

Understanding community information needs through stories

A guide for public health professionals, civil society organizations, and interested community members on how to analyze community stories to foster a healthier information environment.



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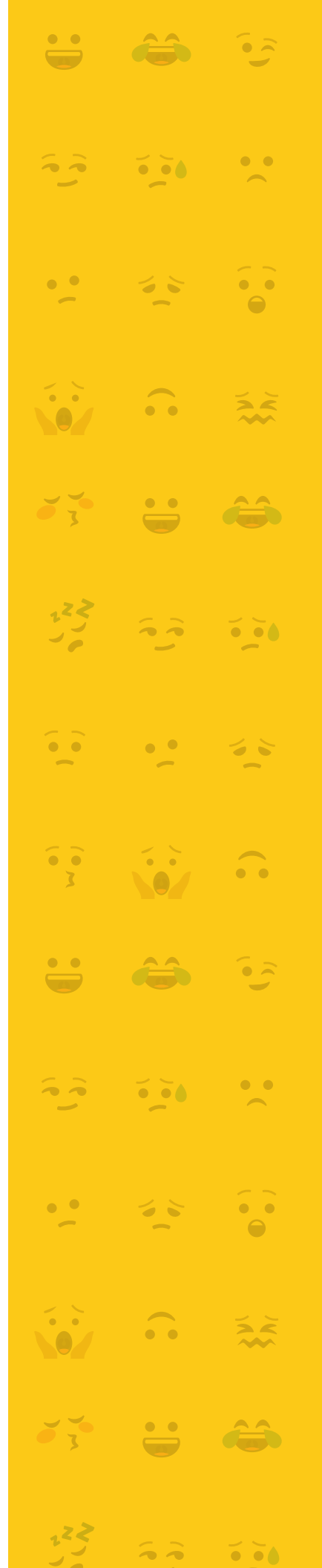
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How a noisy information environment can affect your health



We live in a noisy information environment. It's the volume of the news, it's constant updates on your social media feeds, and sometimes dubious information that pops up in conversations with family and friends, and it can affect your health.



Your information environment is unique to you. It's influenced by socio-cultural and commercial determinants of health, access to the internet, access to media, interactions with individualized content algorithms, geolocation, and sources of information including people and groups that you trust.



When it comes to your health, how do you look for, find, and act on health information, and how does it find you?

- Should you trust that fitness influencer on TikTok?
- Is that ad for the natural cure to diabetes true?
- Why are experts debating the benefits of booster vaccines on TV?
- Why did the local health department issue an alert for a measles outbreak?
- Did the “life hack” shared in the mom group on WhatsApp about using antibiotics to cure kids’ sniffles work?
- Is it true that your aunt, who says she is using a special phone app with sonic vibrations to help her hearing, doesn’t need to go to the doctor anymore?
- When you Google remedies for a weird rash and exhaustion, which website would you trust?



Within your information environment it might be challenging to distinguish accurate from inaccurate health information.¹



During public health emergencies, looking for health information becomes urgent and is complicated by limited availability of credible, accurate information². Lots of concerns and misinformation will circulate while health guidance is trying to keep up with developing science³.



In both day-to-day life and in emergencies, your information environment may make it difficult to find information that can help improve or protect your health.




Social media platforms are designed to show you content that is highly engaging and likely to generate clicks, views, or shares — content⁴ that isn’t always the advice your doctor or a health worker would provide.





Misinformation, or false or inaccurate information, can be spread quickly, including by well-meaning people who believe it to be true.





Disinformation is the purposeful spread of false or inaccurate information, often with political or financial motives, and can cause serious societal harm.


 In low-trust environments, such as communities that have been affected by historic disenfranchisement, violence or humanitarian conflict, people might be less trusting⁵. Vital information from health authorities might not reach them, or be trusted when it does⁶. Even then, the information might not be in a format or language that is easily understood.


 Mis- and disinformation can further erode trust by propagating conspiracy theories. They can also stigmatize groups and promote those who advocate against evidence-based diagnostics, treatments, and health guidance.


 Anytime someone is searching for health information, such as when they have a new symptom or have been recently diagnosed⁷, they might encounter outdated or inaccurate information or mis- and disinformation.


 People's health, digital and media literacy, and access to information sources can affect their ability to navigate this confusing information landscape.


 Navigating an unhealthy information environment may include your questions and concerns going unaddressed, experiencing information overload, sorting through conflicting, outdated or inaccurate information, or encountering information voids, where you look for accurate health information that you trust but can't find it. The potential harms might be making poor health decisions, not seeking needed care, or taking some kind of action that harms your health, such as accepting useless or non-recommended treatments⁸.

