PROJECT INFORMATION

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Creating a Survey of Community Engagement in Research

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Organization

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What was the project about?

In stakeholder-engaged research, patients, families, and other community members are part of a research team. As part of the team, community members can influence the design of a study and other parts of the research process so that the results are useful for their communities.

How research teams involve community members varies across studies. Some involve people in just one part or in a limited way, while others involve people much more. Having a consistent way to assess how involved community members are in a research project may help improve the process and the impact of stakeholder-engaged research.

In this study, the research team created a survey that researchers can use to assess how much community members are involved in research teams.

What did the research team do?

The research team used the Delphi method to create a survey with input from a panel of community members. The Delphi method helps panels share feedback and reach agreement through rounds of discussion and voting.

The panel included 19 patients, advocacy organization members, and researchers. Of the panelists, 63 percent were African American, 32 percent were White, and 5 percent were multiracial. The median age was 55, and 90 percent were women.

The research team started with a list of 11 best practices on how to engage community members in research. The team created survey questions about each practice. The team also developed definitions and scenarios about how research teams involved community members.

In each round of discussion, panelists gave feedback on the materials and decided to keep, change, or remove each survey question based on its importance. The panel reached consensus on the survey questions to include in the final survey.

Patients, caregivers, healthcare providers, and researchers helped design and conduct the study.

What were the results?

The final survey had 32 questions organized by eight best practices. These practices included:

- Focus on community views of health.
- Include community input.
- Make sure partnerships between researchers and the community last.
- Help community members learn and benefit from the research.
- Make sure research teams build on communities' strengths.

- Make sure partnerships involve working together and sharing power.
- Have community members share results of studies.
- Build and keep trust.

Panelists and the research team also created a way to score studies on community engagement. The scoring can show a range of engagement from simply getting input from community members, to having community members be partners in making decisions about the research.

The research team also created a shorter version of the survey that takes less time to complete.

What were the limits of the project?

The research team tested the survey in English. It may not reflect the experiences of people who speak other languages.

Future research could translate the survey and test it with people who speak other languages.

How can people use the results?

Researchers can use the survey to assess how involved community members are in research studies.

To learn more about this project, visit www.pcori.org/ThompsonGoodman384.