

digitalhealth

REWIRED
BIRMINGHAM 12-13 MARCH 2024

Headline Sponsors:

System 
Connecting Care

Graphnet 
Transforming Care

tpp 

Marko Balabanovic

CTO

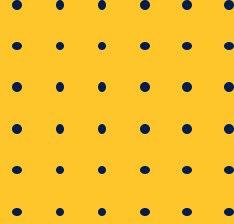
Our Future Health



AI,
DATA AND
ANALYTICS
STAGE

Stage Sponsor:

InterSystems[®]
Creative data technology



From zero to a million

Lessons in scaling health research

Marko Balabanovic
Chief Technology Officer, Our Future Health

Digital Health Rewired
March 2024





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

It is designed to help people live longer, healthier lives through the discovery and testing of more effective approaches to prevention, earlier detection and treatment of diseases.

The **5 million** volunteers sharing information will create an incredibly detailed picture that represents the whole of the UK.

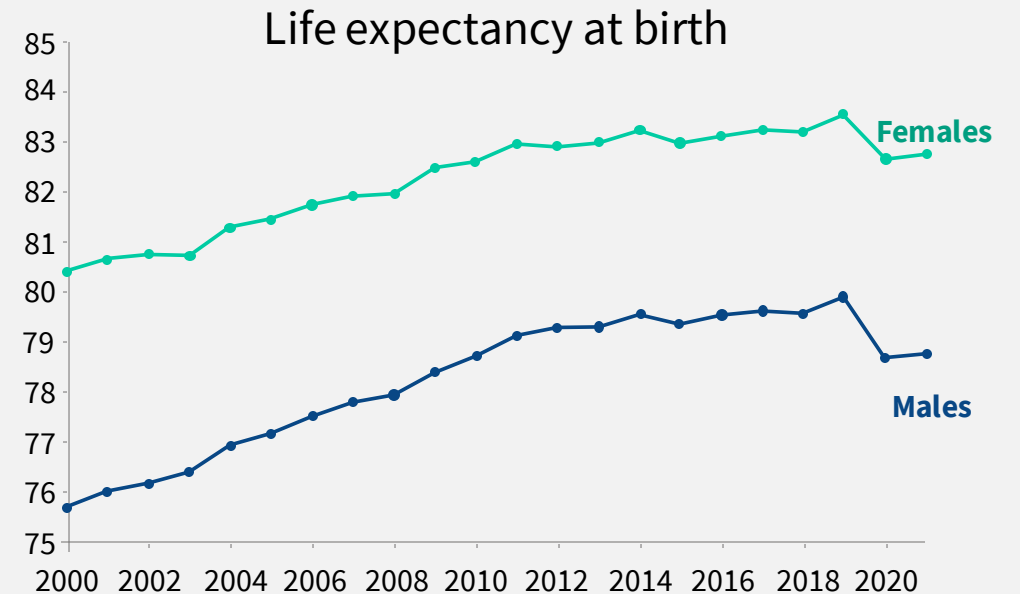
Like many countries, we face an increasing burden in the UK from treating late-stage chronic disease

In the UK, there are 2.5 million people living with **cancer** and by 2030 this figure may be as high as 4 million

There are more than 100,000 hospital admissions each year due to heart attacks. **CVD** is estimated to cost £19 billion a year

The cost of **dementia** is expected to more than double from £26 billion in 2015 to £55 billion in 2040

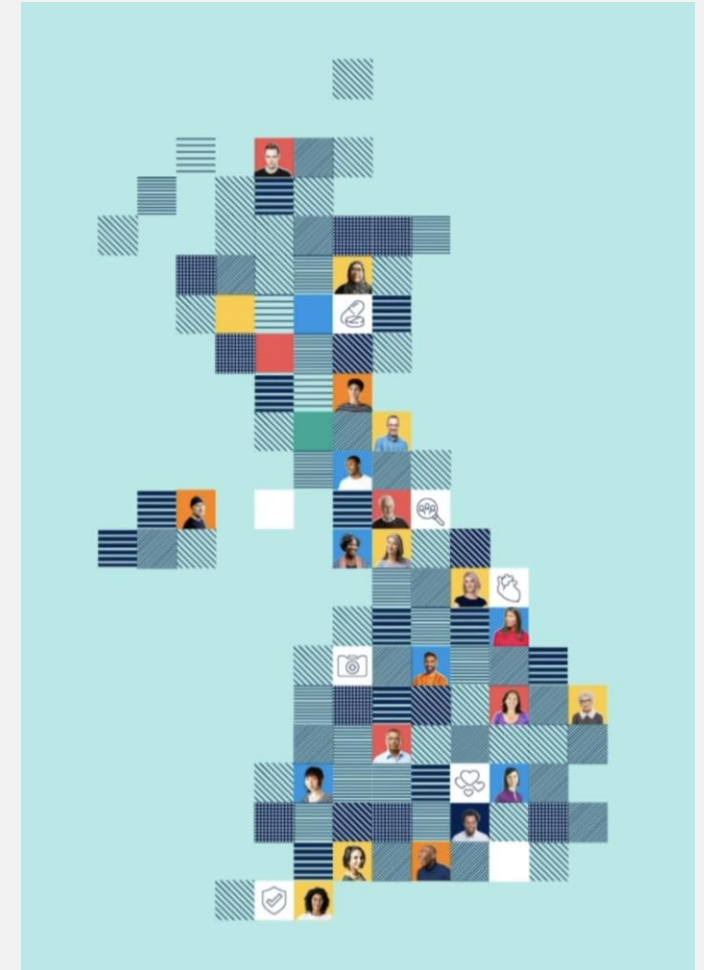
Despite the advances in health care, increases in healthy life expectancy have stalled



Adapted from The King's Fund, 2023.

