









Evaluating the Impact of Patient and Public Involvement in Research

21 October 2025 13.00 – 14.30 Online



Chair and Presenters

Chair:

Halle Johnson, Patient and Public Involvement and Engagement Manager, NIHR School for Primary Care Research

Presenters:

- Sarah Biggs, Public Contributor, Information About Me & NIHR ARC West
- Andy Gibson, Associate Professor in Patient and Public Involvement, University West of England
- Bob McAlister, Public Research Partner, Wales Cancer Research Centre
- Alisha Newman, Senior Research Associate in Patient and Public Involvement & Engagement, Centre for Academic Primary Care, University of Bristol











Session overview

- 1. What we mean by impact in this session
- 2. Things to think about when evaluating the impact of public involvement
- 3. The wider context, common challenges, and good practice
- 4. Introduce four tools that can help you assess public involvement impact
- 5. Questions and discussion

You will leave with a working knowledge of the strengths and weaknesses of four different approaches











What do we mean by public involvement *impact*?

- The difference that public involvement makes to research
- The changes, benefits and learning gained from the insights and experiences of patients, carers and the public

Definitions adapted from the UK Standards for Public Involvement Impact Standard. <u>UK Standards for Public Involvement - Impact</u>





















Better involvement • Better research • Better health

Thinking about Impact

Different kinds of impact which might:

- Stop things happening
- Review (and support) plans already made
- Make positive changes to:
- the research
- the people directly or indirectly involved
- linked to purpose of involvement
- Result in unanticipated impacts

Different time frames and levels

- Within a study or project
- Across a number of related studies
- Related to the culture of research teams and departments















What and when to evaluate



- How would you know that your aims and objectives have been met?
- Are you evaluating process and/or impacts?
- Is your PPIE fit for purpose? For your project, participants and funding bodies?













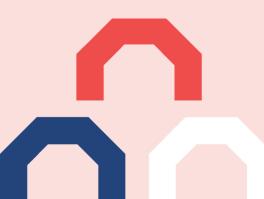




Public perspective: Motivations for involvement and common challenges to impact



- The power to have a voice and equal status with researchers
- The fear of saying what you believe and having it listened to
- The awareness that we can't represent everyone, but we are a voice that comes from the community, patient and carer, tax-payer
- Communication:
 - provide feedback on what has happened/changed
 - acknowledge public contributions
 - Help them understand what are the next steps, when (or if) they can expect to hear back
 - Do you have a point of contact in the team, critical for capturing impact?
 - Be clear on your expectations of public contributors



Good Practice - The UK Standards for Public Involvement



IMPACT

Seek improvement by identifying and sharing the difference that public involvement makes to research

- Understand the changes, benefits and learning gained from the
- insights and experiences of patients, carers and the public

Reflective Questions:

- Are the public involved in deciding what the assessment of impact should focus on, and the approach to take?
- Is it clear what information to collect to help assess impact, including who has been involved and how?
- Are there processes in place to help reflect on public involvement?
- Are the changes, benefits and learning resulting from public involvement acted on?

Find out more: about the six <u>UK standards</u> and their supporting materials, including downloadable documents in different formats.





















Four approaches to evaluating public involvement impact



1. A comprehensive approach:

The Public Involvement Impact Assessment Framework (PiiAF)

2. A pragmatic approach:

The Public Involvement Log.

3. A UK Standards-linked approach:

The Public Involvement in Research Impact Toolkit (PIRIT)

4. A participatory approach:

The Cube framework.











Better involvement • Better research • Better health

A comprehensive approach:

Public Involvement Impact Assessment Framework (PiiAF)



Public Involvement Impact Assessment Framework (PiiAF)



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.



Why do researchers need this?

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.

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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.



Download Guidance Document



Download Executive Summary











A pragmatic approach:

The Public Involvement Log



- Record and monitor the involvement process and immediate outcomes
- Reflective process required to understand impacts and for learning
- Enables the public contributors voice to be heard.
- A good starting point













Using the Impact Log Effectively



- Agree together what you are going to log.
- When, how often and who?
- Form a simple record that acts as a reminder for colleagues of progress to date and actions arising.
- Use this report to present findings together as part of knowledge dissemination.



