

health+TM Long COVID

Human-Centered Design Report

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health+™ Long COVID

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November 2022



“We have to be looked at as partners. Not to be talked down to, or to be dismissed, but to be considered the experts on our bodies—because we are.”

—Imani, interior designer, sister, and person with Long COVID

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**“I don’t have time to be a professional patient.
I’m still living my life.”**

**—Shannon, student, medical research intern,
and person with Long COVID**

Executive Summary

Executive Summary

In April 2022, the Biden administration issued the Presidential Memorandum on Addressing the Long-Term Effects of COVID-19, directing the U.S. Department of Health and Human Services (HHS) to coordinate a government-wide response to the long-term effects of COVID-19. As mandated in the memorandum, HHS published two reports in August, *Services and Supports for Longer-Term Impacts of COVID-19* and the *National Research Action Plan on Long COVID*.

Building on this momentum, the Health+ Long COVID Human-Centered Design Report complements the findings and recommendations of these earlier reports by broadening the conversation and elevating what is often underrepresented in Long COVID statistics, scientific literature, and policy making—the narratives and expertise of people with Long COVID and what they want and need to live better, healthier lives. Differences between these three reports may occur due to varying methodologies, but they share a common goal: to improve the quality of care and life for those impacted by Long COVID.

To ensure the lived experiences and perspectives of people impacted by Long COVID are integrated into the social, public health, and economic solutions being created to support the Long COVID community, the Health+ Long COVID program used a process called human-centered design, which centers the very people impacted by a particular health challenge in understanding and developing solutions to it. From the start, we worked closely with people and communities impacted by Long COVID. As active participants, they informed our research plan, shared their experiences and expertise with us, reviewed our draft findings to ensure they were accurate and representative, and recommended solutions.

This report, a result of this process, includes an exploration of how and why the impact of Long COVID on individual lives varies from person to person, the reasons for which have the potential to increase health disparities between peoples and communities. The symptoms of Long COVID can be mild and barely perceptible, or they can be ever-present and wholly debilitating. However, it is not simply the severity of Long COVID and the conditions associated with it that influence Long COVID's impact on someone's life, but a range of social determinants of health as well. These determinants include one's geographic location; financial stability; discrimination from health care providers due to race, ethnicity, age, gender, or sexual orientation; support from one's workplace or educational setting; insurance status; and the presence or absence of a support network. While the data on the disproportionate impact of Long COVID across different communities is incomplete, it is strongly believed that people of color are more likely to be affected by Long COVID, as a result of their increased likelihood to become infected with COVID-19 and lower access to health care.¹ Additionally, Long COVID is more common in bisexual and trans people due to lower access to health care and stigma regarding their gender or sexuality.²





“It’s great that we’re starting to see funding for research, but **long-haulers need to be able to survive and make it to see the answers from that research.** ... These people are losing their homes, they’re losing their cars, they’re rationing medications. They’re not going to doctors because they can’t afford the copays.”

—Amalee, Long COVID advocate, mother, and person with Long COVID



This report also describes an ideal treatment journey or set of steps for seeking care. However, most, if not all, people we spoke to with Long COVID struggle to access the care they need. Through interviews and journey mapping activities with people with Long COVID, we identified pain points and barriers each step of the way that make accessing care a sometimes insurmountable battle. In addition to some of the social determinants listed already, these barriers include lack of knowledge about Long COVID amongst health care providers, anti-patient bias, poor care coordination, and testing that is insufficient to detect abnormalities.

Lastly, research takeaways and recommendations are organized into an opportunities framework, as seen on the right, for advancing equitable change across public, health care, assistance, and innovation ecosystems. These recommendations are intended to holistically support people with Long COVID by enlisting change from a range of audiences, including health care providers, assistance providers, educators, employers, researchers, advocacy organizations, and the general public.

With between five and 30% of people developing Long COVID after a COVID-19 infection,³ this report is a call to act with urgency to design and implement solutions for people with Long COVID. While we may not yet have the science to understand why Long COVID happens, we can act now to create what people with Long COVID want and need to improve their health and live a higher quality of life.

Opportunities Framework

VISION FOR THE INNOVATION ECOSYSTEM:

Treatments, tests, care paths, and cures that improve the quality of care and life for people with Long COVID.

OPPORTUNITY: Expand support and resources for advocacy efforts led by people with Long COVID and allies.
FOR: Advocacy organizations, pharmaceutical companies, and philanthropic entities.

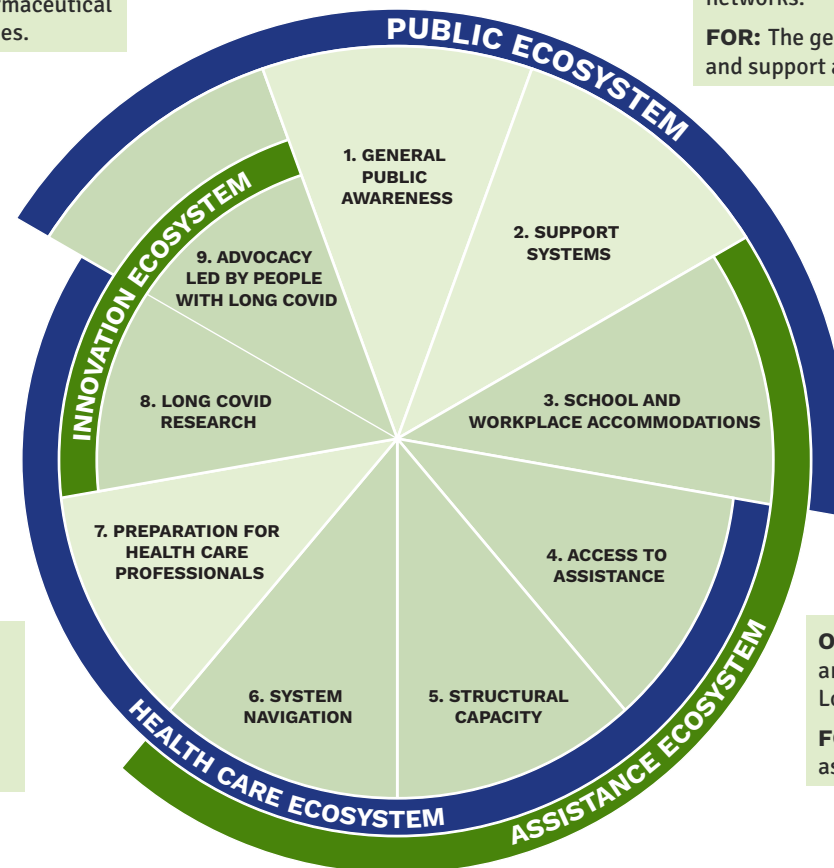
OPPORTUNITY: Increase public awareness around Long COVID, and establish public policies that protect everyone from Long COVID.
FOR: The general public.

OPPORTUNITY: Assist people with Long COVID in building or boosting their support networks.
FOR: The general public, health care providers, and support and assistance providers.

VISION FOR THE PUBLIC ECOSYSTEM:

Safe, responsive, and supportive conditions that enable people with Long COVID to more fully engage in the world around them.

OPPORTUNITY: Expand pathways for Long COVID research that can spur rapid innovation and breakthroughs.
FOR: Medical researchers and advocacy organizations.



OPPORTUNITY: Support schools and workplaces to affirm, support, and accommodate people with Long COVID and their caregivers.
FOR: Educators and employers.

OPPORTUNITY: Train and resource health care providers to adequately identify and assist people with Long COVID.
FOR: Health care providers, and schools of medicine and public health.

OPPORTUNITY: Increase access to disability and other assistance programs for people with Long COVID and their caregivers.
FOR: Health care providers, support and assistance providers, and insurance providers.

VISION FOR THE HEALTH CARE ECOSYSTEM:

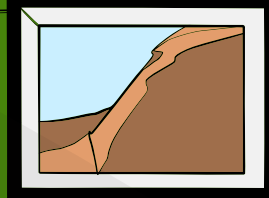
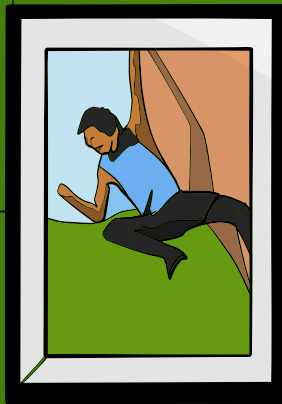
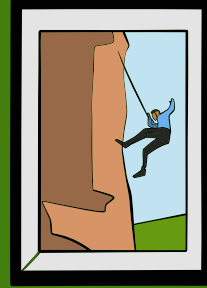
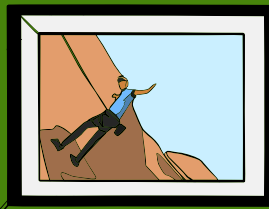
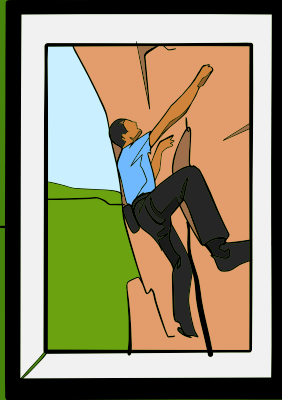
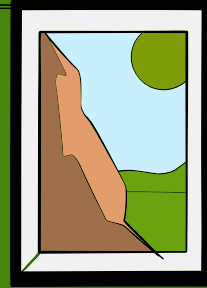
A health care system that is resourced and structured to support people with Long COVID.

OPPORTUNITY: Remove the care navigation and coordination burden from people with Long COVID and their caregivers.
FOR: Health care providers, and support and assistance providers.

OPPORTUNITY: Increase the capacity of health care and assistance systems to support the increase in need.
FOR: Health care providers, and support and assistance providers.

VISION FOR THE ASSISTANCE ECOSYSTEM:

Support and assistance that allows people with Long COVID to do what's most important—focus on their health.



Introduction

Introduction

Within weeks of the first documented cases of COVID-19 in the United States in 2020, people who had been infected, from all backgrounds and communities, began reporting symptoms lasting or fluctuating for weeks, months, and—with the passage of enough time—years. “Long COVID,” one of the many terms used to describe this infection-associated chronic illness, is now estimated to affect between 7.7 and 23 million Americans (at the time of this report’s publishing).⁵ This number will only continue to grow as COVID-19 continues to circulate.

Long COVID is still not well understood by researchers, health care providers, and the general public more than two years into the pandemic. This lack of clarity worsens and adds confusion to an already difficult experience for people with Long COVID who seek visibility, validation, and ultimately, solutions.

This uncertainty doesn’t make Long COVID any less real for people living with it, their caregivers, family members, and communities. Based on the severity of someone’s Long COVID symptoms and other contextual determinants, such as their financial stability, access to health care, or presence or absence of a support network, Long COVID can cause

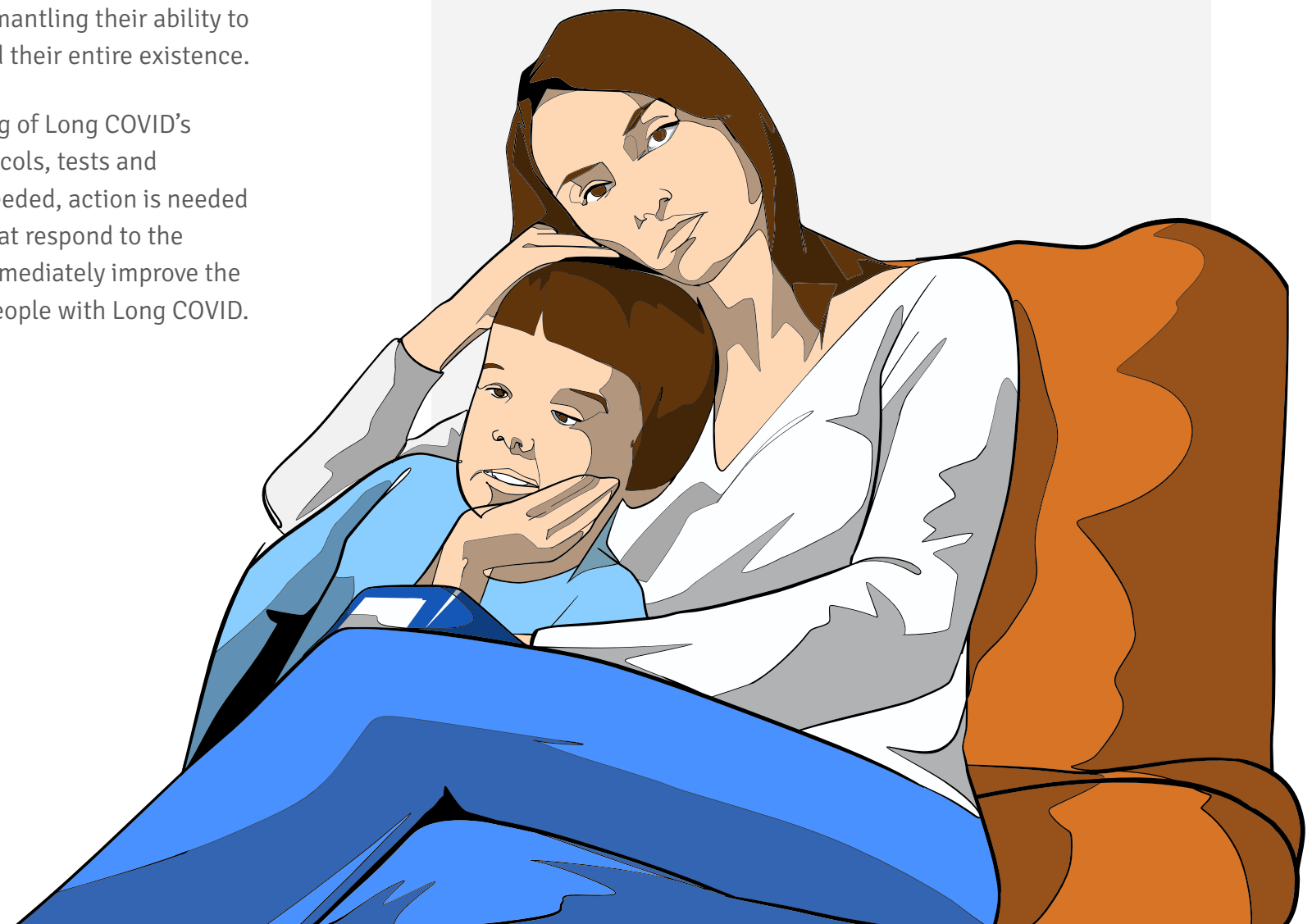
minor interferences in someone’s daily life; or, it can be extremely disruptive, dismantling their ability to work, their sense of self, and their entire existence.

While a better understanding of Long COVID’s pathologies, diagnosis protocols, tests and treatments is desperately needed, action is needed now to advance solutions that respond to the urgency of this crisis and immediately improve the quality of life and care for people with Long COVID.



“My son is nine. He was seven at the time he got COVID. He said to me recently, **‘Mom, I don’t even remember what my life was like before.’** I don’t remember what it feels like to not be in pain or feel sick.”

—Rebecca, therapist, mother to two children with Long COVID, and person with Long COVID



Understanding Long COVID Through a Human-Centered Lens

To ensure that solutions are implemented that respond to the real and immediate needs of people impacted by Long COVID—people with Long COVID, their caregivers, health care researchers and professionals, and Long COVID advocacy groups—HHS selected Coforma’s Health+™ program and its human-centered design process to launch Health+ Long COVID. The goal of this process is to understand the lived experiences and needs of people impacted by Long COVID across the United States, and to identify opportunities to improve government services and simultaneously advance interagency efforts to increase their quality of life and care. This report, commissioned by HHS and independently produced by Coforma, is a result of the Health+ Long COVID cycle.



What is Human-Centered Design?

Human-centered design is a creative approach to problem solving that centers the process and solutions around the people and communities who are impacted. Using qualitative research, this approach humanizes the problems at hand by viewing lived experiences and perspectives as valuable and necessary in solving the problems, and can augment clinical and public health research and initiatives.

How Does Health+ Work?

The Health+ program applies human-centered design and research to cultivate solutions to the most pressing health care challenges. Each Health+ cycle coordinates a collaborative effort that places impacted people at the center of research, problem solving, and innovation. The people impacted are active participants and future solutions are crafted to solve their most pressing challenges.

As of October 2022, two Health+ cycles around COVID-19 have been completed: ***Health+ COVID-19 Patient Journey: Diagnosis Experience*** and ***Health+ Long COVID***. More topics related to COVID-19 are expected to be covered in the future.

The Health+ Long COVID Process

The Health+ Long COVID cycle was conducted through a series of connected phases. In each phase, we learned from and worked collaboratively with people with Long COVID, their caregivers, health care providers, advocates, and other subject-matter experts. For the complete methodology used to complete this cycle, refer to Appendix 3: Research and Design Process.



Discovery

We worked closely with Long COVID advocacy organizations and other community-based organizations to recruit a diverse community of over 60 people to participate in this process. Several of them joined us for a series of discovery workshops to help shape our key learning objectives. Others participated in remote interviews, recorded audio diaries, or wrote us virtual postcards to tell us about their experiences living with and seeking care for Long COVID.



Validation and Ideation

We analyzed and synthesized our research, and data-driven findings were compiled into impact frameworks, treatment journey maps, and opportunity areas. These materials were reviewed by participants to confirm their accuracy and generate recommendations.



