

OPTIMIZING MEANINGFUL ENGAGEMENT OF OLDER ADULTS WITH
MULTIMORBIDITY AND THEIR CAREGIVERS AS PARTNERS IN
HEALTH CARE RESEARCH

OPTIMIZING MEANINGFUL ENGAGEMENT OF OLDER ADULTS WITH
MULTIMORBIDITY AND THEIR CAREGIVERS AS PARTNERS IN HEALTH CARE
RESEARCH

By KRISTINA CHANG, RN, BSCN

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements
for the Degree Master of Science in Nursing

McMaster University © Copyright by Kristina Chang, August 2018

MASTER OF SCIENCE (NURSING) 2018

McMaster University

Hamilton, Ontario

TITLE: Optimizing meaningful engagement of older adults with multimorbidity and their caregivers as partners in health care research

AUTHOR: Kristina Chang, BScN

SUPERVISOR: Dr. Maureen Markle-Reid

NUMBER OF PAGES: xvii, 186

Lay Abstract

The importance of engaging patients with multimorbidity and their caregivers as partners in health care research has been widely recognized. However, little is known about how to best engage and support them in this role. The objective of this study was to examine how researchers can best engage and support older adults with multimorbidity and their caregivers as research partners in health care research teams. The persona-scenario method was used for participants to create fictional stories. These stories were analyzed to shed light on specific strategies that can support older adults and their caregivers as partners on health care research teams, such as a patient-centred approach, identifying and addressing barriers to engagement, and clarifying roles and responsibilities on the research team. The results from this study can be used to inform research, policy, and education on supporting older adults with multimorbidity and their caregivers as research partners.

Abstract

Background: The importance of engaging older adults (≥ 65 years) with multimorbidity and their caregivers as partners in health care research has been widely recognized. Inclusion of patients as research partners has resulted in largely positive effects. However, little is known about how best to engage and support them in this role. The objective of this study was to examine how to optimize meaningful engagement of older adults with multimorbidity and their caregivers as research partners.

Methods: The research objective was addressed using the persona-scenario method. Study participants were older adults with previous experience as a research partner or a research participant. Participants worked in pairs to create a persona and a scenario about how their persona(s) was involved on the research team. Analysis was conducted in two phases: (a) identification of themes, subthemes, and codes using a qualitative descriptive approach, and (b) interpretation of themes and subthemes into design specifications (actions and products).

Results: Four persona-scenario sessions were held with 8 patient participants. Three major themes emerged from the data: (a) recruitment of patient or caregiver research partners (PCRPs); (b) planning for meaningful engagement; and (c) establishing collaborative relationships. These major themes contained 15 corresponding subthemes, and design specifications (52 actions and 37 products). Findings highlight key factors influencing the engagement of older adults with multimorbidity and their caregivers as research partners, such as the need for: early engagement of PCRPs; clarification of PCRPs' roles and responsibilities; a flexible patient-centred approach to PCRP involvement; identifying and addressing barriers to their engagement (e.g., caregiving support, transportation); training about research; and continued dialogue and feedback to clarify roles and manage expectations. The results are important for identifying ways to promote greater

patient engagement in research and ensure that the research reflects the needs of the patients it strives to serve.

Acknowledgements

Thank you to Dr. Maureen Markle-Reid for being my supervisor, and to the members of my thesis supervisory committee for sharing their expertise: Dr. Ruta Valaitis, Dr. Nancy Carter, and Dr. Carrie McAiney.

Thank you to the eight participants for sharing their experiences, and for contributing their time to this research. I hope that this research will endeavour to honour your contributions. Thank you to Laurie Kennedy, Conrad Worrall, and the administrators and staff at the Aging, Community and Health Research Unit for their dedication to the successful recruitment, data collection, transcription, and completion of my study. Thank you to the Aging, Community and Health Research Unit, McMaster University, and the Registered Nurses Foundation of Ontario for their financial support. Thank you to Mary Lynn Taylor for her guidance as the Nursing Graduate program administrator.

I would also like to thank Dr. Richard Booth, Donna Kern, and Heather Reid for their encouragement and mentorship. Special thanks to Jesse Tolan, Ashley Fr-O'Rourke, Angela Koipuram, and Dr. Sue Bookey-Bassett for their advice and support.

Finally, I would like to express my deepest gratitude to my excellent family and friends, who supported me through this journey. Thank you especially to Amy Chang, Ryan Chang, and Sarah Dougherty. Your love, support and encouragement propelled me forward.

Table of Contents

Reflective Summary: Personal Characteristics 1

Introduction and Background 2

 The Value of Engaging Patients and Caregivers as Partners in Health Care Research 5

 Engaging Older Adults with Multimorbidity and Their Caregivers as Partners in Health Care Research 8

 The Current Drivers for Policy Changes that Encourage Engagement of Patients and Caregivers as Partners in Health Care Research 11

 Organization of the Thesis 12

Chapter 2: Literature Review 15

 Literature Search Strategy and Selection Criteria 15

 Selection criteria. 15

 Results 16

 1. Planning for older adult and caregiver engagement as partners in health care research. . 16

 2. Recruiting older adult PCRPs in health care research. 18

 Identifying criteria for selecting PCRPs. 18

 Understanding the potential PCRPs’ motivations and interests for becoming involved in research. 19

 Assessing individual PCRPs’ needs for support related to involvement in research (e.g., consider physical and mental health, social determinants of health) and managing expectations of involvement in the research. 19

 Assessing and addressing PCRPs’ training needs. 20

3. Engagement of older adults and caregivers in different phases of the research	21
process.....	21
Identifying research priorities and shaping the research question.	21
Designing the intervention.	21
Persona-scenario method.	22
Experience-based co-design.....	23
PANORAMA Panel: Open space technology, world café, and charrette.....	26
Administering or pilot testing a questionnaire.	29
Serving as recruiters or data collectors.	29
Developing and pilot testing a questionnaire.	29
Developing and implementing a knowledge translation and exchange plan.	30
Involving patients in the development of a KTE plan.	30
Participating in KTE activities.	31
Summary.....	32
Research Objective	35
Research Question	35
Chapter 3: Methods.....	36
Study Setting.	37
Sampling and Recruitment Strategy	37
Recruitment strategies.....	39
Data Collection	39
Data Analysis	44

First phase: Identification of themes, subthemes and codes using a qualitative descriptive approach.....	45
Second phase: Interpreting subthemes and codes into design specifications.	46
Ethical Considerations	47
Rigour and Trustworthiness.....	47
Credibility.....	47
Transferability.....	48
Dependability.....	48
Confirmability.....	48
Chapter 4: Results	49
Recruitment and Participants	49
Persona-scenario session 1: Summary of caregiver persona.	51
Persona-scenario session 2: Summary of older adult with multimorbidity persona.....	53
Persona-scenario session 3: Summary of older adult and caregiver persona.	53
Persona-scenario session 4: Summary of caregiver persona.	54
First Stage: Identification of Themes, Subthemes and Codes	55
Second Stage: Interpretation of subthemes and codes into design specifications	58
Theme 1: Recruitment of PCRPs.....	59
Subtheme 1: Communicate expectations of PCRPs involvement.	59
Subtheme 2: Use a variety of recruitment strategies and methods.	62
Subtheme 3: Identify PCRPs caregiving needs and consider ongoing respite options as needed.	63

Theme 2: Planning for Meaningful Engagement	65
Subtheme 1: Determine PCRPs’ training and support needs related to research.	65
Subtheme 2: Be flexible with the PCRPs’ capacity to be involved and reduce the burden of participation for caregivers	68
Subtheme 3: Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings.	70
Subtheme 4: Identify a primary contact for the PCRPs within the research team.....	72
Subtheme 5: Use information and communication technology (ICT) to support information sharing between PCRPs and the researchers.	73
Subtheme 6: Partner with community-based organizations to support PCRPs’ ability to engage.	75
Theme 3: Establishing Collaborative Relationships	76
Subtheme 1: Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building.....	76
Subtheme 2: Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team.	80
Subtheme 3: Respect and treat PCRPs as subject matter experts based on their lived experience.	82
Subtheme 4: Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs.	83
Subtheme 5: Provide facilitation that encourages equal participation among PCRPs.....	84
Subtheme 6: Provide PCRPs with regular updates on the progress of the research.	86
Chapter 5: Discussion	88

Summary of Findings.....	90
Recruitment of PCRPs.....	90
Communicate expectations of PCRPs involvement.....	90
Use a variety of recruitment strategies and methods.....	90
Identify PCRPs’s caregiving needs and consider ongoing respite options as needed....	91
Design specifications for “Recruitment of PCRPs”.....	91
Communicate expectations of PCRPs involvement.....	91
Use a variety of recruitment strategies and methods.....	92
Identify PCRPs’s caregiving needs and consider ongoing respite options as needed....	92
Planning for meaningful engagement.....	92
Determine PCRPs’s training and support needs related to research.....	93
Be flexible with the PCRPs’s capacity to be involved, and reduce the burden of participation for caregivers.....	93
Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings.....	94
Identify a primary contact for PCRPs within the research team.....	96
Use information and communication technology (ICT) to support information sharing between PCRPs and researchers.....	96
Partner with community-based organizations to support PCRPs’ ability to engage. ...	97
Design specifications for “Planning for meaningful engagement”.....	97
Determine PCRPs’s training and support needs related to research.....	97
Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings.....	98

Use information and communication technology (ICT) to support information sharing between PCRPs and researchers.	99
Partner with community-based organizations to support PCRPs’ ability to engage. ...	99
Establishing collaborative relationships.	99
Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building.	100
Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team.	101
Respect and treat PCRPs as subject matter experts based on their lived experience.	102
Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs.	103
Provide facilitation that encourages equal participation among PCRPs.	103
Provide PCRPs with regular updates on the progress of the research.	104
Design specifications for “Establishing collaborative relationships”.	104
Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building.	104
Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team.	104
Respect and treat PCRPs as subject matter experts based on their lived experience.	105
Implications for Policy, Research, and Education	106
Implications for research.	106
Implications for policy.	107
Implications for professional education.	109
Strengths and Limitations	110

Persona-scenario method.	110
Snowball sampling strategy.	111
Demographics of recruited study participants.	112
Conclusion	113
References.....	114
Appendix A: HiREB Study Approval Letter	131
Appendix B: Verbal Consent Script	132
Appendix C: Demographic Survey.....	137
Appendix D: Phone/Email/Regular Mail Reminder to Participants	146
Appendix E: Information and Consent Package	147
Appendix F: Description of the Persona-Scenario Exercise.....	150
Appendix G: Guiding Questions for Persona-Scenario Development (Interview Guide).....	152
Appendix H: Persona-Scenario Session Agenda	157
Appendix I: Persona-Scenario Session – Selected Presentation Slides	158
Appendix J: Summaries of Created Personas and Scenarios	159
Appendix K: Results of Major Themes, Subthemes, and Design Specifications	174

List of Figures and Tables

Figure 1. Level of evidence of documents included in the literature review	17
Table 1. Examples of guiding questions	42
Figure 2. This figure illustrates the two stages of analysis including: (a) inductive coding; and (b) interpreting specifications (e.g., actions and products).....	46
Table 2. Summary of study participants' demographics (n=8).....	49
Figure 3. Summary of recruitment results, created personas and scenarios	52
Table 3. Examples of the subthemes, codes and design specifications for the theme, “recruitment of PCRPs”	60
Table 4. Examples of the subthemes, codes and specifications for the theme, “planning for meaningful engagement”	66
Table 5. Examples of the subthemes, codes and specifications for the theme, “establishing collaborative relationships”	77

Abbreviations and Glossary of Terms

Aging, Community and Health Research Unit (ACHRU): A program of research at McMaster University, Hamilton supported by the CIHR Signature Initiative in Community-Based Primary Health Care and the Ontario Ministry of Health and Long-Term Care Health System Research Fund Program (CIHR, 2013; Ontario Ministry of Health and Long-Term Care, 2015a).

ACHRU Patient and Caregiver Stakeholder Group: A group of older adults with patient or caregiving experiences who are currently involved in ACHRU studies as co-researchers, or advisors.

Caregiver: A caregiver refers to an informal, unpaid family member or a friend who assists and supports an older adult with multimorbidity in their activities of daily living.

Design specifications: Actions, and products that need to occur, or be implemented for an idea (referred to in this study as a code) to come to fruition (Valaitis et al., 2014).

Information and Communication Technology (ICT): Information and communication technology refers to health information and services delivered through communication devices and applications, which include radios, televisions, computers, mobile devices, mobile platforms, mobile phones, network hardware and software, the Internet, as well as satellite systems (Sawesi, Rashrash, Phalakornkule, Carpenter, & Jones, 2016).

Knowledge Translation and Exchange (KTE): Dynamic, collaborative, and iterative processes of integrating, sharing, and exchanging knowledge gained from research with knowledge users (e.g., health care service users, clinicians, policy makers) to improve experiences with the health care system (Canadian Institutes of Health Research, 2016b). These processes may occur at the end of the research study, or throughout the entire research study.

Multimorbidity: The presence of two or more chronic health conditions (Roberts, Rao, Bennett, Loukine, & Jayaraman, 2015; Van den Akker, Buntinx, & Andri Knottnerus, 1996).

Older adult: In this study, an older adult is a person who is 65 years or older.

Older adult and caregiver engagement in health care research: This term refers to older adults with multimorbidity, and patient or caregiving experiences.

Patient: To simplify the language in this study, this term will be inclusive of patients and clients. The author acknowledges that these two terms have very distinct meanings in different sectors.

Patient and caregiver engagement in research: The deliberate process of involving patients and caregivers to co-build research (Health Quality Ontario, 2016b).

Patient-Centred Outcomes Research: Refers to research that focuses on patients and their caregivers in the context of the health care system (Canadian Institutes of Health Research, 2012). According to Patient-Centered Outcomes Research Institute (2012b, para 3.) patient-centred outcomes research also “helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options”.

Patient or caregiver research partner (PCRP): In this study, refers to an individual with patient or caregiving experiences who is meaningfully engaged on the health care research team.

Principal Investigator (PI): The author, Kristina Chang, RN, BScN, M.Sc. in Nursing (student).

Registered Nurse (RN): A nurse who practices within Ontario, and is a member of the College of Nurse of Ontario (College of Nurses of Ontario, 2014).

User-centered design: A methodology originating in computer-interface design, but has since been widely used in eHealth, and participatory research (Sutcliffe et al., 2010).

Declaration of Academic Achievement

The following is a declaration that the content of this thesis was completed by Kristina Chang. It also recognizes the contributions of Drs. Maureen Markle-Reid, Ruta Valaitis, Nancy Carter and Carrie McAiney in supporting the development, implementation, analysis, and reporting of the research.

Reflective Summary: Personal Characteristics

At the time of the study, the PI was a BScN-prepared RN, full-time M.Sc. (thesis-based) student in the Nursing Graduate program at McMaster University, and a part-time research trainee with the Aging, Community and Health Research Unit at McMaster University. The PI had previous clinical experience as a staff nurse in General Medicine at an acute care, community hospital. As a result, the PI had received training and certifications from Humber College in geriatric care, cardiology, and nephrology. The PI's education and experience provided the basis for the study, and the interpretation of the findings.

Introduction and Background

The emergence of patient-oriented research in recent years is an extension of the movement to integrate patient-centred approaches into the delivery of health care (Frank, Basch, & Selby, 2014). Patient-oriented research requires engagement of health care stakeholders, including patients and informal family caregivers, in the research process (CIHR, 2014b; Patient-Centred Outcomes Research Institute, 2015). The need for greater patient and public engagement in health care research has garnered significant attention from governments in the United Kingdom, the United States, and Canada. Nurses are well-positioned to lead the implementation of patient and public engagement initiatives in health care research given their role and scope of practice.

Meaningful engagement of older adults as partners in health care research can provide researchers with a greater understanding of how to appropriately accommodate the health and partnership needs of older adults, and the impact of the patient perspective on research outcomes, and the health care system (CIHR, 2014b). Patients provide unique insight into how they experience health care services, how these services affect their health, and how these services support them in managing their health care needs. Patient engagement can improve the relevance of health research, and help transfer research findings into practice, with the goal of improving patient outcomes (Domecq et al., 2014).

Despite the acknowledgement of the importance of patient engagement in health care research, little is known about how to optimize meaningful engagement of patients and caregivers as research partners (e.g., timing, stage of research, methods of engagement; Abma, Nierse, & Widdershoven, 2009; Carroll et al., 2016; de Wit et al., 2017; Domecq et al., 2014; Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018). Moreover, many patient engagement processes fail to engage vulnerable populations, such as older adults with multimorbidity (two or

more chronic conditions; Roberts et al., 2015; Van den Akker et al., 1996), and their caregivers as research partners (Domecq et al., 2014; Marlett & Emes, 2010; McNeil et al., 2016; The Change Foundation, 2009). Of the few patients who are included as research partners on health care research teams, their patient experiences and perspectives are frequently used as a tokenistic representation for the entire marginalized population of interest (BC SUPPORT Unit, 2016). Having one or two patient or caregiver research partners (PCRPs) speak for a marginalized population may lead to the creation of stereotypes, which fails to accurately capture nuanced perspectives and experiences, and can lead to misrepresenting the marginalized population of interest.

A lack of representation of marginalized populations among research partners may be attributed to research engagement strategies that are insensitive to visible and invisible disabilities of older adults with multimorbidity (Invisible Disabilities Association, 2018), as well as social inequities such as gender, level of education, income, and other life experiences that limit opportunities for individuals of this vulnerable population to be meaningfully engaged in research (Snow, Tweedie, Pederson, Shrestha, & Bachmann, 2013). Researcher efforts to meaningfully engage patients need to balance the needs of the research, including the study timeline, and patient needs (exposure to research opportunity, strengths, skills, language barriers, level of literacy), availability (time), and supports required (resources for training, transportation, caregiving) to commit to the research partner role and activity (Snow et al., 2013). Being aware of potential barriers to patient engagement, and tailoring engagement strategies to the population of interest are crucial considerations when planning for meaningful and sustained patient engagement across the research timeline (Snow et al., 2013). More research is needed to detail effective patient engagement strategies and methods to contribute to the evidence and impact of

patient engagement (de Wit et al., 2017), especially among vulnerable populations such as older adults with multimorbidity and their caregivers (Holroyd-Leduc et al., 2016).

The objective of this study was to examine how to optimize meaningful engagement of older adults with multimorbidity and their caregivers as partners in health care research. The persona-scenario method; a user-centred design approach, was employed to understand the needs and requirements of older adults with multimorbidity and their caregivers to enhance the meaningful engagement of older adults as partners in health care research. This information may inform researchers about the design specifications needed to optimize the meaningful engagement of PCRPs from the perspectives of older adults with multimorbidity and their caregivers. For the purpose of this study, the term patient is inclusive of patients and clients. Family caregivers will hereby be referred to as caregivers, which include family, friends, neighbours and other informal providers of social support or care (CIHR, 2014a).

With origins in user-centered design, the term patient and caregiver engagement in research is defined as a purposeful process to co-build research (Health Quality Ontario, 2016a). Patient participation (as study participant) in research implies passive involvement in research where individuals with patient experiences are research participants, not research partners. The goal of engaging patients and caregivers as research partners is to promote shared decision-making and power within the research team, and minimize the risk of tokenism (Holroyd-Leduc et al., 2016; Nass, Levine, & Yancy, 2012). Tokenism is when researchers involve patients at a minimal level, or only integrate the perspectives of individuals with patient or caregiving experiences to satisfy a funding or policy requirement (Holroyd-Leduc et al., 2016; Nass et al., 2012). The goal of patient and caregiver engagement in research is to foster meaningful engagement, which

values the lived experience and novel insights that individuals with patient or caregiving experiences may share to inform health care research (Nass et al., 2012).

Meaningful engagement refers to conducting patient engagement using an approach that is patient-centred (Alzheimer Society, 2015), gender-sensitive (Snow et al., 2013), inclusive, empowering and collaborative, from the planning stages of research through to implementation and evaluation (CIHR, 2014b; Health Quality Ontario, 2016b; Patient-Centred Outcomes Research Institute, 2016). Meaningful engagement in research focuses on facilitating interactions that are satisfying to the PCRPs (Alzheimer Society, 2015). Optimizing meaningful engagement refers to: (a) accommodating the PCRPs to work on research studies that align with their interests, skills and experiences; (b) considering when and how the PCRPs would like to be involved in the research process (e.g., in consideration of the PCRPs' availability); and, (c) ensuring the PCRPs can maximize their efforts and research contributions in an interaction with researchers that is mutually satisfying (Tunis et al., 2017).

The Value of Engaging Patients and Caregivers as Partners in Health Care Research

Preliminary findings of patient and caregiver engagement in research from Canada, the United Kingdom, and the United States suggest that including individuals with patient or caregiving experiences as PCRPs, especially in the early phases, improves administrative decision-making, as well as the implementation of interventions that produce better study results (Esmail & Moore, 2015; Holroyd-Leduc et al., 2016; O'Mara-Eves et al., 2013). Engagement of patients and caregivers as research partners can influence: (a) the development and implementation of policies and protocols; (b) the hiring, training, and retention of research staff; (c) the allocation of funding; (d) the choice of meeting venue and catering; (e) outreach and communication methods; and, (f) the preparation and provision of documents and materials

(Pizzo, Doyle, Matthews, & Barlow, 2015). Patient and caregiver engagement in research has the potential to enhance the relevance of the research itself, and the widespread dissemination of research findings (International Alliance of Patients' Organizations, 2015; Nass et al., 2012).

Patient and caregiver engagement in research can also contribute to improving the delivery of a patient- and family-centred approach to health care (Fooks, 2013; Holroyd-Leduc et al., 2016). For example, patient and caregiver engagement in research can inform the development of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs; Nass et al., 2012; Selby, Beal, & Frank, 2012), which are self-reported tools or instruments that measure patient-identified priorities in health and the health care experience (Chen, 2014). PREMs and PROMs are still relatively new in their development and validation for different health conditions. There is no standardized approach to collect and report these outcomes (Canadian Institute for Health Information, 2015). Coordinating a consistent approach and use of PROMs and PREMs to measure health outcomes that are relevant to and valued by patients can allow for comparison of data across local, provincial, national and international health systems. A standardized approach to the use of PROMs and PREMs can thus benefit researchers and health policy decision-makers in program evaluations, efficient and effective delivery of health care services, and health policy decision-making (Canadian Institute for Health Information, 2017). PROMs and PREMs also have the potential to help researchers, patients, caregivers, and health care providers more accurately understand the burden of disease on quality of life, and provide opportunities for patients to provide feedback on their health outcomes and health care experiences to improve patient satisfaction (Canadian Institute for Health Information, 2015; Chen, 2014)

Additionally, the meaningful engagement of older adults with patient or caregiving experiences can contribute to intervention designs that are more suitable to the needs of service users (Bellows, Oberman, & Zimmermann, 2012; Marlett & Emes, 2010). Research that has included individuals with patient or caregiving experiences as research partners is more patient-centred (Patient-Centred Outcomes Research Institute, 2015), holds greater credibility in the eyes of individuals who will be implementing the research to practice (Carroll et al., 2016), and potentially leads to greater uptake and use of the research findings compared to research that has not engaged patients as research partners. The involvement of older adults with multimorbidity and their caregivers as partners in health care research has the potential to: (a) build capacity (Alzheimer Society, 2015); (b) equip older adults with multimorbidity and caregivers with the confidence, knowledge, and skills to provide input on their experiences with health care (Evans, Corley, Corrie, Costley, & Donald, 2011; Marlett & Emes, 2010); and (c) to improve patient outcomes (Ontario Ministry of Health and Long-Term Care, 2015b).

It is important to acknowledge that the interest in older adult and caregiver engagement in health care research and patient engagement in research is values-driven. These values include support for: (a) a more democratic process within research by involving individuals that it will affect; and (b) the empowerment of vulnerable populations (e.g., older adults with multimorbidity and their caregivers) to address inequities and transform the health care system (Ocloo & Matthews, 2016). A compelling base of expert opinions and experiences exist to suggest that there is an added value of older adult and caregiver engagement in health care research to improve the relevance, acceptability, and usability of research findings (Domecq et al., 2014; Duffett, 2016; Vat, Ryan, & Etchegary, 2017). Yet, it is an emerging field of research

and lacks empirical evidence to support and optimize its implementation (J. M. Carroll, 2000; Domecq et al., 2014; Manafo et al., 2018).

Engaging Older Adults with Multimorbidity and Their Caregivers as Partners in Health Care Research

While the importance of engaging patients and caregivers in health care research has been widely recognized, there is limited evidence for the process and impact of their involvement. Even less is known about strategies to optimize the engagement of older adults with multimorbidity, Canada's fastest growing segment of the health care population and the highest users of the health care system (McNeil et al., 2016). Older adults with multimorbidity, as health care service-users, have had limited involvement as research partners (Holroyd-Leduc et al., 2016). Most older adults with multimorbidity and their caregivers are involved as recipients of research, such as study participants, rather than as PCRPs on the health care research team. In these instances, older adults with multimorbidity and their caregivers have reported unsatisfying interactions with researchers. Many older adults with multimorbidity and their caregivers have expressed this engagement (as participants, advisors or consultants) in research to be disingenuous (Marlett & Emes, 2010), especially when they perceive that their ideas and concerns have not been validated, or acknowledged in the research (Alzheimer Society, 2015). While engaging older adults with multimorbidity and their caregivers as partners may not be feasible or appropriate for all research teams and situations, this feedback cues researchers to consider other ways that patient engagement in research (e.g., as participants, advisors or consultants) can be optimized and made more meaningful to avoid tokenism.

Moreover, there are multiple barriers to engagement that can influence the ability of older adults with multimorbidity and their caregivers to participate as research partners. These barriers

include: overlooking individual PCRPs' engagement needs (e.g., limited access to training in research and information about opportunities to become involved in research, inaccessible or unwelcoming meeting environments, lack of respite care, and a lack of a culturally sensitive approach to collaboration), disregarding power imbalances between researchers and PCRPs, having research funding constraints (e.g., insufficient funds devoted to activities for meaningful PCRPs engagement), and having limited time to recruit PCRPs (Holroyd-Leduc et al., 2016). Additional barriers may include PCRPs who are experiencing health challenges (Holroyd-Leduc et al., 2016), or are balancing the burden of caregiving responsibilities with their participation as a PCRPs (Marlett & Emes, 2010).

Currently, one in seven Canadians is an older adult, and the proportion of older adults is expected to increase to over one in four Canadians by 2037 (Government of Canada, 2014). Community-dwelling older adults with multimorbidity make up 24% of the older adult population in Ontario, but account for 40% of health care use among older adults (Canadian Institute for Health Information, 2011). The prevalence of chronic conditions among older adults in Canada continues to increase (World Health Organization, 2005) along with their impact on the health care system (Canadian Institute for Health Information, 2011).

Older adults with multimorbidity are high service users, compared to older adults with no, or single chronic conditions (Canadian Institute for Health Information, 2011). The prevalence of chronic conditions among older adults in Canada continues to increase overtime (Canadian Institute for Health Information, 2011; World Health Organization, 2005). For example, the Canadian Cancer Registry Database reported a 9% increase of cancer diagnoses among older adults between 2006 and 2009 (Canadian Institute for Health Information, 2011). In addition, between 2003 and 2009, the Canadian Community Health Survey noted a rise in the

prevalence of both diabetes and high blood pressure in older adults by 4.6% and 6.1% respectively (Canadian Institute for Health Information, 2011). The growing prevalence of chronic conditions and their impact on the Canadian health care system is predicted to be costly. The Canadian Diabetes Association (2009) reported that with increasing prevalence of diabetes among Canadians, the economic cost of diabetes to the health care system was estimated to be \$12.2 billion in 2010. This figure is anticipated to rise by another \$4.7 billion by 2020. The cost of addressing multimorbidity among older adults is further complicated by the way health care services are currently delivered using a single-illness approach rather than a coordinated approach to address multimorbidity (Canadian Institute for Health Information, 2011; Holroyd-Leduc et al., 2016).

The health outcomes and experiences of older adults with multimorbidity within Canada's health care system are directly affected by policy makers who use research to inform their decisions (Holroyd-Leduc et al., 2016). As a vulnerable population who are higher users of the health care system, older adults with multimorbidity should be provided with the opportunity to voice their perspectives and contribute to decision-making related to health care research and health care reform. Caregivers of older adults also play a key role in informing the research team of the older adult's lived experience with multimorbidity (Holroyd-Leduc et al., 2016). Engaging older adult patients with multimorbidity and their caregivers in research allows this underserved and under-researched population an opportunity to share their experiences and interactions with the health care system, (Pizzo, Doyle, Matthews, & Barlow, 2014), including potential issues with equity and accessibility that they experience with their health care services (Age UK, 2011; Holroyd-Leduc et al., 2016).

The Current Drivers for Policy Changes that Encourage Engagement of Patients and Caregivers as Partners in Health Care Research

Engagement of patients and caregivers as partners in research is more advanced in the United Kingdom compared to other countries due to the leadership of INVOLVE, a national advisory group, funded by United Kingdom's National Institute for Health Research to advance and support patient and caregiver engagement as a critical component "in National Health Service (NHS), public health and social care research" (INVOLVE, 2015). This advisory group continues today with a focus on: (a) learning and development, (b) diversity and inclusion, and (c) community and partnerships. In addition, patient and public involvement in research has become a required component for research funding applications to the National Institute for Health Research (National Institute for Health Research, 2014).

By contrast, patient engagement in Canada and the United States has a shorter history. In the US, through the Patient Protection and Affordable Care Act of 2010, the Patient-Centred Outcomes Research Institute (PCORI) was authorized and funded (PCORI, 2012a) by Congress as a non-profit, non-governmental organization to reduce the knowledge-to-practice gap by "[improving] the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decision" (PCORI, 2014, para. 3). Currently, PCORI (2014) continues to fund and disseminate health care research that demonstrates an intent to influence practice change, enhance patient outcomes, and conduct research that is relevant to patients and health care decision-makers.

In 2011, the Canadian Institutes for Health Research (CIHR) announced "Canada's strategy for Patient-Oriented Research (SPOR)" (CIHR, 2016a). This movement towards patient-oriented research was motivated in part to ensure greater accountability and transparency in

research (Allard et al., 2018; Canadian Institute of Health Research, 2015). In 2009-2010, CIHR developed the Health Research Roadmap which featured patient-oriented research as a core component of the next five-year strategy (CIHR, 2012). Consultations were held in 2010 with relevant stakeholders including academics, health care providers and professionals, as well as advocacy groups to develop the strategy for patient-oriented research (CIHR, 2012). This proposed strategy included: capacity building in patient-oriented research to foster expertise among researchers; growing patient-oriented research networks; establishing resource and support units specializing in patient-oriented research; and developing a coordinated approach to knowledge exchange, translation and dissemination (CIHR, 2012). Thus, while older adult and caregiver engagement in health care research is an emerging area of research, it is in alignment with an established, international movement towards innovative strategies and processes to transform health care systems.

Organization of the Thesis

The following provides an overview of the organization of the thesis.

Chapter 2 provides a review of the literature on the engagement of older adults and caregivers as partners in health care research. Three categories of literature emerged from this review: (1) planning for older adult and caregiver engagement in research; (2) recruiting older adult PCRPs in health care research; and (3) engagement of older adults and caregivers in different phases of the research. The results indicate that there is increasing evidence for the benefits of engaging older adult and caregivers as partners in health care research. Older adults and caregivers have been involved as partners in a variety of different ways throughout the research process, which include: (a) identifying research priorities of the study and shaping the research question; (b) designing the intervention; (c) administering and evaluating data collection

tools; and (d) assisting with knowledge translation and exchange activities. However, little is known about the strategies needed to optimize meaningful engagement of older adults with multimorbidity and caregivers as research partners.

Chapter 3 provides an overview of the methods used to address this research objective, including a summary of the persona-scenario method, the sampling and data collection strategy, and the plan for data analyses.

Chapter 4 provides a summary of the results. Three major themes were identified from the five personas and the four accompanying scenarios that were created. Descriptive identification of these themes was followed by an interpretive phase that involved extracting possible actions (activities or processes that need to happen to promote meaningful engagement) and products (products or items are needed to support meaningful engagement) related to the ideas in each of the themes. Three major themes were identified: (a) recruitment of PCRPs, (b) planning for meaningful engagement, and (c) establishing collaborative relationships with older adults with multimorbidity and their caregivers. Fifteen subthemes emerged under these three major themes, and design specifications (actions and products) were translated from the codes. In total 52 unique actions were identified, and 37 unique products were extracted under the themes.

Finally, Chapter 5 compares the study findings to the empirical and theoretical literature on patient engagement as research partners in health care research. The study findings provide new knowledge about the design specifications (actions and products) needed to optimize the meaningful engagement of PCRPs from the perspectives of older adults with multimorbidity and their caregivers. These design specifications are user-centred and are novel in how they have been presented within the context of meaningful patient engagement in health care research teams, and nursing research. The findings from this study contribute to our understanding of the

supports and resources that are needed to enhance the meaningful engagement of older adults with multimorbidity and their caregivers as PCRPs on health care research teams.

Chapter 2: Literature Review

A literature review was undertaken to examine the state of the knowledge related to engagement of patients and caregivers as research partners in health care research.

Literature Search Strategy and Selection Criteria

To identify relevant literature, electronic bibliographic databases were searched for documents between 2010-2017, including the Cochrane Library, CINAHL, PubMed, and Google Scholar. This time period was selected to align with the growing interest and funding dedicated to patient engagement in research (Boote, Wong, & Booth, 2015; CIHR, 2016; INVOLVE, 2015; Patient-Centred Outcomes Research Institute, 2015). With guidance from the Nursing Graduate librarian, the PI employed several search strategies, which included citation searching, forward citation searching or the ancestry approach, and keyword searching. Keywords focused on: “patient engagement research”, “patient engagement in research”, “patient and caregiver engagement in research”, “citizen engagement in research” (the Canadian term for “patient engagement”), and “older adults”.

Selection criteria. Literature was included if it was reported in the English language. All documents that were included in this review pertained to older adults as partners in health care research, where the individuals with patient or caregiving experiences were engaged beyond the role of a study participant, or patient consultation. No restrictions were placed on the type of study design or the study setting. As older adult and caregiver engagement in health care research is a new and emerging area of research, this review included peer-reviewed publications, as well as unpublished ‘grey’ literature (e.g., reports, guides, books, and research briefs). Published commentaries or viewpoints that had relevant titles and abstracts were excluded from the review.

Results

A total of 12 documents were included in this literature review. Six of the 12 documents were unpublished literature: one evidence review (Age UK, 2011); two guidebooks (Alzheimer Society, 2015; Marlett & Emes, 2010); and three reports (Bowen, Dearden, & Peter Wright, 2011; The Change Foundation, 2016; Tran et al., 2016). The other six documents consisted of: two realist syntheses (Holroyd-Leduc et al., 2016; McNeil et al., 2016), three qualitative studies (Evans et al., 2011; Valaitis et al., 2014; Wright née Blackwell, Lowton, Robert, Grudzen, & Grocott, 2017), and one cross-sectional survey (McKevitt et al., 2015). The literature was classified using the evidence-based pyramid (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). Background information and expert opinion forms the foundation of the pyramid, and the quality of evidence progresses to unfiltered information (e.g., case-controlled studies, case series, reports; cohort studies; randomized controlled trials), and then to filtered information (e.g., critically-appraised individual articles, critically-appraised topics, and systematic reviews; see Figure 1).

Three main themes emerged from the literature review related to engagement of patients and caregivers as research partners in health care research:

1. Planning for older adult and caregiver engagement as partners in health care research.
2. Recruiting older adult PCRPs in health care research.
3. Engaging older adults and caregivers in different phases of the research process.

