

Choosing Methods for Patient and Caregiver Engagement:

✓ A Guide for Health Care Organizations

Important Information Before You Get Started

More and more, health organizations are beginning to engage patients and caregivers in the design and delivery of their health care. From the bedside to the boardroom, when patients and caregivers are engaged at the right times and in the right ways, it can have positive impacts on the quality of the health system.

Patient and caregiver engagement may look different depending on the reasons and goals for engagement. This guide is meant to help you and your organization choose the right times and methods to engage with the patients and caregivers you serve.

Knowing when and how to engage patients and caregivers in your organization's work can be challenging. Below is a list of methods to help guide you to do this effectively. Each method may require more or less time and capacity, based on what's required.

How to Get Started

When choosing your method of patient or caregiver engagement, start by considering:

- **Goals of Engagement** – What are the key goals or decisions that need to be made as part of the engagement activity? What is your organization hoping to learn and what are the desired outcomes of engagement? Which methods are most likely to help you achieve these?
- **Access and Equity** – What unique challenges and barriers do patients, their caregivers and staff from your organization face in participating in engagement activities? Which methods will best address these challenges and barriers, and allow for fair and balanced participation?
- **Timelines and Capacity** – How much time and capacity do your patient, caregiver and staff participants have to invest in engagement activities? Which methods best align with their level of investment? What type of engagement method best matches the level of staff experience with engagement?
- **Follow Up** – What level of follow-up will be done with participants? Which methods allow for post-engagement results to be shared with participants in an easy and timely way?

ENGAGEMENT METHOD	WHEN/WHY TO USE IT	EXAMPLE	ADDITIONAL RESOURCES
One-on-One Interviews	<ul style="list-style-type: none"> • To explore an issue in depth with a single patient or caregiver, to help inform a decision or process in your organization • To hear from patients and caregivers who may be unlikely to participate in groups • To help build rapport with individual respondents 	Doing follow-up phone interviews with in-patients one month after their discharge from hospital to examine the quality of their care	<p>Dr. Wayne Weston's <i>Patient-Centered Interviewing</i></p> <p>Dr. Rita Charon's <i>What to Do With Stories: The Sciences of Narrative Medicine</i></p>
Group Discussion (e.g., Focus Groups, World Cafés)	<ul style="list-style-type: none"> • To gather multiple perspectives on an issue, when there aren't enough resources to have individual conversations • To discuss and make decisions on a range of issues that affect patients and caregivers broadly • To enable patients and caregivers to hear and build upon each other's ideas 	Holding a focus group or world café to generate ideas on how to improve patient complaints process at a Community Health Centre	<p>The Office of Quality Improvement's <i>Focus Groups: A Guide to Learning the Needs of Those We Serve</i></p> <p>The Change <i>Foundation's Methods and Practices in Effective Patient and Caregiver Engagement</i></p>
Surveys	<ul style="list-style-type: none"> • To gather information when there is little capacity for your organization to consult patients and caregivers in-person • To gather systematic feedback from a large number of people quickly • To gather feedback on fairly focused questions 	<p>An open-ended survey asking in-patients at a pediatric hospital about their food preferences and desired meal times</p> <p>A closed-ended annual survey asking patients about their thoughts on wait times in the Emergency Department</p>	Dr. Julia Abelson's (McMaster University) <i>Public and Patient Engagement Evaluation Tool</i>

