Perspective

Putting the Public Back in Public Health — Surveying Symptoms of Covid-19

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To address the unprecedented challenge posed by the Covid-19 pandemic, much of the world — including an estimated 90% of Americans — was locked down and socially distanced. Large gatherings were prohibited, most schools and nonessential businesses were closed, and people were asked to stay at home or shelter in place. But as many parts of the United States see a slow decrease in Covid-19 cases, restrictions are gradually being lifted, particularly as the pandemic's devastating economic and social consequences mount. Although decisions to gradually reopen societies are ultimately based on a complex calculus of political, economic, and public health considerations, it's clear that there is a high unmet need for better estimates of communities' burden of Covid-19 to guide such decision making. Fortunately, some mobile symptom-surveillance tools can be used for predictive modeling to address this critical priority.

To date, most projections of the Covid-19 burden have been based on incidence calculated from Covid-19 testing, hospitalizations, and deaths. However, such estimates are severely limited. First, such data are not uniformly collected on a national scale and rely on a patchwork of variable efforts by regional and local public health authorities. There are also substantial delays in reporting and aggregating data and stark discrepancies in how cases and deaths are counted.

Second, despite advances in diagnostics, the availability of testing for infection continues to be limited. This limitation leads to wide variation in the severity of symptoms and the underlying risk profiles used to qualify people for testing in different states and localities. Thus, confirmed incidence based only on Covid-19–positive tests may depend on these factors rather than reflecting true underlying prevalence in a population.

Third, hospitalizations and death rates largely capture more severe cases of Covid-19. Increasing quantities of data are highlighting the importance of identifying asymptomatic or minimally symptomatic persons who may not seek medical care, since they may account for a significant proportion of community spread. Finally, although antibody-based testing is receiving increasing attention, we don't yet know how reliable, accurate, or widely available such assays will be, nor what implications the results will have, including whether positive results will indicate immunity to reinfection.

To address this knowledge gap, new and cost-efficient participatory syndromic-surveillance tools have been developed that can be

used in real time to rapidly address critical near-term needs. These tools work by capturing data on reported symptoms using mobile technology such as phone apps or Internet-based questionnaires, which often provide more timely signals of infectious disease transmission than more traditional sources. For example, we have launched a Covid Symptom Study app (http://covid.joinzoe.com), developed by Zoe Global with scientific input from Massachusetts General Hospital and King's College London, that has been used by nearly 3.5 million people in the United States, the United Kingdom, and Sweden; it collects daily information about whether people feel well, and if not, about their symptoms and whether they have been tested for Covid-19. This tool has also been configured to collect additional data on risk factors for and outcomes of Covid-19 that can be used for real-time epidemiologic studies, especially when embedded within existing population-based cohort studies.[1]

At Boston Children's Hospital, we have adapted a Web- and text-message–based syndromic surveillance tool, FluNearYou (http://flunearyou.org),[2] designed to assess patterns of influenza incidence, into a tool for Covid-19 known as CovidNearYou (www.covidnearyou.org). This platform, which has now captured more than a million reports, is providing insights into Covid-19 symptomology and key demographic risk factors. Syndromic data have been collected by others with the use of fitness trackers, continuous wearable devices, and smart thermometers, all validated to provide early insight into respiratory illness in the community. With each

of these tools, symptom data can be used to model population incidence of Covid-19 in the absence of widespread population testing.[3] Since varied but complementary information is collected with the range of available tools, integrating their output could lead to more robust models.[4]

In the early phases of the pandemic, these estimates were used for real-time assessment of viral spread, including identification of new "hot spots" or regions at high risk for a heavy Covid-19 burden.[5] Many of these tools also entail direct engagement with participants, providing opportunities for real-time communication of study results for public health messaging.

Although syndromic surveillance data play a role in deploying resources to meet surges in health care demand, they may be even more critical for guiding decision making regarding reopening economies and loosening stay-at-home orders. For example, the current White House strategy calls for dependence on data regarding influenza-like and Covid-like illness as part of the gating criteria for easing social distancing guidelines. These data, however, currently rely only on emergency department utilization, which may represent an underestimate, given the documented avoidance of in-person medical care and the explosion of telemedicine visits. Thus, symptom information is vital to providing an earlier window into our progress against viral spread and can be used to complement traditional measures of the pandemic's severity.

Electronically collected symptom data will be particularly important as a readily adaptable tool that can be applied widely in various populations as states move at

variable paces to lift restrictions. Data based on symptom burden have the advantages of avoiding confounding by differences in testing availability and being flexible and sensitive to detecting changes in response to public health recommendations and government mandates.

Nonetheless, crowd-sourced data from mobile apps have limitations. The population providing the information will not perfectly reflect the broader population. Although more than 80% of the U.S. population uses smartphones, there remain many important subgroups, such as older adults and socioeconomically disadvantaged people, whose lack of access to technology will be a barrier to participation. Through the Covid Symptom Study app, we have specifically sought to enhance representation from racial and ethnic groups that are more vulnerable to Covid-19 by recruiting participants within ongoing studies such as the Black Women's Health Study and the Multiethnic Cohort Study and by launching a Spanish-language app.[1] In addition, as with any study that relies on voluntary contribution of data, people's differential willingness to participate may reflect differences in underlying health-seeking behavior and anxiety regarding symptoms.

Moreover, several syndrome-surveillance platforms are already in use, which may lead to consumer confusion; it is thus important for data collectors to collaborate and standardize their platforms through such initiatives as the International Workshop on Participatory Surveillance. Efforts to aggregate data should, however, recognize the potential for compounding limitations related

to representativeness unless platforms are specifically adapted to reach different segments of the population.

Finally, the use of any platform that captures health information must balance concerns regarding privacy and data sharing. Tools based on syndromic surveillance do not require identifying information that can be shared with insurers or public health authorities — a key feature distinguishing them from so-called contact-tracing apps, from which information about Covid-19 testing may be shared publicly, albeit in an anonymized form. As we move forward with app-based syndromic surveillance, it will be critical to differentiate this work from efforts based on contact tracing and to offer output complementary to those efforts' results.

Ultimately, we believe that digital syndromic surveillance as a method of "contactless tracing" holds substantial appeal for the future, beyond the immediate priority of reopening our society. Although caseloads are decreasing, without a universal vaccine or highly effective treatment, we will continue to need to collect data on Covid-19 symptoms for the foreseeable future, particularly given concerns about a resurgence of cases after the summer. These tools will also be valuable for other efforts, including recruiting volunteers for clinical trials, estimating risk of reinfection, and assessing vaccine efficacy on a population scale. Thus, such mobile technology will remain an important weapon in our efforts to defeat Covid-19 and to better position ourselves to respond to the next pandemic.

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