

The Patient and Health Care System: Perspectives on High-Quality Care

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Introduction

In health care, we are humans taking care of other humans. Patients place their trust and their lives and money in the health care system, counting on us to treat their illnesses and help them get healthier. Health care professionals have different roles, as physicians, nurses, administrators, quality and safety professionals, policy experts, lawmakers, and researchers, to name a few, and for the most part, they are united by an overarching desire to heal, provide care, and save lives.

This book is about the interface between the patient and the health care system, where, as they say, the rubber meets the road. This interface between the patient and the health care system is an extremely complicated place where all the good intentions, expertise, and actions come together. In spite of the existing knowledge on achieving health care quality and high-value care, oftentimes we have trouble defining what we should aim for in health care, what our true north is. The metrics we have in place to measure quality, safety, and value do not do sufficient justice to what we seem to be looking for, as professionals, consumers, and stakeholders. If we aim to provide high-quality care that is accessible, affordable, and equitable for everyone, then we ought to have a more inclusive conversation on how to improve health care delivery.

In this book, we have a series of diverse voices and perspectives from those who strive to improve health care delivery and dedicated their careers to the same. This book is written keeping in mind those who have a stake in improving health care. One could easily argue that it includes everyone. The authors built on ongoing conversations and solutions in health care and presented original, creative, and thought-provoking perspectives that go way beyond how topics in quality, safety, and value in health care have been historically treated. The chapters have great diversity in content, style, and perspective, and each stands alone by itself. Readers can elect to read the chapters either in random order or cover to cover. While some authors specifically included a call for action to patients, physicians, nurses, administrators, payers, and policymakers, everyone universally has challenged the reader to reflect more and engage more in solving the problem of health care in a meaningful and reasonable manner. The main goal is for the reader to think about how s/he can contribute to how we solve the problem of health care, which right now is bigger than the solutions we have been able to come up with thus far. There are many individuals who would not be alive or healthy today if not for our state-of-the-art health care system. Yet, it is also true that our health care system has failed some

individuals in one way or another. Because of where the authors live and work, this book is about health care systems in the United States. However, many principles apply to health care systems everywhere in the world.

If the topic of the book sounds complicated, it is because it is. Hence, this book hopes to target key issues at stake and nudge us towards potential actions that each of us can take.

Finally, we would like to highlight the connections among people with diverse professional interests that made this book possible. This book may not have begun if Nadina Persaud from Springer Publishing had not approached Pranavi V. Sreeramoju for a book idea. Pranavi V. Sreeramoju in turn reached out to Alexis Snyder, Stephen Weber, Lynne Kirk, Gary Reed, and Beverly Hardy-Decuir with the book idea and together they shaped the focus and scope of the book. Pranavi V. Sreeramoju uses her training and experience in infectious diseases, health care epidemiology, and, more recently, quality and finance to help improve health care delivery for patients in a large academic medical center and blogs to increase awareness on issues in health care. Stephen Weber has expertise in infectious diseases and health care epidemiology and is a strong advocate for greater leadership in health care delivery improvement as reflected in his chapter on the voice of the physician as well as the epilogue. Alexis Snyder is Patient Family Advisor and Engagement Specialist who is a relentless advocate for making health care delivery as well as outcomes research more patient-centered and more inclusive of the patient and family voice.

Gary Reed led health system quality efforts for many years and currently leads medical school colleges as well as education on quality and safety at a large academic medical center. Lynne Kirk has a wealth of experience in medical education, patient-centered care, and leadership in organized medicine. Last, but not the least, Beverly Hardy-Decuir contributes rich experiences as a nurse and a professional in quality. Each of the authors were identified through existing connections, and they wrote the chapters with the sole motivation of sharing their thoughts and ideas on how to improve health care delivery and received no material compensation for their contributions. Each author's personal and professional experiences with health care are in some way reflected in the chapters. This book is a collective attempt to frame the conversation and use our connections to improve health care delivery. We are thankful to Dhanapal Palanisamy, ArulRonika Pathinathan, Henry Rodgers and Cecily Berberat for their assistance with production and development of the book and to our families for sparing some family time to let us put this together.

