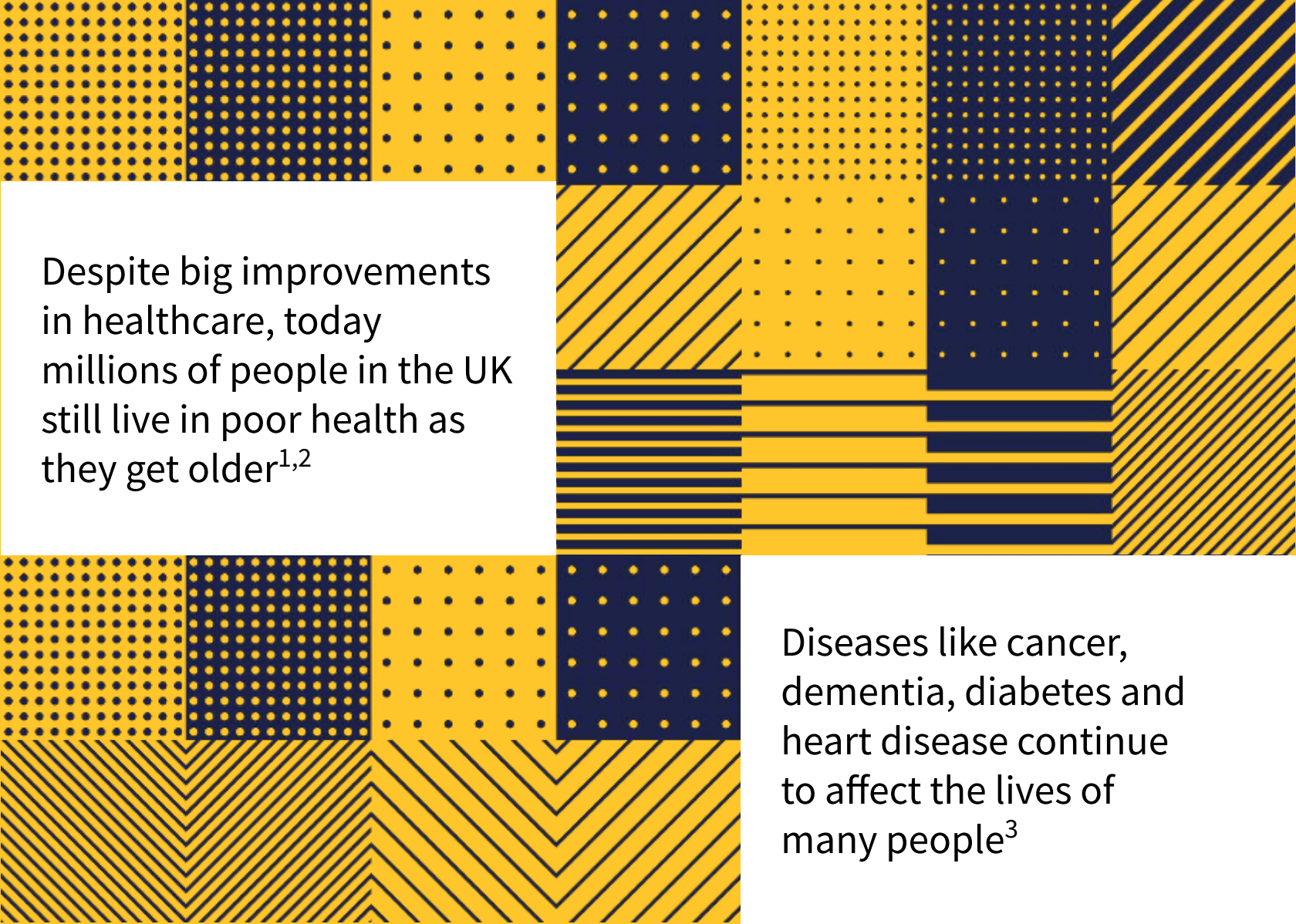


A new national health research cohort in the UK for early detection and prevention research



Andrew Roddam
CEO



Despite big improvements in healthcare, today millions of people in the UK still live in poor health as they get older^{1,2}

Diseases like cancer, dementia, diabetes and heart disease continue to affect the lives of many people³

1. Office for National Statistics. Voices of our ageing population: Living longer lives. Available at: <https://bit.ly/3KcWiRp>. Accessed: February 2023; 2. Age UK. 1.4 million older people aren't getting the care and support they need – a staggering increase of almost 20% in just two years. Available at: <https://bit.ly/3IDRHgP>. Accessed: February 2023; 3. World Health Organisation. WHO reveals leading causes of death and disability worldwide: 2000–2019. Available at: <https://bit.ly/40Ze7JC>. Accessed: February 2023.

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**¹ and by 2030 this figure may be as high as 4 million²

The number of people with **diabetes** is expected to increase from 3.9 million people in 2017 to 4.9 million in 2035³

There are more than 100,000 hospital admissions each year due to heart attacks. **CVD** is estimated to cost £19 billion a year⁴

The cost of **dementia** is expected to more than double from £26 billion in 2015 to £55 billion in 2040⁵

Despite the advances in health care, increases in healthy life expectancy have stalled⁶

Adapted from The King's Fund, 2023.

CVD, cardiovascular disease.

