Engaging Patients and Caregivers in QIP Preparation

1. Introduction

For the last five years, hospitals have been working through an annual cycle of Quality Improvement Plans (QIPs) designed to formally outline their organization’s plan to improve the quality of care they provide. These QIPs are aligned with provincial priorities for quality improvement and articulate a strategy for implementation.

Some hospitals have proactively sought out the perspectives of patients and caregivers to complement the perspectives of staff and clinicians and inform their decisions about the focus of their QIP efforts.

Expectations with respect to engaging patients and caregivers in this annual process have been increasing significantly over the last two years. Last year’s QIP guidance from Health Quality Ontario (HQO) included an expectation for all hospitals to detail in their narrative any patient and caregiver engagement activities undertaken as part of their organization’s QIP development. This year, a new Excellent Care for All Act (ECFAA) regulation (effective September 1st 2015) set a firm requirement that all hospitals must now engage their patients and caregivers in the creation of the annual QIP.

There has been a marked shift within the health care sector focused on enhancing the engagement of patients and their caregivers in the delivery of care; this is often regarded as a move from ‘doing for’ to ‘doing with’ patients and caregivers. This shift reflects a growing understanding that the perspectives of patients and caregivers lend crucial insights to an organization’s quest to improve safety and quality outcomes.

While more action is now required on the part of Ontario’s hospitals, every hospital still has the latitude to craft strategies that take into consideration the particular context within which they operate.

At the Ontario Hospital Association’s (OHA) regional quality and patient safety network meetings this past fall, members were asked to share their organization’s past engagement activities that support the QIP agenda. Through this guidance document, the OHA is pleased to share the insights and plans of member hospitals as a reference to others considering their own activities.

A new Excellent Care for All Act (ECFAA) regulation (effective September 1st 2015) set a firm requirement that all hospitals must now engage their patients and caregivers in the creation of the annual QIP.

Additional resources are also anticipated. HQO will be releasing guidance documents to support organizations across the health care system with their efforts to engage patients and caregivers in QIP development.

The OHA recognizes that hospitals across the province are at different stages of experience with respect to engaging patients and caregivers in the development of the QIP, depending on their context and past work. Hospitals are encouraged to frame their engagement planning each year as an opportunity to strengthen their effort in this area, regardless of what their organization has done in the past, rather than meet or match a specific prescribed set of activities.

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1 While the language of new ECFAA regulations refer to patients and caregivers, it is understood that this is intended as a broadly inclusive set which would include individuals understood as clients, residents, patients, or consumers and all informal caregivers including spouses, partners, biological and chosen family.

2 Balik 2011
2. Summary of Past Activity

As part of the fall regional network meetings for hospital patient safety and quality leaders, the OHA held a series of discussions in November 2015 to ask member hospitals how they have been, or are planning to, engage patients and caregivers in their QIP development, as well as implementation activities for 2015 and 2016. It was immediately clear that each organization has a slightly different timeline, but that regardless of exact dates, all organizations go through similar steps in developing a QIP.

Hospitals were asked to identify which element(s)/step(s) of the QIP cycle their engagement activities fell into:

- Ongoing implementation of the QIP throughout the year
- Internal review, development and prioritization of the QIP
- Presentation/discussion of a draft QIP with the Quality Committee and/or Board
- Consultation with staff, clinicians, and/or indicator teams
- Direct consultation with patients and/or caregivers
- Sign off by the Quality Committee and/or Board
- QIP submission to HQO and public communication (including posting to website)

All health care organizations are required to submit a QIP to HQO every year by April 1st.

Submission of a QIP requires sign off from the Board, and organizations generally have a number of processes and touchpoints that occur annually to support the development of the QIP. Oftentimes, the QIP planning cycle commences with the announcement of the upcoming year’s priority indicators (late October or early November), and between November and April 1st, a number of common activities/steps occur.

After sign-off and QIP submission to HQO, there are ongoing implementation requirements throughout the year. These common steps were used during the discussion.

At the same time, Hospitals were asked to identify which level of engagement those activities fell under:

- Informing
- Consultation
- Involvement
- Partnership
Engaging Patients and Caregivers in QIP Preparation

The results of those discussions are presented here and provide a snapshot (as reported by hospitals) of current approaches to patient and caregiver engagement in QIP development.