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Part I
Voices



Voice of the Patient

1

Alexis A. Snyder

The human voice is the most beautiful instrument of all, but it is the most difficult to play [1]

—Richard Strauss

“Nothing for Us without Us”

A powerful phrase that can be heard from patients, family members, and patient advocates all across our nation. But what exactly does this mean? Let’s first take a closer look at the definition of patient-centeredness. While there may be multiple ways to describe patient-centered care, the National Academy of Medicine defines patient-centered care as, “Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions [2].” To respond to this definition, health care systems have a responsibility to identify what those preferences, needs, and values are, and what is most important to whom, when, and under what circumstances. But how can health care systems achieve this surmountable task? The answer is both simple and complex: ask the patient.

When we talk about patient-centeredness, it only makes sense that the patient, who is at the center of the care, be included in all aspects of their care. After all, systems can’t practice “patient-centeredness” without the “patient.” Patients need to have a voice in the systems that affect the care they receive. But often the patient voice goes unheard. Perhaps because they are afraid to speak up, or too ill and/or devoid of the energy to participate in their care. Maybe there is a cultural piece at play, or a belief system that the professionals know best. Perhaps the patient is skilled at self-advocacy, but systems are not in place to incorporate their voice.

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Whether the patient and their caregivers are willing and able to share their voices or not, the health care system must empower their voices and allow them to come to the forefront. We cannot determine what is most important to patients and families when we don't ask.

The patient voice is vital to understanding the individual needs of the patient in the clinical setting and even more crucial to determining if the programs and services delivered to patients and families work, and for whom and when. We all know the saying... "the best laid plans..." and how this sentence ends. We can incorporate this into health care and patient engagement. Health systems cannot run on assumptions about what patients want. Clinicians, administrators, and health care systems may have the best of intentions when planning and implementing services for patients, but without patient input into these structures and designs, systems may fail at meeting patients' needs, thereby increasing costs. Patient engagement in health care can improve the effectiveness and efficiency of services received. Hospitals that engage patients in care have reduced lengths of stays, decreased adverse events, and even high employee retention rates [3]. Patient and family involvement in decision-making has been associated in primary care settings with improved health status and increased efficiency of care [4].

Incorporating the Patient and Family Voice

How to best incorporate the patient and family voice in health care is often seen as a challenge. How to gather information and include it in practice change and improvement can vary by institution. To understand how to include the patient voice, it's important to first understand that "patient voice" goes beyond the patient and can include family members, caregivers, and even the larger community. Hearing all these voices, and bringing them to the table, has been a long process over the last two decades. Let's take a brief look at some of the milestones that brought the patient voice into health care. Let's start with Patient and Family Advisory Councils, otherwise known as PFACs, which comprise patients, family, and staff members who work together to improve the patient experiences, and help implement change.

In 1998, Dana-Farber Cancer Institute in Boston, Massachusetts, inceptioned one of the first ever Patient and Family Advisory Councils, which became the national model for health care institutions to create PFACs and, therefore, improve the patient experience and ensure patient- and family-centered care [5]. In 2006, the World Health Organization (WHO) created a specific program area within their Patient Safety Program called Patients for Patient Safety [6]. That same year, a Massachusetts statewide consumer health advocacy organization, Health Care for All, in Boston, Massachusetts, organized the Consumer Health Quality Council to advocate for health legislation that ensured Massachusetts health care consumers receive health care that is, "efficient, effective, timely, safe, and patient-centered [7]." For the next 2 years, the council worked on legislation to advocate for an omnibus health care quality improvement bill that led to a number of provisions of the bill becoming law. One of which included a law, enacted in 2008, which required all

Massachusetts hospitals to create and maintain a PFAC. This was followed by a regulation enacted in 2009, from the Massachusetts Department of Public Health (DPH), regarding all Massachusetts hospitals to establish a PFAC by 2010 [8]. As of 2015, there were 97 hospital PFACs across Massachusetts [9], a standard that has set an example and helped the growth of PFACs nationwide. During this same time, the WHO developed a formal position that defines patient and family engagement as, “essential for patient safety and quality improvement efforts [6].”

