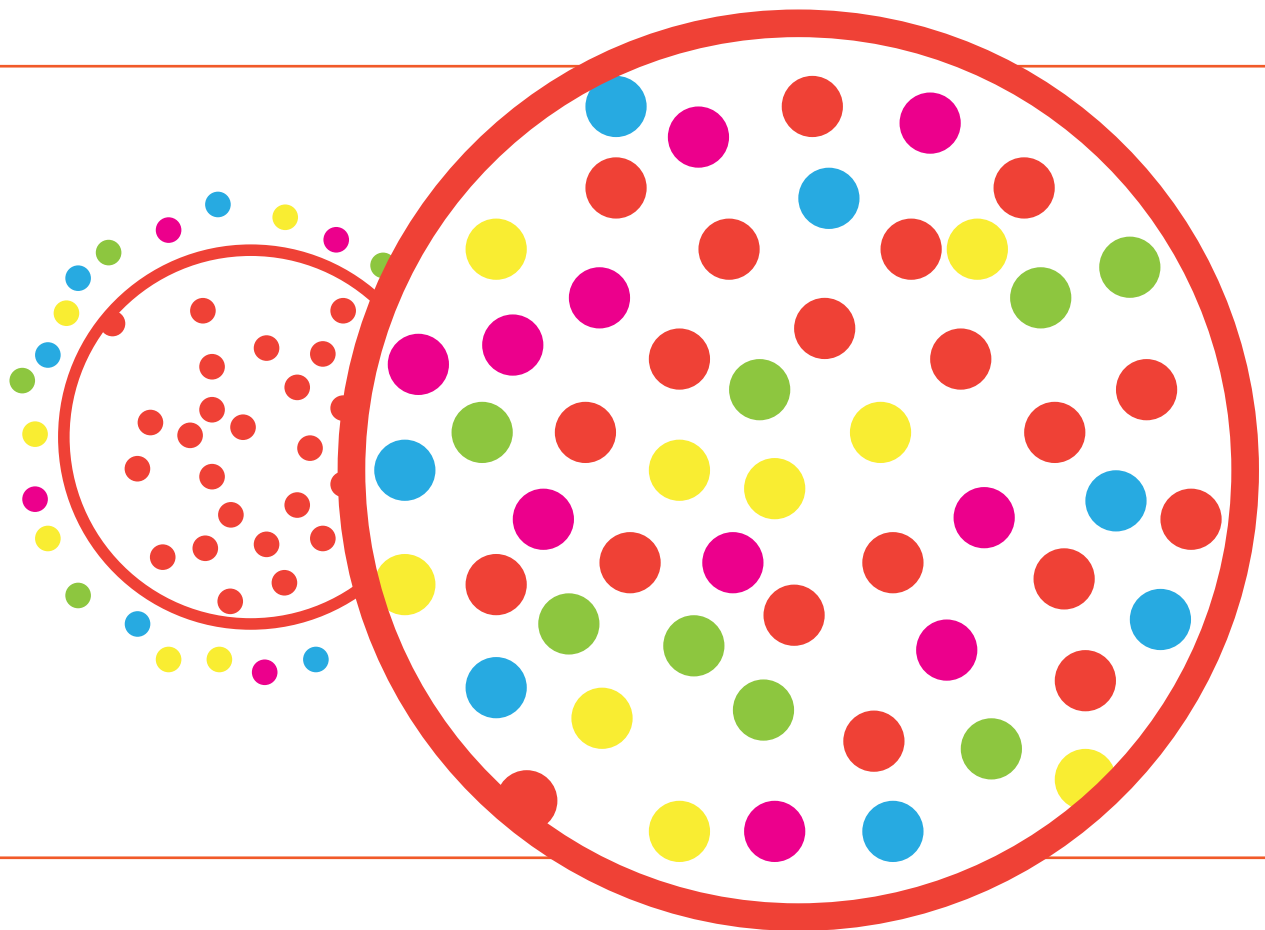


PATIENT ENGAGEMENT HEARD AND VALUED

A workbook for meaningful engagement
of patients that have not traditionally
been heard in healthcare planning



Canadian Foundation for
**Healthcare
Improvement**



British Columbia
Centre of Excellence
for Women's Health



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Introduction

Rationale for the AWESOME Model

Patient engagement is a strategy for designing high quality health care services that are responsive to patients' needs and that empower them to play an active role in their health. Patients provide unique insight into how they experience health care services, how these services affect their health and how these services support them to take control of their own health. However, many patient engagement processes fail to engage vulnerable populations. If we exclude vulnerable populations from patient engagement, we risk making decisions that do not address the needs of populations who may have a high burden of illness and complex care needs.

