

## EVALUATION OF DEMENTIA-FRIENDLY COMMUNITY INITIATIVES

DEMENTIA-FRIENDLY COMMUNITY INITIATIVES: EVALUATING PROCESSES AND  
OUTCOMES

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## LAY ABSTRACT

Persons living with dementia have shared that their communities are not always accessible nor inclusive making it difficult to participate in community life and to navigate public spaces.

Dementia-friendly communities are emerging as one solution to support the wellbeing of persons living with dementia by making communities more dementia-inclusive and accessible.

Dementia-friendly communities have expanded in Canada and globally; however, there is limited evidence of the benefits of these initiatives. For example, we don't know whether dementia-friendly community initiatives improve the quality of life of persons living with dementia. The aim of this thesis was to increase our knowledge about dementia-friendly communities by 1) identifying tools that measure how dementia-friendly a community is, 2) evaluating processes that support the participation of persons living with dementia in public consultations, 3) evaluating the impact of a community mural on raising awareness about dementia. To help achieve these objectives, three studies were conducted. Findings from these studies can be helpful to organizations and individuals working on making their communities more dementia-friendly. Findings also advance our understanding of strategies that can be used to support the participation of persons living with dementia in the development of dementia-friendly community initiatives, and how public art (particularly community murals) could be used to increase community awareness about dementia.

## ABSTRACT

**Introduction:** Dementia-friendly communities are emerging as a promising approach to promote the health and wellbeing of persons living with dementia and to support their desire to age at home. Despite the expansion of DFCs in Canada and globally, there is limited evidence on the benefits (e.g., social and/or financial benefits) of dementia-friendly community (DFC) initiatives, and of processes that support the development and implementation of initiatives. **Purpose:** The purpose of this thesis was to further the knowledge base on DFCs through a comprehensive evaluation of processes and outcomes of a local DFC project titled *Empowering Dementia Friendly Communities, Hamilton and Haldimand*. **Method:** There are three studies that constitute this thesis. The first study is a scoping review in which assessment tools that can be used to conduct quantitative assessments of the dementia-friendliness of a community were identified and examined. The second study is a process evaluation of the processes undertaken to conduct public consultations with persons living with dementia and care partners to learn about their community needs. The third study is an impact evaluation of a Canadian DFC mural on raising awareness about dementia. Guided by community-engaged research principles, community partners (e.g., persons living with dementia and stakeholders working on DFC initiatives) were engaged in all three studies. **Findings:** Scoping review findings indicate that there is a need to develop a comprehensive quantitative tool with strong psychometric properties that captures the community needs of persons living with dementia. The process evaluation emphasizes the importance of engaging persons living with dementia in community initiatives as project partners and project participants. Additionally, recommendations on how to support the engagement of persons living with dementia in public consultations are provided. Lastly, the impact evaluation provides evidence for the positive impact of interactions between persons

living with dementia and community members and the value of public art in increasing community awareness about dementia. Lessons learned from the process undertaken to create the mural are also presented. **Implications:** This body of work supports the advancement of DFC initiatives. Findings suggest areas for future directions, including the need to develop a framework to guide the development and implementation of DFC initiatives, and the need to engage persons affected by dementia from marginalized and underserved communities in the development and implementation of initiatives.

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## LIST OF ABBREVIATIONS

|            |   |
|------------|---|
| ADI        | Alzheimer’s Disease International   |
| A-ADS      | Adolescent Attitudes Towards Dementia Scale   |
| DFC        | Dementia-Friendly Community   |
| DSM        | Diagnostic and Statistical Manual of Mental Disorders   |
| EDFC-HH    | Empowering Dementia Friendly Communities, Hamilton and Haldimand                                    |
| HCoA       | Hamilton Council on Aging   |
| ICF        | International Classification of Functioning, Disability and Health                                  |
| IPS        | Interview Process Satisfaction  |
| MICE       | Memory Inclusive Communities Everywhere   |
| ODSP       | Ontario Disability Support Program  |
| OSPS       | Online Survey Process Satisfaction  |
| OTs        | Occupational Therapists   |
| PEO        | Person-Environment-Occupation   |
| PHAC       | Public Health Agency of Canada  |
| P-PE       | Practical Participatory Evaluation  |
| PRISMA-ScR | Preferred Reporting Items for Systematic Reviews and Meta-Analysis<br>Extension for Scoping Reviews |
| WHO        | World Health Organization   |

## DECLARATION OF ACADEMIC ACHIEVEMENT

This thesis is presented as a sandwich format and it is comprised of a general introduction, three independent manuscripts (Chapters 2 – 4), and an overall discussion. At the time of preparing this thesis, the three independent manuscripts have either been published in peer-reviewed journals (Chapters 2 & 3) or submitted to a peer-reviewed journal (Chapter 4). As a doctoral candidate, I am the first author of all manuscripts and was responsible for leading all stages of each research project. My and the co-author's contributions for each manuscript are described below.

### CHAPTER TWO

**García Díaz, L.,** Durocher, E., Gardner, P., McAiney, C., Mokashi, V., & Letts, L. Assessment tools for measurement of dementia-friendliness of a community: a scoping review. (2022). *Dementia*, 21, 1825-1855. <https://doi.org/10.1177/14713012221090>

#### *Contributions*

Generated the research questions: LGD, ED, CM, LL (Note: Dr. Julie Richardson also contributed to the generation of the research questions)

Designed the study: LGD, ED, CM, LL

Conducted the scoping review: LGD, VM

Drafted the manuscript: LGD

Reviewed and provided feedback on the manuscript: LGD, ED, CM, PG, LL

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## **CHAPTER FOUR**

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## CHAPTER ONE: INTRODUCTION

### Background

*“Enlightening, frightening, loss, challenging, roller coaster, uncertainty, unsettling, stormy, confusing, frustrating, difficult, daunting, anxious, long, and one day at a time”* (Alzheimer’s Disease International [ADI], 2022, p. 55) are words used by persons living with dementia to describe how they feel about their diagnosis. Similarly, as described by a caregiver of a person living with dementia, *“life changes very dramatically when dementia comes to visit, so if you are not prepared or have no means of accessing information, supports, or medical advice, life becomes a vicious cycle of staying upright on the hamster wheel.”* (ADI, 2022, p. 72). A dementia diagnosis not only impacts the person, but it can also have a deep impact on friends, family and the wider community. Although the progression of dementia is inevitable (Alzheimer’s Society UK, 2020), availability of health and community supports, community awareness about dementia, and opportunities for meaningful occupations (both at home and in the community) can shape the experience of living with and caring for a person with dementia (ADI, 2022).

Dementia is not a specific disease, but a term that is used to describe brain syndromes that affect thinking, emotion and behaviour (ADI, n.d.). Symptoms are progressive in nature and may include memory loss, difficulties with judgement, language, problem solving, and changes in mood and behaviour (World Health Organization [WHO], 2021c). Alzheimer’s disease is the most common type of dementia accounting for 60-80% of all dementia diagnoses (WHO, 2021c). Other common types of dementia include vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia (Alzheimer Society of Canada, 2022). It is estimated that 597,300 Canadians are living with dementia (Alzheimer Society of Canada, 2022) costing Canadians approximately \$10 billion annually (Alzheimer Society of Canada, 2016). In

Canada, it is estimated that women living with dementia lose 15.2 years of life in full health due to premature death and disability, and men lose 16.0 years on average (Public Health Agency of Canada [PHAC], 2014). To help address the needs of those affected by dementia, in 2019 Canada adopted a National Dementia Strategy (PHAC, 2019). As noted in the National Dementia Strategy (PHAC, 2019), Canada's three national objectives are to prevent dementia, to advance therapies and find a cure, and to improve the quality of life of persons with dementia and caregivers.

While dementia can shorten the lives of persons living with the condition, its greatest impact is on quality of life, both for the individual with dementia and their caregiver(s) (ADI, 2016). For example, using data from the English Longitudinal Study on Ageing, it was found that persons living with dementia report a decline in social engagement during the first four years after diagnosis (Hackett et al., 2019). In that same time-period, older adults without dementia did not report a change in their social engagement levels (Hackett et al., 2019). It is hypothesized that symptom progression, stigma, and changes in identity contribute to a decline in social engagement (Hackett et al., 2019). A decline in social engagement has been associated with changes in memory (Yin et al., 2019), faster cognitive deterioration (Harsányiová & Prokop, 2018) and impact on quality of life (Hackett et al., 2019), highlighting the need to implement interventions aimed at increasing social engagement in persons living with dementia. For example, community-based interventions, such as dementia-friendly community initiatives, have been found to increase social engagement in persons living with dementia (Darlington et al., 2020), indicating that intervening at the community level is one way to support the social well-being of persons living with dementia. Similarly, to support the quality of life and wellbeing of

persons living with dementia as the condition progresses, non-pharmacological interventions, such as dementia-friendly initiatives, are recommended (Ismail et al., 2020).

In recognition of the global impact of dementia, in 2013 dementia was recognized as a global public health priority (WHO, 2013). To address dementia globally, in 2017 the WHO adopted the *Global Action Plan on the Public Health Response to Dementia* (WHO, 2017). The plan outlines seven key action areas that member states are encouraged to work on to support the lives of persons living with dementia and their caregivers, including “dementia awareness and friendliness” (WHO, 2017). As described in the plan, member states are encouraged to work with persons living with dementia to improve physical and social environments to promote social inclusion (WHO, 2017). To support the implementation of Canada’s national dementia strategy and meet the targets proposed by the WHO, the PHAC has invested over \$10 million in projects aimed at improving the quality of life of persons living with dementia and their carers, reducing risk and stigma, and enabling dementia-inclusive communities (Government of Canada, 2022). The implementation of dementia-inclusive communities will support persons living with dementia to continue to participate in their communities, have access to the services that they need, and be valued as citizens, all of which promote social inclusion and quality of life (WHO, 2021b).

### **A Note on Terminology**

Throughout this thesis I use the words “dementia” and “dementia-friendly communities”; however, it is important to acknowledge that this terminology has been refuted by some persons living with dementia (for examples, see Miyamoto et al., 2011; Swaffer, 2014). The term ‘dementia’ originated from the Latin word ‘demens’ which is defined as “out of one’s mind/senses”, “mad”, “wild”, “reckless”, “foolish” (Latin is simple, n.d.). Similarly, in the

Merriam-Webster online dictionary, in 2022, dementia was defined as “a progressive condition marked by the development of multiple cognitive deficits” and “madness, insanity” (Merriam-Webster online dictionary, n.d.). In attempts to help reduce the stigma associated with the word dementia, the term ‘dementia’ was replaced by ‘major neurocognitive disorder’ in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; American Psychiatric Association, 2013). In the DSM-5, the cluster of neurocognitive disorders (e.g., Alzheimer’s Disease, vascular dementia) is characterized by conditions that have cognitive deficits as the most prominent and defining feature (Sachdev et al., 2014). However, the inclusion of dementia in the DSM-5 implies that dementia is a mental illness. Although the medical definition of dementia does not include the stigmatizing language found in the dictionary, the public often associates dementia with this stigmatizing language (Jellinger, 2010; Low & Purwaningrum, 2020). Publicly, dementia tends to be depicted as deterioration of the brain, and as persons with dementia losing their minds, and consequently their personhood and human rights (Low & Purwaningrum, 2020). As described by a person living with dementia “*the word dementia is a stigma on its own. When persons look through dictionaries and go online and look at what dementia means, it automatically comes up as someone who is mentally ill. But I haven’t got mental health problems, I’ve got dementia.*” (Brooks, n.d.) As a result of the stigma and negative connotation associated with the word dementia, in 2005 the government of Japan changed the word dementia to *ninchishō* which can be translated to “cognitive syndrome” (Miyamoto et al., 2011). Based on my research, no other countries have chosen to use a different word for dementia.

Similarly, the use of the term “dementia-friendly communities” has been criticized by persons living with dementia as it is used to define persons by their diagnosis which

inadvertently encourages segregation rather than inclusion (Rahman & Swaffer, 2018). As expressed by a person living with dementia *“the term ‘dementia-friendly’ has no added value to the lives of persons with dementia... the initiatives of building a caring, responsive and supportive community are good for everyone, not just for persons with dementia. By removing the word ‘dementia’ we are nurturing an inclusive attitude within the community and society.”* (Ong, 2022). Despite the concerns raised by persons living with dementia, the terms “dementia” and “dementia-friendly communities” continue to be used widely. I acknowledge that these terms may not be the most appropriate or the most inclusive, but in the absence of more appropriate terminology, I use them throughout this thesis.

### **Dementia-Friendly Communities**

It is estimated that by 2030 there will be close to one million Canadians living with dementia (Alzheimer Society of Canada, 2022). Approximately 69% of Canadian older adults (65-79 years old) and 58% of older adults over 80 who have dementia, live in the community, outside of long-term care homes (Canadian Institute for Health Information, 2018).

Strengthening of home care and community supports is needed to ensure that Canadians with dementia who live in the community are appropriately supported, which may ultimately help people to remain in the community longer (Canadian Institute for Health Information, 2018).

Dementia-friendly communities (DFCs) are emerging as a promising approach to promote independence and community inclusion of persons living with dementia, and to support their desire to age at home (PHAC, 2021). The aim of DFCs is to support persons living with dementia and their caregivers by: increasing an understanding in the community of how to support persons living with dementia to live well; enabling persons living with dementia to be

active members of their communities; and supporting persons with dementia to remain independent for as long as possible (Prior, 2012).

In an integrative review of dementia-friendly community (DFC) initiatives (Shannon et al., 2019), key attributes of DFCs were identified. As described in the literature (Shannon et al., 2019), DFCs are: places where persons can continue to access and participate in activities that are meaningful to them; an accessible and easy to navigate community; a place where persons feel safe and supported; and a community that recognises and respects the human rights of persons living with dementia. Similarly, in the WHO's toolkit *Towards a Dementia-Inclusive Society: Toolkit for Dementia-friendly Initiatives* (WHO, 2021a), DFCs are described as a place where persons living with dementia have the same rights as everyone else, are entitled to equal opportunities and have equal access to public spaces and services. To support the inclusion and participation of persons living with dementia in their communities, social and physical environments should be addressed (WHO, 2021a).

### ***Social Environment***

Barnett and Casper (2001) define the social environment as social relationships, the immediate physical surroundings and cultural contexts within which a person or a group of persons live and interact. The social environment includes social, human and health services; power relations; social inequality; governments; cultural practices; and beliefs about place and community (Barnett & Casper, 2001). When the social environment is enabling, it facilitates social integration, social support and access to resources, resulting in social inclusion (Scharlach & Lehning, 2013). Stigma and the act of stigmatizing is a common form of social exclusion (Allman, 2013). In an awareness survey conducted by the Alzheimer Society of Canada (Alzheimer Society of Canada, 2017), 51% of Canadians reported having used stigmatizing

language about dementia, 30% admitted to telling dementia-related jokes, and 20% reported that they would avoid seeking help for as long as possible if they thought they had dementia in order to avoid the associated stigma and embarrassment. Stigma can negatively impact the mental and physical health of persons living with dementia, and it can result in social exclusion and in delays in help-seeking and diagnosis (ADI, 2019b; Parker et al., 2020). In recent years, there has been an increase in basic awareness about dementia among members of the general public; however, negative attitudes, misinformation and stigma towards persons living with dementia continue to persist (Cahill et al., 2015; Glynn et al., 2017). Stigma can also result in human rights violations of persons living with dementia (ADI, 2019b), which is why a key action area of DFC initiatives is to ensure that the rights of persons living with dementia are respected (WHO, 2021a). As stated by Shakespeare et al. (2019), *“people with dementia have been fully participating members of their community all their lives but encounter deep-rooted and systemic attitudinal and societal obstacles to continuing to do so following diagnosis.”* (pp. 1080-1081). As a result of the impact that stigma can have on the quality of life of persons living with dementia, stigma reduction is a key element of DFC initiatives (Hung et al., 2021). Although globally there have been many attempts to reduce stigma by raising public awareness about dementia (ADI, 2012), there is limited evidence on the impact of awareness campaigns on the quality of life of persons living with dementia (The Lancet Neurology, 2015).

### ***Physical Environment***

The physical environment refers to the immediate physical surroundings, including built infrastructures such as sidewalks, libraries, parks, grocery stores, and businesses (WHO, 2021a). The physical environment also includes lighting, noise, signages and temperature (WHO, 2021a). Dementia-inclusive design principles include clear signage to support memory,



orientation and way-finding; availability of accessible washroom facilities that are clearly identifiable; using colour contrasts to help identify key objects and to support spatial orientation; availability of accessible seating in public spaces; bright and consistent lighting; and avoiding the use of shiny, reflective and gloss finishes (Global Brain Health Institute, 2020). When dementia-inclusive design principles are used in the built environment, persons living with dementia have been found to be more likely to continue participating in activities that are meaningful to them (Woodbridge et al., 2018) and to feel more comfortable navigating outdoor spaces independently (Seetharaman et al., 2020). Despite the importance of the physical environment on the experience of living with dementia, historically, most DFC initiatives have focused on addressing the social environment (particularly on stigma reduction), with little emphasis on physical environmental modifications (Buckner et al., 2019). DFC initiatives may seek to create safe and accessible physical environments by focusing on: increasing the availability of affordable housing; making public transportation vehicles and stops more accessible; improving neighbourhood walkability; and making public spaces and buildings safer and more accessible (WHO, 2021a).

### **Involvement of Persons Living with Dementia**

Although at the core of DFCs is the person living with dementia, persons living with dementia are not always involved in the development and implementation of DFC initiatives (Mathie et al., 2022). As stated by Kate Swaffer (2014), a person living with dementia, “*the authentic voice of peoples with dementia deciding what is and what is not dementia-friendly are the missing pieces of the dementia-friendly community puzzle, and I believe, without them, no one town can claim to be dementia-friendly.*” (p. 713). Similarly, as stated in the Canadian Charter of Rights for Persons with Dementia (Alzheimer Society of Canada, 2018), Canadians

living with dementia have the right to participate as fully as possible in decisions that affect them, which would include development and implementation of DFC initiatives. By actively participating in decisions that affect them, persons living with dementia are repositioning themselves as active citizens rather than victims of their condition (Bartlett & O'Connor, 2007). To ensure that DFC initiatives meet the needs of community members living with dementia, persons living with dementia must be included in planning and implementation processes. Although there appears to be a universal commitment to engage persons living with dementia in planning processes, there exists a lack of strategic approaches, resources and expertise in how to support persons to participate (Mathie et al., 2022). Additionally, tools and measures are needed to assist stakeholders, including researchers and community organizations, in facilitating the meaningful engagement of persons living with dementia in DFC initiatives and to measure the impact of their involvement (Heward et al., 2017).

### **Evaluation of Dementia-Friendly Community Initiatives**

To date, there is limited evidence on the benefits (e.g., social value and/or cost/benefits) of DFCs (Buckner et al., 2022). As stated by the World Dementia Council (2020), there needs to be a *“better understanding of the evidence base for dementia-friendly initiatives”* (pg. 3). Evaluation of DFC initiatives have primarily focused on the process of becoming a DFC (although a formal recognition process is not always in place), (Dean et al., 2015) and on the perceived benefits of implementing an initiative (Tsuda et al., 2022). For example, in a recent study conducted in Japan, the opening of an inclusive café which provided a space for persons living with cognitive impairment to socialize and learn about different topics related to brain health, resulted in men living with dementia feeling more confident about their ability to live in their community with dementia (Tsuda et al., 2022). The women who participated in the study

reported high levels of social interaction with other members of their community before the café's opening; the café did not have an impact on their level of confidence about their ability to live in their community with dementia (Tsuda et al., 2022). Findings suggest that DFC initiatives can be of benefit to individuals with low levels of social support. Despite the proliferation of DFC initiatives globally (ADI, 2017), there is a lack of appropriate tools to support monitoring of impact and there is a pressing need for evidence on the effectiveness and sustainability of DFC initiatives (Buckner et al., 2022).

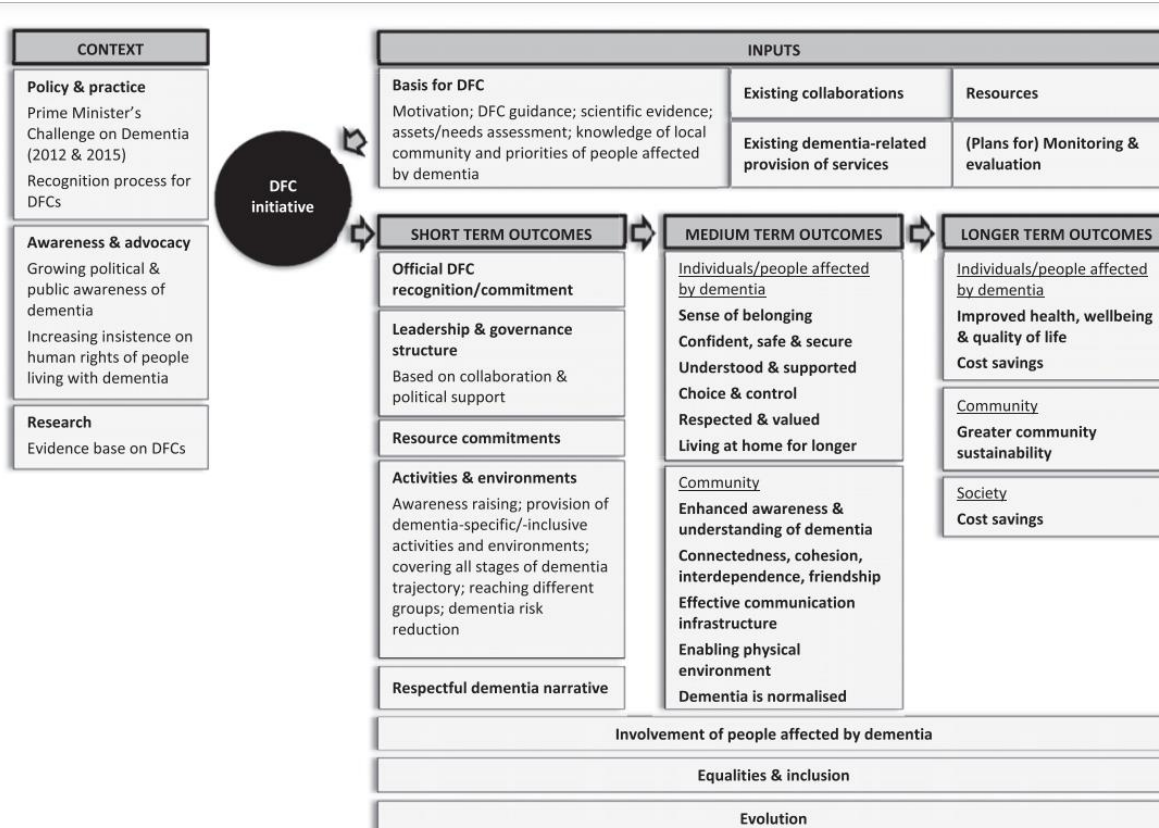
To date, a three-year NIHR Police Research Programme Study in England known as *The DEMCOM study* (Goodman et al., 2020) has been the most comprehensive evaluation research project on DFCs. The study ran from January 2017 to July 2019. The researchers leading the study evaluated how DFCs support persons living with dementia and their caregivers, the approaches that have worked best, and sustainability of DFCs (Goodman et al., 2020). Key findings from the DEMCOM study include: 1) Having a formal recognition program by the local Alzheimer Society provides motivation to develop and implement DFC initiatives; however, achieving a formal recognition requires strong local collaborations and leaders. 2) Exchange of lessons learned between communities working towards becoming dementia-friendly is important, but often difficult. 3) Although dementia risk reduction was acknowledged as important, there is limited evidence of initiatives prioritizing dementia risk reduction programmes. 4) There is early evidence of the positive economic impact of DFC initiatives; however, further research is needed to confirm the social return on investment and to ensure sustainability. Additionally, the team found that when persons living with dementia are aware that their community is working towards becoming dementia-friendly, they are more likely to participate in social activities, be involved

in organized groups, and feel understood and valued for their contributions to their community (Darlington et al., 2020).

An important outcome from the DEMCOM study was the development of an evaluation framework that highlights thematic areas to be considered when evaluating DFC initiatives, and a theory of change that presents inputs, short, medium and long-term outcomes of DFC initiatives (Buckner et al., 2022). The areas of focus for evaluation outlined in the framework include involvement of persons affected by dementia, equalities and inclusion, basis of DFCs, leadership and governance, resources, activities and environments, monitoring and evaluation, and outcomes. The theory of change for DFCs developed by the DEMCOM study team is grounded on the evaluation framework and it outlines what DFCs might achieve at different stages of their journeys (Buckner et al., 2022). Figure 1 provides a summary of the theory of change for DFCs proposed by Buckner et al. (2022).

**Figure 1**

*Buckner et al.'s (2022) Theory of Change for Dementia-Friendly Communities*



*Note.* This figure was produced by Buckner et al. (2022) to provide a visual representation of their proposed Theory of Change for dementia-friendly communities. From “*A Suite of Evaluation Resources for Dementia Friendly Communities: Development and guidance for use*” by Buckner et al., 2022, *Dementia*, 21(8), p. 2399. CC BY-NC 4.0.

## Objective of Thesis

Developing and implementing DFC initiatives is a core component of Canada’s National Dementia Strategy (PHAC, 2019). Similarly, Canadians affected by dementia (including persons with dementia, friends, caregivers and healthcare providers) have identified DFCs as a top research priority (Bethell et al., 2018). In an integrative review of DFC initiatives (Shannon et al., 2019) it was found that most initiatives develop their plan following a similar process: 1) forming a steering group to lead the development of the initiative; 2) identifying and prioritizing community needs; 3) developing an action plan to guide the initiative; 4) implementing the dementia-friendly action plan; and 5) monitoring the progress of the plan. However, continuous

improvement and evaluation of the plan's impact is not always included in the process (Shannon et al., 2019).

Given the expansion of DFCs in Canada (PHAC, 2021), it is timely and essential to conduct evaluation research to understand processes that support the implementation of DFC initiatives and the impact of those initiatives. The overall aim of this thesis is to further the knowledge base on DFCs through a comprehensive evaluation of processes and outcomes of a local DFC project titled *Empowering Dementia Friendly Communities, Hamilton and Haldimand* (EDFC-HH). EDFC-HH was a three-year project (2020-2023) funded by the PHAC. The goal of the project was to compare the development and implementation of DFC initiatives in Hamilton (an urban community with an age-friendly plan) and Haldimand (a rural community, without an age-friendly plan). There are a number of similarities between the EDFC-HH project's logic model (Refer to Appendix A) and the theory of change for DFCs proposed by Buckner et al. (2022), including similar short (e.g., development of an awareness campaign), medium (e.g., persons with dementia feeling respected and valued) and long term outcomes (e.g., enhanced well-being for persons with dementia). In this thesis I aimed to further the knowledge base on DFCs, by achieving the following objectives:

1. Identifying and appraising assessment tools that can be used to conduct quantitative assessments of the dementia-friendliness of a community –To achieve this objective, I conducted a scoping review (Chapter 2, Manuscript 1).
2. Evaluating processes and methods that facilitate the engagement of persons living with dementia in public consultations. –To achieve this object, I conducted a process evaluation of the methods used for the public consultations of the EDFC-HH project (Chapter 3, Manuscript 2).

3. Evaluating the impact of public art on raising awareness about dementia –To achieve this objective, I conducted an impact evaluation of a DFC mural, which was developed as part of the EDFC-HH project to raise awareness about dementia in Haldimand (Chapter 4, Manuscript 3).

Community-based work is not meant to be generalizable (Vavuris, 2021); however, findings and lessons learned from the process and impact evaluations in my research are meant to support stakeholders interested in conducting public consultations with persons living with dementia and in using public art to raise dementia awareness in their community.

### **Involvement and Contributions to the EDFC-HH Project**

Funding for the EDFC-HH project began the year that I started my doctoral studies. My doctoral supervisor, Dr. Letts was invited to join the stewardship group that led the EDFC-HH project and given my professional background with the Alzheimer Society and personal interest in community work, an invitation was extended for me to join the stewardship group. The collaborative stewardship group included membership from the Hamilton Council on Aging, the Alzheimer Society of Brant-Haldimand-Norfolk-Hamilton-Halton, the Geriatric Education and Research in Aging Sciences centre, the Regional Geriatric Program central, McMaster University, Hamilton Health Sciences, the City of Hamilton. The stewardship group planned and drove various activities of the initiative to achieve project goals.

From the inception of the project, there was a willingness from the stewardship group to find synergies between my interests, school requirements, and the goals of the project, which ultimately led to the identification of my role as an evaluator for different parts of the project. I engaged in a reciprocal relationship with the team and in addition to the work presented in this

thesis, I also contributed to other parts of the project (e.g., development of DFC education program) and provided ongoing support.

A year into the EDFC-HH project, two leadership teams of persons living with dementia were created with the purpose of having persons living with dementia develop and implement DFC projects in their respective communities (i.e., Hamilton and Haldimand). Haldimand's leadership team expressed an interest in embedding an evaluation component into one of their projects, and similarly to the stewardship group, the team was willing to engage with me as the evaluator. Through continued engagement, I established a trusting and collaborative relationship with Haldimand's leadership team, and they provided me with the opportunity to lead the evaluation of their first project, a DFC mural.

My involvement with the EDFC-HH project provide me with an opportunity to learn how to build authentic and reciprocal relationships with community partners which are skills that I will continue to use and work on in future projects. Refer to section "Methodology: Community Engaged Research" for more information on how a community-engaged research approach guided the studies presented in this dissertation.

### **Contributions to Rehabilitation Science**

I enrolled in the School of Rehabilitation Science dual degree program to increase my understanding of rehabilitation theory and how occupational therapists can best support persons living with dementia, and to advance rehabilitation research in the area of dementia. The WHO defines rehabilitation as "a set of interventions designed to reduce disability and to optimize functioning in individuals with health conditions so as to enable them to better interact with their environment." (WHO, 2021a, para. 1). In the International Classification Of Functioning, Disability and Health (ICF; WHO 2001), environmental factors are identified as playing a central



role in the experience of disability; an individual can either perceive their environment as a barrier or facilitator to participation, influencing their overall quality of life and wellbeing (WHO, 2001). As illustrated by the ICF's conceptualization of disability, rehabilitation interventions can address individual and environmental factors (including both social and physical factors) to optimize the wellbeing of individuals and enable participation in activities that are meaningful to them. Similarly, addressing environmental factors to enable participation is the driving force behind DFC initiatives.

Persons living with dementia have shared that following the onset of their condition, they experience restricted opportunities for social participation, being treated poorly in public settings (e.g., shops), lack of availability of appropriate services, and inaccessible physical environments, all of which impact inclusion in society and quality of life (Biggs et al., 2019). From a rehabilitation perspective, the environmental barriers faced by persons living with dementia impact their ability to participate in activities that they need and want to do, which puts them at risk for social exclusion. Two decades ago, occupational therapists were called to “engage in community capacity building and societal change beyond the individual” (Christiansen & Townsend, 2004, p. 40). The manuscripts that make up this thesis are focused on community capacity-building related to the inclusion of persons living with dementia in their communities. The three manuscripts that make up this thesis aim to enhance our understanding of: 1) how to assess the dementia-friendliness of a community in order to create more supportive environments for persons with dementia (Chapter 2); 2) the processes that enable participation in public consultations in order to promote the participation of persons with dementia in decisions aimed at supporting their quality of life (Chapter 3); and 3) the impact of public art on awareness about dementia in order to reduce stigma and social exclusion of persons living with dementia (Chapter

4). Thus, this thesis adds to the rehabilitation literature related to dementia by furthering our understanding of how to address barriers that prevent persons living with dementia from fully participating in society and in activities that they need and want to do.

### **Methodology: Community-Engaged Research**

Community-engaged research is intended to generate meaningful and authentic research-community partnerships to increase research impact and quality, build capacity for uptake of evidence-based practices, and improve community and individual health (Luger et al., 2020). Community engagement and participation in research is considered to occur along a continuum (Key et al., 2019). The continuum ranges from *no community involvement* (researcher works independent of community), to *community informed* (community informs the research, but may or may not be involved in the research process), to *community consultation* (community provides input and feedback to inform the research process), to *community participation* (community has an active role in the research process), to *community initiated* (community initiates the research agenda), to *community based participatory research* (researcher and community share equally in decision-making and ownership of the research process), and to *community driven* (community leads and owns the research) (Key et al., 2019).

The importance of engaging persons living with dementia in program development and implementation has been identified by the WHO (2021a), the Alzheimer Society of Canada (2015), ADI (2019a) and the PHAC (2019). The meaningful engagement of persons living with dementia has been a core component of the EDFC-HH project (e.g., there were two persons living with dementia in the stewardship group). Similarly, the meaningful engagement of persons living with dementia and other community partners has been a core component of my doctorate work. Although community partners (e.g., persons living with dementia and the EDFC-HH

stewardship group) were engaged in all three studies that make up this thesis, their level of engagement varied:

1. Manuscript 1 (Assessment tools for measurement of dementia-friendliness of a community: A scoping review (Garcia Diaz et al., 2022)): As recommended by Levac and colleagues (Levac et al., 2010), as part of this scoping review I included a consultation phase with community partners which helped to validate and enhance the results of the scoping review and make them more useful for end-users. Community partners included three healthcare providers (a geriatrician, a nurse and a social worker), two researchers, an executive of an Alzheimer Society, and a community member living with dementia. All the community partners were members of the EDFC-HH stewardship group. During the consultation phase, community partners were presented with scoping review findings and were asked to provide their feedback on the meaning and significance of findings. The feedback provided by community partners informed the discussion section of the manuscript.
2. Manuscript 2 (Engagement of persons with dementia in public consultations: process evaluation (Garcia Diaz et al., 2023)): For this manuscript, community partners (i.e., the EDFC-HH stewardship group) were included as research participants. For this study, community partners were asked to reflect about the processes employed to engage community members living with dementia to learn about their community needs to help determine if these processes were equitable and effective in engaging persons impacted by dementia from varied backgrounds. Additionally, community partners provided recommendations for other stakeholders interested in conducting public consultations with persons living with dementia.

3. Manuscript 3 (Evaluating the impact of the “dementia-friendly communities everywhere” community mural): A practical participatory evaluation (P-PE; Cousins & Whitmore, 1998) research approach guided this impact evaluation. Unlike community-based participatory action research which is typically used to investigate community issues to inform the development of a process and/or program, a participatory evaluation is typically used to investigate the impact and/or implementation of a program or process that has already been developed (Organizing Engagement, 2020). In a recent scoping review on the impact of engaging persons living with dementia in research design (Wang et al., 2019), based on the studies included in the scoping review, the authors found that it wasn’t until 2018 that researchers started to engage persons living with dementia in all stages of the research design process. However, it is important to note that scoping review findings did not capture older research in which persons living with dementia were engaged throughout the research process (e.g., Dupuis et al., 2012; Lopez & Dupuis, 2014), therefore, findings should be interpreted with caution. As part of the EDFC-HH project, a leadership team composed of persons with dementia that live in Haldimand County, was formed to develop and implement DFC initiatives in Haldimand County. The leadership team was engaged throughout the entire research process sharing equally in decision-making and ownership of the research process. The research questions and data collection methods were co-created with the leadership team, and they also helped with participant recruitment and data analysis.

Thus, the studies that make up this dissertation were guided by a community-engaged research approach in which reciprocity and community agency were prioritized. Methods for engaging community members varied from consultation with community partners about different phases of

the research projects, to engagement of community members as research partners (i.e., co-developing research questions and data collection methods).

## **Conclusion**

To develop a more systematic and strategic approach to the advancement of DFCs, a comprehensive evaluation of processes and outcomes of initiatives is needed. This thesis consists of three manuscripts (Chapter 2-4) focusing on the three objectives of the thesis which collectively aim to further the knowledge based on DFCs. In the following chapters I present the findings from the scoping review (Chapter 2), the process evaluation (Chapter 3) and the impact evaluation (Chapter 4). Additionally, in Chapter 5, I provide a comprehensive discussion about lessons learned from the scoping review and evaluating the processes and outcomes of the EDFC-HH project, along with recommendations for future direction.

Together, the manuscripts presented in this thesis provide evidence and insights for how to create enabling environments to support the inclusion and participation of persons living with dementia in their communities, and reflections based on my involvement with the EDFC-HH project.

## References

- Allman, D. (2013). The Sociology of Social Inclusion. *SAGE Open*, 3(1).  
<https://doi.org/10.1177/2158244012471957>
- Alzheimer's Disease International. (n.d.). *Dementia facts & figures*. Retrieved July 25, 2022, from <https://www.alzint.org/about/dementia-facts-figures/>
- Alzheimer's Disease International. (2012). *Overcoming the stigma of dementia*.  
<https://www.alzint.org/u/WorldAlzheimerReport2012.pdf>
- Alzheimer's Disease International. (2016). *Dementia Friendly Communities: Key Principles*.  
<https://www.alzint.org/u/dfc-principles.pdf>
- Alzheimer's Disease International. (2017). *Dementia Friendly Communities: Global developments*. <https://www.alzint.org/u/dfc-developments.pdf>
- Alzheimer's Disease International. (2019a). *World Alzheimer Report 2019: Attitudes to dementia; World Alzheimer Report 2019: Attitudes to dementia*.  
<https://www.alzint.org/u/WorldAlzheimerReport2019.pdf>
- Alzheimer's Disease International. (2019b). *World Alzheimer Report 2019: Attitudes to dementia*. <https://www.alzint.org/u/WorldAlzheimerReport2019.pdf>
- Alzheimer's Disease International. (2022). *World Alzheimer Report 2022 Life after diagnosis: Navigating treatment, care and support*. <https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf>
- Alzheimer's Society UK. (2020). *The progression and stages of dementia*.  
[https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet\\_the\\_progression\\_of\\_alzheimers\\_disease\\_and\\_other\\_dementias.pdf](https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_the_progression_of_alzheimers_disease_and_other_dementias.pdf)
- Alzheimer Society of Canada. (2015). *Meaningful Engagement of People with Dementia A Resource Guide*. <https://alzheimer.ca/sites/default/files/documents/meaningful-engagement-of-people-with-dementia.pdf>
- Alzheimer Society of Canada. (2016). *Prevalence and Monetary Costs of Dementia in Canada*.  
[https://archive.alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia\\_en.pdf?\\_ga=2.82771990.1882157282.1609253863-1039292209.1609253863](https://archive.alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia_en.pdf?_ga=2.82771990.1882157282.1609253863-1039292209.1609253863)
- Alzheimer Society of Canada. (2017). *2017 Awareness Survey*.  
[https://alzheimer.ca/sites/default/files/documents/2017\\_Awareness-survey-executive-survey\\_Alzheimer-Society.pdf](https://alzheimer.ca/sites/default/files/documents/2017_Awareness-survey-executive-survey_Alzheimer-Society.pdf)
- Alzheimer Society of Canada. (2018). *Canadian charter of rights for people with dementia*.  
[https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as\\_charter-of-rights-for-people-with-dementia.pdf](https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as_charter-of-rights-for-people-with-dementia.pdf)
- Alzheimer Society of Canada. (2022). *Navigating the pathway forward for dementia in Canada*.  
[https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path\\_Alzheimer-Society-Canada.pdf](https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada.pdf)
- American Psychiatric Association. (2013). Neurocognitive Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). [https://doi-org.libaccess.lib.mcmaster.ca/10.1176/appi.books.9780890425787.x17\\_Neurocognitive\\_Disorders](https://doi-org.libaccess.lib.mcmaster.ca/10.1176/appi.books.9780890425787.x17_Neurocognitive_Disorders)
- Barnett, E., & Casper, M. (2001). A definition of "social environment." *American Journal of Public Health*, 91(3), 465. <https://doi.org/doi:10.2105/ajph.91.3.465a>
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 107–118.