Today, PFACs are a well-recognized best practice, not only in the hospital setting but in primary care as well, with many systems implementing patient-specific councils in different disciplines such as Pediatrics and Behavioral Health. With agencies such as the WHO, Health Care for All, and others beginning to emphasize the importance of partnering with patients for quality improvement efforts, the role of patients and families began to take on a new meaning, while empowered to use their voices and share their perspectives in a unique way.

Achieving Authentic Engagement

Implementing a PFAC is a move toward patient-centeredness, but it alone does not make a hospital or health care setting patient-centered. To be truly patient-centered, health systems must authentically and fully engage patients and families. Adding a patient and family advisory council shouldn't just check a box on list, or invite patients to weigh in on mundane tasks, such as choosing new paint colors for a waiting area, or providing feedback on the quality of the food and menu choices. While these less meaningful tasks can serve a purpose, they alone do not fully engage patients and allow the health systems to fully utilize, and recognize, the valuable contributions of patients. Partnering with patients to their full potential, in meaningful ways, allows their voices to positively impact program and policy decisions that affect the care they and others receive. Some systems are very good at incorporating the patient voice into planning and development, and implementation and evaluation, while others are still learning. When I think about these inconsistencies in practice, I am reminded of a phrase coined by my daughter's physical therapist to describe the fluctuations in her neuromuscular system, “consistently inconsistent.” “Consistently Inconsistent” seems an appropriate term for how health systems engage patients.

Inconsistencies over how to incorporate the patient voice often exist over confusion between patient engagement and patient experience. Patient experience is defined by the Beryl Institute as, “the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care [10].” In other words, the perception of what the patient is experiencing with every encounter with the health system, be it a phone call, an office visit, and so forth. Every encounter is affected by interactions with staff and providers. Patient engagement can be defined as “patients working in active partnership at various levels across the health care system to improve health and health care [11].” To be truly engaged, the patient must actively participate in their own health care, and/or work to improve the experience for others.

Here we can see how the two concepts, experience and engagement, go hand in hand. When a patient has a poor experience or encounter with the health care system, they may no longer engage. Without engaging, the patient cannot help improve the experience for themselves or for others in the future. Both patient engagement and patient experience play an important role in incorporating the patient voice. Both are necessary to make health systems patient-centered, and components of each are associated with “making it work” for the patient. Yet, often, systems rely on only patient experience measures, such as HCAHPS (Hospital Consumer Assessment of Health Care Providers and Systems) scores [12], to evaluate how the system is engaging patients, and this is where it goes wrong. Measuring patient experience alone does not fully engage patients, and the two are absolutely dependent on each other. Without evaluating the experience of the patient, systems cannot determine where improvement is needed and where to engage patients in process improvement efforts.

Achieving success in patient satisfaction and process improvement relies on both measuring experience and employing active engagement, both of which require the patient voice. The differences between passive and active engagement also play a role in effective communication in engagement. Passive engagement doesn’t necessarily require the presence of patients, and is more about measuring patient experience, such as participating in an online survey. Active engagement, however, requires the presence of patients to interact with the system and to engage with available resources to promote change. So how do health systems include the patient voice and achieve authentic engagement? First let’s take a look at what I will call the three “E’s”.

