State, Tribal, Local, and Territorial Public Health Agency Approaches to Long COVID-19/Post COVID-19 Condition Surveillance

Lessons Learned, Gaps, and Needs

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INTRODUCTION

This document was developed to provide a summary of public health approaches for monitoring and assessing LC/PCC within a jurisdiction with the purpose of using these data to guide public health action. LC/PCC is also known as long-haul COVID, post-acute COVID-19, long-term effects of COVID-19, and a subset of these conditions are known as post-acute sequelae of SARS CoV-2 infection (PASC). While Multisystem Inflammatory Syndrome in Children (MIS-C) is associated with COVID-19 and occurs after a SARS-CoV-2 infection, it is considered a distinct entity and health department MIS-C surveillance is separate from LC/PCC surveillance approaches.

To understand the impact of LC/PCC on state, Tribal, local, and territorial (STLT) communities, and to implement public health activities to mitigate this impact, it is important to have data to understand the prevalence of LC/PCC and the populations impacted at the STLT level. The ASTHO Long COVID Policy Statement recommends four strategies to address Long COVID including improving data collection, surveillance, and research to assess the medical and societal burden of Long COVID, with adequate federal funding to support these efforts. Over the pandemic response, many STLTs developed their own approaches to LC/PCC surveillance despite the significant barriers and challenges to implementing LC/PCC surveillance at the population level. Some challenges include: (1) LC/PCC is a high-volume condition at the population level; (2) LC/PCC is often associated with multiple symptoms, conditions, and syndromes, making surveillance more complex; and (3) STLTs have limited resources for LC/PCC surveillance. Therefore, STLTs may use multiple surveillance approaches using different data sources and types to assess the burden of LC/PCC on their communities. STLTs may also need to triangulate available data from different sources to understand the impact of LC/PCC on their population and subpopulations.

While universal case investigation and contact tracing was being performed, some STLTs were able to conduct follow-up interviews or surveys on persons with laboratory reported SARS-CoV-2 infection several weeks to months after the initial diagnosis to ascertain potential LC/PCC among all or a subset of case-patients. However, as case investigation and contact tracing were scaled back[1], these resources and data became less available. Additionally, this approach had limitations in that the response rates for these follow-up surveys was quite low (for some 5%), this approach only captures those who tested positive for SARS-CoV-2, and there is no comparison group for background rate of symptoms that were assessed. Therefore, other approaches to understand the scope of LC/PCC in jurisdictions were developed and will likely continue to be needed over time.

Moving forward, LC/PCC will likely continue to be monitored at STLTs through community surveys, existing data sources (e.g., clinical sources, healthcare administrative data sources), sentinel surveillance, syndromic surveillance, or a combination of these approaches, as opposed to universal case reporting or LC/PCC disease registries, which are labor intensive and

[1] https://preparedness.cste.org/wp-content/uploads/2022/01/CICT_Partner_Statement_01_24_2022.pdf

require extensive resources. Each jurisdiction must adapt their approaches to local needs, priorities, and available resources.

The objective of this document is to describe STLT LC/PCC surveillance approaches, and to share experiences with these approaches to-date, including examples and models, lessons learned, potential gaps, and needs moving forward. This document aims to provide these experiences and lessons learned to ultimately advance LC/PCC surveillance and guide public health action.

HEALTH EQUITY

STLTs must address and advance health equity during the development, implementation, and analysis of LC/PCC surveillance activities and should focus on communities disproportionately impacted by COVID-19 as they are likely to have a disproportionate LC/PCC burden. It is critical to pay particular attention to populations identified as bearing a disproportionate burden and impact of LC/PCC, including those who identify as Hispanic, Black, Indigenous, and People of Color (BIPOC), those in rural communities, and those with limited access to LC/PCC-focused healthcare which has been mostly available in urban situated academic centers. STLTs should ensure LC/PCC surveillance activities include and assess all populations who experience health disparities including groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion, socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (Healthy People 2030). See Appendix A for models of STLT LC/PCC surveillance approaches which incorporate health equity principles.

LC/PCC DEFINITIONS

Given differing LC/PCC definitions used, current estimates of prevalence and impact of LC/PCC on populations vary widely[2]. Therefore, it is important to work toward standardized definitions, when feasible, to allow comparisons between jurisdictions and when using different surveillance and epidemiologic approaches. However, under the current public health framework it would be extremely challenging to capture the jurisdictional burden of LC/PCC with a single surveillance system given the lack of diagnostic laboratory testing specific for LC/PCC or simple clinical criteria[3]. Therefore, this document does not include a single case definition for STLTs to use for surveillance approaches but will provide examples of definitions that are currently being used by some STLTs and considerations for STLT definitions. Each definition includes a description of symptoms and conditions included and time frame from acute SARS-CoV-2 infection that LC/PCC may occur.

[2] Chaichana U, Man K, Chen A, et al. Definition of Post-COVID-19 Condition Among Published Research Studies. JAMA Network Open. 2023;6(4):e235856. Doi: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2803125
[3] Saydah S, Brooks J, and Jackson B. Surveillance for Post-COVID Conditions Is Necessary: Addressing the Challenges with Multiple Approaches. J Gen Int Med. 2022 Feb;37:1786-1788. DOI: https://doi.org/10.1007/s11606-022-07446-z

At this time, a CSTE position statement for a consensus standardized case definition for classification of individual cases of LC/PCC reported to STLTs has not been developed. For most jurisdictions, case-based reporting is not likely feasible given the complexity and the volume of LC/PCC. Often CSTE position statements are developed to ensure consistent classification of individual case-based reporting of reportable diseases prompting individual public health control measures[4] and LC/PCC is not a nationally notifiable condition, nor a reportable condition in any jurisdiction currently. Individual case-based reporting may lead to a biased sample if relying only on provider-based reporting which tends to be suboptimal for conditions that reply on a clinical diagnosis only, instead of positive laboratory results that are also reported directly by clinical laboratories. Therefore, most STLTs that have implemented surveillance approaches to LC/PCC are not relying on individual case reporting, rather leveraging other data sources similar to other chronic disease surveillance models. If any STLTs proceed with individual case reporting, it would require significant resources. Additionally, if prevalence was to be evaluated, additional resources would be required for follow-up of patients over time, as some patients may recover from LC/PCC. Regardless, LC/PCC definitions will need to be developed and refined to improve consistency across jurisdictions and allow comparisons between epidemiology and surveillance studies. While a consensus case definition has not been developed, CSTE encourages all STLTs to be transparent in the LC/PCC definition used in their jurisdiction to facilitate comparisons and understand potential differences across jurisdictions.

It is important to note that when definitions are developed for public health surveillance, these definitions are not developed for other purposes such as clinical care, access to healthcare or disability benefits, or reimbursement for care. Inappropriate use of public health definitions could potentially lead to a lack of access and inequities in access to clinical services, disability, and insurance coverage as the public health definitions are not developed for these purposes.

