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Trusting the Government to Do the Right Thing: Data Ethics in Australia's Pandemic Response

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Abstract
After a brief overview of ethical issues in an Australian context catalyzed by the current pandemic, this article focuses on data protection in the light of recent debates about COVID-19 data tracking in Australia and globally. This article looks at the issue of trust as a fundamental principle of effective and ethical COVID-safe measures undertaken by the government. Key to ensuring such trust are Habermasian participatory dialogs, which assume trust as a condition of authentic illocution, and an emphasis on short-term data capture.

Keywords: COVID-19; pandemic; data tracking; privacy; trust ethics; end-directed trust

A pandemic response that requires personal burdens and economic costs is only justified if the government can demonstrate that there is a reasonable chance of protecting the public health.[1] This sets up a central issue in any pandemic response: justified public trust in that country's institutions and their actions. Such trust is predicated on various factors such as efficiency, transparency, and equity. An ethical pandemic response would demonstrate equity in resource allocation and adherence to familiar virtues of respect for citizens through taking fair and reasonable action and explaining issues transparently and accountably.

In 2007, writing on influenza pandemic preparedness, Lawrence Gostin and Benjamin Berkman note two major ethical issues.[2] The first is that of distributive justice, namely of access to and allocation of resources, requiring society to balance equitable access against medical vulnerability, and make decisions about categories that determine worth through utility (prioritizing frontline healthcare workers for vaccination or treatment, for example). Distributive justice is usually seen as central to public health initiatives and public trust. One interesting discussion on this topic took place in April 2021 as a result of the country's halting flights for Australian citizens caught in India (they resumed in mid-May, but only at the rate of one per week).[3] The media debate about not offering an exit to Australian citizens and permanent residents, effectively abandoning them in a country with overstretched health services, as well as threatening large fines to anyone who did return, suggested that not all citizens are equal. (Two Australian citizens have died, so far, in India, from COVID-19.) While the debate included accusations of racism against the government, the main issue was that of the responsibility of a government to extricate its citizens from danger, namely the meaning of citizenship equality.[4]

A similar discussion in Australia has revolved around whether the government is doing enough to provide vaccinations for the disabled as well as rural communities.[5] Distributive justice includes the ethical issue of how to determine the "tipping point" where decisions are no longer made under the conditions of normal care because there is a requirement to implement the most effective (whatever that means precisely) use of the relevant resource, due to scarcity.[6] That decision triggers the next ethical dilemma of egalitarianism (first come first served) versus utilitarianism (save the most). Triaging according to maximizing benefit is usually applied as saving either the most lives possible or the most life-years possible. Using comorbidities to estimate long-term survival risks reinforces systemic

disparities in health; however, usually only patients with severe, advanced, and unrecoverable chronic illness resulting in a life expectancy of 12 months or fewer would be considered less eligible for ventilator allocation.[7] Savulescu takes a rather harder look at triaging systems as "sanitizing rationing," defining a "flatten the curve" approach as paternalism:

> …when the doctor claims that they will withhold ventilation when it is harmful, this is a paternalistic value judgement. Where a ventilator has some chance of saving a person's life, it is largely up to that person to decide whether it is a harm or a benefit to take that chance.[8]

Australian COVID-19 hospital figures have been so low in 2020–2021 that the country has been spared such decisions.

The second pandemic ethics issue in Gostin and Berkman's view occurs when individual human rights must be balanced against collective responsibility, as in the case of restrictions on autonomy and privacy due to mandated lockdowns.

Restrictions on movement were made. While reasonable citizens would agree that lockdowns are required to flatten the curve, the debate on whether the impact on both the economy (border closure has decimated Australia's international student market, for example) and mental health means that lockdowns should be shorter than medically advised is an ongoing and well-covered global one. Australia is no exception to this debate, particularly given that one of its cities, Melbourne, at 110 days ranks as having experienced one of the longer global lockdowns (Buenos Aires being the longest). However, restrictions on movement have been greeted by Melbourne citizens with reasonable calm and small protest groups.