This tool for engaging patients includes considerations for conducting patient engagement in a gender-sensitive, inclusive, empowering and meaningful way, from the planning stages through to implementation and evaluation.

How to Use This Workbook

The purpose of this workbook is to assist healthcare decision makers to plan, implement, and evaluate patient engagement processes with a focus on engaging patients whose voices have not traditionally been heard in healthcare planning, such as immigrants and refugees, those of low socioeconomic status, or people dealing with mental health and substance use issues, just to name a few groups. The issues being explored in this workbook are not simple and thus the workbook is not designed to provide the one "right" way to engage patients; rather, it provides a way of thinking about patient engagement to help make it more inclusive and useful for everyone involved. The questions presented are intended to create discussion among the planning team in order to help create a in a gender-sensitive, inclusive, empowering, and meaningful process of patient engagement.

The AWESOME model on the next page shows an overview of the whole process of patient engagement. This workbook provides a series of questions to guide healthcare planners through the steps of the model; however, it should be noted that the process is not completely linear and thus you may find yourself returning to previous questions as you work your way through the handbook.

Importantly, the accompanying AWESOME Patient Engagement Handbook provides in depth discussions of the theoretical underpinnings of the model and should be read before working your way through this handbook.

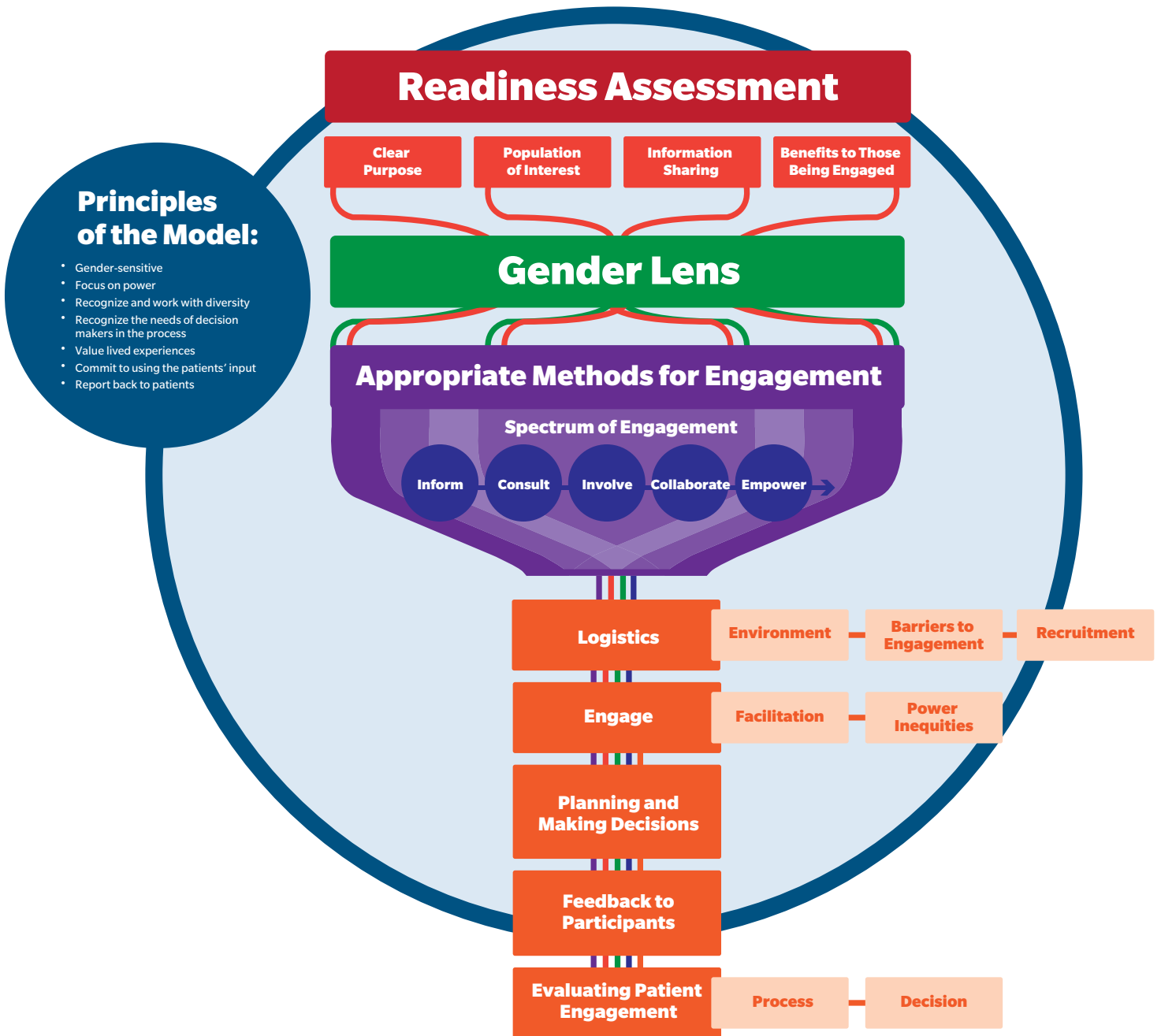
A point about terminology

For consistency, throughout this book, the word "patient" is used to refer to those using (or who could potentially use) a given health service. Some areas of practice tend to use different words for this, such as "client", "resident", "citizen", "community member", or "member of the public". The reader is encouraged to replace "patient" with whichever word most resonates for them in their field.

Also, for this book, "planner" is used to refer to anyone who is planning a health service, which could be a manager, director, front-line care providers involved in planning services, or an entire planning team.

The word "facilitator" is used to refer to the person who is working directly with the patients for the purpose of engaging the patients in planning a given health service. For example, they may be facilitating a focus group or conducting interviews or surveys. The facilitator may or may not be the planner of a given program.

