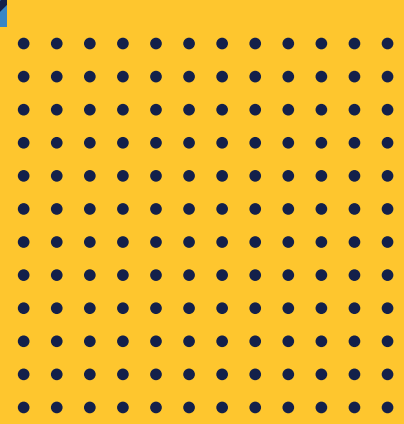
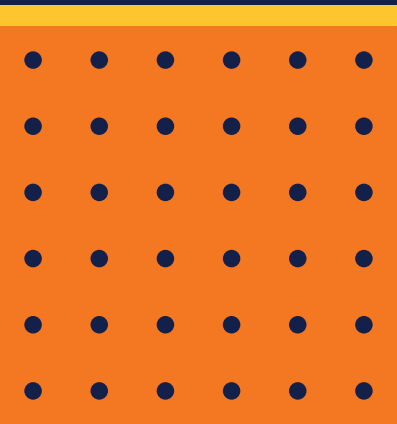
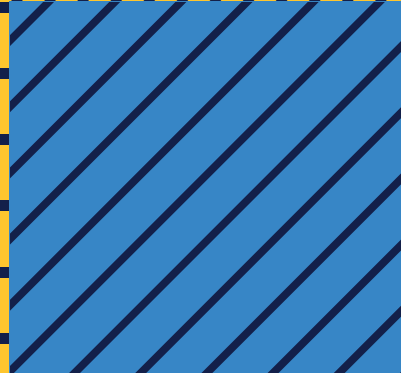
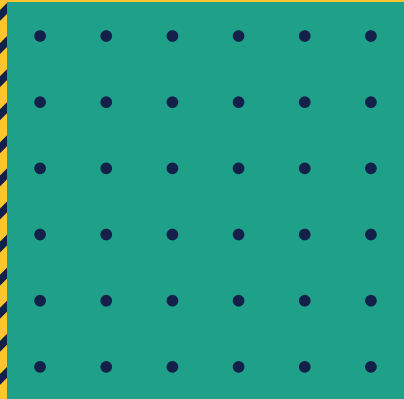
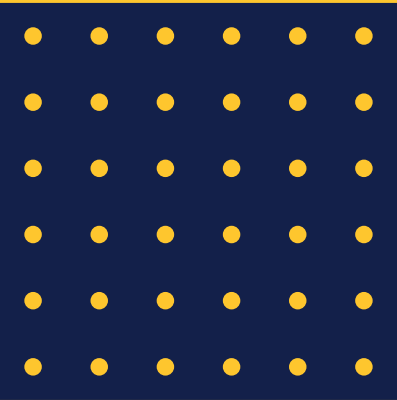


+
Our
Future
Health





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

5 March 2021 (version 1.1)



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
	Filling in a questionnaire about yourself
	Giving a sample of your blood or saliva

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. Risks and benefits of joining
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 0800 XXX XXXX.

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 5 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 Black, Asian 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.

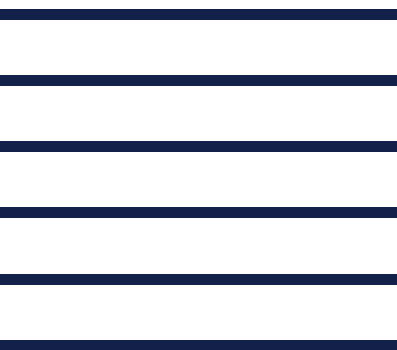
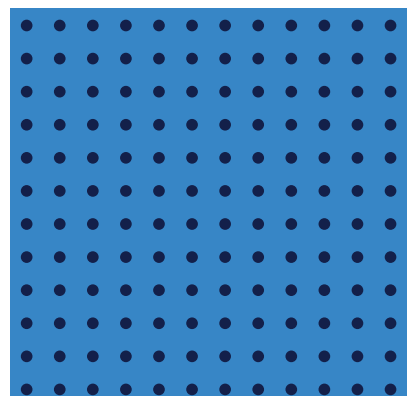
The research programme is run by the Our Future Health charity in partnership with the UK Government, the NHS, other charities and industry.

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 via your GP, hospital, blood donation centre, or a local community group.

