

UK LLC Data Access Public Review Panel Minutes

Friday 18th February 2022

12.30 – 1.30pm

UK LLC STAFF IN ATTENDANCE	
Kirsteen Campbell (Chair)	UK LLC Communications and Engagement Officer
Katharine Evans (Acting Deputy Chair)	UK LLC Data and Security Manager
Rebecca Whitehorn	UK LLC Research Administrator
Four public contributors in attendance	
GUEST SPEAKERS	
Nina Di Cara	University of Bristol
Michaela Benzeval	University of Essex
APOLOGIES	
Stela McLachlan (Deputy Chair)	UK LLC Research Manager

AGENDA

Agenda Number	Time	Presenter	Agenda Item
1.	12.30	All	Introductions
2.	12.40	Nina Di Cara	Presenting project, ref. no: llc_0011 on "Twitter use as a mental health phenotype"
3.	12.45	All	Questions from Data Access Public Review Panel following llc_0011
4.	13.00	Michaela Benzeval	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"
5.	13.05	All	Questions from Data Access Public Review Panel following llc_0012
6.	13.20	All	AOB

Actions

Agenda Number	Presenter	Agenda Item	Action Points
1.	All	Introductions	
2.	Nina Di Cara	<p>Presenting project, reference: llc_0011 on “ Twitter use as a mental health phenotype”</p> <p>The project aims to look into the use of Twitter to understand changes in mental health over time. Twitter is a social networking site where people can post short public updates and interact with other’s posts.</p> <p>The researcher advised that how people use Twitter to talk about topics, the types of words used and the types of content interacted with could be indicative of how a person feels and how their mental health changes. There is a lot of interest surrounding how this data could map mental health over time.</p> <p>The researcher noted that during the COVID-19 pandemic, there was an interest in how social media data could be used to understand how people responded to things such as changes in public health measures being introduced and mental health changes in general. The research aims to investigate this using the linked data.</p> <p>ALSPAC have been linking Twitter data, currently for 660 participants. Those participants are from the index child cohort and some from the parent cohort (2/3 from index children and 1/3 from parent cohort).</p> <p>ALSPAC’s linked data represent some of the best for social media. An issue with social media research is whilst a researcher can collect data permitted to be shared on Twitter, there is little evidence in terms of assessing mental health against the data on how the individual really feels. This is because it is unknown how people feel without actually asking them.</p> <p>By using the linked data, the researcher aims to understand if Twitter is useful for assessing changes in mental health over time. Linking Twitter data from ALSPAC with NHS data will gain stronger evidence of signals picked up from Twitter against how frequently individuals have accessed services or if they required A&E, GP or NHS support.</p> <p>The researchers have done a series of focus groups to understand what participants considered to be acceptable in</p>	

		<p>terms of collecting their social media data. Based on the focus groups and needs of participants, there are a series of restrictions in terms of the social media data accessed by researchers.</p> <p>The researchers have no access to participant’s raw data and can only see anonymised data or specific features of requested data. For example, how many retweets in a certain period.</p> <p>The project hopes to investigate two main hypotheses:</p> <ul style="list-style-type: none"> • If someone’s worsening mental health could have been inferred from their Twitter data beforehand or if their approach to a service such as a GP or accessing an A&E service could have been anticipated by changes in their Twitter data • At population level, to see if overall changes in demand for services could have been inferred by changes in the data collected from Twitter <p>The researcher could determine if Twitter data analysis is a useful method for future use, where similar situations or big events may affect wellbeing and mood, if these are methods that should be used for public health and public monitoring or if they are not applicable to be used at this time.</p>	
3.	All	<p>Questions from Data Access Public Review Panel following llc_0011</p> <p>Panel member queried if digital phenotyping could signal transition, for example, from risk to the need for care. The researcher advised the question of that being possible is outstanding and cannot be answered from current data, and is part of the reason for carrying out this research. A panel member further questioned digital phenotyping serving as a signal – could this work as a signal of relapse or recovery? The researcher advised this method is currently more feasible to indicate improvement or decline. This is where the most interest is from clinicians, to say if someone’s overall presentation online improved or declined rather than used as a diagnostic tool.</p> <p>Panel member addressed that ALSPAC should be written out in full throughout the application as there is no explanation of what it stands for.</p> <p>Panel member queried what Twitter data will be collected, as the lay summary discusses Twitter data in general way. The researcher advised the ALSPAC cohort themselves collect all textual data and metadata from every Tweet. This is the exact time each Tweet was made, number of likes, retweets and</p>	

