's 2011 report *Stepped Care for Self Management Support,* behavioural change is defined to include "goal setting, action planning, problem solving and follow-up" (HCC, 2012, P.32) – all components of care that are supported, and often initiated, by a caregiver. This social support has already been linked to better outcomes for patients with diabetes and those with multiple chronic conditions (HCC, P.15). With the role and concept of the caregiver now being recognized as an asset in overall care, this recognition could in turn be manifested in several design formats.

Human-centred and strategic design principles are positioned to make significant headway in supporting the caregiver by creating systems, services and tools that help recognize the intrinsic value of the caregiver model or concept. By considering the question of "how do public agencies change when people are considered part of the solution—i.e., when people become main actors in the process of conceiving and delivering public services?" (MANZINI AND STASZOWSKI, 2013, P.II), innovative human-centred design solutions can begin to take root. The fact that caregivers often feel that they are struggling alone, because their role and experience are so hard to communicate to others (VANCOUVER COASTAL HEALTH TAKE CARE HANDBOOK FOR CAREGIVERS, 2010, P.24), coupled with the aforementioned noteworthy statistical possibilities of becoming a caregiver, it is clear design should lend its unique ability to raise public awareness and add legitimacy to this issue. It is with this challenge in mind that a primary goal of this Project evolved into the design of a physical tool that serves the dual purpose of recognizing and raising awareness of the role of the caregiver in the community.

3.3 Prevent Caregiver Burnout

In 2012, unpaid family caregivers accounted for nearly 30% of the Canadian population over the age of 15 (CANADIAN PATIENT SAFETY INSTITUTE, 2013, P.5), and provide 80% of the required care in the home (GUBERMAN, 1999, DECIMA, 2002, VCH, 2010, P.2). Those in their care – family members with chronic conditions, disabilities and age-related factors – required such types of care as:

> **Bathing, cleaning, cooking, dental care, dressing, emotional support, exercising, feeding, finances, foot care, grocery shopping, grooming, home repairs, hospital visits, housing, laundry, legal issues, making the home safe, medications, pain management, socializing, toileting, transporting, spiritual care, end-of-life care.... and more** (CAREGIVERS DIRECTORY, 2013, P.4)

These support tasks can often lead to what has been labeled as "caregiver-burnout," a term which explains what happens when social isolation and unmanaged stress arise from the juggling of one's own personal commitments (work/family) with caring for an individual. The tasks taken on by that caregiver can "affect physical, financial, mental and emotional health" (CAREGIVER DIRECTORY, 2013, P.100), leading to caregiver stress, which, in effect, detracts from the management of care of the individual with the chronic condition. To offset this debilitating cycle, many groups, including the Canadian Caregiver Coalition (2013), call for the "formal recognition of and respect for the valuable role of family caregivers in ensuring the sustainability of our health care system, and the continuing prosperity of our country" (P.8), signaling that formal recognition, and therefor policy change, should be a top health priority for all Canadians.

Unfortunately, however important, finding and maintaining funding for programs that recognize and support caregivers is difficult at the best of times. I witnessed firsthand, in a meeting with the Vancouver Coastal Health Community Engagement team, the effect of budgetary cuts as we discussed the brief history of their now-defunct Caregiver Support Program initiative. The program, sponsored and organized by Vancouver Coastal Health, had acknowledged and addressed five elements they identified as key to supporting family caregivers: recognition, education, information, respite and support (HTTPS://WWW.VCH.CA/YOUR_HEALTH/HEALTH-TOPICS/CAREGIVER_SUPPORT/).

Using the premise of this VCH caregiver-oriented program, and influenced by my background in designing for social and health initiatives, I narrowed my project's focus to the design opportunities associated with the elements of **caregiver recognition, information and support**.

3.4 Communicate with the Caregiver

Vancouver Coastal Health, several caregiver alliances, and *The Canadian Caregiver Strategy* all mandate that caregivers have adequate access to both information and support programs to sustain their role as a caregiver. My research has proven that there is not a lack of information available to the caregiver, in fact I have seen the opposite to be true. As described in the introduction section of this thesis, socio-economic and digital literacy barriers stand in the way of information access. I will now introduce another barrier into the design equation, one that has been coined by professor and media scholar Marc Andrejevic as "info-glut" (ANDREJEVIC, 2013, P.1).

Andrejevic (2013) explains that we are currently living in contradictory times, where we now have unprecedented access to technology, and therefore information, yet, "we are simultaneously and compellingly confronted with the impossibility of ever being fully informed "(P.2). In the early stages of the project's primary research, it was found that people were burdened with too much disparate information, not knowing which sources offered concrete, professional advice. Those spoken to and surveyed restated or voiced the same problems - there was not one trusted, reliable source of information, and, there was no way they knew how to meet with people who had similar life responsibilities. Caregivers were asking me to give guidance on where to seek information they could trust and digest in an effective manner that respected the knowledge they had gained by 'guessing and testing,' and that understood and acknowledged the constraints on their time.

In reading that the *Caregiver Roundtable Report* (1999) called for "the creation of a central repository of information that would be easily accessible 24 hours/day," that was attached to the current health system (P.7), a second goal for my thesis emerged from this recommendation. This was the design of a digital tool that curates and shares content from caregiving support programs and initiatives. Further co-creative sessions that I set up and led called for an in-person education/support component, and the design of accompanying print materials to inform the community of this initiative, thus mirroring the recommendation of the Roundtable report.

The need for supportive information is an underlying and fundamental theme constant throughout this thesis, and this theme is further reinforced by the Canadian Caregiver Strategy as an example of "evidence-based decision making." It follows that the use of participatory design methods which support the use of evidence-based decision-making and put the needs of the user at the centre of the design process is also a goal and design opportunity. Participant research, combined with literature reviews and design theories, create a framework for an effective design process that looks to transform organizational practice "by constantly repositioning real human beings in the centre of design and service management decisions." (JONES, P.299)

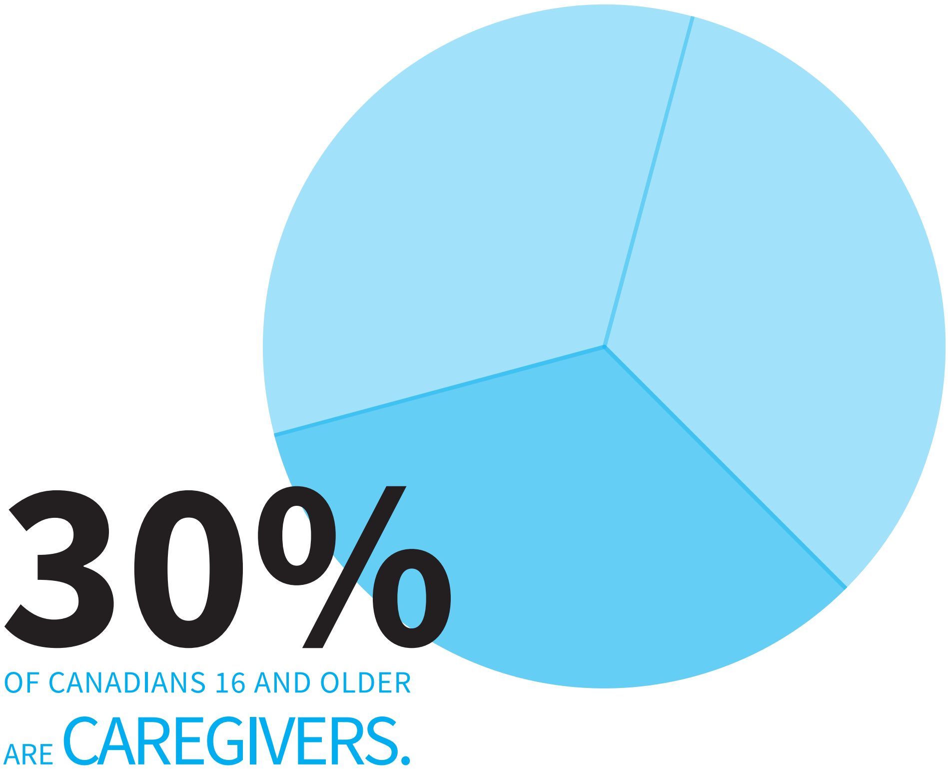


FIGURE 10.0: In 2012, unpaid family caregivers accounted for nearly 30% of the Canadian population over the age of 15 *(Canadian Patient Safety Institute, 2013, p.5)*

“

SANDERS AND STAPPERS, Convivial Toolbox

In the past two decades, the study of people as users of products, services and environments has grown both in industry and in practice. We will refer to this area as “design research.” It is research to inform and inspire the design and development process.

4.0 PRIMARY RESEARCH

NARRATIVE | 2014 | SPRING

Prior to this stage, the focus of my thesis project was on designing a digital tool that could help communities self-mobilize to create networks that support their members as they live with a chronic illness/condition. The perceived design opportunity was to create a system that could offer a digital space to help people in need in their everyday lives that did not already exist – a system that was intuitive, organic and responsive, not adding to the clutter and complexities of daily living. I would create a self-care technology, a social care-giving Application (app) designed to make the lives of those in British Columbia living with a chronic condition easier and with fewer complications. The platform would have a place to request help from your "network" with tasks such as rides to medical appointments, everyday housework and emotional support. During the early phases of participant research, I began to see research results and trends that shifted away from, and basically contradicted, my thesis project's initial goals and intentions of designing an App.

When asked in my survey if respondents consult 'apps' for health information, the overwhelming response (86%) was 'no.' These respondents were patient advocates, 75% of whom had someone in their network with a chronic condition, and half of whom (47%) had someone in their care with a chronic condition. Though these results were not scientific in nature, intuitively I knew that they pointed to an unmet need. The most poignant results came in the comment section of my survey. Respondents expressed needs for help with adapting to home support, finding disease specific items, managing finances and overall companionship for the person in their care. Unquantifiable concerns such as issues of respite, language barriers, socio-economic factors and disease-specific obstacles for care were raised.

The preponderance of research led to the realization that I was looking too closely at statistics and not at barriers. After taking a step back and re-evaluating my process, I began to see patterns emerging from the research and taking tangible shape. Those who had responded to my surveys, and, those who I had spoken to had done so on behalf of someone in their care. The common thread that tied everyone together was caregiving – the process became clear and would need to be refined. The focus would need to shift to providing support to the caregiver.

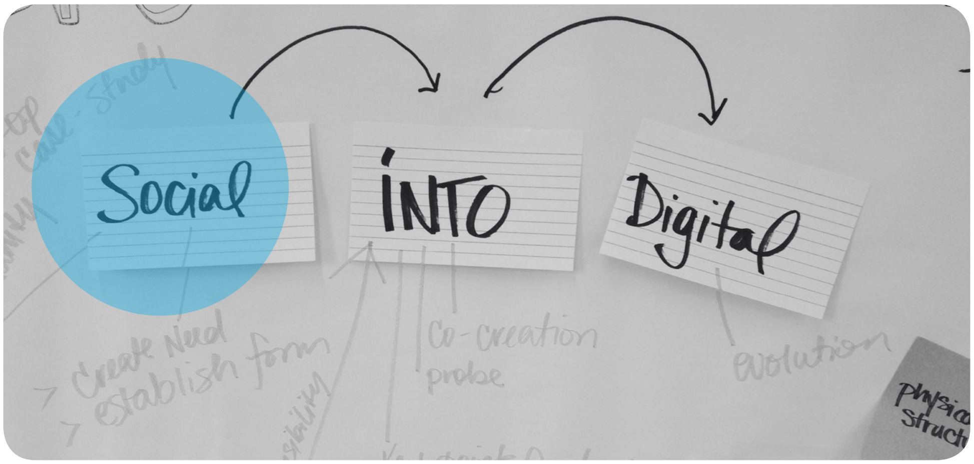


FIGURE 11: Early brainstorming in the studio

4.1 Overview

With design not revealing it's potential to impact health services (JONES, 2013, P.310),due to both an antiquated understanding of design in the health professions, and to a lack of awareness among designers (ASSADBEIGI, 2012, P.14), and many publications heralding a call to action for designers to join the healthcare conversation in more than just a passive visual communicative role (JONES, TULUSAN, ASSADBEIGI), my focus on primary research collection was twofold:

- Firstly, I set out to learn from people who are actively engaged with the health system on the barriers of self-management and shortcomings in caregiver support. Primary research methods included surveys, a co-creation session, interviews (formal, informal and informational), ethnographic research, and my work as the designer for the Research & Development team at Providence Healthcare and clients in health services.

- Secondly, I discussed the current view of the role of a designer in a health service with health professionals and created the Caregiver Access Network (CAN) to explain where design methods could aid in the development of services that were user/patient-centred.

The conceptualized or envisioned scenario of the Caregiver Access Network allowed me to explain visually to both participant user groups the methods a designer could use to identify, articulate and meet their needs.

In research with the Providence Health Care team, it became apparent that professionals in the healthcare field (and the funding bodies that support the health services and delivery system) are well-versed in extrapolating meaning from quantitative findings. However, this skill does not translate well with the qualitative findings their patient-centred projects often generate.

The designer's skill both to navigate through and to purposefully apply the various components of human-centred design and to identify the 'big picture' lend themselves well to the resolution of the problem of interpreting and distilling meaning from qualitative research. Beyond merely interpreting results, empathetic design methods employed by the designer can enrich the process and "fill this much needed design gap, thereby improving healthcare as a whole" (ASSADBEIGI, 2012, P.14).

Research Methods detailed in the The Social Health Project thesis are as follows:

- Online Survey (60 Respondents)
- Co-Creation Session (30 attendees)
- Interviews (8 - both formal and informal)
- Health Design Case Study and Team Designer (Providence Health Care Residential Care For Me Project)
- Ethnographic 'Day-in-the-life' Nurse Shadowing
- Personal Narrative as Design Probe

4.2 The Social Health Project Online Survey

The Social Health Project Research Survey was designed and conducted in the Spring of 2014, after gaining Research Ethics Board Approval. The initial purpose of the Research Survey was to assess the current use of the participant's social 'network' when faced with the challenge of a chronic health condition. The results of the study were to be collected and analyzed, with the information being used to provide direction for the design of a digital tool for communities to support their citizens as they face health challenges. Adults eighteen years of age and older were invited to participate in the survey which was developed on *Fluid Surveys* in order to comply with Canadian privacy laws and Emily Carr's Research Ethics Board regulations (REB).

- The survey was active for a period of two weeks. I recruited respondents through e-mail using my own network – this process included people from the community organization I volunteer for, the housing co-operative I live in, those who took part in my undergraduate thesis research at Emily Carr, and my friends and family (and their networks). The Survey was also posted on the REB survey invitation page on the Emily Carr University website.

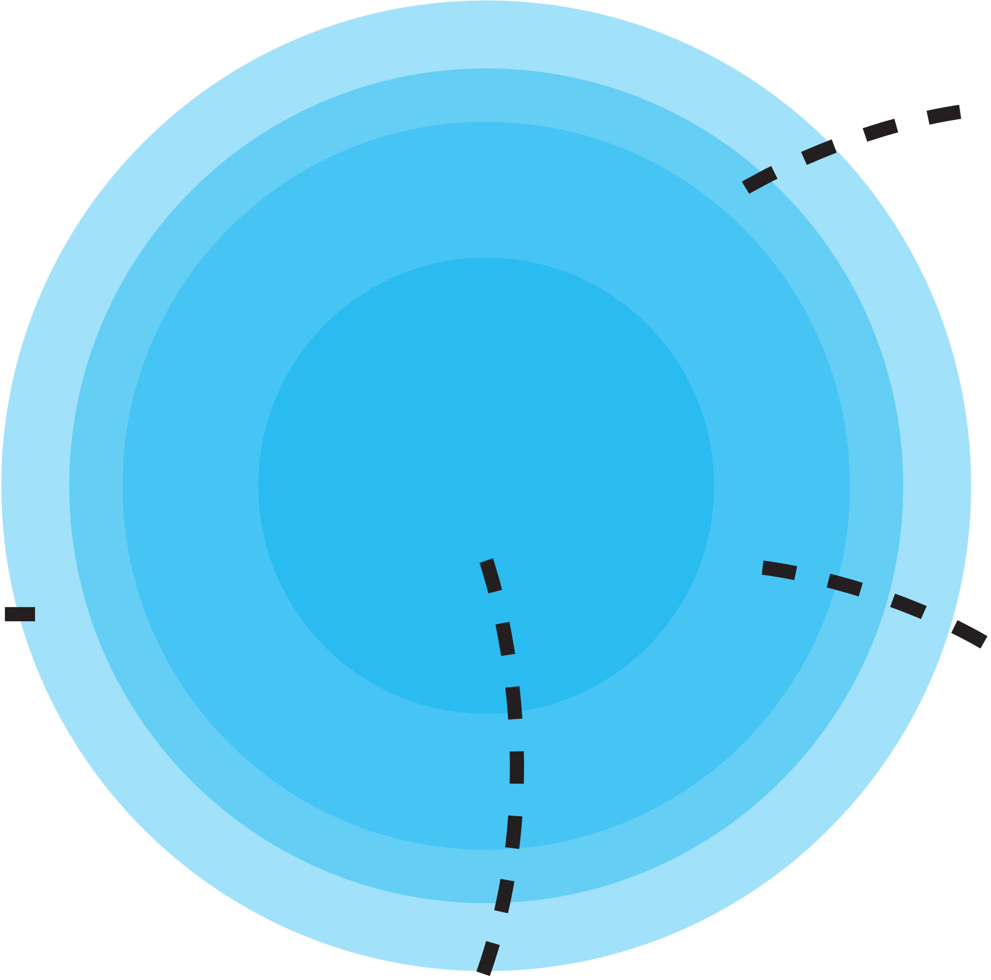
- A total of 60 people responded in this time period. I decided to close the Survey when I was satisfied I was receiving no new results and a sufficient amount of time had passed for those invited to take part in the research. The survey results can be found in the Appendix.

4.3 Analysis of Results

- After collecting and interpreting the data from the Survey, I found that of those surveyed nearly half (48%) of people have or have had a chronic condition, and, nearly half (47%) have or have had someone in their care with a chronic condition. This insight into the breakdown of participants led me to believe that caregivers and those with chronic conditions were almost equally represented in my cohort.

The Social Health Project Online Survey

FIGURE 12.0: Charting results from the online survey.



86%

WOULD NOT CONSULT ‘APPS’ FOR HEALTH INFORMATION

75%

HAD SOMEONE IN THEIR NETWORK WITH A CHRONIC CONDITION

45%

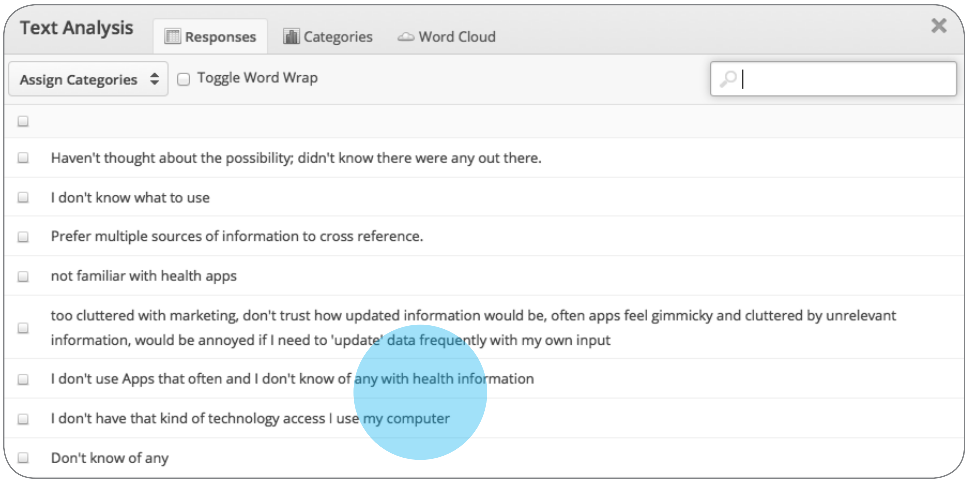
HAD SOMEONE IN THEIR CARE WITH A CHRONIC CONDITION

- Another significant finding was that caregivers could themselves also potentially suffer from chronic conditions.

- Moving further into the Survey, I discovered that 75% of participants had someone in their ‘network’ with a chronic condition. These findings, combined with detailed comments added to the Survey by respondents in regards to resources for people with chronic conditions, were in fact the ‘voices’ of the caregivers themselves, asking for information on behalf of someone else.

- A significant statistic was that at 83%, the vast majority of those surveyed responded that they consult the Internet for health information and yet the respondents were overwhelmingly adverse (85%) to consulting an App for health information, providing a myriad of reasons. FULL RESULTS IN THE APPENDIX.

As I began to chart these results, I could see that my original intention of creating a personal health-management App for those with a chronic condition would not serve the public in the way I had initially hypothesized. I began to plan and organize a co-creation session to test my new concept, a support network for caregivers of those with chronic conditions.



☐

☐ Haven't thought about the possibility; didn't know there were any out there.

☐ I don't know what to use

☐ Prefer multiple sources of information to cross reference.

☐ not familiar with health apps

☐ too cluttered with marketing, don't trust how updated information would be, often apps feel gimmicky and cluttered by unrelevant information, would be annoyed if I need to 'update' data frequently with my own input

☐ I don't use Apps that often and I don't know of any with health information

☐ I don't have that kind of technology access I use my computer

☐ Don't know of any

FIGURE 13: A section of the online survey – respondents detailing reasons they would not consult an App for healthcare.

4.4 Co-Creation Session

In the fall of 2014, I held a co-creative session inviting members of the public to learn more about my project and engage in a series of unique design tasks. Over the 4-hour period, I was able to work with approximately 30 people, running them through the exercises (see Appendix, 99–103) and engaging them in informal interviews during the session.

FIGURE 14: A group being led through the co-creation session.

4.5 Analysis of Results

When asked what problem people with chronic conditions in their neighbourhood or social network presently faced, the results mirrored those of the preceding survey, and added an empathic underpinning to the session. **Participants spoke of "social isolation"** and "invisibility" and the issue of recognition– already a focus of my research. They also felt that there was "not enough help to remain independent," and a "lack of awareness of resources available." These findings added further validity to my CAN online aggregated content system. As I probed the participants about visual design of the service/system, common threads of “simple interface” and continued end-user involvement in the design process arose:

- Participants surprised me with their desire for printed information, as I had assumed that the delivery of digital content was easier for the user than a 2D take-away. Pamphlets, posters, newsletters and stickers were discussed as options to “spread the word” about and publicize the ‘service.’
- Participants described a concept of a physical item that remained with the caregiver that could relieve some of the social isolation and remind the caregiver they are surrounded by a community or network of support.

4.6 Interviews

Interviews, “a fundamental research method for direct contact with participants” (HANINGTON, MARTIN, 2012, P.102) are a vital part of collecting personal experiences and perceptions. For my interview process, I focused on what Hanington and Martin call “stakeholder interviews,” described and defined as interviews with “people who may have a vested interest in the particular inquiry” (P.102). The formal interviews were structured and scripted to allow for ease of analysis and interpretation. They included:

- Family Caregiver; Raymond Galbraith
- Quality Improvement Specialist, Providence Health Care; Sonia Hardern
- Corporate Director, THINK PHC; Catherine Helliwell
- Adam King; Provincial Lead, Health Promotion & Prevention, Perinatal Services BC
- Community Psychologist; Bethan Llyod

- The Vancouver Coastal Health Community Engagement Team
- The BC Quality Patient Safety Council

FIGURE 15: An informal interviewee learning more about my early research

research method

4.7 Health Design Case Study Providence Health Care “Residential Care for Me”

After being invited to speak about my project at a digital health conference in the Fall of 2014, I was approached by Catherine Helliwell and Sonia Hardern, Corporate Director, THINK PHC, and Quality Improvement Specialist with the Providence Health Care Research + Development Team, to meet with them to discuss my project and their own “Residential Care for Me (RCFM)” initiative they are currently leading.

Helliwell and Hardern had been employing design methods to re-imagine residential care, and, were at a strategic standstill trying to interpret and share their findings and *“tell the story of residential care.”* Helliwell explained that the Team’s introduction to design came after working alongside the Institute for Health Care Improvement (IHI) to learn the Institutes's particular research approach. As their work with IHI concluded, Helliwell and Hardern had developed an awareness of design thinking and principles, and realized that key design principles were missing from the IHI approach. Helliwell explains, “we felt that we’d hit on something that was more aligned with our thinking and therefore slowly began to self-teach design thinking and incorporate it into our R&D practice.” (PERSONAL INTERVIEW, JANUARY 2015)

At that point, the RCFM had been working for several months. The Team had spent hours watching, listening and talking to residents, families and staff, as well as doing research on care homes around the world. After joining the Team, I conducted an ethnographic research session at a residential care facility and later attended a meeting with a Social Sciences and Humanities Research Council Researcher conducting research into best practices in worldwide residential care.

My role with the Team quickly evolved into that of resident designer. As resident designer I utilized my skill-set and experience to facilitate Team discussions to identify and hone in on common themes and ideas, and, to visually and tangibly demonstrate the design process for circulation/dissemination throughout the Providence network. After working with the Team, **my concept of caregiving expanded to include those who had placed a family member in residential care.** I was well-positioned to recognize the need for additional information on a variety of overlooked aspects of caregiving, including paid-companionship, interpretive services, and the need to better explain the process of placing a loved-one in a care facility.

4.8 Ethnographic 'Day-in-the-life' Nurse Shadowing

On joining the RCFM Team, I was invited to participate in their ethnographic research process. With a definition of caregiving now expanded to include those caregivers who have a loved one in a care facility, I was able to use this knowledge to further the Social Health Project, test my framework and assumptions, and add to the PHC findings.

To prepare for my "day-in-the-life nurse shadowing", I studied the methods outlined in the IDEO Human Centred Design toolkit on ethnographic research (HTTP://WWW.IDEO.COM/WORK/HUMAN-CENTERED-DESIGN-TOOLKIT/). The toolkit is one of many deployed by the world-renowned design research firm. The open-sourced toolkit explains the phases and stages of the Human-Centred Design (HCD) process. Divided into three phases, "Hear, Create and Deliver", the kit walks the user through the steps involved in conducting research and gaining insight into the people being designed for. My focus for the nurse shift-shadowing was the "Hear" stage, as it is in this phase of design research that designers are tasked with the gaining of a greater understanding of the communities being served by design through observation and storytelling methods.

To further prepare, I studied Sanders and Stappers (2012) methods of extrapolating tacit knowledge from those I would be observing. Having been immersed in the fast-paced environment of the hospital setting, I was aware that my time with the nurse and staff at the facility would be best used if I could interpret knowledge that was both communicated verbally and non-verbally. In The Convivial Toolbox, Sanders and Stappers discuss their "Say/Do/Make" co-creative methodology, explaining "Do" as a strategy that involves day-in-the-life ethnographic research. "Do" is posited as a technique that is scientific in nature, as it can be "conducted by an unobtrusive researcher objectively" (P.67), although when studying what people 'do' there is only a certain amount of anonymity that you can maintain if you are present and recording action. The authors are wise to make proper note of this and, to give some suggestions on how to make the research less invasive. Adding this method to the IDEO HCD toolkit creates a rich, multi-layered technique that doesn't use one element in exclusion to the others, but combines them to best "explore people's experiences" (P.66).

Upon completion of the 'day-in-the-life" research shift, a personal narrative of the nurse shadowing was shared with the Providence team for feedback. Interviews with both Helliwell and Hardern were conducted for insight into the need for a designer to be involved in the development of new health care delivery services and, these insights were used to add weight to the developing design-for-health framework I was creating for the SHP.

4.9 Personal Narrative as Probe

In her thesis, *Talking Things,* former Emily Carr Master of Design student, Zara Contractor (2013) constructs a method that elicits "narrative empathy through dialogic learning and storytelling" (P.20) through design. In examining her research and toolkit, I found Contractor's description of her methods as a dance between and among participants, identifying recurring themes through storytelling to ring true in my own work. Her acknowledgment of "the universality of our experiences" (P. 79) was especially poignant, and, one that was easily understood by health professionals who are trained to notice and report recurrences, measures and trends in their respective fields.

Concurrent with my study of storytelling as a design method, the nurse-shadowing exercise presented a timely opportunity to use a personal narrative as a tool to elicit feedback from the SHP's participants. Motivated by the understanding that personal narratives can be used for "capturing and describing a subject so that the most resistant reader will be interested in learning more about it," (GUTKIND, 1997, P.1) I began to narrate my experience. The narrative outcome from the nurse-shadowing exercise were significant to approximately 5000 written words. Using the narrative as a base or premise for further research, I shared the piece with Helliwell and Hardern of PHC and Raymond Galbraith, my father, and a full-time caregiver.

It was in this manner that the narrative story became a means to "begin a conversation about possibilities that might exist by design," (HANINGTON & MARTIN, 2012, P.54) and as such evolved into a type of cultural probe. After reading my nurse-shadowing narrative, Hardern was inspired by my personal experience, and viewed the RCFM design process in a new light:

> It makes me think about our sharing back of resident observations with the residential leaders. The impact of our stories for the leaders, much like with yours, came from hearing about the impact of the experience on us as outsiders to their world. (PERSONAL INTERVIEW, JANUARY 2015)

The insight gained from examining the interdependent relationship between my experience and another person's interpretation of that experience inspired me to add this technique to my design-for-health framework.

PEOPLE BETWEEN LIFE AND DEATH ENCUMBERED NOT JUST BY ILLNESS OR AGE, BUT THE CONDITION OF THE INSTITUTION AROUND THEM.

AN ELDERLY MAN IS FEEDING HIS WIFE...SLOWLY, WITH THE CARE OF A SACRED RITUAL, HE RAISES THE SPOON, AND OFFERS IT TO HER, NEVER TAKING HIS EYES OFF HER FACE. I CAN'T WATCH, BUT I CAN'T LOOK AWAY.

'WHY IS THERE ONLY ONE BED?' I ASK. 'THIS IS THE PALLIATIVE ROOM,' SHE ANSWERS. THIS IS THE ROOM WHERE PEOPLE COME TO DIE.

THEY ARE RUNNING A CITY WITH THE RESOURCES OF A FAMILY HOME.

FIGURE 16: A portion of the writing for the Personal Narrative as Probe research.

“

Alastair Fuad-Luke, Design Activism

The terms ‘inclusive’ and ‘universal’ are often interchangeable but imply that the intention of this kind of design approach is that no one is excluded from access or use of a design product, service or outcome.