Another aspect of such restrictions is the right to leave the country, with strict waivers for those only with specific reasons allowed to go, and who must undergo 2 weeks of hotel quarantine (for which they must pay) on return. Does the government have the right to effectively "jail" its citizens within fortress Australia? Australia's outward travel ban may be in violation of its obligations under the 1966 *International Covenant on Civil and Political Rights*, which it ratified in 1980.[9] Several legal challenges have been made to travel bans, with the fourth being rejected in May 30, 2021, on the grounds that it would limit the Health Minister's powers under the 2015 *Biosecurity Act* to impose measures to prevent the spread of COVID-19.[10]

Other issue relating to autonomy is that of mandatory vaccination, and attendant issues such as mandated vaccination passports, and whether healthcare workers should be required to vaccinate.[11] There is precedent in Australia. Certain vaccinations for children are already linked in Australia to access to childcare and benefits under "no jab no pay" legislation.[12] The population is in tune with government policy on this issue; a 95% coverage in terms of child vaccination was reported in the country in May 2021.[13]

The size of the anti-vaxxer movement in Australia is difficult to measure, although vaccine hesitancy —a different and larger category—rose in the country in April–May, due to a slow government rollout and media hype around the risk of blood clots from the AstraZeneca mandated vaccine for those over age 50. This raised the issue of whether the government is ethically obligated to provide vaccine choice. Given the low risks associated with AstraZeneca, yet also the ban on that vaccine by certain European countries (France and Germany both raised the age at which the vaccine could be administered, although Germany later reversed that decision), vaccine fear has been an issue for those in the 50–60 age bracket. Should the government have acted to offer choice? As of the end of April 2021, fewer than 50% of those over age 50 were allegedly willing to be vaccinated, but this changed, however, when Melbourne saw another outbreak and went into lockdown again on May 28, 2021. Numbers heading for vaccination hubs soared.

What other ethical issues have been raised? Ben Bramble identifies the following: lockdown versus herd immunity, immunity passports, Personal Protective Equipment (PPE) shortages, triaging, the duty to assist, the duty of onlookers, and vaccine trials.[14] He omits economic issues under lockdowns and related debates around welfare and the efficacy of capitalism, and environmental issues. The pandemic has focused attention on the close link between human health and ecosystems, from wet markets and food resourcing to smog reduction under lockdowns, while unfortunately diverting resources from ecological projects to pandemic response.[15]

The Australian government's COVID-19 Health and Research Advisory committee defined the following topics at a 2020 workshop: resource allocation; implementation of public health measures; issues faced by healthcare providers; impact on Aboriginal and Torres Strait Islander peoples and communities; research ethics, and emerging from the pandemic—future planning.[16]

One particular issue that has received less attention that might be expected is that of the ethics surrounding data privacy. This may be because it is an extension of a long-running debate on what health data should be collected and stored, and for how long. The debate is often seen within the broader societal issue of who captures data and protects it (as Facebook failed to do from Cambridge Analytica), and how is it used—cue headlines about selling Facebook data to firms targeting minors with alcohol ads. An investigation by the Australian Broadcasting Corporation in 2018 found that HealthEngine, Australia's biggest medical appointment booking platform, was sharing people's personal information with personal injury law firms.[17]

The regulatory environment within which Australian healthcare data are managed includes the 2020 *Privacy Amendment of Public Health Contact Information*, established in Australia to provide stronger privacy protections for users. Use of Healthcare Identifiers and access to the My Health Record system are governed by the *Healthcare Identifiers Act 2010* (HI Act) and the *My Health Records Act 2012*, the *My Health Records Rule 2016*, and the *My Health Records Regulation 2012*.[18] These require, as one would expect, organizations collecting data to protect it from access, modification, or misuse.

Data sharing for international collaboration is one area that has expanded under COVID-19. Australian hospitals "own" the data of any medical trials, which are managed by those institutions' Health Information Managers, with ethics approval being required for any access. However, the EU's 2018 General Data Protection Directive (GDPR) has opened up a not yet entirely resolved question about to what extent GDPR restrictions can be imposed on Australian health researchers.[19] Views on the ethics of private data often use the argument that the individual is obligated to share data for the cause of scientific advancement. However, there is a difference between the consent given by those who participate willingly in medical trials, for instance, and general opening of population data sets. Another view is that medical data have value and those requested to share them should be aware of such "potential value"—difficult however to quantify.[20]

What has changed in terms of data management under COVID-19 in Australia? An amendment put to the Australian parliament in late 2020 made it mandatory from March 1, 2021, for vaccine providers to report all newly administered vaccines (particularly for COVID-19 and flu vaccinations) to the Australian Immunisation Register (AIR).[21] This raised data concerns; however, only approximately 10% of Australians have opted out of "My Health Record," the government's online information summary of patients' key health data.[22] This confidence in (or apathy toward) such data capture is probably due to the option provided, requesting permanent deletion of one's own record. The first reassurance in terms of consent to data capture, storage, and management seems to be the reassurance that it is temporary—"ethics exposure" is limited.