		<p>replies. Researchers can access derived data from the text but not the text itself.</p> <p>Panel member stated, under the justification of sensitive data requested, the project requests data related to ethnicity and gender to ensure the algorithms are not biased towards particular groups. The panel member queried the researcher’s plan to ensure the research is not biased towards particular groups beyond that, for example, those with different protected characteristics. The researcher advised there is little information about other protected characteristics that may influence how people express their mental health online. The protected characteristics stated are primarily used as there is existing evidence of people from different ethnicities, genders and ages expressing mental health differently in their behaviour.</p> <p>A panel member queried why this research chooses to use Twitter data rather than other social media platforms. The researcher explained that current access to Facebook and Instagram data is blocked for researchers, unless participants are donating it themselves. This means participants downloading from their accounts and emailing files to researchers, which is not feasible for this project. Important to consider in the future if better access controls are set up.</p>	
<p>4.</p>	<p>Michaela Benzeval</p>	<p>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"</p> <p>Understanding Society are funded to look at all aspects of people’s lives, not just health. Households originally selected are representative of the whole of the UK. Everyone in those households are interviewed annually. Participants are interviewed face-to-face, on the web and by telephone. When the pandemic started, face-to-face interviews were dropped. Monthly surveys began in April 2020. Participants were asked about everything happening in their lives during the pandemic. One of the topics asked was regarding health conditions and if individuals were receiving expected/planned treatments. If participants had access to healthcare they expected or planned, whether that was their decision or NHS, was it a hospital visit or by phone, digital consultations, etc.</p> <p>The researcher explained that the aim of this project is to look at the wider impact of receiving treatment or not receiving treatment on the rest of a person’s life, such as employment, relationships, wellbeing and education (children).</p> <p>In 2021, Understanding Society asked participants for consent to link with NHS records and for those who did, the data has</p>	

		<p>been linked at the UK LLC. The researcher aims to use linked data to look at who received treatment and who did not. For those whose needs were not met, the researcher will assess the impact on their lives and consider what different groups in the population have been affected differentially (age, income, ethnicity, gender).</p> <p>Findings will be discussed with Understanding Society's Partnership and Policy Forum to discuss what happens next, how they share findings and influence change.</p> <p>Understanding Society engage participants from the design of the study and the findings from it using a participant panel. They engage with participants through interviewers who are carefully trained. Their Partnership and Policy Forum made up of government departments and charities help to consider how findings are shared in ways that may influence policy.</p>	
<p>5.</p>	<p>All</p>	<p>Questions from Data Access Public Review Panel following llc_0012</p> <p>Panel member queried how Understanding Society have analysed their own data from their own study. What is the reason for gaining access to NHS data. The researcher advised that Understanding Society have self-reports about participant's conditions and if their access to healthcare during the pandemic was affected. Participants were not asked about specific treatments received. Access to NHS data will provide details of what treatments participants received during that period and if they relate to the condition the individual reported to the study.</p> <p>Panel member questioned private sector data records that might be on a participant's GP records, as this could skew results. The researcher advised private care was not considered but is something they could look at.</p> <p>Panel member suggested that the researcher should consider the elective care recovery plan that has recently come out regarding the impact of delayed healthcare on mental health. The researcher has not yet seen this but will look into it.</p> <p>Panel member commented on a section in the lay summary mentioning that the project will look into what groups have been impacted by the reduction in hospital admissions (age, ethnicity and gender). The panel member queried if the data includes those with other protected characteristics. The researcher advised that they collect data, such as sexual orientation. They have information on other protected characteristics but most likely do not have the sample size for those who have also consented to NHS linkage to look at all of them in detail.</p>	

6.	All	AOB	
----	-----	-----	--