Empower, Engage, and Emplace

Empower patients to take an active role in their own health care. Rather than ask questions that passively engage the patient, such as “How do you feel?” or “How was your visit?”, ask patient-centered questions that promote active engagement, such as “How can I best help?” and “What can we do differently?” Support patients and their families by valuing what they have to say. If you are going to ask what is most important to them, be ready to hear the answer. When patients feel respected and listened to, they feel empowered to actively participate in their own care. Empower patients to advocate for themselves, and if they are able for others, so that they may help make the experience for others more positive. Create a supportive environment where patients and their caregivers can be listened to without being judged and are valued for what they have to offer. When patients feel valued for their opinion, they realize they have a voice that can be used to make a difference for others as well. Listen to what the patient or family member is telling you; truly listen. Don’t dismiss concerns over symptoms. Patients are the experts of their bodies; providers are the experts of medicine; work together. Providers and health care systems can best help patients in their times of need when patients, as well as their caregivers, are fully included in decision-making. Collaborate with patients 1:1

through shared decision-making to promote autonomy, and consistency with treatments, while creating stronger and more confident patients who have a voice in, and some control over, their own health. Believability and trust go a long way. It is very difficult to imagine what someone else is going through when it doesn't directly affect us. As the old saying goes, "You can't understand someone until you've walked a mile in their shoes." This is why we truly need to listen to patient stories, learn from them, and ask how we can improve next time. And this goes for patients of all ages, even children.

Samantha,¹ age 11, loved to read. She would read book after book, sometimes for hours at a time. Then one day, she stopped reading. Not only did she stop reading for fun, she stopped reading for homework too. Already under the care of an ophthalmologist for other medical reasons, her mother scheduled an appointment for Samantha. At the appointment, Samantha received a clean bill of eye health. Samantha informed the doctor that she was having some difficulty reading. The doctor who had just given Samantha a brief vision test, seemed surprised. She stated "I don't see any medical reason for that" and "You are too young to be needing reading glasses." Samantha still insisted she could not see the words on a page well, but her voice went unanswered. With her mother's persistence, the doctor did one more vision test. Nothing new was revealed, and the doctor was ready to send Samantha home telling her mother "there is nothing wrong with her vision, it's likely an excuse to not complete her homework."

Knowing this was not the case, Samantha's mother persisted again, pointing out that Samantha loves to read, has stopped, and there must be a reason. The doctor hesitated for a moment, but then suggested Samantha might like to see a specialized optometrist who could perhaps provide some exercises to help eye fatigue, but she was not sure it would make a difference. A couple of weeks later, Samantha was seen by the optometrist, who uncovered that Samantha's eyes were having difficulty converting between seeing at a distance and then up close; she diagnosed Samantha with Convergence Insufficiency, a disorder in which the eyes are unable to work together to look at nearby objects, causing double or blurred vision; something that isn't typically detected in routine eye exams or vision screenings [13].

Samantha received an eyeglass prescription that allowed her eye muscles to relax and enable them to more easily adjust between near and far, and soon thereafter she was enjoying reading again. Sometimes health problems are not obvious, as was the case with Samantha. There is a metaphor in the patient world that says, "When you hear hoof beats, don't assume to find a horse, you just might find a zebra." In other words, don't assume the obvious, and take the time to think outside the box, because even though it might sound like a horse, it might actually be a zebra.

Good doctor-patient relationships foster positive experiences that lead to positive engagement. Relationships with a health system actually start before the patient even walks through the door. It starts with the first person the patient has contact with and, if we are talking about an outpatient visit, for example, the first point of

¹The patients' stories in this chapter are based on real-life events, only the names of the patients have been changed to protect their privacy.

contact is likely with a support person over the phone. After that, the experience continues with the front line staff at the appointment. This interaction can actually make or break an appointment. If the patient has a poor experience with the phone support or the front line staff in person, no matter how much the patient likes the provider, it may still reflect negatively on the overall experience, leaving the patient to consider going elsewhere, where they may feel more respected. It's no coincidence that "hospital" can be found in the word "hospitality," which by definition means "the quality or disposition of receiving and treating guests and strangers in a warm, friendly, generous way [14]." While this is sometimes hard to do, it must be done to establish a good rapport with the patient. No matter how much the patient values the provider, the value can be diminished, and as we learned earlier, poor experience can lead to poor empowerment, and poor engagement.

