

Technical Appendix: Promising Practices and Indicators for Caregiver Education and Support Programs

November 30, 2011

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Ontario

Echo: Improving Women's
Health in Ontario

Écho : pour l'amélioration
de la santé des Ontariennes

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Context for the research study

In December 2010, Echo: Improving Women's Health in Ontario funded this study to determine the current best practice programs and tools that provide education and support to family members and friends who care for others and to create recommendations for cost effective education support priorities for a range of people across Ontario. Echo's request for Saint Elizabeth researchers to undertake this work was designed to build on the Ontario Ministry of Health and Long-term Care's 2008 Workshops "Caring about Caregivers," and was intended to inform ECHO's future work and engagement with others interested in supporting people who provide care and support on a voluntary basis.

Caregiver involvement

Saint Elizabeth researchers were committed from the beginning of this project to carry out the research in a way that empowered caregivers interested in participating in this research, by providing them with significant opportunities for steering the research, participating as key informants, and reflecting on the analyzed data, research results and project outputs.

Research team interaction

Regarding research team meetings, we learned early-on that adjustments had to be made to the typical format and proceedings of a research steering committee in order to engage caregivers in the process and accommodate their unique needs for participating. In usual circumstances, and for other projects, research team members often meet in-person in an office location, and when team members are unable to participate in person or are geographically dispersed, a teleconference format is often used. .. As one of our caregiver research team members was currently very active in providing care and support to a family member, she attempted to participate in the meetings using a teleconference, as travelling to in-person meetings would be very inconvenient based on her care responsibilities. However, we learned from her that the teleconference format was alienating and depersonalizing. Therefore, a decision was made, with the caregiver research team member's enthusiastic consent, to gather in her home for our steering committee meetings.

Involving caregivers in the research

The project's six-phase methodology (described more fully below) was designed to provide multiple ways for caregiver input and engagement throughout the entire research study process.

In the first phase, caregivers were involved in the steering committee; sharing their own personal experiences with caregiving, providing guidance and advice to the research team on approaches to participants, as well as on the analysis of the data collected over the course of the project. As our experience with ensuring active involvement of one of our caregiver research team members showed, we needed to further adapt our approach to steering committee meetings to ensure that meetings were convenient for other caregiver participants. Accordingly, we held meetings in at least three sites, joined by teleconference: our caregiver research team member's home, at the Woolwich Community Health Centre (nearby the workplace and home of other caregiver-members), and at Saint Elizabeth's offices in Markham. We offered as well to host other sites, in Whitby, for example, but the other caregiver participants found teleconferencing to be appropriate and acceptable.

In Phase 3, we solicited caregivers' stories through an internet site. Though we requested gently that they touch on their experiences with education and support programs, we encouraged them to provide their personal experiences providing care and support as fully as they wished. This provided the research team with rich descriptions of some caregivers' overall experiences, and helped the research team situate the role of education and support programs within the caregivers' experiences with family members and the health care system.

In Phase 6, we sought the views and experiences of caregivers directly in focus groups and key informant interviews. Our original plan had been to conduct focus groups only. However, from our review of the academic literature and caregiver input in our steering committee meetings, we recognized that caregivers' preferences for one-on-one or group sessions (for education and support programs) could differ according to the unique needs of each individual caregiver. Therefore, it was decided that caregivers should also be provided the opportunity to comment on the key findings of the research in either a one-on-one or group format. Accordingly, two key informant interviews were conducted with caregivers who were unable to participate in one of the seven focus groups, either due to conflicts with the date and time of the session, or because they lived far away from the location of the session. We also provided this opportunity to our steering committee members, and conducted two additional key informant interviews with caregiver members.

In this phase, we also incorporated what we learned from the literature and caregiver input concerning the conduct of group and one-on-one sessions. Specifically, we tried to make that sure the participants of the focus group sessions were as comfortable as possible in the setting, and that the focus group exercise imposed as little pressure and stress on them as we could manage. We therefore offered to pay for, and if possible, arrange for respite care while caregivers attended the sessions, and this offer was taken up in a few cases. (Incidentally, research team members experienced first-hand the frustrations caregivers face when they are arranging respite – lead times for arranging respite are longer than sometimes convenient, and finding the right respite provider is often difficult.)

We tried to conduct the focus group sessions in a way that would gather data for the project, but that would also enable the participants themselves to benefit in some way from participating in the sessions. We therefore conceived and conducted these focus group sessions as 'one-off, mini-support group sessions,' since we knew from our review of the literature that support groups can increase caregiver knowledge and satisfaction, reduce loneliness and social isolation, and initiate feelings of empowerment. In two of the focus group sessions, participants exchanged email addresses and telephone numbers to be able to maintain contact among themselves, and to provide mutual support.

One caregiver provided feedback after one of the sessions:

"Thank you for your presence today. I normally do not do groups so it was surprising to me that I would feel so comfortable with three strangers. I was particularly impressed with our ability to 'listen and hear' each other; a very necessary skill when caring for those with dementia and Alzheimer's. I will take advantage of the links you have provided."

