Developing a plan for patient and public involvement in the Centre for Reviews and Dissemination (CRD) at the University of York

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About CRD and systematic reviews

The Centre for Reviews and Dissemination (CRD) at the University of York is part of the National Institute for Health Research (NIHR). We carry out systematic reviews on important health and public health questions. Systematic reviews are studies that bring together the results of previous research (often randomised trials) about particular treatments. Researchers who do systematic reviews try to uncover all the relevant studies worldwide and to evaluate them in a fair and objective way.

The value of patient and public involvement (PPI) in research is becoming widely recognised. We wanted to find out where and how PPI could be embedded in the systematic review process at CRD.

Overview

Forming a working group to explore, enable and enhance PPI:

- We sought advice and help from a PPI advisor.
- We asked for volunteers from staff: there was a high level of interest and the CRD researchers were selected to represent a range of interests and experience.
- In response to an advert drafted by the group, we received a large number of applications from some very strong public/patient candidates with wide experience of informing and contributing to research. Following short listing and interviews two lay representatives joined the group.
- The final working group includes two lay members, a PPI advisor and six CRD researchers and has met four times over 10 months.

Strategic objectives identified

Develop a coordinated approach to PPI in CRD research.

Build capacity for PPI.

Contribute to the evidence base about PPI in systematic reviews.

Exploring the issues

We explored what approaches to PPI have been used by other organisations in their systematic reviews (e.g. Cochrane Collaboration groups). We found no overall policies and few descriptions or evaluations of PPI in systematic reviews.

We consulted with all CRD researchers in small groups:

- Use of PPI in eight reviews; helping an advisory group shape review question.
- Identified experiences; perceived barriers and facilitating factors.
- Concerns identified were lack of necessary resources and insufficient advance planning adding to researcher scepticism and risking tokenism.

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We identified potential for public/patient involvement at all stages – in the right circumstances. The stages are:

- **Deciding what to research**: what topics should be examined, what aspects are important?
- **Deciding how to do it**: e.g. how should the effects of a treatment be measured?
- **Doing it**: the actual review process
- **Commenting on the report**: making recommendations or setting out the implications for practice or more research
- **Disseminating it**: letting people know the results
- **Ensuring its relevance**: strategy and governance/oversight

Enabling PPI

Three options were identified and fully explored. All options had time and cost implications.

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<th>Option</th>
<th>Project-by-project PPI: A flexible approach where individual researchers choose whether, when and how to involve patients.</th>
<th>PPI through an advisory group: Advisory group of public/patient members meeting three times/year co-chaired by a researcher.</th>
<th>A network approach to PPI: A database of a wide range of patient and community groups who have expressed interest in involvement with CRD.</th>
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<td>Main advantages</td>
<td>Flexibility. Rapid response to opportunities. Supported by centralised guidance without needing to maintain a permanent group.</td>
<td>Chance to lead in this area and promote public understanding of systematic reviews. Systematic approach: easy to monitor and evaluate impact.</td>
<td>Develops ongoing relationships. Potential to raise awareness amongst a wider number of patient groups about systematic reviews.</td>
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<td>Main disadvantages</td>
<td>Potential for inconsistency: hard to monitor implementation. Limited opportunity for ongoing relationships, learning and development for researchers or lay members. Hard to recruit for more general reviews. Does it convey our commitment to PPI?</td>
<td>Involves only a small number of lay people. Would the workflow fit with the meeting schedule? Professionalising patient and public members.</td>
<td>Need to develop relationships with enough willing individuals/groups and keep contacts up-to-date.</td>
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The decision

A flexible project-by-project approach supported by centre-wide resources and policy.

The future

- Enhancing PPI.
- Implementation of project-by-project PPI.
- Raising awareness and providing support.
- Ensuring momentum with practical and awareness raising measures.

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The authors of this poster form the CRD PPI Working Group. This poster presents independent work and the views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.