The AWESOME Model



Principles of Engaging Diverse Voices in Health Services Planning:

- **Be gender-sensitive:** This model pays explicit attention to the similarities and differences in women’s and men’s experiences, challenges, and ways of engaging.
- **Focus on Power:** The model pays explicit attention to power dynamics and calls for the redistribution of power among participants, including both the patients and the planners. Power dynamics should be considered throughout the process, from setting the initial agenda, to deciding how to engage patients, to examining what type of evidence is considered valuable and how it affects the planning.
- **Value lived experiences:** The lived experiences of patients are an important form of evidence that should be considered when planning healthcare. This information cannot be obtained without engaging patients.
- **Recognize and work with diversity:** Patient engagement needs to acknowledge and work with the strengths, abilities, resources, and interests of the populations being engaged.
- **Recognize the needs of decision makers in the process:** Decision makers also have needs that must be addressed for patient engagement to be successful such as timelines, costs, or the specific question that must be answered. This model is intended to provide support to decision makers.
- **Commit to using patients’ input:** If planners are offering previously unheard people a chance to speak, they have a responsibility to do something with what they contribute and to be transparent about how they use this input.
- **Commit to feed back information about what was done with the patients’ input:** Patients need to be able to see how their input affected the program. It demonstrates that their input has been valued and respects their time and contribution.

Gender Lens

The first principle – be gender-sensitive – is illustrated on the model as a “gender lens”. This is meant as a prompt to reflect on the experiences of diverse groups of women and men and how those experiences can affect all aspects of patient engagement, including the lived experiences that patients might share through patient engagement, the barriers to accessing patient engagement opportunities, as well as the ways in which they engage.

Readiness Assessment

Before embarking on patient engagement, it is important to ensure you can commit the time and resources needed to do so in a meaningful way. Moreover, you must be able to commit to using patients' input in the planning and to being transparent about how you will use that input, in order to be respectful to the patients you will engage.