Public Involvement Log

Date	Project	Type of involvement	Who took part	Outcome*	Impact**	Reflections/learning

^{*}Outcome: Immediate, demonstrable change

^{**}Impact: Sustained change, can be intended/unintended, positive/negative











Completed log example

Date	Project	Type of involvement	Who took part?	Outcome	Impact	Reflections/learning
03/04/2018	ROSS study: To inform the funding application of a feasibility clinical trial in the CV-BRC comparing surgery for 3 different kinds of heart valve	Proposal planning meeting	PI, PPI lead, trial manager. Surgeon was involved in developing the group but did not attend (at request of PPI lead). 7 members of the public who had experiences of living with heart valve replacement and 6 'carers' who participated in the main group discussion but also a split off group	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 Unanticipated: New support measures put in place for the trial in cases where emotional toil became an issue for participants 3 members of the public became coapplicants on the proposal	Anticipated: Improved project proposal with appropriate outcome indicators. Unanticipated: The trial became more responsive to patients' personal needs Unanticipated: Genuine project co- production Unanticipated: Development of Arco Study Unanticipated Ross used in best practice examples	Ensure views of carers/significant others are accounted for. Involve at earlier stage to avoid amendments. Develop PPI to include collaborative work moving forward Develop engagement at earliest opportunity











Key points: Public Involvement Log

- Available in different formats
- A tool for reporting, reflecting and learning
- Designed to include the views of researchers and public contributors
- Time-efficient
- Can be developed to meet study needs
- Available as an online tool
- Keep colleagues informed about PPIE progress.

Free download at: https://arc-w.nihr.ac.uk/patient-and-public-involvement-impact-log/















A UK Standards-linked approach: Public Involvement in Research Impact Toolkit (PIRIT)

Development context:

- Partnership project began in 2020
- Marie Curie Research Centre and Wales Cancer Research Centre, Cardiff University
- Project team 4 public members and 2 researchers
- Integrate the principles of the UK standards into practice
- Pragmatic framework to support impact from planning through to reporting
- Can be applied across different research settings













What is PIRIT?

Two pragmatic tools to help you to:

1

Plan and integrate public involvement in research

2

Track public contributions and the difference they make

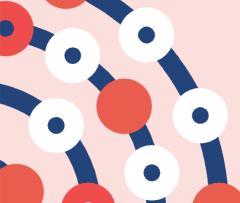
3

Report impact against the UK Standards for Public Involvement





Free for users under certain conditions





PIRIT Planning Tool

Involving the appropriate population

- A | Public contributor opportunities and involvement mechanisms
- The public contributor person specification reflects the group or population of research interest. (Inclusive Opportunities)
- The public contributor role profile is written in lay language and reflects the anticipated involvement opportunities and timelines.

 (Communications, Inclusive Opportunity)
- Objectives for public contributor's negotiated and agreed with the (Working Together)
- Different levels and types volvement opportunities are available a spectrum of contributes (Inclusive Opportunities Vorking Together)
- Access to study meetings/discussions is enabled for all public contributors including virtual attendance/platforms where physical attendance is not possible or appropriate.

 (Inclusive Opportunities, Working Together)
- B | Public contributor recruitment
- All available means of public contributor recruitment have been considered and utilised to enable the target population to apply.

 (Inclusive Opportunities)

- C | Costing and funding public involvement activities
- Public involvement is costed into the grant reflecting anticipation out of pocket exputing sertaking B | Public
 - sub in ad
- Public contributo for time spent on based on current time commitmen and support requ (Governance)
- D | Public contri and training
- Public contributo of contact for the them and offer si (Governance, Su

See section 4f coordination

| Public contributor recruitment

- All available means of public contributor recruitment have been considered and utilised to enable the target population to apply.

 (Inclusive Opportunities)
- Public contributors are recruited at the prefunding stage. (Governance)
- Public contributors act as co-applicant on the grunt. (Governance, Working Together)
- Additional Public contributors are recruited when funding is awarded.

(Inclusive Opportunities, Governance)



