

Andrew Trehearne

00:00:00	It falls to me to give you a little bit of a potted history of UK Biobank. I was trying to think whether the Leeds Assessment Centre is open but it was probably seven or eight years ago I should say when we wrote to you and asked you if you would like to be part of this amazing project, the intention of which is to follow the health of half a million people aged 40-69 during the recruitment phase you know for the next 10, 20, 30 years and perhaps longer. Massive undertaking something like this had never quite been done before, certainly not in the numbers, certainly not for asking all the information – detailed information about your lifestyle, your health and all the measures that we took – how tall you were, how you measured round the waist and those sorts of things.
00:00:55	So nothing quite like this had ever been undertaken before. No one was quite sure that it would be successful, people thought that it would not be possible to recruit half a million people across the country and yet we pressed on.
00:01:10	You can see from the map there were 22 recruitment centres up and down the country. At any one time we were recruiting between 600-700 people a day so it became a bit of an industrial process to some degree in terms of making sure that our systems worked and that those blood samples that we took from you, the urine samples that we took from you could be taken away, stored, frozen down and used for analysis at a later date.
00:01:39	Leeds was our best performing assessment centre. 44,000 people from in and around the Leeds area took part in UK Biobank. So 44,000 people just like you came to that building in Leeds City Centre, went through the process, filled in the questionnaires, were weighed, measured and we took blood. I mean just a massive, an amazing achievement I think and I have to say it was all done, on time and within budget. It was a tremendous achievement so we're really grateful to all those people who came along and said they would help us.
00:02:20	Just a brief reminder of what it was that we did. We asked for your permission to follow your health over many years. We asked you lots and lots of questions on that touchscreen questionnaire about where you lived, who you lived with, whether you owned your own home, whether you had a mortgage. Questions about your health, questions about your family health, questions about your parents, your birth weight. I mean just a huge number of questions which we thought would be of interests to scientists at some time in the future without really knowing what sorts of questions they might be asking. So we were trying to cover as many bases as we could.
00:03:03	Later on in the project as we became more experienced in collecting that data, we took some eye measurements and photos of eyes for a number of participants. We did a hearing test. We measured heart rate and the heart. We undertook some mental health questions and we asked more about people's diet and in fact if you have an email address and I think it's quite likely that most of you do, you may well have received further emails from us asking you to help yet more, tell us more about your diet, help us out with cognitive function tests. The most recent one was asking a little bit about the sorts of jobs that you had particularly with in regard to lung health.
00:03:51	So lots and lots of information has been collected and it's all enormously useful or will be enormously useful for health research in the future.