The Royal Australian College of General Practitioners, however, did recommend that this be made clearer, that is, that (1) the Government provide a full and detailed privacy disclosure statement and consent form for GPs to provide to their patients and (2) that patients should be able to opt out of reporting their personal information to the AIR (the GP would then be able to report de-identified information and not be fined).[23]

One significant aspect of COVID-19 data has been that of data tracking in terms of movement. Tracking is either private or public, as we can differentiate between tracking by phone (which can be left at home) versus tracking via CCTV (which cannot be circumvented as easily).[24] The Australian National COVID-19 Privacy Team convened in June 2020 to develop COVID-safe guidance and referrals from a variety of agencies.[25] The first approach was to promote the Australian COVIDSafe app, which approx. 5.6 million people (around 22% of the total population) downloaded within days of the launch on April 27, 2020.[26] Interest then stalled, numbers rising only to around six million, partly due to reports of limited efficacy.[27]

In the Australian context, it is difficult to assess whether issues of data privacy have influenced the lack of take-up, or whether the lack of perceived need, given low COVID-19 infection numbers in Australia, is the main driver. Given low numbers, the app is therefore limited (60% of the population and up is usually

required for any efficacy). There has been some ambiguity around how the main telcos in Australia share data on person mobility with the government or not.[28] However, a privacy survey conducted by the Office of the Australian Information Commissioner (OAIC) in 2020 noted that 60% of respondents agreed that "some concession must be made to privacy protections to combat COVID-19 for the greater good." The same proportion agrees that these concessions can be made as long as they are not permanent.[29] Tracking data are deleted after 21 days.[30]

Upon its release, COVIDSafe was supported by interim privacy protections outlined in a determination made under the *Biosecurity Act 2015*. On May 16, 2020, the OAIC was granted additional functions and powers in relation to COVIDSafe under Part VIIIA of the *Privacy Act 1988* (Privacy Act), which governs Australia's digital landscape. The protections put into this legislation included oversight by the OAIC, which only received 11 complaints in the second half of 2020, and voluntary deletion of data on request and "at the end of the pandemic."[31]

The *Privacy Act 1988* is currently under review to "ensure privacy settings empower consumers, protect their data and best serve the Australian economy,"[32] with the discussion paper on submissions to be released in 2021. The Privacy Act provides 13 Australian Privacy Principles (APPs), ranging from guidelines around market use, to access and security, to more specific situations such as international data sharing.[33] The main criticism of the *Privacy Act* is that it has limitations; we "lack a law that gives people the right to claim damages for release or misuse of private information," unlike New Zealand or the UK.[34]

Digital COVID-19 tracking apps or CTAs such as COVIDSafe are varied and complex and can be multi-component and co-dependent, so difficult to regulate.[35] They can also be vulnerable to cyber-attack.[36] QR location check-in software has now become the Australian standard for contact tracing. According to government data, more than 91,000 Victorian organizations signed up for the free Victorian Government QR Code Service across 125,000 different locations—with more than 21.5 million check-ins—an average of 280,000 a day.[37] A further push to get customers to use QR codes at every public place visited began in mid-March after it was revealed that one restaurant attended by a COVID-positive person had collected less than 50% of customers' tracking data on the night he dined there. On-the-spot fines were instituted of AUD1,652 (approx. 1,000 Euro). A 3-week check of app usage in April indicated that 37% of businesses were non-compliant.[38] Enforcement of the use of check-in QR codes at every place visited in Australia during the Melbourne May–June 2021 lockdown revealed the inefficiency of the COVIDSafe app, with the state government admitting that its usefulness for contact tracing (as opposed to manual tracing) was minimal. On June 2, check-ins using the Service Victoria app became mandatory in that state (it has been mandatory in another Australian state, New South Wales, since January 1, 2021).

Data tracking requires a society accustomed to high levels of voluntary compliance (such as Canada and Scandinavia) or one that will submit to coercive measures (Hong Kong, Singapore, China, Russia). Israel repurposed its location data collected for counterterrorism purposes to map COVID-19 transmission—a controversial move that the country's Supreme Court decision could not continue without legislation and oversight.[39]

The ethics of contact tracing are usually explained/justified by reference to a government's duty of care toward its citizens. However, there is potential to argue that tracing engages human rights concerns.[40] The World Health Organization notes issues such as de-identification, proportionality, and adequate consent and has suggested a list of 27 limitations on such apps ranging from the requirement it be temporary to "voluntariness" and citizen engagement.[41] Contract tracing apps in fact raise a number of ethical issues, such as:

> Which safeguards should be designed in the technology? Who should access data? What is a legitimate role for "Big Tech" companies in the development and implementation of these systems? How should cultural and behavioral issues be accounted for in the design of these apps? Should use of these apps be compulsory? What does transparency and ethical oversight mean in this context?[42]

Vicki Xafis et al.[43] note "potential misuse by state or private app developers," who…could potentially share the data with law enforcement, for the purpose of monitoring purported contacts between those

suspected of crimes…to track the activities of political dissidents… or more generally using location data to build consumer profile and inform market analytics.

