PROJECT INFORMATION

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Developing a Process to Help Community Stakeholder Organizations Set Research Agendas

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What was the project about?

Research teams usually decide on research agendas, or issues and questions to study in research projects, even when community stakeholder organizations, or CSOs, such as healthcare networks and patient organizations, are involved.

In this project, the research team explored a process for helping CSOs create research questions and set research agendas.

What did the research team do?

The research team worked with six CSOs in California, New York, and Oklahoma. They developed an agenda-setting process with five steps. In this process, CSOs

1. Chose the community's 15 most pressing issues
2. Created rules for decision making informed by what matters most to the community
3. Reduced the list to the top three issues, based on the rules created in step 2
4. Collected and weighed information on the top three issues
5. Decided on a final issue by weighing the costs and benefits

To help CSOs decide on the final issue in the fifth step, the research team created a six-topic decision guide. The topics were

- **Risk-benefit ratio:** The chance of a major change in the health of the community
- **Reduced uncertainty:** The chance that strong science supports the research
- **Feasibility:** The chance that the changes required by the research could happen in the real world
- **Sustainability/durability:** The chance that changes from the research, and their effects, would last
- **Reach:** The chance that many patients or community members could benefit from the research
- **Person-centered and community-aligned:** Confidence that the research will strengthen health care and address the needs, values, and goals of the community

Each topic had a set of questions to help CSOs decide between issues.

CSOs used the decision guide in one of two ways. Some groups had discussions using a *value tree* picture. The picture showed each topic from the guide and a discussion question on a leaf of a tree. Other groups did a rating exercise. In this exercise, members used a scale of 1 to 10 to rate the chance that the research would improve each guide topic. They also rated their confidence in that rating and how

important information on that topic was to decision making.

Patients, doctors, researchers, and CSO staff gave feedback throughout the study.

What were the results?

CSOs said that using the value trees helped them talk about important values that they didn't usually discuss when making decisions.

CSOs said using the rating exercises helped them learn new things to think about before deciding to invest time and other resources into ideas for improving community health. But the groups also said they had a hard time rating certain topics, especially

- Risk-benefit ratio

- Reach
- Person-centered and community-aligned

What were the limits of the project?

The decision guide may be too complex for lay audiences to use, especially in a short time. Future research could adapt the decision guide so that the questions make more sense to patients and community members.

How can people use the results?

CSOs can use these results to help set agendas for research.

To learn more about this project, visit www.pcori.org/Nagykaldi307.