

Research: How to Become Patient Centric

Patients are rock stars. For centuries and most notably in the past several decades, they've single-handedly brought about major change in medical research and practice. Because of their hard work, they've become respected advocates, subject matter experts and trusted sources. They help shape the future of medicine and give it a humane approach. They are the drivers of treatments and cures.

Because of this, patients **MUST** have a seat at the table.

Use this worksheet to ensure patients are always involved where the science is happening.

1. What is your mission? As you build out your goals, always keep your mission top of mind.

2. What is the science that most interests your organization? What is the most promising research being done?

3. List the organizations invested in that research:

4. Which of these organizations have a patient advisory board/committee? What does it look like? What do they do? How often do they meet? Is it honorary in nature or are the patients empowered?

5. Now think of patients who have an interest in research or have a background in science: Ask them if they'd be willing to form a team of patient research advocates.

6. Together, create a research participant bill of rights for your disease. Use these questions for guidance: What should clinical research trials look like? What clinical trial practices would be best for patients and researchers? For an example, [see the Patient-Centric Trial Design \(PaCTD\) Rating Criteria](#)

7. Conduct a survey on what motivates patients to join a clinical trial and what they feel ethical practices are. This will help persuade drug sponsors that they will fill their trials faster if they take on humane and patient-centric practices. [Here is an example of a survey I AM ALS did on this topic.](#)



8. What connections does your team have with researchers, biopharmaceuticals, institutions and government agencies?



Now it's time to bring everyone together! Introduce your team to your collective connections, reach out to organizations who work with patients and reach out to those who don't. Show them your research participant bill of rights and explain how better clinical trial design is a win-win for patients AND researchers! Way to go on being a mover and shaker!