1. NHS England. Living with and Beyond Cancer. Available at: <https://bit.ly/3XEPC1o>. Accessed: February 2023; 2. NCRI. Living With and Beyond Cancer. Available at: <https://bit.ly/3luSKIM>. Accessed: February 2023; 3. GOV.UK. New centre opens to search for next generation of diabetes treatment. Available at: <https://bit.ly/3lt6LAB>. Accessed: February 2023; 4. British Heart Foundation. UK Factsheet. Available at: <https://bit.ly/2O7jqBc>. Accessed: February 2023; 5. Alzheimer's Research UK. Action plan for dementia. Available at: <https://bit.ly/2Nx7coZ>. Accessed: February 2023; 6. The King's Fund. What is happening to life expectancy in England? Available at: <https://bit.ly/3KuC45Z>. Accessed: February 2023.

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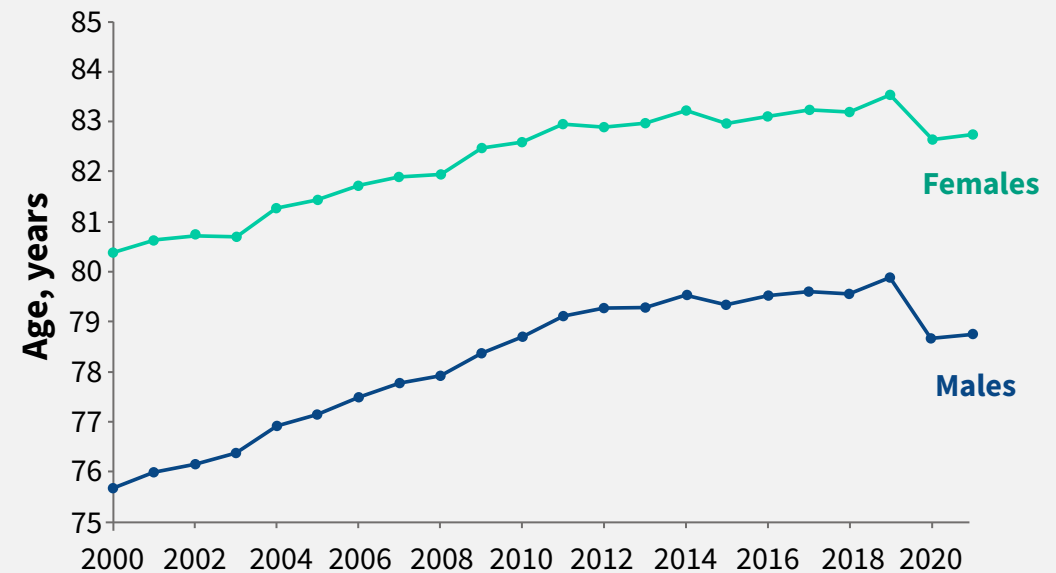
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Life expectancy at birth



Adapted from The King's Fund, 2023.

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2. NCRI. Living With and Beyond Cancer. Available at: <https://bit.ly/3luSKIM>. Accessed: February 2023;
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4. British Heart Foundation. UK Factsheet. Available at: <https://bit.ly/2O7jqBc>. Accessed: February 2023;
5. Alzheimer's Research UK. Action plan for dementia. Available at: <https://bit.ly/2Nx7coZ>. Accessed: February 2023;
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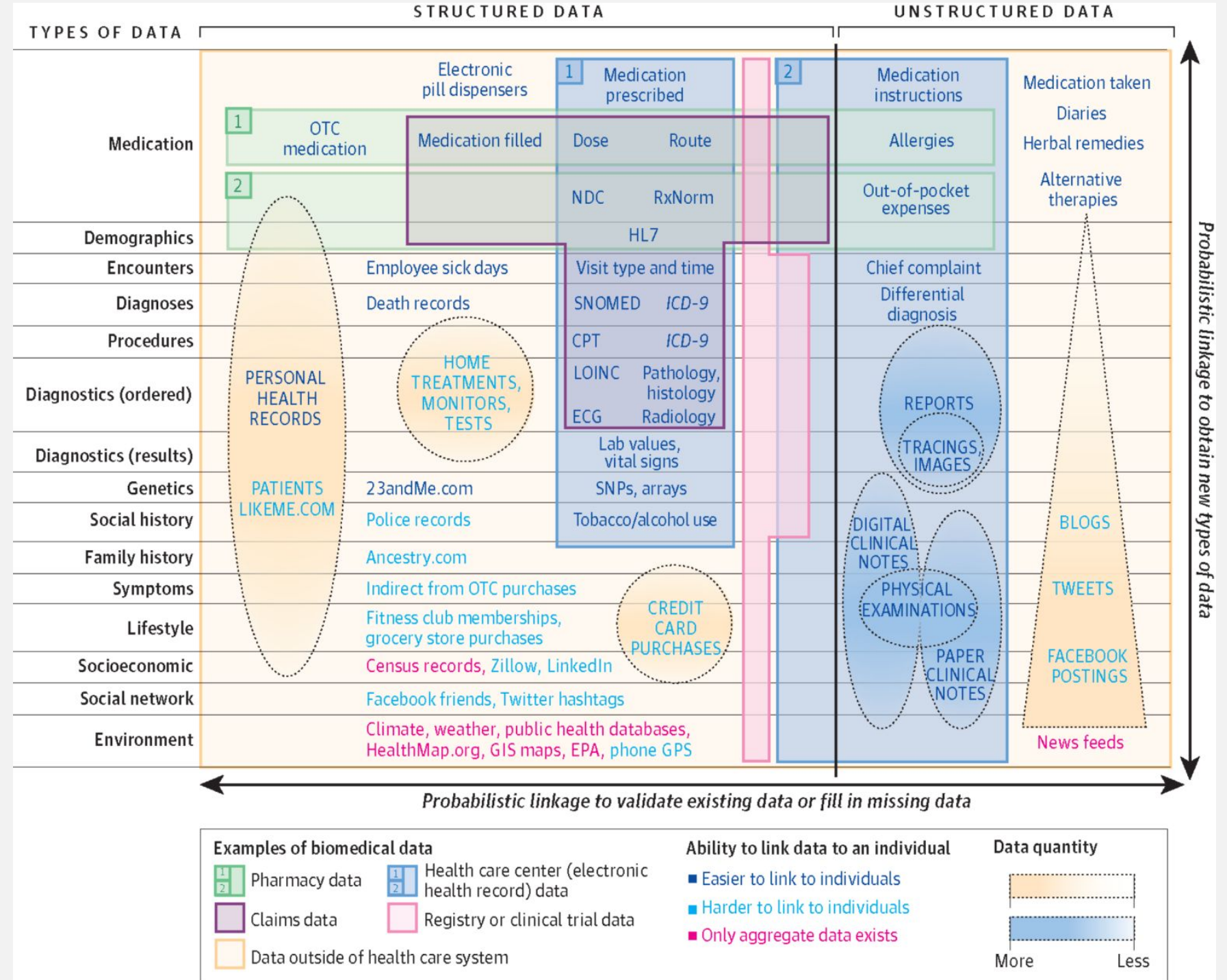