 This can have real-world consequences on individual and public health. Examples include people with cancer choosing alternative treatments over evidence-based ones⁹, or parents refusing vaccines for their children because of long-debunked vaccine safety myths on social media¹⁰.

 This is a global problem. A rapidly digitizing society makes it so much easier to spread low-quality, harmful information almost instantly. In fact, because social media platforms make money by keeping users engaged, this can incentivize the spread of misinformation because it is highly engaging¹¹.

 People working in public health are struggling to understand the scope of the unhealthy information environment problem, and how to address it.

 Without assessing how infodemics and the information environment affect specific communities, we are unable to develop effective solutions.



People working in public health are struggling to understand the scope of the unhealthy information environment problem, and how to address it.



So what's the bottom line?



The information environment surrounds us, at the individual level, within our family and friend circles, and our communities. It includes the health systems that serve us and our wider society.



Because infodemics have diverse impacts, they affect different groups of people and levels of society differently.



Understanding those impacts can help public health professionals and community-based organizations design better ways to meet people's information and health service delivery needs. They can also help with longer-term planning for better tailoring health services to community preferences.



Solutions may include: improving communications and community engagement, improving digital content, optimizing delivery of health information and services, working with trusted messengers, fixing confusing health policy, prebunking and debunking misinformation, promoting peer-to-peer engagement, and improving health literacy.



Ready to problem-solve?

¹ van Kessel, R., Wong, B. L. H., Clemens, T., & Brand, H. (2022). Digital health literacy as a super determinant of health: More than simply the sum of its parts. *Internet interventions*, 27.

² Centers for Disease Centers for Disease Control and Prevention. (n.d.). CERC : *Psychology of a crisis*. Centers for Disease Control and Prevention. <https://stacks.cdc.gov/view/cdc/60292>

³ Do Nascimento, I. J. B., Pizarro, A. B., Almeida, J. M., Azzopardi-Muscat, N., Gonçalves, M. A., Björklund, M., & Novillo-Ortiz, D. (2022). Infodemics and health misinformation: a systematic review of reviews. *Bulletin of the World Health Organization*, 100(9), 544.

⁴ Gisondi, M. A., Barber, R., Faust, J. S., Raja, A., Strehlow, M. C., Westafer, L. M., & Gottlieb, M. (2022). A deadly infodemic: social media and the power of COVID-19 misinformation. *Journal of medical Internet research*, 24(2), e35552.

⁵ Koehle, H., Kronk, C., & Lee, Y. J. (2022). Digital Health Equity: Addressing Power, Usability, and Trust to Strengthen Health Systems. *Yearbook of Medical Informatics*, 31(01), 020-032.

⁶ Ekezie, W., Maxwell, A., Byron, M., Czynnikowska, B., Osman, I., Moylan, K., ... & Pareek, M. (2022). Health communication and Inequalities in primary care access during the COVID-19 pandemic among ethnic minorities in the United Kingdom: lived experiences and recommendations. *International Journal of Environmental Research and Public Health*, 19(22), 15166.

⁷ Luo, A., Qin, L., Yuan, Y., Yang, Z., Liu, F., Huang, P., & Xie, W. (2022). The effect of online health information seeking on physician-patient relationships: systematic review. *Journal of Medical Internet Research*, 24(2), e23354.

⁸ Wilhelm, E., Ballalai, I., Belanger, M. E., Benjamin, P., Bertrand-Ferrandis, C., Bezbaruah, S., ... & Purnat, T. D. (2023). Measuring the burden of infodemics: Summary of the methods and results of the Fifth WHO Infodemic Management Conference. *JMIR infodemiology*, 3(1), e44207.

⁹ Johnson, S. B., Park, H. S., Gross, C. P., & Yu, J. B. (2018). Use of alternative medicine for cancer and its impact on survival. *JNCI: Journal of the National Cancer Institute*, 110(1), 121-124.

¹⁰ Geoghegan, S., O'callaghan, K. P., & Offit, P. A. (2020). Vaccine safety: myths and misinformation. *Frontiers in microbiology*, 11, 372.

¹¹ Wang, Y., McKee, M., Torbica, A., & Stuckler, D. (2019). Systematic literature review on the spread of health-related misinformation on social media. *Social science & medicine*, 240, 112552.



How to use this guide



How might we understand people's information needs around a health topic? The answer may be stories!



People's brains are wired to remember information, especially if it is formatted as stories. Stories are more engaging than numbers or dry facts. We tell stories to share experiences of the world around us, good and bad, and how change has affected us.



Stories can help us process things that have happened to us, to connect with others, to explain complex concepts, and to share information.



People are experts on their own experiences, and those experiences are valuable for understanding their relationship to health.