1. Planning for older adult and caregiver engagement as partners in health care research. Prior to engaging older adults and their caregivers in health care research, it is paramount for researchers to have an engagement plan (Age UK, 2011a). In developing a patient engagement

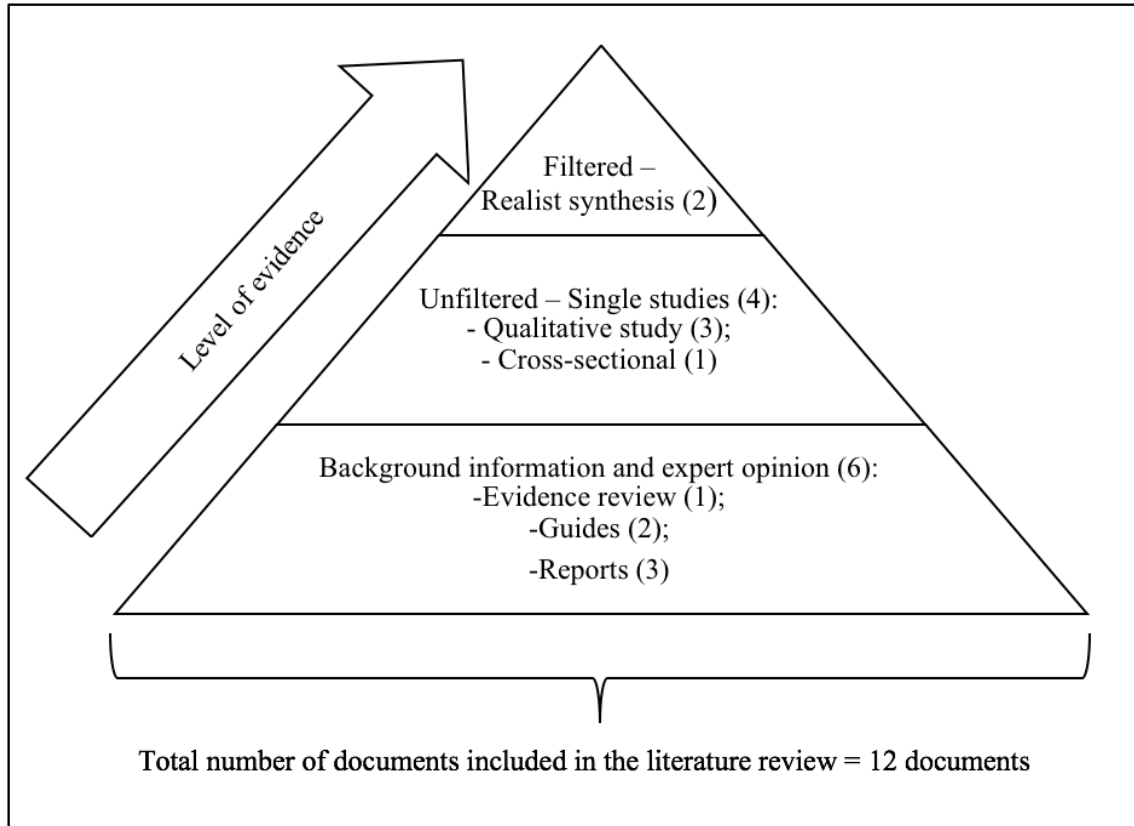


Figure 1. Level of evidence of documents included in the literature review

plan, researchers should: (a) review the study budget for patient and caregiver engagement; (b) understand where opportunities for engagement exist (e.g., specific activities); (c) identify or anticipate the potential risks of engagement (e.g., safety of partners, breach of confidentiality); (d) consider the organizational culture of the health care research team, and the buy-in for patient and caregiver engagement among researchers, administrators, and research staff; and (e) consider modes of communication (e.g., the use of ICT [telephone, email, remote attendance]) including the guidelines for communication with PCRPs (e.g., communication channels, ensuring confidentiality, resolving conflicts; Age UK, 2011a).

The evidence suggests that researchers should receive training to support meaningful engagement of older adults with multimorbidity and their caregivers in research (Holroyd-Leduc et al., 2016). Training should involve the discussion of topics, such as collaborative practice (Dahrouge, 2017;

Marlett & Emes, 2010; McNeil et al., 2016), how to receive criticism, effective communication and facilitation of team and stakeholder (e.g., community outreach) meetings, leadership skills (Holroyd-Leduc et al., 2016), conflict resolution (Age UK, 2011), cultural sensitivity and empathy (The Change Foundation, 2016), and how to establish relationships with older adults, and their caregivers (The Change Foundation, 2016). Overall, the plan for engagement should be revisited on a regular basis, and evaluated by the health care research team, which includes the PCRPs (Age UK, 2011a; Alzheimer Society, 2015).

2. Recruiting older adult PCRPs in health care research. Once a plan for engagement has been established, strategies for identifying and recruiting patient partners need to be identified. Four main themes were identified related to recruiting older adult PCRPs in health care research: (a) identifying criteria for selecting PCRPs, (b) understanding the potential PCRPs motivations and interests for becoming involved in research, (c) assessing individual PCRPs needs for support related to being involved in the research, (d) assessing and addressing PCRPs training needs.

Identifying criteria for selecting PCRPs. Researchers should carefully consider the criteria for selecting PCRPs. Characteristics of interest are often governed by the needs of the research or may be mandated by the funding authority (Age UK, 2011). Individuals who are already active members within their networks or communities are usually more approachable and interested in being involved as partners in research (Age UK, 2011a). While having research partners who are actively engaged, and socially well-connected citizens is valuable, these individuals may not be representative of the research population of interest. Thus, researchers should also consider recruiting patients through partnerships with clinicians and health care providers, community-based organizations, health and social services providers, or special-interest groups to help identify more isolated groups of individuals (Age UK, 2011a; Alzheimer Society, 2015; Arthritis Research Canada,

2017). When recruiting older adults with multimorbidity as PCRPs, researchers should also consider ways to simultaneously engage their caregivers as a strategy to address the older adult's health challenges as a barrier to engagement (Holroyd-Leduc et al., 2016).

Understanding the potential PCRP's motivations and interests for becoming involved in research. After identifying potential PCRPs, it is important for researchers to work with potential PCRPs to understand their motivations and interests for becoming involved in the research (Alzheimer Society, 2015). Understanding their motivations and interests can help researchers to involve PCRPs in meaningful ways. An informal assessment (e.g., conversation) with interested PCRPs regarding their interests, abilities, and experiences will help to determine the study or research activity that will be mutually fulfilling and satisfying for both the researchers and the patient or caregiver (Alzheimer Society, 2015). In some cases, a pre-screening process or interview may be needed to identify a good fit between the PCRPs' needs and interests, and the available research opportunities (Alzheimer Society, 2015).

Assessing individual PCRP's needs for support related to involvement in research (e.g., consider physical and mental health, social determinants of health) and managing expectations of involvement in the research. Once the PCRPs have agreed to become involved, a needs assessment is recommended, using formal or informal methods, to better understand and accommodate each PCRP's participation needs (Alzheimer Society, 2015). An assessment of the PCRP's needs, knowledge, and experience with research can help to gauge their values and expectations regarding their involvement in research (Marlett & Emes, 2010). McKeivitt et al. (2015) noted that without an explicit discussion of role expectations, PCRPs may be unaware of their role as a partner on the health care research team, or that they are taking part in research at all. The needs assessment can also help to facilitate discussions about the partner's preferences to be

acknowledged for their contributions, such as the acceptability of honorariums for their participation (The Change Foundation, 2016). It is also important for researchers to identify potential barriers to participation (e.g., low socioeconomic status, lack of transportation, poor mental or physical health), as well as strategies to address these barriers (Holroyd-Leduc et al., 2016).

Assessing and addressing PCRPs' training needs. Researchers should also assess each PCRPs' learning needs related to the research process, cultural context, and literacy levels (McNeil et al., 2016). Training should be tailored to individual needs, with the goal of building capacity and self-confidence (Age UK, 2011; McNeil et al., 2016; The Change Foundation, 2016). Suggested training topics could include: information about the research topic (Tran et al., 2016), leadership (Holroyd-Leduc et al., 2016), public speaking (Age UK, 2011), research methods, ethical conduct in research (Evans et al., 2011), field work skills (e.g., conducting interviews or surveys; Marlett & Emes, 2010), and how to write reports on the research conducted by PCRPs to update other members of the research team. Researchers should also provide resources and materials such as a comprehensive orientation package or workbooks to accompany the training (Marlett & Emes, 2010).

Marlett & Emes (2010) suggested that the training session for patient partners be less than four hours in duration. The training sessions should involve sufficient time for small group discussions to practice the newly learned skill (e.g., skills in data collection such as conducting surveys and questionnaires). Overall, researchers should conduct ongoing assessments of the PCRPs' training needs, and reflect upon the training together (e.g., via informal discussion) to evaluate changes in the PCRPs' self-confidence (Marlett & Emes, 2010) and the effectiveness of the engagement process (Alzheimer Society, 2015).

3. Engagement of older adults and caregivers in different phases of the research

process. Four main themes were identified related to engagement of older adults and caregivers as partners in different phases of the research process: (a) identifying research priorities of the study and shaping the research question; (b) designing the intervention; (c) developing and pilot testing a questionnaire; and (d) developing and implementing a knowledge translation and exchange plan.

Identifying research priorities and shaping the research question. PCRPs should be involved in the early phases of the research, such as in identifying the research priorities, shaping the research questions, and developing the study protocol (Evans et al., 2011). The early engagement of PCRPs in identifying research priorities fosters a trusting working relationship between researchers and PCRPs (Evans et al., 2011; Holroyd-Leduc et al., 2016) and helps to ensure that research priorities will be relevant and meaningful to older adults and caregivers (Evans et al., 2011). Ensuring the relevance of the research can ultimately improve the uptake of the research findings in practice. Interviews, focus groups, and surveys have been used to identify and determine relevant research priorities (Age UK, 2011; Marlett & Emes, 2010), however, there is little direction to describe specific strategies or tools that are most effective to facilitate and elicit the perspectives of older adult and caregiver research partners. For example, older adult research partners felt that focus groups were tokenistic because they did not receive recognition (e.g., acknowledgment) for sharing their perspectives, or because they did not perceive any benefits from their involvement in the session (e.g., they were not presented with the impact of their perspectives in shaping the research; Marlett & Emes, 2010).

Designing the intervention. Five main strategies were identified from the literature to engage PCRPs in co-designing interventions: (a) persona-scenario method (Valaitis et al., 2014);

(b) experience-based co-design (Bowen et al., 2011; Robert, 2013; Wright née Blackwell et al., 2017); (c) open space technology (Owen, 2004); (d) world café (The World Cafe, 2018); and (e) charrette (Michigan State University & National Charette Institute, 2016). All of these strategies utilized some form of user-centred design, an approach that focuses on tailoring an intervention specifically to the end-user's requirements (e.g., the needs and experiences of older adult patients with multimorbidity or caregivers who are engaged as partners in research).

Persona-scenario method. The persona-scenario method is a relatively new user-centred approach to intervention co-design (Valaitis et al., 2014). By first using the persona-scenario exercise, participants with a common characteristic of interest (e.g., older adults with multimorbidity) are paired off and prompted by guiding questions to create a fictitious, but relatable persona, which they then use to create a scenario (e.g., a story about how their persona co-designs a potential health care intervention). These personas and scenarios are audio-recorded and then analyzed by the researchers to interpret design specifications (actions and products), which inform the development of the user-centred health care intervention.

Valaitis et al. (2014) described engaging older adults with patient experiences in persona-scenario exercises to co-design four components of the online component of a complex primary care intervention, TAPESTRY (Teams Advancing Patient Experiences: Strengthening Quality). The online component of TAPESTRY used a system of connected technologies (e.g., an application, an online tool, and electronic health records) to help at risk individuals, including older adults and persons with multimorbidity, improve their social engagement within their community and communication within their circle of care (Health TAPESTRY, 2014). Attendees, which included older adult patients, health care providers and staff, and volunteers, were partnered to create fictitious but relatable personas and then developed stories about how

their persona interacted with TAPESTRY (Valaitis et al., 2014). This creative process allowed older adults to produce additional patient-relevant design specifications (e.g., actions to achieve a theme or idea, and items to actualize the action) for the health care research team to consider for implementation. Inclusion of the patient perspective in co-designing TAPESTRY had the potential to improve the usability and acceptability of the health care intervention.

Experience-based co-design. Experience-based co-design is an approach to intervention co-design that draws upon the concepts and methods from user-centred design, participatory action research, learning theory, and narrative-based approaches to change (Robert, 2013).

Differentiating itself from user-centred design, experience-based co-design aims to understand how health care staff and patients experience health care services through storytelling (Tsianakas et al., 2012). This structured approach includes six stages (Robert, 2013). First, the researchers set up the study (Robert, 2013). In the second stage, the health care staff's experiences are captured through participant observation and semi-structured interviews (Robert, 2013).

Simultaneously, in the third stage, the researchers conduct filmed unstructured narrative-based interviews with patients and caregivers where participants are asked to describe their experiences with the health care service since admission (Robert, 2013). These filmed interviews are then condensed to the key points (Robert, 2013). All of the patient and caregiver participants are then invited to watch a compilation of the filmed narratives and engage in an emotional mapping exercise to collectively reflect on the emotional significance of the captured key points (Robert, 2013). Stage four of the approach is where all of the patient, caregiver, and staff participants are invited to an event to view the compilation of filmed narratives and review the priorities for service improvement identified by staff, and patients and caregivers from the interviews (Robert, 2013). Occurring at the same event, stage five requires the participants to break off into four to

six smaller working groups to co-design how improvements to the health care service will be implemented (Robert, 2013). After this event, the small working groups will continue to meet over a period of three months to develop their implementation plan (Robert, 2013). Stage six concludes with all participants rejoining to share what they have achieved in the small working groups, and to plan for the next steps (Robert, 2013).

The following are selected examples of how experience-based co-design has been used in health care settings to identify older adult palliative care patient and caregiver priorities for a quality improvement initiative (Wright née Blackwell et al., 2017), and to co-design improvements to a hospital's outpatient services for older adults and their caregivers (Bowen et al., 2011). Experience-based co-design provides a structured approach for patients, caregivers, and health care staff to co-design a better health care service or care pathway by: (a) sharing stories of personal encounters and interactions with various components of the health care service; (b) working collectively to identify priority items for improvement based on the shared narratives; and/or (c) collaboratively redesigning an improved service (Wright née Blackwell et al., 2017).

In a qualitative study using experience-based co-design, Wright née Blackwell et al. (2017) reflected upon the feasibility of the approach as a quality improvement intervention for older adult palliative care patients, their family caregivers, and health care staff in the emergency department setting. The health challenges experienced by the older adult palliative care patients ultimately prevented them from participating in the co-design activity (stage four and beyond of the six-stage experience-based co-design approach). For example, many of the vulnerable, older adult palliative patients and their family caregivers were unable to leave their homes, but the researcher accommodated this barrier to participation by filming narrative-based interviews with

patients and caregivers in their homes. The staged approach of experience-based co-design allowed the researcher to be flexible and pragmatic with the patient and caregiver participants' capacity to be involved in the research process.

Bowen et al. (2011) described the impact and use of experience-based co-design in a one-year service improvement project to guide the development of innovative improvements to the hospital's outpatient services. Patients, caregiver, and staff participants were more actively involved in this co-design activity compared to the study by Wright Nee Blackwell et al. (2017). For example, patient and caregiver participants attended the co-design event, met with staff participants in subsequent small working group meetings over the course of two months, and developed proposals to implement service improvements. The greater involvement of patients and caregivers in these co-designing activities may be related to the fact that they were relatively healthy (outpatient clinic patients), which increased their capacity to be involved in this phase of the research process. Bowen et al. (2011) asserted that the experience-based co-design approach does not need to be implemented by an experienced researcher, but can be readily implemented by trained health care staff. For example, the researchers provided some of the research study's staff participants with training on how to conduct narrative-based interviews. The researchers then delegated the staff participants to conduct interviews with the patient and caregiver participants.

While the experience-based co-design approach enabled patient, caregiver, and staff participants to share their stories to identify priority areas for improvement, Bowen et al. (2011) reflected that the approach is limited because it does not offer direction on how to design solutions to address identified areas for improvement. For example, patient and caregiver participants indicated that hospital parking and traffic was a barrier to getting to their

appointments on time. While developing the proposal to address this issue, the researchers noted that patient, caregiver, and staff participants struggled to develop solutions to address this barrier because they lacked the technical expertise (e.g., traffic management, engineering). As a result, the researchers introduced a traffic management engineer, and graphic designers to the working group to draw on their expertise.

Bowen et al. (2011) also noted that when using this approach to co-designing interventions, researchers need to ensure that all participants felt that their experiences were valued, that they had a sense of control in the co-design activity, and that they had ownership over the project. The addition of the traffic management engineer and graphic designers was pivotal to furthering the proposal and enhancing the likelihood of implementing the identified improvements. However, patients, caregivers and staff had less of a direct role in developing the solutions as the traffic management engineer and graphic designers gradually assumed leadership of the project. To ensure that patient, caregiver, and staff participants continued to feel involved in the co-design, the researchers tried to maintain ongoing communication and provide updates on the project such as through “lunchtime ‘show and tell’ events, and newsletters” (Bowen et al., 2011, p.8).

PANORAMA Panel: Open space technology, world café, and charrette. The Change Foundation (2016) utilized the PANORAMA panel to gather patient perspectives and experiences with health care services to inform several initiatives; one of which was concerned with redesigning the role of patient navigators. The PANORAMA panel consisted of 31 individuals who were either receiving ongoing patient care, had at least one chronic condition, or were caregiving for someone who had a chronic condition. This report described three dynamic methods to engage panel members in sharing their ideas and eliciting their perspectives to

collaboratively redesign health care services, which included: (a) open space technology; (b) world café; and (c) charrette.

Open space technology is a “participative planning method” used by the Change Foundation (2016), which involves stakeholders voluntarily come together at an event (e.g. conference) to discuss a specific topic (e.g., patient engagement in health care research), and to re-evaluate a complex, unifying topic of interest. This method requires participants to work in groups consisting of 20-400 participants where they must self-manage the agenda (what they would like to work on) and can take place over a span of eight hours to two days (Owen, 1997). Due to the time required for this method to be effective, it is often employed in conference environments (Owen, 1997). The group determines its own leadership and functioning, and the method works best when there is no detailed agenda, predetermined outcomes or solutions to guide the process (Owen, 1997). The Change Foundation (2016) suggested the use of open space as an example of a method to facilitate discussions around participant-identified priorities.

World café was also used by the Change Foundation (2016) to engage patients (including older adults) as partners in the co-design of a health care research intervention. Participants gathered around tables in small groups to discuss a question or topic of interest for 20-30 minutes, and afterwards move onto a new table (The Change Foundation, 2016). This method required a facilitator to remain at each table to summarize and relay the discussions from all previous participants to the table’s new participants (The Change Foundation, 2016). Key points from this small group discussion can either then be summarized by the researchers and presented back to participants, or participants in the small groups can select their key discussion points to present back to everyone (The Change Foundation, 2016). The world café concludes by having

all participants vote for the top or priority points by dotmocracy (votes by dot stickers or markings with a pen) or electronically (The Change Foundation, 2016).

Charette is a collaborative strategy for multi-disciplinary teams to engage in public outreach to establish a design for health care research interventions used by the Change Foundation (2016). A charrette is a workshop that is led by the design team (researchers) to gather the public (patient and caregiver) perspective and interpret it into a design that can be implemented (The Change Foundation, 2016). Patient and caregiver participants are first invited to an orientation stakeholder meeting where the design team provides background information, and works with participants to create preliminary designs (The Change Foundation, 2016). The design team continues to work on the ideas, and participants are invited to visit the design team's workplace to provide reactions to the design, and share any additional ideas to refine the design (The Change Foundation, 2016). The design team then presents the proposed design in the second stakeholder meeting to receive feedback from participants (The Change Foundation, 2016). Overall, researchers should set aside a minimum of four days to conduct a charrette (Michigan State University & National Charette Institute, 2016).

These three design methods enabled PANORAMA panel members to collaboratively co-design the patient navigator role. Through using three different co-design strategies, panel members shared their patient perspectives, which informed and ultimately re-shaped the researchers' understanding of the role, and its acceptability among patients. While the PANORAMA panel's experiences are not generalizable, their thoughts on the patient navigator role were particularly insightful to the research team. For example, panelists expressed a desire for an existing provider within their circle of care to manage the navigator role. The addition of a

health care provider to the patient's circle of care was never previously considered by researchers as a burden to the patient's experience within the health care system.

Administering or pilot testing a questionnaire. Older adults and their caregivers have been involved in evaluating interventions by serving as recruiters or data collectors, or developing and pilot-testing a questionnaire.

Serving as recruiters or data collectors. Evans et al. (2011) described how older adults, who were not affiliated with the community-health research team, were involved in recruiting study participants and conducting in-depth patient interviews as part of evaluating an intervention. Interested individuals were invited to attend an information session on the research study followed by training on the: (a) research process; (b) ethical conduct; (c) recruitment of study participants; and (d) organization and conduct of interviews (Evans et al., 2011). These older adult recruiters and data collectors were compensated for their time and travel expenses (Evans et al., 2011). Through their involvement in the research, the older adult research partners developed confidence in their research skills, and skills in conducting interviews with participants (Evans et al., 2011). Their improved self-concept empowered them to become actively involved in research beyond the initially outlined activities, such as evaluating the effectiveness of the study participant recruitment strategies, and the interview guide (Evans et al., 2011).

Developing and pilot testing a questionnaire. Marlett & Emes (2010) engaged older adults in face-to-face meetings to develop and pilot-test a questionnaire as a component of a larger qualitative study. Based on their experiences, Marlett and Emes (2010) developed a general outline to describe the process of involving older adult research partners for researchers to reference as a resource. The researchers first summarized background knowledge of the

research study and questionnaires (as a data collection tool), and then collaboratively discussed with the older adult research partners topics of interest to address in the questionnaire (Marlett & Emes, 2010). Then in the large group, researchers continued to brainstorm potential questions (e.g., open-ended, or semi-structured) with older adult research partners (Marlett & Emes, 2010). Researchers then reduced the potential list to several questions, and pre-test the questionnaire on the older adult research partners (Marlett & Emes, 2010). Finally, the researchers asked the older adult research partners to administer the questionnaire to each other to elicit feedback on the flow, language and readability of the tool (Marlett & Emes, 2010). This process engaged older adult researcher partners to develop the questions, and make decisions on the questions that would be included. However, Marlett and Emes did not explicitly discuss optimal proportions of older adults to researchers in the working groups, the length of time required to implement this process (e.g., number of required meetings), or the flexibility to explore alternative options to meet (e.g., web conferencing if face-to-face interaction was not feasible). The researchers maintained that with adequate training, older adult research partners could effectively conduct standardized questionnaires even if they did not have extensive knowledge of the research methods (Marlett & Emes, 2010).

Developing and implementing a knowledge translation and exchange plan. Two main themes were identified related to developing and implementing a knowledge translation and exchange (KTE) plan.

Involving patients in the development of a KTE plan. McNeil et al. (2016) reported that end-of-grant KTE was “a key mechanism” (p.11) for maintaining sustained interactions between older adult research partners and researchers. Older adults and caregivers who were involved in developing an end-of-grant KTE plan reported that they were more knowledgeable about ongoing

research and KTE activities. This knowledge better informed their understanding of the research or study timeline and role expectations as a research partner, as well as helped them to identify opportunities for their engagement. In addition to providing role clarity, older adults and caregivers who contributed to developing an end-of-grant KTE plan gained a better understanding of how their contributions would be valued and acknowledged, which encouraged their continued engagement.

Participating in KTE activities. PCRPs were involved in a number of different KTE activities, including: (a) developing resource guides or toolkits; (b) co-presenting at speaking engagements; and (c) reviewing materials (e.g., pamphlets or research briefs) before public dissemination for their appropriateness (in language and content), and readability.

The Alzheimer Society (2015) worked with its patient and caregiver advisory committee to develop a resource guide for the meaningful engagement of persons living with dementia and their caregivers, which included tools and strategies for KTE activities. This resource guide was developed for staff (including researchers) and volunteers who work with people with dementia (Alzheimer Society, 2015). This resource guide described additional activities for KTE, which included speaking engagements, and reviewing documents for public dissemination (Alzheimer's Society, 2015).

For PCRPs who were comfortable with public-speaking, the resource guide offered tips and strategies to encourage them to speak at public policy, fundraising, or educational events (Alzheimer Society, 2015). The resource guide described the benefits of speaking engagements to be two-fold by providing PCRPs with a platform to share their lived-experience, as well as exposure for the Alzheimer Society and its research (Alzheimer Society, 2015). It was important to consider that the preparation required for older adults to become involved in public-speaking engagements may vary depending on the needs of the research partner. For the Alzheimer Society (2015), preparation entailed having a staff member available to offer support to the PCRP before, during, and after the

speaking engagement (e.g., to outline and prepare the format of the presentation, organize transportation to the speaking event, manage audience questions at the speaking event, and debrief about the experience with the research partner).

PCRPs can also be involved in reviewing materials from a patient's perspective (e.g., pamphlets, or research briefs) to comment on the materials' level of readability and appropriateness (Alzheimer Society, 2015). This may enhance the relevance of the research materials and improve the uptake of the research. Improving the readability of research materials for patient and caregiver audiences may reduce barriers for the members of the public to access and understand the research, and contribute to fostering more inclusive environments for interactions between researchers and the public (Holroyd-Leduc et al., 2016). The Alzheimer Society (2015) noted that this activity could be done one-on-one or in a group setting. A researcher was needed to support the PCRPs in reviewing materials, and explain the expectations and timeline for feedback (Alzheimer Society, 2015).

Summary

There is increasing evidence for the benefit of patient and caregiver engagement as research partners. However, relatively little is known about the resources and strategies needed to optimize meaningful engagement, as well as facilitators and barriers to the meaningful involvement of patients and caregivers as research partners. The literature suggests that patient engagement at different points in the research process is feasible, but more research is needed to identify methods for achieving optimal engagement. Moreover, the relevance of this literature to older adults with multimorbidity and their caregivers is undetermined. There is limited understanding, from the perspective of older adults with multimorbidity and their caregivers, on how to meaningfully engage older adults with multimorbidity and their caregivers as research

partners. Furthermore, the specific actions (what activities or processes need to happen for the event to occur), and products (what product or items are needed to support the action) which researchers may employ to optimize meaningful engagement of patients as research partners in different phases of the research process are unknown. The published literature presents high-level strategies that provide limited direction to operationalize and optimize patient engagement in health care research, while unpublished documents present actionable strategies but lack credibility, dependability, and confirmability (Lincoln & Guba, 1985). For example, with regards to the Alzheimer Society's (2015) resource guide, it is unclear as to what extent the advisory committee members were involved in producing the resource guide (e.g., co-design vs. consultation), and by what means they were involved (e.g., face-to-face meetings, teleconference, web conference, etc.).

The most widely cited barrier to meaningful patient and caregiver engagement is time and resources. Thoughtful efforts to engage older adults with multimorbidity and their caregivers in health care research are time and resource intensive. Meaningful engagement of older adults with multimorbidity and their caregivers requires a significant investment of time, as well as financial and human resources to appropriately and effectively involve PCRPs in meaningful ways. Moreover, the organization and timing of opportunities is a significant factor to ensuring meaningful engagement in research. Researchers may identify several excellent opportunities for engagement of patients and caregivers in research, but it may not be feasible to recruit PCRPs that adequately represent the target population within the time frame for the study.

The organizational culture and buy-in for patient and caregiver engagement are critical to building and maintaining engagement. In addition to being time intensive, strategies to facilitate patient and caregiver engagement can be costly. They may involve the need for additional

research staff and remuneration of research partners for their time and travel. Funding agencies that value the engagement of older adults and caregivers as research partners are needed.

The research literature on meaningful engagement in research is limited in both quantity and quality. Only six unpublished documents, three qualitative studies, two realist syntheses, and a peer-reviewed document of low-quality design (e.g., cross-sectional design) were included in this review. Documents included in this review could have also been limited by the search itself. The literature search could have been limited by the terms “patient engagement in research”, and “citizen engagement in research” as different countries refer to the term in different ways (e.g., the United States refers to “patient engagement”, Canada refers to “citizen engagement”, and the United Kingdom refers to “public involvement”).

Research Objective

The objective of this study was to examine how to optimize meaningful engagement of older adults with multimorbidity and their caregivers in health care research.

Research Question

What are the design specifications required to optimize meaningful engagement of older adults with multimorbidity and their caregivers in health care research?

Chapter 3: Methods

This study was conducted in accordance with the “Tri-Council Policy Statement, Ethical Conduct for Research Involving Humans” (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). Ethics approval for the study was obtained from the Hamilton Integrated Research Ethics Board (HiREB [#2513]; see Appendix A for HiREB approval letter).

The research objective was addressed using the persona-scenario method (Valaitis et al., 2014). A key aspect of the persona-scenario method is the active engagement of participants (Mao, Vredenburg, Smith, & Carey, 2005) through the use of the persona-scenario exercise. This involves study participants working in groups (at minimum in pairs) to create a fictitious, but relatable persona that is a composite of their characteristics and experiences (Valaitis et al., 2014). A scenario is a short story that communicates information from which to draw requirements for an innovation. Unlike traditional qualitative data collection methods, such as an interview or a focus group, the persona-scenario method is more pragmatic in identifying the needs and requirements of its participants. The pragmatism of persona-scenarios is due to the constraints that are placed on the participants when the persona is only allowed to interact within the existing tool, intervention, system or process described in the problem-based scenario (Gulliksen et al., 2003; Valaitis et al., 2014). For example, rather than discussing hypothetical transportation options for community-dwelling older adults, persona-scenario participants must describe how their persona (e.g., a 75-year-old female caregiver, with vision deficits, living in rural Ontario) will realistically meet with the health care research team at an agreed upon location. Persona-scenarios have been shown to be an effective method for co-designing and

implementing interventions, such as eHealth interventions (Chiu, 2015; Karimi, 2016; Reeder & Turner, 2011), and co-writing clinical study protocols (Weng, McDonald, Sparks, McCoy, & Gennari, 2007). Persona-scenarios have also been identified as an effective approach for the early engagement of key stakeholders to promote uptake of a primary care health service intervention (Valaitis et al., 2014).

The application of the persona-scenario method to identify the needs, requirements and limitations of older adult PCRP with multimorbidity, especially in designing nurse-led health care research interventions, is a novel approach in the Nursing discipline.

Study Setting. This study was supported by, and coordinated from, the Aging, Community and Health Research Unit (ACHRU) at McMaster University. The ACHRU is a program of research at McMaster University supported by the CIHR Signature Initiative in Community-Based Primary Health Care and the Ontario Ministry of Health and Long-Term Care, Health System Research Fund Program (CIHR, 2013; Ontario Ministry of Health and Long-Term Care, 2015a). Co-led by Drs. Maureen Markle-Reid, Jenny Ploeg, and Ruta Valaitis, the aim of this pan-Canadian program is to promote optimal aging at home for older adults with multimorbidity and to support their family caregivers (ACHRU, 2016). The ACHRU is a program of research made up of 13 funded studies that was co-developed with a diverse group of stakeholders including: decision-makers at local, provincial, and national levels; health care service providers; and patients and caregivers (ACHRU, 2016).

Sampling and Recruitment Strategy

Study participants were older adults ≥ 65 years of age, mentally competent to give informed consent, competent in English, able to travel to McMaster University to participate in a

persona-scenario session, and had previous experiences as either a research participant, or research partner (ACHRU, 2016b; Toupin-April et al., 2017).

To validate their ability to provide informed consent to enrol in the study, participants needed to score ≤ 4 on the Short Portable Mental Status Questionnaire ([SPMSQ]; Pfeiffer, 1975). To achieve representation of older adults with multimorbidity (two or more chronic conditions), the presence of chronic conditions was preferred, but not required. Likewise, there was a preference to recruit older adults with caregiving experiences (e.g., as an informal family or friend caregiver for persons with multimorbidity), to achieve a better understanding of their unique perspectives, however this was not a requirement for participation. In total, the PI aimed to recruit 8-10 study participants, to achieve a rich description of experiences with research (Marshall, Bryan; Cardon, Peter; Poddar, Amit; Fontenot, 2013; Valaitis et al., 2014). Data collection occurred until ‘data saturation’ was reached. That is, no new ideas were emerging from the data. The goal was to obtain sufficiently rich, deep, and complex scenarios (Baker & Edwards, 2012) to provide “a new and richly textured understanding of experience” (Sandelowski, 1995, p.183). A common misconception about sampling in qualitative research is that numbers are unimportant in ensuring the adequacy of a sampling strategy. Yet, sample sizes may be too small to support claims of having achieved either informational redundancy or theoretical saturation, or too large to permit the deep, case-oriented analysis that is the *raison-d’être* of qualitative inquiry. Determining adequate sample size in qualitative research is ultimately a matter of judgment and experience in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed, and the research product intended to address the research objective (Sandelowski, 1995).

Recruitment strategies. Participants were recruited to the study using purposive snowball sampling strategy. The PI recruited participants from ACHRU studies and the ACHRU patient and caregiver stakeholder group, and a community network, the Circle of Friends (a peer-based program for isolated seniors). The ACHRU administrator identified potential participants who met the study's eligibility criteria.

Eligible participants were invited to participate in a persona-scenario session that was approximately two hours in duration. The PI followed up with potential participants by phone to obtain their verbal consent to participate (see Appendix B for the study's verbal consent script). Verbal informed consent was obtained instead of written informed consent to reduce the burden on study participants.

Participants were notified that verbal consent would be audio recorded and documented. After participants provided verbal informed consent, baseline data were obtained using a sociodemographic questionnaire developed by the PI (see Appendix C). A date and time for the persona-scenario session was arranged following completion of the demographic questionnaire. Study participants were informed that they would receive a reminder by phone, e-mail or Canada Post within one week of the scheduled appointment time (see Appendix D). An overview of the research was attached to the reminder, as well as a copy of the study's information and consent form for the participant's own record (Appendix E).

Data Collection

Persona-scenario exercises were led by the PI with the help of research assistants. They took place in the ACHRU at McMaster University, and were scheduled at times that were convenient to the participants (See Appendix F for a description of the persona-scenario exercise). The PI received support from staff and students affiliated with ACHRU to coordinate

and conduct the research. The PI provided an orientation on the persona-scenario exercise and method to an ACHRU research assistant and two undergraduate research trainees who assisted the PI with note-taking during the four persona-scenario sessions.

Study participants were paired and organized into sessions based on whether they identified themselves as having experience as a patient or as a caregiver of an older adult with multimorbidity. Participants then worked in pairs through the guiding questions to create a fictitious but authentic persona that represented them, or people like themselves (older adults with multimorbidity, or caregiving experiences). They were asked to use their persona in a scenario or story that represented involvement in research as a research partner. Two packages of guiding questions were provided to help participants develop their personas and scenarios: one for individuals with patient experiences, and one for individuals with caregiving experiences. The guiding questions were derived from the main categories of literature on patient engagement described in Chapter 2, including:

1. Planning for older adult and caregiver engagement as partners in health care research.
2. Recruiting older adult PCRPs in health care research.
3. Engaging older adults and caregivers in different phases of the research process.

Once finished, each pair presented their persona and scenario in the form of a story (see Table 1 for examples of guiding questions and Appendix G for the complete set of guiding questions [interview guide]).

The session facilitators asked study participants to consider the following prompts as they created their personas:

1. Name, age, gender, marital status;
2. Level of education;

3. Living condition at home (For example: apartment, two-story house; living alone, with a spouse, a family caregiver);
4. Previous or current job;
5. Health situation: your main character will be an older adult with many long-term health problems;
6. Experience with research;
7. Comfort with, and experience with technology.

A total of four persona-scenario sessions were held with two participants at each session.

At the beginning of each persona-scenario session, participants were provided with an agenda,

Table 1. Examples of guiding questions

Themes of patient engagement	<u>Examples of guiding questions to prompt the development of the scenario(s)</u>
1. “Planning for engagement”, and “Recruitment of PCRPs in health care research”	1. How does your character find out about the health care research, and obtain the invitation to be a partner (co-researcher) on the health care research team?
2. “Recruitment of PCRPs in health care research”	2. How was your character contacted for the chance to be involved on a health care research team?
3. “Planning for engagement”, and “Engagement of PCRPs in different phases of the research”	3. What kind of training was provided to your character about health care research, if any, and how was it provided? <ul style="list-style-type: none"> a. How does your character share with researchers the kind of training or support he or she will need to be an effective partner on the team, if any? 4. As a partner (co-researcher), what is your character’s role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role? 5. How will your character communicate important patient considerations about the research to the health research team, if at all? 6. What happens at research team meetings? How is your character involved in making decisions within the research team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there? 7. How does the researcher/s interact with your character, and vice versa? 8. What materials were provided to your character and others and in what form? 9. How has your character contributed to the research? 10. What kind of resources and supports does your character receive to participate in research, if any? 11. How does your character use technology, if at all, in this story? 12. How does your character stay involve, if at all, with the research study if it takes place over a long period of time? 13. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results?

followed by a 15-minute introductory presentation, which included examples from the literature on ways to meaningfully engage older adults and caregivers in health care research to provide context for the creation of persona and scenarios (see Appendix H for the agenda and Appendix I for the presentation slides).

