

OHT Patient, Caregiver & Community Engagement Learning Series

Module 5: Preparing for Engagement Activities

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How to Use This Workbook

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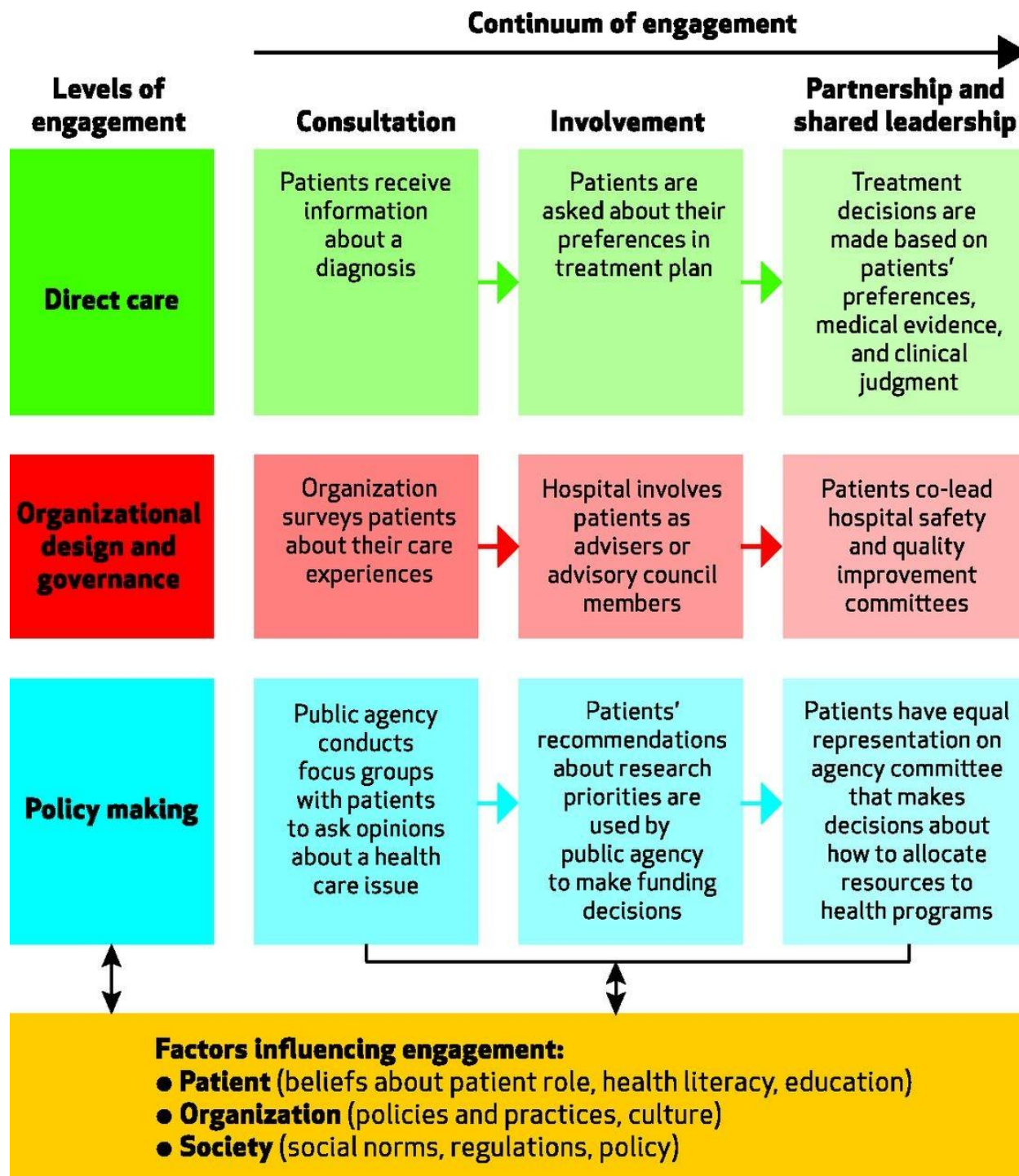
The materials in this workbook are general guidelines only. This workbook is not intended to provide legal advice. If there is a discrepancy between this document and any applicable legislation, the legislation will always prevail.

Document Layout

This workbook consists of five sections. **Section one** defines engagement and co-design. We include a framework, which outlines places where engagement activities occur as well as different *degrees* of engagement. **Section two** outlines how we can prepare for engagement activities including co-design. **Section three** reflects on how to ensure meaningful engagement activities. **Section four** covers organizational readiness for engagement including how to build engagement capable environments. **Section five** includes other resources.

