



**Healthspan
Connect**

Programme of Research



PARTICIPANT INFORMATION SHEET

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KING'S
College
LONDON



ADULT PARTICIPANT INFORMATION SHEET

Healthspan Connect

- Thank you so much for your interest in taking part in Healthspan Connect.
- This information sheet will **explain the study, what taking part involves, any benefits and risks, how your information will be used and protected, and your rights as a participant** (including your right to withdraw at any time).
- Please **take your time** to read this carefully so that you understand everything.
- If you need to, **take a break** in between sections.
- If you have any questions, please contact us using the details at the end of the information sheet.

WHAT IS HEALTHSPAN CONNECT?

Healthspan Connect is an ongoing **research programme** that looks at **how and why people age the way they do**. It aims to better understand health problems, how diseases develop, and what helps people stay healthy for longer.

By following a **diverse group of people over time**, the study will learn more about **how things like biology, lifestyle, and the environment affect our health**. The goal is to find ways to **help people live longer, healthier lives**.

Healthspan Connect aims to:

- Learn how diseases develop, including heart disease, cancer, diabetes, and conditions that affect the brain.
- Study how people age and find out what factors help people stay strong and healthy as they get older.
- Look at health risks by examining things like genes, lifestyle, and where people live.
- Find ways to support healthy ageing – by discovering what helps people stay independent and live well for longer.



WHY AM I BEING INVITED TO TAKE PART IN HEALTHSPAN CONNECT?

You can take part in Healthspan Connect if you:

- Were **born in and/or are resident in the UK**
- **Are age 12 or older**, although most of our studies are for people aged 18 and older
- Can take part using a **computer, tablet, or smartphone** with internet access



12 +



With your permission, we may also invite family members and household members to take part in Healthspan Connect so that we can further investigate how genetics and the environment affect health.

This **information sheet** gives details about what taking part involves.

WHERE WILL THE STUDY TAKE PLACE?

Most of the study will happen **remotely**, which means you can **take part from home**. You may be asked to fill in online questionnaires or send samples using home collection kits.



From time to time, we may invite you to visit a clinic for certain tests or measures. These visits will be optional, and we'll give you all the information you need in advance. **Most study visits take place at St Thomas' Hospital in London.**

WHAT DOES TAKING PART IN HEALTHSPAN CONNECT INVOLVE?

Healthspan Connect is an ongoing research programme **made up of different studies**.

Most of the time, you'll be asked to **collect samples or information at home**. **Occasionally**, we may invite you to visit a **research clinic** to collect samples or carry out certain tests.

If you choose to take part, you'll be invited to **join studies that are relevant to you**. For each study, we will provide an **information sheet** which will explain what is involved. In these studies, you may be asked to:

1



Fill in online questionnaires about your health, lifestyle, and background.

2



Provide biological samples, such as blood (for DNA and other components), hair, nails, stool, saliva, semen, or tissue samples (biopsies).

3



Use smart devices or phone apps to track things like your health, diet, sleep, mood, movement, location, and exercise.

4



Take part in psychological tests and activities to help us understand brain function.

5



Have clinical assessments and tests, such as physical measurements, fitness tests, skin and dental checks, allergy testing, eye and hearing tests, taste tests, and other sensory tests (like checking temperature sensitivity).

6



Take part in interviews or focus groups (group discussions) to share your thoughts and experiences.

7



Help collect samples from where you live, like drinking water, soil, or dust.

If you give permission, we may also **link to your health, education, and environmental records** to build a more complete picture of your health and environment.

We may also invite you to take part in studies that involve **changes to lifestyle or diet**. This could include trying dietary supplements, probiotics, following a specific diet, or making other non-medical changes.

You might also be invited to have your **photo or video taken** to help us promote the study, but we'll always **ask for your permission first**.

We will store your samples and data in the Healthspan Connect Biobank (REC ref 25/NW/0359).

We do not usually give incentives for completing Healthspan Connect studies. However, we may sometimes offer vouchers or entry into a prize draw after you complete a sub-study. We will let you know if this is the case on the study information sheet.

DO I HAVE TO TAKE PART IN HEALTHSPAN CONNECT?

No, it's **completely your choice** whether you want to take part in Healthspan Connect.

If you do decide to join, you may be invited to take part in individual research studies related to Healthspan Connect's goals. **Each time, you can choose whether you want to take part.**



We will give you a study information sheet that explains what the study is all about. This will help you decide if you would like to take part. You can also email or phone the research team if you have any questions.

