

## The Oxford Biobank

## Information Leaflet





















Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM)
University of Oxford, Churchill Hospital
Oxford, OX3 7LE

#### What is the purpose of the Oxford Biobank?

Environmental factors such as diet, smoking, obesity and lack of exercise together with inherited (genetic) factors increase the risk of developing heart disease and diabetes. The aim of the study is to gain a better understanding of these inherited factors and to investigate why some people develop these conditions and others do not.

#### Why should I take part?

The Oxford Biobank is collecting a wide range of data including a genetic sample from healthy individuals, aged 25-55; people with Type 2 diabetes aged 25-75; people who joined the NIHR Bioresource from the INTERVAL or COMPARE study and a workplace-based (OUH) recruitment of people aged 25-55. By volunteering to participate, you help us to carry out research in a number of different diseases and conditions like diabetes, obesity, heart disease and other metabolic illnesses. Your participation may also help in the development of new treatments for these illnesses, helping future generations.

## Do I have to take part?

No. It is up to you to decide. If you decide to take part you will be invited to an appointment, which will take about 1 hour. If you have diabetes you can also choose for your contact details to be retained in a Type 2 diabetes register, and not participate in the BioBank. You may withdraw at any time and this will not affect any health care you receive in the future.

#### What are the exclusion criteria?

If you have a severe ongoing illness you would not be able to take part. Pregnant women are also excluded but you might like to take part after your pregnancy.

## What happens if I agree to take part?

- If you agree to help us, one of our team will contact you to arrange your visit to the Clinical Research Unit at OCDEM, Churchill Hospital, Oxford.
- The night before your appointment you will be asked not to eat or drink anything after 9 pm except water.
- During your visit one of the nurses will explain about the study and ask you to sign the consent form if you agree to take part.
- We will discuss your medical history and family history.

- We will measure blood pressure, height, weight, waist and hip circumference, and body fat by pinching the skin on your arm, hip, back and thigh.
- We will take up to a 50 ml blood sample (10 teaspoons) and we may ask for a urine sample too.
- We will perform a DEXA scan of your total body and regional fat; if you are breast feeding you will not be offered the scan. Please see the additional information sheet regarding the DEXA scanner.
- The whole visit will last approx 60 minutes and you will be offered a snack before you leave.

## Will taking part in the study be kept confidential?

Yes. The data that we obtain from you will be strictly confidential. All study records and samples will be identified only by a code which is a unique identifier in our database. We will only use your personal and contact details where this is necessary to contact you about future studies. Information that can identify you is stored securely in a department that routinely handles sensitive information and procedures are in place to ensure the highest possible data security and integrity.

Any data released to researchers will be in an electronic form and will be pseudonymised; it will contain no means of identifying you outside of our secure system. If your samples are released for further analysis to scientific collaborators, for example academic or industry, those researchers can request information such as your BMI, age, blood sample results etc, which will enable them to analyse their data. However, none of your personal information or data that could be traced to you will be released. Responsible members of the University of Oxford and regulatory organisations may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

For more information of how your data will be used, how long it will be held, and your rights please follow the link to our Privacy Notice below -

http://www.oxfordbiobank.org.uk/for-volunteers/data-protection/

# What are the possible disadvantages or risks of taking part?

- Blood sampling may cause some discomfort and a possibility that a small bruise may develop.
- The DEXA scan will involve exposure to a small amount of radiation, please see the attatched DEXA information sheet.

#### What are the possible benefits of taking part?

There are no advantages but the study will allow us to have a better understanding of common diseases and how to prevent them.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the OBB Team (01865-857284). If you remain unhappy and wish to complain formally, the University of Oxford has a formal complaints procedure and one of the team members will provide you with the information. The University of Oxford takes responsibility for the biobank and has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in the Biobank.

#### What happens to the samples?

We perform some biochemical analyses on the samples soon after your visit. Remaining samples will be stored in freezers in a secure area within OCDEM. These may be used for future analysis when new methods are developed.

Samples will be used to determine your genetic makeup; this may include determining the sequence of all or part of your DNA code.

We may also isolate and test other components of your blood such as RNA and protein.

Should you decide to withdraw from the study at any time, you can choose to have the samples destroyed.

## What will happen to the study results?

Following your visit day we will send you a letter, either by post or email, containing some key blood results, your blood pressure and your BMI. If there is an abnormal result we will contact you and discuss options and may advise you talk to your GP.

If you have diabetes we will not send results as we assume that your GP is checking your blood results regularly, and we will ask you to give informed consent for us to access your medical records.

You will not be identified personally in any report or publication.

#### **Future studies**

If you agree to participate in the Oxford Biobank we might approach you at a later date to ask if you are willing to participate in more detailed studies. At that time you are completely free to state that you are not willing to participate, and you should not feel committed to participate because you have previously donated a blood sample.

## Who is organising and funding the Oxford Biobank?

The Research is organised by a team from the Oxford Centre for Diabetes, Endocrinology & Metabolism, Churchill Hospital, Oxford and is funded by the NIHR Oxford Biomedical Research Centre.

#### How do I take part?

If you decide that you would like to take part or you have any queries about anything regarding the Oxford Biobank please contact the team on:

Phone: 01865 857284

Email: <a href="mailto:obb@ocdem.ox.ac.uk">obb@ocdem.ox.ac.uk</a>

Address: OBB Team, Clinical Research Unit OCDEM, Churchill Hospital, Oxford, OX3 7LE

## Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by South Central-Oxford C Research Ethics Committee, (ID 23/SC/0411).

#### **Further information**

If you would like more information before deciding, please visit our website at:http://www.oxfordbiobank.org.uk/

Reasonable travel expenses and parking expenses will be reimbursed

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This site map can be found at the following link:

www.ouh.nhs.uk/hospitals/churchill/documents/ch-site-map.pdf





NIHR Oxford Biomedical Research Centre