

## UK LLC Linked Data Review Panel Meeting

9-10am Monday 21.02.2022

UK LLC STAFF IN ATTENDANCE	
Robin Flaig - Chair	UK LLC Deputy Director
Stela McLachlan	UK LLC Research Manager
Jacqui Oakley	UK LLC Senior Research Manager
Emma Turner	UK LLC Senior Data Manager and Research Fellow
Rich Thomas	UK LLC Senior Data Manager
Rebecca Whitehorn	UK LLC Research Administrator
UK LLC VANGUARD MEMBERS IN ATTENDANCE	
Frank Kee	NICOLA
Charlotte Neville	NICOLA

### Actions

**#013** Application llc\_0011 requires a slight reframing and adding details to section 3.8

**#014** Researcher to advise why they do not ask for HES Inpatient, the Mental Health Services Dataset

**#015** UK LLC data team to advise the researcher that they need to request both the HES A&E and the Emergency Care Data Set (ECDS) datasets (needs to be clear on data request form)

**#016** The researcher must provide a description of Twitter data, explaining the derived value of the Tweet

**#017** Add more information to public benefit explanation and around dissemination

**#018** UK LLC Application and Data teams will contact the researcher for application llc\_0012 regarding additional data

**#019** A more detailed reference to being part of LHW in areas such as dissemination is required

**#020** The researcher should flesh out dissemination and Public Involvement sections beyond existing brief sentences.

**Next available number is #021**

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	<b>Introductions</b>	
2.	All	<p><b>Presenting project, ref. no: llc_0011 on “ Twitter use as a mental health phenotype”</b></p> <p>This application is applying to use just one study’s data. Panel member suggested the researcher should request HES inpatient data and Mental Health Services dataset. The researcher mentions the mental health dataset later in the application but</p>	<p><b>#013</b> Application llc_0011 requires a slight reframing and adding details to section 3.8</p> <p><b>#014</b> Researcher to advise why they do</p>

		<p>has not requested the mental health dataset. This may be an omission on the researcher’s part.</p> <p>Panel member noted issues with data request. The researcher is requesting A&amp;E dataset which is historic data, they need to request ECDS. As mentioned in the beginning of the application, members of the public may not be aware that “NHS Mental Health Data” will mean looking at A&amp;E data. Issues around use of language in the lay summary – what exactly does the researcher mean by accurate, reliable, and consistent? Mention of bias – is this from Twitter or NHS data? The mention of COVID-19 additionally seems slightly tenuous.</p> <p>Panel member noted the application lacks an explanation of how the research will inform changes in health and social care. The application requires a slight reframing and details added to section 3.8.</p> <p>Panel member considered that the researcher may be trying to suggest people are doing research on mental health using Twitter data, but there is not a scientific basis for it. However, the researcher does not ask for mental health services data, rather mainly GP data. The researcher does not mention comparing self-reported data to Twitter data. The panel suggested the public benefit section required improvement.</p> <p>Panel member noted that when Twitter is data discussed throughout the application, the researcher is not specific about what those data looks like. For example, a raw Tweet will not be analysed, it is the natural language processing outputs (derived values about tweets). This requires explanation in the application.</p> <p>Panel member raised two points: this is the first application that brings data into the UK LLC application – is a supplementary form needed? The Twitter data incoming to participants (is the Twitter data inclusive of what people are tagged or mentioned in, for example) considering online bullying debates that effect mental health. Panel member advised the data is what people Tweet and Retweet.</p> <p>Panel member queried, if when the Twitter data is deposited into the UK LLC, will that be a part of ALSPAC’s dataset that other researchers will use. A panel member with previous experience advised it will not be.</p> <p>Panel member suggested considering reputational risk. If it is not clear that the researchers will not be receiving full text Tweets, there may an ethic and reputational implication when the public see UK LLC are providing social media data.</p>	<p>not ask for HES Inpatient, the Mental Health Services Dataset</p> <p><b>#015</b> UK LLC data team advise the researcher that they need to request both the HES A&amp;E and the Emergency Care Data Set (ECDS) datasets (needs to be clear on data request form)</p> <p><b>#016</b> The researcher must provide a description of Twitter data, explaining the derived value of the Tweet</p> <p><b>#017</b> Add more information to public benefit explanation and around dissemination</p>
--	--	--	---

		<p>The panel noted good public involvement in the set up but no public dissemination in dissemination section. Question on if the researcher is planning to do an exhibit on this?</p> <p><b>Summary:</b></p> <ul style="list-style-type: none"> <li>• The researcher should advise why they do not ask for in-patient psychiatric data, mental health services dataset.</li> <li>• UK LLC Data Team will advise the researcher about A&amp;E data changing to new dataset (needs to be clear on data request form).</li> <li>• The researcher must provide a description of Twitter data, explaining the derived value of the tweet.</li> <li>• Add more information to public benefit explanation and around dissemination.</li> <li>• Approved subject to above comments being addressed</li> </ul>	
3.	All	<p><b>Presenting project, ref.no.: llc_0012 on "Impacts of the COVID-19 pandemic on access to elective care in the UK: An analysis of linked <i>Understanding Society</i> and NHS electronic records data"</b></p> <p>Panel member queried why the researcher does not request A&amp;E data. The UK LLC applications and data team should suggest this is added to the data request as A&amp;E is an historic dataset. The researcher provided good justification for data and is not resisting their code lists.</p> <p>The data request is suitable as the researcher wants to look at disruption in health care should not want to restrict the project by looking at only certain conditions.</p> <p>Panel member queried if the researcher would want any GDPR data and questioned if the data goes back pre-pandemic or if it is from the beginning of the COVID-19 pandemic. Would the data note if someone had a pre-historic health condition? Panel member suggested that because the data advises of those shielding, it would tell if someone had a pre-existing health condition of those specific ones it picks out. UK LLC panel member confirmed this GDPR data goes pre-pandemic.</p> <p>In stage 2 of the application review process, the UK LLC could make suggestions of additional data the researcher could request that might benefit research outcomes. The UK LLC could advise applicants of additional data to improve outcomes of their research.</p> <p>Panel member queried if the researcher should request waiting list information data. There is not a clear articulation of the difference between emergency and elective admissions in HES data. Those patients who go private may affect this data. Panel member noted it is unclear how else to obtain waiting list data other than GP data. The researcher seems to focus on admitted patient care and outpatient care, which is not a huge sample and</p>	<p><b>#018</b> UK LLC Data Team will contact the researcher for application llc_0012 regarding additional data</p> <p><b>#019</b> A more detailed reference to being part of LHW in areas such as dissemination is required</p> <p><b>#020</b> The researcher should flesh out dissemination and Public Involvement sections beyond existing brief sentences</p>

		<p>therefore could be limiting themselves. The panel member further noted that the researcher might benefit from more data, potentially around cancer registry data.</p> <p>Panel member suggested that as part of stage 2 for applications with limited numbers of participants the UK LLC data team could advise on how much linked data might be available for the research.</p> <p><b>Summary:</b> recommendation to approve subject to the following condition:</p> <ul style="list-style-type: none"> <li>• UK LLC data team will contact the researcher regarding additional data.</li> <li>• A more detailed reference to being part of LHW in areas such as dissemination is required.</li> <li>• The researcher should flesh out dissemination and PPIE sections beyond existing brief sentences.</li> <li>• The researcher is already working on improving the lay summary.</li> </ul>	
4.	All	AOB	