Participants can decide how the situation will enable the persona to carry out actions (Carroll, 2000). Scenarios usually begin as a standard, mundane situation as close to a real-life experience as possible for participants to work through (Carroll, 2000). The scenarios become more productive in facilitating concrete and enlightening discussions about the needs of participants when their persona encounters a barrier or challenge that they must interpret and solve (Carroll, 2000). The first persona-scenario session was a trial-run with two participants to determine the timing of the agenda, as well as the flow of the persona-scenario exercise and discussion, and the readability of the guiding questions (interview guide). The data collected from the trial-run session were included in the analysis. Through the trial-run session, participants confirmed that the 15-minute introductory presentation and examples of ways of engaging patients and caregivers as partners were important to understand what was being asked of them. The trial-run helped to more accurately estimate the length of time required to create the persona and scenario, collect data, and summarize the developments in the group discussion. For example, through the trial-run, it was confirmed that at least one persona and one scenario could be created within the two-hour time frame for each session. Furthermore, the trial-run ensured that improvements to the persona-scenario exercise could be made in a timely manner for the next persona-scenario session. Minor wording adjustments were made to the 15-minute introductory presentation, as suggested by participants from the trial-run. However, no changes were suggested to the interview guide.

During the creation of the persona-scenarios, the note-taker captured the key points of the participants' design choices. This summary was projected onto a screen for the participants to view in real-time. After participants created their persona and at least one scenario, the PI verbally summarized the details of their character(s) and story. This allowed the participants to verify the accuracy of the notes captured in real-time, rather than returning transcripts to participants to provide feedback.

Lay language was used to improve the readability of the introductory presentation, and the guiding questions. For example, the terms “persona” and “scenario” were replaced by “character” and “story” respectively. The creation of person-scenarios was audio-recorded to capture the dialogue that occurred between participants. Light refreshments and parking vouchers were provided to the participants during each session, and a \$50 gift card honorarium was provided at the end of the session to each participant as a token of appreciation for their time and contributions to the research.

Data Analysis

The persona-scenario sessions were digitally recorded, and all data were uploaded to NVivo (Version 11.3.2, 2016) for analysis. The audio recordings and notes taken during the persona-scenario sessions were transcribed verbatim and checked by the PI for accuracy prior to analysis. The personas were summarized from the notes that were documented by the note-taker during the persona-scenario sessions. The notes were validated for accuracy by the study participants during the discussion period in each session. The PI transcribed and corrected the transcripts where needed and maintained summary notes and field notes from each session. Through this process, the PI listened to the audio-recordings and read the transcribed content several times to identify common themes. While the personas provided necessary context for the

scenarios, the scenarios provided the data for analysis (coding). The analysis was conducted in two phases: (a) identification of themes, subthemes, and codes using a qualitative descriptive approach; and (b) interpretation of themes and subthemes into design specifications (actions and products).

First phase: Identification of themes, subthemes and codes using a qualitative descriptive approach. In keeping with a qualitative descriptive approach, the transcripts describing the scenarios were coded into descriptive qualitative codes staying as close to the data as possible (Sandelowski, 2010). These codes were then collapsed into themes. The aim of the analysis was to produce a direct “descriptive summary of the data” (Sandelowski, 2000, p.339) where the analysis is organized in such a way that resonates with the data (e.g., chronologically, or most common to least common theme, or from general to unique cases). There is no intention to interpret the data using existing theories (Sandelowski, 2010). Using NVivo (Version 11.3.2, 2016), the PI began by creating codes from phrases within the content of the first transcript, summary notes, and field notes. It is important to note that the frequent occurrence of codes may be indicative of its importance and commonality in the content (Vaismoradi, Turunen, & Bondas, 2013). These codes were then collapsed into broader themes and subthemes (Neergaard et al., 2009).

Major themes were categories of broad unifying ideas to address the research objective regarding how to optimize the meaningful engagement of older adults with multimorbidity, and their caregivers as partners in health care research. The PI also created memos to keep track of significant or contentious codes, and subthemes. The coding and development of themes was completed by the PI and checked by the PI’s thesis supervisor and committee member (Valaitis), who is an expert in the persona-scenario method. In an iterative process, the PI then worked with

her thesis supervisory committee to develop a list of the major themes, subthemes, and codes to further support rigour.

Second phase: Interpreting subthemes and codes into design specifications. The next phase of analysis involved interpretation of subthemes and codes into design specifications. Design specifications include actions required to achieve the theme or idea, and items that are required to actualize the action. For example, for the code, “ads should have high print to text contrast, and easily read colours”, the corresponding action created was, “design visually appealing materials with graphics, and easily legible text”. The corresponding product was “printed flyers”.

The PI’s thesis supervisor and thesis committee member audited a sample of the codes, actions and products to ensure that they fit. Afterwards, the major themes, subthemes, and corresponding design specifications were confirmed in meetings with the PI’s supervisor and thesis supervisory committee members (see Figure 2 for an illustration of the two-stage data analysis process).

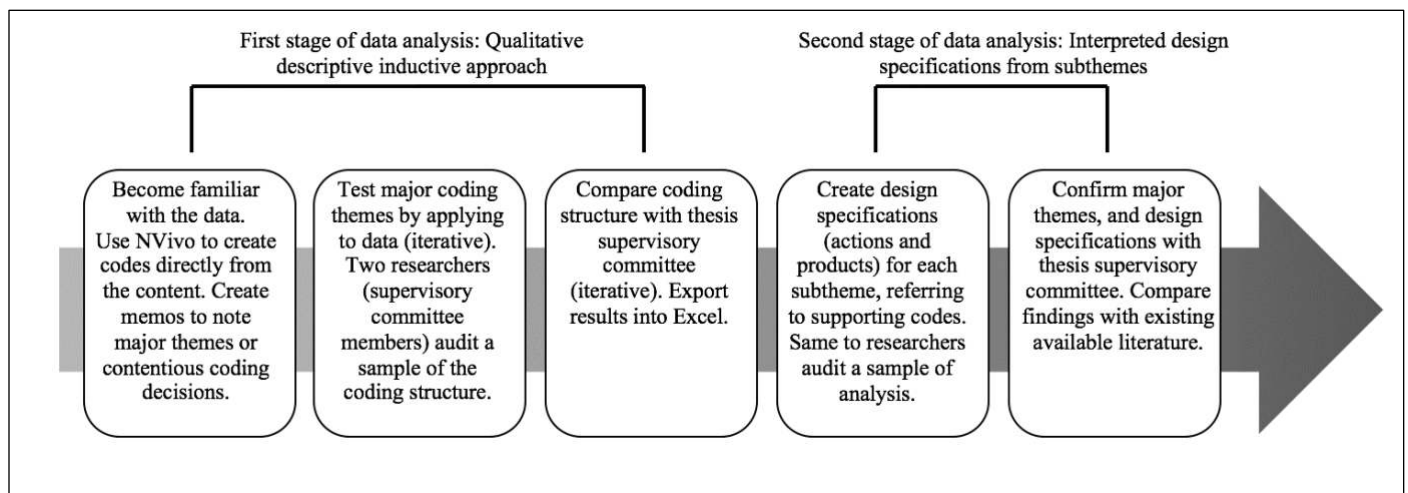


Figure 2. This figure illustrates the two stages of analysis including: (a) inductive coding; and (b) interpreting specifications (e.g., actions and products).

Ethical Considerations

All participants provided informed verbal consent for participation, which was audio-recorded. Verbal consent was selected over written consent due to: (a) the allotted two-hour time limit for the entire persona-scenario session (inclusive of the introduction, the 15-minute informative presentation, the persona-scenario exercise, the discussion, and administration of the honorarium and reimbursement for transportation); and (b) the logistics of obtaining written consent (Duggleby et al., 2017) from each potential participant before conducting a persona-scenario session.

Furthermore, if the PI had decided to obtain informed written consent via a scheduled face-to-face appointment prior to the persona-scenario session, the coordination would be at an additional financial and human resource cost to the PI and would potentially be an additional burden to the study participant's participation. In addition, by obtaining verbal consent as was done in this study, participants were provided with at least two weeks between the phone call (providing informed verbal consent), and the scheduled persona-scenario session to reconsider their commitment to participate in this study.

Confidentiality of data was maintained using unique identifiers and data were stored offline by the PI and her supervisor in password-protected files on a password-protected personal computer in a secure office space. Consent forms with identifying information and all physical documents were stored in a secure cabinet in ACHRU. Data will be kept for the required seven years.

Rigour and Trustworthiness

Credibility. The PI maintained a reflexive field diary to demonstrate credibility and document the qualitative inquiry process (Lincoln & Guba, 1985; Rew, Bechtel, & Sapp, 1993).

Credibility of the study findings were also achieved by: (a) confirming the accuracy of documented notes from the persona-scenario sessions with study participants during the discussion period; and (b) receiving clarification on emerging themes in consultation with the PI's thesis supervisor and supervisory committee members (Creswell, 2013).

Transferability. The PI demonstrated transferability of the proposed study findings through the provision of the study participants' demographic information, and a rich description of the older adults' perceptions of the major themes which optimize the meaningful engagement of older adults with multimorbidity and their caregivers as PCRPs in health care research (Lincoln & Guba, 1985).

Dependability. Dependability or reliability of the findings were achieved using a variety of strategies, including: the consistent documentation of collected evidence; training received in a two-day Patient and Public Engagement workshop; and the establishment of a coding structure audited by the PI's thesis supervisor and supervisory committee members (Lincoln & Guba, 1985).

Confirmability. Confirmability of the study findings was demonstrated through reflexive journaling, documentation of the collected raw data, confirming the accuracy of documented notes from the persona-scenario session in real time with participants, and an audit trail documented as memos in NVivo (Version 11.3.2, 2016) software to maintain transparency in the decision-making process (Lincoln & Guba, 1985).

Chapter 4: Results

Recruitment and Participants

Four persona-scenario sessions were held over four months with eight patient participants. Six of the eight participants had experience as PCRPs. The remaining two had experience as a study participant. Table 2 summarizes demographic characteristics of all participants. All the participants reported experiences as a patient; seven reported experiences as an informal caregiver. The seven participants with experience as an informal caregiver reported a mean of 14 years of caregiving experience; four of these informal caregivers were caregiving at the time of the study. Two thirds (63%) of the older adult participants were women, three quarters (75%) were ≥ 75 years of age, and similar proportions were married (38%), or widowed/divorced (38%). Participants had a mean of five chronic conditions, and almost all (88%) of the participants had multimorbidity (two or more chronic conditions). A little more than one-third (38%) of participants had annual incomes of less than \$50,000. Most (87.5%) had completed post-secondary education. All participants were Caucasian and spoke English as their primary language.

Table 2. Summary of study participants' demographics (n=8)

Total	n	%
Experiences with health care research		
PCRP	6	75
Research participant	2	25
Patient or caregiver experiences		
Patient	8	100
Caregiver	7	87.5
Gender		
Male	3	37.5
Female	5	62.5
Age group		
65-69 years old	1	12.5
70-74 years old	1	12.5
75 + years old	6	75

Total	n	%
Formal or informal caregiver		
Formal (e.g., nurse)	1	14.3
Informal (e.g., spouse or partner, parent or parent-in-law, friend, neighbour)	6	85.7
Assistance with informal caregiving		
Yes	4	66.6
No	2	33.3
Living accommodation		
House or condominium	5	62.5
Retirement home	2	25
Supportive housing	1	12.5
Marital status		
Married or living with partner	3	37.5
Never married	2	25
Divorced, annulled, or widowed	3	37.5
Education		
Completed secondary school	1	12.5
Completed some post-secondary education	2	25
Completed post-secondary education	5	62.5
Employment status		
Part-time	1	12.5
Retired	7	87.5
Total annual household income		
\$10,000-\$50,000	3	37.5
\$50,000-\$100,000	2	25
\$100,000 or greater	2	25
Prefer not to answer	1	12.5
Born in Canada		
Yes	7	87.5
No	1	12.5
Ethnicity		
Caucasian	8	100
Primary language		
English	8	100
Living situation		
Live alone	5	62.5
Spouse or partner	3	37.5
Presence of Multimorbidity		
Yes	7	87.5
No	1	12.5

	Mean	SD	Range
Years of informal caregiving experience	14.2	6.9	3-24
Number of chronic conditions	5	3.4	1-12

There were two participants at each persona-scenario session. Where possible, participants were paired based on whether they had experience as a patient or a caregiver. Five personas were created during the four persona-scenario sessions: three caregiver-personas and two patient personas (see Figure 3). Patient participants brought perspectives related to the ways in which they could be engaged in different phases of the research process. The personas are summarized below (see Appendix J for participants' detailed responses to the persona-scenario guiding question):

Persona-scenario session 1: Summary of caregiver persona. Ruth (82 years of age) was a caregiver persona. Two participants created this persona based on their caregiving experiences. Ruth is married and is the primary caregiver to her husband, Benjamin (Ben) who is in the mild to moderate stages of dementia. Ruth has early symptoms of Parkinson's disease, although they're not noticeable to others yet, hypertension, and osteoarthritis. Ruth and Ben live in a bungalow in suburban Hamilton. Ben is beginning to have behavioural symptoms (e.g., sometimes agitated and unable to tolerate or engage in social settings). He also has hypertension, renal disease, and is obese. Ruth and Ben have two children: a daughter who lives in Halifax, and a son in Vancouver. Ruth is a retired elementary school teacher, with an undergraduate degree. She has had experience as a research partner with the Board of Education. She played a role in developing new intervention strategies for students with special needs. Ruth is comfortable with some forms of technology (e.g., e-mail, basic cellphone, typewriter), and is willing to learn how to use new communication technologies (e.g., Skype). When she was still teaching in the 1990s, she had difficulty integrating new technologies into the development of report cards formatting and ended up retiring shortly after.

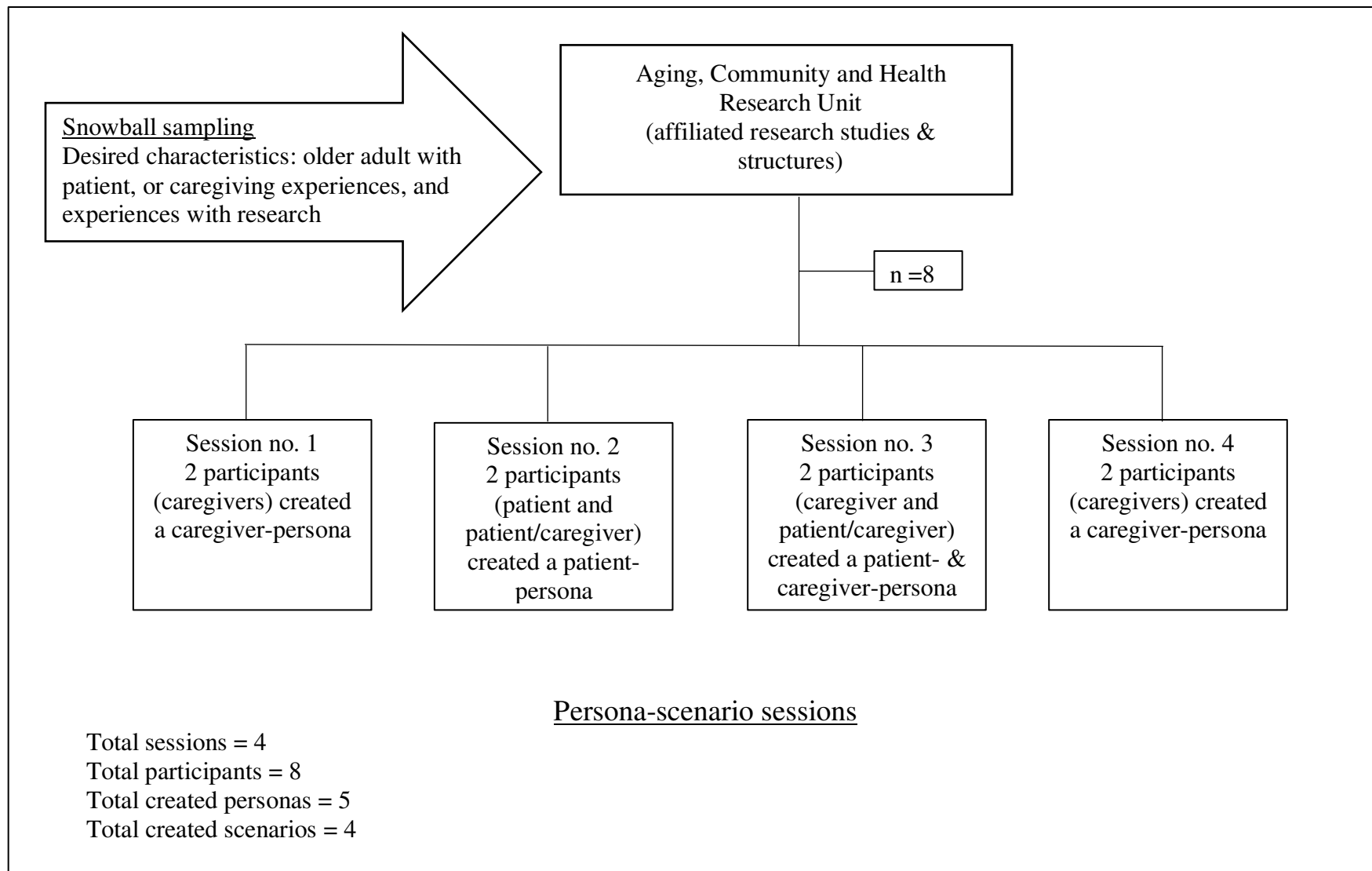


Figure 3. Summary of recruitment results, created personas and scenarios

Persona-scenario session 2: Summary of older adult with multimorbidity persona.

The two participants created this (older adult with multimorbidity) persona, which was a composite of both of their experiences with multimorbidity, and one participant's particular caregiving experiences for an older adult with multimorbidity. Myrtle (70 years of age) has Type 2 Diabetes that she manages with medications. She also has problems with mobility and pain due to arthritis (walks with a cane), osteoporosis, hypothyroidism, and is overweight. She wears glasses and has dentures. She lives alone with a cat in an apartment on the East Mountain in Hamilton. She has three children: A son works and lives in Fiji, a son who lives in British Columbia and a daughter with two grandchildren who lives near Hamilton. Myrtle still works part-time as a book-keeper and has a car that she is able to use to drive to her clients in Hamilton. She graduated from college where she studied bookkeeping and married shortly thereafter to stay at home with her children. Her previous research experience consists of being a study participant in a diabetes drug trial. Myrtle is also comfortable with using technology such as the computer (for book-keeping) and learned how to use Skype to keep in touch with her kids and extended family.

Persona-scenario session 3: Summary of older adult and caregiver persona. Matilda (69 years of age) and Matt (70 years of age, caregiver) were the personas created in the third session. The two participants created both a patient and a caregiver personas and scenario based on their experiences with multimorbidity, and one of the participant's experiences as an informal caregiver for. Matilda has been married to Matt for 50 years and is in the middle-stage of dementia (e.g., memory loss of recent and some major events, dependence on Matt for carrying out activities of daily living such as hygiene care and dressing, withdrawing from management of financial activities and use of the computer). She also has Type 2 Diabetes and hypertension.

Although previously independent, more recently Matilda has needed to rely upon Matt for help with self-care and resents her dependence on him. Matt has Type 2 Diabetes, and his eyesight is also deteriorating which led to him recently losing his driver's license. Matilda and Matt live together in a house in Scotland, Ontario, which is a rural community about an hour away from McMaster University. Matt is the primary caregiver to Matilda but requires help with groceries and housecleaning. They have a neighbour who helps to pick up the groceries and drives them to medical appointments. Matilda is a retired high school teacher, and a community leader at their church up until two year ago (with the onset of dementia). Matt is a retired auto mechanic. He is not very social but continues to accompany Matilda to church. In her previous career, Matilda was involved in collecting data within her classroom for research with the Ontario Institute for Studies in Education. She also used to be skilled with the computer and the Internet. Matt does not have any research experience, but is interested in participating in this caregiver research study to help manage his caregiving responsibilities. He is not very comfortable with technology but uses a cellphone.

Persona-scenario session 4: Summary of caregiver persona. Henry (77 years of age) is the persona created in the fourth persona-scenario session. This is a caregiver persona that was created by two male participants with caregiving experiences for older adults with multimorbidity. Henry has cardiac issues, Type 2 Diabetes, and is slightly overweight. Henry is married and is the primary caregiver to his wife, Eleanor (75 years of age), who has moderate cognitive decline and is in the early-stage of dementia (e.g., decreased memory of recent events, difficulty concentrating, withdrawing from domestic activities that she used to carry out, in denial of symptoms). Due to Eleanor's increased forgetfulness and decreased ability to concentrate, Henry has recently had to be more vigilant monitoring Eleanor in her daily

activities. They live together in a two-story detached home in Hamilton and have three children who live locally in western Canada and in the United States. Henry owns a vehicle and can still drive himself around. He is usually responsible for maintenance duties around the home and Eleanor is responsible for housekeeping and domestic duties. Eleanor has recently lost interest in her daily duties and needs help around the house. Henry is a high school graduate and is a retired licensed carpenter. He occasionally does handyman work on contract. He also attends seniors' hobby groups at the local community centre with Eleanor; Henry enjoys woodcarving, and Eleanor enjoys the crafts group. Henry has no previous experience with research but he's beginning to worry about Eleanor's declining memory and health and would like to learn more about what he can do to help. He is also comfortable with using e-mail, and Skype (to keep in touch with his children).

First Stage: Identification of Themes, Subthemes and Codes

Initially, several major themes were identified in the first stage of data analysis. Similar major themes were then refined and collapsed in an iterative process until three major themes emerged from the text data. The PI used these three major themes to help organize the data at a high level. The three major themes included: (a) Recruitment of PCRPs; (b) Planning for meaningful engagement; and (c) Establishing collaborative relationships. The relationships between these major themes are fluid; they are not presented in a linear, ordered process, but are interrelated. For example, recruitment of PCRPs does not need to occur before researchers can plan for the PCRPs' meaningful engagement in health care research. Fifteen subthemes emerged under these three major themes (Table 3). The reader may note that some subthemes resonate with more than one major theme. These instances are not uncommon, and further affirm the interconnected relationship between major themes. Furthermore, a few subthemes emerged from

some but not all the persona-scenarios. However, the inclusion of these subthemes adds richness to the major theme.

Table 3. Summary of the major themes, corresponding subthemes, and example codes

Themes	Sub-themes	Selected examples of codes
Recruitment of PCRPs	1. Communicate expectations of PCRPs' involvement	<ul style="list-style-type: none"> • PCRP will not walk into the first meeting not knowing the opportunities and expectations of participation.
	2. Use a variety of recruitment strategies and methods	<ul style="list-style-type: none"> • Post or distribute flyers in senior community centres, community-based organizations (e.g., Parkinson Canada, Alzheimer Society of Canada), or religious organizations.
	3. Identify PCRPs' caregiving needs, and consider ongoing respite options as needed	<ul style="list-style-type: none"> • Allow caregivers to bring their loved ones with them to the meetings.
Planning for meaningful engagement	1. Determine PCRPs' training and support needs related to being involved as a research partner	<ul style="list-style-type: none"> • Note PCRPs' abilities, and interests after they have learned about the research to optimize their contributions.
	2. Be flexible with the PCRPs' capacity to be involved, and reduce the burden of participation for caregivers	<ul style="list-style-type: none"> • PCRPs can be involved in ways that they will feel comfortable.
	3. Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings	<ul style="list-style-type: none"> • Researchers provide basic overviews of the research using lay language. • Physical accommodations discussed during the first meeting. • For the meeting venue, a local community centre is preferred to the university – more easily accessible by public transportation.

Themes	Sub-themes	Selected examples of codes
Planning for meaningful engagement	4. Identify a primary contact for the PCRPs within the research team	<ul style="list-style-type: none"> • Have someone for PCRPs to go to for help, or to give feedback.
	5. Use information and communication technology (ICT) to support information sharing between PCRPs and research team	<ul style="list-style-type: none"> • Use ICT to share research or meeting materials.
	6. Partner with community-based organizations to support PCRPs' ability to engage	<ul style="list-style-type: none"> • Partnerships with community-based organizations can fund and provide respite care while the caregiver is attending research meetings.
Establishing collaborative relationships	1. Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building	<ul style="list-style-type: none"> • Researchers communicate options for PCRP to network with other PCRPs (if interested).
	2. Integrate PCRPs' ideas and experiences to shape the research and acknowledge PCRPs' contributions to the research team	<ul style="list-style-type: none"> • PCRP ideas are reflected in the research. • Give verbal appreciation to PCRPs for their involvement and contributions.
	3. Respect and treat PCRPs as subject matter experts based on their lived experience	<ul style="list-style-type: none"> • PCRP are Subject Matter Experts. • Value PCRP for their knowledge (e.g., from past profession, their health [condition, etc.] and lived-experience).
	4. Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs	<ul style="list-style-type: none"> • Confidentiality is reinforced frequently within the team.
	5. Provide facilitation that encourages equal participation among PCRPs	<ul style="list-style-type: none"> • Researchers lead research meetings/sessions. • Ensures equal input sharing by all PCRP at meetings.

Themes	Sub-themes	Selected examples of codes
Establishing collaborative relationships	6. Provide PCRPs with regular updates on the progress of the research	<ul style="list-style-type: none"> • Research team keeps PCRPs in the loop as opposed to having gaps in between contact.

Second Stage: Interpretation of subthemes and codes into design specifications

In total, 52 actions and 37 products were extracted from the subthemes (duplicate actions, or products across themes were counted as one action or product, respectively). For example, the product of a study timeline appears under the major themes, “Recruitment of PCRPs”, and, “Planning for meaningful engagement”. However, a study timeline was only counted as one unique product. A detailed summary of the major themes, their corresponding subthemes, codes, and related design specifications (actions and products) is presented in Appendix K. The reader may notice that some subthemes or codes (e.g., an idea or phrase) resonate with more than one theme but has been organized under the major theme where the PI, in consultation with her supervisor and supervisory committee member, interpreted it to be the most meaningful and fit best. For example, under the major theme, “Establishing collaborative relationships”, the first subtheme concerning the provision of opportunities for PCRPs to socialize with other PCRPs emerged when participants described the recruitment of their persona. Thus, this subtheme could be organized by the timing of its occurrence (under the major theme of “Recruitment of PCRPs”) but instead was organized by its content/activity where it is believed to be more meaningful. In addition, some codes were not feasible to implement within the role or were scope of practice of a researcher. For example, participants from session three created a scenario where the researchers were responsible to ensure that their personas were transitioned from the health research intervention (e.g., regular interactions with a social worker) to similar community health

and social care support services after the study was completed. This code was reported in the data but because referring to health and social care support services is not within the role or scope of practice of a researcher, the PI did not interpret an action or product for this particular code.

Theme 1: Recruitment of PCRPs

The first main theme that emerged was “recruitment of PCRPs” to optimize the meaningful engagement of PCRPs on health care research teams. This encompassed the older adult personas’ first point of contact with the researchers up until they agreed to participate as a partner in the research. Three main subthemes were identified as influencing the recruitment of patients and caregivers as partners in research, including: (a) communicate expectations of PCRPs’ involvement; (b) use a variety of recruitment strategies; and (c) identify PCRPs’ caregiving needs, and consider ongoing respite options as needed. Table 3 provides examples of codes and design specifications for each of the subthemes related to recruitment of PCRPs

Subtheme 1: Communicate expectations of PCRPs’ involvement. Researchers need to identify potential opportunities for PCRPs to become involved in the research before recruiting PCRPs. Participants discussed how this strategy prepared PCRPs for what to expect when they commit to the research opportunity:

Have a discussion of role expectation and commitment at this point [the first point of contact or research meeting].... Just the basic aspects of it.... Cause you don’t want it to be too onerous...., it’s too much information to absorb. (persona-scenario session 2, March 22, 2017)

Participant 104: So maybe that would have been explained to her then in that first telephone conversation?... If she called the Parkinson’s Association.

Table 3. Examples of the subthemes, codes and design specifications for the theme, “recruitment of PCRPs”

Subthemes	Example codes	Design specifications	
		Actions	Products
1. Communicate expectations of PCRPs’ involvement	PCRPs will walk into the first meeting knowing the opportunities for involvement in the research and the researchers’ expectations of their role	Provide an overview of the PCRPs’ role and opportunities for involvement in the research (e.g., responsibilities, minimum time commitment, required contributions, meeting locations)	A formalized agreement or protocol on PCRPs engagement in research (e.g., purpose, time commitment, role, expectations)
2. Use a variety of recruitment strategies and methods	Ads should have high print to text contrast, and easy to read colours	Design visually appealing materials with graphics and legible text.	Printed flyers with lay language
3. Identify PCRPs’ caregiving needs, and consider ongoing respite options as needed	Researchers to pay for respite care, or to compensate caregivers for daytime meetings	Discuss caregivers’ respite needs and support options	A contact list of community- based agencies that provide caregiver support/respite

Participant 102: “Here are the opportunities that we will offer”.

Participant 104: “And these would be the expectations when you come” So she wouldn’t just walk into the meeting not knowing. (persona- scenario session 1, March 10, 2017)

Study participants also indicated that researchers would need to inform their persona of the research opportunity and role expectations for their persona to feel safe and comfortable to attend any research meeting:

Participant 105: I would think so. I think I would want to know what the expectation is from my role, I wouldn’t want to go and just have, “This is what we’re doing, and are you interested in doing it?”, and I’m going to say, “What do you want from us?”.

Participant 106: “What’s going to happen to me?”, yeah. (persona-scenario session 2, March 22, 2017)

Clear communication of the expectations of PCRPs was important for their persona(s), as it provided the persona(s) with greater knowledge of the PCRPs’ role and time commitment to make an informed decision before agreeing to participate in the research. Providing potential PCRPs with a fuller understanding of the role expectations and time commitment empowered PCRPs to discuss with researchers how they could be meaningfully engaged in the research. For example, participants highlighted the importance of providing PCRPs with information on potential research opportunities prior to the first research meeting. A potential action related to this idea is to provide PCRPs with an overview of the PCRP role (e.g., responsibilities, minimum time commitment, required contributions, meeting locations) to communicate the various options for involvement. A product that could be used to support this activity is a formalized agreement or protocol on PCRP engagement in research to guide this discussion.

Subtheme 2: Use a variety of recruitment strategies and methods. Participants identified the need to use of a variety of recruitment strategies. These included passive recruitment strategies where projects are posted and could be found by patients (e.g., by telephone, radio advertisements, or attending a meeting) to communicate their interest:

[Ruth] has shown an interest in an ad by the Parkinson’s association (a poster and newsletter). The poster read: ‘Help us create the future’ [The poster] had a high print to text contrast, in easily read colors, with large-print, with a phone number – enough to peak her interest.... Ruth used the telephone to call the number on the poster to find out about the study. (persona-scenario session 1, March 10, 2017)

Participant 107: Henry heard an announcement on the radio in which the research team were asking for partners, and also saw a recruitment flyer at the front desk of the local community centre which advertised a presentation to learn about symptoms of “short-term memory loss” That’s really what got him interested in the first place–.... “I need to know more about this”. (persona-scenario session 4, April 10, 2017)

Other active recruitment strategies were suggested including: (a) asking existing PCRPs to reach out to their personal networks, (b) reaching out to community health and social services partners, or (c) approaching potential PCRPs at local community centres or places of religious worship.

While discussing their health challenges and daily lives over coffee, [Myrtle’s] book-keeping client, who is also her friend and is involved in the research program, mentions the research program in passing.... she sees that Myrtle may have some interest in this as well, so she said, “Oh, I have the researcher’s card. I can share contact information with you”. She gives Myrtle the research unit’s business card and encourages her to contact

the researchers to become a research partner. (persona-scenario session 2, March 22, 2017)

When Matt was approached by the researchers at church. (persona-scenario session 3, April 4, 2017)

Recruitment strategies need to be tailored to the unique needs and characteristics of older adults. Some participants described that recruitment was enhanced when health care research teams supported strategies that included community outreach efforts, such as working with community leaders (e.g., religious leaders and faith communities), or presentations at community events and centres (e.g., community recreation centres). Other participants described recruitment strategies that leveraged established partnerships with local health care service providers, providing researchers opportunities to connect with potential participants. A commonly valued quality by the personas was researchers who were flexible and adaptable to the needs of older adults with multimorbidity and their caregivers. A potential action related to social-marketing and community outreach recruitment strategies included designing visually appealing recruitment materials with graphics, easily legible text, and lay-language messaging. A product that could be used to support this activity is printed flyers that used lay language.

Subtheme 3: Identify PCRPs' caregiving needs and consider ongoing respite options as needed. Participants indicated that the PCRPs' caregiving needs influenced their decision to participate in the research:

Ruth is concerned for her husband while participating in the research and would like to bring him along, rather than have home care, as her husband's social skills are well enough so that he will not be a nuisance during her participation....The possibility of a "friendly visit" is also a consideration during her participation, so Ben can stay at home

in a familiar environment....Ruth will also ask the research team if they offer compensation for paid home care during the day of participation....Respite care may be available for Ruth's husband, paid for by the research unit. (persona-scenario session 1, March 10, 2017)

However, Matt was really concerned about who would look after [Matilda] if he was away at the research meeting.... The research team contacted the neighbor to help to look after [Matilda] while Matt was at the coffee meeting.... At times where Matt is at the church for the community project and Matilda is not, the neighbor, Social Worker, or other church members will help care for Matilda at home. (persona-scenario session 3, April 4, 2017)

Eleanor did not attend and is in another area of the community centre doing crafts, while waiting for Henry to finish attending the presentation.... Eleanor is comfortable at home while Henry attends the researcher meetings, and [Henry] is okay with letting her stay at home so long as she does not drive anywhere. (persona-scenario session 4, April 10, 2017)

This data suggests that the caregiver's need for support is a significant factor influencing their decision to participate in the research. Among these three scenarios, participants identified several strategies to support caregiver involvement as a research partner, including researchers: making home visits; providing caregiver research partners with funding for respite care; allowing PCRPs to bring their loved one with them to the meeting (or venue); allowing PCRPs to attend the meeting remotely (e.g., via web or teleconference); or having a family friend or neighbour provide respite care so that the PCRP can attend research team meetings. A potential action

related to supporting caregivers to be involved as research partners included proactively identifying caregivers' respite needs and potential support options (e.g., community health partners). A product that could be used to support this activity is a list of community-based services that provide respite care.

Theme 2: Planning for Meaningful Engagement

The second main theme that emerged was planning for meaningful engagement of PCRPs on health care research teams. This involved planning for the first health care research team meeting and sustaining PCRP engagement in subsequent meetings for the duration of the research (e.g., sharing research findings). Six subthemes were identified related to planning for meaningful engagement: (a) determine PCRP's training and support needs related to research; (b) be flexible with the PCRP's capacity to be involved and reduce burden of participation for caregivers; (c) plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings; (d) identify a primary contact for PCRPs within the research team; (e) use information and communication technology (ICT) to support information sharing between PCRPs and researchers; and (f) partner with community-based organizations to support PCRPs' ability to engage. Table 4 provides examples of codes and design specifications for each of the subthemes related to planning for meaningful engagement.

Subtheme 1: Determine PCRP's training and support needs related to research.

