

MyPaTH Story Booth FAQs

Q: My organization does not have an audiobooth. Can we still collect stories?

A: Yes! In fact, the patients who have partnered with the PaTH team in developing the Story Booth project have emphasized the need to collect stories in a way that is convenient for people who are ill – especially phone-based conversations. Most of the stories in the current archive have been collected over the phone. While the audio quality does vary somewhat across formats, multiple modes of story collection has enabled a broader range of voices to be heard.

Q: What if I do not have a lot of resources to devote to story collection?

A: Very little effort or resources are needed to partner with the MyPaTH Story Booth project. An existing approved IRB allows for recruitment in coordination with community organizations, and informed consent is gathered by Story Booth staff over the phone. IRB approval can be quickly obtained for flyers that are tailored to your target population and Story Booth staff can manage scheduling/reminders for telephonic story-telling sessions.

Q: How does the archive facilitate research partnerships?

Each story-teller is asked whether they are interested in learning about opportunities to partner as a stakeholder in research related to their story. Among the first 153 participants, 63% expressed such interest, and will be contacted in response to researcher requests to see if they might be interested in introductions.

Q: What data are collected with the stories?

A: Each story-teller completes a brief survey that includes demographics (age, sex, race/ethnicity, 2-digit zip), their perspective (caregiver or patient), whether they are interested in hearing of research engagement opportunities, level of interest in having their story posted to the internet, and the topics discussed in the story (e.g., type of health care interactions, anatomic location of a health problem).

Q: Does the Story Booth archive include stories from research participants?

A: While the main goal of the MyPaTH Story Booth project is to share patient and caregiver stories, we are currently working with a PCORnet team to pilot the collection of stories by research participants and hope to be able to expand that activity.

Q: How will researchers be able to access stories?

A: Researchers will be able to sign into an online portal to search the archive for stories that are related to their research goals (the portal is slated to go live in fall, 2017). They can use a simple click-license to listen to stories for insight into patient/caregiver perspectives that can inform better patient-centered research questions. Formal qualitative analysis of narratives will use an expedited data sharing agreement.

Q: Is there an option for sharing stories more widely on the Internet?

A: Yes – participants can give permission for their story to be posted online (please see http://pathnet-work.org/Community/story_booth.html for select stories). This site was developed based on advice from our partnering patients and caregivers, who stressed that it is critical for patients to be able to support each other through stories through broad sharing practices.