

UK LLC Linked Data Review Meeting – Minutes

09:30am – 10:30am

31<sup>st</sup> January 2025

UK LLC STAFF IN ATTENDANCE	
<u>Name</u>	<u>Position</u>
Andy Boyd	UK LLC Co-Director (Chair)
Abigail Hill	Research Manager (Data)
Rachel Calkin	Research Manager (Data)
Rebecca Whitehorn	UK LLC Research and Communication Coordinator
Richard Thomas	UK LLC Senior Data Manager
Stela McLachlan	UK LLC Research Manager
<u>UK LLC VANGUARD MEMBERS IN ATTENDANCE</u>	
<u>Name</u>	<u>Institution</u>
Andrew Wong	University College London
Archie Campbell	University of Edinburgh
Celestine Lockhart	King's College London
David Buchanan	University of Edinburgh
Ellena Badrick	Born in Bradford
Gerome Breen	King's College London
Gulsah Akdag	King's College London
Helen Fisher	King's College London
Hiten D. Mistry	University of Leicester
Mark Adams	University of Edinburgh
Mark Mumme	University of Bristol
Megan Skelton	King's College London
Ray Leal	King's College London
Stefan Sprinckmoller	King's College London

**AGENDA**

Agenda Number	Presenter	Agenda Item
1.	Chair	Introduction
2.	All	<p><b>Application:</b> llc_0035</p> <p><b>Title:</b> "External validation of SNOMED-based mental health phenotypes, and their patterns of clinical presentation in the context of the COVID-19 pandemic."</p> <p><b>Primary Applicant:</b> Ann John</p>
		AOB

**Minutes**

Agenda Number	Application Feedback and Outcome
1.	<p><b>Introduction/Conflicts of interests</b></p> <p>Chair introduced one application for review during this meeting: llc_0035</p> <p>No conflicts of interest were declared.</p>
2.	<p><b><u>Application title and name:</u> llc_0035 “External validation of SNOMED-based mental health phenotypes, and their patterns of clinical presentation in the context of the COVID-19 pandemic.”</b></p> <p><b><u>Primary Applicant:</u> Ann John</b></p> <p><b><u>Institution:</u> Swansea University</b></p> <p><b><u>Summary of Key Points and Recommendations from Data Access Public Review:</u></b></p> <p>That the applicant should be advised to:</p> <ol style="list-style-type: none"> <li>1. Specify that the research can inform future pandemics as an impact for the public good</li> <li>2. Add information to the public involvement section regarding where the public have been involved in the design of the project and how they will be involved in communications and dissemination of results</li> <li>3. Include psychosis or generalise more about the diagnoses that will be covered by this research in the lay summary</li> <li>4. Articulate in the application if regional differences will also be considered in the analyses plan to identify potential regional inequalities.</li> </ol> <p><b><u>Panel Feedback on the application</u></b></p> <p>The panel agreed that there is clear public benefit, and the use of NHS England data is appropriate.</p> <p>The panel raised concerns regarding potential data quality issues resulting from changes in coding practice and code systems over time (e.g., migration to SNOMED codes) as cross validating data can result in biased data. It was identified that this research group is an experienced user of electronic health records so is likely aware of this, but it was agreed to pass this observation to the research team given the nature of the proposal.</p> <p>The panel agreed that there is acceptable and standard risk of disclosure in this project.</p> <p>The panel suggested that the researcher should define specific times periods before; during and after the pandemic. They should consider if there is enough follow-up time after the pandemic.</p> <p><b><u>Panel Feedback on data requested</u></b></p>

The panel agreed that the data requested is proportionate for the project, however time points before, during and after the pandemic should be specified.

The panel noted that the application aims to look at just SNOMED codes from primary care. The panel queried why ICD coding, HES and mental health secondary care datasets are not included.

It was observed that the data request form differs from data requested in the application form. Born in Bradford, Twins UK and GLAD are listed in the data request for but not the application form. This is to be clarified by the researcher and the application form updated appropriately.

The panel highlighted that an old version of the data request form was used and suggested the researcher uses the new version, as TEDS data are now available, and the applicants should consider using this additional data.

The panel discussed the limitations of the English GP dataset held by UK LLC and whether it is inclusive of all mental health codes. UK LLC data team advised that it is not inclusive of all mental health codes and that they will provide an inclusion code list for the GDPR data held in UK LLC to the applicants. The panel advised that any reporting of the research would have to make data limitations very clear to readers.

**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:**

The application is **approved, subject to minor changes:**

- Specify future pandemics as an impact to public good.  
**Instruction to the applicant:** wider identified benefits need to be described.
- Dissemination of results to public.  
**Instruction to the applicant:** Add information to public involvement section regarding where the public have been involved in the design of the project and how they will be involved in communications and dissemination of results
- Consider including psychosis or generalise more about the diagnoses that will be covered by this research in the lay summary.  
**Instruction to the applicant:** Please make considerations relating to this guidance and any appropriate changes to the lay summary and application.
- Consider the value of testing for regional differences and potential inequalities  
**Instruction to the applicant:** Please make considerations relating to this guidance and add to the protocol section based on this.
- There is a concern that cross validation can result in bias.  
**Instruction to the applicant:** Consider the risks of using older EHR data for the comparison "ground truth" aspect of the study as multiple reasons may likely impact on alignment of coded EHR diagnosis and participant reported outcomes (e.g. code mappings, QOF etc.).
- In the second part of this project, there aren't specific time points stated for comparing mental health conditions.  
**Instruction to the researcher:** Please specify time periods before, during and after the pandemic.
- The end of the pandemic is ambiguous.  
**Instruction to the researcher:** Please consider if there is enough follow-up time prior to the pandemic to carry out analyses.
- An old version of the data request form was used, which does not include the TEDS dataset.  
**Instruction to the researcher:** Please migrate the data requests to the new data request form and ensure this matches to what is stated on the application form. Consider including the TEDS dataset.
- Request is to get all GP data.  
**Instruction to the researcher:** Please restrict your request to a providedodelist. Amend application list appropriately based on the GDPDR code inclusion list.
- Clarity on reporting of data weaknesses.  
**Instruction to the researcher:** Please update the protocol to make clear that you will fully discuss data weaknesses: especially, but not exclusively, those relating to coding change over time and the limitations of GDPDR.

	<p>Additionally, UK LLC needs to make applicants aware that:</p> <ul style="list-style-type: none"> <li>-GLAD did similar study and that they will be depositing derived data from their study in the next data update to UK LLC.</li> <li>-MHSDS is a mixture of ICD codes and SNOMED.</li> </ul>
	<p><b>AOB</b> <b>N/A</b></p>

**\*Categories of decisions explained**

<b><u>Panel Decision</u></b>	<b><u>Description</u></b>
<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			