

Engaging Canada's Older adults in health
TECHnology innovation ecosystems

The ECOTECH Project

by

Heather McNeil

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EXAMINING COMMITTEE MEMBERSHIP

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

External Examiner

TANIA STAFINSKI, PhD
Director, Health Technology and Policy
Unit in the School of Public Health,
University of Alberta

Supervisor(s)

PAUL STOLEE, PhD
Professor, School of Public Health and
Health Systems, University of Waterloo

Internal Member

JOSEPHINE MCMURRAY, PhD
Adjunct Professor, School of Public Health
and Health Systems, University of Waterloo

Internal-external Member

JENNIFER DEAN, PhD
Assistant Professor, School of Planning,
University of Waterloo

Other Member(s)

KERRY BYRNE, PhD
Adjunct Professor, School of Public Health
and Health Systems, University of
Waterloo

KELLY GRINDROD, PharmD
Assistant Professor, School of Pharmacy,
University of Waterloo

AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

Introduction

Technological innovation offers many opportunities and challenges to support the health and well-being of older adults. Increasingly, the value of developing regional infrastructure that supports and drives innovation in local clusters is recognized. This innovation typically arises from collaboration among researchers, government and industry (Etzkowitz & Leydesdorff, 2000). Application of this collaborative framework is emerging in the health sector in the context of innovation to support an aging population. Current trends towards transparency, citizen empowerment and the democratization of health support the need to understand the engagement of end users (specifically older adults and their caregivers) in the development of community infrastructure that supports innovation in health.

The Engaging Canada's Older adults in health TECHNOLOGY innovation ecosystems: ECOTECH Project aims to expand our understanding of how older adults and their caregivers might have greater involvement in the regional innovation ecosystems that may support development of new health and aging-related technologies and other innovations.

Methods

This project consisted of a three phase integrated mixed methods study with a focus on knowledge exchange throughout. Phase I was a scoping review of the available literature on Regional Innovation Ecosystems (RIEs) to inform hypothesized modifications to current collaborative models of innovation and learn from initiatives outside of health that currently incorporate end user engagement. Phase II included

interviews and focus groups with stakeholders including older adults and representatives from university, government, and industry to explore current practices in Canada for engaging end users in health innovation and explore opportunities for participation in Regional Health Innovation Ecosystems (RHIEs). Informed by these results, Phase III was a Concept Mapping exercise following the methodology of Kane and Trochim (2007). Data were collected through and analyzed using the Concept System software (2015). Multivariate statistical techniques (multidimensional scaling and cluster analysis) were applied to create a framework of priorities.

Results

Although the literature revealed that there are a variety of roles that end users currently take on in RIEs, little discussion was available on the role that vulnerable populations play. These findings informed the interview phase which revealed an interest and readiness in some engagement of older adults and their caregivers in RHIEs. Enhancing their involvement will require a recognition of the need for diversity of older adult and caregiver representation, consideration of barriers such as system constraints and traditional partnerships, and recognition of multiple roles that older adults could play in health innovation. A seven cluster framework of priorities has emerged with specific actions to be taken to engage older adults and their caregivers in RHIEs.

Conclusions and next steps

Greater involvement of older adults and caregivers in health and aging innovation can result in new technologies and processes that are more likely to meet their needs and preferences. This study identified directions and strategies for their enhanced involvement in regional ecosystems for innovation. Continued collaboration with

stakeholders will allow the results of this study to be used in developing RHIEs in Canada. The next steps of this work will involve implementation of the framework of priorities in Canadian RHIEs. This evolution of current collaborations will support the development and appropriate adoption of health and aging technologies and innovations that have the potential to improve the health and well-being of older adults and their caregivers.

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DEDICATION

This thesis is dedicated to my family, for your love and support I am forever grateful.

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CHAPTER 1 INTRODUCTION AND OBJECTIVES

1.1 Statement of research focus

Society is becoming increasingly digitized with the advancement and proliferation of technologies and the emergence of “e everything” (Olphert & Damodaran, 2007). This digitization offers many opportunities to support and improve the quality of life and well-being of older adults through innovations in health. Health care systems throughout the world recognize the opportunity for innovations in health but have been slow to transfer these advancements into the care they provide (Barlow, 2015; Coughlin & Pope, 2008).

Concurrently, there is a growing realization of the importance of involving patients and the public more broadly in the planning and development of public services (Holosko, Leslie, & Cassano, 2001). This is true in health care where research has identified many potential benefits of public engagement in health research and planning, including improved health outcomes and a more responsive health care system (Scott, 1999).

Increasingly, the value of developing regional infrastructure that supports and drives innovation in local clusters arising from the joint activities of researchers, government and industry is recognized (Dzisah, Zarifa, & Kelly, 2012). However, little is known about the involvement of older adults in the development of community infrastructure that supports innovation in health. The **Engaging Canada’s Older adults in health **TECH**nology innovation ecosystems (ECOTECH)** Project addressed this gap through a three phase integrated mixed methods study which expanded current

understandings of how Regional Health Innovation Ecosystems (RHIEs) can engage older adults and their caregivers in meaningful ways.

1.2 Research questions

The overall objective of the ECOTECH project is to contribute to an improvement of quality of life and well-being for older adults through the creation of a model of engagement of older adults and their caregivers in RHIEs. To do this, the following research questions were examined:

- 1) How have end users been engaged in Regional Innovation Ecosystems?
- 2) What is the interest in and readiness for engagement of older adults and their caregivers in health innovation?
- 3) How can older adult and caregiver engagement in Regional Health Innovation Ecosystems (RHIEs) be realized?

An understanding of how older adults and their caregivers can be engaged in RHIEs could enhance the likelihood that novel products that support healthy aging will be commercialized or successfully disseminated beyond a proof of concept.

1.3 Thesis overview/ structure

This thesis first provides an overview of background information such as key terms and literature to provide context. A summary of the methodology undertaken for this project follows. The three phases of the ECOTECH project are presented as individual manuscripts, each addressing a research question. Although each phase of this thesis has been written as a unique manuscript, it is pertinent to note that results and learning from each phase were integrated into each other as was feasible and necessary to answer the research questions and achieve the overall objectives of this study.

CHAPTER 2 BACKGROUND

This section will provide working definitions of terminology relevant to older adult and caregiver engagement in RHIEs and outline the research gap this study addressed.

2.1 Definitions of key terms

This project is situated within the intersection of many nebulous terms which can be described as concepts of “useful ambiguity” (McLaughlin, 2004) in that the lack of definitional clarity has helped many of these ideas become popular. Despite this, best practice guidelines for transdisciplinary work advocate for the importance of a common language (Smith, 2007); therefore key terms as understood by the author are conceptualized below.

2.1.1 Innovation

For the purposes of this project, innovation will be understood as a learning and searching process to transform knowledge into “novel wealth-creating technologies, products and services” (Cooke, Roper, & Wylie, 2003) where wealth is understood in alignment with the conceptualization of the Conference Board of Canada, 2013 to include both economic and social value. Disruptive innovation, which has become an important term and concept in the innovation literature, is described by (Bower & Christensen, 1995) as innovation that creates new market and value, eventually disrupting an existing market.

2.1.2 Health

It is also important to note that the focus of this project is on innovation with the potential to improve the health and quality of life of older adults. Health here is understood from a broad, social determinants of health perspective. That said, the majority of literature and dialogue in this area focuses on “health care” and the “health care system”. The author presents these within a conceptualization of components of the broader umbrella of health important to understanding older adults’ well-being and quality of life.

2.1.3 Health Innovation

Health innovation combines the idea of innovation presented above in the context of health, as understood from the perspective of the social determinants of health (Public Health Agency of Canada, 2011). Informed by DeWolf (2009), this conceptualization includes four main categories of innovation: finance (e.g., changes to payment structures), process (e.g., system flow improvement), offerings (e.g., advancements in prosthetics), and delivery (e.g., telemedicine). Naylor and colleagues (2015) describe health innovation as including a wide spectrum of activities from technological innovation through to social and policy innovation.

2.1.4 Health Technology

Health technology is a nested concept, understood as a component of the innovation needed in healthcare. As defined by the World Health Organization (2017), “health technology refers to the application of organized knowledge and skills in the form of devices, medicines, vaccines, procedures and systems developed to solve a health problem and improve quality of lives”.

Throughout this project, the ideas of health technology and health innovation are often discussed interchangeably, reflecting the spectrum approach needed in this space for the creation of economic and social value to improve the quality of life and well-being of Canada's older adults.

2.1.5 Engagement

The term “engagement” has been used interchangeably with involvement, partnership, empowerment, collaboration, and co-creation throughout multiple disciplines and areas of literature. There are also a variety of terms used to describe the participant group to be engaged such as patient, citizen, stakeholder, client, public, and community. For the purposes of this project, to reflect the health related nature of this topic, engagement will be understood in alignment with conceptualizations of partnership described by the Canadian Institutes for Health Research (CIHR, 2014): “patient engagement occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge (i.e., the process referred to as “knowledge translation”).” This term is applied beyond research contexts in this project.

2.1.6 Older adults and their caregivers

Older adults have been defined in various ways throughout the health and aging literature. Although the author acknowledges the complexity of understanding aging from possible foci such as biological, psychological, functional, or social aging, for the purposes of feasibility, chronological age will be used to define older adults. At the proposal stage of this project an age of 65 years old was chosen to define this stakeholder

group, however throughout the project and in discussion with committee members and participants, the age range was lowered to involve those who are 55 years and older.

Caregivers of older adults are potential end users of innovative technologies to support healthy aging, and as such represent important perspectives in health innovation in relation to older adult experiences. The extent to which a participant associates themselves with this role will determine their inclusion and importance in this study. The phrasing, “their caregivers”, was chosen in consultation with committee members to reflect the respectful position that the author takes in understanding the role that many family members and friends play in the lives of older adults as informal caregivers.

In relation to innovation in the health and aging space, both of these stakeholder groups are described using a number of terms throughout this thesis including “end user”, “citizen”, and “consumer”. The author acknowledges the work in some areas of health innovation, including that of Health Technology Assessment (HTA), to distinguish between groups that could be categorized as “citizens and public” and those who would be considered “end users, patients, or consumers”. While this distinction is emerging, for this project, terminology was determined based on early discussion and input of stakeholders and is not categorized in this way.

2.2 Current context

Canada’s health care system can be described as a regionally administered universal public insurance program that plans and funds provision of services (Mossialos, Wenzl, Osborn, & Anderson, 2015). While the health care system is valued by the majority of Canadians, it is currently not sufficient for the 21st century (Romanow, 2002).

Some of this complexity can be historically traced to the development of many health disciplines which were traditionally organized by organ systems, resulting in a high degree of specialization (Hogan, 2007). This necessitates the transition of patients between multiple providers and settings in order to receive appropriate care.

Issues with Canada's health system are often most concerning in the care of older adults who are its largest user group and the fastest growing segment of the Canadian population (Canadian Institute for Health Information, 2011). The challenges older adults face within the system have been well documented including the description by Drouin and colleagues (2015) who describe concerns of complex older patients in terms of access, continuity, fragmentation and quality of care. System fragmentation is illustrated in The Change Foundation's (2012) assessment of system navigation experiences of Ontario older adults and their caregivers, finding that only one-third of participants believed that they could easily navigate the system.

The challenges are not unique to Canada and issues with caring for older adults are expected to continue as inadequate health systems worldwide are met with population aging. Globally, there are changing health needs of an aging population and trends of health spending growth (OECD, 2014). There are currently 901 million people aged 60 or over with this section of the global population growing at a rate of around three per cent per year (United Nations, 2015). Compounding this, the "oldest old" demographic (Suzman & Riley, 1985) of the global population is also growing; the number of older adults aged 80 or over is projected to more than triple by 2050. In Canada, the aging population is evidenced by the statistic that for the first time, the number of persons

aged 65 years and older exceeded the number of children aged one to 14 years (Statistics Canada, 2015).

This aging population has been discussed in relation to the economy with data projecting that by 2050, the share of the dependent population is projected to increase in all Organization for Economic Cooperation and Development (OECD) countries (OECD, 2014). Related to health care spending, a recent National Institute for Health Care Management (NIHCM) Foundation report (2012) found that in America, a disproportionate amount of money is spent on older adults with chronic disease. In Canada, the Canadian Institute for Health Information (2011) revealed that health care spending per capita is five times higher for older adults than for younger persons and this trend is growing.

These demographic and economic trends have been presented in the popular media from a largely negative, apocalyptic perspective. “The grey tsunami”, “fading to grey” (Toronto Star, 2015), “navigating the storm ahead” (Furlong & Amin, 2010) and other ageist discourse have dominated popular conversations on aging and the health care system but this trend to blame older adults for issues within Canadian health care systems has been largely misplaced. Many of the identified challenges with health care systems can be attributed to its complexity (Plsek & Greenhalgh, 2001) which causes issues in providing quality care to patients (Institute of Medicine, 2001). Innovation in the form of service delivery, such as the implementation of models of system integration provide evidence-based solutions to many of the issues described above.

An integrated model of health care has been proposed as a potential solution to fragmentation and complexity (Ferrer & Goodwin, 2014; The Change Foundation, 2010).

The core principles of integrated care (Ferrer & Goodwin, 2014) are important in the global quest to improve health care provision (The Change Foundation, 2010). Integrated care brings together stakeholders from across the continuum to work collaboratively to achieve complementary, coordinated services and a unified system (Toscan, Mairs, Hinton, & Stolee, 2012). A number of positive outcomes have been associated with integrated care including increased access to services, improved quality of care, patient safety, and patient and caregiver experience (The Change Foundation, 2010).

In the transformation of health care systems necessary to achieve integrated care, The Crossing the Quality Chasm report (Institute of Medicine, 2001) proposed six highly desirable attributes of new care delivery systems: safety, effectiveness, patient centredness, timeliness, efficiency, and equitability. Ten rules for redesigning health care accompanied this report with two especially relevant to this project: i) the need for care to be customized according to patient needs and values, and ii) the patient as the source of control in the delivery of care. More specific to the Canadian context, Leatt, Pink, and Guerriere (2000) have proposed six evidence-based strategies for the provinces to implement in order to move towards an integrated system: a focus on individualized care; a recognition of primary care as the building block of integration; the need for information technology to create accessible health records; creation of virtual networks to coordinate at local levels; development of appropriate needs-based capitation formulas; and evaluation of changes made towards system integration.

While these models of care and suggestions for patient involvement are important components of improvement of the health care system and outcomes for older adults and

their caregivers, innovation specifically targeted at improving the health and well-being of older adults and their caregivers are needed.

2.3 Addressing the challenge: Innovation for health and aging

Innovation is frequently positioned as a promising way to address issues associated with population aging (Cohen, 2013) and the goal of supporting more active and independent forms of living in old age. Strategies to support the health of the aging population increasingly rely on advances in technology to prevent, detect, and treat complex health problems prevalent among older adults (Dishman, Matthews, & Dunbar-Jacob, 2004).

In order to address the complex challenges facing health care systems, disruptive innovation is needed (Christensen, Bohmer, & Kenagy, 2000; DeWolf, 2009). As technology advances, innovations will play an expanded role throughout the health care system including informing evidence-based decision-making, streamlining referrals, enhancing communication flow between health care providers and empowering patients as partners in their care. Gardner and colleagues (2007) suggest that ensuring access to essential products and services in health involves not only technological but social innovation, which can be understood as advances in social relations of governance and satisfaction of basic needs (Moulaert & Nussbaumer, 2005).

Currently, there are many challenges to innovating in health, including hierarchies (Ferguson & e-Patient Scholars Working Group, 2007), complexity (Plsek & Greenhalgh, 2001) and risk aversion (DeWolf, 2009). Further complications arise from the issue of technology adoption; when health innovation has occurred there are many barriers to adoption even when potential usefulness is well-recognized (Lee & Coughlin, 2015).

Health technology assessment has been viewed as a “fourth hurdle” by industry and innovators (Rogowski, Hartz, & John, 2008). Disruptive innovation in health could “save” the health care system (Christensen et al., 2000) but this has yet to be fully realized.

There are, however, challenges for ideas (no matter how transformative) to be transferred to market. Current best practice models of innovation can be described as open innovation (Chesbrough, 2006) where external ideas are embraced and innovators are encouraged to integrate their ideas with those of others from outside organizations. This knowledge exchange often occurs on a local basis (Bramwell, Hepburn, & Wolfe, 2012a) supporting the value of developing regional infrastructure that drives innovation in local clusters.

“Regional Innovation Ecosystem” (RIE) is the term used synonymously across multiple disciplines including geography (Regional Innovation Systems) and business (Knowledge Clusters) to explain the institutional infrastructure supporting innovation within a region (Asheim, Smith, & Oughton, 2011) and providing the opportunity for disruptive innovation. Silicon Valley is often cited as the quintessential example of a RIE where tremendous economic and technological success has emerged from the knowledge spillover and culture of innovation developed out of regional proximity (Gertler & Wolfe, 2004; Porter, 2001).

The metaphor of the “ecosystem”, from ecology science, is central to RIEs in that ecosystems represent “a portion of the biosphere lodging a community and an environment that are constantly engaged in reciprocal interactions, and infinitely struggling to develop a dynamic equilibrium” (Mortati & Cruickshank, 2011, p. 6).

Ecosystems are understood as open systems with existence determined by constant adaptation to change.

Within an innovation ecosystem, there needs to be a variety of capital available including financial, human, and social (Landry, Amara, & Lamari, 2002). The idea of place, specifically the importance of region, has been widely accepted in the innovation literature (Doloreux & Parto, 2004) recognizing that regions where innovation flourishes have openness, diversity, and tolerance to attract the human and physical capital necessary to form an RIE (Britton & Legare, 2005). More recently, literature on RIEs has begun to recognize the importance of civic capital in the promotion and support of entrepreneurial activity (Bramwell, Nelles, & Wolfe, 2008).

Innovation benefits from evolving and overlapping relationships between academia, government, and industry, known as the Triple Helix (Etzkowitz & Leydesdorff, 2000). The Triple Helix concept explains the interconnected network required to support effective technology commercialization, entrepreneurship, and the translation of scientific findings into economic and social development (Bramwell, Hepburn, & Wolfe, 2012b; Dzisah et al., 2012; Etzkowitz, 2011). This metaphor is useful in capturing the complexity and dynamic nature of relationships necessary to support RIE development.

Emerging literature supports the evolution of the Triple Helix model to conceptualize the importance of environmental and civil society helices, describing development with metaphors such as “Quadruple”, “Quintuple” or N-tuple helices (Alizadeh, 2010; Carayannis & Campbell, 2012; Colapinto & Porlezza, 2012; Leydesdorff, 2012; Mulyaningsih, 2015). These evolutions begin to theorize the

community as an important “innovation base” (Alizadeh, 2010, p. 2) but are underdeveloped in terms of the roles that actors in new helices should play and have yet to be adopted by the main stream literature in this area.

Evolutions of the Triple Helix link to the idea of social capital in the formation of networks. Connections, as described by the social capital literature, have been theorized as either bonding or bridging (Putnam, 2001). From this perspective, inclusive networks are described as bridging social capital in ways that involve outward or diverse associations; bonding social capital conceptualizes exclusive networks made up of homogeneous groups (Nyqvist, Gustavsson, & Gustafson, 2006). In the establishment of RIEs, the idea of bridging social capital is especially useful as it recognizes the value of relationships built with individuals outside of the immediate network as important in the acquisition of new information and opportunities (Macinko & Starfield, 2001). This acquisition is important in creating trust (Gertler & Wolfe, 2004) necessary for collaboration and is a concept hypothesized to be important in translating the concept of RIE into the health innovation sector which has been slow to adopt collaborative models (Prada, Mccauley, Garrett, & Macgregor, 2013; Sebastianski et al., 2015).

2.3.1 Regional Health Innovation Ecosystems

In response to challenges and opportunities in health innovation, the concept of RIEs is emerging in the health sector, but has developed at a slower pace than in other industries where this collaboration has proven valuable (Prada, Mccauley, Garrett, & Macgregor, 2013). “Regional Health Innovation Ecosystems” (RHIEs) is the term that has evolved from the literature on regional innovation as a potential mechanism to improve commercialization and spur disruptive innovation in health.

As discussed in the RIE literature, by constructing a network of necessary stakeholders, innovators in other industry sectors have proven that knowledge spillover, talent acquisition, resource sharing and other positive effects are generated (Ahn, Hajela, & Akbar, 2012; Asheim & Gertler, 2006).

Since the concept of RHIEs is novel, the partnerships necessary to create successful innovation networks in health are unknown. The understanding of the civil society helix discussed in the emerging RIE literature above, evolving beyond the Triple Helix to Quadruple, Quintuple or N-tuple theories of innovation (Alizadeh, 2010; Carayannis & Campbell, 2012; Colapinto & Porlezza, 2012; Leydesdorff, 2012; Mulyaningsih, 2015) might be important in health innovation.

The involvement of civil society is particularly salient in health as it aligns with current democratization trends in many health care systems, providing the opportunity for older adults and their caregivers to provide direction and agency to all of the other helices in RHIEs. Support for the civil society helices in health is evidenced by the recognition that involving end users in the design process of innovations has emerged as the quickest and most reliable way to capture the needs of users and consumers (Essén & Östlund, 2011). Engagement with consumers is increasing across innovation sectors as industry begins to recognize the value of their involvement and customers become “richer, demanding, and better educated” (Colapinto & Porlezza, 2012, p. 344). In the context of health innovation “consumers now demand more health information and greater control over health experiences” (Carrera & Dalton, 2014, p.39). Could the involvement of patients, specifically older adults (the highest users of the health care system) and their

caregivers in meaningful partnerships in RHIEs, help to create the conditions necessary for disruptive innovation in health?

2.4 Engagement

There has been increasing interest in involving patients and caregivers in health care research and planning (Holosko et al., 2001; Jansen, Baur, de Wit, Wilbrink, & Abma, 2015) and there is current recognition that in order to improve the health care system to meet Canada's evolving health needs, patient engagement must be supported (Denis, Davies, Ferlie, & Fitzgerald, 2011; Elliott et al., 2016; Jenkins et al., 2011). Meaningful opportunities are needed to provide a voice for patients and their caregivers in the health care system through performance measurement and reporting of patients' experiences (McMurray et al., 2015a, 2015b).

Patient engagement has been discussed at multiple levels of the health care system. At a micro level, the importance of patient-centred care has been accepted and is a current goal of many health care systems (Institute for Medicine, 2001). This concept is linked with patient engagement at the macro level of health system planning; in order to have a system that responds to the needs of patients at the point of care, their input and values need to be known. However, Hicks and colleagues (2012) found that current conceptualizations of shared decision making by patients are often tokenistic, in that there is often only an illusion of choice for patients and their caregivers. Engagement in system development and planning makes it possible for patients to be meaningfully engaged in their health, "promoting greater patient responsibility and optimal usage of health services which ultimately leads to improved health outcomes, quality of life and

patient satisfaction” (Harkness, 2005, p.1) and a more responsive health care system (Department of Health, 1999).

There are many methods for involving the public in health-related research and planning. Technology is emerging here with many application for engagement such as “e government”, offered as a mechanism through which administrations are “hoping to improve communication with citizens to enhance the democratic process, encourage wider citizen participation, and reduce social exclusion” (Olphert & Damodaran, 2007, p.492). This digital revolution has provided opportunities for communities to play significant roles in decision-making processes, knowledge production and distribution (Alizadeh, 2010).

Technology enabled or not, engagement efforts range from meaningful opportunities (such as deliberative democracy approaches as discussed by De Vries and colleagues (2010)) to less impactful, tokenistic efforts. In examining this range, partnership approaches to patient engagement have the potential for the whole to become greater than the sum of its parts (McLaughlin, 2004). Archambault (2011) suggests that active public involvement as partners in the development of health services is central to a health care system that is “responsive to a patients’ needs and values” (p.1).

There is also a wealth of literature supporting not only the essential role that informal caregivers (such as family and friends) play in the health care system but the impact that issues in the health care system have on them (Byrne, Orange, & Ward-Griffin, 2011; Elliott, Forbes, Chesworth, Ceci, & Stolee, 2014; Giosa, Stolee, Dupuis, Mock, & Santi, 2014). Given their central role in the circle of care to ensure healthy aging and quality of life, it is important that caregivers of older adults be included in

complex health decisions and therefore be considered in patient engagement activities (Stolee et al., 2015).

While an in-depth examination of the specific nuances of caregiver engagement in RHIEs is beyond the scope of this project, caregivers are potential end users of innovative technologies to support healthy aging, and as such represent important perspectives in health innovation in relation to older adult experiences.

Although there is an extensive body of literature on patient engagement in health, there remains a need to understand the best ways to engage older adults in health care research, planning, and decision-making (Stolee et al., 2015). To address this gap the Geriatric Health Systems (GHS) Research Group at University of Waterloo has completed a realist synthesis (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013) on older adult engagement in health care research, planning and decision making, focusing on the engagement of older adults (Stolee et al., 2015). This work resulted in the development of the *CHOICE Engagement Framework*, and associated strategies for engaging older adults and caregivers.

The CHOICE project revealed that older adults want meaningful opportunities for engagement in health research and planning (McNeil et al., 2016). The idea of partnerships offers an opportunity to provide this meaningful engagement, but also creates complexity (McLaughlin, 2004) in engaging older adults in health innovation. Partnerships have been defined in numerous ways but typically include aspects of trust and interdependence of participants. McNeil and colleagues (2016) have identified common principles in engaging older adults and their caregivers in the broad domain of

health research and planning, however there is a need to build on this understanding to learn how best to engage older adults as meaningful partners in RHIEs.

2.5 The intersection of innovation, health, and aging

At the intersection of technology design, older adults and well-being, is a field called Gerontechnology, which focuses on “designing technology and environment for independent living and social participation of older persons in good health, comfort and safety” (“International Society for Gerontechnology,” 2015). While research in this emerging field is important, it has been viewed as paternalistic by critics such as Peine and colleagues (2014) for broadly following a biomedical model of aging. In response, Peine and colleagues (2014) theorize the engagement of older adults in technology development as co-producers, advocating for an advanced role of older adults in the innovation and design of technology. This conceptualization has roots in early work by Mumford (1991) who described four reasons why end user participation in technology design is “rare” (p.270) despite recognized benefits: i) a lack of knowledge of how to organize participation, ii) organizational cultures that do not support participation of end users, iii) technical specialists wanting to maintain design control, and iv) disempowered users not being able to voice dissatisfaction with a system. Mumford (1983, 1991) advocated for cultural change within innovation organizations and promoted user participation throughout the process of computer system design.

Building on this work, the concept of “patient-centred innovation” is useful in describing the intersection of meaningful engagement and health innovation. A recent search the author conducted for the term “patient-centred innovation” retrieved 45 results on Google Scholar and 7 480 on Google. This concept, like its parent “patient centred

care” has various interpretations (Reed, Conrad, Hernandez, Watts, & Marcus-Smith, 2012; Wen & Tucker, 2015) with little consensus on a definition and an obvious lack of theorization. Although ideas of involving patients in innovation are central in this literature, the random sample of articles reviewed focus on innovation for improving patient-centred care at the clinical decision-making level. While this is an important component and rationale for innovation in health, there is opportunity for a more systemic conceptualization of patient-centred care that encourages meaningful engagement at the level of health innovation research and planning.

The idea of providing for and achieving excellence in patient experience is becoming a key focus in Canadian health care systems. This is evidenced in health policy (Drummond, 2012; Romanow, 2002) and research funding opportunities (The Change Foundation, 2015). Recently CIHR recognized the importance of patient engagement in health innovation by including the concept “patient centred innovation” in their updated model for patient advisory boards. The goal of their new model of patient engagement is to “enhance collaboration and transversal thinking across Institutes and stakeholder communities” with one of the boards focusing on “patient-centred health innovation” (CIHR, 2015).

The area of Health Technology Assessment (HTA) has emerged to play an important role in advancing the concept of patient-centred innovation. A recent report on engagement in HTA identified four benefits of involving patients in HTA broadly described as democratic, scientific, instrumental, and developmental (Public & Subcommittee, 2015). These arguments for the engagement of patients as important in achieving legitimate and transparent decisions about health technologies, and producing

more robust and comprehensive evaluations ultimately leading to better quality decisions (Public & Subcommittee, 2015) while specifically discussed in the context of HTA, are applicable to other aspects of innovation in health.

Patient involvement in HTA aligns with a growing body of literature that focuses directly on the involvement of the consumer in technology development, described as “user-centred design” (Endsley, 2011). This literature emerged in opposition to the current “technology-centred” systems that are ubiquitous in the information age. The underlying philosophy of user-centred design is appropriate when designing within complex systems (Endsley, 2011) and forms the rationale underlying participation of end users in health innovation more broadly.

Literature in this area is developing, and these views are shared with the current work of some researchers in the AGE-WELL Network (2016) who aim to understand how older adults can be more meaningfully involved in the development of health technology. The purpose of ECOTECH is to build on these understandings to extend the conceptualization of older adult engagement in health innovation beyond the current trend of designers and consumers to meaningful partners, active planners, and decision makers in RHIEs.

Chapter 3 STUDY RATIONALE AND METHODS

This section will provide an overview of the methods undertaken to answer the research questions.

3.1 Research gap

As discussed, regional innovation ecosystems (Doloreux & Parto, 2004) have been recognized in many sectors as important mechanisms for the uptake and commercialization of innovation. Central to innovation ecosystem development theory is the Triple Helix model (Etzkowitz & Leydesdorff, 2000) representing intentional partnerships between university, industry, and government. Specific to health, the development of Regional Health Innovation Ecosystems (RHIEs) has lagged behind other industries, but is attracting attention (Prada et al., 2013a; Williams et al., 2014a). Current trends towards transparency, citizen empowerment and the democratization of health suggest the need for an additional thread in the Triple Helix (academia, government, and industry) to account for end user engagement (patients and the broader public) in RHIEs.

The ECOTECH project has addressed this gap in the field of health innovation to explore the evolution of the Triple Helix model related to RHIEs, understanding the potential for engagement of older adults.

3.2 Philosophical assumptions and project overview

Given the broad range of challenges the health care system faces, health research needs to employ processes and methods that can address complexity. The ECOTECH project used transdisciplinary participatory integrated mixed methods with a focus on

knowledge exchange throughout. The following section provides the research design and data collection details.

3.2.1 Research design

The pragmatist paradigm, aligned with the classical pragmatist work of Peirce, James, and Dewey (Johnson & Onwuegbuzie, 2009) was the guiding philosophy of this project. The strategy of inquiry that ECOTECH employed was a variation of Participatory Action Research (PAR) (Kemmis & Wilkinson, 1998; Rosas, 2012). Complementing this, to answer the research questions, integrated mixed methods (Tashakkori & Teddlie, 2003) were employed.

3.2.2 Stakeholder theory

Stakeholder theory, as described by Mitchell and colleagues (1997) was used as a theoretical conceptualization to support this project. Originating from the work of Edward (1984) based on literature in strategic management, corporate planning, systems theory, organization theory, and corporate social responsibility, this theory addresses “any group or individual who can affect, or is affected by, the achievement of a corporation’s purpose” (vi). The attributes of stakeholders described by Mitchell, et al. (1997) including power, legitimacy (socially accepted and expected behaviors), and urgency (considerations of timing of participation) framed the author’s initial understanding of the potential engagement of older adults and their caregivers in RHIEs. This lens was useful throughout the project to consider as themes emerged.

3.2.3 Participatory methods

A key feature of Participatory Action Research (PAR) is to produce social change (Maguire, 1987). PAR “evolved as an alternative system of knowledge production, challenging the premise and assumptions of conventional social science research methodology” (Rosas, 2012, p.8). It has been defined in various ways across multiple disciplines but can be commonly understood “as a qualitative research inquiry in which the researcher and the participants collaborate at all levels in the research process (participation) to help find a suitable solution for a social problem that significantly affects an underserved community (action)” (Creswell et al., 2007, p.256).

PAR facilitates communication and opportunities for all involved to learn to collaborate (Reason & Bradbury, 2008), acknowledging the multiple perspectives and knowledge sources of the stakeholders involved (Jansen et al., 2015). Most importantly, as discussed by Stringer (2014), a principal element of participatory research is to improve quality of life for communities.

According to Creswell’s (2007) comparison of characteristics of qualitative design, participatory methods were an appropriate methodological design for ECOTECH given: i) the community action focused *research questions* which ECOTECH seeks to address, ii) the *chosen unit of analysis* as the community necessary for health innovation, iii) the *data collection form* of mixed methodology, and iv) the *data analysis strategy* which sought to “involve the community in decisions as to how to analyze the data” (p.241).

3.2.4 Transdisciplinarity

Complexities of aging, health and the health care system require approaches to knowledge generation that encourage working across disciplines to include a diverse collaboration of stakeholders at all levels of the system (Trochim & Kane, 2005). Many traditional attempts at end user involvement in health care research and planning can be described as tokenistic (McNeil et al., 2016) and lacking actions necessary to establish meaningful partnerships. To overcome these, best practices for transdisciplinary working were undertaken.

Support for transdisciplinarity in this project comes from the position of ECOTECH researching on the cusp of a number of disciplines including business, health, gerontology, technology, and social justice. ECOTECH followed emerging best practices in transdisciplinary working, starting with the creation of a team that has been built to reflect the perspectives necessary to meet the project objectives (see Appendix A for team description).

3.2.5 Mixed methods

In social and human sciences, mixed methods have “come of age” (Creswell, 2003, p.4) as an approach to research that combines both qualitative and quantitative data to answer a given research question (Johnson & Onwuegbuzie, 2009). Mixed methods have been growing in acceptance in health science research as the necessity to translate knowledge, and the imperative to involve the community in research have been increasingly acknowledged (Tashakkori & Teddlie, 2003).

As Tashakkori and Teddlie (2003) have discussed, mixed methods research can provide better inferences than certain methods on their own. Social phenomena require

mixed methods to best understand complexities (Tashakkori & Teddlie, 2003). As discussed above, participatory methods can employ the use of mixed methods to gather data to answer the research question (Creswell et al., 2007).

