Improving clinical research across the UK: who, why, how?

The UK Clinical Research Collaboration (UKCRC) is a partnership of organisations working to revitalise the environment for clinical research in the UK. Through a coordinated programme of work the UKCRC Partners are working to harness and build on the huge research potential of the NHS. The ultimate aim is to benefit patients and the public by establishing the UK as a world leader in clinical research. The strength of the UKCRC is that it brings together the main UK funding bodies, academia, the NHS, regulators, industry and patients. An important part of the UKCRC's agenda is to find effective ways to involve and engage patients and the public in this broad programme of change.

The UK Clinical Research Network (UKCRN) forms one of the key components of UK Clinical Research Collaboration's work to build up the infrastructure for clinical research in the NHS. This Network is in place to provide the support to facilitate clinical trials and other well-designed studies. It is tasked with developing support for clinical research in the UK, aiming to improve patient care and allow people across the country access to the best treatment. Therefore a common theme that runs throughout its work is Patient and Public Involvement. The UK Clinical Research Network believes that active patient and public involvement is needed if it is to achieve a programme of research which directly benefits, and reflects the needs and views of, patients and the public.

Involving clients and their carers as equal partners on a project using electronic communication

Sue Ashby works as a member of a research team organising meetings within a project which aims to improve care for older people.

The research team are interested in a type of care known as Intermediate Care. This involves looking after a person in their own home or other suitable place providing care which would have otherwise required staying in hospital. The project looks at how different professionals work together to provide this care. The research team are clients and carers, health and social care staff and experienced researchers. We believe that it is important to involve clients and carers because they can guide the research and ensure that we include their views and experiences as they are ultimately the service users. To fully involve this team we are using electronic communication (e-mail, web pages and a discussion forum) which gives the members who are situated in different areas a way in which to communicate together at the same time.

Sue will talk about how the clients and carers as equal partners of the project team are supported using this form of communication, how it facilitates participation and how changes were made.

Carer Survey for Cardiac Patients

The Carer Questionnaire Project aims to identify the timeliness, quality and different types of information carers receive regarding their relatives' cardiac condition. It seeks to discover the perceptions and experience carers have had regarding the following:

- Being present at the patients' diagnosis and understanding the impact it had on their future lives.
- Awareness of the organisations or authorities, Age Concern PALS, Citizens Advice Bureau and the Social Services Carers Team and the support these organisations can provide to the patient and carer.
- Were the needs of the carer considered and information provided?
- Involvement of carers in the discharge planning process
- If the home care provided met the needs of the patient and carers

The questionnaire was developed in collaboration with the project team above: a patient who had undergone Cardiac Surgery and a Researcher for advice. The questionnaires were piloted with a number of carers who were caring for people with Coronary Heart Disease. The questionnaire was amended following the comments we were given regarding the questionnaire during the piloting phase. We ain to disseminate the findings widely and to influence practice. Information need and the role of the carer will be discussed.

Involving visually impaired people in research: a case study

This poster outlines how visually impaired people are being involved in an ongoing research study by a student (Catherine Beverley) at the University of Sheffield. The research concerns the health and social care information needs of people with a visual impairment.

At the start of the project, Catherine attended three local visual impairment support groups in Sheffield to discuss the research questions and methods.

Five visually impaired people also act as advisors to the research. They are consulted on a regular basis, and have helped with the design and analysis of an interview study and audio diary study.

What will you learn from this poster?

- Tips on how to involve visually impaired people in research.
- Suggestions for evaluating public involvement in research.

Young People's Reference Group on Public Health:

methods and achievements

This paper will report on the development and progress of a Young People's Reference Group on Public Health which has been established through the collaboration of three organisations. The group is organised by the National Children's Bureau on behalf of the Public Health Research Consortium (PHRC), with funding from INVOLVE. The PHRC is funded by England's Department of Health and brings together researchers from across ten UK institutions in an integrated programme of research. The Young People's Group aims to contribute to the work of the PHRC and the wider public health agenda.

The aims, objectives, activities and outcomes of the group will be shared. This will include how young people were recruited, their reasons for involvement, the methods of involvement adopted, outcomes achieved and the results of the corresponding evaluation being undertaken of the processes and impact of the group. Barriers and achievements will be discussed to facilitate shared learning. This will particularly focus on how young people can participate effectively in research and policy development within public health.

Getting started with involving the public in public health research

This information sheet includes information on who to involve and how to find the right people.

No. of pages: 2

It’s our project! People with learning difficulties managing and doing research

We are a group of people with learning difficulties called the Learning Difficulties Research Team. The Department of Health asked us to find out all about good ways to involve people with learning difficulties in research. We are doing this by looking at what’s happened in 12 research projects funded by the government through the Valuing People white paper. We want to find out:

1. ?How people with learning difficulties got involved in these research projects.

2. What works and what doesn’t work about involving people with learning difficulties in research.

We are travelling around the country to meet people and ask them questions about their views and experiences. After we finish interviewing people we will put all our information together and publish a report, run a conference and do other things to tell people what we’ve found out.

This is an exciting project because we are the researchers and we are also running the project ourselves. We manage the money, make all the decisions and do the research.

We would like to tell people how we set up, manage and run a proper research project as a group of people with learning difficulties. We would like to tell people how we have learnt

to do good, inclusive, empowering and accessible research and how we have overcome challenges and difficulties.

We can do this in the paper format, with questions and discussion or we can run a workshop. Both formats will be fully accessible. The workshop format would focus on what people with disabilities or other `service users' can do to have more control over research and what non-disabled researchers can do to support us.

Knowing how: a guide to getting involved in research

Authors: Lisa Thorne, Rachel Purtell and Lisa Baxter

The aim of the project was to find out how much lay people are actively involved in research outside the health service, and to use what was learned to make recommendations for health research.

No. of pages: 26