

Embedding patient
voices at the heart of
healthcare systems and values

Marie Ennis-O'Connor

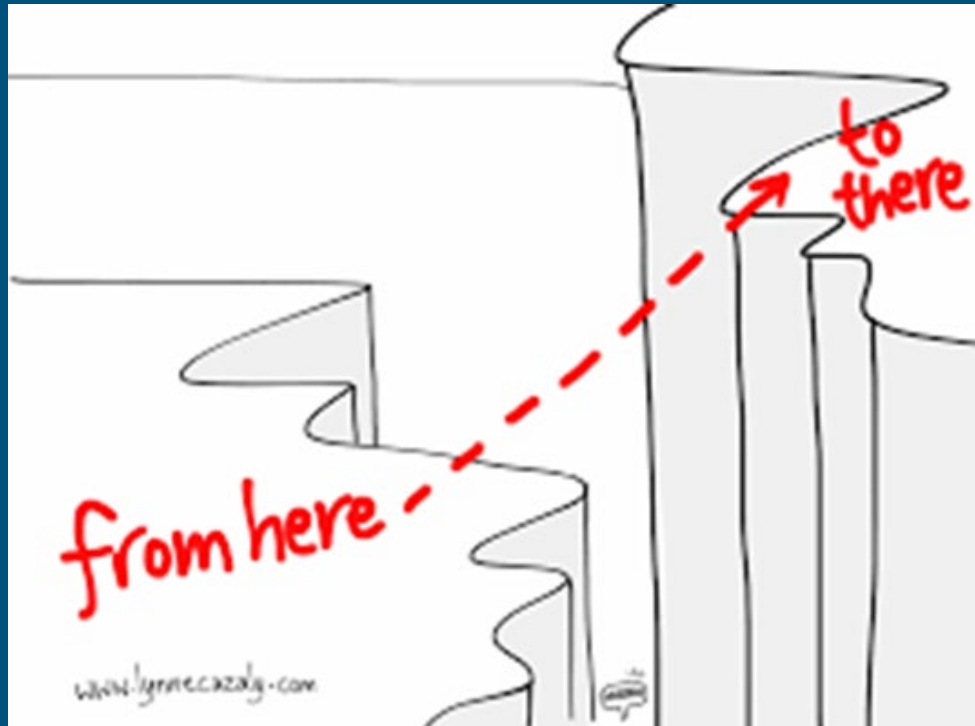


A little bit about me

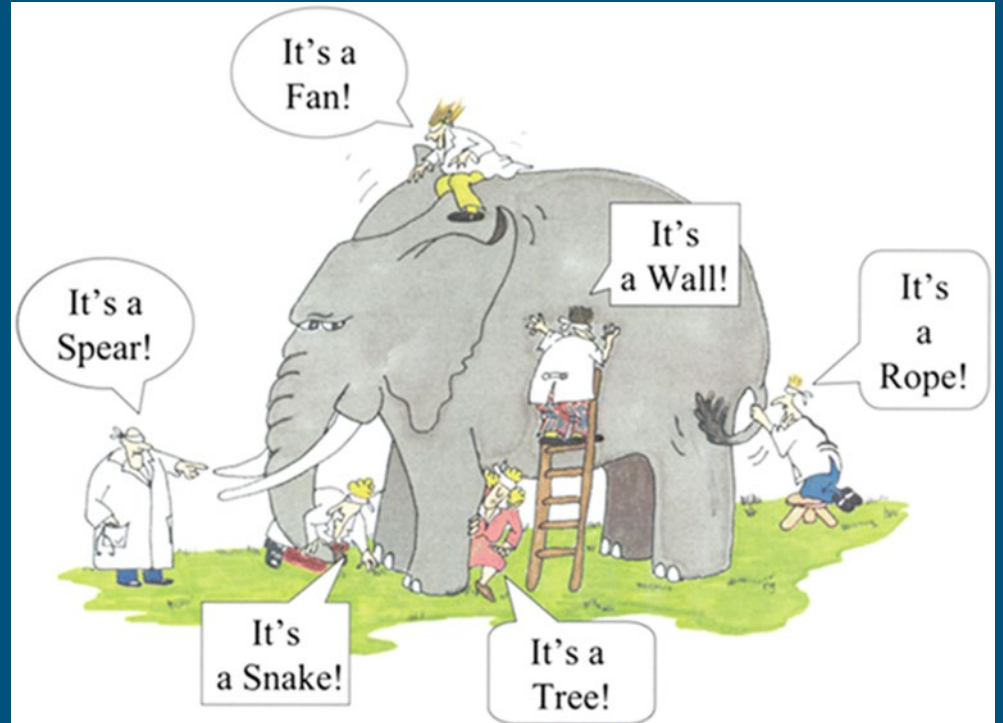
An accidental tourist finds her way through cancer land.