If a study includes tests, you can choose to do all, some, or none of them. You can change your mind about doing the tests at any time. If you do agree to do any tests, we'll ask you to sign a special form (called a consent form) to show you agree.

DO I NEED TO DO ANYTHING TO PREPARE FOR A RESEARCH VISIT?

If you agree to come in for a visit, we'll give you **clear instructions** in advance.

This might include things like completing a questionnaire, collecting a sample, or not eating beforehand. We'll also explain what will happen during the visit. **If you have diabetes, please contact us so we can make sure the visit is safe and suitable for you.**



You can always **get in touch with the research team if you have any questions about the visit.** The ways you can get in touch are at the bottom of this information sheet.

WILL I BE GIVEN ANY MEDICATION AT THE VISIT?

Depending on the tests you're taking part in, we **may give you medication** such as eye drops or a local anaesthetic (a numbing medicine) before certain procedures, like a biopsy.

We only use approved and commonly used medications. You will not be asked to take any experimental or unapproved medicines as part of this study.



LINKING TO YOUR DATA

When we use services like healthcare or education, **information about us is collected and stored** by different organisations. Data linkage means **bringing this information together** from your official records.

This **helps Healthspan Connect collect useful data** without needing extra time or effort from you.

We will **always ask for your permission** before we request any of this information.

If you agree, we may link your health, education, or environmental records that are held by trusted organisations and government bodies.

Data linkage has several benefits for both you and the researchers:

- Some people may find it hard to take part in Healthspan Connect studies. Data linkage is a simple way to still be part of important research.



- Even if you've taken part in many studies, there may still be some missing information. Linking to your official records can help fill in the gaps and give us a better overall picture.
- Some details, like the exact name and dose of a medicine you were given in the past, might be hard to remember. Data linkage helps us collect accurate details like these.

To do this, we will **securely share your name, date of birth, and NHS number** with the organisations that hold your records.

They will send us the relevant information, and we will **remove anything that could directly identify you** before it's added to our database. We will then match this information to your Healthspan Connect records using a special code that doesn't reveal who you are.

Some studies may ask you to use **wearable devices or mobile phone apps** to collect information about your health and lifestyle.

Wearables are items you can wear, such as a watch, wristband, or patch, which can measure things like your heart rate, sleep, activity, or movement.

We will **tell you exactly what data the device or app will collect and how long you will need to use it**. If you are using your own device, we will explain how to give us permission to share the data with us.



All information collected from a wearable will be **stored securely and linked to your study record** using a **special code instead of your name**.

Some studies may ask to **link to your retail loyalty card data** (e.g. Nectar cards or Boots Advantage cards). We will tell you which card we want to link to and when we will access the data.

If you join Healthspan Connect, you'll be asked to say which types of records, if any, you are happy for us to link to. **You can change your mind at any time** by getting in touch with us.

To learn more about the kinds of data we link to, and how it works, please click here: <https://healthspanconnect.kcl.ac.uk/participants/data-linkage-for-participants/>

The UK Longitudinal Linkage Collaboration

The UK Longitudinal Linkage Collaboration (UK LLC) is a **secure national system for linking data used in long-term research studies**.

It is led by the **Universities of Bristol and Edinburgh**.

UK LLC makes it easier for researchers to access linked data that can help improve public health and wellbeing. By bringing together information about health, social factors, behaviour, and the economy, it **supports important research for the public good**.

The data is **stored securely at Swansea University** and **managed by the University of Bristol**.

The UK LLC **helps researchers answer important questions by bringing together different types of data**. It holds research data shared by study groups (called cohorts) and links it to health, environmental, education, and other official records - but **only when permission has been given**.

Healthspan Connect will **share some of its data with the UK LLC** and **allow it to link to participants' health, education, and environmental records**, but only based on the preferences you **choose on your Healthspan Connect Informed Consent Form**.

All data held by the UK LLC is **de-identified at every stage**. This means your personal details are removed so that neither researchers nor UK LLC staff can identify you from the data.

Researchers can **apply to use the data** held in the UK LLC. However, Healthspan Connect will keep **full control over who can access any of its data**.

Every request to use Healthspan Connect data will be carefully reviewed by the **Healthspan Connect Governance and Resource Access Management Committee**. Only approved researchers who are doing genuine health research that benefits the public will be given access. This process is explained in more detail in the section 'What will happen to my data and samples?'

More information about the UK LLC is available on their website: <https://ukllc.ac.uk/>

WHAT ARE THE ADVANTAGES OF TAKING PART?

