

**UK LLC Linked Data Review Meeting – Minutes**

**09:30am – 10:30am**

**29<sup>th</sup> November 2024**

<b>UK LLC STAFF IN ATTENDANCE</b>	
<b>Name</b>	<b>Position</b>
Robin Flaig	UK LLC Co-Director (Chair)
Stela McLachlan	UK LLC Research Manager (Applications)
Jacqui Oakley	UK LLC Head of Operations
Rebecca Whitehorn	UK LLC Research and Communication Coordinator
Emma Turner	UK LLC Senior Data Manager and Research Fellow
Katharine Evans	UK LLC Senior Data Manager (Governance and Users)
Richard Thomas	UK LLC Senior Data Manager
<b>UK LLC VANGUARD MEMBERS IN ATTENDANCE</b>	
<b>Name</b>	<b>Institution</b>
Asad Masood	University of Leicester
Andrew McMillan	King's College London
Stefan Sprinckmoller	King's College London
Ellena Badrick	Born in Bradford
Mark Mumme	University of Bristol
Andrew Wong	University College London
Helena Ahlfors	NIHR BioResource

**AGENDA**

<b>Agenda Number</b>	<b>Presenter</b>	<b>Agenda Item</b>
1.	Chair	<b>Introduction</b>
2.	Chair	<b>New ToR document</b> UK LLC have updated ToR so that the quorum is five members in attendance.
3.	All	<b>Application: llc_0026</b> <b>Title: "Capturing ethnicity in UK electronic health records and longitudinal studies"</b> <b>Primary Applicant: Venexia Walker</b>
4.	All	<b>Application: llc_0034</b> <b>Title: "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".</b> <b>Primary Applicant: Dr Megan Skelton</b>
		<b>AOB</b>

## Minutes

Agenda Number	Application Feedback and Outcome
1.	<p><b>Conflicts of interests:</b></p> <p>One panel member has been involved around discussions for llc_0026, agenda item 3. They will not take part in decision making for the outcome of this application.</p>
2.	<p><b>New ToR document</b></p> <p>Following the discussion at the previous meeting the Chair updated the panel that quorum will be five, with at least two members representing the Longitudinal Population Study community and the Chair or Deputy Chair.</p> <p>New ToR is approved. Any additional comments should be sent to the Chair.</p>
3.	<p><b><u>Application title and name:</u> llc_0026 “Capturing ethnicity in UK electronic health records and longitudinal studies”</b></p> <p><b><u>Primary Applicant:</u> Venexia Walker</b></p> <p><b><u>Institution:</u> University of Bristol</b></p> <p><b><u>Summary of Key Points and Recommendations from Data Access Public Review Panel</u></b></p> <p>The Panel agreed that the new Public Involvement plan is now satisfactory. The Panel however agreed that the lay summary still needs work and have agreed to assist in amending it.</p> <p><b><u>Panel Feedback on the application</u></b></p> <p>This application was previously reviewed by this panel and the Data Access Public Review Panel. Previous feedback recommended that this application should have a more robust public involvement plan due to the focus involving sensitive data and suggested the applicant should consult someone with ethnicity expertise. It was also noted that the emphasis on COVID-19 was not prominent enough in the research proposal. This project was additionally not approved by all studies with similar feedback from this panel.</p> <p>The Panel questioned if the revised application has enough public involvement to warrant approval. The Panel agreed it has done enough and is satisfactory for approval.</p> <p>The Panel questioned whether there is potentially a reputational risk in how the results of the project might be reported, given the sensitive subject of the NHS recording of ethnicity data and the pandemic. They highlighted that work done with public representatives from one LPS indicated that, particularly around COVID-19 data, there was bad press around the disproportionate impact of COVID-19 on ethnic minorities. The public representatives expressed concern about their future engagement with studies, specifically around the use of their data and how the media will portray it. Publication review was suggested as an option to mitigate this risk.</p>

The Panel further questioned if the LPS are representative enough to answer this question properly. The Panel suggested a scoping feasibility phase.

