



National Institute for Health Research

Public Involvement in Research: Impact Exchange Workshop

London, 29 November 2017

Presentations and discussions

Workshop facilitation and report: Maryrose Tarpey




#impactppi

Aims of the workshop



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- To exchange information about how organisations – federal/ state-wide/ national – currently report the impact of their public involvement activities
 - To explore the potential to develop a shared approach to assessing impact of public involvement in research
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Contributors

- Convened by the NIHR's Central Commissioning Facility and the NIHR Public Involvement Senior Leadership Team in discussion with Anne McKenzie, Consumer and Community Health Research Network, Western Australia
- **25 workshop participants*** from a number of different countries, and settings including public involvement leads within organisations, and public contributors involved in research commissioning within the NIHR and other UK funding programmes.

* Links to presentations and other information are highlighted in the same way throughout this report. Alternatively you can download all the linked materials [from here](#) in one document. If you are a member of the public and would like a paper copy of the report or any of the related documents please contact the CCF PPI team. Contact information is given at the end of this report.

What the workshop covered



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Session 1: Introductions and interests

Session 2: Information exchange - presentations and discussion

Session 3: Identifying emerging themes

Session 4: Small group discussions of three emerging themes

Session 5: Reflections on the day

Session 6: What next?

Session 1: Introductions & interests



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Welcome and introductions from Simon Denegri, NIHR National Director for Patients & the Public in Research and Maryrose Tarpey

Simon spoke of the increasing interest in the impact of public involvement in research as part of a wider focus on assessing the impact of publicly funded programmes despite the challenges of assessing something that is not easily measured.

Workshop participants discussed their interests in the impact agenda and [what they would like to get out of the day.](#)

Session 2: Outline



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Presenters from six organisations - federal/ state-wide/ national - provided information on how their organisations currently report the impact of their public involvement activities

Presenters were asked to respond to three questions :

1. What information does your organisation routinely collect and share about your public involvement activities?
2. Who are the key audiences you report to about achievements and impact (eg researchers, members of the public, funders)?
3. What ideas and/or plans does your organisation have for reporting impact of public involvement in research?

In advance of the workshop, presenters had also provided [background information](#) on the purpose of their organisations and public involvement activities undertaken.

Session 2: Presentations



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Links to individual presentations:

- [National Institute for Health Research, England](#)
(**Simon Denegri**, National Director for Patients & the Public in Research)
- [Patient-Centered Outcomes Research Institute \(PCORI\), United States of America](#)
(**Kristin Carman**, Director of Public & Patient Engagement & **Laura Forsythe**, Director for Evaluation & Analysis)
- [Public Health Agency, Northern Ireland](#) (**Claire Fordyce**, PPI Senior Officer)
- [Voluntary Sector Shared Learning Group on Involvement, United Kingdom](#)
(**Bec Hanley** & **Matt Murray**, Shared Learning Group)
- [Saskatchewan Centre for Patient-Oriented Research \(SCPOR\), Canada](#)
(**Malori Keller**, Patient Engagement Platform Lead, Health Quality Council)
- [Consumer & Community Health Research Network \(CCHRN\), Western Australia](#)
(**Anne McKenzie**, Head of CCHRN)

Session 2: Discussion summary



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- **Why** does PPI have to justify its existence in ways that no other parts of research (e.g. health economics, statistical analyses) are expected to do?
- **Audiences:** identify who wants to know about PPI impact - senior 'leaders', public members, funders, researchers - **then** what information those particular audiences need

Assessing impact of involvement:

- Important to understand what we want to get out of the involvement activity at the beginning – not as an afterthought - and *then* go back at the end to see whether outcomes were as expected.
- How can you distinguish the impact of well-integrated PPI? It becomes invisible
- Are we asking what the impact is in the right way – who are we asking and when?
- Why aren't we asking members of the public what impact they are having? AND what more can we learn from the public?

Use of stories/ case studies:

- Stories of involvement tend to be all about process – not really about what changed as a result of involvement.
- Stories of involvement are and will remain very important. They bring research to life.

Session 3: Identifying emerging themes



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The emerging themes selected for discussion were:

Before breaking for lunch, workshop participants **identified emerging themes** based on the morning discussions about the impact of involvement. Participants were then given three votes to highlight the theme(s) they were most interested in discussing during the next session.