There are a number of approaches to mixed methods design (Creswell, 2003); the ECOTECH project will employ an integrated mixed methodology (Trochim & Kane, 2007). As described by Tashakkori & Teddlie (2003), fully integrated mixed model research designs allow for multiple approaches to data collection, conversion and analysis where both concurrent and sequential data collection are incorporated.

3.2.6 Concept mapping

Aligned with the transdisciplinary participatory design undertaken in the ECOTECH project, Concept Mapping (Kane & Trochim, 2007) blending both qualitative and quantitative methods was undertaken to create a model answering the question of how older adult engagement in Regional Health Innovation Ecosystems (RHIEs) can be realized.

Structured group conceptualization, or concept mapping methodologies, have been used by social researchers for many years (Bickman & Rog, 2008). The term “concept mapping” has been used throughout the social science literature to refer to methods that produce a map of the ideas of an individual or a group (Trochim & Kane, 2005). These methods differs from the group Concept Mapping (CM) methodology chosen for this project as CM is a structured, participatory design for researching group processes (Rosas, 2012). Specifically, CM is defined as “a methodology that creates a stakeholder-authored visual geography of ideas from many communities of interests, combined with specific analysis and data interpretation methods, to produce maps that can then be used

to guide planning and evaluation efforts on the issues that matter to the group” (Kane & Trochim, 2007, p.7).

CM can be described as an integrated mixed method (Kane & Trochim, 2007) as it combines group processes such as brainstorming and unstructured sorting (qualitative techniques) with multivariate statistical methods of multidimensional scaling and hierarchical cluster analysis (quantitative methods).

Specifically relevant to health research, Trochim and Kane (2005) discuss four characteristics of CM that support the methodology: i) the ability to integrate input from multiple stakeholders with differing content expertise and interest; ii) sophisticated and rigorous multivariate data analyses to construct concept maps; iii) the creation of a visual that describes combined thinking of a group; and iv) guidance for immediate action planning or evaluation through the concept maps produced. Many health related studies have used the CM methodology to address various complexities of research in the field including multidisciplinary (Holmes, Fairchild, Hyer, & Fulmer, 2003), lack of relevant theory (Burke, 2005) and context specific knowledge translation strategies (Kasehagen et al., 2014; Kelly, Baker, Brownson, & Schootman, 2007; Lobb, Pinto, & Lofters, 2013). The rationale for Concept Mapping for this final stage of the project is at least twofold:

i) CM has an advantage over other relationship identifying techniques such as factor analysis because it is able to handle a wider variety of data (Fitzgerald & Hubert, 1987) and presents results in ways that are more easily interpreted; and

ii) The methodology inherently values community engagement building in participation by experiential users in a meaningful way.

To the author's knowledge, although there has been one study (Hanson et al., 2013) that has used this integrated qualitative and quantitative method with older adult participants, this is the first application of this technique with older adults and their caregivers to study engagement in innovation. Differing from Hanson and colleagues (2013), in order to ensure diverse older adult perspectives were represented, the suggestion of Kane and Trochim (2007) to use both online and offline modalities throughout the project was adopted, making this study novel in its approach.

3.3 Project overview

This project consisted of three phases described sequentially but which overlapped and influenced each other through the integration of data analysis and results (Creswell, 2003; Tashakkori & Teddlie, 2003):

Phase I: Scoping review

A scoping review of the available literature on end user involvement in Regional Innovation Ecosystems (RIEs) was conducted to understand how consumers have been engaged in innovation collaborations.

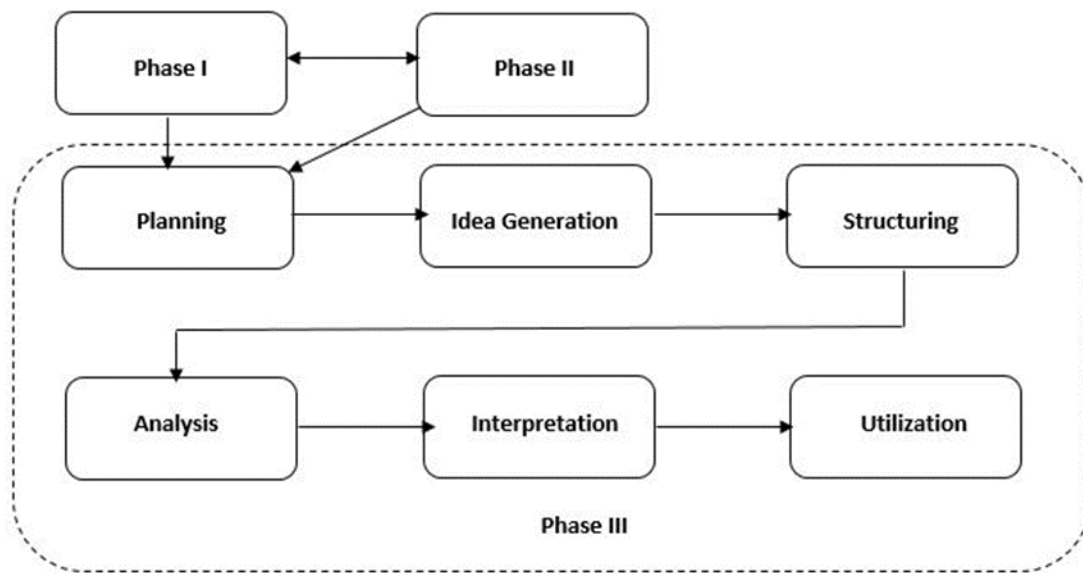
Phase II: Focus Group and Individual Interviews

Focus group and individual interviews with stakeholders important for understanding older adult engagement in health innovation including older adults and caregivers, Triple Helix members, and health care providers were conducted. These interviews were informed by the themes and understandings generated in the literature review on RIEs.

Phase III: Concept Mapping

Informed by the results of Phase I and II, Concept Mapping as described by Kane and Trochim (2007) was undertaken to further generate ideas directly from members of the Triple Helix, older adults and caregivers, and health care providers about older adult engagement in health innovation through RHIEs. Figure 3.3.1 below provides a depiction of the research design. Stakeholders were actively engaged throughout the project.

Figure 3.3.1: Study flow diagram



3.4 Recruitment

A diverse and representative sample of stakeholders including: i) Triple Helix members such as industry leaders, university representatives, researchers, and policy makers; ii) older adults and caregivers; and iii) health care providers were recruited through existing networks of committee members involved in the ECOTECH project as well as through AGE-WELL. To the extent that it was feasible, diversity was achieved in geographical and stakeholder perspectives.

Participants from multiple regions across Canada (e.g., Waterloo, Surrey, Ottawa, Toronto, Edmonton) were recruited to i) minimize potential issues of feasibility of data collection, and ii) increase generalizability of results. Because of the novelty of RHIEs, the representation of each helix is limited. While (arguably) more established in British Columbia, the concept of RHIEs is emerging and developing in Ontario regions.

3.4.1 Ethics clearance

Ethics clearance for this project has been granted by the University of Waterloo Research Ethics Board (ORE #21329). All participants signed an informed consent form prior to the interviews (see Appendix B for ethics documents). All participant information related to the study is kept in a secure location, on a password encrypted hard drive.

CHAPTER 4 WHERE ARE THE CITIZENS IN REGIONAL INNOVATION ECOSYSTEMS? A SCOPING REVIEW

4.1 Outline

Background: The importance of regional support for innovation has been widely recognized. Regional innovation ecosystems (RIEs) provide a platform for partnerships between stakeholders representing industry, government, and academia; typically modeled as a Triple Helix (Etzkowitz & Leydesdorff, 2000). Current societal trends support the evolution of this model to include the community. The objective of this review was to scope the available literature for learning on how citizens have been engaged in regional partnerships for innovation, while identifying gaps and areas for future work.

Method: A scoping review (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010) of engagement efforts of citizens in RIEs was conducted. Six stages of review, including knowledge exchange consultations were undertaken.

Results: The literature on engagement of citizens in regional innovation ecosystems is under-developed. Of 315 peer reviewed articles, 231 mentioned a term synonymous with "end user" but only eight discussed the idea to any level of detail. These articles and the grey literature included (n=10) revealed two prominent themes and four sub-themes of how end users have been engaged in RIEs: i) citizen empowerment in innovation development through social computing and "lead user" roles, and ii) co-production and collaboration roles for citizens including living labs and evolutions of the Triple Helix model.

Conclusion: When citizens are considered, they are currently engaged in RIEs in a heterogeneous manner. This review has identified evidence of existing engagement efforts, gaps in the existing literature, and lessons for citizen engagement in innovation partnerships. Although there is agreement in the literature that user engagement in RIEs is a positive and appropriate evolution of traditional Triple Helix partnerships, agreement on models or best practice guidelines to involve citizens in RIEs was not apparent. Examples of empowered roles for citizens in innovation and co-production models, such as the Quadruple Helix model, can therefore inform the next phases of this project where an understanding of how older adults can be engaged in regional collaborations to support innovations for health and aging will be developed.

4.2 Introduction

As developed countries move from resource-based to knowledge economies, ideas are an important engine of growth (Romer, 1986). Through the creative process, ideas in the form of imagined changes and opportunities for societal impact are expressed as innovation. There are however challenges for ideas (no matter how transformative) to be transferred to market in order to affect social change. These issues have been broadly conceptualized into a number of themes, specifically relevant to this project are the commercialization viability of research which has been described as “the valley of death” (Merrifield, 1995), and the disconnect between academic and business culture where differing motivations impede the transfer of basic research into commercially viable products (Gunasekara, 2006; Hallam & DeVora, 2009).

In response to these challenges, current best practice models of innovation can be described as open innovation (Chesbrough, 2006) where external ideas are embraced and innovators are encouraged to integrate their ideas with those of others from outside organizations. This knowledge exchange often occurs on a local basis (Bramwell et al., 2012a) supporting the value of developing regional infrastructure that drives innovation in local clusters. The concept of regional innovation ecosystems (RIEs) is a well-established model of this type of open innovation. RIEs can be understood as interconnected networks that support effective innovation commercialization, entrepreneurship, and the translation of scientific findings into economic and social development (Bramwell, Hepburn, & Wolfe, 2012b; Etzkowitz & Leydesdorff, 2000) knowledge created in a trilateral network of university, government and industry partners called the Triple Helix (Etzkowitz & Leydesdorff, 2000). The Triple Helix model of

partnership in RIEs describes a relationship in which innovations emerge from collaboration and co-creation among these different actors. Partnerships in RIEs have been recognized as a mechanism for the uptake and commercialization of innovation to benefit the local economy (Wolfe, 2009) and more broadly, overcome the challenges noted above of transferring innovation to market to affect social change. Doloreux and Parto (2004) published a comprehensive scoping review on RIEs, which has contributed to the broader area of research with the Triple Helix dominating the collaborations.

There is a substantial body of literature supporting what has been discussed as “end user” or “citizen” engagement within the individual organizations involved in Triple Helix partnerships. This involvement has been expressed in academia with the rise of participatory research methods (Andrews, Newman, Meadows, Cox, & Bunting, 2012), in industry with involvement of consumers in technology development, described as “user-centred design” (Endsley, 2011), and trends in government towards increasing public participation in governance (Holosko et al., 2001). Although there is interest in and are developments towards the participation of citizens within organizations involved in Triple Helix partnerships it has been recognized that despite positive efforts, there is little consensus on how to engage citizens, and issues of tokenism in existing efforts have been identified (McNeil et al., 2016). Further, at the level of the ecosystem, considerations of the involvement of citizens in RIEs partnerships is underdeveloped and has not been the focus of study in this area. Theories in this area are emerging which expand the Triple Helix, but have not been fully understood by researchers or those in these partnerships, leaving a gap in current understanding (Arnkil, Järvensivu, Koski, & Piirainen, 2010.). A scoping review (Arksey & O’Malley, 2005; Levac et al., 2010) was

conducted to identify where these gaps in understanding are and lay the groundwork for future work in this area, while answering the question of how citizens have been engaged in RIEs.

4.3 Methods

Given the breadth of this topic, which intersects a number of emerging areas, a scoping review following the methodology of Arksey and O'Malley (2005) and Levac, Colquhoun, & O'Brien (2010) was chosen as the preferred synthesis method. Arksey and O'Malley (2005) suggest the purpose of a scoping review is to identify gaps in the existing literature, informing where more research may be needed in a specific area of study. In contrast to a systematic review, a scoping review is less likely to assess the quality of the included studies and includes a range of study designs from both the published and grey literature (Levac et al., 2010). The six stages of a scoping review recommended by Arksey and O'Malley (2005) including their option of consultation which Levac, Colquhoun, & O'Brien, (2010) describe as "essential" to inform and validate the findings were conducted. *Stage one* involved identifying the research question; *stage two* identified relevant studies; *stage three* was the process of study selection; *stage four* involved charting the data; *stage five* was a process of collating, summarizing and reporting the results; and *stage six* was an opportunity for citizen input on the findings, providing insights beyond that in the available literature.

4.3.1 Stage one

In *stage one*, the research question of “how have citizens been engaged in Regional Innovation Ecosystems?” was identified to scope the current evidence and discover gaps in understanding to lay the groundwork for future work in this area.

4.3.2 Stage two

During *phase two* the search strategy was developed as part of a larger project of our group on regional innovation ecosystems (<http://agewell-nce.ca/age-well-core-research-projects#wp72>) to identify relevant studies. This project, the Developing Regional Health Innovation Ecosystems (DRiVE) study is working to resolve Canada’s struggle to translate knowledge from research into commercially viable products and processes to transform health care systems for aging adults through the development of a Theory of Action for regional health innovation ecosystems.

4.3.2.1 Search strategy

The following search strategy was developed and run in consultation with the University of Waterloo’s Health Sciences Librarian. PubMed, Scopus, Compendex, Inspec, PsycInfo, Business Source Complete, and ABI were searched for key terms on the concepts of government, university, industry, innovation, cluster, and technology as described below. Search was modified for requirements of each database.

Limit year 2004 and beyond:

ab(partnership*OR relationship* OR collaborat* OR network* OR cluster* OR community networks OR “Interinstitutional Relations” OR “community institutional relations” OR “innovative milieus” OR “industry cluster”

AND

(government* AND universit* AND industr*) OR (government* AND universit*) OR
(universit* AND industr*) OR (government* AND industr*) OR helix OR *system*
AND
ab(innovat* OR technolog* OR entrepreneur* OR start-up* OR technology OR
“organizational innovation” OR information science)
AND
ab(local* OR region* OR place OR geograph* OR “regional scale” OR “regional
capital”)

This search was designed to identify articles on the focus of this review capturing the breadth of knowledge currently available on RIEs. To answer the research question of how citizens have been engaged in these partnerships, it was expected that examining the body of work on RIEs would ensure a thorough scope of the literature.

Retrieved articles were limited to those available in English. A date limit of 2004 to present was decided on reflecting the important contribution to the literature in this area by Doloreux and colleagues (2004). There were no limits applied to the country of study or publication origin. Other exclusion criteria included book reviews, conference proceedings without direct or obvious link to the topic, and articles focusing on organizational, environmental or biological ecosystems. Articles were included if they had a regional ecosystem focus, included two or more of university-research/industry-commercial/government-policy relationships, and discussed innovation. Hand searching of the relevant journals was also conducted.

Using search strategies developed in consultation with the Health Sciences Librarian, Google and Google Scholar were also used to identify relevant grey literature and articles not retrieved through specific database searches. Due to the proliferation of the grey literature in the area of RIEs, Google was searched using both natural language searches and the following Boolean search strategy adapted from the database search:

region* AND innovation AND (*system* OR incubator OR hub OR cluster OR helix OR network OR collabor* OR coalition) AND (citizen OR end user OR customer OR consumer OR client OR lead user OR participa*)

The natural language searches involved similar terms to the Boolean search as well as others gathered from preliminarily reviewed literature. Papers from all databases were aggregated in RefWorks for title sorting. Google and Google Scholar title searching occurred as import was conducted. Abstract review occurred in RefWorks for all papers. Aggregated citation information was exported to an Excel worksheet for full paper review and data collection.

4.3.3 Stage three

The database of articles accepted for the full text abstraction of the research group's review were imported into NVivo 11 (QSR, 2012). Using NVivo's search function, this file was examined for the key terms related to "end user" listed above. Articles that include any one of these terms in the full text were identified and reviewed for inclusion in the review. Included articles from the grey literature underwent the same process.

4.3.4 Stage four

Stage four involved a charting process recommended by Arksey and O'Malley (2005) in which the articles were read in full and their data abstracted into an excel spreadsheet including the area of innovation, the methods of end user engagement, outcomes (if included) of the engagement, the population that was engaged, and any theories identified in the study related to citizen engagement in innovation partnerships.

4.3.5 Stage five

Stage five of this review involved collating, summarizing and reporting the results of the peer reviewed and grey literature. NVivo 11 (QSR, 2012) software was used for emergent thematic analysis (Creswell, 2003) of the included articles focusing on the theories and practice (processes, methods, challenges and outcomes if stated) of end user engagement in RIEs. Interpretation bias was minimized through at least two qualitative techniques: i) an Audit Trail (see Appendix D) as discussed by Lincoln and Guba (1982) was employed to ensure confirmability, and ii) triangulation of the data (Johnson & Onwuegbuzie, 2009) was conducted by comparing the themes and findings with those of the qualitative interview phase (McNeil, 2017b).

4.3.6 Stage six

In alignment with the participatory nature of this project and following Levac and colleagues (2010) mandatory sixth stage and Arksey and O'Malley's suggestion for scoping reviews, consultations occurred with a partnership group of citizens interested in the topic of innovation. Participants were recruited from the Seniors Helping As Research Partners (SHARP) group (<https://uwaterloo.ca/geriatric-health-systems-research-group/sharp>). This *sixth stage* was an appropriate opportunity for knowledge translation (Levac et al., 2010) and incorporation of insights beyond those available in the published literature. These consultations occurred throughout the review process, from confirmation of importance and relevance of the research question to discussion of results which were incorporated into the findings of the review. The components of this project involving

community consultation received ethics clearance from the University Of Waterloo Office Of Research Ethics (ORE# 21329).

4.4 Results

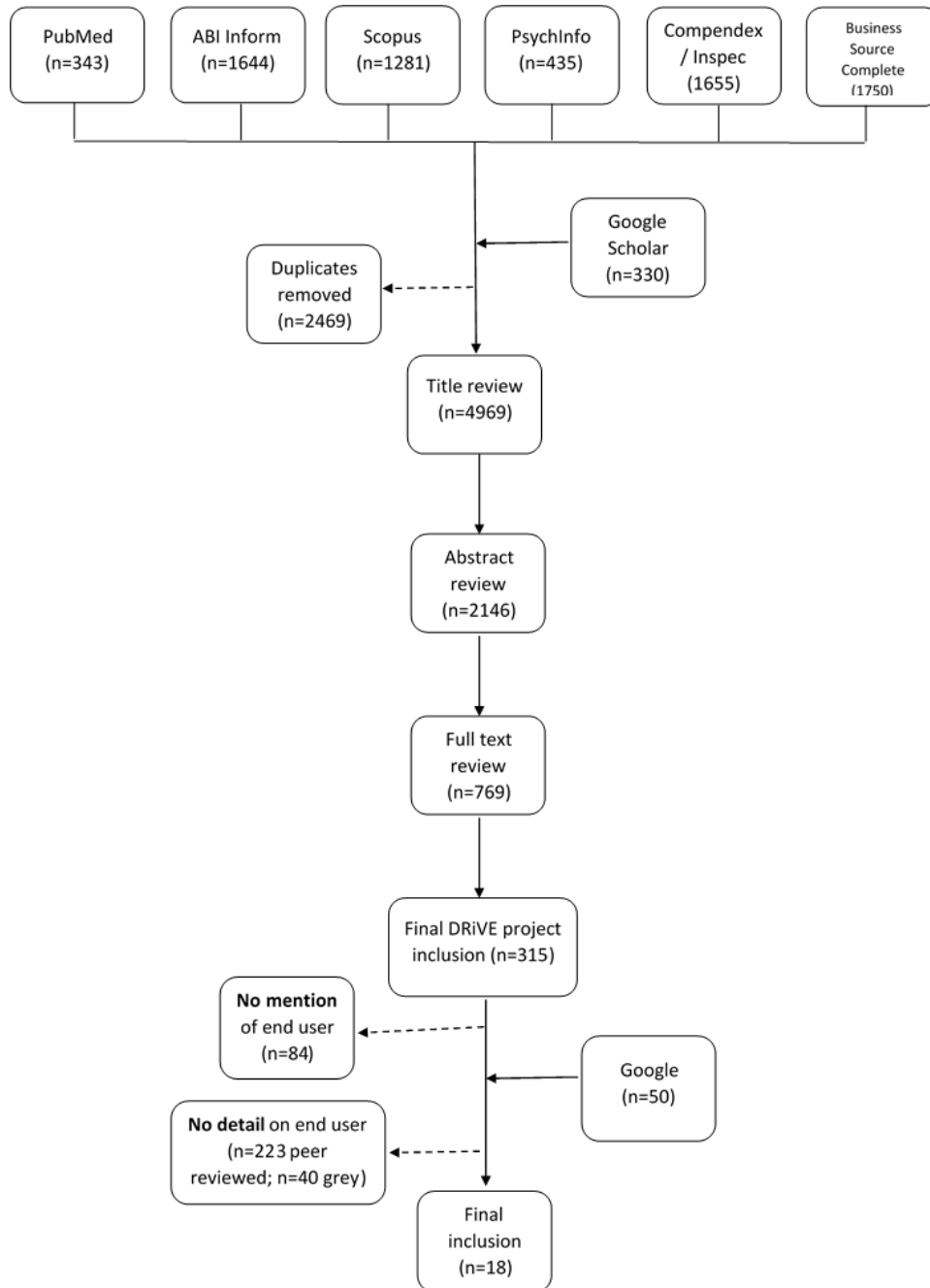
The search of peer-reviewed literature yielded 315 articles on RIEs, which were analyzed for content and focus on citizen engagement. While 231 articles mentioned “end user” or a synonymous term, only eight articles discussed this idea with any degree of detail to answer the question of how citizens have been engaged in RIEs.

Many of the excluded articles discussed the idea of end user as a firm or organization utilizing a product. This conceptualization of end user is outside the scope of this review. As mentioned in the methods section, there is a vast body of literature on user-centred design. Some of the 231 articles that mentioned citizens in RIEs were excluded upon further review because they focused on the idea of the end user as a study participant, or someone on whom innovations were tested at some phase in the development process, often before going to market.

Over 1.75 million results were returned from the Google searches. Pages of Google results were reviewed; each hit was visited and studied for inclusion until the relevancy of returns diminished (usually around eight pages of results). 50 articles were retrieved from this process for further review. This heterogeneous literature included white papers, presentations and organizational documents revealing citizen engagement efforts within the various actors of Triple Helix partnerships and at the level of RIEs. Upon review of the full text, ten of these results met the inclusion criteria and were included in the final review. Original articles included in reviews and literature syntheses

which met the inclusion criteria were reviewed for relevant content. Figure 4.4.1 below depicts the inclusion and exclusion process.

Figure 4.4.1: Flow diagram of inclusion/ exclusion process



As described in stage five of this review, the included articles were analyzed and information was charted. Table 4.4.2 below provides a final list of included articles and a summary of the information retrieved through this process; terms presented in the table are described in the glossary below and discussed in the results section.

Table 4.4.2: Included articles

Citation	Country	Method	How have end users been engaged?	Discussion of impact of engagement	Impact of engagement
Database Search Results					
Belussi, Sammarra, & Sedita, 2010	Italy	Case study	Open innovation	Yes	External relationships have a positive and significant impact on innovation.
Bramwell, Nells, & Wolfe, 2008	Canada	Case study	Cluster dynamics	Yes	Interaction between Triple Helix actors and community associated with R&D transfer, skills provision, international cachet, and informal knowledge networks.
Carayannis & Campbell, 2009	United States	Case study	Quadruple helix; Mode 3	Yes	Democratization of innovation
Chaminade & Vang, 2008	India	Case study	Lead users	No	
Oksanen, 2014	Finland	Case study	Collaboration; social media	No	
Park, 2014	Hungary	Interview	Helices models	No	
Pascu & Van Lieshout, 2009	Spain	Literature review	Living labs, open innovation,	Yes	Active end-user participation; novel services

			social computing		
Schoonmaker & Carayannis, 2012	Greece, Portugal, United States	Case study	Quadruple helix; Mode 3	No	
Grey Literature Search Results					
Arnkil et al., 2010	Finland	Review	Quadruple helix	No	
CoR Guide, 2016	Europe	Report	Quadruple helix	Yes	Shared ownership of innovative solutions with citizens; increased synergy between actors
Eskelinen et al., 2015	USA	Guidebook	Living labs	Yes	Faster and improved acceptance; End users gain greater sense of empowerment and ownership.
European Communities, 2008	Belgium	Multiple Case Studies	Living labs	Yes	Improve the efficiency of the innovation process; Contribute to better take-up of R&D results; Improve competitiveness of industry.
GSMA, 2012	Finland	Report	Living labs, social computing	Yes	Active citizenship
HLG Secretariat, 2014	Belgium	Report	Quadruple helix, open innovation	Yes	Foster creative thinking; dynamic, enabling environments for innovation
Markkula & Kune, 2015	Europe	Paper	Quadruple helix	No	

Salmelin, 2014	Europe	Special Feature	Quadruple helix	No	
Schaffers & Santoro, 2010	Italy	Analysis of policy instruments	Living labs, open innovation	Yes	Developing, validating and integrating new ideas; easier scaling up local services and products to other markets
Renders & Sleenckx, 2012	Europe	Paper	User driven innovation	No	

Glossary of terms in table:

Open innovation: models of innovation are “characterized by firms’ adoption of an open innovation strategy, which overcomes not only the boundaries of the firms but also the boundaries of the region” (Belussi, Sammarra, & Sedita, 2010, p. 710).

Cluster dynamics: The Harvard Business Review (2017) defines “a cluster is a geographic concentration of related companies, organizations, and institutions in a particular field that can be present in a region, state, or nation.” Dynamics describe the function within these clusters including cooperation, firm structure, and knowledge flows (Bramwell et al., 2008).

Quadruple helix: Described by Caryannis and Campbell (2009) as the “media-based and culture-based public” (p.20)

Mode 3: a type of knowledge creation that relies on the interaction of people, culture and technology that “shape the co-evolution of knowledge with the knowledge-based and knowledge-driven, gloCal economy and society” (Caryannis & Campbell, 2009, p.6).

Lead user: a recognition of users as developers of new products, describing the citizen as the head or leader of innovation development (Chaminade & Vang, 2008).

Living Lab: Described by Eskelinen and colleagues (2015) as “user-driven innovation environments where users and producers co-create innovation in a trusted, open ecosystem that enables business and societal innovation” (p. 12).

Social Computing: the use of the internet and Web 2.0 as platforms for horizontal sharing of information between users, causing users to become, as Pascu & van Lieshout (2009) describe, “empowered”.

User driven innovation: “User Driven Innovation (UDI) makes use of information on customers, user communities and customer companies, and engages users as active participants in innovation activities” (Renders & Sleenckx, 2012, p.11).

The most common method of the included articles from the peer-reviewed literature was case study methodology, with six articles incorporating this into their study design. The grey literature was more heterogeneous, with reports being the most common type of document. There was a variety of locations where the studies took place, with representation across Europe, Asia and North America. The most common discussion of how end users were engaged was through the Quadruple Helix model. Impact of engagement efforts was not widely reported.

4.4.3 Key themes

The available literature demonstrates a heterogeneity in how citizens have been engaged in Regional Innovation Ecosystems (RIEs). A discussion which emerged in the literature about the importance and impact of user engagement in RIEs was useful in understanding the evidence in this area. Specifically, the engagement of users in RIEs was demonstrated through two prominent themes and four subthemes in the accepted articles: i) citizen empowerment in innovation, including sub-themes of “lead users” and “social computing” and ii) co-production with community members through sub-themes of living labs and partnership roles for citizens in evolutions of the Triple Helix model.

4.4.4 The importance and impact of users in RIEs

The community has a role to play in the creation and development of RIEs. Bramwell and colleagues (2008) discuss the importance of the community for innovation in local regions. Their case study of the Canadian region of Waterloo, Ontario, reveals the importance of civic capital (Bramwell et al., 2008) or the building of trust and collaboration among actors in RIEs. Reports from various European bodies have noted

the relevance of end users as part of the innovation ecosystems (CoR Guide, 2016; Salmelin, 2014; European Communities, 2008). A study of the firm's use of "external resources" noted "clients and customers" as the most relevant and often used sources of knowledge, emphasizing the importance of close relationships with customers and end users (Belussi, Sammarra, & Sedita, 2010). Others have recognized the value in creating new relationships between people and technology through mechanisms that engage end users in innovation ecosystems (Eskelinen, Lindy, Marsh, & Muentekunigami, 2015.).

User engagement in RIEs has been found to have a variety of impacts. Belussi and colleagues (2010) found that relationships external to those in RIEs have a positive and significant impact on innovation. Specific impacts of interaction between Triple Helix actors and the community in RIEs include R&D transfer, skills provision, international cachet, and the development of informal knowledge networks (Bramwell et al., 2008). Case studies completed by the European Communities (2008) found that involving end users in RIEs through living labs improved the efficiency of the innovation process, contributed to better take-up of R&D results, and improved the competitiveness of industry. Co-production techniques with end users have also been found to achieve faster and improved acceptance of innovations by citizens, providing community members with an increased sense of empowerment and ownership in RIEs (Eskelinen et al., 2015). Beyond this, engagement efforts with the public, as described by Caryannis and Campbell (2009), have high level societal impacts. These authors share the relationship between knowledge, innovation and democracy, discussing the "democratization of innovation" (von Hippel, 2005 in Caryannis & Campbell, p. 25) and

the important role of the public in achieving the goals and objectives of innovation ecosystems.

4.4.5 Citizen empowerment in innovation

A prominent theme that emerged in the literature was the idea of citizen empowerment in innovation. Included articles discussed ideas of user-expert relations, where an understanding of the interaction between those within RIE partnerships, shared knowledge, and exchange of information between stakeholders in what can be understood as multi-way dialogues were discussed. RIEs that empower citizens and end users, acknowledge the creative capacity of these actors and the role that they could play (given access to information and power) in innovation throughout an ecosystem. Involvement here was described beginning in technological development through to other phases of innovation, including planning of innovation initiatives, research, and policy agenda setting. Empowerment can also be understood as an outcome of engagement efforts in RIEs, with one study discussing the shared ownership of innovative solutions with citizens (CoR Guide, 2016) that resulted from collaboration with citizens.

4.4.5.1 Social computing

Some articles discussed the role that citizens could play in RIEs to be virtual community involvement initiatives, through social media (Oksanen, 2014) and other forms of online information sharing. Pascu & van Lieshout (2009) discuss this involvement as “social computing”, describing the internet and Web 2.0 as platforms for horizontal sharing of information between users. The authors describe this sharing of information and data between customers to cause users to become ““smarter”, more

demanding, and more aware of the choices – in one word, empowered” (p. 83). This information sharing was also described as open access to data, where an understanding that publically accessible data has the potential to enhance citizen knowledge and understanding, improving the potential for active citizenship (Summary & Infoshare, 2007). The role of the end user in these descriptions of RIEs is that of providing collective intelligence, where the more citizens that are engaged in a project working together, the more powerful the innovation becomes. Building on these ideas, and more specific to the leadership role that empowered users can take on in RIEs, is the idea of citizens as lead users.

4.4.5.2 Lead users

Citizens are engaging in RIEs as leaders in the innovation community, as described through the discussion of “lead users” and the related concept of user driven innovation. While innovations can be created in the response of a “producer” to an identified “user” issue (Castellacci, 2006; Jeppesen and Molin, 2003; Luthje et al., 2005 in Chaminade & Vang, 2008) it has been suggested that improvements also occur outside of this “user-producer” interaction where consumers independently respond to issues and innovate independently. This recognition of users as developers of new products that are commercially successful describes the citizen as the head, or leader of innovation development generating the term “lead user”. Lead users have been described as consumers that perceive needs before the majority of others and develop their own innovative adaptive solutions (Jeppesen and Frederiksen, 2006 in Chaminade & Vang, 2008).

Relatedly, the concept of user driven innovation processes emerged in the literature, where the purpose is to develop new concepts, products and services that address user needs and values (Renders & Sleenckx, 2012). One conceptualization of this from the Nordic Innovation Centre report (in Renders & Sleenckx, 2012) discusses four categories of citizen involvement in innovation processes from testing, where users test prototypes, through to exploration, participation, and innovation, where users are understood as experts. This understanding of citizens as innovators aligns with the lead user conceptualization above.

The benefits of these leadership roles for users in innovation ecosystems are associated with current motivations towards disruptive innovation where, “interaction with users might provide incremental innovations while interaction with lead users might be more important for more radical innovations and thus more valuable for the innovative firm” (Chaminade & Vang, 2008, p. 4). Consultations in this phase of the project supported this theme, revealing that older adults believe their experiences with the health care system and aging in general situates them in an important position to share knowledge and ideas needed to truly achieve innovation in this space. Building on the empowerment theme, partnerships and co-production activities with users emerged as a way that citizens have been involved in RIEs.

4.4.6 Co-production with community members

Co-production and partnerships in innovation was a prominent theme in the literature. Many documents discussed the value of these partnership approaches, describing the importance of including citizens in the innovation process from the initial

phases through processes of co-creation (Salmelin & Commission, 2007). These types of approaches were found to be adopted at the level of regional planning initiatives where discussions of innovation ecosystems included governments, business, academia and citizens. The objective of this involvement of end users in partnerships was described as fostering creative thinking, and dynamic, enabling environments for innovation (European Commission, 2014). Underlying motivation for citizen involvement included a belief that co-creation with end users from the beginning of RIE development might create new markets, products and services. This forward thinking approach to innovation was reflected in the literature through two related ways that end users have been engaged in partnership approaches in RIEs, living labs and quadruple helix models of innovation.

