

Technical Brief Number 45

# Long COVID Models of Care



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## Long COVID Models of Care

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## None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

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## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new healthcare technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy, or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857 or by email to epc@ahrq.hhs.gov.

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## **Key Informants**

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the Technical Brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The Task Order Officer and the EPC work to balance, manage, or mitigate any conflicts of interest.

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## **Peer Reviewers**

Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. The conclusions and synthesis of the scientific literature presented in this report do not necessarily represent the views of individual reviewers. AHRQ may also seek comments from other Federal agencies when appropriate.

Peer Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. The Task Order Officer and the EPC work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

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## Long COVID Models of Care

## **Structured Abstract**

**Background.** Long COVID is characterized by persistent, new, or relapsing symptoms following severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection. A standardized and reliable definition is needed to accurately identify patients with long COVID, and a number of models of care have been developed or proposed to provide the services needed to manage this complex condition.

**Purpose.** The purpose of this Technical Brief is to summarize definitions of long COVID and describe what is known about long COVID models of care, including models currently in use, promising approaches, advantages and disadvantages of models in different populations and settings, barriers and facilitators to implementation, access and equity issues, and needed research.

**Methods.** We performed searches in electronic databases from 2021 to November 2023, reviewed reference lists, searched grey literature sources, and interviewed Key Informants. We described key definitions of long COVID, identified components characterizing different long COVID models of care, developed a framework to categorize models based on these components, described representative practice- and systems-based models of care, and identified future research needs.

**Findings.** We identified five definitions for long COVID based on clinical criteria and one proposed definition based on a summary symptom score. Clinical definitions varied with regard to requirement for documenting acute SARS-CoV-2 infection, timing of onset, and duration of symptoms. One newly proposed definition developed using data from people with symptoms for greater than 6 months is based on exceeding a threshold on a composite symptom score and requires further validation.

Based on 49 long COVID models of care described in the literature review or by Key Informants, we identified five key principles of long COVID care: (1) core "lead" team; (2) broad multidisciplinary expertise; (3) broad range of diagnostic and therapeutic services; (4) patient-centered, individualized, and equitable care; and (5) capacity to meet demand. Models of care varied with regard to how they addressed these principles. We developed a framework for describing and categorizing long COVID models of care based on seven key components that varied across models: (1) home department or clinical setting; (2) clinical lead; (3) co-location of other specialties; (4) role of primary care; (5) population managed; (6) use of teleservices; and (7) whether the model was practice- or system-based. Using this framework, we described 10 representative practice-based and 3 systems-based long COVID models of care. There was overlap between model components as well as variability within the same model. Across models, implementation strategies addressed multispecialty collaboration, use of systematic intake and assessment methods, care coordination, and education and training of clinic staff. Research is needed to understand appropriate methods for measuring quality of care, approaches for providing access to underserved populations, strategies to ensure sustainability, provision of long COVID care in areas lacking multidisciplinary expertise, optimal education and training and care coordination methods, outcomes of long COVID models of care, and strategies for integrating long COVID management into primary care. Decisions about long COVID models of care may best be tailored to address the unique milieu of each implementation setting, leveraging the resources and expertise available.

**Conclusions.** Definitions of long COVID vary and efforts are ongoing to develop a more standardized and reliable definition. A framework based on key model components may be useful to describe and categorize different long COVID models of care. Research is needed to clarify optimal long COVID models of care in different settings and to understand effective strategies for overcoming implementation barriers, including integration of long COVID management in primary care. The models of care presented in this Technical Brief may help inform the individualized implementation of long COVID models of care in different settings.

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## **1.1 Introduction**

A large, growing population has experienced severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection. Although symptoms of acute coronavirus disease 2019 (COVID-19), the disease caused by SARS-CoV-2, typically last ~2 to 4 weeks, a significant proportion of recovering patients experience persistent, new, or recurrent symptoms.<sup>1-5</sup> Several terms have been used to refer to this condition, including "long COVID," "post-COVID syndrome," or "postacute sequelae of SARS-CoV-2 (PASC)." Long COVID can affect multiple organ systems, with wide variability across individuals in symptoms and symptom combinations. Manifestations include cognitive impairment; fatigue, often with postexertional malaise; sleep disturbance; pain; cardio-pulmonary symptoms; anosmia and dysgeusia; headache; depression and anxiety; gastrointestinal symptoms; and dysautonomia (including postural orthostatic tachycardia syndrome).<sup>2,6-8</sup> The duration of long COVID ranges from weeks to years and may follow a relapsing and remitting course.<sup>9</sup> Long COVID severity ranges from relatively mild to severely disabling, impacting quality of life, psychological well-being, functioning, and ability to work and attend school.<sup>10</sup> The U.S. Department of Health and Human Services has issued guidance confirming that long COVID can be considered a disability under the American with Disabilities Act.<sup>11</sup> Although there is no specific diagnostic test for long COVID, several case definitions have been proposed.<sup>12-14</sup> A standardized, valid, and reliable definition for long COVID is needed to guide clinical care and inform future research, and definitions of long COVID are evolving.<sup>15</sup>

Long COVID is an important public health issue that the U.S. government has highlighted as a clinical, policy, and research priority.<sup>16,17</sup> The risk of long COVID appears to vary according to a number of factors, including acute COVID-19 severity, age, sex, smoking status, body mass index, pre-existing conditions, vaccination status, and others.<sup>18,19</sup> Given the large number of individuals who have experienced acute COVID-19, the burden of long COVID appears to be substantial. However, estimates of long COVID vary depending on the population evaluated and methods used to define and measure long COVID.<sup>8,19,20</sup> In one systematic review of 120 studies, the pooled prevalence of persistent symptoms, functional disability, or pathological changes in adults or children at least 12 weeks post SARS-CoV-2 infection was 42 percent.<sup>19</sup> However, individual study estimates ranged from 0 to 93 percent. Factors potentially associated with variability in prevalence estimates included differences in populations assessed, study design, and methods for ascertaining and defining long COVID. In addition, studies had methodological limitations, including lack of control groups, and estimates did not account for severity of symptoms. In comparative studies, the prevalence of symptoms was about 10 percent higher in patients with long COVID compared with test-negative, untested, or other controls. In the United States, national estimates of long COVID also vary. In the 2022 National Health Institute Survey, 6.9 percent of adults self-reported having long COVID and 3.4 percent reported currently having long COVID;<sup>21</sup> in the U.S. Census Bureau's ongoing Household Pulse Survey, the corresponding rates in October 2023 were higher at 14.3 and 5.3 percent, respectively.<sup>22</sup> In both surveys, the definition of long COVID was based on self-reported symptoms present for at least 3 months after having COVID-19 (based on a positive test or clinical diagnosis), that were not present prior to being infected. Among participants in the Household Pulse Survey with prior COVID-19, approximately 26 percent of respondents reported long COVID.<sup>22</sup> Of those with persistent symptoms, approximately one-quarter reported significant activity limitations due to

the symptoms. The Household Pulse Survey also found that persistent symptoms were more frequent in Hispanic/Latino patients (29%) than non-Hispanic Asian (15%), Black (26%), or White (25%) patients (data not available for Native American patients), and in patients with disability (43%) compared to those without disability (22%) indicating potential disparities in long COVID impact. Data on incidence of long COVID in children are limited, but suggest that it is less common than in adults.<sup>23,24</sup> Emerging evidence suggests disparities in diagnosis of long COVID, with potential underestimation among non-White or Hispanic individuals and people of lower socioeconomic status.<sup>25</sup>

The pathophysiology of long COVID appears multifactorial, potentially involving immune dysregulation, microbiota dysbiosis and occult viral persistence, blood clotting and endothelial dysfunction, and dysfunctional neurological signaling.<sup>1,2,5,26</sup> Many features of long COVID resemble those observed in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS),<sup>2,27,28</sup> a syndrome often associated with prior viral infection, and other infection-associated chronic illnesses (e.g., persistent or post-treatment Lyme disease, multiple sclerosis after Epstein-Barr virus infection). Approximately 50 percent of patients with long COVID meet criteria for ME/CFS and most patients with long COVID report postexertional malaise, a cardinal ME/CFS feature.<sup>2,29,30</sup> The extent to which long COVID represents a form of ME/CFS or is a distinct condition is uncertain. However, given the observed similarities between ME/CFS and long COVID,<sup>3</sup> experience managing ME/CFS may inform management of long COVID, and some proposed models of care address both conditions.<sup>31</sup>

#### **1.1.1 Current Practices**

As for many other chronic conditions, the goal of treatment for long COVID is to manage symptoms, improve function, and optimize quality of life.<sup>32-35</sup> Although no curative treatment is currently available for long COVID, limited evidence suggests that improvements in long COVID symptoms may occur over time for some people.<sup>36,37</sup> Evaluation and treatment recommendations are based on available clinical research and expert opinion. In most patients, fatigue management with energy conservation strategies (e.g., pacing), and, when appropriate, an individually titrated, symptom-guided return-to-activity program, are components of care; other treatment components are highly variable and tailored for each individual's presentation.<sup>2,3,38,39</sup> Because long COVID can manifest as a variety of symptoms affecting multiple organ systems, effective management often requires expertise and coordination among multiple specialties, applying a whole-patient perspective that addresses long COVID symptoms within an individual's psychological, social, and medical context.

Models of care broadly define the way health services are organized and delivered for a particular condition or conditions within a health system. Successful models of care enable provision of necessary services and impact the quality and outcomes of care. Components or elements that constitute models of care may include the clinical setting (e.g., inpatient or outpatient, primary care or specialty clinic); payment structure and access; multidisciplinary team composition; other staffing required; mechanisms for coordination/collaboration; testing and treatment services provided; education, training, and outreach; method of delivering services (e.g., face-to-face or virtual); provision of home-based care; and others.<sup>40</sup> A variety of long COVID models of care have been proposed or implemented, including primary care integrated, specialty-based, or standalone clinics, with variability in the above factors.<sup>33,40-45</sup>

## 1.1.2 Objective of Technical Brief

The purpose of this Technical Brief is to summarize definitions of long COVID and describe what is known about long COVID models of care, including models currently in use; promising new approaches; advantages and disadvantages of different models in different populations and settings, barriers, and facilitators to implementation; access and equity issues; and needed research. A Technical Brief does not synthesize data on outcomes and grade evidence, or draw conclusions about comparative effectiveness. Rather, it seeks to summarize what evidence is available, provide a conceptual or organizational framework to understand key components of the intervention of interest, highlight promising new and innovative strategies, describe barriers to implementation, and provide guidance on future research directions and priorities. The focus of the Technical Brief is on implementation of long COVID models of care in U.S. settings. Guiding Ouestion 1 addresses definitions used for long COVID and Guiding Ouestions 2 to 5 address characteristics of long COVID models of care. Specifically, Guiding Questions 2 and 3 describe different models of care and the context in which they have been implemented, Guiding Question 4 describes information on the use of and effectiveness of long COVID models of care, and Guiding Question 5 describes gaps in our understanding of long COVID models of care. This Technical Brief is intended to inform clinicians, patients, payers, healthcare systems, policymakers, and researchers; guide future implementation and healthcare delivery efforts; and provide the basis for a potential future technical brief update or full systematic review. Appendix A contains sample questions for Key Informants, Appendix B contains search strategies, Appendix C contains the literature flow diagram, Appendix D contains the included studies list, Appendix E contains the excluded studies list, Appendix F contains the data elements abstracted into the evidence tables, Appendix G contains the evidence tables for the included studies in Guiding Question 1, Appendix H contains the evidence tables for the included studies in Guiding Questions 2 through 5, and Appendix I contains details of models described by Key Informants.

## **1.2 Guiding Questions**

The questions below guided our work in developing a framework and description of research, ongoing efforts, and promising directions in long COVID models of care.

- 1. How has long COVID been defined?
- 2. What are the different types or models of care that have been proposed or used in clinical practice?
  - a. What are the potential advantages and disadvantages of long COVID models of care?
  - b. What are the components of different models of care?
- 3. Context of models of care:
  - a. In what settings and for whom are these models currently implemented?
  - b. Are there special considerations for implementing these models for adults, children, and disadvantaged populations influenced by social determinants of health?
  - c. What are potential facilitators and barriers to implementation, including resources needed, and how do barriers vary according to the setting?

- d. What kinds of training, certification, staffing, and other resources are required to develop and sustain these models of care?
- 4. What have published and unpublished studies reported on the use of and effectiveness of models of care for long COVID? Describe:
  - a. Patient population, practice setting, and country/location
  - b. Details on model of care, including the types of interventions used and specifics of pharmacological and nonpharmacological treatments, provider type/staffing needs, methods for coordination of care, educational and training components, implementation strategy, mode of delivery, visit frequency, and other factors
  - c. Study design/size
  - d. Comparator if relevant
  - e. Concurrent/prior treatments
  - f. Length of followup
  - g. Outcomes measured
  - h. Adverse events/harms/safety issues reported
- 5. What are gaps in our understanding of long COVID models of care?

## 2. Methods

As long COVID is a new condition and published literature on models of care is currently limited, this Technical Brief integrates input from Key Informants with searches of the published and grey literature to inform the above Guiding Questions.

### 2.1 Data Collection

#### **2.1.1 Discussions With Key Informants**

In order to obtain information on current and promising long COVID models of care, we assembled a diverse group of Key Informants. Key Informants were selected to provide broad and balanced perspectives on long COVID models of care in the United States, and included individuals with experience in: (1) developing and implementing models of care; (2) developing guidelines on evaluation and management of long COVID; (3) expertise in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) models of care (given similarities to long COVID); (4) providing patient perspectives; and (5) development of long COVID policy. The Key Informants included researchers, clinicians, representatives of professional societies and organizations, patient group representatives, and representatives of Federal agencies. Key Informants were involved with implementation of long COVID models of care in various healthcare settings, including academic medical centers, a nonacademic managed health system, private practice, and the Veterans Affairs Health System. We selected Key Informants to provide multidisciplinary representation, including expertise in adult and child/adolescent COVID-19, expertise in equity and social determinants of health, and lived patient experience.

We organized and facilitated a series of virtual discussions with Key Informants (individuals or small groups) to obtain input on the Guiding Questions. Members of our research team and the Agency for Healthcare Research and Quality (AHRQ) Task Order Officer attended the calls. On the calls, we engaged Key Informants using an informal group discussion approach to elicit perspectives on specific long COVID models of care, insights on where and how the models of care were established, and how they have evolved and are evolving. Topics of discussion with Key Informants included which long COVID models of care are in use (including models not described in the published literature); the settings and populations in which various models have been implemented; insights into what components are critical; barriers or facilitators to implementation; applicability to U.S. practice; patient preferences regarding different models of care; relevance of ME/CFS models of care; and future directions, including promising new and innovative models and strategies for implementation and sustainability (Appendix A). We also asked about specific populations managed in different models of care; outcomes data; variability across models in intensity, goals, and components of care; the feasibility and applicability of models of care to different populations and settings, and whether particular approaches may be particularly suitable for specific settings and populations. The calls were recorded, and notes from each call were shared with participants for additions, corrections, and clarifications. Following the calls, we contacted Key Informants if needed for additional details on specific models of care that they were involved with. The feedback from the Key Informants was integrated with the expertise of our project team and the evidence identified through the published and grey literature to develop a framework for describing long COVID models of care, based on key components, to help organize and provide a structure for future research and discussions in this topic.

#### 2.1.2 Published Literature Search

An experienced research librarian created search strategies of search terms and medical subject headings (MeSH) for long COVID models of care and performed searches on the following databases: Ovid Medline, PsycINFO, the Cochrane Library, SocINDEX, Scopus, Embase, and CINAHL. The full search strategies are shown in **Appendix B**. The searches were restricted to 2021, corresponding to when long COVID models were first described, to November 2023. We also reviewed reference lists and conducted a supplemental search (no date restriction) for systematic reviews on ME/CFS models of care, which may provide relevant background considerations for long COVID models. We supplemented the electronic database searches with a review of reference lists of identified publications for additional relevant studies.

## 2.1.3 Grey Literature Search

In order to ensure that we included studies of long COVID models of care published outside of the standard medical literature, we supplemented our search of electronic databases with grey literature searches. We searched websites of national and international government agencies with long COVID initiatives (e.g., Centers for Disease Control and Prevention [CDC], National Institutes of Health, National Institute for Health and Care Excellence [NICE] UK, National Health Service [NHS] UK, Canadian Agency for Drugs and Technologies in Health, Health Information and Quality Authority [Ireland], National Clinical Evidence Taskforce-COVID-19 [Australia], Provincial Health Services Authority [Canada] and other organizations with long COVID initiatives, such as the Strategy for Patient Oriented Research Evidence Alliance, Department of Veterans Affairs [VA], American Academy of Physical Medicine & Rehabilitation [AAPM&R], and Project Extension for Community Healthcare Outcomes [ECHO]). Grey literature studies were assessed for eligibility using the same approach described in the published literature search section (**Appendix B**). We also searched ClinicalTrials.gov and Health Services Research Projects in Progress website for relevant ongoing studies.

**Supplemental Evidence and Data for Systematic Reviews:** Supplemental Evidence and Data for Systematic Reviews were requested for this Technical Brief, but none were received.

## 2.2 Process for Selecting Studies

We included publications that described long COVID definitions and systematic reviews or primary studies of long COVID models of care. All citations identified through searches underwent dual independent review by trained members of the research team for eligibility based on whether they addressed the Guiding Questions. For Guiding Question 1, we focused on "key" long COVID definitions, defined as official definitions from governmental agencies, nongovernmental organizations (e.g., World Health Organization [WHO]), or professional societies with specific criteria for long COVID (e.g., criteria for acute SARS-CoV-2 infection, timing and duration of symptoms, and/or types of symptoms). Definitions not issued by governmental agencies or professional societies were also included if they were developed using formal quantitative methods and provided specific criteria. We excluded "informal" definitions which did not provide specific criteria, were not issued by governmental agencies or professional societies, or that primarily or exclusively referred to "official" definitions. For Guiding Question 4, we determined eligibility using predefined inclusion/exclusion criteria, organized using the PICOTS (population, intervention, comparator, outcome, timing, study design) framework (**Table 1**). The other Guiding Questions were descriptive and inclusion was not based on formal PICOTS criteria. We excluded studies that focused on the effectiveness of specific interventions for long COVID without describing a model of care, and restricted inclusion to English language studies. Articles describing proposed or theoretical long COVID models of care were included if they provided sufficient information about key components of the model (e.g., clinical setting, staffing, multidisciplinary team, coordination of care approach), but we noted models that had not actually been implemented.

Studies marked for possible inclusion by either team member underwent full-text review. Each full-text article was independently reviewed by two trained members of the research team for inclusion or exclusion on the basis of the eligibility criteria. If the reviewers disagreed, conflicts were resolved by discussion and consensus or by consulting another member of the research team. Reasons for exclusion at the full-text stage were recorded. DistillerSR was used to assist in managing the study selection process and EndNote software was used for reference management.

Table 1. Inclusion and exclusion criteria for Guiding Question 4 on the	use and effectiveness of
long COVID models of care	

PICOTS	Include	Exclude
Populations	Patients with long COVID (any definition)	Patients who do not meet
	- Including adults or children/adolescents	definitions for long COVID
Interventions	Long COVID models of care, including	Studies of interventions for specific
	concurrent/prior treatments	long COVID symptoms
Comparators	Will include studies of long COVID models of care without a comparator, as well as studies that	
	compare long COVID models of care with one another	
Outcomes	Measures of use or access	
	Quality of life	
	Function	
	Outcomes related to specific long COVID	
	symptoms	
	Patient satisfaction	
	Harms	
Timing	Any	
Study Design	Systematic reviews	Nonsystematic reviews
	Randomized controlled trials	Studies without original data
	Observational studies, including cohort studies,	Non-English language
	case control studies, and other experimental and	Nonhuman subjects
	nonexperimental study designs	-
Setting	Any country	

Abbreviations: COVID = coronavirus disease; PICOTS = Populations, Interventions, Comparators, Outcomes, Timing, Study Design, Setting.

## 2.3 Data Organization and Presentation

## 2.3.1 Information Management

For each model of care described in the literature or in Key Informant interviews, we recorded information on the model description or name; geographic and clinical setting; population served; disciplines included in the model and their location; intake, screening, and followup methods; methods of coordinating care; primary care role; use of services; and educational or training components. For Guiding Question 4 (outcomes of long COVID models of care), we planned to also record comparators (if any), outcomes, study designs, and methods (**Appendix H**). However, only one noncomparative study reported outcomes,<sup>46</sup> which we

#### 2. Methods

described in the findings. Data abstractions were performed by one team member and were reviewed for completeness and accuracy by another team member.

#### 2.3.2 Data Presentation

Findings are presented in the order of the Guiding Questions. We categorized and summarized findings from the grey literature and the Key Informant interviews qualitatively, including assessments of applicability of different models of care to U.S. settings. Factors to inform applicability assessments included the country/geographic location of the model, clinical setting, patient population (e.g., definition used for long COVID, insurance status), availability of interventions and services offered, and type and feasibility of funding. Models developed and implemented in the United States were highlighted and discussed separately from non-U.S. models.

We also developed a framework for describing long COVID models of care based on key characteristics that defined models and distinguished one model from others. We applied the framework to describe a set of representative models of care, based on the literature review and Key Informant interviews. Our approach to developing a conceptual framework was informed by a prior Technical Brief on models of care for medications for treatment of opioid use disorder that developed a framework to describe different models of care based on factors such as methods used for integrating/coordinating care; methods for screening patients and performing intake; use of telehealth; educational components; and categorization as practice- or systems-based models.<sup>47</sup> Using the framework developed for models of care for treatment of opioid use disorder as a starting point, we adapted the framework for long COVID models of care based on the findings of the literature search and Key Informant discussions. We had planned to explore opportunities to present findings graphically as an evidence map to visually represent the state of the science on different long COVID models of care is currently almost entirely descriptive, this was not done for the current report.

## 3. Findings

## 3.1 Overview

We had discussions with 18 Key Informants: 14 were clinicians with experience developing or working in a long COVID model of care; 2 had expertise in policy and implementation; and 2 represented the patient perspective (of whom one also conducted patient-centered research). Other characteristics of the Key Informants are shown in **Table 2**. The moderated discussions were conducted over seven phone calls, with one to five Key Informants participating in each call. The calls lasted from 30 to 60 minutes. The discussions did not use specific questions, but were based on the topics addressed in the Guiding Questions (**Appendix A**). All conversations took place in June to August 2023. A summary of the models of care described by the Key Informants, including key characteristics of the models, is shown in **Appendix I**.

A total of 1,960 citations were identified in searches of electronic databases and review of reference lists and 11 additional citations were identified in grey literature searches. A total of 8 publications were identified to inform Guiding Question 1 (definitions of long COVID). For long COVID models of care (Guiding Questions 2 to 5), we abstracted data from a total of 27 publications (Appendix G and H). A figure depicting the literature flow is available in Appendix C, and a full list of included and excluded studies is shown in Appendixes D and E, respectively.

Key Informant Details	Characteristic	Number of Key Informants (Total Number of Key Informants = 18)
Background of Key Informants	<ul> <li>Clinicians with experience developing or working in a long COVID model of care</li> </ul>	14
	Expertise in policy or implementation	2
	Patient perspective <sup>b</sup>	2
Federal or non- Federal perspective	At Federal agency or involved in implementation of long COVID models of care in Federal settings	4
	Non-Federal	14
Patient population	Adults	14
	Children or adolescents	4
Clinical specialties <sup>c</sup>	<ul> <li>Physical medicine and rehabilitation</li> </ul>	5
	<ul> <li>Pulmonary/critical care medicine</li> </ul>	1
	Cardiology	1
	Infectious disease	1
	<ul> <li>Primary care/family medicine</li> </ul>	2
	Psychology	1
	Psychiatry	1
	Physical therapy	1
	Geriatrics/palliative medicine	1
	<ul> <li>Myalgic encephalomyelitis/chronic fatigue syndrome</li> </ul>	1
	Neurology	2

Abbreviations: COVID = coronavirus disease

<sup>a</sup> Key informant discussions were conducted in compliance with the Paperwork Reduction Act. The discussions did not use specific questions, but were based on the topics addressed in the Guiding Questions.

<sup>b</sup> One of the Key Informants representing the patient perspective also conducted patient-centered research

<sup>c</sup> Some Key Informants had more than one clinical specialty

#### 3.2 Findings, Guiding Question 1. Long COVID definition

#### **3.2** Guiding Question 1. How has long COVID been defined?

We identified six key long COVID definitions described in the published or grey literature (Table 3). Five were official definitions issued by governmental agencies or nongovernmental organizations and one was a proposed definition (postacute sequelae of SARS-CoV-2 infection [PASC] score), developed by the Researching COVID to Enhance Recovery (RECOVER) research initiative.<sup>55</sup> Other long COVID definitions have been described, but met our criteria for informal definitions.<sup>12,56-65</sup> Key Informants who reported using a formal definition to identify patients with long COVID described using one of the key definitions (primarily the Centers for Disease Control and Prevention [CDC], the Department of Health and Human Services [DHHS], or the World Health Organization [WHO] definition), and did not describe use of other definitions, including the recently published PASC score.<sup>55</sup> However, they noted in-progress work in this area, including a committee convened by the National Academies of Sciences, Engineering, and Medicine (NASEM) to examine the current DHHS definition.<sup>66</sup> A survey of 45 long COVID clinics conducted between March and May 2021 did not include a question on specific long COVID definitions used, but asked respondents about clinic eligibility criteria.<sup>67</sup> It found that 42 percent of long COVID clinics reported that they did not use specific inclusion criteria, 42 percent used a specific timeframe since diagnosis or acute illness (9% <1 month, 22% 1 to 2.9 months, and  $11\% \ge 3$  months); 36 percent required a positive COVID test, 9 percent required patients to have been hospitalized due to COVID, 9 percent required patients to have been in the intensive care unit due to COVID, and 18 percent used other eligibility criteria (13% used a symptom description/questionnaire, 2% determined eligibility based on rehabilitation needs, and 2% required patients to be medically stable). A review of 24 international clinical guidelines and two models of care for long COVID found that four guidelines used the UK National Institute for Health and Care Excellence (NICE) definition, two guidelines used WHO definition, and one guideline referenced both the NICE and WHO definitions.<sup>68</sup> Although other guidelines did not describe using a specific definition, most guidelines described duration criteria for long COVID. Fourteen guidelines and both models of care defined long COVID as symptoms present at least 4 weeks after acute infection, two guidelines defined long COVID as symptoms present at least 2 weeks after acute infection, and five guidelines defined long COVID as symptoms present at least 12 weeks after initial infection.

The key definitions had a number of similarities, although there were also some important differences. The definitions are generally consistent in describing presence of persistent, new, or recurrent symptoms, and indicating the multisystemic and variable presentation of long COVID. All definitions are based on clinical presentation and do not use formal (quantitative) scoring criteria, except for the recently proposed PASC score (developed as part of the RECOVER initiative).<sup>55</sup> Definitions vary with regard to criteria regarding timing of onset and duration of symptoms. There was initially some variability across definitions with regard to requiring laboratory testing to confirm SARS-CoV-2 infection; however, all of the key definitions now permit either confirmed or clinically probable or suspected infection/COVID-19. The World Health Organization originally provided different definitions for adults and children/adolescents (**Table 3**). However, WHO definitions for adults and children/adolescents were unified in February 2023. The other definitions do not specify ages or distinguish by age group.

Two of the key definitions were developed in the United States by **DHHS**<sup>12</sup> and **CDC** and are similar.<sup>69</sup> Both definitions require presence of symptoms at least 4 weeks since onset of confirmed or suspected COVID-19. In the DHHS definition, which was developed later (with input from CDC), a confirmatory test is also not required (i.e., a clinical diagnosis is sufficient).

#### 3.2 Findings, Guiding Question 1. Long COVID definition

The NICE definition differs from the U.S. definitions by stratification of long COVID/post-COVID symptoms into two conditions based on the duration of symptoms.<sup>14</sup> "Ongoing symptomatic COVID-19" is defined as the presence of symptoms for 4 to  $\leq$ 12 weeks and "post-COVID-19 syndrome" as presence of symptoms for >12 weeks. As in the DHHS and CDC definitions, acute COVID-19 can be either confirmed or suspected. In addition to persistence of symptoms, the NICE definition also requires that symptoms are not explained by an alternative diagnosis.

The **World Health Organization** defines long COVID as probable or confirmed initial SARS-CoV-2 infection and presence of new or persistent symptoms for at least 2 months, with onset within 3 months of the initial infection.<sup>13</sup> Initially, WHO provided two separate definitions for long COVID in adults<sup>13</sup> and children.<sup>70,71</sup> The original pediatric definition required confirmed SARS-CoV-2 infection and presence of one or more new persistent physical symptoms for at least 12 weeks.<sup>70,71</sup> However, in February 2023,<sup>72</sup> the pediatric definition was changed to unify it with the adult WHO definition for long COVID.