Are we there yet?



The PPI elephant in the room



6 Questions to frame our discussion

1. What is PPI?
2. Why do patients engage with PPI?
3. What is the value of PPI?
4. Who do you plan to include?
5. How do you plan to include them?
6. What constitutes meaningful engagement?

1. What is PPI?

PPI occurs when individuals *meaningfully* and *actively collaborate* in the governance, priority setting, and conduct of research, as well as in summarising, distributing, sharing, and applying its resulting knowledge.

- HRB definition

PPI is a democratic right

“The people have the **rights** and **duty** to participate individually and collectively in the planning and implementation of their health care”

- *WHO Declaration of Alma Ata 1978*

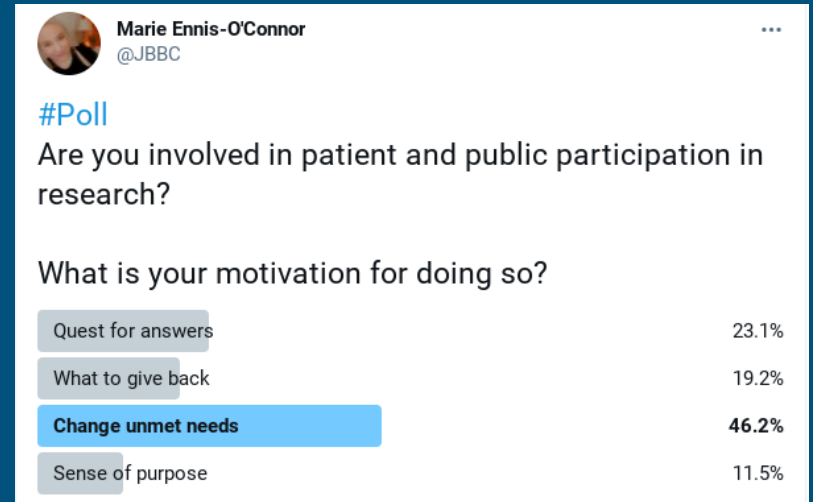


To-For-With



2. Why do patients engage with PPI?

- Quest for answers
- Want to give back
- Want to change unmet need
- Sense of purpose



A brick in the wall



“It’s the knowledge and the feeling that you're going to help somebody somewhere, maybe in the future, but at least you're putting, as a friend tells me, a brick in the wall.”

