

2024-25

Annual Participant Newsletter

From data to discovery



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Welcome to the newsletter

The last twelve months have seen UK Biobank go from strength to strength, as you will see from all the brilliant stories in this year's newsletter.

We have more researchers working with more of our data than ever before, making discoveries which could revolutionise how we understand human health.

We have also been delighted to work with a wide range of funders, supporters and stakeholders who help to make our work possible.

We hosted two Secretaries of State for Science, Innovation and Technology in 2024. First, Michelle Donelan in February and later Peter Kyle in July, who was joined by Science Minister, Lord Patrick Vallance. The second visit was part of a new funding announcement for UK Biobank from the UK Government and Amazon Web Services of £16 million.

After having a tour of UK Biobank and meeting two participants, Peter Kyle commented **“you can't not be inspired and totally energised.”**

All of our work is thanks to you, our participants. Thank you once again for your support.



*Professor Sir Rory Collins
Principal Investigator and Chief
Executive, UK Biobank*



Celebrating 10 years of the imaging study

In April 2024, UK Biobank celebrated the 10-year anniversary of our imaging study. The study aims to scan the bodies of 100,000 of our participants. We have collected more than 850 million images so far, providing researchers with detailed medical scans of major organs around the body.

We have now imaged more than 95,000 participants, getting closer to our 100,000 target.

Researchers from around the world have used your imaging scans to power research and publish more than 14,000 scientific papers on diseases such as dementia, heart disease and osteoporosis.

When we reach our 100,000 target, we will concentrate on inviting participants back for a second set of scans. Multiple scans at different time points allow researchers to understand how changes to your organs as you age link to diseases like dementia, heart disease, and cancer. Please keep an eye out for your invitation!

“**Thank you so much to all of our amazing participants. Without you, this project would not be possible.**”

Tonia Didcott, Bristol Imaging Centre Operations Manager.

“**It’s quite fascinating because you can help to provide information which can lead to great medical advances.**”

John, a UK Biobank participant speaking to BBC after his imaging appointment.

Artificial intelligence spots arthritis in routine bone density scans

Researchers from the University of Bristol used bone-density scans from around 40,000 UK Biobank participants to develop an artificial-intelligence tool that can spot subtle hints of osteoarthritis. Similar automated systems could eventually help to catch early-stage arthritis even when doctors aren’t specifically looking for it. Physiotherapy could then be prescribed to stop the condition from getting worse and increase the amount of time living in good health.

Reference: Osteoarthritis and Cartilage Open, June 2024

You said, we did

“The MRI scanner rooms can feel cold.”

Warm blankets are now available if you need them.

“I don’t think that the gowns fit well.”

We have improved our selection of gowns for your comfort and dignity.

“I’m unsure how data from my scans is helping science.”

The scientific impact of your time and effort is displayed on screens in the imaging centres.

“I would like to receive a reminder about my appointments.”

We will now call you a week before your appointment to check in, alongside our usual reminder email and text message.

A step closer to your GP data

We are delighted the Government has announced it will help UK Biobank to access your GP data. We have not been able to access GP data across England on a large scale, except during COVID when it proved incredibly valuable, despite having your consent to do so (we have access in Scotland and Wales).

You do not need to do anything. We will be applying to NHS England to access your GP data and make it available to approved researchers. We will receive only coded data related to diagnoses, prescriptions and referrals, not any confidential notes. As always, any information that identifies you is never shared with researchers to protect your confidentiality.

“**My family has generational cardiac disease and this link to my GP records will be invaluable for preventing and better understanding future cardiac disease through the generations.**”

Sean, a UK Biobank participant.

UK Biobank moves to the cloud

Researchers starting new projects can now only access UK Biobank data through our cloud-based Research Analysis Platform. This means researchers (with limited exceptions) will no longer be able to download data, and instead will log in and analyse data within the secure platform. It's a bit like a reference library where researchers come to look up information, but they can't remove or copy any of the books. This will enhance security by giving us more control over the huge amount of data we now hold.

A new era of brain health research

UK Biobank data has huge potential for helping scientists to understand brain health conditions, such as Alzheimer's disease and Parkinson's disease. We are planning a ground-breaking new study with participants with brain-related health conditions, including those affecting their movement or memory. We would like to invite them to a research centre to have a brain scan, provide a blood sample and complete some cognitive tests. The study is being designed with the help of UK Biobank participants, people with a brain health condition, and those who support and care for them. More information will be coming soon!

Building an unprecedented world-leading dataset

Over the next few years, we will be measuring the levels of proteins in the blood samples you have generously donated. Understanding how protein levels can influence disease could help develop ways to detect diseases earlier.

