Our Future Health



Bringing people together to develop new ways to prevent, detect and treat diseases

September 2026 (version 4.2)







You are being invited to take part in a research programme called Our Future Health.

Taking part involves:

	Reading some information about Our Future Health
	Reading and signing a consent form
	Giving Our Future Health permission to access, store and link to your health-related data
	Filling in a questionnaire about yourself
	Giving a sample of your blood

Before you decide whether to join, it is important that you understand more about Our Future Health. Please read the information provided here, which includes:

1. About Our Future Health.
2. What joining involves.
3. How we protect your data and samples.
4. Benefits and risks of taking part.
5. How we are run and funded.

If you have any questions, please get in touch by emailing us at **support@ourfuturehealth.org.uk** or calling us on **0808 501 5634**.

1. About Our Future Health

What is Our Future Health?

Our Future Health is the UK's largest ever health research programme.

Today, too many people spend many years of their later lives in poor health. The aim of Our Future Health is to help future generations live in good health for longer.

Our Future Health plans to collect information and samples from up to five million adults across the UK. Researchers will be able to apply to study the information and samples to make new discoveries about health and disease.

Discoveries made through Our Future Health could lead to new ways to predict, prevent and detect diseases earlier in life when they can be treated more easily, including diseases such as dementia, cancer, diabetes, heart disease and stroke.

We are inviting you to join Our Future Health and share your health information to help make these discoveries about health and disease.

We are encouraging people from all backgrounds and ethnicities to take part in Our Future Health. In the past, people from Asian, Black and minority ethnic communities, and people with lower incomes, have not been well represented in research studies. This has meant that new discoveries have not helped everyone equally.

The research programme is run by the Our Future Health charity in partnership with the UK Government, Life Sciences industry and charity partners, and the healthcare systems of all UK nations.

Why am I being invited to join Our Future Health?

You are being invited to join Our Future Health because you are over the age of 18 years and you live in the UK. You may have heard about the research programme from a number of different places, for example via the NHS (such as a hospital, or your GP) or you may have received a letter, email or text about the research programme.

Do I have to join Our Future Health?

No. Joining is entirely your choice. You may want to discuss your decision with friends or family. If you join and then change your mind, you can leave at any time – please see the "What if I change my mind and want to leave the programme" section for more information.

2. What joining involves

What will I be asked to do if I join Our Future Health?

If you decide to join Our Future Health, we will ask you to:

- **Read and sign a consent form.** This is a document that will ask you to provide confirmation that you agree to take part in Our Future Health and will include a request for your permission to:
  - **Permit us to access health-related records about you.** We will access, store and link to health-related records about you to maintain an accurate picture of your health. Health-related records may include, for example, information collected during interactions you had with a health care professional, details of specific diseases like cancer and how they were treated, test results, and medical images, such as from scans. These records may be held by the NHS or other organisations (for example disease or condition specific registers, GP practices, opticians or blood donor centres) within the UK. Examples of health-related datasets we may link to can be found on the Our Future Health website: (https://research.ourfuturehealth.org.uk/data-and-cohort/#linked-health-records-data)
  - To link to these health-related records, we will securely share some of your identifiable data, like your name, date of birth or your NHS number, with the organisation holding the records. This is to ensure we link to the correct record.
  - We will keep collecting information about you from health-related records as the research programme goes on, for many years. This means if you remain in the research programme, we will continue to collect information about you over the course of your lifetime.
- **Fill in a questionnaire about yourself.** We will ask you to complete a questionnaire about your lifestyle and health. The questionnaire will be separated into sections, and you don't have to complete it all at once. Some of the questions will ask about things that some people feel are private, such as your weight or income. We ask these questions because there is often a link between these factors and people's health. You may find it uncomfortable to be asked questions about your health, background or lifestyle in our questionnaires. You do not have to answer every question if you do not want to.
- **Give a sample of your blood.** If you agree to take part, we will ask you to provide a blood sample. Exactly when we collect your sample will depend on where you go to provide it. Please see the "How will you collect my sample?" section for more information.
- **Have some physical measurements taken.** You may also have some physical measurements taken when you provide your blood sample, such as:
  - Blood pressure and pulse rate.
  - Sitting and standing heights.
  - Waist, hip and neck circumferences.
  - Weight and body fat composition.