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 withdraw at any time.



2. What joining involves

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

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

- **Read and sign a consent form.**
- **Give permission for us to access health-related records about you.**
In the consent form, you will be asked to give permission for Our Future Health to access, store and link to health-related records about you held by NHS Digital and other UK NHS bodies. We will keep collecting this information as the study goes on, for many years.
- **Fill in a questionnaire about yourself.**
We will ask you to complete an online questionnaire including questions about your lifestyle and health. It will ask things that some people feel are private, such as your weight or income. (We will ask about your income because there is a link between income and health. We want researchers to be able to make discoveries that help reduce health inequalities.) You don't have to answer every question. The questionnaire should take 30-40 minutes, but you don't have to complete it all at once. You can do a little at a time.
- **Give a sample of your blood or saliva.**
There is more information about this in the following sections.

How will you collect the sample?

Most people will be asked to provide a blood sample for Our Future Health, but some will be asked to provide a saliva sample instead. This is because saliva is easier to collect at home.

If we ask you to provide a **blood** sample, this will be taken by a health professional at a routine health appointment or at an appointment booked by the Our Future Health team.

If we ask you to provide a **saliva** sample, we will send you a pack in the post with instructions so you can collect a small sample and post it back to us. You might also be asked to provide a blood sample in the future.

What will you do with my sample?

If you have provided a blood or saliva sample, we will extract **DNA** (genetic information) from it.

DNA contains lots of tiny variations or **variants** that contribute to many of the differences between people. Some of these variants influence a person's risk of developing different diseases. Some DNA variants are **common**, and some are **rare**.

A technology called a **SNP array** looks for some common variants in your DNA.

We will run a SNP array to look at your DNA.

There are also other technologies that read DNA sequences. For example, **genome sequencing** reads and records almost all the DNA in your genome (your complete set of DNA), including both common and rare variants.

We might use these other technologies to look at your DNA.

We will store your samples and DNA for future research.

Over the coming years, if you have provided a blood sample, researchers will look to see if other natural substances in your blood, called **biomarkers**, are linked to early signs of diseases.

Will I receive any results from my samples?

We are not planning to provide you with results from your samples at this time.

In the future, we might get in touch to ask if you would like to receive personal results from your samples, or your data. If we do get in touch for this reason, we will give you more information and the chance to ask questions. You can then say yes or no.

Will you contact me again in the future?

If you agree, we would like to contact you again in the future.

Reasons we might want to contact you are to:

- send you news and updates about the research programme
- ask you about your experiences of taking part
- ask you to complete another questionnaire
- ask your permission to collect health-relevant information about you from other sources
- invite you to attend an appointment to give a (further) blood sample
- invite you to attend an appointment for other assessments, such as imaging
- ask if you would like to receive personal information arising from your samples or data
- invite you to take part in other research studies.

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 might be from universities or companies involved in health research, such as pharmaceutical and health technology companies. The researchers may be in the UK or in any other countries that work to our standards.

We will have a clear process in place to confirm the identity and credibility of researchers and their research organisations who apply to do research with Our Future Health.

Approved researchers will be able to apply to do research studies with the data, samples, or participants from Our Future Health.

An Access Review Committee including experts and members of the public will carefully review every application. They will only approve health-related research that is for public good and that comes from legitimate researchers.

Proposals from every type of research organisation will be held to the same standards.

Researchers can apply to access Our Future Health for two kinds of research:

- research that only uses Our Future Health data and samples
- research that involves re-contacting participants in Our Future Health

Research that only uses Our Future Health data and samples

Some approved research studies will look at the data or samples collected 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 participants in Our Future Health

Some approved research studies will build on the data and samples collected by Our Future Health.

The researchers conducting these studies will need to contact participants to do this, for example to ask for further information or samples, run a clinical trial of a new medicine, or test new ways to detect disease early.

For some of these studies, the researchers will want to contact participants based on health-related information about them. These studies might involve participants receiving results or learning new information about their health or risk of disease.

We might contact you about taking part in a study like this. If we do, we will give you some information about it, and you can then say yes or no to receiving further information.

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

If you say yes, the researchers will contact you with more details about the study. You can then choose whether or not to take part in the study. If you say no at this stage, they will not contact you about the study again.

