Importance of a Long COVID definition in public health

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Utah Department of Health & Human Services

CSTE
Council of State and Territorial Epidemiologists

Goals of public health

- Understand disease burden and trends
- Identify risk and protective factors
- Prevent disease, disability, injury, and premature death
  - Ensure resources are available
    - Testing, treatment, prevention, information
- Achieve health equity and improve the health of all groups

Goals of public health: Long COVID

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Need to understand who is affected

Need a standard definition

Approach to tracking Long COVID

Model disease tracking on that used for infectious diseases

- Laboratory based trigger
- Clear definition and easily collected

Long COVID does not fit into infectious model

- Absence of laboratory result trigger
- Complex definition
  - variety of presentations
  - varies over time
- No universal definition

Example: MIS-C - Multisystem Inflammatory Syndrome in Children

An illness characterized by all of the following, in the absence of a more likely alternative diagnosis*:

- Subjective or documented fever (temperature ≥38.0 **AND**
- Clinical severity requiring hospitalization or resulting in death **AND**
- Evidence of systemic inflammation indicated by C -reactive protein ≥3.0 mg/dL (30 mg **AND**
- New onset manifestations in **at least two** of the following categories:

1. Cardiac involvement indicated by:
   - Left ventricular ejection fraction <55%, **OR**
   - Coronary artery dilatation, aneurysm, or ectasia, **OR**
   - Troponin elevated above laboratory normal range, or indicated as elevated in a clinical note
2. Mucocutaneous involvement indicated by:
   - Rash, **OR**
   - Inflammation of the oral mucosa (e.g., mucosal erythema or swelling, drying or fissuring of the lips, strawberry tongue), **OR**
   - Conjunctivitis or conjunctival injection (redness of the eyes), **OR**
   - Extremity findings (e.g., erythema [redness] or edema [swelling] of the hands or feet)
3. Shock**
4. Gastrointestinal involvement indicated by:
   - Abdominal pain, **OR**
   - Vomiting, **OR**
   - Diarrhea
5. Hematologic involvement indicated by:
   - Platelet count <150,000 cells/ µL, **OR**
   - Absolute lymphocyte count (ALC) <1,000 cells/µL

Efforts underway in a variety of states

Goals –

- Understand burden of Long COVID and spectrum of illness
- Understand trends over time
- Identify risk/protective factors
- Uncover inequities
- Identify opportunities for linkage to care and interventions

    - Model-based estimation of burden
        - Using data studies and literature and extrapolation
    - Direct data collection from population

Utah-specific Long COVID work

Utah Department of Health & Human Services

Prevalence of Long COVID

Representative data

Information meant to reflect an overall population

- Estimate how many people are affected by Long COVID
- Estimate the overall population care needs

Behavioral Risk Factor Surveillance Survey

- A long-standing CDC survey that collects extensive information on people's health
- Utah added 12 questions specifically about Long COVID

Utah DHHS Office of Health Equity survey

- Targeted to collect information from people in underrepresented groups

Impact of Long COVID

Non -representative data

Focus on those people most likely to be affected by Long COVID

- Information meant to reflect those most likely to need support or resources

People accessing health care - number of people who are seen by medical providers for Long COVID

- All payers claims database – insurance claims for 80% of Utahns
- Emergency room visit data – discharge diagnoses for all people seen in the emergency room
- Electronic case reporting – diagnoses for all people seen in one of Utah's largest health systems
- Data from the Long COVID clinic at the University of Utah – specialty clinic

People who haven't presented to health care

- Community health worker surveys
  - In-depth survey of people in underserved communities who have Long COVID
- Long COVID Facebook group survey

Lessons learned

Clinical diagnosis codes (ICD)

- Rates are much lower than studies and surveys suggest
- Likely an artifact due to
  - underdiagnosis of patients
  - underutilization of code
  - inability to access healthcare

Surveys

- Rely on self-report
- No standard to ask

Standard case definitions will help

Important considerations for Long COVID definition- public health perspective

We need a consistent and stable definition!

- Allow for comparison between jurisdictions and populations

The definition used for public health surveillance will need to:

- Be simpler than those used in research settings
  - Resource limitations
- Consider self-diagnosis
  - Populations unable to access health care or afford complex diagnoses
- Not connected to COVID-19 test documentation

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Efforts underway in a variety of states

Goals- to understand burden, spectrum of illness, inequities, risk/protective factors, trends, identify opportunities for interventions.

- Cross sectional surveys
  - Using information from surveys to estimate overall population
- Model-based estimation of burden
  - Using data studies and literature and extrapolating
- Sentinel surveillance
  - Evaluating a subset of people coming for care
- Syndromic surveillance
  - Evaluating emergency room visits
- Analysis of insurance claims and other administrative clinical data