Developing a practical approach to evaluating public involvement in research

A workshop by:
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With contributions from public members of the People in Health West of England strategy group

Newcastle
16 November 2018
Programme: Conference workshop

3.15pm  Participant introductions
3.20pm  Introduction to the conference workshop
3.25pm  Full workshop programme
          Thinking about evaluation: issues and challenges
3.35pm  A pragmatic approach: Impact log
3.45pm  A participatory action approach: Cube framework
3.55pm  The Public Involvement Impact Assessment Framework (PiiAF)
4.05pm  Group work: your feedback on our workshop
4.15pm  Key points
4.20pm  End
Full workshop programme

30 mins  Welcome and personal aims
45 mins  A note on terminology
          Evaluation approaches, issues and challenges
          Overview of relevant NIHR* policy and the National Standards for Public Involvement
15 mins  Break
15 mins  A pragmatic approach: Impact log
20 mins  A participatory action approach: Cube framework
25 mins  The Public Involvement Impact Assessment Framework (PiiAF)
1 hour   Individual and group work to consider options

*NIHR: National Institute for Health Research
Evaluating public involvement: some questions

• Should we evaluate public involvement and if so, why?
• Who is setting the evaluation agenda?
• What type of evaluation?
• Process and/or impacts?
• A question of values?
Debates and controversies around evaluating public involvement:

How you think about public involvement matters!

For example, as an intervention or a conversation?
Thinking about impact

• Different kinds of impact
• Different time frames
• More embedded involvement may make it more difficult to identify individual contributions
Standard 1: INCLUSIVE OPPORTUNITIES
We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER
We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING
We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS
We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT
To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE
We involve the public in our governance and leadership so that our decisions promote and protect the public interest.
Standard 5: IMPACT

To drive improvement, we capture and share the difference that PI makes to research.

We can learn from both positive and negative impacts of public involvement in research. By sharing this learning we can improve what we do.

5.1 We involve the public in the assessment of public involvement in research

5.2 We record our agreed purpose for public involvement and its intended outcomes

5.3 We collect information that will help us assess the impact of public involvement in research

5.4 We reflect, learn and report the extent to which we have met our intended purpose and predicted outcomes
The three evaluation approaches

- A pragmatic approach: Impact log
- A participatory action approach: Cube framework
- A comprehensive approach: The Public Involvement Impact Assessment Framework (PiiAF)
A pragmatic approach

- Record and monitor the involvement process and immediate outcomes
- Reflective process required related to impacts:
  - Immediate and longer term
  - Anticipated and unanticipated
Involvement activity, impact and outcomes log

Project name: .............................................................................................................................
Involvement lead/researcher organising activities: .................................................................
Aim of involvement : ..................................................................................................................
..................................................................................................................................................

<table>
<thead>
<tr>
<th>Date</th>
<th>Aim of activity</th>
<th>Involvement activity</th>
<th>Outcome of PI activity</th>
<th>Impact of PI activity</th>
</tr>
</thead>
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Stage of project cycle: 

Involvement activity:

Who took part:

How involvement took place:
Example:
Public involvement in planning a research about heart valves
<table>
<thead>
<tr>
<th>Date</th>
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<th>Impact of PI activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/04/18</td>
<td>To develop a project proposal meeting NIHR requirements regarding public involvement</td>
<td>Stage of project cycle: Proposal planning for a clinical trial comparing surgery for 3 different kinds of heart valve</td>
<td>Clinical trial outcome measures were modified to include factors clinicians had not previously factored in based on people’s lived experiences, e.g. the quality of life variable, the emotional toil of an operation</td>
<td>Anticipated: Improved project proposal with appropriate outcome indicators which met NIHR PI requirements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Involvement activity: Proposal planning meeting</td>
<td>Unanticipated: New support measures put in place for the trial in cases where emotional toil became an issue for participants</td>
<td>Unanticipated: The trial became more responsive to patients’ personal needs</td>
</tr>
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<td>Who took part: Principal Investigator and members of the public who had experience of living with a heart valve</td>
<td>Unanticipated: Genuinely project co-production</td>
<td>Unanticipated: Genuine project co-production</td>
</tr>
<tr>
<td></td>
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<td>How involvement took place: Consultation organised by PI specialist to inform the project proposal development</td>
<td>3 members of the public became co-applicants on the proposal</td>
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Evaluating the involvement process

Public involvement as a knowledge space:

A space where different forms of knowledge can interact on an equal basis
Cube framework for understanding involvement

- Organisation changes
- Organisation resists change
- One way to be involved
- Many ways to be involved
- Strong voice
- Weak voice
- Public concerns
- Organisation's concerns

One way to be involved
Many ways to be involved
Organisation changes
Organisation resists change
Strong voice
Weak voice
Public concerns
Organisation's concerns
On here put whether you think the public voice (patients, carers etc) has been listened to and acted on.
Many ways to be involved

Organisation's concerns

Public concerns

Organisation resists change

Management changes

PenPIG

Strong voice

Weak voice

One way to be involved
Welcome to the PiiAF website

PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.

How are the public involved in research?

Examples include helping decide which research should be done and how it is done; collecting and analysing data and developing research instruments.

Who is PiiAF for?

PiiAF is aimed at researchers but members of the public interested in getting involved in research may also find it useful and some people have used it in training for researchers and the public.

Why do researchers need this?

Most major funders in health research now require applicants to involve members of the public. The guidance is designed to be used at the time research ideas and funding proposals are being developed.

Who are we?

The PiiAF Study Group includes academics, public involvement facilitators from NIHR Research Networks and members of the public, supported by a grant from the UK Medical Research Council.

http://piiaf.org.uk/
Public Involvement Impact Assessment Framework (PiiAF)

Part 1
- Values associated with public involvement in research
- Practical issues shaping public involvement in research
- Impacts of public involvement in research
- Approaches to public involvement in research
- Research focus and study design

Part 2
- Phase 1: Laying the Foundations
- Phase 2: Developing your intervention theory
- Phase 3: Identifying possible effects of context on impacts of public involvement
- Phase 4: Formulating assessment questions and study design

Developing an Impact Assessment Plan
Bringing it all together

• A pragmatic approach: Impact log
• A participatory action approach: Cube framework
• A comprehensive approach: The Public Involvement Impact Assessment Framework (PiiAF)

You can read more about these approaches in the Guidance Document on evaluating PI in research, available at https://bit.ly/2LL4QNV, or visit the Resources page on the People in Health West of England (PHWE) website.
Group work: Your feedback on our workshop

From what you have learned today, do you think that our full workshop can help put evaluation into practice?

• If yes, how?

• If no, what are your suggestions for improvements?
Key points from group work
Thank you!!

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