

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

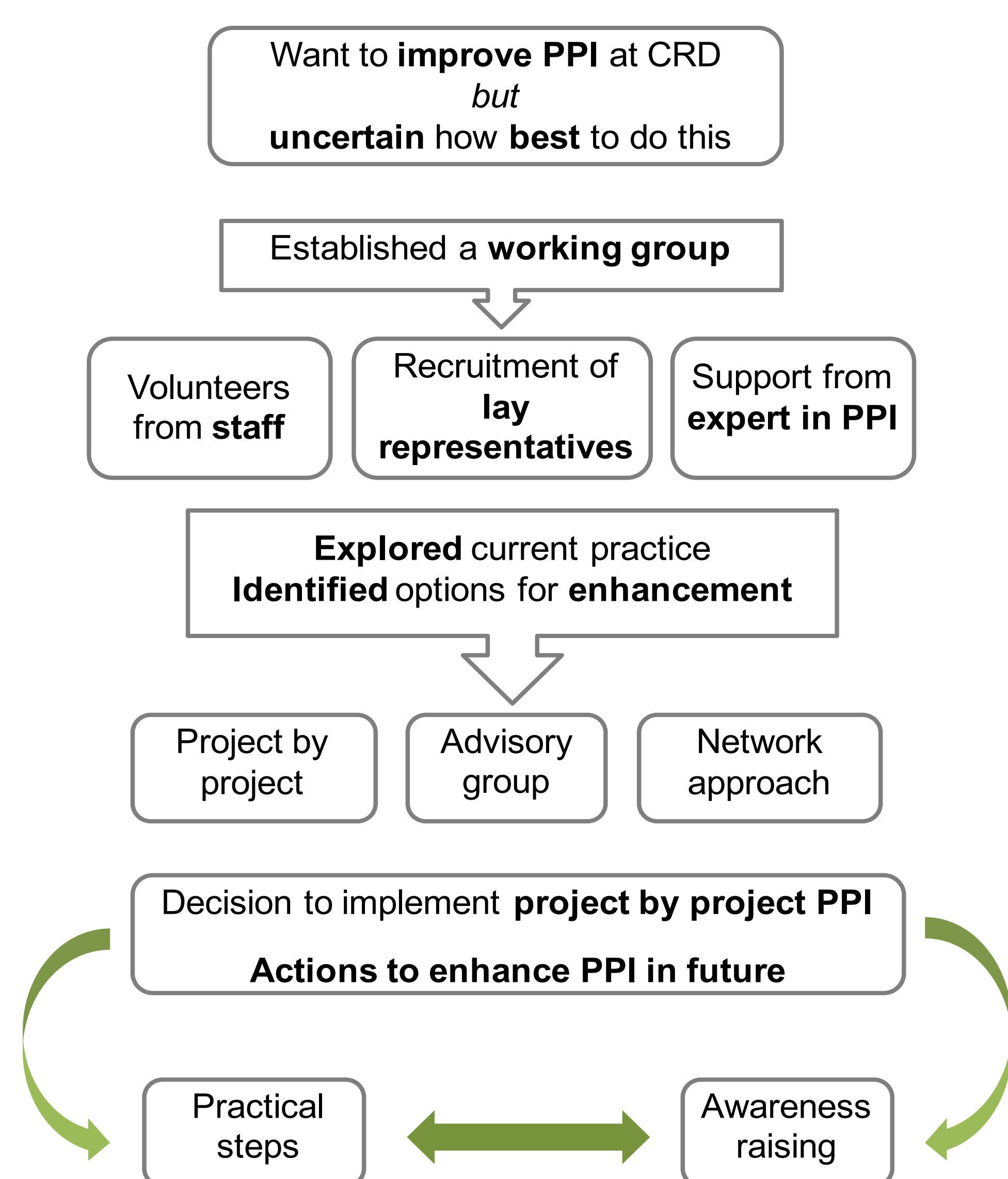
The Centre for Reviews and Dissemination (CRD) at the University of York is part of the National Institute for Health Research (NIHR). We carry out systematic reviews on important health and public health questions.

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 issue

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.

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.

Option	Project-by-project PPI: A flexible approach where individual researchers choose whether, when and how to involve patients.	PPI through an advisory group: Advisory group of public/patient members meeting three times/year co-chaired by a researcher.	A network approach to PPI: A database of a wide range of patient and community groups who have expressed interest in involvement with CRD.
Main advantages	Flexibility. Rapid response to opportunities. Supported by centralised guidance without needing to maintain a permanent group.	Chance to lead in this area and promote public understanding of systematic reviews. Systematic approach: easy to monitor and evaluate impact. Develops ongoing relationships, learning and development for both researchers and lay members.	Develops ongoing relationships. Potential to raise awareness amongst a wider number of patient groups about systematic reviews.
Main disadvantages	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?	Involves only a small number of lay people. Would the workflow fit with the meeting schedule? 'Professionalising' patient and public members.	Need to develop relationships with enough willing individuals / groups and keep contacts up-to-date. May raise expectations which cannot be met – people may agree to join the network but never be asked to take part in a review.

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.

Practical steps	Awareness raising actions
<ul style="list-style-type: none"> • Develop guidance for CRD staff on undertaking PPI. This will include: <ul style="list-style-type: none"> - Practical advice - Potential resources, local and national - Case studies • Provide an induction pack for people public/patient contributors to explain what they can expect from us and what we will expect from them. • Implement an expenses/payment policy for public/patient contributors. • Conduct a face to face training session for CRD staff (with a PPI advisor and a lay representative) to launch the guidance. 	<ul style="list-style-type: none"> • Hold a seminar on PPI in systematic reviews. • Implement a register to collect information about PPI in projects at CRD so we can learn from each other's experience. This will capture: <ul style="list-style-type: none"> - Methods used - Experience with successful and unsuccessful research proposals - Resource use • Work towards appointing a patient/public representative to the CRD advisory board.