# Ingredients for successful patient engagement:

# Making patient engagement a way of life

#### **KEY MESSAGES:**

- » Formal and informal opportunities for patients to communicate are both vital
- » Adequate resourcing is required for patient engagement to be effective
- » Patient and family representatives require dialogue and feedback to clarify their roles and manage their expectations

#### INTRODUCTION

Hearing the voices of patients, families and caregivers is essential to transforming healthcare. In 2010, the Canadian Foundation for Healtcare Improvement began funding teams to investigate methods of improving the quality of care and the effectivenss 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 importance of making patient engagement a way of life. Patient engagement, a partnership between professionals and patients, results in better outcomes for all participants—but only if it is built into all aspects of the system, including its structure, mission and processes.

# PROMISING PRACTICES FOR MAKING PATIENT ENGAGEMENT A WAY OF LIFE

Hearing the patient voice is at the heart of an exciting shift in healthcare. When we listen deeply to people's stories, we all benefit. The truth of an individual's journey through the system has the power to identify unforeseen problems, create new awareness and motivate all concerned to make appropriate changes. This can—and must—happen at all levels of an organization.

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.

There are a number of methodologies available that can help institutions bring patients, families and staff together to work cooperatively to benefit all. For example, Experience-Based Design, an approach developed by the NHS Institute for Innovation and Improvement in the UK, looks carefully at all aspects of a process and elicits the emotional experience of all the participants, revealing problem areas in order to eliminate their causes. It results in co-designed solutions that can improve patient outcomes, safety, efficiency and satisfaction.

The following promising practices have been shown to help make patient engagement a way of life at the personal, unit, hospital and system levels:

- » Provide opportunities for patients to communicate
- » Ensure adequate resourcing
- » Build in continued dialogue and feedback

### 1. PROVIDE OPPORTUNITIES FOR PATIENTS TO COMMUNICATE

In order to make patients' voices heard, there need to be opportunities, both formal and informal, for patients to talk with staff and leaders so that their personal experience can be heard and understood and can influence change. It is particularly important that front-line care providers, including doctors, nurses and other professionals, listen to feedback from their patients to discover better ways to serve them.



# Strategy in action

At St. Joseph's Healthcare Hamilton<sup>1</sup>, doctors, nurses, patients, managers, administrators and scientists were brought together to talk about what would be important attributes of a new service being developed. After surveying a large number of patients, it became clear that staff assumptions about what was important were inaccurate. The survey showed that what patients actually wanted was to be respected, to interact with knowledgeable staff, to get appropriate information and to be involved in their care and decision–making. The results demonstrated that the only way to get an accurate picture of what is important to patients is to ask them directly.

#### 2. ENSURE ADEQUATE RESOURCING

Resourcing is vital to allow staff and management dedicated time to work with patients. This can involve establishing well-resourced mechanisms through which to provide patients and families with a way to express their views that is built into institutional governance systems, not an adjunct.

Adequate resourcing also implies that there are established mechanisms to disseminate and apply the results of patient engagement.

<sup>&#</sup>x27;See "Patient input on developing early intervention mental health services" at St. Joseph's Healthcare / McMaster University <a href="https://www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx">www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx</a>



# Strategy in action

The Patient and Family Advisory Council at Cancer Care Ontario<sup>2</sup> is engaged in consulting with planners and providers of service at the provincial level. Members of the Council sit on committees that address navigation, measuring patient experience and patient-reported outcomes, as well as those working toward redefining palliative care. The Council acts as an available resource for staff who wish to access a patient perspective. Similarly, at The McGill University Health Centre in Montreal patient advisors are involved in redesigning programs that will affect five hospitals.

# 3. BUILD IN CONTINUED DIALOGUE AND FEEDBACK

Patient engagement is a departure from traditional practice, not only for the healthcare system, but for the patients and their families who are involved in such initiatives. Institutions that have implemented patient engagement strategies have found that continued dialogue and feedback are required to help patients and families, as well as front-line staff, understand their roles and to manage their expectations.



## Strategy in action

Alberta Health Services<sup>3</sup> developed a resource kit for patients, providers and leaders as a way to enable patient-centred care across the province with the goal of improving patient experience. This readiness kit continues to grow and evolve based on the emerging needs and experiences of staff and patients engaging with the system.

## **CHALLENGES TO MAKING PATIENT ENGAGEMENT A WAY OF LIFE**

Involving patients in the planning and delivery of care is a radical departure from the status quo. Traditional medical practice has always privileged education over experience, so it is inevitable that a change to this pattern will provoke resistance. Staff may feel that their expertise is being challenged. There may be fears that patients will see the faults of the system and that the focus will only be on the negative aspects of the care experience. Trusting that a sick patient or emotional family member might have vital input may be a stretch for some people.

Evaluation of the results of patient engagement strategies is important to demonstrate their impact. Mechanisms to examine the impact of patient engagement on indicators such as average length of stay, rates of alternative-level-of-care stays, re-admissions, medical errors and falls need to be built in from the start, not approached as an afterthought.

<sup>&</sup>lt;sup>2</sup>See "Engaging survivors to improve patient experiences throughout the cancer journey" at Cancer Care Ontario www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx

<sup>&</sup>lt;sup>3</sup>See "All aboard for patient engagement: A readiness toolkit for patients, providers and leaders" at Alberta Health Services www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement/Projects2010.aspx

#### CONCLUSION

Changing the culture to one where patient engagement becomes a way of life takes time, strategies, resources—human, financial and educational—and a sustainability plan. Acknowledging the value of relationships with patients and their families must be embedded as a core value of the organization. Opportunities must be built in for people to tell their real stories, and for those stories to have impacts. Time must be set aside to build trust. Patient engagement requires a comprehensive approach hard-wired and programmed into the everyday structure and culture of an organization. To sustain it, we must acknowledge that it is a continuous process that honours and benefits all of us.

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