What We Heard:
Engagement Report on the Working Definition for Long COVID

Presented to the Committee on Examining the Working Definition for Long COVID, at the National Academies of Sciences, Engineering, and Medicine

JUNE 2023

Prepared by EnSpark Consulting

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Contents

Thank You

This report is written with appreciation for the almost 1200 questionnaire respondents, 134 people who attended a 2.5-hour long online focus group, over a dozen staff who facilitated and took notes for the focus groups, and 16 members of the National Academies Committee on Examining the Working Definition for Long COVID who are devoting hours of time to examining the ways in which the U.S. Government's definition of Long COVID can best serve the hundreds of thousands of Americans impacted by Long COVID.

About EnSpark Consulting

EnSpark Consulting, led by Laura Gramling, designed and implemented the multi-party process that collected and analyzed the data in this report. EnSpark Consulting has a long track record for bringing together a wide range of voices to deal with issues of strategy, performance assessment, idea generation, inclusivity, and transformation.

EnSpark's systematic process has helped multiple corporations, nonprofits, and government agencies identify and reach their goals. Laura's July 2020 book on virtual meetings — written and published early in the pandemic — exemplifies the firm's commitment to knowing when to use new technologies, and even better, when not to use them.

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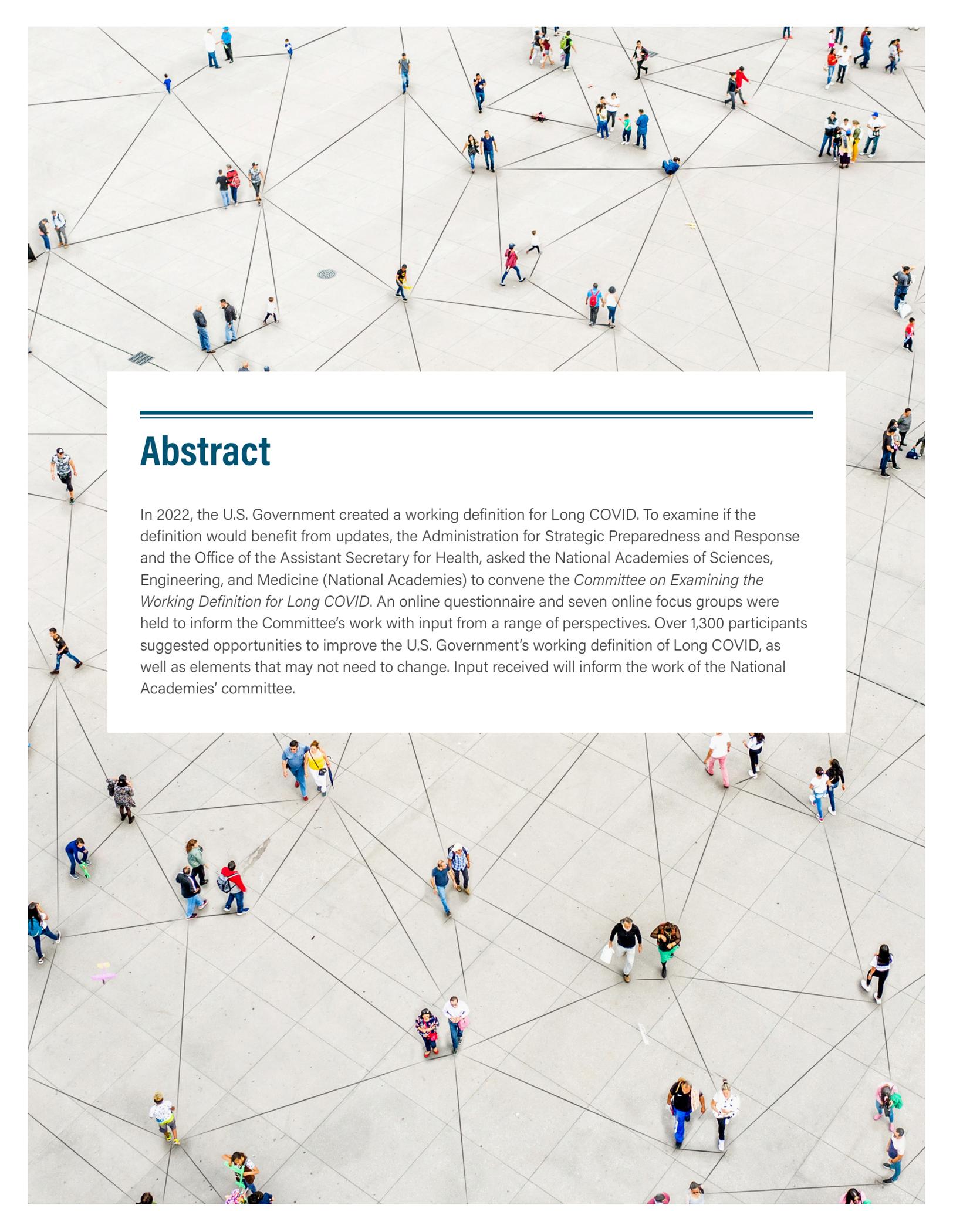
Abstract

In 2022, the U.S. Government created a working definition for Long COVID. To examine if the definition would benefit from updates, the Administration for Strategic Preparedness and Response and the Office of the Assistant Secretary for Health, asked the National Academies of Sciences, Engineering, and Medicine (National Academies) to convene the *Committee on Examining the Working Definition for Long COVID*. An online questionnaire and seven online focus groups were held to inform the Committee's work with input from a range of perspectives. Over 1,300 participants suggested opportunities to improve the U.S. Government's working definition of Long COVID, as well as elements that may not need to change. Input received will inform the work of the National Academies' committee.

Executive Summary

EXAMINING THE U.S. GOVERNMENT'S WORKING DEFINITION OF LONG COVID

A working definition of Long COVID was developed in 2022 by the U.S. Department of Health and Human Services (HHS) in collaboration with other departments and coincident with engagement of patient groups, medical societies, and experts inside and outside the government:

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.[i]

The Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH), asked the National Academies of Sciences, Engineering, and Medicine (National Academies) to undertake a multi-perspective engagement process to examine the U.S. Government (USG) current working definition of Long COVID and related technical terms.

The National Academies' *Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats* was charged with developing a workplan and engagement process for examining the current USG working definition of Long COVID and related technical terms. After an initial scoping phase to develop the work plan, a diverse committee made up of individuals with relevant expertise and experiences, the *Committee on Examining the Working Definition for Long COVID* (committee), was assembled to carry out the plan.

A series of activities were held to allow the National Academies' committee to examine and explore these issues with others who brought in additional expertise and experience related to Long COVID. In addition, EnSpark Consulting was contracted to develop and run an engagement process, as well as provide analysis of the data collected.

HEARING FROM PEOPLE IMPACTED BY AND INTERESTED IN LONG COVID

An engagement process enabled the committee to solicit input from patients, caregivers, researchers, practitioners, health agencies, health policy and advocacy organizations, payors, and health industry businesses.

Over 1,300 participants were involved in two key engagement activities:

Questionnaire (April 17, 2023 – May 12, 2023): A questionnaire was sent to interested and impacted people and was also publicly shared by invited participants. Respondents had the opportunity to provide specific feedback on key issues, concerns, and areas of improvement of the current working definition. Responses are not representative.

Virtual Focus Groups (April 26, 2023 – May 8, 2023): Seven facilitated virtual focus groups were held for people with Long COVID experience and expertise, to explore how a definition could be used and areas of improvement for the current working definition.

Additional engagement efforts led by the National Academies include information-gathering sessions at committee meetings (March 31, April 14, and May 12, 2023), an Online Public Comment Portal (April 10 – June 12, 2023), and a Hybrid Symposium (June 22 – 23, 2023) where the Committee will review all the input received and hold further discussions.

KEY THEMES FROM PARTICIPANT INPUT

Uses and Number of Definitions

Purposes and contexts for using a Long COVID definition. Participant input showed that Long COVID definitions are being used in a variety ways and for a mix of purposes. The questionnaire indicates that patients, patient organizations, clinical practitioners, researchers, and the general population most commonly use a definition to explain Long COVID to others. Focus groups underlined that not all uses may require the same level of exactness in the definition.

Number of definitions. Participants in the focus groups agreed that a broad definition is necessary for ensuring as many patients as possible are included, which would reduce the likelihood of worsening inequities. At the same time, participants noted that a broad definition might not be suitable for all uses. To address this, many focus group participants suggested a nested definition — beginning with a broad and inclusive definition understandable to the

general public, followed by subsequent, related definitions with technical and scientific language suitable for different use cases. Questionnaire respondents were almost evenly split when asked their opinions on whether there should be one definition or multiple definitions for specific use cases.

Feedback on the Current Definition

General level of satisfaction with the working definition. Over half of the questionnaire respondents were satisfied with the current definition. Levels of satisfaction and dissatisfaction were similar across group affiliations and among those who have Long COVID. While a minority of questionnaire respondents liked another definition more than the USG working definition, most of those respondents preferred the World Health Organization (WHO) definition[ii] for Long COVID.

Specific phrases in the working definition. Overall, most questionnaire respondents would keep the individual phrases as-is or they would make minor modifications, however, a smaller minority favored major changes to some elements or dropping them from the definition entirely. Both the questionnaire respondents and focus group participants identified similar topics when asked what they would change (e.g., more information about impairment, specific signs and symptoms, altered time of onset).

Key Aspects of the Definition

Attribution to infection. There were mixed levels of support for updating the definition to include how a COVID-19 infection was confirmed prior to developing Long COVID. Less than a third of questionnaire respondents thought that adding this would improve the definition. Over a third agreed that adding specific biomarkers, however, would improve the definition. Focus group participants raised that laboratory confirmation of COVID-19 infection would be too exclusive. Some suggested that a patient-centered definition that attributes infection according to patients' lived experience of the illness would be more appropriate.

Diagnosis. Participant input was varied on the topic of how the diagnosis of Long COVID should be approached in the definition. Patients, caregivers, and patient advocates recommended prioritizing the patient's experience and judgment. Researchers, clinical practitioners, and practitioner organizations recommended focusing diagnosis on the body systems affected after a COVID-19 infection and ensuring patients are screened for other known post-viral illnesses.

Onset. Participants broadly agreed that there does need to be language in the definition about the onset of Long COVID. However, many viewed the 4-week window used in the working definition as too short. Others cautioned that including a specific timeline of onset might result in unintentionally excluding patients from disability benefits, and may also obscure how different symptoms of Long COVID may emerge in a range of time frames.

Duration. Participants raised that the duration of Long COVID is an important but ambiguous topic that needs to be addressed in the definition. Focus group participants noted that

Long COVID may manifest in different ways and last different lengths of times, and it is yet unknown whether Long COVID symptoms will persist indefinitely. Focus group participants suggested pairing symptoms by their phase of onset (acute, subacute, chronic) with the duration of those symptoms. Respondents of the questionnaire called for a Long COVID definition to focus more on long-term and lifelong symptoms than on short-term symptoms.

Symptoms. It was important to both sets of participants to include the most common symptoms within the definition of Long COVID, with an emphasis on the relapsing and remitting nature of Long COVID symptoms. A number of focus groups noted that many people will understand the illness through symptoms, from patients experiencing symptoms and living with chronic conditions, to clinicians diagnosing patients, to researchers understanding disease etiology, to administrators and policymakers disbursing benefits and establishing eligibility guidelines. Questionnaire respondents also shared the importance of including frequency of symptoms in the definition.

Impairments. Participants consistently called for refining the concept of impairment in the definition for Long COVID, as many patients find that their symptoms interfere with daily functioning (such as socially, occupationally, their mental health, and other areas of daily life). Focus group participants stressed that emphasizing, or not emphasizing, impairment in a Long COVID definition could impact degrees of access to disability accommodations. There was mixed support in the questionnaire about whether the definition would be improved by strengthening the language about how severe the symptoms are.

Considerations for Any Changes to the Definition

Equity. Questionnaire respondents and focus group participants agreed that it was important that the definition applies equitably to all people with Long COVID**.** Both sets of participants raised that requiring an official COVID-19 diagnosis may be a burden or impossible in many situations, as well as that a definition for Long COVID needs to recognize that different people have different symptoms and experiences. When asked if the definition for Long COVID should use plain language — understandable to persons of any education level — 9 in 10 questionnaire respondents agreed.

Application of the Definition to Pediatric Populations. Of particular concern to focus group participants was ensuring that there is a Long COVID definition suitable for children, noting that pediatric cases of Long COVID may present differently than adult cases. Participants also called for some consistency between the adult definition of Long COVID and any subgrouping for children to ensure that children with Long COVID conditions still have a diagnosis when they turn 18.

Advice for the National Academies Committee. Participants in the focus groups were asked to offer advice to the National Academies' committee charged with examining the USG's working definition for Long COVID. Many comments were shared related to the importance of engagement with patients and patient groups, coordination with the Social Security Administration[1], and the need to pair any new definition for Long COVID with a dissemination and education campaign to inform the public and professionals who work in fields related to Long COVID.

NEXT STEPS

The National Academies' committee will receive this report in advance of their symposium in late June 2023. The committee will review all the input received and then explore key emerging themes with other key interested and impacted people.

The committee may conclude its work by considering stakeholder input and information gathered through their other activities, to produce a short consensus report. This report may put forth new Long COVID definition(s) and related technical terms, along with descriptions of the circumstances under which these new definitions and terminology might be adopted.
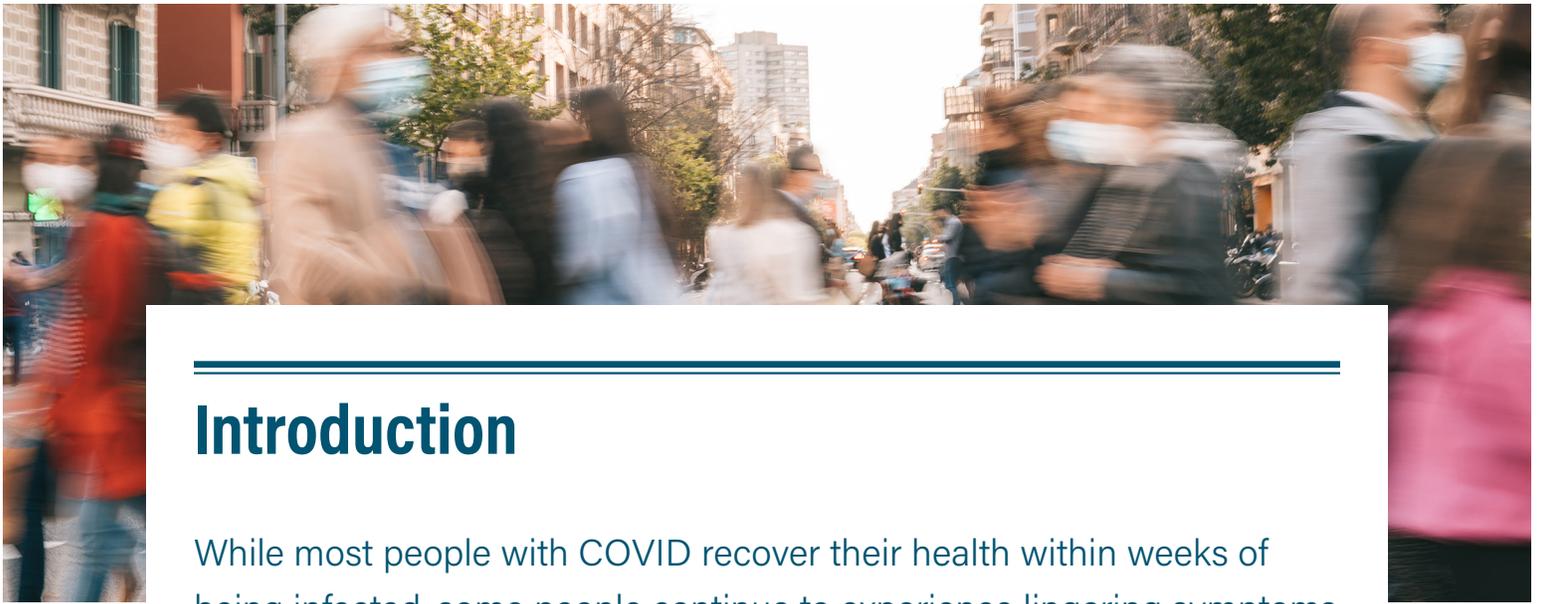
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1   Upon request of the U.S. Social Security Administration (SSA), a different National Academies committee is reviewing the long term health impacts stemming from COVID-19 and the implications for the Social Security Administration.

Introduction

While most people with COVID recover their health within weeks of being infected, some people continue to experience lingering symptoms for months or longer, or may have new or recurring symptoms at a later time — even if the infection was asymptomatic.[iii] This condition is commonly known as "long-haul COVID" or "Long COVID", as coined and advanced by patients around the world.[iv] The phrase Long COVID points to technical terms such as Post-COVID-19 conditions (PCC), Post-acute Sequelae of SARS-CoV-2 infection (PASC), and other related terms.

Long COVID is a serious national and global concern, with medical, social, economic, and personal impacts. In May 2023, the National Center for Health Statistics stated that 15% of all adults in the United States have experienced Long COVID.[v]

A working definition of Long COVID was developed in 2022 by the U.S. Department of Health and Human Services (HHS) in collaboration with other departments, including subject matter experts at the HHS Office of the Secretary, Centers for Disease Control and Prevention (CDC), and National Institutes of Health, as well as from engaging with patient groups, medical societies, and experts inside and outside the government:

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.[vi]

NATIONAL ACADEMIES COMMITTEE ON EXAMINING THE WORKING DEFINITION OF LONG COVID

To examine if the U.S. Government's (USG) working definition of Long COVID would benefit from refinement, the Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH), asked the National Academies of Sciences, Engineering, and Medicine (National Academies) to undertake a multi-perspective engagement process to examine the USG current working definition of Long COVID and related technical terms.

The National Academies' *Standing Committee on Emerging Infectious Diseases and 21st Century Health Threats* was charged with developing a workplan and engagement process to examine and refine the current USG working definition of Long COVID and related technical terms. After an initial scoping phase to develop the work plan, a diverse committee made up of individuals with relevant expertise and experiences was assembled to carry out the plan, the *Committee on Examining the Working Definition for Long COVID* (committee).[2]

A series of workshops were held for the committee to examine and explore these issues with others who brought additional expertise and experience related to Long COVID. In addition, EnSpark Consulting was contracted to develop and run an engagement process, as well as provide analysis of the data collected.

This report was prepared by EnSpark Consulting and contains details on the scope, objectives, activities, and results of the engagement process.

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2   View committee membership at www.nationalacademies.org/our-work/examining-the-working-definition-for-long-covid

Engagement Process

The multi-perspective engagement process enabled the committee to solicit input from patients, caregivers, researchers, practitioners, health agencies, health policy and advocacy organizations, payors, and health industry businesses. A total of 1,315 participants were involved in engagement activities.

Three key principles guided the engagement process:

- Commitment to inclusion to ensure a wide set of perspectives are heard.

- Development of a fair and equitable process to ensure all participants have the information they need to fully participate, as well as accommodations necessary to enable their participation.

- Transparency in the process and in the documentation of findings from the engagement.

This report offers an analysis of input heard through two key opportunities hosted by the committee:

Questionnaire (April 19, 2023 – May 12, 2023): An online questionnaire was sent to interested and impacted people and organizations. It was also publicly shared by invited participants. Respondents had the opportunity to provide specific feedback on key issues, concerns, and areas of improvement of the current working definition.

The questionnaire was created using Qualtrics and completed questionnaires were stored in Qualtrics's secure servers online.

The questionnaire (Appendix E) contained 37 questions, none of which was required to be answered. Twenty-five questions were about Long COVID (16 multiple choice and nine open-ended questions) and 11 were demographic questions (10 multiple choice and one open-ended question).

Virtual Focus Groups (April 26, 2023 – May 8, 2023): Seven facilitated virtual focus groups were held with invited people and organizations to deepen the shared understanding of the concerns and areas of improvement of the current working definition.

Seven facilitated virtual focus groups were held with invited individuals and organizations to explore concerns and areas for the improvement of the current USG working definition of Long COVID:

- *Researchers* (April 26): For those who conduct research and report results to the scientific or medical community.

- *Practitioners* (April 28): For those who provide health care and for professional associations who provide clinical guidance.

- *Patients, Caregivers, and Patient Organizations* (April 29): For those who are living with Long COVID, supporting someone affected, and for groups who advocate on behalf of Long COVID patients.

- *Health Agencies* (May 2): For those who lead or deliver programs that provide public health or community services.

- *Health Policy and Health Advocacy Organizations* (May 4): For organizations who advance health care and health policy through data analysis, funding research, advocacy, supporting initiatives, or making recommendations.

- *Payors and Health Businesses* (May 5): For businesses that provide health insurance as well as businesses that produce drugs, tests, devices, procedures, etc. related to Long COVID.

- *All Categories* (May 8): For those unable to attend the session for their sector.

Each online focus group session was 2.5 hours long. The majority of each session was spent in small group discussion to ensure participants were able to share their views and hear from others. Facilitators and notetakers supported the discussions.

The sessions began with a brief welcome and context setting presentation. Participants joined a breakout group and engaged in two 35-minute small group discussions. Each breakout group discussion was followed by a brief plenary discussion. Key discussion questions for the focus groups were:

- How might you use a definition of Long COVID?

- What feedback do you have about the USG's working definition, or other definitions, of Long COVID?

- What challenges might there be in using the current USG definition, or other definitions? What might address those challenges?

- What should the National Academies' committee keep in mind to make sure the definition does not unintentionally make it harder for people with Long COVID to get healthcare, workplace support, or other things they need? Consider in particular the challenges faced by historically marginalized peoples.

- What advice do you have for the National Academies' committee charged with reviewing the USG's definition of Long COVID?

All those invited to participate in the questionnaire and focus groups will be sent a link to this report.

Additional engagement efforts led by the National Academies include:

Information-gathering sessions at committee meetings (March 31, 2023, April 14, 2023, and May 12, 2023): At these information-gathering sessions, the committee heard from federal, state, and local agencies on ongoing efforts on Long COVID, and perspectives from researchers, practitioners, and patients about defining Long COVID.

Online Public Comment Portal (April 10, 2023 – June 12, 2023): An open comment portal was available on the project website for the public to provide comments and submit resources about the current working definition.

Hybrid Symposium (June 22, 2023 – June 23, 2023): A two-day, hybrid workshop with a diverse range of interested and impacted people will be held for the committee to review all the input received and to hold further discussions.

The committee may conclude its work by considering stakeholder input and information gathered through their other activities, to produce a short consensus report. This report may put forth new Long COVID definition(s) and related technical terms, with descriptions of the circumstances under which these new definitions and terminology might be adopted.

Who Participated

Invited participants of the focus group and questionnaire were those who:

- Have significant direct expertise with Long COVID / post COVID conditions, autoimmune diseases, public health, epidemiology, infectious disease, or other related fields.
  and/or

- Are a patient, caregiver, or representative of a patient organization for those with lived experience of Long COVID.
  and

- Contribute to an equitable list of participants that covers a full spectrum of impacted and interested people, geographies, and demographics.

Using the above involvement criteria, a list of impacted and interested people was developed through recommendations from the National Academies staff, *Committee on Emerging and Infectious Diseases and 21st Century Health Threats*, and the *Committee on Examining the Working Definition for Long COVID*, as well as OASH and research done by EnSpark Consulting public health advisors. People on this list were invited to participate in the focus groups and/or questionnaire.

The questionnaire was also publicly available.

QUESTIONNAIRE PARTICIPANTS

The questionnaire was available for 24 days between April 19 and May 12, 2023. There were a total of 1,181 responses to the questionnaire, with 732 responses (62%) being fully completed. Respondents who did not complete the questionnaire had their partial responses included in the analysis.

