Involving Patients and the Public in your Research – Why, How and When?

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Enhancing your research

Dr Kathryn Martin
What it is....What it isn’t
Members of the public are acting as ‘specialist advisors’ if they are involved in planning or advising on research.

Ethical approval is not required for these activities.

NIHR Involve – invo-org
Identifying and Prioritising
Commissioning
Involvement throughout the Research Cycle
Apply to your research. Ask yourself...

1. How can I incorporate PPI into my research? Where would I start?

2. Who would I involve?

3. What PPI activities would I incorporate and where do they map onto the Research Cycle?

4. What potential barriers might I encounter?

5. What resources are needed? Do I need further training?
PPI is like a fruit cake...
There are many resources for your PPI Toolbox
Funders & PPI: how to address PPI in your grant application

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Research and Innovation
PPI and Research Funders

PPI is not just an expectation but more often a requirement of many funders. It not only encourages a people-centred approach to research but also empowers individuals and helps society value the work. Here are some key benefits:

- **Creates people-centred research** - more likely to be relevant to challenges and needs of society;
- **Empowers people** – by helping them access, use, respond to, and create research and innovation;
- **Helps society value your work** – bridging the gaps between funders, the researchers they fund and society - so research is trusted and valued by people & society.
Funding Panels and PPI

PPI reps sit on or advise funding panels directly e.g. CSO, CRUK, Stroke Association, NIHR, NHSG Endowments and influence funding decisions e.g.:

- Help to prioritise proposals based on need;
- Help identify ethical or practical issues;
- Comment on lay summaries;
- Comment on feasibility and relevance of any planned PPI.
Incorporating PPI in your Grant Application

Funders usually want to understand the role of PPI in the development of your proposal, as well as in plans for management and dissemination of your research. This can be evidenced in various ways e.g.

- Lay summaries;
- Dedicated PPI sections e.g. CSO, NIHR, Stroke Association;
- PPI in research plan e.g. reviewing materials, comment on study design
- Impact & Dissemination Plans, e.g. UKRI, Wellcome;
- Representation in study management or as co-applicants/partners;
- Costs.
PPI in Grant Applications – Top Tips

• Read the guidance and understand the funder’s expectations;

★Ensure Lay Summary is lay!★

• Ensure PPI plans are relevant to the proposal & involve the right people;

• Draw attention to the good work you’ve already done “We held a scoping workshop with diabetes patients to understand…”;

• Highlight where the PPI will contribute to your study “the questionnaire will be co-developed with patients who have experience of…”

• Name as co-Is (with their permission!) or in an other appropriate role;

★Include costs★
PPI Grant Applications – Costs

PPI costs can usually be requested in your application; including these shows your intent and commitment to PPI; e.g. consider:

- Focus groups (travel, refreshments, room hire, childcare, transcribing)
- Questionnaire/survey costs (mailing, printing, telephony, translation)
- Workshops (travel, refreshments, accommodation, room hire)
- Advisory committees (travel expenses, honoraria)
- ‘Tokens of appreciation’ – e.g. vouchers – follow UoA finance regs, donation to networks.
PPI & Funding – more info.

• Please contact me directly with any follow up queries:

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Why? Who? How?

Dr Barbara Gorgoni

PERU
Who?

- Patients
- Potential patients
- Carers
- Users of services
- Organisations representing service users
How?

Consultation → Collaboration → Co-production

- Meetings: face-to-face/online
- Focus groups
- Public events
- Workshops
- Interviews
- Surveys
- Steering groups
How?

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Accessibility
Convenience
Incentives
Recruitment

• Start as early as possible
• Be clear about commitment and expectations
• Offer training and support

Allow time!
Recruitment

- Advertise in GP surgeries & outpatient departments
- Local newspapers and radio
- To local or national patient support groups and voluntary organisations
- Community organisations
- Word of mouth
- Online
  - ✔ Social media
  - ✔ Websites
  - ✔ e-newsletters/emails

Advantages

Advantages

and barriers
Dissemination

• Involve patients and public in developing and delivering activities
• Reach appropriate audience
• Conferences, workshops, articles
• Public events
Public Events

- Café MED & Café Sci
- British Science Week
- May Festival
- Techfest
- AHRC Being Human Festival
- ESRC Festival of Social Science
- Talking Science radio show
- Doors Open Day
- Explorathon
- Cell Block Science
Online activities

• Websites
• Podcasts
• Webinars, panels, debates
• Facebook live
• Twitter chats
• YouTube videos
• Remote radio
PPI Group

- Core group: 10-14 members of the public
- Quarterly meetings: 26 May 2021
- Call for researchers to work with the group
  - return interest form by 17 May

www.abdn.ac.uk/smmsn/ppi
Support

• ISSF PPI Fund:
  ✓ Activities that will benefit one or more stages of your research
  ✓ Range of costs
  ✓ Next deadline September 2021, TBC

Transforming the world with greater knowledge and learning

Thank you!