4.4.6.1 Living Labs

Citizens were described as playing a role in RIEs through co-production of innovation in living labs. Though not specifically sought out, living labs emerged in the literature as a way that citizens are engaged in RIEs. While this term has been used in a variety of ways, living labs are meant to place citizens at the centre of innovation, co-creating new concepts and solutions to the specific needs of local contexts and cultures. Living labs are “user-driven innovation environments where users and producers co-create innovation in a trusted, open ecosystem that enables business and societal innovation” (Eskelinen et al., 2015, p. 12).

The living lab approach is recognized as a method that actively engages various actors at an early stage in the research trajectory (Pascu & van Lieshout, 2009; Schaffers & Santoro, 2010). Living labs differ from traditional test beds or research methodologies in that they are meant to be less top-down. Where traditional research is often controlled

by the designers and researchers, living labs are meant to allow for the role of everyday life experiences to be part of the innovation process. The living lab concept has gained traction in many places as a developmental methodology that values the opinions of citizens by collaborating with them. Pascu and van Lieshout (2009) describe this through a discussion of the fundamental role of users in not only testing and validating new services and products (Schaffers & Santoro, 2016) but are also in innovating to develop new services and uses of devices and technologies.

Leading the way for this approach to innovation is the European Network of Living Labs (ENoLL) (Eskelinen et al., 2015). This effort was established in Finland as an international, non-profit, independent association of living labs. As evidence of the popularity of this concept, the membership of ENoLL has grown from 16 when established in 2010 to over 3 000 labs innovating on a broad range of issues. In the included literature, the discussion of living labs was often linked with discussions of smart cities (European Commission, 2014; Summary & Infoshare, 2007)), and while interesting to understand where this literature is situated, an analysis of this topic is beyond the scope of this review.

Despite the promise of this approach to user engagement in RIEs which emerged in the literature, Schaffers and Santoro (2010) caution that there is a need to establish validated methodologies, experiences and practices of user engagement in living labs in order to fully understand the impacts for innovation. Another challenge with living labs arose from the consultation stage of this project. When presented with the work on living labs, citizens revealed that although the premise of users co-creating innovation with others in RIEs in an open environment aligns with their perception of the roles that end

users should be playing in RIEs, the language was unclear and created a barrier to their understanding. Specifically, consultations revealed that the term “living labs” was found by users to be jargon, reflecting what seemed to them as language of researchers. This jargon was discussed as a potential barrier to involvement in partnerships with other actors in RIEs.

4.4.7 Citizen partnerships for innovation: evolution of the Triple Helix model

The most commonly cited way that end users were engaged in RIEs was through partnership models as described in Quadruple Helices. In these evolutions of the Triple Helix, the citizen was described as part of a collective that creates a supportive culture for innovation (Schoonmaker & Carayannis, 2012). It has been suggested that the Triple Helix is no longer relevant in the current context of the increasingly connected and digital world (CoR Guide, 2016). What is necessary instead is a bottom-up process of exploration and discovery that includes the community in multi-dimensional teams and networks (Markkula & Kune, 2015). The role of civil society in the new innovation context is described by Schoonmaker and Carayannis (2012) to “embody the forces that come together to generate innovation” (p.2).

This recognition supports the modelling of at least a fourth helix in RIE partnerships. Carayannis and Campbell (2009) are credited with beginning the evolution of the Triple Helix with their theorization of Mode 3 knowledge production and discussion of the Quadruple Helix. They discuss the importance of the fourth helix of “media-based and culture-based public” (p.20) as it relates to a broader discussion of knowledge creation in the 21st century that they describe as Mode 3 (Carayannis & Campbell, 2009). While an in depth exploration of Mode 3 knowledge creation is beyond

the scope of this paper, it is relevant to note that this type of knowledge creation relies on the interaction of people, culture and technology that “shape the co-evolution of knowledge with the knowledge-based and knowledge-driven, gloCal¹ economy and society” (p.6). Mode 3 knowledge production supports the discussion of end users and citizens interacting with other partners in RIEs.

Following this theorization, the literature is varied in interpretation of who the fourth helix is, with conceptualizations ranging from Caryannis & Campbell’s (2009) interpretation of the public and media generally to intermediary organizations, non-governmental organizations, patient organizations, citizen groups, and everyday citizens, the understandings that most align with the scope of this work is the fourth helix as the community of end users and citizens (CoR Guide, 2016; Markkula & Kune, 2015; Salmelin, 2014).

Recognizing this diversity and other gaps in this literature, Arnkil and colleagues (2010) put forward a definition of this innovation model which emerged from their work exploring the Quadruple Helix; “it is an innovation cooperation model or an innovation environment in which users, firms, universities and public authorities cooperate in order to produce innovations. These innovations can be anything considered useful for partners in innovation cooperation; they can be, for example, technological, social, product, service, commercial, and non-commercial innovations” (p.8). The European Commission and HLG report (2014) describes a related concept, public-private-people partnerships (PPPP, or P4) in RIEs, which describe partnerships directly including people as

¹ The term “glocal” can be understood as, reflecting or characterized by both local and global considerations. See <https://hbr.org/2004/09/how-global-brands-compete> for an example of use.

stakeholders in bottom-up and participative strategies. A key component of these PPPPs is to make people and civil society more visible in collaborative undertakings (European Commission, 2014).

Throughout the grey literature, organizations have endorsed the value of citizen engagement in arrangements that support regional innovation. Some actors in Triple Helix partnerships recognise that without end user involvement there is a significant gap in innovation processes, noting the participation of citizens, end users and customers as a gap to be filled in RIEs (Salmelin, 2014; Schoonmaker & Carayannis, 2012). The benefits of this approach to RIE partnership has been noted, with one report stating "... by involving citizens in a quadruple innovation helix as active agents, we are moving to a win-win game instead of a win-lose game" (Salmelin, 2014, p. 1). In application, this acknowledgement does appear to have a geographic component with literature from Europe revealing RIE partnerships seem to be evolving towards the Quadruple Helix model (CoR Guide, 2016); evidence of this trend in North America was less apparent.

Although promising, this discussion was tempered with an understanding that in order to realize these benefits, the identified challenge of effectively collaborating between societal partners (Markkula & Kune, 2015) needs to be overcome. The TACTUS report (2012) found that in order to involve users in the innovation process, firms must be aware of the complexity of involving users and be open to new methods and tools. Oksanen (2014) also describe areas to be aware of in collaborative efforts within RIEs, including the necessity of agreements and shared financial efforts, open dialogue encouraging actors in RIEs to express their views, and the necessity of common vision where partners see their success associated with the success of ecosystem.

Beyond the evolution of the Quadruple Helix model, Quintuple (the environment), and n-tuple models were found in the literature as further extensions of the modeling by Carayannis and colleagues (Park, 2014). These discussions build on interactions between Triple Helix partnerships to further emphasize the feedback mechanisms between external environments and actors in the Helices (Park, 2014). While these models discuss the users of innovation as part of helix partnerships (typically as the fourth helix), this further modeling is beyond the scope of this review.

4.5 Discussion

This review has revealed how citizens have been engaged in Regional Innovation Ecosystems (RIEs) through a description of the various roles and partnerships available in the literature. Gaps and opportunities for future research in this area have also been identified. The findings reveal that end users have been engaged in RIEs along what could be considered various levels of involvement, ranging from empowered roles in innovation initiatives to partnerships and co-production with traditional Triple Helix actors in RIEs and an emerging discussion of true integration in Quadruple Helix models.

In understanding these levels, spectrum theories of engagement have been used to model citizen and lay involvement in interactions outside of innovation between stakeholders and organizations. The International Association for Public Participation (IAP2), for example, created the Public Participation Spectrum to describe types of engagement with stakeholders and communities, showing increasing levels of public impact as the spectrum progresses from ‘inform’ through to ‘empower’ (IAP2, 2007). Recognized challenges with this linear approach to understanding engagement would

caution an interpretation of user engagement in RIEs that follows this type of understanding (McNeil, 2016)

In contrast, Stakeholder theory (Mitchell, Agle, & Wood, 1997), is a useful lens to analyze these types of relationships for innovation. Mitchell and colleagues (1997) discuss the role and identification of a stakeholders to be based on examinations of power, legitimacy and urgency. In thinking about the types of involvement end users play in RIEs, understandings of power as discussed by Mitchell et al. (1997) inform the discussions of citizen empowerment. A stakeholder group's power here is based on their ability to "impose their will" or in the case of RIEs, voice their experiences and innovate. As traditional Triple Helix relationships evolve the Quadruple and other models, shifts in power will be necessary. Mitchell and colleagues (1997) support this change, describing power as a non-steady state, or "transitory" among stakeholders.

The lead user role for citizens in RIEs also suggests that with a shift in power, these leaders can be valuable as partners in helices to advance the innovation process from what has been understood as incremental innovation to more disruptive innovations (Chaminade & Vang, 2008). This potential for engagement will only be realized in RIEs where there are mechanisms for empowering citizens to innovate and present these innovations. Chaminade and Vang (2008) caution that there are some limitations in this literature, as user-producer innovation models often rely on assumptions of equality in terms of social capital and other resources needed to act on knowledge sharing. The idea of lead users extends this challenge, creating an overly simplified view of power equity in these collaborations.

Further interpretation of these findings and understandings of power dynamics among stakeholders suggest that engagement of citizens in regional collaborations, including evolutions of the Triple Helix model, relate to social capital in the formation of networks. The rationale for the importance of community engagement in RIEs through the discussion by Bramwell et al. (2008) of civic capital is aligned with trust and community values, relating to the more commonly discussed idea of “social capital” (Bourdieu, 1986; Coleman, 1988; Putnam, 1993; 2001).

Social capital is an umbrella term to describe the idea of an indispensable and essential condition of stable democracy (Fukuyama, 1999); in general, conceptualizations of social capital commonly include ideas such as social trust, norms, and values of a community. Social capital theories originate from debates in the sociology literature as described by Putnam (1993, 2001), Coleman (1988), and Bourdieu (1986) and became prominent in the literature during the 1980s as a sociological invention (Malecki, 2012), popularized by policy-makers at the time. In the context of RIEs, social capital is relevant as it refers to connections among individuals, social networks, and the norms, values and trust that arise from them. This underlying mechanism supports the role of the community in the development of regional capacity and development of RIEs and is useful when thinking about the challenges identified in this review to citizen engagement in RIEs.

The related term, civic capital, as defined by Wolfe (2009) as “interpersonal networks and solidarity within a community based on a shared identity, expectations or goals and tied to a specific region or locality” (p. 184), describes citizens as engaged in RIEs through community organizations. In his 2009 synthesis of literature on cluster

development, Wolfe comments that leaders emerge from the community to build and formalize collaborative networks within and between communities, with their contribution to the RIE being a bridging effect on the gaps commonly occurring both between communities and between local governments and community actors. This engagement describes the role of the citizen as a community developer, working to strengthen ties within a RIE.

Connections, as described in the social capital literature, have been theorized as either bonding or bridging (Putnam, 2001). From this perspective, inclusive networks are described as bridging social capital that involve outward or diverse associations; bonding social capital conceptualizes exclusive networks made up of homogeneous groups (Nyqvist, Gustavsson, & Gustafson, 2006). In the establishment of RIEs, the idea of bridging social capital is especially useful as it recognizes the value of relationships built with individuals outside of the immediate network as important in the acquisition of new information and opportunities (Macinko & Starfield, 2001).

The area of literature that emerged revealing impacts of citizen engagement in RIEs relates to this concept. Collaborations are important to bridge “the valley of death” as described by the impacts noted of R & D transfer and easier scaling up local services and products to other markets (Bramwell et al., 2008; European Communities, 2008; Schaffers & Santoro, 2010).

Along with highlighting ways that citizens have been engaged in RIEs, this review identified gaps in the literature. Although partnerships with citizens in the helix of RIEs have begun to be applied in some regions, these discussions were high level, with

limited information to action this involvement. The TACTICS report (Renders & Sleeckx, 2012) for example, found that despite enthusiasm for engagement efforts with citizens, most companies “have no or little experience how to involve and interact with ‘the User’ in their innovation process” (p.17). Consultations with citizens confirmed this gap, with their interest in understanding specific ways that they could be engaged in RIEs.

There was also a notable lack of theory or critical analysis in the reviewed articles. Citizens and users were discussed as a homogeneous population, with no discussion of diverse needs or approaches to how vulnerable groups could be engaged in RIEs. This could be problematic when thinking about “social computing” for example, as populations who do not have access to or proficiency on the Internet would be excluded from this form of empowerment in innovation without consideration of how their voice could be represented. Actions that could be taken to implement user engagement in various RIE sectors such as health and aging were also not apparent, leaving room for investigation of difference between areas of innovation.

4.6 Limitations

At least two limitations affected this project. The first is one that is common to transdisciplinary projects, the issue of terminology used across and between disciplines (Meyer, 2007). Specifically, the use of the term “end user” which was a chosen term from the conceptualization of this project, became challenging throughout the review. Challenges with this term arose because “end users” have been discussed in various bodies of literature to refer to a variety of different stakeholders. To overcome this issue,

the authors consulted with Health Science Librarians to ensure that any possible MeSH (in PubMed) or key terms were used in database searches and to test the key words before they were included in the search. Abstract and full text review of the papers were also important to develop sensitivities to the language used in this project.

The second limitation arose from the challenge raised by Godin and colleagues (2015) in that there are no recognized best practices for a grey literature search. Given the breadth of information available on the Internet, it was important to consult with librarians and have discussions with the research team to ensure that the scope was clear and that the necessary information was found for inclusion in this review.

4.7 Conclusion

Citizens are currently engaged in innovation partnerships in a heterogeneous manner. Two key themes and four subthemes emerged from the accepted articles. Citizens have been engaged in Regional Innovation Ecosystems (RIEs) in empowered roles in innovation, including “lead users” and “social computing”. Co-production with community members was another prominent theme describing involvement of the community through living labs and partnership roles for citizens in evolutions of the Triple Helix model. Although there is agreement in the literature that user engagement in RIEs is a positive and appropriate evolution of traditional Triple Helix partnerships, agreement on models or best practice guidelines to involve citizens in RIEs are currently not available.

This scope of the literature has identified a gap in the area of user engagement in RIEs. Specific discussion of vulnerable populations did not emerge from the data. Future

research should address this by examining the possible ways in which vulnerable populations, including older adults, the disabled, socially isolated population, and those citizens from low socio-economic situations could be engaged.

In the next phases of this project, this gap will be addressed with the development of an understanding of how to engage older adults and their caregivers in innovation for health and aging through consultations with stakeholders and a Concept Mapping methodology.

CHAPTER 5 “THAT’S THE WAY THINGS SHOULD BE DONE”: CONSULTATIONS ON OLDER ADULT AND CAREGIVER ENGAGEMENT IN RHIEs

5.1 Outline

Introduction: It is well recognized that innovation is supported by local regions that have strong partnerships among academia, government, and industry. These partnerships or Regional Innovation Ecosystems (RIEs) increasingly recognize the value of collaborating beyond this Triple Helix (Etzkowitz & Leydesdorff, 2000) to include collaborations with civic society. Building on the lessons from the first phase of the ECOTECH project, specifically, that there is a role for the community to contribute to RIEs (McNeil, 2017a) this study aims to understand the interest in, and readiness for, engagement of older adults and their caregivers in regional collaborations that support health and aging innovation.

Methods: Five focus group interviews with older adults and caregivers (n=10;8;8;6;3) and individual interviews with representatives from university, government, community and industry (n=29) were conducted. Interviews were recorded and transcribed; analysis followed the emergent coding methodology of Creswell (2003) and Morse and Richards’ (2013).

Results: Although there is a desire by stakeholders in RHIEs to engage older adults and their caregivers, currently in Canada they have little meaningful involvement. Stakeholders identified four themes and a number of subthemes including a recognition of the need for diversity of older adult and caregiver representation, and considerations of barriers to older adult and caregiver engagement in health and aging innovation ecosystems.

Conclusion: Results of this study suggest an interest in, and readiness for, some degree of older adult and caregiver engagement in RHIEs. A need was identified to understand how to more meaningfully engage the older adult and caregiver community in RHIEs. Themes from this study will be integrated into the third phase of the ECOTECH project to contribute to this understanding through the creation of a framework of priorities for older adult and caregiver engagement in RHIEs

5.2 Introduction

The aging of the Canadian population (Statistics Canada, 2015) coincides with a number of other significant societal changes including rapid advances in technological innovation and increasing democratization of knowledge production.

At the individual level, innovation contributes to preserving health and well-being of older adults and their caregivers, supporting the opportunity to remain independent as long as possible (Dishman, Matthews, & Dunbar-Jacob, 2004). At the population level, the value of innovation lies in helping to compress morbidity and improve quality of life throughout the life course (WHO, 2013). As people age, they often become more frequent users of the health care system. Currently, Canadians over the age of 65 consume roughly 44% of Canadian health care budgets (Canadian Medical Association, 2013) and governments are concerned about health care systems' capacity to provide quality services in future. Innovation offers an opportunity to amend this trend.

In order to innovate to truly support older adults and their caregivers however, it is important to examine factors both inside and outside the health care system to understand the “bigger picture” of health (The Public Health Agency of Canada, 2011, p.1). The social determinants of health (SDH) perspective is useful in conceptualizing this. As described by the Public Health Agency of Canada (2011), the SDH describe the linkages between the social, environmental, and health services that interact to impact health. It is the complex interactions of social, economic, environmental, and individual factors that determine health (Public Health Agency of Canada, 2011).

Strategies to support the health of the aging population increasingly rely on innovation to prevent, detect, and treat complex health problems prevalent among older adults (Dishman et al., 2004). Despite the many opportunities innovation presents for improving the health and quality of life of older adults and their caregivers, there are recognized challenges to innovating in health, including hierarchies (Ferguson & e-Patient Scholars Working Group, 2007), complexity (Plsek & Greenhalgh, 2001) and risk aversion in health care systems (DeWolf, 2009). Further complications arise from the issue of technology adoption within the health care system and among older adults and their caregivers. When health innovation has occurred there are many barriers to adoption even when potential usefulness is well-recognized (Lee & Coughlin, 2015).

One recognized response to this challenge is collaboration among partners for innovation. The concept of regional innovation ecosystems (RIEs) is a well-established model of interconnected networks that support effective technology innovation commercialization, entrepreneurship, and the translation of scientific findings into economic and social development (Bramwell et al., 2012a; Etzkowitz & Leydesdorff, 2000). The Triple Helix model of partnership in RIEs describes a relationship in which innovations emerge from collaboration and co-creation among academics, government representatives, and industry stakeholders (Etzkowitz & Leydesdorff, 2000).

Of particular relevance to health and aging, the development of Regional Health Innovation Ecosystems (RHIEs) has lagged other industries, but is attracting attention (Prada et al., 2013b; Williams et al., 2014b). A component that is expected to be important in RHIEs, is engagement of end users, but little was known about their role in RIEs. In order to understand this, and scope the available literature for gaps and

opportunities for further research, a scoping review (McNeil et al., 2016) was undertaken. This study identified two themes and four sub-themes of how citizens are engaged in RIEs. One gap that was identified was a lack of discussion of how to engage specific groups, such as vulnerable populations in RIEs. These findings will be integrated into this next phase of work to answer the research question of understanding the interest in and readiness for engagement of older adults and their caregivers in regional collaborations that support health and aging innovation.

5.3 Methods

Following guidelines for integrated mixed methods studies (Tashakkori & Teddlie, 2003), the results of the previously conducted literature review (McNeil et al., 2016b) were integrated into this phase by providing the investigator with a deep understanding of the topic and informing the development of the interview guides (see Appendix C).

To understand the interest in and readiness for older adult and their caregiver engagement in RHIEs, individual and focus group interviews were conducted with stakeholders involved in emerging Canadian RHIEs. Because of the variety of stakeholders traditionally involved in RIEs, it was important to hear from a variety of perspectives. To accomplish this, consultation methods were carefully selected. Individual interviews were conducted with government representatives, academics, those involved in industry, and providers working in health and community services for older adults and their caregivers. Feasibility issues in gathering the appropriate number of participants needed for focus group interviews with the Triple Helix stakeholder groups (following the guidelines of Krueger & Casey (2009) of eight to ten participants), was

part of the rationale for the decision to conduct individual interviews with these participants at locations and timing of their convenience.

Focus groups were conducted with older adults and their caregivers, with an effort to create homogeneous groups. Separate interviews were conducted with older adults and their caregivers living in the community, and older adults in congregate living. These relatively homogeneous groups decreased the chances of power differentials and encouraged comfort of the participants so that participants could speak openly and honestly (Krueger & Casey, 2009).

Focus group and individual interviews were recorded and transcribed. Analysis was conducted as data were gathered using emergent coding (Creswell, 2003) following the four phases of coding described by Morse and Richards (2013). Data collection continued until a saturation of themes was reached, which was understood as evident when no new themes or ideas emerged from interviews with participants (Morse, 1995). Since it is the richness of the data that is important to achieve saturation (Morse, 1995), the process of data analysis concurrent with data collection was useful in recognizing this important saturation stage in the data collection and analysis process described below.

As qualitative research requires the researcher to be familiar with and immersed in the data to be analyzed (Bradley, Curry, & Devers, 2007) the interview and focus group transcripts were first reviewed without coding. Following this, Morse and Richards' (2013) four phases of coding were used: descriptive, topic, analytic, and theme coding. This coding was conducted using NVivo11 (QSR International, 2012).

Descriptive coding was conducted to record factual information about the data and make connections between the context and the information provided by the participants (such as participant demographics and experiences with health and aging innovation). Following this, topic coding provided an overview of the reoccurring topics which emerged in the data; codes were created based on the ideas discussed in the transcripts. Next, analytic coding sorted codes into broader categories and theme coding involved making connections between these as data were reviewed and themes threaded throughout the interviews were identified to sort categories into themes and subthemes (Morse & Richards, 2013). This process was aided by the NVivo 11 software, as categories created in the analytic coding process could be lumped together into subfolders to identify themes and subthemes in the data. This was an iterative process, requiring the researcher to review the data multiple times.

The quality of the data was ensured using three techniques proposed by Creswell (2003) to validate the accuracy of the findings: i) member-checking was conducted by taking the themes back to interested participants to ensure stakeholders felt that they were accurately represented; ii) detailed descriptions of the findings were created to provide readers with a sense of a shared experience with the data; and iii) a peer debriefing exercise to check the reliability of the coding where a committee member independently coded a sample of interviews followed by a discussion about the codes and emerging themes.

An Audit Trail (see Appendix D) as discussed by Lincoln and Guba (1982) was used to enable readers to follow the progression of events in the study and understand the researcher's logic (confirmability). Another tool to ensure rigour in this study was the use

of triangulation of the data (Johnson & Onwuegbuzie, 2009). This occurred by comparing the themes revealed in this qualitative interview phase with those from the previously conducted literature review (McNeil, 2017a).

5.4 Ethical Considerations

Ethics clearance was obtained for this study through the University of Waterloo's Office of Research Ethics (ORE #21329). Prior to each interview, participants had an opportunity to review a consent document which explained the purpose of the study, presence of the digital recorder, opportunity to withdraw participation or data, and the confidentiality and anonymity of their responses.

5.6 Results

Individual interviews were conducted with 29 Triple Helix stakeholders involved in health and aging innovation ecosystems at varying stages of development in Canada. Five focus group interviews were conducted. Three focus groups were convened with community dwelling older adults and caregivers (n=10;8;8) and two with older adults living in an assisted living home (n=6;3). Due to geographical constraints, individual interviews were conducted with an older adult living in long-term care and with a caregiver. Table 5.6.1 describes the gender, role and geographical location of participants. Throughout this project (as with the other phases of the ECOTECH study), older adults and caregivers from the Seniors Helping as Research Partners (SHARP) group (<https://uwaterloo.ca/geriatric-health-systems-research-group/sharp>) were engaged. SHARP group members participated through multiple focus groups with a less-structured

approach from the other consultations to allow for meaningful involvement in the project, such as raising questions or issues with the topics of discussion.

Table 5.6.1: Participant description²

Primary Role in Ecosystem	n	Gender	Location
Older adult and caregiver (community dwelling)	12	M=3, F=9	Guelph, ON; Toronto, ON
Older adult (congregate living)	10	M=3, F=4	Oakville, ON; Vancouver, BC; Waterloo, ON
Industry Representative	8	M=4, F=4	Cambridge, ON; Vancouver, BC; Waterloo, ON
Government Representative	5	M=1, F=4	Vancouver, BC; Waterloo, ON
Academic	7	M=4, F=3	Vancouver, BC; Montreal, QB
Care providers working in health and community services	9	M=2, F=5	Kitchener, ON; Vancouver, BC; Waterloo, ON

Thematic analysis revealed four key themes which emerged from 57 individual codes to answer the research question of understanding the interest in, and readiness for, engagement of older adults and their caregivers in Canadian RHIEs. Table 5.6.2 below outlines the key themes and subthemes, and provides example codes.

Table 5.6.2: Summary of themes

Theme	Subthemes	Example Codes
Older adults and their caregivers want to be more	More meaningful engagement than the current state is needed	Involvement in research Involvement in planning

² Total n in table is different from numbers reported above, as some older adults and their caregivers from the SHARP group participated in multiple focus groups. "Care providers" here refers to persons in a paid caregiving role.

Theme	Subthemes	Example Codes
involved in innovation for health and aging	Valuing experiential knowledge of older adults and their caregivers Diversity and multiple roles for older adults and their caregivers	Heterogeneous population Different living situations Experience of aging
Triple Helix stakeholders envision a greater role for older adults and their caregivers to play in RHIEs	Current state of involvement Diverse stakeholder experiences with traditional RHIE partnerships	Want to hear older adult and caregivers' ideas Open to involvement Current engagement program
Understanding the impact of older adults and their caregivers engagement in RHIEs	Improved innovation Societal benefits	Help technology fail fast Improvement of technology Technology that works for older adults and their caregivers
Barriers to more meaningful engagement in RHIEs	Ageism and power differentials Communication Access to information	Respect Stereotypes Traditional views Information overload

5.6.3 Older adults and their caregivers want to be more involved in innovation for health and aging

Older adults and their caregivers want to be meaningfully engaged in RHIEs. Many feel that the current status quo of involvement in innovations for health and aging could be enhanced. Two ideas were shared for how to achieve this increased involvement: valuing the experiential knowledge of older adults and their caregivers, and recognizing the diversity of these groups by allowing for multiple forms of engagement.

5.6.3.1 *More meaningful engagement than the current state is needed*

In focus group interviews with older adults, a variety of examples were used by participants to describe RHIEs and the potential relationships and exchanges within these. When discussing partnership approaches to innovation, older adults and their caregivers explained that they do not currently feel like active participants or partners in RHIEs. For example, when asked if technology developers approach them to ask about what they need or want, older adults in one focus group were discouraged, replying,

No, it doesn't exist at the moment. – Older adult

It was evident from many of the interviews with older adults and their caregivers that they would like to be more involved in RHIEs. Many recognized the benefit of getting involved. Older adults and their caregivers shared their views that engagement in RHIEs could allow for them to meaningfully contribute to innovations that impact health and well-being.

I'm thinking "that's the way things should be done. All these areas should get together for the common good." - Older adult

I think it's a necessity to get the two [older adults and other stakeholders in the ecosystem] together. Because otherwise how does a professional know what's going on inside of me. You know, if they have no idea as how an ordinary person lives. - Older adult

Older adults and their caregivers had a feeling of being excluded from the typical Triple Helix partnerships in RHIEs, or of something missing from the current societal conversations about innovation for health and aging,

The three wonderful institutions in there. The community, where seniors live, not mentioned. - Caregiver

Data revealed that more meaningful engagement of older adults and their caregivers is needed than is currently perceived in RHIEs. Participants discussed the importance of valuing the experiences of older adults and their caregivers as a necessary step towards increasing their role in innovation ecosystems for health and aging.

5.6.3.2 Valuing experiential knowledge of older adults and their caregivers

The importance of recognizing experiential knowledge of older adults and their caregivers emerged from the data. Older adults and their caregivers felt that in innovating to improve health and quality of life of older adults, it is important to understand the lived experience of aging. This was expressed as participants wanting innovators to not only have empathy for the aging experience, but to better understand what it is like to get older, from a holistic perspective of physical, mental, emotional, and social aging. Research and development of technologies and innovations would then have more potential to work for those who need them. Older adults and their caregivers expressed disillusionment and frustration from the lack of understanding conveyed in their interactions with other stakeholders in RHIEs who are working in the area of health and aging innovation.

I'm wondering if any of these people ever do think along the lines of the general public and how can we actually get them to that point where they will involve the general public. - Older adult

Why don't we get a group of us [older adults] together and ask "what could technology do to make your lives better?" Instead of just assuming what will work

for us? And I don't mean just when it's time to test something out, it has to be before all of that! - Older adult

How do we feel when we're old? You don't know how it feels to be in this body, the challenges. You just don't, no matter what you say. I have a very dear friend who can barely hear and even to the doctor she says "I'm very hard of hearing" and people say "oh that's ok" and then go on. So it's not an understanding of what's going on." - Caregiver

Some participants felt that more could be done by stakeholders in RHIEs to understand the aging experience.

You know the saying, "put yourself in someone's shoes"? Well I think it would go a long way for young people and those involved in studying and making new tech for us, to get a taste of what it is like for us. Like, you know when I am out at a store, people think just because you have one disability you have all sorts of disabilities. - Older adult

Aligned with the value the older adults and caregivers placed on experiential knowledge, some Triple Helix stakeholders who had experience engaging with the community also expressed the value of experiential knowledge.

We had patients come and speak to what the pain points were along the journey. The problem with these kind of chronic diseases is that they [patients] are the only people who are on that journey. No one else is, so the clinicians see only a silent fraction of it, not the whole thing. - Government representative

Although expressed as "a problem", this participant acknowledged the experiential knowledge held by those who will benefit from innovations in RHIEs and the importance of understanding this. This theme was also expressed in the data as a lack of experiential knowledge among those innovating for older adults and their caregivers. In discussing how research agendas are current set, one participant explained,

... two types, those in the real world with experience of being with seniors. The other are academic engineers (i.e., image processing and wanting to apply to the elderly). They come with a solution looking for a problem, and they problematize the world and tack on the solutions – rather than understanding the people and solving their problems. - Academic

And how do you support the interplay or the sharing of information and the, um, collaboration to get the best out of the, and the best value as well as the most for the patient and, and maybe even engage the patient? – Innovator

There's a lot of things we could be doing, but we aren't talking to the people we need to, to understand the issues. – Care provider

Appreciation for “those in the real world with experiences of being with seniors” was contrasted with an approach which is *technology-* and *problem-* rather than *person-* centred. Some participants seemed to place a lower value on the idea of involving older adults and their caregivers, discussing engagement as something that might be done in the future.

We're [SPOR] not partners with [the ecosystem], but we certainly talk about how we might be partners at some point. – Government representative

The data reveal a theme of timing considerations of engagement efforts with community stakeholders such as older adults and their caregivers. This was a consideration for Triple Helix stakeholders, with some participants seeing engagement as more appropriate at later stages of planning or development of RHIEs. The discussion of CIHR's Strategic Patient Oriented Research Initiative (SPOR) as not currently being involved in the innovation ecosystem was an example of this.

5.6.3.3 Diversity and multiple roles for older adults and their caregivers

In thinking about engagement for planning and developing innovations for health and aging, an understanding of diversity was important to the older adult and caregiver participants.

There are different levels of age, I mean what do you consider older? Because younger seniors or people who aren't quite seniors yet might have a different perspective than people who are already experiencing old age. – Older adult

You know we need people who are inventors and we need people who are at all different stages, we would want different types of people to be involved, like different ages because, younger seniors or people who are not quite seniors yet might have a different perspective than people who are already seniors, or who are older seniors. – Older adult

Since aging creates such a heterogeneous group it is important that we make efforts for diversity of age, gender, economic status, health conditions... and this is why the engagement of caregivers on behalf of those who might be compromised to fully participate or speak up for themselves. – Caregiver

Yeah, because not everyone has the same issue to bring to the table. If you have 20 people, guaranteed, 18/20 will have something different. Maybe similar experiences but not, you know. Everybody has different issues that they're dealing with. Positives and negatives. You know, sometimes to see it is if, when you're making a cake, you have a lot of things to put into it so the cake will, will come out and it's edible. Many, many ingredients to make one good thing. – Older adult

One way in which this diversity of opinion expressed itself in this study was in the different meanings of innovation for health and aging between those living in the community and those in congregate living situations. In the conversations with those in the congregate living settings, innovation was discussed as being process-oriented, such as changes to procedures and routines in their living environment. The importance of

innovating in less high-tech ways was highlighted, with some participants communicating a perceived burden of learning new technologies.

Well, the innovation of this place is not into iPads. – Older adult

I just can't imagine becoming enmeshed in another piece of equipment... I'm saying I'm scared to death of the idea, but if you can teach me how to do it, maybe. What's the purpose of... for you or for us having this? – Older adult

This conversation led into the important innovations the residents felt were needed in their home. Participants talked about issues with meal times, making appointments, and the levels of care required by the residents living in the home.

We're talking about the process of how things, decisions are made. Having ... having residents have more of a voice in terms of what the population looks like, that could be innovation as well. – Older adult

They have a lot of ideas on things that they think could improve... not so much a focus on operational efficiency but they see kind of gaps where, where some things could help and it's a different kind of innovation because for the most part, they're not thinking oh we could use this technology to do this. – Care provider

Those working in these care environments reflected on the different approaches needed to understand innovations for health and aging needed in congregate living situations. One participant shared views on the importance of process innovation in the form of culture change needed to involve staff in health and aging innovation. The perceived barriers to engaging these staff were noted.

We need a better foundation for knowledge translation (KT)... put the KT person on the operations side and see if that gets them any further- have a better

understanding of the operational challenges, maybe be able to see firsthand what the [long-term care homes] are struggling with most. – Care provider

For the care staff, I think they see this is onerous because we're asking them to do stuff that's above and beyond what their traditional job is. So I think the solution there is we need to change it what the traditional job is and it's not that I want to add things to your plate. It's that I want to eventually make your life easier but I need your help to do that and if you don't trust me to do that, then you're going to think this is onerous. If you know that this is the way we make your life easier, then you'll be willing to kind of help a little bit with that. - Care provider

Healthcare providers and those working with older adults support engagement and experiential knowledge needed for innovation. Community dwelling older adults also spoke about process innovation, for example about changes they desired in the healthcare system. The first quote below describes a desire to be involved in making changes to the healthcare system. In contrast to discussions with older adults living in congregate arrangements, discussions of products and technologies that might be useful to them were more prominent.

