

Public and patient involvement in primary care research: establishing and maintaining public partners

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Today...

Definitions:
Are we all on
the same
page?

Case study

Why PPI?

Avoiding
tokenism



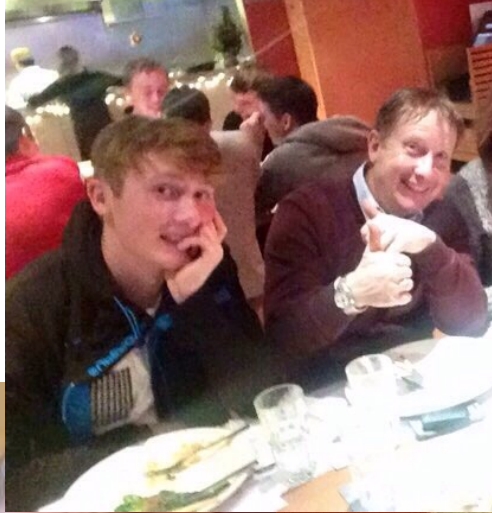
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Let's listen to the public, patient: what matters? What will work? Communicate clearly



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Researchers....



Survey



Cochrane Database of Systematic Reviews

Palliative care interventions in advanced dementia (Review)

Volume 27, Issue 5 May 2015, pp. 847-856

Cited by 4
Access

Longitudinal costs of caring for people with Alzheimer's disease

Paddy Gillespie (a1) (a2), Eamon O'Shea (a1) (a2), John Cullinan (a1), Jacqui Buchanan (a3) ...
<https://doi.org/10.1017/S10416102140002062> Published online: 22 September 2014



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What is public and patient involvement?

Research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them.

“Nothing about us, without us”

