

A description of research priority setting (and the presence of PPI in priority setting) amongst the main UK clinical research funders - Proposal to the James Lind Alliance

1. Introduction

The aim of this project is to carry out a preliminary scoping exercise to find out how clinical research bodies set their priorities and whether and how patients and the public are involved in this work.

This will help JLA to:

- Make informed decisions about how best to work with research funders and know when they can add value to decision-making
- Know how best to present 'worked up' shared clinical and patient priorities to research funders
- Strengthen their relationship with research funders and extend their networks

It will also provide evidence of the extent of PPI in setting priorities in health research within the UKCRC.

There are five key stages to the project plan (described in detail in section 3). These are:

- Stage 1: Initial preparation
- Stage 2: Literature review
- Stage 3: Initial mapping of priority setting processes within different research funding bodies
- Stage 4: Detailed mapping of selected funding bodies
- Stage 5: Final report

2. Our team

Bec Hanley and Kristina Staley will undertake this project. We run a small company called TwoCan Associates, which specialises in promoting and supporting user and carer involvement in health and social care. Further information about our relevant skills and experience can be found in Appendix One.

3. Planned programme of work

Stage 1: Initial Preparation

It will be important for us to meet with the project commissioners early on to:

- Establish expectations of the project
- Identify issues of particular interest or concern
- Agree the final plan of work, including timescales

Stage 2: Literature Review

We will undertake a rapid appraisal of the key publications on research priority setting (including those identified in the brief and any new papers listed on the invoNET library). We will also look for further examples of PPI in research priority setting within the UKCRC

Activities Log and liaise with the UKCRC PPI Project Group to check whether any similar work is taking place.

We will also carry out a brief phase of desk research to obtain further information about each of the research funding organisations being considered for interview.

At the end of this stage we will produce:

- a brief summary of this literature review drawing out the key issues relevant to this project.
- a list of relevant funding organisations who could be invited to be interviewed in the next stage with a brief synopsis of their remit, size etc.
- a draft interview schedule for use in the next stage
- a draft letter of invitation to send to potential interviewees

It would be helpful to then meet with the project steering group to discuss and finalise the list of funding organisations to be interviewed and the questions we will ask. We think it will be important to select a wide range of organisations to cover priority setting at different levels, different methods of setting priorities, different types of organisation and different levels of PPI.

We would also like input from the group as to the most relevant and useful way of structuring the interim report.

Stage 3: Initial mapping of priority setting processes

With the help of the JLA Strategy and Development Group and other partners we will identify one or two key people to interview in each research funding organisation. We anticipate that at this stage this is likely to be staff working within the organisations. We will write to each potential interviewee explaining the project and JLA's views of shared priorities. We will also explain the potential benefits of participation.

We think it important to meet people face-to-face to establish good relations and create a safe space to share learning and experience. We do not wish to make organisations nor individuals feel like they are being scrutinised, and will explain the project in terms of an exploration how PPI in priority setting could be improved. We also believe that meeting people face-to-face will be important to strengthen relationships and extend networks. However, we will also offer people the choice to be interviewed on the telephone if they prefer.

We will arrange all interviews at a time and place to suit the interviewees and seek permission to tape-record for accuracy in note-taking. We will explain that it will not be possible to keep the information about their organisation confidential as we will be producing a report that describes how their organisation works. However, we will also offer each interviewee an opportunity to express their general views on PPI in priority setting anonymously and this information will not be attributed to any individual or organisation in the report.

Through the interviews we will obtain information and descriptions of current research priority setting activity and any PPI in this work. We will then produce an outline of the interim report and discuss this with the project commissioners. Once agreed, we will produce this report in full with an executive summary. We will also draw out recommendations for the next stage.

It would be helpful to meet with the Steering Group to discuss this interim report and agree how to proceed with the next stage.

Stage 4: Detailed mapping of selected funding bodies

Based on our current knowledge of how research funding bodies set research priorities and the level of PPI in this work, we anticipate that there will be few research organisations who are taking a strategic approach to PPI in priority setting.

We therefore suggest carrying out an additional set of interviews within three different funding organisations to discuss with other relevant stakeholders how decision-making processes could be adapted or changed to enable priorities identified through the JLA approach to influence how funding is allocated.

