

Writing a patient and public involvement section

Roy Powell, PhD

Research Design Service

Royal Devon & Exeter Foundation NHS Trust -1992





- 1 Gloucester
- 2 Bristol (North Bristol NHS Trust)
- 3 Bristol (BRI)
- 4 Bath
- 5 Taunton
- 6 Salisbury
- 7 Exeter
- 8 Bournemouth
- 9 Plymouth
- 10 Truro

South West Region
Research and Development Support Units

1992



Late 1990s - conference on User Involvement, University of Exeter

The role of Folk.us

The main role of Folk.us is to support patients, service users and carers to design and undertake their own research across a health or social care issues that are important to them. This means we take a small number of research ideas from patients, service users and carers' suggestions and work with them to develop these ideas into full, credible and rigorous research proposals.

The aim is that the patient-, service user- and carer-led research proposals are presented to funders for consideration and, if successful in obtaining funding, Folk.us then continues to support the patients, service users and carers in working on the research projects.



Rachel Purtell

University of Exeter, UK

Rachel Purtell is a disabled women and a disability activist. She is a research fellow at Peninsula College of Medicine and Dentistry, University of Exeter, where she is the Director of the Department of Health funded Folk.us, (Forum for Collaboration with Users in Research) research project. The aim of Folk.us is to change research culture in Health and Social Care so that research and the implementation of research results reflects the inspirations and issues of those who use health and social care services.

2001



Small Voices Big Noises

Lay involvement in health research: lessons from
other fields

by Lisa Baxter, Lisa Thorne, & Annie Mitchell

Small voices big noises: executive summary

October 2001. Lay involvement in health research: lessons from other fields.

Authors: Lisa Baxter, Lisa Thorne and Annie Mitchell

This project was undertaken in association with Folk.us (the Forum for Collaboration with Users in Research) at Exeter University. It was designed to investigate the extent and nature of the involvement of lay people in research in fields other than health and to highlight lessons that can be transferred to health research.

1996

- To facilitate the involvement of patients and the public in medical/ clinical/ healthcare research.
- Simon Denegri – Clinical Director & National Director for Public Involvement NIHR.
- 1998 conference: 100 delegates. 2014 conference: 600 delegates.



INVOLVE



**National Institute for
Health Research**

NIHR patients and the public

Winter 2017



Clinical research: 'Better if it's done with patients rather than to them'


"We see patients as a partner that holds our hand throughout the process and actually makes us a better research funder and a better research organisation as a result" says Simon Denegri, NIHR National Director for Patients and the Public in

Research in the latest Business of Discovery Podcast <https://soundcloud.com/allangaw/podcast-15-patient-and-public-involvement-with-mr-simon-denegri>

