THE CHANGE
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

LESSONS FROM
CHANGING CARE

The Discovery Phase of Experience-based Co-Design

JUNE 2018

CHANGING
CARE

ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think-tank that works to inform positive change in Ontario's healthcare system. With a firm commitment to engaging the voices of patients, family caregivers, and health and community care providers, the Foundation explores contemporary healthcare issues through different projects and partnerships to evolve our healthcare system in Ontario and beyond. The Change Foundation was created in 1995 through an endowment from the Ontario Hospital Association and is dedicated to enhancing patient and caregiver experiences and the quality of Ontario's health care.

ACKNOWLEDGEMENTS

The Change Foundation acknowledges the four Changing CARE project teams – Connecting the Dots for Caregivers, Cultivating Change, Embrace and Improving CARE Together – for their hard work and dedication to improving the experiences of caregivers in their respective communities.

The Foundation would also like to acknowledge the caregivers and providers who participated in engagement opportunities through the Changing CARE projects and, as a result, helped to improve the experiences of caregivers in their communities.

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MESSAGE FROM THE PRESIDENT

Family caregivers are the backbone of our healthcare system. Without them, in many ways, the system would crumble.

So when we talk about system change, the conversation must include the caregiver voice, and the caregiver perspective.

But what does it look like to *truly* include the caregiver voice, and to *truly* embed the caregiver voice in the healthcare system? Not to check a box. But to affect *real* change?

While there isn't a one-size-fits-all answer to that question, this report is meant to start filling in the knowledge gap with some of the lessons our four Changing CARE teams have learned on their journeys so far.

In 2015, The Change Foundation launched its current strategic plan – *Out of the Shadows and Into the Circle* – which focused on improving the caregiver experience in Ontario. But we knew we couldn't do that without listening – and I mean really listening – to caregivers, so that the system could be designed to meet their needs. And so, in 2015-16, we engaged with family caregivers, and health and community care providers, across the province through The Caring Experience initiative.

And as a "think-tank that does" we soon moved into action — we launched Changing CARE so that we could apply what we learned in real world settings.

In 2017, after a long and detailed search, the Foundation identified four key partnerships from across Ontario to receive funding and support over the next three years to improve the caregiver experience for their individual populations.

All four partnerships were designed with caregivers in key design and decision-making roles. The partnerships are now leaders in caregiver recognition, support and integration in the Ontario healthcare system and are changing the way healthcare organizations, providers, patients, and caregivers work together.

The Changing CARE teams are including caregivers every step of the way, making adaptations for the setting and remaining flexible and open to the spirit of co-design. For these teams, caregiver engagement isn't a checklist exercise, it's core to their being and crucial to their success.

Just as The Change Foundation spent the early stages of our strategic plan really listening to caregivers, the Changing CARE teams kicked off their projects in the same way. Now that we're more than a year into Changing CARE, it's the ideal time for us to stop and reflect on the collective path we've taken so far, and release our learnings on the engagement phase of co-design.

We've tried to present practical, *how-to* tips to help guide organizations in their caregiver and provider engagement efforts – but bear in mind, each of the Changing CARE teams approached engagement with caregivers and providers slightly differently. These are our learnings from our experiences in four very different sites that treat very different populations. As I mentioned earlier, the solution is not one size fits all.

This is the first in a series of reports that will focus on learnings from the Changing CARE projects. We expect to release the next one — on the lessons learned during the co-design phase of the projects — later this year. We hope they will help you use and adapt what we've learned to help you co-design solutions in your own setting. After all, our intention with Changing CARE isn't to limit better caregiver experience solely to those sites. We want to see improved caregiver and provider experience all across Ontario, and beyond. This report is the first step on that journey.

Sincerely,

Cathy Fooks
President & CEO

INTRODUCTION

What do we mean by *discovery*?

Experience-based co-design (EBCD) is a fundamental feature of the Changing CARE projects. It is an approach that enables staff, patients and caregivers to co-design services and care pathways together in partnership. In other words, *we listen to our users and then go off with them to do the designing*.[1] The Change Foundation brought 135 people, including caregivers, from the four Changing CARE projects together in March 2017 for a one and a half day training session focused on giving the teams a common solid foundation in experience-based co-design and quality improvement methods. The training also provided an opportunity to build cohesion both within and among the Changing CARE projects.

In the discovery phase of EBCD, the Changing CARE projects sponsored various engagement opportunities with family caregivers and providers to gain a deeper understanding of their respective experiences. What they learned from caregivers and providers during the discovery phase influenced their improvement and innovation efforts moving forward.

This learning report will focus on what the Changing CARE projects have learned during these initial engagement efforts. The projects will continue to engage with caregivers and providers since discovery is not a linear process — rather, it can be an ongoing process to gain new insight. It makes sense, at this point, to pause and reflect on what has been learned so far.

The Changing CARE projects engaged with caregivers and providers using surveys, one-on-one interviews, small group discussions, and larger focus group discussions.

[1] See The Point of Care Foundation for a description of the EBCD methodology.

