

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 RESEARCHERS:

- 1 BE TRANSPARENT ABOUT ALL ASPECTS OF THE PROJECT.** Inform patients about the overall goal and objectives of the research project and how their involvement fits into the bigger picture. Specifically, describe how their participation will be used for research and help manage their expectations by sharing what the research will and will not do.



#ProTip: Share updates with patients along the way—include all progress, including the milestones met, setbacks, and plans for dissemination. Provide a project timeline for patients to visualize the research project and their role within it.

- 2 AVOID JARGON.** Instead, use words or phrases that are more widely understood. If you must use jargon, explain the terms, concepts, and spell out acronyms. Provide a glossary of terms for patients to refer to. Consider budgeting for a language interpreter, especially if you are working with patients or caregivers who speak English as a second language.



- 4 COMMIT TO A COMMUNITY.** Many know that the outcomes of the research project may not necessarily benefit them, but they see it as a potential solution to address problems that affect people like them. When designing research projects with communities, consider multiple research questions or projects that build on each other.



- 3 VALUE THE PATIENT'S TIME AND LIVED EXPERIENCE.** Make it easy for patients to engage in research projects. Budget early for honoraria and be transparent about the time commitment. Schedule meetings and project events at a time and place that works best for them.



If meeting in-person, provide a stipend or reimburse for associated expenses, such as travel, lodging, and parking.

- 5 ACKNOWLEDGE THE DISTRUST THAT PATIENTS MAY HAVE FOR RESEARCH.** Many patients and communities have an inherent distrust for healthcare providers and researchers. When inviting patients to engage in research, acknowledge the discomfort and distrust that they may feel by having an honest conversation about any potential reluctance and historical community harms.



#ProTip: Have a written community agreement or memorandum of understanding, specifically describing your role, and theirs, in creating a safe space for patients to engage.