While many STLTs developed LC/PCC definitions depending on the setting and data analyzed, two of the most commonly used definitions to-date include the World Health Organization (WHO) clinical case definition and the interim U.S. government working definition (see Table of commonly used LC/PCC definitions). In October 2021 the WHO developed a clinical case definition of LC/PCC by a Delphi consensus process. In 2022, the interim U.S. government working definition of Long COVID-19 was developed by the Department of Health and Human Services (HHS) in collaboration with the CDC, National Institutes of Health (NIH), and other partners. In Spring 2023, the National Academies of Sciences, Engineering, and Medicine convened a Committee on Examining the Working Definition for Long COVID and related technical terms and will consider refinement, dissemination, harmonization, and implementation of LC/PCC definitions, including for public health purposes. These efforts aim to improve standardization and harmonization of definitions across jurisdictions, studies, and settings.

[4] CSTE Position Statements website

In addition to harmonizing a LC/PCC definition across fields, it is important that any definition also be inclusive of the broad presentation of those experiencing LC/PCC. In a recent peer-reviewed publication[5], Pan et al. suggest that a LC/PCC definition be defined as "*signs and symptoms following initial SARS-CoV-2 infection, that persist for more than one month (in mild cases), and more than three months (in cases severe enough to warrant oxygen support), which have a disproportionately severe effect on a patient's quality of life, far beyond what is expected from their initial infection*." This definition adds components emphasizing that 1) the condition is beyond expected compared to recovery from a severe illness, 2) incorporates the concept of the effect on quality of life, and 3) acknowledges that LC/PCC can be present even in those whose persistent symptoms can be explained (as such symptoms may be a result of an acute SARS-CoV-2 infection).

Other approaches to defining LC/PCC have incorporated traditional epidemiologic methodologies. The RECOVER study recently developed a definition of PASC based on a prospective longitudinal observational cohort study which evaluated nearly 10,000 adults with and without SARS-CoV-2 infection and identified 37 symptoms as more often present at 6 months after SARS-CoV-2 infection compared to no infection and a data-driven scoring framework was developed using 12 symptoms which were most associated with PASC, including post-exertional malaise, fatigue, brain fog, dizziness, GI symptoms, palpitations, changes in sexual desire or capacity, loss of or change in smell or taste, thirst, chronic cough, chest pain, and abnormal movements.[6] This framework may assist STLTs when using LC/PCC definitions focused on a LC/PCC syndrome versus other post-COVID-19 complications (such as stroke, diabetes, or cardiovascular complications).

Many definitions incorporate laboratory confirmation of SARS-CoV-2 infection (a probable or confirmed SARS-CoV-2 case[7]); however, early in 2020 laboratory testing access was challenging due to limited testing capacity, with testing not available for persons with milder illness. Over time, as over-the-counter (OTC) at-home testing access has improved, laboratory-based testing is used less often. It is estimated that a majority of those infected with SARS-CoV-2 may use at-home testing and these at-home test results are not readily or consistently available to STLT health departments to confirm case status. If an LC/PCC definition requires laboratory confirmation of SARS-CoV-2 infection, the definition may result in underestimation of the true burden of LC/PCC or may overestimate the likelihood or severity of LC/PCC after infection due to a selection bias for those who are sicker or higher risk seeking medically attended care and laboratory testing for SARS-CoV-2. Additionally, a definition including a laboratory reported positive SARS-CoV-2 test result may be impacted by disparities in access to laboratory-based testing, affecting conclusions that can be drawn about the whole population. However, without SARS-CoV-2 test positivity in the definition, there could be a lack of specificity clouding an

[5] Pan D, Pareek M. Toward a Universal Definition of Post-COVID-19-Condition: How do we proceed? JAMA Network Open. 2023;6(4):e235779. DOI: https://doi.org/10.1001/jamanetworkopen.2023.5779
[6] Thaweethai T, Jolley S, Karlson E, et al. Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection. JAMA. 2023;doi:10.1001/jama.2023.8823
[7] CSTE Update to the standardized surveillance case definition and national notification for SARS-CoV-2 infection (the virus that causes COVID-19): https://cdn.ymaws.com/www.cste.org/resource/resmgr/ps/ps2022/22-ID-01_COVID19.pdf.

understanding of the impact of LC/PCC over time and could lead to overestimation of LC/PCC which can have an adverse impact on resource allocation. Many STLT definitions address these concerns by including a SARS-CoV-2 positive test result in the definition, however, allowing an at-home test performed and reported by the individual, although this approach may not always be feasible when performing analyses of existing data sources without patient interviews or surveys. Some surveys ask if someone was clinically diagnosed with COVID-19 in the first few months of the pandemic in Spring 2020 to address the access to testing concerns, though the validity and consistency with this approach is challenging. An additional possible solution could be a classification of cases into those with laboratory confirmatory tests and those without laboratory evidence.

Another key component of any definition, which alters the sensitivity and specificity of the definition, is whether a shorter timeframe after SARS-CoV-2 infection such as four weeks (similar to the HHS definition) or a longer timeframe such as 90 days (similar to the WHO definition) is used. When STLTs choose a definition the pros and cons of the shorter or longer timeframe after SARS-CoV-2 infection need to be considered and the definition should be tailored to the aims of the evaluation and available data, and the timeframe used should be shared.

Future considerations for STLT LC/PCC definition development should include how to best address and develop a stratification for understanding the impact of LC/PCC on daily activities. Additional detail is provided, where appropriate, for definitions used with specific data sources highlighted in the sections below. See Appendix A for models of STLT LC/PCC surveillance definitions.

PUBLIC HEALTH SURVEILLANCE METHODS

Surveys

During the course of the pandemic, many STLTs developed their own survey methodology and tools to assess burden of LC/PCC in their jurisdictions, while other STLTs used previously validated instruments, participated in multisite CDC-funded collaborative studies along with academic partners, or added questions to existing federal health surveys.

Cross-Sectional STLT-Developed LC/PCC Surveys:

To have jurisdictional-level assessments of LC/PCC burden, many STLT health departments performed cross-sectional surveys as the methodology of choice given available resources and the shorter timeframe in which a cross-sectional survey could provide information at least for a point of time during the pandemic. Cross-sectional surveys, however, are of limited utility to understand the ongoing burden of LC/PCC over time. Ideally, surveys would be repeated at set intervals to assess persistence and changes in LC/PCC symptoms and impact on activities of daily living among a cohort longitudinally over time. Preferably, there would be a control group surveyed as well, to assist in interpretation of the results. However, these additional components require staff time and resources.