- <https://doi.org/10.1016/j.jaging.2006.09.002>
- Bethell, J., Pringle, D., Chambers, L. W., Cohen, C., Commisso, E., Cowan, K., Fehr, P., Laupacis, A., Szeto, P., & McGilton, K. S. (2018). Patient and Public Involvement in Identifying Dementia Research Priorities. *Journal of the American Geriatrics Society*, 66(8), 1608–1612. <https://doi.org/10.1111/jgs.15453>
- Biggs, S., Carr, A., & Haapala, I. (2019). Dementia as a source of social disadvantage and exclusion. *Australian Journal on Ageing*, 38(S2), 26–33. <https://doi.org/10.1111/AJAG.12654>
- Brooks, M. (n.d.). “The word dementia is a stigma on its own.” Dementia Diaries. Retrieved September 19, 2022, from <https://dementiadiaries.org/entry/3215/the-word-dementia-is-a-stigma-on-its-own>
- Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., & Goodman, C. (2019). Dementia Friendly Communities in England: A scoping study. *International Journal of Geriatric Psychiatry*, 34(8), 1235–1243. <https://doi.org/10.1002/gps.5123>
- Buckner, S., Lafortune, L., Darlington, N., Dickinson, A., Killett, A., Mathie, E., Mayrhofer, A., Woodward, M., Goodman, C., & Buckner, S. (2022). A suite of evaluation resources for Dementia Friendly Communities: Development and guidance for use. *Dementia: The International Journal of Social Research and Practice*. <https://doi.org/10.1177/14713012221106634>
- Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public’s knowledge and understanding of Alzheimer’s disease and dementia. *Alzheimer Disease and Associated Disorders*, 29(3), 255–275. <https://doi.org/10.1097/WAD.0000000000000102>
- Canadian Institute for Health Information. (2018). *Dementia in home and community care*. <https://www.cihi.ca/en/dementia-in-canada/dementia-care-across-the-health-system/dementia-in-home-and-community-care>
- Christiansen, C., & Townsend, E. (2004). *Introduction to occupation: The art and science of living*. Prentice Hall.
- Cousins, B., & Whitmore, E. (1998). Framing participatory evaluation. *New Directions for Evaluation*, 1998(80), 5–23. <https://doi.org/10.1002/ev.1114>
- Darlington, N., Arthur, A., Woodward, M., Buckner, S., Killett, A., Lafortune, L., Mathie, E., Mayrhofer, A., Thurman, J., & Goodman, C. (2020). A survey of the experience of living with dementia in a dementia-friendly community. *Dementia: The International Journal of Social Research and Practice*, 20(5), 1711–1722. <https://doi.org/10.1177/1471301220965552>
- Dean, J., Silversides, K., Crampton, J., & Wrigley, J. (2015). *Evaluation of the York dementia friendly communities project*. [file:///C:/Users/laura/Downloads/evaluation\\_of\\_the\\_york\\_dementia\\_friendly\\_communities\\_programme.pdf](file:///C:/Users/laura/Downloads/evaluation_of_the_york_dementia_friendly_communities_programme.pdf)
- Diaz Garcia, L., Durocher, E., Gardner, P., McAiney, C., Mokashi, V., & Letts, L. (2022). Assessment tools for measurement of dementia-friendliness of a community: A scoping review. *Dementia (London, England)*, 21(5), 1825–1855. <https://doi.org/10.1177/14713012221090032>
- Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia

- context. *World Leisure Journal*, 54(3), 240–254.  
<https://doi.org/10.1080/04419057.2012.702454>
- Garcia Diaz, L., Durocher, E., Gardner, P., McAiney, C., & Letts, L. (2023). Engagement of Persons with Dementia in Public Consultations: Process Evaluation. *Journal of Community Engagement and Scholarship*, 15(2). <https://doi.org/10.54656/JCES.V15I2.449>
- Global Brain Health Institute. (2020). *Dementia Inclusive Community Guide from a Universal Design approach Creating communities that include and support people with dementia*. <https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/Guidance-and-Guidelines/Dementia-Inclusive-Community-Guide-from-a-Universal-Design-approach-2020-.pdf>
- Glynn, R. W., Shelley, E., & Lawlor, B. A. (2017). Public knowledge and understanding of dementia—evidence from a national survey in Ireland. *Age and Ageing*, 46(5), 865–869. <https://doi.org/10.1093/AGEING/AFX082>
- Goodman, C., Arthur, A., Buckner, S., Buswell, M., Darlington, N., Dickinson, A., Killett, A., Lafortune, L., Mathie, E., Mayrhofer, A., Reilly, P., Skedgel, C., Thurman, J., & Woodward, M. (2020). *National Institute for Health Research Policy Research Programme Project Dementia Friendly Communities: The DEMCOM evaluation (PR-R15-0116-21003)*. <https://doi.org/10.18745/PB.23477>
- Government of Canada. (2022). *Dementia Strategic Fund: Submit proposals for awareness raising initiatives*. <https://www.canada.ca/en/public-health/services/funding-opportunities/grant-contribution-funding-opportunities/dementia-strategic-fund-awareness-raising-initiatives-request-funding.html#a1>
- Hackett, R. A., Steptoe, A., Cadar, D., & Fancourt, D. (2019). Social engagement before and after dementia diagnosis in the English Longitudinal Study of Ageing. *PLOS ONE*, 14(8), e0220195. <https://doi.org/10.1371/JOURNAL.PONE.0220195>
- Harsányiová, M., & Prokop, P. (2018). Living condition, weight loss and cognitive decline among people with dementia. *Nursing Open*, 5(3), 275–284. <https://doi.org/10.1002/NOP2.137>
- Heward, M., Innes, A., Cutler, C., & Hambidge, S. (2017). Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement. *Health & Social Care in the Community*, 25(3), 858–867. <https://doi.org/10.1111/HSC.12371>
- Hung, L., Hudson, A., Gregorio, M., Jackson, L., Mann, J., Horne, N., Berndt, A., Wallsworth, C., Wong, L., & Phinney, A. (2021). Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontology & Geriatric Medicine*, 7, 1–13. <https://journals.sagepub.com/doi/pdf/10.1177/23337214211013596>
- Ismail, Z., Black, S. E., Camicioli, R., Chertkow, H., Herrmann, N., Laforce, R., Montero-Odasso, M., Rockwood, K., Rosa-Neto, P., Seitz, D., Sivananthan, S., Smith, E. E., Soucy, J. P., Vedel, I., Gauthier, S., Gauthier, S., Menard, M. C., Lacombe, G., Chayer, C., ... Watt, J. (2020). Recommendations of the 5th Canadian Consensus Conference on the diagnosis and treatment of dementia. *Alzheimer's & Dementia*, 16(8), 1182–1195. <https://doi.org/10.1002/ALZ.12105>
- Jellinger, K. A. (2010). Should the word ‘dementia’ be forgotten? *Journal of Cellular and Molecular Medicine*, 14(10), 2415. <https://doi.org/10.1111/J.1582-4934.2010.01159.X>
- Key, K., Furr-Holden, D., Lewis, E., Cunningham, R., Zimmerman, M., & Johnson-Lawrence, V. (2019). The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Progress in Community Health Partnerships*:



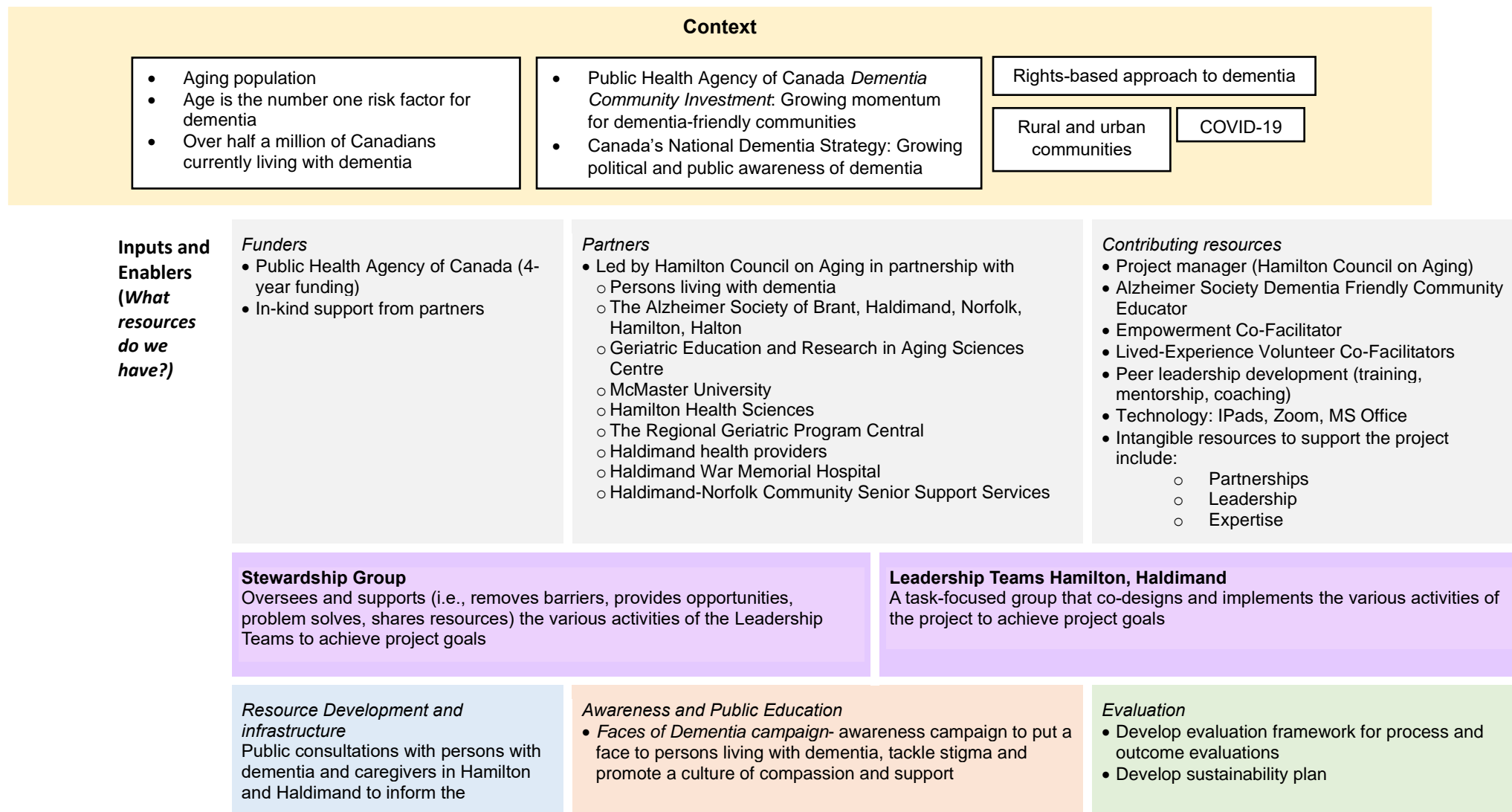
- Research, Education, and Action*, 13(4), 427–434. <https://doi.org/10.1353/cpr.2019.0064>
- Latin is simple. (n.d.). *demens, dementis M*. Retrieved September 19, 2022, from <https://www.latin-is-simple.com/en/vocabulary/adjective/3508/>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(1). <https://doi.org/10.1186/1748-5908-5-69>
- Lopez, K. J., & Dupuis, S. L. (2014). Exploring meanings and experiences of wellness from residents living in long-term care homes. *World Leisure Journal*, 56(2), 141–150. <https://doi.org/10.1080/16078055.2014.903724>
- Low, L. F., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, 20(1), 1–16. <https://doi.org/10.1186/S12877-020-01754-X/TABLES/1>
- Luger, T. M., Hamilton, A. B., & True, G. (2020). Measuring Community-Engaged Research Contexts, Processes, and Outcomes: A Mapping Review. *The Milbank Quarterly*, 98(2), 493–553. <https://doi.org/10.1111/1468-0009.12458>
- Mathie, E., Antony, A., Killett, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M., & Goodman, C. (2022). Dementia-friendly communities: The involvement of people living with dementia. *Dementia: The International Journal of Social Research and Practice*, 21(4), 1250–1269. <https://doi.org/10.1177/14713012211073200>
- Merriam-Webster online dictionary. (n.d.). *Definition of Dementia*. Retrieved September 19, 2022, from [https://www.merriam-webster.com/dictionary/dementia?utm\\_campaign=sd&utm\\_medium=serp&utm\\_source=jso nld](https://www.merriam-webster.com/dictionary/dementia?utm_campaign=sd&utm_medium=serp&utm_source=jso nld)
- Miyamoto, M., George, D. R., & Whitehouse, P. J. (2011). Government, professional and public efforts in Japan to change the designation of dementia (chihō). *Dementia: The International Journal of Social Research and Practice*, 10(4), 475–486. <https://doi.org/10.1177/1471301211416616>
- Ong, E. (2022, August 15). *Real inclusion is still far*. LinkedIn. <https://www.linkedin.com/pulse/real-inclusion-still-far-emily-ong/>
- Organizing Engagement. (2020). *Participatory action research and evaluation*. <https://organizingengagement.org/models/participatory-action-research-and-evaluation/>
- Parker, M., Barlow, S., Hoe, J., & Aitken, L. (2020). Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics*, 32(5), 611–634. <https://doi.org/10.1017/S1041610219002229>
- Prior, P. (2012). *Knowing the foundations of dementia friendly communities for the North East*. [https://www.housinglin.org.uk/\\_assets/Resources/Housing/OtherOrganisation/dementiacommunities.pdf](https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/dementiacommunities.pdf)
- Public Health Agency of Canada. (2014). *Mapping connections: An understanding of neurological conditions in Canada*. [https://publications.gc.ca/collections/collection\\_2014/aspc-phac/HP35-45-2014-eng.pdf](https://publications.gc.ca/collections/collection_2014/aspc-phac/HP35-45-2014-eng.pdf)
- Public Health Agency of Canada. (2019). *A dementia strategy for Canada: Together we aspire*. [https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/NationalDementiaStrategy\\_ENG.pdf](https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/NationalDementiaStrategy_ENG.pdf)
- Public Health Agency of Canada. (2021). *A Dementia Strategy for Canada: Together We Achieve - 2021 Annual Report*. <https://www.canada.ca/en/public->

- health/services/publications/diseases-conditions/dementia-strategy-annual-report-parliament-2021.html
- Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities. *Dementia: The International Journal of Social Research and Practice*, 17, 131-137. <https://doi.org/10.1177/1471301217751533>
- Sachdev, P. S., Blacker, D., Blazer, D. G., Ganguli, M., Jeste, D. V., Paulsen, J. S., & Petersen, R. C. (2014). Classifying neurocognitive disorders: the DSM-5 approach. *Nature Reviews Neurology*. <https://doi.org/10.1038/nrneurol.2014.181>
- Scharlach, A. E., & Lehning, A. J. (2013). Ageing-friendly communities and social inclusion in the United States of America. *Ageing & Society*, 33, 110–136. <https://doi.org/10.1017/S0144686X12000578>
- Seetharaman, K., Shepley, M. M., & Cheairs, C. (2020). The saliency of geographical landmarks for community navigation: A photovoice study with persons living with dementia. *Dementia*, 20(4), 1191–1212. <https://doi.org/10.1177/1471301220927236>
- Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in Mind: Thinking Differently About Dementia and Disability. *Dementia: The International Journal of Social Research and Practice*, 18(3), 1075–1088. <https://doi.org/10.1177/1471301217701506>
- Shannon, K., Bail, K., & Neville, S. (2019). Dementia-friendly community initiatives: An integrative review. *Journal of Clinical Nursing*, 28(11–12), 2035–2045. <https://doi.org/10.1111/jocn.14746>
- Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly: *Dementia: The International Journal of Social Research and Practice*, 13(6), 709–716. <https://doi.org/10.1177/1471301214548143>
- The Lancet Neurology. (2015). Increasing the power of public awareness campaigns. *The Lancet Neurology*, 14(7). [https://doi.org/10.1016/S1474-4422\(15\)00105-2](https://doi.org/10.1016/S1474-4422(15)00105-2)
- Tsuda, S., Inagaki, H., Okamura, T., Sugiyama, M., Ogawa, M., Miyamae, F., Edahiro, A., Ura, C., Sakuma, N., & Awata, S. (2022). Promoting cultural change towards dementia friendly communities: a multi-level intervention in Japan. *BMC Geriatrics*, 22(1), 1–13. <https://doi.org/10.1186/S12877-022-03030-6/TABLES/4>
- Vavuris, T. (2021). There is no generalizability in community-based work. In J. Min Choi & J. Murphy (Eds.), *Community-Based Service Delivery*. Routledge. <https://doi.org/https://doi.org/10.4324/9781003020783>
- Wang, G., Marradi, C., Albayrak, A., & van der Cammen, T. J. M. (2019). Co-designing with people with dementia: A scoping review of involving people with dementia in design research. In *Maturitas*, 127, 55-63. <https://doi.org/10.1016/j.maturitas.2019.06.003>
- Woodbridge, R., Sullivan, M. P., Gilhooly, K. J., Gilhooly, M., McIntyre, A., & Wilson, L. (2018). Use of the physical environment to support everyday activities for people with dementia: A systematic review. *Dementia*, 17(5), 533–572. <https://doi.org/10.1177/1471301216648670>
- World Dementia Council. (2020). *Defining dementia friendly initiatives: Presenting a global evidence base for dementia friendly initiatives World Dementia Council Leading the Global Action Against Dementia Paper 1 Produced in partnership with.* [https://www.worlddementiacouncil.org/sites/default/files/2020-12/DFIs - Paper 1\\_V18.pdf](https://www.worlddementiacouncil.org/sites/default/files/2020-12/DFIs - Paper 1_V18.pdf)
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health World Health Organization Geneva ICF ii WHO Library Cataloguing-in-Publication Data International classification of functioning, disability and health : ICF.*

- World Health Organization. (2013). *Dementia a Public Health Priority*.  
<https://www.who.int/publications/i/item/dementia-a-public-health-priority>
- World Health Organization. (2017). *Global action plan on the public health response to dementia: 2017-2025*. <http://apps.who.int/bookorders>.
- World Health Organization. (2021a). *Rehabilitation*. <https://www.who.int/news-room/fact-sheets/detail/rehabilitation>
- World Health Organization. (2021b). *Towards a dementia inclusive society*.  
<https://www.who.int/publications/i/item/9789240031531>
- World Health Organization. (2021c, September 2). *Dementia*. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Yin, J., Lassale, C., Steptoe, A., & Cadar, D. (2019). Exploring the bidirectional associations between loneliness and cognitive functioning over 10 years: the English longitudinal study of ageing. *International Journal of Epidemiology*, 48(6), 1937–1948.  
<https://doi.org/10.1093/IJE/DYZ085>

## Appendix A

### DFCC-HH Project's Logic Model



**Activities  
(What do we do?)**

development and implement of dementia-friendly action plans

- Identify target demographics in need of dementia-friendly resources/tools (i.e., healthcare providers, business owners, banks)
- Virtual launch of project

**Outputs  
(What do activities create?  
How many?  
How much?)**

*Resource Development and infrastructure*

- 305 persons were engaged in the public consultations (234 Hamilton, 71 Haldimand)
- “What we heard” summary for both Hamilton and Haldimand
- 5 dementia-friendly recommendations to be integrated into the Age Friendly-Dementia Friendly Plan in Hamilton
- 5 dementia-friendly action recommendations identified in Haldimand
- 2-5 Dementia-Friendly Action Plans identified for development and implementation (1-3 in Hamilton, 1-2 in Haldimand)

*Awareness and Public Education*

- 10 persons (person living with dementia and/or their families, friends, and caregivers) profiled through the *Faces of Dementia* campaign
- Development of a video and photos
- Host virtual Launch Event introducing the *Faces of Dementia* campaign for 100 persons in Hamilton and 50 in Haldimand
- Develop 5 dementia-friendly resources/tools for target demographics

Use education tools to reach 600 individuals

*Evaluation*

- Annual evaluation of processes and outcomes
- Sustainability plan
- Evaluation findings reported to funder and stakeholders
- Develop KT tools of lessons learned and share with local and national stakeholders

**Short term outcomes  
(1-3 years)  
(Why are we doing this? What do we hope to achieve?)**

*Resource Development and infrastructure*

- Enhanced well-being for persons with dementia and caregivers
- Decreased feelings of social isolation for persons with dementia and caregivers
- Increased choice and use of dementia services
- Increased caregiver supports
- Increased opportunities for community participation for persons with dementia
- Increased safety for persons with dementia in the community

*Awareness and Public Education*

- Increased knowledge and understanding about dementia and its impact
- Increased number of community members aware of and educated in dementia
- Increased number of healthcare providers educated in dementia care
- Increased number of dementia-friendly businesses

*Evaluation*

- Evaluation findings inform development, ongoing quality improvement, and sustainability of initiative
- Evaluation findings support the expansion of dementia-friendly communities

**Medium term outcomes (4-9 years)**  
*(What are the long-term benefits?)*

- Extrinsic*
  - Stigma reduction
  - Increased knowledge and understanding about dementia and its impact in Hamilton and Haldimand
  - Social and physical environments are designed to support persons with dementia
- Intrinsic*
  - Enhanced well-being for persons with dementia and caregivers
  - Decreased feelings of social isolation for persons with dementia and caregivers
  - Persons with dementia feel understood, respected, and supported by their community
  - Persons with dementia have opportunities and feel empowered to contribute in meaningful ways to community life
  - Persons with dementia feel a sense of belonging

- Enhanced knowledge about how to create dementia-friendly initiatives in distinct communities
- Enhanced knowledge of how to engage persons living with dementia in developing plans and policies that reflect their perspectives and needs

**Long term outcomes (10+years)**  
*(What are the ultimate goals?)*

- Enhanced well-being for persons with dementia and caregivers
- Decreased feelings of social isolation for persons with dementia and caregivers
- Stigma reduction
- Increased knowledge and understanding about dementia and its impact
- Delayed move into long term care/length of time for which persons with dementia can continue to be supported in their community
- Reduction of health care costs
- Dementia-friendly considerations given when new community areas are built
- Improved and safe physical environment considerations for persons with dementia in the community
- Satisfying quality of life for persons living in the community with dementia and their caregivers
- Increased number of dementia-friendly communities in Canada

## CHAPTER TWO

TITLE: Assessment Tools for Measurement of Dementia-Friendliness of a Community: A Scoping Review

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## Abstract

**Background:** A quantitative assessment of the dementia-friendliness of a community can support planning and evaluation of dementia-friendly community (DFC) initiatives, internal review, and national/international comparisons, encouraging a more systematic and strategic approach to the advancement of DFCs. However, assessment of the dementia-friendliness of a community is not always conducted and continuous improvement and evaluation of the impact of dementia-friendly initiatives are not always undertaken. A dearth of applicable evaluation tools is one reason why there is a lack of quantitative assessments of the dementia-friendliness of communities working on DFC initiatives. **Purpose:** A scoping review was conducted to identify and examine assessment tools that can be used to conduct quantitative assessments of the dementia-friendliness of a community. **Design and methods:** Peer-reviewed studies related to DFCs were identified through a search of seven electronic databases (Medline, CINAHL, PsychInfo, EMBase, EMCare, HealthStar and AgeLine). Grey literature on DFCs were identified through a search of the World Wide Web and personal communication with community leads in Australia, Canada, New Zealand, the United Kingdom and the United States. Characteristic of identified assessment tools were tabulated, and a narrative summary of findings was developed along with a discussion of strengths and weaknesses of identified tools. **Results:** Forty tools that assess DFC features (built environment, dementia awareness and attitudes, and community needs) were identified. None of the identified tools were deemed comprehensive enough for the assessment of community needs of people with dementia.

**Keywords:** Dementia-friendly, baseline assessment, measurement of dementia-friendliness, survey, questionnaire, dementia friendly community



## **Introduction**

The recognition of dementia as an urgent global public health issue (World Health Organization, 2017) has led to a growth in dementia-friendly community (DFC) initiatives around the world (Alzheimer's Disease International, 2017). A DFC is focused on the inclusion of people with dementia and on stigma reduction so that persons with dementia feel better understood, respected and supported, and can remain engaged in their communities for as long as possible (Alzheimer's Disease International, 2016b; Alzheimer Society of Saskatchewan, 2017).

For DFCs to be supportive and safe for people with dementia, built and social environments in the community need to be considered (Courtney-Pratt et al., 2018; Sturge et al., 2021). For example, when the social environment is disempowering and stigmatizing, people living with dementia may lose motivation to participate in occupations that are meaningful to them (Teitelman et al., 2010) and may avoid asking for help (Milby et al., 2017). Dementia awareness campaigns can help combat stigma and increase awareness of how to support someone living with dementia, making the social environment more supportive for people with dementia (Hebert & Scales, 2019; Sturge et al., 2021). Similarly, implementing environmental design principles (such as enhanced lighting and appropriate use of colours) can improve walkability and safety (Kerr et al., 2012), making the built environment more supportive for people with dementia. As described by people living with dementia, DFC characteristics include (Alzheimer's Australia, 2014; City of Burnaby, 2017; Wu et al., 2019):

- community awareness about dementia
- dementia training for health and community organizations
- support to remain living at home
- access to timely-diagnosis and to adequate and affordable home health care

- dementia-specific recreational and social programs
- age and dementia-friendly environmental features such as legible signage to help people with cognitive impairment navigate their community safely
- inclusive public transportation such as accessible bus stops
- availability of respite care for caregivers

When developing a DFC initiative, most communities follow a similar process: forming a steering group; identifying and prioritizing community needs; developing a dementia-friendly action plan(s); implementing and monitoring the progress of the plan(s); and evaluating the plan's impact (Shannon et al., 2019). To evaluate the plan's impact, assessment of the dementia-friendliness of the community before and after implementation of the plan(s) is needed.

In the published literature, quantitative and qualitative methods have been used to assess the dementia-friendliness of a community. Qualitative methods are typically used to understand processes and reasons why an intervention (such as a DFC initiative) resulted in the observed impact/outcome, when engaging marginalized communities or when quantitative tools may be difficult to administer (Rao & Woolcock, 2003). Qualitative methods in the reviewed literature have included focus groups and walking interviews (Alzheimer's Disease International, 2016a; Alzheimer's Society UK, 2013; Alzheimer Society of Saskatchewan, 2017) and they have been used to elicit information about the experience of living with dementia, such as the impact of stigma on community participation and access to care (Alzheimer's Society UK, 2013).

Quantitative methods are typically used to measure changes and impact over time, drawing inferences from observed statistical relations, and gathering responses on a broad range of topics (Rao & Woolcock, 2003). Quantitative methods in the reviewed literature have included surveys,

which have been used to gather information on a broad range of topics such as transportation and community services (Alzheimer's Disease International, 2016a).

Public documents and research articles are available to guide stakeholders in the planning of a DFC initiative (see, e.g., Heward et al., 2017; World Health Organization, 2021). However, little attention has been paid to the evaluation of DFC initiatives, resulting in a lack of guidance about how to assess dementia-friendliness. As described in a scoping review of characteristics and foci of DFCs in England by Buckner et al.(2019), commonly used impact indicators include the number of “Dementia Friends” (i.e., someone that learns about dementia by watching an educational video (Alzheimer's Society UK, 2017a)) and “Dementia Friend Champions” (i.e., volunteers who teach others how to support people with dementia (Alzheimer's Society UK, 2017c)); number of dementia-friendly businesses and activities; and the recognition of the community as dementia-friendly by the local Alzheimer's Society (Buckner et al., 2019). These indicators provide useful information about community interest in working towards becoming “dementia-friendly”; however, they do not provide an indication of change in the dementia-friendliness of the community (such as evidence of barriers to participation being removed) and impact of the initiative on the well-being of people impacted by dementia. Similarly, in an integrative review of international research conducted on DFC initiatives, Shannon et al.(2019) found that a baseline assessment of the dementia-friendliness of a community is not always conducted, and continuous improvement and evaluation of the impact of dementia-friendly initiatives are not always undertaken (Shannon et al., 2019; Turner & Morken, 2016). Possible explanations for why DFC initiatives have not focused on evaluation include complexity of the initiatives (Shannon et al., 2019) and a lack of applicable evaluation tools (Hebert & Scales, 2019).

Although qualitative methods can elicit rich and detailed information about the experiences of people with dementia, such as community enablers and barriers, this information is subjective and does not provide a comprehensive or generalizable cross-section of the population of people living with dementia. In recognition of this, some communities have utilized surveys to assess the dementia-friendliness of their community, which has allowed them to obtain responses from a larger sample and the ability to measure change over time. However, in the absence of established DFC assessment tools, communities have developed their own tools (e.g., surveys) to assess how dementia-friendly their community is (see, e.g., Alzheimer's Society UK, 2013). While self-developed DFC surveys allow assessment to be tailored to the needs of a particular community, without a rigorous method of survey construction it is difficult to evaluate the accuracy of the assessments. As a result of a lack of confidence in an assessment's findings, tools cannot be used to evaluate progress within a single community in response to initiatives and to conduct comparisons between communities.

In the process of designing tools to assess the impact of interventions, validity, reliability, and responsiveness to change are important factors to consider (Gadotti et al., 2006). Validity refers to the extent to which the assessment tool measures what it intends to measure (Rossi et al., 2004). Reliability refers to the extent to which the measurement is consistent and reproducible (Rossi et al., 2004). Responsiveness to change refers to the ability for a tool to pick up changes over time in what is being measured (Husted et al., 2000). Without demonstrated validity, reliability and responsiveness to change, a baseline quantitative assessment has little utility as an evaluation tool, as it is not guaranteed to capture the impact of an initiative over time.

A quantitative assessment can support planning, internal review, evaluation of impact, and national/international comparisons, encouraging a more systematic and strategic approach to the

advancement of DFCs (Buckner et al., 2019). The integrative and scoping reviews about DFCs conducted by Shannon et al.(2019) and Buckner et al.(2019) identified a lack of outcome and impact evaluations in existing DFC initiatives. A dearth of applicable evaluation tools has been cited as a reason for the lack of assessments of dementia-friendliness (Hebert & Scales, 2019). There is a need for quantitative assessment tools and guidance for community leaders and stakeholders on how to select or construct assessments of dementia-friendliness. To build on this work, the aims of this scoping review were to: 1) identify assessment tools that have been developed to conduct quantitative assessments of the dementia-friendliness of a community; 2) review DFC domains covered in the identified tools to assess whether they are sufficiently comprehensive to evaluate the dementia-friendliness of a community; 3) investigate whether identified assessment tools have been assessed for reliability, validity, and/or responsiveness to change; and 4) describe how identified assessment tools have been used in local contexts and in research. This research will provide guidance to stakeholders working on DFC initiatives that wish to determine baseline dementia-friendliness, measure progress and/or evaluate the impact of their initiative. Findings from this review will be of use to dementia-friendly researchers, community leaders and stakeholders.

### **Review Question(s)**

1. What assessment tools have been developed to quantitatively assess the dementia-friendliness of a community?
2. Are the identified tools sufficiently comprehensive to use in assessing dementia-friendly features in a community?
3. Have the identified tools been assessed for reliability, validity, and/or responsiveness to change?

4. How have the identified tools been used in research and in practice related to DFCs?

## **Methods**

This scoping review was conducted in accordance with the Joanna Briggs Institute methodology for scoping reviews (Peters et al., 2020). This method is based on the earlier work of Arksey and O'Malley (2005) and Levac, Colquhoun and O'Brien (2010). As recommended by Levac and colleagues (2010), to validate and enhance the results of the review and make them more useful for end-users, a consultation phase was included. The scoping review protocol was registered within the Open Science Framework (registration <https://osf.io/zbvvy5/>) and it is being reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018).

## ***Inclusion criteria***

**Concept.** In this review, we considered studies and reports that identify tools that have been designed to assess the dementia-friendliness of a community by evaluating one or more of the following DFC domains (Alzheimer's Disease International, 2016a; World Health Organization, 2007):

- transportation
- housing
- outdoor spaces and buildings
- businesses
- legal and advanced care planning services
- financial services
- dementia awareness
- care throughout the continuum

- memory loss supports and services
- emergency planning and first response
- respect and social inclusion
- independent living
- civic participation and engagement
- dementia-accessible community activities social
- quality of life

The domains were informed by the Alzheimer’s Disease International key outcomes of DFCs (awareness and understanding of dementia; increased social and cultural engagement for the person with dementia; legal and other measures in place to empower people with dementia to protect their rights; increased health and community services that respond to the needs of people with dementia; and actions to improve indoor and outdoor spaces; Alzheimer’s Disease International, 2016a), and the World Health Organization (WHO) age-friendly domains (outdoor spaces and buildings; transportation; housing; social participation; respect and social inclusion; civic participation and employment; community support and health services; World Health Organization, 2007).

**Context.** In this review, community refers to a geographic location. Assessment tools that have been developed to investigate dementia-friendly environments in healthcare organizations, such as long-term care homes, were not included in this review.

**Types of sources.** In this review, we considered peer-reviewed studies, policy papers, websites and grey literature on published organizational reports. Only quantitative assessment tools were considered. Proprietary tools under copyright were included in the review if they could be viewed without paying a fee.

### *Search strategy*

Assessment tools were identified through three channels: 1) a search of peer-reviewed articles related to DFCs; 2) World Wide Web search of grey literature on DFC initiatives; 3) personal communication with community leads. All searches were conducted between January 2021 and April 2021.

**Peer-Reviewed Literature.** The search strategy was developed in collaboration with a health science librarian at McMaster University, Canada. In keeping with the Joanna Briggs Institute method, a three-step search strategy was used. An initial search of Medline and CINAHL was undertaken using the keywords: dementia or Alzheimer, (community or communities) OR (neighbourhoods or neighborhoods), inclusive or friendly, rating scale or evaluation tool or assessment, or evaluation. This initial search was followed by an analysis of the text words contained in the title and abstract of retrieved articles, and of the index terms used to describe the articles. A second search using all relevant identified keywords and index terms was undertaken across all seven included databases: Medline, CINAHL, PsychInfo, EMBase, EMCare, HealthStar and AgeLine. Third, the reference lists of all identified articles were searched for additional studies.

Only studies written in English were reviewed. We did not limit the date of the search as we recognized that, as a relatively new topic, most of the identified sources would be relatively recent.

**World Wide Web search of Grey Literature.** In Shannon et al.'s (2019) integrative review, research about DFCs was found to have been conducted in Canada, Australia, New Zealand, and the United Kingdom. Grey literature sources from these countries were identified by a search of the World Wide Web using Google advanced search functions. In addition, the United States has



a national Dementia Friendly America (Dementia Friendly America, 2015) which is a network of communities working towards becoming dementia-friendly. As this network has a wide reach, we also identified grey literature sources from the United States. Sources included toolkits, reports and DFC websites. The terms used in the search included dementia-friendly community report, dementia-friendly community assessment, dementia-friendly assessment, dementia-friendly community toolkit and dementia-friendly community survey.

**Personal Communication with Community Leads.** Grey literature sources were also identified through personal communication with community representatives from communities that have conducted DFC initiatives in Canada, Australia, New Zealand, the United Kingdom and the United States. Community representatives were identified in DFC websites, reports, and through the research team's network. Snowball sampling to identify other community representatives was also used. Community representatives were asked whether and how they had measured the dementia-friendliness of their community. If they had conducted an assessment, they were asked which tool(s) they had used, or had considered using, for their assessment.

### *Selection of sources of evidence*

Following the search, all identified citations were collated and uploaded into Covidence (Veritas Health Innovation, n.d.) and duplicates were removed. Titles and abstracts were screened by LGD and VM using the inclusion criteria for the review. In cases where it was not clear whether the source met the inclusion criteria, the document was retrieved and included for the full-text review. The full text of selected documents was retrieved and assessed in detail against the inclusion and exclusion criteria by LGD and VM. Sources that did not include a quantitative tool, did not focus on DFCs, or included a tool identified elsewhere were excluded. Disagreements that arose between reviewers were resolved through the involvement of LL.

To investigate how the tools found in peer-reviewed articles have been used in research related to DFCs, the database in which the article was found, and Google Scholar were used to identify all manuscripts that have cited the article. The title and abstract of all “cited by” manuscripts were scanned and those related to DFCs underwent a full-text review. The names of all identified tools were also searched in Google to investigate whether these have been used in the grey literature or by other communities working on a DFC initiative.

### ***Charting the data***

To assess and compare the assessment tools, every question in each tool was categorized by LGD and VM according to the domain of dementia-friendliness it addressed (refer to eligibility criteria). For questions that had multiple sub-questions, the sub-questions were treated as separate items. During the review, four domains were added to the extraction tool (indoor spaces; participation in leisure activities; healthcare services; and communication and information) as many of the identified tools had questions associated with these areas. In addition, information about tool developers; year the tool was created; languages in which the tool is available; country in which the tool was developed; whether people with dementia were involved in tool development; whether theory guided tool development; reliability, validity and responsiveness to change of the tool (when available); number of demographic questions; and number of open-ended questions were extracted.