Participants highlighted the importance of determining PCRPs' training and support needs related to being involved as a research partner. This can be done through the use of a formal needs assessment (e.g., a checklist of skills) or through an informal discussion (e.g., a one-on-

Table 4. Examples of the subthemes, codes and specifications for the theme, “planning for meaningful

Subthemes	Example codes	Design specifications	
		Action	Product
1. Determine PCRPs’ training and support needs related to being involved as a research partner	Assess PCRPs’ abilities, and interests after they have learned about the research to optimize their contributions	Discuss PCRPs’ interests through an informal conversation (via phone, or in-person) after s/he has learned about the research study. Help the PCRPs to create a list of self-identified strengths and abilities that they can bring to the team and use this list to align their skills to the study or project.	A list of self-identified strengths and abilities that the PCRPs can bring to the team (e.g., different ways to contribute to the research team)
2. Be flexible with the PCRPs’ capacity to be involved, and reduce the burden of participation for caregivers	After initial involvement in research, further contributions by PCRPs can be renewed based on their availability and the opportunities for involvement	Renegotiate each PCRPs’ level of commitment on an ongoing basis (depending on interests, abilities, and availability).	A ‘living’ agreement for participation or agreement on role expectations and time commitment for all team members
3. Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings	For the meeting venue, a local community centre is preferred to the university – more easily accessible by public transportation	Ensure meeting venue is functionally accessible (e.g., to visual, hearing, or mobility impairments), and at a convenient location (e.g., accessible via walking or public transportation).	A venue that is accessible (e.g., located near public transportation) and the provision of physical and functional accommodations as needed (e.g., a sound system to amplify conversations)
4. Identify a primary contact for PCRPs within the researcher team	Have someone for PCRPs to go to for help, or to give feedback	Designate a research staff member to regularly communicate with PCRPs, and to answer questions or receive feedback.	A role description for this primary contact (with respect to their role to support PCRPs)

Subthemes	Example codes	Design specifications	
		Actions	Products
5. Use information and communication technology (ICT) to support information sharing between PCRPs and researchers	Use ICT to share research or meeting materials	Prepare electronic and physical copies of meeting materials to be distributed before/at meetings (e.g., on an encrypted USB, or hard copies through confidential mail where appropriate).	Funding for ICT provision and support (from national funding bodies, community organizations, or special-interest groups)
6. Partner with community-based organizations to support PCRPs' ability to engage	Liase PCRP with primary care clinicians as resources to help with management of progressive conditions	Partner with community-based organizations to identify and suggest potential health care and social services that PCRPs may consider approaching.	A list of community health and social care services and supports (as previously mentioned)

one conversation). This was important to understand the persona's training and support needs and determine where the older adult would be interested in making contributions to the research.

[Matt] has no previous experience with research but became interested in participating in a caregiver research study to help manage his responsibilities caring for Matilda.... Matt was approached to receive extra training from the researchers and the Alzheimer's Society, but he decided to go to the Scotland library to attend a video conferencing session instead because he was unable to accommodate the time provided by the researchers. This training session was set up through local librarian. (persona-scenario session 3, April 4, 2017)

Participant 104: And I wonder too about her own emotional status. Often people with Parkinson's... experience depression... So, the researchers certainly may recognize that they need to have interactions with her in different ways. I mean, there might be days where she's not up to coming to a meeting. So, what other opportunities would there be for her to participate? Face-to-face and with other people may not always fit her state..., both the researchers and the participants can set up the most advantageous conditions possible. (persona-scenario session 1, March 10, 2017)

Researchers need to be proactive in planning for meaningful engagement. This includes determining each PCRPs' research interests and training needs to develop a training plan.

Subtheme 2: Be flexible with the PCRPs' capacity to be involved and reduce the burden of participation for caregivers Participants identified the need for researchers to be flexible in how the PCRPs are involved in the research and consider how to reduce the burden of participation for caregivers. Researchers should be flexible with respect to: (a) the time PCRPs are willing to commit to the role; (b) the nature of their involvement in the research (e.g.,

providing feedback, shaping the research question, co-design); and (c) how PCRPs attend the research meetings (e.g., home visits, teleconference, web conference).

Ruth may need an alternative to in-person attendance if her husband is not well or exhibiting signs of distress associated with Ruth leaving the house, as he may not feel like a priority for her anymore. This may cause increased friction and stress between Ruth and her husband, which may complicate her contributions to the research on reliable basis.... And when you have a big day-long meeting you might want to make other activities or resources available [for Ben]. (persona-scenario session 1, March 10, 2017)

If Myrtle couldn't make it due to health conditions or any other reasons, then she can have a conference call. (persona-scenario session 2, March 22, 2017)

In all four scenarios, participants created persona(s) that encountered realistic challenges, due to an exacerbation of their chronic conditions or because of caregiving responsibilities, while trying to meaningfully engage in research. Participants identified the need for researchers to consider alternative ways for PCRPs to attend research meetings. For example, a PCRP with mobility and pain issues may not be able to travel to the meeting venue. Participants identified the importance of researchers checking-in with the PCRPs on a regular basis to ensure that the role and time commitments are manageable and do not overwhelm self-care and caregiving responsibilities. Participants suggested that researchers provide short-term opportunities for engagement to minimize the time commitment of the PCRP and the impact of their involvement on caregiving responsibilities. A potential action related to this idea was to provide PCRPs with short-term opportunities within the research. A related product is a study timeline indicating the type and timing of these activities within the research would take place.

Subtheme 3: Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings. Participants highlighted the importance of considering the content, duration, location, and format of the meetings, as well as the proportion of researchers to PCRPs at each meeting. The following excerpts from the scenarios identify concerns such as time commitments, use of lay language, transportation to the research team meetings, and the need for accommodations for physical limitations:

Researchers review each research partner’s functional ability to utilize technology related to the research, and accommodate functional disabilities, using technology where applicable (e.g., touch screens and tablets for issues with finger dexterity). (persona scenario session 1, March 10, 2017)

Participant 103: I think we have to stop using the term “research” so much, cause certain people that I work with are scared and they don’t want to participate.... So we need to present the research team in a way that’s...comfortable..., I’d use...research project or community project. (persona-scenario session 3, April 4, 2017)

Researchers need to provide accommodations for physical limitations, and use everyday language to describe the research opportunity to make PCRPs feel comfortable as part of the research team. The following excerpts from the notes and transcripts of session 1 and 2 discuss how researchers addressed PCRPs’ barriers to participation, especially with regards to involving PCRPs in decision-making, and ensuring their sustained engagement over the length of the study timeline (e.g., for a prolonged period of time, beyond attending one research meeting):

Participant 102: If Ruth is unable to attend a decision-making meeting, she will be provided with the option to listen to an audio recording of the meeting, accompanied by a

summary with key points for her to review. (persona-scenario session 1, March 10, 2017)

If Myrtle couldn't make it due to her health conditions or any other reasons, then they [the researchers] can have a conference call. She is comfortable with using the phone. (persona-scenario session 2, March 22, 2017)

Researchers need to make the older adult PCRPs' comfort a priority, by accommodating the PCRPs to continue to be involved in ways that work best for him/her. Researchers should explore ways of facilitating the inclusion of PCRPs if they are unable to attend in-person (e.g., attending by teleconference if the PCRPs prefer communication by telephone). Researchers who make a conscious effort to consider any barriers to participation in the research (e.g., consider the PCRPs' strengths and availability) demonstrate to the PCRPs that their presence is wanted, and that their perspectives are valued in the research process.

Furthermore, participants noted that the older adults' transportation needs are an important consideration in determining the research meeting's location. For example, it may not be feasible for the older PCRPs to travel from their rural community to the nearest academic institution. If researchers failed to address the PCRPs' transportation needs (e.g., lack of transportation to the meeting venue), participants discussed that their personas would be unable to overcome this barrier to engagement. As a result, the participants chose to hold the research meetings at the local church that was within walking distance from the personas' house.

Participants highlighted the need for researchers to create an environment that is inclusive and accessible to older adults with multimorbidity. This includes addressing any physical, mental or socioeconomic barriers to their participation, such as physical or mental health challenges, caregiving responsibilities, access to ICT, and access to transportation to the meeting venue.

Potential actions related to this idea were to orient the PCRPs to the research, and to prepare the content, materials, and logistics for subsequent research meetings in consideration of each PCRP's barrier(s) to participation and support needs. Participants suggested that researchers could provide a presentation to potential PCRPs on the research study. A potential action related to this idea was to provide background materials in lay language so that they can be clearly understood by PCRPs. A related product is a PowerPoint presentation that provides a brief overview of the study, the study timeline, and role expectations.

Subtheme 4: Identify a primary contact for the PCRPs within the research team.

Participants identified the need for a primary contact for the PCRPs within the research team. This individual will be responsible for organizing the research meetings, facilitating communication between the PCRPs and the researchers, and addressing the PCRPs' questions and concerns.

Researchers made clear to Myrtle that she could contact a staff member at the research unit (e.g., research coordinator) for health accommodations, or if she needed any help (e.g., concerns with training, to provide feedback)... Having someone organize the [research] meetings.... If there is a conflict – If she was comfortable with other researchers, she would speak up to them, or otherwise direct it privately [to a research staff]. I don't think she'd want to be involved if it's not communicative. [Myrtle] would leave the program (persona-scenario session 2, March 22, 2017)

If Matt still has some questions, a researcher or research staff will direct him to supportive resources. (persona-scenario session 3, April 4, 2017)

Researchers or research staff should be in contact with the PCRPs on a consistent basis to establish a trusting and supportive professional relationship, which can enable meaningful PCRP

engagement. An example of a code supporting this subtheme was expressed as the risk of PCRPs leaving the research team if the group is uncommunicative when a conflict exists. The action translated from this code was to have the primary contact (research staff) receive training on topics such as patient engagement, effective communication and facilitation of team meetings, cultural sensitivity and empathy, confidentiality, and conflict resolution. The corresponding product included training materials or resources for researchers pertaining to these topics. These could be existing resources or new resources related to these topic areas.

Subtheme 5: Use information and communication technology (ICT) to support information sharing between PCRPs and the researchers. Participants indicated that ICT could be used to support effective communication and information sharing between PCRPs and the research team. For example, ICT could be used as an alternative to in-person meetings where the PCRP's input was required to make a decision, share meeting minutes and the upcoming agenda, and obtain PCRP's feedback on a data collection tool:

The possibility of Ruth utilizing a communication tool such as Skype, would benefit her on the days that she does not feel able to leave the home, which would hopefully optimize her contributions.... Ruth receives various forms of materials from the researchers by means of Purolator (hard-copies and USB keys etc.), email attachments.... So people might not be so good at keyboards and they need touch screen...., there needs to be a real careful review of their functional level and their ability to use technology with or without accommodation for access...., we won't know until [the researchers] have the funds available to make that accommodation requirement, and people who are skilled as people who to teach and train how to use technology will. Otherwise you have to plan for the lowest tech interventions and cost more time.... Cause if everything is electronic, you

have better sources of print data to deal with. (persona-scenario session 1, March 10, 2017)

I'm also envisioning having some pamphlets available for some of the support groups that are out there. (persona-scenario session 3, April 4, 2017)

Participants indicated that the persona's first point of contact with the researchers (e.g., at the first research meeting or orientation to the research) would be the most appropriate time for researchers to identify, discuss and confirm the PCRPs contact information, their preferred mode of communication and their comfort with the use of ICT (e.g., email or telephone). Based on this code, the action interpreted was of researchers conducting round table discussions on the PCRPs' comfort with use of ICT in small groups (e.g., five PCRPs and two researchers). A semi-structured discussion guide, or a checklist that assessed the participant's skills and comfort with technology was the product that the PI interpreted to guide these roundtable discussions.

Participants included the use of ICT in all four scenarios and ensured that any new forms of ICT (e.g., video or web conferencing solutions) were accompanied with appropriate training. If insufficient funds were available to provide ICT and the necessary training related to ICT, researchers proposed to adopt lower technological interventions (e.g., telephone calls, or hiring a research staff to coordinate face-to-face meetings). Participants indicated that the cost of ICT to support information sharing is unknown. A potential action related to the use of ICT included considering the cost implications related to the mode of engagement (e.g., use of digital ICT, which include applications, devices and systems that allow people to communicate electronically in digital form vs. lower-tech forms of ICT that are not integrated with computer networks such as telephones). Related products to support this action includes funding for ICT support; digital ICT (e.g., software and licensing, access to web platforms, tablets, etc.); lower-tech ICT

interventions (e.g., using telephones in combination with mailing hard-copies of documents to PCRPs, or home/in-person visits); and ICT support (e.g., personnel or system to troubleshoot issues with ICT, or a contingency plan if ICT fails).

Subtheme 6: Partner with community-based organizations to support PCRPs' ability to engage. Participants suggested that partnering with other organizations, such as health and social service providers and advocacy groups can be used to address barriers to PCRPs participation in research. These community-based organization could potentially assist in providing respite services, transportation to a research team meeting, or funding opportunities.

And you need partners. Research people need partners who can actually deliver the services for respite, or for transportation. To make sure that people can get to participate in the activities. And the Parkinson's group can help with communications because not only are you going to publish the research, but they can put stuff out in their newsletter. And they can also help to pay for some of the incidental costs for some of the stuff that you can't get the major research funders to pay for because I know there are a whole bunch of things that are excluded. (persona-scenario session 1, March 20, 2017)

The research team should have a social worker to help with caring for Matilda while Matt is at the research meetings. (persona-scenario session 3, April 4, 2017)

Partnering with community-based organizations or service providers can be used as a strategy to access supports for the PCRPs that would otherwise be outside of the researchers' capacity (e.g., due to insufficient funding, or outside of the researcher's role and scope). These partnerships also have the potential to expand the researchers' networks and can be used as a vehicle for disseminating research findings. Participants indicated that partnerships between researchers and community-based organizations can provide researchers with access to potential

funding opportunities for caregiving or respite care services to support PCRPs. A potential action related to this idea is for the researchers to establish partnerships with community-based organizations. A related product is a list of community-based services and supports for PCRPs to consider.

Theme 3: Establishing Collaborative Relationships

The third main theme that emerged was establishing collaborative relationships with older adults with multimorbidity and their caregivers to optimize the meaningful engagement of PCRPs on health care research teams. Six subthemes emerged related to establishing collaborative relationships: (a) provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building; (b) integrate PCRPs' ideas and experiences to shape the research and acknowledge PCRPs' contributions to the research team; (c) respect and treat PCRPs as subject matter experts based on their lived experience; (d) ensure confidentiality or non-disclosure of sensitive information shared by PCRPs; (e) provide facilitation that encourages equal participation among PCRPs; and (f) provide PCRPs with regular updates on the progress of the research. Table 5 provides examples of codes and design specifications for each of the subthemes related to establishing collaborative relationships.

Subtheme 1: Provide opportunities for PCRP to network or socialize with other PCRPs to build trust and for relationship building. Participants highlighted the importance of providing PCRPs with the opportunity to socialize with other PCRPs to develop peer relationships and foster a network of PCRPs. This opportunity to socialize was described by participants as being especially meaningful to socially isolated older adults or caregivers

Table 5. Examples of the subthemes, codes and specifications for the theme, “establishing collaborative relationships”

Subthemes	Example codes	Design specifications	
		Actions	Products
1. Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationships building	Researchers communicate options for PCRPs to network with other PCRPs	Provide the option for PCRPs to opt out of networking or socializing opportunities.	(Consenting) PCRPs’ contact information compiled in a list to be shared amongst PCRPs
2. Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team	Create a visually-appealing log to keep track of PCRPs’ contributions, but not as complicated as a Gantt chart	Design a visually appealing log for all team members (researchers and PCRPs) to keep track of their involvement in the research study.	A print or electronic log to keep track of PCRPs’ contributions
3. Respect and treat PCRPs as subject matter experts based on their lived experience	Avoid treating PCRPs like study participants	Treat PCRPs as you would when inviting other researchers to the health care research team, as equally knowledgeable experts.	An agreement for participation or agreement on role expectations and time commitment for all team members
4. Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs	Have a safe communication channel for PCRPs, without fear of confrontation	Ensure PCRPs are aware of the communication channels within the team, and that they feel comfortable to ask questions or voice concerns.	Research staff identified by researchers as primary contact to PCRPs
5. Provide facilitation that encourages equal participation among PCRPs	Sets aside time for meetings to include a question and answer period	Consider allotting time during the research health team meetings for a question and answer period.	Allotted time during meetings for question and answer period

Subthemes	Example codes	Design specifications	
		Actions	Products
6. Provide PCRPs with regular updates on the progress of the research	Research team reports to PCRPs on how their feedback is integrated into the research	Maintain regular communication with PCRPs via e-mail or a newsletter, even if they are not directly involved in the current phase (e.g., data analysis).	Newsletter or e-mail template for providing updates to PCRPs

The group of people with Parkinson's are given the opportunity to exchange telephone numbers and email addresses (networking opportunity) some do, and some opt not to.

(persona-scenario session 1, March 10, 2017)

Have snacks. And lots of times when you're having an informal type of thing like that people are more open to talking as well.... But I wouldn't think that this happens all the

time. (persona-scenario session 2, March 22, 2017)

So, the meetings are very social. They provide coffee and biscuits, and so it's almost like a social time with questions by the research team who lead the session.... And that works very well for Matt, because he's socially not.... By interaction with other caregivers in the area, Matt learns about other resources in the community that he

wouldn't normally hear about if he didn't attend the meetings. (persona-scenario session 3, April 4, 2017)

Participants described informal settings (e.g., snack time) for PCRPs to socialize amongst themselves and to develop trusting and communicative relationships. Peer socialization allowed PCRPs to share their combined knowledge of helpful community resources that others may not have been aware of before becoming a research partner. However, participants acknowledged that these socializing opportunities would not be a mandatory component of the PCRP role. For example, participants indicated that PCRPs were able to opt out of these group socials if they felt uncomfortable with sharing their contact information or socializing with others. A potential action related to this idea was to allow PCRPs to opt out of social networking if they feel uncomfortable (e.g., to share contact information). A related product was to share a contact list of only the consenting PCRPs' contact information among the research team.

Subtheme 2: Integrate PCRPS' ideas and experiences to shape the research and acknowledge PCRPs' contributions to the research team. Participants highlighted the importance of creating a safe and relaxed environment for the PCRPs to feel comfortable and willing to share their ideas and experiences with the health care research team.

See there's an interesting thing about orientation to research... because they all need to be comfortable with the disclosure that they have that disability, and that they are willing to share their life experience with each other. (persona-scenario session 1, March 10, 2017)

The research team leader told them that they would prefer to have both [Matt and Matilda] involved so that they can really assess where [the progression of her dementia] going, and also have her ideas reflected in the research.... Let's say this is a two-year research study and Matt's been involved since the beginning to help determine the needs and priorities of caregivers. (persona-scenario session 3, April 4, 2017)

Meetings will involve sharing input [on the caregiving tools and resources] by all partners in the research team. (persona-scenario session 4, April 10, 2017)

Researchers must clearly communicate to PCRPs that an expectation of the PCRPs role is to be willing to share ideas and their patient and caregiver perspectives within the group and among the health care research team members. For example, participants indicated that researchers would design a meeting environment that allowed PCRPs to feel comfortable and willing to disclose personal information, such as their disabilities, and share life experiences. A potential action to facilitate this idea include researchers creating opportunities for PCRPs to share their stories, life experiences, and ideas with other PCRPs and the broader research team. A related product is an agreement for (PCRPs) participation, as well as a non-disclosure agreement.

In three out of the four scenarios, participants identified the importance of acknowledging PCRPs contributions to the research team. This could be achieved by: (a) keeping a log to organize and acknowledge each research team member's commitments and contributions, (b) verbally acknowledging the PCRPs contribution, or (c) acknowledging the PCRPs contributions in a publication. The following quotes provide examples of ways of acknowledging PCRPs for their contributions to the research:

Well if you have a running, sort of log, of the progress that she's made in her participation in the research that tells her that she's completed the tasks that you've need help with, and that's she's provided the information that you needed. That gives her a lot of reinforcement.... You could use a Gantt chart to say to someone this is all the stuff we'd hope that you'll be able to be involved with, and this is our schedule for you to be involved, but it is subject to your availability, and we will schedule around your availability.... I mean, there are lots of other ways to make a graphic.... You know, that's perhaps a lot more friendly than a Gantt chart..., but maybe even just a checklist would be sufficient. (persona-scenario session 1, March 10, 2017)

“Oh, you're doing such a good job! We really love having you here”..., she really needs that cause she's lonely. So she needs that validation, exactly.... Encouragement to keep participating.... That she's contributing and that it's valued. (persona-scenario session 2, March 22, 2017)

Henry receives verbalized appreciation or thanks from the researchers.... Henry is asked for permission prior to being mentioned in published materials. (persona-scenario session 4, April 10, 2017)

Participants generally valued verbal appreciation and affirmation over financial remuneration. However, the value of each of these forms of acknowledgement may differ for each PCRPs and thus, warrants further discussion in consultation with each PCRPs. For example, participants from session one described how researchers could create a visually appealing log to keep track of the PCRPs's contributions. Potential actions related to this idea was to design a visually appealing log for all research team members to keep track of their contributions to the research. A related product could be a printed or electronic log for everyone to document their contributions to the research.

Subtheme 3: Respect and treat PCRPs as subject matter experts based on their lived experience. Participants highlighted the importance of respecting and acknowledging the knowledge and expertise PCRPs bring to the research related to their own experience living with multimorbidity and/ or caregiving. Researchers recognizing PCRPs as colleagues was described by participants as an essential component of the research team environment, and indicated that this fostered collaborative working relationships.

And the team provides a presentation and creates an opportunity for everyone who's interested in the research project to do a little networking and socializing together so that there's a bonding opportunity both between the potential Subject Matter Experts and research team.... Research partners are considered Subject Matter Experts. (persona -scenario session 1, March 10, 2017)

Henry will partner with the research team and will share valuable real-life experiences from the perspective of a caregiver caring for someone with early dementia. (persona scenario session 4, April 10, 2017)

Participants frequently referred to PCRPs as ‘subject matter experts’ to demonstrate the expectation that PCRPs should be treated as colleagues among researchers. It was emphasized that patient and caregiver perspectives and lived experiences are considered valued expertise, and so PCRPs should be treated with the same dignity and attention as a researcher with professional or academic qualifications. In addition, participants highlighted the need for researchers to avoid treating PCRPs like study participants. An action related to this idea was to treat PCRPs as if they were fellow researchers invited onto the health care research team, as equally knowledgeable experts. A related product is an agreement for participation or an agreement on role expectations and time commitments for all members of the health care research team to agree upon.

Subtheme 4: Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs. Participants highlighted the need to ensure confidentiality of sensitive information to promote effective communication and trusting, professional relationships:

It’s important for the research partners to trust the researchers. If there is a conflict, Myrtle needs to feel comfortable to speak with the other researchers privately, otherwise she will leave the research program. (persona-scenario session 2, March 22, 2017)

He needs to make sure that he’s not going to compromise Eleanor..., that it’s not personalized. He needs confidentiality.... He needs to feel comfortable to talk about these issues.... He doesn’t want to be identified..., you would tell Henry where a safe communication channel is.... You sort of let Henry know [which researcher] is in charge of the project.... Henry is given a “safe-communications channel” where he can discuss tensions with other partners/issues safely and without fear of confrontation (persona-scenario session 4, April 10, 2017)

Participants identified confidentiality as a key factor to enabling the development of a trusting relationship between researchers and PCRPs. To accomplish this, participants envisioned researchers calling the PCRPs' attention to a "safe communication channel", or a way in which information flowed and was confidentially shared and received within the research team (e.g., via e-mail, telephone, or in-person communication). This safe communication channel was facilitated by a research staff identified by researchers as the primary contact of the research team for PCRPs. Any concern brought to the primary contact's attention would be discussed in confidence to protect the PCRPs' trust and mitigate potential confrontations with other members within the research team. To operationalize the idea of maintaining a confidential and safe communication channel, the associated action was for researchers to ensure that PCRPs are aware of the communication channels within the team (e.g., primary contact), and feel comfortable to ask question or voice concerns. The relating product was a research staff member who is identified by researchers as the primary contact to PCRPs.

Subtheme 5: Provide facilitation that encourages equal participation among PCRPs.

When participants were prompted to consider who would be leading the research meetings, they unanimously identified that a researcher should lead the research team meetings. The lead researcher's ability to facilitate a meeting with PCRPs will substantially affect the PCRP's level of trust and safety in knowing that their voice will be heard among the group.

Participant 105: I would think the researcher should be the leader... to have me lead that.... Makes absolutely no sense.... I haven't done the in-depth research and background... to be able to lead the meeting.

Participant 106: And the researcher needs to keep the people back on track, and keep it focused. (persona-scenario session 2, March 22, 2017)

One researcher should be able to throw out ideas, [someone] who can draw out the caregivers. To draw out Matt, you can talk about something totally unrelated to the community project like, “are there any other snacks that you would prefer”, and then you can pinpoint with Matt something related back to the community project.... There are research leads, who manage the agenda of the sessions and contact partners to discuss favorable days to meet.... Meetings will involve input sharing by all partners in the research team.... There is time for questions and answers. That works very well for Matt because he’s an introvert.... (persona-scenario session 3, April 4, 2017)

Participants unanimously identified researchers as appropriate facilitators for research meetings because of their background knowledge and skills in research (e.g., conducting and presenting research, organizing and leading meetings, working with diverse stakeholders). In addition, while participants did not explicitly refer to training for researchers in the scenarios, they maintained that the researchers would need to possess expertise in the following areas in order to effectively facilitate a meeting involving PCRPs: patient and public engagement in health care research, facilitation skills, problem-solving and conflict management, as well as empathy and accessibility. Participants identified the importance of researchers being skilled at leading and facilitating group discussions, such as being able to throw out ideas to the group to draw out (introverted) PCRPs into the meeting’s conversations. Potential actions related to this idea were having researchers and research staff receive training on how to facilitate and lead group discussions involving PCRPs to ensure that all PCRPs have an equal opportunity to share, contribute, and ask questions. A related product is training materials or resources on topics such as leadership and group facilitation that are tailored to the researchers’ learning needs.

Finally, while participants insisted that researchers lead meetings, they inadvertently alluded to the inherent power imbalance that patients and caregivers perceive in their relationship with researchers due to the PCRPs' limited knowledge, skills, or lack of formal training in research.

Subtheme 6: Provide PCRPs with regular updates on the progress of the research.

The provision of regular updates to PCRPs on the progress of the research was highlighted as a factor influencing the development of collaborative relationships between researchers and PCRPs. A spectrum of ICT products could be used to facilitate ongoing communication with the PCRPs (e.g., emailing brief research updates, mailing a USB to PCRPs, printed newsletters, telephone calls, in person updates). The mode of communication will depend on the PCRP's knowledge, level of comfort, and access to ICT.

Research partners received ongoing updates on the progress of the study (via e-mail), especially when not directly involved (e.g., data analysis). Six months after the data analysis is completed, the research team will meet again with the partners at the church to provide an update on how the feedback was integrated into the research. (persona-scenario session 3, April 4, 2017)

Updates are sent via email and research partners are kept in the loop with the useful information, the progression of the study, and meeting summaries are provided to the partners via email as well. And it's important to keep regular contact as you mentioned, so that Henry is interested and involved but also feels like he's not being left out of the loop. (persona-scenario session 4, April 10, 2017)

Providing regular updates to PCRPs on the progress of the research was described as

a key strategy to enhance communication and establish relationships with PCRPs. Potential actions related to this idea were to establish each PCRP's preferred form of communication to receive the regular updates, in addition to maintaining regular communication, and avoid making PCRPs feel left out of the loop. A related product is to provide regular updates using a variety of modes, e.g., e-mail, USB, phone, printed materials such as a newsletter, or an electronic template to create research briefs or summaries.

Chapter 5: Discussion

The importance of engaging patients and caregivers as partners in health care research has been widely recognized. However, a paucity of knowledge exists on how to optimize their meaningful engagement as research partners on health research teams (Domecq et al., 2014; Shippee et al., 2013), such as in the co-design of health research interventions (Donetto, Tsianakas, & Robert, 2014). Even less is known about the meaningful engagement of vulnerable populations, such as older adults with multimorbidity and their caregivers (Bowen et al., 2011). For example, in a systematic review which included 10 studies, Smith et al. (2012) examined the effectiveness of health care interventions for older adult patients with multimorbidity, but none of them addressed interventions that were co-designed with the patients and caregivers. The objective of this study was to examine how to optimize the meaningful engagement of older adults with multimorbidity and their caregivers as partners in health care research. To this author's knowledge, this is the first study to explore strategies for optimizing the meaningful engagement of older adults with multimorbidity as partners in health care research. In contrast to previous studies, which focused primarily on researchers' experience with patient engagement, this study highlighted the importance of examining engagement from a patient perspective. Current evidence regarding strategies to optimize meaningful patient engagement in health care research has largely been based on researchers' perspectives (Tran et al., 2016).

Moreover, it is significant to note that limited guidance exists in the literature to implement meaningful patient engagement in research (Boivin, Lehoux, Burgers, & Grol, 2014; Holmes, Bryan, Ho, & McGavin, 2018). Patient engagement strategies are often discussed in terms of ideas or concepts, but the details are not usually expanded upon (Boivin et al., 2014). Existing literature on patient engagement in research has mostly developed within the last ten years and is

largely based on weak evidence (Holmes et al., 2018), such as reviews and commentaries of researchers' experiences (Brett et al., 2014; Domecq et al., 2014; Wilson et al., 2015). In addition, a paucity of knowledge exists to define effective, or "successful patient engagement" (Holmes et al., 2018, p.41). To address this gap in knowledge, the persona-scenario method produced detailed design specifications (actions and products), which operationalized this study's themes and subthemes in practice. These design specifications have the potential to address gaps in inequity related to PCRP engagement in research, and to serve the needs of older adults with multimorbidity and their caregivers. In the following summary of findings, the PI focused on design specifications that were validated in the existing literature, and identified selected examples of novel specifications.

The findings highlight factors, which influence the engagement of older adults with multimorbidity and their caregivers as partners in health care research. These factors include engaging PCRPs early in the research, clarifying the PCRPs' roles and responsibilities, adopting a flexible patient-centred approach to PCRP involvement, respecting PCRPs as colleagues and acknowledging their contributions, identifying and addressing barriers to PCRP engagement (e.g., caregiving support, transportation), providing initial and ongoing training about research, and facilitating continued dialogue and feedback to clarify roles and manage expectations. Regarding the latter, ICT can be a useful tool to support ongoing communication and sharing information between researchers and PCRPs. In addition, researchers should adopt a variety of recruitment strategies and methods to improve the likelihood of reaching potential PCRPs with diverse life experiences. Moreover, the findings highlighted that research team meetings that included opportunities for socialization play a key factor in enhancing trust, and PCRP engagement in the research. Furthermore, researchers need to consider the most appropriate

meeting structures (e.g., meeting formats, locations and venues, meeting materials and equipment, human resources) to accommodate the needs of the PCRPs and enhance their ability to engage in the research. Additionally, researchers should consider partnering with community-based organizations to expand their knowledge of services that can support PCRPs' ability to engage in research.

Summary of Findings

Fifteen subthemes emerged under the three major themes: (a) Recruitment of PCRPs; (b) Planning for meaningful engagement; and (c) Establishing collaborative relationships (with older adults with multimorbidity PCRPs). Many of the subthemes fit under more than one theme, suggesting that they are synergistic and cumulative. In total 52 unique actions were identified, and 37 products were extracted under the three major themes.

Recruitment of PCRPs. Three subthemes emerged under the theme, “Recruitment of PCRPs”, which included: (a) communicate expectations of PCRP involvement; (b) use a variety of recruitment strategies and methods; (c) identify PCRP's caregiving needs and consider ongoing respite options as needed.

Communicate expectations of PCRP involvement. The ideas expressed in these subthemes are consistent with the literature in that researchers should consider the context, issue and needs of their research (Dahrouge, 2017), and also be knowledgeable of the activities, policies and outcomes of PCRP engagement on their research (Age UK, 2011) before seeking out and recruiting potential PCRPs.

Use a variety of recruitment strategies and methods. The recruitment methods that were identified by study participants were consistent with the existing literature and can be categorized into two strategies: (a) social marketing, and (b) community outreach (Vat et al.,

2017). Vat et al. (2017) defined social marketing as passive recruitment methods such as “advertisements on the radio, TV, newspapers, social media and public spaces such as churches, schools, libraries and waiting rooms” (p.6). In contrast, recruitment using community outreach involved more active methods, such as “town hall meetings, contact with community leaders, booths or presentations at community events, fairs and festivals” (Vat et al., 2017, p.6). The finding that several different recruitment strategies are required is consistent with the literature. The Alzheimer Society (2015) identified the importance of employing a variety of recruitment methods that consider the “cognitive and communication abilities, and social and cultural circumstances” (p.8) of the target group.

Identify PCRPs’ caregiving needs and consider ongoing respite options as needed. The finding that it is important to identify PCRPs’ caregiving needs and considering ongoing respite options is consistent with that of Dahrouge (2017) who reported that individuals with multimorbidity and their caregivers have a greater likelihood of encountering barriers to engagement in research due to their physical or mental health, or social determinants of health (e.g., income, social status, education, culture, social and physical environments). Thus, researchers should adapt recruitment strategies, such as providing respite or caregiving options for caregivers (Age UK, 2011; Holroyd-Leduc et al., 2016) to accommodate and optimize the engagement of these individuals in the research (Dahrouge, 2017).

Design specifications for “Recruitment of PCRPs”.

Communicate expectations of PCRPs involvement. To address recruitment of PCRPs in health care research, examples of products included preparing a study timeline to communicate roles and responsibilities and the time commitment required by PCRPs. These products are consistent with the literature, such as when Duffett (2016) recommends the development of “a formal

written patient engagement plan” (p.1) that includes: expectations regarding time commitment, and from researchers (and other members of the research team); extent of engagement on research activities (and areas with flexibility for change); and details to compensate research partners for their time and contributions to the research.

Use a variety of recruitment strategies and methods. Participants recommended the use of a variety of recruitment strategies, such as word of mouth, flyers and newsletters, radio advertisements, personal invitations from former PCRPs, and reaching out to community organizations. This finding is consistent with the Alzheimer Society (2015), which suggested recruiting potential participants through “clinics, websites, consumer mail-outs, support groups, and local action groups” (p.8). An example of a novel action to address recruitment of PCRPs involved researchers connecting with potential PCRPs over coffee, where afterwards, interested individuals could then decide to contact the researchers by phone using the contact information provided on the research team’s business card. The accompanying product for this strategy was business cards with the research team’s contact information.

Identify PCRP’s caregiving needs and consider ongoing respite options as needed. Some of the respite or caregiving support options were not appropriate or feasible for health care researchers to provide PCRPs. For example, participants suggested that researchers identify and refer PCRPs to health and social services, including respite care services within their community. Because an action directly interpreted from this idea was outside of the researchers’ scope of practice, the action instead was to obtain funding to provide support tend research team meetings. The product was funding to support caregiving respite services.

Planning for meaningful engagement. Six subthemes emerged under the theme, “Planning for meaningful engagement”, which included: (a) determine PCRP’s training and support needs

related to being involved as a research partner; (b) be flexible with the PCRPs' capacity to be involved, and reduce the burden of participation for caregivers; (c) plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings; (d) identify a primary contact for the PCRPs within the research team; (e) use information and communication technology (ICT) to support information sharing between PCRPs and researchers; and (f) partner with community-based organizations to support PCRPs' ability to engage.

Determine PCRPs' training and support needs related to research. Participants indicated that researchers need to be proactive in determining the PCRPs' training and support needs to reduce any potential barriers to their engagement. This finding is consistent with the literature that identifies the importance of training to provide PCRPs with knowledge about the research process, such as how to collect and evaluate evidence. Although the aim is not to train PCRPs as researchers, they are better able to contribute if they have a basic understanding of research methods (Duffett, 2016; Forsythe et al., 2015; Hewlett et al., 2006; Lockey et al., 2004). Researchers should be sensitive to the needs of PCRPs as it builds trust in the researcher-PCRP relationship and contributes to researchers' understanding about how to better empower the PCRP to meaningfully engage in the research (Abma et al., 2009). Moreover, according to Lockey et al. (2004), understanding PCRPs' training and support needs can be mutually beneficial for researchers to determine the appropriate training content, frequency of training, and ongoing supports that PCRPs require.

Be flexible with the PCRPs' capacity to be involved, and reduce the burden of participation for caregivers. In planning for meaningful engagement, participants indicated that researchers should be flexible with PCRPs in their ability to commit to the role, their role expectations, the

extent of their involvement in various activities across the research timeline, and how they participate in research team meetings. Researchers who adopt these patient-centred approaches (e.g., in consideration of the PCRPs' support needs, and research interests) enable continued PCRPs engagement in research activities (e.g., in the decision-making processes; Snow et al., 2013). For example, researchers should consider making home visits to PCRPs who are unable to travel to the meeting or allow PCRPs to attend meetings remotely via teleconference or web conference. This finding is consistent with that of the Alzheimer Society (2015), which highlighted the importance of researchers "[being] flexible" (p.11) with PCRPs' ability to engage in the research. This is especially important given that older adults with multimorbidity and their caregivers may experience fluctuations in their health due to the presence of chronic conditions, which may affect their abilities to contribute as PCRPs to the research. Researchers should be particularly sensitive to the risk of overburdening PCRPs with unrealistic expectations of their availability (time commitments) and capacity to contribute (Snow et al., 2013). For example, with respect to engaging PCRPs in co-presenting at public events, they may feel uncomfortable with public speaking or travelling to unfamiliar venues. A finding from this study was that researchers should allow ongoing negotiation and discussion of PCRPs involvement and commitment to the PCRPs role. Researchers who lack a patient-centred approach to their patient engagement strategy can lead PCRPs to perceive that they are not valued, heard or respected, which may lead to PCRPs withdrawing from the research (Alzheimer Society, 2015; Snow et al., 2013).

Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings. Participants indicated that the format for the first research team meeting should include time allotted for PCRPs to socialize with one another

and other members of the health care research team. This opportunity to socialize can be done either informally over snacks and coffee, or through more formal mechanisms, such as through a question and answer format (Abma & Broerse, 2010). These findings are consistent with those in the existing literature, which recommends that researchers ensure that the first meeting maintains a balance between didactic, participatory, and social activities to sustain the PCRPs' interest in the research (Age UK, 2011).

Participants identified potential barriers to engagement of PCRPs in health care research that need to be addressed when planning for meaningful engagement. These were concerns that were typical in the formative stages of a developing research team (Snow et al., 2013). Potential barriers to meaningful engagement included: (a) lengthy duration and inappropriate frequency of meetings (e.g., too many or too infrequent); (b) meeting group sizes that are not conducive to PCRP engagement (e.g., too many or too few participants); and (c) inaccessible meeting location and venue. Participants also discussed potential strategies to address these barriers to engagement. Potential strategies to address these barriers included: (a) limiting the time commitment of the PCRP role; (b) forming small working groups of PCRPs; (c) providing accommodations for older adults with visible and invisible disabilities; and (d) providing accommodations for caregiving needs. For example, participants discussed the importance of reducing barriers for PCRPs to engage in research meetings, such as ensuring that: (a) meetings are confined to one and a half hours in duration and are held in the daytime; (b) forming a team that consists of a ratio of five PCRPs to two researchers; and (c) using an accessible meeting environment that considers accessibility by public transportation, offers public or validated parking, and is a physical space that is accessible to wheel-chairs or assistive devices. The Alzheimer Society (2015) affirmed that researchers should ask PCRPs about their level of

comfort to travel to and from the meeting venue and their access to transportation (Age UK, 2011) to identify whether a more accessible and conveniently located meeting venue should be selected or if transportation support is needed. Furthermore, Snow et al. (2013) identified the importance of considering the meeting venue's proximity to institutional settings when working with the patient population. Existing literature suggests that having the meetings at a convenient and familiar venue (Age UK, 2011), limiting the time commitment, and accommodating visible and invisible impairments or disabilities (Invisible Disabilities Association, 2018; Snow et al., 2013) contribute to an "inclusive mechanism and processes" (Canadian Institutes of Health Research, 2014, p.10) to enable patient engagement. Finally, research partners should be provided with the opportunity to evaluate the research team's patient engagement plan, and the flexibility to negotiate on items where appropriate (e.g., time commitment, accommodations, type of compensation for travel, caregiving services, or participation; Duffett, 2016).

Identify a primary contact for PCRPs within the research team. Participants identified the importance of having a dedicated research staff member to support PCRPs as a critical strategy for optimizing meaningful engagement in research. This finding is consistent with Snow et al. (2013), who suggested that PCRPs may not always feel comfortable discussing their questions or concerns with other PCRPS or researchers. Thus, identifying a primary contact for PCRPs can help to establish a safe communication channel and reduce any power imbalances within the healthcare research team.

Use information and communication technology (ICT) to support information sharing between PCRPs and researchers. In planning for meaningful engagement, participants indicated that ICT should not be used as a replacement for face-to-face interactions. This finding is consistent with the existing literature that suggests that ICT is not an appropriate or effective tool

for all PCRPs (Age UK, 2011). The type of ICT should be tailored to the needs and level of comfort of each PCRP (Age UK, 2011). A key finding that is also consistent with the literature is that PCRPs may not always favour the use of higher-tech ICT such as smart phones applications, web-based platforms, or online forums.

Partner with community-based organizations to support PCRPs' ability to engage.

Participants identified that partnering with community-based organizations (e.g., health care and social service providers, advocacy groups, organizations) can be used to address barriers to PCRP engagement, such as balancing caregiving responsibilities and accessing transportation. These findings are consistent with the existing literature in that researchers need to build partnerships with other organizations to leverage shared resources, experiences and connections (The Change Foundation, 2016). Partnering with other community-based organizations can lead to collaborative partnerships in research, minimize the financial and human resource cost to one organization, and lead to a more efficient use of every team member's time. Depending on the context of the research, it may be helpful for the researchers to have already established a collaborative partnership with a community-based organization; however, it may also be beneficial for PCRPs to be involved in cultivating a partnership with the community-based organization of interest especially if a personal connection exists (e.g., the PCRP is a member of the community of interest).

Design specifications for "Planning for meaningful engagement".

Determine PCRP's training and support needs related to research. An example of a product that could be used to understand the PCRPs' abilities and interests related to research, is to help the PCRPs create a list of self-identified strengths and abilities that they can bring to the team and use this list to align their skills to the study or project. Another novel product that could be

used is an outline or informal script for researchers to guide their conversation with PCRPs about their research abilities and interests. Participants identified different types of training that could be used to empower PCRPs in their role, including: (a) training for a specific research activity (e.g., to review research proposals), or (b) training for PCRPs to be involved in several aspects of the research (e.g., on patient engagement, the use of ICT to communicate effectively within the health care research team, on crisis management) (Lockey et al., 2004). A number of products currently exist that could be used to support training of PCRPs, such as the Partners in Research course provided by the Ontario SPOR SUPPORT Unit (2018); applicant training and resources provided by PCORI (2013); and the patient, family and health care provider tools and resources made available by Health Quality Ontario (n.d.). Participants indicated that training was an incentive for their involvement in the research. Snow et al. (2013) explained that training may be an incentive as it provides PCRPs with the opportunity to gain knowledge and new skills, particularly if the content is directly relevant to their lives (e.g., recognizing symptoms of memory loss and cognitive decline).

Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings. Participants emphasized that when planning and organizing the first meeting, researchers should provide a presentation that succinctly summarizes the research (e.g., study or program timeline, the team roles and responsibilities, time commitment, required contributions, meeting locations) but limits details (e.g., research methods) that may overwhelm potential PCRPs with too much information. Participants also underscored that potential PCRPs should be allowed at least one week's time to think about the opportunity before committing to the role. The Change Foundation (2016) affirmed this action by describing that the first meeting should begin with a clear description of the aims of the

research. The Change Foundation elaborated that potential products to support this action would be for the description of the research to include a summary of everyone's roles, research activities, time commitment, and expected outcomes of patient engagement. This format should be combined with opportunities to socialize with others (PCRPs, researchers, staff, community-based partners) or to engage in social learning (Abma & Broerse, 2010; Hewlett et al., 2006).

Use information and communication technology (ICT) to support information sharing between PCRPs and researchers. Participants discussed the importance of researchers determining the PCRP's comfort level with ICT and ways in which ICT could be used to support information sharing (e.g., web conferencing solutions, mobile or web platform, e-mails, or phone) among the research team. A novel action that was identified from this idea was to identify and understand the PCRP's level of comfort with ICT and willingness to learn new forms of ICT if training is provided. The product was a checklist to identify the PCRP's abilities, experiences, and comfort with ICT.

Partner with community-based organizations to support PCRPs' ability to engage. Participants suggested that researchers could partner with social workers to provide caregiver support to enable PCRPs to participate in the research. The action was that researchers should establish partnerships with community-based organizations to share information about their services to potentially interested PCRPs seeking caregiving support. The related product to develop and distribute these community-based organizations' contact information to PCRPs was a list of community health and social care services and supports.

Establishing collaborative relationships. Himmelman (2001) described characteristics of a collaborative relationship to include:

Exchanging information, altering activities, sharing resources, and a willingness to enhance the capacity of another for mutual benefit and a common purpose; it requires the highest levels of trust, considerable amounts of time, and an extensive sharing of turf.

Collaboration also involves sharing risks, resources, and rewards and, when fully achieved, can produce the greatest benefits of mutual action. (p.278)

Participants described aspects of a collaborative, reciprocal relationship (Patient-Centred Outcomes Research Institute, 2016) between researchers and PCRPs which involved participating in decision-making in the team and having their ideas integrated into the research. Participants did not discuss collaboration to the extent of achieving high levels of trust, spending substantial time, and sharing “turf” that includes “risks and resources” (Himmelman, 2001, p.278). This may be because the participants only had experience as a PCRP in the early stages of the research.

Six subthemes emerged related to the theme of, “Establishing collaborative relationships”, which included: (a) provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building; (b) integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team; (c) respect and treat PCRPs as subject matter experts based on their lived experience; (d) ensure confidentiality or non-disclosure of sensitive information shared by PCRPs; (e) provide facilitation that encourages equal participation among PCRPs; and (f) provide PCRPs with regular updates on the progress of the research.

Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building. Participants identified opportunities to socialize or network. Participants identified the importance of researchers establishing a safe and trusting relationship

with PCRPs to enhance meaningful engagement. The development of trusting relationships requires the provision of time and opportunities for social interaction (Age UK, 2011). Health Quality Ontario (2016) maintains that meaningful engagement entails “authentic” and “mutually beneficial relationships” (p.8) between PCRPs, researchers, and organizational partners.

Furthermore, Tran et al. (2016) asserted that opportunities for PCRPs to socialize and build relationships with researchers, especially through “informal interaction” (p.12), can result in substantial changes to the power dynamics in the relationship, which can enable greater PCRP leadership and meaningful engagement in the research.

Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team. For researchers to establish collaborative relationships with PCRPs, participants identified the importance of listening to the PCRPs’ ideas and perspectives, integrating their ideas into the research, and then acknowledging PCRPs’ contributions to the research. These findings are consistent with the Canadian Institutes of Health Research's (2014) Strategy on Patient Oriented Research which maintains that health care research should be “informed and co-directed” (p.10) by PCRPs. Tran et al. (2016) reported that a key strategy for enhancing meaningful PCRP engagement is to ensure that the voices of PCRPs are acknowledged and used to influence the research. PCRPs’ experiences, opinions, and insights are needed to shape the researchers’ understanding of the topic of interest and improve the relevance of the health care research itself (The Change Foundation, 2016). Participants indicated that recognizing the efforts and contributions of PCRPs is as important as integrating their ideas and perspectives into the research. Many participants in this study described PCRP that expressed altruistic intentions to engage in the research, and that they were motivated by the hope that their contributions would improve the usefulness of the research. The researchers play a key part in

reassuring PCRPs of the value of their unique contribution: personal experience with multimorbidity and caregiving. Age UK (2011) reported that many older adults with multimorbidity and their caregivers ultimately want to be involved in research that will “make a difference” (p.20). Undoubtedly, current literature also supported the idea that participants’ contributions should be accounted for or integrated into the research to avoid tokenistic engagement of PCRPs. At the very least, PCRPs should be publicly acknowledged for their involvement in the reporting of research (e.g., reports, publications, presentations).

Respect and treat PCRPs as subject matter experts based on their lived experience.

Researchers respecting PCRPs as colleagues, which was mentioned in the third subtheme, was a key component described by participants to establish collaborative relationships. Participants unanimously identified that PCRPs need to be treated by researchers as experts in bringing the lived-experience and experiential knowledge to the research team. These ideas are consistent with the guiding principles of patient engagement as described by the Alzheimer Society (2015) and the Canadian Institutes of Health Research's (2014) Strategy for Patient Oriented Research. Tran et al. (2016) reported that patient advisory board members preferred when researchers respected them “as a colleague” (p.13) in their interactions on a research team. Researchers who assumed a paternalistic attitude, in believing that they knew best, hindered establishing an authentic and respectful working relationship with PCRPs (Alzheimer Society, 2015). Respect for PCRPs lived-experiences and experiential knowledge is therefore imperative to enabling the meaningful engagement of PCRPs in the research process (Canadian Institutes of Health Research, 2014), and may potentially help to neutralize the inherent power imbalance between researchers and patients and caregivers.

Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs.

Confidentiality is a familiar and foundational concept of ethical practice to researchers (Canadian Institutes of Health Research et al., 2014). Trust and safety are viewed as key facilitators to the development of a collaborative relationship with PCRPs to optimize meaningful engagement, especially for vulnerable or marginalized populations (Snow et al., 2013). Ensuring the confidentiality and privacy of shared (sensitive) information during health care research team meetings contributes to creating a “safe environment” for all attendees, including PCRPs as well as researchers (Dahrouge, 2017, slide 30).

Provide facilitation that encourages equal participation among PCRPs. Participants described scenarios where researchers facilitated meetings, initiated dialogue with PCRPs who were not as vocal during meetings and managed the agenda items. None of the participants envisioned their persona(s) to hold greater roles of leadership in the scenarios (e.g., co-leading research meetings, setting the agenda). This may have been attributed to their own personal experiences in research, which were limited to early stages of engagement, or their lack of comfort in this role. These findings are consistent with the literature in that the researchers chairing of research meetings is crucial in enabling PCRPs to contribute. The researcher plays an important role in facilitating research meetings, encouraging inclusivity in sharing ideas (Canadian Institutes of Health Research, 2014), and minimizing power imbalances between researchers and PCRPs (Dahrouge, 2017). Researchers need specific skills in facilitating meetings that involve PCRPs as PCRPs may (initially) feel uncomfortable participating in team meetings (The Change Foundation, 2016). Snow et al., (2013) clarified that it may not always be appropriate for researchers to facilitate meetings if they are not open to patient perspectives and potential criticisms. This may create mutual discomfort and become a barrier to meaningful

PCRPs engagement. In this case, Snow et al. (2013) suggested that third-party facilitators who are external to the research study (or program) be employed to manage the research meetings.

Provide PCRPs with regular updates on the progress of the research. Finally, participants identified the importance of continued dialogue and feedback from PCRPs to clarify roles, manage expectations and sustain their engagement in the research. This is particularly important given that PCRPs may not be involved in all aspects of a research project. This finding is consistent with the current literature which recommends that researchers stay in regular touch with PCRPs using different strategies, for example, newsletters, research briefs, and different modes of communication, e.g., phone, e-mail (The Change Foundation, 2016).

Design specifications for “Establishing collaborative relationships”.

Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building. Participants indicated that the provision of opportunities for PCRPs to network or socialize with other PCRPs is a key component to establishing trusting, collaborative relationships. A novel action that was identified from this idea was to provide PCRPs with the options to network (e.g., share contact information with other PCRPs) if they felt comfortable. The related product to support networking was for researchers to develop and distribute a list of PCRPs’ contact information that could be shared among the PCRPs.

Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team. Furthermore, in discussing ways to acknowledge PCRPs’ contributions to the research team, some participants envisioned the creation of a visually-appealing log to keep track of everyone’s contributions. A novel action to support this idea was to design a visually appealing log for all team members (researchers and PCRPs) to keep track of

their involvement in the research study. The supporting product was a template for a log to keep track of PCRPs involvement that will be available to team members in print and electronically.

Participants indicated that financial remuneration was not a preferred form of recognition to acknowledge the PCRPs contribution to the research team. This is consistent with existing literature in that financial remuneration is not appropriate in all circumstances, and may be insufficient on its own as an incentive to patient engagement (Snow et al., 2013). However, the Change Foundation (2015) highlighted the need for financial compensation as a strategy to support “fair, equitable, and barrier-free patient engagement” (p.6). Researchers should determine if they are able to provide financial compensation to PCRPs for their time and contributions. No best practice guidelines on patient engagement currently exist to determine an appropriate pay for financial compensation (The Change Foundation, 2015). Thus, the Change Foundation concluded, in consultation with four professional experts in patient engagement, that minimum wage was an appropriate rate for PCRPs, unless PCRPs were recruited based on a specific a professional skill set or education. Ultimately, the appropriateness of financial remuneration (Age UK, 2011) or compensation (The Change Foundation, 2016) for the PCRPs time, travel, and contributions to the research should be determined on a case by case basis.

Respect and treat PCRPs as subject matter experts based on their lived experience.

Finally, participants discussed strategies where researchers demonstrated respect and treatment of PCRPs as colleagues, and experts of the lived experience. However, researchers who have not had previous experiences working with patient and caregivers as research partners on health care research teams, may be unfamiliar with, for example, the relationship dynamics of the PCRPs-researcher relationship and addressing inherent power imbalances. Thus, the novel action to support this idea was for researchers and research staff to receive training on topics that would

support them in their role in relation to PCRPs, such as patient engagement in research. The supporting product was training materials or resources on patient engagement. This finding is consistent with existing literature, where Lockey et al. (2004) asserts that researchers and research staff should identify training that would benefit and further their understanding of the PCRPs that they'll be working with, and how to best support PCRPs.

Implications for Policy, Research, and Education

Implications for research. Noteworthy of these findings is that the three major themes related primarily to the early stages of engagement in research (e.g., recruitment, planning for meaningful engagement, and establishing relationships). This may be a reflection of the fact that participants had more experience as PCRPs in the early phase of research, and thus, could not comment on their involvement in other aspects of the research, such as co-designing, implementing or evaluating interventions. These findings contribute to a foundational understanding of how to engage and build relationships in early phases of the research and helps to inform how researchers can sustain a meaningful level of PCRP engagement over an extended period of time (Duffett, 2016; Manafo et al., 2018). These findings also highlight factors of patient engagement that resonate with existing literature, such as the core elements of the BC SUPPORT Unit's patient engagement framework, as described by Holmes et al. (2018), which include recruitment of patient research partners, initial and ongoing training, and "support for administrative, logistical, financial, and psychosocial" (p.42) concerns. Nevertheless, future research is warranted that involves older adult patient and caregiver participants who have, and can speak to, experiences in all aspects of the research process.

These findings can be used to develop KTE product (e.g., a toolkit, or resource guide) for use by health care researchers to promote meaningful engagement of patients and caregivers as

research partners. Nurse researchers should consider the applicability of the findings to their own research. Similar to the research briefs and guides that have been produced by INVOLVE UK (2018) and Nass, Levine, & Yancy (2012), a research brief can be summarized for each major theme of this study, or all of the findings from this study can be condensed into a comprehensive lay language guide for researchers. The electronic files of these documents can then be made available online for public dissemination.

Implications for policy. The detailed design specifications to optimize older adult and caregiver engagement in research have the potential to inform policy related to enhancing meaningful engagement of older adults with multimorbidity and their caregivers in research. The study's findings, such as strategies for researchers to establish collaborative relationships with PCRPs, could have policy implications at the local organizational level, such as through universities, and nursing professional associations, and then within provincial and national governments, or organizations.

Uptake of this study's findings within one research team could encourage its uptake among other academic colleagues and networks. For example, the subthemes that relate to confidentiality and meeting decorum could inform the development of a policy that outlines the ACHRU's approach to engaging older adults with multimorbidity and their caregivers as research partners. The acceptability of this policy's implementation could encourage the development of a shared policy for patient and caregiver engagement in research for larger university organizations. For example, the ACHRU is part of the McMaster Institute for Research on Aging (2018), which is an umbrella organization that mobilizes researchers within the university to collaborate on strengthening efforts towards research in aging. Health care organizations and professional nursing associations display increasing interest and focus on

patient engagement in research to improve accountability to the public, patient safety, as well as patient health care outcomes and experiences (Ontario Ministry of Health and Long-Term Care, 2015b; Registered Nurses' Association of Ontario, 2017). These commitments to patient engagement in research at the organizational level highlight the importance of nurse researchers to meaningfully engage with patients and caregivers in health care research.

Continued support to develop research in this area requires support from funding agencies as well as the governing bodies or leadership teams overseeing these organizations (e.g., McMaster University, RNAO's board of directors), and a strategic plan of action to operationalize the intent. Research, academic, and professional organizations may commit to supporting the meaningful engagement of older adults with multimorbidity and their caregivers in health care research, but without established policies or procedures for patient engagement, and effective communication within the health care research team, researchers are unprepared to respond to stakeholder feedback and contributions to the research (Age UK, 2011). This disorganized response can lead to patients and caregivers becoming disinterested in the research opportunity altogether. For example, McMaster University (2016) committed to a strategic plan between 2016-2021 to strengthen public engagement beyond the campus setting, which involves conducting research with or for the public. The university's commitment is supported by structures, such as the Network for Community-Campus Partnerships, to manage and achieve the strategic plan, and to direct funding opportunities towards goals such as encouraging research whose findings will benefit the public. This organizational support and strategic planning for patient and public engagement enables researchers to foster a dynamic organizational culture that values and operationalizes the meaningful engagement of older adults with multimorbidity and their caregivers in the research process.

Finally, this research can influence policy at the provincial level and national organizations or government. As previously established, the findings of this study contribute to patient-centred outcomes research, which can eventually support patient-relevant and evidence-informed decision-making by health policy makers. Moreover, the findings from this research, and its related KTE products could be disseminated among researchers affiliated with the Ontario Strategy for Patient-Oriented Research (SPOR) Support Unit (OSSU), and the Canadian Institute of Health Research's Strategy for Patient Oriented Research (SPOR) to encourage decision-making, funding, and policies that support patient and caregiver engagement in research. The OSSU and Canada's SPOR are provincial and national networks, respectively, that consist of "researchers, patients, clinicians, policy makers, industry representatives, and other health systems professionals" (Ontario SPOR Support Unit, 2017).

Implications for professional education. As previously established, older adult and caregiver engagement in research is an emerging field of research. There is no consensus on the training required to prepare researchers for older adult and caregiver engagement in research, nor is there a consensus on recommended training for PCRPs. The findings from this study identify potential areas for interprofessional training of researchers and clinicians on patient and family engagement in research. On the individual and team level, researchers may benefit from attending workshops on patient-centred research to discuss processes, methods, and strategies of engagement. In addition, the topic of patient engagement in health care research should be included in nursing undergraduate and graduate education.

The education and training of nurse researchers and research staff could benefit from topics such as: effective engagement with older adults (with multimorbidity) and caregivers, specific to a chronic condition if required; how to facilitate communication and team meetings;

and how to improve accessibility and dismantle barriers to access (e.g., Accessibility for Ontarians with Disabilities Act). Thus, it may be advantageous to include patient and caregiver engagement in research as a seminar or unit topic within the Nursing Research course for Undergraduate Nursing students, as well as within the Fundamentals of Health Research and Evaluation course as a requirement of the Nursing Graduate program.

Strengths and Limitations

Persona-scenario method. The persona-scenario method was well received by the older adult participants. The benefit of the persona-scenario method over other qualitative methods is the development of detailed scenarios, which led to an abundance of rich and descriptive design specifications to operationalize the themes, subthemes and codes) that emerged from the data.

However, there is no consensus on the best way to apply the method, and it would greatly benefit from further insights to its use in health care research. Specifically, there is a need for more explicit guidelines on how to conduct the persona-scenario exercise, the analysis, and reporting of results. For example, there is limited knowledge about the recommended sample size for this method. Moreover, this study's set-up for the persona-scenario exercise included a projector screen to display the notes taken from the participants' discussion in real time. The decision to use technology such as a projector screen was not informed by existing literature but was intended to make the process easier for participants to review their created personas, scenarios and discussions. Participants agreed that this set up helped them to better understand the result of the exercise. With regards to data analysis, this study contributed to existing knowledge by elaborating that it is a two-stage process that includes a qualitative descriptive inductive approach.

Finally, little is known about the human and ICT resources required to effectively conduct the persona-scenario exercise (e.g., depending on the session size, the method ideally requires a session facilitator, note-taker, transcription services), manage the data (e.g., NVivo vs. Microsoft Excel), and analyze the data (e.g., duration of time and number of researchers involved). It is important to note that the persona-scenario method, including the two-phase data analysis is resource-intensive. In this study, the PI worked in small sessions of two participants each. Thus, when research trainees were unavailable, the PI could reasonably manage to facilitate a session and take notes of the created scenario for member-checking. However, in sessions with multiple participants, this would be very difficult. The session facilitators and note-taker(s) should receive training prior to leading a session. Moreover, the PI facilitated the persona-scenario sessions, which may have influenced where time was spent to probe certain areas that were of interest to the PI rather than participants. Samples of the PI's analysis were audited by the PI's thesis supervisor and committee member to address this issue. Furthermore, the data analysis for this study was human resource and time intensive. The PI and four researchers (the PI's supervisor and three committee members) were involved in this iterative and intensive data analysis process that spanned over a year.

Snowball sampling strategy. A purposive snowball sampling strategy was used to recruit eligible participants to this study. The incorporation of a sample of older adult participants with varied experiences as a research participant or a research partner was a strength. Given the inclusion criteria (e.g., older adults with experience as a study participant or research partner, and patient or caregiving experience, presence of multimorbidity preferred), this sampling strategy allowed the PI to readily recruit potential study participants who under normal circumstances would be difficult to reach. However, this sampling strategy also has the potential

to recruit like-minded individuals. A future study on this topic could incorporate different sampling strategies including maximum variation to see if more varied and textured experiences with research can be explored in scenarios. The transferability of the findings is limited potentially by the snowball sampling strategy, and lack of diversity in the sample that was obtained through a single research unit in southern Ontario. These relate to the limitations noted in the following section.

Demographics of recruited study participants. It is important to consider that because realistic personas were created, the personas reflected the demographic characteristics of the study participants which included: having at least completed high school education; earning middle-class income; having a permanent place of residence; having access to a telephone and radio; or having access to transportation to the community centres or places of worship despite physical, mental, or cognitive health challenges. The sociodemographic characteristics and experiences of the participants were homogenous. As a result, the recruitment strategies and patient engagement methods created and discussed among this study's participants may reflect their own demographic characteristics and privileges. Therefore, there is a need to recruit a more diverse population in future research in terms of characteristics such as race, income, and education.

Participants' lack of experience in research played a significant role in the creation of the personas and scenarios, and limited the discussions to the early phases of the research process. Future research is warranted that involves participants who have experience designing, implementing, or evaluating health care research interventions, and the development and implementation of KTE plans.

Conclusion

Meaningful engagement of patients and caregivers as research partners is a key component of patient-centred research. Research that is grounded in patient perspectives and priorities will enhance study design, interpretation of findings, and dissemination and uptake of the results. This study's findings expand our understanding of the factors influencing the optimal engagement older adults with multimorbidity as research partners. The findings demonstrate that to optimize meaningful patient engagement among older adults with multimorbidity and their caregivers, considerations must be made to support the needs and perspectives of PCRPs during their recruitment, to plan for meaningful engagement, and to establish collaborative relationships. In addition, the persona-scenario method is a promising design that encourages the active engagement of patients and caregivers as research partners in the co-design, implementation, evaluation of health care research, and the dissemination of research findings (e.g., providing feedback on what findings should be shared, and how they should be disseminated).

References

- Abma, T. A., & Broerse, J. E. W. (2010). Patient participation as dialogue: setting research agendas. *Health Expectations*, *13*(2), 160–173. <http://doi.org/10.1111/j.1369-7625.2009.00549.x>
- Abma, T. A., Nierse, C. J., & Widdershoven, G. A. M. (2009). Patients as partners in responsive research: methodological notions for collaborations in mixed research teams. *Qualitative Health Research*, *19*(3), 401–415. <http://doi.org/10.1177/1049732309331869>
- Age UK. (2011). *Engaging with older people evidence review*. Retrieved from <http://www.ageuk.org.uk/professional-resources-home/knowledge-hub-evidence-statistics/evidence-reviews/>
- Aging Community and Health Research Unit. (2016a). About ACHRU, research overview. Retrieved May 4, 2017, from <https://achru.mcmaster.ca/about-achru>
- Aging Community and Health Research Unit. (2016b). Research overview. Retrieved September 5, 2017, from <https://achru.mcmaster.ca/about-achru>
- Allard, J., Ballesteros, F., Anthony, S. J., Dumez, V., Hartell, D., Knoll, G., ... Fortin, M.-C. (2018). What does patient engagement mean for Canadian National Transplant Research Program Researchers? *Research Involvement and Engagement*, *4*(13), 1–10. <http://doi.org/10.1186/s40900-018-0096-0>
- Alzheimer Society. (2015). Meaningful engagement of people with dementia: A resource guide. Retrieved May 4, 2017, from http://www.alzheimer.ca/~media/Files/national/Meaningful-engagement/Meaningful_Engagement_e.pdf
- Arthritis Research Canada. (2017). Arthritis Patient Advisory Board. Retrieved May 4, 2017, from <http://www.arthritisresearch.ca/our-team/arthritis-patient-advisory-board>

Baker, S. E., & Edwards, R. (2012). How many qualitative interviews is enough? *National Centre for Research Methods Review Paper*, 1–42.

<http://doi.org/10.1177/1525822X05279903>

BC SUPPORT Unit. (2016). *Building momentum for patient engagement in BC research*.

Vancouver. Retrieved from <http://bcsupportunit.ca/wp-content/uploads/2016/09/Building-Momentum-for-Patient-Engagement-in-BC-Research-May-11-2016-Final-v2.pdf>

Bellows, M., Oberman, H., & Zimmermann, M. (2012). Ingredients for successful patient engagement: Meaningful recruitment of patient and family advisors. Retrieved May 4,

2017, from [http://www.cfhi-fcass.ca/sf-docs/default-](http://www.cfhi-fcass.ca/sf-docs/default-source/collaborations/PEP_Brief_Recruitment_EN.pdf?sfvrsn=0)

[source/collaborations/PEP_Brief_Recruitment_EN.pdf?sfvrsn=0](http://www.cfhi-fcass.ca/sf-docs/default-source/collaborations/PEP_Brief_Recruitment_EN.pdf?sfvrsn=0)

Boivin, A., Lehoux, P., Burgers, J., & Grol, R. (2014). What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation. *The Milbank Quarterly*, 92(2), 319–350. Retrieved from

<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=24890250%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=cctr&NEWS=N&AN=CN-01000153>

Boote, J., Wong, R., & Booth, A. (2015). “Talking the talk or walking the walk?” A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations*, 18(1), 44–57. <http://doi.org/10.1111/hex.12007>

Bowen, S., Dearden, A., & Peter Wright, S. (2011). Different views: Including others in participatory health service innovation. In J. Buur (Ed.), *PINC 2011: Participatory innovation conference 2011* (pp. 230–236). Sonderborg, Denmark: University of Southern Denmark. Retrieved from <http://shura.shu.ac.uk/3536/>

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R.

(2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*, 17(5), 637–650.

<http://doi.org/10.1111/j.1369-7625.2012.00795.x>

Canadian Institute for Health Information. (2011). Seniors and the health care system: What is the impact of multiple chronic conditions? Retrieved from

<https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1575>

Canadian Institute for Health Information. (2015). PROMS: Background document. Retrieved December 13, 2017, from

https://www.cihi.ca/sites/default/files/document/proms_background_may21_en-web.pdf

Canadian Institute for Health Information. (2017). Patient Reported Outcome Measures.

Retrieved May 9, 2017, from <https://www.cihi.ca/en/patient-reported-outcome-measures>

Canadian Institute of Health Research. (2015). Canada's Strategy for Patient-Oriented Research:

Patient Engagement Framework at a Glance. Retrieved August 27, 2018, from

http://www.cihr-irsc.gc.ca/e/documents/spor_panel-en.pdf

Canadian Institutes for Health Research. (2012). Canada's Strategy for Patient-Oriented

Research. Retrieved December 18, 2017, from <http://www.cihr-irsc.gc.ca/e/44000.html>

Canadian Institutes of Health Research. (2012). CIHR'S citizen engagement handbook.

Retrieved May 5, 2017, from <http://www.cihr-irsc.gc.ca/e/42196.html>

Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research.

Retrieved August 11, 2017, from http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Canadian Institutes of Health Research. (2016a). Evaluation of the Strategy for Patient-Oriented

- Research. Retrieved July 6, 2018, from <http://www.cihr-irsc.gc.ca/e/49937.html>
- Canadian Institutes of Health Research. (2016b). Knowledge translation. Retrieved September 5, 2017, from <http://www.cihr-irsc.gc.ca/e/29418.html#2>
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). *Ethical conduct for research involving humans*. Ottawa, ON. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
- Carroll, J. M. (2000). Five Reasons for Scenario-Based Design. *Interact Comput*, 13(1), 43–60.
- Carroll, S. L., Embuldeniya, G., Ableson, J., Berkesse, A., McGillion, M., & Healey, J. S. (2016). Examining perceptions of barriers to patient engagement in clinical research among research scientists in a cardiovascular research network. *Canadian Journal of Cardiology*, 32(10), S136. <http://doi.org/https://doi.org/10.1016/j.cjca.2016.07.205>
- Chen, J. (2014). *Patient reported outcome measures and patient reported experience measures - A rapid scoping review*. Kensington, New South Wales. Retrieved from http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0009/281979/ACI_Proms_Premis_Report.pdf
- Chiu, S. (2015). *End user engagement in developing a self-care online app*. McMaster University. Retrieved from https://macsphere.mcmaster.ca/bitstream/11375/18774/2/Chiu_Stephanie_A_2015December_MSceHealth.pdf
- CIHR. (2013). CBPHC Innovation team: Jenny Ploeg. Retrieved August 5, 2017, from <http://www.cihr-irsc.gc.ca/e/47160.html>
- CIHR. (2014a). Patient engagement. Retrieved August 3, 2017, from <http://www.cihr->

irsc.gc.ca/e/45851.html

CIHR. (2014b). Strategy for Patient-Oriented Research: Patient engagement framework.

Retrieved August 3, 2017, from <http://www.cihr-irsc.gc.ca/e/48413.html>

CIHR. (2016). SPOR networks. Retrieved August 3, 2017, from [http://www.cihr-](http://www.cihr-irsc.gc.ca/e/45854.html)

irsc.gc.ca/e/45854.html

College of Nurses of Ontario. (2014). Become a Nurse. Retrieved August 12, 2017, from

<http://www.cno.org/en/become-a-nurse/>

Creswell, J. W. (2013). *Qualitative inquiry & research design* (3rd editio). Thousand Oaks:

SAGE Publications.

Dahrouge, S. (2017). Patient engagement in research: Module 2 - Patients with complex needs.

Patient Engagement Research Centre. Retrieved from <https://www.patientengagement-phcresearch.com/>

de Wit, M., Kirwan, J. R., Tugwell, P., Beaton, D., Boers, M., Brooks, P., ... Gossec, L. (2017).

Successful stepwise development of patient research partnership: 14 years' experience of actions and consequences in outcome measures in rheumatology (OMERACT). *Patient, 10*(2), 141–152. <http://doi.org/10.1007/s40271-016-0198-4>

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... Murad, M. H.

(2014). Patient engagement in research: A systematic review, 1–9.

