GEORGE & FAY YEE
Centre for Healthcare Innovation

Current as of May 20, 2020

Methods of Patient & Public ENGAGEMENT

A GUIDE

Helping your team find the right way(s) to engage with patients and the public at any stage of your research project or program

Active and meaningful patient and public engagement can occur at all phases and stages of research. It's never too late (or too early) to start engaging people with lived experience in making decisions about your health research project or program.

This guide will help you explore options for participatory approaches and engagement methods at various stages of research, and various levels of patient and public partner involvement.

For every research stage

Identifying & prioritizing
Research design
Development of grant proposal
Preparation for execution
Data collection
Data analysis
Dissemination
Implementation Evaluation

And every level of engagement

Consult
Collaborate
Patient-Public Directed

chimb.ca

Strategy for Patient-Oriented Research SPOR Putting Patients First

Winnipeg Regional Health Authority / Office régional de la santé de Winnipeg
Caring for Health / À l'écoute de notre santé

University of Manitoba

This work is licensed under CC BY-NC-SA 4.0

Participatory Methods for Patient & Public Engagement in Health Research

What is Patient & Public Engagement in Health Research?

Patients, informal caregivers, families, friends, communities, and members of the public with lived experience of health conditions having a say in research decision-making as **patient and public partners** in research.

How to Use This Participatory Methods Tool

This tool was developed through process mapping of various participatory approaches to the stages of the research process. The purpose of this tool is to allow research teams to explore potential participatory approaches/ engagement activities for various stages of the research process. Each approach is assigned a number, and mapped to the various stages of research and levels of engagement described below. Some approaches may be useful for more than one stage of the research process, or more than one level of engagement. Descriptions and resources for each approach are included.

Stages of Research

- **Identifying & Priotizing:** Determining research priorities, selecting research questions, and/or choosing outcome measures of importance to people with lived experience of a health condition
- **Research Design:** Planning the research study, including methods for recruitment and data collection that are sensitive and appropriate to the needs of people with lived experience
- **Development of Grant Proposal:** Preparing a funding application to fund the research project or program
- **Preparation for Execution:** After funding has been received, preparing to recruit and collect data
- **Data Collection:** Conducting the research, through qualitative, quantitative or mixed methods approaches
- **Data Analysis:** Analyzing and interpreting research findings in the real-world context of the lives of people with lived experience
- **Dissemination:** Determining how and with whom to share the research findings
- **Implementation:** Applying research findings in healthcare service and delivery
- **Evaluation:** Determining the success of specific aspects of research (including patient and public engagement), or the overall research project or program

Levels of Engagement

The level of engagement refers to the amount of involvement and power that patient and public partners will have in actually making decisions about the research process.

Consult: A '**low**' level of engagement, the primary goal at the consult level of patient and public engagement is to obtain **feedback or input** on one or more research decisions. Decision-making power about the research lies entirely with researchers.

Collaborate: A '**moderate**' level of engagement, the primary goal at the collaborate level of patient and public engagement is to actively partner with patient and public partners on one or more research decisions. Decision-making power is shared between researchers and patient and public partners.

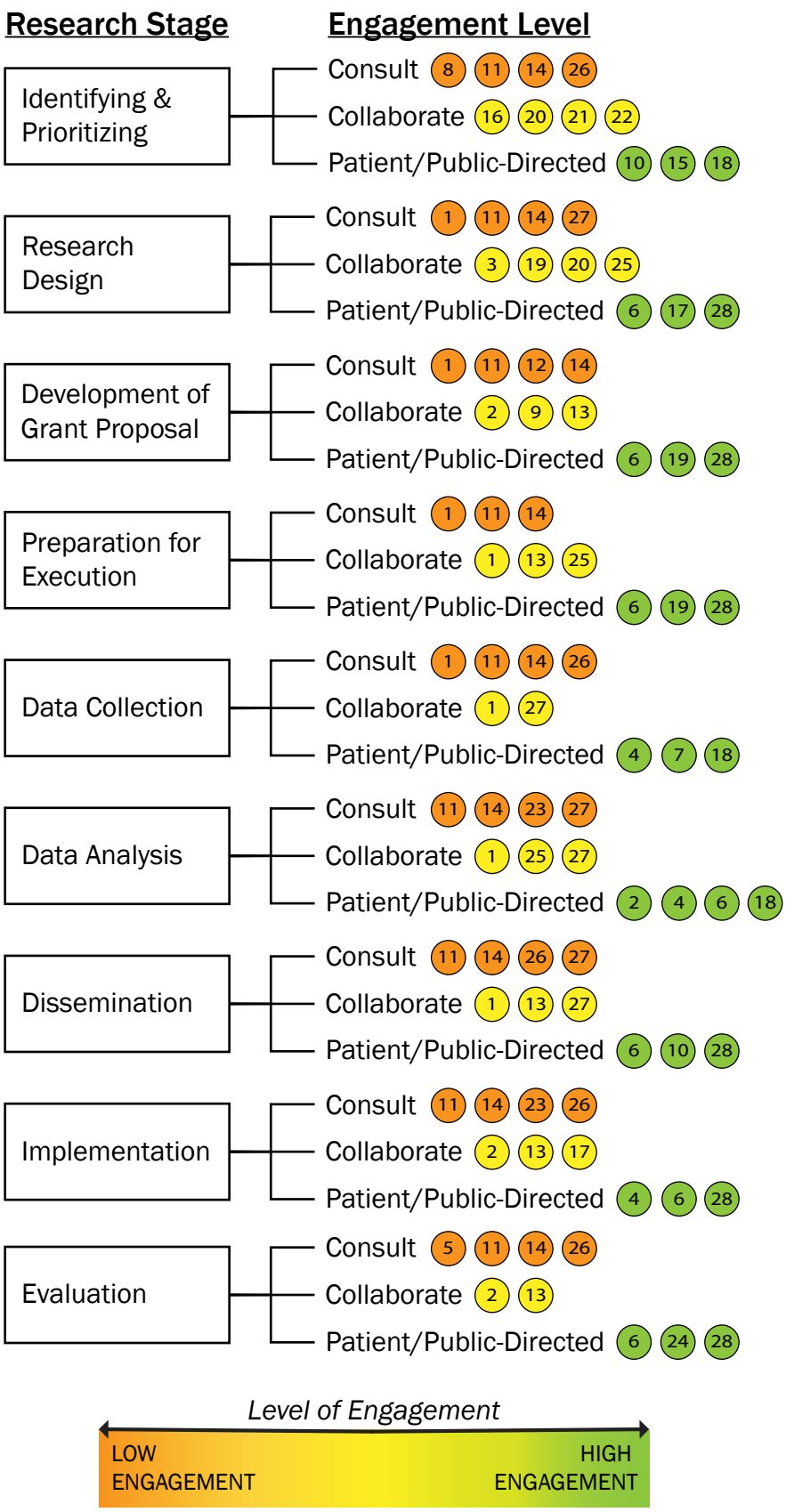
Patient/Public-Directed: A '**high**' level of engagement, the primary goal at the patient/public-directed level of patient and public engagement is for patient and public partners to actively control, direct, and manage the research process. Decision-making power lies entirely with patient and public partners.

New to Patient and Public Engagement?

For an introduction to patient and public engagement in health research, view our 'PE 101' series on our blog, KnowledgeNudge at www.medium.com/knowledgenudge/patientengagement

This work is licensed under CC BY-NC-SA 4.0

Participatory Methods for Patient & Public Engagement in Health Research



Methods Legend

1. Advisory group
2. Appreciative inquiry
3. Charrettes
4. Citizen Juries®
5. Comment forms
6. Conversation circles
7. Deliberative Polling®
8. Delphi process
9. Dialogue technique
10. Digital storytelling
11. Discussion groups
12. Fishbowl process
13. Focused conversations
14. Interviews
15. James Lind Alliance
16. Nominal group technique
17. Open space meetings
18. Participatory decision-making
19. Participatory design
20. Patient journey mapping
21. Patient observation of existing services
22. PhotoVoice
23. Public meeting/ town hall
24. Reality check
25. Study circles
26. Surveys/ questionnaires
27. Workshops
28. World Café

This work is licensed under CC BY-NC-SA 4.0

1. Advisory Group

This method involves a group of patient and public partners that meets regularly to help inform, provide insight, and provide different perspectives around important research decisions in the *research design, development of grant proposal, preparation for execution, data collection, data analysis* and/or *dissemination* stages. Beyond informing research decisions, Advisory Groups can help co-develop specific tools and products as part of the research project, and implement research decisions.

The Advisory Group should reflect diverse voices and perspectives. Consider who is affected differently by the health condition being studied; who has different access to healthcare services; what the different stages of the health condition are; and how these different perspectives can be brought to the table.

