

Role Description of PPI Representative in HSC Research & Development Division, Public Health Agency (HSC R&D)

Background

Clinical research aims to help improve health and wellbeing by increasing our understanding of the diagnosis, treatment and prevention of disease. If we are to improve health and social care we need more knowledge and more innovation in the application of knowledge.

HSC R&D was established in 1998 to support and encourage health and social care research & development in Northern Ireland through direct funding for research studies as well as investment in training and infrastructure to build local capacity for research.

This document sets out the roles and responsibilities for the PPI Representatives who work in partnership with HSC R&D Division, Public Health Agency to implement Patient and Public involvement in HSC Research in Northern Ireland.

Responsibilities

It is not intended that the PPI representative will represent any group of patients or organisation but will lend his/her individual perspective as a member of the general public or a patient, client or carer with experience of a particular illness, condition or service.

The PPI representative may be asked to:

- sit on research funding award panels
- attend meetings of committees/groups
- review research documents
- take part in research steering groups
- respond to consultations
- undergo relevant training
- assist researchers with grant applications
- assist with PPI training for researchers

Through these activities he/she may be asked to give views on the:

- topics researchers are studying
- research questions they are asking
- wording of patient information sheets
- methods of recruitment of patients or clients to research studies
- burden/impact of a participant taking part in a study
- value for money of a study
- the way in which the research findings are being shared

Support

HSC R&D will ensure the provision of an ongoing programme of support which will be tailored to individual needs. This may include:

- a named point of contact
- induction
- mentorship
- training e.g. in the research process/being heard
- travelling expenses and subsistence
- written guidance
- study days
- visits to Research Centres
- other activities identified by PPI representative

Person Specification:

Essential Attributes

- an ability to listen to others and express views in a polite but effective manner
- interest in and commitment to improving health and social care

Desirable Attributes

- knowledge or experience of a specific illness or social care context
- confidence to discuss issues with health and social care professionals
- knowledge or experience of the research process
- experience of taking part in meetings or panels
- experience of reading documents and providing feedback