I think us in the SHARP group are helping to put it [the healthcare system] into the right direction. – Older adult

So that's why I think this idea of partnership is interesting, particularly because of course you wouldn't be expected to be an engineer by trade, or, have worked with computers all your life, but if you were to sit down at a table with people who did in the development stages, maybe that would change, what they made.
– Older adult

... I mean you don't, you don't learn any of this technology until you do it.
– Caregiver

Well we just, we don't have the uh, at, at our age the education and background that people currently working in technology would have, but I still think we would have some valuable input. – Older adult

Along with this diversity, there are a variety of roles that older adults and caregivers want to contribute to a RHIE. Some of these roles might be more traditional and commonly established, for example older adults spoke of volunteer work within one of the partner organizations of a RHIE.

Well, the people that live in [the ecosystem] could volunteer at some of the facilities within the university or within the hospitals. – Older adult

With this type of involvement, participants highlighted the importance of being aware of available assets and bringing them together. In the context of understanding how to get involved in an RHIE, one participant suggested,

So if there was like a central place where we could go to, maybe some link to the university and at that site other links to go to these other sites that pertain to seniors' health, it might be an easier way for seniors to navigate and find the information of interest to them. – Older adult

Engagement was discussed as virtual involvement, with some older adults and their caregivers expressing that this might be an option for people to get involved who could not physically attend due to geography, mobility or health issues or who had caregiver commitments at home.

I was wondering if they could set up a website so that all over Canada people could be involved. – Older adult

Older adults and caregivers expressed other roles that would be of interest to them in RHIEs. Some older adults and their caregivers might want to be engaged on a research team, while others might want to be involved in a committee or board creating strategic or ecosystem priorities or in understanding regional capacity.

There might be different roles for different people to play depending on their age, their personality or what they might want to do... It's like a huge chain with some people coming up with ideas and some testing them out and we're part of the chain. - Older adult

...and part of their work is involved in healthcare, the digital part. And I was thinking well "why don't we give them a call? As senior people you might know someone in the area that might help out in that area." - Older adult

Getting all these different areas together and I really got fired up about that. So I'm thinking to myself "what can I do to help this?" - Older adult

Given the diversity of the older adult and caregiver populations, RHIEs looking to engage these stakeholders should consider flexible approaches to involvement.

Consulting with a heterogeneous group of older adults and caregivers about their preferences for engagement might reveal important modifications that need to be made to ensure readiness for their meaningful engagement.

5.6.4 Triple Helix stakeholders envision a greater role for older adults and their caregivers to play in RHIEs

While stakeholders involved in Canadian innovation for health and aging discussed the roles that older adults and their caregivers typically play in innovation, such as involvement in user-testing activities and early phase technology development, opportunities for engagement at the level of regional partnerships were rare.

Patients also have ideas actually, and that's probably an untapped resource in the innovation ecosystem is really getting patients engaged. – Government representative

Other stakeholders from the Triple Helix supported the principle of engagement of older adults and their caregivers in the organizations involved in RIEs for health and aging.

A parcel of that is a basic principle that patients need to be involved at all levels both in setting research priorities and establishing what outcomes are relevant and participating in research and participating in the actual conduct of research and in the uptake and dissemination of it. – Academic

Some participants highlighted this involvement as a missing component in RHIEs.

What I think is missing and innovation, uh, communities bring to the table, is the opportunity to bring all these parts together and say, uh, it's a safe environment to try out new products, new ideas, new services where a customer ... You have a community of people that are ... The, the Health Authority actually brings the patients to the table. You could say they have access to, to the citizens. Turns out that the city actually has better access to the individuals than the Health Authority does because the city actually runs, uh, or at least facilitates, hundreds of clubs, hundreds of community organizations. And if you're trying to reach out to individual citizens, a lot of them don't think of themselves as patients. They think of themselves as people. – Industry representative

We're moving away from fund and forget... and there are a confluence of factors coming together, not even separate from the beginning but swirling around, that are leading to, to one day, we're probably going to think it's absolutely crazy that we haven't involved patients and the public in major decisions about what to fund and how to do things and so on. – Government representative

While it was generally agreed upon that there is a greater role that older adults and their caregivers could play in innovation for health and aging, there were diverse

experiences and perspectives as to what engagement of older adults and their caregivers in RHIEs currently occurs in Canada.

5.6.4.1 Diverse stakeholder experiences with traditional RHIE partnerships

In understanding the desire for older adults and their caregivers to have a meaningful role in RHIEs, there are a variety of perspectives from government, academia and industry representatives about extending traditional Triple Helix partnerships to engage the community. Some stakeholders in Canadian RHIEs perceive that they are meaningfully engaging the community in the ecosystem.

Sure, oh, for sure. The community was involved whether it was through any of the care homes. Whether it was through, I mean, [the local hospital], that's another hub that was set up. The community of course, had to be involved. For sure.

- Government Representative

They [patients] come with unbelievable ideas, so in these regional workshops that we held to try and get partnering going ... is to sort of get industry together with health care organizations with patients who can then describe the experience. Clinicians and health care organizations can also look at their perspective on that as well and come up with solutions that will improve the pathway. – Academic

Along this line, specific programs that encourage community engagement with various partners of the innovation ecosystem were mentioned, for example, academics discussed the SPOR initiative by the Canadian Institute of Health Research (CIHR) as a mechanism of engagement.

We're part of CIHR's SPOR. That is all about having patients engaged at the beginning of developing research plans. Research teams helping to identify research priorities, being involved in sort of the implementation of research, not with respect to going out and doing it, but being on a research committee that oversees research implementation for individual studies. – Academic

What I love about this, is that patients are involved up front, right at the beginning to tell us how they would like to be engaged in our efforts as we are moving forward with SPOR. – Academic

By contrast, some stakeholders representing the Triple Helix described a currently limited role of the community in RHIEs which involved more traditional innovation partnerships.

Because we don't interact directly with patients that might be a better question for someone you might be interviewing from [the hospital] or [the health authority].
- Industry representative

When representatives from these areas were interviewed they did not have examples of engagement of older adults and caregivers in their RHIEs.

I'm sure that we just, we don't actually know what it means on so many different levels to actually engage people. – Government representative

Or, as reflected in the quote below, stakeholders did not feel that they have the skills to meaningfully engage the community in the RHIE.

...Um, we've had a little to no success in engaging people...
- Government representative

When asked about the ecosystem's connections to the broader community the response by this health services provider was,

Um, I don't think so. Not from where I'm sitting. – Care provider

Others recognized the limitations of what was being done to engage the community and expressed an interest in expanding the role of older adults and their

caregivers in innovation ecosystems for health and aging as a next step in the development of the ecosystem.

So that's work to be done, um, and we are in ... In active conversations around how we can ... How we should be, um, telling our story in a broader sense and penetrating more the ... the community. So for us it was more let's see what matters first and that's the awareness, uh, within the tech community and the business community and such but of course it matters, you know. We need to penetrate that ... That ground level as well. So we haven't done a great job at that. - Government representative

So, you start thinking bigger, you have to think about the community and the community in a broader sense. - Industry representative

So, so, I think it would be really good for people involved in doing research to really connect with people in the outside world and say, "Well, this is what I'm doing," and then the person in the outside world is, "Oh, that's interesting," but you can bet your bottom dollar that half of them say, "Well, what value is this? How is it going to help? How is it going to help me? How is it going to contribute to, you know, society?" You know, because um, you know there is this idea of us being in our ivory towers, which is a very, very fair comment in many ways. So we could actually go out and connect with the real world and do very short presentations and say to people, "This is what we're doing." You get a lot of feedback very quickly. - Academic

These quotations support the theme that emerged from the perspectives of older adults and caregivers; more meaningful engagement than the current state is needed in RHIEs. Triple Helix representatives lamented the status quo in engagement efforts and expressed a readiness to involve the broader community in the work that they do for innovation in health and aging.

5.6.5 Understanding the impact of older adults and their caregiver engagement in RHIEs

5.6.5.1 Improved Innovation

Consultations revealed that engagement of older adults and their caregivers in RHIEs could yield insights into values, preferences, experiences and traditions that can enhance the value, acceptability and use of technologies. This impact was important to older adult and their caregivers, who expressed that they wanted to see their involvement in innovation to have meaning or value.

I think the idea sounds okay. But I think, as long as it achieves something. An improvement. In whatever you're talking about. I mean, some progress.

– Older adult

In discussing the impact that engagement of older adults and their caregivers in RHIEs might have, one caregiver said,

Change isn't always good... we can alert them to what we see as the pitfalls or dangers, we can think about oh well, what if I had to do this or that, we can say well you better think about this. - Caregiver

Participants felt that involvement in innovations from idea generation, planning and partnership development could have a positive impact on the innovations produced down the line in RHIEs.

5.6.5.2 Societal Benefits

Older adults and their caregivers communicated societal benefits to their participation in RHIEs. This theme was raised by many older adults and was expressed as a duty they could perform or role they could play in their communities. Reflecting on the value of engagement for the greater good of society one older adult shared,

A significant role that we as seniors can play in our collective future is to establish priorities and that is essential to make the most of our time and contribution to know the most important things to go after, with technology for example. - Older adult

In regards to acceptability, it is important to understand what the value of technology is to older adults and their caregivers.

People like to think that technology and innovation somehow will solve all the world's problems. I'm of a different generation so I really can't stand the 'innovation' word. I just think there needs to be some common sense. There's a lot of healthcare related issues that have nothing to do with technology and I'm not convinced that technology is going to solve them. I'm talking about the social determinants of health basically. - Government representative

Technologies need to respond to our needs! - Older adult

I was born in 1930 and I ... I think I'm uh, intelligent and well. I'm ... I'm well. And all this technology that's come in, I ... I don't think it's very useful.
- Older adult

If you don't see a benefit in using it, it would probably be more complicated than it's worth, I'd imagine. Yeah. - Older adult

I find that the computer is about as far as I really want to go with the gadgets. I have a simple cell phone. I really don't want to get into all those things. And I realize that's very backward looking of me, because in theory, I'm in good health and ... and my mind is still working reasonably well. But there's just so much I don't want to push my mind to do. I guess that's the only way I can explain it.
- Older adult

I mean, hearing that is so important because a lot of the technology developers, you know, they see it from maybe a younger point of view, where everyone wants technology, why wouldn't you want technology, you know? - Care provider

The emergence of this theme in the data reflects the importance of considering value of innovation to older adults and their caregivers. In developing engagement opportunities in RHIEs, a clear motivation for involvement for older adults and their caregivers early in the planning and development of partnerships for innovation is the opportunity to positively impact the direction of innovation to help ensure value of what is created. In order for this impact to be realized, RHIEs need to be ready for increased engagement of older adults and their caregivers. Participants shared barriers to this engagement in RHIEs.

5.6.6 Barriers to more meaningful engagement in RHIEs

Despite the enthusiasm from participants in this study for more meaningful engagement of older adults and their caregivers in RHIEs, a discussion of possible barriers emerged. These can be broadly understood as societal ageism, and issues with communication and access to information.

5.6.6.1 Ageism and power differentials

A central concern among older adults that emerged in this study was the idea of ageism. In discussing why older adults feel excluded from innovation partnerships, some older adults do not feel that it is currently socially acceptable for them to be included in partnerships for innovation in health and aging.

Ageism, is still alive and well... Unfortunately. - Older adult

People's overall attitude- we have to pursue this. I'm a human being and others owe it to me to treat me as that. We need to see the person first! - Older adult

And they can better understand the effect on us. As real people and not just some old thing. – Older adult

The focus group participants were passionate about this, connecting the perceived exclusion of older adults and caregivers from technology and innovation development to a more systemic, societal issue. When asked about how this situation could be improved, three ideas were shared: i) respect for older adults, ii) encouraging older adults to share their experiences with ageism and get involved, and iii) encouraging intergenerational interactions.

It was just more appropriate here saying what would help would be a little more respect for the talents and abilities of older people. – Older adult

And I feel it's up to us to get that info to the table. – Older adult

I think one interesting approach that I have seen is that students, from design school, when they come here [long term care home] to work on projects that design living areas for us, they spend some time in a wheel chair. And when I was with them I challenged them to go out to the mall in them. I think they were shocked by the experience they had. And that's a good thing, you know?
– Older adult

It is important what you are studying, but until you can figure out how we can encourage generations to interact and have meaningful conversations, nothing will change. – Older adult

We've got to teach people that we aren't all stupid just because we're over 65! Anyone can come up with a good idea, about something, no matter what their age or what they're doing. – Older adult

These responses to ageism and societal barriers to involvement highlight the advocacy role that some older adults feel is important and are willing to play,

encouraging older adults to “speak up” about their experiences with ageism and participate more fully in society through intergenerational relationship building.

The presented responses to ageism and societal change require acknowledgement from other stakeholders, such as younger partners in RHIEs which might be challenged by power differentials that are perceived by older adults and their caregivers. This power imbalance was highlighted by multiple stakeholder groups interviewed. For example, when discussing interaction between older adults and their caregivers and those conducting research in health and aging, an academic highlighted power differentials by commenting,

Yeah, absolutely, because they're [older adults] just intimidated quite frankly by the situation and I think that you need folks who can actually be the cultural bridges. – Academic

In a focus group discussing experiences in partnerships for innovation, older adults shared their thoughts on needing to know how to share information with professionals,

We need a way to present it, otherwise we're dominated. – Older adult

An increased role for different stakeholders, or a partnership with those who traditionally are seen as users or patients, will require those who currently hold decision-making roles to be open to partnerships with community members. Some participants were unsure if this would be acceptable to those who currently cooperate in Triple Helix partnerships in ecosystems for health and aging innovation.

That was my next thing that maybe professionals aren't really ready to allow the general public to have their opinion. Professionals are very possessive of their position. – Older adult

But I have to caution you because it's always let's do a focus group. Let's do a trial, then let's get our data or whatever else. And, it seems like they were looking for a certain outcome. They essentially want to use this as a marketing factor that we trialed this and this many people like it and this many people ... And they adopted it. – Care provider

Readiness for older adult and caregiver involvement is unfortunately dampened by issues of tokenism and exploitation as described above that can occur in citizen engagement efforts. Challenges were also raised that community representatives are held to different standards than those in traditional positions of power.

I get a little bit frustrated when people say, “maybe the public won't be able to be unbiased”, well do you think an academic is completely unbiased when they bring their voice to a decision-making table? – Government representative

I have always been interested myself in lay vs expert. How come we call some people experts and some people lay, and what is the difference? And I'm not suggesting there is a difference, but it's important to explore. – Academic

Although this cannot be said for all professionals, the perspective that community members have of those in positions of power might influence engagement opportunities. The barriers that emerged to engagement of older adults and their caregivers at a systemic level, were conveyed as interpersonal challenges, such as communication and information sharing issues.

5.6.6.2 Communication

Communication emerged as a significant barrier related to the readiness of Canadian RHIEs for more meaningful engagement of older adults and their caregivers. Older adults reflected on the way that healthcare providers speak to them as an example of this. When describing typical interactions with physicians, one older adult said,

He's not on the same level as you. Because he thinks you just won't understand what he's saying. - Older adult

Participants shared that if the paternalistic way that they were normally talked to continues in innovation ecosystems, then partnerships, or more meaningful engagement, would not work. Other stakeholders felt that the challenges with communication were more about connecting the actors necessary for innovation, with one Triple Helix stakeholder commenting,

You know, that ... that ... I think that's the problem with a lot of health innovation currently. The people who make these products aren't talking to the right people.
- Academic

In RHIEs looking to more meaningfully engage older adults and their caregivers, a first step might be to encourage communication between stakeholders following guidelines for respectful, transdisciplinary interactions.

5.6.6.3 Access to information

Meaningful engagement of older adults and caregivers in RHIEs is also challenged by access to information. Concerns related to access to information emerged in the data in a few key ways. Some older adults felt that in health innovation and technology they are “*not experts*” (older adult) so would need to be caught up to the other stakeholders in the ecosystem.

... education. You can see some of a project and it looks really great but unless, and following into that, you've got an interest in it and a willingness to participate and that trust and confidence that comes with knowledge, you know education... And then going to seminars, workshop, and website, that's info.
- Older adult

When older adults and caregivers felt that they were able to access information, a general theme of information overload emerged. Older adults and their caregivers shared their frustrations in not being able to locate the best quality information to keep informed and up to date. This was highlighted by a caregiver who said,

Like what I notice from my perspective is that the information is out there but you have to know how to really hunt to find it. - Caregiver

In response to this challenge, one stakeholder offered a way that information can be used as a support to improve older adults and their caregivers' health and quality of life,

Um, but, if we ... if we can get information to people like seniors and caregivers in a more timely manner, then they're going to make better decisions, they're going to be better informed about what's available, they're going to be better supported in making use of the ... those technologies and getting access to them.
- Academic

The emergence of perceived barriers to collaboration with older adults and their caregivers in RHIEs is important in assessing the readiness for older adults and their caregivers to be more meaningfully engaged in these partnerships.

5.7 Discussion

Although there is clear interest in older adult and caregiver engagement in Regional Health Innovation Ecosystems (RHIEs), readiness for this is a more complex question. The results of this project revealed that currently, there is little meaningful involvement of older adults and their caregivers in Canadian communities of innovation for health and aging. Enhancing the involvement of older adults and their caregivers will

require a recognition of the need for diversity of older adult and caregiver representation, considerations of barriers to involvement, and recognition of multiple roles that older adults and their caregivers could play in health innovation.

This study revealed that traditional partners in regional innovation ecosystems, or Triple Helix stakeholders, envision a greater role for older adults and their caregivers to play in RHIEs. Stakeholders agreed that more meaningful engagement of older adults and their caregivers is needed than is currently the case. This theme is supported by recent work such as the SPOR initiative of CIHR, and in health technology assessment (HTA), where a model of patient engagement was released to respond to the recognized need to involve patients throughout the HTA process (Abelson et al., 2016); this work could be better integrated into RHIEs. These results also align with findings of the phase I literature review for this project, which revealed a movement towards greater community involvement in RIEs such as support for Quadruple helix models of stakeholders (McNeil, 2017a).

The valuing of the experiential knowledge of older adults and their caregivers that emerged from the data is supported by extensive literature on patient engagement, where there has been increasing interest in involving patients and caregivers in health care research and planning (Holosko et al., 2001; Jansen et al., 2015). There is a recognition that in order to improve the health care system to meet Canada's evolving health needs, patient engagement must be supported (Denis et al., 2011).

Patient engagement has been discussed at multiple levels of the health care system. At a micro level, the importance of patient-centred care has been accepted and is a goal of many health care systems (Institute of Medicine, 2001). This concept is linked

with patient engagement at the macro level of health system planning; in order to have a system that responds to the needs of patients at the point of care, their input and values need to be known. As Naylor (2015) and others have noted, as the Canadian population ages and those with chronic conditions want to have a greater say in their health care, the system needs to evolve so that patient-centred approaches become the norm.

Collaboration with citizen groups (such as older adults) in health care planning is a step towards making health system decisions that legitimately reflect the social values of the public (Bombard, Abelson, Simeonov, & Gauvin, 2011). Engagement of older adults and their caregivers in RHIEs could be understood as part of this system level involvement.

However, as Hicks and colleagues (2012) found, current engagement efforts, such as conceptualizations of shared decision making by patients are often tokenistic, in that there is only an illusion of choice which “deflects problem solving and discussion away from a productive examination of the differences between healthcare system offerings and client needs” (p.1). Further studies have revealed that although there is a recognition of the importance of meaningful patient engagement for innovation in the healthcare system, these efforts are under-developed in Canada (Naylor et al., 2015).

In response to this, some have suggested that engagement of citizens in health needs to be encouraged from the top. Naylor and colleagues (2015), for example, have suggested that the shift towards a truly patient-centred health system requires an adoption at the leadership level of a way of working that truly integrates patients’ values, experiences and perspectives. Engagement in system development and planning, such as opportunities for engagement in RHIEs, make it possible for the community to be meaningfully engaged in their health, “promoting greater patient responsibility and

optimal usage of health services which ultimately leads to improved health outcomes, quality of life and patient satisfaction” (Harkness, 2005, p.1) and a more responsive system (Scott, 1999). Movements towards general engagement throughout the health system supports a readiness for older adult and caregiver engagement in RHIEs.

In understanding readiness for engagement of older adults and their caregivers in RHIEs, however, considerations of diversity of older adults and their caregivers in their use of technology and their participation in RHIEs is important. This theme is reflected in various bodies of literature, from an understanding of technology adoption to demographic trends of acceptance and usage of technology among older adults. Diversity in technology adoption among older adults has been investigated and explained by early theories such as Rogers' (1995) Theory of Diffusion of Innovations and Davis' Technology Acceptance Model (TAM) (1989). The Diffusion of Innovations model describes a continuum of innovation adoption, with late adopters at one extreme who tend to be skeptical about innovations and early adopters who tend to feel more confident and willing to take chances, feeling less anxious about innovations (Rogers, 1995). Results from this project revealed different approaches to innovation among older adults as well as multiple roles that they would want to take on in RHIEs. Diversity is important in planning for older adult and caregiver engagement in RHIEs as a lack of diversity in engagement is a common critique of patient engagement efforts across the health care system (McNeil et al., 2016).

In this study, older adults and their caregivers discussed the importance of understanding the impact of their engagement in RHIEs on the technologies and innovations that are developed. This impact can be understood using the lens of Davis'

TAM (1989) which discusses the causal relationships between system design features, perceived usefulness and ease of use, attitudes toward using a given technology, and actual usage. These models have proven useful in current understandings of health innovation diffusion (Green, Ottoson, García, & Hiatt, 2009; Grindrod, Li, & Gates, 2014; Pai & Huang, 2011; Silvestre, Sue, & Allen, 2009). In this study, the diversity that emerged among participants in terms of their understanding of innovations for health and aging is supported by this model. This model can be extended to examine the results of this study as desired involvement in RHIEs was discussed as a potential mechanism for increased usefulness and actual usage of innovation by older adults and their caregivers.

Despite this interest, the proliferation of innovation, and the promises of these technologies for improving health and quality of life, some older adults and their caregivers feel that they are waiting for the potential of innovation to be realized in positively affecting their lives. Increased involvement in RHIEs might increase this, however, a connection emerged to the barriers to more meaningful older adult and caregiver engagement in RHIEs highlighted throughout the study. One explanation of the lack of enthusiasm for developing meaningful partnerships with older adults and their caregivers in RHIEs was a discussion of ageism.

As a systematic process of stereotyping older people on the basis of their older age (Butler, 1969), ageism leads to beliefs that older adults have little to contribute to society. Ageism can be expressed as marginalization and exclusion of older adults in their communities (Barnes, Blom, Cox, & Lessof, 2006) and at a societal level, negative images of aging and ageism can contribute to older adults' social exclusion.

In the context of health, ageism can be understood as a product of biomedical models of aging, which socially construct aging as a process of physical decline (Estes & Binney, 1989; McHugh, 2003). These widely held theories create conceptualizations of aging as disease-oriented, associated with “inevitable decline, disability, degeneration, and death” placing aging under the domain of medicine (Estes & Binney, 1989, p. 588). Biomedical models of aging are so ingrained in contemporary Western society that their influence can be seen across contemporary culture including on: the organization of research priorities, the discourse of popular media (McHugh, 2003), the production and reproduction of lay knowledge, professional and occupational structures (Koch & Webb, 1996), and the public policy agenda around aging (Estes & Binney, 1989). Related to these biomedical models, “anti-aging” movements have arisen, cultivating a culture of combat against the natural aging process and glorifying impossible ideals for aging (McHugh, 2003).

In the emerging area of partnerships for health innovation, the identification of ageism across societal institutions is particularly relevant. Specific to the development of RHIEs, ageism affects older adults’ participation in that they are excluded from the labor market and are expected to live retired lives (Vitman, Iecovich, & Alfasi, 2013). This issue has also been noted in health care; as Ozdemir and Bilgili (2014) note, “society’s and professionals perceptions of aging, perspectives and biases affect the quality of services offered to the elderly” (p.128). Bayer and Tadd (2000) have noted ageist trends in health research, with unnecessary exclusion of older adults from health research because of ageist attitudes persistent in the health research community. These troubling

trends have impacts on the health and quality of life of older adults, limiting the benefits of health advancements from equally affecting older adults (Bayer & Tadd, 2000).

Challenging these ageist perspectives and societal trends, The World Health Organization (2007) has recognized older adults as an important resource for their families, communities and economies. Two theories in the formation of knowledge align with this more positive recognition of older adults: transdisciplinary working, and the age-friendly communities movement. The age-friendly communities movement attempts to combat ageism by encouraging active ageing through opportunities for health, participation and security in order to enhance quality of life as people age. To enable aging in place and active aging, and to make communities more age-friendly (WHO, 2007), the factors that encourage ageism at the local level need to be addressed. Recognizing that ageism endures in environments where intergenerational interactions are limited (Uhlenberg, 2000), opportunities for the meaningful integration of older adults in the mainstream of social life are key components of age-friendly communities (WHO, 2007). The societal challenge of ageism can be resisted through opportunities for face-to-face interactions, promoting the establishment of social relationships (Vitman et al., 2013).

Although endeavors to increase age-friendliness in communities are benefitting older adults, ageism remains impactful across society; especially relevant to this study is its existence in the technology and innovation sectors. The relationship of older adults with technology is complex. Even though ageism has an impact on how technology is developed and marketed and on how older adults adopt new technologies, some scholars believe that technology has the potential to reduce ageism (Cutler, 2005).

In order to achieve this, and in recognition of the complexities of health and the health and care system which supports older adults and their caregivers through the aging process, approaches to knowledge generation are needed that encourage working across disciplines and inclusion of a diverse collaboration of stakeholders at all levels of the system (Trochim & Kane, 2005). However, many traditional attempts at these collaborations with end users in health care research and planning can be described as tokenistic (McNeil et al., 2016) and lacking actions necessary to establish meaningful partnerships. These tokenistic approaches were also evident in this study with Triple Helix stakeholders describing potential involvement of older adults and their caregivers in exploitative ways. For these approaches to generate meaningful collaborations needed to achieve the above stated potentials of innovation to support health and aging, the idea of transdisciplinary working is useful.

Transdisciplinarity, as described by Choi and Pak (2006), transcends traditional boundaries of roles, enabling multidisciplinary teams to resolve complex problems. Although the discussion of transdisciplinary working in RHIEs as a resolution to ageism might seem like a chicken and egg argument, as Mercer et al. (2015) have stated, studies that aim to understand the intersection of older adults and technology require the involvement of many different stakeholders. As discussed by Smith (2007), the overall goal of transdisciplinary research is to provide a link between research knowledge and decision-making processes to seek solutions that are “feasible, socially acceptable, appropriate, effective and sustainable” (p.161). By focusing on a problem that is stated in language broader than any one discipline and using synthesized methods, Grey Connolly

(2008) suggest that the value of transdisciplinarity is the ability to translate knowledge across traditional lines.

This way of working, or forming partnerships for knowledge production, might be useful in overcoming the barriers to older adults and caregiver participation in RHIEs that emerged in this study. Since this type of working is accepted by and advocated for in respected teams working on innovation for health and aging, such as the AGE-WELL network, and there is a general acknowledgement of the need for culture change in institutions involved in RHIEs, the readiness for older adult and caregiver engagement in RHIEs might be more positive than the data in this study would suggest.

A limitation of this study was the challenge of recruiting vulnerable populations to participate in research. Despite the best efforts of the research team, older adults and caregivers representing low socio-economic or culturally diverse groups were not engaged in this project. In order to ensure this perspective was included in this study, agencies that work with these groups were contacted to participate, however their participation was minimal.

5.8 Conclusion

Results of this study suggest an interest in, and readiness for, improvements in older adult and caregiver engagement in Canadian RHIEs. A need was identified to understand how to more meaningfully engage the older adult and caregiver community in partnerships working on innovations for health and aging. Barriers to engagement emerged including societal ageism and power differentials, and issues with communication and access to information. Awareness of the perceived barriers to

engagement in RHIEs is important as plans move forward to engage older adults and their caregivers in innovations for health and aging.

Recognizing the interest and readiness, the next phase of this study will build on the presented results to identify specific directions and strategies for older adult and caregiver involvement in regional ecosystems for health and aging innovation.

Collaborations are continuing with transdisciplinary stakeholders from this project to develop a framework of priorities to understand meaningful engagement of older adults and their caregivers in Canadian RHIEs.

CHAPTER 6 ECOTECH FRAMEWORK OF PRIORITIES

6.1 Outline

Background: Health innovation offers potential benefits for the well-being of older adults and caregivers. Regional Innovation Ecosystems (RIEs), involving a “triple helix” of industry, government and academic stakeholders, have been proposed to support development and commercialization of new technologies and innovations. Previous work identified that older adults and their caregivers want to be, but are currently not, meaningfully engaged in these ecosystems in health and aging (McNeil, 2017b). This study sought to understand how their role could be enhanced and created a framework of priorities to assist with implementation of this engagement.

Methods: Integrating results from phases I and II of ECOTECH, a Concept Mapping project (Kane & Trochim, 2007) was undertaken. Six phases blending qualitative and quantitative methods were undertaken to answer the research question of how older adult and caregiver engagement in Regional Health Innovation Ecosystems (RHIEs) can be realized. Stakeholder participation was emphasized throughout.

Results: After a brainstorming phase, 62 statements were sorted by stakeholders revealing a seven cluster framework of priorities: public forums, co-production and partnerships, engagement, linkage and exchange, developing cultural capacity, advocacy and knowledge translation, and investment in the ecosystem. Ratings of importance and feasibility of these ideas identified implementation strategies and next steps.

Conclusion: This study identified directions and strategies for their enhanced involvement in RHIEs. Next steps of this project include continued collaboration with stakeholders from this project to develop Canadian RHIEs that can support the health and well-being of older adults and their caregivers.

6.2 Introduction

Innovation for health and aging offers potential benefits for the well-being of older adults and their caregivers and society more broadly. There are however challenges for ideas, no matter how transformative, to be transferred to market. These issues are complex, but two components are especially salient: the commercialization viability of research which has been described as “the valley of death” (Merrifield, 1995) and the disconnect between academic and corporate cultures where differing motivations of business and research impede the transfer of basic research into commercially viable products (Gunasekara, 2006; Hallam & DeVora, 2009).

It is known that Regional Innovation Ecosystems (RIEs) (Doloreux & Parto, 2004), involving a “triple helix” of industry, government and academic stakeholders (Etzkowitz & Leydesdorff, 1995), offer support to these challenges allowing for the development and commercialization of new technologies and innovations. Increasing understanding of the benefits of co-production with end users suggest a need for an additional thread in the Triple Helix to account for citizen engagement in RIEs. Engagement with consumers is increasing across innovation sectors as industry begins to recognize the value of their involvement and customers become “richer, demanding, and better educated” (Colapinto & Porlezza, 2012, p. 344). These trends support the creation of a Quadruple Helix model including end users in regional innovation partnerships (Carayannis & Campbell, 2009).

In health and aging innovation, the development of regional capacity through Regional Health Innovation Ecosystems (RHIEs) has trailed other industries, but is attracting attention (Prada et al., 2013; Williams et al., 2014). The involvement of civil

society is particularly relevant in health as it aligns with current democratization trends in many health care systems, supporting opportunities for the community to provide direction and agency to the other helices in RHIEs. Support for this civil society helix in health is evidenced by the recognition that involving end users in the design process of innovations has emerged as the quickest and most reliable way to capture the needs of users and consumers (Essén & Östlund, 2011). In the context of health innovation there is a demand by patients and caregivers for more health information and greater control over health experiences (Carrera & Dalton, 2014, p.39).

When this engagement occurs, there has been many identified benefits in health care including improved health outcomes and patient and provider experiences, better financial performance, and strengthened communities (British Columbia Ministry of Health, 2011; Health Council Canada, 2011). Active public involvement through partnership roles in the development of health services is central to a health care system that is “responsive to a patients’ needs and values” (Archambault (2011, p.1).

These improvements to Canada’s health care system often most affect the care of older adults who are its largest users and fastest growing segment of the Canadian population (Canadian Institute for Health Information, 2011). There is also a wealth of literature supporting not only the essential role that informal caregivers (such as family and friends) play in the health care system but the impact that issues in the health care system have on them (Byrne, Orange, & Ward-Griffin, 2011; Elliott, Forbes, Chesworth, Ceci, & Stolee, 2014; Giosa, Stolee, Dupuis, Mock, & Santi, 2014). Given their central role in the circle of care to ensure healthy aging and quality of life, it is important that

caregivers of older adults be included in patient engagement activities (Stolee et al., 2015).

More opportunity for involvement in RHIEs is not only theoretically appropriate, but have been supported by older adults and their caregivers and Triple Helix stakeholders involved in Canadian RIEs innovating in health and aging (McNeil, 2017b). Could the involvement of the community, specifically older adults and their caregivers in meaningful partnerships in RHIEs, help to create the conditions necessary to bridge the “valley of death” in health innovation? Building on previous work which identified a gap in understanding of the role that citizens could play in RIEs (McNeil, 2017a) and supported engagement of older adults and their caregivers in these arrangements to support health and aging innovation (McNeil, 2017b), this study aims to answer the third research question of this three phase study (ECOTECH), to understand how older adult engagement in RHIEs can be realized.

6.3 Methods

The methods section begins with a discussion of the study sample followed by a description of each of the six phases of the concept mapping process.

6.3.1 Study Sample

The selection of participants was important in this project. Given that “conceptualization is best when it includes a wide variety of relevant people” (p.35), representative sampling was employed (Kane & Trochim, 2007). Sample sizes of CM projects vary, usually within a range of between ten and 40 participants. Larger sample sizes are possible with no “strict limit” (p.36) of participants and possibilities of greater reach enabled by the use of the Internet for data with The Concept System software

(2015) as a platform to both gather information and analyze the data generated throughout the CM process.