By taking part, you'll be **helping to advance ageing and health research** that could benefit people in the future. You can keep up to date with what we're learning by visiting our website.

In some studies, you may receive **health test results** that could be useful for your GP. These results might help identify any health conditions early (see Test Results below for more information).



TEST RESULTS

The tests we do are for research purposes and are **not the same as a health check with your doctor**.

However, some of the tests can help **spot possible health problems**. We'll let you know in the study information sheet if a test could be useful for your health, whether you'll receive any results, and when.

If you want to understand what your results mean for your health, we recommend **discussing them with your GP**. We do not send your routine results to your GP unless there are incidental findings that may need to be followed up. In that case, we may contact both you and your GP.

Some tests we do, like microbiome tests, are useful for research but **don't yet have a clear meaning for health**.

Others, like genetic tests, are done in research labs and not in clinical labs, so they **can't be used to diagnose medical conditions**. Because of this, **we won't share results from these types of tests**.

ZOE Research Personal Data

NOTE: This is only relevant to you if you have previously participated in research studies run by ZOE (the ZOE Health Study and/or the PREDICT studies).

If you consented specifically to this, ZOE will share with us the personal data (including health data) it holds about you from its research studies. We may link this data to the other data we collect about you for Healthspan Connect, only for the sub-studies you sign up to.

This is optional - you can still participate in Healthspan Connect if you do not give this consent for ZOE to share this data with us.

For more information on the types of data ZOE may share with us, please see the relevant privacy policies below:

- If you participated in the [ZOE Health Study](#).
- If you participated in the [PREDICT Study](#).

WHAT ARE THE DISADVANTAGES OR RISKS OF TAKING PART?

Most people will not experience any serious side effects while taking part in Healthspan Connect studies.

However, depending on the study and the tests you take part in, you may experience some **minor side effects**, such as:

- Some questionnaires may include questions on sensitive topics. We will let you know in the information sheet.
 - Slight discomfort when giving a blood sample.
 - Mild discomfort when having a cannula (small tube) inserted. There is also a small risk of infection or tenderness afterwards.
 - Temporary redness on the skin from some sensory tests.
 - If you choose to have a biopsy, it may leave a small scar. There is also a small chance of bleeding, tenderness, or infection.
 - There is a small risk of a reaction to the local anaesthetic (numbing medicine) used during a biopsy. The research team is fully trained to manage this. You should not take part in a biopsy if you are allergic to anaesthetics.
-
- For certain specialised procedures, you'll have an extra consultation with a trained member of the research team so you can fully understand any risks before you decide whether to take part.

There are also some risks related to data privacy and security. You can read more about how we protect your information in the sections 'Your data and confidentiality' and 'What happens to my data and samples' below.

HOW WILL YOU CONTACT ME?

- We may contact you in different ways, such as by phone, text message, email, or letter, **depending on the permissions and preferences you've given us**.
- We'll also keep you updated through our social media channels and by sending regular newsletters and emails about new developments and upcoming studies within Healthspan Connect.



YOUR DATA AND CONFIDENTIALITY

We will keep all information collected about you as part of Healthspan Connect **strictly confidential** and we will store it according to the UK General Data Protection Regulation 2018 and Data Protection Act 2018.

We will store all your data using a unique code, instead of your name. Your personal details, such as your name, address, full date of birth, and contact information, will be kept in a separate, secure database, which may include storage on a secure third-party server.

Only authorised Healthspan Connect researchers and staff will be able to access this, and only for things like managing your participation in the study.

When we share your data with researchers, it will be **pseudonymised**, meaning it's linked only to your unique code, not your name.

We may also share your birth month and year, but **nothing that can directly identify you**. You cannot be personally identified from the data we share. **We treat it as a potential criminal offence to misuse data**, including trying to re-identify someone without permission.

We may share data with **third-party platforms for research purposes**. These platforms will be described in each sub-study Volunteer Information Sheet and will meet King's College and Healthspan Connect data requirements for data storage, including General Data Protection Regulation 2018.

Only the test results that we send to you (and your GP, where applicable) will contain any personal information.

Sometimes we work with service providers to help us to carry out our research (e.g. to send out large numbers of postal kits), and **we may need to share some of your personal information with them, but only under strict contracts**.

More information about how we handle your data is available in the **Privacy Notice on our website (ADD)** and from the **King's College London Information Compliance team and Data Protection Officer**, available on info-compliance@kcl.ac.uk.



WHAT WILL HAPPEN TO MY SAMPLES AND DATA?