While many STLT health departments developed and administered surveys to assess LC/PCC in their jurisdictions, the Utah Department of Health and Human Services (UT DHHS) developed a survey that community health workers deployed to local health departments (LHD) and community-based organizations (CBO) could administer. This survey allowed LHDs and CBOs to assess LC/PCC symptoms, severity, and duration; access to care and resources; and impact on quality of life within their communities served. Considerations for STLTs developing and conducting LC/PCC surveys are included in Appendix B while examples of STLTs approaches are included in Appendix A.

Validated LC/PCC Surveys:
Using validated surveys including symptom screeners and functional scores such as the COVID DePaul Symptom Questionnaire (DSQ) COVID[8] and the Long COVID Symptom and Impact Tools validated and constructed from patients' lived experience[9] can reduce survey development time and resources and improve the validity of the data. However, these validated surveys can be detailed, lengthy, and challenging to implement in an applied public health setting while trying to answer public health questions rather than conducting research. Additionally, some may not be available to the public or may be costly.

To better understand the severity of LC/PCC on populations and subpopulations, some STLTs have evaluated impact on daily activities of living within survey tools. Tools that are widely used and focused on a functional assessment of symptoms include the Post-COVID-19 Functional Status (PCFS) scale[10] and the Patient-Reported Outcomes Measurement Information System (PROMIS)[11].

It is also important to understand the cultural limitations of validated surveys depending on the population and language with which a survey tool was validated. The Ho-Chunk Nation developed their own survey tool, available in the appendix, for the Ho-Chunk Nation Department of Health COVID-19 Impact Study, because they were unable to find any validated survey tools that were used in Tribal populations. When developing surveys, it is essential to consider historically marginalized populations and consider how to ensure the methodology for case enrollment is proportionate and representative of the whole population. Additionally, when surveying historically marginalized population members it is important to ask questions such as: Is the survey tool culturally appropriate? How does the survey benefit this Tribe or group of people? Do the survey findings provide immediate benefit to those who participated? Will the survey data be shared back with the community? What will be done with the data? In

[8] https://www.researchgate.net/publication/360476212_DePaul_Symptom_Questionnaire-COVID
[9] Tran V-T, Riveros C, Clepier B, et al. Development and Validation of the Long Coronavirus Disease (COVID) Symptom and Impact Tools: A set of patient-reported instruments constructed from patients' lived experience. Clin Infect Dis. 2022;74(2):278-87. DOI: https://doi.org/10.1093/cid/ciab352
[10] Klok FA, Boon G, Barco S, et al. Euro Resp J. 2020;56:2001494. https://erj.ersjournals.com/content/erj/56/1/2001494.full.pdf
[11] Ganesh R, Ghosh A, Nyman M, et al. PROMIS Scales for Assessment of Persistent Post-COVID Symptoms: A Cross Sectional Study. J Prim Care Community Health. 2021 Jan-Dec;12:21501327211030413. https://commonfund.nih.gov/promis/index

the model shared in Appendix A of the Ho-Chunk Nation report, the data were used to develop integrated treatment plans, ensure access to resources, and enhance vaccine education.

National LC/PCC Surveys:
There are several approaches used for national surveys including:

1. *Incorporating LC/PCC Questions Into Routinely Performed Federal Surveys*: CDC, other federal agencies, and STLTs have incorporated LC/PCC questions into routinely performed cross-sectional nationally representative health surveys, such as annual population-based jurisdictional surveys. Examples include:
    - The CDC National Health Interview Survey (NHIS) incorporated NHIS 2022 LC/PCC questions (pages 850-856).
    - The 2022 Behavioral Risk Factor Surveillance System (BRFSS)[12] included two questions about COVID-19 and LC/PCC. The Utah Department of Health and Human Services plans to add additional questions to assess symptoms, impact on quality of life, and access to care to those who answer 'yes' to the current LC/PCC question (https://healthassessment.utah.gov/access-brfss-data/).
    - The National Health and Nutrition Examination Survey (NHANES) 2021-2022 incorporated questions on COVID-19 and LC/PCC (starting on page 8).
    - The U.S. Census Bureau Household Pulse Survey in June 2022 added questions to its online survey about LC/PCC and its impact on day-to-day activities.
2. *Federal Surveys with State-Level LC/PCC Data*: Select nationally administered surveys provide state-level data on LC/PCC.
    - The U.S. Census Bureau Household Pulse Survey website provides a percent who ever experienced LC/PCC as a percentage of all adults, by state, starting in June 2022.
    - The BRFSS data website will provide state/territorial/metropolitan-level (where available) estimates of LC/PCC prevalence once 2022 data are publicly available.
3. *One Time National Surveys*: Additional one-time national LC/PCC surveys were performed such as the American Red Cross and the CDC survey administered through an internet panel to a nationwide sample of U.S. adults aged 18 years[13,14,15].

Benefits of national survey approaches are consistency over time, sustainability, and decreased STLT resources required. However, limitations include the number of questions that can be asked and the breadth and depth of understanding of LC/PCC impact at the STLT jurisdictional level as only select surveys allow for jurisdictional level data, primarily at the state and territorial level, so these approaches are less useful for local and tribal public health agencies.

[12] BRFSS LC/PCC questions are available on CSTE Connect for CSTE members and health departments.
[13] Wanga V, Chevinsky J, Dimitrov L, et al. Long-Term Symptoms Among Adults Tested for SARS-CoV-2 – United States, January 2020 – April 2021. MMWR 2021 Sept 10;70(36):1235-1241. DOI: https://www.cdc.gov/mmwr/volumes/70/wr/mm7036a1.htm
[14] Post-COVID conditions and healthcare utilization among adults with and without disabilities—2021 Porter Novelli FallStyles survey - ScienceDirect
[15] American Red Cross survey questions are available on CSTE Connect for CSTE members and health departments.

Finally, there can be significant delays in availability of these data limiting real-time public health response utility during a pandemic response. CDC Post-COVID Conditions: CDC Science offers information on national LC/PCC surveys and other studies initiated to better understand and estimate burden of LC/PCC nationally. The federal website COVID.gov - For Innovators and Researchers also lists federal LC/PCC surveys. See Appendix A for additional models of STLT LC/PCC survey tools and approaches.

Use of Existing Data Sources to Understand LC/PCC Burden

Use of existing data sources for analytic approaches include the use of electronic health records (EHR), electronic case reporting (eCR), health information exchanges (HIE), All Payer Databases or hospital discharge databases to understand the burden of LC/PCC in jurisdictions. Often when using existing healthcare data sources, STLTs use ICD-10 codes to identify LC/PCC. Approaches such as these were included in the 2022 Report on Long COVID in Colorado.