Following recommended practice from the Concept Systems training (2015), a core group of stakeholders was recruited to participate throughout the project in an in-depth role. These participants were recruited from the Seniors Helping as Research Partners (SHARP) group. The SHARP group is a sustainable network of older adults who collaborate with the Geriatric Health Systems Research Group to advance the development of research priorities and collaborate on research projects, with an aim of improving the health care system for older adults. The group of core stakeholders were community dwelling older adults and caregivers over the age of 55.

For the other participants in this study, efforts were undertaken to recruit and engage a heterogeneous group representing the stakeholder groups typically important in regional innovation ecosystems, including academics, government/ decision-makers, and industry representatives, as well as a diverse population of older adults and their caregivers.

Snowball sampling and email recruitment was used for all of the stakeholder groups.

Although recruitment challenges occurred for participation of technology developers and health care providers in this study, their participation in phase II of ECOTECH (McNeil, 2017b) ensured that their ideas were integrated into the brainstorming statements and so were represented throughout the study.

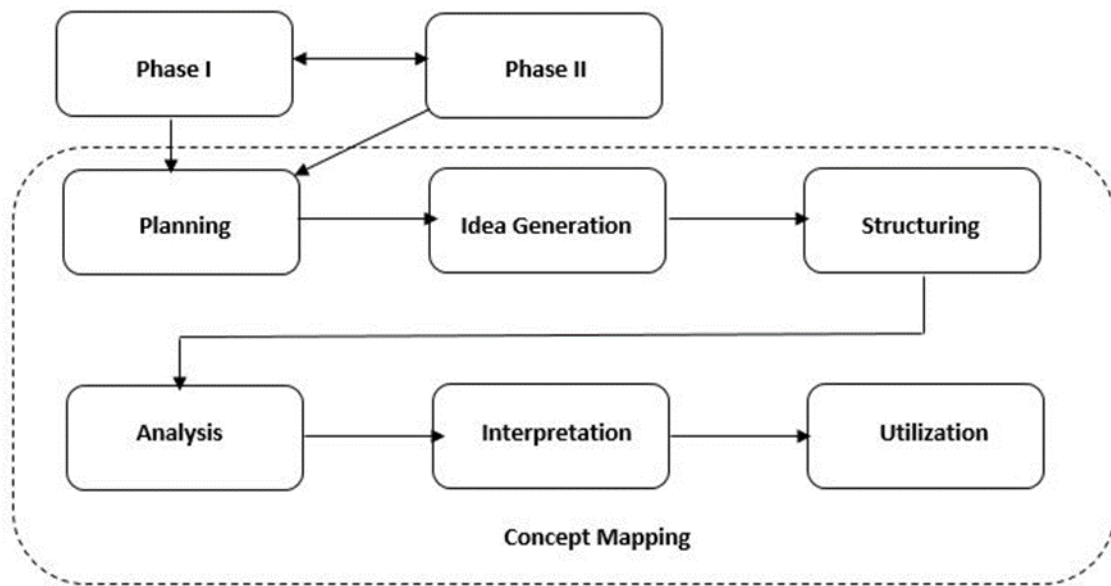
For the older adult and caregiver groups, in-person recruitment, posted recruitment flyers and ‘gatekeepers’ were also used in order to recruit a diverse sample to participate. Depending on location, different individuals (such as community workers and health care providers in targeted long term care homes) acted as ‘gatekeepers’, approaching potential

participants on behalf of the research team. Diversity here was mainly achieved in living situation (e.g., congregate vs. community living), age, and health status.

6.3.2 Six phases of Kane and Trochim's (2007) CM

Concept mapping involves six steps: planning, idea generation, structuring, analysis, interpretation, and utilization (Kane and Trochim, 2007). Figure 6.3.2.1 below provides an overview of the phases conducted as integrated within the broader ECOTECH study.

Figure 6.3.2.1: Methods flow diagram



6.3.2.2 Planning

Building on learnings from earlier phases of ECOTECH, the CM process began with outreach to stakeholders to discuss the project. The sample size for the first step of this phase was n=10 (Krueger & Casey, 2009) for the core group of stakeholders. The author acted as a facilitator throughout this process, following best practice guidelines

(Kane and Trochim, 2007) and training received from Concept Systems (2015). Using the results and themes generated in Phase II of ECOTECH, initial conversations helped to provide conceptualization of the key research questions and information about the project to stakeholders. A draft focus prompt was presented at this time to the group as a starting point for conversation.

Following this introduction to the project stakeholders were guided to work together in a small group format to i) improve the draft focus prompt which was used in the idea generation phase; ii) decide on the foci for the rating activity; and iii) identify potential participants for the following phases. An example of an improvement to the draft focus prompt was the removal of the term “Regional Health Innovation Ecosystem”. Through discussion this was deemed to be jargon, which would be challenging for some participants to understand. The group settled on the term “community” to reflect the idea of regional innovation ecosystems.

Through an iterative process in collaboration with the core stakeholder group members and thesis committee members, the following introduction and focus prompt were created. These were piloted with a small group of stakeholders for readability and clarity:

Introduction: This project aims to expand our understanding of how communities can engage older adults and their caregivers in meaningful ways in innovation for health and aging. Specifically, with this brainstorming activity, our goal is to use your insight and experience to better understand how older adults and their caregivers can contribute to ensure that they are active participants in innovation that helps meet their needs related to health and aging.

Focus Prompt: “A specific way that older adults and their caregivers can help our communities develop innovative technologies to support health and aging is...”

Discussion and collaboration also confirmed the two areas of interest for the rating activities: importance and feasibility. Stakeholders felt that these commonly used foci were appropriate for this project as they would be beneficial in determining next steps for implementation of brainstormed ideas. Because of the ambiguity of the idea of feasibility, discussion took place about key factors involved in feasibility such as social acceptance and financial/ economic appropriateness that would be used to explain to stakeholders the definition for this project.

6.3.2.3 Idea Generation

The goal of this phase was to generate the data that will be used throughout the remaining stages of CM. This phase is usually, but not necessarily, accomplished through brainstorming, either live or virtually over the Internet (Jackson & Trochim, 2002). Participants were asked to brainstorm ideas in response to the focus prompt generated in the planning phase. In person participation was offered as an option to older adult participants. Once participants consented to be involved they were asked about their desired platform of participation. In the case of in-person participation, a focus group (n=8) was conducted to collect data on brainstormed ideas. The focus group was recorded and transcribed verbatim. Ideas generated from the focus prompt were entered into the Concept System software (2015) manually.

Other stakeholders were asked to participate in the idea generation phase through the online brainstorming option. This activity was available from August 11th 2016 to September 6th 2016. Participants were asked to log into the Concept System software and

share their ideas in response to the focus prompt. After acceptance of the consent, the following three steps were followed by participants:

- i) In the text box provided, participants wrote a statement that completed or answered the brainstorming question. Participants were encouraged to add as many statements as they desired. They were asked to keep each statement brief, with just one thought per statement. A word limit of 150 was suggested for each statement;
- ii) Participants selected the “add this statement” option after each statement or idea. Their statement was then saved and added to the list of collected statements at the bottom of the page;
- iii) Participants were asked to review the other statements to see if their idea had already been included. They were able to search the list of collected statements using the search function provided.

Following best practice guidelines for this phase, ideas generated from phases I and II of the project were manually entered into the system by the author. Themes from these phases were broken down into their most basic ideas, and jargon was avoided for clarity and understanding by all stakeholder groups. For example, the idea of “living labs” emerged in phase I as a mechanism for end user engagement in RIEs. When discussing this term with the core stakeholder group it was determined that although the underlying ideas of participant involvement in co-design of innovations was important, the term itself would not be clearly understood by many of the expected stakeholders, especially older adults and their caregivers.

6.3.2.4 Sorting

Previous CM studies have found that the idea generation phase often produces a number of statements that may overlap or not directly respond to the focus prompt (Concept Systems Facilitator Training, 2015). A sorting sub-phase, or “idea analysis” is therefore suggested after the closure of the brainstorming activities to clean the data and to “slim down” the concepts generated to no more than 100 ideas, as suggested in the Concept Systems Facilitator Training (2015). Due to the needs of the stakeholder populations engaged in this project, it was determined in consultation with committee members that this project should have fewer than the maximum 100 statements. The brainstormed ideas were organized using Excel to remove duplicates and amend wording for clarity of ideas. Statements were then coded in NVivo by key themes to ensure that the final list of statements was true to original participant content and concise.

A total of 83 statements were generated through the brainstorming phase. Analysis revealed key themes including systemic changes, individual approaches, collaborations, improvements to current practice, novel ideas and methods, and processes central to older adult engagement in RHIEs. After further thematic analysis and duplication removal, 62 individual statements were kept for the next phases of sorting and rating ideas (see Table 6.4.4.3 for list of statements).

6.3.2.5 Structuring

Once the final list of idea statements was generated, participants were asked to participate in two structuring activities: sorting and rating, which took place from September 7th to October 11th 2016. An appropriate minimum sample size for this phase is between 20 and 30 participants (Rosas & Kane, 2012). It is recognized that this sample

size can be challenging to achieve with stakeholders who are less familiar with using online software systems, such as some older adults and their caregivers (Hanson et al., 2013). The sorting activity is a more time-consuming and higher level activity than the other phases as it requires a more in-depth grasp of content. Therefore, not everyone who participates in the rating activity is expected to sort the ideas (Concept Systems, 2015).

This process was completed in The Concept System software (2015) for the majority of stakeholders by first organizing the idea statements into categories and labelling each category with a theme they found appropriately described the grouping (Kane & Trochim, 2007). Participants were asked three demographic questions; they then followed the steps below.

Sorting instructions

In this activity, participants were asked to categorize the statements, according to their view of meaning or themes. To do this, they were asked to sort each statement into piles in a way that made sense to them by:

- i) Reading through the statements in the Unsorted Statements column on the left of the screen;
- i) Sorting each statement into a pile they create;
- ii) Grouping the statements for how similar in meaning or theme they are to one another. They were asked to avoid creating piles according to priority, or value, such as 'Important', or 'Hard To Do';
- iii) Giving each pile a name that describes its theme or contents;
- iv) Putting a statement alone in its own pile if it is unrelated to all the other statements;

- v) Making sure every statement is put somewhere. They were asked not to leave any statements in the Unsorted Statements column.

Participants vary in how many piles they create, but The Concept Systems Training (2015) suggested that between five to 20 piles works well to organize statements. For older adult participants and others who do not feel confident with the software, Kane and Trochim (2007) describe a few options for participation in this phase. Interested older adults were convened and an in person manual sorting process was facilitated using the same process that was conducted online but with cards identifying each idea statement. Some participants finished their sorting early and worked on rating sheets at the meeting, while others took the rating activity home with them and returned the completed response by mail or in person at a later date. Other older adults who were recruited to participate but who did not have the ability to travel to the in-person sorting and rating session were sent rating sheets and or were met with in person at a location of their convenience (e.g., in one case in a long-term care facility) to participate in the study.

Rating instructions

Following the completion of the sorting activity based on similarities, participants were asked to rate each of the idea statements. The rating foci generated in the planning phase were used to ask participants to make judgements about each statement. Ratings were designed with Likert response scales and instructions for the activity encouraged participants to make a relative judgement on the value of the statements. Throughout this phase a consultant from Concept Systems Global was helpful in sharing experiences and best practices in recruitment strategies.

6.3.2.6 Analysis

Once the structuring phase was complete, analysis was conducted using the Concept Systems software. Multivariate statistical techniques including Multidimensional Scaling and Hierarchical Cluster Analysis were applied and bridging analysis was conducted to depict results of the sorting activity in map form (Kane & Trochim, 2007).

Streiner, Norman and Cairney (2015) discuss the process of multidimensional scaling as a mechanism to index how “close” ideas are to each other and to understand the underlying dimensions through an evaluation of this nearness. Multidimensional scaling is useful in revealing underlying patterns to understand relationships in data and to reduce a large number of variables into a smaller number of factors (Streiner et al., 2015). The Concept System software (2015) created a similarity matrix as the basis for the two-dimensional multidimensional scaling that was run to map the brainstormed statements into a two-dimensional (X, Y) plot (Kane & Trochim, 2007). The output of this analysis was a “point map” consisting of dots representing brainstormed statements. Quality of this analysis was assessed by a stress index. Stress here was measured by the discrepancy between the distances of points on the map and their original value in the similarity matrix. This value was used to determine the degree to which the map represents the grouping data; meta-analysis has revealed that an ideal stress value should range between 0.205 and 0.365 (Kane & Trochim, 2007).

The Concept System software (2015) was then used to apply hierarchical cluster analysis as described by Kane and Trochim (2007) to group individual statements into clusters. A key decision in this analysis was the number of clusters to apply; the author decided on the final number of clusters appropriate for the final map by first deciding on

upper (20 clusters) and lower (4 clusters) limits to the desired number of clusters and then working with committee members to “find the cluster level that retains the most useful detail between clusters while merging those that in the context sensibly belong together” (Kane & Trochim, 2007, p.103). An agglomerative method (Kane and Trochim, 2007) was then applied by merging statements together at each stage of cluster analysis and reviewing the merging at each stage to observe how the statements were clustered.

When agglomeration was determined to best represent the data, two cluster options emerged as being the most suitable to describe the data; a seven cluster and a ten cluster solution (see Appendix E for ten-cluster solution). Team member discussion was important here in determining which map would be the most appropriate; factors that were considered in deciding between the two maps included: audience for the final product, expected and anticipated use of the map, and level of detail acceptable for this project.

Mathematically, the Concept System software provides a numerical value called a “bridging value” that was useful in this process as well as in later interpretation of the map. The bridging value was calculated for both individual statements and for clusters as a number between zero and one. Bridging values assist in understanding the relationships between the statements in a concept map. Bridging values that are higher (closer to one) indicate that a statement “bridges” areas of the map, meaning that it is a link between more distant areas of the framework. Lower bridging values (closer to zero) indicate an anchor in the map, or a statement that was sorted by many people along with others that are more immediately adjacent to it. Anchor statements are suitable to explain the

position of content within a certain area of the framework. These values are also calculated by cluster to help with interpretation of the relationships at a higher level.

Because the decision process on determining the final number of clusters in a map has been described by Kane and Trochim (2007) as challenging with a large number of participants, two mechanisms were used to gather feedback and member check the chosen seven cluster solution before the final solution was determined. Two conference poster presentations to stakeholders representing research, industry, policy, and older adults and their caregivers were undertaken. For these presentations, the seven cluster solution was chosen to gain feedback on the preliminary framework and to understand if more detail would be appreciated by these stakeholder groups. The second mechanism to gather feedback on the framework was a core stakeholder meeting (n=6) at which the seven cluster model was presented and discussed with question prompts to gain an understanding of whether the solution was appropriate and to understand usability. Opinions from both activities demonstrated satisfaction with the framework and ensured that there was no need for further detail. The final product was therefore a seven cluster map representing a framework of priorities for the engagement of older adults and their caregivers in RHIEs, which was determined by the researchers and core stakeholder group to offer the most conceptual clarity.

6.3.2.7 Interpretation and Utilization

Once the final cluster map was chosen, tools generated from The Concept System software (2015) such as Pattern matches and Go-zones were generated from the rating data. Pattern matching as described by Kane and Trochim (2007) commonly uses a ladder graph to show correlations between a chosen pair of rating values. This graph displays

lines connecting cluster rating values on a pair of scales (commonly demographic groups or rating foci). A Pearson product moment correlation is presented to show the overall strength of correlation.

To interpret the relative ratings of the individual statements both by cluster and by the full map, go-zone graphs are used. These bivariate X-Y graphs display quadrants created using the means for each rating variable (Kane and Trochim, 2007). “Go-zones” refer to the upper right quadrant where the statements with the highest relative importance and feasibility ratings are found. This go-zone quadrant on the graph gets its name from the implications for planning and implementation, where high ratings values usually indicate the most actionable ideas (Kane and Trochim, 2007).

These tools were useful in describing the framework of priorities and can be used to help build consensus on action for next steps for this project such as the use of the model (Kane & Trochim, 2007). A final meeting with the core stakeholder group was conducted to understand best approaches for knowledge translation and usability of the results.

This study received ethics clearance from the Office of Research Ethics at the University of Waterloo (#21329) and all participants provided informed consent to participate in the project.

6.4 Results




The results section begins with a summary of participant demographics. Results of sorting analysis are presented next through maps produced from the sorting activities of the structuring phase. Following this, tools for interpretation of the results from the rating activities are presented including rating scores, pattern matches and go-zones.

Figures 6.4.1 to 6.4.3 below provide description of stakeholders that participated in the phases of CM except the brainstorming activity. As recommended by the CM methodology, the brainstorming activity was conducted anonymously to encourage creativity and flexibility in response so demographic data are not presented for this phase.

Figure 6.4.1: Description of sorting participants

n= 28

Gender

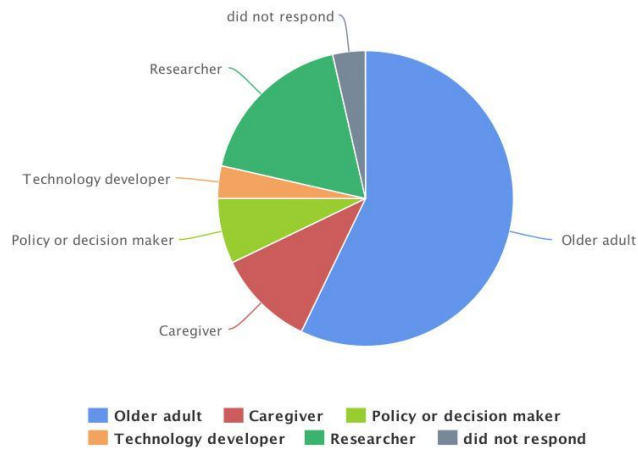
Participant Question	Option or Statistic	Frequency	%
Gender	 Female	19	67.86%
	 Male	8	28.57%
	Other		
	 did not respond	1	3.57%
		28	100.00%

Age

Age	Minimum:	30
	Maximum:	83
	Count:	26
	Low:	31
	High:	77
	Median:	66
	Mode:	68
	Average:	59.77
	Std. Dev.:	15.67
<i>did not respond:</i>		2

Role

Role	 Older adult	16	57.14%
	 Caregiver	3	10.71%
	 Policy or decision maker	2	7.14%
	Healthcare provider		
	 Technology developer	1	3.57%
	 Researcher	5	17.86%
	 did not respond	1	3.57%
		28	100.00%



Level of Engagement

Level of engagement	Frequency	Percentage
Limited engagement	7	25.00%
Moderate engagement	7	25.00%
Meaningful engagement	13	46.43%
did not respond	1	3.57%
Total	28	100.00%

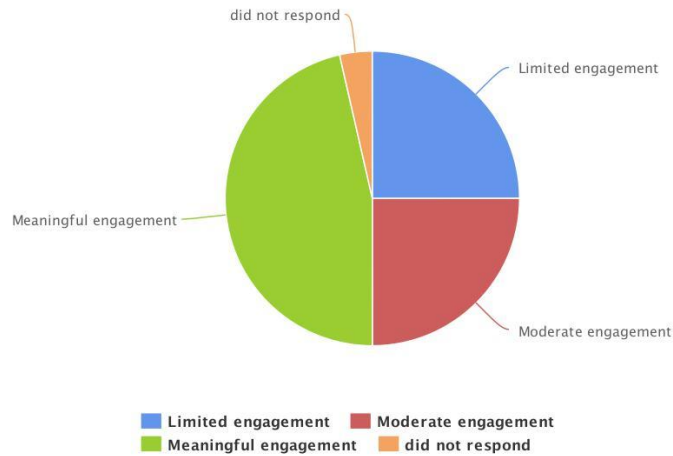


Figure 6.4.2: Description of importance rating participants

n= 31

Gender

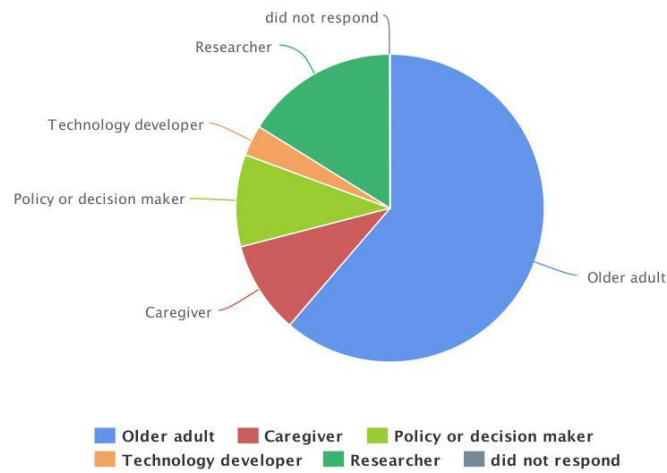
Participant Question	Option or Statistic	Frequency	%
Gender	Female	21	67.74%
	Male	10	32.26%
	Other	0	0.00%
	did not respond	0	0.00%
		31	100.00%

Age

Age	Minimum:	30
	Maximum:	91
	Count:	30
	Low:	31
	High:	83
	Median:	68
	Mode:	68
	Average:	62.60
	Std. Dev.:	16.42
	did not respond:	1

Role

Role	Count	Percentage
Older adult	19	61.29%
Caregiver	3	9.68%
Policy or decision maker	3	9.68%
Healthcare provider	0	0.00%
Technology developer	1	3.23%
Researcher	5	16.13%
did not respond	0	0.00%
Total	31	100.00%



Level of Engagement

Level of engagement			
	■ Limited engagement	10	32.26%
	■ Moderate engagement	10	32.26%
	■ Meaningful engagement	11	35.48%
	□ did not respond	0	0.00%
		31	100.00%

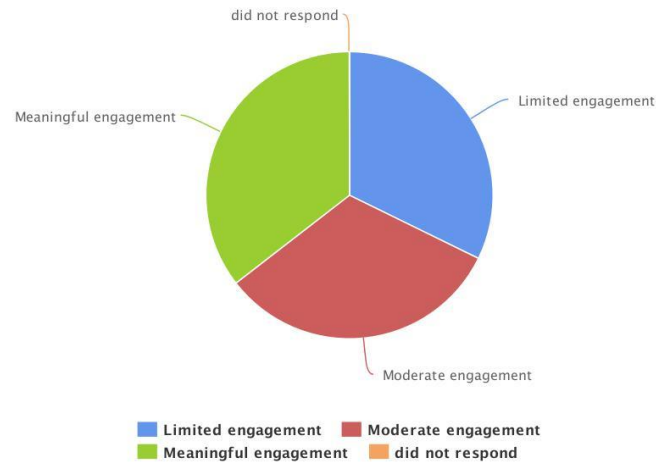


Figure 6.4.3: Description of feasibility rating participants

n= 24

Gender

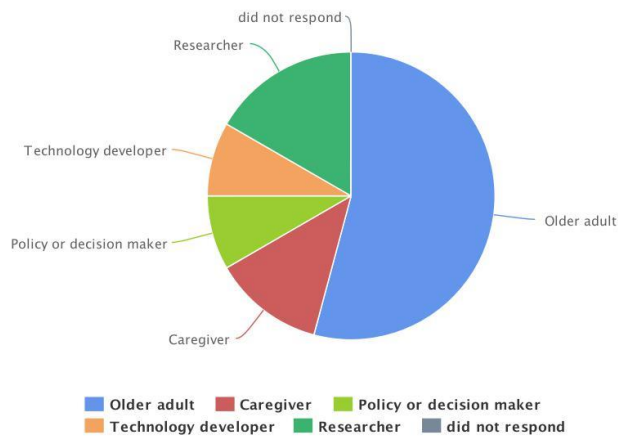
Participant Question	Option or Statistic	Frequency	%
Gender	■ Female	14	58.33%
	■ Male	10	41.67%
	Other		
	□ did not respond	0	0.00%
		24	100.00%

Age

Age	Minimum:	30
	Maximum:	83
	Count:	23
	Low:	31
	High:	82
	Median:	63
	Mode:	77
	Average:	60.22
	Std. Dev.:	16.41
	did not respond:	1

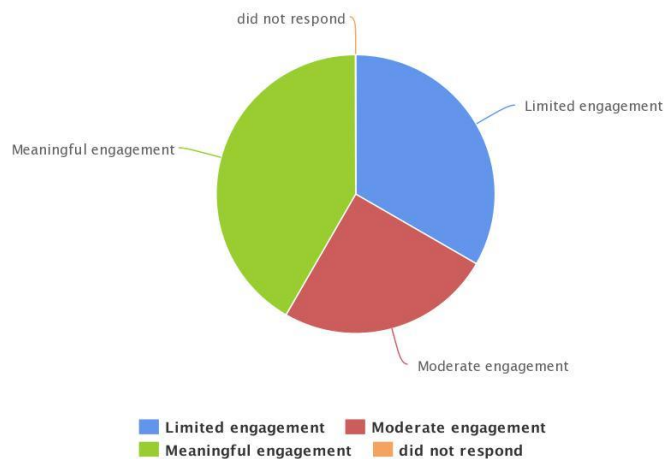
Role

Role	Count	Percentage
Older adult	13	54.17%
Caregiver	3	12.50%
Policy or decision maker	2	8.33%
Healthcare provider	0	0.00%
Technology developer	2	8.33%
Researcher	4	16.67%
did not respond	0	0.00%
Total	24	100.00%



Level of Engagement

Level of engagement	Count	Percentage
Limited engagement	8	33.33%
Moderate engagement	6	25.00%
Meaningful engagement	10	41.67%
did not respond	0	0.00%
Total	24	100.00%



Participation varied between the three activities where demographic information was gathered with 28 participants sorting, 31 participants rating importance, and 24 participants rating feasibility. The age range across the activities was between 30 years old and 91 years old. Consistent with Canadian demographics among older adults (Statistics Canada, 2011) the gender proportion was over 60% female in the first two activities. When participation dropped in the third activity this proportion dropped slightly to 54% female participants which was expected as the proportion of those self-identifying as older adults also decreased for this activity.

The distribution of stakeholders remained consistent across the activities, with the highest representation of those choosing to identify in the role of “older adult”. It is important to note that these demographics were self-reports and participants were asked to choose only one role. Amongst Triple Helix stakeholders, the chosen response was sometimes surprising to the researcher with consequences for the data. For example, none of the participants self-identified as a health care provider even though some participants were recruited because of this role; they also had another role (e.g., researcher) and chose this as representative of their perspective.

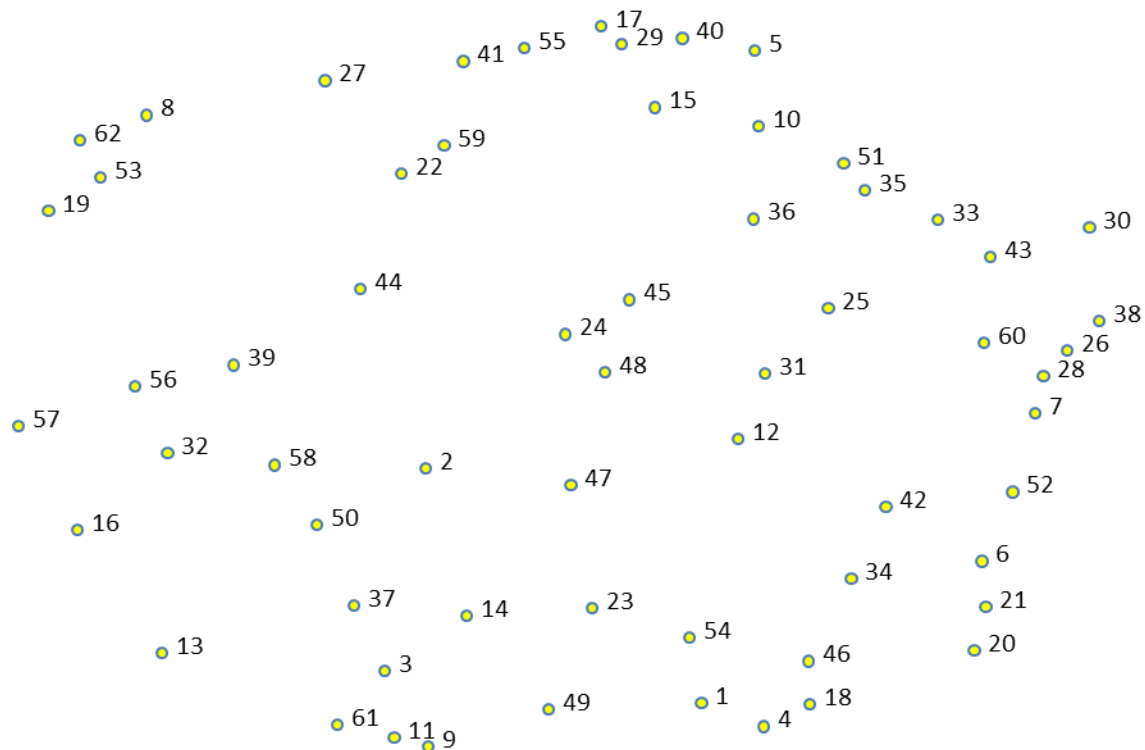
Ideal sample size as described by Rosas and Kane (2012) of a minimum range of 20-30 participants was achieved for all of the activities. The rating of feasibility activity achieved the lowest participation rate. Interestingly this activity retained fewer participants than the activity anticipated as being most challenging for recruitment, the sorting activity. Lower participation in this activity can be understood as due to i) drop off as this was the third of three activities and ii) relative complexity of the idea of feasibility. Trends in self-reported levels of engagement of participants’ in their local

RHIE support this explanation with higher proportions of “meaningfully engaged” participants in the sorting and rating of feasibility activities. These trends indicate that those who considered themselves to be more meaningfully engaged in RHIEs were more likely to participate in the more challenging activities and remain invested in the project through to completion.

6.4.4 Sorting

Analysis of the sorting activity, through multidimensional scaling of the 62 statements sorted by participants, revealed the point map presented in Figure 6.4.4.1 below. This map graphically displays how closely related each of the statements are to each other. Interpretation relies on relative distance with statements placed within the map to represent a geography of the ideas that were sorted.

Figure 6.4.4.1: Point map



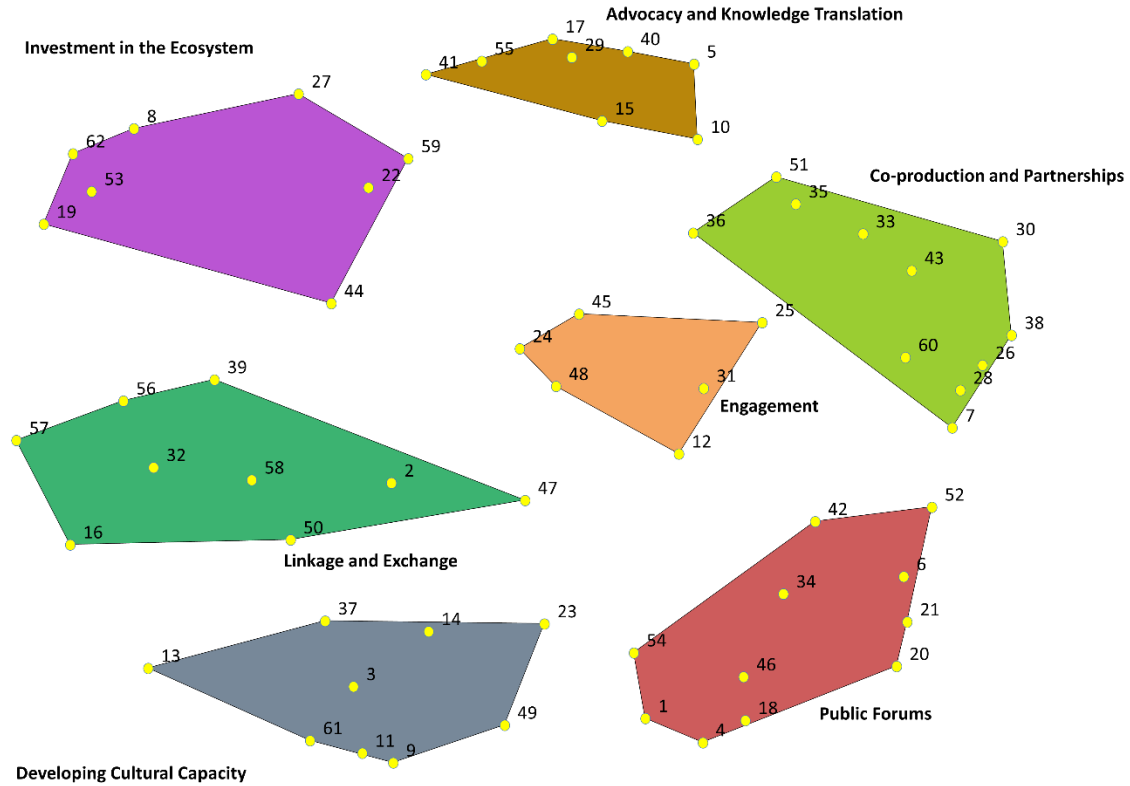
After 16 iterations and a condition of one relationship, this map yielded an acceptable final stress value of 0.350. In this phase of concept mapping, a filter in the form of a condition in the number of relationships can be used to ensure the data remains meaningful, or limits the amount of noise in the data. The condition of one relationship was chosen to specify a similarity cut-off value. In the analysis, values in the similarity matrix that were at or below the cut-off value of one were set to zero for the analysis. If only one user placed two statements together in a pile, the analysis kept it as though no users placed the statements together. This condition filters out spurious relationships between statements, and ensures that “noise” was limited in the sorts. The Concept Systems training suggests that cut-off values should be less than two unless there are a large number of available sorts for the analysis.

The stress value of 0.35 falls in the high range of normal and is consistent with the known complexity of the research topic (Kane and Trochim, 2007; Rosas and Kane, 2012). In this map, each point represents an individual statement with similar ideas located closer to each other on the map and less similar ideas located further apart.

The statements were then statistically clustered into similar ideas or concepts using hierarchical cluster analysis. Following discussion with thesis committee members and the core stakeholder group a seven cluster framework of priorities was determined to best represent the data as presented in the cluster map in Figure 6 below.

