M4: Now, next up is Jon Snow, who's chairing a discussion amongst participants, Jon. There's a hard stop at 11 o'clock, because Jon's got the seven o'clock news tonight in London and, if he's not there, I'm dead meat. So Jon, it's over to you.

Thanks very much. Well, as somebody who's day job is generally bad news, there is something incredibly exciting about what we've been exposed to here and what we know of Biobank. All of us are participants in the trial. I was very excited to be approached, years ago, and I immediately signed up, I had no hesitation at all. Did anybody have any hesitation about signing up? Why, on earth, did you sign up?

M1: Well, I signed up because I'd been a blood donor and it seemed like a logical progression from doing that kind of thing, to, when I was asked to do it, it really didn't take a lot of thought to sign up. It seemed such a positive thing to do.

And [?Jo], you've actually had various things like the scan?

F1: Yes, that's right.

I haven't, I must admit and I'm a bit jealous, really.

F1: I did enjoy it. I am that sad kind of individual, but I did find it an interesting process. One of the things that I particularly remember was when I was in the scanner, you had to do some cognitive tests as well, and I really enjoyed doing that, it was an interesting way to spend a Sunday afternoon, basically.

Alan, use your own mic, no problem.

M2: I don't know if it works, oh, it does, yes.

Alan, have you had any actual tests, et cetera, beyond having [over speaking 00:02:06]?

M2: I started way back in, I think it was 2006. It was for selfish reasons originally, I thought, oh good, I'll get a free medical check and everything, but then I realised that you don't any feedback, but I still continued, because it was obviously, it became important and I thought, it's useful, so I'll continue, but I haven't had any scans at the moment, but I've had lots of other things, cognitive tests and environmental stuff.
Christina, what was your motivation in getting involved in the first place?

F2: Probably a little bit of enlightened self-interest and also, it sounded like a lot of fun. You got to do the cognitive tests and the hearing tests and you got to sit down and play on computers and this sort of thing, but having listened to everything Biobank is doing, I'm hoping to live long enough to actually benefit from some of the research. I joined in 2006, when I was only in my forties, so yes, I'm going for it and maybe I'll be the last man standing, who knows.

I think the interesting thing is that as it's grown to 500,000, I think it's 503,000 people are now involved, there's a sort of sense of pride that it's happened and that we're part of it. Don't you find that?

F2: Yes, absolutely. I'm really very proud of being in Biobank and I enjoy telling people about it and even though there is no feedback, as I said, if my contribution can help to unlock some of the mysteries of disease and what have you then, yes, why not, go for it.

Morag, what's your experience, been? Have you, how extensively have you been tested?

F3: I've done the initial test twice, I've done the scans, I've done the Fitbit, I've done the online, so I've been quite heavily involved in it from quite early on.

How long did you have to wear the Fitbit?

F3: I can't remember. I think it was a week, yes.

And did you emerge any the wiser, or you don't know what it told you?

F3: I don't really know what it told me, actually, so yes.

And your experience?

F4: After the initial examinations and tests and so on, I have done online surveys and I also wore the Fitbit for a week.

Are you a natural joiner?

F4: Yes.
You are. It's interesting that Simon is a blood donor.

F4: Yes, I'm a blood donor as well.

Is everybody a blood donor? I'm not, I had hepatitis, whatever, whichever one you live after having.

[Laughter]

M2: I'm gay, I'm not allowed to.

Really?

M2: No.

F: [?Are they not? 00:04:52]

M2: [Unclear words 0:04:52.6] I don't think they've changed it yet. I'm a gay man and I haven't, we weren't allowed and I don't think we still are allowed to give blood.

M: [Unclear phrase 00:05:01].

M: [?You can sense that 0:05:06.5]

F2: I got thrown out, because I have a blood transfusion in 1994, so I was cast aside in the '90s, after the CJD problem.

Actually, electronics, I suggest I have one microphone which I will hand around to everyone and, if you turn all the others off, that might be the clever thing to. I know nothing about. In the immortal words of Jon Snow from Game of Thrones, 'I know nothing', but I know nothing about electronics, but I think that is a much better way of doing it, is just have one microphone and then we won't be in contact with whatever extra-terrestrial experience is going on above us. How interested are you actually in the outcome of the research? Do you go to the website? Do you look at? Does anybody here? Tell us what you're interested in.

F2: Well my background was originally environmental science and before I was an inspector of health and
safety, I was a nurse. So I'm very interested in what the genome, the type of the research that is coming out on the genome type, but one of the things which I think would be interesting, perhaps UK Biobank would do in the future, I've been reading recently about research into bioelectricity. The fact that we're not just little bags of chemicals, but all those ions pumping backwards and forwards and the effect that electrical fields may or may not have on the body. So that's one area which I hope in the future might bear fruit and also the microbiome, I'm very interested in the microbiome.