Useful for:

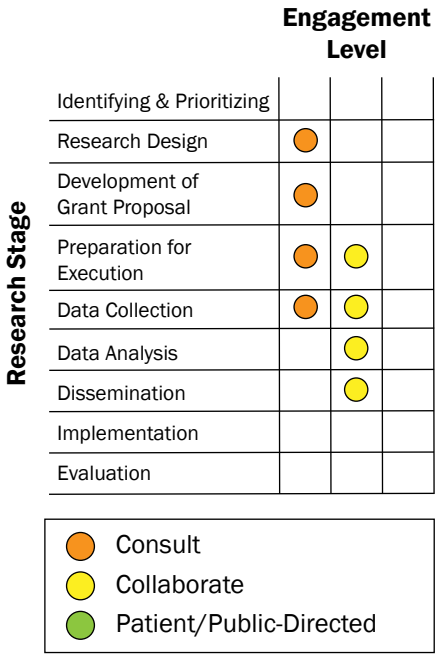
- Maintaining open dialogue about complex research decisions
- Creating open channels of communication and connections with communities to ensure the research reflects the needs of those with lived experience
- Building rapport and trust among patient and public partners in the Advisory Group as well as researchers

Additional Resources:

1) Agency for Healthcare Research and Quality (AHRQ): Working with Patients and Families as Advisors Implementation Handbook

Note: It is important that Advisory Groups have a very clear and specific purpose, and the research team is held accountable for communicating with the Advisory Group on how their input has informed research decisions.

Collaboratively building a *Terms of Reference* or *Guiding Principles* document can help Advisory Group members and researchers better understand roles, responsibilities, and expectations.



This work is licensed under CC BY-NC-SA 4.0

2. Appreciative Inquiry Process

This process takes a strengths-based approach to collaboratively making a research decision — focusing on what's working, rather than what's not working.

The Appreciative Inquiry Process is also known as the 4-D cycle, as it involves four stages:

1. **Discover**
2. **Dream**
3. **Design**
4. **Destiny**

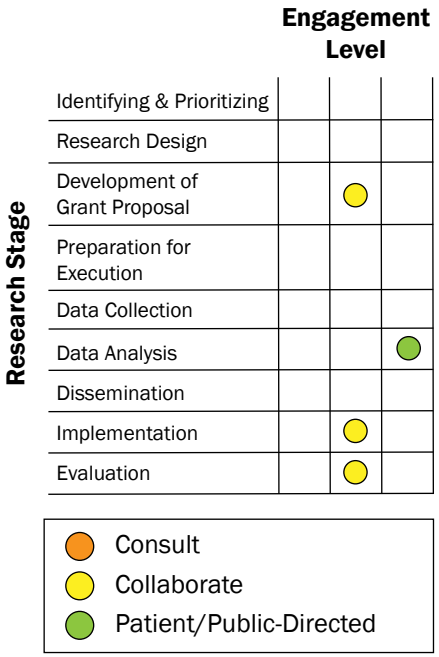
The Appreciative Inquiry Process begins by choosing a research decision the group wants to explore in the *development of grant proposal, data analysis, implementation*, and/or *evaluation* stage (e.g. "what outcome measures should we look at?" or "how will we evaluate success in this project?"). The process then involves discovering what people appreciate and like about the topic. The next steps are to dream and envision as a group what could be, and then design what should be. The last stage is an active phase that considers what needs to be done to make it a reality.

Useful for:

- Generating new research priorities, questions, outcomes, and areas of evaluation
- Creating a shared vision for both researchers and patient and public partners
- Deciding on and committing to research decisions that will be actionable, with accountability to patient and public partners

Additional Resources:

1) Positivity Strategist: Appreciative Inquiry - Overview of Methods, Principles and Applications
2) The Center for Appreciative Inquiry: Generic Processes of Appreciative Inquiry
3) Mohr BJ, Watkins JM. The Essentials of Appreciative Inquiry: A Roadmap for Creating Positive Futures. Pegasus Communications, Waltham, MA: 2002



This work is licensed under CC BY-NC-SA 4.0

3. Charrettes

These are intensive workshops that bring together patient and public partners, health researchers, healthcare practitioners, decision-makers, and policy-makers. Charrettes are particularly useful for coming to consensus on decisions about the *research design* stage, as it allows participants to gain a baseline understanding of the research topic, learn from each other's perspectives, debate and discuss alternatives, weigh choices, and set priorities.

The Charrette process begins with general sessions to review key issues, outcomes, and processes, and gather any aspirations or concerns. Then the process splits the topics into 'assignments' distributed to sub-groups for discussion (e.g. "what is the best way to collect data?" or "who should be collecting the data?"). Sub-groups discuss their 'assignment' and then share with the larger group. Following this, sub-groups discuss feedback from the larger group, and the process is repeated until consensus can be reached around research decisions being discussed. It is important that researchers are present as a resource for sub-groups, to provide supports and any additional information needed to come to a decision.

Useful for:

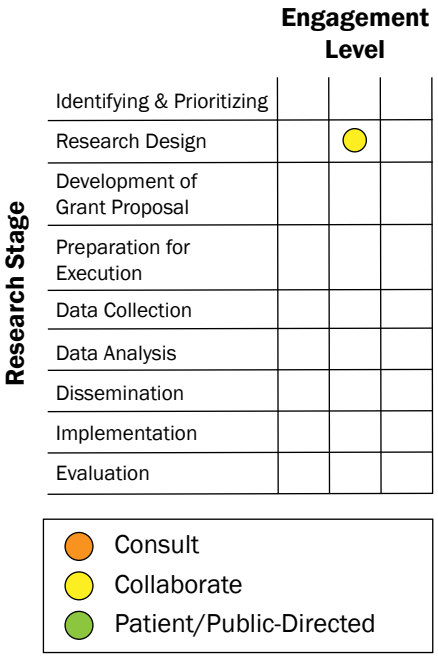
- Co-developing research design with patient and public partners so methods are sensitive and appropriate to people with lived experience of a health condition
- Helping to amalgamate diverse perspectives and elements into the design of a research project

Additional Resources:

1) Slocum, N. Participatory Methods Toolkit: A practitioner's manual. The King Baudouin Foundation, the Flemish Institute for Science and Technology Assessment (viWTA), and the United Nations University, 2003. Available from: www.kbs-frb.be or www.viWTA.be or www.unu.cris.edu

Note: Preparation is key and Charrettes can take many months to organize. Charrettes run from three days to two weeks. The number of participants can range from 50 to over 1,000. When running a Charrette, it may be beneficial to use other participatory methods (e.g. briefings, interviews, panels, review sessions, World Cafés, participatory decision-making) to support involvement of patient and public partners.

It is also a good idea to use professionally trained facilitators.



This work is licensed under CC BY-NC-SA 4.0

4. Citizen Juries®

In this approach, a 'jury panel' is created, consisting of a diverse group of patient and public partners who are randomly selected (using scientific polling). Health researchers, healthcare professionals, community organizations, policy-makers, and decision-makers are seens as 'witnesses' who provide the jury with information about key aspects of the research decision to be made in the *data collection, data analysis* and/or *implementation* stage (e.g. information on different ways to collect data; information about the data that was collected that the jury will be asked to theme and interpret; or different ways of implementing research findings in practice). The jury can engage witnesses in conversation and ensure all questions they have are answered. The jury then deliberates over the research decision that must be made, using one of a variety of participatory approaches to come to consensus. Health researchers agree ahead of time to commit to the jury's decision. The jury often provides their decision in the form of a report to health researchers, which may include concrete recommendations for action.

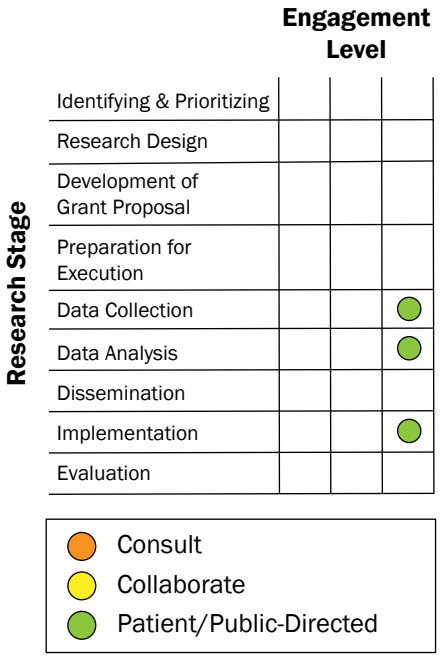
Key Characteristics:
Patient and public partners are randomly selected, representative, informed, impartial, and deliberative.

Useful for:

- Facilitating highly focused dialogue on key research decisions
- Making research decisions that reflect patient and public partner needs and perspectives
- Observing how attitudes around particular research decisions are articulated and changed

Additional Resources:

1) United States Environmental Protection Agency: Public Participation Guide: Citizen Juries®
2) Purdam, K. What are Citizen Juries®? CCSR University of Manchester, 2012. Available via email from: kingsley.purdam@manchester.ac.uk



This work is licensed under CC BY-NC-SA 4.0

5. Comment Forms

These can be done in paper format or online, and they address a decision in the *evaluation* stage of the research process. Comment forms are distributed to patient and public partners and returned to the research team upon completion.

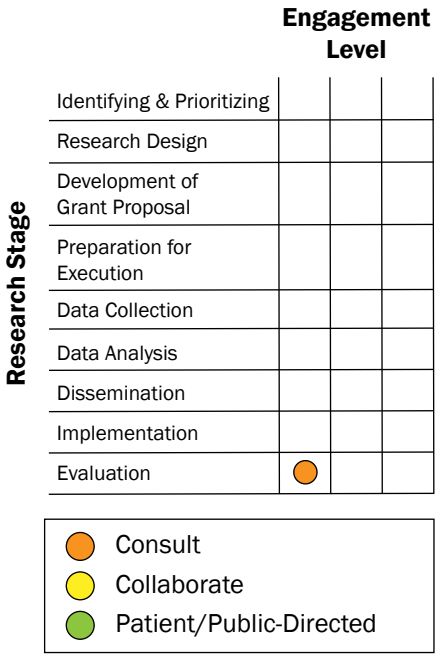
Note: The questions posed on Comment Forms will focus the types of responses received.