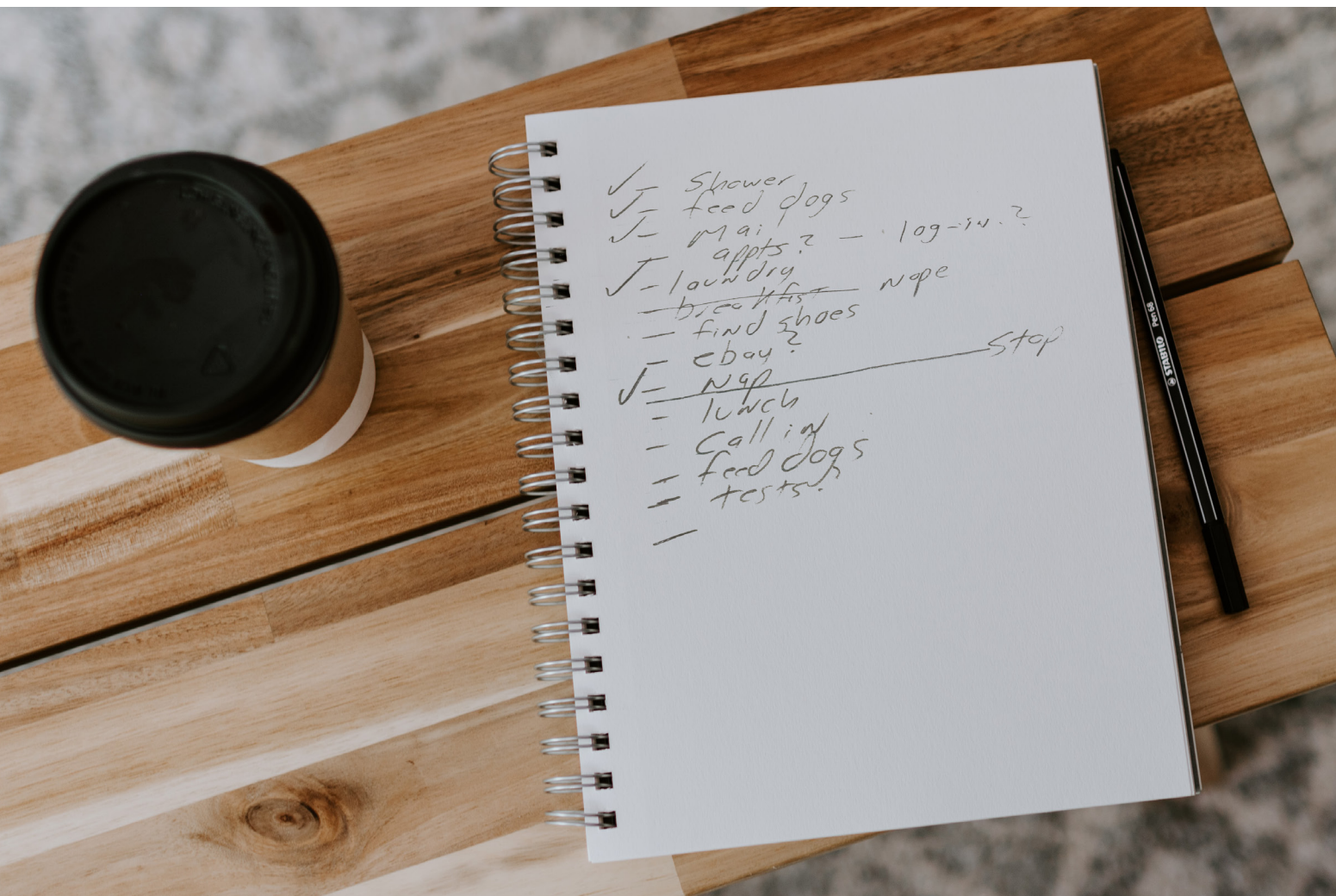
Implementation

A Healthathon will bring together people with Long COVID, caregivers, health care providers, advocates, and other subject-matter experts, to create or elevate solutions that respond to the opportunity areas identified in this report. (At the time of this report's publishing, the Healthathon has yet to take place.)

Defining Long COVID

Overview

While policymakers, researchers, public health professionals, and health care providers are expanding our collective understanding of Long COVID day by day, the illness is not yet well understood. Therefore, aligning on a definition—or even a name—for Long COVID is a difficult task, and “official” names and definitions change from institution to institution.



Existing Definitions of 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 acute 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, prepared by the Department of Health and Human Services⁶

“Post COVID-19 condition is defined as the illness that occurs in people who have a history of probable or confirmed SARS-CoV-2 infection; usually within three months from the onset of COVID-19, with symptoms and effects that last for at least two months. The symptoms and effects of post COVID-19 condition cannot be explained by an alternative diagnosis.”

—World Health Organization⁷

“Some people who have been infected with the virus that causes COVID-19 can experience long-term effects from their infection, known as post-COVID conditions (PCC) or long COVID. People call post-COVID conditions by many names, including: long COVID, long-haul COVID, post-acute COVID-19, post-acute sequelae of SARS CoV-2 infection (PASC), long-term effects of COVID, and chronic COVID.”

—Centers for Disease Control and Prevention⁸

Long COVID, as Defined by People with Long COVID

We analyzed over thirty definitions of Long COVID supplied by people with Long COVID and their caregivers, and a few patterns emerged. Definitions for Long COVID from people with Long COVID:

Acknowledge a change in the state of one's health before and after an initial COVID-19 infection.

Definitions are broad enough to encompass symptoms that persist after an infection, as well as new symptoms and health impacts that emerge:

“Health complications arising from COVID that occur after the initial acute illness.”

—Alexandra, lawyer, daughter, and person with Long COVID

“Long COVID is a worse state of health following a COVID infection.”

—Maya, recent college graduate, business analyst, and person with Long COVID

Compare the state of one's capabilities and quality of life before and after an acute COVID-19 infection.

Many people defined Long COVID as a shift in how they have to approach each day:

“[Long COVID] is a change in how I have to live my life. I can't conform to the traditional nine-to-five in the same way anymore, because my body is prioritizing healing over everything else.”

—Tara, recent graduate, theater producer, and person with Long COVID

Some people use analogies to describe their experience:

“My kids [who have Long COVID] say, ‘I used to be a Lexus, and now I'm a broken Honda.’

—Rebecca, therapist, mother to two children with Long COVID, and person with Long COVID

Definitions echo a change in identity that many people with Long COVID experience:

“The old Kyle was Kyle, the sales manager guy, the marathon guy. Now I'm Kyle, the guy who gets the mail and walks the dogs.”

—Kyle, hardware sales manager, father, and person with Long COVID

Emphasize a desire to define Long COVID broadly, so as to include a range of symptoms, related conditions, and lived experiences.

“In the stuff that [my advocacy group has] been putting out, we've been using the terminology ‘Long COVID and its associated conditions,’ because then we're highlighting the dysautonomia and the ME/CFS and all of these other things that are prevalent in the Long COVID community.”

—Amalee, Long COVID advocate, mother, and person with Long COVID

People with Long COVID want a definition that reflects their own experiences, but not at the expense of others. This reflects a sense of solidarity that is strong within the Long COVID community:

“It's important to stay broad, because [Long COVID] happens along a spectrum affecting us all slightly differently.”

—Ximena, graduate student, mother, and person with Long COVID

Terms

Throughout this report, we will use various terms to describe experiences related to Long COVID and parts of our research process, including those below. For a full list of terms, see Appendix 2, Glossary.

Caregiver: A person who provides support for another individual living with disabilities who might have a broad range of needs. They can be “family, kin, and grandparent caregivers” or direct care workers. A family, kin, or grandparent caregiver is someone who cares for members of their family of origin, or for their family of choice. A direct care worker provides caregiving support in home and community-based settings as part of their paid employment.⁹

Cognitive dysfunction or impairment (aka “brain fog”): Deficits in attention and concentration, verbal and nonverbal learning and recall, short-term and working memory, visual and auditory processing, problem solving, processing speed, and motor functioning. This is a symptom that many, although not all, people with Long COVID experience.

Contextual support: Other factors that contribute to the intensity and nature of Long COVID’s impact on a person’s life. Also referred to as “social determinants of health,” these are conditions that affect a wide range of health, functioning, and quality-of-life outcomes and risks. In this report, contextual support describes a range of resources that may or may not be available to someone, and barriers to health care, support, and overall living stability.

Disability insurance: Disability insurance is a form of insurance that replaces lost income for someone with psychological disorders or an injury, illness, or condition that causes them physical impairment or incapacity to work. It ranges from paid sick leave, short-term disability benefits (STD), and long-term disability benefits (LTD) provided by federal programs from the Social Security Administration, some state-sponsored plans, and private, paid programs from commercial insurers.

Human-centered design (HCD): A creative approach to problem solving that centers the process and solutions around the people and communities who are impacted. Using qualitative research, this approach humanizes the problems at hand by viewing lived experiences and perspectives as valuable and necessary in solving the problems, and can augment clinical and public health research and initiatives.

Infection-associated chronic illnesses: Illnesses that include a patient history of infection by viral or bacterial pathogens followed by long-lasting and often debilitating symptoms including severe fatigue, cognitive impairment, and multi-organ dysfunction. Examples of infection-associated chronic illnesses include: Long COVID or post-acute sequelae of COVID-19, myalgic encephalomyelitis/chronic fatigue disease (ME/CFS), persistent or post-treatment Lyme disease, and multiple sclerosis.

Long-hauler: A term created by Amy Watson, a person with Long COVID, in 2020, when she created the Facebook group “Long Haul COVID Fighters.” It is often used by people with Long COVID to describe the COVID-related health challenges and disruptions in their daily lives.

Opportunity area: Synthesized from our human-centered design research, we identify the major issues faced by the Long COVID community and separate them into specific opportunity areas for improvement. These opportunity areas encompass what work needs to be done to improve the quality of life and care for people impacted by Long COVID, based on what are the highest priority issues for them, as well as what solutions will have the most impact from their perspective.

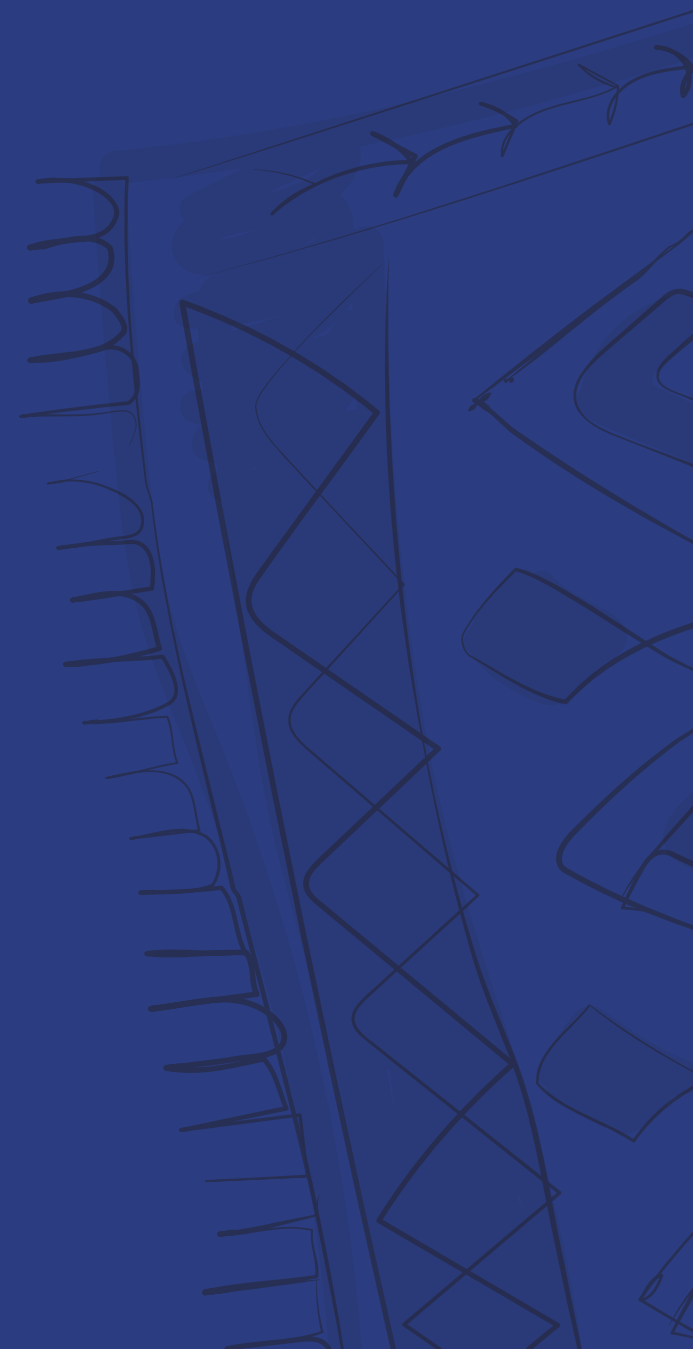
Long COVID clinics: Care centers or clinics established to identify patients with Long COVID and deliver early multidisciplinary health care services, from screening for disease outcomes, early rehabilitation, and targeted specialist referrals. Multidisciplinary teams are from a broad range of specialties and focused on addressing the issues of COVID-19 recovery. Long COVID clinics may also be referred to using other terms, including Post-COVID Care Centers, Post-COVID Recovery Clinics, and Comprehensive COVID-19 Centers.

Severity: The nature and intensity of the symptoms and health impacts experienced by someone with Long COVID, as well as their duration over time. Some people experience mild symptoms, while others are physically and cognitively debilitating.

Subject-matter expert: An individual who by education, training, or lived experience is a recognized expert on a particular subject or topic.

The Department of Health and Human Services (HHS): The U.S. federal government agency responsible for protecting the public’s health and providing important services. The Department of Health and Human Services works with state and local governments throughout the country to do research and provide public health services, food and drug safety programs, health insurance programs, and many other services.

**LIVING WITH LONG COVID:
Long COVID's Impact**





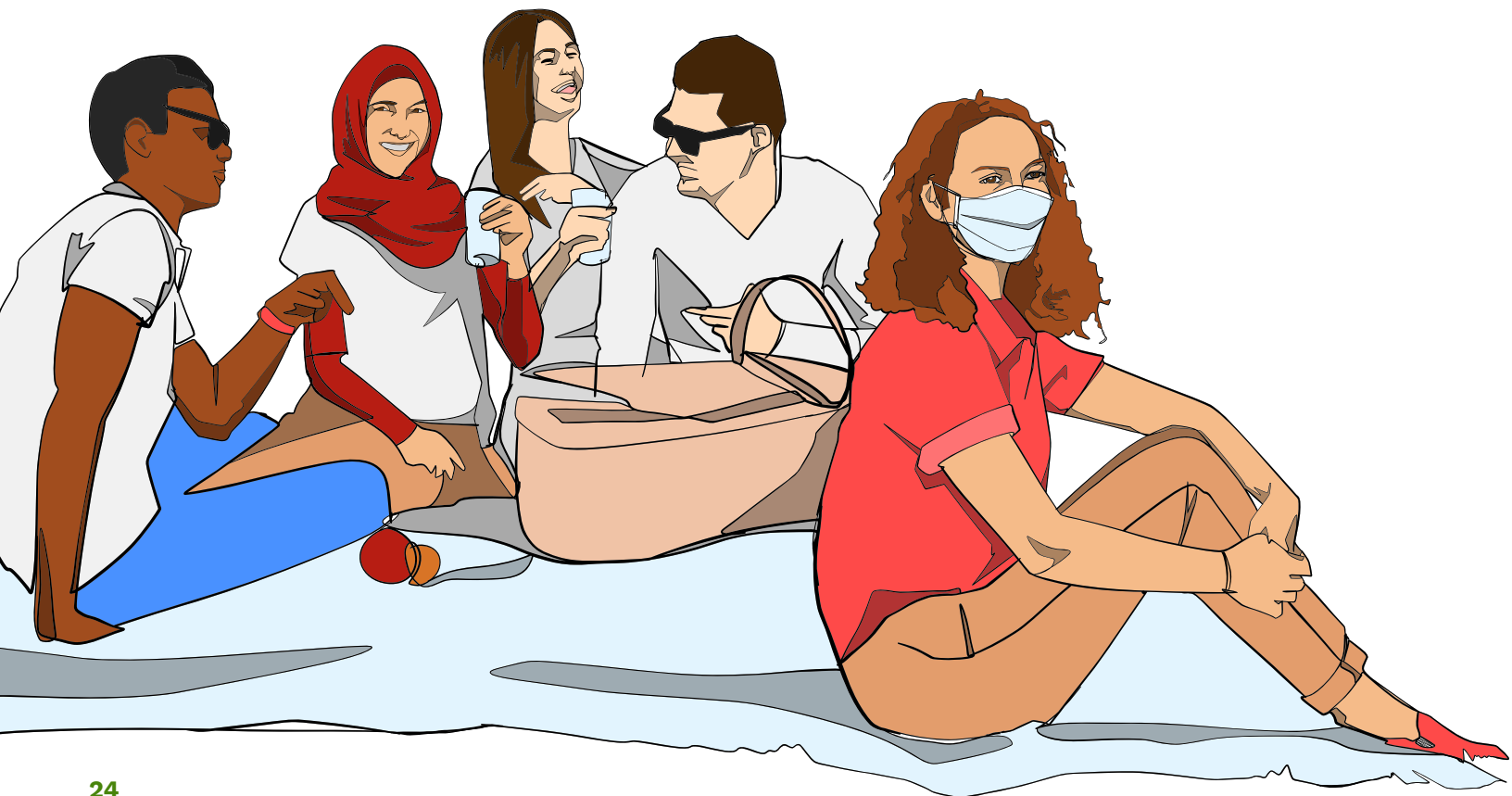
Living with Long COVID:

Long COVID's Impact

Overview

Long COVID has been called “a silent epidemic”¹⁰ and a potential “mass disabling event.”¹¹ But what does this impact look like at the scale of one person's life?

The intensity and nature of the impact Long COVID has on people's lives varies dramatically. This variance is caused primarily by two factors:



1. Severity of Long COVID:

Here, “severity” encompasses the nature and intensity of the symptoms and health impacts experienced, as well as their duration over time. Some people experience mild symptoms, while others experience physically and cognitively debilitating ones.

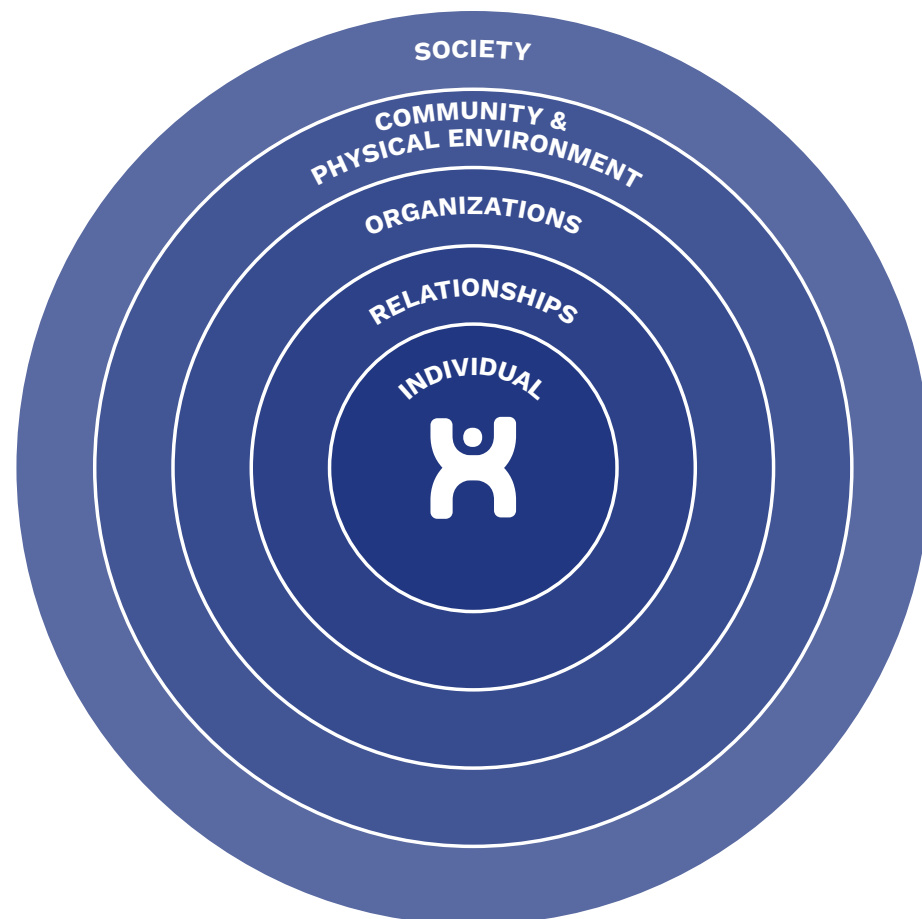
Some of the most common symptoms include: fatigue, post-exertional malaise, hair loss, chronic pain, cognitive dysfunction (“brain fog”), neurological tremors, depression, anxiety, cardiac impairment, pulmonary impairment, and an altered sense of taste or smell.¹² However, the list of potential symptoms someone with Long COVID may experience is in the hundreds. Long COVID can also lead to the onset of other chronic conditions, including diabetes, myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS), and heart disease.¹³

Long COVID symptoms may be experienced for a few months or weeks but dissipate with time. Other symptoms may be experienced for many months or even years, and while they may fluctuate, they do not disappear. Although people with a more severe initial infection are more likely to develop Long COVID, Long COVID symptoms can arise in anyone who had COVID-19, regardless of the severity of their initial infection.¹⁴

2. Contextual Support:

The other factors that contribute to the intensity and nature of Long COVID’s impact on a person’s life can be described comprehensively as “contextual support,” also referred to as “social determinants of health.” These are conditions that affect a wide range of health, functioning, and quality-of-life outcomes and risks.¹⁵ In this report, contextual support describes a range of resources that may or may not be available to someone, and barriers to health care, support, and overall living stability.