If we could spot the patterns of how and why diseases start, treatments could begin sooner, and might be more effective

It might even be possible to prevent some illnesses from developing in the first place

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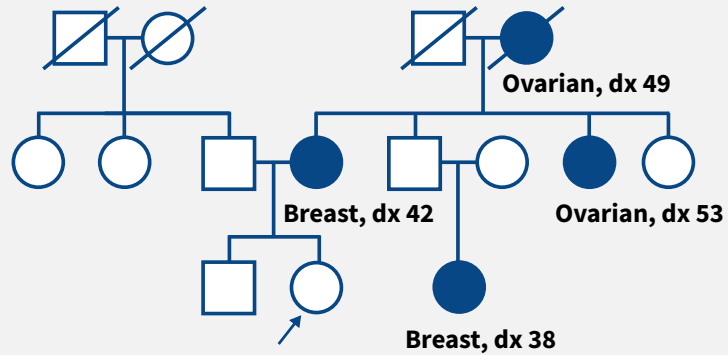
To truly make an impact on the lives of individuals, we need to broaden our focus from what happens when someone seeks care, to preventing them from developing the disease



How can genetics tackle the problem of chronic disease?

Mendelian inheritance of single gene disorders¹

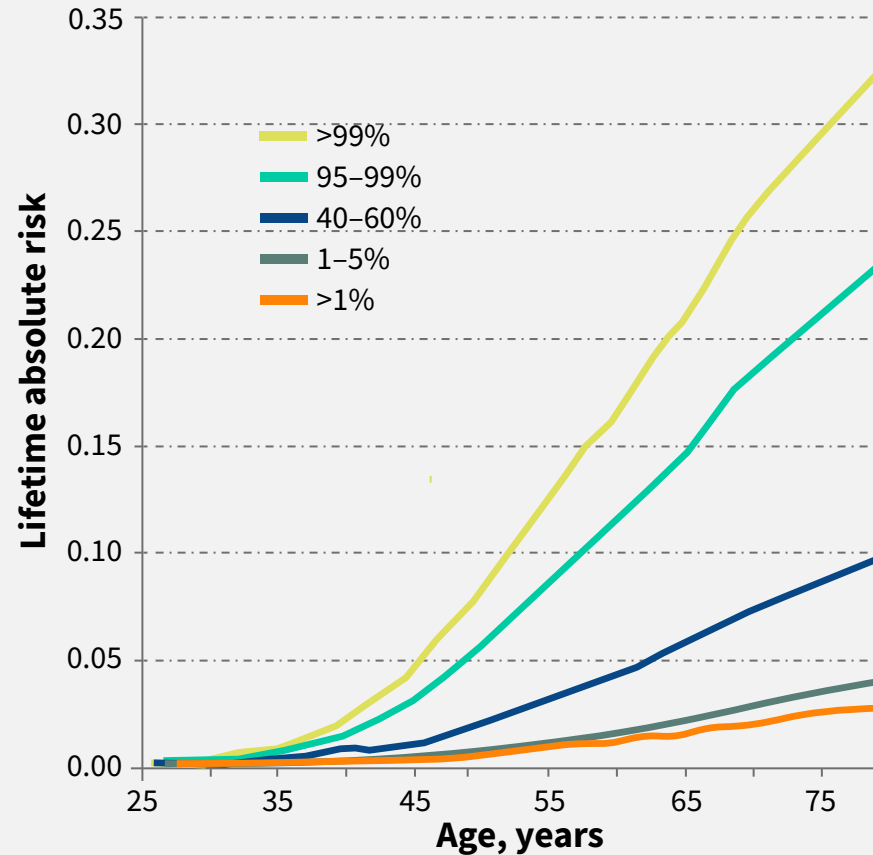
Classic *BRCA1* pedigree



Polygenic risk – a normal distribution of risk composed of a large number of gene variants that have small individual effects



Risk according to PRS percentile²



Breast cancer

- **94,075 cases**
- **69 case-control studies**
- **313 SNP PRS**
- **Top 5% vs median – ~3-fold**
- **Top 5% vs bottom 5% – ~6-fold**

