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# COLLECTING COMMUNITY STORIES

**A TOOLKIT DEVELOPED IN PARTNERSHIP WITH MYPATH STORY BOOTH**

Version 1.0

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## Introduction

The scientific community has shown increased interest in understanding the role of personal narrative in health research and practice as evidenced by the surge in literature on the topic in recent years. In fact, more than 1,000 articles on the topic of narrative medicine have been published in 2017 alone.

Not coincidentally, people have begun demanding an overhaul on the methods by which medical research and clinical practice are conducted. More specifically, there is an outcry for health researchers and clinicians to engage in meaningful relationships and express authentic empathy with their community members. Giving people a voice and providing them space and time to tell their story is an important way to build these relationships and allow empathy to unfold.

Collecting personal stories helps build relationships and increase trust, and can ultimately improve health outcomes by informing the formulation of research questions that truly matter to your stakeholder community. Their rich and meaningful feedback also enables researchers and clinicians understand and better serve the needs of their communities in immediate and tangible ways.

## About MyPaTH Story Booth

PCORnet's MyPaTH Story Booth project, founded by the PaTH Clinical Data Research Network, is focused on establishing a resource for patients and caregivers throughout PCORnet and beyond. The overall aim of the project is to build a better understanding of stakeholder experiences and perspectives and the Story Booth team is ready to provide support for patient-focused organizations whose community members may be interested in sharing their stories.

Participants interested in sharing will audio-record a story about their health, illness, or experience with the health care system in a quiet and comfortable space or over the phone. They are welcome to record their story with a friend or family member or with a member of the MyPaTH research staff. Participants also complete a brief questionnaire which can be adapted to include your organization allowing storytellers to indicate their connection to your team and enabling you to easily search the archive for their narratives.



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## About this Toolkit

This toolkit is designed to help you collect rich and meaningful stories from your community. Materials in this toolkit include sample flyers and brochures and interview prompts from MyPaTH's Story Booth project and are meant to guide you as you set up a Story Booth program for your network. Please keep in mind that materials can be adapted to your community with approval from the MyPaTH Story Booth IRB. The packet also includes a copy of the official MyPaTH Story Booth consent form in case it is helpful to review.

Using this toolkit, you will be able to collect and archive your community's stories in partnership with the MyPaTH Story Booth team. As a Story Booth partner, you will collect stakeholder stories remotely using a central telephone number. Each de-identified audio file is archived in the central MyPaTH Story Booth database where it can be accessed for future use by researchers or clinicians wishing to learn more about stakeholder experiences and find inspiration for research projects.

If you're ready to start collecting stories from your community as a MyPaTH Story Booth Partner, please contact Kathleen McTigue at [mctikm@upmc.edu](mailto:mctikm@upmc.edu) or Barb Postol at [postolba2@upmc.edu](mailto:postolba2@upmc.edu).

Now dive into the toolkit and get started!





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## MyPaTH Story Booth FAQs

### **Q: My organization does not have an audio booth. 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?**

**A:** 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 storyteller completes a brief survey that includes:

- Their demographics (e.g. - age, sex, race/ethnicity, 2-digit zip)
- The perspective from which they are telling their story (e.g. - caregiver, patient, friend etc.)
- The topic(s) discussed in the story (e.g. - type of health care interactions, anatomic location of a health problem)
- Their level of interest in:
  - Hearing more about research engagement opportunities
  - Having their story posted to the internet

### **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 expand that activity in the future.



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**Q: How will researchers be able to access stories?**

**A:** Researchers will sign in to an online Story Booth portal to search the archive for narratives related to their research goals. Using a simple click-license, a researcher can easily access the stakeholder stories that are crucial to generating more 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 on the [Story Booth website](#). The site was developed based on advice from our partnering patients and caregivers, who stressed how vital it is for patients to be able to support one another through broadly shared stories.





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## MyPaTH Story Booth:

### Sample script for recruitment phone calls

The following script can be used to guide the conversation when conducting phone calls with potential Story Booth Participants. Use the sample to develop a conversation appropriate for your community and your story collection process.

