

OHT Patient, Caregiver & Community Engagement Learning Series

Module 2: Bearing Witness to Lived Experience Workbook

*“That which is spoken from the heart is heard from the heart”
– Author unknown*

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Acknowledgements

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RESEARCH

Research, “Beyond catharsis: The nuanced emotion of patient storytellers in an educational role”. Principal investigator: Dr. Lorelei Lingard., 2015. Co-investigators: Lisa Hawthornthwaite, Lauren Lee, Taylor Roebbotham.

PUBLICATIONS

Lingard, L., Hawthornthwaite, L., Roebbotham, T., Lee, Lauren. “Beyond catharsis: the nuanced emotion of patient storytellers in an educational role”. *Medical Education* 2017.

Hawthornthwaite, L., Roebbotham, T., Lee, L., O’Dowda, M., Lingard, L. “Three Sides to Every Story: Preparing Patient and Family Storytellers, Facilitators and Audience Members for Patient Experience Curriculum”. *The Permanente Journal* 2017.

WEBSITES

Healthcare Excellence Canada www.healthcareexcellence.ca

The Institute of Patient and Family-Centred Care www.ipfcc.org

Manitoba Trauma Information and Education Centre <https://trauma-informed.ca/>

BOOKS

Charon, Rita. 2006. *Narrative Medicine. Honoring the Stories of Illness*

Crocker, Liz, Johnson, Bev. 2006. *Privileged Presence, Personal Stories of Connections in Health Care.*

Frank, Arthur, W. 2010. *Letting Stories Breathe – a Socio-Narratology.*

Larin, Linda R. 2014. *Inspired to Change. Improving Patient Care One Story at a Time.*

Robins, Sue. 2019. *Stories of a life lived in health care. Bird’s Eye View.*

How to Use This Workbook

To Cite this Document

You may with proper citing share resources within this document for your own purposes. Please use the following citation when referencing or using any materials from this document:

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Working Group Members: Lisa Hawthornthwaite, Laurie Maltin, Beverley Pomeroy, Emily Cordeaux, Irene Wright, Sandra Holdsworth, Michelle Marcinow, Kerry Kuluski.

Legal

The materials in this workbook are general guidelines only. This workbook is not intended to provide legal advice. If there is a discrepancy between this document and any applicable legislation, the legislation will always prevail.

Document Layout

This document is organized into three parts. The **first part** is geared toward the person (e.g., patient or caregiver) who is sharing their story. The **second part** is geared toward group facilitators to guide them on how best to support the person sharing their story as well as people receiving the story. The **third part** includes additional resources on trauma informed practices, storytelling and a self-care example template that can be provided to people when sharing and receiving stories.

Part 1: Telling Your Story

Acknowledgements: Lisa Hawthornthwaite, Sue Robins, Dr. Shannon Arntfield, Lauren Lee, Mim O'Dowda, and Laurie Maltin

STORYTELLING – GETTING STARTED

Why Tell Your Story?

Stories have the power to connect people in a meaningful way. By sharing moments from your illness or health care journey you can help others. By hearing your story, you are allowing others to better understand the patient experience and think about what can make it better.

We share stories with purpose, in order to:

- Listen, honour and learn from those who have experienced illness and care
- Inspire ideas for change in the health care system
- Promote healing relationships and principles of person-centred care (respect, dignity, communication, information sharing and collaboration)

Deciding to share your story

It can often feel like patients and caregivers involved in health systems activities are expected to share stories about their illness or health care journey. In reality, patients and caregivers choose when, if, and how they share their experiences.

There can be many benefits to sharing your story that can make it an empowering experience. Sharing your story can be therapeutic and contribute to your personal growth. It can also help others better understand health care experiences that could happen to anyone. By sharing your experiences and journey you teach others about the power of human connection, resiliency and empathy. The impact of sharing your story can extend to making a positive difference in the health care system.

While there can be many benefits to sharing your story, there can also be risks. It can be a vulnerable experience to share your story and you may fear being judged. Revisiting the past can also trigger strong emotional responses, leading the storyteller to re-experience trauma. Additionally, both negative and positive feedback from those receiving the story can leave the storyteller feeling overwhelmed. This workbook is intended to

help storytellers and facilitators work together to maximize the benefits of storytelling while minimizing possible risks.

