DCU REC Guidance on Public Involvement in Research

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1. Guidance statement

DCU is committed to the meaningful, ethical, and proportionate involvement of members of the public in research conducted under its auspices. Public involvement in research can enhance the relevance, quality, accountability, and societal impact of that research. It reflects DCU's commitment to transparency, collaboration, and public value in research practice.

This Guidance Statement establishes the principles, governance expectations, and procedural standards for the appropriate planning, conduct, documentation, and reporting of public involvement across all research activities undertaken by staff, students, and collaborators affiliated with DCU.

2. Definition and scope

For the purposes of this document, public involvement in research refers to research carried out with or by members of the public, rather than to, about, or for them. Such individuals include service users, product users, policymakers, civil and civic society organisations, industry partners, members of the public, and other relevant stakeholders. Public involvement may take place at any stage of the research lifecycle, including the development of research priorities, the formulation of research questions, study design, governance oversight, interpretation of findings, dissemination, and implementation planning.

Public involvement is distinct from research participation. Individuals contributing through public involvement are not research participants and should not be treated as such. Their role is advisory, collaborative, or co-productive in nature, rather than as data sources.

The term 'Public and Patient Involvement (PPI)' is used in health and social care research as a specific application of these broader principles. Where research concerns health, clinical, or social care topics, the PPI framing may be appropriate, and researchers should refer to relevant funder guidance accordingly. However, the principles set out in this document apply to public involvement across all disciplines.

This guidance applies to all research activities undertaken in the name of DCU, regardless of funding source or discipline, where public involvement is included or proposed.

3. Distinguishing public involvement from research activity

It is essential that public involvement activities are not used as a mechanism to collect research data from human participants without appropriate ethical approval. The distinction between involvement and research must be clearly understood and maintained.

Where individuals are asked to provide views, feedback, or advice about the design, conduct, or dissemination of a research study, the activity constitutes public involvement. Where individuals are asked to provide information about their personal experiences, behaviours, or circumstances to be used as primary data for analytical or evidentiary

purposes, the activity constitutes research and requires review and approval by the Research Ethics Committee (REC).

Where uncertainty exists, researchers must seek guidance from REC prior to commencing the activity.

4. Ethical principles and governance of public involvement

Although formal Research Ethics Committee approval is not required for public involvement activities, ethical principles remain fully applicable. Researchers are responsible for ensuring that public involvement is conducted in a manner that is respectful, transparent, and proportionate to the level of risk involved.

Researchers must ensure that the purpose of the public involvement activity is clearly explained, that participation is voluntary, and that contributors understand the scope and boundaries of their involvement. Contributors must be informed that they may withdraw at any time without disadvantage. The PI or research team's contact details for follow-up queries must be provided. Any personal data that is gathered from public contributors must be handled in compliance with DCU's Data Protection Policy (see https://www.dcu.ie/data-protection-unit).

Particular care must be taken when public involvement includes children and young people, vulnerable adults, or discussion of sensitive subject matter. In such cases, researchers must undertake a proportionate risk assessment, consider safeguarding implications, and ensure that appropriate support mechanisms are in place should distress arise (see https://ppinetwork.ie/resource/ethical-collaboration-with-children-and-young-people-in-research/; https://pubmed.ncbi.nlm.nih.gov/29440127/; https://pubmed.ncbi.nlm.nih.gov/30607259/). Researchers must also ensure that identifiable or raw research data are not shared within involvement activities.

Public involvement must be declared within associated research ethics applications where early involvement has informed study design.

5. Principles of meaningful and inclusive involvement

Public involvement undertaken within DCU must be purposeful and non-tokenistic. Researchers must be clear about how public contributions will inform research decisions and must provide feedback to contributors regarding the influence of their input. Meaningful involvement requires openness to challenge and willingness to adapt research processes where appropriate.

Communication must be clear, accessible, and free from unnecessary technical language. Researchers are responsible for ensuring shared understanding of tasks, expectations, and objectives (see https://pmc.ncbi.nlm.nih.gov/articles/PMC7296703/ for sample involvement matrix) Where technical terminology is unavoidable, it must be explained in plain language.

Although formal consent forms are not required for public involvement, informed agreement is essential. Contributors must be given sufficient information to make an informed decision about their involvement, which may include matters such as data sharing and processing arrangements, how their contribution may feature in outputs such as

publications, and what decision-making rights, if any, they hold within the project. Agreement should be revisited at appropriate intervals, particularly in long-running projects.

DCU is committed to inclusive opportunities for public involvement (see https://hrci.ie/a-friendly-guide-to-edi-in-ppi/). Recruitment strategies should reflect the population of interest and seek to minimise barriers to participation. Reasonable adjustments should be made to facilitate participation, including the use of virtual platforms, flexible scheduling, and accessible formats or using a mixed mode approaches as relevant (in-person and digital). Opportunities for involvement should be varied to allow differing levels of contribution according to interest, experience, and capacity.

