

CAN WE TALK ABOUT PATIENT ENGAGEMENT?



Since more patients and caregivers are being asked to engage in Patient-Centered Outcomes Research (PCOR) as partners and advisors, the Patient Insight Institute patient community identified actionable tips for both researchers and patients/caregivers to ensure this engagement is of maximum benefit and impact to all involved.

TIPS FOR PATIENTS AND CAREGIVERS:

1 REMEMBER: YOU'RE NOT AN IMPOSTER.

While it may feel uncomfortable to participate in a research project as a non-healthcare or scientific expert, remember that you have a unique and valuable perspective and are deserving to be in the same room and table as any other professional. Only you are the expert of your own experiences.



2 COMMUNICATE OPENLY.

Don't be afraid to ask questions—any questions—about the research project (i.e., Who will it impact? How will the findings be disseminated?) and don't minimize your voice or experiences. Be open about your expectations around privacy and confidentiality, and only share what you're comfortable sharing.



4 MANAGE EXPECTATIONS.

It's important to understand what research can and cannot do. While research projects, particularly health services and patient-centered outcomes research, may help address problems that patients experience, know that the research project alone is one step of many.



3 LEARN MORE ABOUT THE RESEARCH

While you're certainly not expected to become an expert on the research topic, it's okay and appropriate to want to learn more about it. Ask the researchers to point you to reputable sources (i.e., journal articles) to learn more. If you have the time and resources, attend conferences on the research topic.



5 ADVOCATE FOR YOURSELF.

Ask how the researchers will honor your time and expertise, and don't be afraid to offer suggestions about what they can do to make it easier for you to engage. Challenge ideas that don't make sense. Remember that you always have an out if the project no longer meets your expectations.

