

UK LLC Data Access Public Review Panel

Friday 24th June 2022

12.30 – 1.30pm

ATTENDANCE	
Kirsteen Campbell – Chair	UK LLC Communications and Engagement Officer
Stela McLachlan – Deputy Chair	UK LLC Deputy Director
Rebecca Whitehorn – Administrative Support	UK LLC Research Administrator
UK LLC DATA ACCESS PUBLIC REVIEW PANEL MEMBERS	
Five UK LLC Data Access Public Review Panel Members in Attendance	
GUEST SPEAKERS	
Olivia Hamilton	University of Glasgow
Francisco Perez-Reche	University of Aberdeen

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introduction Updates from previous meeting
2.	12.40	Olivia Hamilton	Presenting project, ref. no: llc_0015 on “Socio-demographic determinants of COVID-19”
3.	12.45	All	Questions from Data Access Public Review Panel following llc_0015
4.	13.00	Francisco Perez-Reche	Presenting project, ref.no.: llc_0025 on “Using metabolomics to better understand COVID-19 symptoms”
5.	13.05	All	Questions from Data Access Public Review Panel following llc_0025
6.	13.20	All	AOB

Next available number is #005

Minutes

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	<p>Introductions</p> <p>Updates from previous meeting</p> <p>The panel were updated on the status of all UK LLC applications, from llc_0001 to llc_0025. Applications llc_0001 to llc_0009 are active in the Trusted Research Environment (TRE), meaning at researchers are doing analysis in the UK LLC TRE.</p> <p>Applications llc_0010, llc_0012, llc_0013 and llc_0014 are approved and moved to contract signing phase. Application llc_0011 is on hold as comments from Linked Data Review Panel are to be addressed. LlC_0017 to llc_0024 are in contract signing phase. Linked Data Review Panel has declined application llc_0016 as it is unclear where the data will sit between DPUK and the UK LLC. This needs clarified before proceeding.</p> <p>Applications llc_0015 and llc_0025 will be presented during this current meeting.</p>	
2.	Olivia Hamilton	<p>Presenting project, ref. no: llc_0015 on “Socio-demographic determinants of COVID-19”</p> <p>The researcher presented their project on inequalities of COVID-19 infection, explaining that everybody is at risk of catching COVID-19, but not everyone is at an equal risk. The differing level of risk could be due various personal characteristics (age, sex, and ethnicity) or due to different personal circumstances (financial, living and work). All characteristics come together and could contribute to an individual’s risk of either catching, or not catching COVID-19.</p> <p>The researcher explained that public involvement have been included at several stages of the work and will continue during future stages. The project is embedded within the National Core Studies who have their own public involvement strategy which the researcher will use. Two public panel members sit on the executive board of the National Core Studies and therefore have an oversight of all the work being done.</p> <p>The public have also been involved with selecting the questions for data that the researcher will be working with. The public have been involved with designing some of the questions for COVID-19 surveys and involved with putting ethics applications in.</p>	

		<p>Members of public advisory group review any public facing outputs from the research, such as infographics, summaries of research results and animations.</p>	
<p>3.</p>	<p>All</p>	<p>Questions from Data Access Public Review Panel following Ilc_0015 “Socio-demographic determinants of COVID-19”</p> <p>Panel member questioned the lay summary and queried the word “sex” rather than “gender”. The researcher advised they are looking at sex assigned at birth, as they just have male/female data.</p> <p>Panel member queried the term ‘finance’ in the lay summary and questioned if the researcher meant social economic factors. The researcher advised that finance could be difficult to measure. The research has data on people’s monetary income, however that is not completely reliable. They are using several different markers for finances, e.g., a question asking if people are struggling financially, or if someone owns their house rather than renting.</p> <p>Panel member questioned what the age range will be and why the researcher singled out ethnic minority women without a University degree. The researcher explained that there are many characteristics that could advantage or disadvantage someone’s likelihood of catching COVID-19. Those three factors are; being in an ethnic minority group, being female and those without a university degree are more likely to report having COVID-19, which could be due to having public facing jobs.</p> <p>Panel member raised a question around ethnic minority women more likely to have reported having COVID-19 as the researcher’s example. How would they know if they had not reported COVID-19 within this example? The researcher advised that the COVID-19 infection data will come from NHS health data in addition to self-reported study data. They will have test data from the community and hospital test data, which will show both positive and negative data. However, the researcher noted they do not have data on those who don’t test at all, which is a limitation of the study.</p> <p>Panel member asked if the predicted variables in the application are of themselves, predictors. For example, wealth by age. They asked how the researcher would get an appropriate outcome from their analyses. The researcher advised of a diagram in the full application showing a causal model, with age sex and ethnicity at the top, COVID-19 at the bottom and a mix of variables falling in between on the causal pathway.</p>	

