INTRODUCTION

Hearing the voices of patients, families and caregivers is essential to transforming and improving the healthcare system. In 2010, the Canadian Foundation for Healthcare Improvement began funding teams to implement small-scale projects aimed at improving the quality of care and effectiveness and efficiency of health services. Key to all projects was engaging patients in the design, delivery and evaluation of the projects. Funded teams were required to evaluate their patient engagement processes, outputs and outcomes, including any impact on the quality, effectiveness, or efficiency of services. In May 2012, six months prior to the end of their two-year funding cycle, the first cohort of teams came together to articulate lessons learned from these projects. This series of briefs presents the themes and shares lessons learned to date and, where possible, provides concrete examples of successful strategies.

One of the themes that emerged from the discussion is the importance of adequate preparation in advance of implementing patient engagement strategies. Currently, when preparing to implement change strategies, healthcare organizations tend to include patient engagement as an afterthought. At best, such approaches lead to strategies that are not substantively informed by patient perspectives; at worst, they alienate the very patients the strategy is trying to address.

The Canadian Foundation for Healthcare Improvement is dedicated to accelerating healthcare improvement and transformation for Canadians. The Patient Engagement Projects initiative supports project teams to improve the effectiveness and efficiency of health services by engaging patients and families in their design, delivery and evaluation.
PROMISING PRACTICES FOR PREPARING FOR PATIENT ENGAGEMENT

A commitment to meaningful patient engagement requires attention from the very beginning of the preparatory process. This involves several key steps:

1. KNOW YOUR ENVIRONMENT

An evaluation and environmental scan serves to identify key needs as they relate to patient engagement. Specifically, such a scan can provide an understanding of system- and practice-level factors that can affect implementation of a strategy and identify the key stakeholders who need to be involved—a task that is seldom as obvious as it might seem. Additionally, having the key stakeholders involved in the decision-making process can also be beneficial in avoiding outrage, even if a decision made would have been exactly the same without their involvement.

The evaluation and environmental scan is critical for:

- making a case for adequate resources;
- developing specific strategies; and
- considering a process for implementation.

Strategy in action

The BC Ministry of Health\(^1\) wanted to train a diverse group of patients and providers to be effective partners in health system redesign. Partners in the team conducted surveys and interviews to determine key learning areas for this province-wide initiative. As a result, it developed three learning modules, one each in English, Mandarin and Punjabi. The modules include a healthcare system overview, communication skills and methods to engage in healthcare redesign.

2. RESOURCE ADEQUATELY

Developing an effective patient engagement strategy requires a substantial investment of time and energy from multiple stakeholders. It is not a “top-down” undertaking, but rather a partnership, one in which all participants must be heard and feel valued for their contribution. All stakeholders need a clear understanding of the expectations and parameters of their involvement. Mechanisms are needed to support the expression of a diversity of opinions in a collaborative way. The resources required to achieve these measures as the foundation for meaningful engagement are often underestimated.

Strategy in action

The Toronto Rehabilitation Institute-University Health Network\(^2\) used a structured consensus-building q-sort methodology (Parker et al., 2006) that involved patients, families, as well as staff and leaders in prioritizing safety indicators for rehabilitation. Critical to the success of this session was fostering an open and receptive environment that enabled consensus to emerge despite diverse and often conflicting opinions.

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\(^1\)See “Your Voice Counts: Training patients to be effective in designing the system” BC Ministry of Health Services
www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx

\(^2\)See “Engaging patients and families to develop safety indicators” at the Toronto Rehabilitation Institute
www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx
3. PLAN FOR THE DURATION

Effective planning involves determining the appropriate level and duration of engagement according to the type of the project. Some projects may involve patient engagement in the development stage while for others it may be appropriate throughout the life of a project and an important component of quality improvement. Regardless, without this planning, the likelihood of success is imperilled.