How will you collect my sample?

You will be asked to provide a blood sample for Our Future Health. We want to make taking part as easy as possible.

If you are invited to take part at an Our Future Health centre or community pharmacy, an appointment can be booked at a time that suits you.

As our programme expands, we may try new ways of making it easier to participate. For example, we may explore offering participants an opportunity to provide their blood samples at home.

If you are invited to take part through your GP practice or hospital, we will make sure that your blood sample is taken during a routine appointment.



What will you do with my sample?

Once we have collected your blood sample, it will be divided into smaller samples. We will use one of the samples to extract **DNA** (genetic information) and the rest of the samples will be stored for future research. For example, in the future, we may use some of your stored samples to look at cholesterol, or blood sugar levels.

Although over 99% of DNA is the same for all humans, there are lots of tiny differences in people's DNA. These differences are called **variants**, and they contribute to many of the differences between people, such as a person's blood type. Some variants are **common** and some are **rare**.

Importantly, some variants influence a person's risk of developing different diseases.

We'll use a technology called a **Single Nucleotide Polymorphism array (SNP array)** to look at some of the variants in your DNA.

If possible, we may also use a process called **genome sequencing** and other genetic technologies to look at your DNA. Genome sequencing reads and records almost all the DNA in your genome (your complete set of DNA).

Your samples and DNA will be stored in our tissue banks for future analysis by researchers.

In the future, researchers may also use your sample to measure other parts of your blood, to see if they are linked to health and risk of disease.



Will I receive personal results from my samples and data?

At your appointment, you may be offered results from the measurements taken, such as your blood pressure. These measurements are taken for research purposes and are not intended as a personal health check. Our Future Health is a research programme and does not form part of your routine clinical care.

As Our Future Health is a research programme, your information will not be used in the diagnosis or treatment of disease, and you will not automatically receive personal feedback about your samples, DNA or other data.

But in the future, we will get in touch to ask if you would like to receive personal feedback from your samples, DNA or other data. You might learn new information about your health or risk of diseases such as diabetes and heart disease from this feedback. We will always give you more information and the chance to ask questions before you make your decision, and you can say yes or no.

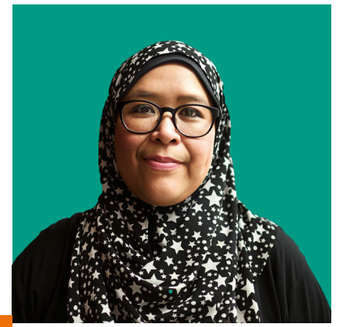
Will you contact me again in the future?

If you agree to take part in Our Future Health, we may contact you again in the future. You can update your preferences on what further communication you would like to receive from us at any time, either directly from the emails we send you, or through your online account. However, you will not be able to opt-out of all communication without withdrawing from the research programme (for more information on withdrawing from the programme, please see the "What if I change my mind and want to leave the programme?" sub-section).

Reasons we might want to contact you include (but are not limited) to:

- Send you news and updates about the research programme.
- Ask you about your experiences of taking part.
- Ask you to complete more questionnaires.
- Ask for your permission to collect relevant information about you from other sources.
- Invite you to attend an appointment to give (further) biological samples including blood.
- Invite you to attend an appointment for other assessments, such as imaging.
- Ask if you would like to receive feedback about your health or risk of disease.
- Invite you to take part in other research studies. This may be based on health-related information about you, such as your genes, lifestyle habits or medical conditions.
- Invite you to take part in, or contribute to the development of, public or promotional materials and/or activities to support the programme.