These factors can be organized across several different “levels,” depicted below and described to the right.



Individual

Personal characteristics, skills, and other factors

- Health literacy.
- Capacity to advocate for yourself in health care, workplace, and educational settings.
- Pre-existing health conditions and co-morbidities.
- Financial stability.
- Languages spoken.

Relationships

Family, friends, and other social connections

- Presence of someone who can serve as a supportive caregiver, if needed.
- Presence of a reliable support network of family and friends.
- Participation in online or in-person affinity groups.

Organizations

Schools, workplaces, and other groups

- Job stability and flexibility.
- Ability of employers and school administrators to provide reasonable accommodations and modifications.
- Insurance coverage.
- Presence of support organizations (e.g., faith-based institutions) that offer various forms of support.

Community and Physical Environment

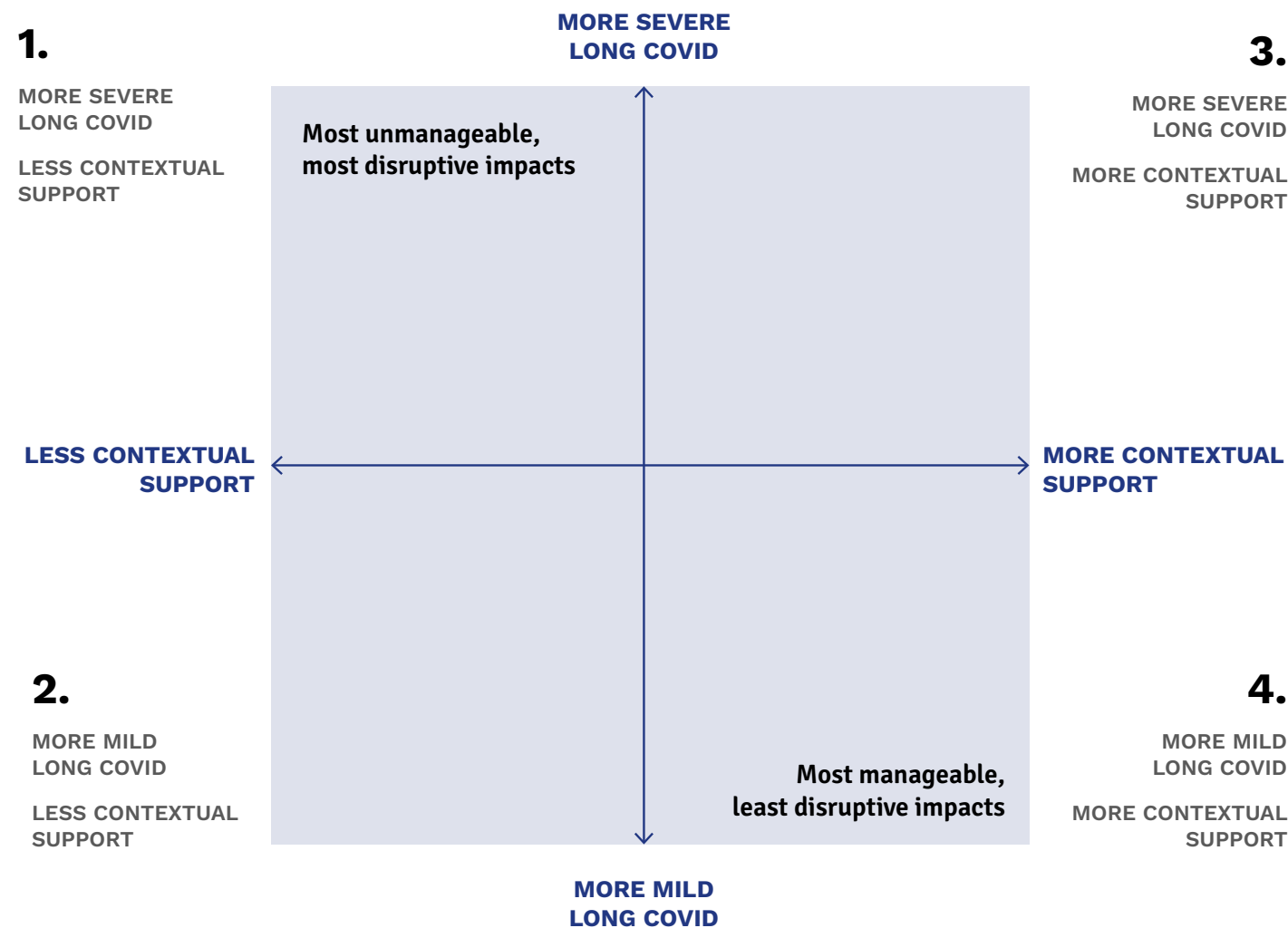
Housing, public spaces, and neighborhood characteristics

- Access to stable, affordable, accessible housing.
- Access to physical, mental, and behavioral health care.
- Access to healthy foods.
- Access to disability and other food, rent, and bill payment assistance programs.

Society

Policies, cultural norms, and politics

- Stigma and bias towards one’s identity (e.g., as a person with a disability, a person of color, or as a child).
- Structurally discriminatory or inequitable practices and policies that under-resource communities and regions of health care, healthy food, and safety.
- Politicization of COVID-19 and level of awareness of Long COVID.



While no two experiences with Long COVID are the same, we can begin to break down different experiences according to these factors to illuminate the differences and commonalities across people’s experiences with Long COVID and its impact on their lives.

1. More Severe Long COVID + Less Contextual Support

With less access to resources and fewer supports available, a severe case of Long COVID can send far-reaching shocks through someone’s life and have devastating impacts.

Challenges these individuals face

- They need robust medical assistance but have a more difficult time accessing care for a number of reasons, including being under- or uninsured, having fewer financial resources, or lacking transportation.
- They need a constellation of assistance programs but may have a more difficult time applying for aid, given their symptoms and unstable context.
- Their ability to stay employed or in school is directly affected, leading to increased financial instability.
- Their illness may affect their housing stability, leading to an increased chance of eviction or homelessness.
- They may have a higher prevalence of morbidities and pre-existing conditions, particularly in unhoused individuals, which can complicate diagnosis and treatment.

“I lost my job. I lost my house. I lost my roommates.

I couchsurfed for five months after that. I didn’t have the funds [for an apartment], because I had already been living paycheck to paycheck. ... I had worked in entertainment—and then entertainment died. There was no future.”

—Tara, recent graduate, theater producer, and person with Long COVID

2. More Mild Long COVID + Less Contextual Support

With less access to resources and fewer supports available, even a milder case of Long COVID can add complexity and difficulty to people's lives.

Challenges these individuals face

- Long COVID may impact their performance at work or school. They may need accommodations that they are unable to get.
- They may doubt or second guess their health experiences, and may feel uncomfortable opening up to colleagues, family, friends, and providers.
- They may have fewer support networks or supportive individuals to assist as needed.
- They may feel isolation as a result of being unable to do as much as they did prior.

“I can't do everything all at one time. One task for one time, that's it. I don't multitask anymore. If I'm going out to get the mail, or if I'm taking the cats out when they want to go outside, that's all I'm doing.”
—Madison, product designer, sister, and person with Long COVID

3. More Severe Long COVID + More Contextual Support

More resources and support mean more “guardrails” to prevent a severe case of Long COVID from totally upending someone's living stability. Nonetheless, the illness can still be devastating to the individual and their loved ones.

Challenges these individuals face

- They need robust medical assistance, and spend inordinate time, energy, and money seeking care.
- Their caregivers take on many additional responsibilities, such as attending medical appointments, filing paperwork, and doing household chores.
- They may need to leave work or school, permanently or temporarily. Even with assistance, they may struggle to apply for disability insurance.
- Because their ability to stay employed or in school is directly affected, they may question their self-worth and identity.

“I used to have purpose. My day was filled with things that I was excited about, projects that I wanted to do, people that I wanted to see. ... Now my life is pretty much just me, my three dogs, and Netflix.”
—RaMell, jewelry designer, entrepreneur, and person with Long COVID

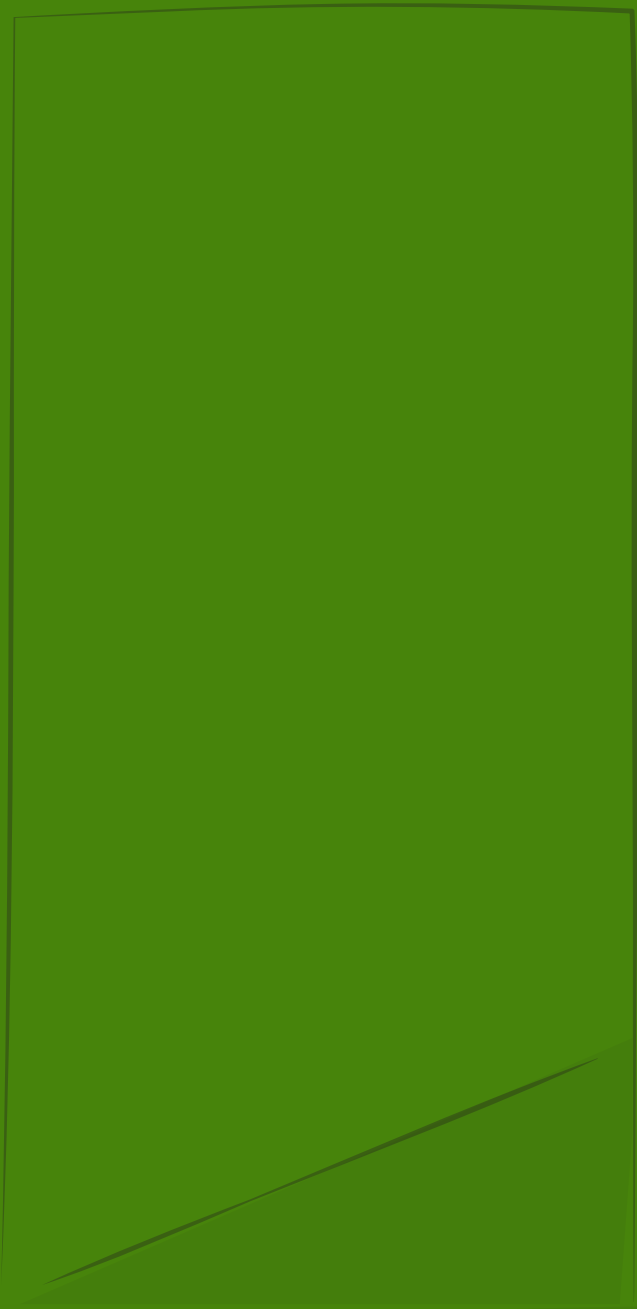
4. More Mild Long COVID + More Contextual Support

A milder case of Long COVID, even with more resources and support in place, may still cause complications and frustrations, but they are generally manageable.

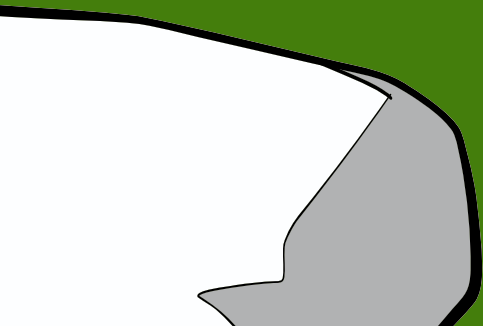
Challenges these individuals face

- They may have difficulty working or studying the same way they did before. They may need changes or adjustments in workplace and educational settings.
- They may second-guess the validity of their symptoms, and/or may not be able to tie symptoms back to COVID-19.
- They may feel isolation as a result of being unable to do as much as they did prior.

“I used to like running when I had the time, but this is when I wonder, like, **is this Long COVID, and do I need to be seen? Or am I just aging and a little more out of shape than I was before?** And that's part of why I don't get seen. I don't want them to just tell me, ‘Oh, you've put on some weight. Make some life changes and you'll be just fine,’ because I know I need to do that, too.”
—Briyana, nonprofit administrator, mother, and person with Long COVID



SEEKING SOLUTIONS:
The Treatment Journey



Seeking Solutions: The Treatment Journey

Through our research with people with Long COVID, their caregivers, and health care providers, we learned about a wide range of experiences people have seeking medical assistance.

Ideal Journey

Before we explore the actual experiences people with Long COVID and their caregivers have seeking treatment, let's look at what an ideal care journey might look like.

Note: This treatment journey may not be applicable or relevant to everyone with Long COVID. If symptoms are extremely mild or are noticeably improving, a person may not require this level of care.



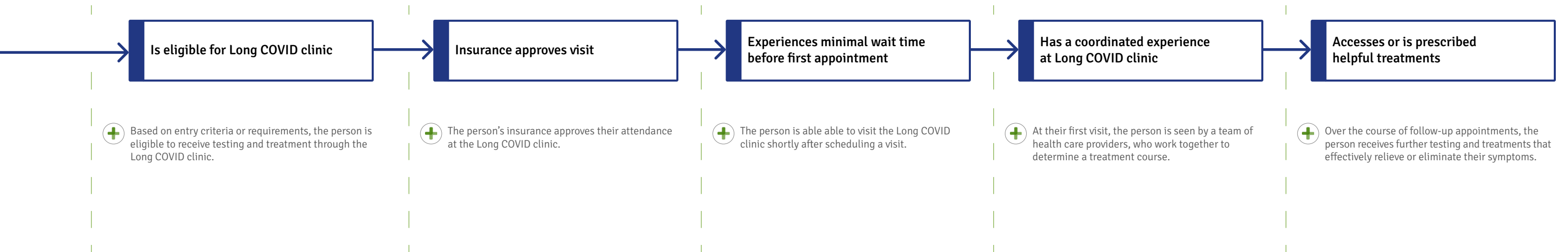
+ To begin, a person experiencing Long COVID-like symptoms schedules a visit with a health care provider (likely their primary care provider) or visits an urgent care center or emergency room.

+ At the appointment, the health care provider listens to and validates the experiences the person is describing, and has enough knowledge about Long COVID to elevate it as a possible cause.

+ The health care provider uses a set of diagnostic criteria based on patient-reported outcomes and biomarkers to diagnose the person with Long COVID. They may order other tests in the meantime to confirm the diagnosis and rule out other possibilities, but the diagnosis allows the person to more easily access Long COVID-related treatments, file for disability insurance, and request workplace accommodations.

+ The health care provider refers the person to the closest Long COVID clinic.





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Pain Points

The ideal journey is not the care journey most, if any, people with Long COVID have currently. Each step of the way is far more complex.

A variety of other convoluted paths and pain points are typical of most care journeys. These barriers make the care journey more difficult. At each step of the way, some people may be unable to continue.

⚑ A person may be prevented from seeking out care. For example, a symptomatic child whose parents do not know about Long COVID may be unable to access care.

⚑ A person may worry about affording care due to being under- or uninsured, and choose not to seek care.

⚑ A person may not trust health care providers and choose to look towards alternative sources for information and solutions.

⚑ A person may not know about Long COVID, and instead assume symptoms are related to allergies, aging, or stress.

⚑ A health care provider who is either not versed in Long COVID and infection-associated chronic illnesses or who harbors stigma against chronic illness and COVID-19 may misdiagnose a person's symptoms. Common misdiagnoses include anxiety and depression.

⚑ A health care provider may not believe the person and dismiss their symptoms entirely.

⚑ The health care provider may be reluctant to diagnose them with Long COVID, and instead send them to one or more specialists for further testing. Because the demand for specialists relevant to Long COVID has skyrocketed, people often endure significant wait times for appointments. A person may spend months, or even a year, waiting for a specialist appointment.

⚑ Because of inadequacies in today's testing capabilities, testing often turns up normal results for people with Long COVID. In these instances, they may be sent to another specialist, or simply told there's nothing wrong with them.

⚑ If the person is not referred to a Long COVID clinic but is instead referred to a range of specialists, they are on their own to coordinate, schedule, track, and travel to and from many appointments.

⚑ A Long COVID clinic may be too far from their home to be a realistic option for care.

Consequences

These barriers to care are difficult for anyone, but they are easier to overcome when a person has sufficient financial resources, time, health literacy, and extensive support networks. This unequal access to care can lead to a further increase in health disparities.

➡ Many people are not receiving the medical attention they need.

➡ Official statistics on the prevalence of Long COVID may be undercounts, making it more difficult to allocate resources adequately.

➡ A person may waste time and money trying treatments and medicines that are ultimately unhelpful.

➡ A person may lose trust and faith in their health care providers, and decide not to pursue care any longer.

➡ A person may endure symptoms daily while they wait for their appointments.

➡ A person is more likely to be denied financial assistance from disability insurance without a diagnosis and certifications from specialists. They may also have more difficulty requesting accommodations from their employers or schools.

➡ After being dismissed and told there's nothing wrong, a person might become so desperate as to try untested or even dangerous treatments.

➡ A person may be too impaired by their Long COVID symptoms to be able to manage the care coordination process for themselves, which may lead to unscheduled or missed appointments, and ultimately, the end of receiving care.

➡ A person may not be able to travel regularly, or travel great distances, either because of their Long COVID symptoms, or because of other life circumstances. Unless they have the assistance of a caregiver, they may be unable to access the care they need.

