

ENGAGING THE CF COMMUNITY IN RESEARCH

The CF Foundation can help you engage people with cystic fibrosis and incorporate their voice into the decision making process throughout the clinical trial development life cycle.



WHY INCORPORATE THE COMMUNITY INTO RESEARCH?

By engaging the CF community in clinical research, sponsors can:

- Enhance study design and improve feasibility
- Direct research toward questions that matter most to people with CF
- Leverage the experience of the community to promote trust and demonstrate that patients are at the center of your research
- Contribute to creating a more informed patient population

HOW CAN RESEARCHERS INCORPORATE COMMUNITY FEEDBACK?

The CF Foundation can facilitate community feedback to inform your research priorities and study design. Opportunities to partner with the community occur throughout all the stages of a clinical trial, and you can use existing data or collect new insights to inform your research project. Based on your goals and objectives, the CF Foundation will work with you to determine which mechanisms are most appropriate.

To inform your research project, community members can provide input on:



Eligibility Criteria

Are the enrollment criteria feasible?



Scientific Relevance

Is the trial studying something that will be meaningful to the CF community?



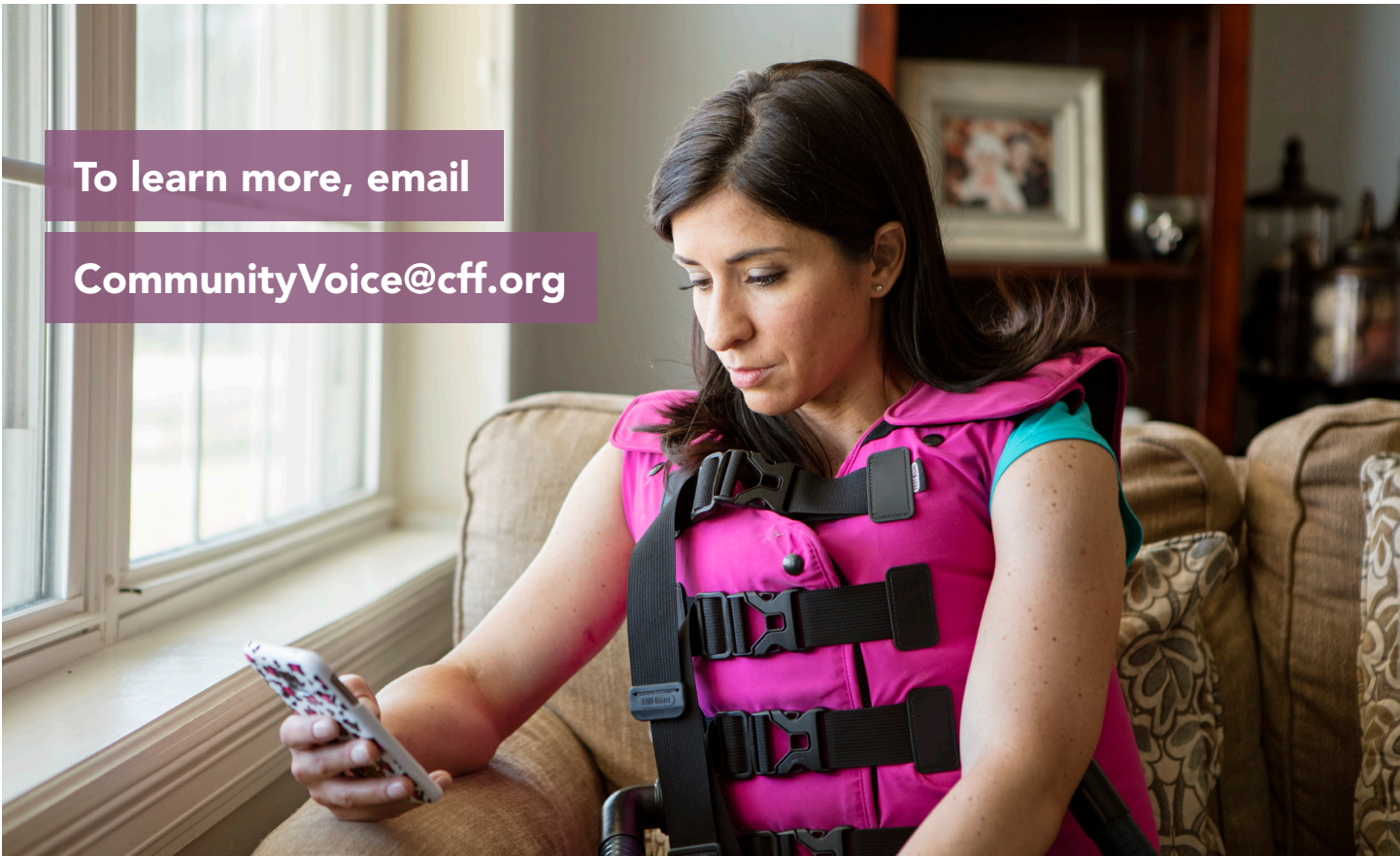
Procedural Burden

How feasible is the schedule of events?
What are the perceived risks and benefits of participation?



Communication

How effective are patient-facing clinical trial communications?
Do they provide the information patients want and need?



To learn more, email

CommunityVoice@cff.org

HOW IS COMMUNITY FEEDBACK COLLECTED?



Data Repository

Existing data from previous community research, including community interest in clinical trials and common barriers to participation



Surveys

Quantitative feedback from a wide audience of people with CF and their family members



Focus Groups

In-depth, qualitative insights in a smaller virtual group setting

Feedback can be gathered from a broad, representative group of over 1,000 people with CF and their family members, or collected from smaller groups with specific research experience, skills or training. The CF Foundation will work with you to determine the best approach to collecting community feedback for your project.

We can provide in-house expertise in:

- Data analysis
- Survey design
- Focus group facilitation

Surveys and focus groups are hosted in-house by the CF Foundation. Data and results reports are delivered in the format of your choosing.

There is no cost for this service. Community feedback is intended to help direct research toward questions that matter most to patients, to enhance study design, and improve feasibility of CF clinical trials. The CF Foundation does not conduct market research on behalf of industry sponsors or solicit community feedback on specific drugs or products.