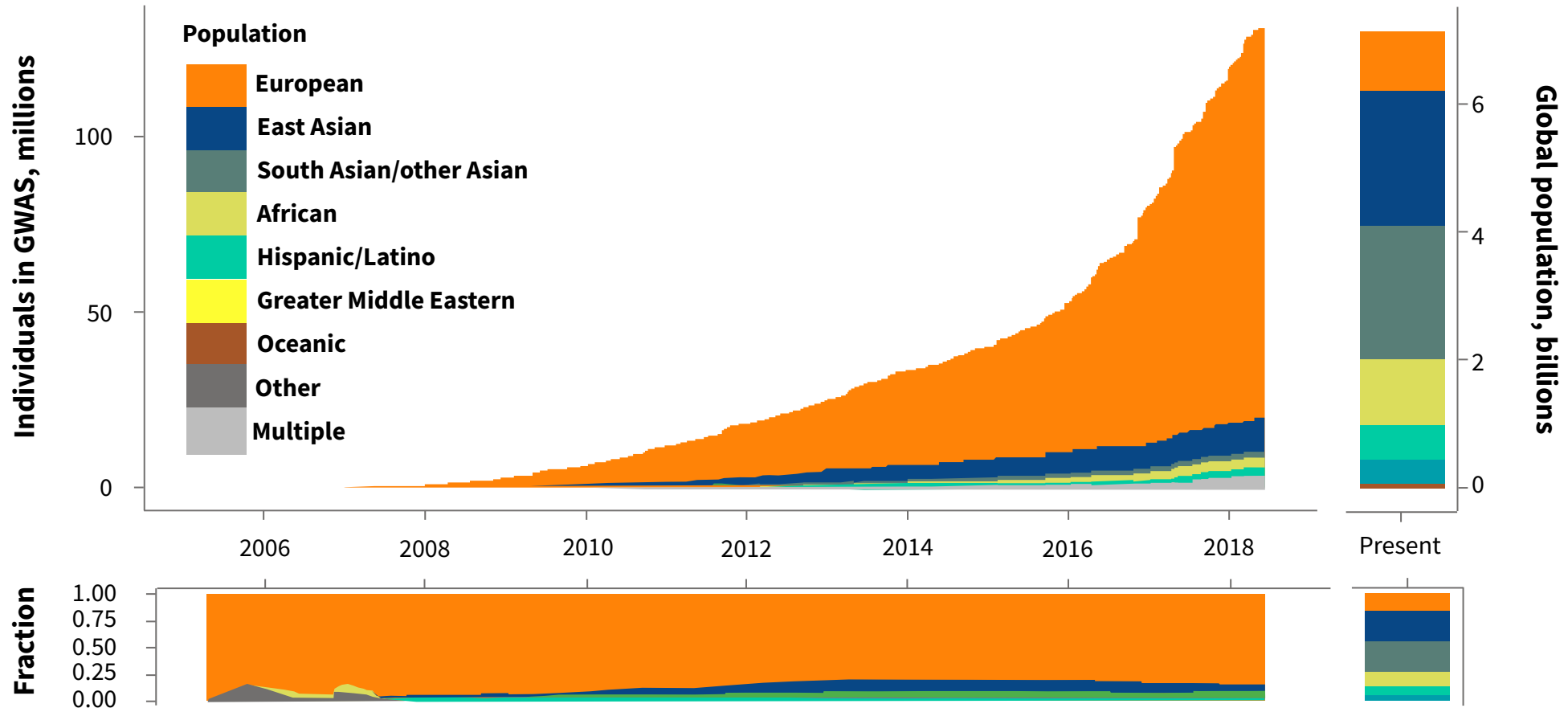
BRCA1, breast cancer gene 1; dx, oncotype DX; PRS, polygenic risk score; SNP, single nucleotide polymorphism.

1. Adapted from PDQ Cancer Genetics Editorial Board (2022). Genetics of Breast of Gynecologic Cancers (PDQ®): Health Professional Version. National Cancer Institute (US): Bethesda;

2. Adapted from Mavaddat N, et al. *Am J Hum Genet.* 2019;104:21–34.

However we need to be cautious as it may further exaggerate health disparities

Ancestry of GWAS participants over time compared with the global population



GWAS, genome-wide association studies.
Adapted from Martin AR, et al. *Nat Genet.* 2019;51:584–91.

Our Future Health

A world-leading resource for early detection and prevention research

In partnership with



- The UK's largest ever health research programme, designed to enable the discovery and testing of more effective approaches to prevention, earlier detection and treatment of diseases
- It will collect and link multiple sources of health and health-relevant information, including genetic data, across a cohort of **5 million people that truly reflects the UK population**
- A resource for academic and commercial researchers to undertake discovery research on early indicators of disease, plus the opportunity to re-contact participants on a risk-stratified basis for further research

At enrolment:

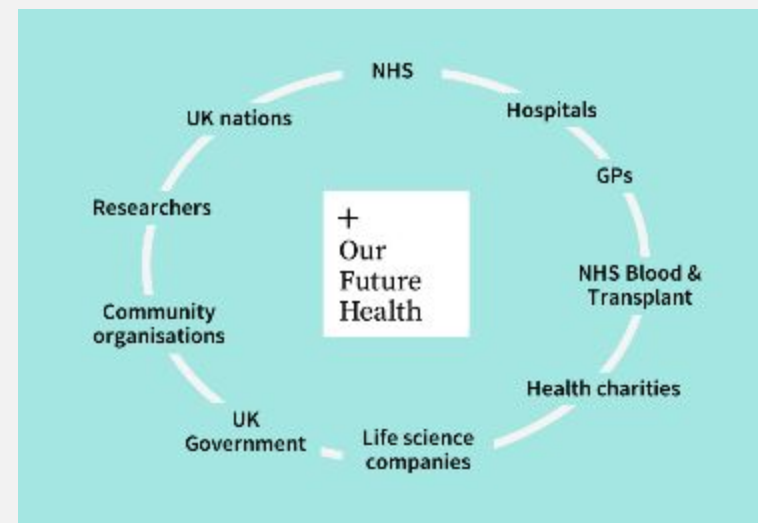
- Self-report health and lifestyle questionnaire
- Physical measures
- Blood sample

