



INFORMATION LEAFLET for Repeat Assessment Visit

You are being invited to take part in a repeat assessment visit for UK Biobank. Please note that this invitation for a repeat assessment is not based on any information that has already been collected about you, either at your initial assessment visit or afterwards.

Before you decide whether to attend, please take the time to read this leaflet carefully. It explains why we are asking you to help in this way and what it would involve. Taking part is entirely optional.

If anything is not clear, or if you would like more information, please telephone free of charge on 0800-0-276-276 to talk to a member of the project team. More information about UK Biobank is available at www.ukbiobank.ac.uk. At the repeat assessment visit, there will be a further opportunity to ask any questions that you might still have.

Thank you for your continued support of UK Biobank.

Contact details:

UK Biobank
1-4 Spectrum Way
Adswood
Stockport
Cheshire
SK3 OSA

Email: ukbiobank@ukbiobank.ac.uk

Freephone: 0800-0-276-276

What is the purpose of UK Biobank?

The purpose of UK Biobank is to support research that leads to improvements in the prevention, diagnosis and treatment of a wide range of different illnesses (such as cancer, heart disease, diabetes, dementia, and joint problems).

In particular, UK Biobank allows scientists to study how the health of the 500,000 participants is affected by their lifestyle, environment and genes. By analysing the answers, measurements and samples collected from participants, researchers should be able to work out why some people develop particular diseases while others do not.

This research should help to find new ways to prevent premature death and disability from many different diseases. Taking part in UK Biobank is not intended to help participants directly. However, it should give future generations a much better chance of living their lives free of diseases that disable and kill.

Why do you want to see me again?

We need to repeat the initial assessment (questions, measurements and samples) every few years in different samples of the participants so that scientists who use the resource can take account of changes in the health and lifestyle of the UK Biobank participants over time.

Invitations to a repeat assessment are not based on any information that has already been collected about participants. Instead, they are being sent to participants who live in the area surrounding the repeat assessment centre at UK Biobank's coordinating centre in Stockport.

We should like you to attend a repeat assessment visit whether you are in good health or have health problems, and whether you have a disability or may require help reading questions during the visit. You can still take part even if you might not be able to undergo some of the physical measurements.

If you might need extra assistance to attend the assessment centre, or want to tell us about anything that may make it easier for you to attend, please telephone 0800-0-276-276.

Do I have to take part in this repeat assessment?

No; attendance is entirely voluntary. Even if you do not attend, your participation in UK Biobank will continue to be of value for research.

What happens DURING the repeat assessment visit?

The repeat assessment visit should take between 2-3 hours. During the visit, you would:

- Have the chance to ask any questions that you might have before agreeing to having the repeat assessment.
- Answer questions on your health, lifestyle and diet, memory, work and family history. Although you have answered these questions before, this information will allow scientists to take account of any changes in the health and lifestyle of participants over time.
- Have non-invasive measurements of blood pressure, pulse rate, height, weight, body fat, vision, fitness, grip strength, bone density and lung function (including some that you may not have had at your initial assessment visit). Again, repeating the measurements will allow scientists to take account of any changes over time.
- Give small samples of blood (about 3 tablespoons), saliva and urine for long-term storage and analysis (including genetic data).
- Receive information about some of your measurements, although the visit is not intended to be a “health check”. (None of your individual results will be released to your doctor or anyone else.)

Note: If, for any reason, you are not able to undergo some of the physical measurements then you can still have the assessment.

What happens AFTER the repeat assessment visit?

Your blood, urine and saliva samples would not generally be analysed immediately following collection. Instead, during follow-up over the next few decades, your stored samples would be analysed for approved medical and other health-related research.

As was agreed at the initial assessment visit, UK Biobank will follow the health of all of the participants for many years. This is being done through medical records and other records that may be related to health (e.g. occupational or residential information).

At some time in the future, you might be re-contacted by UK Biobank and asked more questions, although giving such additional help would be entirely optional. Similarly, you might be asked to attend another repeat assessment visit, although attendance is optional.

What should I do if I am willing to attend?

Please let us know as soon as possible if you are willing to attend a repeat assessment visit. This can be done in a number of ways.