You do not have to say yes to taking part in any other research studies or provide any other information or samples.



Who will do the research and how will it work?

Some of the research will be done by researchers at Our Future Health, but most of it will be carried out by other researchers.

These researchers may be from countries around the world and could be from organisations such as universities, charities or industry.

Any researcher who applies to do research will need to go through a strict application process, where their proposals will be carefully reviewed by an Access Board. The Access Board includes scientific experts and initially, members of the public, but will later include members of the public taking part in the Our Future Health programme.

The Access Board will only approve health-related research proposals that are for the public good and come from registered researchers. Any researchers who are granted access will only be able to see de-identified data about you. This means that they will not be able to see your name, contact details or any information that will directly identify you as an individual. In addition, researchers who are granted access will also need to sign an agreement that says they will not try to re-identify any of the participants from the data they are able to see.

Researchers will be able to apply to do two kinds of research:

- Research that only uses data and samples held by Our Future Health.
- Research that involves re-contacting people taking part in Our Future Health. You will be recontacted directly by Our Future Health, and not by researchers. All identifiable details about you will be withheld from researchers unless you consent to these being shared.

Research that only uses data and samples held by Our Future Health

Some approved research studies will look at the data or samples held by Our Future Health to make discoveries about human health and disease.

The data and samples you provide to Our Future Health could help in making these discoveries.

Researchers working on these studies will not have access to your name or contact details.

Research that involves re-contacting people taking part in Our Future Health

Researchers might want to invite you to take part in new research studies. You may be invited based on health-related information about you. These studies could involve you receiving feedback in the form of results or learning new information about your health or risk of disease. Sometimes researchers look at people who have a risk of disease, as well as those who do not. If you are invited to take part in a future study, it does not necessarily mean you have a risk of that disease. You will be given information to help you make your decision about taking part.

If you are identified for a particular research study, the following steps will happen:

Step 1: Our Future Health will first contact you to give you some information about the study you have been identified for. You can say yes or no to receiving further information.

Step 2: If you say no, we will not contact you again about that study.

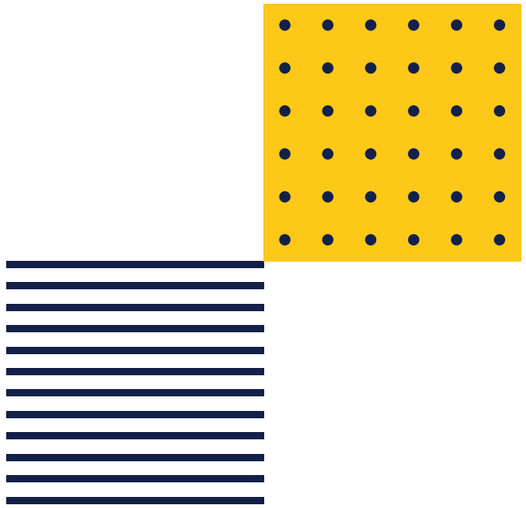
Step 3: If you say yes, we may direct you to make contact with the study team, or with your additional consent, we will pass your contact details to the researcher or organisation that is running the study. They may invite you to take part and provide some more information about the study.

We will only share your contact details, information, or data with researchers or research organisations running approved additional research studies if you give us your specific consent to do so.

How long will I be involved for?

Our Future Health will run for a very long time. We hope to collect as much information as we can about participants' health as they get older, so researchers can look back to find the earliest signs of diseases.

That's why, if you decide to take part, we would like to be able to keep track of your health for the rest of your life, using your health records. Researchers may continue to use your data in studies, even after you die, or if you lose mental capacity. For more information on how we look after your data, please see section 3: "How we protect your data and samples".



What if I change my mind and want to leave the programme?

You can withdraw from Our Future Health, or reduce your involvement, at any time.

