

Surveillance for Post-COVID Conditions Is Necessary: Addressing the Challenges with Multiple Approaches



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Although the availability of effective vaccines raises optimism for the control of SARS-CoV-2 transmission in the USA, public health systems must prepare to respond to all COVID-19 health impacts, particularly post-COVID conditions (PCCs).^{1,2} PCCs consist of new, returning, or ongoing health problems diagnosed in people with a history of SARS-CoV-2 infection, typically present at least 4 weeks after infection.³ While PCCs are still being defined and characterized, PCCs could potentially affect millions of Americans.^{1,2}

The national public health response to PCCs requires access to high-quality data to estimate PCC incidence, characterize presentation, and identify pre-disposing risk factors. Identifying groups of people most impacted by PCCs with a particular eye to health disparities, geographic diversity, and potential barriers to care is a priority. Public health practitioners can use these findings to design and target strategic interventions within healthcare systems and affected communities to understand, mitigate, manage, and prevent PCCs, as well as track how the burden of PCCs is changing and how well interventions to address disproportional impacts are performing.

The Centers for Disease Control and Prevention (CDC) and the National Institutes of Health, as well as other public health partners, have established several initiatives to assess the magnitude of PCCs.³ Examples of surveillance initiatives to date include use of cross-sectional health surveys,^{4,5} prospective cohorts,⁶ and electronic health record (EHR) analyses.^{7,8} Each of these surveillance initiatives (and others, such as sentinel surveillance systems) will face several challenges. Primary among these are accurately identifying PCCs and determining the extent to which PCCs are causally related to SARS-CoV-2 infection.

PCCs are reported by individuals with both symptomatic and asymptomatic initial infection. Many people who experience mild or asymptomatic SARS-CoV-2 infections do not

receive PCR or antigen testing at the time of acute infection,⁹ making it more challenging to attribute later symptoms to SARS-CoV-2 infection. Symptoms associated with PCCs are heterogeneous and often non-specific, overlapping with many common medical conditions, and may be difficult to fully capture in any single data system.^{4,10}

Given both the large number of affected persons and the clinically diverse nature of PCCs, a single prospective nationwide surveillance system would require multiple efforts to identify, classify, and follow each case of SARS-CoV-2 infection over time. Such a large and comprehensive system would be resource-intensive and take an unacceptable period to develop. Gathering more data is important to guide effective management and prevention of PCC. Effectively gathering data by assembling and triangulating information from multiple sources will require coordination around definitions and statistical methods for estimation of PCCs.

CROSS-SECTIONAL HEALTH SURVEYS

Many ongoing public health efforts that estimate the burden of disease rely on health surveys (e.g., the National Health Interview Survey, National Health and Nutrition Examination Survey, and the Behavioral Risk Factor Surveillance System) that capture self-reported symptoms and health conditions among persons who report testing positive or negative for SARS-CoV-2. These large cross-sectional surveys can improve our understanding of the prevalence of PCCs over time. However, these sources do not always provide a complete clinical characterization of ongoing symptoms or conditions. The surveys may not necessarily include a comparison group (e.g., persons without SARS-Cov-2 infection) to draw inferences about attributable risk. CDC is presently working with several state health departments to implement PCC surveys among persons who tested positive for SARS-CoV-2 and is including questions related to PCCs in future national health surveys.

PROSPECTIVE COHORT STUDIES

Epidemiologic cohort studies that prospectively collect detailed clinical and behavioral data over time about people who have tested positive or negative for SARS-CoV-2 infection can also provide data on incidence of PCCs. Compared with cross-sectional surveys, prospective cohort studies are

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less prone to recall bias and can provide greater certainty about temporal associations between SARS-CoV-2 infection and subsequent PCCs (i.e., evidence of causality). Early in the pandemic, CDC established several prospective cohort studies to provide such information that will enhance the characterization of the natural history of SARS-CoV-2 infection.^{3,6}

ELECTRONIC HEALTH RECORDS

EHR analyses have several strengths, as they comprise large datasets of diverse patient populations, longitudinal health information (including pre-pandemic medical histories), and catchment areas that approximate population denominators, thereby allowing for calculation of population-based rates that might be generalizable to the larger population. Analyses using EHR data can be limited by lack of representativeness since persons without health insurance, without access to healthcare, and who do not use the health care system are often not captured. While EHR relies on diagnostic coding, individuals with debilitating symptoms that are not captured with coding may be under-ascertained. Despite these limitations, CDC and public health partners are leveraging the strengths of several EHR datasets to estimate the magnitude and identify risk factors for PCCs.^{4,5}

SENTINEL SURVEILLANCE

Sentinel surveillance for monitoring of PCCs would consist of closed clinical networks (e.g., a health maintenance organization) with a defined and constant set of clinical centers, where both SARS-CoV-2 infections and PCCs can be tracked. Such sentinel surveillance can capture the totality of patients' clinical experiences and be used to (1) closely monitor trends in the incidence of PCCs, (2) fully characterize and identify risk factors for PCCs, and (3) provide estimates of persons with ongoing PCCs. CDC is hoping to establish such a system through a cooperative agreement with a number of partners called TrackPCC (available on www.grants.gov).

In summary, CDC and public health partners are applying multiple surveillance methods, including cross-sectional health surveys, cohort studies, EHR analyses, and sentinel surveillance, to fully characterize the natural history of COVID-19 and PCCs. These surveillance methods are complementary, providing both a broader and deeper assessment of PCCs than any single system alone. They will increase our ability to measure the impact of PCCs across racial and ethnic populations, urban and rural communities, and among those with and without healthcare access. These multiple methods are also redundant enough that key information can be verified across platforms to provide a detailed picture of PCCs in the USA. Collectively, these systems will help to determine the resources necessary to care for persons affected by these emerging, complex, and multifaceted conditions and to, hopefully, identify and develop interventions to prevent PCCs.

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