From “best practice programs” to “promising practices and indicators”

As noted above, this study started with the goal of identifying current best practice programs and tools, but early on, in the course of the search of research studies on caregiver education and support programs, it became apparent that, at least in the research community, it was unlikely that we would be able to identify “best” practices and tools. The research literature on caregiver education and support programs and approaches is vast and no consensus has emerged on standard methods for measuring and assessing effectiveness, or reporting the features of programs that are being evaluated. Nonetheless, there are a number of trends in the literature that emerge as potential guideposts for improving caregiver education and support programs.

In June 2011, Echo published the *Ontario Women’s Health Framework*.¹¹ This Framework articulated a vision for improving women’s health in Ontario and strategic priorities based on the identification of gaps and opportunities for effecting change. One priority is to “design and implement care delivery systems that strengthen the reliability and quality of care.” (p.27) As evidence-based standards of care assist in reducing inequities in health, the Framework calls for the development and implementation of “practice standards that include specific evidence-based gender and sex considerations.”

While this study has identified promising practices and indicators rather than practice standards, the intent and purpose of the strategic priority was applied in this work.

Six-phase methodology

Phase 1

A **steering committee** was formed to guide the study and reflect on analyzed data and results. Members of the steering committee were as follows:

Danielle Bender, Research Associate, Saint Elizabeth
Catherine Brookman, VP, Research & Program Development, Saint Elizabeth
Maria Giusti, Caregiver and Certified Bookkeeper
Kathy Hickman, Education Manager, Alzheimer's Society of Ontario
Paul Holyoke, Director, Research & Program Development, Saint Elizabeth
Mavis Jones, Knowledge Translation Specialist, Echo-Ontario
Heather Keller, Professor, Department of Family Relations & Applied Nutrition, University of Guelph
Lynda Kohler, Caregiver and Program Coordinator, Woolwich Community Health Centre
Maddi Levinson, Social Worker, Circle of Care
Lisa Manuel, Director, Changing Lives & Family Violence Programs, Family Service Toronto
Dawna Saba, Caregiver
Elizabeth Tapping, Caregiver and Research Team Member

Phase 2

A **search of published research studies** was conducted to identify information regarding education and support programs for caregivers, and the best practices for providing education and support. Approximately 284 articles were reviewed and, of those, the findings from 113 were included in the final report, based on their relevance to this project.

Phase 3

People were invited to **share stories of caregiving** and experiences with educational and support programs they have encountered on www.CareToKnow.org, the knowledge exchange and social networking site of the Saint Elizabeth Care to Know Centre. Four responses were received and these were combined with the stories we heard from caregivers on our steering committee during our meetings.

We also conducted a **jurisdictional review**, to identify key examples of education and support programs in Ontario and across Canada. An online request for information about education and support programs was sent to program providers, as well as researchers, and all were asked to forward it to interested colleagues, associates, friends and relatives. A total of 77 responses to the survey were received. This was supplemented by an additional review of online and printed information concerning available education and support programs.

Phase 4

This phase focused on the articulation of **draft promising practice indicators** of effective educational and support programs and tools. We began with 4 promising practice themes and 11 indicators, which was then revised to 5 themes and 15 indicators, based on our analysis of feedback from the caregiver stories and steering committee members.

Phase 5

These draft promising practice indicators were then made available for broad **stakeholder consultation**, by posting them on the Care to Know Centre website and e-mailing the consultation document to contacts who had expressed an interest in this project. Two responses to the consultation request were received.

Phase 6

This phase involved **focus groups and interviews** to confirm findings from phases 3, 4 and 5, and then a final workshop to validate the findings and recommendations for next steps.

Seven focus groups were conducted with caregivers in locations across Ontario, with a total of 23 participants who provided their perspectives on caregiving and their education and support needs. The breakdown by location was as follows:

Location	Number of Participants
Chatham	1
Huntsville	3
Kingston	1
London	1
Ottawa	5
Thunder Bay	8
Toronto	4

An additional 4 caregivers participated in key informant interviews. Seven caregiver education and support program representatives provided commentaries and examples of the indicators through individual key informant interviews.

Combined, these perspectives shaped the final promising practice indicators.

Once we arrived at the final promising practice indicators and had drafted recommendations for next steps, we held a half-day workshop for our steering committee members, their guests, as well as caregiver education and support program representatives and key stakeholders, in order to present the findings of the project and obtain feedback regarding the recommendations and potential next steps. In addition to the research team members, eight people attended the workshop, and feedback from the participants was incorporated into the project's final report, particularly with respect to the recommendations.

Attachment 1 - Ethics approval

This project was approved by the York Central Hospital Research Ethics Board (905-883-1212, extension 7569). The approval letter is included on the follow page.

