

Final Report Executive Summary



HSC R&D Division Final Progress Report

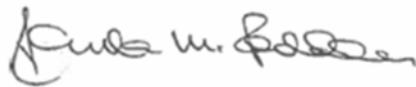
Final Reports should be submitted via electronic copy to HSC R&D Division within 6 weeks of the request. The report should be completed on the attached form in clear typescript. Please extend boxes as required. Please adhere to any word limits. These reports may be subject to external peer review. Details from the Final 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	The Value of Lived Experience: Introductory Training on Research Involvement for Service Users and Experts by Experience
Award Holder Name (Employer)	Professor Paula McFadden (Ulster University)
Host Research Organisation	Ulster University
Award Duration	6 weeks
Award Start Date	06.10.25
Award End Date	28.11.25
Name of Lead Supervisor: (only applicable to training awards)	Paula McFadden

Signature

Award Holder Signature:



Date: 20/01/26

Evidence Brief

(1 page: which may be used for dissemination by HSC R&D Division)

Why did we start?

(The need for the research and/or Why the work was commissioned)

Patient and Public Involvement and Engagement (PPIE) is now recognised as essential to high-quality, ethical and impactful health and social care research. Despite this, many people with lived experience report limited access to structured education or training that would enable them to engage confidently and meaningfully in research roles beyond participation. This small grant was awarded to pilot an introductory training course designed specifically for service users and experts by experience, addressing risks of tokenistic involvement and supporting the development of confident, informed research contributors.

What did we do?

(Methods)

We delivered a six-week, 10 credit, Level 4 academic module part-time introductory course titled *The Value of Lived Experience: Introductory Training on Research Involvement for Service Users and Experts by Experience*.

The course was delivered online and fully completed, with maximum uptake of funded places. Teaching was interactive, accessible and co-produced, covering research methods, ethics, trauma-informed practice, and opportunities for involvement. Participants completed weekly reflective learning tasks, providing formative feedback throughout.

What answer did we get?

(Findings)

Participant reflections demonstrated increased confidence in understanding research language, methods, and ethical processes. Participants developed awareness of different roles service users can play in research (participant, advisor, peer researcher), the importance of safeguarding and trauma-informed approaches, and the value of lived experience as expertise.

Feedback showed a clear shift from viewing research as technical or inaccessible towards seeing it as collaborative, ethical and relevant to real-world service improvement. Participants reported readiness to engage in future advisory, governance and participatory research roles.

What should be done now?

(Practice/Policy Implications and/or Recommendations)

The pilot demonstrated the value of structured, accessible PPI capacity-building. Further delivery and scale-up of this model would strengthen the quality, confidence and sustainability of service user involvement in research across Northern Ireland.

Embedding similar training within research infrastructure would support funder expectations, improve research relevance, and enhance ethical practice.

Final Report

(no more than 20 pages)

Please structure the report using the headings below

- **Background**

Involvement of service users and people with lived experience is a core expectation of contemporary health and social care research. However, meaningful involvement requires more than invitation; it requires preparation, support and equitable access to research knowledge. Without this, involvement risks being tokenistic and burdensome for participants. This pilot course was developed to address this gap by providing introductory research education tailored to service users, aligning with HSC R&D priorities and best-practice guidance on PPIE.

- **Aims and objectives**

To pilot an accessible introductory training course that empowers service users and experts by experience to engage meaningfully in research.

Objectives

- To demystify research concepts, language and processes
- To build confidence in understanding research roles and ethics
- To support non-tokenistic, trauma-informed involvement
- To prepare participants for future advisory, peer or participatory research roles

- **Methods**

The course ran over six weeks (two hours per week) and was delivered online via interactive lectures, discussion and reflective activities. Teaching content covered historical perspectives on research, PPIE principles, research ethics, qualitative and quantitative methods, and opportunities for involvement. Participants completed weekly reflective learning tasks, which also served as formative feedback and evidence of learning outcomes. All funded places were filled, and the course was completed in full.

- **Personal and Public Involvement (PPI)**

This project placed lived experience at the centre of delivery. Participants were not passive recipients of information but active contributors to discussion, reflection and learning. Teaching materials were designed to be accessible and sensitive to participants' experiences, particularly where discussions related to trauma, safeguarding and vulnerability. The course itself functioned as a mechanism for strengthening PPI capacity, equipping participants with the knowledge and confidence needed to engage safely and effectively in future research involvement.

- **Findings**

Analysis of participant reflections highlighted several key outcomes:

- 1) **Increased confidence and understanding:** Participants reported greater confidence using research terminology and understanding research processes.
- 2) **Recognition of lived experience as expertise:** Reflections consistently framed lived experience as a valuable and necessary form of knowledge.
- 3) **Ethical and trauma-informed awareness:** Participants demonstrated strong awareness of safeguarding, consent, emotional safety and the need for trauma-informed research practice.

- 4) Readiness for involvement: Participants identified specific opportunities for future engagement, including advisory groups, peer research and governance roles.

Overall, the feedback showed a clear developmental trajectory from uncertainty about research to informed, reflective readiness with potential for research involvement.

- **Conclusion**

The pilot course successfully achieved its aims. Participants completed the course with increased confidence, knowledge and ethical awareness, demonstrating readiness for meaningful research involvement. Maximum uptake and completion indicate strong demand and acceptability. The findings support the value of structured PPI capacity-building as a foundation for high-quality, inclusive research.

- **Practice and Policy Implications/Recommendations**

This pilot highlights the importance of investing in service user education as part of research infrastructure. Capacity-building supports better quality PPI, reduces risks of tokenism, and enhances ethical and trauma-informed practice. Embedding similar training within research programmes would strengthen alignment with funder expectations and improve the relevance and impact of health and social care research.

- **Pathway to Impact**

Input:

HSC R&D Small Grant funding; academic staff time; and service user participation.

Activities:

Course delivery, interactive teaching, reflective learning, participant engagement.

Outputs:

A cohort of trained, confident service users; learning materials; formative feedback evidence. Each student successfully completed micro-credentials 10 academic credits, Level 4 AQA.

Outcomes:

Improved confidence, knowledge and readiness for potential involvement; capacity building and strengthened PPI knowledge and skills.

Impact:

Enhanced quality and potential sustainability of service user involvement in future research; stronger ethical and inclusive research practice; readiness for further funding and scale-up.

- **Relevant Logos**