Engage. What does engagement mean to you? One good definition to consider is "A mutually beneficial interaction that results in participants feeling valued for their unique contribution [15]." If we use this definition, how can we apply this to patients and their interaction with the health care system? The answer is start with engaging patients, caregivers, and the larger community often and in meaningful ways. Create an atmosphere of trust and value what patients and families have to offer. Collaborate with patients to their fullest potential by engaging them in activities that make a real difference; activities that rely on the patient perspective to support and enhance the goals and outcomes of the project, as well as the overarching goals of the health system—a unique contribution that is "mutually beneficial."

If we think about active versus passive engagement, and apply it to this definition, we may really be defining authentic engagement as moving across a path from low involvement or inclusion, to high engagement and partnership. This spectrum of engagement can be looked at on a continuum from low level, where patients are involved by merely informing them, to a high level of engagement where systems partner with patients to achieve a mutually beneficial interaction. This continuum of engagement has been defined by Health Canada, the department of the government of Canada with responsibility for national public health [16], as part of their tool kit for public involvement in decision-making [17], and it can easily be applied to achieving authentic patient and family engagement (Fig. 1.1).

This model of involvement and decision-making gives us a clear framework that helps explain the difference between involvement and engagement and how both have a place in how health system decisions are made, to what degree the patient voice is able to have an influence, and how much influence on those decisions and, ultimately, on outcomes. We can also use this spectrum of engagement to define whether health systems and providers are delivering services *TO* patients, *FOR* patients, or *WITH* patients, a concept more simply known as *TO FOR WITH*.