**Strategy in action**

St. Joseph’s Healthcare Hamilton and McMaster University used an iterative process for soliciting the preferences and opinions of patients about the characteristics a service would ideally possess to engage those experiencing their very first symptoms of mental illness. Project leaders first sought input via focus groups about what content should be included in surveys to other patients. Results were then fed back to the groups to solicit further reactions, provide context and consider further content for the next survey. This approach was helpful in maximizing participant involvement by offering opportunities to process and interpret key data, thereby involving patients in novel tasks and providing project leaders with a fresh and rich perspective.

4. GET READY FOR PARTNERSHIP

A key part of preparation is making sure participants have the necessary knowledge, skills, resources and will for effective engagement. Ensuring participants are fully prepared is especially important when discussing complex issues and helps build the confidence of participants to engage at their full capacity. Building confidence is critical in transforming participants from being passive, simply absorbing information, to engaged participants who provide valuable insight and suggestions. Preparing participants may also involve providing training for speakers to help them understand that they are representing others when they speak.

**Strategy in action**

The Empowerment Council, a consumer/survivor advocacy organization located at the Centre for Addiction and Mental Health (CAMH), was a key partner in the development of a speaker series in which former inpatient clients with schizophrenia held talks with inpatient staff about care quality and recovery. This partnership allowed for an orientation of speakers that went far beyond just addressing the nature of the talks, the venue and the goals of the project. Based in extensive experience with consumer survivor communities and advocacy, Empowerment Council members provided new speakers with a historical context for consumer feedback and addressed sensitive messaging around their telling stories that do not simply represent themselves but represent the broader consumer community.

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1See “Patient input on developing early intervention mental health services” at St. Joseph’s Healthcare / McMaster University [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx)

2See “Bringing a recovery focus to schizophrenia services through client narratives” at the Centre for Addiction and Mental Health [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx)
5. MAKE IT LAST

In a resource-stretched environment, with many challenges to address, ensuring the sustainability of patient engagement can be difficult. Nonetheless, several elements help to ensure sustainability, including: embedding patient engagement strategies in existing education and quality improvement structures; ensuring patient engagement initiatives are not seen as stand-alone projects but as “business-as-usual”; and conducting evaluations that measure the outcomes of patient engagement strategies. These measures should be considered in the preparatory stages of any project, but particularly in cases where continued feedback and relevance are important.

Strategy in action

The BC Ministry of Health\(^4\) has built in ongoing work and related funding in Your Voice Counts after the project funding is completed. This will include work through the University of British Columbia’s Intercultural Online Health Network, which provides culturally appropriate self-management support on the internet to Aboriginal and multicultural patients, families and caregivers in BC, and ImpactBC’s Patient Voices Network which is a mechanism to recruit, train and support patients and their families to participate in primary healthcare changes on an individual, community and system level.

CHALLENGES IN ACHIEVING READINESS

Financial pressures, perceived power differentials, different knowledge bases and diverse and conflicting opinions can all be challenges in preparing patients, staff and leaders for effective patient engagement. One of the greatest challenges is avoiding the risk of tokenism, which simply reinforces the problems that true patient engagement strategies are designed to address. Novel collaborative approaches that bring together a wide range of stakeholders can be particularly effective in mitigating some of these challenges.

Other potential obstacles include processes that invite patient participation on some aspects of the project only or that are clearly an afterthought. This kind of variance, while typically inadvertent, can re-inforce tokenism and an “us-versus-them” attitude. In contrast, careful preparation that focuses on the structures and mechanisms necessary to engage patients in all facets of the project benefit everyone.

CONCLUSION

Preparing people and contexts for patient engagement can be a new experience in many care settings. Stakeholders need to have a clear understanding of what will happen and why, be engaged in a sustainable way and have structures and processes in place that ensure patient engagement is regarded as an integral component of the regular work and mission of the organization.

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\(^4\)See “Your Voice Counts: Training patients to be effective in designing the system” BC Ministry of Health Services [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx)
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