

SUBMISSION FROM THE MASON INSTITUTE FOR MEDICINE LIFE SCIENCES AND THE LAW, THE UNIVERSITY OF EDINBURGH, SCHOOL OF LAW

The Mason Institute is an interdisciplinary network at the University of Edinburgh. The Institute investigates the ethical, legal, social and political issues at the interface between medicine, life sciences and the law. The MI provides internationally recognised academic and policy leadership in the socio-legal, medical and life science governance, and bioethics fields.

This submission is provided in response to UK Parliament's Human Rights Committee call for evidence on the human rights implications of the Government's response to COVID-19. We note that the Committee is seeking views on the following three questions, which we address in turn below:

1. What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?
2. What will the impact of specific measures taken by Government to address the COVID-19 pandemic be on human rights in the UK?
3. Which groups will be disproportionately affected by measures taken by the Government to address the COVID-19 pandemic?

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

Measures taken by the Government must comply with the Human Rights Act 1998 as well as all international human rights instruments to which the UK is a signatory.¹ To comply, the Government must not only refrain from instituting measures that infringe human rights, but also ensure effective protections against infringements by state and private actors, and provide effective remedies where rights are infringed.

We recommend that the Government conduct and publish transparent human rights impact assessments of all COVID-19 legislative and policy measures.² In doing so they should work closely with the Equality and Human Rights Commission, and civil society (particularly those groups who may be disproportionately affected by these measures - see Q3 below) to ensure compliance and help build trust.

¹ These include the European Convention on Human Rights (ECHR); the European Social Charter; the International Covenant on Economic, Social and Cultural Rights (UNCESCR); the International Covenant on Civil and Political Rights (ICCPR); the UN Convention on the Rights of the Child (UNCRC); the Convention on the Elimination of All Forms of Discrimination Against Women (UNCEDAW); the International Convention on the Elimination of All Forms of Racial Discrimination (UNCERD); and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

² Human rights impact assessments have proven to be an important mechanism for building human rights and equality into the development of policies and practices across the public sector in Scotland (see www.equalityhumanrights.com/en/advice-and-guidance/equality-and-human-rights-impact-assessment-project).

We agree with the Scottish Human Rights Commission that human rights impact assessments “can set legal ‘red lines’ below which state actions must not fall” and protect against disproportionate impacts on the those who face most disadvantage.³ Nevertheless, the Government’s legal and ethical obligations are not exhausted by compliance with human rights law: all measures must also be compliant with other legislation that may be implicated in COVID-19-related measures, *inter alia*, the Equality Act 2010, The Privacy and Electronic Communications (EC Directive) Regulations 2003, and the Data Protection Act 2018; and be defensible with respect to their impacts on human health and wellbeing and the principles of justice.

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

(i) Decision-making in delivery of critical and end of life care

- Decisions about allocation of critical care, or the application of ‘Do not attempt cardio-pulmonary resuscitation’ (DNACPR) orders, must not be made on the basis of patients’ age, sex, (dis)ability, capacity for independent living, or other characteristics, where these characteristics have no direct bearing on expected clinical outcomes.
- However, allocating critical care on the basis of expected clinical outcomes can still result in potentially unlawful discrimination, where either access to care or outcomes themselves are influenced by social and health inequalities or disability.
- Omissions by the Government to ensure that health care providers are aware of their obligations to provide non-discriminatory access to life-sustaining treatment could fail to comply with the state’s positive responsibilities under ECHR/HRA Art.2 (right to life) and Art.8 (right to private and family life), and UNCESCR Art.12 (the right to the highest attainable standard of health). Guidance or policies on provision of life-saving treatment that discriminate, or blanket policies implementing DNACPR orders across specific groups, may also be in violation of ECHR/HRA 1998 Art.14 (entitlement to enjoy Convention rights and freedoms without discrimination).
- Indirect discrimination in provision of critical care or implementation of DNACPR orders on the basis of protected characteristics (including age and disability) is unlawful under Equality Act 2010 where these practices cannot be justified as proportionate means of achieving a legitimate aim.
- **We recommend that:**
 - ***The Government provide healthcare professionals with unambiguous guidance on the need to make decisions about critical and end of life care on an individual basis, in discussion with patients or their families, and according to clinically relevant considerations in ways that do not perpetuate systematic indirect discrimination.***
 - ***It is the Government’s responsibility to ensure that all such guidance is informed by robust understanding of the risks of systematic discrimination resulting from***

³ Scottish Human Rights Commission, ‘Human Rights Impact Assessment’ <https://www.scottishhumanrights.com/economic-social-cultural-rights/impact-assessment/#impact-assessment-5309>(accessed 22/05/20).

existing health and social inequalities. Discriminatory outcomes warrant concern even where these are not in violation of specific legal provisions.

(ii) Provision of personal protective equipment (PPE) and testing for health and social care professionals

- ***The Government has a responsibility to ensure that appropriate PPE are available to all staff, and to provide testing where necessary to secure their health and safety.*** Failure to do so may be in violation of UNCESCR Art.7 (the right to safe and healthy working conditions) and Art.12 (right to the highest attainable standard of health), to professionals' right to a safe and healthy workplace under the Health and Safety at Work etc Act 1974, and to professionals' own and patients' / clients' ECHR/HRA Art.2 right to life.

