# Take Charge Of Your Lealth Today. Be Informed. Be Involved



**ESTHER BUSH** 

### Stories

As Hurricane Katrina unearthed the vulnerabilities of New Orleans' working poor, COVID-19 has similarly revealed the cracks within the United States' system, especially at this time when our society expects more from those who often have the least resources and little or no safety net

or no safety net. While many people in the United States have adopted behaviors to minimize the spread of COVID-19 during the past seven months, our dependence on certain sectors of the workforce to keep ALL people in the United States well has become increasingly clear. The bare bones approach to everyday activities has made us come to realize how much we rely on grocery store workers, transportation providers, people who care for children and the elderly, medical and safety personnel and others, a majority of whom are African American and "their family's primary income earners.'

Stress on these workers daily—from the mounts pressure of providing for the family, concerns of finding and affording safe child care when schools and daycare centers are closed and the chronic worry of remaining protected, while relying on public transportation to go to work often in settings with groups of people or the public at large. The stress is magnified as months of cautious behavior has caused us to limit our human interactions, and, therefore, has greatly reduced the number of opportunities to simply tell the story of what we are going through.

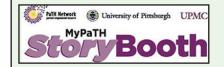
A new approach being taken by researchers at the University of Pittsburgh School of Medicine and the Johns Hopkins University School of Medicine creates an outlet for these stories not only be told but to be captured so that the experiences may potentially benefit others.

As referenced in this page's overview, Dr. McTigue, associate professor of medicine at Pitt's School of Medicine, explains, "Telling stories empowers people and helps them understand that their voices can be heard. My hope is that if we use community members' stories as entries to conversations between them and researchers, it will help to establish a level of trust in a relationship that can move forward and be productive. Patients have such powerful lived experiences. Researchers have technical and literature-based experiences. When you put them together, there's wonderful potential for learning new things. We're hoping that storytelling can help form

these relationships. To people making their way through these challenging days, I urge you to consider participating in Pitt's Story Booth project. It will do you a world of good to just simply talk about these past months. Your sharing of what you are going through, how you are coping and what you are feeling might be the key to the development of more meaningful assistance for others in similar situations. At a time when people can most benefit from telling exactly what they are going through and feeling, having those stories heard by researchers might also benefit our entire community-a rare win-win opportunity during these very trying times.

## Do you have a COVID-19 story to tell?

Has the global COVID-19 pandemic been especially hard on you? Have you gotten the virus, cared for someone who has had COVID-19 or been forced to make tough decisions between your health and your job? If so, you are not alone. Many people



have been affected by the virus and have stories to tell about their experiences—especially the caregivers among us.

During the COVID-19 global pandemic, it has become increasingly clear that the definition of essential caregivers includes more than health care professionals. People who work in grocery stores, food service, hospitality, child and elder care, retail, security and health care are also frontline workers people who have been deemed essential to the economy or to the basic functioning of every-day life. These industries have been hit hard by COVID-19-either because of job loss or risk of exposure to the virus. Many of these essential jobs are held by African American women—67% of whom are, according to the Center for American Progress, their family's primary income earners. Some caregivers have to go to work to support their families, which also increases their potential exposure and puts their families at risk. The stress on these caregivers has been intense, and many of them have a story to tell about their experiences in the past several

Story Booth is a research project that collects people's stories and lived experiences. The project started in 2016 as a way to collect people's personal stories about health experiences and share them with researchers.

"The mission of Story Booth is to promote patient-centered research," says Kathleen M. McTigue, MD, MPH, MS, associate professor of medicine, University of Pittsburgh School of Medicine. "We wanted to make it easier to foster the development of research that addresses questions patients feel are important. Stories are just so powerful. They are an incredible way to communicate; they can cross cultures, and they're a way to convey very technical information without using very technical language."

People who volunteer to share their stories with Story Booth often record them over the telephone and agree to allow researchers to listen to the stories. The idea is that if researchers know what topics people think are important, researchers will design studies around those topics. Then, those studies can, hopefully, generate findings that may better people's health.

Dr. McTigue, also associate



Story Booth—Caring during COVID Story

When [the pandemic] hit and we were told to shelter in place, it hadn't hit me yet. I was still going to the store without a mask or gloves, but then I started to see the shelves emptied of hand sanitizer, hand soap, toilet paper, etc. I hadn't really felt the impact of it. I was in shock. Then, I started wearing gloves, a hat, a double mask, and I was really scared—really petrified of people and of being in public spaces. But I had to go out and get necessities. I also have an 80-year-old mother who lives on the other side of town. She definitely couldn't be going out shopping, so I had to be the one to do it. One time, I had just come from dropping off groceries to my mom and had to drive back across town to get home and unload my groceries. At the time, they didn't know whether the virus could last on packaging, so I put my groceries on the floor and used bleach mixed with water to wipe everything down before I put it away. I just broke down. It was a lot. I had to remember everything I touched before I got into the house and then everything I had touched once I got inside the house and clean it all. It was overwhelming. I think I had a panic attack or something. Then, I would go to the grocery store and have to tell my mom that they had run out of a lot of things and we were just going to have to take what we could get. It took about until the middle of May before I felt like I had a groove. But then I started seeing people without masks because they thought [the pandemic] was over. People stopped social distancing. We opened up way too early. I just need to do whatever I have to in order to keep myself and my mother safe. It still scares me when people get too close or they're not wearing masks or wearing them appropriately. I wonder when I'm going to snap out.