- 450 family caregivers were engaged across the four Changing CARE projects.
- Over 600 staff participated in the discovery phase engagement sponsored by the Changing CARE projects.

Engagement during the Discovery Phase

450 Caregivers

606 Providers

Who are the Changing CARE projects?

Connecting the Dots for Caregivers brings together six local healthcare organizations and family caregivers to create tools and resources that will help caregivers feel more supported, valued, respected and engaged in their essential role. Project partners include the Huron Perth Healthcare Alliance, Alzheimer's Society of Perth County, the STAR Family Health Team (FHT) and the North Perth FHT, One Care Home and Community Support Services, and the South West Local Health Integration Network. Over a period of five weeks, the project team sponsored 36 engagement events across Huron and Perth: community forums, coffee chats, provider sessions, and individual interviews. In total, they engaged with 251 people: 121 caregivers and 130 healthcare providers (including 28 physicians).

Cultivating Change aims to co-design, with caregivers and providers, a caregiver friendly hospital and community. The project partners in Toronto — Sinai Health System and WoodGreen Community Services — will build a culture of care in which caregivers are partners, not visitors, and where caregivers are formally identified, valued for their deep knowledge and actively listened to. The project team recruited caregivers from in-patient units, as well as caregivers accessing community services and supports. Data from provider process mapping exercises and 21 one-on-one interviews was used to create personas and a journey map to anchor emotions to touchpoints of the stroke healthcare journey, which were used by the 38 participants at a brainstorming event with caregivers, staff and community partners.

CHANGING CARE
EMBRACE
J'EMBARQUE

Embrace aims to improve interactions between family caregivers and doctors, nurses, therapists and other providers. Embrace focuses on caregivers of those with mental health and addiction challenges who often play a crucial role in the recovery process. The partners are the Cornwall and District Family Support Group, and the Community Addiction and Mental Health Centre of Cornwall Community Hospital. Embrace brings together providers and caregivers to co-design sustainable solutions that support the caregiver's role and recognizes the value of the caregiver's contribution. They engaged with over 500 people in Cornwall and the surrounding region: 206 caregivers (in interviews and small groups), and 308 providers and other staff (308 surveys, 262 in 41 focus groups).

CHANGING CARE
IMPROVING CARE
TOGETHER

Improving CARE Together aims to improve family caregiver engagement and acknowledgement in program planning and direct clinical care at all sites of St. Joseph's Health Care London. The initial focus will be on rehabilitation and geriatric care. They plan to: (i) include the caregiver and their assessment in the care plan; (ii) recognize the caregiver's role and importance to the patient's care; and (iii) provide education and support to ensure caregivers are full partners in care and feel comfortable in their role. The team mailed letters to past patients with follow-up phone calls to recruit caregivers to participate in individual interviews — 92 patients and caregivers. Additionally, focus group interviews were conducted with 140 providers and other staff from across the organization.

This paper describes what the Changing CARE projects learned during their discovery phase of the experienced-based co-design. There are 40 practical tips that are organized in five sections: project planning; engagement planning; recruitment for engagement; engagement; and post engagement.

> *To reach family caregivers living in a rural community, we knew we needed to take a grassroots approach. We leveraged our community partners — both inside and outside of health care — to connect us with caregivers. In hindsight, this allowed us to build initial awareness of our project, forge new relationships and reinforce others. As our work evolves, these relationships will be critical to helping us spread our work within our partner organizations and across Huron Perth.*
>
> —**Connecting the Dots for Caregivers**

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CONNECTING THE DOTS
FOR CAREGIVERS

OVERVIEW

OVERVIEW

Lessons from Changing CARE: The Discovery Phase of Experience-based Co-Design

PROJECT PLANNING

1. Dedicated leadership at the executive, project and managerial levels is crucial to the success of the engagement process and the overall project.
2. Understand organizational culture and requirements.
3. Ensure there are resources to establish an effective project team responsible for project planning.
4. Dedicate time to team building and establishing trust.
5. Leverage the influence of champions within departments, units or community organizations.
6. Establish a baseline so that you understand the experience of caregivers and providers before you engage with them.

ENGAGEMENT PLANNING

7. Create an engagement plan. Co-create the plan with caregivers and providers.
8. Think carefully about the appropriateness of different engagement methods.
9. Consider involving a core group of caregivers in the interviewing process. Make sure they are well prepared.
10. Agree on compensation guidelines to financially recognize the time people commit to the project and to engagement.
11. Think through a comprehensive communications plan, including regular communication updates on the engagement process and outcomes.
12. Plan for a process and resources to support caregivers who may be emotional or experience stress during engagement events.
13. Make sure all partners have a shared understanding and commitment to the engagement plan.

RECRUITMENT FOR ENGAGEMENT

14. Dedicate project resources to recruitment.

Recruiting Caregivers

15. Use multiple and creative recruitment strategies.
16. Use different strategies to recruit a diverse group of caregivers that are often not heard from.
17. Be prepared to offer a broad range of supports to ensure that caregivers can participate.
18. Be prepared to promote the benefits of participation with caregivers. Provide scripts or talking points so recruiters know how to respond when people decline to participate.