I confess, I was rather intrigued that the organisers of this conference were able to retrieve me from that morass of emails and contacts they had and say, 'Do you want to come to this conference?', and I thought, how do they find me? That's extraordinary, because I'm just an ordinary citizen, but if they wanted me for other reasons, which is rather interesting. I wondered whether, there are lots of researchers here and I don't know how often you actually meet the people you're using the information about. Are there any questions from any of the researchers that they would like to ask of the people who are in your hands, or in your brains? Anybody got any interesting questions from the floor as to our motivation or disturbance in becoming any part of your research? No, because you know everything. Ah, there is a good question there, yes, down the side.

F5: [Unclear words 00:07:52] and I was part of the team that put together the online mental health questionnaire and, at the time that we suggested it, there was some discussion about whether people would be happy to give their experiences of mental health, or whether they would be quite reluctant to do that and I wonder if you could tell me what your opinions are about giving researchers information about your mental health, as well as your physical health?

Did everybody get that? Morag, why don't you?

F3: From my point of view, it's anonymous. It's the same as giving information on IBS, on fitness, on your diet, so for me, I didn't have an issue with it. I think it's really interesting that there's research going in to it and I think the more research that's done, the better, so for me, I just think it's a positive.

Anybody else have a thought on that? No. What about the questions which clearly was coming up in the ethical area. Do you have any feelings about? You do, you mean about commercial companies being involved? What are your…?

M2: Well, obviously, it's all, most of the questions I had have been answered in the previous speeches about Regeneron and GSK and the ethics of having private companies involved in this, but I was quite concerned, someone, the lady who's talking about the research, who mentioned Google and I thought, my God, you know,
really? What on earth would Google want with information from Biobank? Obviously, it would be societal and lifestyle kind of things and would they be using that information to target people even more than they do now? So, it's quite scary, Google, so I'd like an answer on that if possible.

Google is such a fascinating issue. On the one hand we use it absolutely every second of every day and yet on the other hand we're also slightly frightened of it. So why don't we just ask Mike to spell out, oh Rory, sorry, to spell out?

M3: I think this comes back to the point about who might use these data and why might you want them to use it. Typically, one thinks about health research being done by health researchers, by doctors, but actually, as we move in to this data on enormous scale and trying to pick out patterns in the data, increasingly, we're seeing more and more mathematicians, statisticians, informaticians becoming important in the use of the data. So when we look at genetics, actually a lot of people who work in universities in genetics come from mathematical backgrounds, statistical genetics background and as the data become increasingly complex, we need the combination of biological understanding and abilities with data. So I understand your concern.

[Over speaking 00:11:16] said the word 'Google' yet.

M3: I understand your concern about you Google, Apple, Facebook wanting to use these data. I hope they will, because they have the people who can use data on this scale and pull out signal that many of us, from a more classical biomedical area, don't have. So if they start using it, they are, you are going to bring out things that we wouldn't otherwise know, that will be helpful for research, but they have to do so under exactly the same rules. Under the rules of engagement that they use it for, the things that they say they do, they do it under contract, they have a contractual obligation to follow those rules.

I could see a number of researchers there nodding their heads and it would be really interesting if you could give us one little insight in to how you've intersected with Google to carry out a piece of research. Is that a sensible question, or a stupid question? How you've intersected? I'd like to ask one of the researchers how they've intersected with Google to carry out a piece of research. You ma'am in the blue cardi, I saw you nodding your head and I wondered whether you, yes, can I ask you? Is there a particular piece of work you've done and Google's been invaluable? Is that a terrible thing to ask you?

F6: Hello, my name is Judy Lenane and I'm actually a speaker later this afternoon. I don't work for Google, I'll just say that now, but I do work for, [noise from microphone] is there a position that's better?

[Unclear words 00:13:08]
F6: Okay. What we're, what I'm the chief clinical officer for a company called iRhythm Technologies and we are working with the Biobank to bring out the cardiac imaging, looking at your ECG data and it is, as Rory was talking about, what is so important, is really looking at these large data sets and really being able to understand. My example and why I was nodding and what we're going to talk more about, is the problem of atrial fibrillation and now we have a way to pull 1.5 million heartbeats from each one of us and to be able to use the big data analytics of like a Google and to be able to understand what's going on with this very, very bad disease, atrial fibrillation. How can we make it better? How can we prevent it? How can we control it? How can we improve people's lives to stop that first stroke? And that's really what I get really excited about when I think about the big data analytics and what does it mean to me as a person? And that's why I was nodding and saying, 'Yes, Google is big, but you need to look at how can we take this data and really transform care'.