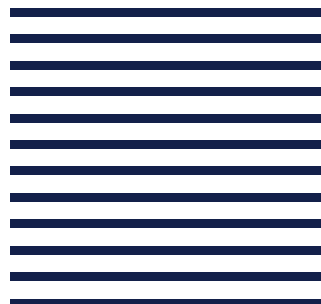
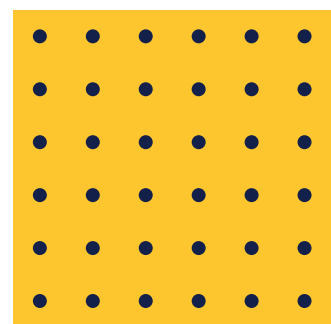
We will never give your contact details to researchers unless you give us your permission.

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 people's 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.

You can read more about how we will use and look after your data below, and you can read our privacy policy.



Can I withdraw from Our Future Health?

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 withdrawal¹
2. Full withdrawal²

More information about each of these options is provided in the Table below.

If you would like to withdraw, you can do this by filling in a form, which you can find on our website here.

If you would like to stay in the study but do not want to hear from us, you can change your contact preferences on the website at any time.

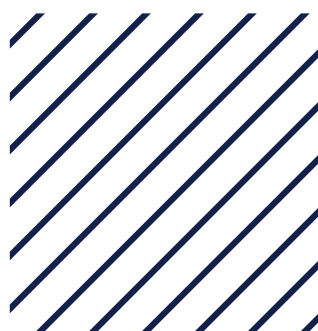
¹Partial withdrawal. This means we will not contact you again, or obtain any further information from your records, but we can continue to analyse the samples and data you provided before you withdrew.

² Full withdrawal. This means we will not contact you again and we will destroy all the data and samples we collected from you. However, it won't be possible to remove your data from any research that took place before your exit.

Withdrawal options

	Option 1: Partial withdrawal	Option 2: Full withdrawal
We can continue to obtain new information from your health records and other data sources	NO	NO
We can continue to use the samples and data you already provided	YES	NO*

*We will destroy the samples and data we have for you. However, it won't be possible to remove your data from any research that took place before your exit.



3. How we protect your data and samples

Who is responsible for your data and samples?

We at the Our Future Health charity will be responsible for your data and samples and will control who has access to them. Looking after your privacy and the security of your data is very important to us.

Our Future Health is the sponsor and data controller for this research programme. Health-related information is regarded as a special category of information as defined by the General Data Protection Regulation (GDPR). Our Future Health will be using information from you and your health-related records to undertake this research programme.

Data and sample storage

We will store and manage your data securely and to the highest industry and professional standards, in compliance with data protection laws. Full details of where and how we store your data is available via our privacy policy. We 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 in transit and at rest, and stored according to strict security standards.

Identifiable data, such as your name, address and GP details, will be removed from your samples, extracted DNA, and health-related data, including genetic data, and stored securely and separately.

The samples will be stored as directed by the Human Tissue Act. Blood will be frozen and stored for future analysis. The storage and analysis of all blood and saliva samples will be done at accredited research facilities. Your de-personalised samples, extracted DNA, and health-related data, including genetic data, could be sent to approved processors outside the UK for analysis.

Data and sample access

A limited number of staff at Our Future Health will have access to your personally identifiable data, so we can contact you.

We will need to share some of your identifiable data (for example, your name and address) with a third-party processor, for example to get access to health-related records about you that are stored by NHS bodies, or to send you a saliva kit. We will only share what is absolutely necessary, and strict controls will be in place to protect your personal data.

As part of their duties running Our Future Health, the staff who have access to your identifiable data will also have access to the link between this and your samples and health data. If you lose mental capacity, we would like to continue processing your de-personalised data to enable research into health and disease; however, we will break the link with your identifiable data to ensure we comply with the Mental Capacity Act.

Approved researchers conducting studies that only involve Our Future Health data, will access your de-personalised data for the research via a secure research environment. It will never be possible for researchers to download your de-personalised data from the secure research environment.

Approved researchers conducting studies that involve re-contacting participants (for example, to collect more information or samples), will be given your name and contact details only if you give your permission.

We will never allow access to your data for anything other than for health research that is for the public good. We will never sell or provide your personal identifiable data for the purposes of advertising or, for example, to insurance companies.

