

Long COVID Narrow v1 Definition Factsheet & Technical Brief

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Definition Purpose: To assist state, local, tribal, territorial, and federal public health practitioners in identifying patients likely to have long COVID (also commonly described as Post-COVID Complications (PCC) or long-haul COVID) by reviewing visits in the emergency department (ED) setting and to help with trend monitoring for long COVID related visits using syndromic surveillance data.

New or Revised Definition:

☒ New Definition

☐ Revision of Existing Definition

Date Added to ESSENCE: December 2024

Definition Description: 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 both discharge diagnosis AND 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: Primary

Trend monitoring: Secondary

Early outbreak detection: Not Intended as Use Case

Emergent Condition: Not Intended as Use Case

Justification for Definition Development: 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

Development Methods: 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.

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

1. Run definition evaluation using Syndrome Evaluation Toolkit ([sara-chronister/syndrome-definition-evaluation: R code for evaluation of NSSP BioSense ESSENCE syndrome definition results using ESSENCE APIs. \(github.com\)](https://sara-chronister.github.io/syndrome-definition-evaluation/)) to evaluate definition component performance.
 - a. Query Parameters:
 - i. Start Date: 1/1/2023
 - ii. 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. Probable: 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. Maybe: 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. Unlikely: 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.

Validation Results: This query does a good job at capturing long COVID related visits and excluding visits not related to COVID. The positive predictive value (PPV) for capturing probable and maybe long COVID related visits was 66% in WA, 78% in Tacoma-Pierce County (LHJ in WA), 79% in KY, 83% in VA, and 52% in NE*. The average PPV across all jurisdictions was 72%.

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

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

- Inclusions based on long COVID related discharge diagnosis codes:
 - The visit is included if in addition to one of the free text inclusion terms below, it also contains:
 - A discharge diagnosis code of Post-COVID conditions (U099 or 1119304009), History of COVID-19 (Z8616), or Post-Viral Fatigue Syndrome (G933)
- Inclusions based on free text terms:
 - The visit is included if in addition to one of the discharge diagnosis codes above, it also contains:
 - “had covid”, “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”
 - The above must exclude:
 - Concurrent free text terms:
 - “had covid test”, “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”

Limitations: Most false positives are visits that have current COVID-19 infection or infection less than one month ago. These visits are difficult to exclude due to inconsistencies in the use of the U09.9 code. Sometimes, providers code the U09.9 code less than one month following COVID-19 infection as indicated via free-text. These visits will

need to be excluded via manual review. Further, acute COVID free-text exclusion criteria could cause false negatives for health encounters for long COVID symptom exacerbation due to recent reinfection.

Plain Language Syntax Description: This definition will pick up visits with a discharge diagnosis code related to long COVID AND 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 BOTH discharge diagnosis AND 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	U099	Post-Covid Conditions (ICD-10)
	Z8616	History of Covid-19 (ICD-10)
	G933	Postviral and related fatigue syndromes (ICD-10)
	1119304009	Chronic post-COVID-19 syndrome (SNOMED)
Chief Complaint History, also apply to: Triage Notes Orig, Admit Reason Combo	long term covid	
	Had 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		
Chief Complaint History, also apply to: Triage Notes Orig, Admit Reason Combo	positive for covid on [MTWFS0-9]	
	covid positive on [MTWFS0-9]	
	Had covid test	
	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 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 [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	

Table 2. ESSENCE syntax, Long COVID Narrow v1 Definition

Discharge Diagnosis Parsed Free Text:

^;U099^,or,^;Z8616^,or,^;G933^,or,^;1119304009;^

AND

Chief complaint history also apply to Triage Notes Orig, Admit Reason Combo:

(,^had covid^,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,(,^had covid test^,or,^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].5w^,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:

^;U099^,or,^;U09.9^,or,^;Z8616^,or,^;Z86.16^,or,^;G933^,or,^;G93.3^,or,^;1119304009;^

AND

Chief complaint history also apply to Triage Notes Orig, Admit Reason Combo:

(,^had covid^,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,(,^had covid test^,or,^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].5w^,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^,)