Aims of the programme

- 1. Facilitate discovery and translational research** by academic, charity and commercial researchers by building a programme that generates and links multiple components of health and health-relevant information on five million people in the UK
- 2. Estimate personal disease risk** information for participants, based on **genetic** and **non-genetic** information, and offer this to participants who wish to receive it
- 3. Re-contact sub-groups of participants** generally or based on personal characteristics or indicators of disease risk for additional biological samples, questionnaires, or invitations to take part in clinical trials and other studies by academic, charity and commercial researchers



Funding and partnerships

- Our Future Health is designed to harness the power of collaboration
- **We're combining support from industry, charities and government** to build a world-leading health research programme
- Backed by £79M grant funding from the government via UK Research & Innovation (UKRI), and over £150M from Founding Members, with an additional £51M government funding announced in the 2023 Autumn statement. We are registered as a charity with the Charity Commission for England and Wales and OSCR, the Scottish Charity Regulator.

Funders



Affiliate charities





11 volunteers
May 2021

Growth since the start

Current

1.25M consented participants

600K full participants who have
a good blood sample and a
completed questionnaire

2023 in numbers

480,107 clinic appointments

212 locations

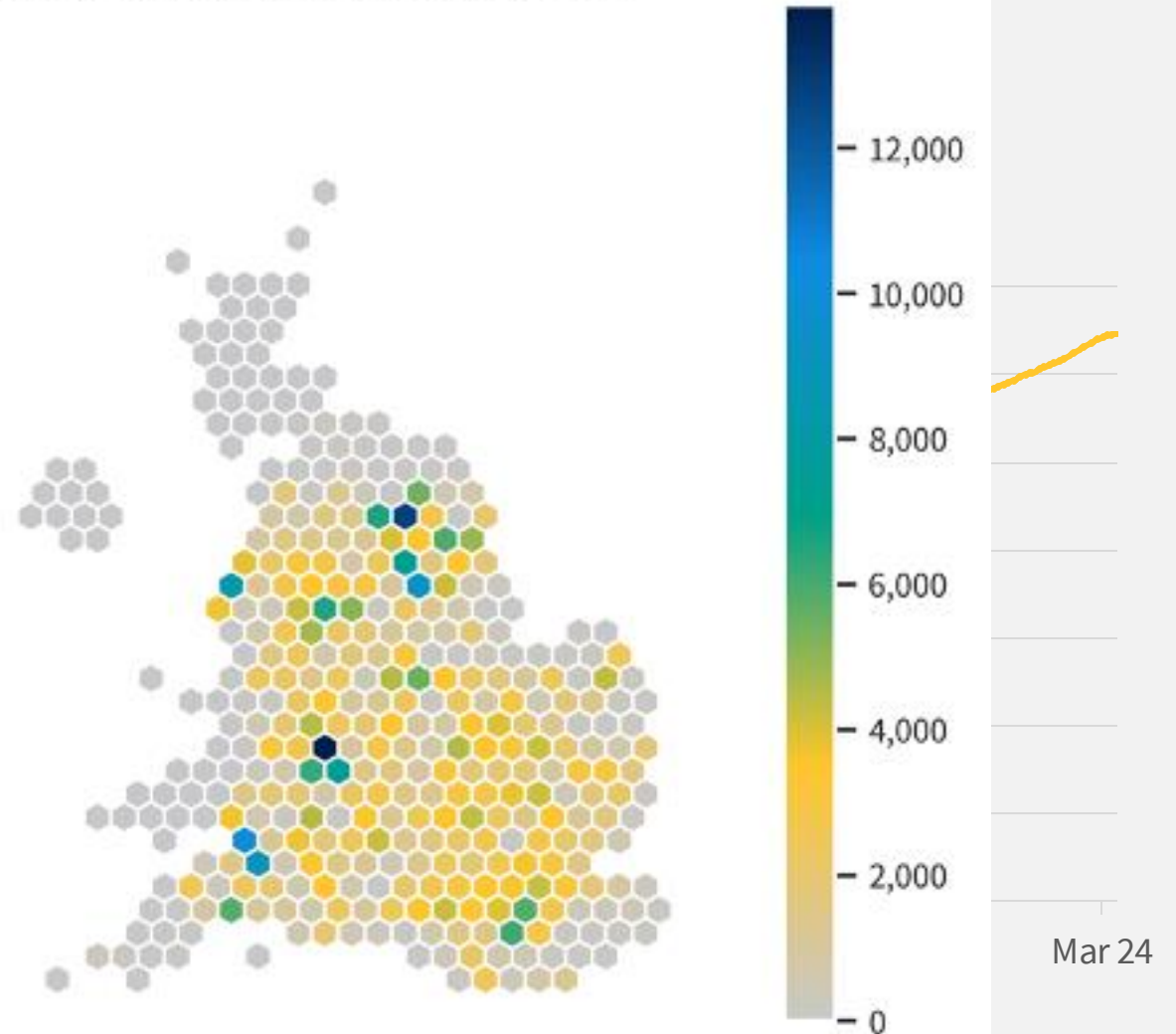
5,037 litres of blood

37,312 metric tons of participants

Jun 22 Sep 22

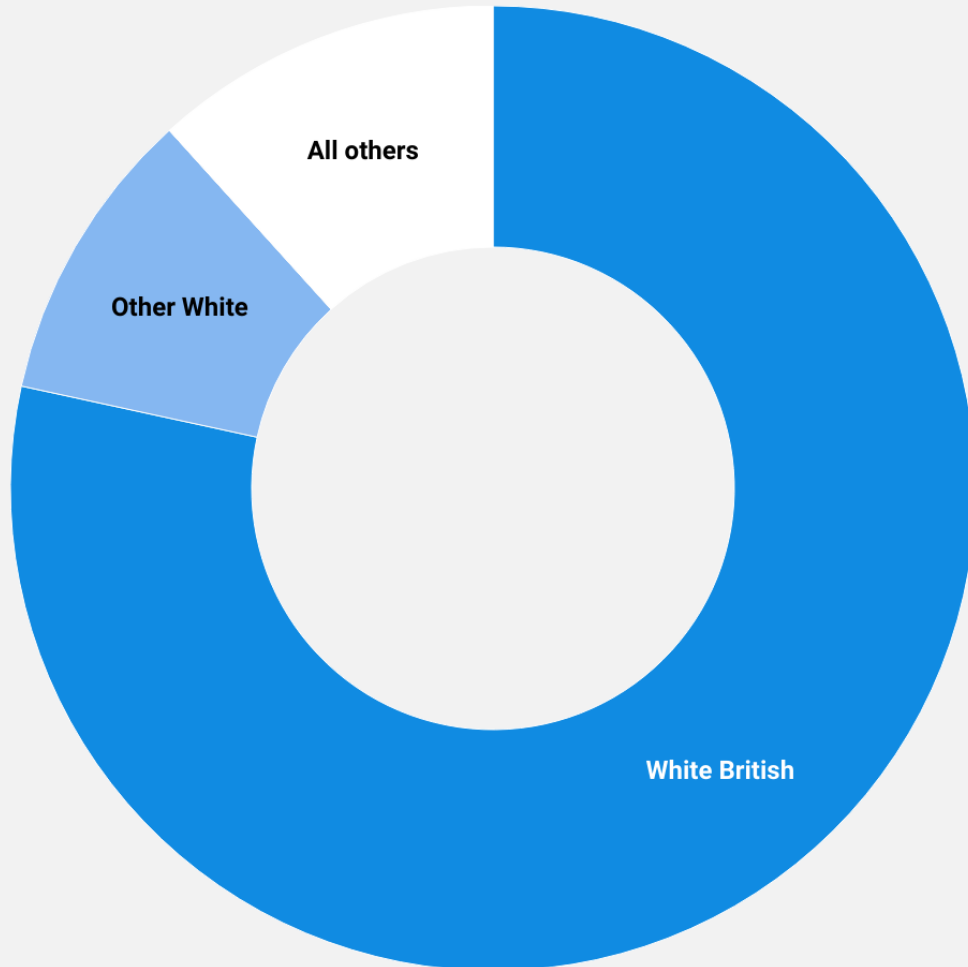
Full Participants by UK Local Authorities (2019)