6.4.4.2 Figure 6: Cluster map

ECOTECH Framework of Priorities for Engaging Older Adults and their Caregivers in RHIEs



This map demonstrates the major concepts and interrelationships of ideas as expressed by participants. When interpreting the map, it is important to remember that the closer the points are on the map, the more frequently they were interpreted by participants as being related. There is a difference between clusters in their density, or how close the individual statements were mapped. Clusters that are denser, with points closer together indicate more similarity between the ideas. Clusters where the statement points are further apart are more conceptually disparate.

This graphical representation or map expresses the framework of priorities in the language of the participants as “cluster labels”. These labels were chosen with assistance

from the content analysis performed on the suggestions from participants. This content analysis is a function built into the Concept Systems software which looks for themes and patterns in the labels suggested by participants. Labels are ranked for interpretation by the analyst to assist with cluster labelling. Bridging values were also used to finalize cluster labels. The statements with the lowest bridging values, indicating that they were sorted predominantly with statements close by, were used as a guide to label the theme for each cluster. Bridging values of the individual statements within each cluster are reported in Table 6.4.4.3. As displayed in Figure 6, the following seven cluster labels were chosen: public forums, co-production and partnerships, engagement, linkage and exchange, developing cultural capacity, advocacy and knowledge translation, and investment in the ecosystem.

Table 6.4.4.3: Statements by cluster with bridging values

Cluster	Statement	Bridging Value
Public Forums		0.34
	54. create an accessible seniors' information centre.	0.23
	46. provide opportunities for older adults and caregivers to become educated in basics of research methods.	0.25
	42. interact with students to get them interested in health and aging innovation.	0.27
	1. begin a public forum where older adults can nurture an innovation ecosystem from within.	0.28
	34. have a place in the community where seniors and their caregivers are encouraged to go to share their ideas and or experiences related to health and aging.	0.28
	4. join or start online discussions about health and aging innovation.	0.32
		0.35
	0.38	

	<p>21. by attending workshops and events related to innovation in health and aging.</p> <p>18. seek out information on innovation in health and aging to stay up to date.</p> <p>6. provide options to participate remotely in discussions with those involved in innovation.</p> <p>20. participate in conferences about health and aging.</p> <p>52. share their opinions at local technology pitch events related to health and or aging.</p>	<p>0.43</p> <p>0.46</p> <p>0.49</p>
Co-production and partnerships	<p>36. have residents of long term care be involved in their facility's ethics committees to make decisions about projects taking place related to innovation.</p> <p>33. have seniors' care facilities involved in research on innovation in health and aging.</p> <p>60. become a partner on research and or innovation development teams.</p> <p>43. get involved in decisions related to the creation of new innovations for health and aging.</p> <p>35. get involved in resident councils in long term care or assisted living to raise issues of innovation and technology development.</p> <p>51. develop partnerships between groups interested in health and aging innovation.</p> <p>28. by volunteering with an organization within the ecosystem.</p> <p>26. getting involved with research projects about innovation in health and aging.</p> <p>7. caregivers with experience who are no longer active in their role can provide input to those involved in innovation.</p> <p>38. get involved in innovation projects early (e.g., from planning phases) to that opinions can have an impact.</p>	<p>0.00</p> <p>0.13</p> <p>0.22</p> <p>0.26</p> <p>0.27</p> <p>0.35</p> <p>0.36</p> <p>0.36</p> <p>0.40</p> <p>0.42</p> <p>0.47</p>

	30. to get involved in innovation from planning stages in healthcare to set the innovation agenda.		
Engagement	<p>45. involve care providers who develop relationships with older adults and caregivers in innovation.</p> <p>31. identify older adults who are technology "super users" and engage them in implementation processes.</p> <p>12. video older adults performing daily tasks and share this with those in innovation ecosystems to show them our difficulties.</p> <p>48. involve older adults and caregivers in dialogue with technology companies to influence their technology development.</p> <p>24. brainstorm ideas for innovation to support health and aging, using "techies" and health care providers as advisers when needed.</p> <p>25. innovators should make personal visits to older adults and their caregivers to understand their needs and or issues.</p>	0.00	0.06
Linkage and Exchange	<p>47. give older adult and caregiver groups the contact information of local companies engaged in community and technology innovation with specific areas of their development to contact and offer input.</p> <p>2. for developers to recognize the diversity of the older adult population in terms of technology use.</p> <p>50. video caregivers performing daily tasks and share this with those in innovation ecosystems to show them the difficulties of caregiving.</p> <p>39. give local companies engaged in community and technology innovation the contact information for all older adult and caregiver groups so that they</p>	0.06	0.51
		0.16	
		0.31	
		0.37	

	<p>can contact them for their feedback on research and product development.</p> <p>58. collect feedback from various stakeholders to evaluate innovation collaboration efforts.</p> <p>56. gather information from senior community centres about innovation needs in health and aging.</p> <p>32. test existing technologies and give feedback on usability.</p> <p>16. empower care providers that work with older adults and caregivers so that they can innovate.</p> <p>57. encourage communication between those interested in innovation (e.g., researchers, government, business, older adults and caregivers).</p>	<p>0.44</p> <p>0.64</p> <p>0.75</p> <p>0.83</p> <p>1.00</p>
Developing Cultural Capacity	<p>23. advertise opportunities for seniors and caregivers to give their input on innovation in local media outlets.</p> <p>49. use local media outlets (cable and radio) to engage older adults and caregivers about innovation for health and aging.</p> <p>14. coach or mentor others in the ecosystem.</p> <p>11. work to remove the mystique and fear from use of technology.</p> <p>37. teach those involved in the local ecosystem how to attract the attention of older adults and their caregivers.</p> <p>9. support seniors who are not tech savvy to use computers to access information related to health and aging.</p> <p>3. for researchers to keep older adults informed on the results of their involvement in innovation.</p> <p>61. setting up peer networks for seniors to learn technology.</p> <p>13. use social media to raise awareness of issues in health and aging innovation.</p>	<p>0.12</p> <p>0.30</p> <p>0.31</p> <p>0.36</p> <p>0.37</p> <p>0.40</p> <p>0.41</p> <p>0.43</p> <p>0.81</p>
		0.39

<p>Advocacy and Knowledge Translation</p>	<p>15. tell associations (e.g., Cancer, Alzheimer's, ALS) to spend some of their time/resources identifying technology solutions currently available to help deal with day to day activities. 29. advocate for innovation from other communities to be applied locally. 17. talk to local government representatives about experiences in health and aging. 40. advocate to local health and social care decision-makers about innovation in health and aging. 10. create advocacy groups for older adults and caregivers interested in health and aging innovation. 5. to get involved with local health decision making network (such as the LHINs in Ontario) to raise issues related to innovation in health and aging. 55. advocate to change the status quo of finished products being imposed on seniors. 41. advocate for universal access to internet for everyone.</p>	<p>0.32</p> <p>0.24</p> <p>0.28</p> <p>0.28</p> <p>0.28</p> <p>0.29</p> <p>0.31</p> <p>0.40</p> <p>0.50</p>
<p>Investment in the Ecosystem</p>	<p>44. ensure that interested staff members involved in seniors' care have an opportunity to provide perspective on innovative technologies. 59. encourage local organizations working on innovation in health and aging to consult with older adults and caregivers. 22. reach out to local business association about innovation in health and aging. 8. for financial incentives to be provided to companies engaging the input of seniors and caregivers. 27. advocate for the flow of information directly from seniors and their caregivers to those who can address the issues at hand.</p>	<p>0.56</p> <p>0.25</p> <p>0.28</p> <p>0.28</p> <p>0.64</p> <p>0.66</p> <p>0.69</p>

	62. for incentives (other than financial) to be provided to companies engaging the input of seniors and caregivers. 53. support investment in evidence based solutions. 19. to give seniors a small payment of appreciation for their involvements in the ecosystem.	0.73 0.94
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The seven clusters demonstrate a comprehensive range of thought with engagement as a central link to this framework. This configuration suggests that the specific ideas in the engagement cluster could serve to link the other aspects identified by participants. This map also indicates that perceived mechanisms through which older adults and their caregivers could be engaged in RHIEs can be understood in at least seven distinct areas that could be addressed at policy and planning levels.

The core stakeholder meeting to discuss the final cluster solution revealed some important input into the usability of the framework. The core stakeholder group confirmed that the cluster labels were representative of the ideas they sorted and that the seven cluster map was appropriate. There was also a discussion of the explanation of the necessity of retaining the original numbers when listing items in each cluster. This discussion was helpful in understanding how best to display that information for other knowledge translation initiatives.

6.4.5 Description of clusters in framework of priorities

Public Forums

The first cluster, **public forums**, includes 11 statements. The bridging value of this cluster is 0.34 with individual statement values ranging from 0.23 to 0.49. The ideas sorted in this cluster are related to the idea of place. Many of the statements connect ideas

about having a physical place for interactions within the innovation ecosystem. Within this place, opportunities for events and activities can occur to increase knowledge capacity of stakeholders. These activities included the provision of research methods training to older adults and their caregivers in case they would like to get involved in a project, conferences and workshops for all stakeholders to gain knowledge about health and aging, and pitch events for interaction and sharing of experiences in health and aging.

Co-production and Partnership

The **co-production and partnerships** cluster is made up of 11 statements about roles and perspectives of stakeholders interacting in the ecosystem. The bridging value of this cluster is 0.29 and statement bridging values range between 0.00 and 0.47. The statement with the 0.00 bridging value, the lowest bridging value in this cluster, sorted primarily with other statements close by, has a theme of increasing older adults' decision making abilities and was used as a guide to label the theme for this cluster. Ideas in this cluster represent opportunities for co-production that vary in involvement of stakeholders with the idea of partnerships and having a shared responsibility for innovation. Some older adults and their caregivers would like to partner in innovation (e.g., from planning stages) and others would like to be involved in the more traditional role of a volunteer within an organization which was seen here as being a part of the partnership spectrum for co-production in RHIEs. There is a diverse use of technology among older adults, so it is important to have older adults and their caregivers involved in testing and interacting with technologies created to support their needs.

Engagement

With a cluster bridging value of 0.06, the **engagement** concept is the anchor for this map. Through multiple iterations, the sorting of statements within this cluster stayed central to the framework. The low statement bridging values ranging from 0.00 to 0.14 indicate that the six statements that make up this cluster were frequently sorted with each other. Engagement, the cluster title, remained the same as that identified by the Concept Mapping Global System as recurrently described by participants' sort labels. Statements in this cluster included ideas of interactions between stakeholders, opportunities to understand and learn from older adults and their caregivers, brainstorming, and dialogues between stakeholders involved in innovation.

Linkage and Exchange

In contrast, the **linkage and exchange** cluster is found to be a bridging cluster. With a bridging value of 0.51, ideas here help to link to others in the map. Statement bridging values range from 0.06 to 1.0 among nine statements. The statement with the bridging value of 1.0, "encourage communication between those interested in innovation", highlights the importance of communication to engagement in innovation ecosystems. This cluster is about how connections are made with stakeholders. Statements in this cluster included ideas about feedback and generating connections between stakeholders so that they can have the opportunity to reach out to each other.

Developing Cultural Capacity

The **developing cultural capacity** cluster is made up of nine statements. With a cluster bridging value of 0.39 and statement bridging values ranging from 0.12 to 0.81, this cluster incorporates a range of ideas about the use of media to create awareness,

coaching and mentoring stakeholders in the ecosystem, and other ways to bridge cultural divides. Ideas of media use range from traditional mechanisms of local media advertisements on cable and radio, to more modern social media platforms. Cultural capacity here incorporates the idea of increasing the technological capacity of older adults through peer networks and access to information.

Advocacy and Knowledge Translation

Advocacy and knowledge translation is comprised of eight statements which include ideas about advocating for flow of information, changing the status quo, and getting government and decision makers involved in innovation ecosystems for health and aging. With a bridging value of 0.32 and individual statement bridging values ranging from 0.24 to 0.50, this cluster can be interpreted as another anchor cluster; ideas here were consistently sorted together. This anchor position aligns with the centrality of knowledge translation to engagement activities. In order for older adults and caregivers to be meaningfully engaged in RHIEs they need to have access to information and be able to share their experiences with other stakeholders.

Investment in the Ecosystem

As another bridging cluster, the **investment in the ecosystem** cluster incorporates ideas of creating buy-in in the ecosystem, economic development, and incentives for older adults, their caregivers and companies involved in innovation for health and aging. These ideas link to other clusters, represented with the bridging value of 0.56. The eight ideas in this cluster have statement bridging values ranging from 0.25 to 0.94. This connection demonstrates the support necessary for many of the ideas in this cluster (e.g.,

financial reimbursement and incentives). In order to actualize these there needs to be buy in throughout the RHIE on the importance of the civic society helix.

6.4.6 Rating

Analysis of the two rating activities completed in the structuring phase revealed a number of trends. The point rating maps presented in Figure 6.4.6.1 and 6.4.6.2 below display the statements as revealed in the point map (above) now represented with bars indicating the average rating for each statement.

Figure 6.4.6.1: Importance point rating map

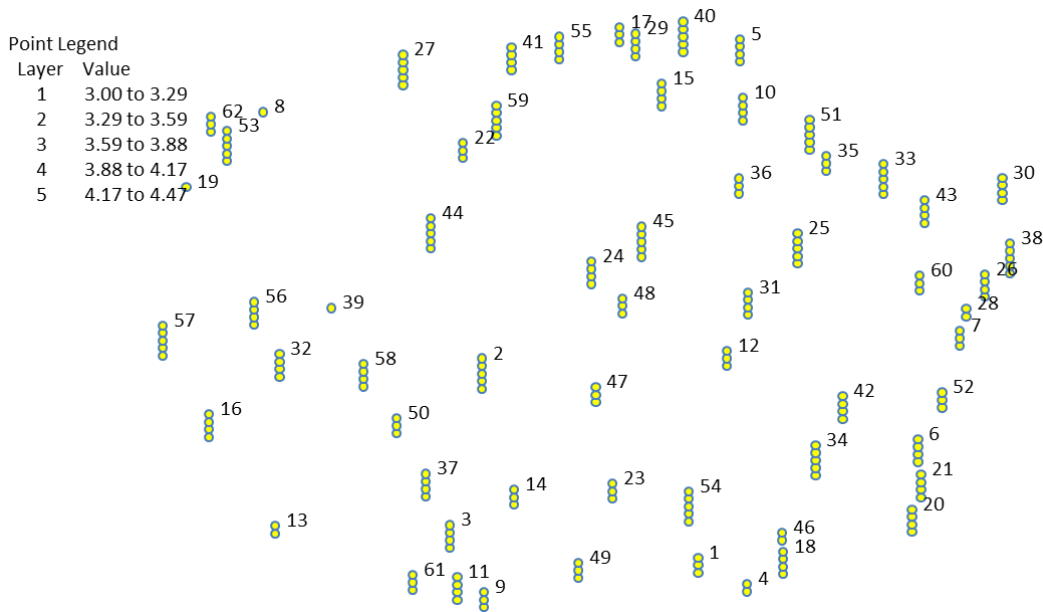
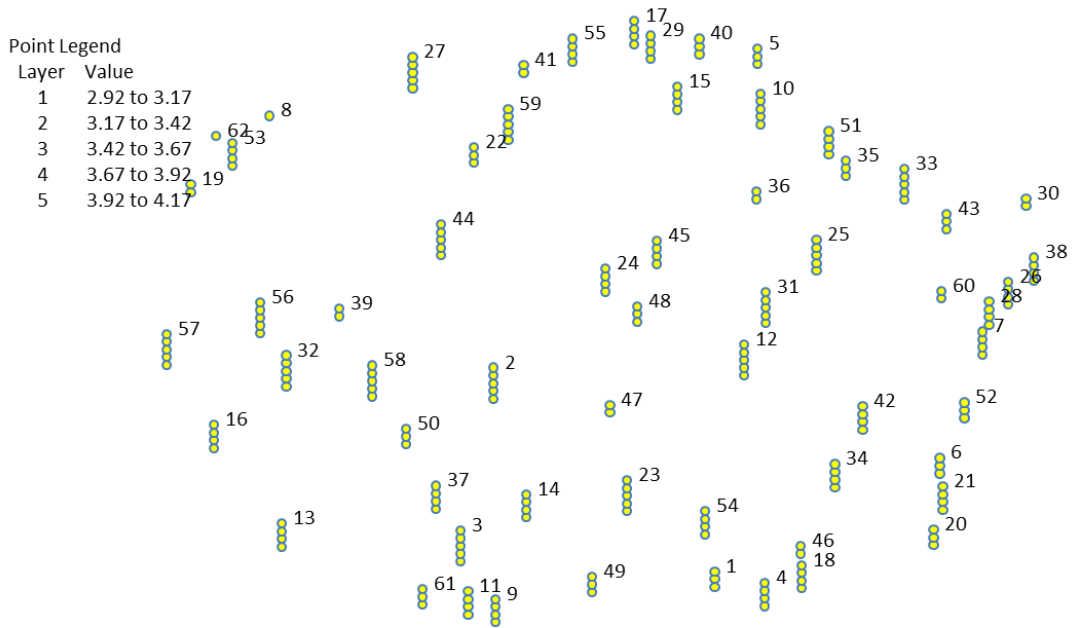
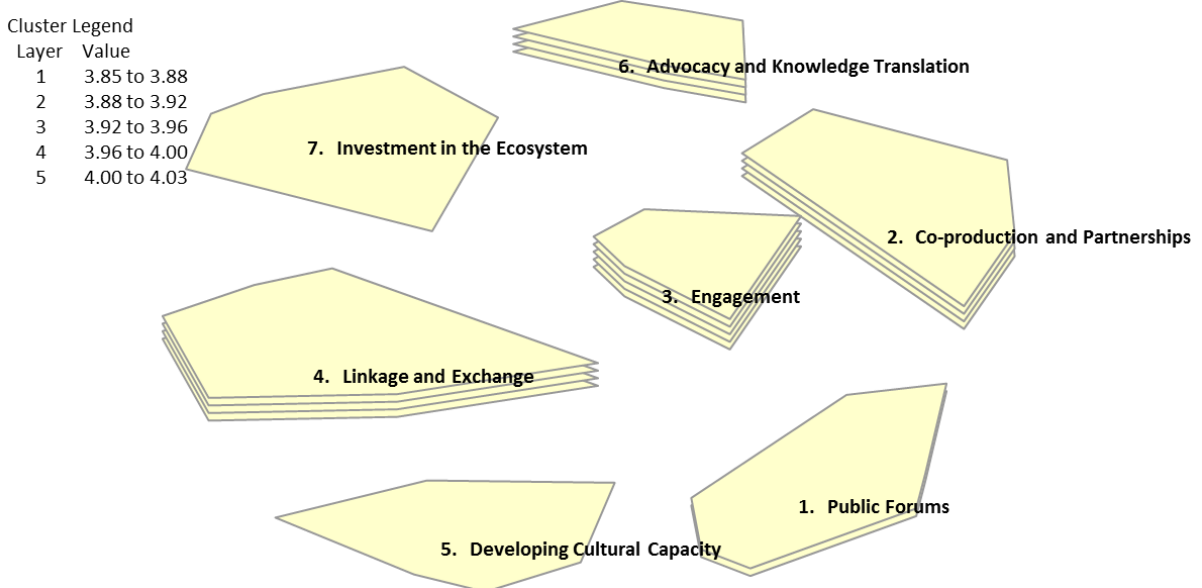


Figure 6.4.6.2: Feasibility point rating map



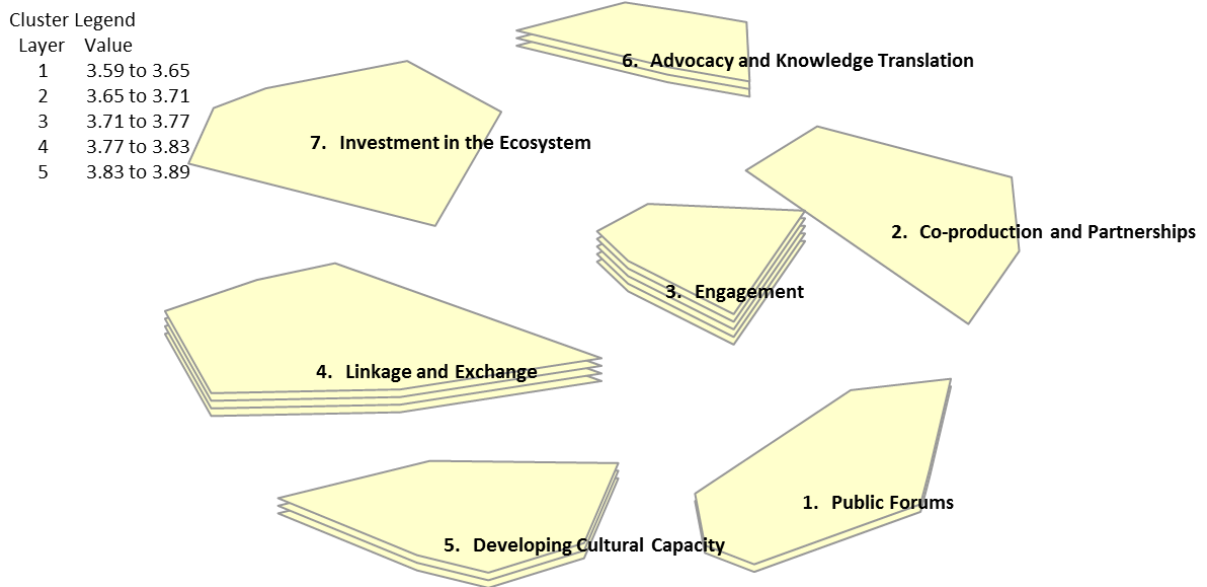
These maps represent the value dimension of the statements, defined by the participants. Patterns in the maps reveal areas that are consistently high and low. Building on these maps, cluster rating maps displayed in Figures 6.4.6.3 and 6.4.6.4 visualize the average ratings by cluster.

Figure 6.4.6.3: Importance cluster rating map



These results reveal that Engagement is considered relatively more important than the other clusters, followed by the Co-production and Partnerships, Linkage and Exchange, and Advocacy and Knowledge Translation clusters.

Figure 6.4.6.4: Feasibility cluster rating map



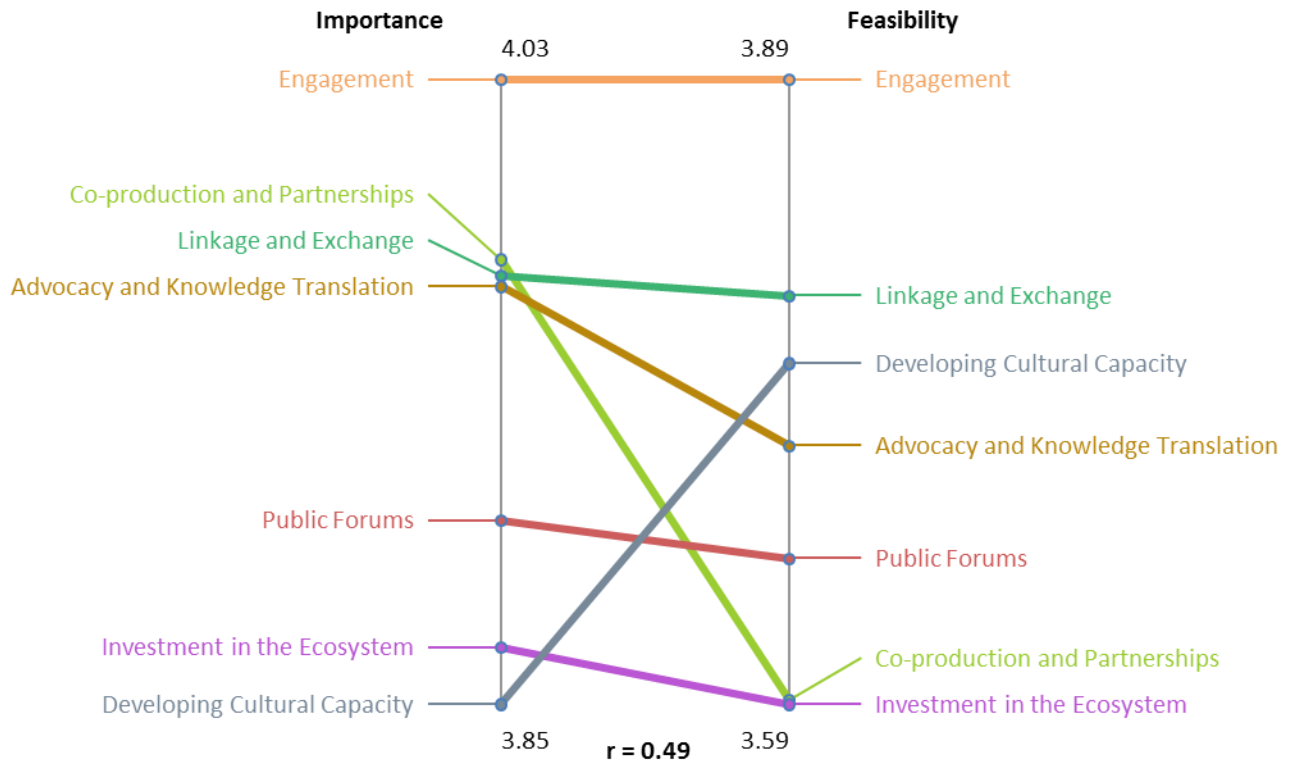
Engagement was rated on average as the most feasible cluster. Co-production and Partnerships, and Investment in the Ecosystem were rated as relatively less feasible. These cluster rating maps provide information to guide interpretation and utilization. For example, although all of the statements in the framework are important, cluster ratings reveal a smaller number which could be understood as priorities. An understanding of feasibility of clusters could point to questions of implementation, guiding further work to understand lower ratings and perceptions. It is important to note however, that in both of the cluster rating maps averages are not always an indicator of the rated values of the individual statements within each cluster. Pattern matching and go-zone maps provide clarity on this point.

6.4.7 Pattern Matching

Pattern matching graphs were created to understand average cluster ratings for the data between both demographic groups and rating variables. Although the sample size was not large enough to compare each stakeholder group individually by ratings of the variables of interest, pattern matches were created to explore differences between older adults and their caregivers with the other stakeholders combined together (researchers, decision-makers, those working in health and aging services, and innovators). The pattern match ladder graph created from the feasibility ratings data of older adults and their caregivers compared to the other stakeholders, indicated a nonlinear relationship, with a correlational value of $r=0.13$. The pattern match comparing the importance ratings data of older adults and their caregivers with the other stakeholders, again indicated no linear relationship, with a correlational value of $r=-0.11$.

The only analysis which produced a linear relationship was that between the rating variables of importance and feasibility, pictured in Figure 6.4.7.1 below. This pattern match indicated an overall moderately positive relationship between importance and feasibility, with a correlational value of $r=0.49$. A summary of this pattern match graph follows.

Figure 6.4.7.1: Pattern match: Importance vs. feasibility



The importance ratings (n=31) ranged higher than those of feasibility (n=24) with cluster importance ratings ranging from 4.03/5 to 3.85/5 and cluster feasibility ratings ranging from 3.89/5 to 3.59/5. A comparison by cluster revealed trends of both discrepancy and agreement between the rating variables. Table 6.4.7.2 displays results of significance testing using unpaired t-tests conducted using the Concept Systems Global software, between ratings variables by cluster.

Table 6.4.7.2: Summary of importance vs. feasibility ratings

Cluster	t-test	Decision
Public Forum	t(20)=2.5592 p < 0.02	*Reject the null hypothesis that there is no difference between this rating scores of the importance and feasibility.
Co-production	t(20)= 3.7090 p < 0.002	*Reject the null hypothesis that there is no difference between this rating scores of the importance and feasibility.

and Partnership		
Engagement	t(10)=1.2900 p>0.05	Fail to reject the null hypothesis that there is no significant different between the ratings for engagement of importance and feasibility.
Linkage and Exchange	t(15)=2.0234 p>0.05	Fail to reject the null hypothesis that there is no significant different between the ratings for linkage and exchange of importance and feasibility.
Developing Cultural Capacity	t(9)=1.6455 p>0.05	Fail to reject the null hypothesis that there is no significant different between the ratings for developing cultural capacity of importance and feasibility.
Advocacy and Knowledge Translation	t(14)= 2.8520 p < 0.01	*Reject the null hypothesis that there is no difference between this cluster on rating scores of importance and feasibility
Investment in the Ecosystem	t(14)=1.1675 p > 0.05	Fail to reject the null hypothesis that there is no significant different between the ratings for developing cultural capacity of importance and feasibility.

Visually, compared to the other clusters, the largest difference on the pattern match graph was found between the ratings of importance and feasibility for the Co-production and Partnerships cluster. Represented by the strongly sloped line between the variables, this cluster was rated as the second most important (3.98/5) but also one of the least feasible (3.59/5), a statistically significant difference. Among the participants, there was no statistically significant difference between ratings of importance and feasibility in four of the clusters (Engagement; Linkage and Exchange; Investment in the Ecosystem; Developing Cultural Capacity). In general, these relationships can be seen in the latter graph with the relatively flat lines between the variables' ratings. Somewhat surprising in the ladder graph, was the lack of a statistically significant difference found between the

rating variables for the developing cultural capacity cluster. Even though the line between the importance and ratings clusters on the graph has a visually steep slope, analysis suggested a failure to reject the null hypothesis that there was no significant difference between the ratings for the variables in this cluster.

Significant differences represent meaningful dissimilarities in the ratings, showing potential areas for further investigation and utilization of the findings. Differences between rating variables in the three significant clusters (Advocacy and Knowledge Translation; Co-production and Partnership; Public Forum) indicate potential areas for further investigation in order to understand why participants perceived differences in ratings between importance of the cluster and feasibility as rated on the five point Likert scale. In implementing the framework of priorities, it would be reasonable to explore these differences to identify potential gaps between needs and resources.

Analysis was also conducted within the rating variables to understand the perceived rating differences between clusters. Unpaired t-tests were conducted using the Concept Systems Global software, significant differences are reported below along with a summary of key findings.

Table 6.4.7.3: Within rating variable comparisons

Rating Variable	Clusters Compared	t-test	Decision
Feasibility	Engagement and Co-production and partnerships	t(15)= 3.2372 p < 0.01	*Reject the null hypothesis that there is no difference between clusters on rating scores of feasibility.
	Engagement and Public forums	t(15)=3.2090 p < 0.01	*Reject the null hypothesis that there

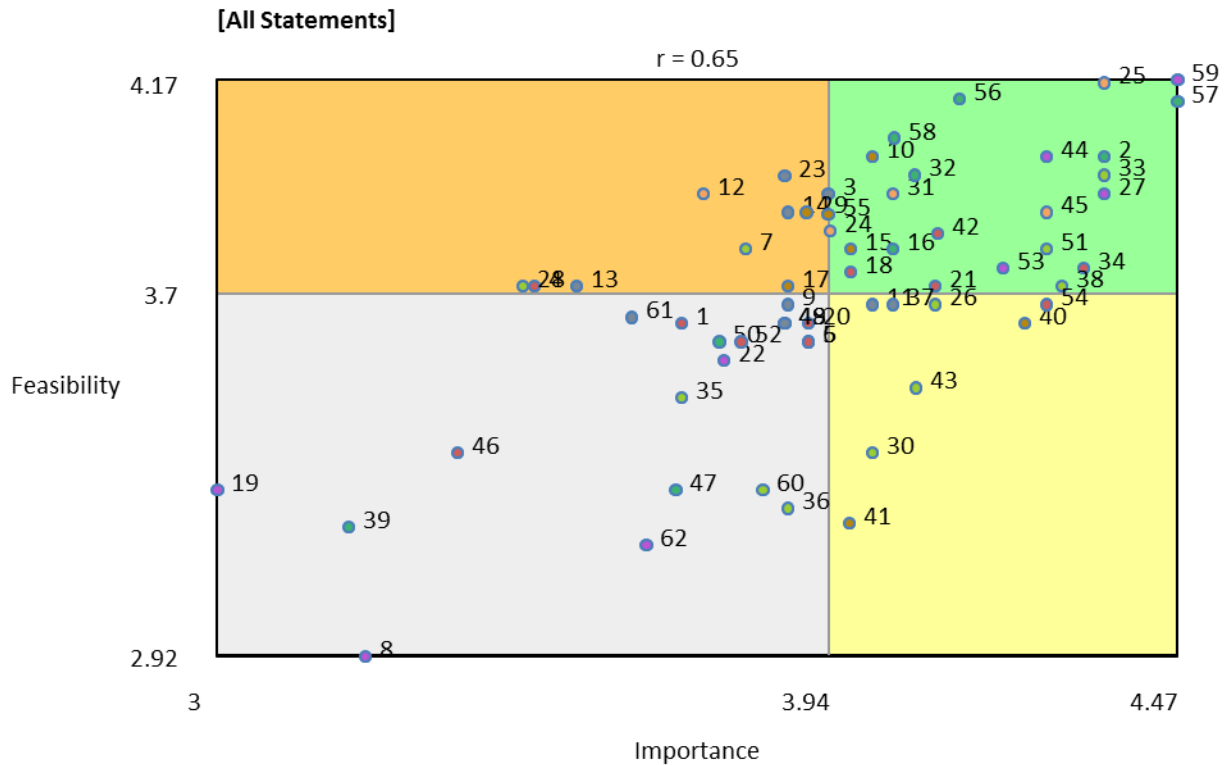
Rating Variable	Clusters Compared	t-test	Decision
			is no difference between these clusters on rating scores of feasibility.
Importance	All clusters		No relationships where found to be statistically significant as demonstrated by $p > 0.05$ for all comparisons.

The ladder graph visually demonstrates the significant difference found between feasibility ratings of the Engagement and Co-production clusters with the Engagement cluster rated as the most feasible cluster (3.89/5) and the Co-production and Partnerships cluster rated as the least feasible cluster (3.59/5). The significant differences may be helpful when implementing this framework of priorities with the clusters of Co-production and Partnership and Public Forums perceived to be less feasible than the other clusters. The lack of statistically different importance ratings between clusters indicates that all of the clusters fall within a range considered to be important by participants. Further comparison of ratings data is presented below through go-zone graphs.

