

UK LLC Linked Data Review Meeting - Minutes

Friday 26 January 2024

UK LLC STAFF IN ATTENDANCE	
Name	Position
Andrew Boyd	UK LLC Co-Director
Robin Flaig (Chair)	UK LLC Co-Director
Jacqui Oakley	UK LLC Head of Operations
Stela McLachlan	UK LLC Research Manager
Emma Turner	UK LLC Senior Data Manager and Research Fellow
Katharine Evans	UK LLC Governance and Policy Manager
Rebecca Whitehorn	UK LLC Research and Communication Coordinator
UK LLC VANGUARD MEMBERS IN ATTENDANCE	
Name	Institution
Andrew McMillan	TEDS
Andrew Wong	MRC Unit for Lifelong Health and Ageing at UCL: 1946 NSHD and SABRE
Archie Campbell	Generation Scotland
Celestine Lockhart	TEDS
Ellena Badrick	Born in Bradford
Andy Heard	AIRWAVE
Genevieve Lachance	Twins UK
Laura Cocking	NIHR Bioresource
Mark Mumme	ALSPAC
Thomas McGregor	TEDS

Actions

[#1] Section 3.13 in application form to be amended and rephrased for research beyond COVID-19.

Agenda Number	Application Feedback and Outcome
1.	Declaration of interests: N/A
2.	Review of previous minutes and actions: Panel chair advised that UK LLC Data Access Public Review panel will now review and provide feedback on public good relating to project applications.

3.

Application: llc_0030

Title: "Investigating the association of long-term air pollution exposure with risk and severity of SARS-CoV-2 infection"

Primary Applicant: Annalan Navaratnam

Summary of Key Points and Recommendations from Data Access Public Review Panel

Data Access Public Review Panel raised concerns over lack of Public and Patient Involvement and Engagement (PPIE) plans and dissemination of results. Concerns were raised over the possibility of media producing negative stories for patients and public living in high pollution areas. The panel recommended PPIE at the dissemination stage as the results of the study could change health care for high-risk groups living in areas of high pollution or location. The applicant clarified that they would keep reports to population level but recognise there needs to be PPIE at that stage.

The Panel also flagged a lack of plans to disseminate the results directly to the public and the Panel expected to see dissemination to patient groups or charities that support patients at high-risk of infection.

Feedback on the application:

The Panel noted that this is significant application using geo-spatially linked data, and we're pleased to see this come to review.

The Panel noted the clear NHS and public benefit of the application. However, section 3.11 of application form stated 'it doesn't impact people' which was used to justify not doing PPIE.

The Panel recommended a clear public involvement plan before approving.

The Panel agreed that there was a plan for dissemination of results, however it is not broad enough and the panel suggested the researcher should work with the public on this.

The Panel highlighted that UKRI and government have launched the Clean Air Program which is a large strategic investment to understand the impacts of air pollution on health outcomes. They suggested that that this presents a real opportunity to work with them to promote findings and public dissemination, to maximise on the potential impact of this important work.

Feedback on requested data:

The Panel noted the request for 'NAME THE DATA_SET' and agreed that this was a reasonable request.

The Panel noted that the applicant requested medicines dispensed in primary care to determine people with immunosuppressant medications. Medicines dispensed in primary care are currently restricted in purpose (for safety and efficacy only) and therefore this request cannot currently be fulfilled. The Panel suggested that the applicant work with UK LLC to explore other sources for this data such as shared GP data.

The Panel noted that the following data was not requested, which could be helpful to address the research question, and queried whether this was an oversight:

Centre for Longitudinal Studies (CLS) data – available geospatially linked

One of the EXCEED COVID-19 follow up questionnaires

The Panel highlighted that ALSPAC is listed as postcode-linked and flagged the fact that these data are available geocoded to full address.

The Panel highlighted an issue relating to the use of special category sensitive data. The personal data revealing racial or ethnic origin; the application requested SABRE data; however, these data are not linked to NHS records. There was a lack of justification as to how ethnicity will inform results. The panel suggested that there should be more justification and explanation regarding the use of ethnicity in the project.

Panel member highlighted the applicant requests some mental health information however within the context this is a reasonable request.

NHS Requirements Met?

Justification for NHS data? Yes

Panel agreed that the intended purpose is only achievable with NHS data.

Panel agreed that the application does not generate any additional unacceptable risks of disclosure of patient identity.

Panel agreed that there is no potential to bring UK LLC or owners of data deposited into UK LLC into disrepute.

Panel agreed there is a clear legal basis for use of data in UK LLC.

Panel agreed that there is a clear legal basis for any processing of linked NHS data.