#### SCRIPT:

Hello. Mr./Mrs./Ms. \_\_\_\_\_, my name is \_\_\_\_\_ [YOUR NAME] and I'm from the \_\_\_\_\_ [INSTITUTION NAME]. I am working with \_\_\_\_\_ [INVESTIGATOR NAME]. I am following up with you regarding the MyPaTH Story Booth research study.

The purpose of this research study is to make a collection of patient and caretaker stories as a resource for researchers interested in developing research questions based on your perspectives and in studying patient or caregiver perspectives on specific health problems.

You will be asked to participate in a one-on-one conversation with a friend, family member, caretaker, or research staff member. The conversation will last up to 20 minutes and will be audio-recorded. You will also be asked to complete a few survey questions.

If you are interested in participating in the MyPaTH Story Booth, I will ask you for your contact information and if you want to participate, we can get you signed up.

Do you have any questions before I continue?  
**[DOCUMENT QUESTIONS AND ANSWERS HERE]**

Next, I'm going to give you some information about the MyPaTH Story Booth study, so you will know what will be asked of you if you choose to participate.

If you agree to be in this study, you will be asked to complete a brief survey right before and right after your conversation. These questions take just a few minutes.

You will be asked to tell a story pertaining to your experiences as a patient, or experiences providing care for someone else who is ill. This story should last about 20 minutes. You can bring a friend or family member to ask you questions that help tell your story, or we will provide a conversation helper.



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You will be asked if you would like to have your photograph taken which is completely optional.

If researchers want to contact you about possible opportunities related to their studies, we are willing to facilitate introductions. We will not do so without your permission. You are not obligated to follow-up with any such introductions. The study will also provide other optional opportunities (such as to receive the PaTH e-newsletter, or the potential to have your audiotape linked to the PaTH website). You are welcome to participate (or not) in any that you choose.

What questions can I answer for you?

*[DOCUMENT QUESTIONS AND ANSWERS HERE]*

*Continued on next page*

*Continued...*

If you have questions or concerns, my name again is \_\_\_\_\_ **[YOUR NAME]** and the \_\_\_\_\_'s **[NAME OF LOCAL INSTITUTION]** principal investigator is \_\_\_\_\_ **[INVESTIGATOR NAME]**.

We can be reached at \_\_\_\_\_ **[PHONE NUMBER]** or e-mail address is \_\_\_\_\_ **[E-MAIL ADDRESS]**.

**Are you interested in participating?**

*Participant answers:*

**NO:** Thank you for your time. Please feel free to contact us should you have further questions. [End call.]

**YES:** Great. I will send you some information prior to the appointment which will provide information on what will occur at our meeting. [Send them "**What to expect instructions**" document.]

Set up date and time for interview\*

**Date:** \_\_\_\_\_

**Time:** \_\_\_\_\_

\* **Remind patient to arrive a few minutes early to appointment.**





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## What to Expect as a Story Booth Participant

*Note: Use this sample document to develop an easy-to-understand overview of your story collection program. This document can be provided as supplemental information for participants and potential participants alike.*

A MyPaTH Story Booth interview includes participating in a one-on-one conversation with a conversation helper, and completing a brief questionnaire. The conversation helper may be a friend, family member; caretaker or research staff member. The conversation will last up to 20 minutes and will be audio-recorded.

You will be asked to tell a story pertaining to your experiences as a patient (for example, your personal experience with illness or your interactions with the health care system) or your experience providing care for someone else who is ill.

At the start of your session, a MyPaTH Story Booth staff member will explain the Story Booth process and review the consent document. If you come alone, the staff member will offer to assist as the conversation helper. Prior to the interview, you may want to chat briefly with your conversation helper about what aspects of your story that you are interested in sharing, to help them choose the best questions to ask you.

## There are 7 basic steps:

1. **Welcome:** A staff member will provide background information about the MyPaTH Story Booth, explain his or her role in the process, and answer any questions you may have.
2. **Prep:** A staff member will walk you through the informed consent document, which speaks to the goals of the project and your rights as a research participant. You will receive a physical copy of the consent form for your records.
3. **Pre-interview survey questions:** Participants who will audio-record a story will complete a brief survey prior to the interview.
4. **Sound check:** Once you are ready to proceed, the staff member will make sure you are comfortable and positioned well for recording. S/he will also check the equipment.
5. **Interview:** You will have 20 minutes to speak about your personal experience as a patient or your experience providing care for another individual who is ill.

