

Camden Coalition's story sharing consent collection tool

When & how to use this tool

This story sharing consent collection tool is used by Camden Coalition staff to:

- Discuss opportunities for story sharing with people with lived experience (including but not limited to clients and participants in our care management and community engagement programs); and
- Document the informed consent of the individual with lived experience to participate in the opportunity.

Before having a conversation, the responsible staff person should collect and record all the details needed to fill out the "about this project" section. This tool is meant to support staff in having thorough and thoughtful conversations about story sharing. Staff can read and/or paraphrase the information as they review it and modify the conversation as appropriate. We estimate that consent conversations using this tool should take about 15 min to complete.

To complete the consent process, please record all responses from the prospective story sharer as well as collect their signature. Then upload the completed document to this SharePoint folder: [Story sharing consent forms](#) (in Communications - Approved comms resources).

If you have questions or need support with this process, please reach out to a member of the Community Engagement or Communications departments.

Background: our story sharing values

The Camden Coalition's mission is to improve the health and well-being of people with complex needs, and we believe that people with lived experience should be partners in this work. First-hand experience navigating health and social care systems holds so many lessons for what works well, what does not, and what is needed. We value opportunities to support people in sharing their stories and amplifying this expertise to local and national audiences.

Our storytelling efforts are informed by five core values:

- **Equity:** Everyone has personal stories about health and healthcare, but people don't have equal access to the microphone. We draw attention to storytellers and experiences that are often pushed to the margins.
- **Autonomy:** Everyone's story is their own. We partner with people and communities to share their experiences in ways that feel authentic and empowering for them.
- **Safety:** We prioritize the physical, emotional, and mental well-being of all people who share their experiences. We gather informed consent and use trauma-informed practices.
- **Parity:** We value lived experience and compensate people for their expertise, time, and labor wherever possible.
- **Strengths-based:** We share stories that go beyond a problem someone has experienced to show their strengths and who they are.

Consent conversation guide – begin here

About this project

Note: The Camden Coalition staff person holding this story consent conversation should collect the following information in advance so it can be shared while reviewing this form.

We are asking you to: _____ (e.g. share your story, let us interview you, let us photograph/record you, etc.) for the purpose of _____.

This opportunity is related to: _____ (e.g. any relevant projects, initiatives, goals, or policy priorities that relate to why the Camden Coalition is supporting this opportunity).

This story will be shared/published in the following places: _____ (e.g. name of publications, websites, media sources, Coalition materials, etc.)

As part of the interview, we will:

- ☐ Take pictures of you
- ☐ Audio record your voice
- ☐ Video record you
- None of the above

Compensation

If monetary compensation is being provided:

In return for your time and contributions, you will receive compensation in the amount of _____.

We can pay this amount to you by check or by gift card. We pay more than \$600 in compensation to you in a calendar year we will issue you a 1099 tax form to report this income. Please keep in mind that receiving additional income can affect your eligibility for public benefits like SNAP, Medicaid, or subsidized housing. Please let us know if you have any questions about this! This amount is the total we anticipate paying for this opportunity. We do not expect there would be additional compensation for this same opportunity (such as royalty payments).

How would you like to be paid?

- ☐ Check
- ☐ Direct deposit
- ☐ Gift card

If monetary compensation is not being provided:

Unfortunately, we are not able to provide compensation for this project, however we hope that your participation is still beneficial to you in the following ways: _____ (e.g. provides an opportunity to speak out about issues you care about, helps to educate others about issues that impact people like you, provides a personal development opportunity, etc.)

Approving final version

For some story sharing opportunities, you will be able to see a copy of the final version of your story and make edits before it is shared publicly. For other opportunities this is not possible.

For this project you: **do/do not** (*staff person should indicate which one*) have ability to review and edit the final version of your story before it is shared publicly.

Taking back permission

For some story sharing opportunities you will be able to contact us down the line if you no longer want your story shared (for instance, a video we have on our website). For other opportunities, we do not have the ability to prevent your story from being shared publicly if you change your mind (for instance, stories that are published in a newspaper).

For this project you: **do/do not** (*staff person should indicate which one*) have ability to take back your permission for this story to be shared.

To revoke story-sharing permission, where possible, please contact our Communications department at news@camdenhealth.org.

Your rights

If you choose to share your story, you have the right to:

- **Decide when, how, and for what purpose you share your personal stories and lived experiences.**
 - Taking part in this interview, picture, or video is voluntary. Your participation is completely up to you. You do not have to agree to do an interview or let us take pictures or video of you. Your decision (yes or no) will not affect your being able to receive services from us or any of other organization.
- **Receive all the information and support you need to feel comfortable sharing your story.**
 - We want to ensure you have complete and accurate information about this story sharing opportunity so you can decide if it is a good fit for you to participate in. We will also offer support and reasonable accommodations so you feel comfortable and confident in sharing your story.
- **Stop the interview, picture, or video recording at any time.**
 - During the interview or while we are taking pictures or recording video, you can ask us to stop. You do not need to give us a reason for stopping.

