

A Toolkit for Libraries & Community-Centered Storytelling



# **STORYCORPS**





# ALL OUR VOICES: Conversations about Health & Wellness

RARY TOOLKIT

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# ALL OUR VOICES: Conversations about Health & Wellness

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# WELCOME

Since 2003, StoryCorps has given over 600,000 people of all backgrounds and beliefs the chance to record interviews about their lives and preserve them in the Library of Congress. An important part of this effort has been connecting with individuals and community organizations to create a culture of listening across the United States with the simple concept of asking people to honor one another with an interview.

Sitting at the center of public and civic life, libraries are the ideal place to carry out StoryCorps' mission: to strengthen and build connections between people, to teach the value of listening, and to weave into the fabric of our culture the understanding that everyone's story matters. During a time of increased uncertainty amid the global pandemic, libraries play a crucial role in keeping our communities connected and informed.

Libraries are a lifeline to the world. Libraries make communities healthier. We can read books and research articles about health outcomes, disparities, and the patient experience, but the connection and learning that comes from storytelling is unparalleled. I am profoundly moved by the spoken and unspoken in these conversations, and it doesn't end when the recording is finished."

> Gillian Kumagai, MLIS, AHIP Librarian, Stanford Health Library *Stanford Health Library is a NNLM Member Organization*

# ABOUT THIS TOOLKIT

This toolkit was created in partnership with the <u>Network of the National Library of</u> <u>Medicine</u> (NNLM) as part of its national initiative to support awareness of the <u>All of Us</u> <u>Research Program</u> (*All of Us*). In partnership, StoryCorps and NNLM support the power of libraries in their role as disseminators of health information and offer these tools to preserve the rich diversity of health experiences through the stories of people from across the United States.

Conversations about health and wellness are a meaningful way to build connection, support, and understanding among community and family—whether the conversation is recorded or not. Considering the lack of diverse representation in recorded history and in medical research, the **All Our Voices** toolkit aims to expand the conversation and inspire people to tell their health and wellness stories, in their own voices.

We hope you'll use the resources in this toolkit to create a culture of listening and sharing around health and wellness topics in your community.

# With this toolkit, you will be able to:

- Give patrons and community members particularly those underrepresented in biomedical research—**free digital tools to record, share, and preserve their health and wellness stories**, in their own voices;
- Join libraries across the country to contribute to the growing collection of health stories in the <u>StoryCorps Archive</u> by adding recordings to the <u>All Our Voices Community Page</u> collection;
- Offer engaging virtual or in-person programming at your library, including hosting a listening event to elicit dialogue about health and well-being and the importance of participating in biomedical research.



# Why public libraries?

- Public libraries are community hubs and know their local communities. As a "third place" where patrons spend time outside of home and work, they provide space for community activities, offer technology and access to digital information, and support lifelong learning.
- Public libraries provide access to trusted health information for library users of all ages, which can aid in patrons' decision-making about their health and that of their loved ones.
- Public libraries create and enhance local networks for disseminating health information and addressing the health needs of their communities.

# THE IMPORTANCE OF STORYTELLING

StoryCorps interviews are designed to give participants an opportunity to build connection and understanding. The interviews are intended to help participants feel that they themselves, and their stories, have value.



I wish that as Black women, as a Black community, we talked more about these types of things. Just like we talk about heart disease, stroke, diabetes, and how it runs in the family. Same thing when it comes to preterm birth, when it comes to infant mortality. And it's like, well, why don't we talk about these things? Why aren't these normal *conversations?* And partly because it's normalized. We think it's okay to deliver a baby at 23 weeks."

> Sabrina Beavers, StoryCorps Participant

#### StoryCorps interviews have shown:

- Reflecting on one's personal narrative is part of the healing process. For people experiencing challenging health circumstances, it can be especially important to develop control over their story and comfort in sharing that story with others.
- Storytelling allows us to weave together new stories about ourselves. Each conversation can provide space for people to articulate how the story of a diagnosis or illness relates to the larger narrative of who they are.
- Storytelling connects us to those who have had similar experiences, fostering community and a sense of support. People learn new ways to cope with illness, build connections, and feel less alone in their health journeys.
- Listening to other people's experiences can also positively impact the listener, boosting empathy, creating connection, and inspiring them to have more conversations with loved ones.

The results from StoryCorps' 2019 Participant Survey<sup>1</sup> show that, for the majority of participants, StoryCorps interviews are achieving these outcomes.

- After their StoryCorps interviews, 81% of participant survey respondents felt more connected to their interview partners.
- 78% felt that they and their interview partners better understood each other's experiences, views, feelings, or actions.
- 79% felt that, after their interviews, they would think of their own lives or experiences as meaningful or mattering to others.

StoryCorps interviews also inspire participants to take actions in their lives based on the experience of connection-building conversation.

- After their interviews, 73% of participant survey respondents felt more likely to connect with others who have similar experiences or backgrounds.
- 52% felt more likely to become involved in a social or political cause pertaining to themselves or their interview partners.
- 66% of those who participated through an organization apart from StoryCorps plan to begin or increase involvement with that organization.

StoryCorps interviews have repeatedly demonstrated the value of these personal conversations to participants, their families, and the organizations that serve them. By affirming the value of the individual through attentive conversation, StoryCorps interviews can directly combat the feelings of isolation, low self-esteem, and anxiety that may arise through challenging health journeys.

When applied to a health context, sharing stories, particularly about a challenging health experience or diagnosis, can help people make sense of their situation and find support in their community. When faced with illness, sharing our stories can support healing on an individual and community level.

# LIBRARY SPOTLIGHT: Stanford Health Library

Stanford Health Library is a consumer health library with the mission of providing scientifically based medical information to help people make informed decisions about their health and healthcare.

Each day, patients, family, friends, and caregivers come to the library and talk about their experiences of illness, sharing uncertainty, laughter, tears, gratitude, stories of their family, what it means to be a patient, and so much more.

Here is some of what Stanford Health Library heard from participants after recording with StoryCorps:

66 You taught me every story is worth being told, no matter how small. Thank you for that."

**6 6** Thank you for providing the space for me and [my interview partner] to connect like that. It was the most meaningful conversation I've ever had with him, and you helped make it happen."

1 In 2019, 834 participants out of a total 6,787 responded to our online survey, for an overall response rate of 12%. This is a slightly lower response rate than in previous years due to the survey's unavailability for approximately three months of the year (July-September) as StoryCorps switched database platforms.

# WHY USE THE ALL OUR VOICES TOOLKIT?

Sharing stories about health and wellness is an excellent way to engage with patrons, inspire community conversations, and promote awareness about underrepresented health topics.

Engaging in programming to record, share, and explore health-related stories can help your library forge new local partnerships, engage new audiences, and even attract additional sources of funding. Using our digital tools to focus on health and wellness conversations is valuable for libraries and patrons alike:



# HOW TO USE THIS TOOLKIT

Learn how your library can use StoryCorps' model and archive of stories to promote connection virtually and in person and inspire discussions around health and well-being.

Along with a series of how-to guides for participants, promotional flyers, and discussion guides, the toolkit highlights free StoryCorps resources, including the <u>StoryCorps App</u>, <u>StoryCorps Connect</u>, and <u>StoryCorps DIY</u>, StoryCorps' online learning platform.

Recognizing the crucial role libraries play in maintaining and supporting healthy communities, we invite you to:





# RECORD COMMUNITY CONVERSATIONS

We'll introduce you to the StoryCorps App and StoryCorps Connect technologies for recording and archiving conversations, and offer strategies for encouraging people to record and share their health stories, on an individual level or as part of a community-wide recording campaign.





# EXPLORE THE ARCHIVE

Use the StoryCorps Archive as a valuable research tool for librarians, patrons, and community members to hear stories from people with experiences like theirs. Use the power of the archive to establish connections within and between communities based on shared experiences.





# LISTEN TO AND SHARE STORIES

Use the resources in this toolkit to host a virtual or in-person listening event at your library featuring StoryCorps stories, and encourage meaningful community dialogue about health and wellness topics. Whether you have limited time, or want to engage more in-depth, the toolkit is designed for you to "pick and choose" at your own pace, based on your interests and needs. You could host a listening event, launch a recording campaign in your community, start using the StoryCorps Archive to support patron research, or all three!

This toolkit is divided into two parts: this guide for library staff to plan and host recording events at their libraries, and the appendix, which includes the following sections:

#### PARTICIPANT RECORDING PACKET

Materials that you can print or share directly with your patrons. This section includes everything they need to know to participate in the recording process and join the conversation.

#### **PROGRAMMING TOOLS**

Activities, discussion guides, and curated playlists of StoryCorps stories to share with your patrons.

#### **PROMOTIONAL MATERIALS**

Flyers, templates, and resources for promoting a recording campaign and listening event at your library.

Throughout the toolkit you will find library case studies, links to helpful resources, and more ideas to expand your programming:

# **QUICK LINKS**

If your time is limited, stick to the **QUICK LINKS** box at the end of each section. These links will guide you through everything you will need to use StoryCorps' model and resources at your library.

# LIBRARY SPOTLIGHT

In each section you will find examples of programming from other libraries in the **LIBRARY SPOTLIGHT** heading.

# **DIG DEEPER**

If you have the capacity to develop more indepth programming, we've provided links to resources and prompts with **DIG DEEPER** suggestions in each section, to review at your own pace.

# **PATRON RESOURCES**

There are a number of printable resources you can download and share with your patrons. Look for this label at the end of each section, or visit the **Participant Recording Packet** section of the appendix.

We hope that these resources are a valuable addition to your work-let's begin!



# **RECORDING CONVERSATIONS**





# INTRODUCING STORYCORPS

A StoryCorps interview is an opportunity to record an uninterrupted, intentional conversation with someone you know about anything you'd like, from favorite memories to important life questions. It's also a way to connect with family and friends in a time when visiting in person is extremely limited.



# Get to know StoryCorps by listening to stories from our collection.

Here are a few StoryCorps "classics"—stories that have stuck with us over the years and reminded us over and over again of the power of listening. All videos and content in this playlist can be found at storycorps.org.

# **An Intro to StoryCorps from Our Founder Dave Isay** (3 min.)

# **Featured Animations:**



Silvia's Legacy (2.5 min.)



# Leading the Way (2.5 min.)



**Q&A** (3 min.)



Chloe Longfellow (2.5 min.)



A Wonderful Life (3.5 min.)



**No More Questions** (3.5 min.)



Danny & Annie (6 min.)



Lessons Learned (3 min.)



Leonardo's Dreams (3 min.)



Through storytelling initiatives at your library, your patrons can add to the growing national collection of health and wellness stories in the StoryCorps Archive via the **All Our Voices** campaign. In this section, we'll walk through: Life would be different if I hadn't shared my story. I got it all out and now am able to share it with others."

StoryCorps Participant

- Free StoryCorps tools for recording and archiving conversations.
- Ideas for recruiting participants.
- Ways to promote your recording project.

### **START RECORDING AT YOUR LIBRARY**

We're encouraging libraries across the country to share StoryCorps' recording model and digital tools with their patrons. Share these resources to help build this growing collection of health and wellness stories that represent all our voices in the <u>All Our Voices Community Page</u>.





# OUR TOOLS FOR RECORDING STORIES

StoryCorps offers two free digital tools to record and preserve stories either remotely or in person:

 If the conversation will be between two people in the same place, it can be recorded using the <u>StoryCorps App</u>. The free mobile app guides users through the interview experience from start to finish with easy-to-use tools to help prepare interview questions and record high-quality conversations from a mobile device, no matter where they are.

# Quick How-To Video: Use the StoryCorps App to Record in Person

2. If the conversation will be between two people in different locations, it can be recorded using the web-based platform StoryCorps Connect. Developed in March 2020 in response to the COVID-19 pandemic, StoryCorps Connect is a first-of-its-kind platform that enables participants to record a StoryCorps interview with a loved one remotely using video conference technology and to archive the audio in the StoryCorps Archive.

**Quick How-To Video**: Use StoryCorps Connect to Record Virtually



# JOIN THE ALL OUR VOICES COMMUNITY & RECORDING CAMPAIGN

Record Your Conversation: Step by Step





# JOIN THE ALL OUR VOICES COMMUNITY PAGE

Patrons can add their story to a growing collection of community voices from across the country by joining the <u>All Our Voices Community Page</u> in the StoryCorps Archive. Once they are a member, they will be able to add their recording to the collection. Encourage participants to use the keyword **#AllOurVoices** when archiving their recording, and watch the collection grow by searching for **#AllOurVoices** in the StoryCorps Archive! Because it is recorded, it lifts up the importance of the conversation. And, the questions were so great and in-depth—I would never have thought to ask them on my own."

StoryCorps Participant



# All Our Voices

Public Community 

Community Organizations

f 🙆 😏 🗞 Conversations about health and wellness More

🛃 JOIN

## Do you or your patrons need help?

Find more in-depth, step-by-step instructions in the Participant Recording Packet or go to support.storycorps.org.

# DIG DEEPER

Do you want to learn more about "Community Pages" in the StoryCorps Archive and how to create one at your library? Visit this guide to create, populate, and share your own community page.



# **PATRON RESOURCES**

We've created the **All Our Voices Participant Recording Packet** to guide participants through the recording process from start to finish. Share the packet as a digital guide, or print copies to have available in your library. The packet includes the following sections:

- 1. About StoryCorps/NNLM
- 2. Join the All Our Voices Community & Recording Campaign
- Conversation Tips & Considerations for Recording Health Stories
- **4.** Custom Questions for Health & Wellness Conversations
- 5. Planning for Your Conversation
- Continuing the Conversation: Reflections and Next Steps





#### **Frequently Asked Questions:**

#### What technology do patrons need to use StoryCorps Connect or the app?

- With the <u>StoryCorps App</u>, participants can record in person using a smartphone (Apple iPhone or Android) or tablet. They'll need to download the StoryCorps App from the App Store, Google Play, or Amazon Store. One person will need to create a StoryCorps account to proceed.
- With <u>StoryCorps Connect</u>, participants can record remotely, with each person joining via a computer or other internet-connected device with a camera and microphone. One person will need to set up the recording and invite their partner to join by visiting storycorpsconnect.org. Both participants will be prompted to create or log into an existing StoryCorps account.