While it may be feasible for STLTs to use existing clinical data sources, there are also significant challenges. The ICD-10 code was introduced for LC/PCC (ICD-10 code U09.9) in October 2021, however, several STLTs have evaluated healthcare provider use of LC/PCC ICD-10 codes and found that the coding was not in frequent use, limiting the utility of current ICD-10 code based evaluations in some jurisdictions and to assess trends over time[16]. Additionally, without consensus on a clinical definition, healthcare providers may find it challenging to implement coding practices for LC/PCC. To counter these concerns some STLTs, such as the Utah Department of Health and Human Services, have engaged in educational efforts with healthcare providers regarding recognition, diagnosis, and the importance of coding for LC/PCC. Additionally, some STLTs are evaluating symptom codes which may be commonly associated with LC/PCC to further refine their approach.

Other data sources may exist outside of routine health department surveillance systems that may be considered for further understanding of LC/PCC burden and impact within jurisdictions. For example, workers compensation claims may provide a different type of data on the impact of LC/PCC on a population, such as described in the New York State Insurance Fund (NYSIF) Shining a Light on Long COVID: An Analysis of Worker's Compensation Data.

See Appendix A for additional details and models of STLT LC/PCC evaluations of existing data sources to understand burden of LC/PCC.

Modeling LC/PCC Burden

A modeling-based approach to estimating burden of LC/PCC in jurisdictions may be a useful tool to augment surveillance efforts. The Colorado Department of Public Health and Environment used published data about the rate and duration of LC/PCC to provide an estimate of the likely burden of LC/PCC in Colorado. Additionally, the Washington Department of Health is using a

[16] Zhang H, Honerlaw J, Maripuri M, et al. Characterizing the use of the ICD-10 code for Long COVID in 3 US Healthcare Systems. MedRxiv preprint. 2023; doi:https://doi.org/10.1101/2023.02.12.23285701

modeling-based exploration to estimate LC/PCC burden in Washington State by county. See Appendix A for additional details of these STLT LC/PCC modeling estimates of LC/PCC burden.

Sentinel Surveillance

Sentinel surveillance can provide detailed data on a subset of the population that might offer insight to experiences by the larger jurisdiction. LC/PCC sentinel surveillance approaches have been developed nationally. There is opportunity to expand sentinel surveillance efforts, including in conjunction with existing sentinel surveillance systems, such as the Emerging Infections Program (EIP) COVID-19-associated Hospitalization Surveillance Network (COVID-NET). If samples are representative of the general population, this can be an efficient way to assess trends, burden, and required resources without needing to capture every individual with LC/PCC. However, to ensure high quality data and representative samples, these efforts require significant staff time and resources.

Some examples of national LC/PCC sentinel surveillance:

- CDC's Tracking Burden, Distribution, and Impact of Post COVID-19 Conditions in Diverse Populations for Children, Adolescents, and Adults (TrackPCC) is a multi-year sentinel surveillance project initiated in September 2022 which encompasses both passive and active surveillance and long-term follow-up of cohorts. As part of passive surveillance, TrackPCC will collect information at four surveillance sites from electronic health records of patients who test positive for SARS-CoV-2 infection for up to five years to estimate incidence of symptoms and conditions occurring after SARS-CoV-2 infection. Every quarter, new cohorts of patients who tested positive for SARS-CoV-2 will be added to the surveillance system, and those who previously tested positive will be followed for the development of PCC symptoms and conditions. As part of active surveillance, TrackPCC will survey a sample of patients who test positive for SARS-CoV-2 from the four surveillance sites for on-going symptoms three months after infection and then every six months for up to 18 months. This will provide estimates of the prevalence of symptoms that continue for more than three months after COVID-19 illness and provide information on symptom duration, severity of symptoms, impact on day-to-day activities, and associated health disparities. (Sites and partners include Abt Associates, Indiana University, Temple University, University of Arizona, and Comagine Health Collaborative: Boise State University, Utah Health Information Network, and Bronx Regional Health Information Organization, in collaboration with state or local public health departments).
- The **COVID**- **S**tandardized **E**valuation of **L**ong-term **E**ffe**ct**s (COVID-SELECT) CDC-funded California Department of Public Health (CDPH) EIP COVID-NET site with academic and healthcare partners aims to advance the understanding of the development and early stages (first 2-5 years) of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and ME/CFS – like Post-COVID Conditions (PCC), risk factors, and associated public health burden to inform diagnosis and management of these conditions and potential approaches to sentinel surveillance for LC/PCC.

Syndromic Surveillance

Several STLTs have used syndromic surveillance systems to better understand primarily emergency department (ED), but also urgent care center (UCC) and primary care visits for LC/PCC. Most STLTs have focused these efforts on analyses of the LC/PCC ICD-10 code (U09.9); however, some STLTs have also assessed other symptoms or diagnoses that might be associated with LC/PCC (e.g., the postural orthostatic tachycardia syndrome (POTS) code (G90.A)).

The benefits of using syndromic surveillance are the near real-time access to data accessible to health departments. Limitations include limited and differential use of LC/PCC ICD-10 codes in EDs and UCCs and variations in STLT development of and access to syndromic surveillance in their jurisdiction. Additionally, syndromic surveillance could lead to underestimation of LC/PCC as patients experiencing LC/PCC may not often present for ED or UCC care unless experiencing acute symptoms. While it is more common for patients to present to primary care settings for LC/PCC symptoms, syndromic surveillance has limited availability in these settings.

Further validation of syndromic surveillance approaches, definitions, and instruments would be useful for STLTs who may want to initiate or improve their approaches. See Appendix A for STLT models using syndromic surveillance systems to estimate burden of LC/PCC.

LC/PCC EDUCATION, COORDINATION, AND COLLABORATION

An integral role of STLTs is to educate healthcare providers and the public, coordinate partners and stakeholders, and convene expert workgroups including community members and those living with LC/PCC. Educational activities with these groups are critical to inform and improve STLT LCC/PCC surveillance as data collection and surveillance is impacted by healthcare provider diagnoses and, if using existing data sources, by healthcare provider documentation (i.e., coding). Convening expert groups and community advisory boards, including those with lived experience, can provide valuable insight for the development of informed and equitable surveillance approaches and to prioritize data collection and surveillance needs. Many STLTs led important coordination and collaboration efforts in their jurisdictions. See Appendix A for models of STLT LC/PCC coordination and collaboration activities.

LESSONS LEARNED

Finding a long-term home for LC/PCC surveillance and public health data evaluation remains a challenge within many STLT health departments. While chronic disease programs may be well suited to engage with healthcare providers and the public to address this chronic condition and its impacts, in some STLTs infectious disease programs have been primarily involved in this work to-date as they may have led SARS-CoV-2 infection surveillance efforts. Some STLTs have one organizational unit for all LC/PCC activities (e.g., LC/PCC activities all reside in the Chronic Diseases Program in the health department) with cross-collaboration as needed, while others have different aspects of the LC/PCC public health response addressed in different organizational units (e.g., LC/PCC education and outreach within Chronic Disease Programs and

surveillance within the Infectious Diseases or general Epidemiology Programs) with cross-collaboration, as appropriate. Cross-collaboration with chronic disease, infectious disease (including COVID-19/respiratory diseases), and surveillance/epidemiology, as well as linkages to areas of health departments engaged in healthcare access, health equity, and community engagement, are needed to optimally address LC/PCC.