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March 31, 2011

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Fax: 416-619-4092
Email: catherinebrookman@saintelizabeth.com

CC: Paul Holyoke, PaulHolyoke@saintelizabeth.com

Study Title: Informal Caregiver Education: Best Practices for Empowering Caregivers

- YCH Research Application Dated: March 17, 2011
- Appendix A - Research Protocol Dated: March 17, 2011
- Appendix B - Principal Investigator CV Dated: March 17, 2011
- Appendix C - Caregiver Story Collection Information and Assents Dated: March 17, 2011
- Appendix D - Key Informant Information Letter and Consent Form Dated: March 17, 2011
- Appendix E - Focus Group Information Letter and Consent Form Dated: March 17, 2011
- Appendix F - Budget Dated: January 12, 2011
- Appendix G - Impact Analysis Dated: March 17, 2011
- Appendix H - Letter from Leigh Heydon, ECHO, regarding peer review process Dated: n/a

Dear Dr. Brookman:

The York Central Hospital (YCH) Research Ethics Board (REB) acknowledges receipt of and approves all documents noted above pertaining to the study titled: **Informal Caregiver Education: Best Practices for Empowering Caregivers**; and grants approval of the study for one year which is to be conducted in accordance with all submitted and approved documentation.

If during the course of the project, there are any confidentiality concerns, changes in the approved protocol or subject information or new information that must be considered with respect to the project, these should be brought to the attention of the REB. The YCH REB acknowledges that the data will be transported electronically and/or physically off site. In the event of a privacy breach, you are responsible for reporting the breach to the YCH REB. As the submitting Investigator, you are responsible for the ethical conduct of this study.

Should this project extend beyond one year, you are responsible for maintaining ongoing ethical approval with consideration to the date noted on this letter. The REB must also be notified of the completion or termination of this study and a final report provided. If you have any questions regarding this letter, please contact the REB Research Coordinator, Abel Cheng at 905-883-1212 ext 7569.

Sincerely,

A handwritten signature in black ink that reads 'Abel Cheng'.

Abel Cheng, *BSc, MEd (c), CCRP*
Research Coordinator for the YCH Research Ethics Board (REB)
York Central Hospital, 10 Trench St., Richmond Hill, ON, L4C 4Z3
Email: acheng@yorkcentral.on.ca
Phone: 905-883-1212 ext 7569

The YCH REB operates in compliance with: the Tri-Council Policy Statement (TCPS): Ethical Conduct of Research Involving Humans; the International Conference on Harmonization (ICH) Good Clinical Practice (GCP) guidelines; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Personal Health Information Protection Act (PHIPA) and all applicable regulations. The YCH REB is also registered with the U.S. Office for Human Research Protections (OHRP).

Attachment 2 - Information and Consent Letters

The following pages contain the content of the information letters and consent forms for the focus groups, caregiver key informant interviews and education and support program representative interviews.

These letters were sent to participants in advance of the focus group or interviews and written consent was obtained for all participants.

[Focus Group Information Letter and Consent Form]

[date]

Dear [name of participant],

Re: Discussion Group on Education and Support Programs for Individuals Helping Someone to Stay at Home

On behalf of a group of researchers at Saint Elizabeth Health Care,¹ I am writing to tell you about a research study on education and support offered to individuals who provide care to a family member or friend to help them stay at home. The study is funded by Echo: Improving Women's Health in Ontario. You have indicated that are interested in sharing your views on this topic.

Most care partners across Ontario provide care to family and friends with little formal training or support. This caregiving is critical, yet it can place the individuals who are providing it under a great deal of strain. With your help, we want to determine the current promising practice education and support programs and/or tools and create recommendations for cost-effective care partner education support priorities in Ontario.

You have inquired about participating in a group discussion of what we have found in our research so far. The group discussion will be held at the **[location and time]**. In the group discussion, you will be free to agree or disagree, or remain neutral towards what we've found. Our next steps in the research will be guided by what you and other people involved in the discussions have to say.

The group discussion will be recorded so we won't miss anything anyone says, but the recordings and any notes of the discussion will be kept confidential to the fullest extent possible by law. The recordings and the notes will be kept secure on encrypted computers or in a locked file cabinet and only research staff will have access to them. If we use a quote from the discussion in reporting our findings, we will make it anonymous. We will delete the recordings in 2016.

If you indicate that you are interested, we will mail or email you a summary of the research team's findings from all the discussion groups.

We do not foresee any risks or discomfort to you from participation in this study.

¹ The research team is composed of Danielle Bender, Catherine Brookman, Paul Holyoke, Justine Toscan and Betty Tapping. Our contact details are at the end of this letter.

A member of the research team will telephone you a few days before the focus group date above, to confirm that you are still interested in participating and to answer any additional questions you may have. Participation is completely voluntary and should you decide that you no longer wish to participate, please contact Jessie DeSouza (1-800-463-1763 ext. 6463 or jdesouza@saintelizabeth.com).

If you do participate, we'll need your written consent on the attached form. We will ask you to sign it when we meet for the group discussion (additional copies will be made available to you on that day). You and the research team will each have a copy.