Useful for:

- Obtaining individual feedback and perspectives around research decisions
- Creating an opportunity for those who may be less vocal in a larger group to share their thoughts and perspectives about research decisions
- Receiving feedback focused on a particular research decision (e.g. evaluation metrics of importance to those with lived experience of the health condition being studied)

Additional Resources:

1) Fisheries and Oceans Canada. Consultation Toolbox: A Guide to Undertaking Consultations. Fisheries and Oceans Canada: Ottawa, ON. 2004. Available from: http://www.dfo-mpo.gc.ca/Library/282189.pdf



This work is licensed under CC BY-NC-SA 4.0

6. Conversation Circles

Also known as 'revolving conversations', this is a leaderless meeting process typically used for more complex research decisions that may invoke strong emotions, as it supports learning and relationship- building. The Conversation Circle begins with four patient and public partners sitting in a circle in the middle of a larger group of patient and public partners. Only the inner circle speaks, the outer circle is responsible for listening. A convener introduces the central research decision to be addressed in the inner circle discussion. The research decision discussed may be in the *research design, development of grant proposal, preparation for execution, data analysis, dissemination, implementation* and/or *evaluation* stage.

Patient and public partners can leave the inner circle at any time, and return again. If patient and public partners in the larger circle want to join the inner circle discussion, and they want to talk to a specific person, they stand directly behind that person's chair, signaling to the inner circle that they want to join in. The more people line up, the stronger the signal to the inner circle that they must conclude their remarks and make their seat available to someone else. The main discussion points are noted on a flip chart, and those who do not feel comfortable joining the inner circle discussion can share their thoughts by putting a sticker next to the top three points that resonate with them on the flip chart at the end of the meeting.

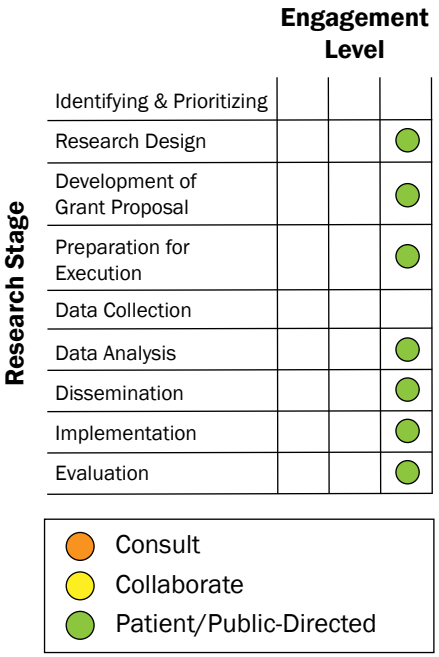
Note: A trained facilitator should observe the Conversation Circle and take notes on discussion points, which will inform the research decision(s) being made.

Useful for:

- Meetings where minimal facilitation is required, and ownership and empowerment of patient and public partners in research decision-making is optimal
- Creating open and honest discussions between patient and public partners about research decisions where minimal background information is required

Additional Resources:

1) The Knowledge Sharing Toolkit: Samoan Circle
2) National Coalition for Dialogue & Deliberation (NCDD): Samoan Circle



This work is licensed under CC BY-NC-SA 4.0

7. Deliberative Polling® Process

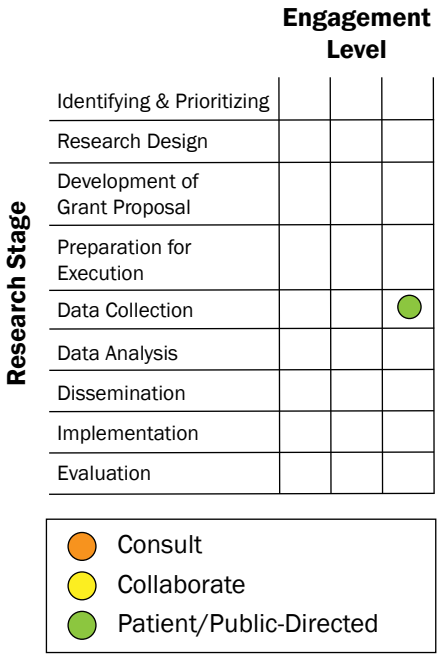
This is a highly structured method intended to measure the opinions of a statistically valid sample group of patient and public partners, both before and after they have had the opportunity to learn more about a particular research decision and discuss it with different perspectives. The Deliberative Polling® process can be used for making a research decision in the *data collection* stage. Patient and public partners are polled at the very beginning of the activity, and then following the activity, to see whether opinions change as a result of the information sharing and deliberation that occurs. The Deliberative Polling® process itself can include speakers (e.g. health researchers, healthcare professionals, consumer organizations, decision-makers, policy-makers, or patient and public partners), panels, information materials, and more around the research decision to be made.

Useful for:

- Acquiring insight on a complex research decision (e.g. "how can data be collected in a way that is sensitive and appropriate for the real-world context of people living with this health condition?")
- Engaging a large group of patient and public partners around a health research decision, including those less inclined to speak (as polling is done anonymously)
- Creating an opportunity for patient and public partners to develop informed opinions about a particular research decision

Additional Resources:

1) Participedia: Deliberative Polling®
2) Style, L. Campus Conversations: A Handbook for College Level Deliberative Polling®. Carnegie Melon. Available from: caae.phil.cmu.edu/cc/
3) Fishkin HS, Luskin RC. Experimenting with a Democratic Ideal: Deliberative Polling and Public Opinion. Acta Politica. 2005;40:284-98



This work is licensed under CC BY-NC-SA 4.0

8. Delphi Process

This is a method for reaching a consensus as a group. It can be used in patient and public engagement when trying to come to consensus around a research decision in the *identifying & prioritizing* stage. Consensus through the Delphi Process is accomplished through a series of 'rounds' of questionnaires, interspersed with controlled feedback.

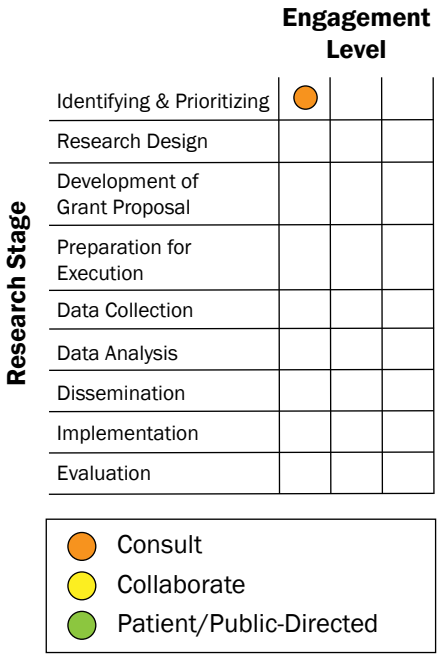
The Delphi Process begins by providing patient and public partners with some background information about the research topic that will help them make the decision, and asking them to respond. The first round is typically open-ended, to identify issues for subsequent rounds (e.g. "what would help you in navigating your day-to-day life living with this health condition?"). The following rounds are usually more specific, to address particular questions or issues, and typically involve ranking or rating techniques (e.g. ranking priorities for research from a list of ideas created in an earlier round). The Delph Process continues until all patient and public partners are satisfied with their responses, and no further changes are required.

Useful for:

- Achieving consensus in an area of uncertainty; the Delphi Process can stimulate new ideas about research decisions (e.g. priorities, outcomes) that are important to patient and public partners
- When the group is unable to meet in person (due to geographical or other barriers), the process can be done online — this is important to consider for obtaining diverse perspectives (i.e. people who live in urban/rural areas, those of varying age, ability, socioeconomic status, gender expression and identity, ethnicity, culture, religion, sexual orientation, etc.)
- Achieving anonymity (if patient and public partners prefer)
- Enabling patient and public partners to share experiential knowledge without being influenced by other perspectives or experiences

Additional Resources:

1) Powell, C. The Delphi technique: myths and realities. J Adv Nurs. 2003;41(4):376-82
2) Haughey, D. Delphi Technique: A Step-by-Step Guide. Project Smart. Available from https://www.projectsmart.co.uk/delphi-technique-a-step-by-step-guide.php



This work is licensed under CC BY-NC-SA 4.0

9. Dialogue Technique

This technique values the art of patient and public partners coming together to listen to one another and challenge each other to look beyond one's own perspective on a research decision. Dialogue Technique can be used to make a resarch decision in the *development of grant proposal* stage. Patient and public partners are brought together to explore diverse perspectives in a safe environment that creates spaces for learning, shared meaning, and aligned actions around research decisions that matter most to people with lived experience of a health condition.