Will you be able to engage patients early enough in the process to be able to incorporate their input into the planning process?

- Yes
- No

Is your system ready to respond to what you are going to hear from the patients? How do you know?

Are you ready and able to commit the necessary time and resources to ensure equitable access for marginalized populations to the engagement process?

How will the findings from patient engagement be used? What impact will they have on the planning?

What do you perceive to be the risks related to engaging patients, to yourself, your program, and the patients? How will you minimize the risks?

Clear Purpose

Thinking about the specific purpose for engaging patients will help you to design a patient engagement experience that meets the needs of the planning, as well as well as outlining to patients what they can expect from the experience.

For more details about agenda setting in patient engagement, see section 4.1 of the handbook.

What is the target program?

What is the purpose of the target program?

How do you want the target program to differ from the current state?

What will the patients contribute to the planning?

What other input, aside from the patients' input, will contribute to planning (e.g., research findings)?

Describe the constraints you face in planning this program (e.g., budget, staffing levels, decisions that have already been made).

This will help manage patients' expectations

Population of Interest

Marginalized groups of people often experience increased rates of illness and greater barriers to health services. Including marginalized groups of women and men in patient engagement is crucial for ensuring that services address their needs. An important step towards building inclusive patient engagement processes is deciding who needs to be included, or in other words: defining the population of interest. Planners should reflect on what groups of individuals are experiencing barriers to attending the program. It is important to be concerned about meeting the needs of not only the patients that the program serves, but also the needs of the patients that the program should be serving, but isn't.

For more details about subpopulations that may have barriers to health and to engagement, see section 4.2 of the handbook.

Describe the patients that your program is intended to serve?

Do women and men experience the health issue/healthcare service similarly or differently from each other? (If your service only serves one gender, leave this section blank).

Are there groups of women or men who have more vulnerabilities and/or higher rates of illness related to your target program are? If yes, describe what makes them more vulnerable or more ill.

Are there groups of women or men who face substantial barriers to accessing your services. If yes, describe who they are and what challenges they face.

Are there groups of women or men who do not optimally benefit from your services? If yes, describe who they are and what challenges they face.

Describes ways in which the target program addresses differences that arise from variations in sex, gender, and diversity of your patients.

Do you need to involve proxies for any of the groups (e.g., family members representing people with dementia, parents representing their children)? If yes, who are these proxies?

Thinking about the questions in this section, whose voices do you need to hear? You may have as many populations of interest as you deem appropriate.

Information Sharing

Both the patients and the planners should have the same clear understanding of why patients are being engaged. While it is critical that patients have information about planning and how their input will feed into that planning, it should be balanced with the commitment being asked of them.

For more details about sharing information with patients, see section 4.7 of the handbook.

What information about the planning (e.g., purpose of the engagement, constraints on planning, other information being fed into the planning process) do the patients need to be able to participate?

Is there a concept (or concepts) that patients are expected to understand in order to participate in a meaningful way? If yes, what is the concept (or concepts) and how will you ensure they understand it?

How will you convey the required information to the patients?

Benefits to Those Being Engaged

Both planners and patients contribute time and energy to patient engagement and so it should be worth their while. Planners benefit from patient engagement by learning how to provide better care to patients, in addition to being paid their salary to be there. The benefits to patients are not always as direct. Through patient engagement can help transform care to better meet patients' needs, it may not affect the services for the specific patients who participate. Processes that are not inherently beneficial to the patient participants require extra considerations to motivate them to attend and to show respect for their contributions.

For more details about creating incentives, see section 4.3 of the handbook.

How will participation in patient engagement affect the services the patients receive?

- Do they regularly visit this service (e.g., some who lives in a residential care facility or who receives ongoing care for a chronic condition) or is their interaction time-limited or a single event (e.g., care in a maternity ward or a visit to an emergency department)?
- Will this patient engagement affect the care of the patients who participate and/or the care of future patients?

Aside from changes to care, how will participating in patient engagement benefit the patients you engage?

