Surveillance is underestimating the burden of the COVID-19 pandemic

So far in the COVID-19 pandemic, surveillance systems are not monitoring ill health and long-term implications of COVID-19, only deaths are reported. Most are also not tracking all cases, only positive tests are counted. Underestimating the number of cases means inadequate control of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection and failure to support those who do not recover quickly from COVID-19. We must universally agree and implement surveillance case definitions for infection and recovery.

Across the world, some people with symptoms of COVID-19 are not being tested for SARS-CoV-2 infection because tests are either not available or inaccessible, particularly in low-resourced contexts. Some people do not seek testing when they experience symptoms of COVID-19 because of worries about income, caring responsibilities, or stigma implications of testing positive for SARS-CoV-2 and having to isolate. Some people might test negative, particularly if testing takes place too early or too late in the course of SARS-CoV-2 infection.[1] We need to count this wider pool of cases, including people who either test negative or are not tested but fulfill clinical criteria for COVID-19.

The most recent WHO public health surveillance guidance asks countries to report probable cases, in addition to confirmed cases.[2] The definition of a probable case of COVID-19 includes someone meeting clinical criteria and who is a contact of a probable or confirmed case, or a suspected case with chest imaging findings suggestive of COVID-19. It is important to consider how such definitions are practically implemented. Despite the US Centers for Disease Control and Prevention (CDC) recommending in April, 2020, to include probable cases in surveillance,[3] many US States do not report these data. Also, existing definitions of a probable case are dependent on interaction with health systems and, thus, might also miss a substantial proportion of people with SARS-CoV-2 infection. This situation can be mitigated by incentivising people with symptoms to approach health care and seek testing, by removing barriers, financial detriments, and the stigma of diagnosis, and by active symptom screening in workplaces or educational settings.

A universal surveillance case definition of recovery from COVID-19 is still absent. Many people have prolonged symptoms, ill health, and reduced functionality for months, even if they were not hospitalised for SARS-CoV-2 infection.[4] We must move long-haul COVID from anecdote to something that is routinely quantified and monitored, as is currently being done with deaths and positive tests.[5] To make this move, we must count COVID-19 cases beyond positive test statistics. We also need to define recovery, taking into account symptom duration, fluctuation, severity, quality of life, and functionality, and not base this definition solely on testing negative for active SARS-CoV-2 infection or discharge from hospital.

We must measure the proportion of cases with prolonged ill health, not only to provide support and care but also to redefine the true effect of the pandemic and inform the appropriate response to it. We can only capture this information by having infection case definitions that are not entirely based on laboratory confirmation to form the denominator for the recovered cases.

Improving the reporting of non-laboratory-confirmed clinical cases by practically establishing how existing systems can do so is vital. Public health bodies must also universally agree definitions of what constitutes recovery, to estimate the true burden of ill health associated with SARS-CoV-2 infection.

I have had prolonged symptoms of COVID-19. I declare no other competing interests.

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1 Caruana G, Croxatto A, Coste AT, et al. Diagnostic strategies for SARS-CoV-2 infection and interpretation of microbiological results. *Clin Microbiol Infect* 2020; **26:** 1178–82.
2 WHO. Public health surveillance for COVID-19: interim guidance. Aug 7, 2020. https://www.who.int/publications/i/item/who-2019-nCoV-surveillanceguidance-2020.7 (accessed Aug 24, 2020).
3 US Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19): about CDC COVID-19 data. July 13, 2020. https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/about-us-cases-deaths.html (accessed Aug 24, 2020).
4 Tenforde MW. Symptom duration and risk factors for delayed return to usual health among outpatients with COVID-19 in a multistate health care systems network—United States, March–June 2020. *MMWR Morb Mortal Wkly Rep* 2020; **69:** 993–98.
5 Alwan NA. A negative COVID-19 test does not mean recovery. *Nature* 2020; **584:** 170.

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For the **CDC COVID-19 data tracker** see https://www.cdc.gov/covid-data-tracker/#cases