(iii) Access to non-COVID-related healthcare

- While health resources inevitably need to be redirected to care for COVID patients, ***the Government must ensure that there is proportionate and justifiable balance between resources dedicated to the emergency response and resources allocated to other key areas of healthcare***, such as cancer screening and treatment, and reproductive health services. Failures to achieve such a balance may not be compliant with the Government's positive responsibilities under ECHR/HRA Art.2 (right to life) and Art.8 (right to private and family life), and UNCESCR Art.12 (right to the highest attainable standard of health). Such failures may also result in systematic discrimination (for example, gender- or age-based discrimination in access to health care) in ways that are unlawful under the Equality Act 2010.

(iv) Processing of sensitive personal data (including the introduction of government-sanctioned apps for contact-tracing and the establishment of new data initiatives).

- Gathering and processing of personal data by apps and within and between databases raise serious concerns about infringements of privacy, discrimination and stigmatisation, and has potential for unprecedented levels of enduring population surveillance and social control.
- Respect for privacy is not only critical to protect individual rights, but also to maintain trust in public institutions, which in turn is important to promote compliance with public health interventions.
- Privacy concerns are particularly acute because of the involvement of non-government actors, including private companies, in the design and development of apps and the processing of personal data, without transparent oversight. Under UN Guiding Principles on Business and Human Rights, the Government is responsible for ensuring activities are compliant with international human rights law, including activities carried out with/by private companies. Involvement of private companies also risks data being transferred outside the EU and the protections of the GDPR.
- Processing and retention of information relating to an individual's private life by public authorities and private actors may constitute interference with private life under Art. 8 of the ECHR/HRA 1998. Article 8 is a qualified right, but any interferences must be lawful, necessary and proportionate. As health data are considered inherently sensitive, heightened standards of protection and justification for any infringements apply.

- **We recommend:**
 - **Robust independent oversight of the design, purpose and functionality of new databases and apps, how data is collected, processed and shared, and the role of third-party actors in this.**
 - **The Government must be transparent about the objectives for which these databases and apps are introduced, how data will be used (including any further prospective uses), and the identities and roles of all partners and contractors involved.**
 - **Public engagement and deliberation are critical for understanding public concerns, demonstrating commitment to transparency and priorities, and building trust.**
 - **Apps must be designed to collect and process minimum identifying sensitive data by the least privacy-infringing means required to perform their necessary function and their use subject to regular review**
 - **There must be a commitment to cease processing and storage of personal data at the end of the public health emergency, underpinned by in-built design capabilities.**

(v) Lockdown

- Requirements to stay at home are likely to have a disproportionate impact on several groups, including women and children and those living with disabilities, chronic conditions, mental health problems and social care needs (see further below).
- There has been a rise in domestic violence/abuse as a result of lockdown.⁴ By failing to meet this risk with additional provisions for safeguarding at-risk family members Government may be failing to meet its obligations under ECHR/HRA 1998 Art.2 (right to life) and Art.8 (right to private and family life) and its obligations under UNCRC Art.17 to protect children from neglect, maltreatment and abuse.
- **We recommend that any future implementation of recommendations from public health models that depend on longer-term home-confinement of particular segments of society, be evaluated in relations to obligations under human rights instruments above and the Equality Act 2010.** Failure to do so may also infringe the ECHR/HRA Art.14 right to freedom from discrimination in respect of protections under Art.8 (right to private family life) and Art.5 (right to liberty).

(vi) Changes to asylum and resettlement policy and practice

- Changes (including paused asylum interviews and delays to appeals) may infringe asylum seekers' UDHR Art.14 right to asylum and ECHR/HRA Art.8 right to private and family life, as well as denial of wide range of a rights as a result of statelessness.
- Rehousing of asylum seekers by Local Authorities and private landlords may be a violation of Art.8 rights to private and family life and the right housing and an adequate standard of living under UDHR Art.25. Where housing supplied precludes self-isolation, this may violate

⁴ Bradbury-Jones, C., & Isham, L. (2020). The pandemic paradox: the consequences of COVID-19 on domestic violence. *Journal of clinical nursing*.

asylum seekers' Art.2 right to life and right to the highest attainable standard of health in accordance with UNCESCR Art.12.⁵

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

Many of the measures implemented and proposed by the UK Government raise considerable ethical and social justice concerns and are likely to exacerbate existing social and structural inequalities. There are also likely to be significant long-term physical and mental health impacts across all the groups listed below. Going forward, all proposed models and public health measures should incorporate an analysis of how they might affect particular segments of the population, supported by data collection (segregated by social and economic factors) to track differential and potentially discriminatory effects. Below we highlight issues affecting specific groups, which require urgent attention.

Women

- Restrictions in access to reproductive and sexual health care as a result of the pressures on healthcare and lockdown.⁶
- Rise in domestic violence/abuse as a result of lockdown and increased economic hardship.⁷
- Loss of (already precarious or informal) employment and threats to future employability (particularly affecting black and minority ethnic (BAME) women) as a result of the economic environment and disproportionate share of informal caring roles.
- Risks of disproportionate harm as a result of over-representation in institutional caring roles exacerbated by shortage of PPE.

