Engagement & co-design
inventory of resources
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. Created in 1995 through an endowment from the Ontario Hospital Association, the Foundation is dedicated to enhancing patient and caregiver experiences and Ontario’s quality of health care.

Acknowledgements

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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.
# Table of Contents

About the co-design and engagement resource inventory: ........................................... 4  
Overall resources to support your engagement & co-design journey: ...................... 5  
Setting up .................................................................................................................. 8  
Discovery: Collect staff, patient & caregiver experiences ........................................ 11  
Co-design events ....................................................................................................... 15  
Make the changes ..................................................................................................... 19  
Celebrate, renew ....................................................................................................... 22  
Creative Commons Requirements: ......................................................................... 23
About the co-design and engagement resource inventory:

Co-design and engagement are key ingredients to advancing meaningful change. There is a growing body of evidence that shows co-design improves how patients and families experience care, the relationship between patients and providers, and how service is delivered.\(^1\)\(^2\) The Ministry of Health requires “demonstrated history of meaningful patient, family and caregiver engagement” as an essential component for system change to models of integrated care. When they are up and running, the Ministry expects Ontario Health Teams to “uphold the principles of patient partnership, community engagement, and system co-design.”

The Change Foundation has worked in partnership with family caregivers, patients and healthcare providers across the health and social care system – this work has deepened our knowledge and experience of co-design and engagement, and we’ve translated our learnings into various tools, tips and resources. To build on our goal of advancing positive change, we created this inventory to support individuals, organizations and community coalitions as they build their capacity for engagement and co-design.

Orientation to the inventory: Evidence-based co-design (EBCD)

Underpinning our learning journey was the U.K.’s Point of Care Foundation’s Evidence Based Co-Design (EBCD) framework. We used the six phases of EBCD to orient you to the tools and resources included in this inventory.

The opening section profiles resources that are more overarching in scope, followed by the six sections of EBCD. The majority of resources were developed by the Change Foundation or by the Foundation’s Changing CARE teams. We’ve also included a few resources developed by other organizations that we have found useful.

In order to be responsive to the range of knowledge and experience that individuals and organizations have with co-design and engagement, and the range of unique needs, resources in the inventory are categorized to one of three applications:

- deepening your knowledge and understanding of engagement and co-design
- learning the how-to
- using plug and play resources that are adaptable to your context.

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1 Bate, Paul & Robert, Glenn. 2006. Experience-Based Design: From Redesigning the System Around the Patient to Co-designing Services with the Patient. Quality & safety in health care. 15. 307-10.
The Change Foundation

Overall resources to support your engagement &
co-design journey

The resources in this section are focused on building your capacity in EBCD methodology. The videos of previous conference presentations highlight the importance of engagement and the PowerPoints slides and guides walk you through how to conduct your own engagement and co-design sessions/events.

[PowerPoint]: (The) 101 of engagement & co-design — A step by step guide | The Change Foundation (September 2019)

Using engagement and co-design as an approach to quality improvement can take more time but results in impactful and meaningful change. Through these PowerPoint slide decks you will learn how to practically apply the theory and frameworks of EBCD in your own projects. The presentations are divided into two volumes. The slides can be copied and pasted into presentations you may be working on to help build the case to use co-design methodology, and to explain the process. Complementary Checklists of Considerations for the first four phases of EBCD are also available.

Volume One covers:
1. What is Experience-Based Co-Design (EBCD)?
2. Why use co-design methodology?
3. Preparing your organization for co-design

Volume Two covers:
1. How to co-design (using the 6 steps of EBCD)?

[Video]: Caregivers and healthcare providers share their thoughts on the value of co-design | The Change Foundation (January 2019)

Listen to caregivers and senior leadership of the Change Foundation’s Changing CARE projects share their experience with co-design, as they emphasize the powerful potential of enabling both caregivers and healthcare providers an equal voice at the table, and a role in designing solutions that work for everyone. Use this video (2 minutes) to help build the case for co-designing initiatives.
[Toolkit]: Experience-based co-design (EBCD) | The Point of Care Foundation (2013)

This toolkit outlines a powerful and proven way of improving the patients' experience of services and guides you through understanding how you can use EBCD to meet your aims. Through step-by-step guidance, videos of people who have taken part in EBCD projects and downloadable resources, such as template forms, letters, presentations and other materials, the toolkit helps you plan and carry out this approach.