Are there skills that participation might foster? If yes, will this be relevant to the life circumstances of the population of interest.

Will participants be remunerated for their participation? If yes, how?

Appropriate Method for Engagement

There is no one ‘correct’ engagement method for a given project. The method(s) should be appropriate for the unique barriers and motivation to participate faced by your population(s) of interest and for the type of input you need. Furthermore, multiple methods can be used to all feed into the same process.

For more details about choosing a method for engagement, see section 4.5 of the handbook.

The International Association of Public Participation (IAP2) Spectrum of Public Participation* divides participation into five categories of increasing engagement.

	Inform	Consult	Involve	Collaborate	Empower
Public Participation Goal	To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decision.	To work directly with the public throughout the process to ensure that public issues and concerns are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise to the Public	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and issues are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

For the purposes of this workbook, the “Inform” category has not been included in the options as it does not include obtaining any input from the patients.

What level of participation would be most appropriate for your purpose and population of interest?

- Consult see page 25 of the handbook for guidance
- Involve see page 27 of the handbook for guidance
- Collaborate see page 28 of the handbook for guidance
- Empower see page 28 of the handbook for guidance

*© International Association for Public Participation www.iap2.org. Available at <http://iap2canada.ca/Default.aspx?pageId=1020549>.

Section 4.5 of the handbook provides examples of different methods that fall within the different levels of participation. Use the guidance there to help you choose a method (or methods) of engagement.

What method(s) will you use to engage the patients?

- | | |
|--|---|
| <input type="checkbox"/> Advisory Committee | <input type="checkbox"/> Participatory Decision Making/Design |
| <input type="checkbox"/> Citizen Juries | <input type="checkbox"/> Patient Observation of Existing Services |
| <input type="checkbox"/> Comment forms/Surveys | <input type="checkbox"/> Patient Journey Mapping |
| <input type="checkbox"/> Focus Groups | <input type="checkbox"/> Public meeting |
| <input type="checkbox"/> Forum | <input type="checkbox"/> Suggestion/Feedback Box |
| <input type="checkbox"/> Interviews | <input type="checkbox"/> Townhall meeting |
| <input type="checkbox"/> Opinion Polls | <input type="checkbox"/> Workshops |

Use this space to document why you decided on the particular method(s) that you choose:

Logistics

Once you have chosen your method(s) for engagement, you need to think about the logistics of the event.

Environment

The location and setting of engagement plays a large role in who attends the engagement event and how they participate. The environment is comprised of a number of factors, including the geographic location, the type of institutions that are located in and around the venue (and the implications for the patients), the physical layout of the room, the people who are in the room, and the time and day that engagement occurs. (If the engagement is not in-person, like an opinion poll or survey, the “environment” would be whether it is online, by mail, or over the phone.) Deciding on the environment is complex and must accommodate the needs of the population of interest, as well as the needs of the engagement method.

For more details about engaging patients in environments that work for them, see section 4.8 of the handbook.

For in-person methods of engagement:

Where does the population of interest reside?

Has the population of interest experienced oppression? Are the locations where they would feel uncomfortable? If yes, describe.

Is there a place where the population of interest typically goes (e.g., social services, social clubs, etc.)? If yes, describe.

Are there community partners who can provide space for engagement?

What days of the week/times of the day are patients likely to be available? (e.g., Are they employed? Are they caregivers?)

Does the population need specific services to be able to participate (e.g., childcare, food, assisted access, interpreter services)? If yes, describe.

For at-a-distance methods of engagement:

Does the population of interest have:

- Internet access? Yes No
- computer skills sufficient to complete an online survey? Yes No
- telephone access? Yes No
- mailing address? Yes No
- literacy skills sufficient to complete a written form? Yes No
- language skills sufficient to complete a written form?
– if no, can you have the form translated? Yes No

Barriers to Engagement

Getting to know the population of interest and understanding what they need to participate is the first step to minimizing the barriers to participating in patient engagement.

For more details about barriers, see sections 3.1 and 4.4 of the handbook.

What do you anticipate will be the barriers to engagement for your population(s) of interest?

How do you intend to mitigate those barriers?