Public Involvement in Research Impact Toolkit

PIRIT Planning Tool

Version 1 | Launched 6th February 2023











PIRIT Planning Tool

Involving the appropriate population

AI	Public contributor opportunities and involvement mechanisms	CI	Costing and funding public involvement activities
	The public contributor person specification reflects the group or population of research interest. (Inclusive Opportunities)		Public involvement is costed into the grant reflecting anticipated costs relating to out-of-pocket expenses and payment for
	The public contributor role profile is written in lay language and reflects the anticipated involvement opportunities and timelines.		time undertaking involvement activities. (Governance) Public contributors are offered reimbursement
	(Communications, Inclusive Opportunities)	Ш	for expenses such as accommodation, travel,
	Objectives for public contributor's activity are negotiated and agreed with them. (Working Together)		subsistence, and where possible, these costs are paid for in advance. (Governance, Working Together)
	Different levels and types of involvement opportunities are available to encourage a spectrum of contributions/contributors. (Inclusive Opportunities, Working Together)		Public contributors are offered payment for time spent on involvement activities based on current tariffs which reflect the time commitment, experience, knowledge, and support required of the involved public.
	Access to study meetings/discussions is		(Governance)
	enabled for all public contributors including virtual attendance/platforms where physical	DI	Public contributors support
	attendance is not possible or appropriate. (Inclusive Opportunities, Working Together)		and training Public contributors are given a main point
BI	Public contributor recruitment		of contact for the study who will liaise with them and offer support as appropriate.
	All available means of public contributor		(Governance, Support & Learning)
	recruitment have been considered and utilised to enable the target population to apply. (Inclusive Opportunities)		See section 4 for public involvement coordination and documentation.
	Public contributors are recruited at the pre- funding stage. (Governance)		Public contributors are provided with and/or signposted to mentoring and training
	Public contributors act as co-applicant on the grant. (Governance, Working Together)		to support their involvement. (Support & Learning)
	Additional Public contributors are recruited when funding is awarded. (Inclusive Opportunities, Governance)		nd out about 'Enabling Involvement Fund' schemes which provide funds to support the development of early-stage public

The difference public contributors make to the research question and design

A | Informing research priorities

The research question is informed by a local/ national research prioritisation exercise involving public contributors. (Inclusive Opportunities)

B | Shaping the research question

A strategy to ensure that the extent and limitations of the research question are understood by public contributors has been devised.

(Communications, Support & Learning)

Public contributors are involved in the formulation of the research question to ensure relevant to the needs of the population of interest.

(Inclusive Opportunities, Working Together)

C | Research methods acceptability and accessibility

Public contributors are involved in the scoping of potential research methods to ensure they answer the research question and fully consider the patient context. (Inclusive Opportunities, Governance)

D | Defining the study outcomes and measures

Public contributors are involved in the development of the study outcomes. (Governance, Working Together)

Public contributors are consulted on and understand study outcome measures, and their relationship with the defined outcomes. (Communications, Working Together)

Public contributors are satisfied that outcomes and measures are appropriate to the research population. (Governance, Working Together)

The difference public contributors make to the conduct of research

Α	Eth	ical	consi	iderat	ions

the ethics panel meeting.

Public contributors are involved in identifying ethical considerations.
(Governance, Working Together)

Public contributors are invited to attend

B | Study participant recruitment

(Governance, Working Together)

Public contributors are involved in establishing study participant recruitment strategies to ensure it is carried out in an appropriate manner.

(Inclusive Opportunities, Governance)

C | Assessing the accuracy and accessibility of study information

Public contributors are invited to draft and/or review lay language sections/documents used in the study. (Working Together)

Public contributors assess all patient facing study information to confirm that it is comprehensive, easily understood, and accessible to participants in relevant formats. (Working Together, Governance)

D | Assessing participant burden

Public contributors are consulted to ensure that there is no prohibitive responsibility for study participants or those supporting them to participate. This burden could include financial costs or time costs.

(Governance, Working Together)

Public contributors are involved in reviewing participant assessments to consider whether it is sensible and appropriate, and that no excess data is collected. (Governance, Working Together)

E | Contribution to meetings

Public contributors are part of the governance groups and can contribute to governance, study management and project meetings. (Governance, Working Together)

Public involvement activity as outlined in sections 1 to 3 can be described in funding applications as proof of early public involvement in study design/bid preparation.











