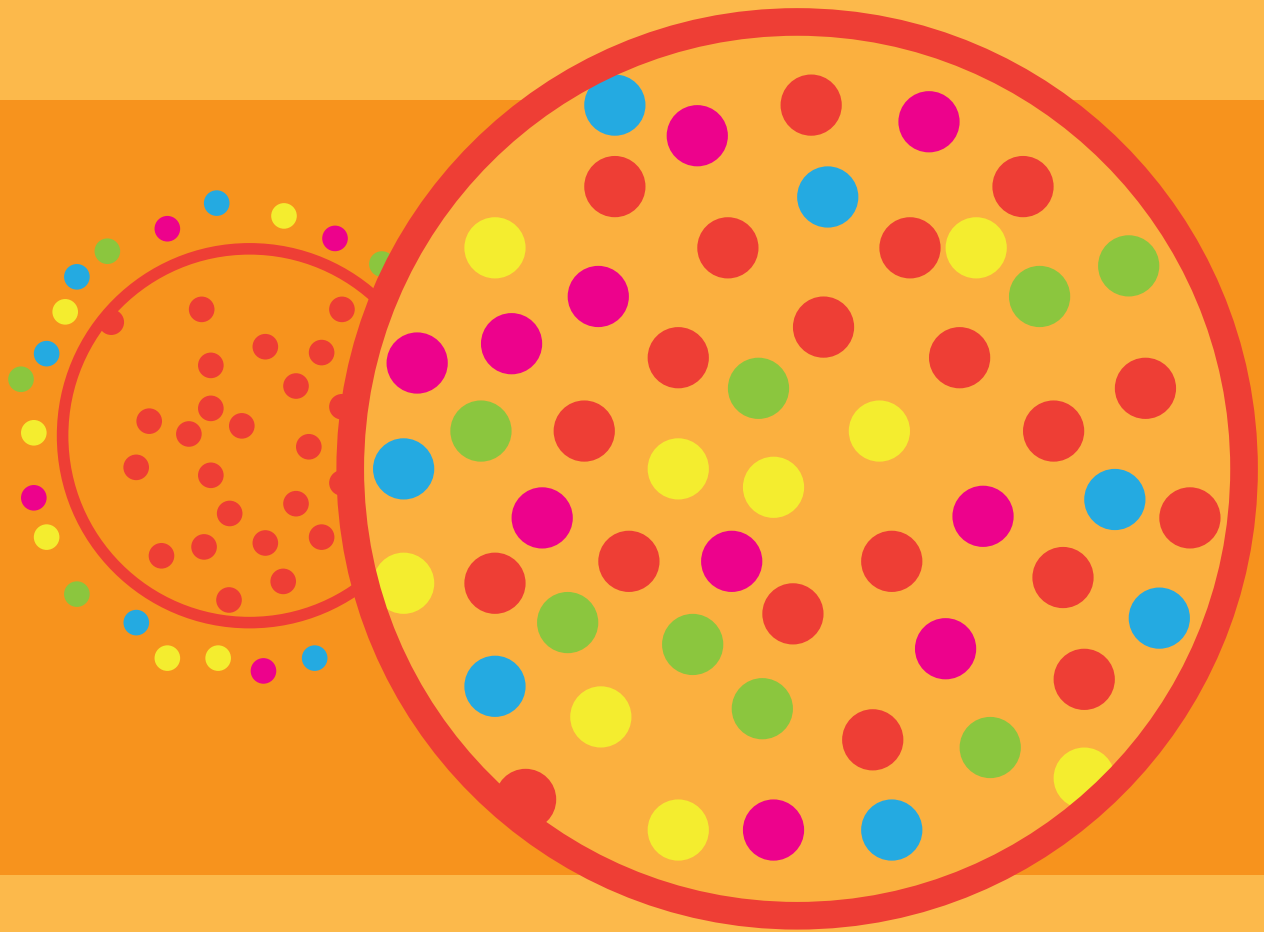


PATIENT ENGAGEMENT HEARD AND VALUED

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



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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, in this book, “planner” is used to refer to anyone who is planning a health service, which could be a manager, director, front-line care provider 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 them 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.

1. Introduction

1.1 The goal of this handbook

Patient engagement is a strategy for designing high quality health services that are responsive to patients’ needs and empower them to play an active role in their health. Patients provide unique insight into how they experience healthcare 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 vulnerable populations are excluded from patient engagement, planners 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.

The purpose of this handbook 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.

The issues being explored in this handbook are not simple and thus the handbook 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 handbook:

- Describes the characteristics of patient engagement that exclude marginalized people from participating in patient engagement.
- Outlines the implications of excluding marginalized patients from patient engagement.
- Identifies pitfalls throughout the patient engagement process through which marginalized people may become excluded and identifies strategies to prevent and overcome these challenges.
- Provides examples from two case studies of programs using the model to engage marginalized patients in health services planning.

It is not the intention of this handbook to provide guidance about how to conduct the various methods of engaging patients (e.g., surveys, workshops, citizen juries, etc.). Rather, this handbook provides guidance to choosing among various methods and some considerations with respect to engaging with issues related to gender and marginalized populations.

1.2 The AWESOME Project

This handbook was derived through the work of the AWESOME Project, a two-year study aimed at creating an effective, sustainable model for meaningfully engaging a diverse group of women in program and policy planning. The Fraser Health Women's Health Team with a collaborator from the British Columbia Centre of Excellence for Women's Health (BCCEWH) undertook the AWESOME project through two phases, first developing a model for engaging marginalized women based on qualitative inquiry and then implementing and evaluating the model. Funding for the project was provided by the Canadian Foundation for Healthcare Improvement and Fraser Health, with in-kind contributions from BCCEWH.

Phase 1

In the first phase, we conducted a qualitative inquiry to develop a theory for engaging marginalized patients in health services planning and then translated the theory into a model for engaging marginalized women in health services planning. The qualitative inquiry included:

- a review of 18 articles that described projects where diverse or marginalized populations were engaged in health services or policy planning
- interviews with 13 women exploring how they would want to participate in health services planning and how they would define effective patient engagement
- interviews with 19 health service planners and researchers from Fraser Health and other local health service organizations who had experience engaging patients; many of these individuals had engaged people whose voices have not traditionally been heard in health services planning
- analysis of the interview data using a grounded theory approach

Sections 2, 3, 4, and 5 of this handbook represent a synthesis of the findings from phase I.

Phase 2

In the second phase we implemented the model in two Fraser Health clinical programs and evaluated how the model supported patient engagement and how patient engagement affected health service planning. These included:

1. Public Health used the model to engage patients in planning a new Family Visiting program in which Public Health Nurses will provide home visits to pregnant and new parenting women in vulnerable families. The planning team engaged 70 pregnant or newly parenting families who were potential users of this service. The engagement planners engaged families from populations with potential vulnerabilities, including refugees and new immigrants, young mothers, low-income mothers, and fathers.

2. The Diabetes Self-management Education program in the Fraser Health Primary Care Program used the model to engage patients in the redesign of the diabetes education curriculum, which is provided in both English and Punjabi. The planning team engaged 9 patients who had participated in either the English or Punjabi diabetes education sessions.

Examples from these two case studies are provided throughout the handbook to illustrate the concepts being presented.

2. Hearing patients' voices: what is patient engagement?

2.1 What is it?

The term “patient engagement” is used in this handbook to describe patients participating in systems level planning. It is not used in the sense of patients being engaged in making decisions around their own individual care. “Patient” refers to a person who is currently a patient, has been a patient in the past, or is a potential future patient of health services, while “engagement” includes Ableson, et al.’s¹ three criteria: 1) information about the issue is provided to the participants, 2) participants have the opportunity to discuss the issue amongst themselves and potentially with the decision maker, and 3) there is an explicit process for collecting the input from the participants.

There are many different ways to engage patients. In the health sector in British Columbia (BC), the patient engagement process often consists of teaching patients how to participate in healthcare planning discussions, and then matching them with opportunities to contribute their “patient” perspective, which is the strategy used by the Patient Voices Network².

2.2 Why engage patients in health services planning?

Historically, healthcare planning has been the domain of policymakers and healthcare administrators. Patient engagement is a way for healthcare systems to incorporate the knowledge and experiences of patients into decision making in order to make healthcare systems more responsive to patients’ preferences, values, and needs.

Patient engagement has been identified by British Columbia health authorities^{3,4}, Health Canada⁵, the Canadian Foundation for Healthcare Improvement (CFHI)⁶, and the Health Council of Canada⁷ as a promising strategy for supporting health service planning. Patient engagement can advance planners’ knowledge of the patient journey through services and inform planners about what patients value in health services. Or, as was stated by one health planner in an interview, we engage patients “because they’re the client, and so we should be tailoring our services to the needs of the client. And what better way to find out the needs than to speak directly to the clients?”



"I think when there are those "aha" moments for clinicians in particular, when they hear something that might be difficult to hear, but they have a preconception about how clients are experiencing things, and then they hear something that is totally not consistent with their perception. And it can be really powerful."

-Healthcare planner

2.3 The spectrum of participation

Patient engagement needs will vary depending on many factors, including the resources and capacity that patients and planners have for patient engagement, and planners' capacity to address patients' input. The International Association of Public Participation divides participation into five categories of increasing intensity and duration of participation on their Spectrum of Participation^{8*}, which is commonly used by health services planners to guide their engagement methods. The categories describe how those who plan programs and services work with the public or patients to incorporate their input into the planning process. The categories are:

- *Inform*: planners provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.
- *Consult*: planners obtain public feedback on analysis, alternatives and/or decision
- *Involve*: planners work directly with the public throughout the process to ensure that public issues and concerns are consistently understood and considered.
- *Collaborate*: planners partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.
- *Empower*: planners place final decision-making in the hands of the public.

3. Not all patients are heard: traditional ways of engaging patients may exclude marginalized populations

Often, patient engagement strategies are developed to meet planners' needs, so engagement processes end up reflecting the time and resources that the planner can commit to patient engagement, as well as how they intend to use patients' input into planning. In these instances, patient engagement strategies are often not sensitive to gender and diversity, and do not account for how different women's and men's abilities, resources and social contexts influence their participation in engagement. This is the case despite evidence documenting the inequities experienced by certain groups with regard to the burden of illness and access to responsive, appropriate, and acceptable health services^{9,10}. Furthermore, traditionally people engage patients without addressing the research that suggests gender, education, and other life experiences affect both participation styles and rates. That is, they assume that all patients are the same: they bring the same capacities, skills, time, resources, and needs to the planning process. Yet these, and other findings suggest that patient engagement in healthcare planning should be tailored to the particular patients being served – or who should be served but currently are not – by a given program^{11,12}. Universalistic, "one-size-fits-all" approaches to engagement may not enable diverse groups of men and women to participate in decision-making about programs and policies intended to meet their needs or enable planners to develop interventions with a diverse range of patients in mind.

