OHT Patient, Caregiver & Community Engagement Learning Series

Module 6: Engagement Methods

Acknowledgements

How to Use This Workbook

To Cite this Document

You may (with proper citing) share resources within this document for your own purposes. Please use the following citation when referencing or using any materials from this document: Engagement Methods Working Group. Engagement Methods Workbook. OHT Patient, Caregiver & Community Engagement Learning Series. 2023

Working Group Members: Alyssa Gremmen, Patrick Feng, Kerry Kuluski, Reham Abdelhalim, Michelle Marcinow, Junhee Baek, Susan Palijan, Marianne Saragosa, Marissa Bird

Legal

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 three sections. **Sections** 1 reviews a couple of key definitions. **Section 2** outlines four examples of engagement and co-design methods (world café, persona development, scenario development, and patient journey mapping). **Section 3** provides links to "how to" guides/videos when using virtual tools such as jamboards and miro to support your co-design work.

Section 1: Definitions

As outlined in the previous workbook ("Preparing for Engagement Activities") the terms engagement and co-design are sometimes used interchangeably. "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)" (Preparing for Engagement Activities Working Group, 2023). In the following sections of the workbook we review some common methods for co-design activities including World Café, persona development, scenario development and patient journey mapping.

Section 2: Co-Design Examples
Example #1: World Café

One way to engage people in structured conversations is through a method called **World Café**. The World Café method was designed in 1995 by Juanita Brown and David Isaacs (CHI KT Platform 2019). Groups of 3-4 participants rotate as a group between different tables to have focused conversations (you can even add some tablecloths and play some coffee house tunes to emulate the café atmosphere!) Each table has a facilitator who poses a specific topic/question. Each discussion typically lasts about 20 minutes. Key ideas can be written onto chart paper or sticky notes. After the group rotates to a *new table,* the facilitator provides an overview of what was shared from the *last group* and the *new group* is invited to build upon the previous groups insights. The great thing about this method is that it can be used for multiple purposes/ stages in a project. For example, the world café might be used as an initial "kick off" meeting between stakeholders to set proprieties for a project. It can also be used to identify key components of a project or intervention that is under development. For example, in a study on delayed hospital discharge led by Kuluski et al (2020), initial focus groups (small group discussions) were held with patients, caregivers and care providers to learn about key challenges during a delayed hospital discharge. After those focus groups, the research team compared notes and identified key "pain points" identified by patients, caregivers *and* care providers. These pain points became topics of discussion for the world café, where the participants started to build components of an intervention.

There are key principles to support the successful delivery of a World Café experience:
1. **Set the context** (you might want to put some boundaries around the discussion- what is on/off the "table?"- no pun intended!)
2. **Create safe and accessible spaces** (find out in advance what makes participants feel safe in a discussion. What needs and preferences do they have for participation? For example, in meetings with lots of different types of stakeholders, it might be important to group all patients together, all caregivers together; all care providers together, etc., to avoid discomfort that may arise due to power differences).
3. **Explore research questions that matter** (questions posed to the group need to be relevant to their real-world concerns).
4. **Encourage everyone to contribute** (provide different modes of participation including writing ideas on index cards or sticky notes, participating verbally, etc.).
5. **Connect diverse perspectives** (this occurs when the table facilitator links ideas between groups).
6. **Listen together for patterns and insights** (active listening/ listening to understand. Paying attention to repeated words and themes as well as what is *not* being said).
7. **Share collective discoveries and decisions**- the last part of the World Café entails the whole group coming together for what is called "the Harvest." During

the harvest, all participants to silently reflect for a few minutes then engage in open discussion of core highlights. The facilitator can help create connections between ideas in this final synthesis.

Café to Go! A Quick Reference Guide for Hosting World Café published by the *World Café Community Foundation Creative Commons Attribution* www.theworldcafe.com provides a useful guide to preparing for and conducting world cafes. The guide includes information on **how to create questions** for table discussions (clear open-ended questions that are thought provoking, generate energy, and focus the inquiry). The guide also provides tips for table facilitators (including working with the planning team to learn about the purpose of the café and discussing who should be invited to participate; welcoming participants as they enter; clearly explaining the purpose of the cafe; explaining café etiquette and guidelines, including on chart paper or through handouts at the table). We recommend using this guide when planning your World Café activity.

Example #2: Developing Personas

Developing personas (fictional characters that comprise characteristics of the participants you are working with) is another way to support your co-design work. Some people develop personas from existing data sets (such as through a cluster analysis of variables from health administrative data). Another way to create personas is with participants themselves. For example, in a project led by Dr. Marissa Bird she worked with parents of children with medical complexities (Bird et al 2021). The goal of her project was to design virtual care improvements to support these parents/caregivers in their care journey. To start the project, Dr. Bird pulled together a group of parents of children with medical complexities and asked them to fill out the worksheet below. Another way to accomplish persona development is through a group of people (who already share some characteristics) who draw on their collective wisdom to create someone like themselves.

