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CSTE Long COVID Workgroup Mtg #5 Notes and Action Items

Date:	**Monday March 27, 2023**		
Start/End Time:	2pm – 3pm EST	Meeting Link:	https://zoom.us/j/96736891635?pwd=YVlJUGkySE5Yb3VEM0daci9sa2MxQT09

Attendees

X	Name(s)	Organization	X	Name(s)	Organization
Meeting Participants					
X	Kalyani McCullough	California	X	Chanis Olavarria	Puerto Rico
	Rachel Herlihy and Brian Erly	Colorado		Mikyla Sakurai	Urban Indian Health Institute, Tribal Epidemiology Center
X	Sarah Reed-Thryselius	Ho Chunk Nation	X	Rachel Kubiak	Utah
	Robert Graff	Idaho	X	Caitlin Pedati	Virginia Beach
-	John Prather	Kentucky	X	Arran Hamlet	Washington
	Nikki Jarrett, Peggy Stemmler	Maricopa County	X	Hannah Segaloff	Wisconsin
	Katie Brown	Massachusetts		Julianna Reece	Navajo Nation and CDC Healthy Tribes
X	Robert Orellana	Michigan	X	Cria Perrine, Priti Patel and Sharon Saydah	CDC, PCC
X	Jay Desai, Julie Hoffer, Kate Murray	Minnesota	X	Marcus Plescia	ASTHO
X	Bo Katic and Emma Price	New Jersey	X	Andrew Adams, Marci Layton, Sunbal Virk, Colin Gerber	CSTE
X	Anne Schuster	New York City	X	Elizabeth Dufort, Brad Hutton	HHC/CSTE
-	Jessica Kumar	New York State		Samuel Packard	Columbia U SPH

Agenda

#	Topic	Time	Items
1.	Welcome and Overview	5 mins	**Welcome, Marci Layton, CSTE**

2.	Brief Summary of 4th Meeting	5 mins	**Brief Summary of 4th Meeting and Timeline, Liz Dufort, HHC**
			• Notes from meeting #4 (3/13/23) have been posted on CSTE Long COVID-19/PCC Workgroup Basecamp: https://3.basecamp.com/3164497/projects/31326418
			• STLT presentation from Sarah Reed-Thryselius, Ho Chunk Nation
			  • Report: https://health.ho-chunk.com/CV19/COVID-19_Impact_Study_Executive_Summary.pdf
			• Discussed outline and content of document
			• Discussed 1 key theme – 'definitions'
			• Timeline and Tentative Plan for the CSTE Long COVID document
			  • Today: Mon. March 27th – 5th Meeting
			  • *Mon. April 10th – 6th meeting – HOLD*
			  • *Mon. April 24th – 7th meeting – HOLD*
			  • Mid to late April - present to other stakeholders
			  • *The CSTE Core Epi WG (HOLD 4/19th)*
			  • *Program and Policy (P&P) Committee*
			  • *All State Epi call*
			• Objectives for today's meeting:

#	Topic	Time	Items
			• 1 STLT brief presentation – Arran Hamlet, Washington State, CDC EISO, modeling • Discuss outline and content of document • Discuss 1 key theme – 'Surveys'

3.	STLT Presentation	15 mins	**STLT Presentation, Arran Hamlet, Washington State, CDC EISO**
			• Modeling-based exploration of estimating Long COVID burden in Washington State
			• We define Long COVID regardless of cause:
			  o May be due to COVID or severity of illness or due to hospitalization.
			  o Symptoms experienced for 3 months or more following infection, may be new, recurring, or exacerbated per-existing conditions.
			• CDC has been asking questions as part of the Household Pulse Survey.
			  o 5.3% of WA adults are currently estimated to have Long COVID from Feb 1-13th (18+ years in WA).
			• Stochastic mechanistic compartmental model treats hospitalized and non-hospitalized COVID differently. Unreported and reported cases are estimated, with simulated unreported cases.
			• Integrating into pre-existing data processes, so as to not add to WA DOH staff burdens.
			• Important to address Long COVID burden estimates by age, R/E, sex, vaccination status, and county.
			  o For probability of Long COVID there are 8 age groups, 5 R/E groups, 2 sexes, 3 vaccination statuses, and 39 counties.
			• Single model run, with information imported through an array of sources.
			• Estimated 80% of symptomatic COVID is not reported.
			• Most of the information is missing, so can't give a direct estimate, but still useful to show disparities.
			• Feeding in real world data.
			• Probabilities of Long COVID and duration of Long COVID are both considered and are taken from Household Pulse and the scientific literature.
			• A selection of these values are 'fit' so the model matches household pulse estimates. These values are then put in a cube for fit.
			• Estimates similar to the Household Pulse Survey.
			• Females have a higher burden.
			• Those identifying as Black and those as Hispanic or Latino have the highest burden.
			• Long COVID is concentrated in younger age groups (30-39 and 40-49 have the highest burden).
			• Different across the state, highest in Central and Eastern WA.
			• Summary:
			  o Long COVID is significantly impacting the day-to-day life of many Washingtonians.
			  o An estimated 100,000 Washingtonians are currently estimated to be living with significant activity limitations.
			• Limitations:
			  o Assumptions made: ~80% of symptomatic cases are missing, so we have no demographic information. Blanket changes made for Omicron and long COVID.
			  o Needs further external validation.
			  ▪ Additional survey data?
			  ▪ Comparison with analysis with EHR?

#	Topic	Time	Items

			• Q: Can the methods be shared with other jurisdictions?
			  o This is the intent once further validation is accomplished.
			  o It is coded in R. Currently under development. Will be able to share. But, needs additional validation by external partners. Hopefully, will share with default data input ability.
			  o Currently, working with clinical partners to validate
			• Q: Vaccination rates by county – how does it compare?
			  o Part of it does, but it is complicated
			• Q: Have you already identified external partners (either through EISO or other CDC partners) to validate your model?
			  o Always looking for external partners for validation. Has been in touch with the group at CDC. Interested in working with other states, because this is who this was developed for.
			  o Michigan, Utah, and PR are interested and can be in touch. PR could compare with their survey prevalence rates
			• Q: What factors were used to contribute to someone's risk of developing Long COVID?
			  o Different groups above, lead to risk of developing COVID and then modulate based on whether omicron was dominant or not, as probability is different between pre-Omicron and post-Omicron waves.
			  o 6-7 different factors were used to determine an individual's probability of developing long covid, including whether hospitalized.
			• Q: Of the symptomatic cases missing, were you able to find any patterns? That is, were certain cases more likely to having missing data over others
			  o Certain categories more missing than others, R/E. but, not able to find any clear patterns.

4.	Refine Outline of Planned CSTE Long COVID-19 Surveillance Document	15 min	**Refine Outline of Planned CSTE Long COVID-19 Surveillance Document**
			• Overall agreement was expressed on the outline and topics covered in the draft document.
			• Question on whether CSTE is considering a survey to assess other STLTs on what they are doing for Long COVID and what they are interested in doing (outside of this WG)?
			  o We compiled the activities of STLTs on this WG and will try to incorporate some of them into the document and/or an appendix.
			  o We discussed surveying other STLTs and this will continue to be considered moving forward. We will document the information from this WG in an appendix and this could be expanded upon if time/resources allow for a broader survey. CSTE is trying to balance how often we survey State Epis and just surveyed about the end of PHE and ASTHO is doing another survey. We could use the new CSTE Connect online community. However, we would want to keep the survey simple.
			• Understand about survey fatigue but would be beneficial to hear from others not on the WG.
			• Feedback that surveys need to be included in the document in at least one location. Some tools can be included in a few different sections.
			• And need to refer to case reporting.

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			• Modeling – we can look at where that fits in – potentially uder 'Use of existing data sources' is where it is currently, using ELR as a basis for modeling. But, other thoughts and feedback are welcome.
5.	Discuss 1 Key Theme	15 min	**Discuss 1 Key Theme – Surveys** • Reviewed three types of survey approaches and discuss pros and cons in the document. 1) Validated survey: Might improve the accuracy and may improve time to create the survey, but might be challenging to implement given they are lengthy and too challenging to implement in applied PH manner. We will likely link to existing validated surveys. Please share any validated surveys you have used. But, there are cultural limitations of validated surveys depending on the population it is validated with. Multisite survey in collaboration with CDC or academic partners. 2) Incorporate questions about Long COVID into larger routine jurisdictional community based surveys: Improves sustainability and consistency over time, but less depth and breadth of understanding of Long COVID impact. 3) Cross sectional Long COVID surveys: Accessible to many throughout the first three years of the pandemic, but limited ability to understand impact over time. NYC mentioned attempting to engage in a longer cohort approach. • Examples/models: o Focused survey: Ho Chunk Nation – survey in their report. o CA o PR o NYC o MI work with U of MI – MiCRESS study. o WI o NJ • This section is a little more unwieldy because there were a lot of approaches here. • CDC will share health surveys they have used. The Household Pulse Survey or HIS or NHANES or BRFSS and some other survey instruments. Or internet based survey and American Red Cross survey. Sharon will share these. • Challenges that STLTs have faced in developing surveys include: o The time frames: 4 weeks versus 90 days/3months. o And how the questions are asked matters: o CDPH asks: Recovery vs persistent symptoms results. For example: Do you feel you are back to your baseline level of health and function (before your COVID infection). Second question: have you had symptoms that have lasted 4 weeks or longer? Fewer people respond yes to the latter, than the former. And not always the same people. About a third replies consistently between the two questions. Do we keep asking both questions or go to one? o NYC asks: Initial symptoms? yes or no to a wide range of different symptoms. For each question endorsed will ask if they still have it. With infection dates and survey dates to consider where they fall within the different time periods, so they can look at both 4 weeks and 12 weeks. How would you rate your general

#	Topic	Time	Items
			health before you got COVID and as of today, how would you rate your general heath? o MN: Designed a survey in use for approximately 3 weeks now, ask about return to pre-COVID health as well as any symptoms that are ongoing or continuing. Trying to capture all points. Haven't yet analyzed. o WI: Similar approach to MN. But, also surveyed those without COVID, so asked about them to rate their health before the pandemic and then at the time of the survey. Which also revealed interesting results for those who did not have COVID. o CDC: Thinking about the fact that how we define Long COVID is dependent on how we define the acute illness of COVID. Do we want to address this at all in this document? o Reinfections – how do we address this without things getting too complicated? o CA: Asks people about severity of their acute infection, which is the strongest correlation that they see between severity of initial infection and probability of Long COVID. Do we allow self-report or do matching with ELR? Same for reinfection. Pros and cons with both. So much less data moving forward with ELR. So, so far, relying on self-reporting. o Having a section on ELR versus self-reporting would be good to have in there, because those who are ELR are different if medically attended. o Helpful to have this information for those considering doing these surveys. One STLT can't get ethical clearance to link survey data with vaccine data, so rely on self-reporting for vaccine status. Capture a lot of data on vaccinations and reinfections, but trying to figure out how to analyze that with so many different issues with reporting and testing at different times (early on issues very different than now, both with underestimates with ELR). All these should be considered by people looking at this data. o Ho Chunk Nation: Experienced symptoms? Y/N, if Yes, can be consistent or from time to time. Are they continuing to have symptoms or has it stopped? If continuing to have symptoms or are they having periods of impact from symptoms? Not always answered the same. o PR: Asked about pre-COVID health status, acute infection symptoms, acute symptoms in first 2 months, symptoms for 2 months or more, symptoms at time of interview? o MI: Reinfection assessment analyses will be difficult with asymptomatic and mild acute symptoms not being reported. • We will work to get these points into a draft and can review during out next meeting.
6.	Themes and Next Steps	5 mins	**Themes and Next Steps** • **Next meeting - HOLD - Monday April 10th 2-3 PM ET (Mtg #6)** • WG is in favor of meeting for a 6th meeting on Mon 4/10. • Next meeting members would like a brief presentation on sentinel surveillance or syndromic surveillance and then rest of the time discussing the document. • Please reach out if interested in presenting one of those topics.

Action Items

[From last meetings, until closed]

#	Activities/Deliverables	Action Item/Responsible	Due Date	Status
1.	Definitions	❑ Send **jurisdictional definitions and surveys used** (and pros/cons and for different purposes/goals) to contribute to the document → to Andrew (aadams@cste.org), Marci (mlayton@cste.org), and Liz (elizabethdufort@gmail.com)	4/7/23	Pending
2.	Surveys	❑ Send **jurisdictional approach to health equity** models to Andrew/Marci/Liz	4/7/23	Pending
3.	Next Meeting Brief Presentation	❑ If interested in **presenting your jurisdiction's surveillance model to the WG (particularly if related to sentinel surveillance or syndromic surveillance)**, please email Liz (elizabethdufort@gmail.com)	4/7/23	Pending
4.	Document	❑ Send **other content or comments for inclusion in the document** to Andrew/Marci/Liz	4/7/23	Pending