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.

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" (third bullet point). One of the ways stakeholders working on DFC initiatives can uphold this right is by engaging persons living with dementia in the initiatives'

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

[2] 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.

planning processes, both as project partners[1] and as participants[2] 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 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 antioppression 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

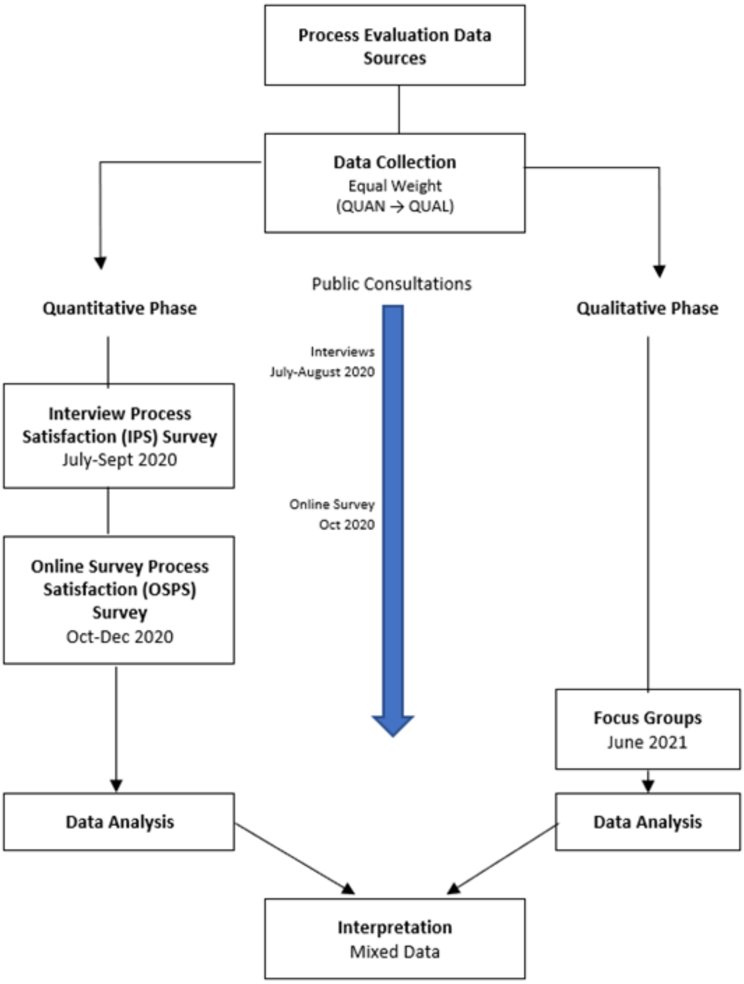
This process evaluation was guided by a partially mixed-methods sequential equal status design (Leech & Onwuegbuzie, 2009). Unlike a fully mixed-methods design in which data are mixed throughout the research process, in this type of research design, the quantitative and qualitative phases of the project 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.

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

Figure 1. Process Evaluation Data Sources, Public Consultation Timeline, and Research Design



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.

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 (α = .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 (α = .83). Descriptive information on the process satisfaction survey respondents is summarized in Table 2.

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.

Table 1. Mapping of Process Satisfaction Survey Questions to Rowe and Frewer's (2000) Framework for Evaluating Public Engagement

Criterion	Interview process satisfaction survey	Online survey process satisfaction survey
Resource accessibility	• Overall, how satisfied were you with the format? (*satisfied/neutral/ dissatisfied*) • Is there anything that you would change about this community engagement process or how you were involved? (*satisfied/neutral/ dissatisfied*)	• Overall, how satisfied were you with the format? • Is there anything that you would change about this community engagement process or how you were involved? (*satisfied/neutral/dissatisfied*) • Were the instructions in the survey clear? (*yes/no/I don't know*) • Did you have any difficulties completing the survey? (*yes/no*) • Do you prefer to complete surveys online or in print? (*online/print/both are good to me*) • Is there anything that we could have done differently to make it easier for you to complete the survey?
Task definition	• I understood what this project was all about. (*agree/disagree/neutral*) • My questions about this process were answered to my satisfaction. (*agree/ disagree/neutral*)	• I understood what this project was all about. (*agree/disagree/neutral*)
Transparency	• I understood what will happen next with all the information I and others have provided for this project. (*agree/neutral/disagree*) • Overall, how satisfied were you with your involvement in this project? (*satisfied/neutral/dissatisfied*)	• I understood what will happen next with all the information I and others have provided for this project. (*agree/neutral/ disagree*) • Overall, how satisfied were you with your involvement in this project? (*satisfied/ neutral/dissatisfied*)
Independence	• I felt comfortable answering the questions. (*agree/neutral/disagree*) • I felt like I could speak freely. (*agree/neutral/disagree*) • I understood the questions that the facilitators were asking. (*agree/ neutral/disagree*)	• I felt comfortable answering the questions. (*agree/neutral/disagree*) • I felt like I could share my opinions. (*agree/neutral/disagree*) • I understood the questions being asked. (*agree/neutral/disagree*)

Table 2. Descriptive Information of Process Satisfaction Survey Respondents

Variable	Interview process satisfaction survey (*N* = 53)	Online survey process satisfaction survey (*N* = 50)
Respondent group		
Person living with dementia	12 (23%)	2 (4%)
Care partner	23 (43%)	25 (50%)
Other (e.g., family member, friend)	18 (34%)	23 (46%)
Community		
Hamilton	35 (66%)	39 (78%)
Haldimand	17 (32%)	6 (12%)
Other/unspecified	1 (2%)	5 (10%)
Gender*		
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%)
Age		
Mean (SD)	68.5 (11)	60 (14)
Range	39–87	32–86
Median	69.5	59
Visible minority identity*		
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.

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.

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).

Table 3. Evaluation Criteria and Data Sources

Criteria	Data sources
Representativeness	• *What We Heard* report (demographic information) • Focus groups • Project's proposal
Independence	• Process satisfaction surveys • Focus groups
Early involvement	• Focus groups
Influence	• *What We Heard* report
Transparency	• Process satisfaction surveys
Resource accessibility	• Process satisfaction surveys • Focus groups
Task definition	• Process satisfaction surveys • Focus groups

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.

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.

Table 4. Process Evaluation Assessment Results

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

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.

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