3.1 How exclusion happens: traditional models are blind to diversity and gender

What patients are engaged about

Abstract healthcare issues such as planning overarching healthcare strategies, as opposed to direct health services, are not directly relevant to the lives of many patients. Indeed, most patients would need to be “trained” or prepared to provide input on many abstract issues in order to be able to meaningfully engage in discussions on them. In fact, this is what some advocate and many provinces, including BC, have generated patient engagement initiatives that support patients being trained or “activated” to fully participate. The time required for such preparation may dissuade groups who experience challenges in life from engaging as engaging on issues not relevant to them would likely take a low priority relative to more pressing issues in their lives, such as individual health services, safety, food security, or child care responsibilities. Conversely, patients may spend more time and effort engaging around a program that they have more continued interaction with, such as services for chronic conditions such as mental health services, because the impact of their engagement will have direct impact on their own or their family’s care¹³.

Patients’ barriers to attending engagement

Diverse and marginalized populations experience barriers to attending a patient engagement session, because they do not learn about the patient engagement opportunity, they do not want to participate or they cannot get to the place where the engagement happens, whether it is at a physical or a virtual location. Once patients are at a patient engagement session, they may encounter other barriers to participating in a meaningful way.

Inequities in patient engagement reflect other social inequities as marginalized segments of society tend to have lower participation^{11,14}. In a review of engagement processes, one study found that participation was lower among individuals with language barriers, substance abuse, cognitive limitations, a psychiatric diagnosis and sight deficiency, especially among people who have more than one of those characteristics¹². There are many ways in which these groups come to be excluded from patient engagement.

Learning about the opportunity

Many patients are excluded from patient engagement before they even have the chance to consider attending, because they do not learn about the opportunity. People are recruited for patient engagement through many channels, though often they are solicited through health service providers from whom they receive care. Many of the groups that have not traditionally been heard in health services planning, including people impacted by substance use, mental health issues, trauma, and poverty or people who are new immigrants, may not access health services, and as such may not learn about patient engagement opportunities if patients are only recruited through existing services¹³.

People may not learn about patient engagement for other reasons. They may have language barriers which prevent them from understanding solicitations that are in English. Furthermore, English speaking health services providers may only seek input from English speaking patients. In the literature on patient engagement events, interpreters were rarely provided; even when working with immigrant populations the expense of an interpreter was seen as prohibitive for a patient engagement project¹⁵. Likewise, providers may not seek input from patients with low cognitive function.

Deciding to participate

By choosing to participate in patient engagement, people are deciding that they are willing to commit time and energy because they believe that there is some value to their participation. The amount of time and energy that participants need to commit will vary depending on the engagement method. In the literature, single engagement events were successful at engaging many participants^{14,16} while deeper levels of patient engagement, with recurring events, often started with a good participation rate though attrition happened over time. The people who left often cited the time and responsibility commitments required as the reason for leaving^{17,18,19,20}.

Patients also have to feel that they have the capacity and skills to participate in patient engagement. Certain groups of women may be less likely to see themselves as having something to contribute to policy building because of past experiences with institutional prejudices, and internalized stereotypes about their political abilities^{21,22}. Across the literature and interviews, many women who had a history of trauma or substance use had negative experiences with healthcare providers, where they felt that providers stigmatized them, and so they felt either like they did not have something important to say, or that the healthcare providers would not want to listen to them. This sentiment may deter certain women and men to choose to engage in patient engagement^{11,14}.

In interviews, some women also expressed fear of going to a new health or social services setting for the first time. Others expressed distrust in these types of institutions. These concerns would likely deter people from choosing to participate in patient engagement with an unfamiliar organization.

Getting there

Even when people have learned of an opportunity to participate and they want to participate, other factors can prevent them from actually attending patient engagement activities. Barriers that were frequently discussed in either or both the literature and interviews with health service planners and patients included, childcare responsibilities, care responsibilities for another adult, inflexible employment schedules, household responsibilities, access to transportation, unstable housing, unpredictable schedules, food insecurity, and basic survival.



“It’s a big waste to plan services that nobody wants and to deliver them in a way that is useless or harmful. And those things happen all of the time. So my view would be that engaging our clients or engaging our patients early and often and in meaningful ways is integral to ensure our accountability to them and to the systems that we work in as well, right, who always want to know that we are doing the right things for the right people and the outcomes are good. And if we’re doing the wrong thing to begin with, we will never get there-Healthcare planner.”

Different people experienced these barriers to different degrees depending on the resources that they had available to them. Women are likely to experience many of these barriers due to gender-prescribed roles. Providing care to family, including children, and aging parents, is a significant priority and responsibility of many women, and can be a barrier to participating because of the time involved and their inability to leave dependents alone or afford alternative caregivers or respite. Many gender-related barriers are compounded by low socioeconomic status. Low socioeconomic status is also associated with many participation barriers particularly at more intense levels of engagement. In the literature, engagement methods with recurring events, such as advisory panels, that had membership from people who were marginalized on a dimension other than income, (including Aboriginal health, sexual assault of non-verbal women, and intellectual disability research advisory panels) had strong consistent membership^{19,23,24}. In contrast, projects engaging economically disadvantaged individuals, such as homeless individuals and members of minority groups from diverse economic backgrounds, described participants often missing engagement sessions because they prioritized survival issues, such as housing and food security, over participation in engagement^{17,18}.

The setting of the engagement event may also present barriers to potential participants. Some participants were physically incapable of getting to the event, such as housebound individuals²⁵.

How patients are silenced

Even when people are motivated to participate and overcome the barriers to attending an engagement event, there are still potential barriers to meaningful engagement. Many of these barriers lie in the location of power in an engagement process, specifically the ways that power is produced, maintained, and transformed. Through a variety of mechanisms, power dynamics shape whether certain groups of people participate, how they participate, and how their participation is legitimized as knowledge to inform healthcare decisions. Meaningfully engaging diverse groups of patients begins by addressing these power dynamics, specifically the power dynamics between the various participants and between the facilitators and the participants.

To maximize engaging the people who are appropriate for a given patient engagement opportunity, some of the factors that should be considered include:

- when the patient engagement is scheduled (e.g., holding a patient engagement event during a weekday will exclude many working people).
- where a patient engagement is held (e.g., holding an event at a healthcare site that is hard to reach for those who use transit can exclude lower income individuals; holding an event at a site in a city can exclude those who live in more rural and remote areas).
- how a patient engagement is conducted (e.g., an online survey will exclude those without access to the Internet; a workshop focused on reviewing scientific literature would exclude individuals who perceive themselves to lack high-level reading and analytic skills).

- who facilitates the engagement (e.g., power differentials between patients and healthcare professionals can affect who will engage and to what extent they are willing to share. For example, having healthcare professionals who provide service to clients involved in the engagement process may stifle patients from expressing criticism for fear their healthcare may be affected. Lack of respect and not being listened to were commonly mentioned by patients as potential barriers in our interviews. For patients who have experienced significant disrespect and been stigmatized during their interactions with the healthcare system, such as individuals with mental illness or addictions, facilitators will need to work hard to build trust) .
- the capacity of patients to participate (e.g., for those with limited capacities, such as patients with dementia or children, planners may need to provide child care, engage family members as proxies, and/or be creative in how they design their patient engagement events).

Lack of safety and comfort

Across the literature and in interviews, a common theme that prevented meaningful participation was participants not feeling safe or comfortable to share their thoughts and experiences with healthcare. Many informants who were impacted by trauma, substance use, and mental health issues, described a history of feeling mistreated by healthcare providers, which made them distrust the system and reluctant to participate in patient engagement. Moreover, because healthcare is in many ways a deeply private issue, many topics have sensitive elements, which people may not feel comfortable discussing with others.

The setting could also make people feel uncomfortable, either by being too formal, such as a research setting²⁴, or being in a space associated with negative experiences (e.g., in or near an immigration or law enforcement office)¹⁶.

Other factors that affect participants' feelings of safety and comfort relate to the facilitator and the other participants, which will be described in the following two sections.

Facilitators

Power dynamics between facilitators and the participants shape how knowledge is generated, how problems are defined, and what ideas inform healthcare decision-making^{14,26}.

In the literature, authors noted that Engagement facilitators and sponsors typically have more social capital than many participants and this power imbalance can have potential impact on the engagement process. Some participants felt the facilitators represented institutions who had violated their trust in the past, leading them to be less honest about their values, preferences and needs²⁰, or to be skeptical of the engagement process²⁵.

In the interviews, patients described a variety of ways that healthcare practitioners or planners acting as facilitators could make them uncomfortable. In particular, they worried that negative feedback may have repercussions for their care²⁵, and that they would not want to make providers feel bad by criticizing them. They also said that facilitators could make them feel uncomfortable through their dress and their speech, by wearing suits and speaking in ways that they do not understand. Furthermore, planners and women said that facilitators could silence people by not being open to the varied ideas and topics that were important to the patients.

Participants silencing each other

In addition to the power dynamics between the participants and facilitators, the power dynamics between participants also influenced how knowledge was generated and what information informed healthcare decisions. Several of the processes described the tendency for professional participants to dominate the engagement events either by precluding the others from participating through their use of formalized language²⁰, or simply by being present because the other participants tended to believe that they were the most knowledgeable about a subject¹⁹. These engagement processes were not successful at reallocating power to participants whose lived experience could inform health services planning. Many participants did not believe that they were equipped with the skills to participate fully or found that the process privileged professionals who had knowledge of the jargon and process^{19, 20, 23}.

Power dynamics between groups may prevent people from sharing issues that are construed as deviant, particularly when inherently linked to intimate parts of their lives and their bodies. For example, people may feel uncomfortable speaking about issues of substance use or sexual activity or reproductive health around people who do not share those experiences. It is necessary to uncover these differences and sensitivities and to build engagement structures that are sensitive to participants' needs in order to foster meaningful engagement

Although power dynamics between patients may be responsible for preventing marginalized people from meaningfully participating, facilitators bear responsibility for creating engagement processes that empower all participants and legitimize lived experience as evidence. Engagement processes that do not empower marginalized participants may generate knowledge that reflects the views of participants with power.

Style of engagement

Different people have different styles of engaging, and the engagement process can legitimize or prioritize some styles over others. In particular, participants will differ in their ability to deliberate over issues. Deliberation requires articulate communication, which is formal, general, and based on presenting "objective" points¹⁴. This is a skill that is learned formalized through education, and more typical of educated men²⁶. Speech that is emotional (specifically angry, hurt, or passionate), metaphorical or narrative, and includes gestures tends to be used more often by women, particularly minority women²⁶. This type of communication, considered to be false, weak, or unknowing, is not taken seriously in certain dialogue structures²⁶.

Furthermore, some people do not feel comfortable speaking up, competing to speak or sharing orally at all. Those who are more introverted or take longer to process and articulate their thoughts may be left out of processes that are based on sharing in groups yet many engagement processes rely upon the ability to share in front of others.

Types of evidence

Barnes & Rogers¹⁴ criticized engagement processes, such as citizen workshops and citizen juries, in which citizens receive evidence presented by “expert panels” then deliberate on the issue and make a decision. They concluded that these forums predetermine what evidence is important and do not provide adequate space to learn from the patients’ experience-based evidence.