		<p>Panel member noted that the researcher does not include participant’s health history in the analyses. The researcher noted this point and will consider this variable to stratify analyses.</p> <p>Panel member queried if vaccination status affects COVID-19 status in blood tests. The researcher advised that vaccination status will be coming from vaccine records and self-reported vaccination status. Panel member further asked if blood tests would reliably identify those who have had COVID-19. The researcher advised that anti-body tests are typically reliable to identify if someone has had COVID-19. However, they are defining COVID-19 cases from NHS health data, from PCR testing, and lateral flow testing.</p> <p>Panel member asked how the researcher defines COVID-19 severity. The researcher advised they are looking at COVID-19 severity as a secondary aim of the research study.</p>	
<p>4.</p>	<p>Francisco Perez-Reche</p>	<p>Presenting project, ref.no.: llc_0025 on “Using metabolomics to better understand COVID-19 symptoms”</p> <p>The researcher explained that the effects of COVID-19 depend on the individual case, and symptoms vary substantially. Some people show no symptoms, some show few symptoms while others have a variation of symptoms and some may die. It is important to understand the reasoning behind this.</p> <p>It seems to be clear that older patients are more likely to be more severely affected by COVID-19, in addition to those with previous conditions such as cardiovascular disease or diabetes. However, these factors cannot be taken as a rule to decide who will have severe symptoms, as not everyone of an older age or with previous conditions will be badly affected by COVID-19.</p> <p>This suggests that there is something in the biology of individuals that is not coded in their age or if they have previous conditions that will determine if someone will have severe COVID-19 symptoms or not.</p> <p>This project will look at blood tests to find out if there are differences between those who experience severe symptoms and those who do not. The blood tests contain information on more than 150 blood markers. The information from NHS health data and study questionnaires will be crucial for this project to know what patients tested positive for COVID-19 and what symptoms they had. Blood markers could be used to predict if someone is at risk of severe COVID-19 symptoms. Using blood markers will lead to a more accurate prediction of COVID-19 severity.</p>	

		The findings could indicate those who are more at risk of experiencing adverse symptoms of COVID-19 could be better protected.	
5.	All	<p>Questions from Data Access Public Review Panel following llc_0025</p> <p>Panel member queried the lay summary and objectives. The lay summary mentions middle age, whereas the aims and objectives talks about all age groups. The researcher advised the lay summary might not be clear enough, however the project should include all age groups as COVID-19 affects all ages and the biology of individuals matters more than just their age.</p> <p>Panel member further asked if the researcher is going to look at socio-economic factors, as medical interventions may vary. The researcher advised that the project is complex as there are so many blood markers and statistically, they will all have to be taken into account. They will not look at socio-economic factors in the first instance.</p> <p>Panel member mentioned more clarity and explanation on confounders would benefit the application. The panel member further queried the mention of symptom patterns in the application, as this is not clear. The researcher advised this is based on a study carried out by other researchers within CONVALESCENCE group, with the idea of looking at individuals and a set of 10 symptoms, such as sore throat. Researcher explained that you could essentially cluster patients into two: one where patients are generally well and those that are unwell.</p> <p>Panel member queried public involvement, as it appeared there was no public involvement in the design of the study. Panel member further asked if they are looking at outcomes in addition to outputs. The researcher advised that the research project has just been finalised and the public involvement will start once the research begins. The researcher also advised they are going to look at outcomes in addition to outputs.</p> <p>Panel member questioned the research objectives regarding symptom patterns and biomarkers. The researcher advised that they will restrict dates, therefore will not consider different COVID-19 variants and vaccinations. They will look at the beginning of the pandemic. The researcher advised they would obtain blood markers relevant to COVID-19 in general, such as high cholesterol.</p>	
6.	All	AOB	

		<p>Panel member questioned public involvement used by the applicants. Should they outsource other public involvement groups? UK LLC chair advised that their public panel should be sufficient, as the groups have been set up specifically for their purpose.</p>	
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