The Panel highlighted how difficult it is to get an accurate recording of ethnicity particularly with NHS data. The panel noted that as LPS data is self-reported and dependent on how ethnicity is asked. For example, there might be a lot of 'other' responses from participants. This project should identify the difference between NHS and LPS data. It was also noted that some LPS harmonise their ethnicity variable in a variety of ways including with NHS data or across multiple waves of data collection.

The panel reviewed whether COVID-19 is integrated enough into the application. They noted that it is mentioned and satisfactory.

**Panel Feedback on data requested**

None.

**Ethics:** Under UK LLC Ethics

**NHS Digital Requirements met?** (see Annex 1):

	Y/N
<b>1. Project</b>	Y
1.1	Y
1.2	Y
1.3	Y
1.4	Y
<b>2. Data</b>	Y
2.1	Y
2.2	Y
2.3	Y
2.4	Y
2.5	Y
2.6	Y
2.7	Y
2.8	Y
2.9	Y
2.10	Y
2.11	Y
<b>3. Security</b>	Y
3.1	Y

**Decision and instructions:**

Application is approved, subject to minor changes.

	<ul style="list-style-type: none"> <li>• The project meets criteria laid out by NHS England; however, it is unclear whether LPS hold enough data across multiple ethnicities to support this research. <b>Instruction to applicant:</b> Please consider a scoping feasibility stage before beginning project.</li> <li>• The applicant should consider if there is enough ethnic diversity within the requested sample. In addition, we note that some of the ethnicity variables from LPS have been harmonised and may only be applicable for Aim 3. <b>Instruction to the applicant:</b> Liaise with UK LLC Access Team regarding harmonised ethnicity variables. UK LLC to approach every LPS requested with the question on harmonisation of ethnicity variable.</li> <li>• There is a risk that results of this study could be mis-reported causing reputational damage. Following discussion with UK LLC Management Group it is agreed that there should be a publication review of this application by UK LLC and LPS included on this application if they wish to do so. <b>Instruction to the applicant:</b> All publications for this project will be sent to the LPS for publication review with a two-week time limit for responding as well as undergoing UK LLC Publication review.</li> </ul>
4.	<p><b><u>Application title and name:</u></b> llc_0034 “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”.</p> <p><b><u>Primary Applicant:</u></b> Dr Megan Skelton</p> <p><b><u>Institution:</u></b> King’s College London</p> <p><b><u>Summary of Key Points and Recommendations from Data Access Public Review Panel</u></b></p> <p>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 should consider including the impact of shielding during COVID-19 on anxiety and depression.</p> <p><b><u>Panel feedback on the application</u></b></p> <p>None.</p> <p><b><u>Panel feedback on data requested</u></b></p> <p>The applicant is only requesting GP data linkage. The Panel highlighted that this is a subset GP record. The Panel further noted that there are other relevant mental health datasets that the applicant can request, depending on if they are also interested in primary care datasets. The UK LLC Team confirmed that the applicant is only interested in GP data.</p> <p>The Panel noted that part of the project is about comparing anxiety and depression before and after COVID-19. They questioned if there is any GP data predating COVID-19 and if the comparison would be possible. The UK LLC Team confirmed the GP record goes back long before COVID-19, but it is limited to certain codes.</p>

**Ethics:** Under UK LLC Ethics

**NHS Digital Requirements met? (see Annex 1):**

	Y/N
1. Project	Y
1.1	Y
1.2	Y
1.3	Y
1.4	Y
2. Data	Y
2.1	Y
2.2	Y
2.3	Y
2.4	Y
2.5	Y
2.6	Y
2.7	Y
2.8	Y
2.9	Y
2.10	Y
2.11	Y
3. Security	Y
3.1	Y

**Decision and instructions:**

Application is approved, subject to minor changes:

- **Instruction to the applicant:** We note that GP data is a subset of the full Primary care record and is limited to specific codes. We also note that Shielding status is not recorded in NHS England datasets and to address the impact of shielding on anxiety and depression during the pandemic self-reported shielding status may be the only option.

