



How to: The Practicalities of Patient and Public Involvement

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Session Outcomes

By the end of today, you will:

- Understand more about where patients, carers and the public can add value to your work
- Understand the theory behind patient involvement to help you develop your own involvement ideas
- Have some practical tips to draw upon in planning your own activities

What is Patient and Public Involvement and Engagement (PPIE)?

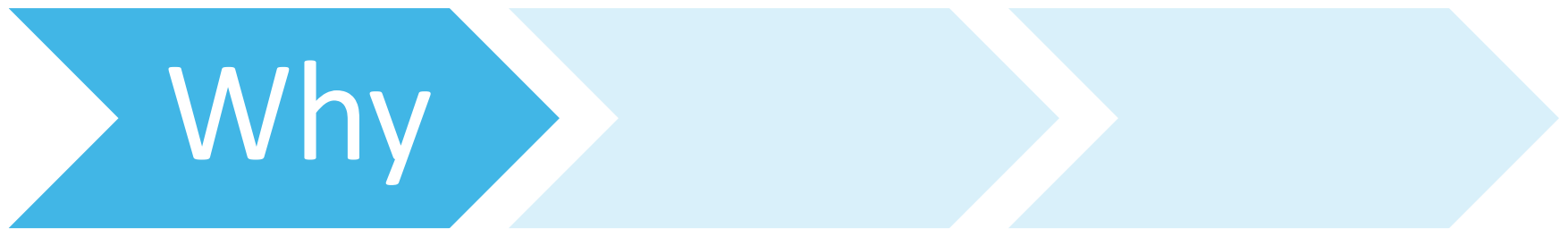
Patient and Public Involvement and Engagement (PPIE) describes the different ways patients, carers and the public can work with us on health and care projects and programmes to inform and shape outcomes.

PPIE enables patients, carers and the public to become protagonists in health and social care and acknowledges them as experts by experience.

Planning for Patient and Public Involvement and Engagement

There is no one-size that fits
all in PPIE

Three steps to excellent involvement:



Why: Your purpose

- The best involvement projects have a clear purpose behind them. Why are you doing this?
- Ask yourself:
 - How will involvement and engagement **add value to your work?**
 - What do **you** want to get out of this involvement?
 - What do you want **those you're working with** to get out of this?



Purpose

A diagram illustrating the process of converting a purpose into aims. A blue rounded rectangle labeled 'Purpose' is at the top, with a dark blue downward-pointing arrow leading to a green rounded rectangle labeled 'Aims' at the bottom.

Aims

Convert your purpose into
aims by being SMART:

SPECIFIC
MEASURABLE
ACHIEVABLE
REALISTIC
TIME-BOUND

Three steps to excellent involvement:





Don't cluster people together in one
'general' pool



Who: The people

People with lived experiences of conditions

Families and friends who have experiences of conditions

Formal and Informal Carers who have experiences of conditions

People at risk of certain conditions

Health and social care service users

People targeted by specific public health initiatives

Organisations representing service users

People who live in specific geographies

People who have certain characteristics

Who could you involve?

- Who is it you need in the room to meet the aims of your project?
 - Look back to your aims: these will guide you in identifying the people
- What *do you know* about these people? What do you *need to find out*?
- Where may these people be that you need to reach?

Where could you find people?

- Clinics/surgeries
- Community groups
- Healthwatch
- Local charities – Council for Voluntary Services
- National charities
- Patients In Research & NHS Get Involved websites
- Local authority Public Health teams
- Social media
- Via existing PPIE Teams/Lists

