Long COVID Broad v1 Definition Factsheet & Technical Brief

<u>Authors</u>: Lauren Norris, MHS¹; Sara Chronister, MPH¹; Connor D. Pomeroy, MPH²; Priscilla Owusu-Mensah, MPH³; Abida Anwar, PhD⁴; Jordan Urrate, MPH⁴; Jennifer Walker, MPH⁴; Ciara Seals, MS⁴; Brittany Yarnell, MPH⁵; Gabriel Haas, MPH⁶; Lee Hundley, MPH⁷; Carolyn Adam, MPH⁷,8; Jacob Gunnell⁷; Sahaj Parekh, MPH⁷; Alison Hopkins, MPH, RN⁷; John Prather, MBA⁷

- ¹ Washington Department of Health
- ² Tacoma Pierce County Health Department
- ³ Virginia Department of Health
- ⁴ Harris County Public Health Texas
- ⁵ Nebraska Department of Health and Human Services
- ⁶ Kansas Department of Health
- ⁷Kentucky Department for Public Health
- ⁸ CDC Foundation

Points of contact:

Lauren Norris (Lauren.Norris@doh.wa.gov) - Washington Department of Health

<u>Definition Purpose:</u> To assist state, local, tribal, territorial, and federal public health practitioners in trend monitoring for long COVID (also commonly described as Post-COVID Complications (PCC) or long-haul COVID) related visits in the emergency department (ED) setting using syndromic surveillance data.

New or Revised Definition:

☐ Revision of Existing Definition

Date Added to ESSENCE: December 2024

<u>Definition Description</u>: The definition should capture visits presenting for long COVID, defined as symptoms or conditions that continue or develop at least four weeks after initial COVID-19 infection. These symptoms/conditions are non-specific and may include tiredness/fatigue, brain fog, shortness of breath, cough, chest pain, irregular heartbeat, headache, sleep problems, dizziness, depression and/or anxiety, diarrhea, stomach pain, joint and/or muscle pain, changes in smell and/or taste, and more. The definition should not capture visits for current COVID-19 infection or COVID-19 infection less than three weeks ago. The definition should not require confirmation of previous COVID-19 positivity. The definition should require either discharge diagnosis <u>OR</u> free-text indication of suspected long COVID. This definition utilizes the discharge diagnosis parsed free text, chief complaint history, triage notes orig, and admit reason combo fields. Jurisdictions that do not have all these fields can still utilize the definition without problem, as ESSENCE will query available fields only. If you do not wish to query specific fields (ex: triage notes orig), we recommend manually applying the definition syntax to your fields of interest rather than using the CCDD category.

Use-Cases for Definition:

Case-finding: Secondary
Trend monitoring: Primary

Early outbreak detection: Not Intended as Use Case Emergent Condition: Not Intended as Use Case

<u>Justification for Definition Development</u>: There is no previously existing long COVID query definition and there is nationwide interest in monitoring trends in long COVID visits using syndromic data. The definition presented here is based off work initially done by Kansas and Nebraska Departments of Health and presented at the 2022 Sys Symposium (2022 SyS Symposium Slides - OneDrive (sharepoint.com)).

Data Source During Development: Emergency Department Visits

<u>Development Methods</u>: Subject matter experts from seven jurisdictions (WA; VA; Harris County, TX; Pierce-Tacoma County, WA; NE; KS; KY) created and validated the definition using ED visit data from January – December 2023.

- 1. Literature review on long COVID to identify common symptoms and complaints and alternative syndrome names.
- 2. Search for diagnosis codes (International Classification of Diseases, 10th Revision (ICD10-CM) and Systematized Nomenclature of Medicine (SNOMED)) relevant to long COVID.
- 3. Query relevant diagnosis codes under Discharge Diagnosis Parsed and relevant free text terms under Chief Complaint History in ESSENCE and run text analysis to identify: 1. Any missing, relevant diagnosis codes and/or free text terms to include, 2. Any irrelevant diagnosis codes and free text terms to exclude.
- 4. Update definition to include free text and diagnosis code inclusion and exclusion terms.
- 5. Validate definition using validation steps outlined below.