The National Institutes of Health-sponsored multi-institutional **RECOVER Initiative** published a preliminary research definition for long COVID in May 2023.<sup>55</sup> This definition differs from those described above by being quantitative, as it is based on a composite symptom score (PASC score) rather than a set of clinical criteria. The PASC score was derived from an analysis of data from a longitudinal cohort of patients to identify symptoms present more often at 6 months or longer in patients with probable, suspected, or confirmed SARS-CoV-2 infection compared with patients without infection. Participants in the cohort with SARS-CoV-2 infection varied with regard to timing of presentation (within 30 days to up to 3 years from acute infection) and enrollment occurred during different phases of the pandemic (including the pre-Omicron era). The PASC score is based on 12 symptoms assigned a value of 1 to 8 (smell/taste [score 8], postexertional malaise [7], chronic cough [4], brain fog [3], thirst [3], palpitations [2], chest pain [2], fatigue [1], sexual desire or capacity [1], dizziness [1], gastrointestinal [1], and abnormal movements [1]). A summed cutoff score of  $\geq 12$  was used to classify patients as having long COVID. Additional validation of the PASC score is not yet available, and the applicability of the PASC score among patients with symptoms for <6 months has not been evaluated. A commentary on the PASC score noted that multiple definitions may be required because long COVID may represent different processes.<sup>73</sup>

To inform the in-progress work of its Committee on Examining the Working Definition for Long COVID, NASEM commissioned an engagement report based on input from almost 1200 questionnaire respondents and 134 focus participants.<sup>15</sup> The report found that over half of the questionnaire respondents were satisfied with the current DHHS definition. Of those who liked another definition, most preferred the WHO definition. A key theme in the report was the suggestion for a nested definition beginning with a broad and inclusive definition understandable to the general public, followed by more specific definitions with technical and scientific language suitable for different uses. There was a lack of consensus for having a single overarching definition for long COVID or a need for multiple definitions (e.g., for different phenotypes). The report also noted the suggestion to ensure that a long COVID definition be suitable for children, while striving for consistency with the adult definition to the extent possible. Other report findings included variable support for updating the definition to require confirmation of SARS-CoV-2 infection; many participants viewing 4 weeks from acute infection as too short a threshold; need to acknowledge variability in symptom duration; importance of specifying symptoms; need to incorporate the concept of impairment in the definition of long

#### 3.2 Findings, Guiding Question 1. Long COVID definition

COVID; and importance of ensuring that the definition is applied equitably to all people with long COVID. The work of this NASEM committee is ongoing and its proposed definition(s) is pending.

#### Table 3. Long COVID definition criteria

Source	A outo Diagnosia	Time Since	Symptom Characteristics
Source Centers for Disease Control and Prevention <sup>69</sup> (definition for "post-COVID conditions") https://www.cdc.gov/coronavirus/2019- ncov/hcp/clinical-care/post-COVID-conditions.html	Acute Diagnosis Confirmed or clinically diagnosed SARS- CoV-2 infection	Acute Infection ≥4 weeks	Symptom Characteristics Ongoing/persistent following the acute phase, or new or recurrent
UK National Institute for Health and Care Excellence (NICE) <sup>14</sup> https://www.nice.org.uk/guidance/ng188	Suspected or confirmed COVID- 19	Long COVID includes the following: Ongoing symptomatic COVID-19: 4 to ≤12 weeks Post-COVID-19 syndrome: >12 weeks	Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis
U.S. Department of Health and Human Services <sup>12</sup> https://www.COVID.gov/assets/files/National- <u>Research-Action-Plan-on-Long-COVID-</u> 08012022.pdf	COVID-19 or SARS-CoV-2 infection	≥4 weeks	May be multisystemic, may present with relapsing- remitting pattern or worsening over time, with the possibility of severe and life-threatening events months or years after infection
Researching COVID to Enhance Recovery (RECOVER) <sup>55,73</sup>	Suspected, probable, or confirmed SARS- CoV-2 infection	PASC score evaluated ≥6 months after acute symptoms onset or test date <sup>a</sup>	PASC score ≥12, based on 12 items (each assigned 1 to 8 points, maximum score 34)
World Health Organization (Adult and Pediatric [since February 2023]) <sup>13</sup>	Probable or confirmed SARS- CoV-2 infection	≥2 months, onset within 3 months of initial infection	New onset following initial recovery from an acute COVID-19 episode, or persistent from the initial illness May fluctuate or relapse over time
World Health Organization (Pediatric [prior to February 2023]) <sup>70,71</sup>	Confirmed SARS- CoV-2 infection	≥12 weeks	One or more new persistent physical symptoms May fluctuate or relapse Effect daily function Cannot be explained an alternative diagnosis

Abbreviations: COVID = coronavirus disease; COVID-19 = coronavirus 2019; PASC = postacute sequelae of COVID-19; RECOVER = Researching COVID to Enhance Recovery; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2.

<sup>a</sup> The PASC score was evaluated at  $\geq 6$  months from symptom onset or test date, with applicability to patients with symptom onset <6 months prior unknown.

**3.3** Guiding Question 2. What are the different types or models of care that have been proposed or used in clinical practice?

- a) What are the potential advantages and disadvantages of long COVID models of care?
- b) What are the components of different models of care?

#### 3.3.1 Long COVID Models of Care: Overviews and Summaries

We identified four publications providing overviews or summaries of long COVID models of care, with descriptions of variability in structure and components. One publication was a survey of 45 U.S.-based long COVID clinics,<sup>67</sup> one was a scoping review,<sup>74</sup> one was an environmental scan of Canadian long COVID clinics,<sup>75</sup> and one was a review of international long COVID guidelines and models of care (**Appendix Table H-4**).<sup>41</sup> We identified no systematic reviews on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) models of care.

A survey developed as part of the American Academy of Physical Medicine and Rehabilitation's (AAPM&R) Long COVID Initiative obtained responses from 45 US-based long COVID between March to May 2021.<sup>67</sup> It found that 82 percent had been created as new clinics and 13 percent evolved from a pre-existing clinic. The home department was physiatry (40%), pulmonology (22%), internal medicine (16%), family medicine (4%), or physical therapy (2%). The number of specialties considered part of the treatment team (defined as routinely seeing patients, or routinely seeing patients and available during the initial visit) varied: 2-5 (20%), 6-10 (55%), or >10 (31%). The most common specialties that were part of the treatment team were physical therapy (89%), pulmonology (82%), physical medicine and rehabilitation (78%), neurology (73%), cardiology (69%), neuropsychology (64%), psychology (64%), speech and language pathology (62%), occupational therapy (62%), psychiatry (60%), internal medicine (51%), social work (40%), and family medicine (33%). The clinics reported variability in the number of specialties available for the initial visit (1 specialty [27%], 2-5 specialties [31%], 6-10 specialties [31%], and >10 specialties [11%]) and the number of specialties routinely involved in the initial visit (1 specialty [40%], 2-5 specialties [44%], 6-10 specialties [13%], or >10 specialties [2%]). The most commonly reported specialties available to see patients during the initial clinic visit were physiatry (53% of clinics), pulmonology (53%), physical therapy (51%), internal medicine (44%), occupational therapy (36%), neurology (33%), psychology (33%), speech and language pathology (33%), family medicine (31%), cardiology (29%), psychiatry (27%), and social work (24%). About half (49%) of the clinics reported use of formal interdisciplinary meetings to discuss cases.

A scoping review of long COVID rehabilitation models of care (searches through April 2022) included 37 articles (reviews, proposed models, surveys, editorials, and others).<sup>74</sup> Thirty articles described which healthcare professionals were necessary to provide long COVID rehabilitation services. The number of proposed professions ranged from 1 to 7, with a total of 10 professions described (physiotherapists [97%], occupational therapists [73%], psychologists [53%], speech and language therapists [43%], physiatrists [27%], social workers [23%], neuropsychiatrists [23%], dieticians or nutritionists [20%], cardiopulmonary specialists [5%], and orthopedists [5%]). Eighteen articles in the scoping review described proposed clinical components or functions of long COVID rehabilitation models of care. The most commonly described clinic components were multidisciplinary teams (95%), continuity or coordination of

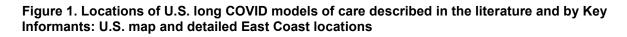
care (58%), patient-centered/shared decision-making (53%), integrated care (53%), evidencebased care (42%), guided self-management (42%), patient needs management (42%), case management (37%), and partnership with a research institution (37%). The most commonly described clinic functions were standardized symptom assessment/screening (100%), telehealth and/or virtual care (74%), followup system (68%), referral system (63%), and home-based care (37%).

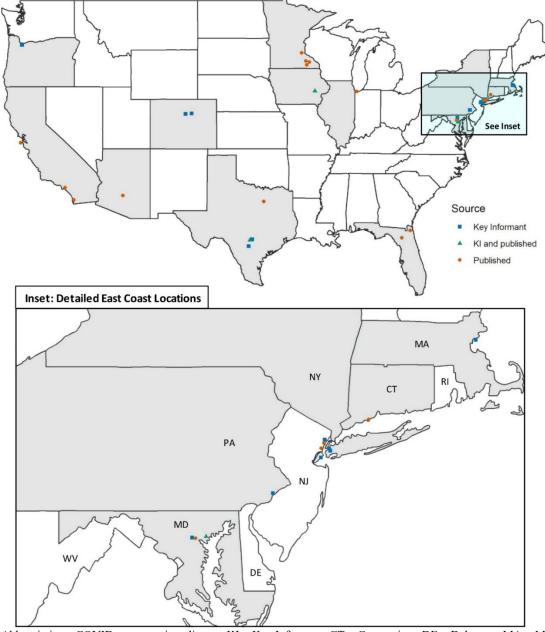
An environmental scan that focused on long COVID clinics in Canada in October to November 2022 classified the clinics into types.<sup>75</sup> Among 25 identified clinics, 28 percent were classified as "units" (dedicated ward or center providing services at 1 location), 36 percent as "coordinated efforts" (care not limited to specific centers or spaces providing integrated care and support across different specialists), 12 percent as "programs" (a set of services providing dedicated care across multiple centers or locations), and 8 percent as general chronic care support (care provided for different health conditions, including but not dedicated only to long COVID). The clinic setting was hospital only (17%), primary care only (4%), academic only (9%), hospital and primary care (4%), hospital and academic (52%), and hospital, academic, and primary care (13%).

A review of international guidelines and models of care for long COVID commissioned by the Health Information and Quality Authority of Ireland (searches through September 2022) described recommendations on service planning from 14 guidelines.<sup>41</sup> Recommended service planning elements were agreed referral pathways among inpatient, primary care, community-based and specialty clinics (29% of guidelines), continuity or coordination of care (64%), hybrid in-person and remote services (21%), integrated multidisciplinary services (21%), multidisciplinary care coordinated by primary care (14%), and implementation of a team-based approach (7%).

## **3.3.2 Long COVID Clinics: Primary Publications**

From our literature review, we identified articles describing 31 long COVID clinics or models of care (reported in 25 publications) (Appendix H).<sup>46,56-65,76-89</sup> Figure 1 shows the locations of 18 U.S.-based models.<sup>56,58,61,65,76,78,81,84,86,87,89</sup> Three articles described five long COVID clinics within the Mayo Clinic system;<sup>58,78,84</sup> one article described five clinics in Texas, California, Minnesota, and Florida;<sup>65</sup> and one article described two clinics/models in Taiwan.<sup>57</sup> The other publications each described one clinic or model. Four of the clinics/models were proposed or theoretical;<sup>57,62,77,83</sup> otherwise publications described existing long COVID clinics. Publications were often missing important details to clearly describe the clinic structure or the model of care used. The models varied with regard to the population managed (adults, children and adolescents, or both) and geographic setting (country), though most (58%) were implemented in the United States (Table 4). One model described using the NICE definition for long COVID<sup>46</sup> and six models used a duration of >4 weeks or 30 days without specifying a formal definition; otherwise, definitions or criteria for long COVID were not reported. All clinics/models focused on patients with long COVID except for two,<sup>46,76</sup> which also managed patients with ME/CFS or other postinfection fatiguing illness. Four clinics were described as managing socioeconomically disadvantaged populations<sup>61,65,76,81</sup> and one clinic treated patients in the VA system.<sup>65</sup>





Abbreviations: COVID = coronavirus disease; KI = Key Informant; CT = Connecticut; DE = Delaware; MA = Massachusetts; MD = Maryland; NJ = New Jersey; PA = Pennsylvania; RI = Rhode Island; WV = West Virginia. Note: All models focused on adults except for 5 that focused on children, and 4 that focused on mixed populations of adults and children.

Long COVID Models of	Long COVID models of care described	Number of Models (Total Number
Care Elements	Characteristics	of Models of Care or Clinics = 31)
Existing vs. proposed or	Existing models	27
theoretical models	Proposed or theoretical models	4
Population	Children and adolescents	1
	Children and adults	5
	Adults	4
	<ul> <li>Age not specified, but appeared to focus on adults</li> </ul>	21
Long COVID definition	NICE	1
	<ul> <li>Duration &gt;4 weeks or &gt;30 days, without describing a specific definition</li> </ul>	7
	<ul> <li>Definition or criteria for long COVID not described</li> </ul>	23
Geographic setting	United States	18
	United Kingdom	3
	Canada	2
	Taiwan	2
	Germany	1
	France	1
	Ireland	1
	Australia	1
	Egypt	1
	<ul> <li>Proposed clinic without specific geographic location</li> </ul>	1
Primary clinical	Primary care	6
department or clinical	Specialty department	10
lead	<ul> <li>Physiatry</li> </ul>	4
	<ul> <li>Pulmonary</li> </ul>	2
	<ul> <li>Psychology</li> </ul>	1
	<ul> <li>Neurology</li> </ul>	1
	<ul> <li>Multiple specialties</li> </ul>	2
	Case manager	1
	Integrative medicine	1
	Mobile clinic	1
	Primary clinical department not described or unclear	12

Table 4. Characteristics of long COVID models of care described in the literature

Abbreviations: COVID = coronavirus disease; NICE = National Institute for Health and Care Excellence

**Primary clinical department or clinical lead:** The primary clinical department or clinical lead varied across models. Six models (reported in 4 publications)<sup>61,65,76,78</sup> were primary carebased and 10 models (reported in 9 publications)<sup>46,56,57,65,78,84,86,87,89</sup> were specialty-based. Of the six primary care-based models, five described dedicated long COVID clinics led by primary care and one (Mayo Clinic Arizona)<sup>78</sup> described a primary care-integrated model, in which long COVID care was provided in primary care, rather than in a separate long COVID clinic. Of the 10 specialty-based models, the primary clinical specialty was physiatry in four models, pulmonary in two models, psychology in one model, neurology in one model, and multiple specialties in two models (**Table 4**). Other individual models were led by a case manager,<sup>57</sup> based in integrative medicine (University of Florida COVID Restore clinic),<sup>65</sup> or used a mobile clinic.<sup>80</sup> In 12 models, the primary clinical department or lead was not described or was unclear.

**Clinical specialties and professions:** Although all models adhered to a multidisciplinary approach, the number and type of clinical specialties or professions described as being involved in the model varied. For 22 clinics/models that provided this information, the number of

specialties or professions described for each clinic/model ranged from 3 to 17 (median 10) **(Table 5)**. A total of 39 different specialties or professions were described by at least one clinic/model, most commonly cardiology (73%), pulmonology (68%), psychology (64%), physical therapy (64%), physiatry (59%), neurology (55%), psychiatry (50%), otorhinolaryngology (45%), infectious disease (36%), primary care (36%), occupational therapy (36%), speech and language pathology (36%), nephrology (27%), and neuropsychiatry (27%). Other clinical specialties or professions were described in 20 percent or fewer clinics/models. Two clinics/models described on-site co-location of multiple "core" specialties or professions;<sup>56,61</sup> otherwise, the location of involved specialties or professions was not well described. Findings should be interpreted with caution, as publications did not necessarily provide comprehensive lists of clinical specialties; in addition, most publications did not describe the degree of involvement by various specialties. However, the specialties or professions described may provide some indication of those considered more important for management of long COVID, as well as the breadth of expertise and services potentially required or considered important in long COVID models of care.

Table 5. Disci	рш	es	n ic	ong	CU	עוע	CIII	lics	lae	nun	ea	Iron	i ui	еш	era	ure																	1		r r			<u> </u>		
Author Country	Primary Care <sup>a</sup>	<b>Occupational Medicine</b>	<b>Preventive Medicine</b>	PM&R	Psychiatry	Psychology	Neuropsychiatry	Allergy and Immunology	Infectious Disease	Pulmonology	Sleep Medicine	Neurology	Cardiology	Pediatrics	Otorhinolaryngology	Gastroenterology	Nephrology	Hematology	Endocrinology	Geriatrics		Intensive Care Medicine	Dermatology	Hepatology	Rheumatology	Immunology	Chronic Fatigue	Integrative Medicine	Wellness Coaching	Physical Therapy	Occupational Therapy	Speech and Language Pathology	Diet/Nutrition	Autonomic Patient Education	Social Work	Infection Control	Pharmacy	Counseling	Nursing	#
Ahmad <sup>81</sup> U.S.	-	-	-	1	1	-	-	-	-	1	1	-	1	-	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	-	-	10
Aiash <sup>85</sup>	-	-	-	1	-	-	-	-	-	1	-	-	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	1	1	1	1	-	-	-	-	-	1	9
Egypt Bailey <sup>56</sup> U.S.	-	-	-	-	1	-	-	-	1	1	-	1	1	-	1	1	1	1	1	-	-	-	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	_	-	12
Brigham <sup>87</sup> U.S.	1	-	-	1	1	1	-	-	1	1	-	1	1	-	1	-	1	1	-	-	-	-	1	1	-	-	-	-	-	1	1	1	-	-	-	-	1	-	-	17
Chuang⁵ <sup>7</sup> Taiwan	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	-	1	-	-	-	-	6
Ganesh (Mayo Clinic COVID-19 Activity Rehabilitation Program) <sup>78</sup> U.S.	1	1	1	1	_	1	-	1	1	1	-	1	1	1	1	_	_	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	13
Ganesh (Mayo Clinic Arizona, Mayo Clinic Florida, Mayo Clinic Rochester Post-COVID Care Clinic) <sup>78</sup> U.S.	1	1	1	1	-	1	-	1	1	1	-	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	13
Ganesh (Mayo Clinic Post- COVID-19 Care Clinic) <sup>58</sup> U.S.	1	-	1	-	-	1	-	1	1	1	-	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	10

Author Country	Primary Care <sup>a</sup>	<b>Occupational Medicine</b>	Preventive Medicine	PM&R	Psychiatry	Psychology	Neuropsychiatry	Allergy and Immunology	Infectious Disease	Pulmonology	Sleep Medicine	Neurology	Cardiology	Pediatrics	Otorhinolaryngology	Gastroenterology	Nephrology	Hematology	Endocrinology	Geriatrics		Intensive Care Medicine	Dermatology	Hepatology	Rheumatology	Immunology	Chronic Fatigue	Integrative Medicine	Wellness Coaching	Physical Therapy	Occupational Therapy	Speech and Language Pathology	Diet/Nutrition	Autonomic Patient Education	Social Work	Infection Control	Pharmacy	Counseling	Nursing	#
Harenwall <sup>46</sup> U.K.	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	-	-	-	-	-	-	5
Ladds <sup>59</sup> U.K.	-	1	-	1	1	-	-	-	-	1	-	1	1	-	1	-	-	-	1	-	-	-	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	12
List <sup>61</sup> U.S.	1	-	-	-	1	1	-	-	-	1	-	-	1	-	-	-	1	1	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	8
Lutchmansingh <sup>89</sup> U.S.	-	-	-	-	1	-	-	-	-	-	1	1	1	-	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	7
Morrow <sup>82</sup> U.S.	-	-	-	1	-	1	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	1	-	-	-	-	6
O'Brien <sup>63</sup> Ireland	-	-	-	-	1	1	-	-	1	1	-	-	-	-	-	-	-	-	-	-	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	6
Parker <sup>83</sup> Not specified	1	-	-	1	-	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	-	-	1	-	1	-	-	9
Santhosh <sup>86</sup> U.S.	1	-	-	-	1	1	-	-	-	1	-	1	1	-	1	-	-	-	-	1	-	-	-	-	-	-	1	-	-	1	1	1	-	-	-	-	1	-	-	13
Vanichkachorn <sup>84</sup> U.S.	-	1	1	1	1	-	1	-	1	1	-	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	-	1	-	-	-	-	-	13
Verduzco- Gutierrez (UTSW COVID Recover) <sup>65</sup> U.S.	-	-	-	1	1	-	1	-	-	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1	-	7
Verduzco- Gutierrez (UT Health San Antonio) <sup>65</sup> U.S.	-	-	-	1	-	1	1	-	-	-	-	-	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	6

Author Country	Primary Care <sup>a</sup>	<b>Occupational Medicine</b>	Preventive Medicine	PM&R	Psychiatry	Psychology	Neuropsychiatry	Allergy and Immunology	Infectious Disease	Pulmonology	Sleep Medicine	Neurology	Cardiology	Pediatrics	Otorhinolaryngology	Gastroenterology	Nephrology	Hematology	Endocrinology	Geriatrics	Radiology	Intensive Care Medicine	Dermatology	Hepatology	Rheumatology	Immunology	Chronic Fatigue	Integrative Medicine	Wellness Coaching	Physical Therapy	Occupational Therapy	Speech and Language Pathology	Diet/Nutrition	Autonomic Patient Education	Social Work	Infection Control	Pharmacy	Counseling	Nursing	#
Verduzco- Gutierrez (VA Greater Los Angeles Healthcare System) <sup>65</sup> U.S.	-	-	-	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	3
Verduzco- Gutierrez (Hennepin Healthcare) <sup>65</sup> U.S.	1	-	-	-	-	-	1	-	-	1	1	1	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	-	-	1	-	-	-	-	11
Verduzco- Gutierrez (University of Florida COVID Restore) <sup>65</sup> U.S.	-	-	-	1	1	1	-	-	1	1	-	1	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	1	-	1	-	-	-	-	-	-	-	-	-	10
Number of models including specialty/ profession (%)	8 (36)	4 (18)	4 (18)	13 (59)	11 (50)	14 (64)	6 (27)	3 (14)	8 (36)	15 (68)	3 (14)	12 (55)	16 (73)	3 (14)	10 (45)	2 (9)	6 (27)	4 (18)	2 (9)	1 (5)	2 (9) (	1 5)(*	3 14)	2 (9)	2 (9)	1 (5)	2 (9)	1 (5)	2 (9)	14 (64)	8 (36)	8 (36)	3 (14)	1 (5)	4 ) (1 8)	1 (5)	4 (18)	1 (5)	1 (5)	10 <sup>ь</sup>

Abbreviations: PM&R = physical medicine and rehabilitation; UT = University of Texas; UTSW = University of Texas Southwestern Medical Center; VA = Veterans Affairs.

<sup>a</sup> Includes general internal medicine

<sup>b</sup> Median number of specialties or professions in a model

**Referral/intake:** Regarding methods for referring patients into the long COVID models, clinics varied with regard to whether patients could self-refer or had to be referred by a physician. Four clinics/models described more proactive assessment and followup of patients with acute COVID-19 to identify patients who develop long COVID and might be suitable for management in the long COVID clinic.<sup>81,83,87,89</sup> For 14 clinics/models, there was some description of methods for coordinating services, although specific details were limited. Personnel described as having care coordination responsibilities included a designated case manager or care coordinator, allied health professional, or physician or other member of the care team. For initial screening and assessment, 14 clinics/models described use of a standardized questionnaire<sup>56,60,64,65,76-79,85</sup> and 3 clinics/models described standardized diagnostic testing.<sup>58</sup> The diagnostic tests varied and included various lab tests (e.g., complete blood count, complete metabolic panel, ferritin, C-reactive protein, procalcitonin, d-dimer, COVID-19 antibody testing, urinalysis, autoimmune screening), 6-minute walk test, pulmonary function testing, chest imaging, electrocardiogram, echocardiogram, and neuropsychological examination.

**Telehealth services:** Teleservices were widely used. For eight clinics/models, the initial visit was specifically conducted as a virtual visit.<sup>63,65,78,89</sup> Otherwise, all clinics/models that described use teleservices generally offered virtual visits as an option for initial or followup visits, or as an option for provision of some services (e.g., telerehabilitation, mental health helplines, health coaching, neuropsychological evaluation). Two clinics were designed as entirely or almost entirely virtual<sup>63,65</sup> and one clinic included implementation of a remote patient monitoring program.<sup>87</sup>

**Role of primary care**: For clinics/models that were not primary care-based, the role of primary care was not well defined. One clinic noted that "patients may initiate followup with primary care at any time,"<sup>62</sup> one clinic described providing recommendations to the primary care clinician following discharge from the long COVID clinic,<sup>81</sup> three clinics described the long COVID clinic as integrated with or providing support to primary care without providing further details,<sup>60,86,87</sup> and one clinic described transition to primary care following symptom resolution and normal pulmonary function tests.<sup>89</sup> An ongoing randomized controlled trial is evaluating the use of telementoring (Project ECHO [Project Extension for Community Healthcare Outcomes]) to support management of long COVID in primary care.<sup>76</sup>

**Followup, training/education/use of algorithms, and funding:** When reported, with the exception of one clinic that administered a weekly virtual telerehabilitation course,<sup>46</sup> the timing of initial followup visits ranged from 1 to 3 months, with subsequent followup at 3- to 6-month intervals. Thirteen clinics/models reported development and implementation of training or algorithms on management of long COVID,<sup>60,65,76,78,84,86,87,89</sup> including training and educational efforts aimed at primary care clinicians.<sup>65,78</sup> Among U.S. long COVID clinics/models, details regarding the need for or receipt of funding to support clinic sustainability was not reported.

**Applicability to the United States:** Determining the applicability of non-U.S. clinics/models to U.S. settings was a challenge due to lack of details regarding clinic/model components and structure, including funding mechanisms and the degree to which the clinic/model was tailored or adapted to the setting in which it was implemented. Several publications on non-U.S. clinics/models<sup>57,59,60,79,85</sup> described multidisciplinary, specialty-based long COVID clinics that appeared similar to those described in U.S. settings.<sup>56,58,65,81,84,86,89</sup> Non-U.S. clinics that differed from U.S. clinics included a UK clinic that adapted an existing, 7-week, psychology-led interdisciplinary virtual rehabilitation course for patients with ME/CFS to patients with long COVID-19,<sup>46</sup> a German mobile long COVID outpatient clinic (grant-funded as a demonstration

project<sup>80</sup>), a Taiwanese case manager-led multidisciplinary model,<sup>63</sup> and an Irish all-virtual multidisciplinary clinic.<sup>57</sup> Three publications described systems-based approaches that might be more difficult to implement in settings in which healthcare is more fragmented. In these models (one model in the UK<sup>64</sup> and two proposed models in Canada and Australia<sup>62,77</sup>) the severity of patient symptoms were used to match patients to different clinical tiers or "streams" of care with varying intensities of services.

#### **3.3.3 Long COVID Clinics: Key Informant Interviews**

We obtained information on 20 long COVID clinics or models of care (Appendix I) from interviews with 15 Key Informants (3 Key Informants were not involved in a clinic or model of care). All of the models were U.S.-based (Figure 1). One Key Informant described five proposed or implemented model types for the Veterans Affairs (VA) health system (Multidisciplinary Team, Long COVID Clinic, Long COVID Clinic and Board, Long COVID Hub and Spoke, and National Tele-E-Consultation for Long COVID) and one Key Informant provided two specific examples of VA models in Texas. Two Key Informants worked in and described the same model (University of Texas San Antonio Post COVID Recovery Clinic). This model and one other (Pediatric Post-COVID-19 Rehabilitation Clinic, Kennedy Krieger Institute) were also described in the literature (Table 6).<sup>65,82</sup> The populations managed were primarily (70%) adults and most clinics (85%) exclusively managed patients with long COVID. One proposed model developed by the COVID-19 Longhauler Advocacy Project has not yet been implemented;<sup>90</sup> otherwise the Key Informants described existing long COVID models. None of the clinics were specifically created to manage low socioeconomic or otherwise underserved populations, though several Key Informants noted that underinsured and uninsured patients are seen in the clinic.

Primary clinical department or specialty of clinical lead: Among 13 actual/existing clinics, four clinics/models are led by a primary care clinician (family medicine or pediatrics) or palliative care/geriatrics physician (including two models for the VA system in Texas) and 9 clinics are led by another specialist (4 physiatry, 1 infectious disease, 2 pulmonary, 1 pulmonology and neurology, 1 pediatric critical care and neuro-trauma recovery program). The Key Informants noted that most long COVID clinics developed within the departments or clinics in which patients with long COVID symptoms were frequently seen and clinicians had an interest in managing this condition. One Key Informant described practicing outside of a formal long COVID clinic or model of care, providing services for patients with long COVID in a psychiatry private practice and referring to other specialties as needed. One of the proposed VA model types (Long COVID Clinic and Board) is designed to be led by an advanced practice practitioner; otherwise, clinical specialties or professions are not specified in the five proposed VA model types (can be primary care clinician or specialist). The proposed COVID-19 Longhauler Advocacy Project model describes involvement by an extensive set of clinical specialties and professions with comprehensive expertise in the many conditions which may occur in adults and children with long COVID.<sup>90</sup>

**Clinical specialties and professions:** All Key Informants described the importance of access to multiple clinical specialties and professions. Key Informants described referral for more specialized testing (e.g., dysautonomia evaluation, cardiopulmonary exercise testing, neuropsychiatric evaluation), unless those services were available directly in the clinic, including through co-located specialties. In nine clinics, initial evaluation and management was performed by an individual physician or within one specialty, with referrals to other specialists as needed. This approach was consistent with the VA Long COVID Clinic model type. In models in which

multiple specialties were not co-located within a single clinic, Key Informants noted that it was difficult to specify which specialties were involved in the model, as the relationships with specialists varied from regular referrals with close collaboration to infrequent referrals with limited collaboration. However, specialties and professions that were frequently mentioned as being involved in long COVID care were physiatry, pulmonology, psychology, neurology, cardiology, infectious disease, otolaryngology, physical therapy, occupational therapy, and speech and language pathology. Key Informants noted that availability of physical therapy and occupational therapy services with expertise in managing long COVID was critical to manage symptoms such as fatigue (including energy conservation methods and individualized return to activity, if appropriate), dyspnea, decreased endurance, and dizziness or lightheadedness (including symptoms related to postural orthostatic tachycardia syndrome).