Recruitment

Recruitment involves reaching out to the identified populations of interest and providing recruitment information in a way that is understandable and shows how engagement is relevant to them.

For more details about recruiting patients for engagement, see section 4.8 of the handbook.

In addition, it is important to recognize that selecting which patients have access to patient engagement opportunities is a form of power and which patients are selected can shape the patient input that is fed into the planning process. Efforts should be made to break down barriers to participation and to avoid privileging patients who, for example have more education or who are deemed easier to work with by planners. Consideration should also be given to how to solicit the voices of patients who currently do not access services, as opposed to only engaging those who attend services.

List your population(s) of interest.

Answer the following questions for each of your population(s) of interest.

How many people do you want to engage from this group?

Are there any organizations that can support you to recruit people from this group? If yes, identify the organization name and a contact person from the organization that you can approach.

If you get more interested participants than you can accommodate, how will you choose which participants to accept?

How will you present the opportunity to each group? (e.g., poster, presentation, in person, word of mouth, etc.)

Engagement

Facilitation

The patient engagement facilitator(s) will substantially affect patients’ perceptions of trust and safety and the way that they engage. Facilitators should be chosen in relation to who the patient population is and what they are being asked to do in patient engagement.

For more details about facilitation, see section 4.6 of the handbook.

Deciding if the health services planner for the target program should be the facilitator of the patient engagement requires thinking about the specific engagement situation, as well as what resources you have at your disposal. The following questions can serve as a guide to thinking through some of the issues.

Question:	Consideration:	Your thoughts:
Do you have experience facilitating a diverse group of people?	If no, consider using an experienced (co-) facilitator.	
Is this an emotional topic? Will you feel vulnerable or defensive if patients tell you negative things about your services or project negative emotions on you?	If yes, consider using a facilitator from outside your program.	
Will patients have to disclose potentially sensitive information?	If yes, consider whether it is appropriate to use a facilitator from outside your program (to maintain confidentiality) or if someone from within the program with whom the patients already have a trusting relationship would be more appropriate.	
Will patients feel comfortable giving you honest feedback?	If no, consider using a facilitator from outside your program.	
How does your gender, social, and cultural position differ from your participants? Can you communicate meaningfully with your participants?	Consider what would be the most appropriate for a facilitator given the gender(s), and social and cultural position of the patients. Consider using a (co-) facilitator who is a patient peer, front-line staff member who works with the population of interest, or a community-based agency partner.	
Do you speak the same language as the participants?	If no, consider using a facilitator who speaks the same language as the patients and an interpreter who can interpret the discussions between the patients and the facilitator for you.	
Will the facilitator need to know a lot about the program and issue to facilitate effectively?	If yes, consider having someone involved in the program as the facilitator. If there are issues around sensitivity of information or patients not feeling comfortable giving feedback to someone who they already know, consider having someone involved in the program but who has not worked directly with the specific patients.	

Given the questions above, who would be most appropriate to facilitate the patient engagement and why?

Power Inequities

A number of elements may be considered in order to create an engagement process that empowers the participants to contribute in a way that is meaningful for themselves and for health services planning.

One consideration is whether different groups of people should be engaged separately.

For more details about building safety and trust, and creating space for everyone to participate, see section 4.6 of the handbook.

Question:	Consideration:	Your thoughts:
Are there different subgroups who will be engaged?	If there are not different subgroups, there is no need to separate different groups.	
Are the issues being discussed of a sensitive nature?	Consider if the different groups will be comfortable discussing this sensitive issue with people from different groups.	
Are there power dynamics between the patient participants (e.g., between women and men, between people with more or less education, between people with different cultural backgrounds)?	If power dynamics have the potential to silence some patients, consider engaging the groups separately.	
How does your gender, social, and cultural position differ from your participants? Can you communicate meaningfully with your participants?	Consider what would be the most appropriate for a facilitator given the gender(s), and social and cultural position of the patients. Consider using a (co-) facilitator who is a patient peer, front-line staff member who works with the population of interest, or a community-based agency partner.	
Will patients feel comfortable speaking honestly and openly about their experiences among different people?	If patients are unlikely to feel comfortable speaking openly and honestly among different groups, consider engaging the groups separately.	
Are the issues being discussed specifically related to sex, gender, or diversity?	If yes, consider if engaging the groups separately will provide more space for patients to discuss their issues openly.	

