

UK standards for Public Involvement in Research: a 'test-bed' project with the Northern Ireland Cerebral Palsy Register

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Introduction and Aim

In 2018 the UK National Institute for Health Research published six draft 'Standards for Public Involvement in Research'¹. The Standards aim to improve the quality and consistency of public involvement (PI) in research. The Northern Ireland Cerebral Palsy Register (NICPR), a confidential record of children with cerebral palsy covering over 40 birth years, was one of 10 'test-bed' projects competitively selected to pilot the Standards. This project aimed to test three of the six Standards in the activities of the NICPR from May 2018-2019.



Methods and Results

Standard 2, '**Working together**', was tested through creation of a PI group comprising people with cerebral palsy, their families, friends and carers. In collaboration with the research team, the group identified and defined their terms of reference, activities and training needs.

Standard 2

Working together – we create and sustain respectful relationships, policies, practices and environments for effective working in research.



Standard 2, '**Working together**', was met within the study timeframe. Creating a PI group was successful but time-consuming due in part to organisational requirements aligned with new General Data Protection Regulations.

Standard 4, '**Communications**', was tested by developing jargon-free communications for various stakeholder audiences, including parents / guardians, children, clinicians and people with communication difficulties.

Standard 4

Communications - we provide clear and regular communications as part of all involvement plans and activities.



Standard 4, '**Communications**', was **partially met** within the study timeframe and required significant time and input from the research team. Additional funding has now been allocated to fully meet this Standard.

Standard 5, '**Impact**', was tested by development of standardised evaluation processes so that evaluation of NICPR PI activities was embedded and undertaken in a proactive, rather than reactive, manner.

Standard 5

Impact - we assess, report and act on the impact of involving the public in research.



Standard 5, '**Impact**', was **not achieved** within the study timeframe. Development of standardised evaluation processes, endorsed by the new PI group, was delayed due to the length of time taken to convene the group.

Conclusion and Recommendations

The Standards provided a useful framework for structuring and embedding meaningful PI in our research. The 'test-bed' network created a supportive implementation environment and facilitated sharing of knowledge, resources and expertise.

Successful PI using the draft Standards as a framework requires:

- sufficient investment of time from public members and researchers
- dedicated and sustained funding
- focused PI activities
- shared reflection and evaluation of impact.

References

1. Standards Development Partnership, 'National Standards for Public Involvement in Research'. (2018) Available at: https://www.nihr.ac.uk/news-and-events/documents/Public_Involvement_Standards_March%202018_WEB.pdf

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