In five clinics, initial evaluation and management was performed by a co-located multidisciplinary team, with the number of specialties ranging from two to five or more. Among the clinics that have been implemented the University of Colorado Post COVID clinic appeared to be the most extensive, with pulmonary/critical care, integrative medicine, physiatry, cardiology, physical therapy, and occupational therapy as on-site specialties. The co-located, multidisciplinary approach was consistent with the VA Multidisciplinary Team Model. The model proposed by the COVID-19 Longhauler Advocacy Project also used a multidisciplinary team approach, with co-location of primary care and many clinical specialties with expertise in the conditions associated with long COVID in adults as well as children.<sup>90</sup>

**Referral/intake:** Regarding intake methods, two clinics/models used active followup of patients with acute COVID-19 to identify those that developed long COVID; in addition, active outreach was described as an option for all five VA model types. In the other models, intake occurs via patient self-referral, physician referral, or both. Ten clinics had a staff person assigned to assist with care coordination; in the other clinics, care coordinator. Five Key Informants described clinics which had developed educational materials or implemented standardized algorithms or templates for management of long COVID, including educational materials aimed at primary care clinicians. Key Informants from the VA also noted that the VA is working on developing educational guidelines for providers managing long COVID.

Telehealth services: All Key Informants reported use of teleservices. The Virtual Clinic for Veterans in San Antonio, Texas was designed as a fully virtual clinic and the VA Hub and Spoke Model for Veterans Integrated Service Network (VISN) 17 (VA Heart of Texas Health Care Network) used a fully virtual teleconsultation "hub" (clinic providing centralized higher level of care for more complex or seriously affected patients or those requiring specialized services or testing) to work with "spoke" clinics (dispersed, local clinics providing lower levels of care). The University of Texas San Antonio Post COVID Recovery Clinic was described as being primarily virtual, though in-person visits were also offered. The Key Informant from the COVID-19 Longhauler Advocacy Project felt that telehealth visits were preferred from the patient perspective, given the complexity of long COVID, but that in-person visits could be necessary in some situations.<sup>90</sup> The VA has proposed two other models in which teleservices are a defining feature. The VA Long COVID Clinic and Board model is intended for settings that lack expertise in long COVID. Patients are evaluated in a local long COVID clinic led by an advanced practice practitioner and presented to a virtual board of specialists who provide consultation and guidance. The VA National Tele-E-Consultation for Long COVID is intended as a safety net for areas with even less access to long COVID care (i.e., no long COVID clinics are available). In

this model, centralized teleconsultation services are provided to help clinics without long COVID expertise manage long COVID.

**Role of primary care:** Most Key Informants described primary care clinicians as primarily being involved in referring patients. Although the Key Informants noted that increased coordination and integration with primary care would be ideal, they described most primary care clinicians as not being heavily involved in ongoing management of long COVID and challenges in handing off care back to primary care, due to factors such as lack of training, lack of support, time constraints, or patient complexity. As described above, four clinics are led by clinicians with a primary care background (family medicine, pediatrics, or geriatrics) and an interest in long COVID; however, these clinics focus on management of COVID-19 and are not designed or intended to provide primary care. Some Key Informants noted that the approach used in integrative medicine is well suited for the whole health approach recommended for long COVID,<sup>39,91</sup> though few Key Informants reported integrative medicine involvement in their clinic.

**Followup, education/training/use of algorithms, and funding:** Key Informants described variability in followup intervals. Some Key Informants noted more frequent (e.g., monthly or bimonthly) followup in the first few months after initial evaluation, with longer interval between followup visits for most patients after that. Other Key Informants noted that followup was individualized for each patient according to complexity and severity of symptoms.

In general, Key Informants described following published guidelines (e.g., guidelines from AAPM&R<sup>92</sup> or VA<sup>39</sup>) for management of long COVID, including testing and management of specific symptoms. Five Key Informants noted that their clinics had developed educational materials or implemented standardized algorithms or templates for management of long COVID, including educational materials aimed at primary care clinicians. Key Informants from the VA also noted that the VA is working on developing educational guidelines for providers managing long COVID. Key Informants generally described high demand for the long COVID clinics and several Key Informants reported long wait times to get into the clinic. With regard to billing and payments, the Key Informants did not report issues with insured patients, although some Key Informants noted the importance of having staff with expertise in billing for management of long COVID. For uninsured and underinsured patients, a few challenges or issues were described. One Key Informant noted that its long COVID clinic did not have the ability to manage uninsured patients, one Key Informant in private practice reported not accepting insurance (selfpay only), two Key Informants noted that noninsured patients have to self-pay or apply for financial assistance, one Key Informant reported placing underinsured or uninsured patients on a waitlist and seeing a small number pro bono each week, and one Key Informant reported applying for funding for managing the uninsured population. One Key Informant that reported treating a large Hispanic population described use of interpreters and Spanish-speaking patient advocates; specific methods or strategies for managing underserved communities/populations were otherwise not described.

	Long COVID Models of Care	Number of Models (Total Number			
Model Elements	Characteristics	of Models of Care or Clinics = 20)			
Existing vs. proposed or	Existing models	19			
theoretical models	<ul> <li>Proposed or theoretical models</li> </ul>	1			
Population	Children and adolescents	4			
	Children and adults	2			
	Adults	14			
Clinical conditions	Long COVID only	17			
managed	Long COVID, ME/CFS, chronic Lyme disease, and Ehlers-Danlos syndrome	1			
	Children with neurotrauma following intensive care unit admission for long COVID or other clinical conditions	1			
	Children with long COVID who also meet criteria for ME/CFS	1			
Primary clinical	Primary care	4			
department or clinical	Palliative care/geriatrics	1			
lead	Specialty department	9			
	<ul> <li>Physiatry</li> </ul>	4			
	<ul> <li>Pulmonary/critical care</li> </ul>	4			
	<ul> <li>Infectious disease</li> </ul>	1			
	<ul> <li>Primary clinical department not specified (proposed models)</li> </ul>	6			

Table 6. Characteristics of long COVID models of care described by Key Informants

Abbreviations: COVID = coronavirus disease; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome

### 3.3.4 Framework for Long COVID Models of Care

Based on the literature review and Key Informant interviews, we identified five key principles for long COVID models of care: (1) core "lead" team with knowledge and expertise in long COVID, (2) ready access to broad multidisciplinary expertise, (3) ready access to a broad range of evidence-based diagnostic and therapeutic services, (4) provision of patient-centered, individualized, and equitable care, and (5) capacity to meet high demand for long COVID care in population served. We identified 10 model components or characteristics that appeared to be useful for describing long COVID models and the variability in their approaches to meeting these principles. The components were: (1) home department or clinical setting (e.g., primary care clinic, specialty clinic, or standalone long COVID clinic); (2) clinical lead; (3) co-location of other specialties; (4) primary care role; (5) population managed; (6) methods for intake and initial visit (including methods for identifying potential long COVID patients, referral to the long COVID clinic, and methods for initial evaluation, including personnel performing the evaluation and use of standardized algorithms); (7) care coordination methods; (8) use of teleservices; (9) education, training, and outreach initiatives for clinicians and patients; and (10) whether the model was practice-based or systems-based. Practice-based models were defined as those that could be implemented in an individual clinic or health system. Systems-based models have clinical components across multiple levels of the healthcare system to provide care throughout a network or local region.<sup>47</sup> A systems-based model may comprise one or more practice-based models.

From these 10 components, we retained 7 as a framework to describe and categorize models of care. Although methods for intake and initial visit, care coordination methods, and education, training, and outreach initiatives are important for describing models of care and facilitating implementation, they are relevant across models and variability in these components did not appear to be useful for distinguishing different models. Therefore, we did not include these in the

framework for categorizing models of care. The components used to categorize the models were: (1) home department or clinical setting; (2) clinical lead; (3) co-location of other specialties; (4) primary care role; (5) population managed; (6) use of teleservices; and (7) practice- or systems-based.

**Table 7** summarizes representative practice- and system-based models, describes the key components, and lists examples from the literature and Key Informant interviews for each model type. The descriptions for each model included the key defining features, usually based on one or a few components. For example, in most models of care, whether visits are virtual or in-person is not a defining feature, but for some models, being virtual is the key defining feature. The descriptions also described potential advantages and disadvantages of different models. The list of models was limited by the available information; in addition, components of each model are not mutually exclusive, and there is variability within a particular model. Most model types appeared applicable to children or adults, though in practice care has often been provided in separate clinics because of differing presentation and expertise needed to manage long COVID in different age groups.

### **3.3.5 Practice-Based Models**

### 3.3.5.1 Single Specialty-Based Long COVID Clinic

The Single Specialty-Based Long COVID Clinic was one of the more common model types. In this model the long COVID clinic was based in a specialty department with a physician lead. Other specialties and professions were not co-located within the clinic, but were available through referrals, as were additional testing services. Systems should be in place to facilitate timely referrals and coordination of care, including communication and collaboration with primary care, though the robustness of such systems vary. This model leveraged existing expertise and interest in long COVID in the home department, and was usually led by a physician from a specialty commonly involved in long COVID care. Examples included the VA Long COVID Clinic model (which can be led by either a specialist or primary care clinician), Penn Medicine COVID Recovery Clinic, and the University of Texas San Antonio Post COVID Recovery Clinic.<sup>65</sup>

### 3.3.5.2 Primary Care-Led Long COVID Model

The Primary Care-Led Long COVID model was similar to the single specialty-based long COVID clinic, with the main difference being that it is based in a primary care department with a primary care lead. An advantage of this model was that it may help preserve specialty capacity and resources. Instead of all patients being evaluated by a specialist in the Single Specialty-based model, patients in the Primary Care-Led Long COVID model were referred as needed to specialists and for additional testing. As in the specialty-based model, systems to facilitate timely referrals and optimize coordination of care are critical. Although this model was led by primary care, the main purpose of the clinic was to manage long COVID, not provide primary care. However, because it is managed by primary care clinicians, some primary care needs could be addressed, such as for patients without a primary care provider. In addition, by being based in primary care, this model could potentially facilitate referrals to establish primary care, coordination of primary care clinicians to manage long COVID outside of the long COVID clinic. Examples of this model are the Kaiser Long COVID Clinic pilot, Mayo Clinic Rochester Post-COVID Care Clinic,<sup>78</sup> Mayo Clinic Florida PASC Clinic, and New York

City Health & Hospitals COVID-19 Centers of Excellence;<sup>61</sup> the VA Long COVID Clinic model may be led by a specialist or a primary care clinician.

### 3.3.5.3 Multidisciplinary Long COVID Model

In the Multidisciplinary Long COVID model, multiple specialties commonly involved in long COVID care were co-located within a single clinic. Therefore, patients could be seen by multiple specialties at a single visit, reducing the inconvenience and burdens of multiple visits or appointments, and potentially improving coordination and collaboration among the co-located specialties. As in the models described above, patients may need to be referred for specialties or services not available within the clinic. This model posed additional administrative challenges related to coordinating multiple involved specialties with dedicated time in the clinic, and would likely be relatively resource-intensive. In addition, this model is likely only feasible for large health systems with extensive multidisciplinary expertise. An example of this model is the University of Colorado Post COVID Clinic. The proposed model from the COVID-19 Longhauler Advocacy Project describes a very extensive, comprehensive model with coordinated services from many clinical specialties and professions co-located in the clinic.<sup>90</sup>

### 3.3.5.4 Advanced Practice Provider-Led Model

The Advanced Practice Provider-Led model was a variation of the above three models, in which the lead was an advanced practice provider rather than a physician. The advanced practice provider worked with a physician or physician team readily available for consultation. A potential advantage of this model was that it may be more resource-efficient and help increase capacity to manage long COVID, although support to perform optimally in this role, such as educational training and mentoring, will be important considerations. An example of this model is the New York University (NYU) Post-COVID Care Program.

### 3.3.5.5 Primary Care Management of Long COVID Model

In the Primary Care Management of Long COVID model, management of long COVID was integrated and dispersed into primary care clinics, rather than provided in a designated long COVID clinic. Patients were referred to specialists and other services as needed. For this model to be successful, strategies to support primary care clinicians in managing long COVID are critical, including provision of education and training, implementation of evaluation and management algorithms, and systems and staff to assist with coordination of care. On-site integration of other specialties and professions (e.g., psychology, neurology, physical therapy, occupational therapy, speech and language pathology, or others) and some aspects of diagnostic testing for long COVID could be integrated into primary care to facilitate long COVID management, though we did not identify models that describe doing this. This model could substantially increase capacity to manage long COVID in settings that lack specialists or in which demand for long COVID care cannot be met by long COVID clinics. In addition to ensuring that primary care clinicians remain abreast of new developments and guidance in a rapidly evolving area, successful implementation of this model will require sufficient time for primary care clinicians to manage long COVID. An example of this model is the Family Health Centers of San Diego clinic, which is currently conducting a randomized controlled trial to evaluate effects of use of teleconsultation (via the ECHO Project) to support primary care management of long COVID, and the New York City Health & Hospitals COVID-19 Centers of Excellence.<sup>61,76</sup> Both of these models focus on care of uninsured, low-income, and underserved

populations. A related model is *Integrative Medicine Management of Long COVID*, in which long COVID management is provided in an integrative medicine clinic providing a holistic approach.<sup>65</sup>

### 3.3.5.6 Virtual Long COVID Clinic Model

The defining characteristic of the Virtual Long COVID Clinic model was that it is designed to be fully virtual, and it can be applied to any of the models described above (each of which may use teleservices to varying degrees). The virtual model may provide additional convenience, reduce burdens and fatigue on patients, and may require less resources compared with in-person clinics, but some patients may prefer face-to-face interactions. In addition, patients must have access to and be able to use technologies used to deliver virtual services, and some services or testing may require face-to-face visits. Examples of this model are the Beaumont Hospital COVID Recovery Service in Ireland (a virtual multidisciplinary long COVID model<sup>63</sup>) and the Virtual Clinic for Veterans in San Antonio, Texas.

### 3.3.5.7 Mobile Long COVID Clinic Model

The defining characteristic of the Mobile Long COVID Clinic model was the use of mobile health units to provide long COVID care, primarily in an initial evaluation role. In this model, the initial assessment and basic testing was performed in the mobile unit by a physician, with referrals to specialists for followup care and testing as necessary. This model was designed for more rural settings in which patients would have to travel large distances to access long COVID care. A potential disadvantage of this model is that the mobile unit approach likely limits the services that can be provided, and its suitability for ongoing management is unclear. This model has been evaluated for initial evaluation as a demonstration project in Germany.<sup>80</sup>

### 3.3.5.8 Long COVID Clinic and Board Model

In the Long COVID Clinic and Board model, patients were evaluated in a long COVID clinic led by an advanced practice provider. Rather than working in a clinic with physicians, the advanced practice provider presented the long COVID cases to a board of long COVID specialists via telehealth. The model was intended for more rural areas that lack expertise in long COVID. It is one of the model types proposed and being implemented by the VA.

### 3.3.5.9 Long COVID or Other Complex Conditions Model

The Long COVID or Other Complex Conditions model was similar to the multidisciplinary long COVID clinic model, with the primary difference being that rather than focusing only on patients with long COVID, patients with other similar and/or complex conditions such as ME/CFS, post-treatment Lyme disease Syndrome, Ehlers-Danlos Syndrome, or others were also managed in the same clinic. In this way, expertise and experience from managing from one or more of these conditions could be applied to the others. In addition, this model may provide opportunities to better understand how optimal management may differ for each condition. Example of this model are the Center for Recovery from Complex Chronic Illness at Mt. Sinai and the Primary Care Wellbeing Service, Bradford District Care National Health Service Foundation Trust.<sup>46</sup>

### 3.3.5.10 ME/CFS in Long COVID Model

The defining characteristic of the ME/CFS in Long COVID model, a specialty-based model, was that it focused on the subset of patients with long COVID who also meet criteria for ME/CFS, in a preexisting ME/CFS clinic. This model leveraged prior experience in managing ME/CFS. However, patients with long COVID who did not meet criteria for ME/CFS were not included in this model, who would need to be managed in another clinic. An example of this model is the Pediatric Chronic Fatigue Syndrome Clinic at Johns Hopkins.

### **3.3.6 Systems-Based Models**

### 3.3.6.1 Hub and Spoke Model

The Hub and Spoke Model is a systems-based approach comprised of clinics that provide care for less complex patients (spokes) and regional centers (hubs) that care for more complex patients and provide consultative services to the spokes. In the context of long COVID, the spokes can be primary care clinics or other clinics that provide long COVID care, but lack extensive expertise and resources. Coordination and integration occur between and within the hub and spokes, and visits and consultation may be virtual or in-person. Hub and Spoke Models are designed to increase access to long COVID care outside of large or tertiary care centers by providing structured support for management of long COVID outside of these settings. An example of this model is the VA Hub and Spoke Model implemented in the VISN 17 region of Texas, which uses a virtual hub.

### 3.3.6.2 Tiered Care Model

In the Tiered Care model, different clinical tiers or streams of care were created that varied with regard to intensity of services. Patients with long COVID underwent a triage assessment (which could be virtual or in-person) and were assigned to a care tier based on their symptom severity. For example, lower-tier care might involve education and information on self-management, with higher-tier care involving multidisciplinary rehabilitation (virtual or face-to-face). Patients could move from one tier to another as their condition evolves. The tiered care model was designed to provide the appropriate level of care while conserving more intensive and scarcer long COVID services for those needing it. Examples of this model include the DisCOVeRY model proposed in Australia,<sup>77</sup> the proposed Alberta Health Services Provincial Post COVID-19 Rehabilitation Response Framework,<sup>62</sup> and the Community COVID-19 Multidisciplinary Team Pathway in the United Kingdom.<sup>64</sup> We did not identify an example of a tiered care model implemented in the United States.

### 3.3.6.3 Centralized Teleconsultation Model

The Centralized Teleconsultation model provided centralized teleconsultative services for clinicians who lack expertise in long COVID and are practicing in areas without long COVID clinics. In this model, clinicians managing long COVID in primary care or other clinical settings consulted with a centralized teleconsulting service providing the necessary expertise. This model was intended to serve as a safety net when other long COVID models of care are not available. This model was proposed by the VA (National Tele-E-Consultation for Long COVID), but it has not yet been implemented.

Type of Long COVID Model Single Specialty- Based Long COVID Model	Home Department or Clinical Setting Specialty clinic (e.g., physiatry, pulmonary, infectious disease, or other)	Clinical Lead Specialty physician	Co-Location of Other Specialties No	Role of Primary Care Referral to clinic; otherwise not specified	Population Managed Exclusively long COVID	Use of Teleservices Variable	Practice- or Systems- Based Practice- based	Model Examples VA Long COVID Clinic, Penn Medicine COVID Recovery Clinic, UT San Antonio Post COVID
Primary Care-Led Long COVID Model	Primary care (e.g., family medicine, general internal medicine, geriatrics, pediatrics)	Primary care clinician (managing long COVID, not providing primary care)	No	Referral to clinic; otherwise not specified	Exclusively long COVID	Variable	Practice- based	Recovery Clinic Kaiser Long COVID Clinic pilot, Mayo Clinic Rochester Post- COVID Care Clinic, Mayo Clinic Florida PASC Clinic, NYC Health & Hospitals COVID-19 Centers of Excellence
Multidisciplinary Long COVID Model	Usually standalone clinic or specialty clinic	Usually specialty physician	Yes	Referral to clinic; otherwise not specified	Exclusively long COVID	Variable	Practice- based	University of Colorado Post COVID Clinic; COVID-19 Longhauler Advocacy Model (proposed)
Advanced Practice Provider- Led Model	Varies	Advanced practice provider	Variesª	Referral to clinic; otherwise not specified	Exclusively long COVID	Variable	Practice- based	NYU Post-COVID Care Program
Primary Care Management of Long COVID Model	Primary care	Primary care physician (managing long COVID and providing primary care)	Varies <sup>a</sup>	Management of long COVID	Long COVID integrated with management of primary care	Variable	Practice- based	Family Health Centers of San Diego
Virtual Long COVID Clinic Model	Varies (virtual)	Varies	Virtual	Referral to clinic; otherwise not specified	Exclusively long COVID	Fully virtual	Practice- based	Beaumont Hospital COVID Recovery Service (Dublin, Ireland), Virtual Clinic for Veterans in San Antonio, Texas
Mobile Long COVID Clinic Model	Mobile unit	Varies	No	Referral to clinic; otherwise not specified	Exclusively long COVID	No	Practice- based	German demonstration project

Table 7. Representative long COVID models of care

Type of Long COVID Model	Home Department or Clinical Setting	Clinical Lead	Co-Location of Other Specialties	Role of Primary Care	Population Managed	Use of Teleservices	Practice- or Systems- Based	Model Examples
Long COVID Clinic and Board Model	Varies	Advanced practice provider	No	Referral to clinic; otherwise not specified	Exclusively long COVID	Teleconsultati on with long COVID specialty board	Practice- based	VA Long COVID Clinic and Board Model
Long COVID or Other Complex Conditions Model	Usually specialty	Usually specialty physician	Varies <sup>a</sup>	Referral to clinic; otherwise not specified	Long COVID and other similar and/or complex conditions	Varies	Practice- based	Center for Recovery from Complex Chronic Illness at Mt. Sinai
ME/CFS in Long COVID Model	Specialty (ME/CFS clinic)	Expert in ME/CFS	No	Referral to clinic; otherwise not specified	Long COVID meeting criteria for ME/CFS	Varies	Practice- based	Pediatric Chronic Fatigue Syndrome Clinic at Johns Hopkins
Hub and Spoke Model	Varies	Hub: Expert in long COVID Spokes: Usually primary care clinicians	Hub: May be co-located Spoke: No	Management of long COVID in spokes; referral to hub	Exclusively long COVID	Varies	Systems- based	VA Hub and Spoke Model (VISN 17)
Tiered Care	Varies	Higher tier: Expert in long COVID Lower tier: Patients may be self- managed	Higher tier: May be co- located Lower tier: No	Referral; otherwise not specified	Exclusively long COVID	Varies; lower tier care may be primarily virtual	Systems- based	DisCOVeRY <sup>b</sup> model (proposed, Australia); Alberta Health Services Provincial Post COVID-19 Rehabilitation Response Framework
Centralized Teleconsultation Model	No home department	None	Not applicable	Management of long COVID patients	Exclusively long COVID	Tele- consultation with experts in long COVID	Systems- based	VA National Tele-E- Consultation for Long COVID Model (proposed)

Abbreviations: COVID = coronavirus disease; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NYC = New York City; UT = University of Texas; PASC = postacute sequelae of COVID-19; VA = Veterans Affairs; VISN 17 = VA Heart of Texas Health Care Network.

<sup>a</sup> Other specialties may be co-located or may be in separate locations from the long COVID clinic.

<sup>b</sup> Acronym not defined in the publication.

### 3.4 Findings, Guiding Question 3. Context of models of care

### **3.4** Guiding Question 3. Context of models of care

#### a. In what settings and for whom are these models currently implemented?

The long COVID models of care described in the literature and by Key Informants have been implemented in academic medical settings or large integrated health systems with access to multidisciplinary expertise. Therefore, it was not possible to determine the extent to which long COVID models have been implemented outside of these settings.

## b. Are there special considerations for implementing these models for adults, children, and disadvantaged populations influenced by social determinants of health?

Each of the models of care described in Guiding Question 2 could theoretically be implemented for adults, children, or mixed populations. However, long COVID presents differently in adults and children and may require different expertise to manage, creating potential logistical and staffing challenges for mixed clinics to ensure that all relevant expertise is available. For managing relatively low numbers of children with long COVID, integration into primary care (e.g., the Primary Care Based Management of Long COVID Model) or expanding to manage children with other conditions (e.g., the Long COVID or Other Complex Conditions Model) might be suitable strategies.

Several models of care described in Guiding Question 2 focused on uninsured, low-income, and medically underserved patients.<sup>61,65,76</sup> Two<sup>61,76</sup> used a model in which long COVID care is integrated into primary care (Primary Care Based Management of Long COVID Model). Another uses the Single Specialty-based Long COVID Clinic Model with an emphasis on virtual services. Barriers noted in this clinic include higher no-show rates, more difficulty using telemedicine, and communication barriers, including need for translators for a heavily Spanish-speaking population.<sup>65</sup> Some Key Informants reported being unable to see or limiting clinic access for uninsured or underinsured patients, or requiring that such patients self-pay.

## c. What are potential facilitators and barriers to implementation, including resources needed, and how do barriers vary according to the setting?

Initial long COVID clinics were primarily developed by clinicians with an interest in managing this condition who recognized an unmet need and leveraged available expertise, infrastructure, and resources.<sup>93</sup> Therefore, most long COVID clinics were located within the specialty in which there was a clinical nidus of interest. As models of care for long COVID have evolved, there has been interest in integrating long COVID management in primary care<sup>94</sup> or developing standalone, multidisciplinary models. Key Informants described existing collaborative and coordination networks, availability of long COVID guidelines, implementations of algorithms and education on long COVID management, and support from health systems leadership as important for developing and sustaining long COVID clinics. Models that use advance practice providers in lead roles or a tiered care approach could be useful in settings in which resources are more limited. Key Informants generally reported that given the high demand for long COVID services, sustainability could be achieved as long as patients have insurance and can be billed (see above). One Key Informant specializing in management of children with long COVID who meet criteria for ME/CFS reported receipt of philanthropic support and some COVID clinics have received grant funding, including the University of

### 3.4 Findings, Guiding Question 3. Context of models of care

Colorado Post COVID Clinic, a Multidisciplinary Long COVID Model that may be more resource-intensive.

An important barrier has been difficulty in integrating long COVID management in primary care or coordinating management between long COVID clinics and primary care. Key Informants described several issues, including lack of training of primary care clinicians, lack of resources to integrate long COVID management in primary care, low interest in primary care, and lack of time in primary care. Models that include dedicated resources to provide education and support to primary care clinicians and integrate frequently used specialties and services for long COVID into primary care (e.g., neuropsychology, neurology, physical therapy, occupational therapy, speech and language pathology) could be useful for expanding needed access beyond long COVID clinics.

Another important challenge has been how to provide long COVID care in settings that lack access to multidisciplinary expertise (e.g., many rural settings). The Hub and Spoke Model and Centralized Teleconsultation Models are systems-based models designed to increase access to care in such settings, as are practice-based models that emphasize virtual visits. Barriers to use of such models include difficulty using or lack of access to telemedicine. The Centralized Teleconsultation Model proposed by the VA is intended to serve as a safety net model when other models are not available or feasible.

## d. What kinds of training, certification, staffing, and other resources are required to develop and sustain these models of care?

Key Informants noted that the development of guidelines from professional societies and governmental agencies has been important for improving the management of long COVID, and endorsed the need to keep up-to-date on current guidance, which is changing rapidly. VA Key Informants noted that the VA is developing educational materials for clinicians managing long COVID and other Key Informants described the development of educational and training materials as well as implementation of algorithms and protocols to guide management. Although several Key Informants noted the availability of tele-education on long COVID via Project ECHO, ECHO was not formally incorporated in any of the models of care that we identified, other than one clinic which is conducting a randomized controlled trial on utilization of Project ECHO in a primary care managed model.<sup>76</sup> At this time, Key Informants noted the importance of having staff with expertise in billing for long COVID and dedicated staff for coordination of care, given the multidisciplinary nature of long COVID.

A 2023 survey of 33 participants in AAPM&R PASC Collaborative addressed aspects related to sustainability.<sup>95</sup> It found that 3 percent (1/33) participants reported that their long COVID clinic had been shut down. Most respondents (73%) reported an unchanged budget for their long COVID clinic and half of survey respondents reported being understaffed. A number of survey respondents described concerns about the long-term sustainability of their clinic due to staffing issues, burnout, or other factors. Efforts to address burnout included increasing the number of physicians or staff and increasing appointment lengths. Approximately two-thirds of respondents described demand as stable or increased. Nearly 30 percent described a clinic wait time of 3 months or more, 10 percent 8 to 12 weeks, and 23 percent 4 to 8 weeks.

### 3.5 Findings, Guiding Question 4. Effectiveness of models of care

# **3.5** Guiding Question 4. What have published and unpublished studies reported on the use of and effectiveness of models of care for long COVID?

The effectiveness of long COVID models of care has not been established. One before-after study reported use of and outcomes of a model of care for long COVID.<sup>46</sup> It evaluated a psychology-led, multidisciplinary clinic in the UK that was originally developed to treat patients with ME/CFS and was adapted to treat patients with long COVID (n=149). In the study, patients underwent a 7-week virtual rehabilitation course (1 hour weekly) that followed a whole system, biopsychosocial, interdisciplinary approach. The intervention was delivered by a team consisting of clinical psychologist, physiotherapies, occupational therapist, dietician, speech and language therapies, assistant psychologist, and personal support navigator with support from a team administrator and addressed multiple areas including education on postviral fatigue, sleep optimization, nutrition, swallowing, activity management, energy conservation, stress management, breathing optimization, managing setbacks, and signposting to appropriate resources and services. The mean duration of symptoms was 6 months and 13 percent of patients had been hospitalized for COVID-19; 88 percent were female and 74 percent were White (26% Black, Asian, and minority ethnic). Among patients with followup scores (n=76), the overall health score (0 to 100 scale) improved from 48.5 (standard deviation [SD] 22.0) prior to the course to 58.6 (20.1) after the course, and the EQ-5D-5L (0 to 1 scale) improved from 0.55 (SD 0.22) to 0.62 (SD 0.22), with 54 percent reporting improvement in overall health state. Limitations of the study include lack of comparison group and high attrition. In addition, it was not possible to determine if observed outcomes were related to the model of care or the rehabilitation course intervention.