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Anonymous Comment Boxes	<ul style="list-style-type: none"> To hear feedback on sensitive issues, or when patients and caregivers may fear reprisal for their comments 	Placing comment boxes in the family recreation room at a Long-Term Care Home, and asking family members to comment on the quality of their experience	
Creating and sustaining Patient and Caregiver Advisory Councils (including Resident and Family Councils)	<ul style="list-style-type: none"> When there are high-priority, long-term planning and decisions that need to be made within your organization When significant relationship building between a health care organization and its patients and caregivers is needed To identify long-term priority areas for patient safety and quality improvement initiatives To provide strategic direction and feedback on the organization's priorities and planning 	Inviting the Patient and Family Advisory Council to review and approve your organization's annual Quality Improvement Plan	<p>To help establish a council:</p> <ul style="list-style-type: none"> Health Quality Ontario's guide on Recruiting for Diversity Health Quality Ontario's guide on Creating an Effective Terms of Reference Health Quality Ontario's guide on Choosing Meaningful Projects <p>To effectively engage with advisors on a council:</p> <ul style="list-style-type: none"> Agency for Healthcare Research and Quality's Working With Patient and Families as Advisors Institute for Patient- and Family-Centred Care's guide for the Staff Liaison to Patient and Family Advisory Councils Ontario Association of Residents' Councils guide on Supporting Your Home's Residents' Council The Change Foundation's Should Money Come into It?

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Committees, Task Forces	<ul style="list-style-type: none"> • When your organization has a need to draw from various patient and caregiver perspectives for a single project that requires ongoing commitment • To integrate patient and caregiver voices in high-impact decision-making processes regarding care delivery 	Inviting patient and caregiver advisors to sit on a committee to review ways of reducing unnecessary transfers from Long-Term Care Homes to Emergency Departments	<p>Institute for Patient- and Family-Centered Care's guide on <i>Involving Patients and Families on Committees and Task Forces</i></p> <p>Vancouver Coastal Health's <i>Guidebook for Patients and Caregivers Sitting on Committees</i></p> <p>Change Foundation's guide on <i>Rules of Engagement: Lessons from PANORAMA</i></p>
Meeting with Patient and Caregiver Associations	<ul style="list-style-type: none"> • To recruit specific patient and caregiver populations to seek their input on organizational projects 	Meeting with a support group for patients with chronic kidney disease to determine how to improve patient experience at the dialysis clinic	<p>To engage specific patient and caregiver populations:</p> <ul style="list-style-type: none"> • <i>Ontario Association of Residents' Councils</i> • <i>Family Councils Ontario</i> • <i>Patients Canada</i> • <i>Patients for Patient Safety Canada</i>
Storytelling	<ul style="list-style-type: none"> • When patients, caregivers and health care staff are interested – and comfortable – to draw from lived experiences to address a topic or issue • To build empathy around an issue, and best visualize a range of health care experiences 	Opening board meetings and team huddles with a patient or caregiver story, followed by a discussion on what follow-up actions can be taken in response to the story	<p>Health Quality Ontario's checklist for Supporting Patients and Caregivers to Share Their Story</p> <p>Cancer Care Ontario's Regional <i>Storytelling Toolkit</i></p> <p>The University of Alberta's <i>Guide to Storytelling</i></p>
Experience Based Co-Design	<ul style="list-style-type: none"> • To partner with patients and caregivers to design programming and services based on their feelings and experiences 	<p>Patients and staff co-designing a peer mentorship program in which curriculum is generated from the past experiences and emotional “touch points” of mentors</p> <p>Supporting patient and caregiver advisors to co-design surveys and partner in data collection and analysis</p>	<p><i>The King's Fund toolkit on Experience Based Co-Design</i></p> <p>The PACER (Patient and Community Engagement Research) program housed by the University of Calgary</p> <p><i>The King's Fund Patients as Partners: Guide to Co-Design</i></p>

[Patient-Centered Interviewing](http://www.cfpc.ca/uploadedFiles/Education/Patient%20Centred%20Interviewing.pdf) [www.cfpc.ca/uploadedFiles/Education/Patient Centred Interviewing.pdf](http://www.cfpc.ca/uploadedFiles/Education/Patient%20Centred%20Interviewing.pdf)

[What to Do With Stories: The Sciences of Narrative Medicine](http://www.cfp.ca/content/53/8/1265.full.pdf+html) www.cfp.ca/content/53/8/1265.full.pdf+html

