

Identifying & Prioritising

Patients and family advisors can:

- 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

Design:

Patient and family advisors can:

- 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

Development of the Grant Proposal:

Patients and family advisors can:

- 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

Preparation for execution of the study:

Patients and family advisors can:

- 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

Data Collection:

Patients and family advisors can:

- Draft/revise study materials and protocols
- Assisting with the recruitment of study participants
- Assist with conducting interviews and surveys

Analysing and Interpreting Data:

Patients and family advisors can:

- 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

Dissemination:

Patients and family advisors can:

- 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

Implementation:

Patients and family advisors can:

- 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.

Monitoring and Evaluation:

Patients and family advisors can:

- 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