If the provisional appointment on your invitation letter is convenient for you, then you can confirm it by:

- Visiting the project website at www.ukbiobank.ac.uk;
- Completing and returning the enclosed pre-paid reply form; or
- Telephoning 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm).

If the appointment is not convenient then you can change it easily by telephoning 0800-0-276-276.

Appointments are generally available to start from 8:00am to 6:00pm every day of the week (Monday to Sunday) in order to help you to find a time that is convenient for you.

The assessment centre is on the ground floor of the coordinating centre and plenty of free parking is available outside of it. It has easy wheelchair access. Please let us know if you need any special assistance (e.g. have poor vision or are hard of hearing).

What should I do if I am not willing to attend?

If you do not want to take part then we should be grateful if you would tell us so that someone else can be given the appointment. You can cancel the appointment by:

- Visiting the project website at www.ukbiobank.ac.uk;
- Completing and returning the enclosed pre-paid reply form; or
- Telephoning 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm).

What can I do if I am unsure about attending?

More details about UK Biobank are given in the rest of this leaflet. If this does not answer your questions, then please telephone us free of charge on 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm) and ask for more information. Alternatively, if you can access the internet (perhaps at home, work or in the local library) then more details are available at www.ukbiobank.ac.uk.

At the start of the repeat assessment visit, there will be a further opportunity to ask any questions that you might still have.

Can I claim travel expenses for attending?

Yes; you can claim back any reasonable travel expenses (including standard train and bus fares, and mileage for car journeys). A claim form will be provided at the end of your repeat assessment visit, and it would help us if you attached your travel receipts.

Car parking at the assessment centre is free. For those travelling by train, free transfers are available from Stockport station. If registered as disabled, you can also claim the travel expenses for a companion.

Please telephone 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm) if you have any questions about travel to the assessment centre.

Do I need to do anything BEFORE the assessment visit?

The most important thing to do is to confirm that you can attend on a day and time that is convenient for you. We shall then send you written confirmation of your appointment, along with directions to the assessment centre.

A short pre-visit questionnaire will be included so that you can make a note about certain things that you might not otherwise remember:

- All medications, vitamins or supplements you are taking regularly.
- All operations that you have had at any time in the past.
- Serious medical conditions that seem to run in your family.
- Your birth weight, whether breastfed, and place of birth (if known).

How do I prepare for the repeat assessment visit?

When you attend your assessment appointment, please:

- Bring your completed pre-visit questionnaire, and the directions for the assessment centre so you don't have difficulties finding us.
- Bring any reading glasses that you use as you will need to be able to read clearly from a computer screen (if you wear contact lens it might be easier for the eye test if you wear your glasses instead).
- Please wear light loose-fitting clothing. If possible, avoid wearing stocking/tights (to make measurements that need bare feet easier) and long skirts/dresses (to make the fitness test easier).

- Be prepared to spend up to 3 hours in the assessment centre. Refreshments (such as salads, sandwiches, tea, coffee and soft drinks) will be provided at the end of the visit (after the blood samples have been collected).

Do I need to do everything at the repeat assessment visit?

No. If you feel uncomfortable about answering certain questions then you do not need to answer them. Similarly, if you do not want to have certain measures, or to give a urine or saliva sample, tell the staff.

We do, however, need your agreement to take blood samples, which will be stored and used in approved research.

Are there any risks for me in attending a repeat assessment?

Undertaking a repeat assessment should not cause you any harm.

It is possible that you may be slightly uncomfortable with some of the questions asked, or measurements made, during the assessment visit. You will be able to skip all such questions or measures. You may feel some discomfort when you have blood taken, although our staff are specially trained to reduce this risk.

The repeat assessment visit is not a “health check”: it is not intended to change directly what happens to people who attend. You would only be given the results of some of the standard measurements (e.g. blood pressure) that were made during your assessment visit.

Over the coming years, a very wide range of tests will be done on your blood, urine and saliva samples for approved health-related research. None of your particular results will be given to you, your doctors or anyone else. So, taking part should not have any adverse effects on you (including your ability to get insurance).

Participation involves a minimal risk in relation to the use of personal information. Great care will be taken to ensure the confidentiality of all data (see below). Information that might identify you will be removed from any information and samples provided to researchers in order that they cannot be traced back to you.

