

Public Involvement

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About public involvement (PI)

- “We define public involvement in research as research being carried out ‘**with**’ or ‘**by**’ members of the public rather than ‘**to**’, ‘**about**’ or ‘**for**’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.” (www.nihr.ac.uk/patients-and-public/).
- Patients, carers and people who use health and social care services.
- Expected by research funders who often include lay members on panels.
- Evidence that PI improves research relevance, quality and impact.

How the RDS NW can help

- Advisers/case managers – PI advice available for every case.
- Specialist Advisers - for extra help with complex issues.
- Resources on RDS NW web pages
- Links on RDS NW web pages, e.g. to INVOLVE.
- RDS NW public involvement fund scheme.

Public involvement fund

- www.rds-nw.nihr.ac.uk/public-involvement/fund.
- Researchers in the North West.
- In receipt of advice from RDS NW.
- Developing proposal for national, peer-reviewed open call funding competitions for applied health or social care research.
- At any stage prior to final submission.

Public involvement fund

- What can it be used for?:
 - setting up meetings with groups of patients, carers, service users or the public e.g. venue, providing refreshments
 - reimburse patients, carers etc. for their time
 - reimbursing PI collaborator (e.g. involve in writing grant)
 - reimburse any out-of-pocket expenses incurred by members of the public such as travel, subsistence and carer costs
 - not for research itself.

Public involvement fund

- How much?:
 - usually in region of £350 per project
 - application for PI funding should include
 - Clear outline of the planned PI activity
 - total amount applied for
 - a break down of costs.

Process notes

- To support the development and design of research studies, not studies already underway.
- The award is claimed via submission of receipt then reimbursement.
- PIF applications are reviewed by two senior PI advisers.
- Up to 6 weeks for a review and decision but can do urgent reviews.
- Can award more than £350 but this is for exceptional cases.
- Short evaluation of the PI activity to be returned as part of the award.

Public involvement fund: examples

The researcher will visit a patient experience group to tell them about the proposed idea and ask interested members to join in a consultation group discussion. Their views will be sought on the best time and place for this to happen and any other needs they may have to allow them attend. Discussions will focus on identifying issues from their ‘lived experience’ perspective to ensure our study addresses their needs and aspirations. Advice gained can then be built into the study while it is still at proposal development stage. We plan to have a service user reference group as part of the study and will also seek advice from participants as to how this could be set up and function well. Costs:

- Attendance fee for six service users to attend two hour consultation meeting £20 i.e. £10 per hour per person times six = £120
- Travel cost re-imburement at estimated local cost of £6 per person = £36
- Catering – light refreshments = estimate £30
- Community venue hire = estimate £100

Total = £286

Public involvement fund: examples

I propose to use this public involvement fund to support the use of a “research buddy” in the development of an application. This is a relatively underused patient and public involvement (PPI) methodology, but has been employed successfully in systematic review projects (reference). The approach has been shown to provide similar advantages to other methods of PPI that work with more than one person. The plan is for my “research buddy” to be a long-term partner in my research project, with a view to becoming an integral part of the research team. This doesn’t have to be the same person throughout the project; research buddies can change if circumstances dictate. The “research buddy” will have input to all stages of the research process. The application will include provision for training for the “research buddy” and a budget to attend conferences. I have already identified a member of the public to be my research buddy from a local PPI group. In the preparation for the application, I have followed INVOLVE guidance and propose to use this to fund the following:

- “Research buddy” remuneration for meetings, including preparation time (12 hours x INVOLVE day rate @ £150 a day) = £ 225
- Meeting room hire – nil
- Snacks and refreshments for meetings – three meetings x £7.50 = £22.50
- Travel expenses for three meetings, estimated at £20 per meeting = £60

Total = £ 307.50

Thinking about Public Involvement

- ✓ Is your lay summary understandable?
- ✓ Have you demonstrated sufficient public involvement in the development of the application?
- ✓ What plans are in place for public involvement during the research?
- ✓ Has a budget been included for planned public involvement during the research project?
- ✓ How have you considered diversity and inclusion?

Resources for PI planning

- RDS NW PI - www.rds-nw.nihr.ac.uk/public-involvement.
- INVOLVE - www.invo.org.uk.