One study that evaluated a mobile long COVID unit in Germany reported high overall patient satisfaction (mean score >4 points on a 0 to 5 Likert scale), though patients were less enthusiastic about preferring an appointment in the mobile outpatient unit or a standard outpatient clinic (mean score 2.5 points on a 0 to 5 Likert scale).<sup>80</sup> The study did not assess health outcomes.

An in-progress randomized controlled trial comparing weekly multidisciplinary team-based virtual education and case-consultation (Project ECHO) versus standard Webinars and courses in a primary care managed long COVID model (Family Health Centers of San Diego) was designed to assess patient outcomes through 12 months, with estimated completion in January 2025.<sup>76</sup>

# **3.6** Guiding Question 5. What are gaps in our understanding of long COVID models of care?

Important gaps exist in our understanding of long COVID models of care. Regarding definitions of long COVID, research is needed on the validity and reliability of existing definitions, as well as new definitions that may be developed in the future. This includes the need to further validate the PASC score, the first definition to use a composite symptom score rather than clinical criteria.<sup>55</sup> Research is also needed to clarify whether long COVID can be classified into distinct phenotypes, and if so, whether multiple definitions are required.<sup>73</sup> Studies are also needed to determine the applicability of definitions in different populations defined by age, sex, gender, race/ethnicity, and other factors.

Regarding long COVID models of care, an important limitation of the published literature is suboptimal reporting of important components, making it difficult to fully and accurately characterize different models of care. A more systematic approach to describing models of care (e.g., utilizing the 10 components we describe in Guiding Question 2), could help to standardize descriptions of models of care and facilitate future implementation and research efforts.

The scalability of the long COVID models of care that have been implemented in the United States is uncertain. Specifically, they don't include specific mechanisms to facilitate expansion to serve the entire population, particularly uninsured, underinsured, or underserved populations. Given that access to specialty and multidisciplinary care is limited for many U.S. populations, models that integrate management of long COVID in primary care may be particularly suitable for expanding access. However, implementation of such models in the United States has been limited. Therefore, a critical gap is understanding effective strategies to integrate long COVID management in primary care, including resources and support required. Other important gaps in our understanding of long COVID models of care include optimal methods for measuring quality of care; strategies to ensure sustainability; methods to increase access, given high demand and long wait times; and strategies to provide long COVID care in areas lacking multidisciplinary expertise. There is also a need to understand advantages and disadvantages of managing children and adults in the same or separate clinics and management of long COVID with ME/CFS or other complex conditions. Evaluation of components that are applicable regardless of the long COVID model of care, such as optimal methods of education and training, incorporation of standardized evaluation and management algorithms, which clinical specialties and professions are required, and optimal methods for care coordination, would be useful to inform all models. Research is needed to understand whether approaches proposed and evaluated in other countries. such as use of mobile units or a Tiered Care Model, can be applied to U.S. settings. Research is needed to understand factors affecting implementation, optimal implementation processes, and outcomes, in order to better understand approaches to address challenges and support large scale use and sustainability of effective models.<sup>96</sup>

### 4. Summary and Implications

Long COVID is a new condition that emerged during the COVID-19 pandemic. Management of long COVID is complex, given its variable presentation, need for broad multidisciplinary expertise, and evolving guidance on optimal treatment approaches. In a short period of time, a number of long COVID models of care have been developed and implemented to meet the large and growing demand.

A standardized, valid and reliable definition is needed to accurately identify patients to be managed in long COVID models of care. We identified five key definitions based on clinical criteria that are generally consistent in requiring presence of persistent, new or recurrent symptoms, and indicating the multisystemic and variable presentation of long COVID. However, there is variability across definitions with regard to requiring confirmatory testing for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, timing of onset, and duration of symptoms. Rather than utilizing clinical criteria, the recently published (May 2023) postacute sequelae of SARS-CoV-2 (PASC) score proposes a research definition for long COVID that is based on a cutoff score on a composite symptom score,<sup>55</sup> but such score-based criteria require further development and validation. Work to develop a new definition for long COVID by a National Academies of Sciences, Engineering, and Medicine (NASEM) committee is in progress.<sup>66</sup> Areas highlighted as important considerations for developing a standardized definition include whether there should be separate definitions for adults and children; whether there should be a single definition versus multiple definitions for specific uses; whether there are distinct long COVID phenotypes that warrant different definitions; whether confirmatory SARS-CoV-2 infection testing should be required; the length of symptoms to define long COVID; which symptoms should be specified in the definition; the need to incorporate the concept of disability; the importance of ensuring that the definition does not have negative impacts on equity; and the advantages and disadvantages of clinically based criteria versus a quantitative approach (e.g., symptom score). Current definitions do not address whether long COVID is a form of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) or represents a distinct condition; research to clarify differences and similarities between long COVID and ME/CFS could be helpful to inform future definitions.

Regarding long COVID models of care, a literature review and interviews with Key Informants identified approximately 49 models that have been implemented or proposed. We identified five key principles for long COVID models (core "lead" team with expertise; broad multidisciplinary expertise; broad range of diagnostic and therapeutic services; patient-centered, individualized, and equitable care; and capacity to meet demand) and seven components that varied across models aiming to meet these principles and appeared useful to characterize different models (home department or clinical setting; clinical lead; co-location of other specialties; primary care role; population managed; use of teleservices; and practice- or systemsbased). Using this framework, we described 10 representative practice-based and 3 systemsbased models.

Challenges in defining the models is that details on key components of published of models have been lacking and there is overlap between models as well as variability within models. In addition, published data on outcomes of models is extremely limited and information on whether and how models have changed over time was lacking. Only one study<sup>46</sup> reported outcomes of a model; however, the study used a before-after design without a comparison to another long COVID model of care, and it was not possible to determine whether observed outcomes were related to the model of care or the specific intervention used. Some models of care were designed

#### 4. Summary and Implications

to provide access to long COVID care in areas lacking multidisciplinary expertise by focusing on use of teleservices or by implementing a systems-based approach (e.g., Hub and Spoke or Tiered Care Model). Tiered Care Models<sup>62,64,77</sup> and a Mobile Unit Model<sup>80</sup> have been proposed or implemented in other countries, with uncertain applicability to U.S. settings. Although most long COVID clinics have either focused on adults or children, some clinics manage mixed populations. Additionally, most models have focused on long COVID, but some address long COVID along with related or similar conditions such as ME/CFS. Although all models could manage underserved populations, details regarding specific approaches to do so were lacking, and Key Informants noted challenges in managing uninsured and underinsured patients due to lack of reimbursement. Although Key Informants noted that models that integrate long COVID management into primary care is important to meet high demand, they noted challenges in ensuring appropriate training, increasing primary care engagement, and ensuring sufficient staff and specialist support.

The ideal model of care for a particular setting is likely to depend on a number of local factors, such as the expertise available, interest in managing long COVID, the population being served, resources available, geographic factors, and others. A **key finding** is that several Key Informants and a survey commissioned by the American Academy of Physical Medicine and Rehabilitation (AAPM&R)<sup>95</sup> noted that some efforts to implement long COVID models of care have faced challenges due to burnout or concerns about financial sustainability. Decisions about long COVID models of care may best be individualized to address the unique milieu of each implementation setting. For example, the Virtual, Hub and Spoke, and Primary Care Management Model are all potential strategies to provide long COVID care in areas lacking multidisciplinary expertise. The choice between these models may vary depending on factors including resources available for implementation, the availability of a Hub, familiarity and comfort with virtual services, and primary care interest and engagement in managing long COVID. In some situations, it may be appropriate to use elements of different models of care or to link models of care (e.g., Primary Care Management of Long COVID with Multidisciplinary Long COVID Model in a Hub and Spoke approach).

Regarding the specific clinical specialties and professions involved, a **key finding** is that that the requirements do not necessarily vary from model to model. Rather, all models should be designed to include access to the most commonly involved specialties and professions (e.g., physiatry, pulmonology, cardiology, neurology, psychiatry, neuropsychology, infectious disease physical therapy, occupational therapy, and speech and language pathology), with streamlined pathways to involve others as needed, including specialized services (e.g., dysautonomia testing and management). Provision of physical therapy and occupational therapy with expertise in long COVID was generally viewed as a fundamental requirement for any long COVID model. Similarly, all models of care should be designed to provide evaluation and testing in accordance with published guidance. Given the complexity of managing long COVID and the evolving nature of guidance on evaluation and management, integration of educational and training components was also viewed as important for any model of care. Key Informants viewed having staff members with expertise in billing and coordination of care important for financial sustainability and success.

Particular challenges in rural settings include a lack of multidisciplinary expertise and long travel distances, which can be particularly burdensome in patients with long COVID due to long travel times and potential exacerbation of symptoms. Models of care that may be more applicable to rural settings address some of these issues by utilizing teleservices (e.g., virtual

### 4. Summary and Implications

visits, teleconsultation, and teleconsultation), advance practice providers, mobile long COVID units, and systems-based approaches such as the Hub and Spoke Model. A key challenge is to identify effective models and strategies to integrate long COVID management into primary care, in order to meet high and growing demand that cannot be met by specialty-based models.

There is a need for more standardized and complete reporting of long COVID models of care, in order to accurately categorize models and aid implementation efforts. **Suggested minimum reporting elements are shown in Box 1.** We also identified a number of important gaps in understanding long COVID models of care, including optimal methods for measuring quality of care; approaches for providing access to uninsured, underinsured, or underserved populations; strategies to ensure sustainability; methods to increase access while maintaining quality of care; strategies to provide long COVID care in areas lacking multidisciplinary expertise; optimal methods of education and training and care coordination; and outcomes of long COVID models of care. Research in these areas would be helpful for informing future efforts at dissemination and expansion of long COVID care. In the meantime, this Technical Brief describes a number of long COVID models of care that have been developed or proposed, in order to help inform current and future implementation efforts.

Box 1. Suggested minimum reporting elements for long COVID models of care Suggested Minimum Reporting Elements

Su	ggested minimum Reporting Elements
•	Primary (home) department or clinical setting
•	Clinical lead
•	Co-location of other specialties
•	Primary care role
•	Population managed
•	Intake and initial visit methods
•	Care coordination methods
•	Use of teleservices
•	Education, training and outreach methods
•	Practice- or systems-based
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Abbreviations: COVID = coronavirus disease

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## **Abbreviations and Acronyms**

Abbreviation/Acronym	Term
AAPM&R	American Academy of Physical Medicine & Rehabilitation
AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
COVID	coronavirus disease
COVID-19	coronavirus disease 2019
DHHS	U.S. Department of Health and Human Services
ECHO	Project Extension for Community Healthcare Outcomes
KI	Key Informant
ME/CFS	myalgic encephalomyelitis/chronic fatigue syndrome
NASEM	National Academies of Sciences, Engineering, and Medicine
NHS	National Health Service UK
NICE	National Institute for Health and Care Excellence UK
NYC	New York City
PASC	postacute sequelae of SARS-CoV-2
PICOTS	population, intervention, comparator, outcome, timing, study design
PM&R	physical medicine and rehabilitation
RECOVER	Researching COVID to Enhance Recovery initiative
SARS-CoV-2	acute respiratory syndrome coronavirus 2
SD	standard deviation
UT	University of Texas
UTSW	University of Texas Southwestern Medical Center
VA	Department of Veterans Affairs
VISN	Veterans Integrated Service Network
VISN 17	VA Heart of Texas Health Care Network
WHO	World Health Organization

## **Appendix A. Sample Questions for Key Informants**

- 1. Models that you are aware of, including:
  - a. Location of clinics (e.g., primary care, specialty clinics, standalone clinics)
  - b. Disciplines involved
  - c. Treatments/tests offered
  - d. Populations managed
  - e. Methods of coordination
  - f. Use of telehealth
  - g. Education/training components
  - h. Other key factors?
- 2. Innovative or promising models of care and key components
- **3.** Relevance/applicability of ME/CFS models of care, or models of care for other chronic conditions
- 4. Frameworks for describing/categorizing long COVID models of care
- 5. Barriers and facilitators to implementation
- 6. Funding and sustainability of long COVID clinics

## **Appendix B. Search Strategies**

Ovid MEDLINE(R) ALL 1946 to December 7, 2023

- 1 Post-Acute COVID-19 Syndrome/
- 2 SARS-CoV-2/ or COVID-19/
- 3 (long\* or post\*).ti.

4 ((long\* or post\*) adj (COVID or COVID-19 or COVID19 or coronavirus\* or corona virus\* or 2019-nCoV or 19nCoV or 2019nCoV or nCoV or nCoV or "CoV 2" or CoV2 or SARS-CoV-2 or SARS-CoV2 or SARSCoV-2 or SARSCoV-2 or SARSCoV2 or SARS-2 or severe acute respiratory syndrome coronavirus 2 or 2019-novel CoV)).ti,ab,kf.

5 ("post-acute sequelae of COVID-19" or "postacute sequelae of COVID-19" or PASC).ti,ab,kf.

- 6 1 or (2 and 3) or 4 or 5
- 7 Models, Organizational/
- 8 exp "Continuity of Patient Care"/
- 9 exp Patient Care Management/

10 ((model\* or plan\* or deliver\* or framework\* or multidisciplin\* or interdisciplin\* or network or pathway\* or protocol\*) adj3 (care or healthcare or service\*)).ti,ab,kf.

- 11 or/7-10
- 12 6 and 11
- 13 limit 11 to COVID-19
- 14 (long\* or post\*).ti.
- 15 13 and 14
- 16 12 or 15
- 17 limit 16 to english language
- 18 limit 17 to yr="2021 -Current"

### Cochrane Central Register of Controlled Trials November 2023

- 1 Post-Acute COVID-19 Syndrome/
- 2 SARS-CoV-2/ or COVID-19/
- 3 (long\* or post\*).ti.

4 ((long\* or post\*) adj (COVID or COVID-19 or COVID19 or coronavirus\* or corona virus\* or 2019-nCoV or 19nCoV or 2019nCoV or nCoV or n-CoV or "CoV 2" or CoV2 or SARS-CoV-

2 or SARS-CoV2 or SARSCoV-2 or SARSCoV2 or SARS2 or SARS-2 or severe acute respiratory syndrome coronavirus 2 or 2019-novel CoV)).ti,ab,hw.

5 ("post-acute sequelae of COVID-19" or "postacute sequelae of COVID-19" or PASC).ti,ab,hw.

- 6 1 or (2 and 3) or 4 or 5
- 7 Models, Organizational/
- 8 exp "Continuity of Patient Care"/
- 9 exp Patient Care Management/

10 ((model\* or plan\* or deliver\* or framework\* or multidisciplin\* or interdisciplin\* or network or pathway\* or protocol\*)) adj3 (care or healthcare or service\*)).ti,ab,hw.

- 11 or/7-10
- 12 6 and 11
- 13 limit 12 to yr="2021 -Current"

### Cochrane Database of Systematic Reviews 2005 to December 7, 2023

1 ((long\* or post\*) adj (COVID or COVID-19 or COVID19 or coronavirus\* or corona virus\* or 2019-nCoV or 19nCoV or 2019nCoV or nCoV or nCoV or "CoV 2" or CoV2 or SARS-CoV-2 or SARS-CoV2 or SARSCoV-2 or SARSCoV-2 or SARSCoV2 or SARS-2 or severe acute respiratory syndrome coronavirus 2 or 2019-novel CoV)).ti,ab.

2 ((model\* or plan\* or deliver\* or framework\* or multidisciplin\* or interdisciplin\* or network or pathway\* or protocol\*)) adj3 (care or healthcare or service\*)).ti,ab.

3 1 and 2

### APA PsycInfo 1806 to December Week 1, 2023

- 1 SARS-CoV-2/ or COVID-19/
- 2 (long\* or post\*).ti.

3 ((long\* or post\*) adj (COVID or COVID-19 or COVID19 or coronavirus\* or corona virus\* or 2019-nCoV or 19nCoV or 2019nCoV or nCoV or nCoV or "CoV 2" or CoV2 or SARS-CoV-2 or SARS-CoV2 or SARSCoV2 or SARSCoV2 or SARSCoV2 or SARS-2 or severe acute respiratory syndrome coronavirus 2 or 2019-novel CoV)).ti,ab.

- 4 ("post-acute sequelae of COVID-19" or "postacute sequelae of COVID-19" or PASC).ti,ab.
- 5 (1 and 2) or 3 or 4
- 6 exp clinical models/
- 7 "continuum of care"/ or aftercare/ or health care delivery/ or "quality of care"/

8 ((model\* or plan\* or deliver\* or framework\* or multidisciplin\* or interdisciplin\* or network or pathway\* or protocol\*)) adj3 (care or healthcare or service\*)).ti,ab.

- 9 6 or 7 or 8
- 10 5 and 9
- 11 limit 10 to english language
- 12 limit 11 to yr="2021 -Current"

### Elsevier Scopus December 7, 2023

(((TITLE ("long COVID") OR TITLE ("post COVID") OR TITLE ("post-acute sequelae of SARS-CoV-2") OR TITLE (pasc))) AND ((TITLE (care OR healthcare OR "health care" OR service OR services) AND TITLE (model\* OR deliver\* OR framework OR protocol\* OR pathway)))) OR ((ABS ("long COVID" OR "post COVID" OR "post-acute sequelae of SARS-CoV-2" OR pasc)) AND (ABS ((care OR healthcare OR "health care" OR service OR services) AND (model\* OR deliver\* OR framework OR protocol\* OR pathway)))) AND PUBYEAR > 2020 AND PUBYEAR < 2024 AND (LIMIT-TO (SUBJAREA, "MEDI") OR LIMIT-TO (SUBJAREA, "SOCI")) AND (LIMIT-TO (DOCTYPE, "ar")) AND (LIMIT-TO (AFFILCOUNTRY, "United States") OR LIMIT-TO (AFFILCOUNTRY, "United Kingdom") OR LIMIT-TO (AFFILCOUNTRY, "Canada")) AND (LIMIT-TO (LANGUAGE, "English"))

EBSCOHost SocINDEX December 7, 2023

- S1 DE "COVID-19 pandemic"
- S2 TI long or post
- S3 S1 AND S2

S4 TI "long COVID" OR TI "post COVID" OR TI "post-acute sequelae of SARS-CoV-2" OR TI pasc

S5 S3 OR S4

S6 DE "MEDICAL care" OR DE "ADVANCE directives (Medical care)" OR DE "CHILD health services" OR DE "COMMUNITY health services" OR DE "CURATIVE medicine" OR DE "DENTAL care" OR DE "DISCRIMINATION in medical care" OR DE "EMERGENCY medical services" OR DE "HEALTH equity" OR DE "HEALTH facilities" OR DE "HEALTH self-care" OR DE "HEALTH services accessibility" OR DE "HETEROSEXISM in medical care" OR DE "HOSPITAL care" OR DE "HUMANISTIC medicine" OR DE "MANAGED care programs" OR DE "MEDICAL charities" OR DE "MEDICAL compliance" OR DE "MEDICAL screening" OR DE "MENTAL health services" OR DE "OCCUPATIONAL health services" OR DE "OUTPATIENT medical care" OR DE "PARENTAL notification (Medical law)" OR DE "PATIENT care" OR DE "PATIENT-centered care" OR DE "PRENATAL care" OR DE "PREVENTIVE health services" OR DE "PREVENTIVE medicine" OR DE "PRIMARY health care" OR DE "RURAL health services" OR DE "SCHOOL health services" OR DE "TRANSCULTURAL medical care" OR DE "WOMEN'S health services"

S7 S5 AND S6

### EBSCOHost CINAHL Plus with Full Text December 7, 2023

S1 (MH "Post-Acute COVID-19 Syndrome")

S2 TI "long COVID" OR TI "post COVID" OR TI "post-acute sequelae of SARS-CoV-2" OR TI pasc

S3 (MH "Patient Care Plans+") OR (MH "Nursing Care Plans+") OR (MH "Protocols+") OR (MH "Multidisciplinary Care Team") OR (MH "Continuity of Patient Care+") OR (MH "Disease Management") OR (MH "Case Management") OR (MH "Family Centered Care+") OR (MH "Nursing Care+") OR (MH "Patient Handling")

S4 (MH "Models, Theoretical+") OR (MH "Nursing Models, Theoretical+")

S5 TI model\* OR deliver\* OR framework OR protocol\* OR pathway

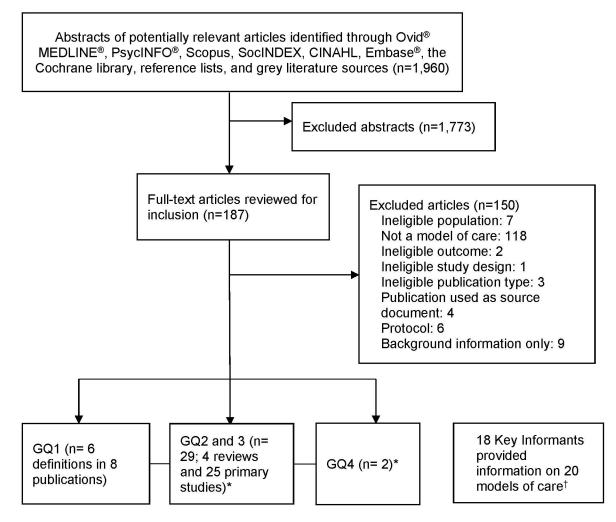
- S6 TI care OR healthcare OR "health care" OR service\* OR program\* OR plan\*
- S7 S5 AND S6
- S8 S1 OR S2
- S9 S3 OR S4 OR S7
- S10 S8 AND S9

### Elsevier Embase December 7, 2023

('long COVID'/exp OR 'COVID long-hauler' OR 'COVID-19 long-hauler' OR 'chronic COVID syndrome' OR 'chronic COVID-19' OR 'long COVID' OR 'long haul COVID' OR 'long haul COVID-19' OR 'long hauler COVID' OR 'post COVID 19 fatigue' OR 'post COVID 19 neurological syndrome' OR 'post COVID 19 syndrome' OR 'post COVID fatigue' OR 'post COVID impairment' OR 'post COVID syndrome' OR 'post-COVID condition' OR 'post-COVID-19 condition' OR 'post-acute COVID syndrome' OR 'post-acute COVID-19' OR 'post-acute COVID-19 fatigue' OR 'post-acute COVID-19 neurological syndrome' OR 'post-acute COVID-19 syndrome' OR 'post-acute sequelae of sars-cov-2 infection' OR 'pasc') AND ('patient care'/exp OR 'care, continuity of OR 'continuity of care' OR 'continuity of patient care' OR 'episode of care' OR 'patient care' OR 'patient care management' OR 'patient centered care' OR 'patient helper' OR 'patient management' OR 'patient navigation' OR 'patient-centered care' OR 'patient care planning'/exp OR 'patient care plan' OR 'patient care planning') AND [english]/lim AND (2021:py OR 2022:py OR 2023:py) AND ('article'/it OR 'review'/it)

## Appendix C. Literature Flow Diagram

#### Figure C-1. Literature flow diagram



Abbreviations: CINAHL = Cumulative Index to Nursing and Allied Health Literature; GQ = guiding question.

\* Two studies are included in both GQ2 and 4.

<sup>†</sup> Two models of care were described in both the literature and by a Key Informant.

Guiding Question 5 is not included in the diagram because it is based on the results of Guiding Questions 2 through 4.

## **Appendix D. Included Studies List**

- Ahmad M, Kim K, Indorato D, et al. Post-COVID care center to address rehabilitation needs in COVID-19 survivors: a model of care. American Journal of Medical Quality. 2022 May-Jun 01;37(3):266-71. doi: 10.1097/JMQ.00000000000014. PMID: 34369895.
- Aiash H, Khodor M, Shah J, et al. Integrated multidisciplinary post-COVID-19 care in Egypt. Lancet Glob Health. 2021 07;9(7):e908-e9. doi: 10.1016/S2214-109X(21)00206-0. PMID: 34019842.
- Bailey J, Lavelle B, Miller J, et al. Multidisciplinary Center Care for Long COVID Syndrome-A Retrospective Cohort Study. Am J Med. 2023 May 22doi: 10.1016/j.amjmed.2023.05.002. PMID: 37220832.
- Brigham E, O'Toole J, Kim SY, et al. The Johns Hopkins post-acute COVID -19 team (PACT): a multidisciplinary, collaborative, ambulatory framework supporting COVID -19 survivors. American Journal of Medicine. 2021 04;134(4):462-7.e1. doi: 10.1016/j.amjmed.2020.12.009. PMID: 33444589.
- Brugler Yonts A. Pediatric long- COVID: a review of the definition, epidemiology, presentation, and pathophysiology. Pediatr Ann. 2022 Nov;51(11):e416-e20. doi: 10.3928/19382359-20220913-06. PMID: 36343180.
- Centers for Disease Control and Prevention. Post-COVID Conditions: Overview for Healthcare Providers. 2022. https://www.cdc.gov/coronavirus/2019ncov/hcp/clinical-care/post-COVIDconditions.html. Accessed Aug 18 2023.
- Chuang HJ, Lin CW, Hsiao MY, et al. Long COVID and rehabilitation. Journal of the Formosan Medical Association. 2023 Apr 13;13:13. doi: 10.1016/j.jfma.2023.03.022. PMID: 37061399.
- Decary S, De Groote W, Arienti C, et al. Scoping review of rehabilitation care models for post COVID -19 condition. Bulletin of the World Health Organization. 2022 Nov 01;100(11):676-88. doi: 10.2471/BLT.22.288105. PMID: 36324552.

- Department of Health and Human Services, Office of the Assistant Secretary for Health. National Research Action Plan on Long COVID. Washington, DC: 2022. https://www.COVID.gov/assets/files/National-Research-Action-Plan-on-Long-COVID-08012022.pdf.
- Dundumalla S, Barshikar S, Niehaus WN, et al. A survey of dedicated PASC clinics: characteristics, barriers and spirit of collaboration. PM&R. 2022;14(3):348-56. doi: 10.1002/pmrj.12766. PMID: 35038230.
- Family Health Centers of San Diego. Does a Technology Enabled Multi-disciplinary Teambased Care Model for the Management of Long COVID and Other Fatiguing Illnesses Improve Clinical Care of Patients and Represent a Sustainable Approach Within a Federally Qualified Health Center? [Trial registry record Clinical trial protocol]. 2021. https://classic.clinicaltrials.gov/ct2/show/NCT05 167227.
- Ganesh R, Grach SL, Ghosh AK, et al. The Female-Predominant Persistent Immune Dysregulation of the Post-COVID Syndrome. Mayo Clin Proc. 2022b Mar;97(3):454-64. doi: 10.1016/j.mayocp.2021.11.033. PMID: 35135695.
- Ganesh R, Vanichkachorn GS, Munipalli B, et al. Postacute sequelae of SARS-CoV-2 infection—lessons learned from a coordinated health system response. Mayo Clinic Proceedings: Innovations, Quality and Outcomes. 2022;6(4):311-9. doi: 10.1016/j.mayocpiqo.2022.05.007. PMID: 35669936.
- Gross R, Lo Re V, 3rd. Disentangling the Postacute Sequelae of SARS-CoV-2: E Unibus Pluram (From One, Many). JAMA. 2023 Jun 13;329(22):1918-9. doi: 10.1001/JAMA.2023.8961. PMID: 37227710.
- Haas R, M W. CADTH Health Technology Review: Specialized Clinics and Health Care Professional Resources for Post–COVID-19 Condition in Canada. Canadian Journal of Health and Technologies. 2023;3(2):1-30.
- 16. Harenwall S, Heywood-Everett S, Henderson R, et al. Post-COVID-19 syndrome: improvements in health-related quality of life following

psychology-led interdisciplinary virtual rehabilitation. Journal of Primary Care & Community Health. 2021 Jan-Dec;12:1-12. doi: 10.1177/21501319211067674. PMID: 34939506.

- Health Information and Quality Authority (Ireland). International review of clinical guidelines and models of care for long COVID. 2022:1-201.
- Hitch D, Holton S, Garnys E, et al. Discovery: a co-designed and evidence informed model of care for people with long COVID...22nd international conference on integrated care, May 23-25, 2022, Odense, Denmark. International Journal of Integrated Care (IJIC). 2022;22(S3):1-2. doi: 10.5334/ijic.ICIC22200. PMID: 161095896.
- Ladds E, Rushforth A, Wieringa S, et al. Developing services for long COVID: lessons from a study of wounded healers. Clinical Medicine. 2021 Jan;21(1):59-65. doi: 10.7861/clinmed.2020-0962. PMID: 33479069.
- Levin A, Malbeuf M, Hoens AM, et al. Creating a provincial post COVID -19 interdisciplinary clinical care network as a learning health system during the pandemic: integrating clinical care and research. Learning Health Systems. 2022 May 15;7(1):e10316. doi: 10.1002/lrh2.10316. PMID: 35942206.
- List JM, Long TG. Community-based primary care management of 'long COVID ': a center of excellence model at NYC health+hospitals. American Journal of Medicine. 2021 10;134(10):1232-5. doi: 10.1016/j.amjmed.2021.05.029. PMID: 34270990.
- Lutchmansingh DD, Knauert MP, Antin-Ozerkis DE, et al. A Clinic Blueprint for Post-Coronavirus Disease 2019 RECOVERY: Learning From the Past, Looking to the Future. Chest. 2021 Mar;159(3):949-58. doi: 10.1016/j.chest.2020.10.067. PMID: 33159907.
- Manhas KP, O'Connell P, Krysa J, et al. Development of a novel care rehabilitation pathway for post- COVID conditions (long COVID) in a provincial health system in Alberta, Canada. Phys Ther. 2022 09 04;102(9):04. doi: 10.1093/ptj/pzac090. PMID: 35778936.
- 24. Montani D, Savale L, Beurnier A, et al. Multidisciplinary approach for post-acute COVID -19 syndrome: time to break down the walls. European Respiratory Journal.