Collect enough stories of people's experiences related to a health topic, and you can spot patterns in the narratives.



People from the same community as where the stories originated can best identify those patterns.



Story collection and analysis should be done by the community, for the community, to generate insights and recommendations that benefit the community and inform all partners working toward improving health.



This guide helps you plan an evaluation of how a community has been affected by its information environment through stories.



The guide was built on a pilot project in 2023. Members of the infodemic management community, convened by the World Health Organization, analyzed stories of how the COVID-19 pandemic and accompanying infodemic affected people in public health. Those stories were then analyzed by other members of the same community.





This guide leverages some aspects from Most Significant Change (MSC) methodology¹², which aims to understand the impact of a program or topic on a community through stories.




The guide is designed for researchers, public health professionals, civil society organizations, and anyone interested in understanding how the information environment affects conversation and attitudes about a health topic.


Story collection and analysis should be done by the community, for the community.

 However, anyone can use this guide to examine any issue if there is an unhealthy information environment that may be affecting a group of people and their access to credible, accurate information. This may include social issues such as gender-based violence, civic participation and democracy, racism and stigma, climate change, and other social and development topics.

 The story collection and analysis process is designed to complement existing efforts to diagnose and address health system challenges, improve community engagement, improve communication, and build trust with communities.

 The guide offers a general approach to how you can collect, analyze and act on the stories of lived experiences of a community to improve access to and use of health information and health services.

3 At different stages of the guide, specific steps can be customized in three ways depending on your context and project needs.

 Before developing a project protocol (or plan), fully read through the guide. This will help inform your planning, timelines, and partner and community outreach.

Here are the guide's steps at a glance:



¹² Davies, R., & Dart, J. (2005). The 'most significant change'(MSC) technique. *A guide to its use*.



Before getting started



Partner with a public health-focused organization

If you are not from a public health organization, identify ones you can work with whose mission aligns with the aims of the project. They should be focused on the health topic of interest and/or serve the population of focus, and be in a position to help implement recommendations and solutions identified in the project. It's essential to work with the community of focus from day one, and the partner organization should help facilitate this. These organizations can provide expertise, technical input, access to people and communities who might want to submit stories or analyze them, potential funding, links to networks, and can serve as a sounding board throughout the project. They are a critical component to the project because they can help bridge the gap between project outputs and community impact. Without this important step, you may be able to collect and analyze stories and develop recommendations, but they may not be informed by the realities of your health topic, and you may not have anyone who can take action on your insights, and the project becomes a report that sits on a shelf instead of improving people's health.



Aim to involve someone who is an expert on the health topic and another person who is an expert on the community of focus, such as a community leader.

Gather available data

Understand the health topic of concern and the community of focus by collecting any relevant available data. This might include public health reports on the topic, news coverage of the topic, opinion polls, routine health system data, situational reports (during emergencies), peer-reviewed articles, social media reports, or infodemic insights reports. The more specific to your community of focus the better, which means national-level data will be less useful than a report from the state where your community of interest resides. Your community of focus might not be geographically bound, so think about what organizations might collect and publish data on it. For example, if you want to focus on young people, you might want to know who collects data about young people and the chosen health topic. These data sources can help you fill in knowledge gaps and identify potential topics you might want to ask about when collecting stories. They can also help you pinpoint where to go to collect stories and who to talk to.

It is a good idea to speak to informal leaders and practice leaders in the community of focus to let them know this work is about to start. They know the community best, and you want to ask and confirm that they think it is a good idea to do this work, and to build trust and engagement. They will have ideas for you in developing your plan, which will help make your work successful. For example, they will help you identify local resources and capacities and the timing for stages of work, and more importantly, how to make sure real action follows the work.

Identify resources and capacities

Map which people and organizations you might want to contact or collaborate with. Determine the time, people, and funding required to implement the project. Assess what kind of institutional support is available to you, such as free meeting space, digital tools, or funding. The more stories you want to collect, the more complex the project will become.

Connect to expertise

Aim to involve someone who is an expert on the health topic and another person who is an expert on the community of focus, such as a community leader. Other kinds of expertise, such as behavioral science, epidemiology, communications, infodemic management, health equity, and health promotion expertise, may also be beneficial to seek out. These experts can provide technical feedback throughout your project.

Build a team

It will take a small team of two to six people with different skill sets and roles to run this project, keeping it nimble and productive. Choose roles based on the size and scope of the project. For example, you will need people who will engage the community of focus, solicit or collect stories, manage the project, facilitate the discussions, take notes, and develop and disseminate the reports. Having familiarity with the community of focus — which may include having community ties, speaking the language, and having an understanding of the partner landscape — is critical. Develop a clear outline of team members, roles and responsibilities, and a way to coordinate and communicate, which may be a WhatsApp group, a Slack channel, or regularly scheduled in-person meetings. Your community's preference for communication will likely influence this. Ensure there is a central file repository where all project information can be documented and archived.

