

UK LLC Linked Data Review Meeting – Minutes

09:30am – 10:00am

28th March 2025

UK LLC STAFF IN ATTENDANCE	
<u>Name</u>	<u>Position</u>
Robin Flaig	UK LLC Co-Director (Chair)
Emma Turner	Research Fellow
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
Lidis Garbovan	UK LLC Research Fellow
UK LLC VANGUARD MEMBERS IN ATTENDANCE	
<u>Name</u>	<u>Institution</u>
Andrew Wong	University College London
Archie Campbell	University of Edinburgh
Ellena Badrick	Born in Bradford
Gerome Breen	King's College London
Helena Ahlfors	NIHR Bioresource
Helen Fisher	King's College London
Hiten D. Mistry	University of Leicester
Laura Meldrum	King's College London
Mark Mumme	University of Bristol
Megan Skelton	King's College London
Ray Leal	King's College London

AGENDA

Agenda Number	Presenter	Agenda Item
1.	Chair	Introduction
2.	All	<p>Application: llc_0037</p> <p>Title: “The role of sociodemographic factors in attendance at cancer and cardiovascular disease screening and in emergency cancer diagnosis before, during and after the COVID-19 pandemic in people with severe or complex mental illness.”</p> <p>Primary Applicant: Naomi Lauanders</p>
		AOB

Minutes

Agenda Number	Application Feedback and Outcome
1.	<p>Introduction/Conflicts of interests</p> <p>Chair introduced one application for review during this meeting: llc_0037</p> <p>No conflicts of interest were declared.</p>
2.	<p><u>Application title and name:</u> llc_0037 “The role of sociodemographic factors in attendance at cancer and cardiovascular disease screening and in emergency cancer diagnosis before, during and after the COVID-19 pandemic in people with severe or complex mental illness.”</p> <p><u>Primary Applicant:</u> Naomi Launders</p> <p><u>Institution:</u> University College London</p> <p><u>Summary of Key Points and Recommendations from Data Access Public Review:</u></p> <ul style="list-style-type: none"> • Please show that the PPIE group is used in all states of the research, including design through to dissemination and communications of findings • The use of PPIE groups could be broadened nationally such as by recruiting through the People in Research website if NIRH funded. • Clarify in the lay summary that the population is only those with severe mental illness. For example, that the comparisons are not to the general population which is implied in the first paragraph of the lay summary • Clarify if the focus is schizophrenia or if this is just used as an example • Clarify if the focus is adults or does it include people of all ages • It mentions data on education, housing, finances but no mention of employment data. Please clarify. • Is the proposed research using a Quality and Outcome Framework? • In addition to saying people with severe mental illness are less likely to attend for screening health checks, it should also say people with severe mental illness have a considerably reduced life expectancy. For example, people with schizophrenia have an average life expectancy of 58 years compared to about 80 years for the general population. • Clarify how you will deal with potential predictors such as living alone, lower income and lower level of education • It would be helpful to understand further why the focus is on the period of Covid-19 given the restrictions around that period on everyone it would have had a detrimental effect on people presenting to services. • Maybe missing a sentence to clearly outline public benefit <p><u>Panel Feedback on the application</u></p> <p>The panel agreed there is a clearly articulated scientific and wider societal impact.</p> <p>The panel raised concerns over the description of mild, moderate and severe mental health, rather than just the mention of severe mental health illness (SMI) within this project. The</p>

panel suggested that the researcher should stratify mild, moderate, and severe mental health and note if there are any differences.

The panel noted that depression is included in the project's definition of SMI and that the GP codes listed have medications for lithium's and anti-psychotics but not anti-depressants. The panel suggested that the researcher should clarify if the project aims to look at severe depression or psychotic depression and then state the relevant medication required.

The panel suggested a full severe mental illness category and a less severe category should be implemented in the project.

The panel queried screening time periods, as the project proposes to look at three different cancers that all have different screening windows (e.g., annual bases vs screening windows of three years). They questioned if there is enough follow up time to look at pre-COVID and COVID.

The panel highlighted a potential risk of using data held within UK LLC as there might be small numbers of data and follow-up time, rather than just using GP data.