- Anne

From knowledge gaps to care gaps



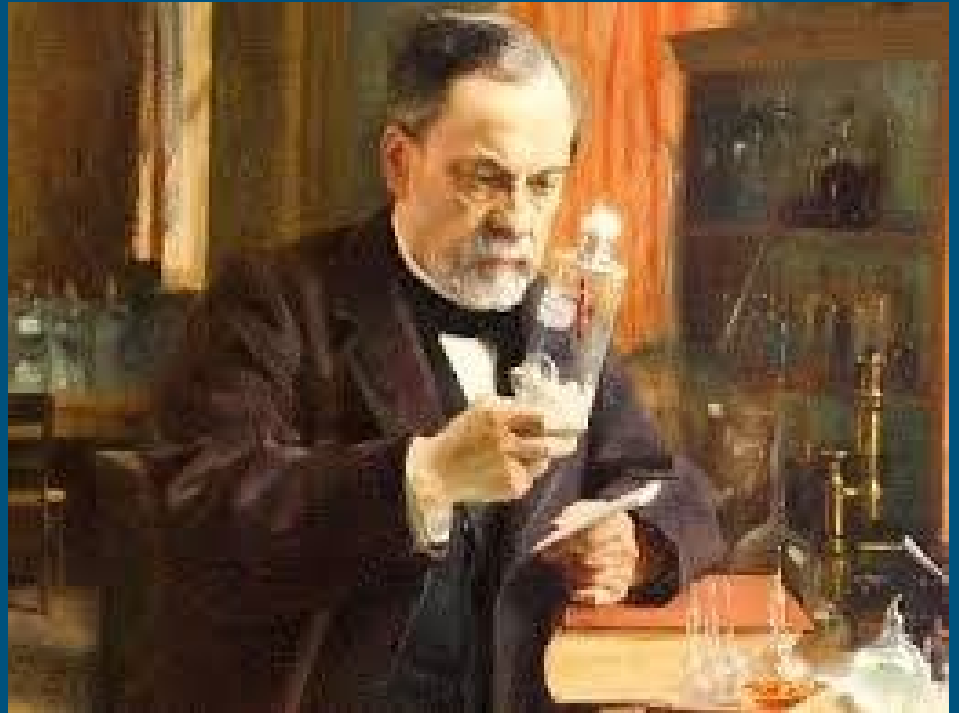
3. What is the value of PPI?

- Broadens the **research agenda** beyond that set by health professionals and researchers.
- Better **alignment of research** objectives through priority-setting activities.
- Better insight into **research gaps**.
- Better **quality research**- more relevant and responsive to patient needs.

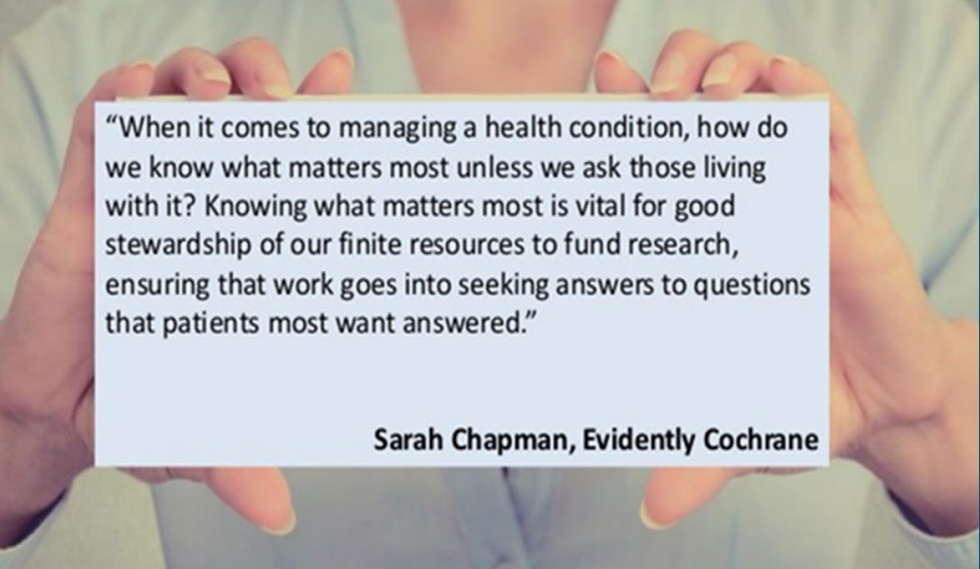
True value lies in impact

“To him who devotes his life to science, nothing can give more happiness than increasing the number of discoveries, but his cup of joy is full when the results of his studies immediately find practical applications.”

Louis Pasteur



Who knows better than the patient?

A photograph showing a person's hands holding a white rectangular card. The card contains a quote in black text. The background is a soft-focus image of a person's torso and arms, suggesting a clinical or professional setting.

“When it comes to managing a health condition, how do we know what matters most unless we ask those living with it? Knowing what matters most is vital for good stewardship of our finite resources to fund research, ensuring that work goes into seeking answers to questions that patients most want answered.”

