UK
Longitudinal
Linkage
Collaboration

UK LLC Data Access Public Review Panel: Public Good Considerations

This document has been developed to aid the UK LLC Data Access Public Review Panel (DAPRP) with their remit to consider whether applications to access data held in the UK LLC Trusted Research Environment are in the public good.

National Data Guardian (NDG) definition – public benefit

"Public benefit means that there should be some 'net good' accruing to the public; it has both a benefit aspect and a public aspect. The benefit aspect requires the achievement of good, not outweighed by any associated risk. Good is interpreted in a broad and flexible manner and can be direct, indirect, immediate or long-term. Benefit needs to be identifiable, even if it cannot be immediately quantified or measured. The public aspect requires demonstrable benefit to accrue to the public, or a section of the public."

To consider public benefits, we recommend referring to NDG guidance that asks if the research may:

Help the health and care system to better understand the health and care needs of populations?
Lead to the identification or improvement of treatments or interventions, or health and care system design, to improve health and care outcomes or experience?
Help to manage the response to communicable diseases and other risks to public health, such as pandemic planning and research?
Advance understanding of regional and national trends in health and social care needs?
Advance understanding of the need for, or effectiveness of, preventative health and care measures for particular populations or conditions such as obesity and diabetes?
Better inform those planning health services and programmes, for example, initiatives to improve equity of access, experience and outcomes in the short or long term?
Inform decisions about how to effectively allocate and evaluate funding according to health needs?
Provide a mechanism for checking the quality of care? This could include identifying areas of good practice to learn from, or areas of poorer practice which need to be addressed.
Support knowledge creation or exploratory research (and the innovations and developments that might result from that exploratory work)?
Advance understanding of the needs of carers supporting family members?
Other public value (please explain below)

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Risks of harm

The UK LLC DAPRP are also asked to consider the risk of harms to those whose data is being used, or those who may be impacted or omitted from any research carried out within the UK LLC TRE.

Examples are provided in the table below to support the Panel's understanding of what these sorts of risks might look like in UK LLC data access applications or the likelihood of it happening. The list of potential risks in the table below are based on UK Statistics Authority Centre for Applied Ethics, Public Good Checklist.

<table>
<tr><td colspan="2">Risk of Harms</td></tr>
<tr><td colspan="2">A reminder of the key mitigations in place to manage the risks associated with data use:

Trusted Research Environments are highly secure computing environments where data is securely accessed. It can't be removed, shared or copied.
Researchers and organisations are required to sign contracts stating their organisational and personal responsibilities.
All applicants must be ONS Accredited Researchers to be permitted in to the TRE, showing they are trained in the correct ways to work with data.</td></tr>
<tr><td>Potential Risks</td><td>What this could look like in practice/Is this likely to happen with a UK LLC application?</td></tr>
<tr><td>Is there potential for the work to be used to make decisions about individuals or to identify individuals? If yes, what ramifications may this have for any individuals?</td><td>The data held in the UK LLC TRE has been de-identified, meaning no individuals can be identified, therefore it is highly unlikely for any research using data held in the UK LLC TRE to be used to make a decision about, or to identify, anyone at an individual level.</td></tr>
<tr><td>Is there potential for the work to be used to make decisions about, or to identify, particular groups or communities within society? What ramifications may this have for them?</td><td>It is possible that findings could be used to advise decisions about particular groups or communities.
For example, a project looking at the health outcomes of people with COVID-19 by ethnicity could identify findings that are relevant to ethnic minority communities.
It would not be possible for applicants to access data to be able to identify individuals within groups/communities.
Where research findings show a group/community have worse outcomes (health, social, financial) this is where the benefit to the public must be made clear.</td></tr>
</table>

Is there potential for harm, distress or stigmatisation for individuals or groups who are a) included as data subjects in the work b) may be impacted as a result of the findings of the research (including social, environmental, economic, physical or mental health impacts)? If so, how can these risks be minimised?	As the Longitudinal Population Study participants, who are the data subjects, have volunteered to be part of their study, the panel do not require to review the potential harms of the data subjects, as this responsibility sits with each individual study. Each study conducts their own due diligence and has ethical approval in this area and they all require to approve each data access application. Within UK LLC, it is possible that research findings could be released that highlight the individual studies whose data was used in the research. This means that participants in these studies may become aware that their data was used for a UK LLC research project. This is where the Panel needs to consider the proposed public benefits to data access vs the proposed use of data along with the planned public involvement and dissemination plans of information to the participants.
Does the work involve using data related to sensitive or personal information or protected characteristics, sensitive cultural or social contexts, or engaging with vulnerable groups? How are these being managed?	There will be applications seeking to access sensitive data. For these, UK LLC requires ethics and public involvement to assess that the benefits outweigh the risks. There is no direct contact with vulnerable groups. The Panel would need to consider if the risks and mitigations in place are sufficient across the ethics and application forms.