Patient engagement strategies can prevent people from contributing their lived experience as evidence when issues are defined by the facilitators and “expert” evidence is prioritized. Expert evidence may include testimonials from “certified” or “deemed” experts or written submissions from scientific or legal professionals. This definition of “evidence” may prevent patients from challenging the experts and sharing their unique discourses of illness and how problems are defined.

3.2 The implications: creating and perpetuating inequities

Patient engagement has the potential to make programs and policies more responsive to the public. As such it may also reflect and maintain health inequities by reproducing social marginalization through the engagement structure and process. The patterns that support some populations to participate while excluding other populations reproduce social and health inequities. In order to engage diverse populations, patient engagement must not only fit planners’ needs, but also those of the patients’ life contexts.

The resources needed to be healthy and to access safe and appropriate healthcare overlap with the resources necessary to meaningfully participate in traditional patient engagement strategies. Barriers may be material, physical, psychological, or social in nature^{11, 12, 14, 27}.

Without hearing the voices of those who are marginalized, planners may not be able to understand the barriers to health and healthcare that they confront, and thereby cannot transform systems to respond to the needs of marginalized patients and support improved health.



“The way that we design health systems and the way that we develop and deliver health services has been a major part of the problem when it comes to perpetuating certain forms of inequality or marginalization. And it can be part of the solution as well. And so being aware of those histories and the contemporary practices that perpetuate these relations, it gives us an opportunity to be self-reflexive in our own practice and to really think about what meaningful change looks like, and we will not get there if everything is top-down all the time. We must have ground up”

-Healthcare planner

4. Hearing all voices: Creating patient engagement situations that meaningfully include those whose voices have not traditionally been heard in health services planning.

As previously discussed, there are various pitfalls throughout the patient engagement process which may lead to marginalized populations being excluded, from defining the specific questions that patients are engaged to address to translating patients' input into planning. This section walks through strategies to support marginalized patients' participation in engagement.

4.1 Engaging around issues that matter to patients: who has the power to set the agenda.

Issues of power arise right from the initial decision about what patients should be engaged about – setting the agenda is a form of power. By deciding what patients are going to be asked about – and not asked about – healthcare planners are exerting power to guide what gets discussed and what does not.

However, healthcare planners work within constraints as to what their program can do and what influence patient input can have on a program. Thus, a balance must be struck as to setting an agenda for engaging patients that is within the scope of what the patients' input can influence, but still providing as much room as possible for patients to be engaged on issues that matter to them. In addition, it is important to be clear about the purpose of the engagement, to be thoughtful in how the purpose may exclude some groups of people, and to be creative about how to address these issues. Remember that the reason patients are being engaged in the first place is that they have a perspective that healthcare planners do not have, so it is important to be open-minded to their perspectives, as they may bring up issues, concerns, and potential solutions that planners did not anticipate.

Patients should be engaged around issues that matter to them. When patients have more ongoing interaction with a healthcare service, such as a medical clinic they regularly attend or a program for a chronic condition, they may be more likely to engage as there will be an impact of their engagement on their own or their family's care. However, this does not mean that patients are never motivated to engage in areas that will not directly impact them. Many of the patients interviewed noted that improving health services for other people is a motivator to become engaged.

Be clear about the purpose for the engagement. Patient engagement can be ineffective or tokenistic if there is not a clear reason for it or clear understanding of how it is going to inform health services planning. "We want to get their input" is not a clear purpose. Describe what patient engagement is intended to achieve and how the population of interest might contribute to planning. For example, in the Family Visiting case, the planners wanted to know how patients experienced relationships with healthcare providers and ways that they could design the Family Visiting program to foster nurse-client relationships that would work for patients.

Example from case studies:

Family Visiting

When engaging patients about their needs in the Public Health Family Visiting Program, the engagement sessions were framed to be relevant to parents' experiences. The facilitator elicited parents' stories of their challenges with child rearing, the ways that a family visiting nurse could have supported them, and the ways that a relationship with a nurse could support them or create further health service barriers.

Diabetes Education

In the Diabetes Education program, the planners wanted to know how the patients experienced the diabetes education sessions, what information the patients retained, and how the education affected their diabetes self-management so that they could re-design the program to enhance retention and application of information and skills by the patients.

How the purpose is defined will affect the types of contribution patients can make, so it is important to consider whether the purpose excludes the experiences of particular populations. For example, if patients are being engaged to determine what information should be in written materials, patients who have language barriers or low literacy would be excluded. Thus, the purpose could be expanded to engage patients with language barriers or low literacy to inform what should be included in terms of visual representations that do not require the ability to read in English or other forms of media, such as audio.

Tips for Healthcare Planners:

- While “we want to get their input” is not a clear purpose, having a patient engagement event to ask patients about their issues and concerns (basically, asking patients what they would like to be engaged about) can be – as long as you have a concrete plan of how you can take that input and use it in a way that will address those concerns.
- Listen to patients' concerns on a regular basis to learn what matters to them. Everyday interactions with patients are opportunities for patients to set the direction for patient engagement activities.
- Patient engagement can occur in day-to-day interactions with patients, such as asking members at a group session how they want to see the group work and what they hope to have the group achieve.
- Be open-minded with respect to what you hear from patients and, wherever possible, be flexible in adapting to their input.

4.2 Engaging patients with diverse experiences: identifying the subpopulations that may have barriers to health and barriers to engagement.

As previously discussed, developing an appropriate patient engagement strategy is not only about meeting the needs of planners and programs, but also about fitting the engagement to patients. Determining the population that will be engaged is a step that requires careful consideration and is a precursor to determining the method and logistics of engaging patients. Thought should be given to what the program is intending to do and identifying the target population. Moreover, healthcare 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.

Healthcare planners sometimes speak of “hard to reach” populations, but it may be useful to turn this notion around and conceptualize healthcare services and patient engagement opportunities as being the thing that is “hard to reach”.

Thinking about services and opportunities from the patient’s perspective, rather than privileging the system and expecting patients to conform to it, can help uncover potential barriers.

Tips for Healthcare Planners:

- Many community agencies provide support to various diverse populations and can often help to identify people who healthcare might not otherwise be reaching, the types of barriers they face, as well as helping recruit individuals who would be interested in participating. In addition, they may be able to provide access to space that is familiar, comfortable, and more easily accessible to your population of interest.
- Ask the patients who else is missing from the engagement. Having patients engage their peers can be an effective way to overcome a number of barriers, including language barriers and building trust.
- Ask patients what the barriers are to being involved in a specific patient engagement opportunity. Resources such as interpreters, childcare, transportation, and providing the “right” facilitator for engagement can all help overcome barriers.
- Hold patient engagement events at times and places that work best for patients, rather than privileging the schedules and locations of the planners.
- Multiple types of engagement that work for different people can be used simultaneously to feed into the same process.

Examples from case studies:

Diabetes Education

The Punjabi speaking population was seen as an important group to engage for the Diabetes Education program, as the program is offered in both English and Punjabi and people of South Asian descent are known to be particularly at risk for type II diabetes. Deciding on this population of interest had implications for the way that the sessions were organized, such as the need for a Punjabi-speaking facilitator and interpreter.

Family Visiting

The Family Visiting program planners decided to engage with the many different populations who would qualify for the Family Visiting program, including young mothers, Aboriginal mothers, low-income mothers, and fathers, so the engagement required multiple events tailored to each of these groups.

4.3 Creating participation incentives that are relevant to the select populations.

Barriers to participation and motivation to participate in patient engagement are two sides of the same coin. The patient engagement literature shows that when patient engagement requires greater time and commitment from patients, patients need greater incentive to commit their time and energy. The barriers to participation may be amplified among marginalized populations who lack social or economic resources, such as patients who are new immigrants or refugees, and patients who are impacted by poverty, trauma, mental health or substance use. By participating in patient engagement they are giving up other opportunities, which may amount to childcare costs, lost wages and missed opportunities for social support.

Generally, people are motivated to participate in patient engagement if they find the issues are relevant to their lives and they believe that participation will benefit them in some way. What people consider to be a benefit comes in many forms, such as having a chance to give back and have their voices heard, changing services that have an impact on their lives, or benefiting directly from the patient engagement experience. What motivates patients will depend on their life context, the relevance of the issue to their life, and the actual engagement strategy. As will be discussed in the following section, many strategies can reduce the barriers to participating so that patients do not need enormous incentives to participate. Nonetheless, increasing their interest in the process and outcome will lead to more meaningful engagement.

Examples from case studies:

Diabetes Education

Since patients who had already completed the Diabetes Education sessions were the target audience, there was no incentive that they could improve services for themselves. Patients were told that they had the opportunity to share their ideas, and were also offered a dinner and an honorarium to thank them for their time. Recruitment was nonetheless challenging because the motivation to participate was not very large.

Family Visiting

A variety of patients' input was sought for Family Visiting program planning, and thus it was necessary to consider different motivators for different populations. Meals and honoraria were provided for all participants. As well, the engagement provided a venue for families who had either had positive experiences or negative experiences to speak about their experiences and to give back to improve the future experiences of families.

Types of Incentives

Being heard, sharing experiences, and giving back “makes you feel like you’ve got something important to say”

Across the literature and interviews, many people said that they were motivated by having the chance to share their experiences, help people, give back to the community, or improve services for others. Some also said that they enjoyed the opportunity to hear from others who had similar experiences. However, sharing experiences was contingent on the relevance of the patient engagement topic to patients' life experiences: people said they wanted to participate when they felt like they had something valuable to contribute.

When the patient engagement topic was more abstract, requiring patients to reflect on policy and services rather than their experiences, the process became motivating to professionals and advocates involved in the area, and less so for the patients^{19,24}. For example, one project focused on regional sexual assault prevention and response for non-verbal women, though the project did not have a lot of participation from non-verbal women, and the non-verbal women who did attend were not able to meaningfully contribute²⁴.

Giving back and having their voices heard is sufficient motivation for many diverse groups when the engagement methods require less commitment^{14,16}. However, with more intense levels of participation, where greater time and commitment are required, the barriers to participation are amplified and so more significant motivation might be required.

Improving services

As mentioned in the previous section, people were motivated by the opportunity to give back and improve health service for others. Improving health services for themselves was also a significant incentive for many.

The literature suggests that people who have prolonged or frequent contact with particular health services (for a particular condition, such as mental health services) may be motivated to participate by the potential to improve health services for themselves^{18,20,28-32}.

Members of minority cultural groups were motivated to participate by the desire to make services more culturally appropriate, safe, and accessible^{15,23}. However, as previously described, diverse patient groups participated less when the engagement topic was general or abstract. For example a project that focused on increasing cultural safety for Aboriginal people across a health authority was successful at engaging community organization representatives, but not Aboriginal community members themselves¹⁵.

Opportunities to gain skills and learn new things

Patients were also motivated to participate when the act of participating resulted in direct benefit, such as providing a social opportunity or opportunity to meet new people, training and education, or increased confidence^{18,25}, gaining skills that could be applied elsewhere, including employment^{15,18,20}, reducing isolation, developing community networks and furthering personal growth and employability²⁰.