5.0 SECONDARY RESEARCH (DESIGN THINKING)

5.1 Human-Centred Design

Human Centred Design is a key component of the foundation of the design methodology for this thesis.

Human-Centred Design is focused on the people for whom the system/product/service, etc. is intended for. This methodology examines the unique needs of the end-user and breaks down the process into the categorizing topical lenses of: "Desirability, Feasibility, and Viability", questioning throughout the design process if and how the HCD concept fits into and meshes with these lenses. With many health authorities adopting and implementing the concept or strategy of patient-centred care, and, with those authorities having to constantly question which programs are feasible and viable in order to obtain the necessary funding, the principles of HCD seem to directly fit with the fundamental tenets of this health care services delivery strategy. As stated by the Corporate Director of THINK PHC, Catherine Helliwell, in an interview for The Social Health Project,

> **If done properly, (the ethnographic and human-centred approach) is the place from which the emotion and passion for change can best be generated and can help us imagine a very different approach to health** (PERSONAL INTERVIEW, JANUARY, 2013)

5.2 Strategic Design

With a multitude of design theories and methods having been inspired by the social sciences, design can be described as an objective practice that focuses on "problem framing and problem solving" (MOOTEE, 2013). Many other disciplines (business, communications, health) have adopted "design thinking" into their processes, as the focus on human emotion has the power to influence core values (P.528), and drive strategic innovation. Strategic design principles ensure that the "unarticulated, unmet and unknown needs" (P.552) of the user are taken into account, creating an environment where the user is central to the prosperity of the system. As explained by Ezio Manzini and Eduardo Staszowski (2014) in their *Exploring The Intersection of Design, Social Innovation and Public Policy*, strategic design builds value for the users of systems as interactions are redesigned, shaping new relationships and greater public collaboration (P. 23). This HCD approach builds foresight into the system – a strategy at the forefront of The Social Health Project thesis.

5.3 Storytelling in Design

In her thesis, Talking Things: Bridging Social Capital through Transformation Design, Contractor explores the exchange of personal narratives as a design method, and introduced me to the theory of narrative empathy and the techniques of design-storytelling. Contractor (2013) explains how personal narratives gave her audience opportunity to connect their unique life experiences with her own (P. 11).

This concept opened a new area and fertile ground of study that enabled me to explore the values and dynamics of personal narrative, and, to dovetail those narratives with the designed outcome. I began to look for both precedents and further research in this field, and, I was delighted to find many parallels in John Kolko's (2011) writing on design and in his book, The Theory of Synthesis. Having previously assumed that a designer must remain as objective as possible and maintain distance from the design task at hand. Kolko's approach was instrumental in adding personal "legitimacy" to my desire to weave my story of being deeply affected by the health system into the fabric of my thesis project - a task that became less daunting when Kolko (2011) stated, "the point is that in design, one should not try to escape one's past, emotions, or upbringing in an attempt to be more "objective" because these elements are central to making sense of a complicated problem." (P. 12)

Uncertainty and transparency are the underpinnings of story-telling, design and health. Story-telling, design and health are not linear in nature – they can be messy and unpredictable. Personal narrative is an important vehicle through which we communicate experiences and is a tool that can bring together and unify the messy and the unpredictable. This thesis postulates that personal narrative is an invaluable and serviceable method of explaining and supporting the design process. In *Talking Things,* Zara Contractors (2013) examines in great detail "what currently exist(s) in the realm of community engagement and storytelling," and, develops what she describes as a "tool-kit" for other designers seeking to use "narrative, empathy, (and) dialogic learning" (CONTRACTOR 15-16). By using this tool, and, by recognizing the synchronous relationship between personal narratives, storytelling, and the design process, the process of writing this thesis is conceptualized in a way that allows for the designer to reflect upon adding this personal narrative as a tool to use in his/her design practice.

Throughout this thesis, objective and evidence-based decision making are blended with an empathetic narrative – a key strategy for the designer explaining the design process and its methodologies. The layering of quantitative and qualitative methods within the narrative contributes to a greater understanding of the underlying structure of this thesis project. This symbiotic hybrid is at the heart of the Social Health Project, giving it both cohesion and clarity.

5.4 Meta Design

Meta-design, which "creates new media and environments that allow the owners of the problems to act as designers" (FUAD-LUKE, 2009, P.151), goes beyond the user-centred and participatory design methods that are well-known in today's design community. Meta-design encourages and empowers people to take ownership of and responsibility for their problems. This is an especially important element in a health-design project, where behaviour-change solutions provide an opportunity for personal and social growth, and where the health system is seriously underfunded. By purposefully and consciously under-designing the project's designed system, it will "permit the system to evolve" (FUAD-LUKE, 2009, P.151) as the end-users engage in its continued design through use.

Using the knowledge and insight gained from meetings and discussions during primary research for the project, I have found those in the field of health often lack the ability to envision elements of an imagined system without having the components readily available. In my various meetings with health authorities, I have discovered that a working prototype (CAN Card, website mock-up, etc) is needed to start a dialogue and access points of view. In this way, developing and sharing under-designed prototypes is key to the success of the system, and allows it to grow and evolve to suit the needs of the intended users and allow for cooperative interaction between stakeholders. This is summed up well by Fuad-luke (2009) when he explains how Meta-Design operates as “an adaptive seeding process that establishes the conditions for unforeseen opportunities to emerge” (P.219).

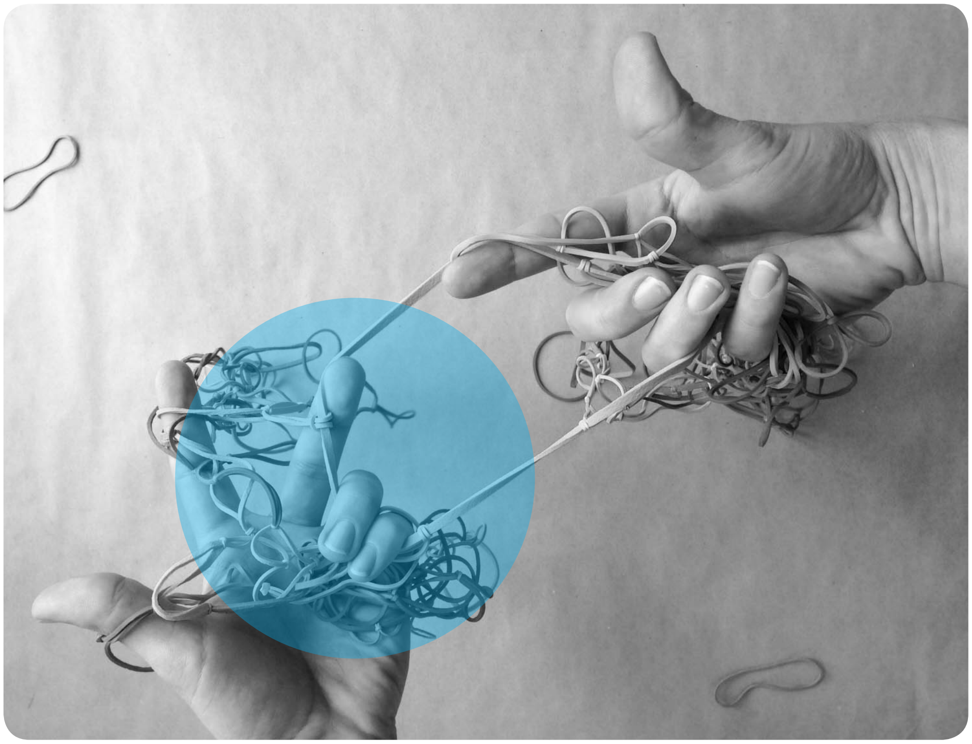


FIGURE 17: Early studio explorations into the visual representation of a network.

5.6 SECONDARY RESEARCH (PRECEDENTS)

5.5 Social Networks

I began to look into research on social networks and health digital management, finding that current statistics were showing that more and more people were turning to the Internet for health/medical information to maintain their own health as well as their understanding of how to treat an illness (LEFEBVRE & BORNKESSEL, 2013, P.1)*. Adding to this is the fact that "almost half (48%) of users who go online for health information do so on behalf of someone else"* (LEFEBVRE & BORNKESSEL, 2013, P.1)*. Correlations between the patient and their support network emerged, and, as a result, I decided to further narrow my thesis focus to this relationship and to create a collaborative environment where families and friends (patient advocates/caregivers) would be able to contribute to the well-being of the patient.*

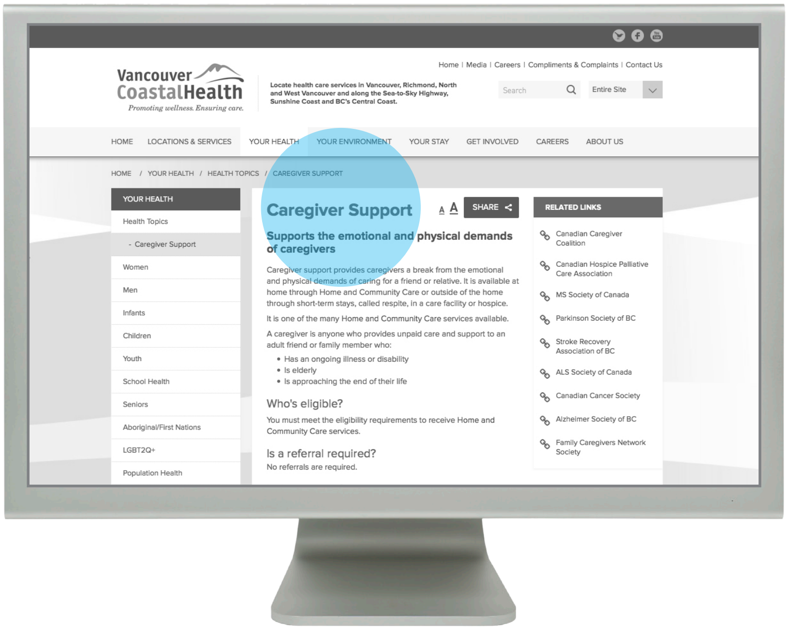
Damon Centola, an assistant professor at the MIT Sloan School of Management, has reached the conclusion that "individuals are more likely to acquire new health practices while living in networks with dense clusters of connections — that is, when in close contact with people they already know well" (CENTOLA, 2010, 03). This bodes well for the design concept of connecting people to a community of support and care when the probable and seemingly unavoidable caregiving challenge arises. With a background in research for behaviour change, I am confident that messages that communicate a new strategy or method to the caregiver would have greater resonance if said caregiver was connected to others in the same situation as they would ultimately hear the strategy from multiple sources, peers and health authorities alike. With "almost half (48%) of users who go online for health information doing so on behalf of someone else the significance of this latter finding is that even people who do not have access to the Internet may be affected by the online behaviours of others who know or care for them." (LEFEBVRE & BORNKESSEL, 2013, P.2 : RETRIEVED FROM HTTP://CIRC.AHAJOURNALS.ORG/)

Caregivers who are supported in their role are in a better position to care for their loved ones and for themselves. The Health Council of Canada recently reported that multi-faceted approaches to management of care provided the most beneficial results, recognizing that "the programs showing the greatest and most sustained effects combined two or more interventions, such as a group class in self-management and training for health care providers" (HCC, P.23). Therefore, designing a system combining the digital element of an information-based website with a face-to-face education and group support program and a community awareness element would benefit the "approximately 1.6 million (or one in three) British Colombians (who) are experiencing at least one or more chronic health conditions" (BC MINISTRY OF HEALTH, SELF-MANAGEMENT SUPPORT: A HEALTH CARE INTERVENTION, 2011, P.4). This interconnected network would provide a foundation for the caregiver to access information, to develop a knowledge and evidence-based skill-set and to access assistance and support – all serving to mitigate the isolation inherent in their role. The network - online, in person, and in the community – would deliver a triangulated support space that is currently unavailable to the caregiver. As explained further by Tulusan, the network is the "product" of the service, allowing a "support space" that is available even before a problem arises. (TULUSAN, 2004)

In discussing the role of the designer in creating a "social" network, it is important to remain grounded and respectful and to accept and follow the advice of design-guru, John Thackara (2006) when he describes a network starting out small and growing in a natural, gradual manner. His guidance includes the message to "act lightly, sense the feedback, act again" (P.215).

5.6 SECONDARY RESEARCH (DIGITAL PRECEDENTS)

Many precedents in the field of caregiving (both current and defunct) were consulted in the design of the Caregiver Access Network. Content and categorization from these precedents was used to determine the hierarchy of information and usability of the Caregiver Access Network website. The CAN prototype website (caregiveraccessnetwork.ca) curates content from these, and other websites and services that are directed toward supporting the caregiver.



Locate health care services in Vancouver, Richmond, North and West Vancouver and along the Sea-to-Sky Highway, Sunshine Coast and BC's Central Coast.

Caregiver Support

Supports the emotional and physical demands of caregivers

Caregiver support provides caregivers a break from the emotional and physical demands of caring for a friend or relative. It is available at home through Home and Community Care or outside of the home through short-term stays, called respite, in a care facility or hospice.

It is one of the many Home and Community Care services available.

A caregiver is anyone who provides unpaid care and support to an adult friend or family member who:

- Has an ongoing illness or disability
- Is elderly
- Is approaching the end of their life

Who's eligible?

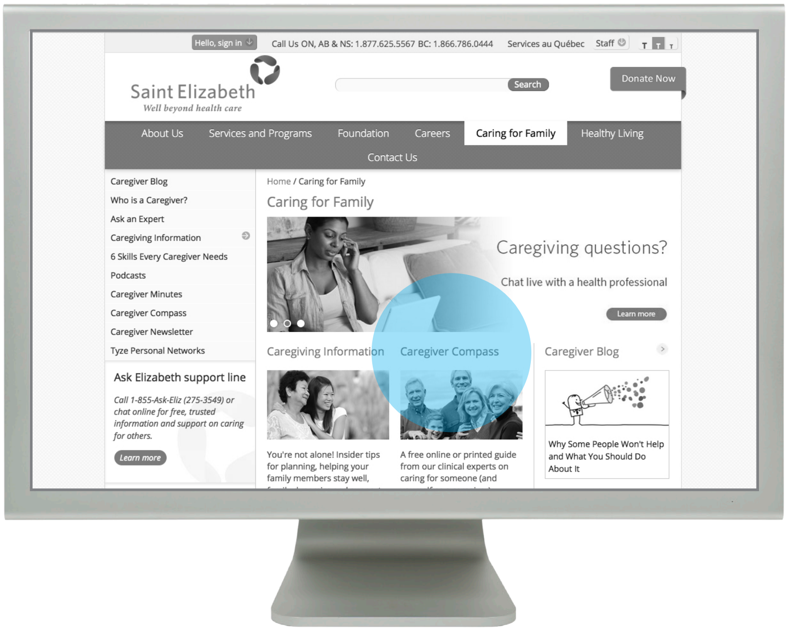
You must meet the eligibility requirements to receive Home and Community Care services.

Is a referral required?

No referrals are required.

Vancouver Coastal Health | www.vch.ca/caregiver-support/

Vancouver Coastal Health Caregiver support "provides caregivers a break from the emotional and physical demands of caring for a friend or relative. It is available at home through Home and Community Care or outside of the home through short-term stays, called respite, in a care facility or hospice."



Ask Elizabeth support line

Call 1-855-Ask-Eliz (275-3549) or chat online for free, trusted information and support on caring for others.

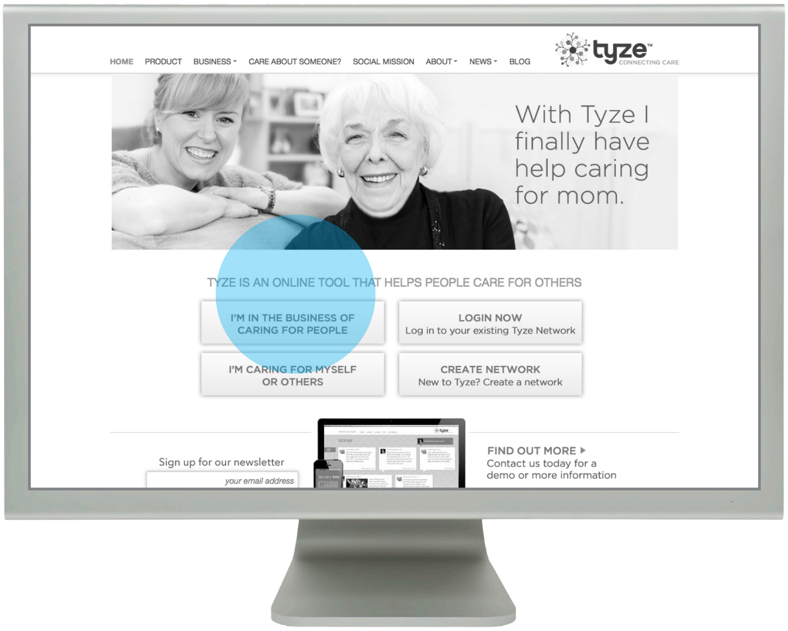
You're not alone! Insider tips for planning, helping your family members stay well,

A free online or printed guide from our clinical experts on caring for someone (and

Why Some People Won't Help and What You Should Do About It

Saint Elizabeth | www.saintelizabeth.com/Caring-for-Family

"Saint Elizabeth has been delivering exceptional health care in people's homes and communities and providing sustainable social contributions in Canada for over a century. As a national award-winning not-for-profit and social innovator, Saint Elizabeth is a known leader in pioneering health practices, spreading cutting-edge knowledge and delivering high-quality compassionate care."



TYZE IS AN ONLINE TOOL THAT HELPS PEOPLE CARE FOR OTHERS

Contact us today for a demo or more information

TYZE | www.tyze.com

"TYZE is an online tool that brings people together around someone receiving care. TYZE allows you to privately communicate with family, friends and helpers about you or the person you care about."

Caregiver Connect

Caregiver Connect is a new section on our website designed to connect caregivers to us, to resources, and most importantly, to each other. Here is what you can find here:

- **Family Care Navigator**, FCA's custom state-by-state resource locator, will connect caregivers to resources closest to them.
- **Research Registry** connects caregivers to clinical trials & research on behalf of themselves and the loved ones they care for.

Family Caregiver Alliance | www.caregiver.org

Founded in the late 1970s, FCA was "the first community-based nonprofit organization in the country (USA) to address the needs of families and friends providing long-term care for loved ones at home. We illuminate the caregivers' daily challenges to better the lives of caregivers nationally, provide them the assistance they need and deserve, and champion their cause through education, services, research and advocacy."

There may be times when you or your family/caregivers need help finding information or voicing a concern. Your local VON staff or District Executive Director should be able to help. If you need further help or information, our Office of Client Relations is available to provide confidential assistance.

VON offers more than 75 different home care, personal support, and community services to enhance each client's quality of life by providing them with the personal assistance and the support needed to make them comfortable in their own home. We've been doing so for more than 110 years.

VON Canada (Victorian Order of Nurses) is Canada's largest, national, not-for-profit, charitable home and community care organization.

Victoria Order of Nurses | www.von.ca

"VON, a charity guided by the principles of primary health care, works in partnership with Canadians for a healthier society through: Leadership in community-based care, delivery of innovative, comprehensive health and social services, influence in the development of health and social policy."

Established in 2000, the Canadian Caregiver Coalition (CCC) is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada.

Our mission is to enhance the quality of life for family caregivers through advocacy and synergistic partnerships.

Together we strive to achieve our vision of "a Canada that recognizes, respects, and values the integral role of family caregivers in society".

It's not if, it's when you will be a family caregiver

The Canadian Caregiver Coalition defines family caregivers as *family members and other significant people (as identified by the care recipient) who provide care and assistance to individuals living with a debilitating physical, mental or cognitive condition.*

Caregivers hail from all walks of life; often undertaking caregiving responsibilities due to sudden health crises, and commonly, the onset of chronic conditions.

Click the picture below to learn more about family caregivers in Canada.

Recognizing and Valuing the Caring Experience as an Employment Asset (Jan 21 2015)

The Canadian Caregiver Coalition congratulates the Employer Panel for Caregivers for their insightful and beneficial report released on Tuesday January 20.

Bill 21 – Leaves to Help Families, passed today in the Ontario Legislature (April 29, 2104)

The CCC sends a special thank-you to the 8 million caregivers across Canada (April 5 National Caregiver Day)

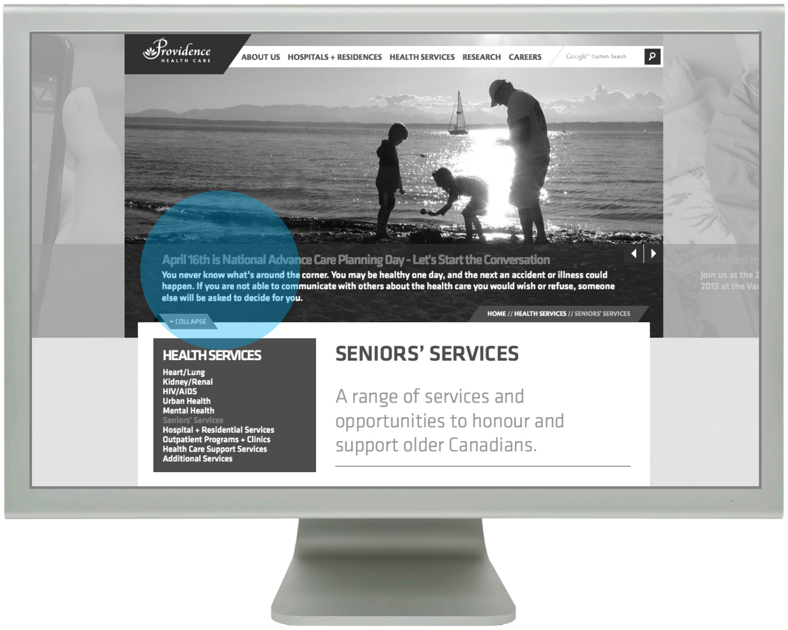
Statement by the Honourable Alice Wong, Minister of State (Seniors), on National Caregiver Day (April 5 2014)

Important Tax Information for Caregivers (March 2014)

A helpful listing of the various caregiver tax credits to help you minimize the financial burden of caregiving.

Canadian Caregiver Coalition | www.ccc-ccan.ca

Established in 2000, the Canadian Caregiver Coalition (CCC) is "a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada." Their mission is to "enhance the quality of life for family caregivers through advocacy and synergistic partnerships."



April 16th is National Advance Care Planning Day - Let's Start the Conversation

You never know what's around the corner. You may be healthy one day, and the next an accident or illness could happen. If you are not able to communicate with others about the health care you would wish or refuse, someone else will be asked to decide for you.

SENIORS' SERVICES

A range of services and opportunities to honour and support older Canadians.

Providence Health Care | www.providencehealthcare.org

"Providence Health Care offer a range of residential and non-residential services to older Canadians. We are guided by our Eden philosophy, which honours elders for their wisdom, gives opportunities to engage in meaningful activities and to connect with the community."

the How section

DESIGN BRIEF

DESIGN FRAMEWORK

CONCLUSION

APPENDIX

“

JOHN THACKARA, In The Bubble

Shared visions act as forces for innovation, and what designers can do is imagine some situation or condition that does not yet exist, but describe it in sufficient detail that it appears to be a desirable new version of the real world.

6.0 DESIGN BRIEF: CAN SYSTEM

NARRATIVE | 2013 | FALL

My original intention for this thesis was to design a digital self-care technology application that responded to the needs of the chronically ill person. This was due in large part because of my mother's life-altering journey with quadriplegia, and, the commensurate journey and tremendous effort on my father's part to become her full-time caregiver. My early research demonstrated a real and pressing need to support people with chronic, non-communicable illnesses, as they are "now the greatest cause of morbidity worldwide," (MATHESON, KLUGL & ENGEBRETSEN, 2013). *With evidence-based research increasingly pointing to the reality that "virtually everyone develops chronic disease and most people develop multiple chronic diseases"* (MATHESON, KLUGL & ENGEBRETSEN, 2013), *my thesis was planned to draw attention to our current lack of preparedness for the anticipated effect of a chronic health condition on both the individual's life and on the Canadian health system.*

I was naturally attracted to the work of Helen Hamlyn Centre for Design researcher, Indri Tulusan. Her Circles of Care project, focused on the "in-between space between self-help and the expert help of medical professionals that has received little attention from designers, manufacturers, service or social providers" (TULUSAN, 2004, P.10) *and demonstrated a need for the design of a network for people central to the care of a person with a chronic condition (patient). This network includes family, friends, colleagues and neighbourhood facilities, both who and which care for and assist patients in their daily lives and compliment the medical system.*

6.1 User Criteria

My participant research has found that unpaid family caregivers do not fully use all the civic and non-governmental caregiving services available. They are often unaware of the variety of resources and how to access them. This is further complicated by the fact that there is no centralized location from which information is disseminated.

This gap in knowledge is in itself a design problem and not one that can be solved by information and technology alone. Human Centred Design research and methods are well-situated to support the call for and implementation of patient-centred care strategies. The Social Health Project's goal is to design a network (with both online and face-to-face components) for unpaid familial caregivers caring for persons with chronic illnesses/conditions that encompasses the following aspects:

- **RECOGNITION:** In order to maintain a consistent level of support for the person in their care, caregivers themselves need to be a part of a health system that acknowledges their own unique needs.
- **INFORMATION:** Design a digital tool/resource that follows the Medical Library Association Guidelines for online health information, and collects and shares content from caregiving support programs and initiatives.
- **SUPPORT:** Using human-centred design methods, support the use of evidence-based design and put the needs of the user at the centre of the design process.
- **MEET THE NEEDS OF THE CITY OF VANCOUVER'S 2014-2025 HEALTHY CITY STRATEGY:** With both short-term goals and long-term "healthy city" targets in place, and, with research being conducted and shared, this citywide initiative provided a pathway for timely and evidence-based conclusions. Drawing from the Strategy's

numerous goals/targets, I chose to highlight “Goal 4” and “Goal 7,” as they allowed for me to also gain a greater understanding of, and empathy for, the role a designer could play in designing a municipally funded social health service:

- Goal 4: Healthy Human Services: Vancouverites have equitable access to high-quality social, community, and health services.”
- 2025 targets: Increase the percentage of Vancouverites who report having access to services when they need them by 25% over 2014 levels
- Goal 7: Cultivating Connections: Vancouverites are connected and engaged in the places and spaces that matter to us.”
- 2025 targets: All Vancouverites report that they have at least four people in their network that they can rely on for support in times of need

6.2 Design Framework

The project follows the framework developed through the SHP research for designing for health systems and services, as described below:

Have Disruptive Ideas:

Change comes when you ask the difficult questions that aren’t immediately answerable. Challenge normal conventions, and be prepared for push-back.

Use evidence-based design:

Throw away assumptions and make connections between evidence and application. For example, healthcare often has “an antiquated approach and infrastructure to support any design solution related to technology.”* There may not be an App for that – so new technologies can’t always be the expected solution. *Catherine Helliwell, THINK PHC

Provide Social Proof:

Prove there is a social need for your intentions and let that be your driver. People will lend their time and effort to your work if they understand the intrinsic value in your concept.

Take Creative Action:

Follow Human-Centred Design principles and involve your end-users as often as possible in the process. Through the use of a variety of co-creative practices, participant research, and under designed prototypes, the goal will become clear.

Tell a Story:

People are empathetic creatures and more often than not make decisions based on emotion. Tell the story of your project to help them understand and connect with your cause.

Design (Simple) Advocacy:

Simple solutions have the greatest impact. In a fast-paced system as seriously underfunded as health care, simple is key. Design your message so that it can be digested easily by a broad and diverse population.

Invite & Invoke:

Think you have hit the nail on the head? Share! Share! Share!.
Appeal to people to offer you their take on your system, design, tools...
Be prepared to hear some disruptive and unsettling ideas.

The Social Health Project Design Framework

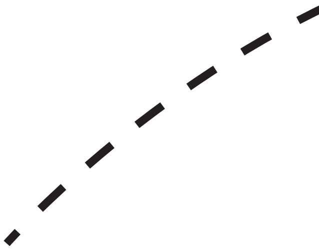
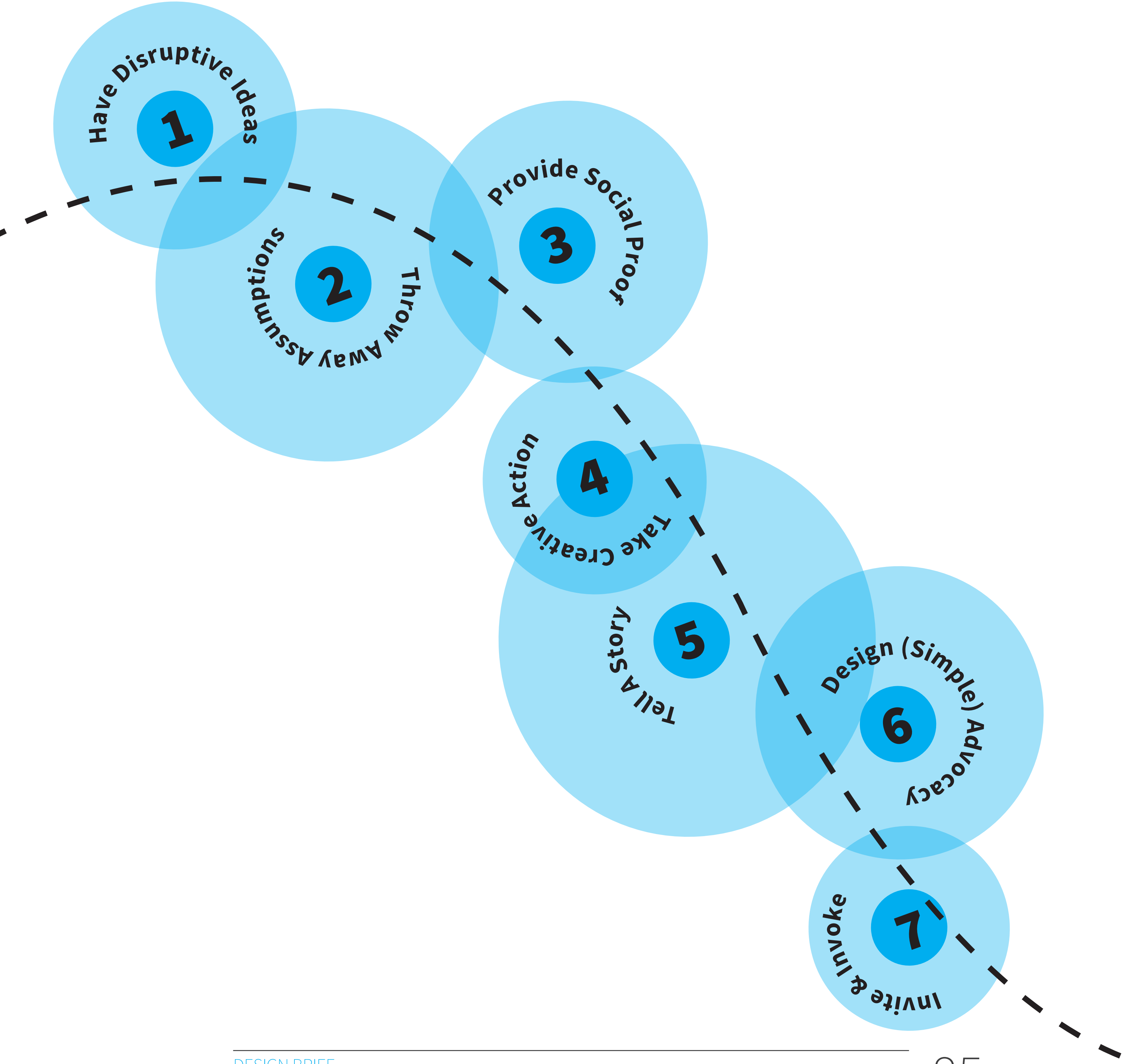


FIGURE 19.0: Graphic representation of the design-for-health framework used for the project.