A consortium of companies has provided funding for this huge task. A pilot study analysed blood samples from 50,000 participants - already making this the largest study of its kind in the world. The data from this pilot study has proven so valuable for research that blood samples from a further 250,000 participants are going to be analysed, with the aim to eventually do this for all half a million of our participants.

See page 12 for how our blood protein data is driving breakthroughs in dementia research.

Childhood sweet tooth linked to diabetes in middle age

Children who grew up eating little sugar have a lower risk of type 2 diabetes and high blood pressure later in life. This is even true for babies whose pregnant mums ate a lower-sugar diet, health questionnaires and medical records from 60,000 UK Biobank participants born during post-war sugar rationing have revealed. The amount of sugar infants had when they started to eat solid foods seemed to make the biggest difference.

Study leader Tadeja Gracner from the University of Southern California, USA, hopes that her work will make baby food companies consider reducing the sugar content in their products.

Reference: Science, October 2024



New treatment for rare blood cancer after genetic link discovery

Genetic data from all 500,000 UK Biobank participants have revealed a link between a rare blood cancer and a genetic glitch that causes iron overload. This has led to the development of a drug that could replace the frequent blood withdrawals people with this condition have to undergo – an arduous process that can lead to chronic fatigue.

The condition, called polycythemia vera, leads to an overproduction of red blood cells, which puts people at high risk of heart attacks, strokes and blood clots. **“It was amazing – this project went from concept to clinical trial in four years,”** says the study’s co-leader, Cavan Bennett from the University of Melbourne in Australia.

Reference: Blood, March 2023



“ The [World Health Organization] says that children below the age of two should actually not be consuming added sugar at all, but that is much easier to know than to comply with.”

Tadeja Gracner, study leader.



Meet the Participant Advisory Group

You, our participants, are at the heart of UK Biobank and in many cases you know best how we can get things right.

Our Participant Advisory Group (PAG) plays a central role in ensuring we hear and act upon the views and opinions of our participants. The 18 members bring an inspiring range of life experiences to help guide our work.

The PAG provides advice on a wide range of activities including:

- communication with participants and the public
- resolving issues relating to collecting, storing and sharing participant data
- designing UK Biobank studies.

In 2024, the PAG helped to develop a new strategy for involving participants in our work, advised us on the new UK Biobank website, and gave their views on requests from researchers to access UK Biobank data.

Get in touch

We are always looking for participants who are willing to get involved and provide their views on UK Biobank's work. You do not need to have any prior knowledge of health research.

Please email ppierecruitment@ukbiobank.ac.uk to express your interest and we will be in touch. We would love to hear from you.



Scan the code to find out about other ways we involve participants and how you can be involved.



“ Being a member of the Participant Advisory Group is both interesting and a responsibility. The members have a wealth of knowledge and experience which is freely offered in discussion.”

Carrol,
Participant Advisory
Group member.

Blood analysis predicts dementia years before diagnosis

Four proteins found in blood could eventually reveal developing dementia long before someone starts noticing symptoms. Researchers examined thousands of proteins in the blood samples of more than 50,000 UK Biobank participants. Four of these biomolecules were present at higher levels in the blood of apparently healthy people who would later be diagnosed with dementia, including Alzheimer's disease.

Early diagnosis and treatment are key to helping people live well with the condition. **“We can quite reliably predict dementia 15 years before the diagnosis of the disease,”** says the study's co-leader, Jian-Feng Feng from China's Fudan University. His team is now working on creating a simple and inexpensive test that could be used in clinics.

Read more about how we're building a world-leading protein dataset on page 7.

Reference: Nature Aging, February 2024

Genetic tests could create better depression treatment

DNA analysis of more than 5 million people, including 370,000 UK Biobank participants, has revealed almost 700 genetic differences in people with depression. The researchers eventually hope to uncover how this affects what antidepressant works for people. For this, the team also looked at GP records of 230,000 UK Biobank participants as well as more than 170,000 UK Biobank participants' replies to an online mental health questionnaire.

“That's really unique data, because it's telling us not just what the doctor thinks, but what does that person with depression think about their treatment,” says the study's co-leader, Cathryn Lewis from King's College London, UK. Eventually, genetic testing could help doctors to match their patients with the right antidepressant.

References: Cell, January 2025; medRxiv preprint, October 2024; medRxiv preprint, November 2024



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“UK Biobank’s accessibility, high-quality data and global collaborative environment were game changers.”