#### Can a patron list their story as private after recording?

- Yes. After recording, participants will be prompted to publish their interview to the StoryCorps Archive, making the recording publicly available online at archive.storycorps.org and sharing it with the American Folklife Center at the Library of Congress. Then they will have the option of choosing among three privacy settings that control how accessible the recording is on the StoryCorps Archive:
  - Everyone: Your interview and related information are available to anyone on the web.
  - **StoryCorps Community:** Your interview and related information are available to anyone with an account on the StoryCorps Archive.
  - Private: Your interview and related information are private.

Learn more here. Patrons can also opt not to publish the recording. Those recording using the app have an additional option to save the recording to their device without publishing it to the StoryCorps Archive. If using StoryCorps Connect, there's no way to save it to your local device.

AN IMPORTANT NOTE ABOUT PRIVACY & SHARING: Regardless of what participants select as a privacy setting, please be aware that StoryCorps may use recorded interviews and other materials in the following ways, including but not limited to: broadcasts on public radio, animated and other audiovisual content, educational use, and any other StoryCorps programs. StoryCorps can also share recorded interviews with community and media organizations for use on their platforms and sites.

#### What do patrons need to know about sharing potentially sensitive health information?

Participants should only share information about their own health that they are comfortable with, and be mindful not to reveal identifying information about others, especially if mentioning diagnoses someone may not want shared publicly. We recommend interview partners check in with each other before, during, and after the conversation to review any personal or sensitive information that may come up during the interview. Direct participants to the <u>Conversation Tips & Considerations for Recording Health Stories</u> section of the <u>Participant Recording Packet</u> to learn more. Interview partners should also discuss in advance whether or not they would both like to share their conversation in the StoryCorps Archive.

#### How can I prepare patrons for difficult conversations?

Sharing a personal health story requires strength and a certain level of vulnerability. This is especially true when sharing stories related to difficult diagnoses or challenging health situations. As you prepare for the recording campaign, consider how best to support patrons throughout the process and how your library and community can create a safe space for sharing. By ensuring patrons are well prepared before a recording, you can help provide a more meaningful storytelling experience. Learn and share more tips for recording health stories in our Conversation Tips section of the Participant Recording Packet.

For troubleshooting and more detailed how-tos, please visit our Help Center at support.storycorps.org.



# RECRUITING PARTICIPANTS

Now that you're familiar with our free tools and the **All Our Voices** recording campaign, it's time to start building engagement and spreading the word to your community. As we grow our collection of health-focused stories, consider setting specific recording and recruitment goals:

- How might you invite patrons and community members to take part? What is important for them to know? What questions might they have? How would you describe the project?
- Whom will you invite to record from your library community? What voices and perspectives are important to include?
- How can you encourage community participation?
- How can you partner with local community organizations to support this work?

**CONSIDER YOUR COMMUNITY:** What local medical or health-related community organizations could you partner with to expand your reach?

# LIBRARY SPOTLIGHT: Otis Library

In 2016, StoryCorps visited Otis Library in Norwich, CT, where participants shared stories about how they were affected by the closing of Norwich State Hospital, a key provider of mental health services in the community. Many of the library's patrons are former patients or staff at the hospital, and the library hoped to use the StoryCorps recordings as a space to reflect on larger themes relating to community health and mental health.

# **RECRUITING TIPS FROM PAST STORYCORPS PARTNERS**

- Extend a personal invitation. Don't rely solely on group emails/announcements. Reach out personally to someone who would benefit from participating.
- Frame the recording as an opportunity to add voices to the broader conversation about health and wellness, with an emphasis on capturing the diversity of health experiences across the country.
- Start with your network. Encourage library staff and/ or volunteers to record stories as you are building your recording campaign. Seeing stories available on the <u>All Our Voices Community Page</u> will inspire more community engagement and participation.
- Connect and collaborate with community partners. Attend community events to share information about the project.
- Share examples of select stories and animations to promote better understanding about the interview process and give participants an idea of what they

may want to discuss. Find curated story playlists in the <u>Sharing Stories</u> section of this toolkit or explore storycorps.org for more.

- Remind participants of their privacy options and that they can choose whether to share their recording or keep it private. Many may wish to share the recording with only a few close friends and family members. Encourage patrons to focus on the conversation first, and then decide if and how they would like to share it.
- Thoughtfully prepare participants. Offer "office hours" to talk about the project in person or in a virtual environment. Library staff may go over the <u>Participant Recording Packet</u>, review what will happen during a recording, discuss the topics that the subjects want to cover, and suggest ways to get the conversation flowing.



# **TIPS FOR PROMOTION**

- Spread the word. Use the sample text and flyer templates in the appendix to share this opportunity on your website, via email, and on social media.
- Establish a timeline and goals. Mapping out timelines and goals for the interviews your community will record is a great motivator for participation.
- Host a "Recording Day" or "Recording Week" (virtually or in person) with specific interview collection goals. Challenge your community to record a set number of stories by a certain date. Promote the campaign for 3-4 weeks on social media leading up to your designated day.
- Kick off your recording campaign with a listening event. Find more tips in the Sharing Stories section of this toolkit.
- Highlight your library's resources. Use the campaign to spotlight health resources at your library and connect recording to regularly scheduled health-focused events or programming.

- Emphasize important calendar dates to encourage theme-based discussion. Choose a specific holiday, anniversary, or themed month (like Breast Cancer Awareness Month) to inspire participants to record conversations. Collect and share stories in the month leading up to that day. Find some suggestions for calendar-based promotion in the *Healthcare Date Pegs Calendar.*
- Share the Participant Recording Packet. Make copies readily available for download or have hard copies available in the lobby of your library.
- Debrief and share positive experiences. Follow up with participants to hear more about their experience. Were there any challenges, surprises, or memorable moments? If participants enjoyed the experience, encourage them to record again with a different partner. Have participants who have already recorded their story go around and talk about their experience to inspire others to participate. Highlight a patron experience in an upcoming newsletter or social media post.

# LIBRARY SPOTLIGHT: Stanford Health Library

**66** I do group presentations, table at community events, distribute collateral materials, share our stories on SoundCloud, and have listening stations in the library. These purposeful introductions to our partnership are a great way to encourage listeners and storytellers, but it comes up organically in conversations on a regular basis. Those who are familiar with StoryCorps are quick to tell me about their favorite clip or how they felt listening to a story. Those who aren't familiar with it are amazed at the chance to record a conversation about whatever is meaningful to them. Offering an established and recognized storytelling opportunity is an important way to serve our patrons, amplify the voices of our community, and engage new library users."

**Gillian Kumagai, MLIS, AHIP** Librarian, Stanford Health Library



# • DIG DEEPER: CONTINUE THE CONVERSATION



If you are interested in building long-term storytelling programming at your library, we invite you to explore **StoryCorps DIY**.

StoryCorps DIY is a collection of multimedia resources for educators, libraries, and nonprofit organizations who want to embed StoryCorps practices into their classrooms and communities. These self-paced, asynchronous courses give you tools, insights, and knowledge to capture milestones, create connections, and fuel learning within your community. StoryCorps DIY is best suited for groups and organizations that wish to create a sustainable community program around storytelling.

In our **Fundamentals Course**, we share best practices to create your own StoryCorps-inspired recording project, including program planning, recruiting and preparing participants, facilitating and recording, equipment recommendations, and archiving and sharing your stories. From there, you can go deeper, with even more insights on using the StoryCorps model in your community.



# **SECTION RECAP: Quick Links**

# PARTICIPANT RESOURCES, DIGITAL TOOLS, & HELP:

StoryCorps App StoryCorps Connect

Participant Recording Packet

All Our Voices Community Page

All Our Voices Activities Sheet

Help Center: support.storycorps.org StoryCorps DIY: diy.storycorps.org StoryCorps Terms of Use



# **EXPLORING THE ARCHIVE**





# EXPLORING THE STORYCORPS ARCHIVE

StoryCorps' Archive is one of the largest born-digital collections of human voices, featuring tens of thousands of conversations recorded across the United States and around the world, with new conversations added every day. The StoryCorps Archive platform was developed as a resource for people who have recorded with StoryCorps and the general public, as well as students, educators, researchers, non-commercial media makers, community partner organizations, and others involved in scholarly or cultural work.

The StoryCorps Archive and the stories it holds offer valuable insight from diverse perspectives on health and well-being. In this section we will share ways to explore the archive and guide your patrons to use the archive as a resource and inspiration for their own health and wellness conversations.

You can access StoryCorps stories online in two different places:

#### archive.storycorps.org

Explore the **StoryCorps Archive** of thousands of full-length, unedited (usually 40-minute) conversations facilitated by StoryCorps, and thousands more recorded by users throughout the country using the StoryCorps App and StoryCorps Connect. These interviews are also archived at the American Folklife Center at the Library of Congress.

#### storycorps.org/stories

Explore the **Broadcast Collection** of stories edited and shared by StoryCorps as audio clips or animations. You can use the search function to find stories with specific keywords.

#### **A Note on User-Generated Content**

The StoryCorps Archive contains user-generated content that is not reviewed before it is posted online. While we adhere to a strict set of Community Guidelines and work to maintain a culture of tolerance and acceptance, not all published content will be appropriate for all individuals. We ask library staff to familiarize themselves with the StoryCorps Archive, and to review the <u>Community Guidelines</u> and <u>Terms of Use</u> at archive.storycorps.org, before recording or adopting the project.

*I'm hoping that the section of the interview talking about the illness might touch others with the same illness. It's very difficult to connect with other people facing this condition."* 

StoryCorps Participant

Follow StoryCorps on social media to discover stories from our collection.



# **EXPLORE THE ARCHIVE: CONVERSATIONS ABOUT HEALTH AND WELLNESS**

The StoryCorps Archive has hundreds of health-focused stories. You just need to dig to find them! Invite your patrons to engage with the StoryCorps Archive as a valuable resource in the following ways:

- Learn search tips to explore the digital collection, finding special interest stories or themes.
- Perform medical-related searches to hear first-person accounts of people living with specific illnesses.
- Create "collections" of curated conversations to group favorite stories.
- Get creative. Use the archive as a part of larger programming. Some ideas:
  - Host a "book" group to discuss stories from the archive. Use the curated playlist to get started.
  - Share StoryCorps stories with support groups.
  - Use in educational programming to promote information literacy: send students on an archive scavenger hunt, for example.

Find more activities you can share with your patrons in the <u>Programming Tools</u> section of the appendix, including <u>Activities for Exploring the StoryCorps Archive</u>.





# SEARCHING THE STORYCORPS ARCHIVE

Each StoryCorps interview in the archive is tagged with relevant keywords, place information, and descriptions of the conversation. You can search this metadata in the online archive and sort by date, names, keywords, organizations, location, and language. Conversations can also be grouped into Community Pages—like the #AllOurVoices Community Page.

To search the StoryCorps Archive, first create a free account and log in. It's possible to search publicly listed interviews in the archive without an account, but you will have access to a larger collection of stories when logging in with an account.

If you search the word *health*, for example, you will have access to 723 public interviews (as of the date we performed our search), but if you log into your Online Archive account, you will have access to 8,458.

SEARCH INTERVIEWS	CLEAR
health	٩
591 MATCHES , LOG IN TO VIEW ALL 8253	

If you have already recorded a conversation on StoryCorps Connect or the StoryCorps App, you can log into your existing account.

To create your account, click on the "LOG IN" button and follow the instructions.



# **General Search**

You can search for interviews by typing a term or phrase into the search box, as with *health* above. If you are searching a phrase, use **quotations** around the entire phrase, as with "physical therapy" shown here:





# REFINE

English

DATE RANGE	CLEAR
RECORDED BY	CLEAR
Recorded by StoryCorps	3
KEYWORDS	CLEAR
<ul> <li>personal experiences</li> </ul>	2
college	3
craft, skills, and procedures	2
first impression of America	2
memories of growing up	2
56 MORE >	
ORGANIZATIONS	CLEAR
No matching terms.	
PLACES	CLEAR
No matching terms.	
LANGUAGES	CLEAR
✓ Spanish	3

# KEYWORDSCLEARImage: personal experiences62Image: personal experiences62Image: Spouse62Image: personal experiences62Image: personal experiences62<

## **Refine Search**

The example of "physical therapy" returns 362 interviews, which is a lot! Use the **Refine** options on the left side of the webpage to refine those results using the following categories:

- Date Range
- Recorded by (Users or StoryCorps)
- Keywords
- Organizations
- Places
- Languages

You can refine your search using more than one category—for example, Keywords and Languages. Refining our "physical therapy" search using the keywords "personal experiences" and the language Spanish, yields three interviews.

You can also choose more than one option in a Refine category. If you want to choose two keywords, choose your first keyword—the search results will update automatically. Then choose the second, and your search results will update again. The results will be interviews that include **both** of your chosen keywords.

1



If you don't see what you're looking for on the short list under one of the categories, there may be more options available. Click on "MORE," and a new box will pop up with more options. Use the search bar to search within that list, or scroll though through to choose what you're looking for. Once you've chosen, hit "UPDATE QUERY" in the bottom right.

Search FILTER		
Religious Beliefs And Practices (27)	Birth Of First Child (25)	Social Beliefs And Practices (24)
School Day Memories (23)	College (22)	Cohorts (Groups Of Friends) (21)
Illness (18)	Family Traditions (17)	Family Trips And Excursions (16)
Injuries (14)	Craft, Skills, And Procedures (13)	Accidents (11)
Family Characters (11)	Regimens (9)	Family Doctor Stories (8)
Economic Beliefs And Practices (7)	Influential People (7)	Physical Therapy (7)
Political Beliefs And Practices (7)	Pregnancy And Pre-Natal Care (7)	Appearance (6)
Childhood Games (6)	Family Naming And Nicknames (6)	Historical Events/People (6)
Family Expressions (5)	Family In-Jokes (4)	Family Members In History (4)
Family Reunions (4)	First Impression Of America (4)	Money (4)
Polio (4)	Prejudice (4)	Car Accident (3)
Chemotherapy (3)	Church (3)	Dancing (3)
E	A	
SHOW MORE ¥		UPDATE QUERY

At any time, you can clear your choices from each category. Your choices in the other categories will remain. If you want to clear your entire search and start a new search for interviews, click "CLEAR" over the search box.

