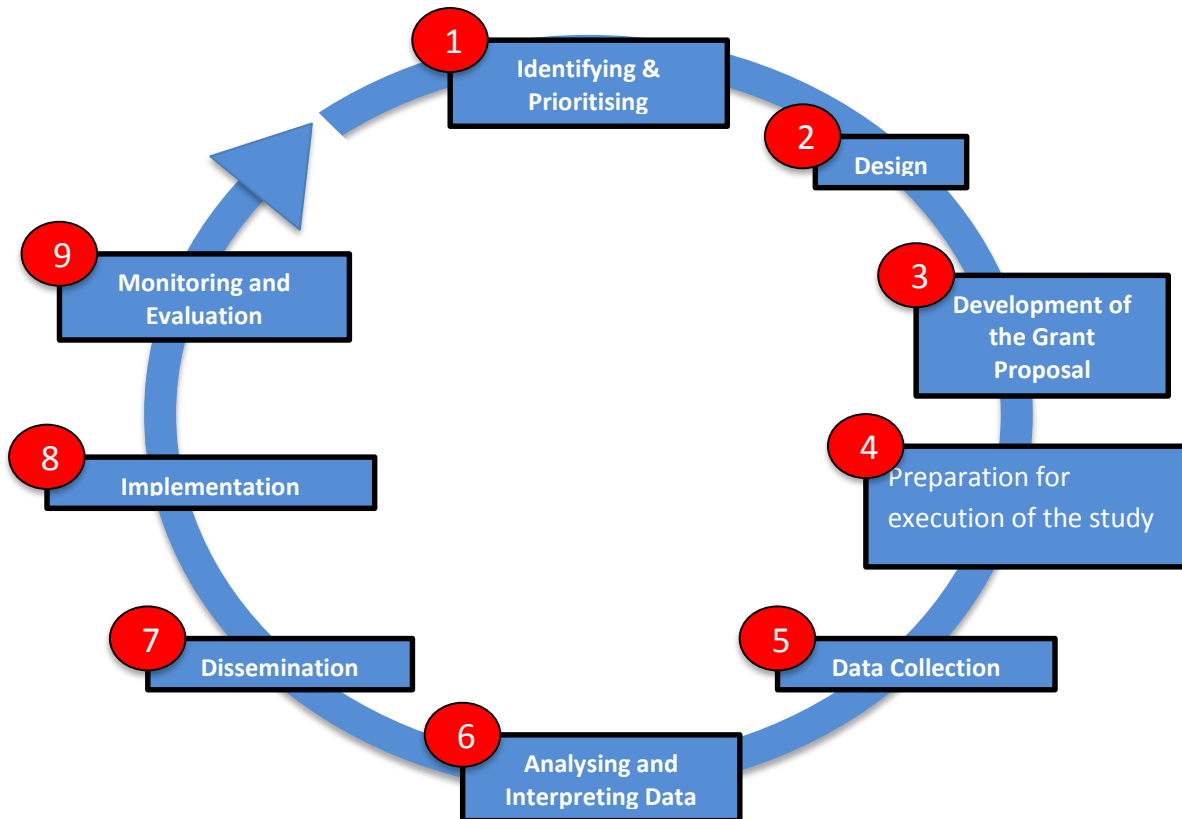


# Roles for Patients in Research

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Source: Izabela Szelest, Research Facilitator, College of Medicine, University of Saskatchewan



## 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