

**Empowering Dementia Friendly Communities  
Hamilton, Haldimand**

**Evaluation of the  
Faces of Dementia Campaign,  
Launch Events and Community Exhibits**

**Final Report  
Executive Summary**

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**Prepared by the GERAS Centre for Aging Research  
George Ioannidis, PhD  
Loretta M. Hillier, MA**

**To request a copy of the full report please contact:**

Hamilton Council on Aging: [info@hamiltoncoa.com](mailto:info@hamiltoncoa.com) or call (905)777-3837 ext. 12434

Geras Centre for Aging Research: Dr. George Ioannidis [ioannidis@HHSC.CA](mailto:ioannidis@HHSC.CA) or  
call (905) 521-2100 ext. 12437

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## Executive Summary

The *Empowering Dementia-Friendly Communities Hamilton, Haldimand* project proposes to integrate a Dementia Friendly Community Plan with Hamilton’s municipal Plan for an Age Friendly City (2020-2025). The Empowering Dementia-Friendly Communities Hamilton, Haldimand project is a collaborative initiative, led by the Hamilton Council on Aging (HCoA), citizens and a multi-disciplinary team of organizations including persons living with dementia, the Alzheimer Society of Brant, Haldimand Norfolk, and Hamilton Halton, the GERAS Centre for Aging Research, the Regional Geriatric Program central, McMaster University, Haldimand-Norfolk Community Senior Support Services, Hamilton Health Sciences, Haldimand War Memorial Hospital and the Age-Friendly Hamilton Collaborative Governance Committee. This project is funded by the Public Health Agency of Canada. GERAS’ role in this initiative is to develop and implement an evaluation of the Dementia Friendly Communities project.

Building on the findings of an extensive community consultation to better understand the experiences, challenges and ideas of persons affected by dementia and leveraging the universally beneficial outcomes and influence of Age Friendly Hamilton, this project aims to:

1. Optimize the wellbeing of people living with dementia and/or their family/friend care partners.
2. Promote awareness of dementia and its risk factors by supporting innovative approaches that tackle stigma and promote compassion and support.
3. Undertake intervention research to assess the effectiveness of the program or initiative and promote/apply this knowledge.

A key project activity is the development of a “Faces of Dementia” Campaign to showcase the need for a Dementia Friendly Community strategy. The campaign consists of a video and portraits that profiled seven persons living with dementia as an opportunity to explore lived experiences with stigma within the community and opportunities for creating more dementia friendly communities. The Faces of Dementia campaign was designed to build off the Hamilton Council on Aging Portraits of Aging Campaign. The campaign process involved a virtual group meeting to introduce participants to each other and to describe the campaign process, one-to-one interviews with the campaign facilitators to explore themes to be highlighted in the campaign, in-person filming conducted by Atomic Spark Productions, portrait photography by Tae Photography, a group debriefing meeting, a virtual intimate campaign launch (May 3, 2022) for participants, their friends and family, and project partners, including representatives from the Hamilton Council on Aging and a virtual public launch (May 12, 2022). The campaign itself and its promotion was developed and led by Kite String Marketing with communications support from Dovetail Communications. A broad-based advertising strategy was used to promote the campaign via print media, radio, television and social media.

To promote the campaign, community exhibits were launched in both Hamilton and Haldimand county. The community exhibit in Hamilton was held at the Sackville Hill Seniors Community Centre with a launch event held on September 26, 2022. The community exhibit in Haldimand was held at the Minga Café in Dunnville with a launch event on October 12, 2022. The gallery opening events were promoted broadly in each community as an opportunity to meet and network with members of the campaign and project team, learn more about the making of the

campaign and aspirations for it and to start conversations about creating dementia friendly communities. The exhibits were in place in each location for six weeks. In Haldimand and Hamilton, accessibility accommodations and travel assistance were made available to attend community events.

This report describes the methods and results of an evaluation of the Faces of Dementia campaign, launch events, and community exhibits.

**Evaluation Objectives:** The objectives of this evaluation were to:

- i) Describe the development and implementation of the Faces of Dementia campaign and implementation of the launch events;
- ii) Describe key informant perspectives on the development and implementation of the Faces of Dementia campaign;
- iii) Describe the ways in which participation in the Faces of Dementia campaign affected participants;
- iv) Describe attendees (campaign participants, project partners, family, friends, general public) perceptions of the launch events/ community exhibits; and,
- v) Describe the ways in which the Faces of Dementia campaign affected viewers/ audiences (launch events, community exhibits).

**Design and Sources of Information:** A mixed methods (quantitative, qualitative) approach was used to evaluate the outcomes associated with dementia awareness campaign and launch events (summative evaluation) and to describe the development and implementation of this project (formative evaluation). Sources of information included:

- ***Tracking of Campaign Development and Implementation*** by project staff of key outputs from the project program logic model were used to describe the development and implementation of the Faces of Dementia campaign, launch events and community exhibits.
- ***Reflective Journaling*** maintained by the campaign facilitator and coordinator provided an opportunity to describe the process of creating the campaign with persons living with dementia, including adaptations that were made and new learnings.
- ***Survey of Campaign Participants*** (N = 3) assessed their reactions to the campaign, including satisfaction with experience, the affect of their involvement, and their perceptions of their community as dementia friendly and the importance of this project.
- ***Interviews with Campaign Participants*** (N = 5) gathered more in-depth information about their perceptions of the campaign and potential outcomes.
- ***Survey of Launch Events*** (N = 106) **and** ***Community Exhibit Audiences*** (N = 46) assessed their perceptions of the campaign and impact on anticipated outcomes.
- ***Key Informant Interviews*** conducted at two time points (May 2022, N = 8; Winter 2022-23, N = 7) gathered in-depth information about the development and implementation of the Faces of Dementia campaign, launch events and community exhibits.
- ***Community Exhibit Guest Books*** in both Hamilton and Haldimand yielded a total of 28 feedback entries.

**Research Ethics Board Approval:** As the objectives of this evaluation are considered quality improvement, research ethics board approval was not required. A waiver for approval was received the Hamilton Integrated Research Ethics Board (HiREB), McMaster University.

**Data Collection and Analysis:** The GERAS evaluation team was responsible for survey administration and interview completion. Descriptive statistics (frequencies, means, standard deviation) were generated for all numerical survey data. Campaign launch and community exhibit survey data were analyzed by community (Hamilton, Haldimand) and respondent group (person living with dementia, care partner, all others). Analysis of open-ended survey questions and interviews was consistent with recommended practices for qualitative evaluation data.<sup>1</sup> Descriptive qualitative content analysis was conducted to understand the experiences and perceptions of persons interviewed for this evaluation (campaign participants, key informants).<sup>2</sup> Interview transcripts were reviewed to generate broad categories and identify reoccurring themes in the data.

## Key findings

### Evaluation Objective I: Describe the Development and Implementation of the Faces of Dementia Campaign and Implementation of the Launch Events

This report describes the development and implementation of the Faces of Dementia Campaign in terms of recruitment efforts, how the campaign itself was developed, campaign materials created (videos, posters), campaign webpage content, campaign launch events, campaign promotion and reach, and community exhibits. Over 275 people attended the campaign launch events, the campaign website and online campaign materials have had over 4,500 views and while it is not known how many people viewed the community exhibits, over 800 campaign materials (gallery guides, project brochures, buttons/ magnets) were distributed. The campaign reached over 16 million people through paid media coverage including advertising in print, bus shelters, radio and television (excluding earned media coverage).

### Evaluation Objective II: Describe Key Informant Perspectives on the Development and Implementation of the Faces of Dementia Campaign and Launch Events

#### Campaign Participant Perspectives

Overwhelmingly, participants were extremely happy with how the campaign was developed, the end products and the launch events, reporting on positive feedback received from others.

*“In terms of the campaign itself and the presentation that was happening that day [intimate launch], amazing. Absolutely amazing! I loved it!... Everybody loved it. Everybody that I've spoken to or called or emailed me had said that it was amazing.”*

Campaign participants identified a number of key messages that they wanted to communicate through the campaign and reported that their vision for the campaign was realized and the key messages that they wanted to convey were well communicated.

<sup>1</sup> Patton, M.Q. (2002). *Qualitative Evaluation and Research*. Thousand Oaks, CA: Sage.

<sup>2</sup> Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77-84.

### ***Campaign visions:***

- Educate people about dementia
  - Encourage people to be kinder to those who are struggling
- Convey that people with dementia are still themselves, “able” and active
  - Provide hope to those living with dementia
- Realistically portray what it is like to live with dementia
- Reduce negative reactions to ‘Dementia’

*“Just show people what it is like living with it [dementia], but I like what the campaign did, we can do stuff... That we still are sociable and still want to do things, we still have interests. We have families that are also dealing with it.”*

*“SHOW what we CAN do... Every time I watch it, its so well done... I think they all [campaign materials] were wonderful. They all showed off a side of people living with dementia that was good.”*

### **Key Informant Perspectives**

Generally, the Faces of Dementia campaign events products were well received by interviewed key informants.

Key informants particularly liked the:

- focus on the experience of living with dementia from the perspective of those with lived experience
- active involvement of persons living with dementia in driving the campaign
- representation of people living with dementia in the local communities
- emotionally moving nature of the campaign
- high quality of campaign materials
- Commitment of participants to the campaign.

*“What I loved about it was the deep human element that was shared through this. It brought the people from being statistics to names on a page, to vibrant people with their own stories and a story that can transform other people’s lives.”*

*“I think probably what I liked the best is that it truly was the voices of people living with dementia that were the driver and that were heard.”*

*“I really liked some of the nuances that we were able to achieve with this campaign. So, in this particular campaign it is more representative of the people living with dementia in our communities.”*

*“I thought it was just elegantly simple, beautifully executed, transformative story telling in a visual manner.”*

***Factors enabling campaign development:*** Key informants identified a number of factors that they perceived were instrumental to facilitating the development of the campaign:

- Willingness of campaign participants to share their stories
- Collaborative and effective leadership and partnerships
- Dedicated project staff
- Commitment to ensuring that voice of persons living with dementia was central to the campaign
- Production service providers’ willingness to let participants lead the campaign
- Use of technology to support efficient communication and launch attendance
- Group planning meetings with the participants
- Effective management of pandemic restrictions
- Right expertise involved.

*“I think we had some real champions. We had real champions that model living well and I think that they are a real inspiration when they’re talking to other people.”*

*“I think the stewardship group worked extremely well together and our persons living with dementia group as part of the leadership team, have blown me away.”*

*“We have a project manager and project coordinator who are incredible.”*

*“I think what has enabled it to be so successful is we’re working with persons living with dementia... ‘nothing for us without us.’”*

***Adaptations required to produce the campaign:*** A number of adaptations were required during the development phase of the campaign due to changing COVID-19 pandemic restrictions and participant needs; these adaptations included:

- Management of changing COVID-19 pandemic restrictions
  - Use of technology; support to participants to use technology
- Provision of supports for campaign participants to feel comfortable during filming
- Reducing fast pace of activities and allowing participants to participate to the extent to which they are comfortable
- Involvement of the care partner of a campaign participant further along in the disease process.

***Challenges experienced in developing the campaign:*** Several challenges to the development of the campaign were identified:

- Participant recruitment (finding individuals willing to share their stories publicly)
- Recruitment for diversity
- COVID-19 pandemic restrictions which limited in-person gathering)
- Funding limitations

*“We wanted to have a real diverse group of participants as we could... ... to have more participation that truly reflects the community. So logistically that was a challenge but it was an important one to undertake.”*

*“There is still so much stigma associated with this disease that people are hesitant to come out in such a public way.”*

*“COVID 19 was a huge challenge to this project. It delayed the project for 2 years with just ever-changing risk factors and safety protocols, and then even with scheduling and the screening. Sometimes people failed the screening the day of the in-person filming, which was a delay. So, there was a bunch of things and uncertainties you just couldn’t control because of COVID. So that’s been a challenge.”*

***Suggestions for Campaign Improvements:*** Generally, key informants were satisfied with the campaign and identified few suggestions for improvements; identified suggestions may inform ongoing/ future work on the campaign or serve as advice to others developing similar campaigns:

- Increase diversity representation
- Leverage relationships with organizations that serve diverse populations
- Create recruitment materials in languages other than English
- Promote the campaign more broadly to increase awareness

*“I think having even more diverse voices speak and we really would like to do that. That would just make it more powerful... I think that’s really important, that the voice represent diversity and background, but also in the disease progression.”*

**Key Lessons Learned in Developing the Campaign:** Identified lessons learned in developing the campaign can serve to inform similar campaigns developed in other jurisdictions.

- Ensure the authentic participation of persons living with dementia
- Secure dedicated project staff to support campaign development
- Allow sufficient time for campaign development
- Secure sufficient funding
- Invest time to prepare for filming key messages
- Leverage existing relationships with specific communities to support recruitment
- Ensure a clear understanding of the communities involved
- Be intentional in planning a campaign
- Be open about intentions in selecting participants for diversity.

*“Make sure you co-design with people of lived experience and make sure that your key message of whatever campaign you’re doing, come from the people affected by dementia. Its simple but it was very powerful.”*

*“So having a project manager made a huge different so I think just more of that. That would be my counsel moving forward, is just having a designated person who sees everything and is kind of a maestro.”*

*“Its [campaign development] not something you can do quickly... I think that time is an important resource.”*

*“Funding is a very important, adequate funding is a very important resource.”*

**Campaign Promotion:** Key informants were very pleased with how the campaign was promoted, highlighting the following:

- Wide reach with a variety of mediums
- Active involvement of project partners and campaign participants in the promotion
- Campaign was well resourced
- Strong media coverage
- Access to additional information via a variety of mechanisms
- Ongoing promotion
- Consistent messaging across all promotional materials
- Photography accurately conveyed the key campaign messaging

*“I think the best part about the promotion is that it kept going. It wasn’t just one and done because I think its important work.”*

*“I really liked that the campaign members themselves were actively involved in a lot of the campaign promotion ... they were active participants well after the campaign had been created and they stayed engaged in many different ways.”*

**Challenges Experienced in Promoting the Campaign:** A few challenges experienced in promoting the campaign were identified:

- Selecting an exhibit location within a wide rural geography
- Delayed campaign production limited time for promotion
- Having external service providers created delays when revising promotional materials

*“There were challenges in terms of getting the materials and places, these posters are big and getting them someplace where lots of people could see them. In Haldimand that’s tough because Haldimand is a community of lots of little communities so it was great to do it in Dunnville but a lot of people who live in Haldimand never go to Dunnville.”*

*“I think that one of the things that was difficult was the timing of the campaign. So, because of COVID the campaign was launched near the end of the project so I’m not sure that we were really fully able to benefit from the outcomes of the campaign or where that campaign could have taken us, just because of the timing that it was launched.”*

**Suggestions for Improvements to the Campaign Promotion:** Although key informants expressed satisfaction with the promotion of the campaign they identified a number of

*“I think that people can often become really engaged through social media and comments and feedback and I think we could have maybe done a bit more to reach more people on social media.”*

*“I think just that we probably could use more [media promotion], could use more of it. I don’t think we did too much radio. It would have been cool if we did more TV because a lot of people don’t have access to the internet.”*

*“Certainly, if we had a little bit more funding... Promotion costs money and it would have been really cool to have been able to feature that on primetime TV.”*

suggestions for improvements, many of which would have been implementable had there been more time for promotion:

- Increase social media presence
- Increase media promotion (radio, television)
- Increase funding for promotion
- Provide greater recognition for those working ‘behind the scenes’
- Increase promotion by project partners and funder
- Hold community exhibits in various locations.

**Key Lessons Learned in the Promotion of the Campaign:** Identified key lessons learned in promoting the campaign can serve as advice, or directives, to others interested in developing a similar campaign in effort to enable dementia friendly communities:

- Co-designing the campaign with person with dementia facilitated campaign promotion
- Established networks and partnerships can assist in campaign promotion
- Wide representation (diversity) in campaign participants is important
- Awareness raising campaign is critical to affecting change
- Create multiple opportunities for launching and exhibiting the campaign.

*“We said this all along, that the importance of engaging those that are going to be speaking as part of the campaign early on and throughout the campaign was really important and it made the campaign that much stronger. So, raising awareness about the impact or what its like to be a person living with dementia. So, what was really critical was those people who were engaged in the video were actually part of the campaign and were actually available and speaking to it and helping us promote it.”*

### Evaluation Objective III: Describe the Ways in Which Participation in the Faces of Dementia Campaign Affected Participants

Campaign participants, as reported in a survey, agreed that they felt comfortable sharing their experiences with dementia for this project, that their involvement will affect community change and that their participation in the campaign was a positive experience. As a key outcome indicated for this project, it was anticipated that 80% of respondents would perceive participation in the campaign as a positive experience; all three of the participants who completed a survey reported that their involvement in the campaign was a positive experience.

As related to impacts associated with the campaign, the majority of participant survey respondents (67%) agreed that as a result of the campaign, they felt better able to share their experiences with dementia, and learned new things about dementia. All of the survey respondents agreed that as a result of the campaign, they were more aware of the stigma associated with dementia and believe the campaign will be effective in increasing community awareness about the lived experiences of persons living with dementia.

Interviewed campaign participants and key informants identified a number of the ways in which the campaign impacted campaign participants.

- Empowerment to engage in community advocacy
- Increased capacity and confidence
- Increased desire to contribute more in the community
- Reduced social isolation
- Increased understanding of the personal impacts of dementia
- Increased encouragement and support to be active

*“What its done [participation in the campaign] is its broadened my horizons in the key areas that affect me and that I want to do further advocacy work.”*

*“And watching [campaign participant]... watching her do stuff that she said was way out of her comfort zone, but doing so remarkably, a great job.”*

*“I feel like I’m doing something and if anybody wants to join in, it feels great. I’ve been so isolated for years here and then finally being part of a program, it’s been great.”*

### Evaluation Objective IV: Describe Attendees’ Perceptions of the Campaign, Launch Events, Community Exhibits and Faces of Dementia Website

**Perceptions of the campaign launch events:** The majority of intimate launch survey respondents

*“The launch event was great. I appreciated the land acknowledgement. The timing of having it over lunch worked for me. I liked the friendly energy.”*

*“Have [sic] a virtual event made it so easy, no figuring out driving, parking, seating...”*

*“I loved hearing the meaning of the colours and that being behind the camera was a learning experience from the lens of the target market, and the underlying goal to capture the person, the dignity and humanity.”*

(91%) reported that they were ‘satisfied’ (22%) or ‘very satisfied’ (73%) with the campaign launch event. Similarly, the majority of public launch survey respondents (95%) reported that they were ‘satisfied’ (31%) or ‘very satisfied’ (64%) with the campaign launch event.

Comments made by respondents of intimate and public launch surveys about the campaign events reflected their satisfaction with the organization of the event, the convenience of the virtual format, and hearing from the creative team.

**Perceptions of campaign:** The majority of intimate and public launch survey respondents (95%) reported that they were ‘satisfied’ (22%) or ‘very satisfied’ (73%) with the campaign. Similarly, the majority of community exhibit survey respondents (76%) reported that they were ‘satisfied’ (22%) or ‘very satisfied’ (54%) with the campaign.

Chatroom comments made about the campaign by those in attendance at the public launch reflected perceptions that the campaign was beautifully produced, inspiring, empowering, and impactful, particularly as related to changing attitudes about dementia. Many attendees expressed gratitude for having access to the campaign and communicated intentions to share the campaign with both personal and professional networks and in their role as educators.

*“Incredible messages of hope and purpose. Thanks to all of you for sharing your stories and faces with us!! People living with dementia are LIVING, and this is what your video reminds the world about!”*

*“This is such a strong example of authentic partnerships and the power of these approaches for changing understandings and inspiring change.”*

*“Can’t wait to share this with my network. Thank you so much to everyone for this great and important work you are doing!”*

**Perceptions of the Community Exhibit Launch Events:** The community exhibit launch events were perceived favorably by interviewed key informants; their comments reflected:

- Events were well attended
- Events were interactive and engaging
- Exhibits were interactive
- Significant opportunity to have conversations about dementia

*“I think that the campaign and those in-person events provided the opportunity to talk about dementia and understand dementia differently. I think people who are members of the campaign living with dementia, talking to people and talking about the campaign and talking about their experiences, I think that’s where the learning really happens. I think people take a lot away from that and transform how they think and behave.”*

- Good to have campaign participants in attendance
- Joyful tone to the events
- Development of new community connections
- Venue selection impacted reach
- Positive feedback received

### **Evaluation Objective V: Describe the Ways in Which the Faces of Dementia Campaign Affected Viewers/ Audiences (Launch Events, Community Exhibits, Website)**

The majority of launch event and community exhibits attendees (>84%) agreed that they have a greater understanding of what it is like to live with dementia (86%) and the stigma associated with dementia (86%), intended to use what they learned in the campaign in their interactions with persons living with dementia (91%) and to make their community more dementia friendly (84%) and are more aware of this dementia friendly community project (91%). Fewer, but still the majority of respondents (72%) agreed that they learned new things about how to make their community dementia friendly.

*“An insightful and educating picture of the lives of the participants who are dealing with dementia.”*

*“So I think people, there are many situations where people living with dementia got a message of hope, received a message that this isn’t the end of the world that they and their family members often think it is. And that there are lots of other people out there living with this disease and that I am not alone.”*

*“So, for the people living with dementia I think that campaign again has the most potential to really reduce stigma.”*

*“I think it impacts everybody. Having the information, knowing about the campaign, seeing the campaign, reading the newsletters, participating in the workshops, it all helps to change people’s perspective, like it did mine...understanding more about the person with dementia having so much more agency than what I really gave them credit for. So, I guess one of the big lessons for me, and I keep having to learn this over and over, is not to underestimate people.”*

- Openness to acknowledge dementia and remain active
- Identification with campaign participants
- Increased community awareness will reduce stigma and improve quality of life for people living with dementia
- Increased understanding of what it is like to live with dementia
- Increased awareness of the need for and interest in dementia friendly community education
- Increased interest from other communities in creating dementia friendly communities
- Increased acceptance of all persons experiencing challenges
- Community change

Key informants identified a number of impacts associated with the campaign and community exhibits:

- Increased sense of hope among persons living with dementia
- Increased awareness of the capabilities of persons living with dementia
- Reduced stigma and more inclusive communities
- Increased understanding of dementia and the experience of living with dementia
- Increased recognition of the need to support the autonomy among persons living with dementia
- Increased access to dementia related community services

Some of the comments made by survey respondents about their satisfaction with the campaign and launch event highlighted the impacts associated with the campaign as related to increasing awareness of the experience of living with dementia, and providing hope to those diagnosed with dementia.

### ***Impacts associated with the campaign/ community exhibits:***

Campaign participants identified a number of impacts associated with the campaign for other persons living with dementia, their care partners and community:

*“Well, I think it will open the world up because a lot of times they [persons with dementia] don’t do things because they hide away in their houses. And I think once people start to see this it will open up better avenues for people living with dementia in the communities.”*

*“I think it’s a constant educational thing and I think this [campaign] will be very helpful in terms of that because it has people like myself and a lot of others that are articulate and still say: ‘Well, of course we have Alzheimer’s, but that doesn’t mean we can’t participate.’”*

*“This program that we have started, its aim was for dementia, but really its going to benefit everybody. Anybody that has any kind of challenge, its not about tolerance, its not about being friendly, its about acceptance... To me its about being inclusive and accepting.”*

**Conclusions:** Based on the findings of this evaluation, the following conclusions can be made:

- The data collected from the various sources of information for this evaluation provide both quantitative and qualitative evidence that the Faces of Dementia campaign was well received by campaign participants, project staff, partners, and attendees of the campaign launch events and community exhibits, who mostly represented the general public. The campaign was valued for its:
  - co-design with persons living with dementia, with its emphasis on focusing on the visions and needs of the campaign participants;
  - clear key messaging that tackles misconceptions and stigma about dementia by highlighting that people living with dementia are still ‘able’ and active and contributing members of their communities;
  - diverse representation;
  - visual appeal;
  - products (video, posters) that generate feelings of empowerment, hope, and inspiration; and,
  - potential to increase awareness about the capabilities of persons living with dementia, and reduce stigma and social isolation
  
- Key informants (campaign participants, project staff and partners) identified a number of important impacts associated with the campaign. Most significantly, campaign participants experienced enhanced well-being through their involvement with the campaign, which they described as providing them encouragement, support, and confidence to reengage and be active in their community, reducing their social isolation with the formation of new friendships and activities, and empowering them to engage in other advocacy-related activities. For participants, their involvement in the campaign was perceived as a positive experience. Other key informants described/ observed impacts related to increased awareness of the experience of living with dementia and capabilities of persons living with dementia, reduced stigma as people become more open to acknowledging dementia and remaining active, and increased interest from other communities in creating dementia friendly communities. The launch activities (campaign and community exhibits) provided a significant opportunity to not only promote the campaign itself but to have meaningful conversations about the experience of living with dementia and how this can be improved with dementia friendly communities; these events also resulted in the formation of new relationships with individuals and organizations interested in being involved in future project activities and connected members of the general public with dementia related community services (e.g., Alzheimer Society). Considering the visions that participants had for the campaign related to awareness raising, realistic portrayal of what it is like to live with dementia and to reduce stigma, along with the goals of the Empowering Friendly Dementia Community Hamilton, Haldimand, it can be concluded that the campaign was successful in meeting these objectives. It is important to note that while the campaign had some significant outcomes, the potential for even greater impact may have been realized had the campaign been developed, as planned, in Year 1 of this project with three years in which to promote and grow the campaign. Although the COVID-19 pandemic was a significant challenge for this project, strategies implemented for managing pandemic restrictions (e.g., use of

videoconferencing for gathering) proved to be successful as possible under these conditions.

- Key to the success of the campaign were the promotional activities (paid and earned media attention, social media) that brought people to the Faces of Dementia website, launch events, and community exhibits. The various promotional strategies demonstrated that the campaign reached over 16 million people, locally, provincially, nationally, and internationally. The campaign participants were instrumental in promoting campaign, reflecting the value they placed the campaign and its potential to affect community change. Worth noting is the front page feature article in the Hamilton Spectator on the Faces of Dementia campaign featuring one of the participants.
- The campaign garnered a lot of attention from other communities interested in creating dementia friendly communities and creating a similar awareness raising campaign. This evaluation has identified key lessons learned in the development and promotion of the campaign that can serve to inform future work in this area not only in the Hamilton and Haldimand regions but also other jurisdictions. Key lessons specific to authentic involvement and co-design by persons living with dementia, the need for dedicated project staff to support the work, sufficient funding and time, and community relationships to support recruitment will help to ensure the success of similar projects.
- A key message heard in the evaluation was that this campaign was a good ‘start’; there are ideas, plans, and a desire to continue to grow the campaign by increasing the diversity represented with the inclusion of participants at different disease stages, of different ages and from different ethnocultural groups and creating campaign materials in different languages. The success of this current campaign and lessons learned from this campaign will place future activities in a good position to move forward the project’s agenda to affect community change in a meaningful and impactful way.

***Limitations:*** There are a number of limitations associated with the evaluation of the Faces of Dementia campaign. Campaign participants and project key informants were significant sources of information for the evaluation. While the general public, as attendees of the launch events and community exhibits did provide some feedback on their perceptions of the campaign and potential impacts/ outcomes, more input from the Hamilton and Haldimand communities would have provided greater insights into the impacts of the campaign at a community level. There were no feedback submissions on the Faces of Dementia website, likely because of the placement of the feedback request at the bottom of the webpage, where it may not have been viewed by those who clicked on links to other sources of information. The request for feedback respondents’ name and contact information may also have discouraged some people from providing feedback. The campaign had roughly 10 months (May 2022 – February 2023) of promotion, which may not have been sufficient time to demonstrate quantifiable community level impacts; this may have been possible if the campaign had launched earlier so that there were more opportunities to collect data from the community. In this evaluation, we used the Dementia Community Attitudes Scale, a standardized tool that measures community attitudes about dementia. In this evaluation it was used to assess the attitudes of attendees of the campaign launch events and community exhibits, demonstrating, overall, positive attitudes about dementia.

However, it is not possible to determine the direct effect of the campaign on these attitudes. Future campaign initiatives should attempt to employ pre-post methods to measure change in attitudes due to campaign activities.

## Introduction

The *Empowering Dementia Friendly Communities in Hamilton and Haldimand* project proposes to enable the Hamilton Council on Aging (HCoA) to continue and expand the development of dementia friendly communities in Hamilton and Haldimand. The Empowering Dementia-Friendly Communities Hamilton, Haldimand project is a collaborative initiative, led by the Hamilton Council on Aging (HCoA), citizens and a multi-disciplinary team of organizations including persons living with dementia, the Alzheimer Society of Brant, Haldimand Norfolk, and Hamilton Halton, the GERAS Centre for Aging Research, the Regional Geriatric Program central, McMaster University, Haldimand-Norfolk Community Senior Support Services, Hamilton Health Sciences, Haldimand War Memorial Hospital and the Age-Friendly Hamilton Collaborative Governance Committee. This project is funded by the Public Health Agency of Canada. GERAS' role in this initiative is to develop and implement an evaluation of the Dementia Friendly Communities project.

This project proposes to integrate a Dementia Friendly Community Plan with Hamilton's municipal Plan for an Age Friendly City (2021-2026). Building on the findings of an extensive community consultation to better understand the experiences, challenges and ideas of persons affected by dementia and leveraging the universally beneficial outcomes and influence of Age Friendly Hamilton, this project aims to:

- 1) Optimize the wellbeing of people living with dementia and/or their family/friend care partners, to create:
  - a) Enhanced social wellbeing and social inclusion from those persons living with dementia and their care givers who had opportunities to express themselves and be heard.
  - b) Increased understanding about what helps create a city environment that is truly dementia friendly.
  - c) Enhanced wellbeing and social inclusion for persons living with dementia, their families, friends and care partners.
- 2) Promote awareness of dementia and its risk factors by supporting innovative approaches that tackle stigma and promote compassion and support, leading to:
  - a) More people including persons living with dementia, their caregivers, service providers and the community at large recognizing stigma and risk factors associated with dementia to create more inclusive, dementia friendly communities.
- 3) Undertake intervention research to assess the effectiveness of the program or initiative and promote/apply this knowledge to:
  - a) Support expansion of the project's reach to new communities, sectors, populations and/or jurisdictions to enhance knowledge about how to create dementia friendly communities.

A key project activity is the development of a "Faces of Dementia" Campaign to showcase the need for a Dementia Friendly Community strategy and to increase awareness about the experience of living with dementia so as to reduce stigma. Community members living with dementia were recruited to be profiled in the campaign, consisting of videos, posters and other

campaign materials. The campaign was officially launched in May 2022, with two launch events and was promoted online, in the media, and in community exhibits in Hamilton and Haldimand.

This report describes the methods and results of an evaluation of the Faces of Dementia campaign, launch events, and community exhibits.

## Evaluation Methods

A program logic model for the Faces of Dementia campaign, launch events and community exhibits to inform the evaluation. Program logic models provide a good starting point for developing evaluation frameworks. They provide a vehicle for creating a shared understanding of a program, highlighting the activities that need to be accomplished in order to achieve desired goals and can be used to facilitate program development, management, and evaluation.<sup>3,4</sup> A program logic model for the campaign and its promotion is presented in Appendix A.

The evaluation was focused with input from project staff, individuals involved in developing the campaign, and the Dementia Friendly Communities project Stewardship Group.

### Evaluation Objectives

The identified objectives of this evaluation were to:

- (i) Describe the development and implementation of the Faces of Dementia campaign and implementation of the launch events:
  - Identified outputs associated with the creation of the Faces of Dementia campaign (e.g., # campaign participants, # products created) and launch events (e.g., # events, # attendees) as listed in the Program Logic Model.
- (ii) Describe key informant (campaign participants, project manager, interview facilitator, coordinators) perspectives on the development and implementation of the Faces of Dementia campaign with persons living with dementia and campaign promotion, in terms of:
  - Campaign facilitating factors, challenges/ barriers, suggestions for improvement, key lessons learned, identification of additional resources or supports needed to make this type of project successful;
  - Campaign materials/ process as a vehicle for information sharing; and,
  - Perceptions of the campaign promotion including challenges, suggestions for improvement and key lessons learned.

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<sup>3</sup> Cooksy L.J., Gill, P., & Kelly, A. (2001). The program logic model as an integrative framework for a multimethod evaluation. *Evaluation and Program Planning*, 24, 119-128.

<sup>4</sup> Julian, D.A. (1997). The utilization of the logic model as a system level planning and evaluation device. *Evaluation and Program Planning*, 20, 251-257.

- (iii) Describe the ways in which participation in the Faces of Dementia campaign affected participants in terms of:
  - Satisfaction with their experience in the campaign (group meetings, one-to-one interviews, and filming process to share their experiences) and outcomes (campaign materials - stories, film, social media clips, website landing page);
  - Overall perceptions of their experience in the campaign (negative, positive); and,
  - Experience with/ understanding of stigma.
  
- (iv) Describe attendees (campaign participants, project partners, family, friends, general public) perceptions of the campaign, launch events/ community exhibits and Face of Dementia website, in terms of:
  - Satisfaction with the campaign, launch events, exhibits and website; and,
  - Perceptions of the community exhibit launch events.
  
- (v) Describe the ways in which the Faces of Dementia campaign affected viewers/ audiences (launch events, community exhibits, website) in terms of:
  - Understanding of the lived experiences of / stigma experienced by persons living with dementia;
  - Change in attitudes about dementia;
  - Increased awareness of the Dementia Friendly Community projects in Hamilton and Haldimand;
  - Impact on intentions to change personal/ professional behaviours based on learnings from the campaign; and,
  - Perceptions of community as dementia friendly and the importance of having dementia friendly communities.

## **Design and Sources of Information**

A mixed methods (quantitative, qualitative) approach was used to evaluate the outcomes associated with dementia awareness campaign and launch events (summative evaluation) and to describe the development and implementation of the campaign (formative evaluation).

## **Tracking of Campaign Development and Implementation**

To describe the development and implementation of the Faces of Dementia campaign, launch events and community exhibits, key outputs as outlined in the program logic model were tracked using an excel spreadsheet completed by project staff. This information was tracked from the start of campaign development (September 2021) to February 2023. Outputs related to the Faces of Dementia campaign included:

- # Persons living with dementia participating in the campaign (Hamilton, Haldimand)
- # Persons living with dementia invited to participate in the campaign but declined, withdrew (Hamilton, Haldimand)
- Recruitment strategies
- # Project staff / Facilitators

- # Workshop/ group meetings with participants
- # Individual meetings/ interviews with participants
- # Participant interviews completed and filmed
- # Participants completing portrait photography
- Faces of Dementia campaign film length
- # Short clip variations/excerpts for social media and alternative use
- Length of short clip variations
- # Posters and social media content created
- # social media posts and analytics
- # Campaign tools/resources
- Landing page for campaign materials

Outputs related to launch events and community exhibits included:

- # Campaign launch events
- Location of launch events (community) and format (in-person, virtual)
- # Campaign participants attending the intimate launch event.
- # Campaign participants' family and friends attending the intimate launch event.
- # General public members (Hamilton, Haldimand) attending campaign launch events
- # media requests related to launch events (Hamilton, Haldimand)
- # interviews completed related to launch events (Hamilton, Haldimand)
- # community gallery exhibits (Hamilton, Haldimand) and locations
- # community gallery exhibits (Hamilton, Haldimand) attendees photo/audio gallery exhibits
- Paid media advertising and reach

## Reflective journaling

The campaign facilitator and coordinator maintained reflective journaling as an opportunity to describe the process of creating the campaign with persons living with dementia, including adaptations that were made and new learnings. Reflective journaling as an evaluation tool provides a good opportunity to document the development and implementation of a new program and share new learnings and phenomena of interest as they occur from the perspective of those involved in program development. In this instance, reflective journaling can provide insights into the process used with persons living with dementia to develop a dementia awareness campaign. In this evaluation, critical reflective inquiry was used, consisting of three phases: descriptive, reflective and critical/emancipatory phases, with the following instructions:<sup>5</sup>

- ***Descriptive phase:*** Select a situation or discussion of relevance to reflect on – describe the situation/ discussion as well as your actions, thoughts and feelings about it.
- ***Reflective/ Interpretation phase:*** Reflect and interpret the situation; consider reflecting upon the situation against your personal beliefs, assumptions/ expectations, or knowledge.

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<sup>5</sup> Kim, HS. Critical reflective inquiry for knowledge development in nursing practice. J Adv Nurs 1999;29(5):1205-1212. doi: 10.1046/j.1365-2648.1999.01005.x.

- **Critical/ emancipatory (change) phase:** Focus what can be done to correct or change ineffective actions (conclude what you can learn from the situation and how it can be applied next time).

This reflective process is also referred to as the three W's to writing reflectively: *What, So What* and *What next*.<sup>6</sup> The journaling was guided by a series of questions that are not necessarily prescriptive. It was suggested that journaling be completed soon after each meeting, or interview with campaign participants and after any meetings or discussions that resulted in decisions or changes to the implementation process. Questions used to guide the reflective journaling are presented in Appendix B.

## **Interviews with Campaign Participants**

Individual interviews were conducted with campaign participants to gather more in-depth information about their perceptions of the campaign and potential outcomes. Questions were asked about:

- Their thoughts on the campaign (what they liked, didn't like);
- Their thoughts on the campaign materials and website landing (what they liked, didn't like);
- Effectiveness of the campaign in communicating the key messages they wanted to share;
- Suggestions for improving the campaign; and
- Impacts (actual, potential) associated with the campaign (personal, other persons living with dementia, community at large).

The guide for this interview is presented in Appendix C. A modified (simplified) interview guide (minus prompts) was distributed to interview participants prior to the interview for their review; this version of the interview guide is also presented in Appendix C.

Invitations to participate in an interview were distributed following the intimate campaign launch event (May 3, 2022). Interviews were completed by the GERAS evaluation team. All campaign participants were invited to complete an interview and they were provided the option of doing this either via telephone or videoconferencing (Zoom) as they preferred. It was anticipated that the interviews would be approximately 30 minutes in length. All interviews were audio recorded with participant permission and transcribed by a professional transcription service.

## **Survey of Campaign Participants**

Following the intimate and public launch events and completion of the interviews with campaign participants, they were invited to complete an online survey to assess their reactions to the campaign. Questions were asked about:

- Their satisfaction with their experience in the campaign (5-point scale: very dissatisfied, somewhat dissatisfied, neutral, somewhat satisfied, very satisfied);
- Their level of agreement (disagree, neutral, agree) with various statements about their comfort in sharing their experiences with dementia, ability to share their experiences with dementia, their participation as a positive experience, increased awareness of how people

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<sup>6</sup> Journey. How to Write Reflectively. <https://journey.cloud/reflective-journal/>

experience dementia, and various impacts of the project on creating community change; and,

- The extent to which they perceive their community to be dementia friendly and this initiative to be important (5-point scales: 1 = not at all; 5 = extremely).

Respondents were also given with an opportunity to provide additional comments about their experiences in the campaign (open-ended question). It was anticipated that 80% of the respondents would perceive participation in the campaign as a positive experience. The survey is presented in Appendix D.

The campaign participant survey was administered on-line via Survey Monkey ([www.surveymonkey.com](http://www.surveymonkey.com)). Survey distribution was consistent with the method of survey distribution described by Dillman;<sup>7</sup> participants were invited to complete the survey via e-mail and follow-up reminders to complete the survey distributed one week prior to the deadline date and the day of the deadline date. Respondents were given a two-week time period in which to complete the survey. The survey invitation and reminders are presented in Appendix E. Paper versions of the survey were available upon request; one participant requested a paper survey. The survey was delivered via postal delivery service, accompanied by a self-addressed and stamped envelope.

### **Survey of Launch Event and Community Exhibit Audiences**

Audience members of the intimate and public launch events were surveyed to gather their perceptions of the campaign and impact on anticipated outcomes. Questions were asked about:

- Their satisfaction with the campaign and launch event/ community exhibit (5-point scale: very dissatisfied, somewhat dissatisfied, neutral, somewhat satisfied, very satisfied);
- Their level of agreement (strongly disagree, disagree, neutral, agree, strongly agree) with various statements about the impact of the campaign on their understanding of dementia, stigma, new learning about dementia friendly communities, intentions to apply new learnings, and increased awareness of the Empowering Dementia Friendly Communities, Hamilton, Haldimand project;
- Impact of the campaign on attitudes about dementia, as measured by the Dementia Community Attitudes Scale, a 10-item standardized tool to assess changes in attitudes about dementia specially created to measure community attitudes for community-based initiatives;<sup>8</sup> and,
- The extent to which they perceive their community to be dementia friendly and this initiative to be important (5-point scales: 1 = not at all; 5 = extremely).

Respondents were also given with an opportunity to provide additional comments about the campaign and launch event/ community exhibits (open-ended question). In addition, there were demographic questions related to:

- Community in which launch event/ community exhibit was attended,
- Respondent group (person living with dementia, care partner, family member or friend, general public)

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<sup>7</sup> Dillman, D.A. (2000) *Main and internet surveys. The Tailored Design Method 2<sup>nd</sup> Ed.* New York: John Wiley.

<sup>8</sup> Read, ST, Wynaden, D, Albrecht, MA, et al. Development of the dementia community attitudes questionnaire. *Dementia* (London) 2021; 20(6):1940-1957. Doi: 10.1177/1471301220977649.

- Care partner relationship to the person living with dementia (spouse/ partner, adult child, extended family member, friend, other)
- Gender (female, male, gender fluid/ non-binary/ two-spirit);
- Year of birth (age was calculated as the difference between survey distribution date and year of birth)
- Identification as Indigenous or a visible minority.

This survey is presented in Appendix F.

This survey was administered to attendees of the campaign launch events on-line via Survey Monkey ([www.surveymonkey.com](http://www.surveymonkey.com)). As part of the virtual campaign launch events (intimate and public), the purpose of the survey and encouragement to complete the survey were announced at the end of the event. Launch participants were sent an invitation to complete the survey via email by project staff. Survey distribution was consistent with the method of survey distribution described by Dillman;<sup>9</sup> participants were invited to complete the survey via e-mail immediately following the launch events and follow-up reminders to complete the survey distributed one week prior to the deadline date and the day of the deadline date. Respondents were given a two-week time period in which to complete the survey. The survey invitation and reminders are presented in Appendix G.

For the community exhibits, audiences were able to access the survey via a Quick Response (QR) code posted at the exhibit with a request for feedback. In addition, paper copies of the survey were available during the exhibit time period; a survey collection box was available for the submission of completed surveys. The surveys were collected at the time that the exhibit was dismantled. To incentivize survey completion, respondents were invited to provide their name and contact information to be entered into a draw for a \$250 gift card. For both the online and paper versions of the survey, survey responses were submitted separate from the gift card contact information so that the two could not be linked and survey respondents remained anonymous.

### **Faces of Dementia Community Exhibit Guest Books**

A guest book was present at both the Hamilton and Haldimand community exhibits for audiences to provide their name and feedback. The guest book was available at the community exhibit launch events and remained in place for the duration of the exhibits.

### **Faces of Dementia Campaign Website Feedback**

Audiences viewing the Faces of Dementia Campaign online were encouraged to provide feedback on the campaign and to how they are using it in their own communities. The following invitation was posted on the Faces of Dementia website:

**We want to hear from you!**

We want your feedback! Tell us what you think of the Faces of Dementia campaign, and how you're using it in your own community!

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<sup>9</sup> Dillman, D.A. (2000) *Main and internet surveys. The Tailored Design Method 2<sup>nd</sup> Ed.* New York: John Wiley.

Respondents we asked to provide their name and email address. This invitation was posted at the time that the website went live (May 2022) and remains active.

## **Key Informant Interviews**

Individual key informant telephone interviews were conducted to gather in-depth information about the development and implementation of the Faces of Dementia campaign, launch events and community exhibits. Questions were asked about:

- Their perceptions of the campaign and launch events/ community exhibits (what they liked, didn't like)
- Understanding (insights) of how to create and implement a dementia awareness-raising campaign as related to:
  - facilitating/ enabling factors,
  - challenges/ barriers,
  - suggestions for improvement,
  - key lessons learned,
  - identification of additional resources or supports needed to make this type of project successful,
  - adaptations made to create the campaign (e.g., related to COVID-19 pandemic restrictions, specific participant needs, or specific community needs)

Respondents were also given with an opportunity to provide additional comments about the campaign and launch event/ community exhibits.

A first set of interviews were conducted following the intimate launch event (May 3, 2022), which focused on key informants' perceptions of the campaign itself (campaign materials, videos, portraits) and the process of developing the campaign. In the winter of 2022-23, a second set of interviews were conducted to capture key informants' perceptions of the promotion of the campaign (launch events, public promotion, and community exhibits). For efficiency, interview questions related to the campaign promotion were integrated into the interviews conducted for the annual project evaluation. The guides for these interviews are presented in Appendix I.

Invitations to participate in the first set of interviews were distributed following the intimate campaign launch event (May 3, 2022); interviews to participate in the second set of interviews were distributed on December 13, 2022. Individual telephone interviews were completed by the GERAS evaluation team. For each set of interviews, a purposeful sampling strategy, stratified by region (Hamilton, Haldimand, was used with the intention of gathering a broader range of perspectives for the evaluation, including members of the project staff (project manager, campaign facilitators), Stewardship Group, and campaign service providers (Kitestring, Atomic Spark, Tae Photography). It was estimated that 8 – 10 interviews would be conducted at each point in time, however the aim was to conduct the interviews to the point of the saturation (i.e., no or limited additional information was generated from the last interviews completed); if needed additional individuals would be selected to participate in an interview. It was anticipated that the interviews would be approximately 30 minutes in length. All interviews were audio recorded with participant permission and transcribed by a professional transcription service.

## Research Ethics Board Approval

As the objectives of this evaluation are considered quality improvement, research ethics board approval was not required. A waiver for approval was received the Hamilton Integrated Research Ethics Board (HiREB), McMaster University.