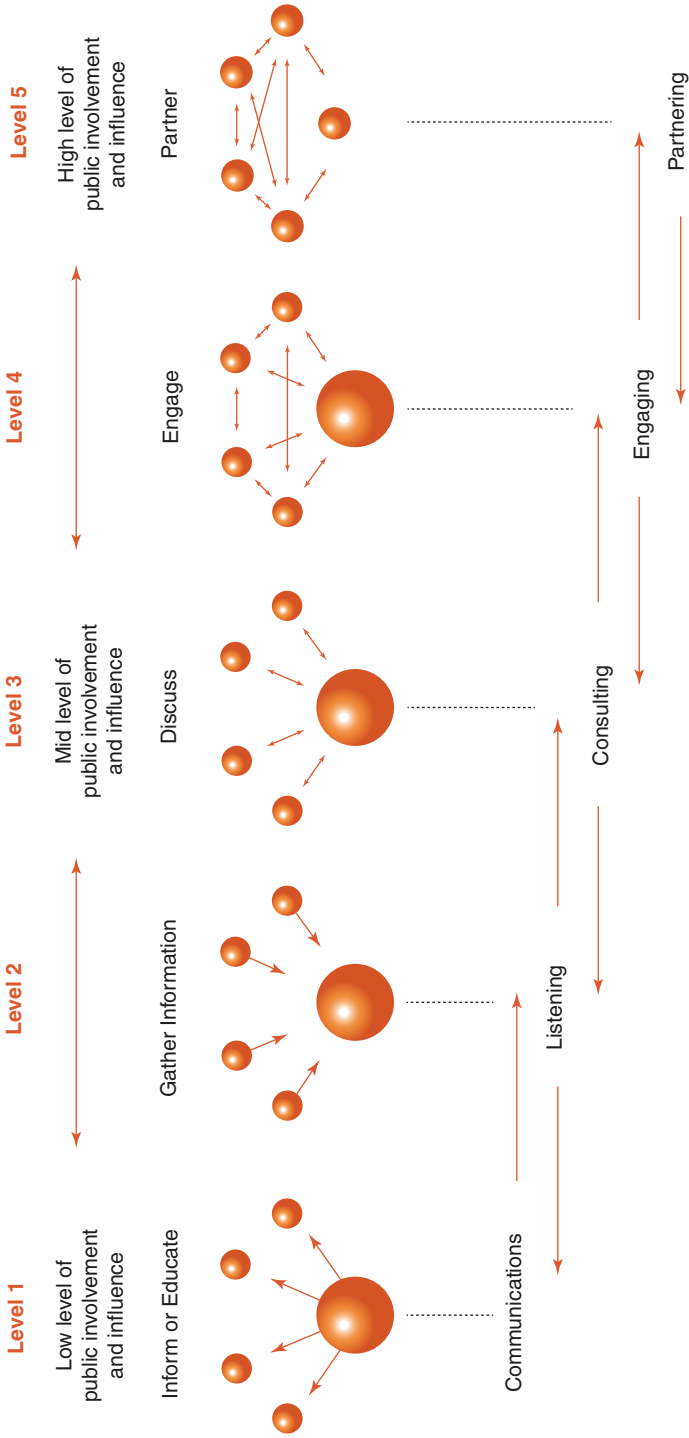


Fig. 1.1 Health Canada's public involvement continuum. (Adapted from Patterson Kirk Wallace as cited in Health Canada 2000)

***TO* the Patient is a Nonexistent to Low Level of Engagement**

At this level (level 1), the patient is mostly involved or informed rather than engaged. Information is delivered *TO* the individual patient and family via fact sheets, patient-care guides, or advertisements, such as the pharmaceutical commercials that flood us with a lot of information in a very short amount of time. This level of involvement with PFACs and other patient groups only notifies and explains processes or programs that are already in place, where decisions have already been made. At this level of passive engagement, or really involvement, the patient voice is nonexistent and does not have any influence on decisions, policies, or outcomes.

Systems that listen *TO* the patient begin to move from involvement to a low level of engagement:

At this level (level 2), health care systems and providers gather information from individual patients and families by asking passive questions about their symptoms and/or concerns, “What’s bothering you?” At this level, information is gathered from larger groups of patients and families via public comment opportunities, focus groups, questionnaires, and surveys. The patient voice is present at this level, but it does not necessarily influence decisions, policies, or outcomes.

***FOR* the Patient is a More Moderate Level of Engagement**

This level (level 3) encourages discussion *FOR* the benefit of patients and families, where health systems and providers have a mutual interest in an issue that may or may not lead to a mutually beneficial solution. At this level, individual patients may be encouraged to have a discussion about their symptoms, and/or concerns, with the use of more active questions, “What can we do for you?” Larger groups of patients can participate in advisory councils, advisory boards, and round table discussions that focus on what they can do *FOR* patients and families. The patient and family voice begins to be more integrated into what can be done *FOR* the patient, and can be passive or active. The voice at this level may or may not have influence on decisions, policies, or outcomes.

***WITH* the Patient Begins a Higher Level of Engagement**

At this level (level 4), health systems and providers engage *WITH* individual patients and families to set goals and make shared decisions. At this level, larger groups of patients and families can be seen in work groups and committees, where mutually beneficial goals are worked on *WITH* patients, but which goals to work on are not necessarily decided by patients. The patient and family voice is actively present, and it will likely have an influence on decisions, policies, and outcomes.

Partnering *WITH* patients to develop solutions is at the highest level of engagement:

At this level (level 5), goals are conceptualized together, and set out to achieve a mutually beneficial solution through collaboration. The system and patients work side by side, co-designing plans, and even co-investigating research. The health system and patients agree on best ways to implement plans into practice. The voice

is most active and influential at this level, where success depends on collaboration and partnership.