Dialogue Technique uses five basic principles:

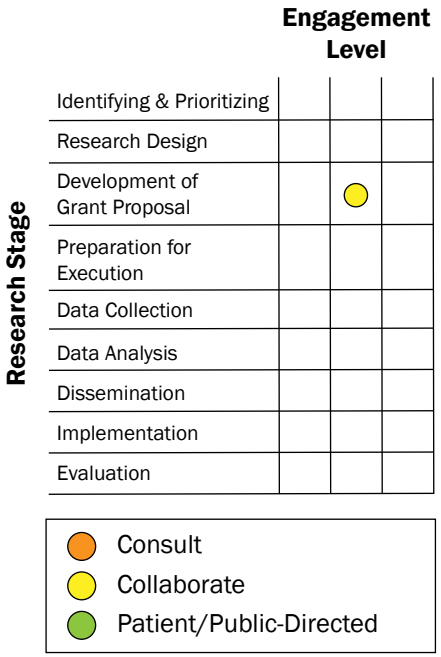
1. **Pay attention** to your own personal intentions with regard to the research decision being discussed
2. **Balance the need for advocacy** with a desire for inquiry when it comes to the research decision being discussed
3. **Build shared meaning** with one another around the research decision being made as a group
4. **Use self-awareness** to help in making research decisions (i.e. understanding how the social locations you inhabit work within larger systems of power and oppression that impact people's health and access to healthcare and other social services)
5. **Explore impasses**; see disagreement and conflict as opportunities to learn and grow, as well as to resist and renegotiate power within the group

Useful for:

- Shared research decision-making among diverse patient and public partners, in order to build shared meaning and understanding around a research topic
- Exploring patient and public partners' thoughts and feelings on a complex research decision that has no clear answer
- Establishing safe spaces where disagreement about a research decision can be addressed and embraced

Additional Resources:

1) Project Innovation: Skill Toolkit, Participatory Methods, Dialogue. Available from http://www.socialinnovationtoolkit.com/data/skills/downloads/pi_skill_dialogue_v1.pdf
2) Luck, R. Dialogue in participatory design. Design Studies. 2003;523-35



This work is licensed under CC BY-NC-SA 4.0

10. Digital Storytelling

This is an innovative way for patient and public partners to inform research decisions in the *identifying & prioritizing* and/or *dissemination* stage. In Digital Storytelling, patient and public partners are brought together to create a short video (less than five minutes) and share their stories and voices, from perspectives that are typically less heard in health research. Stories can be a combination of recorded narratives with music, images, or video footage. The video can help the research team to prioritize areas that people with lived experience of a health condition feel should be investigated further in the research process.

Useful for:

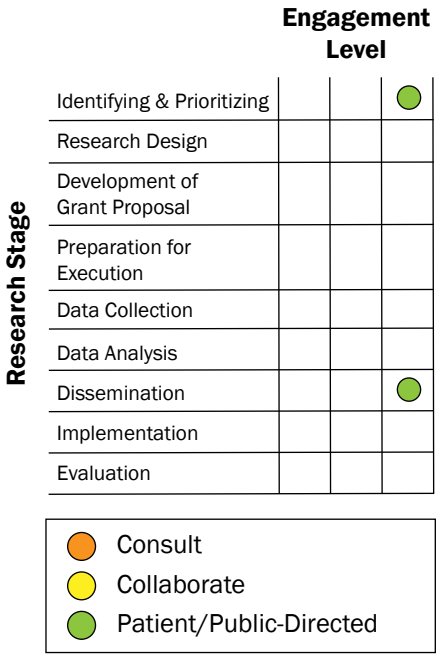
- Creating opportunities for patient and public partners to share their stories or ideas regarding the research
- Gaining a better understanding of diverse perspectives around research decisions
- Allowing for patient and public partners' creative self-expression
- Sharing powerful stories and creating opportunities for change in the research process

Additional Resources:

1) Wilson, C. What is Digital Storytelling and How to Get Started. Athabasca University E-LAB, 2020.

Examples:

1) Heyes, S. 6 Great Examples of Digital Storytelling. 8 Million Stories, 2012. Available from https://8ms.com/blog/6-great-examples-of-digital-storytelling/
2) Bennett, ML. Thesis: Digital Storytelling with First Nations Emerging Adults in Extensions of Care. Faculty of Social Work, University of Manitoba, 2016. Available from: mspace.lib.umanitoba.ca



This work is licensed under CC BY-NC-SA 4.0

11. Discussion Groups

These are one-time, highly facilitated small group discussions that typically consist of five to ten individuals who are representative of the population from which experiential knowledge is sought. Individuals in the Discussion Group focus on one research decision to be made in *any* stage of the research process. Though the terms are often used interchangeably, Discussion Groups are different from focus groups. Whereas focus groups are used to collect qualitative data aimed at answering a research question, the goal of Discussion Groups is to involve patient and public partners in making decisions about the research process.

Useful for:

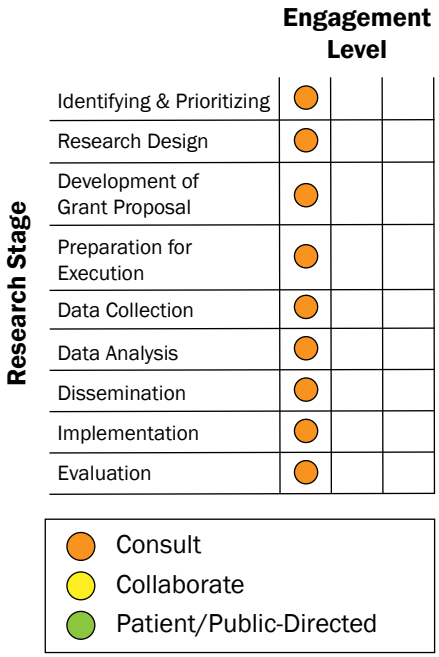
- Identifying public opinion and encouraging open debate around a research decision
- Providing opportunities for engagement of voices traditionally less heard in health research
- Providing insightful information for evaluation of the research project
- Using previously analyzed data to generate alternate interpretations

Additional Resources:

1) KnowledgeNudge: Methods in Patient Engagement, Focus & Discussion Groups
2) Community Toolbox: Chapter 3, Section 6. Conducting Focus Groups
3) Conducting a Focus Group: How to Get Started — A Beginner's Guide to Getting Feedback. 2015. Available from https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/212/2015/04/ManualFocusGroupHowtoGetStarted.pdf

Examples

1) Redman-MacLaren M, Mills J, Tommbe R. Interpretive focus groups: a participatory method of interpreting and extending secondary analysis of qualitative data. Glob Health Action. 2014;7:10
2) Bagnoli A, Clark A. Focus groups with young people: a participatory approach to research planning. J Youth Studies. 2010;13(1)



This work is licensed under CC BY-NC-SA 4.0

12. Fishbowl Process

This process involves a research team (including patient and public partners) opening up their meeting(s) to the general public, and inviting people to observe while they hold a regular meeting. The Fishbowl Process allows members of the general public to witness how decisions are made within the research team. It provides communities with the opportunity to ask questions and provide comments around research decisions in the *development of grant proposal* stage.

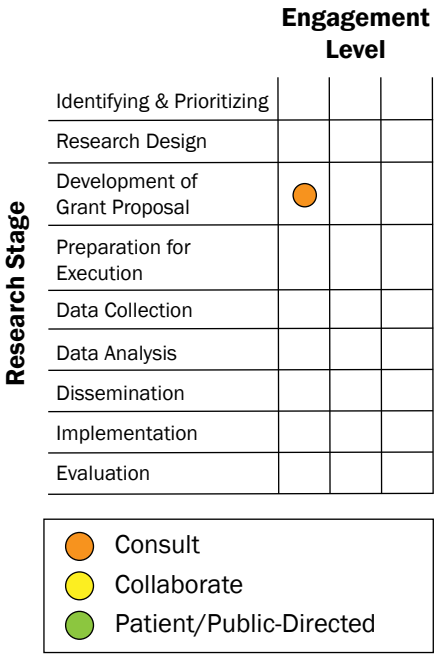
Note: Have one chair at the research team table open so that members of the public can come in and join the team, and get a chance to speak at the table.

Useful for:

- Providing transparency and increasing trust among the public and the research team
- Sharing honestly with the general public how health researchers, patient and public partners, healthcare professionals, decision-, and policy-makers work together to make research decisions
- Addressing complex research topics and decisions that require additional insight and perspectives

Additional Resources:

1) Knowledge Sharing Tools and Methods Toolkit: Fish Bowl. Available from http://kstoolkit.org/Fish+Bowl



This work is licensed under CC BY-NC-SA 4.0

13. Focused Conversations

This technique is a structured approach to discussing complex research decisions with patient and public partners, and helping people come to their own conclusions on the research decision. Focused Conversations can be used in the *development of grant proposal, preparation for execution, dissemination, implementation*, and/or *evaluation* stage of research.

Note: Focused Conversations may be very quick (a few hours) or long (a few days), depending on the topic.

The facilitator, who remains neutral throughout, first presents the group with the goal of the discussion (the decision that needs to be made). Secondly, the facilitator lays out the experiential goal of the discussion (i.e. what is the purpose of involving patient and public partners in making this decision). For example, the experiential goal may be something like "working together collaboratively, we want everyone to feel empowered and feel that they can take ownership of this research project and its direction". The Focused Conversation then moves on to a series of questions.