- Consent to link with NHS records and additional data sources
- Consent for re-contact to offer feedback to participants, including genetic risk
- Consent to re-contact for invite to provide additional data collection, samples, or to take part in new clinical studies

- Stored baseline plasma, buffy coat and DNA samples
- Genotype array on all participants
- Possibility of additional sources such as digital/wearable device data collection in the future

Our Future Health is designed to harness the power of collaboration across the life sciences sector and health ecosystem

- We're combining support from industry, charities and government to build a world-leading health research programme
- Backed by £160m from industry founding members, £79m from Innovate UK and supported by 14 charities



Funders

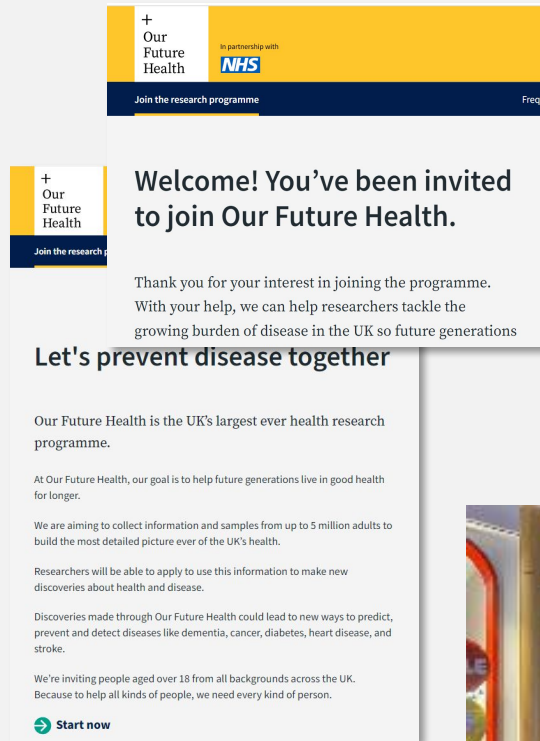


Affiliate charities



Our Future Health will recruit 5 million adults into a prospective cohort that truly reflects the UK population

Sign-up/invitation



Welcome! You've been invited to join Our Future Health.

Thank you for your interest in joining the programme. With your help, we can help researchers tackle the growing burden of disease in the UK so future generations

Let's prevent disease together

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

At Our Future Health, our goal is to help future generations live in good health for longer.

We are aiming to collect information and samples from up to 5 million adults to build the most detailed picture ever of the UK's health.

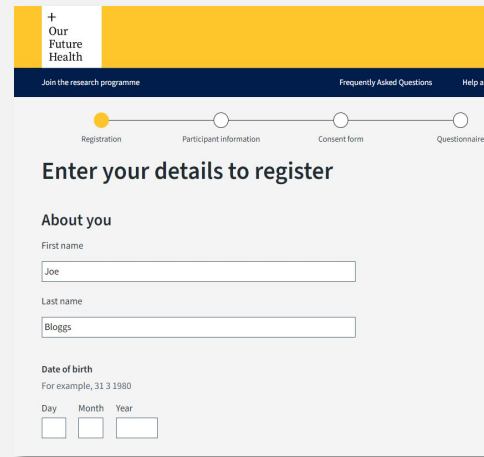
Researchers will be able to apply to use this information to make new discoveries about health and disease.

Discoveries made through Our Future Health could lead to new ways to predict, prevent and detect diseases like dementia, cancer, diabetes, heart disease, and stroke.

We're inviting people aged over 18 from all backgrounds across the UK. Because to help all kinds of people, we need every kind of person.

[Start now](#)

Register



Enter your details to register

About you

First name
Joe

Last name
Bloggs

Date of birth
For example, 31 3 1980
Day Month Year

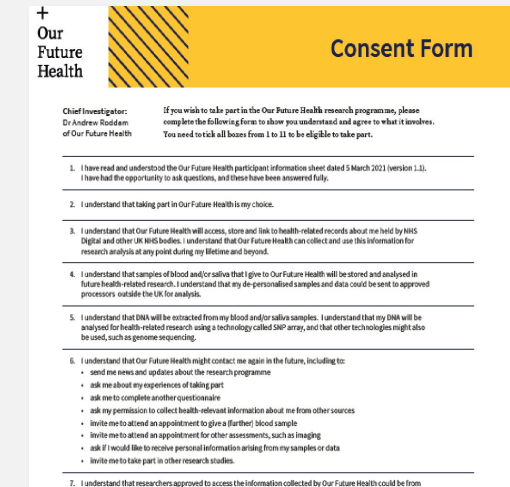
Information

You'll need to complete the following steps online:

1. Register by creating an account
2. Read about the programme (Participant Information)
3. Consent to take part
4. Complete a questionnaire about you and your health (5 sections)

After joining, you'll be sent a kit to provide a sample of your saliva, which you'll need to send back to us.

Consent



Consent Form

Chief Investigator: Dr Andrew Roddam of Our Future Health

If you wish to take part in the Our Future Health research programme, please complete the following form to show you understand and agree to what it involves. You need to tick all boxes from 1 to 11 to be eligible to take part.

