

What if I want to report an incident which occurred during the research?

If for any reason during the research you feel you have been hurt either physically, emotionally or psychologically it is important that you report it to the Research and Development Department.

You can telephone or write to the Research and Development Department at the address overleaf.

Useful contacts and publications:

Research and Development Forum
www.rdforum.nhs.uk

Research Governance Framework Document
www.dh.gov.uk

Office of Research Ethics Committee NI (OREC NI)
www.hscbusiness.hscni.net

Help and support can be obtained from:

Margaret Smyth
Research Governance Manager
R&D Office, Governance Dept.,
Bush House
Antrim BT41 2QB
Tel. 028 9442 4653
E mail:

Frances.Johnston@northerntrust.hscni.net

Mary Mc Donald
Research Governance Administrator
Tel.028 9442 4441

E mail:
mary.mcdonald@northerntrust.hscni.net

Marian McConway/Katrina Gray
Research Governance HCO
Tel 028 9442 4751

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A Patient and Public guide to participating in research in Northern Health and Social Care Trust



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What does research mean?

The NHS defines research as work which aims to produce new knowledge. This knowledge should be available to all those who can benefit from it. Good research addresses important issues aimed at improving care and standards in our society. Health services research and development is carried out for a variety of reasons such as:

- To test unproven treatments
- To measure how effective aspects of the health and social care service are

What does it mean to participate in research?

Participation in research requires you to assist the Researcher with the project. This may involve any or all of the following:

- Providing your personal experience
- Providing samples e.g. blood
- Providing information

Exactly what is being asked of you will be explained in an information sheet for each project which fully informs you about the research. You should not hesitate to ask any questions if the information and explanations are not clear to you. Your involvement may generate considerable knowledge regarding your illness or

medical condition and possibilities for progress.

How might I take part in research and what do I need to do?

Someone working in the health and social care service that wishes to undertake research may approach you. It may be your doctor, nurse or any other member of staff or a student from your local university.

They will explain to you what the research involves and provide you with written information on the research. You will be given time to think about the information and given the opportunity to ask any questions regarding the research. If you decide to take part in the research you will be asked to sign a consent form which means you are happy to take part in the research. The research should have been approved by both an Northern Ireland Research Ethics Committee and the NHSCT Research Governance Committee. If you are in any doubt ask the Researcher about this.

“Every individual is important and deserves to be treated with respect. It is important that research is done with participants rather than on them”.

What if I change my mind once the research starts?

If for some reason you decide you do not want to be involved in the research anymore, you can leave at anytime. Your health care treatment will not be affected if you decide not to participate anymore.

You can always volunteer to take part in future research.

Can I be identified?

The Researcher undertaking the research is bound by a strict code of conduct where the dignity, rights, safety and well-being of each participant are their prime consideration. The appropriate use, protection and confidentiality of personal information are part of the Researcher's duty of care to you.

(Data Protection Act 1998 and Health Act 1999)

Research may be anonymous, meaning you are not known by the Researcher (e.g. postal). At other times you will be known by the Researcher (e.g. interviews) in such instances the Researcher will identify you by a given number and your personal details will remain confidential.