Questionnaire respondents do not reflect a random sample. Respondents came from two sources: experts and leaders in the field of Long COVID who were invited by the National Academies to take the questionnaire via a personalized email link, as well as individuals who used a general link that was forwarded by the invited group.

Participants were not included or excluded based on demographics (e.g., age of adult, gender, ethnicity or race, religion, education, socioeconomic status, or geography). However, it was required that questionnaire participants were at least 18 years of age.
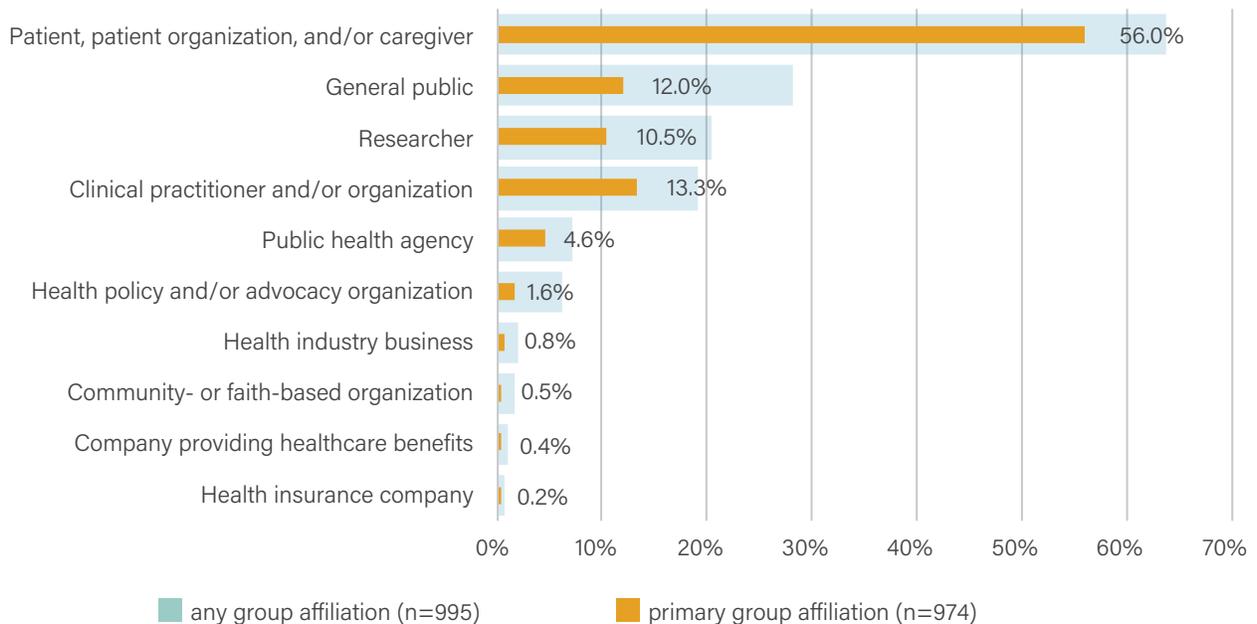
Response and completion rate

The National Academies invited 444 individuals with expert knowledge and experience to complete the questionnaire. Of those, 123 individuals (28%) responded to the questionnaire, including 111 (25%) who fully completed the questionnaire. 1,057 responses were received from individuals invited to participate in the survey through snowballing, including 620 (59%) that were fully complete.

The questionnaire was designed to be accessible for a range of education levels. The median time respondents took to complete the questionnaire was 11 minutes and 52 seconds. The Spanish language version of the questionnaire received 11 responses (1% of all responses).

Questionnaire responses by group affiliation

The questionnaire asked two questions about groups with which they identify (Figure 1). The first question allowed respondents to select all that apply, while the second question asked them to identify the group with which they *most* identify. Results from the second question (primary group affiliation) will be used when reporting questionnaire responses by affiliation group.

Questionnaire respondents by multiple and primary group affiliations

Group	Primary group affiliation
Patient, patient organization, and/or caregiver	56.0%
General public	12.0%
Researcher	10.5%
Clinical practitioner and/or organization	13.3%
Public health agency	4.6%
Health policy and/or advocacy organization	1.6%
Health industry business	0.8%
Community- or faith-based organization	0.5%
Company providing healthcare benefits	0.4%
Health insurance company	0.2%

any group affiliation (n=995)   primary group affiliation (n=974)

Figure 1. Questionnaire respondents by multiple and primary group affiliations. Not all respondents who selected multiple group affiliations identified their primary group affiliation.

The distribution of respondent group affiliation was influenced by the different methods of receiving notice about the questionnaire. Invitations to a respondent group with diverse Long COVID experiences and knowledge across sectors were sent by email, and therefore these responses are reflective of that diversity. The anonymous links were available to the general public and were disproportionately completed by patients, patient organizations, and/or caregivers. For more details about the distribution of group affiliation based on the questionnaire type, see Figure B1 in the Appendix.

Questionnaire response demographics

The questionnaire featured demographic questions to better understand who the respondents were. The demographic questions were prefaced with a disclaimer that they were anonymous and voluntary, and these questions were asked at the end of the survey. Fewer answers were received to these questions in comparison to the questions pertaining to Long COVID. Among respondents who were invited to take the questionnaire, response rates for demographic questions ranged from 70-87%, while the anonymous link respondent response rates for demographic questions were 46-57%. Additional demographic figures can be found in Appendix B.

Respondents who answered demographic questions were overwhelmingly white, female, highly educated, lived in urban or mostly urban areas of the United States, and had a total household income of at least $100,000.

Race. Of the 58% of respondents who answered the question about their racial background, 86% described themselves as White (Figure B2).

Gender. Respondents were also disproportionately female. Of the 61% of respondents who answered the question about gender, 73% said they were female (Figure B3).

Education. Respondents were highly educated. Of the 61% of respondents who answered the question about education, 62% said they had a graduate or professional degree (Figure B4).

Location. Respondents were primarily based in the United States. Of the 58% of respondents who answered the question about their location, 92% resided in the United States while the remaining locations were outside the United States.

Long COVID. Respondents were asked whether they identify as a person with Long COVID (Figure 2). Over half of questionnaire respondents identified as having Long COVID and over 9 out of 10 respondents who had Long COVID identified as the patient, patient organization, and/or caregiver primary group affiliation.

Number of respondents who identify as a person with Long COVID[3]

Group affiliation	Person with Long COVID	Person without Long COVID
All respondents with a group affiliation (n=974)	524	450
Patient, patient organization, and/or caregiver (n=545)	486	59
Researcher (n=102)		95
Clinical practitioner and/or organization (n=117)		103
Public health agency (n=45)		41
Health policy and/or advocacy organization (n=16)		14
Health industry business (n=4)		3
Health insurance company (n=5)		5
Company providing healthcare benefits (n=2)		2
Community- or faith-based organization (n=8)		8
General public (n=130)		120

■ Person with Long COVID　　■ Person without Long COVID

Figure 2. Percentage of questionnaire respondents who identified as having Long COVID, by group affiliation.

Patients. The 622 questionnaire respondents who identified as a "patient, patient organization, and/or caregiver group" were asked to further specify their experience with Long COVID (to which they could select all that apply). 86% said they were a person with Long COVID. Patient advocacy organization was selected by 16% of respondents, while caregivers to adults were 6%, and caregivers to youth were 5%. There was considerable overlap between patients, patient organizations, and/or caregivers. For instance, over three-quarters of Long COVID patient advocacy organization respondents also said they were people with Long COVID. About one-third of caregivers to adults with Long COVID also have or have had Long COVID, and nearly half of caregivers to youth with Long COVID also have or have had Long COVID.

3　Only people who identified as a patient, patient organization and/or caregiver were asked if they have Long COVID.

FOCUS GROUP PARTICIPANTS

Seven focus groups were held in April and May 2023, involving 134 people.

Affiliation. The two largest groups of participants were researchers and patients/patient organization representatives.

Primary sector affiliation of focus group participants

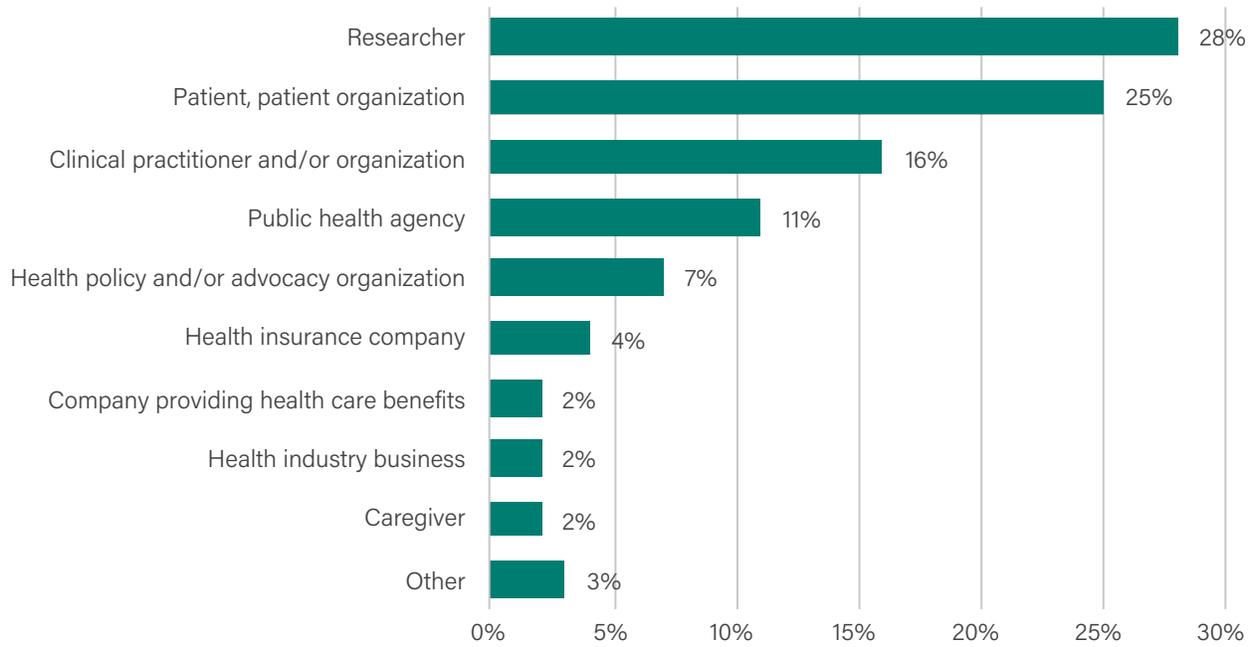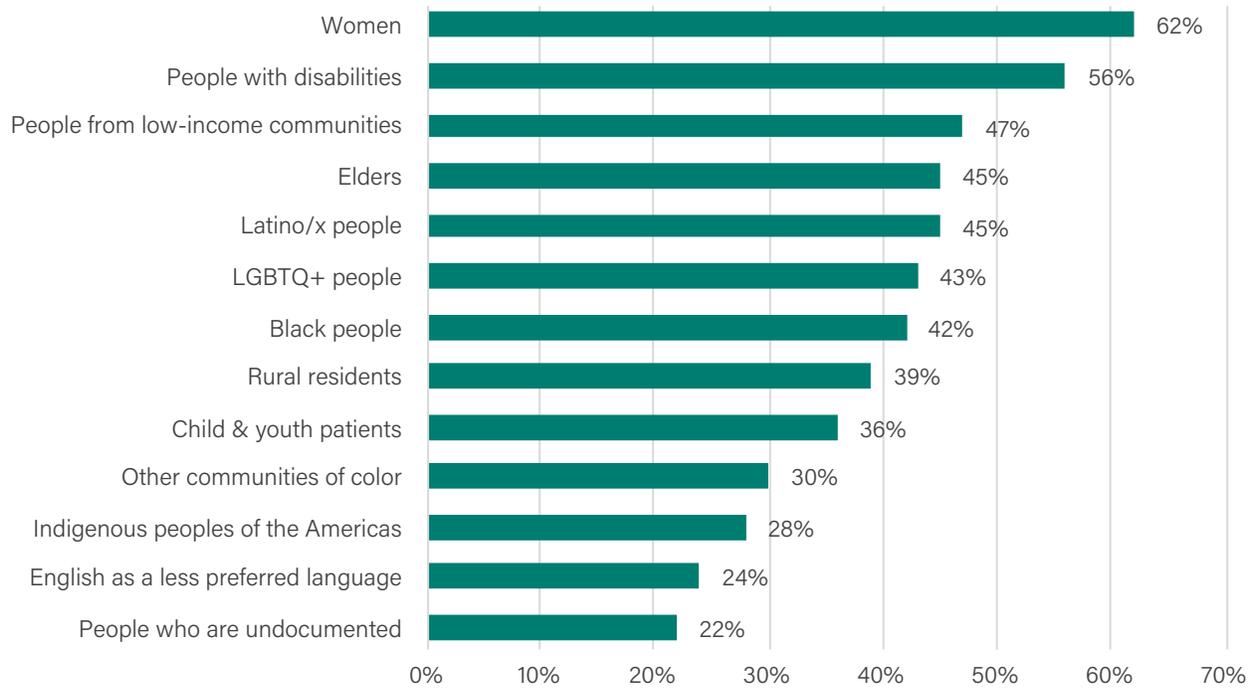| Sector	Percentage
Researcher	28%
Patient, patient organization	25%
Clinical practitioner and/or organization	16%
Public health agency	11%
Health policy and/or advocacy organization	7%
Health insurance company	4%
Company providing health care benefits	2%
Health industry business	2%
Caregiver	2%
Other	3%

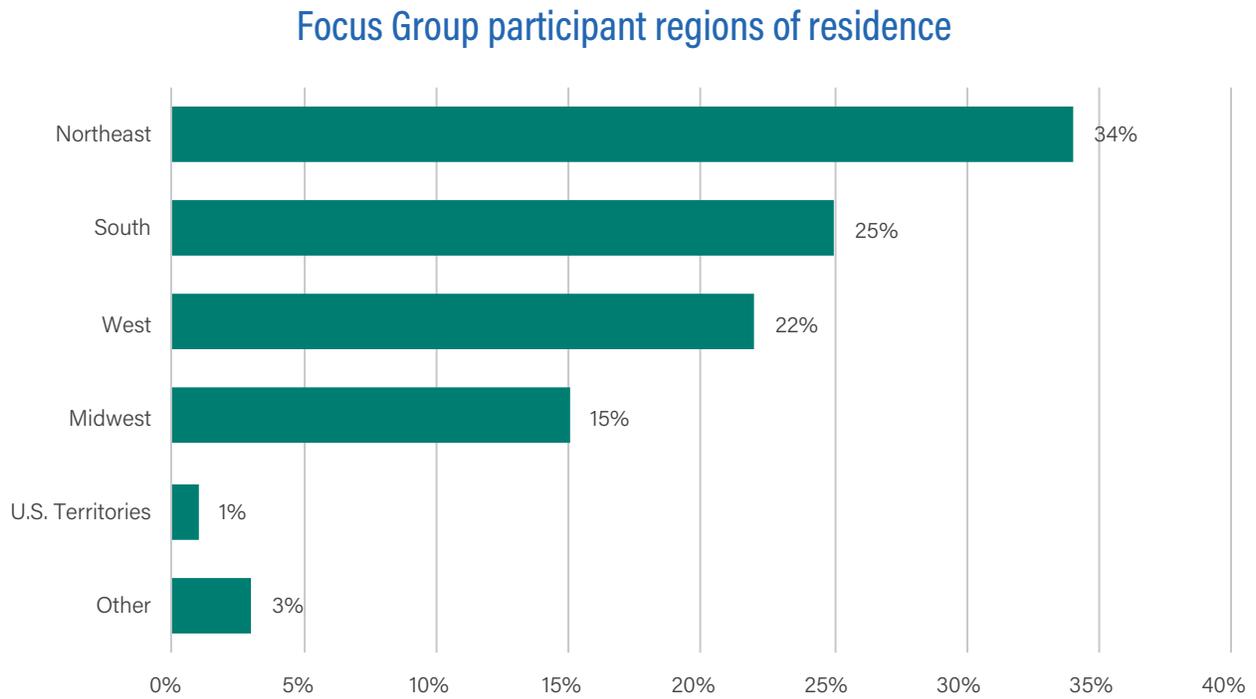*Figure 3: Primary sector affiliation of focus group participants.*

Diversity. Focus group participants represented a wide range of identities and groups, either personally or through whom their organization serves:

Focus Group participant identities and/or organizational service focus

Identity/Group	Percentage
Women	62%
People with disabilities	56%
People from low-income communities	47%
Elders	45%
Latino/x people	45%
LGBTQ+ people	43%
Black people	42%
Rural residents	39%
Child & youth patients	36%
Other communities of color	30%
Indigenous peoples of the Americas	28%
English as a less preferred language	24%
People who are undocumented	22%

Figure 4: Focus group participant identities and/or organizational service focus (select all that apply)

Location. Most focus group participants reported that they reside across the USA, while some participants were from the U.S. Territories and international countries:

Focus Group participant regions of residence

Region	Percentage
Northeast	34%
South	25%
West	22%
Midwest	15%
U.S. Territories	1%
Other	3%

Figure 5: Focus group participant region of residence.

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Data Analysis Approach

QUESTIONNAIRE

A multi-step data analysis process was performed to develop key findings from the questionnaire. First, all questionnaires with responses were accepted. This enabled gathering as much information from respondents as possible, but may have resulted in fewer responses for questions in the latter sections of the questionnaire.

Second, a descriptive analysis was conducted of the demographic questions and the primary group affiliations among the responses. This provided insight into who took the questionnaire and how to best subgroup the responses by group affiliation.

Third, a textual analysis was performed of open-ended responses and responses that allowed respondents to specify other answers. These answers were grouped thematically to further inform the findings.

Finally, the questionnaire responses were organized along the key themes that emerged during discussions in the focus group.

FOCUS GROUP

Data was collated and cleaned (e.g., misspellings and abbreviations) in documents produced for each focus group. NVivo (released in March 2020)[vii] was used to perform thematic identification and analysis of the focus group data. Three file types were produced from each of the seven focus groups:

- Notetaker notes: notes generated from the plenary session and breakout room discussions of the focus groups.
- Zoom transcripts: a transcript of Zoom discussion during the plenary session and each breakout room of the focus groups.
- Zoom chat transcripts: a transcript of Zoom chat during the plenary session.

NVivo produced an automatic thematic analysis to identify themes and sub-themes present in the transcripts. To gain a broader sense of the themes discussed in each focus group, a thematic analysis was performed within the transcripts for each focus group, and again across all transcripts. This allowed for the assessment of topics dominant in each focus group and of how the focus group themes compared to the overall focus group engagement effort.

What We Heard

The sections below provide an analysis of participant input from the questionnaire and focus groups.

The reader of this report may wish to keep in mind that:

- Key themes represented below are considerations for the committee charged examining the working definition for Long COVID; and,

- Participants are not a representative sample, rather they are a mix of experts and leaders in the field of Long COVID, as well as individuals connected to those people.

USES AND NUMBER OF DEFINITIONS

Purposes and contexts for using a Long COVID definition

Summary: Participant input showed that Long COVID definitions are being used in a variety of ways and for a mix of purposes. The questionnaire indicates that patients, patient organizations, clinical practitioners, researchers, and the general population most commonly use the definition to explain Long COVID to others. Focus groups underlined that not all uses may require the same level of exactness in the definition.

Key findings from the Questionnaire

Over two-thirds of questionnaire respondents had either read a definition for Long COVID or made use of a Long COVID definition, while about one-fifth said they had neither read nor made use of a Long COVID definition.

Among those who answered that they had made use of any Long COVID definition, 84% used the definition to explain to others what Long COVID is (Figure 6). About one-half used it to better understand an illness that they or someone else was experiencing. Understandably, certain use cases were more prevalent among different respondents depending on their primary group affiliation or occupation. For example, aside from explaining to others what Long COVID is, the most common use among researchers was to request funding for a study (60%), and among clinical practitioners, it was used to diagnose patients (80%) and to talk to patients about their prognosis (75%).

How have you used a Long COVID definition before? (Select all that apply) (n=331)
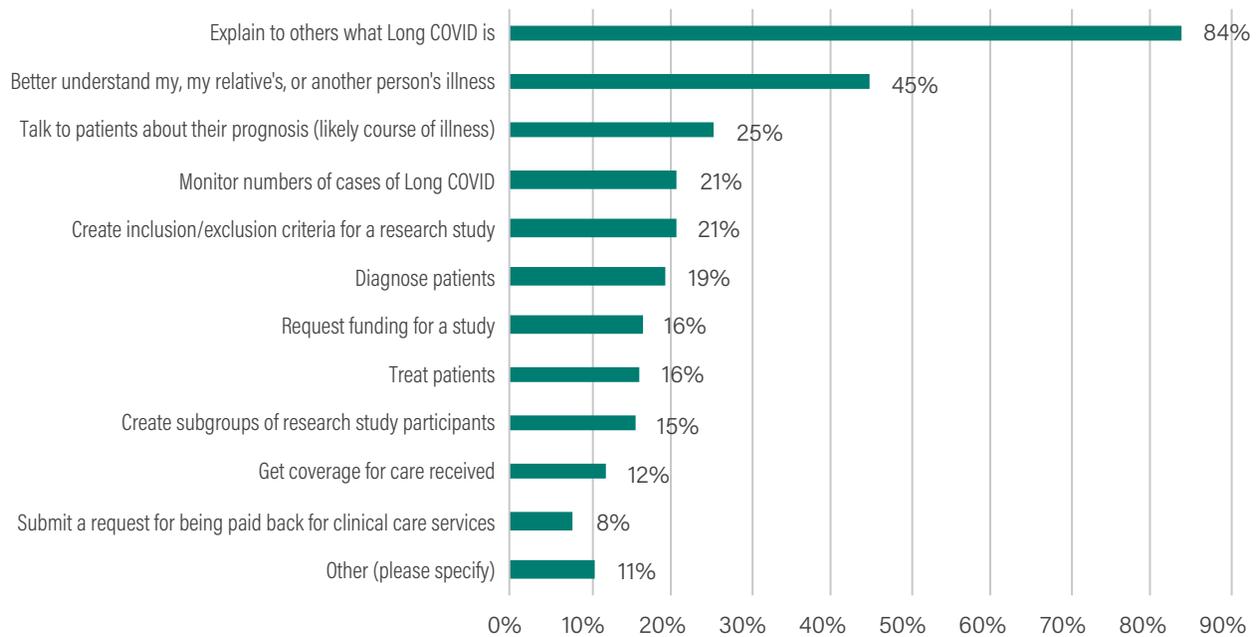

Use case	Percentage
Explain to others what Long COVID is	84%
Better understand my, my relative's, or another person's illness	45%
Talk to patients about their prognosis (likely course of illness)	25%
Monitor numbers of cases of Long COVID	21%
Create inclusion/exclusion criteria for a research study	21%
Diagnose patients	19%
Request funding for a study	16%
Treat patients	16%
Create subgroups of research study participants	15%
Get coverage for care received	12%
Submit a request for being paid back for clinical care services	8%
Other (please specify)	11%

Figure 6. Various use cases of Long COVID definitions.

A number of comments in the questionnaire highlighted the need for a definition that can be applied across contexts, such as, *"We need to ensure that the definition can be operationalized in the workplace, in health care, and in government services."*

Key findings from Focus Groups

The majority of focus groups described that they would use a Long COVID definition for their occupations — i.e., research study design, conducting public health surveillance, advising on federal and state policy for health and disability benefits, clinical diagnosis (in order to make informed treatment and referral decisions), healthcare provider education, and public education.