[Video]: Innovation, inspiration, integration - co-designing for health and wellbeing with individuals and communities | Breakfast with the Chiefs, Longwoods (October 2019)

Longwoods held a Breakfast with the Chiefs on the global movement of integrated care. The session (60 minutes) included a global review of lessons emerging from across the world, and the opportunity for integrated care within Ontario. Eileen Dahl, remembered as a patient partner and panelist, shared powerful reflections on the importance of co-design and partnership with patients and caregivers to realize the full potential of integrating and connecting care.

[Toolkit]: Patient and family-centred care | The Point of Care Foundation (April 2016)

This is a step-by-step guide to help improve processes of care and staff and patient interactions, using a technique called Patient and Family-Centred Care (PFCC). PFCC is a simple, step-by-step method for understanding what a care experience is like, what needs to change, and which small improvements can make a big difference to patients, families and staff alike. It is the application of co-design methodology specifically focused on improving a care experience (i.e., discharge). If you are interested in quality improvement initiatives centered on improving the experience of family caregivers, this toolkit can be very helpful.
Health Quality Ontario has gathered a collection of resources in consultation with patients and family members to offer a variety of ways patients and families can play an active role in partnering effectively with health providers and organizations – including understanding the power of patient partnering, learning how to become an advisor, and ways to effectively share your story.

The Change Foundation and Carole Anne Alloway, a family caregiver, presented the keynote address at the 18th IFIC annual conference in Utrecht, The Netherlands in 2018. The keynote (30 minutes) is a powerful and thought-provoking message around engaging with patients, caregivers, healthcare providers and citizens to co-design integrated care. The presentation slides can be downloaded from repository of conference slide decks, Plenary 4 Carole Anne Alloway – Co-designing policies and strategies.pdf. Use the keynote to help facilitate buy-in within your organization to support the shift to shared power in decision-making by committing to co-designing solutions.

This video (3:30 minutes) developed by the Connecting the Dots project (Changing CARE) highlights how using co-design methods to gain insights from patients, caregivers and healthcare providers can be valuable in quality improvement efforts. Caregivers and healthcare providers share their experience of partnering and co-designing together. This video can be used at the beginning of a discovery or co-design session to introduce the concept of co-design and articulate how the approach can facilitate meaningful change.
The resources in this section can support you in the initial step of setting up. Use them to help build the foundation to be able to facilitate your engagement and co-design efforts. You will need to think about some foundational considerations such as guiding principles around how to compensate participants, and strategies for engaging with hard to reach groups (e.g., applying an equity lens).

[PowerPoint]: Building capacity for an equity lens in engagement | The Change Foundation (2019)

The Change Foundation has developed an equity framework and process to help guide its engagement efforts. This presentation outlines the overarching guiding principles and pillars that informed the approach in applying an equity lens to engagement. It provides a contextual overview, illustrating why an equity lens is important, and highlights the need to evolve systems of care and engagement as the Ontario population changes. The presentation can be used by those who are interested in developing and/or adopting an equity framework to help guide their engagement efforts.

[Tool]: Health Equity Impact Assessment (HEIA) | Ontario Ministry of Health and Long-Term Care (Spring 2012)

The Health Equity Impact Assessment (HEIA) (version 2.0) is a decision support tool which guides users through the steps of identifying how a program, policy or initiative will impact population groups in different ways. It includes a template and a workbook that walks users through the five steps: 1) Scoping, 2) Potential Impacts, 3) Mitigation, 4) Monitoring, and 5) Dissemination.
[Report]: Implementation guide: Caregivers as partners in project planning  | Changing CARE (2018)

The Embrace project (Changing CARE) developed an implementation guide to help the project partner with caregivers throughout the project. This guide includes project planning tips and elements to consider when partnering with caregivers to collaborate and co-design solutions together.

[Report]: Lessons from Changing CARE: The discovery phase of experience-based co-design  | The Change Foundation (June 2018)

The Change Foundation’s Changing CARE projects co-designed solutions with family caregivers and healthcare providers to improve the caregiver experience. This learning report focuses on what these projects learned through their phase of listening and engaging with family caregivers and healthcare providers, including learnings on project planning. The following ‘summary’ tip sheets are also available:

- 6 Tips for Project Planning

[Report]: Should money come into it? a tool for deciding whether to pay patient- engagement participants  | The Change Foundation (March 2015)

As patient engagement activities become more common and compensation is a question, the Change Foundation has developed some materials to support you in answering the question: Should patient and family-caregiver participants be paid? This paper discusses the process to create the decision tool, the decision tool scoring, and any limitations and requirements of using the tool. A one-pager that highlights seven key aspects to consider in the decision-making process has also been developed:

- 7 things to think about when considering compensation
A decision tool that was developed by the Change Foundation for their own use—to help make decisions, on a case-by-case basis, whether to pay patient engagement participants or engagement participants more broadly (i.e. caregivers). You are free to adopt the tool as is, adapt it for your needs, or use it as a springboard to discussion.
The following is a collection of resources that can support you in planning and executing discovery sessions. Discovery is the engagement phase of co-design, and is an opportunity to listen to patients, caregivers, healthcare providers, staff and citizens to help you understand the environment and experience from their individual perspective.


