



UK LLC Data Access Public Review Panel

Friday 22nd November 2024

12:30pm – 13:30pm

Attendance	
Kirsteen Campbell	UK LLC Public Involvement and Communications Manager (Chair)
Stela McLachlan	UK LLC Research Manager (Deputy Chair)
Rebecca Whitehorn	UK LLC Research and Communications Coordinator
6 Panel Members attended	UK LLC Data Access Public Review Panel
Guest Speakers	
Dr Megan Skelton	King's College London

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introduction
2.	12.45	Stela McLachlan	Presenting application, ref. no: llc_0026 on "Capturing ethnicity in UK electronic health records and longitudinal studies"
3.	12.50	All	Comments from Data Access Public Review Panel following llc_0026
4.	13.05	Dr Megan Skelton	Presenting application, ref. no: llc_0034 on "Comparison of electronic health record versus self-reported measures of anxiety and depression symptoms and disorders in the Twins Early Development Study (TEDS) and Genetic Links to Anxiety and Depression (GLAD) Study".
5.	13.10	All	Questions from Data Access Public Review Panel following llc_0034
	13.25	All	AOB

Minutes

Agenda Number	Presenter	Agenda Item
1.	All	<p>Introductions UK LLC Team announced new public panels at UK LLC:</p> <ul style="list-style-type: none"> • Confidentiality and Due Diligence panel • Smart Data PPIE Working Group • Terms of Reference for Data Access Public Review Panel <p><u>Annual Q&A with UK LLC Management Team</u> Currently looking to schedule this for end of January 2025 or start of February 2025.</p>
2.	Stela McLachlan	<p>Presenting application, ref. no: llc_0026 on “Capturing ethnicity in UK electronic health records and longitudinal studies”</p> <p>The UK LLC Research Manager discussed changes made to this application, on behalf of the applicant. This was previously reviewed by the Data Access Public Review Panel. The applicant addressed the comments from this panel, the UK LLC Linked Data Review Panel and returned the application.</p> <p>The applicant addressed the lay summary and public involvement sections as per the feedback.</p>
3.	All	<p>Comments from Data Access Public Review Panel following llc_0026</p> <p>The Panel noted that the lay summary is over the word limit. They queried if appendices are allowed for additional information to the lay summary. UK LLC Team advised appendices are not used for this purpose. The Panel suggested using headings to clarify the applicant’s aims to better structure the lay summary.</p> <p>The Panel highlighted that it is impressive to see public involvement plans throughout, in the design, interpretation of findings and communications of results.</p> <p>The Panel agreed to help amend the lay summary to cut down on words. This will be followed up via email.</p>
Feedback and outcome		<ul style="list-style-type: none"> • The Panel to edit the lay summary and send new version to Panel Chair.
4.	Dr Megan Skelton	<p>Presenting application, ref. no: llc_0034 on “Comparison of electronic health record versus self-reported measures of anxiety and depression symptoms and disorders in the Twins Early</p>

		<p>Development Study (TEDS) and Genetic Links to Anxiety and Depression (GLAD) Study”.</p> <p>The applicant provided a summary of the work proposed in the application.</p> <p>The applicant explained that their application will use the Twins Early Development Study (TEDS) and Genetic Links to Anxiety and Depression (GLAD) study. It aims to investigate the relationship between self-reports of anxiety and depression from the two Longitudinal Population Studies (LPS) and their linked General Practice Data for Planning and Research (GDPPR). This will indicate if both data sources are comparable. For example, if a LPS participant were to drop out, researchers could use their GDPPR medical records to complete missing data. Findings could additionally indicate how big the treatment gap is, specifically during the COVID-19 pandemic, for those who experience anxiety and/or depression but never receive any medical attention.</p> <p>The applicant noted that they have done patient and participant work with the TEDS study focus group, who are supportive of this work.</p>
5.	All	<p>Questions from Data Access Public Review Panel following llc_0034</p> <p>The Panel noted that anxiety and depression can be two different things. They questioned if the applicant would look if people have had anxiety and/or depression, and if the depression is reoccurring with a bipolar illness. The Panel further asked if the applicant would investigate if people accessed Cognitive Behavioural Therapy online in the absence of support from the National Health Services.</p> <p>The applicant advised that the questionnaire items are specifically for anxiety and for depression. They will also look at diagnostic codes for anxiety and for depression separately. However, there is a lot of symptoms overlap and comorbidity between anxiety and depression so they will also look at them together. The applicant noted that people may have looked for help elsewhere. There is information within the LPS data regarding if people have sought help elsewhere for their diagnoses.</p> <p>The Panel suggested differentiating between self-diagnosis and clinical diagnosis.</p> <p>The applicant agreed and noted that this is asked within LPS questionnaires, and a benefit of linking data. They further noted that PPIE work has highlighted which diagnosis to take as the truth, as the GP may not necessarily be correct in their diagnosis or mistakenly writing a wrong diagnostic code.</p>