Many STLTs reported that they were under resourced, and continue to have limited staff to perform high-quality, longitudinal, representative surveys or sentinel surveillance to better understand local burden and community and subpopulation LC/PCC needs over time. While these programmatic challenges have certainly made LC/PCC surveillance difficult, STLTs have been resourceful and thoughtful in addressing the needs as they see best in their communities.

GAPS AND NEEDS MOVING FORWARD

Multiple approaches to LC/PCC surveillance are likely needed to understand the breadth and depth of LC/PCC in jurisdictions and its impact on the population and subpopulations. However, the initial approach will depend on resources available in each jurisdiction with an ultimate goal of a multi-pronged approach that leverages different data sources.

STLTs need adequate resources for staff dedicated to LC/PCC surveillance and data processing capacities such that LC/PCC data are available to STLTs and their communities in a timely manner, including race and ethnicity and other data to assess and address disparities. Long-term funding would support surveillance efforts nationally. Additionally, flexible funding for planning for, responding to, and recovering from public health emergencies, including infectious disease responses, would allow STLTs to pivot resources as acute needs and priorities shift. Finally, support for regional LC/PCC Centers of Excellence to engage in collaborative efforts between STLTs and academic LC/PCC care providers should be expanded to further public health surveillance aims.

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Appendix A: State, Territorial, Local, and Tribal Long COVID-19/Post-COVID-19 Conditions Public Health Data and Surveillance Working Models

This section includes a brief description of select LC/PCC projects carried out by different STLTs at the time of writing (*through August 2023*) and is not meant to be a complete list of all STLT approaches to monitoring or addressing LC/PCC in their jurisdictions.

LC/PCC surveillance models advancing health equity:

⇒ The Ho-Chunk Nation Department of Health COVID-19 Impact Study assessed the prevalence of LC/PCC in order to capture the duration and severity of illness, type of symptoms experienced, impact on daily living, social/material resources, and demographics among Ho-Chunk Tribal members. They used members' stories and symptom experiences to identify resources and create an integrated treatment plan in clinic and community settings including Medical, Behavioral Health, Public Health, and Community Health services and outside referrals. The health department also used the study to change how they promoted vaccines with an emphasis on preventing LC/PCC.

⇒ Several STLTs created workgroups or advisory committees with diverse community members to ensure STLT approaches to LC/PCC surveillance include health equity considerations. For example:

- The California Department of Public Health (CDPH) established a statewide Tribal Health Long COVID-19 Workgroup which meets regularly to share information and data collection strategies.
- The Minnesota Department of Health (MDH) has been convening 'Community Voices' which is a group of partners, leaders, and organizations serving diverse and marginalized communities that include people with LC/PCC, to inform intersectional approaches to and prioritization of public health activities.
- The Michigan Department of Health and Human Services established a Racial Disparities Task Force at the beginning of the pandemic and offered testing in areas with high social vulnerability index. Over the pandemic, these sites evolved to include vaccinations, COVID-19 and non-COVID-19 related wrap around health services and looked to address immediate impacts and upstream factors that placed marginalized populations at a higher risk for experiencing LC/PCC.

⇒ It must be acknowledged and addressed that public health data evaluation and surveillance rely on equitable access to laboratory testing and healthcare. Similarly, equitable access to vaccinations and therapeutics may reduce the burden of LC/PCC among highly impacted communities. Following health equity principles, the Puerto Rico Department of Health (PRDOH) was able to develop and implement a test-to-treat model, adapted to the needs of the local population. Following its success, PRDOH established a collaboration with HRSA and Federal Qualified Health Centers (FQHCs) to provide testing, clinical evaluation, and rapidly linking patients to treatment for

underserved populations. To reduce access to barriers for vulnerable populations, divisions of PRDOH collaborated to offer at-home testing and treatment coordination for patients eligible for monoclonal antibody therapies. Today Puerto Rico has readily available 21 Test to Treat Sites across the island. Further, every week, more than 100 community testing sites are available island wide free of cost. Other testing initiatives to provide access to socially vulnerable communities still available include: home testing distribution, Long Term Care Facilities, and school (K-12) testing site visits (Summary of pillars of the COVID-19 response In Puerto Rico, Standing Up a Test to Treat Model During a Surge of COVID-19 Cases, Health Equity: Standing up a Test to Treat Model During a Surge of COVID-19 Cases).

LC/PCC Definitions:

⇒ The PRDOH adapted its definition following the recommendations of a panel of experts surveyed by the World Health Organization (WHO) (WHO, 2021). See the Special Report on the Prevalence of Post Acute Sequelae of COVID-19 in Puerto Rico.

⇒ The Washington State Department of Health developed a modeling approach for LC/PCC (*see section on modeling)*. They used the US Census Bureau/National Center for Health Statistics Household Pulse survey definition of LC/PCC as symptoms experienced for three months or more following infection, which may be new, recurring, or exacerbated pre-existing conditions, regardless of cause, whether the symptoms were directly due to SARS-CoV-2 infection or whether the symptoms were due to severity of illness or hospitalization.

⇒ The NYC DOHMH, when describing survey data, reports on the percentage of people who have had long-term symptoms that they attribute to COVID-19, given the challenges of defining LC/PCC and the limitations of survey data. The NYC DOHMH is addressing equity concerns by not requiring a positive laboratory test in the survey tool to lead to the next question about potential post-COVID-19 symptoms.

LC/PCC Surveys:

1. *Multisite Surveys:*

⇒ A CDC multi-jurisdictional LC/PCC online survey in partnership with Maine, New Jersey, New York, Wisconsin, was initiated in early 2021. Through this multisite evaluation, adults were surveyed through an email-based survey who tested positive for SARS-CoV-2 and had self-reported acute infection and LC/PCC lasting four weeks or more to estimate prevalence of PCC and identify demographic and disease-specific risk factors for developing LC/PCC. Two abstracts were presented at the 2022 CSTE conference and a manuscript with findings is in process.

⇒ The CDC-sponsored Innovative Support for Patients with SARS-COV-2 Infections (COVID-19) Registry (INSPIRE) is a national, prospective, multicenter, longitudinal cohort study across eight regions in the U.S. (IL, CT, WA, PA, with two sites in TX and CA). INSPIRE was a CDC and academic collaboration evaluating incidence and risk factors through a web-based approach which collected data from December 2020 to March 2023. INSPIRE follows cases in adults who test positive for SARS-CoV-2 infection and a comparison

group of adults who test negative for SARS-CoV-2 every three months for up to 18 months. Participants complete detailed surveys, including information on social determinants of health, and provide linked electronic health information. Enrollment is now complete and data collection and analysis are ongoing. The INSPIRE study partnered with state health departments to identify individuals who had recently tested for SARS-CoV-2.