## **Results View**

Adjust the presentation of results by using options just below the search bar and above the results. You can change how many items, or interviews, display per page. You can also sort your results by oldest or newest or relevance to your original search term and any refining you do.





## **Suggested Keywords for Health Stories**

Test out some of these keywords in the archive. These are just a few ideas to get started. What keywords are missing from this list? What might you add?

Aging	Caregiving	Grief	Mental Illness
AIDS	Chronic Illness	Healthcare	Mental Wellness
ALS	COVID-19	Heart Surgery	Mindfulness
Alzheimer's	Cystic Fibrosis	Heart Transplant	Nursing/Nurses
Asperger's	Death	HIV	Organ Donor
Assisted Living	Dementia	Hospice, Hospice Care	Palliative Care
Autism	Diagnosis	ICU	Pediatric
Breast Cancer	Disability	Infant Mortality	Physical Therapy
Cancer	Doctor	Kidney	Pregnancy & Prenatal Care
Cancer Survivor	Donor, Donating (Blood)	Medical Research	PTSD
Cardiac Arrest	End of Life	Memory Loss	Traumatic Brain Injury

As you begin to search the StoryCorps Archive, you may find certain favorite stories you would like to save or group in a collection. There are a number of helpful FAQs on how to save favorites and make collections here:

Can I create a playlist or a collection of interviews? How do I save my favorite interviews in the archive?





# CURATED HEALTH STORIES FROM THE ARCHIVE

Using some of the search parameters above, we have assembled a collection of healthfocused stories, along with the search terms used to find each story. This list is available to share with your patrons in the **Programming Tools** section of the appendix.

## **Shalonda Griffin and Gregory Jones**

August 7, 2019 Recording Length: 22:25 minutes



lives and marriage.

#### **SEARCH TERMS:** DIABETES, ILLNESS, HOSPITALS

# Alexander Feliz, Cynthia Cross, and Nico West

September 25, 2019 Recording Length: 37:29 minutes



Cynthia Cross (61) talks with friends and colleagues Alexander Feliz (49) and led them to the field of medicine, the issue of health

Shalonda Griffin (40) and

her husband Greg Jones

(40) reflect on the health

issues Greg has faced over

the past 12 years and how

navigating different medical

challenges has affected their

care, the "human side" of healthcare, social determinants of health, and advice for others.

SEARCH TERMS: HEALTH INEQUITY, PHYSICIAN SCIENTIST, **EPIGENETICS** 

#### **Tiffani Martin and Lisa Winkley**

November 6, 2019 Recording Length: 36:44 minutes



through good times and bad.

SEARCH TERMS: DISABILITIES, BEING BLIND, DISEASES, HEALTH

## **Olivia Wein and Harrison Wein**

May 28, 2015 Recording Length: 40:47 minutes



Harrison Wein (46) interviews his wife of 25 years, Olivia Bae Wein (48), about being diagnosed with stage 4 non-Hodgkin's lymphoma as a teenager. Olivia talks about being

involved in a clinical trial at the National Institutes of Health (NIH), and Harrison remembers meeting her in college.

SEARCH TERMS: DIAGNOSIS, NON-HODGKIN'S LYMPHOMA, **CLINICAL TRIAL** 

Nico West (43) about what

inequity and disparities in



## Lindsay Sheehan and Sonya Ballentine

January 28, 2016 Recording Length: 37:08 minutes



Colleagues Sonya Ballentine (48) and Lindsay Sheehan (36) discuss their work for a program at the Illinois Institute of Technology that seeks to improve healthcare for African Americans with

Joyce-Anne Velez (58) and her friend Aida Richardson

diagnosis of breast cancer,

dealing with her treatment,

educators (or promotaras) in

(59) talk about Aida's

and both being health

mental illness. Sonya is an African American woman with mental illness who started as a research participant and moved into a research partner position.

**SEARCH TERMS:** ANXIETY DISORDER, BIPOLAR DISORDER, COMMUNITY-BASED PARTICIPATORY RESEARCH

#### **Aida Richardson and Joyce-Anne Velez**

October 7, 2009 Recording Length: 39:43 minutes



the Latinx community.

# **SEARCH TERMS:** BREAST CANCER, HEALTH EDUCATION, PROMOTARAS

## Nikesha Williams and Christa Sylla

December 1, 2018 Recording Length: 39:25 minutes



Friends and colleagues Nikesha Williams (32) and Christa Sylla (39) share their connections and origins with traditional African dance, and the importance of self-care and healthy habits in their

lives. Skip to the 20-minute mark for specific discussion about self-care.

#### SEARCH TERMS: SELF-CARE

## Karen Cook, Andrew Cook, and Michelle Haney

February 27, 2019 Recording Length: 55:05 minutes



Andrew Cook (22), his mother Karen Cook (64), and Andrew's teacher Dr. Michelle Haney (50) talk about their relationships to each other, Andrew's self-advocacy and self-determination, access to

education and opportunities for people with disabilities, and Andrew's future goals.

**SEARCH TERMS:** PEOPLE WITH DISABILITIES, SELF-ADVOCACY, ACCESSIBILITY FOR PEOPLE WITH DISABILITY

## **Daniel Abril and Gloria Abril**

March 8, 2013 Recording Length: 40:40 minutes



Gloria Abril (62), an advocate for her nephew Daniel Abril (25), interviews him about his struggle with mental illness and what has been most challenging throughout his journey.

**SEARCH TERMS:** NATIONAL ASSOCIATION FOR MENTAL ILLNESS, MENTAL HEALTH, DEPRESSION, ADVOCATE

#### **Jason Foster and Steven C. Collins**

February 13, 2006 Recording Length: 42:19 minutes



Jason Foster (35) and his friend and co-worker Steven C. Collins (52) talk to each other about their experiences as cancer survivors. They share a comprehensive, insightful,

and open conversation about difficult subjects, including prostate cancer and testicular cancer.

**SEARCH TERMS:** ILLNESS, TESTICULAR CANCER, SUPPORT SYSTEM, CROHN'S DISEASE



## Sonya Begay and Kayle Eppele

June 11, 2020 Recording Length: 39:34 minutes



Sonya Anne Begay (63) is interviewed by her granddaughter Kayle Nanah Eppele (19) about how her family came together, her worries about her family in the Navajo reservation, and

the lack of resources for underserved communities and elders.

**SEARCH TERMS:** COVID-19 PANDEMIC, QUARANTINE EXPERIENCES

# **Stories Recorded in Spanish:**

The StoryCorps Archive contains stories recorded in many different languages. We searched conversations recorded in Spanish to find this health-focused recording. You can find more stories at archive.storycorps.

## Jorge R. Miranda Massari and Herbert Massari Sánchez

January 22, 2010 Recording Length: 35:39 minutes



Herbert Massari Sánchez (86) y su sobrino Jorge R. Miranda Massari (50) conversan sobre el estado de las farmacias en Puerto Rico en las últimas décadas de los 1800s y las primeras décadas

de los 1900s, y también conversan sobre sus vidas como farmaceuticos y padres.

Herbert Massari Sánchez (86) and his nephew Jorge R. Miranda Massari (50) talk about pharmacies in Puerto Rico in the late 1800s and the early 1900s, about their lives, and about parenthood.

#### SEARCH TERMS: FARMACEUTICO, ILLNESS, CURES

# **SECTION RECAP: Quick Links**

StoryCorps.org

<u>StoryCorps Archive</u>—archive.storycorps.org Broadcast Collection—storycorps.org/stories

StoryCorps Help Center

<u>Community Guidelines</u> Terms of Use

# **PATRON RESOURCES**

Find more activities you can share with your patrons in the <u>Programming Tools</u> section of the appendix, including:

Searching the StoryCorps Archive

Activities for Exploring the StoryCorps Archive





# **SHARING STORIES**





# THE POWER OF LISTENING AND ENGAGING WITH STORIES

# Why Share Stories about Health and Wellness?

StoryCorps' mission is to preserve and share stories in order to build connections between people and create a more just and compassionate world. We share stories from our archive to listen to and learn from one another. Listener survey results show that StoryCorps content is shifting how listeners feel about other people and society, as well as how they think and behave after their exposure to StoryCorps. With increased knowledge and empathy, listeners will feel more connected to those around them and take these feelings into the world in positive ways.

According to **2019 Online Listener Survey**<sup>1</sup> results, listening to StoryCorps stories effected changes in empathy, human connection, and perception of society at large:

- 94% of online survey respondents reported that listening to StoryCorps helped them better understand the experiences of people who are different from them.
- 89% said that listening to StoryCorps made them feel connected to others.
- 85% said that they felt positively about society as a result of listening to StoryCorps.

6 It is impossible to be involved in a StoryCorps interview and not be changed in some way."

StoryCorps Participant

Listening to StoryCorps also influenced participant thoughts and actions inspired by listening:

- > 87% reported that StoryCorps had helped them better understand certain social events, issues, or policies.
- Listening to StoryCorps inspired **70%** to think about how society could be improved.
- 65% were moved to express gratitude to someone in their lives, and 62% to strengthen connections with family or friends.
- 60% were inspired to speak with a friend, colleague, or family member about a social or political issue after listening to StoryCorps.
- **54%** became more interested in a social or political issue after listening to StoryCorps.

1. In 2019, 321 listeners responded to the online listener survey. Of these, 40% listen to StoryCorps three or more times per month.



By listening to and participating in conversations about health and wellness, people can be inspired to actively participate in and learn about their own health, build connections, and feel less alone in their health journeys. We hope that sharing these stories deepens dialogue in your community.

In this section, you will find:

- Links to curated story playlists from StoryCorps' Broadcast Collection.
- Ideas for sharing health and wellness stories to spark community dialogue.
- **Everything you need to host a listening event** featuring stories about health and wellness.

# LIBRARY SPOTLIGHT: Stanford Health Library

6 Our participants have ranged in age from 10 to 90-something and have recorded in multiple languages. We have heard from patients, caregivers, family members, doctors, nurses, patient transporters, facilities staff, and others. No two stories are alike, but there are common threads: the impact of illness, the importance of relationships, how people want to be seen, understood, and remembered. Storytelling and listening help us build empathy and compassion and promote healing, resilience, and stronger communities. This has come to life in our work with StoryCorps."

Gillian Kumagai, MLIS, AHIP Librarian, Stanford Health Library



# SHARE STORIES AND CELEBRATE YOUR COMMUNITY

Sharing examples of recorded StoryCorps conversations is a great way to build excitement about recording. And because the StoryCorps Archive is online, sharing stories with your community is easy! Consider hosting a community gathering to share example stories and encourage patrons to start recording on their own. Community events can be a great way to connect to neighbors and friends about specific health topics and provide your library an opportunity to build relationships with and collaborate with other community organizations.



# EVENT PLANNING

A StoryCorps All Our Voices event can be as simple as bringing community members together in conversation, hosting an event at your library, or creating a public event in partnership with another nonprofit organization, school, or faith community. Regardless of what you do, center your event around the spirit of sharing, while acknowledging that, for some, the stories and memories that come up around health and wellness topics may be challenging.

Your event could build awareness of a specific health topic and encourage larger discussions around the impact of health and wellness on people in our communities. There are many ways to engage patrons and bring communities together:

- MEET AND GREETS: Have audience members pair up and ask each other questions from the <u>All Our</u> <u>Voices Custom Questions</u> list. Encourage them to record a story from home using the StoryCorps App or StoryCorps Connect.
- SCREENINGS: Screen the All Our Voices animation "Destined to Be" and use the <u>Discussion Guide</u> to spark dialogue among community members.
- ▶ **WORKSHOPS:** Use StoryCorps stories to support existing health and wellness workshops or support groups at your library or in partnership with community organizations.
- LISTENING EVENTS: Invite your community to listen to health and wellness stories. These events could demonstrate the importance of sharing health journeys, provide examples of community support, and show the impact participating in medical research can have on finding cures for diseases.

# LIBRARY SPOTLIGHT: Embudo Valley Library and Community Center, New Mexico

In 2019, the library collaborated with Barrios Unidos, an organization supporting families fighting addiction, to record stories of people affected by opioid abuse. After recording with StoryCorps, they edited select stories and hosted a virtual listening event: "Their Heart Is to Serve: Compassionate Conversations about Healthcare in Northern New Mexico." Led by library staff, community members, participants, and representatives from local community health organizations listened to stories and reflected together on community health resources and needs. See the full event info here: **embudovalleylibrary.org/news-blog-posts/their-heart-is-to-serve** 



## **CONSIDERATIONS FOR VIRTUAL EVENTS**

Virtual events offer an exciting opportunity to build community, even when we aren't able to be together physically. The chance to connect online with others can increase accessibility for some, provide opportunities for others to improve their digital literacy, and allow a wider reach for programming at your library. While it may take some adjustment to get used to our new virtual "normal," we do hope the materials in this toolkit will help you reimagine the possibilities of connecting virtually. Here are a few tips for hosting a virtual listening event:

- Choose a format. Decide how interactive you want your event to be to determine if you'll host on a webinar or meeting platform. What will the format be? Do you want participants to see and hear each other?
- Test your tech. Be sure to test any video or audio ahead of time.
- Allow time to practice. Offer patrons an opportunity to get comfortable with the platform you're using during a guided practice session ahead of the event.
- Strength in numbers. Have a team of staff or volunteers to help run the program, each with designated roles: someone to host, another to monitor your chat and questions, and someone designated to support with technology and/or run your slides.
- Encourage conversation. Foster connections and community-building by providing opportunities for interaction and reflection: chat, spoken Q&A, reflection questions, breakout groups. Encourage people to ask questions and make comments using the chat function. It may be helpful to have a second person monitoring the chat for the lead facilitator. Experiment with breakout groups to increase engagement. If you have a large enough group, try creating small group discussions in breakout rooms.
- Consider accessibility. We recommend providing Remote CART services during your virtual event. Providing live captions supports those who are deaf, hard of hearing, new English language learners, and those who learn best visually, making your event accessible to an even wider audience.