Focused Conversation questions are based on four stages of thinking:

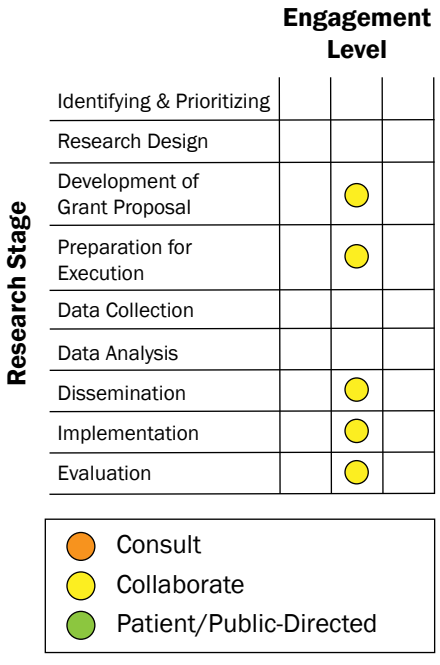
1. **Objective:** review facts about the research decision
2. **Reflective:** review emotional responses and reactions to the research decision
3. **Interpretive:** review meaning and significance of the research decision
4. **Decisional:** consider how the research decision will be put into action

Useful for:

- Reviewing a variety research decisions in various stages of the research
- Getting very specific feedback and opinions from patient and public partners around research decisions

Additional Resources:

1) Talking Together, A Discussion Guide for Walking Together. Focused Conversations: Fact Sheet. Available from https://www.learnalberta.ca/content/aswt/talkingtogether



This work is licensed under CC BY-NC-SA 4.0

14. Interviews

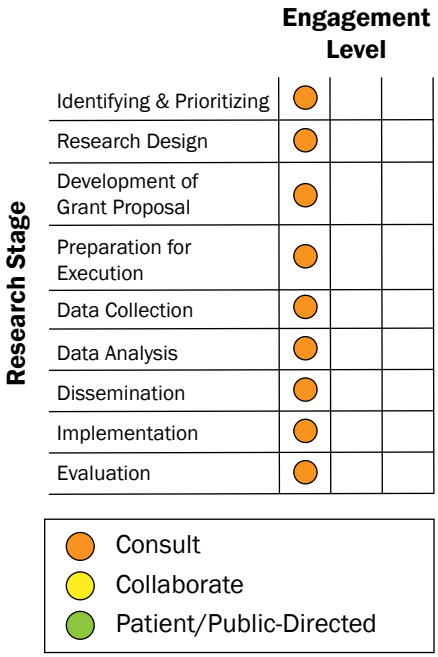
These can be conducted on a one-on-one basis, or in a small group setting. Questions and/or the focus of discussion may be structured or semi-structured, and are designed for a specific purpose — to help inform a decision about a specific stage of the research process. Interviews can be used for research decisions in *any* stage. It's important to meet patient and public partners where they are at (i.e. in a location that is comfortable, convenient, and safe for them) for Interviews. Though face-to-face is often the preferred method, interviews can be done virtually or over the phone.

Useful for:

- Building patient and public partner relationships
- Gaining deeper insight into individual perspectives
- Bringing to light unique solutions and ideas for decisions about the research process that may not have previously been considered
- Explorative inquiry and answering open-ended questions that can delve into the experiential knowledge of patient and public partners, in turn informing research decisions

Additional Resources:

1) Krishnaswamy, A. Participatory Research: Strategies and Tools. Practitioner: Newsletter of the National Network of Forest Practitioners. 2004;22:17-22
2) Salmon A. Walking the talk: how participatory interview methods can democratize research. Qual Health Res. 2007;17(7):982-93



This work is licensed under CC BY-NC-SA 4.0

15. James Lind Alliance

The James Lind Alliance (JLA) Priority-Setting Partnership (PSP) method enables healthcare professionals, patients, and caregivers to work together in *identifying & prioritizing* important uncertainties in a particular health area (whether a specific health condition, or healthcare programs, services, and interventions) that could be addressed by research. This rigorous method has been used beyond the scope of treatment uncertainties and in other areas of research priority-setting.

Note: The James Lind Alliance method requires a large amount of resources, supports, and time commitment.

The JLA method consists of:

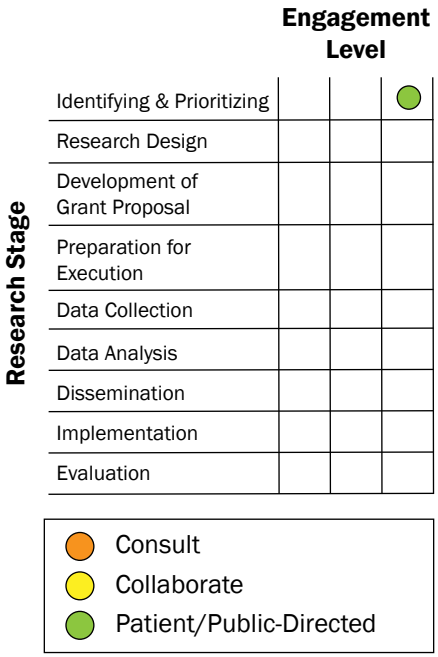
- Bringing together patient partners, informal caregivers, and healthcare professionals on equal footing to identify treatment uncertainties which are important to all groups
- All groups working together to prioritize the identified uncertainties
- Using knowledge synthesis methods (e.g. scoping reviews) to determine whether any previous research has been conducted regarding the identified uncertainties
- Producing a final list (often a 'top ten') of jointly agreed upon research priorities, publicizing them widely, and making sure other uncertainties are recorded and available for researchers and research funders to access

Useful for:

- Providing a rare and valuable opportunity for patients, caregivers, and healthcare professionals to work together to shape the research agenda

Additional Resources:

1) James Lind Alliance Guidebook, available from http://www.jla.nihr.ac.uk/jla-guidebook/
2) KnowledgeNudge: Part I, Introduction to the James Lind Alliance
3) KnowledgeNudge: Part II, The James Lind Alliance



This work is licensed under CC BY-NC-SA 4.0

16. Nominal Group Technique

This technique is a structured approach for small groups to come to consensus about a research decision in the *identifying & prioritizing* stage. In the Nominal Group Technique, a group of patient and public partners is divided into smaller groups. A moderator poses a question to everyone, and within the smaller groups, patient and public partners take turns responding to the question. The small groups then work together to prioritize the responses, ideas, and suggestions of all the small group members.

The four steps of the Nominal Group Technique are:

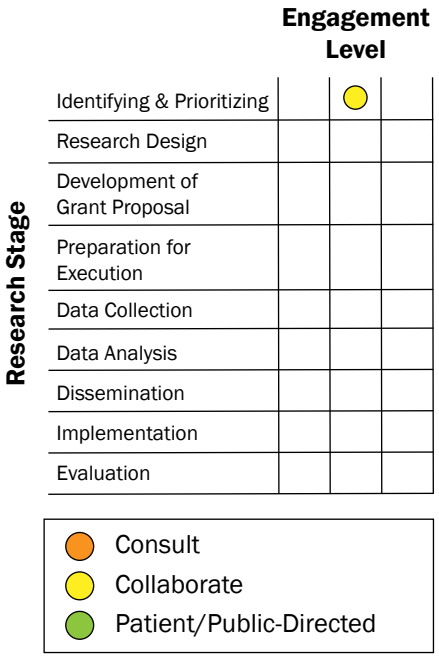
1. **Generate** ideas about a research decision
2. **Record** ideas about a research decision
3. **Discuss** ideas about a research decision
4. **Vote** on ideas about a research decision

Useful for:

- Helping patient and public partners generate and prioritize their ideas and thoughts around research decisions that matter most to them
- Allowing everyone involved a chance to speak, voting power, and preventing highly vocal participants from dominating the discussion

Additional Resources:

1) Centers for Disease Control and Prevention. Gaining Consensus Among Stakeholders Through the Nominal Group Technique. 2018. Available from https://www.cdc.gov/healthyyouth/evaluation/pdf/brief7.pdf



This work is licensed under CC BY-NC-SA 4.0

17. Open Space Meetings

These are patient and public partner-directed meetings that can be used to make research decisions in the *research design* and/or *implementation* stage. At the beginning of the Open Space Meeting, an 'open space convener' helps facilitate and support patient and public partners to decide upon an agenda, identify different people to lead small group sessions on research decisions to be made, and assign topics to meeting spaces and times. Patient and public partners get to choose which sessions to attend, depending on their interests and concerns. Open Space Meetings are about having discussions versus didactic "eyes forward" presentations. Following the breakout groups, everyone reconvenes to share decisions made in the smaller groups. The role of the researcher is as a resource support, providing additional information as needed in order for patient and public partners to come to consensus on a research decision.

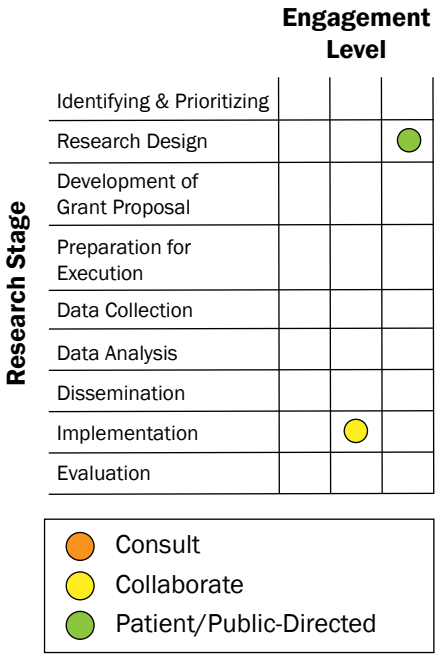
Useful for:

- Giving power and control to patient and public partners around research decisions that are important to people with lived experience
- Creating an opportunity for research decisions to address and reflect the needs and experiences of a large group with diverse interests

Additional Resources:

1) OpenSpaceWorld.org: What is Open Space Technology?