**Participants who are telling their story:** If you are asked a question that you don't want to answer, there is no need to answer it. Please just respond that you'd prefer to skip that question. We are only interested in hearing about the parts of your story that you are interested in sharing.

*CONTINUED*



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***Participants who are serving as a conversation helper:*** We ask that you have a chat with your friend or colleague, asking questions that help them tell their story. You may find it helpful to talk briefly before the recording starts, in order to find out what parts of their story they are interested in telling, and whether there are topics that they want to avoid. If your friend or colleague finds that he/she is uncomfortable answering a question that you ask, that's fine. Please just move on to another question. If it is helpful to you, you may use questions that we provide on our "Potential Interview Prompts" page.

6. **Post-interview survey questions:** You will complete a brief survey following the interview.
7. **Post-survey photo:** If you consented to providing a photo one will be taken at this point.

## Interview Tips and Suggestions

- If you have scheduled an interview in advance, please arrive 10-15 minutes before your scheduled interview time.
- Feel free to ask the research staff any questions you may have about the consent form or the overall MyPaTH Story Booth experience.



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This document includes sample survey questions and story interview prompts. The first two sections can be used to guide the development of your own survey questions. Surveys can be used pre- and post- story collection and will help identify demographic information about each participant and specific information about the health experience they describe in their story.

The last section provides potential interview prompts a participant can use to guide the telling of their story. Alternatively, the questions can also be used by a friend or family member or a staff person to guide the participant as they tell their story.

## PRE-STORY SURVEY QUESTIONS:

Welcome to MyPaTH Story Booth! We're so pleased that you are interested in sharing your story. Please tell us a little about yourself.

**1. How did you learn about the MyPaTH Story Booth?**

- a. Path website
- b. Advertising near the booth
- c. From my doctor or doctor's office
- d. From a research registry
- e. Other: \_\_\_\_\_

**2. What is your age? \_\_\_\_\_ (numeric field)**

**3. What is your sex?**

- a. Male
- b. Female
- c. Comment: (Open text field for comment) \_\_\_\_\_
- d. Prefer not to answer

**4. What is the highest degree or level of school you have completed?**

- a. 8th grade or less
- b. Some high school, but did not graduate
- c. High school graduate or GED
- d. Some college or 2-year degree
- e. College graduate
- f. More than a college degree
- g. Prefer not to answer

*CONTINUED ON NEXT PAGE*

**5. What is your race or ethnicity? (check all that apply)**

- a. Asian (i.e. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)
- b. Black, African American, African, or Afro-Caribbean (i.e. African American, Haitian, Nigerian, etc.)
- c. Hispanic, Latino, or Spanish origin (i.e. Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Colombian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
- d. Middle Eastern/North African
- e. Native American, American Indian or Alaskan Native (i.e. Navajo, Mayan, Tlingit, etc.)
- f. Native Hawaiian or Other Pacific Islander (i.e. Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongan, etc.)
- g. White (i.e. German, Irish, Lebanese, Egyptian etc.)
- h. Some other race or origin (please specify)\_\_\_\_\_
- i. Prefer not to answer

**6. What language do you mainly speak at home?**

- a. English
- b. Spanish
- c. Chinese
- d. Some other language (please print):\_\_\_\_\_
- e. Prefer not to answer

**7. Would you like to learn more about the path network or ways to participate in research studies? (check all that apply)**

- I would like to receive the quarterly path e-newsletter
  - Email: \_\_\_\_\_
- I would like to hear about opportunities to work with researchers on a research project related to my story.
  - Please contact me:
    - Email: \_\_\_\_\_
    - Phone: \_\_\_\_\_
- I am interested in learning about opportunities to act as a patient partner in research related to my story.
  - Please contact me:
    - Email: \_\_\_\_\_
    - Phone: \_\_\_\_\_
- Other patients or researchers may listen to my story on the path ([www.pathnetwork.org](http://www.pathnetwork.org)) or pcornt Commons ([www.pcorntcommons.org](http://www.pcorntcommons.org)) websites. I understand that my name will not be shown with my story.
- You may include my photo with my story on the path or pcornt Commons websites.



