M: That's far too big a task. I'd never dream of keeping you in order Rory. So, Carolyn and Rory have already given you quite an overview of the way the access process works. I thought I would try to very briefly give you some understanding of what's in our minds as an access subcommittee overseeing this and what the principles are that guide us in driving the issues. So the first thing is, half a million people gave their samples and data to this venture and they did not do that in order that it should lie around in a store somewhere. They did that in order that something useful should be done with it. The thing that motivates us first and foremost is recognising that as many people as possible should be using the resource in order to turn a set of samples and basic health information into something that is useful for the future. However, there are obligations that go with that. We're obliged and must protect the privacy and the conditions of consent of the people who participated and we have to protect Biobank as a whole against damage to its reputation which could erode the trust of the participants and that could be the end of the story. Maintaining trust by behaving properly is critical to us.

So how do we square all that? Firstly, we have been driving and Carolyn's explained this, to make things easier by making a set of fair, reasonably transparent objective principles on which decisions are made so that it isn't any more arbitrary than any adjudicating process must be on individual applications. Secondly, speeding it up and diminishing the bureaucracy by delegating, by simplifying, by constantly nagging away at it. It's a great tribute to Rory, Carolyn and her team and the way they've implemented new systems and are still implementing new management systems, the hard work they've put in that access times have come down and down and are going to go down much further. So the resource is, as we have been told, available to bona fide researchers for health-related research in the public interest. So what's a bona fide researcher? Well, that's very light touch stuff. It's someone who gives some evidence of being a serious and competent person to conduct this type of research.

So they're in a post with a company or a university or a research institute. They have some evidence of having published or they are a student being supervised by someone with some evidence of competence. As long as there is enough evidence that they are what they claim to be, people who can responsibly use data of this sort and as long as there is some way in which there is a responsible entity that will stand behind them and make sure that they do behave properly and abide by the rules of the game, that's taken for granted. Health-related research is a term that is easy in the huge majority of cases, because the majority of people want to use the resource to study disease in one way or another. It's easy to extend that to methodological applications, to some aspects of training. Where it sometimes gets more difficult is where it slides into - what would be an example? So anthropological type applications. You clearly need to understand population structure to be able to interpret health-related genomic data.

So you couldn't possibly ban it all, but people who seem to be edging towards studies that look at the implications of genetics on race and IQ might be stretching us a bit and those would be flagged for further consideration. Generally speaking if it wasn't a good case for agreeing, they wouldn't go forward. So provided you tick those two boxes, which the huge majority of applications do, data applications are simply sent
through with the minimum possible fuss. Samples are a different story. So the principle is, data agree it, unless there's a positive reason to refuse. The samples, as Rory has said, are not there forever. Once they're used, they're used. It's worse than a grants committee. A grants committee will get another budget next year. We won't. Once these are gone, they're gone. So we are as tight as we can be with them.

In order to agree to the use of samples, we would want an application to, firstly be scientifically excellent, taken for granted, address a seriously important issue. As Rory said, use the prospective nature of the cohort not just a convenient source of ascertaining cases that could be ascertained otherwise, and produce new information on a sizeable fraction or preferably the whole cohort to be incorporated into that for future use by other researchers. Not a lot of applications tick all those four boxes easily. It's not that we don't want to agree them. It's that we are fighting with a compromise between the pressure to maintain the resource for future use and the pressure to agree perfectly good applications that were at a funding committee I would nod at on the way through. We have to be tough. So those are the principles on which we try to look at the applications that come through to us.

I think this is work in progress. I think we've come a long way forward to developing consistent policies that help us get through the business as quickly as possible and as fairly as possible. I think these criteria may well evolve over time and I'm quite sure that there are better things that we could do and better ideas that we should have and if any of you have got any of those to contribute, you're more than welcome. Thank you very much.

[Applause]

[END OF TRANSCRIPT]