It sounds as if you're the driver in this and not Google.

F6: Correct.

You're using Google as a resource?

F6: We actually use Amazon's web service platform, because this is so much data. We just, there's no way any one company can store that and as the Biobank is talking about trying to store this much data and manage this much data and then use it to get to answers and there are things that we don't know today that we are going to discover and that's what's really exciting to me, as an individual and also as someone in this field.

That's really fascinating, because in the end, that's all about computing. Even more than it is about actual raw medicine.

F7: Hello, my name's [?Zayna Mathey 00:15:19], I work at the UCL Institute of Ophthalmology.

Is there a, why don't we turn all the other mics off, except for this one?

Hello, so my name's Zayna, I work at the UCL Institute of Ophthalmology and Moorfields Eye Hospital and just going back to the subject of Google, there's not a lot that contractually people can say about what Google are doing, but if you go on the data showcase of Biobank, you can look at the approved research and one of the applications that, well the Google application they've put in. You can read about, their abstract, the summary of what they're planning to do with the data that they've applied for and if you look at it, it will tell
you that it's actually to do with retinal imaging, so taking photos of the eye and trying to use the data to help us understand more about eye disease and that sort of thing. So if you go on the Biobank website, you can read up a bit more about it and hopefully that helps.

That's really helpful, yes, thank you very much, but I can tell you're always going to be anxious. Yes, you are, well it's good to have somebody in the data set who is anxious, because that's what Lady Hayman's for, is to respond to those concerns. Does anybody else have any?

M1: I was just going to say that, when I started, when I became a participant, I naively thought this was going to be about the research establishment in the public sector being the recipients of the data that I was providing and I think it would be, it's important ass you develop this project, to embrace those of us who had that rather sort of narrow perspective, because as the availability of that data comes across both globally and beyond the public sector, I'm starting to have one or two questions and concerns about how that information and what derives from that information in terms of treatments and who those treatments will be available to. Maybe they won't be quite exclusively available, for example. I'm starting to have one or two questions about that, although that's not to undermine my commitment and my admiration for what's being achieved and what will be achieved.

I want to bring Rory back in a moment, but what did strike me when he was talking about GSK, for example, was the idea that we were going to know something in nine months that would otherwise take ten years to extract. Am I right? Yes. Do you want to respond? Let me give you this one, because we're going to stick to one mic. Then we don't get a whistle.

M3: Yes, I think it's really important that everybody plays by the same rules and that we do ensure that they are playing by the rules, but I think there is this question of, 'Is it better not to know, or is it better to have a system that allows us to know things that we wouldn't otherwise know?', and I think that's true of the GSK Regeneron. I think it's true of the informatics and some of that's in academic areas, so with the brain imaging, brain images are a little bit like blood samples. They're pretty meaningless, until you can analyse them and, actually, the brain images are being analysed by international academic groups of largely physicists, who are used to using this kind of enormous data, turning it in to what we call derived variables. Hundreds of different derived variables about your brain that can then be used by researchers and I see the same thing with the informatics industry, Google, Apple. We have anxieties, but we all use them, because they allow us to do things that we wouldn't otherwise be able to do and I think that that's the kind of balance that we have to get with UK Biobank. UK Biobank's an experiment. It's an experiment in, 'Can you do things on this scale? Can you have an open access resource and control it and manage it?', and we have to, with Helene and the EGC's help, we have to work out how to manage that experiment and with the participants. Work out the way to
squeez the most out of it, but do so in a way that is acceptable, ethical, so there is no right answer. I don't know, Helene?

F8: Not so much on that, but there's a question that I wanted to put to the panel. One of the things we often find ourselves wrestling with, is trying to put ourselves in the position of participants on issues about re-contact and whether we are bombarding people with too many requests to do things, or whether we're being maternalist and protecting people from things that they want to do and many of you are blood donors, are natural volunteers, I think, and happy to be approached, but maybe not typical. Not everyone in the half million is and I think that's very pertinent when the approach is not from Biobank itself, but often researchers will come to Biobank and they want to be allowed to approach, or ask Biobank to approach on their behalf, to participate in other studies, which are not Biobank studies. So it's that question about third-party approaches. Do you want to be, Biobank to be used as a platform, if you like, with a filter, but as a platform for other people who might come from completely different organisations, with different views about privacy or anonymity, or anything else?

M2: Sorry, if I may ask a question? [Unclear words 00:21:42]

Let's get the microphone, shall we?

M2: I had a question, not talking about third party, but also just about Biobank itself. Does it have any policy in place about how often participants are contacted? Is it going to be every three months, every year, and do you have any policy in place about, 'Oh, this guy, we've had, he's been three times this year, maybe we should leave him alone now'?. I don't know.