Of course, even if you sign the consent, you can leave the discussion at any time, and if you wish, we will remove your part in the discussion. If you decide to withdraw, your decision will have no effect on your relationship with Saint Elizabeth Health Care, any of the researchers, or any organization associated with the research.

If at any time you have questions, please feel free to contact me using the contact information below. If you have any questions about your rights as a participant, you can contact the York Central Hospital Research Ethics Board (905-883-1212, extension 7569).

We look forward to the potential of meeting with you to benefit from your knowledge on care partner education and support. We sincerely hope that you will consider participating.

Sincerely,

[Name and position of researcher]

The research team

Danielle Bender, Research Associate
Saint Elizabeth Health Care
DanielleBender@saintelizabeth.com

Catherine Brookman, Vice President, Research and Program Development
Saint Elizabeth Health Care
CatherineBrookman@saintelizabeth.com

Paul Holyoke, Director, Research and Program Development
Saint Elizabeth Health Care
paulholyoke@saintelizabeth.com

Betty Tapping, Caregiver
btapping@rogers.com

Justine Toscan, Research Associate
Saint Elizabeth Health Care
JustineToscan@saintelizabeth.com

CONSENT TO PARTICIPATE IN RESEARCH STUDY: Discussion
group on education and support programs for individuals helping
someone to stay at home

1. My name is _____.
2. I have read and understood the attached letter describing the above titled research study.
3. I agree to participate in this study through a discussion group held at _____.
4. Except if restricted below, I agree the research team can use quotes from what I say in the discussion group if they are made anonymous.
 I do not want the research team to use quotes from what I say in the discussion group.
5. I understand that if I choose to withdraw from the study, the recording of my discussion contributions will be destroyed.
6. I have been given a copy of this consent.

Participant's signature: _____ Date: _____

Participant's address: _____

Participant's Phone Number: _____

Participant's email: _____

Please send me a summary of the team's findings from the interviews with me and others.

Research team member's signature: _____ Date: _____

Investigator's contact information:

[Key Informant Information Letter and Consent Form - Caregiver]

[date]

Dear [name of participant],

Re: Key Informant Interviews: Promising Practices for Care Partner Education and Support Programs

On behalf of a group of researchers at Saint Elizabeth,² I am writing to tell you about a research study we are conducting regarding education and support programs offered to people who provide care to a family member or friend to help them stay at home. The study is funded by Echo: Improving Women's Health in Ontario.

As an individual who provides this type of help and support, we have identified you as a key source of information for our study. We would like to interview you in order to benefit from your knowledge and experience.

Here is some background about our study. Many people across Ontario provide care to family and friends with little formal training or support. This caregiving is critical yet it can place a great deal of strain on the people providing the care. Our goal is to determine the current “promising practice” programs and/or tools that provide care partner education and support, and to create recommendations for cost effective education and support priorities for a range of caregivers across Ontario.

If you agree to participate in this research, a member of our team will interview you about your experiences with providing care and your experience with care partner education and support programs.

The interview will last for approximately one hour and will be recorded so we won't miss anything you say, but the recording and any notes will be kept confidential to the fullest extent possible by law. The recording and notes will be kept secure on encrypted computers or in a locked file cabinet and only research staff will have access to them. We will delete the recordings in 2016. The research team may use quotes from your interview to reinforce our report on the findings of this research; however, all quotes will be made anonymous.

If you indicate you are interested, we will mail you a summary of the team's findings from the interviews with you and others.

² The research team is composed of Danielle Bender, Catherine Brookman, Paul Holyoke, Justine Toscan, and Betty Tapping. Our contact information is at the end of this letter.

We do not foresee any risks or discomfort to you from your participation in this research. Of course, your participation is completely voluntary and you may choose to stop participating at any time. Even after the interview, you can decide to withdraw from the study, the recording from your interview will be deleted, and your decision will have no effect on your relationship with anyone at Saint Elizabeth.

If you wish to participate, we'll need your written consent. Please fill in the consent form below and bring to your interview; or if your interview will be by telephone, please fax or mail using the contact information at the bottom of this letter. Please keep a copy for your records.

If at any time you have questions, contact me at the address, phone number or email address on the consent form. If you have any questions about your rights as a participant, you can contact the York Central Hospital Research Ethics Board (905-883-1212, extension 7569).

We look forward to interviewing you to benefit from your experience in providing care and support. I will call you within the next week to confirm your interest, and to answer any additional questions you might have. If you agree to participate, we will schedule an in-person or telephone interview at a location and/or time that is convenient for you.