Recruiting Providers

19. As with caregivers, be prepared to promote the benefits of participation to providers.
20. Share information with staff and leadership to increase understanding of the project goals and the purpose of engagement.
21. Be clear on the purpose of the engagement and who should be there (and who should not be there).
22. Build time into providers' schedules to allow for participation in engagement events.

ENGAGEMENT

23. Make it easy and enjoyable to participate. Don't forget to provide snacks or meals, and hot drinks.
24. Make adjustments along the way, especially if people are asking similar questions or if you find that the questions you are asking are being interpreted differently.
25. Ensure a balance between allowing enough time for interviews and group discussions while respecting schedules.
26. See the engagement as an opportunity to identify both caregivers and providers who want to stay involved in the project.

Caregiver Engagement

27. Try to hear from caregivers when the experience is recent.
28. Have a process and resources to support caregivers who may be emotional or experience stress during interviews or group events.

29. Engagement through interviews or group meetings can be helpful and even therapeutic for caregivers — informal peer to peer support amongst caregivers can spontaneously emerge.
30. In-person interviews provide an opportunity to develop relationships with individual caregivers.

Provider Engagement

31. Be flexible and offer multiple options for providers to participate.
32. Consider a tiered approach to engagement with providers.
33. Be prepared – providers can also be caregivers.
34. Have a plan on what to do when managers or supervisors show up at a staff engagement session even when they were asked not to.
35. Create opportunities to have direct conversations with physicians about the project goals, their experience interacting with caregivers, and ideas for improvement.

POST ENGAGEMENT

36. When there are a series of engagement events, celebrate milestones and successes along the way, and when targets are met.
37. Be prepared for increased awareness about caregivers following the engagement process. There may be increased requests for support and interest in follow-up engagement.
38. Develop strategies and tactics to ensure that caregivers can continue to participate and be authentically engaged.
39. Ensure ongoing communication with key stakeholders, including department champions and supervisors.
40. Report back on what you heard and what you plan to do next. This is a best practice for community engagement.

PROJECT PLANNING

Courtesy of Improving CARE together

A. PROJECT PLANNING

It is important to take the time up front to get a sense of how ready your organization and partners are for your project on a cultural and policy level.

1. Dedicated leadership at the executive, project and managerial levels is crucial to the success of the engagement process and the overall project.

- Leaders need dedicated time to commit to the project, rather than trying to keep it going off the side of their desk. All four Changing CARE projects have strong executives responsible for achieving the project goals. The Change Foundation included *demonstration of executive level leadership* as one of the requirements in the competitive process to select the Changing CARE sites. The Foundation knew from previous experience with its PATH project[2], as well as from emerging evidence, that leadership is an attribute for successful quality improvement.
- Engage senior leadership early in the process through leadership committees or events. Improving Care Together engaged with over 200 leaders across St. Joseph's Healthcare London's five sites at an annual leadership conference.
- In a multi-organization partnership, it is important to involve leaders from all partners and secure their buy-in for the project.
- Think carefully about representation on the project steering/executive committee. This project leadership table should include leaders from partner organizations, caregivers and other key stakeholders.

> "You'll learn about your organization — you don't know what you don't know."
>
> —PROJECT MANAGER

2. Understand organizational culture and requirements. Organizational systems and policies will impact how you engage with caregivers and providers.

- Organizational rules related to privacy regulations may require that caregivers be recruited through letters to patients. Improving Care Together recruited caregivers through letters to patients, which had implications for project timelines.
- Existing policies or standards within the organization have to be considered when establishing compensation guidelines to recognize the contributions of caregivers (e.g., as members of the project team, or as participants in engagement events). Build in time to get corporate approval. Some projects had to establish a new

[2] From 2012 to 2014, The Change Foundation invested in the Partners Advancing Transitions in Healthcare (PATH) project in Northumberland, Ontario. In the PATH project, patients, caregivers and providers co-designed improvements across the continuum of care.

organizational procedure for caregivers to be reimbursed and compensated for their participation (see tip 10).

- Organizational rules and protocols may challenge the ability to provide all team members, including caregivers who may not be employed by the organization, with access to project files. This may be a particular challenge for two-partner or multi-partner projects. For example, one of the partners of Cultivating Change had difficulty accessing the Changing CARE shared files until an exception from corporate requirements was secured.
- There may be corporate policies and informed consent procedures for the use of photos and videos of engagement event participants (and the person they are speaking about in the video).
- In multi-organization partnerships, consider the requirements and policies of all the organizations and make adjustments where possible. For example, the six partners of Connecting the Dots for Caregivers have their own human resources policies, finance processes and communication protocols that have to be considered.

3. Ensure there are resources to establish an effective project team responsible for project planning.

- The project manager is a critical role. They need to be able to lead a team, work effectively with executives and manage the project. For projects with two partners, a project manager at both sites can help to sort out different organizational systems (e.g., computers, room bookings, etc.) and keep respective organizational leadership informed of progress.
- The project manager needs additional team members to take on leadership for specific components of project planning and implementation.
- Consider including someone from the unit or department where the project is starting, so they can provide an insider's perspective on the culture and operations of the unit, and play an important role in championing the project within the unit (i.e., secure provider buy-in).
- Consider hiring a caregiver to be a member of the project team. Embrace hired a caregiver as a project co-lead to keep the vision clear and help set project priorities. The caregiver co-lead has access to other caregivers and acts as a champion for the project. She was able to recruit caregivers to participate in the experience-based

co-design training event, and help plan the engagement process.