<u>Validation Methods:</u> Participating jurisdictions classified visits into true and false positives and compared positive predictive value.

- 1. Run definition evaluation using Syndrome Evaluation Toolkit (<u>sara-chronister/syndrome-definition-evaluation</u>: R code for evaluation of NSSP BioSense ESSENCE syndrome definition results using ESSENCE APIs. (github.com)) to evaluate definition component performance.
 - a. Query Parameters:

i. Start Date: 1/1/2023ii. End Date: 12/31/2023

iii. Facility Type: Emergency Care

iv. HasBeenE: Yes

- 2. Complete a manual review of visit data details for a random sample of records and classify visits into probable, maybe, and unlikely long COVID related and compare positive predictive value across jurisdictions. See manual review criteria below:
 - **a.** <u>Probable:</u> These visits explicitly stated that they have been experiencing ongoing symptoms for more than four weeks after their COVID infection or that they were previously diagnosed with long COVID.
 - b. <u>Maybe:</u> Includes visits that presented with symptoms that are consistent with long COVID (chest pain, SOB, abdominal pain, weakness/fatigue, etc.) but there was no information to confirm that they previously were COVID positive at least four weeks prior (i.e., they had U099 code but no covid history information). Also includes visits that were exhibiting long covid symptoms greater than three weeks but less than four weeks post covid infection.
 - c. <u>Unlikely:</u> Includes visits that are currently COVID positive or tested COVID positive less than three weeks ago. Include visits that are clearly not related to long COVID (stroke, drug withdrawal, other infections, etc.)
- 3. Update definition based off findings from manual review.
- 4. Repeat steps 1-4 until happy with final definition draft.

<u>Validation Results:</u> The positive predictive value for capturing probable and maybe long COVID related visits was 51% in WA, 74% in Tacoma-Pierce County (LHJ in WA), 61% in KY, 81% in VA, 30% in NE*+, and 84% in Harris County (county in TX). The average PPV across all jurisdictions was 70%**. The broad version picks up 2-3x the visit volume compared to the narrow definition. This definition is more likely than the long COVID narrow definition to return visits not clearly related to COVID or long COVID. See Limitations section for additional information on the limitations associated with the U09.9 ICD-10 code.

^{*}Validated without applying to Admit Reason Combo field due to absence of field in jurisdiction.

⁺Validated using modified validation criteria. Visits presenting with a U09.9 code and no other mention of COVID or long COVID were classified as "unlikely" instead of "maybe".

^{**} NE not included in average due to difference in evaluation criteria used.

<u>Definition Fields and Structure:</u> The Discharge Diagnosis Parsed Free Text field (also applied to Chief Complaint History, Triage Notes Orig, and Admit Reason Combo) is used to query discharge diagnosis codes and free text with exclusions (as necessary), to develop the syndrome definition. This broad definition requires EITHER discharge diagnosis OR free-text indication of suspected long COVID.