If you have any concerns about these or any other issues, please call 0800-0-276-276 or look on our website at www.ukbiobank.ac.uk

How will information about me be kept confidential?

UK Biobank has put a number of rigorous procedures in place to protect the confidentiality of participants. These include:

- Keeping information that might identify individuals (such as their name and address) separate in UK Biobank's databases from other information about participants.
- Computer security to block unauthorised access (for example, by "hackers") to the computers that hold personal information.
- Access to personal information is restricted within UK Biobank, and all staff sign confidentiality agreements as part of their employment contracts.
- Data or samples provided to researchers will not include personal identifying details.

This should prevent information that identifies any participant from being used – inadvertently or deliberately – for any purpose other than to support approved research that is in the public interest.

Who will be able to use my information and samples?

Data and samples from UK Biobank participants are available only to researchers who have relevant scientific and ethics approval for their research. This includes researchers who are working in other countries and in commercial companies looking for new treatments.

Results from any tests made on participants or their samples will be put in the UK Biobank database so that they are available to all approved researchers. Scientists must also publish the results of all research based on the resource so that people can benefit from it.

Insurance companies and employers will not be given any individual's information, samples or test results, and nor will we allow access to the police, security services, relatives or lawyers, unless forced to do so by the courts.

Results of research conducted on the UK Biobank resource will be made available to participants, and anyone else who might be interested, at www.ukbiobank.ac.uk.

How do I withdraw if I want to do so?

UK Biobank will be most valuable if people do not withdraw from it. Consequently, participants are asked to discuss any concerns that they might have with a member of the project team if they are considering withdrawal from the project.

You can withdraw by telephoning us on 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm) or by writing to the coordinating centre office. This would allow us to discuss your concerns with you and to determine the desired level of withdrawal from the following options:

- *“No further contact”*: This means that UK Biobank would no longer contact you directly, but would still have your permission to retain and use information and samples provided previously and to obtain and use further information from your health records.
- *“No further access”*: This means that UK Biobank would no longer contact you or obtain further information from your health records in the future, but would still have your permission to use the information and samples provided previously.
- *“No further use”*: This means that, in addition to no longer contacting you or obtaining further information about you, any information and samples collected previously would no longer be available to researchers. UK Biobank would destroy your samples (although it may not be possible to trace all distributed sample remnants) and would only hold your information for archival audit purposes. Your signed consent and withdrawal would be kept as a record of your wishes. Such a withdrawal would prevent information about you from contributing to further analyses, but it would not be possible to remove your data from analyses that had already been done.

If, having discussed the options and your concerns, you did decide to withdraw then we would send you a Withdrawal Form to confirm your wishes in writing. This form can be completed by you or, if you are not able to do so for some reason (such as illness), by someone able to act on your behalf.

Who is organising and funding UK Biobank?

UK Biobank has been set up by the Medical Research Council and Wellcome Trust health research charity. It is also supported by the Department of Health, the Scottish and Welsh Governments, health research charities (such as the British Heart Foundation) and the National Health Service.

UK Biobank is a not-for-profit charitable company that acts as the legal owner and guardian of the database and sample collection. The charity's role is to protect this valuable resource so that scientists can do a wide range of health-related research in the future.

UK Biobank collaborates with scientists from many British and overseas universities and research institutes, who have helped develop its design. These plans have been approved by the NHS North West Research Ethics Committee. In addition, the independent Ethics and Governance Council monitors the development and use of the resource (see www.egcukbiobank.org.uk).

What happens if something goes wrong?

The risks of participants suffering harm as a result of taking part are minimal, but UK Biobank has insurance cover in place to provide compensation for any negligent harm caused by participation.

Who do I contact if I have any concerns?

If you have any concerns or complaints about anything to do with UK Biobank then you can telephone us free of charge on 0800-0-276-276 (Mon-Sun; 8.00am to 7.00pm) and ask to speak directly to a senior member of the team. Alternatively, if you would like to write to the person in charge, please send your letter to:

Professor Sir Rory Collins
UK Biobank
1-4 Spectrum Way
Adswold
Stockport
Cheshire
SK3 OSA

Email: ukbiobank@ukbiobank.ac.uk

We shall reply to your letter promptly in writing, unless you enclose your telephone number and wish to discuss your concerns with us.

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