1
Have Disruptive Ideas
2
Throw Away Assumptions
3
Provide Social Proof
4
Take Creative Action
5
Tell A Story
6
Design (Simple) Advocacy
7
Invite & Invoke

6.3 Structural Criteria

A model of “design as a research tool” has been recommended by design researcher, Indri Tulusan. In her *Circles of Care*, Tulusan (2004) proposes that design can be used as a way of creating awareness, and challenging our perceptions and relationship with technology (P.15). With the project’s focus on the caregiver, his/her relationship with the current health system plays a foundational role in the design of the communication material for the CAN (Caregiver Access Network) service. Caregivers are in constant communication with various health professionals, including doctors, rehabilitation experts, nurses, pharmacists, etc. These users have spent time accumulating and digesting information from a vast array of healthcare sources: digital, printed and face-to-face communication. The user group has a predefined view of what health communication materials ‘look like,’ and the CAN communication materials must reflect this, or the “service and information design approaches may “under-conceptualize” the problem” (JONES 1531). Jones warns that borrowing methods from other areas is not a successful practice when designing health applications, and that a designer must be aware of the systems users are predisposed to use and understand (2014). The communications package also recognizes that users are diverse, have different digital abilities, and should maintain a language “at a grade 6 level of reading comprehension” (BETHAN LLOYD, INTERVIEW, NOVEMBER 2014 & PROVIDENCE HEALTH CARE RCFM TEAM IN PERSONAL COMMUNICATION)

Following the aforementioned guidelines, the design package consists of the following components:

- A prototype of a website developed in sufficient detail so that it could be fully realized with proper funding and a team of professionals. (This site would be re-developed to suit the needs of the organization or health authority maintaining the system/program)

- A series of 2D take-aways for promotion and information developed through co-creation sessions and designed for use in the community setting
- A series of info graphics and a short explanatory video to explain service and designed outcomes

Caregiver Access Network (CAN) Technical Criteria:

- The Caregiver Access Network is a network comprised of the "CAN Card", a website and a series of free drop-in sessions at community centres. The name, Caregiver Access Network, and the accompanying acronym can, CAN, were conceptualized, designed and developed after research and discussion with a community psychologist using accessible language. The term "access" is a positive concept pointing toward entry or availability, defined as "the right or opportunity to use or benefit from something," (HTTP://WWW.THEFREEDICTIONARY.COM/ACCESS). The term "network" roughly means "a group of people who exchange information, contacts, and experience for professional or social purposes" (HTTP://WWW.THEFREEDICTIONARY.COM/NETWORK). By combining the terms, the result is the title of a system that is easy to understand and the acronym is both encouraging and supportive.

6.4 The CAN Card

The CAN Card (FIGURE 20, P.89) is a physical, plastic, business-card sized card that is given to the caregiver at certain touch-points in the system which I have identified through user-centred research and discussions with health authorities. The card is a tool that serves three purposes: drawing in and connecting caregivers with access to support via the caregiver access network website, providing caregivers with discounts to local community services via card use at local retailers enrolled in the system, and raising awareness in the community through continued use of a consistent and accessible graphic language.

- The CAN Card will be made available to caregivers in various locations or situations, preferably during the beginning of their caregiving experience. These ‘locations’ or ‘situations’ in the system can include a social worker at a hospital, a family physician, a church group, a family member or friend, a medical specialist and a community centre/ pharmacy/ lab pamphlet. The card will come attached to a pamphlet that contains vital information on who the card is designed for, and, how and why to activate the card and enter the Caregiver Access Network system. During discussions with the Vancouver Coastal Health Community Engagement Team, it was identified that a second, key-chain sized card (FIGURE 20, P.89) should accompany the CAN Card for visibility and ease of use.

- The CAN Card information material will give the caregiver instructions on how to log-on to the caregiveraccessnetwork.ca website and create an account to activate their card. The benefit of registering their card is access to discounts at local retailers and a monthly newsletter, but the information on the website will be accessible to those who do not wish to register their card, as access to information is key to support.

- The CAN Card will provide the caregiver with discounts at local retailers in their area. Retailers will be invited to participate in creating this community network and will display a can sticker facing outwards on their shop window to show they are a part of the Caregiver Access Network (CAN). Examples of this component of the network in action could be as basic as a local coffee shop giving a discount on coffee and a muffin for caregivers, and, as complex as a discount on fitness or relaxation classes at a community centre or yoga studio. The most important part of this element in the Caregiver Access Network (CAN) system is the community support the caregiver will experience on a daily basis.

- The third component of raising awareness in the community through a consistent and easily communicable graphic and accessible language is a primer for those who are not already in the role of caregiver, and, are also not living with a chronic condition. The messaging of support and information services within communities will become commonplace, so that when the time comes, members in the community will be equipped in advance with the knowledge where to turn for assistance and direction.

This card provides membership to the Caregiver Access Network • Upon activation, you may use this card to receive benefits associated with the Caregiver Access Network • Look for the ***can*** logo in your community or online at:

caregiveraccessnetwork.ca

FIGURE 20.0: The Caregiver Access Network card and accompanying key chain card.

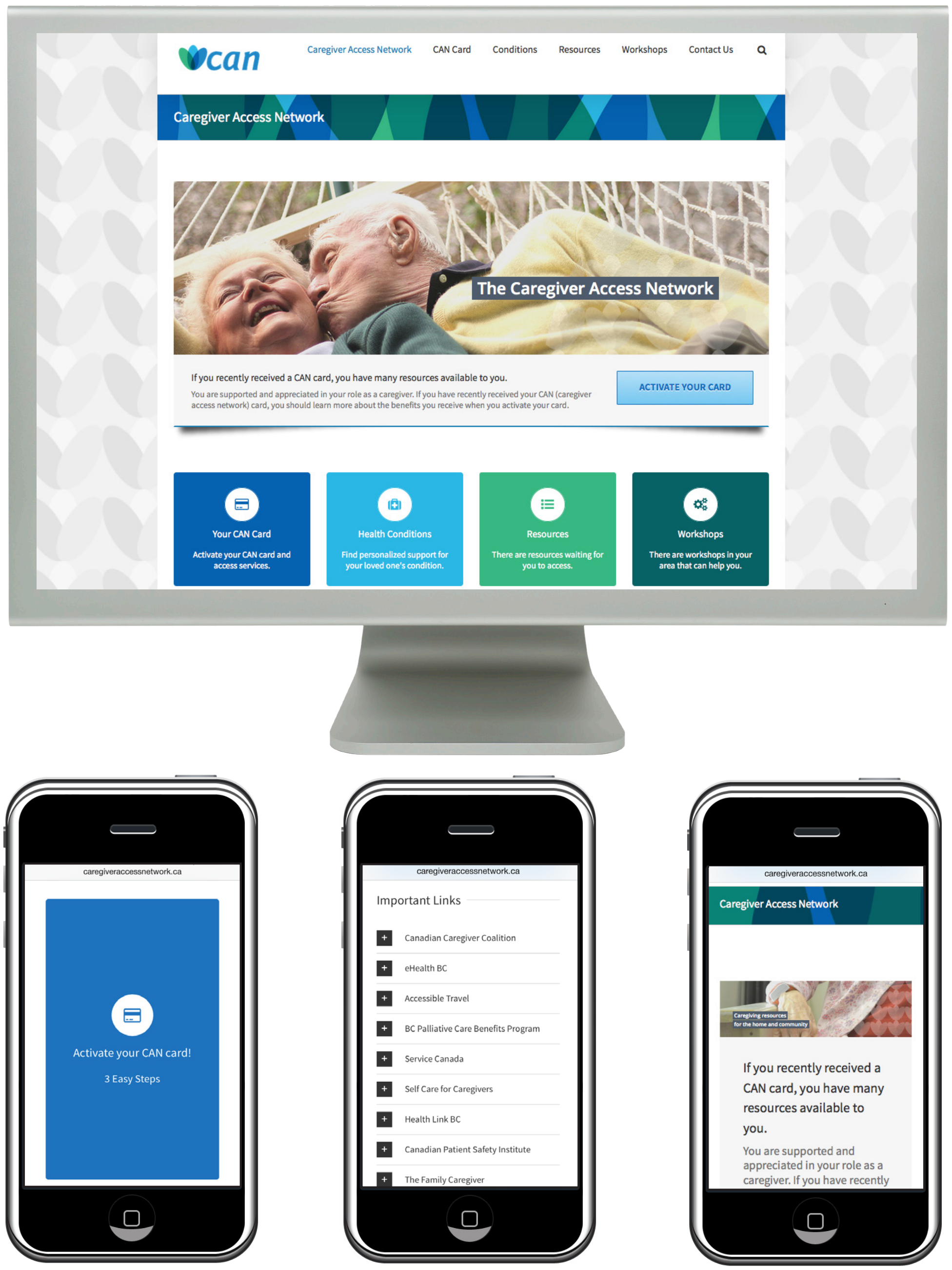
6.5 The caregiveraccessnetwork.ca Website

The website is based on precedents in the field, websites for caregivers and their families, brochures and guides for caregivers and recommendations by governing bodies such as Health Canada. For the purpose of the working model, the content has been taken and developed from current websites and programs, as well as defunct initiatives focused on caregiver support in Canada. The sections and menus are designed with best web practices for ease of use. There are several access points for each one piece of information to ensure that caregivers are able to gain knowledge on their specific needs as well as overall caregiving tips and workshops available to them.

- There are a series of workshops explained in detail on the website. The workshops may be a Caregiver Access Network (CAN) initiative in a community centre setting, or, may be located off-site at a local hospital or community health clinic. The external workshops will be submitted to and posted on the website on a monthly basis via independent contributors with specialized access to the site. The Wordpress platform allows for differing access to a website and for contributors to be able to upload content but not to either change or effect other content on the site.

- The website has a “call to action” to register the can Card the caregiver has received. After registration, the caregiver will receive an eNewsletter to the email address they have provided. The eNewsletter will provide the caregiver with further information on services available to them.

- There is a brief survey on the website that helps the user determine their immediate needs if they are uncertain how to immediately engage. The survey aggregates content from the CAN site and sends the registered user an email containing links to various points of interest.



If you recently received a CAN card, you have many resources available to you.

You are supported and appreciated in your role as a caregiver. If you have recently received your CAN (caregiver access network) card, you should learn more about the benefits you receive when you activate your card.

Activate your CAN card and access services.

Find personalized support for your loved one's condition.

There are resources waiting for you to access.

There are workshops in your area that can help you.

If you recently received a CAN card, you have many resources available to you.

You are supported and appreciated in your role as a caregiver. If you have recently

FIGURE 21.0: Screenshots of the CAN online system on various devices.

6.6 The Community Centre Drop-in Outreach Series

Another component of the system is a drop-in community-centre based program Caregiver Access Network coffee series for caregivers. This face-to-face interaction supports the City of Vancouver "Healthy City" goal of Cultivating Connections, connecting Vancouverites to "at least four people in their network that they can rely on for support in times of need." (CITY OF VANCOUVER COMMUNITY SERVICES - SOCIAL POLICY DIVISION 2014). The community centre locate was chosen after learning that 83% of residents in Vancouver live within a fifteen-minute walk of two or more "community-hubs", such as a local community centre.
(CITY OF VANCOUVER, 2013. RETRIEVED FROM: HTTP://VANCOUVER.CA/PEOPLE-PROGRAMS/HEALTHY-HUMAN-SERVICES.ASPX)

The hour-and-a-half sessions will run bi-weekly and will be a place for caregivers to meet other caregivers to share their stories over a cup of coffee. The sessions will rotate through the community centres as scheduled and will include a CAN representative as a facilitator for discussion and information dissemination. The caregivers who access this service will be able to add their issues, topics and concerns to the content of the session. The coffee will be donated by a community sponsor.

This card provides membership to the Caregiver Access Network • Upon activation, you may use this card to receive benefits associated with the Caregiver Access Network • Look for the *can* logo in your community or online at:

caregiveraccessnetwork.ca

201400112345

FIGURE 22.0: The call to action to "activate" the CAN card upon receipt of the card using the CAN number.

6.7 Use-case Scenario (step-by-step)

The CAN card and accompanying literature will be shared with the caregiver at multiple touch-points in the health system (as determined by primary research) and beyond.

- These points include, but are not limited to; in hospital, via a social worker, a General Practitioner, a public health unit, a health specialist, a church, community centre or other municipal services.
    - Other services may include retailers promoting and accepting the CAN card at their location.

FIGURE 23.0: The CAN card attached to an explanatory brochure.

- After being given the CAN card, there are instructions to “activate” the card on the caregiveraccessnetwork.ca website. (FIGURE 21.0, P.91)
    - » Upon activation, the caregiver is registered in the CAN system, and will have access to discounts at their local community retailers.
    - » The retailers who choose to be a part of the CAN system serve the dual purpose of raising awareness of the network in the community, and of visibly supporting the role of the caregiver in society.
    - » The Caregiver will be sent email newsletters, a conduit for support and services as they are developed by health authorities and public agencies.

FIGURE 24.0: The CAN Card being used at a local retailer.

- For the caregiver who prefers not to activate their card, the CAN card still acts as a tool to make them aware of the caregiveraccessnetwork.ca website, a venue for curated caregiver support and services.
- Via the website, the caregiver is presented with the opportunity to attend drop-in sessions at their local community centre, where designates from health agencies provide workshops around caregiver needs
    - » The CAN system offers a free, drop-in coffee series, in which a community sponsor provides coffee during bi-weekly drop-in sessions at the community centre. Caregivers and the person in their care are both welcome at these events, and information is provided on the caregiveraccessnetwork.ca website.

FIGURE 25.0: The CAN brochure in a pharmacy setting.

6.8 Aesthetic Criteria

The healthcare community is a discerning, evidence-driven audience. Often there are a number of constraints which manifest themselves and are equal in length to the design criteria, as the stakeholders are numerous. The clear and concise sharing of information is key. In the search for visual design precedents for the aesthetic design of the CAN system, I used my professional and academic design skills and practice as tools to search for new health authority clients, and, to keep “tabs” on recent and current precedents and trends in the healthcare and services sector. This action supplemented my design-for-health expertise and knowledge-base, and, provided an up-to-date understanding of current industry expectations.

The aesthetics have been determined by the collection of data from a co-creation workshop, a broad health-design precedent study, and from my understanding and current work as a designer in the field of health.

6.9 Usability and Design Precedents

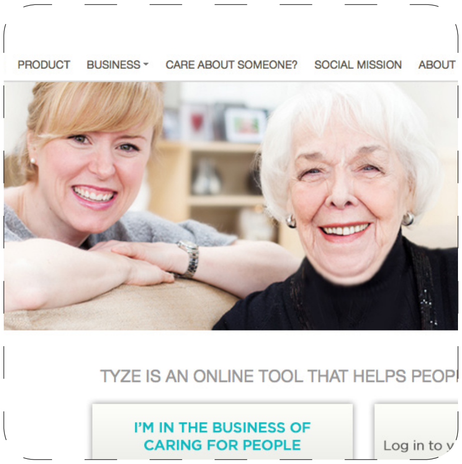
Current usability standards were researched for the development of the online CAN presence. A Wordpress website was chosen and prototyped for the system to as it allows for multiple authors, forms and plug-ins to aid in the delivery of content.

The following visual precedents (PP. 98 - 101) represent a selection of the precedents consulted in the development of the visual identity of the CAN system. They include both client-based and world-wide health design initiatives. The visual design elements drawn on provide the project with a solid visual foundation.

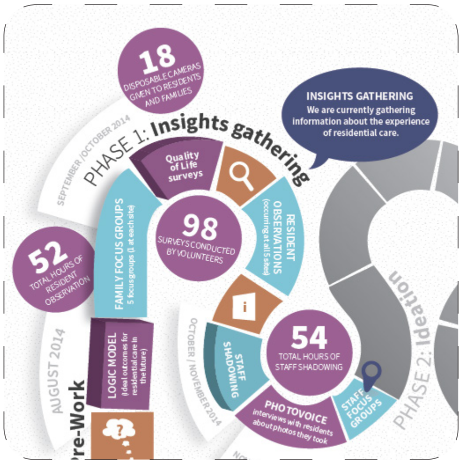
FIGURE 26.0: The CAN explanatory brochure in a pharmacy location.

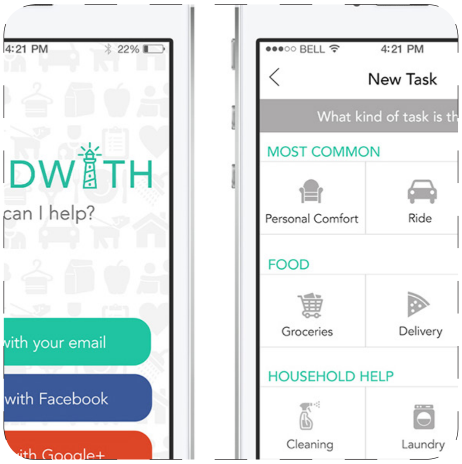
6.10 **VISUAL PRECEDENTS**

Getting immunized a
and easy. Easier thar
cancer in the prime c
a woman born betwe
it's free.



TYZE IS AN ONLINE TOOL THAT HELPS PEOP





What was learned from these precedents:

WIRED Magazine: How Restyling the Mundane Medical Record Could Improve Health Care

TYPOGRAPHY

COLOUR

LAYOUT

SIMPLICITY

http://www.wired.com/2013/01/medical-record-

Don’t Get Screwed by Cancer Website and App

TYPOGRAPHY

LARGE CALL TO ACTION BUTTONS

ICONS

EASY TO READ TEXT

http://dontgetcancer.ca

TYZE Personal Networks:

PEOPLE TOGETHER

COLOUR

MULTI-GENERATIONAL PEOPLE

LARGE CALL TO ACTION BUTTONS

http://tyze.com/

Providence Health Care Residential Care for ME:

LANGUAGE

DESCRIPTIVE TEXT

LARGE CALL OUTS

DROP SHADOW

StandWith App

TYPOGRAPHY

COLOUR

ICONS

LARGE CALL TO ACTION BUTTONS

http://www.standwith.com

St. Paul’s Hospital AMS Annual Report

COLOUR

OPACITIES

TYPOGRAPHY

CLEAR IMAGES

6.11 **VISUAL DESIGN**

COLOUR

LAYOUT

SIMPLICITY

TYPOGRAPHY

ICONS

EASY TO READ TEXT

PEOPLE TOGETHER

MULTI-GENERATIONAL PEOPLE

LARGE CALL TO ACTION BUTTONS

DESCRIPTIVE TEXT

LARGE CALL OUTS

DROP SHADOW

ICONS

LARGE CALL TO ACTION BUTTONS

OPACITIES

CONSISTENCY

CLEAR IMAGES

How the information was applied:

can

Caregiver Access Net

Caregiver Access Network

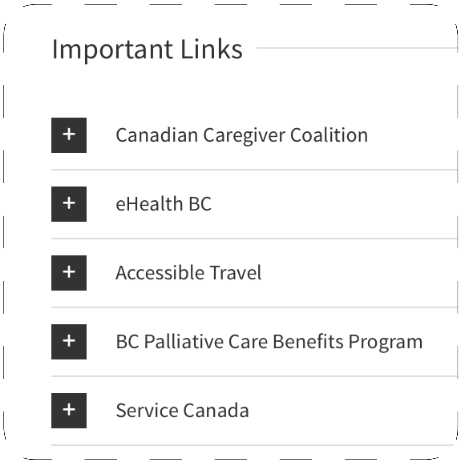
If you recently received a CAN card, you have man

You are supported and appreciated in your role as a car
access network) card, you should learn more about the

About the Caregiver

The Caregiver Access Netwo
over 8 million Canadians whc
long-term health condition, a

We echo The Canadian Careg
of and respect for the valu
sustainability of our health c
country," ensuring this a prior



Important Links

- \+ Canadian Caregiver Coalition
- \+ eHealth BC
- \+ Accessible Travel
- \+ BC Palliative Care Benefits Program
- \+ Service Canada

7.0 **CONCLUSION**

NARRATIVE | 2013 | FALL

Early in the conceptualizing and research phase for this thesis, I spoke with a woman who told me the story of how she cared for her mother as her mother battled cancer. The woman talked of the outpouring of help and well-wishes from friends and family, and how sometimes all she needed was to know she wasn't the only person awake in the middle of the night as she watched her mother sleep. "You should design something," she said, "something that helps people feel less alone." (Personal communication, October 2013)

The story she told that day stuck with me, and, I questioned how design research and methodologies could contribute to the emotional and psychological well-being of the caregiver. Through personal experience, I was able to make a connection between the well-being of the caregiver and that of the patient or person with a chronic condition, and I began to understand this relationship as being central to the delivery of 'people-centred care' (VCH, PHC). But the question remained, how could a designer make a caregiver "feel less alone"?

Through extensive primary and secondary research, I found that for the Caregiver to be supported through design, I must make the case for the implementation of design methods in healthcare services.

The Social Health Project challenged the traditional view of design in the health system, and through the development of the CAN service, proved the potential of the uses of design-oriented research methods in healthcare services and initiatives. This new paradigm of the designer being involved in the project/process from the outset and on to the conclusion (and beyond) allows for the system to evolve organically and meet the needs of the intended user. With this being a practical/social application of Meta-design, the SHP demonstrated the validity of this new design-for-health model for designers to use when working with multidisciplinary teams of health professionals and workers in the field of health.

Through the blending of both anecdotal and personal experience with existing literature, models and precedents, evidence-based design decisions led to the creation of a method to apply to other health care issues/projects. The exploration of a personal narrative and story-telling techniques provided evidence of the essentialness of telling the story of healthcare, as it invites new HCD perspectives. This approach proves that HCD methods are well-suited to be applied to health care and the delivery of health care services.

Though the project changed course since it’s early stages of research, it stayed true to the goals outlined by the City of Vancouver’s Healthy City Strategy. Design methods and theory were used to create a service (CAN) that gives “equitable access to high quality health services” (GOAL 4), and a space in which Vancouverites could “have at least four people in their network that they can rely on for support in times of need” (GOAL 7 - CITY OF VANCOUVER COMMUNITY SERVICES - SOCIAL POLICY DIVISION 2014)

The research conducted has accumulated a wealth of information and resulted in several meaningful outcomes, including a prototype of a service that meets and anticipates the needs of the caregiver, and, a model that describes the potential of employing and involving a designer at the outset of a healthcare-based initiative. These actions represent a selection of the outcomes from the body of work that went into the crafting of this thesis, and, as definitive as they may appear, they are far from resolution and conclusion. Healthcare, by its very nature and dynamic, provides an endlessly changing and shifting environment for design challenges, especially when designers heed the call to “help clinicians and patients navigate complex situations” (JONES, 2013, P.310). To make significant gains beyond this point requires the energy not of a single designer, but of public health institutions that are made aware of the role of design and designers who focus on the complicated and dynamic needs of those navigating this system.

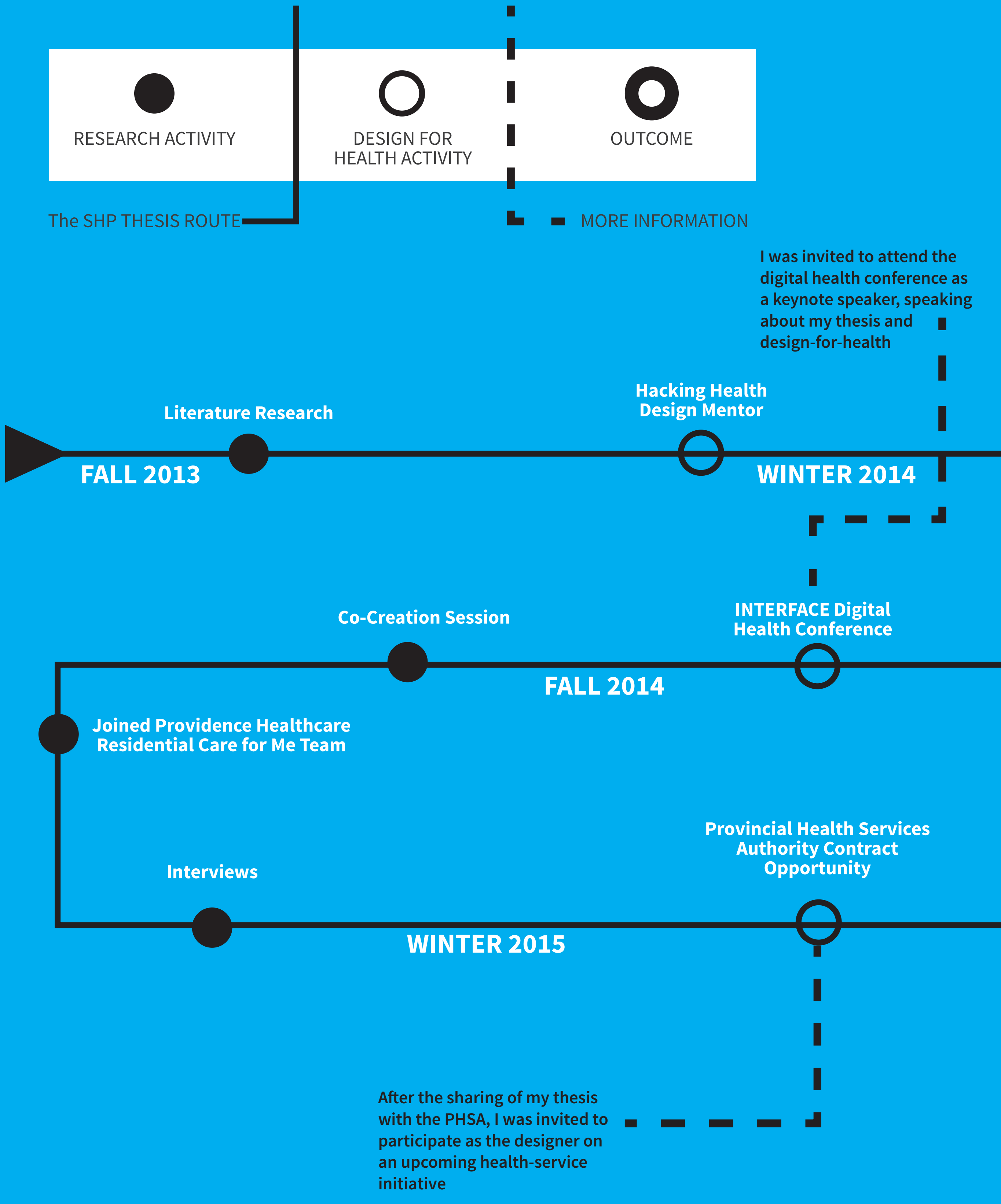
The only solid conclusion from the Social Health Project is that we must continue to **design things that make people feel less alone.** The caregiver is but one unsupported asset of the health system, and designers trained to work in a health-service environment are poised to uncover new ways to support the patient. Though this thesis touched on one aspect of care, a growing and aging population will bring with it a continued need to sustain health services with new modes of thinking. As Helliwell states (2015);

> We need to honour the rich and deep knowledge of health care providers and staff and work in partnership with others (designers to name but one) to help us generate the solutions for a system that is built for all of us” (HELLIWELL, PERSONAL INTERVIEW, JANUARY 2015).

THE SOCIAL HEALTH PROJECT

My sincere gratitude extends | To those who participated in my research and offered their personal stories of caregiving and living with a chronic condition | To those who gave me the opportunity to interview them, both formally and informally | To my colleagues and professors at Emily Carr University for their ongoing support and patience while the project changed (time and time again) | To my supervisor, Deborah Shackleton, for everything (!) | To my family, most notably my father, Raymond Galbraith, to whom this work is dedicated.