- Inclusions based on long COVID related discharge diagnosis codes:
 - The visit is included if it contains:
 - A discharge diagnosis code of Post-COVID conditions (U099 or 1119304009) or Post-Viral Fatigue Syndrome (G933)
 - Visits with G933 are only included if they also have free text mention of "covid"
- Inclusions based on free text terms:
 - The visit is included if it contains:
 - "long term covid", "post acute covid", "post acute sequela" and "covid", "long haul covid", "long covid", "post covid", "after covid", "pots" and "covid", "viral fatigue syndrome" and "covid"
 - Visits picked up via free text inclusion terms must not include:
 - Concurrent free text terms:
 - "positive for covid on [MTWFS0-9]", "covid positive on [MTWFS0-9]", "covid positive mond", "covid positive tue", "covid positive wed", "covid positive th", "covid positive fri", "covid positive sat", "covid positive sun", "covid positive today", "covid positive yesterday", "covid positive [0-9][0-9]/", "covid positive [0-9]/", "positive for covid mond", "positive for covid tue", "positive for covid wed", "positive for covid th", "positive for covid fri", "positive for covid sat", "positive for covid sun", "covid today", "covid yesterday", "covid this", "positive for covid [0-9][0-9]/", "positive for covid [0-9]/", "resolved post covid", "post covid result", "covid" and "shot" or "vacc" or "vax" or "vaccine" or "booster" or "immunization" or "injection" or "exposure" or "reaction", "requested covid test", "covid [123] w", "covid [123]w", "covid x[123][wd]", "covid x [123][wd]", "covid x[123] [wd]", "covid x [123] [wd]", "covid positive [123] [wd]", "covid positive [123][wd]", "covid positive x[123][wd]", "covid positive x [123][wd]", "covid positive x[123] [wd]", "covid positive x [123] [wd]", "covid [12].5 w", "covid [12].5w", "covid x[12].5w", "covid x [12].5w", "covid x[12].5 w", "covid x [12].5 w", "covid positive [12].5 w", "covid positive [12].5w", "covid positive x[12].5w", "covid positive x [12].5w", "covid positive x[12].5 w", "covid positive x [12].5 w", "covid three [wd]", "covid two [wd]", "covid one [wd]", "covid a [wd]", "covid positive three [wd]", "covid positive two [wd]", "covid positive one [wd]", "covid positive a [wd]", "days post_covid", "[23] weeks post_covid", "[23] wks post_covid", "wk post_covid", "week post_covid", "twoish weeks post_covid", "two weeks post_covid", "two wks post_covid", "three weeks post_covid", "three wks post_covid", "recently covid", "recent covid", "hx pots", "covid [123] ago", "covid three ago", "covid two ago", "covid one ago", "covid positive [123] ago", "covid positive three ago", "covid positive two ago", "covid positive one ago", "covid [1-9] day", "covid [12][0-9] day", "covid x[1-9] day", "covid x[12][0-9] day", "covid x [1-9] day", "covid x [12][0-9] day", "covid positive [1-9] day", "covid positive [12][0-9] day", "was positive last w", "covid last [TWFS]", "covid last mond", "covid positive last [TWFS]", "covid positive last mond", "[23] wks after covid", "[23] weeks after covid", "wk after covid", "week after covid", "two weeks after covid", "two wks after covid", "three weeks after covid", "three wks after covid", "after covid check_up", "medical clearance"

<u>Limitations:</u> By design, this definition picks up all visits presenting with the U09.9 (Post-COVID conditions) ICD-10 code. We found that sometimes providers may improperly use this code for patients currently infected with COVID-

19 or those recently infected (less than 3-4 weeks ago). As a result, this query picks up some false positives with current or recent COVID-19 infection, as determined via review of free-text fields. These visits will need to be excluded via manual review. The definition also picks up some visits that are not at all related to COVID-19 (ex: injury, alcohol withdrawal, stroke, etc.). Sometimes, hospitals enter diagnosis codes from a patient's full medical history. As a result, visits with the U09.9 code may reflect a prior history of post-COVID conditions rather than the current reason for visit being for post-COVID conditions. Use the long COVID narrow definition, which requires both a long COVID related discharge diagnosis code AND free-text term, to better exclude these non-COVID related visits.

<u>Plain Language Syntax Description:</u> This definition will pick up visits with a discharge diagnosis code related to long COVID OR a free-text term/phrase related to long COVID in the chief complaint, triage notes, or admit reason. It aims to exclude visits with a free-text mention of recent COVID infection, though additional manual review may be required to exclude these visits due to variations in free-text language/coding.

Detailed Definition Components

Table 1. Inclusion and exclusion terms

This definition requires EITHER discharge diagnosis OR free-text indication of Long COVID. It aims to exclude current or recently (<4 weeks) positive COVID-19 visits as well as visits presenting for COVID-19 vaccination, exposure, etc.