### ***Collating, summarizing and reporting results***

After completion of the data extraction, the characteristics of all assessment tools included in this scoping review were tabulated. Details about the author(s), type of tool, year of publication, country of origin, developers, psychometric properties (if any), target population and type of questions included were compiled. A narrative summary describing how the results relate

to the review's objectives was developed along with a discussion of strength and weaknesses of identified tools.

### ***Consultation with stakeholders***

The objectives of the consultation phase were to share findings with stakeholders and discuss the meaning and significance of the findings. Stakeholders working on developing and implementing a DFC initiative in urban and rural communities were invited to participate in the consultation. LGD presented the search strategy and preliminary findings to attendees, which was followed by a discussion of the results.

### **Results**

A total of 38 abstracts were identified in the database search. After the removal of duplicates, 21 articles remained. Five articles were excluded after title and abstract review. A total of 16 articles underwent full-text review. Four conflicts were identified at the full-text stage and a third reviewer was involved to resolve the conflicts. A total of 6 peer-reviewed articles were selected for final inclusion (Darlington et al., 2020; Fleming et al., 2017; Griffiths et al., 2018; Mitchell & Burton, 2006; Read et al., 2020; Wu et al., 2019) (Figure 1).

A total of 42 grey literature sources were identified through the World Wide Web search. Four reports (Catenbury District Health Board, 2015; Dementia Australia, 2016, 2018; National Alzheimer's and Dementia Resource Center, 2019) included multiple assessment tools (for example, one checklist for indoor spaces and one for outdoor spaces). Each assessment tool was assessed independently and was considered as an individual source, for a total of 47 independent sources. After the exclusion of sources that did not meet the inclusion criteria, 31 sources remained. Seven of the sources mentioned the use of quantitative assessment tools but did not include the tool in their report. LGD contacted the authors of those reports and three of them

shared their assessment tool with the research team (City of New Westminister, 2016; City of North Vancouver, 2016; City of Richmond, 2019). A total of 29 grey literature sources were deemed to meet the criteria for final inclusion (Figure 1).

Sixteen community representatives were contacted by LGD (Canada n = 5, New Zealand n = 1, Australia n = 2, the United Kingdom n = 5, the United States n = 3). Five assessment tools were identified through this method and included in the review (Central Coast Council, 2017; Community Partners in Action Innisfail, 2020; Dementia-Friendly Rotorua Steering Group, 2017; Hamilton Council on Aging, 2020; National Alzheimer's and Dementia Resource Center, 2019). None of the identified tools were proprietary tools under copyright. After compiling all sources, 40 unique tools that were developed to quantitatively assess the dementia-friendliness of a community were identified (Figure 1).

**Figure 1.** PRISMA diagram of scoping review process [Inset Figure 1]

### *Characteristics of included tools*

The 40 tools included were developed between 2006 and 2020, with 33 developed between 2016-2020. Table 1 provides a summary of the characteristics of the 40 tools identified. Eighteen of the tools are checklists for indoor and/or outdoor dementia-friendly environments, twenty-two are related to living in the community with dementia or dementia attitudes and knowledge. Fourteen of the tools were developed in Australia, eight in the United States, eight in the United Kingdom, seven in Canada, two in New Zealand and one in Taiwan. Approximately 50% of the tools were developed for “other” target populations (e.g., architects). The most frequent developers of tools were not-for-profit organizations (47.5%), followed by researchers (30%), and local government (22.5%). The development of the Dementia Community Attitudes questionnaire (Read et al., 2020) was guided by the tripartite model of attitude (Breckler, 1984;

Rosenberg, 1960). An existing theory or framework was not reported to have guided the development of any other of the tools identified.

**Table 1.** *Tool Characteristics* [Insert Table 1]

### ***Involvement of people living with dementia in tool development***

Nineteen of the assessment tools were developed with the input of people living with dementia. However, level of involvement varied. The development of two of the tools (Dementia Engagement and Empowerment Project, 2017b, 2017a) was led by people living with dementia. Three of the tools (Alzheimer’s Australia NSW, 2011; Mitchell & Burton, 2006; Wu et al., 2019) were developed based on an initial consultation with people living with dementia. After the consultations, people living with dementia were engaged throughout the development of items and piloted the tool. Fourteen of the tools (Alzheimer Society of British Columbia, 2016; City of New Westminister, 2016; City of North Vancouver, 2016; City of Richmond, 2019; Community Partners in Action Innisfail, 2020; Darlington et al., 2020; Dementia-Friendly Rotorua Steering Group, 2017; Dementia Australia, 2018; Fleming et al., 2017; Hamilton Council on Aging, 2020; Read et al., 2020) were developed based on existing tools and relevant research and involved people living with dementia in the review of drafts. Six of the tools (ACT on Alzheimer’s, 2015; Griffiths et al., 2018; National Alzheimer’s and Dementia Resource Center, 2019) did no engage people living with dementia in tool development.

### ***Assessment of dementia-friendly community domains***

Understanding which DFC domains are currently being assessed can help determine whether existing tools are sufficiently comprehensive to be considered for use in assessing DFC features. This can be done by determining the number of items per dementia-friendly domain. Table 2 provides a summary of the total number of questions per tool, including the number of

items per dementia-friendly domain, number of open-ended questions, number of demographic questions, and year when the tool was developed. The total number of questions varied between 6 and 113, with the minimum and maximum number of questions per domain ranging from 0 to 55, respectively. Some of the tools had an even distribution of questions per domain (see, e.g., Darlington et al., 2020), while others heavily weighted certain domains over others (see, e.g., Dementia Engagement and Empowerment Project, 2017b). Only one tool had questions related to the financial services domain (Dementia Friendly Community Marinette, 2016) and only three addressed the independent living (ACT on Alzheimer's, 2015; Darlington et al., 2020; Dementia Australia, 2016) and emergency planning and first response (ACT on Alzheimer's, 2015; Dementia Friendly Community Marinette, 2016; Hamilton Council on Aging, 2020) domains. None of the tools had questions that represented all domains of dementia-friendliness. The five domains covered by the greatest number of tools included: outdoor spaces and buildings; dementia awareness/attitudes; civic participation and engagement; transportation; and dementia-specific community activities/services. None of the tools included questions associated with domains of: legal and advanced care planning services; care throughout the continuum; and memory loss supports and services. Where used, open-ended questions included: what respondents had stopped doing because of their dementia; recommendations for making their community dementia-friendly; and perceived barriers to participation. Of the 14 tools that included demographic questions, only four (ACT on Alzheimer's, 2015; Darlington et al., 2020; Hamilton Council on Aging, 2020; Harder+Copmany Community Research, 2016) included questions about ethnic background.

**Table 2.** *Summary of assessment tools included in the review* [Insert table 2]

### ***Psychometric Properties***

Only three tools (Fleming et al., 2017; Griffiths et al., 2018; Read et al., 2020) had validity and reliability information available. None reported responsiveness to change. Griffiths et al. (2018) reported internal consistency of three subscales (Personal Sacrifice  $\alpha = .79$ ; Empathy with People with Dementia  $\alpha = .69$ ; and Perceptions of Dementia  $\alpha = .61$ ) and convergent validity ( $r = .47, p < .001$ ). Fleming et al. (2017) reported inter-rater reliability and internal consistency by assessing different “touch points” along a journey to a destination (approach to entry, entry space, route to the destination, destination, route from the destination). Inter-rater reliability ranged from  $r = .65$ - $.90$  and internal consistency from  $\alpha = .59$ -. $82$ . Read et al. (2020) reported internal consistency of three factors (Engagement =  $\alpha 0.855$ ; Challenges =  $\alpha 0.785$ ; Decision-making  $\alpha = 0.709$ ). An expert reference group assessed the content validity of Read et al.’s (2020) scale, and face validity was assessed by asking participants (including people living with dementia) if the questions were acceptable and easily understood.

### ***Uptake of identified assessment tools***

We were only able to find uptake information for four of the tools (ACT on Alzheimer’s, 2015; Dementia Action Alliance, n.d.; Griffiths et al., 2018; Mitchell & Burton, 2006). Mitchell and Burton’s (2006) checklist for designing dementia-friendly outdoor environments was found to be used in one study (Biglieri, 2018). Biglieri (2018) investigated the financial feasibility of implementing Mitchell and Burton’s (2006) recommendations and concluded that applying recommendations was financially feasible. Three studies (Farina, Hughes, Griffiths, & Parveen, 2020; Farina, Griffiths, Hughes, & Parveen, 2020; Griffiths, Cheong, Saw, & Parveen, 2020) used Griffiths and colleagues Adolescent Attitudes Towards Dementia scale (A-ADS; Griffiths et al., 2018). The scale was used to evaluate the impact of an education session on adolescents’

experiences and perceptions of dementia (Farina et al., 2020) and on pharmacy and medicine undergraduate students in Malaysia (Griffiths et al., 2020). In addition, the A-ADS scale was further validated and a brief version of the scale created (Farina et al., 2020). Table 3 provides a summary of studies that used these two tools.

**Table 3.** *Summary of studies that have used identified tools* [Insert Table 3]

According to what we found in our searches, the ACT on Alzheimer's (2015) Community Needs Assessment has been used by approximately 40 communities in the United States and the Dementia-Friendly Physical Environments checklist by the Dementia Action Alliance (Dementia Action Alliance, n.d.) by approximately 49 establishments in the United Kingdom. Establishments included medical practices, religious facilities, retirement homes, retail businesses, airports, libraries, recreation centers and museums. Lastly, it is worth noting that the checklist for dementia-friendly environments developed by Innovations in Dementia (2012) informed the development of the Dementia Australia (2018) and Canterbury District Health Board (2015) checklists. Similarly, the checklist by the Alzheimer Society of British Columbia (Alzheimer Society of British Columbia, 2016) was informed by Mitchell and Burton's (2006) checklist.

### ***Dementia knowledge attitude scales***

In our search we identified assessment tools designed to measure dementia knowledge and attitudes towards people living with dementia (Annear et al., 2017; Baker et al., 2018; Lundquist & Ready, 2008; O'Connor & McFadden, 2010; Read et al., 2020; Shanahan et al., 2013). Read et al.'s (2020) Dementia Community Attitudes Questionnaire was the only one included in the scoping review as it was specifically developed to support DFC initiatives.



## ***Consultation***

LGD held three consultation sessions. Seven stakeholders participated in the consultations. Participants included healthcare providers (a geriatrician, a nurse, a social worker), two researchers, an executive of an Alzheimer Society, and a community member living with dementia. Significance of the findings were discussed. Participants recognized that most of the identified tools were developed by not-for-profit organizations and highlighted the need for partnerships between people living with dementia, researchers and not-for-profit organizations. Similarly, participants identified the need for funding bodies to support quality improvement efforts so that appropriate resources are allocated to evaluation. In addition, in the three consultation sessions the importance of co-designing tools with people living with dementia was highlighted. Participants raised the concern that in not involving people living with dementia in all stages of tool development there is a risk that questions included in the tool may not reflect community priorities, as identified by people living with dementia.

## **Discussion**

The purpose of this scoping review was to identify and examine quantitative tools that assess the dementia-friendliness of a community. Forty tools that quantitatively assess the dementia-friendliness of a community were identified. Most of the identified tools (82.5%) were developed between 2016 and 2020, making it evident that there is an increased interest in having tools that assess domains of dementia-friendliness. In Canada (Public Health Agency of Canada, 2019), the United States (U.S. Department of Health and Human Services, 2018), the United Kingdom (Department of Health, 2015), Australia (Australian Health Ministers Advisory Council, 2015) and New Zealand (Alzheimers New Zealand, 2015), governments have identified DFCs as an area of focus in national dementia plans, which has resulted in an emergence of DFC

initiatives. However, the emergence of DFC initiatives has led to an overlap in efforts, where individual communities create a new tool, with little awareness of similar tools already in existence. In addition, majority of the identified tools do not meet the standards of rigorous methodology for survey construction.

The tools identified in this review can be divided into three categories, specifically, tools that assess: the built environment; dementia awareness and attitudes; and community needs of people with dementia.

### ***Built environment***

DFC initiatives have been critiqued for focusing on attributes of the built environment, as opposed to the social environment (Førsund et al., 2018; Hebert & Scales, 2019; Lin et al., 2015). This critique is supported by the number of checklists (45%) developed to enhance indoor and outdoor physical spaces (Alzheimer's Australia NSW, 2011; Alzheimer's Society UK, 2017b; Alzheimer's WA, 2016; Alzheimer Society of British Columbia, 2016; Catenbury District Health Board, 2015; Dementia Action Alliance, n.d.; Dementia Australia, 2018; Dementia Engagement and Empowerment Project, 2017b, 2017a; Innovations in Dementia, 2012; Mitchell & Burton, 2006; The Brenda Strafford Foundation, 2019). Enhancing the built environment improves accessibility making it easier for people with dementia to navigate public spaces. However, to support independence and safety, enhancement of the social environment is also needed. For example, it is estimated that 30% to 70% of people with dementia become lost at least once during the course of the disease (Bowen et al., 2011; Pai & Lee, 2016). In qualitative studies conducted in the United Kingdom (Bartlett & Brannelly, 2019) and in Sweden (Olsson et al., 2013), people living with dementia were asked how they deal with becoming confused when navigating familiar spaces. In both studies, participants reported relying on community members

to help them find their way home if they were to get lost (Bartlett & Brannelly, 2019; Olsson et al., 2013), emphasizing the need for dementia awareness to reduce stigma and public education on how to support people living with dementia. Only two of the tools that assess the built environment (Dementia Engagement and Empowerment Project, 2017a, 2017b) include items related to the social environment (e.g., staff seem friendly). Although the built environment may be easier to assess than the social environment, we believe that tools that assess the dementia friendliness of the built environment should also consider social aspects of the environment as this would provide a more comprehensive assessment of the dementia-friendliness of public spaces.

Fleming et al.'s (2017) Dementia-Friendly Communities Environment Assessment Tool is the only tool in this category that has been assessed for reliability and validity. None of the tools have been assessed for responsiveness to change. To ensure that tools that assess the built environment are valid, reliable and can detect change, future research about these tools should focus on conducting psychometric testing. This would increase their utility in research and in evaluation of DFC initiatives.

### ***Dementia awareness and attitudes***

Two peer-reviewed tools (Griffiths et al., 2018; Read et al., 2020) that assess dementia awareness and attitudes were identified and both have been assessed for reliability of validity. Read et al.'s (2020) Dementia Community Attitudes Questionnaire is a ten-item questionnaire that assesses community attitudes towards people living with dementia. Read et al. (2020) conducted preliminary psychometric testing and had promising results; however, to establish convergent validity, further testing is needed. Similarly, Griffith et al. (2018) conducted preliminary psychometric testing on the Adolescent Attitudes Towards Dementia Scale with

adolescents in the United Kingdom, but further validation is needed with adolescents from other countries. Future research on tool development for the assessment of dementia-friendliness should focus on conducting psychometric testing of these scales, including testing for responsiveness to change.

To increase the relevance and utility of research outcomes, engagement of people with dementia in research has become increasingly common (Gove et al., 2017; Miah et al., 2019). Similarly, involvement of people with dementia is a core element of DFC initiatives (Alzheimer's Disease International, 2016a). Six of the identified tools were developed without input from people with dementia. These six tools primarily assess attitudes towards dementia and outcomes of education and training sessions. Even though tools that assess dementia awareness and/or attitudes towards people with dementia are developed for the general public or a specific audience (such as healthcare providers), to ensure that items in the tool reflect the stigma that people with dementia experience, people living with dementia should be involved in their development.

As described by Alzheimer's Disease International (Alzheimer's Disease International, 2016a), reduction of social stigma surrounding dementia and empowerment of people with dementia are two key objectives of DFC initiatives; therefore, the development and uptake of valid and reliable tools that measure stigma towards people living with dementia is important. Five tools identified in the search (Annear et al., 2017; Baker et al., 2018; Lundquist & Ready, 2008; O'Connor & McFadden, 2010; Shanahan et al., 2013) were not included in the final review as they did not meet the inclusion criteria. However, these tools could be used to evaluate dementia-friendly projects aimed at targeting stigma and raising awareness of dementia. Other reviews have been conducted on the use of dementia knowledge scales to support dementia

awareness campaigns and education programs (Resciniti et al., 2020; Spector et al., 2012; Sullivan & Mullan, 2017). Although these tools can support the evaluation of increased knowledge of dementia and stigma reduction, to increase our understanding of the impact of initiatives that address dementia attitudes and awareness, future research should focus on evaluating whether and how those initiatives impact the wellbeing of people living with dementia.

### ***Community needs of people with dementia***

Two peer-reviewed tools (Read et al., 2020; Wu et al., 2019) that assess community needs of people with dementia were identified. Neither tool evaluates all DFC domains, nor have they been assessed for validity, reliability or responsiveness to change. After reviewing the tool by Wu et al. (2019), it was determined that the authors created a list of DFC indicators rather than an assessment tool. These indicators could be used as a basis for tool development. Read et al.'s (2020) tool was developed to assess the experience of living with dementia in a community with an existing dementia-friendly initiative, so it would not be suitable for a baseline assessment of dementia-friendliness.

Three of the DFC domains that we had included in our data extraction tool are not assessed by any of the identified tools: legal and advanced care planning services; care throughout the continuum; and memory loss supports and services. Thus, based on our inclusion criteria, none of the identified tools could be used to assess all DFC domains; stakeholders that wish to assess all DFC domains would need to use multiple assessment tools. In addition, only one tool (Dementia Friendly Community Marinette, 2016) included a question that assessed the financial services domain. In two studies – a systematic review and meta-analysis (Curnow et al., 2019) and a scoping review (Morrisby et al., 2018) – that investigated the evidence of needs of

people with dementia, memory and money management were identified as two of the top five needs. Given that memory and money management support have been identified by people with dementia as priorities, it is important for tools aimed at assessing community needs of people with dementia to evaluate if these priority needs are being met by existing programs and services. Similarly, it is estimated that less than 40% of people with dementia worldwide have the opportunity to participate in advanced care planning (Sellars et al., 2019). In a recent umbrella review of effectiveness of advanced care planning for people with dementia (Wendrich-van Dael et al., 2020), advanced care planning was found to be associated with decreased hospitalizations and increased concordance between care received and prior wishes. To ensure that people with dementia can participate fully in decisions that affect them from point of diagnosis to palliative care, assessment tools should include questions related to legal and advanced care planning services.

We encourage people living with dementia, national Alzheimer Society associations and researchers to collaborate on developing and validating questionnaires that assesses different domains of dementia-friendliness. This collaboration would ensure that questions reflect community priorities of people living with dementia and it could also enhance uptake of assessment tools. An important objective of DFCs is to ensure that the community needs of people with dementia are being met and respected, one way of doing that is by recognizing and respecting their human rights (Alzheimer's Disease International, 2016a); therefore, we encourage tool development to be guided by existing charters of rights for people with dementia (see, e.g., Charter of Rights for People with Dementia and their Carers in Scotland; Alzheimer Scotland, 2009; Canadian Charter of Rights for people with dementia; Alzheimer Society of Canada, 2018). In addition, only 14 of the tools included demographic questions, of which only

four included questions related to ethnic background (ACT on Alzheimer's, 2015; Darlington et al., 2020; Hamilton Council on Aging, 2020; Harder+Copmany Community Research, 2016). Individuals from ethnic minorities have been found to have higher prevalence of dementia (House of Commons All-Party Parliamentary Group on Dementia, 2013), to experience shame and stigma of dementia within their communities (Mukadam et al., 2011), and to be at a higher risk of underdiagnosis than white Caucasians (Tsoy et al., 2021). To ensure that DFC initiatives address the needs of ethnic minorities, we encourage that tools include demographic questions that capture participants' ethnic background. When analyzing the data, comparing responses by ethnicity would provide a better understanding of community needs of individuals from ethnic minorities. These results could be used to develop a targeted DFC action plan that adequately addresses the needs of ethnic minorities.

### ***Need for a dementia-friendly community framework***

The three domains not covered by any of the identified tools are also domains not included in the age-friendly community framework proposed by the World Health Organization (WHO; World Health Organization, 2007). Out of the dementia-specific domains included in this review, dementia awareness/attitudes and dementia-specific community activities/services are the two most often covered by the tools (covered in 20 and 14 tools, accordingly). However, the other dementia-specific domains (emergency planning and first response; independent living; financial services; legal and advanced care planning services; care throughout the continuum; and memory loss supports and services) are rarely or not at all covered. Research shows that not all age-friendly communities are necessarily dementia-friendly (Turner & Morken, 2016); therefore, tools meant to assess the degree to which communities are dementia-friendly need to expand beyond the eight age-friendly community domains proposed by the WHO. An absence of

an overarching framework equivalent to the one available for communities pursuing age-friendliness has resulted in communities around the world using various frameworks and approaches to develop their DFC initiative (Turner & Morken, 2016). Thus, a comprehensive DFC framework is needed to support a systematic approach to the development and assessment of DFC initiatives, including the development of a quantitative tool that captures all DFC domains identified in the framework.

It is worth noting that even though we did not include a domain associated with caregiver support, we acknowledge that it is important for DFC initiatives to consider enhancing supports for caregivers. Approximately 60% of people with dementia live at home and require support while living there (Canadian Institute for Health Information, 2018; Harrison et al., 2019). Caregivers of people with dementia have reported higher levels of stress than caregivers of persons with a physical disability (Ory et al., 1999; Sörensen & Conwell, 2011). Moreover, in a systematic review and meta-analysis (Toot et al., 2017), caregiver burden was found to be associated with an increased risk of nursing home placement for people with dementia. Given the significant impact that caregiver support has on dementia care and the health of the caregiver, we encourage the inclusion of questions related to availability and quality of existing caregiver services and supports in DFC assessment tools.

Although in this scoping review we focused on quantitative assessment tools, we believe that a mixed- methods approach (e.g., surveys and interviews) would provide the most comprehensive approach to the assessment of dementia-friendliness in a community. A qualitative assessment would complement quantitative data by capturing more rich information about the distinct cultural, ethnic and gender factors that impact the experience of living with dementia in the community. A mixed-methods approach also provides the opportunity to engage



people that may find it difficult to complete a quantitative assessment or that prefer to voice their opinions in other ways (such as through interviews), increasing accessibility and representation of participants.

### **Limitations**

This review was limited to English-language, peer-reviewed and grey literature. While a rigorous search method was performed, it is possible that relevant literature was missed. We limited our outreach to community representatives from primarily English-Speaking countries (Canada, the United States, the United Kingdom, Australia and New Zealand); it is possible that relevant community surveys in other countries or not known to our representatives were missed. Moreover, all the tools included in this review were developed in high income countries, which limits the transferability of the findings to low- and middle-income countries. The community needs of individuals with dementia who live in low-and middle-income countries may differ from the needs of people living in high-income countries, as well as types of DFC interventions that are implemented; different assessment tools may therefore be needed to assess the dementia-friendliness of those communities.

### **Conclusion**

In this scoping review we identified 40 tools that assess DFC features (built environment, dementia awareness and attitudes, and community needs). Thirty-four of the identified tools were found in the grey literature, suggesting that there is a lack of published peer-reviewed research on quantitative assessment tools to support the evaluation of dementia-friendliness of a community. None of the identified tools were deemed comprehensive enough for the assessment of community needs of people with dementia. In an effort to minimize the number of tools available and encourage a more systematic and strategic approach to the advancement of DFCs,

future research in this domain should be focused on adapting existing tools in order to include all DFC domains and on conducting psychometric testing to allow for comparisons to be made within and across communities. In addition, to ensure that tools developed are relevant, accessible and useful, we recommend the involvement of people with dementia in tool development; the inclusion of demographic questions that capture the diversity of community members; and the development of partnerships between researchers, people with dementia and national Alzheimer Society associations for the development, uptake and psychometric testing of the tools.

## References

- ACT on Alzheimer's. (2015). *Dementia Friendly Communities Toolkit: Community Needs Assessment*. <https://www.actonalz.org/assess>
- Alzheimer's Australia. (2014). *Living with dementia in the community: Challenges and opportunities*.  
[https://www.dementia.org.au/sites/default/files/DementiaFriendlySurvey\\_Final\\_web.pdf](https://www.dementia.org.au/sites/default/files/DementiaFriendlySurvey_Final_web.pdf)
- Alzheimer's Australia NSW. (2011). *Building Dementia and Age-Friendly Neighbourhoods*.  
<https://www.dementiaaction.org.uk/assets/0000/8251/20110803-NSW-PUB-DementiaFriendlyNeighbourhoods.pdf>
- Alzheimer's Disease International. (2016a). *Dementia Friendly Communities: Key Principles*.  
<https://www.alzint.org/u/dfc-principles.pdf>
- Alzheimer's Disease International. (2016b). *World Alzheimer Report 2016 Improving healthcare for people living with dementia coverage, Quality and costs now and In the future*.  
[www.daviddesigns.co.uk](http://www.daviddesigns.co.uk)
- Alzheimer's Disease International. (2017). *Dementia Friendly Communities: Global developments*. <https://www.alzint.org/u/dfc-developments.pdf>
- Alzheimer's Society UK. (2013). *Building dementia-friendly communities: A priority for everyone*.  
[https://actonalz.org/sites/default/files/documents/Dementia\\_friendly\\_communities\\_full\\_report.pdf](https://actonalz.org/sites/default/files/documents/Dementia_friendly_communities_full_report.pdf)
- Alzheimer's Society UK. (2017a). *Become a Dementia Friend*.  
<https://www.dementiafriends.org.uk/WEBArticle?page=become-dementia-friend>
- Alzheimer's Society UK. (2017b). *Dementia-Friendly Business Guide*.  
<https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/making-organisations-dementia-friendly/businesses>
- Alzheimer's Society UK. (2017c). *What is a Dementia Friends Champion?*  
<https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.X9fgSthKhPY>
- Alzheimer's WA. (2016). *Guidelines for the development of dementia-friendly communities: Alzheimer's WA dementia friendly communities audit and planning tool*.  
[https://www.alzheimerswa.org.au/wp-content/uploads/2018/05/Webready-DFC-guidelines-rebrand-July-2017\\_V2.pdf](https://www.alzheimerswa.org.au/wp-content/uploads/2018/05/Webready-DFC-guidelines-rebrand-July-2017_V2.pdf)
- Alzheimer Scotland. (2009). *Charter of Rights for People with Dementia and their Carers in Scotland*.  
[https://www.alzscot.org/sites/default/files/images/0000/2678/Charter\\_of\\_Rights.pdf](https://www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf)
- Alzheimer Society of British Columbia. (2016). *Dementia-friendly communities local government toolkit*. [https://archive.alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/dfc/dfc\\_toolkit\\_v.jan2016.pdf](https://archive.alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/dfc/dfc_toolkit_v.jan2016.pdf)
- Alzheimer Society of Canada. (2018). *Canadian charter of rights for people with dementia*.  
[https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as\\_charter-of-rights-for-people-with-dementia.pdf](https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as_charter-of-rights-for-people-with-dementia.pdf)
- Alzheimer Society of Saskatchewan. (2017). *Dementia friendly communities: Municipal Toolkit*.
- Alzheimers New Zealand. (2015). *Achieving a dementia friendly New Zealand*.  
<https://www.alzheimers.org.nz/getattachment/Who-We-Are/About-us/Alz-NZ-Strategy-Achieving-a-Dementia-Friendly-NZ.pdf/>

- Annear, M. J., Toye, C., Elliott, K. E. J., McInerney, F., Eccleston, C., & Robinson, A. (2017). Dementia knowledge assessment scale (DKAS): Confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, *17*(1). <https://doi.org/10.1186/s12877-017-0552-y>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory and Practice*, *8*(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Australian Health Ministers Advisory Council. (2015). *National Framework for Action on Dementia 2015-2019*. [https://www.health.gov.au/sites/default/files/documents/2020/01/national-framework-for-action-on-dementia-2015-2019\\_0.pdf](https://www.health.gov.au/sites/default/files/documents/2020/01/national-framework-for-action-on-dementia-2015-2019_0.pdf)
- Baker, J. R., Low, L. F., Goodenough, B., Jeon, Y. H., Tsang, R. S. M., Bryden, C., & Hutchinson, K. (2018). The Kids Insight into Dementia Survey (KIDS): development and preliminary psychometric properties. *Aging and Mental Health*, *22*(8), 947–953. <https://doi.org/10.1080/13607863.2017.1320703>
- Bartlett, R., & Brannelly, T. (2019). On being outdoors: How people with dementia experience and deal with vulnerabilities. *Social Science and Medicine*, *235*, 112336. <https://doi.org/10.1016/j.socscimed.2019.05.041>
- Biglieri, S. (2018). Implementing Dementia-Friendly Land Use Planning: An Evaluation of Current Literature and Financial Implications for Greenfield Development in Suburban Canada. *Planning Practice & Research*, *33*(3), 264–290. <https://doi.org/10.1080/02697459.2017.1379336>
- Bowen, M. E., Mckenzie, B., & Rowe, M. A. (2011). Prevalence of and antecedents to dementia-related missing incidents in the community. *Dementia and Geriatric Cognitive Disorders*, *31*, 406–412. <https://doi.org/10.1159/000329792>
- Breckler, S. J. (1984). Empirical validation of affect, behavior, and cognition as distinct components of attitude. *Journal of Personality and Social Psychology*, *47*(6), 1191–1205. <https://doi.org/10.1037/0022-3514.47.6.1191>
- Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., & Goodman, C. (2019). Dementia Friendly Communities in England: A scoping study. *International Journal of Geriatric Psychiatry*, *34*(8), 1235–1243. <https://doi.org/10.1002/gps.5123>
- Canadian Institute for Health Information. (2018). *Dementia in Canada*. <https://www.cihi.ca/en/dementia-in-canada>
- Catenbury District Health Board. (2015). *Developing a dementia-friendly Christchurch: Perspectives of people with dementia*. [https://ageconcerncan.org.nz/wp-content/uploads/2017/01/Developing\\_a\\_Dementia-Friendly\\_Christchurch.pdf](https://ageconcerncan.org.nz/wp-content/uploads/2017/01/Developing_a_Dementia-Friendly_Christchurch.pdf)
- Central Coast Council. (2017). *Dementia-friendly Central Coast Framework*. <https://www.centralcoast.tas.gov.au/wp-content/uploads/2017/10/Dementia-Friendly-Central-Coast-Framework.pdf>
- City of Burnaby. (2017). *Burnaby Dementia-Friendly Community Action Plan*. <https://www.burnaby.ca/Assets/Burnaby+Dementia-Friendly+Community+Action+Plan.pdf>
- City of New Westminister. (2016). *Dementia-Friendly Community Action Plan 2016*. [https://www.newwestcity.ca/database/files/library/City\\_of\\_New\\_West\\_Dementia\\_Friendly\\_Community\\_Action\\_Plan\\_Report\\_2016\\_8\\_2.pdf](https://www.newwestcity.ca/database/files/library/City_of_New_West_Dementia_Friendly_Community_Action_Plan_Report_2016_8_2.pdf)
- City of North Vancouver. (2016). *Dementia-friendly North Shore action plan*.

- <https://www.cnv.org/city-services/planning-and-policies/initiatives-and-policies/dementia-friendly-north-shore-action-plan#:~:text=The goal of the Dementia,as possible in our community.>
- City of Richmond. (2019). *Dementia-friendly community plan*.  
[https://www.richmond.ca/\\_\\_shared/assets/Dementia-Friendly\\_Community\\_Action\\_Plan\\_201954645.pdf](https://www.richmond.ca/__shared/assets/Dementia-Friendly_Community_Action_Plan_201954645.pdf)
- Community Partners in Action Innisfail. (2020). *Innisfail Dementia Friendly Community Questionnaire*.
- Courtney-Pratt, H., Mathison, K., & Doherty, K. (2018). Distilling authentic community-led strategies to support people with dementia to live well. *Community Development*, 49(4), 432–449. <https://doi.org/10.1080/15575330.2018.1481443>
- Curnow, E., Rush, R., Maciver, D., Górska, S., Forsyth, K., & Orska, S. G. (2019). Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis. *Aging & Mental Health*, 25, 397–407. <https://doi.org/10.1080/13607863.2019.1695741>
- Darlington, N., Arthur, A., Woodward, M., Buckner, S., Killest, A., Lafortune, L., Mathie, E., Mayrhofer, A., Thurman, J., & Goodman, C. (2020). A survey of the experience of living with dementia in a dementia-friendly community. *Dementia (London, England)*, 0(0), 1471301220965552. <https://doi.org/10.1177/1471301220965552>
- Dementia-Friendly Rotorua Steering Group. (2017). *Building a dementia-friendly community: First steps for a dementia-friendly Rotorua*.  
[https://www.rotorualakescouncil.nz/Rotorua2030/portfolios/people/Documents/Final\\_Dementia-friendly\\_Rotorua\\_Report.pdf](https://www.rotorualakescouncil.nz/Rotorua2030/portfolios/people/Documents/Final_Dementia-friendly_Rotorua_Report.pdf)
- Dementia Action Alliance. (n.d.). *Dementia Friendly Physical Environments Checklist*.  
[https://www.dementiaaction.org.uk/assets/0000/4336/dementia\\_friendly\\_environments\\_checklist.pdf](https://www.dementiaaction.org.uk/assets/0000/4336/dementia_friendly_environments_checklist.pdf)
- Dementia Australia. (2016). *Creating Dementia-Friendly Communities: A Toolkit for Local Governments*.  
<https://www.dementia.org.au/sites/default/files/NATIONAL/documents/Dementia-friendly-communities-toolkit-for-local-government.pdf>
- Dementia Australia. (2018). *Creating Dementia-Friendly Communities: Community Toolkit*.  
[https://www.dementiafriendly.org.au/sites/default/files/resources/The-Dementia-friendly\\_Community-Toolkit.pdf](https://www.dementiafriendly.org.au/sites/default/files/resources/The-Dementia-friendly_Community-Toolkit.pdf)
- Dementia Engagement and Empowerment Project. (2017a). *Is this inside public space dementia-inclusive? A checklist for use by dementia groups*. <https://www.dementiavoices.org.uk/wp-content/uploads/2017/09/Inside-checklist.pdf>
- Dementia Engagement and Empowerment Project. (2017b). *Is this outside public space dementia-inclusive? A checklist for use by dementia groups*.  
<https://www.dementiavoices.org.uk/wp-content/uploads/2017/09/Outside-checklist.pdf>
- Dementia Friendly America. (2015). <https://www.dfamerica.org/>
- Dementia Friendly Community Marinette. (2016). *Dementia Friendly Community Survey*.  
<http://dfcwi.com/dementia-friendly-community-survey/>
- Department of Health. (2015). *Prime Minister’s Challenge on Dementia 2020 Implementation Plan*. [www.nationalarchives.gov.uk/doc/open-government-licence/](http://www.nationalarchives.gov.uk/doc/open-government-licence/)
- Farina, M., Hughes, L., Griffiths, A., & Parveen, S. (2020). Adolescents’ experiences and perceptions of dementia. *Aging & Mental Health*, 24, 1175–1181.