- Build in communications support from the beginning. Communications specialists play an important role in developing a strategic communications approach, and they can proactively manage stakeholder relations and event planning. One project hired a communications specialist well into the engagement process, and felt they should have had them on board earlier to provide leadership on outreach, promotion and communications, and free up the project manager to focus on other priorities.
- Administrative support should also be built in from the beginning. There can be extra challenges when the project is a partnership between two or more organizations. For example, Cultivating Change secured administrative support through one partner but had to work through a process to access calendars and book rooms at the partner organization.

> "Creating a true partnership between our two organizations has been worth the time and effort it takes to create new processes for collaboration."
>
> —PROJECT MANAGER

4. Dedicate time to team building and establishing trust.

- Spend time to get to know team members and others who are participating in the project. Schedule time together and establish a *safe zone* where people can tell their stories.
- Make sure people are well prepared to participate. An orientation meeting before the experience-based co-design training event helped people to understand the project goals and the purpose of the training, as well as to get to know other participants before the training.
- Provide opportunities for team members and other participants to understand how to use technology to support their participation (e.g., using computer software, scheduling meetings, etc.).
- Establish protocols for communication so people are up to date on developments and can bounce ideas off one another. Weekly check-in meetings, team huddles, copying all those involved on emails, and hosting regular meetings with senior staff can facilitate communication.

5. Leverage the influence of champions within departments, units or community organizations to help secure buy-in and participation, gain access to caregivers and providers, and promote participation in engagement opportunities.

- Recruit one or two staff champions or *point people* on participating units to promote and explain the project goals. A couple of the projects recruited social workers who had access to the units and were able to approach current patients and caregivers to participate in engagement, as well as recruit providers to participate in engagement opportunities.
- Work with managers to ensure buy-in from providers and other staff.
- Consider establishing a community advisory group — a broader group of community stakeholders — to provide input into the engagement phase, to report back to on engagement findings, and to influence what happens in the community to support patients and caregivers.
- In multi-partner projects, involve a variety of front line staff and leaders from partner organizations in learning opportunities. Connecting the Dots for Caregivers identified staff and leaders from partner organizations to participate in the experience-based co-design training event which supported their ability to promote and champion the project and engagement opportunities.

6. Establish a baseline so that you understand the experience of caregivers and providers before you engage with them.

- Conduct a baseline survey to get a sense of the current caregiver experience, and the experience of providers interacting with caregivers. It is important to get a baseline picture before you engage with caregivers and providers. Interviewing and asking questions of caregivers and providers can, in itself, get people to think and act differently.

> "We have a caregiver who claims that the project has already made a big difference in her experience in the Emergency Department – and we haven't done anything there except conduct some interviews and invite some of the staff to a co-design event."
>
> —PROJECT MANAGER

> *Including caregivers on our team during the discovery phase was key to our success. Not only were they our link to hidden caregivers of someone with an addiction and/or mental health illness, their voice also shaped our interview questions and methods. We heard early on in the planning stage that we had to be prepared to lend support to those we interviewed, since many of their stories were hard to tell, and hard to hear. We had trained support and informational resources available for the caregivers interviewed and for the caregivers who did the interviewing.*

—**Embrace**

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ENGAGEMENT PLANNING

B. ENGAGEMENT PLANNING

Engagement planning includes how the engagement will be planned, deciding on engagement methods, and policy and process considerations for engagement.

7. Create an engagement plan. Co-create the plan with caregivers and providers.

- Identify a core group of caregivers to co-create and update the caregiver engagement plan. A number of projects co-created with a core group of caregivers, including co-design of the caregiver interview guide.
- Identify a core group of providers to help design the provider engagement plan. This planning includes clarification of definitions. For example, one of the projects realized early in the process that emergency department physicians call themselves caregivers. Clarifying terms was an important first step.
- Build a plan that lets you connect with caregivers in areas that are convenient and comfortable for them. This can be particularly challenging in rural communities.
- Allow for some flexibility in your timelines so that you can make adjustments if needed. For example, one project didn't have in-house expertise on survey and interview guide design. In retrospect, they would have adjusted the timelines to get external advice before proceeding.
- Depending on your community, build in translation support to ensure that you are able to reach diverse groups of caregivers. This was particularly important for Cultivating Change, which is serving a diverse community in downtown Toronto.

8. When developing the engagement plan, think carefully about the appropriateness of different engagement methods.

- Allow for separate, mixed, individual and variable sized engagements, so caregivers and providers have options, and can choose an option that fits their comfort level.
- Be flexible. Do what works for the caregiver. Some caregivers agreed to participate if they could bring the person they were supporting to the engagement event.
- Be sensitive to the unique challenges of smaller communities where people know each other and have personal relationships. There may

be particular concerns about privacy and confidentiality.