Quotes

🗣️ "I didn't want to go to the hospital because I didn't have insurance. ... If I did have health insurance, I would do whatever the doctors told me. Like, 'hey, you need to see a cardiologist.' I would go to the cardiologist."

—Carlos, office manager, fiancé, and person with Long COVID

🗣️ "One of the doctors said, 'Oh, this is all in his head. You know, maybe if you stop talking about, he'll forget about it.'"

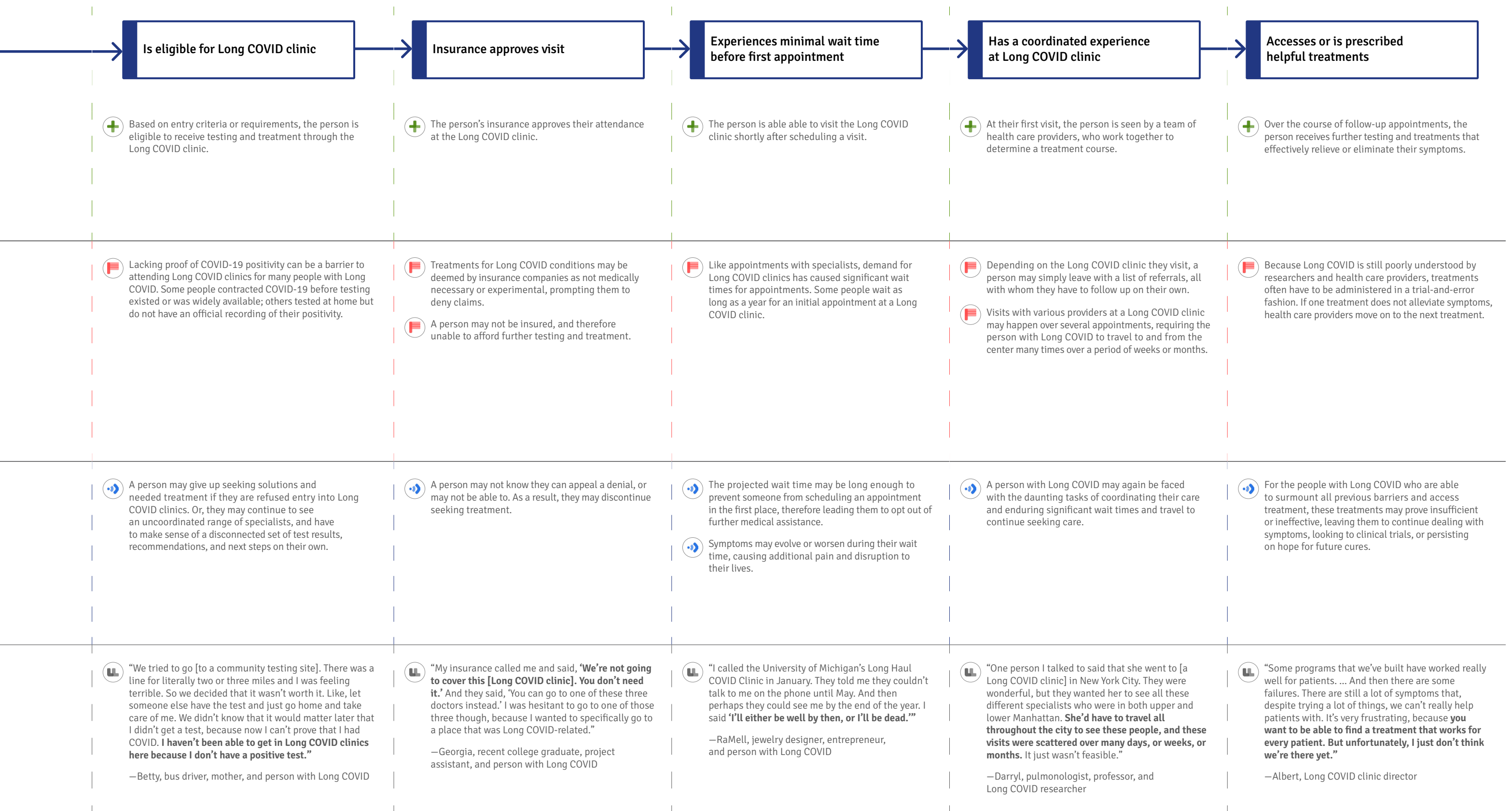
—Rebecca, therapist, mother to two children with Long COVID, and person with Long COVID

🗣️ "I had already been to several doctors at this point. I went to urgent care. I went to a pulmonologist and a cardiologist a number of times. I went to a lot of different doctors and they were absolutely unresponsive. They would look at my chest. 'X-Ray is clear. There's nothing wrong with you.' 'Your EKG is fine. There's nothing wrong with you.' ... So, I decided to try ivermectin. The FDA and the CDC were both saying don't take it. But I was desperate."

—Agatha retired professor, writer, and person with Long COVID

🗣️ "I've had to see 40 different doctors to get to the right specialists."

—Amalee, Long COVID advocate, mother, and person with Long COVID

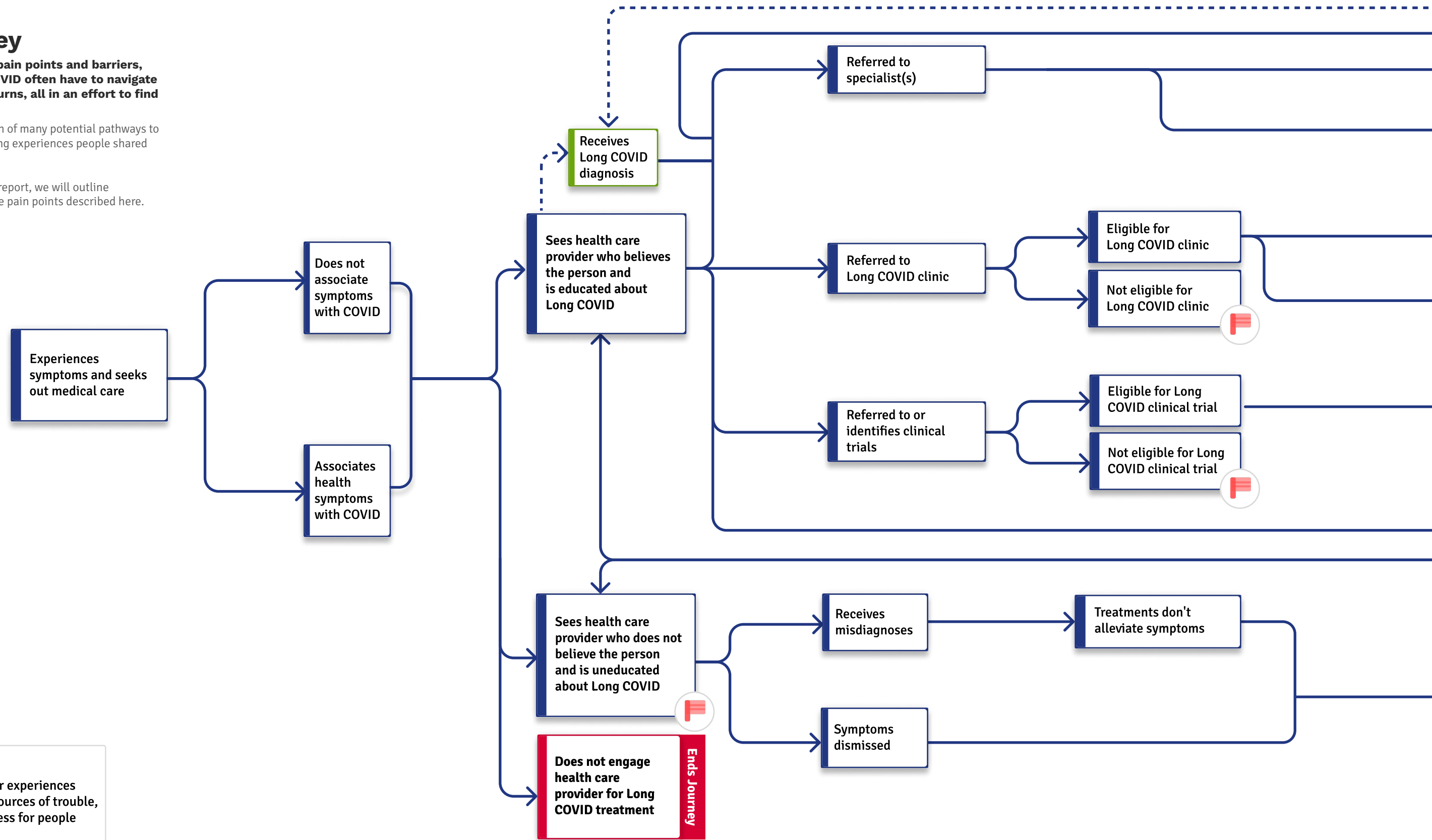


Actual Journey

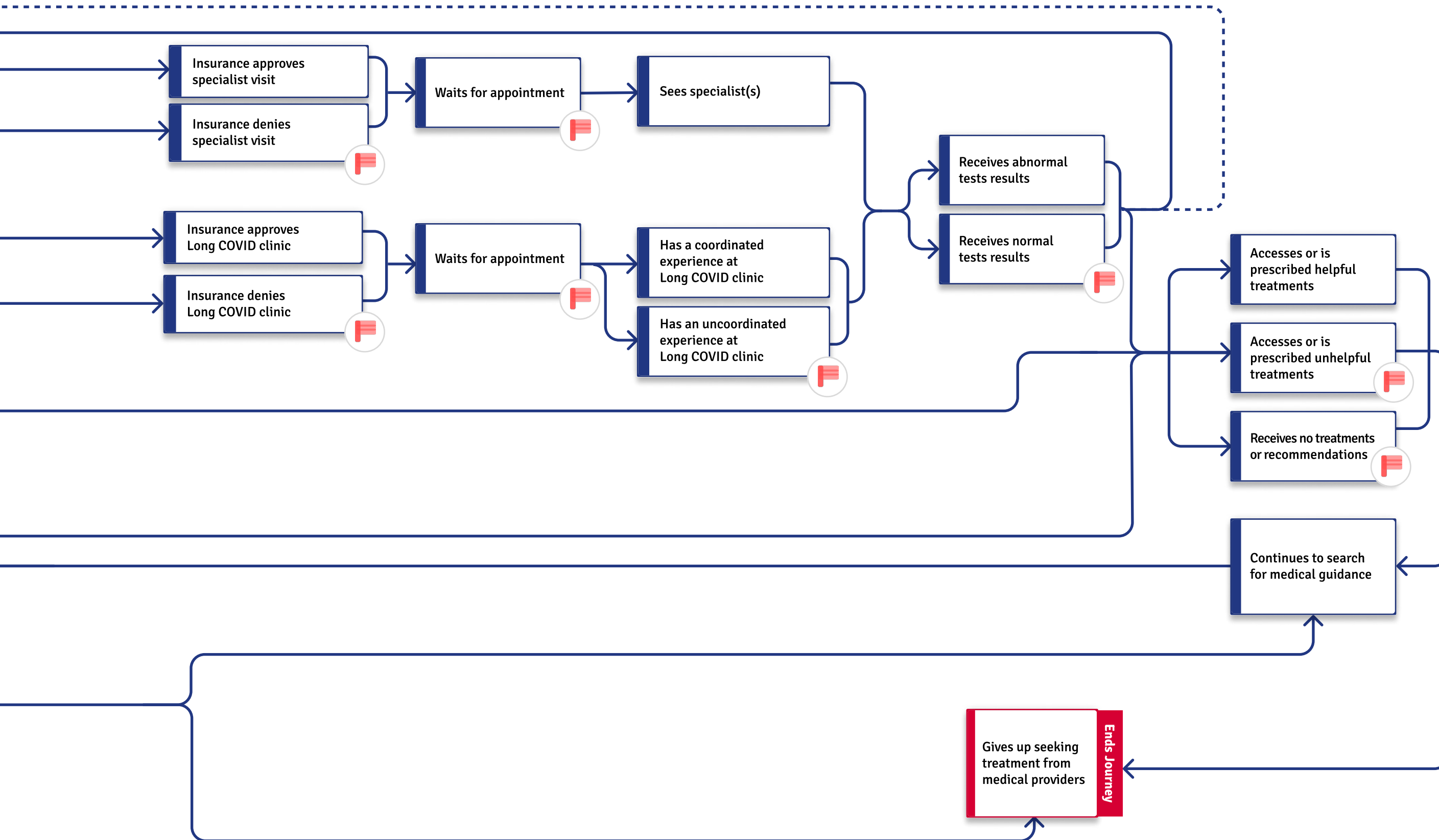
As a result of these many pain points and barriers, people living with Long COVID often have to navigate a labyrinth of twists and turns, all in an effort to find answers and relief.

This map shows the aggregation of many potential pathways to care and is based on the differing experiences people shared with us during our research.

In the following section of this report, we will outline opportunities for addressing the pain points described here.



Pain Points
Specific problems or experiences that are recurring sources of trouble, annoyance, or distress for people with Long COVID.





**TAKING ACTION:
Improving the Quality
of Life and Care**





Taking Action:

Opportunities to Improve the Quality of Life and Care for People Impacted by Long COVID

A Framework for Addressing the Long COVID Experience

Through our research, we identified nine opportunity areas, each of which are explained in the following pages. Altogether, they influence four ecosystems—public, assistance, health care, and innovation—which influence a person with Long COVID’s experience either directly or indirectly.

Within each of these opportunity areas, we will share an insight, or brief takeaway from research, followed by additional related information. Then we share an opportunity statement, or defined area for problem solving, along with an emerging set of recommendations. These recommendations are intended to holistically support people with Long COVID by enlisting change from a range of audiences, including health care providers, assistance providers, educators, employers, researchers, advocacy organizations, and the general public. With the implementation of all of these recommendations, efforts should be made to direct resources towards

marginalized and historically-underserved areas and communities, including communities of color, LGBTQ+ individuals, disabled individuals, older adults, and those living in rural or tribal regions.

All recommendations were either suggested or inspired by our research participants. In some cases, the Coforma team refined suggestions in order to make them more concrete while still adhering to the general vision provided by the participant. For the complete list of recommended ideas organized by opportunity area, see Appendix 1, Full List of Recommendations.

Opportunities Framework

VISION FOR THE INNOVATION ECOSYSTEM:
Treatments, tests, care paths, and cures that improve the quality of care and life for people with Long COVID.

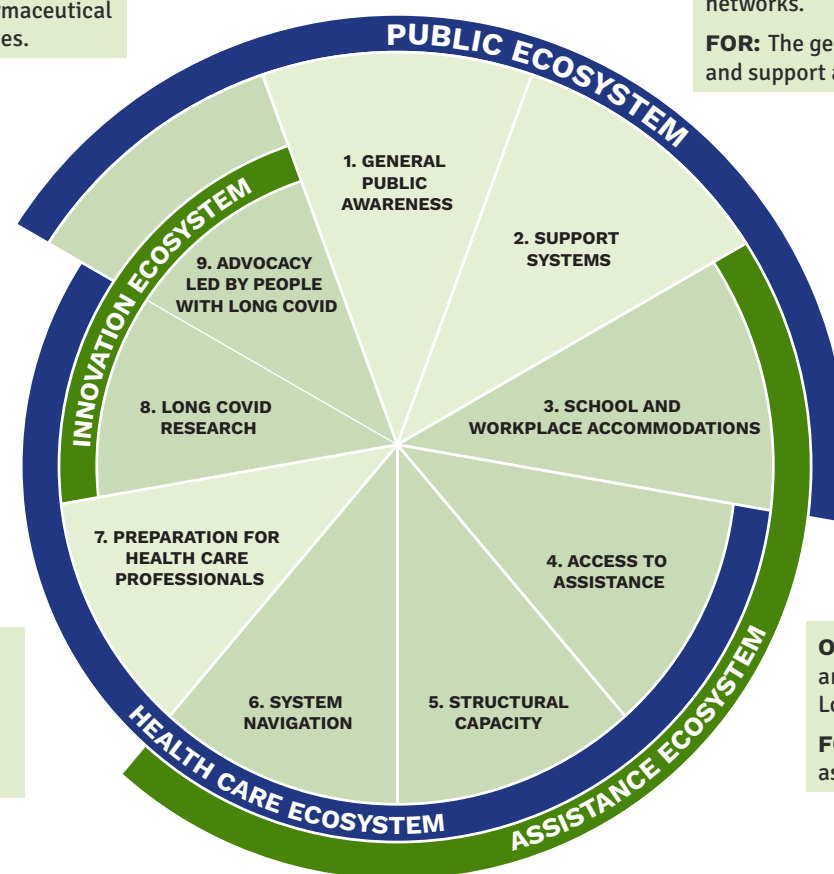
OPPORTUNITY: Expand support and resources for advocacy efforts led by people with Long COVID and allies.
FOR: Advocacy organizations, pharmaceutical companies, and philanthropic entities.

OPPORTUNITY: Increase public awareness around Long COVID, and establish public policies that protect everyone from Long COVID.
FOR: The general public.

OPPORTUNITY: Assist people with Long COVID in building or boosting their support networks.
FOR: The general public, health care providers, and support and assistance providers.

VISION FOR THE PUBLIC ECOSYSTEM:
Safe, responsive, and supportive conditions that enable people with Long COVID to more fully engage in the world around them.

OPPORTUNITY: Expand pathways for Long COVID research that can spur rapid innovation and breakthroughs.
FOR: Medical researchers and advocacy organizations.



OPPORTUNITY: Support schools and workplaces to affirm, support, and accommodate people with Long COVID and their caregivers.
FOR: Educators and employers.

OPPORTUNITY: Train and resource health care providers to adequately identify and assist people with Long COVID.
FOR: Health care providers, and schools of medicine and public health.

OPPORTUNITY: Increase access to disability and other assistance programs for people with Long COVID and their caregivers.
FOR: Health care providers, support and assistance providers, and insurance providers.

VISION FOR THE HEALTH CARE ECOSYSTEM:
A health care system that is resourced and structured to support people with Long COVID.

OPPORTUNITY: Remove the care navigation and coordination burden from people with Long COVID and their caregivers.
FOR: Health care providers, and support and assistance providers.

OPPORTUNITY: Increase the capacity of health care and assistance systems to support the increase in need.
FOR: Health care providers, and support and assistance providers.

VISION FOR THE ASSISTANCE ECOSYSTEM:
Support and assistance that allows people with Long COVID to do what's most important—focus on their health.

