



UK LLC Data Access Public Review Panel

Friday 24th January 2025

12:30pm – 13:30pm

Attendance	
Robin Flaig	UK LLC Co-Director (Chair)
Stela McLachlan	UK LLC Research Manager (Deputy Chair)
Rebecca Whitehorn	UK LLC Research and Communications Coordinator
Karen Williams	UK LLC Data Access Committee
Marie McDevitt	UK LLC Data Access Committee
Fatima Rami	UK LLC Data Access Committee
Rebecca Harmston	UK LLC Data Access Committee
Guest Speaker(s)	
Marcos Del Pozo Banos	Swansea University

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introduction & Updates
2.	12.40	Marcos Del Pozo Banos	<u>Application:</u> llc_0035 <u>Title:</u> “External validation of SNOMED-based mental health phenotypes, and their patterns of clinical presentation in the context of the COVID-19 pandemic.”
3.	12.45	All	Comments from Data Access Committee following llc_0035
	13.00		AOB

Minutes

Agenda Number	Presenter	Agenda Item
1.	All	<p>Introductions Updates from previous meeting</p>
2.	Marcos Del Pozo Banos	<p>Presenting application, ref. no: llc_0035 <u>Title:</u> “External validation of SNOMED-based mental health phenotypes, and their patterns of clinical presentation in the context of the COVID-19 pandemic.”</p> <p>The researcher provided a lay summary of the work proposed in the application.</p> <p>The research aims to see how presentations of mental health conditions in primary care have changed over time, specifically in the context of the COVID-19 pandemic. Firstly, they will identify GP codes for mental health conditions in primary care, and link these to Longitudinal Population Study (LPS) participants’ self-reported mental health data.</p> <p>The researcher explained that England has moved from using Read Codes to SNOMED codes. The list of codes to identify mental health conditions are still in the Read Codes system. They will migrate these codes into the new SNOMED system, enabling them start working with English mental health data.</p> <p>The researcher will access self-reported LPS mental health data (phenotypes) and link these with routine primary care data (using new SNOMED codes) to map code lists. They can improve the quality of code lists, so correspondence is better. The researcher can then look at the presentations of mental health conditions before, during and after the COVID-19 pandemic.</p> <p>The researcher explained that they have extensively engaged with DATAMIND’s Super Research Advisory Group where the feedback was positive. They have further co-designed surveys to facilitate discussions with young people about mental health.</p> <p>They explained the immediate public good benefits:</p> <ol style="list-style-type: none"> 1. Improve ability to identify mental health conditions in primary care electronic health records 2. Improve the quality of research 3. Inform and improve clinical practice and policy makers 4. Describe how the pandemic impacted mental health presentations which will help in preparing for future health crises and in reverting an increasing trend of mental health conditions

		<p>5. Help identify gaps in primary care by comparing LPS data to routine health records</p>
<p>3.</p>	<p>All</p>	<p>Comments from Data Access Committee following Ilc_0035</p> <p>The panel suggested that the researcher should specify in the application that this work would be beneficial for future pandemics. The researcher agreed.</p> <p>The panel noted that the application only noted neuroses (depression and anxiety) and suggested that the researcher should include psychosis or generalise the lay summary to say mental health conditions. The panel questioned why the application stated early psychosis but not schizophrenia and bipolar. The researcher noted that this work will cover 15 different conditions: depression, anxiety, ADHD, ASD, cognitive disorder, eating disorders, bipolar disorder, schizophrenia, all psychotic disorders, drug use, alcohol use, self-harm, suicide attempts, psychological distress and emotional problems. This is stated in the latter part of the application. The researcher agreed to amend the text referenced by the panel to cover more conditions.</p> <p>The panel questioned if the researcher would consider regional inequalities. The researcher explained that they will look at data regarding household income and it is noted that these data will not represent the whole range of inequalities. They will also look at gender and ethnicity when considering inequalities in their analyses.</p> <p>The panel questioned if the research would consider a specific age-range. The researcher advised that they would consider all ages at this stage to maximise the cohort size and the quality of the results and findings.</p> <p>The panel suggested more emphasis regarding public involvement in the design of this application. They suggested that the researcher includes details on public involvement in communications and dissemination of the results.</p> <p>The panel questioned if the researcher would capture different presentations of neurodiversity and people with learning disabilities, as they often present with anxiety, stress and depression differently to neurotypical people. The researcher explained that this is an early stage of research, and they are trying to find those who present with mental health conditions. Unpicking what codes are used for different groups may happen in the future as it requires a lot of extra work.</p>

		<p>The panel asked if those with disabilities, neurodivergence and long-term health conditions could affect how they interact with primary care. Some patients were told to shield longer than other, some preferred using telephone and others couldn't attend face-to-face appointments. The panel asked if this would affect the data. The researcher explained that these details will be included in analyses. They explained that they have completed a piece of work looking at vaccinations during COVID-19 and those specifically suffering from mental health conditions. They differentiate between those who had early access to a vaccination and those who had to isolate more than others. This will be incorporated in the analyses. For this current application, they will not look at specific health conditions as that would create a large and complex piece of work.</p> <p>The panel noted that the new list of codes (SNOMED) would replace codes already used in patient records (Read codes) and questioned if this would impact diagnoses. The researcher explained that there would not necessarily be any impact as this is an observational study. However, in the past, where clinicians have not used direct codes, the research team have successfully pushed for practice changes. For example, in the context of self-harm, they are now in the process of trying to push for a list of clear codes (a list of 5 or 6). This is an additional part of the research.</p>
<p>Feedback and outcome</p>		<ul style="list-style-type: none"> • Note any points here that the presenter is asked to action from the panel and if the presenter has agreed to take action <ol style="list-style-type: none"> 1. Specify future pandemics as an impact to public good 2. 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 3. Include psychosis or generalise more about the diagnoses that will be covered by this research in the lay summary 4. Articulate in the application that regional inequalities will be considered in analyses.
	<p>All</p>	<p>AOB</p>