"I think for me, my input is very important. My words are important
That's all I got."

– Patient

However, it is necessary to examine whether the benefits are relevant to the life context of the marginalized populations who are to be engaged. For example, economically marginalized people who have a number of survival related challenges may not find the same things to be motivating as people who have steady employment.

Both planners and female patients said that opportunities for social connection were a draw for women, particularly if they were able to bring children. Women felt valued when the engagement presented opportunities that might be challenging to access in their daily lives, such as a healthy meal for themselves and their children, a celebration, or an event where they received a service such as health information or a salon day. These were especially valued by women who were impacted by poverty. Women were also drawn to a safe opportunity to share their stories with women who have similar experiences, and to have their stories listened to^{14,15,16}. As well, many women were motivated by opportunities to improve care for their children^{20,25}.

Remuneration

Remuneration is a small incentive for patients. It can support some patients who are giving up other economic opportunities and some patients said that it made them feel like planners respect their time and contribution. However, remuneration by itself is likely not a sufficient incentive for most patients to participate.

Tips For Healthcare Planners:

- When trying to identify incentives for patients think about what you are asking them to do, and what challenges they will have to overcome.
- Think about how the experience of engaging relates to patients' lives.
- Benefits that might motivate people to participate in patient engagement include:
 - Having one's voice heard
 - Giving back to the community and helping others
 - Improving services for others
 - Improving services for themselves and those they care for
 - Gaining new knowledge
 - Learning new skills and gaining experience that may be relevant to employment
 - Meeting new people and participating in social activities
 - Gaining professional contacts
 - Remuneration

4.4 Reducing the barriers that prevent people from attending patient engagement

As mentioned in the previous section, motivation to participate in patient engagement and barriers to participating are interconnected. Furthermore, what is considered to be a barrier will depend on who the population of interest is, and what economic and social resources they have. 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. One strategy that has been cited widely across the literature and in interviews with planners was the suggestion that working with community-based agencies who work with the population of interest was a way to learn about the needs of the client population and their health services needs. Furthermore, many of the barriers to attending engagement can be overcome by working with community based agencies.

Working with community-based organization

Working with community-based agencies to engage patients in health service planning can help to overcome barriers related to finding the population of interest, motivating them to participate, and supporting them to attend^{17,18,23,25}.

Community-based agencies often have relationships with clients who are not being seen in health services because their mandate is completely different. For example, women may attend an information session at an immigrant serving organization to learn about how to obtain a social insurance card and learn about employment opportunities or to attend a language class. These are not in themselves direct health services. Community-based organizations may support planners to learn about the population of interest's needs, and how to engage the population in a meaningful way. Community-based agencies may also help planners to access select patient populations¹³.

Planners interviewed said that in addition to helping planners connect with hard-to-reach populations, community-based agencies are able to reduce many of the barriers that prevent patients from choosing to participate. Many people trust the community organizations they access services from, so an invitation to participate that is endorsed by the community-based agencies may be considered trustworthy and more relevant to their experience. If patients are personally invited by someone they know, they may believe they have the capacity to participate. Working with community-based agencies that people trust and feel comfortable with also reduces the anxiety or fear that participants may have of patient engagement.

As described by the patients and planners who were interviewed, the location of engagement could be a barrier for patients. Community-based agencies may loan or rent their spaces for engagement, which would make patients feel more comfortable because they will likely be comfortable in the space and know how to get to there. Frequently, community spaces also have places for childcare and have accessible transportation.

Another benefit of working with community-based agencies is that it may also be possible to plan engagement around times when people are already at the location. Women who have children often have challenges getting their children prepared and ready to go somewhere. By working with a community-based agency, it may be possible to plan an engagement before or after a regularly held group activity or service access time.

Examples from case studies:

Diabetes Education

The program planners wanted to speak to a variety of patients who had attended the education sessions, so it was important to consider the range of challenges different people might have with attending such an event. The sessions were held during the evening because many participants worked during the day, or, in the case of several of the elderly patients, relied on their adult children to drive them after work. Parking for the sessions was paid for by the program, as the high cost of parking was a known barrier at this site. Punjabi-speaking staff broke down the language barriers to recruit participants and to facilitate the engagement session with Punjabi-speaking participants.

Family Visiting

Community-based organizations played a large role in breaking down the barriers to engaging the various populations. Community-based agencies provided recruitment support and familiar space for engagement. Many also allowed patient engagement to take place before or during regular group meeting times, which reduced the additional time commitment needed to participate. Childcare was available during all sessions when it was needed.

Adding engagement to existing interactions with the population of interest (community or health)

Some of the successes in deeper participation came from engagement processes that were added to existing interactions between patients and practitioners, particularly in community-based health services where patients had recurring appointments²⁸⁻³². In these processes, patients did not bear additional costs to getting to an engagement event. This may decrease the barriers to engaging vulnerable patients because the patient is already in frequent contact, and it may be easier to build trust with the participants. Furthermore, patients may directly benefit from changes to the services as a result of their participation which may be highly motivating. However, there is potential to exclude people who do not access the services when recruiting current patients. Deeper levels of engagement that were not built into service provision had challenges maintaining participation rates over time^{18,20}. For example, a panel of homeless individuals worked on decisions affecting their healthcare through a series of meetings. Despite providing food and opportunities to learn skills, engagement was not sufficiently motivating for participants to prioritize it and participation was often low¹⁸. While adding engagement to existing interactions is useful, many planners have said that engagement should be built into any service delivery model, suggesting an ongoing process of engagement in health services.

Other strategies for reducing barriers

Outside of working with community-based agencies, a few practical strategies can reduce many of the barriers that prevent marginalized patients from participating. Reducing any costs associated with participating will make it easier for marginalized groups to attend. This includes providing childcare, transportation stipends, honoraria and food so that the participants do not need to acquire these themselves^{14,16,17,15,20,18}. Providing flexible opportunities to engage is important, since some marginalized people may have limited life skills, in addition to barriers that result in challenges with keeping appointments and getting places on time^{15,17,19,24}.

Tips For Healthcare Planners:

- Community organizations can provide access to clients who are not accessing health services and help you learn about the barriers that patients experience and how to minimize them.
- Community organizations may have resources, such as space and childcare facilities that patients are familiar with and comfortable visiting.
- Hold engagement before, after, or during times when the population of interest is already at the patient engagement location, such as after a patient group meeting, or embedded within an existing service in an ongoing manner.
- Reduce material barriers, such as childcare and transportation costs.



“So I think it was really good when we do those things that if we are going to give a choice and a voice for the women, we have to make sure it’s one that we can give them. Because sometimes when the advisory group would meet, they would want to have input on things that they just couldn’t ha-... like we don’t have more finances and we don’t have more resources, so we can’t have an outreach worker and we can’t do whatever, but it’s important that wherever there is an ability to help us make decisions within our constraints that we allow that.”

– Healthcare planner

Examples from case studies:

Diabetes Education

The planners had constraints to the scope of their program that meant they could not hand over the decision to the patients, so “Empower” was not an option. They wanted to obtain feedback from patients who had gone through the education session to hear about how patients experienced their current curriculum, so patients were not likely to be highly motivated to spend a lot of time working with planners, so they did not choose “Collaborate”. However, they were in a stage of planning where they had not yet decided on a program design – the planners would be able to shape at least some of the program to address issues that the patients raised. Thus, they chose “Involve”.

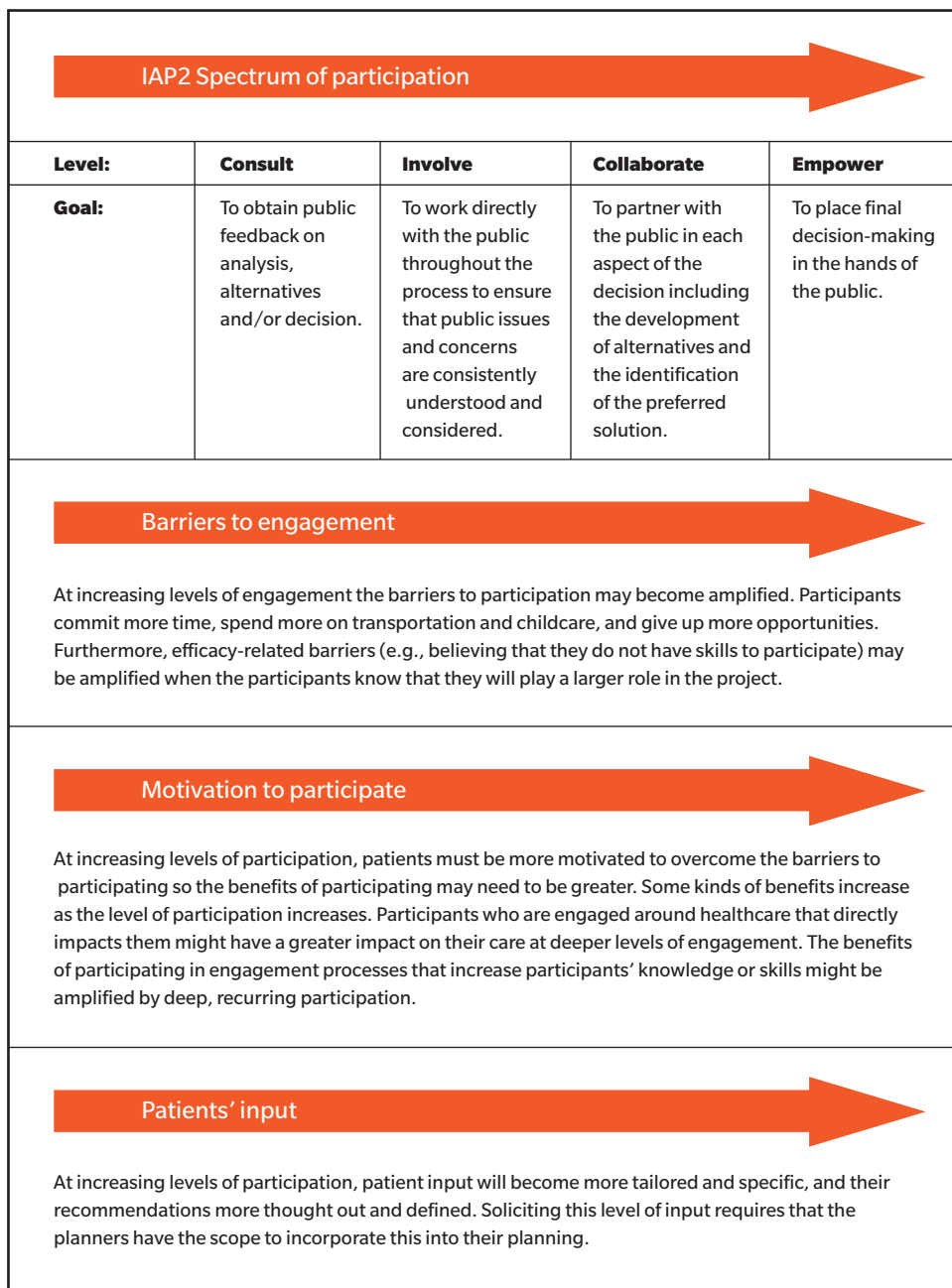
Family Visiting

The planners knew they did not have the ability to hand over the decision to the patients, so “Empower” was eliminated as an option. Since their population of interest was vulnerable new mothers and families, the planners knew many patients had competing priorities and it would be unlikely that they could engage for extended periods of time, so “Collaborate” was also eliminated. “Involve” was chosen as they knew they were at a point in planning where patient issues could be used to inform the planning. Moreover, since mothers are highly affected by the services provided by Public Health Nurses, they were motivated to give feedback and had a lot of ideas to contribute about their experience and how to improve the service. Thus, they chose “Involve”.