A discovery phase report captures the narrative and bridges “what was heard” from engagement participants with “what is being done”. It is a tool that can be used to follow-up with participants to inform them of how their participation has influenced next steps (i.e. identification of priority areas). This is an example of a discovery phase report from the Embrace Changing CARE project.

[Tool]: Co-design and engagement activity templates to consider | The Change Foundation (April 2020)

The Change Foundation has been partnering with Ontario Health Teams (OHTs) to help support the co-creation of system transformation in local communities. Leveraging the Foundation’s expertise, several symposiums and workshops have been taking place, bringing together community stakeholders in shared purpose. In these engagements, different activities are used to build group cohesion, address barriers, celebrate community strengths, and identify principles to guide collaborative work. Consider using some of these activities in your next engagements.

The templates below include instructions on how to conduct the activities and can be printed as is or customized for your engagement. They can be used to help develop participant and facilitator packages for any engagement and co-design event, small or large.

- Facilitator worksheets
- Participant worksheets

How-to Plug and play
[Report]: Lessons from Changing CARE: The discovery phase of experience-based co-design | The Change Foundation (June 2018)

The Change Foundation’s Changing CARE projects co-designed solutions with family caregivers and healthcare providers to improve the caregiver experience. This learning report focuses on what these projects learned through their phase of listening and engaging with family caregivers and healthcare providers in their communities. The report, first in the Lessons from Changing CARE series, presents 40 practical, how-to tips to help guide organizations in their caregiver and provider engagement efforts. The following ‘summary’ tip sheets are also available:

- 5 steps to successful engagement
- 7 tips for engagement planning
- 9 tips for recruiting caregivers and providers for engagement
- 13 tips for engagement with caregivers and providers
- 5 tips for post engagement
[Tool]: Public and Patient Engagement Evaluation Tool (PPEET) | McMaster University (August 2018)

The Public and Patient Engagement Evaluation Tool (PPEET) is a set of three questionnaires that when used together provide a comprehensive evaluation of public and patient engagement within your project and/or organization. Included in this guide are the surveys, appendices with additional questions to consider (i.e., demographic questions), instructions on how to administer and key considerations for projects and/or organizations to make prior to implementation. These questionnaires are also applicable to evaluate the engagement in your co-design sessions.

- The patient questionnaire focuses on obtaining a participants’ assessment of the key features of the public and patient engagement initiative. Two versions are available recognizing that engagement may occur long-term/over time or may be a point-in-time.

- The project questionnaire enables you to review and assess the planning, execution, and impact of the public and patient engagement component of specific projects that are being carried out within your organization (i.e., quality improvement, planning and design). The tool has been split into three distinct modules.

- The organization questionnaire assesses how engagement, as an organizational activity and responsibility, is being carried out within organizations. Results from the questionnaire will be useful for tracking trends over time, to document organizational improvements in public and patient engagement, and to perform annual audits.

Building Knowledge
How-to
Plug and play
Example: Workshop (summit) materials | Changing CARE (June 2018)

WoodGreen Community Services (a project partner of the Cultivating Change Changing CARE project) held a full-day Caregiver Summit with caregivers, staff, and healthcare providers to talk about how WoodGreen could be transformed into being caregiver-friendly. Through this discovery workshop, several themes emerged which became priority areas for quality improvement initiatives. To facilitate the workshop, the team prepared facilitator guides, participant evaluation forms and activity sheets. These materials can be used as an example to facilitate your own discovery sessions.

- PowerPoint
- Table Facilitators Guide for Caregiver Summit
- Evaluation Form for Caregiver Summit
- Activity 1: Start with the Person
- Activity 2: What does a caregiver-friendly community experience look like?
- Activity 3: How can we enhance our services to become more caregiver-friendly?
Co-design events

The following resources can support you in planning, conducting, and evaluating your co-design event after you have conducted an initial discovery session to understand the current environment and priority areas to focus your co-design efforts. Co-design events can take a variety of forms: they can be large and involve many participants talking about general themes; they can be small with a limited number of participants focusing on a specific change initiative; and they can be time limited or continuous and embedded in daily project activities.

