

## Written evidence from the UK Pandemic Ethics Accelerator (TYO 04)

### Public Administration and Constitutional Affairs Committee Coronavirus Act 2020 Two Years On inquiry

This submission provides evidence relating to **the use of data in policy and decision making** as it relates to the following topics of interest to the Committee:

- The transparency surrounding the use of data in decision-making relating to the renewals of the Coronavirus Act 2020.
- The evidence and procedures underpinning the six-monthly and annual renewal processes for the Coronavirus Act 2020 since its entry into force in March 2020.

We bring to bear expertise in the ethics of public data, particularly in domains of health and social care, as well as findings from the UKRI Pandemic Ethics Accelerator on the use of data in the covid-19 pandemic.

#### Executive summary

We present evidence that shows:

- The Coronavirus Act 2020 (the Act) led directly and indirectly to the creation, expansion and interlinkage of public-private data gathering infrastructure on a huge scale.
- The expansion of data gathering and data-use in policy was accompanied by ethical debate about trade-offs between, for instance, individual privacy and central government control, or the need for transparent commissioning versus commercial constraints.
- So far, scrutiny of the Act has failed to systematically evaluate the matters at the heart of these concerns.
- Two years on, there should now be a clearer picture of trade-offs and impacts on different individuals, groups and communities in the UK.
- As part of debates about further policy extensions, sunseting, or new forms of scrutiny, there is the need for public debate, deliberation, transparency and accountability mechanisms that reflect societal needs, norms and public values and how these have sometimes shifted during the pandemic. This is vital if trust in public institutions such as the NHS is to be maintained.
- **We recommend the establishment of a Select Committee inquiry** or independent review to **systematically review the collection of, and use of data in public policy decision making**, as well as the impact it has had on reducing the spread of covid-19.

#### 1. The *policy problem* the Coronavirus Act addresses has changed significantly in two years

1. In March 2020, Coronavirus was a long-term problem with no immediate solution. The Act was a radical and temporary policy change to regulate personal and organisational activities across the United Kingdom. The Act was predicated on getting the virus under control with a focus on (i) individual behaviour change, (ii) restrictions on movement and

economic activity, and (iii) the subsequent need for financial and institutional support in health sectors and across the wider economy.

2. The Act was written and passed in the face of significant uncertainty and ambiguity about the direct effects of covid-19 on the health of individuals, and about the impacts of the provisions of the Act on individual behaviour and well-being, on society and on the economy.
3. Since March 2020, major changes have taken place relevant to the ongoing scrutiny and renewal of the Act.
4. Most significantly, the definition of the *policy problem* has evolved. According to the Secretary of State for Health and Social Care, "the country's main line of defence [has shifted] from lockdowns to vaccinations".<sup>1</sup> It now seems likely that another shift in policy will be required, as governments frame responses to the pandemic and possible future endemics in terms of 'living with covid' over the coming years.

## 2. UK data infrastructure and evidence gathering capacity has grown

5. Knowledge about the virus has been informed by the rapid building of social, institutional and technological infrastructures for gathering evidence about the virus, about the impact of the virus, and about positive and negative impacts of legislative interventions mitigating and adapting to the virus have been established. These include:
  - i. NHS branded public-private Test and Trace infrastructure such as the NHS Covid App.
  - ii. Extensions to the NHS App, for instance the integration of vaccination certificates new links to GP data systems.
  - iii. Priority shielding and vaccine priority lists which integration national level data, local authority data and GP data systems.
  - iv. National, European, and global immunity certification systems that operate at and within national borders
  - v. New, expanded, and experimental datasets collated by the Office for National Statistics.<sup>2</sup>
  - vi. New and expanded data infrastructure across health and social care sectors such as the Care Home Capacity Tracker.<sup>3</sup>
  - vii. Expansion of public research based public health surveillance such as the ZOE Covid-19 Symptom Study App.<sup>4</sup>
  - viii. The interlinkage and sharing of data between public health and researcher, departments and public services including public health data facilitated by COPI

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<sup>1</sup> Hansard. (2021). Coronavirus Act 2020 (Review of Temporary Provisions) (No. 3) on Tuesday 19 October 2021.