1. I have read and understood the Our Future Health participant information sheet dated 5 March 2021 (version 1.1). I have had the opportunity to ask questions, and these have been answered fully.
2. I understand that taking part in Our Future Health is my choice.
3. I understand that Our Future Health will access, store and link to health-related records about me held by NHS Digital and other UK NHS bodies. I understand that Our Future Health can collect and use this information for research analysis at any point during my lifetime and beyond.
4. I understand that samples of blood and/or saliva that I give to Our Future Health will be stored and sent to approved processors outside the UK for analysis.
5. I understand that DNA will be extracted from my blood and/or saliva samples. I understand that my DNA will be analysed for health-related research using a technology called SNP array, and that other technologies might also be used, such as genome sequencing.
6. I understand that Our Future Health might contact me again in the future, including to:
 - send me news and updates about the research programme
 - ask me about my experiences of taking part
 - ask me to complete another questionnaire
 - ask my permission to collect health-relevant information about me from other sources
 - invite me to attend an appointment to give a (further) blood sample
 - invite me to attend an appointment for other assessments, such as imaging
 - ask if I would like to receive personal information arising from my samples or data
 - invite me to take part in other research studies.
7. I understand that researchers approved to access the information collected by Our Future Health could be from



Physical measurements



Blood sample

1. About you and your household

How would you prefer to receive your height and weight?

In person Online

Weight

In person Online

Questionnaire

Recruitment commenced in October 2022; we are seeing approx 1500 participants per day at 23 venues in 4 regional areas

Shopping Centres



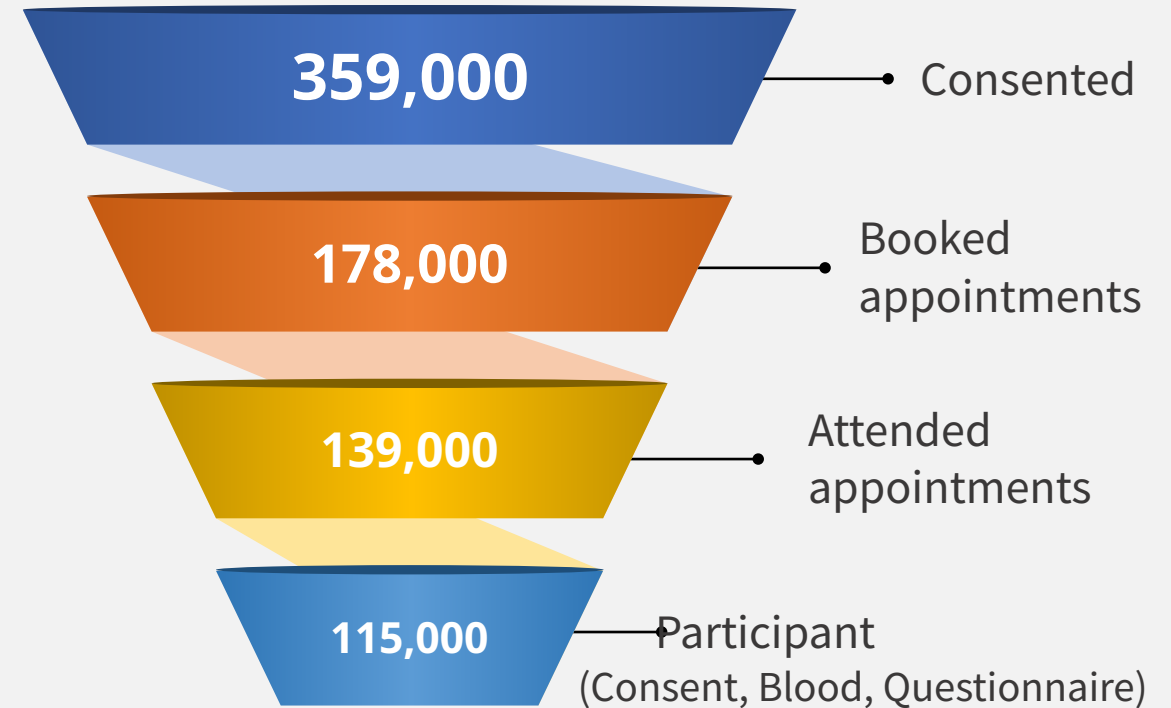
Pharmacies



Universities

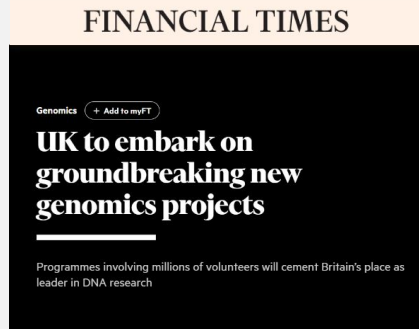


Mobile units



We have had significant national and local media coverage – 500+ hits over 3 months

- ITV News; Talk TV/radio
- Features in FT, The Times, Daily Express
- Local press in our recruitment locations e.g. Birmingham, Wakefield, Bradford, Bolton, Rochdale



This man has a plan to save the NHS — but he needs your help

A world-leading scheme could be the saviour of the NHS and prevent ailments including cancer and dementia before they take a hold of your body, this chief medical officer told Express.co.uk.



