

## News

# ‘Watershed’ moment as doctors’ records linked to UK Biobank

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Twenty years ago, half a million middle-aged Britons signed up to do something that would change medicine for ever. They walked into pop-up clinics, gave a few blood samples and agreed to be contacted in the future. Then they signed a form allowing researchers to look at their medical records and got on with their lives.

They had joined UK Biobank. And while they might have anticipated that over the past two decades — during which they got sicker and older, developed chronic conditions and caught minor sniffles — all that data would have been used to inform medical discoveries, they would have been wrong.

Until now. After a years-long battle against bureaucracy, the initial promise of what was already a world-changing study has been fulfilled.

GP medical records can at last be

linked in full to UK Biobank, in a “watershed” moment that will enable researchers to understand the causes and progression of diseases and ageing in unprecedented detail.

“Overnight, we will have information on conditions that are largely diagnosed and managed in primary care, like arthritis and the forms of pain, diabetes, depression, asthma, impaired vision [and] migraine,” said Naomi Allen, chief scientist of UK Biobank.

The scheme was conceived after the millennium. The idea was that half a million Britons would be followed from middle age to death in a detail never before achieved. The ambition was astonishing: the study planned to sequence half a million genomes at a time when doing so would have cost tens of billions. Today, they have done that.

When UK Biobank participants ended up in hospital, or returned for scans or follow-ups, all that data could be

compared and analysed. This continued right up to the final data point they would give, when they died.

How do genes relate to cancer? How does lifestyle relate to chronic illness? Thousands of papers have relied on UK Biobank data but there has been a big gap in the picture: GP records remained inaccessible or, at best, partial.

The reason why was that GPs had to take on legal liability for handing over the data of each patient. Practically, said Allen, that made it unworkable. “It’s not the GPs’ fault. It’s that they had legal liability for the data and they’re very busy individuals,” Allen said.

A huge source of medical insight therefore remained untapped.

That has changed. NHS England has taken on the legal liability for UK Biobank GP records, and for the records of people in other similar studies who have already given consent.

Liam Smeeth, director of the London

School of Hygiene and Tropical Medicine, said the sudden inclusion of the data would “transform [our] understanding of diseases, and how to prevent and treat them”.

“Researchers like me will be able to use the data to understand what’s really causing disease, and why some drugs work for some people and not others,” he said. “We will solve so many major health challenges that affect us today, and we’ll do so because of this initiative to make these data available now.”

Allen said that the announcement had come at exactly the right time. UK Biobank is entering the prime of its life — as its participants are leaving theirs.

“The average age of our participants is now 73,” she said. “As the cohort ages, they’re going to be going to their GP a lot more regularly with hearing loss, vision loss, diabetes, arthritis. Without GP data, we just won’t know when these were first diagnosed.”