- <https://doi.org/10.1080/13607863.2019.1613343>
- Farina, N., Griffiths, A. W., Hughes, L. J., & Parveen, S. (2020). Measuring adolescent attitudes towards dementia: The revalidation and refinement of the A-ADS. *Journal of Health Psychology*. <https://doi.org/10.1177/1359105320953479>
- Fleming, R., Bennett, K., Preece, T., & Phillipson, L. (2017). The development and testing of the dementia friendly communities environment assessment tool (DFC EAT). *International Psychogeriatrics*, 29(2), 303–311. <https://doi.org/10.1017/S1041610216001678>
- Førsund, L. H., Grov, E. K., Helvik, A. S., Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of lived space in persons with dementia: A systematic meta-synthesis. *BMC Geriatrics*, 18(1), 33. <https://doi.org/10.1186/s12877-018-0728-0>
- Gadotti, I., Vieira, E., & Magee, D. (2006). Importance and clarification of measurement properties in rehabilitation. *Revista Brasileira de Fisioterapia*, 10(2), 137–146. <https://doi.org/10.1590/s1413-35552006000200002>
- Gove, D., Diaz-Ponce, A., Georges, J., Moniz, E., Moniz-Cook, E., Mountain, G., Chattat, R., & Europe, A. (2017). Alzheimer Europe’s position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health*, 22(6), 723–729. <https://doi.org/10.1080/13607863.2017.1317334>
- Griffiths, A. W., Cheong, W. L., Saw, P. S., & Parveen, S. (2020). Perceptions and attitudes towards dementia among university students in Malaysia. *BMC Medical Education*, 20(1), 1–7. <https://doi.org/10.1186/s12909-020-1972-5>
- Griffiths, A. W., Parveen, S., Shafiq, S., & Oyebode, J. R. (2018). Development of the Adolescent Attitudes towards Dementia Scale (A-ADS). *International Journal of Geriatric Psychiatry*, 33(8), 1139–1145. <https://doi.org/10.1002/gps.4907>
- Hamilton Council on Aging. (2020). *Empowering Dementia-Friendly Communities: Hamilton, Haldimand*. [https://coahamilton.ca/wp-content/uploads/2021/06/HCOA\\_WWH\\_EN\\_June2021.pdf](https://coahamilton.ca/wp-content/uploads/2021/06/HCOA_WWH_EN_June2021.pdf)
- Harder+Copmany Community Research. (2016). *Age and Dementia Friendly Community Survey*. [https://extranet.who.int/agefriendlyworld/wp-content/uploads/2016/06/Age-and-Dementia-Friendly-San-Diego-Baseline-Survey-V2\\_Long-Version\\_20....pdf](https://extranet.who.int/agefriendlyworld/wp-content/uploads/2016/06/Age-and-Dementia-Friendly-San-Diego-Baseline-Survey-V2_Long-Version_20....pdf)
- Harrison, K. L., Ritchie, C. S., Patel, K., Hunt, L. J., Covinsky, K. E., Yaffe, K., & Smith, A. K. (2019). Care Settings and Clinical Characteristics of Older Adults with Moderately Severe Dementia. *Journal of the American Geriatrics Society*, 67(9), 1907–1912. <https://doi.org/10.1111/jgs.16054>
- Hebert, C. A., & Scales, K. (2019). Dementia friendly initiatives: A state of the science review. *Dementia: The International Journal on Social Research and Practice*, 18(5), 1858–1895. <https://doi.org/10.1177/1471301217731433>
- Heward, M., Innes, A., Cutler, C., & Hambidge, S. (2017). Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement. *Health & Social Care in the Community*, 25(3), 858–867. <https://doi.org/10.1111/HSC.12371>
- House of Commons All-Party Parliamentary Group on Dementia, S. (2013). *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*. [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg\\_2013\\_bame\\_report.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf)
- Husted, J. A., Cook, R. J., Farewell, V. T., & Gladman, D. D. (2000). Methods for assessing responsiveness: A critical review and recommendations. *Journal of Clinical Epidemiology*, 53(5), 459–468. [https://doi.org/10.1016/S0895-4356\(99\)00206-1](https://doi.org/10.1016/S0895-4356(99)00206-1)

- Innovations in Dementia. (2012). *Developing dementia-friendly communities: Learning and guidance for local authorities*.  
<https://www.local.gov.uk/sites/default/files/documents/developing-dementia-frien-411.pdf>
- Kerr, J., Rosenberg, D., & Frank, L. (2012). The Role of the Built Environment in Healthy Aging: Community Design, Physical Activity, and Health among Older Adults. *Journal of Planning Literature*, 27, 43–60. <https://doi.org/10.1177/0885412211415283>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5(1). <https://doi.org/10.1186/1748-5908-5-69>
- Lin, S., Marcus Lewis, F., & Williamson, J. (2015). *Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future*.  
<https://doi.org/10.1093/geront/gnu122>
- Lundquist, T. S., & Ready, R. E. (2008). Young adult attitudes about Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 23(3), 267–273.  
<https://doi.org/10.1177/1533317508317818>
- Miah, J., Dawes, P., Edwards, S., Leroi, I., Starling, B., & Parsons, S. (2019). Patient and public involvement in dementia research in the European Union: A scoping review. *BMC Geriatrics*, 19(1), 1–20. <https://doi.org/10.1186/s12877-019-1217-9>
- Milby, E., Murphy, G., & Winthrop, A. (2017). Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis. *Dementia: The International Journal of Social Research and Practice*, 16(5), 611–628.  
<https://doi.org/https://doi.org/10.1177/1471301215612676>
- Mitchell, L., & Burton, E. (2006). Neighbourhoods for life: A checklist of recommendations for designing dementia-friendly outdoor environments. *Quality in Ageing and Older Adults*, 7, 26–33.
- Morrisby, C., Joosten, A., & Ciccarelli, M. (2018). Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. *International Psychogeriatrics*, 30(1), 5–14.  
<https://doi.org/10.1017/S1041610217001491>
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26, 12–20.  
<https://doi.org/10.1002/gps.2484>
- National Alzheimer's and Dementia Resource Center. (2019). *Measuring the Impact of Dementia-Friendly Education and Training Session: A toolkit*.  
<https://nadrc.acl.gov/details?search1=172#result>
- O'Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the dementia attitudes scale. *International Journal of Alzheimer's Disease*.  
<https://doi.org/10.4061/2010/454218>
- Olsson, A., Lampic, C., Skovdahl, K., & Engström, M. (2013). Persons with early-stage dementia reflect on being outdoors: A repeated interview study. *Ageing and Mental Health*, 17(7), 793–800. <https://doi.org/10.1080/13607863.2013.801065>
- Ory, M. G., Hoffman III, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. *The Gerontologist*, 39(2), 177–185. <https://doi.org/10.1093/geront/39.2.177>
- Pai, M.-C., & Lee, C.-C. (2016). The Incidence and Recurrence of Getting Lost in Community-Dwelling People with Alzheimer's Disease: A Two and a Half-Year Follow-Up. *PLOS ONE*, 11(5), e0155480. <https://doi.org/10.1371/journal.pone.0155480>

- Peters, M., Godfrey, C., McInerney, P., Munn, Z., Tricco, A., & Khalil, H. (2020). Chapter 11: Scoping Reviews (2020 version). In E. Aromataris & Z. Munn (Eds.), *JBIM Manual for Evidence Synthesis*.
- Public Health Agency of Canada. (2019). *A dementia strategy for Canada: Together we aspire*. [https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National Dementia Strategy\\_ENG.pdf](https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National Dementia Strategy_ENG.pdf)
- Rao, V., & Woolcock, M. (2003). Integrating Qualitative and Quantitative Approaches in Program Evaluation. In F. Bourguignon & L. Pereira Da Silva (Eds.), *Evaluating the Poverty and Distributional Impact of Economic Policies: A General Introduction*. World Bank and Oxford University Press.
- Read, S. T., Wynaden, D., Albrecht, M. A., & Toye, C. (2020). Development of the dementia community attitudes questionnaire. *Dementia: The International Journal of Social Research and Practice*, 0(0), 147130122097764. <https://doi.org/10.1177/1471301220977649>
- Resciniti, N. V., Tang, W., Tabassum, M., Pearson, J. L., Spencer, S. M., Lohman, M. C., Ehlers, D. K., Al-Hasan, D., Miller, M. C., Teixeira, A., & Friedman, D. B. (2020). Knowledge evaluation instruments for dementia caregiver education programs: A scoping review. *Geriatrics & Gerontology International*, 20(5), 397–413. <https://doi.org/10.1111/ggi.13901>
- Rosenberg, M. J. (1960). *Attitude organization and change: An analysis of consistency among attitude components*. Yale University Press.
- Rossi, P., Lipsey, M., & Freeman, H. (2004). *Evaluation: A systematic approach* (7th ed.). Sage Publications, Inc.
- Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fetherstonhaugh, D., McInerney, F., Sinclair, C., & Detering, K. M. (2019). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. *Palliative Medicine*, 33(3), 274–290. <https://doi.org/10.1177/0269216318809571>
- Shanahan, N., Orrell, M., Schepers, A. K., & Spector, A. (2013). The development and evaluation of the DK-20: A knowledge of dementia measure. *International Psychogeriatrics*, 25(11), 1899–1907. <https://doi.org/10.1017/S1041610213001142>
- Shannon, K., Bail, K., & Neville, S. (2019). Dementia-friendly community initiatives: An integrative review. *Journal of Clinical Nursing*, 28(11–12), 2035–2045. <https://doi.org/10.1111/jocn.14746>
- Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. In *American Journal of Geriatric Psychiatry* (Vol. 19, Issue 6, pp. 491–496). Elsevier B.V. <https://doi.org/10.1097/JGP.0b013e31821c0e6e>
- Spector, A., Orrell, M., Schepers, A., & Shanahan, N. (2012). A systematic review of “knowledge of dementia” outcome measures. *Ageing Research Reviews*, 11(1), 67–77. <https://doi.org/10.1016/j.arr.2011.09.002>
- Sturge, J., Nordin, S., Sussana Patil, D., Jones, A., Légaré, F., Elf, M., & Meijering, L. (2021). Features of the social and built environment that contribute to the well-being of people with dementia who live at home: A scoping review. *Health and Place*, 67, 102483. <https://doi.org/10.1016/j.healthplace.2020.102483>
- Sullivan, K. A., & Mullan, M. A. (2017). Comparison of the psychometric properties of four dementia knowledge measures: Which test should be used with dementia care staff? *Australasian Journal on Ageing*, 36(1), 38–45. <https://doi.org/10.1111/ajag.12299>



- Teitelman, J., Raber, C., & Watts, J. (2010). The Power of the Social Environment in Motivating Persons with Dementia to Engage in Occupation: Qualitative Findings. *Physical & Occupational Therapy In Geriatrics*, 28(4), 321–333.  
<https://doi.org/10.3109/02703181.2010.532582>
- The Brenda Strafford Foundation. (2019). *Dementia Friendly Business Self-Assessment Checklist*. <https://www.dementiafriendlyalberta.ca/resources/templates-and-resources.html>
- Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *International Psychogeriatric Association*, 29(2), 195–208.  
<https://doi.org/10.1017/S1041610216001654>
- Tricco, A. C., Lillie, E., Zarin, W., O, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*, 169, 467–473. <https://doi.org/10.7326/M18-0850>
- Tsoy, E., Kiekhof, R. E., Guterman, E. L., Tee, B. L., Windon, C. C., Dorsman, K. A., Lanata, S. C., Rabinovici, G. D., Miller, B. L., Kind, A. J. H., & Possin, K. L. (2021). Assessment of Racial/Ethnic Disparities in Timeliness and Comprehensiveness of Dementia Diagnosis in California. *JAMA Neurology*, 78(6), 657–665.  
<https://doi.org/10.1001/JAMANEUROL.2021.0399>
- Turner, N., & Morken, L. (2016). *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*. <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2016/Better-Together-Research-Report.pdf>
- U.S. Department of Health and Human Services. (2018). *National Plan to Address Alzheimer's Disease: 2018 Update*. <https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf>
- Veritas Health Innovation. (n.d.). *Covidence systematic review software*. [www.covidence.org](http://www.covidence.org)
- Wendrich-van Dael, A., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *International Journal of Nursing Studies*, 107.  
<https://doi.org/10.1016/j.ijnurstu.2020.103576>
- World Health Organization. (2007). *Global Age-Friendly Cities: A Guide*. [www.who.int/ageing/publications/Global\\_age\\_friendly\\_cities\\_Guide\\_English.pdf](http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf)
- World Health Organization. (2017). *Global action plan on the public health response to dementia: 2017-2025*. <http://apps.who.int/bookorders>.
- World Health Organization. (2021). *Towards a dementia inclusive society*. <https://www.who.int/publications/i/item/9789240031531>
- Wu, S., Huang, H., Chiu, Y., Tang, L., Yang, P., Hsu, J., Liu, C., Wang, W., & Shyu, Y. L. (2019). Dementia-friendly community indicators from the perspectives of people living with dementia and dementia-family caregivers. *Journal of Advanced Nursing*, 75(11), 2878–2889. <https://doi.org/10.1111/jan.14123>

**Table 1. Tool Characteristics**

|  | Number of tools (%) | Citations  |
|--|---------------------|--|
| Type of tool                                   |                     |  |
| Checklist                                      | 18(45%)             | Alzheimer’s Australia NSW, 2011; Alzheimer’s Society UK, 2017b; Alzheimer’s WA, 2016; Alzheimer Society of British Columbia, 2016; Catenbury District Health Board, 2015; Dementia Action Alliance, n.d.; Dementia Australia, 2018; Dementia Engagement and Empowerment Project, 2017b, 2017a; Innovations in Dementia, 2012; Mitchell & Burton, 2006; The Brenda Strafford Foundation, 2019   |
| Survey   | 22(55%)             | ACT on Alzheimer’s, 2015; City of New Westminister, 2016; City of North Vancouver, 2016; Community Partners in Action Innisfail, 2020; Darlington et al., 2020; Dementia-Friendly Rotorua Steering Group, 2017; Dementia Australia, 2016; Dementia Friendly Community Marinette, 2016; Fleming et al., 2017; Griffiths et al., 2018; Hamilton Council on Aging, 2020; Harder+Copmany Community Research, 2016; National Alzheimer’s and Dementia Resource Center, 2019; Read et al., 2020; Wu et al., 2019 |
| Country where it was developed                 |                     |  |
| Canada   | 7(17.5%)            | Alzheimer Society of British Columbia, 2016; City of New Westminister, 2016; City of North Vancouver, 2016; City of Richmond, 2019; Community Partners in Action Innisfail, 2020; Hamilton Council on Aging, 2020; The Brenda Strafford Foundation, 2019   |
| The United States                              | 8(20%)              | ACT on Alzheimer’s, 2015; Dementia Friendly Community Marinette, 2016; Griffiths et al., 2018; Harder+Copmany Community Research, 2016; National Alzheimer’s and Dementia Resource Center, 2019  |
| The United Kingdom                             | 8(20%)              | Alzheimer’s Society UK, 2017b; Catenbury District Health Board, 2015; Darlington et al., 2020; Dementia Action Alliance, n.d.; Dementia Engagement and Empowerment Project, 2017a, 2017b; Innovations in Dementia, 2012; Mitchell & Burton, 2006   |
| Australia                                      | 14(35%)             | Alzheimer’s Australia NSW, 2011; Alzheimer’s WA, 2016; Central Coast Council, 2017; Dementia Australia, 2016, 2018; Fleming et al., 2017   |
| New Zealand                                    | 2(5%)               | Catenbury District Health Board, 2015; Dementia-Friendly Rotorua Steering Group, 2017  |
| Other  | 1(2.5%)             | Wu et al., 2019  |
| People with dementia involved tool development |                     |  |
| Yes  | 19(47.5%)           | Alzheimer’s Australia NSW, 2011; Alzheimer Society of British Columbia, 2016; City of New Westminister, 2016; City of North Vancouver, 2016; City of Richmond, 2019; Community Partners in Action Innisfail, 2020; Darlington et al., 2020; Dementia-Friendly Rotorua Steering Group, 2017; Dementia Australia, 2018; Dementia Engagement and Empowerment Project, 2017a, 2017b; Fleming et al., 2017; Hamilton Council on Aging, 2020; Mitchell & Burton, 2006; Wu et al., 2019                           |
| No   | 6(15%)              | ACT on Alzheimer’s, 2015; Griffiths et al., 2018; National Alzheimer’s and Dementia Resource Center, 2019  |
| Unknown  | 15(37.5%)           | Alzheimer’s Society UK, 2017b; Alzheimer’s WA, 2016; Catenbury District Health Board, 2015; Central Coast Council, 2017; Dementia Action Alliance, n.d.; Dementia Australia, 2016; Dementia Friendly Community Marinette, 2016; Harder+Copmany Community Research, 2016; Innovations in Dementia, 2012; The Brenda Strafford Foundation, 2019  |

|                             |           |   |
|-----------------------------|-----------|---|
| Target population           |           |   |
| People with dementia        | 15        | ACT on Alzheimer's, 2015; Central Coast Council, 2017; City of New Westminster, 2016; City of North Vancouver, 2016; City of Richmond, 2019; Community Partners in Action Innisfail, 2020; Darlington et al., 2020; Dementia-Friendly Rotorua Steering Group, 2017; Dementia Australia, 2016; Dementia Engagement and Empowerment Project, 2017a, 2017b; Fleming et al., 2017; Hamilton Council on Aging, 2020; Harder+Copmany Community Research, 2016; Wu et al., 2019  |
| Caregivers                  | 7         | ACT on Alzheimer's, 2015; Central Coast Council, 2017; City of North Vancouver, 2016; Community Partners in Action Innisfail, 2020; Dementia-Friendly Rotorua Steering Group, 2017; Hamilton Council on Aging, 2020; Wu et al., 2019  |
| General public              | 9         | ACT on Alzheimer's, 2015; Central Coast Council, 2017; Dementia Friendly Community Marinette, 2016; Harder+Copmany Community Research, 2016; National Alzheimer's and Dementia Resource Center, 2019; Read et al., 2020   |
| Other                       | 24        | ACT on Alzheimer's, 2015; Alzheimer's Australia NSW, 2011; Alzheimer's Society UK, 2017b; Alzheimer's WA, 2016; Alzheimer Society of British Columbia, 2016; Catenbury District Health Board, 2015; Dementia-Friendly Rotorua Steering Group, 2017; Dementia Action Alliance, n.d.; Dementia Australia, 2016, 2018; Fleming et al., 2017; Griffiths et al., 2018; Harder+Copmany Community Research, 2016; Innovations in Dementia, 2012; Mitchell & Burton, 2006; The Brenda Strafford Foundation, 2019; Wu et al., 2019 |
| Multiple audiences          | 9         | ACT on Alzheimer's, 2015; Central Coast Council, 2017; City of North Vancouver, 2016; Community Partners in Action Innisfail, 2020; Dementia-Friendly Rotorua Steering Group, 2017; Fleming et al., 2017; Hamilton Council on Aging, 2020; Harder+Copmany Community Research, 2016; Wu et al., 2019   |
| Tool developers             |           |   |
| Not-for-profit organization | 19(47.5%) | ACT on Alzheimer's, 2015; Alzheimer's Australia NSW, 2011; Alzheimer's Society UK, 2017b; Alzheimer's WA, 2016; Community Partners in Action Innisfail, 2020; Dementia Action Alliance, n.d.; Dementia Australia, 2016, 2018; Dementia Engagement and Empowerment Project, 2017a, 2017b; Innovations in Dementia, 2012; The Brenda Strafford Foundation, 2019   |
| Local government            | 9(22.5%)  | Catenbury District Health Board, 2015; Central Coast Council, 2017; City of New Westminster, 2016; City of North Vancouver, 2016; City of Richmond, 2019; Dementia Friendly Community Marinette, 2016; Hamilton Council on Aging, 2020  |
| Researchers                 | 12(30%)   | Alzheimer Society of British Columbia, 2016; Darlington et al., 2020; Dementia-Friendly Rotorua Steering Group, 2017; Fleming et al., 2017; Griffiths et al., 2018; Harder+Copmany Community Research, 2016; Mitchell & Burton, 2006; National Alzheimer's and Dementia Resource Center, 2019; Read et al., 2020; Wu et al., 2019   |

**Table 2. Summary of assessment tools included in the review**

| Assessment tool   | Domains<br>(Numbers in each cell represent the number of items within each DFC domain in the tool) |   |    |   |   |   |    |   |   |   |   |   |    |   |    |    |   | Number of Open-ended questions | Number of Demographic questions | Total number of questions in tool | Year |   |    |      |      |
|---|--|---|----|---|---|---|----|---|---|---|---|---|----|---|----|----|---|--------------------------------|---------------------------------|-----------------------------------|------|---|----|------|------|
|   | A  | B | C  | D | E | F | G  | H | I | J | K | L | M  | N | O  | P  | Q |                                |                                 |                                   |      | R |    |      |      |
| 1. Dementia-friendly community indicators (Wu et al., 2019)   | 4  |   | 8  | 4 |   |   | 3  |   |   |   |   |   | 1  | 9 |    |    | 3 | 1                              |                                 |                                   |      |   | 33 | 2019 |      |
| 2. A checklist for designing dementia-friendly outdoor environments (Mitchell & Burton, 2006)             |  |   | 48 |   |   |   |    |   |   |   |   |   |    |   |    |    |   |                                |                                 |                                   |      |   | 48 | 2006 |      |
| 3. Adolescent attitudes towards dementia scale (Griffiths et al., 2018)                                   |  |   |    |   |   |   | 23 |   |   |   |   |   |    |   |    |    |   |                                |                                 |                                   |      |   | 23 | 2017 |      |
| 4. Dementia friendly communities environment assessment tool (Fleming et al., 2017)                       |  |   |    |   |   |   |    |   |   |   |   |   |    |   | 37 |    |   |                                |                                 |                                   |      |   | 37 | 2017 |      |
| 5. National evaluation of dementia-friendly communities (Darlington et al., 2020)                         | 2  |   | 3  | 1 |   |   | 2  |   |   |   | 1 | 1 | 8  | 1 |    | 4  |   | 6                              |                                 |                                   |      | 5 | 8  | 42   | 2020 |
| 6. Dementia community attitudes questionnaire (Read et al., 2020)   |  |   |    |   |   |   | 10 |   |   |   |   |   |    |   |    |    |   |                                |                                 |                                   |      |   | 10 | 2020 |      |
| 7. Alzheimer's WA dementia friendly communities audit and planning tool (Alzheimer's WA, 2016)            |  |   |    |   |   |   | 14 |   |   |   |   |   | 8  | 6 | 18 |    |   |                                |                                 |                                   |      | 2 |    | 48   | 2016 |
| 8. Dementia Friendly Community Survey, Marinette (Dementia Friendly Community Marinette, 2016)            |  |   | 2  | 2 |   | 1 | 3  |   |   | 1 |   |   | 1  | 1 |    | 1  | 3 | 3                              |                                 |                                   |      | 1 | 5  | 24   | 2016 |
| 9. Age and dementia friendly community survey, San Diego (Harder+Copmany Community Research, 2016)        | 15   | 7 | 7  |   |   |   |    |   |   |   | 9 |   | 7  | 1 |    | 11 | 6 | 12                             |                                 |                                   |      | 1 | 21 | 97   | 2016 |
| 10. Is this outside public space dementia-inclusive? (Dementia Engagement and Empowerment Project, 2017b) |  |   | 55 |   |   |   |    |   |   |   |   |   |    |   |    |    |   |                                |                                 |                                   |      | 2 |    | 57   | 2017 |
| 11. Creating dementia-friendly communities: Outdoor areas and buildings (Dementia Australia, 2018)        |  |   | 19 |   |   |   |    |   |   |   |   |   |    |   |    |    |   |                                |                                 |                                   |      |   |    | 19   | 2018 |
| 12. Creating dementia-friendly communities: Indoor areas (Dementia Australia, 2018)                       |  |   |    |   |   |   |    |   |   |   |   |   |    |   | 19 |    |   |                                |                                 |                                   |      |   |    | 19   | 2018 |
| 13. Creating dementia-friendly communities: Social engagement (Dementia Australia, 2018)                  | 1  |   |    | 1 |   |   | 2  |   |   |   | 2 |   | 3  | 4 |    | 2  |   | 1                              |                                 |                                   |      |   |    | 16   | 2018 |
| 14. Creating dementia-friendly communities: Employment, volunteering and study (Dementia Australia, 2018) |  |   |    |   |   |   |    |   |   |   |   |   | 11 | 1 |    |    |   |                                |                                 |                                   |      |   |    | 12   | 2018 |
| 15. Is this inside public space dementia-inclusive? (Dementia Engagement and Empowerment Project, 2017a)  |  |   |    |   |   |   |    |   |   |   |   |   |    |   | 76 |    |   |                                |                                 |                                   |      | 2 |    | 78   | 2017 |

| Assessment tool  | Domains<br>(Numbers in each cell represent the number of items within each DFC domain in the tool) |   |    |    |   |   |    |   |   |   |    |   |    |    |    |    |   | Number of Open-ended questions | Number of Demographic questions | Total number of questions in tool | Year |      |      |
|--|--|---|----|----|---|---|----|---|---|---|----|---|----|----|----|----|---|--------------------------------|---------------------------------|-----------------------------------|------|------|------|
|  | A  | B | C  | D  | E | F | G  | H | I | J | K  | L | M  | N  | O  | P  | Q |                                |                                 |                                   |      | R    |      |
| 16. Dementia-friendly community questionnaire Rotorua (Dementia-Friendly Rotorua Steering Group, 2017) | 4  | 1 | 2  | 4  |   |   | 4  |   |   |   | 19 |   | 2  | 2  |    | 19 | 2 |                                | 1                               | 2                                 | 62   | 2017 |      |
| 17. Dementia-friendly outdoor environment checklist, BC (Alzheimer Society of British Columbia, 2016)  |  |   | 40 |    |   |   |    |   |   |   |    |   |    |    |    |    |   |                                |                                 |                                   | 40   | 2016 |      |
| 18. Good dementia-design checklist, Christchurch (Catenbury District Health Board, 2015)               |  |   | 15 |    |   |   |    |   |   |   |    |   |    |    |    |    |   |                                |                                 |                                   | 15   | 2015 |      |
| 19. Checklist for Transport Providers, Christchurch (Catenbury District Health Board, 2015)            | 6  |   |    |    |   |   |    |   |   |   |    |   |    |    |    |    |   |                                |                                 |                                   | 6    | 2015 |      |
| 20. Creating dementia-friendly communities: Outdoor environments (Dementia Australia, 2016)            | 1  |   | 14 |    |   |   |    |   |   |   |    |   |    |    |    |    |   |                                |                                 |                                   | 15   | 2016 |      |
| 21. Creating dementia-friendly communities: Indoor environments (Dementia Australia, 2016)             |  |   |    |    |   |   |    |   |   |   |    |   |    |    | 18 |    |   |                                |                                 |                                   | 18   | 2016 |      |
| 22. Creating dementia-friendly communities: Social engagement (Dementia Australia, 2016)               | 1  |   | 1  |    |   |   |    |   |   | 1 |    | 7 | 1  |    |    |    |   |                                |                                 | 3                                 | 14   | 2016 |      |
| 23. Dementia-friendly survey: community members (Dementia Australia, 2016)                             | 1  |   | 2  | 3  |   |   | 3  |   |   | 7 | 7  | 1 | 2  |    | 17 |    |   |                                |                                 | 1                                 | 1    | 45   | 2016 |
| 24. Dementia-friendly survey: Business (Dementia Australia, 2016)                                      |  |   |    |    |   |   | 9  |   |   |   |    |   |    |    | 1  |    |   |                                |                                 | 2                                 | 1    | 13   | 2016 |
| 25. Dementia-friendly Richmond Public Engagement Survey (City of Richmond, 2019)                       | 2  | 2 | 2  | 3  |   |   |    |   |   | 2 |    | 1 |    |    | 23 |    |   |                                |                                 | 6                                 | 7    | 48   | 2019 |
| 26. Community survey Central Coast (Central Coast Council, 2017)                                       | 1  |   |    | 2  |   |   | 31 |   |   | 2 |    | 2 |    |    |    |    |   |                                | 2                               | 4                                 | 13   | 57   | 2017 |
| 27. Dementia and age-friendly outdoor design checklist (Alzheimer's Australia NSW, 2011)               |  |   | 10 | 5  |   |   |    |   |   |   |    |   |    |    |    |    |   |                                | 2                               |                                   |      | 17   | 2011 |
| 28. Dementia friendly business self-assessment checklist (The Brenda Strafford Foundation, 2019)       |  |   | 3  |    |   |   | 5  |   |   |   |    | 3 |    | 49 |    |    |   |                                | 1                               |                                   |      | 61   | 2019 |
| 29. Community-needs assessment (ACT on Alzheimer's, 2015)  | 6  | 6 | 2  |    |   |   | 9  |   |   | 3 | 13 |   | 34 |    |    | 27 | 2 |                                | 7                               | 4                                 | 113  | 2015 |      |
| 30. Physical environment checklist (Alzheimer's Society UK, 2017b)                                     |  |   | 3  | 54 |   |   |    |   |   |   |    |   |    |    |    |    |   |                                |                                 |                                   |      | 57   | 2017 |
| 31. Dementia-Friendly North Shore: Public Perception Survey (City of North Vancouver, 2016)            |  | 1 | 1  |    |   |   | 2  |   |   | 1 |    |   | 1  |    |    |    |   |                                | 2                               | 2                                 | 10   | 2016 |      |
| 32. Dementia-friendly New West community survey (City of New Westminister, 2016)                       | 7  |   | 1  |    |   |   | 2  |   |   | 1 |    | 1 | 1  |    |    |    |   |                                | 14                              | 8                                 | 35   | 2016 |      |

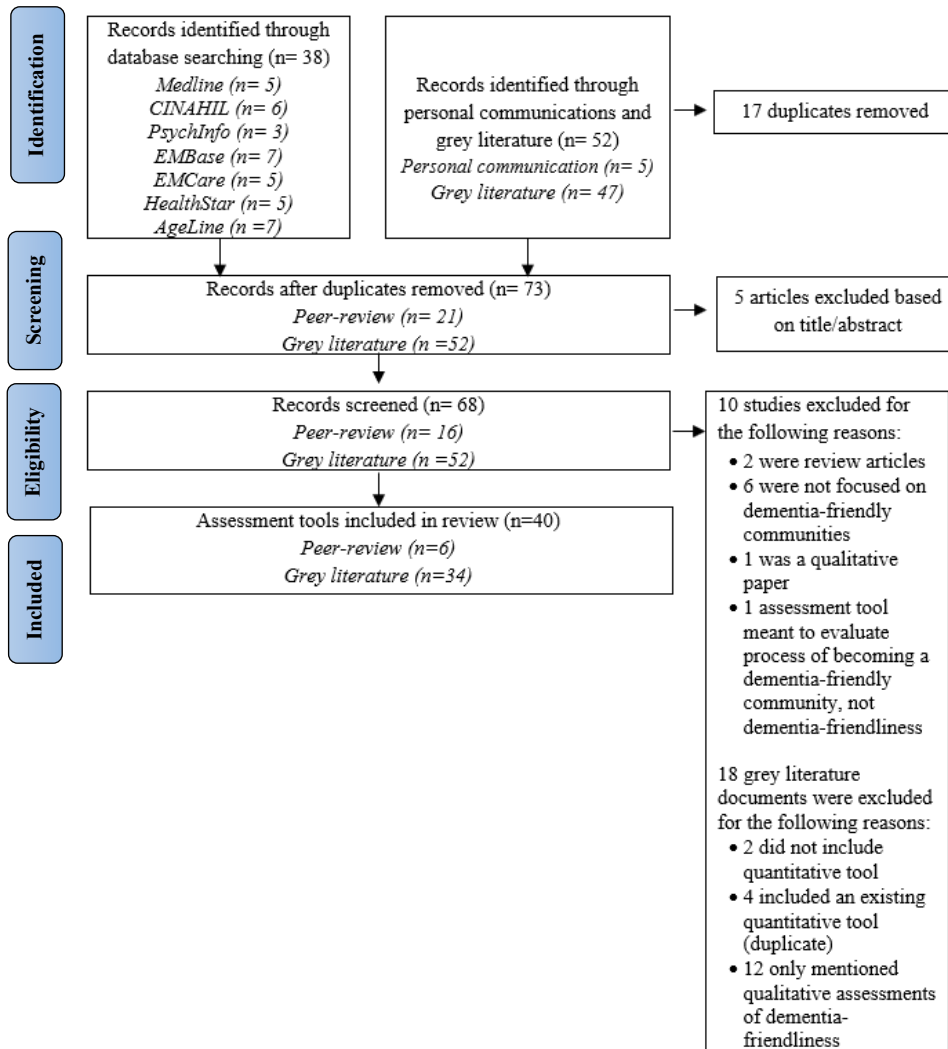
| Assessment tool   | Domains<br>(Numbers in each cell represent the number of items within each DFC domain in the tool) |   |   |   |   |   |    |   |   |   |   |   |   |   |    |   |   | Number of Open-ended questions | Number of Demographic questions | Total number of questions in tool | Year |      |
|---|--|---|---|---|---|---|----|---|---|---|---|---|---|---|----|---|---|--------------------------------|---------------------------------|-----------------------------------|------|------|
|   | A  | B | C | D | E | F | G  | H | I | J | K | L | M | N | O  | P | Q |                                |                                 |                                   |      | R    |
| 33. Empowering dementia-friendly communities, Hamilton, Haldimand- Public Consultations (Hamilton Council on Aging, 2020)   | 1  | 2 | 2 | 5 |   |   |    |   |   | 5 | 4 |   | 5 | 4 |    | 5 | 1 | 4                              | 4                               | 2                                 | 44   | 2020 |
| 34. Checklist for dementia-friendly environments (Innovations in Dementia, 2012)  |  |   |   |   |   |   |    |   |   |   |   |   |   |   | 15 |   |   |                                |                                 |                                   | 15   | 2012 |
| 35. Dementia Friendly Physical Environments Checklist (Dementia Action Alliance, n.d.)  |  |   |   |   |   |   |    |   |   |   |   |   |   |   | 20 |   |   |                                |                                 |                                   | 20   | N/A  |
| 36. Innisfail Dementia Friendly Community Questionnaire (Community Partners in Action Innisfail, 2020)  |  |   |   |   |   |   | 6  |   |   |   | 4 |   |   |   |    | 1 |   | 1                              | 2                               | 4                                 | 18   | 2020 |
| 37. Brief Tool for Dementia-Friendly Education and Training Sessions- Individual Trainings: Pre-Workshop Questions (National Alzheimer's and Dementia Resource Center, 2019)                |  |   |   |   |   |   | 7  |   |   |   |   |   |   |   |    |   |   |                                |                                 |                                   | 7    | 2019 |
| 38. Brief Tool for Dementia-Friendly Education and Training Sessions- Individual Trainings: Post-Workshop Questions (National Alzheimer's and Dementia Resource Center, 2019)               |  |   |   |   |   |   | 16 |   |   |   |   |   |   |   |    |   |   |                                | 1                               |                                   | 17   | 2019 |
| 39. Brief Tool for Dementia-Friendly Education and Training Sessions- Organizational or Sector Trainings: Pre-Workshop Questions (National Alzheimer's and Dementia Resource Center, 2019)  |  |   |   |   |   |   | 7  |   |   |   |   |   |   |   |    |   |   |                                |                                 | 1                                 | 8    | 2019 |
| 40. Brief Tool for Dementia-Friendly Education and Training Sessions- Organizational or Sector Trainings: Post-Workshop Questions (National Alzheimer's and Dementia Resource Center, 2019) |  |   |   |   |   |   | 19 |   |   |   |   |   |   |   |    |   |   |                                | 1                               |                                   | 20   | 2019 |

DFC domains: A) Transportation, B) Housing, C) Outdoor spaces and buildings, D) Businesses, E) Legal and advanced care planning services, F) Financial services, G) Dementia awareness/attitudes, H) Care throughout the continuum, I) Memory loss supports and services, J) Emergency planning and first response, K) Respect and social inclusion, L) Independent living, M) Civic participation and engagement, N) Dementia-specific community activities/services, O) Indoor spaces, P) Participation in leisure activities, Q) Healthcare, R) Communication and information.

**Table 3. Summary of studies that have used identified tools**

| <b>Authors</b>                       | <b>Year</b> | <b>Title</b>   | <b>Aim</b>   | <b>Sample</b>   | <b>Setting</b>  | <b>Tool used</b>         |
|--------------------------------------|-------------|--|--|---|---|--------------------------|
| Biglieri.                            | 2018        | Implementing dementia-friendly land use planning: An evaluation of current literature and financial implications for Greenfield development in suburban Canada | To validate the build environment recommendations made by Burton & Mitchel (2006) through planning and dementia literatures, as well as through financial feasibility and planning policy implementation analysis. | Planning and dementia literatures. Financial feasibility was assessed using pro forma analysis. | Town of Whitby, a midsize suburban municipality in Ontario, Canada. | Mitchell & Burton (2006) |
| Farina, Hughes, Griffiths & Parveen. | 2020        | Adolescents' experiences and perceptions of dementia   | To evaluate the impact of a Dementia Friends class (a 6-minute interactive class about dementia) on adolescents' experiences and perceptions of dementia.  | Adolescents in school years 9-13 (typically aged 13-18)   | Four schools across Sussex, England                                 | Griffiths et al. (2018)  |
| Griffiths, Cheong, Saw & Parveen.    | 2020        | Perceptions and attitudes towards dementia among university students in Malaysia   | To evaluate the impact of a one-hour education session for pharmacy and medicine undergraduate students.   | Pharmacy and medicine undergraduate students.   | University in Malaysia.   | Griffiths et al. (2018)  |
| Farina, Griffiths, Hughes & Parveen. | 2020        | Measuring adolescent attitudes towards dementia: The revalidation and refinement of the A-ADS  | To further validate the A-ADS and to investigate if it was possible to reduce the number of items in the A-ADS without affecting its validity.   | Adolescents (ages 13-18) attending secondary schools.   | South East England secondary schools.                               | (Griffiths et al., 2018) |

**Figure 1. PRISMA diagram of scoping review process**





### CHAPTER THREE

TITLE: Engagement of Persons with Dementia in Public Consultations: Process Evaluation

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## **Abstract**

When developing dementia-friendly communities (DFCs), engaging persons living with dementia in public consultations is critical. However, due to a lack of resources and expertise in how to support the involvement of this group, persons living with dementia are not always included in the development and implementation of DFC initiatives. To better understand processes and methods that facilitate the engagement of persons living with dementia in public consultations, we evaluated the public consultation processes of a Canadian DFC initiative. A partially mixed-methods sequential equal status design guided this process evaluation. Data sources included surveys completed by public consultation participants, focus groups with the group members who led the public consultation process, and the report outlining consultation findings. Study results highlight the strengths and limitations of public consultations, offer recommendations for engaging persons living with dementia in public consultations, and emphasize the importance of including persons living with dementia in DFC initiatives as project partners and public consultation participants.

*Keywords:* dementia-friendly communities, public engagement, dementia, evaluation, people living with dementia, community engagement

## Introduction

It is estimated that over half a million Canadians currently live with dementia, and this number is expected to almost double by 2033 (Chambers et al., 2016). While dementia can shorten the lives of persons living with the disease, its greatest impact is on quality of life, both for the individual with dementia and their caregiver(s) (Alzheimer's Disease International, 2016). Dementia-friendly communities (DFCs) are emerging as a promising approach to help improve quality of life for persons with dementia and their caregivers (World Health Organization, 2021). A DFC is defined by Alzheimer's Disease International (2016) as "a place where people living with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential" (p. 10). Public consultations with persons living with dementia are central to the development of a DFC, as these individuals' perspectives can help identify community needs, barriers to participation in community life, and strategies for making a community dementia friendly. In this paper, the term "public consultations" refers to the process of gathering information about the views and opinions of the public (e.g., persons living with dementia) so that they can be incorporated in the development of law, policy, and/or programs (Government of Canada, 2022). Public consultations may include public opinion surveys, citizen panels, focus groups, and interviews (Rowe & Frewer, 2000).

Reshaping communities through public engagement is a citizenship right (Biglieri, 2021). In relation to dementia, Bartlett and O'Connor (2010) defined social citizenship as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social position and the

upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (p. 37)

As suggested by this definition, citizenship and rights are interconnected. In the Canadian Charter of Rights for People with Dementia (Alzheimer Society of Canada, n.d.), persons living with dementia have the right to “participate in developing policies that affect [their] life” (Right number two). One of the ways stakeholders working on DFC initiatives can uphold this right is by engaging persons living with dementia in the initiatives’ planning processes, both as project partners<sup>1</sup> and as participants<sup>2</sup> in activities developed by initiative leaders. Although the involvement of persons living with dementia has been identified as a key principle in the development and implementation of DFC initiatives (Alzheimer’s Disease International, 2016; World Health Organization, 2021), due to a lack of resources and expertise in how to support their involvement, persons living with dementia are not always involved in these planning processes (Mathie et al., 2022) or consulted about their needs (Buckner et al., 2019). For example, in a scoping review of DFCs in England, of the 100 examined DFCs, only 27 reported consulting with persons living with dementia about DFC priorities (Buckner et al., 2019). Similarly, Mathie et al. (2022) described the engagement of persons living with dementia in DFC initiatives across England as “valued consumers of DFC services rather than partners and opinion leaders” (p. 14), with limited evidence of coproduction within DFCs.