Follow existing guidance

Your project might require clearance or agreement from different organizations involved and adherence to organizational policies. Because this project collects data from people and uses it to inform public health efforts, it may be considered research. This means you should first seek guidance from your organization's research ethics committee or similar body on obtaining research determination before proceeding with project planning or collecting any data. Other special policies may be in place that govern how you engage with specific people or communities, such as working with vulnerable groups (e.g., children or people with disabilities) or discussing topics that may be sensitive or stigmatizing, such as drug use or reproductive health. Double-check on existing norms and guidance on community engagement, including unwritten norms. It may be helpful to understand how previous similar projects engaged the community of focus. Make sure you document everything and check in frequently with the team, technical experts, and responsible organizations throughout the project.



Planning and setting objectives



First, **define what you're investigating:**

- the population of focus
- the health topic
- time frame
- place
- expected information environment elements or impacts (e.g., questions, concerns, information voids, mis- or disinformation, stigma or other specific harms)
- Change you want to understand in your project

Complete this sentence:

By analyzing stories, we want to understand how the information environment on **[health topic]** affected **[the population of focus]** in **[place]** and **[time frame]**? How were **[infodemic impacts]** characterized and how were **[changes]** described by the storytellers?



Next, **define how your investigation will work with different partners**, specifically people, communities, or organizations that could:

- provide access to potential participants who want to share stories for collection
- provide access to potential focus group participants who can analyze stories
- for communities or organizations: Benefit from having the project's evaluation results and recommended solutions shared with them
- for communities or organizations: Be accountable for planning or implementing concrete solutions to identified information environment gaps

Complete this sentence:

We can work with **[people/communities/orgs who have stories to share]** to collect stories and recruit focus group participants who can analyze the stories from **[people/communities/orgs with potential focus group participants]**. We want to share the learnings from this evaluation with **[people/communities/orgs who would benefit from the results]** and the **[population of focus]**. Ultimately, we want to engage **[accountable organization]** to take action to address identified gaps.



Put it all together in a project protocol (or plan), including previously defined:

- population of focus
- health topic
- time frame
- place
- expected information environment elements or impacts
- change you want to investigate

You will also need to start thinking and planning in more detail about the logistics and scope of the project. More specific considerations are outlined in the chapters that follow. Depending on how many stories, your time frame, and how many focus group discussions you will have, the protocol may be more or less complex. Here is a suggested list of components to include in a complete protocol, but do tailor to your situation.

Criteria for inclusion and exclusion of:

- Storytellers, or people from the community of focus who submit a story
- Stories
- Focus group participants (analysts) who will read and discuss stories

Example: Your project wants to understand the experiences of older African-American residents in urban neighborhood X on their use of local parks to support their health in a story analysis project conducted in English. Example inclusion/exclusion criteria for storytellers may include:

Inclusion criteria:

- Resident of neighborhood X
- Identifies as African-American
- Has lived in neighborhood X for at least two years
- Is 60 or older
- Is able to communicate in English to tell their story

Exclusion criteria includes people who do not fit these criteria.

For the overall project, choose a target number of stories to collect and a target number of focus groups to hold. This will also help you determine how many story analysts need to be recruited. The protocol should contain the following:

- Number of stories to collect (sample of stories)
- How stories will be screened (in addition to inclusion/exclusion criteria)
- Target number of stories to be analyzed
- Number of focus groups and focus group participants

Community engagement and dissemination planning:

- Plans for how to engage community in storytelling project
- How to solicit and collect stories, including what incentives (monetary or other) may be offered
- How to recruit focus group discussion participants, including what incentives (monetary or other)
- How to disseminate and share final report and collect community feedback

Also, include all templates and scripts that will be used to collect and analyze data, such as:

- Story collection template
- Facilitator discussion guide for focus groups
- Rapid note-taker template based on discussion guide
- Any story analysis templates
- Informed consent for story collection
- Informed consent for focus group participation

Plan for how to organize, implement and document project:

- Project budget
- Outline of project team and partner roles and responsibilities
- Filing system for stories, consent forms, and focus group discussion materials and recordings
- Focus group participant log, including assigned stories and contact information
- Standard operating procedures (SOPs) and logs on soliciting and collecting stories and participant recruitment



Build a one-pager written in simple language about your project that includes the following:

- The challenge
- How the project helps tackle the challenge
- Overview of project steps
- Organizations involved in the project
- Resources/support needed from the community
- How the community can get involved (e.g., providing stories, participating in focus groups, attending a dissemination meeting)
- How participating individuals and community can benefit from this project
- The privacy and/or confidentiality policy in place
- Point of contact for further information

You can use the sentences you constructed from the templates above to build some key messages for this one-pager. You might want to consider developing a simple graphic or short video that can easily be shared on social media and messaging apps to urge people to get involved. You could suggest having a place online where project information is readily available, like a designated social media page or a webpage on the hosting organization's website.