[Example]: Co-Design Orientation Sessions for Caregivers and Healthcare Providers | Changing CARE (Summer 2018)

It is important to prepare and build the capacity of family caregivers and healthcare providers to be able to meaningfully participate in co-design sessions. Co-design is still quite a unique and novel approach and for many, it will be their first time participating as equals and colleagues. Setting the context, priorities, and explaining the process are key to enabling both caregivers and providers to actively collaborate. Caregivers and healthcare providers may have different questions and concerns and it is important to host these sessions separately in recognition of this. Below are two examples of slide decks that were used to facilitate an orientation session to co-design initiatives to better support caregivers caring for someone who has experienced a stroke within the Cultivating Change Changing CARE project:

- Caregiver orientation slide deck (PowerPoint)
- Healthcare provider orientation slide deck (PowerPoint)

Consider using elements from these slide decks in building your own orientation materials.
[Report]: Lessons from Changing CARE: Co-design events | The Change Foundation (January 2019)

The Change Foundation’s Changing CARE projects co-designed solutions with family caregivers and healthcare providers to improve the caregiver experience locally. The second learning report in this series highlights learnings from initial co-design events to address priority areas for improvement. The report presents 16 practical, how-to tips to help guide organizations to plan and facilitate their co-design events and follow-up with co-design participants. Notable surprises the teams encountered are also documented. A supplementary “summary” tips sheet is also available:

- 10 tips for co-design events

[Example]: Materials used to facilitate a co-design workshop in palliative care | Changing CARE (September 2018)

The Cultivating Change Changing CARE project included palliative care under their umbrella of quality improvement efforts. Using a co-design approach, the team facilitated a series of workshops. In this particular session, a Sharing Circle was included to recognize an element of Indigenous culture. Below are materials used to conduct the co-design workshop with caregivers, staff, and healthcare providers. These examples can be used to develop your own set of co-design materials.

- Agenda
- Facilitator’s guide
- Sharing circle – Anishnawbe Health Toronto
- 8 caregiver vignettes
- Activity 1 – Empathy mapping board
- Activity 1 – Empathy mapping work sheet
- Activity 2 – Idea description board
- Palliative care co-design slides
[Example]: Materials used to facilitate a co-design workshop in stroke care | Changing CARE (December 2017)

To facilitate a co-design session with the focus of improving the caregiver experience in stroke care, the Cultivating Change Changing CARE project held a series of workshops with caregivers, staff and healthcare providers on the unit. Below are materials from a co-design session. These examples can be used to develop your own set of co-design materials.

- Agenda
- Facilitator guide – Review of current state
- Stroke journey map
- Example of completed journey map
- Key themes stroke co-design
- 4 Persona examples:
  - Asfiya persona
  - Jessica persona
  - Maria persona
  - Paul persona

[PowerPoint]: Prototype of the planning and co-design process | The Change Foundation (April 2020)

This slide deck — a prototype framework — highlights the co-design approach the Change Foundation is using with Ontario Health Teams (OHTs) to define shared purpose and advance integrated care in Ontario. The slides can be adapted for any engagement or co-design session.
[PowerPoint]: Shifting mindset and behaviours | The Change Foundation (April 2020)

This slide deck provides an overview of the fundamental shifts that help support communities as they transition to working in a more connected and integrated way. Initially this list was called “seismic shifts.” These shifts reflect changes in the mindset and behaviors of partners working together. The slides can be used in co-design sessions to help set the context around working from a strengths-based perspective.

[Video]: The Caregiver Wishlist – Co-Design in Action | The Change Foundation (June 2018)

“There is nothing to compare like lived experience” – Carole Anne Alloway (Family Caregiver). We know that no two caregiving experiences are the same, but the wish for better communications, caregiver identification, assistance with system navigation, respect and empathy from healthcare providers, discharge training and more, transcend disease, diagnosis and journey. This video (5:00 minutes) highlights the journey of co-designing the Caregiver Wishlist with 16 diverse caregivers. The Wishlist is something organizations can leverage as a foundation on their own journey to improve the caregiver experience or build something similar through their Discovery sessions. It also serves as an example of how engagement can yield insights into where the need is and enable responsive efforts.
Make the changes

After you have co-designed the solution “change idea,” the next step is to pilot the change to be able to identify whether the co-designed solution leads to the desired improvement and intended impact. You may decide to conduct a single pilot study to evaluate the outcomes of the co-designed solution or conduct several Plan-Do-Study-Act (PDSA) cycles over a period of time. Testing is essential before implementation to work out the kinks but remember a solution that works in one unit, program or care setting will require adaptation in another – there very rarely is a “one size fits all” solution. The resources below can help with you with testing, implementing, spreading, scaling and sustaining your co-designed solutions.

