

UK LLC Data Access Public Review Panel Minutes

Friday 22nd April 2022

12.30 – 1.30pm

UK LLC STAFF ATTENDANCE	
Kirsteen Campbell - Chair	UK LLC Communications and Engagement Officer
Stela McLachlan – Deputy Chair	UK LLC Research Manager
Rebecca Whitehorn – Administrative Support	UK LLC Research Administrator
Four public contributors in attendance	
Guest Speakers	
Richard Shaw	University of Glasgow
Emanuele Di Angelantonio	University of Cambridge

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introduction Updates from previous meeting
2.	12.40	Richard Shaw	Presenting project, ref. no: llc_0010 on “Association of COVID-19 and Long COVID with disruption in employment and finances”
3.	12.45	All	Questions from Data Access Public Review Panel following llc_0010
4.	13.00	Emanuele Di Angelantonio	Presenting project, ref.no.: llc_0014 on “TRACK-COVID study: a population-based epidemiological investigation of COVID-19 virus infection”
5.	13.05	All	Questions from Data Access Public Review Panel following llc_0014
6.	13.20	All	AOB

Actions

#001 Documentation for this meeting to be uploaded onto the UK LLC Public Involvement Teams site

#002 Members asked to accept or decline future meeting invites

#003 Members asked to complete and return checklist to UK LLC staff

Next available number is #004

Minutes

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	<p>Introductions</p> <p>Update on application llc_0011 from the previous meeting. This application has been approved in principle. The applications and data team are awaiting final details before approval.</p> <p>Application llc_0012 has been approved by the Linked Data Review Panel.</p>	
2.	Richard Shaw	<p>Presenting project, ref. no: llc_0010 on “Association of COVID-19 and Long COVID with disruption in employment and finances”</p> <p>The overall aim of the project is to investigate the consequences of COVID-19 or long-COVID on employment and/or financial circumstances.</p> <p>Long-COVID being symptoms that last >12 weeks. This tends to be a major threat to society as some struggle to work and support themselves and families. Evidence comes from a small number of international studies and there has been little work on this in the UK. It is important to undertake this work in the UK as the policy context is unique, such as how COVID-19 affects employment may differ between individuals. For example, the furlough scheme.</p> <p>The data required for this is held within the UK LLC Trusted Research Environment (TRE) and can help with this project. The research would use eight longitudinal studies linked to healthcare records. The researchers will look at employment status, how many hours worked and finances around March/April (end of financial year), then link to health data.</p> <p>The cohort studies changed to self-report measures; however, these are not recorded consistently across all cohorts. The researcher will supplement this information with data from health records.</p> <p>With these data, the researcher can look at people’s experience with COVID-19 and their occupational and financial outcomes. By accessing the data held in the UK LLC</p>	

		<p>TRE, the researcher can combine data from different cohorts and link with health records.</p> <p>To maximise the benefit of results, the researcher will present preliminary results to the CONVALESCENCE patient advisory group. They will also look to draft a cabinet briefing to inform policy and additionally press release results and have broad academic outcomes. They will develop skills to improve research in the future.</p>	
<p>3.</p>	<p>All</p>	<p>Questions from Data Access Public Review Panel following Ilc_0010</p> <p>Panel member queried section 3.9 regarding public involvement strategies and asked if the public will be involved in the design or interim findings. The researcher advised the National Core Studies (NCS) have public involvement integrated throughout the programme and have an input throughout.</p> <p>Panel member further queried the age group of the cohorts being aged 25-66. The researcher advised that there are difficulties with including those under the age of 25 as some may be students. The researcher aims to concentrate on people in employment. There is a further complication with looking at the impact of COVID-19 on how things would change in education amongst school leavers and those at university. This is a separate research question.</p> <p>Panel member asked if members of the PPI group are currently living with long-COVID and further asked how the research group would support members of PPI living with long-COVID. The researcher advised that his CONVALESCENCE group is specifically looking at long-COVID and discussed what they could consider this within this project.</p> <p>Panel member asked how access to data within the UK LLC would help this study as all the data is anonymised. The researcher advised that study data is pseudo-anonymised and there are two key benefits from accessing the UK LLC; it is much easier putting all data from multiple cohorts together as a large group of people are required to investigate this topic. The other key benefit is access to healthcare data linked to study data. This pseudo-anonymised data means anything identifying the individual has been removed but their data can still be linked to health records.</p> <p>Panel member asked how the researcher will identify who is in employment. The researcher advised that when study surveys were conducted, participants were asked at that</p>	