The second issue of effective data tracking appears to be that of consent; democracies are more likely to accept such surveillance for a limited time.

What ethical framework helps us navigate this issue? Transparency and trust are key to consent by the public. The Australian government has been criticized for conflicting (or lacking) government messages on vaccine rollout and exit strategies. Accusations leveled include the belief that the government uses natural disasters for political gain; referencing the nation's security allows the government to move outside normal day-to-day politics and to justify emergency measures. The role of the media has been problematic. While mainstream media have provided valued insight into the government's handling of the pandemic, they have also occasionally overstepped. The public naming of "BBQ man," an asymptomatic COVID-19 carrier who visited 20 outlets for a BBQ retail chain while carrying out auditing work, was seen by most as an unnecessary overstepping of privacy ethics guidelines by the major Australian news outlet that publicly named him, arguing this was in the public interest.

Perhaps an ethics of trust might provide insight here. The argument would be that such trust in institutions is a consequence of such bodies demonstrating clear ethics processes for the collection, storage, and management of data that follow established ethical principles of non-malevolence and respect for individual right to privacy and to human dignity.[44] HJN Horsburgh suggests that trust is part of moral agency.[45] This is not going so far as to say that trust is akin to a Kantian moral imperative, or "perfect duty,"[46] not least as Kant can be ambiguous on this point, seeing deception is part of the social game. Relational ethics would mean arguing that we operate autonomously within the social contract, the greater good usually seen as individual good, and vice versa. A virtue ethicist would argue that a virtuous person would operate for the good of others, assuming no threat to personal dignity. Thus, the argument is that in crisis situations such as a pandemic that affects the entirety of society, the social good allows temporary invasion of privacy to be seen as ethical and acceptable.

James Moor's argument (based on Anita Allen and Ruth Gavison) for "restricted-access privacy" suggests that rather than arguing for any intrinsic value to privacy, it is more useful to rely on situational ethics, differentiating, for example, between naturally private and normatively private in order to create clear guidelines for situations where limited data intrusion is permitted.[47]

James Childress argues for a presumptivist approach that engages the public, that is, emphasizes social collaboration. He argues that the engagement of the public in public health deliberation is an indispensable part because members of society are political and social stakeholders.[48] This implies that the ethics of trust is a question of discourse ethics in the Habermasian sense, through which the categorical imperative becomes a collective imperative. Jürgen Habermas' participatory dialog implies a pre-acceptance of trust (of participants to enter the dialog meaningfully and sincerely and to embark on cooperative actions that will feed back to our subjective belief systems). In this instance of social collaboration, the intention of the speaker relies arguably on trust.[49] Both speaker and hearer trust in the authenticity of illocution and on the rational motivation for developing agreed norms. Thus "agreement in the communicative practice of everyday life rests simultaneously on intersubjectively shared propositional knowledge, on normative accord, and on mutual trust."[50]

Critics of Habermas point to the over-optimistic nature of the view that those engaged in dialog will be capable of reason, and of truthfulness. Yet without that aim, discourse is doomed, like the species, to fail. Trust enhances cooperation; trust requires citizen engagement in the parameters and privacy incursions inherent in protecting their safety, thus limiting governmental ability for biosurveillance in its negative sense.

Justified trust may secede to the ethical question of which kind of trust is better here—truth-directed or end-directed.[51] Trust can be seen not as ideal but as useful within interrelational, dialog-oriented ethical praxis with specific utility. End-directed trust can be seen as short-term and as reliant on citizen autonomy. Such social compliance, necessary for public health measures to succeed, ignores the issue of rational trust for a trust one can live with, one that reassures and can be seen, therefore as undermining its own premise.

Autonomy within participatory dialog therefore becomes key.[52] Reminders of citizen autonomy to citizens locked in fortress Australia would be a healthy, albeit currently missing, strategy, as well as key to building public trust in pandemic management, especially of personal data.

Notes

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