



# Ingredients for successful patient engagement: Real engagement for real improvement

## KEY MESSAGES:

- » Engaging patients is critical to understanding their experience of illness and care; this, in turn, can lead to person-centred changes in practice, service delivery and outcomes.
- » Embedding patients in decision-making structures within multiple levels of organizations will sustain real and ongoing patient engagement.
- » The ability to demonstrate the positive outcomes of patient engagement related to effectiveness, efficiency and improved patient experience will ensure its sustainability.

## INTRODUCTION

Hearing the voices of patients, families and caregivers is essential to transforming healthcare. In 2010, the Canadian Foundation for Healthcare Improvement began funding teams to investigate methods of improving the quality of care and the effectiveness and efficiency of health services by engaging patients in their design, delivery and evaluation. Funded teams were required to evaluate their intervention's patient engagement processes, outputs and outcomes, including its impact on the quality of services. In May 2012, six months prior to the end of their two-year funding cycle, the first cohort of the teams came together to begin to articulate lessons learned from these projects. This series of briefs presents the themes that arose and shares lessons learned to date in each of these areas.

One of the key themes that emerged from this discussion is the need to have in place the mechanisms that make real engagement possible and that promote real improvement. We highlight a number of key strategies that organizations can use to engage patients and families.

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 TO ACHIEVE REAL ENGAGEMENT

### 1. ENSURE A SAFE EMOTIONAL AND PHYSICAL SPACE

Patient stories form the foundation of meaningful patient engagement. Providing a welcoming space to share experiences goes beyond physical space. It also requires openness to understanding and learning from patient experience. It requires a genuine intent to co-create something different than what would be developed by staff or patients alone. It may sometimes be difficult to be open to hear patient stories as they may highlight some aspects of care that require change and improvement. Nonetheless, in the interest of real improvement, staff and decision-makers must, if necessary, change their typical behaviour to create a safe space for meaningful engagement.



#### *Strategy in action*

At the Canadian Centre for Addiction and Mental Health<sup>1</sup> (CAMH), former patients were invited to share their stories of recovery with inpatient unit staff. Patient stories focused on their experiences with recovery and their interactions with the healthcare system. While evaluation of this initiative is ongoing, anecdotal reports indicate that staff have a greater understanding of what it is like to experience mental illness, which has facilitated dialogue among patients and staff.

### 2. EMBED PATIENTS IN ORGANIZATIONAL STRUCTURES

Formally aligning patient engagement strategies with existing organizational structures and processes ensures sustainability of engagement activities. Balancing representation among the various stakeholder groups will help to ensure multiple perspectives are heard. Tracking patient representative requests through formal documentation, such as meeting minutes, provides some accountability for committees to honour patient voices. Linkages created at different levels of the system strengthen accountability and ensure sustainability of the process. For example, front-line managers can be embedded into patient forums or committees so that accountability linkages are strengthened. Meaningful engagement requires continuous involvement of all stakeholders in an iterative process; involvement of patients at one point in time only may not allow adequate time to create new learning that will lead to improved processes of care. It is particularly important to involve patients in the planning stages so that the process is truly collaborative and not unduly influenced by one stakeholder group. If all stakeholders are not involved early in the planning stage, it is unlikely that engagement will adequately represent multiple perspectives.



#### *Strategy in action*

At the Toronto Rehabilitation Institute<sup>2</sup>, patients and families are working with staff and leaders to develop the necessary infrastructure for quality improvement initiatives. Together, these stakeholder groups have developed a framework for quality improvement based on structure, process and outcome, to be implemented within inpatient units. Engagement of patients and families is embedded within this framework for ongoing sustainability within local improvement processes.