Get project sign-off and approval

from partner organizations, any ethics or institutional review boards, and community-level leadership before beginning story collection. This step can take time, so plan ahead to obtain necessary sign-offs well in advance.



Story collection preparation



Develop a story collection template

based on your approved plan. A template should contain the following elements, but tailor to your situation.

- Overview of the project
- Point of contact for project
- Benefits and risks of participating
- Expectations for storyteller
- Name of storyteller
- Location of storyteller
- Storyteller phone number
- Storyteller e-mail address

Note: You may not need to collect personally identifiable information from a storyteller, but it can help to double check if there are any questions or follow-up needed after their story submission, or so you can share the project results with the people who contributed to the project. Additionally, some projects may choose to solicit stories that will become public and the storyteller agrees to have their name and/or location associated with their story.

Story title

Story (provide a prompt that focuses on understanding a perspective, a reaction or change related to health topic and information environment).

- **Potential storytelling prompts that focus on capturing change or impact may include (choose and tailor one or several for template):**
 - Can you tell us about a time when you experienced...?
 - How did recent discussions and information about **[health topic]** affect you?
 - What happened recently that affected how you perceive **[health topic]**?
 - How did you feel when **[public health event]** happened? What did you do next?
 - How did the information environment change for you as **[public health event]** happened?
 - When **[public health event]** happened, how did you look for information on **[health topic]** ?
 - How did you feel and respond when **[health topic]** became a challenge in your life?
 - What were some of the positive or negative impacts you experienced around **[health topic]**?
 - What change have you seen in relation to **[public health event]** and how it affected you?
 - Whom do you trust most when it comes to health information?
- **Informed consent statement (which needs to be signed)**



Identify the spaces (online and/or offline) where your population of focus spends time and **from which you may collect stories**. Then determine the most appropriate way to reach participants. Choose where to collect stories in three ways:

- 1 Location-specific:** If the people you want to collect stories from are specific to a place (e.g., neighborhood, local health department, district), you can go to the places they frequent and speak to venue owners or organizational leadership about collaborating to collect stories.
- 2 Interest-specific:** Look for interest-based groups (e.g., member-based associations, sporting clubs, subreddits, specific online communities) and approach them to collaborate on story collection from their membership.
- 3 Sector-specific:** Look for organizations that include and represent people who may contribute stories (e.g., professional associations, faith coalitions, academia, business coalitions, health systems, media outlets, civil society organizations) and approach them to collaborate on story collection from their membership.



Choose a target number of stories to collect. We suggest a minimum of 30 to allow for wider representation of stories and to have enough stories in focus groups to discuss and whittle down to a handful of representative experiences. However, you should increase the number if you have a very broad health topic, a very large population to include or more available resources.



Choose how to collect stories in three ways:

1. Ask people to write down their stories and submit them (in person or online)
2. Ask people to record their stories on audio or video and upload them
3. Interview people to record their stories (written, audio, video)

Note: There are also alternative ways to collect stories and experiences to health topics, such as through art, comic books, or photographs, which also have their own evaluation methodologies you may be interested in exploring (e.g., PhotoVoice for photos, art-based evaluation).



If you're **collecting stories in person:** Train story collectors on the process of approaching people in the community, discussing the process, obtaining informed consent, interviewing/soliciting the story from interested storytellers, and documenting it.



If you're **collecting stories online:** Set up a web form or webpage where you explain the project, define what kinds of stories you're looking for, provide a section for informed consent and make it easy for people to enter or upload their stories.



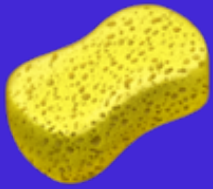
Carefully **choose your community entry point and format.** Having a community liaison or respected leader introduce the project on your behalf can improve acceptance and participation.



Make a plan for how to **collect stories from different quieter "corners"** of the chosen community so that you include more perspectives in the full story collection. Community leaders or experts can provide suggestions on how to do this.



Launch your story collection period.



Story cleaning



Once you have collected all the stories, **double-check that all information is complete** and that you have received informed consent from all storytellers. Log all information in a spreadsheet including story title, link to story, storyteller name or code, and whether informed consent was obtained and where it is documented.