4.5 Matching the engagement method to the needs of planners and patients.

Before choosing a specific method, consideration should be given to the level of engagement that is appropriate for both the needs of the healthcare planners and the needs of the patients.

Recall the spectrum of participation[†] from section 2.3. For the purposes of this handbook, we have excluded the “Inform” category as it does not include obtaining any input from the patients and hence cannot truly be considered an engagement process.



[†] © International Association for Public Participation www.iap2.org

Choosing an engagement method

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 (e.g., one could "consult" by conducting surveys for those who have access to the Internet as well as interviews with those who do not and feed the patient input for both methods into program planning).

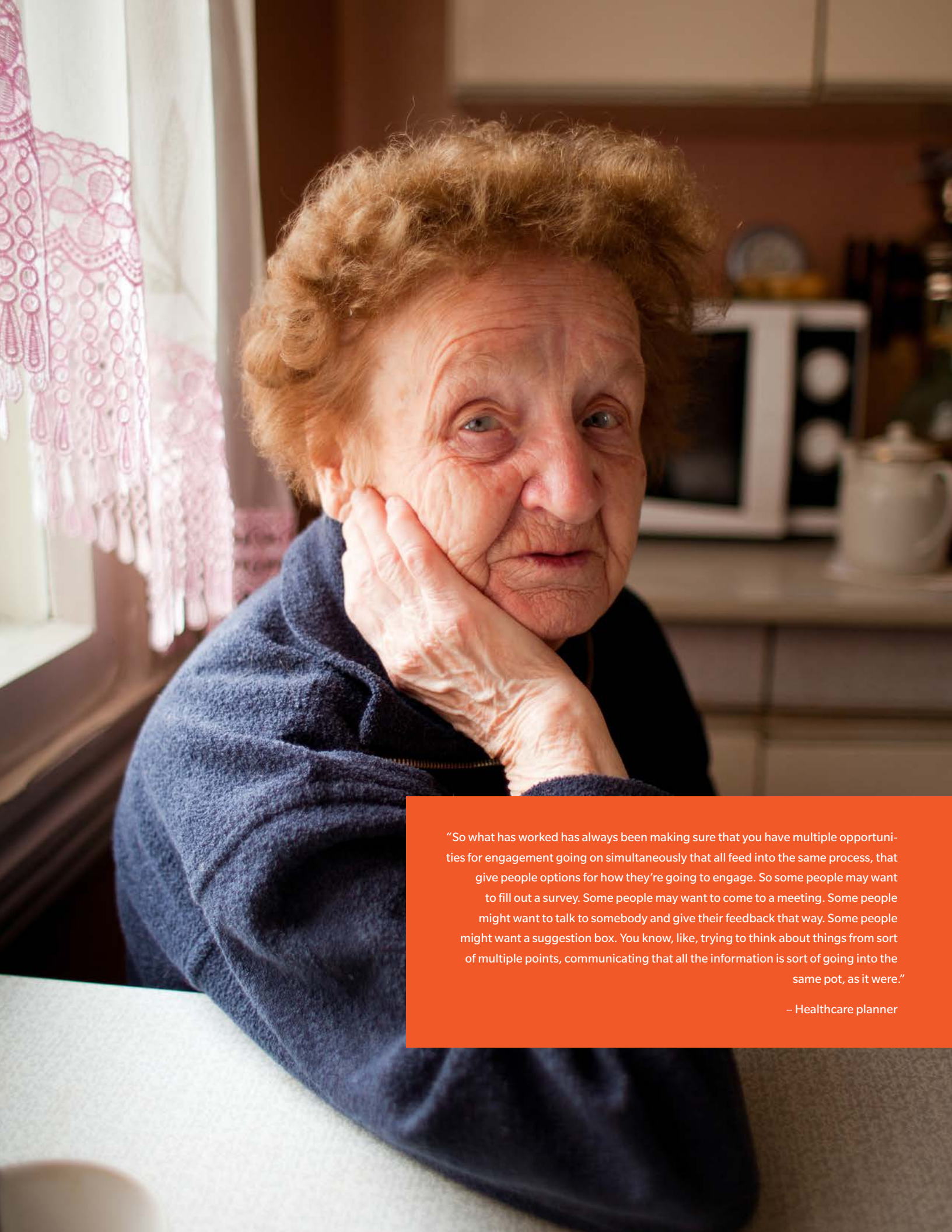
The following is a list of methods that are commonly used for engaging patients, outlining some of the issues related to marginalized patients. (The Appendix includes some suggested reading for further information on each method). Note that this is not an exhaustive list of all engagement methods, and some of these methods can be combined.



Consult

Consult involves obtaining patient feedback on analysis, alternatives, and/or decisions that planners have already created.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Opinion poll	<ul style="list-style-type: none"> a paper or electronic tool with a number of preselected options presented to participants for them to select their preference usually a single event 	<ul style="list-style-type: none"> good for sensitive or controversial topics quick, requires limited commitment 	<ul style="list-style-type: none"> literacy barriers language barriers qualitative information and experiences are limited 	soliciting opinions of patients on specific topics
Suggestion/feedback box	<ul style="list-style-type: none"> submission of suggestions, comments, or feedback at the site of care delivery can ask for feedback on questions about specific topic or ask for any and all feedback 	<ul style="list-style-type: none"> can be anonymous patients can raise issues with existing services good for sensitive or controversial topics allows patients to set the agenda 	<ul style="list-style-type: none"> excludes populations who are not currently accessing the service may not be clear mechanism to address concerns raised 	soliciting broad feedback from clients or trying to learn about issues facing patients that planners might not be aware of
Comment forms and surveys	<ul style="list-style-type: none"> a paper or electronic tool that participants fill out by themselves or with assistance used to gather opinions, feedback, and basic information that is easily quantified. usually a single event 	<ul style="list-style-type: none"> can be anonymous good for sensitive or controversial topics quick, requires limited commitment 	<ul style="list-style-type: none"> literacy barriers language barriers qualitative information and experiences are limited 	soliciting opinions, feedback, and other simple information on specific questions or topics
Forums, public meetings, town hall meetings	<ul style="list-style-type: none"> a large group convenes to discuss their opinions, ideas, preferences, and experiences often includes speakers who present information about the subject followed by audience participation can be a single event or recurring 	<ul style="list-style-type: none"> open door to everyone may be inviting many people can participate potential to have great diversity in the room and for people to hear different perspectives 	<ul style="list-style-type: none"> if open to general public, marginalized groups may be less likely to participate may amplify the differences in participants' abilities in large groups some groups of people are less likely to participate may not be good for sensitive topics 	soliciting input from a large number of people
Focus groups	<ul style="list-style-type: none"> a group of people (5-10) gathered together to discuss questions that are posed by a facilitator used to gather information about opinions, ideas, preferences and experiences not used to build consensus, but rather to collect information usually a single event 	<ul style="list-style-type: none"> can be good for sensitive topics discussion between participants generates new ideas elicits experiential evidence not anonymous or completely confidential 	<ul style="list-style-type: none"> some participants may dominate the discussion determining who gets invited to the focus group can shape the feedback received if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> in-depth information required from the patients. benefits to bringing patients together to discuss the topic are foreseen.
Interviews	<ul style="list-style-type: none"> one person, or a few people, answering questions posed by an interviewer. There is no discussion between participants in group interviews used to gather information about opinions, ideas, preferences, and experiences usually a single event 	<ul style="list-style-type: none"> good for sensitive topics elicits experiential evidence allows more flexibility in location than a focus group as interview can go to each participant 	<ul style="list-style-type: none"> no discussion between participants means less opportunity to flesh out ideas more time consuming for planner to book and conduct individual interviews if language barriers are an issue, interpreter will be required 	<ul style="list-style-type: none"> in-depth information from the patients is required the topic is sensitive sufficient time and resources are available to conduct interviews



“So what has worked has always been making sure that you have multiple opportunities for engagement going on simultaneously that all feed into the same process, that give people options for how they’re going to engage. So some people may want to fill out a survey. Some people may want to come to a meeting. Some people might want to talk to somebody and give their feedback that way. Some people might want a suggestion box. You know, like, trying to think about things from sort of multiple points, communicating that all the information is sort of going into the same pot, as it were.”

– Healthcare planner

Involvement

Involvement means working with patients during the planning process to ensure their concerns are understood and considered in the planning. This means that the planners do not yet have a set of alternatives about which they are asking patients' for their opinion, but rather patients are contributing to creating the alternatives.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Workshop	<ul style="list-style-type: none"> • convening a group of people to work on an issue • if the group is large, the participants are divided into smaller groups • within the workshop, a number of strategies may be used to work through activities • may be single or recurring events 	<ul style="list-style-type: none"> • a number of different strategies can be used to encourage discussion and joint problem-solving • discussion between participants generates new ideas • elicits experiential evidence 	<ul style="list-style-type: none"> • some participants may dominate the discussion • determining who gets invited to the workshop can shape the feedback received • if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> • in-depth information is needed from the patients • potential for patients to help generate ideas for elements of the program or alternative ways of delivering services • benefits to bringing the patients together to discuss the topic are foreseen
Advisory committees	<ul style="list-style-type: none"> • a group of people are convened to provide advice, information, feedback or guidance to a working group. The group can consist of only patients or can be a mix of patients and planners • usually recurring events with the same membership throughout the process 	<ul style="list-style-type: none"> • opportunity for patients to build skills • deepens the understanding of patients' issues • develops a sense of community among participants • participants feel increased investment in the outcome 	<ul style="list-style-type: none"> • requires large commitment • may amplify the differences in participants' abilities • determining who gets invited to can shape the feedback received • if language barriers are an issue, interpreter(s) will be required 	<ul style="list-style-type: none"> • planners can support patients to be involved for the length of time and the depth of participation required
Patient observation of existing services	<ul style="list-style-type: none"> • patients observe existing services in action to provide a patient perspective on potential areas for improvement • patients may interview current patients about their experiences 	<ul style="list-style-type: none"> • values the experiences and perspectives of marginalized populations 	<ul style="list-style-type: none"> • may require a large commitment • may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> • a better understanding of the patient perspective of existing services can inform improvements to the system

Collaborate

Collaborate involves working with the patients in all aspects of the planning, including developing the options and alternatives to be considered and deciding upon the final program.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Participatory decision-making or design	<ul style="list-style-type: none"> patients participate in the decision-making/designing at various stages from the exploration and definition of the problem to developing solutions participation is recurring 	<ul style="list-style-type: none"> opportunity for patients to build skills deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> requires large commitment may require increased knowledge and skills by participants may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> planners can support patients to be involved for the length of time and the depth of participation required to include them throughout the whole planning process.
Patient journey mapping	<ul style="list-style-type: none"> patients and providers come together to map out the healthcare journey as a way to understand the patient experience and then analyze the resulting map to look for ways to improve programs and/or systems 	<ul style="list-style-type: none"> deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> excludes people who do not have access to healthcare services 	<ul style="list-style-type: none"> a better understanding of the journey of a patient through a program or system can inform improvements by identifying the service gaps

Empower

Empower takes this one step further and places the final decision making power in the hands of the patients.