The panel highlighted that the researcher is aware of small data numbers, however the advantage of applying to UK LLC is the access to self-report data from Longitudinal Population Studies (LPS) to broaden the category of individuals with mental health conditions.

The panel noted that the objective of the application is mental health impairment rather than psychosis.

The panel questioned the cardiovascular focus in application as there isn't as much explanation or justification in comparison to cancer screening in the application. The panel agreed that this needs more explanation, specifically around cardiovascular disease and prescribed medications for antipsychotics.

The panel queried the COVID-19 factor in the confounders section as they were a unique event, and questioned if these would reflect general healthcare use more widely. The panel additionally noted work that has been done to look at the likelihood of those with mental health conditions receiving the COVID-19 vaccine. They suggested that the applicant should consider those who received a complete programme of vaccinations, including boosters.

The panel questioned if an individual's capacity would be taken into account. If an individual did not have full capacity, then they are not making a complete decision. Although it might be difficult to distinguish what individual has capacity, the applicant should take this into account.

The panel suggested that the applicant should clearly define what specific groups will be included and what the outcomes are. For example, simplifying the project scope to only look at cancer screenings or additionally clearly define and explain the cardiovascular screening aspect.

The panel suggested to include geographical location as a confounder as mental health provision, cancer and cardiovascular screening differs around the UK.

The panel agreed the is a clear NHS benefit subject to defining definitions of SMI and clearly explaining project aims (expanding the cardiovascular aspect).

Panel Feedback on data requested

The panel agreed that the data request is proportionate and minimised sufficiently.

The panel agreed that there is justification for using special category of sensitive data, subject to the applicant clearly defining their project scope.

The panel agreed that the applicant should clarify the benefits of using linked data within UK LLC, and clarify self-report data and the role that plays within this project.

The panel noted that the researcher has included depression codes as a way of excluding them from their analyses as sometimes, early Alzheimer’s is coded as depression. The panel recommended that this should be clearly stated in the application.

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:

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

- Stratify mild, moderate and severe mental health and clearly define SMI.
Instruction to the applicant: Please expand the scope of the research to look at the differences between mild, moderate and severe mental illness in cancer screening. Please consider how prescribed medications might impact these definitions, e.g. antidepressant medications.
- Add justification to the cardiovascular disease focus of project and prescribed medications for antipsychotics.
Instruction to the applicant: Please expand and clarify the cardiovascular aspect of the project and add more detail regarding the cardiovascular screening aspect or remove it entirely. Additionally, consider that people being cared for in mental health trusts have cholesterol screening as part of their care. Please clarify the use of antipsychotics.
- Consider possible confounders if an individual has been admitted to and cared for in hospital for severe mental illness.
Instruction to the applicant: Please clarify what confounders there may be based on if someone has been looked after in hospital for severe mental illness. Please consider how capacity might interact with treatments.
- Consider the definition of Severe Mental Illness.
Instruction to the applicant: Please clearly define Severe Mental Illness.
- Consider various time periods of cancer screenings.
Instruction to the researcher: Please provide evidence that time periods for various cancer screenings have been accounted for, and what implications this may have for follow-up in the three different time periods.
- Consider small data numbers within LPS and note benefits of using UK LLC.
Instruction to the researcher: Please clarify the use of UK LLC and explain the benefit of using this linked data resource.
- Consider confounders for individual not attending cancer screenings.
Instruction to the researcher: Please consider the implications of significant impairment and what that might mean as a confounder for;

 - individuals themselves not attending screenings or;
 - for family having the individual turn up for screenings or;
 - mental health trusts pushing vaccinations
- Geographical location of individuals may impact healthcare provision, or access to services.
Instruction to the researcher: Please consider a geographical confounder in the project.
- The justification for including requests for depression codes is not explained.
Instruction to the researcher: Please clearly state that depression codes are requested as a way of excluding them from analyses, as sometimes early Alzheimer's is coded as depression – if looking at SMI only.

	AOB N/A
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***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	

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"> 1. Personal data revealing racial or ethnic origin; 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. Data				
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?				

3. Security				
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			