

## Supporting Patients and Caregivers to Share Their Stories:

# ✓ A Best Practice Checklist for Health Care Professionals

### Why Are Health Care Stories Important?

Health care professionals may gather patient and caregiver stories to add lived-experiences to annual reports, staff or board education, promotional videos, or to be shared at team huddles. Listening to and gathering patient and caregiver stories can help you to:

- Visualize diverse patient and caregiver experiences
- Put a face to the numbers, and provide experiences that the data cannot tell us
- Understand the complex choices that patients and caregivers must make along their health care journey
- Build trust and relationships between patients, caregivers and health care professionals
- Use stories as part of health education and quality improvement

### How Can You Support Patients and Caregivers to Share Their Story?

As the person gathering their story, patient and caregiver storytellers are trusting you to use their stories responsibly. Securing prior and informed consent from patients and caregivers to share their stories is a vital part of the story-gathering process.

The best practice checklist below helps you to support patients and caregivers to share their stories in ways that make them feel safe and informed. Consult the checklist at each stage of your story-gathering process.

#### Best Practice Checklist: Planning

**Identify Your Goals** – Think carefully about the purpose and goals of your story-gathering. Consider what types of stories you're interested in hearing, and how patient and caregiver stories may be used to support your work.

**Craft an Invitation Letter** – Craft a [short and easy-to-read invitation letter](#) for potential participants. Include background and context for why they're being asked to share their story. To help prepare storytellers, give them a list of real or sample questions to expect.

#### *Key Questions for Health Care Professionals to Consider:*

- *What is the purpose and goals of your story-gathering (for example, for a full patient profile in a public report, or to gain a single quote)?*
- *What types of stories are you interested in gathering (for example, the direct care experience of a patient, or the experience of a caregiver)?*

## Best Practice Checklist: Story-Gathering

- Be Considerate of Emotions** – Stories about health care experiences may bring up feelings of anger, regret, grief or trauma for patients and caregivers. Coach patient and caregiver storytellers on what emotions to expect before asking them to recount their experiences.
- Use Different Story-Gathering Methods** – Allow storytellers to share their stories in the ways they prefer. Methods may include in-person or over-the-phone interviews, questions sent over email, or having storytellers share their experiences through creative formats. Read [\*What To Do With Stories: The sciences of narrative medicine\*](#) to learn more about story-gathering methods.
- Communicate Clearly** – No matter what story-gathering method you choose, make sure to communicate in ways that patients and caregivers understand. Avoid health system terms, acronyms and jargon. Use the [\*Centre for Disease Control's Plain Language Thesaurus for Health Communications\*](#) to find simple replacements for complex health terms.

*Key Questions for Health Care Professionals to Consider:*

  - Will the story be audio or video recorded? Will the storyteller be asked to have their picture or video taken? If so, make this clear to storytellers as early as possible.
  - Are you planning on using the story for a single quote, biographical profile or other reasons? Let storytellers know what you plan to do with the experiences they share.

## Best Practice Checklist: Getting Consent

- Get Written Consent** – After you've heard and documented their story, make sure storytellers sign a consent and release form. Go through the consent form with storytellers. Make time to answer questions about the consent process. If the person sharing the story has a parent or guardian responsible for them, ask the parent or guardian for written consent.
- Get Verbal Consent** – Send a follow-up [\*thank you and final sign-off email\*](#). It's important that patient and caregiver storytellers see the final version of their story. For example, if their story is being used as part of a report, share the full report with them and ask them to validate the accuracy of the story and the context it's shared in. Get verbal approval of the final product.
- Assess Publication Risks** – Let storytellers – and any parent(s) or guardian(s) that may be responsible for them – know the possible outcomes of you publishing their story (for example, they may receive interview requests from media). Ask if publishing their story will create any challenges or risks. Ask if any family members or loved ones will be negatively impacted by their story being shared publicly. If the answer is yes, encourage storytellers to get approval from them before publication. If the answer is no, go ahead with publishing or sharing the story.

*Key Questions for Health Care Professionals to Consider at This Stage:*

- Did you do everything you could to secure informed consent from the storyteller and any parent(s) or guardian(s) that may be responsible for them?

[\*\*What To Do With Stories: The sciences of narrative medicine\*\*](#) [www.cfp.ca/content/53/8/1265.full.pdf+html](http://www.cfp.ca/content/53/8/1265.full.pdf+html)

[\*\*Plain Language Thesaurus for Health Communications\*\*](#) [www.depts.washington.edu/respcare/public/info/Plain\\_Language\\_Thesaurus\\_for\\_Health\\_Communications.pdf](http://www.depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf)

[\*\*Short and easy-to-read invitation letter\*\*](#) [www.hqontario.ca/Portals/0/documents/pe/invitation-letter-template.docx](http://www.hqontario.ca/Portals/0/documents/pe/invitation-letter-template.docx)

[\*\*Thank you and final sign-off email\*\*](#) [www.hqontario.ca/Portals/0/documents/pe/thank-you-final-sign-off-letter-template.docx](http://www.hqontario.ca/Portals/0/documents/pe/thank-you-final-sign-off-letter-template.docx)

If you have any questions or comments, or would like more details on this topic, contact engagement@hqontario.ca.

For related tools and resources visit Health Quality Ontario's Patient, Caregiver and Public Engagement Hub: [www.hqontario.ca/toolsandresources](http://www.hqontario.ca/toolsandresources)