We will store all data and samples you provide in our **Healthspan Connect Biobank** (REC REF: 25/NW/0359).

We will store your clinical, genetic and questionnaire data in a **secure electronic database** so it can be used in this study and future research projects.

Your biological samples will be processed and stored at our laboratory (run by the Department of Twin Research and Epidemiology, based at St Thomas' Hospital, London) or in one of our approved biorepositories.

HOW WILL WE USE INFORMATION ABOUT YOU?

We will need to use information from you and, if you consent, from your medical records for this research project.

This information will include your **initials, NHS number, name, contact details** and **date of birth**.

This data may include things like photographs, images, scans, X-rays, genetic information, location details, questionnaire answers, linked records, clinical data, and biological samples.

People will use this information to do the research or to check your records to make sure that the **research is being done properly**.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

King's College London is responsible for looking after your information. We will share your information related to this research project with the following types of organisations, and to access:

- Healthcare records available through the NHS and their GP
- Education records held by the Department for Education
- Environmental records such as information held by organisations such as the ONS or Centre for Hydrology and Ecology based on postcodes

We will keep all information about you **safe and secure** by storing all your data using a **unique code, instead of your name**.

Your **personal details**, such as your name, address, full date of birth, and contact information, will be kept in a **separate, secure database**. Only authorised Healthspan Connect researchers and staff will be able to access this, and only for things like managing your participation in the study.

INTERNATIONAL TRANSFERS

We may share data about you **outside the UK for research-related purposes**. Over time, Healthspan Connect may collect thousands of pieces of information and samples from you and other participants.

Since we can't analyse all of this ourselves, we allow **approved researchers outside of Healthspan Connect to request access** to this data to help maximise the scientific benefit of your contribution.

If this happens, we will only share the **data that is needed**. We will also make sure you can't be identified from the data that is shared, where possible. This may not be possible under certain circumstances – for instance, if you have a rare illness, it may still be possible to identify you.



If your data is shared outside the UK, it will be with researchers **approved by the Healthspan Connect Governance and Resource Access Management Committee**. Researchers in the UK or abroad must clearly explain their research project and why it's scientifically valuable. The Committee will then decide whether to approve the request. If approved, only the **minimum amount of data or samples needed** for the project will be shared.

Most requests will come from academic researchers working at universities. A small number may come from commercial companies. However, **stricter rules apply to commercial researchers**. While they may request access to data and samples, **we do not share your linked health, education, or environmental records with them. You can tell us your preferences about this on the Healthspan Connect Informed Consent Form**. We do not allow your DNA to be used for any research related to human cloning.

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a **similar level of protection as it does under UK law**.

We will make sure your data is safe outside the UK by doing the following:

- some of the countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK
- we use specific contracts approved for use in the UK which give personal data the same level of protection it has in the UK. For further details [visit the Information Commissioner's Office \(ICO\) website](#)
- we do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- we need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
- we have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when we legally have to. For further details about UK breach reporting rules [visit the Information Commissioner's Office \(ICO\) website](#)

HOW WILL WE USE INFORMATION ABOUT YOU AFTER THE STUDY ENDS?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that **no one can work out that you took part in the study**.

We will keep your study data for a **maximum of 10 years** after the completion of our research. The study data will then be fully anonymised and securely archived or destroyed.



WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

- You can **stop being part of the study at any time**, without giving a reason, but we will keep information about you that we already have.
- If you choose to stop taking part in the study, we would like to continue collecting information from your linked records, such as health data from the NHS. **If you do not want this to happen, tell us, and we will stop.**
- You have the right to ask us to **remove, change or delete data** we hold about you for the purposes of the study. You can also **object to our processing of your data**. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

More details can be found in the section CAN I LEAVE HEALTHSPAN CONNECT?

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED?

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK:

- at <http://www.hra.nhs.uk/patientdataandresearch>
- <https://www.kcl.ac.uk/research/research-environment/rgei/research-ethics/use-of-personal-data-in-research>; or
- by asking one of the research team using the details at the end of this information sheet
- by sending an email to our Data Protection Officer at info-compliance@kcl.ac.uk

We will keep all your information safe and secure, following UK laws (UK General Data Protection Regulation 2018 and Data Protection Act 2018), and all samples will be stored according to the rules in the Human Tissue Act 2004.

Any **intellectual property** (such as discoveries or inventions) that comes from the study will **belong to King's College London**. You will not own the data or samples you provide, or any results that come from them.

WHO ORGANISES AND FUNDS HEALTHSPAN CONNECT?

