How to volunteer

If you are eligible to participate in our dynamic consent study you may receive a letter or an email from a health professional with the Oxford University Hospitals. They will provide you with details of when and where the focus groups are being held and help you to organise your visit.

For more information go to:



http://www.publichealth.ox.ac.uk/helex

Oxford University Hospitals





THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

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Centre for Health, Law and Emerging Technologies at Oxford

Making Consent Dynamic





Exploring new ways to give consent and manage your personal information

The Dynamic Consent Interface: what is it?

When you decide to participate in medical research, e.g. by giving a blood or tissue sample to a biobank, your consent is collected on a form which is then filed away. We are developing a new system using a Tablet (like an I-pad) that would allow patients and donors to give consent electronically.

Biobank Personal Assistant My Consent Choices My samples may be used by: research institutes that are members of the original study (excluding those on your exclude-list any study in the same research field as the original study (excluding those on your exclude-list any research field (excluding those on your exclude-list) OR apply custom preferences for individual samples. Excluded Research Fields Custom Preference Profiles

The new system would allow you to keep track of your data, including a record of what samples you have donated and what they have been used for. It would also allow you to monitor and update your consent choices over time. For example, you may want to allow your samples to be used in a new research project or might want to put some limits on what kinds of research can be done using your personal information.

The idea behind the Tablet interface is to make it quick, easy and safe for you to track your involvement with on-going research projects.

What can you do to help?

We have developed a prototype model of the Tablet which has some basic options installed. What we want to do now is get feedback from people who have experience of participating in research to make sure that what we have developed so far is useful and relevant.

We are looking for volunteers to attend an informal discussion ('a focus group') in Oxford. You will get to explore the prototype tablet and take part in a group discussion about it with other volunteers. We are interested to know whether, and how, you think it might be useful, what kinds of options you would like to see included or removed, and any other ideas or suggestions you have.

Volunteers will only be required to attend one focus group, which will last no longer than two hours.

Who is carrying out the focus groups?

Academics from the HeLEX Centre and the LSE will conduct the focus groups in Oxford.

Will my data be confidential?

Yes. Your personal information and your opinions will be kept confidential and only used by members of the project team to evaluate responses to the tablet.

Do you have approval to carry out this study?

We have the favourable opinion of an NHS Research Ethics Committee for this study (with REC ref no: 10/H1207/37).