Involving Patients in Research
Best practices from the Expert Interviews Project

Center for Evidence-based Policy
Oregon Health & Science University
Making decisions about your health can be confusing, complicated, and feel like a lot to handle. It is even harder if you do not have the right information. But getting the right information can be hard too. The Patient-Centered Outcomes Research Institute (PCORI) wants to make sure you have what you need to make decisions that are right for you.

In 2010 Congress passed a bill to help improve the health of all Americans (this is called the Patient Protection and Affordable Care Act). PCORI was created as part of this act to find answers to questions important to patients. Patients need to be involved to make sure that researchers ask and answer the right questions. PCORI wants to make sure that many types of patients, with different backgrounds and experiences, are a part of getting the best possible answers for these important health questions.

Being involved in research is a new idea for many people and there is not one best way to do it. PCORI is creating a guide to help researchers work with patients to get the best answers. This guide will help make sure future research projects include patients and others in important ways. To help make this guide, PCORI asked the Center for Evidence-based Policy at Oregon Health & Science University to talk with patients, caregivers, and experts in patient and public involvement, and gather their advice about the best ways to include and support patients in research processes. This project was called the Expert Interviews Project.

What We Did

The Expert Interviews Project started in November 2011 and ended in March 2012. The project included:

- An Advisory Panel of 11 individuals, including patients, to provide input on all parts of the project
- 87 interviews with national and international experts in patient and public involvement
- 12 group discussions in six US states with 123 patients, caregivers, and members of the public
What We Found

We identified 8 key steps for involving patients. When these steps are followed, both patients and researchers are more likely to have rewarding experiences, and the results are more likely to answer questions important to patients.

Plan for patients to be involved. This includes having clear goals for the project, knowing why patients are included, and when patients will be included. To do this, researchers must think about the needs of patients and communities, and make it easy for them to be involved.

Make a process to find and include patients and others in research. This includes planning for who will be involved, when they will be involved, and how they will be involved.

Learn from patient views and opinions. There are many ways researchers can learn from patients such as online forums, focus groups, interviews, conferences and meetings, surveys, community events, and others.

Train and support both patients and researchers. Being involved in research is new to many patients, and working with patients in this way is new to many researchers. It is important for everyone involved to have the information, skills, and support to be involved in a way that makes the research better.

Share results. One of the most important steps is making sure that the information gets to the people that need it, and in ways that are easy to access and use.

Build ongoing relationships. It is important that patients who are involved in research can stay in touch with the people they work with and have the option to be involved in other projects.

Communicate with respect. Both researchers and patients need to clearly, and respectfully, communicate their expectations and needs.

Provide enough resources. Involving patients in research takes time, money, and staff. It is important that projects commit the resources needed to make sure involvement makes a difference.

Although there is no simple answer for the best ways to include patients in research, we found three underlying factors for success: respect, good communication, and having enough time, money, and other resources to devote to involving and supporting patients.
Why Does This Matter?

PCORI wants to make sure that researchers ask and answer questions important to patients, and that the research is user-friendly, and shared in ways that are easy to access and understand. In order to do this, patients must be involved. Knowing key steps to patient involvement will help make the experience valuable and positive for everyone. PCORI hopes that the research it funds will help improve health care and support individuals making complicated and difficult decisions for themselves and their loved ones.

What Now?

The Expert Interviews Project ended in March 2012. PCORI is using the information from this project and several others to create a guide for future research projects on how to involve patients. PCORI’s guide will be available to the public in late 2012.

How Do I Get Involved?

If you would like to learn more about how you can be involved in PCORI’s research, please look for opportunities at www.pcori.org, or by contacting PCORI at:

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