Information Sharing on COVID: Risks and Benefits

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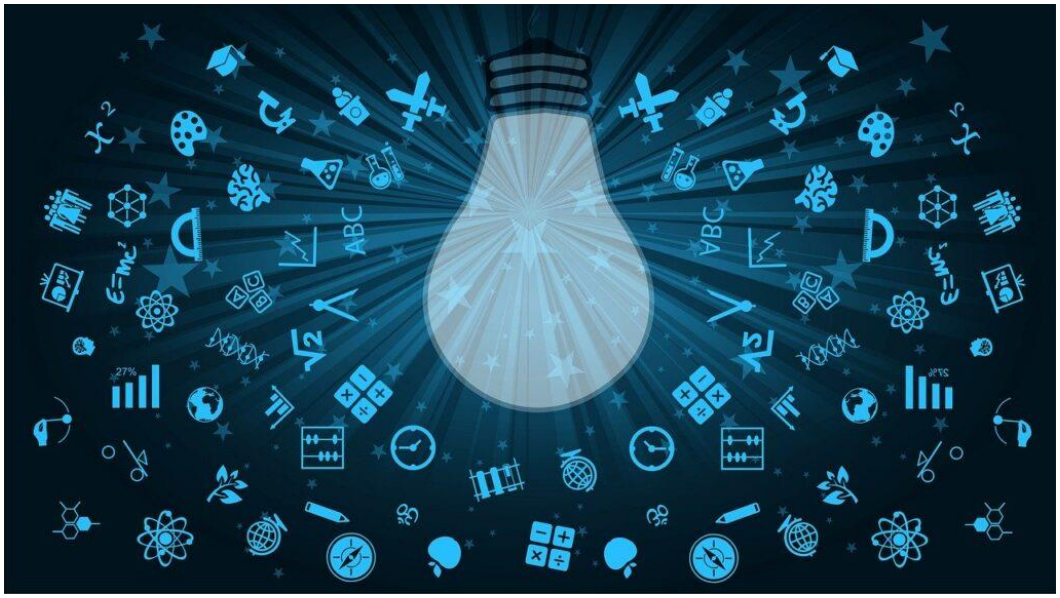

Ireland has made extraordinary advices, though its surveillance and data management, in terms of providing the general public with key information about the current epidemic. Whether or not many elements of this information are truly universal and user-friendly, relying as they do on some carful navigation — as well as a working understanding of epidemiology — is uncertain, however.

Yet, either way, one key piece of information continues to be hard to determine. For many, an ideal data environment would be one in which we would be able to see new cases as they emerge each day, by location. In this way, even if numbers cannot be exact — or may be biased because of testing center locations, time lags, overlooking asymptomatic cases, or other reasons — the general public at least has a routine understanding of where outbreak hot spots are.

This used to be a common response to epidemics: in the time of scarlet fever, a red ribbon would be placed outside the door of an infected house — warning

others that quarantine was in progress and to approach, if at all, with caution. Likewise, Ebola outbreak control depends on detailed public understanding of outbreak locations. Yet, at the same time, in the modern developed world we have become – generally speaking, rightly – more and more concerned with ensuring that health information is kept private. In this way, as with HIV/AIDS, it has become impossible to stigmatize or discriminate anyone because of their health condition, and also thus facilitates the tracking and diagnosis of reportable conditions.

This has been, under normal circumstances, a welcome and humanitarian development. Thus, the disclosure of street address, personal information, or other details of those infected in an outbreak situation has been rightly ruled out on privacy, confidentiality, stigma and anonymity grounds. And yet one wonders whether there is a threshold at which such ethical and legal ideals have to bow to public health needs.

Fortunately, there are other options available. Ireland has small area maps, called electoral or census divisions, that have recently been used to display cumulative cases of infections since March. This data is publicly available, though it is not regularly updated. In a further precaution – one that further reduces resolution and usability of the information, but also improves data protection – cumulative cases are grouped according to number range, such as from zero to five, or twenty to forty.

Yet to see a cumulative map is often to see a *de facto* representation of a regional situation in March or April — which may have no connection at all to what is happening in a particular area on a day-to-day basis. The cumulative figures may also give a wrong impression of places that may, ironically, now be the safest in the country, as the epidemic has already taken its toll and worked through them. Such information therefore needs to be interpreted with caution.

The government and other state bodies have provided a range of reasons as to why it is not safe to trust the general public with any more detailed information. As noted above, asymptomatic cases are invisible; there may be biases in areas which have more testing centers. The tests are not totally accurate; people may get a false sense of security of they live in low-incidence places. There are, also, time lags in testing results, so the figures given to us on a certain day do not necessarily reflect the day before. And perhaps above all, social unrest may result from specific communities being revealed as high-incidence areas.

Yet, with all of these limitations and qualifications, public understanding of the distribution across (and, much more importantly, within) counties of new cases each day may be the only verified information that we have to be able to guide our response, individually and nationally. While the ethical and legal tenets of public health information are to be lauded, there is also a need for the perfect not to be the enemy of the good: a need for decision-makers to

acknowledge that we are not living in normal times, in which normal rules apply.

The benefits of having all factual information, however numerous the limitations, about the epidemic's geographical distribution made available to the general public, may thus vastly outweigh the downsides. The public's only other option appears to be a reliance on tabloids and rumours to give us news of outbreaks – as was the case in Sligo – which is cannot possibly be a preferable option.

Thus, if government can adapt their data sharing rules to share surveillance information back to the public, we may have a much stronger chance at controlling outbreaks in the winter. A further consideration is the way in which the national contact tracing app would be greatly strengthened by this information – at the tap of a screen, recent cases in one's immediate locale, anywhere in the country, could be displayed.

In the long term, this also feeds in to a regional lockdown approach that involves avoiding the entire country grinding to a halt for what may often be highly localized issues. What if all of the new cases on a certain day are all occurring in a single electoral division, for example – as opposed to an equal spread throughout the country? The disclosure of this information will therefore facilitate public understanding of why services in one part of the country can continue to operate as normal, while others are closed down. 'Self-enforced contact tracing', in which those in outbreak areas become more vigilant and mindful of their movements, is also greatly facilitated.

The alternative is not a pleasant one, and may not be worth the risk: a second wave situation under a surveillance system that does not share all meaningful information with the general public. In China, as we saw earlier in the year, this reticence led to serious public health repercussions that could perhaps have been avoided. Ireland must continue to learn, and act on, these vital lessons.

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