

*CREATE – READi Action Team Project Final Report*

# The Dementia Society of Ottawa & Renfrew County



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# Acknowledgments

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# Abstract

This report details an 8-month project researching levels of awareness and access to support resources by young caregivers of people living with dementia. The project grew out of a need to understand the gap in young caregivers accessing support resources. Following regular meetings with representatives from the Dementia Society of Ottawa and Refrew County and conducting a literature review, the authors devised an online survey that was distributed during July and August of 2020 via DSORC's network. Some of the key findings of this survey suggested the creation of a one-stop hub for information and services, including more culturally appropriate resources, more flexible scheduling for meetings and activities, and using social media (Facebook groups in particular) to exchange ideas and build community. This research was conducted exclusively online as a result of the COVID-19 pandemic, which highlighted the possibilities of expanding online resources as a means to facilitate access to caregiver support. These and other findings are consonant with the literature and suggest that optimization of communication, especially at primary points of care or referral, are crucial to successful and healthy caregiving.

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# List of Abbreviations

ATP – *Action Team Project*

CREATE – *Collaborative Research and Training Experience program*

DSORC – *The Dementia Society of Ottawa and Renfrew County*

NSERC – *The Natural Sciences and Engineering Research Council*

READi – *The Research and Education in Accessibility, Design, and  
Innovation training program*

# Introduction

## ***The CREATE-READi Action Team Project***

Research and Education in Accessibility, Design, and Innovation (READi) is an interdisciplinary post-secondary accessibility-training program funded by the Collaborative Research and Training Experience Program (CREATE) of the Natural Sciences and Engineering Research Council (NSERC). The READi program gathers a diverse cohort of students from Carleton University, University of Ottawa, and Queen's University who study in different fields (from industrial design to music) and receive training and guidance in accessibility related issues. Within the READi program, students participate in Action Team Projects (ATPs), 8-month interdisciplinary projects focused on real-world accessibility issues in collaboration with an external READi partner.

## ***Dementia Society Project Overview***

Our community project was developed in collaboration with the Dementia Society of Ottawa and Renfrew County (DSORC), a non-profit organization that supports people living with dementia and their caregivers offering a variety of services to meet their needs. Our project meant to explore support resources for young caregivers of people living with dementia, while finding ways to increase awareness of such resources. Through collaboration with community partners and our project coordinators, we were able to develop research methods and recommendations specific to young caregivers and their respective needs.





Figure 1. Dementia Support Group at the DSORC (via LinkedIn)

*Project Goal:*

*“Explore a **support resource** for **young caregivers** (of people living with dementia), while finding ways to **increase awareness** of such resources within Ottawa.”*

# Background

## ***The Dementia Society of Ottawa and Renfrew County***

The Dementia Society of Ottawa and Renfrew County (DSORC) is a local organization which helps more than 7,500 people every year with the aid of community partners, volunteers and donors (DSORC, 2019). The DSORC works with several partners and members of the community to provide care, support, and resources for individuals living with dementia and their respective caregivers. While working with this organization and its team, we were able to explore many aspects of dementia which could be improved through further research and project collaboration. Our goals were to develop a means of cultivating updated research about dementia and DSORC resources, while also using methods to gather real-time feedback from individuals currently using the services provided by DSORC and similar dementia-friendly organizations.

## ***Research Question***

Preliminary research, market analyses, and community-partner meetings identified a lack of participation and use of support and resources by young caregivers. This population of caregivers stood out as an opportunity to find solutions to increase awareness of DSORC resources and potentially improve access to these tools for younger caregivers in response to their specific needs. A young caregiver is generally characterized as a person who cares for an individual (living with dementia), falling within 18-35 years old. Because of this, their needs for support and additional resources may differ from caregivers with more experience or different daily schedules. Currently, DSORC provides dementia-related information, self-care information, social media education and awareness, peer support groups, caregiver coaching, among other resources to their young caregiver groups (DSORC, 2019). It led our team to discuss what is preventing young caregivers from engaging with these resources and what is hindering their awareness and access to these tools and support resources? Our aim for this project was to *explore a support resource for young caregivers (of people living with dementia), while finding ways to increase awareness of such resources within Ottawa*. Our hope for this project is to conclude how young caregivers can be more involved in dementia-friendly organizations, while also finding out specific resources and/or tools that are specific to the needs of these individuals.