Method	What is it?	Issues for marginalized populations		Consider this method when
		Benefits	Challenges	
Participatory decision-making or design	<ul style="list-style-type: none"> patients participate in the decision-making/designing at various stages from the exploration and definition of the problem to developing solutions participation is recurring 	<ul style="list-style-type: none"> opportunity for patients to build skills deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> requires large commitment may require increased knowledge and skills by participants may amplify the differences in participants' abilities 	<ul style="list-style-type: none"> planners can support patients to be involved for the length of time and the depth of participation required to include them throughout the whole planning process.
Patient journey mapping	<ul style="list-style-type: none"> patients and providers come together to map out the healthcare journey as a way to understand the patient experience and then analyze the resulting map to look for ways to improve programs and/or systems 	<ul style="list-style-type: none"> deepens understanding of patients' issues develops a sense of community among participants participants feel increased investment in the outcome 	<ul style="list-style-type: none"> excludes people who do not have access to healthcare services 	<ul style="list-style-type: none"> a better understanding of the journey of a patient through a program or system can inform improvements by identifying the service gaps

4.6 Supporting meaningful participation & avoiding the practices that silence people.

Even when a patient has made it all the way to attending patient engagement, there are still many ways in which they may be silenced in the process. 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.

Building safety and trust

Across the literature and interviews, both patients and planners emphasized that building patients' trust in the process and ensuring that they feel safe is an important foundation for engaging marginalized populations. Trust is particularly important when the topic is a stigmatized issue; without trust, participants may feel exploited or re-traumatized if the topic draws upon previous traumas.

Across the literature and interviews, patients and planners had a range of ideas for how processes can build patients' trust. As described in section 4.4, working with community-based agencies helps to build a trusting relationship with participants when patients already trust the organization. Furthermore, community-based agencies may be able to facilitate the patient engagement, or teach the facilitators how to appropriately engage with the particular population^{17,25}.

For many patients it is important to have a chance to become acquainted with one another and build rapport before divulging personal information about themselves. The opportunity to meet and share over food is one strategy for promoting this trust and relationship building^{14,16}. In the literature patients said that food demonstrated that planners valued their participation^{14,16,18,20}. This sentiment was echoed by patients in the interviews. This is particularly important for those who give up other opportunities to attend, such as participants impacted by poverty, who give up free meals elsewhere¹⁸.

Facilitation

The patient engagement facilitator(s) will substantially affect participants' 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.

Throughout the interviews, patients said that it was important for the facilitator to be authentic, which they described as being open to hearing what they had to say, and not coming with preconceived judgments about the patients or their experience. Planners echoed this in the interviews and explained that people need to be self-aware and honest with themselves about their ability to engage a group of people that may be very different from themselves. In order to facilitate patient engagement, facilitators may need to be removed from the program. If not removed from the program, facilitators should not be defensive about the subject, and to be open to what they might hear. They also should be capable of relating to the population of interest and able to support patients to explore a variety of topics, including potentially sensitive topics that might make both the patients and facilitator uncomfortable.

Considering all of these issues is important for choosing a facilitator who can best support patients to participate meaningfully.

Engaging unique groups separately

In addition to the facilitator, the other people who are present will have an effect on how each person participates in engagement. In both the literature and interviews, planners explained that normalizing patients' experiences and making participants feel like they could relate to others creates an inclusionary environment where participants felt comfortable to participate.

Grouping participants who share similar backgrounds or similar experiences can make participants feel comfortable^{14,15,16}. In particular, it is important to group people who have similar experiences when the experiences are stigmatized experiences such as trauma, and mental health or substance use issues. It may not be safe for participants to share the experiences of their lives, particularly if other participants are sharing evidence that is not personal. When people have similar experiences and backgrounds, they can draw more support from other participants who can echo and expand upon their experiences.

Similarly, the presence and contribution of professionals can make some patients feel uncomfortable, particularly when all participants are engaged with the expectation that they will each contribute the evidence that is relevant to them. Creating a situation in which patients are expected to present the experience of their lives while professionals present the evidence of objective facts, such as budget numbers or utilization statistics, can make patients feel vulnerable and make them less open to sharing. One planner said that such situations mean that the confidential conversations do not happen in the room, and so the patients' voices are missed. In the literature, some projects did attempt to limit the contribution of professionals through various strategies, yet many patients still felt marginalized in their presence and tended to defer to the professionals believing that they had greater capacity and insight on the issue^{19,20}.

Gender dynamics within groups may also be silencing. When the topic falls more within the purview of one gender, the other may be excluded. Conversely, gender-relevant discussions may not surface when another gender is present. One planner also found that depending on the generation, men tended to dominate the discussion because of the types of employment experiences and related skills men and women of older generations have encountered. Determining whether to engage men and women separately will depend upon the topic, whether it is sensitive in general, or gender-sensitive in the broader context, and on who the people are who are being engaged. The influence of gender may only become visible when men and women are engaged in separate groups. This would also be true for any LGBTQ identifying people. Planners should avoid assuming a topic is or is not gender-sensitive but rather treat this as question to learn more about in a given context.

Examples from case studies:

Diabetes Education

Two separate groups were held, one in Punjabi, one in English. The planners determined that the topic – how the diabetes education supported self-management – was not a sensitive issue, so each group was diverse with both men and women of various ages. The facilitators were health service planners or providers from the program, though they were not the provider who delivered the classroom education. The planners felt it was important for the facilitator to understand the program, so they could discuss specific parts of the program with the patients, but felt that having the facilitator not be the person who delivered the program to those specific patients was important so patients would have less apprehension regarding providing negative feedback.

Patients were provided meals at the beginning, with a chance to chat with one another. Following that, the facilitator led the patients through a discussion to understand what their experience was like and how they had been able to use the education to self-manage their diabetes. The facilitator unpacked the ideas to learn what the patients valued about the education and what more they would want to support their self-management goals.

Creating space for everyone to participate

Regardless of who is present and whether the group is homogeneous or diverse, facilitators may set the stage for everyone to participate by emphasizing the value of hearing from everyone in order to understand the full range of experiences and gain a clear picture of the issue. In order to promote this, engagement sessions should be set up so that patients can share the experiences that they think will be important (this will be covered in greater detail in the following section). Throughout engagement, it is important for facilitators to reflect on whether the process is privileging people with more education, power, influence, or confidence.

In interviews, some patients said that it was challenging to participate in group discussions because they were more introverted and they did not feel like they had the opportunity to contribute. Planners noted that within any selected patient engagement method, providing more than one way to participate will support people who are not comfortable or confident with the dominant participation style. One planner recommended always handing out paper and pens for people to write down private notes or to write down notes for themselves. Projects described in the literature went beyond and provided video, drawing, and a graffiti wall for participants to write their ideas. Facilitators can also play a role in watching people's body language to monitor their engagement and provide opportunities for them to contribute in private.

Throughout the literature other strategies were used to create space for everyone to participate, such as using a game to engage participants²⁹ or working with the participants to develop and articulate their ideas prior to bringing them into a formal setting²⁴. This enabled the participants to clearly develop and articulate their position prior to entering into an environment where the presence of professionals could otherwise silence them.

Unpacking lived experience into evidence

Across the literature and interviews, many planners said that engaging patients, particularly marginalized patients, should be for the purpose of understanding their experiences, preferences, and values in order to plan services that are more patient-centred. This is opposed to many traditional patient engagement models that place patients into ongoing discussions that centre on, for example, resource allocation and scientific evidence.

In order to support patients to share the experiences that they feel are most important or relevant, facilitators can use a patient-centred approach to facilitation, in which they give participants the power to name and define the issues. In the literature, facilitators did this by finding out what was important to the participants and what they wanted to achieve through engagement by surveying them, asking the participants what question should be asked^{17,25}, by asking participants what problems they saw, how they would define it, what solutions they would propose^{14,16}, and asking them to tell stories²⁴. Patients may also benefit by receiving information about the health service planning, although providing research evidence to patients risks sending them the message that the research evidence represents the "truth" and does not leave room for their experience, particularly if their experience runs counter to the accepted evidence²³.

Patient-centred facilitation requires some degree of flexibility with the agenda, as patients may define the issue differently than anticipated. In interviews, planners spoke of the importance of letting patients vent and work through an issue that is their priority before getting to the planners' priorities. For example... This supports patients to express their values and demonstrates respect for their power to define the issue.

Hearing patients' experiences illustrates how services do or do not meet patients' needs, but it may not be sufficient information to plan patient-centred services. Facilitators may need to help patients unpack the issues to come to a better understanding of why the experiences are important to them, what the experiences meant to them, what they prefer and value, and why they value this.

Tips For Healthcare Planners:

- Provide opportunities for people to get to know each other.
- Provide food and a comfortable space.
- Choose a skilled facilitator who the participants will be comfortable with.
- Engage groups separately when there are potential power imbalances between patient groups, or potential for some groups to feel that their experiences are deviant related to other participants' experiences.
- Provide other ways to participate for patients who may not be comfortable with the selected method.
- Focus on understanding the patients' experience. Do not just ask what happened, but ask why it matters to patients.

4.7 Sharing information with participants

Asking patients for their input without providing information, such as the scope of the program being planned, the constraints on the planning, etc., can set up unrealistic expectations for patients. As a result they might feel like their input was ignored if they provided feedback that was outside the scope of the planning. Both the patients and 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. They should not be expected to learn skills or a great detail about the program as a requirement to participate. Patients should receive information about the decision that is being made, including what they will contribute and what constraints and knowledge will affect the planning. This information should be presented in a way that the participants can understand and additional information should be provided at the patients' request.

Examples from case studies:

Family Visiting

The Family Visiting Program seeks to provide care to patients who are marginalized on a variety of dimensions (including poverty, social exclusion, and age) so planners determined that it was important to engage a wide range of vulnerable groups who were potential patients of the program. It was thought that different groups would have unique vulnerabilities, needs and experiences, so different groups were engaged separately so that patients could discuss and unpack their experiences with patients who had similar experiences.