What to Include?

At first, most people approach telling their health care story in the same way – they start at the beginning and move through to the end, explaining the step-by-step chronological details of what happened along the way. This kind of storytelling can be valuable for your personal understanding, but can sometimes be challenging for an audience to follow or connect with if there is too much focus on.

We suggest the following structure for organizing your story:

Introduction (10% of your speaking time) – Tell us who you are as a person. This is the ideal place to set the scene for your story by briefly describing yourself, you or your loved ones illness or injury and the timeframe. This is the opportunity to offer context and orient the audience to the story they are about to hear.

Describe a moment in care (40% of your speaking time) – Select a moment/situation that, either positively or negatively, reflects one of the principles of patient-centred care, for example, a time when you felt empowered or disempowered, respected or disrespected, in your journey. Ask yourself the following questions as you organize your thoughts: ***What were you thinking? How did you feel? What fears did you have? What was the impact of the experience on you or your family?***

Describe a second moment in care (40% of your speaking time) – Using the above framework, select a second example using a different principle. Ask yourself the same questions.

Conclusion (10% of your speaking time) – This is the opportunity to link any negative experiences with suggestions for how the situation could have been made better for you. In the case of positive experience, tell us what the ‘difference makers’ were for you.

How to Share Effectively

Prior to presenting your story, it’s important to reflect on your audience and the ways you can set the stage for a meaningful discussion on the issues you have brought into focus.

Use this checklist to ask yourself the following:

- **Did I make my story easy to follow?** Perhaps ask a friend or facilitator for their impression of the ‘takeaways’ to make sure the audience will receive the message you intended.
- **Did I share my feelings, not just the facts?** Facts are important, but always anchor your stories with how the action/inaction made you feel or changed your experience. Always remember to share only what you are comfortable sharing – that is your decision to make.
- **Did I stay within my speaking time?** Staying within your allotted time will ensure there is the opportunity afterward for valuable discussion with the audience.
- **Am I okay with giving permission to the audience to have an open discussion?** Set the tone for the audience and invite them to speak openly about the story they have just heard. Remind them that we are there to learn from each other.
- **What do I need to make my experience of telling my story more comfortable and safe?** Am I prepared if some of the audience members make me feel judged? **In addition** are there practical things that will make the experience of telling my story more comfortable, such as water, tissues, sitting vs. standing or the use of a microphone? Never hesitate to ask for what you need.

What to Expect?

Be aware that writing and speaking about health care experiences can activate trauma; our own and that of others reading or listening. Storytellers tells us that navigating their emotion can be difficult at times and it is a memorable aspect of the experience. If you feel emotional this is ok, pause and take some deep breaths. Don't force yourself to continue right away. Let the audience know you need a moment before you can move on. The moderator will support you and is available to ask another presenter to speak if you need more time. At any time you have the choice and control to stop sharing. What you are doing is very important, and the listeners will benefit very much from hearing you speak. And, remember, everyone has stress before public speaking, even the most practiced person.

Print this checklist below and use it to discuss the session you have been invited to. This is a recap of the document. It is meant to help you reflect on how you feel and discuss the support you need to present your story.

- I am motivated to use my lived experience to improve healthcare.
- I am clear about the goal of sharing my story.
- I know what I need in order to feel confident in my ability to share my story.
- I have the choice and control to turn down an invitation to speak if it does not feel right for me.
- I have thought about the vulnerability that comes with sharing personal experiences.
- I feel comfortable with the facilitator of the presentation or meeting.
- I am aware of who I can turn to if I have a question, concern or would like support.
- I feel comfortable asking for what I need to share my story.
- I am clear about the date, location and time of the presentation.
- I understand how long the presenters expect me to speak.
- I know if there are other speakers, and the order in which we speak.
- I know the size of the audience and the roles people have in healthcare.
- I have made sure water, tissues and a microphone will be available.
- The physical environment and space feels safe (e.g., I'm able to stand or sit in a space and proximity to the audience that makes me feel most comfortable, the lighting is comfortable for me).
- I have someone to translate if I am speaking a language that is different from that of the audience.
- I am prepared to be at the presentation location 30 minutes prior to the start time.