4 Public involvement coordination and documentation

A	Project team public involvement knowledge and role	CI	Capturing the impact of public involvement on the research
	There is a designated member of the study team who is the main point of contact for the involved public, who will liaise with them and offer signposting and support as appropriate. (Governance, Support & Learning, Working		A record of public contributions and their influence/impact on study decision-making is kept and updated as contributions occur. (Impact, Communications) The records are regularly reviewed, and
	Together) The project team is familiar with the UK Standards for Public Involvement in Research and the principles that underpin them. (Support & Learning, Governance) Project team training on public involvement is identified and undertaken if required. (Support & Learning)		ontributions shared with relevant parties so that study decisions are influenced in real times the project progresses. (Working Together, Communications, Impact Use the PIRIT Tracking Tool to support recording and reporting against the UK Standards for Public Involvement in Research
ВІ	Public involvement record keeping	DΙ	Ongoing researcher and public contributor meetings
	There is a dedicated folder within the electronic project file to document all public involvement activities. (Governance, Impact)		Meetings between the researcher(s) and the public contributors are scheduled and held throughout the project.
	The negotiated objectives for public contributors' activity are documented during study set up with timelines. (Working Together, Governance, Impact)		(Governance, Working Together) Meeting papers/discussion topics are circulated one week before a meeting. (Communications, Working Together)
	Public involvement activity throughout the project is recorded including emails and other pertinent communications. (Working Together, Governance, Impact)		Public contributors' activity is reviewed against the set objectives and timelines at agreed intervals. (Governance, Working Together, Impact)
	A means of recording public involvement reflections is available to the researchers and public contributors to record reflections or activities not captured by meeting minutes or	ΕĮ	Reflecting on public involvement activity during the research
	other recording mechanisms. (Working Together, Impact)		Reflection on public involvement approaches, processes, and practice are part of the regula meetings. (Impact, Support & Learning, Working Together)
			Learning from the reflections on the public involvement activity is shared to inform

processes, and practice. (Support & Learning,

Communications, Impact)

The difference public contributors make to the research outcomes and dissemination of results

AI	Contextual interpretation of data and findings
	Public contributors are involved in the process of interpreting the research results in the context of the study population. (Governance)
B	Dissemination strategy
	Public contributors help develop results dissemination strategies. (Governance, Communications)
	Public contributors play a role in disseminating the results. E.g. to relevant patient/interest groups and the public. (Communications, Working Together)
CI	Public involvement in academic outputs
	Public contributors are on the circulation list for results/report of findings to the research team. (Working Together, Communications)
	Public contributors write or contribute to sections of study papers/reports and are named co-authors. (Working Together, Governance)
	Public involvement activity is outlined in the main project paper. (Working Together, Governance)
	Public contributors are invited and costed to attend conferences to jointly present or lead on presentation of findings. (Working Together, Communications, Support & Learning)



- Public contributors are invited to use social media to disseminate results with informal training if required. (Support & Learning, Communications)
- Public contributors are invited to monitor social media for references to the study. (Working Together, Communications)











The difference public contributors make to the implementation of findings

A | Pathway to practice

Public contributors are involved in consideration of how the conclusions of the research will be embedded in professional practice, for example: Government policy, clinical guidelines, commissioning, and implementation.

(Governance, Working Together)

ВΙ	Assessing research impa	ect:
	patient groups and clinic	al sites

Public contributors are invited to liaise with specific patient groups and practice sites to monitor how study findings are received and acted upon.

(Working Together, Communications)

7 Public contributor debriefing

- A | Assessing the outcomes of planned public involvement activity and how public involvement has informed the project
- Public contributors are invited to meet to discuss their impact on the study. (Impact, Working Together, Governance)
- Public contributors are invited to meet to reflect on and discuss potential improvements to public involvement approaches, processes, and practice. (Working Together, Support & Learning, Governance)

Reporting the difference public involvement has made to the research and lessons learned

A | Reporting and promoting public involvement impact

- Public contributors are invited to draft a report of their involvement and its impact for inclusion in or to be the focus of a paper, poster, or presentation. (Working Together, Impact, Communications)
- Evidence of the difference public contributions have made to the research is included in all outputs relating to the study, e.g., papers, funder reports, impact cases, and Research Excellence Framework (REF) returns. (Impact, Communications, Working Together)
- Publicity specifically focused on sharing the impact of public involvement on the study is generated and promoted e.g., news articles, blogs, case studies, conference posters, presentations, and papers. (Communications, Impact, Working Together)

B | Public involvement learning and development

- Opportunities to share public involvement learning and good practice with colleagues and wider audiences are identified. (Working Together, Impact)
- Public contributors co-develop and co-deliver learning/good practice sessions. (Support & Learning, Working Together, Communications)











11 | PIRIT Planning Tool 12 | PIRIT Planning Tool

PIRIT Tracking Tool

1. Involvement Activity:

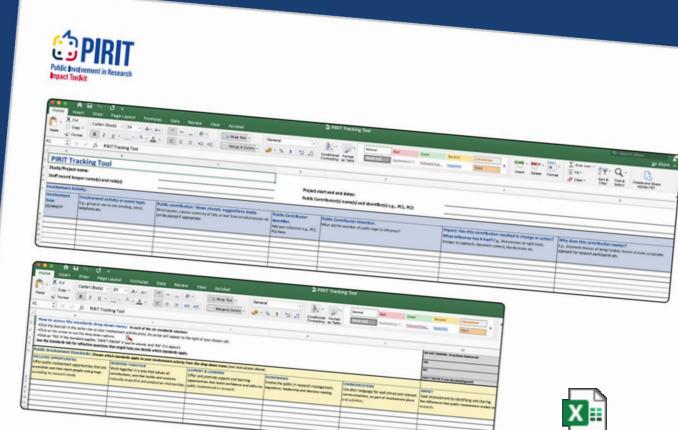
- When and how the public contributed
- What they hoped to influence
- What changed (if anything)
- Why it matters (so what?)