# Methods & Approach

## *Secondary & Primary Research*

From initial conversations with Dean from DSORC, the action team was presented with three broad avenues for the focus of the project. These avenues were:

- 1 Improving the young caregiver support program at DSORC,
- 2 Improving how DSORC provides dementia-education to the general public (especially those affected most by dementia and/or caregiving),
- 3 Optimizing how referrals are carried out (especially a diagnosis of young onset dementia).

As a group, we agreed to focus on young caregiver support aspect with a slight extension to the educational aspect. Our initial research question was therefore, “How can we improve the implementation and dissemination of information, education and resources for young caregivers?”. To get a better understanding of what dementia-related information, education and resources exist, our team wrote a literature review. From the literature review, we developed of market analysis comparing the pros and cons of different dementia support tools and resources.

Following the completion of the literature review and market analysis (before the COVID-19 pandemic), Dean provided us with feedback for ongoing monthly support groups hosted by DSORC for young caregivers. Dean mentioned that attendance to these support groups was habitually low. Thus, our team shifted the research focus to a two-part question, “What are the causes of low attendance in these support groups and what are ways that we can encourage young caregivers to use existing support resources?” To obtain answers to this question, we created a survey that was distributed to members who have attended the DSORC young carer support group, as well as those receiving support from a network of dementia-friendly organizations existing in Ontario.

## ***Literature Review***

The literature review, found in Appendix A, consists of four main sections: general health-related dementia information, information about young carers and young onset dementia, information covering dementia-friendly organizations in Ontario, and descriptions of existing tools and support for caregivers.

The literature review contributed to the later steps in the project in various ways. First, the dementia-related biology and Canadian statistics showed the effects of dementia in different age groups and the effects of dementia on a national scale. Young carer information gave insight on their generalized living circumstances and work-life balance challenges. Furthermore, information about DSORC and existing dementia support organizations, as well as information about existing support tools and educational tools put to sight options available to the public for adapting to dementia.

## ***Market Analysis***

The market analysis, included in Appendix B, is an Excel file with four sheets: support/communication, education, assistive technologies and building awareness. Each sheet is a matrix containing the name of the product/tool, examples of modality, an overview of the tool, its origin, whether it exists at DSORC or not, key features, challenges, drawbacks and references. Due to circumstances imposed by COVID-19, the most useful sections of the market analysis were support/communication and software-based assistive technologies. The market analysis showed that webinars and live video chat platforms such as Zoom, Skype and YouTube are commonly accessible and effective means for communicating with young caregivers.

## ***Online Survey***

Using insights from the literature review and results from the market analysis, our team created an online survey, which can be found in Appendix C. In order to answer the research question, we constructed the survey in a way that gives us a better understanding of who identifies as a young caregiver, and an assessment of what dementia-support tools are being used and of people's level of awareness about a variety of dementia-related subjects. The survey contained five sections in the following order: demographics, caregiver-care receiver relations, evaluating current support tools, assessing caregiver needs and public awareness.

During the dissemination of the survey to dementia-care organizations in Ontario, we gave the option for participants to answer whichever questions they'd like to and in the depth at which they felt comfortable. This flexibility in surveying was to encourage maximal participation. The survey was available to participants between July and August 2020 and yielded 18 respondents.

Using the charts in Appendix C.1, a two-step analysis was carried out to draw meaning from the survey results. After identifying three age groups of respondents, we determined the distribution of ages of participants who responded to each question; participant numbers corresponding to responses were color-coded based on age. Next, we examined the age distribution per question to identify age-related trends in dementia caregiving and make recommendations based on those trends. These recommendations include appropriate next steps for DSORC in advancing its young caregiver support group and ideas directed to DSORC for additional avenues to provide young caregiver support.

## ***Study Limitations***

One limitation of the market analysis is that the 'Building Awareness' section has not been completed due to focus being on 'Support/Communication'. Future work would look at methods existing in the market for promoting dementia awareness.

