Patient & Public Involvement (PPI) in Research

Guide for Researchers

Author(s):
Sharon Nolan, Communication & PPI Manager, North Bristol NHS Trust in collaboration with
Amanda Burston, PPI Co-ordinator, Musculoskeletal Research Unit, School of Clinical Sciences, University of Bristol

CONTENTS

1. PURPOSE & SCOPE

Guidance from the Department of Health, the NHS and INVOLVE[1] stress the importance of Patient & Public Involvement (PPI) in all aspects of research and our practice should reflect this. All funders, notably the National Institute for Health Research (NIHR) require PPI in the planning stages of grants prior to their submission. Applications that contain evidence of well-conducted PPI are more likely to attract funding.

This guide has been designed for researchers who are employed by the NHS or who are working collaboratively with the NHS.

2 DEFINITIONS

2.1 Service User

By service user we adopt the INVOLVE[1] definition and therefore the term 'service user' includes:

- patients
- informal (unpaid) carers
- parents/guardians
- users of health and social care services
- disabled people
- members of the public who are the potential recipients of health promotion programmes, public health programmes, and social services interventions
- groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services.
- organisations that represent people who use services

2.2 Types of Involvement

INVOLVE guidelines state that active PPI in research is different from simply asking service users to take part in a research study. It ensures that researchers focus on what is important to service users. It is involving service users in the research process – not to or about them.

INVOLVE defines types of involvement as:

- **Consultation:** Researchers consult service users about the research e.g. through individual contacts, one-off meetings
- **Collaboration:** This includes active, on-going partnerships between researchers and service e.g. involvement of service users on project steering groups or as a research partner on a project
- **User-Led / User Controlled:** Service users lead the research and are in control of the research. This is often, through a community or voluntary organisation led by service users.

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[1] INVOLVE www.invo.org.uk

3. A PLANNED APPROACH

Developing a planned approach to service user involvement is vital to its success. Planning is key to effective service user involvement. A plan will help you be clear about:

- **Why** **you want to involve service users**
- **Who** **to ask and to get involved**
- **Where** **and when to involve them**
- **How** **best to do it and how often**
- **What** **resources are needed in terms of staff and money**
- **What** **you will need to get started**

TwoCan Associates[2] have developed a routemap for organisations that commission or fund research who wish to involve service users in their work. It provides advice on where to start as well as lessons from organisations that have already involved service users.

4. TYPES OF ACTIVITY SERVICE USERS CAN BE INVOLVED IN

There are a number of ways that you can involve service users in research plans, depending on the level of service user involvement that is needed and over what period.

Ways of facilitating involvement

Group meeting	Creating an ongoing service user panel to discuss research ideas or projects
One to one meeting	Sometimes there may be a need to have a one-to-one meeting between a service user and a researcher due to work/carer/or health commitments. If a researcher needs to do this then they should follow their organisation's Health & Safety Working Alone policy guidelines
One-off meetings	with service users e.g. a group who meet through a charity already
Virtual readers' panel	to comment on documents for research projects e.g. patient information leaflets Plain English summaries, questionnaires etc
Project Steering Group	Service users being involved in project steering group meetings on an ongoing basis (INVOLVE guidelines recommend two service users per project)

Types of Activity

- Working alongside researchers and research teams for the whole life-cycle of research studies
- Input in the planning stages of grant applications including commenting on and refining research ideas
- Sitting on steering or oversight committees or groups – costs for which could be funded from successful grants
- Commenting on Plain English summaries, commenting on questionnaires
- Giving feedback and comments on a particular project
- Suggesting new research ideas
- Collecting and analysing research data alongside researchers

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[2] www.twocanassociates.co.uk/routemap

- As applicants on new grant applications

5. NHS RESEARCH ETHICS AND R&D APPROVAL

Approval from an NHS Research Ethics Committee or from NBT R&I is not required solely for involving service users in PPI activities, as they are discussing research plans and are not participants in a research study. Normal regulatory, NHS and ethics committee approvals apply for the research study itself in the usual way.