		<p>specific time if they were employed, if so, was it part time, how many hours, if they were on a furlough scheme.</p> <p>Panel member suggested that the lay summary might need additional work and to make the aims and benefits clearer.</p> <p>Panel member asked for clarification in the application regarding some individuals being able to work from home. Panel member questioned how the researcher will deal with these different things? The researcher advised they have a separate project looking at home working already.</p> <p>Panel member queried if the work considers the impact of COVID-19 and long-COVID on mental health and employment. The researcher advised he has a separate ongoing project with the UK LLC looking at mental health. Once two separate analyses are carried out, they might look at how they inter-relate to each other.</p>	
4.	Emanuele Di Angelantonio	<p>Presenting project, ref.no.: llc_0014 on “TRACK-COVID study: a population-based epidemiological investigation of COVID-19 virus infection”</p> <p>TRACK-COVID is a study set up during the initial phase of the pandemic in June 2020 with the idea to understand immune response of individual’s reaction to infection of COVID-19. The idea was to recall participants already recruited in other studies run over the last 10 years, for example, blood donors. They would be sent questionnaires regarding COVID-19 symptoms every four weeks and then have remote collection of a blood sample every six weeks. Around 20,000 donors were recruited up to December 2021.</p> <p>The idea of this was to track the immune response of blood donors to the COVID-19 and COVID-19 vaccination.</p> <p>The research will look into how vaccine and antibody response will vary according to population, individuals, and individual characteristics before and during the pandemic. The researchers would like to harvest this data as much as possible by using data from hospital records, test results and vaccination status. This will allow them to better characterise the immune response following COVID-19 infection and/or COVID-19 vaccination in addition to re-infection and hospitalisation.</p>	
5.	All	<p>Questions from Data Access Public Review Panel following llc_0014</p> <p>Panel member queried, that as the research is based on a group of blood donors, they may take better care of their health than other patients. Would the antibody response in this population</p>	

		<p>be representative of those with long-term conditions who could be at higher risk of COVID-19?</p> <p>Blood donors are generally a healthy population. Another advantage of using these blood donors is that they already have a lot of information recorded. For example, they have information regarding genetic make-up. This will allow to better characterise the biological response in more detail.</p> <p>Panel member queried how access to UK LLC will help this specific study. The researcher advised that through the linkage with electronic health records, the researcher will be able to access more precise information about infection, hospitalisation, and vaccination status. This will provide a more precise time stamp on the immune response against infection, vaccination and hospitalisation.</p> <p>Panel member asked if young people are involved and about public involvement in the dissemination – are there any plans to involve the public in the upstream work. The researcher advised blood donors community usually range from age 18 and over and further explained that the public panel have been involved since the setting of the study. They have a large panel of the public who attend every meeting they hold for the unit. They review proposals and are involved in applications. A large group of public contributors communicate through emails. The public are additionally involved in the review of this study, every time there is an update.</p> <p>A panel member expressed concern of how representative blood donors are of the community at large. The researcher advised it is a broad group, but not representative of the general population. Blood donors tend to be healthier and white (compared to other ethnic backgrounds). Panel member asked why they do not consider more representation from the general population. The researcher explained they are interested in questions relevant to the blood donation system and they represent a group that can be helpful to study, especially for a biological question.</p> <p>Panel members expressed concern over using a population of blood donors may ‘exclude’ data collection from patients who are unable to donate blood.</p> <p>The researcher advised this depends on the research question someone would want to answer. For example, if the question were regarding the prevalence of vaccination status in the UK, then blood donors would be the completely wrong population to do this study. There are slightly different concepts.</p> <p>Panel member asked if the researcher is comparing self-reported infection and fortification to Public Health England (PHE) testing data as some members of the public have had COVID-19 but have not reported their results. Would this affect study results?</p>	
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6.	All	<p>AOB</p> <p>The group will move to uploading any documentation for this panel onto Teams to fall in line with our Information Security Policy rather than attaching documents via email. A link will be provided a to the Teams page.</p> <p>Panel members to complete review checklist and send back.</p> <p>The minutes of the meeting will be sent to everyone attending to review.</p>	<p>#001 Documentation for this meeting to be uploaded onto the Teams site</p> <p>#002 Members asked to accept or decline meeting invitations</p> <p>#003 Members asked to complete and return checklist to UK LLC staff</p>