6. Resourcing and remuneration

Public involvement must be appropriately resourced. Researchers are required to cost involvement activities within funding applications wherever public involvement is proposed. This includes payment for contributors' time in line with recognised national guidance and reimbursement of reasonable out-of-pocket expenses such as travel, accommodation, and subsistence.

Reimbursement mechanisms must be transparent and timely. Contributors should not be financially disadvantaged as a result of their involvement.

In addition to financial recognition, appropriate acknowledgment should be provided where warranted, including acknowledgement in publications, co-authorship where criteria are met, invitations to attend conferences, and formal recognition of contribution.

7. Roles, responsibilities, and support

Each research project involving public involvement must designate a member of the research team as the primary contact for public contributors. This individual is responsible for coordinating involvement activities, ensuring administrative documentation is maintained, and providing support and signposting as required.

Researchers must ensure they possess, or acquire, appropriate skills to facilitate effective public involvement. Where necessary, training in involvement facilitation, communication, and ethical practice should be undertaken. Freely available online training is provided by UCC: https://ucc.instructure.com/courses/56578. The national PPI network calendar of events is a further useful source for researchers https://ppinetwork.ie/events-calendar/.

Public contributors should receive clear role descriptions written in accessible language. Objectives for involvement should be negotiated and documented. Where required, training and mentoring should be offered to enable contributors to participate confidently and effectively.

All research projects should foster a culture of mutual respect where the lived experience of the public is valued as highly as academic/researcher expertise.

8. Integration across the research lifecycle

Public involvement should be considered at the earliest feasible stage of research development and may appropriately continue throughout the project lifecycle. This includes, where relevant:

- contributing to the formulation of research questions
- shaping study design
- reviewing participant materials
- advising on recruitment strategies
- contributing to governance discussions
- assisting in interpretation of findings
- co-authoring outputs
- supporting dissemination
- advising on implementation pathways

The level and intensity of involvement should be proportionate to the scale, complexity, and risk profile of the research project.

9. Documentation and impact reporting

Systematic documentation of public involvement activity is required. Research teams must maintain a record of planned objectives for involvement, activities undertaken, and the influence of public contributions on study decisions. Reflection on the process and lessons learned should also be captured.

Evidence of involvement and its impact should be included in relevant outputs, including funding applications, funder reports, academic publications, impact case studies, and DCU reporting exercises. Transparent documentation strengthens accountability and demonstrates DCU's commitment to meaningful public involvement. Supportive tools to ensure comprehensive documentation are available here:

GRIPP2 https://www.bmj.com/content/358/bmj.j3453

PiiAF https://www.bangor.ac.uk/health-sciences/documents/piiaf-guidance-jan14.pdf

10. Publication of public involvement outputs

Outputs arising from public involvement activity may be disseminated or published, provided that it is clearly stated that the activity constituted public involvement rather than research data collection. Public contributors have the right to be recognised for their work through co-authorship or formal acknowledgement. Before naming a public contributor as a co-author or listing them in the acknowledgements of a publication, researchers must ensure that the contributor has given explicit consent to be publicly identified.

11. Compliance and oversight

Compliance with this guidance is mandatory for all research conducted under the authority of DCU. Oversight responsibility rests with DCU REC, which will provide advice, support interpretation of this document, and monitor adherence where appropriate.

Sources and further reading

UCD guidance on public engagement with research:

https://www.ucd.ie/research/portal/t4media/Engage%20Your%20Research%20Final%20Dec%202021.pdf

IUA guidance on public engagement with research:

https://www.iua.ie/wp-content/uploads/2023/12/Guide-IUA-Engaged-Research-Principles-Good-Practices-2022-Update_V5-471-3.pdf

PPI Ignite Network Statement on PPI and Research Ethics Approval:

https://ppinetwork.ie/wp-content/uploads/2024/01/REC-approval-statement-Final-Jan2024.pdf

NIHR Public Involvement in Research Impact Toolkit:

https://hrc-braininjury.nihr.ac.uk/pirit

QUB guidance on appropriate use of PPI:

https://www.qub.ac.uk/Research/Governance-ethics-and-integrity/FileStore/Guidance%20on%20the%20appropriate%20use%20of%20PPI%20v4.0.pdf

UCC Digital Badge for Researchers:

https://ucc.instructure.com/courses/56578

World Café method:

https://theworldcafe.com/key-concepts-resources/world-cafe-method/

Mahony, N., & Stephansen, H. C. (2017). Engaging with the public in public engagement with research. *Research for all*, *1*(1).

Mitchell, S., Slowther, A. M., Coad, J., & Dale, J. (2018). The journey through care: study protocol for a longitudinal qualitative interview study to investigate the healthcare experiences and preferences of children and young people with life-limiting and life-threatening conditions and their families in the West Midlands, UK. *BMJ open*, *8*(1), e018266.