The following tables include examples of patient engagement during QIP development and implementation. It is an organized summary that will enable hospitals to review ideas from peers regarding future plans. Each table represents a step in the QIP process, and engagement activities are categorized according to engagement level.

In summary, it is clear that there is some clustering of activity:

- Many hospitals are drawing on patient-reported data from general experience/satisfaction measurement tools/surveys and patient relations activity to inform indicator selection.
- Common approaches to engaging patients and caregivers include both one-off sessions, such as patient focus groups, and discussion by standing groups like a Patient and Family Advisory Committee (PFAC).
- Some hospitals are engaging patients and caregivers in the ongoing work of implementing QIPs throughout the year (for example, including patient advisors on quality improvement committees).
- There is an opportunity to better engage patients and caregivers specifically around decision making and approval of the QIPs.

Engagement activities (or techniques), regardless of the subject matter, are generally organized on a spectrum from one way information delivery to some form of partnership, shared decision making, or empowerment. Several such spectrums have been developed including the well-known International Association of Public Participation Spectrum.

More recently a healthcare specific model: the **Multidimensional Framework for Patient and Family Engagement in Health and Health Care** published by Carmen et al in 2013 has received wide spread attention in Ontario. A simplified spectrum based on these sources was used during the discussion.
The OHA encourages hospitals and other health delivery organizations to use the following table of activities as a menu of potential ideas which may assist them in strengthening their own engagement efforts.

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<thead>
<tr>
<th>Ongoing QIP Implementation and Change Management: (Monthly review of QIP, Operational Quality &amp; Patient Safety activities, Quality/Indicator teams activities)</th>
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<tbody>
<tr>
<td><strong>INFORMING</strong></td>
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<td>Patient/Caregiver Advisors participating on committees</td>
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<td>Patient and Family Advisory Council inform change ideas</td>
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<td>Post-discharge phone calls with specific questions related to quality improvement</td>
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## Indicator Development:
(Internal review, development and prioritization)

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<tr>
<td>Focus groups</td>
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<td>Pre-discharge survey</td>
<td>Feedback Post card</td>
<td>Discussion with community advisory council/resident advisory council</td>
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<td>Post-discharge calls</td>
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## Presentation / Discussion of Draft QIP with Quality Committee and/or Board

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<td>Partner with current patient advisors on QI projects to develop new change ideas</td>
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<td>Patient/Family Council review and discuss indicators</td>
<td>Engage PFAC and PEP on QIP development</td>
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<td>Family Advisory Council and Residents Advisory Council consultation</td>
<td>Engage Family Advisory, Youth Advisory, Children’s Advisory councils</td>
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<td>Discuss QIP with Client Experience Council</td>
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<td>Community and CEO town halls</td>
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### Targeted Consultations with staff and clinicians, indicator teams, or other stakeholders

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<td>Engagement between patients and staff at the operations lead level</td>
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### 3. Appropriate Engagement at Different Levels

Hospitals across the province have different levels of experience in their engagement work generally, and their specific efforts to engage patients and caregivers in their QIP development process. In an effort to provide helpful guidance to organizations at various stages of development, the following information is broken down based on an organization’s past experience. When engaging patients and caregivers as part of the QIP development process, consider where your hospital fits in according to the following three broad levels of experience:

#### Early in the Journey

Organizations that have not yet actively involved patients in the discussion on QIP development; staff may already be reviewing patient experience data for change ideas.

#### Work in Progress

Organizations that already provide some opportunity for patients and caregivers to learn about and comment on the annual QIP, although this engagement opportunity may be limited to involvement at only one point in the annual process.

#### High Performing

Organizations that include engagement activities at several points in the QIP development cycle, with at least some opportunities for patients and caregivers to act as partners with staff in the development process. This also includes patient and caregiver participation in the implementation of QIP activities throughout the year.
On the following pages, you will find some specific ideas on ‘taking the next step’ for organizations at each of these three levels of experience. Before moving on to the specific section most relevant to your organization, there are several general points which are always important to consider:

- **Discussion Preparation**

  Members point out that engaging patients and caregivers is not as easy as simply including them in a regularly scheduled business meeting. Like many other subjects, QIP details may be complex and include significant historical context. Without appropriate preparations, patient and caregiver participants may be at a significant disadvantage when participating with staff or other stakeholders who are more familiar with the material. Take an opportunity to consider what information may need to be translated from technical/business language to plain language for use in engagement activities (even if that means you will need to translate it back again after the discussion).