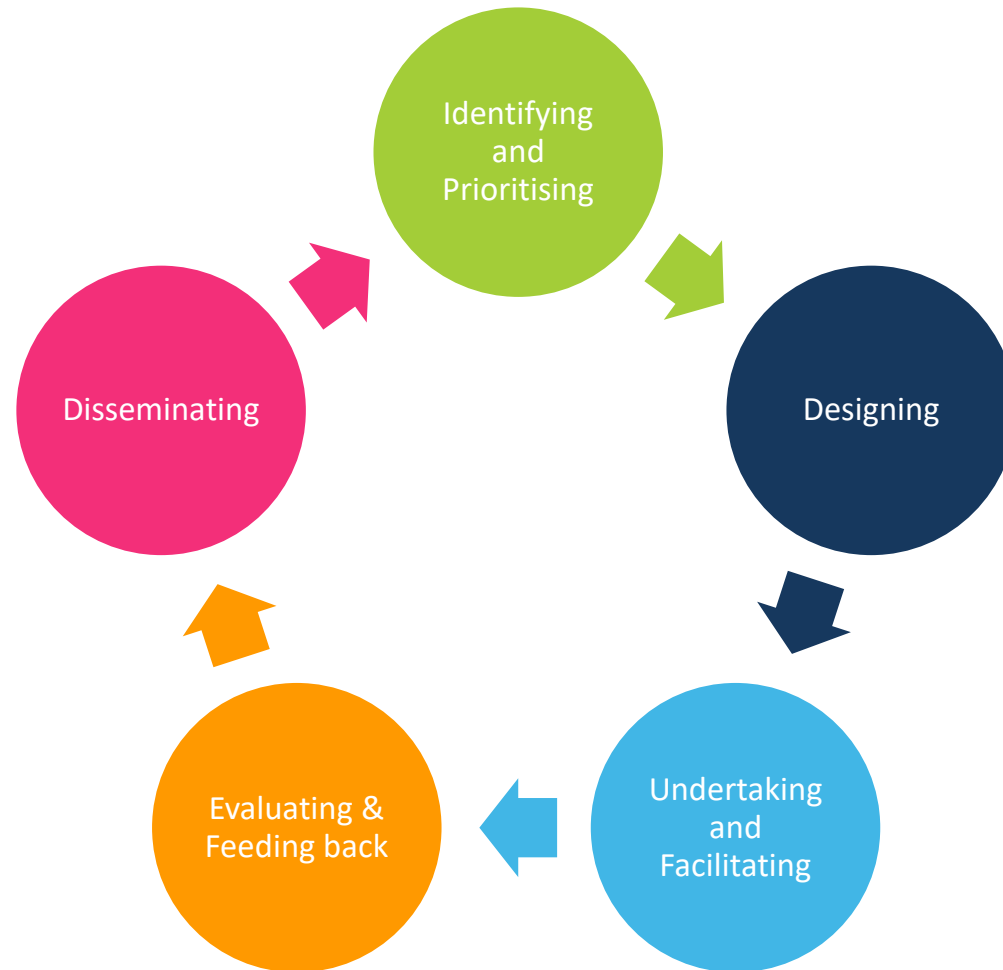
How do you get them on board?

- Have conversations and build relationships:
 - What are you doing? Why are you doing it? Why do you want them involved?
- Write advertisements:
 - **Who** are you looking for? **What** are you looking to do? **How** are you going to do this? **When and where** will this take place? **Will** people get reimbursed for their time? **Go here** to contact or further information.

Three steps to excellent involvement:



Where could there be opportunities?



Creating opportunities

- Patient involvement can take place at several parts of projects
- Look for places where there are opportunities for people to **shape and influence what is happening** as a result of their involvement
- You can involve people in multiple places or just once
 - Just remember to be proportionate to your aims and your resources

What PPIE opportunities could look like in teaching and education

Patients being involved in designing simulations

Patients co-delivering training courses

Patients becoming mentors

Patients facilitating or supporting feedback sessions

Writing articles and blogs about the work

Patients working with you to prioritise and develop curricular

Designing activities

- What sort of activities would support your aims?

Consulting

Asking for public feedback to inform decisions & shape outcomes

Involving

Working with publics to understand perspectives & consider outcomes together

Collaborating

Working in partnership throughout decision making & outcome generation

Co-creation

Working together collaboratively from the start in a democratic way that distributes power

Designing activities

- Think about the things you know about the people you want to work with:
 - What sort of activities might suit them?
 - What times, days, locations, durations?
- Is this going to be a one off activity or a long-term project?