- I am clear about whether I will be staying for the entire presentation or will be leaving after my presentation.
- I have a plan for how I would cope if storytelling causes a strong emotional response.
- I understand silence may come after I share my story while the audience processes their thoughts and feelings.
- I am prepared to engage with the audience regarding my story.
- I have considered my boundaries and know what I do not feel comfortable talking about (impact on family).
- I will adapt if things do not go as planned.
- I am comfortable debriefing with the facilitator following the presentation.

Part 2: Storytelling Facilitation- Getting Started

How Stories Help Us Learn

We share stories with purpose, in order to:

- Listen, honour and learn from those who have experienced illness and care
- Inspire ideas for change in the health care system
- Promote healing relationships and patient-centred care

The patient and care partner (i.e., caregiver) perspective can be effectively delivered by patient and family storytellers involved in educational forums, workshops and panel presentations. Through the sharing of personal moments interacting with the health care system, patients and families offer valuable insight on what works well and what could be improved.

Initially, such sessions were thought to have two main components – the speakers who share stories and the audience, comprised of providers,

administrators, researchers or leaders, who receive them. Through experience, the role of the facilitator has come into greater focus as a third important player in the dynamics of reflective learning.

Serving as a liaison between the speakers and the audience, while also setting the tone and foundation for the session, the importance of the facilitator cannot be overlooked.

The Facilitator will take responsibility for:

- Understanding the readiness of the group of people who will hear the story (see **Health Care Partner Readiness Checklist in the resources section of the document (section 3)**).
- Recruiting patients and families to participate as storytellers for a patient experience panel.
- Preparing storytellers for his/her role on the panel.
- Promoting a safe environment for reflective and productive group discussions
- Providing session evaluation tools.
- Liaising with all parties after sessions to reinforce learning and discuss further opportunities.

Session Planning Checklist

In Preparation for the Session:

- Have you met with the meeting chair or conference planner who requested a patient partner lived experience story to hear about their goals of the presentation?
- Have you provided the person requesting a patient storyteller the information about the purpose of storytelling and the value for teaching patient and family-centred?
- Have you considered what prefacing and introductory comments you will make at the session, for example, preparing the audience to hear potentially negative aspects of the patient care and illness experience?
- Do you have a self-care guide/ resources to share with the storyteller?

- Do you have a good understanding of patient-centered care and the goals of storytelling? This will help you make connections for the audience and promote strong post-sharing discussion.
- Have you communicated with potential storytellers to develop a mutual understanding of the goals of the session? This is a great opportunity to build rapport with the speakers, exchange information and ask clarifying questions.
- If the session is occurring at the same hospital or institution that harm occurred ensure storyteller has supports in place (e.g., meeting them at front doors to provide assistance and guidance to mitigate recurring harms).

The Day of the Session:

- **Have you considered**
- Have you organized the logistics of the session, such as ensuring the session room has the necessary technical equipment and comforts for the speakers, including water bottles, microphones and Kleenex, table set up, slide decks, and parking passes?
- Have you finalized the presentation slide decks and printed feedback/evaluation surveys to be completed by the audience members?
- Have you scheduled the speakers at least 30 minutes in advance of the session, to finalize the order of speakers or relay any additional information?

The Role of the Facilitation – During the Session

Prefacing/Introductory Comments to the Audience:

- Provide introductory comments on the principles of patient and family-centred care and deliver context-setting information on patient storytellers and purpose of sharing patient and family stories for the education event.

- Express gratitude and humility for the opportunity to hear about the experiences of others and inform the audience that they will be asked to reflect upon the stories and participate in an open discussion following the panel session.
- Make note of resources or self-care document that is available for everyone (Scroll to the end of this workbook for an example).

Leading Post-Sharing Discussion:

- Be comfortable with silence following a story – the dialogue will eventually come, but do not rush to jump in and push/direct the discussion. Expect there to be emotion and emotional shifts experienced by storytellers and members of your audience.
- Relay a message from the storyteller to the audience that it is a safe environment for open discussion. Then, as much as possible, encourage conversation between the storytellers and audience that is unfiltered by the facilitator. The role is not about sharing the facilitator's own wisdom, but to encourage and support others in the room to do so.
- Be mindful of acknowledging/appreciating all comments, perspectives while resisting the inclination to correct or debate with audience members who may not be as open-minded or receptive.
- Take note of behaviours or principles of patient-centered care that were not reinforced as a result of the discussion. The facilitator can revert to such themes to jumpstart discussion.