Variable Type	Terms	Description (Diagnosis Codes Only)		
Inclusions:				
Discharge Diagnosis Parsed Free Text also apply to: Chief Complaint History, Triage Notes Orig, Admit Reason Combo	U099	Post-Covid Conditions (ICD-10)		
	G933 and covid	Postviral and related fatigue syndomes (ICD-10)		
	1119304009	Chronic post-COVID-19 syndrome (SNOMED)		
	long term covid			
	post acute covid			
	post acute sequela and covid			
	long haul covid			
	long covid			
	post covid			
	after covid			
	pots and covid			
	viral fatigue syndrome and covid			
Exclusions:	,			
Discharge Diagnosis Parsed Free Text also apply to: Chief Complaint History, Triage Notes Orig, Admit Reason Combo	positive for covid on [MTWFS0-9]			
	covid positive on [MTWFS0-9]			
	covid positive mond or tue or wed			
	or th or fri or sat or sun or today or			
	yesterday			
	covid positive [0-9][0-9]/			
	covid positive [0-9]/			
	positive for covid mond or tue or wed or th or fri or sat or sun			
	covid today			
	covid yesterday			
	covid this			
	covid [0-9][0-9]/			
	covid [0-9]/			
	resolved post covid			
	post covid result			
	covid and shot or vacc or vax or			
	vaccine or booster or			
	immunization or injection or			
	exposure or reaction			
	requested covid test			

covid [123] w	
covid [123]w	
covid x[123][wd]	
covid x [123][wd]	
covid x[123] [wd]	
covid x [123] [wd]	
covid positive [123] [wd]	
covid positive [123] [wd]	
covid positive [123][wd]	
covid positive x [123][wd]	
covid positive x[123] [wd]	
covid positive x [123] [wd]	
covid [12].5 w	
covid [12].5w	
covid x[12].5w	
covid x [12].5w	
covid x[12].5 w	
covid x [12].5 w	
covid positive [12].5 w	
covid positive [12].5w	
covid positive x[12].5w	
covid positive x [12].5w	
covid positive x[12].5 w	
covid positive x [12].5 w	
covid three [wd]	
covid two [wd]	
covid one [wd]	
covid a [wd]	
covid positive three [wd]	
covid positive two [wd]	
covid positive one [wd]	
covid positive a [wd]	
days post covid	
[23] weeks post covid	
[23] wks post covid	
wk post covid	
week post covid	
twoish weeks post covid	
two weeks post covid	
two wks post covid	
three weeks post covid	
three wks post covid	
recently covid	
recent covid	
recent covia	

hx pots	
covid [123] ago	
covid three ago	
covid two ago	
covid one ago	
covid positive [123] ago	
covid positive three ago	
covid positive two ago	
covid positive one ago	
covid [1-9] day	
covid [12][0-9] day	
covid x[1-9] day	
covid x [1-9] day	
covid x[12][0-9] day	
covid x [12][0-9] day	
covid positive [1-9] day	
covid positive [12][0-9] day	
was positive last w	
covid last [TWFS]	
covid last mond	
covid positive last [TWFS]	
covid positive last mond	
[23] wks after covid	
[23] weeks after covid	
wk after covid	
week after covid	
two weeks after covid	_
two wks after covid	
three weeks after covid	
three wks after covid	
after covid check_up medical clearance	
ineulcal clearance	

Table 2. ESSENCE syntax, Long COVID Broad v1 Definition

<u>Discharge Diagnosis Parsed Free Text also apply to Chief Complaint History, Triage Notes Orig, Admit Reason</u> Combo:

(,^;U099^,or,^;1119304009;^,or,(,^covid^,and,^;G933^,),or,^long_term covid^,or,^post_acute covid^,or,(,^post acute sequela^,and,^covid^,),or,^long haul covid^,or,^long_covid^,or,^post_covid^,or,^after covid^,or,(,(,!pots!,or,^[;.,]pots[;.,]^,),and,^covid^,),or,(,^viral fatigue syndrome^,and,^covid^,),),ANDNOT,(,^positive for covid on [MTWFS0-9]^,or,^covid positive on [MTWFS0-9]^,or,^covid positive mond^,or,^covid positive tue^,or,^covid positive wed^,or,^covid positive th^,or,^covid positive fri^,or,^covid positive sat^,or,^covid positive sun^,or,^covid positive today^,or,^covid positive yesterday^,or,^covid positive [0-9][0-9]/^,or,^covid positive [0-9]/^,or,^positive for covid mond^,or,^positive for covid tue^,or,^positive for covid wed^,or,^positive for covid th^,or,^positive for covid fri^,or,^positive for covid sat^,or,^positive for covid sun^,or,^covid today^,or,^covid yesterday^,or,^covid this^,or,^covid [0-9][0-9]/^,or,^covid [0-9]/^,or,^resolved post covid^,or,^post covid result^,or,(,^covid^,and,(,^shot^,or,^vacc^,or,^vax^,or,^booster^,or,^immunization^,or,^injection^,or,^expo sure^,or,^reaction^,),),or,^requested covid test^,or,^covid [123] w^,or,^covid [123]w^,or,^covid x[123][wd]^,or,^covid x [123][wd]^,or,^covid x[123] [wd]^,or,^covid x [123] [wd]^,or,^covid positive [123] [wd]^,or,^covid positive [123][wd]^,or,^covid positive x[123][wd]^,or,^covid positive x [123][wd]^,or,^covid positive x[123] [wd]^,or,^covid positive x [123] [wd]^,or,^covid [12].5 w^,or,^covid [12].5 w^,or,^covid x[12].5w^,or,^covid x [12].5w^,or,^covid x[12].5 w^,or,^covid x [12].5 w^,or,^covid positive [12].5 w^,or,^covid positive [12].5w^,or,^covid positive x[12].5w^,or,^covid positive x [12].5w^,or,^covid positive x[12].5 w^,or,^covid positive x [12].5 w^,or,^covid three [wd]^,or,^covid two [wd]^,or,^covid one [wd]^,or,^covid a [wd]^,or,^covid positive three [wd]^,or,^covid positive two [wd]^,or,^covid positive one [wd]^,or,^covid positive a [wd]^,or,^days post_covid^,or,^[23] weeks post_covid^,or,^[23] wks post covid^,or,^wk post covid^,or,^week post covid^,or,^twoish weeks post covid^,or,^two weeks post_covid^,or,^two wks post_covid^,or,^three weeks post_covid^,or,^three wks post_covid^,or,^recently covid^,or,^recent covid^,or,^hx pots^,or,^covid [123] ago^,or,^covid three ago^,or,^covid two ago^,or,^covid one ago^,or,^covid positive [123] ago^,or,^covid positive three ago^,or,^covid positive two ago^,or,^covid positive one ago^,or,^covid [1-9] day^,or,^covid [12][0-9] day^,or,^covid x[1-9] day^,or,^covid x[12][0-9] day^,or,^covid x [1-9] day^,or,^covid x [12][0-9] day^,or,^covid positive [1-9] day^,or,^covid positive [12][0-9] day^,or,^was positive last w^,or,^covid last [TWFS]^,or,^covid last mond^,or,^covid positive last [TWFS]^,or,^covid positive last mond^,or,^[23] wks after covid^,or,^[23] weeks after covid^,or,^wk after covid^,or,^week after covid^,or,^two weeks after covid^,or,^two wks after covid^,or,^three weeks after covid^,or,^three wks after covid^,or,^after covid check up^,or,^medical clearance^,)

Addendum: Modified Syntax

If using a local version of ESSENCE (other than NSSP), please use the appropriate corresponding fields/coding to best match this factsheet. If you are using discharge diagnosis instead of discharge diagnosis parsed, we recommend using the below syntax that expands ICD-10 codes to include both versions with and without decimal points.