F2: Can I ask a backup question? Going back a little bit, you've talked about the agreement you have, where people have to respect confidentiality, et cetera, et cetera. What sort of monitoring do you have in place to make sure that the people who've signed up to use the data, actually stick to that agreement and that they use the data properly?

M3: So to the first question on how often do we re-contact, we've tried to not do it too often, so vague if you like. Partly because we haven't got the resources to do it, but with, for example, the web questionnaires, or the requests to do activity monitors, we've been trying to keep it at no more than once every six months, or something like that, but we certainly get requests to do more of these web questionnaires. Obviously, we have the imaging, where we're starting to ask more and more people to come and do that and we know that's a very, four and a half hours visit, so there was certainly more things that we could ask and that was really Helene's question, 'Are we asking too little? Are we asking too much?'. We try to make it quite clear that it's voluntary
and to a question that was asked earlier about re-contact, we have also had the request, 'Can we with these external re-contacts, re-contact particular individuals, perhaps the ones whose cognitive function is going more rapidly?', and we've said, 'No, not directly', because that would involve feedback. With respect to people trying to identify participants, I think, was that the question, are they?

F2: No, it was more about monitoring. You have an agreement when people use your data, they have to sign up to certain agreements. How do you monitor those agreements to make sure that they're actually sticking to their side of the bargain?

M3: Well, it is difficult to know what's going on in private. We have the option, under the material transfer agreement, to go and audit organisations. Also, they do things and that are then made public, either by presentation, that are beyond the remit. Often this is enthusiasm, rather than anything else, but we contact them and say, 'Remember what you agreed to do', and 'If you do this again, there are penalties in terms of, you won't be able to use the resource again, your institution will be advised', et cetera, et cetera. Particularly in the, and your funders, in the academic area, that can be quite a negative thing. With commercial, obviously more difficult and so one is expecting commercial to be more compliant with a contractual agreement and they have lawyers, we have lawyers, to ensure that they understand the contract. So there is a level of trust, but a contract in place and the ability toward it.

I must admit that I'm rather relieved when I'm contacted by Biobank, because I feel I still exist and that I'm still part of the trial. They haven't decided I've died, or kicked me off, because I wasn't interesting enough. Did you have a very quick question?

M4: It's eleven o'clock, I've got to get you out of here.

Oh well, let's just have one quick question, yes. You've already asked a question, but you're going to be allowed again.

M5: I feel greedy, but basically, with reference to being contacted by other trials and whether this is good or bad. I participate in a fringe trial done by the University of Dundee, relating to hypertensive medicines and I was very happy to participate, so long as it doesn't interfere with the main trial. Thank you.

If you heard that, it was just that he was contacted by a French survey, but he said he'd do it, as long as it didn't conflict with what he was doing.

M4: Well, I must bring this session to an end. Jon, thank you very much indeed for chairing it. You are
notorious.

[Unclear words 00:26:54] for being part of Biobank.

M4: But you're very well known for your ties and those of you watching on the television at seven o'clock tonight, will notice this tie. Also, for the socks, although I'm a bit disappointed today.

I'm sorry about that. [Unclear words 00:27:08] a bit more sober.

M4: However, we have prepared, specially [sic] for you, your very own Biobank tie. So thank you very much indeed.

My goodness.

[Applause]

M3: It's now a coffee break for half an hour and do talk to any of the speakers about and ask any question you like, so thank you very much.

[Music]

Voiceover: Something special is happening in this rather ordinary looking building. This home to UK Biobank, the most detailed and exciting scientific study of our time. UK Biobank puts the United Kingdom at the very heart of global efforts to defeat diseases like dementia, cancer, stroke and heart attacks, that tend to strike in mid to later life. We have followed half a million volunteer participants who've provided information about their health and wellbeing for research. Currently thousands are being scanned by MRI, one of the brain and the other the heart and abdomen. They also undergo a full body bone scan and we take pictures of key arteries that take blood to the brain. All our participants are here for altruistic reasons, there is no feedback on results. However, if a potential serious abnormality is spotted during the scan, we will inform the participant and their GP. Before they go home, there's a little bit more to do. They donate a sample of blood, for a wide range of important analyses. Blood samples from all UK Biobank participants are stored here at minus 80. These are being turned in to detailed genetic data and other information which is revolutionising health research. This facility is based in Cheadle, Stockport, with others planned in Newcastle and Reading. The scans are already being used in pioneering results and the results published in academic literature. This work is galvanising new approaches to research and new ways of working. Collaborations between areas of health science that might never have worked closely together before. UK Biobank has built a unique.
[END OF TRANSCRIPT]