Section 1: Engagement? Co-Design? What's the Difference?

Put simply, engagement refers to connecting with others or working together. Co-design, is a type of engagement where people come together to *build* or *create* something, generally for the purposes of improvement (of a product, service, process system or tool). It is helpful to think of engagement along a continuum. The figure below by Carman et al (2013) outlines the different places that engagement activities take place (the first column) as well as the *degrees* of engagement (see continuum of engagement along the top of the figure - ranging from low levels of engagement at the far left, to greater degrees of engagement at the far right).



As noted in the Carman framework, engagement can occur in a clinical encounter (between a clinician and a patient), within an organization or community as well as in policy-making. Similarly, James Conway from the Institute for Healthcare Improvement describes engagement as occurring in different settings: during the care experience, within the clinic or ward, within a health care organization, and within the larger community.

Now let's walk through the different *degrees* of engagement as depicted in the Carman Framework. Let's start with clinical engagement. A lower degree of clinical engagement, *consultation*, refers to a patient receiving information from a clinician such as a diagnosis. A patient becomes more *involved* when asked about their preferences

regarding their treatment plan. Finally, *partnership* (greater degree of engagement) is evident when patient preferences, along with medical evidence and clinical judgement are considered. For our purposes (and likely more relevant for Ontario Health Teams), let's consider engagement *within organizations*. In this sphere, consultation may refer to surveying a population to learn about their needs. *Involvement* may refer to having patient and caregiver partners on planning committees or advisory councils. Finally, *partnership* is evident when patient and caregiver partners are co-chairs on committees, assume more of a leadership role, and participate in activities like co-design as equal partners with other stakeholders (including researchers, program leads, clinicians, members of our communities, decision makers, etc.). Patient and caregiver partners may have different preferences for engagement. As noted by Carman different factors influence patient preferences and possibilities for engagement including the person's belief about their role, their literacy and education; the culture and readiness of the organization; and social norms and policy in broader society.

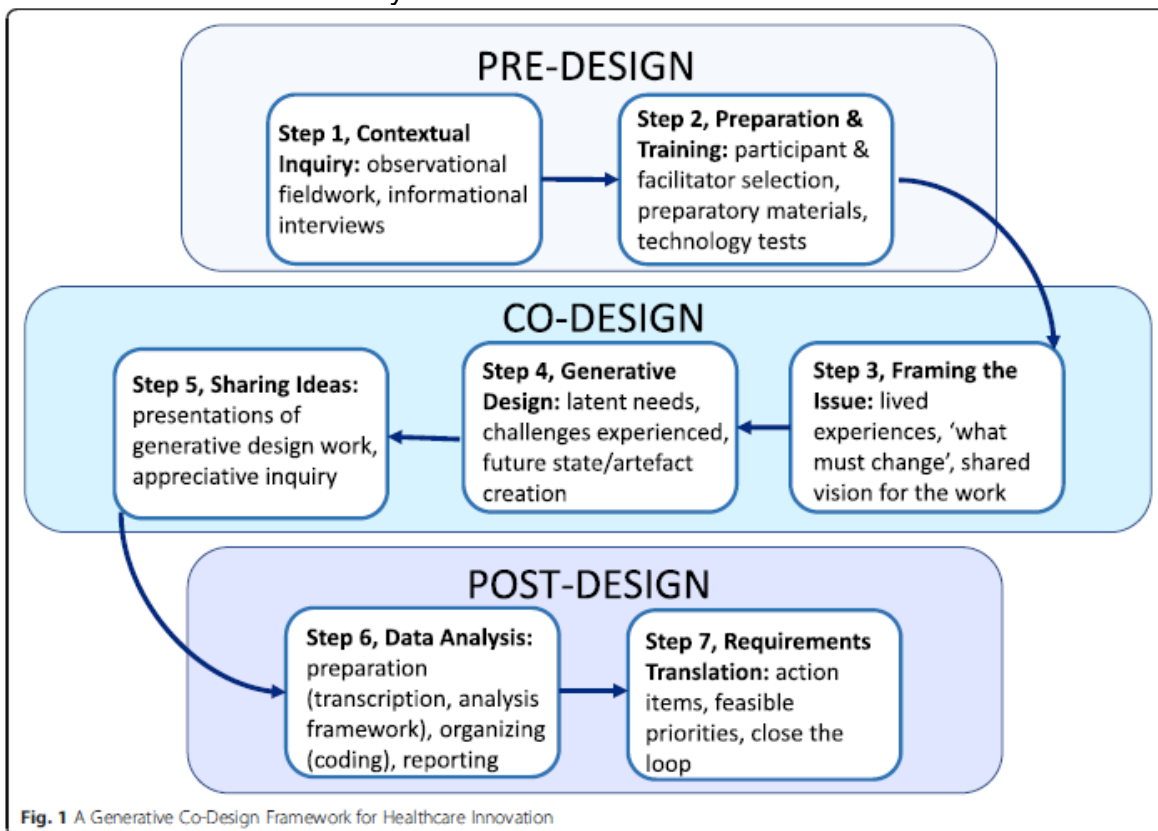
Section 2: Preparing for Engagement Activities