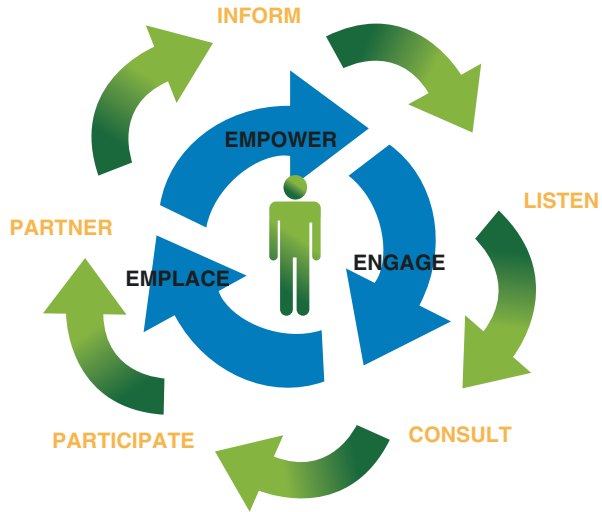
Successful examples of patient collaboration can be found in numerous partnerships between patients and hospitals. A PFAC member, and patient, mentioned during a meeting how much better it is to heal when it's quiet—noting that the in-patient areas of the hospital are noisy places where patients cannot rest at night. The PFAC worked with the hospital to come up with a set of best practices to quiet the patient areas at night. Not only did the new practices lead to an increase in patient satisfaction, other hospitals took note and followed suit. At a pediatric hospital, the parents of the PFAC noted that the children who were having teeth surgically removed in the outpatient dental unit were sad when returning home without a tooth to put under the pillow for the tooth fairy. The PFAC worked with child life representatives of the hospital to provide small surprise gifts from the “tooth fairy” left for the children in the recovery room.

Emplace plans into practice. Sometimes even the best laid out plans seem to fall wayside for lack of follow through. Such as “weren't we going to start...” and “oh yeah, we never let so and so know...” Other times, plans cannot be implemented for a number of reasons, and that's ok, but it is not simply enough to ask for patient feedback and input. You need to circle back, and let folks know what changes are being worked on and how they will be put into practice, as well as when plans cannot be implemented and why. If you are going to encourage and welcome the patient voice, you need to close the loop on the engagement cycle.

Communication is key. Think about the last time you asked a friend or family member for help or their advice. They may have helped you with an important decision or helped lay out a plan to tackle a problem. Whether you chose to listen to their advice or follow through with the plan or not, one thing is almost certain. The next time you spoke with them they likely asked how things panned out. You were likely eager to follow up with them, and thanked them for their assistance. Your friend was probably happy to be informed and felt valued; and the next time you need help, they will likely be happy to assist. It's human nature to be curious about a turn of events, but, more importantly, people need to feel valued for their opinion and thanked for their efforts. The same is true when engaging with patients and families. Even the highest level of engagement depends on communication and follow-up. When patients are engaged in a plan or project, and given an opportunity to contribute their voice, they feel valued. However if they never hear back on how their voice may have helped influence change, the value gets lost and they are less likely to use their voice the next time it's needed.

If we look back at the public involvement continuum from Health Canada again, we see that true engagement does not move on a spectrum from left to right only, it goes back from right to left again. Authentic engagement moves from informing, to listening, to consulting, to partnering, but partnering successfully is contingent on

Fig. 1.2 Circle of engagement. (© Alexis Snyder, 2018)



consulting, listening, and sending information back again. So, perhaps, another way to look at this continuum of engagement is not from left to right and back again, but as a continuous circle of events, all connected to the 3 E's: Empower, Engage, and Emplace (Fig. 1.2).

Common Obstacles to Patient Engagement

Understanding how to best engage with and hear the patient voice is only the beginning. To truly have the patient voice represented across all aspects of the health care system, the obstacles that prevent it from happening need to be understood. Even when providers and health systems have the skills and tools in place to achieve authentic engagement, the patient voice may still be difficult to hear, or altogether muted.

One of the first and, sometimes, most prominent stumbling blocks is poor communication. As touched upon earlier, a provider may have communication skills and a wonderful rapport with their patient, but the channels to foster that communication may be in need of repair.

Take, for instance, Mary.¹ Mary is experiencing gastrointestinal (GI) pain and is referred by her GI provider to a sub-specialist and instructed to call and make an appointment. The next day, Mary calls the specialist's office and is informed by the scheduler that patients are not allowed to switch physicians and she will not book the appointment. Mary tries to explain that she was instructed to call, but her voice goes unheard. Mary reaches back out to the first specialist, and has a difficult time getting in touch with them, leaves messages with their scheduler, and so on and so forth. For days nothing gets done about scheduling the appointment;