6. APPROACHING SERVICE USERS

- Before contacting service users who are current/former patients, **YOU MUST** speak to the clinician responsible for that patient's care in the first instance - he/she will know whether that patient would be suitable/able to participate in patient involvement work
- If you are in a support function, contact clinical areas within the Trust to ask for help in identifying patients. **YOU MUST** check on CERNER that patients are not deceased before making contact.
- It is best practice to write to a service user in the first instance to ask if they would like to be involved. In the letter include that they can expect a telephone call from you within the next few days or coming week
- It is good practice for the person who is contacting the service users to be the person who will be acting as the ongoing PPI contact (see below). This maintains continuity and helps to build a relationship and trust
- Consider how many service users you can include. For example, on a service user panel this should be 8-10 maximum and will vary depending upon your requirements
- Consider a range of demographics: age, gender, ethnic minorities
- Ensure service users understand what taking part will entail: explain what you will provide (e.g. expenses, support and information) and what their role is
- Involve service users as early as possible in the research process
- Use accessible language. Avoid jargon and acronyms

7. PPI CONTACT /CO-ORDINATOR

- It is important that service users involved in research have a person who they can contact if they have any questions or concerns
- The PPI contact or co-ordinator is likely to be an identified person within the research team. He/she is the person that service users can talk to before or after meetings with researchers.
- This provides service users with the chance to discuss anything they would like clarification about and mention things that they did not want to say during meetings.
- Ensure that service users have the contact details of this person and that they agree on the best means to contact one another. You may also want to discuss and agree best times and days for contact

8 . ORGANISING A PPI PANEL MEETING (Logistics)

Consider:

- Where to hold your meeting (how will people get there – transport availability, (car parking can be an issue if held at Southmead),
- How often you will be meeting

- What time to hold the meeting (some people work full-time, need to consider childcare, or they may be a carer)
- What room bookings are needed/hire costs
- What refreshments are needed (tea/coffee/water and light refreshments?)
- Is the venue accessible to people with mobility problems (are there stairs, a lift, ramps?)
- Is the venue able to accommodate the needs of everyone (accessible 'disabled' toilets, tape loop system)?

9. TO ARRANGE A SERVICE USER PANEL/PANEL MEETING

There are many different ways to run a panel meeting. These are some suggestions that you might like to consider in planning and running a panel meeting

Before The Meeting

- Create a meeting schedule. Consider using Google's Doodle[3] calendar (ensure the service users you are inviting know how to use it)
- Send out (by email or post depending on individual preference – remember not everyone has regular access to email/internet) invitation letters, maps, parking arrangements, research topics to be discussed, together with a brief bibliography of all the staff involved in the meeting e.g. professional background, area of interest etc., to members of the service user panel
- Check compatibility of documents. It is probably best to use Word 2003 if you need to use Word format.
- Create documents as pdfs to reduce file sizes and to protect the content
- Send the pre-meeting information to those in the panel who cannot attend the meeting
- If feedback is requested by post, some panel members may wish to have their feedback photocopied and sent back to them so they have a complete record of their involvement
- Organise the meeting room and refreshments ensuring that dietary requirements are taken into account
- Telephone/text every service user on the panel a couple of days before the meeting as a reminder
- Print documentation to be discussed at meeting as well as sending to service users. Some panel members may need to be provided with additional copies at the meeting
- Prepare travel expense forms and attendance sheets
- Collate a list of charities/organisations that can provide support
- Print place names for all people (service users and researchers) attending your meetings

First Panel Meeting

- Keep it simple, do not overload the session with too much information
- Use this session to allow the members to become familiar with PPI and what it is, purpose etc
- This will be the first time they have all met, so make time for introductions.
- Who is their key contact? How can they be contacted? Email/phone
- Allow time for a refreshment break so the panel can mingle with each other
- Explain that this is a research panel and NOT a service delivery experience panel
- Explain what is expected of them i.e. attend each meeting, read any paperwork and return it where required
- Give them examples of the type of language you will be using
- Show them examples of a Plain English summary or examples of current projects you are working on
- Let them know they can interrupt if they don't understand what you are saying (they may not have heard the terms 'quantitative'/'qualitative' / 'dissemination' for example)