Note: Open Space Meetings are extremely flexible. Ensure the meeting space is a large room (for plenary sessions) and has a a sufficient number of breakout rooms for smaller group discussions. Ensure there are enough recorders to capture what is being discussed in the breakout groups.



This work is licensed under CC BY-NC-SA 4.0

18. Participatory Decision-Making

This is a process that allows patient and public partners to collaboratively make research decisions in the *identifying & prioritizing, data collection*, and *data analysis* stage. It involves finding a common ground and making decisions that are acceptable to all patient and public partners involved. With Participatory Decision-Making, everyone in the group must agree with a decision. Often, patient and public partners are collaboratively involved in decision-making at various stages of the research process, from exploration and definition of the problem to development of solutions and interventions. Participation in decision-making is recurring.

Participatory Decision-Making consists of nine steps (using *identifying & prioritizing* as an example):

1. **Define** the research decision that needs to be made ("which research priorities mean the most to us?")
2. **Share** experiential knowledge as a group
3. **Brainstorm** potential research priorities
4. **Discuss** all the different suggested research priorities
5. **State the list** of research priorities
6. **Debate** and discuss
7. **Restate the final list** of research priorities
8. **Test** for consensus
9. **Consensus** or major objections

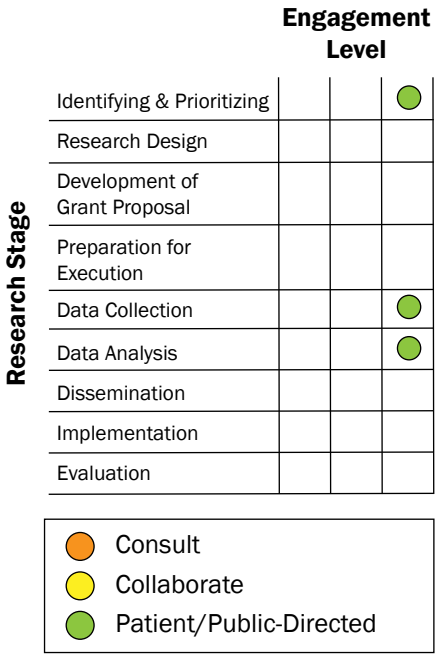
Useful for:

- Gaining a deeper understanding of patient and public partners' concerns around a research decision
- Providing opportunities for patient and public partners to build skills
- Developing a sense of community among patient and public partners and researchers
- Providing patient and public partners with an increased sense of investment in the research project

Additional Resources:

1) People & Planet: Participatory Decision-Making, Introduction
2) Kaner, S. Facilitator's Guide to Participatory Decision-Making. Jossey-Bass, San Francisco: 2014.
3) CFHI: Patient Engagement Heard and Valued Handbook
4) CFHI: Patient Engagement Heard and Valued Workbook

Note: Participatory Decision-Making requires a large time commitment from patient and public partners. It may require increased knowledge and skills by patient and public partners, and may amplify differences in patient and public partners' abilities. Research teams should choose this method *only* if they have the capacity and resources to help engage patient and public partners in decision-making at various stages of the research process.



This work is licensed under CC BY-NC-SA 4.0

19. Participatory Design

This is an approach that brings together patient and public partners, health researchers, healthcare professionals, decision-makers, policy-makers, and community organizations to collaboratively explore research decisions in the *research design, development of grant proposal* and/or *preparation for execution* stage. Participatory Design can be used to bring individuals from these groups together several times throughout the research project, starting from the initial exploration and definition of the research problem, to the development of research design. The Participatory Design method is best if health researchers can support and facilitate meaningful engagement of patient and public partners throughout the duration of the project, and at the depth necessary for Participatory Design decision-making.

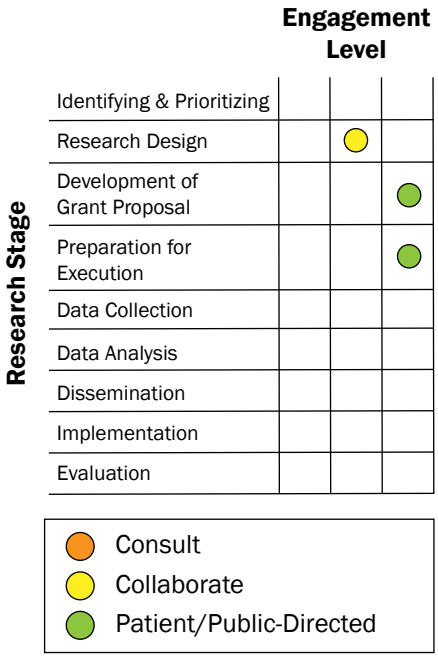
Useful for:

- Gaining insight from patient and public partners on research decisions
- Creating opportunities for patient and public partners to build capacity, skills, and strengths in research
- Improving researchers' capacity to engage with patient and public partners in the collaborative design of research projects
- Working together as a team towards a common goal

Additional Resources:

1) Participate in Design: What is Participatory Design? Available from participateindesign.org
2) Information & Design: Participatory design. Available from https://infodesign.com.au/usabilityresources/participatorydesign/
3) UX Passion: Participatory Design: What is it, and what makes it so great?
4) CFHI: Patient Engagement Heard and Valued Handbook
5) CFHI: Patient Engagement Heard and Valued Workbook

Note: Participatory Design requires a large time commitment from patient and public partners. It may require increased knowledge and skills by patient and public partners, and may amplify differences in patient and public partners' abilities. Research teams need to provide accessible supporting materials to help patient and public partners in Participatory Design decision-making processes.



This work is licensed under CC BY-NC-SA 4.0

20. Patient Journey Mapping

This technique brings together patient and public partners and healthcare professionals to map out the healthcare journey as a way to understand patient and public partners' experiences. The resulting map is then analyzed to discover ways to improve delivery of programs and/or services. The Patient Journey Mapping collaborative approach often helps identify knowledge and service gaps, which can then be used to inform the *identifying & prioritizing* and/or *research design* stage of the research.

Useful for:

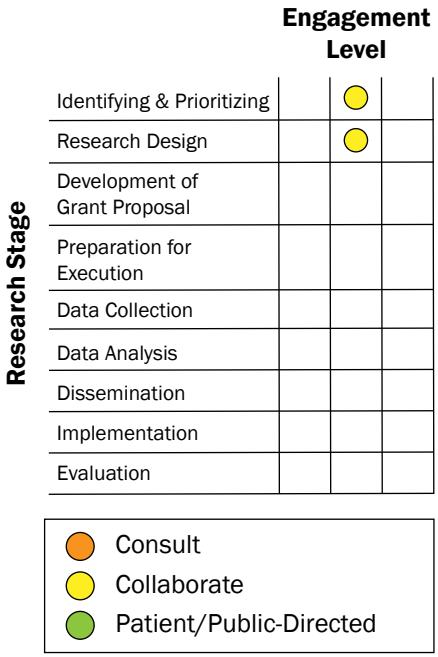
- Gaining a deeper understanding of patient and public partner needs and concerns with regards to specific healthcare programs, services, or interventions in order to inform research priorities and/or questions
- Developing a sense of community among patient and public partners
- Having patient and public partners feel more invested in research

Additional Resources:

1) CFHI: Patient Engagement Heard and Valued Handbook
2) CFHI: Patient Engagement Heard and Valued Workbook
3) Trebble TM et al. Process Mapping the Patient Journey: An Introduction. BMJ. 2010;341:c4078.

Key Characteristics:

Patient Journey Mapping may exclude people who do not have access to healthcare programs and services due to physical barriers (e.g. geographical barriers, living in urban/rural communities) as well as systemic barriers (e.g. racism, colonialism, sexism, cis-sexism, heterosexism, classism, sizeism, ableism). It is important to consider who is affected differently by the health condition being researched, who has different access to programs and services, and how to include diverse perspectives in research decision-making.



This work is licensed under CC BY-NC-SA 4.0

21. Patient Observation of Existing Services

This approach involves patient and public partners observing existing healthcare services in action, in order to provide their perspective on gaps in service and potential areas of improvement. These observations can then be used to inform research decisions in the *identifying & prioritizing* stage. In Patient Observation of Existing Services, patient and public partners are often the ones to interview current patients and healthcare professionals about their experiences with healthcare service, program, or intervention delivery, and use this to help inform research decisions.