Total Full Participants up to March 2024

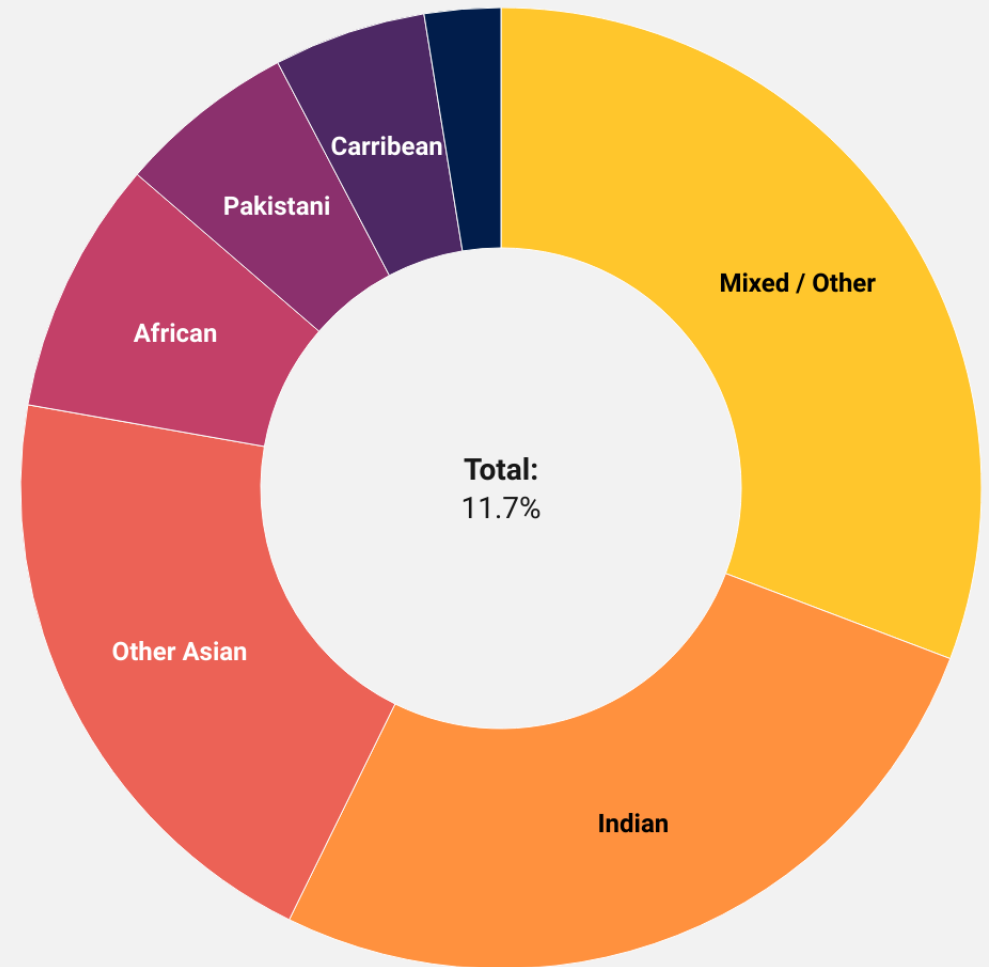


Ethnicities of full participants

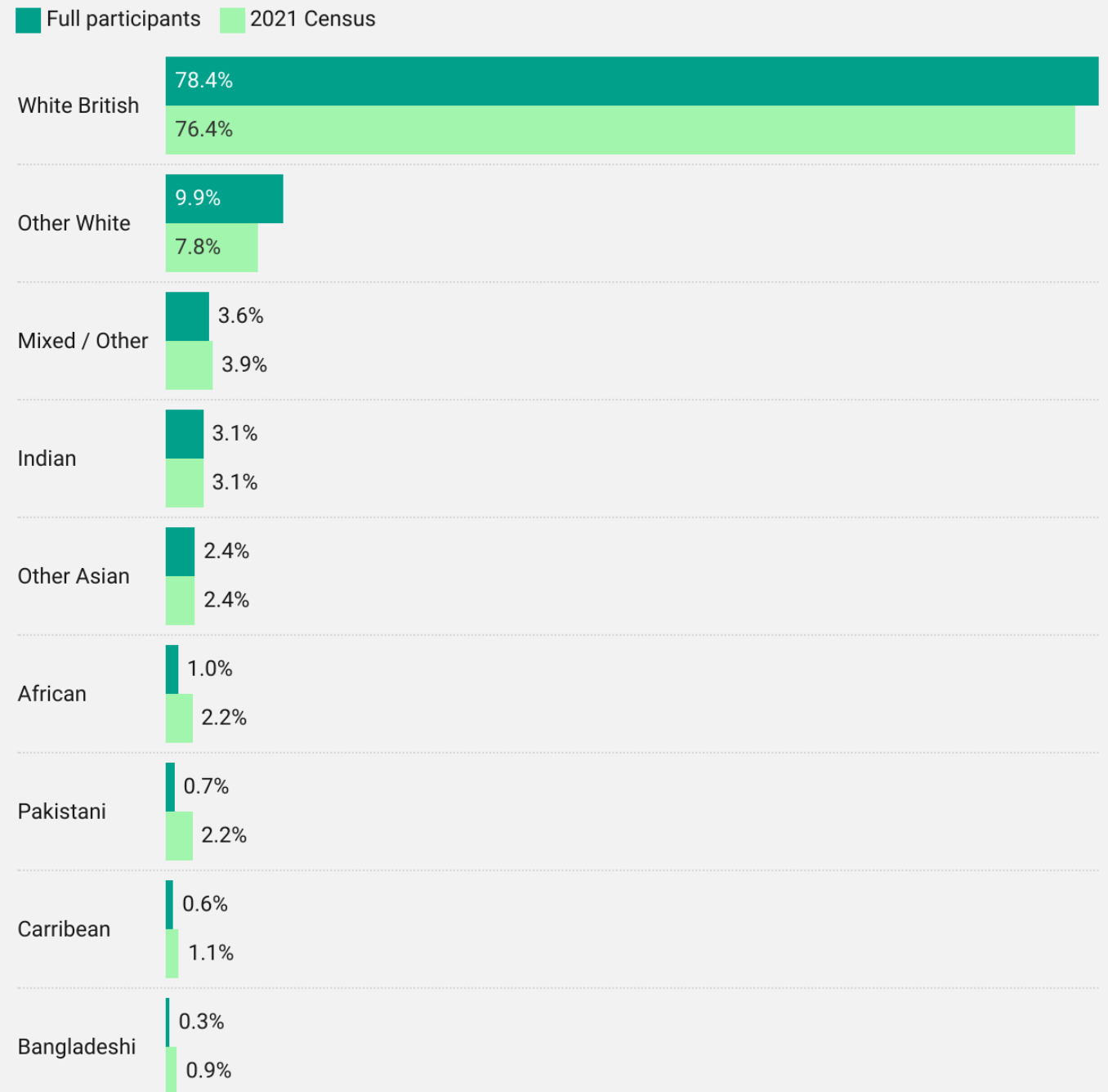
White British (78.4%) Other White (9.9%) All others (11.7%)



Mixed / Other (3.6%) Indian (3.1%) Other Asian (2.4%) African (1.0%) Pakistani (0.7%)
Carribbean (0.6%) Bangladeshi (0.3%)



Ethnicities compared to census





- Pharmacy clinic
- Mobile / pop-up clinic

2 clinics - 9 appointments
July 2022



How does it all work?



Volunteers are invited (or hear about us)

+ Our Future Health

In partnership with **NHS**

Address
Address
Address
Address

Dear (First name),

An invitation to take part in research to help prevent, detect and treat disease

You are invited to take part in a new health research programme. A letter explains what is involved and what to expect.

Today, too many people spend many years of their lives in hospital. We want to help researchers prevent, detect and treat diseases like dementia, cancer, heart disease and stroke.

Our Future Health will be the UK's largest ever health research programme. People over the age of 18 can help us by taking part in research.

Taking part involves:

1. answering some online questions about your health
2. giving Our Future Health permission to use your data
3. providing a blood sample and having your blood pressure (or other tests) at one of our local research sites

Your data will be stored and managed securely and in compliance with data protection laws.

Scan this QR code for more information and to sign up

Or visit ourfuturehealth.org
Your invite code is 0407

If you have any questions, please call 0800 500 000

Yours sincerely,

Raghib Ali
Dr Raghib Ali OBE MD FRCP(UK)
Chief Medical Officer & Joint Chief Investigator
Our Future Health, NHS Consultant in Acute Medicine