Donetto, S., Tsianakas, V., & Robert, G. (2014). *Using Experience-based Co-design (EBCD) to*

improve the quality of healthcare: mapping where we are now and establishing future directions. London. Retrieved from

<https://www.kcl.ac.uk/nursing/research/nru/publications/reports/ebcd-where-are-we-now-report.pdf>

- Duffett, L. (2016). Patient engagement: What partnering with patient in research is all about. *Thrombosis Research*, *150*, 113–120. <http://doi.org/10.1016/j.thromres.2016.10.029>
- Duggleby, W., Ploeg, J., McAiney, C., Fisher, K., Swindle, J., Chambers, T., ... Pollard, L. (2017). Study protocol: pragmatic randomized control trial of an internet-based intervention (My tools 4 care) for family carers. *BMC Geriatrics*, *17*(1), 181. <http://doi.org/10.1186/s12877-017-0581-6>
- Esmail, L., & Moore, E. (2015). Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *Journal of Comparative Effectiveness Research*, *4*(2), 133–145. <http://doi.org/10.2217/cer.14.79>
- Evans, S., Corley, M., Corrie, M., Costley, K., & Donald, C. (2011). Evaluating services in partnership with older people: Exploring the role of ‘community researchers.’ *Working with Older People*, *15*(1), 26–33. <http://doi.org/10.5042/wwop.2011.0117>
- Forsythe, L. P., Ellis, L. E., Edmundson, L., Sabharwal, R., Rein, A., Konopka, K., & Frank, L. (2015). Patient and Stakeholder Engagement in the PCORI Pilot Projects: Description and Lessons Learned. *Journal of General Internal Medicine*, *31*(1), 13–21. <http://doi.org/10.1007/s11606-015-3450-z>
- Frank, L., Basch, E., & Selby, J. V. (2014). The PCORI Perspective on Patient-Centered Outcomes Research. *JAMA*, *312*(15), 1513–1514. <http://doi.org/10.1007/s40271-014-0065-0.7>
- Government of Canada. (2014). Government of Canada — Action for seniors report. Retrieved August 3, 2017, from <https://www.canada.ca/en/employment-social-development/programs/seniors-action-report.html?=&wbdisable=true>
- Gulliksen, J., Goransson, B., Boivie, I., Blomkvist, S., Persson, J., & Cajander, A. (2003). Key

principles for user-centred systems design. *Behaviour & Information Technology*, 22(6), 397–409. <http://doi.org/10.1080/01449290310001624329>

Health Quality Ontario. (n.d.). Patient engagement tools and resources. Retrieved May 11, 2018, from <http://www.hqontario.ca/Engaging-Patients/Patient-Engagement-Tools-and-Resources>

Health Quality Ontario. (2016a). Engaging with patients: Stories and successes from the 2015/2016 quality improvements plans. Retrieved from <http://www.hqontario.ca/portals/0/documents/qi/qip/engaging-with-patients-en.pdf>

Health Quality Ontario. (2016b). Ontario's patient engagement framework: Creating a strong culture of patient engagement to support high quality health care. Retrieved August 11, 2017, from <http://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

Health TAPESTRY. (2014). Who are health TAPESTRY clients — TAPESTRY website. Retrieved December 18, 2017, from <http://healthtapestry.ca/about/health-tapestry-clients>

Hewlett, S., De Wit, M., Richards, P., Quest, E., Hughes, R., Heiberg, T., & Kirwan, J. (2006). Patients and professionals as research partners: Challenges, practicalities, and benefits. *Arthritis & Rheumatism*, 55(4), 676–680. <http://doi.org/10.1002/art.22091>

Himmelman, A. T. (2001). On coalitions and the transformation of power relations: Collaborative betterment and collaborative empowerment. *American Journal of Community Psychology*, 29(2), 277–284. <http://doi.org/https://doi.org/10.1023/A:1010334831330>

Holmes, B. J., Bryan, S., Ho, K., & McGavin, C. (2018). Engaging patients as partners in health research: Lessons from BC, Canada. *Healthcare Management Forum*, 31(2), 41–44. <http://doi.org/10.1177/0840470417741712>

Holroyd-Leduc, J., Resin, J., Ashley, L., Barwich, D., Elliott, J., Huras, P., ... Muscedere, J.

(2016). Giving voice to older adults living with frailty and their family caregivers:

Engagement of older adults living with frailty in research, health care decision making, and in health policy. *Research Involvement and Engagement*, 2(1), 23.

<http://doi.org/10.1186/s40900-016-0038-7>

Idoughi, D., Seffah, A., & Kolski, C. (2012). Adding user experience into the interactive service design loop: a persona-based approach. *Behaviour & Information Technology*, 31(3), 287–303. <http://doi.org/10.1080/0144929X.2011.563799>

International Alliance of Patients' Organizations. (2015). Involving patients and the public in new research journal: International Alliance of Patients' Organizations. Retrieved August 3, 2017, from <https://www.iapo.org.uk/news/2015/may/26/involving-patients-and-public-new-research-journal>

Invisible Disabilities Association. (2018). How do you define invisible disability? Retrieved March 12, 2018, from <https://invisibledisabilities.org/what-is-an-invisible-disability/>

INVOLVE. (2015). About INVOLVE. Retrieved August 3, 2017, from <http://www.invo.org.uk/about-involve/>

INVOLVE UK. (2018). Briefing notes for researchers. Retrieved June 4, 2018, from <http://www.invo.org.uk/resource-centre/resource-for-researchers/>

Karimi, R. (2016). *Enhancing a home care eHealth application for stroke survivors with multiple chronic conditions bringing primary care into the circle of care*. McMaster University.

Retrieved from

https://macsphere.mcmaster.ca/bitstream/11375/19219/2/Karimi_Rojin_2016April_MSceHealth.pdf

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalist inquiry*. Newbery Park: SAGE Publications.

Lockey, R., Ahmed, S., Bennett, C., Gillingham, T., Millyard, J., Parfoot, S., ... Sitzia, J. (2004).

Training for service user involvement in health and social care research: A study of training provision and participants experiences (The TRUE Project). Worthing and Southlands Hospitals NHS Trust. Eastleigh. Retrieved from <http://www.invo.org.uk/wp-content/uploads/2011/12/TRUEfinalreport130404.pdf>

Madsen, S., & Nielsen, L. (2014). Exploring persona-scenarios - Using storytelling to create design ideas. *IFIP Advances in Information and Communication Technology*, 316, 57–66. http://doi.org/10.1007/978-3-642-11762-6_5

Manaf, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: A scoping review of the “how” and “what” of patient engagement in health research. *Health Research Policy and Systems*, 16(5), 1–11. <http://doi.org/10.1186/s12961-018-0282-4>

Mao, B. J., Vredenburg, K., Smith, P. W., & Carey, T. (2005). User-centered design practice. *Communications of the ACM*, 48(3), 105–109. <http://doi.org/10.1145/1047671.1047677>

Markle-Reid, M., Weir, R., Browne, G., Henderson, S., Roberts, J., Gafni, A., & Wong, M. (2004). *Frail elderly home care clients: The costs and effects of adding nursing health promotion to personal support services.* Ottawa, Ontario. Retrieved from http://www.fcass-cfhi.ca/Migrated/PDF/ResearchReports/OGC/markle_final.pdf

Marlett, N., & Emes, C. (2010). *Grey Matters: A guide to collaborative research with seniors.* Calgary, Alberta. Retrieved from <http://press.ucalgary.ca/books/9781552382516>

Marshall, Bryan; Cardon, Peter; Poddar, Amit; Fontenot, R. (2013). Does Sample Size Matter in Qualitative Research?: a Review of Qualitative Interviews in IS Research. *Journal of Computer Information Systems*, 54(1), 11–22. <http://doi.org/10.1111/jan.12163>.

- McKevitt, C., Fudge, N., Crichton, S., Bejot, Y., Daubail, B., Di Carolo, A., ... European Implementation Score (EIS) Collaborative Group. (2015). Patient engagement with research: European population register study. *Health Expectations*, 18(6), 3248–3261. <http://doi.org/http://dx.doi.org.libaccess.lib.mcmaster.ca/10.1111/hex.12315>
- McMaster Institute for Research on Aging. (2018). About us. Retrieved July 3, 2018, from <https://mira.mcmaster.ca/about/about-us>
- McMaster University. (2016). Network for community-campus partnerships: Strategic plan 2016-2021. Retrieved July 3, 2018, from https://macconnector.mcmaster.ca/docs/default-source/default-document-library/nccp-strategic-plan_2016-2021_final.pdf?sfvrsn=6c58beb0_0
- McNeil, H., Elliott, J., Huson, K., Ashbourne, J., Heckman, G., Walker, J., & Stolee, P. (2016). Engaging older adults in healthcare research and planning: A realist synthesis. *Research Involvement and Engagement*, 2(10), 10. <http://doi.org/10.1186/s40900-016-0022-2>
- Michigan State University, & National Charette Institute. (2016). Process: Tools and techniques for collaboration by design. Retrieved March 7, 2018, from <http://www.canr.msu.edu/nci/nci-charrette-system/process>
- Nass, P., Levine, S., & Yancy, C. (2012). *Methods for involving patients in topic generation for patient-centered comparative effectiveness research: An international perspective*. Washington, DC. Retrieved from <https://www.pcori.org/assets/Methods-for-Involving-Patients-in-Topic-Generation-for-Patient-Centered-Comparative-Effectiveness-Research---An-International-Perspective.pdf>
- National Institute for Health Research. (2014). *Patient and public involvement in health and social care research*. London. Retrieved from <https://www.nihr.ac.uk/about->

us/CCF/funding/how-we-can-help-you/RDS-PPI-Handbook-2014-v8-FINAL.pdf

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description

- the poor cousin of health research? *BMC Medical Research Methodology*, 9(April 2016),

52. <http://doi.org/10.1186/1471-2288-9-52>

O'Mara-Eves, A., Brunton, G., McDaid, D., Oliver, S., Kavanagh, J., Jamal, F., ... Thomas, J.

(2013). Community engagement to reduce inequalities in health: A systematic review,

meta-analysis and economic analysis. *Public Health Research*, 1(4), 1–526.

<http://doi.org/10.3310/phr01040>

Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: progressing patient and

public involvement in healthcare improvement. *BMJ Quality & Safety*, 25(8), 626–632.

<http://doi.org/10.1136/bmjqs-2015-004839>

Ontario Ministry of Health and Long-Term Care. (2015a). Ministry research funding

opportunities. Retrieved August 5, 2017, from

http://www.health.gov.on.ca/en/pro/ministry/research/hsrf_program.aspx

Ontario Ministry of Health and Long-Term Care. (2015b). *Patients first: Action plan for health*

care. Ontario Ministry of Health and Long-Term Care. Toronto, ON. Retrieved from

http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/

Ontario SPOR Support Unit. (2017). About us: Ontario SPOR SUPPORT Unit. Retrieved

August 9, 2017, from <http://ossu.ca/about-us/>

Ontario SPOR SUPPORT Unit. (2018). Online POR training courses. Retrieved May 11, 2018,

from <http://ossu.ca/training/online-por-training-courses/>

Owen, H. (1997). A brief user's guide to open space technology. Retrieved March 6, 2018, from

http://www.openspaceworld.com/users_guide.htm

Owen, H. (2004). Author. Retrieved March 7, 2018, from <http://www.ho-image.com/author.htm>

Patient-Centered Outcomes Research Institute. (2012a). Our funding. Retrieved September 4, 2017, from <https://www.pcori.org/about-us/financials-and-reports/our-funding>

Patient-Centered Outcomes Research Institute. (2012b). Patient-Centered Outcomes Research. Retrieved July 5, 2018, from <https://www.pcori.org/research-results/patient-centered-outcomes-research>

Patient-Centered Outcomes Research Institute. (2013). Applicant training. Retrieved May 11, 2018, from <https://www.pcori.org/funding-opportunities/applicant-training>

Patient-Centered Outcomes Research Institute. (2014). Our story. Retrieved September 4, 2017, from <https://www.pcori.org/about-us/our-story>

Patient-Centred Outcomes Research Institute. (2015). What we mean by engagement. Retrieved February 5, 2017, from <https://www.pcori.org/engagement/what-we-mean-engagement>

Patient-Centred Outcomes Research Institute. (2016). Engagement rubric for applicants. Retrieved August 11, 2017, from <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>

Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 23(10), 433–441. <http://doi.org/10.1111/j.1532-5415.1975.tb00927.x>

Pizzo, E., Doyle, C., Matthews, R., & Barlow, J. (2015). Patient and public involvement: How much do we spend and what are the benefits? *Health Expectations*, 18(6), 1918–1926. <http://doi.org/10.1111/hex.12204>

Reeder, B., & Turner, A. M. (2011). Scenario-based design: A method for connecting information system design with public health operations and emergency management.

- Journal of Biomedical Informatics*, 44(6), 978–988. <http://doi.org/10.1016/j.jbi.2011.07.004>
- Registered Nurses' Association of Ontario. (2017). Patient and public engagement. Retrieved January 13, 2018, from <http://rnao.ca/about/PPE>
- Rew, L., Bechtel, D., & Sapp, A. (1993). Self-as-instrument in qualitative research. *Nursing Research*, 42(5), 300–301. <http://doi.org/10.1097/00006199-199309000-00012>
- Robert, G. (2013). Participatory action research: using experience-based co-design (EBCD) to improve healthcare services. In S. Ziebland, J. Calabrese, A. Coulter, & L. Locock (Eds.), *Understanding and using experiences of health and illness* (pp. 138–149). Oxford.
- Roberts, K. C., Rao, D. P., Bennett, T. L., Loukine, L., & Jayaraman, G. C. (2015). Prevalence and patterns of chronic disease multimorbidity and associated determinants in Canada. *Health Promotion and Chronic Disease Prevention in Canada Research, Policy and Practice*, 35(6), 87–94. Retrieved from http://pubmedcentralcanada.ca/pmcc/articles/PMC4910465/pdf/35_6_1.pdf
- Sackett, D. L., Straus, S. E., Richardson, W. S., Rosenberg, W., & Haynes, R. B. (2000). *Evidence-based medicine: how to practice and teach EBM* (2nd ed.). Edinburgh: Churchill Livingstone.
- Sandelowski, M. (1995). Focus on Qualitative Methods Sample Size in Qualitative. *Research in Nursing Health*, 18, 179–183. <http://doi.org/10.1002/nur.4770180211>
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing & Health*, 23, 334–340. Retrieved from <http://www.wou.edu/~mcgladm/Quantitative Methods/optional stuff/qualitative description.pdf>
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in*

Nursing and Health, 33(1), 77–84. <http://doi.org/10.1002/nur.20362>

Sawesi, S., Rashrash, M., Phalakornkule, K., Carpenter, J. S., & Jones, J. F. (2016). The impact of information technology on patient engagement and health behavior change: A systematic review of the literature. *JMIR Medical Informatics*, 4(1), e1.

<http://doi.org/10.2196/medinform.4514>

Selby, J. V., Beal, A. C., & Frank, L. (2012). The Patient-Centered Outcomes Research Institute (PCORI) National Priorities for Research and Initial Research Agenda. *JAMA*, 307(15), 1583–1584. <http://doi.org/doi:10.1001/jama.2012.500>

Shimmin, C., Wittmeier, K. D. M., Lavoie, J. G., Wicklund, E. D., & Sibley, K. M. (2017). Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis. *BMC Health Services Research*, 17(539), 1–10. <http://doi.org/10.1186/s12913-017-2463-1>

Shippee, N. D., Domecq Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., ... Murad, M. H. (2013). Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations*, 18(5), 1151–1166.

<http://doi.org/10.1111/hex.12090>

Smith, S. M., Soubhi, H., Fortin, M., Hudon, C., & O'Dowd, T. (2012). Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ (Clinical Research Ed.)*, 345, e5205. <http://doi.org/10.1136/BMJ.E5205>

Snow, B., Tweedie, K., Pederson, A., Shrestha, H., & Bachmann, L. (2013). *Patient engagement: Heard and valued*. Surrey, BC. Retrieved from http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf?sfvrsn=2

The Change Foundation. (2009). *Charting a new path - Part 2: Creating meaningful*

- partnerships in care: Lessons from West Northumberland. English.* Retrieved from <http://www.changefoundation.ca/charting-a-new-path/>
- The Change Foundation. (2015). Should money come into it? Retrieved May 9, 2017, from <http://www.changefoundation.ca/patient-compensation-report/>
- The Change Foundation. (2016). Rules of engagement : Lessons from Panorama. Retrieved May 9, 2017, from <https://www.changefoundation.ca/rules-of-engagement/>
- The World Cafe. (2018). About us. Retrieved April 12, 2018, from <http://www.theworldcafe.com/about-us/>
- Toupin-April, K., Barton, J., Fraenkel, L., Li, L. C., Brooks, P., Wit, M. De, ... Tugwell, P. S. (2017). Toward the development of a core set of outcome domains to assess shared decision-making interventions in rheumatology: Results from an OMERACT Delphi survey and consensus meeting. *The Journal of Rheumatology of Rheumatology The Journal on August, 44*(Part 1), 1–7. <http://doi.org/10.3899/jrheum.161241>
- Tran, B., Leese, J., MacDonald, G., Gulka, L., Hoens, A., Kerr, S., ... Li, L. (2016). *It IS about us ! Patient engagement in health research.* Richmond, Canada.
- Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., & Wiseman, T. (2012). Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Support Care Cancer, 20*, 2639–2647. <http://doi.org/10.1007/s00520-012-1470-3>
- Tunis, S. R., Maxwell, L. J., Graham, I. D., Shea, B. J., Beaton, D. E., III, C. O. B., ... Tugwell, P. (2017). Engaging stakeholders and promoting uptake of OMERACT core outcome instrument sets. *The Journal of Rheumatology, 44*(Part 1), 1–9. <http://doi.org/10.3899/jrheum.161273>

- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15(3), 398–405. <http://doi.org/10.1111/nhs.12048>
- Valaitis, R., Longaphy, J., Nair, K., Agarwal, G., Griffith, L., Kastner, M., ... Straus, S. (2014). Persona-scenario exercise for codesigning primary care interventions. *Canadian Family Physician*, 60(3), 294–296.
- Van den Akker, M., Buntinx, F., & Andri Knottnerus, J. (1996). Comorbidity or multimorbidity : what's in a name? A review of literature. *European Journal of General Practice*, 2(2), 65–70. <http://doi.org/10.3109/13814789609162146>
- Vat, L. E., Ryan, D., & Etchegary, H. (2017). Recruiting patients as partners in health research: A qualitative descriptive study. *Research Involvement and Engagement*, 3. <http://doi.org/10.1186/s40900-017-0067-x>
- Weng, C., McDonald, D. W., Sparks, D., McCoy, J., & Gennari, J. H. (2007). Participatory design of a collaborative clinical trial protocol writing system. *International Journal of Medical Informatics*, S246, S245-251. <http://doi.org/10.1016/j.ijmedinf.2006.05.035>
- Wilson, P., Mathie, E., Keenan, J., Mcneilly, E., Goodman, C., Howe, A., ... Peckham, S. (2015). Research with patient and public involvement: A realist evaluation – the RAPPORT study. *Health Services and Delivery Research*, 3(38). <http://doi.org/10.3310/hsdr03380>
- World Health Organization. (2005). *Facing the facts: The impact of chronic disease in Canada*. Retrieved from http://www.who.int/chp/chronic_disease_report/media/CANADA.pdf
- Wright née Blackwell, R., Lowton, K., Robert, G., Grudzen, C., & Grocott, P. (2017). Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and

outcomes. *International Journal of Nursing Studies*, 68, 83–94.

<http://doi.org/10.1016/j.ijnurstu.2017.01.002>

Appendix A: HiREB Study Approval Letter



Hamilton Integrated Research Ethics Board

3 January 2017

Project Number: 2513

Project Title: Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

Student Principal Investigator: Ms. Kristina Chang

Local Principal Investigator: Dr. Maureen Markle-Reid

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
appendix a study timeline	02/Dec/2016	1
appendix b invitation v.2 clean	21/Dec/2016	2
appendix c telephone oral consent v.2 clean	21/Dec/2016	2
appendix d researcher log for consent	02/Dec/2016	1
appendix e data collection sheet (demographic)	02/Dec/2016	1
appendix f e-mail reminder v.2 clean	21/Dec/2016	2
appendix g overview of persona-scenario session	02/Dec/2016	1
appendix h persona-scenario agenda	02/Dec/2016	1
appendix i infographic research process	02/Dec/2016	1
appendix k participant ICF package v.2 clean	21/Dec/2016	2
kc v.2 protocol submission clean	21/Dec/2016	2

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**. If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

A handwritten signature in black ink, appearing to read "Kristina Trim".

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; for studies conducted at St. Joseph's Hospital, HiREB complies with the health ethics guide of the Catholic Alliance of Canada

Appendix B: Verbal Consent Script

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

Introduction:

Hello, my name is Kristina Chang and I am a Master's student at McMaster University. Through your involvement with the Aging, Community and Health Research Unit at McMaster University, it was previously indicated that you may be interested in learning more about research opportunities. I am calling about a research study where we need your help to learn how to involve older adults as partners on our research teams in the best way possible. Your participation in this study would be completely voluntary. Is now a good time to talk about the study? If not, when is a good time?

What will happen during the study?

As part of graduate program in Nursing at McMaster University, I am carrying out this study to understand how to involve and support older adults to work as partners on a research team in the best way possible.

Can we review the information that was provided to you by the Co-Scientific Directors of Aging, Community and Health Research Unit?

- *PI will review eligibility criteria and potential participant will confirm his/her eligibility to participate in the study.*
- *If the potential participant does not meet the eligibility criteria, the PI will explain why and thank them for their time and interest in the study.*
- *If the potential participant does meet the eligibility criteria:*

Thank you for reviewing this information with me. Based on the information that you have provided, you are eligible to participate in this study. Now, let me provide you with more information about the study.

It is important for older adults to work with researchers. Older adults can help research teams:

- Develop research questions that are important for older adults;
- Consider ways to recruit older adults to participate in research;
- Understand the research results and identify key messages;
- Share research results with audiences that are important to older adults.

You are invited to attend a meeting where we will ask you to work with another older adult to create a realistic but imaginary (fictitious) story or two about working on a research team. Before the meeting, we will be asking you some questions about income, education, and long-term health problems to better understand you and your experiences. At the meeting, we will first explain a little about how research works, and then we will ask you to create your stories. We will help to walk you through the process of creating your stories. With your permission, the whole meeting will be audio recorded. We may contact you after the meeting if we have

questions about your stories. The stories that you create will help us design better ways to involve and support older adults to work on a research team. This meeting will take 2 hours, and we can set up a time that will work for the both of us. Overall, we are looking to include 8-10 older adults in this study.

Are there any risks to doing this study?

We do not foresee that there will be any harms or discomforts from participating in this study. You may feel uncomfortable with sharing your opinions and ideas, but you have the right to refuse to answer any of the questions.

Are there any benefits to doing the study?

We cannot promise you any personal benefits from participating in this study. We hope to learn more about how to best involve and support older adults as partners on a research team.

Will I be paid to participate in this study?

If you decide to participate in this study, you will receive a \$50.00 gift card at the end of the session as a token of appreciation for sharing your time, experiences, and opinions. Light snacks will be provided at the session, and we will provide a \$30.00 taxi chit for transportation.

Will there be any costs to me in this?

We will only require your time to attend the face-to-face meeting. There will be no costs to participate in this study.

Will my information be kept private?

The information collected through this study will be organized and held by researchers from McMaster University. As required by law, your information will not be shared with anyone except with your permission.

Your personal information, such as your name and contact information, will be removed from notes and the audio recording to be replaced with a participant number. Audio recordings will be transcribed, and your personal information will not be included, but replaced with the participant number in the document. Demographic information about your personal characteristics, such as your age, gender and profession, will also be collected in a survey. All collected information will be securely stored in a locked office at McMaster University until the end of the study, and for no longer than 2-3 years. Information stored on computers will be protected by a password. If the results of the study are published, your name and personal information will not be released without your permission to do so.

What if I change my mind about being in the study?

It is important for you to know that you can choose not to participate in this study. You can also withdraw from the study at any time, even after giving consent. We can also remove your data from the study if it has not been included in the study yet.

The investigators may also withdraw you from this study if circumstances arise which warrant it. Your privacy will be protected as mentioned above, but if the law requires it, we will reveal certain personal information in cases of suspected neglect or abuse.

How do I find out what was learned from the study?

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary and what would be the best way to get this to you.

Questions about the study

If you have questions or need more information about the study itself, please contact the Local Principal Investigator, Dr. Maureen Markle-Reid at McMaster University, (insert contact information) or the Principal Investigator, Kristina Chang at (insert contact information)

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

Do you have any questions or would like any additional details? [*Answer questions*]

Are you interested in participating in the study?

- *If the potential participant refuses to participate in the study, thank them for their time. The reason for refusal will be documented.*
- *If the individual agrees to participate in the study, proceed with conducting the SPMSQ. If the individual is unable to meet the criteria of the SPMSQ to provide consent, inform the individual that they are ineligible for the study and thank them for their time.*
- *For eligible participants, notify them that the following section for oral consent to participate in the study will be audio-recorded.*

**PARTICIPANT INFORMATION SHEET
CONSENT STATEMENT**

	Yes	No
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time, without having to have a reason and without affecting your medical care?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to your data, including personally identifiable information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have any questions about the study?	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to have more time to consider participating in this study? If yes, what time would be best for a follow-up call?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
If no, do you have any reason for not participating?	<input type="checkbox"/>	<input type="checkbox"/>

Oral consent of research participant:

Name, Participant

Date (DD/MMM/YYYY)

Signature of person obtaining consent: “I believe that the participant understands what is involved in the study and voluntarily agrees to take part in it.”

Name, Person Obtaining Consent

Role in Study

Signature of Person Obtaining Consent

Date (DD/MMM/YYYY)

SCRIPT FOR DATA COLLECTION SHEET

Explain that the data collection will take about 20 minutes.

If the participant is agreeable, then proceed with the data collection, otherwise negotiate a time to call the participant again for the data collection and set up an appointment time for the persona-scenario exercise.

Thank you again for your time and participation in the study. Before we end this call, what date and time would be good to follow-up with the demographic survey? What date and time would be good for you in the next two weeks to meet us at McMaster University?

Please feel free to contact me (Kristina), the principal investigator, or Dr. Maureen-Markle Reid, the Local Principal Investigator, if you have any questions at (*give McMaster email address and telephone number*). I will be sending this information to you shortly by email and regular mail, as well as the information and consent package that we just went through, and an overview of what will be discussed at our face-to-face meeting.

Appendix C: Demographic Survey

DATA COLLECTION SHEET

Interview Date: <input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/> <div style="display: flex; justify-content: space-around; font-size: small;"> Month Day Year </div>	Participant # (office use only): <input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>
---	--

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE

QUESTION	RESPONSE	INCORRECT RESPONSE
1. What is the date, month, and year?		
2. What is the day of the week?		
3. What is the name of this place?		
4. What is your phone number?		
5. How old are you?		
6. When were you born?		
7. Who is the current prime minister?		
8. Who was the prime minister before him?		
9. What was your mother's maiden name?		
10. Can you count backward from 20 by 3's?		

TOTAL NUMBER OF ERRORS _____

SCORING:

- More than 4 errors indicate cognitive impairment.
- Allow one more error for an individual with grade school education.
- Allow one less error for an individual with education beyond high school.

5. What is the highest level of education that you have completed?

- | | |
|--|---|
| <input type="checkbox"/> ₁ No Schooling | <input type="checkbox"/> ₆ Completed a community college, technical college, or post-secondary program (e.g. trade, technical or vocational school, CEGEP) |
| <input type="checkbox"/> ₂ Elementary school (8 th grade / less) | <input type="checkbox"/> ₇ Completed a bachelor's degree (e.g. B.A., B.Sc., B.S.N.) |
| <input type="checkbox"/> ₃ Did not complete secondary or high school | <input type="checkbox"/> ₈ Completed a graduate degree or professional degree (e.g. MD, DDS, DMD, DVM, OD, Masters, PhD) |
| <input type="checkbox"/> ₄ Completed secondary school or high school | |
| <input type="checkbox"/> ₅ Had some university / college education | |

6. Please provide your **current** employment status by choosing the main one which applies to you.

- | | |
|--|--|
| <input type="checkbox"/> ₁ Employed full-time (including self-employed or on a work training program; 30 or more hours each week) | <input type="checkbox"/> ₅ Unable to work due to a long-term sickness or disability |
| <input type="checkbox"/> ₂ Employed part-time (including self-employed or on a work training program; under 30 hours each week) | <input type="checkbox"/> ₆ Looking after your home/family |
| <input type="checkbox"/> ₃ Unemployed and looking for work | <input type="checkbox"/> ₇ Retired from paid work |
| <input type="checkbox"/> ₄ At school or in full-time education | <input type="checkbox"/> ₈ Doing something else |

7. Please estimate in which of the following groups your total annual household income falls?

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Less than \$10,000 | <input type="checkbox"/> ₄ \$50,000 to less than \$70,000 | <input type="checkbox"/> ₇ Prefer not to answer |
| <input type="checkbox"/> ₂ \$10,000 to less than \$30,000 | <input type="checkbox"/> ₅ 50,000 to less than \$100,000 | |
| <input type="checkbox"/> ₃ \$30,000 to less than \$50,000 | <input type="checkbox"/> ₆ \$100,000 and greater | |

8. Were you born in Canada?

- ₁ Yes → Go to question 10 ₂ No

If no, in what year did you first come to Canada? _____ (enter year)

9.

10. In what country were you born?

- | | | | |
|---|---|---|---|
| <input type="checkbox"/> ₁ Jamaica | <input type="checkbox"/> ₆ Hong Kong | <input type="checkbox"/> ₁₁ Philippines | <input type="checkbox"/> ₁₆ Vietnam |
| <input type="checkbox"/> ₂ France | <input type="checkbox"/> ₇ Hungary | <input type="checkbox"/> ₁₂ Poland | <input type="checkbox"/> ₁₇ Sri Lanka |
| <input type="checkbox"/> ₃ Germany | <input type="checkbox"/> ₈ India | <input type="checkbox"/> ₁₃ Portugal | <input type="checkbox"/> ₁₈ Netherlands/Holland |
| <input type="checkbox"/> ₄ Greece | <input type="checkbox"/> ₉ China | <input type="checkbox"/> ₁₄ United Kingdom | <input type="checkbox"/> ₁₉ Other – specify: _____ |
| <input type="checkbox"/> ₅ Guyana | <input type="checkbox"/> ₁₀ Italy | <input type="checkbox"/> ₁₅ United States | |

11. You may belong to one or more racial or cultural groups on the following list (**check all that apply**).

INTERVIEWER: Read categories to respondent and mark up to 4 responses that apply. If respondent answers “mixed” or “bi-racial”, probe for specific groups and mark each one separately (e.g. White, Black, Chinese).

Are you....?

- | | |
|--|--|
| <input type="checkbox"/> ₁ White | <input type="checkbox"/> ₇ Arab |
| <input type="checkbox"/> ₂ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.) | <input type="checkbox"/> ₈ Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, etc.) |
| <input type="checkbox"/> ₃ Chinese | <input type="checkbox"/> ₉ West Asian (e.g., Afghan, Iranian, etc.) |
| <input type="checkbox"/> ₄ Black | <input type="checkbox"/> ₁₀ Korean |
| <input type="checkbox"/> ₅ Filipino | <input type="checkbox"/> ₁₁ Japanese |
| <input type="checkbox"/> ₆ Latin American | <input type="checkbox"/> ₁₂ Other (specify): _____ |

12. What language(s) do you usually speak at home? **Check as many as apply.**

- ₁ English
₂ French
₃ Other language (please specify) _____

13. Do you currently live with someone? (**You may check more than one box.**)

- | | |
|---|---|
| <input type="checkbox"/> ₁ Live alone | <input type="checkbox"/> ₅ Children |
| <input type="checkbox"/> ₂ Spouse or partner | <input type="checkbox"/> ₆ Family members (please specify) _____ |
| <input type="checkbox"/> ₃ Friend(s) | <input type="checkbox"/> ₇ Other (please specify) _____ |
| <input type="checkbox"/> ₄ Live in group setting with non-relative (e.g., retirement home) | |

INTERVIEWER: Check “yes” only for conditions confirmed by a doctor or for which the participant is taking prescription drugs.

Chronic Condition	Yes	No
Cardiovascular		
Atrial fibrillation		
Cholesterol problem (e.g. hyperlipidemia)		
Coronary artery disease (include ischemic heart disease, angina, previous heart attack)		
Congenital malformed valve, valve heart disease or replacement		
Hypertension (high blood pressure)		
Heart failure (including heart valve disease or replacement)		
Peripheral vascular disease		
Stroke (cerebrovascular accident or transient ischemic attack)		
Respiratory		
Asthma		
COPD (chronic obstructive pulmonary disorder), chronic bronchitis, emphysema		
Pulmonary fibrosis (or bronchiectasis)		
Other lung conditions (e.g. pulmonary fibrosis, cystic fibrosis)		
Mental/Mood Disorders		
Depression		
Anxiety		
Schizophrenia or bipolar disease		
Anorexia or bulimia		
Gastrointestinal		
Stomach problem (e.g. gastric reflux or peptic ulcer symptoms)		
Colon problem (e.g. chronic inflammatory disease, irritable bowel syndrome, or diverticulitis)		
Chronic indigestion (dyspepsia)		
Constipation		
Bowel obstruction (acute or chronic)		
Stool incontinence		
Endocrine		
Diabetes		
Thyroid disorders		
Liver		
Chronic liver disease (including chronic hepatitis or cirrhosis)		
Kidney and Urogenital Disorders		
Chronic kidney disease or failure (including other kidney disease i.e. kidney stones, alport syndrome, kidney leaking, etc.)		
Recurrent urinary tract infection		
Bladder problems (including cystitis, prolapse or repair)		
Bladder incontinence		
Gout		
Prostate disorders		
Sexual disorder (including erectile dysfunction)		
Hearing and Vision		

Chronic Condition	Yes	No
Blindness and low vision		
Glaucoma		
Macular degeneration, diabetic retinopathy, Fuchs disease, and other vision disorders		
Hearing loss (hearing problems and vestibular disorders)		
Neurological		
Alzheimer disease or another form of dementia		
Nerve damage (e.g. peripheral neuropathy)		
Epilepsy		
Multiple sclerosis		
Parkinson's disease		
Musculoskeletal		
Arthritis/ osteoarthritis/ osteoporosis		
Rheumatoid arthritis, other inflammatory and systemic connective tissue disorders		
Pain		
Painful condition (e.g. chronic back pain, fibromyalgia, tendonitis, bursitis, etc.)		
Migraine		
Substance abuse		
Alcohol problems		
Other substance misuse		
Infection		
Chronic sinusitis		
HIV		
Other		
Cancer in the past 5 years (including melanoma, but not other skin cancers; including precancerous cells)		
Blood disorders (including anemia and low red blood cell count)		
Psoriasis or eczema		
Sleep wake disorders (including insomnia, sleep apnea, narcolepsy)		
Other chronic conditions – please specify:		

8. What is the highest level of education that you have completed?

- | | |
|--|---|
| <input type="checkbox"/> ₁ No Schooling | <input type="checkbox"/> ₆ Completed a community college, technical college, or post-secondary program (e.g. trade, technical or vocational school, CEGEP) |
| <input type="checkbox"/> ₂ Elementary school (8 th grade / less) | <input type="checkbox"/> ₇ Completed a bachelor's degree (e.g. B.A., B.Sc., B.S.N.) |
| <input type="checkbox"/> ₃ Did not complete secondary or high school | <input type="checkbox"/> ₈ Completed a graduate degree or professional degree (e.g. MD, DDS, DMD, DVM, OD, Masters, PhD) |
| <input type="checkbox"/> ₄ Completed secondary school or high school | |
| <input type="checkbox"/> ₅ Had some university / college education | |

9. Please provide your **current** employment status by choosing the main one which applies to you.

- | | |
|--|--|
| <input type="checkbox"/> ₁ Employed full-time (including self-employed or on a work training program; 30 or more hours each week) | <input type="checkbox"/> ₅ Unable to work due to a long-term sickness or disability |
| <input type="checkbox"/> ₂ Employed part-time (including self-employed or on a work training program; under 30 hours each week) | <input type="checkbox"/> ₆ Looking after your home/family |
| <input type="checkbox"/> ₃ Unemployed and looking for work | <input type="checkbox"/> ₇ Retired from paid work |
| <input type="checkbox"/> ₄ At school or in full-time education | <input type="checkbox"/> ₈ Doing something else |

10. Please estimate in which of the following groups your total annual household income falls?

- | | | |
|--|--|--|
| <input type="checkbox"/> ₁ Less than \$10,000 | <input type="checkbox"/> ₄ \$50,000 to less than \$70,000 | <input type="checkbox"/> ₇ Prefer not to answer |
| <input type="checkbox"/> ₂ \$10,000 to less than \$30,000 | <input type="checkbox"/> ₅ 50,000 to less than \$100,000 | |
| <input type="checkbox"/> ₃ \$30,000 to less than \$50,000 | <input type="checkbox"/> ₆ \$100,000 and greater | |

11. Were you born in Canada?

- | | |
|---|--|
| <input type="checkbox"/> ₁ Yes → Go to question 10 | <input type="checkbox"/> ₂ No |
|---|--|

If no, in what year did you first come to Canada? _____ (enter year)

12. In what country were you born?

- | | | | |
|---|---|---|---|
| <input type="checkbox"/> ₁ Jamaica | <input type="checkbox"/> ₆ Hong Kong | <input type="checkbox"/> ₁₁ Philippines | <input type="checkbox"/> ₁₆ Vietnam |
| <input type="checkbox"/> ₂ France | <input type="checkbox"/> ₇ Hungary | <input type="checkbox"/> ₁₂ Poland | <input type="checkbox"/> ₁₇ Sri Lanka |
| <input type="checkbox"/> ₃ Germany | <input type="checkbox"/> ₈ India | <input type="checkbox"/> ₁₃ Portugal | <input type="checkbox"/> ₁₈ Netherlands/Holland |
| <input type="checkbox"/> ₄ Greece | <input type="checkbox"/> ₉ China | <input type="checkbox"/> ₁₄ United Kingdom | <input type="checkbox"/> ₁₉ Other – specify: _____ |
| <input type="checkbox"/> ₅ Guyana | <input type="checkbox"/> ₁₀ Italy | <input type="checkbox"/> ₁₅ United States | |

13. You may belong to one or more racial or cultural groups on the following list (**check all that apply**).

INTERVIEWER: Read categories to respondent and mark up to 4 responses that apply. If respondent answers “mixed” or “bi-racial”, probe for specific groups and mark each one separately (e.g. White, Black, Chinese).

