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

Let's prevent disease together

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

Diseases like cancer, dementia, diabetes and heart disease continue to affect the lives of many people\textsuperscript{3}

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 million\(^2\).

The number of people with diabetes is expected to increase from 3.9 million people in 2017 to 4.9 million in 2035\(^3\).

There are more than 100,000 hospital admissions each year due to heart attacks. CVD is estimated to cost £19 billion a year\(^4\).

The cost of dementia is expected to more than double from £26 billion in 2015 to £55 billion in 2040\(^5\).

Despite the advances in healthcare, increases in healthy life expectancy have stalled\(^6\).

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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.
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.
Mendelian inheritance of single gene disorders

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

How can genetics tackle the problem of chronic disease?

Breast, dx 38
Breast, dx 42
Ovarian, dx 49
Ovarian, dx 53
Breast, dx 38

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

Risk according to PRS percentile

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.

However we need to be cautious as it may further exaggerate health disparities in Ancestry of GWAS participants over time compared with the global population.

GWAS, genome-wide association studies.
Our Future Health
A world-leading resource for early detection and prevention research

- 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
- re-contact to offer feedback to participants, including genetic risk
- 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
Our Future Health will recruit 5 million adults into a prospective cohort that truly reflects the UK population.
Recruitment commenced in October 2022; we are seeing approx 1500 participants per day at 23 venues in 4 regional areas.

Data as at 30 March 2023
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
We use continuous advertising to build awareness and drive response to invitations

- Reinforcing and maintaining awareness following initial launch
- Combination of outdoor (bus sides, posters) and geo-targeted social media (FB, Instagram, Youtube)
  - 33.9m digital ads displayed (October to January)
  - 3.72m engagements (views, likes, shares, comments)
  - 3.08m video views
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
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
We’re running a powerful series of volunteer testimonials on our digital channels

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

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

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

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”

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

**At recruitment**
- Baseline questionnaire
- Blood sample
- Consent to recontact
- Genetic data
- Hospital, death and cancer registers

**In the future**
- Primary care
- Personal data (wearables, sensors & apps)
- Other administrative data (e.g. census, environmental)
- Data from completed research studies
- Other survey modules (e.g. diet and exercise)

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”?