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[3] www.doodle.com

- Explain and agree on need to maintain confidentiality
- Give a deadline if asking for panel members comments
- Provide a pre-paid envelope if asking service user members to return any documents
- Provide placenames/name badges
- Provide dates for future meetings
- Consider distributing the INVOLVE useful public information pack www.invo.org.uk see that explains what PPI is, including a jargon buster
- Provide pens and paper for making notes
- Use a flip chart to note comments during the meeting
- Ask people how they would like to be contacted in the future either by email, phone etc
- Ensure the meeting ends on time
- Make it fun

After the meeting:

- Provide feedback to the researchers (verbally or from typed notes)
- Provide feedback by post or email to service user members if requested. Some members may wish to have their feedback sent back to them so they have a complete record of their involvement
- Contact the service user members following the meeting to ask for feedback and act as a general point of contact
- Provide feedback to service user members who were unable to attend the meeting
- Maintain a finance log for patient travel expenses, refreshments etc

10. ONE-TO-ONE MEETINGS WITH SERVICE USERS

Another format for involvement is inviting individual service users to take part in one-to-one meetings with a researcher or research team. These may include early planning and project design meetings, and steering or oversight groups once a project has started. Many of the principles described above still apply. Some additional things to consider are:

- Providing clear, documented information about what the arrangement between service users and researchers if (e.g. how often will you meet, what is the purpose of the meetings, what expenses and other support will you provide to the service user, what their role will be)
- Schedule meetings to fit service users' availability
- Maintain contact between researcher/research team and the service users
- Provide feedback updates to service users about the project

11. READERS' PANEL

You may find that some service users may prefer to be part of a 'readers' panel' rather than attend meetings. It is important that you treat this group of service users in exactly the same way as you would in face-to-face meetings.

- Ensure you give your readers panel plenty of notice to read and return any documentation
- Send out any documents by email or post depending on individual preference
- Check compatibility of documents. It is probably best to save documents as Word 2003 if you need to use the Word format

- Generally create documents as pdfs to reduce file sizes and protect the Trust logo
- Ensure there is a dedicated contact available to answer any questions they may have
- Ask yourself if it is clear to you what you are asking them to read/comment on?
- Give a deadline for their comments

12. FINANCE

Payment to service users

It is important that when service users are being asked by NBT to be involved in PPI activities that they are reimbursed for out-of-pocket expenses i.e. travel and parking. There is no current policy at NBT for payment of service users time to attend meetings or activities. Below are some useful points to consider:

- When costing a research study ensure you include expenses for PPI
- Consider providing service users with shopping vouchers
- Travel expenses can be paid at **45p per mile per meeting up to 10,000 miles in a tax year 25p per mile** thereafter (a sample spreadsheet for monitoring spend can be found in PPI documentation No 19 below) plus reimbursement of parking costs
- Please check the INVOLVE website (www.invo.org.uk) for advice on payment to panel members for tax & benefit purposes.
- Additional expenses include provision for light refreshments
- Ensure you keep an audit trail of monies/vouchers given to service users. (A sample signatory sheet can be found PPI documentation No 19 below).

Other financial issues to consider (these should all be costed into your study)

- Consider room hire costs if holding meetings off-site
- Consider costs of overtime for reception staff if holding meetings on-site out of hours
- Printing, postage, stationery and dissemination expenses
- Cost of refreshments

13. TIPS FOR RESEARCHERS PLANNING TO DISCUSS PROJECTS WITH A PPI PANEL

- Pre-meeting – discuss your document/proposal with the person chairing the panel or the dedicated PPI contact– this will enable you to decide whether nor not the proposal needs to be discussed at the next scheduled meeting or whether it can be sent to a virtual readers' panel
- The PPI contact will advise the time schedule for submitting material and format for posting
- Use diagrams where possible, and avoid medical, scientific terms and jargon
- Explain research and medical terminology (they may not heard of the terms quantitative, qualitative and dissemination for example)
- Talk slowly
- Ask if they have questions and provide time and space for questions
- Always feedback to the panel where you are in your research process and importantly, whether you have changed your approach following their feedback/input (this is also important to include in any of your grant applications)
- If you asking service users to comment on information before or after the meeting. Ask how they would like the information, ie: electronic or paper copy with prepaid envelope. Ensure you give them a date for when you would like the information back.

