### Ways Community Members Can Participate in the Stages of Research

#### 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

#### 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