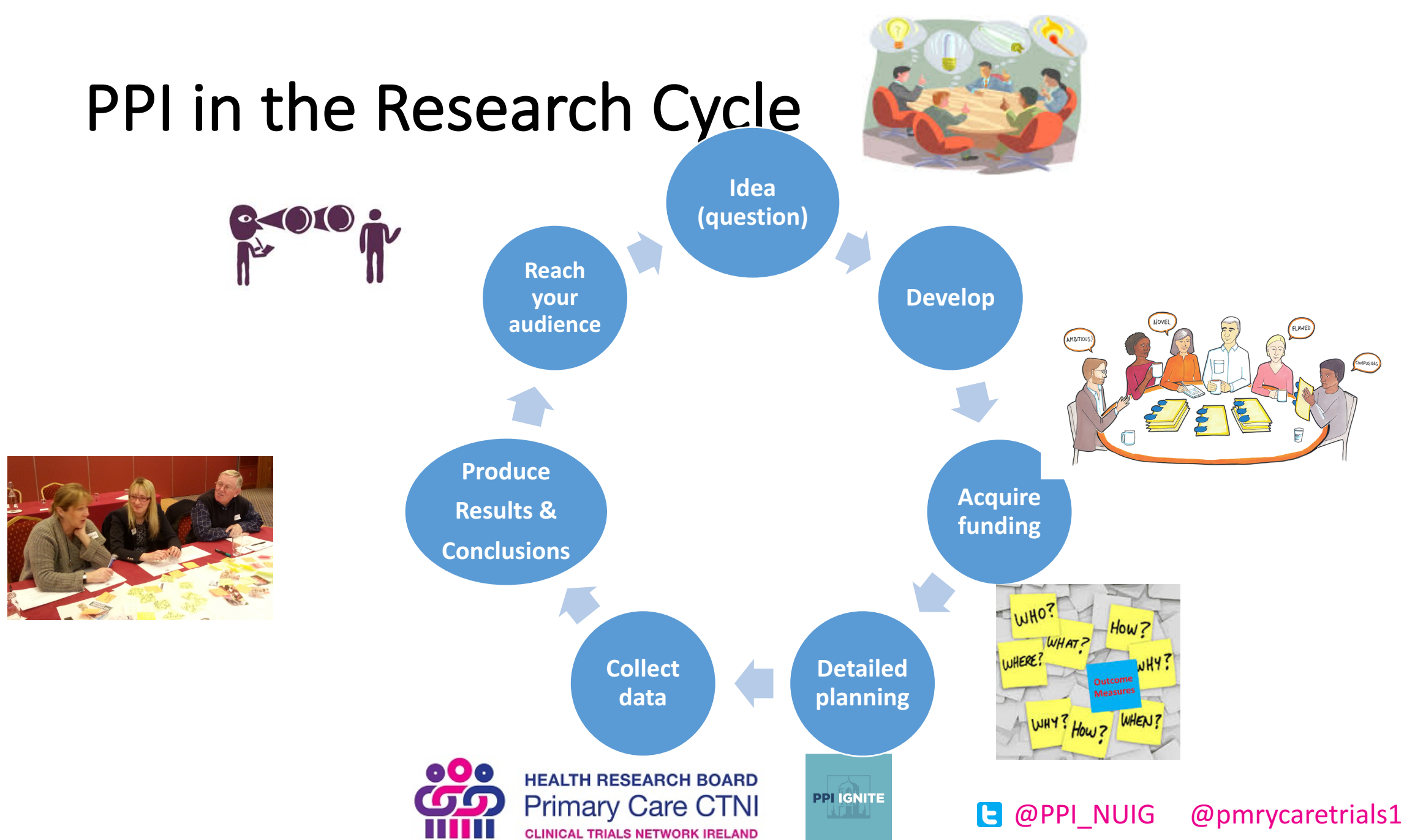
Involve Organisation UK

www.invo.org.uk

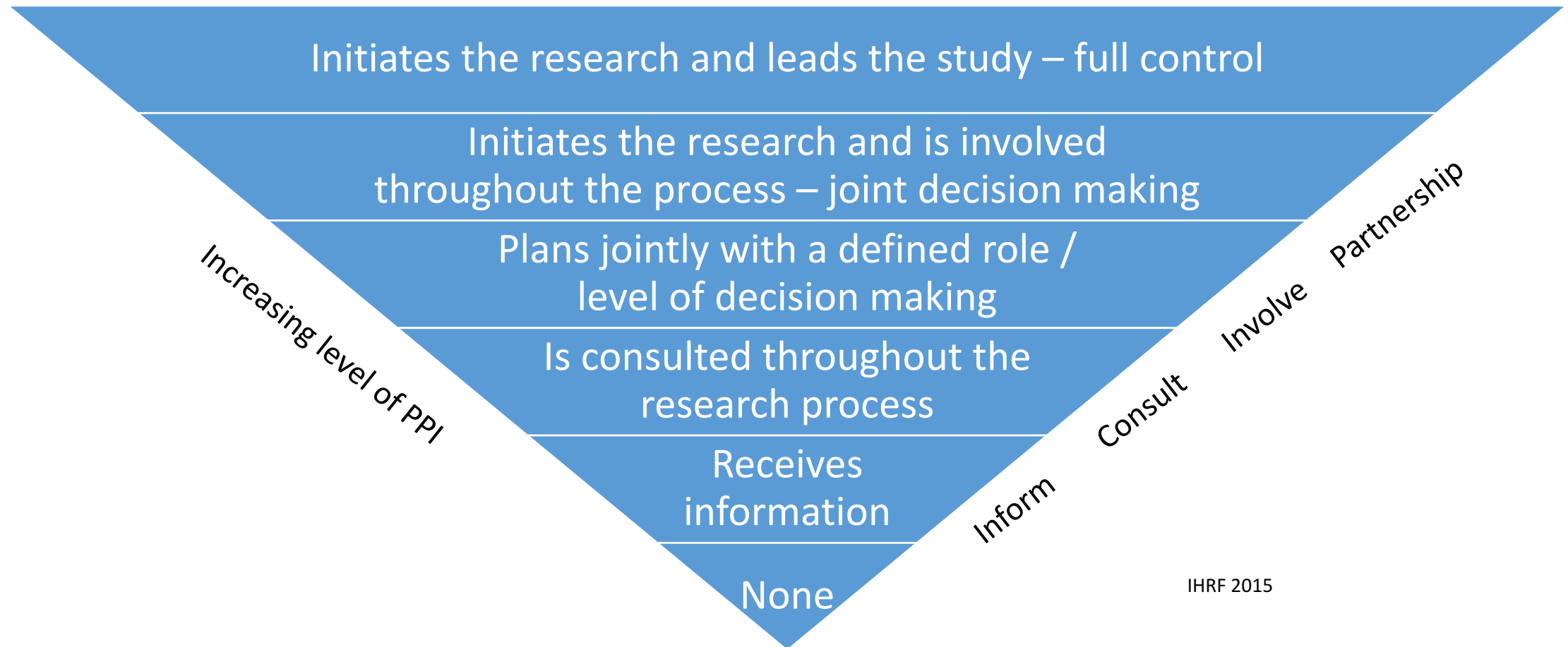
“that people who are likely to be using new treatments are directly involved in, and shape, the decisions made to produce the new treatments”