> We need to ensure that the definition can be operationalized in the workplace, in health care, and in government services.
>
> — Questionnaire Respondent

Patients, patient advocates, and caregivers described uses for a Long COVID definition that were important at an individual level. This included uses like patient advocacy — i.e. a Long COVID definition could help get patients access to treatment, disability benefits, and accommodations. One participant said, *"[I would use it] with healthcare, with employers, with family members and friends, disability claims/[Social Security Disability Insurance], to enable other social services needs."* A participant with a pediatric focus spoke about using a definition, *"To help children with Long COVID access resources and medical care."*

Others talked about using a definition to validate personal experiences and find support, such as, *"To educate doctors,"* or *"Help you find empathy or support from family/friends/community members (while people without a diagnosis who are ill are often treated poorly by friends/family/coworkers/ community members who think they are faking."*

One participant conceptualized the differences among use cases this way: *"How do we reconcile clinical and research purposes [of a definition]? We felt that, potentially, we need to think about [both] a clinical and a research definition for Long COVID... remembering that both definitions might influence either. Because when it comes to the research, we have to be able to know who has Long COVID in order for us to have a case group versus a control group."*

Focus group participants also raised uses for a Long COVID definition that they thought were important potential uses, such as raising awareness of the illness through public and health care provider education, legislation development, funding research and treatment, and more.

Number of Definitions

Summary: Participants in the focus groups agreed that a broad definition is necessary for ensuring as many patients as possible are included, which would reduce the likelihood of worsening inequities. At the same time, participants noted that a broad definition might not be suitable for all uses. To address this, many focus group participants suggested a nested definition — beginning with a broad and inclusive definition understandable to the general public, followed by subsequent, related definitions with technical and scientific language suitable for different use cases. Questionnaire respondents were almost evenly split when asked their opinions on whether there should be one definition or multiple definitions for specific use cases.

Key findings from the Questionnaire

The questionnaire asked if there should be one or multiple Long COVID definitions and respondents did not favor any one option (Figure 7). Different group affiliations showed slight variations among whether the group preferred one definition or more than one. A majority of researchers and clinical practitioners and/or organization respondents who were invited to take the questionnaire preferred one definition and also had the fewest percentage of respondents saying they were not sure or had no opinion. A plurality of patients, patient organizations, and/or caregivers who were invited to take the study said they would like more than one definition.

Do you think there should be one definition for Long COVID that applies to everyone, or should there be different definitions depending on how it is used and who it is used for? (n=770)
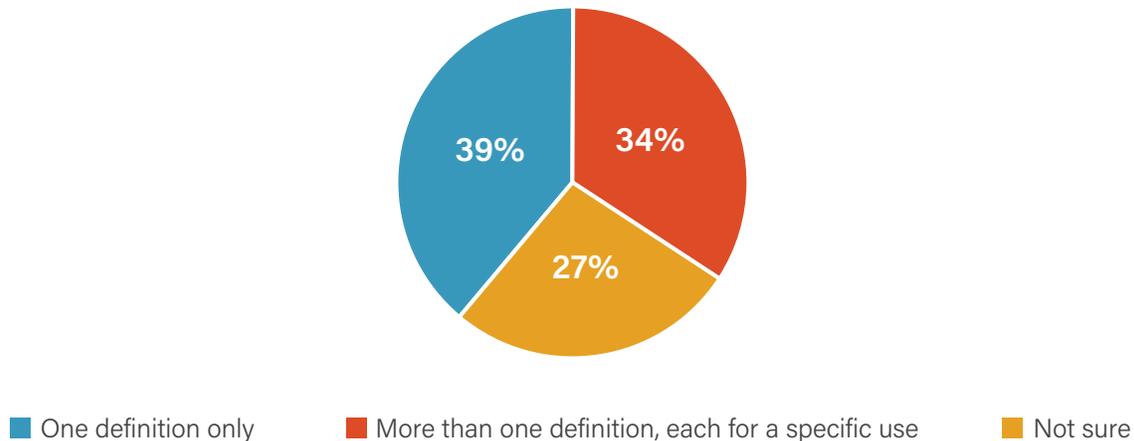

Legend: One definition only · More than one definition, each for a specific use · Not sure

Figure 7. Preferences for the number of definitions for Long COVID

Key findings from the Focus Groups

The focus groups worked to balance the need for a broad and inclusive definition with potential approaches that may make it more operational. For instance, researchers and health policy and health advocacy participants flagged that a broad definition supports access to services for people with Long COVID. The health policy and health advocacy focus group highlighted that a broad definition would promote health equity. For example, some participants mentioned things like, *"I think the broad definition is really, really important to make sure we're not pushing people out of getting the help they need."*

Yet, there were also contrasting viewpoints that a broad definition would create additional problems. For instance, some practitioners said, *"[What] I am looking for is not a broad definition right now. I'm looking for something that would be scientifically very specific so that I can narrow down my patient population who has Long COVID."*

Focus group participants tended to approve of the possibility of multiple definitions for Long COVID; they specifically called for a nested definition — where each definition is contained in the preceding definition. For example, it would begin with a broad and inclusive definition that is understandable to the general public. Then the definition would feature subsequent and related definitions with technical and scientific language suitable for different use cases. For example, a participant described their thinking of the nested definition framework: *"Suggestion of a nested definition: 1-broad, 2-more specific for policy, 3-more detailed for application purposes."*

Similarly, a participant phrased the idea this way: *"Who are we trying to capture [for this definition] that could benefit for research, for their accommodations, for their insurance coverage, disability care access? Because to me, that is such a fundamental question that drives a lot of how we then end up defining [it]. Because if we lump everybody together, I totally agree it also makes it very difficult to interpret research studies. It also makes it difficult to understand care pathways for individuals. I would be a proponent for precise but possibly multiple definitions."*

In another focus group, the nested definition concept was phrased this way: *"Maybe beneath the definition … there's some sub-definitions or some sub-group. So, here's the definition, and here's the critical context to understand within that — whether that's further discussing the spectrum of severity or further discussing the specific phenotypes... I feel like that also is important, because in terms of the definition — trying to inform policy, trying to inform research, trying to inform clinical [care] — it seems like we definitely need that additional context when understanding and discussing and trying [to read] the definition."*

FEEDBACK ON THE CURRENT DEFINITION

General Level of Satisfaction with the Working Definition

Summary: Over half of the questionnaire respondents were satisfied with the current definition. Levels of satisfaction and dissatisfaction were similar across group affiliations and among those who have Long COVID. While a minority of questionnaire respondents liked another definition more than the USG working definition, most of those respondents preferred the World Health Organization (WHO) definition[viii] for Long COVID.

Key findings from the Questionnaire

Overall, respondents were broadly satisfied with the current USG definition for Long COVID (Figure 8). Half of respondents were either extremely satisfied or somewhat satisfied with the definition, about one-fifth were neither satisfied nor dissatisfied, and one in three were somewhat or extremely dissatisfied. This trend was found across group affiliations. Respondents who were invited to take the survey were less likely to say they were neither satisfied nor dissatisfied, but did not favor being satisfied or dissatisfied.

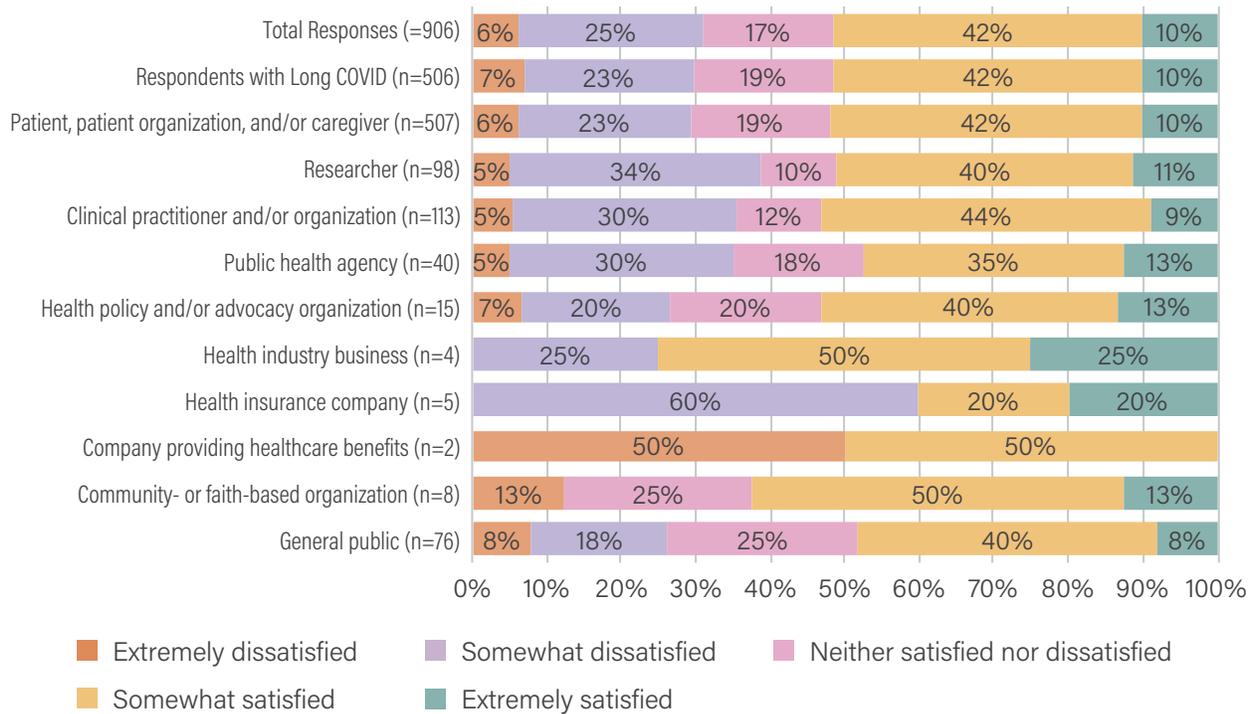## How satisfied are you with the current USG Long COVID definition (n=906)

Figure showing satisfaction levels by group affiliation:

Group	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied
Total Responses (=906)	6%	25%	17%	42%	10%
Respondents with Long COVID (n=506)	7%	23%	19%	42%	10%
Patient, patient organization, and/or caregiver (n=507)	6%	23%	19%	42%	10%
Researcher (n=98)	5%	34%	10%	40%	11%
Clinical practitioner and/or organization (n=113)	5%	30%	12%	44%	9%
Public health agency (n=40)	5%	30%	18%	35%	13%
Health policy and/or advocacy organization (n=15)	7%	20%	20%	40%	13%
Health industry business (n=4)		25%		50%	25%
Health insurance company (n=5)		60%		20%	20%
Company providing healthcare benefits (n=2)	50%			50%	
Community- or faith-based organization (n=8)		13%	25%	50%	13%
General public (n=76)	8%	18%	25%	40%	8%

Figure 8. Satisfaction with the current USG Long COVID definition among group affiliations

Reasons for dissatisfaction

Respondents who said they were either extremely or somewhat dissatisfied with the working definition for Long COVID were asked to select reasons why they were dissatisfied. The most common reasons for dissatisfaction with the working definition for Long COVID were that it should include specific signs, symptoms, and conditions and that the definition is too broad (figure 9). Additionally, respondents felt that the working definition does not capture the seriousness or severity of their Long COVID symptoms.

> The most common reasons for dissatisfaction with the working definition for Long COVID were that it should include specific signs, symptoms, and conditions and that the definition is too broad.

Please explain why you are dissatisfied with the current definition. (Select all that apply) (n=265)
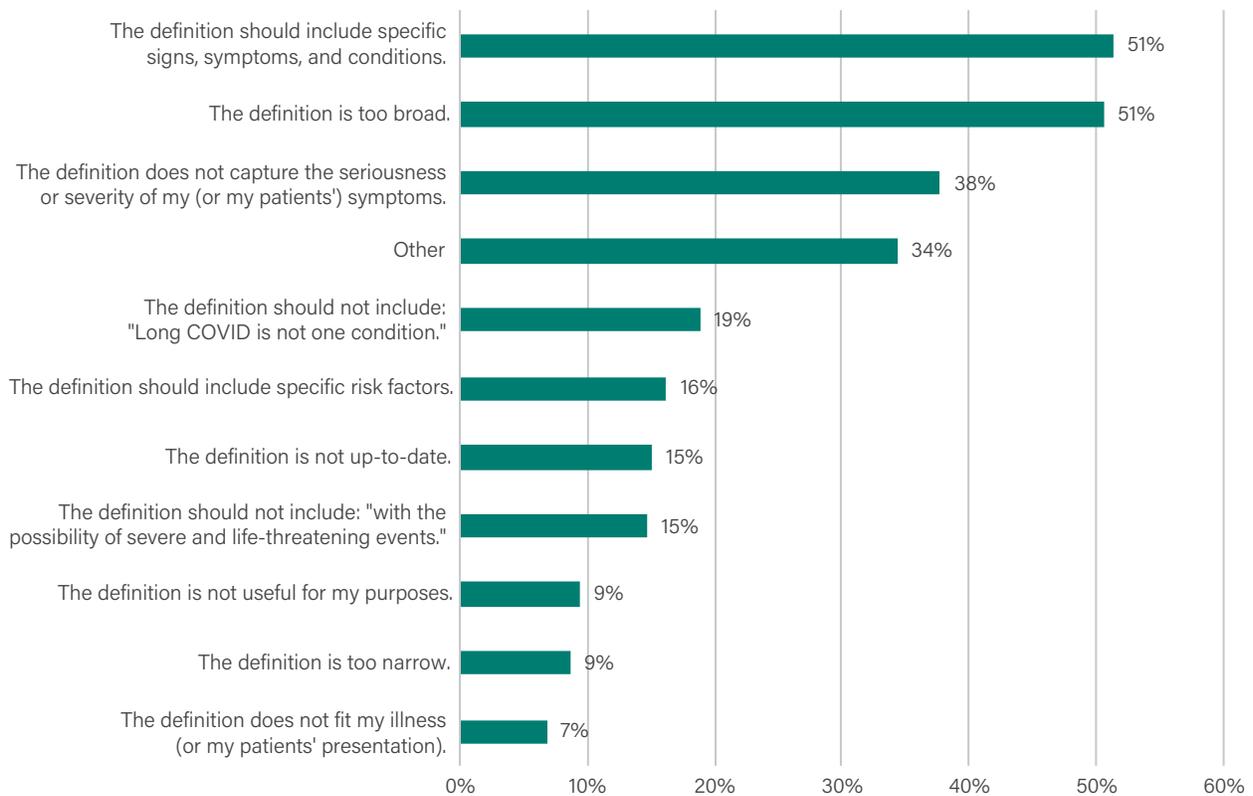

Reason	Percentage
The definition should include specific signs, symptoms, and conditions.	51%
The definition is too broad.	51%
The definition does not capture the seriousness or severity of my (or my patients') symptoms.	38%
Other	34%
The definition should not include: "Long COVID is not one condition."	19%
The definition should include specific risk factors.	16%
The definition is not up-to-date.	15%
The definition should not include: "with the possibility of severe and life-threatening events."	15%
The definition is not useful for my purposes.	9%
The definition is too narrow.	9%
The definition does not fit my illness (or my patients' presentation).	7%

Figure 9. Reasons for dissatisfaction with the working definition of Long COVID.

Among patients, patient organizations, and/or caregiver respondents, the most commonly referenced reason that they were dissatisfied with the definition was that the definition does not capture the seriousness or severity of Long COVID symptoms (Figure 10). Other main reasons for this group were that the definition should include specific risk factors, and that the definition was too broad. Respondents who were invited by email and those who used the anonymous link answered this question similarly, except that those who were invited to take this questionnaire selected "The definition does not fit my illness" more often than "Other".

Patient, patient organization, and/or caregiver (n=139)
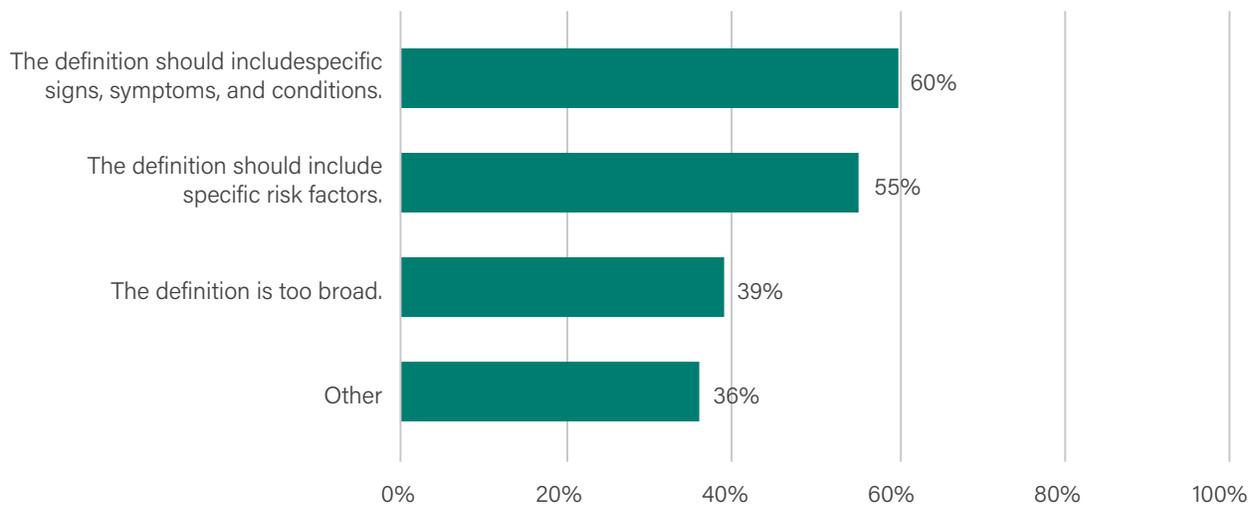
Figure 10. Reasons for dissatisfaction with the definition for Long COVID among patients, patient organizations, and/or caregivers

Among clinical practitioners and/or organization respondents, the chief reasons selected were that the definition is too broad, that it should include specific signs, symptoms, and conditions, and the phrase "with the possibility of severe and life-threatening events" should not be included (Figure 11). Among this group who were invited to take the questionnaire, the fourth most commonly cited reason for dissatisfaction was tied, and also included "the definition should include specific risk factors" and "the definition should not include "Long COVID is not one condition."

Clinical practitioner and/or organization (n=37)
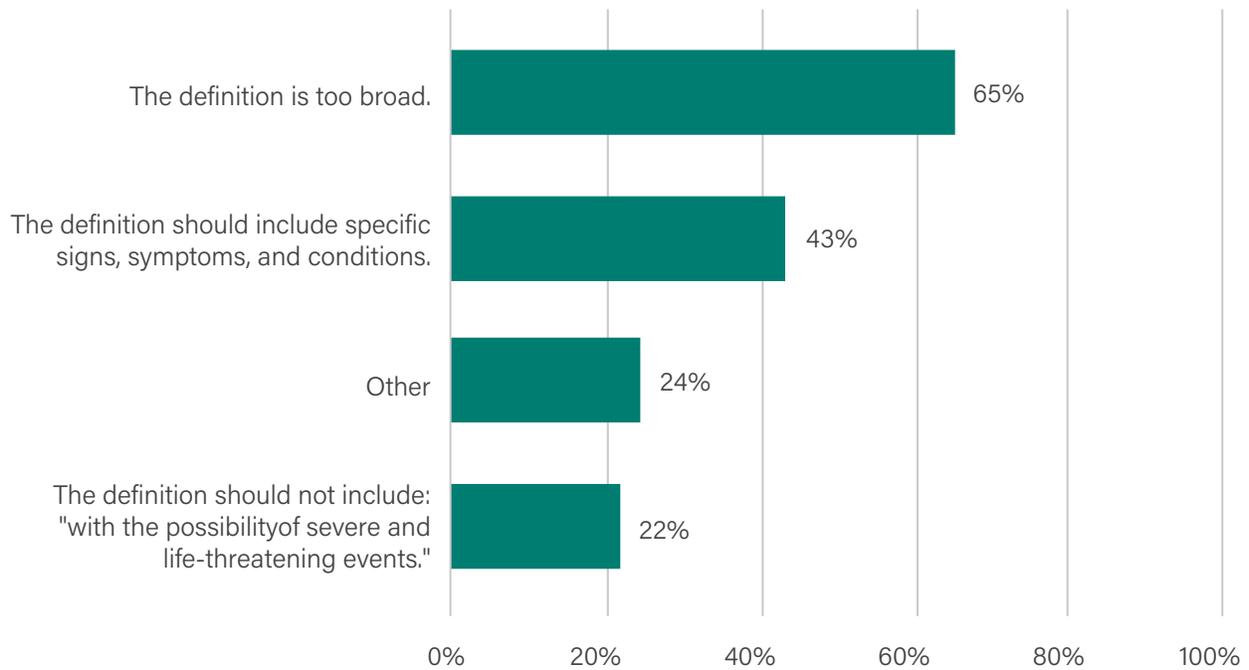
Figure 11. Reasons for dissatisfaction with the definition for Long COVID among clinical practitioners and/or organizations

Among researchers, the main reasons for dissatisfaction were how broad the definition was, that it needed to include specific signs, symptoms, and conditions, and disliked the phrase "Long COVID is not one condition" (Figure 12). Researchers who were invited to take this questionnaire also had a tie for the fourth most common reason for dissatisfaction, including "the definition should include specific risk factors" and "the definition is not up-to-date."

Researcher (n=37)

Reason	Percentage
The definition is too broad.	78%
The definition should include specific signs, symptoms, and conditions.	43%
Other	41%
The definition should not include: "Long COVID is not one condition."	24%
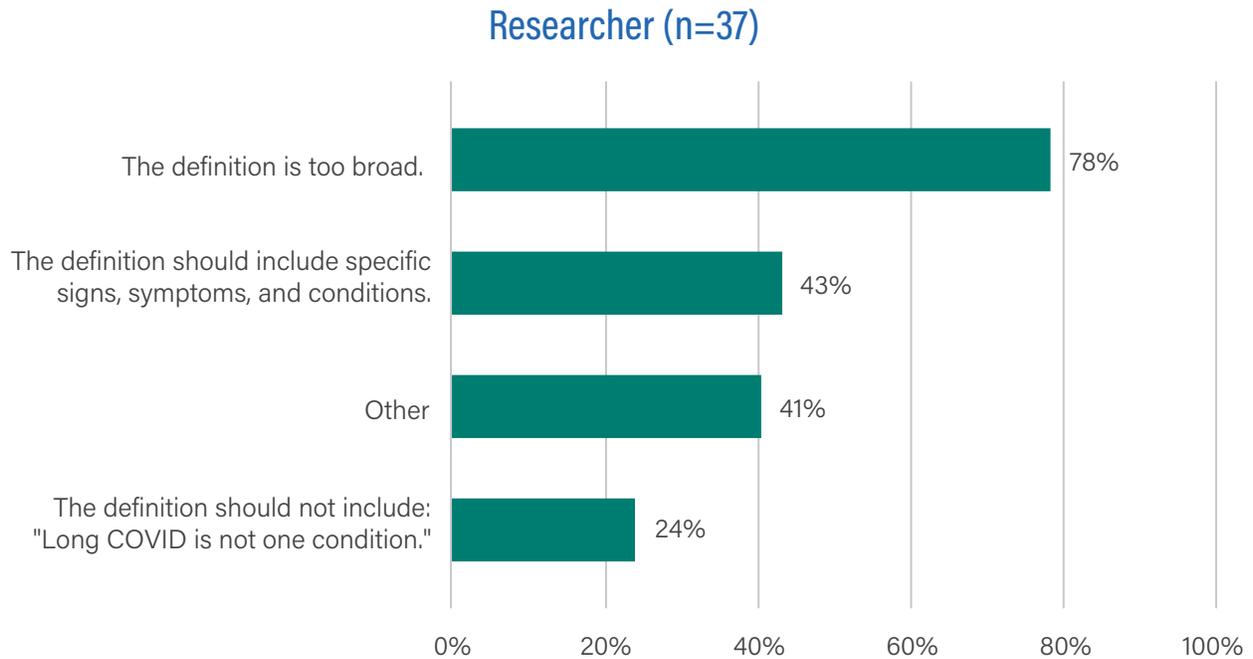
Figure 12. Reasons for dissatisfaction with the definition for Long COVID among researchers

Among all other questionnaire respondents, the most common reason for dissatisfaction were that the definition should include specific signs, symptoms, and conditions, the definition is too broad, and that the definition should include specific risk factors (Figure 13). Respondents could also add their reasons for dissatisfaction when they selected "Other." The most common theme among these responses was that explicitly mentioning the 4-week window may not be appropriate for all users of the definition. For example, one respondent answered, *"4 weeks is not well grounded in the literature — to be distinguished from other post viral sequelae, we should consider 3 months; however 4 weeks may be most appropriate for [Human Resources]/disability reasons."*

Other questionnaire respondents highlighted the need for a definition to differentiate between those with Long COVID, and those who had COVID-19 and are experiencing health issues. For example, one respondent said the *"Definition should be able to help differentiate Long COVID from normally occurring illnesses. Since 80% of Americans have been infected, you need to be able to differentiate health problems caused by Long COVID from [those] which normally otherwise appear."*

All other respondents (n=52)

The definition should include specific signs, symptoms, and conditions.	52%
The definition is too broad.	52%
Other	33%
The definition should include specific risk factors.	21%
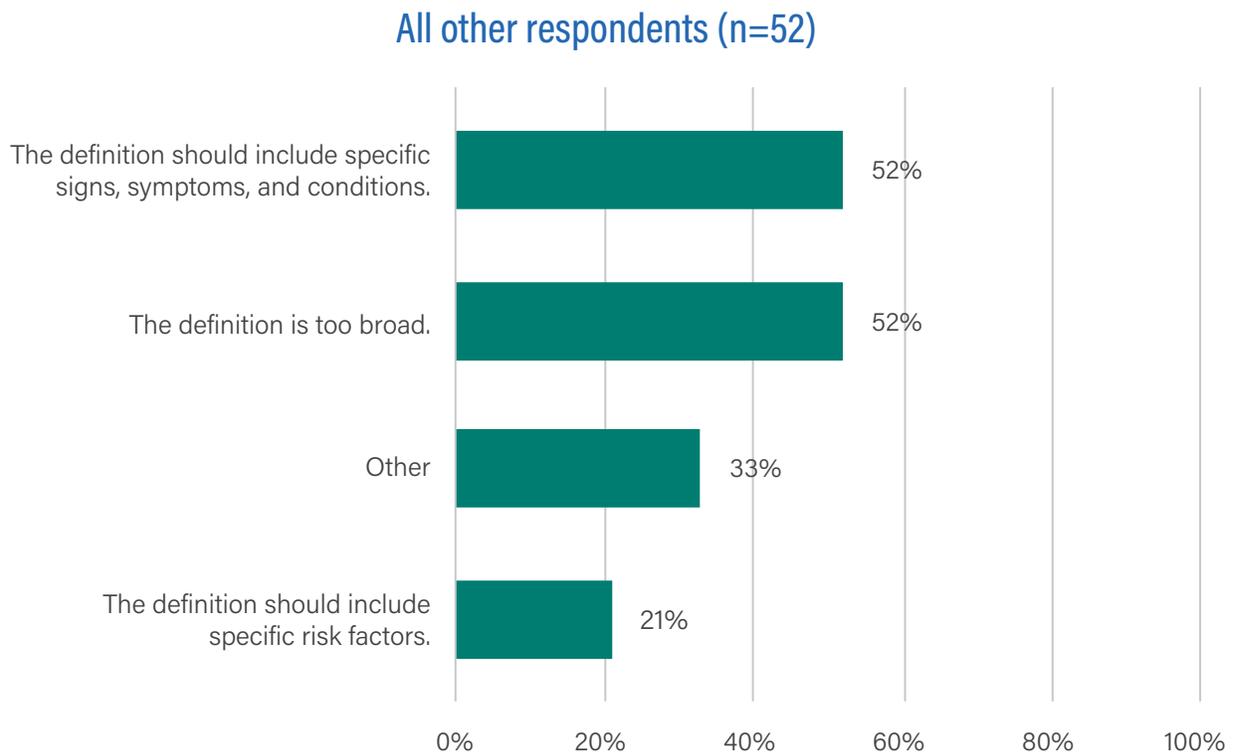
Figure 13. Reasons for dissatisfaction with the definition for Long COVID among all other respondents

Overall, questionnaire respondents felt that the working definition for Long COVID is too broad. This sentiment was the most commonly cited reason for dissatisfaction among a majority of group affiliations.

Preferences for other Long COVID definitions

After questionnaire respondents were asked about their satisfaction with the current USG Long COVID definition, they were asked whether they had preferences for any other Long COVID definition (Figure 14). Of those who answered this question, only 15% answered "Yes." Respondents were given an option to specify which definition they preferred over the USG working definition. The most commonly preferred Long COVID definition was the definition by the World Health Organization. Other preferred definitions mentioned at least once include the ones by the Centers for Disease Control and Prevention, National Institute for Health and Care Excellence, Department of Health and Human Services, Body Politic, Solve ME/CFS Initiative, American Medical Association, Long COVID Alliance, and the Government of Canada.

Do you like any Long COVID definitions more than the current USG working definition? (n=661)
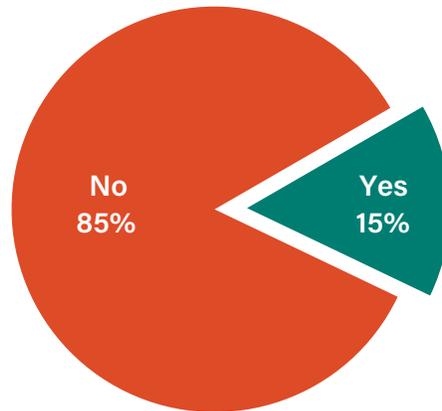
Figure 14. Assessing the favorability of other Long COVID definitions

Specific Phrases in the Working Definition

Summary: Overall, most questionnaire respondents would keep the individual phrases as-is or they would make minor modifications. However, a smaller minority favored major changes to four phrases or dropping them from the definition entirely. Both the questionnaire respondents and focus group participants identified similar topics when asked what they would change (e.g., more information about impairment, specific signs and symptoms, altered time of onset).

Key findings from the Questionnaire

The questionnaire asked respondents to consider the constituent parts of the current working definition. Respondents were asked if each phrase should be included in a future definition without changes, with only minor changes, with many changes, or should not be included at all. Overall, over half of respondents felt that six of the seven parts of the working definition for Long COVID do not need any changes. A minority favored major changes to four phrases, or dropping them from the definition entirely.

The following statements are from the USG's current working definition for Long COVID. Do you think they should be included in a future definition for Long COVID?
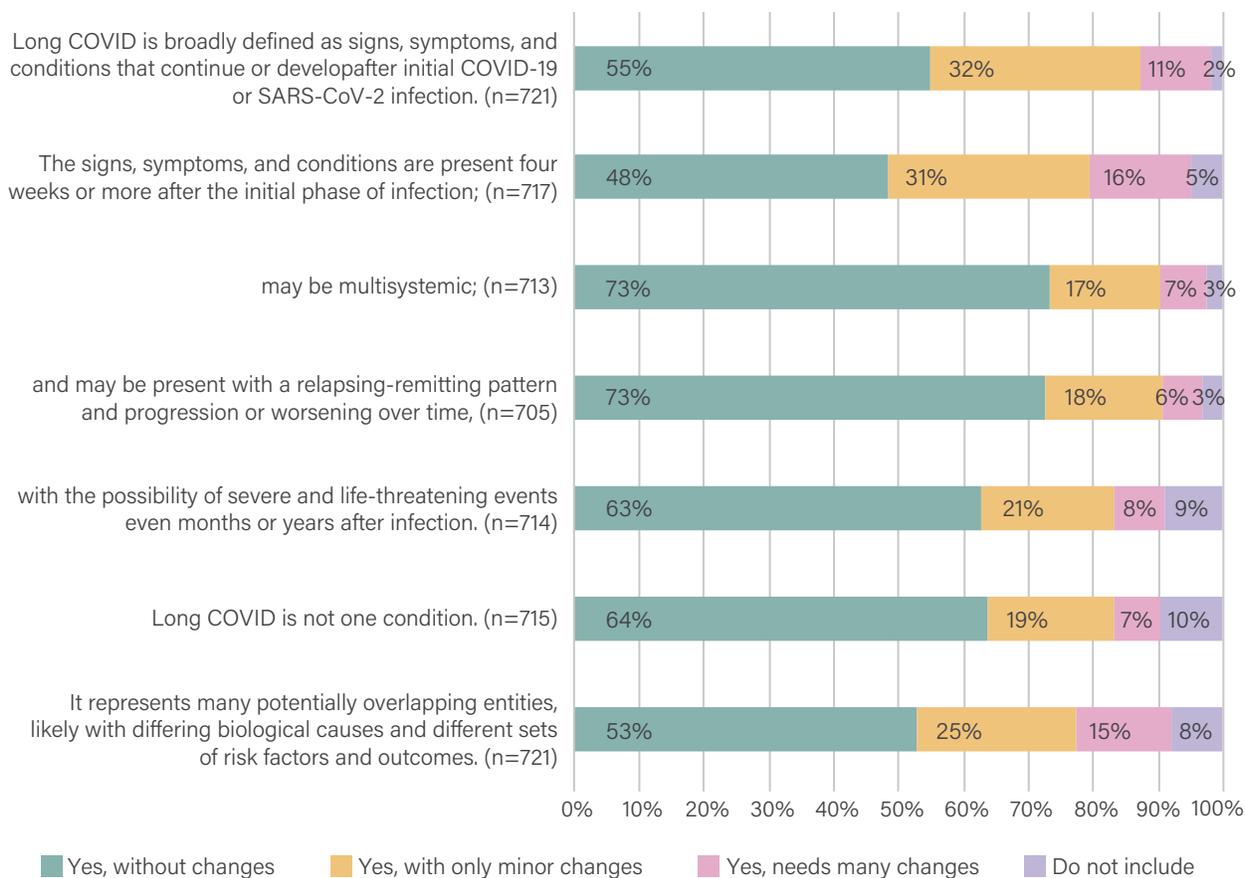

Statement	Yes, without changes	Yes, with only minor changes	Yes, needs many changes	Do not include
Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. (n=721)	55%	32%	11%	2%
The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; (n=717)	48%	31%	16%	5%
may be multisystemic; (n=713)	73%	17%	7%	3%
and may be present with a relapsing-remitting pattern and progression or worsening over time, (n=705)	73%	18%	6%	3%
with the possibility of severe and life-threatening events even months or years after infection. (n=714)	63%	21%	8%	9%
Long COVID is not one condition. (n=715)	64%	19%	7%	10%
It represents many potentially overlapping entities, likely with differing biological causes and different sets of risk factors and outcomes. (n=721)	53%	25%	15%	8%

Figure 15. Recommendations about what to keep in a future definition for Long COVID

Questionnaire results show that a majority of respondents who were invited to respond based on their expertise with Long COVID thought that certain aspects of the working definition could be included in a future definition for Long COVID without changes (Table 1). Invited respondents in particular, however, recommended that other sections of the current working definition be revised either with minor changes, many changes, or should have their inclusion reevaluated all together.

Key findings from the Focus Groups

See below for focus group comments on specific phrases in the working definition such as multisystemic, relapsing and remitting, life-threatening, overlapping entities, four weeks, and more.

Table 1. Invited questionnaire respondents' three most common recommendations for a future Long COVID definition, within each category: include without changes, with minor changes, make many changes, or do not include.

Respondent recommendations about specific elements of the current USG definition for Long COVID.

Retain *without changes*	Respondent support
May be multisystemic;	68%
And may be present with a relapsing-remitting pattern and progression or worsening over time,	59%
Long COVID is not one condition.	59%
Make *minor changes*	
Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection.	35%
and may be present with a relapsing-remitting pattern and progression or worsening over time,	26%
It represents many potentially overlapping entities, likely with differing biological causes and different sets of risk factors and outcomes.	26%
Make *many changes*	
The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection;	29%
It represents many potentially overlapping entities, likely with differing biological causes and different sets of risk factors and outcomes.	16%
Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection.	11%
Do *not include*	
with the possibility of severe and life-threatening events even months or years after infection.	28%
It represents many potentially overlapping entities, likely with differing biological causes and different sets of risk factors and outcomes.	11%
Long COVID is not one condition.	9%

KEY ASPECTS OF THE DEFINITION

Attribution to Infection and Biomarkers

Summary: There were mixed levels of support for updating the definition to include how a COVID-19 infection was confirmed prior to developing Long COVID. Less than a third of questionnaire respondents thought that adding this would improve the definition. Over a third agreed that adding specific biomarkers, however, would improve the definition. Focus group participants raised that laboratory confirmation of COVID-19 infection would be too exclusive. Some suggested that a patient-centered definition that attributes infection according to the patient's lived experience of the illness would be more appropriate.

Key findings from the Questionnaire

The questionnaire asked respondents how the current definition for Long COVID could be improved. Respondents were given a list of possible options and they could select as many as they agreed with. When asked if adding attribution to infection would improve the definition for Long COVID, fewer than one-third of questionnaire respondents agreed. This feeling varied among group affiliations (Figure 16).

When asked whether specific biomarkers should be included to improve the definition for Long COVID, about one-third of overall respondents agreed with this approach. Agreement varied by specific group affiliations (Figure 16).

How might the current definition for Long COVID be improved (Attribution to Infection) (n=743)
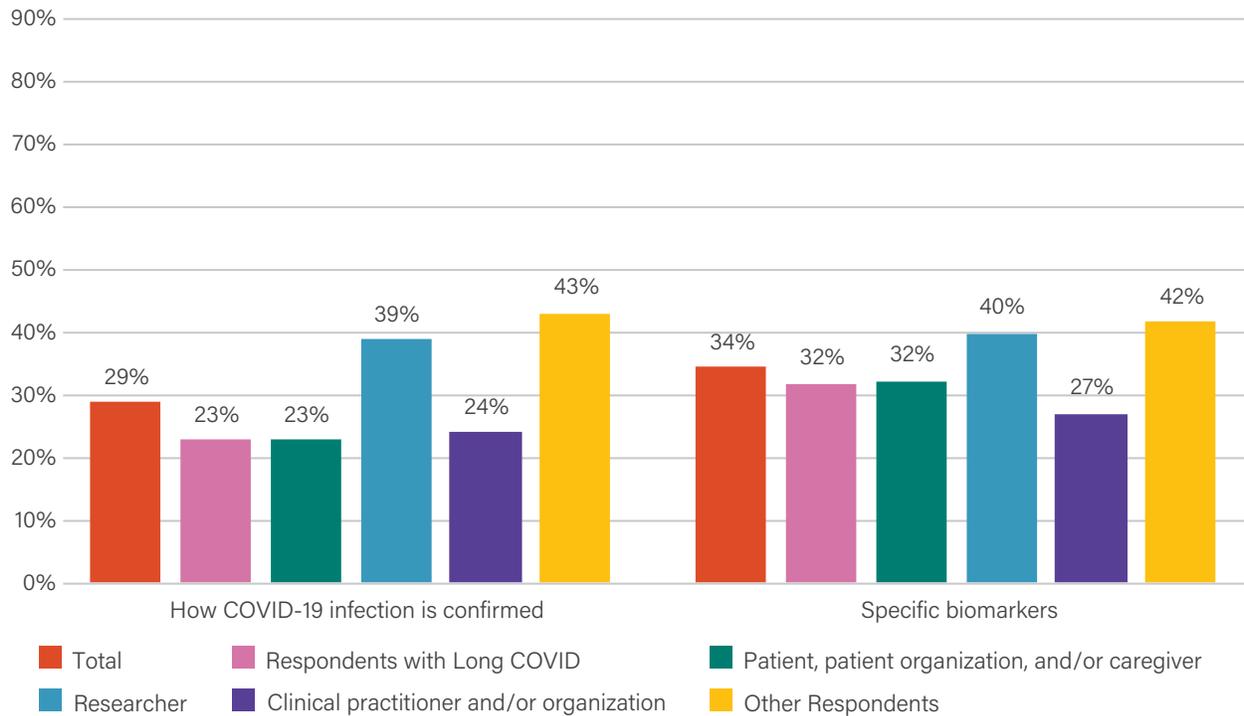
Figure 16. Questionnaire responses to how the definition for Long COVID could be improved related to the attribution of infection

Key findings from the Focus Groups

Focus group participants shared that the definition for Long COVID needs to be inclusive when attributing it to a COVID-19 infection. Participants noted that existing barriers to healthcare, and that the ubiquity of at-home COVID-19 test kits mean that many people who may have Long COVID were never diagnosed by a doctor.

Additionally, other respondents highlighted that, as over 94% of the American population has a history of COVID-19,[ix] requiring a laboratory confirmation of a COVID-19 infection may result in barriers to health coverage and/or benefits. Many Long COVID patients tested at home or had COVID-19 before testing was available. One focus group participant shared, *"A lot of marginalized people didn't have access to testing, and a lot of people in city centers got infected very early in the pandemic when testing was not available. That includes some of our poorest citizens."*

In one focus group, there was a feeling that laboratory confirmation of COVID-19 infection is too exclusive and a patient-centered definition is more appropriate. Participants supported including phrases such as *history of confirmed or suspected COVID-19* or *probable COVID-19* to make the definition more inclusive.

Focus group participants also noted that there are few biomarkers that can be easily tested with a high degree of sensitivity to assess COVID-19 infection and wondered how feasible that would be. *"We don't have good biomarkers,"* said one participant, *"and I anticipate in a few years' time, we probably will have more in the way of biomarkers to help define at least some of the taxonomy or phenotypes, or whatever we call them. I think it's good to acknowledge that we anticipate the evolution of the definition."*

Long COVID Diagnosis and Alternate Diagnoses

Summary: Participant input was varied on the topic of how the diagnosis of Long COVID should be approached in the definition. Patients, caregivers, and patient advocates recommended prioritizing the patient's experience and judgment. Researchers, clinical practitioners, and practitioner organizations recommended focusing diagnosis on the body systems affected after a COVID-19 infection and ensuring patients are screened for other known post-viral illnesses.

Key findings from the Questionnaire

Questionnaire respondents were given a list of changes that could be made to improve the current definition and were asked to select the one(s) that they agreed with. When asked about whether the definition needs language about excluding alternative diagnostics, only one-quarter of questionnaire respondents agreed. However, this sentiment varied greatly by the respondent's group affiliation (Figure 17).

Respondents were also asked whether it should be the patient's judgment on whether they have Long COVID or not. Overall, one-quarter of respondents agreed. Notably, about a third of patients, patient organizations, and/or caregivers and the general public agreed with that aspect of diagnosis, while researchers and clinical practitioners and/or organizations were much less likely to agree (Figure 17).

Asked whether the Long COVID definition needs a statement that other diagnoses should be considered before a Long COVID diagnosis (differential diagnosis), only a fifth of all respondents agreed. However, this too was driven by the respondent's group affiliation (Figure 17).

How might the current definition for Long COVID be improved? (Diagnosis) (n=743)
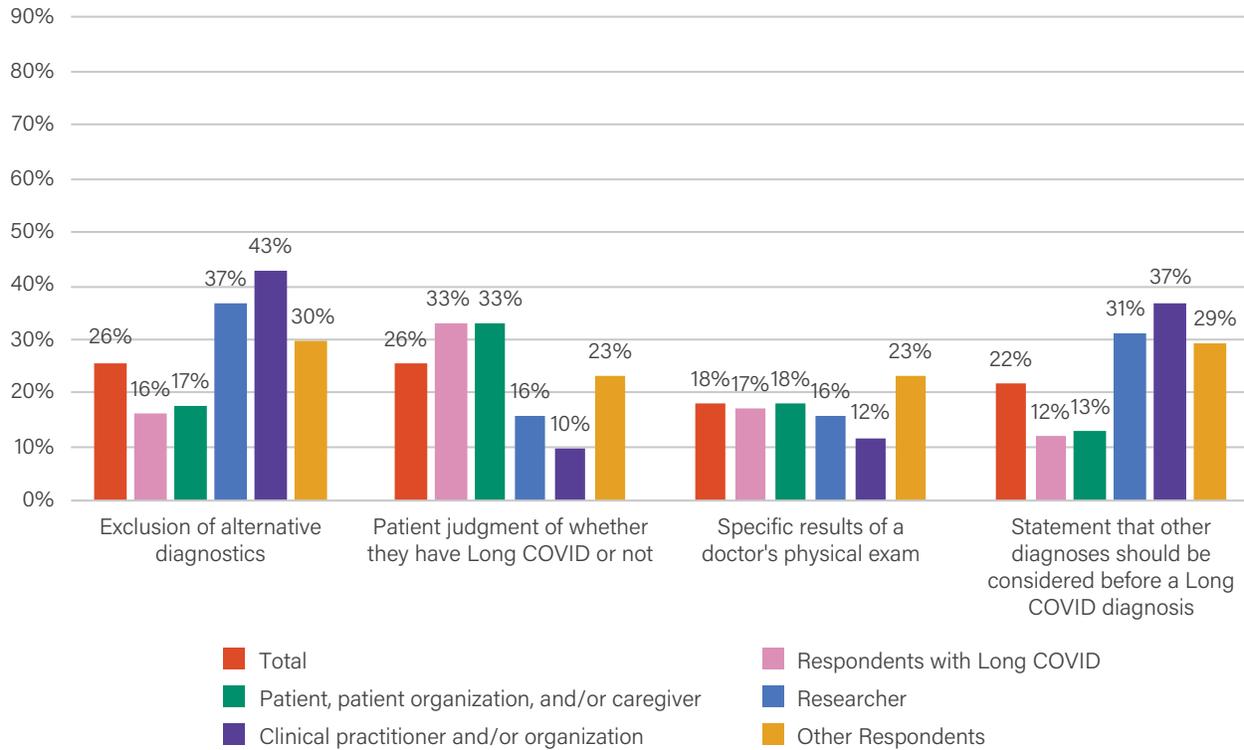

Figure 17. Questionnaire responses to how the definition for Long COVID could be improved related to diagnosis

Key findings from the Focus Groups

Focus group participants also had differing opinions about whether other diagnoses should be considered before a Long COVID diagnosis. For instance, one participant said, "*we have unfortunately seen many important diagnoses missed because they were attributed to post-acute COVID, and then people wait for a Long COVID clinic, and they get their lung cancer diagnosed or something like that. I wouldn't make it a diagnosis of exclusion. I would encourage providers that it should have language that it says after evaluation for other potential conclusions.*"

Focus group participants also highlighted the importance of differentiating existing post-viral diagnoses from Long COVID diagnoses (differential diagnoses). For instance, one focus group talked about screening the Long COVID population for other known post-viral conditions like postural tachycardia syndrome (POTS), orthostatic intolerance and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation symptoms (MCAS), post-intensive care syndrome (PICS) syndrome, etc.

Additionally, participants suggested separating diagnoses based on their organ systems. Some focus group participants also suggested incorporating signs, symptoms, and conditions into the definition, including statements like, *"Separate all the organ system-specific diagnoses that we're considering, whether it's POTS (postural tachycardia syndrome) or Afib (Atrial Fibrillation) for cardiology, and keep those almost just as a diagnosis of that organ system as opposed to a Long COVID diagnosis. Then leave all the non-specific COVID-related non-organ system [symptoms] in that dumping term Long COVID… We know that after viral infections, you can get a lot of post-viral residual effects that are non-specific for several weeks out. That's one of the suggestions that I think could work."*

Onset

Summary: Participants broadly agreed that there does need to be language about the onset of Long COVID. However, many viewed the 4-week window used in the working definition as too short. Others cautioned that including a specific timeline of onset might result in unintentionally excluding patients from disability benefits, and may also obscure how different symptoms of Long COVID may emerge in a range of time frames.

Key findings from the Questionnaire

Most questionnaire respondents recommended the Long COVID definition should include information about the onset of the disease. There were differing viewpoints, however, on how to do that. One respondent indicated that *"the time frame is critical. I think 4 weeks is too short. WHO uses 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation. I think this is much better."*

Other respondents mentioned that the current language regarding onset of Long COVID symptoms is too vague for users or the definition. Other respondents also added that it might be beneficial to differentiate between the onset of different phases of Long COVID, particularly since some patients with severe illnesses or hospitalization may experience acute conditions near to or exceeding four weeks since infection.

When asked if the definition should include a description of the earliest time after infection that a symptom can be considered Long COVID, 51% of questionnaire respondents agreed (Figure 18). Researchers, clinical practitioners and/or organizations, and all other respondents were more receptive to this suggestion than were patients, patient organizations, and/or caregivers.

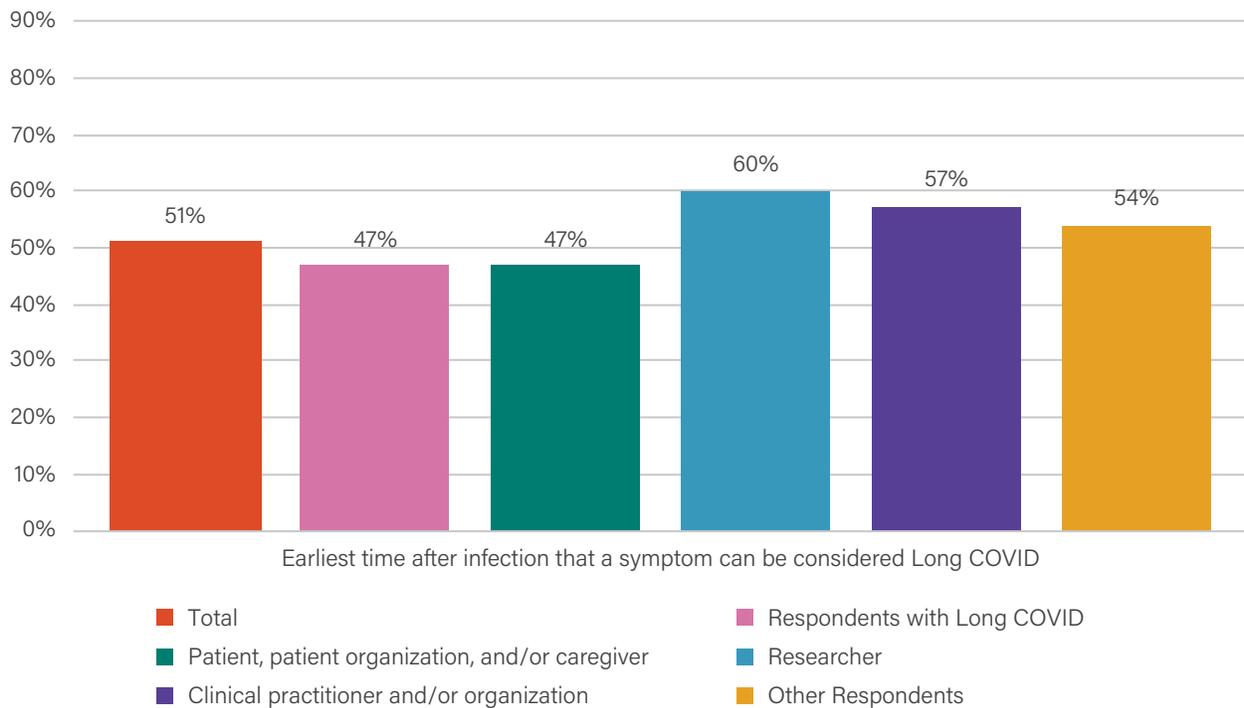## How might the current definition for Long COVID be improved? (Onset) (n=766)

Figure 18. Questionnaire responses to how the definition for Long COVID could be improved related to onset

Key findings from the Focus Groups

Focus group participants explored the advantages and disadvantages of a four-week onset timeline. For instance, some indicated that, *"if early treatment will help to decrease later incidence, [physicians] need to identify people early."* Disadvantages included that having a four-week timeline for the start of Long COVID was too short, particularly since some illnesses will resolve shortly after. "*Four weeks is not enough time for a Long COVID diagnosis. Since the natural history is that people get better over time, you don't want to spend a lot of time and effort on people who are going to get better in a little while."*

Additionally, other participants mentioned that a four-week timeline does not necessarily cover symptoms that do not start with an acute COVID-19 infection, such as neurological symptoms.

Some called for the committee to, *"Carefully review timeframe of onset/duration and consider defining acute, post-acute, and Long COVID separately."* Focus group participants suggested approaches such as infection related-symptoms (up to 4–5 weeks), acute post-COVID symptoms (from week 5 to week 12), long post-COVID symptoms (from week 12 to week 24), and persistent post-COVID symptoms (lasting more than 24 weeks).

Others recommended using a patient-centered approach, *"How we define the onset I think is the trickiest part. Can we just say 'the patient said this is the onset?' Because that's how it usually happens with most syndromes - and syndromes are just what we don't have a defined cause for at the moment. Because if you start narrowing down what we mean by the onset, that's when, from a patient's point of view, insurance companies can play around with that."*

Duration

Summary: Participants raised that the duration of Long COVID is an important but ambiguous topic that needs to be addressed in the definition. Focus group participants noted that Long COVID may manifest in different ways and last different lengths of times, and it is yet unknown whether Long COVID symptoms will persist indefinitely. Focus group participants suggested pairing symptoms by their phase of onset (acute, subacute, chronic) with the duration of those symptoms. Respondents of the questionnaire called for a Long COVID definition to focus more on long-term and lifelong symptoms than on short-term symptoms.

Key findings from the Questionnaire

When respondents were given a list of options that might improve the definition for Long COVID, more than half of all respondents suggested detailing the duration of long-term symptoms (Figure 19). When asked about whether the inclusion of the duration of short term symptoms would improve the definition for Long COVID, just over a quarter of respondents agreed. Among patients, patient organizations, and/or caregivers and clinical practitioners and/ or organization respondents, fewer than one in four agreed. However, researchers and all other respondents were more likely to agree with the inclusion of short term duration symptoms in the definition.
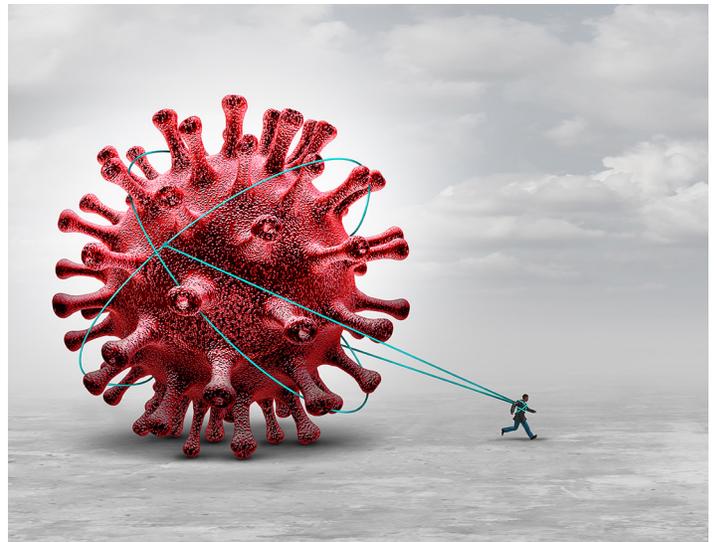
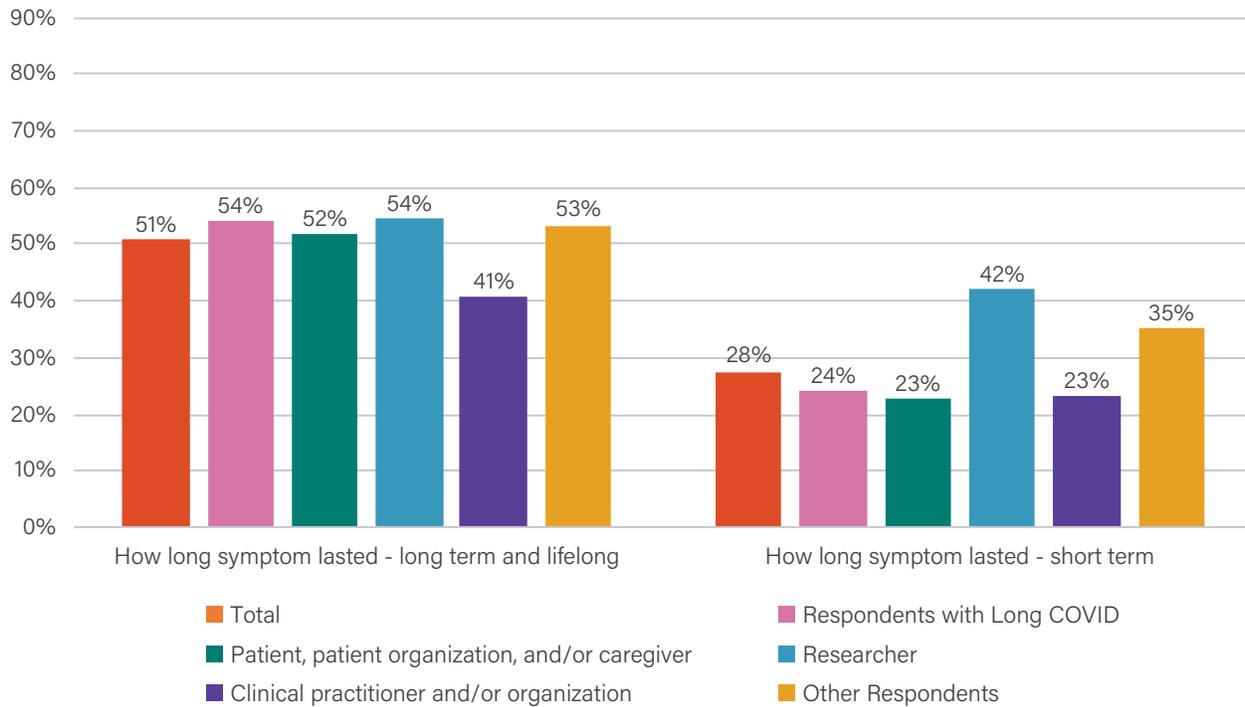## How might the current definition for Long COVID be improved? (Duration) (n=766)

Figure 19. Questionnaire responses to how the definition for Long COVID could be improved related to duration

Key findings from the Focus Groups

Many participants in the focus groups stressed the importance of understanding and prioritizing long-term symptoms over the short-term symptoms that appear after the initial COVID-19 infection. In the researcher focus group, one participant added: *"There are people for whom acute symptoms fade, and they have a period of wellness and then their long-term symptoms arise several months after the original acute infection. It's not the most common pattern, but it's common enough that we keep seeing it, and I'm not sure that the timeline that we have here really will accommodate that."*

Additionally, a focus group participant shared, *"We also know from [Office for National Statistics] ONS data and other data that about half of the people who are sick at one month will recover by three months. That is maybe a cause to push the onset and duration a little bit out."*

Symptoms

Summary: Participants considered it important to include the most common symptoms within the definition of Long COVID, with an emphasis on the relapsing and remitting nature of Long COVID symptoms. A number of focus groups noted that many people will understand the illness through symptoms, from patients experiencing symptoms and living with chronic conditions, to clinicians diagnosing patients, to researchers understanding disease etiology, to administrators and policymakers disbursing benefits and establishing eligibility guidelines. Questionnaire respondents also shared the importance of including duration and frequency of symptoms in the definition.

Key findings from the Questionnaire

Questionnaire participants felt strongly that any definition should include specific symptoms of Long COVID. While the understanding of Long COVID symptomatology is still evolving, respondents were asked *how* symptoms should be included in a Long COVID definition. More than three quarters of all respondents agreed that the Long COVID definition should include the most common symptoms. One respondent who agreed with this statement continued: *"It's impossible to give the full range of symptoms & experiences — so futile to try and list; instead carve off clearly defined subgroups and give them specific diagnoses e.g., lung damage following SARS-CoV-2 infection, and for the rest assume [Long COVID] can cause any conceivable symptom. Patients' symptoms need to be investigated irrespective of whether they made it on to a list or not BUT one symptom needs to be highlighted because few doctors understand it and it's very common and serious: post exertional malaise."*

> It's impossible to give the full range of symptoms & experiences — so futile to try and list; instead carve off clearly defined subgroups and give them specific diagnoses.
>
> — Focus Group Participant

The questionnaire asked respondents whether or not the definition for Long COVID would be improved by including how often the symptoms happen. Overall, about one-third of respondents agreed that including the frequency of Long COVID symptoms would improve the definition. However, fewer clinical practitioners and/or organizations and other respondents agreed with this.

How might the current definition of Long COVID be improved? (Symptom frequency) (n=766)

Legend:
- Total
- Respondents with Long COVID
- Patient, patient organization, and/or caregiver
- Researcher
- Clinical practitioner and/or organization
- Other Respondents

Values shown: 37%, 40%, 39%, 42%, 29%, 33%
X-axis label: How often the symptom happen
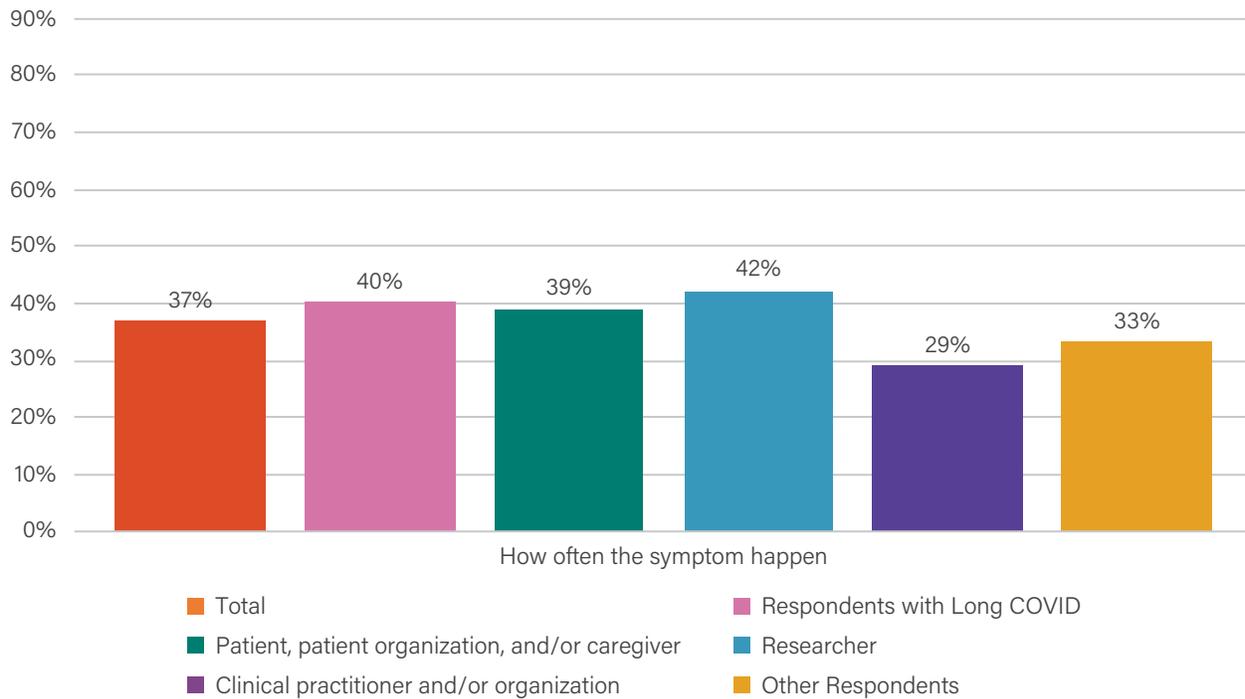
Figure 20. Questionnaire responses to how the definition for Long COVID could be improved related to symptoms

Additionally, respondents stressed the importance of including language about new symptoms being linked to a COVID-19 infection. In the questionnaire, nearly 8 in 10 respondents either strongly or somewhat agreed with having a statement about new symptoms being linked to a COVID-19 infection, as opposed to less than 1 in 10 either strongly or somewhat disagreeing.

Key findings from the Focus Groups

Respondents from different focus groups had mixed opinions about keeping "multisystemic" in the definition instead of specifically mentioning symptoms. One participant said, *"Multisystemic is a very broad term–we can't think of any illness that doesn't affect many systems. But capturing the involvement of multiple systems, multiple conditions and multiple biological causes, risk factors and outcomes is important in the current definition."*

They also stressed different reasons for the importance of *how* symptoms would be included in the definition for Long COVID. For instance, patients highlighted how including common symptoms might improve broad understanding about Long COVID: *"[the definition could include] a subheading of some specific examples or perhaps most common symptoms, just to help clarify what some of the concerns might be that patients are experiencing."*

Patients also discussed how including a list of possible symptoms and diseases associated with Long COVID would help them and the general public understand the breadth and severity of Long COVID. Related, a participant shared a clinical importance for including the most typical symptoms: *"I do think that listing the three or four major symptoms that most studies are showing — brain fog, fatigue, shortness of breath — should be part of the definition."* Another participant recommended, "C*ognitive dysfunction is as important to include as physical symptoms, especially since cognitive dysfunction is highly stigmatized."*

Others however, raised the drawbacks of including specific symptoms in a Long COVID definition: *"I think there's both an advantage and a real danger of listing specific symptoms because there's then a tendency for people to fixate on the symptoms that are listed and ignore the several hundred that are not listed, and that can do a tremendous disservice to people. A lot of my work has been with the [American Disability Act] and cancer patients and certainly the revision of the ADA after its inception was to correct some of the problem of loopholes, where people were falling through the cracks of the definition of disability and therefore not entitled to disability benefits."*

Many patients and others in the focus group approved of the "relapsing-remitting" language in the current definition of Long COVID. Some added that their relapsing-remitting symptoms affected their ability to receive appropriate care from physicians who did not understand this pattern, or who were perceived to be skeptical. For instance, one focus group participant added, *"Many of my patients, when we would talk about the definition, would find it validating that the definition itself from the WHO said that the symptoms were intermittent. I think that's a key part of the definition, because the patients have often experienced medical gaslighting. A lot of that is due to the inconsistency of the symptoms. I liked having that phrase in the definition that I can tell my patients, 'Look, that's part of this condition, and this is what you could show your employer and your family.' I like that."*

Participants in focus groups found that using the phrase "entities", when describing comorbidity, was too vague to be helpful. They called for using accurate terminology like syndrome, condition, disease, etc.

> Patients discussed how including a list of possible symptoms and diseases associated with Long COVID would help them and the general public understand the breadth and severity of Long COVID.

Impairments

Impairments. Participants consistently called for refining the concept of impairment in the definition for Long COVID, as many patients find that their symptoms interfere with daily functioning (such as socially, occupationally, their mental health, and other areas of daily life). Focus group participants stressed that including, or not including, impairment in a Long COVID definition could impact degrees of access to disability accommodations. There was mixed support in the questionnaire about whether the definition would be improved by adding language about how bad or severe the symptoms are.

Key findings from the Questionnaire

Over three-quarters of respondents overwhelmingly recommended that the Long COVID definition should include severe impacts on normal daily activities. This included almost 9 out of 10 patients, patient organizations, and/or caregivers.

Similarly, respondents recommended that there should at least be a statement about a COVID-19 infection making pre-existing health conditions worse. This included 8 out of 10 patients, patient organizations, and/or caregivers.

When asked if the definition for Long COVID should include common comorbidities, half of respondents agreed (Figure 21). Although agreement was similar among group affiliations, it was higher for the general public and patients, patient organizations, and/or caregivers than it was for researchers or clinical practitioners and/or organizations.

Questionnaire respondents were also asked whether the definition would be improved by adding language about how severe the symptoms are. Overall, just under half of respondents indicated that this would improve the definition. There were differences in opinion between group affiliations where at least half the patients, patient organizations, and/or caregivers and researchers thought it would improve the definition, while only one-third of clinical practitioners and/or organization thought the same.

Finally, respondents were asked if it would improve the definition to include language about the impact on daily activities that Long COVID may cause. Among all respondents, 7 in 10 agreed with this addition. Similar to the previous question, however, clinical practitioners and/or organizations were less likely to agree with this statement.

> Over three-quarters of questionnaire respondents overwhelmingly recommended that the Long COVID definition should include severe impacts on normal daily activities.

How might the current definition for Long COVID be improved? (Impairment) (n=766)
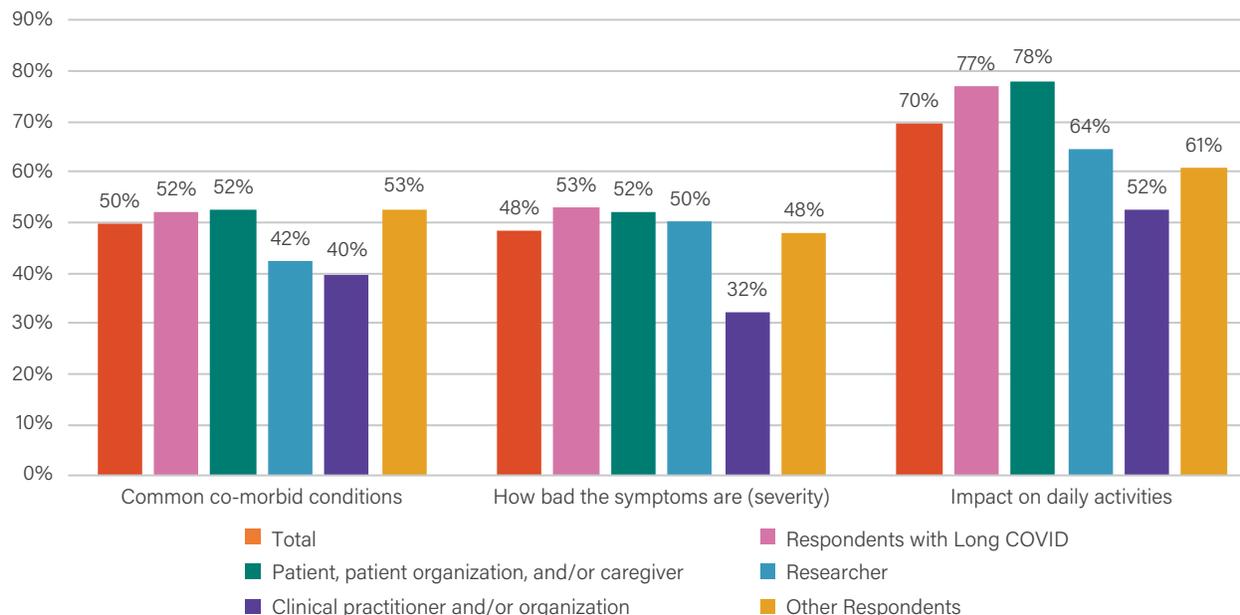
Figure 21. Questionnaire responses to how the definition for Long COVID could be improved related to impairment

Key findings from the Focus Groups

Focus group participants said that it was important to include language about Long COVID symptoms interfering with daily functioning, including socially, occupationally, their mental health, and other areas of daily life. For example, a participant said, *"What we need to be able to do with the definition, or a subset of it, is determine a degree of impairment because so many people are disabled."* Another underlined the importance of including impairment in the definition, because many of the symptoms are invisible, *"When I think about Long COVID, it's about the symptoms that are causing functional impairment that you do not see."*

Focus groups generally disliked the term "life-threatening", suggesting it could engender fear and anxiety. One participant shared, *"The last thing I think about is whether this Long COVID thing is life-threatening. I think that's superfluous in this definition and may be misleading."* Many suggested "life-threatening" could be changed to describe the impairment that is typical with Long COVID.

Focus groups raised the point that the inclusion of impairment in a Long COVID definition could impact degrees of access to disability accommodations. In the patients focus group, for instance, there were discussions about disability benefits, insurance, accommodations, and claims. For the participants, it was important to differentiate who is eligible for disability benefits, whether it is short or long term disability. There were also concerns how a new definition might affect what their insurance may cover or decline to cover. One participant noted that the work being done to improve the definition of Long COVID should be done in coordination with the Social Security Administration (SSA) to ensure that Long COVID patients are receiving the best care that they are entitled to.

CONSIDERATIONS FOR ANY CHANGES TO THE DEFINITION

Equity

Health equity is about "understanding how racism, ableism, and discrimination, along with provider bias, are associated with health care access, symptom recognition, disease progression, and severity of Long COVID in communities that are disproportionately disadvantaged and other people who are underserved, as well as improving data collection, integration, and use so that data can be disaggregated for these populations who are at higher risk and used to inform equity-centered response decisions."[x]

Summary: Questionnaire respondents and focus group participants agreed that it was important that the definition applies equitably to all people with Long COVID. Both sets of participants raised that requiring an official COVID-19 diagnosis may be a burden or impossible in many situations, as well as that a definition for Long COVID needs to recognize that different people have different symptoms and experiences. When asked if the definition for Long COVID should use plain language — understandable to persons of any education level — 9 in 10 respondents agreed.

Key findings from the Questionnaire

When asked about the inclusivity of a definition for Long COVID, 9 in 10 of questionnaire respondents said that a definition for Long COVID needs to recognize that different people have different symptoms and experiences.

When asked if the definition should avoid excluding the full range of symptoms and experiences of Long COVID, nearly half of questionnaire respondents agreed with this sentiment. Over half of respondents agreed from health policy organizations, as well as patients, patient organizations, and/or caregivers.

The questionnaire also asked about equity and the attribution of infection, namely if the definition should require people to have tested positive for COVID-19. Overall, two-thirds of respondents thought the definition should not require a definitive diagnosis for COVID-19. Three-quarters of patients, patient organizations, and/or caregivers recommended this, while just about half of researchers and clinical practitioners and/or organizations did so. A comment received in the questionnaire was, *"Recognize that there is a lack of diagnostic tests available; that even if they are available, your doctor may not be willing to order them for you; that many people cannot afford testing; that many of the tests Long COVID patients are sent come back [negative] and then we are told there is nothing wrong with us. Proper diagnostic tests don't seem to be able to find anything. And that medical gaslighting is a big issue."*

All respondent affiliations had broad agreement that the definition should recognize that groups with a higher likelihood of the chronic illnesses associated with Long COVID should not be overlooked for a Long COVID diagnosis, with 57% overall agreeing.

When asked if it was important for the definition to reflect how Long COVID could cause money problems for some people, 70% of patients, patient organizations, and/or caregivers thought that was important, while just about one-quarter of public health agency respondents thought so (Figure 22).

When asked whether the definition should recognize that things like poverty, race, and where you live can affect your chances of developing Long COVID, overall over half agreed with this sentiment. Of note, half of patients, patient organizations, and/or caregivers agreed with this, but 85% of health policy organization respondents, 63% of researchers, 63% of public health agency respondents, and 59% of clinical practitioners and/or organizations thought that this should be kept in mind when developing a definition for Long COVID.

What should we keep in mind to make sure the definition is inclusive and supports all people with Long COVID to get healthcare, workplace support, or the other things they need? (Select all that apply) (n=757)

Category	Percentage
Recognize that different people have different symptoms and experiences	92%
Don't only include people who tested positive for COVID-19 in the definition, because not everyone has access to tests	65%
Think about how Long COVID could cause money problems for some people	58%
Consider that some groups have a higher likelihood of chronic illness (e.g., diabetes) but they shouldn't be overlooked if this symptom is also common with Long COVID	57%
Recognize that things like poverty, race, and where you live can affect your chances of developing Long COVID	55%
Avoid a definition that excludes the full range of symptoms and experiences of Long COVID	48%
Other	12%

Figure 22. Assessing the inclusivity of a definition for Long COVID

Comments were also shared about explicitly linking the definition for Long COVID to equity considerations due to the impact that COVID-19 and Long COVID has had at an individual level and also within communities that have less access to care and/or economic resources. One respondent commented, *"It could be helpful to include a specific statement around health equity in Long COVID. That would maybe be a little unusual to include in a definition, but it is important. If not in the definition, somewhere else."*

Participants raised that requiring an official COVID-19 diagnosis may be a burden or impossible in many situations, and using phraseology such as *suspected* or *confirmed COVID-19 infection* or something similar would be more equitable.

Lastly, when asked if the definition for Long COVID should use plain language — understandable to persons of any education level — 9 in 10 respondents agreed.

Key findings from the Focus Groups

Throughout the focus groups, participants shared the importance of ensuring that the definition applies equitably to all people with COVID-19. They raised that requiring an official COVID-19 diagnosis may be a burden or impossible in many situations, and that using phraseology such as *suspected* or *confirmed COVID-19 infection* or something similar would be more equitable.

Related, focus group participants described how some people with Long COVID may not show abnormalities on routine testing, as they have syndromic illnesses that aren't easy to diagnose — and these people should not get dismissed or overlooked.

Additionally, focus group participants wanted the definition to help discern how acute COVID and its sequelae manifest in underrepresented communities — BIPOC,[4] low socio-economic status, LGBTQ+,[5] and those with pre-existing health conditions.

Participants shared that they did not want a definition for Long COVID to make things worse for patients, particularly those in marginalized communities. One health care practitioner said, *"As a person who interacts with patients, who are primarily patients of color, the definition is really important."* Focus groups discussed that the USG's definition of Long COVID has implications on people's access to disability benefits, the ability of students to access accommodations at school, the ability of employees to get workplace accommodations, and more.

Another equity theme in focus groups was that the definition should be patient-centered. Focus group participants suggested balancing pathological measures of Long COVID with patient-centered understandings of the illness. For example, one participant said, *"It should be based on what the person is experiencing that determines whether they qualify for care, not whether they meet a formal definition."*

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4   Black, Indigenous, and People of Color
5   Lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual and other related terms (such as non-binary and pansexual)

Focus groups recommended the definition reflect cultural humility[6,xi] and sensitivity. For example, one focus group member commented, *"Then there's also a cultural aspect in some communities where if you literally are not dropping [to the floor], even if you feel that you're going to drop [to the floor], if you're not on the floor, you're fine to go to work. That is really, really, really problematic with a condition like Long COVID where your prognosis is significantly negatively affected when you try to do something like push through."*

Application of the Definition to Pediatric Populations

Focus group participants described the need to ensure that anyone who contracted COVID-19 and then developed Long COVID would be included in the definition. Of particular concern to focus group participants was the need to ensure that any Long COVID definition would be suitable for children as well as adults.

In the focus groups, participants noted that pediatric cases of Long COVID may present differently than adult cases. Participants were concerned that a definition that does not cover children or does not tell adults how to identify potential indicators of Long COVID is that it may leave children and their families without the necessary access to healthcare that they need. For instance, one participant said, *"the definition of long COVID gives parents the impression that it should happen within the infection phase, that it starts within four weeks. When it comes to syndromes, we often don't see the symptoms of syndromes until three to six months out. Parents are not connecting what they're seeing three and six months out to the fact that the kid had an infection six months ago."*

Participants also called for consistency between the adult definition of Long COVID and any subgrouping for children — i.e., making sure that children with Long COVID conditions still have a diagnosis when they turn 18.

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6 "Cultural humility is a reflective process of understanding one's biases and privileges, managing power imbalances, and maintaining a stance that is open to others in relation to aspects of their cultural identity that are most important to them"

Advice for the National Academies Committee

Respondents in the questionnaire and participants in the focus groups were asked to offer advice to the National Academies' committee charged with examining the USG's working definition for Long COVID.

Key findings from the Focus Groups

Focus group participants shared advice about how to achieve a definition that is both operational for varied uses and widely acceptable to all users of the definition. Although many different themes arose in the discussions, one theme that was consistently heard was that the National Academies committee should **listen and learn from Long COVID patients**. For example, one participant said, *"Do what you're doing — listen to the people who have been experiencing the disease, but also to people who will need to use the definition in their work."*

Another theme that emerged was that for a definition for Long COVID to be successful, the National Academies committee should **consult with disability and healthcare experts**. Focus group participants shared comments such as, *"Talk to SSA about whether any changes to the definition could make it easier to qualify for disability benefits."*[7] Another participant said, *"There is no need to reinvent the wheel. Use the experience from ME/CFS to help formulate the definition after a thorough review of the controlled trials that are out there."*

Focus group participants also emphasized the need to **consider the context in which the definition will be used**. A participant said, *"Remember why you have a definition to begin with. You can't start to form policies until you even know what you're looking at. On some level, it's disingenuous to ask about a definition of COVID without understanding how it's going to interconnect with all sorts of existing structures and policies."*

Another common advice was for the committee to **focus on the necessary attributes of a definition**. One participant stated, *"It is important to consider the different 'needs' of the definition. For example, researchers want reproducibility; clinicians/patients want to help people get treatment."*

Additionally, most participants advised that **the definition needs to be understandable to the public** for it to be used by those who develop it. One participant mentioned, *"Patients need to be able to understand it and see themselves in the definition, because they may need to advocate for themselves or their loved ones for initial care (or continued care or recognition)."*

Other participants went further, suggesting that not only does the definition need to be understandable, but it also **needs to be transparent about our current understanding**. For example, one participant said, *"Use this as an opportunity to be transparent about what we know and what we don't know."*

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7   Upon request of the U.S. Social Security Administration (SSA), a separate National Academies committee is reviewing the long term health impacts stemming from COVID-19 and the implications for the Social Security Administration.

Finally, another major piece of advice given by participants was that refining the definition for Long COVID is just the first step — there needs to be a **plan for the dissemination and adoption of the new definition**. For example, one participant stated, "*In addition to the definition, provide guidance on how the definition should be applied in different settings.*"

Key findings from the Questionnaire

One area of advice for the committee that was explored in the questionnaire was whether the definition should recognize that our understanding of Long COVID is still changing. 9 in 10 questionnaire respondents either strongly or somewhat agreed (Figure 23). This result was consistent across group affiliations.

Recommendations about our current understanding of Long COVID (n=839)
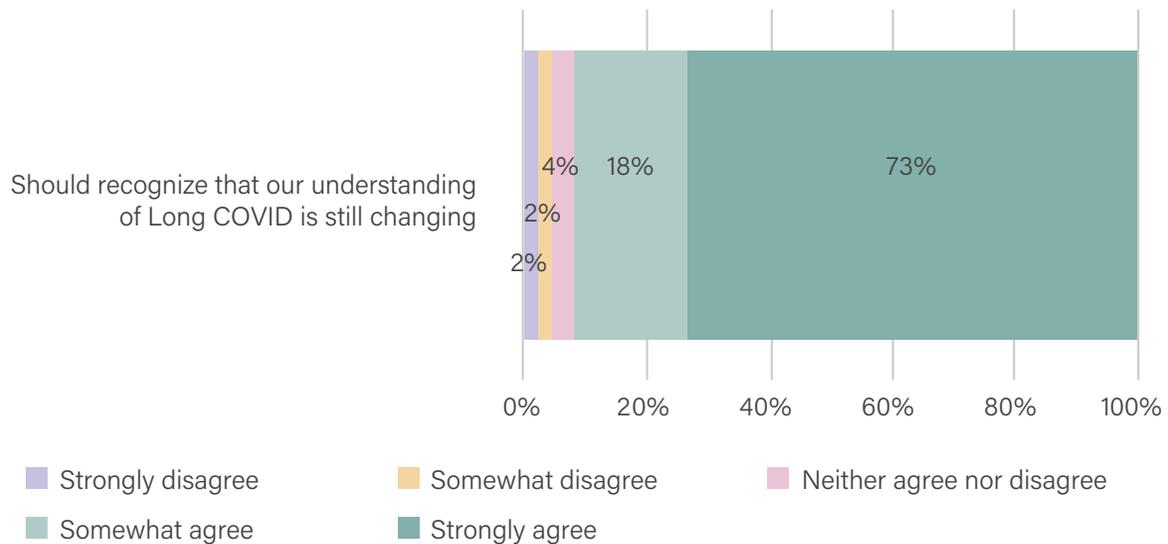
Figure 23. Questionnaire responses to questions about Long COVID and our current understanding

Limitations

The online questionnaire and online focus groups engagement activities both had limitations. The questionnaire's limitations mainly result from the non-representative sample of respondents. While the National Academies invited experts from across the healthcare and science fields who had experience with Long COVID, achieving a 25% response rate, those responses disproportionately were from three main group affiliations. As such, many of the questionnaire analyses were aggregated to all respondents or a select number of group subsets.

All partially completed questionnaires were included in the analysis. Some questions were therefore answered more than others, which limited the ability to subgroup latter questions that received fewer completed answers.

Furthermore, the anonymous link elicited additional responses, and while not inherently a limitation, the optional demographic questions included in the questionnaire were answered by only 46-57% of the anonymous link respondents (vs. 70-87% of email invitees). This limited the ability to assess the overall respondent demographics.

Analysis of the focus groups were limited by the ability of participants to take part in sessions that were not specially within their expertise. For instance, a patient advocate could attend a researcher session, limiting the ability to discern which themes were distinct in different participant groups.

Both engagement activities were offered in a limited timeframe. The authors of this report believe the 24 days that the questionnaire was available was sufficient time to complete it and provide comments — the median time to complete the questionnaire was 12 minutes. The compressed timeframe impacted the research team's ability to send invitations to potential focus group participants in advance of the focus group.

Additionally, the short timeframe did not provide sufficient time for outreach to Spanish-speaking audiences. While a Spanish-language version of the questionnaire was provided, only 11 responses were received (1% of all responses). Some inquiries about the Spanish-speaking focus groups were received, but a Spanish-language focus group was not hosted due lack of registration.

Lastly, compressed engagement timelines resulted in little possibility to respond to gaps in participant representation.

Conclusion

Throughout the stakeholder engagement activities, questionnaire respondents and focus group participants have shared how Long COVID is having a tremendous impact on people living with the illness. The USG's definition for Long COVID is critically important to supporting these patients, as well as their families, workplaces and communities — through research, healthcare, benefits, accommodations, and more.

This committee's work may help bridge some of the important and distinct needs for a definition of Long COVID. As one focus group participant said: "*This is really just a first step. This is really more of a 'creating a shared understanding of what Long COVID is.'*"

Participants clearly highlighted that our understanding of Long COVID is still changing, and the definition should evolve as well. "*The definition has to make clear,*" said a focus group participant, that, "*either during the actual wording of the definition or in parenthesis at the end of the definition, that this is evolving... That tells people that the definition is paramount and fixed as of the data or whatever information is available as of that particular date.*"

As of this date, spring 2023, it is clear that the National Academies committee's work on examining the definition for Long COVID is an important contribution to helping ensure that subsequent steps will meet the needs of people with Long COVID, and those supporting them.

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Appendices

APPENDIX A: FOCUS GROUP PARTICIPANT FEEDBACK

At the end of each focus group, participants were invited to share their feedback about their experience. Using a 5 point rating scale (where 1 = Strongly disagree, 5 = Strongly agree), the overall average result of the following questions was 94% agreement.

Table 2. Focus group participant feedback

I was sufficiently able to express my views	4.8/5
I learned from others' contributions	4.7/5
Project materials and presentations were clear and understandable	4.8/5
Discussions honored participants' lived experiences	4.7/5
Discussions were balanced	4.7/5
Facilitators were not biased	4.9/5
I understand what will happen with the input provided	4.4/5

About the process, focus group participants said:

"This was an excellent exercise and great discovery mechanism to help us better define future complex health issues"

"Thank you so much for the opportunity to learn and help understand this difficult problem!"

"Thank you for including our voice."

APPENDIX B: QUESTIONNAIRE RESPONDENT DEMOGRAPHICS

The questionnaire featured demographic questions to better understand who the respondents were. The demographic questions were prefaced with a disclaimer that they were anonymous and voluntary, however fewer answers were received for these questions than the questions pertaining to Long COVID.

Group Affiliation / Questionnaire Method

Primary group affiliation of respondents by questionnaire method (total answering n=974)
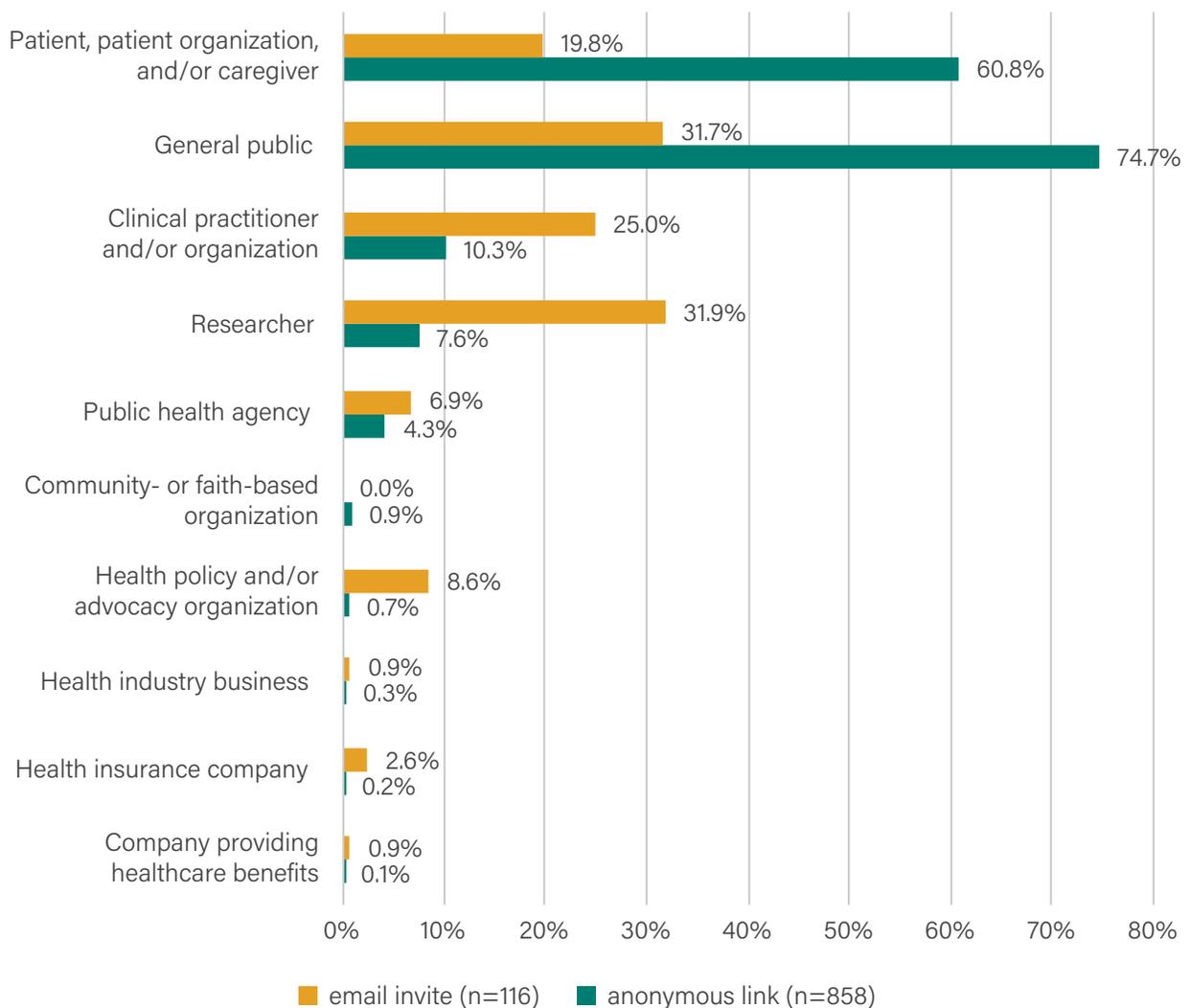
Figure B1. Percentage of responses by primary group affiliation and respondent questionnaire type

Racial background of responses submitted via anonymous link (n=557)

Legend:
- American Indian or Alaska Native or Indigenous or Native American
- Asian or Asian-American
- Black or African-American
- White
- Other (please specify)

Values: 4%, 3%, 4%, 84%, 5%
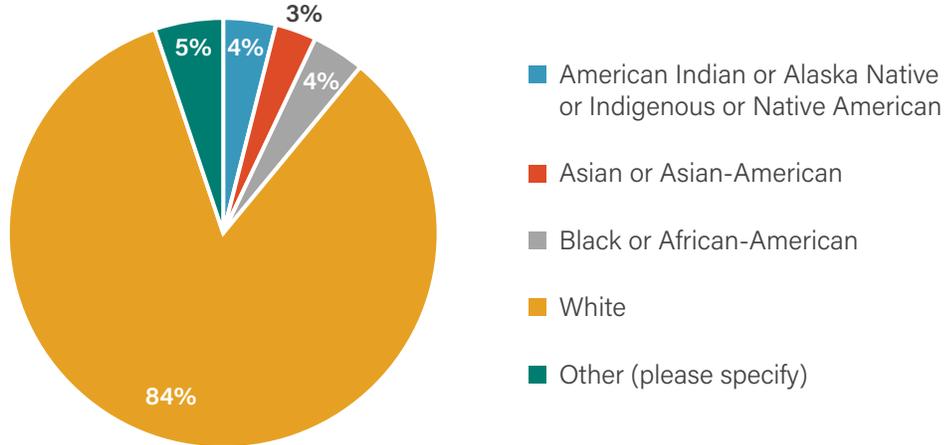
Racial background of responses submitted via email invitation (n=104)

Legend:
- American Indian or Alaska Native or Indigenous or Native American
- Asian or Asian-American
- Black or African-American
- White
- Other (please specify)

Values: 3%, 1%, 14%, 5%, 77%
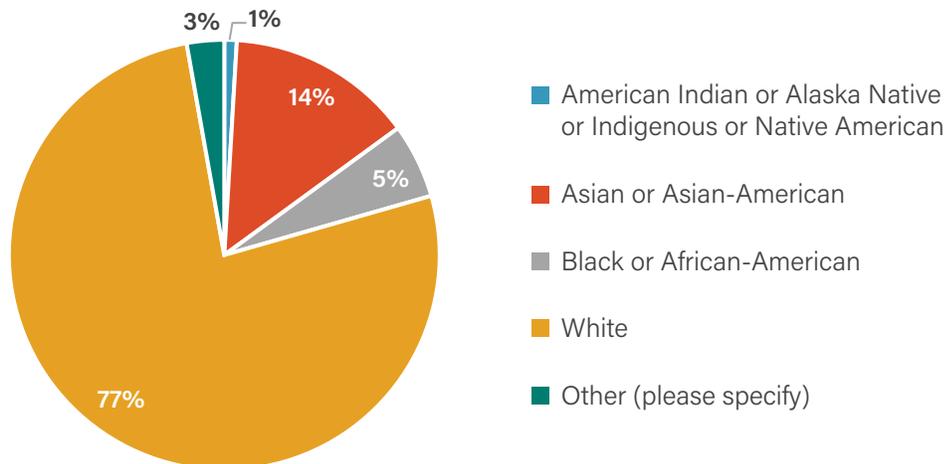
Figure B2. Racial background of respondents by questionnaire type

Distribution of respondents by gender (total n=608)

Legend: anonymous link (n=594), email invite (n=104)

