



UK LLC Data Access Public Review Panel

Friday 16th August 2024

12:30pm – 13:30pm

Attendance	
Kirsteen Campbell	UK LLC Communications and Engagement Officer (Chair)
Stela McLachlan	UK LLC Research Manager (Deputy Chair)
Rebecca Whitehorn	UK LLC Research and Communications Coordinator
Four Panel Members attended	UK LLC Data Access Public Review Panel
Guest Speakers	
Professor Ann John	Swansea University
Dr Sharon Neufeld	University of Cambridge

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introductions Updates from previous meeting
2.	12.45	Professor Ann John (AJ)	Presenting application, ref. no: llc_0032 on “Predictors of suicide ideation, suicide attempts, and self-harm among adolescents in the UK prior to and during/after COVID-19”
	12.50	All	Questions from Data Access Public Review Panel following llc_0032
3.	13:05	Dr Sharon Neufeld (SN)	Presenting application, ref. no: llc_0033 on “Community mental health treatment and subsequent outcomes in children and young people: what works, for whom, and why?”
	13:10	All	Questions from Data Access Public Review Panel following llc_0033
	13.25	All	AOB

MINUTES

Agenda Number	Presenter	Agenda Item
1.	All	<p>Introductions Updates from previous meeting and introductions from new and existing panel members.</p>
2.	AJ	<p>Presenting application, ref. no llc_0032 on “Predictors of suicide ideation, suicide attempts, and self-harm among adolescents in the UK prior to and during/after COVID-19”</p> <p>The researcher provided a summary of the work proposed in the application.</p> <p>The researcher explained that their proposed application will investigate factors associated with the transition from suicidal and/or self-harm thoughts to behaviours. They will investigate if these factors changed during the COVID-19 pandemic and identify what factors are involved in the transitional behaviours.</p> <p>The researcher explained that they co-lead on a project called DATAMIND which also is a partner of UK LLC. DATAMIND have a ‘Super Research Advisory Group’ (SRAG) who were actively involved in the development of the MRC:DATAMIND bid and that the SRAG discussed this project extensively. They plan to use participants from SHARE UK to create a group of people under the age of 40. They will work with this group throughout the project, including when they start developing results.</p> <p>Questions from Data Access Public Review Panel following llc_0032</p> <p>The panel requested that the researcher adds annual figures against the mention of suicide being the leader of deaths in young people. They additionally noted an area of the lay summary requiring more context; “the third largest cause [of what] for middle-aged adults”. For example, this could be ‘cause of mortality’.</p> <p>The panel queried if there would be reference to sexual abuse as a factor for suicidal ideation and/or self-harm in this project. There is only a reference to domestic abuse and adverse experience in childhood within the application form. The researcher advised that they have done work on childhood maltreatment, including child sexual abuse which reoccurred when they carried out a review of child deaths by suicide. In the initial analysis, they will explore each associated variable identified from previous literature.</p> <p>The panel highlighted a report by The Lancet (The Lancet Psychiatry Commission on youth mental health) exploring youth mental health. This specifically looks at ‘global mega-trends’ impacting young people and mental health; the three main ones being inaction around climate change, intergenerational inequality and adversity linked to the coronavirus pandemic. The researcher mentioned they are one of the co-authors on this report and agree that they should focus on long-term effects rather than</p>