Chair of Trustees: Professor Sir John Bell GBE FRS FMedSci
Our Future Health is a company limited by guarantee and registered with the Charity Commission for England and Wales (charity number SC050917). Registered office: 100, The Quadrant, London W1 8DB

Page 1 of 2

Dear Peter,

We're inviting you to take part in Our Future Health research programme, which will transform the prevention, detection and treatment of dementia, cancer, heart disease and stroke.

Be one of the first

You're doing something amazing when you take part in Our Future Health. You'll help NHS Blood and Transplant research, and there are enough donations from different people to help us. You will also offer us information about your research.

You can still sign up even if your next donation is in the next few weeks. Everyone over the age of 18 and living in the UK can help.

Let's prevent disease together

Thank you for your support,

Professor David Roberts
Medical Director - Pathology
NHS Blood and Transplant

Dr Raghib Ali OBE MD FRCP (UK)
Chief Medical Officer & Joint Chief Investigator
Our Future Health

Help

Today, from COVID-19 to stroke

+ Our Future Health

In partnership with **NHS**

[Join Our Future Health](#) Registered participant? [Sign in](#)

Our research mission Get involved Protecting your data About us News & stories

Let's prevent disease together

We're bringing together 1 million people to help prevent, detect and treat disease.

The UK's largest health research programme

Our Future Health is a charity working in partnership with the NHS, other charities and industry.

You can make a difference

Many of us have experienced the devastating effects of cancer, diabetes, dementia and heart disease.

Having people of different ages, backgrounds and communities join the programme means we can get enough information about how diseases affect all people.