It is important to spend time doing preparatory work before jumping into engagement activities like co-design. Any engagement activity needs a pre-phase, an activity phase and a post phase. In this workbook, we focus on the pre-phase.

- In the **pre-phase**, you are connecting with (and identifying) stakeholders to participate in your activity (including patient and caregiver partners with lived and living experience that align with the co-design focus).
- As noted in our previous modules, it is important to take time to build relationships and trust with stakeholders and assess readiness (of all parties, not just patient and caregiver partners) to participate. Assessing readiness is required to ensure that co-design spaces feel safe and participants feel comfortable connecting and sharing. They may be at a phase in their journey where co-design is not the most suitable activity (so other forms of engagement can be explored).
- Important barriers to engagement need to be assessed at this stage including logistical barriers (like transportation, parking, scheduling and trade-offs in activities that will have to be made by participants).
- Spending the necessary time with all stakeholders, including patient and caregiver partners is required to brief them on the upcoming activity, answer questions, outline what to expect and discuss the goals of the activity to assess alignment in expectations.
- Clearly outlining available resources (compensation, food, parking, tech support, etc.) at the outset.

Bird et al (2021) designed a **Generative Co-design Framework** for Healthcare Innovation (see figure below). In this framework, the pre-design phase consists of two steps: **contextual inquiry** (observational fieldwork and informational interviews), **preparation, and training** (participant and facilitator selection, preparatory materials and technology tests). The phases that follow (co-design and post-design) will be explored in our next session and workbook. To put this into context, if an Ontario Health Team is designing a new pathway for better access to mental health treatment for youth, contextual inquiry may consist of doing an environmental scan and some interviews to learn how the current systems works (including barriers to access among



youth). From there youth with lived and living experience on the topic of inquiry, and perhaps peer workers, families, and providers, would be approached to assess interest in participating in co-design activities. An assessment of the learning needs of these stakeholders would take place along with pre-meetings to prepare them for the co-design activity (including reviewing and designing agendas, reviewing discussion topics, flow of the day, resources provided, etc.). Ideally, participant stakeholders would be involved in the actual design of the session by incorporating their input. To manage expectations, discuss *what's in and what's out* so that people are familiar with the scope of work and limits of the activity.







Section 3: How do you ensure a Meaningful Engagement Experience?

The Ontario Caregiver Organization developed Rules of Engagement (Guidelines which capture Caregiver Perspectives on Meaningful Engagement). The guidelines, adapted from materials originally developed by The Change Foundation in collaboration with caregivers and patients, include 15 approaches for health care organizations to use when engaging caregivers, which are also applicable to patient partners. A full PDF copy of the Guidelines can be found here <https://ontariocaregiver.ca/engagement-and-co-design-inventory-of-resources/>

Some examples from these guidelines are provided below.

Engagement Principle	Engagement Principles	The Desired Caregiver Experience
<p>Consider a range of engagement formats</p> 	<ul style="list-style-type: none"> • Offer a number of ways for caregivers to help improve the quality of health care and the health care experience. • Formats should be dependent on the objectives and stage you are at within your engagement work. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • participate in multiple ways and in the language of their choice (i.e. share healthcare experience in writing, share a video, provide written feedback, attend a meeting with interpretation). • be selected for the 'right' format for the 'right' goal. This could be achieved through a chart/tool for when to use different formats (i.e. courses for individual learning, Town Halls for broad community reach, etc.). • be encouraged to share their story (experience) because organizations recognize that storytelling is important. This shows the power of narrative and allows organizations to benefit from different experiences.
<p>Recruit wisely</p> 	<ul style="list-style-type: none"> • Recruit wisely. • Aim for a mix of people who are new to public engagement and those who are experienced or even seen as champions in the role. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • be valued for different skills/roles. (organizations will get something new and different from each engagement opportunity) • have their skills and interests aligned with the opportunity, topic, or engagement formats. • be approached by someone they already know. • see healthcare organizations partner with other organizations to develop recruitment strategies to reach specific communities. • have barrier-free opportunities to participate. • have a variety of different level and time commitments for participation to ensure there is flexibility and respect for each person's time and availability. • have increased representation and ensure a diverse range of people from each community's demographics are involved. • be paid for their time to contribute.

