

UK LLC Linked Data Review Panel Meeting

9-10am Monday 25.10.2021

UK LLC STAFF IN ATTENDANCE	
Andy Boyd	UK LLC Director
Robin Flaig - Chair	UK LLC Deputy Director
Jacqui Oakley	UK LLC Senior Research Manager
Emma Turner	UK LLC Senior Data Manager and Research Fellow
Stela McLachlan	UK LLC Research Manager
Rich Thomas	UK LLC Senior Data Manager
Katharine Evans	UK LLC Data and Security Manager
Kirsteen Campbell	UK LLC Communications and Engagement Officer
Rebecca Whitehorn	UK LLC Research Administrator
UK LLC VANGUARD MEMBERS IN ATTENDANCE	
Neil Walker	NIHR BioResource
Genevieve Lachance	Twins UK
Andrew Wong	MRC Unit for Lifelong Health and Ageing at UCL: 1946 NSHD (1946 National Survey of Health and Development) SABRE (Southall and Brent Revisited)

Actions:

#001 Application llc_0003 - Public Benefit and Benefit to NHS to be clarified

#002 UK LLC to improve guidance on application form

#003 PPIE group to receive and feedback on lay summary

#004 Revise all lay summaries and make suggestions.

#005 Lay summary guidance to be drafted.

#006 UK LLC to clarify question 3.12 on application

#007 Prepare standard text to researchers describe their publications and dissemination

#008 Clarify in Vanguard what the data output process is to clarify that data will not be identifiable

#009 Final approval on the lay summaries with public contributors

#010 UK LLC to amend wording regarding sensitive data

Next available number is #011

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	Introduction	
2.	Stela Robin	<p>Overview Terms of Reference of our contract with NHS Digital</p> <p>Review of applications for the use of NHS Digital Data, ensuring the use is in the public benefit.</p> <p>Five safes considered. The UK LLC will review CVs to ensure researchers have appropriate training and ONS accreditation prior to access. The use of NHS Digital Data must be crucial for the research results.</p>	
3		<p>Application llc_0003</p> <p>Title: Mental health and wellbeing consequences of experiencing COVID19</p> <p>Primary researcher: Richard Shaw</p> <p>The excel spreadsheet and application form for applicants should map, however due to timings with these first applications, it is possible they will not. In future the researcher will receive excel spreadsheets and application forms at the same time so they should match.</p> <p>Concerns around the use of death data - the spreadsheet indicates data for cause of death (COVID-19 specific death) however, the form focuses on death for censoring. The applicant is not justifying data request for the cause of death in addition to the fact of death.</p> <p>Overall scope not coherent. One of three aspects set out was to define COVID-19 – this could be better addressed as a shared project across Longitudinal Health and Wellbeing CONVALESCENCE.</p> <p>The social outcomes section is out of scope and should be removed and resubmitted as a separate project.</p> <p>Panel member suggested it would be better as a separate project. Benefits of transparency, have separation between coherent sets of questions.</p> <p>If the outcomes are considered to influence mental health and the researcher wishes to take that approach, then it is an amendment. If they want to research this separately from mental health then it is a separate application.</p>	

		<p>No clear expected measurable benefits to NHS.</p> <p>Better guidance from UK LLC to show more detail is required from the applicant.</p> <p>Cohorts are insisting on detailing dissemination during the process of gaining approval from NHS Digital. The benefits should reflect in projects reviewed.</p> <p>Summary:</p> <ul style="list-style-type: none"> • The lay summary is not entirely lay. Public contributors to give specific feedback on this. • Clarify outcome for each application: reject, revise or approve. • This could be approved for mental health release, subject to a clarification around death data. If the applicant wishes to, they can amend further to explain the societal impacts. • Approved subject to revision around the terms and conditions UK LLC have laid down. If they do a full-scale amendment then the application will come back to the group. 	<p>#001 Public Benefit and Benefit to NHS to be clarified</p> <p>#002 UK LLC to improve guidance on application form</p> <p>#003 Public contributors to receive and feedback on lay summary</p>
4		<p>Application llc_0004 Title: Examining the serological response to SARS-CoV-2 infection and vaccination across the National Core Studies Primary researcher: Olivia Hamilton</p> <p>Improvement for the lay summary is required.</p> <p>This application has a tightly defined scope, it is topical and the question is clear and understandable.</p> <p>The researcher is requesting access to GP data but does not justify the reason. It does not cross-reference into application and isn't clear on the excel.</p> <p>One panel member is involved in this application and advised the researcher may want to introduce a new analyst but this shouldn't impact the scope of the project.</p> <p>Query over the researcher requesting predominantly Understanding Society data. Panel member advised the analysis plan is to be confirmed. There may be other study approval for this in place. It would be good to get clarity from where the researcher wants to expand to in the future.</p>	<p>#004 Revise all lay summaries and make suggestions.</p> <p>#005 Lay summary guidance to be drafted.</p>

		<p>Summary:</p> <ul style="list-style-type: none"> • Clarity is required regarding the researcher’s interest in mortality for censoring but then asking for specific cause mortality. • UK LLC potentially need to amend the data request pro forma (add the derived COVID dataset as a product) to reduce researchers repeatedly requesting various data to define COVID. UK LLC to supply the core definition dataset and researchers can either use this or use those data within it to define COVID cases. • Approved subject to revision of clarification around GP, death and lay summary. 	
5		<p>Application llc_0005 Title: Are immune-mediated diseases risk factors for long COVID? Primary researcher: Dylan Williams</p> <p>Lay summary needs revised.</p> <p>Issues regarding named researchers on this application and who is accessing data. If an individual is included as a named researcher, they should have evidence of safe researcher training (ONS).</p> <p>Clarification is required concerning who is accessing data directly and who is providing academic input. Panel member suggested the named researchers remain on this application and agreed with the tick box option. E.g., are these people accessing data? Yes/no? CVs and safe researcher accreditation are only required if they are going to access the data.</p> <p>Summary:</p> <ul style="list-style-type: none"> • Clarify question 3.12 regarding what the UK LLC mean by enhancement of the research database. • Approved subject to clarification on above point. 	<p>#006 UK LLC to clarify question 3.12 on application</p>
6		<p>Application llc_0006 Title: Comparing the burden of long COVID in the community as measured by self-report and electronic health records: a study by the CONVALESCENCE consortium Primary researcher: Dylan Williams</p> <p>Issues around dissemination. UK LLC need to be clearer about what is expected. Prepare standard text to the researchers to describe what their publications and disseminations are.</p> <p>Both centralised accredited function and researchers will review outputs.</p>	<p>#007 Prepare standard text to researchers describe their publications and dissemination</p> <p>#008 Clarify in Vanguard what the data output process is to</p>

		<ul style="list-style-type: none"> • Regarding the justification of sensitive data, the researcher should revise and amend wording as they mention they do not use sensitive data yet they talk about ethnicity. • UK LLC to amend the wording in the form to clarify what is meant by sensitive data. • Approved subject to the few minor amendments and a revised lay summary. 	
8		AOB n/a	