By taking part, you can help researchers prevent, detect and treat diseases.

1,082,855
people are already taking part, to prevent disease together

Updated 29 November 2023 at 1:47pm

Who can take part

They attend an appointment to provide a blood sample and have some measurements taken



Our Future Health dashboard showing appointment status and a blood pressure measurement form.

Appointments (Last updated at 13:00)

Not yet arrived: 124 | **Waiting: 134** | In progress: 7 | Done: 187

Time	Status	Duration
08:20	Waiting	22mins
08:20	Waiting	18mins
08:20	Waiting	14mins
08:20	Waiting	11mins
08:40	Waiting	10mins
09:00	Waiting	6mins w
09:00	Waiting	5mins w
09:00	Waiting	3mins w
09:20	Waiting	>1mins

Blood pressure

Systolic: / Diastolic: mmHg

Heart rate: beats/minute

Appointment submitted Thank you

What to do next

- Remind the participant to complete their questionnaire in the next week if they have not done it already.
- Thank the participant for taking part in Our Future Health.

[Go to waiting participants](#)

[View not yet arrived participants](#)

© Our Future Health 2022

Our Future Health is a company limited by guarantee registered in England and Wales (number 12212468) and a charity registered with the Charity Commission for England and Wales (charity number 1189681) and OSCR, Scottish Charity Regulator (charity number SC050917). Registered office: 2 New Bailey, 6 Stanley Street, Manchester M3 5GS.

They complete a questionnaire about their lifestyle and health

Questionnaire

You are now ready to start the online questionnaire.

Please be reassured that all of your answers will be treated confidentially. The information you give us will have your name removed, so that no individual could ever be identified by the data.

There are 5 sections of multiple choice questions to complete.

- Section 1 - You and your household (4 - 6 minutes)
- Section 2 - Work and education (3 - 5 minutes)
- Section 3 - Lifestyle (10 - 15 minutes)
- Section 4 - Family health (8 - 10 minutes)
- Section 5 - Your health (10 - 12 minutes)

The whole questionnaire should take around 35 minutes.

Your answers will be saved as you go along. If you stop at any point, you can come back and complete the questionnaire from where you left off.

1. About you and your household
4 - 6 minutes
This section is about you and your home.

This first set of questions is designed to collect important information about you and your home. This information will be used to generate personalised health advice and recommendations.

What sex were you registered with at birth?
A question about gender identity will follow later in the questionnaire.

Female
 Male
 Intersex
 Prefer not to answer

3. Your lifestyle
Thinking about the last 4 weeks, how many minutes did you usually spend walking on a typical DAY?

Enter minutes
| Minutes

Do not know
 Prefer not to answer

[← Previous question](#)

5. Your health history
Over the last two weeks, how often have you been bothered by any of the following problems?

▶ Further support for your mental health

Little interest or pleasure in doing things

Feeling down, depressed, or hopeless?

Trouble falling or staying asleep, or sleeping too much?

Feeling tired or having little energy?

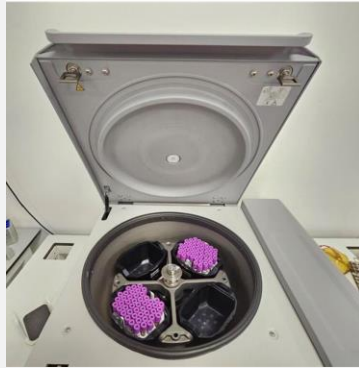
Poor appetite or overeating?

Feeling bad about yourself - or that you are a failure or have let yourself or your family down?

Trouble concentrating on things, such as reading the newspaper or watching television?

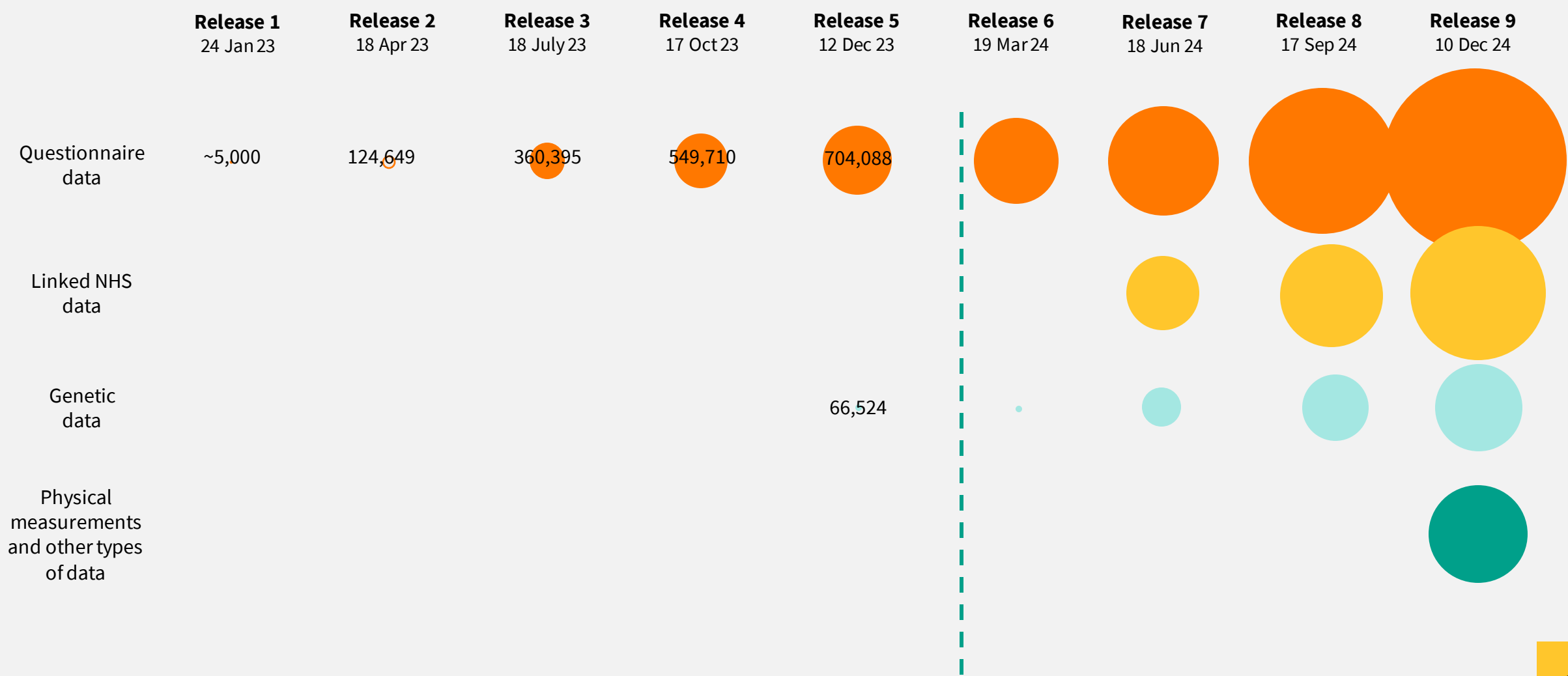
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?