PERSONA DEVELOPMENT WORKSHEET

Question	Answer
My name is:	
I am _____ years old:	

Question	Answer
I am a:	Please circle one of the followings: Man Woman Non-Binary
My caregiver role:	• •
Any other jobs that I have:	• •
Other important caregivers/team members:	• •
I typically provide ___ hours of care to a child with medical complexities in a	Please circle one of the followings. Day Week
Important care tasks that I do are…	• •
Typical assistive technologies that I interact with/use to provide care:	Please circle one of the followings. Wheelchair Home oxygen Tracheostomy G/J tube feeds Hearing aids Dialysis Non-invasive ventilation Invasive ventilation Long-term IV/port CSF shunt Other: Other:

Question	Answer
Highlights of my role…	• •
Challenges/frustrations of my role…	• •
My comfort level with technology:	Please circle one of the followings: Not comfortable A little comfortable Mostly comfortable Very comfortable
The technology devices I use most often are:	Please circle one of the followings. • Mobile phone • Tablet • Land line • Remote monitor (e.g. Fitbit or vital signs monitor) • Desktop computer • Webcam • Laptop computer • Other:
Please circle one of the followings. **I prefer to communicate with other caregiver/team members:**	On the phone Over email By video call In person
Other important details about me:	• • • •

Depending on your population of study, and project focus, you can customize the template (add or remove questions) to suite your learning needs.

Example #3: Developing Scenarios

Developing scenarios can be the logical next step after creating personas (see above for information on how to create personas). Pulling through the same example of Dr.

Bird's research study of parents of children who have medical complexities, let us consider what it would look like to develop a scenario with this group. Dr. Bird is seeking to better understand how to support partners of children with medical complexities through virtual technology. In order to do that she started by asking participants to brainstorm challenges, followed by choosing one challenge to focus on and eventually brainstorming solutions. The scenario development worksheet below has several components to work through. To reiterate, first, you **brainstorm the challenge**, then you **choose what challenge to work on**, then you **explore the challenge deeply** by answering a series of questions (see below) and then **brainstorm the solution**. The worksheet below walks through these different steps with instructions.

Scenario Development Worksheet

Challenge Brainstorm

- Before we start building a new virtual care system, the first step is to specify a challenge for each group to work on
- For the next 5 minutes, brainstorm all the challenges you can think of for your persona!
- A challenge could be something like…
  - "I know my child well, but when I am working with a new home healthcare provider, they don't have anyone except me to ask for support if they have a question. This means I need to be available all the time."
  - "As a hospital-based healthcare provider, I receive very little information about how children are doing at home, and need to see them in person in a clinic appointment in order to check in."
- Facilitators will keep notes of all the brainstormed challenges below, and these will be passed on to the research team.
- Ready? 5:00 on the clock!

Challenge Brainstorm:

-
-
-
-
-

Challenge Selection

- Now that you have a good list of challenges to choose from, talk to your group members to select one challenge to work on.
- This challenge should be something that you feel would be an important issue to tackle for your persona.
- Remember, if your group picks a challenge to work on that is not your first choice, the research team will review all brainstormed challenges, and you will get a chance to let us know of important points that may have been missed after our co-design meeting.

Write down the challenge you have selected here:

-
-
-
-
-
-

Challenge Exploration

- Now, let's work on really understanding the challenge
- Answer the following questions…

Challenge Exploration
- Who is affected by this challenge?

- What is the most difficult thing about the challenge for your persona?

- How often does this challenge come up?

- How serious of a problem is the challenge when it does come up?

- What are some of the consequences or long-term effect of having to face this challenge?

- Are there any benefits or good things that come from facing this challenge?

- Any other important points?

Solution Brainstorm

- The last and most exciting step of our persona scenario exercise is solution creation!
- Now, imagine a world where your persona has access to a new way of caring for medically complex children, where they can use remote access to healthcare providers and services in order to provide care.
- The new way of providing care can include changes in how we provide care, who is involved in care, or use of technology, etc., that you would like to see.
- Answer the following questions…

A New Virtual Way to Provide Care
- In this new model of care, what would be different about how care is provided?

- How would this help to solve the challenge for your persona? What about this solution would help to solve the challenge?

- What settings or places would implement this new model of care?

- Who are the important people for your persona to be able to connect with in order to use this new model of care?

- What kinds of technologies are needed in the new model?

- If the new model of care affects any of the following categories, how are they affected?
  - How information is provided or communicated:

  - How families receive support:

  - How healthcare providers receive support:

  - How care is coordinated:

- Any other important points?

Example #4: Journey Mapping

A journey map has been described as a patient-oriented project that is undertaken to understand **barriers**, **facilitators, experiences, and interactions that patients and their caregivers (e.g., family and friends) have** with services (Davies et al., 2023). It considers their journey as they **enter, navigate, experience and exit** one or more services in a health system. A journey map is a visual or descriptive map that outlines various phases (such as entering an emergency room, getting admitted to a hospital, getting access to treatments, and then leaving the hospital) of a healthcare journey (Davies et al., 2023). Typically, these phases may be described as 'key moments' or even 'pain points' in a journey. The participants themselves determine the phases as they share their experiences (typically through interviews or focus groups).