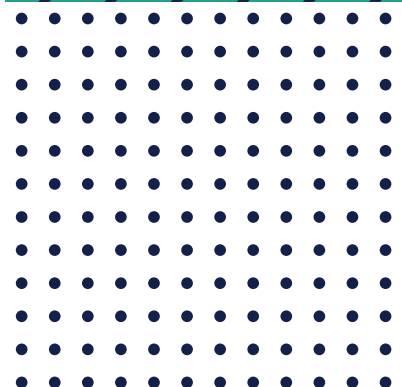
We will never allow your samples to be used in research involving animals or to create cell lines (an immortal group of cells used in research) without your express permission.

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 is used?

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

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By sending an email to support@ourfuturehealth.org.uk
- By calling us on 0800 XXX XXXX



4. Risks and benefits

What are the risks?

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 precautions using state of the art security to protect your data so the risk of a breach of privacy is very low. However, the risk can never be zero. There is a small risk that if there were to be a security breach, then someone could see or use the data we have about you.

You may find it uncomfortable to be asked questions about your health, background or lifestyle in our questionnaires. You can skip some questions if you wish to.

In the future, if you opt 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 might also be asked to share the new information with your life or medical insurer, if you have one. We will not share information about you with your life or medical insurance company.

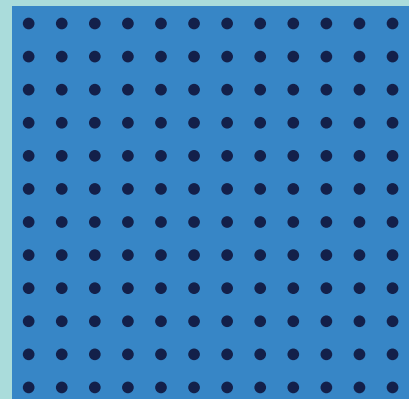
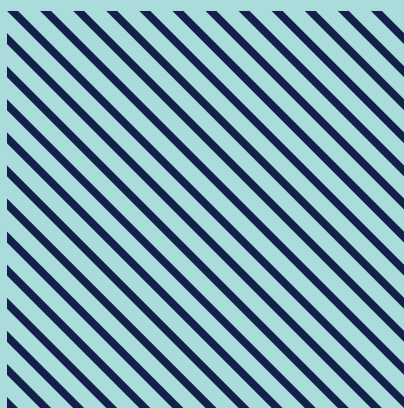
There may also be other risks that we don't know about yet, and we will get in touch if a new risk emerges.

What are the benefits?

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 might contact you to offer you some information 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 healthcare companies.



5. How is Our Future Health run and funded?

About our funding

Our Future Health is funded by £79 million from UK Research and Innovation (UKRI). This is taxpayer money that supports science and research. This funding is being used by the Our Future Health charity to set up and begin to run the programme.

Our Future Health is a very large programme and we are bringing in funding partners including companies that make medicines and equipment used in healthcare. We will always be open about who funds Our Future Health and this information can be found on our website 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 review process*.

All other researchers approved to do research using Our Future Health, will help with its running costs on a means-tested basis.

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

How we are run

The Our Future Health charity is working with other organisations such as the NHS and charities to deliver this programme. Our Future Health also has a number of advisory groups who advise on areas including science, ethics, diversity and inclusion. You can read more about how Our Future Health is run and our advisory groups on our website ourfuturehealth.org.uk/about-us.

What will happen to the findings from the research?

Discoveries made via 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 the development of Our Future Health. This involvement includes focus groups, interviews, and a public advisory panel.

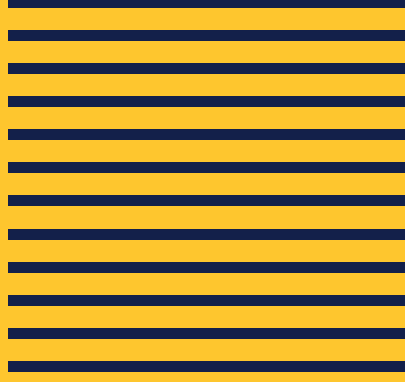
Who has reviewed and approved Our Future Health?

The Our Future Health research programme has been reviewed by a number of independent expert individuals and groups, and reviewed and approved by the Cambridge East NHS Research Ethics Committee.



Concerns and complaints

If you have concerns about any aspect of this research programme, please contact us on support@ourfuturehealth.org.uk or 0800 XXX XXXX. If you remain unhappy or concerned and wish to complain formally, you can do this by contacting XXXXX



If you have any questions, please get in touch by emailing us at support@ourfuturehealth.org.uk or calling us on 0800 XXX XXXX.