Although best practices have not been developed for conducting public consultations with persons living with dementia, ample information and recommendations exist for involving

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<sup>1</sup> When persons living with dementia are involved in the design, delivery, and management of the DFC initiative, they are being engaged as partners.

<sup>2</sup> When persons living with dementia participate in activities developed by those leading the DFC initiative (such as sharing their views during a consultation process or contributing data in other ways), they are being engaged as participants.

persons living with dementia as research participants (see, e.g., Cridland et al., 2016; Novek & Wilkinson, 2019; Phillipson & Hammond, 2018). Examples of such recommendations include providing options for the location and format of the engagement method (e.g., interview, focus group, arts-based project; Novek & Wilkinson, 2019) and ensuring that team members are knowledgeable about dementia (Cridland et al., 2016). Additionally, in a scoping review by Phillipson and Hammond (2018), photo elicitation, ethnographic observation, visual and sensory adaptations to interviews, and participatory techniques that included hands-on involvement were identified as frequently used qualitative methods for engaging persons living with dementia as research participants. Similarly, Webb et al. (2020) have recommended allocating time for relationship building with persons living with dementia in research protocols and considering the use of qualitative methods when engaging persons living with dementia as research participants. Lastly, flyer distribution, newspaper stories, and word of mouth have been identified as the most successful strategies for recruiting persons living with dementia and caregivers for research studies (Beattie et al., 2018; Leach et al., 2016). Recommendations such as these could be used by stakeholders working on DFC initiatives to inform the engagement of persons living with dementia in different project activities, such as public consultations.

In our literature review, we found little guidance about methods that support the engagement of persons living with dementia in public consultations. To better understand processes and methods that facilitate the engagement of persons living with dementia in public consultations, in this study we conducted a process evaluation of a Canadian DFC initiative's public consultations. The aim of the public consultations was to gather information to inform the development of community action plans to improve the social inclusion and quality of life for persons with dementia in two communities: the City of Hamilton and Haldimand County, Ontario. The public

consultations took place during the COVID-19 pandemic, thus stakeholders relied on communication technology (e.g., video calls, online surveys, and phone calls) for the community engagement process. Our evaluation was conducted to assess the effectiveness of the engagement methods employed to conduct the public consultations and to develop recommendations for engaging persons living with dementia in such consultations. The process evaluation helped the research team answer three research questions:

1. What was the effectiveness of the public consultation engagement methods and processes employed to engage persons impacted by dementia to learn about their community needs?
2. What were the benefits and challenges of using communication technologies to conduct public consultations remotely with persons living with dementia?
3. What should stakeholders working on a DFC initiative consider when engaging persons living with dementia in public consultations?

Since all aspects of the public consultation process could impact the outcome of the public consultations (e.g., who is engaged in the consultations and the information gleaned from consultations), in this evaluation, we took into consideration the entire process (i.e., from the development of the funding proposal for the project to the outcome of the consultations).

## **Methods**

For context, we first provide an overview of the Empowering Dementia-Friendly Communities–Hamilton and Haldimand (EDFC-HH) project, followed by a description of the public consultation process undertaken by the EDFC-HH team. We then describe the methods used to evaluate that process.

## **Public Consultations**

EDFC-HH is a 3-year project (2020–23) funded by the Public Health Agency of Canada. The goal of the project is to compare the development and implementation of DFC initiatives in Hamilton and Haldimand County, Ontario. Because of the COVID-19 pandemic, consultations with persons living with dementia and caregivers to learn about their community needs were conducted entirely with communication technologies (telephone, online surveys and Zoom). The COVID-19 pandemic has highlighted the importance of access to and the ability to use communication technologies; however, technology alone is insufficient for reaching vulnerable populations (Xie et al., 2020). The “digital divide” refers to gaps in access to information and communication technologies between different groups of people (Van Dijk, 2006). Four factors have been found to affect whether a person (with or without a disability) will use information and communication technologies such as cell phones, computers, and laptops: motivation to use technology, access to technology, knowledge of how to use technology, and ability to use technology (Van Dijk, 2006). As a result of the program's necessary reliance on communication technologies, individuals who had access to and were able to use the internet, a phone, a tablet, and/or a computer were the ones engaged in the public consultations.

A task-focused working group planned, organized, and drove the various activities of the public consultations. The working group was composed of nine people, including two persons living with dementia (serving as project partners), three researchers, two health care providers, and two community partners (representatives from a local senior center and the local regional geriatric program).

## **Public Consultation Engagement Methods**

The public consultations took place between June and October 2020 and consisted of one-on-one interviews and an online survey. The aim of the public consultations was to gather insights and perspectives from persons living with dementia and caregivers about the experiences of and challenges faced by persons living with dementia in Hamilton and Haldimand. Thus, caregivers were asked what they thought persons living with dementia in their community needed; they were not asked about their own community needs. To participate in the public consultations, individuals had to (a) identify as living with dementia and reside in either Hamilton or Haldimand or (b) identify as a caregiver for a person with dementia living in either Hamilton or Haldimand. Participants did not require a formal dementia diagnosis to participate in the public consultations. The outcomes of the public consultations are summarized in the Hamilton Council on Aging's (HCoA; 2021) report *What We Heard*.

### ***One-on-One Interviews***

Seventy-one interviews (with 54 caregivers and 17 persons living with dementia) were conducted in the summer of 2020. Participants were given the option to be interviewed over the phone or through Zoom. Sixty-nine participants chose a telephone interview, and two chose a video call. Empathy interviewing techniques (Nelsestuen & Smith, 2020) guided the development of the semistructured interview guide. Empathy interviewing is typically used in design thinking (Razzouk & Shute, 2012) to explore the experiences, challenges, and motivations of people (Köppen & Meinel, 2015). Questions for persons living with dementia included “Would you share one thing that you like to do in the community?” Questions for caregivers included “Would you like to share one thing that [the person you are caring for] likes to do in the community?”

### ***Online Survey***



To build on interview responses, in the fall of 2020, an online survey was made available for persons living with dementia and caregivers living in Hamilton and Haldimand. The survey questions were informed by the eight age-friendly community domains outlined in the framework developed by the World Health Organization (WHO; 2007): communication and information, social participation, respect and social inclusion, transportation, housing, civic participation and employment, outdoor spaces and buildings, and community support and health services. The survey included at least one question per domain. For example, the question “My community/local area is accessible as I can travel around without challenges (*disagree, agree, I don't know*)” assessed the transportation domain. Additionally, open-ended questions, such as “What would make it easier for people with dementia to participate more fully in community life?”, aimed to gather insights about the experiences of and challenges faced by persons living with dementia. Participants were given the option to complete the survey online or to have a print copy mailed to them. Sixteen persons living with dementia and 218 caregivers responded to the online survey.

### **Public Consultation Recruitment Strategies**

Specific strategies were used to recruit participants for the interviews and for the online survey. The agency funding the project restricted the EDFC-HH team from publicly speaking about it until the funder had formally announced its funded projects. However, in order to adhere to proposed timelines, recruitment of potential interviewees needed to start before this announcement. Therefore, a public recruitment campaign was not undertaken for the interviews, and instead, initiative partners and direct service providers identified and approached potential interviewees directly. Initiative partners and direct service providers then shared potential

interviewees' contact information with the EDFC-HH project coordinator with the participants' consent.

In August 2020, once the funding agency announced its funded projects, the working group was able to turn to public strategies to recruit participants for the online survey. In October 2020, a private-sector marketing firm undertook a 3-week public campaign to promote the online survey. Other recruitment strategies included direct outreach to community organizations, paid print and online advertising, an editorial, a social media campaign, and newspaper articles. The newspaper articles consisted of a three-part series about living with dementia (Iqbal, 2020b, 2020c, 2020d) and two articles about the EDFC-HH project and the online survey (Fehr, 2020; Iqbal, 2020a). Additionally, to encourage the participation of diverse and marginalized communities (e.g., Indigenous Peoples, ethnocultural groups, and the LGBTQ2S+ community), over 300 diverse community-based and health organizations, faith community groups, and advocacy groups were informed about the EDFC-HH project and invited to complete the survey. All recruitment materials were available in English and in French.

### **Process Evaluation Methods**

The research team that conducted the present process evaluation included a human rights and anti oppression researcher, a health services researcher, and rehabilitation sciences researchers with backgrounds in occupational therapy, bioethics, and gerontology. Rowe and Frewer's (2000) framework for evaluating public engagement guided this process evaluation. We chose this framework because its proposed criteria aligned with the research questions. It also provided guidance for determining whether processes used in the public consultations were equitable and effective in engaging persons of varied backgrounds impacted by dementia. This

evaluation considered seven criteria from the framework that most closely aligned with the research questions:

- Representativeness: Participants in the public consultation should comprise a broadly representative sample of the population of interest.
- Independence: The consultation process should be conducted in an independent, unbiased way.
- Early involvement: The public should be involved as early as possible in the consultation process.
- Influence: The output of the consultation process should have a genuine impact on policy/programming/intervention.
- Transparency: The public should have access to information about the process and decisions being made.
- Resource accessibility: Participants should be provided with various ways to participate in the consultations.
- Task definition: The nature and scope of the consultation should be clearly defined.

Two criteria proposed by Rowe and Frewer (2000) were not included in our process evaluation. First, *structured decision-making* was not evaluated, as the outcome of the public consultations was a summary of participants' community experiences and not decisions about DFC action plans. Second, *cost-effectiveness* was not evaluated, as the cost of the public consultations did not address any of the research questions.

### **Process Evaluation Data Sources**

This process evaluation was guided by a partially mixed-methods sequential equal status design (Leech & Onwuegbuzie, 2009). Unlike a fully mixed-methods design in which data are

mixed throughout the research process, in this type of research design, the quantitative and qualitative phases of the project have equal weight and are conducted sequentially, the data sets are analyzed separately, and mixing takes place at the interpretation stage (Leech & Onwuegbuzie, 2009). Data sources for this process evaluation included process satisfaction surveys completed by individuals who participated in the public consultations, transcripts of focus groups with members of the working group, the *What We Heard* report (HCoA, 2021), and the proposal to the funding agency. Figure 1 summarizes the study timeline and research design.

**[Insert Figure 1 here]**

### ***Quantitative Data: Process Satisfaction Surveys***

Processes and outcomes of all phases of the EDFC-HH project are being evaluated for quality improvement purposes, and these evaluation components are to continue until the project's completion. Two process satisfaction surveys that reflected the two consultation formats—the interview process satisfaction (IPS) survey and the online survey process satisfaction (OSPS) survey—were developed as part of this quality improvement initiative (i.e., a standardized method was not used). Two persons living with dementia were involved in the development of the surveys. Additionally, the surveys were pilot tested with five individuals: one person living with dementia and four caregivers. For this process evaluation, the research team used survey results to conduct secondary data analyses.

Following their participation in the public consultations, participants were asked if they were interested in providing feedback about their experience by completing a process satisfaction survey. Individuals who expressed an interest in completing the process satisfaction survey were emailed a survey or had one delivered via postal delivery service as applicable.

The IPS survey consisted of 14 questions, including “I felt like I could speak freely (*agree/neutral/disagree*).” The OSPS survey consisted of 15 questions, including “Did you have any difficulties completing the survey? (*yes/no*).” Additionally, both surveys included nine demographic questions related to respondent group (person living with dementia, caregiver), geographic location, residence, living situation, gender, and identification as Indigenous or a visible minority.

Data from nine of the 14 questions on the IPS survey and 12 of the 15 questions on the OSPS survey were included in this process evaluation study, as were the demographic questions. The selection of the questions used for this evaluation was guided by Rowe and Frewer’s (2000) framework and by the research objectives. Table 1 provides a summary of the criteria and corresponding survey questions.

**[Insert Table 1 Here]**

A total of 103 people completed a process satisfaction survey. Of the 71 individuals who participated in the one-on-one interviews, 62 (87%) expressed interest in completing the IPS survey, and 53 (86%) completed it ( $\alpha = .82$ ). Of the 234 individuals who completed the online survey, 81 (34.6%) expressed interest in completing the OSPS survey, and 50 (62.5%) completed it ( $\alpha = .83$ ). Descriptive information on the process satisfaction survey respondents is summarized in Table 2.

**[Insert Table 2 here]**

### ***Qualitative Data: Focus Groups***

Working group members (the task-focused group that planned, organized, and drove the various aspects of the public consultation) and the two individuals who conducted the interviews

were invited to participate in one or more of the following focus groups based on their expertise and role in the public consultations.

1. Focus Group A: All members of the working group were invited to participate in a focus group to share their insights about the strengths and limitations of the processes used to conduct the public consultations. Focus group participants were asked eight questions, including “Could you give me an example of how participants were enabled to share their thoughts?” Focus group participants were also asked if they had any recommendations for other stakeholders interested in conducting public consultations with persons living with dementia.
2. Focus Group B: An important element of the consultation process was inclusion of persons living with dementia as project partners. We invited the two working group members living with dementia to a focus group to share their experiences as project partners and their perceptions of how their inclusion affected the consultation process. Focus group participants were asked seven questions, including “Were people living with dementia meaningfully engaged throughout the consultation process? Please explain.”
3. Focus Group C: The two interviewers and the two working group members who supervised and created materials for the interviews were invited to share their experiences with the interview process and their insights about the benefits and challenges of using empathy interviewing. Focus group participants were asked six questions, including “What were the benefits and challenges of the empathy interviewing approach?”

The first author (LGD) conducted the focus groups. LGD is also a member of the working group; therefore, she had an insider’s perspective of the public consultation process.

### ***Other Data Sources***

In the project's proposal as submitted to the Public Health Agency of Canada, it was outlined that the public consultations would target at least 300 individuals affected by dementia, with at least 100 from the Haldimand region and 200 from Hamilton. These numbers were used to assess whether participation targets were met. Additionally, the HCoA's (2021) *What We Heard* report was used to assess the implications of the consultations (i.e., influence) and whether representativeness was achieved. Table 3 provides a summary of which data sources were used to assess each evaluation criterion.

**[Insert Table 3 here]**

### **Data Analysis Strategy**

Qualitative (focus groups) and quantitative (process satisfaction surveys) information was equally important in addressing the research questions. The quantitative measures were used to gather information about public consultation participants' demographic characteristics (representativeness), their satisfaction and comfort with the methods employed to engage them (resource accessibility and independence), and their understanding of how their responses would support the overall project (task definition). The qualitative data were used to assess working group participants' perceptions of the strengths and limitations of the public consultations (early involvement, resource accessibility, and independence) and their recommendations for conducting public consultations with persons impacted by dementia. Both quantitative and qualitative data were used to assess the benefits and challenges of relying on communication technology for the public consultations.

For the quantitative information (process satisfaction surveys), descriptive statistics (means, standard deviations, frequencies) were generated for numeric variables. Pearson chi-square tests for independence were used to examine differences in process satisfaction survey

responses between individuals who participated in the interview and online survey. For questions using a 5-point Likert scale, response choice categories were combined to create three categories: *agree* (*strongly agree* and *agree* combined), *neutral*, and *disagree* (*strongly disagree* and *disagree* combined). Significance level was set at  $p < 0.05$ . All statistical analyses were completed using STATA/IC 16.

For the qualitative information (focus groups), audio recordings were transcribed by the first author (LGD), and all identifiable information was removed in the transcription process. Focus group data were analyzed using deductive content analysis (Elo et al., 2014). Deductive content analysis is used when the structure of the analysis is operationalized on the basis of a framework or previous knowledge (Elo et al., 2014). Rowe and Frewer's (2000) evaluation criteria were used to develop a categorization matrix in which each evaluation criterion was a "category" (Elo & Kyngäs, 2008). Data were coded for correspondence with evaluation criteria (refer to Table 3). For example, a focus group comment that "We [the working group] could have offered people the option of having a telephone interview instead of the survey" was coded as corresponding to resource accessibility, as it related to formats available to participate in the public consultations. Based on the results, LGD and LL assessed to what extent the public consultations achieved each evaluation criterion (i.e., criterion achieved, not achieved, or partially achieved).

To ensure accuracy and trustworthiness of findings, member checking with focus group participants was used as part of the data analysis. Participants were asked to review a provided summary of the results based on their own experience with the consultation process. Three individuals provided feedback. Most of the feedback pertained to the recommendations for other



community stakeholders interested in conducting public consultations with persons living with dementia. The recommendations were updated accordingly.

### **Ethical Approval**

This study was approved by the Hamilton Integrated Research Ethics Board (Project 13321). The focus groups were conducted using the Zoom platform. Focus group participants were provided with an information letter and a consent form a week prior to the focus group and were asked to email LGD their signed consent form before the meeting. Prior to starting the focus group, LGD read the consent form and gave participants the opportunity to ask questions. Verbal consent to participate in the study and record the videoconference was obtained from all participants prior to starting the focus group. Only the audio recordings were used for this study. Completion of process satisfaction surveys constituted implied consent.

### **Results**

A total of four focus groups were conducted:

- Focus Group A (working group members' insights about the strengths and challenges of processes used to conduct the public consultations): Ten working group members participated in one of two focus groups (five participants per group).
- Focus Group B (insights from working group members living with dementia about their experiences as project partners): Two working group members living with dementia participated in Focus Group B.
- Focus Group C (insights about the benefits and challenges of empathy interviewing from the individuals involved in the interview process): Two working group members and the two individuals who conducted the interviews (the interviewers were not working group

members) participated in Focus Group C. One of the working group members who participated in this focus group did not participate in Focus Group A.

Three individuals participated in more than one focus group. Although there is a risk that these individuals' opinions may be weighted more heavily than those of other participants, the use of different questions in each focus group was intended to mitigate potential overrepresentation of individuals who participated in more than one focus group.

Focus group findings, along with secondary analyses of the process satisfaction surveys, the *What We Heard* report, and the EDFC-HH project's proposal, were used to assess the extent to which the public consultations achieved the evaluation criteria. Table 4 provides a summary of our assessment.

**[Insert Table 4 here]**

### **Representativeness**

Public consultations were evaluated in terms of the criterion of representativeness, or the idea that public consultation participants should be a representative sample of the population of interest. From the demographic information presented in the HCoA's (2021) *What We Heard* report and findings from the focus groups, it appears that public consultation participants represented a portion of the population of interest; however, focus group participants commented that important voices were missed. Therefore, representativeness was determined to be partially achieved.

The *What We Heard* report (HCoA, 2021) stated that 305 persons impacted by dementia participated in the consultation process, exceeding the 300-participant target. However, not all targets were met:

- 71 of the public consultation participants were from Haldimand; therefore, the 100-participant target for that location was not met.
- Only 14 of the public consultation participants identified as a member of a visible minority.
- 11% of participants were persons living with dementia, 89% were caregivers.

The authors of the report also stated that “the lack of in-person engagement resulted in a loss of representation from people who are socially isolated [or] without access to the Internet” (p. 5). A focus group participant also mentioned, “through the recruitment process we recruited people that were probably already connected to services, and perhaps some that use social media, but there is still a big pocket of people that we missed” (S05). In addition, focus group participants commented that individuals who did not speak English or French and individuals with a disability, such as hearing impairment, were not engaged in the public consultations. Thus, despite best efforts, important voices and opinions were not represented in the public consultation process.

Similarly, individuals in the mid–late stages of dementia, and caregivers caring for people in those stages, were underrepresented. As described by a member of the working group, “Our questions were more targeted for people in early–mid stage dementia, so caregivers of people in the advanced stages of the disease expressed that they didn’t feel the consultations applied to them” (I02). Likewise, one of the process satisfaction survey participants commented, “Some of the questions didn’t necessarily match our experiences. It would have been helpful having a choice of ‘other’ with a comment box” (OSPS survey participant). Therefore, consultation findings may be missing important information about community needs from individuals in the mid and late stages of dementia.

## **Independence**

Public consultations were evaluated in terms of the criterion of independence, or the idea that the process, including management of the participation process, is unbiased. As mentioned by Rowe and Frewer (2000), one way of obtaining independence is by appointing a management team that includes members from diverse bodies. Therefore, the appointment of a working group to lead the public consultation process with representation from diverse organizations supported independence. In addition, independence was supported by public consultation participants' reported levels of comfort answering questions: Of all OSPS survey respondents, 93% expressed feeling comfortable answering questions, 92% indicated they felt they could share their opinions, and 96% reported they understood the questions that were asked.

The aim of the process consultations was to gather insights about community experiences of persons living with dementia from the perspectives of caregivers and persons living with dementia. Thus, caregivers were asked what they felt persons living with dementia needed in their community. Focus group participants commented that the answers provided by the caregivers may have biased community needs that would benefit caregivers and not persons living with dementia: "Some caregivers struggled answering questions about the needs of the person they were caring for and turned it around and answered about their needs" (I04). Similarly, focus group participants expressed that online survey responses may have been biased by the questions included in the survey that were guided by the WHO's (2007) age-friendly community framework: "We tried to structure the survey to closely align with the age-friendly community framework instead of seeing where the survey would take us" (F05). Although the age-friendly community framework was helpful when developing the online survey, important issues specific to dementia may have been missed. For example, focus group participants

commented that although public consultation participants were asked if their community had public spaces to meet up with friends and family, there were no follow-up questions about the dementia-friendliness of those places. Additionally, there were no questions about community members' awareness and understanding of dementia.

Lastly, when engaging persons living with dementia remotely, it was not possible to control who was in the room when the interviews were conducted and whether somebody helped the person complete the online survey. It is possible that the support and/or presence of another person could have impacted the way persons living with dementia answered the questions. As one of the working group members living with dementia shared:

Some people living with dementia don't speak up when they are with their care partners.

They are afraid of disappointing or upsetting their care partners by honestly speaking about their struggles. In Zoom, you don't know who is outside the camera, so we can never be sure about the answers they [persons living with dementia] are giving. (P02)

Thus, one limitation of conducting the public consultations remotely was not knowing whether participants' home environments influenced their responses.

### **Early Involvement**

Public consultations were evaluated in terms of the criterion of early involvement, or the involvement of the public should happen as early as possible. Early involvement was achieved by engaging persons living with dementia as project partners throughout the consultation process. As expressed by one of the focus group participants, it is essential and beneficial to involve persons living with dementia at all stages of the consultation process: “[persons living with dementia] not only bring expertise about living with the condition, but they also have great

connections to other people living with dementia” (F05). Focus group participants identified other potential benefits of involving persons living with dementia as project partners:

- Combating stereotypes held by some of the working group members. As a result of their experience with the public consultation process, some of the focus group participants have started advocating for the inclusion of persons living with dementia in program development in their workplaces.
- Developing dementia-friendly public consultation materials.
- Providing the opportunity to pilot test the survey and interview guide to ensure clarity and accessibility.

Relatedly, focus group participants stated that early involvement of individuals from diverse communities and/or organizations that support them would have been beneficial. However, working group members expressed that more time would have been needed to equitably engage individuals from diverse communities: “We would have needed at least six months to really understand what is needed to move the project forward and who we needed to involve. Relationship building takes time” (F04). Moreover, when reflecting on the process of obtaining funding for the overall project, working group members mentioned that as part of the funding proposal they needed to identify targets for the public consultations and anticipated outcomes. Had the funding agency not required them to identify these targets and outcomes, the working group felt the methods for engagement may have differed: “Funding is typically based on outcomes, but we forget about how important the process [of public engagement] is and the impact of that process. . . . For communities to do more impactful work, we need to focus on process” (F05). Thus, focus group participants expressed that having a longer timeline for the engagement process would have been beneficial.

## **Influence**

Public consultations were evaluated in terms of the criterion of influence, which refers to the outcome of impact of the policy/program/intervention. Based on the recommendations and findings gleaned through the public consultations, two leadership teams of persons living with dementia, one for Hamilton and another for Haldimand County, were developed. The teams' mandate is to raise awareness about dementia and to develop programs and practices aimed at improving the quality of life of persons living with dementia. The creation of the leadership teams addresses three of the themes that emerged from the public consultations (HCoA, 2021): empowering persons living with dementia, challenging stigma and building understanding, and fostering social inclusion and participation. The consultations' influence was demonstrated by the creation of these two leadership teams.

## **Transparency**

Public consultations were evaluated in terms of the criterion of transparency, or the idea that those consulted should have access to information about the process and decisions being made. Overall, 58% of all process satisfaction survey participants (both IPS and OSPS survey participants) agreed that they understood what would happen with the information provided. The proportion of people who reported that they understood how their information would be used differed by consultation format. People who participated in an interview were more likely than people who participated in the online survey to report they understood how their information would be used (71% vs 44%, respectively),  $X^2(2, N = 102) = 8.04, p = 0.018$ . As shared by two OSPS survey participants, "Clearer direction of how my information [would be used] would have been nice" and "I would have liked an explanation of how my information will be shared with Alzheimer Society staff." These comments suggest that online survey participants were not

clear about who would have access to their information and what it would be used for; therefore, transparency was not achieved.

### **Resource Accessibility**

Public consultations were evaluated in terms of the criterion of resource accessibility, or the idea that public consultation participants should be given various options to provide input. Resource accessibility was supported by the number of formats available for the public consultations. Seventy percent of the OSPS survey respondents reported satisfaction with the survey format, and 81% of the IPS survey respondents reported satisfaction with the interview format. This difference was not statistically significant,  $X^2(1, N = 102) = 3.469, p = .176$ . Regardless of format, most process satisfaction survey participants identified that they were satisfied with the consultation formats.

Among persons living with dementia who participated in the public consultation, a higher proportion participated in an interview compared with the online survey,  $X^2(1, N = 305) = 16.5, p = .0001$ ; persons living with dementia were more likely than caregivers to participate in the interviews. Focus group participants perceived the interview process as a strength of the consultation and attributed the success to the use of empathetic interviewing. As explained by one of the focus group participants, “Participants shared with us that they found sharing their stories valuable. That is why we chose empathetic interviewing. We wanted to make sure we were adding value to those whom we engaged” (F05).

Twenty-three percent of the OSPS survey respondents indicated that they prefer to complete pen and paper surveys, suggesting that not everyone favors online surveys. In addition, 98% indicated that the instructions of the survey were clear, and 86% reported that they did not have any difficulties completing the survey. These responses indicate that the survey was



reported to be accessible to most. However, even though technology, language, and accessibility support were available, when reflecting on the process, focus group participants stated that these options were not clearly advertised. If the availability of accessibility support had been made more obvious, a more diverse group of individuals with diverse needs may have been more likely to consider participating in the public consultations. Therefore, lack of clarity in recruitment materials may have influenced representativeness.

### **Task Definition**

Public consultations were evaluated in terms of the criterion of task definition, or the idea that the scope of the consultation has been clearly defined. For this process evaluation, task definition was assessed by evaluating whether public consultation participants understood the aim of the consultations and whether their questions were answered to their satisfaction. Overall, 79% of process satisfaction survey participants indicated that they understood what the public consultations were about. Additionally, 87% of the IPS survey participants indicated that their questions about the consultations were answered to their satisfaction.

The online survey recruitment strategy helped raise awareness about DFCs and the aim of the public consultations, contributing to the scope of the consultation being clearly defined. However, because of delays in the funding announcement, speaking publicly about the project was not permitted while recruitment for the interviews was underway. As expressed by one focus group participant:

If we had been able to publicly talk about the project, I think there would have been a greater understanding of what the interviews were for. I don't think people fully understood why we wanted to hear from them. More time spent on awareness before the public consultations would have been beneficial. (I01)

For the online survey, a marketing agency was hired. Focus group participants identified the work of the marketing agency as having been beneficial for recruiting and raising awareness about DFCs: “What facilitated the recruitment was the communication strategy developed by the marketing agency. It made the communication and outreach process very easy” (S01). Therefore, focus group participants identified raising awareness about DFCs prior to the public consultations as a lesson learned.

### ***Recommendations for Engaging Persons Living With Dementia in Public Consultations***

Based on their experience conducting the public consultations for the EDFC-HH project, focus group participants provided recommendations for engaging persons living with dementia in public consultations:

1. Include persons living with dementia at all stages of the consultation process.
2. Clearly state whom you want to hear from (e.g., person living with early-stage dementia).
3. Think about how to make the engagement valuable for persons living with dementia.

What is in it for them?

4. When possible, consider giving persons living with dementia and caregivers the option of being interviewed or completing a survey.
5. Consider using empathy interviewing. In our consultations, this interviewing method made persons living with dementia feel valued and heard and resulted in a rich understanding of their community needs.
6. Persons living with dementia can have more than one disability; therefore, it is important to provide accessibility support. For example, if the person has hearing difficulties, use a platform that provides closed captioning. The availability of these supports needs to be

clearly advertised in recruitment emails, posters, and communications with community members and stakeholders.

7. Clearly state how the information will be used. If engaging people through a survey, consider including a video explaining the scope of the project, how the public consultations are supporting the project, and what to expect next.

8. Consider hiring a marketing agency to help with participant recruitment and to raise awareness about the project. Make sure the marketing agency staff understand dementia and how to work with persons living with dementia.

## **Discussion**

The aim of this process evaluation was to assess the effectiveness of the public consultation processes employed for the EDFC-HH project and to develop recommendations for conducting public consultations with persons living with dementia.

### **Public Consultation Strengths**

Thirty-three persons living with dementia and 272 caregivers participated in the public consultations. The public consultation process was strengthened by the engagement of persons living with dementia as project partners and public consultation participants, the various ways in which persons living with dementia and caregivers could participate in the consultations, the leadership of the working group, and the media strategy used to raise awareness about DFCs and the scope of the EDFC-HH project.

### ***Early Involvement***

The engagement of persons living with dementia has been identified as a core element of DFCs (Buckner et al., 2019; Dean et al., 2015; Heward et al., 2017; Hung et al., 2021; Phillipson et al., 2019). However, in most DFC initiatives, persons living with dementia become involved in

decision-making only once community priorities have been identified (Crampton & Eley, 2013; Mathie et al., 2022) or to participate in specific activities, such as awareness campaigns (Phillipson et al., 2019). A strength of the public consultations for the EDFC-HH project was the engagement of persons living with dementia throughout the entire process as project partners. Having two persons living with dementia as project partners was crucial for developing accessible and dementia-friendly materials, raising awareness about the project, and recruiting other people living with dementia to pilot test materials and to participate in the consultations. Additionally, focus group participants shared that the inclusion of persons living with dementia as members of the working group challenged their assumptions about dementia. Similarly, in a qualitative study that investigated the impact of involving persons living with dementia in research, researchers reported that the engagement of persons living with dementia as coresearchers led them to continue to involve persons with lived experience in other research projects (Miah et al., 2019). Thus, involving persons living with dementia as project partners and participants was found to be a powerful way of combating stigma.

### ***Resource Accessibility***

Public consultation participants and working group members described the empathy interviewing approach used for the interviews as a strength of the consultations. In this type of interview, open-ended questions are used to elicit stories about specific experiences to help uncover needs or to identify issues that need to be addressed (Nelsestuen & Smith, 2020). Empathy and dialogue are central principles of design thinking (Köppen & Meinel, 2015) and experience-centered design (Wright & McCarthy, 2010). Although experience-centered design is usually used in human-computer interaction projects, it has been proposed that experience-centered design principles (such as working together to imagine futures) could contribute to

experience-centered projects, particularly when working with people facing difficult circumstances, such as persons living with dementia (Morrissey et al., 2017). Results from this evaluation support the benefits of using experience-centered design principles in public consultations with persons living with dementia. The empathy interview process provided working group members with a rich understanding of the difficulties that persons living with dementia face in their communities. In future public consultations with persons living with dementia, other experience-centered design and/or design thinking methods, such as arts-based methods, could be used to engage persons living with dementia who are in the later stages of the disease or who have difficulties with written and/or spoken communication (Smith & Phillipson, 2021).

### ***Task Definition***

Raising awareness about the need for DFCs and the purpose of the EDFC-HH project was an important element of the recruitment strategy. Emails, social media posts, and newspaper articles were used to accomplish this goal. Newspaper stories have been identified as a successful strategy for recruiting caregivers of persons with dementia (Leach et al., 2016). Similarly, the focus group participants perceived the articles as a strength of the recruitment process. However, focus group participants shared that reliance on the internet for recruitment could have contributed to the lack of engagement from diverse communities. Negative attitudes and beliefs about dementia in ethnic minority communities have been cited as one reason why it can be difficult to recruit people impacted by dementia from these communities (Waheed et al., 2020). Dementia education alongside community outreach and partnership building may be a necessary first step in engaging people from ethnic minority communities (Waheed et al., 2020; Wong et al., 2019), which may be more successful using in-person approaches.

## **Public Consultation Limitations**

Remote engagement was a weakness of the public consultation process. Since participants were engaged remotely, the working group could not control for the influence of external factors (e.g., the presence of another person) on participants' answers. Additionally, relying on communication technology for the engagement process meant that only individuals who had access and the ability to use a phone, laptop, and/or tablet were able to participate in the public consultations. Reliance on communication technology for the recruitment and engagement of participants could be a reason why more caregivers than persons living with dementia participated in the public consultations.

### ***Task Definition***

Persons living with dementia and their caregivers have identified transparency about their influence on research and community projects as a core element of citizen engagement (Great Britain Department of Health, 2016). Individuals who participated in the public consultations reported not fully understanding the next steps of the project and how the information they provided would be used. Interview participants were more likely than online survey participants to understand how their information would be used. This suggests that it was not clear to participants what the aims of the survey were and how the results would be used. Videos explaining how to complete an online survey have been recommended as a tool to support the independence of persons living with dementia in completing such surveys (Alzheimer's Society UK, n.d.). Similarly, to increase transparency, an introduction video could be used to explain the purpose of the survey, who the survey is for, how the data will be used, and the project's next steps.

### ***Independence***

A limitation of conducting the public consultations remotely was not knowing how public consultation participants' environment might affect their answers. For example, if the person living with dementia needed support completing the survey, their supporter could have influenced their answers (Darlington et al., 2020). As reported by focus group participants, if the person living with dementia is being interviewed remotely with family/friends in the room, they may not provide honest answers if they think their responses will have a negative impact on their caregivers/family/friends. To encourage forthright answers from persons living with dementia when doing an interview remotely, it may be beneficial to encourage the person to participate in the interview in a quiet place and without another person present in the room. However, some people may want to have someone in the room with them if they do not feel safe or comfortable alone. Having flexibility in how consultation data are collected also applies to online surveys. Participants should be offered the option of conducting the survey over the phone if they are having difficulties with the online format.

A greater number of persons living with dementia participated in the interviews as compared to the online survey, with the majority choosing a telephone over a Zoom interview. This discrepancy suggests that persons living with dementia who participated in the consultations prefer interviews over surveys and are more comfortable with more familiar forms of communication technologies (i.e., telephone). The consultations were conducted at the beginning of the COVID-19 pandemic when many people were still getting used to videoconferencing software. As a result of the pandemic, comfort levels using videoconferencing services, such as Zoom, may have shifted, which could affect how people prefer to be engaged later in or even after the pandemic.

### ***Representativeness***

A limitation of the public consultation process was that only individuals who had access and the ability and/or support to use communication technology were able to participate. Of the 305 people who participated in the public consultations, only 33 (11%) were persons living with dementia. If the option for in-person engagement had been available, more persons living with dementia may have been consulted. Although caregivers may share similar viewpoints to the people for whom they are caring, differences in opinions between caregivers and persons living with dementia have been noted, particularly about topics related to independence and service provision (Rivett, 2017). Though valuable, caregiver opinions may not accurately depict the experience of persons living with dementia, and important community gaps and priority areas could have been missed.

Although the aim of the public consultations was to gather insights from persons in the early and middle stages of dementia, it is important to note that approximately 60% of persons with moderate to advanced dementia live at home (Harrison et al., 2019). To ensure that the community needs of persons living with advanced stages of dementia and their caregivers are addressed in community planning, these individuals should be engaged in public consultations. To support the engagement of persons with advanced dementia in community planning, future research should be done to evaluate engagement methods that are inclusive of persons with advanced dementia, such as art-based engagement methods (see e.g., Fleetwood-Smith et al., 2022; Smith & Phillipson, 2021).

### ***Public Consultation Challenges***

The working group members identified time constraints as a barrier to the engagement of members from diverse communities. Similarly, engaging persons living with dementia in a meaningful way can be time-consuming (Brooks et al., 2017). To obtain funding for a



community development project such as the EDFC-HH project, project leads are typically required to identify the project's scope and expected outcomes in the funding application. These requirements have been identified as a challenge for conducting participatory research in which community members help identify research priorities that matter to them (Hall & Tandon, 2017). To ensure that community members are able to shape the purpose and scope of community development projects, alternative funding structures are needed (Cargo & Mercer, 2008; Corrado et al., 2020). For example, feasibility grants that provide funding for the initial stages of a project, such as time for relationship building and identification of community needs, should be made available (Cargo & Mercer, 2008).

### **Public Consultations and the Digital Divide**

Persons living with dementia and caregivers who had access and the ability to use communication technology were engaged in the public consultations. Therefore, access to technology (including communication technology) and the internet were not identified as community needs, even if they are. According to Statistics Canada (2021), 6% of all Canadians and 17% of adults 65 and older do not have access to the internet at home. Among older adults who have access to technology, 73% have reported needing support using new electronic devices (Anderson & Perrin, 2017). Reliance on communication technology for the public consultation highlights an important consequence of the digital divide: As more essential services and aspects of community life become digital (e.g., online banking, booking a medical appointment), persons with dementia who do not have access to or know how to use communication technology are at risk of not being able to access services and opportunities essential to their well-being. The aim of DFCs is to support persons living with dementia to participate in community life, including accessing health and community services. As these services continue to move to a digital space,

it is important that stakeholders working on DFC initiatives advocate for governments to prioritize closing the digital divide.

### **Study Limitations**

A limitation of this study was the use of Rowe and Frewer's (2000) framework. Although the framework provided a useful guide to assess the strengths and limitations of the public consultations, important criteria could have been missed. For example, focus group participants identified the leadership of the working group as a strength of the process; however, Rowe and Frewer's (2000) framework does not include a criterion for the influence of the management team's work on the outcomes of the public consultation. Strategies and challenges for achieving stakeholder involvement in DFC initiatives have been discussed elsewhere (Heward et al., 2017). Moreover, in this process evaluation we only evaluated the processes used for the EDFC-HH public consultations; we did not use a theoretical framework to address the "why" of the public consultation's outcomes. To better understand how to support the engagement of persons living with dementia in public engagement activities, we recommend the use of engagement theoretical frameworks in future work. Additionally, the process satisfaction surveys were developed to assess public consultation participants' satisfaction with their engagement, not to evaluate the consultation process. Although several questions were applicable to our study (refer to Table 1), using secondary analysis, we were limited to the questions asked in the survey. Lastly, even though the perspectives of persons living with dementia were included in the evaluation, only 27% of process satisfaction participants and two focus group participants identified as living with dementia. To better understand processes and methods that could be used to facilitate the engagement of persons living with dementia in public consultations, a more representative sample of persons living with dementia is needed.