	<p>The Panel questioned how a clinical diagnosis of depression relates to a self-diagnosis. They further questioned how the applicant will distinguish if a participant says they feel depressed rather than receiving a formal diagnosis. The applicant explained they review if the three sources all agree; self-report of diagnosis, the GP record of a diagnosis and the self-report full diagnostic questionnaire.</p> <p>The Panel questioned what data the applicant will use to address the different objectives (linked data, LPS data, or both). The applicant advised that they have LPS self-report data regarding participant diagnosis for depression and have questionnaires based on diagnostic criteria for both anxiety and depression. They will use linked data GP records to investigate if participants have received a diagnostic code for anxiety or depression from their GP.</p> <p>The Panel noted that in some cultures, anxiety and depression is a taboo topic and questioned if ethnicity has been taken into account. They highlighted that depression and anxiety are more prevalent in some groups of the population such as neurodivergent and disabled people, but some experience it differently or do not recognise the symptoms.</p> <p>The Panel further noted that during the pandemic, access to mental health support was limited for those with special educational needs, for neurodivergent people and that family and cultural support networks had an impact on mental health.</p> <p>The Panel additionally highlighted that during the COVID-19 pandemic, shielding and the 'bubble system' did not apply to certain parts of the disabled population. The Panel questioned if medical records of those who are looked after by a paid or unpaid carer would include information about alternative medications that they might be taking.</p> <p>The applicant advised that in future research, they would like to explore if groups are who are being picked up by different sources; if that is differences in ethnic or cultural backgrounds or neurodiversity. They would look if there were groups who meet the diagnostic criteria on the questionnaire but have no GP record. They could look at how much GP contact they had which would show medical help-seeking.</p> <p>If participants aren't receiving a diagnostic coding for anxiety and/pr depression, then there is a possibility that they are being overlooked. The applicant also clarified the point regarding shielding, as in terms of how this impacts mental health and noted they will consider this in the project.</p>
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		<p>The Panel highlighted the anxiety and depression diagnosis treatment gap regarding the data. This gap refers to those with a diagnosis and do not receive treatment. They questioned how the applicant will identify and quantify it - through the sources they mentioned, or will there be another way? The applicant said that they will try to answer this with the information they have. For example, if anxiety and/or depression is recorded from the diagnostic questionnaires but there is no GP record of codes for anxiety or depression, that would indicate that they've never received any medical attention from their GP. Therefore, they would rather refer to this as medical attention rather than treatment, as just having the code does not mean that people go on to receive treatment.</p>
	Feedback and outcome	<ul style="list-style-type: none"> • The Panel noted that the application should clarify that anxiety and depression will be investigated separately but also combined into one category. • The Panel suggested that the applicant should refine which diagnosis is taken as truth – clarify that they are looking at three sources: self-report diagnosis, GP record of a diagnosis and the self-report full diagnostic questionnaire. • The applicant will consider how shielding during the COVID-19 pandemic effected mental health.
8.	All	AOB N/A