Note: If your project has gone through the full research ethical clearance process and your project is expected to adhere to guidance around protecting people's information, you might need to anonymize some data that you collect. The people whose stories you collect should be made fully aware how their information and stories will be recorded, stored, analyzed and used, including personally identifiable information. This should be outlined in your protocol.



Based on your defined topic, community, and expected areas of change, **review all stories and screen out** any stories that do not meet the criteria. It is important that you consider how to avoid bias in this step, such as having multiple team members screen stories and double-check one another's work.



If needed, **convert stories into text-based formats** that allow for easier analysis in three ways:

1. AI-assisted transcription of audio
2. AI-assisted closed captioning of video
3. AI-assisted handwriting/text recognition software

You can also use the more reliable but labor-intensive method of human transcription. However, if you do rely on AI tools, have a human check all text outputs against the originals to ensure accuracy.



De-identify stories by removing identifiable storyteller information, such as names and locations. This will allow for the story analysts to focus on universal themes and experiences rather than particulars.



Check with your community expert on **specific cultural references and slang**, and where appropriate, provide definitions of these to aid understanding in analysis and interpretation.



If needed, **verify the stories with the storyteller** to ensure you have captured their points accurately, especially if there is something missing or meaning is lost due to a transcription or other translation error



Randomize and divide stories equally to assign to focus group participants (we suggest assigning no more than 2-3 stories per person). Stories should be randomly assigned in equal numbers among focus groups. The number of stories to be analyzed per focus group should ideally not exceed 20 stories, or it will be difficult to get through discussing all the stories. These stories will be read by participants before the focus group is convened.



Verify the stories with the storyteller to ensure you have captured their points accurately,



Story analyst recruitment



Define what type of focus group

participant (story analyst) you're looking for and how many you need (aim for 6-8 participants per focus group). They should come from the same community where the stories were collected. Determine inclusion and exclusion criteria.

Note: People who are story analysts don't need to have previous qualitative research or focus-group experience. You should recruit story analysts based on their identity as part of the community of focus, who did not submit a story but could thoughtfully discuss and comment on submitted stories.



Recruit focus group participants in one of three ways:

- 1 Advertise for participants:** You can post ads in social media spaces or on online bulletin boards, or in person at places where your community of focus gathers (e.g., community centers, libraries, houses of worship). You can also ask for partner organizations to share the call for participants, via their mailing lists and social media presences.

+ Benefits: Can yield a more diverse participant pool, especially those not reachable online or not affiliated with partners.

- Potential pitfalls: Can be costly if paying for advertisement, and might attract people who are not eligible to participate.

- 2 Snowball approach:** If you have a previously identified group of people who meet the participant profile, you can ask them to recommend others in their network to participate.

+ Benefits: Can help you identify potential participants from smaller or more close-knit groups, such as religious communities or support groups for people with a specific health condition, and because the recommendation comes from a trusted messenger, likelihood of participation may be higher than trying to cold-call potential participants.

- Potential pitfalls: If the profile of participants you're seeking to involve is marginalized, stigmatized, or has been subject to systemic trauma, take extra care to navigate communications with sensitivity so you don't cause unintended harm. Additionally, people with disabilities such as vision or hearing impairment may need accommodation; this should be planned for. Seek expert advice as appropriate.

- 3 Connect with representative organizations for nominations:** Work through your public health and community partner organizations to extend the invitation to participate through their networks.

+ Benefits: Higher likelihood of identifying participants who fit the desired profile.

- Potential pitfalls: Participants will only be from audiences organizations already have and you might miss out on other perspectives.



Host a project overview meeting.

Outline expected participant contributions, answer remaining questions and obtain informed consent from all participants. Log all this information, including participant names, phone numbers and email addresses, whether informed consent has been obtained, and assigned focus group session.



Assign participants stories to read before the focus group

(no more than 2-3 per person). Update participant log with this information.



Convening focus groups and conducting story analysis



Double-check that you have all the essential elements needed to conduct an analysis of stories:

- Stories
- Focus group participants who represent the community which the stories were collected from, have given informed consent and have the availability, language skills, and internet access to participate fully (if online)
- Facilitator guide and note-taker templates
- One facilitator and two note-takers per focus group. They should have been trained on facilitator guide and note-taking templates, respectively
- For in-person: Sticky notes, pens, table that all participants can gather around
- For virtual: A virtual web conferencing tool, and a virtual whiteboard where stories can be visually represented, sorted, and discussed



Design the focus group discussion of stories in three ways:

- 1 In-person approach:** Print out the stories, gather focus group participants, and host the focus group in a room with a large table, where printed stories can be moved around, sorted, annotated, and piled together.