00:03:59	So those blood samples that we took, it was only three or four table spoons full. People thought it was a lot more. In part that is because of the tubes that the blood was collected in had some liquid in it already because the blood samples would have been stored in different ways so that scientists have the choice in the future of how those blood samples are used. So they store them in different ways to ensure that they can be kept over a long period of time in a variety of different systems.
00:04:30	This picture here, this is the freezer in Manchester. If ever you land at Manchester Airport, about a minute before landing if you're on the left-hand size, look out the window you can see two huge great nitrogen tanks outside a big flat building. That is UK Biobank. The nitrogen tanks... the biggest nitrogen tanks in the country feed this system here which is a robotic storage system. The robot which is about twice the height of an individual moves up and down this track and operates at -20 so if you have to service it, you're going to need a cup of cocoa afterward at the very least. People do go in there and service these things. But the robot opens these draws on the left and right and randomly places your samples of blood and urine at -80. And altogether, because each of those tubes of blood that we took is sub-divided into a smaller tube. We have 15 million tubes stored in this system. Obviously the crucial thing is we need to find those, we need to retrieve those samples of blood and urine in the future when we need to and so they are all barcoded individually in such a way that we can go back and find the sample of blood or urine and what that might mean is if in 10 years' time scientists are investigating let's say prostate cancer and they're looking for 1,000 people who haven't developed... a thousand men who haven't developed prostate cancer and a thousand men who have and they're interested in what the blood might tell them, so the genetics might tell them, we can identify those individuals and then we can go back into this store and find those blood samples, pick them out and send them away for analysis.
00:06:24	They are enormously high-tech, it couldn't possibly be done without the sort of IT equipment that's basically leading edge, systems to connect to this sort of system to allow us to store and retrieve samples and do that securely. So there's the individual information about you your name, your address isn't identified... won't be identified and isn't provided to the scientists you know with the information that we send them for their analysis.
00:06:57	Now, I have to just do something here. This takes a bit of time to warm up but you may remember this. It's talking about the spirometry test. <i>[plays video]</i>
00:07:25	Who remembers this?
00:07:39	Here we go. Come on, come on, keep going, keep going, keep going, keep going, keep going, keep going, keep going. Do you remember doing that? Yes I think we all do. Yeah so that's... that was one of the measures that we took was that horrid thing of blowing into that tube and being told to keep going, keep going, keep going until you feel like your lung's going to come out and you've had enough. Well just as an example that information has already been used in one study. It will be used in lots of studies but it has been used in one study which has already reported and it's looked at the best 50,000 lung functions out of all the Biobank participants and the worst. And it's also looked at smoking and it's tried to find out why some people who smoke still have good lungs and some people who don't smoke have bad lungs and it's come up with some really some very useful and interesting findings and it's just a fantastic example of the way that UK Biobank will be used to find out why some people get ill and why some people don't. Why do some people respond well to therapy and some people don't.

	Why is it that chemotherapy works for some cancer patients and it doesn't for others and can we develop new systems that say would allow us to identify participants/patients who benefit very well with one treatment but not with the other.
00:09:13	So it's about personalising medicine and you can see that the story based on the lung function made the news. This was a piece that was in BBC news just you know trying to explain to people why it is that this resource has been so useful.
00:09:34	So there's a number of ways that the information or the samples that you gave us are being used. Perhaps most excitingly or most interestingly is genetics. So we've gone away and looked at the genetics of all the samples, not because we wanted to do studies but we figure other scientists will know and it's cheaper for us to do this gene analysis ourselves rather than ask scientist to do 50,000 here or 20,000 there. So we've done this and this resource is now available to scientists.
00:10:12	And we have looked at 800,000 little points on the genome which are known to be involved in disease and we've identified those on these half a million anonymous samples, your samples and that information is already playing its part in health research.
00:10:36	There's some other new way of looking at genes. This whole area just advances rapidly every time we look at it which means that from the 80,000 variants that we've looked at you can guess what the rest of the genome looks like and that is allowing scientists to look at up to 70 million little snips on the genome all of which will be helpful in trying to identify why it is some of us might get a particular disease and other people won't.
00:11:04	We have also done some what we call blood based measures. That's looking at things like hormone levels, cholesterol, high cholesterol, and low cholesterol sort of thing that's interested to scientists looking at heart disease. Vitamin D we hear a lot about vitamin D these days, calcium, glucose. Lots of other things which are in our bodies all the time racing around in our blood streams which may be interests to scientists in the future.
00:11:33	And we have... we're going to look at the sorts of infections that people may have had. There will be little markers left in blood from the infections that we've picked up over the years. Tremendous interests in whether infections related to things like cancer. Some blood cancers for instance are believed to be related to certain infections so it would be useful for scientists you know doing those sorts of studies.
00:11:58	We've also... I said this was a potted history. I know that I'm kind of speaking at length but there is so much to say and I'd urge you to look at the website if you really wanted to know a lot more but some of you may have worn our activity monitor, a little wrist monitor for a week. Has anybody here received... yeah lots of you so that's reassuring to know. 100,000 participants have worn one of those things, one in five people, one in five of our participants who was asked to wear have worn it which is no mean achievement in itself and I think says a lot about the people who joined UK Biobank. That data is already being crunched, people are looking at it. This particular, <i>oh sorry let's just go back</i> , you can see this is some data from someone... their day actually so they're asleep here, jogging to work so it's not me! That's the working day I mean goodness me they're jogging on the way home again and then this is their evening activity. So a lot of information. Particularly interesting to scientists who are interested in sleep and people who don't sleep very well, people who get up in the night, people who sleep during the day rather than the evening and that can be linked to illnesses like depression. So a lot of data can be gained from these simple sorts of things.

