UK LLC Data Access Public Review Panel

Friday 9th December 2022

12.30 – 1.30pm

Attendance	
Kirsteen Campbell	UK LLC Communications and Engagement Officer (Chair)
Stela McLachlan	UK LLC Research Manager (Deputy Chair)
Rebecca Whitehorn	UK LLC Research Administrator
Five Panel Members attended	UK LLC Data Access Public Review Panel
Guest Speakers	
Charlotte James	University of Bristol
Ru Jia	University of Nottingham
Venexia Walker	University of Bristol

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	**12.30**	**All**	Introduction Updates from previous meeting
2.	**12.40**	**Charlotte James**	Presenting application, ref. no: llc_0028 on "Identifying clusters of COVID-19 and Long Covid symptoms"
3.	**12.45**	**All**	Questions from Data Access Public Review Panel following llc_0028
4.	**13.00**	**Ru Jia**	Presenting application, ref.no.: llc_0027 on "Mental health and COVID-19 vaccine outcomes"
5.	**13.05**	**All**	Questions from Data Access Public Reivew Panel following llc_0027
6.	**13.20**	**Venexia Walker**	Presenting application, ref.no: llc_0026 on "Capturing ethnicity in UK electronic health records and longitudinal studies."
7.	**13.25**	**All**	Questions from Data Access Public Review Panel following llc_0026
8.	**13.40**	**All**	AOB

Minutes

Agenda Number	Presenter	Agenda Item
1.	**All**	**Introductions** **Updates from previous meeting**
2.	**Charlotte James**	**Presenting application, ref. no: llc_0028 on "Identifying clusters of COVID-19 and Long Covid symptoms"** The researcher began presenting on the application aims; to identify which symptoms of COVID-19 and Long-Covid occur more frequently together. For example, if an individual has a fever, they might be more likely to lose their sense of taste or smell or if they lose their sense of taste or smell, they may be likely to feel tired. The second part of this application will depend on whether the researchers can identify common groups of symptoms and determine what personal characteristics could make an individual more likely to develop a certain group of symptoms. As a result of COVID-19, Long-Covid can now be classed as a new disease, and it is unknown how many are suffering. Long-Covid is difficult to diagnose, and it is possible that some people are more at risk of developing it after having COVID-19. This could be due to certain characteristics, such as age, or how severe the COVID-19 infection was. The research aims to identify these groups of symptoms that are more likely to appear together. A similar study was previously done using 9 cohorts, carrying out a similar analysis to this proposal, but looked at each of the cohorts separately. This work found two groups of symptoms; one represented a recent COVID-19 infection and the other represented past COVID-19 infections (one represented COVID-19, and the other represented Long-Covid). It is harder to identify groups of symptoms that are less common or rarer as there may not be as many examples in a smaller dataset. This application aims to combine data from multiple cohorts, so they have a larger dataset to find rarer symptoms. If the researchers find cluster symptoms and that certain people are more at risk of certain groups of symptoms, it may be possible to identify those at risk of severe symptoms. The outcome of this could influence vaccine policy in the future. By characterising groups of symptoms occurring more commonly together may help with the clinical diagnosis of Long-Covid.
3.	**All**	**Questions from Data Access Public Review Panel following llc_0028** The panel flagged the word "cohort" in the lay summary as this is not appropriate for a lay audience. The researcher advised they would amend the lay summary. The panel suggested the words "groups" or "studies" as lay alternatives.

