



UK LLC Data Access Public Review Panel

Monday 31st March 2025

12:30pm – 13:00pm

Attendance	
Kirsteen Campbell	UK LLC Public Involvement and Communications Manager (Chair)
Robin Flaig	UK LLC Co-Director (Deputy Chair)
Rebecca Whitehorn	UK LLC Research and Communications Coordinator
5 Panel Members attended	UK LLC Data Access Public Review Panel

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introduction & Updates
2.	12.40	Kirsteen	Presenting written researcher feedback <u>Application:</u> llc_0037 <u>Title:</u> “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.”
3.	12.45	All	Comments from Data Access Public Review Panel following llc_0037
	13.00		AOB

Minutes

Agenda Number	Presenter	Agenda Item
1.	All	Introductions Updates from previous meeting

		<p>The panel were made aware of two new datasets added in to the UK LLC Trusted Research Environment:</p> <ul style="list-style-type: none"> • Maternity services dataset • Medicines dispensed in primary care NHS business services authority dataset <p>The panel agreed this was satisfactory.</p> <p>Application llc_0040 will soon show on the UK LLC Data Use Register. This is an application from UK Reach, a new UK LLC partner study in the process of onboarding. This is an application for UK Reach to have access to their own data which following agreement, does not require separate consideration by the Panel.</p>
2.		<p>Discussions around application: llc_0037 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>The panel had provided written comments and feedback to the researcher prior to the meeting. The researcher provided responses to these comments which were shared with the panel.</p> <p>Areas of feedback were:</p> <p>1.1 Is there a public involvement strategy for the project, appropriate for the size and scope of the work?</p> <p>1.2 Is the lay summary able to be understood by the majority of the general public? Does it answer the following questions? A) What is the project aiming to achieve? B) What is the plan to achieve this and how will having access to the data be important? C) How will the work benefit the public?</p> <p>1.3 Is the benefit to health and/or social care, including expected measurable benefits clearly explained?</p>
Feedback and outcome		<ul style="list-style-type: none"> • Please show that the PPIE group is used in all stages 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

	<p>comparisons are not to the general population which is implied in the first paragraph of the lay summary</p> <ul style="list-style-type: none"> • 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>All</p>	<p>AOB</p>