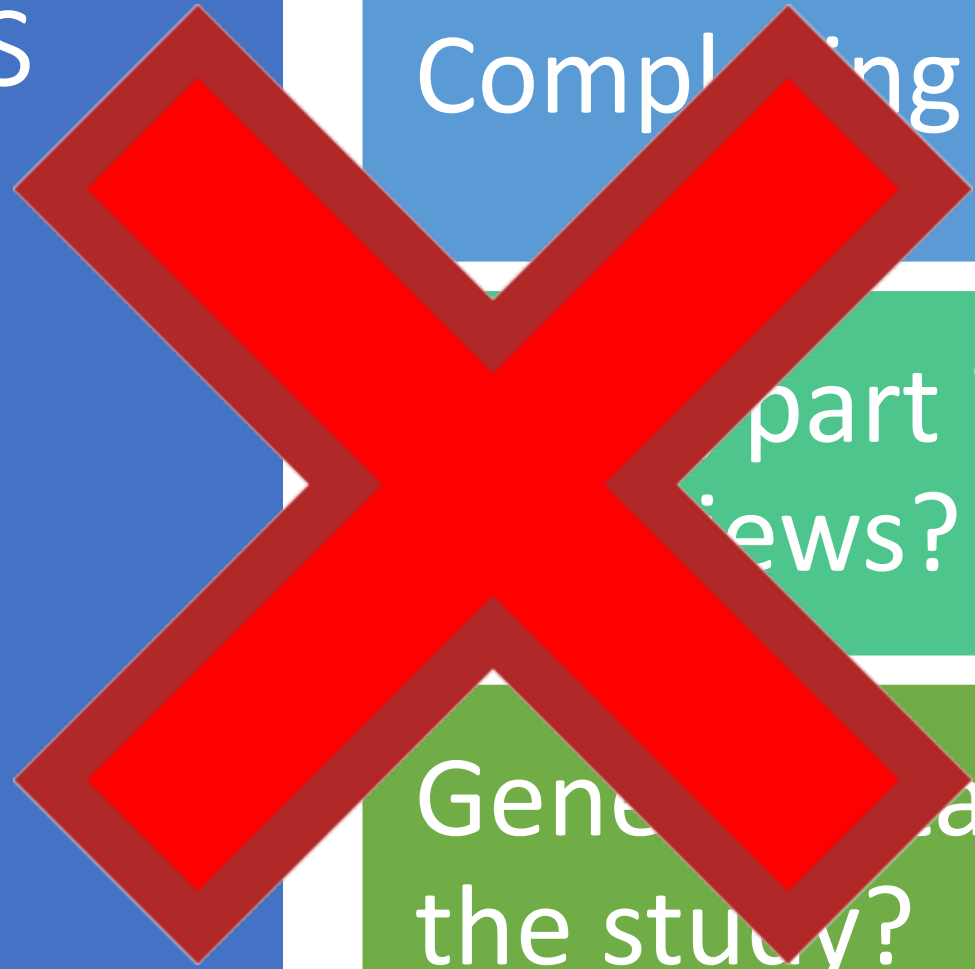




Involving People in Research

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What does
involving
people in
research
actually
mean?



Completing surveys?

part in
views?

Generally taking part in
the study?



Involving people in research is...

“Research that is done ‘with’ or ‘by’ the public not ‘to’, ‘about, or ‘for’ them.” – NHS Health Research Authority

Patient and Public Involvement (PPI)

