

Involving patients and the public in numerical aspects of research – a review of methods and implications for trials

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What methods are available to involve the public or elicit their opinion about numerical aspects of research?

What we did

Reviewed EMBASE (1946-April 2019) with a search strategy focused on stakeholder involvement and participatory research. We included any field of research.



How can we use these methods to involve patients and the public in numerical aspects of trials?

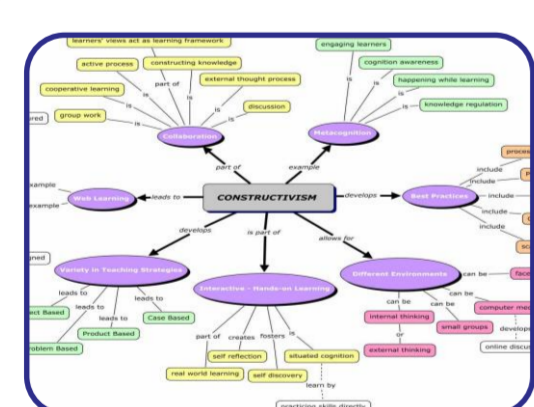
Proposed mapping of methods to different stages of trials (to be agreed at an expert meeting in 2020)

Trial stages	Potential methods
Design (design of the trial, elicitation of target difference, non-inferiority margins)	Ranking or choice-based experiments Focus groups Participatory epidemiology techniques
Conduct (improvement of recruitment & retention discussions)	Causal mapping Focus groups
Analysis & Interpretation (informing the statistical analysis plan and the interpretation of findings)	Participatory modelling Causal mapping Focus groups
Dissemination	Focus groups

What methods have been used to involve patients in numerical aspects of trials?



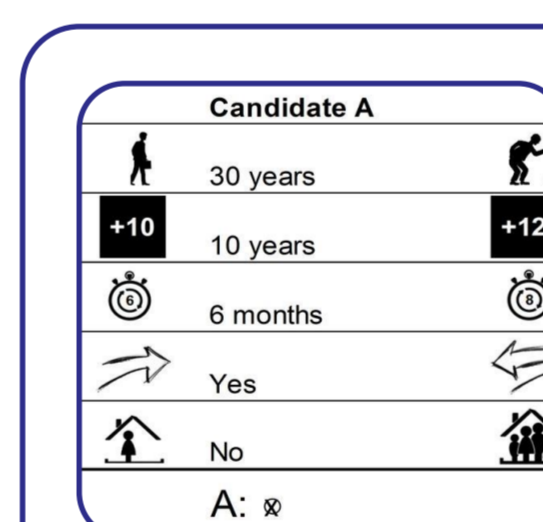
Participatory modelling & participatory dynamic simulation modelling: Participants co-formulate the problem and use modelling practices to aid in the description, solution, and decision-making.



Causal mapping: Cognitive maps can illustrate mental models (cognitive representation of a system) by a simple graphical representation of a person's thinking.



Participatory epidemiology techniques: It uses participatory methods such as: proportional piling, visualisation (mapping, modelling) and diagrammatic techniques (like seasonal calendars).



Ranking or choice-based experiments: Used to elicit patients' and the public's preferences usually through surveys.



Focus groups: A focus group is a group discussion about a specific topic.

Interested in learning more or taking part in the expert meeting?



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What happens next?

We are organising a meeting with experts to agree on the mapping of methods to different trial stages and on the most important numerical aspects of trials that patients can and want to contribute to. We are inviting expressions of interest to take part in the meeting.

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