Some examples of discussion-generating questions are as follows:

- Asking audience members to break into small groups and discuss the question to share back with the group: *Tell each other what impact hearing patient stories had for you.*
- *Are there any new insights into the patient or family experience that you have considered?*

- *Which of the principles of patient and family-centred care were illustrated for you in the story?*
- *What are some barriers that you identified for patient and family-centred care?*
- Provide a summary of the learning at the end of the session.
- Distribute feedback/evaluation forms to audience members.

The Role of the Facilitation – Following the Session

- Plan for a 15-minute debriefing with speakers after any presentation to exchange real-time reflections.
- Provide an invitation/opportunity for speakers and audience members to reach out if they need further support.
- Send a personal note of gratitude and honorarium gift to the speakers for sharing his/her story.
- Follow-up with leaders/organizers after sessions to reinforce learning and plan future opportunities.

Sample scripting for how to introduce a patient experience story or panel presentation with patient experience storytellers for an educational purpose in a meeting or educational session:

- *For these first 5-10 minutes of our meeting we are asking for your presence to listen, and honor learning from the patient experience. Be prepared to discuss insights from a user of the health care system perspective – we will hear what works well and what could be improved from the patient perspective.*
- *It's possible you may have an emotional response to hearing the person's story. Please feel free to initiate your self-care by leaving the room, taking a break, reaching out later to debrief.*
- *After the short patient care story, we would like to hear some of your thoughts and reflect on any lessons learned or inspirations you can share.*

- *I also want to mention briefly that the patient partners who share their lived experience also expect this information to be kept confidential. I trust all of us to be open and respect the perspective of others even when we find something challenging to agree with.*
- *Patient stories offer us unique insights and ideas for change in the system. Sharing and listening to stories promote healing relationships.*
- We are grateful, for [insert names] joining us today, to help remind us of these principles and values of person centred care –respect, dignity, communication, information sharing and collaboration.

Adapted from AMS Phoenix Fellows, Lisa Hawthornthwaite and Dr. Shannon Artfield, Stories of Illness and Health (2016).

Part 3: Resources

Example Self-Care Guide for People Sharing and Receiving a Story

This self-care guide was shared by Bev Pomeroy (Patient and Public Engagement Strategist and one of our session speakers).

The self-care guide was created by the BC SUPPORT Unit Fraser Centre, Marika Sandrelli, Knowledge Exchange Leader, Fraser Health Authority Mental Health and Substance Use, and Fraser Health Authority, Aboriginal Health

This can be used as a template and adapted to include the resources within your OHT. Please note these phone numbers/resources are BC based.

Strengthening the Circle Self-care & safety

We are so grateful that you are joining us! Your health and wellbeing should be honoured.

We want to make sure you feel as supported and safe as possible during the symposium. We have included suggestions for you to think about as

you prepare for and attend the event, so you can be as comfortable and safe as possible.

Self-care online: Sitting in front of your computer all day can be draining. Here are some ideas to help keep you engaged throughout the sessions:

Water, tea or coffee

Snacks

Tissues/Kleenex

Pens/makers and paper

Fidget items or a coloring book

Move your body- take breaks to stretch whenever you need to

There are a number of resources available if you feel you need some mental health support:

For Indigenous mental health:

- The KUU-US Crisis Line Society provides a First Nations and Indigenous specific crisis line available 24 hours a day, 7 days a week. KUU-US Crisis Line can be reached toll-free at 1-800-588-8717. Alternatively, individuals can call direct into the Youth Line at 250-723-2040 or the Adult Line at 250-723-4050.
- The Métis Crisis line is available 24 hours a day, 7 days per week for self-identified Métis people in BC. Call toll-free 1-833-Metis-BC (1-833-638-4722).
- Aboriginal health liaisons connect with Aboriginal patients and family members, health care professionals, and other service providers in the Fraser Salish region to make sure Aboriginal patients receive culturally safe, appropriate, and timely care, whether in hospital or community. To access the services of an Aboriginal Health Liaison, you can call toll free at [1-866-766-6960](tel:1-866-766-6960).