		<p>immediate effects. For example, long-term effects of interruptions like the coronavirus pandemic.</p> <p>The panel queried UK health budgets available for young people and mental health and how this affects treatment provision and access. The researcher agreed that this is a wide-spread issue, from services to research.</p> <p>The panel asked if this project would consider groups of children who are at a higher risk of self-harm and/or suicide, and if interventions will be specifically tailored to work with those groups. The researcher advised that this project will look at components such as neurodiversity and mental health conditions as they are risk factors for these behaviours. This project will form intervention development.</p> <p>The panel noted that some of this work may be limited due to data that is not yet held within the UK LLC Trusted Research Environment, such as childhood sexual abuse.</p> <p>The panel noted the impact of social media and mental health in young people and queried if this would be included in the project. The researcher advised that this is relevant, and they have done other work on the impact of social media and cyber bullying. However, rather than the time spent on social media, it is more the activities/actions of young people while on social media that researchers are saying matters more. They will have to consider the depth of questions asked by the Longitudinal Population Studies.</p> <p>Summary Recommendations (to be taken to Linked Data Panel)</p> <p>Public Involvement Plan</p> <ul style="list-style-type: none"> • No recommendations <p>Public Benefit</p> <ul style="list-style-type: none"> • The researcher should add more information on how this project will inform intervention development.
<p>Feedback and outcome</p>		<p>Note any points here that the presenter is asked to action from the panel and if the presenter has agreed to take action</p> <p>Lay summary</p> <ul style="list-style-type: none"> • The researcher agreed to add some figures regarding how many deaths by suicide in young people for more context. • The researcher agreed to add context to the mention of ‘the third largest cause for middle aged adults’, e.g., the third largest cause of mortality.
<p>3.</p>	<p>SN</p>	<p>Presenting application, ref. no: llc_0033 on “Community mental health treatment and subsequent outcomes in children and young people: what works, for whom, and why?”</p> <p>The researcher provided a summary of the work proposed in the application.</p>

		<p>The researcher explained that their project will use datasets held within the UK LLC Trusted Research Environment to mimic randomized control trials to balance the treated group for mental health, and untreated group for mental health based on background factors (such as education). They will then have a comparison group of those who accessed mental health services and those who didn't access services but needed treatment.</p> <p>They will investigate what measurable outcomes are improving for mental health in young people and compare them to those who didn't access mental health services. They will look at why are they improving, and for whom. For example, the mental health services may work better in urban environments as those who live in rural environments may find it harder to get to appointments.</p> <p>The researcher explained that they will be linking in the findings with policy makers and stakeholders, for example, healthcare workers and young people (they have a young-person patient and public involvement group). Additionally, they have commissioners who they will be disseminating the work to, ensuring the project has maximum impact.</p>
		<p>Questions from Data Access Public Review Panel following llc_0033</p> <p>The panel highlighted that it is important that service interventions are not assumed to make things better and also, must not make things worse. The panel reported a typing error in the abstract relating to the word 'to' as there is a word missing around it.</p> <p>The panel queried if the researcher could include a brief mention of factors that have helped with mental ill-health prevention. The researcher advised that prevention is very important, however they must be focus on the scope of this application. Some preventative factors could go into models they are developing to balance treated/untreated patients, for example factors such as peer or family support.</p> <p>The panel noted recent figures in The Lancet regarding global health budgets devoted to mental health and improvements to mental health services. They highlighted the disparity in figures. At least 45% of the overall disease in young people (aged 10-24) is mental health and suicide. However, less than 2% of the global health budget is spent on young people and mental health care. They asked the researcher if they would take these figures into account when talking about service improvement in the project. The researcher advised that this is a motivation for the project. One way of encouraging governments that they should invest more into young people's mental health services is to illustrate that they work in the real world, making concrete improvement on mental health. This project aims to provide evidence to governments to show real-world work does improve young people's mental health and more should be done, such as improved treatments and more funding.</p>

		<p>The panel highlighted the aspect of family functioning, as children of divorced or separated parents tend to have poorer mental health. Divorce is high in the UK, so this might be an important factor. The panel further noted that in reference to advocating for better mental health services if services are effective, it is beneficial for the researcher to include a cost-benefit analysis at the end of the project. The researcher advised if they have the cost-benefit data, they will add this to the analysis. The researcher agreed that a more stable a young person’s home environment may lead to better mental health. If there is a big enough sample size to investigate treatment effectiveness if parents are divorced, then they will look at this. How well families function is a key component.</p>
		<p>Summary Recommendations (to be taken to Linked Data Panel)</p> <p>Public Involvement Plan</p> <ul style="list-style-type: none"> • Researcher to clarify the reference to annual meetings; with whom are these meetings with? <p>Public Benefit</p> <ul style="list-style-type: none"> • No recommendations
<p>Feedback and outcome</p>		<p>Note any points here that the presenter is asked to action from the panel and if the presenter has agreed to take action</p> <p>Lay summary</p> <ul style="list-style-type: none"> • No recommendations
	<p>All</p>	<p>AOB</p>