Written evidence from the Wellcome Centre for Ethics and Humanities (COV0156)

The Wellcome Centre for Ethics and Humanities is a multidisciplinary research centre, based at the University of Oxford.

The current COVID-19 outbreak clearly presents novel challenges, both in terms of difficulties for maintaining public health but also in assuring that governmental responses are ethically sound and honour, as best as possible, fundamental human rights. Conflicts between values are arising, and in responding to the crisis public officials will have no choice but to adopt substantive stances, prioritising some values while sacrificing others. These decisions cannot be taken lightly. We hope that the recommendations made herein will be taken into consideration, and that the measures to address COVID-19 can be effective in supporting increased public health while valuing and upholding human rights.

Drawing on our expertise in philosophy, social science and history, in this written submission we:

- Outline the Siracusa Principles as a basis for enacting justified restrictions on human rights
- Present a precautionary approach to rights restrictions and encourage evidence based public health measures
- Consider how the implementation of two debated interventions (contact tracing apps and immunity certificates) may affect human rights
- Outline who may be disproportionately affected by government measures and recommended community engagement as essential to ethical governance

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What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?

The Siracusa principles

COVID-19 has clearly presented exceptional circumstances, under which the need for rights restrictions has emerged. The Siracusa principles are widely known, internationally agreed-upon, bases for restricting human rights under exceptional circumstances. The principles allow for rights restrictions, provided that the restrictions are:

- In accord with law
- In the interest of a legitimate objective
- Necessary to achieve the objective
- The least intrusive and restrictive means available
- Based on scientific evidence
- Not drafted or imposed arbitrarily

These principles are a useful basis for investigating the legitimacy and acceptability of the UK's COVID-19 response.

Precautionary approach to regulatory decision-making, plus evidence gathering

Recommendation: In the context of high importance as well as high uncertainty, it is advisable that a precautionary approach to rights restrictions is taken, in tandem with evidence gathering on the efficacy of public health measures.

The precautionary principle in its weakest version asserts that uncertainty regarding the adverse effects of an activity should not automatically bar adoption of measures to prohibit or otherwise regulate the activity (http://www.cserge.ucl.ac.uk/Stewart.pdf#page=6). Stuart et al. propose the following principles:

- Scientific uncertainty should not automatically preclude regulation of activities that pose a potential risk of significant harm
- Regulatory controls should incorporate a margin of safety; activities should be limited below the level at which no adverse effect has been observed or predicted
- Activities that present an uncertain potential for significant harm should be subject to best technology available requirements to minimize the risk of harm unless the proponent of the activity shows that they present no appreciable risk of harm
- Activities that present an uncertain potential for significant harm should be prohibited unless the proponent of the activity shows that it presents no appreciable risk of harm

If public health measures that are restrictive of human rights are implemented despite scientific uncertainty, as per the above principles, on-going assessments of the effectiveness of these measures are crucial to ensuring their continued legitimacy.

It is very difficult to predict how effective a particular measure will be when responding to a novel pathogen. Therefore, as well as learning from relevant historical examples and the measures of other countries, we need real-time monitoring of the effects of the interventions.

Transparency of process and decision-making

There is a general consensus that citizens have a right to access internally held information, as this better enables civil society to: hold government and/or key decision-makers to account; promotes good governance; and improves public policy and efficiency.

Furthermore, evidence shows that in democratic societies people need to understand for compliance with public health measures. The more people know, the more prepared they are, and the more compliant they are.

Transparency in decision-making procedures is crucial not only for the general public, but also for those tasked with the implementation of measures, such as healthcare workers and first responders. With clear guidelines and expectations (e.g. regarding triage decisions), practitioners are better prepared to navigate the tension between individual patient care and public health. Such preparations, in turn, can alleviate potential distress and help to retain vital workers, and thereby support patients' right to life. These principles will extend to other actors tasked with implementing measures, such as school teachers.

Recommendation:

- The public must be given clear information, which is easily accessible and comprehensible. This includes accessibility in multiple languages and information outlining benefits as well as risks.
- Information delivery should be constructed with a comprehensive plan to combat misinformation.
- Workers tasked with implementing public health measures, e.g. healthcare workers, should be equipped with clear institutional guidelines.
- The timelines and reversibility of emergency measures should be publicised, to help navigate post-pandemic work and social life.

What will the impact of specific measure taken by Government to address the COVID-19 pandemic be on human rights in the UK?

Digital contact tracing and exposure notification apps

Digital contact tracing, as an interventional strategy, can be used to trace individuals' movement and to notify people who may have come into contact with positive cases of exposure. Infringement of privacy, potential discrimination, malevolent access to data by third parties, restrictions of freedom of movement are some of the risks that have been associated to these applications.

The principles outlined above are key for an ethical implementation of these technologies:

- There are many uncertainties about the effectiveness of these apps and their potential harms once they are rolled out. A precautionary approach in addition to continuous assessment of efficacy and well-established oversight mechanisms would be advisable.
- The decision-making process underlying the use of these apps has so far being obscure and has been criticised for this. Transparency is key not only as a democratic value but also to ensure trust and therefore effectiveness of the tool.

In assessing the human rights implications of these apps, it may be useful to consider both individual harms as well as societal harms. The former is well understood in terms of violations of individual privacy, whereas the latter relate to the use of data to alter social relations in ways that affect some groups disproportionately. The Cambridge Analytica scandal has shone a light on how data could be repurposed in ways that endanger the democratic process and compromise the values we uphold as a society. In similar ways, retention of health data for research purposes, without the bounds set out by clear legislation provides opportunities for uses that may not be acceptable to society, regardless of whether

such uses result in specific harms to particular individuals. (It is possible to envisage, for example, health data being used to improve efficiency by tailoring health services in ways that do not guarantee equitable provision to different regions/groups).

Immunity certificates

The possibility of immunity certificates (or "passports") as a means of identifying those who have contracted and recovered (or are otherwise immunized) and exempt them from existing lockdown restrictions could alleviate potential human rights violations (for example, they could ease restrictions of movement and the right of assembly), at least for some people.

Notably, this strategy risks incentivizing individuals to deliberately contract the virus, so that they can reap the social and economic benefits of immunity passports. This would be detrimental to both individuals who expose themselves to potential serious illness, and those at risk of onward transmission.

Relatedly, some will be incentivized much more than others - e.g. lower income groups, or those with employment that cannot be undertaken from home. That is, some social and economic groups will be disproportionately affected by the economic impact of 'non-immunity' and care should be taken to ensure that particularly vulnerable groups are not made worse off by governmental responses.

Which groups will be disproportionately affected by measures taken by the Government to address COVID-19 pandemic?

To identify those groups most at risk of social, emotional, psychological, economic and human rights costs of the COVID-19 response, we must consider a risk spectrum. All individuals lie on this spectrum, and level of risk can be determined by i) physical, social, economic, and attitudinal vulnerabilities, ii) severity of change in circumstance, and iii) availability of coping resources.

We outline this risk spectrum and make recommendations as to how harms may be minimised, and equity promoted, below.

A relevant breakdown of vulnerable groups may include:

Physical:

- Clinically vulnerable to COVID-19 (including the elderly) – shielded group.
- People with a medical condition (not clinically vulnerable to COVID-19)
- People with disabilities: intellectual disabilities, mental health, physical disabilities.
- People in prisons: prisoners and prison workers
- People with medical needs but unable to receive care/assessment
- Health and social care workers - higher risk of severe illness, increased working hours

Economic:

- Informal employment: informal workers, sex workers
- Unemployed: job seekers, prison releases
- Formal employment: low income, zero hours contract, significant dependents
- Self-employed (income reduced or curtailed as a consequence of quarantine measures)
- Informal housing: homeless, traveller communities, temporary housing

- Informal migrants: asylum seekers, unaccompanied asylum seeking children
- Formal migrants: refugees, UK citizens abroad

Social:

- Women and girls: domestic violence, reproductive rights (IVF, abortion, FGM), increased caring responsibilities, 70% of the healthcare workforce are women
- Single parent families or parents without extended family support.
- People living alone (increased risk of social isolation)
- Care leavers and looked after children

Attitude:

- Groups vulnerable to increased prejudice and stigma: ethnic minorities

Recommendation: The importance of engagement

Meaningful community engagement is vital for the effective response to the pandemic and for upholding human rights. Engagement helps identify risks and strategies to mitigate harms that are context specific, and allows for disenfranchised groups to acquire a voice.

Engagement is above all a two-way listening process, through a variety of channels and with abundant and effective feedback loops. Feedback, in turn, should generate rapid action. Such action may not always lead to the change desired, but through meaningful engagement decisions can be discussed, responded to or framed differently, ultimately becoming acceptable. Good engagement should not be done *to* communities but must be done *with* communities and *by* communities themselves.

Based on existing historical analysis and social science we recommend the following strategies:

1. Ongoing evaluation of the engagement process to ensure the response being implemented remains appropriate and fair.
2. A form of stakeholder analysis needs to identify the community representatives that people really trust and who will act as a bridge between officials and communities.
3. Clear delimitation and communication of the role of these representatives.
4. Where necessary, an oversight group consisting of representatives of implementers, regulators, and recipients may need to be formed. The group would oversee the implementation and evaluation of any response strategy.
5. Systematic check of impact to vulnerable groups when evaluating potential policies, specifically considering vulnerabilities, severity of impact, and availability of alternative resources. Where a negative impact is necessary, that impact should be flagged up to relevant departments/organisations and mitigation strategies sought. This could increase public trust in the decision-making process.
6. Engagement should give serious forethought to the likely misinformation and disinformation campaigns that will accompany policy announcements, in order to pre-emptively prepare methods of maintaining trust with the public.

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