Why do patient journey mapping? Patient journey maps are typically produced with the goal of improving/informing the quality of care (identifying gaps, to support redesign) and building relationships between patients, caregivers and service providers. Most importantly, it is an opportunity to explore lived experiences of people.

How is patient journey mapping done? In talking to your participants or analyzing the data you have (e.g., from a chart audit, survey, focus group or interview), you would ask the following questions:

- **Stages:** "What are the stages of the patient journey in chronological order?"

- **Actions:** "What are the patient's corresponding actions at each stage?"

- **Touchpoints:** "What are the interactions?"

- **Pain points:** "What is a challenge?"

- **Emotions or feelings at each stage:** "What are emotions or feelings associated with each stage?" if doing this in person, you can have participants choose from a list of 6 positive or 6 negative words.

- **Bright points:** "What is working well?"

Now let us look at a case example using an online program called Miro.

Please click on this link to view the patient journey map: https://miro.com/app/board/uXjVMKDHzUA=/?share_link_id=643656412633

Areas to Focus on in your Journey Mapping Analysis:

- What are the high points? (things that meet expectations, are done well)
- What are the low points (things that do not meet expectations or points of "friction" etc.)
- Creating flow charts, graphs and other diagrams may also help you and your team understand patterns in the journey map
- ***Depending on your purpose for using a journey map, you may have different questions you may explore. You may also explore high and low points in one area of the experience (ex. timelines, relationships, emotions etc.)

Section 3: Examples of Online Tools

There are a number of online tools and resources you can use to support your meetings, engagement activities and co-design activities. Below are some helpful YouTube videos that provide an orientation to different programs as well as links where you can sign up for these programs.

Miro

Go to this link to sign up for Miro

The Visual Collaboration Platform for Every Team | Miro

How-to Videos

https://www.youtube.com/watch?v=kRdtn8G4tII

https://www.youtube.com/watch?v=-6AacVZO37k

https://www.youtube.com/watch?v=mNNPchRnDp8

Jamboards (you need to have or create a Google account to use Jamboard)

How-to Videos

https://www.youtube.com/watch?v=NsUhWnO5xQc

https://www.youtube.com/watch?v=xl5paLS_eTU

https://www.youtube.com/watch?v=K1qS6avlnaE

Mural

Go to this link to sign up for Mural

Mural is a collaborative intelligence company | Mural

How-to Videos

https://www.youtube.com/watch?v=mhslj4-OSRM

Brainstorming and Ideation Resources (a sample)

IDEO U: Brainstorming
An introduction to brainstorming from IDEO, a global design firm that helped pioneer and popularize human-centered, design-based approaches.

Board of Innovation: Our favorite ideation tools
A compilation of downloadable tools that you can use to help plan and facilitate your ideation session.

Valentina Salvi: The master ideation toolbox, part 1 and part 2
Ten tools to try, accompanied by tips, red flags, and online adaptations.

World Café
Through the official World Café website, a number of resources are available:

https://theworldcafe.com/wp-content/uploads/2015/07/Tool_Kit_CheckList.pdf

https://theworldcafe.com/tools-store/hosting-tool-kit/image-bank/

https://theworldcafe.com/tools-store/

In summary, we hope you found this workbook helpful and that it helps you with your engagement and co-design activities!

References

Bird, M., M. McGillion, E. M. Chambers, J. Dix, C. J. Fajardo, M. Gilmour, K. Levesque, A. Lim, S. Mierdel, C. Ouellette, A. N. Polanski, S. V. Reaume, C. Whitmore and N. Carter (2021). "A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework." Res Involv Engagem **7**(1): 12. https://doi.org/10.1186/s40900-021-00252-7

CHI KT Platform. (2019, October 24, 2019). "Methods in Patient Engagement: The World Café."   Retrieved September 6, 2020, from

https://medium.com/knowledgenudge/methods-for-patient-engagement-the-world-caf%C3%A9-8f58b84577a.

Davies, E. L., D. Pollock, A. Graham, R. E. Laing, V. Langton, L. Bulto and J. Kelly (2022). "Reporting of patient journey mapping in current literature: a scoping review protocol." JBI Evid Synth **20**(5): 1361-1368.

Kuluski, K., J. W. Ho, L. Cadel, S. Shearkhani, C. Levy, M. Marcinow, A. Peckham, J. Sandercock, D. J. Willison and S. J. Guilcher (2020). "An alternate level of care plan: Co-designing components of an intervention with patients, caregivers and providers to address delayed hospital discharge challenges." Health Expect **23**(5): 1155-1165.

Preparing for Engagement Activities Working Group (2023). Module 5: Preparing for Engagement Activities. OHT Patient, Caregiver & Community Engagement Learning Series. Toronto, Ontario.

Park, H., H. Monkman, A. Wenger and B. Lesselroth (2020). "Portrait of Ms. Diaz: Empirical study of patient journey mapping instruction for medical professional students." Knowledge Management & E-Learning **12**(4): 469.

The World Cafe (2015). Café to Go! A Quick Reference Guide for Hosting World Café. https://theworldcafe.com/wp-content/uploads/2015/07/Cafe-To-Go-Revised.pdf