Yours sincerely,

[Name and position of researcher]

The research team

Danielle Bender, Research Associate
Saint Elizabeth Health Care
DanielleBender@saintelizabeth.com

Catherine Brookman, Vice President, Research and Program Development
Saint Elizabeth Health Care
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Paul Holyoke, Director, Research and Program Development
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Betty Tapping, Caregiver
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Justine Toscan, Research Associate
Saint Elizabeth Health Care
JustineToscan@saintelizabeth.com

CONSENT TO PARTICIPATE IN A RESEARCH STUDY CALLED:
Key Informant Interviews: Promising Practices for Care Partner Education and Support Programs

1. My name is _____.
2. I have read and understood the attached letter describing the above titled research study.
3. I agree to participate in this study through an interview to be arranged by a research team member.
4. Except if restricted below, I agree the research team can use quotes from my interview if they are made anonymous.

I do not want the research team to use quotes from my interview

5. I understand that if I choose to withdraw from the study, the recording of my interview will be destroyed.
6. I have been given a copy of this consent.

Participant's signature: _____ Date: _____

Participant's address: _____

Participant's Phone Number: _____

Participant's email: _____

Please send me a summary of the team's findings from the interviews with me and others.

Research team member's signature: _____ Date: _____

Investigator's contact information:

[Key Informant Information Letter and Consent Form – Program Representative]

[date]

Dear [name of participant],

Re: *Key Informant Interviews: Promising Practices for Care Partner Education and Support Programs*

On behalf of a group of researchers at Saint Elizabeth,³ I am writing to tell you about a research study we are conducting regarding education and support programs offered to people who provide care to a family member or friend to help them stay at home. The study is funded by Echo: Improving Women’s Health in Ontario.

You have been recognized as a key source of expertise in this area, and we believe your organization’s program titled “[add program name]” displays several of the “promising practice indicators” we have identified to date in our research. We would like to interview you in order to benefit from your knowledge, and to gather some additional information about your organization’s program.

Here is some background information on our study:

Many people across Ontario provide care to family and friends with little formal training or support. This caregiving is critical, yet it can place a great deal of strain on the people providing the care. Our goal is to determine the current “promising practices” applied by programs and/or tools that provide care partner education and support, and to create recommendations for cost effective education and support priorities for a range of care partners across Ontario.

Our research so far has allowed us to identify 15 draft “promising practice indicators” of effective education and support programs. I attach a 5-page description of these for your information. We have identified your program as one which incorporates a number of these indicators. We ask that, as you read through this summary, you consider specific examples of how your program incorporates some of these indicators into the program.

If you agree to participate in this research, a member of our team will conduct an interview with you about certain benefits and drawbacks of current caregiver education and support programs. Specifically we will be asking for additional details about your organization’s program including your own experiences working directly with care partners, your views on our draft “promising practice indicators”, and how they are currently being, or could be, put into practice within your program and others.

³ The research team is composed of Danielle Bender, Catherine Brookman, Paul Holyoke, Justine Toscan, and Betty Tapping. Our contact information is at the end of this letter.

The interview will last for approximately one hour and be recorded so we won't miss anything you say, but the recording and any notes will be kept confidential to the fullest extent possible by law. The recording and notes will be kept secure on encrypted computers, or in a locked file cabinet, and only research staff will have access to them. We will delete the recordings in 2016. The research team may use quotes from your interview to reinforce our report on the findings of this research; however, all quotes will be made anonymous.

If you indicate you are interested, we will mail you a summary of the team's findings from the interviews with you and others.

We do not foresee any risks or discomfort to you from your participation in this research. Of course, your participation is completely voluntary and you may choose to stop participating at any time. Even after the interview, you can decide to withdraw from the study, the recording from your interview will be deleted, and your decision will have no effect on your relationship with Saint Elizabeth Health Care or the researchers.

If you wish to participate, we'll need your written consent. Please fill in the consent form below and bring to your interview; or if your interview will be by telephone, please fax or mail using the contact information at the bottom of this letter. Please keep a copy for your records.

If at any time you have questions, contact me at the address, phone number or email address on the consent form. If you have any questions about your rights as a participant, you can contact the York Central Hospital Research Ethics Board (905-883-1212, extension 7569).

We look forward to interviewing you and benefiting from your knowledge about education and support for informal care partners. I will call you within the next week to confirm your interest, and to answer any additional questions you might have. If you agree to participate, we will schedule an in-person or telephone interview at a location and/or time that is convenient for you.

Yours sincerely,

[Name and position of researcher]

The research team

Danielle Bender, Research Associate
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Betty Tapping, Caregiver
btapping@rogers.com

Justine Toscan, Research Associate
Saint Elizabeth Health Care
JustineToscan@saintelizabeth.com

CONSENT TO PARTICIPATE IN A RESEARCH STUDY CALLED:
Key Informant Interviews: Promising Practices for Care Partner Education and Support Programs

1. My name is _____.
2. Name of organization:
3. My title/role at this organization:
4. I have read and understood the attached letter describing the above titled research study.
5. I agree to participate in this study through an interview to be arranged by a research team member.
6. Except if restricted below, I agree the research team can use quotes from my interview if they are made anonymous.

I do not want the research team to use quotes from my interview

7. I understand that if I choose to withdraw from the study, the recording of my interview will be destroyed.
8. I have been given a copy of this consent.