## CONSIDERATIONS FOR IN-PERSON GATHERINGS

While it may not be possible to host in-person activities safely at this time, here are some tips for hosting future events:

- Be visible. Find a space in your community that is easy for people to get to or that they go to regularly.
- **Keep accessibility in mind.** 
  - Think about time/place, parking, bathrooms, childcare, etc.
  - Is there an elevator and/or flexible seating for people who have difficulty walking or are using wheelchairs? Does the entrance to your event space require climbing stairs?
  - When you promote your event, communicate about these items, and provide contact information for additional accessibility questions or requests.
- Sound check! Will everyone be able to hear? What technology or audio equipment will you use to project sound?
- Choose your stories. What stories or themes feel important to address during your event? Are there any important considerations in terms of choosing stories to play for your intended audience? Refer to the <u>Healthcare Date Pegs Calendar</u> for more ideas.
- Choose a format. Will you leave time for audience questions? If so, who from your organization will be prepared to respond to audience questions?
- Invite guest speakers. Consider who could join as a guest speaker, field expert, or storyteller.


# CURATED STORY PLAYLISTS

Conversations about Health and Wellness from the StoryCorps Broadcast Collection

The **StoryCorps Broadcast Collection** is home to hundreds of stories edited and shared as audio clips or animations, many of which focus on health and wellness topics. Here is a curated collection of stories sorted by theme that you can share with your patrons or use to promote recording programs at your library. Many of these stories focus on topics of diversity in healthcare, genetics and inherited disease, and overall health literacy. Use these stories to spark health and wellness conversations in your community.

Consider sharing some of these playlists in coordination with your existing programming, as part of a listening event, or on date-specific health appreciation days or months—pick and choose what works for you. Visit the <u>Healthcare Date Pegs Calendar</u> for more ideas, and find the full story playlists in the attached appendix. You can share each full playlist as a PDF from the hyperlinks below, or share individual stories on your social media feeds.

#### **CAREGIVER STORIES**

Whether at home in a family setting or in a professional capacity, it takes special strength and patience to be a caregiver. Listen to these stories of caregiver courage and wisdom.

#### PATIENT STORIES: LIVING WITH CANCER

Listen to these StoryCorps participants share wisdom from their own cancer experiences, including personal stories and supporting family and friends.

#### **PATIENT STORIES: LIVING WITH HIV/AIDS**

In these StoryCorps conversations, people share the impact that HIV/AIDS has had upon their lives and the lives of their loved ones.

#### **PEOPLE WITH DISABILITIES**

This collection highlights the voices and unique experiences of those living with disabilities, along with their loved ones who offer support and admiration.

**STORYCORPS.ORG** | **COPYRIGHT** © **2021, StoryCorps Inc.** StoryCorps is an independently funded nonprofit organization. Learn more at storycorps.org. The good thing about telling my story was that it showed that I am not just a kid with a disease. I have friends and ambitions. The story got to be about me as a person and human being."

StoryCorps Participant





#### CIVIC DUTY AND CONNECTION IN THE DAYS OF COVID-19

Despite being miles apart, our new platform, StoryCorps Connect, allows friends and family to interview in the safety and comfort of their own homes. This collection highlights the voices of essential workers and loved ones who have found new ways to connect with each other. Visit the YouTube playlist <u>here</u> or view these stories on the StoryCorps blog <u>here</u>.

#### SAMPLE LISTENING EVENT AGENDA/RUN-OF-SHOW

Use this <u>template slide deck</u> to build your community listening event. Here is a sample agenda for an hour-long event:

- Welcome (5 minutes)
- Introduction to All Our Voices Recording Campaign and StoryCorps (5 minutes)
- Play 2-3 themed stories (10 minutes)
- Guest Panelist (5 minutes)
- Audience Q&A or Activity (15 minutes)
- Closing Story, Thank You, and Call to Action: For example, record your own story and add it to the All Our Voices collection (5 minutes)

#### **PROMOTING YOUR EVENT**

- Partner with Community Organizations: Harness the power of existing (or new!) partnerships to promote your event or to provide panelists. Are there health-related partners who might be interested in co-hosting an event?
- Build a Timeline: Set a date for your listening event and build excitement by sharing posts leading up to your event. Use this <u>All Our Voices Listening</u> Event flyer template to promote your event.
- Get Social: Advertise your event on social media to raise awareness of health conversations and the recording campaign at your library. Use <u>this sample</u> copy to share the stories on social media channels.

We invite you to share stories from the StoryCorps collection as part of your public and educational programming. Please provide credit and mention @StoryCorps in social media posts when possible. Here is sample credit language:

This interview is provided courtesy of StoryCorps, a national nonprofit whose mission is to preserve and share humanity's stories in order to build connections between people and create a more just and compassionate world: www.storycorps.org.



#### "Destined to Be"

Friends Sabrina Beavers and Shantay Davies-Balch work together as community health advocates for Black women's maternal health. At StoryCorps, they talk about the premature birth of Sabrina's daughter, Destiny, and the barriers to good care Black women face during pregnancy.

This StoryCorps story is brought to you in partnership with the Network of the National Library of Medicine and the National Institutes of Health *All of Us* Research Program (*All of Us*).

Find the **Destined to Be Discussion Guide** in the Programming Tools section of the appendix.

Use this guide to prompt conversation at your Listening Event, or on its own to share with patrons.





#### • DIG DEEPER

After you host your first event, you may find community members want to stay connected and continue to engage in discussion. Here are some resources for supporting those connections beyond the initial listening event:

- Writing Groups: Establish writing groups using stories as writing prompts. Download the <u>All Our</u> <u>Voices Activities</u> for three additional exercises. These could be used to support event programming, or shared individually.
- Discussion Groups: Encourage community members to establish regular discussion or support groups around specific topics (consider some of the themes in our playlists above).
- Reading Groups: Develop health-related reading lists using materials in your library. Visit the NNLM Reading List to join the <u>NNLM book club</u>, or use some of the books on the list as a starting point for discussion groups.
- Story Spotlight: As your patrons begin to record, feature their stories in your library's newsletter, or highlight their experiences in a Facebook post.
- Expand Your Reach: Do you want to become more involved in the NNLM All of Us Community Engagement Network (CEN) as a whole? Visit <u>this link</u> to find different engagement opportunities that fit your community's needs and interests.

#### **QUICK LINKS**

#### **PROMOTIONAL TOOLS:**

All Our Voices Promotional Flyer

Join the All Our Voices Recording Campaign

All Our Voices Listening Event Flyer templates

Social Media Sample Text

#### **PROGRAMMING TOOLS:**

All Our Voices Activities

Destined to Be Discussion Guide

Listening Event Slides

**Curated Playlists** 

#### HELP

If you need additional support, please contact our Learning & Engagement team at communitytraining@storycorps.org



# ABOUT STORYCORPS

Founded in 2003 by Dave Isay, StoryCorps has given over 600,000 people of all backgrounds and beliefs the chance to record interviews about their lives. The organization preserves the recordings in its archive and with the Library of Congress and shares select stories with the public through StoryCorps' weekly podcast, NPR broadcasts, animated shorts, digital platforms, and best-selling books. These powerful human stories reflect the vast range of experiences from across the United States, engender empathy and connection, and remind us of our shared humanity.

Over the past 16 years, StoryCorps has continuously developed tools to support communities as they record and preserve their stories in their own words, with a commitment to hearing from those traditionally underrepresented in the media and history books. Libraries and healthcare organizations have been key partners throughout our history. Through several IMLS-funded programs and StoryCorps Legacy, StoryCorps has trained libraries, hospitals, palliative care centers, and other community health organizations to embed storytelling in their programs.



#### **About the StoryCorps Archive**

The StoryCorps Archive is the largest single collection of human voices, featuring conversations recorded in all 50 states and Puerto Rico. The full collection of interviews is housed at the American Folklife Center at the Library of Congress in Washington, D.C.

Visit archive.storycorps.org to access a selection of the interviews shared by people who have recorded a conversation with StoryCorps since 2003. This site represents a growing archive: new interviews are added every day by StoryCorps and by people from across the country and around the world. It was developed as a resource for the public, as well as students, educators, researchers, noncommercial media makers, community partner organizations, and others involved in scholarly or cultural work.

# About the National Library of Medicine's partnership with the *All of Us* Research Program

National Library of Medicine

The National Library of Medicine (NLM) has partnered with the NIH *All of Us* Research Program (*All of Us*) to help public libraries in supporting the health information needs of their users. Through its main outreach initiative, the Network of the National Library of Medicine, NLM provides

(a) health information training for public library staff,

(b) funding and other resources to support health programming and activities, and

(c) connections to medical libraries and other NNLM members in their area.

The NNLM also supports the *All of Us* community engagement activities by leveraging public libraries as community conveners where the public and *All of Us* consortium partners can find help locating information, meeting spaces, and access to technology.

Learn more about how your public library can participate in the program at <u>nnlm.gov/allofus</u>.





#### What is All of Us?

*All of Us* is a national research program whose mission is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for *all of us*.

The goal of the program is to help researchers understand more about why people get sick or stay healthy. By looking for patterns, researchers may learn more about what affects people's health.

All of Us aims to build one of the largest, most diverse datasets of its kind for health research, with one million or more volunteers nationwide who will sign up to share their information over time (it is a 10-year program).

The program aims to reflect the diversity of the United States through its participants. All people living in the United States—not just citizens—will be eligible to participate.

*All of Us* is a bilingual program, with all components of the program available in English and in Spanish. Additional languages will be added in the future.

Learn more about *All of Us* at joinallofus.org/nlm (English) or joinallofus.org/bnm (Spanish).





## NNLM *All of Us* Community Engagement Resources

The **NNLM Community Engagement Network (CEN)** works with storytelling and information organizations, like StoryCorps and public libraries, to promote equal access to reliable health information, education, and conversation for a diverse population. Visit <u>nnlm.</u> <u>gov/allofus</u> to find contacts for your regional medical library (RML) and learn more about this program.

Access the <u>NNLM Community Engagement Toolkit</u> and find a collection of resources, methods, and best practices for organizations engaging their communities, and meaningful ways to build connection, support, and understanding of health and wellness.

nnlm.gov/allofus/communityengagement

Read the NNLM blog "Bringing Health Information to the Community": <a href="mailto:news.nnlm.gov/bhic/">news.nnlm.gov/bhic/</a>

Join *All of Us* to be a part of building a diverse and equitable database for health research and medical breakthroughs: joinallofus.org/nlm

#### **MedlinePlus resources**

MedlinePlus is an excellent source for trusted health information and connection. The website provides knowledge, advice, and additional resources on an extensive range of mental and physical wellness topics. Whether you are looking to understand the concept of precision medicine, or are searching for health issues specific to a certain population, MedlinePlus covers it all. Here are a few helpful links:

#### medlineplus.gov

medlineplus.gov/genetics/understanding/ precisionmedicine/ medlineplus.gov/latinoandhispanicamericanhealth.html medlineplus.gov/lgbtqhealth.html medlineplus.gov/caregiverhealth.html magazine.medlineplus.gov



**APPENDIX** 

#### **PROMOTIONAL MATERIALS**

<b>A3</b>	All Our Voices Promo Flyer
<b>A4</b>	Join the All Our Voices Recording Campaign Flyer
A5	Healthcare Date Pegs Calendar

#### **PROGRAMMING TOOLS**

 A7 HONOR | Searching the StoryCorps Archive
 A10 HONOR | Activities for Exploring the StoryCorps Archive
 A13 HONOR | Curated Health Stories in the Archive
 A16 SHARE | "Destined To Be" Discussion Guide
 A19 SHARE | All Our Voices Activities
 A23 SHARE | Curated Playlists

#### **PARTICIPANT RECORDING PACKET**

P2	Welcome
<b>P7</b>	Join the All Our Voices Community & Recording Campaign
<b>P12</b>	Conversation Tips & Considerations for Recording Health Stories
<b>P14</b>	Custom Questions for Health & Wellness Conversations
<b>P16</b>	Planning for Your Conversation
<b>P18</b>	Next Steps: Reflections and Questions After the Conversation

## PROMOTIONAL MATERIALS



### **STORYCORPS**







#### Join a national health and wellness conversation. It's as easy as 1 - 2 - 3...



1.

Record a conversation about your health journey using free digital tools from StoryCorps.



2. Honoz

Explore other stories about health and wellness in your community and the StoryCorps Archive; add your voice to the collection.



3.

Spread your story and join meaningful community dialogues about health and wellness, at your library and beyond.

# Ask your library staff for more information and join #AllOurVoices today!





## JOIN THE ALL OUR VOICES COMMUNITY & RECORDING CAMPAIGN

Record Your Conversation: Step by Step



# HEALTHCARE DATE PEGS CALENDAR

Consider developing calls to record stories or host listening events and/or community discussions around specific themes or monthly health recognition and awareness days.

- Select a theme from the list below.
- Designate a recording day or week for your community members to share their health stories related to the theme.
- Host a listening event sharing stories based on that theme, either from your community members or from the StoryCorps Archive.
- Use the <u>Curated StoryCorps Story Playlists</u> as a starting point.