8.0 TSHP TIME LINE



● RESEARCH ACTIVITY

○ DESIGN FOR HEALTH ACTIVITY

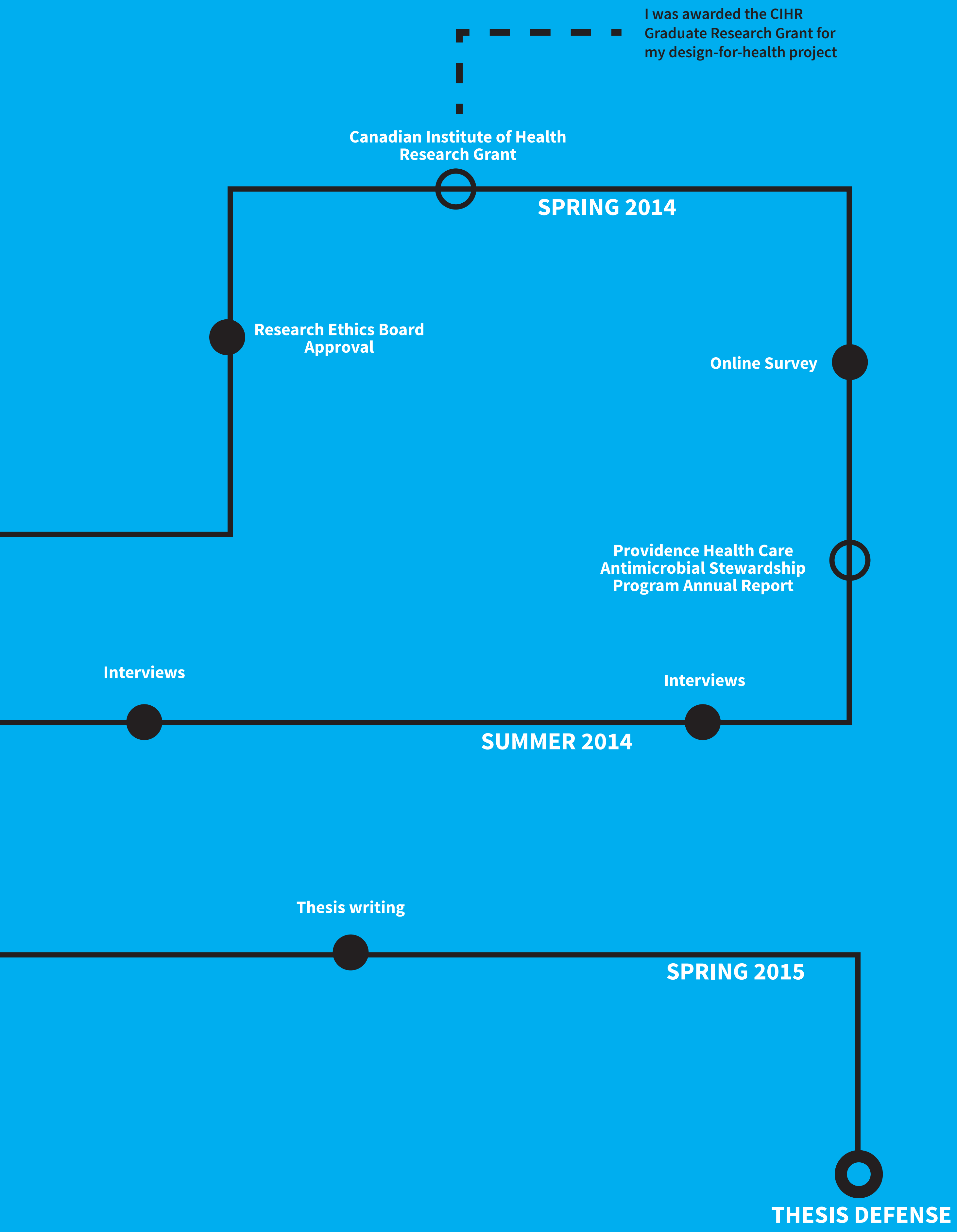
◉ OUTCOME

The SHP THESIS ROUTE

MORE INFORMATION

I was invited to attend the digital health conference as a keynote speaker, speaking about my thesis and design-for-health

After the sharing of my thesis with the PHSA, I was invited to participate as the designer on an upcoming health-service initiative



Research Ethics Board Approval

Canadian Institute of Health Research Grant

I was awarded the CIHR Graduate Research Grant for my design-for-health project

SPRING 2014

Online Survey

Providence Health Care Antimicrobial Stewardship Program Annual Report

Interviews

SUMMER 2014

Interviews

Thesis writing

SPRING 2015

THESIS DEFENSE

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9.1 IMAGE REFERENCES

https://www.flickr.com/photos/adwriter/

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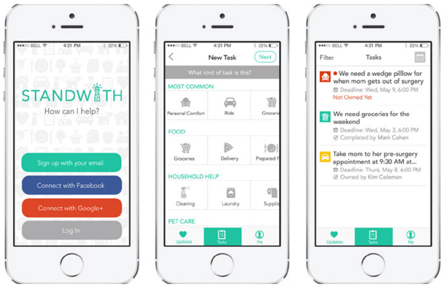


We need a wedge pilllow for when mom gets out of surgery
Deadline: Wed, May 9, 6:00 PM
Not Owned Yet

We need groceries for the weekend
Deadline: Wed, May 3, 6:00 PM
Completed by Mark Cohen

Take mom to her pre-surgery appointment at 9:30 AM at...
Deadline: Thurs, May 8, 6:00 PM
Owned by Kim Coleman

http://www.standwith.com

Providence Health Care:
Residential Care for Me

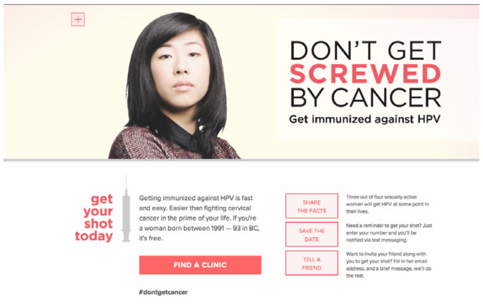
The Residential Care for Me project has been in action for many months. The project team has spent hours watching, listening and talking to residents, families and staff, as well as doing research on care homes around the world. Thank you for allowing us into your lives and sharing your experiences with us. A lot has been done but there is still a lot of work to do!

In January and February, we will spend more time talking to residents who took photos of things that were meaningful for them and will host staff focus groups at all sites. Following that, we will create a list of opportunities for improvement that we will tell you about. Then the fun begins!

Starting March, we will bring residents, families and staff together to think up crazy, wild, new ideas. Together, we will create the solutions that make sense for all of us. That includes you. YOU, the resident. YOU, the family. And YOU, the staff.

Thank you for your patience throughout this project. At any time, if you feel like you haven't heard from us in a while, please ask your Operations Leader for more information.

PHC RCFM Infographic



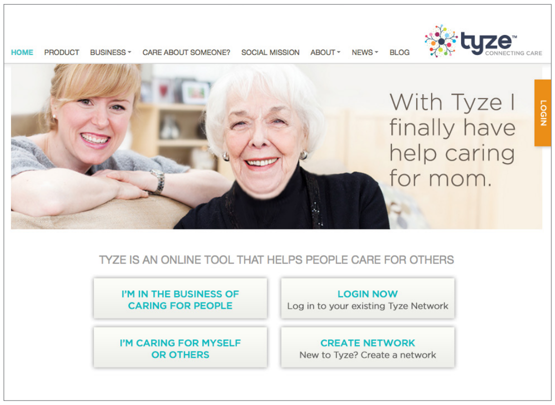
Getting immunized against HPV is fast and easy. Easier than fighting cervical cancer in the prime of your life. If you're a woman born between 1991 — 93 in BC, it's free.

Three out of four sexually active women will get HPV at some point in their lives.

Need a reminder to get your shot? Just enter your number and you'll be notified via text messaging.

Want to invite your friend along with you to get your shot? Fill in her email address, and a brief message, we'll do the rest.

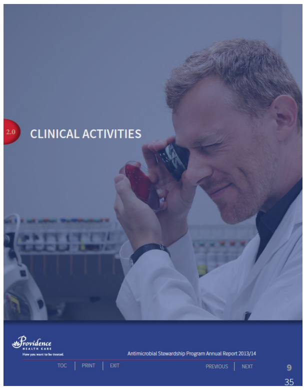
https://www.dontgetcancer.ca



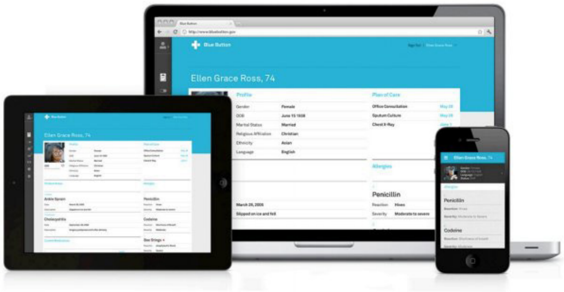
With Tyze I finally have help caring for mom.

TYZE IS AN ONLINE TOOL THAT HELPS PEOPLE CARE FOR OTHERS

https://www.tyze.com



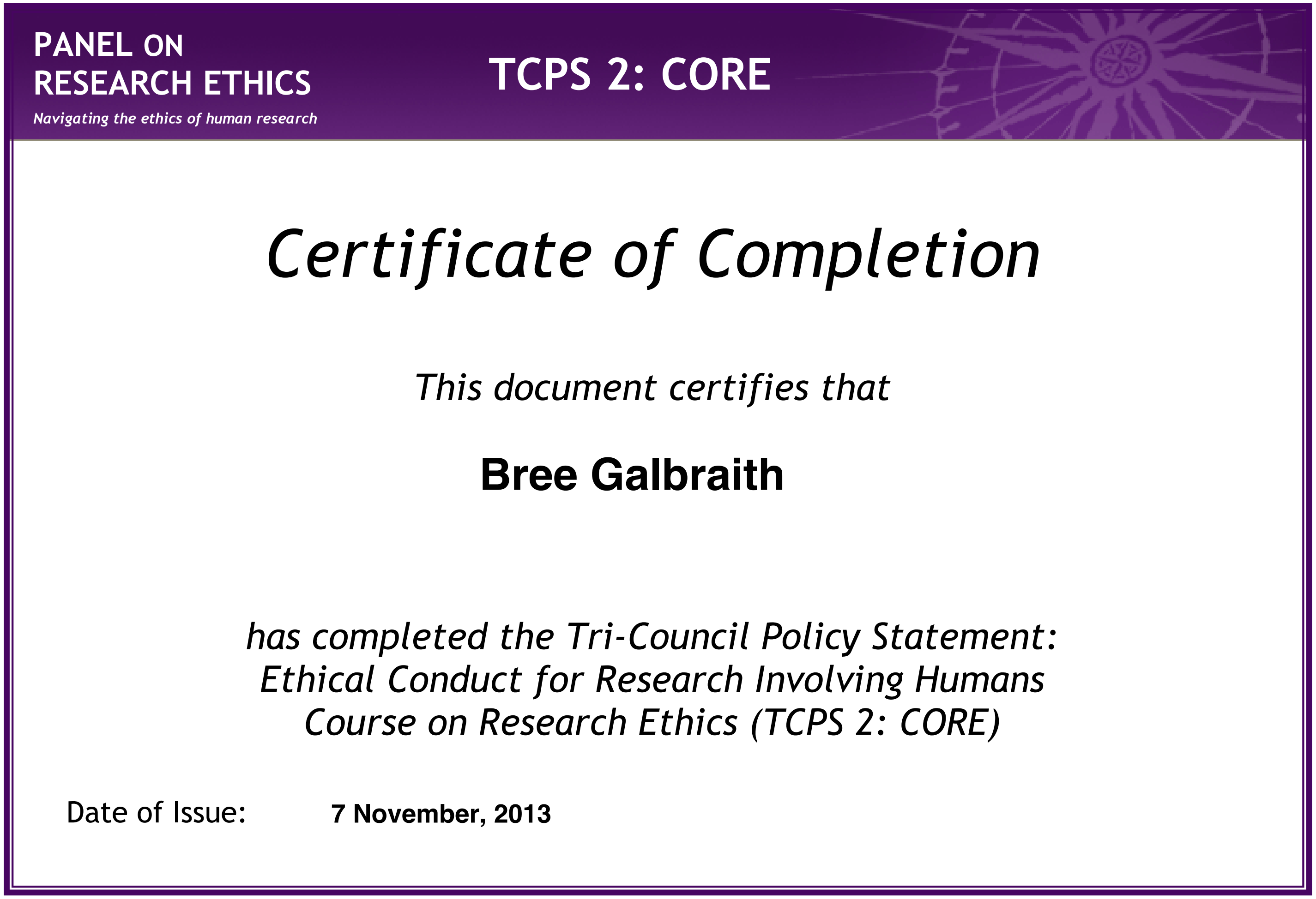
St. Paul's AMS Annual Report 2013



http://www.wired.com/2013/01/
medical-record-

10.0 **APPENDIX**

Research Ethics Course



PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

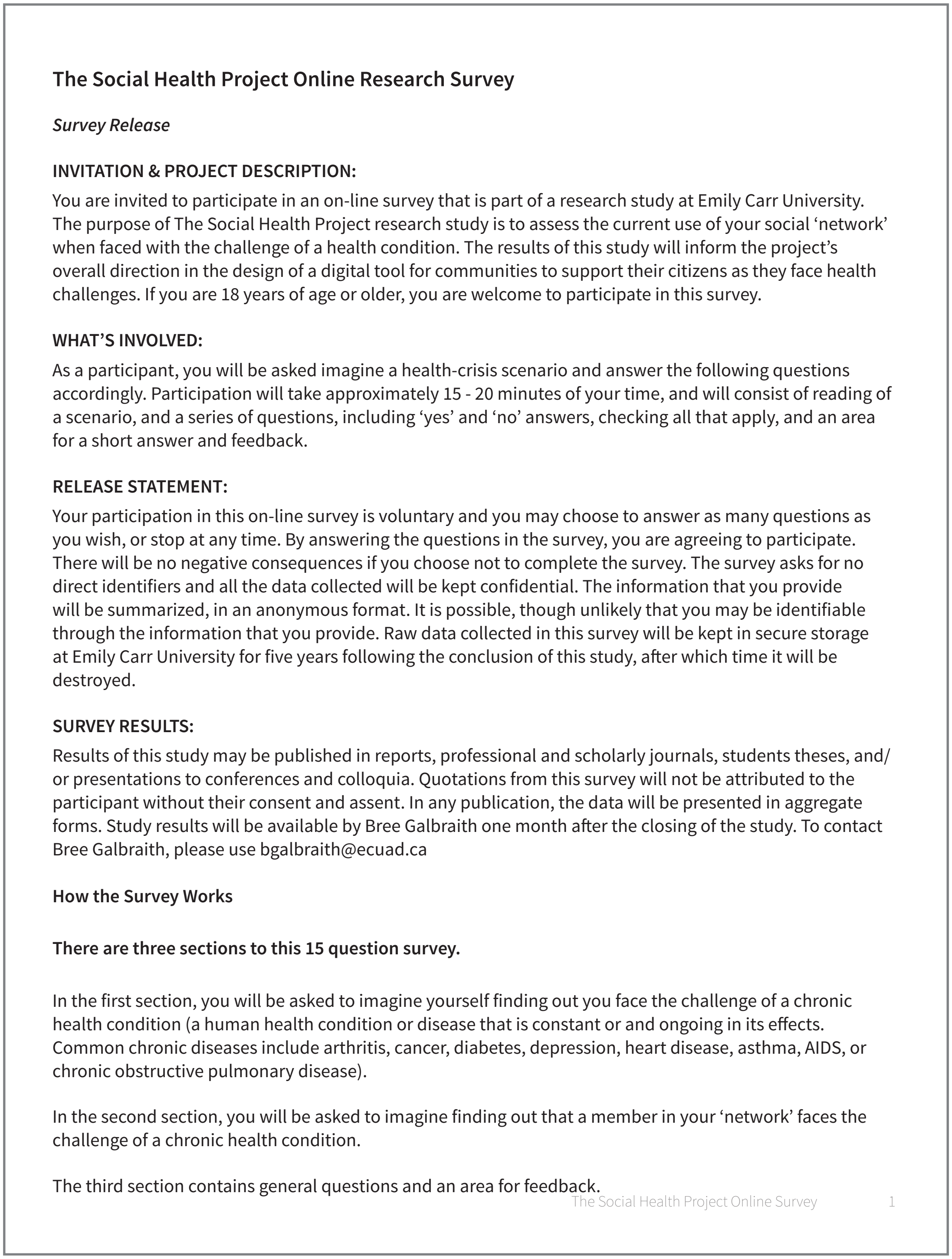
This document certifies that

Bree Galbraith

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

Date of Issue: **7 November, 2013**

Online Research Survey Consent



The Social Health Project Online Research Survey

Survey Release

INVITATION & PROJECT DESCRIPTION:

You are invited to participate in an on-line survey that is part of a research study at Emily Carr University. The purpose of The Social Health Project research study is to assess the current use of your social 'network' when faced with the challenge of a health condition. The results of this study will inform the project's overall direction in the design of a digital tool for communities to support their citizens as they face health challenges. If you are 18 years of age or older, you are welcome to participate in this survey.

WHAT'S INVOLVED:

As a participant, you will be asked imagine a health-crisis scenario and answer the following questions accordingly. Participation will take approximately 15 - 20 minutes of your time, and will consist of reading of a scenario, and a series of questions, including 'yes' and 'no' answers, checking all that apply, and an area for a short answer and feedback.

RELEASE STATEMENT:

Your participation in this on-line survey is voluntary and you may choose to answer as many questions as you wish, or stop at any time. By answering the questions in the survey, you are agreeing to participate. There will be no negative consequences if you choose not to complete the survey. The survey asks for no direct identifiers and all the data collected will be kept confidential. The information that you provide will be summarized, in an anonymous format. It is possible, though unlikely that you may be identifiable through the information that you provide. Raw data collected in this survey will be kept in secure storage at Emily Carr University for five years following the conclusion of this study, after which time it will be destroyed.

SURVEY RESULTS:

Results of this study may be published in reports, professional and scholarly journals, students theses, and/or presentations to conferences and colloquia. Quotations from this survey will not be attributed to the participant without their consent and assent. In any publication, the data will be presented in aggregate forms. Study results will be available by Bree Galbraith one month after the closing of the study. To contact Bree Galbraith, please use bgalbraith@ecuad.ca

How the Survey Works

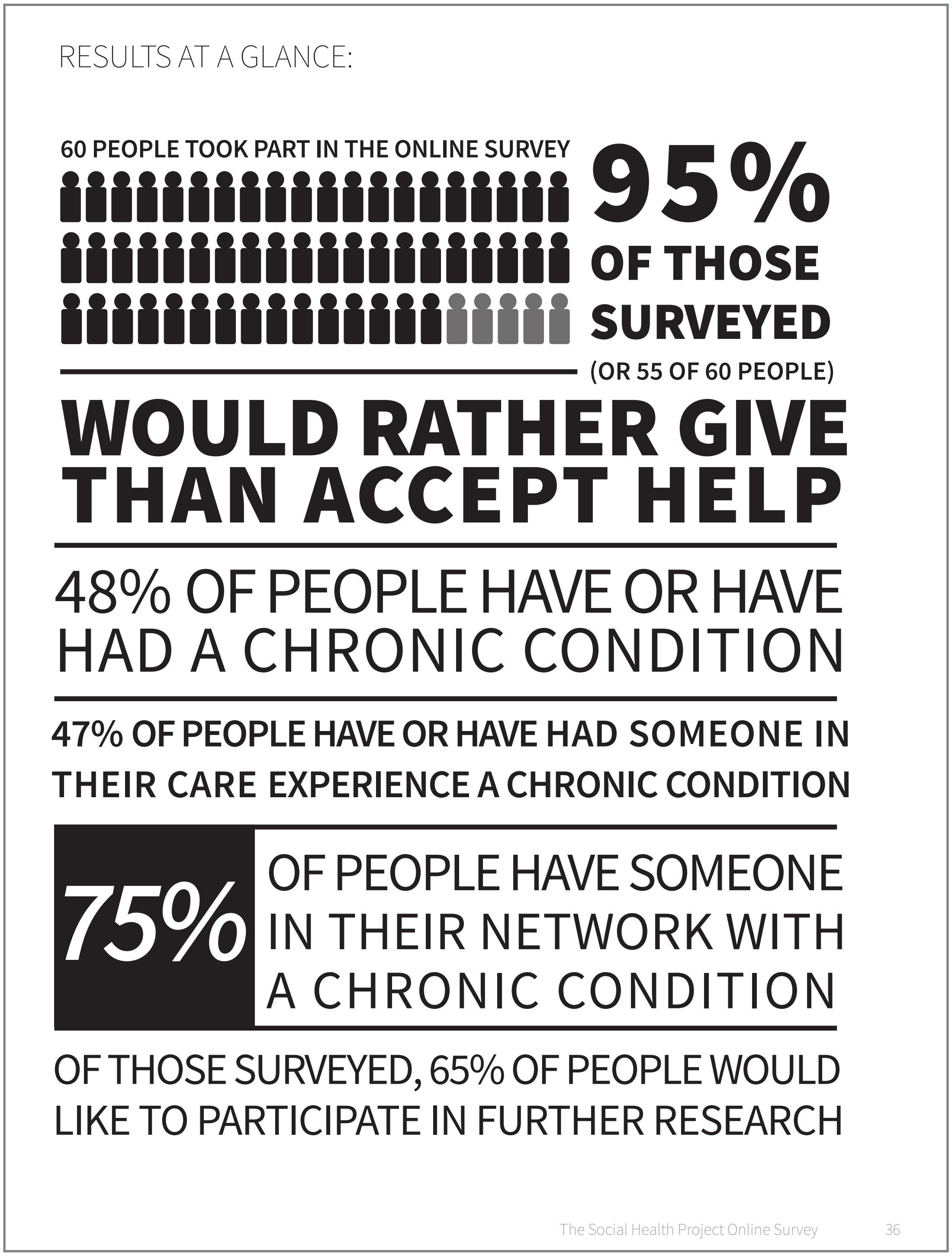
There are three sections to this 15 question survey.

In the first section, you will be asked to imagine yourself finding out you face the challenge of a chronic health condition (a human health condition or disease that is constant or and ongoing in its effects. Common chronic diseases include arthritis, cancer, diabetes, depression, heart disease, asthma, AIDS, or chronic obstructive pulmonary disease).

In the second section, you will be asked to imagine finding out that a member in your 'network' faces the challenge of a chronic health condition.

The third section contains general questions and an area for feedback.

Research Survey results at a glance



RESULTS AT A GLANCE:

60 PEOPLE TOOK PART IN THE ONLINE SURVEY

95%

OF THOSE SURVEYED

(OR 55 OF 60 PEOPLE)

WOULD RATHER GIVE THAN ACCEPT HELP

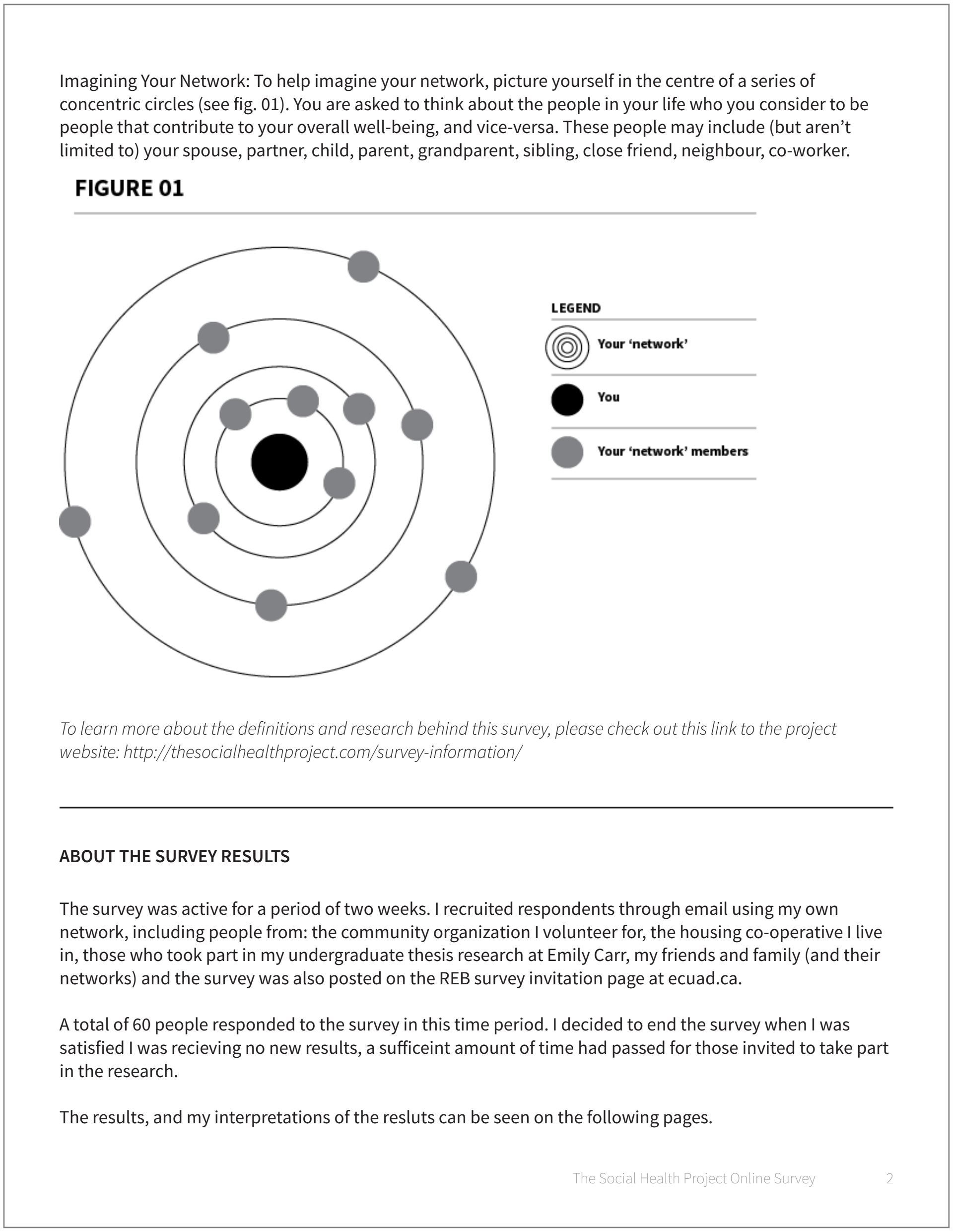
48% OF PEOPLE HAVE OR HAVE HAD A CHRONIC CONDITION

47% OF PEOPLE HAVE OR HAVE HAD SOMEONE IN THEIR CARE EXPERIENCE A CHRONIC CONDITION

75% OF PEOPLE HAVE SOMEONE IN THEIR NETWORK WITH A CHRONIC CONDITION

OF THOSE SURVEYED, 65% OF PEOPLE WOULD LIKE TO PARTICIPATE IN FURTHER RESEARCH

Research Survey results



Imagining Your Network: To help imagine your network, picture yourself in the centre of a series of concentric circles (see fig. 01). You are asked to think about the people in your life who you consider to be people that contribute to your overall well-being, and vice-versa. These people may include (but aren't limited to) your spouse, partner, child, parent, grandparent, sibling, close friend, neighbour, co-worker.

FIGURE 01

To learn more about the definitions and research behind this survey, please check out this link to the project website: http://thesocialhealthproject.com/survey-information/

ABOUT THE SURVEY RESULTS

The survey was active for a period of two weeks. I recruited respondents through email using my own network, including people from: the community organization I volunteer for, the housing co-operative I live in, those who took part in my undergraduate thesis research at Emily Carr, my friends and family (and their networks) and the survey was also posted on the REB survey invitation page at ecuad.ca.

A total of 60 people responded to the survey in this time period. I decided to end the survey when I was satisfied I was recieving no new results, a sufficeint amount of time had passed for those invited to take part in the research.

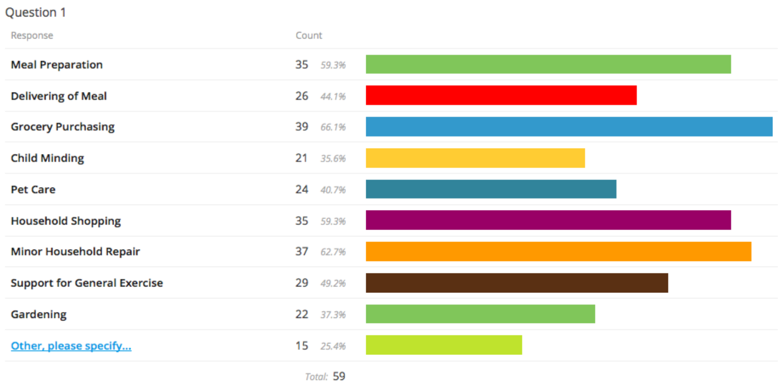
The results, and my interpretations of the resluts can be seen on the following pages.

SECTION 1: ACCEPTING HELP

Question 1

Everyday Help: Upon accepting help from a close member of your network to support the self-management of your chronic condition, please check the following ways in which you may require help (choose as many as apply):

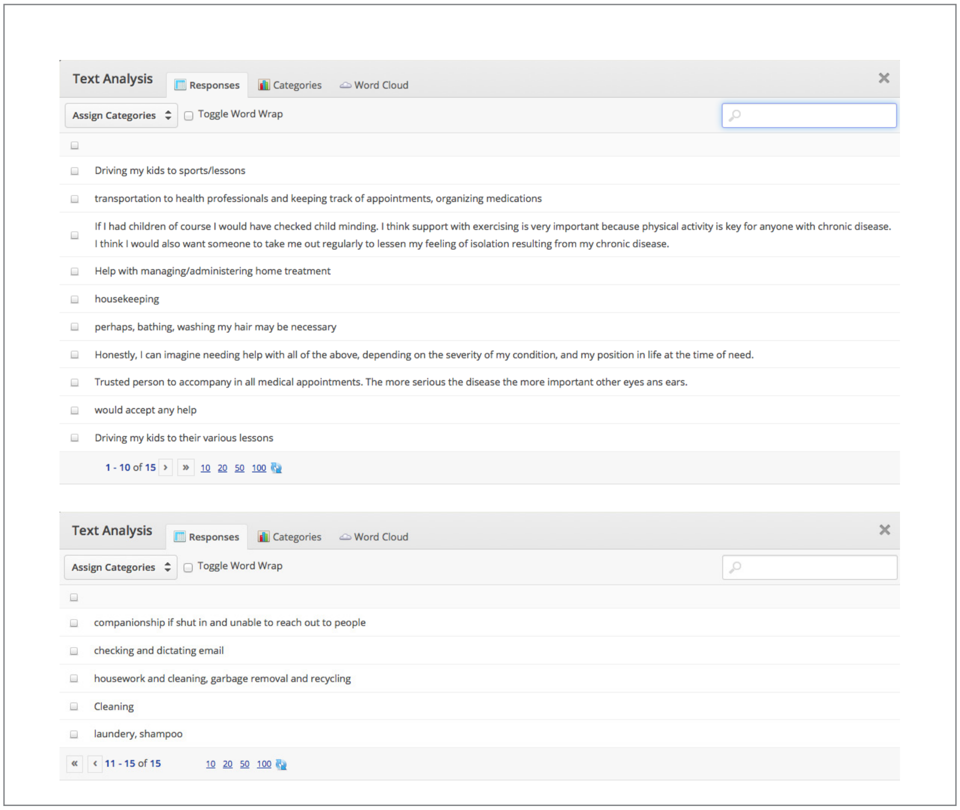
- Meal Preparation
- Delivering of Meal
- Grocery Purchasing
- Child Minding
- Pet Care
- Household Shopping
- Minor Household Repair
- Support for General Exercise
- Gardening
- Other, please specify...