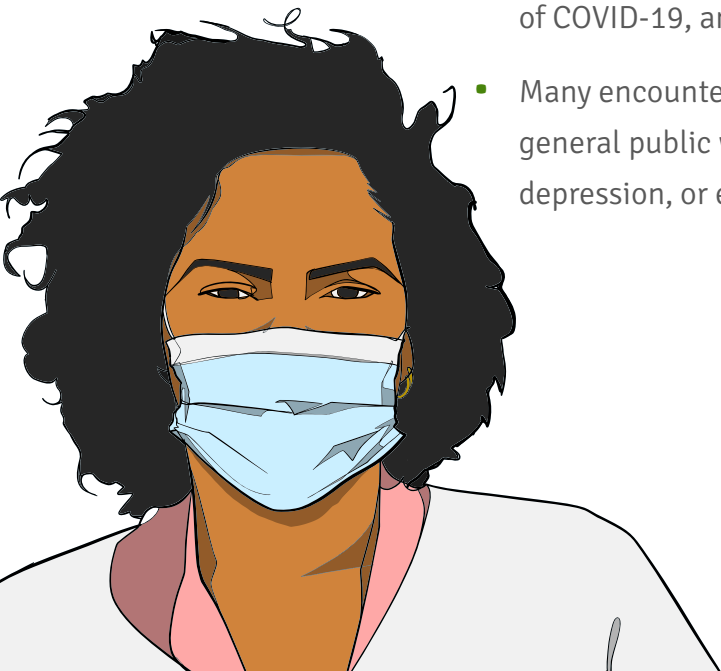
Opportunity Area 1:

General Public Awareness

Insight

People with Long COVID and their caregivers feel marginalized, misunderstood, and isolated by a general public that is impatient for a return to business as usual.

- The perceived lack of official, urgent action from public health officials on Long COVID frustrates people with Long COVID, who recognize the long-term risk of contracting COVID-19 and do not see enough being done to protect the public. Additionally, the dearth of communication can make people more susceptible to misinformation about Long COVID.
- Many people with Long COVID avoid public spaces and events due to a fear of reinfection and the potential worsening of their Long COVID symptoms and health impacts. Some may experience PTSD symptoms as a result of trauma they incurred during their acute infection. The lifting of mask mandates and indifferent attitude towards masking and social distancing typical in many public and private places further isolates people with Long COVID.
- Some people with Long COVID experience hostile interactions and aggressive comments from others in public because of ableism, xenophobia, racism, ageism, the politicization of COVID-19, and a stigma toward people with some chronic illnesses.
- Many encounter situations in which family, friends, and people from the general public write off their symptoms as the byproducts of anxiety and depression, or even worse, laziness and an excuse not to work.



“There are times I want to go out and be in public, but I’m also very skeptical and very frightened about being around lots of people while COVID is still such a rampant virus. **People don’t realize that people are still getting very sick and contracting Long COVID.**”

—Imani, interior designer, sister, and person with Long COVID

“[My son] is terrified of getting COVID himself. He prefers to homeschool for that reason. He has worn a mask even while playing soccer for a full 90 minutes for the last two years. And there have been adults at the games who make fun of him to his face for wearing a mask while he plays. It’s hard on him because he’s doing the right thing. **He’s protecting himself and protecting me from re-infection again. He’s getting made fun of for trying to protect his mom.**”

—Amalee, Long COVID advocate, mother, and person with Long COVID

“**I get a lot of the ‘you’re too young to be disabled’ comments.** Like, random people [on the bus] will say, ‘you need to give up your seat.’ And I’m like, ‘I have a cane. One of my legs doesn’t work properly.’ I usually just try to avoid confrontation because of the sheer amount of violence that the pandemic is propagating.”

—Shannon, student, medical research intern, and person with Long COVID

“[Long COVID] is not a very tangible thing for a lot of people. They don’t see it happening to them or somebody they know, or they don’t realize that what they’re experiencing is Long COVID. I have had conversations with people who are like, **‘Oh, I had COVID, and I’m totally fine, but you know what’s weird? I can never feel the tips of my fingers now.’**”

—Andrea, Long COVID advocate

Opportunity:**Increase public awareness around Long COVID and establish public policies that protect everyone from Long COVID.**

For: The general public.

Recommended Ideas:

- **Federal agency messaging:** Disseminate Long COVID messaging to U.S. government agency leaders and encourage them to amplify and share that Long COVID is real and is a serious public health issue.
- **Safe public space guidelines:** Encourage or mandate policies and protocols regarding masking and social distancing in public spaces that protect people from infection or reinfection and possible Long COVID.
- **Public messaging campaigns:** Launch mass public messaging campaigns, translated into multiple languages and available in alternative formats, to increase the public's literacy and awareness of Long COVID.
- **Vaccine promotion:** Promote vaccination as a preventative measure for Long COVID.
- **Mental health awareness:** Increase general awareness of how Long COVID impacts the mental and behavioral health of people living with the illness and their caregivers.



Opportunity Area 2:

Personal Support Systems

Insight

Supportive family and friends make or break the experience of a person with Long COVID. Often, however, they are absent.

- Supportive caregivers often help with daily activities and responsibilities, provide emotional support and strength, and assist with care coordination. These actions can in turn help reduce psychological distress for a person with Long COVID. However, the role can come with a tremendous mental, emotional, logistical, and financial burden.
- Painful divisions can occur between friends, family members, and even partners when there are misunderstandings about the nature of Long COVID, misconceptions about “what healthy looks like,” and caregiver burnout.
- Children with Long COVID whose parents or guardians do not understand or believe in Long COVID, or do not have the capacity to seek support, are in an especially dangerous position, missing out on necessary health care and school accommodations. Additionally, children do not have established support networks or systems to rely on, like many adults may have.
- Some children whose parents or guardians have Long COVID experience an abrupt shift in their role and responsibilities, taking on caregiving and financial responsibilities they did not have before. Paired with the emotional strain of seeing a parent struggle, these stressors can negatively impact a child’s mental health, cause a decline in their grades and marginalization within their social circles, and make them rethink or give up on future goals for themselves.
- Some people with Long COVID experience ongoing shame and marginalization resulting from the manner in which they got COVID or Long COVID, including those with long-term side effects from vaccines.



“I had to do a GoFundMe [fundraiser] after my hospitalizations, when I had to pay out nearly \$12,000.

I was crying from the generosity that I experienced [from family and friends]. ... It was really moving.”

—Edward, data scientist, writer, and person with Long COVID

“It’s really difficult to maintain sustainable relationships. People want you to get better in a linear timeline. And that’s just not the case for everyone. **People want to move on with COVID, and my body got stuck in 2020.**”

—Emily, hospitality manager, daughter, and person with Long COVID

“Sometimes it’s very frightening [not having a caregiver].

I think, ‘What if I fell down the stairs?’ I’ve had to install shower bars, because if I close my eyes, I get dizzy.”

—RaMell, jewelry designer, entrepreneur, and person with Long COVID

“[My husband] thinks the kids and I just need to toughen up and push through it. ... He doesn’t know what I truly feel like and what the kids truly feel like. He doesn’t want to hear about it anymore. ... **We have talked about divorce**, because I’m not much of a partner to him. I don’t have anything to offer him anymore.”

—Rebecca, therapist, mother to two children with Long COVID, and person with Long COVID

“If I had been younger and dealing with [Long COVID], ... **I would have been subject to my parents being absolute deniers and wouldn’t have been able to get the care that I needed.** [Being in college], I can advocate for myself and get the care I need.”

—Shannon, college student, medical research intern, and person with Long COVID

Opportunity:**Assist people with Long COVID in building or boosting their support networks.**

For: The general public, health care providers, and support and assistance providers.

Recommended Ideas:

- Expanded mental and behavioral health care:** Expand affordable mental and behavioral health support for people with Long COVID, as well as their caregivers and children affected by Long COVID, so that they have support processing the psychological impacts of contracting COVID, living with Long COVID or living with someone who has Long COVID, and the consequences of it on their lives.
- Long COVID explainers:** Create explanatory materials for people with Long COVID to share with family and friends.
- Resources for support groups:** Reinforce existing Long COVID support groups with specialized funding, and develop additional support groups for people with Long COVID and their caregivers.
- Chore and household assistance:** Create or expand assistance programs that help people with Long COVID and caregivers with daily chores, such as grocery shopping and cleaning.
- Financial support for families with children:** Provide financial support for families who need to provide additional care to children with Long COVID.
- Legal protections for children with Long COVID:** Ensure that children with Long COVID are able to access the care they need through the passing of legislation and creation of advocacy and assistance programs.



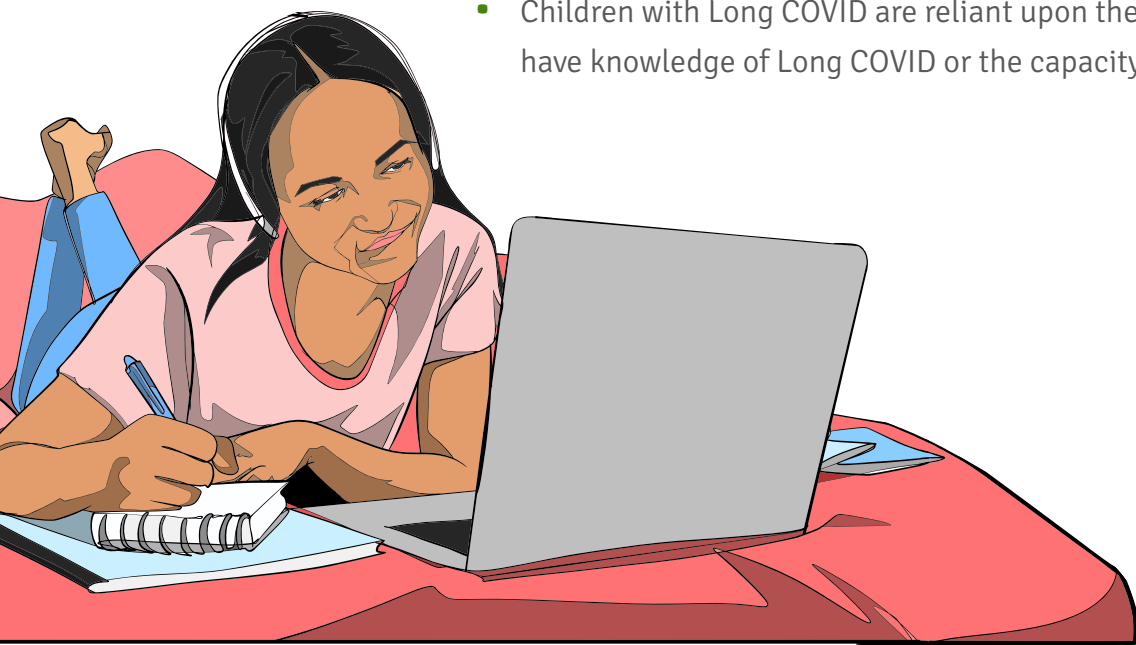
Opportunity Area 3:

School and Workplace Accommodations

Insight

When trying to work or go to school, many people with Long COVID and their caregivers are left to negotiate for accommodations on their own.

- Once someone with Long COVID qualifies as disabled, under federal civil rights laws their workplace and educational setting must provide “reasonable modifications.” However, many workplaces and educational settings are unprepared for the collaborative process of figuring out what changes and adjustments can help someone continue to do their job and perform at school.
- Many people with Long COVID are denied temporary or permanent work or school accommodations, which means they may have to reapply every few months, and struggle to meet performance standards at work or at school. They may decide they must quit or leave, and in some instances, they may even be fired. While not required, lacking a positive COVID-19 test or Long COVID diagnosis can make the request for accommodations even harder to legitimize.
- Those with Long COVID symptoms but without an official diagnosis or positive COVID-19 test often find themselves, and their caregiver, if applicable, engaging in conversations of explanation, feeling the need to justify their situation in hopes of gaining understanding and empathy for their need for accommodations.
- Children with Long COVID are reliant upon their parents or guardians, who may or may not have knowledge of Long COVID or the capacity to successfully advocate on their behalf.



“The disappointing thing is that despite being a very science and evidence-based school, our medical department refused to listen to me. They were like, ‘Oh, you are a one-off case. You are not of our concern.’”

—Shannon, college student, medical research intern, and person with Long COVID

“When I requested accommodations through both my primary care and my GI doctor, neither one of them was willing to sign any kind of ADA paperwork—even though I obviously have disabilities. In fact, my GI doctor said, ‘I don’t even know if you have any disabilities. Why would I fill this out?’ It’s always me pushing back and not getting anywhere.”

—Renee, health insurance agent, animal rights advocate, and person with Long COVID

“As a paramedic, there are really no accommodations for me. I have to be able to run into a burning building, no matter what. I can’t have cognitive dysfunction when I’m drawing up meds to distribute to somebody. So for these types of jobs, it is basically fireable because there are no types of accommodations for this. There needs to be better support for folks in this situation to find a new line of work entirely.”

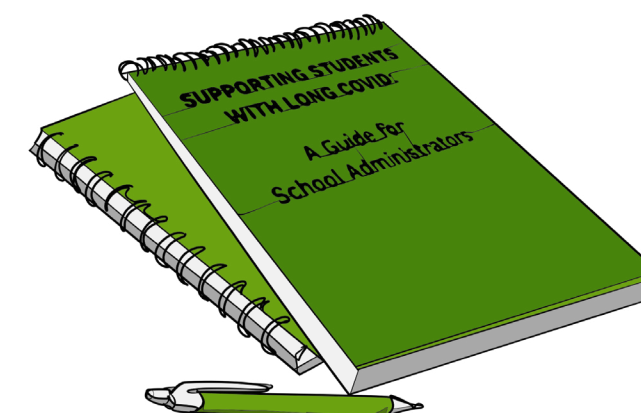
—Amalee, Long COVID advocate, mother, and person with Long COVID

“I’m getting messages from people I know. One told me that one of her kids had COVID and just never bounced back. He can’t remember anything. He doesn’t have energy. She said, ‘I don’t know how to go about getting accommodations in school.’ And these are from educated people of privilege. They can’t figure it out or even know that such accommodations are available.”

—Emily, Long COVID advocate and person recovered from Long COVID

Opportunity:**Support schools and workplaces to affirm, support, and accommodate people with Long COVID and their caregivers.**

For: Educators and employers.

**Recommended Ideas:**

- Revisions to accommodations policies:** Revise federal and state policies that mandate employers and schools to provide adequate support for people with disabilities, including people with Long COVID.
- Long COVID training for workplaces:** Provide training and educational materials for workplaces to build awareness, understanding, and empathy towards potential colleagues with Long COVID, with “how to guidelines” on customizing accommodations to fit the needs of someone with Long COVID.
- Accommodation suggestions by work type:** Develop general accommodations standards for various types of work and workplaces, acknowledging that different kinds of work require different types of accommodations, and breaking up the bottleneck of case-by-case modifications that delay the changes people with Long COVID need to continue working.
- Job transition assistance:** Offer employment assistance for people with Long COVID who can no longer do their jobs and need to seek new employment, such as job-searching assistance and retraining programs.
- Hiring incentives:** Taking inspiration from group specific tax credits such as The Returning Heroes Tax Credit and the Wounded Warriors Tax Credit, expand the Work Opportunity Tax Credit to include hiring people with disabilities.
- Funding for hazard pay and line-of-duty-related infections:** Taking inspiration from the 9/11 Victim Compensation Fund, provide funding for first responders, health care workers, other essential workers, and their survivors and dependents, who were infected by COVID-19 in the line of duty and are now disabled by Long COVID.
- Accommodations guidance for schools:** Provide education, guidelines, recommended accommodations, and ready-made “toolkits” for early childhood, primary, secondary, and post-secondary educational institutions to support students with Long COVID.
- Financial assistance for current and former students:** Offer additional financial assistance to current and former college students with Long COVID, including stipends for increased health care or boarding costs, as well as loan forgiveness for graduates.

Opportunity Area 4:

Access to Assistance

Insight

Although the impact of Long COVID is undeniable to people with Long COVID and their caregivers, many find it nearly impossible to prove their need for assistance.

- People with Long COVID report that they are regularly denied access to assistance programs intended to help with food, housing, and job placement, because they do not meet current eligibility requirements.
- Many people with Long COVID are denied disability benefits because they are not able to get the documentation needed from the appropriate specialists. Specialists have to provide a diagnosis and a prognosis, the latter of which can be hard to determine for some symptoms, like cognitive dysfunction, or those that fluctuate over time.
- Many Long COVID advocates and legal advisors believe that disability insurance administrators operate based on a presumption of denial; therefore, applicants often have to endure rounds of denials before succeeding.
- Many people with Long COVID report the providers and treatments they have found most helpful are not covered by insurance, such as acupuncture, functional health practitioners, and concussion clinics.



“If you’re suffering from brain fog and you don’t have a certification from a neurologist, the insurance company might not approve that claim for that reason. So that’s creating some issues for patients because **it’s costly for them to go get that specialist consultation, and it might take a lot of time.** There might be a long wait as part of this whole process.”

—William, Long COVID advocate and legal advisor

“I sent in my claim. They denied it. I sent a whole bunch of other paperwork. They asked for more paperwork this week. They wanted to know specifically why I cannot work. ... **I did go through some cognitive testing to show the amount of brain fog I have, but again, all of this is variable.** It’s not like every minute of the day is brain fog. I can be pretty high functioning sometimes, but not all day, and I can only do it for so long. I tried to work like this. I tried to do remote work. I tried to work part days, and it didn’t work. So, I’m currently fighting short-term disability.

—Kyle, hardware sales manager, father, and person with Long COVID

“A lot of people get denied because **there’s an assumption that you can do your job sitting.** Or they’ll say, ‘Well, if you can work, then you don’t qualify.’ And that’s where we’ve kind of hit a Catch-22.”

—Octavia, choir director and caregiver to an adult daughter with Long COVID

Opportunity:**Increase access to disability benefits and assistance programs for people with Long COVID and their caregivers.**

For: Health care providers, support and assistance providers, and insurance providers.

Recommended Ideas:

- **Wraparound services at Long COVID clinics:** Consolidate Long COVID treatment and professional help for navigating and understanding existing financial, state, and federal support services under one roof, for example, at Long COVID clinics and other care centers.
- **Referral pathways for benefits application assistance:** Refer people with Long COVID and their families to community-based organizations and programs that can assist them to apply for benefits, and increase funding for those programs to specifically serve people with Long COVID.
- **Flexible workplace reentry programs:** Develop flexible workplace reentry programs so that people with Long COVID can go on and off disability leave for a period of time without needing to reapply, thereby maintaining a percentage or all of their income during that time.
- **Reasonable accommodation consults:** Advocate for the involvement of occupational therapists, vocational rehabilitation specialists, and other disability support professionals in determinations around reasonable accommodations in workplace and educational settings.
- **Disability and caregiver credits:** Create Social Security credits for people with Long COVID and their caregivers.
- **Expedited applications:** Taking inspiration from the TSA PreCheck® program, create an expedited application program that fast-tracks applications for those who receive a Long COVID diagnosis.
- **Update disability criteria and processes:** Revise Social Security Disability Insurance (SSDI) standards for newly disabled people with Long COVID to shorten the application time.
- **Update CMS health plan guidelines:** Change CMS health plan guidelines for insurance and provider contract requirements to align coverage with medical treatments that show improved health outcomes for people with Long COVID.