Trish O'Donovan, PPI contributor,
Primary Care, NUI Galway

PPI in the Research Cycle



PPI spectrum of involvement



IHRF 2015



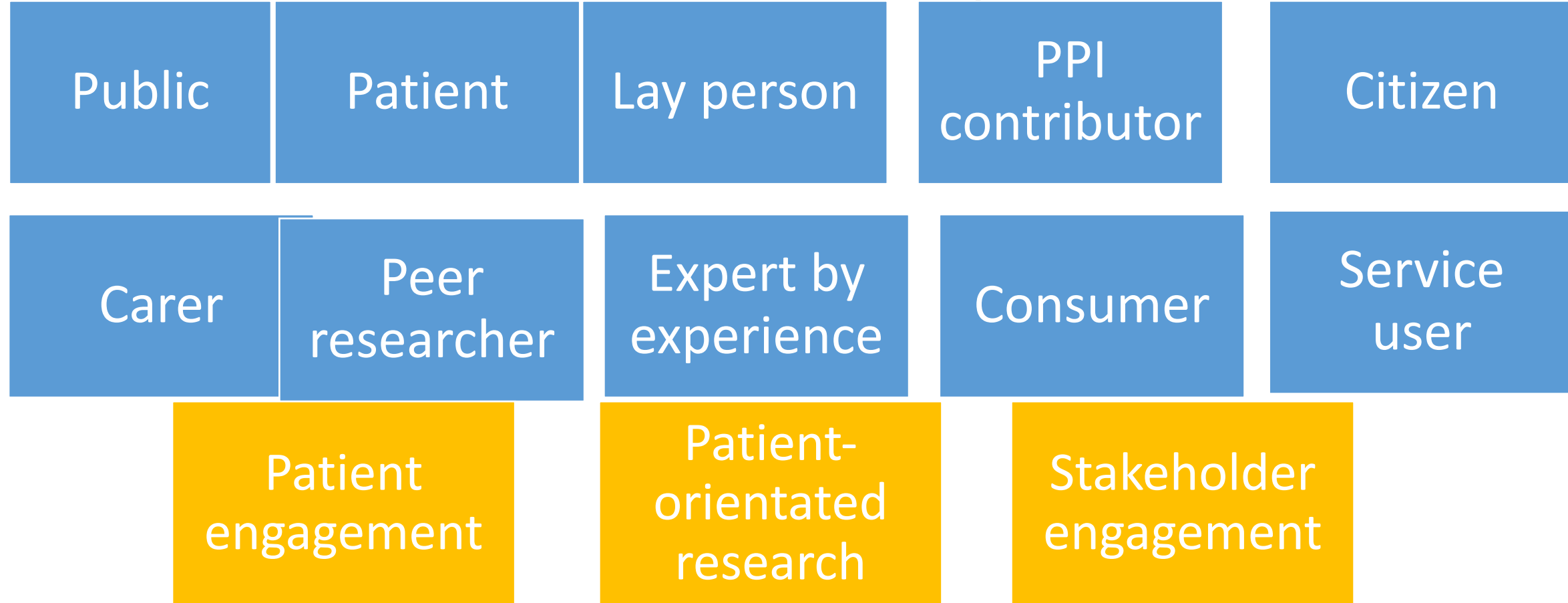
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Who do we mean when we say PUBLIC?



PPI or not?



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Are these PPI activities or not?

- Recruiting study participants
- Disseminating your research to stakeholders
- Peer review of funding applications by patient/public representatives
- Qualitative interviews or focus groups carried out by 'academic' researchers cf Doria et al Res Involv Engagem. 2018; 4: 19)
- Peer interviewing by PPI contributors
- Usability testing for a new device
- Having a PPI contributor as a co-applicant on a funding application