- **Facilitating discussion**

  For any meeting that includes patient and caregiver participants, consider a professionally facilitated discussion to ensure that all participants have the opportunity to clarify any questions and have their perspective heard adequately. Such facilitation should also ensure that the QIP process details and vocabulary are understandable for all participants.

- **Recruiting Participants**

  Regardless of what type of engagement an organization is undertaking, recruitment can always be a challenge. If you are bringing a discussion of your QIP development to one or more existing groups, make a point of communicating the details of the discussion in advance to promote robust attendance. If you need to recruit a group specifically for the discussion of your QIP, members have indicated they found early success coordinating with existing volunteer services staff, patient relations contacts, community engagement and/or auxiliary associations.

  Without appropriate preparations, patient and caregiver participants may be at a significant disadvantage when participating with staff or other stakeholders who are more familiar with the material.

- **Pledging engagement beyond the QIP submission deadline**

  Rather than viewing the April 1st deadline for QIP submission as the end of your engagement efforts, consider detailing in your narrative how you will sustain activity throughout the QIP implementation. As your organization works to act on the QIP throughout the year, explore possibilities for including patients and caregivers in those activities as well as early opportunities to discuss the ongoing impact of the QIP indicator teams and early planning for the next year.
Early in the Journey

Organizations that have not yet actively involved patients in their discussion about QIP development; staff may already be reviewing patient experience data for change ideas.

Analyzing patient-reported experience data and patient relations themes are an important source of data for QIP development. When looking to take a first step in two-way engagement, consider the following ideas:

- If you have an established engagement table/group (PFAC, Community Panel, other), include a QIP learning session on the agenda. While you may already be well underway this year in developing your QIP, it isn’t too late to engage patients and family caregivers. Explain the purpose and process of QIP development, review draft indicators, and invite comments and questions on the priorities for quality improvement at your hospital.

- If you don’t have an established engagement group, don’t let the process involved in starting up a patient and caregiver advisory program stand in the way of a quick win. A single session (focus group or another approach) to discuss QIP planning is possible even without a standing group in place. Build a conversation around an existing and relevant group. Consider going out into the community to talk to groups who would be willing to host the hospital, if no appropriate group exists within the hospital.

- Regardless of which of the two paths above you pursue, consider bringing any relevant results of your patient experience analysis along with your QIP change ideas to a patient and caregiver engagement session for comment. No matter how you are convening a meeting, take your analysis of patient experience, critical incident, and/or patient relations data a step further by using it as evidence to fuel your discussion about QIP planning.

While you may already be well underway this year in developing your QIP, it isn’t too late to engage patients and family caregivers.
Work in Progress

Organizations already providing some opportunity for patients and caregivers to learn about and comment on the annual QIP; however, this engagement opportunity may be limited to involvement at only one point in the annual process.

Building on existing work and successfully engaging patients and caregivers in your QIP development, consider any of the following in an effort to expand your engagement impact.

- Look for opportunities to increase meaningful engagement within the QIP cycle. If you currently have just one point in the process when patients and caregivers are engaged in QIP development, consider creating a second opportunity for participation. You may include a mix of short-term or one-time activities to complement more permanent or long-term mechanisms already in place (such as a Patient and Family Advisory Council). For example, if you already schedule a discussion about QIPs with a patient advisory group, consider recruiting one or more members of that group to help staff draft the publicly communicated final plan to ensure it is written in the most user-friendly way possible.

- Look for opportunities to enhance engagement within the QIP cycle. If you already involve patients and caregivers at a particular point in your QIP planning process, consider how you could move more towards partnership in that part of the process.

- Reference specific change ideas. Move beyond a general discussion about the QIP by taking a closer look at one or more specific indicators or change ideas in detail. You may want to create a two-step process where you begin by asking patients and caregivers to identify which indicators they are interested in exploring, and then reconvening at a later date once appropriate material for such a discussion has been prepared.