Opportunity Area 5: Structural Capacity

Insight

In their quest to access essential health care assistance and support services, people with Long COVID repeatedly hit barriers, big bills, and long wait times.

- A scarcity of medical specialists equipped with knowledge relevant to Long COVID means people with Long COVID often wait for months just to be seen. This is true across the medical field, as well as at Long COVID clinics.
- An understaffed and underresourced Social Security Administration (SSA) means that many people with Long COVID are waiting months to hear updates on their disability applications.
- Some lawyers who provide assistance applying for SSDI are not taking Long COVID cases, viewing the application process as too burdensome or lengthy. This leaves people with Long COVID with few options for legal assistance.



“It takes months and months to get an appointment after you have a referral. I don’t have a referral and I know it would take months to get that. It takes a long time to get into the doctor these days.”

—Matthew, retired business owner, grandfather, and person with Long COVID

“There’s the wait before you get in [to a center], because we see so many patients. That’s the first frustration. And from there, **every break in the cadence causes frustration.**”

—Albert, Long COVID clinic director

“In 2021 ... I paid about \$19,000 out of pocket for medical bills the entire year. **Most of it was on a clinic that helped me recover immensely but was not covered.**”

—Maya, business consultant, daughter, and person with Long COVID

“After every surge, you see that there’s also a surge of patients who want to come see us [at the Long COVID clinic]. The reason is that you have more people being infected with COVID, so there are more people who are having these long-term effects. **So the ebb and flow of patient volumes is very hard to deal with.** How do you staff a practice where you’re going to have low interest or low volume months, and then for some reason, randomly high volume months?”

—Albert, Long COVID clinic director

Opportunity:**Increase the capacity of health care and assistance systems to support the increase in need.**

For: Health care providers, and support and assistance providers.

Recommended Ideas:

- **Improved Long COVID data tracking:** Improve data tracking for Long COVID so that its occurrence is better measured, and responses and resources can be adequately allocated.
- **High-demand specialty area pipelines:** Expand educational programs to train emerging health care providers in high-demand specialty areas.
- **Funding for Long COVID clinics:** Incentivize the creation and development of additional Long COVID clinics with dedicated staff.
- **Expanded Long COVID capacity in the SSA:** Increase resources and staffing within the SSA to handle the influx of people with Long COVID filing for Social Security Disability Insurance.
- **Long COVID care managers:** Establish care managers in the offices of health care providers and hospitals to assist people with Long COVID and their caregivers with scheduling and preparing for appointments, as well as issues with billing and insurance.
- **Long COVID clinic rating system:** Develop evaluation methods for rating the quality of care at Long COVID clinics and share ratings with the public.



Opportunity Area 6: System Navigation

Insight

Navigating health care and assistance systems requires that you educate yourself, advocate for yourself, and coordinate care for yourself. This is a tall order for anyone—much less for someone with a chronic illness.

- The same symptoms that necessitate a person with Long COVID to seek health care and assistance can get in the way of their ability to successfully access them, such as cognitive dysfunction and fatigue.
- Language; cultural barriers; biases against your race or ethnicity, gender, sexual orientation, age, or other aspect of your identity; and a lack of time or financial resources can further complicate the navigation process. Those with prior interfacing with the health care system and assistance programs have an advantage.
- Even many care programs designed for people with Long COVID, such as some Long COVID clinics, provide disjointed care.



“I am the coordinator, I’m the advocate, I’m the insurance specialist—and I’m the patient.”

—Emily, hospitality manager, daughter, and person with Long COVID

“There are some people who have symptoms that are so debilitating that **they cannot complete the application process for disability benefits.**”

—David, Long COVID advocate and legal advisor

“When the PPP loans became available, I couldn’t negotiate them. I couldn’t make heads or tails.

[Later,] the neurologist was able to very quickly discover that my short-term memory was broken.”

—RaMell, jewelry designer, entrepreneur, and person with Long COVID

“Isn’t there a fable about eight blind men who each are touching a different part of an elephant, and none of them are making the connection that all of these things are connected? It feels like that [with Long COVID]. **I’m also a fibromyalgia patient, so I’ve dealt with this kind of stuff before, with not believing that one symptom might be connected to the other.**”

—Renee, health insurance agent, animal rights advocate, and person with Long COVID

“Long-haulers have no team. They’re being ping-ponged from provider to provider. Nobody’s talking. There are drugs interacting that are not supposed to be. Somebody is going for an MRI with contrast today, and a brain MRI with contrast tomorrow, and nobody’s tracking or monitoring these things. **We need teams, not one-offs.**”

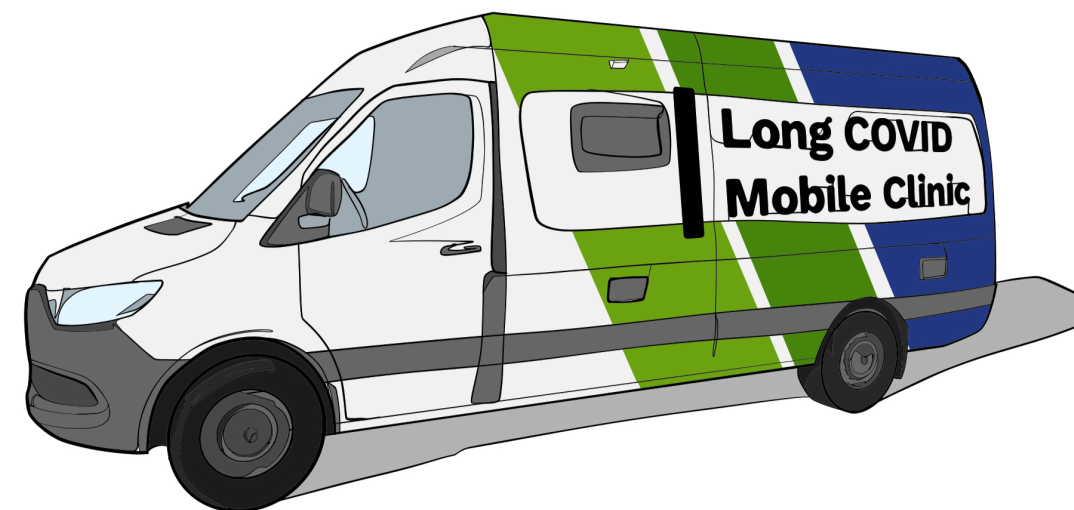
—Amalee, Long COVID advocate, mother, and person with Long COVID

Opportunity:**Remove the care navigation and coordination burden from people with Long COVID and their caregivers.**

For: Health care providers, and support and assistance providers.

Recommended Ideas:

- **Coordinated and comprehensive Long COVID clinics:** Improve coordination between health care providers, researchers, and case managers at Long COVID clinics so that people with Long COVID have a comprehensive, one-stop shop experience.
- **Care navigation support:** Assign care coordinators or case managers to assist people with Long COVID with scheduling and coordinating health care appointments.
- **Disability insurance navigators:** Offer third-party, neutral navigators who can assist people with Long COVID as they apply for disability insurance and other assistance programs.
- **Chronic illness knowledge transfer:** Study and draw on lessons from complex care programs and other models of caring for illnesses such as HIV, cancer, and other chronic illnesses.
- **Long COVID care program incentives:** Offer incentives for health care facilities, medical practices, and health insurers to have a dedicated program and staff trained on Long COVID care coordination and treatment pathways, and who can serve as an in-house advisor to colleagues.
- **Mobile care and telehealth:** Deploy Long COVID-specific mobile units and increase telehealth services for people who have difficulty accessing care, such as those in rural communities.
- **Patient-reviewed informational resources:** Develop informational resources for health care facilities, clinics, providers, and community organizations to easily print and distribute to people experiencing Long COVID symptoms that include vetted, patient-reviewed guidance on how to find care and support.



Opportunity Area 7:

Preparation for Health Care Providers

Insight

Many health care providers aren't adequately prepared to recognize Long COVID, or outright do not believe their patients. This leaves people with Long COVID without answers, options, or at the very least, a validation of their experience.

- Many health care providers, particularly in the primary care community, do not have the knowledge base that would enable them to link a constellation of potential symptoms to Long COVID. As a result, instead of being able to provide a diagnosis and initiate a care pathway during an initial appointment, health care providers may send people with Long COVID to a string of other specialists, delaying diagnosis, treatment, and the ability to apply for disability.
- People with Long COVID symptoms are frequently misdiagnosed by health care providers as functions of stress, anxiety, and depression; or, they are dismissed entirely, with many providers siding with test results—which often come back normal—over the patient's word.
- Long COVID symptoms in children are regularly missed or dismissed by pediatric providers. Children may not have the language to describe what they feel, or they simply may not be believed. As a result, there is often no further investigation of their symptoms.
- People with Long COVID often have to educate their providers about Long COVID, its potential pathologies, treatment options, relevant specialty areas, and clinical trials.
- The current reimbursement structure for health care providers works for simple problems and quick fixes, not complex, chronic illnesses. Providers usually do not have time to review complex patient medical records in advance of an appointment, much less discuss and make sense of a complex combination of symptoms during one.



“I was crying and begging [my PCP] to help me. And **she stared right into that camera and said to me that I was mimicking what I was seeing on television.** But at that time, I was sicker than I had ever been in my life. ... That conversation with her was so devastating. I never wanted to hear her speak to her again.”

—Martha, book editor, volunteer tutor, and person with Long COVID

“I explained [to the doctor] that I'd been having this fogginess in my head for months. It was really freaking me out. And **the doctor started asking me, 'Well, do you take drugs?' And I told him no, I have no interest in that.** And then he just kinda looked at me funny and said, 'Are you sure you don't take drugs?' And I'm like, really? So, he also diagnosed me with anxiety.”

—Carlos, office manager, fiancé, and person with Long COVID

“**We have to find a way that [reviewing medical records and extensive medical histories] can be reimbursed for doctors** so that they're incentivized to do it, because if they don't, you're not going to have enough doctors who are going to take care of these patients. And that will continue to be a problem leading to long wait times, poor coordination of care, or access.”

—Albert, Long COVID clinic director

“In order for patients to qualify for [assistance], doctors have got to put in the medical notes that they suspect their patients have Long COVID. If you don't put that in there, it makes for a horribly long process, and many of us are getting our claims denied. ... **I went to Johns Hopkins and St. Agnes thirteen times. ... When I look over my [medical records], there's nothing about suspected Long COVID.**”

—Imani, interior designer, sister, and person with Long COVID

Opportunity:**Train and resource health care providers to adequately identify and assist people with Long COVID.**

For: Health care providers, and schools of medicine and public health.

Recommended Ideas:

- **Sample care pathways:** Develop and distribute sample care pathways for health care providers, so diagnoses can confidently be made at initial appointments while further testing and treatments are conducted.
- **CPT® code guidance:** Share guidance with health care providers on CPT codes that can be used for Long COVID.
- **Training incentives:** Incentivize training on Long COVID for current health care providers, focusing in particular on the primary care and pediatrics communities, but reaching as broadly as dentists, ophthalmologists, and psychologists who may observe possible symptoms.
- **Health care provider training:** Engage academic partners to launch an expansive outreach campaign to train health care providers through in-person and virtual presentations on what Long COVID is, how to identify it, and suggested care pathways.
- **Regular Long COVID digests:** Regularly distribute educational resources to health care providers broadly with the latest information about Long COVID findings, testing, and treatments.
- **Long COVID education in medical schools:** Increase training on Long COVID and infection-associated chronic conditions in medical schools, and expand course requirements to include “narrative medicine,” an approach that widens the view of people with Long COVID beyond their medical histories.
- **Reimbursements for reviewing complex patient histories:** Revise health care provider reimbursement structures so that they are incentivized to review patient histories in advance of appointments, and are able to spend more time with patients exhibiting Long COVID symptoms or other infection-associated chronic illnesses.

Opportunity Area 8: Long COVID Research

Insight

There is a perception among some Long COVID researchers, advocates, and people with Long COVID that the Long COVID research ecosystem is missing opportunities to dramatically improve diagnosis, treatment, and outcomes of people with Long COVID.

- The desperation and sense of urgency for solutions that many people with Long COVID feel is not matched by the pace and priorities of research at many research institutions.
- There is a widely held perception among Long COVID researchers that many research institutions and laboratories favor National Institute of Health (NIH) funding over private or industry funding. However, there is also a perception that NIH's approach to Long COVID is incremental and focused on understanding pathology, not treatments or testing.
- Many of the leading researchers who are investigating breakthrough technologies, treatments, and tests are forced to seek alternate funding sources, special permission from their institutions, and complete the research on top of a full workload.
- Recruitment for NIH's RECOVER Initiative appears slow and lacking diversity, which delays the progress of research itself.



“We are able to fill cohorts [for research studies] overnight, because this is the most motivated group of people you’ve ever seen. **People are desperate for help** and they are willing to help themselves and each other by participating.”

—Emily, Long COVID advocate and person recovered from Long COVID

“We need faster research from NIH-sponsored initiatives. Everyone wants to trial Paxlovid and Long COVID. **If the NIH funds a study on Paxlovid, we won’t have results for five years.**”

—Jonathan, physical therapist and Long COVID researcher

“Private donors are picking up a lot of the actual research that moves. NIH grants are only good for very conservative, step-wise research. ... Say I apply to the NIH. The average time for review for a grant takes eight months to two years. So we may not even have a grant decision for two years! And then—yes, this happens—the reviewer may have already published in the field and they’re not really open to your new findings, and they can literally just slam your grant. **There’s a point where you go like, ‘Is this worth it?’**”

—Theresa, microbiologist and Long COVID researcher

“**This is our night and weekend work.** We still need to keep all of our other clinical trials on track, but because of the lack of government funding, we’re just doing this on our own dime. There’s a very real chance that, if our funding situation doesn’t improve, we’ll need to close up shop, because we’re spending our savings to do this work.”

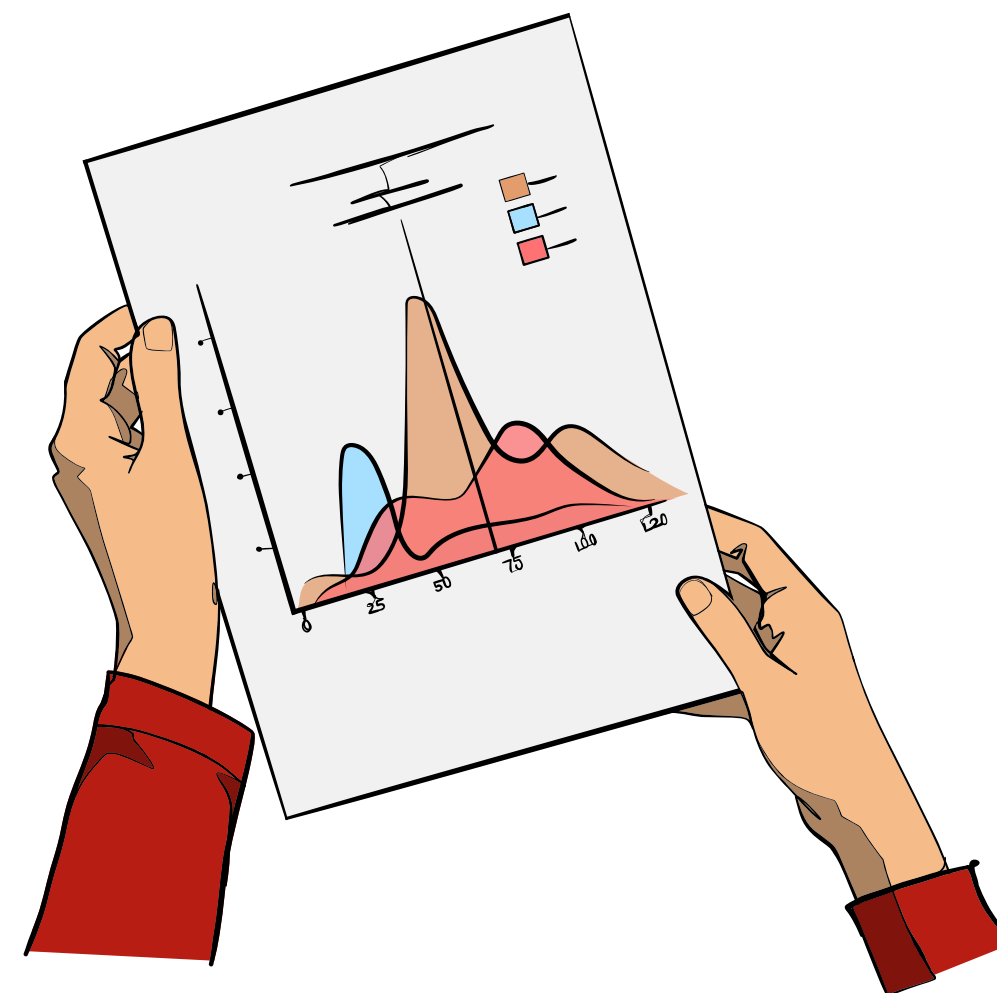
—Jonathan, physical therapist and Long COVID researcher

Opportunity:**Expand pathways for Long COVID research that can spur rapid innovation and breakthroughs.**

For: Medical researchers and advocacy organizations.

Recommended Ideas:

- **Increased research funding:** Increase federal funding for Long COVID research.
- **Research innovation pipeline:** Allocate a percentage of federal funding for Long COVID research towards “high-risk, high-reward” research, proposals of which are reviewed and prioritized both by researchers, as well as by people with Long COVID. These research initiatives would have shorter timelines for research to encourage rapid learning and development.
- **Global knowledge exchange:** Broker connections globally to identify what other health care professionals and researchers are doing and learning.
- **Recruitment partnerships:** Work with grassroots partners and advocacy groups to rapidly recruit a more racially, ethnically, and culturally diverse cohort to participate in the RECOVER Initiative.
- **Alternative funding models:** Leverage other innovation funding models, such as venture capital and crowdfunding.



Opportunity Area 9:

Advocacy Led by People with Long COVID

Insight

Advocacy organizations led by and for people with Long COVID have mobilized to fill critical gaps since the beginning of the pandemic, and yet many are operating on volunteer hours and shoestring budgets.

- Advocacy efforts led by people with Long COVID have provided invaluable insights and information to researchers.
- Advocacy efforts led by people with Long COVID have also become a source of mutual assistance and community for many people impacted firsthand by Long COVID, providing everything from moral support to step-by-step assistance applying for disability insurance.
- Despite the numerous critical roles they play, these organizations have limited resources.



“We are in a funding crisis. Our funding actually runs out at the end of this month. In order to keep us running for an extra few weeks, we have become volunteers and we’re no longer receiving a salary.”

—Emily, Long COVID advocate and person recovered from Long COVID

“Funding has been a chronically difficult issue in this space. ... **We’ve had no resources whatsoever to provide for them as far as financials or manpower, but we have found a way to help everyone that’s come to us,** without a dollar to spend on it.”

