Public Health Agency
Research and Development

HSC R&D Division Final Report

PPI in Research Small Grant Scheme

Updated March 2026

Reports should be submitted via electronic copy to HSC R&D Division within 6 weeks of the request.
The report should be completed on the attached form in Arial 11. Please extend boxes as required. Please adhere to any word limits. These reports may be subject to external peer review.
Details from the Report may be placed on the HSC R&D Division website and shared with appropriate key stakeholders or members of the public.

HSC R&D Division Award Details

HSC R&D File Reference	STL/5562/19
HSC R&D Funding Scheme	PPI in Research Support - Small Grant Scheme
Project Title	What Matters Most in Managing Headache: A Co-Designed Exploration of Priorities, Practices, and the Potential Role of Digital Support
Award Holder Name (Employer)	Dr Joanne Marley (Ulster University)
Host Organisation	Ulster University
Award Duration	
Award Start Date	01.06.25
Award End Date	27.02.26

Signature

Award Holder Signature: [redacted]

Date: 19.05.26

Evidence Brief for PPI in Research Small Grant Scheme

(2 pages: which may be used for dissemination by HSC R&D Division)

Why did we start? (The purpose and need for the PPI initiative)	Chronic headache is in the top 3 causes for morbidity in all income groups, it poses considerable personal and societal burden, costing the UK NHS £1 billion each year in direct costs with a further £7 billion in lost productivity. In Northern Ireland, neurology outpatients are oversubscribed, over 5000 neurology referrals are for headache diagnosis and management. Despite this, little is known about the experiences of those living with these conditions and the healthcare professionals providing services. Digital and AI tools are increasingly used in healthcare and in everyday life, yet we do not know how people with lived experience, or the clinicians who support them, view the role of these tools in headache care. This PPI initiative set out to bring these voices together to identify shared priorities for future research and service development.
What did we do? (Please comment on how the UK Standards for Public Involvement guided your plans and what you did)	We delivered a programme of engagement activities, we met with specialist interest groups, local charities and individuals with lived experience, these discussions informed the design of a workshop. The workshop involved 21 people with lived experience and 5 multidsciplinary health professionals working in this area. Contributors worked in small facilitated groups exploring barriers to accessing services, research and service priorities, and views on digital technology and AI in headache care. Additional smaller meetings were held with autistic individuals in more accessible formats, and with individuals who were unable to attend the workshop. We met separately with clinicians to refine priorities raised by lived-experience contributors. Contributors who wished to remain involved were invited into project steering groups. Our approach was guided by the UK Standards for Public Involvement, particularly Inclusive Opportunities, Working Together, Governance and Impact

What did we achieve? (Please describe any outputs and the short and longer-term impacts of this initiative)	The engagement work has led to different streams of work 1. Following discussions arising from the engagement, we revised a planned grant application to focus on autistic people with headache. Contributors and healthcare professionals described managing headache in autistic people as difficult, and noted that autistic people had been excluded from headache research. This focus formed the basis of a successful £100,000 external award for a 24-month feasibility study. The steering group established during the PPI initiative continues as PPI partners on the funded study. 2. Since the engagement, additional individuals have approached us interested in developing research in this area. We are currently working on two systematic reviews and exploring how PPI can be embedded within them, including co-authorship. We have also built a wider network of contributors who have indicated an interest in engaging in further headache research.

Evidence Brief

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What should be done now? (Practice/Policy Implications and/or Recommendations for PPI in HSC Research)	The personal and societal burden of headache is substantial, yet research infrastructure for headache in Northern Ireland remains limited. Where research infrastructure is thin, PPI is essential to identify priorities and build the foundations for future work. Engagement formats need to be flexible and adaptive to engage individuals and groups in meaningful PPI. This is particularly true for those who may, for a variety of reasons, find it more difficult to engage in these activities. Support in terms of time could be helpful in facilitating PPI - for example, training for lived experience applicants on co-authoring grants etc.
What do you feel has been the **most significant impact** of being awarded the PPI in Research Small Grant?	The most significant impact has been the translation of information gathered via a small PPI award into a £100,000 externally funded feasibility study on an under-served population. The autism focus emerged from discussions with lived experience and health care professionals. The steering group established during the PPI initiative continues as PPI partners on the funded study, providing continuity from priority-setting through to research delivery. This would not have been possible without the resource provided by the small grant to bring contributors and clinicians together at the priority-setting stage. We have developed a wider network of individuals interested in research in this area
Do you have any **'lessons learned'** from your PPI experiences during your award that would serve as useful learning for others in the future?	In some of our PPI engagement we brought service users together with service providers, we found this generated very useful dialogue and understanding from different perspectives. In particular in relation to digital innovations and AI we found that service users and service providers held similar positions on where technology could be useful and where they had concerns.