Engagement Principle	Engagement Principles	The Desired Caregiver Experience
<p>Be clear about your purpose, objectives and scope of influence</p> 	<ul style="list-style-type: none"> • Be clear about your purpose, objectives and scope of influence. • From the start, give your participants clear understanding of the engagement's purpose, objectives, conditions for success, and level of involvement. • Tell the participants the level of influence or authority your organization has to implement changes and be clear about the of your organization's power from the start. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • not feel rushed (i.e. having too many topics on the agenda) and attend meetings set up to get meaningful input. • know what topics are within scope. • know that all ideas are welcome to stimulate ideas on how to address or identify future projects, but there may need to be a 'parking lot' list for ideas that are not included/ possible in the current topic. • feel heard and know that there is enough time for conversation, and they will not be rushed. • understand the roles and responsibilities for other people involved before the meeting/engagement event starts. • know what they have shared accountability of and what they have individual accountability for.
<p>Give participants the tools they need</p> 	<ul style="list-style-type: none"> • Give participants the tools they need. • Provide participants with accessible, relevant, and balanced resources and support, so they can build their knowledge and skills. This will also increase their confidence and capacity to engage. 	<p>Caregivers want:</p> <ul style="list-style-type: none"> • a Glossary of terms (acronym list) often used in healthcare organizations • good storytelling examples & tips for "how to tell my story". • a caregiver advocacy toolkit. • evaluations to provide feedback. (pre and post engagement opportunities) • a technology 101 overview - someone from the organization to check with them to be sure they have the technology knowledge and tools to be able to participate. • information provided ahead of any meetings or activities, to give them time to prepare. (this reflects that people learn/process/prepare differently) • a clear description of what 'involvement' means and what it looks like for the organization that they are involved with. • an overview of the Ontario health care system • an orientation to the project, topic and all the partners involved. • a list and summary of who's involved in the project/ committee/engagement opportunity. • regular communication updates. • jargon to be avoided and not used at the meeting or in the materials. (i.e. language is not a barrier to their participation) • a buddy system (peer connection) for patients and caregivers.

Engagement Principle	Engagement Principles	The Desired Caregiver Experience
<p>Give participants the recognition they deserve</p> 	<ul style="list-style-type: none"> • Give participants the recognition they deserve. • Always acknowledge the contributions and impact of participants when reporting to the public and other audiences. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • be asked at the beginning of their involvement about how they want to be recognized. • be recognized in a way that is meaningful for them (different formats include honorariums, covering costs to participate, written or verbal thank yous). • A standardized approach (detailed in Terms of Reference or other guidance documents) to recognition to ensure everyone has the same understanding.
<p>Report back</p> 	<ul style="list-style-type: none"> • Commit to a feedback loop at the beginning and follow through. • Tell or show participants what you did, or didn't do, with their information or advice. • Reporting back is also linked to how you've acknowledged them in your activities or materials. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • see what has changed or what progress has been made based on their involvement. • a feedback loop that they understand and can rely on. This can take many forms including meeting minutes, follow-up and thank you letters, and regular communications. • be told or shown how their feedback was used (or not used and why). Updates can be given at the next meeting or in a summary letter/email. They are interested in the long-term impact of their involvement as well – a letter, call or email outlining how the change has impacted the lives of patients/caregivers, or how it has been sustained for 6 or 12 months, is also important. • a report back as an important act of recognition or acknowledgement.

Section 4: Assessing Readiness for Engagement and Building Engagement Capable Environments

Assessing Readiness for Engagement

It is important that the onus of engagement readiness not be placed on patient and caregiver partners. Organizational preparation and readiness is critical. Below we provide a Readiness Assessment for health care partners (also provided in the workbook for module 2).