## Conclusion

As described by Biglieri (2021), “reshaping the city through public engagement in the planning process is a citizenship right” (p. 312). However, due to lack of resources and expertise in how to support the engagement of persons living with dementia in planning processes, these individuals are not always involved in the development and implementation of DFCs (Mathie et al., 2022). There is limited research on who can participate in public consultations, who can access public consultation engagement tools, and how best to engage typically excluded groups, such as persons living with dementia, in planning processes (Biglieri, 2021). This process evaluation was conducted to better understand processes and methods that facilitate the engagement of persons living with dementia in public consultations. The results of this evaluation indicate that to develop equitable and adequate engagement procedures, appropriate time and resources need to be allocated to the engagement processes of DFC initiatives. Additionally, engaging persons living with dementia as project partners and public consultation participants was identified as necessary for developing DFC initiatives. Without the contribution of persons living with dementia in DFC initiatives, there is the risk of perpetuating the stigma and exclusion from society that these individuals experience (Swaffer, 2014), of using engagement methods not suitable for them (Biglieri, 2021), and of implementing community initiatives that do not meet their needs (Mathie et al., 2022). If persons living with dementia are excluded from decision-making processes such as public consultations, they will continue to be perceived as a vulnerable group that needs to be cared for (Low & Purwaningrum, 2020) rather than as citizens of the communities where they live. Recognizing that persons living with dementia can meaningfully contribute to the development of inclusive communities and supporting their engagement in community development initiatives will lead to a shift from

planning *for* to planning *with* persons living with dementia (Biglieri, 2018). It is our hope that the results from this study are used by community stakeholders working on DFC initiatives to support persons living with dementia in enacting citizenship roles. To ensure that the right of persons living with dementia to be involved in shaping the places where they live is respected, their engagement in community development planning processes needs to become the norm, not the exception.

The authors have no competing interests to declare.

## References

- Alzheimer's Disease International. (2016). *Dementia friendly communities: Key principles*.  
<https://www.alzint.org/u/dfc-principles.pdf>
- Alzheimer Society of Canada. (n.d.). *Canadian charter of rights for people with dementia*.  
[https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as\\_charter-of-rights-for-people-with-dementia.pdf](https://archive.alzheimer.ca/sites/default/files/files/national/advocacy/charter/as_charter-of-rights-for-people-with-dementia.pdf)
- Alzheimer's Society UK. (n.d.). *Using video technology to connect people with dementia*.  
<https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/supporting-inclusion/using-video-technology-connect-people-dementia>
- Anderson, M., & Perrin, A. (2017). *Tech adoption climbs among older adults*.  
<https://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/>
- Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. The Policy Press.
- Beattie, E., Fielding, E., O'Reilly, M., Brooks, D., MacAndrew, M., & McCrow, J. (2018). Recruitment of individuals with dementia and their carers for social research: Lessons learned from nine studies. *Research in Gerontological Nursing, 11*(3), 119–128.  
<https://doi.org/10.3928/19404921-20180308-01>
- Biglieri, S. (2018). Implementing dementia-friendly land use planning: An evaluation of current literature and financial implications for Greenfield development in suburban Canada. *Planning Practice and Research, 33*(3), 264–290.  
<https://doi.org/10.1080/02697459.2017.1379336>
- Biglieri, S. (2021). The right to (re)shape the city. *Journal of the American Planning Association, 87*(3), 311–325. <https://doi.org/10.1080/01944363.2020.1852100>
- Brooks, J., Savitch, N., & Gridley, K. (2017). Removing the “gag”: involving people with dementia in research as advisers and participants. *Social Research Practice, 3*–14.
- Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., & Goodman, C. (2019). Dementia friendly communities in England: A scoping study. *International Journal of Geriatric Psychiatry, 34*(8), 1235–1243. <https://doi.org/10.1002/gps.5123>
- Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annual Reviews of Public Health, 29*, 325–350.  
<https://doi.org/10.1146/annurev.publhealth.29.091307.083824>
- Chambers, L. W., Bancej, C., & McDowell, I. (Eds.). (2016). *Prevalence and monetary costs of dementia in Canada*. Alzheimer Society of Canada.  
[https://archive.alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia\\_en.pdf](https://archive.alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia_en.pdf)
- Corrado, A. M., Benjamin-Thomas, T. E., McGrath, C., Hand, C., & Laliberte Rudman, D. (2020). Participatory action research with older adults: A critical interpretive synthesis. *The Gerontologist, 60*(5), e413–e427. <https://doi.org/10.1093/GERONT/GNZ080>
- Crampton, J., & Eley, R. (2013). Dementia-friendly communities: What the project “Creating a dementia-friendly York” can tell us. *Working with Older People, 17*(2), 49–57.  
<https://doi.org/10.1108/13663661311325463>
- Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research, 26*(13), 1774–1786.

- <https://doi.org/10.1177/1049732316637065>
- Darlington, N., Arthur, A., Woodward, M., Buckner, S., Killeit, A., Lafortune, L., Mathie, E., Mayrhofer, A., Thurman, J., & Goodman, C. (2020). A survey of the experience of living with dementia in a dementia-friendly community. *Dementia: The International Journal of Social Research and Practice*, 20(5), 1711–1722.  
<https://doi.org/10.1177/1471301220965552>
- Dean, J., Silversides, K., Crampton, J., & Wrigley, J. (2015). *Evaluation of the York dementia friendly communities programme*. <https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 4(1), Article 215824401452263.  
<https://doi.org/10.1177/2158244014522633>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Fehr, P. (2020, November 3). Survey will help build dementia-friendly cities. *The Hamilton Spectator*. <https://www.thespec.com/opinion/contributors/2020/11/03/survey-will-help-build-dementia-friendly-cities.html>
- Fleetwood-Smith, R., Tischler, V., & Robson, D. (2022). Using creative, sensory and embodied research methods when working with people with dementia: A method story. *Arts & Health*, 14(3), 263–279. <https://doi.org/10.1080/17533015.2021.1974064>
- Government of Canada. (2022, October 21). *Public consultations*.  
<https://www.justice.gc.ca/eng/cons/index.html>
- Great Britain Department of Health. (2016). *Dementia 2020 citizens' engagement programme: Toolkit for engaging people with dementia and carers*.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/564973/Dementia\\_toolkit.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/564973/Dementia_toolkit.pdf)
- Hall, B. L., & Tandon, R. (2017). Participatory research: Where have we been, where are we going? – A dialogue. *Research for All*, 1(2), 365–374. <https://doi.org/10.18546/rfa.01.2.12>
- Hamilton Council on Aging. (2021). *What we heard report: Empowering dementia-friendly communities project: Hamilton and Haldimand*. [https://coahamilton.ca/wp-content/uploads/2021/06/HCOA\\_WWH\\_EN\\_June2021.pdf](https://coahamilton.ca/wp-content/uploads/2021/06/HCOA_WWH_EN_June2021.pdf)
- Harrison, K. L., Ritchie, C. S., Patel, K., Hunt, L. J., Covinsky, K. E., Yaffe, K., & Smith, A. K. (2019). Care settings and clinical characteristics of older adults with moderately severe dementia. *Journal of the American Geriatrics Society*, 67(9), 1907–1912.  
<https://doi.org/10.1111/jgs.16054>
- Heward, M., Innes, A., Cutler, C., & Hambidge, S. (2017). Dementia-friendly communities: Challenges and strategies for achieving stakeholder involvement. *Health & Social Care in the Community*, 25(3), 858–867. <https://doi.org/10.1111/HSC.12371>
- Hung, L., Hudson, A., Gregorio, M., Jackson, L., Mann, J., Horne, N., Berndt, A., Wallsworth, C., Wong, L., & Phinney, A. (2021). Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontology and Geriatric Medicine*, 7.  
<https://doi.org/10.1177/23337214211013596>
- Iqbal, M. (2020a, November 2). Do you have dementia or care for someone who does? The Hamilton Council on Aging wants to hear from you. *The Hamilton Spectator*.  
<https://www.thespec.com/news/hamilton-region/2020/11/02/do-you-have-dementia-or-care-for-someone-who-does-the-hamilton-council-on-aging-wants-to-hear-from-you.html>

- Iqbal, M. (2020b, November 9). Living with dementia: A Hamiltonian's journey from wanting to die to finding new life with Alzheimer's. *The Hamilton Spectator*. <https://www.thespec.com/news/hamilton-region/2020/11/09/living-with-dementia-a-hamiltonians-journey-from-wanting-to-die-to-finding-new-life-with-alzheimers.html>
- Iqbal, M. (2020c, November 10). Living with dementia: The difficult decision to move a loved one to long-term care. *The Hamilton Spectator*. <https://www.thespec.com/news/hamilton-region/2020/11/10/living-with-dementia-the-difficult-decision-to-move-a-loved-one-to-long-term-care.html>
- Iqbal, M. (2020d, November 11). Three ways Hamilton can be more friendly for those with dementia. *The Hamilton Spectator*. <https://www.thespec.com/news/hamilton-region/2020/11/11/three-ways-hamilton-can-be-more-friendly-for-those-with-dementia.html>
- Köppen, E., & Meinel, C. (2015). Empathy via design thinking: Creation of sense and knowledge. In H. Plattner, C. Meinel, & L. Leifer (Eds.), *Design thinking research* (pp. 15–28). Springer, Cham. [https://doi.org/10.1007/978-3-319-06823-7\\_2](https://doi.org/10.1007/978-3-319-06823-7_2)
- Leach, M. J., Ziaian, T., Francis, A., & Agnew, T. (2016). Recruiting dementia caregivers into clinical trials: Lessons learnt from the Australian TRANSCENDENT Trial. *Alzheimer Disease and Associated Disorders*, 30(4), 338–344. <https://doi.org/10.1097/WAD.0000000000000149>
- Leech, N. L., & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs. *Quality & Quantity*, 43, 265–275. <https://doi.org/10.1007/s11135-007-9105-3>
- Low, L.-F., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, 20(1), Article 477. <https://doi.org/10.1186/s12877-020-01754-x>
- Mathie, E., Antony, A., Killest, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M., & Goodman, C. (2022). Dementia-friendly communities: The involvement of people living with dementia. *Dementia: The International Journal of Social Research and Practice*, 21(4), 1250–1269. <https://doi.org/10.1177/14713012211073200>
- Miah, J., Dawes, P., Edwards, S., Leroi, I., Starling, B., & Parsons, S. (2019). Patient and public involvement in dementia research in the European Union: A scoping review. *BMC Geriatrics*, 19(1), Article 220. <https://doi.org/10.1186/s12877-019-1217-9>
- Morrissey, K., McCarthy, J., & Pantidi, N. (2017). The value of experience-centred design approaches in dementia research contexts. In G. Mark & S. Fussell (Eds.), *CHI '17: Proceedings of the 2017 CHI conference on human factors in computing systems* (pp. 1326–1338). Association for Computing Machinery. <https://doi.org/10.1145/3025453.3025527>
- Nelsestuen, K., & Smith, J. (2020, October). Empathy interviews. *The Learning Professional*, 41(5), 59–62. <https://learningforward.org/wp-content/uploads/2020/10/tool-empathy-interviews.pdf>
- Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia: The International Journal of Social Research and Practice*, 18(3), 1042–1059. <https://doi.org/10.1177/1471301217701274>
- Phillipson, L, Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost, D., & Hasan, H. (2019). Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia: The International Journal of Social Research and Practice*, 18(7–8), 2679–2694.

- <https://doi.org/10.1177/1471301218754455>
- Phillipson, L., & Hammond, A. (2018). More than talking: A scoping review of innovative approaches to qualitative research involving people with dementia. *International Journal of Qualitative Methods*, 17. <https://doi.org/10.1177/1609406918782784>
- Razzouk, R., & Shute, V. (2012). What is design thinking and why is it important? *Review of Educational Research*, 82(3), 330–348. <https://doi.org/10.3102/0034654312457429>
- Rivett, E. (2017). Research involving people with dementia: A literature review. *Working with Older People*, 21(2), 107–114.
- Rowe, G., & Frewer, L. J. (2000). Public participation methods: A framework for evaluation. *Science, Technology and Human Values*, 25(1), 3–29. <https://doi.org/10.1177/016224390002500101>
- Smith, L., & Phillipson, L. (2021). Thinking through participatory action research with people with late-stage dementia: Research note on mistakes, creative methods and partnerships. *International Journal of Social Research Methodology*, 24(6), 775–780. <https://doi.org/10.1080/13645579.2020.1810997>
- Statistics Canada. (2021). *Access to the internet in Canada, 2020*. <https://www150.statcan.gc.ca/n1/daily-quotidien/210531/dq210531d-eng.htm>
- Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia: The International Journal of Social Research and Practice*, 13(6), 709–716. <https://doi.org/10.1177/1471301214548143>
- Van Dijk, J. A. G. M. (2006). Digital divide research, achievements and shortcomings. *Poetics*, 34(4–5), 221–235. <https://doi.org/10.1016/j.poetic.2006.05.004>
- Waheed, W., Mirza, N., Waheed, M. W., Blakemore, A., Kenning, C., Masood, Y., Matthews, F., & Bower, P. (2020). Recruitment and methodological issues in conducting dementia research in British ethnic minorities: A qualitative systematic review. *International Journal of Methods in Psychiatric Research*, 29(1), Article e1806. <https://doi.org/10.1002/MPR.1806>
- Webb, J., Williams, V., Gall, M., & Dowling, S. (2020). Misfitting the research process: Shaping qualitative research “in the field” to fit people living with dementia. *International Journal of Qualitative Methods*, 19. <https://doi.org/10.1177/1609406919895926>
- Wong, R., Amano, T., Lin, S.-Y., Zhou, Y., & Morrow-Howell, N. (2019). Strategies for the recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. *Current Alzheimer Research*, 16(5), 458–471. <https://doi.org/10.2174/1567205016666190321161901>
- World Health Organization. (2007). *Global age-friendly cities: A guide*. [https://apps.who.int/iris/bitstream/handle/10665/43755/9789241547307\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/43755/9789241547307_eng.pdf)
- World Health Organization. (2021). *Towards a dementia-inclusive society*. <https://www.who.int/publications/i/item/9789240031531>
- Wright, P., & McCarthy, J. (2010). *Experience-centered design: Designer, users and communities in dialogue*. Springer.
- Xie, B., Charness, N., Fingerma, K., Kaye, J., Kim, M. T., & Khurshid, A. (2020). When going digital becomes a necessity: Ensuring older adults’ needs for information, services, and social inclusion during COVID-19. *Journal of Aging & Social Policy*, 32(4–5), 460–470. <https://doi.org/10.1080/08959420.2020.1771237>



**Table 1**

*Mapping of Process Satisfaction Survey Questions to Rowe and Frewer's (2000) Framework for Evaluating Public Engagement*

| <b>Criterion</b>              | <b>Interview process satisfaction survey</b>   | <b>Online survey process satisfaction survey</b>   |
|-------------------------------|--|--|
| <b>Resource accessibility</b> | <ul style="list-style-type: none"> <li>• Overall, how satisfied were you with the format? <i>(satisfied/neutral/dissatisfied)</i></li> <li>• Is there anything that you would change about this community engagement process or how you were involved? <i>(satisfied/neutral/dissatisfied)</i></li> </ul>              | <ul style="list-style-type: none"> <li>• Overall, how satisfied were you with the format?</li> <li>• Is there anything that you would change about this community engagement process or how you were involved? <i>(satisfied/neutral/dissatisfied)</i></li> <li>• Were the instructions in the survey clear? <i>(yes/no/I don't know)</i></li> <li>• Did you have any difficulties completing the survey? <i>(yes/no)</i></li> <li>• Do you prefer to complete surveys online or in print? <i>(online/print/both are good to me)</i></li> <li>• Is there anything that we could have done differently to make it easier for you to complete the survey?</li> </ul> |
| <b>Task definition</b>        | <ul style="list-style-type: none"> <li>• I understood what this project was all about. <i>(agree/disagree/neutral)</i></li> <li>• My questions about this process were answered to my satisfaction. <i>(agree/disagree/neutral)</i></li> </ul>   | <ul style="list-style-type: none"> <li>• I understood what this project was all about. <i>(agree/disagree/neutral)</i></li> </ul>  |
| <b>Transparency</b>           | <ul style="list-style-type: none"> <li>• I understood what will happen next with all the information I and others have provided for this project. <i>(agree/neutral/disagree)</i></li> <li>• Overall, how satisfied were you with your involvement in this project? <i>(satisfied/neutral/dissatisfied)</i></li> </ul> | <ul style="list-style-type: none"> <li>• I understood what will happen next with all the information I and others have provided for this project. <i>(agree/neutral/disagree)</i></li> <li>• Overall, how satisfied were you with your involvement in this project? <i>(satisfied/neutral/dissatisfied)</i></li> </ul>   |
| <b>Independence</b>           | <ul style="list-style-type: none"> <li>• I felt comfortable answering the questions. <i>(agree/neutral/disagree)</i></li> <li>• I felt like I could speak freely. <i>(agree/neutral/disagree)</i></li> <li>• I understood the questions that the facilitators were asking. <i>(agree/neutral/disagree)</i></li> </ul>  | <ul style="list-style-type: none"> <li>• I felt comfortable answering the questions. <i>(agree/neutral/disagree)</i></li> <li>• I felt like I could share my opinions. <i>(agree/neutral/disagree)</i></li> <li>• I understood the questions being asked. <i>(agree/neutral/disagree)</i></li> </ul>   |

**Table 2***Descriptive Information of Process Satisfaction Survey Respondents*

| <b>Variable</b>                     | <b>Interview process satisfaction survey (N = 53)</b> | <b>Online survey process satisfaction survey (N = 50)</b> |
|-------------------------------------|---|---|
| <b>Respondent group</b>             |   |   |
| Person living with dementia         | 12 (23%)  | 2 (4%)  |
| Care partner                        | 23 (43%)  | 25 (50%)  |
| Other (e.g., family member, friend) | 18 (34%)  | 23 (46%)  |
| <b>Community</b>                    |   |   |
| Hamilton                            | 35 (66%)  | 39 (78%)  |
| Haldimand                           | 17 (32%)  | 6 (12%)   |
| Other/unspecified                   | 1 (2%)  | 5 (10%)   |
| <b>Gender*</b>                      |   |   |
| Female                              | 38 (72%)  | 36 (72%)  |
| Male                                | 11 (21%)  | 9 (18%)   |
| Gender fluid/nonbinary/two spirit   | 0   | 2 (1%)  |
| Preferred not to answer             | 2 (4%)  | 2 (4%)  |
| <b>Age</b>                          |   |   |
| Mean (SD)                           | 68.5 (11)   | 60 (14)   |
| Range                               | 39–87   | 32–86   |
| Median                              | 69.5  | 59  |
| <b>Visible minority identity*</b>   |   |   |
| Yes                                 | 1 (2%)  | 2 (4%)  |
| No                                  | 47 (89%)  | 44 (88%)  |
| Preferred not to answer             | 3 (6%)  | 2 (4%)  |

Note: Percentages will not add to 100% due to missing data.

**Table 3***Evaluation Criteria and Data Sources*

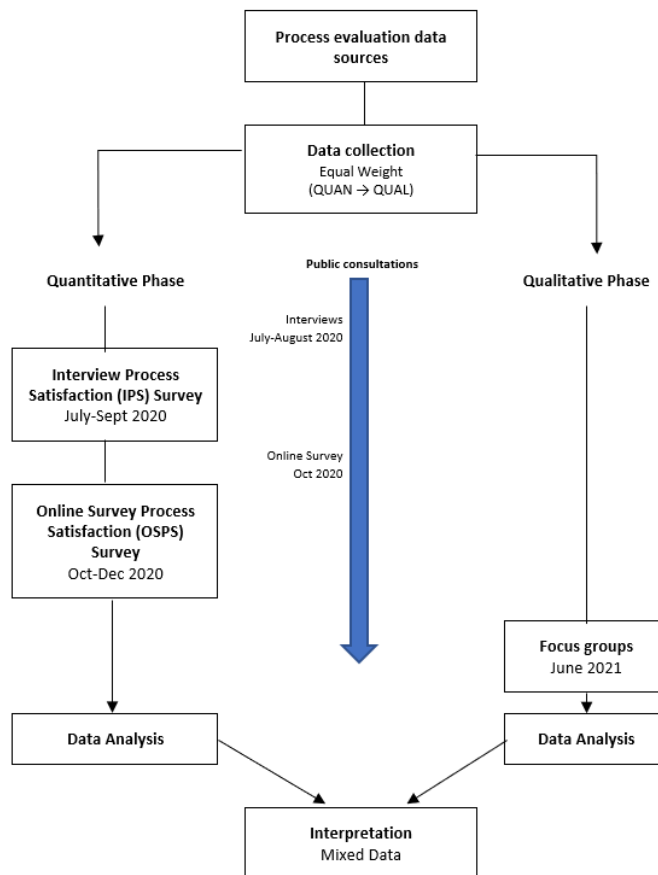
| <b>Criteria</b>        | <b>Data sources</b>   |
|------------------------|---|
| Representativeness     | <ul style="list-style-type: none"> <li>• <i>What We Heard</i> report (demographic information)</li> <li>• Focus groups</li> <li>• Project’s proposal</li> </ul> |
| Independence           | <ul style="list-style-type: none"> <li>• Process satisfaction surveys</li> <li>• Focus groups</li> </ul>  |
| Early involvement      | <ul style="list-style-type: none"> <li>• Focus groups</li> </ul>  |
| Influence              | <ul style="list-style-type: none"> <li>• <i>What We Heard</i> report</li> </ul>   |
| Transparency           | <ul style="list-style-type: none"> <li>• Process satisfaction surveys</li> </ul>  |
| Resource accessibility | <ul style="list-style-type: none"> <li>• Process satisfaction surveys</li> <li>• Focus groups</li> </ul>  |
| Task definition        | <ul style="list-style-type: none"> <li>• Process satisfaction surveys</li> <li>• Focus groups</li> </ul>  |

**Table 4***Process Evaluation Assessment Results*

| <b>Criterion</b>  | <b>Assessment</b>   |
|---|---|
| Representativeness<br>→ <i>What We Heard</i> report, focus groups, project's proposal | <b>Partially achieved:</b> Important voices were missed (e.g., individuals in the mid and late stages of dementia).   |
| Independence<br>→ Process satisfaction surveys, focus groups                          | <b>Partially achieved:</b> Relying on communication technology added potential bias to public consultation participant respondents.   |
| Early involvement<br>→ Focus groups   | <b>Achieved:</b> Persons living with dementia were involved as project partners throughout the consultation process.  |
| Influence<br>→ <i>What We Heard</i> report  | <b>Achieved:</b> The influence of the results of the public consultations was demonstrated by the creation of two leadership teams.   |
| Transparency<br>→ Process satisfaction surveys  | <b>Not achieved:</b> Individuals who participated in the public consultations through the online survey were not clear about how their information would be used.   |
| Resource Accessibility<br>→ Process satisfaction surveys, focus groups                | <b>Partially achieved:</b> Although a number of formats were available to support participation in the public consultations, availability of accessibility support was not clearly stated in recruitment materials. |
| Task definition<br>→ Process satisfaction surveys, focus groups                       | <b>Achieved:</b> The majority of process satisfaction survey participants indicated that they understood what the public consultations were about.  |

**Figure 1**

*Process Evaluation Data Sources, Public Consultation Timeline, and Research Design*



## CHAPTER FOUR

TITLE: Impact Evaluation of a Dementia-Friendly Community Mural: Planting a Seed for Change

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## **Abstract**

Stigma against persons living with dementia negatively impacts their quality of life. One of the aims of dementia-friendly community initiatives is to reconstruct public perceptions of dementia through dementia awareness campaigns. In this paper we present the findings of an evaluation of the impact of a Canadian dementia-friendly community mural on raising awareness about dementia, and lessons learned from the process undertaken to create the mural. Using a practical participatory evaluation research approach, the research questions and data collection methods were co-created with the team that lead the community mural, which was comprised of four people living with dementia. Numerous data collection methods were used to support this outcome evaluation including observations, interviews and focus groups, and social media tracking. Findings indicate that while the process of creating the mural, and the mural itself, have planted a seed for increased dementia awareness and inclusion of persons living with dementia in the community, to create social change complementary awareness raising efforts (such as a social media campaign) are needed.

**Keywords:** community mural; dementia; dementia-friendly communities; public art; stigma

## **Background**

Dementia is a general term that describes a group of symptoms caused by disorders affecting the brain (World Health Organization [WHO], 2012). The disorders are progressive in nature and may lead to changes in thinking, memory, emotional regulation, judgement, and language (WHO, 2021). Dementia is one of the major causes of dependence and disability worldwide (Frankish & Horton, 2017) and in 2012 it was recognized as a global health priority by the WHO (WHO, 2012). It is estimated that 597,300 Canadians currently live with dementia (Alzheimer Society of Canada, 2022).

Stigma against persons living with dementia negatively impacts their quality of life (Nguyen & Li, 2020). Stigma refers to negative stereotypes, attitudes and beliefs that a society or a group of people have about something (Thornicroft et al., 2007), for example, persons living with dementia. As a result of public misunderstanding and lack of knowledge about dementia, many persons living with dementia have shared feeling excluded from their social circles and no longer being taken seriously by their friends and family (van Wijngaarden et al., 2019). Additionally, negative societal attitudes and beliefs about dementia can create fear of a dementia diagnosis and how a person and their caregivers may be treated after a diagnosis, which can lead to delays in help-seeking behaviours (Parker et al., 2020). Relatedly, common stereotypes of persons living with dementia include lower cognitive competence and the person being aggressive, which can result in discrimination towards them by healthcare providers (Gove et al., 2016; Nguyen & Li, 2020). The negative impact that stigma can have on the lives of persons living with dementia and their caregivers highlights a need for interventions and campaigns aimed at reconstructing public perceptions of dementia.

Dementia-friendly community (DFC) initiatives are intended to support the quality of life of persons living with dementia by changing and/or creating social and physical environments to promote equal access to opportunities, public spaces and services, and prevent discrimination (WHO, 2021a). An important component of DFC initiatives is raising awareness and public knowledge of dementia (Alzheimer's Disease International, 2016). Dementia awareness campaigns are typically aimed at achieving one or more of the following: increasing understanding about dementia, including recognition of early signs and symptoms; reducing stigma and discrimination towards persons living with dementia and their care partners; educating the public about risk reduction behaviours; and sharing stories about living with dementia (Matsumoto et al., 2021; Phillipson et al., 2019).

Dementia awareness campaigns tend to involve the creation of posters, social media cards, video vignettes and/or infographics about dementia/living with dementia (Alzheimer's Disease International, 2022). Community murals have been described as a form of public art that promote "community pride and commitment to justice while teaching outsiders about the struggles of traditionally oppressed people" (Conrad, 1995, p. 98). Although community murals have not traditionally been used to raise awareness about dementia, historically, murals have been used as a way to increase knowledge about a local issue, and to encourage further public discourse and community action to address the issue (Burnham, 2011; Szőke & Parizeau, 2019). Community murals have been used to resist harmful public narratives and increase knowledge of a number of topics including suicide (Mohatt et al., 2013), mental health (Ho et al., 2016), COVID-19 (McEwan et al., 2022) and gentrification (Schrader, 2017). However, to our knowledge, community murals have not been used to raise awareness about dementia.



In a discussion paper published over two decades ago, Hall and Robertson (2001) argue that despite claims that public art could create social change, “very little satisfactory evaluation of these claims has taken place” (p. 18). Twenty years after the discussion paper was published, findings from a systematic review on the impact of public art on cities, places and people’s lives indicate that there continues to be a lack of studies on how communities experience, perceive and engage with public art (Cheung et al., 2021). Relatedly, in a scoping review of the evidence on the role of the arts in improving health and well-being, of the 900 identified studies, none evaluated the impact of community murals on raising awareness of dementia or other issues impacting the community (WHO, 2019). Without evidence of impact of murals, it cannot be argued that community murals help to create social change. To advance knowledge about the impact of community murals in creating social change, specifically in communities working towards being dementia-friendly, this study evaluated the impact of a DFC mural aimed at raising awareness about dementia. This impact evaluation sought to answer the following research questions:

1. Does the mural capture the public’s interest?
2. Does the mural encourage the public to learn more about the work of the team leading the project?
3. Does the mural encourage and inspire the public to act?
4. Does the mural encourage the public to have conversations about dementia and/or DFCs with their social circle?
5. What lessons can be learned from the process undertaken to create this community mural?

## **Methods**

We first provide an overview of the community mural project, which is followed by a description of the methods used to evaluate the mural's impact.

### ***“Dementia-friendly communities for everyone” mural project***

In 2020, the Hamilton Council on Aging received funding from the Public Health Agency of Canada to engage persons living with dementia, care partners, and other stakeholders in the development, implementation, and evaluation of DFCs in Hamilton and Haldimand County (located in Ontario, Canada). Haldimand County has a population of approximately 49,000 people, with an estimated 21% of residents being 65 years and older (Statistics Canada, 2021). Haldimand County is composed of six small urban areas: Caledonia, Dunnville, Hagersville, Jarvis, Townsend and Cayuga.

To lead the initiative in Haldimand County, the Memory Inclusive Communities Everywhere (MICE) team, a group of four people living with dementia who reside in Haldimand County, was established in the summer of 2021. For their first project, the MICE team decided to create a community mural to achieve their goal of raising awareness about dementia in their community; they started working on the community mural project in the fall of 2021. The MICE team intentionally chose to create a community mural as their first project because both the process of creating the mural, and the mural itself, presented opportunities to actively engage with community members to raise awareness about dementia and promote inclusivity. Figure 1 provides a timeline of the process undertaken to create the community mural, including how community members were engaged throughout the process.

**[Insert Figure 1]**

In February 2022, residents of Haldimand County were invited by the MICE team to submit an original two-dimensional art piece to communicate what “Dementia Friendly Communities for Everyone” might look like (Botting, 2022b). Thirteen artists submitted their artwork and three pieces were selected by the MICE team and two community members to be displayed on a community mural (Renzella, 2022). One of the selected pieces was created by a member of the MICE team; she did not participate in the selection of process and re-joined MICE team meetings once the winning pieces had been selected.

The three winning art pieces were photographed, enlarged, and adhered to an aluminum panel. The mural was displayed on the outside wall of a pharmacy in Caledonia (see Figure 2 for a picture of the mural). The mural was unveiled in September 2022, during World Alzheimer’s month (Botting, 2022a). For the unveiling of the mural, the MICE team organized a community festival that included a community fair and marketplace, free seminars, children’s crafts, and “memory Olympics”. For the memory Olympics, community members were asked to complete several tasks while undergoing a dementia simulation (e.g., wearing glasses to blur vision). The events and seminar topics were chosen by the MICE team. This was done in accordance with an asset-based community development approach (Rahman & Swaffer, 2018), which is grounded in the premise that community members can drive community development processes themselves by identifying community needs and responding to them through the identification and mobilisation of assets (e.g., resources, people, etc). Hence, this project presents an example of an initiative that was designed in relation to “what people and communities already possess and are capable of doing” (Rahman & Swaffer, 2018, p. 132).

**[Insert Figure 2]**

### ***Outcome evaluation methods***

A practical participatory evaluation (P-PE; Cousins & Whitmore, 1998) research approach and a mixed method design (Creswell & Plano, 2017) were used for the evaluation. Unlike participatory action research, which is typically used to explore community issues and inform the development of a process and/or program, a participatory evaluation is typically used to investigate the impact of a program or process that has already been developed (Organizing Engagement, 2020). The core premise of a P-PE is that stakeholder engagement in the evaluation process should enhance the relevance, ownership and utilization of evaluation outcomes (Cousins & Whitmore, 1998). With the MICE team's consent, LGD (principal investigator) attended all MICE team meetings from September 2021- December 2022. To ensure that this outcome evaluation would support the objectives of the MICE team, the MICE team dedicated three team meetings to the evaluation of the mural. LGD facilitated these meetings, and together with the MICE team, the research questions and data collection methods were decided upon. For the other meetings, LGD sat primarily as an observer to gather information about processes undertaken for the project.

### ***Data collection methods***

There is limited guidance available about how to evaluate the impact of public art (Milne & Pojani, 2022). Gressel (2012) has proposed analyzing media coverage, conducting observations, and administering surveys as data collection methods that can be used to evaluate the impact of public art. Taking into consideration Gressel's (2012) propositions, multiple data collection methods were used to support this outcome evaluation. Table 1 provides an overview of the data collection methods used to evaluate each research question.

**[Insert Table 1]**

### *Community boards*

To encourage members of the public to think about what they can do to make their community more dementia-friendly, on the day the mural was launched, LGD set up two community boards by the mural. Each board had one question on it, “How does it feel to have this mural in our community?” and “What will you do to make our community more dementia-friendly?” Cue cards and pens were available for individuals who wished to answer the questions. Answers were pinned to the board. LGD and a volunteer supervised the boards to ensure that comments were retained once posted. An “online community board” consisting of an online survey was also developed for individuals who wanted to answer the questions at a later time, and to allow for a longer data-collection period. The survey included the two questions posted on the in-person community boards and a third question to assess whether the mural encouraged the public to have conversations about dementia and/or DFCs with their social circle, “Have you had conversations about the mural with your friends or family?”. Participants were able to select one of three answers, each with a corresponding follow-up question:

- Yes → Could you please share with us what the conversation was about?
- No → Is there a reason why you have not had a conversation about the mural with your friends or family?
- Not yet, but I will be talking about this with my friends or family in the future → Could you please share with us what you plan on talking with your friends or family about?

A QR code, which directed members of the public to the survey, was adhered to the mural at the launch event, and included in promotional materials. The online survey was available for two months.

### *Observations*

To evaluate whether the mural captured the public's interest, using non-participant observation (Ciesielska & Boström, 2018), LGD observed and tracked the numbers of times someone slowed down to look at the mural, took a picture of/with the mural, appeared to stop to read the mural's description, and/or appeared to be discussing the mural with the person(s) with whom they were. To perform these observations, LGD sat on one of the two benches placed in front of the mural. Observations occurred the day after the launch of the mural; the weekend following the launch of the mural; and two, four, six and eight weeks after the launch.

#### *MICE website tracking*

To assess whether the mural encouraged members of the public to learn more about the work of the MICE team, a QR code was developed directing individuals to MICE's website ([www.micehaldimand.ca](http://www.micehaldimand.ca)). The number of people who accessed the hyperlink through the QR code was tracked for two months. The QR code was displayed by the mural and in the launch event's program.

#### *Social media posts and media requests*

To evaluate whether the mural captured the interest of the public, for the two months following the launch, the research team tracked the number of individuals who engaged with social media posts posted by community partners (e.g., likes, comments and shares) and media requests to learn more about the mural and the work of the MICE team. LGD used her personal social media accounts to track publicly available social media posts about the mural on Twitter, Instagram and Facebook.

#### *Interviews and focus group*

To evaluate if the mural captured the interest of the public, and to understand what lessons were learned in developing and implementing this project, in December 2022, the MICE team was

invited to participate in a focus group with LGD. Additionally, the project coordinator, the artists who won the mural competition, and the pharmacist who provided wall space outside of his pharmacy to display the mural, were invited to participate in an interview with LGD. Focus group and interview participants were asked questions about their perceptions of the impact of the mural and lessons they learned from their involvement with this project. Questions included “When reflecting about the process of this project, is there anything that you would have done differently? Is there something that worked well?” and “Do you think, so far, the mural has achieved what you had hoped?” The focus group and interviews were conducted using the Zoom platform. Only the audio recordings were used for this study. Table 2 provides the evaluation’s timeline.

**[Insert Table 2]**

### **Ethics Approval**

This study received approval from the Hamilton Integrated Research Ethics Board (Project 15031).

### **Data analysis**

The qualitative data (community boards, focus group and interview transcripts, and comments on social media posts) and quantitative data (observation counts, social media and media requests tracking, and tracking of engagement with MICE’s webpage) were equally important in addressing the research questions.

LGD and LL analyzed the qualitative data using content analysis (Elo & Kyngäs, 2008). Content analysis is used to examine text intensively for the purpose of classifying text into categories that represent similar meanings (Elo & Kyngäs, 2008). The focus group and interview transcripts were imported into Dedoose (SocioCultural Research Consultants LLC, 2019), a

program designed to store and organize qualitative data. Initial coding for the focus group and interview transcripts was conducted in the Dedoose platform. Once initial codes were finalized, all codes and associated quotations were transferred to an excel spreadsheet where they were further refined. The community board responses were imported to an excel spreadsheet. LGD went through the community board responses first and developed a coding sheet which was used by LGD & LL to analyse the data. Once all data from the community boards were organized into codes, codes were grouped into categories. Moreover, the qualitative information from the community boards was quantified by providing a summary of the number of responses that fell under each category. Lastly, to generate the list of lessons learned from the process undertaken to create the mural, LGD went through the answers provided by interview and focus group participants related to this research question (e.g., “When reflecting about the process of this project, is there anything that you would have done differently? Is there something that worked well?”) and recorded all of the points raised by participants. LGD shared the preliminary list with the MICE team to check for accuracy and the list was updated accordingly.

Quantitative data consisted of: tracking number of times members from the public interacted with the mural; tracking of likes, comments and shares of social media posts posted by community partners; tracking of media requests; and tracking of how many people accessed a hyperlink directing them to MICE’s website via QR code. The data were tracked overtime to see if there was an increase in engagement with the mural after media events, social media posts and other communication strategies. Excel was used to generate descriptive statistics for the numeric variables.

Integration of the qualitative and quantitative data happened at the interpretation and reporting stages using a weaving narrative approach (Fetters et al., 2013). This approach involves



including both quantitative and qualitative results together (through narrative) on a topic-by-topic basis. LGD shared preliminary findings with the MICE team and discussed with them the meaning and significance of findings. The MICE team's feedback was integrated in the interpretation of findings.

## **Results**

For reporting purposes, we first provide an overview of the collected data, followed by the evaluation findings. The results are organized and presented by research question.