<sup>2</sup> See <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases>

<sup>3</sup> Getting the basics right in digital social care transformations (2021) by O'Donovan in *The BMJ*. <https://blogs.bmj.com/bmj/2021/11/09/cian-odonovan-getting-the-basics-right-in-digital-social-care-transformations/>

<sup>4</sup> Real-time tracking of self-reported symptoms to predict potential COVID-19 (2020) by Menni et al in *Nature Medicine* <https://doi.org/10.1038/s41591-020-0916-2>

6. These data systems and infrastructure change the context of scrutiny in two regards.
  - I. They **provide evidence to assist the scrutiny of the Act**, not available in March 2020, reducing uncertainty in some cases, but also increasing ambiguity in others (for instance when competing evidence points to divergent options for strategic action).
  - II. Given the role data now plays in decision making in government, in the economy and across health and social care sectors, **data infrastructure must also be the focus of new and strengthened scrutiny** on pandemic policy to ensure they align with public values and are accountable.

### 3. Reasons for scrutinising data-use in pandemic policy

7. The expansion of data infrastructure (§2) to gather and interlink data has been met by debate over their ethical implications. In the early days of the pandemic these debates can be characterised as arguments over **trade-offs between privacy on the one hand and centralised control and surveillance** on the other. Examples include concerns about the *NHS covid-19 contact tracing app*, proposed *immunity certification systems*,<sup>6</sup> and systemic gaps in social care data.<sup>7</sup>
8. A second set of ethical concerns arose around how the infrastructures have been built. These include concerns about the involvement of multinational firms and consultancy staff in public health infrastructure, especially the NHS, and cost and value-for-money concerns about capital expenditure and operational costs and accountability.<sup>8</sup>
9. **Two years on, there should now be a clearer picture between of the value of this trade-offs.** For instance, has it been worth handing over all this data in order to enable test and trace?
10. Despite the expansion of available public data noted above, **these data have not been systematically used to clarify these trade-offs.** We note that transparency in the use of data is vital if public trust in public institutions is to be built and maintained. Indeed, there is some evidence that suggests a diminishing trust in health institutions such as the NHS.<sup>9</sup> At the very least, public trust in public institutions cannot be taken for granted.

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<sup>5</sup> Debate needed on post-pandemic rules for medical data (2021) By O'Donovan in *Research Professional News*. <https://www.researchprofessionalnews.com/rr-news-political-science-blog-2021-12-debate-needed-on-post-pandemic-rules-for-medical-data/>

<sup>6</sup> O'Donovan, C., Smallman, M., & Wilson, J. (2021). *Immunity certification infrastructures and ethics: Principles and strategies for decision making*. UK Pandemic Ethics Accelerator. <https://ukpandemicethics.org/wp-content/uploads/2021/05/Immunity-certification-infrastructures-and-ethics-3.pdf>

<sup>7</sup> O'Donovan, C. (2021). *Issues and options for UK social care data policy*. UK Pandemic Ethics Accelerator. <https://ukpandemicethics.org/wp-content/uploads/2021/11/Data-use-EA-LTCcovid-seminar-report-16-November.pdf>

<sup>8</sup> Coronavirus: lessons learned to date. UK Parliament Health and Social Care Committee. <https://committees.parliament.uk/work/657/coronavirus-lessons-learnt/news/157991/coronavirus-lessons-learned-to-date-report-published/>

