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Patient & public involvement in health research

A perspective from the National Institute for Health Research, UK

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National Institute for Health Research

- Largest health funder in UK, founded 2006
- Patient & public involvement is a standard expectation
- “Going the Extra Mile”
- UK Standards for Public Involvement

“Public involvement can improve the quality and relevance of research, as well as serving the broader democratic principles of citizenship, accountability and transparency”

The UK Standards for Public Involvement

- **Inclusive opportunities** Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
- **Working together** Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
- **Support and learning** Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
- **Governance** Involve the public in research management, regulation, leadership and decision making.
- **Communications** Use plain language for well-timed and relevant communications, as part of involvement plans and activities.
- **Impact** Seek improvement by identifying and sharing the difference that public involvement makes to research

The improvement journey

"*We are guided by the strategy set out in our Going the Extra Mile report (NIHR 2015), with its vision of a population 'actively involved in research to improve health and wellbeing for themselves, their families and their communities'. We know that we have much further to go if we are to ensure that the involvement of diverse patients, service users, carers and communities in research is inclusive, consistently makes a difference and avoids tokenism.*"

Best Research for Best Health: The Next Chaper, June 2021

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