

Understanding the Research Cycle

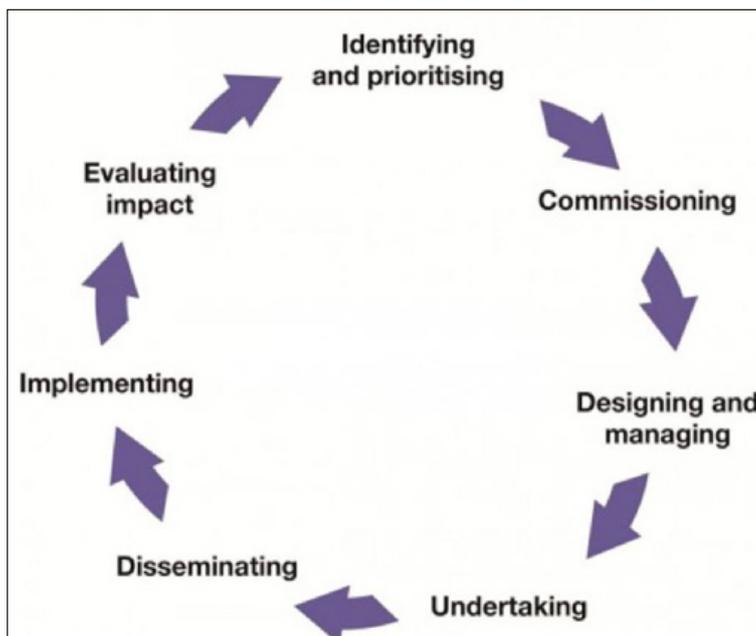
A guide for JIGSAW-E Patient Panel members and Partners



This information is to help you understand the research cycle and how the UK team try to involve the public within its different stages. Some projects can cover a long period of time, over many years.

Patient and Public Involvement and Engagement is important in each stage of the research cycle. This is because patients have personal knowledge and experience of living with a condition. They can provide a different perspective that can help to improve the quality and relevance of a project.

A lot of this information has been taken from Involve Briefing Notes for Researchers Feb 2012 – www.invo.org.uk.



JIGSAW-E is the project name for the implementation stage of the research cycle for the MOSAICS research project. Patient and Public Involvement and Engagement has been a part of MOSAICS and will now be part of JIGSAW-E through you - our European Patient Panel and Partners.

The Research Cycle in Detail

1) Identifying and Prioritising

In the UK, the National Institute for Health Research Evaluation Trials and Studies Coordinating Centre (known as NETSCC) encourage individuals or organisations to suggest topics for research. Another organisation, The James Lind Alliance, sets up partnerships between patients, carers and clinicians to identify and prioritise the treatment uncertainties which they agree are the most important for research.

2) Commissioning

In the UK, usually a Research Funder or Commissioner such as the National Institute for Health Research (NIHR) or Arthritis Research UK, etc. will put out a funding call asking researchers to put together a Grant Proposal on predetermined topics in order to bid for funding.

In some cases members of the public will have been involved in the identification and prioritisation of the topics by the funding organisation.

3) Designing and Managing

Several funding bodies now ask researchers to describe in their funding grant applications how they have

involved the public in the design and management of their project.

At Keele we have members of the public who have joined our Research User Group (RUG) and are part of advisory groups for different research projects. RUG members may be asked to help with the original grant application, by commenting on how important and

relevant they feel that this topic is to the end users of research – patients.

RUG members may be asked for suggestions on how practical and feasible they think the recruitment process is going to be – are they likely to recruit the needed number of participants to the project, for example.

This may be the end of RUG members' involvement within a particular project if it has not gone on to secure funding.

However if the project is funded they may be able to be involved in developing or reviewing the information leaflets, consent forms and questionnaires that are going to go out to the public. One of the main ways to get involved in the management of a project as a patient is to sit on a steering group.

4) Undertaking

Members of the RUG can help in looking at different types of evidence and in interpreting the literature from a patient perspective.

Members of the RUG can help in the analysis and interpretation of the research data, or findings. They may help to identify themes that the researchers may have missed.

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5) Disseminating

Members of the RUG always want to ensure that the findings are presented to the outside world in order to change clinical practice for the better.

6) Implementing

Patients are passionate about making sure that research results are put into practice. They may be able to establish relationships with key agencies and policy makers here in the UK. Two RUG members have joined the UK part of the JIGSAW-E Patient Panel and will now be involved in the implementation of this project across Europe.

7) Evaluating Impact

The Keele PPIE team work with researchers to document the PPIE within their projects and evaluate their impact.

PPIE support for JIGSAW-E

- At least two lay members should be a part of each Project Group. Staff members should not outnumber lay members if possible.
- It would be useful for lay members to have a glossary of scientific or complex terms to refer to.
- It is important to make sure that lay members' needs are met - for example parking, accessibility, refreshments and expenses, and that they are given suitable comfort breaks during the meeting.
- Lay members should have time and opportunity to ask questions.
- Lay members are welcome to comment on their experience, positive or negative, to ensure meaningful involvement for all members.