—adapted from a Story Booth recording of a woman's experience living through the COVID-19 pandemic as someone who is HIV positive and caring for her aging mother

professor of epidemiology at Pitt's Graduate School of Public Health, explains that 72% of storytellers have expressed an interest in getting involved in health research as partners who help guide the research process. Story Booth research port team-building by introducing storytellers and researchers with shared health interests. She says, "Telling stories empowers people and helps them understand that their voices can be heard. My hope is that if we use community members' stories as entries to conversations between them and researchers, it will help to establish a

level of trust in a relationship that can move forward and be productive. Patients have such powerful lived experiences. Researchers have technical and literature-based experiences. When you put them together, there's wonderful potential for learning new things. We're hoping that storytelling can help form these relationships."

In more recent stories submitted to Story Booth, people have shared stories about COVID-19—being ill with the virus, trying to access testing and trying to keep themselves or their loved ones healthy. The most common theme is that this

is a very stressful time.

"People talk about how tremendously difficult it is to be struggling with this major health problem at the same time the country and the health system are also struggling with learn-



KATHLEEN M., MD, MPH, MS

ing how to adapt to it," says Dr. McTigue.

Frontline caregivers in the health care field also have an opportunity to be involved in the nationwide Healthcare Worker Exposure Response and Outcomes (HERO) registry. According to Dr. McTigue, the HERO registry is a collection of health care workers—doctors, nurses, respiratory technicians, people who work at front desks in hospitals or outpatient clinics, in food service or in hospital housekeeping—anybody in the course of their job who might be exposed to a patient who has COVID-19.

"Researchers hear what people in health care settings are worried about in this age of COVID-19," says Dr. McTigue. "They've also built in a story-telling component. One of those most exciting parts is that anyone who joins the registry is able to learn about opportunities to get involved in COVID-19-related research. We're hoping this is a way to help our local health care workers get access to studies that are addressing COVID-19 in various ways, including preventive trials."

Dr. McTigue wants people to know that it is an important time to be involved with research.

"The only way we can find out what's being done right and what people are worrying about is to actually talk with people, which is what the Story Booth is trying to do," says Dr. McTigue. "We want to find ways to protect people who are at the highest risk for getting COVID-19, are going out every day to take care of others and who could really benefit the most from research—whether that's to help them deal with stress or find vaccines to avoid infection."

To learn more about Story Booth, visit https://www.crhc.pitt.edu/PaTHStoryBooth/index.aspx. To find out how to become involved with the HERO registry, visit https://heroesresearch.org/.

## How do I vote with a mail-in ballot

Because of COVID-19, many people are deciding to complete mail-in ballots instead of in-person polling. You can request a mail-in ballot at VotesPA.com or by calling 1-877-votespa. Once you've received your mail-in ballot, open it up, and check out the materials. Inside, you'll find:

1. Your ballot

2. An envelope in which to place your ballot,

also known as the secrecy envelope 3. A larger mailing envelope in which to place the smaller/secrecy envelope that should hold your ballot. On the outside of the larger envelope, fill out your return address and then sign and date it in the spaces provided.

Does your mail-in ballot envelope include each of those items? Great! If not, contact your county election office. Allegheny County can be reached by visiting www.allegheny-county.us/elections or calling 412-350-4500.

How to: mail-in ballot video here: https://ti-nyurl.com/y8xtgd33

You can mail your ballot or drop it off at the Allegheny County elections office on the sixth floor of the County Office Building (Room 601) at 542 Forbes Ave. (downtown). You can also drop it off at several county-wide satellite early-voting locations, like the South Park Ice Rink and CCAC Homewood, on Oct.

10-11, 17-18 and 24-25. These satellite offices will also provide the opportunity to apply for, complete and turn in mail-in ballots at the same time.

To be counted, your completed mail-in ballot must be postmarked by 8 p.m. on Election Day, Nov. 3, and received by your county election office by 5 p.m. on Nov. 6.

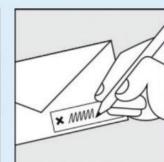
All county polling places will be open on November 3 should you decide to vote in person. For the first time, you will need an ID or a bill in your name. If you have already requested a mail-in ballot and now want to vote in person, bring your mail-in ballot with you to your polling place.

Image Credit: VotesPA.org

#### How do I vote with a mail-in ballot?



Mark your ballot, following the instructions.



2. Place your ballot in the secrecy envelope and then put the secrecy envelope into the official envelope. Be sure to sign the declaration, or your ballot may not count.



 Return your ballot so it arrives at the <u>county election office</u> or other designated locationon time.









