UK LLC Data Access Public Review Panel Agenda

Friday 13th May 2022

12.30 – 1.30pm

ATTENDANCE	
Kirsteen Campbell – Chair	UK LLC Communications and Engagement Officer
Robin Flaig – Acting Deputy Chair	UK LLC Deputy Director
Rebecca Whitehorn – Administrative Support	UK LLC Research Administrator
Six Public Contributors in attendance	
GUEST SPEAKERS	
Stela McLachlan	University of Edinburgh and UK LLC Research Manager
Sarah Bauermeister	University of Oxford and Dementias Platform UK (DPUK)

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	**12.30**	**All**	Introduction Updates from previous meeting
2.	**12.40**	**Sarah Bauermeister**	Presenting project, ref. no: llc_0016 on "Effect of life course stressors and cognitive status on mental health outcomes during the Covid-19 pandemic"
3.	**12.45**	**All**	Questions from Data Access Public Review Panel following llc_0016
4.	**13.00**	**Stela McLachlan**	Presenting project, ref.no.: llc_0017 on "Quality checks, curation and methodological enhancement of the UK LLC Partner Studies using linked data"
5.	**13.05**	**All**	Questions from Data Access Public Review Panel following llc_0017
6.	**13.20**	**All**	AOB

#004 UK LLC staff to identify resources for longitudinal study explanations or training resources around this.

#005 UK LLC staff will pull together a glossary or terms of reference for jargon.

Next available number is #006

Minutes

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	**Introductions**	
2.	Sarah Bauermeister	**Presenting project, ref. no: llc_0016 "Effect of life course stressors and cognitive status on mental health outcomes during the Covid-19 pandemic"** The project is to investigate the impact of COVID-19 on mental health, specifically on those who have experienced life-course stress and mental health problems prior to, and during the pandemic. The impact of COVID-19 on mental health has been almost like a second pandemic, and those with existing mental health illness have been impacted by the exposure of access to care and the impact of not being able to visit family. The researcher has been working on a project over the last year looking at this and the impact of those with mental health problems. With this project, the researcher is hoping to use UK population cohorts across the UK LLC and DPUK to look additionally at those with pre-existing life-course stress. They are particularly interested in life-course stress, as stressful experiences across the lifespan have an accumulative effect, both physically and psychologically. E.g., childhood stress is associated with smaller brain volume in adulthood. The research will consider participants in the cohorts who have experienced childhood stress, life-course stress and poor mental health. Additionally, it will look at those during the COVID-19 pandemic who have experienced poor mental health and how this has impacted them. The research will look at how this has additionally impacted those with low cognitive function and dementia. By undertaking this research, the researcher can highlight those more at risk of mental health issues for further pandemic management. The outcomes are important for risk management. The researcher will be investigating within the DPUK infrastructure space and using the linkage provided by UK LLC.	

3.	All	**Questions and comments from Data Access Public Review Panel following llc_0016:**	
		Panel member asked, regarding dementia patients, how is this data used within UK LLC as it is de-identified? The researcher advised this is assessed through self-reports through cohorts such as ELSA, where participants were asked if they were affected by COVID-19.	
		The researcher advised that within some cohorts, there is a question asking if a doctor has diagnosed them with dementia. This is self-reported and de-identified. The focus of this application is not dementia, it is to understand the impact of COVID-19 on mental health.	
		A question proposed regarding time points of data collection, e.g., data collected before the pandemic. The researcher advised the four cohorts used have different time points of data collections, from 1946 onwards. They will also be looking at mental health collected 5, 4 and 3 years before the COVID-19 pandemic to draw up a trajectory of mental health.	
		An explanation of the public involvement strategy was questioned. The researcher advised that this is a pilot project where they are assessing interoperability between DPUK and the UK LLC. They are going to assess the interoperability between using linkage and non-linkage cohorts. Once they have assessed this pilot project, they may build on the outcomes, a larger scale project in which the public will be involved.	
		It was advised that the lay summary is not written in plain English and should be completely re-written.	
		It was asked if all ages are included in the study. The researcher advised age is not the focus of the study. The age range will focus on middle age to older adults.	
		Panel member queried if carers will be involved in what the consultation or communication will look like. The researcher advised this will depend on the outcome and suggested they might look at cognition and brain function as an interaction.	
		Concerns were raised around the study relying on self-reported COVID results or national testing. The researcher advised they look at COVID questionnaires filled in through participants but they will also have linked health data through UK LLC so they will have a mixed report of data.	
		Life stressors were queried. The researcher advised that across the cohorts, they will be collating variables (measures)	

		on life stressors and will work on a factor analysis to reduce and combine these and focus on childhood, physical or emotional life-course stress. This will be part of the analytical work.	
4.	Stela McLachlan	**Presenting project, ref.no.: llc_0017 on "Quality checks, curation and methodological enhancement of the UK LLC Partner Studies using linked data"** This is a methodological proposal as part of the agreement with studies; that they have access to linked data for their own participants for the purpose of doing this kind of work. This proposes to give access to the study for linked data within the Trusted Research Environment for just their own study participant's data. Data managers of the studies will access linked health records for their participants, allowing them to conduct data quality checks. For example, to compare data participants self-report in study questionnaires compared to their health records. They will also be able to look into more detail about particular events, e.g., how bad their COVID-19 infection was in self reports vs health records. More detail and information will be accessed through linked health data. With access to linked data, they can verify if and when certain events happened, for example, heart disease in health records will have dates. A triangulation of information can also be carried out, meaning the same analysis can be done with study data and linked health data to confirm the validity of the work. All of this improves data and in turn improves research.	
5.	All	**Questions from Data Access Public Review Panel following llc_0017** A panel member commented on the section advising there are no outputs. It was advised there is a positive output as it will result in clean data and this should be publicised. Further comments from the panel advised that this project has so much value. Regarding the project overview section, a panel member asked for a more detailed explanation or an example. The researcher explained that if events such as heart disease are being studied, people report this usually by saying they had, for example, heart disease. People don't often remember, recall or don't know details e.g., exact type of heart disease. It was questioned how different variants of COVID-19 can be tested - if different variants of COVID-19 can be measured	

		against different types of heart disease. The researcher advised this would be a great project for looking at this.	
6.	All	AOB	**#004** UK LLC staff to identify resources for longitudinal study explanations or training resources around this. **#005** UK LLC staff will pull together a glossary or terms of reference for jargon.