2021;58(1):2101090. doi: 10.1183/13993003.01090-2021. PMID: 33958429.

- 25. Morrow AK, Ng R, Vargas G, et al. Postacute/long COVID in pediatrics: development of a multidisciplinary rehabilitation clinic and preliminary case series. American Journal of Physical Medicine & Rehabilitation. 2021 12 01;100(12):1140-7. doi: 10.1097/PHM.00000000001896. PMID: 34793374.
- 26. National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), and Royal College of General Practitioners (RCGP). COVID-19 rapid guideline: managing the long\_term effects of COVID-19. 2022:1-118
- O'Brien H, Tracey MJ, Ottewill C, et al. An integrated multidisciplinary model of COVID -19 recovery care. Ir J Med Sci. 2021 May;190(2):461-8. doi: 10.1007/s11845-020-02354-9. PMID: 32894436.
- 28. Parker AM, Brigham E, Connolly B, et al. Addressing the post-acute sequelae of SARS-CoV-2 infection: a multidisciplinary model of care. The Lancet Respiratory Medicine. 2021 11;9(11):1328-41. doi: https://dx.doi.org/10.1016/S2213-2600(21)00385-4. PMID: 34678213.
- 29. Parkin A, Davison J, Tarrant R, et al. A multidisciplinary NHS COVID -19 service to manage post- COVID -19 syndrome in the community. Journal of Primary Care & Community Health. 2021 Jan-Dec;12:21501327211010994. doi: 10.1177/21501327211010994. PMID: 33880955.
- 30. Provincial Health Services Authority. The Post-COVID-19 Interdisciplinary Clinical Care Network offers education, care, and research opportunities to support patients experiencing post-COVID symptoms and their health-care providers. http://www.phsa.ca/ourservices/programs-services/post-COVID-19care-network.
- Santhosh L, Block B, Kim SY, et al. Rapid design and implementation of post- COVID -19 clinics. Chest. 2021 08;160(2):671-7. doi: 10.1016/j.chest.2021.03.044. PMID: 33811910.
- 32. Soriano JB, Murthy S, Marshall JC, et al. A clinical case definition of post-COVID-19 condition by a Delphi consensus. Lancet Infect

Dis. 2022 Apr;22(4):e102-e7. doi: 10.1016/s1473-3099(21)00703-9. PMID: 34951953.

- Stallmach A, Katzer K, Besteher B, et al. Mobile primary healthcare for post- COVID patients in rural areas: a proof-of-concept study. Infection. 2023 Apr;51(2):337-45. doi: 10.1007/s15010-022-01881-0. PMID: 35831582.
- Stephenson T, Allin B, Nugawela MD, et al. Long COVID (post- COVID -19 condition) in children: a modified delphi process. Arch Dis Child. 2022 07;107(7):674-80. doi: 10.1136/archdischild-2021-323624. PMID: 35365499.
- 35. Thaweethai T, Jolley SE, Karlson EW, et al. Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection. JAMA.

2023 Jun 13;329(22):1934-46. doi: 10.1001/JAMA.2023.8823. PMID: 37278994.

- 36. Vanichkachorn G, Newcomb R, Cowl CT, et al. Post- COVID -19 syndrome (long haul syndrome): description of a multidisciplinary clinic at mayo clinic and characteristics of the initial patient cohort. Mayo Clinic Proceedings. 2021 07;96(7):1782-91. doi: 10.1016/j.mayocp.2021.04.024. PMID: 34218857.
- 37. Verduzco-Gutierrez M, Estores IM, Graf MJP, et al. Models of care for postacute COVID -19 clinics: experiences and a practical framework for outpatient physiatry settings. American Journal of Physical Medicine & Rehabilitation. 2021 12 01;100(12):1133-9. doi: 10.1097/PHM.00000000001892. PMID: 34793373.

## **Appendix E. Excluded Studies List**

- 1. Evaluation of the use of REAC protocols in comparison with conventional therapies or placebo as a treatment for reducing symptoms of Post-COVID Syndrome in adults. 2021 PMID: CN-02282837. Exclusion reason: Not a model of care
- The Impact of a Web-Based Platform for Quality of Life and Muscle Health in Patients With Long COVID: a Pilot Study. 2022 PMID: CN-02423024. Exclusion reason: Not a model of care
- Care of people with post-COVID-19. Australian Journal of Herbal & Naturopathic Medicine. 2022;34(3):100-1. PMID: 159369042.
   Exclusion reason: Not a model of care
- National commissioning guidance for post COVID services. NHS England. 2022:1-39.
   Exclusion reason: Not a model of care
- Cognitive rehabilitation for long COVID.
  2023;6(4):311-9. doi:
  10.1016/j.mayocpiqo.2022.05.007. PMID: CN02514645 Exclusion reason: Not a model of care
- Australian guidelines for the clinical care of people with COVID-19. 2023. https://app.magicapp.org/#/guideline/L4Q5An/se ction/jDJJJQ. Exclusion reason: Not a model of care
- Abramoff BA, Dillingham TR, Brown LA, et al. Psychological and cognitive functioning among patients receiving outpatient rehabilitation for post-COVID sequelae: an observational study. Archives of Physical Medicine and Rehabilitation. 2023;104(1):11-7. doi: 10.1016/j.apmr.2022.09.013. PMID: 36202227. Exclusion reason: Not a model of care
- Abrashkin KA, Zhang J, Poku A. Acute, Postacute, and Primary Care Utilization in a Home-Based Primary Care Program During COVID-19. Gerontologist. 2021 01 21;61(1):78-85. doi: https://dx.doi.org/10.1093/geront/gnaa158. PMID: 33045054. Exclusion reason: Not a model of care
- Aiyegbusi OL, Hughes SE, Turner G, et al. Symptoms, complications and management of long COVID: a review. Journal of the Royal Society of Medicine. 2021 09;114(9):428-42. doi: 10.1177/01410768211032850. PMID:

34265229. Exclusion reason: Not a model of care

- 10. Al-Aly Z, Bowe B, Xie Y. Long COVID after breakthrough SARS-CoV-2 infection. Nature Medicine. 2022 07;28(7):1461-7. doi: 10.1038/s41591-022-01840-0. PMID: 35614233.
  Exclusion reason: Not a model of care
- Al-Hakeem M, Hossain S, Alam MZB, et al. Neuropsychological assessment for COVID-19 affected people in Bangladesh: call to attention. Neuropsychological Rehabilitation. 2023 Jan;33(1):189-91. doi: 10.1080/09602011.2021.1979596. PMID: 2023-46966-003. Exclusion reason: Not a model of care
- Albu S, Rivas Zozaya N, Murillo N, et al. Multidisciplinary outpatient rehabilitation of physical and neurological sequelae and persistent symptoms of COVID-19: a prospective, observational cohort study. Disabil Rehabil. 2022 Nov;44(22):6833-40. doi: 10.1080/09638288.2021.1977398. PMID: 34559592. Exclusion reason: Not a model of care
- Almgren J, Löfström E, Malmborg JS, et al. Patients' health experiences of post COVID-19 condition—a qualitative study. International Journal of Environmental Research and Public Health. 2022;19(21):13980. doi: 10.3390/ijerph192113980. PMID: 36360860. Exclusion reason: Not a model of care
- AlRadini FA, Alamri F, Aljahany MS, et al. Post-acute COVID-19 condition in Saudi Arabia: a national representative study. Journal of Infection and Public Health. 2022;15(5):526-32. doi: 10.1016/j.jiph.2022.03.013. PMID: 35429791. Exclusion reason: Not a model of care
- Anonymous. National Institute for Health and Care Excellence (NICE). 2021 10 29;10:29.
   PMID: 35438859. Exclusion reason: Not a model of care
- Astin R, Banerjee A, Baker MR, et al. Long COVID: mechanisms, risk factors and recovery. Exp Physiol. 2023 01;108(1):12-27. doi: 10.1113/EP090802. PMID: 36412084.
  Exclusion reason: Not a model of care
- 17. Avancini A, Belluomini L, Benato G, et al. Exercise for counteracting post-acute COVID-19

syndrome in patients with cancer: an old but gold strategy? Acta Oncol. 2022 03;61(3):388-92. doi: 10.1080/0284186X.2021.2009565. PMID: 34854782. **Exclusion reason:** Not a model of care

- Ayoubkhani D, Khunti K, Nafilyan V, et al. Post-COVID syndrome in individuals admitted to hospital with COVID-19: retrospective cohort study. BMJ. 2021 03 31;372:n693. doi: https://dx.doi.org/10.1136/BMJ.n693. PMID: 33789877. Exclusion reason: Not a model of care
- Barbara C, Clavario P, De Marzo V, et al. Effects of exercise rehabilitation in patients with long coronavirus disease 2019. Eur J Prev Cardiolog. 2022 05 25;29(7):e258-e60. doi: 10.1093/eurjpc/zwac019. PMID: 35078233.
   Exclusion reason: Not a model of care
- 20. Barshikar S, Laguerre M, Gordon P, et al. Integrated Care Models for Long Coronavirus Disease. Phys Med Rehabil Clin N Am. 2023 Aug;34(3):689-700. doi: 10.1016/j.pmr.2023.03.007. PMID: 37419540. Exclusion reason: Used as source document
- Beauchamp MK, Janaudis-Ferreira T, Wald J, et al. Canadian thoracic society position statement on rehabilitation for COVID-19 and implications for pulmonary rehabilitation. Canadian Journal of Respiratory, Critical Care, and Sleep Medicine. 2022;6(1):9-13. doi: 10.1080/24745332.2021.1992939. Exclusion reason: Not a model of care
- Binka M, Klaver B, Cua G, et al. An elastic net regression model for identifying long COVID patients using health administrative data: a population-based study. Open forum infect. 2022 Dec;9(12):ofac640. doi: 10.1093/ofid/ofac640. PMID: 36570972. Exclusion reason: Not a model of care
- Blitshteyn S, Whiteson JH, Abramoff B, et al. Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of autonomic dysfunction in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). PM&R. 2022 Oct;14(10):1270-91. doi: 10.1002/pmrj.12894. PMID: 36169154. Exclusion reason: Not a model of care
- 24. Bouteleux B, Henrot P, Ernst R, et al. Respiratory rehabilitation for COVID-19 related persistent dyspnoea: a one-year experience. Respiratory Medicine. 2021 Nov-

Dec;189:106648. doi: 10.1016/j.rmed.2021.106648. PMID: 34689061. **Exclusion reason:** Not a model of care

- 25. Brennan A, Broughan J, McCombe G, et al. Enhancing the management of long COVID in general practice: a scoping review. Bjgp Open. 2022 Sep;6(3):BJGPO. doi: 10.3399/BJGPO.2021.0178. PMID: 35256357.
  Exclusion reason: Background
- Brough DN, Abel S, Priddle L. A service evaluation of a community project combining psychoeducation and mind-body complementary approaches to support those with long COVID in the UK. Eur J Integr Med. 2022 Oct;55:102182. doi: 10.1016/j.eujim.2022.102182. PMID: 36035093. Exclusion reason: Not a model of care
- Broughton J, Harris S, Beasant L, et al. Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): a qualitative study in England. BMC Health Serv Res. 2017 Jun 2;17(1):384. doi: 10.1186/s12913-017-2337-6. PMID: 28576141. Exclusion reason: Ineligible population
- Burnett D. Interprofessional care for treating long-COVID: a conceptual framework. Journal of Allied Health. 2023 Spring2023;52(1):63-. PMID: 162888002. Exclusion reason: Not a model of care
- Calvo-Paniagua J, Diaz-Arribas MJ, Valera-Calero JA, et al. A tele-health primary care rehabilitation program improves self-perceived exertion in COVID-19 survivors experiencing post-COVID fatigue and dyspnea: a quasiexperimental study. PLoS ONE [Electronic Resource]. 2022;17(8):e0271802. doi: 10.1371/journal.pone.0271802. PMID: 35926004. Exclusion reason: Not a model of care
- Cardins KKB, Uchoa S, Oliveira LVE, et al. Care of people with post-COVID-19 sequelae in the scope of primary health care: scoping review protocol. Int J Environ Res Public Health. 2022 10 27;19(21):27. doi: 10.3390/ijerph192113987. PMID: 36360866. Exclusion reason: Protocol
- Carpallo-Porcar B, Romo-Calvo L, Perez-Palomares S, et al. Efficacy of an asynchronous telerehabilitation program in post-COVID-19 patients: a protocol for a pilot randomized controlled trial. PLoS ONE [Electronic Resource]. 2022;17(7):e0270766. doi: 10.1371/journal.pone.0270766. PMID:

35853037. Exclusion reason: Not a model of care

- Carter SJ, Baranauskas MN. Why obesity and psychological stress matter in recovery of post-acute sequelae of SARS-CoV-2. Obesity. 2022;30(6):1136-8. doi: 10.1002/oby.23442. PMID: 35352508 Exclusion reason: Not a model of care
- Castellucci M. Health systems launching care centers for COVID 'long-haulers'. Modern Healthcare. 2020;50(39):10-. PMID: 146707775. Exclusion reason: Not a model of care
- 34. Cavalcante TF, Lourenco CE, Ferreira J, et al. Models of support for caregivers and patients with the post-COVID-19 condition: a scoping review. Int J Environ Res Public Health. 2023 01 31;20(3):31. doi: 10.3390/ijerph20032563. PMID: 36767926. Exclusion reason: Not a model of care
- 35. Cenko E, Badimon L, Bugiardini R, et al. Cardiovascular disease and COVID-19: a consensus paper from the ESC working group on coronary pathophysiology & microcirculation, ESC working group on thrombosis and the association for acute cardiovascular care (ACVC), in collaboration with the european heart rhythm association (EHRA). Cardiovascular Research. 2021;117(14):2705-29. doi: 10.1093/cvr/cvab298. PMID: 34528075. Exclusion reason: Background
- 36. Cevei M, Onofrei RR, Gherle A, et al. Rehabilitation of post-COVID-19 musculoskeletal sequelae in geriatric patients: a case series study. Int J Environ Res Public Health. 2022 11 21;19(22):21. doi: 10.3390/ijerph192215350. PMID: 36430069. Exclusion reason: Not a model of care
- 37. Cha C, Baek G. Symptoms and management of long COVID: a scoping review. J Clin Nurs. 2021 Dec 15;15:15. doi: 10.1111/jocn.16150. PMID: 34913540. Exclusion reason: Not a model of care
- Chadd K, Chalmers S, Harrall K, et al. An evaluation of speech and language therapy services for people with long COVID in the UK: a call for integrated care. Journal of Integrated Care. 2022doi: 10.1108/JICA-07-2022-0038.
   Exclusion reason: Not a model of care
- 39. Chalmers S, Harrall K, Wong SY, et al. A retrospective study of patients presenting with speech and language therapy needs within

multidisciplinary Long COVID services: a service evaluation describing and comparing two cohorts across two NHS Trusts. Int J Lang Commun Disord. 2023 Mar 14;14:14. doi: 10.1111/1460-6984.12868. PMID: 36916685. **Exclusion reason:** Not a model of care

- 40. Chaplin S. Summary of joint guideline on the management of long COVID. Prescriber.
  2021;32(8):33-5. doi: 10.1002/psb.1941. PMID: 152468378. Exclusion reason: Background
- 41. Chee YJ, Fan BE, Young BE, et al. Clinical trials on the pharmacological treatment of long COVID: a systematic review. Journal of Medical Virology. 2023;95(1):e28289. doi: 10.1002/jmv.28289. PMID: 36349400.
  Exclusion reason: Not a model of care
- 42. Chen C, Haupert SR, Zimmermann L, et al. Global prevalence of post-coronavirus disease 2019 (COVID-19) condition or long COVID: a meta-analysis and systematic review. J Infect Dis. 2022;226(9):1593-607. doi: 10.1093/infdis/jiac136. PMID: 35429399.
  Exclusion reason: Not a model of care
- 43. Chow JSF, D'Souza A, Ford M, et al. A descriptive study of the clinical impacts on COVID-19 survivors using telemonitoring (The TeleCOVID Study). Front. 2023;5:1126258. doi: 10.3389/fmedt.2023.1126258. PMID: 37020492.
  Exclusion reason: Not a model of care
- 44. Chuang HJ, Hsiao MY, Wang TG, et al. A multidisciplinary rehabilitation approach for people surviving severe COVID-19-a case series and literature review. Journal of the Formosan Medical Association. 2022 Dec;121(12):2408-15. doi: 10.1016/j.jfma.2022.02.002. PMID: 35216882. Exclusion reason: Ineligible popualtion
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  Exclusion reason: Ineligible population
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- 132. Svetlana Blitshteyn JHW, Benjamin Abramoff, Iba Azola, Matthew N. Bartels, Ratna Bhavaraju-Sanka, Tae Chung, Talya K. Fleming, Ellen Henning, Mitchell G. Miglis, Sarah Sampsel, Julie K. Silver, Jenna Tosto, Monica Verduzco-Gutierrez, David Putrino Multi-disciplinary collaborative consensus guidancestatement on the assessment and treatment of autonomicdysfunction in patients with post-acute sequelaeof SARS-CoV-2 infection (PASC). PM&R. 2022;14(10):1270-91. doi: https://doi.org/10.1002/pmrj.12894. Exclusion reason: Not a model of care
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   528\_VA. Accessed Aug 18 2023. Exclusion reason: Ineligible publication type
- U.S. Department of Veterans Affairs. Whole Health System Approach to Long COVID.
   Patient-Aligned Care Team (PACT) Guide.
   2022:1-31. Exclusion reason: Used as source document
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- 141. van der Feltz-Cornelis CM, Sweetman J, Allsopp G, et al. STIMULATE-ICP-Delphi (symptoms, trajectory, Inequalities and management: understanding long-COVID to address and transform existing integrated care pathways delphi): study protocol. PLoS ONE [Electronic Resource]. 2022;17(11):e0277936. doi: 10.1371/journal.pone.0277936. PMID: 36449461. Exclusion reason: Protocol
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34772779. Exclusion reason: Not a model of care

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  Exclusion reason: Not a model of care
- 146. Whiteson JH, Azola A, Barry JT, et al. Multidisciplinary collaborative consensus guidance statement on the assessment and treatment of cardiovascular complications in patients with post-acute sequelae of SARS-CoV-2 infection (PASC). PM and R. 2022;14(7):855-78. doi: 10.1002/pmrj.12859. PMID: 35657351.
   Exclusion reason: Background

- 147. Wolf S, Erdos J. Long COVID care pathways: a systematic review. Austrian Institute for Health Technology Assessment GmbH. 2021:1-53.
   Exclusion reason: Not a model of care
- 148. Wolf S, Zechmeister-Koss I, Erdos J. Possible long COVID healthcare pathways: a scoping review. BMC Health Services Research. 2022 Aug 23;22(1):1076. doi: 10.1186/s12913-022-08384-6. PMID: 35999605. Exclusion reason: Background
- 149. Yadav B, Rai A, Mundada PS, et al. Safety and efficacy of ayurvedic interventions and yoga on long term effects of COVID-19: a structured summary of a study protocol for a randomized controlled trial. Trials [Electronic Resource]. 2021 Jun 03;22(1):378. doi: 10.1186/s13063-021-05326-1. PMID: 34082792. Exclusion reason: Not a model of care
- 150. Yang T, Yan MZ, Li X, et al. Sequelae of COVID-19 among previously hospitalized patients up to 1 year after discharge: a systematic review and meta-analysis. Infection. 2022 Oct;50(5):1067-109. doi: 10.1007/s15010-022-01862-3. PMID: 35750943. Exclusion reason: Not a model of care

# Appendix F. Data Elements Abstracted Into Evidence Tables

# Table F-1. Data elements abstracted into evidence tables for studies reporting outcomes of long COVID models of care (Guiding Question 4)

Data Element	Details
Study characteristics	Study design
	Inclusion/exclusion criteria
	Sample size at recruitment and followup rates
Population characteristics	Age
	Race/ethnicity
	Sex and gender
	Long COVID severity and presenting symptoms
	Definition of long COVID, if known
Intervention characteristics	Description of long COVID program/model of care including:
	<ul> <li>The types of interventions used</li> </ul>
	<ul> <li>Diagnostic testing strategies</li> </ul>
	<ul> <li>Provider types/disciplines involved</li> </ul>
	<ul> <li>Mode of delivery, including use of telehealth</li> </ul>
	<ul> <li>Educational or training components</li> </ul>
	Frequency or intensity of visits
	Process for coordinating care
	Methods of followup
	Source and duration of funding
	<ul> <li>Type of patients served (insured/uninsured)</li> </ul>
Comparator	Comparator(s), if any
Outcomes examined	Types of outcomes examined in the study, how they were measured, and main
	findings; identified barriers and facilitators to implementation; patient perspectives
	(preferences, acceptability, satisfaction); impact on equity or disparities
Timing	Timing of outcome measurement (followup)
Setting	Clinical setting (e.g., primary care, specialty clinic, or standalone clinic; type of
-	healthcare organization)
	Country/geographic location

Abbreviations: COVID = coronavirus disease.

### Appendix G. Evidence Table for Included Studies, Guiding Question 1

		Country		
Author, Year	Publication Type	Setting	Definition Source	Long COVID Definition/Criteria
Brugler Yonts,	Journal article	NA	WHO consensus definition	Pediatric long COVID:
<b>2022</b> <sup>1</sup>			developed over 2 Delphi process	-History of confirmed SARS-CoV-2 infection
			sessions	-One or more new persistent physical
See also:				symptoms that:
Stephenson, 2022 <sup>2</sup>				Last a minimum of 12 weeks
				after initial infection
				May fluctuate or relapse
				Effect daily function
				-Cannot be explained by an alternative diagnosis
Stephenson, 2022 <sup>2</sup>	Journal article	UK	Consensus definition of long	Consensus definition:
		NA	COVID in children and young	A condition in which a child or young person has symptoms
See also: Brugler			people developed over 3 Delphi	(at least one of which is a physical symptom) that:
Yonts, 2022 <sup>1</sup>			process sessions and a consensus	<ol> <li>Have continued or developed after a diagnosis of</li> </ol>
			meeting (session 1: n=105; session	COVID-19 (confirmed with one or more positive COVID-19
			2: n=86; session 3: n=77;	tests).
			consensus meeting: n=17)	2. Impact their physical, mental or social well-being.
				3. Are interfering with some aspect of daily living (e.g., school,
			Participants were grouped into the	work, home or relationships).
			following categories:	<ol><li>Persist for a minimum duration of 12 weeks after initial</li></ol>
			Lived Experience	testing for COVID-19 (even if symptoms waxed and waned
			Researcher/Combination	over that period).
			Service Delivery	
				WHO aligned consensus definition (see Brugler Yonts 2022)

#### Table G-1. Details of articles for Guiding Question 1

Abbreviations: COVID = coronavirus disease; EMR = electronic medical record; NA = not applicable; PASCLex = post-acute sequelae of COVID-19 symptom lexicon; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2; WHO = World Health Organization.

### **Appendix G References**

- Brugler Yonts A. Pediatric long-COVID: a review of the definition, epidemiology, presentation, and pathophysiology. Pediatr Ann. 2022 Nov;51(11):e416-e20. doi: 10.3928/19382359-20220913-06. PMID: 36343180.
- Stephenson T, Allin B, Nugawela MD, et al. Long COVID (post-COVID-19 condition) in children: a modified delphi process. Arch Dis Child. 2022 07;107(7):674-80. doi: 10.1136/archdischild-2021-323624. PMID: 35365499.

## Appendix H. Evidence Tables for Included Studies, Guiding Questions 2 Through 5

Table H-1a. Long COVID models of care described in the published or grey literature (name, location, setting, population served, disciplines included)

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Family Health Centers of San Diego, 2021 <sup>3</sup>	Family Health Center of San Diego's Long COVID and Fatiguing Illness Recovery Program ongoing clinical trial (NCT05167227) assessing a teleECHO intervention for clinicians with the intent of improving care	Primary care	USA (San Diego CA) Health system	Presumably adults Health system patients diagnosed with Long COVID, ME/CFS, or other post-infectious fatiguing illness. Focus on uninsured, low-income, and medically underserved persons.	Primary care (physician, PA or nurse practitioner) with or without teleECHO support (randomized trial)
Hitch, 2022 <sup>4</sup>	DisCOVeRY model of care co- designed by healthcare workers and patients	NR	Australia NR	Presumably adults	NR
Ganesh, 2022⁵ Related publications: Vanichkachorm, 2021; Ganesh, 2022b	Mayo Clinic Multidisciplinary Approach Guiding Post-COVID- 19 Investigation, Education and Symptom Management Clinics: Mayo Clinic Arizona Mayo Clinic Florida Mayo Clinic Florida Mayo Clinic Rochester Mayo Clinic Health System	Varies according to clinic Mayo Clinic Florida, Mayo Clinic Rochester, Mayo Clinic Health System: standalone clinic Mayo Clinic Arizona: primary care-based clinic	USA (Arizona, Florida, Iowa, Minnesota, Wisconsin) Setting varies according to clinic (e.g., Mayo Clinic Florida: tertiary care hospital serving patients from southeastern USA, Mayo Clinic Health System: regional health system serving primarily rural patients in MN and WI)	Appears to be children and adults Mayo Clinic patients meeting long COVID criteria	General internal medicine Occupational medicine Preventative Medicine Physical medicine and rehabilitation Psychology Allergy and immunology Infectious disease Pulmonology Neurology Cardiology Pediatrics Otorhinolaryngology Wellness coaching

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Ganesh, 2022b <sup>24</sup> Related publication: Ganesh, 2022	Mayo Clinic Post-COVID-19 Care Clinic	NR	USA (Rochester MN) University hospital	Appears to be children and adults N=108 Median age 46 years 75% female 94% White, 4% Black, 2% American Indian / Pacific Islander 2% Hispanic	General internal medicine Preventive medicine PM&R Psychology Allergy and immunology Infectious disease Pulmonology Neurology Cardiology Pediatrics Otorhinolaryngology
Montani, 2021 <sup>6</sup>	COMEBAC Study (Bicêtre Hospital, Paris)	Outpatient clinic	France (Paris)	Inclusion: age ≥18 years with previous hospital or ICU admission for COVID- 19. At 3-4 months post- discharge, previously hospitalized patients reporting symptoms and all previous ICU patients were eligible for inclusion	Unclear; described as multidisciplinary All patients underwent respiratory assessment, lung CT scan, cardiac assessment, psychological and cognitive assessment (neuropsychologist and psychologist); some also had kidney function assessment
Chuang, 2023 <sup>8</sup>	NA	Model 1 Case manager Model 2 NR; "top down" with pulmonologists and infection specialists described as "first- line" care providers	Taiwan	Model 1 Patients (presumably adults) with persistent debilitating symptoms of COVID infection Model 2 Within 6 months after de- isolation for COVID-19 infection for outpatients, and 3 months for inpatients. Enrolled: Patients from 130 hospitals (n=4,489); primarily outpatients age 30-40 years Insured: 99.9% of national population reported to have National Health Insurance coverage	Model 1 Case manager Physician Physical therapy Occupational therapy Speech language therapy Psychology Dietician Social worker Model 2 Pulmonology and infection specialists with other specialists as needed

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Stallmach, 2023 <sup>9</sup>	Mobile post-COVID outpatient clinic	Unclear; presumably primary care	Germany Rural areas	Presumably adults Patients seeking care at post-COVID clinic with PCR-confirmed SARS- CoV-2 infection ≥12 weeks in the past	Nurse Physician Psychology Referrals as needed to: cardiology, pneumology, radiology
Manhas, 2022 <sup>10</sup>	Alberta Health Services Provincial Post COVID-19 Rehabilitation Response Framework (PCRF)	NR	Canada All heathcare settings (acute inpatient, post-acute inpatient, continuing care, community care)	Presumably adults Any hospitalized patients with COVID-19 and post- acute and community patients with COVID-19 symptoms	NR; framework developed by multidisciplnary group
Ahmad, 2022 <sup>11</sup>	Richmond University (NY) Medical Center Post-COVID Care Center (PCC Center)	Standalone clinic	USA (New York NY) University hospital	Inclusion: age ≥18 years with prior acute COVID-19 infection; proportion insured not reported Area population includes a high proportion of: people with low SES, racial/ethnic minorities, immigrants; area is federally classified as Medically Underserved	Cardiology Gastroenterology Infection control Nephrology Neurology Otolaryngology Pharmacy Physiatry Psychiatry Pulmonary Radiology Sleep medicine
Morrow, 2021 <sup>12</sup>	Kennedy Krieger Institute Post COVID-19 Rehabilitation Clinic	Outpatient clinic NR	USA (Baltimore MD) Urban clinic	Self-referred patients <21 years	Medicine (neurology and pediatric rehabilitation) Physical therapy Behavioral psychology Neuropsychology Social work.
Verduzco-Gutierrez, 2021 <sup>13</sup>	UT Southwestern Medical Center COVID Recover Program	2 physiatry outpatient clinics	USA (Dallas TX) University clinic and "distant ambulatory clinic"	Presumably adults	Physiatry Therapy service Neuropsychology Counseling Partnerships with: autonomic testing laboratory, pulmonology, cardiology, psychiatry