Considerations for sharing personal experiences

Note: you may not need to review this section in depth if you are speaking with someone who is a seasoned story sharer/public speaker.

Sharing our stories can be incredibly powerful. When we share stories in ways that feel good to us, it can inspire change, build movements, create connections to others, and further our own healing. However, certain lived experiences can be very personal, and some experiences can be painful to remember and difficult to share with others. What's most important is to feel in control of how, when, and for what purpose our stories are shared.

Here are a few things to consider before sharing your personal story:

- Do you feel emotionally prepared to share your story? If you are still working through trauma, grief, or find that talking about your experience is very upsetting, you may not yet be ready to share your story publicly.
- How do you feel about your story being out in the world? What details are you comfortable sharing? How might it affect your personal life and professional life, as well as the lives of your family, friends, or significant others, now and in the future?
- Could there be any negative consequences from sharing your story such as impacting your employment, relationships, or involvement with the criminal legal system?
- There are many ways to share your stories publicly. The benefits, risks, and privacy considerations may be different based on where and how you share your story.
- The way other people respond to your story is often supportive but could also be critical. Consider what kind of feedback and support you may need before, during, and after sharing. This could include asking a friend, family member, or support person to be available for you during or after.
- Think about how the level of detail you share might affect your goals. If public education is your goal, and you share a very detailed story, some people may be too triggered to take in your message. To be most effective, consider what key aspects of your story relate to your goals for sharing.

Are you interested in sharing your story, being interviewed, or photographed/recorded for the opportunity described above?

☐ Yes

☐ No

Can we use your real name?

☐ Yes, first name only

☐ Yes, full name

☐ No

If applicable: Can we use your child's name?

☐ Yes, first name only

☐ Yes, full name

☐ No

If applicable: Can we use your child's photo?

- ☐ Yes
- ☐ No

Is it okay for us to tag you on social media?

- ☐ Yes
- ☐ No

If yes, please list the social media accounts or handles we should use to tag you:

- Facebook: _____
- Twitter/X/Bluesky: _____
- LinkedIn: _____
- Other (specify): _____

We want to ensure we honor your story in a meaningful way. If we were to find out that you had passed away, would you be comfortable with us continuing to use this story, video, photo, or audio recording in the future?

- ☐ Yes
- ☐ No

Can we share this story/video/photo/audio recording in other places?

Sometimes we collect stories, video, photo, or audio recordings, but use them for other purposes or projects in the future.

Do we have your permission to use this same story, video, photo, or audio recording for other purposes in the future?

- ☐ Yes, you can use this story, video, photo, or audio recording for any other purpose
- ☐ Maybe, but please contact me first to share the details
- ☐ No, you can only use this story, video, photo, or audio recording for the specific purpose we discussed today

If permission is granted to use this story for other purposes, ask the next two questions. If permission is not granted, skip the next two questions.

For what other purposes are you comfortable with your story being shared? (Check all that apply)

- ☐ All/any
- ☐ Outreach: to help other people learn about and connect with the Camden Coalition's services.
- ☐ Awareness raising: to help more people learn about how experiences like mine affect our communities
- ☐ Policy/advocacy: to advocate for laws and policies
- ☐ Fundraising: to raise money to fund Camden Coalition's services.
- ☐ Training: to help staff and partners in the community do their jobs better.

For the opportunity we're discussing, your story will be shared/published in the following places: _____ (e.g. name of publications, websites, media sources, Coalition materials, etc.)

In what other places are you comfortable sharing this story? (Check all that apply)

- ☐ All/any
- ☐ Media (e.g., newspaper, TV news)
- ☐ Print materials (e.g., brochures, mailings)
- ☐ Online materials (e.g., website, emails)
- ☐ Social media (e.g., Facebook, Twitter, Instagram)
- ☐ Live events (e.g., meetings with legislators, fundraisers, trainings)

Is there anything else you want us to be aware of, or any questions or concerns?

Signature

By signing this form, you agree that the Camden Coalition can use and share your information as described above.

Client/patient/community member name

Client/patient/community member signature

Date

Camden Coalition staff member name

About the Camden Coalition

The Camden Coalition works to improve care for people with complex health and social needs in Camden, NJ, and across the country. The organization implements person-centered programs and pilots new models that address chronic illness and social barriers to health and well-being. Supported by a robust data infrastructure, cross-sector convening, and shared learning, its community-based programs improve outcomes for some of society's most vulnerable individuals. The Camden Coalition's National Center for Complex Health and Social Needs (National Center) connects complex care practitioners with each other and with data, tools, and other resources. For more information, visit www.camdenhealth.org