2. *Questions added into existing surveys:*
   ⇒ In early 2021, the New York City Department of Health and Mental Hygiene (NYC DOHMH) added questions about LC/PCC to the annual Community Health Survey (CHS) and quarterly NYC Health Opinion Poll (HOP). CHS data are made available to the public on the website or through data-specific Data Use Agreements and HOP data are available to the public through a Data Use Agreement. A COVID-19 module with questions was added into the CHS in 2021, 2022, and will be included in the 2023 CHS. The CHS is a probabilistically sampled, population-representative survey that allows calculations of prevalence estimates at the population-level and by respondent characteristics. However, limitations include the timeline for collecting and analyzing these data, as CHS data typically take a year to collect, analyze data, and provide estimates.

3. *LC/PCC-Focused STLT Cross-Sectional Surveys:*
   ⇒ The NYC DOHMH performed the 2022 COVID-19 Experiences Survey, through the DOHMH's Healthy NYC Panel, a probabilistically sampled, population-representative survey which allows calculations of prevalence estimates at the population-level and by respondent characteristics. This survey included almost 2,100 people with suspected previous COVID-19 to gather information about long-term symptoms, disabilities, care, and treatment. NYC DOHMH will be following the quantitative survey up in 2023 with in-depth interviews with ~40 respondents who reported persistent symptoms to assess barriers and facilitators to seeking care for long-term symptoms and to understand inequities in the burden of LC/PCC across the city. The LC/PCC definition is to be determined through a partnership with the Columbia University's "COVID-19 Persistence: Understanding the SARS-CoV-2 Virus and Host Factors in People Who Are Recovering From Their Illness (C-PIC)" study. It is expected that the partnership will help develop a predictive model using clinical and survey data that can be applied to the survey dataset to predict LC/PCC diagnoses were individuals to present with these symptoms to a clinic.
   ⇒ The Wisconsin (WI) Department of Health Services used contact tracing staff to complete a phone survey of WI adult residents who were tested for SARS-CoV-2 at any community testing site in WI between November 2020 and May 2021, to compare the health status between those who did and did not test positive for SARS-CoV-2. Among those who were eligible, sampling was stratified based on timeframe (before or after January 2021) of initial test, age of participant (<50 years of age and 50 years and older), and race (white and not white), and whether they tested positive or negative for SARS-CoV-2. Whenever feasible, questions were adapted from validated questionnaires such

as BRFSS. Adding the control group allowed measurement of LC/PCC symptoms between those with SARS-CoV-2 infection and those who were negative, helping to distinguish the impact of SARS-CoV-2 versus the general impact of the pandemic or other confounding factors. These data were presented at the 2022 CSTE conference and data were presented on the WI Medical Provider Webinar (7/2022).

⇒ California Department of Public Health (CDPH) conducted or collaborated on several surveys:

a) The CalCONNECT Survey is a retrospective, telephone, and SMS text survey on LC/PCC burden initiated in December 2021. An updated version of the survey was released in January 2023.

b) The CalScope survey was a statewide mail-based survey with LC/PCC questions added to a COVID-19 serosurveillance study from a representative sample from the Summer 2022. Enrollment had three waves and LC/PCC questions were added to wave three, enrollment is complete and data analysis in process.

c) The CDC-COPE Collaboration survey is a retrospective, web-based survey to assess overall prevalence, severity, duration, risk factors, and healthcare utilization, with plan to commence survey distribution by email in Summer 2023.

d) INSPIRE is a multi-site prospective cohort study that seeks to characterize LC/PCC. CDPH collaborated with the UCLA and UCSF enrollment sites to achieve a more representative sample of the state.

⇒ The Puerto Rico Department of Health (PR DOH) has completed two different cross-sectional surveys to estimate the prevalence of LC/PCC in Puerto Rico during Phase 1: September 2020- August 2021 and Phase II: December 2021-July 2022. The two surveys might include different populations. The PR DOH LC/PCC website provides information on the survey including a PR DOH Special Report on the Prevalence of Post-Acute Sequelae of COVID-19 and a presentation on the results of the COVID-19 Post-Acute Sequelae Survey (Spanish).

⇒ The Michigan Department of Health and Human Services (MDHHS) collaborated with the University of Michigan to conduct the Michigan COVID-19 Recovery Surveillance Study (MI CReSS study) where adults are randomly selected from a subset of those with an acute COVID-19 diagnosis. The survey, launched in June 2020, performs follow-up for many post-acute outcomes including LC/PCC. MI CReSS short summaries and full length data reports are available on several topics on the MI CReSS Data Reports website.

⇒ The New Jersey Department of Health (NJ DOH) is engaging in a follow-up LC/PCC survey to evaluate a number of additional public health evaluation goals. The survey has several sections including: 1) expanded sociodemographics (to understand ethnic/cultural/socioeconomic status-related disparities in the identification and treatment of LC/PCC), 2) respondents' detailed infection history, reinfection(s) and associated LC/PCC symptoms, 3) employment during the pandemic, job assistance and work productivity, and 4) the impact on the patient, family and community (which obtains further detail on dependents, caregiver status, social support, and mental health). NJ DOH is working to match survey respondent records to immunization information systems data (and other communicable disease records), where appropriate, to better inform the role of data on vaccination(s) as it relates to LC/PCC.

⇒ The Minnesota Department of Health (MDH) is engaged in a statewide phone survey to better understand LC/PCC, symptoms and their impacts on employment, healthcare, daily activities, and quality of life, with community-focused assessments to follow. In addition to English, phone surveys are being conducted in Spanish, Hmong, and Somali by bilingual staff, while other languages are available through a translation service.

LC/PCC Data Analyses with Existing Data Sources:

⇒ The 2022 Report on Long COVID in Colorado details the Colorado Department of Public Health and Environment (CDPHE) collaboration with the Center for Improving Value in Health Care (CIVHC) to provide an overview of the number of Coloradans diagnosed with LC/PCC using the ICD-10 code U09.9 from the Colorado All Payer Claims Database dataset (after the introduction of the code on October 1, 2021). This analysis includes all outpatient encounters of Colorado residents with commercial, Medicare Advantage, and Medicaid and was described by age, gender, race and ethnicity, and county of residence. This data analysis identified over 16,000 individuals with LC/PCC; however, there were several limitations noted including a lack of the ICD-10 code for the first 17 months of the pandemic, and incomplete data availability at the time of analysis in August 31, 2022 (versus the modeling estimates {see details in modeling section} of burden at 228,000 to 651,000 affected Colorado residents through November 2022). The CDPHE also examined emergency department (ED) visits and admission with a LC/PCC billing code to understand burden on the ED and inpatient healthcare system.

