

Including Patient and Family Voices

We know that the patient or family voice can influence healthcare providers and hospital staff to think differently about program design, clinical care, and communication with patients and families.

At BIDMC, providers and staff are frequently inviting patients and family members to share their perspectives by including them in some of the hospital's planning and educational activities.

The guidelines below offer some things to consider when asking individual patients and family members to tell their stories.

At least one month before event

Be in touch with Patient and Family Engagement to talk about the process of selecting an advisor



At least two weeks before event

Have a conversation with the patient/family member to learn about what they are interested in sharing*



After the conversation, take some time to determine if the patient/family member's perspective fits with the message you want to convey to your audience



If it doesn't:

Don't feel obligated to invite them to share their story – talk with Patient and Family Engagement about how to respectfully communicate this to the advisor

If it does:

Work with Patient and Family Engagement to craft the "ask" of the advisor and formally invite them to share their story



As soon as possible after event

Practice!
See tips on the next page for how to prepare with an advisor.

Debrief. Take the time to talk about what went well and what could be changed for the future.

* Even if it doesn't seem like their story will be a good fit for the anticipated forum, we can always learn from their perspective.

Patients and family members may ask you for more information before committing to sharing their stories.

Here are some questions that might be raised:

- When do you want me to speak? What time? For how long?
- Where do you want me to speak? (what site or city?)
- Who is the audience? How many people will be there?
- Will there be video- or audio-taping? Who will have access to the tape afterward?
- Who else will be speaking?
- What is the theme or topic?
- What part of my story do you want to hear?
- Is there a message you want me to leave the audience with? Is there a larger context that would make my story more transferable to other situations?
- What is your presentation style? Do you tend to use a script?
- Is there reimbursement for child care, transportation, or parking? (Patient and Family Engagement may be able to cover these costs, but a small budget to compensate advisors for these expenses should be a consideration of the staff member making the request.)
- Is there an honorarium? (BIDMC Patient/Family Advisors are not usually paid for their time, but it may be suggested that a donation be made to the program.)
- What is your deadline/when do I need to let you know?

How to prepare with an advisor for sharing a story:

- If you will be co-presenting with the advisor, talk with them about your planning, preparation, and presentation style. Are you more of a stream-of-consciousness thinker, or would you script out your remarks? This conversation can be helpful in setting the advisor's expectations for how things will go. Remember to reserve time to practice together. This kind of practice can help the advisor to feel competent in front of an audience and to focus on being the expert of his or her own story.
- If the expectation is that a story will be told in public, take the time to work with the advisor beforehand to decide on a cue that either of you could use to communicate with each other if the advisor needs to take a break, or if you need the advisor to be mindful of time. (If the advisor needs to take a break, they could say, "Talking about this is difficult" and then you can reply, "I understand, how about we stop here. Thank you for coming to share your story with us even though it's difficult." Or if you need the advisor to be mindful of time, you could clasp your watch with your opposite hand or shift your body language to indicate the desire to move on (e.g., lean forward with your hands clasped in front of you, as if you were about to stand up).
- Prepare for managing sharing the story: Develop scripts for if things don't go well, such as: "I can hear how difficult it is to talk about this... and it's because this is so important to us that we asked you to come speak with us today... "thank you so much for sharing your story."