Twitter: <https://twitter.com/NIHRCRN/status/920979316367937536>

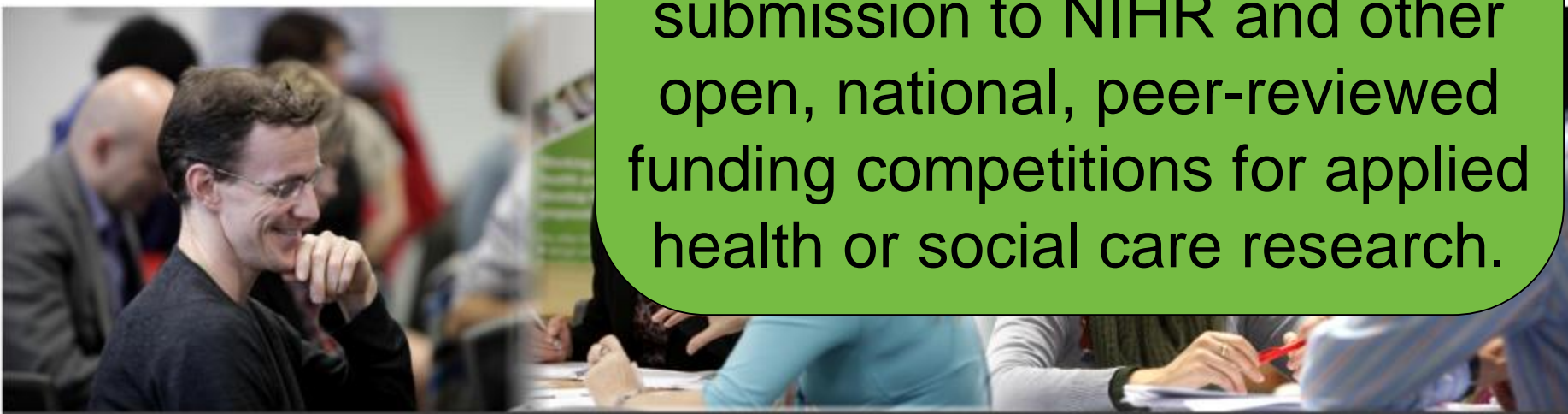


**Read the latest NIHR blog from Zoe Gray, Director of INVOLVE
Climbing the mountain: 21 years of public involvement in
health and care research**



Research Design Service (RDS)

Home → About us → How we are managed → Our structure → Research → Research Design Service



The Research Design Service (RDS) supports researchers to develop and design high quality research proposals for submission to NIHR and other open, national, peer-reviewed funding competitions for applied health or social care research.

Our Research Design Service (RDS) provides support to health and social care researchers across England on all aspects of developing a grant application including, research design, research methods, identifying funding sources and involving patients and the public. Their advice is confidential and free of charge.



In an increasingly competitive research environment, securing funding to conduct health and social care research can be difficult and time consuming. Our Research Design Service (RDS) supports researchers to develop and design high quality research proposals for submission to NIHR [funding programmes](#) and other open, national, peer reviewed funding competitions for applied health or social care research.

RDS advisers in regional centres across England offer a unique breadth of experience and a proven track record in improving funding applications. Their advice is free and confidential.

We advise you to contact your [regional RDS centre](#) at an early stage in your bid development to discuss your research ideas.

Why PPI?



- Improves health outcomes.
- Essential for high quality research. Better questions.
- Strengthens the commitment of Government and NHS to research.
- Must be taken seriously
- It's expected by all major funders
- PPI has its own section in NIHR application forms
- But PPI must also run through entire proposal

We know it's important because



“People-focused research in the NHS simply cannot be delivered without the involvement of **patients and the public**. No matter how complicated the research or how brilliant the researcher, patients and the public always offer unique, invaluable insight.”

Professor Dame Sally C Davies
Chief Medical Officer and Chief Scientific
Adviser, Department of Health

Patient and Public Involvement IS

- Research that is done with or by patients and not to, about or for them.
- Listening and responding to patients' views.
- Working together with patients to develop a good research proposal.
- Developing an on-going, collaborative partnership.
- Commenting on the methods or processes of the research, being actively involved in the research process.

Patient and Public Involvement is NOT


- **It's not Participation:** producing results that answer the research question, being the 'guinea pig'!
- Its not listening to patients to design your service better.
- Its not being part of a focus group using qualitative research methods.



2018 NIHR Stage 2 application form.

Section 10: Patient & public involvement

Please describe how patients and the public have been involved in developing this proposal.

 You should describe who has been involved and why this is appropriate, what role(s) they have played and what influence or change has happened as a result of their involvement.

Text field

350 words

Please describe the ways in which patients and the public will be actively involved in the proposed research, including any training and support provided.

 INVOLVE has developed guidance both on how patients and public can be involved <http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/> and the processes, procedures and values necessary to support this involvement www.invo.org.uk

Patients and public can be involved in every stage of a research project, from developing a proposal through to dissemination and evaluation.

In your description, you will need to say who will be involved and why.

