

q and a afternoon session JULY 2018

We're bang on time. So how much time do you want to allow us for questions, five minutes? Yes, five minutes, okay. So I'm going to allow three or four burning short questions and short answers please. So somebody up here in the front in the pink. I think it's pink, unless I'm colour blind.

F: My name is Irene Siverova. I'm a participant of the Biobank and I'm a supplier of data and a consumer of data and three years ago the labour government decided to create a new initiative and create patient research ambassadors. I would like to ask if your research has public and patient involvement or a patient research adviser, because it's such a nice event with 500,000 people, 50,000, five or something like that, but I would like to see my liver, my brain. I would like to participate in the research which is related to me and probably deliver findings to my community, because sometimes you guys you so enjoy that research that is huge potential or something like that, why can't we stick with lifestyle like this area or smoking or drinking?

I think it's a good point and I think UK Biobank - maybe Andrew you want to take that, because we have had participant meetings where we have participants or maybe Cathy...

Andrew: Yes, so we do involve participants as best we can. We have participant meetings. We encourage them to contact us and talk to us about how the results could be used...

F: [Unclear words 0:02:02].

Yes, I should say my mother-in-law is also a participant.

Cathy: I do think it's a very good point and the previous few meetings we have had involved participants in the same meeting as the scientists and in some respects, that's been very successful, but in other respects it's brought challenges. So we're constantly evolving and experimenting, and we intend in the future to run a series of different types of events - meetings for scientists where science can be discussed perhaps in a way that's not accessible to the vast majority of participants. It will be to some like yourself and that's why you're here, but perhaps not to all. So you've suggested something which that's perhaps a seed, which there may be people who are participants and scientists - and we know some of them already. In fact, there have been some on the platform, but they haven't maybe self-confessed that, but who can plug exactly that gap. So maybe it's happening partly in silence, but perhaps we should be more explicit about it in some of our events, but we do do a lot of this.

Thank you for your question. There's somebody up there in the middle there. Again is it a pink shirt? It's not quite pink actually, but it's close enough.

Okay, [unclear words 0:03:21] from Bar-Ilan University in Israel. All of this new OMIG stuff, compared to

the DNA level is one time short. All of the proteomics and metabolomics are changing during the lifetime, so do you plan or is the idea to do it every few years or every few whatever?

Yes, I think each of you, quick short answers... It's a moving field is probably the question isn't it? So, Adam.

Adam: Yes, that would be great. I think the first challenge is do it in the Biobank at all, but then the fact that there are some serial blood samples taken from people who have come back for other imaging, et cetera, then yes, I think that would be great to do.

Ellen, do you want to... Sorry we'll go to, sorry Peter.

Ellen: Yes, so maybe for DNA methylation or epigenomics it's a little different. I think we will be excited to see at one timepoint could that predict future outcomes, so for epigenomics I think we're talking about one timepoint, but rather see how that could predict future outcome.

Yes and Peter.

Peter: Yes, it's a good point. There's a lot of value in assessing the metabolic profiling at multiple timepoints, so as part of the initiative with UK Biobank we will be measuring around 20,000 samples that are collected in reassessment. Then I think that also other Biobank studies can complement the information that is gained from UK Biobank, which is largely a single timepoint then other studies have reassessment multiple times, so it's not UK Biobank that will give the whole answer. Other studies remain important.

Does anybody have one last burning question? Okay, John Todd.

John: The price that Nightingale and Biobank negotiated must be very competitive for half a million people. Does that mean we can all enjoy that price?

Peter, do you want to disclose that or not? It's up to you entirely.

Peter: Yes, so there's a press release out this morning that details some of these aspects, so the biomarker profiling in this case is fully funded by Nightingale and eventually the data will be released for the biomedical research community, but in the same way as the exome data there will be an exclusivity period before the release.

I think as the committee and I'm involved in the announcements committee, we're looking at other platforms

clearly as we've already heard, but in terms of the robustness and also when they're value for money and I think those discussions are ongoing. I think we're encouraged from the start you've seen so far. Going forward I think we will bring on more platforms to enrich this resource, but we're just taking our time to make sure we get it right and I think that's the key. Okay, I think we'll stop there. I think we all need a bit of caffeine. Thank you for the three young speakers and see you this afternoon.

[Applause]

[END OF TRANSCRIPT]