Question 1

Response	Count	
Meal Preparation	35	*59.3%*
Delivering of Meal	26	*44.1%*
Grocery Purchasing	39	*66.1%*
Child Minding	21	*35.6%*
Pet Care	24	*40.7%*
Household Shopping	35	*59.3%*
Minor Household Repair	37	*62.7%*
Support for General Exercise	29	*49.2%*
Gardening	22	*37.3%*
Other, please specify...	15	*25.4%*
	Total: 59	

Research Survey results



☐

☐ Driving my kids to sports/lessons

☐ transportation to health professionals and keeping track of appointments, organizing medications

☐ If I had children of course I would have checked child minding. I think support with exercising is very important because physical activity is key for anyone with chronic disease. I think I would also want someone to take me out regularly to lessen my feeling of isolation resulting from my chronic disease.

☐ Help with managing/administering home treatment

☐ housekeeping

☐ perhaps, bathing, washing my hair may be necessary

☐ Honestly, I can imagine needing help with all of the above, depending on the severity of my condition, and my position in life at the time of need.

☐ Trusted person to accompany in all medical appointments. The more serious the disease the more important other eyes ans ears.

☐ would accept any help

☐ Driving my kids to their various lessons

☐

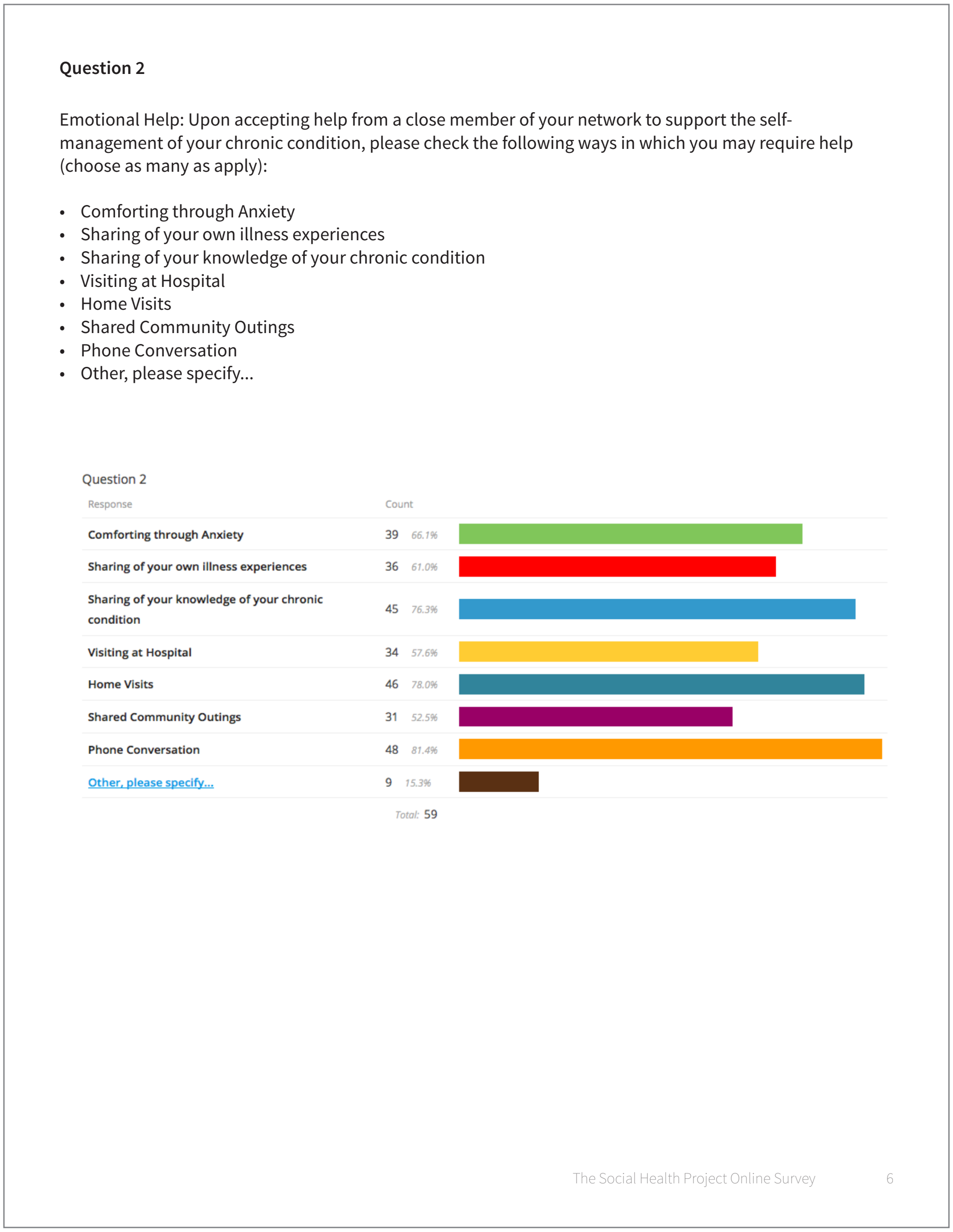
☐ companionship if shut in and unable to reach out to people

☐ checking and dictating email

☐ housework and cleaning, garbage removal and recycling

☐ Cleaning

☐ laundery, shampoo



Question 2

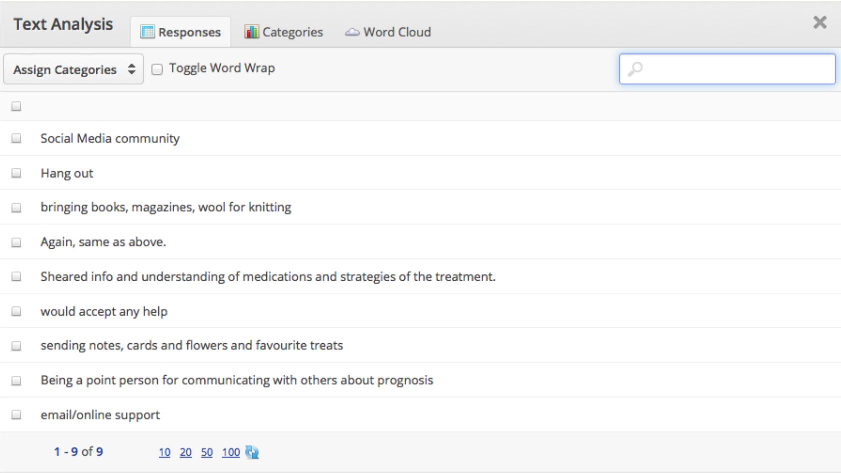
Emotional Help: Upon accepting help from a close member of your network to support the self-management of your chronic condition, please check the following ways in which you may require help (choose as many as apply):

- Comforting through Anxiety
- Sharing of your own illness experiences
- Sharing of your knowledge of your chronic condition
- Visiting at Hospital
- Home Visits
- Shared Community Outings
- Phone Conversation
- Other, please specify...

Question 2

Response	Count	
Comforting through Anxiety	39	*66.1%*
Sharing of your own illness experiences	36	*61.0%*
Sharing of your knowledge of your chronic condition	45	*76.3%*
Visiting at Hospital	34	*57.6%*
Home Visits	46	*78.0%*
Shared Community Outings	31	*52.5%*
Phone Conversation	48	*81.4%*
Other, please specify...	9	*15.3%*
	Total: 59	

Research Survey results



☐

☐ Social Media community

☐ Hang out

☐ bringing books, magazines, wool for knitting

☐ Again, same as above.

☐ Sheared info and understanding of medications and strategies of the treatment.

☐ would accept any help

☐ sending notes, cards and flowers and favourite treats

☐ Being a point person for communicating with others about prognosis

☐ email/online support

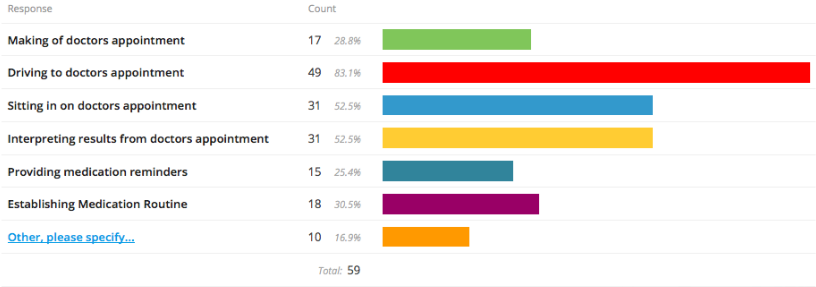
1 - 9 of 9 10 20 50 100

Question 3

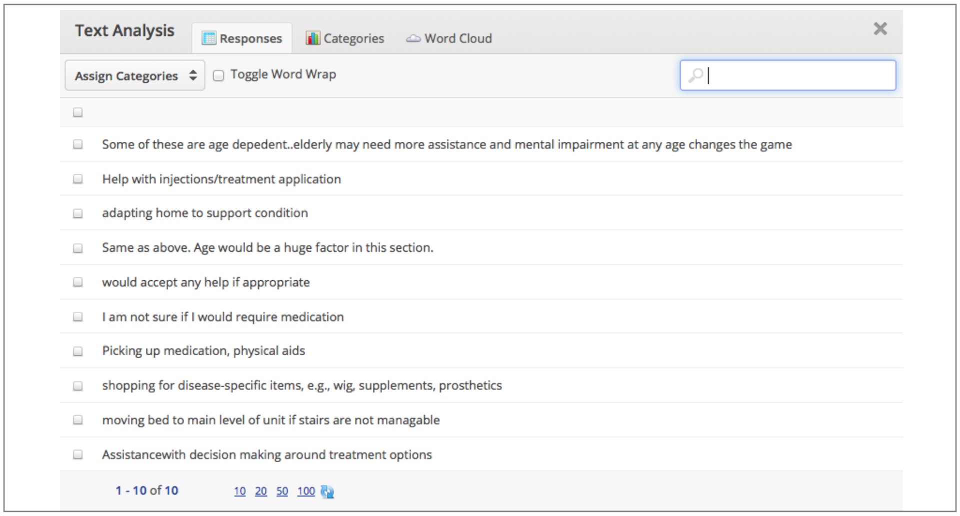
Illness Help: Upon accepting help from a close member of your network to support the self-management of your chronic condition, please check the following ways in which you may require help (choose as many as apply):

- Making of doctors appointment
- Driving to doctors appointment
- Sitting in on doctors appointment
- Interpreting results from doctors appointment
- Providing medication reminders
- Establishing Medication Routine
- Other, please specify...

Question 3



Response	Count	
Making of doctors appointment	17	28.8%
Driving to doctors appointment	49	83.1%
Sitting in on doctors appointment	31	52.5%
Interpreting results from doctors appointment	31	52.5%
Providing medication reminders	15	25.4%
Establishing Medication Routine	18	30.5%
Other, please specify...	10	16.9%
	Total: 59	



☐

☐ Some of these are age depedent..elderly may need more assistance and mental impairment at any age changes the game

☐ Help with injections/treatment application

☐ adapting home to support condition

☐ Same as above. Age would be a huge factor in this section.

☐ would accept any help if appropriate

☐ I am not sure if I would require medication

☐ Picking up medication, physical aids

☐ shopping for disease-specific items, e.g., wig, supplements, prosthetics

☐ moving bed to main level of unit if stairs are not managable

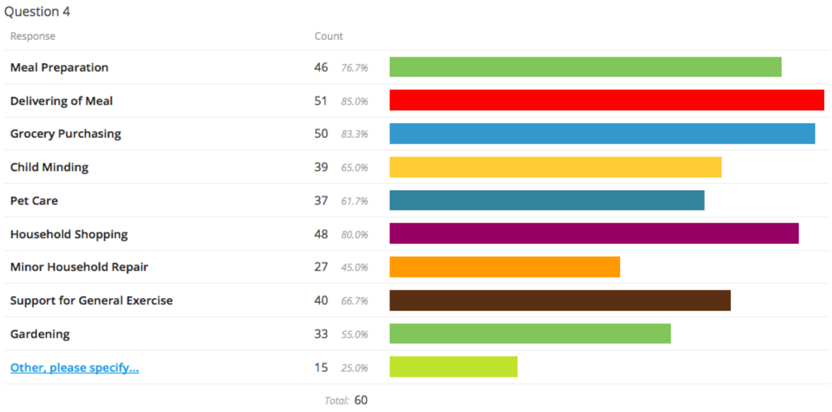
☐ Assistancewith decision making around treatment options

SECTION 2: OFFERING HELP

Question 4

Everyday Help: Upon offering help to a close member of your network to support the self-management of their chronic condition, please check the following ways in which you would be able to help (choose as many as apply):

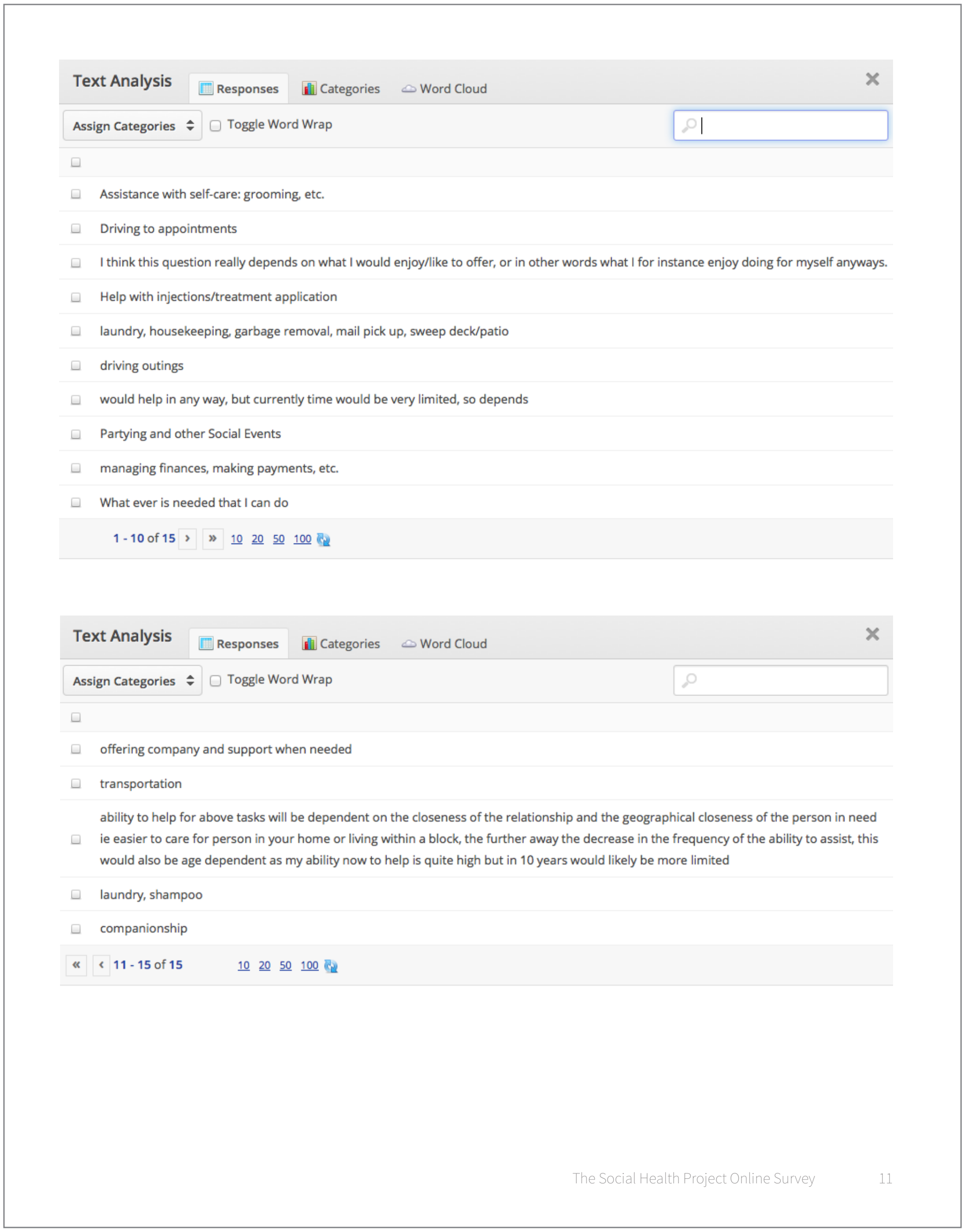
- Meal Preparation
- Delivering of Meal
- Grocery Purchasing
- Child Minding
- Pet Care
- Household Shopping
- Minor Household Repair
- Support for General Exercise
- Gardening
- Other, please specify...



Question 4

Response	Count	
Meal Preparation	46	76.7%
Delivering of Meal	51	85.0%
Grocery Purchasing	50	83.3%
Child Minding	39	65.0%
Pet Care	37	61.7%
Household Shopping	48	80.0%
Minor Household Repair	27	45.0%
Support for General Exercise	40	66.7%
Gardening	33	55.0%
Other, please specify...	15	25.0%
	Total: 60	

Research Survey results



☐

☐ Assistance with self-care: grooming, etc.

☐ Driving to appointments

☐ I think this question really depends on what I would enjoy/like to offer, or in other words what I for instance enjoy doing for myself anyways.

☐ Help with injections/treatment application

☐ laundry, housekeeping, garbage removal, mail pick up, sweep deck/patio

☐ driving outings

☐ would help in any way, but currently time would be very limited, so depends

☐ Partying and other Social Events

☐ managing finances, making payments, etc.

☐ What ever is needed that I can do

☐

☐ offering company and support when needed

☐ transportation

☐ ability to help for above tasks will be dependent on the closeness of the relationship and the geographical closeness of the person in need ie easier to care for person in your home or living within a block, the further away the decrease in the frequency of the ability to assist, this would also be age dependent as my ability now to help is quite high but in 10 years would likely be more limited

☐ laundry, shampoo

☐ companionship

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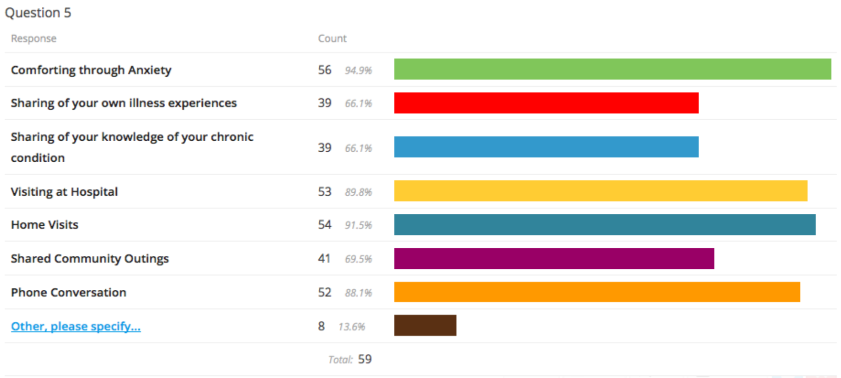
Question 5

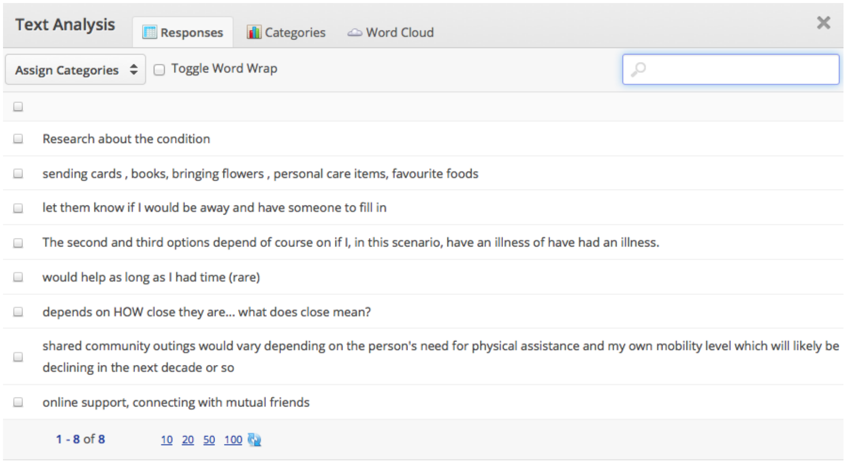
Emotional Help: Upon offering help to a close member of your network to support the self-management of their chronic condition, please check the following ways in which you would be able to help (choose as many as apply):

- Comforting through Anxiety
- Sharing of your own illness experiences
- Sharing of your knowledge of your chronic condition
- Visiting at Hospital
- Home Visits
- Shared Community Outings
- Phone Conversation
- Other, please specify...



Question 5

Response	Count	
Comforting through Anxiety	56	94.9%
Sharing of your own illness experiences	39	66.1%
Sharing of your knowledge of your chronic condition	39	66.1%
Visiting at Hospital	53	89.8%
Home Visits	54	91.5%
Shared Community Outings	41	69.5%
Phone Conversation	52	88.1%
Other, please specify...	8	13.6%
	Total: 59	



☐

☐ Research about the condition

☐ sending cards , books, bringing flowers , personal care items, favourite foods

☐ let them know if I would be away and have someone to fill in

☐ The second and third options depend of course on if I, in this scenario, have an illness of have had an illness.

☐ would help as long as I had time (rare)

☐ depends on HOW close they are... what does close mean?

☐ shared community outings would vary depending on the person's need for physical assistance and my own mobility level which will likely be declining in the next decade or so

☐ online support, connecting with mutual friends

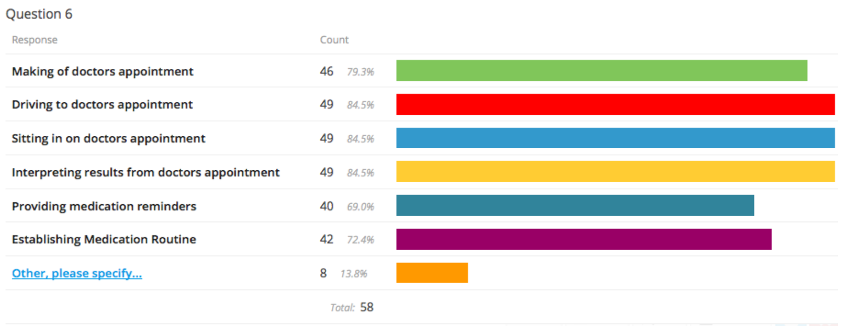
1 - 8 of 8 10 20 50 100

Research Survey results

Question 6

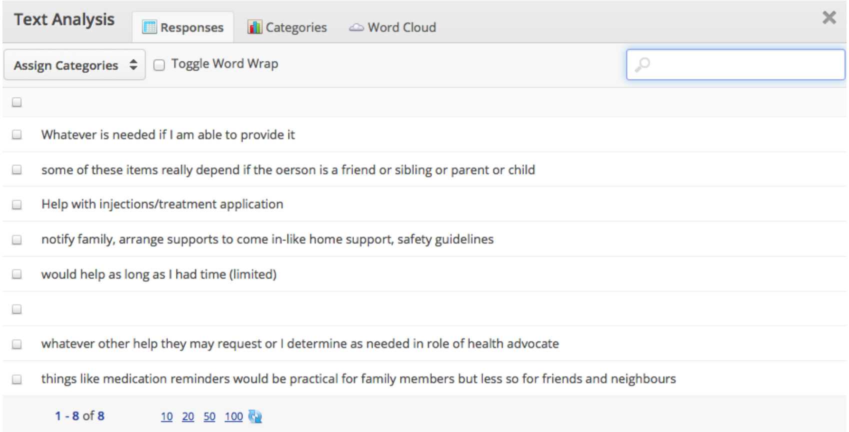
Illness Help: Upon offering help to a close member of your network to support the self-management of their chronic condition, please check the following ways in which you would be able to help (choose as many as apply):

- Making of doctors appointment
- Driving to doctors appointment
- Sitting in on doctors appointment
- Interpreting results from doctors appointment
- Providing medication reminders
- Establishing Medication Routine
- Other, please specify...



Question 6

Response	Count	
Making of doctors appointment	46	*79.3%*
Driving to doctors appointment	49	*84.5%*
Sitting in on doctors appointment	49	*84.5%*
Interpreting results from doctors appointment	49	*84.5%*
Providing medication reminders	40	*69.0%*
Establishing Medication Routine	42	*72.4%*
Other, please specify...	8	*13.8%*
	Total: 58	



☐

☐ Whatever is needed if I am able to provide it

☐ some of these items really depend if the oerson is a friend or sibling or parent or child

☐ Help with injections/treatment application

☐ notify family, arrange supports to come in-like home support, safety guidelines

☐ would help as long as I had time (limited)

☐

☐ whatever other help they may request or I determine as needed in role of health advocate

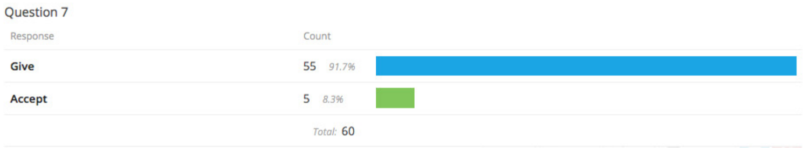
☐ things like medication reminders would be practical for family members but less so for friends and neighbours

SECTION 3: GENERAL QUESTIONS

Question 7

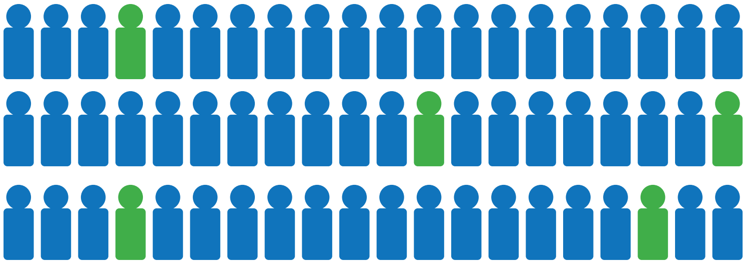
Do you find it easier to GIVE or ACCEPT help to/from others?

- Give
- Accept

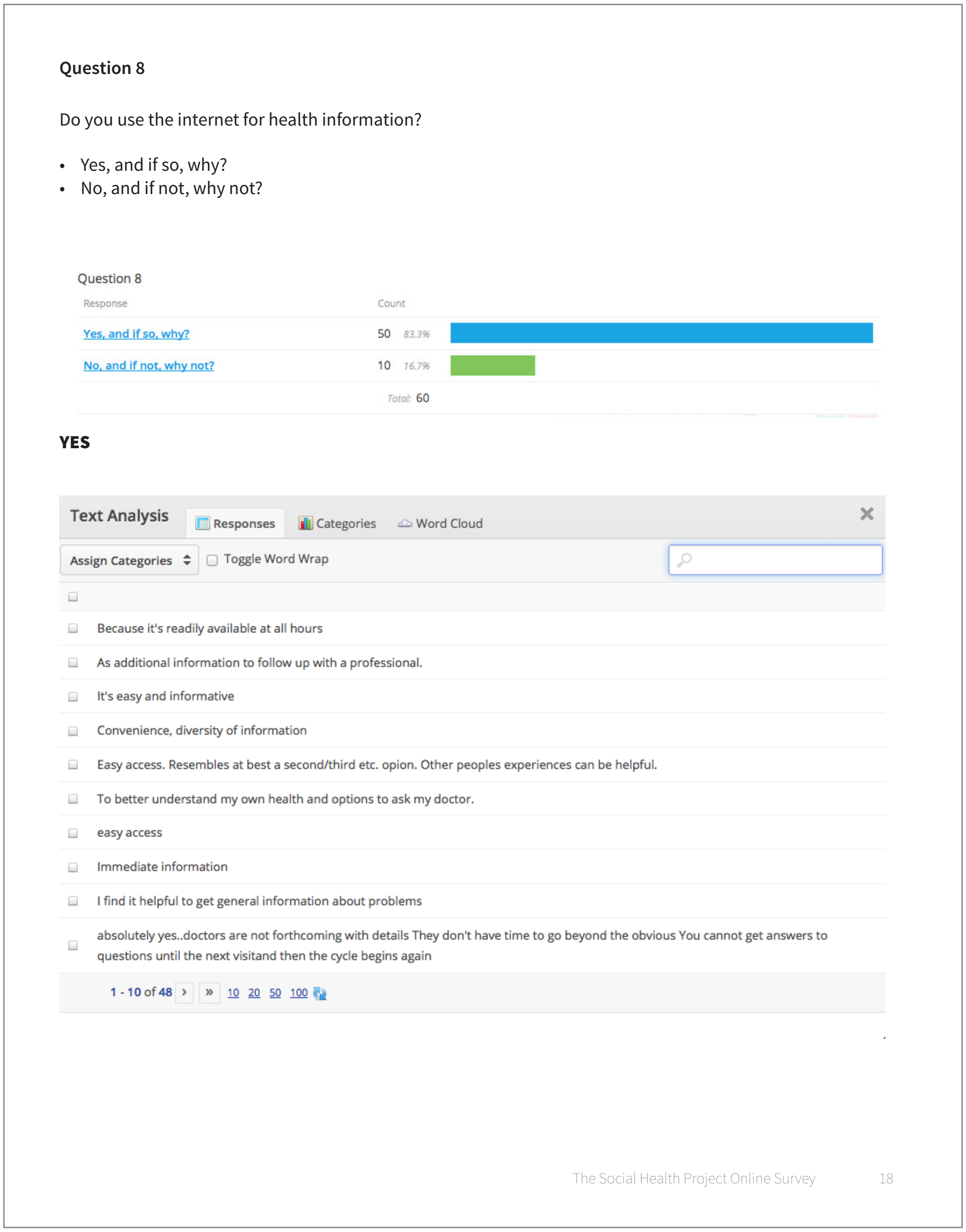


Question 7

Response	Count	
Give	55	*91.7%*
Accept	5	*8.3%*
	Total: 60	



Research Survey results



Question 8

Do you use the internet for health information?

- Yes, and if so, why?
- No, and if not, why not?

Question 8

Response	Count	
Yes, and if so, why?	50	83.3%
No, and if not, why not?	10	16.7%
	Total: 60	

YES

☐

☐ Because it's readily available at all hours

☐ As additional information to follow up with a professional.

☐ It's easy and informative

☐ Convenience, diversity of information

☐ Easy access. Resembles at best a second/third etc. opion. Other peoples experiences can be helpful.

☐ To better understand my own health and options to ask my doctor.