Data values:
- Female: 75.8%, 59.6%
- Male: 21.9%, 40.4%
- Transgender: 0.3%, 0.0%
- I use a different term: 2.0%, 0.0%
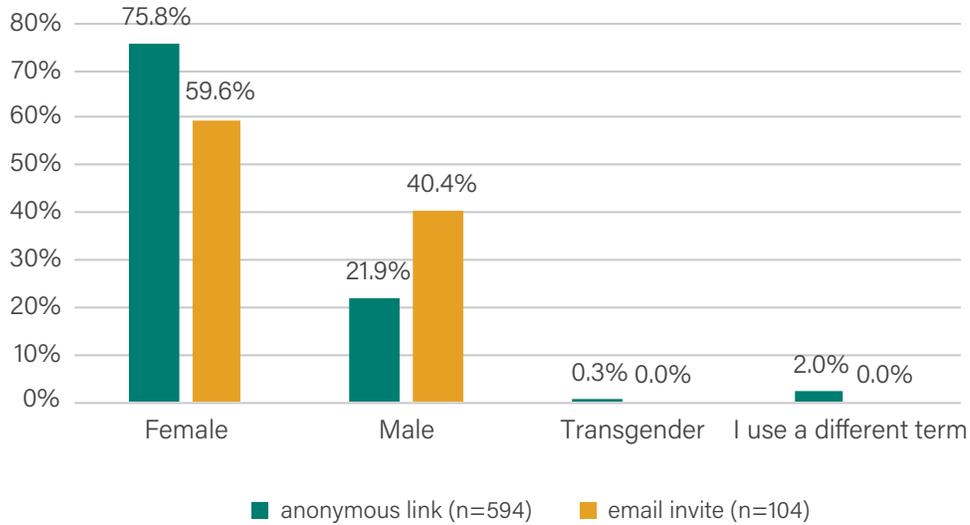
Figure B3. Gender of questionnaire respondents by questionnaire type

Distribution of questionnaire respondent educational attainment
(total n=707)

Legend: anonymous link (n=600), email invite (n=107)

Category	anonymous link (n=600)	email invite (n=107)
Some high school or less	0.3%	0.0%
High school diploma or GED	1.8%	0.0%
Some college, but no degree	6.5%	2.8%
Associates or technical degree	8.7%	0.9%
Bachelor's degree	25.8%	5.6%
Graduate or professional degree	56.8%	90.7%
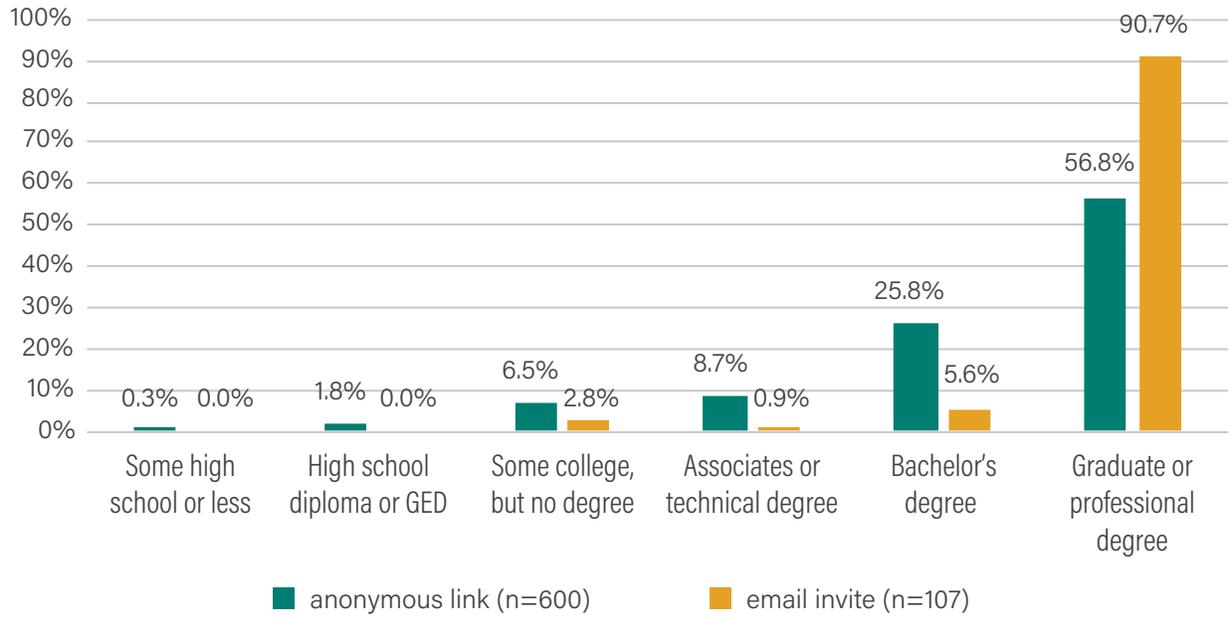
Figure B4. Questionnaire respondent education by questionnaire type

Distribution of questionnaire respondent disability status (total n=666)
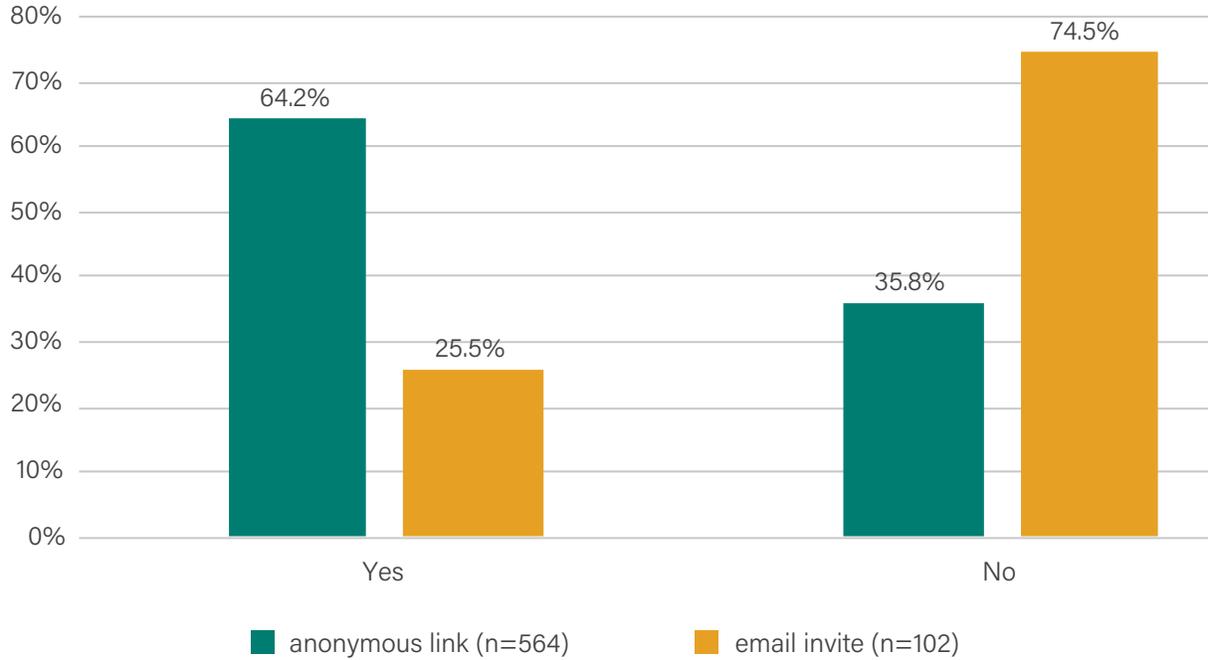
Figure B5. Distribution of respondent disability status by questionnaire type

Distribution of questionnaire respondent age (total n=696)
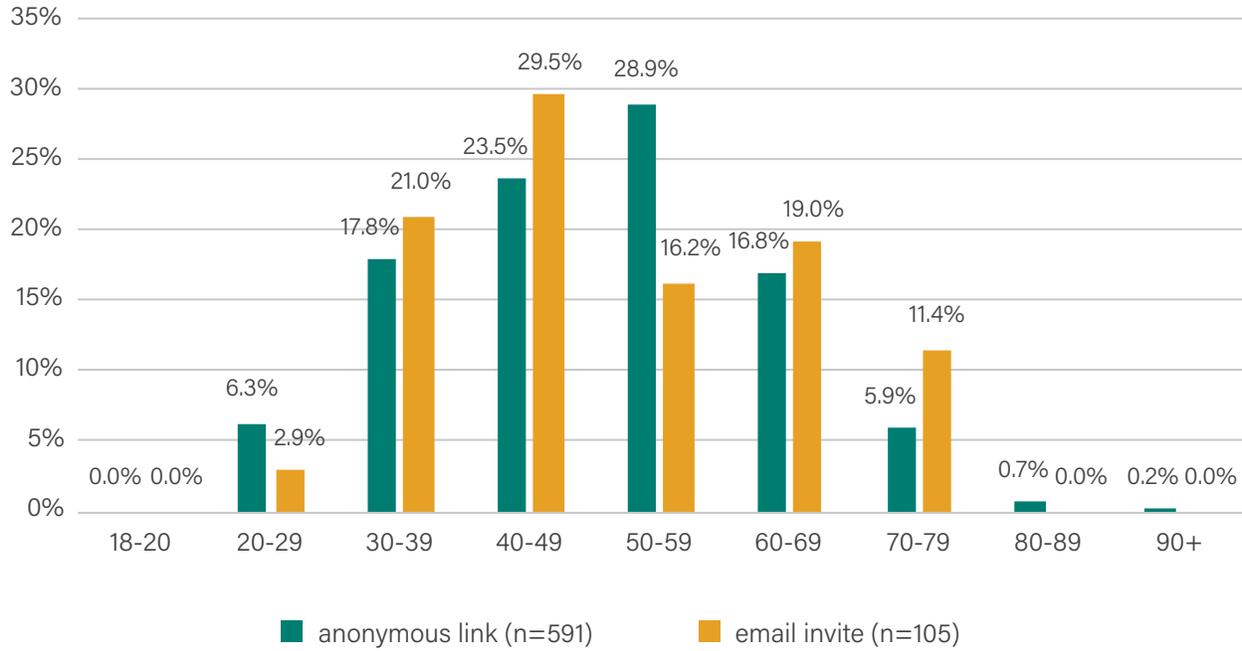
Figure B6. Questionnaire respondent ages by questionnaire type

Distribution of questionnaire respondent urbanness (total n=696)
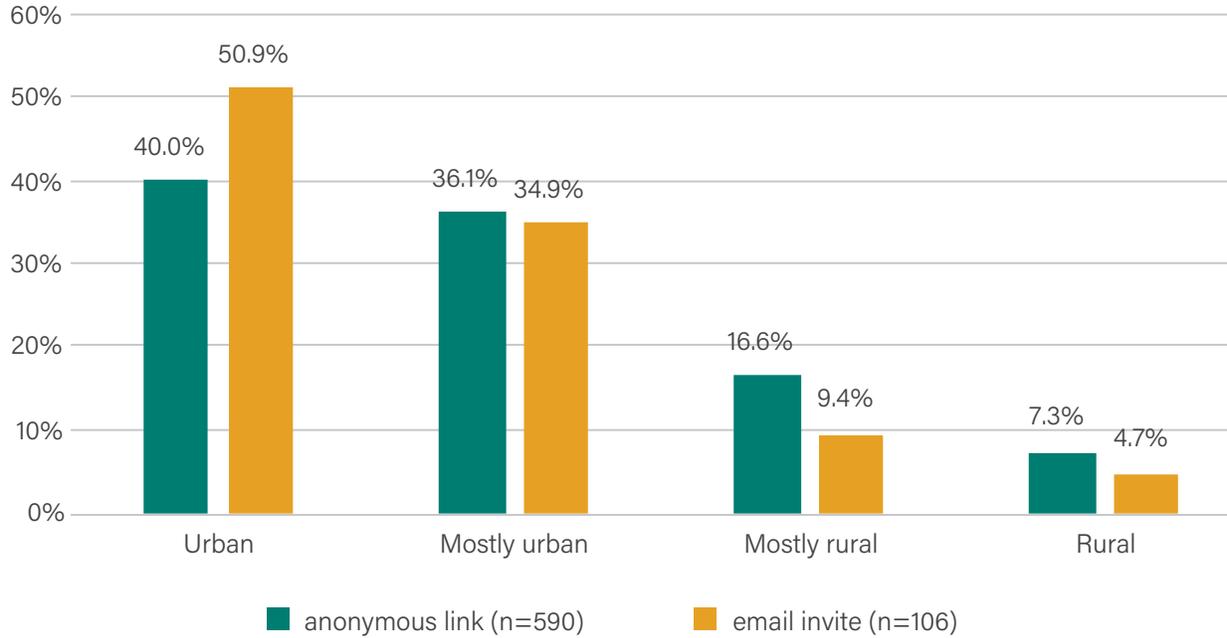
Figure B7. Questionnaire respondent urbanness by questionnaire type

Distribution of questionnaire respondent household income (total n=577)

Income	email invite (n=86)	anonymous link (n=491)
$200,000 or more	55.8%	22.0%
$150,000 to $199,999	15.1%	11.6%
$100,000 to $149,999	10.5%	20.4%
$50,000 to $99,999	11.6%	23.2%
$25,000 to $49,999	3.5%	10.2%
$15,000 to $24,999	1.2%	4.1%
$10,000 to $14,999	1.2%	3.1%
Less than $10,000	1.2%	5.5%

■ email invite (n=86)   ■ anonymous link (n=491)
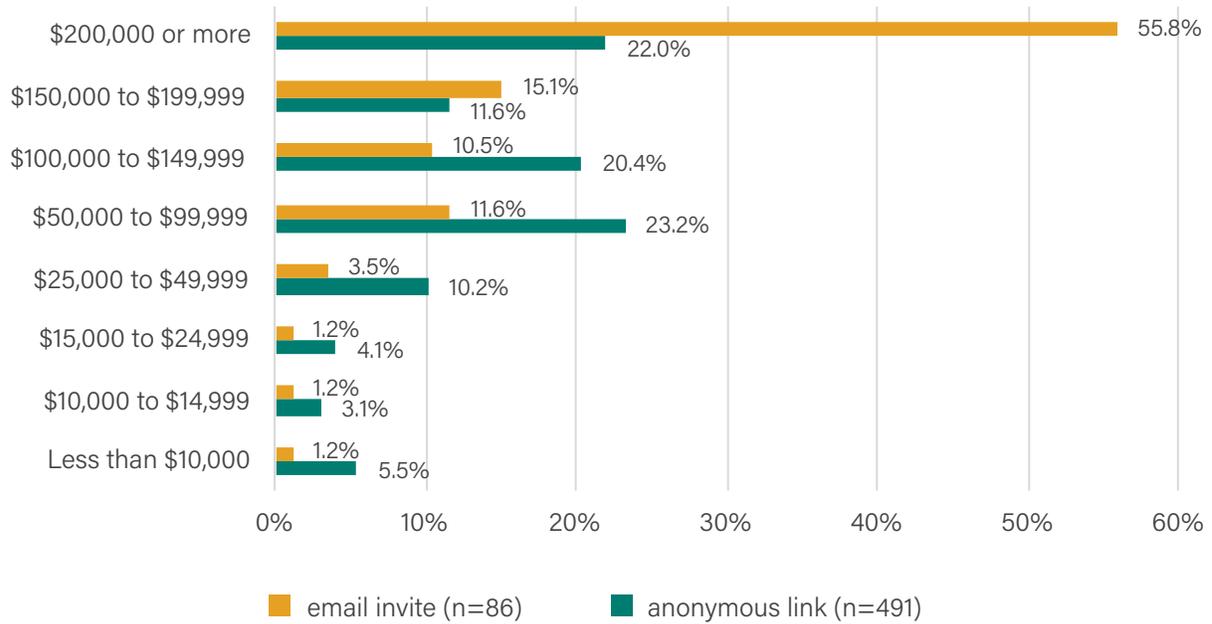
Figure B8. Questionnaire respondent household income.

Distribution of questionnaire respondent Hispanic origin (total n=676)
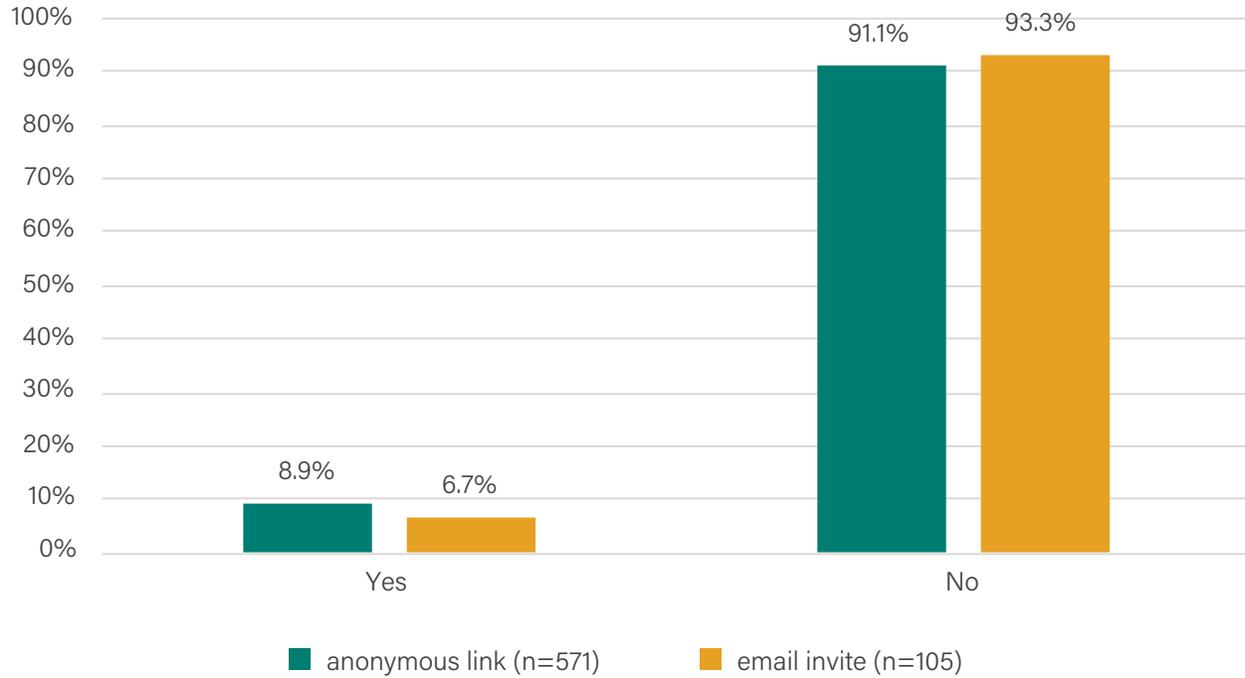
Figure B9. Questionnaire respondent Hispanic origin.

Distribution of questionnaire respondent Middle Eastern or North African origin (total n=664)
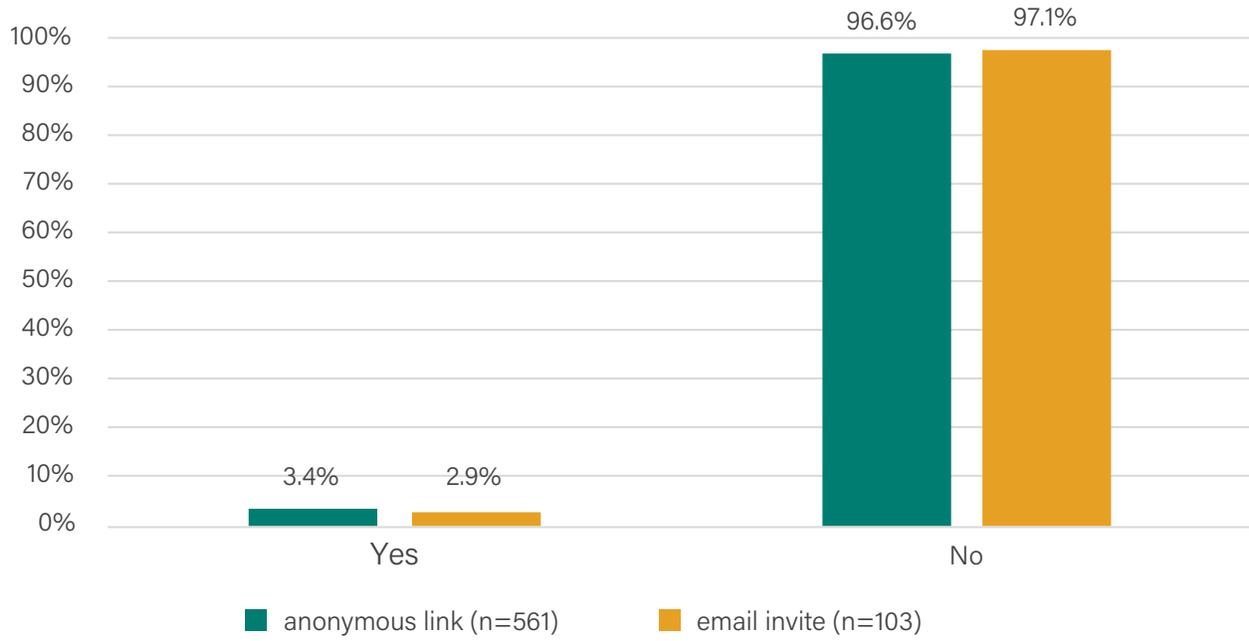
Figure B10. Questionnaire respondent Middle Eastern or North African origin.

Distribution of questionnaire respondents who speak a language other than English at home (total n=690)
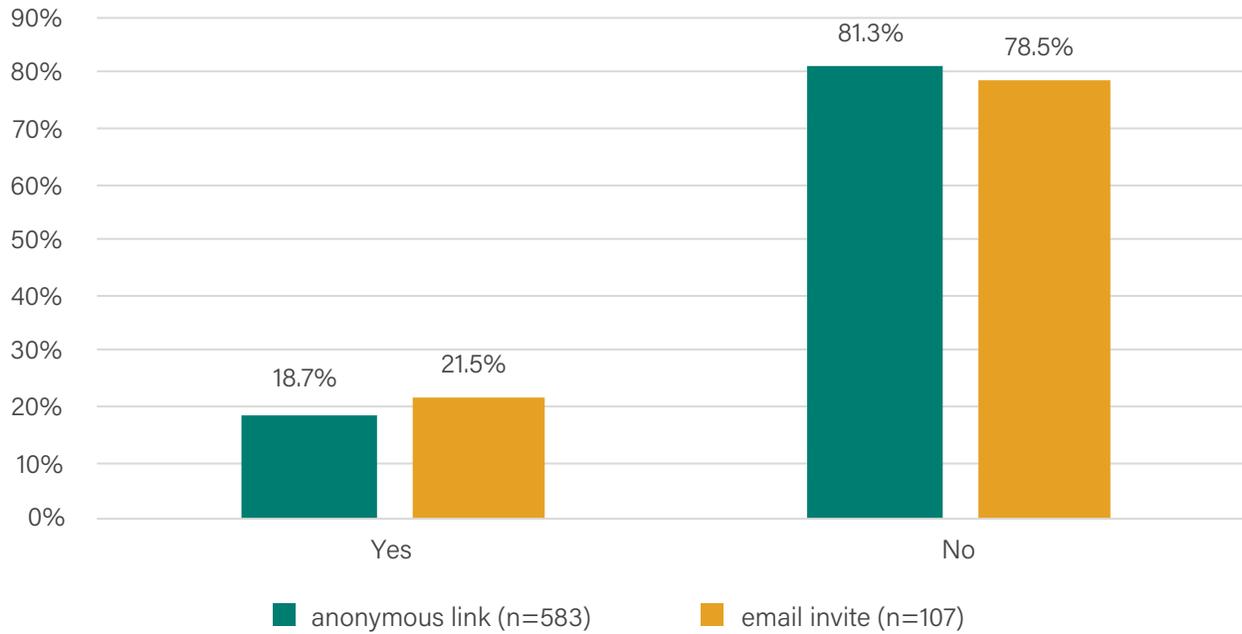
Figure B11. Questionnaire respondent language spoken at home.

APPENDIX C: QUESTIONNAIRE INVITATION

What do you think should be included in the U.S. Government's definition for Long COVID?

The **National Academies of Science, Engineering, and Medicine (National Academies)** *Committee on Examining the Working Definition for Long COVID* invites you to participate in a questionnaire about how to best define Long COVID. The effort is sponsored by the U.S. Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH). Learn more about this effort here.

The term "Long COVID" was coined by patients experiencing lingering symptoms of COVID-19 lasting over 30 days after acute COVID-19 infection. Long COVID is a serious global concern with medical, social, economic, and personal impacts.

The purpose of the questionnaire is to understand various perspectives on Long COVID to examine the U.S. Government's (USG) working definition for Long COVID. We recognize there are many efforts underway trying to understand more about Long COVID, and we hope to learn from these.

Results of this questionnaire and other engagement efforts being held in Spring 2023 will be reviewed by the National Academies Committee on Examining the Working Definition for Long COVID. For details on data collection, please see the questionnaire landing page.

This questionnaire should take **10-15 minutes** to complete and will remain open through **May 12, 2023**.

Follow this personalized link to the questionnaire: [link omitted]

Or copy and paste the URL below into your internet browser [link omitted]

This is your individual link and can only be used by you. *Please share this questionnaire with others using the text and link at the end of this email.*

Thank you for completing the questionnaire,

Committee on Examining the Working Definition for Long COVID, The National Academies of Science, Engineering, and Medicine

Link and suggested text to share with others who may be interested in sharing their views: The National Academies of Science, Engineering, and Medicine (National Academies) Committee on Examining the Working Definition for Long COVID invites you to participate in a questionnaire about how to best define Long COVID. Results will be reviewed by the National Academies as they examine the U.S. Government's working definition for Long COVID.

Share your views on what should be in the U.S. Government's definition for Long COVID: [link omitted] Follow the link to opt out of future emails: [link omitted]

APPENDIX D: QUESTIONNAIRE CONSENT PAGE

Questionnaire on the United States Government's Definition for Long COVID

The National Academies of Sciences, Engineering, and Medicine (National Academies) *Committee on Examining the Working Definition for Long COVID* invites you to participate in a questionnaire about how to best define Long COVID.

This effort is sponsored by the U.S. Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH). Learn more about this effort here.

The term "Long COVID" was developed by patients experiencing lingering symptoms of COVID-19. Long COVID is a serious global issue with medical, social, economic, and personal impacts.

The purpose of the questionnaire is to understand different perspectives on Long COVID, the U.S. Government's (USG) working definition for the illness.

Results of this questionnaire and other input being gathered in Spring 2023 will be reviewed by the National Academies Committee on Examining the Working Definition for Long COVID. We also hope to learn from the many other efforts to understand more about Long COVID.

The current USG working definition for Long COVID is:
"Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes." — National Research Action Plan on Long COVID (Chapter 1, page 14)

Responding to this Questionnaire
This questionnaire should take approximately **10-15 minutes** to complete. The questionnaire will remain open through **May 12, 2023**.

Qualtrics will automatically save your answers as you go through the questionnaire. You can return to this page and finish the questionnaire later.

If you would like to dictate your responses to open-ended questions, you can download a third-party dictation tool (requires Chrome browser). You can also use the Dictate tool in Microsoft Word, and then copy and paste them into this questionnaire.

Voluntary and Anonymous Participation
Your participation in this questionnaire is voluntary and anonymous. You may skip any question that you do not want to answer.

You will be asked questions about how to best define Long COVID. We will also ask for some demographic information to make sure we are hearing from different types of people.

Your responses will be maintained securely on Qualtrics servers and will be deleted six months after completion of the study. Results of the questionnaire will be accessible only to EnSpark Consulting who will provide analysis and prepare a report that will be shared with the National Academies Committee on Examining the Working Definition for Long COVID and will be made publicly available. The National Academies will only receive aggregated data from Qualtrics and not your individual responses.

Thank You for Participating
We look forward to learning everyone's responses to these questions. However, if you feel uncomfortable or unsure about how to answer any question, please feel free to skip it and complete the others.

If you have any questions about this questionnaire, please contact at [contact information].

By clicking the "Next" button below you are confirming that you are at least 18 years of age and agree to participate in this questionnaire.

APPENDIX E: QUESTIONNAIRE

What organization are you affiliated with, if any?

_____

What is your position or title at the organization?

_____

In the context of Long COVID, which group(s) do you identify with, if any? (Select all that apply)

☐ Patient, patient organization, and/or caregiver

☐ Researcher

☐ Clinical practitioner and/or organization

☐ Public health agency

☐ Health policy and/or advocacy organization

☐ Health industry business

☐ Health insurance company

☐ Company providing healthcare benefits

☐ Community- or faith-based organization

☐ General public

☐ Other (please specify) _____

☐ None

Which group do you identify with _most_?

☐ Patient, patient organization, and/or caregiver

☐ Researcher

☐ Clinical practitioner and/or organization

☐ Public health agency

☐ Health policy and/or advocacy organization

☐ Health industry business

☐ Health insurance company

☐ Company providing healthcare benefits

☐ Community- or faith-based organization

☐ General public

☐ Other (please specify) _____

☐ None

Would you consider yourself a person with Long COVID, member of a patient advocacy organization, or caregiver? (Select all that apply)

☐ Person with Long COVID

☐ Member of a patient advocacy organization

☐ Caregiver of an adult with Long COVID

☐ Caregiver of a child or youth with Long COVID

☐ Other (please specify) _____

The current USG working definition for Long COVID is:
"Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes." — National Research Action Plan on Long COVID (Chapter 1, page 14)

How satisfied are you with the current USG Long COVID definition?

☐ Extremely dissatisfied

☐ Somewhat dissatisfied

☐ Neither satisfied nor dissatisfied

☐ Somewhat satisfied

☐ Extremely satisfied

Have you seen or used a published definition for Long COVID definition before today? (For example, published by the USG, U.S. Department of Health and Human Services, World Health Organization, etc.)

☐ Yes, I have read a definition

☐ Yes, I have read and made use of at least one definition

☐ Maybe

☐ No

How have you used a Long COVID definition before? (Select all that apply)

☐ Better understand my, my relative's, or another person's illness

☐ Explain to others what Long COVID is

☐ Submit a request for being paid back for clinical care services

☐ Get coverage for care received

☐ Diagnose patients

☐ Treat patients

☐ Talk to patients about their prognosis (likely course of illness)

☐ Request funding for a study

☐ Create inclusion/exclusion criteria for a research study

☐ Create subgroups of research study participants

☐ Monitor numbers of cases of Long COVID

☐ Other (please specify) _____

Please explain why you are dissatisfied with the current definition. (Select all that apply)

☐ The definition is too broad.

☐ The definition is too narrow.

☐ The definition should include specific signs, symptoms, and conditions.

☐ The definition should include specific risk factors.

☐ The definition does not fit my illness (or my patients' presentation).

☐ The definition does not capture the seriousness or severity of my (or my patients') symptoms.

☐ The definition is not up-to-date.

☐ The definition should not include: "with the possibility of severe and life-threatening events".

☐ The definition should not include: "Long COVID is not one condition."

☐ The definition is not useful for my purposes.

☐ Other (please specify) _____

Do you like any Long COVID definitions more than the current USG working definition?

☐ Yes (please specify which one(s)) _____

☐ No

Please indicate your level of agreement with the following statements.
I recommend that the definition for Long COVID:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Should be as detailed and comprehensive as possible	☐	☐	☐	☐	☐
Should include all key scientific terms	☐	☐	☐	☐	☐
Should use plain language, understandable to persons of any education level	☐	☐	☐	☐	☐
Should recognize that our understanding of Long COVID is still changing	☐	☐	☐	☐	☐

Please indicate your level of agreement with the following statements:
I recommend that the definition for Long COVID should include:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The most common symptoms of Long COVID	☐	☐	☐	☐	☐
No specific symptoms of Long COVID	☐	☐	☐	☐	☐
A statement about new symptoms being linked to a COVID-19 infection	☐	☐	☐	☐	☐
A statement about a COVID-19 infection making pre-existing health conditions worse (for those with a condition)	☐	☐	☐	☐	☐

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The shortest amount of time for having symptoms before it is considered Long COVID	☐	☐	☐	☐	☐
The most common impacts of Long COVID on normal daily activities	☐	☐	☐	☐	☐
The severe impacts of Long COVID on normal daily activities	☐	☐	☐	☐	☐
No specific impacts of Long COVID to normal daily activities	☐	☐	☐	☐	☐

The current USG working definition for Long COVID is:

"Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes." — National Research Action Plan on Long COVID (Chapter 1, page 14)

How might the current definition for Long COVID be improved?

The definition should include the following statements about *symptoms and conditions*: (Select all that apply)

☐ Earliest time after infection that a symptom can be considered Long COVID

☐ How long symptom(s) lasted (duration) - short term

☐ How long symptom(s) lasted (duration) - long term and lifelong

☐ How bad the symptoms are (severity)

☐ How often the symptom(s) happen (frequency)

☐ Impact on daily activities

☐ Common co-morbid conditions (e.g., health conditions that commonly occur with Long COVID)

☐ Other (please specify) _____

☐ The current definition does not need improvement with regards to symptoms and conditions

How might the current definition for Long COVID be improved?
The definition should include the following statements about *diagnosis*: (Select all that apply)

☐ Specific results of a doctor's physical exam

☐ How COVID-19 infection is confirmed (e.g., from a laboratory, imaging (CT scan or X-ray), or other tests)

☐ Patient judgment of whether they have Long COVID or not

☐ Specific biomarkers (e.g., a sign of Long COVID found in blood, other bodily fluids, or tissues)

☐ Exclusion of alternative diagnostics (e.g., Long COVID can be diagnosed only after other conditions are ruled out)

☐ Statement that other diagnoses should be considered before a Long COVID diagnosis

☐ Other (please specify) _____

☐ The current definition does not need improvement with regards to diagnosis

A definition for Long COVID may be used for a mix of reasons, such as for treatment, workplace accommodation, and research. What should we keep in mind to make sure the definition is inclusive and supports all people with Long COVID to get healthcare, workplace support, or other things they need? (Select all that apply)

☐ Recognize that different people have different symptoms and experiences

☐ Recognize that things like poverty, race, and where you live can affect your chances of developing Long COVID

☐ Think about how Long COVID could cause money problems for some people

☐ Don't only include people who tested positive for COVID-19 in the definition, because not everyone has access to tests

☐ Avoid a definition that excludes the full range of symptoms and experiences of Long COVID

☐ Consider that some groups have a higher likelihood of chronic illness (e.g., diabetes) but they shouldn't be overlooked if this symptom is also common with Long COVID

☐ None of the above

☐ Other (please specify) _____

What else should we keep in mind to ensure a Long COVID definition does not increase barriers to healthcare or create other unfair conditions?

_____

Do you think there should be one definition for Long COVID that applies to everyone, or should there be different definitions depending on how it is used or who it is used for? (For example: research vs. clinical care, hospitalized vs. non-hospitalized patients, patients with a positive COVID test vs. those without)?

☐ One definition only

☐ More than one definition, each for a specific use

☐ Not sure

☐ No opinion

The following statements are from the USG's current working definition for Long COVID. Do you think they should be included in a future definition for Long COVID?

	Yes, without changes	Yes, with only minor changes	Yes, needs many changes	Do not include
Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection.	☐	☐	☐	☐
The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection;	☐	☐	☐	☐
may be multisystemic;	☐	☐	☐	☐

	Yes, without changes	Yes, with only minor changes	Yes, needs many changes	Do not include
and may be present with a relapsing-remitting pattern and progression or worsening over time,	☐	☐	☐	☐
with the possibility of severe and life-threatening events even months or years after infection.	☐	☐	☐	☐
Long COVID is not one condition.	☐	☐	☐	☐
It represents many potentially overlapping entities, likely with differing biological causes and different sets of risk factors and outcomes.	☐	☐	☐	☐

You said that you would recommend [a phrase] with *minor changes*. What changes do you think should be made?

_____

You said that you would recommend [a phrase] with *many changes*. What changes do you think should be made?

_____

You said that *you would not recommend* [a phrase]. Why?

_____

Are you have experience with, or knowledge about, other post-infection illnesses (for example, chronic fatigue syndrome (ME/CFS), Epstein-Barr Virus (EBV), Lyme disease, and Ross River Virus (RRV), and orthostatic intolerance (POTS), etc.)?

☐ Yes. (Please specify) _____

☐ No

What lessons can the National Academies learn from other post-infection illnesses in developing a definition for Long COVID? Please specify, if you can, which illness(es) you are referring to.

_____

Are there any resources (for example, existing Long COVID definitions, technical terms, etc.) that the National Academies should review as they examine the working definition for Long COVID? Please include web links as appropriate.

_____

If you have information about Long COVID that you would like to share with the National Academies *Committee on Examining the Working Definition for Long COVID*, you can attach it here.

Do you have any other advice for the committee tasked with examining the USG's current definition for Long COVID?

_____

We know the risks and impacts of Long COVID are not equally distributed across the population.

The following questions help us understand who we are hearing from, and help to ensure that we are hearing from a diverse set of respondents. You can skip any question and your responses will be kept anonymous.

What is your age?

▼ 18-20 ... I prefer not to answer

How would you describe your gender?

☐ Female

☐ Male

☐ Transgender

☐ I use a different term (please specify) _____

☐ I don't know

☐ I prefer not to answer

Where are you located?

▼ Alabama ... Outside of the U.S.

Please specify your location outside of the U.S.

_____

How would you describe the area where you currently live?

☐ Urban

☐ Mostly urban

☐ Mostly rural

☐ Rural

☐ I prefer not to answer

What is the highest level of education you have completed?

☐ Some high school or less

☐ High school diploma or GED

☐ Some college, but no degree

☐ Associates or technical degree

☐ Bachelor's degree

☐ Graduate or professional degree (MA, MS, MBA, PhD, JD, MD, DDS etc.)

☐ Prefer not to say

What was your total household income before taxes during the past 12 months?

☐ Less than $10,000

☐ $10,000 to $14,999

☐ $15,000 to $24,999

☐ $25,000 to $49,999

☐ $50,000 to $99,999

☐ $100,000 to $149,999

☐ $150,000 to $199,999

☐ $200,000 or more

☐ I prefer not to say

Are you of Hispanic, Latino/a/e/x, or of Spanish origin?

☐ Yes

☐ No

☐ I prefer not to answer

Are you of Middle Eastern or North African origin?

☐ Yes

☐ No

☐ I prefer not to answer

What is your racial background? (Select all that apply)

☐ American Indian or Alaska Native or Indigenous or Native American

☐ Asian or Asian-American

☐ Black or African-American

☐ Native Hawaiian or other Pacific Islander

☐ White

☐ Other (please specify) _____

☐ I prefer not to answer

Would you consider yourself to have a disability that impacts your daily life?

☐ Yes

☐ No

☐ I prefer not to answer

Do you speak a language other than English at home?

☐ Yes

☐ No

☐ I prefer not to answer

APPENDIX F: FOCUS GROUP INVITATION

The National Academies of Science, Engineering, and Medicine (National Academies) *Committee on Examining the Working Definition for Long COVID* invites you to participate in an online focus group about how to best define Long COVID. This effort is sponsored by The U.S. Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH). Learn more about this effort here.

[Link] Register to attend a focus group about the US Government's definition of Long COVID.

The term "Long COVID" was coined by patients experiencing lingering symptoms of COVID-19 lasting over 30 days after acute COVID-19 infection. Long COVID is a serious global issue with medical, social, economic, and personal impacts.

The purpose of the focus groups is to understand various perspectives on Long COVID to examine the U.S. Government's (USG) working definition for Long COVID. We recognize there are many efforts underway trying to understand more about Long COVID, and we hope to learn from these.

Seven online focus groups are being held between April 26, 2023, and May 8, 2023.

- Researchers (April 26, 2:00pm-4:30pm Eastern Time)

- Practitioners (April 28, Noon-2:30pm Eastern Time)

- Patients, Caregivers, and Patient organizations (April 29, 3:00pm-5:30pm Eastern Time)

- Health Agencies (May 2, 1:00pm-3:30pm Eastern Time)

- Health Policy and Health Advocacy Organizations (May 4, Noon-2:30pm Eastern Time)

- Payors and Health Businesses (May 5,1:00pm-3:30pm Eastern Time)

- All Categories (May 8, 2:00pm-4:30pm Eastern Time)

[Link] Click here to register for a focus group that best fits your perspective. Please note that registration is limited and a waiting list will be established as needed.

Download the "What to Expect" document for important information about your participation including: format, technology requirements, accessibility needs, participation guidelines, a waiting list, data collection and reporting, and how we will protect your privacy.

For more information about the project, questions, or if you can't attend the session for your sector, or the All Categories focus group, please send your recommendation of an alternate participant to, [contact information].

APPENDIX G: FOCUS GROUP AGENDA

Committee on Examining the Working Definition for Long COVID
Focus Group Agenda

All Categories | Monday 8 May, 2023 | 2:00pm-4:30pm Eastern Time | On Zoom

Purpose
This series of focus groups aims to hear from people with experience and expertise with Long COVID, and discuss together what's important for a definition of Long COVID. This session will hear from those unable to attend the session for their sector.

Agenda
2:00   **Welcome & Introductions**

Presentation: Examining a Definition for Long COVID
National Academies of Sciences, Engineering, and Medicine
How might you use a definition of Long COVID?

Breakout Discussion: Feedback on the Interim Working Definition
What feedback do you have about the U.S. Government's (USG) interim working definition, or other definitions, of Long COVID?
Are there specific statements, key terms, impacts, or concepts that should, or shouldn't, be included in a future definition for Long COVID?

Plenary: Share Back

Break (10 minutes)

Breakout Discussion: Using a Definition of Long COVID
What challenges might there be in using the current USG definition, or other definitions? What could address those challenges?
What should the National Academies committee keep in mind to make sure the definition does not unintentionally make it harder for people with Long COVID to get healthcare, workplace support, or other things they need? Consider in particular the challenges faced by historically marginalized peoples.

Plenary: Reflection
What advice do you have for the National Academies committee charged with reviewing the USG's definition of Long COVID?

Next Steps & Evaluation

4:30   **Adjourn**

Results

The results of these focus groups, along with other input being gathered in spring 2023 will be reported by EnSpark Consulting in a summary report. This report will be publicly available and carefully considered by the National Academies of Sciences, Engineering, and Medicine *Committee on Examining the Working Definition for Long COVID*. Findings will also inform a Committee workshop on June 22-23, 2023, which is open to public observation and comment via online access.

How to Prepare

We want to hear your perspectives about defining Long COVID. Bring your ideas to the questions listed on the first page of this agenda.

If you like, you can also review the U.S. Governments' Working Interim Working Definition for Long COVID:

> Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing– remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.
> Source: HHS (2022). National Research Action Plan on Long COVID.

Optional: If you're curious about other definitions being used, visit the National Research Action Plan on Long COVID, Appendix C: Terminology and Definitions (pdf, page 69) or visit EPICORE's 2023 Long Covid Definitions: Global Examples (pdf).

Technology Requirements

> We recommend that you use a computer with speakers or headphones for the best experience of this event. Some interactivity and accessibility features are not available when using a smartphone or tablet.

Focus Group Participation Guidelines

- Please plan to participate for the full duration of the focus group.
- Respect the opinions of others. Every participant brings information, points of view and ideas to contribute.
- We strive to ensure the safety of participants and speakers. There will be zero tolerance for those who promote violence against others on the basis of race, ethnicity, national origin, sexual orientation, gender identity, religious affiliation, or different ability.
- Respect the privacy of participants—do not share what is said in your focus group with other people.
- Share opportunities for airtime equally. If you've asked a question or shared a comment, ensure that new voices are heard before you contribute again.
- Practice self-care: if you need to get up or take a break, please feel free.

APPENDIX H: FOCUS GROUP "WHAT TO EXPECT"

Focus Groups: What to Expect
Committee on Examining the Working Definition for Long COVID

Overview
The National Academies of Science, Engineering, and Medicine (National Academies) *Committee on Examining the Working Definition for Long COVID* is hosting online focus groups to understand various perspectives about how to best define Long COVID. In addition to these focus groups, the Committee is also learning from interested and impacted people through a questionnaire, open comment portal and a June workshop. Learn more here.

This effort is sponsored by The U.S. Administration for Strategic Preparedness and Response (ASPR) and the Office of the Assistant Secretary for Health (OASH).

Seven focus groups are being held in spring 2023, for the following groups:

- *Researchers* (April 26, 2:00pm-4:30pm Eastern Time): For those who conduct research and report results to the scientific or medical community.
- *Practitioners* (April 28, Noon-2:30pm Eastern Time): For those who provide health care and professional associations who provide clinical guidance.
- *Patients, Caregivers, and Patient organizations* (April 29, 3:00pm-5:30pm Eastern Time): For those who are living with Long COVID, supporting someone affected, and for groups who advocate on behalf of Long COVID patients.
- H*ealth Agencies* (May 2, 1:00pm-3:30pm Eastern Time): For those who lead or deliver programs that provide public health or community services.
- *Health Policy and Health Advocacy Organizations* (May 4, Noon-2:30pm Eastern Time): For organizations who advance health care and health policy through data analysis, funding research, advocacy, supporting initiatives, or making recommendations.
- *Payors and Health Businesses* (May 5, 1:00pm-3:30pm Eastern Time): For businesses that provide health insurance as well as businesses that produce drugs, tests, devices, procedures, etc. related to Long COVID.
- *All Categories* (May 8, 2:00pm-4:30pm Eastern Time): For those unable to attend the session for their sector.

Interim Working Definition of Long COVID
The U.S. Government's current working definition of Long COVID is:

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.

Focus Group Format

Please plan to join for the full session. These 2.5 hour interactive discussions will invite you to share your views on key topics such as:

1. What should be included in a definition of Long COVID, and why?
2. What is needed for a definition of Long COVID to be relevant for your context?
3. What challenges have you experienced, or could anticipate, in applying the current USG definition and/or other existing definitions of Long COVID? How could a better definition help address those challenges?
4. What lessons can the National Academies learn from other post-viral illnesses, or other related fields, to better refine the definition of Long COVID?

The majority of the focus group will be held in small group discussion so you can share your views and hear from others. Facilitators and notetakers will support your discussions.

Technology Requirements

To engage with this online event, you will need a computer (laptop or desktop), tablet or smartphone, with speakers or headphones.

We recommend that you use a computer for the best experience of this event. Some interactivity and accessibility features are not available when using a smartphone or tablet.

Accessibility

The focus groups will be held online, with closed captioning available. Discussion materials will be sent in advance.

If there is anything we can do to better accommodate your participation, please contact Margaret McCarthy at [contact information]. Advance notice is necessary to arrange for some accessibility needs.

Waiting List

If your desired session is full, please join the waiting list, and we will notify you if a registration space becomes available.

Participation Guidelines
- Please plan to participate for the full duration of the focus group.
- We strive to ensure the safety of participants and speakers. There will be zero tolerance for those who promote violence against others on the basis of race, ethnicity, national origin, sexual orientation, gender identity, religious affiliation, or different ability.
- Respect the opinions of others. Every participant brings information, points of view and ideas to contribute.
- Respect the privacy of participants—do not share what is said in your focus group with other people.
- Share opportunities for airtime equally. If you've asked a question or shared a comment, ensure that new voices are heard before you contribute again.
- Practice self-care: if you need to get up or take a break, please feel free.

Your participation in this focus group activity is voluntary, and you may withdraw your acceptance at any time via an email to Margaret McCarthy at [contact information].

Additionally, if, for any reason, you want to leave the focus group before the scheduled finish time, please use the chat function to send an individual Zoom message to Margaret McCarthy.

Data Collection and Privacy
You will be asked at the beginning of the focus group to consent to an audio recording of the session. Your participation is voluntary, and you can decline to comment on any topic that is put to the group for discussion. The audio recording and a transcript prepared by National Academies staff will be stored on password-protected Academies servers until the end of the calendar year. Those who will have access to this meeting recording and transcript will include National Academies staff and the engagement consultant, EnSpark Consulting. Your identity will be kept confidential, and you will not be identified or quoted without your express permission in any publicly-available report.

Your responses will be included in a publicly-available thematic summary and analysis of desirable features of a definition of Long COVID, but will not attribute any response to you without your express permission. EnSpark Consulting will conduct this analysis and draft this report and it will be shared with the National Academies *Committee on Examining the Working Definition for Long COVID* and made publicly available.