

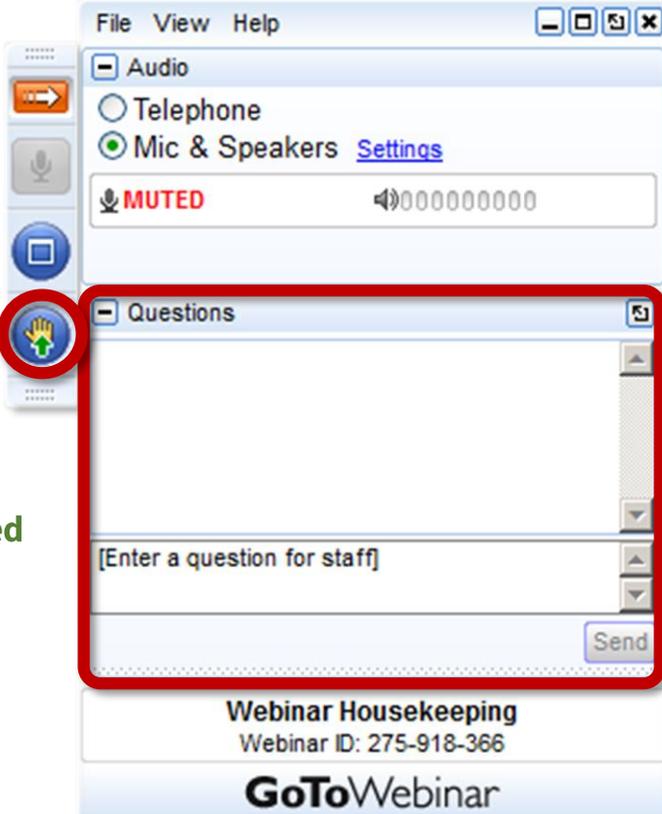
Welcome!

**The webinar “Patient and public involvement
in research: what, why and how?” will begin
shortly**



Taking part in the webinar

- Use chat room for questions and comments
- Session will be recorded
- Presentation will be shared afterwards



The screenshot shows a GoToWebinar interface with two main panels. The top panel is labeled 'Audio' and includes options for 'Telephone' and 'Mic & Speakers' with a 'Settings' link. A microphone icon is shown with the word 'MUTED' in red and a volume level of '000000000'. The bottom panel is labeled 'Questions' and contains a text input field with the placeholder '[Enter a question for staff]' and a 'Send' button. A red rectangular box highlights the 'Questions' panel. On the left side of the interface, there is a vertical toolbar with several icons; the 'raise hand' icon (a hand with a green dot) is circled in red. Two blue arrows point from text annotations to these elements: one from the 'raise hand' icon to the left, and another from the 'Questions' panel to the right.

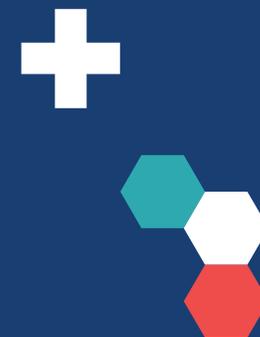
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Submit your questions and comments using the Questions panel

Webinar Housekeeping
Webinar ID: 275-918-366
GoToWebinar



Patient and public involvement in research: What, why and how?