☐ easy access

☐ Immediate information

☐ I find it helpful to get general information about problems

☐ absolutely yes..doctors are not forthcoming with details They don't have time to go beyond the obvious You cannot get answers to questions until the next visitand then the cycle begins again

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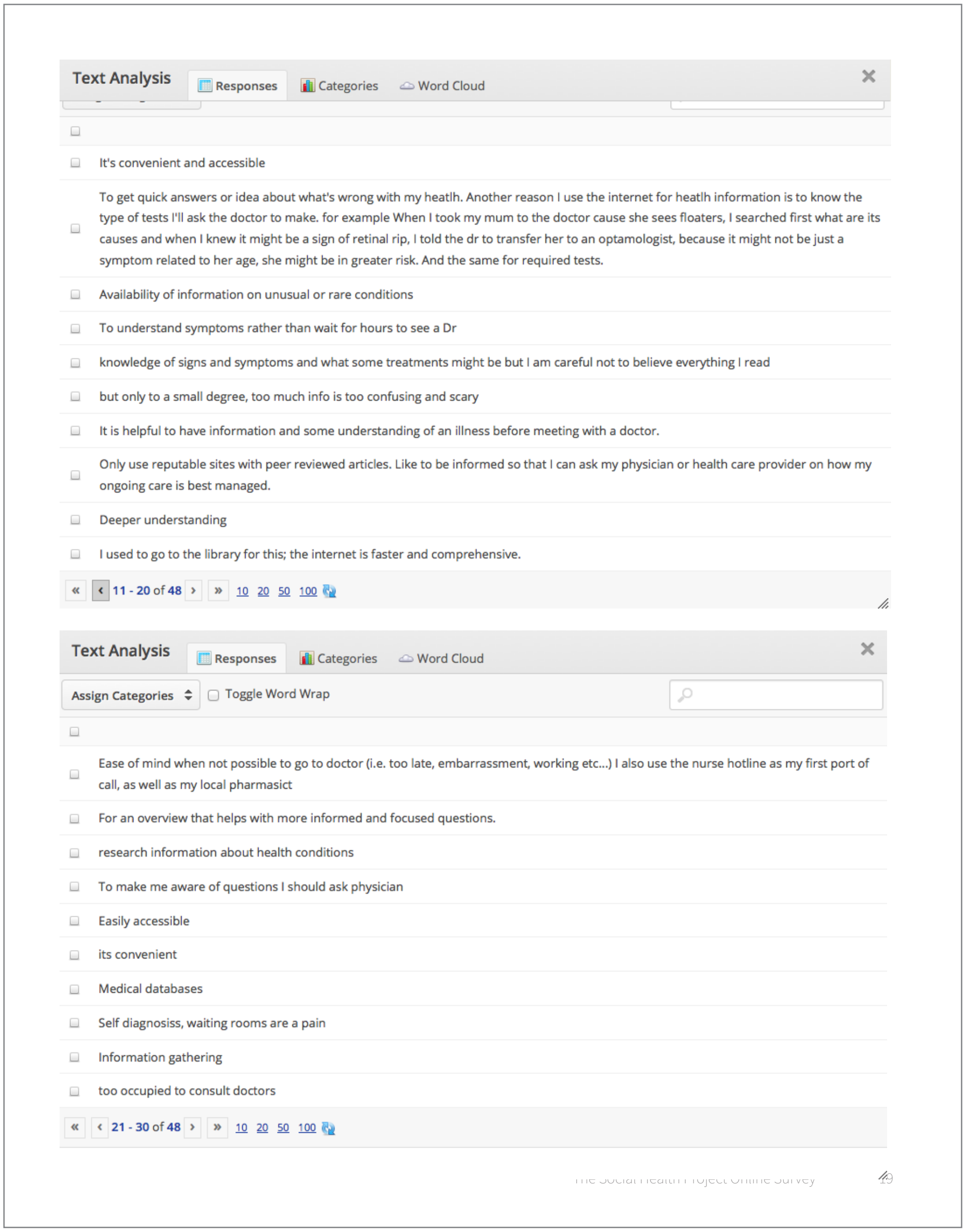


☐

☐ It's convenient and accessible

☐ To get quick answers or idea about what's wrong with my heatlh. Another reason I use the internet for heatlh information is to know the type of tests I'll ask the doctor to make. for example When I took my mum to the doctor cause she sees floaters, I searched first what are its causes and when I knew it might be a sign of retinal rip, I told the dr to transfer her to an optamologist, because it might not be just a symptom related to her age, she might be in greater risk. And the same for required tests.

☐ Availability of information on unusual or rare conditions

☐ To understand symptoms rather than wait for hours to see a Dr

☐ knowledge of signs and symptoms and what some treatments might be but I am careful not to believe everything I read

☐ but only to a small degree, too much info is too confusing and scary

☐ It is helpful to have information and some understanding of an illness before meeting with a doctor.

☐ Only use reputable sites with peer reviewed articles. Like to be informed so that I can ask my physician or health care provider on how my ongoing care is best managed.

☐ Deeper understanding

☐ I used to go to the library for this; the internet is faster and comprehensive.

☐

☐ Ease of mind when not possible to go to doctor (i.e. too late, embarrassment, working etc...) I also use the nurse hotline as my first port of call, as well as my local pharmasict

☐ For an overview that helps with more informed and focused questions.

☐ research information about health conditions

☐ To make me aware of questions I should ask physician

☐ Easily accessible

☐ its convenient

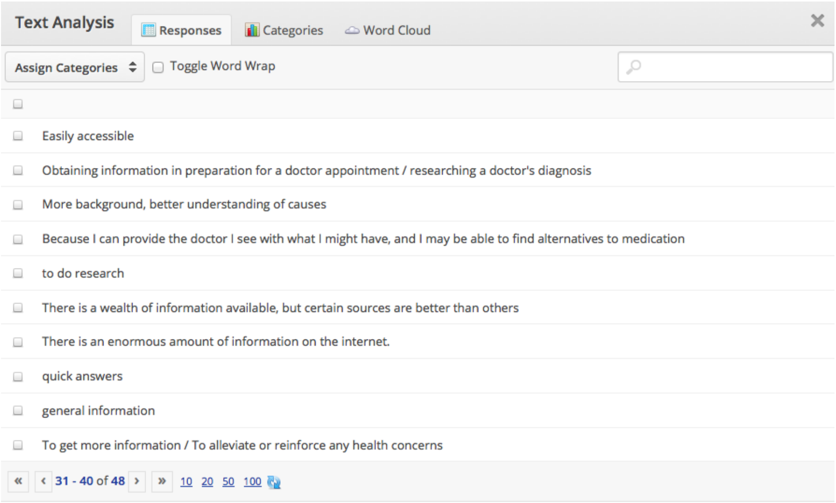
☐ Medical databases

☐ Self diagnosiss, waiting rooms are a pain

☐ Information gathering

☐ too occupied to consult doctors

Research Survey results



☐ Easily accessible

☐ Obtaining information in preparation for a doctor appointment / researching a doctor's diagnosis

☐ More background, better understanding of causes

☐ Because I can provide the doctor I see with what I might have, and I may be able to find alternatives to medication

☐ to do research

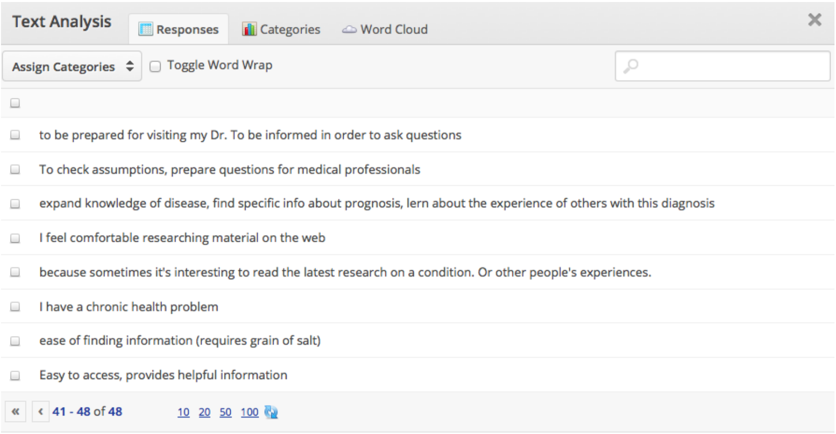
☐ There is a wealth of information available, but certain sources are better than others

☐ There is an enormous amount of information on the internet.

☐ quick answers

☐ general information

☐ To get more information / To alleviate or reinforce any health concerns



☐ to be prepared for visiting my Dr. To be informed in order to ask questions

☐ To check assumptions, prepare questions for medical professionals

☐ expand knowledge of disease, find specific info about prognosis, lern about the experience of others with this diagnosis

☐ I feel comfortable researching material on the web

☐ because sometimes it's interesting to read the latest research on a condition. Or other people's experiences.

☐ I have a chronic health problem

☐ ease of finding information (requires grain of salt)

☐ Easy to access, provides helpful information

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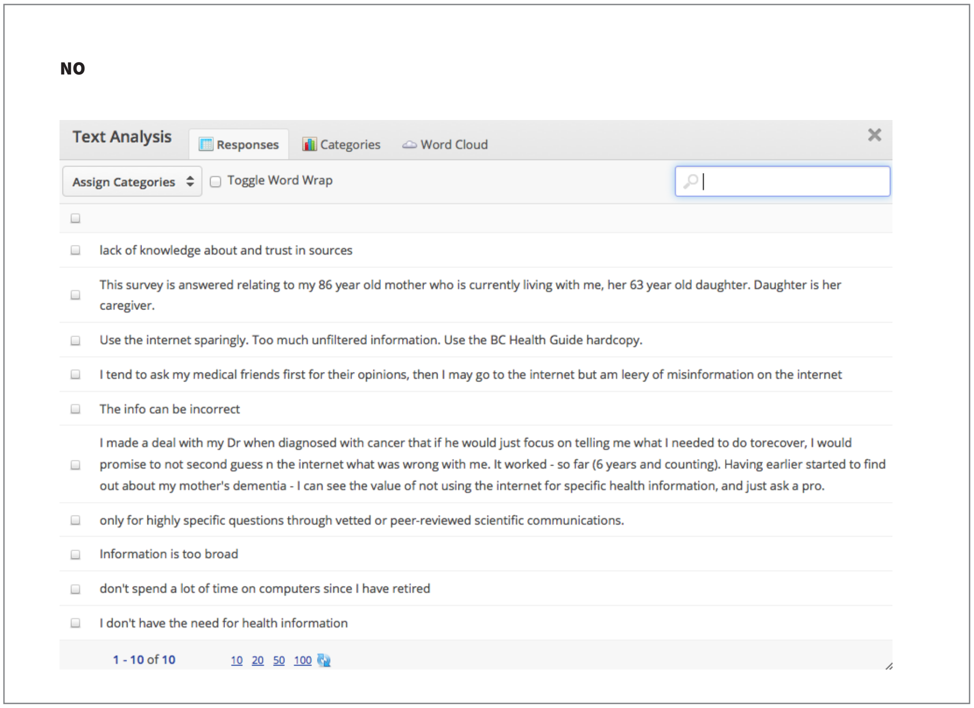


NO

☐

☐ lack of knowledge about and trust in sources

☐ This survey is answered relating to my 86 year old mother who is currently living with me, her 63 year old daughter. Daughter is her caregiver.

☐ Use the internet sparingly. Too much unfiltered information. Use the BC Health Guide hardcopy.

☐ I tend to ask my medical friends first for their opinions, then I may go to the internet but am leery of misinformation on the internet

☐ The info can be incorrect

☐ I made a deal with my Dr when diagnosed with cancer that if he would just focus on telling me what I needed to do torecover, I would promise to not second guess n the internet what was wrong with me. It worked - so far (6 years and counting). Having earlier started to find out about my mother's dementia - I can see the value of not using the internet for specific health information, and just ask a pro.

☐ only for highly specific questions through vetted or peer-reviewed scientific communications.

☐ Information is too broad

☐ don't spend a lot of time on computers since I have retired

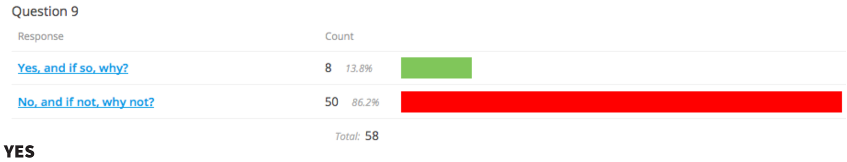
☐ I don't have the need for health information

Research Survey results

Question 9

Do you consult Apps for health information?

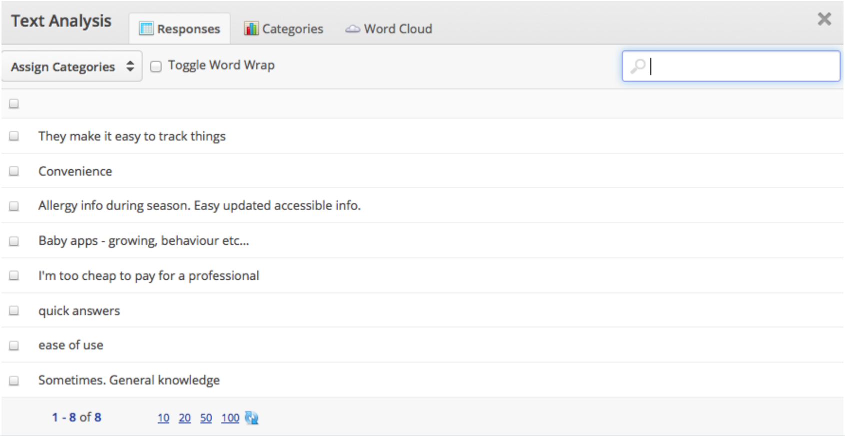
- Yes, and if so, why?
- No, and if not, why not?



Question 9

Response	Count		
Yes, and if so, why?	8	13.8%	🟩
No, and if not, why not?	50	86.2%	🟥
	Total: 58		

YES



☐ They make it easy to track things

☐ Convenience

☐ Allergy info during season. Easy updated accessible info.

☐ Baby apps - growing, behaviour etc...

☐ I'm too cheap to pay for a professional

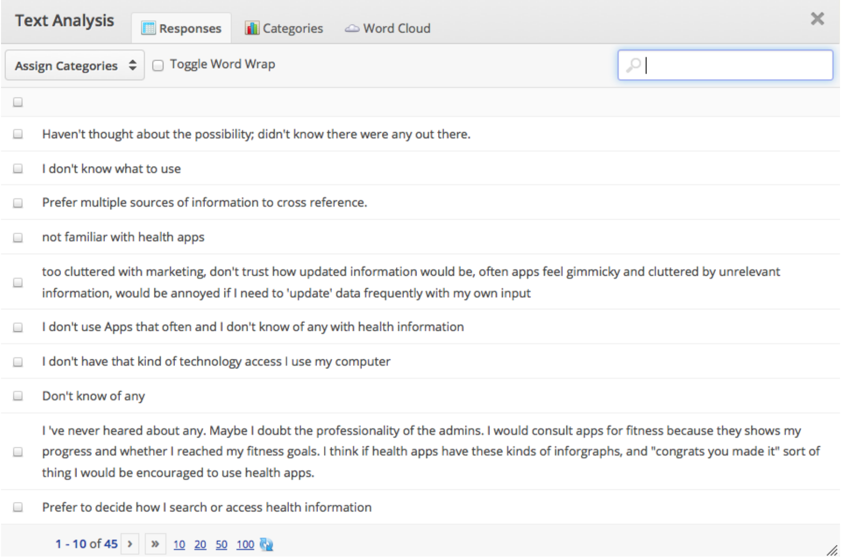
☐ quick answers

☐ ease of use

☐ Sometimes. General knowledge

1 - 8 of 8 10 20 50 100

NO



☐ Haven't thought about the possibility; didn't know there were any out there.

☐ I don't know what to use

☐ Prefer multiple sources of information to cross reference.

☐ not familiar with health apps

☐ too cluttered with marketing, don't trust how updated information would be, often apps feel gimmicky and cluttered by unrelevant information, would be annoyed if I need to 'update' data frequently with my own input

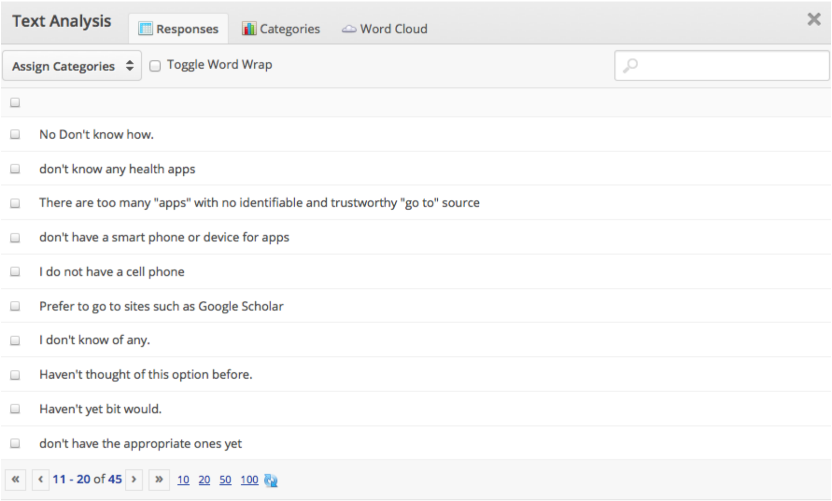
☐ I don't use Apps that often and I don't know of any with health information

☐ I don't have that kind of technology access I use my computer

☐ Don't know of any

☐ I 've never heared about any. Maybe I doubt the professionality of the admins. I would consult apps for fitness because they shows my progress and whether I reached my fitness goals. I think if health apps have these kinds of inforgraphs, and "congrats you made it" sort of thing I would be encouraged to use health apps.

☐ Prefer to decide how I search or access health information



☐ No Don't know how.

☐ don't know any health apps

☐ There are too many "apps" with no identifiable and trustworthy "go to" source

☐ don't have a smart phone or device for apps

☐ I do not have a cell phone

☐ Prefer to go to sites such as Google Scholar

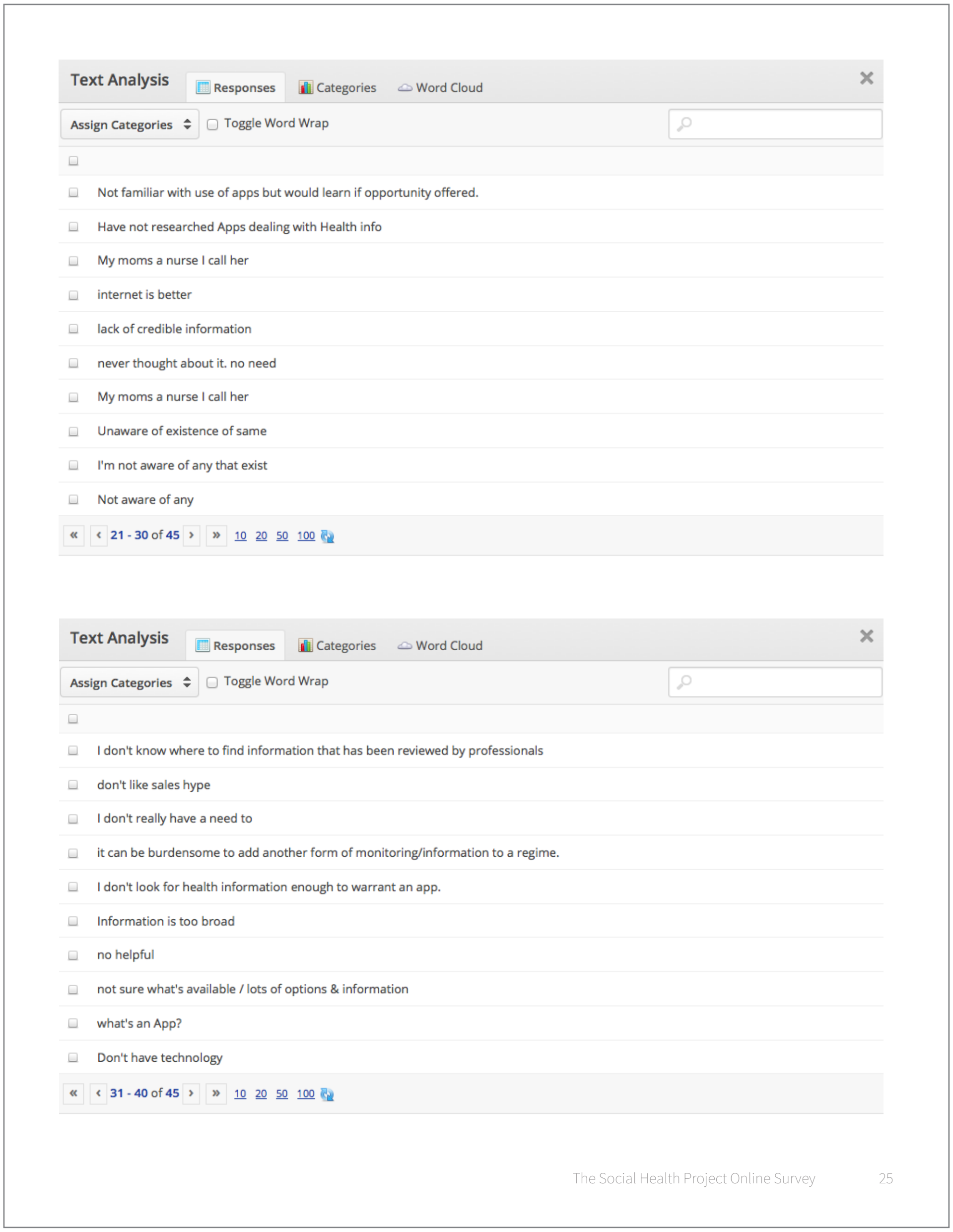
☐ I don't know of any.

☐ Haven't thought of this option before.

☐ Haven't yet bit would.

☐ don't have the appropriate ones yet

Research Survey results



☐

☐ Not familiar with use of apps but would learn if opportunity offered.

☐ Have not researched Apps dealing with Health info

☐ My moms a nurse I call her

☐ internet is better

☐ lack of credible information

☐ never thought about it. no need

☐ My moms a nurse I call her

☐ Unaware of existence of same

☐ I'm not aware of any that exist

☐ Not aware of any

☐

☐ I don't know where to find information that has been reviewed by professionals

☐ don't like sales hype

☐ I don't really have a need to

☐ it can be burdensome to add another form of monitoring/information to a regime.

☐ I don't look for health information enough to warrant an app.

☐ Information is too broad

☐ no helpful

☐ not sure what's available / lots of options & information

☐ what's an App?

☐ Don't have technology

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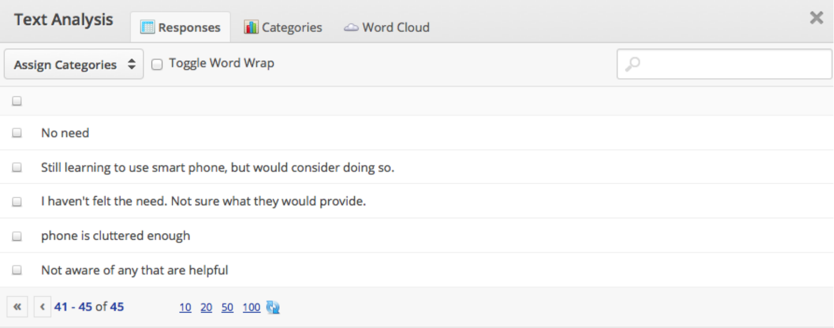


☐ No need

☐ Still learning to use smart phone, but would consider doing so.

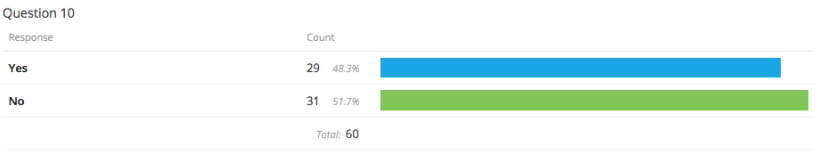
☐ I haven't felt the need. Not sure what they would provide.

☐ phone is cluttered enough

☐ Not aware of any that are helpful

Question 10

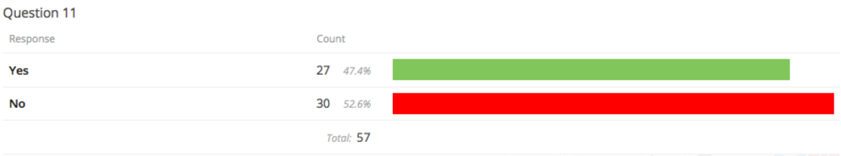
Do you currently have, or have you had, a chronic health condition?
Yes No



Response	Count	
Yes	29	48.3%
No	31	51.7%
	Total: 60	

Question 11

Does someone in your care currently have, or have had, a chronic health condition?
Yes No

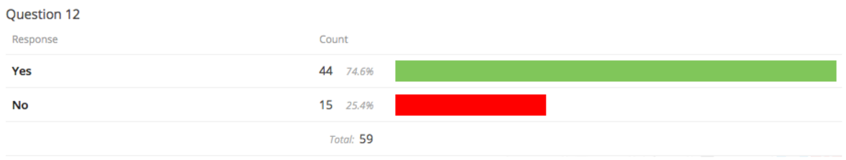


Response	Count	
Yes	27	47.4%
No	30	52.6%
	Total: 57	

Research Survey results

Question 12

Does someone in your ‘network’ currently have a chronic health condition that you are aware of?
Yes No

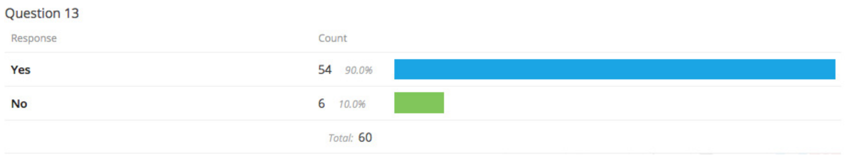


Question 12

Response	Count	
Yes	44 *74.6%*	
No	15 *25.4%*	
	Total: 59	

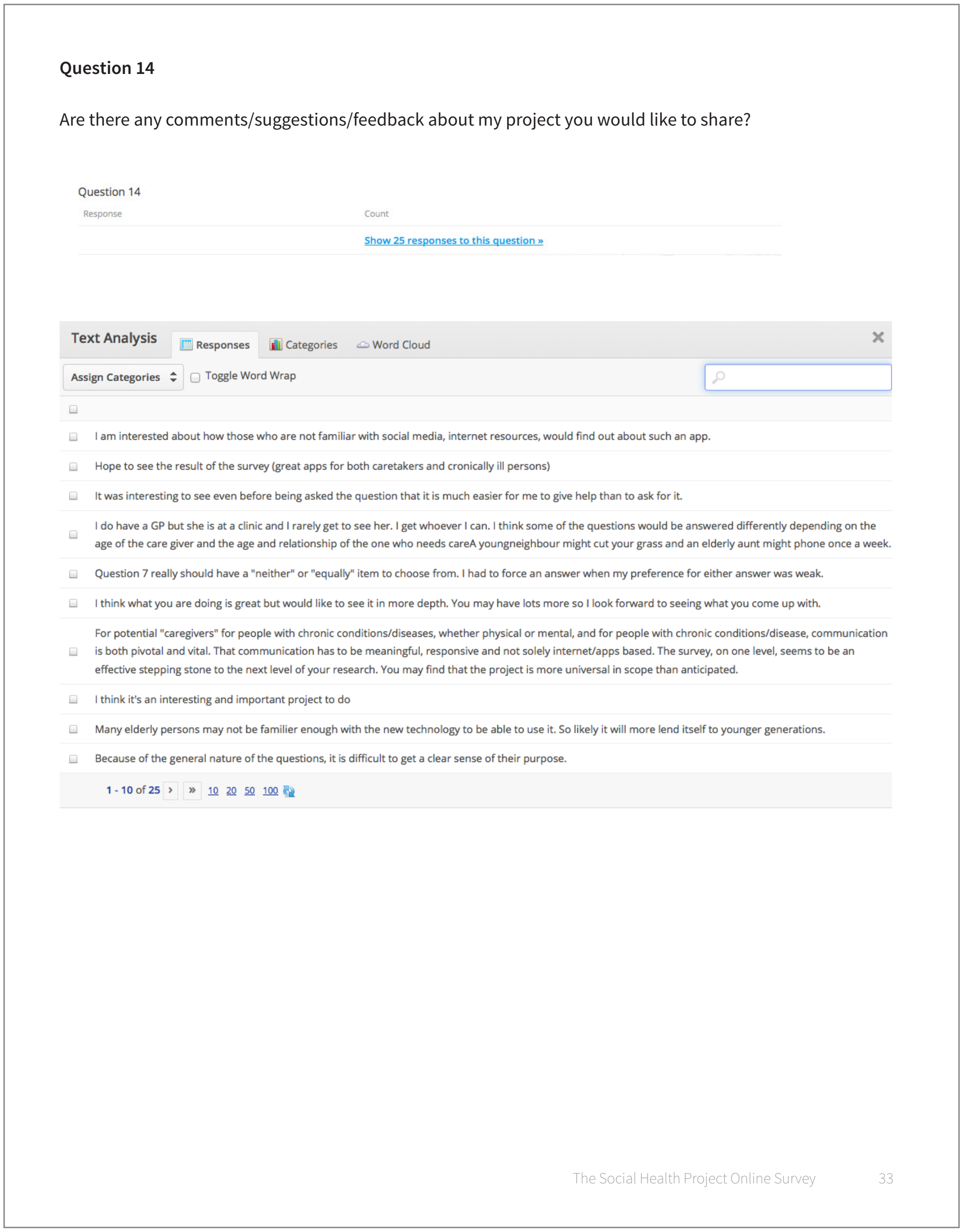
Question 13

Do you currently have a GP (General Practitioner)?
Yes No



Question 13

Response	Count	
Yes	54 *90.0%*	
No	6 *10.0%*	
	Total: 60	



Question 14

Are there any comments/suggestions/feedback about my project you would like to share?

Question 14

Response	Count
	Show 25 responses to this question »

☐

☐ I am interested about how those who are not familiar with social media, internet resources, would find out about such an app.

☐ Hope to see the result of the survey (great apps for both caretakers and cronically ill persons)

☐ It was interesting to see even before being asked the question that it is much easier for me to give help than to ask for it.