## Data Collection and Analysis

The GERAS evaluation team was responsible for survey administration and interview completion. Data were analyzed using SPSS 28.0. (Chicago, IL: SPSS Inc, 2022). Frequencies were generated for all numerical survey data. Campaign launch and community exhibit survey data were analyzed by community (Hamilton, Haldimand) and respondent group (person living with dementia, care partner, all others). Throughout this report average is calculated as the mean score; +/- = standard deviation, which is the average distance between individual scores from the overall average score. Analysis of open-ended survey questions and interviews was consistent with recommended practices for qualitative evaluation data.<sup>10</sup> Descriptive qualitative content analysis was conducted to understand the experiences and perceptions of persons interviewed for this evaluation (campaign participants, key informants) and other sources of feedback (e.g., exhibit guestbooks).<sup>11</sup> Interview transcripts were reviewed to generate broad categories and identify reoccurring themes in the data.

## Results

The following is a summary of the highlights and main themes that have emerged from the evaluation. Where relevant, findings are differentiated by community (Hamilton, Haldimand), respondent group (person living with dementia, care partner, all others), or by survey (campaign participant, launch attendees, community exhibit). In regards to information collected from campaign participants, data is presented across both communities in efforts to protect their anonymity. Detailed results of the tracking of campaign implementation, survey of campaign participants, and launch event and community exhibit surveys are presented in Appendices J to M, respectively.

## Evaluation Response Rates

Response rates for each of the evaluation components is presented in Table 1. Response rates ranged from 26% to 89% across all evaluation components.

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<sup>10</sup> Patton, M.Q. (2002). *Qualitative Evaluation and Research*. Thousand Oaks, CA: Sage.

<sup>11</sup> Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77-84.

**Table 1: Evaluation response rates**

<b>Evaluation Component</b>	<b>Response Rate</b>
Campaign Participant Survey	42.9% (3/7)
Interviews with Campaign Participants	71.4% (5/7)
Survey of Campaign Launch Events <i>Intimate launch</i> <i>Public launch</i>	39.8% (106/266) 56.4% (22/39) 38.7% (84/217)
Survey of Community Exhibits <i>Sackville Hill Seniors Centre (Hamilton)</i> <i>Minga Café (Dunnville)</i>	46* 73.9% (34) 26.1% (12)
Community Exhibit Guest Books <i>Sackville Hill Seniors Centre (Hamilton)</i> <i>Minga Café (Dunnville)</i>	28 entries 22 entries 6 entries
Faces of Dementia Website Feedback	No submissions
Key Informant Interviews June 2022 Fall 2022/ Winter 2023	88.9% (8/9) 70.0% (7/10)

\*Attendance at community exhibits was not monitored so it is not possible to calculate a response rate for surveys completed at these exhibits.

### **Campaign Participant Surveys and Interviews**

The campaign participant survey was completed by 3 of the 7 participants. All campaign participants were invited to participate in an interview; five participants completed an interview. Interviews were conducted between May 6 and 11, 2022. Two interviews were conducted by videoconferencing (Zoom) and three via telephone. For one of the interviews, the campaign participants spouse was present for the interview, but did not direct or lead the participants' responses. The interviews ranged in length from 18 to 30 minutes, with an average of 25.6 ( $\pm$  4.7; median = 26) minutes.

### **Campaign Launch and Community Exhibit Surveys**

In total 39 individuals attended the intimate campaign launch events on May 3, 2022; 22 evaluation surveys were completed for this event, representing a 56% response rate. In total, 341 individuals registered to attend the launch; there were 217 individuals Zoom logins (including panelists), but it was likely that multiple people attended with a single login, so it is not possible to know exactly how many people attended the event. All 341 registrants received an invitation

to complete the survey. Using the number of zoom logins (N = 217) as the denominator, generates a 39% response rate (conservative estimate). In total, 46 community exhibit surveys were completed. As attendance at the exhibit was not monitored, it is not possible to generate a response rate. Of the 46 surveys completed, four were completed online and 42 paper versions were completed. The majority of surveys (71%) were completed as related to the community exhibit held in Hamilton.

Demographic information was collected in the campaign launch event and community exhibit surveys. Across all three surveys, the majority of survey respondents were from Hamilton and area (59%; Table 2). A little over a third of respondents (37%) identified as persons affected by dementia (persons living with dementia, care partners, or family members of persons living with dementia). Respondents ranged in age from 24 to 93 years, with an average age of 59; the majority were woman (78%). Less than 10% of identified as Indigenous (0.7%), or as a visible minority (9.9%).

**Table 2: Campaign Launch and Community Exhibit Survey Respondent Characteristics**

<b>Characteristic</b>	<b>Intimate Launch Survey (N = 22)</b>	<b>Campaign Launch Survey (N = 84)</b>	<b>Community Exhibit Survey (N = 46)</b>	<b>Total (N = 152)</b>
<b>Community</b>				
Hamilton and area	81.8% (18)	44.0% (37)	73.9% (34)	<b>58.6% (89)</b>
Haldimand and area	9.1% (2)	10.7% (9)	26.1% (12)	<b>15.1% (23)</b>
Other/ Unspecified	9.1% (2)	45.2% (38)	0	<b>26.3% (40)</b>
<b>Respondent Group</b>				
Person living with dementia	18.2% (4)	4.8% (4)	2.2% (1)	<b>5.9% (10)</b>
Care partner	9.1% (2)	9.5% (8)	17.4% (8)	<b>11.8% (18)</b>
Family members or friends of a person living with dementia	4.5% (1)	19.0% (16)	28.3% (13)	<b>19.7% (30)</b>
Library/ recreation/ arts/ museum staff or volunteers	0	1.2% (1)	NA	<b>0.7% (1)</b>
Businesses	18.2% (4)	2.4% (2)	NA	<b>3.9% (6)</b>
Faith groups	0	1.2% (1)	NA	<b>0.7% (1)</b>
Media	0	0	NA	<b>0</b>
Elected officials	0	0	NA	<b>0</b>
Policy makers	0	0	NA	<b>0</b>
Funding organizations/ philanthropy	0	1.2% (1)	NA	<b>0.7% (1)</b>
Health care providers/ health system workers	18.2% (4)	19.0% (16)	NA	<b>13.2% (20)</b>
Community services	9.1% (2)	23.8% (20)	NA	<b>14.5% (22)</b>

<b>Characteristic</b>	<b>Intimate Launch Survey (N = 22)</b>	<b>Campaign Launch Survey (N = 84)</b>	<b>Community Exhibit Survey (N = 46)</b>	<b>Total (N = 152)</b>
General public (community at large)	9.1% (2)	7.1% (6)	52.2% (24)	<b>21.0% (32)</b>
Other*	13.6% (3)	7.1% (6)	NA	<b>5.9% (9)</b>
<b>Gender</b>				<b>78.3% (119)</b>
Female	59.1% (13)	79.8% (67)	84.8% (39)	
Male	27.3% (6)	14.3% (12)	8.7% (4)	<b>14.4% (22)</b>
Gender fluid/ non-binary/ two spirit)	0	0	0	<b>0</b>
Preferred not to answer	9.1% (2)	2.4% (2)	2.2% (1)	<b>3.3% (5)</b>
<b>Age</b>	(N = 16)	(N = 74)	(N = 43)	<b>(N = 133)</b>
Average (+/-)	57.0 (17.7)	58.2 (14.4)	61.7 (15.1)	<b>59.2 (15.1)</b>
Range	31 – 86	24 – 92	26 – 93	<b>24 – 93</b>
Median	62	61	65	<b>62</b>
<b>Indigenous identity</b> (First Nations, Métis, Inuit)				
Yes	0	1.2% (1)	0	<b>0.7% (1)</b>
No	90.9% (20)	88.1% (74)	89.1% (41)	<b>88.8% (135)</b>
Preferred not to answer	6.3% (1)	6.0% (5)	8.7% (4)	<b>6.6% (10)</b>
<b>Visible minority identity</b>				
Yes**	9.1% (2)	9.5% (8)	10.9% (5)	<b>9.9% (15)</b>
No	77.3% (17)	79.8% (67)	78.3% (36)	<b>78.9% (120)</b>
Preferred not to answer	9.1% (2)	4.8% (4)	8.7% (4)	<b>6.6% (10)</b>

Note: Percentages may not sum to 100% due to missing data. NA = Not applicable as response choice was not offered. PLWD = Person living with dementia.

\*Other: Advocate; Education-focused organizations/ educator; one or more categories (excluding person living with dementia or care partners); research coordinator; person living with brain injury.

\*\*Visible minority groups endorsed: Arab, Latin American, South Asian (East Indian, Pakistani, Sri Lankan, etc.); Southeast Asian (Vietnamese, Cambodian, Laotian, Thai, etc.) Black; Chinese; Filipino.

## **Faces of Dementia Community Exhibits Guest Books**

Twelve individuals attending the community exhibit in Haldimand signed the guest book, with six providing feedback. For the community exhibit in Hamilton, 25 individuals signed the guest book, with 22 providing feedback.

## Faces of Dementia Website Feedback

There were no feedback submissions on the Faces of Dementia website over a 9 month time period (May 2022-January 2023).

## Key Informant Interviews

**May 2022:** Eight of nine key informants (89%) invited to participate in an interview in the first set of interviews, scheduled and completed an interview. Interview participants represented project staff, project partners, and service providers (Table 3), the majority lived or worked in Hamilton. Interviews were conducted between May 9 and 22, 2022. The interviews ranged in length from 14 to 33 minutes, with an average of 22.3 ( $\pm$  6.5; median = 22.5) minutes.

**Winter 2022 -2023:** Seven of 10 key informants (70%) were invited to participate in the second set of interviews held in December 2022 and January 2023. Interview participants represented project staff and Stewardship Group members, including two with people living with dementia who participated in the campaign (Table 3). Six interviews were conducted via telephone and one via videoconferencing (Zoom). Four individuals also participated in the key informant interviews conducted in June 2022 and two individuals participated in the campaign participant interviews conducted in May 2022; in total six individuals contributed to the interviews across both time periods. Interviews were conducted between December 20, 2022 and January 10, 2023. The interviews ranged in length from 11 to 26 minutes, with an average of 17.6 ( $\pm$  5.3; median = 16.0) minutes. As related to attendance at community exhibit launch events, almost all interview participants attended the launch event at the Sackville Seniors Centre, Hamilton (85.7%; N = 6), four attended the launch event at the Minga Café, Dunnville (57.1%) and four attended both launch events (57.1%).

**Table 3: Key informant characteristics**

<b>Participant Characteristics</b>	<b>June 2022 (N = 8)</b>	<b>Fall 2022 (N = 7)</b>
<b>Group</b>		
Stewardship Group Members*	3 (37.5%)	5 (71.4%)
Project staff	3 (37.5%)	2 (28.6%)
Production/ service providers	2 (25.0%)	0
<b>Location</b>		
Hamilton	6 (75.0%)	5 (71.4%)
Haldimand	2 (25.0%)	2 (28.6%)

## Evaluation Objective I: Describe the Development of the Faces of Dementia Campaign with Persons Living with Dementia and Launch Events

### Recruitment Efforts

While the initial funding proposal for the campaign was targeted at including 10 persons living with dementia, finding individuals interested and willing to share their experiences publicly and during the COVID-19 pandemic proved to be challenging. A search effort was launched in both Hamilton and Haldimand, widely advertising the project via the Hamilton Council on Aging website, free television (Cable 14) and print ads (Metroland News), direct email requests to project partners, health, social, and community services targeted to older adults/ persons living with dementia and with outreach to diverse communities (e.g., local retirement homes, long-term care, adult day programs, Alzheimer Society, Public Health). The various recruitment strategies used are listed in Appendix I. While it is not known exactly how many people were approached about their interest in learning more about or participating in the campaign as invited by individuals outside of the project team, the project team spoke directly with 10 individuals about participating in the campaign (Table 4). Of these 10 individuals, three declined to participate and seven individuals participated in the campaign. Initially, a total of five individuals volunteered to participate in the campaign. As there was limited ethno-cultural diversity among this group of volunteers, additional efforts, through engagement of partner networks and expansion of the recruitment reach to include the Halton region and Six Nations of the Grand River, were made to recruit more diverse participants; these efforts yielded two additional participants, representing South Asian and Indigenous communities.

**Table 4: Campaign participant recruitment**

	Hamilton	Haldimand	Other*	Total
Number of individuals invited to participate in the campaign	5	3	2	10
Number who declined participation	1	2	0	3
Number who agreed but later withdrew	0	0	0	0
Final number of participants**	4 (80%)	1 (33%)	2 (100%)	7 (70%)

Note: This does not include the number of people who were approached about their interest in learning more about or participating in the campaign, as invited by individuals outside of the project team, and who declined to engage to the project team.

\*Individuals recruited when the reach of the project was expanded to included Halton and Six Nations of the Grand Rivers.

\*\*Percentage is based on the number of people who were invited to participate in the campaign.

## Campaign Development

The Faces of Dementia campaign was to be created and launched in each community with a total of 10 participants in March 2020, however, the COVID-19 pandemic, and specifically, 'Stay at home' orders prevented the gathering of people to produce the campaign. As a consequence, this campaign was shifted to Year 3 of the project as pandemic restrictions eased. The Faces of Dementia campaign was designed to build off the Hamilton Council on Aging Portraits of Aging Campaign. While the goal was to produce an awareness raising campaign, the process of authentically and thoughtfully engaging persons living with dementia in the development of the campaign was paramount. An expert facilitator was contracted to co-design and facilitate a supportive, accessible and positive experience for campaign participants. A coordinator was assigned the role of assisting the facilitator in these activities.

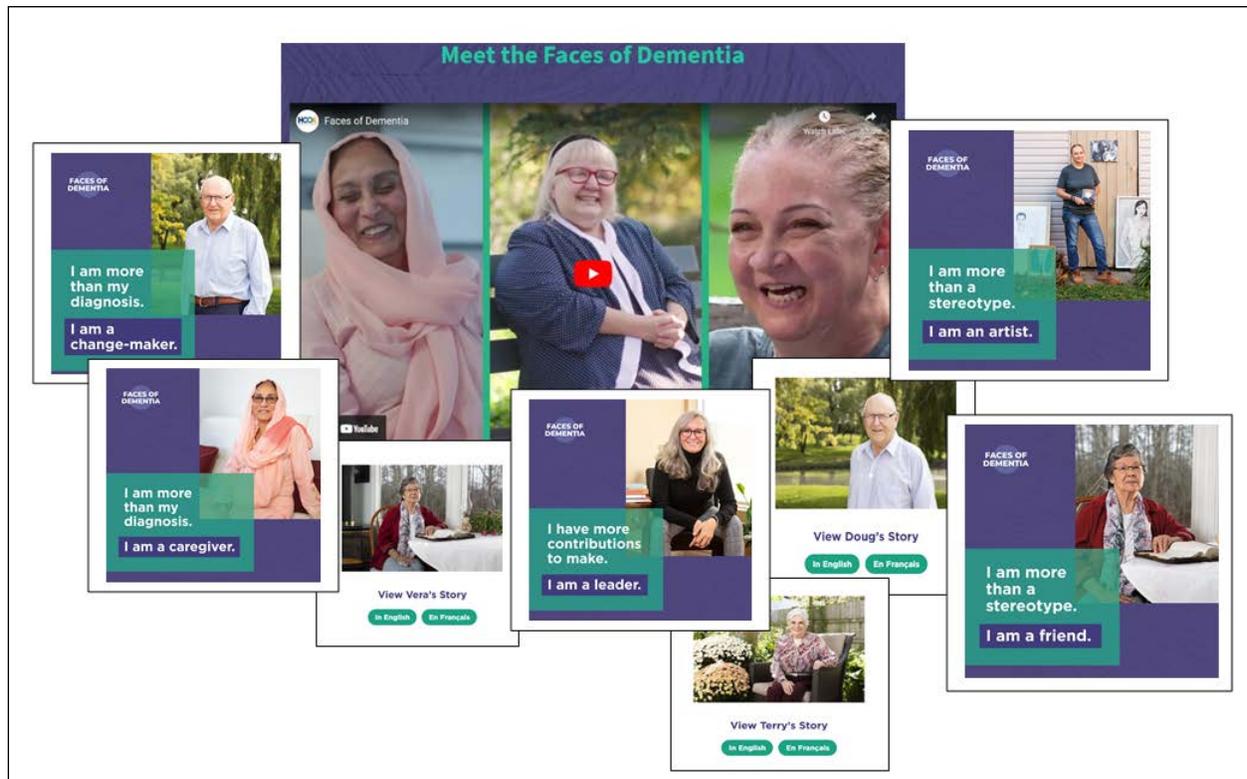
The campaign process involved a virtual group meeting to introduce participants to each other and to describe the campaign process, and ascertain participants' visions and goals for the campaign, and one-to-one interviews with the campaign facilitator to explore themes to be highlighted in the campaign. The initial one-to-one interviews were held with participants as guided by the facilitator, with the project coordinator present to take notes. The goal of these one-to-one interviews was to get to know the participants better and to create rapport and a safe space for conversations about dementia and the campaign. These interviews also provided an opportunity to determine each participants suitability and interest in participating in the various components of the campaign (filmed interview, photography, story sharing). As the campaign was intentionally meant to be directed by persons living with dementia, as a group and individually, the facilitator worked with the campaign participants to identify what they thought should be the key focus and messaging in the campaign (What would be the most important message that you would like the campaign to address?). These virtual interviews (conducted via video-conferencing) were video-recorded, with permission, for accuracy of reporting on participants thoughts on the key campaign messages; these thoughts were summarized and provided to each of the participants.

Shortly following the meetings with five participants (September-October 2021), formal campaign production activities (in-person film/photography) began (mid-October 2021). This production (filming/ photography) was delayed at times due to participant illness, creating delays in completing the campaign. Further delay was created when additional attempts were made to recruit additional participants to reflect the more diverse populations in this region. Pre-interviews and filming of two additional participants occurred in February-March 2022. In-person filming was conducted by Atomic Spark Productions, with portrait photography by Tae Photography. Each participant selected the location in which they wanted to be filmed and photographed; it was suggested they select a location that is meaningful to them. For example, one participant chose a Butterfly Garden as her location as it was a place she often visited and felt a special connection to, with nature representing something she loved. Following the filming, four of the initial five participants attended a group debriefing meeting, which included a screening of the draft video.

## Campaign Materials

The campaign design and its promotion were developed and led by Kitestring Marketing, with Communications support from Dovetail Communications. The campaign consists of a video (4:39 minutes in length) and portraits that profiled seven persons living with dementia as an opportunity to explore lived experiences with stigma within the community and opportunities for creating more dementia friendly communities. A number of resources were created to support the stories of people living with dementia that were part of this campaign (Figure 1). As the key message that the campaign participants wanted to highlight was that they are more than their diagnosis, each participant crafted a personal key message statement (e.g., “I am more than my diagnosis. I am a change-maker/ caregiver.” “I am more than a stereotype. I am an artist/ I am a friend” “I have more contributions to make. I am a leader.” “I have more knowledge to share. I am a teacher.” “I am more than your assumptions. I am a lifelong learner.”). These statements were shared in posters that included portraits of the participants and highlighted in the video (“Meet the Faces of Dementia”) in which each participant discusses their perspective on living with dementia. Short variations (2:14 - 4:09 minutes in length) of the main video were created that tell the story of each campaign participant, highlighting the impact of dementia on their life and their advice for living well with dementia. These short videos were created for six of the campaign participants; for one participant, their story was conveyed via audio. Versions of the videos were created with French captioning.

**Figure 1: Faces of Dementia Campaign\* sample materials**



\*All campaign materials are available at: <https://coahamilton.ca/faces-of-dementia/>

## Faces of Dementia Campaign Website

All campaign materials are available at: <https://coahamilton.ca/faces-of-dementia/>. Hosted by the Hamilton Council on Aging and presented in both French and English, the webpage describes the intent of the campaign, introduces the “Faces of Dementia”, with links to the Campaign video, and shares the compelling stories of each campaign participant. Links are available to more information about the Empowering Dementia Friendly Communities project, opportunities for becoming involved in the project, information on the Dementia Friendly Communities education program for care partners, family and friends of persons living with dementia and local organizations, including businesses, faith communities, and service clubs, and resources, such as “Quick tips for starting your dementia-friendly journey” (available at: [https://coahamilton.ca/wp-content/uploads/2022/12/HCOA\\_Resource\\_Dec1.pdf](https://coahamilton.ca/wp-content/uploads/2022/12/HCOA_Resource_Dec1.pdf)) and a campaign toolkit, available in both English and French, consisting of sharable and printable posters, social media graphics and a media release. Site visitors are given an opportunity to provide feedback (Tell us what you think of the Faces of Dementia campaign, and how you’re using it in your own community!).

As of February 2023, the campaign landing page has had 2,912 views (2,416 unique views). There have been 636 views of the campaign video in English and French and 123 views of the public launch event. Views of the short videos have ranged from 101 to 294. Up to 90 posters, social media graphics, and quick tip sheets have been downloaded from the website.

## Campaign Launch Events

The campaign was launched at two events. The first, held on May 3, 2022, was specifically for campaign participants, their family and friends, project partners, and service providers. The intimate launch event was facilitated by a member of Stewardship Group (Susan Goodman). The agenda consisted of a viewing of the campaign video and posters, an introduction to the campaign participants and campaign creators (Dovetail Communications, Kitestring Marketing, Tae Photography and Atomic Spark Productions). In total, 27 individuals attended this one-hour launch event delivered via Zoom. Attendees included campaign participants and their guests (N = 12), campaign staff, leaders and others (N = 15).

A second, public launch event was held on May 12, 2022. The public launch event was broadly promoted with a media release, social media ads, posters, and via the Hamilton Council on Aging and project partner networks. Attendees were required to register for the event on Eventbrite, an online event management platform; the event was delivered via Zoom. This one-hour launch event was hosted by David Harvey, Lead, Dementia Dialogue project (podcast series on a variety of topics related to living with dementia), and Phyllis Fehr, dementia advocate, member of Empowering Dementia Friendly Communities Hamilton, Haldimand Stewardship Group and person with lived experience featured in the campaign. Opening remarks and welcome were provided by Mary Burnett, CEO Alzheimer Society of Brant, Haldimand, Norfolk, Hamilton, Halton; Panelists included, Pat Spadafora, Consultant; Marin Hudson, Kitestring Marketing and Design; Adam Hislop, Filmmaker, Atomic Spark; Debbie Keay, campaign participant; Doug Schweyer, campaign participant; and Jane Allision, Lead, Dovetail. Campaign posters and videos were revealed. Panelists discussed the development of the campaign and considerations involved, such as taking a person-centred/ person-first approach so

that persons living with dementia directed the project. Attendees were provided an opportunity to provide comments and ask questions in the chat and Q & A boxes. This launch event was recorded and is available for viewing at: <https://www.youtube.com/watch?v=29KoX8iet0o>. In total 341 individuals registered for this launch event; 34% (N = 116) from Hamilton, 10% (N = 34) from Haldimand, and 56% (N = 191) from outside of these areas. There were in total 249 individuals in attendance including campaign participants, staff, leaders, and members of the general public.

Table 5 presents the characteristics of those who registered for the public launch. As attendance at the event as not taken, it is not possible to describe those who attended. Those who registered for the public launch were most frequently from Ontario (84%); other registrants were from provinces outside of Ontario (9%), and other countries (7%), most frequently from the United States (representing 10 states), and also China, Luxemburg, and the United Kingdom. Across all registrants, 31% were from Hamilton and 9% from the Haldimand region. Registrants from Ontario represented all regions of the province:

- Northeast (Cochrane, Ste Sault Marie, Elliot Lake)
- Northwest (Thunder Bay)
- East (Ottawa and area, Belleville, Smith Falls)
- Central East (Toronto and greater area, Durham, Huntsville)
- Central West (Kitchener, Waterloo)
- Southwest (London, Sarnia-Lambton, Corunna).

The majority of respondents were female (81%), did not identify as a member of a racialized or visible minority group (78%) and identified English as their preferred language (99%). Of those who provided their age (N = 123), age ranged from 24 to 88 years, with an average age of 54 years (Table 5).

**Table 5: Characteristics of individuals who registered for the Public Campaign Launch Event**

<b>Characteristic</b>	<b>Public Launch (N = 325)*</b>
<b>Community</b>	
Hamilton and area	30.5% (99)
Haldimand and area	8.9% (29)
Outside Hamilton and Haldimand	60.9% (198)
<b>Geographic Location</b>	
Ontario	84.0% (273)
Other provinces in Canada	9.2% (30)
<i>British Columbia</i>	20.0% (6)
<i>Alberta</i>	23.3% (7)
<i>Saskatchewan</i>	6.7% (2)
<i>Manitoba</i>	13.3% (4)

<b>Characteristic</b>	<b>Public Launch (N = 325)*</b>
<i>Quebec</i> <i>New Brunswick</i> <i>Nova Scotia</i> <i>Prince Edward Island</i>	13.3% (4) 3.3% (1) 16.7% (5) 3.3% (1)
Other countries  <i>Chile</i> <i>China</i> <i>Luxemburg</i> <i>United Kingdom</i> <i>United States**</i>	6.8% (22) 4.5% (1) 4.5% (1) 4.5% (1) 13.6% (3) 72.7% (16)
<b>Age</b> Average (±) Range Median	(N = 123) 53.8 (15.7) 24 – 88 55
<b>Sex</b> Female Male Gender fluid/ non-binary/ two spirit Preferred not to answer	80.9% (263) 13.5% (44) 0.6% (2) 3.7% (12)
<b>Minority Identification</b> Yes    No Preferred not to answer	16.6% (54)     18.5% (10) 81.5% (44) 77.5% (252) 5.8 % (19)
<b>Preferred Language</b> English French	98.9% (321) 1.2% (4)

Note: Percentages may not sum to 100% due to missing data.

\*N – 325, excluding panelists and support staff.

\*\*States: California (2), Florida (1), Georgia (1), Maryland (3), Minnesota (1), Montana (1), North Carolina (1), New Mexico (1), Nevada (3), New York (2).

Based on data from the public launch evaluation survey, respondents most frequently heard about the event from family, friends or colleagues (43%) or direct mail from the Hamilton Council on Aging (27%; Table 6).

**Table 6: Source of information about the public launch event (N = 84)**

Source of Information	% (#)
Direct mail from the Hamilton Council on Aging	26.2% (22)
Social Media	8.3% (7)
Newspaper	0
Family/ Friends/ Colleagues	42.9% (36)
Other*	22.6% (19)

\* Other: Dementia related conference or event; community event, library (Hamilton), YMCA (Hamilton), Canadian Dementia Learning and Resource Network (CDLRN) newsletter, Advanced Gerontological Education (AGE) Inc.

### Campaign Promotion and Reach

**Campaign Advertising:** The campaign was promoted broadly in the community using various media strategies (print ads, website ads, outdoor advertising, radio and television broadcast). The campaign advertising (paid) strategy is summarized in Table 7. Across all mediums, there were over 16,594,795 impressions, with an estimated audience reach of over 16 million.

**Table 7: Summary of the campaign advertising strategy**

Medium	Outputs
<p><b>Print Ads (Daily publications)</b></p> <ul style="list-style-type: none"> <li>Hamilton Spectator (June 15, October 17, 31, November 2, 2022)</li> <li>Hamilton Community News (May 19, June 9, 23, September 30, October 13, 2022)</li> <li>The Sagem* (April 28, June 16, 22, September 29, October 2, 15, 20, 29, November 3, 2022)</li> </ul> <p style="text-align: right;"><b>Total</b></p>	<p>4 Ads: 968,000 views</p> <p>5 Ads: 500,000 impressions</p> <p>9 Ads: 558,00 views</p> <p><b>18 print ads; 1,526,000 views, 500,000 impressions</b></p>
<p><b>Digital (Standard Digital Display Ad Impressions)</b></p> <p><b>Website Ads</b></p> <ul style="list-style-type: none"> <li>Thesagem.ca (June 1 – 30, Sept 22-November 18, 2022)</li> <li>Thespec.ca (June 15, 16, 17 - 30, October 15 - November 5, September 22 – November 13)</li> <li>Thespec.ca: Web page takeovers (June, November)</li> </ul> <p style="text-align: right;"><b>Total</b></p>	<p>100,000 impressions</p> <p>224,601 impressions; 272 Clicks, 0.13% CTR**</p> <p>387,396 impressions, 511 delivered clicks; 0.13% CTR</p> <p><b>761,997 impressions; 783 clicks, 0.13% CTR</b></p>

<b>Medium</b>	<b>Outputs</b>
<b>Outdoor Advertising</b> <ul style="list-style-type: none"> <li>Digital billboard (Hagersville, 2 locations in Hamilton – June 2022)</li> <li>Digital billboard (Hagersville, 2 locations in Hamilton – October 17 – November 14, 2022)</li> <li>Bus shelters (6 locations; June, October, November)</li> </ul> <p style="text-align: right;"><b>Total</b></p>	<p>3,754,877 impressions</p> <p>3,754,877 impressions</p> <p>1,255,144 impressions</p> <p><b>8,754,898 impressions</b></p>
<b>Broadcast Radio</b> <ul style="list-style-type: none"> <li>The Grand 92.9 (June 4 – 25; October 19 – November 9; 120 spots; :30 and :15s each)</li> <li>CHML (June 4 – 25, October 19 – November 9; 180 spots; :30 and :15s each)</li> </ul> <p style="text-align: right;"><b>Total</b></p>	<p>215,900 impressions</p> <p>327,000 impressions</p> <p><b>300 spots; 542,900 impressions</b></p>
<b>Television</b> <ul style="list-style-type: none"> <li>CH Morning Live (June, October 2022; 10-second billboard, three weeks; Multi-zone banner, one week)</li> </ul> <p style="text-align: right;"><b>Total</b></p>	<p>6,035,000 impressions</p> <p><b>6,035,000 impressions</b></p>

\*Haldimand county local paper.

\*\* CTR = Click through rates (% of people who click (access) a hypertext link to an advertisement) ; industry benchmarks are .03% - .08%

\*\*30-second spots from Wednesday, October 19 through Wednesday November 9, 2022; 15-second spots on the Weather segments from Saturday, October 22 to Sunday November 6, 2022.

**Earned media coverage:** The campaign also garnered earned media coverage. In total, there were 8 media requests related to the campaign, launch events, and community exhibits in both Hamilton and Haldimand, representing print media (The Hamilton Spectator, The Sachem), radio (The Grand Radio, CHML Good Morning, CBC Hamilton) and television (CH News, Cable 14). Media interviews were on radio and television and most noteworthy were an editorial (“Changing perceptions about dementia”; May 27, 2022: <https://www.thespec.com/opinion/contributors/2022/05/27/changing-perceptions-about-dementia.html>) and a front page feature story in the Hamilton Spectator (“Dementia awareness campaign aims to break diagnosis stigma; October 12, 2022: <https://www.thespec.com/news/hamilton-region/2022/10/12/dementia-awareness-campaign-aims-to-break-diagnosis-stigma.html>). A television (Cable 14) interview was conducted on October 18, 2022 and a radio (CHML Radio Morning Live) interview was conducted on November 14, 2022 regarding the community exhibits.

**Social Media:** In total 7174 Instagram and Facebook accounts were reached by the campaign (Table 8).

**Table 8: Social media (Instagram and Facebook) indicators**

<b>Indicators</b>	<b>Instagram</b>	<b>Facebook</b>
Accounted reached	864	6,310
Accounts engaged	112	654
Total followers	55	40

### **Community Exhibits**

To promote the campaign, community exhibits were launched in both Hamilton and Haldimand county (Table 9). The community exhibit in Hamilton was held at the Sackville Hill Seniors Community Centre with a launch event held on September 26, 2022, with 90 people in attendance. This event was held in partnership with the Hamilton Council on Aging, which presented an update report on the Council’s work, with the Faces of Dementia as a feature presentation. The Hamilton community gallery was in place until November 18, 2022. The community exhibit in Haldimand was held at the Minga Café in rural Dunnville, Ontario with a launch event on October 12, 2022, with 50 people in attendance. This community gallery was in place until November 18, 2022. A media release and community exhibit launch event posters and flyers were created to broadly promote the events; the events were promoted as an opportunity to meet and network with members of the campaign and project team, learn more about the making of the campaign and aspirations for it and to start conversations about creating dementia friendly communities. Both launch events were attended by campaign participants. In Haldimand and Hamilton, accessibility accommodations and travel assistance were made available for those wanting to attend the launch event. The community exhibits consisted of the campaign posters, with QR codes available to link viewers with the campaign participants stories. For those who do not have internet access, or prefer written materials, a Gallery Guide (brochure) was created to improve accessibility and that provided information about the project and short stories about the campaign participants; 425 galley guides were distributed. In addition, a project (Empowering Dementia-Friendly Communities Hamilton, Haldimand) brochure was created to provide background information on the project, information about available resources, and calls to action on how to get involved for people living with dementia, their care partners, families, friends and general population. This brochure was available for distribution at both community exhibits; 875 project brochures were distributed. In addition, buttons/ magnets of the Faces of Dementia logo were created; 800 were distributed.

**Table 9: Community Exhibit Dates and Location**

<b>Location</b>	<b>Dates</b>
<b>Hamilton and Area</b> Sackville Hill Seniors Community Centre	September 26 – November 16, 2022

<b>Location</b>	<b>Dates</b>
<b>Haldimand and Area</b> Minga Café, Dunnville	October 12 – November 18, 2022

In addition, the Faces of Dementia campaign was promoted through 17 presentations to/at service clubs, university and college groups, conference meetings, Alzheimer Society events, and health care organizations; these presentations are summarized in Appendix I. It is estimated that these presentations reached 4,197 individuals. In addition, the campaign was promoted at eight community events, exhibitions/ fairs via exhibitor booths; these events are summarized in Appendix I. It is estimated that these events reached 1,499 individuals.

### **Assessment of the Dementia Friendliness of Hamilton and Haldimand**

In all of the evaluation surveys administered for this evaluation (campaign participant, campaign launch events, community exhibits), respondents were asked to rate the extent to which their community is currently dementia friendly (5-point scale: Not at all, a little bit, somewhat, very, extremely dementia friendly). Table 10 presents survey respondents' ratings of the dementia friendliness of their community as rated by individuals living in the Hamilton and Haldimand regions. The majority of respondents (87%) provided ratings of these communities as being “not at all” to “somewhat” dementia friendly; most (47%) provided ratings of “somewhat”. This trend in ratings held true regardless of location (Hamilton, Haldimand, Other) or respondent group (persons living with dementia, care partners, others).

**Table 10: Survey respondents' ratings of the dementia friendliness of their community as rated by individuals living in the Hamilton and Haldimand regions\***

<b>Survey</b>	<b>Not at all dementia friendly</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely dementia friendly</b>
Campaign Participant (N = 3)	0	33.3% (1)	0	33.3% (1)	0
Intimate Launch Event (N = 20)**	5.0% (1)	50.0% (10)	35.0% (7)	5.0% (1)	0
Public Launch Events (N = 46)**	10.9% (5)	39.1% (18)	45.7% (21)	4.3% (2)	0
Community Exhibits (N = 46)	8.7% (4)	15.2% (7)	56.5% (26)	15.2% (7)	2.2% (1)
<b>Total (N = 115)</b>	<b>8.7% (10)</b>	<b>31.3% (36)</b>	<b>47.0% (54)</b>	<b>9.6% (11)</b>	<b>0.9% (1)</b>

Note: Percentages may not sum to 100% due to missing data.

\*There were no statistically significant differences in ratings across the two communities so they are presented as one group.

\*\*Excluding respondents who indicated that they did not reside in either Hamilton or Haldimand and areas.

Table 11 presents’ survey respondents’ ratings of the dementia friendliness of their community as rated by individuals living outside of the Hamilton and Haldimand regions (Note: no one completing the community exhibit survey identified as being outside of these communities). Similar to trends observed in Hamilton and Haldimand regions, the majority of respondents (85%) provided ratings of these communities as being “not at all” to “somewhat” dementia friendly; most (55%) provided ratings of “somewhat”.

**Table 11: Survey respondents’ ratings of the dementia friendliness of their community as rated by individuals living outside of the Hamilton and Haldimand regions\***

<b>Survey</b>	<b>Not at all dementia friendly</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely dementia friendly</b>
Intimate Launch Event (N = 2)	0	50.0% (1)	50.0% (1)	0	0
Public Launch Events (N = 38)	13.2% (5)	15.8% (6)	55.3% (21)	13.2% (5)	0
<b>Total (N = 40)</b>	<b>12.5% (5)</b>	<b>17.5% (7)</b>	<b>55.0% (22)</b>	<b>12.5% (5)</b>	<b>0</b>

Note: Percentages may not sum to 100% due to missing data.

In all of the evaluation surveys administered for this evaluation (campaign participant, campaign launch events, community exhibits), respondents were asked to rate the extent to they perceive this initiative to be important (5-point scale: Not at all, a little bit, somewhat, very, extremely important). Across all surveys, the majority of respondents (94%) provided ratings of this project being “very” (34.2%) or “extremely” (59.4%) important (Table 12). This trend in ratings held true regardless of location of respondents (Hamilton, Haldimand, Other) or respondent group (persons living with dementia, care partners, others).

**Table 12: Survey respondents’ ratings of the of the importance of this initiative**

<b>Survey</b>	<b>Not at all important</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely important</b>
Campaign Participant (N = 3)	0	0	0	33.3% (1)	66.7% (1)
Intimate Launch Event (N = 22)	0	0	0	22.7% (5)	77.3% (17)
Public Launch Events (N = 84)	0	0	3.6% (3)	38.1% (32)	57.1% (48)
Community Exhibits (N = 46)	0	0	8.7% (4)	32.6% (15)	56.5% (26)
<b>Total (N = 155)</b>	<b>0</b>	<b>0</b>	<b>4.5% (7)</b>	<b>34.2% (53)</b>	<b>59.4% (92)</b>

Note: Percentages may not sum to 100% due to missing data.

## Evaluation Objective II: Describe Key Informant Perspectives on the Development and Implementation of the Faces of Dementia Campaign

### Participant Perceptions of the Faces of Dementia Campaign and Campaign Materials

Overwhelmingly, participants were extremely happy with how the campaign was developed, the end products and the launch events, reporting on positive feedback received from others.

*“In terms of the campaign itself and the presentation that was happening that day [intimate launch], amazing. Absolutely amazing! I loved it!... Everybody loved it. Everybody that I've spoken to or called or emailed me had said that it was amazing.”*  
[CPID2MAY2022]

Participants identified a number of things that they particularly liked about the campaign; these are summarized in Table 13 and described in more detail below, with illustrative quotes. Generally, participants were very satisfied with campaign materials and there were few things that they disliked about the campaign; things they disliked about the campaign were described as opportunities to improve the campaign or as a focus for future campaigns (these are described under suggestions for improvements).

**Table 13: Participants’ perceptions of the Faces of Dementia campaign products (videos, portraits, posters)**

***Things participants liked about the campaign materials:***

- Campaign is an improvement over similar work
- Campaign planning actively involved persons living with dementia
- Campaign was authentic
- Production/ service providers understood the intent of the campaign
- Production was well executed
- Campaign materials were high quality\*

\*Identified by a single interview participant.

***Campaign is an improvement over similar work:*** Participants described the campaign as unique, attention grabbing, impactful, and as an improvement over similar campaigns produced by other organizations.

*“I’ve seen a lot of this type of work done and done not well. So, my big thing was we have to change the trajectory of this kind of work and we want to be the leaders, so even when I look at some of the campaigns that [other organization] has done over the past 10 years, this one blows them out of the water.”* [CPID1MAY2022]

*“The one thing I liked about this campaign is I haven’t seen anything else like it. I really haven’t. You know, you look at other dementia friendly communities and some of the*

*work that they've done and effort they've put in, but we have really like branched out."* [CPID2MAY2022]

*"I liked those [campaign materials]. [Other organizations], they always do very sterile printed information posters and you want people to join in on this campaign that live in the public, you want the girl that works at the grocery store to say: 'Yea, I understand that now and I can help in the community.' Those posters are nice. You have like, what is it, 5 seconds to get someone's attention?"* [CPID3]

**Campaign planning actively involved persons living with dementia:** Campaign participants were very satisfied with the role that they played in the development of the campaign and their involvement in the decision-making process, such as selecting the photographs used and creating the key messages that were formed the foundation of the campaign. One campaign participant, who is member of the Stewardship Group, appreciated being included in the production company hiring process. The active involvement of participants and their willingness to be involved was valued.

*"When we're talking about just planning it out, people living with dementia were so involved in the actual plans and how things were going to, and even picking which company we were going to go with. We interviewed them and we were included on those interviews because you know, I have certain questions I need to ask that will let me know if I'm going to be comfortable working with them... The planning of it was so exceptional. How they got people so involved. It was amazing."* [CPID1MAY2022]

*"Photographs were so well, so they took, I will tell you, they had to have taken 25 to 50 pictures and then they narrowed it down and then they sent it to us to pick our top five. And that's how we came up with the photographs and that happened to everybody that was involved. And the sayings, we all came up with our own sayings for the campaign. So, it was very individualized."* [CPID1MAY2022]

*"There were samples given to us with regards to I AM THIS and I AM THAT, and then I asked [project coordinator], can I add one more word because she sent me samples and I just thought those were the ones I would go with, and I said can I add one more word and she said: 'Oh yea, you can change them all around.' So, I did. It was personal. They wanted our thoughts."* [CPID2MAY2022]

*"I think its wonderful and what everybody is doing, I really appreciate that. They are making so much effort. I'm very, I can say I'm pleased and glad and whatever words, but I am really appreciating that they are stepping up for this campaign."* [CPID5]

**Campaign is authentic:** The active involvement of people living with dementia contributed to the authenticity of the campaign in that it was a realistic, not made up or 'fake' portrayal of the experience of living with dementia.

*“It was real. All of it was real. It’s the people living with dementia and those things, it was all totally real. This is what we need more of because a lot of the campaigns are all made up.” [CPID1MAY2022]*

*“I think it was being able to draw people’s attention to real people living with dementia. You know sometimes things are staged with Photoshop and all that kind of stuff. This is just all real. It wasn’t fake at all. It was real.” [CPID2MAY2022]*

*“It was well done, in other words, those of us with Alzheimer’s are given the chance to give our own expressions and without much coaching anyway. And then its well put together. So, I think it turns out to be what I would say is authentic... I think its really well done and I think a lot of people have been involved and have contributed their own information or their own understanding of things, and then in that sense I believe it should come across as being something that’s real, that’s authentic, that’s not – how would you put it – commercialized.” [CPID4]*

In contrast, one campaign participant felt they were asked to do things for the video that were not a realistic portrayal of how they lived their life and wished it was more authentic. Having said that, the participant indicated that they were nonetheless satisfied with the campaign overall.

*“I almost think now that maybe just that interview setting didn’t show it [realistic depiction of their life]. Like when I came in the house, they wanted me to like pretend to do things and I really felt uncomfortable doing that. I felt really stupid and I don’t know why they couldn’t have been more casual, like showing me actually doing something in my life.” [CPID3]*

**Production/service providers understood the intent of the campaign:** Participants appreciated that the service providers working on the campaign truly understood their objectives, vision, and intentions for the campaign and were able to deliver on that. It was also appreciated that those involved in the production of the campaign were open to suggestions provided by participants during the filming of the video.

*“When you’re working with [Production company/ service providers], you’re working with them and it seems good but you never know what the final outcome is going to be, and even though they know what our organization is, do they truly get what our vision is or are they going to come out with something that’s not as good quality that I would want? So, when we were getting the materials to us because we only got bits... we only got little bits here and there so as that came in, I thought: ‘Oh, that was good; oh that’s good.’ Then when you see it all together its like: ‘Oh my goodness, they got it!’ They got it!” [CPID1MAY2022]*

*“The people that were doing it [Production company/ service providers] had such an understanding, they got it... and I think that made everybody at ease. There was no tension on the set so to speak, it was just very cordial, very easy going, down to earth, no pressure.” [CPID2MAY2022]*

*“I said no, no, no, we’ve got to do this, we got to do that and they ran with it!”*  
[CPID1MAY2022]

**Campaign production was well executed:** Campaign participants felt that the campaign was executed in a way that made participants feel comfortable to share their experiences and then put together in a way that conveyed the wide range of experiences with dementia and the passion that participants felt in contributing to the campaign.

*“We were all, I didn’t see any nervousness. People were talking freely. We actually I think all spilled our guts and we were able to piece it together in such a beautiful way that it wasn’t, it wasn’t overpowering. It was just a really nice, warm, moving production.”* [CPID2MAY2022]

*“It’s done well and if you look at the scope of what it was identified, it did a good job. It served the purpose. It was very passionate. Everybody was passionate.”* [CPID5]

**Campaign materials were high quality:** One participant commented on the high quality of campaign materials.

*“I think they [campaign materials] were top drawer... I thought all of the material was wonderful. The posters, I thought they were extremely well done.”* [CPID2MAY2022]

### **Campaign participants’ Vision for the Faces of Dementia Campaign: Key Messaging Desired and Achieved.**

Campaign participants identified a number of key messages that they wanted to communicate through the campaign; these key messages are summarized in Table 14 and described in more detail below with illustrative quotes. Generally, participants reported that their vision for the campaign was realized and the key messages that they wanted to convey were communicated.

*“So, for somebody who is seeing it for the first time, the message got through.... those I AM statements were really, really good.”* [CPID2MAY2022]

*“I think as effective as it can be.”* [CPID4]

**Table 14: Campaign participants vision for the Faces of Dementia campaign:  
Key messaging**

<p><b>Campaign visions:</b></p> <ul style="list-style-type: none"><li>• Educate people about dementia<ul style="list-style-type: none"><li>○ Encourage people to be kinder to those who are struggling</li></ul></li><li>• Convey that people with dementia are still themselves, “able” and active<ul style="list-style-type: none"><li>○ Provide hope to those living with dementia</li></ul></li></ul>
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- Realistically portray what it is like to live with dementia
- Reduce negative reactions to 'Dementia'

**Educate people about dementia:** Campaign participants described their desire to educate the community about what it is like to live with dementia and how it effects people differently so that assumptions can not be made about it. Increasing awareness of dementia was thought to be one way to help people seek diagnosis when experiencing symptoms and as an opportunity to advocate and inform the community that persons with dementia require their support.