For more ideas, visit the National Health Observances resources page compiled by the Network of the National Library of Medicine (NNLM): nnlm.gov/allofus/healthobservances

#### Here are a few calendar theme ideas for health-specific conversations:

January	February	March	April
• National Volunteer Blood Donor Month • Cervical Cancer Awareness Month	<ul> <li>Children's Mental Health Awareness Week</li> <li>World Cancer Day</li> <li>National Black HIV/AIDS Awareness Day</li> <li>National Donor Day</li> </ul>	<ul> <li>National Traumatic Brain Injury Awareness Month</li> <li>National Native American HIV/AIDS Awareness Day</li> <li>Trans Day of Visibility</li> </ul>	<ul> <li>Parkinson's Awareness Month</li> <li>National Autism Awareness Month</li> <li>World Health Worker Week</li> <li>World Health Day</li> <li>Healthcare Decisions Day</li> <li>Patient Experience Week</li> </ul>
Мау	June	July	August
ALS Awareness Month National Mental Health Month National Nurses Day	<ul> <li>National Cancer Survivors Day</li> <li>World Sickle Cell Day</li> </ul>	• Americans with Disabilities Act (ADA) Day	<ul> <li>National Immunization Awareness Month</li> <li>Talk to Your Doctor Month</li> </ul>
September	October	November	December
<ul> <li>Blood Cancer Awareness Month</li> <li>World Alzheimer's Month</li> <li>Leukemia, Lymphoma, and Myeloma Awareness Month</li> <li>Healthy Aging Month</li> </ul>	<ul> <li>Health Literacy Month</li> <li>National Medical Librarians Month</li> <li>Pregnancy and Infant Loss Awareness Month</li> <li>Breast Cancer Awareness Month</li> <li>National Mental Illness Awareness Week</li> <li>National Latino AIDS Awareness Day</li> <li>Pregnancy and Infant Loss Awareness Day</li> </ul>	<ul> <li>National Hospice and Palliative Care Month</li> <li>National Family Caregivers Month</li> <li>National Alzheimer's Disease Awareness Month</li> </ul>	• AIDS Awareness Month • World AIDS Day

National Library of Medicine

**STORYCORPS** 



- HONOR | Searching the StoryCorps Archive
- **HONOR** | Activities for Exploring the StoryCorps Archive
- HONOR | Curated Health Stories in the Archive
- SHARE | "Destined to Be" Discussion Guide
- SHARE | All Our Voices Activities
- SHARE | Curated Playlists

**A7** 

A10

A13

A16

A19 A23



Rx







# SEARCHING THE STORYCORPS ARCHIVE

Each StoryCorps interview in the archive is tagged with relevant keywords, place information, and descriptions of the conversation. You can search this metadata in the online archive and sort by date, names, keywords, organizations, location, and language. Conversations can also be grouped into Community Pages—like the #AllOurVoices Community Page.

To search the StoryCorps Archive, first create a free account and log in. It's possible to search publicly listed interviews in the archive without an account, but you will have access to a larger collection of stories when logging in with an account.

If you search the word *health*, for example, you will have access to 723 public interviews (as of the date we performed our search), but if you log into your Online Archive account, you will have access to 8,458.

SEARCH INTERVIEWS	CLEAR		
health	٩		
591 MATCHES , LOG IN TO VIEW ALL 8253			

If you have already recorded a conversation on StoryCorps Connect or the StoryCorps App, you can log into your existing account.

To create your account, click on the "LOG IN" button and follow the instructions.



#### **General Search**

You can search for interviews by typing a term or phrase into the search box, as with *health* above. If you are searching a phrase, use **quotations** around the entire phrase, as with "physical therapy" shown here:





#### REFINE DATE RANGE CLEAR RECORDED BY CLEAR Recorded by StoryCorps 3 **KEYWORDS** CLEAR personal experiences college 3 craft, skills, and procedures 2 first impression of America 2 memories of growing up 2 56 MORE > ORGANIZATIONS CLEAR No matching terms. PLACES CLEAR No matching terms. LANGUAGES CLEAR Spanish English 1 **KEYWORDS** CLEAR

# KEYWORDSCLEARImage: personal experiences62Image: Spouse62Image: Spouse62Image: memories of growing up42Image: Image: Anisotral anecdotes (humorous but true stories)37Image: Image: I

#### **Refine Search**

The example of "physical therapy" returns 362 interviews, which is a lot! Use the **Refine** options on the left side of the webpage to refine those results using the following categories:

- Date Range
- Recorded by (Users or StoryCorps)
- Keywords
- Organizations
- Places
- Languages

You can refine your search using more than one category—for example, Keywords and Languages. Refining our "physical therapy" search using the keywords "personal experiences" and the language Spanish, yields three interviews.

You can also choose more than one option in a Refine category. If you want to choose two keywords, choose your first keyword—the search results will update automatically. Then choose the second, and your search results will update again. The results will be interviews that include **both** of your chosen keywords.



If you don't see what you're looking for on the short list under one of the categories, there may be more options available. Click on "MORE," and a new box will pop up with more options. Use the search bar to search within that list, or scroll though through to choose what you're looking for. Once you've chosen, hit "UPDATE QUERY" in the bottom right.

Search		
Religious Beliefs And Practices (27)	Birth Of First Child (25)	Social Beliefs And Practices (24)
School Day Memories (23)	College (22)	Cohorts (Groups Of Friends) (21)
Illness (18)	Family Traditions (17)	Family Trips And Excursions (16)
Injuries (14)	Craft, Skills, And Procedures (13)	Accidents (11)
Family Characters (11)	Regimens (9)	Family Doctor Stories (8)
Economic Beliefs And Practices (7)	Influential People (7)	Physical Therapy (7)
Political Beliefs And Practices (7)	Pregnancy And Pre-Natal Care (7)	Appearance (6)
Childhood Games (6)	Family Naming And Nicknames (6)	Historical Events/People (6)
Family Expressions (5)	Family In-Jokes (4)	Family Members In History (4)
Family Reunions (4)	First Impression Of America (4)	Money (4)
Polio (4)	Prejudice (4)	Car Accident (3)
Chemotherapy (3)	Church (3)	Dancing (3)
E	* _ 1.1 _ + IM	PL-17
SHOW MORE 🗸		UPDATE QUERY

At any time, you can clear your choices from each category. Your choices in the other categories will remain. If you want to clear your entire search and start a new search for interviews, click "CLEAR" over the search box.

#### **Results View**

Adjust the presentation of results by using options just below the search bar and above the results. You can change how many items, or interviews, display per page. You can also sort your results by oldest or newest or relevance to your original search term and any refining you do.





# ACTIVITIES FOR EXPLORING THE STORYCORPS ARCHIVE

Here are a few activities to explore the StoryCorps Archive. Visit the StoryCorps Help Center at support.storycorps.org for more tips and support.

#### ACTIVITY 1

#### Find Your Favorites & Build a Health & Wellness Collection

#### Length: Short

Interview collections are a great way to help organize interviews by topic, time period, place, event, or other major category. Follow the guidelines below to create a collection of interviews based on your own interests.

- 1. Log into the StoryCorps Archive at archive.storycorps.org.
- **2.** Choose a topic that is important or interesting to you.
- **3.** Search for interviews on the topic you've chosen.
- Once you've found one or more interviews, use the "add to favorites" and "save to collection" features to preserve these stories for later listening.

#### **BONUS ACTIVITY**

Record an interview related to your favorite topic and archive it using keywords to help find the interview.



#### ACTIVITY 2 Health & Wellness Interview Scavenger Hunt

#### Length: Medium

Use the StoryCorps Archive to locate interviews that fit each category below. Add the interviews to your list of favorites as you go along.

- **1.** An interview that is a conversation about health and wellness.
- **2.** An interview that is about a person getting diagnosed with an illness.
- **3.** An interview in a language other than English.
- **4.** An interview that discusses a health and wellness topic about which you'd like to know more.
- **5.** An interview about maternal health.
- **6.** An interview about health and the environment, such as the Flint Water Crisis.
- **7.** An interview about living with a genetic disorder.

#### **BONUS ACTIVITY**

Record an interview using the StoryCorps App or StoryCorps Connect, inspired by one of the interviews you heard.

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#### ACTIVITY 3 In Their Shoes

#### Length: Long

There are hundreds of questions you can ask a person, and hundreds of ways an interview can go. For this activity, find an interview that interests you and listen to all of it (feel free to split up your listening time). Then, complete the tasks below to consider how your interview experience might have been similar or different.

- Were there any questions asked that you really liked? Write these questions down.
- Were there any questions you would have asked that were not included in the interview? Write these questions down.
- 3. Look at the keywords that were used to describe the interview. Were there any keywords that you think should be added?
- Get creative. Draw a picture of something discussed in the interview or write a short reflection on how the conversation relates to a person, event, or experience in your own life.

#### **BONUS ACTIVITY**

Use your questions, keywords, or reflection to plan out a recording using the StoryCorps App or Connect.

#### ACTIVITY 4 Citizen Scientist

#### Length: Long

Citizen science is a collaboration between scientists and those of us who are just curious or concerned and motivated to make a difference. Citizen science is an invitation to everyone to participate in real science—on topics they care about—following protocols for data collection, analysis, and reporting. Citizen science can be fun, but it is also serious science that accelerates research.

With hundreds of interviews housed in the archive, it's not uncommon to find ones that discuss the same topic. For this activity, you will take on the role of a citizen scientist, and use the archive to research a topic of your choosing. Complete the activity by following these steps:

- 1. Select a topic or event that you'd like to explore in the StoryCorps Archive.
- **2.** Using the search box, locate five interviews related to this topic.
- **3.** Using the "subject log," locate segments of the interview that are related to the topic at hand.
- **4.** Write a short article that uses quotes from each interview to tell the story of the event or topic you've chosen.

#### **BONUS ACTIVITY**

Write a set of questions based on your research and interview someone about your topic. Engage with more citizen science projects at <u>scistarter.org/nlm</u>.



#### ACTIVITY 5 Keyword Maze

#### Length: Long

Keywords help us organize and discover interviews within the archive. They also help connect each story with the stories of others across the country. In this exercise, you're going to test those keyword connections and see how far they take you! Complete this activity by following the instructions below:

- 1. Find an interview that interests you. Write down what the interview is about, and why you find it interesting.
- Click on one of the interview's keywords to see other interviews with the same keyword. (Start tracking your steps now.)
- Click on one of these interviews. Then, click on one of its keywords (choose one that's different from your previous choice).
- Repeat 8 more times, so you've viewed a total of 10 different interviews with 10 different keywords.
- **5.** See how far you can get from the first interview's topic, and write down the steps you took to get there.
- Did you reach any "dead ends" where only one interview had the keyword you chose? Retrace your steps backward, documenting as you go along.

#### **BONUS ACTIVITY**

Copy and paste the descriptions of the first and last interviews into a new document. What do they have in common? How are they different? Listen to a few minutes of each interview. Based on what you heard, what other topics would you add as keywords? Some keywords are used more frequently than others. Track how many interviews are listed next to each keyword. Which has the most? The fewest? Why do you think that might be?





# CURATED HEALTH STORIES IN THE ARCHIVE

The StoryCorps Archive has thousands of health-focused stories. You just need to dig to find them! Here is a collection of health and wellness stories, including the search terms used to find each story. Some of these stories are accessible only if you are logged into the StoryCorps Archive. Create your free account and login at archive.storycorps.org.

You can listen to these full conversations at the links below, or jump to different sections of the conversations based on the subject log and time code.

#### **Shalonda Griffin and Gregory Jones**

August 7, 2019 Recording Length: 22:25 minutes



Shalonda Griffin (40) and her husband Greg Jones (40) reflect on the health issues Greg has faced over the past 12 years and how navigating different medical challenges has affected their

lives and marriage.

SEARCH TERMS: DIABETES, ILLNESS, HOSPITALS

#### Alexander Feliz, Cynthia Cross, and Nico West

September 25, 2019 Recording Length: 37:29 minutes



Cynthia Cross (61) talks with friends and colleagues Alexander Feliz (49) and Nico West (43) about what led them to the field of medicine, the issue of health inequity and disparities in

care, the "human side" of healthcare, social determinants of health, and advice for others.

**SEARCH TERMS:** HEALTH INEQUITY, PHYSICIAN SCIENTIST, EPIGENETICS

#### **Tiffani Martin and Lisa Winkley**

November 6, 2019 Recording Length: 36:44 minutes



Friends Tiffani Martin (31) and Lisa Winkley (39) have a lot in common between their family lives. They discuss a number of health issues and how their experiences have strengthened their bond,

through good times and bad.

**SEARCH TERMS:** DISABILITIES, BEING BLIND, DISEASES, HEALTH

#### **Olivia Wein and Harrison Wein**

May 28, 2015 Recording Length: 40:47 minutes



Harrison Wein (46) interviews his wife of 25 years, Olivia Bae Wein (48), about being diagnosed with stage 4 non-Hodgkin's lymphoma as a teenager. Olivia talks about being

involved in a clinical trial at the National Institutes of Health (NIH), and Harrison remembers meeting her in college.

SEARCH TERMS: DIAGNOSIS, NON-HODGKIN'S LYMPHOMA, CLINICAL TRIAL



#### Lindsay Sheehan and Sonya Ballentine

January 28, 2016 Recording Length: 37:08 minutes



Colleagues Sonya Ballentine (48) and Lindsay Sheehan (36) discuss their work for a program at the Illinois Institute of Technology that seeks to improve healthcare for African Americans with

mental illness. Sonya is an African American woman with mental illness who started as a research participant and moved into a research partner position.

**SEARCH TERMS:** ANXIETY DISORDER, BIPOLAR DISORDER, COMMUNITY-BASED PARTICIPATORY RESEARCH

#### **Aida Richardson and Joyce-Anne Velez**

October 7, 2009 Recording Length: 39:43 minutes



Joyce-Anne Velez (58) and her friend Aida Richardson (59) talk about Aida's diagnosis of breast cancer, dealing with her treatment, and both being health educators (or *promotaras*) in

the Latinx community.

## **SEARCH TERMS:** BREAST CANCER, HEALTH EDUCATION, PROMOTARAS

#### **Nikesha Williams and Christa Sylla**

December 1, 2018 Recording Length: 39:25 minutes



Friends and colleagues Nikesha Williams (32) and Christa Sylla (39) share their connections and origins with traditional African dance, and the importance of self-care and healthy habits in their

lives. Skip to the 20-minute mark for specific discussion about self-care.