☐ I do have a GP but she is at a clinic and I rarely get to see her. I get whoever I can. I think some of the questions would be answered differently depending on the age of the care giver and the age and relationship of the one who needs careA youngneighbour might cut your grass and an elderly aunt might phone once a week.

☐ Question 7 really should have a "neither" or "equally" item to choose from. I had to force an answer when my preference for either answer was weak.

☐ I think what you are doing is great but would like to see it in more depth. You may have lots more so I look forward to seeing what you come up with.

☐ For potential "caregivers" for people with chronic conditions/diseases, whether physical or mental, and for people with chronic conditions/disease, communication is both pivotal and vital. That communication has to be meaningful, responsive and not solely internet/apps based. The survey, on one level, seems to be an effective stepping stone to the next level of your research. You may find that the project is more universal in scope than anticipated.

☐ I think it's an interesting and important project to do

☐ Many elderly persons may not be familier enough with the new technology to be able to use it. So likely it will more lend itself to younger generations.

☐ Because of the general nature of the questions, it is difficult to get a clear sense of their purpose.

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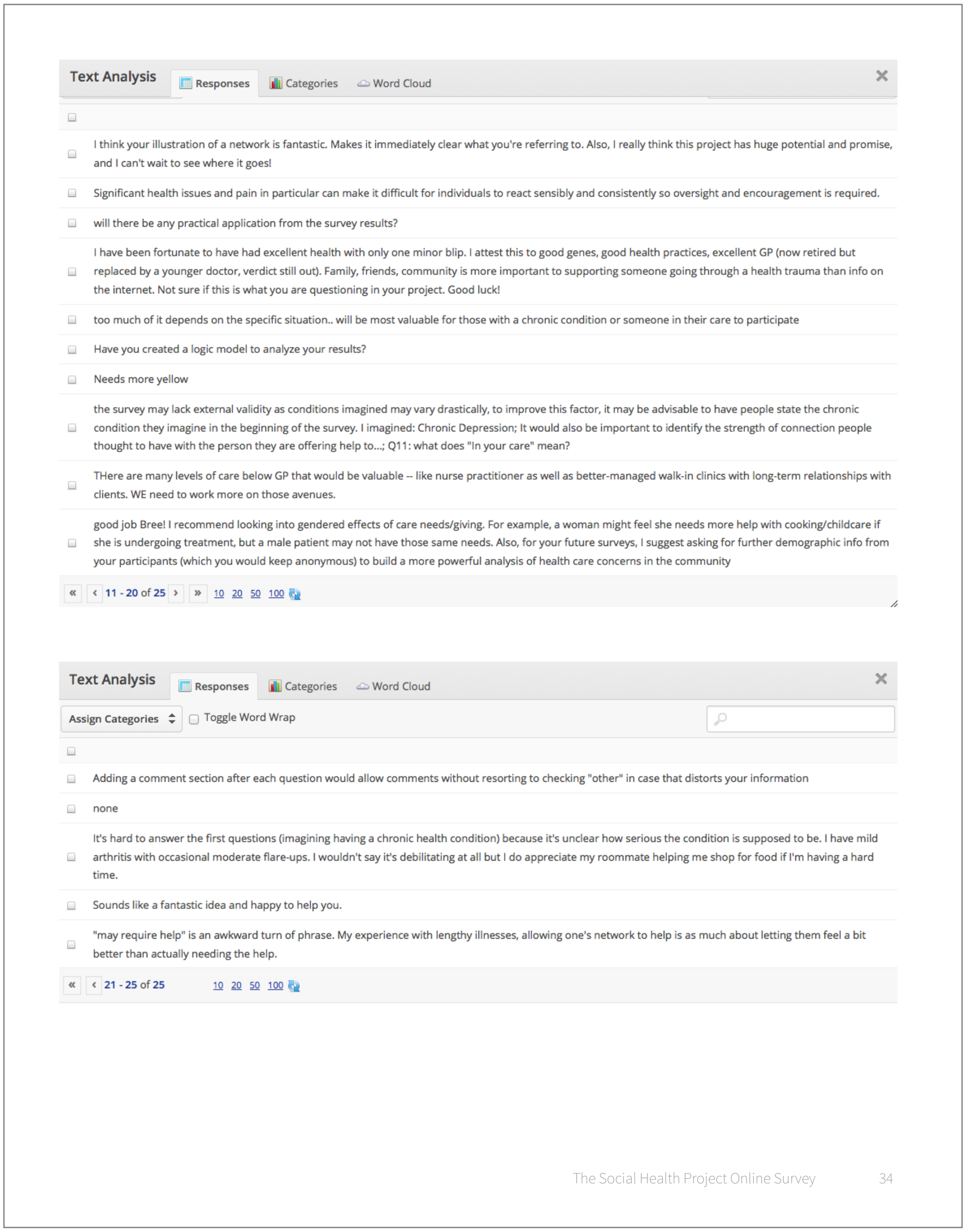
Research Survey results



☐

☐ I think your illustration of a network is fantastic. Makes it immediately clear what you're referring to. Also, I really think this project has huge potential and promise, and I can't wait to see where it goes!

☐ Significant health issues and pain in particular can make it difficult for individuals to react sensibly and consistently so oversight and encouragement is required.

☐ will there be any practical application from the survey results?

☐ I have been fortunate to have had excellent health with only one minor blip. I attest this to good genes, good health practices, excellent GP (now retired but replaced by a younger doctor, verdict still out). Family, friends, community is more important to supporting someone going through a health trauma than info on the internet. Not sure if this is what you are questioning in your project. Good luck!

☐ too much of it depends on the specific situation.. will be most valuable for those with a chronic condition or someone in their care to participate

☐ Have you created a logic model to analyze your results?

☐ Needs more yellow

☐ the survey may lack external validity as conditions imagined may vary drastically, to improve this factor, it may be advisable to have people state the chronic condition they imagine in the beginning of the survey. I imagined: Chronic Depression; It would also be important to identify the strength of connection people thought to have with the person they are offering help to...; Q11: what does "In your care" mean?

☐ THere are many levels of care below GP that would be valuable -- like nurse practitioner as well as better-managed walk-in clinics with long-term relationships with clients. WE need to work more on those avenues.

☐ good job Bree! I recommend looking into gendered effects of care needs/giving. For example, a woman might feel she needs more help with cooking/childcare if she is undergoing treatment, but a male patient may not have those same needs. Also, for your future surveys, I suggest asking for further demographic info from your participants (which you would keep anonymous) to build a more powerful analysis of health care concerns in the community

☐

☐ Adding a comment section after each question would allow comments without resorting to checking "other" in case that distorts your information

☐ none

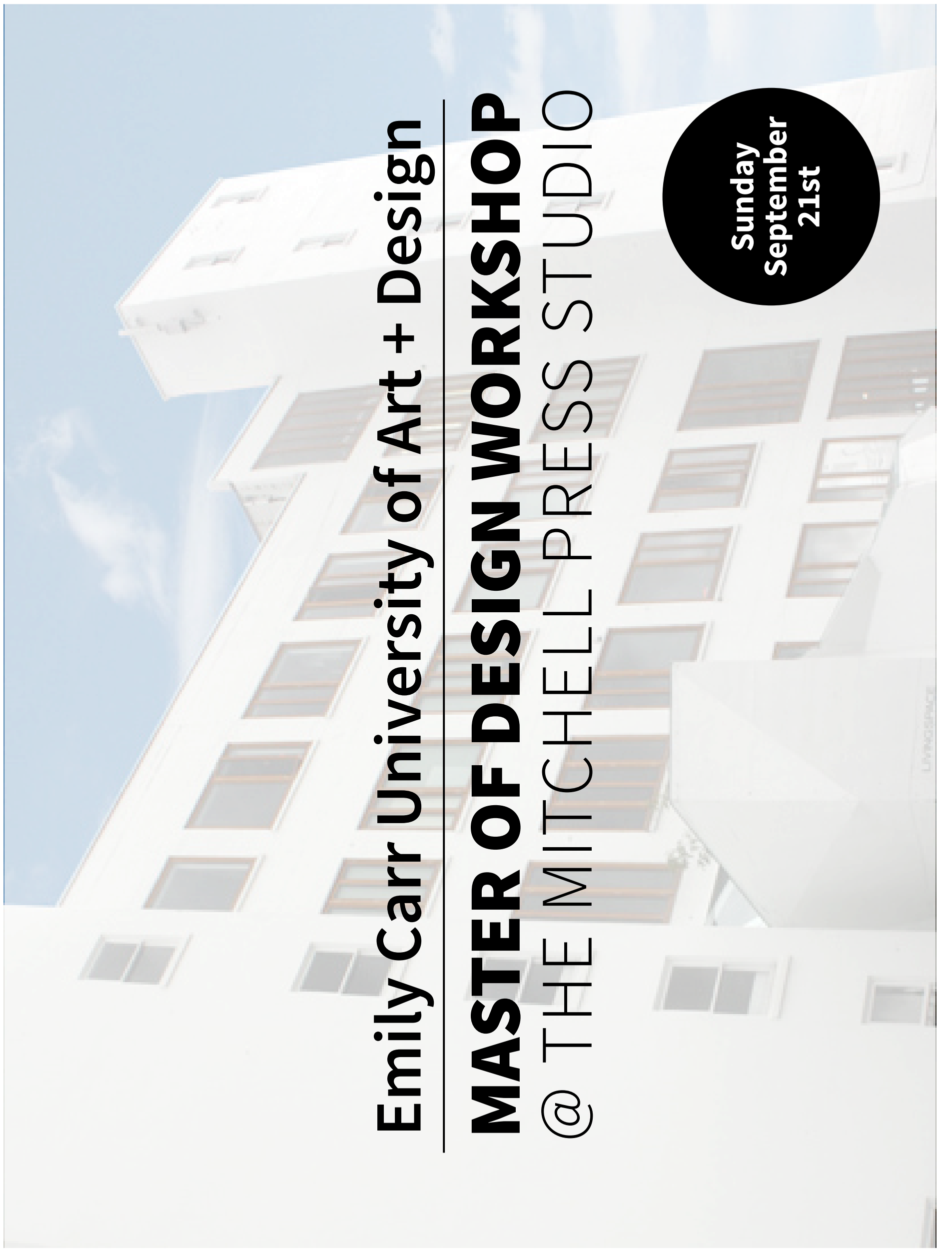
☐ It's hard to answer the first questions (imagining having a chronic health condition) because it's unclear how serious the condition is supposed to be. I have mild arthritis with occasional moderate flare-ups. I wouldn't say it's debilitating at all but I do appreciate my roommate helping me shop for food if I'm having a hard time.

☐ Sounds like a fantastic idea and happy to help you.

☐ "may require help" is an awkward turn of phrase. My experience with lengthy illnesses, allowing one's network to help is as much about letting them feel a bit better than actually needing the help.

The Social Health Project Online Survey 34

Co-Creation Invitation



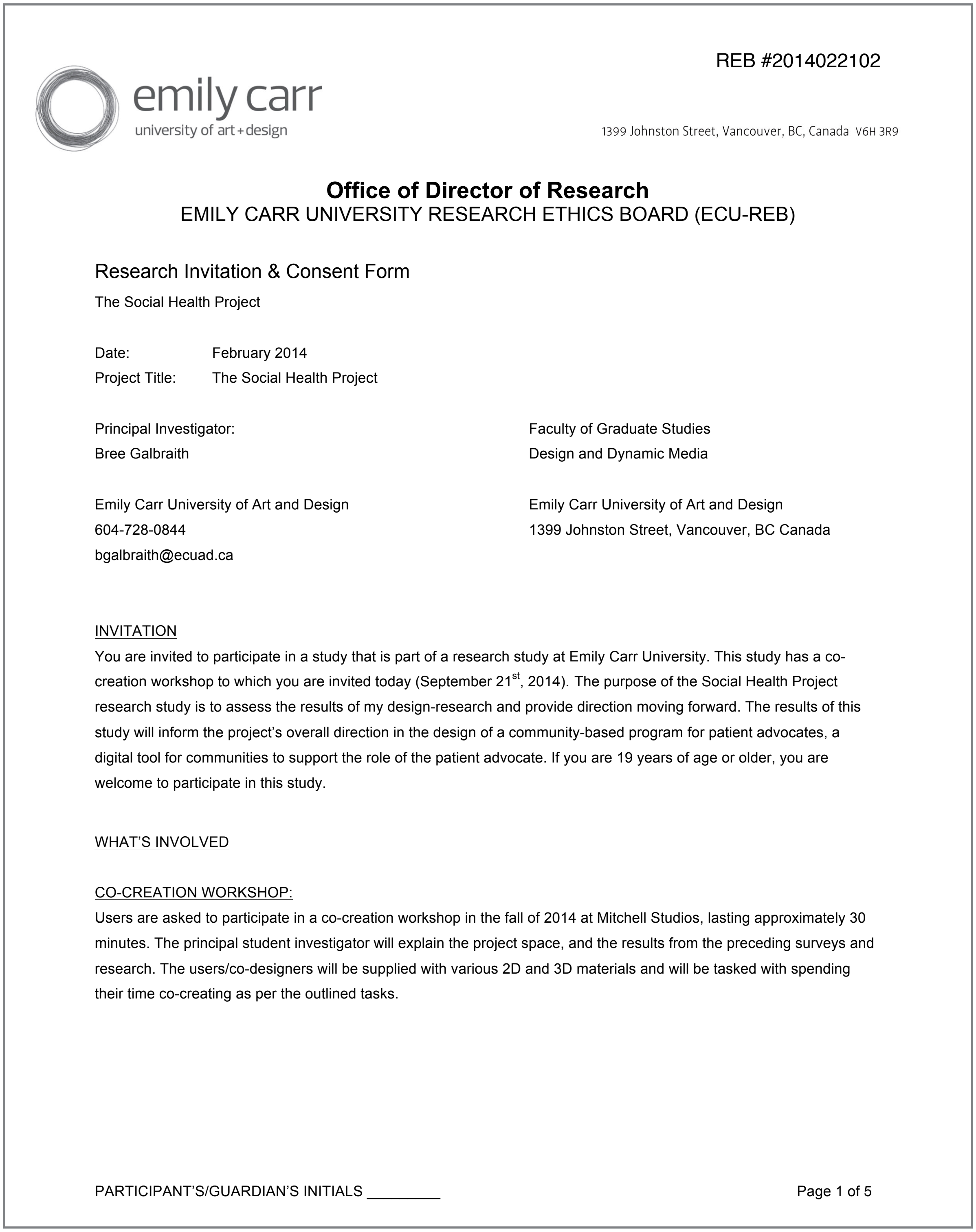
Emily Carr University of Art + Design

MASTER OF DESIGN WORKSHOP

@ THE MITCHELL PRESS STUDIO

Sunday
September
21st

Co-Creation Consent



REB #2014022102

emily carr
university of art + design

1399 Johnston Street, Vancouver, BC, Canada V6H 3R9

Office of Director of Research

EMILY CARR UNIVERSITY RESEARCH ETHICS BOARD (ECU-REB)

Research Invitation & Consent Form

The Social Health Project

Date: February 2014
Project Title: The Social Health Project

Principal Investigator:	Faculty of Graduate Studies
Bree Galbraith	Design and Dynamic Media
Emily Carr University of Art and Design	Emily Carr University of Art and Design
604-728-0844	1399 Johnston Street, Vancouver, BC Canada
bgalbraith@ecuad.ca	

INVITATION

You are invited to participate in a study that is part of a research study at Emily Carr University. This study has a co-creation workshop to which you are invited today (September 21st, 2014). The purpose of the Social Health Project research study is to assess the results of my design-research and provide direction moving forward. The results of this study will inform the project's overall direction in the design of a community-based program for patient advocates, a digital tool for communities to support the role of the patient advocate. If you are 19 years of age or older, you are welcome to participate in this study.

WHAT'S INVOLVED

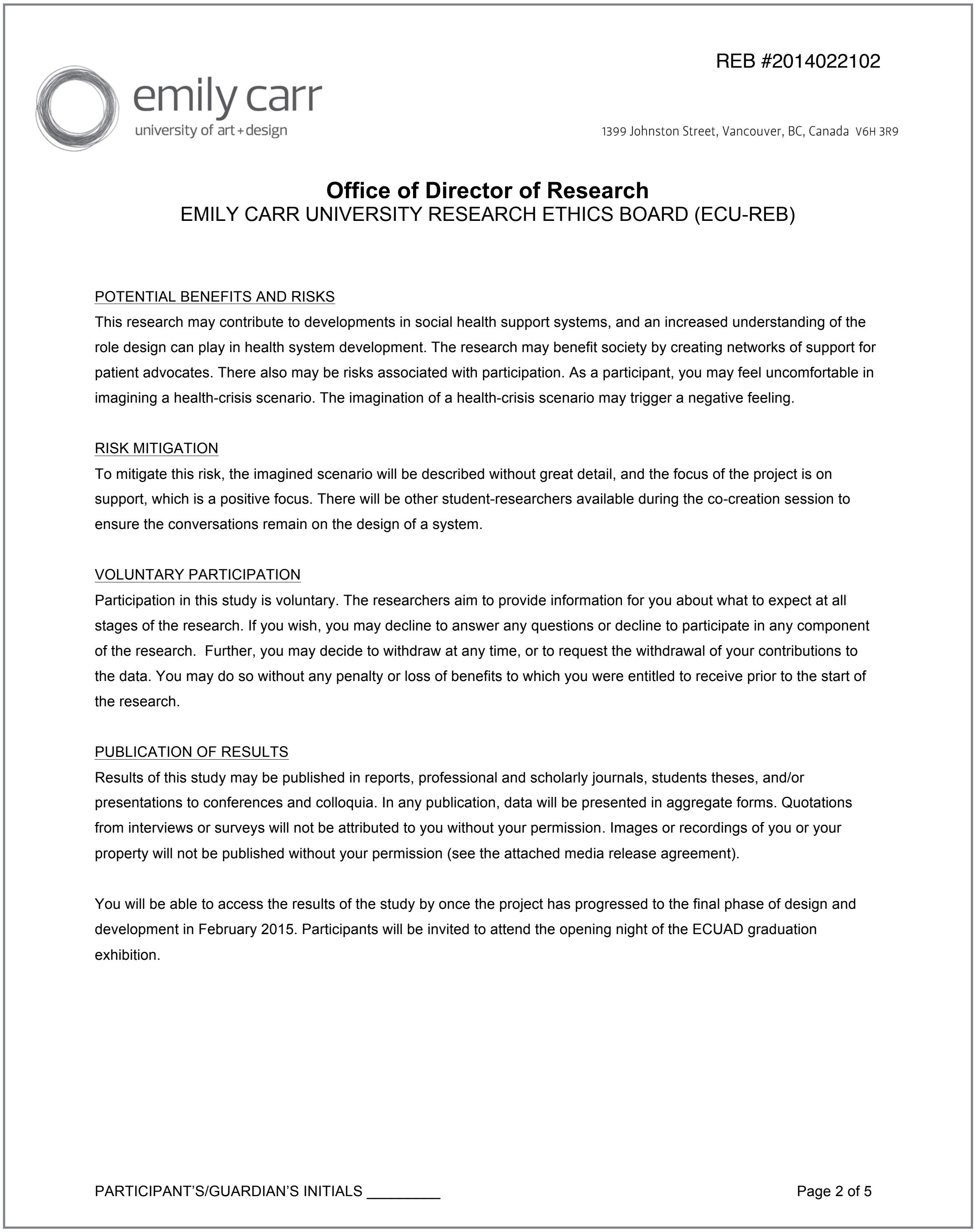
CO-CREATION WORKSHOP:

Users are asked to participate in a co-creation workshop in the fall of 2014 at Mitchell Studios, lasting approximately 30 minutes. The principal student investigator will explain the project space, and the results from the preceding surveys and research. The users/co-designers will be supplied with various 2D and 3D materials and will be tasked with spending their time co-creating as per the outlined tasks.

PARTICIPANT'S/GUARDIAN'S INITIALS _________

Page 1 of 5

Co-Creation Consent



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POTENTIAL BENEFITS AND RISKS

This research may contribute to developments in social health support systems, and an increased understanding of the role design can play in health system development. The research may benefit society by creating networks of support for patient advocates. There also may be risks associated with participation. As a participant, you may feel uncomfortable in imagining a health-crisis scenario. The imagination of a health-crisis scenario may trigger a negative feeling.

RISK MITIGATION

To mitigate this risk, the imagined scenario will be described without great detail, and the focus of the project is on support, which is a positive focus. There will be other student-researchers available during the co-creation session to ensure the conversations remain on the design of a system.

VOLUNTARY PARTICIPATION

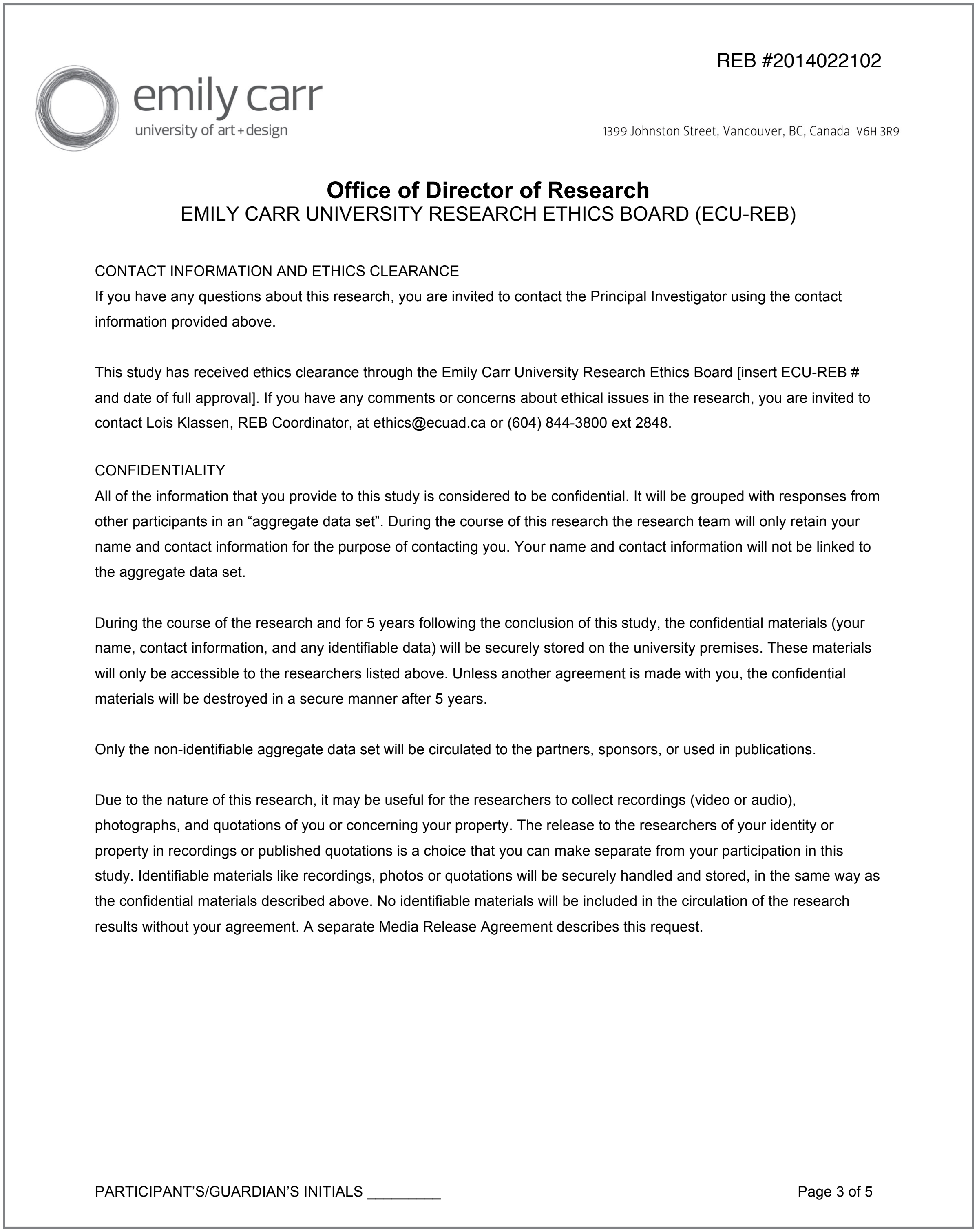
Participation in this study is voluntary. The researchers aim to provide information for you about what to expect at all stages of the research. If you wish, you may decline to answer any questions or decline to participate in any component of the research. Further, you may decide to withdraw at any time, or to request the withdrawal of your contributions to the data. You may do so without any penalty or loss of benefits to which you were entitled to receive prior to the start of the research.

PUBLICATION OF RESULTS

Results of this study may be published in reports, professional and scholarly journals, students theses, and/or presentations to conferences and colloquia. In any publication, data will be presented in aggregate forms. Quotations from interviews or surveys will not be attributed to you without your permission. Images or recordings of you or your property will not be published without your permission (see the attached media release agreement).

You will be able to access the results of the study by once the project has progressed to the final phase of design and development in February 2015. Participants will be invited to attend the opening night of the ECUAD graduation exhibition.

Co-Creation Consent



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CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this research, you are invited to contact the Principal Investigator using the contact information provided above.

This study has received ethics clearance through the Emily Carr University Research Ethics Board [insert ECU-REB # and date of full approval]. If you have any comments or concerns about ethical issues in the research, you are invited to contact Lois Klassen, REB Coordinator, at ethics@ecuad.ca or (604) 844-3800 ext 2848.

CONFIDENTIALITY

All of the information that you provide to this study is considered to be confidential. It will be grouped with responses from other participants in an “aggregate data set”. During the course of this research the research team will only retain your name and contact information for the purpose of contacting you. Your name and contact information will not be linked to the aggregate data set.

During the course of the research and for 5 years following the conclusion of this study, the confidential materials (your name, contact information, and any identifiable data) will be securely stored on the university premises. These materials will only be accessible to the researchers listed above. Unless another agreement is made with you, the confidential materials will be destroyed in a secure manner after 5 years.

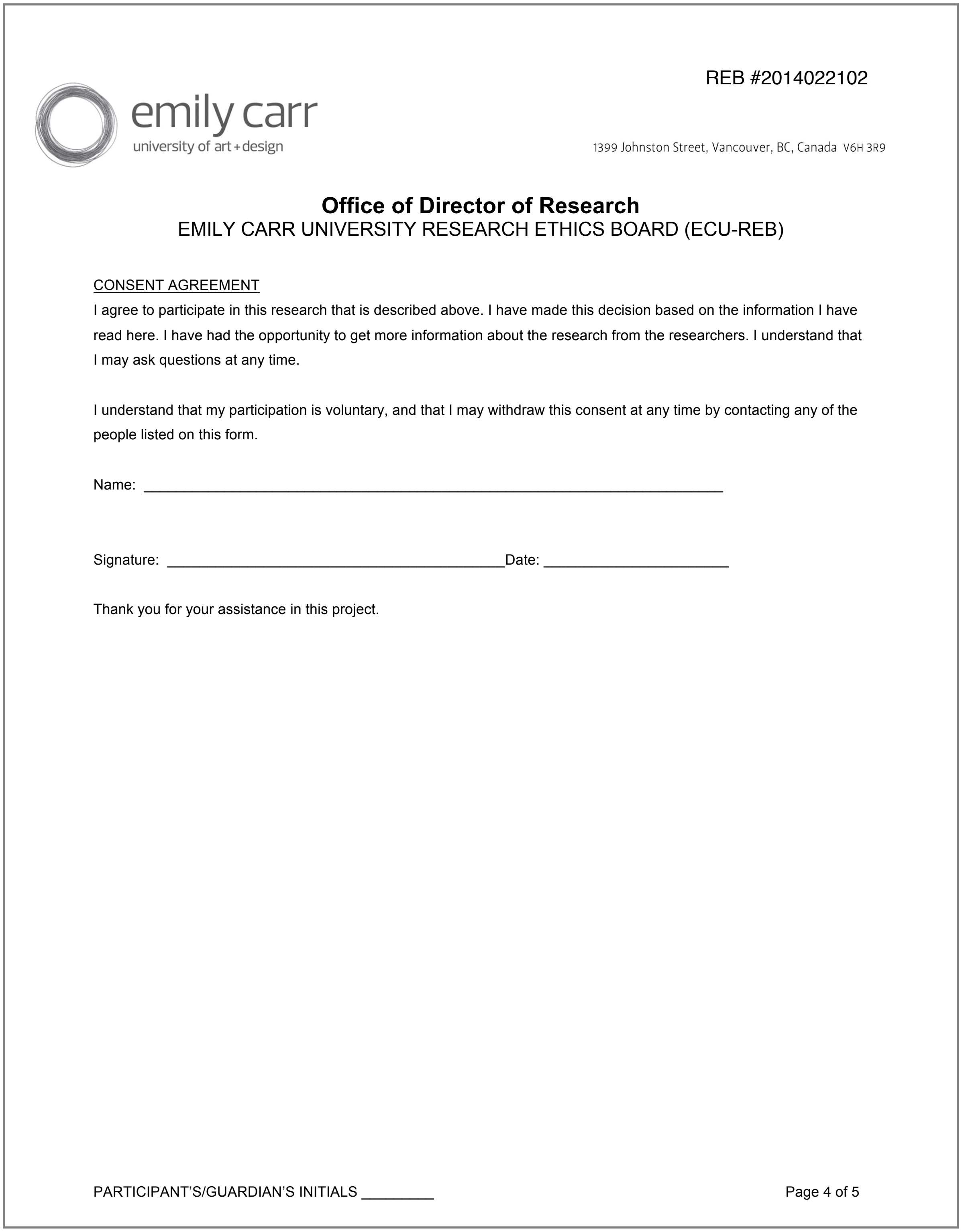
Only the non-identifiable aggregate data set will be circulated to the partners, sponsors, or used in publications.

Due to the nature of this research, it may be useful for the researchers to collect recordings (video or audio), photographs, and quotations of you or concerning your property. The release to the researchers of your identity or property in recordings or published quotations is a choice that you can make separate from your participation in this study. Identifiable materials like recordings, photos or quotations will be securely handled and stored, in the same way as the confidential materials described above. No identifiable materials will be included in the circulation of the research results without your agreement. A separate Media Release Agreement describes this request.

PARTICIPANT’S/GUARDIAN’S INITIALS _________

Page 3 of 5

Co-Creation Consent



REB #2014022102

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EMILY CARR UNIVERSITY RESEARCH ETHICS BOARD (ECU-REB)

CONSENT AGREEMENT

I agree to participate in this research that is described above. I have made this decision based on the information I have read here. I have had the opportunity to get more information about the research from the researchers. I understand that I may ask questions at any time.

