Roles for Patients in Research

1. Identifying & Prioritising
   - Through community representation and organizations help inform research priorities
   - Be consulted about research topics and priorities important to them
   - Collaborate and co-develop with researchers and other key groups topics for research

2. Design:
   - Inform the design of the research study
   - Clarify the research question and affirm its importance
   - Ensure the methods selected are appropriate for patients
   - Co-develop patient recruitment strategy
   - Review and comment on proposed questionnaires and data collection methods

3. Development of the Grant Proposal:
   - Help to ensure that the research proposed and chosen methods are ethical
• Inform areas where patients and the public could be involved
• Define outcome measures
• Advise on the appropriateness of the lay summary
• Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement.
• Become co-applicants

4. Preparation for execution of the study:
• Assist with writing patient information and consent forms
• Review ethics and operational approval applications prior to submission
• Aid in designing the detailed protocol
• Produce research updates that are patient friendly

5. Data Collection:
• Drafting/revising study materials and protocols
• Assisting with the recruitment of study participants
• Assist with conducting interviews and surveys

6. Analysing and Interpreting Data:
• Assist the research team in developing themes from data
• Be consulted to determine if they understand and interpret data the same way as the research team
• Develop more approachable methods to help interpret the data

7. Dissemination:
• Advise on different avenues for disseminating the results
• Author/co-author manuscripts, newsletters and other appropriate information outlets
• Jointly present the findings with researchers
• Write information for local patient groups/hospitals, etc.
• Assist in getting results/findings published on charities/voluntary organization websites
• Help distribute results within their informal network
• Produce summaries of findings

8. Implementation:
• Increase the likelihood that results of research are implemented, by adding validity to the findings
• Develop patient information for new services/interventions within hospitals, clinics, etc.

9. Monitoring and Evaluation:
• Have continued involvement with the study to maintain focus and address issues as they arise
• Collaborate with researchers to evaluate the research process
• Reflect on their role and what they have learned