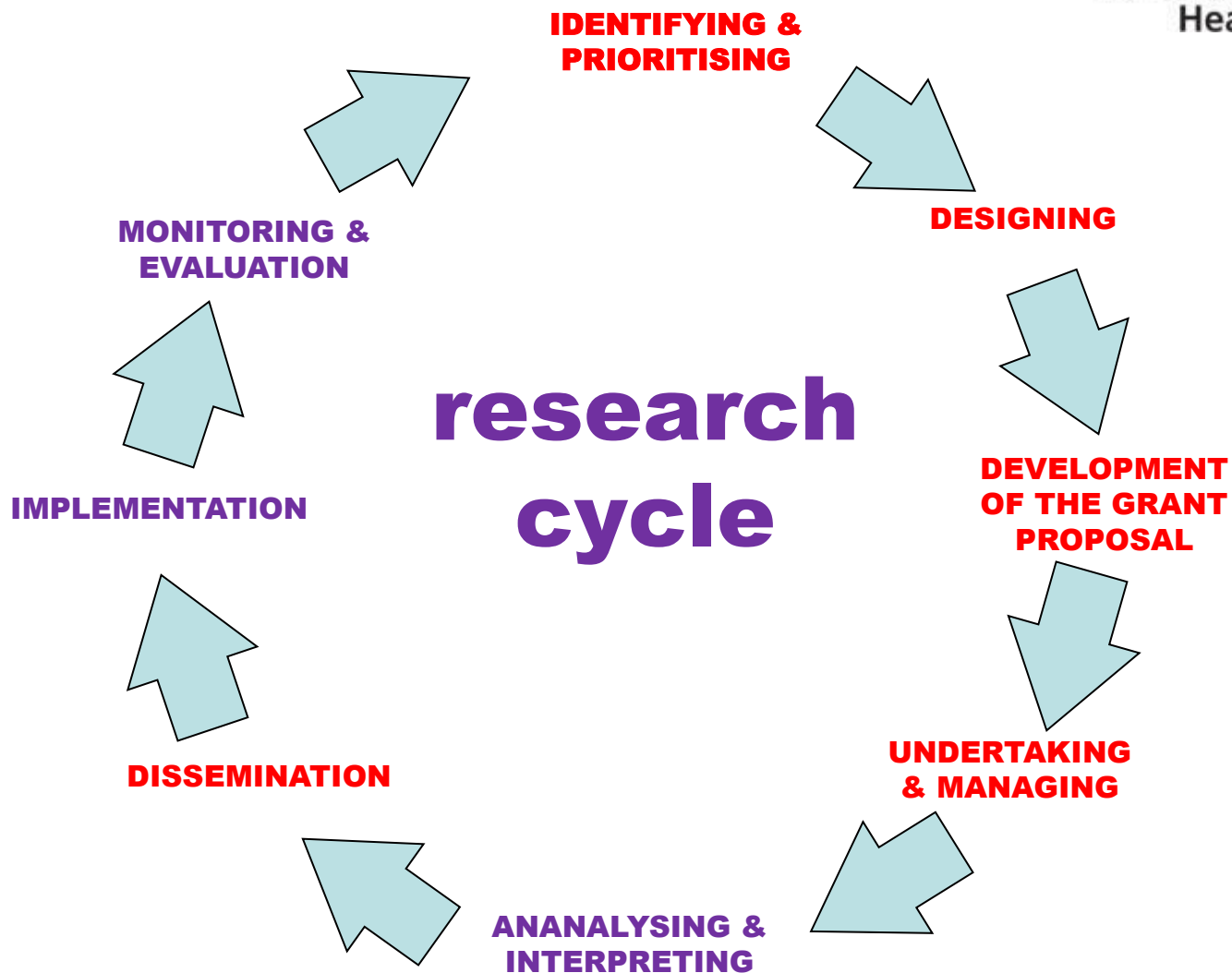
Explain why your approach to public and patient involvement is appropriate for this proposal

Describe how you will support and enable patient and public involvement in your research (e.g., payments, training).

Text field

350 words

In rare cases where proposals do NOT involve patients and the public, clear justification must be provided.



How can PPI help?



At all stages of the research process:

1. **Focussing the question** - Identifying & prioritising topics.
2. **Design** - appropriate materials & methods.
3. **Develop the grant proposal:** lay summary, outcomes.
4. **Undertaking / managing:** PIS/ consent forms, interviews.
5. **Analysis & Interpretation of results:** themes from data.
6. **Dissemination:** patient groups, charities.
7. **Implementation:** patient info for new services.
8. **Monitoring & evaluation:** reflect on what was learnt

Do take it seriously - don't just “tick the box”

- Describe who has been involved at each stage
- Describe what PPI has contributed to the proposal
- Describe how the proposal has benefited from the contribution
- Describe how involvement will continue throughout the project and the on-going contribution you expect it to make
- Include (adequate) costs of PPI in your application


Finding PPI participants/ users of services

- Clinician approaches patients/ carers.
- Self-help groups. Social media closed groups.
- Volunteer database.
- Advertisements in newspapers, posters in waiting rooms.
- Get assistance from INVOLVE/RDS and others e.g. PenCLAHRC has a PenPIG !