Another limitation was found in the survey, which was only available to the public for two months, meaning that the range of responses was not broad enough to make conclusions that are scientifically generalizable. In addition, with the option of allowing partially completed surveys to be submitted by participants, there may have been some bias towards the answers to certain questions and age distributions, which would make it more difficult to interpret trends in the results.

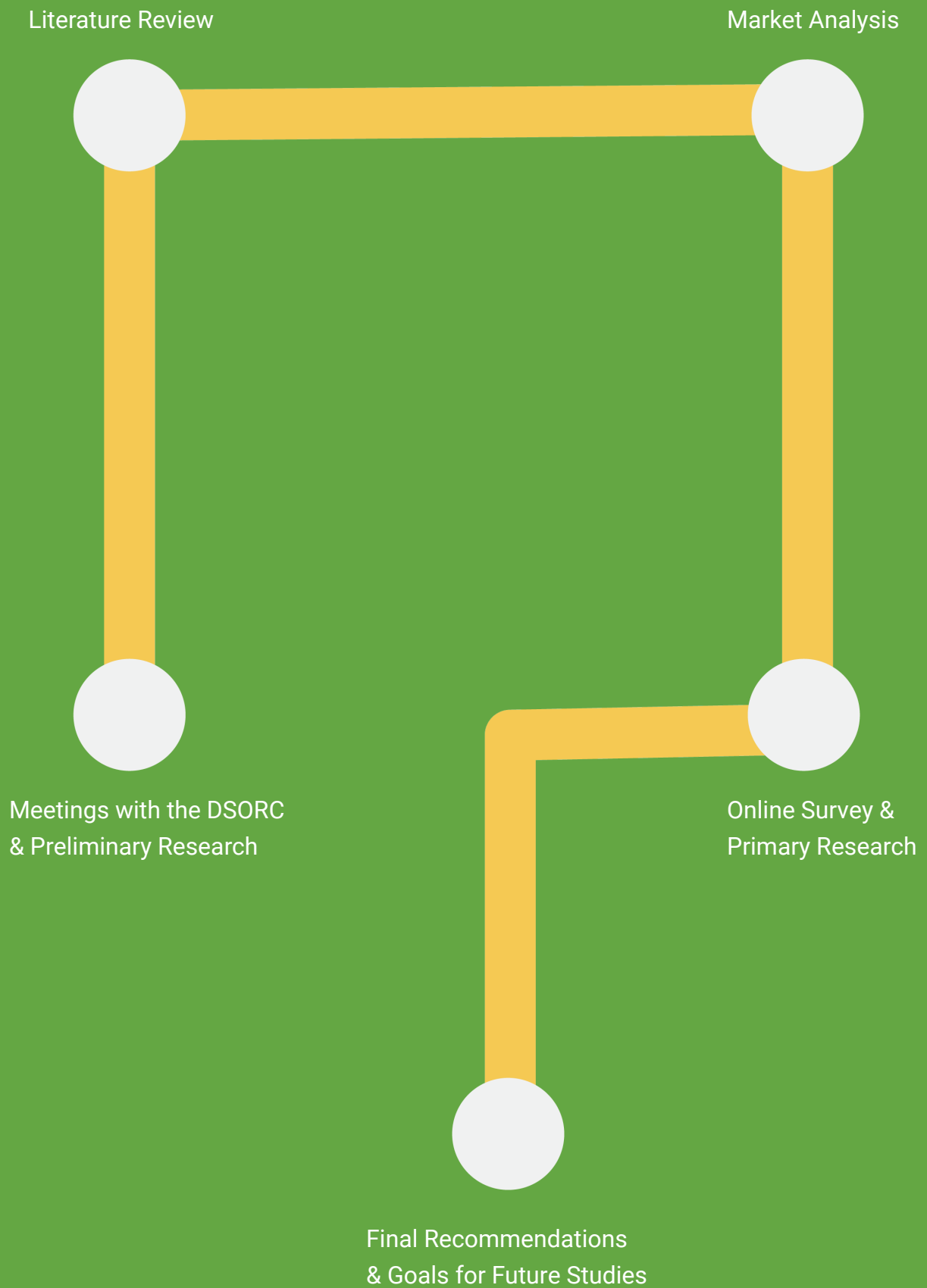


Figure 2. Methodology Framework



# Findings

## *Study Results*

Our survey was conducted exclusively online and was active during July and August 2020. The Dementia Society shared the survey through various online networks. The initial goals of the survey were to increase understanding of who identifies as a young caregiver and assess levels of awareness about a variety of dementia-related subjects. The COVID-19 pandemic posed both an opportunity and a challenge to conducting this survey. Being forced to conduct the survey online reinforced the ease with which we could reach out to care networks across Canada. However, it does raise concerns that potential respondents who would not normally be active online could have been excluded from participating.

Our survey yielded 18 respondents overall. However, a little under half of the responses were incomplete. It should be noted that participants were encouraged to respond only to the questions that they wanted to answer. We did not identify consistent patterns as far as which questions respondents did or did not answer. Variables that might help explain the low number of complete responses, and responses overall, could include the length of the survey and that the survey was only available for two months. It might also be a reminder that a caregiver may want to participate in a survey but not have the time to do so. There were 12 surveys that were nearly completed or entirely completed and for certain questions provided findings that we think are strong enough that they are worth sharing here. In particular, this true for two demographic data points. First, out of 18 respondents who identified a gender, only 1 identified as male and 17 identified as female. Another significant finding is the age distribution of respondents, most (10) identifying as 35 years of age and older while no respondents identified as under the age of 18.

Besides demographics, questions about how well educational tools addressed care giver mental health and cultural contexts of caregiving also yielded notable response distributions. In both cases, respondents suggested that educational tools could include more mental health and cultural components. These findings are supported by the literature. Addressing cultural contexts could remove a potential barrier to accessing care resources and addressing mental health could be an important way of prolonging effective care.



