Security Nexus Perspectives

URGENT POLICIES REQUIRED TO GRANT PUBLIC ACCESS TO PROTECTED HEALTH INFORMATION DURING EMERGENCY DISEASE OUTBREAKS AND PANDEMICS

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Protected health information (PHI) is one of the lynchpins, in medical terms, of modern democratic society. Through associated legislation, individuals are assured of near-total confidentiality in reporting medical conditions to health care providers, independent of their nature. Reportable diseases are a quasi-exception, with certain conditions such as HIV/AIDS being registered in confidential aggregated national and international databases.

With the advent of electronic medical records (EMR) and health management information systems (HMIS), this dynamic is changing: while confidentiality and privacy remain assured, there are more and more ways in which PHI can be centralized, aggregated, and analyzed. In turn, in the event of epidemic outbreaks, decision-makers are better and better equipped to respond.

From the standpoint of public health, health information, and health security, there are increasingly stronger medico-legal arguments for PHI in certain reportable public health emergency situations to be made public, or at least accessible by recognized academic and research entities. While this has a host of potentially complex legal and ethical ramifications, the public health and economic benefits may well outweigh them. At the end stage of an epidemic or pandemic, the need to release this information becomes even more crucial.

With greater public access to demographics and risk factors associated with reportable conditions, for example, a wider range of analysts and academics can immediately begin to make independent and informed decisions on cause, effect, prospects and other elements of epidemiology – a professionally diverse thinking exercise, rather than one that is the exclusive preserve of senior civil servants. Thus, the analysis moves out from the exclusive realm of bureaucrats and their consultants to a more appropriate, more diverse group of experts.

An even more compelling rationale, though, is the concept of essential public epidemic containment information. Without high levels of granularity and resolution in outbreak data – down the details of street

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addresses, ideally, but if not then district or county levels – public health efforts invariably suffer. De-identification and anonymization of such information is common practice. In contrast, vagueness in the precision of details in epidemic situations leaves both public health law enforcers and the general public at a disadvantage. Stigma and suspicion, as well as unnecessary fear and economic decline, inevitably follow as the same blanket policies are enforced across all geographical areas, industries, and demographics -- regardless of disease-related differences.

The availability of more granular information, conversely, results in a well-informed, more resilient public able to make more sensible, evidence-based decisions both within and outside affected geographical areas. Although this challenges the rise of neo-authoritarianism in public health, it also facilitates the construction and removal of *cordon sanitaires* or reverse *cordon sanitaires* (the guarded lines preventing anyone from leaving an area infected by a disease, and thus spreading it). Public responsiveness to legal dictats are thus facilitated and, perhaps most importantly, resources are concentrated in those areas worst-affected.

A similar call for a disaster risk reduction bank was made in the disaster management field, since communities have different needs when a disaster hits and it is senseless to provide them all with the same assistance. The model overcomes barriers to success inherent in traditional top-down approaches to managing crises and recognizes the capacity of well-informed, capable citizens and community organizers to facilitate response and recovery if provided with the opportunity and resources.

In this way, formal or informal *cordon sanitaires* protect both persons within affected areas, heightening their response capacity and awareness; and those outside such areas, helping them to avoid travel to severely-effected places. Access to granular information improves compliance and understanding which negates inaccurate word-of-mouth messaging, and provides far more relevant information for decision-making than the almost irrelevant aggregated data typically provided by government statistics departments. In the current case, unfortunately, public understanding has relied almost exclusively on word of mouth, rumor, and aggregated government statistics.

In this context, many countries are reviewing objections to the acceptability of the use of public health tracking apps -- or have even rapidly developed and implemented them because of their utility in contact tracing efforts. Such systems can be used to let individuals know when they have come in close proximity with a known infected person, and can also signal when it might be time to get tested.

This information enables both governments and individuals to monitor the movement of a disease both geographically and within populations, and target resources and efforts accordingly.

China was one of the first nations to use such an app, Alipay Health Code, in the current global fight against coronavirus. Algorithms monitor the population, dictate quarantines, send personal data to police, and give citizens a color code that impacts movement through entry and exit points. In turn, South Korea acted rapidly to create the app Corona 100m, and a supporting database of confirmed cases that provides detailed information about every infected individual.