High impact branding and collateral at recruitment sites

- Raising awareness on the ground in community locations
- Window displays across high traffic retail sites
- Mobile unit branding
- Collateral to engage walk ups, drive sharing and referrals

Thank you card



Social sharing card



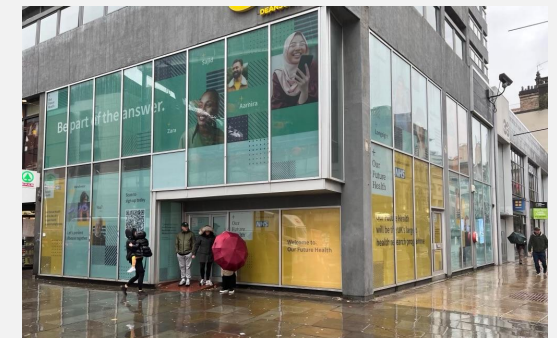
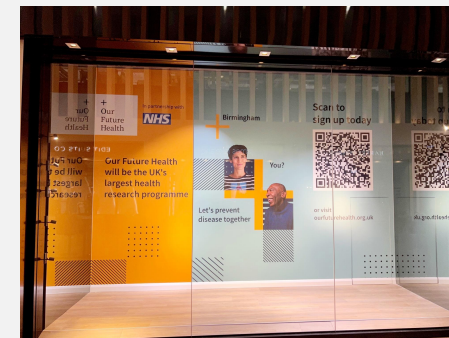
Walk in leaflet



Mobile unit branding



Retail site clinic branding



We've have amazing support across government, academia, NHS, industry and community groups

- Launch events held in each region to meet stakeholders and discuss opportunities for joint working and promotion
- Regional advocates identified to help promote the programme, provide support in local media, hold VIP visits
- Plus, ongoing high level engagement with opinion formers in government, industry and the NHS



"We all stand to benefit from Our Future Health having participants from a wide range of socioeconomic backgrounds and ethnicities, and I would urge all of our communities to get involved"

Mayor of Newham, Rokhsana Fiaz

"Leeds City Council is delighted to see Our Future Health begin its regional roll-out here. This is a large and ground-breaking programme."

Tom Riordan, Chief Executive of Leeds City Council



Simon Lightwood MP on why he's supporting Our Future Health

News - 26 January 2023

The Member of Parliament for Wakefield is encouraging his constituents to join our programme so they can learn about their own health while helping the wider community



Professor Karim Raza: 'Our Future Health can be the next great success story'

Spotlight - 28 October 2022

As Our Future Health launches a hub in Birmingham, local rheumatology researcher and clinician Professor Karim Raza speaks about the game-changing power of our programme.



Professor Karim Raza

'This is a golden opportunity to future-proof our health': Why the Medical Director of Bolton NHS Trust is proud to join our programme

Spotlight - 24 January 2023

Dr Francis Andrews is encouraging the people of Bolton to volunteer for Our Future Health. He explains why he believes it will benefit people now - and in the future



We're running a powerful series of volunteer testimonials on our digital channels

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In partnership with
NHS




“
Joining Our Future Health was a good thing to do. I know that Asians are more susceptible to diabetes, so that's an area of concern.”

+
Prakash
63, Huddersfield

‘I don't have lots of money to give to charity – so I joined Our Future Health as a way of helping others’

Volunteer Voices – 3 February 2023

As part of our Volunteer Voices series, lifelong carer and retired NHS nurse Linda Harris opens up on what it's like to live your life surrounded by disease



Our Future Health @ukfuturehealth · Oct 12

“People like me are needed by researchers. It's important for people from mixed heritage backgrounds to take part.” Renuka shares her story and advice for other people who are considering volunteering for #OurFutureHealth: bit.ly/3AIYEa1



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Renuka's
Story



‘My mother's dementia changed the course of my life. I want to help beat this terrible disease’

Volunteer Voices – 12 January 2023

When Malcolm Gill became a full-time carer, he was horribly unprepared for the life he would lead. Now he's joining Our Future Health so that research can change the way we look at the condition

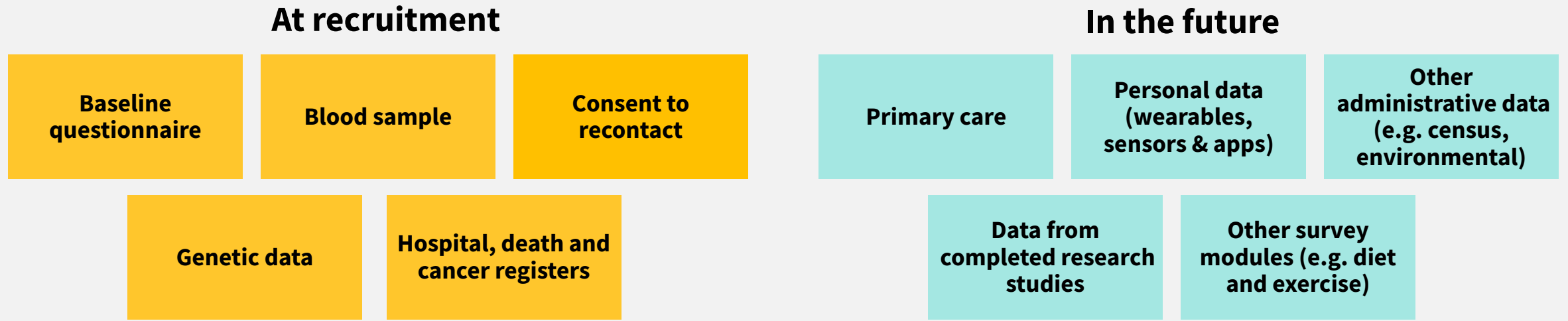


‘I joined Our Future Health because I want to improve diversity in health research’

Volunteer Voices – 20 December 2022

Digital Health Futurist Maneesh Juneja speaks about the power of our programme for future generations – and how it's fixing a problem from the past