[Report]: Lessons from Changing CARE: Testing and implementation of change initiatives
The Change Foundation (April 2020)

The Change Foundation’s Changing CARE projects co-designed solutions with family caregivers and healthcare providers to improve the caregiver experience locally. The third report in the series focuses on what the Changing CARE projects have learned about testing and implementing co-designed change initiatives. The fourteen learnings are organized under three categories: people, process and place. Each of the learnings are illustrated by stories and examples from the Changing CARE projects.

- Tip sheet

[White Paper]: Psychology of change framework
Institute for Healthcare Improvement (IHI) (2018)

The IHI’s Psychology of Change Framework is an approach to advancing and sustaining improvement together with the people directly and indirectly affected by that improvement. The paper is a guide for all leaders interested in understanding the underlying psychology of change and leveraging its power to impact quality improvement efforts.
The Quality Improvement (QI) Essentials Toolkit features tools and templates to launch a successful quality improvement project and manage performance improvement. Each of the ten tools can be used with the Model for Improvement, Lean, or Six Sigma, and includes a short description, instructions, an example, and a blank template. These tools can be used to support the testing and implementation of co-designed improvement initiatives. The QI tools included are:

- Cause and effect diagram (fishbone diagram)
- Driver diagram
- Failure modes and effects analysis (FMEA)
- Flowchart
- Histogram
- Pareto chart
- Project planning form
- Run charts and control charts
- Plan-Do-Study-Act (PDSA) worksheet
- Scatter diagram

This resource provides an overview and a step-by-step guide of how to use Plan-Do-Study-Act (PDSA) cycles as a scientific model to improvement.
**[White Paper]: Sustaining improvement | Institute for Healthcare Improvement (2016)**

This Institute for Healthcare Improvement white paper presents a framework that health care organizations can use to sustain improvements in the safety, effectiveness, and efficiency of patient care. The key to sustaining improvement is to focus on the daily work of frontline managers, supported by a high-performance management system that prescribes standard tasks and responsibilities for managers at all levels of the organization.

**[Tool]: The NHS sustainability model and guide | The National Health Service (June 2017)**

The National Health Service’s (NHS) Sustainability Model and Guide is a diagnostic tool that can be used to identify strengths and weaknesses in an implementation plan and predict the likelihood of sustainability for the change initiative. Ten questions are organized under three domains - staff, process, and organization. The tool can support narrowing in on areas with a lower score to help build a practical strategy that would increase the likelihood of sustainability for an improvement initiative.

**[Video]: What’s an easy way to learn about PDSA cycles? | Institute for Healthcare Improvement (2015)**

Whether or not we recognize it, our daily routines include Plan-Do-Study-Act (PDSA) cycles. In this Institute for Healthcare Improvement’s Open School Short (2:30 minutes), listen to improvement advisor, David M. Williams, explain different ways to learn about improvement by doing it. David shares why iterative testing is a fundamental part of improvement and discusses why and how games, exercises, and activities can foster learning improvement concepts and skills.
Thanking your engagement and co-design participants does not need to be expensive or fancy. More often than not, these are folks who would like to share their experience to help make improvements. A simple gesture of recognition and demonstration that their input was meaningful goes a long way. Don’t over think it.

[Example]: Celebrating the journey through an online photo gallery | Changing CARE (May 2020)

The Embrace project (Changing CARE) created an online photo gallery to thank, recognize, and celebrate the contributions of the family caregivers and the project’s Executive Steering Committee and Advisory Council who helped the project understand and respond to the needs of caregivers in the local community. Along with access to the photo gallery, each family caregiver who partnered with the Embrace project received a thank you letter and a small “I am a caregiver” pin to thank them for their continued commitment, dedication, and courage in sharing their lived experience to make improvements to the caregiver experience at Cornwall Community Hospital.

[Example]: Thanking discovery phase participants | Changing CARE (2019)

The Cultivating Change project (Changing CARE) included the Neonatal Intensive Care Unit (NICU) under their umbrella of quality improvement initiatives to improve the parent caregiver “NICU family” experience. Recognizing that a typical discovery session would not be as feasible with this subset of caregivers, the team asked the parents of infants in the NICU to complete an online poll to help them identify areas of improvement within the NICU to better support and empower them. To thank the NICU families, the project team left a simple thank you note in the main reception area and some healthy snacks for the new parents.
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