- Connecting the Dots for Caregivers planned for a consistent approach of standard guided questions for both caregivers and providers, along with a caregiver survey — co-designed with caregivers and providers.

9. Consider involving a core group of caregivers in the interviewing process. Make sure they are well prepared, through training and support, to conduct *peer to peer* interviews.

- Embrace established a caregiver working group of eleven caregivers who co-designed guidelines for working together, a caregiver interview guide, and a format for taking notes. The project specialist and four caregivers conducted the interviews, and established regular meeting times for updates and debriefs.

10. Agree on compensation guidelines to financially recognize the time people commit to the project and to engagement. It is important to establish a compensation policy early in the process.

- The Changing CARE projects were referred to The Change Foundation's engagement compensation tool to help them think through compensation policies for their engagement process.[3]
- Partners need to confirm whether there are existing policies for compensating patients and caregivers within the organization or with partner organizations. Is there an organizational patient and family advisory council? Are those members compensated? If so, how are they compensated? Are caregivers considered volunteers in the organization that fall under the corporate volunteer policies and compensation guidelines or are caregivers considered to be different? There will need to be discussion about whether alignment with existing policies is important (to avoid inequities between existing forums and the project), or whether the project wants to establish new standards or benchmarks for compensation.
- Compensation policies and recognition guidelines will need to be approved by the executive/steering committee or organizational leadership.
- Include both formal and informal ways to recognize the contributions and participation of caregivers and providers. Two projects landed on separate rates for caregivers (e.g., interviewing other caregivers,

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[3] See The Change Foundation's *Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants.*

participating on planning teams, etc.), executive and advisory members (who were not otherwise paid), and physicians who were losing revenue to participate. Thank-you cards and promotional items were given to caregivers who participated for less than two hours (e.g., caregivers who were interviewed).

- Be prepared for caregivers to decline compensation for their participation. Be sure to demonstrate appreciation for and recognition of their participation in other ways such as a hand-written thank-you card.

11. Think through a comprehensive communications plan, including regular communication updates on the engagement process and outcomes.

- Include internal and external communications, and traditional and social media updates which will require dedicated communications support (see tip 2). This takes time but it helps with awareness of the project.
- Review the communications plan regularly to update and improve it. Connecting the Dots for Caregivers developed a communications framework to improve communications with stakeholders across a broad geographical area and with a number of organizations.
- Establish mechanisms to ensure all partners are up-to-date on communications developments. For example, the project managers from the two Cultivating Change partners meet monthly with their respective communications teams.

12. Plan for a process and resources to support caregivers who may be emotional or experience stress during engagement events (described and illustrated in section D: see tips 28 and 33).

13. Make sure all partners have a shared understanding and commitment to the engagement plan.

- The project steering/executive committee should review and approve the engagement plan.
- In two-partner or multi-partner projects, engage the leadership from all partners so there is agreement on, and support for, the engagement plan.

RECRUITMENT FOR ENGAGEMENT

C. RECRUITMENT FOR ENGAGEMENT

We know that it is difficult to reach caregivers. They are often very busy, sometimes isolated, and just plain tired. As well, caregivers do not necessarily see themselves as caregivers. Rather, they see themselves as parents, spouses, sons or daughters just doing what they should be doing. It can also be difficult to recruit providers who are very busy, working in hectic work environments and facing many competing priorities.

> "I've never seen myself as a caregiver. I'm just a daughter doing what needs to be done."
>
> —CAREGIVER, CONNECTING THE DOTS

14. Dedicate project resources to recruitment. Ensure the project team member has dedicated time to recruit caregivers and providers.

- The projects used different strategies for assigning responsibility for recruitment. In one project, one person was responsible for recruitment of both caregivers and providers. In another, a lead was assigned for caregiver recruitment and another lead was assigned for provider recruitment.
- All the projects found that recruitment of caregivers and providers takes longer than anticipated. Make your best effort to estimate a timeline and then double it.

Recruiting Caregivers

15. Use multiple and creative recruitment strategies. Traditional recruitment approaches may yield limited results. Recruitment through personal and professional networks proved to be an effective strategy for all the Changing CARE projects.

- Posters, postcards, bookmarks, advertisements and articles in local newspapers may help to increase awareness. Show up at local events to promote engagement opportunities. For example, Embrace promoted engagement events at local camp grounds, and summer rib fests. The postcards were useful to have as hand-out information.
- Add the fun factor. A popcorn machine can have a huge impact on the number of people who stop to read a poster or pick-up a postcard or flyer.
- Successful recruitment is often through personal contacts and networks. Word of mouth and face-to-face invitations were more successful at securing participants for engagement events. This was especially true in rural areas. The *caregiver champion* on one project team reached out to her extensive caregiver network. Improving Care Together recruited caregivers through providers on specific units who were aware of caregivers supporting their patients.

16. Use different strategies to recruit a diverse group of caregivers that are often not heard from. Make efforts to recruit caregivers that reflect the community, recognizing that diversity looks different in every community.