1. Identifying and Prioritising research topics

- Be consulted about research topics and priorities important to them as service users.
- Through local user groups and organisations.
- Collaborate with researchers to identify topics for research.
- Identify topics for research themselves.

2. Design

- 
- A horizontal bar composed of several colored segments: green, dark green, orange, purple, red, dark blue, and light blue.
- Getting the research question right / improving it.
 - Inform the design of the research study.
 - Ensure the methods are appropriate to patients/ participants.
 - Refine the inclusion and exclusion criteria. Diversity issues.
 - Sample size – acceptability, attrition, recruitment.
 - Assist with recruitment strategy, information, consent.
 - Review and comment on proposed questionnaires and data collection methods.

3. Development of the Grant Proposal (Can claim expenses from the RDS)



- Help develop the proposal and ensure chosen methods are ethical.
- Inform areas where patients and public could be involved.
- Define outcome measures/end points. Follow-up schedules.
- Advise on appropriateness of the lay summary.
- Raise awareness about costs of involvement and expenses.
- Be named as co-applicants?

4. Undertaking and managing the research

- Aid in designing the detailed protocol.
- Assist in writing the participant information and consent forms.
- On the regular management group to manage/ monitor the research.
- On the independent steering group to oversee the research.
- Produce research updates that are patient/participant friendly – newsletter?
- Can assist in conducting interviews and surveys (with training).

5. Analysing and interpreting the data

- Assist in developing research themes from the data.
- Interpretation of qualitative analysis.
- Understand and interpret data in the same way as the research team?

6. Dissemination




- Advise on different avenues for disseminating results.
- Jointly present the findings with researchers.
- Write information for local patient groups/hospitals, etc.
- Assist in getting results/findings published on charity/voluntary organisation websites.
- Help distribute results within their informal groups.
- Produce summaries of findings.

7. Implementation



- Add validity to findings to increase the likelihood that research results are implemented.
- Develop patient information for new services/interventions within hospitals, GP surgeries, etc.

8. Monitoring and evaluation

- 
- A horizontal bar composed of several colored segments: green, dark green, orange, purple, red, dark blue, and light blue.
- Have continued involvement with the study to maintain focus and address issues as they arise.
 - Collaborate with researchers to evaluate the research process.
 - Reflect on their role and what they have learned.

How can you help PPI ?

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Consider the 4 R's of working together

- **Remit**
- **Role**
- **Relationships**
- **Responsibilities**

PPI - getting it right?



You may need to consider your ways of working, too!

- Accessibility of meeting venues, travel arrangements and payments
- Timing of meetings - what time is the first bus?
- Length of meetings
- Circulation of papers, documents etc - does everyone have email?
- Deadlines / turn-around times
- Methods of communication within the team

How can PPI help?



What not to worry too much about ...

- Philosophical issues of representative-ness
 - Patients v public or community
 - Representative v advisory
 - Lay v expert patient
 - Current service user v former service user

Training for PPI/ user representatives

- INVOLVE training
- Research grant seminars – RDS
- Short research courses – e.g. Dept Social Medicine, Bristol
 - Presentation skills
 - Interviewing skills
 - Qualitative methods.
 - Critical appraisal skills?

Get help ...



- There may be established groups via charities or local support groups e.g. National Obesity Forum
- Local NHS Trust PPI teams - a database of public member's of foundation trusts
- Via your local RDS office - support to run discussion groups and other activities to get patients or public members interested
- Some funding to support pre-application PPI activity

Further Help



- **INVOLVE**
www.invo.org.uk
- **User Involvement in Health Care**
Trisha Greenhalgh, Charlotte Humphrey, Fran Woodard
- **Engaging Patients in Healthcare**
Angela Coulter McGraw Hill
- **PPI Toolkit**
Julia Cartwright, Sally Crowe Wiley-Blackwell