



**Healthspan
Connect**

Programme of Research



PARTICIPANT INFORMATION SHEET

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KING'S
College
LONDON



CHILD 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.
- We have split this information sheet into sections, so read each one and when you are happy with what it says, move on to the next.
- If you need to, **take a break** in between sections.
- There are some sections that we would like you to read through **with your parent/guardian**. We will let you know which ones at the start of the section.
- If you have any questions, please get in touch with us using the details at the end of the information sheet.



SECTION 1

ABOUT THE STUDY

WHAT IS HEALTHSPAN CONNECT?

Healthspan Connect is a big research project that looks at how and why people age in different ways. We want to understand more about health problems. We also want to know how diseases start, so we can help people stay healthy as they get older.

We are following a lot of different people over time. This is so we can see how things like biology (how we are made), daily habits (how we live), and environment (where we live) affect our health. The goal is to find ways to help people live longer, healthier lives.

Healthspan Connect wants to:

- Learn how diseases start, like heart disease, cancer, diabetes, and conditions that affect the brain.
- Find out what helps people stay strong and healthy as they get older.
- Look at things that might be bad for our health by studying our biology (how we are made), daily habits (how we live), and environment (where we live).
- Find new ways to help people stay active, independent and well for longer.



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

You can join if you:

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



12 +



We might also ask your family or the people you live with to join. This is because health can be linked to your family and the place you live.

This **information sheet** explains what happens if you take part.

Before you decide to join, we will **ask a few simple questions** to check that you understand what the study is about. This is to make sure we have explained our study properly. **It is not a test.**



SECTION 2

WHAT TO EXPECT

WHERE WILL THE STUDY TAKE PLACE?

Most of the study will take place **online using a computer, tablet or smartphone**. This means you can **take part from home**. You may be asked to fill in online questionnaires or send samples using special kits we post to you.



Sometimes, we may **invite you to visit a clinic** for certain tests or checks. These visits are **optional**. We will give you all the details before you decide.

Most study visits take place at **St Thomas' Hospital in London**. Sometimes they may be at another research centre in the UK, or even at your home. If you need to travel to a clinic visit, we will **pay back your public transport costs or money needed for petrol**. We will give you all the details about travel costs in the information sheet for each part of the study.

WHAT DOES TAKING PART IN HEALTHSPAN CONNECT MEAN FOR ME?

Healthspan Connect is a research project **made up of different studies**.

Most of the time, you'll **give samples or answer questions** on your computer from home.

Occasionally, we may ask you to come to a visit a research clinic to collect samples or have some tests done.

If you decide to join Healthspan Connect, we will **ask for a parent or guardian's email address and phone number**. This is so we can ask them if they **agree for you to join**, too.

We will send them a link to read the information you have seen for Healthspan Connect. We will then ask them if they are happy for you to join. **If they say no, you will not be able to join**, and we will delete all the information we have about you.



You could still choose to join later if they agree then, or on your own when you are age 16.

If you choose to take part, and your parent or guardian says yes as well, you'll be asked to join studies that are right for you.

For each study, we will give you an information sheet (a bit like this one) that tells you what you would need to do. In these studies, **you might be asked to:**

- 1



Fill in online questionnaires about your health and how you are feeling, your daily routine, where you live, and your background. This helps us build a picture of who you are.
- 2



Give biological samples, such as blood (to look at DNA and other parts of the blood), hair, pieces of fingernails, stool (poo), and saliva (spit). This helps us understand how things like genes (how you are made) can be changed by where you are from and how you live.
- 3



Use smart devices or phone apps to track things like your health, diet, sleep, mood, movement, location, and exercise.
- 4



Do thinking tests and activities to help us understand how the brain works.
- 5



Have health checks and clinic 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



Join 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 and your parent or guardian agree, we may also **link the information you give us to your health, education, and environmental records**. This helps us build a bigger picture of your health and the world around you.

We may also invite you to join studies that involve **changes to your daily routine or diet**. This could include trying vitamins, probiotics, following a special diet, or making other changes that aren't medicines.

You might also be asked to have your **photo or video taken** to help us promote the study. We will always **ask for your permission first**. We will also ask you, parent or guardian.

Any samples or information you give us will be kept safely in the Healthspan Connect Biobank (REC ref 25/NW/0359), which is part of the research programme.

In some studies, when you send back biological samples, you might get an **e-voucher** (usually about £20). Sometimes we may also put you into a **prize draw** after you finish a study. **You will be told if this will happen** in the information sheet for each study.

When you **turn 16**, we will **get in touch to ask if you would like to give your own consent** to carry on in the study as an adult participant.

DO I HAVE TO TAKE PART IN HEALTHSPAN CONNECT?

No, it's **completely up to you** if you want to take part in Healthspan Connect.