+ Benefits: May be more accessible for people who do not have stable internet access or experience with digital tools. Can also allow for participants to more fully interact with the stories and see one another's body language.

- Potential pitfalls: Requires geographic proximity and mutual availability among participants.

- 2 Hybrid approach:** Create different focus groups that may be fully in-person or fully virtual. This is a good option if some participants are geographically clustered, but others are located elsewhere or have schedules that make it difficult to participate in person.

+Benefits: Maximizes participation across locations and time zones.

- Potential pitfalls: Can be more difficult to coordinate.

- 3 Fully virtual approach:** Host focus groups online and use digital conferencing and whiteboard tools.

+Benefits: Can allow for geographically dispersed groups to convene in a virtual space and allow for more flexibility in timing of discussions.

-Potential pitfalls: Can exclude people with low internet connectivity or tech proficiency. Requires facilitators and note-takers to navigate through virtual whiteboards successfully while running focus groups.



Invite participants to focus groups well in advance, and ensure they have all received stories to read before the focus groups begin, with a request to not share outside the focus group. Set expectations that they only need to read the stories and be ready to summarize them and share their thoughts at the focus group.



Remind participants that they should bring their whole selves to the discussion, that they are experts in their own experiences, which will allow them to more reliably interpret important themes from the stories that come from the same community.



Convene the focus group and start with the following:

- Welcome participants
- Introduce yourself and other members of the project team
- Invite everyone to introduce themselves
- Do a break-the-ice exercise (e.g., what is the meaning of your name?)
- Explain how the focus group will run and summarize house rules
- Check that everyone has their assigned stories
 - In-person: Check that everyone has received printouts of their assigned stories
 - Virtual: Check that everyone can use the whiteboard and see their assigned stories
- Invite each participant to summarize their assigned stories



Promote discussions of and reactions to stories in three ways:

- Pair participants or bring them together in subgroups to discuss stories before larger group discussions
- Offer ways for participants to provide feedback in multiple formats (e.g., written, voting, emoji reactions)
- If virtual: Offer ways for participants to provide feedback asynchronously



Ask participants to reflect on the shared stories. Prompts may include:

- Did you have any experiences similar to the storyteller's?
- What element of the story stood out to you the most? Why?
- How did the storyteller experience or describe change?
- What were some of the barriers to or facilitators of addressing the health or information challenge?
- How do the stories you shared relate to the other stories we have already discussed?





Remind participants to focus less on quality of writing or delivery of the story and more about the substance — **what they remember after they have read it.**



As participants say **keywords or repeat topics or themes that were mentioned earlier, write them onto sticky notes** and put them on the work surface. Participants can also help with this.



Halfway through sharing all of the stories, **do a temperature check with the focus group and ask what themes or trends everyone is hearing** and ensure that these have been captured in the sticky notes.



Once all stories have been discussed, **ask participants to sort them into piles near the stickies that reflect major themes of stories.** It is likely that some stories will match multiple themes:


- Virtual: Duplicate the story sticky and move to appropriate themes
- In-person: Add sticky notes of a different color with the story title to appropriate themes




Once stories have been associated with themes, **help participants narrow down the stories to 2-3 that best represent change in their community.** Often, these will include challenges or enablers to positive change. How they whittle down the stories should ideally be decided in group consensus. However, here are three other ways to determine the “winning” stories:


- Participants can vote for their favorite stories through dots (virtual) or show of hands (in person).
- Start with the theme or topic that has the most stories associated with it and discuss whether to choose stories from the three most prevalent themes.
- Conduct a pair-based process of elimination by pairing up participants and asking them to pit their favorite assigned story against their partner's, choose a winner, then meet up with another pair of participants and repeat the process until 2-3 stories are left.


Note: Often, stories will have multiple themes, and can be grouped in multiple ways. Online, you can duplicate a sticky with the story and post them in different places. In person, you can create new stickies with the story title on them and assign them to different themes.


 **Capture the reasons why the 2-3 stories have been chosen**, asking participants to explain why these stories are significant to understanding the impact of the health topic and the information environment on the community.


 Ask participants, based on these stories:


- What recommendations do you have for fixing identified challenges or leveraging identified enablers?
- What actions would support the storytellers if they ever encountered the same situation in the future?

 **Thank participants for their time** and contributions and let them know what will happen after all focus groups are completed.

 **Visually document** the final layout of stickies and stories.

 **Meet with note-takers and review their notes.** Ask them to consolidate their notes into one set per focus group.

 After each focus group, **meet with the project team to discuss what worked well, what needed improvement, and whether any adjustments should be made** for future focus groups.