		The panel noted that the application only mentions sex, so it was reassuring to hear the researcher talk about gender and ethnicity in their presentation. The panel queried listed symptoms in the application and asked if there is capacity to capture 29 other additional symptoms. The researcher advised there is the possibility to capture additional symptoms within UK LLC, as they hope to supplement the study data with Electronic Health Record (EHR) data. There might be additional symptoms within the EHR not asked about in the studies. The panel noted the mention of potential for vaccine programmes during the presentation and suggested this should be enhanced in the application. The researcher should clarify that public involvement is used during the design and dissemination of the application. The panel asked if datasets used in previous analysis will be used for this. The researcher advised they will use as many as possible as they are more likely to identify more groups of symptoms. The researcher has increased the number of studies used from 9 to 15. The panel queried if there would be patient overlap between each cohort. The researcher advised there would not be any overlap. Panel also asked if the data would include vaccination booster information. The researcher advised that they requested linked data for vaccination records. This is not necessarily recorded in study data. This will be included as a co-variant, as symptoms may depend on vaccine uptake. The panel queried they will record patient immune status (if patients are immunosuppressant or have general immune problems). The researcher advised they will look at code lists selected from the linked EHR data requested. The panel asked if the researcher plans to use data from all 15 studies separately, analyse findings and then draw them all together. The researcher advised they will pull data from all 15 studies into one dataset. The panel advised that the lay summary does not make this clear. The researcher will revise this in the lay summary. The panel asked if the researcher would look at self-reported COVID-19 infections or ones recorded from lateral flow tests. The researcher advised they are self-reported via the studies, and if patients have had a positive test, it can also be shown in the linked data.
Feedback and outcome		• **Revise language used in lay summary** • **Clarify the use of public involvement throughout the whole application and project** • **Clarify that 15 studies will be combined into 1 dataset in the lay summary**
4.	**Ru Jia**	**Presenting project, ref.no.: llc_0027 on "Mental health and COVID-19 vaccine outcomes"**

		The researcher presented the application aims; to understand how well COVID-19 vaccines work in those with mental health conditions. The research will look at two different outcomes. The first is the COVID-19 vaccine uptake in those with mental health conditions. The second will consider if those with mental health conditions are more likely to get the COVID-19 infection, get ill, or die after being infected. This is known as 'vaccine breakthrough'. People with mental health conditions are sometimes less likely to engage in preventative healthcare, including the uptake of other vaccines, blood pressure monitoring and certain types of screening. It is known that mental health and factors such as depression and stress affect how well vaccines work. This was established in literature before the pandemic; however, it is unknown how this applies to COVID-19 vaccines. This application proposes to look at how the uptake of COVID-19 vaccine looks in this population and are they at risk of vaccine breakthrough. The researchers will establish cohorts of people with and without mental health conditions using data within UK LLC's TRE. They will estimate the uptake of COVID-19 vaccine and the risks of vaccine breakthrough in these groups of people, compare the results and see if those with mental health conditions are at risk. It is important to investigate this due to the clinical impact. The pressure placed on the healthcare system over the last 3 years is widely known. Researchers need to find out ways to reduce the risks in the future if it is evident that those with mental health conditions are still at risk, less likely to take the COVID-19 vaccine or more likely to get infected even up to the point of vaccination. Ultimately, it is vital to take better care of the patients and take pressure off the primary care system. From a broader outlook, there are other preventative care options that those with mental health conditions may not be engaged in. This research will set an example of how these issues can be investigated in the future.
5.	**All**	**Questions from Data Access Public Review Panel following llc_0027** The panel asked what age groups are involved. The researcher advised that all age groups are included, which is an advantage of using a large database such as UK LLC. In the analyses, they will control for age and other physical conditions that may affect the risk of COVID-19 and vaccine uptake. The panel noted that in the lay summary, it reads as if one study being conducted. However, in aims and objectives, there are two studies mentioned and listed separately. It was suggested that this is mentioned in the lay summary. The researcher advised that this is one large study with two outcomes assessed, the uptake of the vaccine and then vaccine breakthrough. The analyses to estimate the uptake