—David, Long COVID advocate and legal advisor

“We are doing this completely on a volunteer basis. I am working from sunup to sundown pretty much every day of the week and on weekends. There is going to come a point where I just can’t do it anymore. **I’ve exhausted my savings. I’ve racked up credit card debt. I’ve exhausted my retirement account. I can only really continue doing this for so much longer.**”

—William, Long COVID advocate and legal advisor

“[Congress] can say **‘Pfizer, you’re obligated to use one percent of this to support patients or patient advocacy organizations.’** Pfizer and Moderna are not currently really giving that money out. They’re just taking it as profit.”

—David, Long COVID advocate and legal advisor

“When I think about change making historically, there’s been a lot of philanthropic efforts to help that change along. But it is not led by the impacted community, and I think historically, **for that reason, [philanthropy] has been exceedingly problematic and, in many ways, has continued to perpetuate systems as they are, rather than actually transforming them.**”

—Deidre, retail supervisor, daughter, and person with Long COVID

Opportunity:**Expand support and resources for advocacy efforts led by people with Long COVID and allies.**

For: Advocacy organizations, pharmaceutical companies, and philanthropic entities.

Recommended Ideas:

- **Unrestricted grant dollars:** Encourage unrestricted funding from private donors and foundations to advocacy and support organizations, so that they can self-determine how, when, and towards what resources are used.
- **Diversity, equity, and inclusion-related outreach funding:** Provide funding to new and existing support and advocacy groups to increase outreach to and programming for underresourced and underrepresented communities.
- **Ethical compensation guidelines:** Create guidelines for fairly compensating advocacy organizations that partner with institutions (i.e., to identify participants for research studies).
- **Pharmaceutical industry pledges:** Negotiate with pharmaceutical companies to carve out a portion of their funds to support Long COVID advocacy groups.
- **Advocacy organization collaborations:** Collaborate with advocacy organizations that maintain communities and databases of people with Long COVID to recruit for scientific and medical research and track symptoms.
- **Charitable giving tax write-offs:** Increase charitable giving write-offs to 100 percent of one's adjusted gross income to incentive charitable giving from American taxpayers.



Conclusion:

Long COVID will be around long after the pandemic subsides, impacting our communities, our health care system, our economy, and the well-being of future generations. We can reduce the severity and breadth of that impact, however, if we act collectively and urgently. Responding to Long COVID is not and cannot be the responsibility of one agency or organization. It starts with listening to and working as partners with those impacted by Long COVID, and will take concerted, immediate action from many.

Get Involved

This report is just one step in a long-term commitment—it is not an end. For more information on the federal government’s response to Long COVID, visit <https://www.covid.gov/longcovid>. For more information on Health+, visit <https://healthplusprogram.io>.

Appendices

Appendix 1: Full List of Recommendations

Appendix 2: Glossary

Appendix 3: Research and Design Process

Appendix 1:

Full List of Recommendations

The following pages include a comprehensive list of recommendations organized by opportunity area. Within each area, recommendations are designated as “short-term” or “long-term.” All recommendations were either suggested or inspired by our research participants. In some cases, the Coforma team refined suggestions in order to make them more concrete while still adhering to the general vision provided by the participant.

Opportunity 1:
General Public Awareness

Increase public awareness around Long COVID and establish public policies that protect everyone from Long COVID.

For: The general public.

Short-term Recommendations:

Federal agency messaging: Disseminate Long COVID messaging to U.S. government agency leaders and encourage them to amplify and share that Long COVID is real and is a serious public health issue.

Safe public space guidelines: Encourage or mandate policies and protocols regarding masking and social distancing in public spaces that protect people from infection or reinfection and possible Long COVID.

Public messaging campaigns: Launch mass public messaging campaigns, translated into multiple languages and available in alternative formats, to increase the public's literacy and awareness of Long COVID.

Vaccine promotion: Promote vaccination as a preventative measure for Long COVID.

Mental health awareness: Increase general awareness of how Long COVID impacts the mental and behavioral health of people living with the illness and their caregivers.

Opportunity 2:

Personal Support Systems

Assist people with Long COVID in building or boosting their support networks.

For: The general public, health care providers, and support and assistance providers.

Short-term Recommendations:

Long COVID explainers: Create explanatory materials for people with Long COVID to share with family and friends.

Resources for support groups: Reinforce existing Long COVID support groups with specialized funding, and develop additional support groups for people with Long COVID and caregivers.

Long-term Recommendations:

Expanded mental and behavioral health care: Expand affordable mental and behavioral health support for people with Long COVID, as well as their caregivers and children affected by Long COVID, so that they have support processing the psychological impacts of contracting COVID, living with Long COVID or living with someone who has Long COVID, and the consequences of it on their lives.

Chore and household assistance: Create or expand assistance programs that help people with Long COVID and caregivers with daily chores, such as grocery shopping and cleaning.

Financial support for families with children: Provide financial support for families who need to provide additional care to children with Long COVID.

Legal protections for children with Long COVID: Ensure that children with Long COVID are able to access the care they need through the passing of legislation and creation of advocacy and assistance programs.

Opportunity 3: School and Workplace Accommodations

Support schools and workplaces to affirm, support, and accommodate people with Long COVID and their caregivers.

For: Educators and employers.

Short-term Recommendations:

Long COVID training for workplaces: Provide training and educational materials for workplaces to build awareness, understanding, and empathy towards potential colleagues with Long COVID, with “how to’s” on customizing accommodations to fit the needs of someone with Long COVID.

Accommodation suggestions by work type: Develop general accommodations standards for various types of work and workplaces, acknowledging that different kinds of work require different types of accommodations, and breaking up the bottleneck of case-by-case modifications that delay the changes people with Long COVID need to continue working.

Accommodations guidance for schools: Provide education, guidelines, recommended accommodations, and ready-made “toolkits” for early childhood, primary, secondary, and post-secondary educational institutions to support students with Long COVID.

Long-term Recommendations:

Revisions to accommodations policies: Revise federal and state policies that mandate employers and schools to provide adequate support for people with disabilities, including people with Long COVID.

Job transition assistance: Offer employment assistance for people with Long COVID who can no longer do their jobs and need to seek new employment, such as job-searching assistance and retraining programs.

Hiring incentives: Taking inspiration from group specific tax credits such as The Returning Heroes Tax Credit and the Wounded Warriors Tax Credit, expand the Work Opportunity Tax Credit to include hiring people with disabilities.

Funding for hazard pay and line-of-duty-related infections: Taking inspiration from the 9/11 Victim Compensation Fund, provide funding for first responders, health care workers, other essential workers, and their survivors and dependents, who were infected by COVID-19 in the line of duty and are now disabled by Long COVID.

Financial assistance for current and former students: Offer additional financial assistance to current and former college students with Long COVID, including stipends for increased health care or boarding costs, as well as loan forgiveness for graduates.

Opportunity 4: Access to Assistance

Increase access to disability benefits and assistance programs for people with Long COVID and their caregivers.

For: Health care providers, support and assistance providers, and insurance providers.

Short-term Recommendations:

Referral pathways for benefits application assistance: Refer people with Long COVID and their families to community-based organizations and programs that can assist them to apply for benefits, and increase funding for those programs to specifically serve people with Long COVID.

Reasonable accommodation consults: Advocate for the involvement of occupational therapists, vocational rehabilitation specialists, and other disability support providers in determinations around reasonable accommodations in workplace and educational settings.

Long-term Recommendations:

Wraparound services at Long COVID clinics: Consolidate Long COVID treatment and professional help for navigating and understanding existing financial, state and federal, support services under one roof, for example, at Long COVID and other clinics.

Flexible workplace reentry programs: Develop flexible workplace reentry programs so that people with Long COVID can go on and off disability leave for a period of time without needing to reapply, thereby maintaining a percentage or all of their income during that time.

Disability and caregiver credits: Create Social Security credits for people with Long COVID and their caregivers.

Expedited applications: Taking inspiration from the TSA PreCheck® program, create an expedited application program that fast-tracks applications for those who receive a Long COVID diagnosis.

Update disability criteria and processes: Revise Social Security Disability Insurance (SSDI) standards for newly disabled people with Long COVID to shorten the application time.

Update CMS health plan guidelines: Change CMS health plan guidelines for insurance and provider contract requirements to align coverage with medical treatments that show improved health outcomes for people with Long COVID.

Opportunity 5: Structural Capacity

Increase the capacity of health care and assistance systems to support the increase in need.

For: Health care providers, and support and assistance providers.

Short-term Recommendations:

Funding for Long COVID clinics: Incentivize the creation and development of additional Long COVID clinics with dedicated staff.

Long COVID clinic rating system: Develop evaluation methods for rating the quality of care at Long COVID clinics, and share ratings with the public.

Long-term Recommendations:

Improved Long COVID data tracking: Improve data tracking for Long COVID so that its occurrence is better measured, and responses and resources can be adequately allocated.

High-demand specialty area pipelines: Expand educational programs to train emerging health care providers in high-demand specialty areas.

Expanded Long COVID capacity in the SSA: Increase resources and staffing within the SSA to handle the influx of people with Long COVID filing for Social Security Disability Insurance.

Long COVID care managers: Establish care managers in the offices of health care providers and hospitals to assist people with Long COVID and their caregivers with scheduling and preparing for appointments, as well as issues with billing and insurance.

Opportunity 6:
System Navigation

Remove the care navigation and coordination burden from people with Long COVID and their caregivers.

For: Health care providers, and support and assistance providers.

Short-term Recommendations:

Chronic illness knowledge transfer: Study and draw on lessons from complex care programs and other models of caring for illnesses such as HIV, cancer, and other chronic illnesses.

Long-term Recommendations:

Coordinated and comprehensive Long COVID clinics: Improve coordination between health care providers, researchers, and case managers at Long COVID clinics so that people with Long COVID have a comprehensive, one-stop shop experience.

Care navigation support: Assign care coordinators or case managers to assist people with Long COVID with scheduling and coordinating health care appointments.

Disability insurance navigators: Offer third-party, neutral navigators who can assist people with Long COVID as they apply for disability insurance and other assistance programs.

Long COVID care program incentives: Offer incentives for health care facilities, medical practices, and health insurers to have a dedicated program and staff trained on Long COVID care coordination and treatment pathways, and who can serve as an in-house advisor to colleagues.

Mobile care and telehealth: Deploy Long COVID-specific mobile units and increase telehealth services for people who have difficulty accessing care, such as those in rural communities.

Opportunity 7: Preparation for Health Care Providers

Train and resource health care providers to adequately identify and assist people with Long COVID.

For: Health care providers, and schools of medicine and public health.

Short-term Recommendations:

Sample care pathways: Develop and distribute sample care pathways for health care providers, so diagnoses can confidently be made at initial appointments while further testing and treatments are conducted.

CPT® code guidance: Share guidance with health care providers on CPT codes that can be used for Long COVID.

Training incentives: Incentivize training on Long COVID for current health care providers, focusing in particular on the primary care and pediatrics communities, but reaching as broadly as dentists, ophthalmologists, and psychologists who may observe possible symptoms.

Health care provider training: Engage academic partners to launch an expansive outreach campaign to train health care provider through in-person and virtual presentations on what Long COVID is, how to identify it, and suggested care pathways.

Regular Long COVID digests: Regularly distribute educational resources to health care providers broadly with the latest information about Long COVID findings, testing, and treatments.

Long-term Recommendations:

Long COVID education in medical schools: Increase training on Long COVID and infection-associated chronic conditions in medical schools, and expand course requirements to include “narrative medicine,” an approach that widens the view of people with Long COVID beyond their medical histories.

Reimbursements for reviewing complex patient histories: Revise health care provider reimbursement structures so that they are incentivized to review patient histories in advance of appointments, and are able to spend more time with patients exhibiting Long COVID symptoms or other infection-associated chronic illnesses.

Opportunity 8:
Long COVID Research

Expand pathways for Long COVID research that can spur rapid innovation and breakthroughs.

For: Medical researchers and advocacy organizations.

Short-term Recommendations:

Global knowledge exchange: Broker connections globally to identify what other health care providers and researchers are doing and learning.

Recruitment partnerships: Work with grassroots partners and advocacy groups to rapidly recruit a more racially, ethnically, and culturally diverse cohort to participate in the RECOVER Initiative.

Alternative funding models: Leverage other innovation funding models, such as venture capital and crowdfunding.

Long-term Recommendations:

Increased research funding: Increase federal funding for Long COVID research.

Research innovation pipeline: Allocate a percentage of federal funding for Long COVID research towards “high-risk, high-reward” research, proposals of which are reviewed and prioritized both by researchers, as well as by people with Long COVID. These research initiatives would have shorter timelines for research to encourage rapid learning and development.

Opportunity 9:**Advocacy Led by People with Long COVID**

Expand support and resources for advocacy efforts led by people with Long COVID and allies.

For: Advocacy organizations, pharmaceutical companies, and philanthropic entities.

Short-term Recommendations:

Unrestricted grant dollars: Encourage unrestricted funding from private donors and foundations to support and advocacy organizations, so that they can self-determine how, when, and towards what resources are used.

Diversity, equity, and inclusion-related outreach funding: Provide funding to new and existing support and advocacy groups to increase outreach to and programming for underresourced and underrepresented communities.

Ethical compensation guidelines: Create guidelines for fairly compensating advocacy organizations that partner with institutions (i.e., to identify participants for research studies).

Advocacy organization collaborations: Collaborate with advocacy organizations that maintain communities and databases of people with Long COVID to recruit for scientific and medical research and track symptoms.

Long-term Recommendations:

Pharmaceutical industry pledges: Negotiate with Pfizer, Moderna, and other pharmaceutical companies to carve out a portion of their funds to support patient-advocacy groups.

Charitable giving tax write-offs: Increase charitable giving write-offs to 100 percent of one's adjusted gross income to incentive charitable giving from American taxpayers.

Appendix 2:

Glossary

Ableism: Discrimination and prejudice against people with disabilities.

Audio diary: A collection of first-person experience reports in which people verbally record responses or journal entries about their daily lives.

Caregiver: A person who provides support for another individual living with disabilities who might have a broad range of needs. They can be “family, kin, and grandparent caregivers” or direct care workers. A family, kin, or grandparent caregiver is someone who cares for members of their family of origin, or for their family of choice. A direct care worker provides caregiving support in home and community-based settings as part of their paid employment.

Centers for Medicare and Medicaid Services (CMS): A federal agency within the Department of Health and Human Services that administers the Medicare program and works in partnership with state governments to administer Medicaid, the Children’s Health Insurance Program (CHIP), insurance available through marketplaces created under the Affordable Care Act, and health insurance portability standards.

Clinical trial: A research study performed in people aimed at evaluating a medical, surgical, or behavioral intervention. The primary way that researchers find out if a new treatment, like a new drug or diet or medical device is safe and effective in people.

Cognitive dysfunction or impairment (aka “brain fog”): Deficits in attention and concentration, verbal and nonverbal learning and recall, short-term and working memory, visual and auditory processing, problem solving, processing speed, and motor functioning. This is a symptom that many, although not all, people with Long COVID experience.

Contextual support: Other factors that contribute to the intensity and nature of Long COVID’s impact on a person’s life. Also referred to as “social determinants of health,” these are conditions that affect a wide range of health, functioning, and quality-of-life outcomes and risks. In this report, contextual support describes a range of resources that may or may not be available to someone, and barriers to health care, support, and overall living stability.

CPT® code: The Current Procedural Terminology (CPT®) codes offer doctors and health care providers a uniform language for coding medical services and procedures to streamline reporting, increase accuracy and efficiency.

Desk research: Research that is performed at the start of each engagement. It includes reviewing critical papers, studies, and other key publications to develop a comprehensive understanding of the landscape around the health issue placed in focus. Desk research helps our researchers formulate objectives, questions, and goals for their interviews, workshops, and diary studies with people affected by the disease.

Disability insurance: Disability insurance is a form of insurance that replaces lost income for someone unable to work due to psychological disorders or an injury, illness, or condition that causes them physical impairment or incapacity to work. It ranges from paid sick leave, short-term disability benefits (STD), and long-term disability benefits (LTD) provided by federal programs from the Social Security Administration, some state-sponsored plans, and private, paid programs from commercial insurers.

Discovery workshop: A specific activity in the discovery phase when those impacted by the health issue in focus are recruited and engaged for research via interactive group activities. The purpose of the workshop is to inform the subsequent development of a research plan by listening and gathering knowledge from participants, better understanding who the impacted people are, and exploring what it is that they want and need to improve their lives.

Dysautonomia: A term for when the autonomic (automatic) nervous system (ANS) doesn't work as it should. The ANS is responsible for maintaining a constant internal temperature, regulating breathing patterns, keeping blood pressure steady, and moderating the heart rate. It also plays a role in pupil dilation, sexual arousal, and excretion. Conditions that cause dysautonomia usually affect these bodily functions. Dysautonomia is a related condition of Long COVID.

Ecosystem: Something (such as a network of organizations) considered to resemble an ecological ecosystem because of its complex interdependent parts.

Health literacy: The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Human-centered design (HCD): A creative approach to problem solving that centers the process and solutions around the people and communities who are impacted. Using qualitative research, this approach humanizes the problems at hand by viewing lived experiences and perspectives as valuable and necessary in solving the problems, and can augment clinical and public health research and initiatives.

Infection-associated chronic illnesses: Illnesses that include a patient history of infection by viral or bacterial pathogens followed by long-lasting and often debilitating symptoms including severe fatigue, cognitive impairment, and multi-organ dysfunction. Examples of infection-associated chronic illnesses include: Long COVID or post-acute sequelae of COVID-19, myalgic encephalomyelitis/chronic fatigue disease (ME/CFS), persistent or post-treatment Lyme disease, and multiple sclerosis.

Insights: Information and data breakthroughs that reveal behavior patterns, drive decision-making, and point to solutions or ideas.

Journey map: A journey map is a visual representation of a person's experience from beginning to end. It documents the steps they take across the course of the experience, the tools and resources they use to complete certain steps, the challenges or pain points that pose obstacles along the way, and the opportunities for enhancing or improving the experience.

Long-hauler: A term created by Amy Watson, a person with Long COVID, in 2020, when she created the Facebook group “Long Haul COVID Fighters.” It is often used by people with Long COVID to describe the COVID-related health challenges and disruptions in their daily lives.

Medicaid: Medicaid is an assistance program. It serves low-income people of every age. Though a small co-payment for covered medical expenses is sometimes required, people usually pay no part of the costs. Medicaid is a federal-state program. It varies from state to state. It is run by state and local governments within federal guidelines.

Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS): A chronic, complex, neuroimmune (both the immune system and the nervous system) disease associated with neurological, immunological, autonomic, and energy metabolism dysfunction that profoundly limits the health and productivity of people and is often triggered by an infection. ME/CFS is a related condition of Long COVID.