#### SEARCH TERMS: SELF-CARE

#### Karen Cook, Andrew Cook, and Michelle Haney

February 27, 2019 Recording Length: 55:05 minutes



Andrew Cook (22), his mother Karen Cook (64), and Andrew's teacher Dr. Michelle Haney (50) talk about their relationships to each other, Andrew's self-advocacy and self-determination, access to

education and opportunities for people with disabilities, and Andrew's future goals.

**SEARCH TERMS:** PEOPLE WITH DISABILITIES, SELF-ADVOCACY, ACCESSIBILITY FOR PEOPLE WITH DISABILITY

#### **Daniel Abril and Gloria Abril**

March 8, 2013 Recording Length: 40:40 minutes



Gloria Abril (62), an advocate for her nephew Daniel Abril (25), interviews him about his struggle with mental illness and what has been most challenging throughout his journey.

**SEARCH TERMS:** NATIONAL ASSOCIATION FOR MENTAL ILLNESS, MENTAL HEALTH, DEPRESSION, ADVOCATE

#### **Jason Foster and Steven C. Collins**

February 13, 2006 Recording Length: 42:19 minutes



Jason Foster (35) and his friend and co-worker Steven C. Collins (52) talk to each other about their experiences as cancer survivors. They share a comprehensive, insightful,

and open conversation about difficult subjects, including prostate cancer and testicular cancer.

**SEARCH TERMS:** ILLNESS, TESTICULAR CANCER, SUPPORT SYSTEM, CROHN'S DISEASE



#### **Sonya Begay and Kayle Eppele**

June 11, 2020 Recording Length: 39:34 minutes



Sonya Anne Begay (63) is interviewed by her granddaughter Kayle Nanah Eppele (19) about how her family came together, her worries about her family in the Navajo reservation, and

the lack of resources for underserved communities and elders.

**SEARCH TERMS:** COVID-19 PANDEMIC, QUARANTINE EXPERIENCES

#### **Stories Recorded in Spanish:**

The StoryCorps Archive contains stories recorded in many different languages. We searched conversations recorded in Spanish to find this health-focused recording. You can find more stories at <u>archive.storycorps</u>.

#### Jorge R. Miranda Massari and Herbert Massari Sánchez

January 22, 2010 Recording Length: 35:39 minutes



Herbert Massari Sánchez (86) y su sobrino Jorge R. Miranda Massari (50) conversan sobre el estado de las farmacias en Puerto Rico en las últimas décadas de los 1800s y las primeras décadas

de los 1900s, y también conversan sobre sus vidas como farmaceuticos y padres.

Herbert Massari Sánchez (86) and his nephew Jorge R. Miranda Massari (50) talk about pharmacies in Puerto Rico in the late 1800s and the early 1900s, about their lives, and about parenthood.

#### SEARCH TERMS: FARMACEUTICO, ILLNESS, CURES



# "DESTINED TO BE" DISCUSSION GUIDE & REFLECTION QUESTIONS

View the All Our Voices animation as a group and set aside 30 minutes for discussion. These questions can be moderated by a facilitator for a large group, or used as prompts for small group discussions or individual reflection:

- What are your initial reactions to Sabrina and Shantay's conversation? Was the information new to you? Were you aware of the disparities in infant death and maternal mortality, particularly among Black women?
- How does Sabrina and Shantay's story translate to your own community? Do you notice any similarities or differences?
- If you have experienced pregnancy, what are some of the positive experiences you've had? How did your experience compare to Sabrina and Shantay's?
- Both Sabrina and Shantay wish that more people could speak openly about their health issues, particularly maternal health and birth outcomes. Do you agree? What are some ways to encourage dialogue within your community?
- As activists for Black infant health, Shantay and Sabrina advocate for positive patient/ provider relationships. What is your relationship like with your doctor? How important is it to have healthcare providers who listen to your health journey?
- What is a health topic that is important to you? What organizations in your community can offer support and resources for continued dialogue around that issue?



- Sabrina and Shantay show us that their story is not well represented or understood in the wider healthcare community. Are there any health issues you struggle with personally that you feel are overlooked or underrepresented? How would you shift that conversation?
- How can you use the resources at your library to further investigate specific health issues affecting your community (for instance, Black maternal health)?



#### **FURTHER EXPLORATION**

Archive Challenge: If you have more time, locate Sabrina and Shantay's interview in the StoryCorps Archive using the search function only. Try searching by keywords and then by name—are you able to find the interview in the archive?

## ADDITIONAL DISCUSSION & REFLECTION QUESTIONS

- In their full interview, Shantay mentions challenges specific to her rural community. What are some of these issues? Do you experience similar challenges in your community?
- Shantay and Sabrina mention some potential influences on health disparities among Black mothers. What are these influences? Do you see any examples in your own community?
- What are the differences between the full 40-minute conversation and the edited version? What insights do you gain from listening to the full conversation?

#### **CONTINUE THE CONVERSATION**

What resources can you find at your library that relate to the theme of maternal health? Can you develop a reading or listening list to share with your community? Here are a few ideas to get started:

- Reproducing Racism, a podcast episode from Reveal, first aired May 2020. As racial disparities in health come into the spotlight amid COVID-19, this episode explores how the legacy of racism affects maternal health in the United States.
- SisterFriends Detroit is a grassroots community volunteer movement that helps moms gain access to over 100 programs and resources in Detroit. Their mission is to focus on maternal child health and infant mortality reduction, and build a community of support for pregnant mothers.
- "<u>Preterm Birth.</u>" Centers for Disease Control and Prevention, October 30, 2020.
- Amaro, Yesenia. "Fresno County Is in 'State of Preterm Birth Crisis among Women of Color.' What's Being Done?" The Fresno Bee, November 4, 2019.

Roeder, Amy. "America Is Failing Its Black

Mothers," Harvard Public Health Magazine, 2019.



# DESTINED TO BE

Friends Sabrina Beavers and Shantay Davies-Balch work together as community health advocates for Black women's maternal health. They talk about the premature birth of Sabrina's daughter, Destiny, and the barriers to good care Black women face during pregnancy.

This interview was recorded on site at the Sanger Branch of the Fresno Public Library in Fresno, CA. It was recorded in partnership with Valley PBS/Independent Lens in 2019 as part of a project to record stories about health and access to care in rural communities.



#### TRANSCRIPT

- **SHANTAY:** I remember growing up, seeing babies like born really tiny. I didn't know there was a name for it. It was even normal to have Black women die either during birth or soon after. And no one kind of talked about it.
- **SABRINA:** For me, I knew a lot of friends and their families who had suffered with babies that were in the NICU for weeks or who didn't make it home.

And then, it was an eye-opening experience to actually deliver my daughter at 35 weeks and two days' gestation. I still feel overwhelmed about it. Cause it wasn't something that I was prepared for. People talk about pregnancy glow and being able to deliver a full term. I didn't get that experience.

I would have appreciated having that extra time with her in utero to build that bond and for her to come out as healthy as possible. I felt kind of cheated out of the last part of my pregnancy.

**SHANTAY:** You know, I had two babies that were born preterm, and I felt a little cheated too. And I remember feeling depressed because I was like, I took my folic acid, I had a great doctor. I also had a midwife. I had a doula. I even had a spreadsheet where I tracked my vegetables. *(Laughs)* And I felt sad because it feels like even if you have all the information and you do everything right, that you still have a poor birth outcome.

**SABRINA:** I wish that as Black women, as a Black community, we talked more about these types of things. Just like we talk about heart disease, stroke, diabetes, and how it runs in the family. Same thing when it comes to preterm birth, when it comes to infant mortality. And it's like, well, why don't we talk about these things? Why aren't these normal conversations? And partly because it's normalized. We think it's okay to deliver a baby at 23 weeks.

And the only ask that I have is that for my daughter's sake and for the sake of any Black woman here now, or destined to be, that they don't have to experience some of these things. That we figure out how to prevent this from happening.

**SHANTAY:** I'm really happy that we have a healthy Destiny in front of us. And I'm really proud of you. I know it was really hard, and I hope that Destiny continues in our path. That she will be concerned about Black women and Black babies. Cause she's destined to do something.



# ALL OUR VOICES ACTIVITIES

#### ACTIVITY 1 Mapping Your Health Journey

Take some time to represent your health journey in a drawing. What are some of the main events? Who has helped you along the way? Are there any landmarks or meaningful milestones? Consider representing events, people, and memories in an abstract or figurative way.





#### ACTIVITY 2 Visualizing Your Support Network

Where have you found support and healing in your health journey? In the space below, write your name at the center, then add in the people or activities that make you feel healthy. You can draw a picture or write how this person or activity has helped you in your health journey.



#### ACTIVITY 3 Writing Prompts

Take a few minutes to respond to any of the following prompts:

What makes you feel healthy?

How do you take care of yourself?

Make a list of 20 things that support your health and wellness.



Write a letter to your body. What would you say to it during challenging times?

What makes you feel at ease and peaceful?

What are five things that you are grateful for right now?



# CURATED PLAYLISTS

Conversations about Health and Wellness from the StoryCorps Broadcast Collection

The **StoryCorps Broadcast Collection** is home to hundreds of stories edited and shared as audio clips or animations, many of which focus on health and wellness topics. Here is a curated collection of stories sorted by theme that you can share with your patrons or use to promote recording programs at your library. Many of these stories focus on topics of diversity in healthcare, genetics and inherited disease, and overall health literacy. Use these stories to spark health and wellness conversations in your community.

Consider sharing some of these playlists in coordination with your existing programming, as part of a listening event, or during date-specific health appreciation days or months—pick and choose what works for you. Visit the **Healthcare Date Pegs Calendar** for more ideas.

#### **CAREGIVER STORIES**

Whether at home in a family setting or in a professional capacity, it takes special strength and patience to be a caregiver. Listen to these stories of caregiver courage and wisdom.

#### **PATIENT STORIES: LIVING WITH CANCER**

Listen to these StoryCorps participants share wisdom from their own cancer experiences, including personal stories and supporting family and friends.

#### **PATIENT STORIES: LIVING WITH HIV/AIDS**

In these StoryCorps conversations, people share the impact that HIV/AIDS has had on their lives and the lives of their loved ones.

#### **PEOPLE WITH DISABILITIES**

This collection highlights the voices and unique lived experiences of those living with disabilities, along with their loved ones who offer support and admiration.

#### **CIVIC DUTY AND CONNECTION IN THE DAYS OF COVID-19**

Despite being miles apart, our new platform, StoryCorps Connect, allows friends and family to interview in the safety and comfort of their own homes. This collection highlights the voices of essential workers and loved ones who have found new ways to connect with each other. Visit the YouTube playlist here or view these stories on the StoryCorps blog here.



#### **CAREGIVER STORIES**

Whether at home in a family setting or in a professional capacity, it takes special strength and patience to be a caregiver. Listen to these stories of caregiver courage and wisdom:

#### **Caroline Dezan and Maria Rivas**

Recording Length: 2:32 minutes



StoryCorps Legacy gives people with life-threatening illnesses the chance to record their story, and their loved ones a chance to remember. In this recording, we hear from Maria Rivas,

who remembers her mom, Julia Medina. Julia was a single mom who raised ten children while working as a cleaning woman in Fresno, California. For the last six years of Julia's life, Maria took care of her mother as her health deteriorated. She came to StoryCorps to share her mom's story with Caroline Dezan, a social worker at Hinds Hospice.

#### **Ruth Owens and James Taylor**

Recording Length: 2:27 minutes



Ruth Owens has lived her whole life in the mountains of rural Tennessee. She worked as a nurse in the area for over four decades, eventually retiring when she was 85 years old. Now

93, she sat down at StoryCorps with her grandson, James Taylor, who, along with several of her kids and grandkids, followed in Ruth's footsteps to become a nurse. They begin by talking about Ruth's childhood in the late 1930s and how she eventually found her calling.

#### **Olivia Tan Ronquillo and Kenneth Tan**

Recording Length: 3:00 minutes



To Crescenciana Tan, family meant everything. Her grandchildren called her Lola. And they grew up hearing stories about where she came from and the many sacrifices she made

for loved ones. Lola's grandson Kenneth came to StoryCorps in San Jose, California, to tell his mother Olivia about the greatest lesson Lola ever taught him, and the importance of intergenerational caregiving and connection.

#### Leslye Huff & Mary Ostendorf

Recording Length: 2:13 minutes



Partners Leslye Huff (left) and Mary Ostendorf (right) remember caretaking for one of their mothers despite her initial reaction to their love. When Mary introduced Leslye to her mother, Agnes,

they did not immediately reveal to her the nature of their relationship, but during that meeting Leslye felt a connection with Agnes. At StoryCorps, Mary and Leslye discuss how their relationship with Agnes changed in the years that followed.

#### **Candi Reyes and Estela Reyes**

Recording Length: 3:24 minutes



Juan Reyes grew up in a small town in Mexico and immigrated to the United States in the 1940s. He eventually settled in Texas, where he raised his two daughters, Estela and Candi

Reyes. In Juan's later years, his struggle with diabetes intensified, and he became more sick. At StoryCorps in El Paso, Estela and Candi remembered caring for him in his final days.





#### **PATIENT STORIES: LIVING WITH CANCER**

Listen to these StoryCorps participants share wisdom from their own cancer experiences, including personal stories and supporting family and friends.

#### Vanessa Silva-Welch and Arnaldo Silva

Recording Length: 2:10 minutes



Arnaldo Silva noticed a lump on his chest. After going to a doctor and getting a mammogram, he learned that he had breast cancer. Arnaldo's diagnosis and the discovery that he carried a

genetic predisposition to cancer led other members of his family to get tested as well. Soon after, his daughter, Vanessa Silva-Welch, learned that she too had breast cancer. At StoryCorps, they discuss their battles with cancer and how they have become each other's support systems.

#### **Lorraine Benavides**

Recording Length: 2:37 minutes



Lorraine Benavides talks about being diagnosed with cancer, the faith that kept her strong throughout her treatment, and the endless support she received from friends and family.