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

Sometimes we will ask you to come to a research visit for some tests. If you agree to come in for a visit, we'll give you clear instructions beforehand. This might include things like filling in a questionnaire, collecting a sample, or not eating before you come. We will also tell you what will happen during the visit. If you have diabetes, please let us know 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?

This **depends on the tests** you are doing at the visit. We may give you something like eye drops or a local anaesthetic (a numbing medicine) before certain procedures.

We only use medications that are **approved and regularly given by doctors or hospitals.** You will never be asked to take any new or unapproved medicines in this study.





SECTION 3

WHAT WE DO WITH YOUR INFORMATION

***PLEASE READ WITH A
PARENT/GUARDIAN***

LINKING TO YOUR DATA

When you use services like going to the doctor, the NHS, or school, **information about you is collected and kept** by different organisations.

Data linkage means **bringing this information together** from your official records.

This **helps Healthspan Connect collect useful data** without you needing to spend extra time or effort filling in forms to tell us.

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

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

Data linkage can help because:

- Some people may find it hard to take part in Healthspan Connect studies in other ways. Linking to their records 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 a better picture overall.
- Some details, like the exact name and dose of a medicine you were given in the past, might be hard to remember. Linking to your records helps us collect the right 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 information we need for our study. 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 apps** on your phone to collect information about your health and lifestyle.

Wearables are things you can wear, like a watch, wristband, or patch, that measure things such as 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 for**.



If it is your own device, we will tell you how to give us permission to share the data with us.

Any information collected from a wearable will be **kept securely and linked to your study record**. We will **use a special code instead of your name**.

Some studies may ask to **link to your retail loyalty card data** (e.g. 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 can choose which types of records or data, 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 that links data in long-term research studies**.

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

UK LLC helps researchers bring together different types of information, like health, education, the environment, and the economy.

This is so they can **answer important questions and improve public health and wellbeing**.

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

Healthspan Connect will **share some of its study data with the UK LLC**. Healthspan Connect will allow UK LLC to link to participants' health, education, and environmental records, but only based on **what 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 tell who you are.

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

Every request to use Healthspan Connect data will be checked carefully by the **Healthspan Connect Governance and Resource Access Management Committee**. This is a group of researchers working on Healthspan Connect who make sure that the information we collect from you is used in a way that's best for research. Only approved researchers who are doing real health research that will help the public will be given access. You can read more about this 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/>

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).

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](#).

WILL I GAIN ANYTHING BY TAKING PART?

By taking part, you'll be **helping research into ageing and health** that could help people in the future. You can find updates about what we're learning by visiting our website.

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



TEST RESULTS

The tests we do are **for research** and are not the same as a health check with your doctor. Some of the tests can help **spot possible health problems**. We'll **tell you** in the study information sheet if a test could be useful for your health. We will also tell you whether you'll receive any results, and when you will get them.

If you want to know what your results mean for your health, you should **talk to your GP**. We do not usually send your results to your GP unless we **find something important** that might need checking. In that case, we may **contact both you and your GP**.

Some tests we do 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 medical labs, so they **can't be used to diagnose health problems**. Because of this, we won't share results from these types of tests.

ARE THERE DOWNSIDES TO TAKING PART?

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

But depending on the study and the tests you do, you may experience some **minor side effects**, such as:

- Some questionnaires may include questions on personal topics. We will let you know in the information sheet before you start, so you can decide if you want to answer them.
- It may hurt a little when giving a blood sample.
- It may hurt a little when having a cannula (a small tube) put in your arm. 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 deal with this. You should not take part in a biopsy if you are allergic to anaesthetics.
- For certain special procedures, you'll have an extra meeting 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 get in touch with you by phone, text message, email, or letter; it all **depends on how you would like to be contacted**.

We'll also share updates through our social media and by sending regular newsletters and emails. These will tell you about new developments and upcoming studies in Healthspan Connect.



HOW WE KEEP YOUR INFORMATION SAFE

We will keep all information we collect in Healthspan Connect **strictly confidential (private)**, and we will store it according to the **UK data protection laws** (UK General Data Protection Regulation 2018 and Data Protection Act 2018).

We will store all your data using a special 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, safe database, which might include storing it on a secure computer run by another trusted organisation.

Only authorised Healthspan Connect researchers and staff will be able to see this information. They will only be able to use it for things like managing your participation in the study. **This means that you cannot be identified by the information you have given us.**

When we share your data with other researchers, it will be **pseudonymised**. This means it is **linked only to your special 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**. This includes trying to find out who someone is without permission.



Only the test results that we send to you (and your GP, if needed) will contain any personal information. Sometimes we work with service providers to help us to carry out our research (e.g. to send out lots of postal kits). **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.

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.

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.