For Fraser Health Employees:

- The following wellness resources are available for Fraser Health employees: <https://www.fraserhealth.ca/employees/employee-resources/your-health-matters/mental-health#.YKLuatiWycw>

For all BC Residents:

- BounceBack® is a free skill-building program designed to help adults and youth 15+ manage low mood, mild to moderate depression, anxiety, stress or worry. Delivered online or over the phone with a coach, you will get access to tools that will support you on your path to mental wellness.

- BC Mental Health Support Line: 310-6789. Offers emotional support, information and resources specific to mental health in British Columbia. Free and available 24 hours a day.

Strengthening the Circle: De-Briefing:

If you would like some time to de-brief about what you experienced during the Symposium in a sharing circle with Fraser Health Indigenous Cultural Safety, please let us know by emailing culturalsafety@fraserhealth.ca. We will reach out to you with a date and time where an online space will be offered to share your thoughts and feelings in a safe and supported environment.

Health Care Partner Readiness Checklist (Yes/No)

A checklist from Patient Voices Network

Administered by BC Patient Safety & Quality Council

Link to the PDF version: [Health Care Partner Readiness Checklist - Patient Voices Network \(patientvoicesbc.ca\)](https://patientvoicesbc.ca/Health-Care-Partner-Readiness-Checklist-Patient-Voices-Network)

Engaging patients, families, and caregivers to improve services is an important part of a person- and family-centred organization. Your teams' readiness to embrace this type of relationship sets the stage for a successful partnership. **We encourage you to get together with your team and use the questions below as a guide to see if your team is ready.** If you answer no to any of these questions, you may need more time to discuss things before adding to a patient partner to your team.

Question	Yes	No
Do I believe that patients, families, and caregivers bring unique perspectives and expertise to the table?		
Do I work to create an environment in which patients, families, and caregivers feel supported enough to speak freely?		
Do I listen respectfully to the opinions of patients, families, and caregivers?		
Do I consistently let colleagues know that I value the insights of patients, families, and caregivers?		
Do I believe that patients, families, and caregivers bring a perspective to a project that no one else can provide?		
Do I believe that patients, families, and caregivers can look beyond their own experiences and issues?		
Do I believe that the perspectives and opinions of patients, families, and caregivers, and providers are equally valid in planning and decision-making at the program and policy level?		
Do I have experience working with patients, families, and caregivers as partners and/or members of improvement or other teams?		
Do I understand what is required and expected of patients, families, and caregivers who serve as partners and/or members of improvement or other teams?		
Do I clearly state what is required and expected of patients, families, and caregivers in their roles as partners?		
Do I help patients, families, and caregivers set clear goals for their role?		
Do I feel comfortable delegating responsibility to patients, families, and caregivers, and improvement team members?		
Do I understand that an illness or other family demands may require patients, families, and caregivers to take time off from their responsibilities?		

Adapted from Jeppson, E. & Thomas, J. (1994). *Essential allies: Families as advisors*. Institute for Patient- and Family-Centered Care.

Trauma Informed Practice Resources

- Trauma-informed practice guide (2013) https://cewh.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf
- Trauma Training Initiative - Information for Health Professionals, Alberta Health Services: <https://www.albertahealthservices.ca/info/page15526.aspx>
- Manitoba Trauma Information and Education Centre: <https://trauma-informed.ca/>
--> Contains trainings, webinars, resources, definitions, information on how to become a-trauma-informed organization.

Resources on Storytelling from OHTs and health system partners

Greater Hamilton Health Network Patient Storytelling Toolkit

<https://greaterhamiltonhealthnetwork.ca/wp-content/uploads/2022/11/GHHN-Patient-Storytelling-Toolkit.pdf>

Sault Area Hospital (How to Share your Story)

https://www.canva.com/design/DAE9tSDSW6Y/mjpADM_7Q3681RFwYBx0dw/view?utm_content=DAE9tSDSW6Y&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton