

Understanding of Long COVID in Puerto Rico

May, 2023

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Current Efforts for Establishing an Understanding of Long COVID

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- Set up goals and objectives

Goals

- Determine and promote **efforts** aimed at **diagnosing, treating, managing, and providing services for caregivers and PASC patients** aligned with the Human-Centered Design Report.
- Make PASC data on the Puerto Rican population accessible to the population and health professionals.

Objectives

- Educate health providers, patients, and the general population.
- Empower communities to improve the health of PASC patients.
- Increase **peer engagement** with the PR Department of Health.
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Current Efforts for Establishing an Understanding of Long COVID

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- A consensus to select a definition
 - The long COVID team decided to use the World Health Organization (WHO) definition and the term Post-acute sequelae of COVID-19.
 - WHO used a Delphi method that included a range of participants, including patients, policymakers, researchers, and healthcare professionals.
 - The definition from WHO is explicit in recognizing the episodic, fluctuating pattern of symptoms as well as their effects on daily functioning.



Current Efforts for Establishing an Understanding of Long COVID

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Justification for the PASC terminology

- PCC for educational or surveillance purposes in the population could be understood as any condition diagnosed or any symptom after COVID, independent of the relationship.
- PASC was considered a clear term, delimiting symptoms beyond the acute phase of COVID.



**Prevalence of Post-acute Sequelae of
COVID-19 in Puerto Rico,
September 2020 - August 2021**

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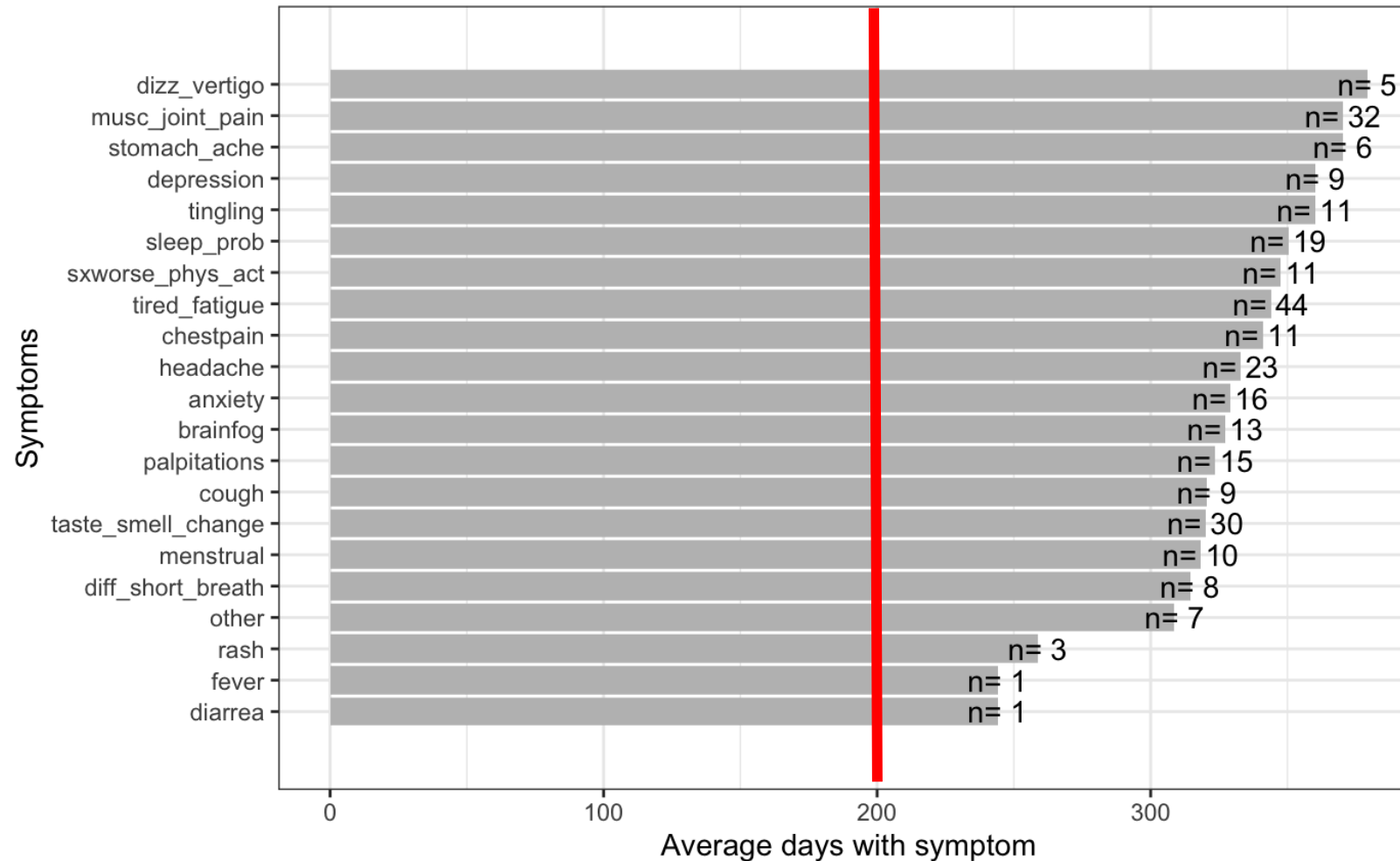
Estimated prevalence and symptom distribution



- We identified **149** patients that met the case definition.
- Leading to a prevalence of **47.5%** (95% CI: 41.9-53.2%)
 - The age group with higher prevalence was those from 50-59 (52.1%)
- On average, patients that meet the case definition presented **4 symptoms that lasted 2 months** or more.

Distribution	# symptoms
Min	1
1st Quartile	1
Median	2
3rd Quartile	5
Max.	18

Most frequent symptoms in patients with post-acute COVID sequelae still present at the time of the interview (n=99)



66.4% of PASC patients reported having symptoms at the time of the interview.

These symptoms lasted up to 6 and a half months after their initial diagnosis of COVID-19.

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Preliminary data about the Prevalence of Post-acute Sequelae of COVID-19 in Puerto Rico, December 2021 - July 2022

Disclaimer: Preliminary results could change in the final reports

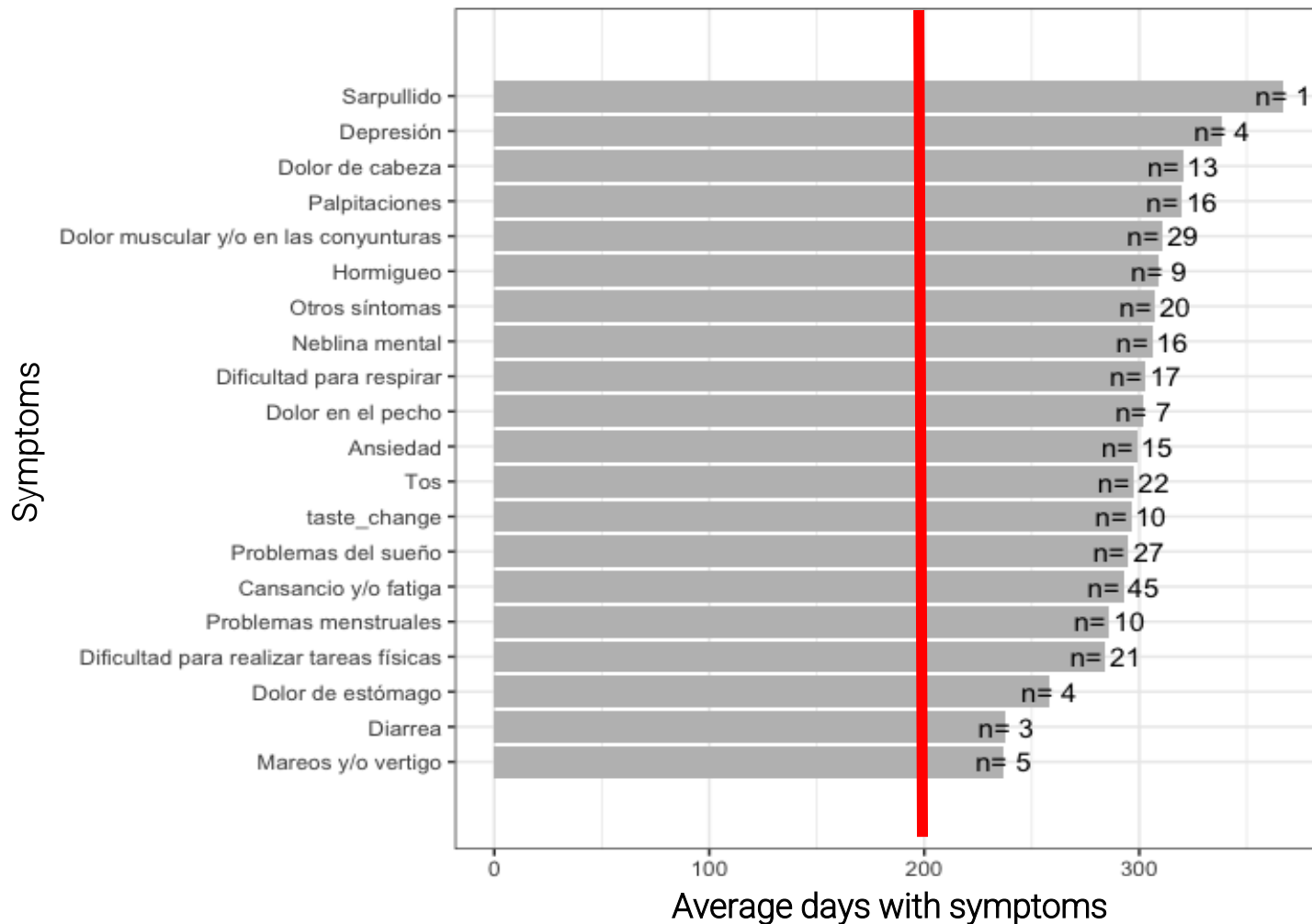
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Estimated prevalence and symptom distribution