Author, Year	Model Description/Name	Model Location and Organization	Setting	Population Served	Disciplines Included in Model
	UT Health San Antonio Program	2 outpatient clinics; UT Health San Antonio Department of Rehabilitation Medicine	USA (San Antonio TX) One university clinic based, one community safety net country clinic	Adults and children Area is described as having "one of the largest majority minority populations in the country" The healthcare safety net center delivers healthcare services to patients without insurance who have increased medical and social vulnerabilities	Physiatry with "asynchronous multidisplinary team" which can include physical therapy, neuropsychology, behavioral health, cardiology, pain management, and neurology
	VA Greater Los Angeles Healthcare System	PM&R department clinic	USA (Los Angeles CA) Urban clinic	Adults VA eligible community- based residents	Physiatrist Physical therapist Neuropsychologist Clinical psychologist
	Hennepin Healthcare	Primary care based	USA (Minneapolis MN) NR	Presumably adults	Primary care Physical therapy Occupational therapy Speech language pathology Social work Nutrition Other specialty clinics (e.g., cardiology, pulmonology, neurology, sleep medicine, ENT, neuropsychology)
	University of Florida COVID RESTORE	Integrative medicine clinic	USA (Gainesville FL) University clinic	Presumably adults Program admission requires any insurance, including those who participate in the financial assistance program	PM&R Integrative medicine Cardiology Pulmonology Renal medicine Neurology Clinical psychology and psychiatry Infectious disease medicine Therapy services

	Madal Daarin (harring)	Model Location and	Country	Dama latian Oamaa l	
Author, Year	Model Description/Name	Organization	Setting	Population Served	Disciplines Included in Model
Parker, 2021 <sup>14</sup>	NA	NR	Not specified (theoretical model)	Presumably adults	Primary care PM&R Physiatry Physical therapy Occupational therapy Speech language pathology Rehabilitation psychology / neuropsychology Neuropsychiatry Pharmacy Social work
Harenwall, 2021 <sup>15</sup>	Primary Care Wellbeing Service, Bradford District Care NHS Foundation Trust	Psychology-led, interdisciplinary existing ME/CFS clinic	UK	Presumably adults Long COVID and ME/CFS n=149 (full sample) Duration from onset of symptoms and enrollment (mean): 6 months Hospitalized for acute COVID-19: 12.8% Female: 88% White: 74% Black, Asian and minority ethnic: 26%	Clinical psychology Physical therapy Occupational therapy Diet/nutrition Speech and language pathology Personal support navigator
List, 2021 <sup>16</sup>	NYC Health+Hospitals COVID-19 Centers of Excellence	3 primary care based clinics	USA (New York NY) Municipal public health system	Presumably adults Population not described; centers are coapplicant with NYC Health + Hospitals designation as federally qualified health centers	Primary care Mental health professionals Cardiology Pulmonology Referral to other specialties as needed (e.g., nephrology, hematology)
Vanichkachorn, 2021 <sup>17</sup> Related publication: Ganesh, 2022	Mayo Clinic COVID-19 Activity Rehabilitation Program	Preventive Medicine / PM&R based	USA (Rochester MN) NR	Presumably adults	Preventive medicine Physiatry Occupational medicine Referral as needed to other specialties (pulmonary medicine, infectious disease, cardiology, brain rehabilitation, chronic fatigue, neurology, psychiatry, EAP, physical or occupational therapy, speech therapy, autonomic patient education)

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Aiash, 2021 <sup>18</sup>	NR	NR	Egypt (Cairo) NR	Presumably adults	Nursing Physiotherapy Phlebotomy Radiology Rehabilitation Physical therapy Other consultants (pulmonology, cardiology)
Parkin, 2021 <sup>19</sup>	Community COVID-19 MDT pathway	NR	UK (Leeds) Regional health system	Inclusion criteria NR Mean age 48 years 68% female 74% not hospitalized during acute COVID-19 82% initially infected in March or April 2020 54% unable to work or working reduced hours	Physiotherapy Occupational therapy Rehabilitation medicine Respiratory medicine Cardiology Other specialists (respiratory nursing, respiratory physiotherapy, dietician, neurological occupational therapy) Referrals can be made to: Community Speech and Swallow service, ENT Speech and Language therapy)
Santhosh, 2021 <sup>20</sup>	UCSF OPTIMAL	Pulmonary / critical care based	USA (San Francisco) University hospital and large county hospital	Presumably adults Focus on hospitalized patients while providing a referral pathway for any COVID-19 survivor with persistent pulmonary and/or rehabilitation needs	Core team: Pulmonary-critical care Psychiatry/psychology Pharmacy Partnerships: Primary care Physical therapy Occupational therapy Speech-language pathology Neurology Cardiology Geriatrics Integrative medicine Otolaryngology

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Brigham, 2021 <sup>21</sup> <i>Related publication:</i> <i>Santhosh, 2021</i>	Johns Hopkins PACT Clinic; additional subclinic COVID-19 Remote Patient Monitoring (RPM) program	Pulmonary and Critical Care / PM&R based; sub-clinic RPM program also coordinated through the Office of Telemedicine and th	USA (Baltimore) University hospital	Presumably adults Focus on hospitalized patients while providing a referral pathway for any COVID-19 survivor with persistent pulmonary and/or rehabilitation needs	Core team: Pulmonary-critical care PM&R Home care physical therapy, occupational therapy and speech language pathology Pharmacy Partnerships: Primary care Psychiatry Psychology Neurology Cardiology Hematology Infectious disease Nephrology Dermatology Hepatology Otolaryngology
Ladds, 2021 <sup>22</sup>	NR	NR	UK NR	Presumably adults	Described as possible specialists and not a definitive list Respiratory medicine ENT Cardiovascular medicine Endocrine Hepatology Rheumatology Immunology Dermatology Neurology Neurophysiology Psychiatry Rehabilitation Occupational health
O'Brien, 2021 <sup>23</sup>	Beaumont Hospital COVID Recovery Service	Virtual multidisciplinary clinic	Ireland (Dublin) Hospital	N=174 Median age 67 years 67% male 22% ICU admission for mechanical ventilationI 11% noninvasive ventilation or high-flow oxygen on a respiratory ward	Respiratory medicine Infectious disease medicine Psychiatry Psychology Intensive care medicine Radiology Pulmonary physiology Phlebotomy

Author, Year	Model Description/Name	Model Location and Organization	Country Setting	Population Served	Disciplines Included in Model
Bailey, 2023 <sup>25</sup>	Northwestern Medicine Comprehensive COVID-19 Center	Multidisciplinary clinic based in neurology department	USA (Chicago- based; patients from 41 states served by clinic) University health system	Presumably adults Insurance not required	Neurology Pulmonology Cardiology Otolaryngology Gastroenterology Infectious disease Endocrinology Nephrology Hematology Dermatology Psychiatry Rheumatology
Levin, 2023 <sup>26,27</sup> See also: http://www.phsa.ca/our- services/programs- services/post-COVID- 19-care-network	Post COVID-19 Interdisciplinary Clinical Care Network PCRCs	Unclear; described as interdisciplinary	Canada (BC)	Presumably adults Individuals with a BC Services Card meeting clinical criteria	NR
Lutchmansingh, 2020 <sup>28</sup>	RECOVERY: Comprehensive Post-COVID Center at Yale	Multidisciplinary, centered in the pulmonary clinic	USA (Bridgeport CT) University pulmonary clinic	Presumably adults Individuals hospitalized with moderate to severe disease, nonhospitalized individuals with persistent respiratory symptoms, and individuals with established preexisting lung disease	Cardiology Neurology Psychiatry Hematology Otolaryngology Sleep medicine Physical therapy

Abbreviations: COMEBAC = Consultation Multi-Expertise de Bicêtre Après COVID-19; COVID = coronavirus disease; CT = computed tomography; EAP = employee assistance program; ENT = otolaryngology; ICU = intensive care unit; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NR = not reported; OPTIMAL = pOst-COVID-19/PosT- Icu MultidisciplinAry cLinic; PACT = The Johns Hopkins post-acute COVID-19 team; PCC = post-COVID care; PCR = polymerase chain reaction; PCRC = post COVID-19 recovery clinic; PM&R = physical medicine and rehabilitation; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2; VA = Veterans Affairs

Table H-1b. Long COVID models of care described in the published or grey literature (location of disciplines, intake methods, screening, post-screening)

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Family Health Centers of San Diego, 2021 <sup>3</sup>	NR	NR	PROM assessment	Quarterly PROM assessment
Hitch, 2022 <sup>4</sup>	NR	NR	Comprehensive assessment using standardized outcome measures + PROMs	Patients allocated to one of two streams of care based on screening findings:
				Supported recovery stream: provides intensive multidisciplinary rehabilitation (available face to face and via tele-rehabilitation)
				Self-managed stream: provides a navigator service (via hotline and email) which serves as a single point of information and onward referral.

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Ganesh, 2022 <sup>s</sup> Related publications: Vanichkachorm, 2021; Ganesh, 2022b	MCR COVID-19 Activity Rehabilitation Program: Preventive Medicine / PM&R based; specialty disciplines location unclear see also Vanichkachorm 2021	Physician or self-referral	Patients complete a 52-question appointment request form Completed forms are reviewed by PASC triage team who develops an individual evaluation plan for each patient	If patient is judged appropriate for PASC clinic, a virtual visit is held to clarify symptoms and set expectations, followed by an in- person visit, additional testing, and in-person or virtual wrap up with the PASC physician.
	Mayo Clinic Rochester Post- COVID Care Clinic: GIM based, specialty disciplines location unclear <i>see also Ganesh 2022b</i> Mayo Clinic Florida PASC: GIM based; specialty disciplines location unclear Mayo Clinic Health System: decentralized; care coordinated locally by "physician champions" Mayo Clinic Arizona: primary care-based			Individual clinics have adapted the model according to their site needs/focus: - Mayo Clinic Rochester COVID- 19 Activity Rehabilitation Program: early rehabilitation and return to work - Mayo Clinic Rochester Post- COVID Care Clinic: post-COVID- 19 syndrome (see also Vanichkachorn 2021) - Mayo Clinic Florida PASC: tertiary care center that sees all patients with PASC - Mayo Clinic Health System: operates on the Extension for Community Healthcare Outcomes model - Mayo Clinic Arizona: primary care-based without central specialty support
Ganesh, 2022b <sup>24</sup> Related publication: Ganesh, 2022	NR	Self-referral or physician referral	<ol> <li>Patients complete a 52-question appointment request form</li> <li>Basic lab testing, autoimmune screening, 6-minute walk test, pulmonary function testing, chest imaging</li> </ol>	Patient questionnaires reviewed by GIM physician 1. Those with symptoms limited to a single organ system were referred directly to the subspecialty team 2. Those with symptoms in multiple organ systems were initially evaluated by a 30-minute virtual visit

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Montani, 2021 <sup>6</sup>	Unclear; described as multidisciplinary assessment in outpatient clinics involved multiple specialists on the same day at a single location	Telephone screening of those meeting inclusion criteria	General condition and symptom questionnaire administered by telephone by a medical officer	If inclusion criteria met, patients were assessed in an outpatient facility (unclear if this includes one or multiple clinics)
Chuang, 2023 <sup>8</sup>	Model 1 NR Model 2 NR	Model 1 NR Model 2 NR	Model 1 Comprehensive evaluation and making the diagnosis of long COVID Model 2 Unclear; pulmonology and infection specialists conducted screenings	Model 1 Patients with debilitating symptoms are referred to a multidisciplinary rehabilitation team at an early stage for a comprehensive assessment of rehabilitation needs and planning of further management Model 2 Establishment of a case management and registration system that includes standardized outcome measures
Stallmach, 2023 <sup>9</sup>	Physician, psychology: in mobile clinic Other disciplines: NR	NR	Structured examination including measurement of vital signs and blood draw (nurse), neuropsychological exam and physical exam and clinical interview (physician)	Referral to other disciplines if needed Patient provided with detailed information on potential therapeutic options; appointments for necessary treatments were scheduled at that tim when possible Written reports sent to patient and GP

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup	
Manhas, 2022 <sup>10</sup>	NR	Initial intake through consultation / provider support via rehabilitation advice line	Specific screening tools, resources and assessments vary according to rehabilitation setting: 1. Acute care and inpatient (ICU, ED, acute inpatient units, inpatient rehab units) 2. Post-acute care (sub-acute, restorative care) 3. Continuing care (hospice, home care, long term care, supportive living) 4. Community care (primary care, ambulatory care, community rehabilitation)	Co-develop with patient a collaborative rehabilitation care plan Ensure care coordination / discharge planning with primary care Followup care based on level of functional impairment: 1. Mild: universal rehabilitation (self management) 2. Moderate: targeted rehabilitation (group classes) 3. Severe impairment: personalized rehabilitation (individual focused, multidisciplinary)	
Ahmad, 2022 <sup>11</sup>	Unclear; patients "referred to specialists within the institution" as needed	Participants were recruited at the time of post-hospital or ER discharge, primary care referral, or self-referral Screening for participation was done by hospital- affiliated internists or family medicine physicians	Initial screening: Physical exam (general assessment, cardiac, respiratory, abdomen and musculoskeletal findings) Lab work and serology (CBC with differentials, CMP, ferritin, CRP, procalcitonin, D-dimer, COVID-19 antibody, urinalysis) Additional screening: completed as needed based on initial findings, including additional respiratory (spirometry, pulmonary function testing, chest radiograph, chest CT), cardiac (ECG, chest radiograph, chest CT) and psychiatric (PHQ-9, GAD) assessment	People with any positive screening were referred to specialist who conducted system-specific history and physicals, reviewed data from initial visits, ordered additional testing or imaging if needed Followup at PCC Center at 1 month, additional followup at 2, 3, and 6 months if needed. Followup visits included full history and physical to address new or ongoing symptoms and offer referrals when appropriate	
Morrow, 2021 <sup>12</sup>	NR	Self-referral	Screening for history of SARS-CoV-2 by clinic directors	In-person or telehealth neuropsychological evaluation within one week of screening; visits were intentionally separated to avoid patient overexertion (fatigue being a common symptom)	

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Verduzco-Gutierrez, 2021 <sup>13</sup>	NR	Referral from acute hospital care or from community- based providers or self- referral	Initial evaluation by designated physiatrists (symptom inventory, severity of acute illness including need for mechanical ventilation, medical complications)	An individualized and symptom- focused treatment plan is developed: 1. Physical symptoms: PT COVID protocol; autonomic testing if indicated 2. Cognitive symptoms: speech language pathology; neuropsychological testing 3. Behavior symptoms: COVID Recover Wellness Group 4. Additional specialty referrals as needed
	NR	Physician or self referral	Questionnaires sent to patients before initial visit at the via MyChart Assessments (usually via telemedicine) of medical, functional, and psychosocial variables, and a virtual physical examination	Referral for further workup, consultation, and treatment on an individual basis; may include any of the multidisciplinary specialties
	NR	Unclear; referrals described as typically originating from: Acute Rehabilitation Unit Primary Care Pulmonary Medicine	Initial sequential evaluation via telemedicine by: Physiatrist Neuropsychologist Psychologist Physical therapist	Referral according to impairment: Functional: home-base COVID- 19 physical therapy for up to 12 weeks 1. Cognitive: memory skills group and speech language pathology or referral to neuropsychology 2. New or worsened mental health symptoms: post-COVID support group or mental health provider 3. Other referrals as needed (e.g., cardiology, pulmonology, neurology, nutrition)

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Verduzco-Gutierrez, 2021 <sup>13</sup> Continued	NR	At primary care visit, patients who initiate post- acute COVID-19 discussion or who present with symptoms are screened	Patients are screened with a symptom/functional screening tool that includes psychosocial evaluation; those who self-present are screened with a short version of the screening tool, those with symptoms are screened with a long version of the screening tool	Depending on screening results, patients may be: 1. Referred to specialty care 2. Referred to PM&R based Post COVID-19 Recovery Clinic (if functional deficits persist >4 weeks after acute infection). Patients can also be directly referred to the clinic from acute hospital care or from the community
	NR	NR	Initial 1-hour consultation (not further described)	Return visits to develop a lifestyle-based integrative health plan addressing nutrition, adaptive coping skills, relaxation practices, and evidence-informed use of supplements, botanicals, and complementary therapies. Patients with mental health
				needs will be referred to an in- person mindfulness-based tools for resilience psycho- educational group facilitated by a mental health professional Health coaching via 30-min in- person or video-enabled telemedicine visit.

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Parker, 2021 <sup>14</sup>	NR	NR	In-person or remote (primary care or PASC clinic) universal screening of COVID-19 survivors including the following elements: 1. Detailed history taking and physical exam 2. Functional needs assessment 3. Mental health and cognitive assessmnt 4. Social work needs evaluation 5. Medication review by a clinical pharmacist 6. Core outcome set for acute respiratory failure and COVID-19	Variable according to screening: 1. Functional impariment: physical therapy, occupational therapy, speech language pathology evaluation 2. Mental health or cognitive impairment: rehabilitation psychology or psychiatry referral 3. Unexplained palpitations or chest pain: ECG (arrhythmia event monitor), cardiology consultation 4. Abnormal lab findings: repeat labs 5. Other persistent, unexplained symptoms (e.g., headache, dizziness): other subspecialty referral
Harenwall, 2021 <sup>15</sup>	Appears to be on site	NR	NR	7-week course
List, 2021 <sup>16</sup>	On site within the Center of Excellence	NR	NR	NR
Vanichkachorn, 2021 <sup>17</sup> Related publication: Ganesh, 2022	NR	NR	Assessment of fatigue, dyspnea, depression/anxiety, brain fog, BP/HR fluctuations, sleep quality, appetite, signs of PE/DVT Review of preexisting conditions, pre- COVID functional status, activities of daily living, and occupational history Identification of patient's treatment goals	<ul> <li>NR; clinic goals included:</li> <li>1. Assess for associated conditions and to detect evidence for decompensation in the early recovery phase</li> <li>2. Facilitate functional improvement</li> <li>3. Facilitate a therpeutic and safe pathway for return to work</li> </ul>
Aiash, 2021 <sup>18</sup>	NR	Self-referral	<ol> <li>Nurse-administered intake questionnaire</li> <li>Diagnostic workup (lab testing, echocardiogram, pulmonary function testing, electrocardiogram)</li> </ol>	Referral to other disciplines if needed Followup visits at 1, 3 and 6 months (more if needed)

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Parkin, 2021 <sup>19</sup>	NR	Referral from primary care (GP), neighborhood community nursing and therapy teams, directly from hospital	Patient provided with screening questionnaire to assess symptom severity and functional disability	Patient is contacted by the         Pathway Coordinator and         treatment plan is formed:         1.Most patients placed on         therapy waitlist and provided         with self-management         advice/materials. Once the         patient is on the active therapy         caseload, baseline outcome         measures (assessing fatigue,         breathlessness, deconditioning,         cognition, anxiety and         depression and pain) are taken         by the lead therapist, with         followup at 8 weeks and 6         months.         2. Patients with specific medical         complexities (Level 3) are         discussed within a weekly virtual         COVID-19 multidisciplinary team         meeting with the intent of linking         patients to appropriate pathways         of investigation and treatment
Santhosh, 2021 <sup>20</sup>	NR; all patients seen by Core team members	NR	NR	Unclear; "outpatient clinic referral coordinators played an essential role in educating and interfacing within patient teams, gathering relevant patient information, confirming referral qualifications, coordinating visit timing, and refining the referral process

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Brigham, 2021 <sup>21</sup> <i>Related publication:</i> <i>Santhosh, 2021</i>	NR; all patients seen by Core team members	Referral under one of the following conditions:1. Patient required ICU- level care for at least 48 hours2. Patient had post- discharge rehab recommendations3. Patient had pre-existing lung disease, significant persistent respiratory problems, new oxygen requirement after discharge, or inpatient pulmonary consult that recommended referral to PACT clniic 	NR	Unclear; "outpatient clinic referral coordinators played an essential role in educating and interfacing within patient teams, gathering relevant patient information, confirming referral qualifications, coordinating visit timing, and refining the referral process" Followup elements included weekly meetings and rounds for providers, medication reconciliation by pharmacists, home care for homebound patients, "co-management and communication" with PCPs
Ladds, 2021 <sup>22</sup>	Unclear; "one-stop shop" clinic described as a potential model	GP or inpatient referral	"Multisystem investigations" to: 1. Exclude red flag conditions 2. Detect and treat new or existing comorbidities 3. Provide best symptomatic management and enable self or professional monitoring of severity	<ol> <li>Rehabilitation: psychological input, specialist input, managing fatigue, individualized pacing and goal-setting, home adaptation or advice/support accessing social care, nutritional advice/support</li> <li>Self-management: home monitoring, patient support groups, advice, information and support (e.g., via apps)</li> <li>General social, financial, cultural, and occupational advice</li> <li>Occupational health input: advice and support to develop return-to-work plan</li> <li>Followup with primary care</li> </ol>

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
O'Brien, 2021 <sup>23</sup>	NR	Referral based on inclusion criteria	Virtual assessment 8-12 weeks after discharge by physician associate including chest x-ray, blood tests, symptom screening, mental health screening, quality of life screening Organization of in-clinic testing needs	<ol> <li>Followup to integrated care (GP, community psychology, physiotherapy) in the community for non-critical patients who have recovered with no clinical concern from multidisciplinary team</li> <li>Followup to in-person clinic 12 weeks after discharge for patients with a clinical concern from multidisciplinary team or those who were managed in the ICU</li> <li>Referral to respiratory clinic for those with abnormal chest x-ray or physiology</li> <li>Referral to COVID-19 survivorship clinic for those with significant functional impairment</li> <li>Followup as needed to Multidisciplinary Post-COVID Mental Health Service (psychiatry, psychology, liaison and community services)</li> </ol>
Bailey, 2023 <sup>25</sup>	In clinic	Physician or self referral Clinic staff determines clinic candidacy	Previsit assessment of cognitive function (PROMIS, NIH Toolbox), fatigue, sleep disturbance, anxiety, and depression (PROMIS)	Those with moderate impairment (>1 SD above the mean) referred to appropriate specialty Further testing, referrals,
				followup visits as needed

Author, Year	Location of Disciplines	Intake Methods	Screening/Assessment	Post-Screening/Assessment Followup
Levin, 2023 <sup>26,27</sup> <i>See also:</i>	NR	Primary care referral	Assessment by a specialist nurse of PROMS, clinical assessment (30 second sit to stand, height, weight,	Repeat of baseline screenings/assessments
http://www.phsa.ca/our- services/programs-			BP), laboratory testing	Based on symptoms/individual needs, patients receive access
services/post-COVID-			Additional diagnostic testing for	to the most appropriate self-
19-care-network			hospitalized patients	<ul> <li>management supports and group learning opportunities:</li> <li>1. Online education modules (self-guided, publicly accessible)</li> <li>2. Clinic orientation video (PCRC participants)</li> <li>3. Symptom-specific virtual group education sessions (PCRC participants; self- registration)</li> <li>4. Targeted virtual group therapy sessions (PCRC participants; invitation only)</li> <li>5. One-on-one therapy (PCRC participants; invitation only)</li> </ul>
				Provincial clinic staff will facilitate If there is need for primary care or specialty consultation
Lutchmansingh, 2020 <sup>28</sup>	NR	Inpatients assessed pre- discharge	Telehealth visit that includes pulmonary consultation, symptom assessment, assessment for	<ol> <li>Followup doctor visits at 3, 6, and 12 months or as needed</li> <li>Extrapulmonary consultation</li> </ol>
		Outpatients with ongoing symptoms referred by	extrapulmonary complications	as needed 3. Rehabilitation: outpatient
		outpatient provider,	In-person visit that includes ongoing	physical / occupational therapy,
		occupational medicine, health system COVID-19 hotline, or self-referral	pulmonary care, physical and occupational therapy assessment, symptom assessment, neurocognitive	pulmonary rehabilitation 4. Lung function testing at 3, 6, and 12 months
			screening, mental health screening, additional subspecialty involvement as needed	5. Additional diagnostic testing as needed (e.g., cardiac testing, neurocognitive testing)

Abbreviations: COVID = coronavirus disease; CT = computed tomography; ECG = electrocardiogram; ED = emergency department; ICU = intensive care unit; GIM = general internal medicine; NR = not reported; PASC = Post-acute sequelae of COVID-19; PACT = The Johns Hopkins post-acute COVID-19 team; PCC = post-COVID care; PCP = primary care physician; PCRC = post COVID-19 recovery clinic; PM&R = physical medicine and rehabilitation; PROM = patient-reported outcome measure; PT = physical therapy; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2

Table H-1c. Long COVID models of care described in the published or grey literature (methods for coordinating services, primary care role, education, frequency of visits, teleservices, funding)

Author, Year	Methods for Coordinating Services	Primary Care Role	Education/Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Family Health Centers of San Diego, 2021 <sup>3</sup>	Unclear	Primary care based	Weekly teleECHO sessions, monthly interactive webinars, and quarterly short courses	3, 6, 9,12, 18, 24, 30 months for clinicians 3, 6, 9, and 12 months for patients (post- assignment to a participating clinician)	Half of participating clinicians will be randomized to receive TeleECHO sessions	NR; study sponsored by Family Health Centers of San Diego
Hitch, 2022 <sup>4</sup>	Supported Recovery stream: designated care coordinator Self-Managed stream: NR	NR	NR	NR	Incorporated into Supported Recovery and Self- Managed streams	NR; authors acknowledge challenges associated with sustained funding due to multidisciplinary nature of long COVID care
Ganesh, 2022 <sup>5</sup> Related publications: Vanichkachorm, 2021; Ganesh, 2022b	Member of General Internal Medicine or Preventive Medicine teams as needed	Primary care involvement varies according to clinic; Mayo Clinic Arizona coordinates PASC care through primary care clinics	PASC teams from Mayo Clinic Florida and Mayo Clinic Rochester have met with Mayo Clinic Arizona primary care clinics to disseminate knowledge and best practices	NR	Initial visit is virtual, subsequent visits may be in-person or virtual	NR
Ganesh, 2022b <sup>24</sup> <i>Related publication:</i> <i>Ganesh, 2022</i>	NR	NR	NR	For those with multiple organ systems, initial 30-minute evaluation For those with no evidence of tissue damage and likely central sensitization syndromes, 8-hour virtual treatment program	Some visits delivered virtually, depending on the patient phenotype	NR
Montani, 2021 <sup>6</sup>	Unclear; appears to be at least partially facilitated by medical officer	NR	NR	NR	Initial screening conducted by telephone	Unclear; study funding from Assistance Publique-Hôpitaux de Paris

Author, Year	Methods for Coordinating Services	Primary Care Role	Education/Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Chuang, 2023 <sup>8</sup>	Model 1 Case manager Model 2 Unclear	Model 1 NR Model 2 NR; "general practitioners play important roles"	NR	NR	NR	Model 1 NR Model 2 National Health Insurance (Taiwan)
Stallmach, 2023 <sup>9</sup>	Hospital-based nurse care coordinator	NR	NR	One 2.5 hour visit	NR	Grant-funded demonstration project
Manhas, 2022 <sup>10</sup>	Varies according to rehabilitation setting; for all settings "a central intake or transition and discharge coordinator should be embedded within existing services to identify rehabilitation needs"	"Patients may initiate follow-up with primary care at any time" "Unattached patients can connect with HealthLink to be attached to Primary Care"	NR	NR	Not specifically integrated but virtual support should be used as appropriate (e.g., telerehabilitation / mental health helplines)	Described as "cost neutral" leveraging existing care pathways and processes
Ahmad, 2022 <sup>11</sup>	NR	NR; PCC team provided recommendations to PCP following discharge from PCC clinic	NR	1 month followup for all PCC Center participants Additional followup at 2, 3, and 6 months if needed. Followup visits included full history and physical to address new or ongoing symptoms and offer referrals when appropriate	NR	NR
Morrow, 2021 <sup>12</sup>	NR	NR	NR	NR	Option for telehealth visit for neuropsychological exam	NR
Verduzco-Gutierrez, 2021 <sup>13</sup>	NR	NR	Weekly meetings to review literature and adapt best practices; no special training	NR	Initial telehealth evaluation conducted during lockdowns	Patient funding requirements: payor status or cash pay

Author, Year	Methods for Coordinating Services	Primary Care Role	Education/Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
	Services coordinated through PM&R team	NR	No formal special training	NR	Assessments described as occurring almost exclusively via telemedicine	NR; text states "this program design optimized access despite funding limitations"
						Patient funding requirements: all payors, including county health coverage
	NR; bimonthly meetings are held to provide care coordination	May refer patient to clinic; other role NR	No special training	Initial visit: 20 minutes per provider up to 90 minutes Followup: 2-3 months later (in person or virtual visit)	Initial visit is virtual, followup visit may be in-person or virtual	Patient funding requirements: VA benefits
	NR	Primary care initiated	Multidisciplinary group created treatment algorithm for use by PCPs	NR		NR
	University of Florida Clinical and Translational Science Institute	Symptom screening as needed	Training for PCPs on symptom screening and referral guidelines	1 hour initial consultation + return visits "over consecutive weeks" + 30 minute health coaching	Health coaching can be conducted in-person or teleheatlh	NR
Parker, 2021 <sup>14</sup>	NR	May conduct initial screening	NR	NR	Initial screening can be conducted remotely	NR
Harenwall, 2021 <sup>15</sup>	NR	NR	Training in "Recovering from COVID" 7-week rehabilitation course	Weekly for 1 hour for 7 weeks	Course is virtual	UK NHS
List, 2021 <sup>16</sup>	NR	Clinic is primary care based	NR	NR	NR	NR
Vanichkachorn, 2021 <sup>17</sup> Related publication: Ganesh, 2022	NR	NR	Occupational therapists staffing the clinic received "specific training" to help patients return to work	NR	Visits could take place in-person, via telemedicine or telephone	NR
Aiash, 2021 <sup>18</sup>	Allied health professional care coordinators	NR	NR	At least at month 1, 3 and 6	None	NR