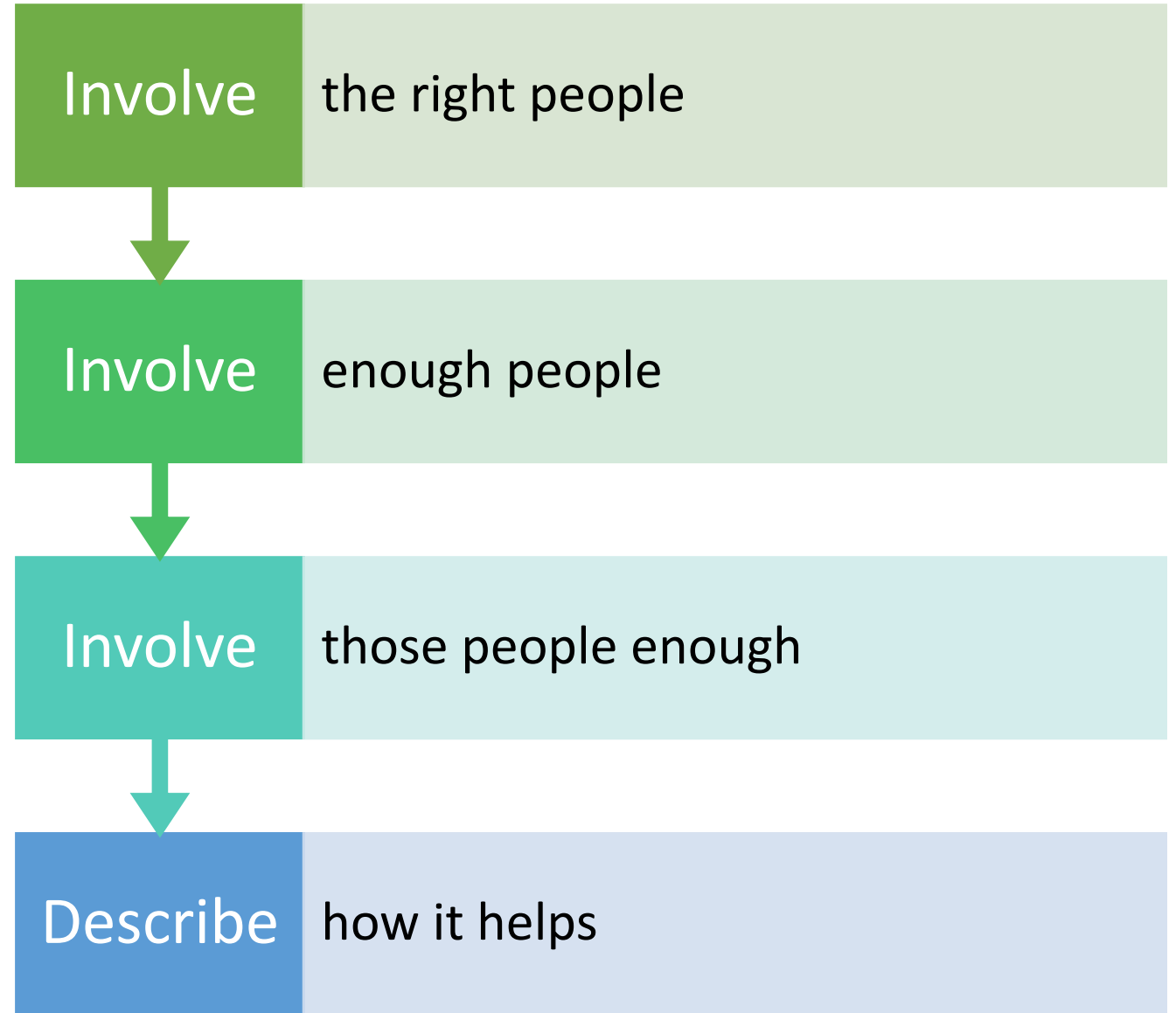
People with the relevant experience contribute to how the research is designed, conducted and disseminated



Involving people in research is...

- Engaging the target population/relevant people in every stage of your planning
- Consulting them on decisions, asking for feedback on questions/questionnaires
- Designing interventions
- Developing outcome measures
- Policy development
- Co-production and co-design

Four principles of meaningful involvement



1. Involve the right people

Who are the right people?