 **Upload** recordings, notes, screenshots, and other focus group documentation **to a central repository for easy reference.**

**Thank participants for their
time and contributions**



Developing story insights and recommendations



Discuss the notes with project team, review the final chosen stories and the pictures of the final layout of stickies and stories.



For each focus group, write a narrative of how the discussion developed, how topics and themes emerged, how stories were reflected upon by the participants, and how they chose 2-3 stories that best represented change in the community.



Compare and contrast findings across focus groups. If there are many common themes or elements, it increases the likelihood that this is representative of the experiences of this community. *You can use the story theme analysis table template for this.*



Write out the above in a report that includes the recommendations made by participants, informed and supported by themes highlighted in chosen stories.



Circulate an early draft of results to informal community leaders, partners and participants for feedback and correction. They will have useful insights and amendments, and will aid the action that will follow the report.



Sharing story insights and promoting action



Prepare to have at least two dissemination meetings, one for the community from where the stories originated, and the other to project partners, including organizations ultimately accountable for implementing recommendations and addressing information and health service delivery gaps



Based on your audience, **develop the report in the most effective format.**

This may be:

- Written report with one-page executive summary
- Executive summary PowerPoint slide
- Narrated video presentation
- Visual storyboard
- Infographic
- Podcast



Choose the appropriate venue and time and meet the community and partners,

and share project overview, results, story excerpts, and recommendations. Leave ample time for Q&A and getting feedback from meeting participants.



At meetings, **discuss and record any follow-up actions**, responsible people/organizations and timelines.



Make a plan for how to follow up on recommendations to see what has changed a month, three months, or six months from now.



Publish the report and stories

(when appropriate) for the public to be able to access.



Celebrate everything the storytellers, you, your team and partners have accomplished!



Tools to help you use this guide

Templates and Tools

The following table contains links to free and editable versions of templates that can assist in several steps of your project. It's important to tailor each to your health topic, population, context, and format (virtual vs. hybrid vs. in-person).

Tool	Use it for...
Project planning tool (Miro)	Working with your project team to plan for all steps of the project. This planning tool is freely available in Miro.
Skills checklist for community story analysis team (Word Doc)	Determining what kinds of skills and team members are needed on the story project team.
Story collection template (Word Doc)	Developing and tailoring a story collection form for your project.
How to set up the virtual focus group story discussion whiteboard (Word Doc)	Designing your virtual focus group whiteboard setup to aid in story analysis and selection.
Whiteboard template for story discussions (Miro)	Setting up whiteboards for focus group discussions in Miro.
Focus group facilitator guide template (Word Doc)	Providing a script for facilitating focus group discussions. This is used by the facilitator.
Focus group note-taker guide template (Word Doc)	Providing a simple, editable document to type notes into that follows the facilitator guide for focus group discussions. This is used by the note-takers.
Story theme analysis table (Word Doc)	To quickly identify common themes or gaps across focus group discussions.
Community stories report outline (Word Doc)	Outlining the outcomes from the focus group discussions and include recommendations for action.
Table of potential solutions for promoting healthier information environments (Word Doc)	Brainstorming potential ways to fix problems identified through story analysis.

Useful Links

Here are links to reputable resources, articles, and toolkits on specific topics to help you plan your project. Be sure to consult local partners and authorities about any existing guidance and tools that might be more appropriate locally.

Most Significant Change (MSC) basics

- Tools4Dev: [Using the 'Most Significant Change' \(MSC\) Technique to measure the intangible](#) article
- Better Evaluation: [Most significant change](#) explainer
- The Monitoring and Evaluation Toolkit: [Most Significant Change](#) article

Institutional Review Board (IRB) and informed consent


- University of Michigan: [Informed Consent Guidance & Templates](#)
- University of Illinois Chicago: [Informed Consent](#) training
- Murray State University: [IRB — The Basics](#) explainer

Culturally sensitive community engagement

- University of Michigan: [Engaging Your Community](#) DEI Strategic Planning Toolkit
- National Center for Cultural Competence: [Checklist to Facilitate Cultural Competence in Community Engagement](#)
- CDC Global Health Equity: [Guiding Principles for Communication](#)

Facilitating focus group discussions

- Social Science & Medicine: [Considerations for Employing Intersectionality in Qualitative Health Research](#), co-authored by Jasmine A. Abrams, Ariella Tabaac, Sarah Jung, and Nicole M. Else-Quest
- Brown University: [Tips on Facilitating Effective GroupDiscussions](#)
- Ohio State University: [Overview of the Process of Conducting Focus Groups](#)



An easy-to-use tool for understanding community information needs by centering community member stories and experiences.

communitystoriesguide.org