Author, Year	Methods for Coordinating Services	Primary Care Role	Education/Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Parkin, 2021 <sup>19</sup>	Allied health professional care coordinators	NR beyond referral	NR	NR; outcome measures assessed at 8 weeks and 6 months	Review of patient questionnaire with the Pathway Coordinator conducted by phone	UK NHS
Santhosh, 2021 <sup>20</sup>	Unclear; outpatient clinic referral coordinators described as playing an essential role in educating and interfacing within patient teams, gathering relevant patient information,confirming referral qualifications, coordinating visit timing,and refining the referral process	Unclear; clinic goal is to support primary care	Stakeholders (ICU physicians, hospitalist and resident teams, case managers) were educated and engaged in several ways, including via communication with network directors, e-mails, PowerPoint presentations, virtual grand round attendance, media / website presence, and other forms of outreach Electronically housed and continually updated faculty development handbooks detailing literature updates, clinic workflow diagrams, and	Initially planned followup at 1, 3, 6, and 9 months, later changed to individualized followup plans with discharge to primary care when appropriate	Telephone visits offered to some patients; one OPTIMAL clinic was largely virtual for initial visits	NR

Author, Year	Methods for Coordinating Services	Primary Care Role	Education/Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Brigham, 2021 <sup>21</sup> Related publication: Santhosh, 2021	Unclear; outpatient clinic referral coordinators described as playing an essential role in educating and interfacing within patient teams, gathering relevant patient information,confirming referral qualifications, coordinating visit timing,and refining the referral process	Unclear; clinic goal is to support primary care	Stakeholders (ICU physicians, hospitalist and resident teams, case managers) were educated and engaged in several ways, including via communication with network directors, e-mails, PowerPoint presentations, virtual grand round attendance, media / website presence, and other forms of outreach Electronically housed and continually updated faculty development handbooks detailing literature updates, clinic workflow diagrams, and protocols were created	Initially planned followup at 1, 3, 6, and 9 months, later changed to individualized followup plans with discharge to primary care when appropriate	Most visits appear to have been telemedicine based	NR
Ladds, 2021 <sup>22</sup>	NR	Initial referral	NR	NR	NR	NR
O'Brien, 2021 <sup>23</sup>	Dedicated physician associate, with oversight from specialty consultants	Management of patients following discharge to integrated care	NR	NR	Initial visit is virtual	NR
Bailey, 2023 <sup>25</sup>	Clinic coordinator; patient liaison	NR	Unclear; screening conducted by "trained clinic staff"	NR; mean 1.3 (range 1 to 6)specialty clinics visited Frequency of specialty clinic referrals: 49% neurology 25% pulmonology 12% cardiology	In-person (51% [588/1151]) or telehealth allowed for initial visit (49% [563/1151])	NR

Author, Year Levin, 2023 <sup>26,27</sup> See also: http://www.phsa.ca/our- services/programs- services/post-COVID- 19-care-network	Methods for Coordinating Services Unclear; "If assessment identifies the need for a physician consultation as part the patient's recovery, provincial clinic staff will facilitate this, whether it be for more general	Primary Care Role Unclear; described as integrated with primary care	Education/Training for COVID Clinic Staff, Including Use of Protocols Unclear; "a provincially accessible accredited education program and a provincial physician "help- line" (both email and telephone-based) were established to support physicians"	Frequency/Intensity of Visits 3, 6, 12 and 18 months	Use of Teleservices In-person and virtual health visits	Clinic Funding PC-ICCN provincially funded; PCRCs funding unclear; "long-term sustainability of the PCRCs and broader network are unknown"
Lutchmansingh, 2020 <sup>28</sup>	medicine needs or sub-specialist need" NR	Transition to primary care following symptom resolution and normal pulmonary function tests	Multidisciplinary discussion of active cases, translational research efforts, revision of clinic processes to meet patient needs and evolving evidence	Followup at 3, 6, and 12 months as needed	Initial visit via telehealth	NR

Abbreviations: COVID = coronavirus disease; ICU = intensive care unit; NR = not reported; OPTIMAL = pOst-COVID-19/PosT- Icu MultidisciplinAry cLinic; PASC = Post-acute sequelae of COVID-19; PCC = post-COVID care; PCP = primary care physician; PCRC = post COVID-19 recovery clinic; PM&R = physical medicine and rehabilitation; VA = Veteran's Affairs

#### Table H-2. Details of review/survey studies

	Data Sources				
	Data Collection	Long COVID			
Author, Year	<ul> <li>Dates</li> <li>45 US-based long</li> </ul>	Definitions	Clinic Characteristics	Patient Characteristics	Other Findings
2022 <sup>29</sup>	COVID (PASC) clinics • March to May 2021		<ul> <li>New PASC clinic: 82% (37/45)</li> <li>Evolved from pre-existing clinic: 13% (6/45)</li> </ul>	<ul> <li>criteria</li> <li>No specific criteria: 42% (19/45)</li> <li>Specific time cines</li> </ul>	<ul> <li>Any barrier to care: 73% (33/45)</li> <li>Need for established protocols (treatment entioned)</li> </ul>
			Clinic home department • PM&R: 40% (18/45) • Pulmonology: 22% (10/45) • Internal medicine: 16% (7/45) • Family medicine: 4% (2/45)	<ul> <li>Specific time since acute illness: 42% (19/45)</li> <li>&lt; 1 month: 9% (4/45%)     </li> <li>1 to 2.9 months:     </li> </ul>	<ul> <li>protocols / treatment options: 45% (20/45)</li> <li>More clinical resources needed (staffing, physician, social work, case manager</li> </ul>
			<ul> <li>Physical therapy: 2% (1/45)</li> <li>Initial screening visit format</li> <li>Telehealth: 33% (15/45)</li> <li>In-person: 29% (13/45)</li> </ul>	<ul> <li>22% (10/45)</li> <li>3 months: 11% (5/45)</li> <li>Positive COVID test: 36% (16/45)</li> </ul>	<ul> <li>support): 24% (11/45)</li> <li>Patient access to behavioral health services: 11% (5/45)</li> </ul>
			<ul> <li>In-person or telehealth: 37% (17/45); primarily based on patient preference (29% [13/45])</li> <li>Specialty disciplines (PM&amp;R, pulmonology, internal medicine, family medicine, physical</li> </ul>	<ul> <li>Prior COVID hospitalization: 9% (4/45)</li> <li>Prior ICU admission</li> </ul>	
			therapy, occupational therapy, neuropsychology, neurology, psychology, speech language pathology, cardiology, psychiatry, social work, other)	<ul> <li>due to COVID: 9% (4/45)</li> <li>Other criteria: 18% (8/45)</li> </ul>	
			<ul> <li>Routinely involved in initial visit:         <ul> <li>1: 40% (18/45)</li> <li>2-5: 44% (20/45)</li> <li>6-10: 13% (6/45)</li> <li>&gt;10: 2% (1/45)</li> </ul> </li> </ul>		
			<ul> <li>Available at initial visit         <ul> <li>1: 27% (12/45)</li> <li>2-5: 31% (14/45)</li> <li>6-10: 31% (14/45)</li> <li>&gt;10: 11% (5/45)</li> </ul> </li> </ul>		
			<ul> <li>Followup visits</li> <li>Routinely scheduled: 76% (34/45)</li> <li>On patient request: 22% (10/45)</li> </ul>		
			Formal interdisciplinary meetings to discuss cases • Yes: 49% (22/45) • No: 51% (23/45)		

	Data Sources Data Collection	Long COVID			
Author, Year	Dates	Definitions	Clinic Characteristics	Patient Characteristics	Other Findings
Decary, 2022 <sup>34</sup>	<ul> <li>19 primary studies identified through MEDLINE, Embase, Web of Science, Cochrane COVID-19 Registry, and CCRCT searches</li> <li>Databases searched from inception to April 2022</li> </ul>		<ul> <li>Clinic components</li> <li>Multidisciplinary teams: 95% (18/19)</li> <li>Continuity or coordination of care: 58% (11/19)</li> <li>Patient-centered / shared decision-making: 53% (10/19)</li> <li>Integrated care: 53% (10/19)</li> <li>Evidence-based care: 42% (8/19)</li> <li>Guided self-management: 42% (8/19)</li> <li>Patient needs assessment: 42% (8/19)</li> <li>Case management: 37% (7/19)</li> <li>Patient education: 32% (6/19)</li> <li>Camunity of practice: 26% (5/19)</li> <li>Patient navigator: 11% (2/19)</li> <li>Patient navigator: 11% (2/19)</li> <li>Patient navigator: 11% (2/19)</li> <li>Asynchronous care: 5% (11/19)</li> <li>Clinic functions</li> <li>Standardized symptom assessment / screening: 100% (19/19)</li> <li>Telehealth and/or virtual care: 74% (14/19)</li> <li>Follow-up system: 68% (13/19)</li> <li>Referral system: 63% (12/19)</li> <li>Social determinants of health assessment: 26% (5/19)</li> <li>Clinical information system: 21% (4/19)</li> <li>Patient support groups: 16% (3/19)</li> </ul>	NR	NR

	Data Sources Data Collection	Long COVID			
Author, Year	Dates	Definitions	Clinic Characteristics	Patient Characteristics	Other Findings
Health Information and Quality Authority (Ireland), 2022 <sup>31</sup>	<ul> <li>Guidelines (n=24) and models of care (n=2) identified through website and grey literature searches</li> <li>August to September 2022</li> </ul>	<ul> <li>Guideline-based definitions</li> <li>Symptoms that persist ≥4 weeks following acute COVID: 58% (14/24)</li> <li>Symptoms persisting for ≥12 weeks post-infection: 21% (5/24)</li> <li>NICE definition (ongoing symptomatic COVID-19 [4-12 weeks] and post-COVID syndrome [&gt;12 weeks]): 17% (4/24)</li> <li>WHO definition (continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation): 8% (2/24)</li> <li>No explicit timeline: 13% (3/24)</li> </ul>		NR	NR

Data Sources				
	Long COVID	Olivia Oberestariation	D-tiont Oberneteriation	
	Definitions	Clinic Characteristics		Other Findings
CADTH Health Technology Reviews (2022) <sup>32</sup> • Published (MEDLINE) and grey literature searches; survey of 25 Canadian post-COVID clinics • October to November 2022	NR	<ul> <li>Clinic type (clinics could be multiple types)</li> <li>Unit (dedicated ward or center that provides services at 1 location): 28% (7/25)</li> <li>Coordinated effort (care not limited</li> <li>to specific centers or spaces providing integrated care and support across</li> <li>different specialists): 36% (9/25)</li> <li>Program (a set of services providing dedicated care across multiple centers or locations: 12% (3/25)</li> <li>General chronic care support (care provided for different health conditions, including but not dedicated only to post–COVID-19 condition): 8% (2/25)</li> <li>Clinic setting/affiliation</li> <li>Hospital only: 17% (4/23)</li> <li>Primary care only: 4 (1/23)</li> <li>Academic only: 9% (2/23)</li> <li>Hospital and primary care: 4% (1/23)</li> <li>Hospital and academic: 52% (12/23)</li> <li>Hospital, academic and primary care: 13% (3/23)</li> <li>Clinic provincial jurisdiction</li> <li>Alberta: 12% (3/25)</li> <li>British Columbia: 4% (1/25)</li> <li>New Brunswick: 8% (2/25)</li> <li>Ontario: 44% (11/25)</li> <li>Quebec: 32% (8/25)</li> <li>Clinic components (reported by provincial jurisdiction [n=5])</li> <li>Virtual/telehealth: 100% (5/5)</li> <li>Integrated referral/care pathway: 3/5</li> <li>Followup system: 100% (5/5)</li> <li>Home-based care: 0% (0/5)</li> <li>Patient needs assessment: 100% (5/5)</li> </ul>	<ul> <li>Population served</li> <li>Age ≥18 years: 85% (17/20)</li> <li>Age 16 to 90 years: 5% (1/20)</li> <li>Any age: 10% (2/20)</li> <li>Eligibility/inclusion criteria (patients could meet multiple criteria)</li> <li>Probable or confirmed COVID-19 and persistent symptoms for ≥4 to 12 weeks that cannot be explained by another illness: 52% (13/25)</li> <li>Physician referral: 40% (10/25)</li> <li>Patient needs at least 2 health disciplines for treatment: 8% (2/25)</li> <li>Patient willing to participate in group interventions: 4% (1/25)</li> </ul>	

	Data Sources Data Collection	Long COVID			
	Dates	Definitions	Clinic Characteristics	Patient Characteristics	Other Findings
CADTH Health Technology			Clinic staffing (reported by provincial jurisdiction [n=4]; one jurisdiction did not report		
Reviews			data)		
(2022) <sup>32</sup>			<ul> <li>Physicians (various specialties): 100% (4/4)</li> </ul>		
(Continued)			<ul> <li>Nurse practitioner or registered nurse: 100% (4/4)</li> </ul>		
			<ul> <li>Care coordinator/health navigator: 50% (2/4)</li> </ul>		
			<ul> <li>Social worker: 100% (4/4)</li> </ul>		
			<ul> <li>Respiratory therapist: 50% (2/4)</li> </ul>		
			<ul> <li>Physiotherapist: 100% (4/4)</li> </ul>		
			<ul> <li>Occupational therapist: 100% (4/4)</li> </ul>		
			<ul> <li>Physiatrist: 25% (1/4)</li> </ul>		
			<ul> <li>Dietician: 25% (1/4)</li> </ul>		
			<ul> <li>Psychologist: 25% (1/4)</li> </ul>		
			<ul> <li>Speech language pathologist: 25% (1/4)</li> </ul>		

Abbreviations: CAIRO = Critical and Acute Illness Recovery Organization; COVID = coronavirus disease; ECMO = extracorporeal membrane oxygenation; ENT = otolaryngology; ICU = intensive care unit; PASC = Post-acute sequelae of COVID-19; PM&R = physical medicine and rehabilitation; NICE = National Institute for Health and Care Excellence; NR = not reported; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2; WHO = World Health Organization

\*Other referral criteria: social determinants of health, surgical ICU survivors, respiratory failure requiring high-flow nasal cannula, mechanical ventilation >4 days, fragility

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# Appendix I. Details of Models Described by Key Informants

	Model		Country	
Key Informant, Title	Description/Name	Model Location and Organization	Setting	Long COVID Definition/Criteria
Jonathan Whiteson, MD (Assistant Professor of Physical Medicine & Rehabilitation, NYU School of Medicine)	NYU post-COVID Care Program Doctors in Manhattan, Brooklyn, the Bronx, and Long Island	Patients are first seen in the Pulmonary division. All patients are evaluated by a NP and then referred out based on patient complaints and needs for specialty care. Patients stay with specialists and do not get referred back out to primary care. Telehealth is utilized by patients with significant disabilities.	US NYU Division of Pulmonary Medicine (academic medical center)	COVID symptoms or related health problems persisting at least 4 weeks after initial infection. Treatment at this program does not require proof of a positive COVID test.
Trevor Hall, PsyD (Associate Professor of Pediatrics, Oregon Health & Science University School of Medicine)	OHSU Pediatric Critical Care and Neurotrauma Recovery Program	Any child presenting to the ICU is offered an opportunity to follow up at the Pediatric Critical Care and Neuro-trauma Recovery Program in the Department of Pediatrics. There are systematic referrals if there is brain involvement. The program is an integrated clinic with a neuro-intensivist and an ICU critical care physician. Children who need specialty care are referred out. Primary care is utilized as much as possible.	US OHSU Pediatric Critical Care and Neuro-trauma Recovery Program, housed in the Department of Pediatrics (academic medical center)	No specific criteria being used before referral
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa) <sup>a</sup>	VA Model #1: Multidisciplinary team	"Veterans are referred to a centralized multidisciplinary team that uses a Whole Health system approach to evaluate, coordinate, and provide care to Veterans with Long COVID through telehealth technology, in-person visits or both." It is a standalone clinic, but can be housed in a specialty clinic, e.g., a neurology clinic (as opposed to a separate building).	US VA	VAs use CDC's definition (symptoms persisting for 4 weeks or longer), though there is some talk about changing the definition. Some clinics use a 12 week timeframe instead.

#### Table I-1a. Details of models described by Key Informants (name, organization, setting, definition)

	Model		Country	
Key Informant, Title	Description/Name	Model Location and Organization	Setting	Long COVID Definition/Criteria
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	VA Model #2: Long COVID Clinic	"Veterans are referred to a Long COVID Clinic that uses a Whole Health system approach to evaluate, manage, and coordinate Long COVID care through decentralized referrals to specialists using telehealth technology, in-person visits or both." Similar to a primary care clinic where patients can be referred out to specialists. Specialists are not contained within this model.	US VA	VAs use CDC's definition (symptoms persisting for 4 weeks or longer), though there is some talk about changing the definition. Some clinics use a 12 week timeframe instead.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	Iowa City Veterans Affairs Long COVID Clinic	The clinic is housed in the pulmonology department and has joined efforts with the neurology department. The organization is consistent with VA Model #2, which is a clinic that could be housed anywhere (e.g., primary care, pulmonary care, rehab), but the key is that the clinic is run in one place. Veterans are referred and then providers can refer out as needed.	US Iowa City VA	At least three months after acute infection.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	VA Model #3: Long COVID Clinic and Board (proposed model not in practice yet)	"Veterans are referred to a Long COVID Clinic that uses a Whole Health system approach to evaluate, coordinate and deliver care to Veterans with Long COVID using telehealth technology, in-person visits or both. A Board, comprised of Specialists, provides consultation and guidance to the clinical care being delivered by the Long COVID Clinic." Model is run by an APP and is meant for rural areas that do not have as many providers. The APP presents cases to specialists similar to a tumor board. The specialists are only talking with the APP, not the veteran, either in person or via telecommunication.	US VA	VAs use CDC's definition (symptoms persisting for 4 weeks or longer), though there is some talk about changing the definition. Some clinics use a 12 week timeframe instead.

	Model		Country	
Key Informant, Title	Description/Name	Model Location and Organization	Setting	Long COVID Definition/Criteria
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, DivisiNeuro- Otology, University of Iowa)	VA Model #4: Long COVID Hub and Spoke	"An established Long COVID program at a hub site provides long COVID care at their local VAMC and to spoke sites (other VAMCs) through telehealth technology, in- person visits or both." Patients are mainly seen at "spokes" and are referred to the hub if need.	US VA	VAs use CDC's definition (symptoms persisting for 4 weeks or longer), though there is some talk about changing the definition. Some clinics use a 12 week timeframe instead.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	VA Model #5: National Tele-E- Consultation for Long COVID	"Nationwide Long COVID telehealth e- consultative care available as a safety net service to qualified VAMCs and VISNs without ready access to long COVID care. Long COVID tele-e-consultation is provided to clinicians through an eConsultation process." Model is meant as a safety net for patients who do not have access to VA models 1 through 4.	US VA	VAs use CDC's definition (symptoms persisting for 4 weeks or longer), though there is some talk about changing the definition. Some clinics use a 12 week timeframe instead.
Sarah Jolley, MD (Assistant Professor of Medicine-Pulmonary Sciences & Critical Care, University of Colorado)	Co-located, integrated clinic Post COVID clinic, University of Colorado	The clinic is based out of the Center for Lungs and Breathing. They have created a separate multidisciplinary clinic within the broader CLB. The clinic is overseen by Dr. Jolley and the multispecialty medicine practice administrator for UCHealth.	US University of Colorado (academic medical center)	Their clinic uses the CDC definition for Long COVID which recognizes the lack of available testing early in the pandemic.
Peter Rowe, MD (Professor of Pediatrics, Johns Hopkins, Director, Children's Center Chronic Fatigue Clinic)4	Pediatric Chronic Fatigue Syndrome Clinic at Johns Hopkins	Dr. Rowe runs this one-person clinic with no administrative help. It is located within the Johns Hopkins health system.	US John Hopkins, Children's Center Chronic Fatigue Clinic (academic medical center)	Clinic is originally for children with ME/CFS, but Dr. Rowe has seen an influx of long COVID patients who present with near identical symptoms.
Benjamin Abramoff, MD, MS (Assistant Professor of Clinical Physical Medicine and Co-Founder and Co- Director of COVID Recovery Clinic)	Penn Medicine COVID Recovery Clinic	The clinic is based in the physiatry department. Patients start at this clinic and then go on to other post COVID clinics (e.g., neurology, pulmonology, and cardiology post COVID clinics).	US Penn Medicine COVID Recovery Clinic (academic medical center)	NR

	Model		Country	
Key Informant, Title	Description/Name	Model Location and Organization	Setting	Long COVID Definition/Criteria
Sarah De Ferranti, MD, MPH (Chief, Division of Ambulatory Cardiology, Associate Professor of Pediatrics, Harvard Medical School)	Division of Outpatient Cardiology, Boston Children's Hospital	The infectious disease group at Boston Children's Hospital set up a program involving a nurse practitioner, a clinician, and a physician who does the intake. Patients are then referred to specialists, including Dr. De Ferranti.	US Division of Outpatient Cardiology, Boston Children's Hospital (academic medical center)	NR
David Putrino, PhD, PT (Director of Rehabilitation Innovation for the Mount Sinai Health System, Professor in the Department of Rehabilitation and Human Performance at the Icahn School of Medicine at Mount Sinai)	Center for Recovery from Complex Chronic Illness, Mt. Sinai	They are a hybrid clinical and research center, considered an outpatient clinical space, housed in the FPA center, attached to the main Mt. Sinai campus. Within the FPA building, a wide variety of specialty care providers are available. Physiatry leads the majority of patient interactions, using multidisciplinary coordination, paired with rehabilitation approaches	US Mt. Sinai Hospital (academic medical center)	Their center uses the WHO definition (3 months from initial acute infection, including confirmed and probable cases. Patients are accepted with or without a positive PCR antibody test.
Laura Malone, MD, PhD (Co-Director, Pediatric Post-COVID-19 Rehabilitation Clinic, Kennedy Krieger Institute, Physician Scientist, Kennedy Krieger's Center for Movement Studies, Assistant Professor, Neurology and Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine)	Pediatric Post- COVID-19 Rehabilitation Clinic, Kennedy Krieger Institute	Integrated, multidisciplinary, outpatient clinic with satellite specialty clinics. Co- director is a pediatric rehabilitation doctor. They work closely with one to two providers who direct any additional referrals to within the Kennedy Krieger Johns Hopkins network, including psychiatry, gastrointestinal, pulmonology, and other common specialties.	US Kennedy Krieger Institute (academic medical center)	CDC's definition (4 weeks) but do not require a positive test.
Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System) <sup>a</sup>	Virtual clinic for Veterans in San Antonio, Texas	Clinic is fully virtual consisting of one full time physician, five nurses, two psychologists, pulmonary nurse practitioners, and one administrator. Nursing staff actively reach out to patients who are at least 4 weeks post a positive COVID test to see if they have any lingering symptoms. If the person has had symptoms for more than 4 weeks and screen positive for long COVID symptoms, the patient can be seen virtually.	US Virtual	CDC's definition

	Model		Country	
Key Informant, Title	Description/Name	Model Location and Organization	Setting	Long COVID Definition/Criteria
Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System)	"VA Hub and Spoke Model"	A telehealth service agreement that allows Dr. Trinh and staff to see patients at other health care systems. The core team includes three physicians, 11 nurses, two psychologists, and three administrators who work with the VA facility.	US VA and virtual	CDC's definition
Monica Verduzco- Gutierrez, MD (Professor and Chair, Department of Rehabilitation Medicine at the Long School of Medicine at UT Health San Antonio) Summer Rolin, PsyD (Assistant Professor of Rehabilitation Medicine, UT Health San Antonio)	UT San Antonio Post COVID Recovery Clinic	A clinic in San Antonio Texas that is based in PM&R. Dr. Verduzco-Gutierrez does all managing and patient coordination herself. After workup is initiated, the patient is referred to providers in the institute such as pulmonology and neurology, and other providers in the community such as rehabilitation, all who are long-COVID literate. They developed a COVID pathway in their medical electronic records so that when a patient reports certain symptoms, it triggers a referral to the appropriate provider.	US University of Texas San Antonio (academic medical center)	Eligibility is kept open. They do not require a positive test. Often it takes patients months to get into the clinic, so they are already having symptoms for over 3 months (closer to WHO definition).
Karyn Bishof (Founder of COVID-19 Longhauler Advocacy Project, Founding Member of Long COVID Alliance)	Proposed model from COVID-19 Longhauler Advocacy Project	Comprehensive post-COVID care center	US Standalone clinic	HHS's definition currently. Likely NASEM definition when it becomes available
Yochai Re'em, MD (Clinical Assistant Professor of Psychiatry, Assistant Attending Psychiatrist, Weill Cornell Medicine)	Private practice psychiatry clinic in New York that sees long COVD patients	Individual provider private practice psychiatry clinic run by Dr. Re'em. It is a hybrid of online and in person.	US Private practice	A patient's presentation and history is used as a guide for deciding whether or not they meet long COVID criteria. He also uses the WHO definition, but it is not his primary guide.
Boris Bayerman, DO (Family Medicine Specialist, Kaiser Permanente Colorado)	Kaiser Long COVID Clinic (pilot)	A Kaiser clinic seeking to integrate primary care into long COVID care management. Included are a family medicine doctor, therapist, social worker, and nurse care coordinator.	US Kaiser Permanente	CDC's definition (4 weeks)

Abbreviations: AAP = American Academy of Pediatrics; CDC = Center for Disease Control; COVID = coronavirus disease; FPA = Faculty Practice Associates; HHS = Health and Human Services; ICU = intensive care unit; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NASEM = National Academies of Sciences, Engineering, and Medicine; NP = nurse practitioner; NYU = New York University; OHSU = Oregon Health & Science University; PCR = polymerase chain reaction; PM&R = physical medicine and rehabilitation; PT = physical therapy; UT = University of Texas; VA = Veteran's Affairs; VAMC = Veteran's Affairs Medical Center; WHO = World Health Organization. <sup>a</sup> These Key Informants described more than one model of care. There is some overlap between the different models they described.

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Jonathan Whiteson, MD (Assistant Professor of Physical Medicine & Rehabilitation, NYU School of Medicine)	Adults No ability to see uninsured people.	Pulmonary care, pulmonology, cardiology, neurology, mental health, physiatry.	The Long COVID care program is housed in the NYU Division of Pulmonary Medicine. Referrals are made to nearby departments, though all specialists are physically separate. Telehealth is utilized as needed.	Initial intake is in person – they transitioned from telehealth as they collect blood and recruit to their research registry on the first visit. Telehealth is available if patients cannot come in. The intake is done by an NP assigned to the clinic and to triage further subspecialty referrals as needed. Patients make it into the clinic via self-referral, primary care referral, active follow up, etc.
Trevor Hall, PsyD (Associate Professor of Pediatrics, Oregon Health & Science University School of Medicine)	Pediatrics in the Critical Care and Neurotrauma Recovery Program with long COVID after they have been referred by the pediatric infectious disease team Model not restricted to children with long COVID	Infectious disease and physical therapy are at the center and other specialties (i.e., rheumatology, cardiology, neurology, etc.) are referred to as needed. In the clinic (Pediatric Critical Care and Neurotrauma Recovery Program) there is a pediatric intensivist and a pediatric neuropsychologist. Other specialties included in the model are pediatric neurology, developmental pediatrics, pediatric psychology, physical therapy, speech-language pathology, occupational therapy, critical care, neurology, neurophysiology, neuropsychology.	The Pediatric Critical Care and Neurotrauma Recovery Program is housed in the Department of Pediatrics. This program collaborates with multidisciplinary experts throughout the OHSU system.	All children presenting to the ICU are offered an opportunity to follow up at the Pediatric Critical Care and Neurotrauma Recovery Program.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa) <sup>a</sup>	Veterans	Cardiology, neurology, pulmonology, physiatry, mental health, others as needed	The multidisciplinary care team is located in one place, but outside referrals are given as needed.	Patients are referred to this clinic by an outside clinician, direct veteran outreach, or veteran self- referral.

