Hi everybody, so yes, I'm going to be talking today about accessing the UK Biobank resource and about what we're doing within UK Biobank to streamline this process. So as a quick review, the UK Biobank resource is an open access resource that's available to all bona fide researchers, to conduct health related science that is in the public interest. It's available for use by researchers from both academia and commercial companies, both within the UK and oversees. We don't give any preferential access to the resource and we grant limited exclusive access for data that has been generated by researchers. We do ask that researchers return their results to UK Biobank within six months of publishing, so that we can incorporate them into the resource and make them available to others.

Applications to access the UK Biobank resource can be broad, they do not need to focus on specific risk factors or health outcomes. They can involve a range of genotypes and phenotypes, or they can be purely methodological in their nature. Our main consideration is that the scope of the research project is clearly defined. Access to the UK Biobank resource opened in March 2012 and since then, researchers have been able to apply to access our data and samples, but in order to do this, they must first of all register with UK Biobank. So this graph shows UK Biobank approved registrations since access launched in 2012. The columns show the number of approved researcher registration per year, while the line shows the cumulative number of approved registrations year-on-year, and you can see that this continuing to increase as the years pass. Which demonstrates the continued interest in the resource from the research community. In March 2019, the access team reached a really exciting milestone, where they registered our 10,000th researcher.

Once a researcher has registered with Biobank, they're then able to apply to access our resource, and this graph shows the number of UK Biobank approved applications. Again, the columns show approved application numbers by year and the line shows the cumulative number of applications as years go by. Again, you can see that this is continuing to increase. In November 2018, the access team approved our 1000th research application, and as of about a week ago, we had over 1300 approved applications. If we look at the locations of UK Biobank researchers worldwide, we can see that it truly is a resource that is of interest to the global community. We have over 4000 researchers registered within the UK, and a similar number in the USA. A large hub of research activity in mainline Europe and smaller hubs in Canada, the China/Hong Kong area, and Australasia and further smaller groups of researchers in other areas.

So how do researchers access the UK Biobank resource? Well, our access procedure is described in our access policy, and is managed via our access management system, or AMS. This process was basically comprised of three main stages. There's researcher registration, where we check the identify of each researcher to confirm their bona fides as part of the approval process. There is the application stage, where we assess whether an application meets the criteria of being for health related research that is in the public interest, and there's an MTA and payment stage, where there is a small cost recovery, access fee, and we require researchers to enter into a material transfer agreement with Biobank, before we can make samples and data available.

How long does it take for researchers to access UK Biobank data? Well, this graph shows the main
timelines from application submission to data release, since access to the resource launched in 2012. Over the years, the UK Biobank teams have worked really hard to reduce these timelines and you can see the result of this, is that it’s gone from taking on average, 50 weeks per project to get through this process in 2012, to 24 weeks in 2018. We’re continuing to work to reduce these timelines and have a goal of reaching a 12-week turnaround time in 2020.

So looking at where the time during that access process is typically spent, once an application has been submitted, there is an initial payment that needs to be made, of £250 before we can progress the application through the process, and in general we spend an average of five weeks per project waiting to receive this payment. After the payment has been received, the application is processed by teams within UK Biobank and during this period, there is communication between our teams and researchers to amend the application. This takes on average nine weeks per application and a lot of this time is spent ensuring that the correct data fields have been selected, to enable to the research to take place. Once this is complete, the UK Biobank teams will approve the application and we then enter the final point on this graph where we need an MTA to be signed and returned to us by the researchers, and the main project payment to be made. This needs to be completed before we can progress to a project started phase and release data or samples, and this final part of the process takes on average ten weeks per project.

So we are working to reduce these timelines and we have a number of process improvements that we will be implementing. One of these is removal of the initial payment fee, so that initial £250 will be combined with the main payment fee, which we request right before your project has started and removing this initial payment will remove a block in the process, which should save on average five weeks processing time per application. We are planning to introduce this in early quarter three of this year, so that’s something that’s going to be coming soon. We're also going to be introducing a standardised basket, to make it easier for researchers to select the data fields that are required for their research and reduce the amount of time that is spent making amendments in this nine-week period. So we should be able to bring that down a bit as well, and again, that is due to be implemented in quarter three of this year.

Additionally, we are working on improving signposting and the health and support available on our websites, we are creating tutorial videos to guide researchers through the stages of the access process, including the signing and returning of MTAs and all of this should be complete and available by the end of this year.

So as researchers, what can you do to speed up the access process? Well, actually, more than half of the overall processing time is in your hands, and considerations you may wish to make include paying online, which is generally faster than paying via BACS, involving your legal team early to ensure that they have seen and are familiar with our MTA terms and conditions. Being responsive to any queries that you get from the access team, and signing and returning your MTAs electronically, via DocuSign.

So just to look quickly at the impact UK Biobank is making, which Rory has touched upon, there are now over 750 published research papers, using the Biobank resource, you can see from this graph that that is
continuing to increase year-on-year, which is really exciting to see. We ask that researchers report all publications to us two weeks ahead of the publication date, as this gives us time to ensure that the scope of the application made to Biobank is inline with the content of the research paper, to ensure that any acknowledgments that are required are in place and to post links to our research papers on our website to further promote to your research. We also ask that any presentation of research at conferences, be it in poster or talk form, are reported to us, along with a copy of an abstract, and we remind you that researchers are obliged to return results to us within six months of publication, so that we can incorporate them into the resource and make them available to others and continue to grow their wonderful UK Biobank resource in this way.

Finally, I want to let our researchers and users know that we have plans to redesign and rebuild the UK Biobank website, so expect to see some changes being implemented soon. Our aim with this is to better lead researchers through various UK Biobank processes, including access. We want to do this by giving you simplified navigation, more effective searching tools, we're looking to present key information to you at the points where you need it, to build a more narrative architecture within the website, and we will also be providing alternative ways for you to discover and explore our resource. You can see here, a wee sneak preview of our vision for this new website and we have web developers from Sigma, who we're working with on this, here today looking to gather feedback. So if you're approached by any of them, please take the time to give them your opinions as this will help us build the best solution.

Finally, your access management team, most of us are here today and we do have a stand in the foyer, so please come and say hello, ask us any questions and put faces to the names behind the emails that you receive. Thanks for your time.

[END OF TRANSCRIPT]