#### **Mark Carles and David Carles**

Recording Length: 3:18 minutes



David Carles and his little brother, Mark Carles, are best friends. Growing up on Staten Island, the two did everything together. But in 2018, Mark's life was upended by a cancer diagnosis at the

age of 24. A year after that diagnosis, the brothers sat down at StoryCorps in New York City to talk about the ways Mark's illness has changed their lives.

#### Dymond Hayes and Tami Hayes

Recording Length: 1:45 minutes



When Tami Hayes received her breast cancer diagnosis, she was a single mom raising her daughter Dymond, who was 13 at the time. The pair spoke at StoryCorps about how they coped and

supported each other along the journey.

#### Hadiyah-Nicole Green and Tenika Floyd

Recording Length: 3:13 minutes



Hadiyah-Nicole Green reminisces with her cousin Tenika Floyd about her Auntee (Tenika's grandmother) and Uncle, and how their battles with cancer inspired her to study physics

and develop a groundbreaking new way to treat cancer.





#### **PATIENT STORIES: LIVING WITH HIV/AIDS**

In these StoryCorps conversations, people share the impact that HIV/AIDS has had upon their lives and the lives of their loved ones.

#### **Peter Byrd and Lisa Roland**

Recording Length: 4:07 minutes



Peter Byrd sat down with Lisa Roland to record this Legacy interview in partnership with Grady Health Ponce De Leon Center in Atlanta, Georgia. Byrd remembers visiting a

psychic three months after he was diagnosed with HIV and the advice he received: "She told me, 'Stop worrying. This is not the end. This is the beginning for you."

#### **Christopher Harris**

Recording Length: 3:33 minutes



At Grady Hospital in Atlanta, Christopher Harris recorded his memories from the early days of the AIDS epidemic. In the early 1980s, his marriage fell apart after he came out as gay. He was diagnosed

with HIV in 1988. At the time, there was only one drug approved to treat the disease, and a diagnosis often meant a death sentence. With StoryCorps, Harris remembered how he came to work with the Atlanta Buyers Club, which distributed medications from the black market to people with HIV before the drugs had been approved by the FDA.

#### **Cristina Peña and Chris Ondaatje**

Recording Length: 2:15 minutes



Cristina Peña was born HIV positive in 1984. Her father died of AIDS. Her mother is still living with HIV today. Cristina was told she was HIV positive when she was nine years old, but she and

her family kept it a secret from her schoolmates and friends. In high school, she met and started dating Chris Ondaatje. One day after school Chris decided to tell Cristina that he was in love with her. That's when Cristina sat him down for a revelation of her own. At the time of this recording, Chris and Cristina had been together for 13 years.

#### Kathleen Payne and Corinthia Isom

Recording Length: 3:03 minutes



Corinthia was only a child when her mom, DeSeane, died from an AIDS-related illness in the mid-1990s. DeSeane had been raising Corinthia alone, but before she passed, she'd arranged

for her daughter to be cared for by a couple she'd met in an LGBTQ gospel choir in New York City. Kathleen was one of the women who took Corinthia in, and they sat down together to remember DeSeane and the start of their relationship.





#### **PEOPLE WITH DISABILITIES**

This collection highlights the voices and unique lived experiences of those living with disabilities, along with their loved ones who offer support and admiration.

#### **Sarah Churchill and Yomi Wrong**

Recording Length: 2:45 minutes



Shortly after giving birth to her third daughter in 1972, doctors told Sarah Churchill that her baby had a rare genetic disorder that caused her bones to break under the slightest pressure. The doctors

told Sarah that she could try to raise a child who might not survive, or she could leave the child at the hospital since she wouldn't live long. That baby was Yomi, who, at the time of this recording, was about to celebrate her 45th birthday. Here, Sarah tells Yomi about the night she was born. This interview was recorded in partnership with the Disability Visibility Project.

#### Meaghan Starkloff Breitenstein and Colleen Kelly Starkloff

Recording Length: 2:17 minutes



In his early 20s, Max Starkloff was in a near-fatal car accident, which left him quadriplegic and living in a nursing home. One day he came across a young woman who worked there, named

Colleen. At StoryCorps in St. Louis, Colleen Kelly Starkloff sat down with her daughter, Meaghan Starkloff Breitenstein, to remember Max and the life that they built together.

#### **René Foreman and Michelle Foreman**

Recording Length: 2:54 minutes



In 1999, René Foreman was diagnosed with esophageal cancer. She underwent surgery that saved her life but also took her voice. Today, René speaks using an electrolarynx—a small device

that produces an electronic voice when she holds it against her throat. René sat down at StoryCorps for an interview with her daughter Michelle.

#### **Russell Lehmann and David Apkarian**

Recording Length: 3:03 minutes



Air travel can be a stressful experience for just about anyone. But for 26-year-old Russell Lehmann, a flight delay or cancellation isn't just a small inconvenience. He was diagnosed with

autism at age 12, and unexpected changes can cause him to have a meltdown—when sensory overload causes him to lose control and break down crying. That's what happened when he tried to catch a flight from Reno, Nevada, to Cincinnati. At StoryCorps, Russell sat down with David Apkarian, an airline employee, to remember that difficult day.

#### Lionel D'Luna, Adrienne D'Luna Directo, and Debra D'Luna

Recording Length: 2:37 minutes



Alexis D'Luna had CHARGE syndrome, a rare, lifethreatening genetic condition that causes a number of birth defects. Alexis was intellectually disabled and legally blind,

and she had hearing problems. She stood just under five feet tall because of deformities in her legs and back. Many children with CHARGE don't live beyond infancy, but Alexis lived to be 25. She died in her sleep in December 2012. Her parents, Debra and Lionel D'Luna, came to StoryCorps with her sister, Adrienne, to remember her.

#### **Bonnie Brown and Myra Brown**

Recording Length: 2:28 minutes



Bonnie Brown, who is intellectually disabled, came to StoryCorps with her 15-year-old daughter, Myra, to share memories of their life together. Despite Bonnie's disability, Myra says

her mom is everything she needs from a parent.











# WELCOME

Since 2003, StoryCorps has given over 600,000 people of all backgrounds and beliefs the chance to record interviews about their lives and preserve them in the Library of Congress. An important part of this effort has been connecting with individuals and community organizations to create a culture of listening across the United States with the simple concept of asking people to honor one another with an interview.

Until this time, StoryCorps interviews have been recorded face-toface. But the largest global health crisis in a century is changing the way we live and interact with our friends, neighbors, and families. With a fierce determination to honor the memories and experiences of our communities, we created a new technology called **StoryCorps Connect** that enables people to record remotely through a computer or a mobile device.

Participants can now record conversations and instantly share them with the <u>StoryCorps Archive</u> and the American Folklife Center at the Library of Congress using either <u>StoryCorps</u> <u>Connect</u> or the <u>StoryCorps App</u>.

We invite you to share a meaningful conversation with someone you care about using StoryCorps digital tools. Whether you are recording remotely or in person, this guide will walk you through the process of recording a StoryCorps interview with a friend or family member from start to finish.

I wish that as Black women, as a Black community, we talked more about these types of things. Just like we talk about heart disease, stroke, diabetes, and how it runs in the family. Same thing when it comes to preterm birth, when it comes to infant mortality. And it's like, well, why don't we talk about these things? Why aren't these normal **conversations?** *And partly* because it's normalized. We think it's okay to deliver a baby at 23 weeks."

> Sabrina Beavers, StoryCorps Participant

ALL OUR VOICES Participant Recording Packet



# ABOUT THE PARTNERSHIP & THIS PACKET

This packet was created in partnership with the <u>Network of the National Library of Medicine</u> (NNLM) as part of its national initiative to support awareness of the <u>All of Us Research Program</u> (All of Us). In partnership, StoryCorps and NNLM support the power of libraries in their role as disseminators of health information and offer these tools to preserve the rich diversity of health experiences through the stories of people from across the United States.

Conversations about health and wellness are a meaningful way to build connection, support, and understanding among community and family—whether the conversation is recorded or not. Considering the lack of diverse representation in recorded history and in medical research, the **All Our Voices** recording campaign aims to expand the conversation and inspire people to tell their health and wellness stories, in their own voices.

We hope you'll use the information in this packet to start and join conversations about health and wellness in your family and community. With resources in this packet, you will be able to:

- Record, share, and preserve your health and wellness stories, in your own voices, using free digital tools;
- Contribute to the growing collection of health stories in the <u>StoryCorps Archive</u> by adding your voice to the <u>All Our Voices Community Page</u> collection;
- Listen to select stories about health and well-being from StoryCorps' collection.




# ABOUT STORYCORPS & THE INTERVIEW MODEL

A StoryCorps interview is an opportunity to record an uninterrupted, intentional conversation with someone you know about anything you'd like, from favorite memories to important life questions. It's also a way to connect with family and friends in a time when visiting in person is extremely limited.

Recording using StoryCorps' digital tools is an opportunity to have conversations and preserve them for generations to come. Each conversation is up to 40 minutes of uninterrupted time with a loved one.

Conversations are about stories, not just facts. There's no right or wrong way to conduct a StoryCorps interview. We invite you to share stories and experiences that are meaningful to you, and ask questions that you've always been curious to ask. Feel free to use the <u>Custom Questions for Health & Wellness Conversations list</u> at the end of this guide for inspiration.

**66** Life would be different if I hadn't shared my story. I got it all out and now am able to share it with others."

StoryCorps Participant







## Get to know StoryCorps by listening to stories from our collection.

Here are a few StoryCorps "classics"—stories that have stuck with us over the years and reminded us over and over again of the power of listening. All videos and content in this playlist can be found at storycorps.org.

**An Intro to StoryCorps from Our Founder Dave Isay** (3 min.)

#### **Featured Animations**



Silvia's Legacy (2.5 min.)



Leading the Way (2.5 min.)



**Q&A** (3 min.)



Chloe Longfellow (2.5 min.)



A Wonderful Life (3.5 min.)



No More Questions (3.5 min.)



Danny & Annie (6 min.)



Lessons Learned (3 min.)



Leonardo's Dreams (3 min.)





# WHY SHARE STORIES ABOUT HEALTH & WELLNESS?

StoryCorps interviews are designed to give participants an opportunity to build connection and understanding, usually with a family member, friend, or other loved one. Our model focuses on the individual and creates a "no wrong answer" environment, fostering communication between the storyteller and the people they know and love. The interviews are intended to help participants feel that they themselves, and their own stories, have a value.

StoryCorps interviews have repeatedly demonstrated the value of these personal conversations to participants, their families, and the organizations that serve them. By affirming the value of the individual through attentive conversation, StoryCorps interviews can directly combat the feelings of isolation, low self-esteem, and anxiety that may arise through challenging health journeys.

When applied to a health context, sharing stories, particularly about a challenging health experience or diagnosis, can help people make sense of their situation and find support in their community. When faced with illness, sharing our stories can support healing on the individual and community levels. It is impossible to be involved in a StoryCorps interview and not be changed in some way."

StoryCorps Participant

#### StoryCorps interviews have shown:

- Reflecting on one's personal narrative is part of the healing process. For people experiencing challenging health circumstances, it can be especially important to develop control over their story and comfort in sharing that story with others.
- Storytelling allows us to weave together new stories about ourselves. Each conversation can provide space for people to articulate how the story of a diagnosis or illness relates to the larger narrative of who they are.
- Storytelling connects us to those who have had similar experiences, fostering community and a sense of support. People learn new ways to cope with illness, build connections, and feel less alone in their health journeys.
- Listening to other people's experiences can also positively affect the listener, boosting empathy, creating connection, and inspiring them to have more conversations with loved ones.

## JOIN THE ALL OUR VOICES COMMUNITY & RECORDING CAMPAIGN

Record Your Conversation: Step by Step





### Create a free account and join the All Our Voices Community in the StoryCorps Archive

Your free account at <u>archive.storycorps.org</u> will be used to prepare, record, save, and share your interviews. You can also use it to browse our collection and listen to stories that others have shared.

To create an account and join the <u>All Our Voices Community Page</u>, follow this link: <u>archive.storycorps.org/communities/all-our-voices/</u><u>register/</u>

If you already have an account, visit <u>archive.storycorps.org/</u> <u>communities/all-our-voices/</u> and click "Join."

### 🗘 TECH TIPS

**If you are using the app,** only the person logged in on their smartphone needs to have an account.

**If you are using Connect,** both people will need to log into their StoryCorps accounts.

# **2** Choose an interview partner to determine your technology (App or Connect)

Consider who you would like to record with and why. Here are some helpful questions to consider:

- Who in your life might find this type of recording meaningful, and what might you wish to share with that person? Consider reaching out to family members, healthcare providers, caregivers, or friends.
- > Who is someone from your community that you want to connect with on a meaningful level?
- What health and wellness stories or memories are important for you to preserve at this time?

Are you and your interview partner in the same location? YES – record using StoryCorps App

How-To Video: <u>Use the StoryCorps App to record in person</u> Get Started: <u>Record Your Story Using the StoryCorps App</u>

Are you and your interview partner in different locations? YES – record using StoryCorps Connect

How-To Video: <u>Use StoryCorps Connect to record virtually</u> Get Started: <u>Record Your Story Using StoryCorps Connect</u>

### **C** TECH TIPS

**If recording in person** with the StoryCorps App, download the free StoryCorps App to a smartphone (iPhone or Android) or Kindle tablet.

If recording remotely, you and your partner will both need access to a computer or tablet with the latest device software, an internet connection, and a microphone and webcam.





- SET A TIME: Reach out to your recording partner and arrange a time when both you and your partner will be relaxed. Choose a quiet, comfortable place where you won't be interrupted. Remember that you will need to have access to Wi-Fi to record your conversation.
- PREPARE YOUR QUESTIONS: Take time to talk with your interview partner about what you'd each like to share during the recording. Use the <u>Custom Questions list</u> and <u>Planning</u> <u>Worksheet</u> included in this packet to prepare together.
- PRACTICE: Whether you are using StoryCorps Connect or the app, we recommend that you record a practice interview to familiarize yourself with the technology.