You don't have to give a reason, but we will ask you to choose between two options:

1. Partial withdrawal[1]
2. Full withdrawal[2]

More information about each of these options is provided below.

[1]Partial withdrawal. This means we will not contact you again, or get any further information from your health records, but we can still analyse the samples and data you gave before you withdrew.

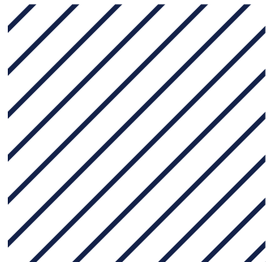
[2] Full withdrawal. This means we will not contact you again and we will destroy all the data and samples we collected from you. An updated research data set is released to researchers every six months. It won't be possible to remove your data from any research that has already started, and from any data sets released for research that were prepared before you withdrew. You can find more information about what happens to your data and samples if you decide to withdraw by visiting our website.

Withdrawal options

	Option 1: Partial withdrawal	**Option 2:** Full withdrawal
Can we continue to get new information from your health records and other data sources?	NO	NO
Can we continue to use the samples and data you already gave?	YES	NO*

*We will destroy the samples and data we have for you. However, it won't be possible to remove them from any research that has already started, and from any data sets released for research that were prepared before you withdrew.

If you would like to withdraw, you can find out more information by logging into your Our Future Health account.



3. How we protect your data and samples

Who is responsible for my data and samples?

Our Future Health will be responsible for your data and samples and will strictly control who has access to them. In addition, any researcher who is granted access will also need to agree to protect your data (please see the "who will have access to my data and samples" sub-section for further information). Looking after your privacy and the security of your data is very important to us. The following sections provide more detail on how your data and samples will be managed.

How will my data and samples be stored?

Your data will be stored and managed securely, in line with data protection laws including the UK General Data Protection Regulation (UK GDPR) and the relevant security standards. Full details of where and how we store your data is available in our Privacy Policy here: **https://study.ourfuturehealth.org.uk/privacy**.

We will publish a current record of where the data is stored, and who processes it, on the Our Future Health website.

All the information we collect about you will be encrypted (described using a code) when it is in transit and at rest, and stored according to strict security standards.

Your samples, extracted DNA, and health-related data (including genetic data) will be de-identified. This means that identifiable data, such as your name, NHS number or address, will be removed from these items and stored securely and separately.

Within the UK, your samples will be stored in line with the Human Tissue (England, Wales and Northern Ireland) Act 2004 and Human Tissue (Scotland) Act 2006, which are UK laws that control how human samples (such as a blood sample) are managed. Your de-identified samples, extracted DNA, and health-related data, including genetic data, could be sent to approved processors outside the UK for analysis, in line with UK GDPR and Our Future Health's Privacy Policy.

Who will have access to my data and samples?

Our Future Health

If you decide to join Our Future Health, we will store the personal identifiable data (such as your name and address) that you provide. A limited number of staff at Our Future Health will have access to this data so we can contact you and link to health-related records about you.

Having access to your personal identifiable data also means that we can link your health-related records to the other data that we collect, for example your genetic data, or your questionnaire data. This helps us build a full picture of your health. Before letting researchers see this information we will remove any information that could be used to identify you.

If you lose mental capacity we would like to continue processing your de-identified data to enable research into health and disease; however, we may break the link with your identifiable data to ensure we comply with the relevant UK nation's law. These laws include The Mental Capacity Act (England and Wales) 2005, Mental Capacity Act (Northern Ireland) 2016 or Adults with Incapacity (Scotland) Act 2000.

Processors for health records

To access health-related information about you that is stored by the NHS and other organisations, we will need to share some of your identifiable data (for example your NHS number, name or date of birth) with them. We will only share what is absolutely necessary, and strict controls will be in place to protect your personal data.

Registered researchers

Registered researchers conducting studies that only involve data held by Our Future Health will only be able to access your de-identified data for their research via a highly secure online data storage system. These secure systems only allow registered researchers to use the data within them for legitimate research purposes. It will never be possible for researchers to download your de-identified data from a secure online data storage system.