2. Involvement Standards:

Which standards the entry relates to

it's a spreadsheet:

















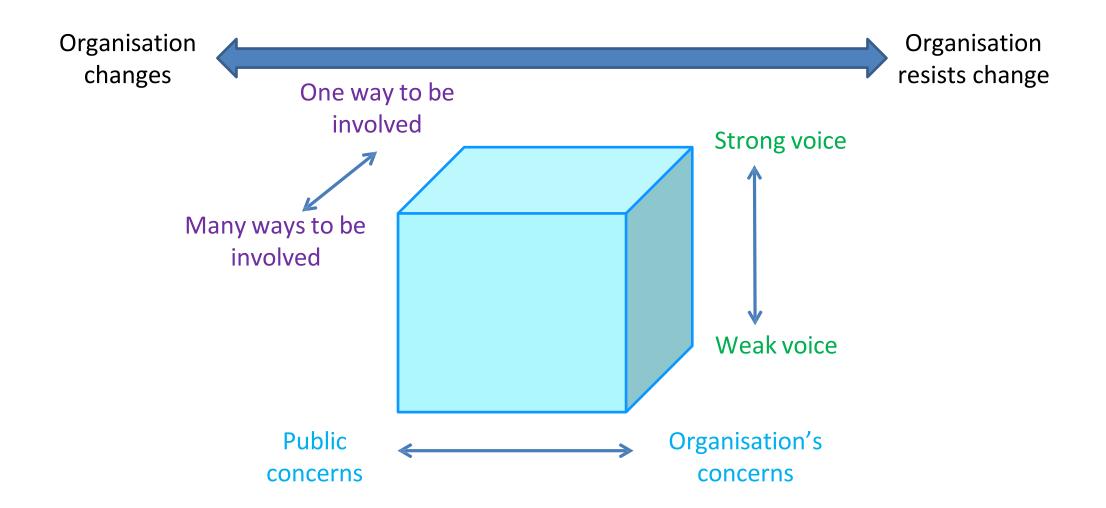
A participatory approach:

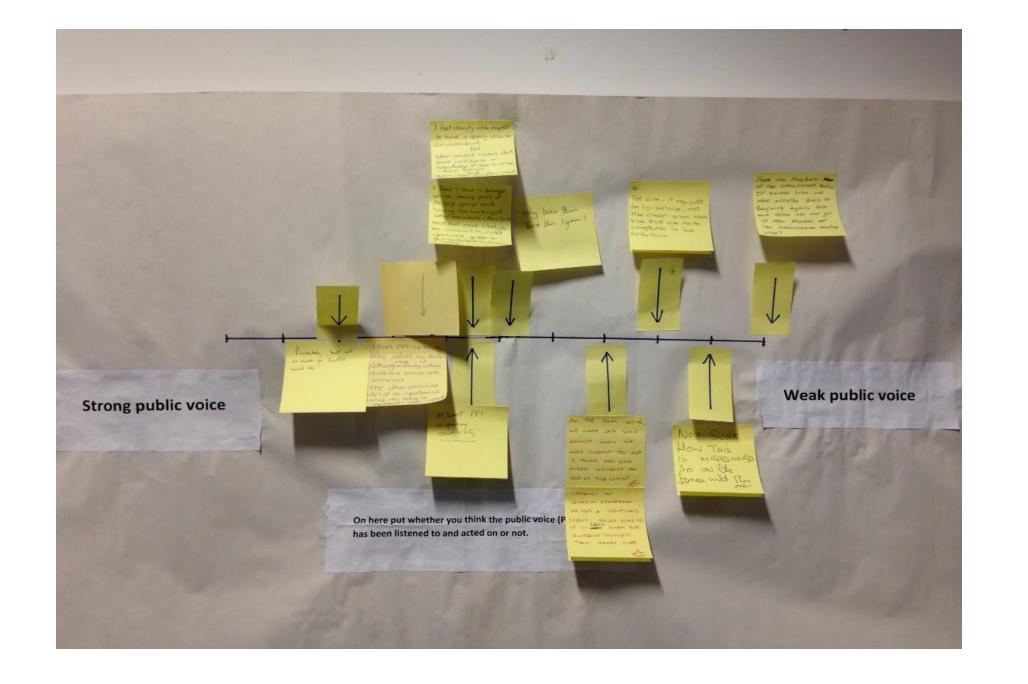
The Cube Evaluation Framework

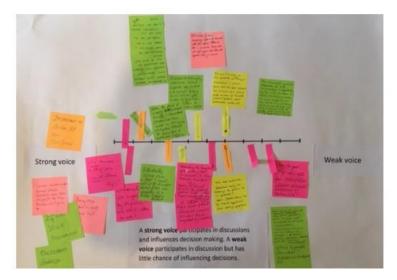
Public involvement as a knowledge space: where different forms of knowledge can interact on an equal basis



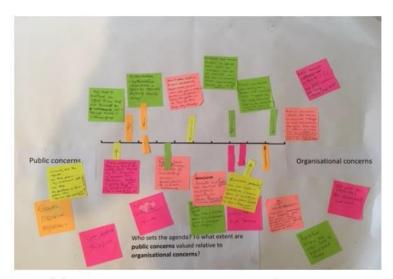
Cube framework for understanding involvement







Strong voice - Weak voice



Public concerns - Organisation's concerns

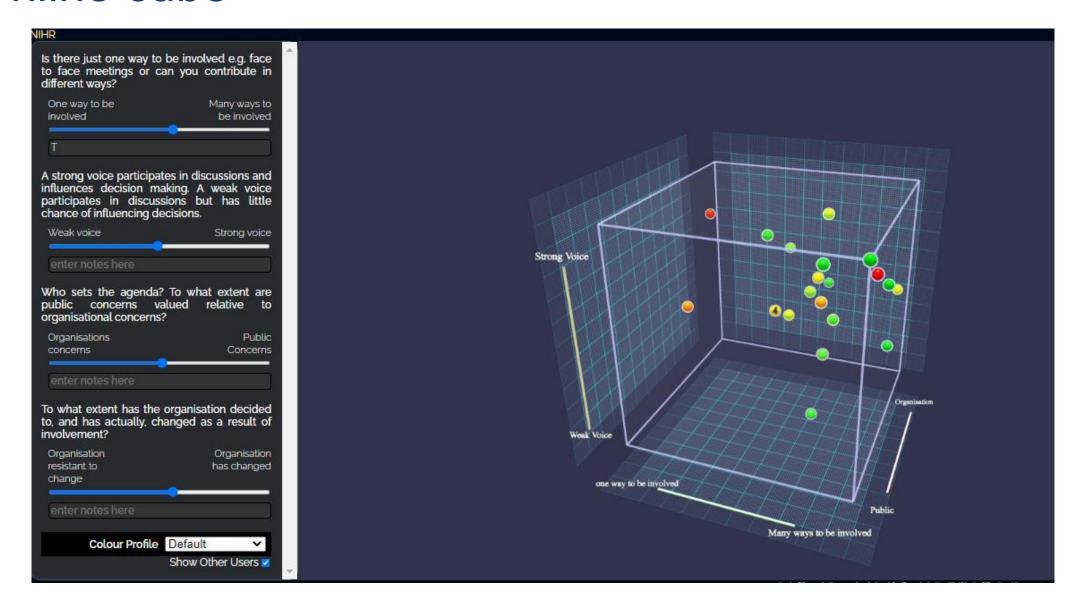


Many ways - One way to be involved



Organisation changes - Organisation resists change

Online cube













Bringing it all together



1. A comprehensive approach:

The Public Involvement Impact Assessment Framework (PiiAF)

• http://piiaf.org.uk/ OR PIIAF-Assessment-Framework-Measuring-PPI-Impact-2014.pdf

2. A pragmatic approach:

The Public Involvement Log.

• https://arc-w.nihr.ac.uk/patient-and-public-involvement/resources/patient-and-public-involvement-impact-log/

3. A UK Standards-linked approach:

The Public Involvement in Research Impact Toolkit (PIRIT)

• https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit

4. A participatory approach:

The Cube framework.

https://john.gundryconsultancy.com/the-online-cube-tool/











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Q&A Discussion













Thank you for taking part in this public involvement impact webinar.

Please share your feedback:



