

Creating evidence and exploring approaches to patient and public engagement and involvement

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Session objectives

Learn together:

1. Critically reflect on levels of involvement
2. Clarify the meaning of common terms
3. Explore approaches to monitoring impact
4. Identify relevant published literature for further learning

Where are you on the ladder?

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Northwest London

Consultation

Co-design

Participation

**Participatory
approaches**

Involvement

**Co-
production**

Engagement

Patient-centred

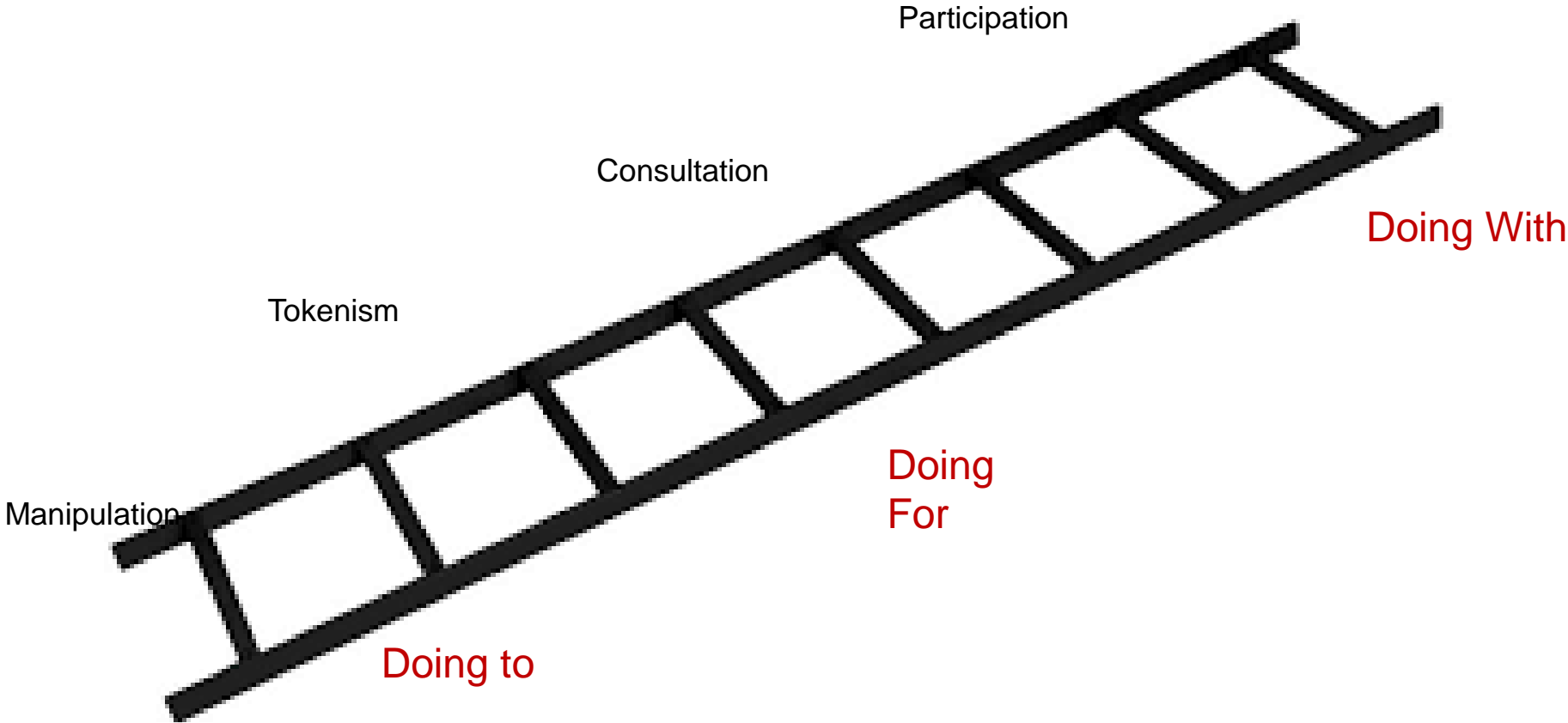
Co-delivery

Statements for ladder exercise

- **My department has completed over 100 FFT questionnaires**
- **We invited patients to speak at our conference about their experience of using our services**
- **Patients and carers were invited to join the interview panel**
- **Patients helped short-list the research applications received for the next round of grants**

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Principles of Participation

- **PURPOSE** – *Why ?* Meaningful involvement needs to have a clear purpose against which it can be monitored.
- **PRESENCE** – level and extent of involvement in the process; ensure it is equal and accessible
- **PROCESS** -The involvement process needs to be carefully planned and thought through, in order to ensure that service users and carers (and everyone) can make the best possible contributions
- **IMPACT** – What difference has the involvement made? Outcomes for the patient, service and organisation.

