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Health surveillance during covid-19 pandemic

How to safeguard autonomy and why it matters

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Societies are responding to the covid-19 pandemic at breathtaking speed. Many of these ad hoc responses will have long lasting consequences, and we must make sure that today's efforts do not threaten 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 those who are potentially infected, trace their contacts, and enforce social distancing. Some have argued that such digital contact tracing could be more effective in controlling the epidemic than mass quarantine ('lockdown').[2]

The Israeli government, for example, authorised the repurposing of an anti-terror phone tracking programme, trawling the location histories of its whole population to monitor and enforce self-isolation of people 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 big providers of mobile payment systems, Alipay and WeChat, released apps that combine users' health, location, and financial data to generate a personal infection risk rating. Government and businesses are using these technologies to decide whether to allow someone to access shops, transport, or public spaces.[4]

US government and state agencies are talking to companies such as Google, Facebook, and controversial startup Clearview AI about using location data mining or facial recognition to trace

infected people and to monitor and enforce isolation.[5] Around the globe, governments are rapidly following in implementing digital contact tracing of people with covid-19.[6]

Surveillance creep

One obvious concern is the high risk of false positive results generated by unreliable, biased, or non-transparent algorithms. Another is "surveillance creep," when surveillance developed for a limited purpose, such as fighting a pandemic or filming traffic violations, becomes used in ever more pervasive and permanent ways. Scholars and activists are already warning that 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. Decades of data show that individuals and societies can only thrive in environments that satisfy basic psychological needs, including autonomy—a sense of having volition and choice in your actions.[8] Surveillance can engender a sense of being controlled and be experienced as thwarting autonomy, with negative effects on motivation and wellbeing.[14 15] It can also spur people to try to evade surveillance and reassert their autonomy. South Korea's use of apps to publicise the movements of people with covid-19 has, for example, raised fears it might lead people to avoid being tested.

Protecting wellbeing

How can we design the health surveillance and AI tools needed to control covid-19 and future pandemics so they don't backfire or affect future wellbeing?

Research on the psychology of surveillance in other areas of healthcare offers helpful clues. Some patients with prostate cancer are offered active surveillance instead of immediate prostatectomy and radiation therapy. Treatment occurs when signs of disease progression appear in regular biopsies or clinical reviews. Researchers found that a strict health surveillance regime did not negatively affect psychological wellbeing when patients understood and endorsed its value.[9]

In the UK the NHS is developing an app that will automate covid-19 contact tracing, following China, Israel, and Singapore. Notably, however, the UK's deployment will be opt-in, and data will be kept private. The development team assessed 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 developing health surveillance systems is to align products with the values of those under surveillance and to communicate to wider society both these underlying values and the reasons for surveillance. Again, health psychology can provide evidence to guide the design of interventions that support patient autonomy,[11][12] and ethical frameworks for AI are increasingly aligning with this principle.[13]

The ethical questions raised by health surveillance will only increase. Often, they are framed as a zero sum trade-off between security and privacy. But the psychology of autonomy suggests a productive alternative—when both sides endorse wellbeing as the jointly valued goal, health surveillance can be a positive sum game, both effective and chosen freely.

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