<sup>1</sup>See “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/Projects2010.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx)

<sup>2</sup>See “Engaging patients and families to develop safety indicators” at the Toronto Rehabilitation Institute [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx)

### 3. FACILITATE PEER-TO-PEER INVOLVEMENT

A culture of peer support creates a space for shared experience. Through peer-to-peer interactions, patients can articulate their experiences in the context of shared understanding. Involvement of peers in service delivery can be beneficial because of the immediate foundation of trust and mutual understanding that can increase engagement of other patients and family members.



#### *Strategy in action*

The Forensic Psychiatric Services Commission in British Columbia<sup>3</sup> hired a peer support worker in 2011. Previous attempts at offering 12-step meetings at the hospital had had limited success, with the average attendance per meeting being one patient. Since hiring the peer support worker, there have been 58 support group meetings offered and attendance numbers have increased substantially, ranging from four to 12 patients per meeting.

The Glenrose Rehabilitation Hospital<sup>4</sup> developed a family-to-family program to connect families with children with disabilities. While the intent of the project was to increase parent empowerment, social support and ability to navigate the service delivery system, the program resulted in greater involvement of parents in the Glenrose Family Advisory Network (GFAN). GFAN is a group of Glenrose staff, administrators, physicians and family members established to obtain family input into service delivery and decision-making within the pediatric rehabilitation division.

### 4. IMPROVE HEALTHCARE DELIVERY BY USING A MULTI-PRONGED EVALUATION STRATEGY

Tangible results can be used to demonstrate the benefits of patient engagement. Monitoring the results of patient input creates a more collaborative environment whereby patients can feel confident that their contribution will be valued and actually used to improve patient care. Demonstration of benefits to patients and all stakeholders in healthcare is necessary to ensure that patient engagement remains valued and embedded in the healthcare system. Stakeholder input on outcomes for evaluation is needed to ensure that the results of the evaluation are meaningful and likely to be used to improve patient care. The use of both qualitative (e.g., patient stories) and quantitative methods of evaluation contributes to a more robust understanding of both the processes and outcomes of engagement; both may be needed to gain the momentum needed to make changes to service delivery.



#### *Strategy in action*

At the McGill University Health Centre<sup>5</sup>, patient representatives were recruited from hospital Patient Committees to participate in a major study of the patient, staff and organizational outcomes of implementing Transforming Care at the Bedside (TCAB). The objectives were to better understand care through the eyes of patients, engage patients in co-design of inpatient care

<sup>3</sup>See “Simulating, studying and sustaining patient engagement in a forensic psychiatric hospital” at the BC Forensic Psychiatric Hospital [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx)

<sup>4</sup>See “Multifaceted parent-to-parent support program within a Family Support Network” at the Glenrose Rehabilitation Hospital, Alberta Health Services [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx)

<sup>5</sup>See “Patients and professionals partner to redesign inpatient care systems: Improving safety, access and work environment” at the McGill University Health Centre [www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx](http://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx)

processes and increase the amount of time nurses spend in direct care activities. Over 20 months, front-line teams and patient representatives on five adult inpatient units at three hospitals were taught skills to improve work processes, patient experience of care, quality of care and work environments. Results of this co-design include: a 10% increase in direct time at the bedside, through eliminating waste and duplication, 30% improvement in responsiveness on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, improved access to care and improved capacity for leadership among front-line staff and patient representatives. Evaluation found that protected release time, dedicated facilitator support, a structured modular approach and executive buy-in were essential infrastructure supports.

## CHALLENGES IN GENERATING ENGAGEMENT

Lack of staff engagement may become a barrier to real patient engagement. By creating a culture that values patient engagement, organizations have found staff to be more involved and engaged in these processes. For example, one organization set expectations for all staff to attend sessions where patients shared their stories about illness and healthcare to better understand the patient experience of care. Other organizations have embedded patients within decision-making structures. Patients may not always feel comfortable sharing their experiences, particularly if they are the only patient representative in a group of healthcare providers and administrators. Balancing the representation on organizational committees has helped shift the dynamics of power and highlight patient perspectives. Other organizations have involved peers to enhance patient engagement.

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