Are you....?

- | | |
|---|---|
| <input type="checkbox"/> ₁ White | <input type="checkbox"/> ₇ Arab |
| <input type="checkbox"/> ₂ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc) | <input type="checkbox"/> ₈ Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, etc) |
| <input type="checkbox"/> ₃ Chinese | <input type="checkbox"/> ₉ West Asian (e.g., Afghan, Iranian, etc) |
| <input type="checkbox"/> ₄ Black | <input type="checkbox"/> ₁₀ Korean |
| <input type="checkbox"/> ₅ Filipino | <input type="checkbox"/> ₁₁ Japanese |
| <input type="checkbox"/> ₆ Latin American | <input type="checkbox"/> ₁₂ Other (specify): _____ |

14. What language(s) do you usually speak at home? **Check as many as apply.**

- ₁ English
₂ French
₃ Other language (please specify) _____

15. Do you currently live with someone? (**You may check more than one box.**)

- | | |
|---|---|
| <input type="checkbox"/> ₁ Live alone | <input type="checkbox"/> ₅ Children |
| <input type="checkbox"/> ₂ Spouse or partner | <input type="checkbox"/> ₆ Family members (please specify) _____ |
| <input type="checkbox"/> ₃ Friend(s) | <input type="checkbox"/> ₇ Other (please specify) _____ |
| <input type="checkbox"/> ₄ Live in group setting with non-relative (e.g., retirement home) | |

Appendix D: Phone/Email/Regular Mail Reminder to Participants

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

(To be sent by the PI one week before the scheduled persona-scenario session)

PHONE SCRIPT

Hello, my name is Kristina Chang and I am a Master's student at McMaster University. I am calling as a reminder that you are invited to take part in a two-hour meeting for a research study at McMaster University on (insert date).

As part of graduate program in Nursing at McMaster University, I am carrying out this study to understand how to involve and support older adults as partners on research teams in the best way possible. We previously spoke on the phone, and you indicated your interest to participate in the study. We would like to remind you that your involvement in this study is completely voluntary and you may withdraw from the study at any time, for any reason, without any questions asked.

I have sent you the study's information package to your email and mailing address. You may review the information to prepare for our face-to-face meeting. The package also has my contact information on it. Please contact me at any time if you have any questions. Thank you.

EMAIL/LETTER REMINDER

Email Subject line: McMaster Study – Supporting Patient and Family Caregiver Engagement in Research

This a reminder that you are invited to take part in a two-hour meeting for a research study at McMaster University on (insert date). As part of graduate program in Nursing at McMaster University, I am carrying out this study to understand how to involve and support older adults as partners on research teams in the best way possible.

We previously spoke on the phone, and you indicated your interest to participate in this study. We would like to remind you that your involvement in this study is completely voluntary and you may withdraw from the study at any time, for any reason, without any questions asked. I have attached a brief overview of the activity for more information on what we will be doing during the face-to-face meeting.

This study has been reviewed and cleared by the Hamilton Integrated Research Ethics Board (HiREB). If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at (905)-521-2100 x 42013.

We would like to thank you in advance for your time and consideration. And we look forward to seeing you at the session.

Kristina Chang RN, BScN
(Insert signature)

Appendix E: Information and Consent Package

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

Investigators:

Local Principal Investigator:

Dr. Maureen Markle-Reid, BScN, MScN, PhD, Associate Professor, Canada Research Chair in Aging, Chronic Disease and Health Promotion Interventions, Co-Director of the Aging, Community and Health Research Unit
School of Nursing
McMaster University
Hamilton, ON, Canada
(Insert contact information)

Principal Investigator:

Kristina Chang, RN, BScN, MScN (student)
School of Nursing
McMaster University
Hamilton, ON, Canada
(Insert contact information)

You are invited to take part in a research study to help us understand how to involve and support older adults as partners on research teams in the best way possible.

To decide whether or not you want to be a part of this research study, you should understand the potential risks and benefits to your involvement. This form will provide you with information about the research study, and will also be reviewed with you.

Your involvement in this study is completely voluntary and you may withdraw from the study at any time, for any reason, without any questions asked, consequences or penalty.

What will happen during the study?

You are invited to attend a meeting where we will ask you to work with another older adult to create a realistic but imaginary (fictitious) story or two about working on a research team. Before the meeting, we will be asking you some questions about income, education, and long-term health problems to better understand you and your experiences. At the meeting, we will first explain a little about how research works, and then we will ask you to create your stories. We will help to walk you through the process of creating your stories. With your permission, the whole meeting will be audio recorded. We may contact you after the meeting if we have questions about your stories. The stories that you create will help us design better ways to involve and support older adults to work on a research team. This meeting will take 2 hours, and we can set up a time that will work for the both of us. Overall, we are looking to include 8-10 older adults in this study.

Are there any risks to doing this study?

We do not foresee that there will be any harms or discomforts from participating in this study. You may feel uncomfortable with sharing your opinions and ideas, but you have the right to refuse to answer any of the questions.

Are there any benefits to doing the study?

We cannot promise you any personal benefits from participating in this study. We hope to learn more about how to best involve and support older adults as partners on a research team.

Will I be paid to participate in this study?

If you decide to participate in this study, you will receive a \$50.00 gift card at the end of the session as a token of appreciation for sharing your time, experiences, and opinions. Light snacks will be provided at the session, and we will provide a \$30.00 taxi chit for transportation.

Will there be any costs to me in this?

We will only require your time to attend the face-to-face meeting. There will be no costs to participate in this study.

Will my information be kept private?

The information collected through this study will be organized and held by researchers from McMaster University. As required by law, your information will not be shared with anyone except with your permission.

Your personal information, such as your name and contact information, will be removed from notes and the audio recording to be replaced with a participant number. Audio recordings will be transcribed, and your personal information will not be included, but replaced with the participant number in the document. Demographic information about your personal characteristics, such as your age, gender and profession, will also be collected in a survey. All collected information will be securely stored in a locked office at McMaster University until the end of the study, and for no longer than 2-3 years. Information stored on computers will be protected by a password. If the results of the study are published, your name and personal information will not be released without your permission to do so.

What if I change my mind about being in the study?

It is important for you to know that you can choose not to participate in this study. You can also withdraw from the study at any time, even after giving consent. We can also remove your data from the study if it has not been included in the study yet.

The investigators may also withdraw you from this study if circumstances arise which warrant it. Your privacy will be protected as mentioned above, but if the law requires it, we will reveal certain personal information in cases of suspected neglect or abuse.

How do I find out what was learned from the study?

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary and what would be the best way to get this to you.

Questions about the study

If you have questions or need more information about the study itself, please contact the Local Principal Investigator, Dr. Maureen Markle-Reid at McMaster University, (insert contact information) or the Principal Investigator, Kristina Chang at (insert contact information).

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

- Do you have any questions or would like any additional details?
- Are you interested in participating in the study?

**PARTICIPANT INFORMATION SHEET
CONSENT STATEMENT**

	Yes	No
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time, without having to having a reason and without affecting your medical care?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to your data, including personally identifiable information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have any questions about the study?	<input type="checkbox"/>	<input type="checkbox"/>
Would you like to have more time to consider participating in this study? If yes, what time would be best for a follow-up call?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
If no, do you have any reason for not participating?	<input type="checkbox"/>	<input type="checkbox"/>

Oral consent of research participant:

Name, Participant

Date (DD/MMM/YYYY)

Signature of person obtaining consent: “I believe that the participant understands what is involved in the study and voluntarily agrees to take part in it.”

Name, Person Obtaining Consent

Role in Study

Signature of Person Obtaining Consent

Date (DD/MMM/YYYY)

Appendix F: Description of the Persona-Scenario Exercise

Persona-Scenario Exercise

Unlike a needs assessment, interview or a focus group, persona-scenarios have the capacity to capture “multiple views of an interaction with diverse kinds and amounts of detailing” (Valaitis et al., 2014, p.1) for the ramifications of design specifications for a patient and caregiver engagement strategy to be understood (J. M. Carroll, 2000).

What Is A Persona?

Personas are “fictitious characters” (Idoughi et al., 2012, p.288) designed by participants to be relatable, and reflect a combination of their personal experiences, characteristics, needs, professional background, emotions and goals (Madsen & Nielsen, 2014). The goal of creating a persona is to understand the contexts of older adults with patient or caregiving experiences. The participants’ perspectives are informed by their needs and experiences in relation to their context, interactions with the health care system, as well as with research and information and communication technology (Chiu, 2015). The result of an effective persona is that it is representative of the intended target sample (J. M. Carroll, 2000; Chiu, 2015; Idoughi et al., 2012), older adults with multimorbidity, and their caregivers.

What Is A Scenario?

Scenarios are problem-based stories that are grounded in reality (Madsen & Nielsen, 2014). The scenario is immediately constrained by the concept of the health care tool, intervention, system, process or intended solution, the setting or culture, and the role of the persona (J. M. Carroll, 2000). For example, participants in this study had to design a scenario centred around an older adult persona with multimorbidity (or a caregiver of an older adult with multimorbidity) who wanted to be a PCRP. Participants were thus constrained to create a

scenario that aligned with the capabilities and resources of their persona (e.g., physical and cognitive function, accessibility to transportation, access to respite care, comfort and accessibility to technology, etc.).

Appendix G: Guiding Questions for Persona-Scenario Development (Interview Guide)

STORY DEVELOPMENT GUIDE FOR THE INTERVIEWER (INCLUDES PROMPTS)

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

BACKGROUND

The Aging, Community and Health Research Unit at McMaster University want to work with older adults, as research partners.

We are interested in partnering with multiple:

- older adults with more than one long-term health problem, and
- family caregivers of older adults (patients) with more than one long-term health problem.

By working closely with patients and family caregivers as research partners, we hope to:

- identify patient and caregiver priorities for research;
- design more useful research;
- find effective ways to recruit older adults to participate in research studies; and
- improve the use of the research results to improve health care and inform health policies.

Little is known about how older adults would like to be approached, involved, and supported as partners in research. Also, not much is known about what older adults think about the use of technology to support them as partners on a research team.

WHAT YOU WILL BE ASKED TO DO

The goal is for you to create realistic stories. You will work with a partner and create a story about how researchers work with people like you to do research. A member of the research team will keep track of the conversation and guide you in developing your story. This entire session will be audio-recorded. These stories will help us understand how we can work better with older adults and caregivers as partners in research.

THE CHARACTER

To create the story, you will first work in pairs to imagine the main character of your story. This character will be imaginary. Your main character will be an older adult who:

- has many long-term health problems, or
- is a caregiver for someone with many long-term health problems.

For your story to be true to real life, you will need to give your character personality. We will give you some questions to guide the creation of your character. It is helpful to have your main character to be as interesting and complex as a real person.

THE STORY

Next, you will create a story for your main character. Create at least one short story for your main character to describe how he or she interacts with others on a research team. You will imagine how your main character will react to a situation given his or her personality and traits. Again, we will give you some guiding questions to help you develop your story.

DISCUSSION

Finally, we will ask you and your partner to present your main character and tell your story to us.

STORY DEVELOPMENT #1

(These guiding questions are intended for participants with experience as a *person with many long-term health problems*)

STEP 1: Create your main character (10-20 minutes)

Your main character will be an *older adult with many long-term health problems*. He or she is living at home in the community. Your main character is an active partner on a health research team. He or she will be working on the health research team to support the study.

To create your character, consider these questions as a guide. What is your character's:

1. Name, age, gender, marital status
2. Level of education
3. Living condition at home (For example: Apartment, two-story house; living alone, with a spouse, a family caregiver)
4. Previous or current job
5. Health situation. Your main character is an older adult with many long-term health problems. [*Prompt*: Think about how your main character may be affected in his or her daily life, and in your story, by having many long-term health problems].
6. Past experience with research [*Prompt*: Study participant, attended an information session, advisor or consultant, partner, none.]
7. Comfort with, and experience with technology [*Prompt*: Previous use or training received for the telephone, email, mobile devices; access to Wi-Fi.]

STEP 2: Create a short story for your main character. Focus on what happens in your story (not how it *could* happen). (30-40 minutes)

1. How does your character find out about the health research, and obtain the invitation to be a partner (co-researcher) on the health research team?
2. How was your character contacted for the chance to be involved on a health research team? [*Prompt*: Does technology (e.g., phone, email, TV, internet) play a role in this?]
3. What kind of training was provided to your character about health research, if any, and how was it provided? [*Prompt*: Was your character emailed information; or did your character attend a seminar, workshop, or webinar?]
 - a. How does your character share with researchers the kind of training or support he or she will need to be an effective partner on the team, if any? [*Prompt*: Group

- discussion on what skills need to be developed to be best involved in research; or a one-on-one discussion with a researcher on knowledge gaps.]
4. As a partner (co-researcher), what is your character's role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?
 5. How will your character communicate important patient considerations about the research to the health research team, if at all? [*Prompts*]:
 - a. How will your character help guide the direction of the research, and research question, if at all?
 - b. Who does your character meet with, and how (e.g., by phone, in person, online). Where and how often do they meet? How does your character get there (e.g., walk, bus, car, etc.)?
 6. What happens at research team meetings? How is your character involved in making decisions within the research team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?
 7. How does the researcher/s interact with your character, and vice versa?
 8. What materials were provided to your character and others and in what form? [*Prompt*: Paper, videos, online, verbal explanations, etc.]
 9. How has your character contributed to the research?
 10. What kind of resources and supports does your character receive to participate in research, if any? [*Prompt*: Transportation, administrative support from researchers, monetary compensation?]
 11. How does your character use technology, if at all, in this story? [*Prompt*: Communication at the meeting, communication in between meetings, reminders, presentations, updates, etc.]
 12. How does your character stay involved, if at all, with the research study if it takes place over a long period of time?
 13. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results? [*Prompt*: Researchers, community agencies, etc.]

STORY DEVELOPMENT #2

(These guiding questions are intended for participants with experience as a *caregiver* for an older adult with many long-term health problems)

STEP 1: Create your main character (10-20 minutes)

Your main character will be an older adult living at home in the community who is a *caregiver* to a friend/family member with many long-term health problems. Your main character is an active partner on a health research team. He or she will be working on the health research team to support the study.

To create your character, consider these questions as a guide. What is your character's:

1. Pick a name, age, gender, marital status
2. Level of education
3. Living situation at home (For example: Apartment, two-story house; living alone, with a spouse)

4. Previous or current job
5. What is the health situation of the person that your character is caring for? [*Prompt*: Think about how caregiving for a person with many long-term health problems may impact your main character's – the caregiver's – story]. You should also consider health problems that your main character may have.
6. Past experience with research [*Prompt*: Study participant, attended an information session, patient or caregiver advocate, partner, none.]
7. Comfort with, and experience with technology [*Prompt*: Previous use or training received for the telephone, email, mobile devices; access to Wi-Fi.]

STEP 2: Create a short story for your main character. Focus on what happens in your story (not how it *could* happen). (30-40 minutes)

1. How does your character find out about the health research, and obtain the invitation to be a partner (co-researcher) on the health research team?
2. How was your character contacted for the chance to be involved on a health research team? [*Prompt*: Does technology (e.g., phone, email, TV, internet) play a role in this?]
3. What kind of training was provided to your character about health research, if any, and how was it provided? [*Prompt*: Was your character emailed information; or did your character attend a seminar, workshop or webinar?]
 - a. How does your character share with researchers the kind of training or support he or she will need to be an effective partner on the team, if any? [*Prompt*: Group discussion on what skills need to be developed to be best involved in research, or in a one-on-one discussion with a researcher on knowledge gaps?]
4. As a partner (co-researcher), what is your character's role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?
5. How will your character communicate important patient or caregiver considerations about the research to the health research team, if at all? [*Prompts*]:
 - a. How will your character help guide the direction of the research, and research question, if at all?
 - b. Who does your character meet with and how (e.g., by phone, in person, online)? Where, and how often do they meet? How does your character get there (e.g., walk, bus, car, etc.)?
6. Who will be caring for your character's friend/family member during the research team meetings?
7. What happens at research team meetings? How is your character involved in making decisions within the team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?
8. How does the researcher/s interact with your character, and vice versa?
9. What materials were provided to your character and others and in what form, if at all? [*Prompt*: Paper, videos, online, verbal explanations, etc.]
10. How has your character contributed to the research?
11. What kind of resources and supports does your character receive to participate in research, if any? [*Prompt*: Respite care, transportation, administrative support from researchers, monetary compensation?]

12. How does your character use technology, if at all, in this story? [*Prompt*: For communication at meetings, communication in between meetings, reminders, presentations, updates, etc.]
13. How does your character stay involved, if at all, with the research study if it takes place over a long period of time?
14. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results? [*Prompt*: Researchers, community agencies, etc.]

Appendix H: Persona-Scenario Session Agenda

Supporting Patient and Family Caregiver Engagement in Research: A Qualitative Study

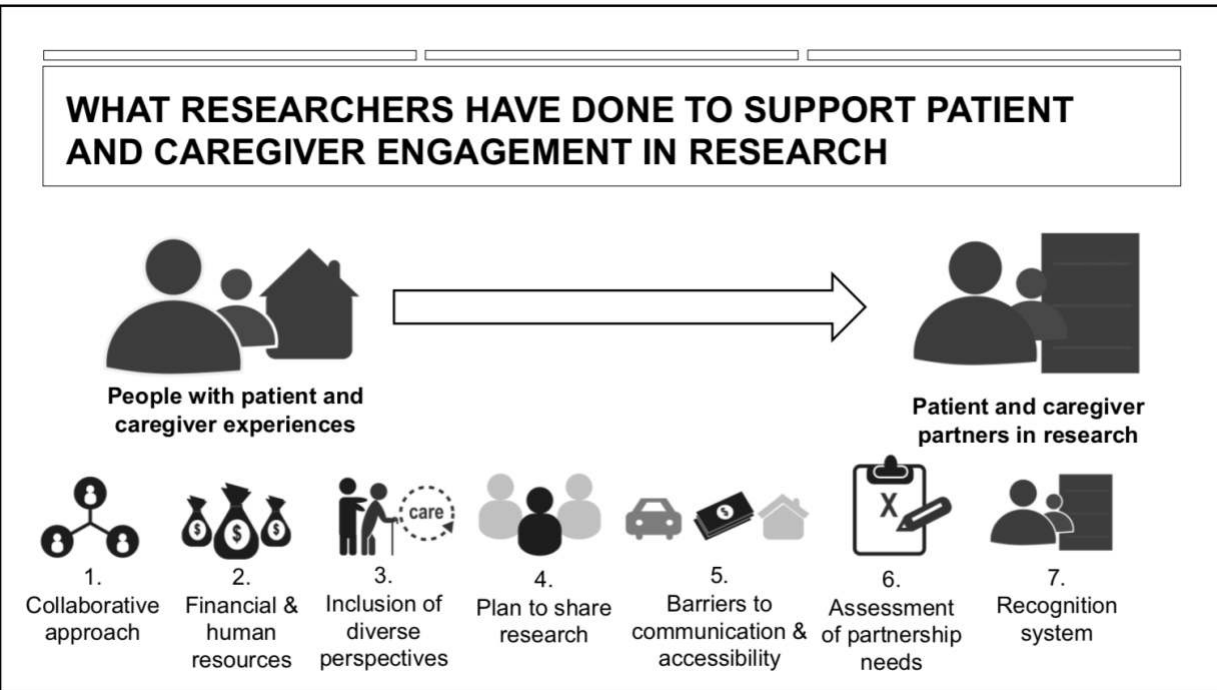
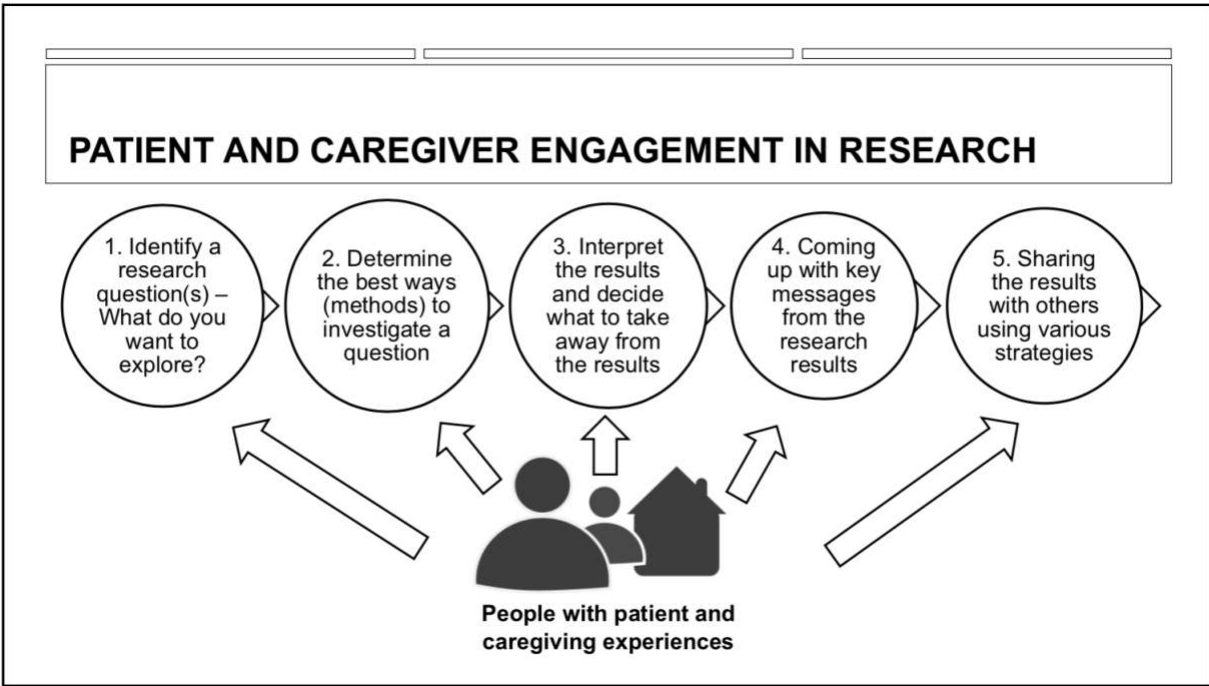
Date: TBA

Time: TBA

Location: HSC – 3N25J, McMaster University

Time	Item	Notes
10 minutes	Welcome <ul style="list-style-type: none"> • Review information on the study, answer questions, and re-affirm consent to participate 	Review facilities, and overview of the session
15 minutes	<i>Introduction to the research process:</i> <ul style="list-style-type: none"> • The Aging, Community and Health Research Unit • Patient and caregiver engagement • Identifying research priorities and shaping the research question • Designing the research intervention (tool, service, process) • Testing the research intervention • Sharing the results of the research • Remuneration to research partners/co-designers 	PowerPoint presentation
10-20 minutes	Create the persona	
30-40 minutes	Create the story	If time available, create another story
15 minutes	Presenting summary of creation, group discussion and debrief of activity	
5 minutes	Thank you for time and contributions	

Appendix I: Persona-Scenario Session – Selected Presentation Slides



Appendix J: Summaries of Created Personas and Scenarios

Persona-Scenario Session 1: Created Caregiver Persona

PERSONA GUIDING QUESTIONS	CREATED PERSONA
1. Name, age, gender, marital status	Ruth (caregiver) <ul style="list-style-type: none"> • 82-year-old woman, married.
2. Health situation	<ul style="list-style-type: none"> • Several chronic conditions: Early symptoms of Parkinson’s (not noticeable to others), hypertension, and osteoarthritis.
3. Living condition at home	<ul style="list-style-type: none"> • Lives with husband, Benjamin (Ben) in a bungalow in suburban Hamilton. <ul style="list-style-type: none"> ○ Caregiver to her husband who has middle-stage dementia. Managing at home, but Ben is beginning to show behavioural problems. ○ Ben also has hypertension, renal disease, and is obese. ○ Two children: a daughter in Halifax; and a son in Vancouver.
4. Education	<ul style="list-style-type: none"> • Completed an undergraduate degree.
5. Past experience with research	<ul style="list-style-type: none"> • Has collected data for research in education with the Board of Education. Played a role in developing new intervention strategies for students with special needs.
6. Employment	<ul style="list-style-type: none"> • Retired, but used to be an elementary school teacher.
7. Experience/comfort with technology	<ul style="list-style-type: none"> • Currently comfortable using email. Has a basic cellphone. Has the desired to learn how to use new communication technologies so that she can contact her children who live far away. • Comfortable using a type writer. • Had difficulty adapting to the integration of new technologies for report card formatting in the 1990s. Retired shortly thereafter.

Persona-Scenario Session 1: Created Scenario with Caregiver Persona

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
1. How does your character find out about the research, and the invitation to be a partner (co-researcher) on the health research team?	<ul style="list-style-type: none"> • Ruth got involved in research through the Parkinson’s Association. <ul style="list-style-type: none"> ○ Is concerned about her own well-being (progression of Parkinson’s) and how it will impact her and her husband’s life.
2. How was your character contacted for the chance to be involved on a health research team?	<ul style="list-style-type: none"> • Ruth saw a flyer ad with the message “help us create the future”, and it caught her eye. Ruth called the researchers using the contact information provided on the flyer. • Ruth (and other respondents to the ad) are invited to an in-person meeting with the research group. There are 8 group members, with three researchers and five respondents.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>3. What kind of training was provided to your character about health research, if any, and how was it provided?</p> <p>a. How does your character share with researchers the kind of training or support he or she will need to be an effective partner on the team, if any?</p>	<ul style="list-style-type: none"> • Each research partner has individual abilities and interests in research and so the researcher should be aware of the participants’ skill set and interests and direct those two things to optimize contributions to the research process. • Ruth may have depression and she may not feel comfortable leaving home to meet in-person every meeting. The possibility of Ruth utilizing a communication tool such as Skype, would benefit her on the days that she does not feel able to leave the home, which would hopefully optimize her contributions. • Researchers offer the opportunity to teach Ruth how to use Skype, and she learns how to use it to set up a Skype teleconference to review research materials. • The researchers and partners work together to set up the most advantageous conditions possible to create options that support the partner’s ability to participate in the research.
<p>4. As a partner (co-researcher), what is your character’s role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?</p>	<ul style="list-style-type: none"> • Research partners are considered Subject Matter Experts. • Research partner’s role on the team was to attend a total of six focus group sessions, once a week early in the research process. • Opportunity at these meetings to network with other research partners, or opt out if not comfortable. • Research opportunities were not presented as long-term commitments. Subsequent involvement was presented to Ruth in phases. She would need to consider both her and her husband’s situations before making any commitment.
<p>5. How will your character communicate important patient considerations about the research to the research team, if at all?</p>	<ul style="list-style-type: none"> • Ongoing communication: Researchers would mail hard copies of meeting documents to Ruth in advance, or she could receive them electronically via a USB key, or email.
<p>6. Who will be caring for your character’s friend/family member during the research team meetings?</p>	<ul style="list-style-type: none"> • Provide alternative meeting options: Researchers offer to make home visits, or Ruth can bring her husband to the meeting venue.
<p>7. What happens at the research meetings? How is your character involved in making decisions within the research team, if at all?</p>	<ul style="list-style-type: none"> • The group of research partners (with Parkinson’s) are given the opportunity to exchange telephone numbers and email addresses. Some do, and others opt not to. At first, the partners are timid and sensitive to how other partners and the researchers perceive them.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?</p>	<ul style="list-style-type: none"> • The group members are all over the age of 65, with Parkinson’s. • Research partners expected to be willing to share their experiences. • If Ruth was to miss a meeting, the researchers would share an audio recording of the meeting, accompanied by a written summary of the meeting. • Ruth is given a checklist to keep a running log of the research tasks or projects that she’s worked on, and this will help to validate her contributions.
<p>8. How does the researcher/s interact with your character, and vice versa?</p>	<ul style="list-style-type: none"> • At the first meeting, the researchers give a presentation and thank those who showed interest in the research. They also provide options for Ruth and others to get to know each other.
<p>9. What materials were provided to your character and others and in what form?</p>	<ul style="list-style-type: none"> • The researchers and Ruth kept track of her contributions through a checklist. This helped to keep everyone accountable. • Ruth receives various forms from the researchers by means of Purolator (hard-copies and USB keys etc.), email attachments.
<p>10. How has your character contributed to the research?</p>	<ul style="list-style-type: none"> • Ruth wants to understand what future the researchers want to create and how the research results might impact on her ability to have an improved quality of life, and to manage her responsibility for her own care and for her role as a caregiver. • Ruth recognizes her condition is in the early stages of Parkinson’s and wants to capitalize on her abilities in their current standing to contribute to the research process, as she wants to see a potentially beneficial outcome of the research on her own condition.
<p>11. What kind of resources and supports does your character receive to participate in research, if any?</p>	<ul style="list-style-type: none"> • Researchers provide transportation compensation. • The researchers also provide caregiving or respite care options (e.g., compensation, or on-site services). • Researchers provide physical accommodations for Ruth’s Parkinson’s.
<p>12. How does your character use technology, if at all, in this story?</p>	<ul style="list-style-type: none"> • Researchers review each research partner’s functional ability to utilize technology related to the research, and accommodate functional disabilities, using technology where applicable (e.g., touch screens and tablets for issues with finger dexterity). • Ruth utilized the telephone to call the number on the poster to find out about the study.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
13. How does your character stay involved, if at all, with the research study if it takes place over a long period of time?	<ul style="list-style-type: none"> An audio recording is taken of each meeting with the option for Ruth to listen to if she is unable to attend the meetings, and follow along with a summary of the key points missed.
14. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results?	<ul style="list-style-type: none"> Not discussed in this scenario.

Persona-Scenario Session 2: Created Older Adult with Multimorbidity Persona

PERSONA GUIDING QUESTIONS	CREATED PERSONA
1. Name, age, gender, marital status	<ul style="list-style-type: none"> Myrtle (older adult with multimorbidity) 70-year-old woman, widowed for five years.
2. Health situation	<ul style="list-style-type: none"> Several chronic conditions: Type 2 Diabetes managed with medications, mobility and pain issues due to arthritis (walks with a cane), overweight, osteoporosis, hypothyroidism, wears glasses and has false teeth.
3. Living condition at home	<ul style="list-style-type: none"> Lives with a cat in an apartment in East Mountain, Hamilton. Three children: A son contracted to Fiji, a son who lives in B.C., and a daughter with two grandchildren who live near Hamilton.
4. Education	<ul style="list-style-type: none"> Graduated from college in book-keeping. Married shortly thereafter, and stayed at home with the kids.
5. Past experience with research	<ul style="list-style-type: none"> Study participant in a diabetes drug trial.
6. Employment	<ul style="list-style-type: none"> Worked part-time as a book-keeper for ‘pin money’. Currently does book-keeping part-time, and has a car to drive herself around the city. Lower-middle class. Not affluent, but lives comfortably.
7. Experience/comfort with technology	<ul style="list-style-type: none"> Experience/comfort with technology: Comfortable with the computer (for bookkeeping), and learned how to use Skype to keep in touch with her kids.

Persona-Scenario Session 2: Created Scenario with Older Adult with Multimorbidity Persona

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>1. How does your character find out about the research, and the invitation to be a partner (co-researcher) on the health research team?</p>	<ul style="list-style-type: none"> • Myrtle got involved through a bookkeeping client/friend who is a current research partner with the health research team. • This friend introduced Myrtle to the research program by giving her a business card for the health research team.
<p>2. How was your character contacted for the chance to be involved on a health research team?</p>	<ul style="list-style-type: none"> • Using the business card, Myrtle called the research program. Over the call, she was interviewed on her life experiences and experiences with research, and was invited to be a research partner. • She was also invited to the orientation (two researchers with five other research partners) at the local community centre where she could decide afterwards whether she wanted to be involved. During the orientation, the researchers would have an extended conversation about role expectations. • The researchers followed-up the phone call, and orientation by emailing Myrtle the information package.
<p>3. What kind of training was provided to your character about health research, if any, and how was it provided? a. How does your character share with researchers the kind of training or support he or she will need to be an effective partner on the team, if any?</p>	<ul style="list-style-type: none"> • Researchers made clear to Myrtle that she could contact a staff member at the research unit (e.g., research coordinator) for health accommodations, or if she needed any help (e.g., concerns with training, to provide feedback). • The first meeting is a one-hour meeting-at a community centre (e.g., St. Helen, Perk, Sackville). Researchers should give potential research partners a summary about the study and give them time to think about it. Snacks would be provided at the meeting. Researchers would also have a discussion of role expectation and time commitment at this meeting. There would also be a social aspect at the end for research partners to get to know one another. <ul style="list-style-type: none"> ○ About five potential research partners attend this meeting. • Researchers provide training on the research topic (osteoporosis), research methods, technology (e.g., Microsoft PowerPoint), and analysis. These trainings would occur once a month, over two years presented with the partners face-to-face.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
4. As a partner (co-researcher), what is your character’s role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?	<ul style="list-style-type: none"> • Research partner’s role on the team: Co-design the intervention, and help to test it out. • Myrtle wants to also be involved in all aspects of the study (e.g., presenting research findings). She would be also involved in developing the research question, and in data analysis.
5. How will your character communicate important patient considerations about the research to the research team, if at all?	<ul style="list-style-type: none"> • If Myrtle couldn’t make it due to health conditions or any other reasons, then she can have a conference call. She is comfortable with using the phone. • The research team can email Myrtle any study related information with decisions for her to review. •
6. What happens at the research meetings? How is your character involved in making decisions within the research team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?	<ul style="list-style-type: none"> • Meetings would take place in a comfortable place, led by the researchers. • Myrtle is flexible with the meeting venue – she can drive.
7. How does the researcher/s interact with your character, and vice versa?	<ul style="list-style-type: none"> • Via email or phone or in person.
8. What materials were provided to your character and others and in what form?	<ul style="list-style-type: none"> • Package of study information either in email or hard copy.
9. How has your character contributed to the research?	<ul style="list-style-type: none"> • Myrtle commits to a two-year study. Wants to learn how to manage her osteoporosis and arthritis pain. • Would meet with the researchers and other research partners once a month over two years.
10. What kind of resources and supports does your character receive to participate in research, if any?	<ul style="list-style-type: none"> • Researchers provide or validate parking. • Researchers or research staff organize the meetings for the research partners. • Research partners may need support with technology (e.g., Microsoft PowerPoint), or with photocopying handouts.
11. How does your character use technology, if at all, in this story?	<ul style="list-style-type: none"> • Alternative meeting options: Conference call, and followed-up with an email on any important decisions that were made for Myrtle to review afterwards.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
12. How does your character stay involved, if at all, with the research study if it takes place over a long period of time?	<ul style="list-style-type: none"> • Ongoing communication: In person, over the phone, or through email. • Important for the research partners to trust the researchers. If there is a conflict, Myrtle needs to feel comfortable to speak with the other researchers privately, otherwise she will leave the research program. • Myrtle needs to regularly receive encouragement from the researchers for her contributions and dedication to the study.
13. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results?	<ul style="list-style-type: none"> • Myrtle would like to share the research findings with other seniors at the local recreational centre. • She could co-present with the researchers to funders, at conferences, or to other stakeholders of the research. If transportation is provided, then Myrtle would be flexible with co-presenting at out-of-town events/venues (e.g., Toronto).

Persona-Scenario Session 3: Created Older Adult with Multimorbidity and Caregiver Personas

PERSONA GUIDING QUESTIONS	CREATED PERSONA
1. Name, age, gender, marital status	<ul style="list-style-type: none"> • Matilda (older adult with multimorbidity) • 69-year-old woman, married (for 50 years).
2. Health situation	<ul style="list-style-type: none"> • Several chronic conditions: Middle-stages of dementia (relies on husband for help), Type 2 Diabetes, and hypertension. • Matilda is not used to asking for help. • Resents husband as she needs to rely on him more for care.
3. Living condition at home	<ul style="list-style-type: none"> • Lives in a house in Scotland, Ontario (a rural community ~1hr away from McMaster University). • Two children: Live in different provinces.
4. Education	<ul style="list-style-type: none"> • Had an undergraduate degree and teaching certificate.
5. Past experience with research	<ul style="list-style-type: none"> • Involved in research with the Ontario Institute for Studies in Education (OISE).
6. Employment	<ul style="list-style-type: none"> • Retired. Used to be a high school teacher, and a community leader in church up until two years ago (due to the onset of dementia).
7. Experience/comfort with technology	<ul style="list-style-type: none"> • Used to be skilled with a computer and the Internet before the gradual onset of dementia.