National Institutes of Health (NIH): The primary federal research agency responsible for biomedical and public health research and made up of 27 different components called Institutes and Centers. Each has its own specific research agenda, often focusing on particular diseases or body systems.

Opportunity area: Synthesized from our HCD research, we identify the major issues faced by the Long COVID community and separate them into specific opportunity areas for improvement. These opportunity areas encompass what

work needs to be done to improve the quality of life and care for people impacted by Long COVID, based on what are the highest priority issues for them, as well as what solutions will have the most impact from their perspective.

Pain point: A specific problem or experience that is a recurring source of trouble, annoyance, or distress.

Paxlovid™ (Nirmatrelvir/ritonavir): An FDA-approved antiviral medication for the treatment of mild-to-moderate COVID-19 in adults and some pediatric patients. Developed by Pfizer, a biopharmaceutical company, Paxlovid is an oral pill that can be taken at home to help keep people who are high-risk from getting so sick that they need to be hospitalized.

Long COVID clinics: Care centers established to identify people with Long COVID and deliver early multidisciplinary health care services, from screening for disease outcomes, early rehabilitation, and targeted specialist referrals. Multidisciplinary teams are from a broad range of specialties and focused on addressing the issues of COVID-19 recovery. Long COVID clinics may also be referred to using other terms, including Post-COVID Care Centers, Post-COVID Recovery Clinics, and Comprehensive COVID-19 Centers.

Post-traumatic stress disorder (PTSD): A mental health disorder that may occur in people after experiencing or witnessing a traumatic event, such as combat, a natural disaster, a serious accident, or sexual assault, or have been threatened with death, sexual violence, or serious injury.

Infection-associated chronic illness: A complex condition or disease characterized by lingering symptoms involving physical, cognitive, emotional, and neurological difficulties after any type of bacterial or viral infection.

PPP loan: The Paycheck Protection Program is a 2020 loan program created by the federal government as a part of the CARES Act to provide small businesses forgivable loans to maintain their payroll, hire back employees who may have been laid off, cover applicable overhead, and other eligible costs.

RECOVER Initiative: The NIH launched the Researching COVID to Enhance Recovery Initiative in 2021 to learn why some people have prolonged symptoms or develop new or returning symptoms after the acute phase of infection.

Severity: The nature and intensity of the symptoms and health impacts experienced by someone with Long COVID, as well as their duration over time. Some people experience mild symptoms, while others experience physically and cognitively debilitating ones.

Social Security Administration (SSA): A federal agency responsible for the administration of social security benefits such as retirement, disability and survivors benefits, and social security income and cards, as well as annual wage reporting programs.

Social determinants of health (SDOH): Social determinants of health are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Subject-matter expert: An individual who by education, training, or lived experience is a recognized expert on a particular subject or topic.

The Department of Health and Human Services (HHS): The U.S. federal government agency responsible for protecting the public's health and providing important services. The Department of Health and Human Services works with state and local governments throughout the country to do research and provide public health services, food and drug safety programs, health insurance programs, and many other services.

Interview: Interviews are conducted one-on-one or in small groups with each of the participating communities. We develop interview guides that are comprehensive, ethical, and sensitive. Our documentation process ensures interviewees' privacy is protected.

Virtual postcard: Similar to a regular postcard, but in a digital format, for people to write about their experiences and daily lives, then send via digital mail or email.

Xenophobia: Discrimination and behavior specifically based on the perception of individuals or groups as foreign or originating from outside a community or nation based on their real or perceived geographic origins, values, beliefs, or practices.

Appendix 3:

Research and Design Process

About Health+™

Health+ (“health plus”) is a trademarked and proprietary program developed by Coforma in 2019, which applies human-centered design (HCD) and research to cultivate solutions to the most pressing challenges in the health care sector. The Health+ research and design methodology utilizes human-centered design that focuses on specific, high-impact health issues, with the goal of developing thoughtful, insightful, and impactful solutions that people can align around. By hearing directly from people living with the high-impact health issue placed in focus, we ensure that future solutions are crafted to solve the most pressing challenges faced by those individuals.

Our Methodology

Discovery

Recruitment: We recruited a diverse community of individuals to learn alongside, including people with Long COVID, their caregivers, health care providers, advocates, and other subject matter experts. We conducted outreach using a variety of strategies: conversations with Long COVID advocacy organizations, including Survivor Corps and Body Politic; social media, including Instagram, Facebook, Reddit, and Twitter; through the networks of our partners at HHS; and through organizations with deep relationships in various communities, including the Tanana Chiefs Conference and the California Center for Functional Medicine.

Research methods: After conducting desk research to review existing white papers, news articles, and reports on Long COVID, we initiated a series of four discovery workshops with people with Long COVID, caregivers, health care providers, advocates, and other subject matter experts. Their expertise and input informed our subsequent research plan and areas of inquiry. We then employed a range of research methods to ensure an accessible, comfortable experience. These included 60-minute, semi-structured, remote interviews; audio diaries; and virtual postcards. Over 60 people with Long COVID, caregivers, health care providers, advocates, and other subject matter experts were engaged.

Areas of inquiry: Research focused on deeply understanding the experiences of identifying, diagnosing, and treating Long COVID; the extenuating impacts of Long COVID on lives, livelihoods, and communities; support and assistance for people living with Long COVID, caregivers, and care providers; perceptions and attitudes about Long COVID; and bright spots, opportunities, and aspirations for improving the quality of life and care for people with Long COVID.

Ideation and Validation

Interviews were coded and analyzed to identify themes and trends across participants' lived experiences. Data-driven findings were compiled into impact frameworks, a treatment journey map, opportunity areas, and recommendations. These materials were reviewed by research participants during validation workshops to confirm their accuracy and elicit further feedback. Their feedback has been incorporated into this report.

Implementation

The challenges that Long COVID and other infection-associated chronic illnesses pose require fresh thinking and novel approaches. “Healthathons”—health-focused innovation sprints with hackathon roots—bring together people with Long COVID, members of the health care community, and other interested parties to develop community-led solutions. By moving quickly from idea to prototype, we can accelerate innovative solutions that truly meet the needs of people living with Long COVID. (At the time of this report's publishing, the Healthathon had yet to take place.)

Gaps and Limitations

Our participant community did not adequately reflect the Long COVID experiences of children, people who are unhoused, people who are currently or formerly incarcerated, and Native Americans and Alaska Natives. In the case of children, we were able to speak with their parents or guardians. In the case of the unhoused and the incarcerated, we interviewed subject matter experts whose nonprofits advocate for or administer support to these individuals. In the case of Native Americans and Alaska Natives with Long COVID, while we did speak to individuals who identify as such, we do not believe we heard from a representative sample, given the diversity of experiences within those communities.

Attributions

To ensure participants' identities are protected, all names have been replaced with aliases. Personal details such as professions and hobbies, which appear both in quotation attributions and occasionally in quotes themselves, have also been changed.

Our Participant Community:

We learned from over 60 people, including people with Long COVID, their caregivers, health care providers, advocates, and other subject-matter experts.

Overview:

4
Discovery Workshops

42
Interviews

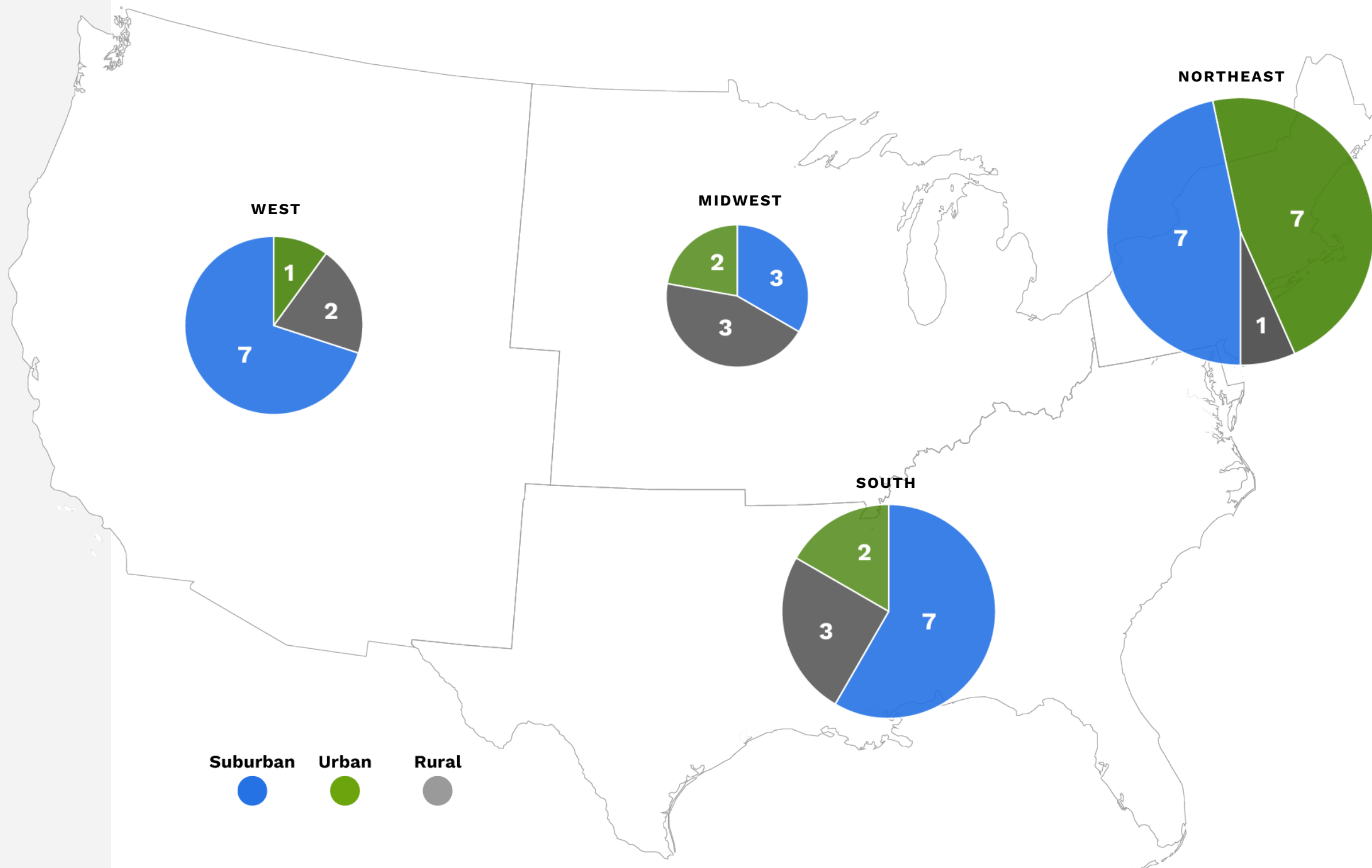
2
Audio Diaries

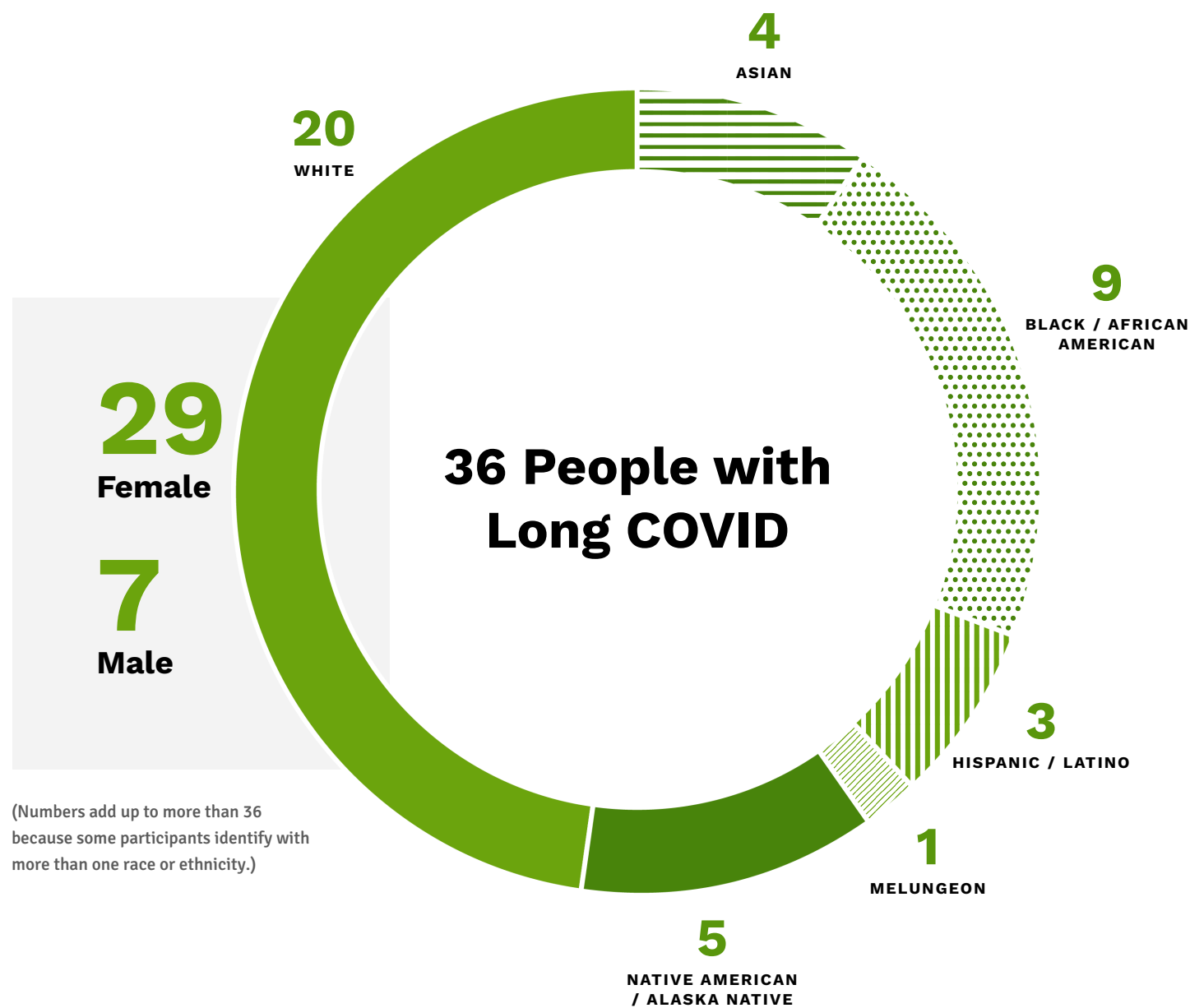
6
Virtual Postcards

10
Research Validation Sessions

Location of Participants

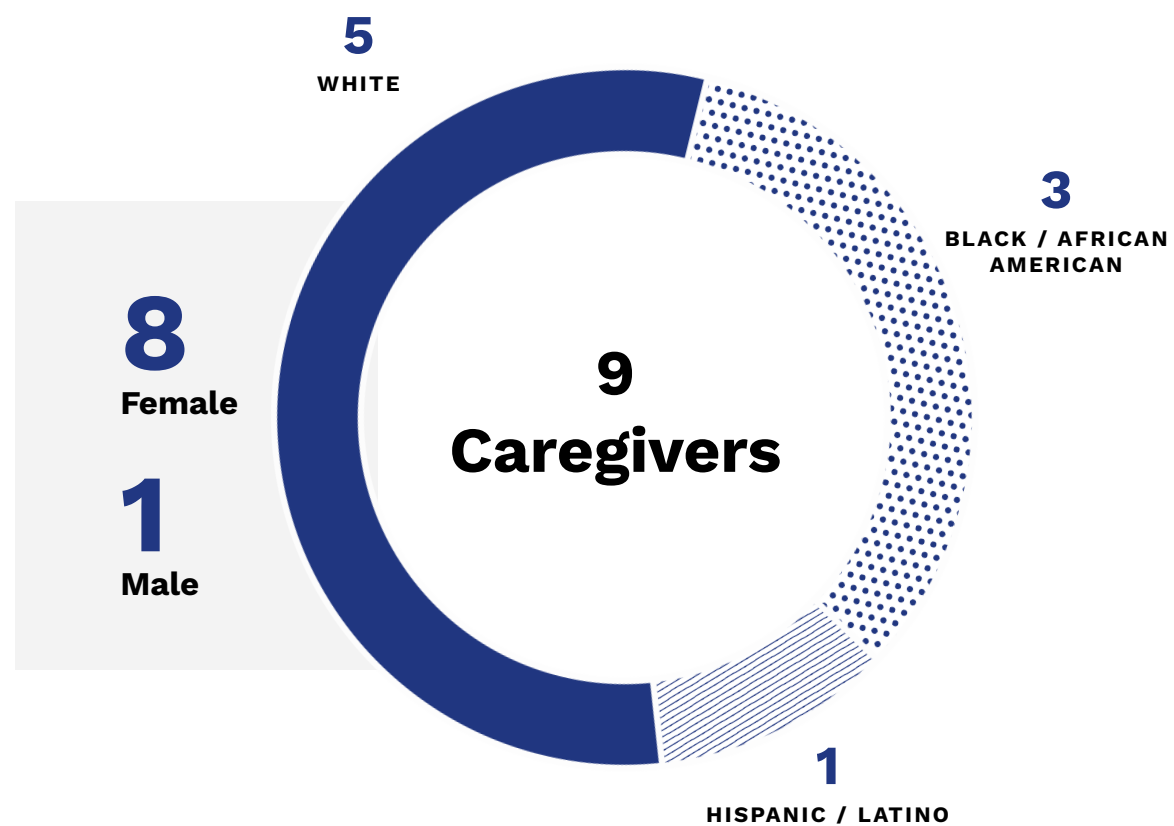
We learned from people with Long COVID and caregivers from across the country. (Health care providers and subject-matter experts not included in totals below.)





The participant community of people with Long COVID also included the following perspectives:

- 3 front-line health care workers
- 2 people who are uninsured
- 4 undergraduate or graduate students
- A range of Long COVID severity levels and dates of infection
- 3 people who identify as LGBTQ



The participant community of caregivers included a range of relationships to the person with Long COVID (e.g., sibling, parent, spouse, significant other, child).

8 Health Care Professionals

- 1 Family therapist
- 1 Functional health doctor
- 1 Functional health nurse
- 1 Medical director of a Post-COVID Care Center
- 1 Nurse
- 1 Physical therapist
- 1 Pulmonary and critical care physician
- 1 Primary care physician

12 Advocates and other subject-matter experts

- 1 Advocate for currently and formerly incarcerated individuals
- 1 Director of health care programs for the unhoused
- 1 Epidemiologist
- 1 Funder of infection-associated chronic illness research
- 1 HHS staff member
- 5 Leaders of Long COVID advocacy organizations (Survivor Corps, COVID-19 Longhailer Advocacy Project, Pandemic Patients)
- 1 Microbiologist
- 1 Public health analyst

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Created by Coforma

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