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Aims

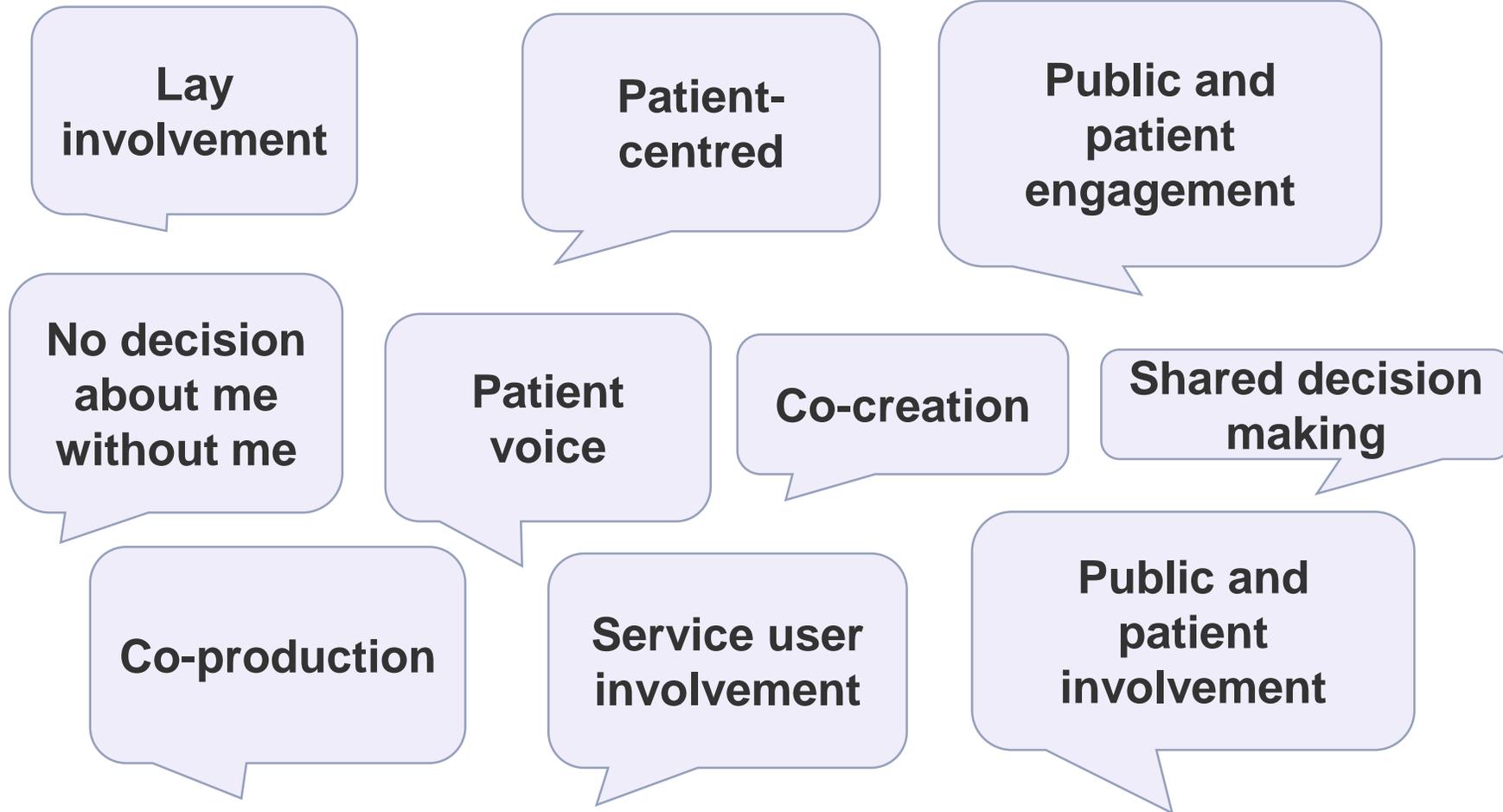
- Background
- What?
- Why?
- How?

About INVOLVE...

- Support active public involvement in NHS, public health and social care research
- Centre of expertise
- Advice, guidance and support
- National Institute for Health Research



Lots of terms...



What do we mean by patient and public involvement?

Involvement - research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them

Participation – where people take part in a research study

Engagement – Where information and knowledge about research is provided and disseminated

(INVOLVE 2012)

Approaches

- Consultation
- Collaboration
- Patient controlled



Why?

- Offers a **different perspective** from rest of the research team
- Potential to **improve** the research quality and relevance
- **Moral imperative**, as research targeting populations or services, publicly funded
- **Standard** for research



National Institute for Health Research

“We expect the active involvement of members of the public in the research that we fund. We recognise that the nature and extent of active public involvement is likely to vary depending on the context of each study or award.

Members of the public will review your research proposal and they also sit on our funding and commissioning boards and panels to support our decision-making.”