11. Increasing ongoing scrutiny of data-use in pandemic policy is also important because scaling back data-use to pre-pandemic levels is not feasible. Data will be vital in helping us understand the problems like long-Covid for instance, which now affect more than a million people in the UK, <sup>10</sup> and require new forms of interdisciplinary medical science to be funded.<sup>11</sup> Data infrastructures are also vital in helping identify ongoing mental health impacts, and the effect of policy on disabled people and marginalised communities.
4. The grounds for examining how the ethical implications and actual impacts of data-use in policy can be accomplished
  12. The Act provides two mechanisms by which Parliament can scrutinise it: (i) the Secretary of State is required to publish a report every two months on the use of non-devolved aspects of the Act. (ii) Every six months MPs vote to renew, or not, the Act's provisions.
  13. Neither of these are sufficient to address the concerns in §3.
  14. In the first instance, better scrutiny might be achieved by granting MPs "the power of initiative" to selectively suspend or expire specific provisions of the Act. MPs at present may only vote to renew or expire the Act in whole. But this procedural fix is unlikely on its own to direct attention towards the complex issues detailed above.
  15. Recent research on public values and ethics commissioned by the UK Pandemic Ethics Accelerator points to some priorities in this area.<sup>12</sup>
    - i. Members of the public have concerns about the secrecy surrounding procurement contracts with private companies, the tendering of PPE contracts, early failures of the track and trace app and the lack of public involvement in decision-making.
    - ii. When asked, they say they want meaningful involvement in decision making on pandemic policy. This might be facilitated through processes such as public dialogues, assemblies, and citizen juries at multiple levels.
    - iii. People want the trustworthiness of national institutions like the NHS and governments to be improved. We note that the conditions in which public trust is built are complex and have shifted significantly over the course of the pandemic. We've seen public trust diminish when public engagement and communication has not been clear. However, one way people say trust can be rebuilt is through visible collaboration across home nations. Data infrastructures are well placed to achieve this but discussions about the public value of these must be made imitated in the public eye.

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<sup>9</sup> Public Trust, Deliberative Engagement and Health Data Projects: Beyond Legal Provisions (2021) by Bharti, O'Donovan, Smallman & Wilson in *Engaging Science, Technology, and Society*. <https://doi.org/10.17351/ests2021.1197>

<sup>10</sup> Office for National Statistics. (2022, January 6). *Coronavirus (COVID-19) latest insights*. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19/latestinsights#long>

<sup>11</sup> Banerjee, A. (2021, March 31). Long covid—Looking across data, diseases, and disciplines. *The BMJ*. <https://blogs.bmj.com/bmj/2021/03/31/long-covid-looking-across-data-diseases-and-disciplines/>

<sup>12</sup> *Pandemic ethics: A public dialogue* (2021) by Hopkins Van Mil and the UK Pandemic Ethics Accelerator <https://static1.squarespace.com/static/56f16de77da24f3e5612733b/t/614c8bae3d881c1e28957279/1632406454206/HVM+Pandemic+Ethics+Report+Sep21.pdf>

- iv. People say they want decision makers to find ways to ensure concerns about individual and collective values are not in conflict. People understand that pandemic decision making is often more complex than arguing for or against personal liberty.
16. Given these findings, we suggest an opportunity to renew covid-19 legislation may be in opening-up debate on the future of the Act and pandemic policy to the UK public.
17. Furthermore, **we recommend the establishment of a Select Committee inquiry or independent review to systematically review the collection of, and use of data for in public policy decision making**, as well as the impact it has had on reducing the spread of covid-19. Any such inquiry would include an element of public deliberation across the UK to understand the diversity of public perceptions of data use.

#### About this evidence submission

This submission was supported by the UK Pandemic Ethics Accelerator (grant number AH/V013947/1). The submission was written by Dr Cian O'Donovan, Dr Melanie Smallman and Professor James Wilson as part of the Accelerator's Data Use workstream. For further details contact Cian O'Donovan at the Department of Science and Technology Studies, UCL, Gower Street, London, WC1E 6BT. Email [c.o'donovan@ucl.ac.uk](mailto:c.o'donovan@ucl.ac.uk).

The submission has been reviewed within the UK Pandemic Ethics Accelerator, a UKRI/AHRC-funded initiative that aims to bring UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during pandemics. We provide rapid evidence, guidance, and critical analysis to decision-makers across science, medicine, government and public health. We also support public debate on key ethical challenges. See <https://ukpandemicethics.org>.

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