Discharge Diagnosis also apply to Chief Complaint History, Triage Notes Orig, Admit Reason Combo:

(,^;U099^,or,^;U09.9^,or,^;1119304009;^,or,(,^covid^,and,(,^;G933^,or,^;G93.3^,),),or,^long term covid^,or,^post_acute covid^,or,(,^post_acute sequela^,and,^covid^,),or,^long_haul covid^,or,^long covid^,or,^post covid^,or,^after covid^,or,(,(,!pots!,or,^[;.,]pots[;.,]^,),and,^covid^,),or,(,^viral fatigue syndrome^,and,^covid^,),),ANDNOT,(,^positive for covid on [MTWFS0-9]^,or,^covid positive on [MTWFS0-9]^,or,^covid positive mond^,or,^covid positive tue^,or,^covid positive wed^,or,^covid positive th^,or,^covid positive fri^,or,^covid positive sat^,or,^covid positive sun^,or,^covid positive today^,or,^covid positive yesterday^,or,^covid positive [0-9][0-9]/^,or,^covid positive [0-9]/^,or,^positive for covid mond^,or,^positive for covid tue^,or,^positive for covid wed^,or,^positive for covid th^,or,^positive for covid fri^,or,^positive for covid sat^,or,^positive for covid sun^,or,^covid today^,or,^covid yesterday^,or,^covid this^,or,^covid [0-9][0-9]/^,or,^covid [0-9]/^,or,^resolved post covid^,or,^post covid result^,or,(,^covid^,and,(,^shot^,or,^vacc^,or,^vax^,or,^booster^,or,^immunization^,or,^injection^,or,^exposur e^,or,^reaction^,),),or,^requested covid test^,or,^covid [123] w^,or,^covid [123]w^,or,^covid x[123][wd]^,or,^covid x [123][wd]^,or,^covid x[123] [wd]^,or,^covid x [123] [wd]^,or,^covid positive [123] [wd]^,or,^covid positive [123][wd]^,or,^covid positive x[123][wd]^,or,^covid positive x [123][wd]^,or,^covid positive x[123] [wd]^,or,^covid positive x [123] [wd]^,or,^covid [12].5 w^,or,^covid [12].5 w^,or,^covid x[12].5w^,or,^covid x [12].5w^,or,^covid x[12].5 w^,or,^covid x [12].5 w^,or,^covid positive [12].5 w^,or,^covid positive [12].5w^,or,^covid positive x[12].5w^,or,^covid positive x[12].5w^,or,^covid positive x[12].5 w^,or,^covid positive x [12].5 w^,or,^covid three [wd]^,or,^covid two [wd]^,or,^covid one [wd]^,or,^covid a [wd]^,or,^covid positive three [wd]^,or,^covid positive two [wd]^,or,^covid positive one [wd]^,or,^covid positive a [wd]^,or,^days post covid^,or,^[23] weeks post covid^,or,^[23] wks post covid^,or,^wk post covid^,or,^week post covid^,or,^twoish weeks post covid^,or,^two weeks post covid^,or,^two wks post covid^,or,^three weeks post covid^,or,^three wks post covid^,or,^recently covid^,or,^recent covid^,or,^hx pots^,or,^covid [123] ago^,or,^covid three ago^,or,^covid two ago^,or,^covid one ago^,or,^covid positive [123] ago^,or,^covid positive three ago^,or,^covid positive two ago^,or,^covid positive one ago^,or,^covid [1-9] day^,or,^covid [12][0-9] day^,or,^covid x[1-9] day^,or,^covid x[12][0-9] day^,or,^covid x [1-9] day^,or,^covid x [12][0-9] day^,or,^covid positive [1-9] day^,or,^covid positive [12][0-9] day^,or,^was positive last w^,or,^covid last [TWFS]^,or,^covid last mond^,or,^covid positive last [TWFS]^,or,^covid positive last mond^,or,^[23] wks after covid^,or,^[23] weeks after covid^,or,^wk after covid^,or,^week after covid^,or,^two weeks after covid^,or,^two wks after covid^,or,^three weeks after covid^,or,^three wks after covid^,or,^after covid check_up^,or,^medical clearance^,)