The blood samples are processed and genotyped



- Our custom genotyping array measures 700K variants
- The 700K include a standard array “backbone”, comprehensive disease- and phenotype-associated variants, variants to augment polygenic risk scores, blood typing variants, pharmacogenetics (PGx) variants, and custom content from our founding and affiliate members and expert working group

Data is released to the trusted research environment quarterly



Researchers can apply, have their study reviewed by the independent Access Board, and gain access to our trusted research environment (TRE)

Log in to researcher account | Create an account

Researcher resources | Apply to access the data | Data and cohort | Analysing the data | Contact us

A world-leading resource for health research

Become a registered researcher at Our Future Health and apply for access to data from the UK's largest health research programme.

Contents

- [Our growing data set](#)
- [About the Our Future Health research programme](#)
- [Our research resources](#)

Our growing data set

Included in the December 2023 release:

704,088
participants with completed baseline health questionnaires

66,524
participants with initial genotype array data

Find out more about the [data and cohort](#).

About the Our Future Health research programme

We're bringing together data from up to 5 million adults in the UK. Researchers can request access to this data and analyse it to discover new ways to

Our Future Health | Synthetic Data Cohort | 5,151 Participants

pheno_v1_0_20230116.dataset | Synthetic Data Cohort | 5,151 Participants

OVERVIEW | DATA PREVIEW

Item	Count / Freq.	Item	Count / Freq.	Item	Count / Freq.
SR_GENDER_1_1	5,151 Participants	SR_ETHNICITY_1_1	5,151 Participants	HOUSEHOLD_INCOME_1_1	5,151 Questionnaires
Male	2,480 (48.1%)	White - English / Welsh / Scottish / Northern Irish / ...	2,480 (48.1%)	Do not know	713 (13.8%)
Female	833 (16.1%)	White - Irish	303 (5.9%)	£31,000 to £31,999	746 (14.5%)
Transgender Male	886 (17.3%)	White - Gypsy or Irish Traveller	232 (4.5%)	Greater than £100,000	741 (14.3%)
Transgender Female	824 (16.0%)	White - Polish	399 (7.7%)	£18,000 to £30,999	722 (14.0%)
Gender variant/non-conforming	851 (16.5%)	Any other white background	275 (5.3%)	Prefer not to answer	721 (13.9%)
Other	884 (17.2%)	Mixed - White and Black Caribbean	253 (4.9%)	Less than £18,000	719 (13.9%)
Prefer not to answer	843 (16.3%)	Mixed - White and Black African	287 (5.6%)		
		Mixed - White and Asian	347 (6.7%)		
		Any other mixed multiple ethnic background	282 (5.5%)		
		Asian or Asian British - Indian	252 (4.9%)		
		Asian or Asian British - Pakistani	279 (5.4%)		
		Asian or Asian British - Bangladeshi	270 (5.2%)		

DNAexus | Remaining 0d 0h 18m 18s | Update duration

File Edit DNAexus View Run Kernel Tabs Settings Help

[DX] TestNotebook.ipynb | Python 3

```

[3]: print("Our Future Health TRE BETA is Live!")
Our Future Health TRE BETA is Live!

[3]: import sys
print(sys.version)
3.5.5 [Anaconda, Inc.] (default, Apr 29 2018, 16:14:56)
GCC 7.2.0

[10]: import matplotlib.pyplot as plt
# Create some data
x = [1, 2, 3, 4, 5];
y1 = [2, 4, 6, 8, 10]; y2 = [10, 8, 6, 4, 2]
# Create a figure and axes
fig, ax = plt.subplots()
# Plot the data
ax.plot(x, y1, label="Stress levels")
ax.plot(x, y2, label="Days to launch")
# Add labels and a title
ax.set_title("Launching Beta TRE")
# Use seaborn library to make it look more visually pleasing
import seaborn as sns
sns.set_style("darkgrid")
# Show the graph
plt.legend()
plt.show()