Some of our charity, academic or industry partners have their own secure data storage systems. They can apply to Our Future Health to have their systems 'accredited'. This means that they have strict reviews of their technical, security, operational and data governance processes. If an organisation has an accredited storage system and they have a study approved by the Access Board, they will be able to hold a copy of de-identified Our Future Health data in their own system to do research. In addition, any researcher or organisation using their own secure data storage system will be reviewed every year to confirm they are still complying with the Our Future Health terms and conditions.

We will never allow access to your data for anything other than for health research that is for the public good. Results that may be shared for the public good include sharing de-identified findings with public bodies such as central and local government, arm's length organisations or public corporations to inform policy and population health planning. De-identified findings may be published in scientific journals or through other forms of media to raise awareness of Our Future Health amongst participants and researchers. We will never sell or provide your personal identifiable data for the purposes of advertising or, for example, to insurance companies.

We will never allow your samples to be used in research involving animals or to create cell lines (an immortal group of cells used in research) without your express permission.

Your name and identifiable information will never be used when the findings from Our Future Health are published and promoted.

Where can I find out more about how my information will be used?

You can find out more about how we will use your information:

- By reading the **Participant privacy notice – Our Future Health**
- By sending an email to **support@ourfuturehealth.org.uk**
- By calling us on **0808 501 5634**

4. Benefits and risks of taking part

What are the benefits of taking part?

Joining Our Future Health is an act to help others. You will be giving your time and data for free to help researchers make discoveries about human health and disease. This will benefit future generations, helping people to live in good health for longer.

In the future, we will contact you to offer you some personal feedback about your health arising from your samples or data. You might find this helpful, but you might not. You will not benefit financially in any way even if discoveries made from Our Future Health lead to commercial gain for researchers.

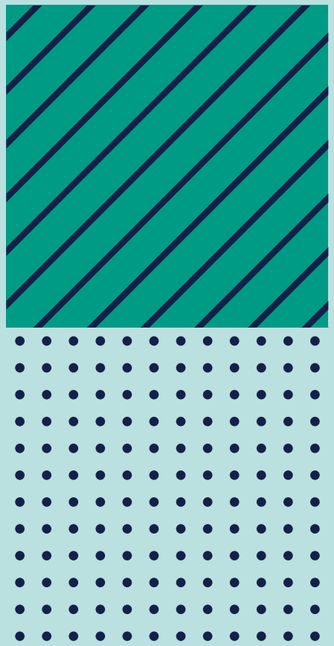
What are the risks of taking part?

There is very little risk of physical injury in taking part. Having a blood sample taken may cause discomfort and minor bruising around the area.

We are taking a lot of security precautions, including being certified according to standards set by the National Cybersecurity Centre and the NHS. However, the risk can never be zero. There is a small risk that, if there was a security breach, someone could see or use the data we have about you.

In the future, if you choose to receive personal health information or agree to take part in additional research studies, you might learn new information about your health that makes you feel worried. You will always have a choice in whether to take part in additional activities. You will never receive health information or be included in further research studies without your express permission.

There may also be other risks that we don't know about yet, and we will get in touch if a new risk emerges.



5. How we are run and funded

About our funding

Our Future Health is funded through the government Office for Life Sciences, the Life Sciences industry and charity partners who will work together to design and deliver the programme.

Our Future Health is a very large programme and we are bringing in funding partners such as charities and companies that conduct health research and make the medicines, tests and equipment used to prevent, detect and treat diseases. We will always be open about who funds Our Future Health and this information can be found on our website **www.ourfuturehealth.org.uk.**

Funding partners will be allowed to apply to do research with the data from Our Future Health. Like all requests, these applications will go through our Access Board*.

All other registered researchers using Our Future Health will help with its running costs on a means-tested basis.