- 1. What is the purpose of measuring impact and how do we do it? (should we be isolating impact of involvement v holistic approach that includes involvement)**
- 2. Who wants to know what?
Can we identify key impacts of involvement by asking audiences what difference they want it to make?**
- 3. How can we be more focused on providing useful case studies/ stories for different audiences?**

Session 4: Theme 1

What is the purpose of measuring impact and how do we do it?



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Summary feedback

Why is this theme important to focus on?

- Measuring impact of involvement on research will influence/ change minds of key audiences and strengthening the evidence base and learning about involvement in research – what works and how
- important to measure the quality of involvement, move the debate on from ‘having to have/add on’ to ‘integrated/ built in’ involvement.

What are the core issues?

- given the growing pressure on resources reporting impact will help to legitimise investment in involvement;
- need to ask the right questions at the right time and capture strategic impact of involvement rather than just focus on the operational/ project level.

What could an international collaboration bring to this theme?

- potential to design an international project e.g. track what is happening and the impact involvement has made in different settings/ structures/research cultures.
- develop a consensus statement on what we mean by impact of involvement in research.

Session 4: Theme 2

Who wants to know what?



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Summary feedback

Why is this theme important to focus on?

- need to establish what each audience (public, funders, researchers etc) want to know about the impact of involvement influencing research.
- Reporting impacts are a key marketing tool/ educational device to persuade and influence

What are the core issues?

- Selecting the right questions to inform impact e.g. purpose of the involvement, who, how, what would do differently, what were the benefits for the research – e.g. relevance, appropriateness?
- tailor questions to identify impacts - for public /advocacy groups ask for their views on what impact or change they influenced by being involved in the research? for funders why might PPI be important to you? What evidence would demonstrate that importance?

What could an international collaboration bring to this theme?

- Develop common templates/ questions on impacts for different audiences – set up a project to standardised internationally?

Session 4: Theme 3

How can we be more focused on providing useful case studies/ stories for different audiences?



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Summary feedback

Why is this theme important to focus on?

- context of austerity – helps to make a case to develop / support involvement in research
- need to ‘do more case studies, but do them better’


What are the core issues?

- understanding the different audiences’ interests – impact case studies need to be tailored to *their* needs
- purpose is to ‘sell’, so need to be selective and set the right questions so the information collected is relevant and can provide answers

What could an international collaboration bring to this theme?

- potential to create ‘meta’ case studies
- explore commonalities, opportunities for added kudos

Session 5: Some reflections on the day



Remember our audiences (public, funders, researchers) are diverse and the impact of involvement will have different meanings for different audiences – this has been said so many times today.



I still question – as others have – why we are still being singled out for scrutiny when other inputs into the research system are not ..however that said I accept we have to be pragmatic and can learn about what works best from reports of impact of and the differences involvement makes in different research settings.

Researchers need assistance to track the impact of involvement in their projects to capture the difference (positive and negative) that involvement makes to research. It would be useful take two or three completed research studies and look back on how involvement impacts/ outputs could have been defined before the studies started. This also links to the development of [Public Involvement Standards](#) and Standard 5 on impact.'

We need to move the debate away from “prove to improve”.. away from the feeling we have to justify the existence of public involvement to actively demonstrate the improvements it brings to research We also must reclaim the value of our stories by being more robust in the way we are telling them! For example, instead of ‘snapshots in time’ lets diarise stories that track involvement throughout the life of projects.



We in England need to realise we may be not as far advanced in thinking about impact of involvement as in other countries – we have a lot to learn.

Session 6: What next?



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Interest and opportunity for future international collaboration were discussed and some initial actions were identified:

Is it possible to develop a common set of questions on impact of involvement – ‘Who wants to know what’?

- NIHR – to ask public contributors what difference they think their involvement has made/ should make to NIHR funded research.
- CCHRN Western Australia – to facilitate a forum meeting in February 2018 to identify key impact measures relevant to different audiences – researchers, consumers/the public and senior research management and government – by asking them what difference they want involvement to make.

The NIHR also hopes to bring some of all of the workshop participants back together in March 2018 as part of an international network meeting.

Thanks and contact information



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Many thanks to all the workshop participants!

If you have any questions or queries about this work please do get in touch:

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