Javier Calvo Marín,
University of Costa Rica

Our global research community

a Keri Multerer, Victoria University of Wellington, New Zealand

After staying home with her children for 15 years, data scientist Keri Multerer taught herself coding and became a researcher. She is now using UK Biobank data to explore how genetic factors combine in determining someone’s risk for diseases such as diabetes. Multerer says the Early Career Researcher Credits she received from UK Biobank **“was fantastic to have, because as an early-career researcher, you don’t know what tools you’re going to need.”**

b Javier Calvo Marín, University of Costa Rica

Javier Calvo Marín’s work focuses on hormone-related conditions. He studies biomolecules found in UK Biobank participants’ blood to explore cardiovascular risk. Ultimately, he wants to use these insights to give his patients practical recommendations for staying healthy later in life.

c Christophe Stevens, Imperial College London, UK

Software engineer Christophe Stevens uses participants’ genetic data to create an algorithm that could help doctors to spot familial hypercholesterolemia – a genetic high-cholesterol condition that goes undiagnosed in around 85% of people who have it. Stevens was the first PhD student to receive financial support from UK Biobank to analyse its data. **“This was quite important to have because I was not funded by any kind of funding body,”**

d Rafaella Rogatto de Faria, University of São Paulo, Brazil

Biomechanics specialist Rafaella Rogatto de Faria uses UK Biobank data to find out what role genes play in cartilage injuries and osteoarthritis, and whether different people would benefit from different treatments. UK Biobank grants reduce financial barriers in lower-income countries: **“UK Biobank takes proactive action to ensure that talent and innovation are not restricted but encouraged.”**

e Kezia Irene, Kalbe Farma, Indonesia

Kezia Irene, a bioinformatics scientist at Indonesia’s largest pharmaceutical company, is working on understanding the role that genes play in obesity. **“Our aim is to use UK Biobank data, especially those of the Asian populations, to validate our findings for Indonesian populations.”** Eventually, she wants to develop personalised recommendations for how to best treat obesity.

Meet the team

The UK Biobank team has doubled in size in the last 5 years! We now have 300 colleagues working in Manchester, Oxford, Bristol, London, Newcastle and Reading.



Willow, Radiographer, Bristol Imaging Centre

Joining UK Biobank was an exciting job opportunity unlike any I had seen before. My role involves performing the four different scans, as well as team management. The shift pattern gives me a great work life balance. In my free time I enjoy swimming and going for walks with my cockapoo Marmite.



Stephen, Participant Resource Centre Advisor, Manchester

I really enjoy interacting with participants over the phone and via email. Our participants are doing a truly wonderful thing for the future. In my spare time, I help family and friends with DIY projects, enhancing skills whilst helping others.



Adunola, Head of Finance, Manchester

I lead UK Biobank's finance team. This involves exploring opportunities to reduce costs, improve our financial performance, and providing expert financial advice to other staff across the whole organisation. Working for UK Biobank is important to me. I am mindful of the role well-funded science and research can play in advancing and improving healthcare and medicine. When my finance hat isn't on, I enjoy working with children and have taught Sunday school for over 15 years.



Megan, Epidemiologist, Oxford

I support researchers to access UK Biobank data alongside conducting my own research. I joined UK Biobank as I was excited to work with an organisation that is aiming to improve the health of the population. I particularly enjoy meeting and talking to participants about how their data is being used; they always ask the best questions and help us to think outside the box. Outside of work, I spend most of my time running after my two boys and baking.

Your agreement with UK Biobank

When you became a participant many years ago, you made an important and generous agreement with UK Biobank.

You gave us permission to:

- access your medical and other health-related records
- store your blood and urine samples long-term
- re-contact you to ask you further questions about your health and invite you to come back for further assessment visits
- use and store this information about you for health-related research in the public interest, even after your incapacity or death.

In return, we agreed to protect your confidentiality and make your data available for ground-breaking health research for the benefit of future generations. You can withdraw your permission for any reason at any time.

Protecting your confidentiality

We know that information about your health and lifestyle is personal and private to you. Information that identifies you – for example, your name, address and NHS number – is never shared with researchers.

We know some of you may be worried about cyberattacks. We are certified to an internationally recognised standard for information security, as well as through a national-level cyber security scheme. This means our people, policies and technology adhere to robust industry standards for data security and we continually update our approach to ensure that your data is protected.

Who can access your data?

Your de-identified data are shared only with approved researchers for health-related research that is in the public interest.

Researchers must work for a credible research organisation. We perform background checks and look at the kind of research they have done in the past. The research they want to do should benefit the health and wellbeing of society and not cause harm. If the application raises any concerns, it is referred to our expert Access Committee, which can consult our Ethics Advisory Committee and Participant Advisory Group.