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## POST-STORY SURVEY QUESTIONS:

### 1. What is your story about? (check all that apply)

- Experiencing symptoms
- Finding out a diagnosis
- Being treated
- Getting tests or advice for how to be healthier
- Communicating with doctors and nurses
- Supporting family members who are sick
- Making decisions about the right health care or treatment for you
- Describing how easy or hard it has been for you to get the health care you need
- Getting health care that is right for your cultural or religious beliefs
- Getting health care that is right for your sexual orientation
- Getting health care that is right for your gender identity
- Other: \_\_\_\_\_

If either “sexual orientation” or “gender identity” is checked the following is displayed:

We have partnered with the Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDEnet). This Patient Powered Research Network was formed because sexual and gender minorities (SGMS) – including those in the lesbian, gay, bisexual, transgender, and queer communities – have notable health and healthcare disparities. PRIDEnet aims to address these shortcomings in data and improve the experience of medical and research participation among SGM people.

Would you like receive more information from PRIDEnet about their work?

- Yes
- No

IF YES: What is the best way for PRIDEnet to reach you? (please check all that apply)

- Telephone me at: \_\_\_\_\_
- Text me at: \_\_\_\_\_
- Email me at: \_\_\_\_\_
- Mail me information at: \_\_\_\_\_
- I would like the Story Booth team to give me a flyer about PRIDEnet at the MyPaTH Story Booth table today

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2. Which health problem is your story about? (check all that apply)

- Blood, heart and circulation
  - For example: heart disease, high blood pressure
- Bones, joints and muscles
  - For example: arthritis, osteoporosis, broken bones
- Brain and nerves
  - For example: stroke, Parkinson's disease, dementia
- Digestive system
  - For example: Crohn's disease, gall bladder, diarrhea, hepatitis
- Ear, nose and throat
  - For example: deafness, swallowing, sinus infections
- Endocrine System
  - For example: diabetes, thyroid, Addison disease
- Eyes and vision
  - For example: cataracts, pinkeye, glaucoma
- Immune system
  - For example: allergies, vaccinations, AIDS
- Kidneys and urinary system
  - For example: kidney stones, urinary incontinence, chronic kidney disease
- Lungs and breathing
  - For example: bronchitis, asthma, interstitial lung disease, pneumonia, lung cancer
- Mouth and teeth
  - For example: tooth decay, gum disease, tonsils, adenoids
- Skin, hair and nails
  - For example: acne, eczema, bed sores, vitiligo, hair loss
- Female reproductive system
  - For example: menstruation, prenatal testing, cervical cancer, infertility, sexually transmitted diseases
- Male reproductive system
  - For example: infertility, enlarged prostate, sexually transmitted diseases
- Mental health
  - For example: depression, anxiety, schizophrenia, bipolar disorder
- Other: \_\_\_\_\_
- Not applicable (for example, your story could address an emotional health problem)

If "Brain and Nerves" is checked the following is displayed:

We have partnered with the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network. This Patient Powered Research Network is made up of participants who have, are at risk for having, or care for someone who has Alzheimer's disease or dementia. Their goal is to speed up development of effective treatments for Alzheimer's disease and related dementias.

Would you like receive more information from the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network about their work?

- Yes
- No

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IF YES: What is the best way for the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network to reach you? (please check all that apply)

- Telephone me at: \_\_\_\_\_
- Text me at: \_\_\_\_\_
- Email me at: \_\_\_\_\_
- Mail me information at: \_\_\_\_\_
- I would like the Story Booth team to give me a flyer about the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network at the mypath Story Booth table today

**3. Is your story about any of the following? (check all that apply)**

- Cancers
- Diabetes
- Genetics/Birth Defects
- Infections Injuries and Wounds
- Mental Health
- Obesity
- Poisoning or poisons in the environment
- Pregnancy and Reproduction
- Substance Abuse
- Having multiple health conditions at the same time
- None of the above