PERSONA GUIDING QUESTIONS	CREATED PERSONA
1. Name, age, gender, marital status	<ul style="list-style-type: none"> • Matt (caregiver) • 70-year-old man, husband to Matilda.
2. Health situation	<ul style="list-style-type: none"> • Several chronic conditions: Type 2 Diabetes, poor eyesight (recently lost Driver’s license).
3. Living condition at home	<ul style="list-style-type: none"> • Primary caregiver to his wife. • Their family doctor recently became concerned about Matilda’s behavioural symptoms, and prescribed a sedative to help manage her behaviour throughout the day. • Matt is not very social, but still attends church regularly with Matilda (the church is within walking distance from their home).
4. Past experience with research	<ul style="list-style-type: none"> • No previous experience with research, but became interested in participating in a caregiver research study to help manage his responsibilities caring for Matilda.
5. Employment	<ul style="list-style-type: none"> • Retired auto-mechanic. • Fixed income. Needed to hire help to clean the house and do the groceries, but unable to afford it on a weekly basis. Has a neighbor that helps to pick up groceries, and drive them to medical appointments from time to time.
6. Experience/comfort with technology	<ul style="list-style-type: none"> • Not very comfortable with technology. Uses the phone, and has a cellphone. Matilda used to be responsible for everything that required the computer.

Persona-Scenario Session 3: Created Scenario with Older Adult with Multimorbidity and Caregiver Personas

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
1. How does your character find out about the research, and the invitation to be a partner (co-researcher) on the health research team?	<ul style="list-style-type: none"> • The researchers went to Matt and Matilda’s church to recruit research partners for their study on caregivers. • It’s a caregiving research study, but the researchers want to also learn from the individuals that they caregivers are caring for. • The research team was partnered with the local Alzheimer’s Society chapter. • The researchers would hold meetings with the research partners at the church once a month every Sunday, after the church service.
2. How was your character contacted for the chance to be involved on a health research team?	<ul style="list-style-type: none"> • Through their visits to the church, the researchers approached Matt to be involved in the study, which offers a one-year support program for caregivers. • Six months would be for holding the workshop sessions where the research team would meet at the church, and then the researchers would take another six months to

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
	<p>analyze all the data and then present it back to the research partners for feedback.</p> <ul style="list-style-type: none"> • Matilda got really upset over the research opportunity because she didn't think that she had a "problem" that needed to be addressed. Matt wondered if Matilda would have to have any involvement in the research • The research team leader told Matt that they would prefer to have both him and Matilda involved in the research. The researchers asked Matt to bring Matilda only on occasion, but not all of the time if she was uncomfortable. However, Matt was really concerned about who would look after Matilda if he was away at the research meeting. • An old friend of Matt and Matilda's, who also works for the Alzheimer's Society, approached Matt over coffee to become a research partner, and this friend would look into supports
<p>3. What kind of training was provided to your character about health research, if any, and how was it provided?</p>	<ul style="list-style-type: none"> • Matt was approached to receive training (content) from the Alzheimer's Society but declined. Matt seeks out training to use technology (e.g., webinars) from the Scotland library (within walking distance from home).
<p>4. As a partner (co-researcher), what is your character's role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?</p>	<ul style="list-style-type: none"> • Research partner's role on the team: Sharing experiences as patient or caregiver, and the challenges with navigating the health care system.
<p>5. How will your character communicate important patient considerations about the research to the research team, if at all?</p>	<ul style="list-style-type: none"> • To draw out Matt, the researchers can talk about something totally unrelated to the community project (e.g., rather than having cookies and biscuits, are there any other snacks that you would prefer?). And then the researcher can direct the conversation with Matt back to something related to the community project.
<p>6. Who will be caring for your character's friend/family member during the research team meetings?</p>	<ul style="list-style-type: none"> • When Matt is at the church for the community project and Matilda is not, their neighbor, Social Worker, or other church members will help care for Matilda at home.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>7. What happens at the research meetings? How is your character involved in making decisions within the research team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?</p>	<ul style="list-style-type: none"> • Researchers explain at the first meeting the expectations of the research study. • Because of the numbers of caregivers that are in the area of Scotland, the researchers decided that they would come to the local church to hold the research meetings. • Once-a-month meetings would be the maximum. The researchers made an exception and held the meetings on Sundays after church. The meetings are an hour-and-a-half long. All partners in research get a ride home from people in the community who are also involved in the research (and still had their licenses). • Meetings are informative, and very social (snacks provided). Led by the researchers, and includes a question and answer period. • The topic of the first few meetings are prescribed by the researchers, and thereafter are informed by the research partners’ needs (e.g., how to handle outburst or arguments, navigating the health care system). • Meetings are very social (coffee and biscuits are provided). Almost a social time with questions provided by the research team. Sessions led by the research team. There are questions and answers. That works very well for Matt because he’s an introvert. • The researchers want the partners to leave with their questions answered and a certain degree of knowledge regarding their health challenges. • If Matt still have some questions, a researcher or research staff will direct you to supportive resources. By interaction with other caregivers in the area, Matt learns about other resources in the community that he wouldn’t normally hear about if he didn’t attend the meetings. • Proportion of meetings: one to two researchers, and six to eight research partners.
<p>8. How does the researcher/s interact with your character, and vice versa?</p>	<ul style="list-style-type: none"> • Researchers need to present the research study or project in a way that’s palatable to the community. Stop using the word “research”. Instead, use “community project”. • Researchers should ask questions to draw out research partners (e.g., What exactly is the problem? Is it that there’s no accessible transportation to health services?). • At the first meeting, have two researchers or research staff present. The same researcher may not be able to come to every meeting, but the partners should be familiar with both researchers. In terms of personality traits, at least one

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
	of the researchers should have strong facilitation skills, who can draw out the research partners.
9. What materials were provided to your character and others and in what form?	<ul style="list-style-type: none"> • Researchers make pamphlets from other community resources/support groups available to the research partners at each meeting.
10. How has your character contributed to the research?	<ul style="list-style-type: none"> • Shapes the research question, and provides feedback on the caregiver support program, and the research findings.
11. What kind of resources and supports does your character receive to participate in research, if any?	<ul style="list-style-type: none"> • The researchers connect Matt and Matilda with a social worker to coordinate and liaise caregiving support. • The researchers have an obligation to ensure that something (e.g., community services) will bridge the caregiving support program for Matt and Matilda after the study has completed. • Researchers talked to caregivers to find out what kind of help/support they will need.
12. How does your character use technology, if at all, in this story?	<ul style="list-style-type: none"> • If the researchers wanted to communicate with Matt it would have to either be face-to-face over the phone, or via Canada Post as Matilda used to be the one that he would rely on for anything related to the computer and Internet, but unfortunately her knowledge is failing her at this time.
13. How does your character stay involved, if at all, with the research study if it takes place over a long period of time?	<ul style="list-style-type: none"> • Ongoing communication: Matt is provided with a phone number to reach the academic researchers in case he needs help.

Persona-Scenario Session 4: Created Caregiver Persona

PERSONA GUIDING QUESTIONS	CREATED PERSONA
1. Name, age, gender, marital status	<ul style="list-style-type: none"> • Henry (caregiver) • 77-year-old, married.
2. Health situation	<ul style="list-style-type: none"> • Several chronic conditions: Cardiac issues, Type 2 Diabetes, slightly overweight.
3. Living condition at home	<ul style="list-style-type: none"> • Lives in a two-story detached home in Hamilton with his wife, Eleanor (75-year-old). • Primary caregiver to Eleanor who has mild dementia. Has recently been more vigilant monitoring Eleanor in her activities. • Owns a vehicle and is still able to drive himself around. • Usually responsible for maintenance duties around the home, and Eleanor is responsible for housekeeping and domestic

PERSONA GUIDING QUESTIONS	CREATED PERSONA
	<p>duties, but Eleanor has recently lost interest and needs help around the house.</p> <ul style="list-style-type: none"> • Three children: One who lives in the area, one who lives in western Canada, and one in the US. • Occasionally babysit their grandchildren.
4. Education	<ul style="list-style-type: none"> • High school graduate.
5. Past experience with research	<ul style="list-style-type: none"> • No previous experience with research. Beginning to worry that Eleanor’s memory and health will continue to decline, and wants to learn more about what he can do.
6. Employment	<ul style="list-style-type: none"> • Retired licensed carpenter. Occasional does ‘handyman’ work on a contractual basis. • Attends seniors’ hobby groups and the local community centre with Eleanor. Henry enjoys wood carving, Eleanor enjoys the crafts group.
7. Experience/comfort with technology	<ul style="list-style-type: none"> • Comfortable using email, and knows how to use Skype to communicate with his children.

Persona-Scenario Session 4: Created Scenario with Caregiver Persona

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
1. How does your character find out about the research, and the invitation to be a partner (co-researcher) on the health research team?	<ul style="list-style-type: none"> • The researchers placed flyers to recruit research partners at the local community centres (e.g., with existing seniors’ programs), and had an ad on the radio. • There’s also a flyer at the front desk of the community centre (that Henry and Eleanor frequent) which displayed symptoms of dementia. • The two-year long study is about ‘short-term memory loss’ (as opposed to ‘dementia’), which grabbed Henry’s attention. • The research study is partnered with the Alzheimer’s Society
2. How was your character contacted for the chance to be involved on a health research team?	<ul style="list-style-type: none"> • Henry heard the announcement on the radio, and then attended an hour and a half long presentation at the community centre.
3. What kind of training was provided to your character about health research, if any, and how was it provided?	<ul style="list-style-type: none"> • Research content training in the form of a presentation is provided at each meeting (e.g., the symptoms to look out for in dementia). • Henry expressed a desire for video conference training.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>4. As a partner (co-researcher), what is your character’s role on the health research team? How was this decided and who was involved in the decision? For how long will your character stay in this role?</p>	<ul style="list-style-type: none"> • Formulating the research question (identifying research priorities); reviewing instruments or tools (via email), providing feedback at face-to-face meetings; figuring out the key findings. • Researchers do not expect research partners to be involved in data analysis.
<p>5. How will your character communicate important patient considerations about the research to the research team, if at all?</p>	<ul style="list-style-type: none"> • The researchers identify a ‘safe-communications channel’ for the research partners. • Confidentiality is key. Henry expressed concern with regards to the information that he’ll be sharing in relation to Eleanor. Henry needs to know that Eleanor will not be identified when he shares his anecdotal experiences. • Research partners must feel safe and comfortable at the meetings to share their experiences.
<p>6. Who will be caring for your character’s friend/family member during the research team meetings?</p>	<ul style="list-style-type: none"> • Eleanor did not attend the first meeting, and is in another area of the community centre doing crafts, while waiting for Henry to finish attending the presentation. • Eleanor is comfortable at home while Henry attends the researcher meetings, and Henry is okay with letting her stay at home so long as she does not drive anywhere.
<p>7. What happens at the research meetings? How is your character involved in making decisions within the research team, if at all? What is the mood like? Is there a leader? Who is it? Are there other older adults / caregivers there?</p>	<ul style="list-style-type: none"> • Meetings are organized and led by the researchers. Meetings are held during the day or afternoons. • Meeting minutes, and research documents are made available to research partners at least a week in advance of meetings. • Meetings are face-to-face (teleconferencing is also an available option). The initial contact should be done by phone. • For the first meeting, Henry attended a day presentation held by the recruiting researchers. • The study pertains to short-term memory loss and Henry is interested in the possibility of getting involved. • The presentation does not focus on commitment of time, but on capturing the interest of potential research partners (e.g., symptoms of dementia). • Henry exchanged contact information with the researchers after the presentation. Henry was also given a pamphlet of information. • Proportion of attendees: two researchers, and four to six potential partners.

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
	<ul style="list-style-type: none"> • For the second presentation/meeting there will be 4-6 partners from the community, and 2 researchers in attendance. • The following sessions are an hour and half in length.
8. How does the researcher/s interact with your character, and vice versa?	<ul style="list-style-type: none"> • Initial contact: phone, further contact: email. Sessions are face-to-face. Tele-conferencing is also available. • Henry is given an alternate safe-communication avenue in which he can safely discuss issues related to the study without the fear of study-partner confrontation
9. What materials were provided to your character and others and in what form?	<ul style="list-style-type: none"> • The research leads provide partners with session “prep” materials prior to the meetings. Research partners are asked to read the materials in order to better prepare them for the meetings. • Henry likes to read prep materials beforehand in order to prepare for the meetings, he receives these materials a week in advance via email. • The meeting summaries are provided to partners via email as well.
10. How has your character contributed to the research?	<ul style="list-style-type: none"> • The researchers are looking for care givers and finding out the perspectives on issues related to care giving. • Henry is involved in formulating the research question (identifying research priorities) as well as during the model stage development, findings and implementation. • Henry is also involved at the “findings” stage where he can provide insight and feedback on how to “deal” with the information.
11. What kind of resources and supports does your character receive to participate in research, if any?	<ul style="list-style-type: none"> • Parking and transportation costs are reimbursed or validated by the researchers. • Henry receives verbalized appreciation/thanks from the researchers as well as a mention in the study findings publications (acknowledgement). • Henry is asked for permission prior to being mentioned in published materials.
12. How does your character use technology, if at all, in this story?	<ul style="list-style-type: none"> • Henry uses email to communicate with the research staff and receives updates from the research staff regarding study progression (when anything useful occurs in order to keep Henry in the loop about the study).
13. How does your character stay involved, if at all, with the research study if it takes	<ul style="list-style-type: none"> • Henry drives to McMaster in order to participate in the study. The research team knows that Henry has flexibility, as he drives, and they try to keep proceeding to an hour and a half so that Eleanor is not alone for too long. If the

SCENARIO GUIDING QUESTIONS	SUMMARY OF SCENARIO
<p>place over a long period of time?</p>	<p>location is too far from Henry’s home, he is given the option to attend via telephone instead of driving.</p> <ul style="list-style-type: none"> • Henry is involved for the entire study length, which is 2 years. • Ongoing communication: Research partners can be reached via email. Received ongoing updates on the progress of the study (via email), especially when not directly involved (e.g., data analysis).
<p>14. How does your character get involved in sharing the results of the study, if at all? With whom does your character share the results?</p>	<ul style="list-style-type: none"> • Henry is not interested in presenting or co-presenting the findings of the research. However, he may be interested in being present at those presentations to participate in answering any questions from other fellow caregivers in the audience.

Appendix K: Results of Major Themes, Subthemes, and Design Specifications

Theme: Recruitment of PCRPs

Subtheme 1: Communicate expectations of PCRPs' involvement

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> • Researchers understand demands of project before recruiting PCRP • PCRP will not walk into the first meeting not knowing the opportunities and expectations of participation 	<ul style="list-style-type: none"> • Review the study timeline and map out opportunities where PCRPs can best contribute and provide input to the research. • Provide an overview of the PCRP's role (e.g., responsibilities, minimum time commitment, required contributions, meeting locations) to communicate the various options for involvement. 	<ul style="list-style-type: none"> • A study timeline that maps out opportunities for PCRP involvement in the research; and • A formalized agreement or protocol on PCRP engagement in research (e.g., purpose, time commitment, role, expectations).

Subtheme 2: Use a variety of recruitment strategies and methods

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> • Recruiting PCRPs based on experience with research may be more relevant than by socioeconomic characteristics. • Ads should have high print to text contrast, and easy to read colours • Messaging – ‘Help us create the future’, use ‘short-term memory loss’ rather than ‘dementia’ • Have existing PCRP reach out to their personal networks (over coffee) • Have business cards with the researchers’ phone numbers provided • Researchers to initiate the first interaction with potential PCRP 	<p>Apply multiple strategies, including:</p> <ul style="list-style-type: none"> • Consider the needs of the research, and recruit PCRPs by the characteristic of interest (e.g., having experience in research, caregiving, or the lived experience); • Design visually appealing materials with graphics, easily legible text, and lay-language messaging; • Distribute recruitment materials through existing PCRP, community partners, and faith-based organizations; • Recruit potential PCRP through face-to-face interaction (e.g., at a 	<p>Recruitment materials to include:</p> <ul style="list-style-type: none"> • A formal written recruitment plan; • Printed flyers with lay language; • Recruitment materials (e.g., research business cards with phone contact information, flyer or pamphlet introducing health care research team); • Radio advertisements; • A contact list of potential PCRP (e.g., phone number, e-mail address, mailing address); and • A telephone script for researchers (to guide the

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Post or distribute flyers in senior community centres, community-based organizations (e.g., Parkinson Canada, Alzheimer Society of Canada), or religious organizations • Announce recruitment for PCRP on the radio • Exchange information with potential PCRPs after meeting them (e.g., providing researchers' business cards with phone numbers; phone calls are preferred over contact via website or e-mail) • Ensure follow-up via phone call within a week of the first interaction • Phone call (interview) leads to being invited to the orientation • Further exchange can happen via e-mail 	<p>community event) to attend the first meeting;</p> <ul style="list-style-type: none"> • Connect with potential public to encourage them to join the research team over coffee; • Consider radio announcements for recruitment; • Have the researcher call the potential PCRPs within a week of making contact to follow-up with the exchange; • Subsequent exchange of information can occur via e-mail; • Phone calls are preferred over website or e-mail interaction (at least for the first interaction); and • Interested individuals can contact the researchers by phone (e.g., researchers' contact information is shared via business cards). 	<p>first conversation with the potential PCRPs).</p>

Subtheme 3: Identify PCRPs' caregiving needs, and consider ongoing respite options as needed

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Researchers make a friendly visit to the PCRPs' home if they prefer staying at home (e.g., due to an exacerbation of a condition, or to care for their loved one) rather than travelling to a public meeting space 	<ul style="list-style-type: none"> • Discuss caregiver respite needs and support options (e.g., community health partners). • Consider strategies to minimize caregiver burden based on above. • Obtain funding to provide support or respite services for caregivers to 	<ul style="list-style-type: none"> • A contact list of community health partners to support caregiving services (e.g., with private agencies, or community-based services); • Funding to support caregiving respite services; and

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Have a community service provider or a PCRP to contact a companion or neighbourhood friend to look after the caregiver’s loved one • Researchers to pay for respite care, or to compensate caregivers for daytime meetings • Allow caregivers to bring their loved ones with them to the meetings • Community centre (meeting venue) offers activities for the loved one while the caregiver is attending the research meeting • If the PCRP’s involvement in the research includes exposure to a new health or social service or product, the researchers should ensure that the PCRPs are linked or referred to a transitional service before the study is completed 	<ul style="list-style-type: none"> • attend research team meetings. • Be flexible and understanding of each PCRPs’ circumstances (and how that may impact their ability to participate). • Consider conducting home visits to engage PCRPs who need to stay at home. • Receive training on cultural sensitivity and empathy. 	<ul style="list-style-type: none"> • Training materials or resources for researchers on cultural sensitivity and empathy (e.g., create own content or refer to content from existing organizations).

Theme: Planning for Meaningful Engagement

Subtheme 1: Determine PCRPs’ training and support needs related to research

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Note PCRPs’ abilities, and interests after they have learned about the research to optimize their contributions • Consider that the PCRPs’ motivation to participate 	<ul style="list-style-type: none"> • Discuss PCRPs’ interests through an informal conversation (via phone, or in-person) after s/he has learned about the research study. Help the PCRPs to create a list of self- 	<ul style="list-style-type: none"> • An outline, or informal script to help the researchers guide the informal conversation about the PCRPs’ interests;

Codes	Specifications	
	Action	Product
<p>may fluctuate based on mood or health status (e.g., depression)</p> <ul style="list-style-type: none"> • Discuss role expectations and commitments (for PCRP and researchers) 	<p>identified strengths and abilities that they can bring to the team, and use this list to align their skills to the study or project.</p> <ul style="list-style-type: none"> • Align the PCRP’s interests with the work that they will be doing to satisfy those interests, and sustain their motivation to be involved. • Be open, communicative, and transparent when negotiating role expectations, and levels of commitment. 	<ul style="list-style-type: none"> • A list of self-identified strengths and abilities that the PCRP can bring to the team (e.g., different ways to contribute to the research team); and • A statement of participation or agreement on role expectations and time commitment for all team members (as previously mentioned).

Subtheme 2: Be flexible with the PCRP’s capacity to be involved, and reduce burden of participation for caregivers

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Opportunities for involvement in research presented to PCRP in short-term phases, and researchers can overlap the timing for each PCRP’s involvement • After initial involvement in research, further contributions by PCRP can be renewed based on their availability and the opportunities for involvement • PCRP can be involved in ways that they will feel comfortable • PCRP concerned about the burden of participating in research on their caregiving role 	<ul style="list-style-type: none"> • Envision opportunities for PCRP involvement in the research, and present them as short-term “phases” or projects. • Renegotiate each PCRP’s level of commitment on an ongoing basis (depending on interests, abilities, and availability). • When discussing level of involvement, researchers can consider the opportunity costs for PCRP (especially those who are caregiving) • Mitigate caregiver burden by being understanding of each PCRP’s circumstances and time commitment, and being flexible with the level of 	<ul style="list-style-type: none"> • A study timeline, with examples of possible short-term “phases” or opportunities for involvement (as previously mentioned); • Alternate forms of contribution to in-person participation (e.g., home visit, teleconference, web conference); • A ‘living’ statement of participation or agreement on role expectations and time commitment for all team members (as previously mentioned); • A role description for researchers (with respect to their role to support PCRPs); and

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • PCRPs participation in research (time away from home) may add friction and stress at home between caregiver and loved one, and this may impede the PCRPs ability to consistently contribute to research • Talk to PCRPs to find out if they're getting the required health care support, and if there are gaps • Travel, time, and resources PCRPs spend to participate in a big, day-long meeting • For PCRPs who are caregivers, their ability to participate in research will fluctuate on the loved one's caregiving needs • For PCRPs who are caregivers, to manage caregiving needs, their involvement depends on alternatives to face-to-face meetings 	<ul style="list-style-type: none"> involvement, and offering alternatives to face-to-face meetings. • Refer PCRPs to potential health care and social services 	<ul style="list-style-type: none"> • A list of community health and social care services and supports for referral.

Subtheme 3: Plan for the first meeting, ensure effective meeting structures and location, and address barriers to participation for subsequent meetings

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Provide a presentation to potential PCRPs on the research team and study <ul style="list-style-type: none"> ○ Don't need to know all the details behind the research ○ Provide an information package 	<ul style="list-style-type: none"> • Produce research background materials in lay language so that they can be clearly understood by PCRPs. • Follow-up with the necessary accommodations. 	<ul style="list-style-type: none"> • A semi-structured guide or agenda for each meeting; • A Microsoft PowerPoint presentation that provides a brief overview of the health care research team or

Codes	Specifications	
	Action	Product
<p>summarizing the basic aspects of the research</p> <ul style="list-style-type: none"> Physical accommodations discussed during the first meeting Researchers provide basic overviews of the research using lay language <ul style="list-style-type: none"> Use the term ‘community project’ instead of the word ‘research’ Give potential PCRPs time to think about committing to the role Researchers provide training on research content (e.g., symptoms and disease process; research methods; data analysis) at every meeting, or on scheduled dates as needed. Have two researchers present so that PCRPs are familiar with both in case one is away Proportion of PCRPs to researchers is governed by the size of the team, and purpose of the meeting When determining meeting duration (e.g., from an hour to an hour and a half), frequency (e.g., quarterly), and held at what of the day (e.g., daytime), consider PCRPs who cannot tolerate long periods of time due to health challenges (e.g., arthritis) 	<ul style="list-style-type: none"> Avoid overwhelming potential PCRPs with too much information. Provide potential PCRPs with at least a week to consider the opportunity to be involved on the health care research team. Based on PCRPs’ needs as previously discussed, create training materials (e.g., manual, presentation content and slides, agenda), and work with PCRPs to schedule time for training to occur (e.g., as a component of every meeting, or during particular meetings). Familiarize PCRPs with the health care research team by having the same two researchers to attend the first meeting, and subsequent team meetings (ensure continuity of interactions with the researchers). The proportion of PCRPs to researchers should be governed by the size of the existing health care research team, and the purpose of the meeting. Plan the frequency and length of meetings in consideration of what is required of the research study and what PCRPs can accommodate. Use ICT to enhance remote participation (e.g., teleconference, web conference, e-mail 	<p>study, study timeline, and role expectations;</p> <ul style="list-style-type: none"> A semi-structured script for researchers to guide a discussion with PCRPs regarding physical accommodations; A pamphlet or information package for PCRPs to take away that summarizes the research team, program, or study; A venue with physical and functional accommodations for accessibility (e.g., a sound system to amplify conversations, located near public transportation); Partnerships with local community centres where the potential research health team meetings may be held; Recruitment and research materials presented in clear, lay language; Training materials for PCRPs on research content and ICT use (e.g., training manual or workbook, photocopied handouts); Sufficient number of researchers to support the PCRPs (e.g., Ideally two researchers should be present in any size group); Meeting durations between an hour to an hour and a half;

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • E-mail study documents (related to decision-making) to the team (including PCRP) for review • Option for researchers to make home visits, or for PCRP to attend meetings via teleconference if unable to attend in person • If absent from the meeting, provide meeting summary and audio recording of the decision-making meeting for the PCRP to review • Physical accommodations discussed during the first meeting • Meetings take place in a friendly, communicative, and comfortable atmosphere • For the meeting venue, a local community centre is preferred to the university – more easily accessible by public transportation • Ensure parking is accessible and reimbursed • PCRP has no method of transportation, doesn't drive anymore • PCRP ride share with other PCRP 	<ul style="list-style-type: none"> • access, audio-recording, electronic meeting minutes) of decision-making meetings. • Follow-up with the necessary accommodations of physical, psychosocial, or mental limitations. • Determine the PCRP's access to a computer, Wi-Fi, e-mail, and a mailing address, and facilitate ways to address access as needed. • Ensure meeting venue is functionally accessible (e.g., to visual, hearing, or mobility impairments), and located at a convenient location (e.g., accessible via walking or public transportation). • (Researchers) receive training as needed (e.g., how to receive criticism, facilitation and leadership, cultural sensitivity and empathy, conflict resolution). • Identify through an informal conversation, during the first interaction with PCRP (e.g., phone call or in-person), each potential PCRP's method of transportation to the meeting venue and need for transportation support (e.g., ride-sharing). • Provide an opportunity for PCRP to discuss 	<ul style="list-style-type: none"> • Health care research team meetings that occur depending on the needs of the study, and what the researchers and PCRP can accommodate; • PCRP's computer, Wi-Fi, e-mail, and a mailing address; • A checklist to identify each PCRP's health and transportation needs and accommodations; • Validated parking; and • Availability of wheelchair accessible parking spaces.

Codes	Specifications	
	Action	Product
	amongst themselves the option of ride-sharing.	

Subtheme 4: Identify a primary contact for PCRPs within the researcher team

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Have someone to organize the meetings with PCRPs • Have someone for PCRPs to go to for help, or to give feedback • Risk of PCRPs leaving the team if it is uncommunicative, and a conflict exists 	<ul style="list-style-type: none"> • Have a research staff member to regularly communicate with PCRPs, to coordinate the logistics of each team meeting, and to answer questions or receive feedback. • Ensure PCRPs are aware of communication channels should any concerns arise (e.g., identified primary contact, and access to their contact information). • Have this primary contact receive training on topics such as patient engagement in research, effective communication and facilitation, cultural sensitivity and empathy, confidentiality, and conflict resolution. 	<ul style="list-style-type: none"> • Research staff identified as primary contact; • A role description for this primary contact (with respect to their role to support PCRPs); • Business cards with contact information of key contact for PCRPs; and • Training materials or resources for researchers on required topics as needed (e.g., create own content or refer to content from existing organizations).

Subtheme 5: Use information and communication technology (ICT) to support information sharing between PCRPs and researchers

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • PCRPs' comfort with technology discussed during orientation • Use ICT to share research or meeting materials 	<ul style="list-style-type: none"> • Conduct a round table discussion within a small group (e.g., five PCRPs and two researchers, as mentioned in the text data) of everyone's comfort with ICT. 	<ul style="list-style-type: none"> • A semi-structured discussion guide, or a checklist of skills/comfort with technology to guide the discussion. • Funding for ICT provision and support (from national

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Have pamphlets and the contact information for community resources available at each meeting • Determine PCRPs' comfort with using e-mail or phone • Use Skype for web conferencing • Electronic accessibility provides better sources of print data to deal with • Use of touch-screen over keyboards for individuals with motor coordination issues • Careful review of each PCRPs' functional level and ability to use ICT (technology) with or without accommodation for access • If the researchers have no funds to support training and provision of technology, they must plan for the lowest tech intervention 	<ul style="list-style-type: none"> • Prepare electronic and physical copies of meeting materials to be distributed before and at meetings, respectively (e.g., on an encrypted USB, or hard copies through confidential mail where appropriate). • Identify and understand PCRPs' level of comfort with ICT, and willingness to learn new forms of ICT if training is provided. • Identify (informally) the need to accommodate for functional or physical impairments. • Compare the costs of ICT and related training to lower tech interventions (e.g., more research staff) to support effective communication. 	<ul style="list-style-type: none"> • funding bodies, community organizations, or special-interest groups); • A checklist to identify the PCRPs' abilities, experiences, and comfort with ICT (as previously mentioned); • Training content for ICT (e.g., presentation, manual or workbook, photocopied handouts); • Accommodations for accessibility (e.g., A/V equipment, touch-screens, wide/sturdy chairs, sufficient space in the meeting room to navigate a walker or a wheelchair); • ICT support (e.g., personnel or system to troubleshoot issues with ICT, or a contingency plan if ICT fails); • Low-tech ICT (e.g., telephone, mailing hard-copies of documents, home or in-person visits); and • A report summarizing the financial comparison and associated implications between ICT and its related training to lower tech interventions.

Subtheme 6: Partner with community-based organizations to support PCRPs' ability to engage

Codes	Specifications	
	Action	Product
Partnerships with community-based organizations can:	<ul style="list-style-type: none"> • Establish partnerships with community-based organizations to receive 	<ul style="list-style-type: none"> • A role description for researchers (with respect

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Fund and provide respite care while the caregiver is attending research meetings • Help to cover incidental costs not covered by research funds • Help with communications to share research findings in newsletters • Liaise PCRPs with primary care clinicians as resources to help with management of progressive conditions • Liaise PCRPs with social workers to help support PCRPs in rural community • Provide transportation to ensure that PCRPs can attend activities with other PCRPs 	<p>support for referral of services.</p> <ul style="list-style-type: none"> • Refer PCRPs to potential health care and social services. 	<p>to their role to support PCRPs); and</p> <ul style="list-style-type: none"> • A list of community health and social care services and supports for referral (as previously mentioned).

Theme: Establishing Collaborative Relationships

Subtheme 1: Provide opportunities for PCRPs to network or socialize with other PCRPs to build trust and for relationship building

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Researchers communicate options for PCRPs to network with other PCRPs (if interested) • PCRPs may be lonely or socially isolated • Learn about other community resources by interacting with other PCRPs • Provide snacks and light refreshments • Social networking may not be the focus all the time 	<ul style="list-style-type: none"> • Allow PCRPs to opt out of networking if they feel uncomfortable (e.g., sharing contact information with other PCRPs). • Consider the feasibility of organizing opportunities within the meetings for PCRPs to socialize or network among themselves if they are interested. 	<ul style="list-style-type: none"> • (Consenting) PCRPs' contact information compiled in a list to be shared amongst PCRPs; and • Light snacks and refreshments.

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> Choice to opt out of networking 	<ul style="list-style-type: none"> Provide light snacks and refreshments during the research meetings. 	

Subtheme 2: Integrate PCRPs’ ideas and experiences to shape the research and acknowledge PCRPs’ contributions to the research team

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> PCRPs must be willing and comfortable to disclose disability and share life experiences with others PCRPs’ ideas are reflected in the research PCRPs identifying research priorities Create a visually-appealing log to keep track of PCRPs’ contributions, but not as complicated as a Gantt chart Give verbal appreciation to PCRPs for their involvement and contributions Receive PCRPs’ permission to mention his/her name in published materials 	<ul style="list-style-type: none"> Create opportunities for PCRPs to share their stories, lived-experiences, and ideas, which will be integrated into the research. Revisit statement on role expectations with PCRPs to confirm comfort and willingness to share ideas. Ensure research priorities are relevant to PCRPs. Design a visually appealing log for all team members (researchers and PCRPs) to keep track of their involvement in the research study. Discuss among the team how each member may contribute to the research, and how these contributions may evolve over time. 	<ul style="list-style-type: none"> A statement of disclosure or revisit the statement of participation/ agreement of role expectations (as previously mentioned) to discuss PCRPs’ willingness to share their ideas and experiences; and A template for a log to keep track of PCRPs involvement that will be available to team members in hard-copy and electronically.

Subtheme 3: Respect and treat PCRPs as subject matter experts based on their lived experience

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> • PCRPs are Subject Matter Experts • Avoid treating PCRPs like study participants (e.g., do not submit them to cognitive testing to determine capacity) • Value PCRPs for their knowledge (e.g., from past profession, their health [condition, etc.] and lived-experience) 	<ul style="list-style-type: none"> • Respect PCRPs for their knowledge and lived experience. • Treat PCRPs as you would when inviting other researchers to the health care research team, as equally knowledgeable experts. • (Researchers) receive training on patient engagement in research. 	<ul style="list-style-type: none"> • A role description for researchers (with respect to their role to support PCRPs, as previously mentioned); • A statement of participation or agreement on role expectations and time commitment for all team members (as previously mentioned); and • Training materials or resources for researchers on patient engagement in research (e.g., create own content or refer to content from existing organizations).

Subtheme 4: Ensure confidentiality or non-disclosure of sensitive information shared by PCRPs

Codes	<u>Specifications</u>	
	Action	Product
<ul style="list-style-type: none"> • ‘Confidentiality’ is reinforced frequently within the team • Have a safe communication channel for PCRPs, without fear of confrontation 	<ul style="list-style-type: none"> • Reinforce the confidentiality of discussions during health care research team meetings. • Ensure PCRPs are aware of the communication channels within the team, and that they feel comfortable to ask questions or voice concerns. 	<ul style="list-style-type: none"> • A statement of confidentiality or non-disclosure agreement between members of the health care research team (as previously mentioned); and • Research staff identified by researchers as primary contact to PCRPs (as previously mentioned).

Subtheme 5: Provide facilitation that encourages equal participation among PCRPs

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Researchers should be able to throw out ideas to draw out caregivers in conversation • Researchers lead research meetings/sessions • Ensures equal input sharing by all PCRPs at meetings • Sets aside time for meetings to include a question and answer period • (Researchers leading the meetings) works well for introverted PCRPs 	<ul style="list-style-type: none"> • (Researchers and research staff) receive training to facilitate and lead group discussions and meetings to ensure that all PCRPs have opportunities to equally contribute (e.g., sharing space to talk) and ask questions. • Manage meeting agendas and minutes. • Consider allotting time during the research health team meetings for a question and answer period. 	<ul style="list-style-type: none"> • Training materials or resources for researchers (e.g., AODA training, leadership training, or effective communication techniques); • Meeting presentations; • Meeting minutes and agenda; and • Allotted time during meetings for question and answer period.

Subtheme 6: Provide PCRPs with regular updates on the progress of the research

Codes	Specifications	
	Action	Product
<ul style="list-style-type: none"> • Research team keeps PCRPs in the loop as opposed to having gaps in between contact • Research team reports to PCRPs on how their feedback is integrated into the research 	<ul style="list-style-type: none"> • Establish PCRPs' preferred form of communication to receive regular updates on the research. • Maintain regular communication with PCRPs via e-mail or a newsletter, even if they are not directly involved in the current phase (e.g., data analysis). • Avoid making PCRPs feel left out of the loop. 	<ul style="list-style-type: none"> • Information and communication technology (ICT; e.g., e-mail, USB, phone); and • Newsletter or e-mail template for providing updates to PCRPs.