The study is run by the **Department of Twin Research and Genetic Epidemiology, King's College London (KCL)**. This is based at St Thomas' Hospital in London.

The Head of Department is **Professor Claire Steves**. The main funding bodies currently supporting the Department and Healthspan Connect include the **Wellcome Trust, the Medical Research Council and the Chronic Disease Research Foundation (CDRF)**. These are charities and organisations that give money to scientists to help answer important research questions.

Future Healthspan Connect studies may be funded by other organisations. We will tell you who is funding each study in the study information sheet.

KCL sometimes works with **commercial (for-profit) organisations**. These organisations can be allowed to access, view and use the Healthspan Connect database. This is always controlled and monitored by Healthspan Connect researchers, and **data is de-identified (your personal details are removed)**. The contracts with these organisations may bring income or profit to KCL. **The Vice President of KCL (Finance) decides how this income is used**, not anyone working on Healthspan Connect.



KCL will **never sell the samples or data you give**. If we share your samples or research data with other researchers (including commercial companies), they must first be **reviewed and approved by the Healthspan Connect Governance and Resource Access Management Committee**. We may charge them a fee to cover the cost of collecting, storing and sharing the samples and data. Commercial companies may be charged more than academic researchers. The fees we receive will help support further research at Healthspan Connect.

If we share data or samples with commercial organisations, we always have **strict agreements (contracts)** in place with them. The agreements might mean that some other organisations might not be able to use Healthspan Connect data or samples in some situations. Agreements might also **limit KCL's ability to profit from our research findings**, unless the commercial organisation is involved.

WHO HAS REVIEWED AND APPROVED THE RESEARCH?

The Healthspan Connect Programme of Research was reviewed and approved by **NHS North West – Liverpool Central Research Ethics Committee** (REC reference **25/NW/0360**).

Healthspan Connect Biobank was reviewed and approved by NHS North West - Liverpool Central Research Ethics Committee (REC reference 25/NW/0359).

These are **special groups made up of people who work in different types of jobs**, who decide if a research project is allowed to take place in the UK.

The **COVID Symptom Study (CSS) Biobank** (REC reference 20/YH/0298) is another research study and biobank run by some of the same researchers who work on Healthspan Connect. A group of volunteers from the CSS Biobank, called the **CSS Biobank Volunteer Advisory Panel**, have looked at the Healthspan Connect research programme and **provided helpful feedback and advice**.

CAN I LEAVE HEALTHSPAN CONNECT?

You can leave (withdraw from) Healthspan Connect at any time, and you do not have to give a reason. This **won't affect your future involvement** with the Department of Twin Research and Genetic Epidemiology, **your medical care, or your legal rights.**

If you decide to leave the study, you can **tell us what you'd like us to do** with your linked records, stored data, and samples. You'll be asked to choose from the following options:

Stored samples:	I am happy for Healthspan Connect to continue storing and using my samples	OR	I would like Healthspan Connect to destroy my samples
Stored research data:	I am happy for Healthspan Connect to continue storing and using my research data	OR	I would like Healthspan Connect to destroy my research data
Linked health, education, and environmental data:	I am happy for Healthspan Connect to continue linking to my health, education, and environmental data	OR	I would like Healthspan Connect to stop linking to my health, education, and environmental data

If you withdraw completely, we will delete your personal details and stop contacting you about any news, events, or studies.

If you'd still like to hear from us but don't want to take part in studies for now, you can choose to change your status to News and Information only. This means we can keep in touch with updates and news, and you can choose to get involved again in the future if you wish.

To change your status or withdraw completely, please contact us using the details at the end of this information sheet.

WHO CAN I CONTACT FOR FURTHER INFORMATION?

If you have any questions or concerns, please contact the Healthspan Connect study team on the details below.

- Email address: healthspan@kcl.ac.uk
- Website contact form: <https://healthspanconnect.kcl.ac.uk/contact-us/>

Healthspan Connect
Department of Twin Research and Genetic Epidemiology
St Thomas' Hospital Campus
4th Floor South Wing D Block
Westminster Bridge Road
London SE1 7EH

WHO CAN I CONTACT IF I WANT TO MAKE A COMPLAINT?

Please contact the Healthspan Connect study team using the contact details above.

If your complaint is not sorted out and you wish to take it further, you can write to Chief Investigator of Healthspan Connect, Professor Claire Steves, using the department address above. You can also contact the Research Governance Office at King's College London – rgo@kcl.ac.uk.

Thank you for taking the time to read this information sheet.