6.4.8 Go-zones

Go-zone displays are bi-variate graphs divided into four quadrants by the mean rating value of each variable, and build on the information provided through the pattern matches to reveal greater within-cluster detail. Figure 6.4.8.1 below presents a go-zone graph of the framework of priorities graphing the results of the rating activities of all the statements in the project with a moderately positive relationship, $r = 0.65$.

Figure 6.4.8.1: Go-zone of framework of priorities



The go-zone quadrant is comprised of a total of 23 statements, representing six of the seven clusters; Table 6.4.8.2 below summarizes these by cluster.

Table 6.4.8.2: Summary of go-zone statements

Cluster	# of statements in go-zone	Statements
Linkage and Exchange	6/9	2. for developers to recognize the diversity of the older adult population in terms of technology use; 16. empower care providers that work with older adults and caregivers so that they can innovate; 32. test existing technologies and give feedback on usability; 56. gather information from senior community centres about innovation needs in health and aging; 57. encourage communication between those interested in innovation (e.g., researchers, government, business, older adults and caregivers); and

Cluster	# of statements in go-zone	Statements
		58. collect feedback from various stakeholders to evaluate innovation collaboration efforts.
Engagement	4/6	24. brainstorm ideas for innovation to support health and aging, using "techies" and health care providers as advisers when needed; 25. innovators should make personal visits to older adults and their caregivers to understand their needs and/or issues; 31. identify older adults who are technology "superusers" and engage them in implementation processes; and 45. involve care providers who develop relationships with older adults and caregivers in innovation.
Investment in the Ecosystem	4/8	27. advocate for the flow of information directly from seniors and their caregivers to those who can address the issues at hand; 44. ensure that interested staff members involved in seniors' care have an opportunity to provide perspective on innovative technologies; 53. support investment in evidence based solutions; and 59. encourage local organizations working on innovation in health and aging to consult with older adults and caregivers.
Public Forums	4/11	18. seek out information on innovation in health and aging to stay up to date; 21. by attending workshops and events related to innovation in health and aging; 34. have a place in the community where seniors and their caregivers are encouraged to go to share their ideas and or experiences related to health and aging ; and 42. interact with students to get them interested in health and aging innovation.
Co-production and Partnerships	3/11	33. have seniors' care facilities involved in research on innovation in health and aging; 38. get involved in innovation projects early (e.g., from planning phases) to that opinions can have an impact; and

Cluster	# of statements in go-zone	Statements
		51. develop partnerships between groups interested in health and aging innovation.
Advocacy and Knowledge Translation	2/8	10. create advocacy groups for older adults and caregivers interested in health and aging innovation; and 15. tell associations (e.g., Cancer Society, Alzheimer Society, ALS Society) to spend some of their time/resources identifying technology solutions currently available to help deal with day to day activities.
Developing Cultural Capacity	0/9	

The go-zone statements, those perceived to be both highly feasible and important by participants, were spread across six of the seven clusters. The Linkage and Exchange cluster was most highly represented here with six of the cluster’s statements. As a proportion of statements in the cluster however, there was a tie between this cluster and the Engagement cluster with both represented by 67% of their statements. No statements from the Developing Cultural Capacity cluster were rated highly enough to fall within the go-zone. The go-zone statements are typically of most interest for planning and implementation, however an analysis of the statements in the other quadrants of the graph can provide insights and can be found in Appendix F. A summary of the statements which fell in the low feasibility and importance quadrant are presented in Table 6.4.8.3 below.

Table 6.4.8.3: Summary of no go-zone statements

Cluster	# of statements in no go-zone	Statements
Public Forums	5/11	1. begin a public forum where older adults can nurture an innovation ecosystem from within; 6. provide options to participate remotely in discussions with those involved in innovation; 20. participate in conferences about health and aging; 52. share their opinions at local technology pitch events related to health and or aging; and 46. provide opportunities for older adults and caregivers to become educated in basics of research methods.
Investment in the Ecosystem	4/8	8. for financial incentives to be provided to companies engaging the input of seniors and caregivers; 19. to give seniors a small payment of appreciation for their involvements in the ecosystem; 22. reach out to local business association about innovation in health and aging; and 62. for incentives (other than financial) to be provided to companies engaging the input of seniors and caregivers.
Developing Cultural Capacity	3/9	49. use local media outlets (cable and radio) to engage older adults and caregivers about innovation for health and aging; 61. setting up peer networks for seniors to learn technology; and 9. support seniors who are not tech savvy to use computers to access information related to health and aging.
Co-production and Partnerships	3/11	60. become a partner on research and/or innovation development teams; 35. get involved in resident councils in long-term care or assisted living to raise issues of innovation and technology development; and

Cluster	# of statements in no go-zone	Statements
		36. have residents of long-term care be involved in their facility's ethics committees to make decisions about projects taking place related to innovation.
Advocacy and Knowledge Exchange	2/8	50. video caregivers performing daily tasks and share this with those in innovation ecosystems to show them the difficulties of caregiving; and 5. to get involved with local health decision making network (such as the LHINs in Ontario) to raise issues related to innovation in health and aging.
Linkage and Exchange	2/9	39. give local companies engaged in community and technology innovation the contact information for all older adult and caregiver groups so that they can contact them for their feedback on research and product development; and 47. give older adult and caregiver groups the contact information of local companies engaged in community and technology innovation with specific areas of their development to contact and offer input.
Engagement	1/6	48. involve older adults and caregivers in dialogue with technology companies to influence their technology development.

Twenty statements were rated to be both relatively low in importance and feasibility. Every cluster had representation in this quadrant with the Public Forums cluster most highly represented and the Engagement cluster least represented. These statements point to a need for further research to understand why participants determined these ideas to be less feasible and important.

6.5 Discussion

Engagement from stakeholders throughout this Concept Mapping project has revealed a framework of priorities to understand how older adult and caregiver engagement in regional health innovation ecosystems (RHIEs) can be realized. Through multidimensional scaling and hierarchical cluster analysis, individual statements or ideas generated by participants about how older adults and their caregivers could be engaged in RHIEs were arranged in a seven cluster framework. This framework and the final list of 62 statements represented a wide range of ideas related to the engagement of older adults and their caregivers in innovation for health and aging and were determined to be acceptable through member checking with stakeholders. Results from this study contributed novel ideas related to this engagement and confirmed previously identified ideas as relevant to this topic.

In order for this engagement to be realized, the ECOTECH framework must be actionable. This project provides direction for this through comparison of ratings data on the clusters in this framework by importance and feasibility which generated an understanding of themes that stakeholders perceived to be most actionable and others that might require further consideration before moving forward. The clear priority for stakeholders was the cluster of Engagement, with high feasibility and importance ratings. Stakeholders perceived the ideas in this cluster to be closely related, anchoring this theme as key to understanding the framework of priorities. The importance of engagement is consistent with the literature and movements towards patient and citizen engagement efforts across health care systems, from engagement efforts with older adults and their

caregivers in clinical decision-making (Elliott et al., 2016) to research and planning efforts (McNeil et al., 2016).

The Canadian government supports engagement efforts through initiatives such as the Strategy for Patient Oriented Research (SPOR) program (CIHR, 2017). SPOR is an investment in patient engagement aiming to improve the experience and outcomes of patients by incorporating research and evidence into better care for patients. The first mechanism that the SPOR invested in to meet this aim was Regional Support Units through the Canadian Institutes for Health Research (CIHR) to support patient-centred research. A component of this initiative is a basic principle that patients need to be involved at all levels, including i) setting research priorities and establishing what outcomes are relevant, and ii) participating in research, uptake and dissemination. The SPOR support units are described by CIHR as playing an important role in developing training programs, forums, and training materials to support patient engagement in research that is related to health and clinical care improvement, and new solutions to problems that are not well managed today (CIHR, 2017). The centrality of the Engagement cluster in the ECOTECH framework of priorities aligns with the strong government support behind consumer engagement.

In contrast, the Co-production and Partnerships cluster was understood as a highly important but unfeasible cluster. This cluster incorporated ideas of varying levels of involvement, from including older adults and their caregivers in brainstorming sessions, to fostering relationships between innovators and older adults and their caregivers. The idea of partnerships offers an opportunity to provide this meaningful engagement, but also creates complexity (McLaughlin, 2004) in engaging older adults in health

innovation. Partnerships have been defined in numerous ways but typically include aspects of trust and interdependence of participants. This importance of a relationship between stakeholders involved in engagement activities has been highlighted in the literature on older adult engagement in healthcare research and planning (McNeil et al., 2016). The extension of this principle to the context of innovation ecosystems is a novel contribution of this study. The Co-production and Partnerships theme has links to best practice guidelines and strategies of current leaders in innovation for health and aging. The AGE-WELL National Center of Excellence (2016) for example supports this type of technology and innovation creation, highlighting the importance of older adult and caregiver co-production in their efforts to innovate.

Through practices of co-production, social capital can be increased. It has been suggested that this occurs through the resulting creation of supportive relationships and an increase in personal self-confidence (Needham & Carr, 2009). Being meaningfully involved in the direction of projects can positively affect the health and well-being of not only oneself, but also of society more broadly. Despite this positive impact, the contrast between perceived importance and feasibility of this cluster raises questions about the status quo of innovation in health and aging. Themes within this cluster of older adults and their caregivers getting involved in research and innovation from early stages of projects were perceived to be important for stakeholders, however were rated as less feasible. Previous work on engagement of older adults and their caregivers in health research and planning has identified environmental or contextual aspects (McNeil et al., 2016) that might be relevant in understanding this disconnect. The importance of establishing an understanding of organizational support for engagement efforts, for

example, will impact time commitments of those conducting research, recognizing that partnership approaches to knowledge generation often take more time (McNeil et al., 2016). Participants' perspectives demonstrated through the misaligned ratings are reflective of a discouraging status quo of innovation in health and aging where co-production and partnership efforts are not thought to be possible.

Even though the Co-production and Partnerships cluster was deemed to be relatively less feasible, its importance cannot be overlooked. Through co-production approaches, older adults and their caregivers can provide valuable resources to a RHIE. These resources come in many forms including personal experiences and the generation of market value through their projected support for use once an innovation is commercially available. These partnerships could not only pull health innovations through the commercialization system, addressing the valley of death discussed in the introduction of this project, but positively affect older adults' health and well-being by increasing their social capital and positively influencing broader societal perceptions of aging.

With an understanding of the perceptions of the current context for RHIEs, to move forward with utilization of this framework through planning and implementation efforts, the individual statements should be considered. Analysis of specific ideas within clusters showed clear priorities for action, with statements emerging in the go-zone graphs that were perceived to be most important and feasible when implementing this framework or thinking about key components. The most highly rated items in the go-zone, statement 59, encourage local organizations working on innovation in health and aging to consult with older adults and caregivers; statement 25, innovators should make

personal visits to older adults and their caregivers to understand their needs and/or issues; and statement 57, encourage communication between those interested in innovation (e.g., researchers, government, business, older adults and caregivers) are presented as a starting point for utilizing this framework.

For direction on implementation of statement 59, the idea of consultations, the International Association for Public Participation (IAP2) has put forward the Spectrum of Engagement (IAP2, 2007), describing public engagement as an activity ranging from a beginning level of informing the public by providing information, to increasing levels of public impact with empowerment of the public at the highest level placing decision-making is in the hands of the public. While many frameworks exist in this area, the second level of this framework, consultation - defined as “obtaining public feedback on analysis, alternatives, and/ or decisions” (IAP2, 2007), is directly relevant to these findings. IAP2 suggests that these consultations occur through public comments, focus groups, surveys, or public meetings. This idea highlights the responsibility of those organizations involved in RHIEs to reach out to older adults and their caregivers.

Unsurprisingly, communication, as highlighted in statement 57, was also ranked as one of the most important and feasible ideas for engaging older adults and their caregivers in RHIEs. A body of literature supports the importance of communication between stakeholders involved in innovation, including in the area of linkage and exchange (Conklin, Annalijn; Hallsworth, Michael; Evi Hatzianandreu; Grant, 2008; Lomas, 2000), the cluster within which this statement falls. The goal of linkage and exchange efforts to close the gap between innovation and action (Conklin et al., 2008),

while accommodating the values of citizens within in a community (Menon & Stafinski, 2005) is an important principle underlying the motivation for RHIEs.

Statement 57 encourages communication between all stakeholders involved in RHIEs. In priority setting for RHIEs and usage of knowledge generated from them, this communication is especially important between decision makers in health and aging and those generating knowledge. The idea of “evidence-informed” priority-setting in health care become important in the 1990s (Lomas, 2000) and has been increasingly recognized in most health systems around the world (Menon & Stafinski, 2005). Of interest to encouraging communication between stakeholders in RHIEs are considerations of recognized challenges to linkage and exchange efforts such as traditional distinctions between research stakeholder communities, different languages and methods of communication (Conklin et al., 2008), time and differing timelines (Lomas, 2000), and process and external factors such as political climate and composition of a project team (Menon, & Stafinski, 2005).

As discussed in previous work, transdisciplinary approaches to knowledge generation and exchange might help to overcome some of these issues to encourage engagement in RHIEs (McNeil, 2017b). Greenhalgh and colleagues (2004) discuss this in the context of culture change, highlighting the importance of interpersonal networks to overcome barriers in linkage and exchange efforts. In their framework for health system change, Greenhalgh and colleagues (2016) highlight the need for “cultural humility” (p. 14) among stakeholders to generate a willingness to engage across traditional boundaries for coordinated action. A step towards this humility is developing a mutual understanding.

The idea of conducting personal visits to older adults and their caregivers to understand their needs and issues as suggested by statement 25, aligns with the "user-centred design" movement which advocates for the direct involvement of the consumer in technology development (Endsley, 2011). This framework of processes emerged in opposition to the ubiquitous "technology-centred" systems in the current information age. The underlying philosophy of user-centred design has been described by (Endsley, 2011) as appropriate when designing within complex systems such as the health care system. This centrality of the user in innovation supports the rationale underlying participation of end users in health innovation more broadly. Specifically, in the field of older adult technology development, the use of in-home interviews and personal visits to older adults has been documented as an appropriate method to generate an understanding of the experience of aging (Eisma et al., 2004). The importance of developing this in depth understanding of a target market is well understood in the field of Gerontechnology (International Society for Gerontechnology, 2015).

Although research in this emerging field is important and these approaches have been adopted, the field of Gerontechnology has been viewed as paternalistic by critics such as Peine and colleagues (2014) for broadly following a biomedical model of aging. In response, Peine and colleagues (2014) theorize the engagement of older adults in technology development as co-producers, advocating for an advanced role of older adults in the innovation and design of technology. This critique reminds those working towards implementation of the ECOTECH framework of priorities that each statement is a component of a broader geography of thought and needs to be considered in relation to other ideas for engagement of older adults and their caregivers in RHIEs.

As part of this geography, some ideas in the framework were understood to be neither important nor feasible. In implementing this framework to make older adults and their caregiver engagement in RHIEs a reality, these statements could be used for discussion about resources, commitment, and current societal will in relation to the framework of priorities. The lowest rated items in the go-zone graph, statement 8, for financial incentives to be provided to companies engaging the input of seniors and caregivers; statement 39, give local companies engaged in community and technology innovation the contact information for all older adult and caregiver groups so that they can contact them for their feedback on research and product development; and statement 19, to give seniors a small payment of appreciation for their involvements in the ecosystem, relate to themes of incentives and facilitating connection.

To facilitate these discussions, the pictorial representation of the Concept Map might be a useful tool when working with stakeholders such as decision-makers, older adults and their caregivers in planning sessions for engagement. This pictorial representation of the framework of priorities could be used in a group setting by encouraging these stakeholders to review the map, reflect on the themes, and review the specific ideas within each cluster on the map. In working with the core stakeholder groups, older adults shared that it would be most useful to provide only the most highly rated statements grouped by cluster for the map to be less overwhelming (see Appendix G for an example). The creation of documents such as this would then help with knowledge translation through the facilitation of a group discussion based on this representation of engagement opportunities. Once the group has achieved some level of

comfort in their discussion, a facilitator could present the lower rated ideas to further explore implementation and next steps for utilization of the framework.

Next steps of this study could include the use of this framework for implementation in various jurisdictions in Canada interested in establishing RHIEs or in improving their engagement efforts with older adults and their caregivers in innovation for health and aging. Concept mapping has been recognized as a tool for action planning because manageable subtopics and tasks emerge from the results (Kane and Trochim, 2007). The rating activity results displayed through the pattern matches and go-zones can be used in the next steps of this work to guide the operation of both broad themes and specific ideas depending on the goals of the activity. Results and next steps for this study also include the potential development of evaluation tools based on the framework of priorities. In order to action many of the individual statements, work will need to be completed with specific jurisdictions to understand their perceptions of responsibility for action on the statements. Although the results of this study can be understood as generalizable, this consultation will improve the use of this framework by individual RHIEs by ensuring that the context of each jurisdiction is considered as implementation of the framework moves forward.

6.5.1 Strengths and limitations

A strength of this project is the standardized concept mapping research approach which relies on meaningful participation of stakeholders from different backgrounds with diverse disciplinary perspectives and life experiences (Kane & Trochim, 2007). The flexible methods used to incorporate the perspectives of older adults and their caregivers who were not able to participate using the online software was important in achieving this

diversity of perspectives. To the research team's knowledge, the use of in person brainstorming, card sorting, and rating with older adults and their caregivers is unique to studies adopting this approach. The work of Hanson and colleagues (2013) described earlier, while a novel entry of these methods into gerontological studies, was limited in that they relied solely on online brainstorming, sorting and rating methods. Their recruitment through email may have limited the contributors who would be able to participate in the project. In contrast, this project's incorporation of in person opportunities to contribute throughout all phases of the concept mapping potentially provided greater diversity of age and life experience with technology and innovation.

The use of the online software enabled participants from many geographical locations to participate in this study. Although, as expected due to location of the research team, the majority of participants were recruited from Ontario, online tools enabled interested participants from across Canada to participate, increasing the generalizability of the results.

Despite this strength, a few challenges arose with the use of this method with the older adult participants, leading to some possible limitations of this study. The first challenge arose in the sorting phase. Some participants experienced challenges with the online software used for participation. Even those older adults who considered themselves computer literate experienced issues with the online software, with one participant commenting that they had found:

“... using this website to be really a challenge in that the response to any input of mine was extremely slow...after establishing a profile, I began to answer the questions....first female, male or other...I clicked the appropriate circle, then waited and waited for the next question to appear.....Age....then waited and waited for the next question...so...totally frustrating! Even my attempt then to sign out was a very long delay. Thought I should

let you know...I don't know what the experience of others has been.....anyway, if that was going to be the experience with 62 questions, I never would have handled it!”

After inquiring with the technicians at The Concept Systems (2015) about this experience, the conclusion was that there might have been a bandwidth issue. Given that some participants might have different internet speeds, including those with low income, or those living in rural or remote locations, there is a possibility that without using in-person data collection, participants will not be representative of diverse populations of interest.

Another participant who self-identified as an older adult blogger commented:

“I did attempt the survey, but have to say 62 questions and format are too long and complex for the average older adult to comprehend. I’m afraid I couldn’t understand the piles concept. Perhaps face to face Panel engagement rather than online would be more productive. No disrespect to your methodology but I do find that younger people do not understand how difficult older people who did not grow up with technology, find the new forms of communication.”

As described in the methods section, given the anticipated challenges associated with the amount of time needed to complete the sorting task, the researchers attempted to synthesize and minimize the total number of statements generated in the brainstorming phase. This proved more challenging than expected given the objective to remain as close to the original statements as possible when synthesizing the ideas. The total of 62 statements could have been seen as a barrier to participation for some participants, limiting the types of participants who completed the tasks. The research team attempted to moderate this effect through the use of in person activities.

Although a desirable option by some of the participants, the amount of time associated with in person sorting proved to be another issue for other older participants. The in person sorting activity was scheduled for a 60 minute session. Although there

were some “fast finishers” in the group who began the rating activity while others remained working on their sorting, many participants spent approximately 90 minutes working on the sorting activity. In debriefing after the session, participants remarked that although they enjoyed the activity, they found it draining. At the end of the sorting session, one participant handed in his completed piles with a note on the top of the cards stating “and now my mind is blank”. This mental and physical fatigue experienced could have contributed a limitation to the quality of the completed sorting. To mitigate this, the author reviewed the submitted sorting data of the participants for completeness and connection to the themes of the project to ensure quality of the data.

A further limitation of the study was the lower than expected recruitment of certain stakeholder groups. Because of these smaller sample sizes, between group comparisons could not be made to the extent the author would have liked. An example of this was the need to collapse older adults and their caregivers into one stakeholder group. In future work, it would be interesting to explore potential differences between older adults and their caregivers in engagement in RHIEs. Since the perspective of both groups was incorporated into the statements, through both participation in the brainstorming phase and phases I and II of the ECOTECH study, this understanding could be achieved through either a reproduction of the sorting and rating activities with larger sample sizes of caregivers or through follow up focus groups with caregivers to inquire about the applicability of the findings from their perspective.

Despite these challenges, the group aggregate map and identification of opportunities and next steps for implementation of this framework of priorities

demonstrates the success of the collaboration efforts, and the usefulness of Concept Mapping for research related to older adults and their caregivers.

6.6 Conclusion

This study identified a framework of priorities for directions and strategies on older adult and caregiver engagement in RHIEs. Implementation of this framework could help to advance the development of theory and evaluation in the area of older adult and caregiver engagement in innovations for health and aging. It is hoped that future planning of interventions and ecosystem development efforts will be improved by the results of this study, specifically through the implementation of the framework of priorities generated from this project.

By answering the research question of how older adult and caregiver engagement can be realized in regional health innovation ecosystems (RHIEs) this project demonstrated the acceptability of Concept mapping as a technique for gerontological research. The next steps of this study involve continuing to collaborate with stakeholders from this project to develop engagement efforts in Canadian RHIEs that can support the health and well-being of older adults and their caregivers.

CHAPTER 7 SUMMARY AND GENERAL DISCUSSION

7.1 Thesis Summary

ECOTECH was a three phase integrated mixed methods study which contributed to the literature by developing an understanding of how older adults and their caregivers can be engaged in RHIEs to enhance the likelihood that novel products that support healthy aging will be commercialized or successfully disseminated beyond a proof of concept. Phase one of this project was a scoping review which answered the research question of how end users have been engaged in Regional Innovation Ecosystems. In alignment with best practices for scoping reviews, this phase also identified gaps and motivation and direction for the next phase of study.

Building on the findings of phase one, that there was a need to better understand the ways in which end users could be engaged in RIEs and the gap in understanding engagement of specific populations, phase two determined the interest in and readiness for older adult and their caregiver engagement in health innovation through a series of focus group and individual interviews. Stakeholders from a variety of roles in RIEs shared that although there is a desire by stakeholders to engage older adults and their caregivers, currently in Canada they have little meaningful involvement. Stakeholders identified themes and subthemes to consider in older adult and caregiver engagement in health and aging innovation ecosystems.

Incorporating findings from the first two phases, phase three was a Concept Mapping project which through six phases of participatory design produced a seven cluster framework of priorities. Composed of 62 specific actions to be taken to engage older adults and their caregivers in RHIEs, this framework established an understanding

of how older adult and caregiver engagement in Regional Health Innovation Ecosystems (RHIEs) can be realized. Ratings activities revealed next steps for implementation through an understanding of the importance and feasibility of the ideas.

7.2 Implications

Innovation had been announced by governments at various levels of influence as a key strategy for the improvement of well-being and quality of life of citizens globally. In Canada, the federal government continues to announce innovation as a priority and produce strategies and frameworks to support innovation across the country. The Conference Board of Canada, for example, has put forward an Innovation Framework which seeks to improve understanding of technological innovation in Canada's health system to improve the system's quality and ultimately impact the health of Canadians (Prada & Santaguida, 2007).

Fostering a culture of innovation has recently been announced as a goal of the national innovation mandate in the Canada 2020 Innovation Project (2017). General strategies to achieve this are known, with documentation in the report recognizing ideas proposed in previous innovation strategies as important and relevant to continue to work towards today. For example, Canada has recognized the importance of collaboration with local social, economic and community development stakeholders across sectors to prepare long-term community innovation plans and strategies (Canada 2020, 2017). How to action this engagement however is not discussed and despite the recognized challenges to innovation in health, current population trends of aging societies require different approaches to addressing issues in both health care and product design (Lee and Coughlin, 2015). It is important that disruptive health innovations make it through "the

valley of death” in order to be able to positively affect the health and well-being of older adults. The social processes that support and hinder the transfer of innovative technologies to older adults are complex, dynamic and not well understood, but engagement in RHIEs could be a necessary step towards improving this.

The Ontario Health Innovation Council (OHIC) has put forward six recommendations for facilitating “person-centred technological innovations” that promote health and well-being (Ontario Health Innovation Council, 2015). Supporting this more engaged approach to innovation is a recognition of the need for health systems to engage consumers in new and innovative ways in an effort to achieve sustainability in a system struggling to cope and meet patient needs and demands (Snowdon, Shell, & Leitch, 2011).

ECOTECH presents a geography of ideas on how to engage older adults and their caregivers throughout the innovation process through a framework of priorities composed of specific actionable items. In order to enhance the likelihood that novel products and services that support healthy aging will be commercialized or successfully disseminated beyond a proof of concept both in the health care system and for individual use, there is a growing realization of the importance of involving the public. ECOTECH contributed to the understanding of how to achieve this with a recognition of gaps and opportunities in the literature, support from stakeholders involved in RIEs, and a framework of priorities of how older adults and their caregivers can be engaged in RHIEs.

The findings of this study also contributed theoretical support for the modelling of at least another helix beyond the traditional Triple Helix to Quadruple (for example older adults and their caregivers) and n-tuple (other potential stakeholders) models.

Stakeholder theory (Mitchell, Agle, & Wood, 1997) was useful in this project to frame themes that emerged of power differentials between actors involved in RHIEs. As modelling of RHIEs continues to develop through the DRiVE project, these theories have potential to support the understandings that emerge.

This modelling could have important applications in the context of health innovations in Canada, for example in the current role of citizen engagement in activities important in the innovation process, such as health technology assessment. The area of Health Technology Assessment (HTA) has emerged internationally and in Canada is led by the Canadian Agency for Drugs and Technologies in Health (CADTH), an independent, not-for-profit organization responsible for providing health care decision-makers with objective evidence to help make informed decisions about the optimal use of health technologies. Underlying their work is a model that identifies specific determinants of technology diffusion, including the needs of the users as a key component (Murtagh, Foerster, & Che, 2009).

Within the global HTA community, CADTH has been recognized as a world leader in patient involvement. Indeed, the CADTH Policy Forum was commended for its ability to bring together different stakeholders in the field of health technology innovation, discuss topics of interest and foster relationships (Menon & Stafinski, 2005).

A recent report on patient engagement in HTA identified four benefits of involving citizen and patients in HTA broadly described as: democratic, scientific, instrumental, and developmental (Public & Subcommittee, 2015). From a democratic perspective, the engagement of patients is important in achieving legitimate and transparent decisions about health technologies. The scientific rationale for patient

engagement in HTA is the value in producing more robust and comprehensive assessments. From an instrumental point of view, better quality decisions are made when the public is involved in HTA. The developmental rationale for patient engagement in HTA is the idea of strengthening the capacity of the public to contribute to issues regarding health technology (Public & Subcommittee, 2015). Specifically, CADTH currently achieves these benefits through their engagement of patients and caregivers in HTA through patient advocacy groups. CADTH has developed a formal approach for incorporating the patient perspective into its Common Drug Review (CDR) process, which delivers formulary listing recommendations for participating publicly funded drug plans to use when making drug coverage decisions (Input, Patient, Input, & Information, 2014).

The findings of ECOTECH suggest that there is room for CADTH to continue to lead in patient involvement in HTA by extending the roles of patients in their HTA practices. For example, aligned with the findings of ECOTECH, HTA could embed linkage and exchange activities to integrate patients, health care providers, policy makers and academics in the creation, implementation and monitoring of health technology assessments (Lee et al., 2003). The findings of this study would support an evolution, as RHIEs develop in Canada, or organizations such as CADTH more purposefully embed into these ecosystems, of the roles of patients both within individual organizations and the broader RHIE. Ultimately, this recognition and engagement will help to overcome societal biases and ageism.

Building Quadruple Helix models to extend the role of patients in HTA, for example, will require that citizens are understood as playing multiple roles in RHIE

partnerships, as consumers of products and services, and contributors and co-creators of new knowledge from their own areas of expertise. The expected outcomes of this approach would be at the individual level, including positive experiences for older adults and their caregivers being meaningful involved in technology innovation and gaining more rapid access to technologies that promote health and well-being as they age. At the community level, strong networks of engagement between “elites” and “ordinary citizens” can accelerate the dissemination of knowledge and strong collective action can help to mobilize external investment in a regional ecosystem (Ornston, 2015). Overall, improvements in quality of life and well-being for older adults generated from both opportunities of increased engagement through RHIEs and the creation of health innovations to support aging well would be expected through the implementation of this framework. Current efforts towards engagement of older adults and their caregivers by Triple Helix stakeholders and their organizations working towards innovation in health and aging could benefit from an understanding of the ECOTECH framework of priorities. The broader ambition of the author is that increased social capital of older adults through meaningful engagement in RHIEs can contribute to a movement against ageist discourse surrounding older adults and technology.

7.3 Strengths and Limitations

The ECOTECH project had a number of limitations which have been discussed in each of chapters four through six; this section discusses the broader limitations of the project and overall strengths. Currently, there are issues of equity and social justice when working with older adults as partners in knowledge creation, and there are challenges with diversity and representation of participants. To overcome these challenges in the

ECOTECH project, the researcher adopted reflexive skills to continuously examine opportunities for recruitment and community collaboration. Further, the research design, in the value of mixed methods research over more traditional methodologies and approaches in the ability to conduct community engaged research (Tashakkori & Teddlie, 2003) was useful. By incorporating a participatory approach and reflecting on capturing the voice of individuals who are isolated from their community, less likely to be engaged, who have lower social capital, or who might not be able spend time engaging in participate in research, this project attempted to achieve diversity of participants. Unfortunately, the author encountered barriers in reaching out to certain stakeholder groups and had limited success with these efforts, limiting the generalizability of this work.

Another limitation of this project is associated with the acceptance of mixed methods and participatory research in the health sciences. Currently, funding in the health sciences is typically distributed by disease or risk-factor specific models with timelines that do not allow for the creation of meaningful partnerships or development of mixed method inquiry (Tashakkori & Teddlie, 2003). This presents a potential barrier for external funding for next steps of this project. It is encouraging to see increased acceptance at the funding level for projects that involve participants (CIHR, 2014). It is hoped that continued advocacy for this type of research will help to change funding and acknowledgement structures (Tashakkori & Teddlie, 2003).

This mixed methods approach can also be understood as a strength of this project. The participatory methods employed ensured the inclusion of different groups of people interested in generating an understanding in an area of research that might positively

affect the communities involved. Further, the integration of learnings from phases I and II of ECOTECH into the group concept mapping phase used robust models and analytics to provide objective results (Rosas, 2012), overcoming what can be seen as a limitation of some qualitative research. The use of multiple perspectives and methods triangulated the data, making the model transferable across Canadian RHIEs working to engage older adults and their caregivers.

7.4 Future research directions

Continued collaboration with stakeholders will allow the results of this study to be used in developing RHIEs in Canada. The next steps of this work could involve implementation of the framework of priorities in Canadian RHIEs. Working with emerging RHIEs in Canada (within the AGE-WELL Network and beyond) to understand priorities for implementing community engagement plans and assess current engagement practices would be an important first step. Once an understanding of the specific strategies in which the stakeholders in the RHIE were interested, an evaluation plan could be developed to study the implementation of the ECOTECH framework of priorities. This implementation and evaluation will be useful in both validating the model of older adult engagement and understanding the implications of engaging older adults and caregivers in RHIEs.

Kane and Trochim (2007) suggest that a Concept Map, such as the framework of priorities that emerged from the ECOTECH project, is an appropriate base for planning and evaluation including the creation of measurement tools. The next steps of this project could include working with an emerging or existing RHIE in Canada to implement strategies identified in the go-zone from the framework of priorities. A first step towards

this would be to validate the acceptability of the ideas in the framework, through discussion with stakeholders in the community of interest. Following this, the creation of an ECOTECH measure to assess and evaluate engagement of older adults and their caregivers in RHIEs could be developed in alignment with the methodologies of Kane and Trochim (2007).

This thesis provided evidence for the suitability of Concept Mapping as a participatory methodology for working with older adults and their caregivers. Adaptations and lessons learned in conducting this study could be implemented in future applications of this method.

7.5 Conclusions

Greater involvement of older adults and caregivers in health and aging innovation can result in new technologies and processes that are more likely to meet their needs and preferences. Through a three phase integrated mixed methods study, ECOTECH identified directions and strategies for their enhanced involvement in Regional Health Innovation Ecosystems. Building on a scoping review of relevant peer reviewed and grey literature, and consultations with various stakeholders involved in Canadian innovation for health and aging, a geography of ideas on how to engage older adults and their caregivers throughout the innovation process was generated, as a framework of priorities composed of specific actionable items.

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Appendices

Appendix A: Team description

Name	Role	Discipline	Known area of expertise
AGE-WELL Network	Collaborator	Transdisciplinary	Triple Helix perspectives
Dr. Kerry Byrne	Committee member	Gerontology	Aging, Caregiver involvement
Dr. Kelly Grindrod	Committee member	Pharmacy	Technology, aging
Mrs. Annette McKinnon	Mentor	Patient advocacy	Patient engagement
Dr. Josephine McMurray	Committee member	Health and business studies	Innovation, health
SHARP group members	Collaborator	Patient advocacy	Patient and caregiver perspectives
Dr. Paul Stolee	Supervisor	Health studies	Aging, health

Appendix B: Ethics documents

Informed Consent- Older adults and caregivers



Date:

Study Name: ECOTECH

Researchers:

Paul Stolee, PhD

Associate Professor

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext. 35879 **Email:** stolee@uwaterloo.ca

Heather McNeil, PhD (Cand.)