*All research applications, whether from funders or researchers at industry companies, academic organisations, government, the NHS, or other charities, will be reviewed in the same way and held to the same standards.

How we are run

Our Future Health is a charity registered with the Charity Commission for England and Wales (charity number 1189681), and the Office of the Scottish Charity Regulator (charity number SC050917). It is also a company limited by guarantee registered in England and Wales (number 12212468).

Like all charities, Our Future Health requires money to operate. However, Our Future Health's ability to trade is limited, because generating revenue is not a charitable purpose, even where it is done to support a charitable activity. We have therefore set up Our Future Health Trading Limited, which is wholly owned by the Our Future Health charity. This is a common operating model for charitable organisations.

The sole purpose of Our Future Health Trading Limited is to generate funds for the Our Future Health charity. It does this through entering into commercial agreements with partners, or by charging access fees for research data in accordance with our access process. In the future, it will charge for services required to enable additional research studies with participants. All profit generated by Our Future Health Trading Limited is returned to the Our Future Health charity to be used to achieve its mission.

We work with other organisations such as the NHS, health charities and companies to deliver this research programme. We also have a number of advisory boards that advise on areas including science, ethics, diversity and inclusion. You can read more about how Our Future Health is run and our advisory boards on our website **www.ourfuturehealth.org.uk/about-us.**

How are commercial companies involved in Our Future Health?

It is possible that research conducted using data from Our Future Health may contribute to the development of new products, such as tests or treatments, that benefit health, and which may eventually become products that make a profit for those companies. Our Future Health receives revenue from access to the research data through Our Future Health Trading Limited.

A core aim of Our Future Health is to enable research that will lead to improvements in the prevention, earlier detection, and treatment of diseases.

Commercial life sciences companies have expertise in discovering, developing, and implementing new products, such as new tests and treatments for cancer. Our Future Health recognises the value of these

companies as partners in funding and delivering advances in health and has partnered with them to add to the funding provided to us from government and charities. By joining forces with these companies across a diverse range of diseases, Our Future Health can also access and support a wider range of research expertise. This knowledge and financial support has enabled Our Future Health to develop a research resource that will accelerate progress and support researchers from many different backgrounds and sectors including the NHS, universities, medical research charities and commercial companies to make new discoveries which can improve health. A full list of organisations that have provided funding can be found at **ourfuturehealth.org.uk/get-involved/partners/**.

Organisations that fund Our Future Health are, like all other researchers, required to submit research applications. These applications are reviewed in the same way as other applicants by our independent Access Board and always subject to the same conditions of access and use explained in this information sheet. Summaries of all approved applications using Our Future Health are made publicly available.

What will happen to the findings from the research?

Discoveries made from Our Future Health will be published in scientific papers and made available online. Your identity and any personal details will be kept confidential.

You should be aware that it will take several years for discoveries to emerge from the research programme.

Any researchers doing research with Our Future Health may profit from discoveries they make.

You can choose to receive regular updates to keep you informed about our progress and the discoveries arising from Our Future Health.

Public involvement

Members of the public have been and will continue to be involved in the development of Our Future Health. This includes focus groups, interviews and a public advisory board.

Who has reviewed and approved Our Future Health?

The Our Future Health research programme has been reviewed and approved by the Cambridge East NHS Research Ethics Committee. The programme approval will be renewed every five years and aspects of the programme may change as it evolves.



Concerns and complaints

If you have concerns about any aspect of this research programme, please contact us on **support@ourfuturehealth.org.uk** or **0808 501 5634**.

If you remain unhappy or concerned and wish to complain formally, you can do this by contacting **complaint@ourfuturehealth.org.uk** or writing to us at Our Future Health, 2 New Bailey, 6 Stanley Street, Salford, Greater Manchester, M3 5GS.

If you have any questions, please get in touch by emailing us at **support@ourfuturehealth.org.uk** or calling us on **0808 501 5634**.

September 2026 (version 4.2)