Sarah Chapman, Evidently Cochrane

Valuing experience-based knowledge

Experts by experience

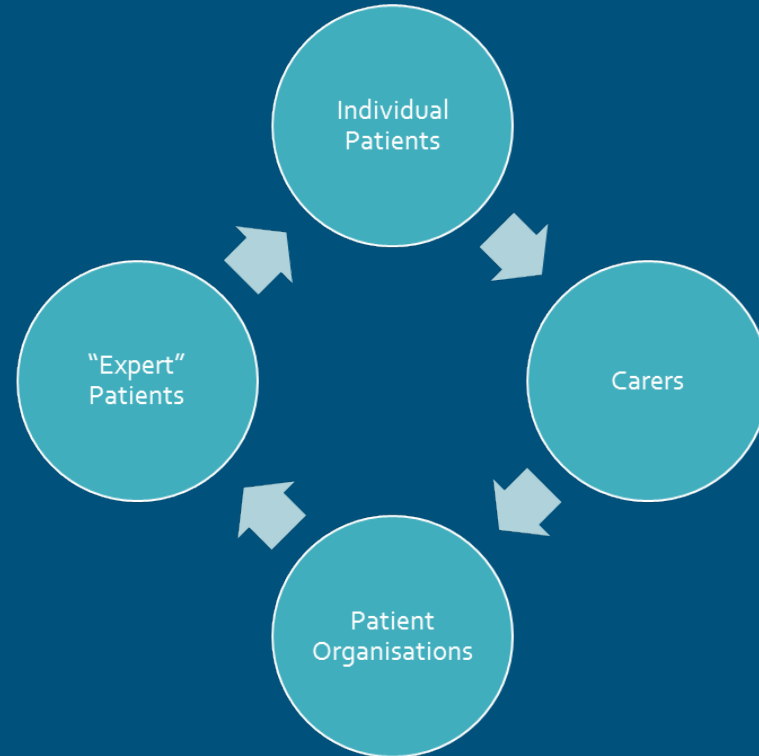
- Patients and carers gain **experiential knowledge** and **expertise** through their direct experience of living with, or caring for someone with a health condition.



If you want to know how well a pair of shoes fit, do you ask the maker, or the wearer?

4. Who should be involved?

Are you clear on who needs to be involved?



Who else needs to be involved?

 **Beccy White**
@BeccyBeccyWhite [Follow](#)

Feeling inspired after today's @NIHRINVOLVE public involvement event.

"Maybe we should be asking 'how to involve researchers in communities?' rather than 'how to involve communities in research?'"

[#InclusiveResearch](#)



“Nobody is hard to reach, if you bother to go and do it!”

Carol Munt, Patient Partner and Advocate with the NHS

Social media outreach



Jo Hutchinson
@JoJoCrads

Trying to narrow down my research question for MSc psychology and interested in women's experience of mammograms at 5 years post treatment for breast cancer. What are the issues for you? [#scanxiety](#) [#mammogram](#) [#breastcancer](#) [#screening](#) grateful for any retweet for max input.

4:42 PM - 13 Mar 2019

37 Retweets 20 Likes

18 37 20

This screenshot shows a tweet from Jo Hutchinson (@JoJoCrads) dated 13 Mar 2019 at 4:42 PM. The tweet discusses her research question for an MSc in psychology, focusing on the experience of women 5 years after breast cancer treatment regarding mammograms. She uses hashtags #scanxiety, #mammogram, #breastcancer, and #screening. The tweet has received 37 retweets and 20 likes. The interface includes a 'Follow' button and icons for replies, retweets, likes, and direct messages.



Cliona de Bhailís
@ClionadeBhailis

I'm looking for young people with disabilities to join the Advisory Committee for my PhD research. Are you aged 15 - 20 and interested in disability, human rights, research or decision making or do you know someone who is? Get in touch!

This screenshot shows a tweet from Cliona de Bhailís (@ClionadeBhailis). She is seeking young people with disabilities (aged 15-20) to join an advisory committee for her PhD research. The topics of interest include disability, human rights, research, and decision-making. The tweet includes a 'Follow' button.