**4. Did you tell your story as:**

- a. Someone with an illness or other personal health concern
- b. A caregiver of someone with an illness

**5. Was your experience with making a MyPaTH Story Booth story:**

- a. Very easy
- b. Easy
- c. Neutral
- d. Difficult
- e. Very difficult

**6. How satisfied were you with the MyPaTH Story Booth process?**

- a. Very satisfied
- b. Satisfied
- c. Neutral
- d. Slightly satisfied
- e. Not at all satisfied

**7. How likely are you to tell a friend about MyPaTH Story Booth?**

- a. Very likely
- b. Likely
- c. Neutral
- d. Somewhat unlikely
- e. Very unlikely

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8. Suggestions for improving how we gather people's health stories? (free text)



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## POTENTIAL INTERVIEW PROMPTS:

### Questions related to a health condition or illness

- Please tell me about your health story.
- Please tell me about the process of learning about your health issue.
- How have you made decisions about what is the right treatment for you?
  - Has anyone or anything made those decisions easier? Or more difficult?
  - How has your culture or religious beliefs shaped your treatment decisions?
- What it is like to live with [your health issue]?
  - In what ways do you look at your life differently now than before you were diagnosed?
- What has it been like for you to receive treatment for this health issue?
  - What has been the easiest part of being treated for this?
  - What has been the most difficult part of being treated for this?
- In what ways has this health issue changed you? What have you learned?
- What advice would you give someone going through a similar situation?
- What would you like doctors or other health care professionals to know when they care for someone with a diagnosis like yours?
- What has been the best part about communicating with your health care team? The most challenging part?
- Has this illness changed you? What have you learned?
- How could the health care system have improved your experiences?
- If you could change one thing about the health care system, what would it be?

### Questions related to living a healthy life

- I hear you are interested in telling us about a program you have been working with, which aims to put you in better touch with your primary care team and help you better take charge of your health.
  - Can you tell me about how that program has affected you?
- What are you doing to be as healthy as you can be?
- What has helped you the most in making preventive health decisions?
- What do you do to eat a healthy diet?
  - Has your health care team helped? How? What could it do better?
- What do you do that helps you to be physically active?
  - Has your health care team helped? How? What could it do better?
- What is the best advice you've received on how to stay healthy? Who did it come from?
- Do you smoke cigarettes? Please tell me about it.
  - Do you want to quit? Have you asked your health care team for help quitting?

## Questions related to working with a primary care team

- I hear you are interested in telling us about a program you have been working with, which aims to put you in better touch with your primary care team and help you better take charge of your health.
  - Can you tell me about how that program has affected you?

## Questions about your experiences being a caregiver

- What has it been like to have a [child, friend, or family member] who is sick?
- How have you supported your friend [or family member] through his/her health issue?
- How has the health care system helped you to provide support? What could it do better?
- What advice would you give to someone whose friend or family member was just diagnosed with \_\_\_\_\_?
- What advice would you give the health care system for improving care for patients like your [child, friend, or family member]?



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## Tips for Story Booth Conversation Helpers

1. Your role as a conversation helper is to help the participant tell a story that he/she wants to share. Talk to the participant before you start and find out what they generally want to discuss. You will have up to 20 minutes to have your discussion.
2. You may find it helpful to identify one or more of the questions ahead of time from those on our prompt sheet. However, these questions are optional.
3. Please let the participant know there are no right or wrong answers and it is fine to skip questions if they want.
4. You may find you only need to ask a single question. For example, you could say, *“Tell me the story about [the topic they want to discuss.]”*
5. If necessary, add follow-up questions to help the story unfold. For example:
  - *What happened next?*
  - *How did that make you feel?*
  - *Can you tell me more about that last point?*
  - Consider questions that help a storyteller unpack and reflect on their experience. For example:
    - *Do you have advice for someone else who ends up in a situation similar to yours?*
    - *Did the story turn out the way you thought it would?*
    - *Looking back, what was the turning point?*
    - *Was there anything unexpected?*
    - *Was there anything really special about your experience?*
6. Be a patient and compassionate listener.



