Principal Investigator: Prof. Ilina Singh, University of Oxford

www.ukpandemicethics.org

UK Pandemic Ethics Accelerator

Seeking Expressions of Interest:

> ### *THE ETHICS OF SELF REPORTED DATA COLLECTION*
>
> **use the following reference for all correspondence and submissions relating to this call: AH/V013947/1/PA2/001**

The UK Pandemic Ethics Accelerator intends to commission a substantial piece of ethics research from an external academic(s) to support its current inquiry. This document sets out the aims and scope of the research envisaged.

Background

During the pandemic there has been an increase in the collection and use of self-reported data from mobile application. For instance, mass participation projects such as the Covid Symptom study by ZOE at King's College London have engaged millions of participants, often in daily self-monitoring activities.

It's not just covid-19 related data. Applications track work activities in an increasing number of commercial sectors including warehouse fulfilment, delivery and office productivity. And the growth of fitness trackers and health and lifestyle apps continues.

For some, these data methods represent new possibilities for citizen health science, for others, problematic new forms of self-surveillance. For some health and social care workers there are obvious benefits: decision making on health-care worker removal from and return to work might reduce transmission. But in other professions, the nature of the decisions data is put to use is not so clear cut. Should employees use self-reporting data in disciplinary processes for example.

In the areas of health trackers apps and infection monitoring, studies so far have tended to focus on the possibilities for data-driven decision making that large scale self-reporting opens up. Less attention has been paid to how practices of self-reporting and data and app infrastructures reshape the social and material stuff of society: people, practices, principles, and the world around them. This review will focus on this gap.

Purpose

To assist the UK Pandemic Ethics Accelerator to develop a broad, comprehensive, and detailed understanding of four cross-cutting key themes of interest:

(i) **Applications and impacts**: How can we understand practices, applications and impacts of large scale self-reported data collection? (ii) **Risks and ethical concerns:** What are the downsides or risk associated with self-reported data applications? Do they focus on any particular groups? What are the major ethical issues? (iii) **Stakeholders:** Are some professions, communities, groups or sectors of society more or less likely to partake in self-reporting activities? For instance health care workers or those in public facing service industries? (iv) **Data:** How is data quality assured and how is self-reported data linked with other data sets and with what impacts?

The UK Pandemic Ethics Accelerator aims to produce leading ethics research and analysis about these interconnected themes or a subset thereof. Interconnections among these areas of interest should be interrogated, and the analysis should identify and illustrate where and how, from an ethics point of view, these areas are linked.

Approach

The analysis should be based on an analysis of the existing literature and other publicly available resources. Much of the information required should be reported descriptively, and analysis of the ethical issues should be presented in a neutral and even-handed way. The analysis must be grounded in contemporary facts and realities; it should not be a purely theoretical piece or rely on speculative cases. Illustrative case studies, based on empirical material, can be very effective in making the point, and would be welcomed as part of the analysis.

The review would be expected to cover:

  (a) OUTLINE SCOPE

    (i) ETHICAL ISSUES, DISTINCTIONS, CONCEPTS, DEFINITIONS

    (ii) DATA, TECHNOLOGY AND INFRASTRUCTURE ISSUES

     (iii) LEGAL AND REGULATORY ISSUES

     (iv) GUIDELINES, BEST PRACTICE, PROFESSIONAL STANDARDS

  (b) IMPLEMENTATION AND GOVERNANCE PROCEDURES

  (c) GAPS, CHALLENGES, RISKS

  (d) OTHER CONCERNS

Scope

Given the nature of the themes relevant to this piece of research, the review may cover some or all of the following levels and jurisdictions:

- ENGLAND
- WALES
- NORTHERN IRELAND
- SCOTLAND
- UK
- EUROPE
- INTERNATIONAL

Information for researchers

We welcome proposals from researchers with complementary expertise working together.

Interested researchers are invited to submit a brief proposal (no more than 1500 words, excl. CVs) setting out how they would meet the objectives outlined in the brief. This should include:

- a brief summary of expertise and 2-page CV of those who will be involved

- up to 5 headline points that the review would be expected to make

- an outline of the proposed approach to fulfilling the brief (research methodology)

- an indicative outline of the final report (which is expected to be 4000 words in length)

An honorarium of **£5000** is offered on completion of this work. This is offered on the understanding that the honorarium reflects five weeks / 25 days of work (To discuss further, please contact Cian O'Donovan, c.o'donovan@ucl.ac.uk)

The proposal should be submitted to the Ethics Accelerator Secretariat (ukpandemicethics@psych.ox.ac.uk) by **Thursday 7th October 2021**, 18:00 BST. The expected date for submission of the final report is **Thursday 3rd February 2022**, 18:00 GMT.

Peer Review

All proposals are subject to internal and external peer review.

All final products for the Pandemic Ethics Accelerator are peer reviewed.

What Will We Do with the Final Review?

We will publish the review, with the researcher(s) identified as authors, on the Pandemic Ethics Accelerator website. We may also write a Policy Brief based on the review; and we may offer researchers an opportunity to write a blog based on the review. In all outputs, the researcher(s) are clearly identified as authors, and the Accelerator is identified as the funder. If there is press or policy interest in the review, we will direct that interest to the author(s).

We ask that the author(s) do not publish the review elsewhere without express permission from the Pandemic Ethics Accelerator.

If authors go on to develop the review for academic publication, the Pandemic Ethics Accelerator would expect to be acknowledged as (one of the) funders of the work.