

Potential Activities for Patient Participation in Clinical Trials

Activities for Patient	Description
	Description
Participation	
Formulating the research	Patients' perspectives on relevant health issues and
question	research questions
Determination of outcomes	Prioritise outcomes that matter most to patients
Designing/ Reviewing	Protocols accessible to participants
Protocols	
Co-creation of materials	Information and consent materials, ensuring they are
	understandable and meet patients' needs.
Recruitment and retention	Help develop strategies to recruit and retain participants
	and act as ambassadors for the trial in the community.
Participation in ethics	Provide the patient's perspective on risk-benefit decisions.
committees	
Creation of tailoring	Interventions for specific populations, creation of materials
interventions	and tools, etc.
Collaboration on	Participate in the dissemination of trial results, helping to
dissemination	communicate results in a way that is understandable to
	other patients and the public.
Impact of results	How trial results affect patients and their care, and help
	identify areas for future research
Evaluation	Evaluate participants' experiences during the clinical trial,
	contributing to improvements for future studies

References:

- Forsythe LP, Carman KL, Szydlowski V, Fayish L, Davidson L, Hickam DH, et al. . Patient engagement in research: early findings from the Patient-Centered Outcomes Research Institute. Health Aff. (2019) 38:359–67. doi: 10.1377/hlthaff.2018.05067
 - https://pubmed.ncbi.nlm.nih.gov/30830822/
- Bird M, Ouellette C, Whitmore C, Li L, Nair K, McGillion MH, et al. Preparing for patient partnership: a scoping review of patient partner engagement and evaluation in research. Heal Expect. 2020;23(3):523–39.10.1111/hex.13040
 - https://pubmed.ncbi.nlm.nih.gov/32157777/
- Shakhnenko I, Husson O, Chuter D, van der Graaf W. Elements of successful patient involvement in clinical cancer trials: a review of the literature. ESMO Open. 2024 Apr;9(4):102947.doi: 10.1016/j.esmoop.2024.102947.
 - https://pubmed.ncbi.nlm.nih.gov/38492274/