<http://www.nihr.ac.uk/funding/public-involvement-in-your-research.htm>

Patient and public involvement is global

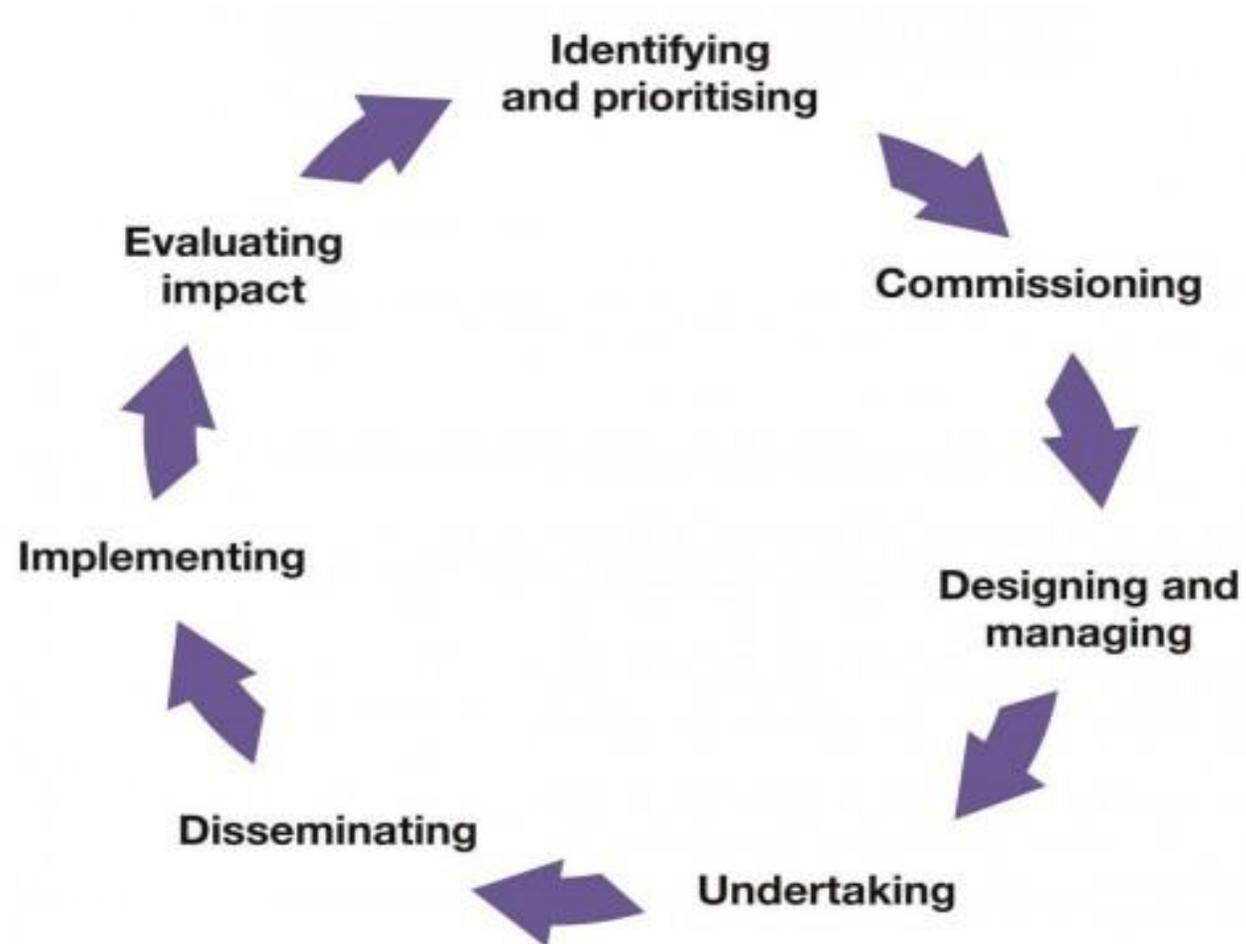
- European Patients' Academy on Therapeutic Innovation
- Clinical Trials Transformation Initiative
- Patients Focused Medicines Development
- Regulators
- Health Technology Assessment Agencies



How?