*“People are asking me things like; ‘what’s it feel like? What’s going on in your brain?’ I realized people really don’t know much about it... Nobody knows what its like and everyone thinks you’re going to be in palliative care in 5 years... I think maybe people would be a little more forgiving if they understand it.” [CPID3]*

*“I was out in the community and as you meet people who have no knowledge of dementia or Alzheimer’s, most often if you say: ‘Alzheimer’s’ it just sort of turns them off, the name itself does. But they don’t really know anything about it and I think this is an opportunity to really say that I have it and others are understanding of it... and I have the chance to explain to people that actually the Faces of Dementia are as many people as there are because we’re all different, but there are some things that you can pick up and one would be you don’t need to treat us any different than you ever have kind of thing, except to recognize sometimes our memory is not so good or that kind of thing, but other than that, try to inform them in terms of how we feel about it.” [CPID 4]*

*“Its like how people, people will know what its all about. .. [Family member], who passed away, had dementia, probably had dementia. One of the key things was that nobody knew, even in the family, what it is happening with them... One of the things that I liked, we want to create awareness and we want to help the cause....Nobody understands and nobody knows what’s going on with them, so awareness is the most important thing.” [CPID5]*

*“I want to tell people I’m doing this for you because that’s what we are. We are advocating for ourselves right now, but to share with the community this is what its like living with dementia, we need your help. I’m doing this for you down the road.” [CPID2MAY2022]*

Increasing awareness of what it is like to live with dementia was viewed as an opportunity to reduce community-related challenges experienced by persons living with dementia by encouraging people to be kinder when they see people struggling.

*“I want their heart strings to be tugged at. I want them to know that inevitably they or somebody that they care about may have to face these challenges and why wait until the need when things can be done now to prevent the challenges, many of the challenges. So, I would like them to be kinder across the board, everybody.” [CPID2MAY2022]*

**Convey that people with dementia are still themselves, “able” and active:** Campaign participants were interested in ensuring that people understood that the diagnosis of dementia does not fundamentally change who are they are, what they like and are able to do and that they can still be active and contribute to their community.

*“We’re still people, we’re still able to do things. We may not be able to do them the same way you and everybody else does, but we’re still able to do them. We just have to adjust the way we do them. We’re still involved. We can still be people. Don’t cut us out. Make sure, if you know somebody, don’t take over for them, let them do it as long as they can.”* [CPID1MAY2022]

*“Just show people what it is like living with it [dementia], but I like what the campaign did, we can do stuff... That we still are sociable and still want to do things, we still have interests. We have families that are also dealing with it.”* [CPID3]

*“Many people whom I know and the initial shock always is a shock to them, and then the second reaction is usually: ‘Well you don’t have it because you’re still the same.’ And I say: ‘Well precisely, that’s what we’re trying to tell you. Listen to us. We’re the same person.’”* [CPID4]

*“There are various faces. Everybody is the same. It doesn’t matter what profession you have; it doesn’t matter what kind of interests you have; if you have dementia it doesn’t mean that you stop living... I didn’t stop my hobbies. I like drawing and doing other things and I didn’t stop that. I was cutting the clothes. I have one granddaughter, I am making her clothes and I enjoy that.”* [CPID5]

Increasing awareness that persons living with dementia can live active, productive lives, was intended to provide hope to those living with dementia by conveying that dementia is not an immediate “death sentence” and that scientific advances may change the disease course.

*“From the very beginning I recognized that you simply have to say: ‘Yes, that’s what I have.’... Sort of like people have to say: ‘I have cancer’. Its not a death sentence as it used to be, and Alzheimer’s is not a sentence to put you in the asylum. Its an ongoing thing but also people are working at trying to discover whether the brain can change or if there are any drugs to change it and that kind of thing. So there’s always opportunity for hope and that kind of thing. That I think is a message that we’re trying to get out.”* [CPID4]

**Realistically portray what it is like to live with dementia:** It was important to participants that the campaign was realistic in its portrayal of dementia and in showing persons with dementia engaged in meaningful activity, not just talking about it, while still conveying that they may experience some struggles that could be overcome with some assistance.

*“We’ve got to show more that people can do more than just sitting at a table answering questions, being interviewed. SHOW what we CAN do... Every time I watch it, its so well done and its so moving I want to cry, but I’m trying to be more upbeat and it just moved*

*people. I think that's what we need. We need to have this hit home and make people open their thoughts and think and I think that's what we're doing... I think they all [campaign materials] were wonderful. They all showed off a side of people living with dementia that was good."* [CPID1MAY2022]

*"People who have dementia and living with dementia can live as well as they can with the resources they have. And I know everyone says that you can live well with dementia, you can adapt, you just have to look at different ways of doing things. And I have a bit of a different perspective. I see it a little more challenging. What I see in individuals with the groups that I've been in and been part of and still do, not everybody is living well with dementia and no matter how hard they try, they don't have that. One of the girls in one of our peer support groups said: 'Why is everybody so happy. Its not real.' And so, I agreed with her openly and publicly... I'm living as well as I can with dementia because not everybody can. I don't want to set people up for failure. I don't want them to think that because they're not feeling the same way as somebody who is living well that they're less than or that they can't pull themselves out of the doldrums or whatever they're going through, because if a person sometimes doesn't have the thoughts of looking at life through a glass half full, its not going to change just because they have dementia. And if we can give them thoughts and ideas about how to maybe help themselves through their journey, sometimes that's all we can do.... So that was one of the messages, that you can live as well as you can with the resources, not to compare yourself to others."* [CPID2MAY2022]

*"We have lost pretty much all of our friends because people are so afraid of where am I. Everyone has a fear of, that you can't speak to me because they don't know if I'm still cognitively there and things like that. Like I have people all the time really surprised I can still talk.... I wanted younger people to say: 'oh, okay, dementia is scary, but,' and I mean we do decline, but we have that period where we are still, we want to go out shopping, maybe we need help with the teller and folks still do this and this."* [CPID3]

**Reduce negative reactions to 'Dementia':** Campaign participants wanted to share with the community how negative reactions to dementia can have determinantal effects on those living with dementia; reducing stigma about dementia was viewed as way to prevent people from avoiding those living with it so that they can continue to be socially active.

*"Some people that I know and people very close to me that will not say that they have Alzheimer's, they simply want to forget it and I don't think that's a very helpful thing, not for them and not for the people around them. I try to encourage people to simply talk about: 'Well, what are you feeling? How is it affecting you and how can we help you understand it or how can they help us to live a relatively normal life?' and that's not easy. You can't just tell people that. You have to demonstrate it and I think that's what my main message is I think, to try to have people being to understand that Alzheimer's, you shouldn't turn away from those who have it. You should continue to have them interact with you and have them as well explain to you what's happening... The word Alzheimer's itself just turns many people away."* [CPID4]

*“Dementia does not rob someone of their dignity. It is our reactions to them that does.”*  
[CPID1MAY2022]

*“There's all these things, but I need help and I don't want people to think I'm stupid because I need help. I love that TV commercial where its English, the girl is the checkout girl and the people start making fun of [the person having difficulty]. I love that commercial. That's exactly it. I know a lot of people don't want to admit that they have dementia.... I tell everybody because I want it to stop being a dirty word.”* [CPID3]

## Suggestions for Improvement and Further Development

Generally, participants reported being very satisfied with the end products for the campaign though gaps in the current campaign were identified as opportunities for future campaigns. These suggestions are summarized in Table 15 and described in more detail below, with illustrative quotes. Almost all participants discussed how the current campaign was a good ‘start’ to affecting community change and had ideas for future campaigns. Addressing identified gaps in the current campaign, it was suggested that attention be directed at early-onset dementia and different cultural, care partner, family, and friend perspectives on dementia.

**Table 15: Suggestions for campaign improvement and future development**

<p><b><i>Suggestions for improvement:</i></b></p> <ul style="list-style-type: none"><li>• Use the Faces of Dementia campaign as the foundation for future campaigns</li><li>• Include early-onset dementia</li><li>• Be more inclusive regarding different perspectives on dementia (cultural, care partner, familial, friends)</li></ul>
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***Use the Faces of Dementia campaign as the foundation for future campaigns:*** Almost all participants described the current campaign as a good ‘start’ or foundation for future campaigns. They had ideas for future campaigns involving more videos, creation of specific tags/ logos to communicate dementia support or that a person has dementia as done with other chronic diseases, or QR codes distributed throughout the community that when scanned share brief key messages about dementia.

*“When I look at it and I compare it to so many other campaigns its so wonderful. I just think we need to keep expanding on it this.... I have another thought for a different campaign. So, let's say you're at Western Park, you're at a big park and you've got people all around sitting on benches, roller skating, riding their bikes, doing all of this. Can you pick out who has dementia? And then if they click on somebody: ‘No, they don't have dementia.” That old fellow sitting on that bench doesn't have dementia, but somebody on roller skates might.”* [CPID1MAY2022]

*“I think it’s a great initial start to getting people realizing that there are people trying to change things, so that’s great... I personally always think people love to join in, they love to paint those rocks, they love to wear those cancer tags... We don’t have a symbol that is just strictly dementia and Alzheimer’s because people love to do these things. They love to help out... I’d be happy to wear a button that a cashier would recognize. It doesn’t have to say anything, it just has to be a support thing. It makes people feel good that they can do a little something. I mean not everyone would do it, but a lot of people would. We don’t give teenagers enough credit and those are really the people that you deal with a lot.... There are so many people that you don’t realize physically to look at them that they need a little help.... You know those things that you put your phone up to it and it scans [QR codes]. All over cities and they don’t say anything, and people are so curious, they just have to put their phone up. It could say: ‘Be nice,’ ask questions, maybe 3-4 sentences. I think that would be a cool idea and its more like people would do it. I think we have to start thinking more in the times that we are in.” [CPID3]*

*“I believe this is a first step on a long road ahead. Its not like one campaign, there’s lots of other things about how they feel, the awareness, but how to identify, how to help and how to support not only from a community perspective, but from a family perspective, caregiver perspective also, to have the empathy to support people with dementia.... There are so many dimensions to address.” [CPID5]*

**Include early-onset dementia:** It was noted that the current campaign focused on older adults with dementia, negating the fact that younger persons can get dementia. It was suggested that the campaign should increase awareness of early onset dementia.

*“The only thing I think we missed was say making sure people understood that people younger than 65 can get dementia.” [CPID1MAY2022]*

*“I think the initial idea was great, but I think it got kind of lost. I feel like it got a little lost in, it was really geared for seniors, senior couples, that kind of thing... there’s lots of us in our early 50s... There’s lots of younger people out there that don’t identify themselves because I mean its still considered a really derogative diagnosis.” [CPID3]*

**Be more inclusive regarding different perspectives on dementia:** It was noted that there are many different perspectives on dementia that impact how persons living with dementia are supported; diverse perspectives exist based on culture, and care partner, family and friend roles. It was suggested that future campaigns include these diverse perspectives and they impact supports for persons living with dementia.

*“I know that everybody was looking and trying really hard for diversity. That’s really hard to do. Culturally and in the community and I think we were successful to a degree, but I just want to be inclusive... I’ve spoken to a couple of individuals who are from different ethnic backgrounds and dementia isn’t something that’s in their vocabulary. They likened it, which really surprised me, they likened it to why do we think our Western way of looking at dementia is better than anybody else’s.” [CPID2MAY2022]*

*“Us [persons living with dementia] being able to do things that still includes all of our family and I mean really Alzheimer’s is more, I feel like I’m just going through life and slowly sliding. Its everyone around me that has to put up with it, so I feel like maybe families could have been included a little bit.” [CPID3]*

*“There needs to be some brainstorming with people to go through their differences that they have, like to how to communicate. There’s a whole family and friend’s perspective. They need to understand.... There was nothing addressing the partner. That needs to be improved. Understand all the stakeholders in this and at a personal level, at a community level. And they need to understand what they can do to help [persons living with dementia]” [CPID5]*

### **Key Informant Perceptions of the Campaign and Campaign Materials**

Generally, the Faces of Dementia campaign products were well received by interviewed key informants, as reflected in the following comments.

*“Its beyond amazing.” [KIID2]*

*“I thought it was so incredibly awesome.” [KIID3]*

*“Overall, I think it was just fantastically done.” [KIID4]*

*“I thought it was all around really great considering the pandemic and all the pivoting that had to happen.” [KIID7]*

*“I found the posters where the people speak very impactful... that was really powerful. And now we’ve got buses with the campaign on their sides, at bus stops, just amazing and big newspaper articles. I can’t get over how its continued to roll out.” [KIID8]*

Key informants identified a number of things that they particularly liked about the campaign; these are summarized in Table 16 and described in more detail below.

**Table 16: Key informants’ perceptions of the Faces of Dementia campaign products (videos, portraits, posters)**

**Things key informants liked about the Faces of Dementia campaign:**

- Campaign focus on the experience of living with dementia from the perspective of those with lived experience
- Active involvement of persons living with dementia in driving the campaign
- Representation of people living with dementia in the local communities
- Emotionally moving nature of the campaign
- High quality of the campaign materials
- Commitment of participants to the campaign

***Campaign focus on the experience of living with dementia from the perspective of those with lived experience:*** Key informants valued that the campaign conveys the experience of living with dementia from the perspective of those with lived experience. A key feature of the Faces of Dementia campaign is that conveys key messages about persons living with dementia being able and active from the perspective of those living with dementia. It was anticipated that this sharing of personal experiences may impact others experiencing dementia, specifically as related to reducing stigma so that those living with dementia are accepted as contributing members of their community. This approach of basing the campaign on the experiences of persons living with dementia was perceived as “powerful”.

*“Just really bringing to light what a person living with dementia experiences, but more importantly breaking down the stigma that a dementia diagnosis doesn’t mean your life is over, which for a lot of years that to a certain degree, even coming from the healthcare field, its not taught that way but its almost implied. So just really bringing to the forefront how that is absolutely not the case and that people living with dementia are still able to be functioning human beings and can contribute to society.” [KIID2]*

*“What I loved about it was the deep human element that was shared through this. It brought the people from being statistics to names on a page, to vibrant people with their own stories and a story that can transform other people’s lives.” [KIID4]*

*“The other thing that I really liked about it was that the messages were so powerful because they were from people living with dementia and I really liked how, I think, at least from what I’m hearing is I really liked how powerful that was, that they were so individualized and I think that having people living with dementia talking about their identity in this way challenges misconceptions about dementia and I think that that’s very powerful... We’ve had, all of us have had received emails, saying that it was really good to finally see and hear from people living with dementia and often these kinds of webinars or education or ideas are really presented by care partners or medical experts, but in this particular case, persons living with dementia who have emailed me said it was really good to see it.” [KIID5]*

*“So first and foremost, I think it was mainly its all the participants and they brought to life their own story. That was the campaign and I loved that... So I think the participants themselves facilitated their own story, and I think [project staff] bringing it back to that concept helped a lot.” [KIID6]*

*“I think what was really important was that we heard from people living with dementia what the key messages of what the campaign should be. I am more. That was very powerful. I am more than my diagnosis. I am a teacher. I am an advocate. Very powerful and because it came from people living with dementia, I think that made it that much stronger. I think the power comes from the people who participated and their sharing of what should be the key messages. I mean there’s nothing more powerful than actually hearing from people directly.” [KIID8]*

**Active involvement of persons living with dementia:** Key informants valued that the campaign was led by persons living with dementia who were actively involved in decision making. The planning process included many opportunities for campaign participants to provide input into the direction of the campaign and decisions about the final products.

*“I think probably what I liked the best is that it truly was the voices of people living with dementia that were the driver and that were heard...I think the fact that it was their voices when so many campaigns or similar ones are from the perspective of care partners. I liked all of it. I think their voices really shone through.” [KIID1]*

*“It was being really mindful of the values that the project has, sticking to that and making sure that the folks who are living with dementia, that have dementia, that really need to be front and center and the center of the team.” [KIID3]*

*“Fundamentally I think we were so conscious about circling back with them [campaign participants] and making sure that they said what they wanted to say and felt heard.... was the I AM statements, and so even there we made sure we went back to the participants to make sure that the statements being captured were the ones that were most important to them. I think there was a lot of going back to the participants and really great commitment to making sure that the film and the posters reflected what they wanted.” [KIID1]*

**Representation of people living with dementia in the local communities:** It was noted that the campaign reflected the diversity that exists among persons living with dementia in Hamilton and Haldimand, in terms of age, gender, sexual orientation, and ethno-cultural diversity.

*“I really liked some of the nuances that we were able to achieve with this campaign. So, in this particular campaign it is more representative of the people living with dementia in our communities and so I feel like that we did a good job at least in advancing that work. As a next step I think there’s a long way that we all need to go, but in this particular case I was really happy that more people would see themselves in the people that were featured in the campaign. So that was one of the things that I really liked about it.” [KIID5]*

*“I think what is the most powerful thing about the campaign is the voices of people with lived experience, the people living with dementia and I’m very proud of the fact that we had diverse voices, we had young, we had older, we had early stages of the disease, later stages of the disease, we had diversity in terms of cultural ethno, cultural backgrounds, sexual orientation, so for me it was really important. I think what is the most powerful thing about the campaign is the voices of people with lived experience, the people living with dementia and I’m very proud of the fact that we had diverse voices, we had young, we had older, we had early stages of the disease, later stages of the disease, we had diversity in terms of cultural backgrounds, sexual orientation, so for me it was really important” [KIID8]*

**Emotionally moving nature of the campaign:** The campaign was described as emotionally moving and heart warming.

*“Every time I watch it, it makes me cry... I think its more moving than I even expected it to be so I consider that a positive.” [KIID2]*

*“It was just so genuine, so – I hate to use the word – but authentic. It wasn’t like somebody saying, can you tell me what its like to blah, blah, blah. It was just from people’s heart and even when the caregiver at one point said: ‘just talk about this’, the lady said what she had to say. It was just so heartwarming.” [KIID3]*

**High quality of campaign materials:** The campaign was perceived to be well produced in terms of the high quality of the products, making the campaign very impactful.

*“It was just so well done. Every part of it I thought was just amazing. I knew what was coming because I knew a bit about the development of it, so I knew what was coming and I was still just blown away by how impactful it was, how well rounded, how just well done.... the video and the posters together just had such an amazing synergy and just resulted in way more than just a video and just posters.” [KIID3]*

*“I thought it was just elegantly simple, beautifully executed, transformative story telling in a visual manner.” [KIID4]*

**Commitment of campaign participants:** The commitment and excitement of those participating in the campaign was valued by key informants as it reflects their satisfaction with the campaign and the value they place in being involved. Despite it being difficult to participant in a very public campaign, one participant was prepared to do this again.

*The one other thing I can speak to around what that I liked best about it, and I think too as an aside, the excitement that the people who participated in the campaign had for the campaign. And just as an aside or for some context for that, I met with [campaign participant to view the launch] .... So, after the event was over, I gave [campaign participant] some flowers and she said; ‘When are we going to do this again?’ And she’s very introverted and she was very worried about being public and it was a tough thing for people to do. So, it was just I guess even how the campaign participants are responding, like the people that were central in felt good about it.” [KIID5]*

Generally, all of the key informants were unable to identify anything that they did not like about campaign or that they were dissatisfied with. One participant, who was very pleased with the campaign, wants ‘more’ of it; they commented that it would have been preferable to have more participants with varied perspectives.

*“What I would have liked to have seen in the campaign I think is more people living with dementia. So certainly, I think being able to have connected with more people, to involve more people and more perspectives and giving more people the opportunity to speak to the things that they want the world to know. I think that would have been nice.” [KIID5]*

## Factors Enabling the Development and Implementation of the Campaign

Key informants identified a number of factors that they perceived were instrumental to facilitating the development of the campaign; these are summarized in Table 17 and described in more detail below.

**Table 17: Factors identified by key informants as facilitating the development of the Faces of Dementia campaign**

***Factors facilitating the development and implementation of the campaign:***

- Willingness of campaign participants to share their stories
- Collaborative and effective leadership and partnerships
- Dedicated project staff
- Commitment to ensuring that voice of persons living with dementia was central to the campaign
- Production service providers' willingness to let participants lead the campaign
- Use of technology to support efficient communication and launch attendance
- Group planning meetings with the participants\*
- Effective management of pandemic restrictions\*
- The right expertise involved\*

\*Identified by single interview participants.

***Willingness of campaign participants to share their stories:*** The campaign would not have been possible without participants who were willing to share publicly that they were living with dementia and who served as effective champions and good models on how to live well with dementia.

*“A huge enabler, was just the absolute commitment and generosity of sharing the stories of the participants. They made it easy, quite frankly... I had no idea how comfortable they would be with acknowledging that they were living with dementia for example. But them being so up front and, so generous was a huge enabler.” [KIID1]*

*“I think just having such an engaged population of people that want to get this information out there I think is amazing.” [KIID2]*

*“So, I know that caregivers are usually put in the center with dementia because the person with dementia, they're usually talking about people who are more advanced and can't talk for themselves, but I really value so much what has happened in this project with people who have dementia being able to support what we're doing.” [KIID3]*

*“I think we had some real champions. We had real champions that model living well and I think that they are a real inspiration when they’re talking to other people.” [KIID5]*

*“I think that we’re very fortunate for the seven people that we ended up with in the campaign because I think for different reasons they all want to share their stories and they all share it differently because they have different stories. How many people live with dementia in our community? Its not something that everybody not only is comfortable to do, but want to do. A lot of people want to keep their stories more private and they don’t want to become that advocate and they don’t, that’s not how they see themselves kind of playing out... [Participant] sees this as an opportunity to help others despite the fact that its very uncomfortable for her to talk about herself. Its very uncomfortable for her to be in the public eye, let alone sharing something this.” [KIID6]*

*“I think the willingness to share and be open about their diagnosis and how that’s impacted their lives from the participants.” [KIID7]*

***Collaborative and effective leadership and partnerships:*** The success of the campaign was attributed to the high level of collaboration and commitment among project partners to a common vision for community change; everyone working together to execute the project plan according their unique expertise (e.g., evaluation of the campaign), including the experience of those living with dementia. It was noted that the goal to create more dementia friendly communities was evident in all decisions that were made. Project partners were identified as critical to the recruitment of campaign participants, in using their networks to identify potential participants and to the completion of the campaign evaluation.

*“I think the Stewardship Group worked extremely well together and our persons living with dementia group as part of the leadership team, have blown me away. Honestly, that we were able to actually pull this all together within a reasonable timeframe within the middle of a pandemic.” [KIID2]*

*“I think again going back to the kind of leadership that this project has had... Having instead of a hierarchy of project management, project manager and then this person, then that person, going down a ladder. Its more that web. I really, really value the Stewardship Group and feeling that everybody is an equal part of the team.” [KIID3]*

*“I think the extreme collaboration and cooperation from everyone involved. And all of the different agencies that go into it, the Hamilton Council on Aging and all of the affiliated people, so you’ve got Alzheimer’s Society and the RIA [Research Institute on Aging] contingent, and then the Haldimand people and just everybody. It’s a community really and the willingness to share information, to know exactly who to connect with, to, the people we worked with like [Project staff] and [Leadership]. They know the people in their orbit as humans with stories to tell and things to do to accomplish together, and to see spirit of collaboration and cooperation made everything possible.” [KIID4]*

*“And then of course our partners, so our partners in the recruitment of people, making those connections with individuals living with dementia who might be interested were also very central.” [KIID5]*

*“Throughout the development I think every single person on the team, the creative team, played a really key role. I’ve heard from many people who actually appreciate the evaluation piece. I know a lot of participants really value kind of making a change and making a difference. They think the evaluation is important. So, I think everybody has their own piece of the puzzle that made it that much more together in the end.”*

*“I think the other thing certainly is the relationships that the Alzheimer’s Society has because we weren’t able to help recruit individuals who reflected more of a broader range of backgrounds. That I don’t think would have happened if we hadn’t had that connection with the Society.” [KIID8]*

*“I think that spirit of wanting to make the world a bit better really shone through and made so much, everything so much easier. And so much more resonant... The thing about it is, this project would help everyone move their own needle closer to their own goals. So, there’s joint impetus to work together. You’re all going to the same pie and there’s enough of the pie to go around if you will. So that’s what I appreciated about it and I think it’s a combination of that intention... When you start out with a certain kind of intention you tend to stay along those lines and even more so, either negative or positive, but intention was so honorable really, I felt. And then through that it informed every other decision that came along.” [KIID4]*

**Dedicated project staff:** Having project staff (project manager and project coordinator) dedicated to facilitating and supporting the development and implementation of the campaign was considered critical to its success. Ability to build relationships and put people at ease were identified as important characteristics for project staff to have for this type of project.

*[Project staff] and [Project staff] are two other enablers who are great... I mean really enablers just in terms of being so committed and dedicated and making sure the process went smoothly... [Project staff] really helped with some of the logistics, setting things up with participants and I think [Project staff] is the master at relationship building, so good with people and I think [they] also really helped to put people at ease.” [KIID1]*

*“Having a project manager like a [Project staff] made everything possible.” [KIID4]*

*“I definitely think to have a central person [project manager role], probably really important for something like this. I would almost go to say it might be more beneficial if you have one central person rather than several. I think to have everyone going back to that person, everything flowing through that person, I think whoever it is yea, its important especially since there are so many, there’s just so many pieces of the puzzle. I think its important.... to have a central person even just in terms of participants, to know who they can contact.” [KIID6]*

*“So, working with the Hamilton Council on Aging, so we worked mainly, directly with [Project staff] on this. Their commitment and [Project Manager] managing the project was really helpful.” [KIID7]*

*“We have a project manager and project coordinator who are incredible.” [KIID8]*

***Commitment to ensuring that voice of persons living with dementia was central to the campaign:*** Key informants noted the importance of making sure that the perspectives of those living with dementia were front and center in the campaign; this is reflected in the training/preparation provided to service providers to ensure they understood the importance of having persons living with dementia lead the campaign messaging.

*“I would say most importantly working with people living with dementia... I think what has enabled it to be so successful is we’re working with persons living with dementia and it kind of brings me back to the Indigenous partners that use the term ‘nothing for us without us.’” [KIID2]*

*“I think it goes way back to the way that the project rolled out kind of. So, I think the way that leadership and especially [Project Manager], I think had the idea of persons living with dementia to be the highlight and that nothing can happen with what we’re doing without that.” [KIID3]*

*“I think one of the things that was very cool was the training of the technical support participants. So, training the videographer or the other people involved in the messaging so that they really understood how important it was to give the voice prominence and to really react and interact with people living with dementia in a way that was respectful and thoughtful.” [KIID8]*

***Production service providers’ willingness to let participants lead the campaign:*** Key informants noted that the production service providers (marketing and design company, video production company) were open to changing course to better reflect the needs and desires of the campaign participants, listened well, and made participants feel comfortable.

*“I think the other enabler I think was just the commitment and willingness of both [marketing and design company] and [video production company] to listen and to make changes based on what made sense as we went along.” [KIID1]*

*“I’ll give a lot of credit to [production company]. They were incredible. They were just really open minded but really easy for everyone to feel comfortable with and work with, so that helped a lot.” [KIID6]*

***Use of technology to support efficient communication and launch attendance:*** The use of technology facilitated the ability to communicate and share information in a timely manner. The use of a virtual platform enabled attendance during the pandemic, particularly for those unable to travel to an in-person and allowed for more national and international attendance, which was instrumental in sharing the campaign concept and inspiring expansion to other locales.

*“I think technology, to be honest. If you think about the ability to quickly respond to things, number one... Share files, send messaging, say I’m thinking about this, what do you think? Schedules. Just all the logistical things that are possible and streamlined, but truly the idea of okay, we’ve got all this beautiful content – what will we do with it? And so, to kick it off because that was the desire was to celebrate it and launch it at the same time, and how do you do that in the current situation, and with some of the participants having maybe some travel barriers? So how do we do that? Virtual, a webinar. Originally, we weren’t certain of the pandemic situation when we first conceived it in January, but it turned out to be, even though we technically may have been able to meet, this technology allowed for literally an international participation and that I think really is the key message at the heart of this aspect is that the borders were really diminished. We were sharing it in the chat, but you know, Luxemburg! ... The message is a universal one, that’s the other thing. The call and the chat, ‘How can we get this across Canada? How can we get this out to the rest of the province? I’m going to take this back to my colleagues in BC.’ Comments like that. I think technology is what allowed that.”* [KIID4]

*“Shifting [public launch] online probably made it a bit more accessible geographic wise, people didn’t have to travel far to get to it or see, they could watch it from the comfort of their own homes.”* [KIID7]

**Group planning meetings with the participants:** The campaign participants met together as a group before and after the campaign filming, which provided an opportunity for them to discuss as a group what they wanted to communicate in the campaign and to become more comfortable with the process.

*“I think what it might have done though is that when – I’m just making the names up for now – for example maybe when [participant] saw [participant] being so forthcoming, it made her feel more comfortable... And then they were bouncing ideas off each other of what they’d like to see... it did trigger ideas with each other about what they thought was important and they all contributed.”* [KIID1]

**Effective management of pandemic restrictions:** The COVID-19 pandemic was identified as a significant challenge to the development and implementation of the campaign, however, pandemic restrictions were managed well moving from indoor in-person activities to virtual gatherings or gathering outdoors (e.g., for campaign filming).

*“I think the way that we had to pivot with COVID from having focus groups, which would have been really quite amazing, but the way that it got pivoted to allow people’s voices, so what we heard, I think that was really the impact, it really was quite ingenious.”* [KIID3]

**The right expertise involved:** The involvement of people who understood the intent of the campaign and the value of focusing on the experiences of the campaign participants and the

creativity and expertise of the production service providers was credited in producing a successful campaign.

*“I think that it was a combination of the right people. So, I think we had the right people, the right expertise on the team.... We had people who were communications and marketing experts, but we had a consultant, and [project staff] a really focused on the experience of the campaign participants and I think that even the vendors that we worked with also really bought into this notion or this focus of people, the campaign participants had to be central the entire time and it wasn’t just about the information we are able to get from them that was making the campaign. It was their experience was positive and that it was meaningful, and we had a big team of people and I think we were able to do that really well. I think that’s one of the enabling factors that helped facilitate the kind of campaign that we came up with.” [KIID5]*

### **Adaptations Required to Produce the Campaign**

Key informants identified a number of adaptations that were required during the development phase of the campaign due to changing pandemic restrictions and participant needs; these adaptations are listed in Table 18 and described below in more detail with illustrative quotes.

**Table 18: Adaptations required to develop the campaign**

<p><b>Adaptations:</b></p> <ul style="list-style-type: none"><li>• Management of changing COVID-19 pandemic restrictions<ul style="list-style-type: none"><li>○ Use of technology; support to participants to use technology</li></ul></li><li>• Provision of supports for campaign participants to feel comfortable during filming</li><li>• Reducing fast pace of activities and allowing participants to participate to the extent to which they are comfortable</li><li>• Involvement of the care partner of a campaign participant further along in the disease process*</li></ul>
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\*Identified by a single interview participant.

**Management of changing COVID-19 pandemic restrictions:** Adaptations were made throughout the development of the campaign to manage changing pandemic restrictions, particularly those that restricted in-person gatherings, which delayed filming and required virtual meetings

*“For the pandemic we had a bunch of delays, and what we tried to do is just accommodate whatever was happening with COVID at the time to ensure people were as safe as possible and sometimes that meant delaying an in-person activity. We implemented screening and we went above and beyond and tried to ensure that people*

*were adhering to all of the safety protocols and that people felt comfortable in their homes and in their spaces. So, there was a lot of even reassurance and talking and communicating with the people who were part of the campaign to ensure that we were all on the same page. Again, delays with COVID screening, the day of we worked with our partners to reschedule, so there were lots of things that we just had to pivot or adapt to in many different ways to do this campaign. ... and even adapt different ways of technology to facilitate the campaign if in-person wasn't going to work, so we were constantly thinking of ideas.” [KIID5]*

*“So, I think when we originally went into this the thought was it would be in-person and when we started the campaign I think the pandemic had already happened, but I think everyone at that point was thinking: ‘Oh, it will be over in a few months.’ And then fast forward a couple years its still here. I think the Hamilton Council on Aging kind of worked through what will this launch then look like now that we know for sure it should be online, the health and safety of the participants that everyone wants to be there.” [KIID7]*

One example of adaptations made during the pandemic, was the use of technology to reduce the number of people present during filming.

*“Technology, so iPads, in the room. iPads being able to support the people that were there so that everybody, they were part of it I guess in different ways and due to COVID we couldn't have a lot of people present, so we had to minimize that. So, we used technology in that way.” [KIID5]*

Similarly, participants required support to assist them with the use of technology to attend virtual meetings, specifically, assisting them with the use of Zoom for meetings and getting them comfortable with it.

*“I think there was some work that was done at the beginning for getting people on Zoom, the technology part, and I think that that may have happened more in Haldimand county; I'm not sure. I know the internet there is quite a bit more iffy and I know that people in Haldimand county tend to be a little bit more geographically isolated because if you live on a farm or if you live on a large property you are physically isolated from a lot of people. So, I think that kind of thing and getting that involvement which Senior Support [Services] out there really helped with.” [KIID3]*

*“In terms of the technology piece, we had that one individual who didn't use a computer so we had to adapt around that. I think that we could have done a much better job. I think we became very dependent on an individual that isn't being paid by our organization in any way to be that conduit of information, so I think we adapted and tried to make things works as best as possible.” [KIID6]*

***Provision of supports for campaign participants to feel comfortable during filming:*** In order to ensure that campaign participants were comfortable it was necessary to identify with them what was needed to make them comfortable, even it deviated from established processes. For example,

filming in the location of their choosing and having the campaign interview conducted by someone of the participants' choosing (i.e., a trusted support), rather than the project's assigned interview facilitator and then additional support was provided to the individual to facilitate the interview.

*"In terms of the support, even when you're thinking about relationships, some of the campaign participants were recruited through certain organizations but we didn't have a direct relationship with them, and so we worked with support workers who did have these relationships already established to ensure that participants felt comfortable. For one example, one of the campaign participants felt far more comfortable with their support worker doing the interview for the short film and so we worked with the support worker to facilitate the interview and we actually had other staff there virtually to support them.... We leveraged the partner relationships and supported participants to be able to engage in the campaign in ways they felt comfortable. We would just support that in different ways." [KIID5]*

*"We did give participants the opportunity to be filmed at a place of their choosing and so from that perspective there was a bit of an adaptation there and it changed things a little bit. For example [participant] wanted to be filmed at the Butterfly Garden in Dundas so all of those things require not adaptation on my part so much but from the film crew and photographer... I think it was so that the film would include something about the person that was really important to them." [KIID1]*

*"They [production company] had some black fly problems as well. Something about critters flying, mosquitos, something that made it challenging... so, just managing the participants to make sure they were as comfortable as possible, managing circumstances." [KIID4]*

***Reducing fast pace of activities and allowing participants to participate to the extent to which they are comfortable:*** It was noted that it took time to understand participant's perspectives and to ensure that everyone was comfortable with how the campaign was progressing and that they were participating to the extent to which they were comfortable.

*"Just a mindfulness and I think a sensitivity to we're in such a hurry all the time, and so slowing down to be just in the moment. That's what I learned from these folks [campaign participants], the beauty of just slowing down and being in the moment. And making sure that we are all comfortable and understand each other, that we're all on the same page. So that was really helpful." [KIID4]*

*"I know it was important to one of our team members that there would be an opportunity for almost like a support group throughout this process... Everybody was a part of it but there was one individual in particular who didn't, it wasn't part of what they wanted to do. They wanted to share their story but they didn't necessarily want to be a part of that. So, they were there to share their story publicly and they didn't want to, they didn't come to those pieces and I think that's perfectly okay... it was just giving people that choice." [KIID6]*

### ***Involvement of the care partner of a campaign participant further along in the disease***

**process:** In one case, the campaign participants' ability to communicate declined after they were recruited, making it difficult for them to participate during the filming; this required the facilitator to rephrase questions and provide participant time to reflect on what they might want to share. In addition, their care partner was recruited to assist in sharing the participants' story.

*"I had to say the biggest challenge for me was interviewing [care partner] and [participant]. Just because [participant] had lost, she didn't have as much access to language as some of the others. [Participant] appeared to be further along in the progression of the disease. It was harder to draw them out, which is what may happen if we have a broader range of people living with the disease, so that was a little bit harder. You could see their frustration, you knew it was there, but they just had a bit more difficulty getting it out, so [care partner] would jump in and speak for them often. On the other hand, it was a very clear example of how this disease affects both of them, not just [the person living with dementia]... Just kept at it or asking things a different way or trying to build on what [care partner] would say... or just giving her a little space to not even answer a question but just offer something she might want to share." [KIID1]*

Many of the adaptations described above, particularly as related to ensuring participant comfort and gearing activities to their ability to participate, are similar to those described in the reflective journaling completed by project staff who assisted the campaign participants to develop the campaign and its key messaging. As described in the reflective journaling presented in Appendix O, there were several key learnings in working with participants to develop the campaign:

- Although pre-planning is important, there should be flexibility in changing the approach to developing the campaign based on personalities of the campaign participants. In this instance, the facilitator changed their approach once they met the participants, who were more open than expected to in sharing their experiences with dementia. This openness enabled the facilitator to delve a little deeper into their experiences.
- Initial meetings with the participants were held via video-conferencing due to pandemic restrictions for gathering in-person. The use of video-conferencing provided a good opportunity for participants meeting in light of pandemic restrictions and still allowed for rapport building and creation of a safe space in which to talk about dementia and participants experiences with it.
- Opportunities for the facilitator to get to know the participants and their stories were important to ensuring the richness of the interviews being filmed. It was recommended that there be enough lead time for the facilitator and participants to get to know each before any filming or photography takes place.
- Filming can be a long, arduous process for participants; there is often much waiting while the film crew prepares their equipment and the environment for filming. When filming occurs in a location that is not the participants' home, it was recommended that to make it easier for participants, they should be told to arrive at the location when the film crew is ready for them, not at the time that film crew arrives to set up. Further accommodations related to filming, should be made based on what is known about the participants.

- When working with campaign participants with care partners present, it is important to inform that the voice of participant is paramount and as such, the participant should be given ample opportunity to respond to questions independently.

## Challenges to the Development of the Campaign

Key informants identified several challenges and barriers to the development and implementation of the campaign; these are summarized in Table 19 and described in more details below with illustrative quotes.

**Table 19: Challenges experienced in the development and implementation of the campaign**

<p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Participant recruitment as impacted by stigma</li> <li>• Recruitment for diversity</li> <li>• COVID-19 pandemic restrictions</li> <li>• Funding limitations*</li> </ul>
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\*Identified by a single interview participant.

***Participant recruitment as impacted by stigma:*** Finding persons with dementia interested and willing to participate in a very public campaign was challenging; the nature of the campaign and the requirement to share personal information made it difficult to recruit, particularly given the stigma exists around dementia. Recruitment was challenged by the large amount of time needed to establish relationships with potential participants, as many people living with dementia do not want others know, precluding their participation in a public campaign. Although there was public advertising a recruitment strategy, no one was recruited this way; all participants were recruited via personal relationships with someone connected through the project. One of the participants was recruited via a social worker with whom she had a relationship; this relationship was leveraged at all stages of the production process to ensure that the participant was informed and comfortable.

*“So being able to connect with individuals who are living with dementia who were interested and would find it meaningful to participate in a public campaign. I think that was challenging.” [KIID5]*

*“And then also it took time to build those relationships, even if people expressed an interest and we were able to make the initial connection, we needed to develop the relationship and trust and lots of communication back and forth. It takes time and its really important and a key thing to know that its about relationships and that relationships take time and you have to build that in and prioritize it. I think one of the other challenges was the stigma. This is again around recruitment, and we know from*

*what we heard during our consultation that many people living in Hamilton and Haldimand don't even want their friends and family to know that they're living with dementia or that they have the diagnosis, and so certainly being part of a public campaign is extremely difficult. So, I think that again speaks to some of the challenges that we experienced during recruitment.” [KIID5]*

*“So, recruitment was a challenge, for sure. I think that was probably one of the biggest challenges. In my experience recruitment has never been this difficult. So, I think part of it was the pandemic, certainly. If it were this type of work in the past probably a lot of our recruitment would have come from in-person effort, and I think with that a lot of the success we had with recruitment actually did come from those – the only place it actually came from – came through existing relationships. It didn't come from anything public that we did. And the more I think about it, and I think I said this before, I think because of the deeply nature of this campaign and the huge ask, its not something people are going to sign up readily by just seeing an ad in the newspaper. They really need to trust somebody before they say you know what, this is something I want to do. And I also don't think its something that everyone is necessarily suited to do.” [KIID6]*

*“There is still so much stigma associated with this disease that people are hesitant to come out in such a public way. So that all the world knows what they are dealing with.” [KIID8]*

**Recruitment for diversity:** Not only was recruitment difficult generally, but initial recruitment lacked cultural and disease stage diversity. While additional participants were recruited that reflected cultural diversity, there was a desire for more diversity in terms of disease stage, socioeconomic status, and greater cultural diversity reflecting the population that lives in Hamilton and Haldimand.

*“I felt they really needed to position the campaign as the first step in the longer process because I said: ‘Don't think for one minute that the people you're interviewing are representative of all people living with dementia’, and there was very little diversity initially... I think it was a gap and not an intentional one by any means, it just reflects the challenges in recruitment.... The biggest gap is in terms of representation. Its very difficult as you know to recruit for any campaign... but I don't have a lot of easy answers because once you get into somebody who is quite far along in the disease progression, its hard not to have a care partner speaking on their behalf, and I still think you could address that. You could acknowledge it and you could take what you learn from people who perhaps are not as far along and adapt it. But at some point, the reality is you probably have to bring the care partner in.” [KIID1]*

*“I think it was just maybe not being able to have as much diversity represented, like people from different walks of life being represented. It tends to be people who access Alzheimer's Society or people who tend to access whatever support services where we were able to have a partnership to tap into who might be agreeable to be part of such a project. I would have really liked to have seen that we had so many people from different cultural backgrounds, but all different areas... Socioeconomic as well because a lot of*

*people who are living in poverty might not have access to technology to be able to participate in something like how we did the ‘What We Heard’ report.” [KIID3]*

*“We wanted to have a real diverse group of participants as we could... because it was looking pretty white there for a while, and that part of the challenge is that representation is so critical and so we set out to have some diversity.... I think we get uncomfortable a bit sometimes talking about these issues, but its so important to openly say: ‘Look, we want to do better and we’re really trying and any input you can offer us is not only sought after, but appreciated. So, let’s work on this together, so let’s find someone who can portray that.’ Because its still the truth, its still happening, we just need to find it and extend, open up our arms and our hearts and our minds to have more participation that truly reflects the community. So logistically that was a challenge but it was an important one to undertake.” [KIID4]*

It was noted that key to overcoming the challenge of recruiting for diversity is leveraging existing relationships to support individuals from diverse backgrounds to participate in the campaign. As an example, recruitment from the Indigenous population was facilitated by an Alzheimer Society staff member who was a member of this community, had an existing relationship with the participant, and who was able to support the campaign participant through the campaign development phase.

*“It was challenging for us to really work through the cultural sensitivities we needed to have at Six Nations [Indigenous community] so fortunately we had a wonderful colleague who works for Six Nations, who really helped us navigate the relationship and made the person we ended up interviewing feel supported and respected, and so those were also, it was challenging because we couldn’t, we knew it wouldn’t work if we hadn’t gone through an intermediary.” [KIID8]*

**COVID-19 pandemic restrictions:** The COVID-19 pandemic delayed the creation of the campaign, which had been initially planned for year 2 of the project, but was completed in year 4. Delays resulted from the inability to congregate in-person to complete filming (particularly during lock-down periods), and cancelled filming when those involved failed screening protocols. The pandemic negatively impacted recruitment as participants could not be recruited from in-person events where the project team could speak directly with them. Similarly, people may have been hesitant due to COVID-19 risks to volunteer for something that required in-person attendance. Pandemic restrictions required that meetings (individual and group) that normally would have been in-person were switched to online, though it was thought that this did not impact the outcome, it created a need to work together in a different way; this challenged communication, when all communication with participants was virtual (via internet, telephone). Filming was conducted outdoors for all but one of the participants, which limited who was present during the filming to support the participant and limited filming in general.

*“Well, I think the pandemic has been a huge challenge for many people, but again, somebody living with dementia can sometimes take longer to learn new things and virtual connection has been a learning tool for many of us... To know that we’ve got people living with cognitive impairment and then trying to expect them to participate and be*

*involved even from a virtual perspective – it’s blown me away at how we’ve been able to bring these people together.” [KIID2]*

*“I love face-to-face, I love to chat and discuss and analyze and brainstorm and all these things, so I do miss that ability because for example, I’ve never met [Project staff] in person. And I’ve worked with them for about 18 months now.” [KIID4]*

*“So, I think part of it [recruitment challenges] was the pandemic, certainly. If it were this type of work in the past probably a lot of our recruitment would have come from in person effort, and I think with that a lot of the success we had with recruitment actually did come from those – the only place it actually came from – came through existing relationships. It didn’t come from anything public that we did... So I think COVID definitely had a hand in it.” [KIID6]*

*“I think [recruitment] was directly impacted by the ongoing pandemic because again this is just me thinking out loud, but I think most people with dementia, they’re the older generation and maybe were a little less willing to be involved with something like this just because of the health risks involved with an ongoing pandemic happening. You’re automatically going to be more face-to-face with people, and so maybe there was some hesitation from some folks there, not really knowing what was in store for them if they were to participate. The pandemic itself was a huge challenge and it kind of turned what would have been maybe a 6-12-month project into a 2 year project because of everything happening in the world.” [KIID7]*

*“We thought we were all set up [to start the campaign] and then we weren’t set up.... Start, stop; start, stop. I wish we had more opportunity to do more filming.... Things that could have made it stronger? Certainly more voices, we wanted 10. But we also have to recognize that it was COVID. People were frightened to come be in public places... certainly there were some challenges with the timing and we had hoped to launch it a year earlier and the same things with the recruitment.” [KIID8]*

*“Like the communication and trying to ask people to do all that communication through the pandemic, you don’t have those open channels. So, [campaign participant] not having access to the internet. Its more time. So, logistically it takes more time and I think its harder to explain those things over the phone rather than in-person. So I definitely think COVID made it a little bit more challenging.” [KIID6]*

*“COVID 19 was a huge challenge to this project. It delayed the project for 2 years with just ever-changing risk factors and safety protocols, and then even with scheduling and the screening. Sometimes people failed the screening the day of the in-person filming which was a delay. So, there was a bunch of things and uncertainties you just couldn’t control because of COVID. So that’s been a challenge.” [KIID5]*

*“And then again with that too, scheduling. So we had a few things that were re-scheduled, so I think it also delayed things a little tiny bit for the end of it. So COVID for sure was a bit of a challenge.” [KIID6]*

**Funding limitations:** Budget constraints were at times a challenge, but were overcome with creative strategies to create the campaign as planned within the budget provided.