Participant's signature: _____ Date: _____

Participant's address: _____

Participant's Phone Number: _____

Participant's email: _____

Please send me a summary of the team's findings from the interviews with me and others.

Research team member's signature: _____ Date: _____

Investigator's contact information:

Attachment 3 - Focus Group Protocol

1. Recruiting participants

Flyers advertising the focus groups will be posted in the 6 planned locations and distributed electronically to hundreds of organizations operating in each of the geographic regions, asking them to assist us with recruitment. Caregivers interested in participating will be asked to contact the Research Team to register and the facilitator for each focus group will followed up with each participant in advance of the session to answer any questions and provide additional information.

2. Purpose of focus groups

The purpose of the focus groups with care partners is to probe the strength of the each of the draft promising practices and promising practice indicators, from the perspective of care partners. This will be accomplished not by asking the care partners' views of the practice indicators themselves (since the indicators have been drafted to convey messages to developers and deliverers of education and support programs), but instead, we will endeavour to hear from care partners about their experiences with various programs, and their commentaries on what worked, what didn't work, what was most helpful and what was missing. Our analysis of the data will help us validate, modify or reject our draft promising practice indicators.

One aspect that we will really want to probe is our finding that one whole indicator theme we have identified appears to be missing from the literature. We have called that theme "Recognize the barriers that care partners experience," and it has 4 indicators: Acknowledge the need for respite, Address accessibility issues, Promote awareness of options, and Find means of encouragement. We want to be able to confirm these findings, or modify our conceptualization of these missing components or the descriptions, or eliminate this theme or one or more of the indicators if we have inappropriately coded and assessed the input from the literature, the jurisdictional review, and the caregiver stories.

3. Recording

With permission from the participants, each focus group session will be recorded.

4. Analytical approach to the data

The data from the focus groups will be analyzed thematically. The analysis of the data will occur recursively during the period of focus groups. As each focus group is concluded, the researcher will record his or her field notes immediately after the session, with notes on the following topics:

1. Highlights about the process – what went well, what went poorly and possible improvements in approach, method, preparation or conduct
2. Highlights about the content of the session
 - a. Were there stories that stood out as particularly illustrative of good or poor practice in education and support programs, and if so, does it illustrate one or more of the indicators we have identified?
 - b. Were there stories that the attendees as a group found particularly compelling? Why did they find it compelling?
3. General observations about the session
4. Any special issues to follow up on afterward?

After each session, the focus group facilitator and one other researcher will listen to the recording of the focus group and code the sessions by identifying possible themes as the recording proceeds. After all the focus groups are completed, all the researchers will meet and compare and discuss the possible themes that they have identified, and agree on a comprehensive list of themes. Then, the researchers will review the draft promising practice indicators and assess whether/how the focus group sessions and the comprehensive list of themes would lead us to confirm, modify or eliminate each of the draft indicators and the indicator themes. Then, the investigators will prepare a final draft of best practices indicators.

5. Preparing for the meeting

The following steps are necessary to ensure a consistent approach, and to make that sure our guests at the focus group sessions are comfortable in the setting, and that this exercise imposes as little pressure and stress on them as we can manage. If possible, we also would like them to be able to take something beneficial from the sessions. If we conceive and conduct these focus group sessions as one-off, mini-support group sessions, we know from our review of the literature that support groups can increase care partner knowledge and satisfaction, reduce loneliness and social isolation, and initiate feelings of empowerment.

1. Ensure that there are beverages for all scheduled attendees, as well as food items. Buy a 'box' of coffee at Tim Horton's or other coffee/tea shops and a variety of donuts, cookies and muffins. In the focus group room, make them accessible.
2. Make sure your recording device is in place before attendees enter the room. Be sure to test it, and have backup batteries.
3. Put chairs all around a table so that each attendees can see everyone else when the focus group is underway.
4. Have tent cards prepared with the attendees' first names on them, and put them in a fan on a table off to the side. Ask each person to put theirs up in front of themselves so that they and you can address them by their names.
5. Greet each person as they come into the room, welcome to the focus group, and thank them for coming.

In addition, each facilitator will review at least pp.19-25 of the [Ontario Women's Health Network Guide to Focus Groups](#) a few hours before the session.

Attachment 4 - Focus Group Script and Questions

Below is the script and questions that are to be used to guide the focus group discussions. This script and questions borrow heavily from the Ontario Women's Health Network Guide:

Good afternoon everyone! I would like to start by welcoming you to this focus group and to thank you for taking the time to participate in our discussion. This afternoon we will be talking about the experiences you have had with care partner education and support programs.

Your contributions will help the researchers identify what works in these programs, and what doesn't, so that we can make recommendations about how to improve these programs, and others, in the future.

Before we continue, let me introduce myself. My name is _____ and I will be your moderator. My role is to encourage and guide our discussion by listening and asking questions. I will be asking lots of questions because I would like as much feedback from you as possible. Your participation and opinions are important! There are no right or wrong answers.