- People with the relevant lived experience of the health condition or situation being researched / the target population
- Often patients, service users, carers
- General public are also sometimes appropriate (lay reviewers)

2. Involve enough people

- The right number of people depends on the research and what the intended benefit is
- Should almost always be more than one person
- Diversity & Inclusivity is important to reflect backgrounds and experiences
- Think about how to involve people well, not everyone has to be involved in the same ways

3. Involve those people enough

- Good to involve the right people in as many elements of the research as possible, keeping it appropriate
- Involving them early on
- Incorporate involvement plans during the planning/proposal stage
- Consider communication before, during and after the research

4. Describe how it helps

Important to communicate *how* people can be involved and *why*

- Must be clearly stated when applying for NHS ethics
- Should detail:
 - Who you are involving & why their experience is relevant
 - How people are being involved
 - How their involvement is helping to make the study more likely to be relevant and acceptable to the target population
 - How you will communicate the study results to the people involved and target population

How?

Before the research begins

- Research questions & outcome measures
- Choosing methods, commenting on design
- Identifying barriers or potential stressors
- Recruitment processes
- Contributing to funding process
- Contributing to ethics
- Working on communication methods/plain English summaries

Example questions to ask
What questions should the research focus on?
Is the study design practical and feasible?
How can the plain English summary be improved?
What needs to be included in the PIS and does it make sense?

How?

During the research

- Research Advisory/Steering groups – C:Evolve, Tenovus
- Co-facilitating focus groups
- Being part of a focus group that informs the research design
- Providing feedback on behalf of a participant group e.g. patient representative
- Longitudinal research – providing feedback and iteration on materials and design throughout

How?

After the research has ended

- Contributing to how the study results are disseminated
- In some cases, actually disseminating the findings at conferences
- Contributing to any future research ideas as a result

Examples

Steering group – C:Evolve

Research Advisory Network – Tenovus

Delphi consensus method/Focus group consultation

Developing outcome measures [all stages]

Developing interventions [all stages]

Lay reviewers/Lay representative

Patient representative

Why?

Research that involves the right people is...

- More relevant to participants
- Designed to be acceptable to participants
- Participant information is understandable to participants
- Better experience of research, not just data
- More effective dissemination and communication

Why?

- Good PPI can produce higher quality research, more likely to be implemented, further funding etc.
- The research produced has been informed by people who are directly affected by the issue, strengthening its relevance to the target population
- More likely to recruit and retain participants
- The population you are researching like to know they are not just being researched for research purposes, taking the time to involve the right people is crucial
- Detailing how you will include the public/patients in your research has become a crucial part of funded research proposals and NHS ethics applications



Example of involvement

C:Evolve – Avatar based counselling platform for young people affected by cancer

- ✓ Designed for young people
- ✓ Designed BY young people
- ✓ Steering group was made up of academics, young persons representative, counsellors, software designers

What's missing?



What is missing?

Considering everything we have just gone over with PPI...

- × There were no young people affected by cancer on the steering group

Why?

- Ethics
- Accessibility

Consequences?

- No recruitment
- No gatekeepers/access



So who
makes the
rules?

There are multiple best practice guidelines and resources to help researchers involve patients and public in their research

Standards and Policies

- The UK Standards for Public Involvement in Research
- NICE Patient and Public Involvement Policy

The law

- Health and social organisations have a legal duty to involve and consult with service users, carers and the public when considering
 - Provision of care
 - Changes in care/decisions that affect the provision of care
- 

UK Standards For Public Involvement



1. Inclusive opportunities: offer public involvement opportunities that are accessible and that reach people and groups according to research needs
2. Working together: work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
3. Support and learning: offer and promote support and learning opportunities that build confidence and skills for public involvement in research
4. Governance: Involve the public in research management, regulation, leadership and decision making
5. Communications: use plain language for well-timed and relevant communications as part of involvement plans and activities
6. Impact: seek improvement by identifying and sharing the difference that public involvement makes to research

Ethical considerations and challenges

Vulnerable populations

Time commitments

Funding – expenses etc.

Accessing/gate keepers

Building relationships

Summary



Involving the right people in your research is crucial for ensuring it best serves the target population



Ultimately research that includes the target population at each stage will be a better quality, higher standard and more successful