### C TECH TIPS FOR RECORDING

You may not be able to choose where you record your conversation, and if so, that's fine. If you do have more than one room to choose from, we recommend that you:

- **USE smaller rooms that have:** carpeted floors, drop ceilings, closed windows and heavy drapes, irregular shapes, full bookcases, hanging clothes
- AVOID using a room that is large and has: uncovered or tiled floors, high ceilings, square shapes, bare walls, big windows without curtains, noisy appliances such as refrigerators and air conditioners
- We recommend sitting in a comfortable chair that locks in a fixed position.
- Consider using headphones or earbuds that have a microphone built in: this will help prevent "echoes" in the recording.
- If you are recording from a laptop, position yourself as close to the laptop as is comfortable for you.
- If you are recording with a phone or a tablet, you may wish to prop up the device on a table so that you don't have to adjust it during your conversation.

- If you prop up your device on a table, we recommend placing it horizontally so as not to cover the device's microphone.
- When recording with phones and tablets, please turn on Airplane Mode, and then turn on Wi-Fi.
- Make sure that your conversation partner can hear you before hitting "Record."
- If you hear disruptive noises such as a microphone rubbing on your partner's shirt, pause the conversation and resolve the issue.

StoryCorps is an independently funded nonprofit organization. Learn more at storycorps.org.



- DISCUSS SHARING & PRIVACY SETTINGS: After recording, you will be prompted to publish your interview to the StoryCorps Archive, making the recording publicly available online at <u>archive</u>. <u>storycorps.org</u> and sharing it with the American Folklife Center at the Library of Congress. Then you will have the option of choosing among three privacy settings that control how accessible the recording is in the StoryCorps Online Archive:
  - *Everyone:* Your interview and related information are available to anyone on the internet.
  - **StoryCorps Community:** Your interview and related information are available to anyone with an account on the StoryCorps Archive.
  - Private: Your interview and related information are private.

Remember that your conversation may touch on sensitive health information. If there are any details or parts of your story that you do not wish to share, review with your partner ahead of time.

**Please note that you may change your privacy settings at any time.** But in order to access your recording later on, you must publish and share your interview with the StoryCorps Archive. You can learn more about privacy settings <u>here</u>.

- If you are recording with the app, you have an additional option to save your recording to your device without publishing it to the StoryCorps Archive. If you would like to record but not share your conversation, you should use the app.
- If using StoryCorps Connect, there is no way to save it to your local device.

Regardless of what you select as your privacy setting, please be aware that StoryCorps may use your interview and other materials in the following ways, including but not limited to: broadcasts on public radio, animated and other audiovisual content, educational use, and any other StoryCorps programs. StoryCorps can also share your interviews with community and media organizations for use on their platforms and sites.

#### PARENTAL OR GUARDIAN CONSENT

Under StoryCorps Connect's terms of use: Children under the age of 13 may not participate in a StoryCorps Connect or app recording, and parental or guardian consent is required for people under the age of 18 to register for a StoryCorps Archive account. You can review StoryCorps' full terms of use at archive.storycorps.org/terms-of-use.

#### **USER-GENERATED CONTENT**

The <u>StoryCorps Archive</u> contains user-generated content that is not reviewed before it is posted online. While we adhere to a strict set of Community Guidelines and work to maintain a culture of tolerance and acceptance, not all published content will be appropriate for all individuals. We also have a flagging mechanism in place to help further identify content that violates our Community Guidelines.





Follow the prompts in either the app or Connect to begin recording, and let the conversation flow! Listen closely, and let your chosen questions guide the discussion, not control it. Make sure you ask follow-up questions. You never know what unexpected and wonderful new things you will learn about a person—no matter how well you think you know them.

Both StoryCorps Connect and the app prompt users in English; however, you may record in any language.

## **S** Preserve your story in the archive

When you're done, click "Stop Recording," and then "Save Interview." You'll then be prompted to select your <u>privacy settings</u>. In order to allow future generations to find, listen to, and learn from the stories you and your partner just shared, you will have the option to share your recording on the StoryCorps website and have it preserved and archived at the American Folklife Center at the Library of Congress.

Participant photos are an important part of the StoryCorps Archive and are included with the interview when it is published to archive.storycorps.org. After your interview, you will be prompted to take a selfie with your partner if using the app. When using StoryCorps Connect, screenshots are taken of participants sporadically over the course of the interview.

After recording, tag your story with any relevant keywords. Keywords are like hashtags, making it easier for you and others to find your interview in our collection. You can also add a title and description to help you keep track of your conversations.

## To add your story to the <u>All Our Voices Community Page</u>, choose "Add to Community" and add the special keyword: #AllOurVoices



Share your interview with the world, or save it for friends and family. Explore the StoryCorps Archive and <u>All Our</u> <u>Voices Community Page</u> for more health stories, and watch the collection grow!



Consider inviting another friend or family member to record.





# CONVERSATION TIPS & CONSIDERATIONS FOR RECORDING HEALTH STORIES

#### **BEFORE YOU BEGIN**

Take some time to check in with your conversation partner. It can be helpful to develop a list of questions you each might want to ask during the recording. Typically, 6-8 questions is a good place to start for a 40-minute conversation. We've provided some suggestions in our <u>Custom Questions for Health & Wellness Conversations</u> list. As always, the best questions are the ones you've always wanted to ask, so feel free to add a few of your own.

#### **INTRODUCTIONS**

Begin by both introducing yourselves. Share your name, age, today's date, where you are recording, and your relationship to your conversation partner. For example:

*My name is* (name). *I am* (age) *years old. Today is* (date), *and I'm speaking with* (partner's name), *who is my* (relationship). *I am recording this interview in* (place, city, state; e.g., "my home in Nome, Alaska").

6 I'm hoping that the section of the interview talking about the illness might touch others with the same illness. It's very difficult to connect with other people facing this condition."

StoryCorps Participant

#### **CONSIDERATIONS FOR RECORDING HEALTH STORIES**

Recording is an opportunity for you to share your story, in your own words, and listen to your partner tell their story. Conversations about health and wellness experiences can be joyful, healing, illuminating, and sometimes hard. Speaking about a difficult diagnosis or challenging medical circumstance can be a struggle for some people. Remember that there is no right or wrong way to have this conversation. All feelings are welcome, like happiness, humor, sadness, anger, or guilt.

We recommend checking in with your partner before, during, and after the conversation to review any personal or sensitive information that may come up during your interview. Are there any details you do not want to include in your recording? Does your partner want to avoid discussing certain information? Only share information about your own health that you are comfortable with, and be mindful not to reveal identifying information about others, especially if you're mentioning diagnoses they may not want shared publicly. You can also talk with your interview partner about whether you would both like to share your conversation in the StoryCorps Archive.

## ALL OUR VOICES

**Participant Recording Packet** 



#### **INTERVIEW TIPS FOR GREAT CONVERSATIONS**

Forty minutes can seem like a long time, but the recording session may go faster than you think. Here are some tips and considerations for recording a conversation with someone about their personal health journey, or sharing a story of your own.

Think about what you want to talk about during your interview before the recording session. Reflect on some of the major people, places, and events of your health story. Consider some of the questions that might come up during conversation or that your interview partner might ask.

**Ask warm-up questions.** Press the record button and follow the prompts to introduce yourself and your partner. Then ask a few warm-up questions, like "Where were you born?" or "Can you describe the first time we met?"

Ask open-ended questions and follow-up questions that elicit great details. "What" and "where" questions are good places to start. Then move on to biggerpicture "why" and "how" questions. Ask open-ended questions that don't assume answers. When you get a good response to a question, consider saying, "Tell me more." Doing so can provoke longer, richer stories.

Think of it as a conversation. You and your partner should feel free to ask one another questions throughout the interview—there is no right or wrong way to do an interview. Try to relax and share what feels natural. It's okay to take breaks, move on from certain questions, and/or have moments of silence throughout your conversation. **Listen closely.** Repeating back what your partner says can be affirming for them and helpful in forming your next question. Allow your partner to talk about their experiences in their own words.

**Be prepared to rephrase.** If at first your partner does not seem comfortable answering a question, consider rephrasing it, offering more context, or asking something different.

**Be prepared for an emotional experience.** The interview can bring up feelings for you and your partner.

**Plan some reflective questions.** Keep an eye on the timer so that you know when there are 10 and 5 minutes left. End your interview with reflective questions, such as "What legacy would you like to leave?"

**Express gratitude.** Take a few minutes at the end of your conversation to tell your partner how much you care about them, and thank the person for the conversation you just had.

**Continue the conversation after the recording stops.** Take the opportunity to follow up on the things you discussed and to continue reminiscing.

#### Be yourself. Be curious. Keep an open heart.





# CUSTOM QUESTIONS FOR HEALTH & WELLNESS CONVERSATIONS

#### **Great Questions for Anyone**

First, here are some great questions you can ask anyone. You can find more suggested questions at our **Great Questions** list on the StoryCorps website here: <u>storycorps.org/participate/great-questions/</u>

- Tell me about the person who has had the greatest influence on your life. What lessons did they teach you?
- Who has been the kindest to you and why?
- Share some important lessons you've learned in life.
- Are there any funny stories people tell about you from when you were growing up?
- What have you accomplished so far—personally and professionally—that makes you proudest? Why?
- Would you be willing to share a happy or sad memory with me?

- What do you feel most grateful for in your life?
- How would you like to be remembered?
- Do you have any regrets?
- Is there anything that you've never told me but want to tell me now?
- Are there things about me that you've always wanted to know but never asked?
- Thinking about future generations, and knowing that they may hear this recording, is there wisdom or advice you would like to share with them?

#### **Questions about Health and Wellness**

Here are some suggested questions for conversations specific to health and wellness topics. Feel free to adjust each question as it fits your individual situation:

#### Talking about health and wellness

- What does your health mean to you?
- What makes you feel healthy? What makes you feel unhealthy?
- How do you take care of yourself? Of others?
- How do you talk about health and wellness with your family or friends?
- Are you familiar with your family's health history?

### **ALL OUR VOICES**

**Participant Recording Packet** 



#### Describing the journey, diagnosis, or illness

- Can you tell me about your health journey? What is important for me to know?
- What health challenges did/do you face? How do they affect your daily life?
- How do you feel about your health journey or condition?
- How did you feel when you received your diagnosis?
- What has been the most challenging part of your health journey?
- How has living through this experience made you feel?
- Are you afraid? What frightens you?

#### Community of care

- Who are some of the caregivers in your life?
- Whom do you call on for support? Why are they special to you?
- Are there things that people do or say that aren't helpful?
- Is there anything that you want me to do differently?
- Do you have any memorable stories of care providers during your health journey?
- What does good care look like to you?
- Have you been a caregiver? For whom and why?
- How has being a caregiver changed you? What lessons have you learned?
- What advice do you have for someone caring for a friend or family member?

#### Finding moments of healing and comfort

- What is the toughest part of your days right now? The best?
- What brings you comfort and hope?
- What has been healing to you during your journey?

#### Managing health in times of COVID-19

- What's the biggest way your life has changed because of the pandemic?
- Has the pandemic made your health journey more difficult? How so?
- Is there someone you can't see right now who you really wish you could?

#### **Reflecting on the journey**

- How has your health journey changed you? Your life?
- How has your health journey been different from what you'd imagined?
- What are some of the most important lessons you've learned during your health journey?
- Do you look at your life differently now than you did before?
- What advice or encouragement do you have for other people with similar health experiences?
- Are there any words of wisdom you'd like to pass along to me?
- If you could send one message to healthcare providers about your experience, what would it be?

This resource is brought to you in partnership with the Network of the National Library of Medicine and the National Institutes of Health *All of Us* Research Program (*All of Us*). To learn more about *All of Us*, go to joinallofus.org/nlm (English) or joinallofus.org/bnm (Spanish).



# PLANNING FOR YOUR CONVERSATION

Below are some specific questions to consider and discuss with your interview partner before you hit record.

Meaningful stories often focus on challenge, choice, and outcome. Reflect on what moments in your life presented you with a challenge. Why did you feel this was a challenge? Why did you make the choice you did? How did the outcome feel? What did you learn? Because it is recorded, it lifts up the importance of the conversation. And, the questions were so great and in-depth—I would never have thought to ask them on my own."

StoryCorps Participant

2.	
3.	
4.	
5.	

#### What are 3-5 main topics that you would like to touch upon in your conversation?

#### Are there any topics you do not want to discuss?

1.			
2.			
3.			
4.			
-			
5.			





#### What are five questions you would like to ask your interview partner?

1.			
2.			
3.			
4.			
5.			

Forty minutes may sound like a lot of time, but a thoughtful question can open up an entire thread of conversation. Feel free to develop your own questions, or use the **Custom Questions** list for inspiration. It can be helpful to start with some general questions before asking about more complex subjects.

#### **Great Follow-Up Questions**

- How did that make you feel?
- What happened next?
- Can you remember a specific time...?
- Can you give me an example?

- Can you paint a picture in words?
- What were you thinking when that happened?
- Is there anything else you'd like to say to me?





# NEXT STEPS

### Reflections and Questions after the Conversation

Whether you record using the StoryCorps App or Connect, listen to stories in the archive, or start a discussion with family or friends, we encourage you to take some time to reflect on the importance of health and wellness conversations.

- > Why is it important to share stories about health and wellness?
- What did you learn from having a health and wellness conversation? What surprised you?
- What role does a library play in keeping a community healthy?
- What health resources does your library offer?

#### Here are a few ways to continue the conversation:

- Search for stories in the <u>StoryCorps Archive</u> and at storycorps.org.
- Ask your library staff for more health and wellness resources at your library.
- Connect with others through the All Our Voices Community Page.
- Learn more about the <u>All of Us</u> Research Program and resources available at your library.
- Record more health and wellness conversations with other friends, family, or community members.

The good thing about telling my story was that it showed that I am not just a kid with a disease. I have friends and ambitions. The story got to be about me as a person and human being."

StoryCorps Participant