Our discussion is being tape recorded. All of your comments and responses to questions will be kept completely confidential. Your name and any other identifiers will be removed from all written records.

Any of the materials that come out of our discussion will be evaluated only by researchers working on this study and will be kept secure and protected.

You will find in front of you, 2 copies of a consent form. It's the same one that we sent out with our information letter. The consent form is meant to help you understand your role and rights in this discussion. Before we continue could everyone carefully read and sign both copies of this form. One of them is for you to keep, and one is for our records. Please let me know if you have any questions.

Allow participants time to read and sign consent form.

Our discussion will last no longer than 90 minutes. We will not be taking a break. If you would like to use the washrooms before we start, they are located <<insert directions>>. Please help yourselves to the refreshments.

Let's start by introducing ourselves. We'll move around the table and you can tell us your name and how long you have lived in _____. As I said before, my name is _____ and I come from _____, and my experiences with caregiving are

Questions

Caregiving for a loved one is important now, and as we think about how things are going in our health care system and the aging of the population, it is expected that there will be more and more caregiving of the kind that you do today.

Care partners, researchers and the health care system have taken an interest in the education and support programs that are available to those who provide care and support to someone to help them stay at home, These programs are meant to help care partners like yourselves to understand what you are getting into, what you need to know, what you'd like to know, and what to expect as you provide care over time.

By show of hands, who has taken part in an education, information, and/or support program related to your caregiving?

For those that don't put up hands – can you tell us a bit about why you have not taken part?

What type of information or help were you looking for? [Ask specific participants with their hands up].

Where did you find out about the program? From a health care provider? In a hospital? From an agency?...

Good experiences

Now, I'd like to focus on some of the best programs and supports that you have encountered while you have been providing care and support over time

Who has had a great experience with an education or support program? [Ask specific participants with their hands up for more details] How did it help you? How did you find out about the program? What was involved? Was it the information? How did you get the information? Was it in writing or on the internet, or Was it the people? What kind of people were they? How did they relate to you?

Has anyone else had a similar great experience or maybe a different kind of great experience? What was that like?

[prompt to respond about experiences receiving informal support if haven't received any formal education or support]

Involvement of care recipient and caregiver

One thing we've wondered about is whether education and support programs for people providing care and support like yourself involve the person you're caring for as well, or do they focus on you and your own needs? Which do you prefer?

Men and women

We have [men and women/just women/just men] in the room. Do you think the program you encountered would be received differently by men and women?

In groups or one-on-one?

In the support or education program, were you provided the help on your own, or were other individuals who provide care and support involved? How did that work? Do you think that was a good approach, or could it have been better?

Positive aspects

Our research group thought about our own caregiving experiences, and we remembered that there were some very difficult periods during caregiving, but there was also a lot of joy and love too. Did/do the education and support programs you participated/participate in emphasize these positive aspects or did they concentrate more on helping you through the hard parts? Do you think that that was good?

Individual Needs

Have the education and supports that you have participated in been suited to your individual needs?

If yes—how?

Did you ever find aspects of a program to not be relevant to your situation?

If yes—Please explain.

Changing needs

Something that the care partners on our advisory group told us to remember is that the experiences of people providing care and support go up and down, there are good days and bad days, and things can change over time. First, do you agree with what our advisory committee told us? If yes—Could you provide an example? If no—Could you describe how your journey in caregiving has gone?

Did the education and support programs you were involved in change with you as your caregiving changed? How did they do that?

Preparedness/pre-planning

Do you think you were prepared for your caregiving? Before it started, did you have an idea what you were getting into? If yes—How did you know? If no—Do you think an educational or support program could have, or should have, prepared you better? How?

Accessibility/respice/awareness of options

Now, we've been talking about the benefits and some of the drawbacks of the content/format of education and support programs. But maybe someone hasn't been able to participate in program for some reason unrelated to the content of the program itself? Is there someone who hasn't been able to participate in a program who wanted to? If yes—What stopped you?

Additional question if there is time:

Re. terminology: caregiver vs. care partner, etc.

Conclusion

This concludes the discussion today. Some of the key themes I've heard are....

Do I have this right? Does anyone have anything else to add?

Thank you very much for your time. You have made a great contribution today. Thank you again.

Attachment 5 - Caregiver Key Informant Interview Protocol

Our goal for interviewing caregivers was to obtain the key informant's perspective on what makes an effective education and support program for care partners, primarily based on his or her experiences (or those of people he/she knows).

Three caregivers were identified through the project's steering committee to participate in interviews, which were conducted in person and recorded, with permission from the interviewee. The interviewer made field notes immediately following the interview and later listened to the recording of the interview to conduct a thematic analysis.

Attachment 6 - Caregiver Key Informant Interview Questions

1. About the caregiving

Could you please tell me about your role in providing care to your family member or friend?

What sorts of help do you provide?

Tell me about how you adapted to your role in providing care at the beginning of your family member/friend's illness? Have your family member's/friend's needs changed over time?