Given the questions above, would it be most appropriate to engage subgroups separately or together and why?

Planning & Making Decisions

The voices of patients are but one of several sources of information that informs program planning. Things like budgets, organizational mandates, practitioner scopes of practice, and research literature, just to name a few, will all be brought to inform the program or service.

For more details about incorporating patients' input into planning, see section 4.9 of the handbook.

How will you incorporate the patients' input into program planning?

Feedback to Participants

After engaging patients, it is important to close the loop. The people who gave up their time and shared their personal stories need to know how the information was used, and if it was not used, then why?

For more details about telling patients how their voices helped shape health services, see section 4.10 of the handbook.

What is your expected timeline for having information about the health services planning to share with the patients?

During or after the engagement session, ask patients:

May we keep in touch with you to tell you how your input is used to shape our health services?

What is the best method to keep in touch with you (e.g., email, phone, mail, posting information at the community agency where the engagement event occurred)?

What method of presentation would be most useful for you (e.g., written document, oral presentation, informal chat)?

Evaluation

Patient engagement requires a great deal of time, resources, and effort on the part of both the patients and the planners – especially when making efforts to tailor engagement to reach marginalized population. Thus, it is important to evaluate patient engagement to determine what value it adds to the planning process. As well, evaluating patient engagement allows us to learn what worked well and how the process can be improved in the future.

Process

Evaluating the process of patient engagement will help you to learn what worked well and what could be done better the next time you undertake patient engagement.

For more details about evaluating patient engagement, see section 5. of the handbook.

What worked well? Why?

What did not work well? Why not?

What would you do differently next time?

Outcome

What was your intended outcome for the program planning process (of which engaging patients was a piece)?

What relevant information was derived from the patients?

How is the program different than it would have been if you had not engaged patients as part of the planning process?

As a result of the patient engagement, what do clinical staff do different to achieve the program's intended outcome(s)?

Have there been other effects of engaging patients aside from the primary outcome?

For the program?

For the staff?

For the patients?

Engagement Plan

Outline your engagement plan.

While all engagement events will be different, there are a few useful things to remember.

- Begin with food and welcoming remarks.
- Provide a clear description of the purpose of the event.
- Describe what will happen at the event.
- Define the roles and responsibilities of everyone in the room.
- Establish ground rules for the engagement event.
- Engage the participants using the method you have chosen.
- Record the participants' input.
- Ask participants how you should inform them about how their input is used.
- Answer participants' questions.
- Thank participants.
- Give remuneration to participants (if applicable).

During the event it is also important to keep a few things in mind:

- Explore the why, not just the what: you may not be able to do exactly what patients want, but if you know why they want it you might be able to find a reasonable alternative.
- Unpack emotion to turn lived experiences into information.
- Be jargon-free and ask others to explain what they mean if they use any jargon.
- Value all types of contribution.
- If using an interpreter, be clear that you would like a verbatim interpretation so that you hear the patients' voices as closely as possible.

Engagement Plan Template

Purpose of the Engagement:

Who will be engaged?

How will the patients be engaged (i.e., method(s) of engagement)? You may want to attach detailed documents, such as an interview or focus group script, or questions for a survey.

What are the expected benefits to patients?

How much will patients be remunerated (if applicable)?

What community-based agency(ies) you will partner for this engagement (if applicable)?

What information will be shared with the patients?

How will patients be recruited?

Where will the engagement take place?

What date/time will the engagement take place?

Arrangements for food:

Arrangements for childcare:

Arrangements for transportation:

Other arrangements:

Facilitator:

Interpreter (if applicable):

Plan to incorporate patient input in the planning:

Plan to feed information about how their input shaped the health service:

Evaluation plan:

Seeking Your Feedback

We would greatly appreciate feedback on this document. As well, if you use our model, we'd love to hear about your experience with doing so.

Please feel free to contact us with any comments, questions, or other feedback at:

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