The facilitator for all of the engagement sessions was independent of the actual Public Health Nurse home visiting program. Patients were given meals or snacks and the facilitator provided an explanation of what the proposed program will do and how the patients' experiences would contribute to the planning. Patients were given pens and paper to write their experiences or ideas, to ensure all patients had an opportunity to contribute as they felt comfortable. Following that, the facilitator lead the patients through a discussion to explore their past experiences with Public Health Nurses and to unpack how these experiences empowered them to control their health and their children's' health or how the experiences might have reproduced health service barriers. For example, several parents voiced concerns related to immunizations. As the facilitator unpacked the emotionally charged experiences, patients explained that the underlying issues were the way in which healthcare providers presented care options, provided information, and responded to patients' decisions. This information has broader implications for working with patients who around value-laden issues beyond just immunizations.

Example from a case study:

Family Visiting

When engaging patients for the Family Visiting program, the workshop facilitators presented information about the parts of the program that had already been decided on (e.g., the program would involve Public Health Nurses visiting (in their homes or other location of the client's choosing) pregnant and new parenting families who can use extra support; there would be approximately 16 such visits between pregnancy and the time the child is 2 years old) and asked for their input on shaping aspects of the program such as how nurses can work to develop a good relationship with the clients, what issues they would find useful to work with a nurse on in this type of program, and how can nurses work to best transition clients out of the program as their child reaches 2 years of age.

When providing information to patients it is important to consider a number of factors, including:

- Literacy and education. Information created for the general public should be understandable for those with low reading comprehension, though it is important to know your audience. There are many people in Canada who have lower literacy.
- Language barriers. Materials may need to be translated into other languages for non-English speaking patients and interpreters (or facilitators who speak other languages) may be required for interviews, focus groups or other in person events.

4.8 Reaching out to the population of interest where they are & engaging in environments that work for them

Recruitment

Purposive sampling, a term that comes from research, is the strategy of recruiting participants for their particular social, economic, and/or cultural characteristics and it is the type of sampling that is necessary to ensure engagement from marginalized groups of women and men. In purposive sampling one reaches out to the identified populations of interest, often through community organizations that work with the population(s) of interest. After identifying and locating the population of interest, recruitment information should be presented to patients—or potential patients—in a way that is understandable and shows why engagement is relevant to them.

One issue to consider in recruitment efforts is the notion of representation. For whom does a given patient speak? Are planners interested in their personal, individual experience or have they been identified as a representative of an identified group of patients? 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 as to how to solicit the voices of patients who currently do not access services, as opposed to only engaging those who currently attend services.

Tips for Healthcare Planners

- Community-based agencies that work with your population of Interest can be a valuable resource for planning your recruitment strategy. They can provide advice on effective ways to present the engagement opportunity and may be able to help conduct the actual recruitment.



“Like, if, say, you can have only one patient [...] can you rotate that person in? And also where’s that person’s accountability as well, right? So are they really here representing themselves, or are they here on behalf of a group? And if so, sort of who authorized them to speak for that group, and what are the mechanisms to keep connected to their constituency, you know
– Healthcare planner?”

“And, again, it can be another way of silencing people, that you end up with these people getting sort of identified as community leaders because they’re actually just the people that are easiest for professionals to work with. They’re not actually the leaders in the community because the real leaders in the community come to meetings and yell at people, and they are really unhappy with what’s going on because they’ve seen it happening for a long time, and maybe they don’t have middle-class sensibilities or knowledge of how to comport themselves at meetings, but those people also need a way in, you know?”
– Healthcare planner

Examples from case studies:

Family Visiting

For the Family Visiting program, planners worked with community-based agencies that work with new immigrants and refugees, young mothers, and socioeconomically disadvantaged mothers, both to recruit patients for engagement and to provide familiar, accessible spaces to hold the workshops.

Diabetes Education

For the Diabetes Education program, the patients to be engaged were those who had previously attended an education session, so recruitment was done using the class lists. The healthcare setting in which the education was previously conducted was deemed to be an appropriate setting as the clients were familiar with it; the main barrier to its accessibility was the high cost of parking, so patients were provided with passes for free parking to attend the workshop.

Engagement Environment

The location and setting of engagement play 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” refers to whether the process 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 be appropriate to the engagement method.

The location and other logistics of the engagement should be designed in a patient-centred way. Holding engagement events in a location that is accessible and familiar to the population of interest, rather than in a healthcare setting, can help reduce barriers like lack of transportation or fear of institutional settings. Choosing dates and times that fit into patients’ schedules, providing childcare for patients with children, reimbursing parking or transit costs, and providing honoraria to acknowledge the opportunities given up to attend the engagement are all ways to help reduce barriers. Providing food for patients can reduce barriers – for example, for those of lower economic status and/or for those with time constraints (especially if the event is held near a typical meal time), but it also shows respect and caring to the patients.

Tips for Healthcare Providers:

- Community-based agencies may be able to provide space for engagement events or provide suggestions of appropriate locations and/or other suggestions about the logistics of the event.





“Makes you feel like what you have to say is important because you guys put the time to make us feel as comfortable by doing these little things. Not that it was necessarily needed or whatever, but it just makes you feel that what you have to say is worthy of going that extra mile and putting this whole thing out, you know.”

–Patient, discussing the significance of food being provided

Examples from case studies:

Since both programs decided to have a facilitator who was external to the program being planned, the engagement facilitators provided the respective planning teams with a report on their respective patient engagement events with the themes that arose from the workshops and quotations that illustrated the themes in the patients' own words. These reports were presented to the planners and the facilitators and planners then discussed how these themes could shape the programs. At the time of writing, both the Family Visiting and Diabetes Education Programs are still in the planning phases, so the final decisions on the program have not yet been made, but several suggestions of how patient input can be used to shape the programs are being worked on. The facilitators will continue to work with the planners as they finish program planning to evaluate the effect of patient engagement.

Interestingly, program planners were able to see ways that the patients' voices could influence other programs on which they work. For example, the Family Visiting team saw ways that the patients' voices could shape education for nurses working with vulnerable populations beyond just the Family Visiting program and the Diabetes Education planner saw ways that the findings from engaging South Asian patients could inform a new South Asian health centre that was starting up.

4.9 Incorporating patient engagement into planning: applying the experiences of unique individuals to programs for populations

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.

Some planners are concerned that asking patients for their input on program planning may set up unrealistic expectations if patients suggest things that are outside the budget or scope of the planning. However, having a clear purpose for the engagement (section 4.1) and sharing relevant information about the constraints and opportunities for the planning (section 4.7) helps to prevent this from happening.

Having leadership and organizational buy-in for engaging marginalized patients can help to ensure that the patients' input is applied to the program or service being planned.

It is important to document how the patients' voices, along with other sources of information, affect the planning. When prominent ideas that emerged in the engagement cannot be addressed, it is important to describe why it is not feasible when feeding information back to patients on how their voices shaped the health service (section 4.10).

Tips For Healthcare Planners

- While not every suggestion made by patients may be feasibly applied to program planning, asking patients what is underlying their suggestions can reveal patients' values and preferences. Surfacing values and preferences may help to generate ideas which are feasible ways to meet those needs.
- Ensuring you have a clear purpose about what you are engaging about and that you share relevant information about the program planning process with the patients will help to make the patient engagement process transparent, useful, and respectful.

4.10 Telling patients how their voices shape health service

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.

Planning to provide feedback:

The first step to providing feedback starts during or immediately after the engagement session. The best way to keep participants informed is by the method that is best for them. During or after the engagement session, ask them:

- if you can keep in touch with them to tell them how their input is used.
- how you can keep in touch with them (email, website, phone, etc.), and what their contact information is.
- how you should inform them about the impact of their input (e.g., document, oral presentation, informal chat).

When creating the actual material to report back to patients, the following information should be included:

- an overview of the engagement process
- an overview of the patients' input
- an overview of the decision made
- how the engagement process affected the decision
- if the engagement process did not affect the decision, explain why
- information about what happens next



“So I think I look at it more the other way around. I think the absence of leadership commitment is actually a barrier to doing it because we don’t build in enough time or resources to actually do the work up front. I mean, it’s a commitment to... I mean, if you want to start something in two months, you’re not going to be able to do it. So it’s actually developing an organizational culture around it so that the things you actually need to do, you can do.”

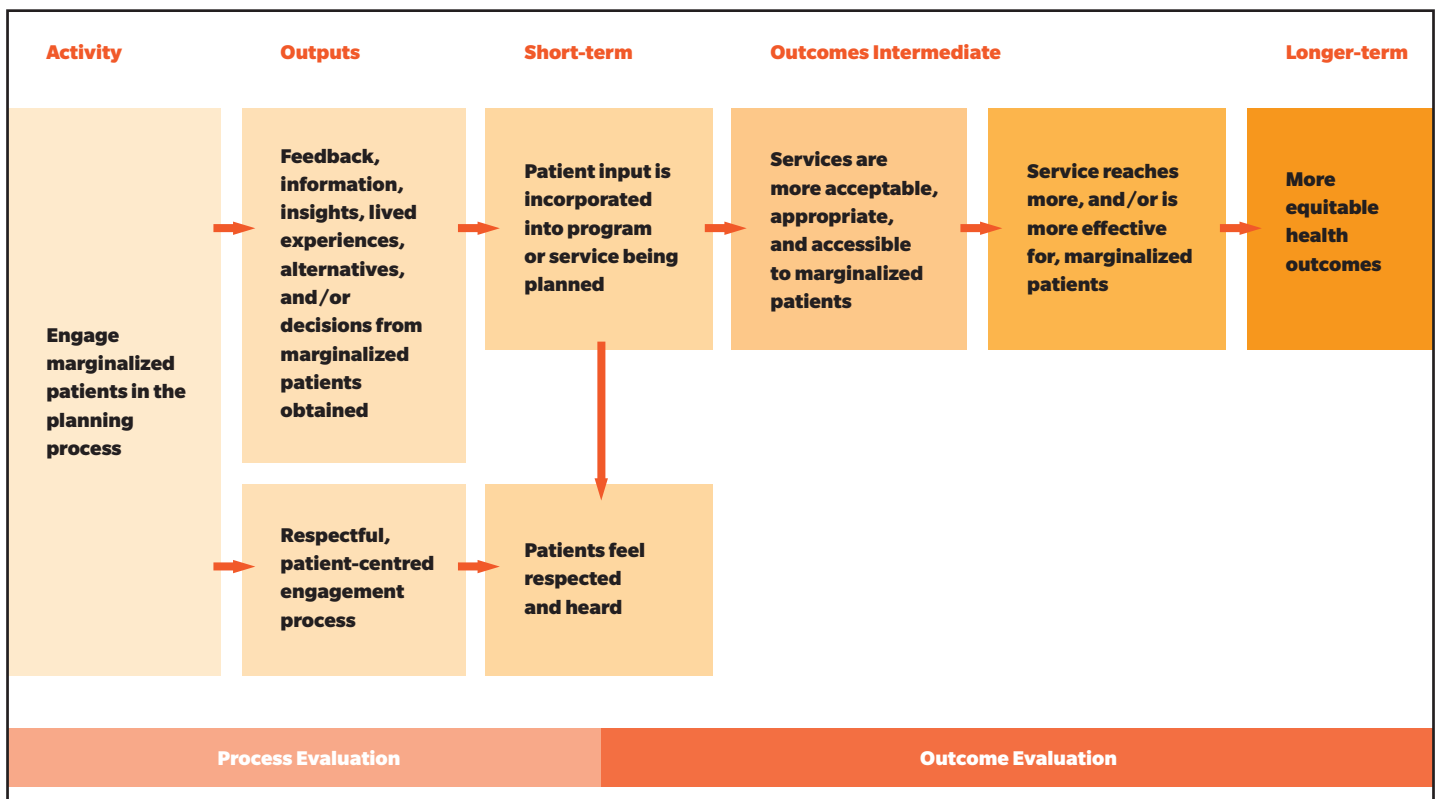
-Healthcare planner

5. 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.