⇒ The CDPHE also evaluated data from the Colorado Hospital Association hospital discharge and ED visit databases searching for a diagnosis code of U09.9 ("Post COVID-19 condition, unspecified"); however, few encounters were identified with a primary diagnosis of LC/PCC during this timeframe (October 2021 to November 2022).

⇒ The Utah Department of Health and Human Services (UT DHHS) is developing a LC/PCC information system with the primary aim of characterizing the burden of LC/PCC in UT. It draws from several sources including longitudinal electronic case reporting (eCR) and all-payer claims databases (APCD) using the LC/PCC ICD-10 code, using data from a LC/PCC clinic for validation. Additionally, the UT DHHS has an active Long COVID-19 Surveillance Workgroup comprised of state and local health department representatives, Tribal partners, patient advocates, disability advocates, and clinicians to identify gaps and best practices. UT DHHS also surveyed local health jurisdictions and Tribal partners using a needs assessment to ascertain priorities; local surveillance data and education were identified as priority areas of interest. Additionally, the UT DHHS has evaluated LC/PCC through syndromic surveillance evaluating visits with the U09.9 ICD-10 code (see syndromic section). Using APCD data, a rate was calculated per 100,000 persons in UT. However, limitations included healthcare provider limited use of the ICD-10 code potentially due to lack of knowledge about its existence or an understanding of when and how to use the LC/PCC ICD-10 code.

Syndromic Surveillance:

⇒ The Kansas Department of Health and Environment and the Nebraska Department of Health and Human Services performed initial explorations into evaluating LC/PCC using syndromic surveillance data to better understand the use of the LC/PCC ICD-10 code (U09.9) and associated symptom codes with a history of COVID code (Z86.16) or LC/PCC code in the ED setting. They found that sleep disorders and abnormalities of heartbeat were the most overrepresented symptoms in the ED when compared to ED visits for all causes.

⇒ The Utah Department of Health and Human Services (UT DHHS) evaluated syndromic surveillance data using the LC/PCC (U09.9) ICD-10 code and identified records with this code, the majority of which (57%) were in primary or urgent care settings (as opposed to EDs).

Modeling LC/PCC Burden

⇒ The 2022 Report on Long COVID in Colorado details the CDPHE process of estimating the prevalence of LC/PCC in Colorado using published data about the rate and duration of LC/PCC to provide an estimate of the likely burden of LC/PCC in Colorado. The analysis followed methods originally developed by Chen et al.[17] in 2022. The inputs include total reported probable and confirmed cases of COVID-19, COVID-19 hospitalizations, and deaths among COVID-19 cases by age and gender in Colorado. LC/PCC rates were derived from published peer-reviewed meta-analyses[7,18] and published CDC estimates. Duration estimates were used to convert rate into person-days of LC/PCC burden. Given published literature of LC/PCC rates almost always includes those with a positive SARS-CoV-2 test, individuals without it may be less likely to have LC/PCC, and therefore were not addressed in this model. Those with at-home OTC positive results were also not included in this model given the lack of public health reporting of these cases (i.e., suspect cases). A range of a rate and burden of LC/PCC in Colorado were estimated given differing data on probability of developing LC/PCC and estimated duration of LC/PCC and expressed total burden as person-days. The estimated LC/PCC total burden ranged from 16.9 to 39.4 million person-days of symptoms, affecting as much as 15% of Colorado's population.

⇒ Washington State has developed a mathematical model-based exploration of estimating LC/PCC burden. The model converts state infections/cases/hospitalizations and outputs age-group/gender/race-ethnicity/vaccination status estimates of LC/PCC at the county level using a stochastic mechanistic compartmental model. County estimates of burden are integrated into pre-existing data processes using electronic laboratory reported SARS-CoV-2 infection data and real-world information imported through an array of

[17] Chen C, Haupert S, Zimmermann L, et al. Global Prevalence of Post-COVID-19 Condition or Long COVID: A meta-analysis and systematic review. J Infect Dis. 2022 Nov 1;226(9):1593-1707. https://pubmed.ncbi.nlm.nih.gov/35429399/

[18] Lopez-Leon S, Wegman-Ostrosky T, Cipatli Ayuzo del Valle N, et al. Long-COVID in Children and Adolescents: a systematic review and meta-analysis. Scientific Reports. 2022 June;12:9950. https://www.nature.com/articles/s41598-022-13495-5.

sources to minimize burden on public health staff members. In this modeling approach, LC/PCC burden estimates incorporate risk by hospitalization, age, race, ethnicity, sex, vaccination status, and county with adjustments for Omicron dominant versus Pre-Omicron dominant timeframes. Probabilities of LC/PCC and duration of LC/PCC are both considered and are taken from national survey data and the scientific literature to estimate how many Washingtonians are currently estimated to be living with LC/PCC. The modeling approach is undergoing refinement, but the results are being used to steer public health action and advocacy both within WA DOH and with external state partners.

STLT LC/PCC Coordination, Collaboration, and Education:

⇒ The California Department of Public Health (CDPH) performed a local health department (LHD) needs assessment: a cross-sectional, web-based, one-time survey to evaluate the needs of LHDs around LC/PCC. Additionally, CDPH distributed a continuing medical education learning series produced by University of California Health to improve healthcare provider education and expand access to quality care. This initiative has been used by many other STLTs and healthcare providers nationally and is a free resource located here: https://health.universityofcalifornia.edu/long-covid-education. This resource was shared by CDPH and other STLTs to improve the provision of care in rural or other underserved settings. Throughout these LHD and HCP activities, CDPH also developed public health priorities by directly engaging with people with LC/PCC.

⇒ The Minnesota Department of Health (MDH) engages in coordination and education efforts to help primary care and other "gatekeepers" to better recognize, coordinate care, and manage symptoms including through the efforts of a Learning Network/Guiding Council of clinicians from across the state which works to improve quality of and access to care for LC/PCC. To educate the public, MDH developed a series of short videos about LC/PCC available in Spanish, Somali, Hmong, and English (available through the Long COVID Playlist on the MDH YouTube channel), posted resources on the MDH Long COVID website and posts regularly on social media, presents to local and Tribal public health, employers and benefits brokers, school nurses and superintendents, legislators, community groups, and Governor's workgroups and councils, often co-presenting with ADA Minnesota (focusing on workplace accommodations, rights under ADA).

⇒ The PRDOH has developed a website to have the estimates of LC/PCC prevalence and educational materials available to the public and has had meetings with some healthcare centers funded by section 330 of HRSA to explore educational needs regarding LC/PCC and develop a recommendations guideline for patient follow-up. PRDOH is also educating in long term care facilities and at educational fairs in collaboration with the PR Commonwealth government and is engaged in unified efforts with the Academy of Medical Directors of Puerto Rico for education regarding LC/PCC.