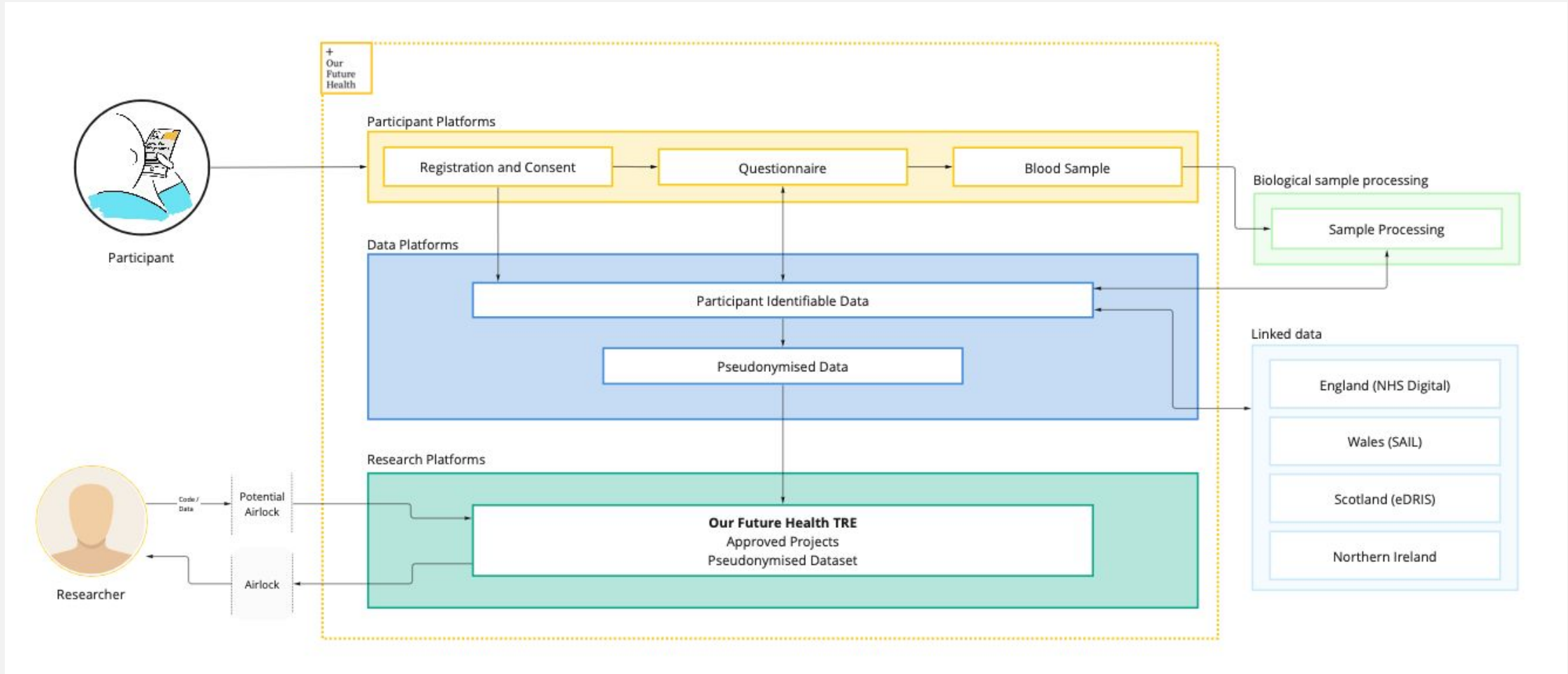
Building a detailed picture of our volunteers using health-related data



Delivering a unique resource enabling discovery and translational research studies

- Data will be made available in a Trusted Research Environment from June 2023
- Research can be based on existing data and stored samples (by end of this year)
- Volunteers provide consent to be contacted for deeper phenotyping, clinical, behavioural, research

Our Future Health Participant & Data Platform



Our Future Health will deliver evidence on the use of genomics in prevention and population health

- In partnership with Illumina, genotype the whole cohort with a custom SNP array incorporating up-to-date sets of disease- and phenotype-associated genetic variants and a backbone optimised for multi-ethnic imputation capability
- In partnership with Genomics plc make available PRSs on 53 common diseases and traits

We will

- Make the genetic and PRS data available to the research community in our TRE
- Offer participants the option of receiving personalised risk assessments incorporating their PRS results
- Work closely with representatives from across the UK health and care sector, including the NHS, to develop the approach to feedback and support if needed
- Invite participants based on their PRS results to participate in future research studies

How will the resource interface with the NHS?

- As part of recruitment, we are measuring and providing to participants information about their BMI, BP, Cholesterol and advice to seek clinical care if appropriate
- We plan to offer health related feedback – this needs to be in collaboration with the NHS to provide a supportive environment. Such feedback will not be “clinical grade” but what do we do about enabling in the clinical record?
- We will have information about PGx genetic variants on up to 5m individuals – how could this information help prescribing in the future?
- We will be generating information about detailed blood typing to the NHS Blood & Transplant Service enabling a continual improvement of the donation/transfusion service
- BUT in the future – how can we effectively inter-operate with the clinical record allowing clinicians access to data we have if appropriate

How are we viewing the potential for use of SNOMED?

- We need to architect our data store which enables the storage of the data types we are considering and allows for future use cases in a way which is reproducible and flexible
- The research community have multiple preferences for “data models”
- Often healthcare data comes in an “aggregated” coding system – e.g. instead of SNOMED codes from EHRs we get ICD coded summaries
- In the UK, once we get primary care data flows, SNOMED will be critical
- But there remain challenges
 - What about participant recorded information? How do we represent genomic data?
 - At what point in the data architecture do we “adopt”?

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Our
Future
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