Health Care Partner Readiness Checklist (Yes/No)

A checklist from Patient Voices Network

Administered by BC Patient Safety & Quality Council

Link to the PDF version: [Health Care Partner Readiness Checklist - Patient Voices Network \(patientvoicesbc.ca\)](https://www.patientvoicesbc.ca/Health-Care-Partner-Readiness-Checklist)

Engaging patients, families, and caregivers to improve services is an important part of a person- and family-centred organization. Your teams' readiness to embrace this type of relationship sets the stage for a successful partnership. **We encourage you to get together with your team and use the questions below as a**

guide to see if your team is ready. If you answer no to any of these questions, you may need more time to discuss things before adding to a patient partner to your team.

Question	Yes	No
Do I believe that patients, families, and caregivers bring unique perspectives and expertise to the table?		
Do I work to create an environment in which patients, families, and caregivers feel supported enough to speak freely?		
Do I listen respectfully to the opinions of patients, families, and caregivers?		
Do I consistently let colleagues know that I value the insights of patients, families, and caregivers?		
Do I believe that patients, families, and caregivers bring a perspective to a project that no one else can provide?		
Do I believe that patients, families, and caregivers can look beyond their own experiences and issues?		
Do I believe that the perspectives and opinions of patients, families, and caregivers, and providers are equally valid in planning and decision-making at the program and policy level?		
Do I have experience working with patients, families, and caregivers as partners and/or members of improvement or other teams?		
Do I understand what is required and expected of patients, families, and caregivers who serve as partners and/or members of improvement or other teams?		
Do I clearly state what is required and expected of patients, families, and caregivers in their roles as partners?		
Do I help patients, families, and caregivers set clear goals for their role?		
Do I feel comfortable delegating responsibility to patients, families, and caregivers, and improvement team members?		
Do I understand that an illness or other family demands may require patients, families, and caregivers to take time off from their responsibilities?		

Adapted from Jeppson, E. & Thomas, J. (1994). *Essential allies: Families as advisors*. Institute for Patient- and Family-Centered Care.

Healthcare Excellence Canada developed the Engagement Capable Environments Self-Assessment Tool, found at this link

<https://www.healthcareexcellence.ca/en/resources/engagement-capable-environments/>



The Engagement Capable Environments Framework (Baker et al 2016), developed by Drs. Jean Louis Denis and Ross Baker (and further by Healthcare Excellence Canada), outlines what needs to be in place to make organizations *engagement capable*. There is a role for leadership, a role for providers/staff and a role for patient and caregiver partners. The freely available, PDF fillable, self-assessment tool (see link above) is meant to be filled out by teams doing engagement activities and provides opportunities to assess each sphere of the framework (patients/caregivers; providers/staff; and leaders) in terms of readiness, current capabilities and opportunities for improvement. It is an excellent tool for self-reflection. We encourage you and your teams to fill this out and revisit it overtime to assess changes in engagement capability.

Example self-assessment questions (from the tool):

Leaders:

1. Leaders have clearly expressed a philosophy of patient- and family-centred care and partnership that is foundational to the organization.
2. Leaders have made an organizational commitment to ensure equity, diversity, and inclusion in engagement initiatives.
3. Leaders ensure there are opportunities for patient partners in leadership/ decision-making roles (e.g. chair/co-chair of organizational committees, on hiring panels, in governance).

Staff and Providers:

1. Staff/healthcare teams have the resources they need to support engagement activities.
2. Staff/healthcare teams are conscious of power imbalances inherent on teams where people have many different roles. Staff seek to create an open, safe, and welcoming environment to minimize these imbalances.
3. Staff/healthcare teams receive training/education to engage with empathy, compassion, and openness to learning. This may include active listening skills, understanding trauma, cultural safety and diversity training.

Patients and Caregiver Partners:

1. Patient partners and staff/healthcare teams develop a shared goal and purpose for engagement.
2. Patient partners have a dedicated staff member or peer mentor for support who they can contact with questions or concerns, before, during and after engagement activities.
3. Patient partners have different opportunities to be engaged based on their skills, interests, and experiences.

For a full list of self-assessment questions go to this link:

<https://www.healthcareexcellence.ca/en/resources/engagement-capable-environments/>

Section 5- Other Resources

Authentic and Meaningful Engagement: The Caregiver Perspective

<https://www.youtube.com/watch?v=jCw-JXoqIKo>

In this video Bianca Feitelberg, Project Lead in Strategic Partnerships & Innovation at the Ontario Caregiver Organization, interviews caregiver partners' Carole Ann Alloway and Omar Khan to capture important and practical examples of how best to engage patient and caregiver partners' in engagement activities.

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