- Understand the panel as a two-way process in which service users and researchers all learn from one another

14. MANAGING RISKS

Multiple contacts: There is a possibility that service users might be contacted by more than one researcher so you may want to check with colleagues if they are already involving the same group of patients

Health and Safety: Please consider health and safety issues and refer to the relevant NBT policies

Confidentiality: It is important to stress to the service users that discussions must not be discussed outside of the meeting(s)

Upset or distress: Sometimes service users can be upset or distressed when discussing topics that they have personal experience of. Consider sourcing reference material or charitable organisations they can go to for further help. Anyone conducting service user involvement should know about this information and be experienced and able to deal with upset should it occur

Lone Working: Please refer to individual site Working Alone Policies. NBT defines a lone worker as any individual who, in the process of carrying out their duties on behalf of NBT, may find themselves working alone or in an area isolated from colleagues. This may include:

- Health professional on home visits
- Staff working in buildings on their own
- Working/visiting service users in their own home
- Working/meeting service users in Trust buildings on their own

15. PUBLICITY

- You should ask service users involved in research if they would agree to engage in publicity to promote PPI in research to include publicity articles within the Trust and possible external organisations
- Service users who would like to engage in publicity should be asked to sign a North Bristol NHS Trust patient consent to photography / video recording form /Level 4.

16. TRAINING FOR RESEARCHERS AND MEMBERS OF THE PUBLC

People and Research West of England are a group of health and social care organisations who are working together to support researchers and members of the public to become involved in research
They offer:

- Learning and development opportunities
- Range of Patient and public involvement resources
- Frequently Asked Questions for researchers
- Frequently Asked Questions for members of the public
- Free individual and organisational membership to receive up-to-date information about PPI opportunities across the West of England

For further information visit: www.prwe.org.uk

17. REFERENCES & RELATED LINKS

INVOLVE

was established to promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used. This site holds a wealth of information and guides to help you to involve service users in research.

http://www.invo.org.uk/

TWOCAN ASSOCIATES ROUTE MAP

www.twocanassociates.co.uk/routemap/

RESEARCH DESIGN SERVICE SOUTH WEST

http://www.rds-sw.nihr.ac.uk
Have dedicated advisors for PPI. They provide support and advice for those developing grant applications for applied health or social care.

USEFUL REFERENCES

How can organisations collaborate to improve involvement?
Produced at UWE on behalf of fourteen stakeholder Organisations in Bristol and the South West
http://hls.uwe.ac.uk/suci/Data/Sites/1/public_involvement_in_research_report_april_2010_final..pdf

18. SITE SPECIFIC POLICIES

For site specific policies employees of each organisation should refer to **their own organisations's** policies as detailed below:

North Bristol NHS Trust Policies can be found: http://nbsvr73/Policies/
University of Bristol Policies: can be found: http://www.bristol.ac.uk/safety/policies/

19. PPI DOCUMENTATION

The documentation below can be obtained by either contacting (Sharon Nolan (NBT)) or (Amanda Burston (UOB)) contact details below:

- Sample Invitation letter and patient Information leaflets
- Sample finance logs
- Sample Signatory sheet

For Researchers working on North Bristol NHS studies please contact:
Sharon Nolan: Communication & Patient & Public Information Manager
Research & Innovation, North Bristol NHS Trust
sharon.nolan@nbt.nhs.uk

Or

For University of Bristol researchers please contact:
Amanda Burston: Patient & Public Co-ordinator (Musculoskeletal Research Unit)
Musculoskeletal Research Unit, University of Bristol, Learning and Research building, Southmead Hospital
amanda.burston@bristol.ac.uk