We used to treat the few researchers applying from insurance companies like other commercial or academic researchers as they may conduct valid health-related research, for example if assessing the risk of disease. However, the Access Committee reviewed this policy and in January 2025, following input from our Participant Advisory Group and Ethics Advisory Committee, decided that applications from insurance companies will no longer be approved.

You can read more about the vetting process and change in policy here: <https://www.ukbiobank.ac.uk/enable-your-research/apply-for-access>

When researchers have finished their projects, they must make their findings available to the scientific community, and return their underlying results to UK Biobank. This openness is a cornerstone of scientific progress.

“ **The agreement between participants and UK Biobank is always at the forefront of our minds. In everything we do, we ask, what would participants expect from us?**”

Nicola Perrin, Chair of the UK Biobank Ethics Advisory Committee.

Online health questionnaires

Our online health questionnaires are a great way for you to give us valuable information from the comfort of your own home!

You can log into the Participant Area of the UK Biobank website and fill in questionnaires at any time. You can save your answers and come back later if you don't want to complete the whole questionnaire in one go.

We work with expert researchers from around the world to write our questionnaires. We use questions that have been proven to get reliable and meaningful answers.

You have been amazing – since 2011, an average of 168,000 participants have responded to each questionnaire. Our health and wellbeing questionnaire is the most popular so far with 201,000 responses.

Different participants respond to different questionnaires, but we have had more than 2.3 million responses in total! We are truly grateful.

Researchers combine your questionnaire responses with other data you have given us to understand what influences health. See page 13 for how researchers are using UK Biobank questionnaire data to match people with depression to the right treatments.



Currently, we have five questionnaires open:

Pain 2

Mental wellbeing

Sleep

Social interactions and focus

Visualisation and memory

Rest assured – your sleep data is now available to researchers

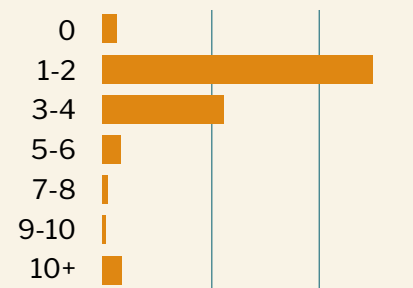
A huge thank you to the 180,000 participants who have completed our sleep questionnaire. It includes a whopping 138 questions about sleep quality, impact on work and family history of sleep. The information you have provided so far was released to researchers in March 2025.

You may be interested to know...



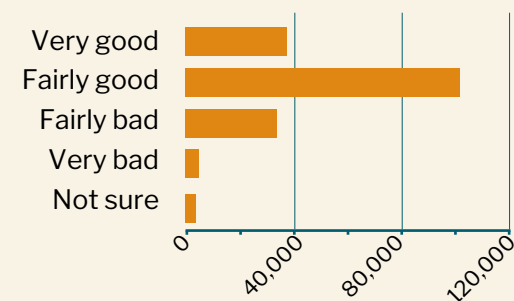
44,481
consider
yourself to be
definitely a
morning-type

On a typical night, many of you are waking up several times in the night.



14,689
consider
yourself to be
definitely an
evening-type

But most of you are fairly good sleepers. You said your sleep quality on a typical night was...



Communications survey

Thank you to the 33,000 of you who completed our 2024 survey and told us about your communication preferences!



The vast majority of you always read the newsletter, whether you get it by email or post.



Some of you use Facebook but most don't use social media channels.