*“The rigorous demands of funding, they can be a challenge at times, but that’s part of the gig. So, there are moments where you have to do things in a certain way just because and we get that, but you know, that’s the only thing and really, that’s a wrinkle. It’s nothing.”*  
[KIID4]

### Suggestions for Campaign Improvements, Further Development, and Sustainability

Generally, interviewed key informants were satisfied with the campaign and identified few suggestions for improvements and further development; providing suggestions for sustainability was more challenging and none were identified. Identified suggestions were primarily aimed at addressing identified challenges related to recruitment and diversity. These suggestions may inform ongoing work on the campaign or inform future campaigns. Suggestions for improvements and further development are summarized in Table 20 and described in more detail below with illustrative quotes.

**Table 20: Suggestions for improvements and further development**

<p><b>Suggestions:</b></p> <ul style="list-style-type: none"><li>• Increase diversity/ representation</li><li>• Leverage relationships with organizations that serve diverse populations</li><li>• Create recruitment materials in languages other than English</li><li>• Ensure everyone understands funding expectations*</li><li>• Create similar campaigns for other community issues*</li><li>• Promote the campaign more broadly to increase awareness*</li></ul>
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\*Identified by single interview participants.

**Increase diversity/ representation:** Addressing the identified challenge of lack of diverse representation in the campaign, it was suggested that the campaign could be improved by increasing diversity (gender, cultural, disease stage, Francophone representation). It was noted that the current campaign was a good start at reducing the stigma associated with dementia so that others may be inspired to participate. It was also suggested that forming relationships with partners/ organizations that serve diverse populations should have occurred earlier and that advertising for the participants should have been translated into different languages.

*“I was thinking more of like racial and cultural diversity, a little more gender...I would love to find a way to have more diversity in terms of disease progression, but it may be, I think we can do that but it may be that we have to capture the voices of people who are further along in the progression in a different way.”* [KIID1]

*“I think what we’re doing now is helping to decrease the stigma. So, decreasing the stigma might actually help more people to participate, recognize the feeling or the sense of this being a safe space, the project itself being a safe space for people.” [KIID3]*

*“That’s a key area of focus [increasing diversity] that I think we need to continue to move in that direction and I don’t think we’ve got it totally figured out, but you know, at least we’re on the right track I think.” [KIID5]*

*“I think having even more diverse voices speak and we really would like to do that. That would just make it more powerful... I think that’s really important, that the voice represent diversity and background, but also in the disease progression. We didn’t have a Francophone, it would have been nice to have a Francophone.” [KIID8]*

One participant noted that while greater diversity would be ideal, it’s important to capture the voices of those willing to share their experiences to end stigma, in efforts to eventually increase diversity representation/ recruitment.

*“I would love to see an increase in diversity eventually... I think that’s important but we have to work with people who want to share their story and be involved to end the stigma. So, I think its important and I think we need to be cognizant of it and I think we need to be always reaching out to other demographics, and honestly, the Indigenous partners especially in our Hamilton Haldimand areas, but I wouldn’t want it to be the total driving force.” [KIID2]*

Related to securing diverse representation for the campaign, it was noted that it would have been advantageous to have made connections with the organizations that assisted in recruiting diverse participants earlier in the recruitment process.

*“I think just in terms of the diversity of the campaign, I think one of the things that I think would have been really, really helpful is that the relationship with organizations and diversity in partners and people involved at the onset so we have that representation. I think that that’s the key to really, to really being able to connect.” [KIID5]*

*“I know in the end when we did the second kind of campaign for recruitment. I know that some of our partners around the table were on top of it and they were contacting them [participants], so I think had that happened sooner or had we addressed it sooner we might have had less of break in the timeline, but I don’t think this is an easy thing to recruit for, at all.” [KIID6]*

Similarly, it was noted that greater efforts could have been made to recruit individuals who did not speak English by promoting recruitment in languages other than English. However, since all recruitment efforts were in English, only English-speaking individuals were recruited.

*“I think we could have done a better job in recruiting individuals that don’t speak English and then in that sense we would have had to deal with translation and interpretation and had that available, but in hindsight when all of our advertising is in*

*English, how effective is that going to be to someone who doesn't speak English.”*  
[KIID6]

**Ensure everyone understands funding expectations:** It was noted that it would be helpful to have a clear understanding of what the funder expects and what needs to be considered when implementing projects funded by government agencies.

*“There was a sense at times of all of us figuring this out for the first time, so I think moving forward, if there could be a playbook, when you're dealing with [funder]; ‘here's what you always need to remember’, asking about this and this and this, stuff like that.”*  
[KIID4]

**Create similar campaigns for other community issues:** The Faces of Dementia campaign demonstrated the value of first-person story telling to reduce stigma and support community members, which can be used as a model for other community issues that need to be resolved.

*“More projects like this need to happen. There's a myriad of issues in the world, sadly, but this kind of proactive, de-stigmatization, myth busting, embracing, story telling is just so vital to enhancing and supporting our friends and neighbours in our community. Its so critical. So, I think it's a real milestone project to demonstrate that, and I would love to do more of these types of things and see more of them out there, where your sole purpose really is to break down some barriers, tell stories and help people understand.”* [KIID4]

**Promote the campaign more broadly to increase awareness:** It was suggested that the campaign should be promoted more broadly in the community in efforts to raise community awareness.

*“I think some of the work they're doing now in taking the posters out and setting up in different public places will help because we need to raise more awareness in the general public.”* [KIID8]

## **Key Lessons Learned in Developing the Campaign**

Key informants identified a number of key lessons learned in the development and implementation of the Faces of Dementia campaign that can serve to inform similar campaigns developed in other jurisdictions. These key lessons are summarized in Table 21 and described in more detail below with illustrative quotes.

**Table 21: Key lessons learned in the developing the Faces of Dementia campaign**

**Key lessons learned:**

- Ensure the authentic participation of persons living with dementia
- Secure dedicated project staff to support campaign development
- Allow sufficient time for campaign development

- Secure sufficient funding
- Invest time to prepare for filming key messages\*
- Leverage existing relationships with specific communities to support recruitment\*
- Ensure a clear understanding of the communities involved\*
- Be intentional in planning a campaign\*
- Be open about intentions in selecting participants for diversity\*

\*Identified by single interview participants.

***Ensure the authentic participation of persons living with dementia:*** A key lesson learned in this campaign was the importance of co-creating the campaign with people with lived experience to ensure that their voices are at the forefront. This requires people forego their own assumptions to allow persons with dementia to become the experts in what it is like to live with dementia. In doing so, the campaign will be more powerful and effective.

*“Just to make sure that whatever the campaign is for, whoever you’re working with make sure its their [persons living with dementia] voices that drive it. I think that’s really important. And it has to be meaningful involvement, you have to really listen to what people have to say.... If you really want the voices of a particular group driving a product then you have to go with what they’re saying. You have to step back and realize this isn’t about you, its not about what you think should be in a campaign. Its kind of like don’t give people the option of telling them its their voice if in the end it really isn’t.”* [KIID1]

*“I think it goes down to making sure that its not service providers coming together talking about people who have a specific illness, regardless of what we’re talking about without ensuring that we’ve got people who live with that condition as part of our planning right from day one.”* [KIID2]

*“I keep saying this: if there was a way to impress upon people, professionals and I’m going to say agency people that are working for different agencies, to kind of let go of their feeling like they’re the expert and their ego perhaps, and that I think having people who have been diagnosed with dementia as a key part of the stewardship group, but also our leadership team. I think that has made a huge difference and that I think plays into it being a safe space for people. I think it has made a huge difference, and not just people who have the diagnosis of dementia being a token part of the group, but really being integral to the way that we function I think has made a huge difference.”* [KIID3]

*“I would say focus on the process of making the campaign, like make the process of building the campaign the priority, and you’ll end up with a campaign and relationships that you couldn’t have imagined at the onset... I think its something you actually need to be very, very intentional about. And sometimes you get really focused on the end product and what you want, instead of the process of building it and co-creating it together. And I think when you do that, you co-create and create the opportunity for people to be really,*

*to feel a real connection with what you're trying to achieve and I think that is when, and be open to that, I think that is when the magic of a campaign that has so much potential is created, when its created together.” [KIID5]*

*“Make sure you co-design with people of lived experience and make sure that your key message of whatever campaign you're doing, come from the people affected by dementia. Its simple but it was very powerful.” [KIID8]*

**Secure dedicated project staff to support campaign development:** Dedicated project staff, with additional supports to meet the needs of participants, are needed to plan and execute the campaign.

*“So having a project manager made a huge difference so I think just more of that. That would be my counsel moving forward, is just having a designated person who sees everything and is kind of a maestro.” [KIID4]*

*“So, support, staff resources. To develop this campaign it took a lot of people working together and so staffing is absolutely necessary – and staffing in terms of support. So, when we were working on this campaign and we were working with people who are living with dementia, all have different needs and really working to accommodate them to feel comfortable, that they had everything they needed and sometimes that was additional support workers, or being in a place where you have enough resources to support what people need is essential to be successful, for sure.” [KIID5]*

**Allow sufficient time for campaign development:** The development of a campaign of this nature requires much time to plan and recruit participants.

*“Sometimes people are constrained by grant parameters that you've got the time, you really need to allow time to recruit if you're going to develop a campaign like this because its not easy. You put an ad in the paper. People aren't going to respond. I think if you're doing something with people living with dementia then I think a lot of it has to be word of mouth which is how we ended up finding [participants]. And to do that you need time. And people resources.” [KIID1]*

*“Its [campaign development] not something you can do quickly... I think that time is an important resource.” [KIID5]*

**Secure sufficient funding:** Adequate funding is needed to achieve the campaign vision and a sufficient budget is needed for quality production services.

*“You also want the company you're working with if you're going to do something with videos, you want a company who has experience and are reputable like [production company] was. So you need to build those things into your budget.” [KIID1]*

*“Funding is a very important, adequate funding is a very important resource.” [KIID5]*

**Invest time to prepare for filming key messages:** Adequate preparation for the filming of key campaign messages is necessary to ensure that clear, succinct messages are communicated and to ensure messages are communicated with a key direction or focus.

*“I think preparation is important before you do something like filming with any group because what I wanted to avoid by having them identify key messages and their I AM statements so you didn’t have someone on the film just rambling and going in all different directions, and that has nothing to do necessary with them having dementia; that’s with everybody.” [KIID1]*

**Leverage existing relationships with specific communities to support recruitment:** Recruitment can be enabled by leveraging the relationships that organizations/ agencies have with diverse communities to facilitate recruitment and to support participants throughout the campaign development process.

*“[Participant] was another example. We went through someone who knew them. So I think that’s an important lesson if you’re reaching out to some of our diverse ethno-cultural communities, we make sure that we work through people who are from that community and know the individual or have worked with the individual so that they feel safe, which is a sad commentary but I think its an important one because mainstream healthcare has not always been very supportive of different communities.” [KIID8]*

**Ensure a clear understanding of the communities involved:** A good understanding of the geographic communities in which campaigns are created is needed to ensure their unique needs and population characteristics are accurately reflected.

*“I think the deeper dive probably into the differences and similarities among the communities, so for example Haldimand is quite different from Hamilton. So that’s one thing I do regret is not necessarily having or taking the time to fully understand the culture of Haldimand region and I believe we could have had more reach there had we done that. I mean I’m certainly happy with it, but that would be a recommendation moving forward is really getting to know the different communities wherever the program is happening.” [KIID4]*

**Be intentional in planning a campaign:** The campaign planning process needs to be intentional about the people selected to be involved and decisions should be based on the values and principles underlying the campaign; everyone involved should be in agreement about the process in which the campaign is be created.

*“I think being intentional is about having the right people involved and I think its very value based. So, if you’re focused on some really core principles of how we will approach this work, then I think, and if everyone is aligned in that, I think you focus more on the process of developing the campaign, the development of it and the inclusion of people living with dementia and that the messages are coming from them and that they’re just kind of a conduit for that to happen, then I think the campaign can be very powerful.” [KIID5]*

**Be open about intentions in selecting participants for diversity:** Selecting participants to represent diverse populations needs to be communicated with potential candidates so that they can make informed decisions about whether they are comfortable with that role and in participating in the campaign.

*“The one thing that I think I learned and actually just in the last few weeks and it was almost my most important learning from this, like of course we want to be up front and honest with people about what we’re doing and why we’re doing it and I think that gives incentive to people who want to participate to participate, because its shared goals. They also want to do that. But I think even more so, so we were having a candid conversation about one of the individuals that participated, had a little bit of trouble with the timing that was delayed due to us seeking more diversity for the campaign which is something that was essential, like we need people to see themselves in this campaign as much as possible. And then there’s that Catch-22 of tokenism so we were having a conversation about it, the people involved in the campaign, but before we recorded their introductions for the live event, the launch, so one of the individuals who identifies as gay, she said: ‘Well, you know what, I want people to know this about me because I want people to see themselves through this campaign.’ I’m like yea, if you’re comfortable sharing that about yourself in the introduction that would be very valuable because you’re going to open people’s eyes.... So I think something that I’ve learned is not only to be upfront and honest about what you're trying to do and all the details about the process so people could make their decisions, but also the whys of the different pieces because that gives people that opportunity to actually decide if that’s something they can help with.”*  
[KIID6]

## Perceptions of the Campaign Promotion

Campaign participants and key informants were asked to comment on their perceptions of the Faces of Dementia Campaign promotion, as related to all promotional activities and materials (posters, portraits, ads, television interviews, newspaper articles); key themes related to the campaign promotion are summarized in Table 22 and described in more detail below with illustrative quotes.

**Table 22: Key informants’ perceptions of the campaign promotion**

***Perceptions of the campaign promotion:***

- Wide reach with a variety of mediums
- Active involvement of project partners and campaign participants in the promotion
- Campaign was well resourced\*
- Strong media coverage\*
- Access to additional information via a variety of mechanisms\*
- Ongoing promotion\*
- Consistent messaging across all promotional materials\*

- Photography accurately conveyed the key campaign messaging\*

\* Identified by single interview participants.

**Wide reach with a variety of mediums:** The campaign was perceived as wide reaching given that it was promoted broadly, across a variety of mediums (print, public ads, television) and has captured attention internationally.

*“I have one, one of the most striking things about the campaign for me has been the reach of the campaign... it really launched some new opportunities in terms of like new kind of connections with like Re-imagining Dementia, which is an international organization with Alzheimer’s Society Ontario, with Alzheimer’s Society Canada, and some of the campaign members have gone on to continue to promote their important message in other ways, so I think that that is a really interesting outcome of a campaign that was intended for Hamilton Haldimand that its being talked about over in the UK, and in Belgium, and reached some global communities. I think that’s really, really striking that it had that kind of impact and reach.” [KIID5]*

*“Talking about the promotion with the media and the television, bulletin boards, the newspaper ads that promoted the work the whole Faces of Dementia team was doing, you could not miss it. You couldn’t not miss the Faces of Dementia. It was everywhere.” [CPID2]*

*“So, promoting it, I just felt like it was everywhere, which is wonderful. It’s a wonderful thing to keep that momentum going. So, I have no complaints at all.” [KIID9]*

*“I liked it because it was out in the public, people got to see it and they got directed to a website that they could go to, to learn more. And as a matter of fact, I was driving down Upper James [Hamilton] yesterday and one of our signs showed up in the bus shelter again.” [CPID1]*

**Active involvement of project partners and campaign participants in the promotion:**

Interviewed key informants valued that project partners and campaign participants were actively involved in promoting the campaign. Project partners used their networks to spread word of the campaign, particularly via social media and the education program. Campaign participants volunteered to participate in media interviews and newspaper features and attended the community exhibits.

*“I really liked that the campaign members themselves were actively involved in a lot of the campaign promotion so, whether that was interviews on TV or articles in the front page of the Spectator, that they were active participants well after the campaign had been created and they stayed engaged in many different ways.” [KIID5]*

*“So, our campaign worked out in a way that I always pictured a campaign to be, and honestly, I felt like it was a dream come true because it was honest, it was out there and*

*used real people... so the way our campaign worked out, and how real people were involved, even in promoting it, I thought it was phenomenal.” [CPID1]*

*“I loved all of it [promotion]. I guess what I liked best about the promotion was the inclusion of everybody. It felt like everybody was working together and this is throughout the whole project. It was really neat to be part of something where it really truly honestly felt like it was a team. There were no egos. And that was just really quite remarkable.... The partners, the people who were on the posters, the education team. I think everybody was promoting every part of it which was really cool.” [KIID3]*

Related to this, was the ability of campaign participants to be involved in the promotion to the extent that they wanted to and that they were given full reign to talk about their experiences without coaching or editing.

*“Being able to tell our stories the way we wanted to tell them.” [CPID2]*

**Campaign was well resourced:** The campaign was perceived as having the resources and expertise needed to be successful.

*“We were well resourced. I think that’s a particular thing that was really kind of important is that this campaign was well resourced and had the expertise and the financial resources to be successful. And so, I mean we had the expertise of a communication person, we had the expertise of that kind of promotion.” [KIID5]*

**Strong media coverage:** The campaign, in both regions, was perceived as having benefited from strong media coverage.

*“Both communities have wonderful assets in terms of newspapers and we had reporters that were interested in both communities so through newspaper ads and media coverage I think was strong. In Hamilton, Hamilton has more outlets and a broader kind of reach and more population, so I think through Hamilton being an urban center and the Spectator reaching so many people, that was a benefit. One of the benefits of that is Haldimand also benefited from that. The Hamilton Spectator, Cable 14 and CHCH news all ran ads or had interviews and reached both communities so that was really good. In Hamilton there are more billboards, there are bus stops and we took advantage of those in Hamilton. Both of the municipalities, the City of Hamilton and Haldimand County, both actively promoted the Faces of Dementia Campaign as well and so that was, both municipalities helped out in that regard.” [KIID5]*

**Access to additional information via a variety of mechanisms:** A positive feature of the campaign was that it was accessible, providing audiences an opportunity to access more information in a number of different ways (email, telephone, online).

*“I liked the accessibility, so having things in a bunch of different formats was really good. So, there was information by email, on the website, you could get information by calling somebody. It was there that people could call [the] phone number to get*

information, and I just think of the variety of potential accessibility needs that people might have.” [KIID3]

**Ongoing promotion:** The promotion was valued for its ongoing and continued nature.

*“I think the best part about the promotion is that it kept going. It wasn’t just one and done because I think its important work.” [KIID9]*

**Consistent messaging across all promotional materials:** The campaign was perceived as effective due the consistent messaging that was communicated across all promotional materials.

*“I think one of the things I appreciated was the sort of consistency of messaging and kind of the visuals I think really were pretty striking and stunning, and having consistency across.... if I think about the campaign itself, the launch events, the website, the [Local newspaper] article, I really did think there was a lot of consistency across those which I think is important in terms of conveying the message.” [KIID10]*

**Photography accurately conveyed the key campaign messaging:** The promotion of the key campaign messages was facilitated by photography that captured the essence of campaign participants to clearly communicate that they are more than their diagnosis.

*“First and fore most the photographer used for the pictures was amazing. She captured the essence of those individuals. I’ve never seen such powerful photography and that came through the posters, the media campaign, the bus shelter... The promotion, I think the pictures...seeing people, they all had very strong messages so that people could understand that there is much more than the disease in this person, that people living with dementia are people with homes and lives and I think that came through very clearly in that promotion materials.” [KDIID8]*

## Challenges Experienced in Promoting the Campaign

A few challenges experienced in promoting the campaign were identified. These challenges are summarized in Table 23; these challenges are described in more detail below with illustrative quotes.

**Table 23: Identification of challenges experienced in promoting the Faces of Dementia campaign**

<p><b>Challenges in promoting the campaign:</b></p> <ul style="list-style-type: none"><li>• Selecting an exhibit location within a wide rural geography</li><li>• Delayed campaign production limited time for promotion</li><li>• Having external service providers created delays when revising promotional materials*</li></ul>
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\* Identified by a single interview participant.

**Selecting an exhibit location within a wide rural geography:** The large rural area making up Haldimand region and perceptions that distances between communities are too far to travel, made it difficult to find the ideal location for the exhibit. It would have been preferable to hold the exhibit in multiple communities across the region, if time had permitted.

*“I think it was the rural community as to where to have it [community exhibit] and almost needing multiple in-person events. I know there was one in Dunnville, but to understand Haldimand... People from Dunnville, I’ve heard people from Dunnville say: ‘Well its all the way in Cayuga!’ They feel like its so far. So, I think that would be a challenge because we have a vast kind of geographical range in Haldimand county even though we’re a small population, it’s a big area so that’s where I would see the challenges.” [KIID9]*

*“There were challenges in terms of getting the materials and places, these posters are big and getting them someplace where lots of people could see them. In Haldimand that’s tough because Haldimand is a community of lots of little communities so it was great to do it in Dunnville but a lot of people who live in Haldimand never go to Dunnville.” [KIID8]*

*“When we did the launch event in Haldimand the attendance was fairly small... I do think you know from a geography point of view, Haldimand is so huge and so that does make it quite tricky because you can’t expect that people are going to drive from Cayuga to Caledonia necessarily or vice versa because you’ve got an event on.” [KIID10]*

**Delayed campaign production limited time for promotion:** Key informants noted that the campaign was intended to be produced in the second year of this project, with the remaining time (2 years) spent on promoting it and spreading the reach of the community exhibits. Production delays created by the pandemic and time needed for recruitment of diverse participants, reduced the amount time available for promotion.

*“I think that one of the things that was difficult was the timing of the campaign. So, because of COVID the campaign was launched near the end of the project so I’m not sure that we were really fully able to benefit from the outcomes of the campaign or where that campaign could have taken us, just because of the timing that it was launched, and that’s due to COVID. When we initially had started talking about the campaign, again you’re talking about traveling and that these exhibits would be in multiple places and in multiple neighbourhoods and reach more people, and again due to the time constraints of the project itself we weren’t able to do that and I think that certainly would have been highly beneficial to reach new neighbourhoods.” [KIID5]*

*“It would be great if we had, I think if we had smaller exhibits that could maybe travel through the library system or something along that line. We had two big exhibits and that was it... There were issues in terms of completing the videos. We probably could have started it earlier but we wouldn’t have had a very reflective group of people and as well as I do think that was really important to our theme, that we have a broader cross section of the people we serve and that delayed us by a good six months. And I think had we been*

*able to do the campaign earlier the way we wanted it done, we would have had more time to promote it... I'm not sure we tapped in to all of the senior's programs, the older adult programs that we could have, but it was just timing more than anything else." KSID8]*

**Having external service providers created delays when revising promotional materials:** One key informant noted that relying on external service providers to create and make changes to promotional material created delays that may not have occurred if work was being done internally. However, it was noted that the quality of the materials outweighed the time delays.

*"So having an external company doing the promotional material meant that we didn't always get information back as soon as possible. Like if I was doing a poster it would have to go through the company that we hired to do the promotional material and it's the difference between waiting several days for something to get back rather than me saying: 'Oh yea, I want to change this' and going ahead and changing it. But I think that was far outweighed by the incredibly beautiful kind of professionalism that all of the media had." [KIID3]*

### **Suggestions for Improvements to the Campaign Promotion**

Although campaign participants and key informants expressed satisfaction with the promotion of the campaign they identified a number of suggestions for improvements, many of which would have been implementable had there been more time for promotion. These suggestions are summarized in Table 24 and described in more detail below with illustrative quotes.

**Table 24: Suggestions for improvement to the Faces of Dementia campaign promotion**

<p><b><i>Suggestion for Improvement:</i></b></p> <ul style="list-style-type: none"><li>• Increase social media presence</li><li>• Increase media promotion (radio, television)</li><li>• Increase funding for promotion</li><li>• Provide greater recognition for those working 'behind the scenes'*</li><li>• Increase promotion by project partners and funder*</li><li>• Hold community exhibits in various locations*</li></ul>
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\* Identified by single interview participants.

**Increase social media presence:** It was suggested the more promotion could have been targeted to social media (e.g., Twitter, Facebook, Instagram) and more outputs monitored (number of engagements, shares and by whom, comments and feedback).

*"I think the one piece I think that we might have been able to do better and in the future, I think it would help to add some more resources to it is I'm not sure that our social media presence, I think that could have been enhanced, the online engagement with the campaign. I think we did do social media promotion, but I think that would have been an*

*area that we could definitely improve on in the future.... like engagement, who was sharing it, how many comments you were receiving, that kind of stuff. I think that people can often become really engaged through social media and comments and feedback and I think we could have maybe done a bit more to reach more people on social media.”* [KIID5]

*“Probably we could have done a better job with social media.”* [KIID8]

**Increase media promotion (radio, television):** Key informants noted that while there was some television and radio promotion, there could have more. It was suggested that having campaign participants (persons living with dementia) interact directly with media may garner more attention, with project partners and funder promoting the campaign more broadly.

*“I think just that we probably could use more [media promotion], could use more of it. I don’t think we did too much radio. It would have been cool if we did more TV because a lot of people don’t have access to the internet.”* [KIID8]

*“It could have been better covered by [Local] TV... The only way I can see it happening is having somebody living with dementia call the stations directly and talk to them because I think when its promoted by an [Marketing] agency, and they have connections, its not the same... Who knows how well they could sell it. A person living with dementia can sell things a lot better.”* [CPID1]

**Increase funding for promotion:** It was noted that promotion costs are high and had there been more funding dedicated to promotion, there may have been more opportunities to promote the campaign more broadly (e.g., Prime time television).

*“Certainly if we had a little bit more funding. We were funded quite a bit. Promotion costs money and it would have been really cool to have been able to feature that on prime time TV.”* [KIID8]

*“More money and funding to do more [promotional] things.”* [KIID3]

**Provide greater recognition for those working ‘behind the scenes’:** It was noted that while the campaign participants received a lot of recognition for their involvement with the campaign, very little attention was paid to those who coordinated, facilitated and produced the campaign. It was felt that those ‘behind the scenes’ who made the campaign possible should have received more attention.

*“The Faces of Dementia and the MICE project and the Hamilton leadership teams and stuff like that, we got a lot of recognition ... And so, I just thought that there was a little bit of missed recognition. We’re the Faces of Dementia in terms of living experience, but there were so many other people who were Faces of Dementia in the project... Perhaps recognizing other people, not just [Project Coordinator] and [Facilitator], but other people who were managing the project... they’re our backbone, so we wouldn’t be as*

*successful as we have been had it not been for the people behind the scenes. So, a little more recognition that way I think would have been nice.” [CPID2]*

**Increase promotion by project partners and funder:** It was noted that while the campaign was well promoted within the funding allotted, the campaign could have been promoted more by project partners (e.g., Alzheimer Society) and the funder (Public Health Agency of Canada, who may have the resources for widespread promotion beyond this region.

*“I think we did as best we could given the resources we had, but boy oh boy, I would have liked to have seen Alzheimer’s Society, Public Health Agency of Canada (PHAC) picking up on some of this and helping promote it more broadly.” [KIID8]*

**Hold community exhibits in various locations:** Although the limited time for promotion prevented more community exhibits from being held across various locations in Hamilton and Haldimand, it was suggested that this would have advantageous to spread the reach of the campaign.

*“I know at some points we had talked about the posters kind of being in the exhibit being a bit more of a traveling exhibit and in the end, it was just like one event in Hamilton and one event in Haldimand. So, I do wonder about whether there might have been some gains to be made from sticking to that original idea. I know there were lots of reasons probably why the switch was made, but if I think about the coffee shop in Haldimand compared to [senior centre], well could we have gone to [coffee shop] in [small community] and asked them if we could do something similar there?” [KIID10]*

## **Key Lessons Learned in the Promotion of the Campaign**

Interviewed key informants identified a number of key lessons learned to date in promoting the Faces of Dementia campaign; these key lessons learned are summarized in Table 25 and described in more detail below with illustrative quotes. These key lessons can serve as advice, or directives, to others interested in developing a similar campaign in effort to enable dementia friendly communities.

**Table 25: Key informant’s identification of key lessons learned in the promotion of the Faces of Dementia campaign**

***Key Lessons Learned:***

- Co-designing the campaign with person with dementia facilitated campaign promotion
- Established networks and partnerships can assist in campaign promotion\*
- Wide representation (diversity) in campaign participants is important\*
- Awareness raising campaign is critical to affecting change\*

- Create multiple opportunities for launching and exhibiting the campaign\*

\*Identified by single interview participants.

**Co-designing the campaign with person with dementia facilitated campaign promotion:** Key informants noted the importance of having campaign participants co-develop the campaign messaging, which led to their being actively involved in and taking some ownership in promoting the campaign.

*“I think one of the key lessons that I had learned in terms of promoting the campaign, one of the things I would say here is that members of the campaign built a lot of capacity for us to promote the campaign more broadly. So members of the campaign because they were really engaged in it and kind of shared that ownership of the campaign, they really brought that campaign to new places and so they’re promoting the campaign within their networks and more broadly and so everybody is kind of doing their part... I would say that the time and intention in co-designing and co-creating the campaign built those champions into the campaign, like built the capacity for more broadly promoting the campaign and a bigger investment of stakeholders... if you co-create people take ownership of it, they’re proud of it and they want to promote it.” [KIID5]*

*“We said this all along, that the importance of engaging those that are going to be speaking as part of the campaign early on and throughout the campaign was really important and it made the campaign that much stronger. So, raising awareness about the impact or what its like to be a person living with dementia. So, what was really critical was those people who were engaged in the video were actually part of the campaign and were actually available and speaking to it and helping us promote it.” [KIID8]*

*“I think really truly understanding the message that you want to get across and again, being inclusive. So having everybody that needs to be at the table. So having, the company that was hired, having [Marketing firm] understand from people who have dementia what its like. So having that connection was I think really important.” [KIID3]*

**Established networks and partnerships can assist in campaign promotion:** Leveraging existing networks and partnerships to promote the campaign can facilitate a broader reach.

*“I think the partners also did that [promote the campaign] and so we had another huge benefit. So I would say that your network and your partnerships are really important to the promotion of a campaign like this.” [KIID5]*

**Wide representation (diversity) in campaign participants is important:** Making sure that the intended audience can see themselves in this campaign highlights the importance of ensuring that there is diversity among campaign participants.

*“Just noting the importance of representation if [other communities] were to do a campaign, having that diverse population and making sure that lots of people can see themselves in these other fine folks that have agreed to do the campaign.” [KIID9]*

**Awareness raising campaign is critical to affecting change:** It was noted that if other communities are interested in creating a dementia friendly community, the development of a similar awareness raising campaign has the most potential to affect change.

*“If another community were to take on this dementia friendly communities, I feel the Faces of Dementia [campaign] is a must, because I think its this initiative that really has the most potential to affect change.” [KIID9]*

**Create multiple opportunities for launching and exhibiting the campaign:** As suggested as an opportunity for improving the promotion of the campaign promotion, it noted that hosting a launch event with campaign participants present is very impactful as it having multiple approaches to exhibiting the campaign.

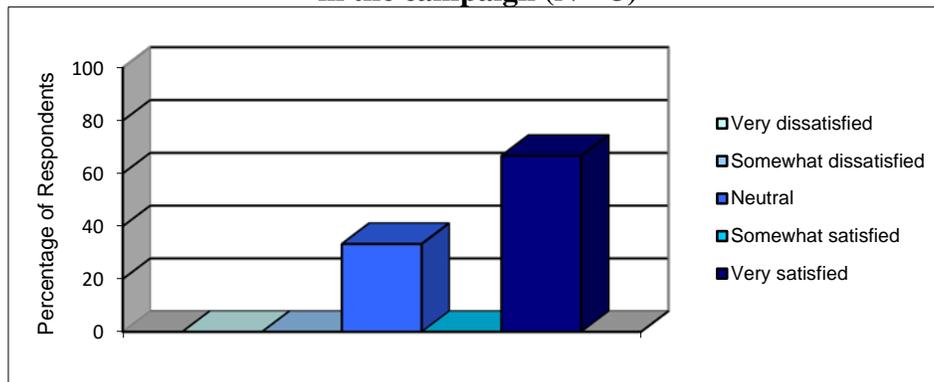
*“I think I do think having an event was really a very positive thing. I think the video in combination with the portraits in combination with the people in the pictures actually being physically present at both places really did have more impact than any one of those alone could have had. So, you know, if I were thinking about lessons to be learned, well that would be one, to think about using multiple approaches to have an impact in the moment, but then creating ways for legacy.” [KIID10]*

### Evaluation Objective III: Describe the Ways in Which Participation in the Faces of Dementia Campaign Affected Participants

#### Participant Experience with the Faces of Dementia Campaign

Figure 2 presents campaign participants’ overall satisfaction with their experience in the Faces of Dementia campaign as reported by survey respondents. Two of the three survey respondents were ‘very’ satisfied with their experience in the campaign; one respondent was ‘neutral’.

**Figure 2: Campaign participants’ ratings of satisfaction with their experience in the campaign (N = 3)**



Campaign participants were asked rate the extent to which they agreed or disagreed with various statements about their involvement in the campaign (3-point scale: disagree, neutral, agree). All of the survey respondents agreed that they felt comfortable sharing their experiences with dementia for this project, that their involvement will affect community change and that their participation in the campaign was a positive experience. As a key outcome indicated for this project, it was anticipated that 80% of respondents would perceive participation in the campaign as a positive experience; as reported in Table 26, all three of the survey respondents agreed that their involvement in the campaign was a positive experience.

**Table 26: Campaign participants’ level of agreement with various aspects of their experience with the Faces of Dementia campaign (N = 3)**

	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>
I felt comfortable sharing my experiences with dementia for this project.	0	0	100% (3)
I believe my involvement in the Faces of Dementia campaign will help to make changes in how my community thinks about dementia.	0	0	100% (3)
My participation in the Faces of Dementia campaign was a positive experience.	0	0	100% (3)

Note: Percentages may not sum to 100% due to missing data.

### **Impacts Associated with Campaign Participation**

Interviewed campaign participants and key informants were asked to identify the ways in which the campaign impacted campaign participants. These impacts are summarized in Table 27 and are described in more detail below with illustrative quotes.

**Table 27: Personal impacts associated with participating in the Faces of Dementia campaign**

<p><b><i>Participant level impacts:</i></b></p> <ul style="list-style-type: none"> <li>• Empowerment to engage in community advocacy</li> <li>• Increased capacity and confidence</li> <li>• Reduced social isolation</li> <li>• Increased desire to contribute more in the community*</li> <li>• Increased understanding of the personal impacts of dementia*</li> <li>• Increased encouragement and support to be active*</li> </ul>
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\*Identified by single interview participants.

**Empowerment to engage in community advocacy:** Several campaign participants reported that their participation in the campaign has motivated them to engage in more advocacy work with a desire to ensure that this work is done well/ appropriately. A key informant also noted that involvement in the campaign empowered participants to become change agents and realize that they had the influence to change attitudes about dementia and become community leaders in other projects.

*“By participating it helps keep my mind engaged. It helps keep me motivated and it gives me this urgency to strive, like really, it has to be done! Its gotta be done right!”*  
[CPID1May2022]

*“What its done [participation in the campaign] is its broadened my horizons in the key areas that affect me and that I want to do further advocacy work.”* [CPID2May2022]

*“For the members I would say the campaign really was a platform to kind of expand and influence the people who are living with dementia and so I think that members of the campaign have really, this provided an opportunity for them to be highly influential, and highly influential to change attitude and perceptions around dementia which is really important. And I think that people living with dementia and their families and care partners will benefit from that.”* [KIID5]

*“The consensus [among Campaign participants] was that each and every one of the persons had no idea what they were capable of doing in the Faces of Dementia. And since that campaign some people have absolutely gone and flourished and taken the lead in other projects.”* [CPID2Winter2023]

**Increased capacity and confidence:** Involvement in the Campaign helped participants change their attitudes about their diagnosis and what they are capable of accomplishing, giving them new found confidence.

*“It’s been very successful and the Faces of Dementia really did change the attitudes of people who have been diagnosed, I really believe that. We really can do more then we or other people might think.”* [CPID2Winter2023]

*“And watching [campaign participant]... watching her do stuff that she said was way out of her comfort zone, but doing like so remarkably, like a great job.”* [KIID3]

*“I certainly perceived that the people featured in the campaign themselves, so the people living with dementia and their care partners, experienced a really positive sense of themselves and themselves making contributions to society.”* [KIID10]

**Reduced social isolation:** Participation in the campaign was identified by one participant as a significant opportunity to increase their social engagement and reduce their social isolation with the development of new friendships.

*“I feel like I’m doing something and if anybody wants to join in, it feels great. I’ve been so isolated for years here and then finally being part of a program, it’s been great.”*  
[CPID3]

*“I developed a lot of new and lasting friendships and not only with people that have the same diagnosis as I do, but others that don’t have the same diagnosis that I do. Even individuals living in the apartment building, they all know about me and they go out of their way, they’re kind. So, my social life and the connections that I’ve developed now, I’m so much more socially active and they actually care about me and they understand me, where I am in place and time.”* [CPID2Winter2023]

*“One of the things I think is just the benefit is the relationships that have been made out of different parts of the campaign. I know that because of the campaign [participant and spouse] have developed a friendship with [participant and spouse].”* [KIID3]

***Increased desire to contribute more in the community:*** A participant reported that participation in the campaign has inspired them to be more involved in educating the community about the needs of people living with dementia and exploring alternative models of community living for people with dementia.

*“I’ve come to wanting to branch out on my own more, like finding what I want to contribute to the community, the Alzheimer’s Society, Hamilton Council on Aging, to look at really, so its educating the community about the needs of people living with dementia, the institutionalization of individuals to long term care facilities, and looking at like smaller communities like maybe a little village... Depending on the size you might have 4-6 people living in a home, 2 PSWs, and a case manager that oversees maybe 6 houses.”* [CPID2MAY2022]

***Increased understanding of the personal impacts of dementia:*** The campaign provided a participant with the opportunity to think about what they think is important to communicate to others about dementia, based on their reflection on how it has affected them.

*“A chance to think myself about how I feel about it and how it has affected me, and then to be able to communicate some of that, and that’s helpful as well. So, you know, it’s got to be a 2-way street.”* [CPID4]

***Increased encouragement and support to be active:*** One participant found that their involvement in the campaign provided enjoyment and support as well as encouragement to remain active.

*“For sure I enjoyed it and it gave me lots of support. In a way that I’m not going to stop anything, and it gives me courage to live and they are doing so much. If I stay back and depress about my stuff, and just say: ‘I’m not going to do anything’, its not good.”*  
[CPID5]

As related to impacts associated with the campaign, the majority of participant survey respondents (>67%) agreed that as a result of the campaign, they felt better able to share their experiences with dementia, and learned new things about dementia. All of the survey respondents agreed that as a result of the campaign, they were more aware of the stigma associated with dementia and believe the campaign will be effective in increasing community awareness about what the lived experiences of persons living with dementia (Table 28).

**Table 28: Campaign participants’ level of agreement with various aspects of their experience with the Faces of Dementia campaign (N = 3)**

	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>
I feel better able to share my experiences with dementia as a result of my involvement in this project.	0	33.3% (1)	66.7% (2)
I learned new things about dementia as a result of participating in this campaign.	0	33.3% (1)	66.7% (2)
I am more aware of the stigma that can be associated with dementia.	0	0	100% (3)
I believe the Faces of Dementia campaign will be effective in increasing community awareness about what it is like to live with dementia.	0	0	100% (3)

Note: Percentages may not sum to 100% due to missing data.

### **Other Persons with Lived Experience and Community Level Impacts Associated with the Faces of Dementia Campaign**

Interviewed campaign participants were asked to identify the ways in which the campaign might impact other persons living with dementia, their care partners, and community. These impacts are summarized in Table 29 and are described in more detail below with illustrative quotes.

**Table 29: Impacts associated with the Faces of Dementia campaign**

<p><b><i>Other persons with lived experience and care partner level impacts:</i></b></p> <ul style="list-style-type: none"> <li>• Openness to acknowledge dementia and remain active</li> <li>• Identification with campaign participants</li> <li>• Increased community awareness will reduce stigma and improve quality of life for people living with dementia</li> </ul>
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**Community level impacts:**

- Increased understanding of what it is like to live with dementia
- Increased awareness of the need for and interest in dementia friendly community education
- Increased interest from other communities in creating dementia friendly communities
- Increased acceptance of all persons experiencing challenges
- Community change

**Other Persons with Lived Experience and their Care Partners Level Impacts**

Two participants indicated that the campaign is unlikely to appeal to or make a difference to those people who do not acknowledge that they have dementia or who are resistant to learning more about dementia.

*“I think as effective as it can be. The thing is that everybody reacts differently as well and they may or may not listen to what we can do, and we also have to live with this kind of thing and some people, sometimes people don’t even let you have the opportunity. But that’s the way it is with anything, really.... I know people who have Alzheimer’s but will not ever say it and don’t want anybody else to say it around them and that’s not very helpful to anybody... it will reach those who are open and therefore may open up more avenues in the community for people to be active with Alzheimer’s or dementia, which is really I think quite helpful.” [CPID4]*

**Openness to acknowledge dementia and remain active:** Several campaign participants were hopeful that the campaign would encourage other persons living with dementia to be open about their diagnosis and that this reduced stigma will encourage them to remain more active in the community.

*“Well, I think it will open the world up because a lot of times they [persons with dementia] don’t do things because they hide away in their houses. And I think once people start to see this it will open up better avenues for people living with dementia in the communities... When I think back to when I got my diagnosis [spouse] didn’t want anybody to know and I said: ‘Are you crazy!’ I says I watched my grandmother and I watched my mother and I am not going to sit down and take this and hide away from people; I just won’t do it.” [CPID1MAY2022]*

*“So maybe some [people living with dementia] may get the understanding that it [dementia] isn’t as frightening as they may think and they’re able to share that they have it with others... just the name kind of scares people away. But that’s because they don’t really understand and people who have Alzheimer’s don’t allow themselves to understand that in fact that’s not the end of the world.” [CPID4]*

**Identification with campaign participants:** It was anticipated that other persons living with dementia may identify with the campaign participants with positive affect.

*“My mom always said you always want to gravitate to people that are like you. So, when you see other people, you're like: ‘Oh, there are other people out there like me.’ So that’s a good thing. Anything public is great. There's nothing that can be terrible because it's something, so it will make a lot of people feel happy.” [CPID2MAY2022]*

***Increased community awareness will improve quality of life for people living with dementia:*** It was felt that increased community awareness about dementia and the supports needed by persons living with dementia will reduce the stigma associated with dementia, increase supports available, and improve quality of life for people living with dementia.

*“There are so many things like the drugs, the community, the support required, there needs to be some understanding in the larger population what dementia is and what kind of supports they need, instead of pushing them further into the disease because people will say: ‘You are crazy’ or something like that. These types of campaigns do help people who have this condition to have a normal life.” [CPID5]*

## **Community Level Impacts**

***Increased understanding of what it is like to live with dementia:*** It was anticipated that the campaign will increase community understanding of what it is like to live with dementia and that people with dementia are able to meaningfully contribute to their community.

*“I think it’s a constant educational thing and I think this [campaign] will be very helpful in terms of that because it has people like myself and a lot of others that are articulate and still say: ‘Well, of course we have Alzheimer’s, but that doesn’t mean we can’t participate.’” [CPID4]*

***Increased awareness of the need for and interest in dementia friendly community education:*** It was anticipated that as the community becomes more aware about the dementia experience, they will recognize the need for more education and become interested in the dementia friendly community education program that is being offered by this project.

*“I think it will start to open their [community] eyes and then to be like: ‘Wow, right.’ The other thing during the launch, we’re going to offer education...so they’re going to have their eyes open and then they’re going to go: ‘Oh, I should do that education.’... There’s so much more to learn and I think that’s what we’re getting out there.” [CPID1MAY2022]*

***Increased interest from other communities in creating dementia friendly communities:*** With the success of this campaign it was anticipated that other communities would be inspired to become create dementia friendly as many communities around the world have expressed an interest in this project.

*“I think this is a precedence, to use a legal term. I think what we have done here is precedent. [Campaign participant] and I, and I’m sure others are too, talk about this*

*program to everybody all the time. I talk to peer support groups in Texas. We talk to people in Great Britain. I've sent them tons of information.... Newmarket wants to start, I was talking to someone in Newmarket, they want to start a program... they want to educate the community... People are like: 'Wow!' And that's exactly what they say: 'Wow!' [CPID2MAY2022]*

**Increased acceptance of all persons experiencing challenges:** While this campaign was focused on creating communities that would be accepting of persons living with dementia, it was expected that this would be applicable to anyone experiencing challenges so that the community will become more inclusive.

*"This program that we have started, its aim was for dementia, but really its going to benefit everybody. Anybody that has any kind of challenge, its not about tolerance, its not about being friendly, its about acceptance... To me its about being inclusive and accepting." [CPID2MAY2022]*

**Community change:** It was anticipated that the Faces of Dementia campaign, along with other project activities, including the Lived Experience Leadership Team and their projects, will facilitate community change towards dementia friendly communities.

*"It's the launch [of the campaign], but then we've got the MICE program [Community mural project in Haldimand] and the newsletter in Hamilton and it's the combination of everything working together that's going to make change." [CPID1MAY2022]*

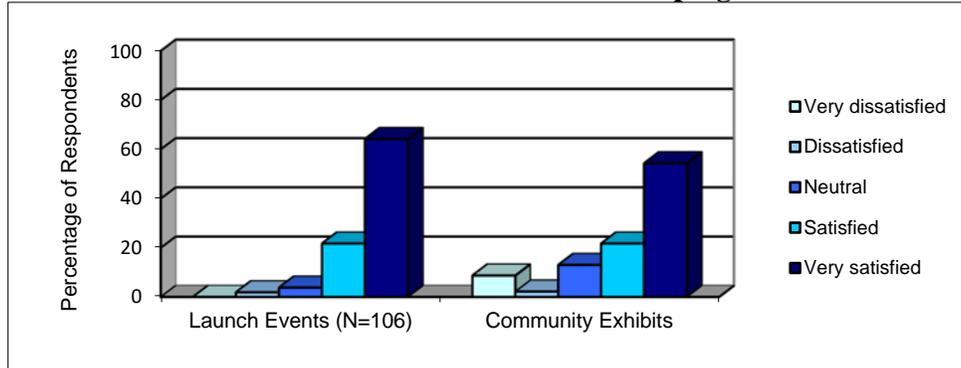
## **Evaluation Objective IV: Describe Attendees' Perceptions of the Launch Events, Community Exhibits, and Faces of Dementia Website**

### **Satisfaction with the Faces of Dementia Campaign**

Figure 3 presents launch event and community exhibit attendees' overall satisfaction with the Faces of Dementia campaign. As there were no significant differences in ratings between the intimate and public launch events, results are presented across both of the surveys for these events. The majority of intimate and public launch survey respondents (95%) reported that they were 'satisfied' (22%) or 'very satisfied' (73%) with the campaign. This trend in ratings held true regardless of location of respondents (Hamilton, Haldimand, Other) or respondent group (persons living with dementia, care partners, others).

Similarly, the majority of community exhibit survey respondents (76%) reported that they were 'satisfied' (22%) or 'very satisfied' (54%) with the campaign. This trend in ratings held true regardless of location of respondents (Hamilton, Haldimand, Other) or respondent group (persons living with dementia, care partners, others). It is important to note that while several (N = 5) respondents indicated that they were dissatisfied with the campaign, their open-ended responses did not reflect this, so the reason for these ratings is not known, and may have been an error.

**Figure 3: Launch event and community exhibit attendees' ratings of satisfaction with the Faces of Dementia campaign**



Note: Percentages may not sum to 100% due to missing values.

Chatroom comments made about the campaign by those in attendance at the public launch reflected perceptions that the campaign was beautifully produced, inspiring, empowering, and impactful, particularly as related to changing attitudes about dementia. Many attendees expressed gratitude for having access to the campaign and communicated intentions to share the campaign with both personal and professional networks and in their role as educators:

*“Beautiful and touching – love this!!!!”*

*“So inspiring to hear the voices of persons living with dementia.”*

*“Very powerful messaging – I can’t wait to see the billboards too!”*

*“I hope the video will be made available for others to use – it is very powerful.”*

*“This is a great initiative! What powerful documents.”*

*“Thank you all! I plan to share this far and wide – including sharing with GPA [Gentle Persuasive Approaches] Certified Coaches across Canada.”*

*“Wow, this is beautiful. Thank you for sharing with the world.”*

*“Everyone needs to see this! Such powerful messages!”*

*“So empowering! Thank you for sharing who you are with the world!”*

*“Incredible messages of hope and purpose. Thanks to all of you for sharing your stories and faces with us!! People living with dementia are LIVING, and this is what your video reminds the world about!”*

*“Will be wonderful to profile and share with our communities – thank you for this tremendous work!”*

*“You’re changing the worldview.... Of persons living with dementia. Nice work to all.”*

*“This is a really great resource to use with students learning about dementia – I am delighted we now have a locally produced resource.”*

*“Really a great film, showing that people with dementia are just people! Less focus on dementia and more on the person is wonderful!”*

*“This needs to be presented country wide.”*

*“This is such a strong example of authentic partnerships and the power of these approaches for changing understandings and inspiring change.”*

*“Such a wonderful way to share this message. I would love to be able to share this with students as well as personal networks.”*

*“The video was enlightening and thought provoking. Thank you.”*

*“Can’t wait to share this with my network. Thank you so much to everyone for this great and important work you are doing!”*

Comments made about the campaign by intimate and public launch survey respondents reflected their satisfaction with the end product, its focus on persons living with dementia, attention to diversity, and how the campaign made them feel (humbled, inspired):

*“Love the video and posters!! It felt very real.”* [Care Partner]

*“A very humbling experience!”* [All others]

*“It was inspiring and completely awesome.”* [All others]

*“Amazing- so inspiring- thank you to all of the participants for candidly sharing their stories and experiences in this change-making project!”* [All others]

*“It is always such an experience to hear directly from those living with a diagnosis. How wonderful is that. Such brave souls.”* [Person living with dementia]

*“This was one of many webinars that I have attended, where I was impressed by the representation of people living with dementia. So many other projects are directed towards caregivers or medical professionals. This Faces of Dementia campaign was truly about dementia and people with dementia.”* [Person living with dementia]

*“Very happy to learn about the direction of this campaign, emphasizing how the lives of people with dementia can be both fulfilling and inclusive. Creating public awareness for that is such a wonderful initiative.”* [All others]

*“Very empowering. It was wonderful to see how people cope with dementia and not let it stop what they love doing.”* [All others]

*“Wonderful campaign to spotlight the person not the disease.”* [All others]

*“Powerful videos and hearing from persons living with dementia is the key part. It was clear and resonated with me.”* [All others]

*“I appreciate the attention to diversity and representing the individuality of the dementia experience.”* [All others]

*“I am so grateful to have able to attend this session - it was very powerful, eye opening and so great that persons living with dementia voice are being heard!”* [All others]

*“There aren't words - moving and an amazing collaboration.”* [All others]

Similarly, comments made about the campaign by community exhibit survey and guest book respondents reflected their satisfaction with the campaign products and exhibit launch events, involvement of persons living with dementia in both the campaign and the launch events, and how the campaign was informative, important and impacted stigmatization of the dementia:

*“Awesome video, wonderful kick-off.”* [Survey - Care partner]

*“Visually appealing, informative, multimedia.”* [Survey - All others]

*“Absolutely beautiful! Thank you!”* [Guest book entry]

*“It was a great event and loved that all of the people with dementia who participated were in attendance.”* [Survey - Care partner]

*“Beautiful community connection.”* [Guest book entry]

*“I like how it was made personal through people's personal stories about dementia.”*  
[Survey - All others]

*“I think this is wonderful and empowering and exactly what should be happening.”*  
[Survey - Care partner]

*“It really put faces to different examples of dementia that were surprising in some instances.” [Survey – All others]*

*“I love that you are making this a comfortable topic.” [Survey - All others]*

*“A lot of very good information. A great event.” [Guest book entry]*

*“So informative and inspiring, such amazing organization. Keep it going.” [Guest book entry]*

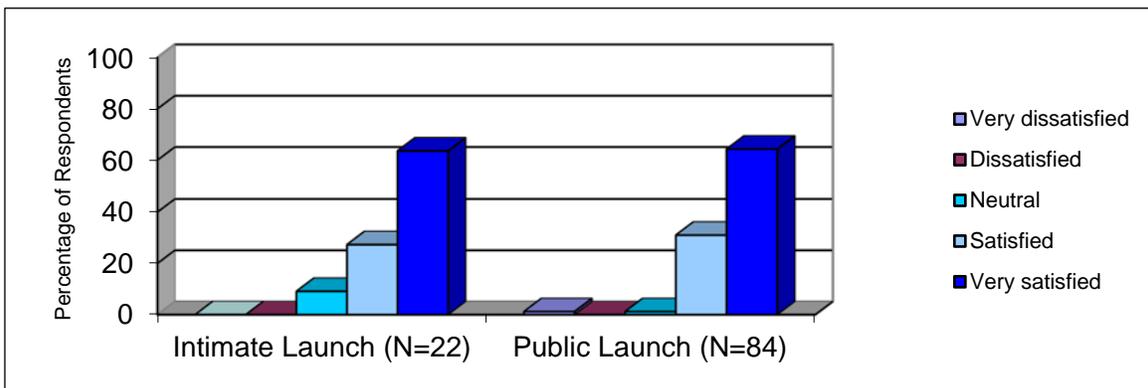
*“Very informative. Wonderful event. I’m glad I came!” [Guest book entry]*

*“Lovely to hear all the support for such an important initiative.” [Guest book entry]*

### Satisfaction with Campaign Launch Events

Attendees of the intimate and public launch events were asked to rate their satisfaction with the launch event. The majority of intimate launch survey respondents (91%) reported that they were ‘satisfied’ (22%) or ‘very satisfied’ (73%) with the campaign launch event (Figure 4). Similarly, the majority of public launch survey respondents (95%) reported that they were ‘satisfied’ (31%) or ‘very satisfied’ (64%) with the campaign launch event.

**Figure 4: Launch event attendees’ ratings of satisfaction with the virtual launch event**



Comments made by respondents of intimate and public launch surveys about the campaign events reflected their satisfaction with the organization of the event, the convenience of the virtual format, and hearing from the creative team.

*“Have [sic] a virtual event made it so easy, no figuring out driving, parking, seating...” [Intimate launch event]*

*“I like the way the group interacted with each other.”* [Intimate launch event]

*“The panel was so varied, honest and open. It was a great event for the participants, the comments following the launch were so positive and excited, confirming just how impactful the presentation was.”* [Public launch event]

*“The launch event was great. I appreciated the land acknowledgement. The timing of having it over lunch worked for me. I liked the friendly energy.”* [Public launch event]

*“I loved hearing the meaning of the colours and that being behind the camera was a learning experience from the lens of the target market, and the underlying goal to capture the person, the dignity and humanity. Thank you. Good insights.”* [Public launch event]

Some additional comments about the campaign reflected people’s perception that this campaign should be considered the “start” and that much more work should be done to increase awareness and reduce stigma.

*“It’s the start of a movement. Now next steps forward for those that will listen.”* [Person living with dementia]

*“It’s a start, which is great, but the focus at present is too much on older people who are already diagnosed with dementia. In order to raise awareness we need to hear more from younger people who have become aware that this illness does not mean that the identity of the individual has been lost. What needs to be tackled is the very real stigma that is attached to the very notion of dementia.”* [All others]

*“There’s still more work to be done for people living with dementia - we on the right track.”* [All others]

### **Perceptions of the Community Exhibit Launch Events**

The community exhibit launch events were perceived favorably by interviewed campaign participants and key informants. Thoughts about the events and what stood out most to them about the events are summarized in Table 30; these perceptions are described in more detail below with illustrative quotes.

**Table 30: Key informants’ perceptions of the community exhibit launch events**

***Perceptions of the Launch Events:***

- Events were well attended
- Events were interactive and engaging
- Exhibits were interactive
- Significant opportunity to have conversations about dementia
- Good to have campaign participants in attendance
- Joyful tone to the events
- Development of new community connections
- Venue selection impacted reach\*
- Positive feedback received\*

\*Identified by single interview participants.

***Events were well attended:*** There was general consensus among those interviewed that the community exhibit events were well attended, with attendance numbers exceeding expectations. It was noted that attendees represented individuals working in the field of dementia/ community services as well as the general public.

*“I thought they were well attended both in Hamilton and in Haldimand.” [KIID5]*

*“I thought it was hugely attended. I didn’t expect to see as many people as I did and I saw a lot of people that I’ve seen in the past, and in my past career choices so it was really nice touching base with everybody.” [CPID2]*

*“I absolutely loved them. I thought they were wonderful, the number of people that showed up and the different chapters they came from and it was interesting. We even had people that don’t work in the area, just regular general public showed up, so it was really, really quite good.” [CPID1]*

*“I think the amazing turnout for both events. So, I think there’s a huge surge out there in our community for more of these types of awareness raising activities and it certainly makes me think... that we have got to get back to doing more of this.” [KIID8]*

*“Both of [Community exhibit launch events] were awesome. They were well organized. They certainly both could have been better attended, but I think people are still nervous about doing things with COVID, and getting in the habit of doing things differently. But given that, the attendance was really good.” [KIID3]*

***Events were interactive and engaging:*** The community exhibit launch events were described as a significant opportunity to interact with and engage the community with this project, particularly through informal conversation.

*“I think that the community exhibits themselves I think were really a creative way to kind of connect people to the message with the use of the posters, I think were really humanizing, beautiful and then the interactive piece, the gallery was a neat way to engage the community and so I really liked, I really enjoyed both the launch events, and then the interactive exhibits themselves.” [KIID5]*

*“I had a lot of questions too. I was asked particularly what I was doing and why I was part of the group and what we were trying to accomplish, and I said we had accomplished and exceeded everything that we had planned to do.” [CPID2]*

**Exhibits were interactive:** Those interviewed liked that the exhibits themselves were interactive, with the use of QR codes to direct audiences to more information about the campaign participants and the project.

*The interactive gallery exhibit. I really liked those events. I thought that while we did a lot of paid promotion and paid advertising and we earned a lot of free media exposure, I think having those in person events in particular with the gallery was really engaging. And so, I really, really liked those.” [KIID5]*

*“What I thought they did that was key was have the QR codes. That was brilliant. I’d never seen that before and I can use that in the future. That is so cool. It makes a static depiction come alive. ...the QR codes to have the voice of the person in the picture.” [KIID8]*

*“Because it had the QR codes on the photos people could still engage a bit more with the videos and the story.” [KIID10]*

**Significant opportunity to have conversations about dementia:** The community exhibit launch events were described as significant opportunities to have important conversations about dementia with attendees, with the potential to change attitudes. Campaign participants were key to these conversations as they shared their experience with dementia and their rationale for being involved in the campaign.

*“I think that the campaign and those in-person events provided the opportunity to talk about dementia and understand dementia differently. I think people who are members of the campaign living with dementia, talking to people and talking about the campaign and talking about their experiences, I think that’s where the learning really happens. I think people take a lot away from that and transform how they think and behave.” [KIID5]*

*“I think the promotional posters that were up really spoke, people were standing by them and talking about them and who we all were.... [Conversation] didn’t stop. It didn’t stop.” [CPID2]*

*“I thought they were amazingly powerful and perhaps what made the Hamilton that much more powerful was everybody was there. All of the participants in the Faces of Dementia campaign were present for that one... People were able to ask them questions*

*and there was lots of milling around that I think was as powerful as the presentation.”*  
[KSIID8]

***Good to have campaign participants in attendance:*** The presence of campaign participants at the community exhibit events was perceived as positive as it provided people the opportunity to ask them questions directly. Watching campaign participants take pride in their involvement in the campaign was also perceived favourably.

*“I thought it was positive the members of the campaign were in attendance.”* [KIID5]

*“So they were, from my perspective, they were both really positive experiences. I loved the fact that the participants from the videos were in attendance. The attendance [by campaign participants] was better I think at the Hamilton event than it was in Haldimand but even so I thought having some of the people actually featured in the videos in the exhibit was really positive.”* [KIID10]

Related to the attendance of campaign participants, it was noted that it was wonderful to see participants being photographed in front of their posters and the pride that it engendered.

*“I think in both locations having the Faces of Dementia, the campaign posters were really quite amazing. Having the people who were in the posters posing with the posters and having their picture taken with that was really, really neat.”* [KIID3]

*“It was probably one of the highlights of my year! It was lovely to meet people in person for one, and the standout, like during the film because I had seen the film multiple times, I instead choose to look at the participants faces of those who actually did the film. Seeing the pride in their face, like it was just very special and that was a huge standout for me.”*  
[KIID9]

***Joyful tone to the events:*** Key informants responded favourably to tone of the community exhibit launch events, which were described as joy to attend, energetic, and ‘the place to be’.

*“The overall feel, tone in the room, was just so positive at both events. It really was a joy to be present.”* [KIID10]

*“The sense, the feeling and the venue for both were really just, I don’t even know how to describe it. It was so amazing because it was, it was energetic, it just felt like the right kind of place to be.”* [KIID3]

***Development of new community connections:*** It was noted that people attending the community exhibit launch events made new community connections, some with individuals representing organizations that could potentially become partners in future dementia friendly community project and some members of the general public being connected with services of the Alzheimer Society.

*“All of the new connections that I made or that I’m aware of that other people made and the new conversations being had. So, I mean from my own personal experience, I met a number of new people from different organizations who were expressed a lot of support that could potentially be future partnerships. And then I know that people were talking about and really engaging with the people who were members of the campaign, and so I thought that that was a really positive thing that those kind of new relationships were formed between campaign members and community partners or service organizations. I thought that that was a really neat outcome of both of the events.” [KIID5]*

*“Even with the general public showing up it brought some things to light in their minds and they asked the questions, and one lady we got, we even got her involved with the Alzheimer’s Society in her area to help her with her husband. So, we were able to do that for a few people actually” [CPID1]*

**Venue selection impacted reach:** One key informant noted that the selection of the Minga Café as the location for the community exhibit in Haldimand county had the potential for broad reach given the traffic of members of the general public through the café. In contrast, having the community exhibit within a senior centre, likely limited the audience to seniors.

*“There’s probably pros and cons to the venue, but when we had the Haldimand event and it was at a coffee shop. There was something kind of cool and funky about having it there, and having those portraits. They actually might have had more potential reach than when we went to [senior center]. When we were at [senior centre] in some ways that venue was really a beautiful venue, we had good attendance, but then I was thinking about it afterwards and when the portraits stayed there afterwards, the main people who walk into [senior centre] are primarily seniors, so I think our reach might not have been as great.” [KIID7]*

**Positive feedback received:** One key informant noted that the community launch events engendered a lot of positive feedback about the campaign, that not only was it beautiful, it was important and many attendees expressed the wish that it had been available when their family member had been living with dementia.

*“I think that the launch, both of them I think what stood out to me was you know, the positive feedback around people’s experience... We got a lot of positive feedback, one that the campaign itself was a beautiful campaign. I heard like personal stories about you know, like care partners, family members, I heard: ‘I wish that this had have been around when my mother was living with dementia.’ So, I did hear a lot of that feedback around ‘I wish’ or that ‘this is really important.’” [KIID5]*

## Evaluation Objective V: Describe the Ways in Which the Faces of Dementia Campaign Affected Viewers/ Audiences (Launch Events, Community Exhibits)

### Affect of the Campaign on Viewers/ Audiences

Launch event and community exhibit attendees were asked rate the extent to which they agreed or disagreed with various statements about the affect that the campaign had on them (5-point scale: strongly disagree, disagree, neutral, agree, strongly agree). As there were no significant differences in ratings between the intimate and public launch events, results are presented across both of the surveys for these events. The majority of launch event and community exhibits attendees (>84%) agreed that they have a greater understanding of what it is like to live with dementia (86%) and the stigma associated with dementia (86%), intended to use what they learned in the campaign in their interactions with persons living with dementia (91%) and to make their community more dementia friendly (84%), and are more aware of this dementia friendly community project (91%). Fewer, but still the majority of respondents (72%) agreed that they learned new things about how to make their community dementia friendly (Table 31).

**Table 31: Launch event\* and community exhibit attendee’s level of agreement\*\* with various impacts associated with the Faces of Dementia campaign**

<b>Impacts</b>	<b>Event</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>
I have a greater understanding of what it is like to live with dementia as a result of the campaign.	Launch events (N = 106)	0	9.4% (10)	88.7% (94)
	Community Exhibits (N = 46)	2.2% (1)	17.4% (8)	80.4% (37)
	<b>Total (N = 152)</b>	<b>0.7% (1)</b>	<b>11.8% (18)</b>	<b>86.2% (131)</b>
I have a greater understanding of the stigma (negative impacts) associated with living with dementia.	Launch events (N = 106)	2.8% (3)	9.4% (10)	87.7% (93)
	Community Exhibit (N = 46)	2.2% (1)	15.2% (7)	80.4% (37)
	<b>Total (N = 152)</b>	<b>2.6% (4)</b>	<b>11.2% (17)</b>	<b>85.5% (130)</b>
I learned new things about how to make my community more dementia friendly.	Launch events (N = 106)	6.6% (7)	17.9% (19)	67.9% (72)
	Community Exhibit (N = 46)	4.3% (2)	13.0% (6)	82.6% (38)
	<b>Total (N = 153)</b>	<b>5.9% (9)</b>	<b>16.4% (25)</b>	<b>72.4% (110)</b>
I intend to use some of the things I learned in this campaign to make sure my interactions with persons living with dementia are welcoming and friendly.	Launch events (N = 106)	1.9% (2)	3.8% (4)	93.4% (99)
	Community Exhibit (N = 46)	2.2% (1)	10.9% (5)	87.0% (40)
	<b>Total (N = 152)</b>	<b>2.0% (3)</b>	<b>5.9% (9)</b>	<b>91.4% (139)</b>

<b>Impacts</b>	<b>Event</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>
I intend to use some of the things I learned in this campaign to make my community dementia friendly.	Launch events (N = 106)	2.8% (3)	10.4% (11)	85.8% (91)
	Community Exhibit (N = 46)	0	19.6% (9)	80.4% (37)
	<b>Total (N = 152)</b>	<b>2.0% (3)</b>	<b>13.2% (10)</b>	<b>84.2% (128)</b>
I am now more aware of the Empowering Dementia Friendly Communities project in Hamilton and Haldimand.	Launch events (N = 106)	5.7% (6)	5.7% (6)	88.7% (94)
	Community Exhibit (N = 46)	2.2% (1)	2.2% (1)	95.7% (44)
	<b>Total (N = 152)</b>	<b>4.6% (7)</b>	<b>4.6% (7)</b>	<b>90.8% (138)</b>

Note: Percentages may not sum to 100% due to missing data.

\*As there were no significant differences in ratings between the intimate and public launch events, results are presented across both of the surveys for these events.

\*\*As rated on a 5-point scale: strongly disagree, disagree, neutral, agree, and strongly agree. Disagree = sum of strongly disagree and disagree ratings; Agree = sum of strongly agree and agree ratings

Some of the comments made by survey respondents about their satisfaction with the campaign and launch event highlighted the impacts associated with the campaign as related to increasing awareness of the experience of living with dementia, and providing hope to those diagnosed with dementia.

*“Profiles emphasized the capabilities of individuals living with dementia, not at all expected. Opened up a whole new world for those not familiar with dementia and how much more is needed to be known. Gutsy.” [Person living with dementia]*

*“I found the launch event to be informative but also tugged at the heartstrings in just the right way.” [All others]*

*The participants stories were very impactful. Sharing these stories with others who are afraid of the stigma around Alzheimer's will be so helpful. [Care Partner]*

*“I realized that I did have some preconceived notions about dementia, and I am happy to have that corrected. While the subject is sad, there were so many moments of joy. Seeing and learning more about dementia and the people who have that diagnosis, and hearing their stories, goes such a long way in understanding and being able to remember going forward in life.” [All others]*

*“An insightful and educating picture of the lives of the participants who are dealing with dementia.” [All others]*

*“It was a wonderful event, with so many personal perspectives and hope. My mother has just been diagnosed with Alzheimer's and is terrified. Participating in the event provided an injection of much-needed hope.” [All others]*

*“You have taken steps so that society can begin to recognize, understand and welcome persons with living with a dementia diagnosis AS THEY ARE...persons of value. One shouldn't have to be brave - they should be accepted without question. You have 'opened the doors of hope' so that this can be possible.” [Public launch event]*

### Impact on Community Attitudes About Dementia

Table 32 presents the results of the Dementia Community Attitudes Scale as completed by launch event and community exhibit attendees. Each item on the scale is scored from 1 (completely incorrect) to 10 (completely correct); higher scores reflect more positive community attitudes towards dementia. Individual items mean scores ranged from 7.1 (main symptom of dementia is not always memory loss) to 9.3 (People with dementia can contribute substantially to their community). Mean scores were highest (>9) for those items related to the key themes in the campaign such as the ability of persons living with dementia to contribute substantially to their community (9.3), importance of maintaining independence (9.0), the right of people living with dementia to be involved in supported decision-making about their future (9.2) and having the potential to improve the lives of people living with dementia (9.0). The total scale mean score (8.6) reflects an overall positive community attitude towards dementia.

**Table 32: Results of the Community Dementia Attitudes Scale as completed by launch event and community exhibit attendees**

Scale items	Average (±) Range Median			
	Intimate Launch (N =22)	Public Launch (N = 84)	Community Exhibits (N = 46)	Total (N = 152)
I have a good understanding of what it would be like to live with dementia	7.2 (2.3) 1 – 10 7	7.3 (2.1) 1 – 10 7	7.8 (2.0) 3 – 10 8.0	<b>7.4 (2.1)</b> <b>1 – 10</b> <b>8.0</b>
The main symptom of dementia is always memory loss.*	7.4 (2.4) 3 – 10 7	7.1 (2.9) 1 – 10 8	7.2 (2.7) 1 – 10 8.0	<b>7.1 (2.8)</b> <b>1 – 10</b> <b>8.0</b>
Medication is the only treatment that can reduce symptoms related to dementia.*	9.0 (1.5) 5 – 10 10.0	8.6 (2.2) 1 – 10 10	8.6 (1.9) 3 – 10 9.0	<b>8.6 (2.0)</b> <b>1 – 10</b> <b>10</b>
There is a range of strategies that can help people with dementia in their everyday lives.	9.2 (1.7) 3 – 10 10	9.1 (1.5) 4 – 10 10	9.0 (1.6) 3 – 10 9.0	<b>9.1 (1.6)</b> <b>3 – 10</b> <b>10</b>
I have the potential to improve the lives of people living with dementia.	9.2 (2.1) 2 – 10 10	9.1 (1.4) 5 – 10 10	8.7 (1.7) 4 – 10 10.0	<b>9.0 (1.6)</b> <b>2 – 10</b> <b>10</b>

Scale items	Average (±) Range Median			
	Intimate Launch (N =22)	Public Launch (N = 84)	Community Exhibits (N = 46)	Total (N = 152)
People with dementia can contribute substantially to their community.	9.5 (1.6) 3 – 10 10	9.5 (1.1) 5 – 10 10	8.8 (1.6) 3 -10 10.0	<b>9.3 (1.4)</b> <b>3 – 10</b> <b>9.3</b>
Maintaining independence is one way to help a person living with dementia.	9.0 (1.4) 5 – 10 10	9.2 (1.3) 3 – 10 10	8.6 (1.7) 4 – 10 10.0	<b>9.0 (1.5)</b> <b>3 – 10</b> <b>10</b>
People with dementia need assistance all of the time.*	9.3 (1.3) 6 – 10 10	8.4 (2.1) 1 – 10 9	7.5 (2.8) 1 - 10 8.0	<b>8.2 (2.3)</b> <b>1 – 10</b> <b>9</b>
People with dementia have the right to be involved in supported decision-making about their future.	9.3 (2.1) 1 – 10 10	9.5 (.96) 5 – 10 10	8.7 (2.0) 2 – 10 10.0	<b>9.2 (1.6)</b> <b>1 – 10</b> <b>10</b>
For people with symptoms of dementia, a diagnosis can inform planning for the future.	8.9 (2.3) 2 – 10 10	9.0 (1.5) 3 – 10 10	9.3 (1.5) 1 – 10 10	<b>9.0 (1.6)</b> <b>1 – 10</b> <b>10</b>
<b>Total Scale Score</b>	8.8 (1.2) 4.7 – 9.9 9.1	8.7 (.93) 5.1 – 10 9	8.4 (1.2) 5.6 – 10.0 8.7	<b>8.6 (1.0)</b> <b>4.7 – 10</b> <b>8.9</b>

\*These items are reverse scored as statements designated as incorrect.

### Impacts Associated with the Faces of Dementia Campaign Community Exhibits

Campaign participants and key informants identified a number of impacts associated with the Faces of Dementia campaign community exhibits. These impacts are summarized in Table 33 and described below in more detail with illustrative quotes.

**Table 33: Impacts associated with the Faces of Dementia Campaign community exhibits as identified by interviewed campaign participants and key informants in Winter 2023**

<p><b><i>Impacts associated with the campaign/ community exhibits</i></b></p> <ul style="list-style-type: none"> <li>• Increased sense of hope among persons living with dementia</li> <li>• Increased awareness of the capabilities of persons living with dementia</li> <li>• Reduced stigma and more inclusive communities</li> <li>• Increased understanding of dementia and the experience of living with dementia</li> </ul>
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- Increased recognition of the need to support the autonomy among persons living with dementia\*
- Increased access to dementia related community services\*

\*Identified by a single key informant.

**Increased sense of hope among persons living with dementia:** The campaign exhibits were perceived as having brought an increased sense of hope to others with lived experience, particularly as related to the increased realization that they are not alone.

*“So I think people, there are many situations where people living with dementia got a message of hope, received a message that this isn’t the end of the world that they and their family members often think it is. And that there are lots of other people out there living with this disease and that I am not alone.” [KIID8]*

*“So for the people living with dementia I think that campaign... provides validation in knowing that the person living with dementia, if they see the film they can recognize that they are really truly not alone.” [KIID9]*

**Increased awareness of the capabilities of persons living with dementia:** It was perceived that people now have a more accurate perception of the abilities of persons living with dementia and recognize that they are capable of doing more than what they may have assumed.

*“Our family’s perspectives have changed and how we were sharing what we were doing. And so, our family members react differently... In a positive way, we’re more capable than what they may have thought we were capable of.” [CPID2]*

*“I think it impacts everybody. Having the information, knowing about the campaign, seeing the campaign, reading the newsletters, participating in the workshops, it all helps to change people’s perspective, like it did mine...understanding more about the person with dementia having so much more agency than what I really gave them credit for. So, I guess one of the big lessons for me, and I keep having to learn this over and over, is not to underestimate people.” [KIID3]*

**Reduced stigma and more inclusive communities:** Key informants noted that the campaign has made a significant start to reducing the stigma associated with dementia that will make the community inclusive for persons living with dementia. In particular, there was hope that conversations had about dementia at the campaign and community exhibits launches made a significant dent in reducing stigma.

*“I think they’ll benefit from hopefully a reduction in stigma around dementia. Hopefully they’ll benefit from people who, service providers, the broader community, their changed perceptions and attitudes around dementia will lead to more inclusive environments, hopefully socially and physical environments, and real considerations around the expressed needs of people who are living with dementia to be actively involved. I think that people living with dementia will benefit from those open conversations about*

*dementia, so that maybe it would be my hope that, that dementia is not as scary, its not as invisible as it has been.” [KIID5]*

*“So, for the people living with dementia I think that campaign again has the most potential to really reduce stigma.” [KIID9]*

*“One of the things that happened [at one of the community exhibit launch events] was there was a woman crying and I went up to her and I said: ‘Are you all right ma’am, is there anything I can do for you? And she said” ‘I’m crying because I know that I can show this to my husband and he will understand that its not the stigma that he thinks.’ So, she has had a husband who was diagnosed with dementia but didn’t want anybody to know, so she said: ‘Finally I have a tool that I can show him so that he will get over his own issues of shame or stigma that he is experiencing as a person living with dementia.’ That was powerful.” [KIID8]*

***Increased understanding of dementia and the experience of living with dementia:*** The campaign was credited with assisting audiences to have a better informed understanding of dementia and what it is like to live with it. It was noted that there were significant learnings about dementia even among professionals that work with persons living with dementia.

*“I’ve benefited from the campaign in many ways. I have learned a lot about dementia and what people living with dementia experience. I have been able to develop like new relationships and partnerships and I’ve benefited and my family has benefited from being involved and I’ve benefited from being able to make a contribution for a positive change. ... My grandmother lived with dementia and I would say that being part of this campaign, so my family was involved in the project in many ways as well, and they reflected and learned from new understanding about dementia and as we’re all aging that’s going to be really important... I have lots of conversations about it personally in my family. So, they benefited from those new perspectives.” [KIID5]*

*“I think any one person, any one person that’s heard of us is going to be changed.” [CPID2]*

*“The key benefit is that people in the community learn more [about dementia] and hopefully take an interest and take the education so that they can be helpful.” [CPID1]*

*“I think [organizations] had some staff who didn’t see the capacity of people as well or as clearly as they should have in people living with dementia. So, I think the stories and hearing about people has really changed some of their attitudes.” [KIID8]*

***Increased recognition of the need to support the autonomy among persons living with dementia:*** For one key informant the campaign served to remind her to provide opportunities for persons living with dementia to contribute autonomously in meaningful ways.

*“Now from what I have learned, the biggest impact for me is to seek my clients out more... I work with people who are further along in their disease process than we are*

*seeing on the leadership team, but still, I've learned now important it is for me to still recognize them as contributing members and look for opportunities that they can be in charge of something or provide input on something. So that's really, I thought I was good at that before, but it just has really become very important to me.” [KIID9]*

**Increased access to dementia related community services:** Recent increases in access to dementia related community services was attributed to the campaign. The example was provided of an online support group lead by two campaign participants that is well attended and provides participants an opportunity to voice their experiences and provide input into the direction of the service; this approach to service provision was directly influenced by the campaign.

*“I know that in my own organization we've attracted more people with early stages of the disease to our services in the last year and I think part of it is this campaign, but also we have a peer led support group that we had started before this campaign that is led by two of the leaders [campaign participants] and that's going gang busters now. Its an online support group and they have up to 20 people participating every week. So creating opportunities for people living with the disease to have a place where they can meet and share and have a voice and influence direction, I think is really one of the key impacts that this campaign has had.” [KIID8]*

## Conclusions

Based on the findings of this evaluation, the following conclusions can be made:

- The data collected from the various sources of information for this evaluation provide both quantitative and qualitative evidence that the Faces of Dementia campaign was well received by campaign participants, project staff, partners, and attendees of the campaign launch events and community exhibits, who mostly represented the general public. The campaign was valued for its:
  - co-design with persons living with dementia, with its emphasis on focusing on the visions and needs of the campaign participants;
  - clear key messaging that tackles misconceptions and stigma about dementia by highlighting that people living with dementia are still ‘able’ and active and contributing members of their communities;
  - diverse representation;
  - visual appeal;
  - products (video, posters) that generate feelings of empowerment, hope, and inspiration; and,
  - potential to increase awareness about the capabilities of persons living with dementia, and reduce stigma and social isolation
- Key informants (campaign participants, project staff and partners) identified a number of important impacts associated with the campaign. Most significantly, campaign participants experienced enhanced well-being through their involvement with the campaign, which they described as providing them encouragement, support, and

confidence to reengage and be active in their community, reducing their social isolation with the formation of new friendships and activities, and empowering them to engage in other advocacy-related activities. For participants, their involvement in the campaign was perceived as a positive experience. Other key informants described/ observed impacts related to increased awareness of the experience of living with dementia and capabilities of persons living with dementia, reduced stigma as people become more open to acknowledging dementia and remaining active, and increased interest from other communities in creating dementia friendly communities. The launch activities (campaign and community exhibits) provided a significant opportunity to not only promote the campaign itself but to have meaningful conversations about the experience of living with dementia and how this can be improved with dementia friendly communities; these events also resulted in the formation of new relationships with individuals and organizations interested in being involved in future project activities and connected members of the general public with dementia related community services (e.g., Alzheimer Society). Considering the visions that participants had for the campaign related to awareness raising, realistic portrayal of what it is like to live with dementia and to reduce stigma, along with the goals of the Empowering Friendly Dementia Community Hamilton, Haldimand, it can be concluded that the campaign was successful in meeting these objectives. It is important to note that while the campaign had some significant outcomes, the potential for even greater impact may have been realized had the campaign been developed, as planned, in Year 1 of this project with three years in which to promote and grow the campaign. Although the COVID-19 pandemic was a significant challenge for this project, strategies implemented for managing pandemic restrictions (e.g., use of videoconferencing for gathering) proved to be successful as possible under these conditions.

- Key to the success of the campaign were the promotional activities (paid and earned media attention, social media) that brought people to the Faces of Dementia website, launch events, and community exhibits. The various promotional strategies demonstrated that the campaign reached over 16 million people, locally, provincially, nationally, and internationally. The campaign participants were instrumental in promoting campaign, reflecting the value they placed the campaign and its potential to affect community change. Worth noting is the front-page feature article in the Hamilton Spectator on the Faces of Dementia campaign featuring one of the participants.
- The campaign garnered a lot of attention from other communities interested in creating dementia friendly communities and creating a similar awareness raising campaign. This evaluation has identified key lessons learned in the development and promotion of the campaign that can serve to inform future work in this area not only in the Hamilton and Haldimand regions but also other jurisdictions. Key lessons specific to authentic involvement and co-design by persons living with dementia, the need for dedicated project staff to support the work, sufficient funding and time, and community relationships to support recruitment will help to ensure the success of similar projects.
- A key message heard in the evaluation was that this campaign was a good ‘start’; there are ideas, plans, and a desire to continue to grow the campaign by increasing the diversity

represented with the inclusion of participants at different disease stages, of different ages and from different ethnocultural groups and creating campaign materials in different languages. The success of this current campaign and lessons learned from this campaign will place future activities in a good position to move forward the project's agenda to affect community change in a meaningful and impactful way.

***Limitations:*** There are a number of limitations associated with the evaluation of the Faces of Dementia campaign. Campaign participants and project key informants were significant sources of information for the evaluation. While the general public, as attendees of the launch events and community exhibits did provide some feedback on their perceptions of the campaign and potential impacts/ outcomes, more input from the Hamilton and Haldimand communities would have provided greater insights into the impacts of the campaign at a community level. There were no feedback submissions on the Faces of Dementia website, likely because of the placement of the feedback request at the bottom of the webpage, where it may not have been viewed by those who clicked on links to other sources of information. The request for feedback respondents' name and contact information may also have discouraged some people from providing feedback. The campaign had roughly 10 months (May 2022 – February 2023) of promotion, which may not have been sufficient time to demonstrate quantifiable community level impacts; this may have been possible if the campaign had launched earlier so that there were more opportunities to collect data from the community. In this evaluation, we used the Dementia Community Attitudes Scale, a standardized tool that measures community attitudes about dementia. In this evaluation it was used to assess the attitudes of attendees of the campaign launch events and community exhibits, demonstrating, overall, positive attitudes about dementia. However, it is not possible to determine the direct effect of the campaign on these attitudes. Future campaign initiatives should attempt to employ pre-post methods to measure change in attitudes due to campaign activities.

## List of Appendices

Appendix A: Faces of Dementia Program Logic Model

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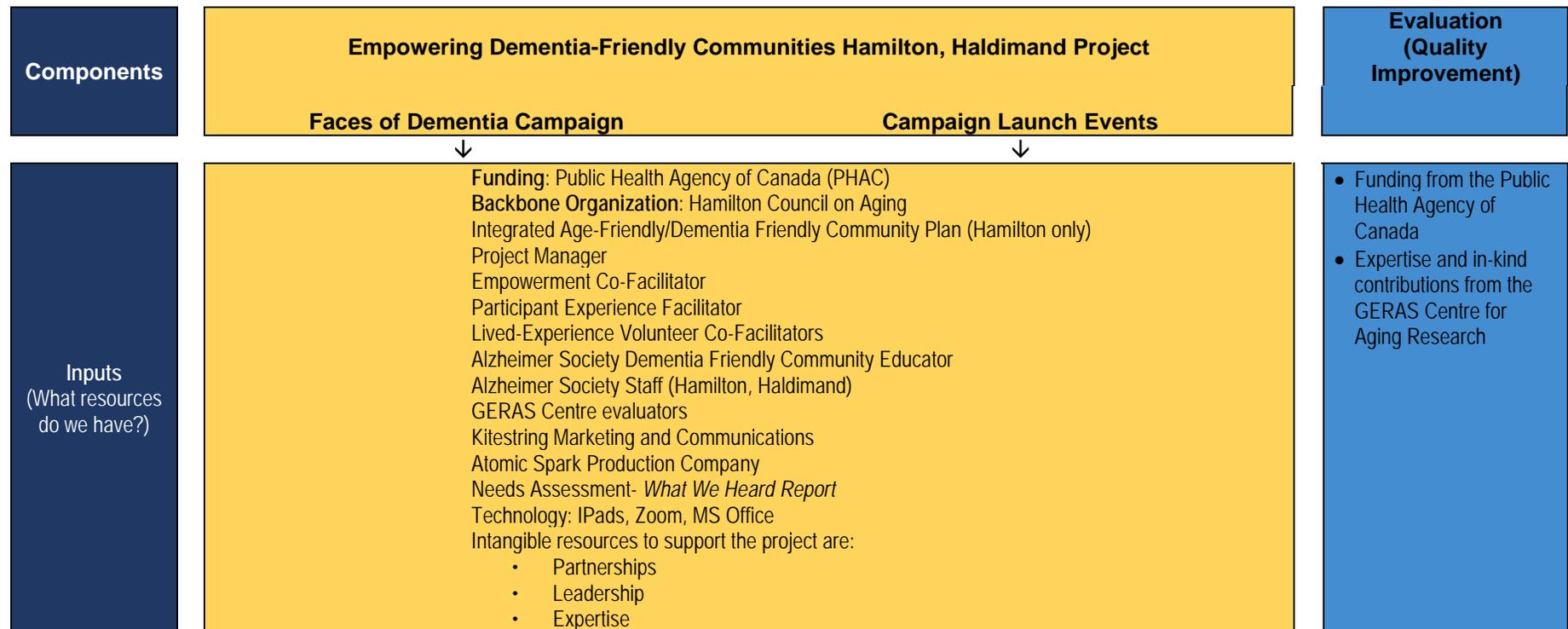
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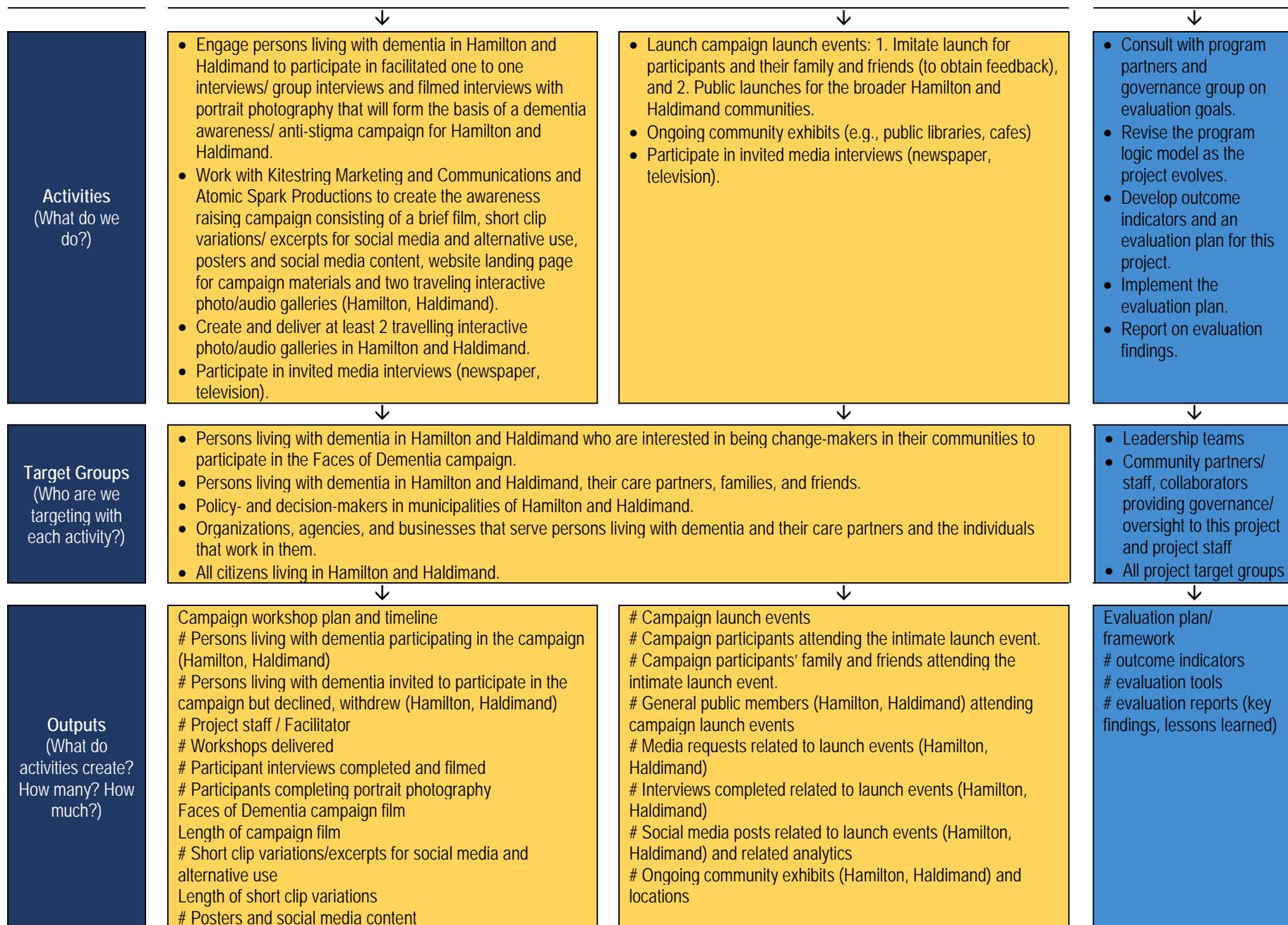
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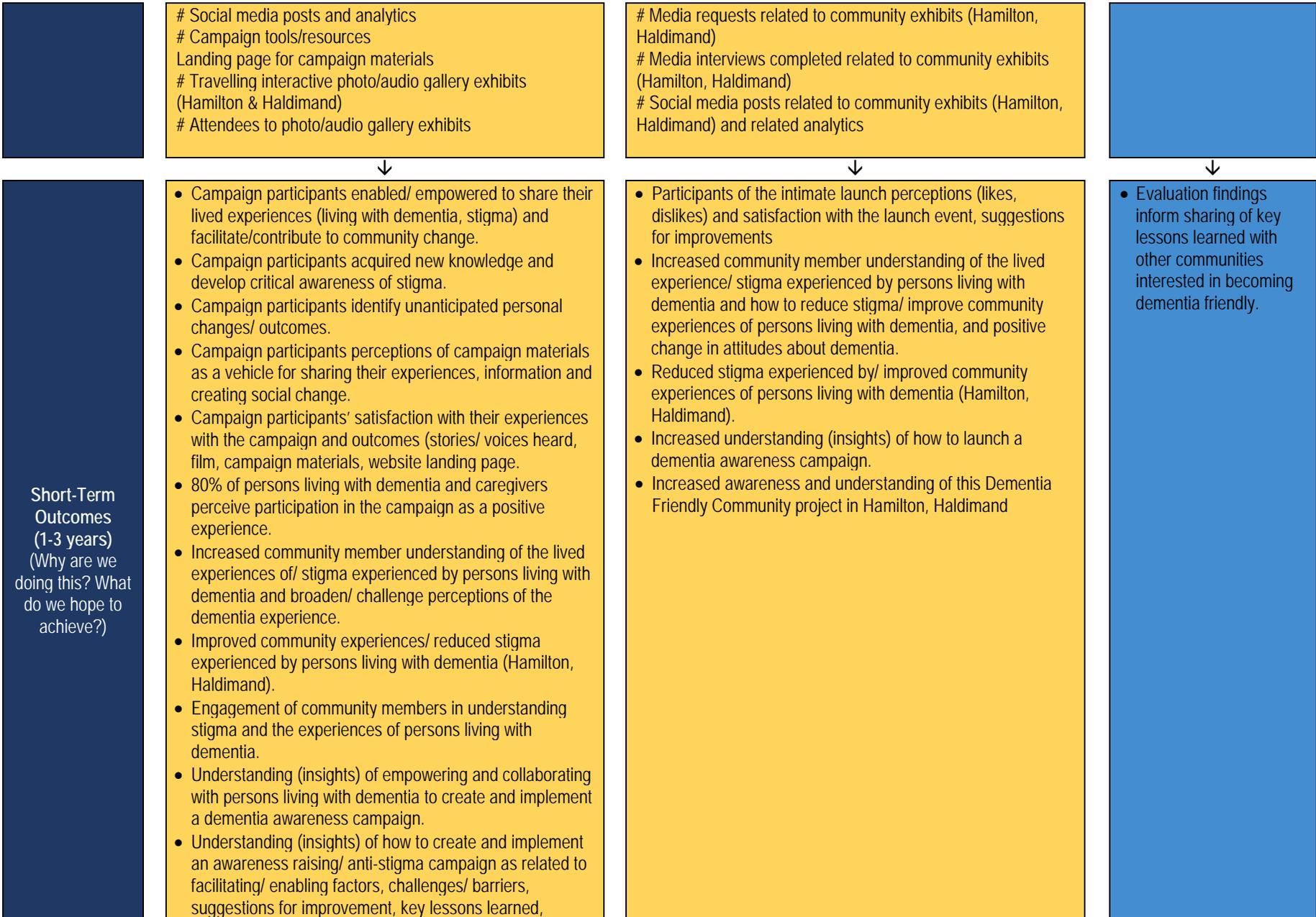
## Appendix A: Faces of Dementia Campaign Program Logic Model

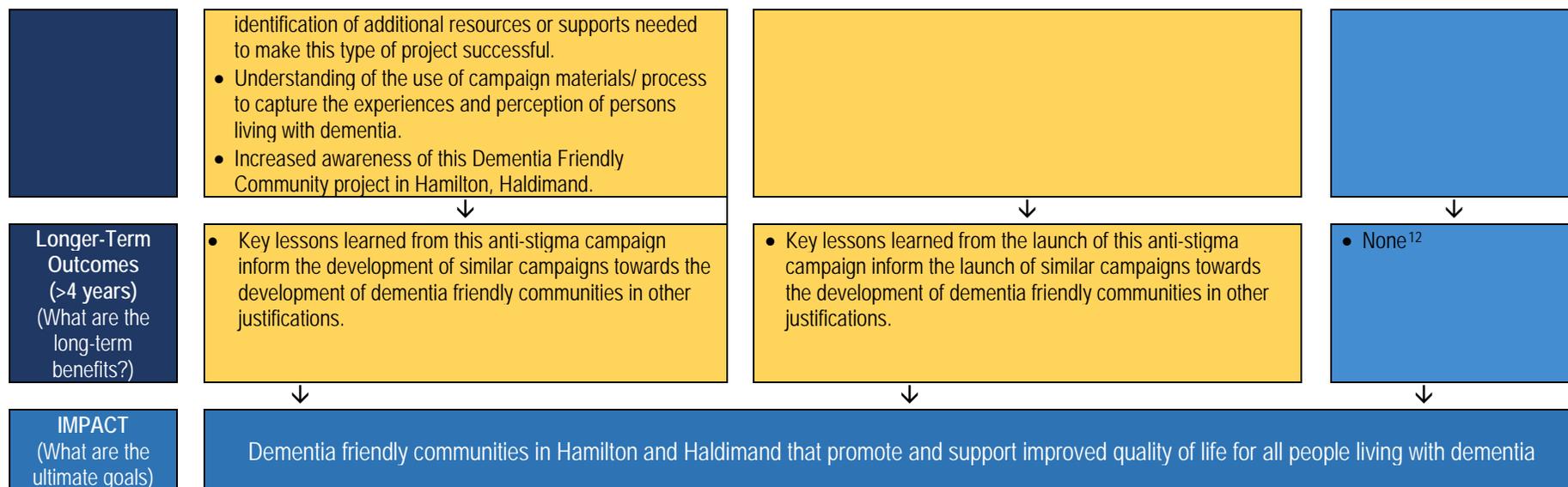
	<b>Empowering Dementia-Friendly Communities Hamilton, Haldimand Faces of Dementia Campaign and Launch Event</b>	
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The Faces of Dementia Campaign is a public awareness campaign aimed at facilitating the sharing of the voices and lived experiences of persons living with dementia with the ultimate goal of reducing stigma and creating inclusive, dementia friendly communities. In this campaign, persons living with dementia will participate in group workshops and one-to-one facilitated interviews to share their experiences with living with dementia. These interviews will form the basis of a brief film (3 – 5 minutes in length), which along with the portrait photography and participant stories will be widely disseminated via posters, social media, and interactive gallery exhibits in Hamilton and Haldimand. The Faces of Dementia Campaign will be launched in two stages, one intimate launch event for the participants and their families and friends, project volunteers/ staff, and a second public launch event held with the broader community at large.









<sup>12</sup> At this point in time there are no plans for ongoing evaluation beyond the timeline of this project as funded by the Public Health Agency of Canada.

## Appendix B: Questions Used to Guide Reflective Journaling



Empowering Dementia-Friendly Communities  
Hamilton, Haldimand

Faces of Dementia Campaign and Launch  
Evaluation: Reflective Journaling



Reflective journaling as an evaluation tool provides a good opportunity to document the development and implementation of a new program and share new learnings and phenomena of interest as they occur from the perspective of those involved in program development. In this instance, reflective journaling can provide insights into the process used with persons living with dementia to develop a dementia awareness campaign.

The following questions can be used to guide journaling – the questions are a guide and do not all necessarily need to be answered. It is suggested that journaling be completed soon after each of the six workshops with campaign participants and after any meetings or discussions which result in decisions or changes to the implementation process.

Critical reflective inquiry, consists of three phases: descriptive, reflective and critical/emancipatory phases.<sup>13</sup>

- **Descriptive phase:** Select a situation or discussion of relevance to reflect on – describe the situation/ discussion as well as your actions, thoughts and feelings about it.
- **Reflective/ Interpretation phase:** Reflect and interpret the situation; consider reflecting upon the situation against your personal beliefs, assumptions/ expectations, or knowledge.
- **Critical/ emancipatory (change) phase:** Focus what can be done to correct or change ineffective actions (conclude what you can learn from the situation and how it can be applied next time).

This reflective process is also referred to as the three W's to writing reflectively: *What, So What* and *What next*.<sup>14</sup>

Consider these questions as you journal:

**Description (What):** Recall a relevant situation/ discussion and describe it.

- What happened? What was the challenge or barrier?
- Who was involved?
- How did you feel about this or how did others respond?

**Reflective/ Interpretation (So what?):** Reflect and interpret the situation/ discussion.

- What is most important / interesting / relevant / useful aspect of the event, idea or situation?  
What is the key lesson learned here?
- How can it be explained?

<sup>13</sup> Kim, HS. Critical reflective inquiry for knowledge development in nursing practice. *J Adv Nurs* 1999;29(5):1205-1212. doi: 10.1046/j.1365-2648.1999.01005.x.

<sup>14</sup> Journey. How to Write Reflectively. <https://journey.cloud/reflective-journal/>

- How is it similar to/different from other situations/issues or from what you expected or know?

**Change (What's next?):** Conclude what you can learn from the event and how you can apply it next time.

- What have I learned?
- How can this situation be changed to improve things going forward or prevent problems moving forward?
- Are there any resources or supports, or sensitivities needed to ensure next steps are successful?

## Appendix C: Guide for the Interviews with Campaign Participants



### Empowering Dementia Friendly Communities Hamilton, Haldimand



### Guide for the Interviews with Faces of Dementia Campaign Participants

**Purpose:** The purpose of this interview is to gather more in-depth information on campaign participant's perceptions of the campaign and potential outcomes.

---

- 1) Recently you had the opportunity to see the Faces of Dementia - the film and individual portraits. What did you think of these things?
  - a. Overall, were you satisfied with how they turned out?
  - b. Was there anything in particular that you like about the campaign?
  - c. Was there anything that you didn't like?
  - d. Did you receive any feedback about it from your family or friends?
- 2) Do you have a chance to review some of campaign materials (videos, posters, portraits) and the website landing? If so, what did you think about these?
  - a. Was there anything in particular that you like about these things?
  - b. Was there anything that you didn't like?
- 3) What were some of the key messages in campaign that you wanted to share with the community about living with dementia, or that you think are important?
  - a. Do you think the campaign conveyed what you wanted to say in the campaign?
  - b. Do you think the campaign was effective in getting those messages across to people?
- 4) In what ways do think the campaign could have been improved?
- 5) We're interested in learning more about the impacts or outcomes of this campaign – the changes that it can potentially bring about in people and the community.
  - a. In what ways have you benefited from participating in this campaign? (Prompts: greater understanding about other people's experiences with dementia, confidence to share your experiences)
  - b. Did you expect that or was that a surprise/ unanticipated?
  - c. In what ways do you think other people living with dementia and their care partners will benefit from this campaign? (Prompts: greater understanding about other people's experiences with dementia, confidence to share their experiences, increased comfort in participating in community living)
  - d. In what ways do you think the community at large will benefit from this campaign? (Prompts: awareness of what it is like to live with dementia and how to improve community living for persons living with dementia).

- 6) One of the goals of this campaign was help people living with dementia to feel more empowered<sup>15</sup>, which involves supporting people living with dementia to:
- feel respected
  - feel open to talk about dementia
  - feel that when they speak, people are listening
  - feel that they are not excluded from things and can be involved in making decisions.
- a. Do you think that the campaign has been able to do this for you?
  - b. Will it help others with dementia to feel this way (feel more empowered)?
  - c. Do you think that the campaign will help others in the community to be respectful of people living dementia, to really listen to them and include them in things and in making decisions?
- 7) Another goal of the campaign, which is also part of supporting people with dementia to feel more empowered, was to help people feel that they could continue to be active in their communities as they have always been and to feel that they could be actively involved in creating change in their communities.
- a. Do you think that the campaign has been able to do this for you?
  - b. Will it help others with dementia to feel this way (feel more empowered)?
  - c. Do you think it will help others in the community, to know that people living with dementia can still continue to be actively involved in their communities?
- 8) Do you have any final or additional comments to make about the Faces of Dementia campaign?

### **Modified version for Interview Participants**

**Purpose:** The purpose of this interview is to learn more about what participants thought of the campaign and their involvement in it.

---

1. Recently you had the opportunity to see the Faces of Dementia - the film and individual portraits. What did you think of these things?
  - a. What did you like about the campaign?
  - b. Was there anything that you didn't like?
  - c. Did you receive any feedback about it from your family or friends?
2. Do you have a chance to look at some of campaign materials (videos, posters, portraits) and the website landing? If so, what did you think about these?
  - a. Was there anything in particular that you like about these things?
  - b. Was there anything that you didn't like?

---

<sup>15</sup> Based on the definition of empowerment proposed by McConnell et al 2019 (doi: 10.1186/s40900-019-0154-2): 'A confidence building process whereby persons 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'.

3. What were some of the key messages in campaign that you wanted to share with the community about living with dementia, or that you think are important?
  - a. Do you think the campaign conveyed what you wanted to say in the campaign?
  - b. Do you think the campaign was effective in getting those messages across to people?
4. In what ways do you think the campaign could have been improved?
5. We're interested in learning more about the impacts or outcomes of this campaign – the changes that it can potentially bring about in people and the community.
  - a. In what ways have you benefited from participating in this campaign?
  - b. In what ways do you think other people living with dementia and their care partners will benefit from this campaign?
  - c. In what ways do you think the community at large will benefit from this campaign?
6. One of the goals of this campaign was to help people living with dementia to feel:
  - respected
  - open to talk about dementia
  - that when they speak, people are listening
  - included and involved in making decisions.
  - a. Do you think that the campaign has been able to do this for you?
  - b. Will it help others with dementia to feel this way?
  - c. Do you think that the campaign will help others in the community to be respectful of people living dementia, to really listen to them and include them in things and in making decisions?
7. Another goal of the campaign was to help people feel that they could continue to be active in their communities and actively involved in creating change in their communities.
  - a. Do you think that the campaign has been able to do this for you?
  - b. Will it help others with dementia to feel this way?
  - c. Do you think it will help others in the community, to know that people living with dementia can still continue to be actively involved in their communities?
8. Do you have any final or additional comments to make about the Faces of Dementia campai

## Appendix D: Survey of Faces of Dementia Campaign Participants



Empowering Dementia Friendly Communities  
Hamilton, Haldimand



### Survey for Faces of Dementia Campaign Participants

Thank you for taking the time to complete this survey! We are interested in learning more about your experience with the Faces of Dementia Campaign.

**Your opinion is important to us!** Survey completion is anonymous – you will not be asked to provide your name.

*Instructions:* To move forward in the survey, please click on the “next” button. To go back to review previous questions, click on the “back” button. To submit your survey once completed, click on the “Submit” button. To leave this survey without saving your responses, please click on the "Exit" button in the right-hand corner.

#### 1. Overall, how satisfied were you with your experience in the Faces of Dementia campaign?

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
<input type="checkbox"/>				

#### 2. Do you agree or disagree with the following statements about your involvement in the Faces of Dementia campaign?

	Disagree	Neutral	Agree
I felt comfortable sharing my experiences with dementia for this project.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel better able to share my experiences with dementia as a result of my involvement in this project.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Disagree	Neutral	Agree
I learned new things about dementia as a result of participating in this campaign.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am more aware of the stigma that can be associated with dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe my involvement in the Faces of Dementia campaign will help to make changes in how my community thinks about dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe the Faces of Dementia campaign will be effective in increasing community awareness about what it is like to live with dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My participation in the Faces of Dementia campaign was a positive experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. How would you rate the extent to which your community is currently dementia friendly?**

Not at all dementia friendly	A little bit	Somewhat	Very	Extremely dementia friendly
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4. This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?**

Not at all important	A little bit	Somewhat	Very	Extremely important
<input type="checkbox"/>				

You have come to the end of the survey. Thank you for sharing your opinions with us. Please click on the “Submit” button below to submit your responses.

## Appendix E: Campaign Participant Survey Invitation and Reminders

### Subject Line: Faces of Dementia Campaign: Feedback Request

Hello!

I hope this message finds you well! You recently participated in the Faces of Dementia campaign as part of the Empowering Dementia Friendly Communities in Hamilton and Haldimand. The GERAS Centre for Aging Research has partnered with this initiative to evaluate the Dementia Friendly Communities project.

We are interested in learning about your experiences in the Faces of Dementia campaign. **We invite you to complete an online survey to share your experiences with us. Your opinion is important to us!**

#### The survey is available at:

<https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

#### The deadline for completing this survey is...

This survey should take less than 10 minutes to complete. Survey completion is anonymous; you will not be asked to identify yourself. Survey completion is voluntary. If you choose not to complete the survey, simply delete this message and delete reminder emails when you receive them. All of the information that you provide on this survey will remain confidential.

Please feel free to contact me if you have any questions about this survey.

Stay safe and be well.

Sincerely,

### Subject Line: Faces of Dementia Campaign Survey Reminder

Last week an invitation was sent to you to provide feedback on your experiences with the Faces of Dementia campaign. If you have already completed the survey, thank you. If you have not, I invite you complete a survey.

#### The survey is available at:

<https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

This survey should less than 10 minutes to complete. **The dead-line for completing the survey is...**

If you have any questions, please do hesitate to me.

Thank you in advance for your time and consideration.

Sincerely,

### Subject Line: Faces of Dementia Campaign Survey Last Call!

**LAST CALL! Tomorrow is the deadline to complete the Faces of Dementia campaign survey.**

**If you have already completed the survey, thank you. If you have not, I invite you to complete a survey.**

**The survey is available at:**

<https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

Thank you.

# Appendix F: Survey of Campaign Launch Event and Community Exhibit Audiences



**Empowering Dementia Friendly Communities  
Hamilton, Haldimand**



## Launch Event and Exhibit Survey

Thank you for taking the time to complete this survey! We interested in getting your feedback on the Empowering Dementia Friendly Communities Hamilton, Haldimand *Faces of Dementia* Campaign.

**Your opinion is important to us!** Survey completion is anonymous – you will not be asked to provide your name.

*Instructions:* To move forward in the survey, please click on the “next” button. To go back to review previous questions, click on the “back” button. To submit your survey once completed, click on the “Submit” button. To leave this survey without saving your responses, please click on the "Exit" button in the right hand corner.

1. In which community did you attend the Faces of Dementia exhibit? (Community exhibit survey only)

- Hamilton and area
- Haldimand and area
- Other, please specify:

2. How did you learn about the campaign launch event? (Launch event survey only)

- Direct mail from the Hamilton Council on Aging
- Social Media
- Newspaper
- Family/ Friends/ Colleagues
- Other, please specify:

3. Overall, how satisfied were you with the Faces of Dementia campaign?

	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="checkbox"/>				

Do you have any comments to make about this?

4. How satisfied were you with the Faces of Dementia virtual launch event? [Not included in the exhibit survey]

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<input type="checkbox"/>				

Do you have any comments to make about the virtual launch event?

5. Do you agree or disagree with the following statements about the affect that the Faces of Dementia campaign had on you?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have a greater understanding of what it is like to live with dementia as a result of the campaign.	<input type="checkbox"/>				
I have a greater understanding of the stigma (negative impacts) associated with living with dementia.	<input type="checkbox"/>				
I learned new things about how to make my community more dementia friendly.	<input type="checkbox"/>				
I intend to use some of the things I learned in this campaign to make sure my interactions with persons living with dementia are welcoming and friendly.	<input type="checkbox"/>				
I intend to use some of the things I learned in this campaign to make my community dementia friendly.	<input type="checkbox"/>				
I am now more aware of the Empowering Dementia Friendly Communities project in Hamilton and Haldimand.	<input type="checkbox"/>				

6. Please read each of the statements below and the select the number that best reflects how correct you think each statement is. 1 = completely incorrect; 10 = completely correct.

I have a good understanding of what it would be like to live with dementia	1	2	3	4	5	6	7	8	9	10
--	---	---	---	---	---	---	---	---	---	----

The main symptom of dementia is always memory loss.*	1	2	3	4	5	6	7	8	9	10
Medication is the only treatment that can reduce symptoms related to dementia.*	1	2	3	4	5	6	7	8	9	10
There is a range of strategies that can help people with dementia in their everyday lives.	1	2	3	4	5	6	7	8	9	10
I have the potential to improve the lives of people living with dementia.	1	2	3	4	5	6	7	8	9	10
People with dementia can contribute substantially to their community.	1	2	3	4	5	6	7	8	9	10
Maintaining independence is one way to help a person living with dementia.	1	2	3	4	5	6	7	8	9	10
People with dementia need assistance all of the time.*	1	2	3	4	5	6	7	8	9	10
People with dementia have the right to be involved in supported decision-making about their future.	1	2	3	4	5	6	7	8	9	10
For people with symptoms of dementia, a diagnosis can inform planning for the future.	1	2	3	4	5	6	7	8	9	10

\*These items are reverse scored as statements designated as incorrect.

7. How would you rate the extent to which your community is currently dementia friendly?

Not at all dementia friendly	A little bit	Somewhat	Very	Extremely dementia friendly
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?

Not at all important	A little bit	Somewhat	Very	Extremely important
<input type="checkbox"/>				

9. Do you have any final comments you would like to make about the Faces of Dementia Campaign or the launch event?

### Demographic Information

The following demographic information will be used to describe the group of individuals that attended the Faces of Dementia launch event and completed this survey.

10. In which community do you live? (Launch Event survey only)

- Hamilton and area
- Haldimand and area
- Other, please specify: \_\_\_\_\_

11. Please identify one group below that best describes you

- Persons living with dementia
- Care partners of a person living with dementia
- Family members or friends of a person living with dementia
- Library/ recreation/ arts/ museum staff or volunteers
- Businesses
- Faith groups
- Media
- Elected officials
- Policy makers
- Funding organizations/ philanthropy
- Health care providers/ health system workers
- Community services
- General public (community at large)
- Other, please specify:

12. What is your gender?

- Female
- Male
- Gender fluid/ non-binary/ two spirit
- I prefer not to answer

13. In what year were you born? \_\_\_\_\_

14. Do you identify as Indigenous; that is First Nations (North American Indian), Métis, or Inuit?

- Yes
- No
- I prefer not to answer

15. Do you identify as a member of a visible minority in Canada?

- Yes
- No
- I prefer not to answer

If "Yes", select the options that you identify with.

- Arab
- Black
- Chinese
- Filipino
- Japanese
- Korean
- Latin American
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Southeast Asian (including Vietnamese, Cambodian, Laotian, Thai; etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Another visible minority group – specify: \_\_\_\_\_

You have come to the end of the survey. Thank you for sharing your opinions with us. Please click on the "Submit" button below to submit your responses.

## Appendix G: Campaign Launch Survey Invitations and Reminders

### Subject Line: Faces of Dementia Campaign: Feedback Request

Hello!

I hope this message finds you well! Thank you for attending the virtual Faces of Dementia launch event – we hope you enjoyed it! As you know, the Empowering Dementia Friendly Communities, Hamilton and Haldimand project is aimed supporting community change towards making our communities more dementia friendly.

As part of the evaluation of this project, we are interested in feedback from attendees on the Faces of Dementia campaign. If you did not complete the survey when it was presented during the launch event, **we invite you to complete an online satisfaction survey now. Your opinion is important to us!**

**The survey is available at:** <https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

### The deadline for completing this survey is...

This survey should take about 5-10 minutes to complete. Survey completion is anonymous; you will not be asked to identify yourself. Survey completion is voluntary. If you choose not to complete the survey, simply delete this message and delete reminder emails when you receive them.

Please feel free to contact me if you have any questions about this survey.

Stay safe and be well.

Sincerely,

### Subject Line: Faces of Dementia Campaign Survey Reminder

Last week an invitation was sent to you to provide feedback on the Faces of Dementia Campaign. If you have already completed the survey, thank you. If you have not, I invite you complete a survey.

**The survey is available at:** <https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

This survey should take about 5-10 minutes to complete. **The dead-line for completing the survey is...**

If you have any questions, please do hesitate to contact me.

Thank you in advance for your time and consideration.

### Subject Line: Faces of Dementia Campaign Survey Last Call!

**LAST CALL! Tomorrow is the deadline to complete the Faces of Dementia Campaign satisfaction survey.**

**If you have already completed the survey, thank you. If you have not, I invite you to complete a survey.**

**The survey is available at:** <https://www.surveymonkey.com/r/...>

*(to access the survey simply click on the link above or cut and paste the link into your browsers address bar)*

Thank you,

## Appendix H: Guide for the Interviews with Key Informants



Empowering Dementia Friendly Communities  
Hamilton, Haldimand

Guide for the Interviews with Faces of  
Dementia Campaign Key Informants  
June 2022



**Purpose:** The purpose of this interview is to gather more in-depth information about the Faces of Dementia campaign materials and the development of the campaign from key informants representing project staff, workshop facilitators, potentially a purposeful sample of Stewardship Group members, and service providers.

---

### Faces of Dementia Campaign

We are interested in your insights into the development of the *Faces of Dementia* awareness raising campaign, i.e., campaign materials, film, portraits and process to capture the experiences and perceptions of persons living with dementia.

1. What did you like best about the Faces of Dementia Campaign?
2. Was there anything about the Campaign that you didn't like?
3. From your perspective what are some of the factors that enabled or facilitated the development of the Faces of Dementia campaign?
4. What were some of the challenges experienced in planning, developing, and implementing this campaign (e.g., recruitment of participants, implementation during a pandemic)?
5. 4a. Do you have any suggestions for how these challenges could be overcome?
6. Are there any ways in which this campaign could have been improved? Are there any resources or supports that would have made this campaign more successful?
7. What key lesson did you learn in developing this campaign that could serve as advice to others interested in developing a similar campaign?
8. Were there any specific adaptations that needed to be made in the development phase (e.g., related to COVID-19 pandemic restrictions, specific participant needs, or specific community needs?)
9. Do you have any final or additional comments to make about the Faces of Dementia campaign or its development?



**Empowering Dementia Friendly Communities  
Hamilton, Haldimand**



**Guide for the Interviews with Faces of  
Dementia Campaign Key Informants  
Fall 2022**

**Purpose: Purpose:** The purpose of this interview is to learn more about what people think of the on-going Faces of Dementia campaign and community exhibits.

**Faces of Dementia Campaign / Community Exhibits**

As you know the Faces of Dementia campaign was launched last May and since then has been promoted broadly and most specific in community exhibits, in both Hamilton and Haldimand. We are interested in your insights into the promotion of the *Faces of Dementia* awareness raising campaign, i.e., public promotion, community exhibits.

1. Did you attend the launch events for the community exhibits?
  - 1a. What did you think of the launch events or the community exhibit? Did anything in particular stand out to you about these events/ exhibits?
2. What did you like best about the promotion of the Faces of Dementia campaign?
3. Was there anything about the promotion of the campaign that you didn't like?
4. Were there any challenges experienced in promoting the campaign?
  - 4a. Do you have any suggestions for how these challenges could be overcome?
  - 4b. Were there challenges unique to each community (urban vs rural)?
5. Are there any ways in which the promotion of the campaign could have been improved? Are there any resources or supports that would have made the promotion more successful?
6. What key lesson did you learn in campaign promotion that could serve as advice to others interested in promoting a similar campaign?
7. Are you able to identify any impacts (benefits, outcomes) associated with the Faces of Dementia campaign/ community exhibits to date as related to:
  - In what ways have persons living with dementia benefited from the campaign?
  - In what ways have you, or your organization, benefited from the campaign?
8. Do you have any final or additional comments to make about the Faces of Dementia campaign or its promotion?

## Appendix I: Campaign Implementation Tracking Results

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
<b>Recruitment Efforts</b>	
# PLWD from Hamilton spoken to/ invited to participate in the campaign but who declined	1 <sup>16</sup>
# PLWD from Haldimand spoken to/ invited to participate in the campaign but who declined	2 <sup>17</sup>
# PLWD from Hamilton who agreed to participate but later withdrew	0
# PLWD from Haldimand who agreed to participate but later withdrew	0
Final # PLWD from Hamilton who participated in the campaign	4
% of those invited	80% (4/5)
Final # PLWD from Haldimand who participated in the campaign	1
% of those invited	33.3% (1/3)
Final # PLWD from outside Hamilton/Haldimand who participated in the campaign	2 <sup>18</sup>
Total number of campaign participants	7
<b>Recruitment Strategies: Requests via</b> <ul style="list-style-type: none"> <li>• Hamilton Council on Aging website</li> <li>• Direct Emails</li> <li>• Direct Requests (to members of the leadership teams) <ul style="list-style-type: none"> <li>○ EDFC Newsletter</li> <li>○ Social Media Posts (Facebook, Twitter, Instagram)</li> <li>○ Mass Email Request to share opportunity (EDFC members)</li> <li>○ Mass Email Request to share opportunity (300 community partners)</li> <li>○ Mass Email Request to share opportunity (local retirement communities, long term care, adult day programs)</li> <li>○ Email request to partners with connections people living with dementia and to harder to reach populations (Alzheimer Society, Haldimand partners)</li> <li>○ Targeted Emails/phone calls to community partners re: outreach to diverse communities (South Asian community, Chinese community, Hamilton Public Health, Black community, Hamilton Centre for Civic Inclusion)</li> <li>○ Mass Email to participants from “Portraits of Aging” Event- similar campaign focused on stigma of Ageism</li> <li>○ Cable 14- Free Listings</li> <li>○ Metroland News- Free listings</li> <li>○ Direct Requests to members of the leadership teams</li> <li>○ Direct Requests through community partners to connect with clients</li> </ul> </li> </ul>	

<sup>16</sup> This was a direct request from a member of the Hamilton Lived Experience Leadership Team.

<sup>17</sup> These were direct requests from a member of the Haldimand Lived Experience Leadership Team.

<sup>18</sup> Identified after expansion of the recruitment reach to include Halton region and Six Nations on the Grand River reserve.

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
<b>Faces of Dementia Campaign Implementation</b>	
# Project staff/ facilitators involved Roles: Facilitator: to design and facilitate supportive, accessible and positive experience to campaign participants. Coordinator: to assist the facilitator in these activities.	2
# workshop/ group meetings with participants	2
# individual meetings/ interviews with participants	14 <sup>19</sup>
# participants completing filming	7
# participants completing portrait photography	7
<ul style="list-style-type: none"> <li>Meeting #1 (September 22, 2021): Meet and Greet (4/5 participants attended; meeting occurred prior to two additional participants being recruited)</li> <li>Meeting #2 (December 20, 2021): Debrief and joint draft video screening (4/5 attended - meeting occurred prior to two additional participants being recruited)</li> </ul>	2
# Individual meetings/interviews with participants <ul style="list-style-type: none"> <li>Meeting #1 (7 virtual; October 5 – 14, 2021): Pre-interviews to get to know participants and understand key ideas they might like to touch upon in filmed interview.</li> <li>Meeting #2 (7 in-person; February 10 – March 22, 2022): Filmed interviews and photography session at a location chosen by each participant. Outtakes used in campaign.</li> </ul>	14
<b>Faces of Dementia Campaign Materials</b>	
Campaign Film Length (minutes)	4:39
# short variations/ short individual filmed stories <ul style="list-style-type: none"> <li>6 in English</li> <li>6 with French captions</li> <li>1 audio story</li> </ul>	13
Length of short clip variations	2:14 – 4:09 minutes
# excerpts for social media and alternative use <ul style="list-style-type: none"> <li>7 of the short films were used on social media (1 integrated film and links to 6 individual filmed stories)</li> </ul>	7
# advertising/ promotional posters created <ul style="list-style-type: none"> <li>Press Release in English &amp; French</li> <li>7 printable posters in English</li> <li>7 printable posters in French</li> </ul>	16
# social media content created <ul style="list-style-type: none"> <li>7 Social Media posters in English &amp; 7 in French created</li> </ul>	14

<sup>19</sup> Two interviews per participant (1 pre-interview; 1 filmed interview); this excludes conversations held prior to the interviews to explain the project and recruit participants.

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
Landing page for campaign materials: <a href="https://coahamilton.ca/faces-of-dementia/">https://coahamilton.ca/faces-of-dementia/</a> or <a href="http://www.facesofdementia.ca">www.facesofdementia.ca</a>	
<b>List/ description of other campaign materials and tools created (other than described above)</b> <ul style="list-style-type: none"> <li>• May 12th Launch Event recording posted to the campaign landing page</li> <li>• Resource: Quick tips to start your dementia-friendly journey posted to website</li> <li>• "About" HCoA webpage - linked from campaign page</li> </ul>	
<b>Web-Analytics: # Downloads/ views for all campaign materials</b>	
Campaign video (views) <ul style="list-style-type: none"> <li>• English</li> <li>• French</li> </ul>	591 45
Short videos (views) <ul style="list-style-type: none"> <li>• Meet Phyllis (English; French)</li> </ul>	236 (230; 6)
<ul style="list-style-type: none"> <li>• Meet Debbie (English; French)</li> </ul>	101 (95; 6)
<ul style="list-style-type: none"> <li>• Meet Doug (English; French)</li> </ul>	160 (138;22)
<ul style="list-style-type: none"> <li>• Meet Terry (English; audio and photography)</li> </ul>	28
<ul style="list-style-type: none"> <li>• Meet Andrea (English; French)</li> </ul>	158 (153; 5)
<ul style="list-style-type: none"> <li>• Meet Vera (English; French)</li> </ul>	117 (98; 19)
<ul style="list-style-type: none"> <li>• Meet Ruby (English; French)</li> </ul>	294 (270; 24)
Printable posters (downloads from website; shared with project partners to disseminate)	25
Campaign landing page views (unique page views)	2,912 (2,416)
Social media posters (downloads from website; shared with project partners to disseminate)	25
May 12 <sup>th</sup> launch event (views)	123
Resource: Quick tips to start your dementia-friendly journey posted to website (downloads)	40
"About" HCoA webpage - linked from campaign page views (unique page views)	556 (457)
<b>Faces of Dementia Campaign Promotion (web analytics provided by Kitestring)</b>	
Instagram indicators (June – November 2022) <ul style="list-style-type: none"> <li>• Accounts reached</li> </ul>	864
<ul style="list-style-type: none"> <li>• Accounts engaged</li> </ul>	112
<ul style="list-style-type: none"> <li>• Total followers</li> </ul>	55
Facebook Indicators (June – November 2022) <ul style="list-style-type: none"> <li>• Accounts reached</li> </ul>	6310
<ul style="list-style-type: none"> <li>• Facebook page visits</li> </ul>	354
<ul style="list-style-type: none"> <li>• Total followers</li> </ul>	40
Social media posts (3 posts per campaign participant from June-December 2022)	21 posts

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
<b>Faces of Dementia Campaign Launch Events</b>	
<b>Intimate Launch Event</b> Date: May 9, 2022	
# campaign participants in attendance	6
# participant family members/ friends in attendance	6
# campaign staff/ leaders/ others in attendance	15
Total attendance	27
<b>Public Launch Event</b> Date: May 12, 2022	
# campaign participants in attendance	7
# campaign staff/ leaders/ others in attendance	242 <sup>20</sup>
Total attendance	249
<b>Social media promotion of launch events</b>	
Instagram posts (84 reached, 91 impressions, 8 likes, 2 comments, 2 shares)	1
Instagram stories (2 link clicks)	4
Facebook posts (475 reached, 23 reactions, 4 link clicks)	3
<b>Media Requests Related to Campaign, Launch Events, Community Exhibits</b>	
# media requests - Hamilton based (The Hamilton Spectator, CH News, CHML Good Morning, CBC Hamilton, Cable 14, The Grand Radio)	6
# media requests - Haldimand based (The Grand Radio; The Sachem)	2
# completed interviews - Hamilton (radio, tv: The Grand Radio; Cable 14)	2
# completed interviews - Haldimand (radio, tv: The Grand Radio)	1
# completed interviews - Hamilton (print: Hamilton Spectator)	2 <sup>21</sup>
# completed interviews - Haldimand (print)	0
<b># Presentations Promoting the Campaign (attendance/ reach)</b>	17 (4,197)
<ul style="list-style-type: none"> <li>• April 14, 2022 McMaster Occupational Therapy Students (55)</li> <li>• May 4, 2022 Keynote, Dementia Learning Summit, Canadian Institute for Seniors Care (1000)</li> <li>• May 19, 2022 McMaster MIRA Age-Friendly University (25)</li> <li>• May 24, 2022 Dementia Working Group Brantford (16)</li> <li>• June 1, 2022 City of Hamilton's Seniors Kick-Off Event (300)</li> <li>• June 7, 2022 ICW – Panel discussion – Cross-Cultural Lessons Learned from COVID-19: Dementia &amp; Wayfinding (200)</li> <li>• June 16, 2022 Cross Canada Conversation – Changing the Culture of Dementia (89)</li> <li>• July 6, 2022 Hamilton Rotary Club (20)</li> </ul>	

<sup>20</sup> 217 less 7 campaign members, plus 6 at viewing events in Hagersville and 26 at AGE Inc.

<sup>21</sup> Signpost/ editorial - front page, feature story that continued inside with several photographs.

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
<ul style="list-style-type: none"> <li>• Aug. 2, 2022 – CRADLE+ Program – Conestoga College Webinar (187)</li> <li>• Aug. 6 2022 Hourglass Awareness Golf Tournament (175)</li> <li>• Sept 22, 2022 Mind Over Matter Podcast: Women’s Brain Health (1114)</li> <li>• Sept. 23 2022, Dr. Anthea Innes presentation to the North Sea Dementia Meeting in Oslo (35 people from 7 countries)</li> <li>• Sept. 27, 2022 AGE Inc Annual General Meeting Keynote (30)</li> <li>• Sept 28, 2022 Dementia Talks: Creating Dementia-Friendly Spaces, Alzheimer Society Canada (269)</li> <li>• Oct 7, 2022 Alzheimer Society Brant Haldimand Norfolk Hamilton Halton (BHNHH) Open House Event Norfolk County (Faces of Dementia) (35)</li> <li>• Oct. 13, 2022 Alzheimer Society BHNHH Open House Event (Faces of Dementia) (35)</li> <li>• Oct. 21, 2022 Canadian Association of Gerontology 2022 Conference in Regina Presentation (500)</li> <li>• Oct. 22, 2022 Alzheimer Societies in Ontario Fall Conference (75)</li> <li>• Nov 15, 2022 Presentation to Greater Hamilton Health Network (OHT) (21)</li> <li>• Nov 15, 2022 Presentation to Ontario Councils on Aging (16)</li> </ul>	
<p><b># Exhibitions/ Fairs/ Booths (reach)</b></p> <ul style="list-style-type: none"> <li>• June 1, 2022 City of Hamilton Seniors Kick-Off Event (300)</li> <li>• May 26, 2022 MIRA Community Research Fair (80)</li> <li>• July 14, 2022 Greater Hamilton Health Network’s Women’s Health Day (54)</li> <li>• Sept. 22, 2022 Dementia Friendly Communities Public Lecture by Dr. Anthea Innes (35)</li> <li>• Sept. 24, 2022 MICE+ Haldimand Festival (150)</li> <li>• Oct. 4, 2022 International Day of Older Persons Event (80)</li> <li>• Oct. 19, 2022 Hamilton Seniors Awards Gala (300)</li> <li>• Oct. 21, 2022 CAG2022 Conference in Regina Exhibition Booth via McMaster Gilbrea Centre (500)</li> </ul>	8 (1,499)
<p><b>Faces of Dementia Campaign Community Exhibits</b>  <b>Locations – # launch event attendees</b></p> <ul style="list-style-type: none"> <li>• Hamilton and area (Sackville Hill Seniors Recreation Centre; September 26 – November 16, 2022)</li> </ul>	90
<ul style="list-style-type: none"> <li>• Haldimand and region (Minga Café, Dunnville; October 12 – November 18, 2022)</li> </ul>	50
<p><b>Media Requests Related to Community Exhibits (included in campaign numbers)</b></p>	

<b>Faces of Dementia Campaign and Launch Events: Key Outputs</b>	<b>Number</b>
<b>Gallery Exhibit Materials</b>	
# posters designed with QR Codes	10 <sup>22</sup>
# posters printed	20 <sup>23</sup>
# Brochures Designed	1
# Brochures Printed/Distributed	1000/875
# Gallery Guides designed	1
# Gallery Guides printed/distributed	500/425
# infographic posters designed	1
# infographic posters printed/displayed	12/12
# promotional materials (buttons/magnets) designed	2 <sup>24</sup>
# buttons printed/magnets distributed	1000/ 800
# Flags (promotion) printed and displayed	10/10 <sup>25</sup>

### **Campaign: Paid Media Coverage**

<b>Outlet</b>	<b>Type</b>	<b>Run Dates (2022)</b>	<b>Impact – People Reached</b>
The Hamilton Spectator	In-paper ads	June 15	Reach: 968,000 readers viewed the ads
		October 17, 31	
		November 2	
Hamilton Community News	In-paper ads	May 19	Reach: 500,000 impressions
		June 9, 23	
		September 30	
		October 13	
The Sachem	In-paper ads	April 28	Reach: 558,000 views of the ads
		June 16, 22	
		September 29	
		October 6, 15, 20, 29	
		November 3	
Thespec.com	Website ads	June 15, 16, 17-30	Reach: 224,601 Impressions 272 Clicks 0.13% CTR (CTR industry benchmarks are .03% - .08%)
		October 15 to November 5	
		September 22 to November 13	

<sup>22</sup> 32”x48” Posters of campaign members with individual QR Codes were designed and printed for display at each location. 1 Intro poster, 1 Closing poster and 1 poster with Faces of Dementia logo

<sup>23</sup> 10 per community exhibit

<sup>24</sup> One button and one magnet were designed, created and distributed throughout the campaign.

<sup>25</sup> 9 Faces of Dementia branded flags lined the entrance of the Sackville Hill Exhibit, 1 flag was posted outside of MINGA Café on a street pole.

<b>Outlet</b>	<b>Type</b>	<b>Run Dates (2022)</b>	<b>Impact – People Reached</b>
Thespec.com	Web page takeovers	June, November	Reach: 387,396 impressions 511 delivered clicks Click Through Rate: 0.13% (CTR industry benchmarks are .03% - .08%)
Sachem.com	Website ads	June	Reach: 100,000
		September 22 to November 18	
Digital Billboards		June, 3 locations	Reach: 7,509,754 total impressions
		October, 3 locations	
		October 17 to November 14	
Bus Shelters		June, 6 locations	Reach: 1,255,144 total impressions
		October/November, 6 locations	
Radio	The Grand 92.9	June 4 to 25, 60 spots	Reach: 215,900 total impressions
		October 19 to November 9, 60 spots	
Radio	CHML	June 4 to 25, 90 spots	Reach: 327,000 total impressions
		October 19 to November 9	
		90 spots	
Television	CH Morning Live	June: <ul style="list-style-type: none"> <li>• 10-second billboard during CH Morning Live, three weeks</li> <li>• Multi-zone banner one week</li> </ul>	Reach: 6,035,000 impressions
		October: <ul style="list-style-type: none"> <li>• 10-second billboard during CH Morning Live, three weeks</li> <li>• Multi-zone banner one week</li> </ul>	

## Appendix J: Campaign Participant Survey Results

**Response rate:** 3/7 (42.9%)

**Note:** Percentages may not sum to 100% due to missing values.

**Overall, how satisfied were you with your experience in the Faces of Dementia campaign?**

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
0	0	33.3% (1)	0	66.7% (2)

**Do you agree or disagree with the following statements about your involvement in the Faces of Dementia campaign?**

	Disagree	Neutral	Agree
I felt comfortable sharing my experiences with dementia for this project.	0	0	100% (3)
I feel better able to share my experiences with dementia as a result of my involvement in this project.	0	33.3% (1)	66.7% (2)
I learned new things about dementia as a result of participating in this campaign.	0	33.3% (1)	66.7% (2)
I am more aware of the stigma that can be associated with dementia.	0	0	100% (3)
I believe my involvement in the Faces of Dementia campaign will help to make changes in how my community thinks about dementia.	0	0	100% (3)
I believe the Faces of Dementia campaign will be effective in increasing community awareness about what it is like to live with dementia.	0	0	100% (3)
My participation in the Faces of Dementia campaign was a positive experience.	0	0	100% (3)

**How would you rate the extent to which your community is currently dementia friendly?**

Not at all dementia friendly	A little bit	Somewhat	Very	Extremely dementia friendly
0	33.3% (1)	0	33.3% (1)	0

**This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?**

Not at all important	A little bit	Somewhat	Very	Extremely important
0	0	0	33.3% (1)	66.7% (1)

**Comments**

- Don't know how dementia friendly the community is
- Thank you to everyone for making this so wonderful.

## Appendix K: Campaign Intimate Launch Event Survey Results



Empowering Dementia Friendly Communities  
Hamilton, Haldimand



Faces of Dementia Campaign Intimate Launch  
Event Satisfaction Survey

**Response Rate:** 56.4% (22/39)

**Note:** Percentages may not sum to 100% due to missing information.

### Community

Community	% (#)
Hamilton and area	81.8% (18)
Haldimand and area	9.1% (2)
Unspecified	9.1% (2)
<b>Total</b>	<b>22</b>

### Response rate based on Group

Group	% (#)
Persons living with dementia (PLWD)	18.2% (4)
Care partners of a person living with dementia	9.1% (2)
Family members or friends of a person living with dementia	4.5% (1)
Library/ recreation/ arts/ museum staff or volunteers	0
Businesses	18.2% (4)
Faith groups	0
Media	0
Elected officials	0
Policy makers	0
Funding organizations/ philanthropy	0
Health care providers/ health system workers	18.2% (4)
Community services	9.1% (2)
General public (community at large)	9.1% (2)
Other*	13.6% (3)

\*Other: Advocate; health professional educator; unspecified

**Overall, how satisfied were you with the Faces of Dementia campaign?**

	<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neutral</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<b>Community</b>					
Haldimand & area (N = 2)	0	0	0	0	100% (2)
Hamilton & area (N = 18)	0	5.6% (1)	0	11.1% (2)	83.3% (15)
Unspecified (N = 2)	0	0	0	0	100% (2)
<b>Total (N = 22)</b>	<b>0</b>	<b>4.5% (1)</b>	<b>0</b>	<b>9.1% (2)</b>	<b>86.4% (19)</b>
<b>Respondent Group</b>					
PLWD (N = 4)	0	0	0	0	100% (2)
Care partners (N = 2)	0	0	0	0	100% (2)
All others* (N = 16)	0	5.6% (1)	0	11.1% (2)	83.3% (15)
<b>Total (N = 22)</b>	<b>0</b>	<b>4.5% (1)</b>	<b>0</b>	<b>9.1% (2)</b>	<b>86.4% (19)</b>

\*Family, friends, general public.

**Do you have any comments to make about this (satisfaction with campaign)?**

**Persons living with dementia**

- *Each and every step of the campaign was well planned and executed.*
- *I was distracted by workmen in my new digs. The part of the meeting I was present was informative and satisfying. Many people new to me reported with passion and clarity.*
- *Profiles emphasized the capabilities of individuals living with dementia, not at all expected. Opened up a whole new world for those not familiar with dementia and how much more is needed to be known. Gutsy.*

**Care partners**

- *love the video and posters!! it felt very real*
- *The campaign is very well done; professional and very considerate of the dignity of the participants.*

## All others

- *I loved being part of this project and seeing it come to fruition. An important step forward in communicating the stories of people living with dementia.*
- *I was impressed with the diverse range of folks who came forward to offer their story and their positive message*
- *Hopefully, it will accomplish its goal of community understanding & awareness*
- *looks great!*
- *Amazing !!!!!*
- *A very humbling experience!*
- *I am blown away by the end result.*
- *It was inspiring and completely awesome*
- *Amazing- so inspiring- thank you to all of the participants for candidly sharing their stories and experiences in this change-making project!*

## How satisfied were you with the Faces of Dementia virtual launch event?

	<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neutral</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<b>Community</b>					
Haldimand & area (N = 2)	0	0	0	0	100% (2)
Hamilton & area (N = 18)	0	0	11.1% (2)	27.8% (5)	61.1% (11)
Unspecified (N = 2)	0	0	0	50.0% (1)	50.0% (1)
<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>9.1% (2)</b>	<b>27.3% (6)</b>	<b>63.6% (14)</b>
<b>Respondent Group</b>					
PLWD (N = 4)	0	0	0	50.0% (1)	50.0% (1)
Care partners (N = 2)	0	0	0	0	100% (2)
All others* (N = 16)	0	0	11.1% (2)	27.8% (5)	61.1% (11)
<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>9.1% (2)</b>	<b>27.3% (6)</b>	<b>63.6% (14)</b>

## Do you have any comments to make about the virtual launch event?

### Persons living with dementia

- *There was not enough time allocated to discuss expectations and promotion of the campaign.*
- *Again I was distracted by the workmen in my unit. It was important they were doing that distracted me. When it was possible for me to participate it was refreshing and satisfying.*
- *Perhaps knowing a little more history of people living with dementia.*

### Care partners

- *have a virtual event made it so easy, no figuring out driving, parking, seating...*
- *It was fun. So great to see the people we have come to know over the past year highlighted in such an excellent campaign.*

### All others

- *I helped organize the event, so I was thrilled overall with how it was received.*
- *I like the way the group interacted with each other.*
- *The facilitation of the event seemed somewhat disorganized.*
- *Seeing everyone was so good!*
- *tricky to make a virtual event work but great job*
- *I found the launch event to be informative but also tugged at the heartstrings in just the right way.*

### Do you agree or disagree with the following statements about the affect that the Faces of Dementia campaign had on you?

	Group	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I have a greater understanding of what it is like to live with dementia as a result of the campaign.	PLWD (N = 4)	0	0	0	50.0% (1)	50.0% (1)
	Care partners (N = 2)	0	0	0	0	100% (2)
	All Others (N = 16)	0	0	5.6% (1)	50.0% (9)	44.4% (8)
	<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>4.5% (1)</b>	<b>45.5% (10)</b>	<b>50.0% (11)</b>
I have a greater understanding of the stigma (negative impacts) associated with living with dementia.	PLWD (N = 4)	0	0	0	50.0% (1)	50.0% (1)
	Care partners (N = 2)	0	0	0	0	100% (2)
	All Others (N = 16)	0	0	11.1% (2)	33.3% (6)	55.6% (10)
	<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>9.1% (2)</b>	<b>31.8% (7)</b>	<b>59.1% (13)</b>
I learned new things about how to make my community more dementia friendly.	PLWD (N = 4)	0	0	50.0% (1)	0	50.0% (1)
	Care partners (N = 2)	0	0	0	50.0% (1)	50.0% (1)
	All Others (N = 16)	5.6% (1)	0	38.9% (7)	16.7% (3)	38.9% (7)
	<b>Total (N = 22)</b>	<b>4.5% (1)</b>	<b>0</b>	<b>36.4% (8)</b>	<b>18.2% (4)</b>	<b>40.9% (9)</b>

	Group	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I intend to use some of the things I learned in this campaign to make sure my interactions with persons living with dementia are welcoming and friendly.	PLWD (N = 4)	0	0	0	50.0% (1)	50.0% (1)
	Care partners (N = 2)	0	0	0	0	100% (2)
	All Others (N = 16)	0	0	11.1% (2)	22.2% (4)	66.7% (12)
	<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>9.1% (2)</b>	<b>22.7% (5)</b>	<b>68.2% (15)</b>
I intend to use some of the things I learned in this campaign to make my community dementia friendly.	PLWD (N = 4)	0	0	50.0% (1)	0	50.0% (1)
	Care partners (N = 2)	0	0	0	0	100% (2)
	All Others (N = 16)	0	5.6% (1)	11.1% (2)	16.7% (3)	66.7% (12)
	<b>Total (N = 22)</b>	<b>0</b>	<b>4.5% (1)</b>	<b>13.6% (3)</b>	<b>13.6% (3)</b>	<b>68.2% (15)</b>
I am now more aware of the Empowering Dementia Friendly Communities project in Hamilton and Haldimand.	PLWD (N = 4)	0	0	50.0% (1)	0	50.0% (1)
	Care partners (N = 2)	0	0	0	0	100% (2)
	All Others (N = 16)	0	5.6% (1)	5.6% (1)	22.2% (4)	66.7% (12)
	<b>Total (N = 22)</b>	<b>0</b>	<b>4.5% (1)</b>	<b>9.1% (2)</b>	<b>18.2% (4)</b>	<b>68.2% (15)</b>

Please read each of the statements below and select the number that best reflects how correct you think each statement is. 1 = completely incorrect; 10 = completely correct. Higher scores reflect more positive community attitudes towards dementia as related to how persons living with dementia can be supported to remain active within their communities, considering their right, capacity, and preferences to do so.

### Community Dementia Attitudes Scale

Average (±) Range Median	Community			Group			Total (N = 22)
	Haldimand (N = 2)	Hamilton (N = 18)	Unspecified (N = 2)	PLWD (N = 4)	Care Partners (N = 2)	All others (N = 16)	
I have a good understanding of what it would be like to live with dementia	10.0 (.) 10 10	6.9 (2.4) 1 – 10 7	7.0 (.) 7 7	8.0 (1.4) 7 – 9 8	5.5 (6.4) 1 – 10 5.5	7.3 (1.9) 4 – 10 7	<b>7.2 (2.3)</b> <b>1 – 10</b> <b>7</b>

Average ( $\pm$ ) Range Median	Community			Group			Total (N = 22)
	Haldimand (N = 2)	Hamilton (N = 18)	Unspecified (N = 2)	PLWD (N = 4)	Care Partners (N = 2)	All others (N = 16)	
The main symptom of dementia is always memory loss.*	9.0 (1.4) 8 – 10 9	7.1 (2.5) 3 – 10 7	8.5 (2.1) 7 – 10 8.5	7.0 (4.2) 4 – 10 7	8.0 (2.8) 6 – 10 8	7.3 (2.4) 3 – 10 7	<b>7.4 (2.4)</b> <b>3 – 10</b> <b>7</b>
Medication is the only treatment that can reduce symptoms related to dementia.*	9.0 (1.4) 8 – 10 8	8.9 (1.6) 5 – 10 10	10.0 (.) 10 10	8.0 (2.8) 6 – 10 8	8.5 (.70) 8 – 9 8.5	9.2 (1.4) 5 – 10 10	<b>9.0 (1.5)</b> <b>5 – 10</b> <b>10.0</b>
There is a range of strategies that can help people with dementia in their everyday lives.	10.0 (.) 10 10	9.0 (1.9) 3 – 10 10	10.0 (.) 10 10	10.0 (.) 10 10	8.5 (2.1) 7 -10 8.5	9.2 (1.8) 3 – 10 10	<b>9.2 (1.7)</b> <b>3 – 10</b> <b>10</b>
I have the potential to improve the lives of people living with dementia.	10.0 (.) 10 10	9.0 (2.3) 2 – 10 10	10.0 (.) 10 10	9.5 (.71) 9 – 10 9.5	10 (.) 10 10	9.1 (2.3) 2 – 10 10	<b>9.2 (2.1)</b> <b>2 – 10</b> <b>10</b>
People with dementia can contribute substantially to their community.	10.0 (.) 10 10	9.3 (1.8) 3 – 10 10	10.0 (.) 10 10	10.0 (.) 10 10	10.0 (.) 10 10	9.3 (1.8) 3 – 10 10	<b>9.5 (1.6)</b> <b>3 – 10</b> <b>10</b>
Maintaining independence is one way to help a person living with dementia.	9.5 (.71) 9 – 10 9.5	8.9 (1.5) 5 – 10 9.5	10.0 (.) 10 10	9.5 (.71) 9 – 10 9.5	8.0 (2.8) 6 – 10 8	9.1 (1.4) 5 – 10 10	<b>9.0 (1.4)</b> <b>5 – 10</b> <b>10</b>
People with dementia need	10.0 (.) 10 10	9.1 (1.4) 6 – 10 10	10.0 (.) 10 10	10.0 (.) 10 10	10.0 (.) 10 10	9.1 (1.4) 6 – 10 10	<b>9.3 (1.3)</b> <b>6 – 10</b> <b>10</b>

Average ( $\pm$ ) Range Median	Community			Group			Total (N = 22)
	Haldimand (N = 2)	Hamilton (N = 18)	Unspecified (N = 2)	PLWD (N = 4)	Care Partners (N = 2)	All others (N = 16)	
assistance all of the time.*							
People with dementia have the right to be involved in supported decision-making about their future.	10.0 (.) 10 10	9.2 (2.6) 1 – 10 10	10.0 (.) 10 10	10.0 (.) 10 10	5.5 (6.4) 1 – 10 5.5	9.7 (.97) 7 – 10 10	<b>9.3 (2.1)</b> <b>1 – 10</b> <b>10</b>
For people with symptoms of dementia, a diagnosis can inform planning for the future.	9.5 (.71) 9 – 10 9.5	9.1 (2.0) 2 – 10 6.5	6.5 (4.9) 3 – 10 6.5	10.0 (.) 10 10	10.0 (.) 10 10	8.6 (2.5) 2 – 10 10	<b>8.9 (2.3)</b> <b>2 – 10</b> <b>10</b>
Total Scale Score	<b>9.7 (.28)</b> <b>9.5 – 9.9</b> <b>9.7</b>	<b>8.6 (1.3)</b> <b>4.7 – 9.8</b> <b>9.0</b>	<b>9.2 (.71)</b> <b>8.7 – 9.7</b> <b>9.2</b>	<b>9.2 (.71)</b> <b>8.7 – 9.7</b> <b>9.2</b>	<b>8.4 (1.6)</b> <b>7.3 – 9.5</b> <b>8.4</b>	<b>8.7 (1.3)</b> <b>4.7 – 9.9</b> <b>9.1</b>	<b>8.8 (1.2)</b> <b>4.7 – 9.9</b> <b>9.1</b>

\*These items are reverse scored as statements designated as incorrect.

### How would you rate the extent to which your community is currently dementia friendly?

	Not at all dementia friendly	A little bit	Somewhat	Very	Extremely dementia friendly
<b>Community</b>					
Haldimand & area (N = 2)	0	50.0% (1)	50.0% (1)	0	0
Hamilton & area (N = 18)	5.6% (1)	50.0% (9)	38.7% (7)	5.6% (1)	0
Unspecified (N = 2)	0	50.0% (1)	50.0% (1)	0	0
<b>Total (N = 22)</b>	<b>4.5% (1)</b>	<b>50.0% (11)</b>	<b>40.9% (9)</b>	<b>4.5% (1)</b>	<b>0</b>

	<b>Not at all dementia friendly</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely dementia friendly</b>
<b>Respondent Group</b>					
PLWD (N = 4)	0	50.0% (1)	50.0% (1)	0	0
Care partners (N = 2)	0	0	100% (2)	0	0
All others* (N = 16)	5.6% (1)	55.6% (10)	33.3% (6)	5.6% (1)	0
<b>Total (N = 22)</b>	<b>4.5% (1)</b>	<b>50.0% (11)</b>	<b>40.9% (9)</b>	<b>4.5% (1)</b>	<b>0</b>

**This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?**

	<b>Not at all important</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely important</b>
<b>Community</b>					
Haldimand & area (N = 2)	0	0	0	0	100% (2)
Hamilton & area (N = 18)	0	0	0	27.8% (5)	72.2% (13)
Unspecified (N = 2)	0	0	0	0	100% (2)
<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>22.7% (5)</b>	<b>77.3% (17)</b>
<b>Respondent Group</b>					
PLWD (N = 4)	0	0	0	50.0% (1)	50.0% (1)
Care partners (N = 2)	0	0	0	50.0% (1)	50.0% (1)
All others* (N = 16)	0	0	0	16.7% (3)	83.3% (15)
<b>Total (N = 22)</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>22.7% (5)</b>	<b>77.3% (17)</b>

**Do you have any final comments you would like to make about the Faces of Dementia Campaign or the launch event?**

**Persons living with dementia**

- *Lets keep working at it!*
- *A lot of effort with a wealth of knowledge from multiple disciplines. A team effort and it shows. It's the start of a movement. Now next steps forward for those that will listen.*

### Care partners

- *I really enjoyed the event*
- *Considering the limitations of our Covid world, the launch event was fine. The Faces of Dementia Campaign is excellent and [Project Coordinator] is to be commended for leading our group throughout the many challenges of online collaboration.*

### All others

- *This is such an important enterprise to move our community forward. As our demographics shift and the population ages, the concept of a dementia-friendly community is critical. The Faces of Dementia Campaign and Launch are important opportunities to elevate understanding and behaviour, and create new actions.*
- *We're glad we decided to let friends, family & neighbours know that my wife is a sufferer*
- *So grateful to be part of this project.*
- *Fabulous job to all!*
- *Great effort and a lot of work. Thank you for everything you do.*

### Demographic Information

#### What is your gender?

	Female	Male	Gender fluid/ non-binary/ two spirit	I prefer not to answer
Haldimand & area (N = 2)	100% (2)	0	0	0
Hamilton & area (N = 18)	61.1% (11)	27.8% (5)	0	11.1% (2)
Unspecified (N = 2)	50.0% (1)	50.0% (1)	0	0
<b>Total (N = 22)</b>	<b>59.1% (13)</b>	<b>27.3% (6)</b>	<b>0</b>	<b>9.1% (2)</b>
<b>Group</b>				
PLWD (N = 4)	50.0% (2)	25.0% (1)	0	25.0% (1)
Care partners (N = 2)	100% (2)	0	0	0
All others (N = 16)	56.3% (9)	31.3% (5)	0	6.3% (1)
<b>Total (N = 22)</b>	<b>59.1% (13)</b>	<b>27.3% (6)</b>	<b>0</b>	<b>9.1% (2)</b>

## Age

	Average ( $\pm$ )	Range	Median
<b>Community</b>			
Haldimand & area (N = 2)	51.0 (17.0)	39 – 63	51.0
Hamilton & area (N = 13)	56.5 (18.2)	31 - 86	61.0
Unspecified (N = 1)	75.0 (.)	75	75.0
<b>Total (N = 16)</b>	<b>57.0 (17.7)</b>	<b>31 – 86</b>	<b>62.0</b>
<b>Group</b>			
PLWD (N = 3)	70.7 (10.8)	63 – 83	66.0
Care partners (N = 2)	64.5 (2.1)	63 – 66	64.5
All others (N = 11)	51.9 (18.7)	31 – 86	50.0
<b>Total (N = 16)</b>	<b>57.0 (17.7)</b>	<b>31 – 86</b>	<b>62.0</b>

**Do you identify as Indigenous; that is First Nations (North American Indian), Métis, or Inuit?**

	Yes	No	I prefer not to answer
<b>Community</b>			
Haldimand & area (N = 2)	0	100% (2)	0
Hamilton & area (N = 18)	0	94.4% (17)	5.6% (1)
Unspecified (N = 2)	0	50.0% (1)	0
<b>Total (N = 22)</b>	<b>0</b>	<b>90.9% (20)</b>	<b>4.5% (1)</b>
<b>Group</b>			
PLWD (N = 4)	0	100% (4)	0
Care partners (N = 2)	0	100% (2)	0

	Yes	No	I prefer not to answer
All others (N = 16)	0	87.5% (14)	6.3% (1)
<b>Total (N = 22)</b>	<b>0</b>	<b>90.9% (20)</b>	<b>6.3% (1)</b>

Do you identify as a member of a visible minority in Canada?

	Yes	No	I prefer not to answer
<b>Community</b>			
Haldimand & area (N = 2)	0	100% (2)	0
Hamilton & area (N = 18)	11.1% (2)	77.8% (14)	11.1% (2)
Unspecified (N = 2)	0	50.0% (1)	0
<b>Total (N = 22)</b>	<b>9.1% (2)</b>	<b>77.3% (17)</b>	<b>9.1% (2)</b>
<b>Group</b>			
PLWD (N = 4)	25.0% (1)	50.0% (2)	25.0% (1)
Care partners (N = 2)	0	100% (2)	0
All others (N = 16)	6.3% (1)	81.3% (13)	6.3% (1)
<b>Total (N = 22)</b>	<b>9.1% (2)</b>	<b>77.3% (17)</b>	<b>9.1% (2)</b>

If "Yes", select the options that you identify with.

	Latin American	South Asian*
Haldimand & area (N = 2)	0	0
Hamilton & area (N = 18)	5.6% (1)	5.6% (1)
Unspecified (N = 2)	0	0
<b>Total (N = 22)</b>	<b>4.5% (1)</b>	<b>4.5% (1)</b>
<b>Group</b>		

PLWD (N = 4)	0	25.0% (1)
Care partners (N = 2)	0	0
All others (N = 16)	6.3% (1)	0
<b>Total (N = 22)</b>	<b>4.5% (1)</b>	<b>4.5% (1)</b>

\*e.g., East Indian, Pakistani, Sri Lankan, etc.

## Appendix L: Campaign Public Launch Event Survey Results

**Note:** Percentages may not sum to 100% due to missing information.

**Response Rate:** 24.7% (84/340), however this is a liberal estimate. In total, 340 individuals registered to attend the campaign launch. It is not possible to know exactly how many people attended as multiple people attended with a single login. All 340 registrants received an invitation to complete the survey. There were in total 217 Zoom logins including the 14 panelists; using 217 as the denominator, generates a 38.7% response rate (conservative estimate).

### Response rate based on community

Community	% (#)
Haldimand and area	10.7% (9)
Hamilton and area	44.0% (37)
Other/ unspecified*	45.2% (38)
<b>Total</b>	<b>84</b>

\*The Zoom attendance report indicates that attendees were from other areas of the province, other provinces in Canada, the United States, and other countries.

### Response rate based on Group (N = 84)

Group	% (#)
Persons living with dementia	4.8% (4)
Care partners of a person living with dementia	9.5% (8)
All others*	85.7% (72)
Family members or friends of a person living with dementia	19.0% (16)
Library/ recreation/ arts/ museum staff or volunteers	1.2% (1)
Businesses	2.4% (2)
Faith groups	1.2% (1)
Media	0
Elected officials	0
Policy makers	0
Funding organizations/ philanthropy	1.2% (1)
Health care providers/ health system workers	19.0% (16)
Community services	23.8% (20)
General public (community at large)	7.1% (6)
Other, please specify**	7.1% (6)

\*All respondents excluding persons living with dementia and care partners and including those who did not indicate their group.

\*\*Education-focused organizations/ educator (2); one or more categories (2; excluding person living with dementia or care partners); research coordinator (1); person living with brain injury (1).

**Note:** There were no statistically significant differences in ratings or Community Dementia Attitudes Scale scores based on community (location) or respondent group.

### How did you learn about the campaign launch event?

	HCoA direct mail	Social Media	Newspaper	Friend/ Family/ Colleagues	Other*
<b>Community</b>					
Haldimand & area (N = 9)	0	11.1% (1)	0	77.8% (7)	11.1% (1)
Hamilton & area (N = 37)	45.9% (17)	0	0	40.5% (15)	13.5% (5)
Other/unspecified (N = 38)	13.2% (5)	15.8% (6)	0	36.8% (14)	34.2% (13)
<b>Total (N = 84)</b>	<b>26.2% (22)</b>	<b>8.3% (7)</b>	<b>0</b>	<b>42.9% (36)</b>	<b>22.6% (19)</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 4)	0	0	0	75.0% (3)	25.0% (1)
Care partners (N = 8)	62.5% (5)	0	0	12.5% (1)	25.0%
All others (N = 72)	23.6% (17)	9.7% (7)	0	44.4% (32)	22.2% (16)
<b>Total (N = 84)</b>	<b>26.2% (22)</b>	<b>8.3% (7)</b>	<b>0</b>	<b>42.9% (36)</b>	<b>22.6% (19)</b>

\*Other: Dementia related conference or event; community event, library (Hamilton), YMCA (Hamilton), Canadian Dementia Learning and Resource Network (CDLRN) newsletter, Advanced Gerontological Education (AGE) Inc.

### Overall, how satisfied were you with the Faces of Dementia campaign?

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
<b>Community</b>					
Haldimand & area (N = 9)	0	0	0	11.1% (1)	88.9% (8)
Hamilton & area (N = 37)	0	0	5.4% (2)	29.7% (11)	64.9% (24)
Other/unspecified	0	2.6% (1)	5.3% (2)	23.7% (9)	68.4% (26)

	<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neutral</b>	<b>Satisfied</b>	<b>Very satisfied</b>
(N = 38)					
<b>Total (N = 84)</b>	<b>0</b>	<b>12% (1)</b>	<b>4.8% (4)</b>	<b>25.0% (21)</b>	<b>69.0% (58)</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 4)	0	0	25.0% (1)	0	75.0% (3)
Care partners (N = 8)	0	0	0	50.0% (4)	50.0% (4)
All others (N = 72)	0	1.4% (1)	4.2% (3)	23.6% (17)	70.8% (51)
<b>Total (N =84)</b>	<b>0</b>	<b>1.2% (1)</b>	<b>4.8% (4)</b>	<b>25.0% (21)</b>	<b>69.0% (58)</b>

**Do you have any comments to make about this (satisfaction with campaign)?**

**Persons living with dementia**

- *So powerful*
- *It is always such an experience to hear directly from those living with a diagnosis. How wonderful is that. Such brave souls.*
- *This was one of many webinars that I have attended, where I was impressed by the representation of people living with dementia. So many other projects are directed towards caregivers or medical professionals. This Faces of Dementia campaign was truly about dementia and people with dementia.*
- *the chosen colors were bleak and depressing, too dark*

**Care partners**

- *Interesting, we were first time participants.*
- *Beautiful campaign. Thank you for providing a platform for people to share their stories. People First.*
- *I am excited to learn more through your website and excited to share the videos and workshops with our community*
- *The participants stories were very impactful. Sharing these stories with others who are afraid of the stigma around Alzheimer's will be so helpful.*
- *My thanks to Canada for initiating this awareness campaign.....and it's not enough to be aware.....we do need action!*

**All others**

- *Very happy to learn about the direction of this campaign, emphasizing how the lives of people with dementia can be both fulfilling and inclusive. Creating public awareness for that is such a wonderful initiative.*

- *I was a bit of a late comer to the campaign and cannot yet comment.*
- *It was great hearing from people diagnosed with Dementia. I found the introduction of the people involved took up most of the time. I wish there was more informative or more discussions focused on new findings, treatments, interaction etc on Dementia in the current social stigma, everyday life, impact in the healthcare system*
- *I find the 'living library' model that was used to share stories is a powerful model.*
- *I thought I would see more coverage out in the community or in the newspaper but perhaps I missed it*
- *It was powerful*
- *Very empowering. It was wonderful to see how people cope with Dementia and not let it stop what they love doing.*
- *I appreciated the comments from the participants. They appeared to be normal functioning people.*
- *Wonderful campaign to spotlight the person not the disease.*
- *I realized that I did have some preconceived notions about dementia, and I am happy to have that corrected. While the subject is sad, there were so many moments of joy. Seeing and learning more about dementia and the people who have that diagnosis, and hearing their stories, goes such a long way in understanding and being able to remember going forward in life.*
- *I am very new to the campaign, therefore don't have enough knowledge to provide a fair assessment. That said, if the Faces of Dementia presentation is a testimony to how things will proceed, then I am confident it will very good!*
- *Absolutely amazing campaign so impressed.*
- *Looked expensive*
- *I think it is a great initiative and I believe this will help with newly diagnosed dementia persons.*
- *It's a start, which is great, but the focus at present is too much on older people who are already diagnosed with dementia. In order to raise awareness we need to hear more from younger people who have become aware that this illness does not mean that the identity of the individual has been lost. What needs to be tackled is the very real stigma that is attached to the very notion of dementia. Re the programme itself: I felt that there was simply too much emphasis on the making of the video by those involved.*
- *Powerful videos and hearing from persons living with dementia is the key part. It was clear and resonated with me.*
- *A welcome addition to the available resource pool about people with dementia.. An insightful and educating picture of the lives of the participants who are dealing with dementia.*
- *The stories shared by persons living with dementia in this campaign are important and impactful. I appreciate the attention to diversity and representing the individuality of the dementia experience.*
- *It is a very important tool to highlight the issues related living with dementia in the community.*

- *I'm excited about this campaign! I love the posters. I will be following up to have a workshop in Dunnville.*
- *Wonderful people to work with!*
- *I enjoyed one of the stories that a panel member provided, referring Dementia to walking down a country pathway and she met head-on with a bear. The symbolism of the bear, was Dementia.*
- *Well done very moving lovely to see real people talking about their experience*
- *I feel that this amazing initiative is so important for every Community. I am inspired and grateful for the amazing work of all the participants and am excited to be apart of it moving forward.*
- *It love it. The presentation today was so immediate and so direct, particularly the voices of some of the participants, [participant] and [participant] most especially, but [participant] and others too, including the team that worked on the film. The messages were so clear: I am more than my diagnosis; I am still me; I may be 20% of what I was before, but that 20% is the most awesome part; I still have much to share; People need 'LUVE'. Powerful messages, terrific film and campaign, looking forward to continuing to advance the concept and practice of Personhood that is at the root of GPA training at AGE.*
- *Excellent info*
- *Awesome! Game changer!*
- *Loved hearing from those who are faced with dementia*
- *So inspiring!*
- *I thought this was beautifully presented. Thank your sharing your lives with us and our community.*
- *Well done. Putting individual faces to a disease, especially dementia, makes such a difference.*
- *the voices of those living with dementia were truly inspirational for all of us....hopefully - we will make an impact beyond our own communities*
- *It was very informative some time you see the symptoms but don't recognize Very educational*
- *Great and inspiring initiative. Need to educate people and outreach more aggressively.*
- *Sharing your story - especially one that includes a diagnosis that impacts cognition - is something that produces great vulnerability. I think the words brave and courage are overused and not really the right thing...because I don't want a world where people have to be brave, I want a world where we can all just BE. You have taken steps so that society can begin to recognize, understand and welcome persons with living with a dementia diagnosis AS THEY ARE...persons of value. One shouldn't have to be brave - they should be accepted without question. You have 'opened the doors of hope' so that this can be possible. I promise to share this far and wide!*
- *I hope that these resources are going to be readily available. They are so powerful.*
- *It was well organized and great presenters/ expert panel.*
- *Excellent work from everyone that was involved!*
- *Absolutely amazing campaign can't wait to share it with my Centres*
- *Love it*

- *I think this was very well presented. It's so often that we only hear from the Care Partners and there is more supports out their for care partners, but we as a society need to remember that the person living with dementia is just as important and deserves the same respect*
- *Wonderful campaign. Great campaign ambassadors. Very hopeful message.*
- *I am so grateful to have able to attend this session - it was very powerful, eye opening and so great that PLWD's voice are being heard!*
- *Fabulous. Beautiful and inspiring.*

### How satisfied were you with the Faces of Dementia virtual launch event?

	<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neutral</b>	<b>Satisfied</b>	<b>Very satisfied</b>
<b>Community</b>					
Haldimand & area (N = 9)	0	0	0	11.1% (1)	77.8% (7)
Hamilton & area (N = 37)	0	0	2.7% (1)	32.4% (12)	62.2% (23)
Other/unspecified (N = 38)	2.6% (1)	0	0	34.2% (13)	63.2% (24)
<b>Total (N = 84)</b>	<b>1.2% (1)</b>	<b>0</b>	<b>1.2% (1)</b>	<b>31.0% (26)</b>	<b>64.3% (54)</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 4)	0	0	0	25.0% (1)	75.0% (3)
Care partners (N = 8)	0	0	0	62.5% (5)	37.5% (3)
All others (N = 72)	1.4% (1)	0	1.4% (1)	27.8% (20)	66.7% (48)
<b>Total (N = 84)</b>	<b>1.2% (1)</b>	<b>0</b>	<b>0</b>	<b>31.0% (26)</b>	<b>64.3% (54)</b>

### Do you have any comments to make about the virtual launch event?

#### Persons living with dementia

- *I found the constant words of praise to be distracting. I'm sure you found this aspect to be very encouraging and I would not like to put a downer on your organization, because it was an excellent presentation, but next time, after the greetings could you ask people to hold their compliments and allow people with questions to address the panel?*

## Care partners

- *Registration for the event was difficult.*
- *Wonderfully warm, supportive and informational!*

## All others

- *The panel was so varied, honest and open. It was a great event for the participants, the comments following the launch were so positive and excited, confirming just how impactful the presentation was.*
- *It was a wonderful event, with so many personal perspectives and hope. My mother has just been diagnosed with Alzheimer's and is terrified. Participating in the event provided an injection of much-needed hope.*
- *There's always room for improvement with new angles and unexplored territories of dementia.*
- *It was very inspiring to see how all these people are coping with this disease.*
- *An excellent and very moving event*
- *Excellent presentation*
- *Well done everyone*
- *Professional, but didn't see the real dementia people live with. If you do this or you change how you do something, doesn't work and don't say you just need the right "tools"*
- *Thought it was amazing and moving.*
- *The introductions were a bit too long.*
- *The launch event was great. I appreciated the land acknowledgement. The timing of having it over lunch worked for me. I liked the friendly energy.*
- *Problems with showing the video slowed down the momentum and sometimes it was difficult to hear [participant].*
- *A few small issues, but they were resolved quickly.*
- *Always a glitch when you do the presentation but you handled it with dignity*
- *I feel closer to the participants who shared their stories and how they felt. That is the power behind this initiative. It is a living, ongoing initiative, not past tense ([question] 2 above "were" should be "are").*
- *Excellent event*
- *There aren't words - moving and an amazing collaboration.*
- *The usual zoom challenges.*
- *Great panelists!*
- *Loved the video and all who shared their experiences. I love everyone's outlook!*
- *I thought it great to have the voices of others involved in creating the films/posters....very cool*
- *Need to have multiple similar sessions*
- *Never got to attend, never received the link until 16.45pm this afternoon*
- *I did not expect to hear the insights from [representative from Kitestring] and the film-maker (his name escapes me right now), but their statements were very powerful too. I loved hearing the meaning of the colours and that being behind the camera was a learning experience from*

*the lens of the target market, and the underlying goal to capture the person, the dignity and humanity. Thank you. Good insights.*

- *What a wonderful launch, thank you!*
- *I actually would have enjoyed an even longer webinar! Everything was very engaging and I felt like time flew by.*
- *I would have like to hear more about how this project could be used across the county as this is such a great message to be spreading.*
- *Fantastic!*

**Do you agree or disagree with the following statements about the affect that the Faces of Dementia campaign had on you?**

	<b>Group</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
I have a greater understanding of what it is like to live with dementia as a result of the campaign.	PLWD (N = 4)	0	0	25.0% (1)	75.0% (3)	0
	Care partners (N = 8)	0	0	37.5% (3)	25.0% (2)	37.5% (3)
	All Others (N = 72)	0	0	6.9% (5)	51.4% (37)	38.9% (28)
	<b>Total (N = 84)</b>	<b>0</b>	<b>0</b>	<b>10.7% (9)</b>	<b>50.0% (42)</b>	<b>36.9% (31)</b>
I have a greater understanding of the stigma (negative impacts) associated with living with dementia.	PLWD (N = 4)	0	0	25.0% (1)	50.0% (2)	25.0% (1)
	Care partners (N = 8)	0	0	12.5% (1)	50.0% (4)	37.5% (3)
	All Others (N = 72)	2.8% (2)	1.4% (1)	8.3% (6)	38.9% (28)	48.6% (35)
	<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>1.2% (1)</b>	<b>9.5% (8)</b>	<b>40.5% (34)</b>	<b>46.4% (39)</b>
I learned new things about how to make my community more dementia friendly.	PLWD (N = 4)	0	0	50.0% (2)	50.0% (2)	0
	Care partners (N = 8)	0	0	25.0% (2)	37.5% (3)	37.5% (3)
	All Others (N = 72)	2.8% (2)	2.8% (2)	9.7% (7)	54.2% (39)	30.6% (22)
	<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>2.4% (2)</b>	<b>13.1% (11)</b>	<b>52.4% (44)</b>	<b>29.8% (25)</b>
I intend to use some of the things I learned in this campaign to make sure my interactions with persons living with dementia are welcoming and friendly.	PLWD (N = 4)	0	0	0	50.0% (2)	50.0% (2)
	Care partners (N = 8)	0	0	0	37.5% (3)	62.5% (5)
	All Others (N = 72)	2.8% (2)	0	2.8% (2)	44.4% (32)	48.6% (35)
	<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>0</b>	<b>2.4% (2)</b>	<b>44.0% (37)</b>	<b>50.0% (42)</b>

	<b>Group</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
I intend to use some of the things I learned in this campaign to make my community dementia friendly.	PLWD (N = 4)	0	0	25.0% (1)	25.0% (1)	50.0% (2)
	Care partners (N = 8)	0	0	12.5% (1)	50.0% (4)	37.5% (3)
	All Others (N = 72)	2.8% (2)	0	8.3% (6)	51.4% (37)	36.1% (26)
	<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>0</b>	<b>9.5% (8)</b>	<b>50.0% (42)</b>	<b>36.9% (31)</b>
I am now more aware of the Empowering Dementia Friendly Communities project in Hamilton and Haldimand.	PLWD (N = 4)	0	25.0% (1)	0	25.0% (1)	50.0% (2)
	Care partners (N = 8)	0	0	25.0% (2)	50.0% (4)	25.0% (2)
	All Others (N = 72)	1.4% (1)	4.2% (3)	2.8% (2)	34.7% (25)	56.9% (41)
	<b>Total (N = 84)</b>	<b>1.2% (1)</b>	<b>4.8% (4)</b>	<b>4.8% (4)</b>	<b>35.7% (30)</b>	<b>53.6% (45)</b>

Please read each of the statements below and select the number that best reflects how correct you think each statement is. 1 = completely incorrect; 10 = completely correct.

### Community Dementia Attitudes Scale

Average ( $\pm$ ) Range Median	Community			Group			Total (N = 84)
	Haldimand (N = 9)	Hamilton (N = 37)	Other (N = 38)	PLWD (N = 4)	Care Partners (N = 8)	All others (N = 72)	
I have a good understanding of what it would be like to live with dementia	6.9 (2.0) 3 – 10 7	7.0 (2.1) 1 – 10 7	7.7 (2.1) 1 – 10 8	7.5 (3.0) 4 – 10 8	6.6 (2.6) 3 – 10 6	7.4 (2.0) 1 – 10 8	<b>7.3 (2.1)</b> <b>1 – 10</b> <b>7</b>
The main symptom of dementia is always memory loss.*	7.1 (2.8) 3 – 10 8	7.3 (2.9) 1 – 10 8	6.8 (3.1) 1 – 10 8	9.5 (1.0) 8 – 10 10	7.3 (3.2) 2 – 10 8.5	6.9 (2.9) 1 – 10 8	<b>7.1 (2.9)</b> <b>1 – 10</b> <b>8</b>
Medication is the only treatment that can reduce symptoms related to dementia.*	8.0 (2.7) 2 – 10 9	8.6 (2.0) 1 – 10 10	8.6 (2.3) 1 – 10 10	10.0 (.) 10 10	9.3 (1.4) 7 – 10 10	8.4 (2.3) 1 – 10 9	<b>8.6 (2.2)</b> <b>1 – 10</b> <b>10</b>
There is a range of strategies that can help people with dementia in their everyday lives.	8.8 (1.6) 5 – 10 9	8.6 (1.9) 4 – 10 10	9.7 (.58) 8 – 10 10	8.5 (1.9) 6 – 10 9	8.3 (2.0) 5 – 10 9.0	9.2 (1.4) 4 – 10 10	<b>9.1 (1.5)</b> <b>4 – 10</b> <b>10</b>
I have the potential to improve the lives of people living with dementia.	9.3 (1.1) 7 – 10 10	8.9 (1.6) 5 – 10 10	9.2 (1.2) 5 – 10 10	9.0 (1.4) 7 – 10 10	8.4 (2.2) 5 – 10 9.5	9.2 (1.2) 5 – 10 10	<b>9.1 (1.4)</b> <b>5 – 10</b> <b>10</b>
People with dementia can contribute substantially to their community.	9.8 (.44) 9 – 10 10	9.2 (1.5) 5 – 10 10	9.7 (.75) 7 – 10 10	8.5 (1.7) 7 – 10 8.5	8.9 (1.9) 5 – 10 10	9.6 (.94) 5 – 10 10	<b>9.5 (1.1)</b> <b>5 – 10</b> <b>10</b>
Maintaining independence is one way to help a person living with dementia.	9.3 (1.1) 7 – 10 10	9.0 (1.6) 3 – 10 10	9.3 (.97) 6 – 10 10	8.5 (3.5) 3 – 10 10	8.6 (1.5) 6 – 10 9	9.3 (1.1) 5 – 10 10	<b>9.2 (1.3)</b> <b>3 – 10</b> <b>10</b>
People with dementia need assistance all of the time.*	9.1 (.83) 8 – 10 9	8.1 (2.2) 3 – 10 9	8.6 (2.2) 1 – 10 9	9.3 (.96) 8 – 10 9.5	7.6 (2.3) 4 – 10 7.5	8.4 (2.2) 1 – 10 9	<b>8.4 (2.1)</b> <b>1 – 10</b> <b>9</b>

Average (±) Range Median	Community			Group			Total (N =84)
	Haldimand (N = 9)	Hamilton (N = 37)	Other (N = 38)	PLWD (N = 4)	Care Partners (N = 8)	All others (N = 72)	
People with dementia have the right to be involved in supported decision-making about their future.	9.3 (1.7) 5 – 10 10	9.4 (1.0) 7 – 10 10	9.7 (.57) 8 – 10 10	9.3 (1.5) 7 – 10 10	8.8 (1.3) 7 – 10 9	9.6 (.86) 5 – 10 10	<b>9.5 (.96)</b> <b>5 – 10</b> <b>10</b>
For people with symptoms of dementia, a diagnosis can inform planning for the future.	8.8 (1.0) 7 – 10 9.0	8.8 (1.6) 3 – 10 10	9.2 (1.5) 4 – 10 10	9.3 (1.5) 7 – 10 10	9.0 (1.2) 7 – 10 9.5	9.0 (1.6) 3 – 10 10	<b>9.0 (1.5)</b> <b>3 – 10</b> <b>10</b>
<b>Total Scale Score</b>	<b>8.5 (.71)</b> <b>7.4 – 9.7</b> <b>8.7</b>	<b>8.5 (1.1)</b> <b>5.1 – 9.8</b> <b>8.9</b>	<b>8.8 (.67)</b> <b>7.3 – 10</b> <b>9.1</b>	<b>8.9 (1.4)</b> <b>7.1 – 10</b> <b>9.3</b>	<b>8.3 (1.4)</b> <b>6.1 – 9.8</b> <b>8.6</b>	<b>8.7 (.84)</b> <b>5.1 – 9.8</b> <b>9</b>	<b>8.7 (.93)</b> <b>5.1 – 10</b> <b>9</b>

\*These items are reverse scored as statements designated as incorrect.

**How would you rate the extent to which your community is currently dementia friendly?**

	<b>Not at all dementia friendly</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely dementia friendly</b>
<b>Community</b>					
Haldimand & area (N = 9)	0	55.6% (5)	44.4% (4)	0	0
Hamilton & area (N = 37)	13.5% (5)	35.1% (13)	45.9% (17)	5.4% (2)	0
Other/unspecified (N = 38)	13.2% (5)	15.8% (6)	55.3% (21)	13.2% (5)	0
<b>Total (N = 84)</b>	<b>11.9% (10)</b>	<b>28.6% (24)</b>	<b>50.0% (42)</b>	<b>8.3% (7)</b>	<b>0</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 4)	25.0% (1)	50.0% (2)	25.0% (1)	0	0
Care partners (N = 8)	12.5% (1)	25.0% (2)	62.5% (5)	0	0
All others (N = 72)	11.1% (8)	27.8% (20)	50.0% (36)	9.7% (7)	0
<b>Total (N = 84)</b>	<b>11.90</b>	<b>28.6% (24)</b>	<b>50.0% (42)</b>	<b>8.3% (7)</b>	<b>0</b>

**This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?**

	<b>Not at all important</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely important</b>
<b>Community</b>					
Haldimand & area (N = 9)	0	0	0	33.3% (3)	66.7% (6)
Hamilton & area (N = 37)	0	0	8.1% (3)	40.5% (15)	51.4% (19)
Other/unspecified (N = 38)	0	0	0	36.8% (14)	60.5% (23)

	<b>Not at all important</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely important</b>
<b>Total (N = 84)</b>	<b>0</b>	<b>0</b>	<b>3.6% (3)</b>	<b>38.1% (32)</b>	<b>57.1% (48)</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 4)	0	0	0	75.0% (3)	25.0% (1)
Care partners (N = 8)	0	0	12.5% (1)	50.0% (4)	37.5% (3)
All others (N = 72)	0	0	2.8% (2)	34.7% (25)	61.1% (44)
<b>Total (N = 84)</b>	<b>0</b>	<b>0</b>	<b>3.6% (3)</b>	<b>38.1% (32)</b>	<b>57.1% (48)</b>

**Do you have any final comments you would like to make about the Faces of Dementia Campaign or the launch event?**

**Persons living with dementia**

- *As an initial campaign it hits the right notes with lots of areas that need tweaking. It did not fully explore the difference between a type of dementia and the stage wherein a diagnosis is given. The symptoms between before and after the age of 65 are similar or the same. People are confused if we say that early onset is a different form of dementia and has its own category. The term onset is very difficult to grasp for the general public composed of multi-ethnic groups. There is too much emphasis of blame towards the community and being a victim rather than focusing on the need to create an awareness that it is an area where the public has to be made aware that it is a disease that require a better understanding.*
- *Well done! Looking forward to more information on community awareness and how to start up a similar program in York Region.*

**Care partners**

- *When are you ready to extend the program to other regions, Peel, Halton?*
- *I enjoyed the presentation and look forward to exploring the website. Thank you*
- *Thank you.....hope your southern neighbors in the States will get on board!*

**All others**

- *I wholly support this campaign. Dementia affects us all one way or another at some point in our lives. Public awareness and support programs so that those affected can have a better quality of life, is good for the whole community.*
- *There's still more work to be done for people living with dementia - we on the right track*
- *Well done!*
- *It was an honor to join to view this presentation. Let's get this city Dementia Friendly!!!*

- *Excellent photography. Well planned commentary from presented.*
- *Very refreshing out look. It will be great once all communities can adopt these principals as a way of life.*
- *In the past year and a half I consulted for three health care companies in Hamilton, and what I learned is that 'today' 1 out 3 (33%) senior citizen has cognitive impairment. For this reason # 9 above [question about the importance of making the community dementia friendly] is extremely important. Even more important is figuring out why that percentage has climbed since the 1980s.*
- *Looking forward to getting all the information to share with my centres*
- *Geared to highly adept people with memory issues.*
- *Thank you to everyone sharing and creating a safe place for people to share.*
- *As someone who works in the field and has aging parents with risks of dementia, I really believe our community could do more. Things like loud music in stores and restaurants. Turn it down and let people enjoy. I genuinely have never gone somewhere to listen to the overhead music. This little change could have a huge impact.*
- *The participants deserve a gold star for opening up their lives a little to strangers like me. I hope there is a significant community impact as a result and that people with dementia will benefit.*
- *Bravo to the team who have worked on this excellent campaign and lots of gratitude to the participants - the faces of dementia - who are sharing their stories with the world. This is an important cause and I hope the campaign/ messaging will spread to other communities.*
- *The participants who shared their stories were very brave and their stories were very moving. My husband had Alzheimer's Disease....we "shared" a 7-year journey. It was a privilege to be his main caregiver but would have been an impossible journey with the help and support we received. Thus, I could identify with the participants to-day and I know their presentations will go much farther than any academic talk or lecture ever could on the subject to create awareness, empathy and information.*
- *I think the format was well received. We could clearly hear each panel member. I can't think of anything that would improve the launch event.*
- *There was a comment made on the presentation and this is an amazing campaign, I agree with the fact that we need to have the caregivers faces as a presence as well. Excellent presentation the visuals and audio were amazing.*
- *It was amazing*
- *I intend to follow the Campaign as it continues, as well as Hamilton Council on Aging and the various supporting organizations (Alzheimer's Society, GERAS, AGE and others)*
- *Exposing oneself to scrutiny is making oneself vulnerable. I would never have known the individuals presented would have had dementia unless they spoke about the diagnosis in their lives.*
- *Having had a Grandmother, Mother, Aunts (on both sides of my family) and have my cousin with ALZ. The more we educate people about dementia the better for all. This was very informative, well done.*

- *Excellent!!!!*
- *Overall thank all of you for your insight and you are changing our world!!!!!!!!!!!!*
- *Well done!! Dementia scares people if they don't know anything about it, or only know the unpleasant parts. I have a better than average understanding from personal experience. My dad (who just recently died) lived with Alzheimer's for many years, & my family ensured he lived a quality life, with dignity, until his natural death. That included living for 6 yrs in a retirement home with lots of activities & social stimulation, & regularly attending some adult day programs in the community. His geriatrician said all that mental & social stimulation was at least as valuable, if not more so, than any available medication, such as Aricept (which he tried but it didn't agree with him). A geriatrician is also valuable to have involved--Dad had a wonderful one through St. Peter's Centre for Healthy Aging, with a team of different disciplines who were also involved as needed.*
- *I would like to hold information session in our Mosque for members to understand from different backgrounds*
- *I was impressed with the number of attendees (200). This shows there is a thirst for educating people. Loved the strategy of getting people suffering from Dementia on the panel in real time. How can I be involved?*
- *Overwhelming gratitude. Fantastic job! I commit to doing my best to share this and contribute to a more dementia-friendly community. <3*
- *Exceptional initiative!!! Congratulations!*
- *Thank you!*
- *Looking forward to sharing the campaign at my facilities*
- *Amazing work, it was great to hear from different people and have various components to the event. Great job!!*
- *Great job!!*
- *I'm looking forward to sharing this information with my Alzheimer Society and hopefully being able to share the video in our education sessions.*

## Demographic Information

What is your gender?

	Female	Male	Gender fluid/ non-binary/ two spirit	I prefer not to answer
Haldimand & area (N = 9)	88.9% (8)	11.1% (1)	0	0
Hamilton & area (N = 37)	83.8% (31)	10.8% (4)	0	5.4% (2)
Other/unspecified (N = 38)	73.7% (28)	18.4% (7)	0	0
<b>Total (N = 84)</b>	<b>79.8% (67)</b>	<b>14.3% (12)</b>	<b>0</b>	<b>2.4% (2)</b>

<b>Group</b>				
Persons living with dementia (N = 4)	75.0% (3)	25.0% (1)	0	0
Care partners (N = 8)	75.0% (6)	12.5% (1)	0	12.5% (1)
All others (N = 72)	80.6% (58)	13.9% (10)	0	1.4% (1)
<b>Total (N = 84)</b>	<b>79.8% (67)</b>	<b>14.3% (12)</b>	<b>0</b>	<b>2.4% (2)</b>

### Age

	<b>Average (±)</b>	<b>Range</b>	<b>Median</b>
<b>Community</b>			
Haldimand & area (N = 9)	52.4 (8.1)	41 – 64	55
Hamilton & area (N = 34)	59.1 (13.2)	28 – 84	63
Other/unspecified (N = 31)	58.8 (16.9)	24 – 92	62
<b>Total (N = 74)</b>	<b>58.2 (14.4)</b>	<b>24 – 92</b>	<b>61</b>
<b>Group</b>			
Persons living with dementia (N = 4)	66.0 (5.5)	62 – 74	64
Care partners (N = 8)	65.9 (14.1)	35 – 84	68.5
All others (N = 62)	56.7 (14.5)	24 – 92	58.5
<b>Total (N = 74)</b>	<b>58.1 (14.4)</b>	<b>24 – 92</b>	<b>61</b>

### Do you identify as Indigenous; that is First Nations (North American Indian), Métis, or Inuit?

	<b>Yes</b>	<b>No</b>	<b>I prefer not to answer</b>
<b>Community</b>			
Haldimand & area (N = 9)	0	100% (9)	0
Hamilton & area (N = 37)	2.7% (1)	86.5% (32)	10.8% (4)

	Yes	No	I prefer not to answer
Other/unspecified (N = 38)	0	86.8% (33)	2.6% (1)
<b>Total (N = 84)</b>	<b>1.2% (1)</b>	<b>88.1% (74)</b>	<b>6.0% (5)</b>
<b>Group</b>			
Persons living with dementia (N = 4)	0	100% (4)	0
Care partners (N = 8)	0	87.5% (7)	12.5% (1)
All others (N = 72)	1.4% (1)	87.5% (63)	5.60
<b>Total (N = 84)</b>	<b>1.2% (1)</b>	<b>88.1% (74)</b>	<b>6.0% (5)</b>

**Do you identify as a member of a visible minority in Canada?**

	Yes	No	I prefer not to answer
<b>Community</b>			
Haldimand & area (N = 9)	0	88.9% (8)	0
Hamilton & area (N = 37)	13.5% (5)	75.7% (28)	10.8% (4)
Other/unspecified (N = 38)	7.9% (3)	81.6% (31)	0
<b>Total (N = 84)</b>	<b>9.5% (8)</b>	<b>79.8% (67)</b>	<b>4.8% (4)</b>
<b>Group</b>			
Persons living with dementia (N = 4)	25.0% (1)	75.0% (3)	0
Care partners (N = 8)	12.5% (1)	87.5% (7)	0
All others (N = 72)	8.3% (6)	79.2% (57)	5.6% (4)
<b>Total (N = 84)</b>	<b>9.5% (8)</b>	<b>79.8% (67)</b>	<b>4.8% (4)</b>

If "Yes", select the options that you identify with. (Please note: More respondents identified a specific visible minority group than indicated above that they identified as a member of a visible minority.)

	<b>Black</b>	<b>Chinese</b>	<b>Filipino</b>	<b>Latin American</b>	<b>South Asian*</b>
Haldimand & area (N = 9)	0	0	0	0	0
Hamilton & area (N = 37)	5.4% (2)	5.4% (2)	0	0	10.8% (4)
Other/unspecified (N = 38)	0	0	2.6% (1)	5.3% (2)	5.3% (2)
<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>2.4% (2)</b>	<b>1.2% (1)</b>	<b>2.4% (2)</b>	<b>7.1% (6)</b>
<b>Group</b>					
PLWD (N = 4)	0	0	25.0% (1)	0	0
Care partners (N = 8)	0	0	0	0	12.5% (1)
All others (N = 72)	2.8% (2)	2.8% (2)	0	2.8% (2)	6.9% (5)
<b>Total (N = 84)</b>	<b>2.4% (2)</b>	<b>2.4% (2)</b>	<b>1.2% (1)</b>	<b>2.4% (2)</b>	<b>7.1% (6)</b>

\*e.g., East Indian, Pakistani, Sri Lankan, etc.

## Appendix M: Community Exhibit Survey Results

**Total number of surveys completed: 46**

Note: Percentages may not sum to 100% due to missing information.

### Response rate based on community

Community	% (#)
Hamilton and area	73.9% (34)
Haldimand and area	26.1% (12)
<b>Total</b>	<b>46</b>

### Response rate based on group

Group	N = 46
Persons living with dementia	2.2% (1)
Care partners of a person living with dementia	17.4% (8)
Family members or friends of a person living with dementia	28.3% (13)
General public (community at large)	52.2% (24)

### Care partners: What is your relationship to the person living with dementia?

Relationship	N = 8
Spouse/ partner	62.5% (5)
Adult child	12.5% (1)
Extended family member (in-law, cousin, niece/nephew, grandchild)	12.5% (1)
Friend	0
Other (not specified)	12.5% (1)

### Overall, how satisfied were you with the Faces of Dementia campaign?

	Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
<b>Community</b>					
Haldimand & area (N = 12)	16.7% (2)	0	16.7% (2)	16.7% (2)	50.0% (6)
Hamilton & area (N = 34)	5.9% (2)	2.9% (1)	11.8% (4)	23.5% (8)	55.9% (19)
<b>Total (N = 46)</b>	<b>8.7% (4)</b>	<b>2.2% (1)</b>	<b>13.0% (6)</b>	<b>21.7% (10)</b>	<b>54.3% (25)</b>

	<b>Very dissatisfied</b>	<b>Somewhat dissatisfied</b>	<b>Neutral</b>	<b>Somewhat satisfied</b>	<b>Very satisfied</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 1)	100% (1)	0	0	0	0
Care partners (N = 8)	0	0	0	12.5% (1)	87.5% (7)
All others* (N = 37)	8.1% (3)	2.7% (1)	16.2% (6)	24.3% (9)	48.6% (18)
<b>Total (N = 46)</b>	<b>8.7% (4)</b>	<b>2.2% (1)</b>	<b>13.0% (6)</b>	<b>21.7% (10)</b>	<b>54.3% (25)</b>

\*Family, friends, general public.

**Do you have any comments to make about this (satisfaction with campaign)?**

### **Persons living with dementia**

(no comments)

### **Care partners**

- *Awesome video, wonderful kick-off.*
- *So awesome to see this gallery.*
- *I think this is wonderful and empowering and exactly what should be happening.*
- *The gallery was positive. The report was somewhat dry.*
- *It was a great event and loved that all of the people with dementia who participated were in attendance.*

### **All others**

- *I like how it was made personal through people's personal stories about dementia.*
- *I love that you are making this a comfortable topic.*
- *I love it so much.*
- *I am so happy I was alerted to this event by a friend!*
- *I only said "somewhat satisfied" because I haven't been keeping up with things/ events. Everything I've seen / heard has been fantastic.*
- *I have not read the material yet. The material was available with the survey. I have read about Age-Friendly (Hamilton) in the Hamilton Spectator but do not remember seeing anything about Faces of Dementia. I can't really complete survey without reading material - will read and proceed. Matter available: Hamilton & Haldimand Luve Ed. 1 Winter 2022; Faces of Dementia Gallery Guide.*
- *Visually appealing, informative, multimedia.*
- *It really put faces to different examples of dementia that were surprising in some instances.*
- *A lot of very good information. Thank you.*
- *Well done!*
- *Would have loved to have a pull quote for each of the people featured or a bit of a written story for those who don't have a data plan.*
- *I think it is a wonderful campaign.*

- *Amazing! So innovative and inspiring.*
- *It would be advantageous to have this exhibit travel to every Long-Term Care Home/ Retirement Home in the Hamilton, Halton, Haldimand area. I also feel that this would be a great display to have in all educational institutions with medical students, nurses in training and PSWs (Private and public institutions such as Stay at Home Nurses, Home Instead) - educate, educate, educate. Display at all the Fairs - Caledonia Fair, Norfolk Fair, Ancaster Fair. Will the pictures be posted on Facebook? At City Hall - election year.*
- *Beautiful*

**Do you agree or disagree with the following statements about the affect that the Faces of Dementia campaign had on you?**

	<b>Community/ Group</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
I have a greater understanding of what it is like to live with dementia as a result of the campaign.	Haldimand & area (N = 12)	0	0	25.0% (3)	16.7% (2)	58.3% (7)
	Hamilton & area (N = 34)	0	2.9% (1)	14.7% (5)	47.1% (16)	35.3% (12)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>17.4% (8)</b>	<b>39.1% (18)</b>	<b>41.3% (19)</b>
	Persons living with dementia (N = 1)	0	0	100% (1)	0	0
	Care partners (N = 8)	0	0	12.5% (1)	50.0% (4)	37.5% (3)
	All others* (N = 37)	0	2.7% (1)	16.2% (6)	37.8% (14)	43.2% (16)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>17.4% (8)</b>	<b>39.10</b>	<b>41.3% (19)</b>
I have a greater understanding of the stigma (negative impacts) associated with living with dementia.	Haldimand & area (N = 12)	0	0	25.0% (3)	8.3% (1)	58.3% (7)
	Hamilton & area (N = 34)	0	2.9% (1)	11.8% (4)	47.1% (16)	38.2% (13)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>15.2% (7)</b>	<b>37.0% (17)</b>	<b>43.5% (20)</b>
	Persons living with dementia (N = 1)	0	0	100% (1)	0	0
	Care partners (N = 8)	0	0	12.5% (1)	50.0% (4)	37.5% (3)
	All others* (N = 37)	0	2.7% (1)	13.5% (5)	35.1% (13)	45.9% (17)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>15.2% (7)</b>	<b>37.0% (17)</b>	<b>43.5% (20)</b>
I learned new things about how to make my community more dementia friendly.	Haldimand & area (N = 12)	0	0	16.7% (2)	16.7% (2)	66.7% (8)
	Hamilton & area (N = 34)	0	2.9% (1)	11.8% (4)	47.1% (16)	35.3% (12)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>13.0% (6)</b>	<b>39.1% (18)</b>	<b>43.5% (20)</b>
	Persons living with dementia (N = 1)	0	0	0	100% (1)	0

	<b>Community/ Group</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
	Care partners (N = 8)	0	0	12.5% (1)	37.5% (3)	50.0% (4)
	All others* (N = 37)	2.7% (1)	2.7% (1)	13.5% (5)	37.8% (14)	43.2% (16)
	<b>Total (N = 46)</b>	<b>2.2% (1)</b>	<b>2.2% (1)</b>	<b>13.0% (6)</b>	<b>39.1% (18)</b>	<b>43.5% (20)</b>
I intend to use some of the things I learned in this campaign to make sure my interactions with persons living with dementia are welcoming and friendly.	Haldimand & area (N = 12)	0	8.3% (1)	16.7% (2)	8.3% (1)	66.7% (8)
	Hamilton & area (N = 34)	0	0	8.8% (3)	42.2% (12)	50.0% (17)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>10.9% (5)</b>	<b>32.6% (15)</b>	<b>54.3% (25)</b>
	Persons living with dementia (N = 1)	0	100% (1)	0	0	0
	Care partners (N = 8)	0	0	12.5% (1)	12.5% (1)	75.0% (6)
	All others* (N = 37)	0	0	10.8% (4)	37.8% (14)	51.4% (19)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>10.9% (5)</b>	<b>32.6% (15)</b>	<b>54.3% (25)</b>
I intend to use some of the things I learned in this campaign to make my community dementia friendly.	Haldimand & area (N = 12)	0	0	16.7% (2)	25.0% (3)	58.3% (7)
	Hamilton & area (N = 34)	0	0	20.6% (7)	38.2% (13)	41.2% (14)
	<b>Total (N = 46)</b>	<b>0</b>	<b>0</b>	<b>19.6% (9)</b>	<b>34.8% (16)</b>	<b>45.7% (21)</b>
	Persons living with dementia (N = 1)	0	0	100% (1)	0	0
	Care partners (N = 8)	0	0	0	25.0% (2)	75.0% (6)
	All others* (N = 37)	0	0	21.6% (8)	37.8% (14)	40.5% (15)
	<b>Total (N = 46)</b>	<b>0</b>	<b>0</b>	<b>19.6% (9)</b>	<b>34.6% (16)</b>	<b>45.7% (21)</b>
I am now more aware of the Empowering Dementia Friendly Communities project in Hamilton and Haldimand.	Haldimand & area (N = 12)	0	0	8.3% (1)	33.3% (4)	58.3% (7)
	Hamilton & area (N = 34)	0	2.9% (1)	0	52.9% (18)	44.1% (15)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>2.2% (1)</b>	<b>47.8% (22)</b>	<b>47.8% (22)</b>
	Persons living with dementia (N = 1)	0	0	100% (1)	0	0
	Care partners (N = 8)	0	0	0	37.5% (3)	62.5% (5)
	All others* (N = 37)	0	2.7% (1)	0	51.4% (19)	45.9% (17)
	<b>Total (N = 46)</b>	<b>0</b>	<b>2.2% (1)</b>	<b>2.2% (1)</b>	<b>47.8% (22)</b>	<b>47.8% (22)</b>

Please read each of the statements below and select the number that best reflects how correct you think each statement is. 1 = completely incorrect; 10 = completely correct.

### Community Dementia Attitudes Scale

Mean (SD) Range Median	Community		Group			Total (N = 46)
	Haldimand (N = 12)	Hamilton (N = 34)	PLWD (N = 1)	Care Partners (N = 8)	All others (N = 37)	
I have a good understanding of what it would be like to live with dementia	8.1 (2.0) 4 – 10 8.0	7.7 (2.0) 3 – 10 8.0	10.0 (.) 10 10.0	8.8 (1.7) 5 – 10 9.0	7.6 (2.0) 3 – 10 8.0	<b>7.8 (2.0)</b> <b>3 – 10</b> <b>8.0</b>
The main symptom of dementia is always memory loss.*	7.0 (3.2) 2 – 10 8.0	7.2 (2.7) 1 – 10 8.0	8.0 (.) 8 8.0	7.9 (2.1) 4 – 10 7.5	7.0 (2.8) 1 – 10 8.0	<b>7.2 (2.7)</b> <b>1 – 10</b> <b>8.0</b>
Medication is the only treatment that can reduce symptoms related to dementia.*	9.2 (1.0) 7 – 10 9.5	8.3 (1.9) 3 – 10 9.0	8.0 (.) 8 8.0	9.3 (2.1) 4 -10 10	8.5 (1.9) 3 – 10 9.0	<b>8.6 (1.9)</b> <b>3 – 10</b> <b>9.0</b>
There is a range of strategies that can help people with dementia in their everyday lives.	9.1 (2.1) 3 – 10 10.0	9.0 (1.6) 6 – 10 10.0	3.0 (.) 3 3.0	9.5 (1.1) 7 – 10 10.0	9.1 (1.3) 6 – 10 10.0	<b>9.0 (1.6)</b> <b>3 – 10</b> <b>9.0</b>
I have the potential to improve the lives of people living with dementia.	9.8 (2.0) 8 – 10 10.0	8.4 (1.8) 4 – 10 9.0	10.0 (.) 10 10.0	9.1 (1.4) 7 – 10 10.0	8.6 (1.8) 4 – 10 10.0	<b>8.7 (1.7)</b> <b>4 – 10</b> <b>10.0</b>
People with dementia can contribute substantially to their community.**	9.5 (.80) 8 -10 10.0	8.6 (1.8) 3 – 10 9.0	10.0 (.) 10 10.0	8.8 (2.4) 3 – 10 10.0	8.7 (1.5) 5 – 10 9.0	<b>8.8 (1.6)</b> <b>3 -10</b> <b>10.0</b>
Maintaining independence is one way to help a person living with dementia.	8.9 (1.4) 7 – 10 10.0	8.4 (1.9) 4 – 10 9.0	10.0 (.) 10 10.0	9.3 (1.2) 7 – 10 10.0	8.4 (1.8) 4 – 10 9.0	<b>8.6 (1.7)</b> <b>4 – 10</b> <b>10.0</b>
	7.8 (2.8) 2 – 10	7.4 (2.8) 1 – 10	10.0 (.) 10	9.3 (1.2) 7 – 10	7.1 (2.9) 1 – 10	<b>7.5 (2.8)</b> <b>1 - 10</b>

Mean (SD) Range Median	Community		Group			Total (N = 46)
	Haldimand (N = 12)	Hamilton (N = 34)	PLWD (N = 1)	Care Partners (N = 8)	All others (N = 37)	
People with dementia need assistance all of the time.*	9.0	8.0	10.0	10.0	7.0	<b>8.0</b>
People with dementia have the right to be involved in supported decision-making about their future.	9.2 (1.6) 5 – 10 10.0	8.6 (2.1) 2 – 10 10.0	10.0 (.) 10 10.0	8.4 (2.9) 2 – 10 10.0	8.8 (1.8) 5 – 10 10.0	<b>8.7 (2.0)</b> <b>2 – 10</b> <b>10.0</b>
For people with symptoms of dementia, a diagnosis can inform planning for the future.	9.5 (.67) 8 -10 10.0	9.2 (1.7) 1 – 10 10.0	10.0 (.) 10 10.0	9.6 (.52) 9 – 10 10.0	9.2 (1.7) 1 – 10 10	<b>9.3 (1.5)</b> <b>1 – 10</b> <b>10</b>
<b>Total Scale Score<sup>26</sup></b>	<b>8.8 (1.0)</b> <b>6.9 – 10.0</b> <b>9.0</b>	<b>9.3 (1.2)</b> <b>5.6 – 10.0</b> <b>8.6</b>	<b>8.9 (.)</b> <b>8.9</b> <b>8.9</b>	<b>9.0 (1.0)</b> <b>7.2 – 10</b> <b>9.3</b>	<b>9.3 (1.2)</b> <b>5 – 10</b> <b>8.7</b>	<b>8.4 (1.2)</b> <b>5.6 – 10.0</b> <b>8.7</b>

\*These items are reverse scored as statements designated as incorrect.

\*\*Significant differences between communities:  $F(1,44) = 6.1, p = 0.017$ .

### How would you rate the extent to which your community is currently dementia friendly?

	Not at all dementia friendly	A little bit	Somewhat	Very	Extremely dementia friendly
<b>Community</b>					
Haldimand & area (N = 12)	8.3% (1)	25.0% (3)	50.0% (6)	8.3% (1)	0
Hamilton & area (N = 34)	8.8% (3)	11.8% (4)	58.8% (20)	17.6% (6)	2.9% (1)
<b>Total (N = 46)</b>	<b>8.7% (4)</b>	<b>15.2% (7)</b>	<b>56.5% (26)</b>	<b>15.2% (7)</b>	<b>2.2% (1)</b>

<sup>26</sup> Higher scores reflect more positive community attitudes towards dementia as related to how persons living with dementia can be supported to remain active within their communities, considering their right, capacity, and preferences to do so.

	<b>Not at all dementia friendly</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely dementia friendly</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 1)	0	100% (1)	0	0	0
Care partners (N = 8)	12.5% (1)	12.5% (1)	75.0% (6)	0	0
All others* (N = 37)	8.1% (3)	13.5% (5)	54.1% (20)	18.9% (7)	2.7% (1)
<b>Total (N = 46)</b>	<b>8.7% (4)</b>	<b>15.2% (7)</b>	<b>56.5% (26)</b>	<b>15.2% (7)</b>	<b>2.2% (1)</b>

**This project is hoping to make Hamilton and Haldimand more dementia friendly. How important do you think this is?**

	<b>Not at all important</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Very</b>	<b>Extremely important</b>
<b>Community</b>					
Haldimand & area (N = 12)	0	0	0	33.3% (4)	58.3% (7)
Hamilton & area (N = 34)	0	0	11.8% (4)	32.4% (11)	55.9% (19)
<b>Total (N = 46)</b>	<b>0</b>	<b>0</b>	<b>8.7% (4)</b>	<b>32.6% (15)</b>	<b>56.5% (26)</b>
<b>Respondent Group</b>					
Persons living with dementia (N = 1)	0	0	0	100% (1)	0
Care partners (N = 8)	0	0	0	12.5% (1)	87.5% (7)
All others* (N = 37)	0	0	10.8% (4)	35.1% (13)	51.4% (19)
<b>Total (N = 46)</b>	<b>0</b>	<b>0</b>	<b>8.7% (4)</b>	<b>32.6% (15)</b>	<b>56.5% (26)</b>

**Do you have any final comments you would like to make about the Faces of Dementia Campaign or exhibit?**

**Persons living with dementia**

- *Show people in a natural setting. Let them choose what goes into the video.*

## Care partners

- *Hospitals need to be more involved!!*
- *Good campaign.*
- *Great campaign and a successful in-person event.*
- *More info on resources (contacts and locations).*
- *Informative exhibit and presentation.*

## All others

- *Beautiful brochure. I love how it was made personal with stories.*
- *Absolutely fantastic; quite likely a life changing event for those who live in fear, or denial of what is happening to them.*
- *Congratulations to all involved. These types of campaigns are so important to our community.*
- *Need more day programs in each community.*
- *The more information we can get on the preliminary stages followed by HOW and WHERE do I go from here.*
- *There was little information at the community exhibit to explain and describe dementia. There was little information of actual steps to address living with dementia. The community exhibit did not provide links/ contact to other existing community resources (i.e., Alzheimer Society).*
- *Keep it up. Education is key.*
- *More education especially at senior centre.*
- *Thank you for engaging up (sic) and giving us knowledge and understanding.*
- *Interesting display.*
- *I'm grateful to see this initiative!*
- *More awareness - getting the word out.*
- *More options for visually challenged individuals or people who don't use smart phones*
- *It is important to increase the number of individuals seeing the videoclips. Should this be on display at the Art Gallery of Hamilton? What next? Individuals diagnosed with dementia will have cognitive decline. How can we support what care will look like? When an individual is at advanced dementia we need to look at what can be done to keep the individual at home. Long-term care is often the next step. Families need to have other options - financial restraints should not dictate the decision. Keeping a loved one at home with family should be a financial option. How can decision makers rethink how funding is distributed for a loved one requiring greater care. What next? How will this support change to the process of getting support for a loved one?*
- *Try and connect with more organizations around the topic of Dementia*

## Demographic Information

### What is your gender?

Gender	Community		Total (N = 46)
	Haldimand (N = 12)	Hamilton (N = 34)	
Female	91.7% (11)	82.4% (28)	<b>84.8% (39)</b>
Male	0	11.8% (4)	<b>8.7% (4)</b>

<b>Gender</b>	<b>Community</b>		<b>Total (N = 46)</b>
	<b>Haldimand (N = 12)</b>	<b>Hamilton (N = 34)</b>	
Gender fluid/ non-binary/ two spirit	0	0	<b>0</b>
I prefer not to answer	0	2.9% (1)	<b>2.2% (1)</b>

### Age

<b>Age</b>	<b>Community*</b>		<b>Total (N = 43)</b>
	<b>Haldimand (N = 11)</b>	<b>Hamilton (N = 32)</b>	
Mean (SD)	51.4 (13.4)	65.3 (14.2)	<b>61.7 (15.1)</b>
Range	30 – 66	26 – 93	<b>26 – 93</b>
Median	54	67	<b>65</b>

Significant difference between communities:  $F(1,41) = 8.0, p = 0.007$ .

### Do you identify as Indigenous; that is First Nations (North American Indian), Métis, or Inuit?

	<b>Community</b>		<b>Total (N = 46)</b>
	<b>Haldimand (N = 12)</b>	<b>Hamilton (N = 34)</b>	
Yes	0	0	0
No	100% (12)	85.3% (29)	89.1% (41)
I prefer not to answer	0	11.8% (4)	8.7% (4)

### Do you identify as a member of a visible minority in Canada?

	<b>Community</b>		<b>Total (N = 46)</b>
	<b>Haldimand (N = 12)</b>	<b>Hamilton (N = 34)</b>	
Yes	0	14.7% (5)	10.9% (5)
No	100% (12)	70.6% (24)	78.3% (36)
I prefer not to answer	0	11.8% (4)	8.7% (4)

If "Yes", select the options that you identify with.

	<b>Total (N = 46)</b>
Arab	2.2% (1)
Black	0
Chinese	2.2% (1)
Filipino	0
Japanese	0
Korean	0
Latin American	0

	<b>Total (N = 46)</b>
South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)	2.2% (1)
Southeast Asian (including Vietnamese, Cambodian, Laotian, Thai; etc.)	2.2% (1)
West Asian (e.g., Iranian, Afghan, etc.)	0
Another visible minority group – please specify	0

## Appendix N: Community Exhibit Guest Book Entries

### Faces of Dementia Community Exhibit Guest Book Feedback

#### Minga Café Community Exhibit: Haldimand and Area

Guest book was signed by 12 individuals, with 6 comments:

- *Thank you for doing this open house.*
- *Beautiful community connection*
- *Absolutely beautiful! Thank you!*
- *What an awesome event – congrats to MICE!!*
- *Wonderful afternoon*
- *So informative and inspiring, such amazing organization. Keep it going.*

### Sackville Hill Senior Centre Community Exhibit: Hamilton

Guest book was signed by 25 individuals, with 22 comments:

- *Very informative. Wonderful event. I'm glad I came!*
- *Lovely to hear all the support for such an important initiative.*
- *Very informative!(2)*
- *So amazing to see this come to fruition!!*
- *Hamilton needs this – good start.*
- *Wonderful presentation.*
- *We really enjoyed our time.*
- *I appreciated getting direct emails for the First Steps Program.*
- *Excellent presentation*
- *Glad to be here!*
- *Awesome day 😊*
- *Congrats on an amazing event!*
- *So well done! Perfect pacing. Appreciate the extended time to socialize!*
- *What an awesome experience! Thank you.*
- *Best wishes. Great work.*
- *Important work*
- *Great work!*
- *Thanks for sharing*
- *Very important!*
- *A lot of very good information. A great event*
- *A lovely presentation. Thank you.*

## Appendix O: Reflective Journaling: Critical Reflective Inquiry Analysis

Description of Situation/ Discussion	Reflection/ Interpretation	Potential Changes/ Key Learnings
<p><b>Introductory meeting with participants from one region ('Meet and Greet'):</b></p> <ul style="list-style-type: none"> <li>• 4 participants; one care partner in attendance for support.</li> <li>• Intended goals were to share campaign rollout details, have participants introduce themselves and, depending on their comfort level, have a beginning conversation about beliefs, attitudes and perceptions of people living with dementia</li> <li>• Given concerns about participants' comfort level with sharing personal stories with relative strangers, they were provided options for the meeting agenda: i) focus on the campaign objectives with no expectations for the to engage or share personal information, or ii) start with introductions and sharing about themselves.</li> <li>• Participants went beyond a general introduction and jumped right into the core of their experiences!</li> </ul>	<ul style="list-style-type: none"> <li>• There were concerns pre-meeting about participants' comfort level and whether there would be a need to 'tiptoe' around some topics rather than be direct.</li> <li>• No need to have worried about participants' comfort level because all were more than willing to share their stories; they were very open to describing their experiences leading up to diagnosis, at the time of diagnosis and since then.</li> <li>• Meeting was described as an enriching experience; provided an overall deeper appreciation for the human-spirit, courage and strength.</li> <li>• Participants' openness, made it easy to facilitate this meeting.</li> <li>• All were excited about the campaign; all want to continue to contribute and thought the campaign was important.</li> <li>• Virtual meeting, while less personal than in-person, was easy for participants to access and still allowed for open discussion and the creation of a 'safe space' in which to discuss dementia and their experiences with it.</li> </ul>	<ul style="list-style-type: none"> <li>• Based on this meeting with participants, the facilitator changed their approach to the interview questions to be used with participants.</li> <li>• The original questions/ guide for the interviews were written before the facilitator met the participants.</li> <li>• Their willingness to openly share their experiences and thoughts, left the facilitator thinking that was possible to comfortably probe a little deeper than if participants had been more reticent.</li> <li>• In a COVID-free environment, an in-person meeting would be desirable, however, in this instance meeting virtually provided a viable and feasible option for participants to attend this type of meeting and allowed for rapport building and creation of a safe space in which to talk about dementia and participants experiences with it.</li> </ul>

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	<ul style="list-style-type: none"> <li>Using a virtual platform did require some time initially to establish rapport and to allow participants to “warm up” to each other. Virtual platform, in comparison to an in-person format, also made it a bit more difficult to step in to redirect conversation as needed.</li> </ul>	
<p><b>Individual Interviews with Participants (4 participants, 1 care partner present):</b></p> <ul style="list-style-type: none"> <li>As was the case in the introductory meetings, the participants were very forthcoming in sharing their experiences with their diagnosis and sharing it with other people.</li> </ul>	<ul style="list-style-type: none"> <li>Participants were described as being so generous in sharing their stories; very self-aware with much insight. Participants’ shared things that the facilitator appreciated (“<i>love it</i>”).</li> <li>The facilitator reflected on how these interviews made them feel noting a profound sense of gratitude for the opportunity to have these conversations and that: “<i>having this window into the lives of the participants is a gift.</i>”</li> </ul>	<ul style="list-style-type: none"> <li>Participants’ openness has enabled the facilitator to delve a little deeper into their experiences.</li> <li>Emerging theme in the interviews is the ‘invisibility’ of dementia and how that can lead others to question the diagnosis (‘I can’t believe you have Alzheimer’s’) or to not understand what the person is experiencing.</li> <li>There appears to be so much stigma in the healthcare system and delays in getting a diagnosis; highlights the need for much more education about dementia in medical schools.</li> <li>Key words/ phrases to describe the conversations were identified: resilience, strength, flexibility, growth, adaptation, coping strategies, humour, love, community, both receiving and giving; from loss to growth: accepting the losses that come with a diagnosis but using that as an opportunity to grow and change.</li> </ul>

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<ul style="list-style-type: none"> <li>The individual interviews were informally video-recorded; a summary of their interview was sent to each participant to review and to think of 2 or 3 key messages they wanted to share during the filming; they were also informed that the facilitator would bring their notes based on their recorded interviews and would be available to prompt as needed during the filming.</li> </ul>	<ul style="list-style-type: none"> <li>The in-person filming would not have gone so smoothly without this preparatory work.</li> </ul>	<ul style="list-style-type: none"> <li>Humour was identified as a coping strategy for the participants.</li> <li>Had the interviews been facilitated without having had the opportunity to get to know the participants and their stories ahead of time, the facilitator would not have known enough about them to draw them out and to build on their responses during the filming.</li> <li>For similar projects in the future, it was recommended that there be enough lead time to incorporate opportunities for getting to know one another before any filming or photography takes place.</li> </ul>
<p><b>Filming with three participants (one care partner present):</b></p> <ul style="list-style-type: none"> <li>Long day (10 hours) with film crew, photographer, assistants, project staff, and participants.</li> <li>Much time spent setting up for filming and still photography.</li> <li>Tiring for participants as filming for each participant took about three hours.</li> <li>Some locations were easier to film in than others (e.g., mosquitos and other bugs made filming in the Butterfly Garden difficult).</li> <li>Some participants found it difficult to pose in positions required by the photographer, either because of mobility issues or the terrain in which they were located (e.g.,</li> </ul>	<ul style="list-style-type: none"> <li>The facilitator noted continual learning from the participants and was again reminded that dementia, at least for some and in the early stages, is invisible; unless the individual tells you otherwise, you can't always 'see' the struggles they face and it is understandable why some people have trouble grasping the reality that the person with whom they are communicating is living with dementia.</li> <li>The facilitators described being in awe of the resilience and strength of the participants in moving beyond their diagnoses, creating adaptive strategies to help them continue to live their lives</li> </ul>	<ul style="list-style-type: none"> <li>Given the great length of time needed to set up for film and photography, in the future it was recommended that participants be invited to show up <u>after</u> the film crew has set up; this might make the experience less drawn out for them.</li> <li>This may be harder to do when the filming is in the participants' home. However, as the filming for two of the participants took place outside at their homes, they could have been invited to stay inside until the film crew was ready.</li> <li>In total, seven people were present for the filming, which might have been</li> </ul>

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<p>uneven ground). Another participant was not comfortable with posing doing activities that she was not really doing (fake or staged actions).</p> <ul style="list-style-type: none"> <li>• One participant was unaccompanied by others for the filming and requested that project staff, whom she had come to know through this project, be present.</li> </ul>	<p>to the fullest; interactions with participants were described as inspirational and gratitude expressed for the opportunity to get to know them.</p> <ul style="list-style-type: none"> <li>• Key messages learned about living with dementia: I'm still me; live in the moment; keep making plans; and, stay engaged.</li> <li>• Participants were striving for authenticity, however, requests to engage in activities or pose in certain ways felt artificial and unauthentic for them.</li> </ul>	<p>overwhelming, especially for one of the participants. Depending on what is known about the participants ahead of time, it might be better for some participants to complete the filming and photography on different days.</p> <ul style="list-style-type: none"> <li>• Consider the conditions of the filming locations and be prepared (e.g., bug spray for outdoor locations during high bug/ mosquito season.</li> <li>• It would have been preferable to get a better sense before the filming/ photography of each participants comfortable level with movement/ positioning requirements for photography in order to prevent participants from being asked to sit/ stand/ move in ways that are not comfortable.</li> <li>• Filming and photography should be as authentic as possible, with minimal staging of activities.</li> <li>• The filming/ photography process can be anxiety provoking; having someone present with the participant is comforting, even if it is project staff they have come know.</li> <li>• Engaging with the campaign participants resulted in a <i>“Deep appreciation for the generosity of people in sharing who they are, opening their home, lives and being so honest with strangers to help others.”</i></li> </ul>

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<ul style="list-style-type: none"> <li>• The interview with one participant who was accompanied by their care partner was challenged by further cognitive decline impacting ability to access language and had difficulty expressing thoughts in words; the care partner frequently jumped in to answer questions ahead of the participant.</li> <li>• While attempts were made to make the participant feel comfortable and while the participant’s body language seemed to reflect that they were comfortable, when the care partner was close there was a sense that the participant was anxious, perhaps feeling pressured to defer to the care partner.</li> <li>• Although the participant spoke independently ‘a bit’, they most often looked to the care partner to respond; while not know for certain, it seemed that the participant may have been primed about what to say and not say.</li> </ul>	<ul style="list-style-type: none"> <li>• The care partners’ behaviour posed a significant dilemma as the intent of the campaign was to amplify the voice of persons with dementia, not their care partners. Moreover, this dyad presented as a team and were it not for the care partner’s involvement, the participant likely would not have participated.</li> </ul>	<ul style="list-style-type: none"> <li>• The facilitator reiterated the intent of the campaign to the care partner and asked them not to jump in until the participant was given ample opportunity to respond independently; this helped for the most part though there were times when they continued to speak for the participant.</li> <li>• The facilitator described this as the interview they were least comfortable with and speculated that had interview been conducted with just the facilitator and participant present, it may have been possible to draw out the participant a bit more, but maybe not.</li> </ul>
<p><b>Second filming day (2 participants):</b></p> <ul style="list-style-type: none"> <li>• Less tiresome day as there was one less participant being filmed and there were places to sit.</li> <li>• No challenges experienced, filming when smoothly.</li> <li>• Participants all seemed very comfortable during the in-person filming.</li> </ul>	<ul style="list-style-type: none"> <li>• In-person filming proceeded well in large part to the amount of pre-film day preparation – the ‘Meet and Greet’ introductory meeting and individual interviews provided the facilitator the opportunity to get to know the participants and to hear their stories ahead of time and gave the participants</li> </ul>	<ul style="list-style-type: none"> <li>• People with dementia want their voices to be heard; they want to share their stories and to help others understand that they are people first and, following their diagnosis, they are adapting and living their lives as best they can every day.</li> </ul>

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	<p>an opportunity to begin to feel comfortable with the facilitator and to be assured that they would have opportunities to talk about what was most important to them.</p>	<ul style="list-style-type: none"> <li>Facilitator reflected on learning ways to adapt the interviews to help create content for the film makers, experimenting a bit more on the second day by approaching the interviews differently with each participant and in different way from the first day. This worked well in terms of generating different perspectives and reducing the sense of repetition in participant responses (e.g., talking about how ‘I’m still here’). While that was a wonderful recurring theme, there was a desire to ‘mix’ the responses up a bit to contribute to richer film content.</li> </ul>
<ul style="list-style-type: none"> <li>Due to COVID-19 restrictions and desire to keep the number of people present to a minimum, project staff (facilitator/ coordinator) were not present during the filming/ photography of two participants.</li> <li>Videographer lead the interviews with the participants during filming and had been prepared with notes from the interviews with these participants.</li> <li>One of the participants was accompanied by a social worker from the Alzheimer Society, who was her liaison support throughout this process.</li> <li>One of the participants is not connected to the internet, so communication was primarily via telephone.</li> </ul>	<ul style="list-style-type: none"> <li>It’s really important to ‘meet participants where they are at’ – ensuring they have the supports needed to participate and changing how people might usually work (e.g., via email, videoconferencing) to interact in ways that are comfortable for participants, such as using the telephone for meetings, or having important supports engaged/ available throughout the process.</li> <li>Alzheimer Society social worker who supported the participant was described as going the extra distance (well beyond the scope/ expectations of her role) to support the participant.</li> </ul>	<ul style="list-style-type: none"> <li>Consider inclusion in the budget of some monetary compensation for external partners who support campaign participants – making it possible for them to participate.</li> </ul>

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<ul style="list-style-type: none"> <li>• First and second days of filming occurred immediately following the Thanksgiving weekend.</li> </ul>	<ul style="list-style-type: none"> <li>• Given that filming was being conducted during the pandemic (fall 2021) and the current uncertainties with the virus and increasing rates, it may not have been wise to film immediately following the Thanksgiving weekend. Participants had visited family members, including unvaccinated children. The facilitator noted that adding to the uncertainty was the fact that this was their first time conducting work in-person and visiting someone's home since the pandemic started.</li> </ul>	<ul style="list-style-type: none"> <li>• Pandemic precautions in place made the situation comfortable and the facilitator found themselves adjusting quickly to the in-person work mode.</li> </ul>
<ul style="list-style-type: none"> <li>• A member of the production crew noted that they didn't know about dementia before this work assignment and how much they had learned; some expressed learning more.</li> </ul>	<ul style="list-style-type: none"> <li>• Unintended impact on increasing the production crews' knowledge of dementia.</li> </ul>	<ul style="list-style-type: none"> <li>• The project has begun to have a ripple effect that may expand to others.</li> </ul>
<ul style="list-style-type: none"> <li>• In subsequent conversations about the campaign with one of the participants, questions were raised that were outside the scope of project, but a connection to available supports via the Alzheimer Society was made.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants comfort level with those involved in developing the campaign resulted in their being open to identifying and discussing issues requiring support.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants should have access to available supports should the need arise during the development of the campaign. New learnings/ reflections about dementia or changes in their condition during the campaign may require assistance.</li> </ul>
<p><b>Virtual debrief meeting</b></p> <ul style="list-style-type: none"> <li>• Some of the participants attended a Zoom meeting to: <ul style="list-style-type: none"> <li>◦ Debrief the film and photo shoot – to share experiences.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• The filming and photo shoot was described by all participants in attendance as positive – one participant described themselves as being on 'a high' for at least two days following the filming.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants' responses provided support for the time spent on the introductory meeting and individual interviews.</li> <li>• No changes were suggested for the debrief meeting, other than a desire for all participants to be present.</li> </ul>

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<ul style="list-style-type: none"> <li>○ Update participants on the next steps (photo selection and campaign timeline).</li> <li>○ Have a conversation about how to extend the campaign and broaden the scope to continue to collect stories about individuals living with dementia.</li> </ul>	<ul style="list-style-type: none"> <li>● The participants reported feeling comfortable and expressed appreciation for the preparation we had done together in the Meet &amp; Greet and in the individual interviews. They were all committed to being upfront and candid about sharing their stories and continuing to the campaign in any way they can.</li> <li>● The facilitator described as gratifying to hear how much participating in the film and photo shoot meant to participants.</li> <li>● One of the participants opted not to attend the meeting as they were not having a good day. This served as a reminder that not every day is a good one for her (or probably for anyone) and made the facilitator wonder how much energy and effort it might take for some to present themselves to others.</li> </ul>	
<p><b>First campaign viewing</b></p> <ul style="list-style-type: none"> <li>● Facilitator’s first viewing of a first cut of the campaign video and additional clip of one of the participants.</li> </ul>	<ul style="list-style-type: none"> <li>● The facilitator felt the production team did “<i>an amazing job</i>” teasing out the key messages that participants wanted to share and recognized the challenge of needing to distill 3 hours of content to 4-5 minutes.</li> <li>● The video was described as emotionally moving.</li> <li>● It was anticipated the video would have a significant impact on viewers; this was</li> </ul>	<ul style="list-style-type: none"> <li>● None noted</li> </ul>

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	<p>attributed to the willingness of the participants to so generously share their stories and their commitment to making a difference in how people view individuals living with dementia.</p> <ul style="list-style-type: none"> <li>• The participants were described as radiating strength and the determination to live their lives to the fullest, each echoing variations on the theme of ‘I’m still me’.</li> </ul>	
<p><b>Meeting to view campaign videos</b></p> <ul style="list-style-type: none"> <li>• Meeting with six of the seven campaign participants to review the campaign video as a group; prior to this meeting, each participant had the opportunity to view the video individually.</li> <li>• The production company was able to create four additional videos on four participants for whom they enough excess footage to delve deeper into their story.</li> <li>• The participants all liked the campaign film which is about four and a half minutes long and did not have any changes to suggest.</li> <li>• As part of the campaign, the marketing company suggested creating ‘I am more’ statements for each participant to include in the campaign promotional materials; this builds on the theme of participants being more than their diagnosis.</li> <li>• At this meeting, participants thought about what they would like to see as their ‘I</li> </ul>	<ul style="list-style-type: none"> <li>• The facilitator described this meeting as “quite moving” and a lovely way to wrap up their time together on this phase of the campaign.</li> <li>• One particularly moving moment was when the spouse of one of the participants asked if his appearance in the video could be edited as he looked like he was tearing up talking about his wife. The other participants were quick to jump in to assure him that they loved that part because it was so authentic, it was from the heart and it was such a human response. As this participant did not know the other participants prior to this experience, it was heartwarming for the facilitator to observe the way the others have welcomed, supported and encouraged the participant and her spouse.</li> <li>• As there was not enough footage for two</li> </ul>	<ul style="list-style-type: none"> <li>• The facilitator noted that while the participants seemed to find their time together rewarding, the facilitator is not sure if anyone found it more rewarding than they did: “<i>They all pulled on my heartstrings and I will never forget the participants and the impact they had on me.</i>”</li> </ul>

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<p>am.....’ statements and they prompted and encouraged each other with suggestions.</p> <ul style="list-style-type: none"> <li>• Participants came up with about five statements per person and seemed to really enjoy the activity; these included: <i>‘I am fearless’</i>, <i>‘I am a writer’</i>, <i>‘I am a changemaker’</i>, <i>‘I am a wife/mother/grandmother’</i>. <i>‘I am resilient’</i>, <i>‘I am a tree hugger’</i>, <i>‘I am a life-long learner’</i>. <i>‘I am a leader’</i>.</li> <li>• The facilitator felt the participants’ ‘I am’ statements were wonderful and proposed a wrap group statement: <i>“We are all advocates”</i>, which the participants like.</li> <li>•</li> </ul>	<p>participants (one who is further along in the progression of the disease and difficulty accessing language) to receive more in-depth, individual videos. The facilitator was concerned that this would be noted and an explanation requested for the absence of these videos for these participants. The facilitator was relieved that while one participant alluded to their individual story, they were able to ‘glide’ past that and focus on the group.</p> <ul style="list-style-type: none"> <li>• Another poignant moment for the facilitator was when the spouse of one participant explained that the participant is teaching them how to cook so when the time comes that they are no longer able to cook, the spouse can take over the cooking responsibilities; an example of cake baking was provided that reflected not only their partnership but the realities they face; while the spouse described this as sad, it was lovely example of their partnership and planning ahead.</li> <li>• The facilitator noted that while all of the participants talked about how much they enjoyed participating in the campaign and the group meetings.</li> </ul>	