

Guidelines for Using Community Voice



Community Voice is a group of more than 800 people with cystic fibrosis and their family members who have signed up to have an active say in projects and initiatives that impact them. This group provides feedback on projects including surveys, focus groups, and committee work. In return for receiving input from Community Voice, those who use the group share the results and impact of their project with the members.

To get started, contact communityvoice@cff.org.

What services does the Community Voice team offer?

- Access to feedback and insights from more than 800 people with CF and their immediate family members, including parents, spouses, and siblings
- In-depth consultation for your project, including:
 - High-level summaries of previous data collected from the CF community on your topic
 - The most effective way to collect feedback from the community
 - Best practices on how to recruit community members into your work
- Guidance on survey development
- Comprehensive data analysis

What is expected of users of Community Voice?

For your project to qualify, it must meet these criteria:

- Fit the mission of the CF Foundation and aim to have a positive impact on the CF Community
- Be sensitive to the community's needs and concerns
- Gather new information that is meaningful to the community
- Contain a description of how the results will be used and the plan to share results with the community
 - We understand that publishing or institutional review board protocol timelines may determine what updates can be shared with the community and when. Our team is happy to work with you to clarify these issues.

How do I cite Community Voice in my work?

- **Surveys:** Cystic Fibrosis Foundation Community Voice. "Name of Survey." Survey. Month Year. Cystic Fibrosis Foundation, Bethesda, MD
- **Focus groups:** Cystic Fibrosis Foundation Community Voice. "Name of Focus Group." Focus Group. Month Year. Cystic Fibrosis Foundation, Bethesda, MD

How do I acknowledge Community Voice in my work?

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