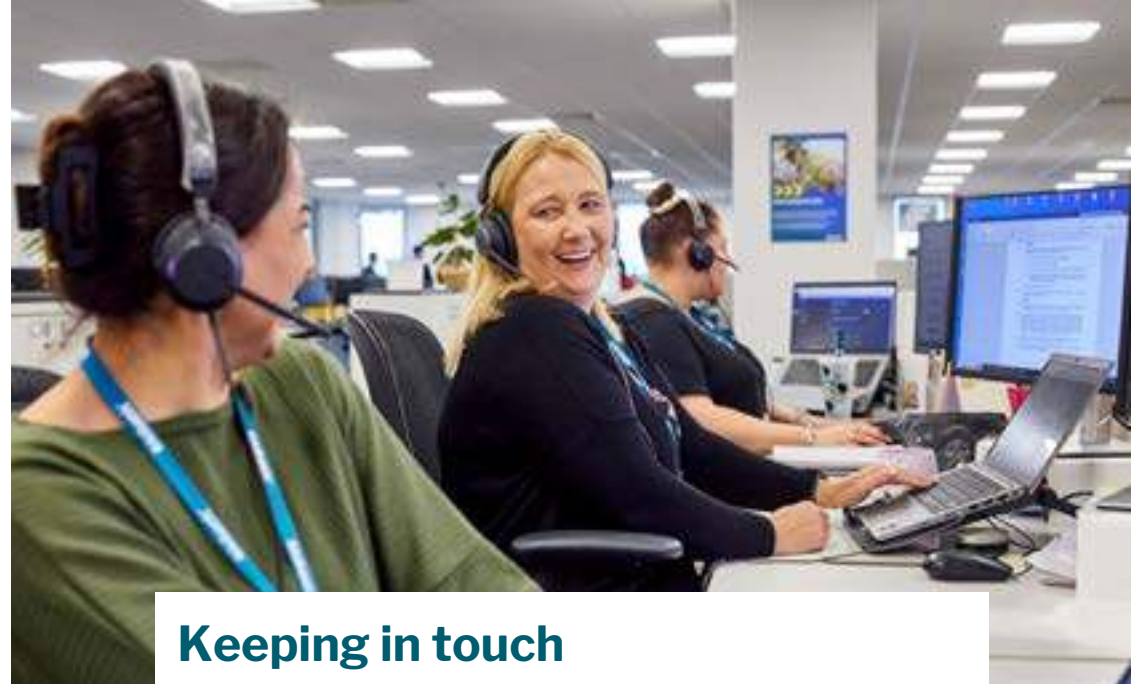
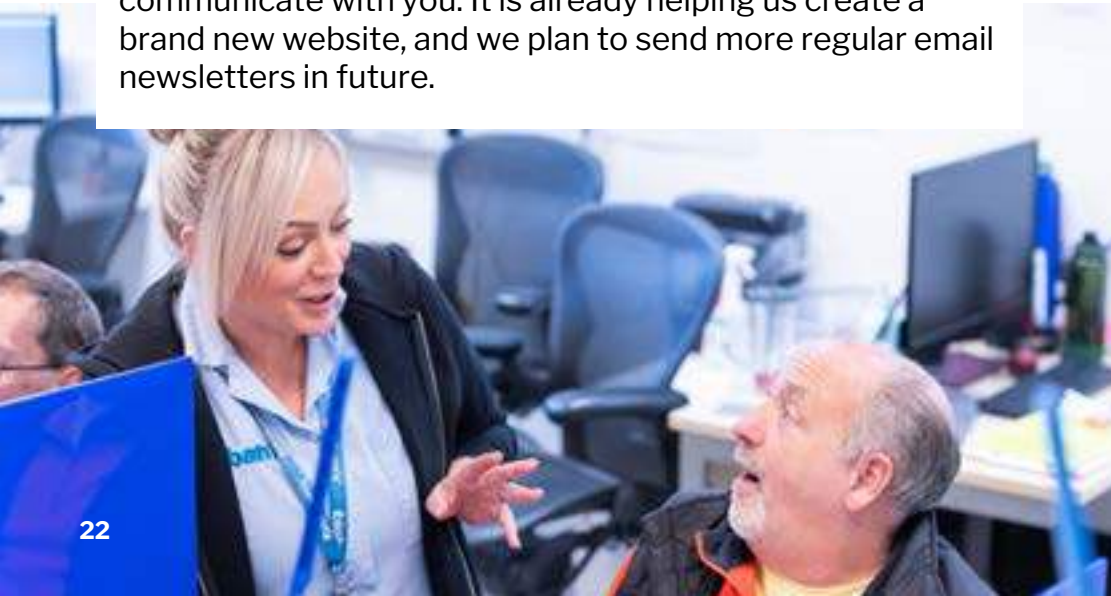


Most of you have a device of some kind, like a computer or a smart phone.



There is interest in a UK Biobank app where you could answer questions about your health and keep in touch.

We are using your feedback to improve how we communicate with you. It is already helping us create a brand new website, and we plan to send more regular email newsletters in future.




Keeping in touch

There are many ways to keep in touch with UK Biobank.

Participant Resource Centre

Our friendly team is ready to answer any queries you have. They can be reached on the phone, email or post:

 Free phone: **0800 0 276 276**
(open 9am-5pm, Mon-Fri)

 Email: ukbiobank@ukbiobank.ac.uk

 Post: 1-2 Spectrum Way,
Adswood, Stockport, SK3 0SA

Social media

We are on all the major social media platforms – just search for **UK Biobank**





Do we have your contact details?

If you have an email address or an updated phone number, please share it with us! This makes it easy for us to tell you how your data is making a difference and invite you to contribute further.

If you would be willing to give us your email address or your contact details have changed, please let us know by contacting the Participant Resource Centre (see page 23) or logging into the Participant Area of the website using your Participant Identification Number.