

# ReseArch with Patient and Public invOLvement: a RealisT evaluation – the RAPPORT study

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## Plain English summary

### Research with patient and public involvement

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## Plain English summary

It is generally accepted that patient and public involvement (PPI) is 'a good thing' and it is now a requirement before most health research is funded. However, there is a need for evidence showing whether or not PPI really makes a difference and, if so, what works and what situations help to create good PPI. This study set out to find that evidence. PPI representatives were involved in this study from start to finish.

We wanted to know:

- what people understood by PPI
- how much and what sort of PPI is in health research
- how PPI changes over time
- the experience of PPI for lay people and researchers
- how PPI works in everyday practice in research teams and organisations
- what impact PPI has on research
- what helps or hinders PPI working well.

Our research looked at cystic fibrosis, arthritis, diabetes mellitus, dementia, public health, and intellectual and developmental disabilities studies in the UK. There were three stages: scoping (looking at research documents), survey (researchers filling in online questionnaires) and case studies. Twenty-two studies were followed for 18 months, with 206 researchers, PPI representatives, funders and network staff interviewed.

Findings showed a range of positive outcomes from PPI. These included identifying research questions and improving recruitment. Good relationships and regular contact between PPI representatives and researchers throughout the study are very important. PPI representatives also need to know if they have been useful. Researchers tended to get better results if they had people skills, were flexible and offered lots of opportunities for involvement.

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