

Common Patient Roles and Examples

Section 2.3





Planning the Study

Patient Partner Roles in planning research study design:

- ✓ Help researchers select study questions.
- ✓ Participate in surveys.
- ✓ Create a meaningful study for other patients.

Conducting the Study

- Review study procedures (i.e., patient recruitment, informed consent and data collection):
 - Assist in recruiting patients and explaining study procedures and findings for easy understanding of other patients.
 - Ensure study materials to include most important information while maintaining ease of understanding.
 - Help with survey development
 - Attend leadership/stakeholder meetings.



Sharing Results

- Sharing research materials with other patients:
 - Patient Partners assist in sharing the results with those who will be affected the most i.e., other patients.
 - Sharing their own experience in the project with other patients.



Using Results

- Shared decision making with healthcare providers and researchers for improving healthcare delivery and outcomes:
 - Assess barriers to engagement of other patients and create solutions.
 - Use gained knowledge in real world settings.
 - Suggest solutions to challenges patients face in managing diabetes and engaging with their healthcare team

"You're the most experienced person on what's happened to you and that experience can really help research. You don't need to try to speak on behalf of all patients, just give your opinion based on what you know." Adele, Keele



References

1. National Institute for Health Research INVOLVE. Public Information Packet (PIP): How to get involved in NHS, public health and social care research. Accessed at <https://www.nihr.ac.uk/documents/public-information-pack-pip-how-to-get-involved-in-nhs-public-health-and-social-care-research/27388>.
2. Patient-Centered Outcomes Research Institute (PCORI). Public and Patient Engagement. Accessed at <https://www.pcori.org/about-us/our-programs/engagement/public-and-patient-engagement>.