- Some projects were trying to hear from caregivers from ethnic and linguistic communities. Others needed to hear from caregivers in rural communities, including Amish and Mennonite communities. Others were trying to engage Indigenous and Francophone caregivers. Some projects developed a targeted plan to engage with young caregivers under 25 years old.
- There may be language barriers for caregivers to participate in engagement opportunities. Cultivating Change reached out to a staff member responsible for the health equity survey that patients completed upon admission, which provided information on language. This staff member identified caregivers who experience a language barrier themselves or support someone with a language barrier, and organized interpretation support for caregivers who participated.
- Most of the projects found it challenging to recruit caregivers that were hard to reach and seldom heard from — especially those caregivers who are overwhelmed and have few resources. In the future, the project teams plan to consider new partnerships and different ways to engage with caregivers.

17. Be prepared to offer a broad range of supports to ensure that caregivers can participate.

- Ensure that participants know they will be reimbursed for travel costs (mileage, public transportation) and parking; but also let them know that other supports can be provided so they can participate (e.g., coverage for respite care for the person they are caring for, a personal support worker to accompany them to the engagement event).

18. Be prepared to promote the benefits of participation. Provide recruiters with scripts or talking points so they know how to respond when people decline to participate.

- Some projects heard “I don’t have time to participate,” “I’m too busy” or “I don’t think I have anything to contribute.” Talking points could include:
  - “We have heard from other caregivers that participating has been helpful.”

    - "Other caregivers have told us that the peer-to-peer support has been beneficial to them."
    - "We heard from others who participated that they learned about resources or programs from other participants."
    - "Other caregivers told us that it was good for them to hear from other caregivers, and to realize that they are not alone and others are also dealing with similar challenges."
- The projects also heard from caregivers who did not want to participate because they "had a good experience" or "everything is working well." Talking points could include:
    - "Actually, we need to hear from you as well about what made it a good experience."

Recruiting Providers

19. As with caregivers, be prepared to promote the benefits of participation to providers.

- Develop talking points so recruiters are prepared to respond to physicians and other staff who may not be keen to participate. Let them know that you want to hear their perspective on what the challenges are, and what the potential solutions might be to make the experience better for them and for caregivers.

20. Share information with staff and leadership to increase understanding of the project goals and the purpose of engagement.

- Identify leaders who are enthusiastic about the project goals and enlist them to sponsor engagement events or promote participation through communication with their staff. Staff are more likely to participate if the initiative is supported by their supervisor or other leaders.
- Use existing staff meetings that providers already attend. Get on the agenda to explain the purpose of the engagement and to invite staff to sign up for the focus group.
- Use convenient locations to share information about the project and to get input. Connecting the Dots for Caregivers held engagement sessions with small groups of physicians in the physician lounge.
- Host a lunch and learn event to increase awareness about the project, including the purpose of the engagement opportunities. For example, Improving Care Together hosted a well-attended lunch and

learn event which aligned with the organization's continuous learning culture.

21. Be clear on the purpose of the engagement and who should be there. This includes being clear on who should not be there.

- Inform potential participants how their input is going to be used.
- Understand the organizational structure. You want to invite people to a forum where they feel free to speak up. They might not feel comfortable speaking if their supervisor is in the room.
- Be prepared to deal with uninvited participants:
  - Some projects reported challenges when people showed up uninvited, including: providers who wanted to attend engagement forums to "just listen"; vendors and staff from support organizations with posters to promote their services; managers who showed up despite being asked not to so that staff could have open discussions.
  - Remind them that clear inclusion and exclusion rules were established in the invitation;
  - Offer other opportunities to learn more about the project outside of the engagement event.
- Consider including support staff, clerks, security and hospitality staff. They also have important observations and insights.

22. Build time into providers' schedules to allow for participation in engagement events.

- A number of projects provided funding for backfills so that nurses and other staff could participate in engagement events.

In the first year of the Improving CARE Together project at St. Joseph's Health Care London, one key learning was the importance of having leadership support at all levels. Leaders from the president and CEO to the front line were engaged in the project to ensure they were aware of and understood the project goals and commitment to supporting them. This helped to set the tone across the organization to begin the culture shift to fully partner with family caregivers and allowed for staff engagement and participation in the project.

—Improving CARE Together

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CARE
IMPROVING CARE
TOGETHER

ENGAGEMENT

D. ENGAGEMENT

In the Changing CARE projects, engagement included community forums, focus group discussions, in-person and telephone interviews, and surveys. The projects wanted to hear from both caregivers and providers. It is important to reiterate to both caregivers and providers how the results of the engagement will be used.

23. Make it easy and enjoyable to participate. Don’t forget to provide snacks or meals, and hot drinks.

- All projects realized early that it was important to meet caregivers and providers where it was convenient for them and at a time that worked for them. For example, Embrace set-up a *Caregiver Corner* on the unit with a staff/team member who was available to meet with family caregivers to hear their stories and suggestions for improvement.
- Providing food encouraged participation. Bringing in pizzas to the emergency department during the night shift presented an opportunity for ED staff to participate in an interview when there was a lull in activity.
- Be prepared to interview caregivers in the moment rather than schedule an interview for a later date. Keep it simple and just ask: ‘Do you have a few minutes now?’