**AOB**

\*Categories of decisions explained

<u>Panel Decision</u>	<u>Description</u>
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<b>Approved</b>	A joint decision approved by panel members. Application approved with no amendments required. Researcher receives an approval letter from the Chair. Signing of contracts is the next stage.
<b>Approved subject to...</b>	A joint decision approved by panel members. Application approval is pending, subject to the researcher addressing amendments requested by the panel. The application will then require final approval from panel Chair. Final approvals can be completed via email.
<b>Declined</b>	

**Annex 1. Review Checklist based on NHS Digital Requirements**

Review Checklist for UK LLC Linked Data Review Panel				
UK LLC reference number:				
Title:				
Date submitted:				
Date approved:				
Overall comments:				
Based on Linked Data Access Committee Terms of Reference with NHS Digital				
1. Project				
Requirements	Explanation	Reviewed	Approved	Comments
1.1 Is there clear public benefit?	Are there clearly articulated scientific and wider societal impacts of the proposed research?			
1.2 Is there clear NHS benefit?	Where linked NHS records are to be used, are there clearly articulated benefits to healthcare provision, adult social care or the promotion of health?			
1.3 Is there a clear plan for dissemination of the results?	Is there a commitment to publish results into the free-to-access public domain? Is there a clear plan for rapid dissemination of COVID-19 insights to the relevant stakeholders?			
1.4 Is there a clear plan for realising the benefits to the NHS?	Where linked NHS records are to be used, has the applicant provided a realistic and comprehensive plan for how their findings will be disseminated to relevant stakeholders in order to achieve the stated benefits?			

2. Data				
Requirements	Explanation	Reviewed	Approved	Comments
2.1 Is the data request proportionate?	Is the data request minimised sufficiently so that all requested data is justified by the stated purpose?			

2. Data				
Requirements	Explanation	Reviewed	Approved	Comments
2.2 Is there clear justification for using Special Category (sensitive) data?	<ol style="list-style-type: none"> <li>1. Personal data revealing racial or ethnic origin;</li> <li>2. Personal data revealing political opinions;</li> <li>3. Personal data revealing religious or philosophical beliefs;</li> <li>4. Personal data revealing trade union membership;</li> <li>5. Genetic data;</li> <li>6. Biometric data (where used for identification purposes);</li> <li>7. Data concerning health;</li> <li>8. Data concerning a person's sex life; and</li> <li>9. Data concerning a person's sexual orientation.</li> </ol>			
2.3 Do any of the data of 'elevated sensitivity', require particular review?	Mental health, sexual health, assisted pregnancy, termination of pregnancy, abuse.			
2.4 Is the request for NHS data justified?	Are a NHS data necessary to realise the intended benefits of the application?			
2.5 Is intended purpose only achievable with NHS data?	Has any request to use NHS data demonstrated how the intended purpose is only possible using NHS data linked to non-NHS data within the UK LLC (i.e. that the request could not be fulfilled by the NHS directly)?			
2.6 Where applicant is a student/PhD student, has their supervisor demonstrated how their use of the data will be adequately supervised?	Have they demonstrated the mechanism of supervision? Are there learning opportunities for the student? Is there practical help offered to student?			



<b>2. Data</b>				
Requirements	Explanation	Reviewed	Approved	Comments
2.7 Does the application generate any additional or unacceptable risks of disclosure of participant identity?	i.e. project is not asking for the data in such a manner that there is a disclosure risk in the data itself (although this might be visible only in the outputs)?			
2.8 Is there potential to bring the UK LLC or the owners of the data deposited in the UK LLC TRE into disrepute?				
2.9 Is there a clear legal basis for this use of the UK LLC data?				
2.10 Is there a clear legal basis for any processing of linked NHS data?				
2.11 Is there commitment from the applicant not to use data for profit-making purposes?				

<b>3. Security</b>				
Requirements	Explanation	Reviewed	Approved	Comments
3.1 Is there any evidence of the applicant's host institution's Information Security certification?	Is there organisational security assurance for applicants requesting linked NHS data? Either: 1. ISO 27001 certification or 2. NHS Digital DSPT reference number or 3. System Level Security Policy (SLSP) or 4. A declaration in contract by the host institution that their Information Security certification is equivalent to NHS Digital DSPT			