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register for access to themselves, so we're seeing increased use or use of the resource. Here are more and more receptors registering and more permissions approved every single year. And with this comes a mobile rich dinosaur. So in 2016 usage of the data was largely limited to North America and Europe. We did have some applications with the intention to clearly see that far more countries are using the data. And that's accompanied by a much higher proportion and other people's faces from outside the UK. UK Biobank researchers it's possible to be using this data to generate new insights into health research. And the increasing research is also requested that means increased impact and we're seeing a large number of publications and citations obviously, I'm also seeing traditional and social media as generating public interest. They mostly provide and health research in general. So we have some general principles of access that we follow. So the data is available to all bonafide researchers for all types of health related research that has any public interest. And this is very important because this is the basis for all participants consent, conservative for their data to be used for health related research. In the public interest. We did not flexible or exclusive access so use of resources on the same basis for academic and commercial researchers. That means there's the same prices on the same vision systems. So researchers who carry out the kind of sampling or enhancement projects, resistance will be lasted for two minutes or the project monitoring. They will receive exclusive access period after the linkage of graduated data to the resource. As you see there's a short actually it's about nine months after that exclusive access period, that data is released to the entire identification of researchers. While they do get that exclusive access all researchers both sample or both academic and commercial can put in some applications water sample data and that is considered on the same basis for those searches. Researchers have to pay for the cost of using the resource. The cost that you pay are not contributing to the setting up of the resource, kind of the enhancements for setting up the resource that's paid for by our funders and by donors. Access to the biological samples because these are limited although we do have quite a lot left of them and principles of beautiful that is more carefully controlled and coordinated. And the sound applications are really carefully considered by our access committee. In general the principles of samples are that the assay should be performed on the whole or significant subset of the cohort, that assay should be validated already validating are saying that they are saying we generate a number of measures that will be usable by lots of other researchers like to see measures that are going to be returned to us throughout the project lifetime. Finally, researchers are required to publish their findings and also return the data so that other researchers can use them. So for example, as things that come back as a return that researchers have generated in Asia are things like the Indian direct phenotypes that Lisa talked about, and various other measures that are available and other times. So what are the steps accessing data? Firstly, the individual researcher needs to register on our access management system which is available here. Check will be informed that you are a bonafide in these sectors. So that means that you're working for a legitimate research organization with a track record of health related research. So if your first person your advisor is to them also willing to register is a two and variable with them. But McGill University, right and Ally University data access systems are pretty simple to sign up to your office. You see that you have an issue associated email you might be required to send your CV in. As always, this is also checked against any international sanctions lists hopefully you're on this. You'll then apply for access for your specific project and fill in an application form. So the application form for the project covers a number of different areas your research questions, the background of your research project, some brief description of the knowledge and the type of data using the expected value of the research and then also alleged summary. So research questions can be broad. They don't have to be very narrow, but they do need to have a clear scope and a definable output. The description of the methods and the data should focus on should be answered with the use of new provided data in mind. You know, we don't need to know about the entire kind of program of research that this is happening in front taxes. You know, it's interesting isn't very detail about the kind of cell culture experiments you're going to be using. Doing. We just need to hear about the methods and things apply to you data. All of these answers should clearly lay out how your research is health related and in the public interest. As I said earlier, that is the basis of all participants consent. So to approve an application you need to know those two points. And then finally, the lay summary this coverage on the website is really important to us. It allows our participants and other members of public to understand how the event is being used to actually be a language that will be assignable to a non scientific member of the public when you apply the application will reviewed by scientific team to check research comes under the basis of consent, and also that the research is feasible in Dubai vaccine. For example, if you currently applied and said you needed transit point data that's not available right now. So we might come back to you and say, I don't think I should be able to do this there. They might ask for some revisions. So the common reason that people are asked for a business application is that there might have been too brief throughout the application. That as I said, the data isn't actually this living, saying they want to use might not actually be available in the UK Biobank. That they focus too much on non UK Biobank plus the project or the value summaries on site. audience. So hopefully, your application is approved and on average, that takes approximately about two weeks after approval to manage your project. So before that access to the data, we must receive the payment of course and also signed NDA from the self in the present entity. And in addition, all collaborators that you have, so if you're the AI Lab, any student or postdoc was going to be accessing your data or any SNMP accessing data should also register to be added to the project. You have as many people as you want. Okay, so this is a overview of relatively low speed it further our access fees. So we have three tiers of access with increasing prices with different data in each. So our tier one data set is available for 3000 pounds for the full three years. That's about 3500 US dollars. And that gives access to tabular, tabular data, so all of the lifestyle and physical measurements that were captured the assessments and all of the links to health outcome follow ups, follow up questionnaires and also phenotypes that have been derived from due to lose access to that last, the biochem classes on chemistry data, Nightingale, proteomics, and also genotyping data. And that's for 6000 pounds or three years of access. And then tier three, which is 9000 consultants accesses access to all of the FBI data. So we've mentioned four plus four, and it sets everything and the secret should note that the sequencing data sets can be used on the research analysis platform, which we're going to go into further later in this day, and they can't be downloaded. The size is just all the other data is available for download at UCI levels. However, some data is available on the research analysis platform at a lower cost. This is where I get slightly confusing. So for example, the genotyping Nightingale data is available on the platform at tier one.