24. Make adjustments along the way, especially if people are asking similar questions or if you find that the questions you are asking are being interpreted differently.

- Make adjustments in response to recurring questions from caregivers or providers. For example, Connecting the Dots for Caregivers had a number of questions from caregivers about privacy, so the team developed privacy rules for engagement to ensure that participant information was kept confidential.
- A number of projects made adjustments to their interview guides during the engagement process and this is ok. In fact, it is standard practice in quality improvement initiatives.
- In community forums or focus groups, the facilitator plays an important role. They have to be skilled at effectively engaging all participants, and know when to make adjustments if necessary.

25. Ensure a balance between allowing enough time for interviews and group discussions while respecting schedules.

- For some caregivers, this is the first time that anyone has asked them or listened to their story. People wanted to share their experience and this can take time.
- For providers, it is also important that the facilitator or interviewer is respectful of established timelines. If the engagement was billed as a one-hour event, make sure it is wrapped up in one hour as most providers will have other commitments. Cultivating Change found it was a fine balance between booking enough time and too much time. They didn't want to take staff away from their duties and they also didn't want to have to book a follow-up meeting.

26. See the engagement as an opportunity to identify both caregivers and providers who want to stay involved in the project.

- Encourage participants to provide their contact information (email, phone number) so you can keep in touch and inform them of project developments and opportunities.
- A number of projects found that the interviews and group discussions offered an opportunity to build relationships with caregivers, many of whom expressed an interest in participating in other project activities.

Caregiver Engagement

27. Try to hear from caregivers when the experience is still recent.

- One project hosted focus groups with caregivers who had been a caregiver within the last year. They found that caregivers who had a recent experience were very detailed in articulating the challenges and missteps, while caregivers who were recalling experiences they had 8 to 12 months earlier were less confident in what went wrong and what could have made it better.

28. Have a process and resources to support caregivers who may be emotional or experience stress during interviews or group events.

- The projects put in place a range of steps to ensure caregivers were supported:
  - identified someone at each location who was available to provide support;

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> “The most positive and unexpected outcome from the interviews were how they were helpful to the caregivers. Repeatedly, caregivers thanked us for listening to their stories.”
>
> —CAREGIVER ENGAGEMENT LEAD

  - acknowledged at the beginning of the engagement session that the content of the discussion was sensitive and may bring back memories and emotions;
  - advised participants that, if at any time, they needed to disengage or needed support, a qualified person was available to help;
  - established an escalation process for urgent situations where caregivers needed immediate support;
  - provided participants with contact information so they could contact the support person privately.
- Embrace trained a small group of caregivers to conduct interviews with other caregivers. They realized after a few interviews that they needed to arrange support for both those being interviewed and those conducting the interviews:
  - caregiver interviewers were trained on what to do if the conversation got beyond their comfort zone;
  - there was regular checking-in with caregivers during the interviews;
  - both the interviewers and interviewees had access to a social worker and a family peer support worker.

29. Engagement through interviews or group meetings can be helpful and even therapeutic for caregivers. Informal peer to peer support amongst caregivers can spontaneously emerge within an engagement event.

- Caregivers in all projects shared that they felt heard, and they appreciated the opportunity to talk about their journey.
- One caregiver noted that her “life has changed” since she shared her story in a video and showed the video to her family. This caregiver has continued as an active member of the project team as it moved into the co-design phase.
- Caregivers who were interviewed often received unexpected help in the form of contact information for resources and support, book titles, and educational programs.

30. In-person interviews provide an opportunity to develop relationships with individual caregivers.

- All of the projects found that strong relationships with caregivers could be established through individual interviews. For example, Improving Care Together found that where they developed a relationship with a caregiver through the interview, they felt comfortable asking for their continued involvement in the project.

Provider Engagement

31. Be flexible and offer multiple options for providers to participate. Adapt the format (e.g., interview, focus group), length of time and setting to accommodate various providers in different settings.

- A number of projects arranged to meet with providers in the evening or at night. Embrace met with physicians, nurses and social workers in the emergency department when there were opportunities to do so between midnight and 6 a.m. Improving Care Together hosted a meeting with nursing and personal support workers in their care environments during the night shift.
- Go to locations that are convenient for providers. For example, units within the hospital and organizations in the community that provide services to a wide variety of patients and caregivers.
- Host the meeting in a venue away from where staff are working. They are likely to be more relaxed.

32. Consider a tiered approach to engagement with providers.

- One project had a successful two-tier process where providers were first surveyed, and then a follow-up focus group was arranged to probe questions that emerged from the survey results.

33. Be prepared – providers can also be caregivers. Providers may provide input from both their provider perspective as well as their experience as a caregiver.

- Most of the projects had experiences in focus group discussions where providers recognized that they were also caregivers, or they spoke from their experience as both a provider and a caregiver.
- One of the projects noted that they need more information on how to support providers who do share their personal stories (e.g., they may feel uncomfortable or question whether they shared too much about their personal experiences).