University of Waterloo

200 University Ave West, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext. 35879 **Email:** hmcneil@uwaterloo.ca

Introduction:

You are being asked to give your permission to participate in a research study called “ECOTECH” conducted by Heather McNeil for her PhD thesis under the supervision of Dr. Paul Stolee.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting the study?

This study is being conducted by Dr. Paul Stolee and Heather McNeil, who are both from the School of Public Health and Health Systems at the University of Waterloo.

Background

What is the purpose of the study?

Innovation offers many opportunities and challenges to support the health and well-being of older adults. Increasingly, the value of developing regional infrastructure that supports and drives innovation in local clusters is understood. This innovation typically arises

from collaboration between researchers, government and industry. This collaboration is emerging in the health sector in the context of innovation to support an aging population. There is a need to understand the engagement of end users (specifically older adults and their caregivers) in the development of community infrastructure that supports innovation in health.

The Engaging Canada's Older adults in health TECHNOLOGY innovation ecosystems (ECOTECH) Project expands our understanding of how Regional Health Innovation Ecosystems (RHIEs) engage older adult end users in meaningful ways.

What am I being asked to do?

You are being invited to participate in two phases of a project which will involve being in a conversation (focus group) with Heather McNeil and participating in a concept mapping activity. Questions will focus on experiences and perspectives of involvement in health innovation.

Phase I will include a conversation that will take place as a focus group, which will be scheduled at your convenience. The conversation will be led in-person by Heather McNeil, and will last for approximately one hour.

Phase II will involve your participation in i) an approximately one hour long brainstorming session which will take place in person in a small group format facilitated by Heather McNeil and ii) sorting and rating of the ideas generated in the brainstorming session (to be conducted online or in person depending on your preference). Sorting and rating are expected to take no longer than a couple of hours of your time in total. Information sessions, run by Heather might be used to help people who have not used the online software to become comfortable and learn The Concept Systems software.

What are the Risks and Discomforts?

We believe that there are no risks or discomforts from your participation in this study.

What are the benefits of the research and benefits to you?

There are no expected direct benefits to participants from their involvement in the project. Increased knowledge about the topic of older adult engagement in health innovation is expected and potential increased social capital gained through involvement in a meaningful project and opportunity to meet others interested in this area (through participation in focus groups) are indirect benefits of participation.

Voluntary Participation

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Withdrawal from the Study

You can stop participating in the study at any time, for any reason, if you so decide.. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality:

All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessible only by the members of the research team. Your name will not appear on any of the data. Only the project team (Dr. Paul Stolee and Heather McNeil) will have access to study data. If you permit the use of data in teaching and demonstration materials, scholarly papers, articles and other publications, and presentations at academic, health care conferences, the quotations used will remain anonymous in any presentations, reports, and publications. Data will be retained for a minimum of 7 years.

Confidentiality will be provided to the fullest extent possible by law. Given the group format of this session we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Paul Stolee either by telephone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Heather McNeil either by telephone at (519) 888 4567 x 35879 or by e-mail (hmcneil@uwaterloo.ca). This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

Conclusion

We are excited about this study and look forward to gaining your insight on your thoughts on and experiences with health innovation. We sincerely hope that you will consider participating.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to being audio recorded.

YES NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES NO

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Heather McNeil and Dr. Paul Stolee of the Department of Applied Health at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing the study to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the study may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

My signature below indicates my consent.

Signatures

Printed Name of Participant	Signature	Date

Printed Name of Principal Investigator/Designated representative	Signature	Date

When this study is completed, we will write up a summary of the results. Would you be interested in receiving a copy?

- Yes, please e-mail me a summary of results. My e-mail address is:

- Yes, please mail me a summary of results. My mailing address is:
- No, I do not wish to receive a summary of results

Informed Consent- Triple Helix and HCP



Date:

Study Name: ECOTECH

Researchers:

Paul Stolee, PhD

Associate Professor

University of Waterloo

200 University Ave W, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext. 35879 **Email:** stolee@uwaterloo.ca

Heather McNeil, PhD (Cand.)

University of Waterloo

200 University Ave West, Waterloo, ON N2L 3G1

Phone: 519-888-4567 ext. 35879 **Email:** hmcneil@uwaterloo.ca

Introduction:

You are being asked to give your permission to participate in a research study called “ECOTECH” conducted by Heather McNeil for her PhD thesis under the supervision of Dr. Paul Stolee.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting the study?

This study is being conducted by Dr. Paul Stolee and Heather McNeil, who are both from the School of Public Health and Health Systems at the University of Waterloo.

Background

What is the purpose of the study?

Innovation offers many opportunities and challenges to support the health and well-being of older adults. Increasingly, the value of developing regional infrastructure that supports and drives innovation in local clusters is understood. This innovation typically arises from collaboration between researchers, government and industry. This collaboration is emerging in the health sector in the context of innovation to support an aging population.

There is a need to understand the engagement of end users (specifically older adults and their caregivers) in the development of community infrastructure that supports innovation in health.

The Engaging Canada's Older adults in health TECHNOLOGY innovation ecosystems (ECOTECH) Project expands our understanding of how Regional Health Innovation Ecosystems (RHIEs) engage older adult end users in meaningful ways.

What am I being asked to do?

You are being invited to participate in two phases of a project which will involve being in a conversation (interview or focus group) with Heather McNeil and participating in a concept mapping activity. Questions will focus on experiences and perspectives of involvement in health innovation.

Phase I will include a conversation that will take place as an individual interview or a focus group, which will be scheduled at your convenience. The conversation will be led in-person by Heather McNeil, and will last for approximately one hour.

Phase II will involve your participation in i) an approximately one hour long brainstorming session which will take place in person in a small group format facilitated by Heather McNeil and ii) sorting and rating of the ideas generated in the brainstorming session (to be conducted online or in person depending on your preference). Sorting and rating are expected to take no longer than a couple of hours of your time in total. There will be optional information sessions run by Heather to help people become comfortable with the online software.

What are the Risks and Discomforts?

This is a minimal risk study. Most key informants are speaking from their experience in a professional and expert position of their involvement in a successful venture. Some of these key informants are in positions of power (e.g. government, industry and academic representatives) and they are not being asked questions that would intrude on their privacy or safety. Some participants may be subordinate to or employed by other key informants, and as such there may be minimal employment risk. In order to safeguard against the noted risk, participants will be reminded that while their names will not be used, and whether they consent to the use of quotes or not, this is a small case study and despite researchers' best efforts to remove identifying information responses may be traceable - they should respond to questions accordingly.

What are the benefits of the research and benefits to you?

There are no expected direct benefits to participants from their involvement in the project. Increased knowledge about the topic of older adult engagement in health innovation is expected and potential increased social capital gained through involvement in a meaningful project and opportunity to meet others interested in this area (through participation in focus groups) are indirect benefits of participation.

Voluntary Participation

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is a question you do not want to answer, you may say, “I don’t want to answer that question.”

Withdrawal from the Study

You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, has no effect on you. employment now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality:

All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessible only by the members of the research team. Your name will not appear on any of the data. Only the project team (Dr. Paul Stolee and Heather McNeil) will have access to study data. If you permit the use of data in teaching and demonstration materials, scholarly papers, articles and other publications, and presentations at academic, health care conferences, the quotations used will remain anonymous in any presentations, reports, and publications. Data will be retained for a minimum of 7 years.

Confidentiality will be provided to the fullest extent possible by law. If participating in any of the group sessions we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Paul Stolee either by telephone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Heather McNeil either by telephone at (519) 888 4567 x 35879 or by e-mail (hmcneil@uwaterloo.ca). This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

Conclusion

We are excited about this study and look forward to gaining your insight on your thoughts on and experiences with health innovation. We sincerely hope that you will consider participating.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to be audio recorded.

YES NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES NO

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Heather McNeil and Dr. Paul Stolee of the Department of Applied Health Sciences at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing the study to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the study may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

My signature below indicates my consent.

Signatures

Printed Name of Participant

Signature

Date

Printed Name of Principal
Investigator/Designated representative

Signature

Date

When this study is completed, we will write up a summary of the results. Would you be interested in receiving a copy?

- Yes, please e-mail me a summary of results. My e-mail address is:

- Yes, please mail me a summary of results. My mailing address is:
- No, I do not wish to receive a summary of results

Feedback Letter

UNIVERSITY OF
WATERLOO



Date

Dear (*Insert Name of Participant*),

I would like to thank you for your participation in this study entitled “ECOTECH”. As a reminder, the purpose of this study is to expand our understanding of how Regional Health Innovation Ecosystems (RHIEs) engage older adult end users in meaningful ways.

The potential scientific benefit of this study is that data collected will contribute to a better understanding of older adult engagement in health innovation and the development of Regional Health Innovation Ecosystems. A potential benefit to you from participating in this study is an increased knowledge about the topic of older adult engagement in health innovation and an opportunity to meet others interested in this area (through participation in focus groups).

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by **[insert date]**, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below. As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Sincerely,
Heather McNeil

University of Waterloo
School of Public Health and Health Systems
Telephone: 519-888-4567 ext. 35879 **Email:** hmcneil@uwaterloo.ca
Website: <https://uwaterloo.ca/geriatric-health-systems-research-group/>

Paul Stolee
Telephone: 519-888-4567 ext. 35879 **Email:** stolee@uwaterloo.ca
Website: <https://uwaterloo.ca/geriatric-health-systems-research-group/>

Appendix C: Interview guides

Phase II focus group guide: Older adults and caregivers

Opening Script:

- Welcome. Please help yourself to refreshments
- Please hand in your completed forms.
- Is everyone comfortable?
- I would like to make some introductions to start.
- Is it OK to start the recorders? (Start recorders)
- Thank you for bringing your expertise and creativity to our focus group.
- Be comfortable and ask questions as needed.
- Please bring your imaginations and forthrightness to the discussion.
- Just to review some group norms:
 - Please feel free to openly contribute to our discussion, listen respectfully and allow one to finish talking before joining in, giving time for all to speak.
 - It's great if you share different opinions or are controversial, so please bring any and all of your ideas forward. You hold unique positions within the organization to speak to customer service and relationships for care, so I'm very fortunate to have your time.
 - Participation is voluntary, details of our conversations are confidential and everyone has indicated that they will respect confidentiality. I will remove any and all identifying features from the transcripts and no one sees them but me. Results are all rolled up together for analysis and presentation purposes.
 - Are there any questions so far?

The purpose of this discussion is to gather information from you on older adult involvement in health innovation.

Innovation is an area that offers many opportunities and challenges to support the health and well-being of older adults.

This project is part of a national research partnership called AGE-WELL which is a pan-Canadian network created to drive technological innovation that benefits older adults. Specifically, my study aims to understand how the perspectives of older adults can contribute to the development of health innovations that benefit older adults through improved QOL and well-being.

Guiding Questions

- 1) What comes to mind when you think about:
 - a. "Health innovation"?
 - b. "Health technology"?
 - c. "Health processes"?
 - i. Are these similar terms? Are there differences?
- 2) Are you interested in health innovation?

- 3) Would you like to be involved in the creation of new health innovations?
 - a. If yes, how/ in what capacity?
 - b. Do you see any barriers to your involvement?
 - i. Do you know how to get involved?
 - ii. Do you have enough information to participate in discussions about technology?
- 4) Have you been involved in health innovation in the past?
 - a. If yes, what did you like about it? What didn't you like?
 - b. If no, why not?
- 5) What is important to you when thinking about health innovation policy?
- 6) Who should be involved in determining the safety of new health innovations/ technologies?
- 7) Recently there has been some discussion about involving older adults in healthcare technology and innovation at a regional/ planning level. There are many existing partnerships encouraged in this area between university, government, and industry stakeholders. Typically, older adults are not involved until a product is developed and ready to be tested. Do you think there is a place for older adults earlier in this process?
 - a. Is yes, what would this look like?
 - b. If no, why not?
- 8) Would you (other your friends/ family members) like to be involved in the creation of new health innovations or technologies?
 - a. If yes, how/ in what capacity?
 - b. If no, why not?
 - c. Do you see any barriers to your involvement?
 - i. Do you know how to get involved?
 - ii. Do you have enough information to participate in discussions about technology?
- 9) Have you been involved in health innovation in the past (e.g. in developing ideas for new technology or testing out a technology)?
 - a. If yes, what did you like about it? What didn't you like?
 - b. If no, why not?

Section 1: GENERAL BACKGROUND INFORMATION

The questions in this section are adapted from (Toscan, Mairs, Hinton, & Stolee, 2012)

1. Please describe your position here at [INSERT LOCATION]?
2. Overall, how many years of experience do you have as an [INSERT POSITION]?
 - Probe: in other facilities, when did you graduate, etc.
3. Have you worked in this industry before?
 - If YES: How long did you work there?

Section 2: ENGAGING OLDER ADULTS IN HEALTH INNOVATION

1. Who in your organization is responsible for innovation?
2. What do you see as important for health innovation in your organization?
3. What is the current role that older adults play in health innovation in your organization?
4. What role do you see as possible for older adults in health innovation?
5. Can you describe a situation where innovation in your organization occurred?
 - Probe: who was involved in this innovation? Why was it successful?

Section 3: ENDING QUESTIONS

These questions are very general questions that were asked to ensure that the participant had expressed everything that they wish to express. Participants also had the opportunity to ask any questions that they might have for the researcher.

1. Is there anything else you would like to tell me about engaging older adults in health innovation?
2. Is there anything that you would like to ask me?

Appendix D: Audit trail template

Date:

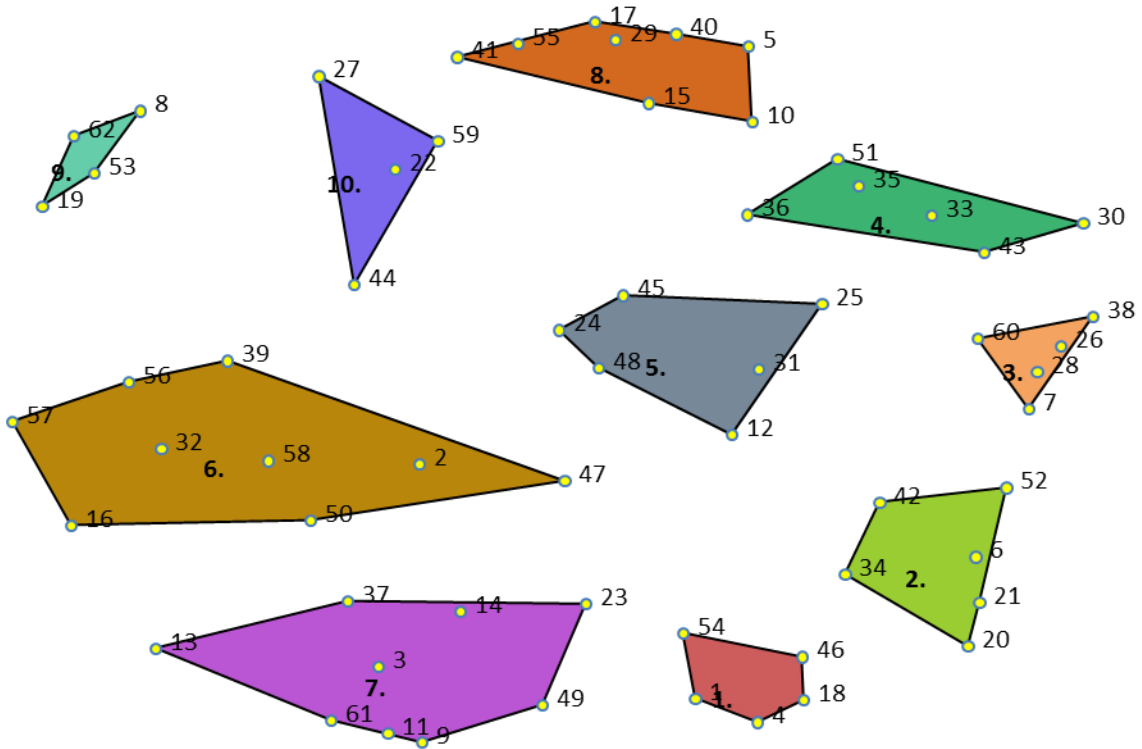
Context (meeting, post interview, writing session, etc.):

Key topic/ theme:

Notes:

Implications for study (e.g., changes to themes, questions for committee members, directions for future research):

Appendix E: 10-cluster solution



Appendix F: Analysis of other quadrants of the graph

Eight statements were found to be highly important but less feasible. Aligning with the pattern match graph of clusters, three of these statements came from the co-production and partnerships cluster:

- 26. getting involved with research projects about innovation in health and aging;
- 30. to get involved in innovation from planning stages in healthcare to set the innovation agenda; and
- 43. get involved in decisions related to the creation of new innovations for health and aging.

Two of the clusters had two statements each in this quadrant:

Developing Cultural Capacity:

- 11. work to remove the mystique and fear from use of technology; and
- 37. teach those involved in the local ecosystem how to attract the attention of older adults and their caregivers.

Advocacy and Knowledge Translation:

- 40. advocate to local health and social care decision-makers about innovation in health and aging; and
- 41. advocate for universal access to internet for everyone.

The final statement in this quadrant from the public forums cluster is of interest for planning:

- 54. create an accessible seniors' information centre.

Inversely, 11 statements were found to be highly feasible but of lower relative importance. Corresponding to the cluster trend observed in the pattern match, four of these statements are from the developing cultural capacity cluster:

- 13. use social media to raise awareness of issues in health and aging innovation;
- 14. coach or mentor others in the ecosystem;

23. advertise opportunities for seniors and caregivers to give their input on innovation in local media outlets; and
3. for researchers to keep older adults informed on the results of their involvement in innovation.

Three statements were from the advocacy and knowledge translation cluster:

29. advocate for innovation from other communities to be applied locally;
55. advocate to change the status quo of finished products being imposed on seniors; and
17. talk to local government representatives about experiences in health and aging.

The co-production and partnership cluster was represented in this quadrant by the following two statements:

28. by volunteering with an organization within the ecosystem; and
7. caregivers with experience who are no longer active in their role can provide input to those involved in innovation.

Public forums and engagement each had one statement that was rated highly feasible but of low importance:

Public forums:

4. join or start online discussions about health and aging innovation.

Engagement:

12. video older adults performing daily tasks and share this with those in innovation ecosystems to show them our difficulties.

In the final quadrant, 20 statements were rated both of relatively low importance and feasibility. Every cluster had representation in this quadrant. Public forums had the highest number of statements, with the following 5/11 statements rating scores falling into this group:

1. begin a public forum where older adults can nurture an innovation ecosystem from within;
6. provide options to participate remotely in discussions with those involved in innovation;
20. participate in conferences about health and aging;

- 52. share their opinions at local technology pitch events related to health and or aging; and
- 46. provide opportunities for older adults and caregivers to become educated in basics of research methods.

Four statements from the investment in the ecosystem cluster were found in this quadrant:

- 8. for financial incentives to be provided to companies engaging the input of seniors and caregivers;
- 19. to give seniors a small payment of appreciation for their involvements in the ecosystem;
- 22. reach out to local business association about innovation in health and aging; and
- 62. for incentives (other than financial) to be provided to companies engaging the input of seniors and caregivers.

Both the developing cultural capacity cluster and co-production and partnerships had three statements in this zone of the graph:

Developing Cultural Capacity:

- 49. use local media outlets (cable and radio) to engage older adults and caregivers about innovation for health and aging;
- 61. setting up peer networks for seniors to learn technology; and
- 9. support seniors who are not tech savvy to use computers to access information related to health and aging.

Co-production and Partnerships:

- 60. become a partner on research and/or innovation development teams;
- 35. get involved in resident councils in long-term care or assisted living to raise issues of innovation and technology development; and
- 36. have residents of long-term care be involved in their facility's ethics committees to make decisions about projects taking place related to innovation.

Two statements from the advocacy and knowledge exchange cluster had rating scores that placed them in the low importance and low feasibility quadrant:

- 50. video caregivers performing daily tasks and share this with those in innovation ecosystems to show them the difficulties of caregiving; and
- 5. to get involved with local health decision making network (such as the LHINs in Ontario) to raise issues related to innovation in health and aging.

The least represented cluster, engagement, had one statement in this zone:

48. involve older adults and caregivers in dialogue with technology companies to influence their technology development.

Linkage and exchange:

39. give local companies engaged in community and technology innovation the contact information for all older adult and caregiver groups so that they can contact them for their feedback on research and product development; and

47. give older adult and caregiver groups the contact information of local companies engaged in community and technology innovation with specific areas of their development to contact and offer input.

Cluster Go-Zones

Although all of the statements are discussed in the full map go-zone graph, go-zone graphs by cluster are useful to understand the relative ratings of individual statements within each cluster for comparison and interpretation.

Public Forum:

The public forum cluster had a moderately positive relationship, $r = 0.66$.

Analysis of this cluster go-zone graph revealed the following five statements as rated highly enough on both importance and feasibility to be in the upper right go-zone quadrant:

18. seek out information on innovation in health and aging to stay up to date;
21. by attending workshops and events related to innovation in health and aging;
34. have a place in the community where seniors and their caregivers are encouraged to go to share their ideas and or experiences related to health and aging;
42. interact with students to get them interested in health and aging innovation; and
54. create an accessible seniors' information centre.

Two statements were rated as highly important but less feasible:

6. provide options to participate remotely in discussions with those involved in innovation; and
20. participate in conferences about health and aging.

One statement was rated as highly feasible but less important:

4. join or start online discussions about health and aging innovation.

Three statements were rated as low in both importance and feasibility:

1. begin a public forum where older adults can nurture an innovation ecosystem from within;
46. provide opportunities for older adults and caregivers to become educated in basics of research methods; and
52. share their opinions at local technology pitch events related to health and or aging.

Co-production and Partnership:

The co-production and partnership cluster was found to have a weak positive linear relationship, with $r = 0.39$. The go-zone for this cluster was comprised of four statements:

26. getting involved with research projects about innovation in health and aging;
33. have seniors' care facilities involved in research on innovation in health and aging;
38. get involved in innovation projects early (e.g., from planning phases) to that opinions can have an impact; and
51. develop partnerships between groups interested in health and aging innovation.

The lower right quadrant was comprised of two statements which were rated highly important but less feasible:

30. to get involved in innovation from planning stages in healthcare to set the innovation agenda; and
43. get involved in decisions related to the creation of new innovations for health and aging.

Inversely, one statement was rated as highly feasible but less important:

7. caregivers with experience who are no longer active in their role can provide input to those involved in innovation; and
28. by volunteering with an organization within the ecosystem.

As with the cluster above, three statements were rated as relatively low in both importance and feasibility:

35. get involved in resident councils in long term care or assisted living to raise issues of innovation and technology development;

- 36. have residents of long term care be involved in their facility's ethics committees to make decisions about projects taking place related to innovation; and
- 60. become a partner on research and or innovation development teams.

Engagement:

Although the engagement cluster was rated highly overall for importance and feasibility, the go-zone graph with a moderately positive relationship, $r = 0.62$, revealed that only one of the statements fell within the go-zone quadrant:

- 25. innovators should make personal visits to older adults and their caregivers to understand their needs and or issues.

In the quadrant below, with rating for high importance and low feasibility, one statement was found:

- 45. involve care providers who develop relationships with older adults and caregivers in innovation.

Two statements were rated as highly feasible and lower importance:

- 12. video older adults performing daily tasks and share this with those in innovation ecosystems to show them our difficulties; and
- 31. identify older adults who are technology "superusers" and engage them in implementation processes.

Two statements were also in the bottom left cluster, rated as relatively low feasibility and low importance:

- 24. brainstorm ideas for innovation to support health and aging, using "techies" and health care providers as advisers when needed; and
- 48. involve older adults and caregivers in dialogue with technology companies to influence their technology development.

Linkage and Exchange:

With a strong positive linear relationship, $r = 0.90$, individual statements in this cluster all fell within two quadrants with inverse meanings, the go-zone and the quadrant

with both low importance and feasibility. This cluster had the most individual statements (six) rated highly enough to be graphed into the go-zone:

2. for developers to recognize the diversity of the older adult population in terms of technology use;
16. empower care providers that work with older adults and caregivers so that they can innovate;
32. test existing technologies and give feed back on usability;
56. gather information from senior community centres about innovation needs in health and aging;
57. encourage communication between those interested in innovation (e.g., researchers, government, business, older adults and caregivers); and
58. collect feedback from various stakeholders to evaluate innovation collaboration efforts.

The remaining three statements in this cluster were graphed in the quadrant with both low feasibility and importance, giving this cluster interesting implications for action:

39. give local companies engaged in community and technology innovation the contact information for all older adult and caregiver groups so that they can contact them for their feedback on research and product development;
47. give older adult and caregiver groups the contact information of local companies engaged in community and technology innovation with specific areas of their development to contact and offer input; and
50. video caregivers performing daily tasks and share this with those in innovation ecosystems to show them the difficulties of caregiving.

Developing Cultural Capacity:

A linear relationship was not found for the developing cultural capacity cluster go-zone graph, $r = 0.15$. There is a visually clustered distribution of these statements around the means of the rating variables. In comparison with other graphs, the statements provide less clarity as to particularly actionable (or less so) statements. Although this is a very weak relationship, the positive nature of the non-linear relationship indicates that on average the statements trend towards more important and feasible ratings. The three go-zone statements are found towards the low range of importance and feasibility for this quadrant:

3. for researchers to keep older adults informed on the results of their involvement in innovation;
14. coach or mentor others in the ecosystem; and
23. advertise opportunities for seniors and caregivers to give their input on innovation in local media outlets.

The four statements in the quadrant representing high importance and low feasibility are relatively lower importance and higher feasibility, clustering them towards the go-zone statements:

9. support seniors who are not tech savvy to use computers to access information related to health and aging;
11. work to remove the mystique and fear from use of technology;
37. teach those involved in the local ecosystem how to attract the attention of older adults and their caregivers; and
49. use local media outlets (cable and radio) to engage older adults and caregivers about innovation for health and aging.

Two statements were rated as lower importance and feasibility, but aging they clustered to the mean:

13. use social media to raise awareness of issues in health and aging innovation; and
61. setting up peer networks for seniors to learn technology.

No statements were rated within the range to be interpreted as relatively high feasibility and low importance.

Advocacy and Knowledge Translation:

In contrast, this go-zone graph displays a weak negative relationship for the advocacy and knowledge translation cluster, $r = -0.10$. Again, there is a visually clustered distribution of these statements around the means of the rating variables providing comparatively less clarity as to particularly actionable (or less so) statements. The negative nature of the non-linear relationship indicates that on average the statements trend towards less important and feasible ratings with only one statement found in the go-zone quadrant:

10. create advocacy groups for older adults and caregivers interested in health and aging innovation.

One statement was also only rated to be of relatively high importance but low feasibility:

40. advocate to local health and social care decision-makers about innovation in health and aging.

In the inverse quadrant of high feasibility and low importance, four statements were found:

15. tell associations (e.g., Cancer, Alzheimer, ALS) to spend some of their time/resources identifying technology solutions currently available to help deal with day to day activities;

17. talk to local government representatives about experiences in health and aging;

29. advocate for innovation from other communities to be applied locally; and

55. advocate to change the status quo of finished products being imposed on seniors.

Finally, for this cluster, the remaining two statements were found in the low importance and low feasibility quadrant:

5. to get involved with local health decision making network (such as the LHINs in Ontario) to raise issues related to innovation in health and aging; and

41. advocate for universal access to internet for everyone.

Investment in the Ecosystem:

With a Pearson product correlation of $r=0.90$, the investment in the ecosystem cluster had a strongly positive linear correlation. As with the linkage and exchange cluster, statements here fell only within two quadrants of the graph. Interestingly, the statements in this cluster were equally divided between these quadrants. This cluster also contains the statement with the most actionable score, statement 59 (encourage local organizations working on innovation in health and aging to consult with older adults and

caregivers), which had the highest importance (4.47/5) and feasibility rating (4.17/5).

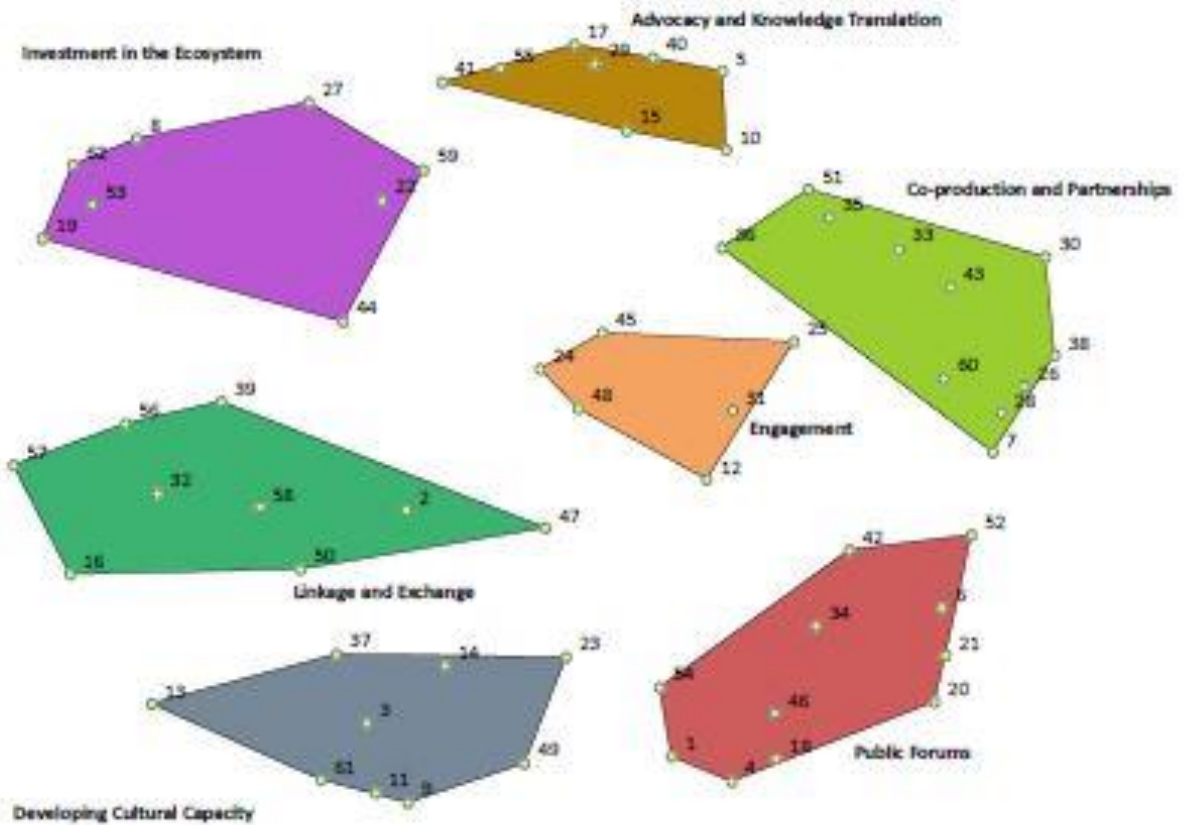
Three other statements in this cluster were rated highly to be graphed in this quadrant:

- 27. advocate for the flow of information directly from seniors and their caregivers to those who can address the issues at hand;
- 44. ensure that interested staff members involved in seniors' care have an opportunity to provide perspective on innovative technologies; and
- 53. support investment in evidence based solutions.

The other half of the statements were rated in the opposite way:

- 8. for financial incentives to be provided to companies engaging the input of seniors and caregivers;
- 19. to give seniors a small payment of appreciation for their involvements in the ecosystem;
- 22. reach out to local business association about innovation in health and aging; and
- 62. for incentives (other than financial) to be provided to companies engaging the input of seniors and caregivers.

Appendix G: Stakeholder modified framework and statements



Each number represents an idea that was sorted by participants according to meaning to them.

Participants provided a name to each cluster of ideas.

Distance in this map represents relationship- the closer ideas are together the more similar they are.

Participants ranked each idea on Importance and feasibility. The top rated ideas overall are highlighted on the next page.

The most highly rated ideas overall on foci of importance and feasibility are presented below. No ideas from Cluster 5 were rated highly enough to be included in this list, however the top idea was chosen to provide a point for discussion of this cluster.

1. Public Forums

18. seek out information on innovation in health and aging to stay up-to-date
21. by attending workshops and events related to innovation in health and aging
24. have a place in the community where seniors and their caregivers are encouraged to go to share their ideas and/or experiences related to health and aging; and
41. interact with students to get them interested in health and aging innovation.

2. Co-production and Partnerships

33. have seniors' care facilities involved in research on innovation in health and aging
38. get involved in innovation projects early (e.g., from planning phases) so that opinions can have an impact; and
42. develop partnerships between groups interested in health and aging innovation.

3. Engagement

26. instruct ideas for innovation to support health and aging using "checkers" and health care providers as advisors when needed
25. innovators should make personal visits to older adults and their caregivers to understand their needs and/or issues
43. identify older adults who are technology "savvy/aware" and engage them in implementation processes; and
45. involve care providers who develop relationships with older adults and caregivers in innovation.

4. Linkage and Exchange

3. for developers to recognize the diversity of the older adult population in terms of technology use
16. empower care providers that work with older adults and caregivers so that they can innovate
41. test existing technologies and give feedback on usability
56. gather information from senior community centers about innovation needs in health and aging
57. encourage communication between those interested in innovation (e.g., researchers, government, business, older adults and caregivers) and
58. collect feedback from various stakeholders to evaluate innovation collaboration efforts.

5. Developing Cultural Capacity

4. for researchers to keep older adults informed on the results of their involvement in innovation.

6. Advocacy and Knowledge Translation

10. create advocacy groups for older adults and caregivers interested in health and aging innovation; and
15. tell associations (e.g., Cancer Society, Alzheimer Society, AIA Society) to spend some of their time/resources identifying technology solutions currently available to help deal with day to day activities.

7. Investment in the Ecosystem

27. advocate for the flow of information directly from seniors and their caregivers to those who can address the issues at hand
44. ensure that involved staff members involved in seniors' care have an opportunity to provide perspective on innovative technologies
54. support investment in evidence based solutions; and
58. encourage local organizations working on innovation in health and aging to consult with older adults and caregivers.