

Ways Community Members Can Participate in the Stages of Research

Start

End

Plan the Study

- P1. Determine the relevance of the research to patients and the public
- P2. Prioritize research questions
- P3. Assess the feasibility of patient involvement
- P4. Identify barriers to continued participation
- P5. Define and assess the relevance of outcomes from a patient perspective
- P6. Answer questions from researchers
- P7. Give approval of the study question and outcomes
- P8. Identify the partnership approach (organizations, public)
- P9. Identify organizations that should be aware of the study and track its progress
- P10. Plan how to engage interest of opinion leads (TV, print radio)
- P11. Contribute to funding application
- P12. Contribute to ethics application for research ethics board
- P13. Review drafts of applications
- P14. Provide letter of support

Recruit and Retain Participants

- R1. Advise on the vocabulary used in the recruitment and study materials
- R2. Use existing networks to advertise the study
- R3. Provide support and information to participants about the specific study or on the experience of participating in research studies in general

Do the Study

- S1. Participate in a trial run of the study to assess the preparedness of the staff and to be able to explain the experience to participants
- S2. Participate in data collection (read study questions to participants, administer interviews)
- S3. Collect feedback
- S4. Identify obstacles as the study progresses

Analyze the Results

- A1. Contribute a unique perspective on the interpretation of data
- A2. Give feedback on potentially counterintuitive results
- A3. Identify how results relate to lived experience
- A4. Place results in a real-world context

Disseminate the Results

- D1. Develop a dissemination plan (study results, policy, guidelines)
- D2. Identify partner organizations
- D3. Identify non-traditional models of dissemination
- D4. Develop a public-friendly version of results
- D5. Present the patient perspective at conferences
- D6. Present in non-traditional settings to reach new audience
- D7. Invite researchers to present at patient advocacy organizations
- D8. Co-publish in non-academic materials
- D9. Participate in the publication committee



Continue the relationship

Evaluate the Study

- E1. Develop key indicators of success and how and when to measure them
- E2. Survey at the beginning, middle, and end of the project
- E3. Ensure the authenticity and value of the patient engagement