

Cross-funder 'common additional PPI questions' for use in Researchfish

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Introduction

This proposal has been developed following discussions with Researchfish, Arthritis Research UK, Parkinson's UK, Marie Curie, CRUK, NIHR and INVOLVE. These funders have expressed a desire to explore if the Researchfish tool can help them to understand better the impact patient and public involvement has. In developing these questions a number of underlying factors have been considered, including:

- Researchfish is perhaps best used as a tool to assess baseline information from across a funding portfolio. The data that are collected doesn't always fulfil a need directly but instead gives an indication of where funders might explore issues further using other approaches, such as other information sources, interviews or detailed case studies.
- The reporting burden on the research community is already significant, therefore data should only be asked for where there is a clear mandate and capability and capacity to analyse those data, and where there is no duplication (eg with other question sets within Researchfish). This information should also be asked for in the most simple way possible.
- Different funders are at different stages of development in terms of how they encourage and support PPI, therefore the questions used need to be able to cope with a wide spectrum. In addition, funders support a wide range of research disciplines, types and approaches – from bench to bedside and everything in between – and these are at different stages of development in terms of the conceptualisation of PPI.
- Funders would find useful a range of information – some of which relates to descriptive and monitoring information, some of which gives further insight into the benefits and difference involving people has made.

Question	Guidance
<p>Q1: Have you involved patients and/or members of the public in your research? A1: *Yes/No/**Not applicable/Unknown</p> <p>**Q2 [Only for those answering Not applicable to Q1] Why was PPI not applicable in your research? A2: [Free text]</p>	<p>Patient and Public Involvement (PPI) in research is an active partnership between patients, members of the public and researchers in the research process. Patient and Public Involvement in research is when research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.</p> <p>These questions do not refer to the recruitment of patients or members of the public as participants or subjects in the research.</p> <p>There is no need to duplicate activities you have already told us about in the 'Engagement activities' section. Where appropriate refer to outputs reported in other sections in Researchfish.</p> <p>For a more detailed explanation of involvement, how it links to and differs from engagement and participation in research see the INVOLVE website. You may also find it helpful to read more about the GRIPP2 reporting checklist.</p>
<p>*If Q1 answered Yes.</p> <p>Q3: How have patients and the public been actively involved in your research? (Please indicate all that apply) A3:</p> <ol style="list-style-type: none"> 1. Prioritising the research question(s) 2. Developing the application for funding 3. Design of the research 4. Management of the research 5. Undertaking the research 	<p>Tell us about the different ways in which patients and the public have been involved in the design and delivery of your research. The following examples may help:</p> <ol style="list-style-type: none"> 1. Identifying and establishing the relative importance of research questions 2. Commented on or helped write the proposal 3. Development of participant information resources, selection or refinement of data collection tools)

<ul style="list-style-type: none"> 6. Analysing and interpreting the data generated by the research 7. Writing up of the research 8. Dissemination of research findings 9. Implementing research findings or recommendations 10. Other (please give details of how patients and the public were involved in your study) [Free text] 	<ul style="list-style-type: none"> 4. Membership of a steering or advisory group 5. Members of the research team, undertaking data collection such as interviews 6. Involvement in data analysis, discussing interpretation of findings 7. Involvement in writing a report, co-authoring a publication 8. Delivering conference presentations, informing patient/community groups, social media 9. Making changes to activities in response to research findings 10. Other ways of involving people not listed above
<p>Q4: What factors contributed to the success of the patient and public involvement in your research? A4: [Free text]</p>	<p>Tell us about the elements you think have made your PPI successful. Funders are keen to identify examples of good practice in involving patients and the public in research and develop the evidence base to articulate the factors associated with successful involvement.</p> <p>There is no need to duplicate activities you have already told us about in the 'Engagement activities' section.</p>
<p>Q5: What have been the challenges of involving patients and the public in your research? A5: [Free text]</p>	<p>Tell us about any aspects of involving people in research that have been challenging and how, where possible, you have overcome these challenges. Funders need to understand these challenges better to develop the evidence-based guidance and support.</p>
<p>Q6. What difference do you think patient and public involvement in your research has made to your research? A6: [Free text]</p>	<p>Tell us about the difference or impact PPI has had on the process of undertaking your research; the difference it has made to your research outputs, outcomes and impacts; and, to you as a researcher. Where appropriate refer to outputs reported in other sections in Researchfish.</p>