Designing activities

- Don't know much about your audience? **ASK!**
 - Ask your peers if they've had any experiences
 - Ask community groups or charities that work with these groups
 - Ask the groups themselves what would work
 - Ask Patient and Public Involvement Colleagues

Barriers to Involvement

- What sorts of things could stop people from working with you?

Practical Things:

- Timings
- Locations
- Language

Systemic Things:

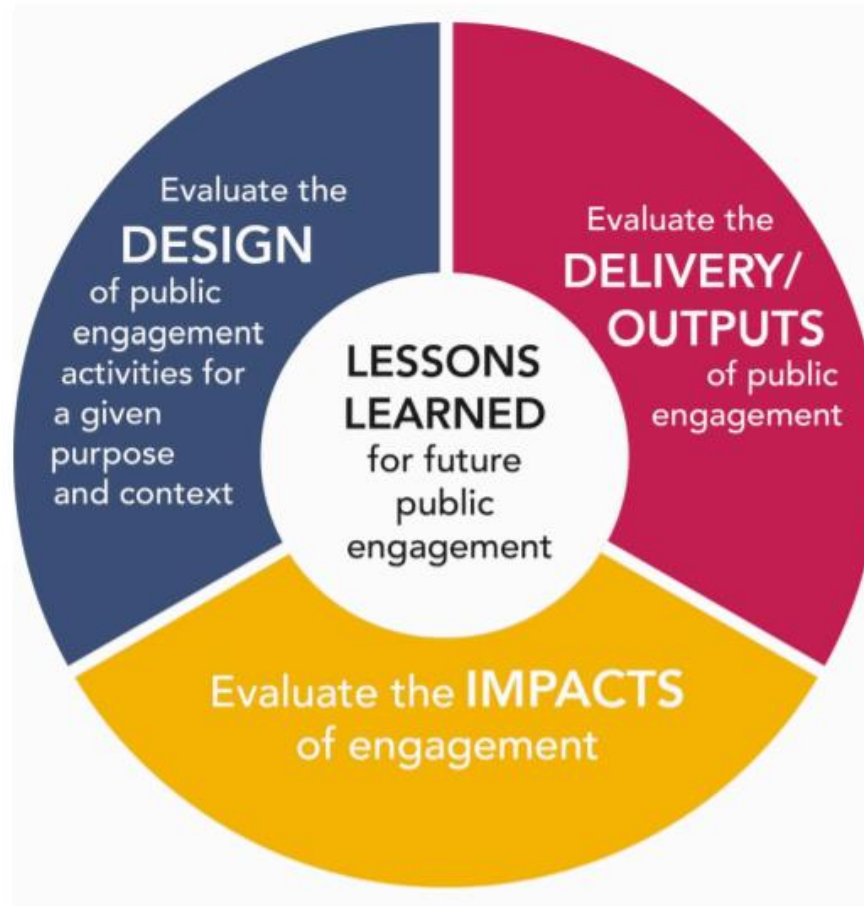
- Accessibility
- Access to equipment
- Power dynamics
- Costs

Minimising Barriers to Involvement

- What can you do differently to help overcome or minimise barriers?
 - Locations that are welcoming, familiar and accessible
 - Times and durations of activities that fit people's lives
 - Using clear, accessible, jargon-free language
 - Create non-hierarchical spaces where everyone can speak and is supported to share their views
 - Paying people for their time and expenses
 - Providing any equipment that is essential

Improving your Patient and Public Involvement and Engagement

Evaluation



Evaluation Process



‘You said... We did’

- It is important that as part of the evaluation and feedback process in your project you tell people about the impact of their work
- What did they tell you? What changed/happened because of that?
- Equally what couldn't be changed and why?