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# Appendices

## Sample Materials



**Consent to Act as a Participant in a Research Study**

**Protocol Title:** MyPaTH Story Booth, Pitt IRB PRO15100466

**Sponsor:** Patient-Centered Outcomes Research Institute (PCORI)

|                                |  |
|--------------------------------|--|
| <b>Principal Investigator:</b> | Kathleen McTigue, MD<br><a href="mailto:Kmm34@pitt.edu">Kmm34@pitt.edu</a><br>412-692-2940 |
| <b>Project Manager:</b>        | Barbara Postol<br>Postolba2@upmc.edu   |

You are being asked to join a research study. This consent form explains the study and your part in it. Please read it carefully and take as much time as you need. Choosing to participate or not participate will in no way influence your relationship with UPMC or the University of Pittsburgh

This study is being conducted by the PaTH network. The PaTH network is sponsored by the PaTH Clinical Data Research Network, which is a partnership between the University of Pittsburgh, UPMC, Penn State Milton S. Hershey Medical Center, Penn State College of Medicine, Lewis Katz School of Medicine at Temple University, Temple Health, Johns Hopkins University, and Johns Hopkins Health System, the University of Utah and University of Utah Health Care, and Geisinger Health System. Our mission is to address questions and concerns that matter most to the communities we serve in order for patients and health care providers to make more informed health decisions. We work to help researchers to understand patients' perspectives and to ensure that research findings are effectively communicated to patients who need them to make health decisions that are right for them.

You can contact the study team (contact information above) to answer any questions you may have about the study at any time.

You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can stop at any time by contacting a member of the study team. There will be no penalty or loss of benefits if you decide to withdraw the study.



## 1. Why is this research being done?

Patient stories provide a powerful framework for understanding patient problems and the larger process of illness, coping, and seeking health care. The purpose of this research study is to generate a collection of patient stories as a resource for researchers interested in developing research questions based on patient perspectives and in studying patient or caregiver perspectives on health and illness. Participants will be asked to participate in a one-on-one interview with a friend, family member, caretaker, or research staff member. The interview will last up to 20 minutes and will be audio-recorded. The recording may be transcribed. Researchers will be permitted to review the audio recordings or transcripts in order to better understand patient perspectives medical issues.

## 2. What will happen if you join this study?

If you agree to be in the PaTH MyPaTH Story Booth, we will collect and use several types of your information. This information will differ, depending on whether you are being interviewed, or whether you are serving as a conversation helper. We will collect contact information from you including things like your name and telephone number.

### ***Individuals who are interviewed:***

- a. **Surveys** — You will be asked to complete a survey when you join the study. The survey includes questions about your demographic information, interest in participating in research studies/collaborations and health symptoms. Researchers will be able to review this survey data. Based off of your survey responses you may elect to receive additional information regarding research studies and/or collaborations.
- b. **Audio recording** — As a participant in this study you will be asked to tell a story pertaining to your experiences as a patient, experiences with personal illness, experiences providing care for a family or friend, or your experiences as a patient in a health system. Any personal information that you disclose when telling your story may be heard by anyone reviewing the PaTH audio files. Therefore, we strongly advise you to not state your name, date of birth or other information that may disclose your identity while participating in the audio recording. For example, do not mention the names of friends or health care providers as you tell your story. Researchers will be able to review the audio file of this story. If you indicate so in the study survey, people will be able to listen to your anonymous story from the Internet. The only information about you that they will have access to is whatever you have included in your recorded story or surveys. The University of Pittsburgh will review all stories before publication on the website and identify any personal names, locations (e.g., city, state), facility names (e.g., UPMC), names of employers or employing institutions, proprietary drug or device names, or other information that is thought to be identifiable. In the event such information is revealed. University of Pittsburgh staff will use audio software to override



it with a “bleep” tone. If your story is chosen for website publication, we will contact you before publication.

- c. **Photograph** — If you choose to provide an optional photograph, researchers will be permitted to view the photograph.
- d. **Future research activities**— In your survey responses, you will have an opportunity to indicate whether you would like to hear about future research opportunities from individuals who listen to the Story Booth archive. If you choose to do so, you will be notified if any researcher asks to be put in touch with you. It will be your decision whether you want to follow-up on such invitations.

***Individuals who serve as a conversation helper.***

If you agree to serve as a conversation helper for a study participant your voice will be recorded subject to the description of “audio recording” above. We strongly advise you to not state your name, date of birth or other information that may disclose your (or anyone else’s) identity while participating in the audio recording. For example, do not mention the names of friends or health care providers as you facilitate the conversation.

**3. How long will you be in the study?**

Information collected for this study will be made available to the researchers indefinitely. This authorization is valid indefinitely or until you formally withdraw your authorization.

**4. How do I withdraw from the study?**

To formally withdraw your consent for participation in this research study you should provide a dated notice of this decision to the principal investigator of this research study at the address listed on the first page of this form. You may send this notification via postal mail, or e-mail. Any identifiable information obtained as part of this study prior to the date that you withdrew your consent will continue to be used and disclosed by the investigators for the purposes described above.

**5. What are the risks or discomforts of the study?**

The risks of this study are minimal. They include psychological discomfort from completing the questionnaires and completing an interview, and the loss of privacy. If there were a security breach to the PaTH MyPaTH Story Booth an unauthorized person could access your information. That would result in loss of privacy. All information is kept on secure servers that require identification and passwords to access.

**6. Who will have access to my data?**

Researchers from participating sites and other institutions will be provided the opportunity to review patient survey responses and audio recordings.



The Patient -Centered Outcomes Research Institute (PCORI), PCORnet, the National Patient-Centered Clinical Research Network, and the Research Conduct and Compliance Office (RCCO) will be permitted access to research data/documents associated with the conduct of this research study

Researchers who request to review the audio files and survey responses from participants must first fill out the MyPaTH Story Booth Access Request Form. The form will be submitted to the study team for review and approval.

If you approve posting your story to the Internet, the general public will be able to listen to it.

Data collected from patients recruited by the University of Pittsburgh team will be stored at the University of Pittsburgh's Center for Research on Health Care Data Center. These data will be stored with study identification numbers only and linkage files will be stored separately. All database access will be limited by role and recorded. All data will be stored in secure, password protected database and will be backed up daily.

#### **7. What will happen to my data?**

The MyPath Story Booth will:

- generate a searchable archive of patient and caregiver narratives
- develop a method for categorizing patient and caregiver narratives collected by the Story Booth
- support health researchers' use of patient and caregiver narratives in formulating patient-centered research questions and in studying patient or caregiver perspectives on health, healthcare, and illness.
- facilitate connections between individuals who have real-world insights and experience with health care or health care delivery and health researchers.

#### **8. Are there benefits to being in the study?**

You will not experience any direct benefit from being in the study.

#### **9. Will it cost you anything to be in this study?**

There is no cost to you to be in this study.

#### **10. Will you be paid if you join this study?**

You will not be paid to be in this study.

#### **11. What other things should you know about this research study?**

Your doctor may also be involved as an investigator in this research study, but you are not under any obligation to participate in any research study offered by your doctor. Before



agreeing to participate in this research study, or at any time thereafter, you may wish to discuss participation in this study with another health professional or other trusted adult, to obtain a 'second opinion' about study participation.

**12. What does your electronic signature on this consent form mean?**

Your electronic signature on this form means that: The above information has been explained to you and all of your current questions have been answered. You understand that you are encouraged to ask questions, voice concerns or complaints about any aspect of this research study during the course of this study, and that such future questions, concerns or complaints will be answered by a qualified individual or by the investigator(s) listed on the first page of this consent document at the telephone number(s) given.

You may always request that your questions, concerns or complaints be addressed by a listed investigator. If you have any questions about your rights as a research subject or wish to talk to someone other the research team, please call the University of Pittsburgh Human Subjects Protection Advocate toll-free at 866-212-2668. By signing this form I agree to participate in this research study. A copy of this consent form will be given to me.

**13. Consent Awareness Questions**

Before consenting to join this study, please answer the following questions:

My participation is voluntary.

**True**

False

*Correct! Because your participation is voluntary you have the right to leave the study at any time.*

*Incorrect. Your participation in this study is voluntary. Because your participation is voluntary you have the right to leave the study at any time. Please try again.*

I may contact a research staff member should I have any questions or concerns.

**True**

False

*Correct! You may contact a research staff member by calling (412) 864-3352 or e-mailing us at [mystory@pitt.edu](mailto:mystory@pitt.edu) if you have any questions or concerns.*

*Incorrect. You may contact a research staff member by calling (412) 864-3352 or e-mailing us at [mystory@pitt.edu](mailto:mystory@pitt.edu) if you have any questions or concerns. Please try again.*

Participation in this study includes being interviewed or serving as a conversation helper for an



audio recording.

**True**

False

*Correct! You will provide or facilitate an audio recorded interview as part of participation in the study.*

*Incorrect. You will provide an audio recorded interview as part of participation in the study. Please try again.*





## Electronic signature

The above information has been explained to me and all of my current questions have been answered. To indicate my agreement to participate in this research study I consent to participate in the study by clicking the 'I agree' box and by completing the fields below.

I agree

Full Name: (first, middle initial, last name)

Birthdate: \_\_/\_\_/\_\_\_\_/ (mm/dd/year)

What is your mother's maiden name?





University of Pittsburgh UPMC

# MyPaTH Story Booth

Would  
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like to



Share  
your  
story?

By sharing stories with researchers, we hope to focus research on topics that are of importance to patients and likely to improve health and health care.

**How:** Share your story by phone or in person at the Falk Medical Building Lobby

**Who:** If you are 18 years or older and able to read and understand English you may be eligible

**Phone:** 412-864-3025

**Email:** [mystory@pitt.edu](mailto:mystory@pitt.edu)

**Facebook:** MyPaTH Story Booth



**PaTH Network**  
patient empowered research



University of Pittsburgh

UPMC

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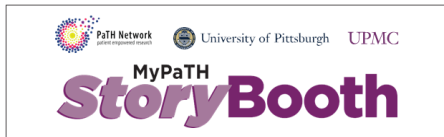
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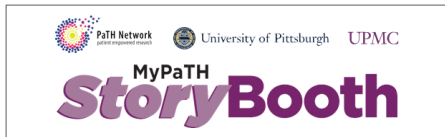
MyPaTH Story Booth



## **“Your voice matters”**

Research Study: The PaTH Network is gathering stories about the patients and caregivers to help researchers better understand their perspectives

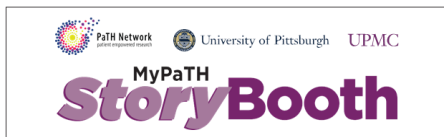
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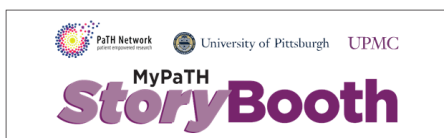
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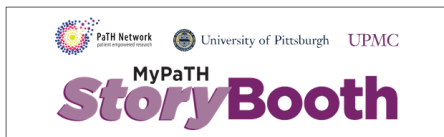
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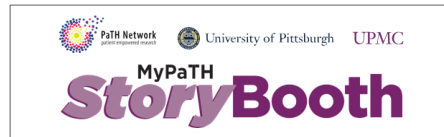
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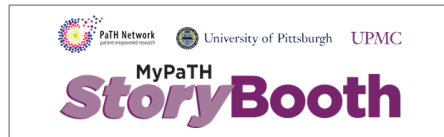
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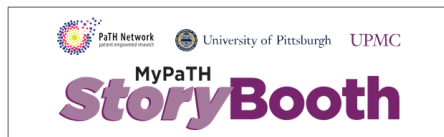
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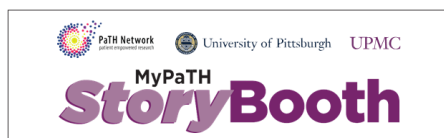
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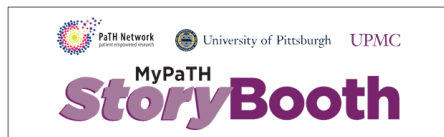
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University of Pittsburgh

UPMC

# MyPaTH *Story* Booth

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