Singapore's TraceTogether is more limited and optional, with only 25% of the population using it. However, the country's SafeEntry is a more robust national digital check-in system that logs details of individuals visiting hotspots; workplaces of essential services; and selected public venues to facilitate contact tracing efforts. The latter is also being used to regulate the reopening process by monitoring health status, geo-positioning in

relation to infections, and entry and exit points. Similarly, Australia's COVIDSafe was downloaded by 20% of the population in the first week, half of the government target of 40%. Although it is not yet mandatory, widespread adoption of the app is likely to become a key condition for reopening offices, restaurants, and other amenities. Italy's new app, Immuni, was downloaded by 500,000 people in the first 24 hours.

While some believe that contact tracing apps produce benefits as soon as users increase above 10 percent of a population, there remain PHI-related shortcomings in these approaches because such apps do not actually measure the circumstances that are known to be important in COVID-19 transmission. This lack of accuracy in granular data makes it difficult for both disease managers and individuals to benefit. Apps with inappropriately short infection-interaction algorithms will show too many people as possibly infected (as has possibly been the case in Singapore), while apps with inappropriately long infection-interaction algorithms will likely flag too few potential viral exposures.

Yet voluntary buy-in to even such limited such efforts will inevitably vary by country, in accordance with what level of privacy is culturally acceptable. While many westerners and other skeptics perceived the actions of China and Korea to be an infringement of personal freedom, PHI, and human rights, others (such as Australia) viewed such information gathering methods as essential in regulating an evidence-based and targeted removal of lockdown efforts; enabling the reopening of society; and helping to restart the economy. The new apps currently being released in Europe send notifications when users get close to other users who have tested positive for the COVID-19 virus. Advances in Bluetooth Low Energy technology enable this to occur without the app gathering information on the identity or the location of its users.

Everyone knows the benefits of having an evidence-base to inform decision making: the better the information, the better the decisions. An informed government is in a better position to increase or decrease *cordon sanitaire* provisions for lockdown and reopening; likewise, a more informed public is more likely to take appropriate steps to self-regulate, accept government decisions, comply with them to reduce the spread of disease. The only questions that may then remain are, *"Do you trust your government and your population not to abuse the data?"* and *"How can the security sector ensure that the data is not abused?"*

In that regard, skeptics will claim that PHI disclosure in emergency situations is an infringement of personal freedom and human rights, or will encourage flight from affected areas, and thus increased epidemic spread. Fears of public health information being reported to General Communications Headquarters (GCHQ) in the United Kingdom will inevitably be conflated with such perspectives. Likewise, concerns of a repeat of Ebola stigma, in which military and police searches were required to expose 'hidden' patients fearful of internment, will be referenced.

Yet surely, many of these considerations have been trumped by repeated human rights infringements and significant curtailments of personal freedoms that have been reported in recent months. The flight concern is easily addressed via movement restriction orders and *cordon sanitaires*. Similarly, those concerned with local-level stigma implications should recognize the intense false stigma that has been prevalent on a much wider scale since pandemic concerns began. As with house-to-house Ebola searches, the social ethical health security optimum therefore trumps the individual (or district level) optimum, in bioethics terms. The need to act on PHI reform in emergency epidemic situations is relatively urgent. Before the concatenation of circumstances that froze the world and its economy repeats itself in the short or long term with subsequent waves of infection, governments should consider enacting PHI policies that enable:

- more informed public decision-making;
- greater academic involvement;
- improved targeting of resources;
- more effective epidemic control;
- relieving the public of unnecessary paranoia; and
- reducing restrictions in non/less-affected areas.

Ultimately, individuals need to have access to accurate, high-resolution information on disease outbreaks. So far, this information, while available, has been the preserve of a select few, and released only in unhelpful aggregated forms to the public. Humanity has been fortunate in recent months that the global public health emergency has not become a complex humanitarian emergency as well. This has now changed in the U.S. where nationwide protests have provided a new hotbed for disease transmission. Now that this concatenation of circumstances has arisen, the availability of PHI to responders and affected individuals as well as to decision-makers is of crucial importance and should be high on the agenda of policy makers.

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