If yes, have you had to change the way you provide care or what you do?

What are your needs in order to be able to provide care to your family member/friend?

(probe – education, emotional support (formal or informal?), respite, help around the house, financial, etc.)

Have these needs changed over time?

What is the most enjoyable part of providing care?

What is the part that you find the most difficult about providing care?

2. About education and supports - general

What sorts of information, education, or support have you received over time as you've provided care?

Who provided this information, education or support, how did you hear about it, and what was the format?

(Probe: was it a formal program, or did they rely on informal support system such as family and friends?)

[If they have participated in a program] How did you learn about the program that helped you?

What do you find the most helpful in terms of information, education and support?

Are there any areas you feel you could have used more information about or help with?

Did you ever want to contact or participate in an education or support program but you were not able to for some reason?

What got in the way?

3. About the draft indicators

Have the education and supports that you have participated in been suited to your individual needs?

If yes—How?

Did you ever find aspects of a program to not be relevant to your situation?

If yes—Please explain.

Some caregivers feel it's important to connect with others who are in similar situation and facing the same types of challenges. Others are happier working through things on their own. Have you been connected with other people providing care like yourself?

If yes— how did you connect with these individuals? Was connecting with them helpful to you?

If no—would you have liked, or would you like to connect with other care partners?

We have learned through this project that many people providing care experience positive feelings from doing so, as well as finding it to sometimes be hard work and a real struggle. Have you found that the education and/or the support you have received (either through formal programs or from family/friends) have focused more on either the positive/uplifting aspects or on the negative/challenging aspects of providing care?

[if they answered that the caregiving changed over time:] You said earlier that your family member's/friends' needs changed over time. Did the program(s) that you were involved in help you through those changes?

If yes-- How did it do so?

Do you have anything else to add to our discussion about your experience providing care?

Attachment 7 - Education and Support Program Representative Key Informant Interview Protocol

Our goals for interviewing representatives from the example programs were:

1. To confirm our understanding of the program their organization delivers (particularly as it relates to our understanding that it meets two or more of our draft promising practice indicators), and to probe whether the program meets more of our draft promising practice indicators than our review of their survey submission revealed
2. If possible, to probe why their programs don't meet some of our promising practice indicators
3. To record the key informant's perspective on what makes an effective program or support for care partners

→ The key informants were approached as experts in developing and delivering caregiver education and support programs, and as such, were invited to review our draft promising practice indicators.

Participants were representatives from 7 of the 8 example programs we identified through the project. One program declined to participate in an interview as they felt they were still in the early stages of developing their program; however, they did agree to information about their program being included in the report. Wherever possible, interviews were conducted in person; however, some of the interviews were conducted by telephone due to scheduling or geographic reasons. Interviews were recorded, with permission from the interviewee.

The interviewer made field notes immediately following the interview and later listened to the recording of the interview to conduct a thematic analysis. A second researcher also listened to the recording of the interview to confirm the identified themes and promising practice indicators met by each program.

Attachment 8 - Education and Support Program Representative Key Informant Interview Questions

1. About the Organization and Person

Could you tell me a little bit about the organization you work for?
(Probes: Structure, location, population served, goals, etc.)

Could you describe your experience interacting DIRECTLY with informal care partners?

What is your perception of what it is like for people who are providing care and support to a family member or friend who needs help to stay at home?

2. About the draft indicators

I hope you had a chance to review our draft promising program indicators. The 5 themes were:

<i>Draft promising practice themes</i>
#1 Respect the holistic needs of care partners - Try to individualize the approach, taking into account gender, culture and the relationship of the care partner and the care recipient
#2 Promote networking between care partners - Connect care partners with similar issues, connect them with community resources, and use on-line interactive resources when possible
#3 Address the emotional context of providing care - Be sure to highlight the positive aspects of providing care, and include strategies to enhance overall wellbeing
#4 Target different stages of providing care - Promote proactive planning by and with caregivers, and address changing needs over time
#5 Recognize barriers that care partners experience - Acknowledge the need for respite, address accessibility issues (i.e. financial and other barriers to participation), promote awareness of different options, and find ways to encourage care partners

Is there one (or more) of these indicator themes that you feel is more important in an education or support program? If yes, why? If no, why not?

Is one (or more) of these themes more difficult than others to apply in a program? If yes, why? If no, why not?

Did you find any of the themes too vague or less important for effective programs? If yes, why? If no, why not?

Is there anything you think should be added to the themes or indicators?

3. About your organization's program

- a) Here is what I understand about your organization's program....[Information from survey response: format, target group, and key goals]

Is my understanding about how the program operates and what its key features are correct?

- b) Based on your response to our online request for information, we identified your organization's program as addressing the following promising practice themes....[go through each highlighted theme and the highlighted draft indicators for each theme]

Could you provide some specific examples? [* specifically probe programs which indicated they take gender into account]

- c) Are there any other indicators that you think your program addresses that we haven't discussed yet? Please provide examples.

[items not checked off on Table 2 ...]