When asked how they would define “successful” patient engagement, patients and planners alike noted that they would consider patient engagement successful if the patients’ input affected the program or service being planned. As one patient said, they would consider patient engagement successful if it was shown “that it actually made a difference, and then you have to know what you’re looking for to make a difference in.” As well, ultimately, patient engagement is intended to affect health services in such a way as to improve health outcomes and, in the case of engaging marginalized populations specifically, to reduce health inequities. One decision maker also noted, “Then you need to assess whether or not you actually met the need it was intended to address.”

The following is a simple logic model describing the intended outcomes of engaging marginalized patients in healthcare planning:



The further to the right you go on the diagram, the longer it will take to see the results. Process evaluation can occur during or soon after the engagement occurs, but it will take longer to see how the information patients provide through the engagement are included in program planning and then how those programs perform over time.

Evaluate the Process

The main evaluation questions for the process are:

- From both the perspective of the patients and the perspective of the planners:
 - What worked well about the process?
 - What didn't work well?
- What would you do differently next time?

Other questions that may be explored in a process evaluation include:

- Were recruitment strategies effective in recruiting participants from the population(s) of interest?
- Were patients satisfied with the process? Did they feel their voices were heard? Did they feel respected?
- Was the information provided by patients used in the planning process? Why or why not?
- What organizational characteristics supported or prevented the incorporation of patients' input into program planning?
- What characteristics of the program being (re)designed supported or prevented the incorporation of patients' input into the program?
- What characteristics of the patients (e.g., gender, age, language, socioeconomic status, etc.) were vital to address in the engagement process and how do the outputs reflect those characteristics?

Evaluate the Outcome

Evaluating the effects of patient engagement entails looking at the effect on the planning, and in turn, how that affected patient care and health outcomes. Standard evaluation methods (e.g., surveys, interviews, focus groups) can be used to address these questions. The main evaluation questions for the outcome are:

- In what ways is the program different than it would have been had patients not been engaged in the planning process?

Other questions that may be explored in an outcome evaluation include:

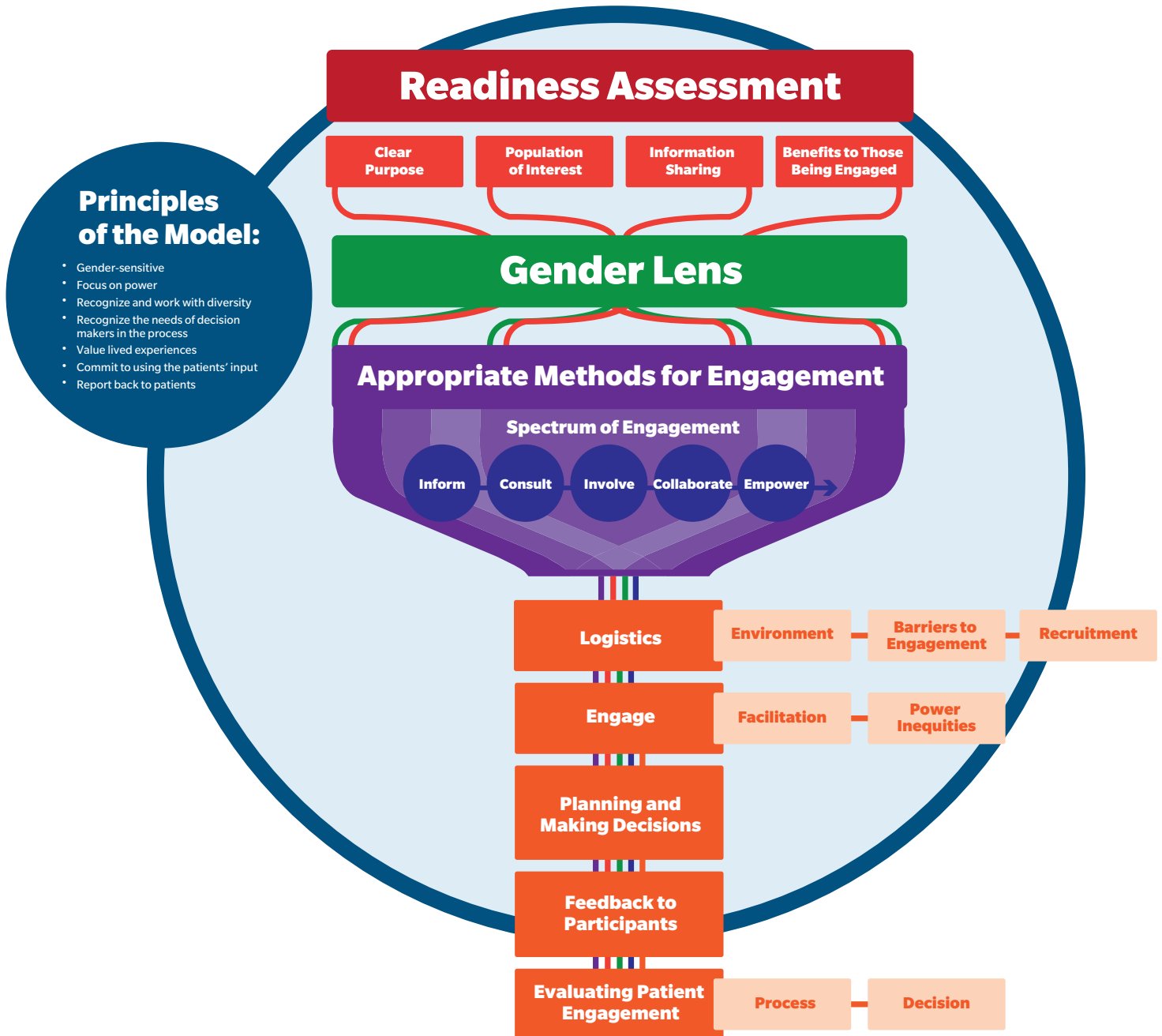
- What issues were raised by patients and how were they addressed in the program?
- Was the patient input used in any unanticipated ways?
- Does the new (or newly redesigned) service better meet the needs of marginalized patients?

Standard evaluation methods (e.g., surveys, interviews, focus groups) can be used to address these questions.

6. The AWESOME Model

To assist health services planners to engage marginalized populations in planning, the lessons from the literature and interviews, as described throughout this handbook, were used to create a model for planning, implementing, and evaluating patient engagement.

The **principles** underlying the model were derived from the project as it explored the various ways in which marginalized populations may be excluded through the patient engagement process.



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.

The **Readiness Assessment** step asks planners to consider if they are able to commit to responding to the input they receive from patients and if they are ready and able to commit the necessary resources to ensure *equitable access* for marginalized populations to the engagement process.

The next set of steps asks planners to consider how marginalized patients will be included, and their voices heard, throughout the patient engagement. These steps are not meant to be linear, but rather will likely be iterative. Planners need to clearly

define why they want to engage marginalized populations in planning their health services (“**Clear Purpose**”) and to think about the power issues that arise from setting the agenda as to why patients are engaged (see section 4.1). They also need to specifically identify the group(s) of patients they should engage (the “**Population of Interest**”) by identifying what subpopulations may have barriers to health and barriers to participating in patient engagement (see section 4.2). In order to participate in a meaningful way, patients need to have information about the ways in which their input can shape the services being planned, as well as the constraints on the planning. Planners need to consider what information will support marginalized patients to engage in a meaningful way, while not overburdening patients with onerous learning requirements that can serve as a barrier to participation (see section 4.7). Planners also need to identify incentives that will motivate the population of interest to participate (“**Benefits to Those Being Engaged**”) (see section 4.3).

The **Gender Lens** prompts planners to reflect on the experiences of diverse groups of women and men and how they 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.

All of the above information is then synthesized to choose a method (or methods) of patient engagement to meet the needs of the population of interest, as well as the needs of the healthcare planners (“**Appropriate Method of Engagement**”) (see section 4.5). This includes the planning and execution of the engagement tailored to the population of interest, including considerations for the environment in which to conduct the engagement (see section 4.8), recruitment of patients (see section 4.8), facilitation that avoids silencing particular groups of patients (see section 4.6), minimizing barriers in the various aspects of engagement (section 4.4), including reducing existing power inequities.

Once input has been provided by patients, planners need to have a way of applying what they learned from patients into the planning process (“**Planning and Making Decisions**”), incorporating it along with other sources of information that are feeding the planning process (see section 4.9). Having set out a clear purpose for engagement and sharing relevant information with patients from the beginning will help to facilitate this process. Providing **Feedback to Participants** closes the loop, demonstrating to patients that their input was heard and had an impact on the planning (see section 4.10).

Finally, it is important to **Evaluate** the patient engagement process and how health service planning was affected by the patients’ input (section 5).

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8. Appendix

Providing guidance on how to conduct the various potential methods of engaging patients in health services planning is beyond the scope of this project; however, the following links are provided to give the reader a general sense of the different methods. Note that many of these resources are gender-blind and diversity-blind (though some make mention of a few considerations with respect to diverse/marginalized/seldom-heard populations), so the learnings from the AWESOME project should be applied when using any of these methods.

Advisory Committees

- A Patient and Family Advisory Council Workplan: Getting Started: http://www.ipfcc.org/advance/IFCC_Advisoryworkplan.pdf

Citizen Juries

- Deliberative Public Engagement: Nine Principles - <http://www.involve.org.uk/wp-content/uploads/2011/03/Deliberative-public-engagement-nine-principles.pdf>
– includes a number of deliberative public engagement methods, including citizens' juries, deliberative workshops, summits, citizen panels, etc.

Comment Forms and Surveys

- Survey Research: <http://www.socialresearchmethods.net/kb/survey.php>

Focus Groups

- Qualitative Research: Introducing focus groups. BMJ 1995;311:299: <http://www.bmj.com/content/311/7000/299>
- Focus Group Fundamentals. Iowa State University – University Extension: <http://www.extension.iastate.edu/publications/pm1969b.pdf>

Forums, Public Meetings, Town Hall Meetings

- Conducting Public Forums and Listening Sessions: <http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-public-forums/main>
- Town Hall Meeting Protocol: http://www.ncspfsig.org/Project_Docs/Town%20Hall%20Meeting%20Protocol.pdf

Interviews

- Health Service Co-Design – Tool 3d: Patient Stories: http://www.healthcodesign.org.nz/03_explore_d.html

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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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