```

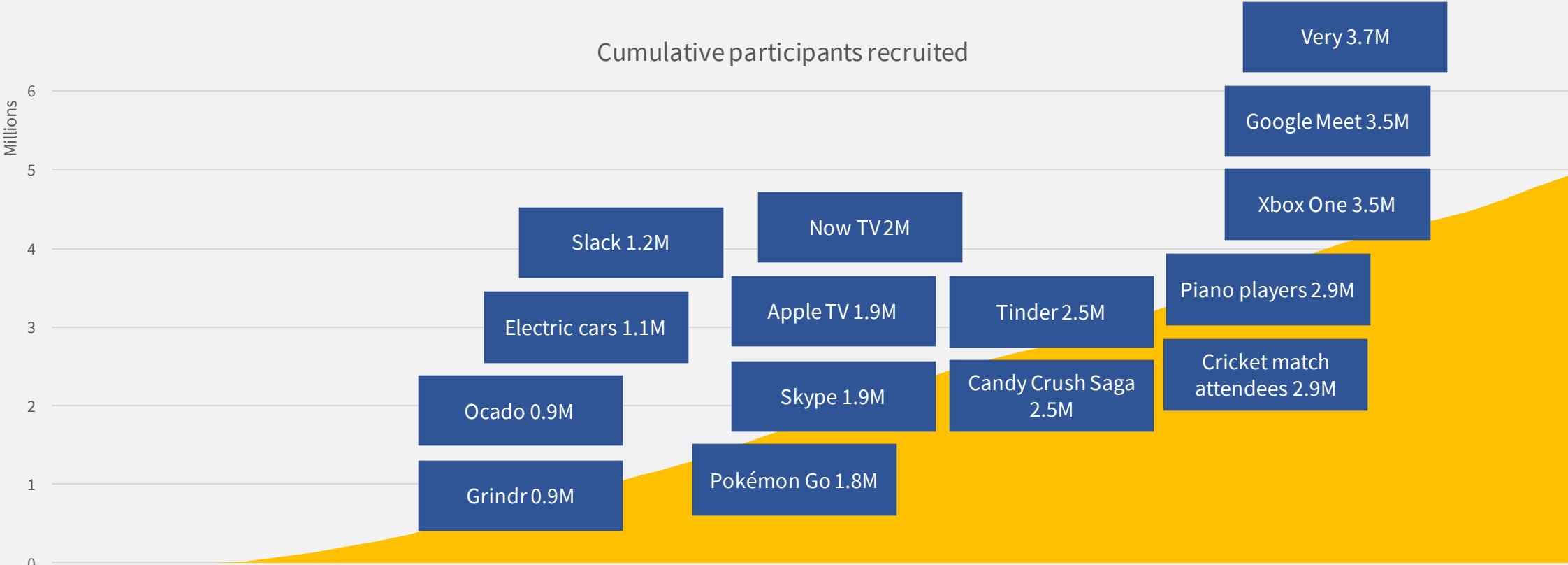
Python 3 | Idle | Mode: Command | Ln 1, Col 1 | DNAexus:TestNotebook.ipynb