		and risk of vaccine breakthrough are different, so in the aims and objectives, they are listed as different outcomes. The panel asked if 6 public contributors is sufficient for such a large study and how the researcher would ensure diversity in the public involvement group. The researcher advised that this is restricted by the amount of funding available and 6 is the maximum number they can recruit. The researcher will aim to recruit more public contributors, will consider diversity and aim to include at least 3 people with lived experience of mental health conditions. The panel asked if the researcher had considered an alternative to virtual public involvement meetings to ensure everyone can take part. They asked what the researcher plans to do with the results of the study to benefit those with mental health conditions. The researcher advised they have begun recruiting the public involvement group and that they would liaise with them to help with dissemination. The researcher noted that they have been advised to take caution with dissemination, as some people with mental health conditions may not have taken a vaccine as a personal choice, rather than due to their mental health condition. It may be difficult to ensure there is no bias because of this finding. This study is observational, so they will only see an association. The researcher will ensure the use of appropriate language.
Feedback and outcome		
6.	**Venexia Walker**	**Presenting project, ref.no: llc_0026 on "Capturing ethnicity in UK electronic health records and longitudinal studies."** The researcher presented background on the application. When a patient registers to a GP in the UK, they must complete a form named the GMS1. This asks for basic details such as name and includes a question asking the patients ethnic group by selecting a box. GPs capture this information to better provide healthcare. One example of this is choosing treatments for an individual with high blood pressure. If a patient is diagnosed with high blood pressure in the UK, they are often offered a hypertensive drug, and the drug initially offered depends on the patient's ethnic group. It is found that people of African or Caribbean origin do not respond well to a certain type of medication called an ACE-inhibitor as well as other ethnic groups. During the pandemic, it was found that people of minority ethnic groups had worse health outcomes of COVID-19 and were more likely to die following COVID-19. This has renewed the interest in recording ethnicity in electronic health records (EHR), as it is important to have this information for research to make ethnic group-specific recommendations. EHRs are one source of looking at ethnicity, however, the researchers are interested in looking at other sources as a comparison. Studies

		such as ALSPAC have collected this information historically and at various points in time have re-asked participants how they identify their race and/or ethnic group. By using UK LLC, all data is in the same place, which allows the researchers to look at different sources of ethnicity data at one time. There are three aims of the application. The first is to compare within each dataset that the researchers can access. Before the researchers can draw comparisons, they first need to decide what the best record of ethnicity is in each dataset. They should then be able to estimate an individual's true ethnicity within each dataset. They can then look at comparing between each dataset. The second aim is to take each of the datasets in turn and compare them with each other. For example, does an individual's GP recorded ethnicity match their hospital-recorded ethnicity, and does that in turn match with self-reported study data. The final aim is to compare EHR and study data. From taking data from longitudinal studies, they are hoping to find out if this is the best way to define ethnicity in EHR. If this can be established, it will help with future research and will hopefully provide guidance to other researchers on how they should use ethnicity going forward.
7.	**All**	**Questions from Data Access Public Review Panel following llc_0026** The panel noted the use of anonymised data. They questioned how the researchers would compare what is recorded in a GP registration form to hospital admission form and a studies form. The researcher advised that the data have already been linked when they access it. They are given a pseudo-identifier and not the real NHS number or any other identifier. There will be a patient ID that they will access, allowing them to extract the same person form GP record, hospital record and study data. The panel noted different groupings and formats for ethnicity and questioned how the researcher will deal with this. The researcher advised they would work with groupings on the GP form (20 different categories) which is the current standard used by GP providers and is also what was asked on the last census documents. Historically, studies have categorised ethnicity differently so it will be a case of mapping. This is finding the comparable group between what is seen in the EHR and what is seen in the study. The panel questioned if the researcher is recording age. The researcher advised that every time ethnicity is recorded on a medical record, there would be a date. They also have access to month and year of birth so can tell someone's age. Additionally in the studies, the questionnaires were sent out at different ages of participants, so it is known when people were asked.

		Panel member questioned the 'prefer not to say' category and asked the researcher how they will deal with this. The researcher advised that this category is helpful as some people have missing data, so choosing not to record information and having missing data are two different things. They use this information to say if the data missing or if they have chosen to withhold this information. The panel questioned the public involvement strategy and the comment of 'feedback will be sought as needed'. They suggested that public involvement should be used more in the design. The researcher noted that previous access to EHR data was through COVID-19 funding so they had prior engagement through long-Covid groups and talking about the use of EHR in research. The researcher agreed that public involvement is important for this study. They are exploring options, have access to groups through the University and can look locally for public involvement. The panel asked if they plan to disseminate the results to different language speakers as this project involves ethnicity. The researcher advised they had not considered this and will take this back to the project team. The panel questioned if all age ranges will be looked at. The researcher advised that different studies look at different age ranges and some are inter-generational, so age will be considered. The panel noted the use of public involvement is the same as on application llc_0028, indicating the possibility public involvement not being done appropriately. The researcher advised that both proposals come from one research group. Public involvement will usually be conducted as one group so both research applications will be presented together to use people's time effectively.
Feedback and outcome		• **Researcher to consider more options for public involvement, such as through university and locally.** • **Researcher to look at plans of disseminating results in different languages.**
8.	**All**	**AOB**