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You can have a low cost, but you wouldn't be able to download the data. And imaging is available at tier three on the platform, but to Uncharted two on the platform and tier three standard data. So I said it's a little bit freezing. So if you want to know the last two years for specific fields, each field on showcase contains a positive which indicates the availability for download and online. So this question says do 201 string so a one means that it's available online at tier one and D two and S two are two different forms of download. So D is download from the research analysis platform and so download bar are simply suites. So this data is available for download at tier two. Each field has that available if you click on costed. You will see a little bit of more of an explanation we go from this and can't quite remember what I said which

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we also do have some reduced access fees available for student researchers and researchers out in cities. Countries so reduce taxes fees of any 500 pound for three years access are available to these researchers provided they use all of the data on the research analysis platform. student projects should be submitted by a student or their supervisor for the sole purpose of forming customers research project and doing things that come out. revisions that come out of that that project should be authored by. In addition, we just announced yesterday our global research access fund where costs of access for researchers at Institute's or conferences can be painful. That doesn't really Falador Japan but if you're from somewhere else and you would like to discuss that with us. Just a couple words on recession answers platform which is open to more depth. This is a platform that allows us to bring the researcher to data, making the data access more widely accessible to researchers around the world is a cloud based platform which provides secure access by providing access and we see that we have a lot of users and that person is using this platform already. And again, this will be covered in much more detail later in the day. But we also have a couple minutes around available to open your receptors that provides for this research analysis. Like to produce visit our news reporter as well as has launched earlier this year, researchers can get support from peers or from providing data and access to on all aspects of data, the touching data, how to use the research analysis platform. And then also, research methods can be discussed with your peers as well. Even with all this data that's available, it's unlikely that we're going to be experts on how to do research or every single piece of data that would give you the chance to talk. So just a few tips to minimize application time tight timeline. The water is often actually after a bottleneck is often actually after approval. It's the MTA signing and payment times. So please talk to your legal and finance teams before you apply not just when it's been approved. So ensure that you will be able to see your standard MTA talk to the finance department about how you're going to theory access fee online and make sure you send that back to the system user can also if we do the only revisions of the vaccinated patients make sure you respond to that as soon as possible. And you can always contact the access team via the ISIS management system has a mesh optic messaging capabilities or by email and in addition if you require some cross tabulations of fields, before you'll find access to understand how many participants are available for your specific research question. So for example, you want to know the number of people who have a certain disease and also have proteomics data available. Just contact that email address and we'll get back to you as soon as we can with so this is the end of our session towards noseless co founders, some economic solid, especially your access to us activity, duel about reviewing your applications and also force our participants. We wouldn't be here without.

14:19

Thank you for the very interesting presentation. I think you mentioned IRB. So I was wondering if that was because I missed it, or is it simply because of the way that the participant had sent it, but it's not required?

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This is not required by us so I don't I don't think it's required by us. It might be required by your institution that the the study as a whole at the beginning was written by

15:00

we have an initial ethics approval, which is then reviewed on a regular basis and a ethics panel as well who give it particular advice, especially with you know, specific applications or questions that have come up or in particular sample size. Well, we need to ensure that we've got that. Yeah, so is the application may prove to be particularly controversial. It tends to have a longer review process that goes to access committee which is staffed by people externals, just agree

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with some aspects of return of results from novices is expected. So how is that managed? It's systematic from all the different

16:05

Yeah, so our system is that it's an online tool, access management system that scales the number of returns that receive means to see to that and it comes of course, as tricky is the researchers should notify us of when publications are upcoming. So if a researcher hasn't explained to us that they return any of those results to us, so for some results can be made available. Freely by researchers, but individual level results because they relate to specific participants can't be made available those sectors should return those to us so that we can make them available for other people. And to enhance

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the sort of unrelated question on the tracking of publication and mention about

17:09

so this is a kind of handled within scientific analysis team. They have, like rectoress that for publications that mentioned UK Biobank we do have a standard acknowledgement that researchers should include in their knowledge in saying that the research was carried out by the UK Biobank under their opposition number of course we can look for that. It's, you know, it's a process that is ongoing refinement, because obviously papers mentioned about like, say authority trying to make every effort to track the.

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Confrontation usually from McGill University. So I have a question about the subject identifiers. Now I apply for it. I have the data I have different subject. Someone else and you know, they'll take the data. It's the same data but the IDs are different. So now if I want to do sort of reproducible science, I've learned by the way I send them all I have different slips. Let's say that they have to now explain them all and test it on the other hand, but on someone else, take my model. They want to test it on the same has not case because they don't have the same identifiers. So is there a way to sort of harmonize that to facilitate reproducibility between, you know, key eyes and labs will have access to the same data.

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So when someone returns data to us, we then provide that data will then bridge to your application ID. So for example, in that situation, you published your model you could return to us a list of the participant identifiers that were in your techniques that are the ones that are in your test data set, and then we make that available to subsequent applications we batch to there are many ideas. If you are collaborating with the researchers prior to coming to you should be completed. We encourage you to add them to our application and then realize that the mistake for application they can then access it into an application. If you really do need to be burdened with tons of different applications. We can consider requests for bridging files on a case by case basis. So get in touch with the abscess management team and then that will be reviewed by the sides to see if it is necessary to

20:00

learn something I didn't know this was possible. The other question so if not, we have a break I think until after the hour