

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

**09:30am – 10:30am**

**23<sup>rd</sup> August 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
Jacqui Oakley	UK LLC Head of Operations
Rebecca Whitehorn	UK LLC Research and Communication Coordinator
Emma Turner	UK LLC Senior Data Manager
Lidis Garbovan	UK LLC Research Fellow (Citizen Panel Lead)
<b>UK LLC VANGUARD MEMBERS IN ATTENDANCE</b>	
<b>Name</b>	<b>Institution</b>
Asad Masood	University of Leicester
Archie Campbell	University of Edinburgh
Celestine Lockhart	King's College London
Ellena Badrick	Bradford Institute for Health Research
Mark Mumme	University of Bristol

**AGENDA**

<b>Agenda Number</b>	<b>Presenter</b>	<b>Agenda Item</b>
1.	Chair	<b>Introduction</b>
2.	Chair	<b>New ToR document</b>
3.	All	<b><u>Application:</u> llc_0032</b> <b><u>Title:</u> “Predictors of suicide ideation, suicide attempts, and self-harm among adolescents in the UK prior to and during/after COVID-19”</b> <b><u>Primary Applicant:</u> Ann John</b>
4.	All	<b><u>Application:</u> llc_0033</b> <b><u>Title:</u> “Community mental health treatment and subsequent outcomes in children and young people: what works, for whom, and why?”</b> <b><u>Primary Applicant:</u> Sharon Nuefeld</b>
		<b>AOB</b>

## Minutes

Agenda Number	Application Feedback and Outcome
1.	<b>Conflicts of interests:</b>
2.	<p><b>New ToR document</b>  <u>Definition of a quorum for the group</u>            The Panel discussed LPS representation in meetings, and how many non-UK LLC staff should be part of the Panel. The Panel suggested that quorum membership should include someone from each LPS involved in application(s) being reviewed.            The Panel noted that it would be useful for studies to attend if there is a specific area of research, they have in depth experience in.</p>
3.	<p><b><u>Application title and name:</u> llc_0032 “Predictors of suicide ideation, suicide attempts, and self-harm among adolescents in the UK prior to and during/after COVID-19”</b>  <b><u>Primary Applicant:</u> Professor Ann John</b>  <b><u>Institution:</u> Swansea University</b>  <b><u>Summary of Key Points and Recommendations from Data Access Public Review</u></b></p> <p>Under the dissemination section, the applicant should add more information in the application of how the project will inform intervention development within the NHS. This also feeds into section 1.2 (clear NHS benefit) in this ToR.</p> <p><b><u>Panel Feedback on the application</u></b>            The Panel mentioned that one hypothesis talks about the Millennium Cohort Study (MCS) and suggested the applicant should reframe this to talk about age, as they are looking at the age pattern of this cohort being different.             The Panel highlighted the results section where the researcher is asked if any of the results might disadvantage anyone. The applicant states they will talk sensitively around suicide and use non-stigmatising language, however there are sub-group analysis they mention within the application which they don’t mention in this section. They refer to data and ethnicity being sensitive but don’t speak about the whole research proposal being sensitive. The applicant should reframe this section.             The Panel requested clarification around the PPIE in this project; is it under the umbrella of DATAMIND and how much of the PPIE is about this project specifically. The Data Access Public Review Panel co-chair explained that the researcher engaged with public groups about this project specifically. This should be added to the application.</p> <p><b><u>Panel Feedback on data requested</u></b>            The Panel highlighted that the linked NHS data requested are not sufficient to answer the research question. One of the key outcomes is people being admitted for self-harm, however there is no request for HES A&amp;E data or HES admitted patient datasets, only outpatient data.</p>

The Panel further highlighted ethnicity in the project, as the application mentioned looking at LPS who have the right kinds of data at the right time points. However, the LPS requested might not have enough ethnic diversity and power to answer questions around ethnicity and what this could mean for their application.

The Panel highlighted linked data requested, in terms of data recorded; where it is recorded and what they could be missing information. For example, the applicant could state they want to look at 'XYZ' but this is poorly recorded in GP data which means they might under record. Similarly with A&E data, they will get the extremes of people rather than a range of people such as missing those with suicide ideation who obtain mental health support which doesn't get fed back into NHS or GP records. This might impact potential outcomes. The applicant should understand exactly what data is held within UK LLC and what is possible.

The Panel suggested a first point to assess if it's feasible to do a subgroup analysis.

The Panel highlighted that GP data for COVID-19 limited the codes that could be shared with the applicant and questioned if any codes relevant to this project would be included in that list. This will be taken to UK LLC Data Team.

The Panel questioned if the applicant has selected a mental health services dataset and then confirmed this had been selected.