4Ps and I: What are they?

They aim to guide conversations to help plan:

- **P**inciples which will be embodied to ensure all involved are valued and respected
- **P**urpose of involvement and how it links to an overarching aim
- **P**resence to clarify who needs to be involved to ensure those involved encompass the variety of experiences/expertise etc. necessary to influence the improvement initiative;
- **P**rocess which will be used to effectively involve all those necessary to influence the initiative;
- **I**mpact that the involvement will have on those involved, and on the improvement initiative.

<http://www.nsun.org.uk/about-us/our-work/national-involvement-partnership/national-involvement-standards-launched>

In association with: National Involvement Partnership | National Survivor User Network | Funded by the Department of Health




4pi National Involvement Standards




Principles Purpose Presence Process Impact

4pi National Involvement Standards




Good involvement has many benefits for all concerned - for individuals, communities, services, professionals and organisations. These are the benefits we identified in our main report 'Involvement for Influence: the 4Pi Standards for Involvement' NIP, 2014.

Why Use 4Pi National Involvement Standards?



4pi National Involvement Standards



Principles Purpose Presence Process Impact

Monitoring or measuring impact

1. Is this important?
2. Impact from whose perspective?
3. Are there examples to share, good and bad?

Should we measure?

Staley *Research Involvement and Engagement* (2015) 1:6
DOI 10.1186/s40900-015-0008-5

RESEARCH INVOLVEMENT
AND ENGAGEMENT

REVIEW ARTICLE

Open Access

'Is it worth doing?' Measuring the impact of patient and public involvement in research



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Abstract: Much of the current debate around the impact of patient/public involvement on research focuses on the lack of empirical data. While a number of systematic literature reviews have reported the various ways in which involvement makes a difference to research and the people involved, this evidence has been criticised as being weak and anecdotal. It is argued that robust evidence is still required. This review reflects on the use of quantitative approaches to evaluating impact. It concludes that the statistical evidence is weakened by not paying sufficient attention to the context in which involvement takes place and the way it is carried out. However, if scientific (systematic, quantitative, empirical) approaches are designed in a way to take these factors into account, they might not generate knowledge that is useful beyond the original context. Such approaches might not therefore enhance our understanding of when, why and how involvement makes a difference. In the context of individual research projects where researchers collaborate with patients/the public, researchers often acquire 'new' knowledge about life with a health condition. This new understanding can be described as experiential knowledge—'knowledge in context'—that researchers gain through direct experience of working with patients/the public. On this basis, researchers' accounts of their experience potentially provide a source of insight and learning to influence others, in the same way that the patient experience helps to shape research. These accounts could be improved by increasing the detail provided about context and mechanism. One of the most important contextual factors that influence the outcome of involvement is the researchers themselves and the skills, assumptions, values and priorities they start with. At the beginning of any research project, the researchers 'don't know what they don't know' until they involve patients/the public. This means that the impact of involvement *within any particular project* is somewhat unpredictable. The answer to the question 'Is involvement worth doing?' will always be 'It depends'. Further exploration of the contextual and mechanistic factors which influence outcomes could give a stronger steer to researchers but may never accurately predict any specific impact.

What are the issues?

- Evidence of impact criticised for being weak and anecdotal
- Some want robust evidence from scientific studies of involvement
- Statistical methods are perceived as being more robust

What's missing?