- We identified **160 (n=398)** patients that meet the case definition.
- Leading to a prevalence of **~40%** (95% CI: 35.4- 45.0%).
- On average, patients that meet the case definition presented 9 symptoms that lasted 2 months or more.

Most frequent symptoms in patients with post-acute COVID sequelae were still present at the time of the interview (n=106)



66.3% of PASC patients reported having symptoms at the time of the interview.

These symptoms lasted up to 6 and a half months after their initial diagnosis of COVID-19.

Sentinel Surveillance System

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- Purpose:

Describe and comprehend the epidemiologic profile of PASC cases and monitor rehabilitation and mitigation strategies implemented for patient recovery.

- Phases:

- Determine and evaluate the resources currently available to PASC patients.

- We have already visited at least one HRSA Community Health Centers Program, which operates 330 health centers in each health region.



Sentinel Surveillance System

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- Evaluate PASC definitions
 - Assess protocols to identify and manage PASC patients
 - Determine educational needs
 - Identify the referral process for specialized doctors



Importance of epidemiological and surveillance considerations in establishing Long COVID definitions

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- Standardization of criteria
- Allow comparison of incidence and prevalence estimates and contributing factors among jurisdictions, nationwide, and research
- Understood the natural history, effects, and epidemiologic profile of the cases
- Identify disparities



Importance of epidemiological and surveillance considerations in establishing Long COVID definitions

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- Various periods of time with specific sorts and combinations of health issues
- Allow the development of public health interventions based on evidence
- Increase awareness and literacy of Long COVID



Lessons learned from past STLT efforts to establish definitions for diseases

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- Use of a system-thinking approach
- All parties must be heard: experts, health care professionals, patients, and advocates
- Establish a broad definition and narrow it according to the scientific evidence
- Consider time and person delimitation



Lessons learned from past STLT efforts to establish definitions for diseases

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- If the definition is still open to anyone, disregard a confirmatory or probable test or a clinical COVID-19 diagnosis, then the specificity could be low.
- Discriminatory clinical criteria for disease surveillance are crucial.
- Balanced clinical criteria should be met to reach sensitivity and specificity. If it is not specific, considerable resources would be required to confirm the cases.
- Ongoing evaluation of the performance of surveillance case definitions



Issues and barriers faced within your agency related to efforts to define Long COVID

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- Internal agreement regarding the selection of the two official definitions
- Heterogeneity in symptoms and their durability
- Mistrust and lack of education among health providers
- Lack of a confirmatory diagnosis test for Long COVID



Issues and barriers faced within your agency related to efforts to define Long COVID

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- Heterogeneity in assessment and internal definitions in health care centers
- Lack of inclusion or recommendation to classify reinfections
- Categorization by severity and manifestations to estimate different burdens: syndromic manifestations, PCC (those that have developed a condition that is already clinically defined), and patients experiencing worsening chronic conditions
- Recovered patient



Efforts to address issues and barriers

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- Educate providers and the population with current information
- Develop a second survey to estimate the prevalence
- Work on the development of the sentinel surveillance system
- Exploring the possibility of developing a volunteer registry



Efforts to address issues and barriers

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- Participating in the CSTE workgroup
- Exchange knowledge and lessons learned from the surveys with other jurisdictions like Minnesota DOH, the Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC), and others
- Participate in meetings with different alliances and nonprofit organizations.



PASC team

- Chanis Olavarría Mercado - Epidemiologist / Disease Intervention Specialist
- Dra. José Oliveras Torres - Medical Countermeasure Coordinator
- Dra. Iris R. Cardona Gerena - Chief Medical Officer
- Dra. Melissa Marzán Rodríguez - Chief Epidemiology Officer
- Dra. Jeniffer Concepción González - CDC Public Health Advisor
- Dra. Jessica Irizarry Ramos - CDC Public Health Advisor