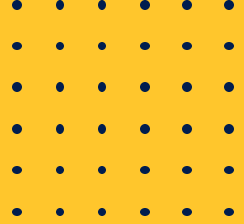


Achieving the growth



5 million volunteers





Collaboration

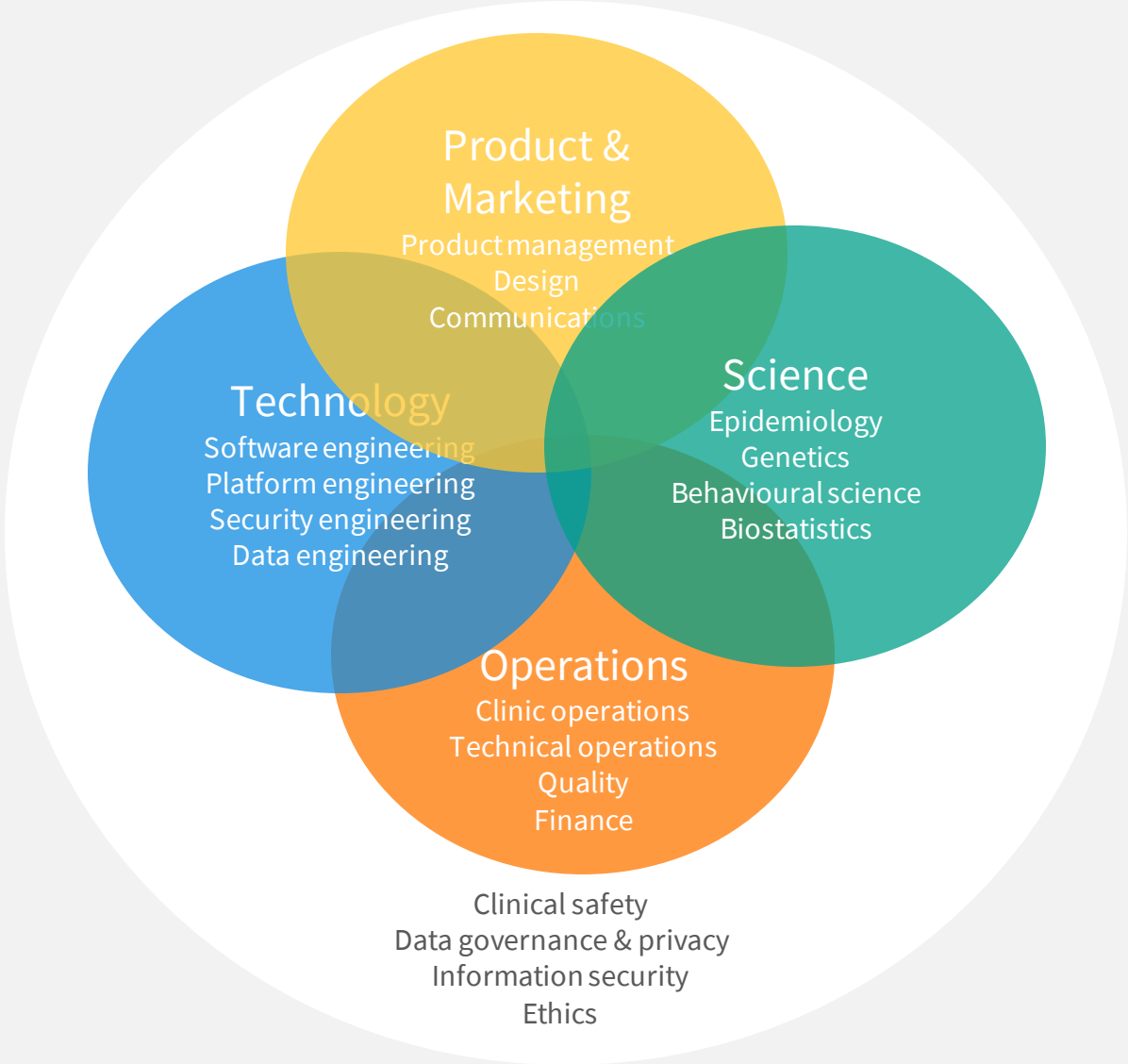
Trust



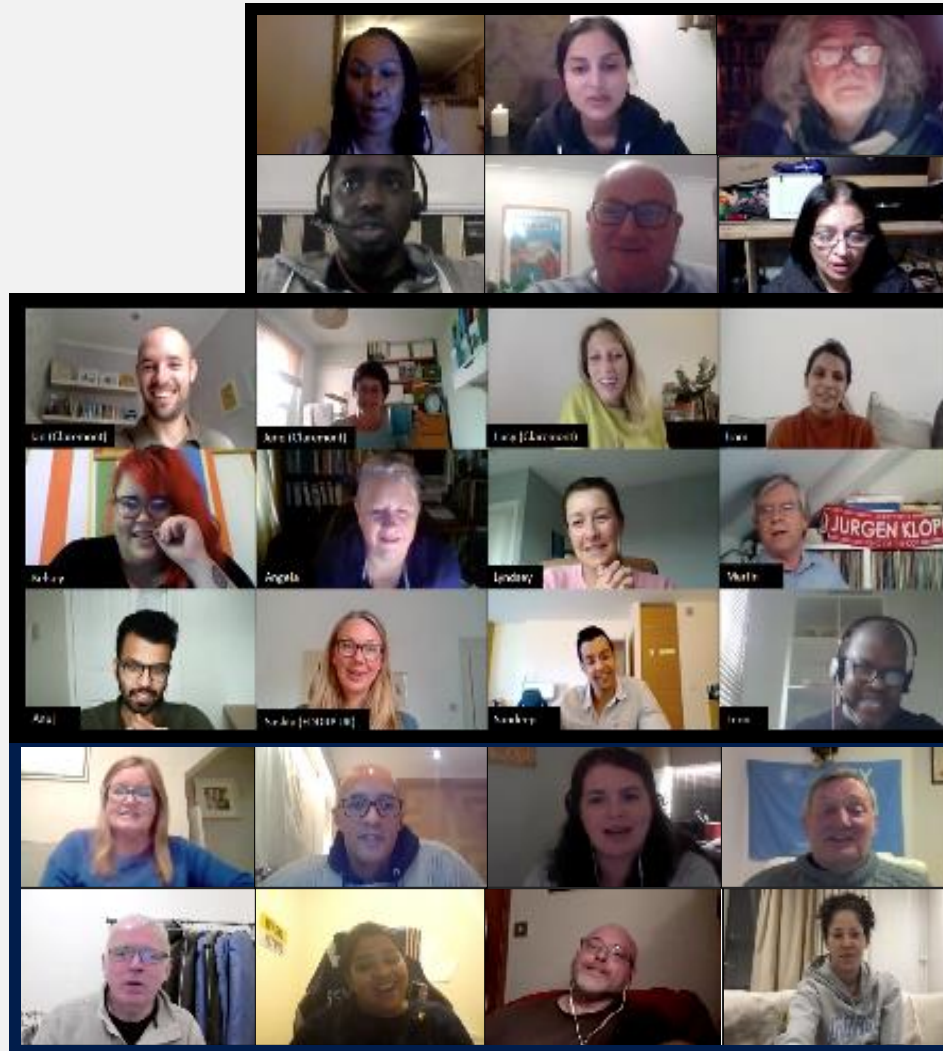
Collaboration with strong delivery partnerships



Collaboration across professional cultures



Collaboration with members of the public and participants



A few examples:

Deliberative dialogues running right now with volunteers and the public to inform our feedback and re-contact policies

3461 members of the public involved in 2022 in various user research activities

4 focus groups, 2 co-design meetings, 21 interviews with the public to **inform the scientific protocol**

18 focus groups, 14 co-design meetings, 21 interviews with the public to **develop the information sheet, consent form, explainer videos & other public-facing materials**

35 cognitive interviews with the public to **inform the questionnaire**

Focus on trust: It's not data. They're people.

Security, privacy, ethics, data governance, data integrity and quality are all much easier to prioritise when you think of them as a **responsibility to the volunteers** who have given up their time to participate.

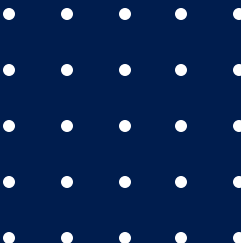
We also have a responsibility to future science. Our research mission is to enable the discovery and testing of more effective approaches to prevention, earlier detection, and treatment of diseases. This depends on a single-minded focus on data integrity and quality, for decades.





A platform for research

What data *do* we have and what data *will*
we have on our volunteers





Our data



In our Trusted Research Environment we have

704,088 participants with completed
baseline health questionnaires

66,524 participants with initial
genotype array data

+



Early linked NHS data

NHS data will be added gradually starting this year, initially through our partnership with NHS England. Over time this data will be UK-wide. Some early data sets we're in the process of receiving following NHS England approval:

- **Hospital Episode Statistics** (HES) 2007/8 onwards: admitted patient care (APC), outpatient appointments, accident & emergency, critical care
- **Death** registrations
- **Cancer** registrations
- National Diabetes Audit

We will continue to on-board more datasets on an ongoing basis, and are continuing to work with the NHS on finding ways to include the primary care data that volunteers have asked to donate.

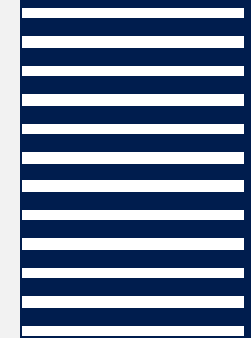




Find out more

Information about our cohort, the data, how to become a registered researcher or apply for a study is all available at:

research.ourfuturehealth.org.uk



Thank you

Any questions?

Our Future Health is a company limited by guarantee registered in England and Wales (number 12212468) and a charity registered with the Charity Commission for England and Wales (charity number 1189681) and OSCR, Scottish Charity Regulator (charity number SC050917). Registered office: 2 New Bailey, 6 Stanley Street, Manchester M3 5GS