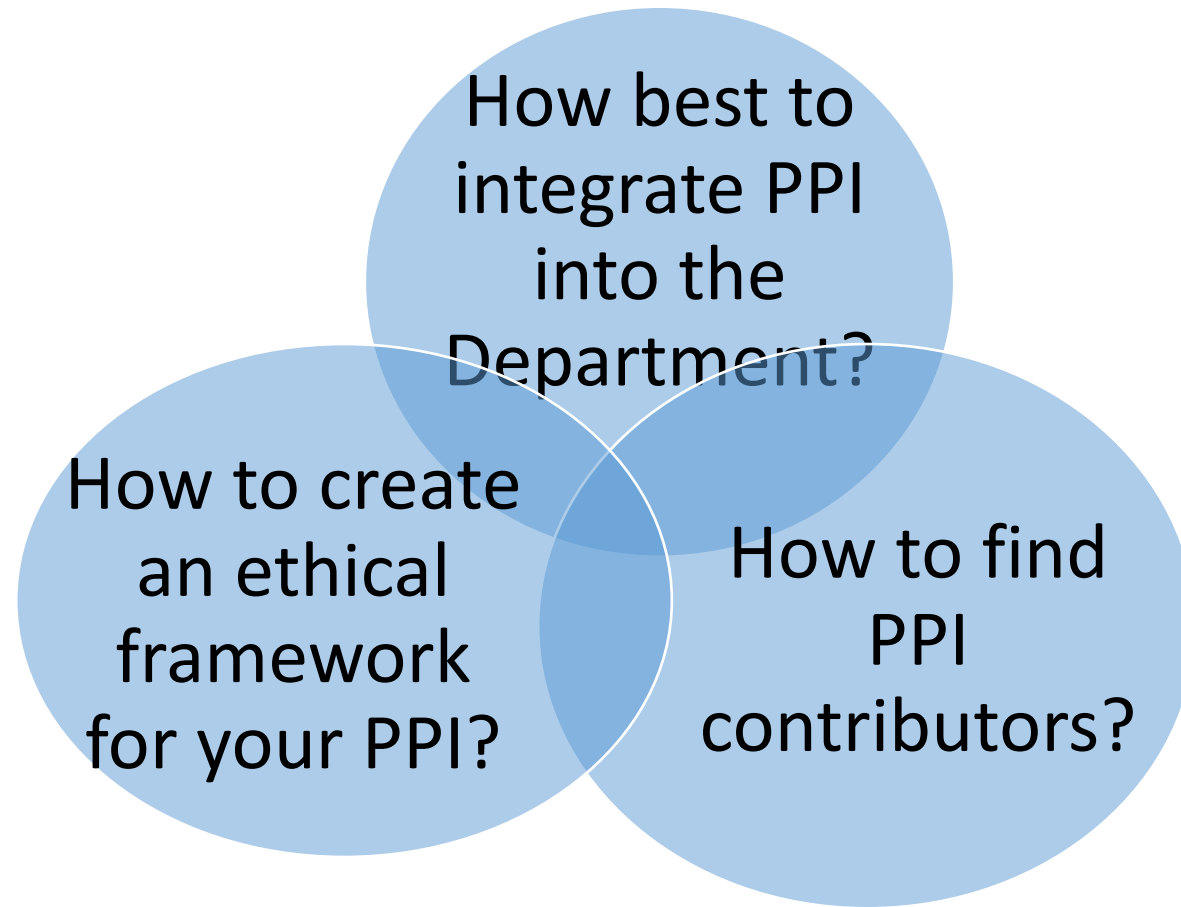
Why PPI?

- **The moral argument**
 - right of citizens to have a voice in the public services paid via taxes (note: diversity)
 - Ethical argument - right to be involved in research “on” oneself
 - Emancipatory argument - validation of lived experience, knowledge
- **The policy argument – public and community involvement in key decisions in healthcare service delivery and in self-management and decision-making in own healthcare**
- **The methodological argument – leads to better research** PPI enhances quality, relevance & acceptability of research to all stakeholders (Brett et al., 2012)

Case study: Department of General Practice, Utopia University

- Existing research areas:
 - Diabetes care (qual and quant)
 - Management of cardiac disease, including secondary prevention
 - Hand hygiene
 - GP stressors
- Funding for three new initiatives:
 - An observational study in diabetes care
 - A qualitative assessment of carer burden in dementia
 - An EU-wide clinical trial on the use of flu vaccine in vulnerable children.

Questions for you



Working ethically: Top tips for researchers

1. Avoid tokenism
2. Create an environment of confidentiality
3. Ensure every voice is heard/inclusiveness
4. Provide required training/knowledge and support to facilitate PPI contributors
5. Allocate sufficient time
6. Communicate clearly at all times

Working ethically: Top tips for researchers

7. Allow the group to develop and evolve
8. Provide for opt-out
9. Work sensitively and emphatically
10. Respect and value lived experience
11. Set clear expectations, which may vary at different stages in a study
12. Always have support

Avoid tokenism – engage in ethical PPI

- Ask questions each time:
 - Is there shared-decision making?
 - Is involvement recognising mutual skills and expertise?
 - Is involvement meaningful for the PPI contributor and for the research team?
 - Does the PPI contributor want the involvement?
 - My playing field or yours?
- Give consideration to the ethics of having a PPI contributor :
 - A co-applicant on a funding application
 - Sitting on a governance committee
 - Co-author on publications
 - Presenting at a conference such as this

What key questions remain unaddressed?



Get started!



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References and useful source

Organisations:

- INVOLVE UK website for resources on Public and Patient Involvement in research <http://www.invo.org.uk>
- Patient-Centred Outcomes Research Institute (PCORI) <http://www.pcori.org>
- www.nuigalway.ie/ppi
- www.primarycaretrials.ie/resources/ppi

Academic papers

- Sherry R. Arnstein's "A Ladder of Citizen Participation," Journal of the American Planning Association, Vol. 35, No. 4, July 1969, pp. 216-224
- Pandya-Woods R, Barron DS, and Elliot J (2017) A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards. Research Involvement and Engagement (2017) 3:6 DOI 10.1186/s40900-017-0058-y
- Brett et al. *Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities* Patient (2014) 7:387–395
- Brett et al *Mapping the impact of patient and public involvement on health and social care research: a systematic review* (2012) Health Expectations, 17, pp.637–650

Thank you!

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