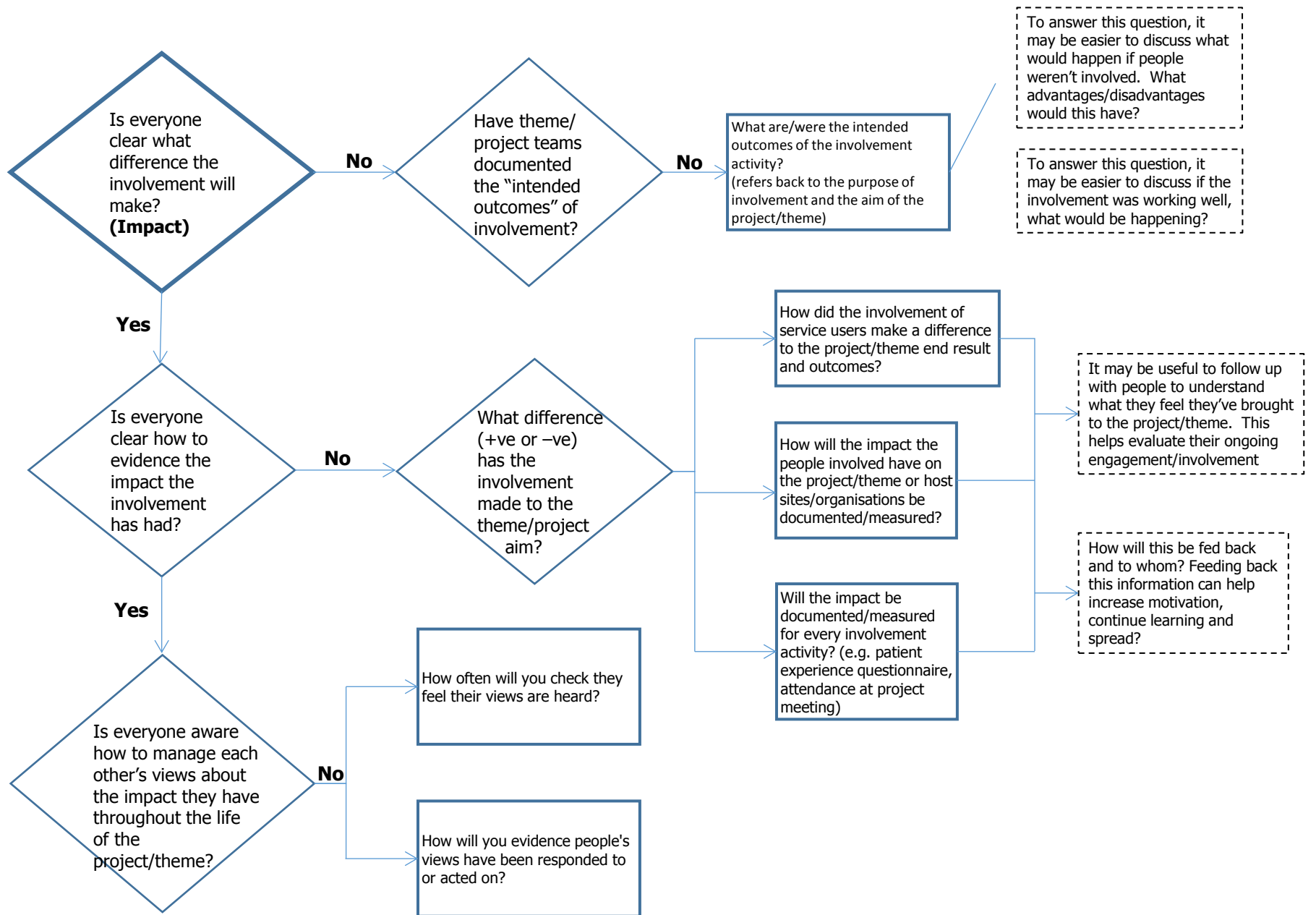
- Statistical evidence will not capture the influence of the context in which involvement took place
- This type of evidence cannot predict if the same results will occur in the same way in other studies

Is there another approach?

- Staley identifies knowledge which emerges from the direct experience of researchers and patients working together
- ‘Knowledge in context’ or ‘insight’

'Evidence' and 'Experiential'

- Data obtained through systematic enquiry
- Objective
- Rational
- Quantitative - measurement
- Knowledge 'in context' gained through experience – insight/wisdom
- Subjective
- Emotional
- Qualitative - description



What will you take away from the session?

Thank you

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Join the Exchange Network

Dates in 2017

Thursday 9th March

Thursday 15th June

Thursday 14th September

Thursday 30th November

What is the Exchange Network?

- A network of people from different backgrounds with a shared interest in improving healthcare, involvement learning and leading together
- A facilitated space that acknowledges and seeks to equalise power differentials between patients, researchers and healthcare professionals in order to learn collaboratively
- A personal development opportunity

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