Claire K @Dr_ClaireK · Mar 15

Calling on any patient representatives who are interested in reviewing our @IrishCancerSoc research grants! Here is how you can get involved!



Become a Patient Panelist

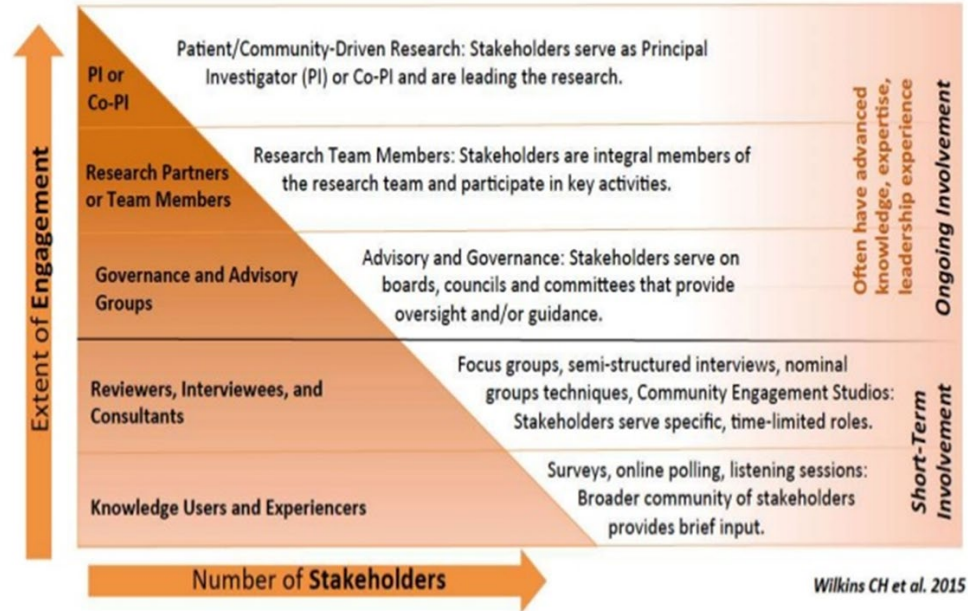


This screenshot shows a tweet from Claire K (@Dr_ClaireK) dated Mar 15. She is calling on patient representatives to review research grants from the Irish Cancer Society. The tweet includes a graphic with the text 'Become a Patient Panelist' and the Irish Cancer Society logo. The graphic features a group of diverse people of various ages and ethnicities.

5. How will you include patients?

PPI exists on a **continuum of participation** ranging from limited participation to a state of collaborative partnership.

The Continuum of Community (Stakeholder) Engagement in Research



Some further considerations

- Where will meetings be held? Are there accessibility issues?
- How will you support PPI partners to participate?
- What is the time commitment expected?
- What preparatory work will be required to carry out in advance of meetings (e.g. reading?)
- How will you onboard patients?
- How do you plan to reimburse PPI participants?
- Will you be including PPI research team members as authors on publications from the project?
- How do you plan to share the outcomes and outputs of the research with people who took part?
- Do you have an 'Open Access' publishing policy?