34. Have a plan on what to do when managers or supervisors show up at a staff engagement session even when they were asked not to.

- Have a one-on-one conversation with the manager or supervisor before the event starts. Explain that the intent is to provide a space where staff feel comfortable talking about their experiences and ideas, and offer another time to meet with them.

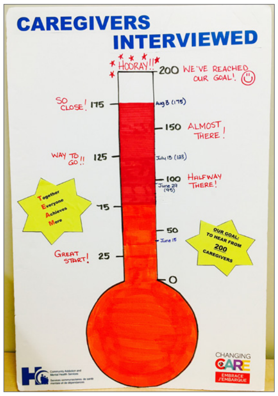
35. Create opportunities to have direct conversations with physicians about the project goals, their experience interacting with caregivers, and ideas for improvement.

- All the teams tried various approaches to connecting with physicians. For example, Improving Care Together knew physicians had a lot to contribute but that their time was tightly booked. They found the best time to connect with physicians was either at the start or at the end of the day.
- Physicians on the project steering committee can make a difference by promoting the project to other physicians. In Cultivating Change, the physician lead provided critical leadership to the physicians who work at one site and his support helped to remove barriers; and the medical lead, caregiver support services provided extensive expertise which made her a valuable asset to the project.

POST ENGAGEMENT

E. POST ENGAGEMENT

There are a number of considerations to keep in mind after specific engagement events and at the completion of the engagement phase.



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36. When there are a series of engagement events, celebrate milestones and successes along the way, and when targets are met.

- One project tracked progress in achieving their goal of interviewing 200 caregivers by the end of the summer with a thermometer. They had a celebratory event with cake when they met their goal two weeks early.

37. Be prepared for increased awareness about caregivers following the engagement process. There may be increased requests for support and interest in follow-up engagement.

- A number of projects found that their engagement with caregivers and providers resulted in increased community awareness of the challenges that caregivers face and increased demand for support. Connecting the Dots for Caregivers noted that organizations in the community were looking for ways to better support caregivers. In the Embrace project, more caregivers were coming to meetings of the Cornwall & District Family Support Group.
- The projects were contacted by caregivers who wanted to stay involved and were looking for other ways to contribute to the project.
- In some projects, caregivers developed their own peer-to-peer network so they could stay connected.

38. Develop strategies and tactics to ensure that caregivers can continue to participate and be authentically engaged.

- Re-purpose existing opportunities and create new opportunities for participation. One project repurposed their caregiver working group, originally established to co-design the interview guide and conduct interviews, to continue to play a role in co-design activities in the project streams and other opportunities (e.g., review of the caregiver survey).

39. Ensure ongoing communication with key stakeholders, including department champions and supervisors.

- Consider different ways to communicate with different audiences, including newsletters, update reports to senior leadership, project updates in newsletters or internal communication of partner organizations.
- Use contact information obtained during sign-in at engagement events to create a distribution list for communication about the project and opportunities for participation.

40. Report back on what you heard and what you plan to do next. This is a best practice for community engagement.

- Consider hosting a follow-up event to report back to those you engaged with to summarize what you heard and what you plan to do next.
- Write a short report – three to five pages – that summarizes what you did, what you heard and what you are doing with it.

CHANGING CARE

EMBRACE
J'EMBARQUE

DISCOVERY PHASE REPORT

Over the summer, the Changing CARE: Embrace team set out to engage a large and representative number of family caregivers and health providers across Cornwall, Stormont, Dundas, Glengarry and Akwesasne.

Listening to family caregivers:

If you were one of the 200 family caregivers who shared your experience with us, you understand how in-depth our conversations were and the effort we made to understand the challenges of family caregivers when they interact with health providers and the addiction and mental health system. We appreciate not only the time that you took to share your experiences with us but also your ideas about what can be done to improve the experience for family caregivers moving forward.

Listening to health providers:

We appreciate the individual contributions of 300 addiction and mental health providers, too. Some attended focus group discussions and others responded to our lengthy survey. We explored how health providers were interacting with caregivers and what benefits providers derive from working with caregivers. We also explored in detail what gets in the way of more widespread relationships and partnerships between patients, family caregivers, health providers, and the broader health and community care system.

New projects are underway:

Now, we have results to share. In this report, we highlight health system barriers and what can be done to create a better experience for family caregivers, health providers and patients. We also have exciting news to share about five new projects that are getting started to improve the situation for everyone in our addiction and mental health system.

Read on to learn where we have been and what we are doing to support family caregivers and health providers in adopting a more collaborative and coordinated approach to patient care across Cornwall, SDG and Akwesasne.

Courtesy of Embrace

> *Recognizing that transitions are often a difficult component of a caregivers' journey across the continuum of care, the Cultivating Change project developed a cross-sector partnership that focused on understanding these diverse experiences. Through extensive engagement and partnerships with caregivers, the project focused on caregivers' experiences of transitioning between various settings in our health and social care sectors. This includes acute care, in- and out-patient care, homecare and community services.*

—**Cultivating Change**

CHANGING
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THE CHANGE
FOUNDATION

ENGAGE, EXPLORE, EVOLVE

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