

PARTICIPANT INFORMATION SHEET

The RAPPORT Study A research team from the Universities of Hertfordshire, East Anglia, Warwick and the London School of Hygiene and Tropical Medicine are carrying out a study into Public involvement in research (PIR) in the areas of diabetes, arthritis, cystic fibrosis, dementia, public health and learning disabilities.

We would like to talk to both researchers and members of the public who are and have been involved in research.

The purpose of this study?

We want to find out how different approaches to public involvement in research influence the way a study is run.

We hope that the information we collect will be used to enable more effective public involvement in research.

We have already looked at documents from a range of studies to obtain details of public involvement activities. We have also carried out a survey of investigators.

We now want to focus on up to 20 studies and look carefully at public or service user involvement in each study over 18 months.

Can you spare 30 minutes to help us with an interview?

We want to talk to members of the public or service users who are involved in studies we are looking more closely at. We would like to talk to you about your experiences

Where and when will this take place?

The interview will take place by telephone and will last for about 30 minutes. We can agree a date and time that is convenient for you. With your agreement we will tape the interview but will delete the recordings at the end of the study.

Typical questions we will ask you:

- What has been your involvement in the research study?
- What support have you received for this role?
- What have you enjoyed/not enjoyed about this role?

If you volunteer to join the study

Your participation in the study is entirely voluntary:

- We would welcome your help but you do not have to get involved in the study.
- If you volunteer to help but change your mind you can withdraw from the study at any time – you do not have to tell us why.
- If you are asked a question which you would prefer not to answer, you do not have to answer it and you do not have to tell us why (you just tell the researcher you would prefer not to answer the question).

Confidentiality:

Any information you provide to us will be treated with full confidentiality:

- Your information will not be passed on to anyone else outside the research team.

- Your information will be stored on a password protected computer which will be kept in a locked office when not being used by the lead researcher.

The information from the project will be used to inform a number of articles for publication in academic journals.

To ensure confidentiality where information is being used in publications which will be seen by others, all information will be anonymised so that no-one who participated in the study can be identified.

Exceptions to confidentiality:

Very rarely there is a risk that you may give us information about misconduct of professionals that have worked with you. If this happens the researcher has an obligation to reveal the details of the misconduct to the relevant authorities. The researcher will discuss this with you before revealing the information and explain why it is necessary.

Consent:

It is up to you if you decide to join the study.

If you agree to take part you will be asked to sign a consent form just before the interview takes place.

We want you to feel fully informed before you give consent. This leaflet provides the most important information but if you need more, or would like something clarified please ask the researcher when you talk, or contact one of the project staff listed at the end of this information sheet.

What if there is a problem?

We don't anticipate any problems but if one arises, for example, if you have a concern about the way you have been dealt with, or about any aspect of this study you should ask

to speak to Patricia Wilson (lead researcher) on: 01707 286391

Should you require independent advice about making a complaint you may wish to contact the Independent Complaints Advocacy Service (ICAS)

Insert local address and telephone number

Who has reviewed the study?

Before they can go ahead, research projects are scrutinised by ethics committees whose job is to protect the interests of everyone who takes part.

This study has been reviewed by Nottingham Research Ethics Committee 1 Proportionate Review Sub-Committee which has made a favourable judgement.

Who is funding the research?

The RAPPORT study is being funded by the National Institute of Health Research Health Service Research Programme in collaboration with INVOLVE. More information on the work of INVOLVE can be found at <http://www.invo.org.uk/index.asp>

Contact names and phone numbers

If you require any further information about the study please feel free to contact me by phone or email.

Patricia Wilson: Lead Researcher

Tel: 01707 286391

Email: p.m.wilson@herts.ac.uk

On behalf of the University of Hertfordshire, the University of East Anglia, the University of Warwick and the London School of Hygiene and Tropical Medicine, we would like to thank you for taking the time to read this information sheet.