Panel agreed that there is a commitment from the applicant not to use data for profit making purposes.

Panel agreed that there is evidence that the applicants host institution has an information security certification.

The Panel flagged public involvement work being carried out by the Bord in Bradford study which appears to be directly relevant to the proposed work and could benefit the applicant's work and which could address the PPIE recommendations made by the Public Group.

The Panel suggested the UK LLC team provide clarification text (around the anonymity of address data) on the UK LLC website.

Ethics:

Approved under UK LLC Ethics as COVID-19 relevant project.

NHS Digital Requirements met? (see Annex 1):

Yes.

***Decision and instructions:**

Approved subject to the following amendments. The revisions should be reviewed by the Panel Chair.

- The lay summary should be revised as per recommendations of the UK LLC body reviewing the same application; the DAC agreed the claims in the summary were quite strong and the ability to set national policies overreaching.
- The study does not have a public engagement plan. We advise that engagement is sought; if not, the study should explain why. **Born in Bradford LPS offered to help, and they have already done PPIE work around this topic – UK LLC to facilitate the contact.**

- Explain the use of ethnicity. We do understand this has to do with an impact of the disease on people from different ethnic backgrounds, but it needs to be clearer in the application.
- Update dissemination plan to include disseminating to the public.

4.	<p><u>Application:</u> llc_0031 <u>Title:</u> “Quality checks, curation and methodological enhancement of the UK LLC Partner Studies using linked data” <u>Primary Applicant:</u> Andrew McMillan <u>Input from Data Access Public Review Panel:</u> The panel did not express any concerns over this project.</p> <p><u>Discussion:</u> The Panel Chair noted that this application came from the LPS TEDS to access TEDS-linked data. Applications from other LPS to access linked-data (through study-zones) have been approved. These applications were approved in May 2022. It was agreed that future applications from LPS to access their own data would be brought to the Data Access Committee for information.</p> <p>The Panel did not raise any concerns over this project.</p> <p><u>Ethics:</u> Approved under UK LLC Ethics as COVID-19 relevant project.</p> <p><u>NHS Digital Requirements met?</u> (see Annex 1): Yes.</p> <p><u>*Decision and instructions:</u></p> <ul style="list-style-type: none"> • Application approved.
5.	<p><u>Application:</u> llc_0028 - Mini PhD Project <u>Title:</u> “Identifying clusters of COVID-19 and Long Covid symptoms” <u>Primary Applicant:</u> Charlotte James <u>Input from Data Access Public Review Panel:</u></p> <p>No issues were raised by the Panel regarding this project proposal.</p> <p><u>Panel feedback on the application:</u> This was a minor amendment to previously approved project to include a PhD student applicant. The student will carry-out a sub-aim which falls under the objectives of the approved project plans.</p> <p><u>Ethics:</u> Approved under UK LLC Ethics as COVID-19 relevant project.</p> <p><u>NHS Digital Requirements met?</u> (see Annex 1): Yes.</p> <p><u>*Decision and instructions:</u> Approved</p> <ul style="list-style-type: none"> • Amendment approved.
6.	AOB

	Panel member suggested a working group to develop thinking around PPIE expectations for applicants. This will be taken to UK LLC Public Involvement team to consider.
	<p><u>Actions</u> [#1] Section 3.13 in application form to be amended and rephrased for research beyond COVID-19.</p>

***Categories of decisions explained**

<u>Panel Decision</u>	<u>Description</u>
Approved	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.
Approved subject to...	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.
Declined	A joint decision determined by panel members. Application will not proceed any further through this process. The researcher receives an official letter from the Chair explaining the outcome of the review.

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?			
2.2 Is there clear justification for using	1. Personal data revealing racial or ethnic origin;			

2. Data				
Requirements	Explanation	Reviewed	Approved	Comments
Special Category (sensitive) data?	2. Personal data revealing political opinions; 3. Personal data revealing religious or philosophical beliefs; 4. Personal data revealing trade union membership; 5. Genetic data; 6. Biometric data (where used for identification purposes); 7. Data concerning health; 8. Data concerning a person's sex life; and 9. Data concerning a person's sexual orientation.			
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?			
2.7 Does the application generate any additional or	i.e. project is not asking for the data in such a manner that there is a disclosure			

2. Data				
Requirements	Explanation	Reviewed	Approved	Comments
unacceptable risks of disclosure of participant identity?	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?				

3. Security				
Requirements	Explanation	Reviewed	Approved	Comments
3.1 Is there any evidence of the applicant's host institution's Information Security certification?	<p>Is there organisational security assurance for applicants requesting linked NHS data?</p> <p>Either:</p> <ol style="list-style-type: none"> 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 			