**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.

- The project meets criteria laid out by NHS England; however, more consideration of the handling of sensitive data was required in the application.  
**Instruction to applicant:** Please refer to mental health, self-harm and suicide as well as ethnicity as sensitive variables (Q3.9, section c).
- The applicant should reframe the MCS as an age-group issue rather than a study specific issue.  
**Instruction to applicant:** Please change this section to refer to the importance of this age group issue rather than the MCS specifically. (Q3.9, section c).
- The Panel recommended that the applicant carry-out a feasibility study before beginning the full study so they can ascertain if there is sufficient power in the ethnic sub-groups they are interested in.  
**Instruction to applicant:** please add feasibility study as a first step in your methods (Q3.9).
- The Panel recommended that the applicant should provide further detail of any public involvement that they have done specific focus groups for this project.  
**Instruction to applicant:** Please insert information about specific PPIE work related to this project (Q3.11).
- The project should be clearer on what could be missing with NHS, GP and study data and how this might impact their analysis.  
**Instruction to applicant:** Please add that in the section about missing data (Q3.9).
- Under the dissemination section, the applicant should add more information in the application of how the project will inform intervention development within the NHS.  
**Instruction to applicant:** Please describe any potential intervention development (Q9.1).
- The Panel recommends adding HES A&E data or HES admitted patient dataset to their data request, to identify self-harm cases.  
**Instruction to applicant:** Please add missing datasets to your data request form.
- The Panel highlighted that GP data for COVID-19 may not have appropriate codes necessary for this research.  
**No instruction.**

4.	<p><b><u>Application title and name:</u></b> llc_0033 “Community mental health treatment and subsequent outcomes in children and young people: what works, for whom, and why?”</p> <p><b><u>Primary Applicant:</u></b> Dr Sharon Neufeld</p> <p><b><u>Institution:</u></b> University of Cambridge</p> <p><b><u>Summary of Key Points and Recommendations from Data Access Public Review Panel</u></b></p> <p>The Panel recommended further clarification of the reference in application to annual meetings in public involvement plan – more detail was requested around the meetings.</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 Panel questioned how well community intervention is recorded in GP data. UK LLC Panel confirmed that the project requests Community Health Services dataset and the IAPT data however it is unknown how well recorded data is within these.</p> <p>The Panel suggested that the applicant should first look at the quality of datasets before beginning the full project work. The application states that the project will investigate to assess the sample size of the data available for service use by relevant moderators and whether this is sufficient for subgroup analysis. The panel suggested that the applicant could further feedback around completeness or validity checks of those datasets.</p> <p>The Panel noted that in addition to sample size, there is also a data quality issue that the applicant hasn’t addressed. For example, is there data on what they are really interested in recorded well, rather than is there enough to do analysis.</p> <p>The Panel linked to the NHS data quality dashboard and suggested providing these to the researcher: <a href="https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/mental-health-data-hub/data-quality/nhs-talking-therapies-dq-dashboard">https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/mental-health-data-hub/data-quality/nhs-talking-therapies-dq-dashboard</a>  <a href="https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/community-services-data-set/data-quality-dashboard">https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/community-services-data-set/data-quality-dashboard</a></p> <p>The Panel suggested collecting feedback from researchers on the quality of data. If applicants are doing a feasibility study before their main project, it was considered of value for UK LLC to actively contact them for feedback to add to UK LLC Guidebook. The Panel additionally noted that it would be helpful for the applicants to write a brief report on indicators of quality.</p> <p>The Panel questioned if the applicant has selected all relevant studies, specifically around the request for NextSteps. UK LLC to suggest this to the applicant.</p> <p>UK LLC will investigate the best way to get Applicants feedback from these projects that investigate the completeness of linked data.</p> <p><b><u>Ethics:</u></b> Under UK LLC Ethics</p> <p><b><u>NHS Digital Requirements met?</u></b> (see Annex 1):</p> <table border="1" data-bbox="603 1966 1123 2033"> <thead> <tr> <th></th> <th>Y/N</th> </tr> </thead> <tbody> <tr> <td>1. Project</td> <td>Y</td> </tr> </tbody> </table>		Y/N	1. Project	Y
	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	
	<b>Decision and instructions:</b> Application is approved, subject to minor changes.			
	<ul style="list-style-type: none"> <li>UK LLC Data Team to check if NextSteps is appropriate given the age range the applicant has selected. <b>Instruction to applicant:</b> Please consider adding NextSteps to the data request.</li> <li><b>Instruction to applicant:</b> The applicant should add the impact of linked data missingness (data quality issue that should be addressed, is data well recorded) and inclusivity of outcomes to the feasibility analysis.</li> <li><b>Instruction to applicant:</b> Clarify references in application to annual meetings in public involvement plan – specify who they are meeting with.</li> </ul>			
	AOB			

**\*Categories of decisions explained**

<u>Panel Decision</u>	<u>Description</u>
<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				
<b>1. Project</b>				
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?			

<b>2. Data</b>				
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			