00:13:18	And all GP's... all participants are registered with their GP's. UK Biobank was able to write to you because you were registered with a GP Practice. The NHS was supportive of what it was we were doing. This will provide information about the sorts of reasons that take us to the GP, migraine, when we're worried about our hearts, you know wide variety of conditions that may not have been reported when you joined the project but which you've since developed or which we have since developed on participant too. So this is crucial to the long-term for UK Biobank.
00:14:01	Obviously the NHS provides majority of health care in the UK and so it's absolutely crucial that once again in an anonymous sort of way we can link to these data sets, these databases, this information and provide it without identifying participants to scientists.
00:14:17	There are lots of questions about what is GP Data and one thing going through out mind at the moment is could we ask for tumour samples? If we know the participants for the cancer do participants think that GP Data is tumour sample data, how would they feel about us accessing this sort of data? I don't want to put you on the spot but I wonder general show of hands, do people think that tumour data, tumour sample collected at a biopsy is the sort of thing that UK Biobank ought to have access to? People feel comfortable with that? It's a question that's you know being discussed at the moment about whether that's the sort of thing that we should do.
00:15:04	We're starting to scan people. Anybody here had an invite to be imaged? One, two, three... did you go? Fantastic thank you very much. This is the next big project, it's a long way away, well it's in Manchester, is that a long way away, perhaps a little too far. However, we understand it's a long way. We would set up a centre in Leeds but these machines cost £2 million it's just not possible to put it in a centre where we recruited. But you will receive an invite and a colleague of mine is going to be talking about that to you later.
00:15:37	Now my last slide is just about how is the resource being used? Well more than 2,000 scientists across the world have now registered to use UK Biobank. I think it's a lot more. They have to show to us that they're bona-fide scientists. They have to have a project that is in the public good and then they can have access to the data and the samples and you know as they require. A lot of scientists are from the UK and you're going to hear from two scientists in Leeds who are already using the resource but also scientists from right around the world and in due course you know we would hope to see many more on that particular slide.
00:16:21	The fact is although UK Biobank has been going for 10 years it's still very early days for the sort of study that it is, we're a prospective study so it takes time to collect information about health, about the sorts of illnesses that we get, about those of us who stay healthy and only then can that data be used and then can that information be used for health research.
00:16:44	So that is just a potted history. I'm going to take a few questions but before I do that I'm going to tell you that in a few moments we'll be talking... we'll hear from Professor Jenny Barrett and Dr Sarah Mackie about some work that they're doing at Leeds University involving UK Biobank data so they've applied to use the resource and they've had that data approve and they're now doing some research.
00:17:15	I'm delighted to see Dr Susan Wallace is here from the UK Biobank Ethics and Governance Council. Now that is a body that is independent of UK Biobank but that was established by our funders to ensure that we carried out the project in an appropriate manner, in a responsible manner. I suppose to an extent they're

	<p>there to protect participants. They describe themselves as a critical friend of UK Biobank which I think is a function that they fulfil but we have Susan Wallace here from the EGC just to talk a bit about their role and the sort of input they've had within the resource. Then we'll be hearing from Martin McKibben also... well he's from Leeds Teaching Hospital who's using data from UK Biobank resource to do this work. Then my colleague Kirsty Lomac will talk very briefly about the imaging study that we hope some... well some of you have been involved with and we hope that others of you may be minded to take part in. And then if we've got time we'll have some discussion at the end. If things roll on and often they do a bit, we're happy those of us who are about to take questions, hang around at the end and talk to you for as long as it takes or you can email us, visit the website www.ukbiobank.ac.uk.</p>
<p>_00:18:33_</p>	<p>So with no further ado I think we will....</p>

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