- Research cycle
- Top tips

The research cycle



Top tips

- Involvement as early as possible
- Accessibility
- Resource patient and public involvement
- Training and support
- Acknowledge expertise of the patient/public
- Manage expectations/clarify responsibilities

Involvement as early as possible

- Establish and maintain a patient and public reference group
- Establish relationships with patient groups/charities



Finding patients/public

- People in Research <https://www.peopleinresearch.org/>
- Clinical Research Network
- Asking community members
- Advertising in GP surgeries, outpatient departments, local newspapers and on the radio
- Talking to local or national patient support groups and voluntary organisations
- Searching online for relevant organisations
- Using online social media such as Facebook or Twitter
- Talking to other health and social care professionals such as community development workers, social workers, health visitors, GP practice managers

Accessibility

- Jargon free
- Acronyms
- Times
- Distance
- Disability

WE NEED SOME NEW JARGON,
THE PUBLIC ARE STARTING TO
UNDERSTAND WHAT WE'RE
TALKING ABOUT!



Resource

- Payment policy
- Expenses
- Build into your research proposal
- Quick and slick

Training and support

- Training in research
- More than one patient/public
- Nominated liaison person
- Feedback
- Acknowledgement



Respect expertise of the patient/public

- Hierarchies of knowledge
- Training
- Regular communication



Managing expectations

- Topic
- Location
- Description of the organisation
- Experience
- Description of the work
- Time
- Payment
- Expenses
- Support/training
- Influence

Summing up

- What
- Why
- How





“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective”

INVOLVE Contacts

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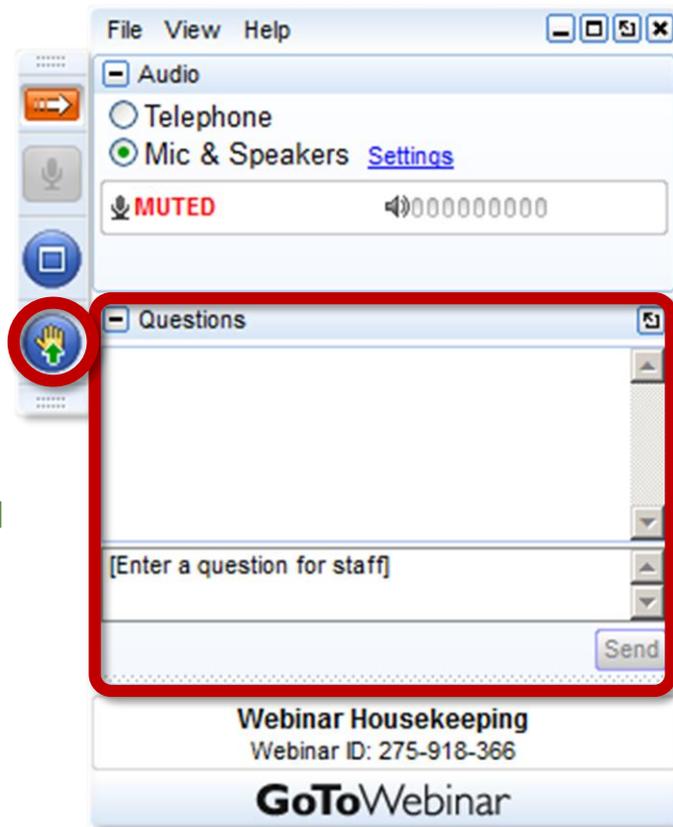
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Questions and answers

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Forthcoming webinars

- Experiences from implementation of PPI in healthcare research in Denmark - lessons learned, examples and a model for starters in PPI - Mogens Horder - University of Southern Denmark | SDU · Institute of Public Health
- Patient and Public Involvement in Evidence Synthesis – Neil Haddaway – Stockholm Environmental Institute
- Contact us if you have ideas for webinars on involvement and engagement in health research for a global audience



Contact us



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<https://www.linkedin.com/company/18982263>



Coming soon