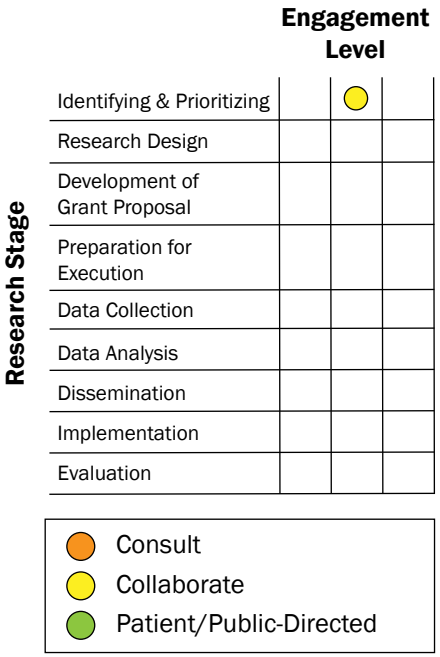
Note: Patient and public partners of varying abilities may choose to engage, in ways that they prefer or feel most comfortable for in Patient Observation of Existing Services.

Useful for:

- Situations where a better understanding of patient and public partner perspectives of existing services can help inform research priority-setting
- Engaging voices traditionally less heard in health research

Additional Resources:

1) CFHI: Patient Engagement Heard and Valued Handbook
2) CFHI: Patient Engagement Heard and Valued Workbook



This work is licensed under CC BY-NC-SA 4.0

22. PhotoVoice

Also known as Photo Novella, this is a creative approach to participatory action research. The PhotoVoice method brings the voices of those traditionally less heard in health research to the forefront. Using images or videos and connected stories, patient and public partners are given the opportunity to empower themselves by sharing their stories and realities around a health condition. Patient and public partners are asked to express their perspective through photography or videography of scenes and images that relate to the research themes, and supplement these with stories that describe the context of their work. The photos/videos and accompanying stories help shed light on patient and public partners' lived experiences. The images/videos and stories also become tools to raise awareness in the community, helping members of the public see the world through the lens of patient and public partners. In the case of patient and public engagement, the PhotoVoice method can be used to help inform research decisions in the *identifying & prioritizing* stage.

Key Characteristics:
Patient and public partners are randomly selected, representative, informed, impartial, and deliberative.

Useful for:

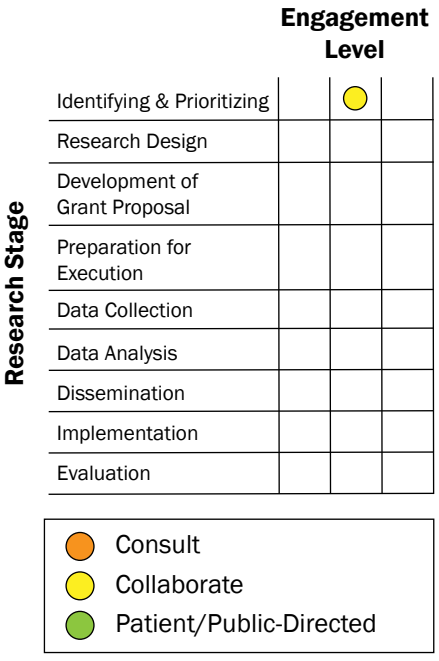
- Representing real-world stories and voices of patient and public partners to inform research
- Providing patient and public partners with the opportunity to reflect on their strengths and concerns, which can in turn inform research
- Promoting critical dialogue and knowledge sharing about important community issues through small and large group discussions of photos/videos and stories
- Strengthening the relevance, value, and importance of research by ensuring responsiveness to the needs of patient and public partners
- Reaching policy-makers and others who can help mobilize change

Additional Resources:

1) Palibroda B et al. A Practical Guide to Photovoice: Sharing Pictures, Telling Stories and Changing Communities. The Prairie Women's Health Centre of Excellence: 2009. Available from http://www.pwhce.ca/photovoice/pdf/Photovoice_Manual.pdf
2) Photovoice.org
3) KnowledgeNudge: Photovoice Three-Part Series

Examples:

1) Homelessness (Wang C & Burris 1997)
2) Indigenous Research (Castledon et al, 2008)
3) Mothers with learning difficulties (Booth & Booth, 2003)
4) Social and health issues of women (Krieg, 2008; McIntyre 2003)
5) Social and health issues of youth (Strack et al, 2004; Wang 1999)
6) Youth with disabilities (Whitney, 2006)



This work is licensed under CC BY-NC-SA 4.0

23. Public Meeting/ Town Hall

These are large organized meetings open to the general public, including people with lived experience of a health condition. Typically, Public Meetings/ Town Halls start with a short presentation by the health researcher to provide background information about the research decision to be made (in the *data analysis* and/or *implementation* stage). The floor is then opened to members of the public, as well as patient and public partners, allowing them to ask questions and share their comments and concerns around the research decision being discussed. The opportunity for the public to engage in dialogue about a particular research decision should be the main focus of the event.

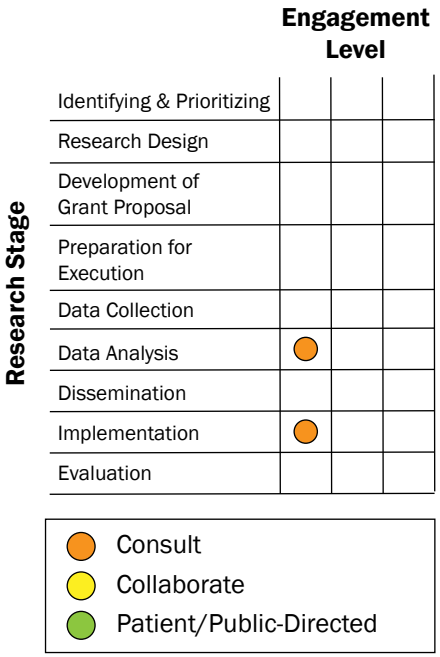
Note: Public Meetings/ Town Halls are open meetings - the direction that the dialogue takes depends on the group the research team is engaging with.

Useful for:

- Sharing information about research projects with the public
- Creating a space for members of the public, and patient and public partners, to share their perspectives on the research
- Engaging and welcoming all patients, caregivers, families, and communities with lived experience to express both positive and negative feedback

Example:

1) Schultz AJ et al. A Community-Based Participatory Planning Process and Multilevel Intervention Design: Toward Eliminating Cardiovascular Health Inequities. Health Promot Pract. 2012



This work is licensed under CC BY-NC-SA 4.0

24. Reality Check

This approach is about listening to people in their own context. The Reality Check approach helps inform research decisions in the *evaluation* stage, and involves researchers going into communities to live with and learn from patient and public partners and their communities. The Reality Check approach provides an opportunity to observe daily life, without interviews, discussion groups, or any type of formal questioning. Instead, the researcher has an opportunity to hear from communities in their daily context. The Reality Check approach is used to learn more from voices often less heard in health research, particularly those that may not attend typical engagement activities. Rather than patient and public partners coming to engage with researchers, the researcher goes to connect with communities and ensure that evaluation of the research project reflects their needs and priorities.

There are 11 elements to the Reality Check approach:

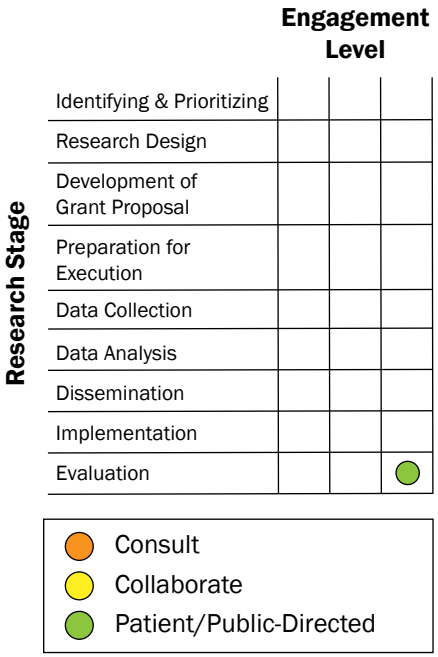
1. **Living with patient and public partners,** instead of them having to leave home
2. **Open conversations** about what success looks like in a research project, and what changes community partners want to see
3. **Learning from communities,** and having them decide how the research project should be evaluated
4. **Centering on the household and family** of patient and public partners
5. **Using the private space of home**, instead of public settings (e.g. institutions)
6. **Accepting multiple realities** instead of gaining consensus
7. **Looking at the entirety of patient and public partners' context**, instead of just specific aspects
8. **Researchers and patient and public partners interacting** in everyday life
9. **Letting experiential knowledge lead the way**
10. **Inclusion of everyone** who is part of patient and public partners' lives
11. **Understanding how the research project can be evaluated over time** when it comes to improvements in health outcomes of communities

Useful for:

- Developing an understanding of community partners' views on change and improvement, providing a more relevant framework for evaluation of the research project or program
- Unpacking barriers and facilitors to achieving research project outcomes, and important evaluation metrics
- Seeing and experiencing how communities navigate their daily lives to gain deeper insight into what success of the research project means for them
- Including diverse perspectives in the evaluation framework
- Ensuring the evaluation framework takes into account change over a longer time period

Additional Resources:

1) Reality Check Approach Community of Practice



This work is licensed under CC BY-NC-SA 4.0

25. Study Circles

These are small groups of approximately 7-12 patient and public partners that meet multiple times to discuss a research decision in the *research design, preparation for execution*, and/or *data analysis* stage. The Study Circle process combines dialogue (including storytelling) and deliberation. Study Circles are structured in a way such that subsequent sessions build on discussions from the previous session. The groups of patient and public partners should be inclusive and open to diverse perspectives.