UK Standards for Patient and Public Involvement and Engagement

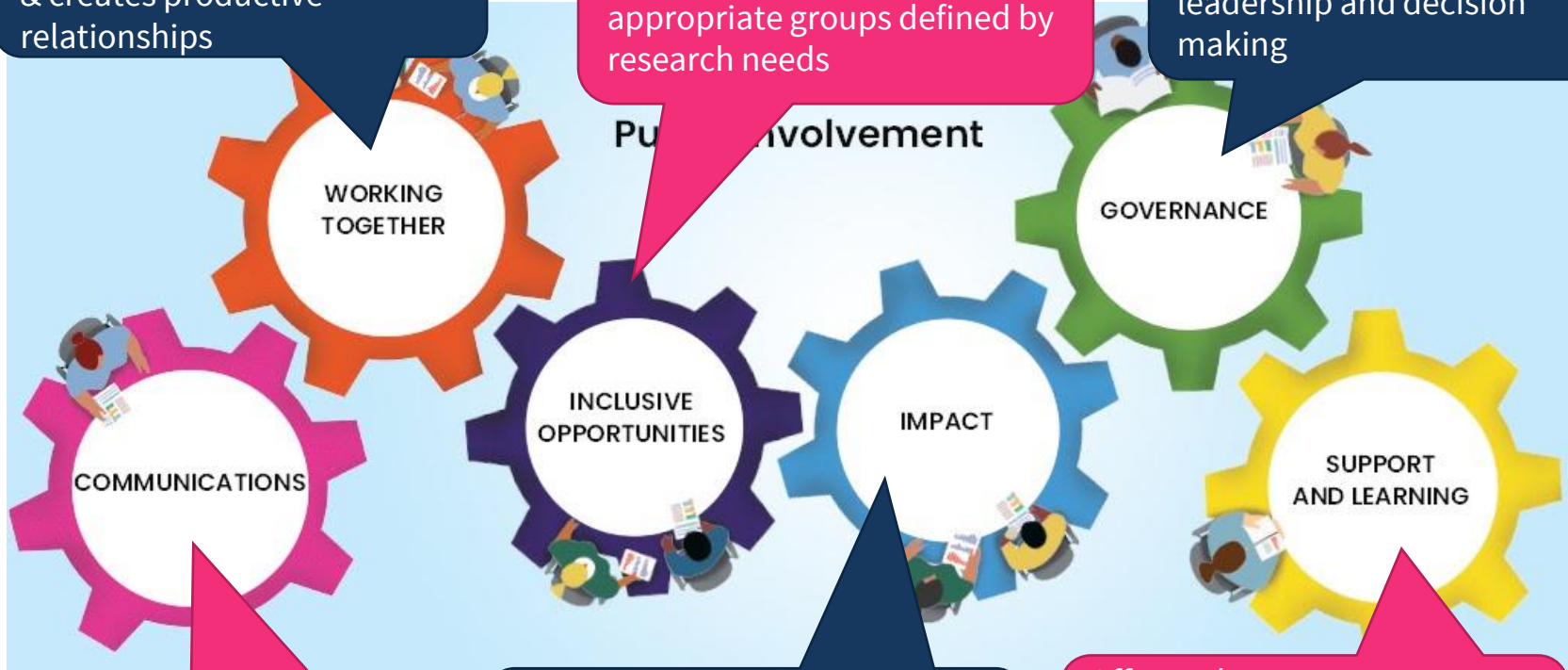
UK Standards For Public Involvement



Work in a way that values all contributions, builds respect & creates productive relationships

Opportunities should be accessible and reach appropriate groups defined by research needs

Involving the public in management, regulation, leadership and decision making



Use plain and accessible language for well-timed communications

Seek improvement by identifying and sharing the difference involvement makes to your work

Offer and promote support and learning opportunities that build skills for public involvement

Questions?

Further resources

- UK Standards for Public Involvement:
<https://sites.google.com/nihr.ac.uk/pi-standards/standards>
- National Co-ordinating Centre for Public Engagement:
<https://www.publicengagement.ac.uk/>
- NIHR's Centre for Engagement and Dissemination:
<https://www.nihr.ac.uk/health-and-care-professionals/engagement-and-participation-in-research/>
- The King's Fund:
<https://www.kingsfund.org.uk/topics/patient-involvement>
- NHS England Involvement Hub:
<https://www.england.nhs.uk/get-involved/>

Thank you

For more information please contact:

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