We need to do better



Lynn Laidlaw #BlackLivesMatter

@lynn_laidlaw



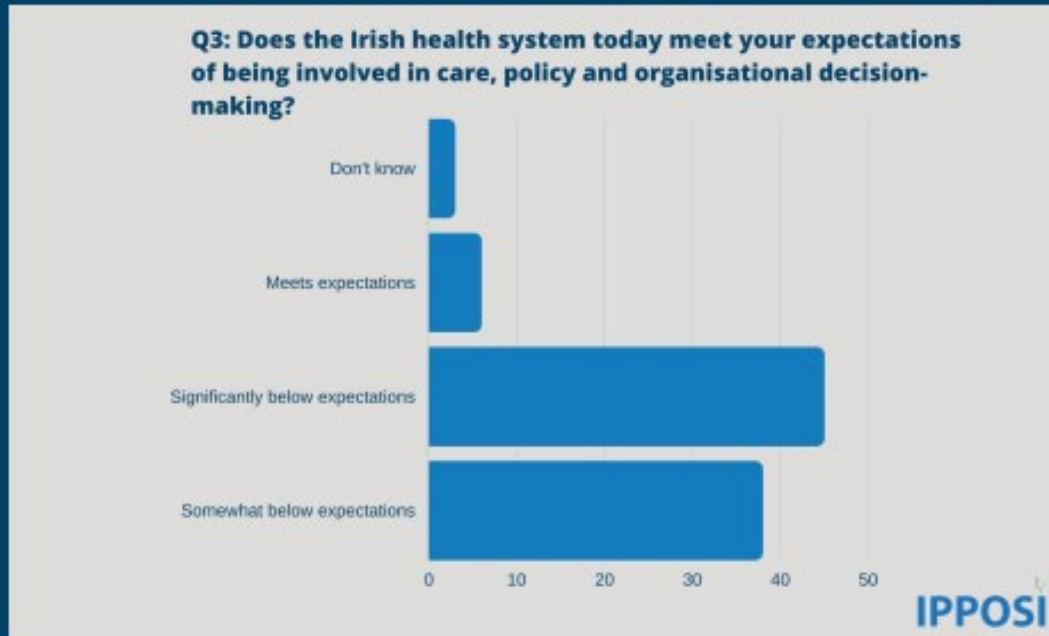
A fantastic study led by patients but someone had to send me a copy as it's paywalled. The people involved had no funding for their time or open access fees. We need to do better.

onlinelibrary.wiley.com/doi/abs/10.1111...

@VBlush @BDevlin1 @SarahSquire73

@NIHRinvolvement

6. What constitutes meaningful involvement?



49%

Almost half of respondents 49% described PPI involvement activity as significantly below their expectations

From tokenism to meaningful involvement

Tokenism

The practice of making only a perfunctory or symbolic effort to do a particular thing.

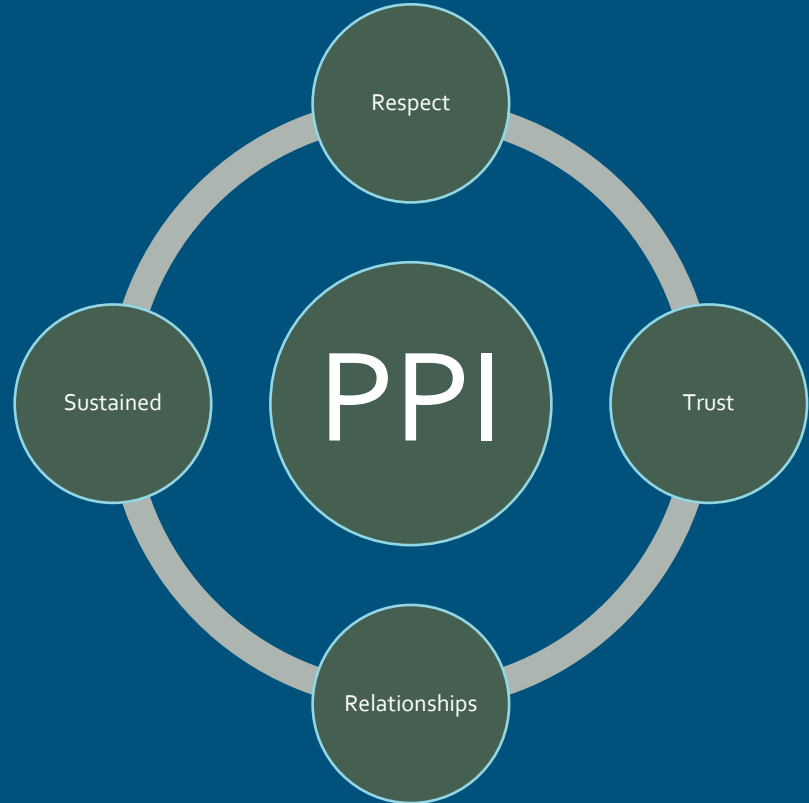




Image source: National Occupational Standards UK