[Focus Groups: A Guide to Learning the Needs of Those We Serve](http://www.oqi.wisc.edu/resourceLibrary/uploads/resources/Focus_Group_Guide.pdf) www.oqi.wisc.edu/resourceLibrary/uploads/resources/Focus_Group_Guide.pdf

[Foundation's Methods and Practices in Effective Patient and Caregiver Engagement](http://www.changefoundation.ca/rules-of-engagement) www.changefoundation.ca/rules-of-engagement

[Public and Patient Engagement Evaluation Tool](http://www.fhs.mcmaster.ca/publicandpatientengagement/ppeet_request_form.html) www.fhs.mcmaster.ca/publicandpatientengagement/ppeet_request_form.html

[Recruiting for Diversity](http://www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf) www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf

[Creating an Effective Terms of Reference](http://www.hqontario.ca/Portals/0/documents/pe/terms-reference-en.pdf) www.hqontario.ca/Portals/0/documents/pe/terms-reference-en.pdf

[Choosing Meaningful Projects](http://www.hqontario.ca/Portals/0/documents/pe/meaningful-projects-en.pdf) www.hqontario.ca/Portals/0/documents/pe/meaningful-projects-en.pdf

[Working With Patient and Families as Advisors](http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf) www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Implement_Hndbook_508_v2.pdf

[Staff Liaison to Patient and Family Advisory Councils](http://www.ipfcc.org/advance/Staff_Liaison.pdf) www.ipfcc.org/advance/Staff_Liaison.pdf

[Supporting Your Home's Residents' Council](http://www.ontarc.com/documents/FINALManual_proofed_01312013_updated_02192013JL.pdf) www.ontarc.com/documents/FINALManual_proofed_01312013_updated_02192013JL.pdf

[Should Money Come Into It?](http://www.changefoundation.ca/patient-compensation-report) www.changefoundation.ca/patient-compensation-report

[Involving Patients and Families on Committees and Task Forces](http://www.ipfcc.org/advance/tipsforgroupleaders.pdf) www.ipfcc.org/advance/tipsforgroupleaders.pdf

[Guidebook for Patients and Caregivers Sitting on Committees](http://www.vch.ca/media/CE_PublicAdvisorsHandbook2011.pdf) www.vch.ca/media/CE_PublicAdvisorsHandbook2011.pdf

[The Rules of Engagement](http://www.changefoundation.ca/rules-of-engagement) www.changefoundation.ca/rules-of-engagement

[Ontario Association of Residents' Councils](http://www.ontarc.com/) www.ontarc.com/

[Family Councils Ontario](http://www.fco.ngo/) www.fco.ngo/

[Patients for Patient Safety Canada](http://www.patientsafetyinstitute.ca/en/About/Programs/PPSC/Pages/default.aspx) www.patientsafetyinstitute.ca/en/About/Programs/PPSC/Pages/default.aspx

[Storytelling Toolkit](http://www.cancercare.on.ca/storytellingtoolkit?utm_source=twitter&utm_medium=social&utm_term=en&utm_content=CCO&utm_campaign=Storytelling) www.cancercare.on.ca/storytellingtoolkit?utm_source=twitter&utm_medium=social&utm_term=en&utm_content=CCO&utm_campaign=Storytelling

[Guide to Storytelling](http://www.hserc.ualberta.ca/TeachingandLearning/VIPER/EducatorResources/~/_media/hserc/Documents/VIPER/Patient_Mentor_Storytelling.pdf) www.hserc.ualberta.ca/TeachingandLearning/VIPER/EducatorResources/~/_media/hserc/Documents/VIPER/Patient_Mentor_Storytelling.pdf

[Experience Based Co-Design](http://www.kingsfund.org.uk/projects/ebcd/experience-based-co-design-description) www.kingsfund.org.uk/projects/ebcd/experience-based-co-design-description

[Patient and Community Engagement Research](http://www.obrieniph.ucalgary.ca/pacer) www.obrieniph.ucalgary.ca/pacer

[Patients as Partners: Guide to Co-Design](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Patients_as_partners.pdf) www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Patients_as_partners.pdf