

Patient and public involvement in clinical research

Understanding what, why and how?

What?

Patient and public involvement in clinical trials is the practice of speaking with members of the society (patients and public) to incorporate their experience in all aspects of clinical research.



Why?



To ensure patient-centered research



To improve the feasibility and conduct of research



To conduct research with more societal perspectives



To meet people's expectations, needs and preferences through research



To reduce the power-imbalance between researchers and public



To enrich research findings



To strengthen people's belief and acceptance in research

Who are 'patients and public' ?

- Healthy people
- Individuals with any illness
- People who have suffered from any illness in the past
- People who may develop any illnesses in the future
- Carers of ill people
- People or organisation who use health and social care services

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As public funds support research for society's benefit, the public and patients have the right to voice their opinion

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Understanding what, why and how?

Involvement, Engagement and Participation



Engagement

Sharing knowledge and information about research with patients and public



Involvement

Involving the public actively in every step of a research study, starting from formulating a research question to disseminating the findings



Participation

Enrolling patient or public in a trial or other research with their consent

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Conducting research ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them

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How can researchers involve patients and public?



Working together as a team, valuing each other’s opinion and perspective



Offering accessible public involvement opportunities that reach larger group



Offering capacity building or training program for public to develop skills to get involved in research with researchers



Offering workshops and training for researchers to build skills in involving patients and public in every step of research cycle.



Involve public in every step: designing, management, regulation, leadership and decision-making



Using jargon-free language to convey information

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Involve as early as possible and share as simply as possible

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