I understand that my participation is voluntary, and that I may withdraw this consent at any time by contacting any of the people listed on this form.

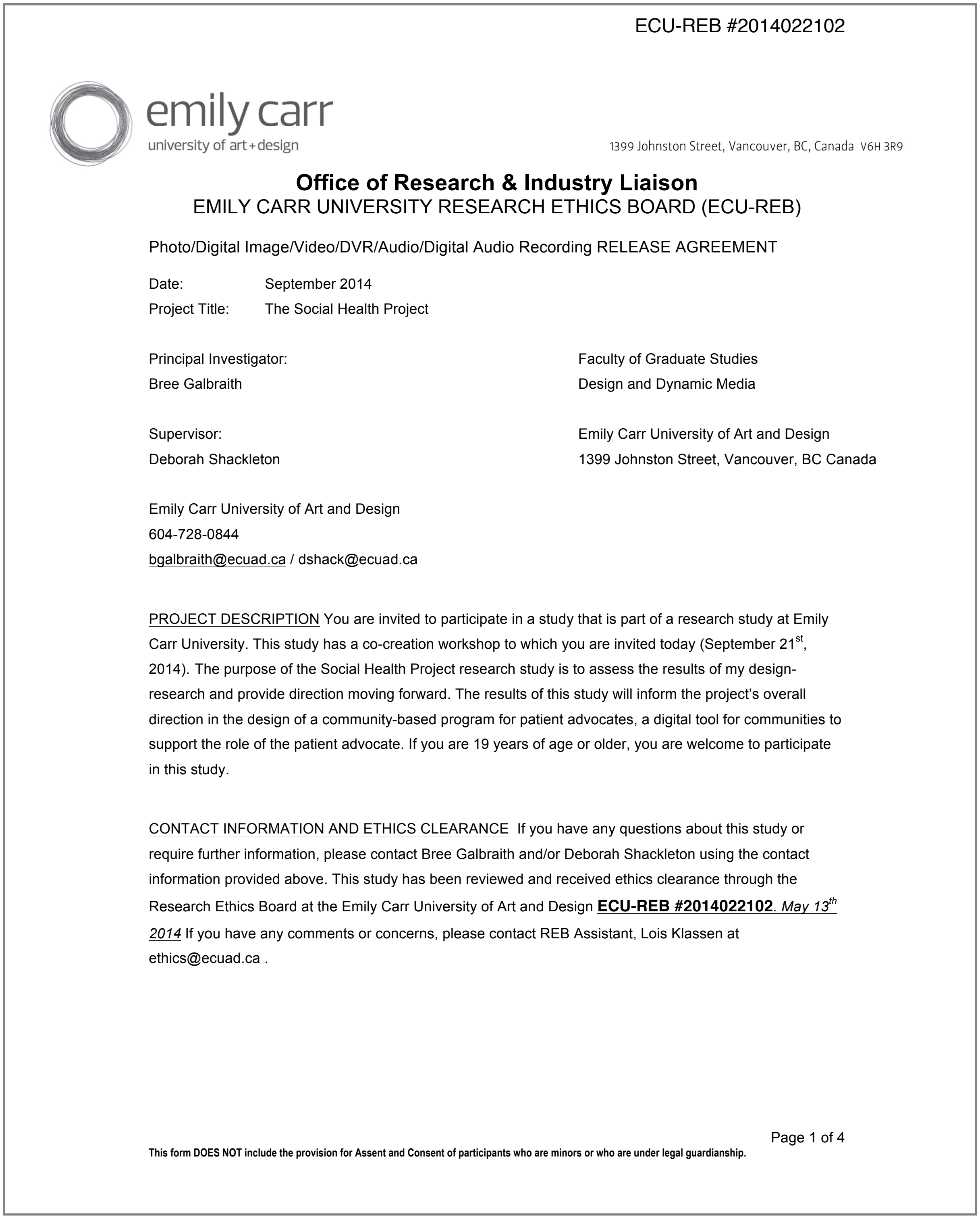
Name: ____

Signature: ___________________________Date: ______________

Thank you for your assistance in this project.

PARTICIPANT'S/GUARDIAN'S INITIALS _________ Page 4 of 5

Co-Creation Consent for image release



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Office of Research & Industry Liaison
EMILY CARR UNIVERSITY RESEARCH ETHICS BOARD (ECU-REB)

Photo/Digital Image/Video/DVR/Audio/Digital Audio Recording RELEASE AGREEMENT

Date: September 2014
Project Title: The Social Health Project

Principal Investigator:	Faculty of Graduate Studies
Bree Galbraith	Design and Dynamic Media
Supervisor:	Emily Carr University of Art and Design
Deborah Shackleton	1399 Johnston Street, Vancouver, BC Canada

Emily Carr University of Art and Design
604-728-0844
bgalbraith@ecuad.ca / dshack@ecuad.ca

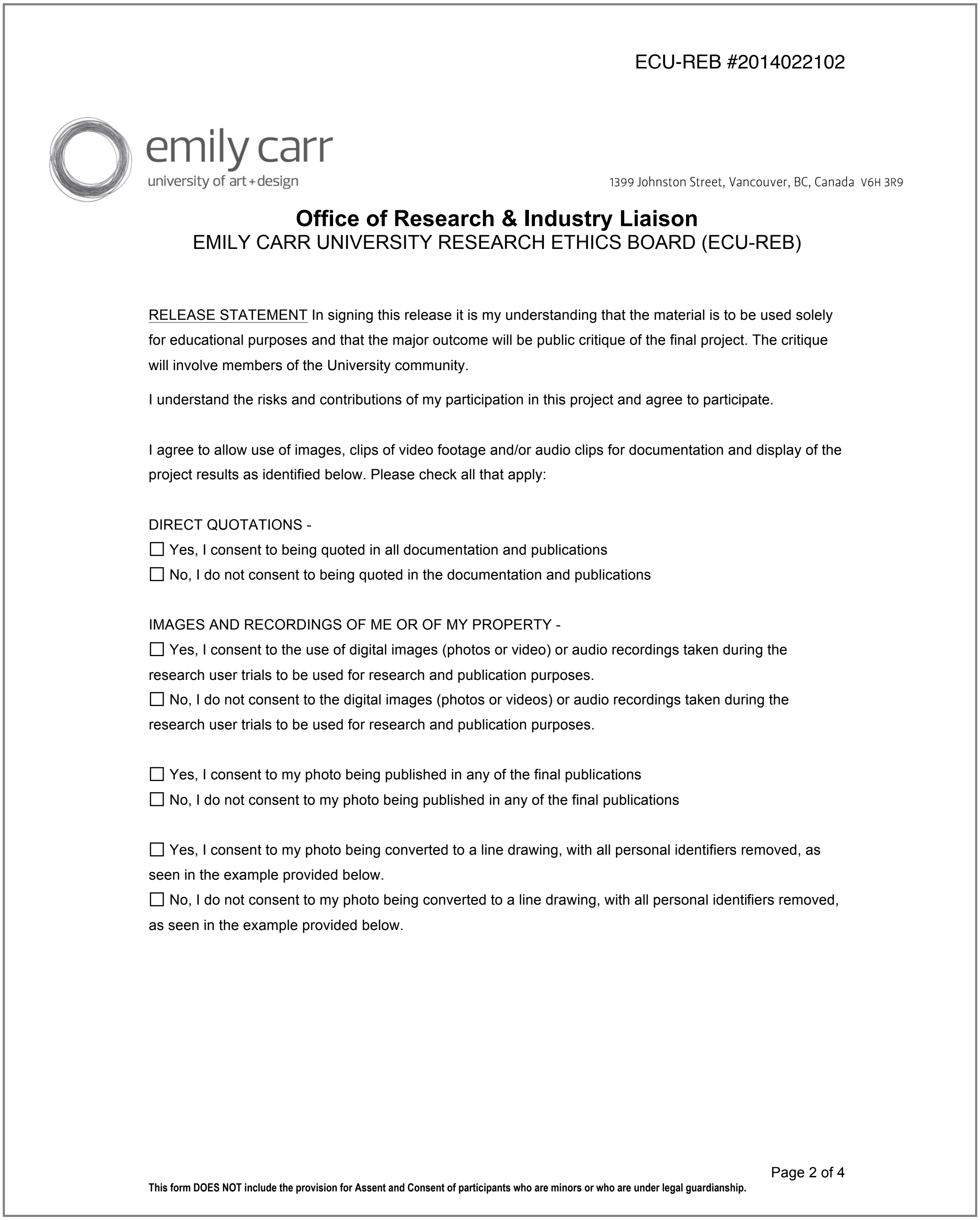
PROJECT DESCRIPTION You are invited to participate in a study that is part of a research study at Emily Carr University. This study has a co-creation workshop to which you are invited today (September 21st, 2014). The purpose of the Social Health Project research study is to assess the results of my design-research and provide direction moving forward. The results of this study will inform the project's overall direction in the design of a community-based program for patient advocates, a digital tool for communities to support the role of the patient advocate. If you are 19 years of age or older, you are welcome to participate in this study.

CONTACT INFORMATION AND ETHICS CLEARANCE If you have any questions about this study or require further information, please contact Bree Galbraith and/or Deborah Shackleton using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at the Emily Carr University of Art and Design **ECU-REB #2014022102**. *May 13th 2014* If you have any comments or concerns, please contact REB Assistant, Lois Klassen at ethics@ecuad.ca .

Page 1 of 4

This form DOES NOT include the provision for Assent and Consent of participants who are minors or who are under legal guardianship.

Co-Creation Consent for image release



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EMILY CARR UNIVERSITY RESEARCH ETHICS BOARD (ECU-REB)

RELEASE STATEMENT In signing this release it is my understanding that the material is to be used solely for educational purposes and that the major outcome will be public critique of the final project. The critique will involve members of the University community.

I understand the risks and contributions of my participation in this project and agree to participate.

I agree to allow use of images, clips of video footage and/or audio clips for documentation and display of the project results as identified below. Please check all that apply:

DIRECT QUOTATIONS -
☐ Yes, I consent to being quoted in all documentation and publications
☐ No, I do not consent to being quoted in the documentation and publications

IMAGES AND RECORDINGS OF ME OR OF MY PROPERTY -
☐ Yes, I consent to the use of digital images (photos or video) or audio recordings taken during the research user trials to be used for research and publication purposes.
☐ No, I do not consent to the digital images (photos or videos) or audio recordings taken during the research user trials to be used for research and publication purposes.

☐ Yes, I consent to my photo being published in any of the final publications
☐ No, I do not consent to my photo being published in any of the final publications

☐ Yes, I consent to my photo being converted to a line drawing, with all personal identifiers removed, as seen in the example provided below.
☐ No, I do not consent to my photo being converted to a line drawing, with all personal identifiers removed, as seen in the example provided below.

Page 2 of 4

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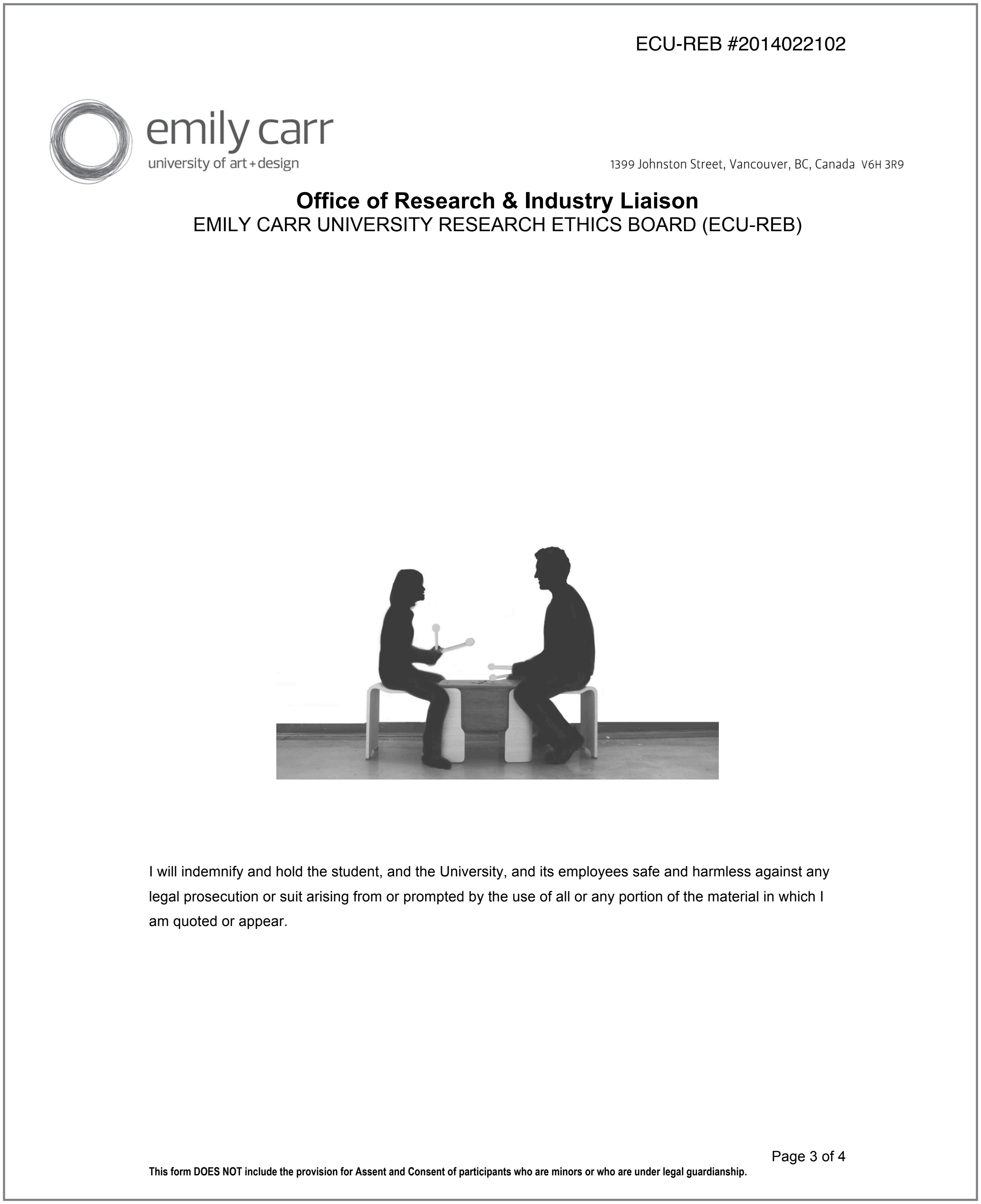
Co-Creation Consent for image release



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I will indemnify and hold the student, and the University, and its employees safe and harmless against any legal prosecution or suit arising from or prompted by the use of all or any portion of the material in which I am quoted or appear.

Page 3 of 4

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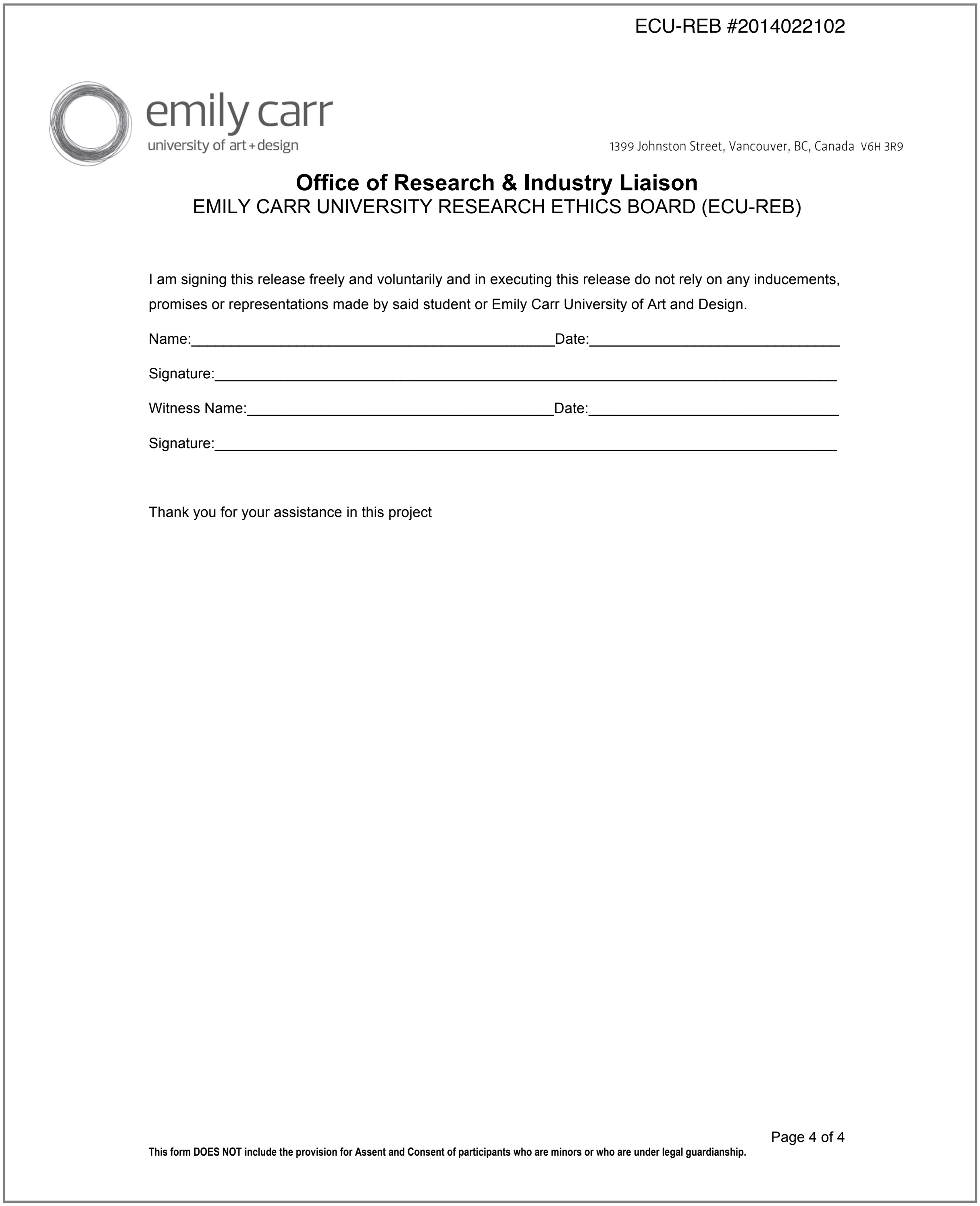
Co-Creation Consent for image release



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EMILY CARR UNIVERSITY RESEARCH ETHICS BOARD (ECU-REB)

I am signing this release freely and voluntarily and in executing this release do not rely on any inducements, promises or representations made by said student or Emily Carr University of Art and Design.

Name:______________________________Date:____________________

Signature:____

Witness Name:________________________Date:____________________

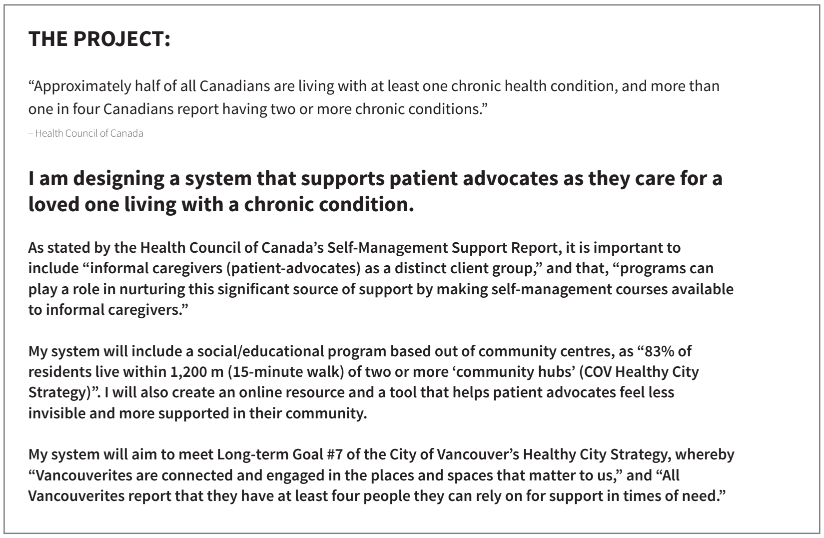
Signature:____

Thank you for your assistance in this project

Page 4 of 4

This form DOES NOT include the provision for Assent and Consent of participants who are minors or who are under legal guardianship.

Co-Creation Activities



THE PROJECT:

"Approximately half of all Canadians are living with at least one chronic health condition, and more than one in four Canadians report having two or more chronic conditions."

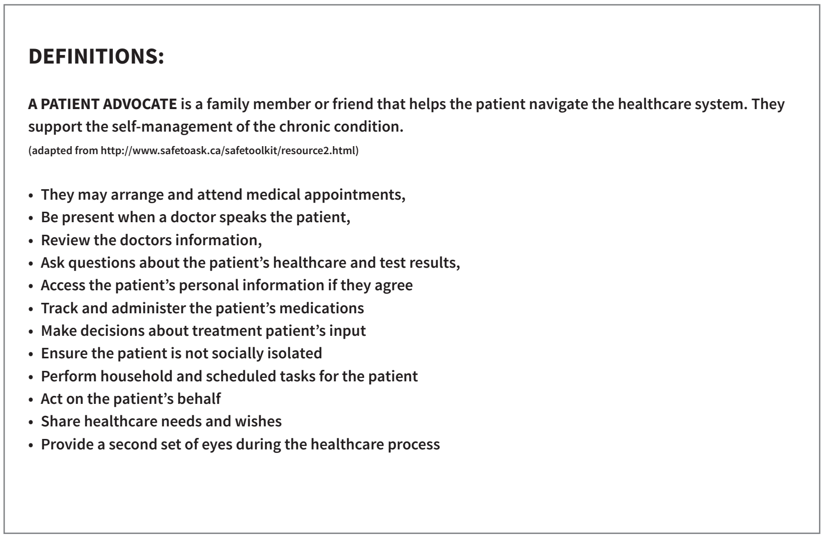
– Health Council of Canada

I am designing a system that supports patient advocates as they care for a loved one living with a chronic condition.

As stated by the Health Council of Canada's Self-Management Support Report, it is important to include "informal caregivers (patient-advocates) as a distinct client group," and that, "programs can play a role in nurturing this significant source of support by making self-management courses available to informal caregivers."

My system will include a social/educational program based out of community centres, as "83% of residents live within 1,200 m (15-minute walk) of two or more 'community hubs' (COV Healthy City Strategy)". I will also create an online resource and a tool that helps patient advocates feel less invisible and more supported in their community.

My system will aim to meet Long-term Goal #7 of the City of Vancouver's Healthy City Strategy, whereby "Vancouverites are connected and engaged in the places and spaces that matter to us," and "All Vancouverites report that they have at least four people they can rely on for support in times of need."



DEFINITIONS:

A PATIENT ADVOCATE is a family member or friend that helps the patient navigate the healthcare system. They support the self-management of the chronic condition.

(adapted from http://www.safetoask.ca/safetoolkit/resource2.html)

- They may arrange and attend medical appointments,
- Be present when a doctor speaks the patient,
- Review the doctors information,
- Ask questions about the patient's healthcare and test results,
- Access the patient's personal information if they agree
- Track and administer the patient's medications
- Make decisions about treatment patient's input
- Ensure the patient is not socially isolated
- Perform household and scheduled tasks for the patient
- Act on the patient's behalf
- Share healthcare needs and wishes
- Provide a second set of eyes during the healthcare process

Co-Creation Activities

DEFINITIONS:

SELF-MANAGEMENT refers to the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management *(Adams, Greiner & Corrigan, 2004).* http://www.selfmanagementbc.ca

SELF-MANAGEMENT SUPPORT is defined as the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support *(Adams, Greiner & Corrigan, 2004).*

CHRONIC CONDITIONS: "Chronic conditions, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are estimated by the World Health Organization to cause 36 million deaths around the world each year. In Canada, few people are untouched by chronic disease or injuries: three out of five people over the age of twenty live with one of these diseases, and four out of five are at risk."
http://www.phac-aspc.gc.ca/

PATIENT ADVOCATE RE-WORDING

I use the term "patient advocate" in my research.

I would like your help in choosing a better term than "patient advocate," as I don't feel it does a good enough job defining the role.

Using the words below, **or by adding your own,** please make word-pairs (example: patient + NEW WORD) that you think suit this person and support their important position.

When you have a term you are satisfied with, please write it on the card provided, and put the card in the box. Write as many as you want to!

Co-Creation Activities

Supporter
Navigator
Guide
Proponent
Scout
Promoter
Pathfinder
Partner
Facilitator
Designer
Backer
Monitor
Researcher
Defender

Architect
Encourager
Activist
Planner
Patient
Patient
Patient
Patient
Patient
Patient
Patient
Patient
Patient
Patient

SHOW YOUR SUPPORT

The Vancouver Coastal Health Community Engagement Framework explains ‘People Centred Care,’ to be a “multidimensional shift by healthcare institutions away from models of healthcare delivery that have often been hierarchical, provider-driven, and depersonalized.”

In their reports, they include research that explains that “The art and science of extending people-centred care beyond the individual client and family into the community at large may be Canada’s unique contribution to this international consensus.”

We are the community. Use these cards to leave a message of encouragement for a patient advocate so that they feel supported in their role as a care-provider. Your message may contain words, images, colours, shapes... there is no wrong answer. Please place your card with the other finished cards on the white poster-board paper.

Co-Creation Activities

COMMUNITY OUTREACH

The Institute for Healthcare Improvement (an independent not-for-profit organization based in Cambridge, Massachusetts) suggests that a main strategy for doctors finding resources for their chronically ill patients is to tour the neighbourhood their patients live in. They recommend:

"Ask patients or staff who live in a neighborhood you serve if they would be willing to lead you on a tour of that neighborhood. As you tour, ask them and/or those you meet along the way, what problems do people with chronic conditions in this neighborhood typically face or typically find most troubling? What resources do people facing these problems find most helpful?"

What problems do people with chronic conditions in this neighborhood typically face or typically find most troubling?

What resources do people facing these problems find most helpful?

Imagine you were met in your neighbourhood and asked these questions. Please answer them on the sheet provided.

COMMUNICATION MATERIAL

Imagine you are in a community centre. In what physical location would you expect to find information about a patient advocate support program?

What form of communication should the information take?
EX: pamphlet, newsletter, poster, website, kiosk…

How/by who would you expect to be informed of such a program?

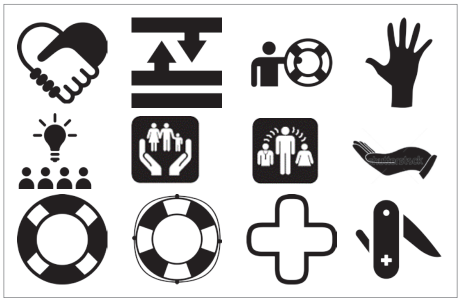
If you imagine yourself as a patient advocate, would you like to have input in the program schedule/information? Why or why not?

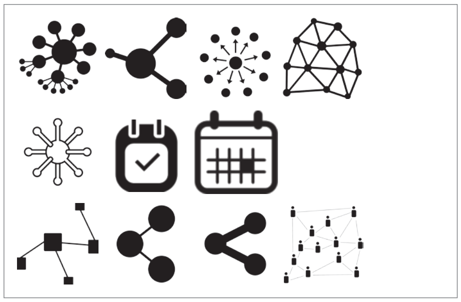
If you imagine yourself taking part in the program, in what way(s) would you like to receive a newsletter about the events/schedule/information? (place an X)

- Via email
- Via Mail (printed copy delivered to your door)
- Downloaded as a PDF from the Community Center Website
- Hard copy at the Community Centre

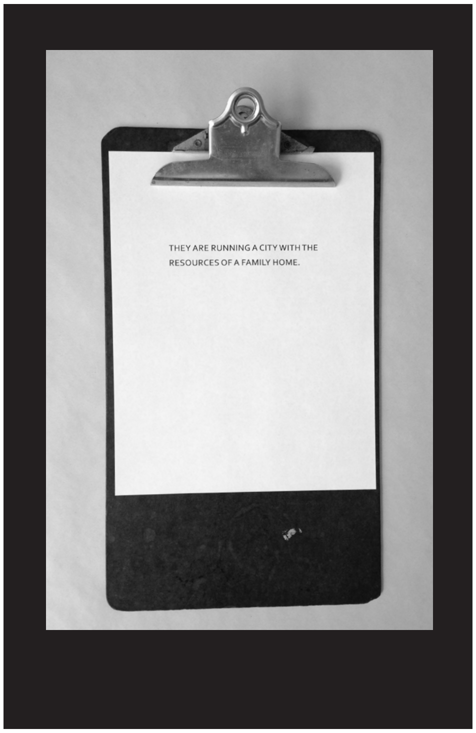
Co-Creation Activities

Which icon represents “support”? Place a ‘X’ next to it. Feel free to draw your own.





PHC RCFM Narrative images



THEY ARE RUNNING A CITY WITH THE RESOURCES OF A FAMILY HOME.

AN ELDERLY MAN IS FEEDING HIS WIFE...SLOWLY, WITH THE CARE OF A SACRED RITUAL, HE RAISES THE SPOON, AND OFFERS IT TO HER, NEVER TAKING HIS EYES OFF HER FACE. I CAN'T WATCH, BUT I CAN'T LOOK AWAY.

'WHY IS THERE ONLY ONE BED?' I ASK. 'THIS IS THE PALLIATIVE ROOM,' SHE ANSWERS. THIS IS THE ROOM WHERE PEOPLE COME TO DIE.

PEOPLE BETWEEN LIFE AND DEATH ENCUMBERED NOT JUST BY ILLNESS OR AGE, BUT THE CONDITION OF THE INSTITUTION AROUND THEM.

PHC RCFM Narrative image

TODAY I SAW WHAT LIFE IS WHEN IT'S FORGOTTEN, AT ITS END, RUN ITS COURSE. TODAY TOO I SAW WHAT LIFE IS WHEN IT'S SELFLESS AND UNWAVERING. THIS WAS THE DAY THAT THE RAW POTENTIAL OF THE PRACTICE OF DESIGN BECAME SO REAL THAT I COWERED IN ITS CLARITY, QUESTIONING MY OWN ABILITIES.

THE SOCIAL HEALTH PROJECT

Bree Galbraith | Emily Carr University of Art + Design