### ***Overview of collected data***

Twenty people contributed to the in-person community boards; 34 contributed to the online survey. LGD conducted seven observations between Sept 25 to Nov 24, totalling 13 hours (refer to Table 2 for the breakdown of hours and times of day). During the two-month period of data collection, there were zero scans of the QR code directing people to MICE's website. Due to lack of data regarding user engagement with MICE's website, the research team decided to include website views from August to November as a data source to determine if a pattern could be noticed between views and events associated with the mural (e.g., promotion of the launch event and launch event).

Over the two-month data collection period, three social media posts by community partners (on Twitter) and two social media posts by members of the public (one in Instagram, one in Facebook) were identified. Both social media posts by members of the public were made by one of the artists (one in Facebook, the other in Instagram). The posts from the community partners had fewer than five likes each and no comments; the Facebook post from the artist had 42 likes and the Instagram post had 12 likes.

Following the launch of the mural, the MICE team had one media request from the local newspaper for more information about the mural and their work. Lastly, five individuals

participated in the interviews (project coordinator, pharmacists and the three winning artists) and all members of the MICE team participated in the focus group. The MICE team member who created one of the winning art pieces participated in a focus group and in an interview. To avoid redundancy, she was interviewed after she had participated in the focus group and was asked if she wanted to elaborate on anything else, or if as an artist, there was something related to the process about which she wanted to comment.

***Did the mural capture the public's interest?***

The observation tracking sheet was originally created to capture information about engagement with the mural by individuals who walked by it. However, the mural was located in a heavy vehicular-traffic area with minimal foot-traffic; therefore, the tracking sheet was modified to capture interactions with the mural from people in cars. A traffic red light was near the mural allowing for the observation of passengers in cars while they were waiting at the light. Based on the observations, on average, one person per hour took a picture of the mural while walking by, someone appeared to be looking at the mural from their car 10.5 times per hour, 1.4 people per hour appeared to be having conversations about the mural in their car, and less than one person per hour appeared to be reading the description of the mural while waking by it (refer to Table 3). Notably, we did not record the number of cars that passed by the mural per hour, and therefore, cannot report on whether our findings indicate that a high or low percentage of people appeared to be intrigued by the mural.

**[Insert Table 3]**

We identified a theme in the analysis of the interviews and focus group noting that **the mural has planted a seed for change**. As described by a focus group participant and an interview participant respectively, *“the mural has started conversations and that’s important”* (07), and

*“the semi-permanence of the mural allows for a constant reminder to be more inclusive and kinder”* (01). The permanence of the mural was described by participants as being important for starting to raise community awareness about dementia. Although findings from our observations, interviews and the focus group indicate that the mural has captured the public’s attention, lack of media requests and engagement with MICE’s website and social media posts suggests that the mural has not encouraged members of the public to learn more about the work of the MICE team.

***Did the mural encourage the public to learn more about the work of the MICE team?***

From reviewing MICE’s website views from August to November, we found that there was a spike in views in September (342 views, compared to 50 views in August, 63 in October and 29 in November), which is the month in which the mural was launched (refer to Figure 3). Review of website views for the month of September indicate that September 23<sup>rd</sup> (the day before the launch for the mural) had the most views, with 41 users engaging with the website. The spike in views could be due to promotional efforts for the MICE festival. However, views did not increase after this date indicating that the mural did not encourage the public to visit MICE’s website to learn more about their work.

**[Insert Figure 3]**

***Did the mural encourage and inspire the public to act?***

From the 54 community board responses to the question *“What will you do to make our community more dementia-friendly?”* 52 people indicated that they will be doing something to make their community more dementia-friendly, and two responded that they will not be doing anything. Five categories of things that people will be doing were identified (refer to Table 4): support all community members, regardless of their diagnosis (32%); seek more dementia

education (30%); raise awareness about dementia (15%); advocate for people living with dementia (4%); volunteer (2%). Six people included in their response more than one thing that they will be doing to make their community more dementia-friendly. Responses to the community board question indicate that the mural encouraged some members of the public to act. Although we did not assess whether people followed through with their proposed actions, this finding reinforces the theme that the mural has planted a seed for change.

**[Insert Table 4]**

Moreover, from the 48 community board responses to the question “*How does it feel to have this mural in our community?*” five categories were identified in the analysis (refer to Table 5): amazing (34%); inspiring (32%); inclusive (22%); source of pride (11%); impartial (1%). Responses to the community board question indicate that the mural elicited positive feelings in most people that contributed to the community boards.

**[Insert Table 5]**

***Did the mural encourage the public to have conversations about dementia and/or DFCs with their social circle?***

From the 34 online-community board responses to the question, “*Have you have conversations about the mural with your friends or family?*” 16 (47%) indicated that they have had conversations with their social circle, 6 (18%) indicated that they have not had conversations with their social circle, and 12 (35%) indicated that they had not had conversations with their social circle yet, but they plan on having one. Additionally, from the interviews, three of the participants indicated that being involved in this project had not resulted in conversations about dementia and/or DFCs with their friends or family. From the 16 people who reported having conversations with their social circles about the mural, five categories of the topics discussed in

their conversations were identified in the analysis (refer to Table 7): the mural (38%); dementia (25%), the MICE team (19%); helping others (12%) and research (6%). Refer to Table 6 for a summary of the categories. Similarly, from the 12 people planning to have a conversation with their social circle, three categories of discussion topics were identified in the analysis: dementia awareness and education (67%); how to support persons living with dementia (25%); and the MICE team (8%). Responses to the online-community board questions indicate that the mural encouraged some people to have conversations with their social circle about dementia, and other topics related to the work of the MICE team. These findings further reinforce that the mural has planted a seed for change.

**[Insert Table 6]**

**[Insert Table 7]**

***What lessons can be learned from the process undertaken to create this community mural?***

Findings from the interviews and focus group were used to compile a list of lessons learned through the process of creating this community mural:

1. For a project to be truly inclusive, it is essential to involve persons living with dementia in planning and implementation processes.
2. Creating the opportunity for persons living with dementia to lead the development and implementation of community projects is a powerful way of combating stigma.
3. A strength of a community mural is that both the process of creating the mural and the outcome can increase awareness and impact.
4. After the launch of the mural, more follow-up activities would have been helpful to increase awareness and encourage people to engage with the mural.
5. A social media campaign could have increased engagement from different age groups.

6. It is important to think about the location of the mural and how people will be interacting with it. Most people saw the mural from their car which could be a reason why nobody scanned the QR code to access MICE's website.
7. It is important to consider which medium will be used to display the artwork. Removable aluminum panels provide the possibility of reinstalling the mural in another location/community.
8. To raise awareness about the mural, leveraging other community projects, such as the local fall fair, may have been helpful.
9. One of the most impactful things about the launch event was having the MICE team sharing their experiences of living with dementia, which provided an opportunity to educate the community about dementia.
10. The MICE festival was intended to bring attention to the mural; however, the mural was a 10-minute walk from the festival and not everyone who attended the festival went to see the mural. Thus, a specific event right by the mural may have brought more attention to the mural.
11. Embedding an evaluation component was identified by the MICE team as a strength of the project. The evaluation helped them stay focused on what they wanted to achieve, added credibility to their work, and elements of the evaluation (e.g., community boards) created opportunities to further encourage people to think about how they can help create more inclusive communities.

Lastly, from the interviews and focus group we learned that the project had a positive impact on everyone involved. As described by two MICE team members "*it [this project] brought us back into the community of doers. That on itself was gigantic.*" (05) and "*I've been sitting at*

*home for year, doing nothing. This project was amazing to do... I am surprised that it became what it did"* (04). As illustrated in the comments, prior to this project, MICE team members were not engaged in community activities. This project provided MICE team members with an opportunity to be meaningfully engaged in a project that was important to them and has empowered them to continue advocating for inclusive communities. Similarly, interview participants shared that involvement with this project resulted in greater awareness about dementia and a shift in their attitudes. As shared by an interview participant, *"you have kind of a stereotype of what someone living with dementia is like, and my stereotype has probably been more on the side of you know, they become very dependent people that don't have much independent ability. And just to see how they [MICE team members] deal with their challenges, that brought more awareness to me of the scope of what people with dementia are able to do."* (08). Thus, findings suggest that an impactful element of dementia awareness raising initiatives is contact between persons living with dementia and members of the public.

## **Discussion**

The aim of this outcome evaluation was to assess the impact of MICE's community mural and to capture lessons learned from the process undertaken to create the mural. Findings from this study add to our understanding of the potential impact that community murals could have on social change, particularly on raising dementia awareness and starting conversations about dementia and DFCs. Although we did not evaluate the long-term impact of MICE's mural, our findings indicate that the process of creating the mural, and the mural itself, have planted a seed for increased dementia awareness and inclusion of persons living with dementia in the Haldimand County community.

### ***Impact of the process undertaken to create the mural***

### *Impact on stakeholders*

As illustrated in Figure 1, the MICE team engaged with community members several times throughout the mural project. Engagement with community members varied from newspaper articles to communication with vendors regarding the display of the mural, and interaction with community members on the day of the mural's launch. Through these engagements, the MICE team had the opportunity to raise awareness about dementia. In accord with previous research, which has shown that opportunities for contact with a stigmatized group of people is an effective strategy to reduce stigma (see e.g., Griffiths et al., 2014), stakeholders who participated in the interviews shared that contact with the MICE team increased their awareness about dementia and challenged their misconceptions about the capabilities of persons living with dementia. Despite the benefits of contact between persons living with dementia and community members, in most dementia awareness raising campaigns, persons living with dementia do not directly engage with community members (Phillipson et al., 2019). Evidence from this evaluation suggests that direct contact between persons living with dementia and community members is an effective way of challenging misconceptions about dementia and reducing dementia-related stigma, emphasizing the importance of providing opportunities for persons living with dementia to be actively involved in planning and implementation processes of dementia awareness campaigns.

### *Impact on MICE team members*

As described by persons living with dementia, empowerment is “a confidence-building process whereby [persons living with dementia] are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources” (McConnell et al., 2019, p. 9). This definition of empowerment aligns with what MICE team members shared about the impact that this project had on them



personally; leading this project made them feel empowered, further increasing their desire to continue advocating for change in their communities. Similarly, persons living with dementia involved in a project from the United Kingdom called the Dementia Engagement and Empowerment Project (DEEP) have expressed that when they are provided with the appropriate supports to lead and manage initiatives, they feel empowered to continue to advocate and create change in their communities (DEEP, 2019; Litherland & Williamson, 2013). The empowerment of MICE team members illustrates that when marginalized populations, such as persons living with dementia, are given the resources and opportunities to lead projects aimed at improving the well-being of the populations that they represent, there is significant potential for impact at the personal (i.e., those leading the project) and community level (i.e., who the project is aimed to target).

MICE team member's comments about the positive impact that the project has had on them personally (e.g., "*it [this project] brought us back into the community of doers. That on itself was gigantic.*" (05)) also support the claim that an asset-based approach creates an opportunity for marginalized individuals to rebuild their confidence and self-esteem and regain motivation for participation in meaningful activities (Rahman & Swaffer, 2018). Importantly, by supporting the engagement of persons living with dementia in community development programs, the autonomy and agency of persons living with dementia and their expertise and contributions are acknowledged and respected.

### ***The impact of the mural***

Through this evaluation, we aimed to evaluate the impact of MICE's mural on community members by assessing whether the mural encouraged community members to learn more about the work of the MICE team, inspired them to act, and/or encouraged them to have conversations

about dementia and/or DFCs with their social circle. Additionally, through observations and social media tracking, we aimed to assess whether the mural captured the interest of community members.

Findings from our observations indicate that the mural captured the attention of some community members driving and/or walking by it. However, lack of media requests and engagement with MICE's website and social media posts suggests that the mural has not encouraged members of the public to learn more about the work of the MICE team, the mural, or to take action by engaging social media to create conversation. Lack of interest from community members to learn more about the meaning of a mural was also found in an evaluation of a mural in Durban, South Africa (Marschall, 1999); even though community members had been passing by the mural regularly, they had not taken a closer look at it and expressed they were not inclined to learn more about it (Marschall, 1999).

As described by Brennan (2019), the creation of participatory public art, such as community murals, promotes the engagement of members from the public through the planning, selection, creation, installation, maintenance and ongoing interaction with the final product. Although the MICE team engaged community stakeholders from the planning through the installation stages, they did not create a plan for engagement following the launch of the mural. Upon reflection, further activities and/or opportunities for members of the public to engage with the themes of the mural could have further spread awareness about dementia and DFCs. A recurrent theme that arose from the interviews and focus group was that a social media strategy to encourage further discussion about what members of the public could do to make their communities more dementia-friendly could have been helpful to increase awareness about the mural. Two principles have been proposed for creating public health initiatives suited to social

media: creating engaging and stimulating content that encourages people to share it with their network, and encouraging interaction with the content through message boards and user-generated content (Kilaru et al., 2014). For example, to encourage people to share a picture of the mural with their social network, the MICE team could have developed a contest inviting members of the public to share a picture of the mural along with what a DFC means to them. The social media campaign would need to be directed at diverse platforms with particular hashtags to reach the desired population.

One way in which community members were engaged after the launch of the mural was through the online-community boards. The community boards served two purposes, they provided data for this evaluation as well as an opportunity to stimulate reflection about the themes of the mural (i.e., dementia and DFCs). When prompted with questions related to the themes of the mural, 96% of respondents who participated in the community boards indicated that they intended to do at least one thing (e.g., volunteer) to make their community more dementia-friendly. Additionally, 82% of respondents who completed the online-community board indicated that they have had or were planning to have a conversation about the mural with their social circle. These findings suggest that using questions to prompt community members to think about the theme(s) of the mural is one way to support community appreciation of the public art piece and to encourage reflection and further discussion. The community boards are one example of what Brennan (2019) refers to as *participatory collective appreciation* –the use of activities and events to promote reflection, encourage dialogue and appreciation of public artwork. Findings from this evaluation suggest that prompting community members with questions about the theme(s) of the mural is one way to promote collective appreciation and to increase awareness about the community issue that stakeholders are working towards.

## **Limitations**

Although in this evaluation we used numerous data collection methods to understand the impact of MICE's mural, our data collection methods have limitations. Firstly, a small number of community members participated in the community boards, and we did not follow up on whether participants in fact acted, as they had indicated they would, to make their community more dementia-friendly; therefore, based on the findings it can only be assumed that the mural inspired participants to think about what they could do to make their community more dementia-friendly. Additionally, Google analytics provided us with information about webpage visits; however, we were not able to track whether the mural and/or promotional efforts were the reason that users visited the webpage. Moreover, the MICE team, project coordinator and artists have a vested interest in the success of the project, and they all commented on the positive impact that the mural has had. To prevent their answers from biasing results, we used multiple data sources to support evaluation findings and when applicable, provided corroborating evidence from other data sources to understand the impact of the mural. Furthermore, we cannot ensure that each count from our observations represents a unique individual; some individuals could have interacted with the mural more than once. Therefore, findings from our observations should be interpreted with caution. Lastly, all of our materials were in English which prevented participation from community members who cannot read or write in English. Further research is needed to understand whether public art could be used to raise dementia awareness in ethnically diverse communities.

## **Conclusion**

Community murals and other forms of public art have been used as a method to raise awareness and encourage discussion about issues impacting the community (Burnham, 2011; Szöke &

Parizeau, 2019). However, there is limited information about the impact of public art on social change. The aim of this evaluation was to advance our understanding of the impact of community murals by evaluating the impact of a community mural that was created to raise awareness about dementia and DFCs. Our findings indicate that public art can plant a seed for social change (e.g., increase dementia awareness and inclusion of persons living with dementia), particularly if the piece is displayed for a prolonged period of time, and if throughout the project there are embedded opportunities for community engagement with educational material about the theme(s) being depicted in the art, and/or direct contact with persons living with the condition about which the art piece is trying to raise awareness. Findings from this evaluation suggest that community murals can be one tool that stakeholders can use to raise awareness about dementia; however, as stated by Kent and Nikitin (2012), “public art projects will be most effective when they are part of a larger, holistic, multidisciplinary approach” (para. 6). Thus, to create social change, complementary awareness raising initiatives, such as community education workshops or a social media campaign, are recommended. These additional activities can encourage further conversations about the art piece and personal action.

## References

- Alzheimer's Disease International** (2016) *Dementia Friendly Communities: Key Principles*. <https://www.alzint.org/u/dfc-principles.pdf> (accessed 25 February 2023)
- Alzheimer's Disease International** (2022) *A Guide to planning a successful World Alzheimer's Month Campaign*. [www.alzint.org/wam](http://www.alzint.org/wam) (accessed 3 March 2023)
- Alzheimer Society of Canada** (2022) *Navigating the pathway forward for dementia in Canada*. [https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path\\_Alzheimer-Society-Canada.pdf](https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada.pdf) (accessed 3 March 2023)
- Botting T** (2022a) What you need to know about MICE Festival Haldimand. *The Haldimand Press*. <https://www.thespec.com/local-haldimand/news/2022/09/04/what-you-need-to-know-about-mice-festival-haldimand.html> (accessed 2 April 2023)
- Botting T** (2022b) Making Haldimand more dementia friendly. *The Hamilton Spectator*. <https://www.thespec.com/local-haldimand/news/2022/02/14/making-haldimand-more-dementia-friendly.html> (accessed 2 April 2023)
- Brennan J** (2019) Public Art and the Art of Public Participation. *National Civic League* **108**(3), 34–44. <https://doi.org/10.32543/naticivirevi.108.3.0034>
- Burnham L** (2011) *A working guide to the landscape of art for change: Community arts at work across the U.S. Animating Democracy*. [https://www.americansforthearts.org/sites/default/files/CommunityArtsWorkAcrossLBurnhamTrendPaper1\\_0.pdf](https://www.americansforthearts.org/sites/default/files/CommunityArtsWorkAcrossLBurnhamTrendPaper1_0.pdf) (accessed 3 March 2023)
- Cheung M, Guaring G, Smith N & Craven O** (2021) The Impacts of Public Art on Cities, Places and People's Lives. *The Journal of Arts Management, Laws and Society* **52**, 37-50. <https://doi.org/10.1080/10632921.2021.1942361>
- Ciesielska M & Boström K** (2018) Observation Methods. *Qualitative Methodologies in Organization Studies*. 33–52. [https://doi.org/10.1007/978-3-319-65442-3\\_2](https://doi.org/10.1007/978-3-319-65442-3_2)
- Conrad D** (1995) Community Murals as Democratic Art and Education. *The Journal of Aesthetic Education* **29**(1), 98–102. <https://www.jstor.org/stable/3333522>
- Cousins B & Whitmore E** (2004) Framing participatory evaluation. *New Directions for Evaluation* **1998**(80), 5–23. <https://doi.org/10.1002/ev.1114>
- Creswell J & Plano C** (2017) *Designing and conducting mixed methods research* (3rd ed.). SAGE Publications.
- DEEP** (2019) *What is deep? As seen through the eyes of London DEEP Gathering*. <https://www.dementiavoices.org.uk/wp-content/uploads/2019/07/What-is-DEEP-A5-Booklet.pdf> (accessed 1 May 2023)
- Elo S & Kyngäs H** (2008) The qualitative content analysis process. *Journal of Advanced Nursing* **62**(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Fetters M, Curry L & Creswell J** (2013) Achieving Integration in Mixed Methods Designs- Principles and Practices. *Health Services Research* **48**, 2134–2156. <https://doi.org/10.1111/1475-6773.12117>
- Frankish H & Horton R** (2017) Prevention and management of dementia: a priority for public health. *The Lancet* **390**(10113), 2614–2615. [https://doi.org/10.1016/S0140-6736\(17\)31756-7](https://doi.org/10.1016/S0140-6736(17)31756-7)
- Gove D, Downs M, Vernooij-Dassen M & Small N** (2016) Stigma and GPs' perceptions of dementia. *Aging & Mental Health* **20**(4), 391–400. <https://doi.org/10.1080/13607863.2015.1015962>
- Gressel K** (2012) *Public art and the challenge of evaluation*.

- <https://createequity.com/2012/01/public-art-and-the-challenge-of-evaluation/> (accessed 12 May 2023)
- Griffiths K, Carron-Arthur B, Parsons A & Reid R** (2014) Effectiveness of programs for reducing the stigma associated with mental disorders. A meta-analysis of randomized controlled trials. *World Psychiatry : Official Journal of the World Psychiatric Association* **13**(2), 161–175. <https://doi.org/10.1002/WPS.20129>
- Hall T & Robertson I** (2001) Public Art and Urban Regeneration: advocacy, claims and critical debates. *Landscape Research* **26**(1), 5–26. <https://doi.org/10.1080/0142639012002445>
- Ho R, Potash J, Ho A, Ho V & Chen, E** (2016) Reducing mental illness stigma and fostering empathic citizenship: Community arts collaborative approach. *Social Work in Mental Health* **15**(4), 469–485. <https://doi.org/10.1080/15332985.2016.1236767>
- Kent F & Nikitin C** (2012) *Collaborative, Creative Placemaking: Good Public Art Depends on Good Public Spaces*. <https://www.pps.org/article/collaborative-creative-placemaking-good-public-art-depends-on-good-public-spaces> (accessed 23 May 2023)
- Kilaru A, Asch D, Sellers A & Merchant R** (2014) Promoting Public Health Through Public Art in the Digital Age. *American Journal of Public Health* **104**(9), 1633. <https://doi.org/10.2105/AJPH.2014.302088>
- Litherland R & Williamson T** (2013) DEEP: The engagement, involvement and empowerment of people with dementia in collective influencing. *Working with Older People* **17**(2), 65–73. <https://doi.org/10.1108/13663661311325481/FULL/PDF>
- Marschall S** (1999) A critical investigation into the impact of community mural art. *Transformation* **40**, 55–86.
- Matsumoto H, Maeda A, Igarashi A, Weller C & Yamamoto-Mitani N** (2021) Dementia education and training for the general public: a scoping review. *Gerontology & Geriatrics Education*, **44**(1), 1-31. <https://doi.org/10.1080/02701960.2021.1999938>
- McConnell T, Sturm T, Best P, Stevenson M, McCorry N, Donnelly M & Taylor B** (2019) Co-producing a shared understanding and definition of empowerment with people with dementia. *Research Involvement and Engagement* **5**(1), 1–11. <https://doi.org/10.1186/S40900-019-0154-2/TABLES/4>
- McEwan C, Szablewska L, Lewis K & Nabulime L** (2022) Public-making in a pandemic: The role of street art in East African countries. *Political Geography*, **98**, 102692. <https://doi.org/10.1016/J.POLGEO.2022.102692>
- Milne C & Pojani D** (2022) Public art in cities: what makes it engaging and interactive? *Journal of Urban Design*, 1–20. <https://doi.org/10.1080/13574809.2022.2121272>
- Mohatt N, Singer J, Evans A, Matlin S, Golden J, Harris C, Burns J, Siciliano C, Kiernan G, Pelleritti M & Tebes J** (2013) A Community’s Response to Suicide Through Public Art: Stakeholder Perspectives from the Finding the Light Within Project. *American Journal of Community Psychology* **52**(1–2), 197–209. <https://doi.org/10.1007/S10464-013-9581-7>
- Nguyen T & Li X** (2020) Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia: The International Journal of Social Research and Practice* **19**(2), 148–181. <https://doi.org/10.1177/1471301218800122>
- Organizing Engagement** (2020) *Participatory action research and evaluation*. <https://organizingengagement.org/models/participatory-action-research-and-evaluation/> (accessed 3 February 2023)
- Parker M, Barlow S, Hoe J & Aitken L** (2020) Persistent barriers and facilitators to seeking



- help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics* **32**(5), 611–634.  
<https://doi.org/10.1017/S1041610219002229>
- Phillipson L, Hall D, Cridland E, Fleming R, Brennan-Horley C, Guggisberg N, Frost D & Hasan H** (2019) Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia: The International Journal of Social Research and Practice* **18**(8), 2679–2694.  
<https://doi.org/10.1177/1471301218754455>
- Rahman S & Swaffer K** (2018) Assets-based approaches and dementia-friendly communities. *Dementia* **17**(2), 131–137. <https://doi.org/10.1177/1471301217751533>
- Renzella M** (2022) DICE mural contest winners announced. *The Haldimand Press*.  
<https://haldimandpress.com/dice-mural-contest-winners-announced/> (accessed 12 June 2023)
- Schrader T** (2017) The Colors of Loisaída: Embedding Murals in Community Activism: *Journal of Urban History* **44**(3), 519–532. <https://doi.org/10.1177/0096144217699173>
- SocioCultural Research Consultants LLC** (2019) *Dedoose Version 8.3.35, web application for managing, analyzing, and presenting qualitative and mixed method research data*.  
[www.dedoose.com](http://www.dedoose.com)
- Statistics Canada** (2021) *Profile table, Census Profile, 2021 Census of Population - Haldimand County, City (CY) [Census subdivision], Ontario*. <https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/page.cfm?DGUIDlist=2021A00053528018&GENDERlist=1&HEADERlist=0&Lang=E&STATISTIClist=1&SearchText=Haldimand+County> (accessed 23 June 2023)
- Szöke T & Parizeau K** (2019) Community-Based Public Art and Gentrification in the Downtown Eastside of Vancouver. *GeoHumanities* **5**(1), 157–177.  
<https://doi.org/10.1080/2373566X.2018.1543554>
- Thornicroft G, Rose D, Kassam A & Sartorius N** (2007) Stigma: ignorance, prejudice or discrimination? *The British Journal of Psychiatry* **190**(3), 192–193.  
<https://doi.org/10.1192/BJP.BP.106.025791>
- van Wijngaarden E, Alma M & The A** (2019) ‘The eyes of others’ are what really matters: The experience of living with dementia from an insider perspective *PLOS ONE* **14**(4), e0214724. <https://doi.org/10.1371/JOURNAL.PONE.0214724>
- World Health Organization** (2012) *Dementia a public health priority*.  
<https://www.who.int/publications/i/item/dementia-a-public-health-priority> (accessed 3 July 2023)
- World Health Organization** (2019) *What is the evidence on the role of the arts in improving health and well-being? A scoping review*.  
[https://apps.who.int/iris/bitstream/handle/10665/329834/9789289054553-eng.pdf?utm\\_source=The+King%27s+Fund+newsletters+%28main+account%29&utm\\_medium=email&utm\\_campaign=11042446\\_NEWSL\\_HMP+2019-11-12&dm\\_i=21A8,6KOEM,KO3F1D,Q6IN9,1](https://apps.who.int/iris/bitstream/handle/10665/329834/9789289054553-eng.pdf?utm_source=The+King%27s+Fund+newsletters+%28main+account%29&utm_medium=email&utm_campaign=11042446_NEWSL_HMP+2019-11-12&dm_i=21A8,6KOEM,KO3F1D,Q6IN9,1) (accessed 2 July 2023)
- World Health Organization** (2021a) *Towards a dementia inclusive society*.  
<https://www.who.int/publications/i/item/9789240031531> (accessed 3 June 2023)
- World Health Organization** (2021b) *Dementia*. <https://www.who.int/news-room/fact-sheets/detail/dementia> (accessed 3 May 2023)



**Table 1.** Research questions and data collection methods.

| <b>Evaluation Question</b>  | <b>Data Collection Methods</b>  |
|---|---|
| Does the mural capture the public’s interest?   | <ul style="list-style-type: none"> <li>• Observations</li> <li>• Interviews and focus group</li> <li>• Social media tracking</li> <li>• Media request tracking</li> </ul> |
| Does the mural encourage the public to learn more about the work of the MICE team?  | <ul style="list-style-type: none"> <li>• Number of QR code scans (QR code directed people to MICE’s website)</li> </ul>   |
| Does the mural encourage and inspire the public to act?   | <ul style="list-style-type: none"> <li>• In-person and online community boards</li> </ul>   |
| Does the mural encourage the public to have conversations about dementia and/or dementia friendly communities with their social circle? | <ul style="list-style-type: none"> <li>• Online community board</li> <li>• Interviews</li> </ul>  |
| What lessons can be learned from the process undertaken to create this community mural?   | <ul style="list-style-type: none"> <li>• Interviews and focus group</li> <li>• Findings from collected data (i.e., all data sources)</li> </ul>                           |

**Table 2.** Impact evaluation timeline.

| <b>Community boards</b>  | <b>Observations</b>     | <b>MICE’s webpage, social media posts and media requests tracking</b>  | <b>Interviews and Focus group</b> |
|--|-------------------------|--|-----------------------------------|
| Sept 24- Public launch: in-person community board  | Sept 25 – 3pm-5pm       | <br>Until November 24, 2022 | Dec 2022- Jan 2023                |
| <br>Online board (until Nov 24, 2022) | Sept 30 – 9am-11am      |  |                                   |
|  | Oct 1 – 10am-12pm       |  |                                   |
|  | Oct 8 – 12pm-2pm        |  |                                   |
|  | Oct 16 – 11:30am-1:00pm |  |                                   |
|  | Oct 24 – 10am-12pm      |  |                                   |
|  | Nov 24 –130pm-230pm     |  |                                   |

**Table 3.** Observation results.

|   | <b>Number of times that someone took a picture of the mural while walking by it</b> | <b>Number of times that someone appeared to be looking at the mural from their car</b> | <b>Number of people that appeared to be having conversations about the mural in their car*</b> | <b>Number of times that someone appeared to be reading the mural's description</b> |
|---|---|--|--|--|
| <b>13 hours of observation</b>              | 13  | 137  | 18   | 8  |
| <b>Number of people on average per hour</b> | 1   | 10.5   | 1.4  | 0.62   |

\* This number was calculated by counting the people in the car that appeared to be having a conversation about the mural. In all cases, two people per car were counted (i.e., 9 cars, for a total of 18 people).

**Table 4.** Community boards answers to the question “*What will you do to make our community more dementia-friendly?*”

|   |          |
|---|----------|
| <b>Support all community members, regardless of their diagnosis</b><br><i>“Be there more for people who need assistance no matter for what. If seeing a need, not wait to ask but offer help and respect what the person would like, to be helped or not to be helped.”</i> | 19 (32%) |
| <b>Seek more dementia education</b><br><i>“I will commit to learning and understanding those living with dementia and their experiences- ask them in which ways I can help.”</i>  | 18 (30%) |
| <b>Raise awareness about dementia</b><br><i>“I will inspire people to learn and ask questions as knowledge &amp; awareness combats stigma.”</i>   | 15 (25%) |
| <b>Advocate for people living with dementia</b><br><i>“Continue to advocate for home health services to allow people to remain at home longer. Caregivers such as spouses and/or children need increased support in term of caregiver relief.”</i>                          | 4 (7%)   |
| <b>Volunteer</b><br><i>“Volunteer wherever I can help.”</i>   | 2 (3%)   |
| <b>Nothing</b>  | 2 (3%)   |

**Table 5.** Community boards answers to the question “How does it feel to have this mural in our community?”

|   |          |
|---|----------|
| <b>Amazing</b><br><i>“Amazing! A real honour.”</i>  | 15 (34%) |
| <b>Inspiring</b><br><i>“It feels ground-breaking and exciting! This is change in the making and I am inspired.”</i>                             | 14 (32%) |
| <b>Inclusive</b><br><i>“It is nice to see representation of all kinds of people in Haldimand county, including people living with dementia”</i> | 10 (22%) |
| <b>Source of pride</b><br><i>“It feels good to acknowledge that there are people with dementia living in our community. Very proud of it!”</i>  | 5 (11%)  |
| <b>Impartial</b>  | 4 (1%)   |

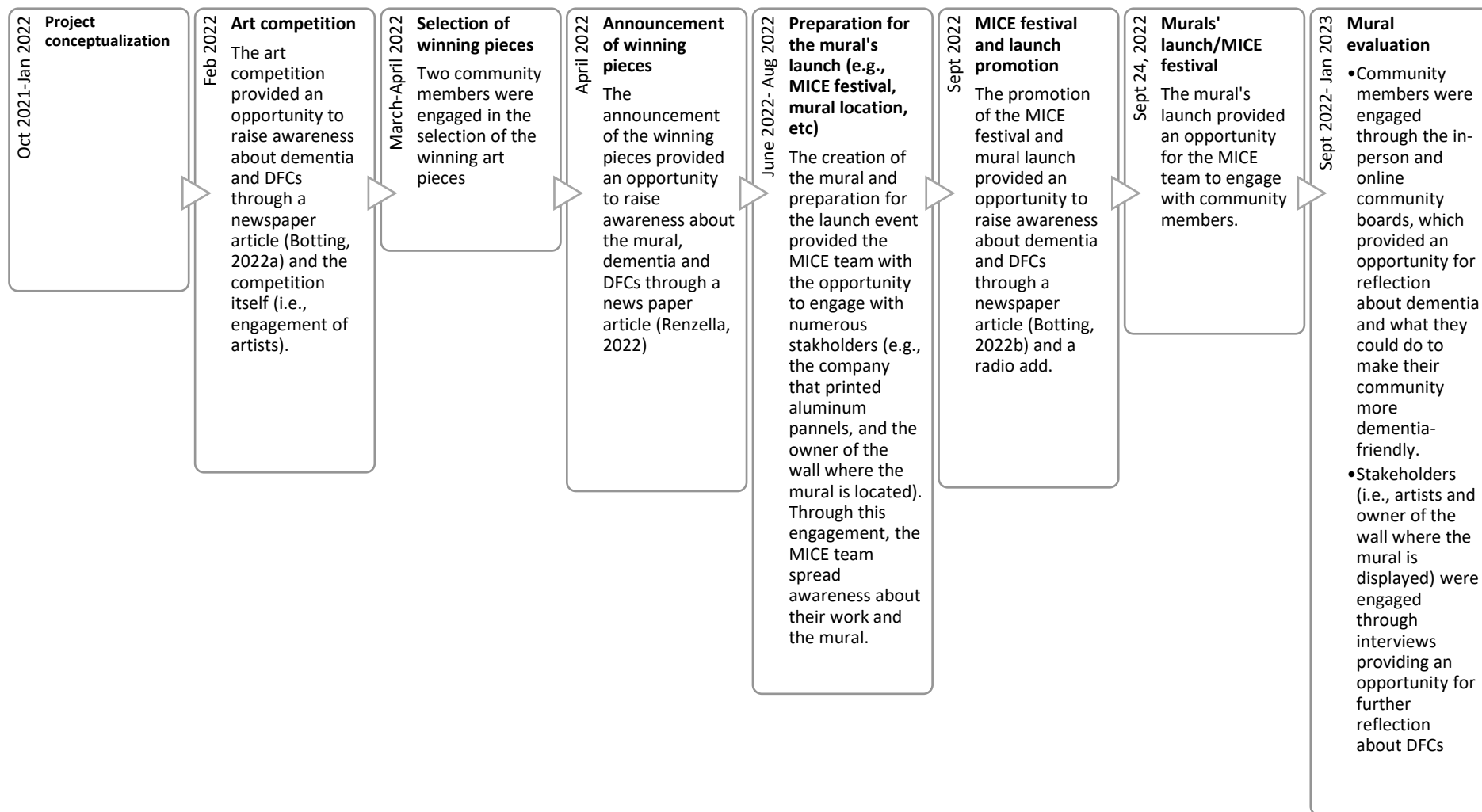
**Table 6.** Online-community board answers to the question “What was the conversation with your friends or family about?”

|  |         |
|--|---------|
| <b>The mural</b><br><i>“We talked about how great it was to have the mural, especially coming from local artists.”</i>             | 6 (38%) |
| <b>Dementia</b><br><i>“How the mural inspired me to learn more about dementia.”</i>  | 4 (25%) |
| <b>The MICE team</b><br><i>“The MICE team and why what they are trying to do in Haldimand is important.”</i>                       | 3 (19%) |
| <b>Helping others</b><br><i>“Being more aware of people that need help in the community, step up and help as much as you can.”</i> | 2 (12%) |
| <b>Research</b><br><i>“Progress in research.”</i>  | 1 (6%)  |

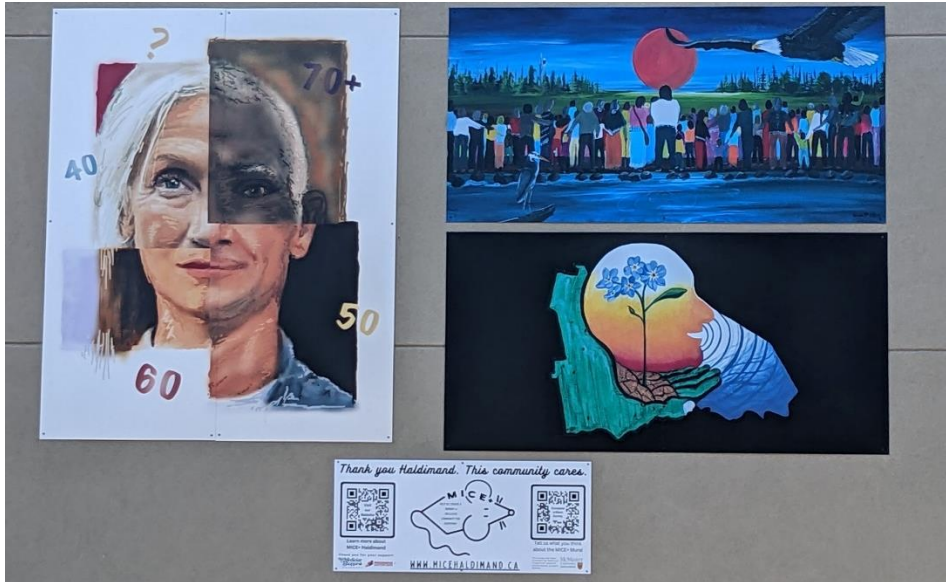
**Table 7.** Online-community board answers to the question “What conversations are you planning on having with your friends/family?”

|  |         |
|--|---------|
| <b>Dementia awareness and education</b><br><i>“Advocating for people living with dementia and talking about what dementia is.”</i> | 8 (67%) |
| <b>How to support persons living with dementia</b><br><i>“The challenges that people with dementia face and how we can help.”</i>  | 3 (25%) |
| <b>The MICE team</b><br><i>“Conversation about the MICE team and what they are doing for our community.”</i>                       | 1(8%)   |

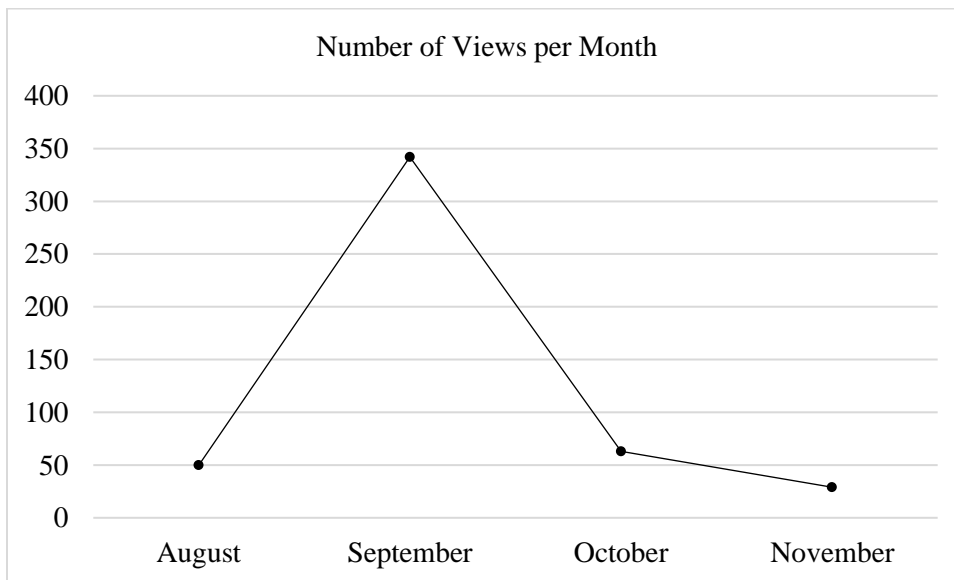
**Figure 1.** Timeline of processes undertaken to create the community mural and engage community members



**Figure 2.** Memory Inclusive Communities Everywhere Community Mural.



**Figure 3.** Number of MICE website views August-November 2022



## CHAPTER FIVE: DISCUSSION

As described by a person living with dementia, “*we all live with a terminal condition –it’s called life. In my world, it is all about the quality of life regardless of any challenges we live with...before there is cure, there is care; never forget that*” (Alzheimer’s Disease International, 2022, p. 37). Dementia-friendly community (DFC) initiatives have emerged as a promising approach to maintaining quality of life after a dementia diagnosis; however, there is currently limited evidence about the impact of these initiatives (Alzheimer’s Disease International, 2022). The overall aim of this thesis was to further the knowledge base about DFCs through a comprehensive evaluation of processes and outcomes of a local DFC project titled Empowering Dementia Friendly Communities, Hamilton and Haldimand (EDFC-HH). I accomplished this aim by identifying and appraising assessment tools that can be used to conduct quantitative assessments of the dementia-friendliness of a community (Chapter 2, Manuscript 1); evaluating processes and methods that facilitate the engagement of persons living with dementia in public consultations (Chapter 3, Manuscript 2); and evaluating the impact of a DFC mural (Chapter 4, Manuscript 3). Together the chapters of this thesis build on and contribute to the literature related to the evaluation of DFCs (Chapter 2), to methods that support the engagement of persons with dementia in public consultations (Chapter 3), and to strategies to increase community awareness about dementia (Chapter 4). These studies were not conducted with the intention of generalizability, but to support the EDFC-HH team with their evaluation efforts. However, some lessons learned from these evaluation studies are transferable and can be used to guide stakeholders working on DFC initiatives, particularly those interested in quantitatively assessing the dementia-friendliness of their community, in conducting public consultations with persons living with dementia, and in using public art to raise dementia awareness in their community.

