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# ImproveDx Newsletter

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## Long COVID Gains Acceptance as Many Questions Remain Unanswered

By Susan Carr, Senior writer

*...covid-19 has brought the complexity of science and policy making in the context of uncertainty into sharp focus.*<sup>1(1)</sup> — Harry Rutter, Miranda Wolpert, Trisha Greenhalgh

The past year has been an exercise in humility. For all that was quickly learned about the new SARS-CoV-2 virus and COVID-19, there have been constant reminders of what is not yet known, including the infection's long-term implications.

In March and April 2020, most COVID-19 patients who managed their symptoms at home and recovered considered themselves fortunate and looked forward to returning to normal in a few weeks, as if they had had the flu or a bad cold. But as April became May, June and beyond, some patients were not able to shake symptoms that came and went like an unpredictable tide. Many drew on past experience and assumed they could tough out the tail end of the illness. Some found that friends, family members and even doctors they consulted for advice attributed their ongoing symptoms to stress, nerves, lack of resolve or a different, underlying condition. It was only when these patients turned to social media for peer support, discovered a growing community of “long haulers,” and started collecting data that the media and medical establishment began to pay attention and realize that for some, COVID is a long-term, perhaps chronic, debilitating illness.<sup>2-5</sup>

Because terminology and definitions are still being developed and data is scarce, the percentage of patients with persistent or chronic symptoms is not yet known.

One of the first studies to measure ongoing symptoms was performed in Italy from late April to late May 2020. It found that 87.4% of patients “reported persistence of at least 1 symptom, particularly fatigue and dyspnea.”<sup>6</sup> The 143 patients included in the study had been hospitalized, discharged, and then tested negative for COVID-19. All were receiving care in a post-acute outpatient service and were surveyed approximately 60 days following the onset of symptoms and 36 days since discharge.<sup>6</sup>

In the United States, the Centers for Disease Control and Prevention's *Morbidity and Mortality Weekly Report* reported data collected on 274 symptomatic patients through phone interviews performed between April 15 and June 25, 2020.<sup>7</sup> Although 7% had brief hospital stays for COVID-19, all had been tested as outpatients and managed the illness through self-care at home. Approximately one-third reported they had not yet returned to “normal health” 2 to 3 weeks after testing positive. The study points out in contrast that 90% of patients with influenza recover to normal health in 2 weeks. The

authors recommend further study and observe that COVID is a prolonged illness for many patients, not just the elderly or those in poor health:

*Notably, convalescence can be prolonged even in young adults without chronic medical conditions, potentially leading to prolonged absence from work, studies, or other activities.* <sup>7(pp996-997)</sup>

Another study of COVID outpatients comes from the [Faroe Islands](#), an archipelago in the North Atlantic, roughly halfway between Norway and Iceland. The islands have a population of fewer than 53,000 people. Between March 3 and April 22, 2020, all patients who tested positive for COVID-19, including children, were invited to participate in a study designed to assess persistence of symptoms.<sup>8</sup> Out of 187 eligible patients, 180 participated, and only eight had been hospitalized. After 125 days, 53.1% reported they continued to experience at least one symptom. Although there was a correlation of increased age with symptom persistence, the authors did not find significant demographic trends and concluded that...it might take months for symptoms to resolve, even among non-hospitalized persons with milder illness course in the acute phase."<sup>8(np)</sup>

Studies like these don't represent the large population of COVID patients who lack a positive test result either through inadequate or inaccurate testing. Patients who experience long COVID and don't have a positive diagnosis of COVID-19 face many uncertainties. Lacking the objective confirmation of a diagnostic test may cast doubt on the validity or origin of symptoms and make it harder for patients to find appropriate treatment. Adding to the uncertainty, long COVID often features debilitating symptoms that fluctuate, with alternating "good" and "bad" days. For many, having had relatively mild symptoms at the outset also means their ongoing health problems seem inconsistent with the commonly held belief that mild symptoms should equate with ease of recovery.

Early reports that the effects of COVID-19 could be long-lasting initially came from patients and the networks they formed on Facebook and other social media platforms. One group, [Patient-Led Research](#), published its [first report](#) in May, which was heralded by Francis Collins, MD, PhD, director of the National Institutes of Health as "the first detailed patient survey of post-COVID syndrome."<sup>9(np)</sup> Based on an

## Symptoms of Long COVID

The [Centers for Disease Control and Prevention](#) identify the following as symptoms associated with long COVID:

The most commonly reported long-term symptoms include:

- Fatigue
- Shortness of breath
- Cough
- Joint pain
- Chest pain

Other reported long-term symptoms include:

- Difficulty with thinking and concentration (sometimes referred to as "brain fog")
- Depression
- Muscle pain
- Headache
- Intermittent fever
- Fast-beating or pounding heart
- (also known as heart palpitations)

More serious long-term complications appear to be less common but have been reported. These have been noted to affect different organ systems in the body. These include:

- Cardiovascular: inflammation of the heart muscle
- Respiratory: lung function abnormalities
- Renal: acute kidney injury
- Dermatologic: rash, hair loss
- Neurological: smell and taste problems, sleep issues, difficulty with concentration, memory problems
- Psychiatric: depression, anxiety, changes in mood<sup>12</sup>

Other groups and researchers have also developed lists of symptoms associated with long COVID. For one example, see the [COVID-19 "Long Hauler" Symptoms Survey Report](#).<sup>13</sup>

And in the United Kingdom, [guidelines published by the National Institute for Health Care Excellence](#)<sup>14</sup> list symptoms for ongoing symptomatic COVID-19 and post-COVID-19 syndrome.

online survey, the report includes responses from 640 patients, roughly 50% of whom were never tested for COVID-19. Among those who had been tested, only 23% tested positive. The authors believe that including only patients who have tested positive would not accurately reflect the nature and incidence of COVID-19 and would do “a disservice to the thousands, if not hundreds of thousands, of people with prolonged symptoms who were unable to access a test early enough in their illness, if at all.”<sup>10(np)</sup>

Nisreen Alwan, an associate professor and consultant in public health in the United Kingdom who experienced intermittent, serious COVID symptoms for months, agrees that testing is a poor measure of long COVID. She recommends using a set of agreed-upon symptoms as “universal and simple criteria” for the incidence of infection as well as recovery. She calls for gathering data on cases regardless of severity and reconsidering the terminology used:

*The “recovery” definition must include duration, severity and fluctuation of symptoms, as well as functionality and quality of life. Everyone who is symptomatic would remain a “case” until they fulfilled the recovery criteria or died.*<sup>11(p170)</sup>

## Diagnosis and Treatment of Long COVID

The symptoms of long COVID are numerous, diverse and may indicate other conditions. Physicians, scientists, and patients have noted, for example, that some long COVID patients meet the CDC’s criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Ed Yong, staff writer for *The Atlantic*, reports that some have mixed feelings about correlating their condition with ME/CFS, resisting the prospect of chronic disability and hesitating to associate themselves with a community of patients who have long been trivialized and discounted.<sup>15</sup> On the other hand, some long COVID patients desperately want a more specific diagnosis for their condition and welcome the CFS/ME label, “treating any diagnosis as more of an anchor than an answer: It’s a starting point for understanding what’s happening to them.”<sup>15(np)</sup> It appears that the ME/CFS community may benefit from what is learned through research focused on long COVID and that COVID patients may benefit from what the ME/CFS community has learned about managing their disease and its impact on their daily lives.<sup>15,16</sup>

David Putrino, PhD, director of rehabilitation innovation for Mt. Sinai Health System in New York, reported during a [Survivor Corps webinar](#)<sup>17</sup> that Mt. Sinai’s Center for Post-Covid Care avoids putting a name on the syndrome. After making a “presumptive positive diagnosis based on symptoms,” the Center concentrates on patient-centric treatment. Putrino explains that a COVID patient’s symptoms may fall into a number of different buckets, including dysautonomia and ME/CFS, but he feels it is too early to know what is causing symptoms to persist and to understand the likely prognosis for individual patients.

Long COVID patients dealing with fluctuating and disparate symptoms are likely to need help from a variety of medical professionals and benefit from a collaborative approach to care.<sup>18</sup> The Center at Mt. Sinai is part of a growing network of [post-COVID care centers](#) in the United States, which are listed by state on an interactive webpage hosted by Survivor Corps, one of the largest online communities and data-gathering groups focused on long COVID. Last October, England’s National Health Service established funding for a network of more than 60 multi-specialty clinics for [long-COVID care](#) throughout the country.

Trish Greenhalgh, a practicing physician in the UK and professor of primary healthcare at the University of Oxford, points out that long COVID patients will most often turn to their general practitioners for help. Acknowledging that COVID-19 presents “a very, very uncertain, highly variable clinical picture,”<sup>2</sup> Greenhalgh hopes that physicians will share honestly with long COVID patients the fact that “we actually don’t know how long this is going to last.”<sup>2</sup> In a Practice Pointer for *The BMJ*, Greenhalgh et al. observe:

*In these uncertain times, one key role that the primary care practitioner can play is that of witness, “honouring the story” of the patient whose protracted recovery was unexpected, alarming, and does not make sense.*<sup>19(6-7)</sup>

Long COVID, the effects of which will challenge health systems, employers, and thousands of patients for years to come, presents an urgent need for patients, clinicians, researchers, policy makers and more to work together. Unfortunate missteps in the early reaction to long COVID have largely been corrected, thanks to the efforts of engaged patients. Going forward, honesty, compassion and collaboration should point the way to understanding and management.

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## Update from the Society to Improve Diagnosis in Medicine

At the end of 2020, the Society to Improve Diagnosis in Medicine (SIDM) unveiled two new resources for the diagnostic quality and safety community and expanded the [Coalition to Improve Diagnosis](#).