BAME groups and immigrant minorities

- 35% of patients in intensive care as a result of COVID-19, and 68% of NHS staff who have died so far, are BAME.⁸ This is likely to reflect multiple complex, intersecting factors including socio-economic inequalities, and disproportionate representation of BAME individuals in caring roles (institutional and informal) and at the frontline of the outbreak. These intersecting factors require thorough investigation
- Impediments such as language affect triage decisions, and how immigration status affects access to health care.
- Loss of (already precarious or informal) employment and threats to future employability as a result of economic impacts.

⁵ The Refugee Council, 'Changes to Asylum & Resettlement policy and practice in response to Covid-19' (18 May 2020) <https://www.refugeecouncil.org.uk/latest/news/changes-to-home-office-asylum-resettlement-policy-and-practice-in-response-to-covid-19/> (accessed 22/05/2020)

⁶ Marie Stopes International, 'Our Response to the COVID-19 Crisis' <https://www.mariestopes.org/covid-19> (accessed 22/05/20)

⁷ Bradbury-Jones, C., & Isham, L. (2020). The pandemic paradox: the consequences of COVID-19 on domestic violence. *Journal of clinical nursing*.

⁸ Tony Kirby. (2020) 'Evidence mounts on the disproportionate effect of Covid-19 on ethnic minorities', *The Lancet*

- Risks of discrimination and stigma arising from public health measures such as tracking apps and facemasks may fall disproportionately on BAME individuals (for example, young men of BAME descent wearing face-coverings may be subject to racial profiling by police, constituting unlawful discrimination under the Equality Act 2010).⁹

Children and young people

- Prolonged school and childcare closures, with consequent loss of education, safeguarding, free school meals, and benefits to social, physical and mental wellbeing, may infringe children and young people's rights under, *inter alia*, the ICESCR and UNCRC.
- Rise in domestic violence/abuse as a result of lockdown and increased economic hardship.
- Loss of contact with non-resident parents where there are inadequate measures to ensure prior contact arrangements may be in violation of Art.8 right to private and family life.
- A significant proportion of unpaid carers, who are disproportionately burdened by the social, economic and mental health impacts of lockdown, are under 18.¹⁰

People with existing conditions and disabilities

- Reduction in existing health, social care and supported living services (engaging numerous articles of the UNCRPD).
- Direct and indirect discrimination in triage and allocation of healthcare resources, including life-saving treatments and critical care
- Delays and difficulties in accessing screening, diagnosis and treatment

People living in poverty

- There is clear evidence that the severity of many impacts is being most harshly felt in areas of multiple deprivation.¹¹
- Those dependent on public services, with restricted access to health and welfare and social care, and those suffering from homelessness and insecure housing, are being exposed to greater risks to their health, safety and wellbeing.¹²
- Those suffering from food precarity are experiencing greater difficulties in accessing food as foodbanks and food distribution charities face yet greater resource and operational challenges.¹³

⁹ Derrick Bryson Taylor, 'For Black Men, Fear that Masks will Invite Racial Profiling', New York Times, 14 April 2020. <https://www.nytimes.com/2020/04/14/us/coronavirus-masks-racism-african-americans.html> (accessed 22/05/20).

¹⁰ For example, this age group makes up around 29,000 of 700,000 carers in Scotland (see, <https://www.gov.scot/policies/social-care/unpaid-carers/>).

¹¹ Office of National Statistics 'Statistical Bulletin 1 May 2020: Deaths involving COVID-19 by local area and socioeconomic deprivation: deaths occurring between 1 March and 17 April 2020'.

¹² Leah Rodriguez, '5 Reasons COVID-19 Will Impact the Fight to End Extreme Poverty' (Global Citizen, 7 April 2020) <https://www.globalcitizen.org/en/content/how-covid-19-impacts-fight-to-end-extreme-poverty/> (accessed 22/05/20).

¹³ The Food Foundation 'COVID-19: latest impact on food', March 2020. <https://foodfoundation.org.uk/covid-19-latest-impact-on-food-2/> (accessed 22/05/20).

- The uninsured and those living on daily income are gravely impacted by business closures, and lack of access to employment.

People with insecure immigration status, migrant workers, refugees and asylum seekers

- These groups will be particularly burdened by the social, economic and mental health impacts as detailed under Question 2. They are also subject to the specific inequity of exposure to the burden of measures introduced to protect citizens without enjoying many of the protections afforded to citizens.¹⁴

Digital divide

- Where key services, information and sources of social support are delivered by digital means there is a significant risk of exclusion of groups without internet access, devices, or digital literacy. This includes socioeconomically deprived groups, older people and those without (reliable) broadband connections.

¹⁴ Institute for Public Policy Research, 'Briefing: Migrant workers and coronavirus: risks and responses', 25 March 2020. <https://www.ippr.org/blog/migrant-workers-and-coronavirus> (accessed 22/05/20).