

This document is intended for patient partners or community groups who are thinking about partnering with researchers. Patient and community partnered research is becoming more common because community members have valuable insight that can help researchers develop research questions that matter the most to the community, design studies that are easier for people to participate in, and share the results of their research outside of academic journals. If you are reading this tip sheet, it is probably because someone asked you or a group you are part of to partner with them. The tips here are meant to help you have the best possible experience partnering with researchers.

Researchers may ask community members to contribute to all parts of their studies, including:

- Identify a research topic that community members care about
- Co-create a research question
- Designing how the study will work – For example, where will people have to come, when, and what will they have to do, in order to participate?
- Picking study results to focus on that matter to patients
- Designing recruitment and study materials
- Understanding the results, and how they might be used in the context of patients' lives
- Considering the implications for patients and communities
- Publicizing their findings outside of academic journals

You might be asked to do all of these things, or only some of them. Any help you can provide is useful!

Before you start the relationship, ask any questions you might have. Some good things to consider are listed below, but make sure you ask anything on your mind. You have a right to ask these questions, and it is helpful to the researchers when you do.

- What is this research about?
- What type of research is it?
 - Is it an observational study? (one that looks at things that are already happening, like what medications providers prescribe)
 - Or, is it an interventional study? (one that tests something new or different, such as adding a new treatment to your medical care).
- Who is on the research team, and what do they do on the team?
 - What is their background?
 - Why do they care about their research topic?
- Who is funding the project?
- How will my input be used?
 - How will you make changes based on what I say?
 - Can you give me some examples of what types of questions you are going to ask me?
- What is the time commitment?
- How much will I be paid, and what is the payment process? (Note: You should expect to be paid.)

- What information do you need from me and why? (Tax forms? Resume?)
 - Can you provide me with any help putting that information together?
- Am I expected to speak for myself, and/or my community? Will there be other community members as part of the study team?
- Are there any details of the study that I need to keep confidential?
- What sort of supports will be provided for me?
 - What training will be available for me?
 - Is there an engagement specialist? – someone who focuses on building relationships between researchers and community members.
 - Will I get feedback on how I am doing as part of the team, and have the opportunity to give feedback to the rest of the team?
 - What language/terms do I need to know to work effectively with you?
- How will results be shared with the people who need them to make health decisions after the study is done?

There are several things about the research process that it may be helpful for you to know.

There are multiple perspectives and goals in play on research teams

- Scientific members of the team are working towards shared goals, but have different perspectives. The community partners' perspective is one perspective, but the scientists are not operating in lockstep with each other and may disagree about what to do. These differences make research projects better.

There are several things that the researchers don't have control over. These include:

- Research timelines are long. Often, once a grant is submitted, it will be a long time before you hear if it is funded. Then it can be many months before the research starts, and years until results are ready for the public.
- Not all research that is planned is ultimately done, often because of a lack of funding. It may be hard to find funding for a particular topic even if the researchers and community partners think it is important.
- Research guidelines and requirements are not determined by the individual researcher. If a researcher you are working with says that something is not "allowed" or "can't be done," always ask why, but know that it may be beyond their control. It can be useful to ask for these guidelines and requirements to be shared.
- Researchers should recognize the importance of compensating you for your time, but you should know they often face some delays. Research funding mostly comes from the government, and so many rules have been set up to ensure that the tax payers' money is spent correctly. University administration can take a long time (weeks or months) to finalize contracts and process payments. This is because the process requires working with many people who have to give approvals, across multiple departments.

Being a researcher is a hard, uncertain path, particularly for scientists who are early in their careers.

- Funding is uncertain and can be hard to get.
- Funding can be limited.
 - The total amount granted might look large, but it gets divided in many ways across many different salaries, equipment, and sometimes several institutions.
 - You are constrained by what you said in the grant. Money is given for specific things, and you can't easily use it for something different. This is to ensure money is spent responsibly.
- Grants take a long time to put together, and frequently don't get funded.
- Attention is divided between multiple research projects, teaching, and their personal lives.