⇒ Given limited use by healthcare providers of the ICD-10 code potentially due to lack of knowledge about its existence or an understanding of when and how to use the LC/PCC ICD-10 code, the UT DHHS engaged in educational efforts for healthcare providers such

as contributing to newsletters, bulletins, and presentations (some CME-eligible) run by numerous clinics and professional networks to raise awareness of LC/PCC and the ICD-10 code.

⇒ Several STLTs, including the Maricopa County Department of Public Health, have disseminated the Long COVID and Fatiguing Illness Recover Program, the CDC-funded monthly ECHO webinar learning series for healthcare providers.

⇒ Several STLTs held symposiums for healthcare provider education including the NYC DOHMH symposium for providers, in collaboration with NYC Health + Hospitals' AfterCare program.

Appendix B. Considerations for STLTs Developing and Conducting LC/PCC Surveys and STLT Approaches and Models

⇒ *Approaches for how to ask questions about LC/PCC symptoms and timeframes*

- Ask about initial symptoms with acute infection (yes/no) to a wide range of listed symptoms. For each initial symptom reported, ask if they still have the symptom(s).
- Ask if symptoms were experienced (*either consistently or from time to time*) (yes/no). If yes, if they currently have any symptoms or have the symptoms stopped? If symptoms persisted, do they experience an impact from the symptoms?
- Ask the individual to rate their general health (or health status) before they had an infection with SARS-CoV-2 and as of today (the time of the survey).
- Assess health status pre-COVID (including symptoms), symptoms developed within 3 months from the acute infection, symptoms that last 2 months or more, and symptoms persistent at the moment of the interview.
- Ask about symptoms lasting longer than four weeks (or 30 days) or 12 weeks (90 days).
- Another option is to avoid strict timeframes when assessing persistence of symptoms after acute COVID-19 infection and ask if symptoms persisted (yes/no) and if yes, for how long?
- One STLT's approach is to ask "From February 2020 until now, do you think you may have had COVID-19?", as this had the best sensitivity and specificity in predicting seropositivity when these data were compared to serosurvey data in their experience.
- Another option is to collect infection dates and survey dates and consider where the individual fits within the different time periods, looking at four weeks and 12 weeks, or potentially other timeframes, categorizing people with persistent symptoms into time intervals such as: 1-<3 months, 3-<6 months, 6-12 months.
- Ideally, ask the same questions to both SARS-CoV-2 infection cases and controls (those without recent SARS-CoV-2 infection) in the timeframe before LC/PCC symptom onset.
- Note that some STLTs have seen differences between questions about recovery versus persistent symptoms, and generally find questions about recovery to be more sensitive, whereas questions about persistence of symptoms seem more specific. Additionally, responses to each question were often not in agreement. For example, the answer to the question "Do you feel you are back to your baseline level of health and function (before your COVID infection)?" may not be in agreement with the answer to the question "Have you had symptoms that have lasted four weeks or longer?"

⇒ *Approaches for how to assess the impact of reinfections*

- Some STLTs ask all of the questions for each infection. However, the survey may become cumbersome. More likely STLTs may capture history of prior infection and reinfections but only ask the list of symptoms once and whether symptoms are still present.
- Another approach is to record infection dates and survey dates.
- Other STLTs ask only about the last infection.

- Other STLTs ask about total number of infections or number of infections within the last year before LC/PCC symptom onset.
- How much is asked about reinfections may depend on whether there is a longer survey (e.g., for instance through email) versus a shorter survey (e.g., through phone).
- Often STLTs rely on self-report for reinfection rather than laboratory-confirmation.

⇒ *Approaches for how to best capture which variant may have been involved in the infection*

- Asking for dates of infection can help estimate the variant involved, however, this can get complicated for data collection with reinfections and recall, or time periods when multiple variants were circulating at similar prevalence.

⇒ *Approaches for how to capture information on the acute COVID-19 illness and any treatment (e.g., antiviral therapy) as these data points could be helpful in identifying the likelihood of developing LC/PCC and mitigation measures of severity or length of LC/PCC.*

- STLTs could ask questions about the severity of the initial illness (e.g., hospitalization, intensive care provision)
- STLTs could inquire about whether antiviral therapy was administered.

⇒ *Approaches for how to best assess vaccination status*

- Ideally, STLTs could link survey data with immunization information system data, when appropriate and allowable.
- Where not feasible, STLTs may rely on self-report of vaccine status and date of vaccine administration.
- STLTs can consider collecting data regarding whether a respondent was vaccinated before first SARS-CoV-2 infection.

⇒ *Approaches for how to approach data analysis*

- With differing levels of reinfections and vaccinations over time, data analysis can become challenging, particularly with so many different issues with testing and reporting at different times (i.e., early on there was limited access to testing, whereas now there are readily available at-home OTC testing not reported to public health, both of which may underestimate SARS-CoV-2 infections and LC/PCC).
- Additionally, reinfection assessment analyses will be difficult with asymptomatic and mild acute symptoms not being reported or tested at all.

Table. Long COVID-19/Post COVID-19 Conditions Definitions

Organization Name	Long COVID-19/Post COVID-19 Conditions (LC/PCC) Definition
WHO clinical case definition	Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.
The interim U.S. government working definition of Long COVID-19	Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing– remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.
The National Institute of Health (NIH)	Ongoing, relapsing, or new symptoms, or other health effects occurring after the acute phase of SARS-CoV-2 infection present four or more weeks after the acute infection.
The Centers for Disease Control and Prevention (CDC)	A wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected with the virus that causes COVID-19.
The United Kingdom's National Institute for Health and Care Excellence (NICE)	Signs and symptoms that develop during or after an infection consistent with COVID-19, continuing for more than 12 weeks and are not explained by an alternative diagnosis.
The American Academy of Physical Medicine and Rehabilitation (AAPMR)	A condition that occurs in individuals who have had COVID-19 and report at least one persistent symptom after acute illness. AAPMR adds that Long COVID encompasses a constellation of varied and ongoing symptoms – even in the same patient across time – and may include neurological challenges, cognitive symptoms such as brain fog, cardiovascular and respiratory issues, fatigue, pain, and mobility issues, among others.
Proposed Definition by Pan and Pareek: Toward a Universal Definition of Post-COVID-19-Condition[19]	Signs and symptoms following initial SARS-CoV-2 infection, that persist for more than one month (in mild cases), and more than three months (in cases severe enough to warrant oxygen support), which have a disproportionately severe effect on a patient's quality of life, far beyond what is expected from their initial infection.

[19] Pan D, Pareek M. Toward a Universal Definition of Post-COVID-19-Condition: How do we proceed? JAMA Network Open. 2023;6(4):e235779. DOI: https://doi.org/10.1001/jamanetworkopen.2023.5779