

Involving Patients in Research - the What, Why, When and How?

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What is patient involvement in research?

Patients as collaborators = actively involved in the development, design, delivery and dissemination of research – **not** the subjects of research.



Why do it?

1. Patients have a right to be involved – “nothing about us, without us”.
2. It improves the quality of research by making it more relevant and useful to the people it intends to help.

The key question

W II FM?

What's in it for me?

How does it work?



Researchers learn from patients' experiential knowledge and this changes their thinking and their plans.

Staley, K. (2017) *Research for All*, 1 (1), 158–67.

What's wrong with this picture?



The statue of King Christian IX was missing...



What's wrong with this picture?



The Palace of the Argentine National Congress



What's wrong with this picture?



Quote from a researcher

“If I design and I make something as an engineer, then I would think there’s nothing wrong with it... But you can never account for all the intricacies that might actually happen when people go to use it. So there would be value in taking people who are from a very technical engineering background and broadening their horizons... to learn from patients and carers...”

Staley et al (2017) *Research Involvement and Engagement* 3:20

W II FM?

Involvement will:

- give you new ideas
- deepen your understanding of what matters to patients
- help you to identify and avoid problems you may not have anticipated
- give you confidence and motivation

A new idea for research

The social and economic impacts of carpal tunnel syndrome... an impact on employment.



Carter et al. (2012) Contemporary Social Science, 8:3, 307-320

What matters to patients



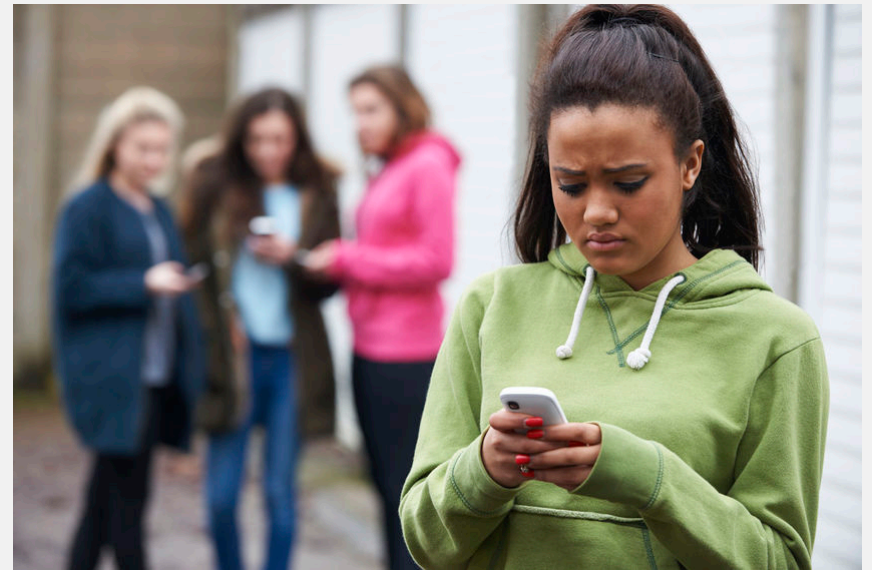
Spending time with the family...

Rose et al. (2011) *International Review of Psychiatry*, 23(1):41–6.

Spot problems and fix them

Text messaging to prevent self-harm – what works?

Owens et al. (2011) Health Expectations, 14(3):285-95



Who to involve?

People with the most relevant experiential knowledge.

People with diverse experiences.



When to do it?

At any and every stage of your research!

The earlier the better...

- Ready to listen
- Open to change
- Not attached to any particular idea



How to do it?



People talk and exchange ideas

Where do projects get discussed?

- Team meetings
- One-to-one meetings
- Departmental talks
- Tea room at work
- Conferences – posters, talks, in the lunch queue, at the bar...
- In the pub...



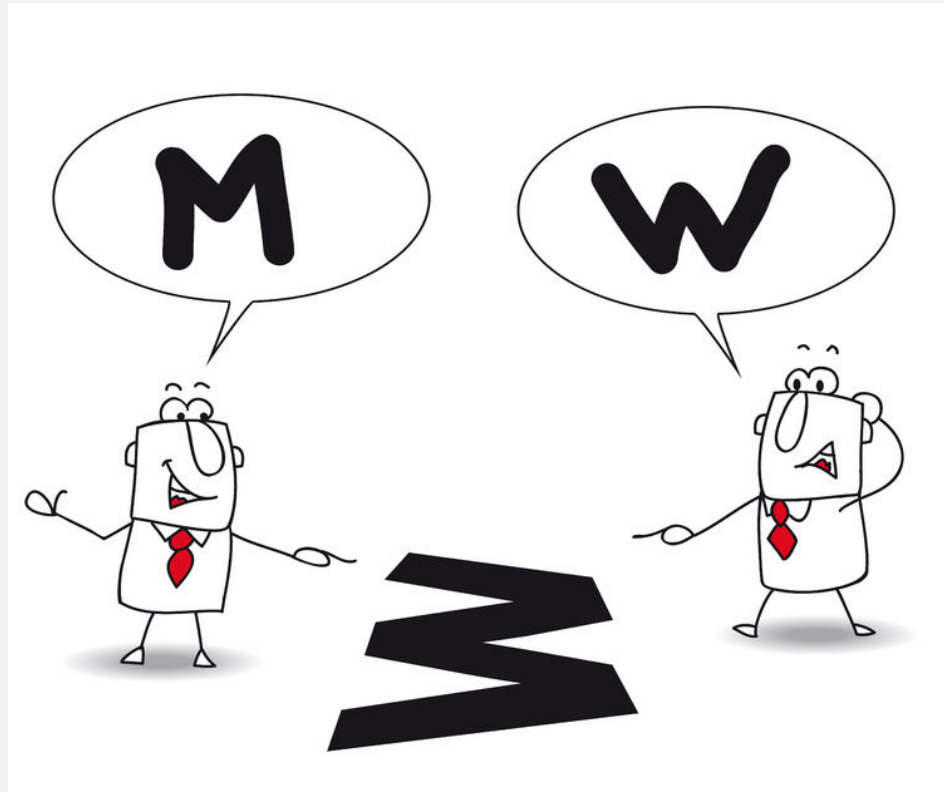
What made it work well?

- A safe, familiar space
- Researcher showed she valued their input
- Gave time for people to relax, gain trust, feel confident
- Showed she was listening and responding

**It's about the quality of the interaction –
not the method**

What can be challenging?

It can feel like conflict.



Dare to disagree

“It's a fantastic model of collaboration – working with thinking partners who aren't echo chambers. I wonder how many of us have, or dare to have, such collaborators... It requires that we find people who are very different from ourselves. That means we have to resist the natural drive to find people mostly like ourselves, and it means we have to seek out people with different backgrounds, with different ways of thinking and different experience, and find ways to engage with them. That requires a lot of patience and a lot of energy.”

Margaret Heffernan, TEDGlobal 2012

What can be challenging?

- you don't speak the same language or follow the same rules
- 'people are messy'

Facilitators – involvement leads



- Translation service
- Power broker
- Conflict resolution
- Leading the process
- Managing people

Where do I start?

- Read the guidance?
- Observe someone else
- Get training?
- Start small & do something simple



How will I know if it is having an impact?



If you are learning, gaining new insights, changing your ideas and plans – then it's working.

Staley (2015), Research Involvement and Engagement, 1:6

W I I FM?

“Working with patients has been some of the most intellectually stimulating work I have ever done...”

Professor Dame Til Wykes, Professor of Clinical Psychology and Rehabilitation at King's College, London

