UK Covid-19 Inquiry: Terms of Reference Consultation

Written response submitted by the UK Pandemic Ethics Accelerator's Data-Use workstream to the online consultation at ukcovid19inquiry.citizenspace.com
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In this submission **we recommend that the UK Covid-19 Inquiry pursue a comprehensive evaluation of data use during the pandemic.** The inquiry should establish how data was used during the covid-19 pandemic, how effective data use was, ethical trade-offs involved in using data at large scale, and gaps that remain today in public data sets, especially on vulnerable people in society. In making these recommendations we bring to bear expertise in the ethics of public health and social care data; expertise in science, technology, and innovation policy; and findings from the UKRI Pandemic Ethics Accelerator on the use of public data and personal data in the covid-19 Pandemic.
We respond directly to the consultation questions as set out below.

Consultation questions

Page 1: Do the Inquiry's draft Terms of Reference cover all the areas that you think should be covered by the Inquiry?
No (Only a yes/no response permitted).

Page 2: Please explain why you think the draft Terms of Reference do not cover all the areas that the Inquiry should address.

We support the aim expressed in the draft terms of reference to examine the availability and use of data and evidence in public health decision making. However, we recommend the inquiry pursue a more comprehensive evaluation of data use. Data use across society and all policy domains was crucial during the pandemic and remains crucial to public health and social care on an ongoing basis. In pursuing a comprehensive evaluation of pandemic data use, the inquiry should consider the effectiveness, ethics and impacts on society of data use during covid-19, as well as the values that informed decisions on data use.
Drawing on expertise in data ethics and data policy, and from work as part of the UKRI Covid Ethics Accelerator, we recommend the inquiry explicitly address the following seven data use issues not included in the draft terms of reference:

1. **How effective was data use during the pandemic**? The inquiry must establish not only what data were used during the pandemic, but how effective different data were in the following ways: (i) How effective was the infrastructure in providing data that was needed for policymaking? (ii) How effective was the take-up of data into policymaking? (iii) Where was data used in a way that made a difference to infection and death rates and what evidence is available to draw future lessons from. Establishing effectiveness is critical for future readiness in the following ways: for deciding between competing economic, ethical, and political priorities; for assessing how the public values data use; and for estimating the public value of data and how data contributes to policy goals such as public health and social care.

2. **What gaps were there in the availability and quality of data necessary to protect vulnerable groups missing at the start of the pandemic? What gaps remain in this data two years on?** The UK government today still does not understand who exactly is in care homes and domiciliary care, where they are and for what duration of time. The inquiry must seek to (a) understand how data systems continue to neglect some vulnerable groups and (b) locate where new or improved accountability structures tied to how data is used might address issues of whose lives are saved and whose are not in public health emergencies.

3. **Who was asked for ethical advice about data use**? In recent years governments have established various regulations and information governance regimes around good data use. The inquiry should establish how these were used during the pandemic and how ethical advice was used to inform decision making about the commissioning, design, and ongoing governance of data use? Also, what ethical values were at stake when ethical issues arose? Did people impacted by data-informed decisions have a say in how data was used? Who should be involved in future ethical discussions and decisions?

4. **What were the value judgements and ethical assumptions made in pandemic data-use? What trade-offs were involved**? At the start of the pandemic many of the usual checks and balances used to safeguard individuals' data and privacy were relaxed in order to expand data systems for tracking disease and human activity. It seems logical that this has helped. For instance, epidemiological studies of the NHS Covid App have shown it had some impact on curbing the spread of the disease. But we still don't know the full extent of undesired or unforeseen second-order and long-term impacts of public health interventions.

5. **When will emergency regulations that have enabled data use at scale end?** To allow rapid data sharing and linking, some of the rules designed to ensure private data is protected were relaxed. For instance research practices that placed a premium on patient privacy have been traded for fast-flowing data. With little fanfare, these changes shift power relationships between citizens, researchers, companies and the state. The inquiry must establish which measures have been ended and procedures for systematically scrutinising and decommissioning emergency measures still in place.

6. **Did public trust in government and NHS data use diminish during covid-19?** The inquiry will play an important role in maintaining trust in data and the organisations that control data as well as rebuilding trust where it has been lost. Precisely accounting for shifts in trust is difficult. However, it is likely that controversies such as the poor design of the original NHS covid app and secret no-bid contracts with technology firms have impacted some people's trust in data use by government and the NHS. The inquiry should aim to establish where shifts in trust have happened and underlying rationale for these as a necessary first step for more robust data governance arrangements in future crises.

7. **What was the use of and public value of citizen collected data?** Throughout the crises, ordinary citizens played an important role contributing their own data to the population health trackers like the NHS covid app and symptom studies like the ZOE App. The inquiry must seek to establish lessons from both successes as well as failures, such as the difficulty of launching the first NHS covid-19 app. Also, as some publicly funded large scale epidemiological studies are shut down, the inquiry should establish the usefulness, or not, of citizen data in tracking emerging variants of concern and new public health risks.

Page 3: Which issues or topics do you think the Inquiry should look at first?

We recognise that the inquiry has many aims and prioritisation is a complex issue. However, one important consideration is the fact that the pandemic is not over.

This submission has already highlighted a number of ongoing issues which the inquiry might consider. When it comes to issues of trust for instance, lessons from the pandemic need to be applied today. For instance, major structural re-organisation is underway in the NHS with the goal being to accelerate digitalization and centralise workforce management. Ensuing changes in how people's health data is managed and integrated across the NHS require the continued trust and cooperation of patients. For this, robust scrutiny of how NHS England use data is needed. Just as important, scrutiny processes and the organisations that run them must be understood by the public, and in turn these organisations must engage with and understand concerns about data use by a diversity of people across the UK. Inquiry findings and recommendations on data use will play an important role in these processes.

The inquiry also has an important role in contributing to working out the public value of pandemic data use. Pandemic data use will continue to be an important ethical, political and public health concern because public data will continue to influence how we respond to immediate and long-term impacts of covid-19. Debate is needed about the public value of maintaining these data systems. The full scope of these debate may or may not be beyond the scope of the inquiry. Nevertheless, the inquiry will play an important role in legitimising these debates, and setting out the lines along which ongoing and future public dialogue can proceed.

Page 4 of 5 Do you think the Inquiry should set a planned end-date for its public hearings, so as to help ensure timely findings and recommendations?

No (Only a yes/no response permitted).

Page 5: How should the Inquiry be designed and run to ensure that bereaved people or those who have suffered serious harm or hardship as a result of the pandemic have their voices heard?

An important societal function of the inquiry is establishing confidence amongst people who have suffered that mistakes uncovered will never be repeated. An inquiry on data needs to find ways to embed lessons in ongoing data governance regimes so that lessons drawn from the inquiry are implemented in a timely way, and the implementation evaluated and improved where appropriate.

About this evidence submission