

Stand in your power: Share your story to help create change

Your voice, your story, and your lived experience have the power to shape systems and guide real change!

If you've been impacted by challenges related to healthcare, housing, or other services, sharing your story can spark change for yourself, your community, and beyond.

If you know others who have faced challenges, invite them to share their stories because every voice has the power to create change.

Why your story matters

- Protect important programs like Medicaid: Now is the time to defend programs that matter. Your story can highlight what is at stake.
- Drive policy and quality improvement: Real stories show what is really happening and help shape the rules and programs to make healthcare work better for everyone.
- Make the data personal: Stories like yours humanize data. They influence decision-makers and have the power to make change.
- Build collective power: When one person shares, others are inspired to do the same.



Be informed: What to consider before sharing

Your story is yours — handle it with care by taking the time to think it through and make sure you feel ready and informed before sharing:

First, ask yourself

- Am I emotionally ready to share my story?
- What level of detail do I want to share?
- Could sharing my story lead to any risks or negative outcomes?

Then, ask the person or organization inviting you to share:

- How and where will my story be used?
- Will I have a say in how it's told? Can I review or revise it?
- Will it be recorded?
- Will my name be shared?
- Could my story be changed or used in a way I don't agree with?
- Are the people collecting stories committed to making real change?
- Will I be paid or supported for sharing my story?
- Is this part of an ongoing relationship, or just a one-time ask?

Ways to get involved

Local examples:

- Learn about and connect with community-based groups and healthcare organizations: – To get started, search “[Your County + State] “community-based organizations”, “community groups,” “health or healthcare advocacy groups” or “advocacy/advisory organizations.” Many local groups offer opportunities to get involved and make a difference. These can include:
 - Housing and homelessness groups (like Continuums of Care or tenant rights organizations),
 - Consumer and patient voice groups (like NAMI affiliates or Mental Health Association chapters),
 - Disease- or condition-specific organizations (like local American Diabetes Association or Relay for Life teams), and
 - Grassroots organizations (like Moms Demand Action, Movement for Black Lives, or faith-based groups).
- Learn more about local Patient and Family Advisory Councils: – Learn whether your local hospital has a Patient and Family Advisory Council (PFAC) that you can join. PFACs are groups of patients and families who share feedback to improve care. Finding the right contact may take some digging – start by checking your hospital’s website or give them a call.
- Connect with your health insurance plan: – Many insurance plans have member advisory councils or committees. These groups invite members to share their experiences and ideas to help shape how services are delivered. You can call the member services number on the back of your insurance card or visit your plan’s website to ask if such opportunities exist or to be directed to the right contact.
- Advocate for local policy changes: – There are many ways to engage with decision-makers in your community. You can:
 - Write a letter or email to public officials about an issue that matters to you
 - Request a meeting with a city council member, county commissioner, or state legislator to share your point of view
 - Submit written comments during public comment periods on policies or regulations being considered
 - Attend public hearings and meetings, such as planning boards, school boards, city council meetings, or county advisory boards, to listen, learn, and speak during designated public comment times

– To get started:

- Use Find and contact elected officials | USAGov to look up your representatives
- Check your city or county government website for calendars of upcoming meetings and hearings
- Call or email the clerk’s office to ask how to sign up for public comment or be added to an agenda

State examples:

- Learn about state-level opportunities: – Check if your state has advisory councils through the health department or other agencies. These councils may focus on topics like youth, disability, or mental health, and often look to members to help inform programs or policies. Examples include Medicaid Advisory Committees, Behavioral Health Planning Councils, Developmental Disabilities Councils, and Youth Advisory Councils.
- To get started, search “[Your State] healthcare advisory councils”.
- Learn about statewide advocacy organizations: – Research and become a member of organizations that focus on advocacy. To get started search “[Your State] advocacy organizations”. Examples of statewide organizations include [Florida Voices for Health](#), [New Jersey Citizen Action](#), [Health Access California](#), and [Citizen Action Wisconsin](#).
- Attend state legislative sessions: – Check legislative schedules online and participate in sessions or public hearings to voice concerns and advocate for health-related legislation. To get started search “[Your State] legislative sessions”.

National examples:

- Learn about and participate in national advocacy campaigns: – Follow national organizations on social media and sign up for newsletters to engage in campaigns to influence change, such as [Community Catalyst](#). To get started, search “national advocacy campaigns + [area of interest (example: mental health)]”
- Learn about and participate in national conferences: – Research and register for national health conferences like [Putting Care at the Center](#) to present in workshops, build skills, and network with other advocates. Many conferences offer scholarships to help with costs.

- Join national communities: – Join communities like the [PFAnetwork](#) or [National Health Care for the Homeless Council](#) to learn with and from others with lived experience. These spaces offer free opportunities for mentorship, skill building, training, and connection.
- Use social media for awareness: – Use platforms like Twitter, Facebook, Instagram, or LinkedIn and join relevant groups with a focus important to you to network, collaborate, and raise awareness on a national scale. Examples of groups to follow include [Justice in Aging](#), [National Consumer Voice](#), [Families USA](#), [National Alliance for Caregiving](#), [Medicare Rights Center](#), [Poor People’s Campaign](#), and [Caring Across Generations](#). Social media links are typically located at the top right or bottom of a webpage.

Tools & resources

- [Visit our webpage](#) to find the 1-pager guide pulled from the content above and share it with your community.
- Tips for sharing your story: [Your Story Can Change Hearts, Minds and Policy | NAMI: National Alliance on Mental Illness](#).
- Want to see how others are sharing their stories? Visit the [Soapboxx story platform](#).
- Interested in learning more about how INSPIRE is working to advance authentic community engagement in healthcare? Visit [camdenhealth.org/inspire](#) for additional resources.

Your experience matters!

When shared with intention and support, your story and experiences can help shape the future of healthcare.





inspire

*community engagement
for better healthcare*