At this stage we cannot identify which organisations would be selected for this in-depth study but we expect the selection criteria to include:

- an example of an organisation where PPI in priority setting is working well
- an example of an organisation where there is currently no PPI in priority setting
- organisations which have expressed an interest in exploring how JLA priorities could feed into decision-making during the interviews in Stage 3
- organisations who are very influential in terms of research budgets and political leverage
- organisations that represent 'typical' models of decision-making processes so that the general lessons are more likely to be widely applicable

We suggest carrying out interviews with at least two or three different stakeholders in each organisation, including a member of staff, a researcher or clinician involved in priority setting and where possible a patient or member of the public who has been involved.

If time allows, it might also be worthwhile interviewing key commentators in this area e.g. members of the UKCRC PPI projects group, members of the Strategy Development Group, to capture their informed views of potential barriers and solutions to increasing PPI in priority setting and developing ways for JLA priorities to influence research funding decisions.

Stage 5: Final report

We will produce a final report that provides an overview of the current status of PPI in priority setting and also makes recommendations for taking this work forward.

We will send a draft report to the Steering Group for comment and then meet with them to present and discuss the final recommendations.

After incorporating the feedback from the Steering Group, we will circulate a final version of the report more widely. It will be important to send a copy to everyone who has been interviewed as part of the project.

4. Support required

We would appreciate the following support from JLA:

- A nominated contact person for the life of the project (we assume this is Sally Crowe)
- Organisation of the Steering group meetings. This includes identifying members, issuing invitations, providing a meeting venue, covering costs of travel, carer costs and any overnight stays.
- Help with getting comments from relevant stakeholders on drafts of the interim and final reports.

Timetable

We have assumed that this project could start in September 2007.

Date	Proposed activity
Sep 2007	Stage 1 – Initial preparation Draft proposal Meet commissioners
Sep – Oct 2007	Stage 2 – Literature review Literature review & summary List of research funders plus synopsis on each one Draft interview schedule & invitation letter Meet Steering group
Oct – Dec 07	Stage 3 – Initial mapping Face-to-face interviews with one key member of staff at approx. 15 funding organisations* (includes time to set up interview, travel time, conduct interview and type up notes) Produce interim report Meet Steering group
Jan – Feb 07	Stage 4 – Detailed mapping Face-to-face interviews with 3 key stakeholders at 3 funding organisations* (includes time to set up interview, travel time, conduct interview and type up notes)
Feb – Mar 07	Stage 5 – Final report Draft final report Finalise report after comments Meet Steering group

*It is not possible to be precise about how many interviews we will be able to conduct within the time available as much depends on the location of the interviewee and

whether they prefer to meet face-to-face or speak on the phone. We will agree with the Steering Group which interviews are a priority and ensure that these are all carried out. We will then try to complete as many interviews as possible, using our time as efficiently as we can (e.g. by arranging more than one interview on the same day in any distant location).

TwoCan Associates - Bec Hanley and Kristina Staley
August 2007

Appendix one – about us and our relevant experience

TwoCan Associates is a small company run by Bec Hanley and Kristina Staley. We specialise in researching, promoting and supporting user and carer involvement in health and social care.

Bec Hanley has spent the past ten years working to promote the involvement of people who use services in health care and health research. Her background is in community development work, and she has experience of promoting and supporting partnerships between local people and a range of agencies. She was the director of the INVOLVE (formerly Consumers in NHS Research) Support Unit for five years. During this time she worked in partnership with people who use services and professionals to develop policy and practice on involvement in research. She is the lead author of INVOLVE's acclaimed 'Involving the public in NHS, public health and social care research', now in its second edition, and of 'Research as Empowerment', published by the Joseph Rowntree Foundation and co-funded by SCIE.

Kristina Staley is an experienced researcher with a background in biomedical science. After gaining her PhD from Cambridge University, and working as a post-doctoral fellow in the USA, she moved into health and science policy working in the Public Health Department at The King's Fund and Sussex University's Science Policy Research Unit. For many years her work focused on involving the public in these policy debates and she has gained considerable experience in making specialist information accessible to the public. She has also developed training materials to help service users and carers get involved in judging the quality of health-related research. She worked with the MS Society for five years to develop a programme of service user and carer involvement in their research and services department.

Almost all of TwoCan's work is undertaken in partnership with service users and carers. Current and recent clients include:

- Macmillan Cancer Support
- The National Patient Safety Agency
- The Open University
- NHS Connecting for Health
- Arthritis Care and the MS Society

More information about TwoCan, our associates and our values are on our website, www.twocanassociates.co.uk.