- Plan deeper and sustained engagement throughout the year on one specific change idea. Move beyond a general conversation about the QIP and enable participation in the planned work of an indicator team, or on a team working on a specific change idea, throughout the year.
Engaging Patients and Caregivers in QIP Preparation

High Performing

Organizations that include engagement activities at several points in the QIP development cycle, with at least some opportunities for patients and caregivers to act as partners with staff in the process. This also includes patient and caregiver participation in the implementation of changes to the QIP throughout the year.

High performing organizations have demonstrated commitment and leadership in engaging patients and caregivers in QIP planning. In the spirit of continuous improvement, consider how you can continue to refine and improve your own engagement efforts.

- Consider equity. Sometimes overlooked or set aside in early engagement activities for pragmatic reasons, ensuring that all perspectives of the population you serve are reflected in your engagement is a challenge worth undertaking. If inviting one or two patient and caregiver representatives to join existing larger team meetings, consider how well they are aware of the diversity of experiences your populations face. Is an analysis of those experiences part of the QIP development process? How could it be incorporated? Consider how accessible regular QIP development processes are and whether or not any special arrangements (or even sessions) may be required to ensure that any member of the population you serve could participate.

- Consider patient and caregiver leadership. If you have not already done so, consider how patients and family caregivers could be invited to take on leadership positions in the development and implementation of your QIP. What would need to change to do so? Is that change possible this year, and if not, how you can you prepare to put it in place next year?

- Look for opportunities to enhance engagement within the QIP cycle. Review your QIP planning cycle to consider if any steps are missing with respect to patient and caregiver participation? Are patient leaders active partners in presenting plans to decision makers?

- Are patient leaders themselves decision makers in reviewing/approving the QIP?
Appendix - List of Hospital Reported Engagement Activities for QIP development (fall 2015)

Ongoing QIP Implementation and Change Management:
(Monthly review of QIP, Operational Quality & Patient Safety activities, Quality/Indicator teams activities)

Consultation
Patient/Caregiver Advisors participating on committees
Patient and Family Advisory Council inform change ideas
Patient/Caregiver Engagement on general Patient Experience and QIP
Post-discharge phone calls with specific questions related to quality improvement

Involvement
Patient/Caregiver Advisors involved in co-design
Family leads on improvement council
Community member on Quality Committee
Patient/Caregiver Engagement on change ideas and implementation
Patient/Caregiver Advisors on indicator teams
A specific Patient/Caregiver participating in all aspects of QIP journey

Partnership
Patients on Improvement Teams
Patients/Caregiver on Professional Practice Policy Committee
Patient/Caregiver Co-leads

Indicator Development:
(Internal review, development and prioritization)

Consultation
Focus groups
Pre-discharge survey
Feedback Post card
Post-discharge calls
Analyze Patient Experience Survey Data
Analyze Patient Satisfaction Survey
Analyze Patient Relations themes
November blitz for Patient experience survey responses
Adding QI or change idea questions to existing survey
Specific QIPs related patient survey

Involvement
Survey to rank draft change ideas
Discussion with community advisory council/resident advisory council
A specific Patient/Caregiver participating in all aspects of QIP journey
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Presentation / Discussion of Draft QIP with Quality Committee and/or Board

Involvement
A specific Patient/Caregiver participating in all aspects of QIP journey

Targeted Consultations with Patients and/or Caregivers

Consultation
Focus Groups
Patient/Family Council review and discuss indicators
Family Advisory Council and Residents Advisory Council consultation

Involvement
Education session with PFAC on QIPs and QIP priorities
Engage PFAC and PEP on QIP development
Engage Family Advisory, Youth Advisory, Children’s Advisory councils
Discuss QIP with Client Experience Council
Community and CEO town halls

Partnership
Partner with current patient advisors on QI projects to develop new change ideas

Targeted Consultations with staff and clinicians, indicator teams, or other stakeholders

Consultation
Staff engagement with Community Engagement Panel
Engagement between patients and staff at the operations lead level
Involve staff in Resident’s Advisory Council and Community Advisory Council discussions
Engage Patient experience steering committee
Patient Experience Rounding

Signoff by Quality Committee and/or Board

Involvement
A specific Patient/Caregiver participating in all aspects of QIP journey

QIPs submitted to HQO; Posted on Hospital Website

Informing
One Page Infographic on QIP designed to make QIP easy to understand for patients

Involvement
Patient’s involved in drafting/reviewing draft narrative
Patient advisors/PFAC develop QIP narrative for posting on public website