Key Characteristics:
Patient and public partners are randomly selected, representative, informed, impartial, and deliberative.

Study Circles have 3 main elements:

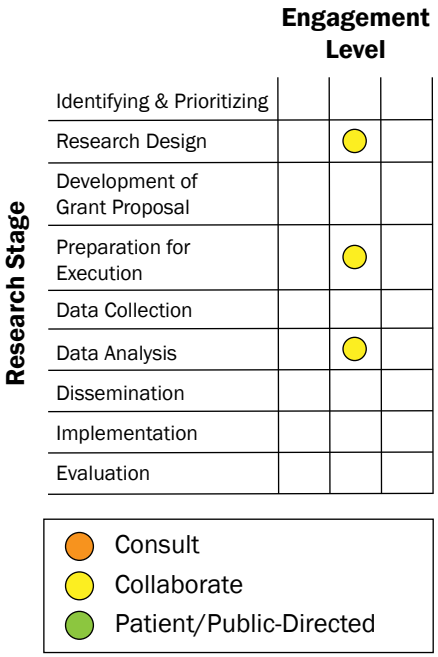
1. **Organization that brings individuals to the table**
   Patient and public partners work with researchers to design the Study Circle process, set goals (including which research decisions to discuss), and plan a launch that includes diverse communities in dialogue. Patient and public partners can be trained to support and facilitated Study Circles.
2. **Dialogue over several sessions**
   Several small groups of patient and public partners gather for the purpose of discussing the research decision, and what matters most to them.
2. **Movement from dialogue to collaborative action**
   Conversations lead to concrete ideas and actions around the research decision (e.g. priorities to be researched). Research teams that include patient and public partners, healthcare professionals, policy-makers, and decision-makers can then work together to implement decisions made in Study Circles.

Useful for:

- Bringing patient and public partners with diverse perspectives and knowledge together to collaboratively make research decisions
- Allowing many different geographically diverse groups to work on their own time on the same research decision
- Encouraging group learning and sharing around a research topic
- Building community capacity to explore potential research questions

Additional Resources:

1) Everyday Democracy: What Works: Study Circles in the Real World



This work is licensed under CC BY-NC-SA 4.0

26. Surveys/ Questionnaires

These are written or verbal questions posed to small representative group of people, to try and make generalizations about a larger population. In the context of patient and public engagement, Surveys/ Questionnaires should only be used if:

- The objective is for data collected to inform a particular research decision; and
- There is no reason for patient and public partners to interact, or for relationships to be built.

Researchers need to consider how they will reach people to respond to the Survey/ Questionnaire (online, telephone, mail, face-to-face), and any biases that may be introduced due to the chosen method(s). A Survey/ Questionnaire can be used to inform research decisions in the *identifying & prioritizing, data collection, dissemination, implementation*, and/or *evaluation* stage.

Useful for:

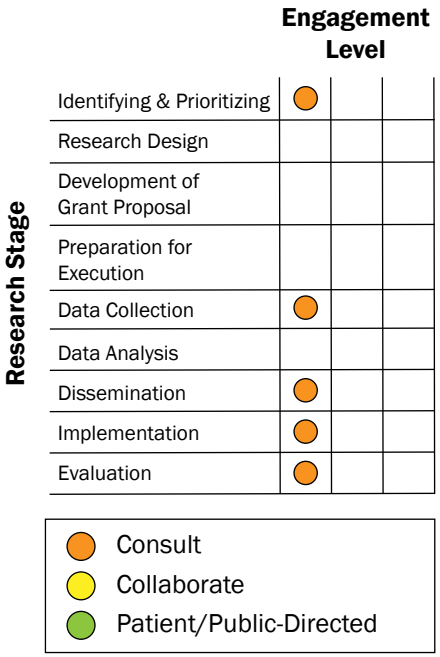
- Gaining insight into opinions and preferences of a population around a research decision
- Collecting quantitative data that will inform a research decision
- Establishing a foundation in order to make comparisons to inform a research decision
- Gaining a better understanding of trends and changes experienced by people with lived experience of a health condition, in order to inform research decisions

Additional Resources:

1) KnowledgeNudge: How to Create Effective Research Surveys, Part 1
2) KnowledgeNudge: How to Create Effective Research Surveys, Part 2

Note: A Survey/ Questionnaire used for patient and public engagement should **not** be used as data in a research study. Patient and public partners are not research subjects/ participants.

For engagement Surveys/ Questionnaires, questions are about a *research decision*. In contrast, if the Survey/ Questionnaire is collecting information as part of a study (e.g. "do you prefer one intervention over another?"), it is survey-based research, not patient and public engagement.



This work is licensed under CC BY-NC-SA 4.0

27. Workshops

This is a type of event that brings patient and public partners together in a collaborative environment to share perspectives, issues, goals and alternative solutions for making a research decision in the *research design, data collection, data analysis*, and/or *dissemination* stage. In Workshops, patient and public partners break into small groups, and work together on designated 'assignments' regarding specific decisions. These 'assignments' should have a clear purpose, and can focus on multiple stages of the research process. Small groups may be facilitated, or be thoughtfully designed for self-facilitation.

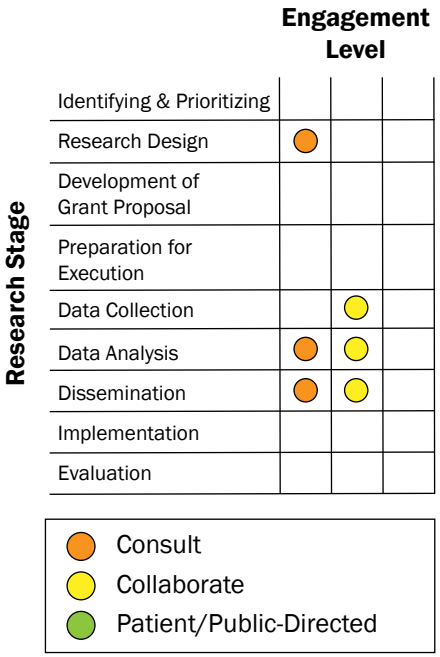
Useful for:

- Providing an opportunity for patient and public partners to learn through discovery and exchange of knowledge with researchers and others with lived experience of a health condition
- Obtaining focused insight, which can then be used directly in the decision-making process for the appropriate stage(s) of research

Additional Resources:

1) Jisc: Planning a Participatory Workshop
2) PRO-IDEAL PLUS Project: Concept and Methodology of Interactive Workshops

Note: An accessible space should be used for a Workshop. Additionally, Workshop 'assignments' need to be accessible for all patient and public partner abilities — making instructions clear and straightforward, avoiding jargon, and providing appropriate supporting materials.



This work is licensed under CC BY-NC-SA 4.0

28. World Café

This technique encourages patient and public partners to come together in simultaneous rounds of converastion about a research decision in the *research design, development of grant proposal, dissemination, implementation*, and/or *evaluation* stage. The World Café process is based on the way groups of people naturally converse with one another in a social café style setting.

Though it seems informal, the World Café has seven underlying principles:

1. **Set the context**
2. **Create safe and accessible spaces**
3. **Explore research decisions that matter** to patient and public partners
4. **Encourage everyone to contribute**
5. **Connect diverse perspectives**
6. **Listen together** for patterns and insights
7. **Share collective discoveries and decisions**

Patient and public partners move between tables, and connect with different individuals, perspectives, and experiential knowledge. Table hosts meet and greet patient and public partners as they arrive, remind people to allow everyone to speak, and take notes about the conversation at the table.

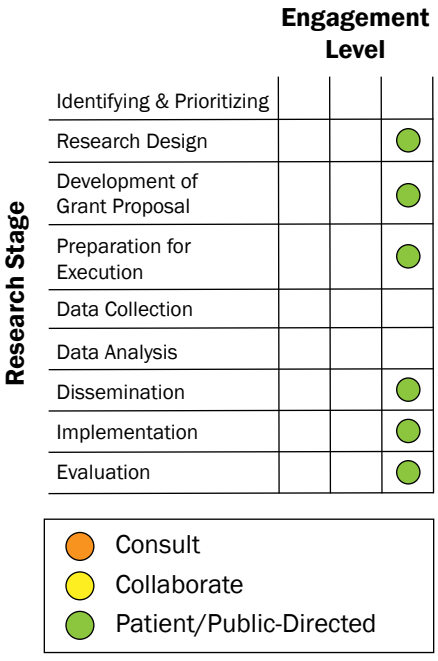
Useful for:

- Creating a safe space for individuals who would not normally come together to have meaningful discussions around research decisions
- Highlighting common threads of discussion and bringing them to light so research decisions reflect the needs and perspectives of people with lived experience of the health condition

Additional Resources:

1) The World Café website: www.theworldcafe.com
2) KnowledgeNudge: Methods in Patient and Public Engagement - The World Café
3) The World Café website: Quick Reference Guide for Hosting a World Café
4) Meadowlark Institute's Resource Guide for the World Café

Note: Each table in a World Café should have compelling questions for discussion prepared, which begin at a general level (e.g. "what helps most with this condition when it comes to everyday living?") and move to more focused questions around the research decision to be made (e.g. "what outcome measures should be included in the research?").



This work is licensed under CC BY-NC-SA 4.0