Ethical Health Surveillance during COVID-19

How to Safeguard Autonomy and Why It Matters

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Societies are responding to the COVID-19 pandemic[1] at breathtaking speed. Many of the ad-hoc responses of the coming months will have long-lasting consequences. Therefore, we must make sure that the efforts of today do not hinder our future wellbeing.

The most consequential transformations may come from new health surveillance technologies that use machine learning and automated decision-making to parse people's digital footprints, identify potentially infected persons, trace their contacts, and enforce social distancing. It has been argued that such digital instant contact tracing could be more effective in controlling the epidemic than traditional means[2]. Thus, the Israeli government authorized the repurposing of an anti-terror phone tracking programme, trawling the location histories of its whole population to monitor and enforce self-isolation of patients who tested positive. Israel's health ministry has since launched a mobile app allowing citizens to check whether they have crossed paths with anyone infected and need to self-isolate[3]. In China, two major mobile payment providers, Alipay and WeChat, released mobile apps that parse users' health, location, and financial data to automatically generate an individual infection risk rating. It is being embraced by government and businesses to decide whether to allow a person to access shops, transport, or public spaces[4]. US government and state agencies are in conversation with companies like Google, Facebook, and controversial startup Clearview AI to use location data mining or facial recognition to trace infections and to monitor and enforce isolation[5]. Around the globe, governments are rapidly following in implementing digital contact tracing of COVID-19[6].

One obvious concern here are false positives generated by unreliable, biased, and/or nontransparent algorithms. Another issue is 'surveillance creep': surveillance that is developed for a limited purpose, like fighting a pandemic or filming traffic violations becomes used in ever-more pervasive, and permanent ways. Scholars and activists are already warning that as with 9/11, much of the surveillance we accept today as 'exceptional means for exceptional times' is here to stay[7].

Beyond potential injustices and compromised civil rights, surveillance also has important psychological consequences. There are decades of data showing that individuals and societies can only thrive in environments that satisfy basic psychological needs, including autonomy: a sense of having volition and choice in one's actions[8]. Varied evidence shows that surveillance

can engender a sense of being controlled and be experienced as thwarting autonomy, with negative effects on motivation and wellbeing. Surveillance can also spur reactance: individuals may try to evade it in order to reassert their autonomy. South Korea's use of apps to publicize movements of Covid-19 patients has, for example, raised fears it might lead some to avoid being tested.

So how can we design the health surveillance and AI tools needed to control COVID-19 and future pandemics so they don't psychologically backfire or hinder our opportunities to thrive in the future?

Work on basic psychological needs in health can give a clue. Take Active Surveillance (AS) therapy, where individuals diagnosed with prostate cancer are offered regular clinical monitoring instead of immediate prostatectomy and radiation therapy. In AS, active treatment is only taken when signs of disease progression appear in regular biopsies or clinical reviews. Researchers found that the strict health surveillance regime of AS did not negatively affect patients' psychological wellbeing when patients understood and endorsed its value[9].

How could this apply for health surveillance? The UK National Health Service (NHS) is now developing an app that will automate COVID-19 contact tracing, following China, Israel, or Singapore. Notably the UK deployment will be opt-in, and data will be kept private. This was a conscious decision of its multidisciplinary team of developers, which considered the ethical concerns and concluded that an opt-in, privacy-preserving design would best support "both reducing the number of cases and enabling people to continue their lives in an informed, safe, and socially responsible way. It offers the potential to achieve important public benefits whilst maximizing autonomy."[10]

More broadly, a key challenge for designers and engineers building health surveillance is to align it with the values of those surveilled, but also to communicate these values and reasons underlying a surveillance technology to foster autonomous endorsement. Again, psychology can provide evidence-based guidance on designing autonomy-supportive interventions[11,12]. Another useful starting point are frameworks for responsible innovation or ethical AI that that broadly align with the biomedical ethics principles, particularly of supporting human autonomy[13].

Ethical concerns around health surveillance will only multiply. They are often cast as a distrusting zero-sum game between public good and private freedoms, where more of one must mean less of the other. The psychology of autonomy suggests a productive alternative: where surveiller and surveilled endorse wellbeing as the jointly valued end, health surveillance can be a positive-sum game – effective and chosen freely.

(words: 796)

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