### Comparative Effectiveness Research Toolkit

Comparative Effectiveness Research (CER) is conducted by comparing two or more diagnostic, treatment, or prevention options to see which is most effective. Patient engagement is a hallmark of effective CER, but many organizations struggle to create effective patient engagement strategies.

To help organizations include patients in CER, SIDM has released a [CER Toolkit](#) derived from learnings shared at its Diagnostic Research Workshop. The toolkit includes a template to help researchers and patients/families formulate CER questions, examples of CER research funded by the Patient-Centered Outcomes Research Institute (PCORI), and other materials that support patient-engagement.

*The Diagnostic Researcher Workshop was convened by SIDM and funded by PCORI's Engagement Award Initiative (EAIN-00009).*

### Mapping the Diagnostic Process

The Diagnostic Process Map is a resource developed by the National Academies of Sciences, Engineering, and Medicine (National Academies) in their 2015 groundbreaking report, [Improving Diagnosis in Health Care](#). SIDM transformed the diagram into an interactive [tool](#) to help in teaching, learning, and improving the diagnostic process. SIDM is also releasing a PowerPoint [template](#) that can help users map errors against the National Academies' diagnostic process diagram and discuss drivers of errors and steps that could prevent future errors.

“Every member of the clinical team, including patients and family, has a role to play in ensuring that diagnoses are accurate, timely, and communicated to the patient,” added Paul Epner, CEO and co-founder of SIDM. “The diagnostic process is a complex and collaborative activity that unfolds over time and occurs within the context of a healthcare system. The Diagnosis Process Map shows typical elements of the diagnostic process, but also recognizes that for some patients, certain steps may be skipped, or the order may be re-arranged. We hope this tool will be useful for patients, educators, researchers, and clinicians as they work to improve diagnostic quality and safety.”

Support for the development of the tool was provided, in part, by the Gordon and Betty Moore Foundation and the Mont Fund.

### **Coalition to Improve Diagnosis**

SIDM has [announced](#) four new members to its Coalition to Improve Diagnosis. Is your organization doing work to reduce harm from diagnostic error? If so, consider joining more than 60 of the nation’s most prominent healthcare organizations working to improve diagnostic quality and safety. For more information, please visit [www.improvediagnosis.org/cid](http://www.improvediagnosis.org/cid)

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## **SIDM Leads New TeleDx Research Effort**

Although telemedicine has been available for decades, the COVID-19 pandemic has transformed its usage overnight. From being a niche resource or a convenient alternative for a small group of patients, remote visits using telemedicine resources have become the mainstay for healthcare delivery. Much has been written about the use of telemedicine, but it has been overwhelmingly focused on treatment and management of chronic disease, not on diagnosis.

The use of telemedicine for diagnosis, called “telediagnosis” or “TeleDx,” at the current scale is unprecedented and creates a pressing need to understand the implications of this transformation on the quality and safety of diagnosis. Will TeleDx lead to even more diagnostic errors, or can it be leveraged to achieve a newer, more favorable climate for diagnosis that facilitates the diagnostic process and results in better care with fewer errors?

To help navigate this new era of healthcare practice, SIDM is leading an effort to capture and synthesize information about the early successes, the greatest challenges, and the most critical unanswered questions in the use of TeleDx. Funded by the Patient-Centered Outcomes Research Institute (PCORI) through a COVID-19 Engagement Award Special Cycle, *Learning While We Build: Identifying the Must-Know Research Questions for Safe and Effective Telediagnosis* launched in July of 2020 and will conclude in June of 2021. The [project](#), led by SIDM in collaboration with an esteemed Advisory Team, began with an extensive literature search and will include listening sessions with five key stakeholder groups: patients, clinicians, clinical practices, telemedicine companies, and hospitals and health systems.

The project team will produce a series of listening session summaries, sharing key takeaways from the discussants, contextualized within related findings from the current literature. A public-facing webinar will be held in May of 2021 to share this body of knowledge and ultimately the entire collection of insights will be analyzed and integrated into a final report.

Collectively the project aims to understand what is working best in the current TeleDx paradigm, where the biggest gaps exist, and what support and education is most needed to effectively achieve high-quality TeleDx. Project learnings can be used by:

- PCORI and other funders, to help prioritize research and funding.
- Patients and patient groups, to learn about and support the effective use of TeleDx in their communities.
- Telemedicine companies, to make products and services most accessible and effective.
- Clinicians, hospitals, and health systems to optimize their own diagnostic processes and learn how to interact most effectively with their patients at a distance.

[Stay tuned](#) for more information about the May 2021 webinar and for project publications anticipated to be in production in early 2021. *This project was funded through a [Patient-Centered Outcomes Research Institute](#) (PCORI) Eugene Washington PCORI Engagement Award (EAIN-00177).*

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