

Presenting with Patients and Families: Considerations for Success

Background:

Patients and families contribute to people-centered care by sharing their experiences through participating in various projects and committees. When shared, their impactful stories connect with people on a human level. The Patient & Family Partnerships and Experience Program (PFPX) provides the following recommendations for creating successful presentations:

Recommendations:

Selecting the Presenter:

Have a conversation with the partner to learn more about their interests and comfort level. Consider whether they are:

- Passionate about improving the healthcare experience for others
- Open to sharing their personal healthcare experiences in a way that feels comfortable for them
- Respectful of diversity and differing perspectives
- Able to use their experiences in a constructive way
- Able to reflect beyond only their own experience to see broader perspectives
- Comfortable speaking with a variety of audiences, including physicians, staff, and leaders
- Open to receiving and giving feedback in a supportive way

Preparing and Practicing Together:

Alongside partners, take some time to:

- Make sure they understand the context of the presentation and who the audience will be. Consider hosting an informative 'orientation session'.
- Co-create an outline or flow for the presentation. Use templates, outlines, or guiding questions to help them structure their presentation. See page 3 for an example.
- Avoid asking partners to "write a short bio" or "tell their story in five minutes," as this can feel
 overwhelming or stressful. Instead, provide space for them to share what feels comfortable and meaningful.
- Identify speaker roles and assign time limits
- Conduct a 'test run' to see if everything runs smoothly, address any concerns that may come up
- Co-develop strategies to ensure that the presentation clear, organized, and engaging
- Offer support and reassurance throughout the process, checking in about the partner's comfort and readiness to present.



Note: Your role is to support partners in sharing their experiences in ways that feel authentic and meaningful, without directing what they choose to share.

Have a Back-up Plan:

Unexpected situations can arise. It's helpful to plan in advance for what to do if a patient or family presenter is unable to attend at the last minute. Consider options such as:

- Presenting on their behalf while honouring their perspective
- Sharing a pre-recorded video or other prepared materials, with the partner's consent

Provide Honoraria and Reimbursement Out-of-Pocket Expenses:

- Make sure patient and family partners know, in advance, which expenses can be reimbursed, and which
 cannot. The most commonly encountered include transportation costs (mileage, bus fare, taxi, parking, etc.),
 printing expenses, meal per diems and accommodation costs if engagement activities take place out of town.
- Refer to PHSA's 'Beyond Grateful Playbook' for the most up-to-date guidance.
- For honoraria-related guidance, refer to <u>this resource</u> or contact the PFPX program at patientexp@bccancer.bc.ca.
- Ensure your program is prepared to cover these expenses.

Resources

<u>Sharing Your Story: Tips for Patients & Families, Institute for Patient and Family Centred Care</u>

<u>5 Tips for requesting stories from patients and caregivers, Patient Advisors Network</u>

Questions?

Contact the PFPX Team to help plan engagement that's inclusive, respectful, and impactful.

Email: patientexp@bccancer.bc.ca

Fill out a request form



Outline for Helping Patients and Families Tell their Stories:

1. The 75-word challenge:

Draft and refine a summary of their diagnosis, treatment, and current situation in no more than 75 words

For example: "My daughter was born unable to breathe or swallow because of a birth defect. She has benefited from advances in medicine and informed, caring, skilled clinicians. She has also suffered from complications because of failure to appropriately resuscitate, inappropriate surgical intervention, inappropriate diagnoses—including meningitis—and other mistakes. I became a patient advocate partially for my own daughter, and to help other parents. I advocate for change in the largest Utah-based health care system."

2. Presentation outline

Introduction

A brief summary of the situation (use the 75-word challenge)

| Middle | | | |
|--|--|---|---|
| What happened from the beginning to the end of my experience? | How did my health care providers affect my experience? | What parts of the experience went well? | How did the experience turn out? |
| When moving through the system, when did I feel supported or lost? | What will my story teach those who are listening? | What am I willing to share? (What do I feel is too private to share?) | What parts of the experience were challenging/successful? |

Conclusion

This is where to offer recommendations, thanks and/or calls to action



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family storytellers and patient and family faculty. *The Permanente journal*, 17(3), e142–e145. doi:10.7812/TPP/12-059. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3783065/