For questions on levels of awareness about dementia, caregivers and dementia-related organizations, respondents skewed toward “Aware” and “Extremely Aware.” However, awareness of dementia-related caregiver tools skewed towards “Neutral” and “Unaware.” One possible interpretation of this data is to confirm that caregivers are aware of what they need to do in their care giving role yet feel they could be assisted by having greater access to and knowledge or resources. Respondents also shared their views on which platforms they would like to see used to promote dementia awareness. The responses included print media, radio announcements and online networks. The most interesting recommendation that we identified was the call by 7 respondents to have more “posters in clinics, care centers, etc.” This raises the question of whether there is a break in communication at primary points of care. The significance of this finding should not be understated as it relates to timely access to information and awareness of tools for providing care and self-care. This parallels the DSORC’s interest in how to optimize communication at points of referral. The lack of input from caregivers younger than 18 also means that a crucial demographic of caregivers is absent from this survey.

# Recommendations

## *What We Found*

Our research has shown that:

- The creation of 'one-stop hub' could facilitate young caregivers' access to resources available for them. Through a 'one-stop hub' young caregivers will be able to "piggy-back" on resources, coordinating and improving efficiencies and effectiveness,
- Social media could be used more effectively to reach out to and engage with young caregivers),
- The category of 'young caregivers' comprised participants whose age was above the commonly used age range for young caregivers. In this sense, self-identification of participants as young caregivers mattered most than year of birth.
- A more flexible schedule could favor participation of young caregivers in meetings and activities aimed at them.

## *Recommendations for the Dementia Society of Ottawa and Renfrew County*

Based on findings, we would encourage the Dementia Society of Ottawa and Renfrew County to consider the following:

- Create a one-stop hub to centralize all information and resources for young caregivers of dementia patients.
- Reach out to young caregivers through the use of new media such as Twitter and Facebook. In particular, the creation of a Facebook group could allow the Dementia Society to increase engagement, leads and conversations, and built a community around a common theme of interest. Facebook groups can be one of the most effective ways to share a space and actively participate in it rather than be fed one-way information.

- Work around caregivers' schedule in planning of meetings and activities. This strange time of on-going pandemic and forced periods of remote working could be used as a learning ground to try out more flexible schedules for online meetings and activities involving young caregivers.

### ***Future Work***

The hope for our research is that this becomes the first step of a much larger project where different aspects of our work, could be further developed and some of our recommendations could be tried out on the ground. Setting up a Facebook group, creating a one-stop information hub and working more flexibly around caregivers' schedule, are immediate solutions to test in a second phase of this project.

In terms of academic work, further research is needed to understand the reason for the gender imbalance among participants and whether a correlation exists between the higher number of female participants and gender roles in the family. Also, more work could be done to expand the definition of young caregiver in light of the fact that our participants identified themselves in this category despite being beyond the typical age-range for that group.

# Conclusion

Our community project with the Dementia Society of Ottawa and Renfrew County took us on a journey to discover the challenges faced by young caregivers dealing with dementia patients and how to work and cope with these challenges. The overarching objective was to find a way to increase caregivers' participation to activities targeted to them.

Our findings showed that participants identified themselves as young caregivers even if the large majority was in the age range 35+. The findings also pointed out to a need to create a one-stop hub for information and services, to work around a more flexible schedule for meetings and activities and to use social media (and Facebook groups in particular) to exchange ideas and experiences, connect people and build a community.

Society would benefit from additional research regarding the planning of pertinent, accessible, cost-effective interventions to help young caregivers better cope with the rigors of caregiving under a variety of circumstances. Determining caregivers' current level of awareness about dementia organizations and dementia related tools, is thus only the first step towards a deeper understanding of a much bigger and complex reality.

*“[...] a **one-stop hub** for information and services, to work around a more flexible schedule for meetings and activities and to use social media (and Facebook groups in particular) **to exchange ideas and experiences, connect people and build a community.**”*

# Reflections

## *Team Reflection*

Throughout this project, our team was able to gain valuable experience and understanding of dementia, caregivers, and working in collaboration with community partners. Our ATP was able to explore how to build upon existing support tools and resources for caregivers, while also finding ways to increase awareness and access to these resources in Ottawa. Through the ATP and READi program, our team was able to takeaway many lessons about human-centered approaches to problem identification and problem solving, in addition to recognizing the importance of empathy and respect in a community project. Our team was able to develop and use a variety of different methods throughout this study to achieve our goals for the DSORC which combined our skills and experience as an interdisciplinary team. This proved to be a valuable lesson in how to work in a group and apply learned skills to a project.

Along with many collective reflections and experiences with this community project, we were each able to takeaway one key thing from this community project:

**Kayla** "This project was a great opportunity to learn about working with community partners and an interdisciplinary team."

**Michael** "The hardest part of a community project is often defining the problem and project focus."

**Brendan** "Doing this work during the ongoing COVID-19 pandemic has highlighted the importance of internet access, literacy and security."

**Frederica** "Is there a correlation between the higher number of female participants and gender roles in the family?"

## ***Accessibility***

The ATP provides an opportunity to learn and apply knowledge about accessibility, research, design, and innovation into real-world community projects. This presented an opportunity to learn more about dementia and the ways that design and research can be applied as a tangible solution for the DSORC and related dementia-friendly organizations. The READi training program has allowed our team to gain skills in recognizing and empathizing diversity in communities and has given us a connection to community partners so that we could apply these learned skills to young caregiver needs and develop a set of recommendations for future work in this area. Through the many experiences offered through READi and the ATP's, we have taken away a new appreciation of accessibility and inclusivity and how design and research may improve some aspect of this in a meaningful and sustaining way.

## ***Community Projects***

Having the opportunity to work with Dean Henderson and his team at the DSORC proved to be a valuable learning experience and chance to build on our personal and collective skills as an interdisciplinary team. We were able to use our individual skills and perspectives to design and execute a real-world community project which could be used to improve aspects of young caregiver outreach and support. We hope that our work will make a difference in what the DSORC does in their future projects. This experience taught us many things about ourselves as individuals and professional students and we look forward to seeing where things go in the future.

# References

The Dementia Society of Ottawa and Renfrew County - DSORC. (2019, August 14). Retrieved October 20, 2020, from <https://dementiahelp.ca/>

# Appendices

Please find the accompanying document with our project appendices.