Findings from the scoping review (Manuscript 1) indicate that to support impact evaluations of DFC initiatives, there is a need to develop a quantitative tool with strong psychometric properties that captures all domains that have been identified by persons living with dementia as important to support community participation and quality of life. Additionally, findings from the process evaluation (Manuscript 2) emphasize the importance of including persons with dementia in DFC initiatives as project partners<sup>3</sup> and project participants<sup>4</sup>, with recommendations provided on how to support the engagement of persons living with dementia in public consultations to ensure that their needs guide the development of local initiatives. Lastly, the impact evaluation (Manuscript 3) provides evidence for the positive impact of interactions between persons living with dementia and community members and the value of public art in increasing community awareness about dementia. Although findings from these studies support the advancement of DFC initiatives, the studies are based on a local project and recommendations may not be transferable to other communities. In this discussion chapter, I highlight and provide a commentary about common themes between manuscripts and provide recommendations and future directions for research and practice.

### **Engagement of Persons Living with Dementia in DFC Initiatives**

As described in Buckner et al.'s (2022) theory of change for DFCs, a needs assessment and knowledge of local priorities of persons affected by dementia inform the development of the short, medium and long-term outcomes of DFC initiatives. As described in Chapter 2, quantitative and qualitative methods have been used to conduct needs assessments and to help

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<sup>3</sup> When persons living with dementia are involved in the design, delivery, and management of the DFC initiative, they are being engaged as partners.

<sup>4</sup> When persons living with dementia participate in activities developed by those leading the DFC initiative (such as sharing their views during a consultation process or contributing data in other ways), they are being engaged as participants.

determine the dementia-friendliness of a community. In chapters 2 and 3, the importance of including persons living with dementia as project partners was identified as a requirement for ensuring engagement methods (both quantitative and qualitative) facilitate participation. For example, a recommendation that came from Chapter 2 was for stakeholders (e.g., community organizations leading the DFC initiative) to engage persons living with dementia in the development of assessment tools to ensure questions included in the tool are relevant and that tools are formatted in a way that is user-friendly and accessible (Diaz et al., 2022). Other benefits of engaging persons with dementia as project partners are highlighted in Chapters 3 and 4 and include facilitating the recruitment of other persons living with dementia for other parts of the project; challenging assumptions about dementia and breaking down stigma; and honouring and respecting the right of persons with dementia to participate (both as project partners and participants) in projects that impact their lives (Diaz et al., 2023).

Lack of expertise in how to support persons living with dementia to participate in DFC initiatives, either as project partners or participants, has been cited in the literature as a reason why persons living with dementia are not always engaged in these roles in DFC initiatives (Mathie et al., 2022). An outcome of the process evaluation (Chapter 3) was a set of recommendations for engaging persons living with dementia remotely in public consultations as project participants<sup>5</sup>. Recommendations include using empathy interviewing techniques when interviewing persons with dementia, and creating a video explaining the aim of the public consultations and how information will support future planning (Diaz et al., 2023). Additionally, since the publication of the process evaluation study, Dementia Australia released a guide to

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<sup>5</sup> It is important to note that since the publication of this manuscript (Manuscript 2), emerging research has been published related to the engagement of people living with dementia in research remotely, which could inform engagement methods for public consultations. Examples include work by Dixon et al. (2021); Hung et al. (2021); Sixsmith (2020); and O'Connell et al. (2021).



meaningful consultation with persons living with dementia (Dementia Australia, 2022). The guide provides similar recommendations identified in the process evaluation with an emphasis on the importance of creating meaningful conversation with persons living with dementia by using methods that facilitate story-telling, such as the empathy interviewing approach used for the EDFC-HH project. To ensure that DFC initiatives are informed by the needs of persons living with dementia, it is recommended for stakeholders working on DFC initiatives to use the recommendations and findings from the process evaluation and the guide by Dementia Australia to support participation of persons living with dementia in their planning processes.

When considering the benefits of engaging persons with lived experience in program development it is important to consider the availability of adequate resources to enable meaningful engagement of diverse participants. While persons living with dementia have reported benefitting from participating in research and program development (see e.g., Litherland & Williamson, 2013) many do so on a voluntary basis, without receiving compensation for their time and expertise. In recognition of the value and expertise that persons with lived experience bring to projects, national (see e.g., SPOR Evidence Alliance, 2019) and international (see e.g., World Health Organization, 2023) frameworks have highlighted the need for persons with lived experience to be compensated for their contributions. Compensation serves as a recognition of the valuable contributions that persons living with dementia bring to a project and it promotes equal power distribution amongst stakeholders, many of whom are paid for their involvement in the project as part of their work roles. Compensation can also enable the participation of marginalized and underrepresented populations with limited financial resources (Refer to section “Inclusion of Marginalized and Diverse Populations” below for a discussion about engaging persons living with dementia from marginalized and underrepresented populations in research

and community work). As DFC initiatives continue to expand in Canada, it is imperative to consider how persons living with dementia could be compensated for their contributions. For example, persons receiving income support from the Ontario Disability Support Program (ODSP) are only able to receive gifts and voluntary payments up to a maximum amount, thus stakeholders would need to consider how persons with dementia on ODSP could be compensated for their time without being penalized.

### **Lack of Guiding Framework**

A common thread presented in Chapters 2 and 3 is the absence of a well-established framework for the development and implementation of DFC initiatives. In lieu of an established framework, stakeholders have used the World Health Organization's (WHO) age-friendly community framework (WHO, 2007) as guidance for the development of their DFC initiatives. As mentioned by a participant that contributed to the process evaluation, "*although the age-friendly community framework was helpful when developing the online survey, important issues specific to dementia may have been missed*". Similarly, a finding from the scoping review was that the three domains not covered by any of the identified tools (legal and advanced care planning services; care throughout the continuum; memory loss supports and services) are domains not included in the WHO's age-friendly community framework (Diaz Garcia et al., 2022). Additionally, as discussed in Chapter 2, caregivers are often the main source of support for persons with dementia living in the community (WHO, 2021a), which is why I argue that caregiver support should be included as a domain in the assessment of the dementia-friendliness of a community.

It is important to note that the scoping review and the public consultations for the EDFC-HH project were conducted before the WHO released their toolkit for dementia-friendly

initiatives (WHO, 2021b). In the toolkit, the WHO presents a dementia-inclusive societies framework. In Table 1, I compare the eight age-friendly community domains proposed by the WHO, the nine activity/outcomes included in the WHO’s dementia-inclusive societies framework, and the domains used for the scoping review that I conducted (Manuscript 1, Chapter 2). As illustrated in Table 1, the nine activities/outcomes included in the dementia-inclusive societies framework align with the age-friendly community framework. However, it is worth noting discrepancies between frameworks, including the use of enabling and dementia-specific language and the inclusion of “awareness raising campaigns” as an activity/outcome in the dementia-inclusive societies framework.

**Table 1.** Comparison of the domains in the WHO’s age-friendly community and dementia-inclusive societies frameworks, and scoping review.

| <b>Age-Friendly Community Framework</b> | <b>Dementia-Inclusive Societies Framework</b>                           | <b>Scoping Review</b>  |
|---|---|--|
| Transportation                          | Enhanced transportation system  | Transportation   |
| Housing                                 | Improve affordable and enabling housing                                 | Housing  |
| Social participation                    | Civic/socio-cultural participation                                      | -Dementia-accessible community activities/services<br>-Participation in leisure activities |
| Respect and social inclusion            | -Improve safety<br>-Awareness raising campaigns                         | Respect and social inclusion   |
| Civic participation and employment      | Civic/socio-cultural participation                                      | Civic participation and engagement   |
| Communication and information           | Use of enabling technology  |  |
| Community support and health services   | -Dementia-friendly business and services<br>-Training/capacity building | Dementia-friendly businesses   |
| Outdoor spaces and buildings            | Remove barriers/improve accessibility                                   | Outdoor spaces and buildings   |
|   |   | Financial services   |
|   |   | Quality of life  |
|   |   | Independent living   |
|   |   | Emergency planning and first response  |
|   |   | Legal and advanced care planning services  |
|   |   | Care throughout the continuum  |
|   |   | Memory loss supports and services  |
|   |   | Caregiver support  |

Note: the rows in blue are the domains not covered by any of the tools that were identified in the scoping review.

Moreover, as illustrated in Table 1, the WHO's dementia-inclusive societies framework is missing the domains that were not covered by any of the tools identified in the scoping review that I conducted. The domains not captured by the WHO's framework are related to services that persons living with dementia have cited as being important to supporting their dignity and quality of life (see e.g., Morrisby et al., 2018; Wendrich-van Dael et al., 2020). Although the WHO's dementia-inclusive societies framework was developed in consultation with persons living with dementia, clinicians and researchers (WHO, 2021), it appears that the age-friendly community framework was used as a reference point which could have influenced the selection of activities/actions included in the framework. Thus, when assessing the dementia-friendliness of a community, it is important for stakeholders to ask questions about availability of dementia-specific services in addition to the domains outlined in the WHO's dementia-inclusive societies framework.

### **Inclusion of marginalized and diverse populations**

A limitation of all the studies presented in this thesis is lack of representation from marginalized and diverse populations. As described in Canada's national dementia strategy (Public Health Agency of Canada, 2019), Indigenous Peoples, individuals with intellectual disabilities, ethnic and cultural minority communities, and the LGBTQ2S+ community face barriers to equitable care and are at a higher risk of developing dementia and/or experiencing significant barriers to diagnosis and access to dementia care. One of the findings from the study presented in Chapter 2 is that only four of the identified tools include questions related to participants' ethnic background. Similarly, only 5% of the individuals that participated in the public consultations for the EDFC-HH project identified as a member of a visible minority (refer

to Chapter 3). Lastly, a limitation of the evaluation of the DFC mural (refer to Chapter 4) is that I did not collect demographic information from individuals who participated in the various forms of data collection, and thus, cannot comment on whether public art could be used to raise dementia awareness in ethnically diverse and marginalized communities. Unfortunately, lack of diversity in dementia research is common (Alzheimer Europe, 2019), which means that clinical, policy and community development decisions based on research findings may only address/reflect the needs of only some groups (e.g., Caucasians) (Brijnath et al., 2022). To promote the participation and involvement of diverse populations in dementia research, it is important for researchers to recognize that many populations have a long history of discrimination, mistreatment and abuse by the medical and scientific communities which has resulted in mistrust and unwillingness to participate in research (Alzheimer's Association, 2018; Alzheimer Europe, 2019; Billan et al., 2020). Use of culturally inappropriate methodologies, and lack of recognition of dementia as a condition in some cultures, are other reasons why diverse communities may not feel comfortable and/or see the value in participating in dementia research (Alzheimer Europe, 2019). To address some of these issues, it has been recommended in the literature that persons from diverse communities be involved as research partners/work in partnership with communities (Brijnath et al., 2022), and that researchers practice reflexivity and positionality as a means to foster respectful relationships and to reduce bias (Alzheimer Europe, 2019). Notably, these recommendations are for the engagement of ethno-cultural communities. Nonetheless, similar recommendations have been made for the ethical engagement of Indigenous Peoples in research, including fostering respectful community partnerships, engaging in reciprocal learning and knowledge translation, and for researchers to be self-reflective in order to achieve cultural safety (Billan et al., 2020).

Additionally, a barrier for the engagement of persons with an intellectual disability and dementia in research is lack of understanding amongst researchers of how to communicate with a person with an intellectual disability, lack of tools to support communication, and lack of insight from the person about their condition (Watchman et al., 2018). To support the engagement of persons with an intellectual disability in dementia research, there is a need for researchers to educate themselves on how to communicate with people with intellectual disabilities, and to develop more communication tools to support participation in research (Watchman et al., 2018). Lastly, to support the engagement of LGBTQ2S+ people living with dementia in research, it is recommended that researchers educate themselves on the history of persecution and discrimination that many LGBTQ2S+ people have lived through, on LGBTQ2S+-affirming language, and on LGBTQ2S+ cultural competency (Alzheimer's Association, 2018).

There is limited data on the impact of dementia on marginalized and diverse communities within Canada (Alzheimer Society of Canada, n.d.-b), but data from the United States of America indicates that stigma, lack of accurate and culturally-appropriate information and services, and mistrust in the system results in delays among members of ethnic communities accessing care and receiving a diagnosis (Lin et al., 2020). In recognition of the importance of removing barriers to equitable care and increasing access to appropriate care, recommendations have been made to support persons living with dementia from marginalized and underserved communities (see e.g., Iroanyah et al., 2021; Eagle & National Institute on Ageing, 2022). Notably, due to a lack of Canadian research on how to support people living with dementia from marginalized and diverse communities, majority of the recommendations available in Canada have been made by advocacy groups. Thus, there is a pressing need for Canadian-focused research in this area in order to validate available recommendations and increase our

understanding of how to appropriately support people impacted by dementia from diverse and marginalized communities. Examples of recommendations include:

- **Ethnic and cultural minority communities:** In an opinion piece about equity, diversity and inclusion in dementia diagnosis in Canada, Iroanyah et al. (2021) provide recommendations for racially-diverse communities to have a planned and systematic pathway to guide individuals in seeking a dementia diagnosis and accessing supports. Recommendations include implementing culturally-safe and appropriate anti-stigma campaigns and creating culturally-friendly dementia services and awareness building (Iroanyah et al., 2021).
- **LGBTQS2 community:** In a recent report focused on enhancing supports for Canadian LGBTQS2 people living with dementia (Eagle & National Institute on Ageing, 2022), the authors recommend developing LGBTQS2-inclusive dementia-related services and community spaces, increasing understanding and awareness of the unique needs and experiences of LGBTQS2 persons living with dementia, and enhancing supports for the LGBTQS2 community and carers through structural and system-level changes.
- **Individuals with intellectual disabilities:** There is currently a lack of Canada-specific recommendations related to supporting individuals living with an intellectual disability and dementia; however, in 2018, an international consensus statement about post-diagnostic support for people with an intellectual disability and dementia was published (Dodd et al., 2018). Recommendations include offering education to people with intellectual disabilities and their caregivers about dementia-specific supports available to them, creating opportunities for people with intellectual disabilities to be a part of dementia-friendly initiatives, creating accessible resources, and building capacity

amongst caregivers and support staff (Dodd et al., 2018). Additionally, guidelines for structuring community care and supports for people with intellectual disabilities living with dementia have been developed in the UK (Jokinen et al., 2013); these could inform the development of community supports in Canada.

Additionally, the Indigenous Cognition & Aging Awareness Research Exchange has developed several culturally appropriate tools to support Indigenous Peoples in Canada. Resources include dementia factsheets (e.g., signs and symptoms of dementia; Indigenous Cognition & Aging Awareness Research Exchange, 2017) and tools for healthcare providers (e.g., the Canadian Indigenous Cognitive Assessment; Indigenous Cognition & Aging Awareness Research Exchange, n.d.). Moreover, the Native Women's Association of Canada developed a toolkit for addressing dementia related stigma with Indigenous specific strategies (Native Women's Association of Canada, n.d.). For example, it is important for stakeholders to be aware of cultural beliefs, such as hallucinations perceived as gifts bringing the person closer to the Creator, when supporting Indigenous Persons.

While each of the populations listed above present with unique needs and preferences, a common theme amongst available recommendations is the importance of safe and appropriate anti-stigma campaigns. Efforts have been made to create dementia awareness campaigns that include individuals from diverse communities (see e.g., Hamilton Council on Aging, n.d.); however, to ensure the content and approaches used are appropriate, targeted campaigns to Indigenous peoples, individuals with intellectual disabilities, ethnic and cultural minority communities and the LGBTQ2S+ community may be needed.

Additionally, throughout this thesis I have used the term “dementia-friendly communities” but in recognition of the lack of inclusion of marginalized and diverse communities in existing



initiatives, I argue that the term “dementia-inclusive communities” is more appropriate. In naming initiatives “dementia-inclusive” there is a call to engage all community members and to create spaces free of harassment, where community members are supported to participate in society, fostering a sense of belongingness. To support the inclusion of all community members living with dementia, more research is needed to inform engagement methods that facilitate participation of diverse and marginalized populations and whether targeted anti-stigma campaigns create greater impact in these populations than existing campaigns.

### **Contributions to Rehabilitation Science**

In Chapter 1, I discussed the International Classification of Functioning, Disability and Health (ICF ;WHO, 2001). In the ICF, environmental factors are recognized as either facilitators or barriers to participation. Relatedly, when supporting clients, occupational therapists (OTs) are guided to consider the impact of environmental factors on their client’s ability to participate in the things that they want and need to do (Law, 1991). A model central to the occupational therapy profession is the Person-Environment-Occupation (PEO) model (Law et al., 1996); I use this model to conceptualize my contributions to rehabilitation science and practice, particularly to occupational therapy.

In the PEO model, occupational performance (i.e., active participation in occupation) and occupation engagement (i.e., the cognitive and emotional factors associated with occupation) are proposed to be shaped by interactions between the person, their environment, and their chosen/needed occupations (i.e., the things that a person wants and needs to do) (Law et al., 1996; Polatajko et al., 2007). Thus, guided by the PEO model, OTs consider person, environment and occupation factors when supporting their clients in engaging and participating in occupations. When working with the community as the client, OTs work and collaborate with

community partners to support communities in achieving their occupational goals (e.g., increase physical activity and community participation), which are often linked to improving population health outcomes (Hyett et al., 2019). Applying the PEO model to DFC initiatives, “participation and engagement in community life” is one of the occupations that OTs are supporting persons living with dementia with doing. As proposed in the PEO model, to maximize participation in community life, OTs can address person (e.g., cognition, behaviours, emotions), environment (e.g., social and physical factors) and occupation factors (e.g., adapting the way a person completes their grocery shopping).

The scoping review (Chapter 2, Manuscript 1) contributes to rehabilitation science and practice in several ways. First, in the scoping review I present a list of DFC domains that have been identified by persons living with dementia as important domains of dementia-friendliness. The domains emphasize the importance of the physical and social environment in supporting persons living with dementia to remain living in their community. Additionally, the list highlights the importance of including rehabilitation scientists and clinicians in DFC initiatives, as they have the knowledge and skills to address several of the domains. For example, OTs can help create dementia-friendly outdoor spaces (Graff et al., 2020), and buildings and can support persons living with dementia to live independently at home (Laver et al., 2017). OTs and other rehabilitation professionals can use this list to advocate for their inclusion in DFC initiatives and related projects. Additionally, the scoping review findings indicate that there is need for the development of a comprehensive assessment tool to support the evaluation of the dementia-friendliness of a community. This gap in our knowledge presents an opportunity for rehabilitation professionals to support the co-development of an assessment tool with persons living with dementia.

One of my aims through the process evaluation (Chapter 3, Manuscript 2) was to better understand how to support the engagement and participation of persons living with dementia in public consultations. An outcome of the process evaluation was a set of recommendations to support the engagement and participation of persons living with dementia in public consultations, which ultimately supports the occupation of civic participation. Recommendations include person (e.g., providing accessibility support), environment (e.g., considering who will be in the room) and occupation (e.g., providing options for participation) factors that together maximize participation of persons living with dementia in public consultations. Rehabilitation professionals working on DFC initiatives, or similar projects, can use these recommendations and other findings presented in the evaluation to support the participation and engagement of persons living with dementia in their project, both as project partners and participants.

As described in the PEO model, the social environment is one factor that could impact occupational engagement and participation. The impact evaluation (Chapter 4, Manuscript 3) was solely focused on the impact of the DFC community mural on the social environment (i.e., raising community awareness about dementia and DFCs). Thus, findings contribute to our knowledge on ways to create supportive social environments by increasing community awareness about dementia. Using the community as the client, occupational scientists, occupational therapy researchers, and OTs working on community initiatives aimed at increasing dementia awareness can use findings from the impact evaluation study to decide whether public art, such as a community mural, could be used as a tool to raise awareness. Relatedly, the lessons learned from the process undertaken to create the community mural can be used by stakeholders, including rehabilitation professionals, interested in implementing a similar project in their

communities. Lastly, the impact evaluation provides an example of methods that rehabilitation professionals could use to evaluate the impact of their initiatives.

Thus, findings from the studies presented in this thesis add to the rehabilitation literature related to dementia and contribute to clinical practice by furthering our knowledge of factors that need to be assessed and addressed to determine the dementia-friendliness of a community (Manuscript 1), processes that enable the participation of persons living with dementia in public consultations (Manuscript 2), and innovative methods that can be used to increase dementia awareness (Manuscript 3). Together these findings further our understanding of how to maximize the engagement and participation of persons living with dementia in community life by addressing person, environment and occupation factors.

### **Moving Forward: Sustainability of DFC Initiatives**

One of the main goals of Dementia-Friendly Canada is to achieve sustainability and expand DFC initiatives across the country (Alzheimer Society of Canada, n.d.-a). To support the growth and impact of DFCs in Canada, information about processes and outcomes that create positive impact (e.g., more inclusive environments that support everyday experiences of persons living with dementia), is needed. Additionally, information about how initiatives can be sustained is critical if we want to create long-lasting impact. In Chapter 1, I introduced evaluation resources for DFCs developed in the UK (Buckner et al., 2022). These resources can guide evaluation plans and help monitor progress overtime. However, unless stakeholders working on DFC initiatives prioritize the monitoring and evaluation of their initiative, there will continue to be a lack of evidence about the social, economic and environmental benefits of these initiatives.

A DFC initiative often requires financial and social resources for the development, implementation and sustainability phases. Taking into consideration the financial and time

investment required to create and sustain DFCs initiatives, I argue that it is imperative to consider synergies with other initiatives. Table 1 highlights that there are more similarities than differences between DFCs and age-friendly communities. As stated by Turner and Morken (2016), “age-friendly and dementia friendly [initiatives] share some fundamental objectives” (p. 3). Addressing the physical environment is a core element of DFC initiatives (World Health Organization, 2021b); however, literature from the United States indicates that in DFCs, the majority of communities tend to be focused on addressing the social environment through dementia awareness campaigns and education for various stakeholders, with limited to no resources allocated to addressing the physical environment (Dickson, 2023). Collaborating with stakeholders working on age-friendly community initiatives is one way to address barriers in the physical environment that prevent persons living with dementia from engaging in community life and accessing the services that they need. In recognition of the synergies between age- and dementia-friendly community initiatives, some Canadian cities have developed an integrated age-and dementia-friendly action plan (see e.g., Township of Langley, 2021). Merging of initiatives may require the refinement of available evaluation frameworks and tools to ensure that evaluation outcomes capture the impact of the initiatives on the lives of persons living with dementia, as well as older adults more generally. Thus, to support the advancement of DFC initiatives and maximize available resources, it is recommended for community leaders to explore synergies amongst existing initiatives and DFCs and when appropriate, to encourage the development of complementary action plans and/or merging of plans.

## **Conclusion**

To support the expansion of DFC in Canada and globally there is a need for evidence on the impact of initiatives on the quality of life of persons living with dementia, and processes that

support the development and implementation of initiatives. The three manuscripts (Chapters 2-4) that make up this thesis contribute to the advancement and knowledge base of DFC initiatives, including recommendations for engaging persons living with dementia in public consultations, and recommendations for community stakeholders interested in developing a DFC community mural. Moreover, as discussed in this final chapter, the work presented in this thesis furthers our knowledge of factors that rehabilitation scientists and clinicians need to assess and address to support the inclusion and participation of persons living with dementia in their community. Findings also highlight the important contributions that OTs can make to DFC initiatives (e.g., addressing person, occupation and environment factors to support community engagement and participation), including supporting the engagement of persons living with dementia as project partners and participants and helping communities achieve important occupational goals.

Lastly, throughout this final chapter I discussed that in order to advance DFC initiatives, 1) persons living with dementia need to be engaged and appropriately compensated for their contributions; 2) a comprehensive DFC framework needs to be developed; 3) marginalized and diverse populations need to be included and consulted; and 4) synergies between DFC initiatives and other initiatives should be explored. Additionally, to ensure that initiatives result in intended outcomes, and to maximize the use of resources, evaluation and monitoring should be considered an essential component of initiatives.

## References

- Alzheimer's Association. (2018). *Issue Brief: LGBT and Dementia*.  
<https://www.alz.org/media/documents/lgbt-dementia-issues-brief.pdf>
- Alzheimer's Disease International. (2022). *World Alzheimer Report 2022 Life after diagnosis: Navigating treatment, care and support*. <https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf>
- Alzheimer Europe. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research*.  
[https://www.alzheimer-europe.org/sites/default/files/2022-01/05706 Alzheimer Europe ethics report 2019\\_92.pdf](https://www.alzheimer-europe.org/sites/default/files/2022-01/05706%20Alzheimer%20Europe%20ethics%20report%202019_92.pdf)
- Alzheimer Society of Canada. (n.d.-a). *Dementia-Friendly Canada*. Retrieved June 14, 2023, from <https://alzheimer.ca/en/take-action/become-dementia-friendly/dementia-friendly-canada>
- Alzheimer Society of Canada. (n.d.-b). *Race and dementia*. <https://alzheimer.ca/en/take-action/change-minds/race-dementia#:~:text=Based on information collected from,data is minimal at best.>
- Billan, J., Starblanket, D., Anderson, S., Legare, M., Hagel, M. C., Oakes, N., Jardine, M., Boehme, G., Dubois, E., Spencer, O., Hotomani, M., McKenna, B., & Bourassa, C. (2020). Ethical research engagement with Indigenous communities. *Journal of Rehabilitation and Assistive Technologies Engineering*, 7. <https://doi.org/10.1177/2055668320922706>
- Brijnath, B., Croy, S., Sabates, J., Thodis, A., Ellis, S., de Crespigny, F., Moxey, A., Day, R., Dobson, A., Elliott, C., Etherington, C., Geronimo, M. A., Hlis, D., Lampit, A., Low, L. F., Straiton, N., & Temple, J. (2022). Including ethnic minorities in dementia research: Recommendations from a scoping review. *Alzheimer's & Dementia : Translational Research & Clinical Interventions*, 8(1). <https://doi.org/10.1002/TRC2.12222>
- Buckner, S., Lafortune, L., Darlington, N., Dickinson, A., Killett, A., Mathie, E., Mayrhofer, A., Woodward, M., Goodman, C., & Buckner, S. (2022). A suite of evaluation resources for Dementia Friendly Communities: Development and guidance for use. *Dementia*, 21, 2381-2401. <https://doi.org/10.1177/14713012221106634>
- Dementia Australia. (2022). *Half the Story - A guide to meaningful consultation with people living with dementia, families and carers*.
- Diaz Garcia, L., Durocher, E., Gardner, P., McAiney, C., Mokashi, V., & Letts, L. (2022). Assessment tools for measurement of dementia-friendliness of a community: A scoping review. *Dementia*, 21(5), 1825–1855. <https://doi.org/10.1177/14713012221090032>
- Dickson, C. (2023). *Collective Care When There Is No Cure: An Evaluation of Dementia Friendly Initiatives* [University of Pittsburgh]. [http://d-scholarship.pitt.edu/44736/1/Chelsea Dickson Essay 2023.pdf](http://d-scholarship.pitt.edu/44736/1/Chelsea%20Dickson%20Essay%202023.pdf)
- Dixon, E., Shetty, A., Pimento, S., & Lazar, A. (2021). Lessons learned from remote user-centered design with people with dementia. In: Brankaert, R., Raber, C., Houben, M., Malcolm, P., Hannan, J. (eds) *Dementia Lab 2021: Supporting Ability Through Design*. D-Lab 2021. Design For Inclusion, vol 2. Springer.
- Dodd, K., Watchman, K., Janicki, M. P., Coppus, A., Gaertner, C., Fortea, J., Santos, F. H., Keller, S. M., & Strydom, A. (2018). Consensus statement of the international summit on intellectual disability and Dementia related to post-diagnostic support Consensus statement of the international summit on intellectual disability and Dementia related to post-diagnostic

- support . *Ageing & Mental Health*, 22(11), 1406–1415.  
<https://doi.org/10.1080/13607863.2017.1373065>
- Eagle, & National Institute on Ageing. (2022). *Coming out and coming in to living with dementia: Enhancing Support for 2SLGBTQI People Living with Dementia and their Primary Unpaid Carers*. [https://egale.ca/wp-content/uploads/2022/04/NIA\\_EGALE\\_MAY12\\_EN.pdf](https://egale.ca/wp-content/uploads/2022/04/NIA_EGALE_MAY12_EN.pdf)
- Graff, M. J. L., Bergamini, L., Chamberlain, M., & Sturkenboom, I. H. W. M. (2020). Occupational therapy in the community. In *Occupational Therapy for Older People* (pp. 33–54). Springer International Publishing. [https://doi.org/10.1007/978-3-030-35731-3\\_3/COVER](https://doi.org/10.1007/978-3-030-35731-3_3/COVER)
- Hamilton Council on Aging. (n.d.). *Faces of Dementia* . Retrieved June 12, 2023, from <https://coahamilton.ca/faces-of-dementia/>
- Hung, L., Yang, S., Gregorio, M., & Phinney, A. (2021). Supporting patient engagement in dementia research via technology during the COVID-19 pandemic. *Innovation in Aging*, 5, 309. <https://doi.org/10.1093/geroni/igab046.1205>
- Hyett, N., Kenny, A., & Dickson-Swift, V. (2019). Re-imagining occupational therapy clients as communities: Presenting the community-centred practice framework. *Scandinavian Journal of Occupational Therapy*, 26(4), 246–260. <https://doi.org/10.1080/11038128.2017.1423374>
- Indigenous Cognition & Aging Awareness Research Exchange. (n.d.). *CICA Toolkit* . Retrieved June 12, 2023, from <https://www.i-caare.ca/cica-toolkit>
- Indigenous Cognition & Aging Awareness Research Exchange. (2017). *Dementia Factsheets*. <https://www.i-caare.ca/factsheets>
- Iroanyah, N., Savundranayagam, M., Mundadan, R., & Sivananthan, S. (2021). Equity, diversity, and inclusion in dementia diagnosis: a Canadian perspective. *Alzheimer's Disease International: World Alzheimer Report 2021*, 235–237. <https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf>
- Jokinen, N., Janicki, M. P., Keller, S. M., Mccallion, P., & Force, L. T. (2013). Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 1–24.
- Laver, K., Cumming, R., Dyer, S., Agar, M., Anstey, K. J., Beattie, E., Brodaty, H., Broe, T., Clemson, L., Crotty, M., Dietz, M., Draper, B., Flicker, L., Friel, M., Heuzenroeder, L., Koch, S., Kurrle, S., Nay, R., Pond, D., ... Yates, M. (2017). Evidence-based occupational therapy for people with dementia and their families: What clinical practice guidelines tell us and implications for practice. *Australian Occupational Therapy Journal*, 64(1), 3–10. <https://doi.org/10.1111/1440-1630.12309>
- Law, M. (1991). The Environmet: A focus for occupational therapy. *Canadian Journal of Occupational Therapy*, 58(4), 171–180. <https://doi.org/https://doi.org/10.1177/000841749105800404>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person-Environment-Occupation Model: A Transactive Approach to Occupational Performance. *Canadian Journal of Occupational Therapy*, 63(1), 9–23. <https://doi.org/10.1177/000841749606300103>
- Lin, P.-J., Daly, A., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., Fillit, H. M., Freund, K. M., & Pei-Jung Lin, C. (2020). Dementia diagnosis disparities by race and ethnicity. *Alzheimer's & Dementia*, 16(S10), e043183. <https://doi.org/10.1002/ALZ.043183>
- Litherland, R., & Williamson, T. (2013). DEEP: The engagement, involvement and



- empowerment of people with dementia in collective influencing. *Working with Older People*, 17(2), 65–73. <https://doi.org/10.1108/13663661311325481/FULL/PDF>
- Mathie, E., Antony, A., Killeit, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M., & Goodman, C. (2022). Dementia-friendly communities: The involvement of people living with dementia. *Dementia: The International Journal of Social Research and Practice*, 21(4), 1250–1269. <https://doi.org/10.1177/14713012211073200>
- Morrisby, C., Joosten, A., & Ciccarelli, M. (2018). Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. *International Psychogeriatrics*, 30(1), 5–14. <https://doi.org/10.1017/S1041610217001491>
- Native Women’s Association of Canada. (n.d.). *Addressing Dementia Related Stigma with Indigenous Specific Strategies*. [https://www.nwac.ca/assets-knowledge-centre/Dementia Stigma Toolkit English new.pdf](https://www.nwac.ca/assets-knowledge-centre/Dementia%20Stigma%20Toolkit%20English%20new.pdf)
- O’Connell, M., Vellani, R., Robertson, S., O’Rourke, H., & McGilton, K. (2021). Going from zero to 100 in remote dementia research: A practical guide. *Journal of Medical Internet Research*, 23, e24098.
- Polatajko, H., Townsend, E., & Craik, J. (2007). Canadian Model of Occupational Performance and Engagement (CMOP-E). In E. Townsend & H. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, wellbeing, & justice through occupation*. (pp. 22–23). CAOT Publications ACE.
- Public Health Agency of Canada. (2019). *A dementia strategy for Canada: Together we aspire*. [https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National Dementia Strategy\\_ENG.pdf](https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf)
- Sixsmith, A. (2020). COVID-19 and AgeTech. *Quality in Ageing and Older Adults*, 21, 247-252. <https://doi.org/10.1108/QAOA-07-2020-0029>
- SPOR Evidence Alliance. (2019). *Patient Partner Appreciation Policy and Protocol*. [https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA\\_Patient-Partner-Appreciation-Policy-and-Procedure.pdf](https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf)
- Township of Langley. (2021). *Age- and Dementia-Friendly Action Plan*. <https://www.tol.ca/en/the-township/resources/plans-reports-strategies/Action-Plans/Age-and-Dementia-friendly-Action-Plan.pdf>
- Turner, N., & Morken, L. (2016). *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*. <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2016/Better-Together-Research-Report.pdf>
- Watchman, K., Janicki, M., Udell, L., Hoagan, M., & Quinn, S. (2018). Consensus statement of the international summit on intellectual disability and dementia on valuing the perspectives of persons with intellectual disability. *Journal of Intellectual Disabilities*, 23, 266–280.
- Wendrich-van Dael, A., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *International Journal of Nursing Studies*, 107. <https://doi.org/10.1016/j.ijnurstu.2020.103576>
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health World Health Organization Geneva ICF ii WHO Library Cataloguing-in-Publication Data International classification of functioning, disability and health : ICF*.
- World Health Organization. (2007). *Global Age-Friendly Cities: A Guide*.

[www.who.int/ageing/publications/Global\\_age\\_friendly\\_cities\\_Guide\\_English.pdf](http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf)  
World Health Organization. (2021a). *Global status report on the public health response to dementia*. <https://www.who.int/publications/i/item/9789240033245>  
World Health Organization. (2021b). *Towards a dementia inclusive society*.  
<https://www.who.int/publications/i/item/9789240031531>  
World Health Organization. (2023). *WHO framework for meaningful engagement of people living with noncommunicable diseases, mental health and neurological conditions*.  
<https://www.who.int/publications/i/item/9789240073074>