#### Table I-1b. Details of models described by Key Informants (population served, disciplines included, location, intake methods)

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Deema Fattal, MD (Chief	Veterans	Cardiology, neurology, pulmonology,	Referral to external specialists.	Patients are referred to this clinic
of Neurology, VAMC,		physiatry, mental health, others as		by an outside clinician, direct
Neurology, Iowa City,		needed.		veteran outreach, or veteran self-
Iowa; VISN23 Neurology				referral.
Representative to				
National VA Neurology				
Field Advisory Board;				
Clinical Professor of				
Neurology, Departments				
of Neurology and				
Otolaryngology				
Department, Division of				
Neuro-Otology,				
University of Iowa)				
Deema Fattal, MD (Chief	Veterans	Pulmonology and neurology; other	Referral to external specialists.	Patients are referred to this clinic
of Neurology, VAMC,		disciplines involved as needed.		by an outside clinician or by self-
Neurology, Iowa City,				referral.
lowa; VISN23 Neurology				
Representative to				
National VA Neurology				
Field Advisory Board;				
Clinical Professor of				
Neurology, Departments				
of Neurology and				
Otolaryngology				
Department, Division of				
Neuro-Otology,				
University of Iowa)				
Deema Fattal, MD (Chief	Veterans	Long COVID board is comprised of	The APP presents long COVID	Patients are referred to this clinic
of Neurology, VAMC,		specialists in cardiology, neurology,	cases to specialists via	by an outside clinician, direct
Neurology, Iowa City,		pulmonology, physiatry, mental health,	telecommunication. Specialists	veteran outreach, or veteran self-
lowa; VISN23 Neurology		and others.	can be located anywhere.	referral.
Representative to			,	
National VA Neurology				
Field Advisory Board;				
Clinical Professor of				
Neurology, Departments				
of Neurology and				
Otolaryngology				
Department, Division of				
Neuro-Otology,				
University of Iowa)				

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	Veterans	There are no requirements for subspecialties at the spokes. Community care referral is another possibility.	One large hub and multiple smaller spokes that are geographically separate but ale to tele-communicate both inside and outside the area.	Intake methods vary (self-referral, primary care referral, active follow up of COVID patients, etc.). Model is meant to be flexible.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	Veterans	Cardiology, neurology, pulmonology, physiatry, mental health, others as needed.	Primary care doctors who have long COVID patients (or who have questions about long COVID) submit an e-consult to a group of long COVID specialists around the country. Ideally, the specialists would respond within three days to answer the question.	Patients are referred to this program by an outside clinician, direct veteran outreach, or veteran self-referral.
Sarah Jolley, MD (Assistant Professor of Medicine-Pulmonary Sciences & Critical Care, University of Colorado)	Adults Patients are asked about insurance but are able to schedule without insurance and opt for self-pay or utilization of the hospital's financial assistance program that allows for subsidized care for uninsured or underinsured patients.	Pulmonary critical care, integrative medicine, cardiology, a physiatrist, a physical therapist whose focus is in post- exertional malaise, and an occupational therapist who is interested in strategies for post-COVID cognitive issues	Pulmonary critical care, integrative medicine, rehab medicine, cardiology, a physiatrist, a physical therapist whose focus is in post- exertional malaise, and an occupational therapist who is interested in strategies for brain fog are co-located in clinic. There is a neurologist and mental health team that they consult outside of the clinic and preferentially send patients to.	Most of the referrals come from internal and external provider referrals. Provider referrals come from primary care and subspecialists. Referrals come from across health systems including many of the health systems in Colorado and the Veteran's Affairs Hospital. Hospitalized patients may be referred by inpatient providers. Patients can also self-refer, but these are a minority of the current patients.

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Peter Rowe, MD (Professor of Pediatrics, Johns Hopkins, Director, Children's Center Chronic Fatigue Clinic)	Children who meet the criteria for ME/CFS. Some children started out at this clinic 25 years ago and are still being seen due to lack of adult clinics. Clinic is funded	One person clinic	In clinic	Pediatric patients who meet the criteria for ME/CFS are referred.
	philanthropically.			
Benjamin Abramoff, MD, MS (Assistant Professor of Clinical Physical Medicine and Co- Founder and Co-Director of COVID Recovery Clinic)	NR	Physiatry, PM&R, neurology, pulmonology, cardiology, physical therapy, speech therapy, occupational therapy.	In clinic and referral to other clinics	NR
Sarah De Ferranti, MD, MPH (Chief, Division of Ambulatory Cardiology, Associate Professor of Pediatrics, Harvard Medical School)	NR	NR	There is a close relationship with specialists, but they are not co-located.	Physician does intake and then refers to specialists
David Putrino, PhD, PT (Director of Rehabilitation Innovation for the Mount Sinai Health System, Professor in the Department of Rehabilitation and Human Performance at the Icahn School of Medicine at Mount Sinai)	Adults and children in separate centers Most patients are insured. Under insured or noninsured patients are put on a waitlist, and physicians see a couple non-insured patients per week, pro bono	The center itself consists of physiatry plus allied health - speech, OT and PT, and close ties to neuropsychology for severe cognitive impairment. They are in the process of building a social worker component. Patients can be referred out to other specialists within the building (the top five specialties that receive referrals are cardiology, pulmonology, gastroenterology, serology, and occasionally neurology)	The clinic is located in the FPA center, attached to the main Mt. Sinai campus. Within the FPA building, a wide variety of specialty care providers are available, making referrals easy.	The referrals are a mix of self- referral, referral from the center for post-COVID care that is primary care-led and engages in active follow-up of COVID-19 patients.

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Laura Malone, MD, PhD (Co-Director, Pediatric Post-COVID-19 Rehabilitation Clinic, Kennedy Krieger Institute, Physician Scientist, Kennedy Krieger's Center for Movement Studies, Assistant Professor, Neurology and Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine)	Pediatrics Insured, applying for funding to help with uninsured population	Pediatric neurology and pediatric rehabilitation, behavioral psychology, social workers, and physical therapy.	Pediatric neurology and pediatric rehabilitation, behavioral psychology, social workers, and physical therapy are in clinic. Patients are referred to specialists in the Kennedy Krieger Johns Hopkins network as needed.	Most commonly either self-referral or another physician referral (either PCP or within the healthcare system).
Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System) <sup>a</sup>	Veterans in South Texas	Psychology and pulmonology located in clinic, with associations with cardiology, speech, social work, and whole health. Also associated is a vestibular audiologist, a tinnitus audiologist, and a dietician, as well as pharmacy, chaplaincy, immunology, neurology, and PM&R.	MDs/NPs/RNs/Psychologists are all at home, the program support assistants are in the office. The other specialty disciplines are in outpatient clinics.	Nursing staff actively reach out to patients who are at least 4 weeks post a positive COVID test to see if they have any lingering symptoms. If the person has had symptoms for more than 4 weeks and screen positive for long COVID symptoms, the patient can be seen virtually. In South Texas, they have over 17,000 COVID-positive veterans, and the staff have screened around 90% of those patients through direct phone calls and letters.
Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System)	Veterans in South Texas, both urban and rural who have benefits through the VA	Psychology, nurses, MD/DOs.	Doctors, psychologists, nurses, and administrators are located at the hub VA. Spoke sites are where patients are located. They are seen in their home.	The nurses perform the initial active outreach and during that time, will also screen the veteran for long COVID symptoms. They are able to access a list of veterans who have a history of COVID19 (National Surveillance Tool and CDW(Corporate Data Warehouse)). From the list, they call the veterans who are at least 4 weeks post COVID, then screen.

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Monica Verduzco- Gutierrez, MD (Professor and Chair, Department of Rehabilitation Medicine at the Long School of Medicine at UT Health San Antonio) Summer Rolin, PsyD (Assistant Professor of Rehabilitation Medicine,	Primarily adults (there is a pediatric rehab medicine doctor who will see some individual kids) and Dr. Verduzco-Gutierrez will occasionally see older adolescents. Non-insured patients have to cash pay. Underinsured are	<b>Disciplines Included in Model</b> The model is primarily housed in PM&R clinic but they make asynchronous referrals to specialists who have been taking care of people with Long COVID in their subspecialty (neurology helps with POTS and neuromuscular diagnosis, pulmonary takes care of ILD, etc.)	Location of Disciplines Patients can be referred within the institute such as pulmonology and neurology, or to other providers in the community such as rehabilitation, all who are long- COVID literate.	Intake Methods Self-referral of referral from anywhere in the community.
	Large Hispanic population, many of whom have insurance, but some do not.			

Key Informant, Title	Population Served	Disciplines Included in Model	Location of Disciplines	Intake Methods
Karyn Bishof (Founder of COVID-19 Longhauler Advocacy Project, Founding Member of Long COVID Alliance)	Adults and pediatrics With or without insurance, underserved populations	Neurology with many sub-specialties, cardiology, including those familiar with autonomic dysfunction and inflammatory conditions of the heart, infectious disease doctors who are familiar with viral persistence, post-viral and post-infectious illness, hematology and oncology, rheumatology, immunology, allergy geneticists, especially those familiar with connective tissue diseases, gastroenterology, including motility specialists, including eosinophilic esophagitis and urinary incontinence, those familiar with autonomic dysfunction and inflammatory disorders, pulmonology, respiratory therapist and rehab, reproductive health, sex specialists, obstetrics and gynecology, urology, endocrinology, and nephrology, otolaryngology, head and neck surgeons, speech therapists, sleep specialists, pain specialists, PM&R, and mental health professionals, especially those with experience in complex chronic illness and CPTSD and PTSD.	Disciplines co-located within one clinic. All services would be in house, with referrals to specialists as needed.	Referrals are not required. Intake would start with the patient preloading the comprehensive post-COVID care center with all of their medical records, which will be reviewed by the center, and the center will determine what specialists need to be part of that patient's care team.
Yochai Re'em, MD (Clinical Assistant Professor of Psychiatry, Assistant Attending Psychiatrist, Weill Cornell Medicine)	Adults Dr. Re'em does not accept insurance, but bills through Headway, a tool that allows one to be a service- rendering provider as opposed to a billing provider operating within a virtual clinic.	Psychiatry, with referral to other providers in the area at Columbia and Cornell universities.	Patients with non-psychiatric symptoms are referred to external clinics.	Combination of referral from other psychologists/psychiatrists, referral from non-mental health specialists with long COVID focus, primary care, and self-referral.
Boris Bayerman, DO (Family Medicine Specialist, Kaiser Permanente Colorado)	Adults in the Kaiser system Services are billed through insurance	Family medicine, with referrals to other specialties within the Kaiser system (e.g., speech therapy, physical therapy)	Disciplines are located within the Kaiser system. Some are located within the same building and some are in outside Kaiser clinics.	Family doctor and nurse care coordinator screen patients

Abbreviations: AAP = American Academy of Pediatrics; COVID = coronavirus disease; CPTSD = complex post-traumatic stress disorder; DO = doctor of osteopathic medicine; FPA = Faculty Practice Associates; ICU = intensive care unit; ILD = interstitial lung disease; MD = medical doctor; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NP = nurse practitioner; NR = not reported; NYU = New York University; OHSU = Oregon Health & Science University; OT = occupational therapy; PM&R = physical medicine and rehabilitation; POTS = postural orthostatic tachycardia syndrome; PT = physical therapy; PTSD = post-traumatic stress disorder; UT = University of Texas; VA = Veteran's Affairs; VAMC = Veteran's Affairs Medical Center.

<sup>a</sup> These Key Informants described more than one model of care. There is some overlap between the different models they described.

Table I-1c. Details of models described by Key Informants (screening, post-screening, methods for coordinating service, primary care role)

Key Informant, Title	Screening/Assessment	Post-Screening/Assessment Followup	Methods for Coordinating Services	Primary Care Role
Jonathan Whiteson, MD (Assistant Professor of Physical Medicine & Rehabilitation, NYU School of Medicine)	NPs take health history and discuss symptoms	After first appointment, patients are referred to nearby post- COVID specialists, where a full evaluation is done and a treatment plan is created.	The NP who does the intake coordinates sub-specialty referrals. All the treating team members use a common EMR and communicate through that EMR to discuss cases, request evaluations etc. the clinic has a dedicated administrator who manages logistic issues.	Not directly involved
Trevor Hall, PsyD (Associate Professor of Pediatrics, Oregon Health & Science University School of Medicine)	Most patients have a joint visit with a pediatric critical care doctor and a pediatric neuropsychologist. Some patients, depending on needs, meet with a pediatric neurologist or developmental pediatrician. This first appointment lasts one to two hours.*	After 4 to 6 weeks post-discharge, Dr. Hall sees children for a brief cognitive and emotional exam. Long-term recovery followup includes a treatment plan with specialists tailored to the child's specific needs.	Coordinated by the infectious disease and physical therapy teams.	The department prioritizes involving primary care when possible.
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro- Otology, University of Iowa) <sup>a</sup>	Taken from OHSU webpage Nurses perform screening, vitals, and care management and coordination.	Patients are followed up by specialists located within the multidisciplinary team, or referred out, or switch to community care as needed.	Medical support assistant and nurses are responsible for scheduling and coordination	The main role of primary care is referring patients to the clinic.

Key Informant,		Post-Screening/Assessment	Methods for Coordinating	
Title	Screening/Assessment	Followup	Services	Primary Care Role
Deema Fattal, MD	Nurses perform screening,	Care is managed through	Medical support assistant and	Can be housed in primary care.
(Chief of Neurology,	vitals, and care management	decentralized referrals to	nurses are responsible for	
VAMC, Neurology,	and coordination.	specialists using telehealth, in-	scheduling and coordination	
lowa City, lowa;		person visits, or both.		
VISN23 Neurology				
Representative to				
National VA				
Neurology Field				
Advisory Board;				
Clinical Professor of				
Neurology,				
Departments of				
Neurology and				
Otolaryngology				
Department,				
Division of Neuro-				
Otology, University				
of Iowa)				
Deema Fattal, MD	Nurses perform screening,	Care is managed through	Medical support assistant and	NR
(Chief of Neurology,	vitals, and care management	decentralized referrals to	nurses are responsible for	
VAMC, Neurology,	and coordination.	specialists using telehealth, in-	scheduling and coordination.	
lowa City, Iowa;		person visits, or both.		
VISN23 Neurology				
Representative to				
National VA				
Neurology Field				
Advisory Board;				
Clinical Professor of				
Neurology,				
Departments of				
Neurology and				
Otolaryngology				
Department, Division of Neuro-				
Otology, University				
of lowa)				

Key Informant, Title	Saraaning/Accessment	Post-Screening/Assessment	Methods for Coordinating	Brimany Caro Bolo
Deema Fattal, MD	Screening/Assessment	Followup The long COVID board provides	Services	Primary Care Role
(Chief of Neurology,	Nurses perform screening, vitals, and care management	instructions to the AAP, who can	Medical support assistant and nurses are responsible for	Can be housed in primary care.
VAMC, Neurology,	and coordination.	then refer patients to specialists.	scheduling and coordination. APP	
lowa City, Iowa;			evaluates and treats at the	
VISN23 Neurology			recommendation of the Board.	
Representative to			recommendation of the board.	
National VA				
Neurology Field				
Advisory Board;				
Clinical Professor of				
Neurology,				
Departments of				
Neurology and				
Otolaryngology				
Department,				
Division of Neuro-				
Otology, University				
of lowa)				
Deema Fattal, MD	Nurses perform screening,	Patients are seen (likely via video)	Medical support assistant and	The spokes are all likely primary
(Chief of Neurology,	vitals, and care management	by the hub providers. Follow up	nurses are responsible for	care.
VAMC, Neurology,	and coordination with hub site.	tests can be done locally at the	scheduling and coordination.	
Iowa City, Iowa;		spokes or in the community.		
VISN23 Neurology		Patients can be seen more than		
Representative to National VA		one time by hub providers.		
Neurology Field Advisory Board;				
Clinical Professor of				
Neurology,				
Departments of				
Neurology and				
Otolaryngology				
Department,				
Division of Neuro-				
Otology, University				
of Iowa)				

Key Informant, Title	Screening/Assessment	Post-Screening/Assessment Followup	Methods for Coordinating Services	Primary Care Role
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro- Otology, University of Iowa)	Local providers followup on e- consult recommendations.	A nurse coordinator checks that the local providers followed on the e-consult.	Clinician to e-consult back to clinician. A designated coordinator is ideal, and they are building a more permanent model 5 base in Texas.	Primary care doctors submit e- consultation requests to experts, then it is up to the referring physician to create a plan of care/referrals for the patient.
Sarah Jolley, MD (Assistant Professor of Medicine- Pulmonary Sciences & Critical Care, University of Colorado)	Nurse navigator does pre-visit screening and contact with patients.	Followup times vary substantially, as some patients can get better in a couple months and transition back to primary care, while other will have symptoms for longer and stay within the multidisciplinary structure for longer. They work closely with the project ECHO team, and are working on implementing tele-consultation for consistency.	Nurse navigator coordinates care.	The program tries to involve primary care and keep them a part of the team. As patient's needs change, they transition to a primary care clinic. About one third of patients go on to integrated primary care.
Peter Rowe, MD (Professor of Pediatrics, Johns Hopkins, Director, Children's Center Chronic Fatigue Clinic)	Dr. Rowe takes some of the calls requesting consultation from physicians, and the others are screened by a research assistant for a study they have initiated.	Follow up visits are 45 to 60 minutes long, with follows ups every month or two. Patients are followed up for multiple years sometimes. There are not add-on clinics to transition patients to, so many of them will stay at this clinic into adulthood.	Care coordination is a shared responsibility. There is a clinic nurse who helps answer Epic My Chart requests and messages, does some of the scheduling that a medical office coordinator might otherwise handle, and helps with prescription refills and accommodation letters.	Usually primary care providers are involved in referring patients for the study, but they are so over-extended in this area that they prefer that the clinic handle as much of the specialty level care as they can.

Key Informant, Title	Screening/Assessment	Post-Screening/Assessment Followup	Methods for Coordinating Services	Primary Care Role
Benjamin Abramoff, MD, MS (Assistant Professor of Clinical Physical Medicine and Co-Founder and Co-Director of COVID Recovery Clinic)	Initial visit is usually a virtual tele-health visit, and is a 60 minute comprehensive evaluation. Based on the patient's symptoms, they will either be referred to other specialists or be treated within the clinic.	All patients are followed up for at 3 months, often in person	No designated coordinator, but there is a case manager built into the clinic.	NR
Sarah De Ferranti, MD, MPH (Chief, Division of Ambulatory Cardiology, Associate Professor of Pediatrics, Harvard Medical School)	NP, clinician, and physician work to refer patients to specialists. Specialist appointments are almost always in person	NR	NR	NR
David Putrino, PhD, PT (Director of Rehabilitation Innovation for the Mount Sinai Health System, Professor in the Department of Rehabilitation and Human Performance at the Icahn School of Medicine at Mount Sinai)	Initial intake is with a physiatrist and is usually telehealth; 3 weeks before the initial visit, the patient is scheduled for a series of blood draws and online evaluations with an advanced practice provider (physician's assistant) and patients complete a series of patient reported outcomes. At the intake appointment, the physician is primed on all results of tests and evaluations. Intake lasts approximately 1 hour. Physician will make determinations for further testing, medications, PT interventions, additional screening, and specialist referrals. Almost all patients are referred to PT.	Patients are followed up monthly. Data suggests that it usually takes patients about 3 months in the clinical program to experience noticeable gains in function (doubling of activity tolerance, halving of fatigue, general reduction of the number of symptoms being reported by about 40%).	There is a designated care coordinator who checks in with the patient after the initial visit and walks them through scheduling and next steps.	The clinic works closely with the Center for Post-COVID Care at Mt. Sinai, which consists of primarily of primary care providers. If patients are referred from the center for post- COVID care (largely PCP-led), they work collaboratively with primary care. If patients self-refer, the center does their best to facilitate patient needs without involving other specialties.

Key Informant,		Post-Screening/Assessment	Methods for Coordinating	
Title	Screening/Assessment	Followup	Services	Primary Care Role
Laura Malone, MD, PhD (Co-Director, Pediatric Post- COVID-19 Rehabilitation Clinic, Kennedy Krieger Institute, Physician Scientist, Kennedy Krieger's Center for Movement Studies, Assistant Professor, Neurology and Physical Medicine and Rehabilitation, Johns Hopkins University School of Medicine)	Patients come for a 4 to 5 hour evaluation and see Dr. Malone for pediatric neurology, as well as a pediatric rehabilitation doctor who co-directs the clinic with her. They also have behavioral psychology, social workers and physical therapy, and a dedicated nurse in the clinic. After the patient is evaluated by the group, the patient is provided with a summary of recommendations from all of the evaluations. There are also expedited evaluations with neuropsychology and an education specialist for patients who need it. They work closely with providers who direct any additional referrals to within the Kennedy Krieger Johns Hopkins network to get patients to be seen more quickly. This includes psychiatry, gastrointestinal, pulmonology, and other common specialties.	Nurse practitioner sees patients for followup. Patients are more likely to follow up at the clinic than move on to primary care.	There is a clinic coordinator who is more administrative, a nurse, and a nurse practitioner who sees some of their followup patients and who helps with some of the care coordination. The care coordination is divided between the three, depending on the needs of the patient.	Not directly involved. Pediatricians are communicated with, depending on interest and availability.

Key Informant,		Post-Screening/Assessment	Methods for Coordinating	
Title	Screening/Assessment	Followup	Services	Primary Care Role
Hanh Trinh, MD	Dr. Trinh does the initial	They see patients every 3 months	A program nurse manager helps	Primary care refers patients to the
(Assistant Professor	assessment, then depending		coordinate and tracks all data.	clinic. When veterans are
of Medicine,	on patient needs, will alert			discharged, they return to their
Division of	team members to schedule the			primary care who will continue their
Geriatrics,	patients for additional testing			care plan.
Gerontology and	and resources.			
Palliative Medicine,				
University of Texas				
Health Science				
Center at San				
Antonio, Staff				
Geriatrician, Rural				
Home-Based				
Primary Care at the				
South Texas				
Veterans Health				
Care System) <sup>a</sup>				
Hanh Trinh, MD	Veterans who screen positive	Patients are mailed a COVID kit	Program nurse manager. All of the	Not involved, except placing
(Assistant Professor	for long COVID symptoms and	which includes digital	nurses are case managers	consults to the long COVID clinic.
of Medicine,	desire follow up will then be	thermometer, pulse oximeter,		
Division of	fully assessed by an MD or	magnifying glass as needed, BP		
Geriatrics,	NP. There are bi-monthly IDT	monitor as needed, guide to the		
Gerontology and	meetings to discuss all new	program and resources. They are		
Palliative Medicine,	patients.	discharged when they are stable,		
University of Texas		or near baseline of health with a		
Health Science		good care plan and PCP follow		
Center at San		up.		
Antonio, Staff				
Geriatrician, Rural				
Home-Based				
Primary Care at the				
South Texas				
Veterans Health				
Care System)				

Key Informant, Title	Screening/Assessment	Post-Screening/Assessment Followup	Methods for Coordinating Services	Primary Care Role
Monica Verduzco- Gutierrez, MD (Professor and Chair, Department of Rehabilitation Medicine at the Long School of Medicine at UT Health San Antonio) Summer Rolin, PsyD (Assistant Professor of Rehabilitation Medicine, UT Health	Patients are seen primarily via telehealth though can be in person. Initial visit is a 45 minute telehealth consultation. Workup is initiated, and the patient is sent to providers within the institute such as pulmonology and neurology, and other providers in the community such as rehabilitation, all who are long- COVID literate. Dr. Verduzco- Gutierrez does all managing and patient coordination.	Dr. Verduzco-Gutierrez does ongoing care if there is a specific request to. Patients are given follow-up appointments about every 3 months to follow up on issues by the PM&R physician. Patient will also see other physicians who have similar backgrounds in long COVID care. There are follow ups if additional tests or imaging need to be ordered, or if there is further specialty care to be referred to	Dr. Verduzco-Gutierrez manages patients and facilitates coordination.	If follow up is not needed, patients are triaged to their primary care provider for long term management. There is a county clinic focusing on long COVID that primary care has taken over, and they refer to Dr. Verduzco-Gutierrez for certain cases. The primary care clinic only takes patients already established within the county health system. There is also separate primary care in the system that co-manages care.
San Antonio) Karyn Bishof (Founder of COVID- 19 Longhauler Advocacy Project, Founding Member of Long COVID Alliance)	First appointment is a 1-2 hour intake with physicians that the site determined needs to be part of the patient's initial team. Based on the team's patient care plan, the patient is scheduled for testing all in one day.	The patient then follows up via telehealth with their care team of providers to discuss findings and a treatment plan. Patients should repeat specialty testing at least every 4 to 6 months, with interim care with a highly trained post- COVID primary care physician.	Designated care coordinator	Interim care with a highly trained post-COVID primary care physician between follow ups at the long COVID clinic.
Yochai Re'em, MD (Clinical Assistant Professor of Psychiatry, Assistant Attending Psychiatrist, Weill Cornell Medicine)	The first meeting is 1 hour, and Dr. Re'em does a standard psychiatric intake. Intake is tailored to long COVID. From there, they decide if they will do medication management, medication management plus therapy, or therapy alone. Most patients receive ongoing care.	Dr. Re'em does individual medication management and psychotherapy, as well as group therapy. Dr. Re'em offers supportive psychotherapy for groups of people with long COVID that meets once per week. If a patient is seeing other providers, Dr. Re'em usually maintains communication with the other provider so he can use it in his psychotherapy work with the patient, as well as understand what is going on with the patient outside of psychotherapy.	Dr. Re'em does all coordination.	Dr. Re'em prefers to co-manage patients with other specialties, and makes referrals for patients as much as he can to find a primary provider to manage overall care.
Boris Bayerman, DO (Family Medicine Specialist, Kaiser Permanente Colorado)	Patients are screened and assessed by a family doctor and nurse care coordinator, the latter of which helps with follow up which includes patient follow up within 2 weeks).	Patients are followed up after 2 weeks	A nurse care coordinator arranges follow ups	Dr. Bayerman would act as the primary care physician. Other primary care physicians would be able to refer patients to this pilot program.

Abbreviations: AAP = American Academy of Pediatrics; COVID = coronavirus disease; ECHO = Extension for Community Healthcare Outcomes; EMR = electronic medical record; IDT = interdisciplinary team; NP = nurse practitioner; NYU = New York University; OHSU = Oregon Health & Science University; PCP = primary care physician; PT = physical therapy; UT = University of Texas; VA = Veteran's Affairs; VAMC = Veteran's Affairs Medical Center.

<sup>a</sup> These Key Informants described more than one model of care. There is some overlap between the different models they described.

	Education and Training	,,,,,,,	,	
Key Informant, Title	for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Jonathan Whiteson, MD (Assistant Professor of Physical Medicine & Rehabilitation, NYU School of Medicine)	Monthly meetings and educational presentations, journal clubs, etc. Articles and publications are shared to continue learning process. Patient support group run through psychology where patient education is provided.	Visits to MDs are typically 30 minutes and are based on need. The rehab MD sees patients typically every 3-4 months. Other subspecialists may be every 6 months. Therapists see patients twice per week for the necessary duration of the therapy. General rehab therapy visits are 30 minutes. Cardiac rehab for POTS, and pulmonary rehab are 60 minutes	There is a virtual urgent care service, as well as the option to do a tele-health appointment for patients with disabilities.	No external funding. Only patients with insurance can be seen. Most insurance are accepted.
Trevor Hall, PsyD (Associate Professor of Pediatrics, Oregon Health & Science University School of Medicine)	None	Patients are seen once with some followup and advocacy as needed.	Telehealth is utilized when possible.	Insurance
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa) <sup>a</sup>	The VA is working on educational guidelines for long COVID.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Telehealth is utilized.	Government

### Table I-1d. Details of models described by Key Informants (education, frequency of visits, teleservices, funding)

	Education and Training for COVID Clinic Staff, Including Use of			
Key Informant, Title	Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	The VA is working on educational guidelines for long COVID.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Telehealth is utilized.	Government
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	Patient education material is offered from the Veterans Health Administration.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Telehealth is utilized.	Government

	Education and Training for COVID Clinic Staff, Including Use of			
Key Informant, Title	Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	The VA is working on educational guidelines for long COVID.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Telehealth is utilized by APP when communicating with the long COVID board, and can also be used between the patient and APP.	Government
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	The VA is working on educational guidelines for long COVID.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Telehealth is utilized.	Government

Key Informant, Title	Education and Training for COVID Clinic Staff, Including Use of Protocols	Frequency/Intensity of Visits	Use of Teleservices	Clinic Funding
Deema Fattal, MD (Chief of Neurology, VAMC, Neurology, Iowa City, Iowa; VISN23 Neurology Representative to National VA Neurology Field Advisory Board; Clinical Professor of Neurology, Departments of Neurology and Otolaryngology Department, Division of Neuro-Otology, University of Iowa)	The VA is working on educational guidelines for long COVID.	Depends on patient. Patients are often seen every 3 to 6 months and referred to multiple other clinics.	Completely telehealth.	Government
Sarah Jolley, MD (Assistant Professor of Medicine-Pulmonary Sciences & Critical Care, University of Colorado)	Their program has learned from other, successful models, such as the transgender clinic.	Patient visit frequency is defined by ongoing symptoms and severity and can range from monthly to every 3 to 6 months. Patient visits typically last 1 to 3 hours depending on the specialties being seen. All attempts are made to consolidate visits on a single day across specialists for greater ease for the patients and family members. For patients traveling from out of town, all efforts are made to schedule needed testing around the time of the visit to minimize back and forth travel.	Initial appointments are usually in person, but tele-services are utilized subsequently.	UCHealth-no other unique funding. All providers are providing their clinical time on top of their usual clinical duties without dedicated funding towards clinical effort. Insurance is billed for patients with insurance. Patients without insurance can be seen and enrolled in the hospital's financial assistance program which subsidizes care for uninsured patients.
Peter Rowe, MD (Professor of Pediatrics, Johns Hopkins, Director, Children's Center Chronic Fatigue Clinic)	They spend a lot of time communicating with referring physicians about how they can provide care for ME/CFS patients that are either over our age limit for pediatric care, or when simply unable to fit them in for appointments. They have produced Primers and webinars that they direct them to, and other educational materials on managing problems.	Follow up every one or two months. Appointments are usually 45 minutes long.	Tele-medicine is utilized.	Philanthropy

	Education and Training			
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Benjamin Abramoff,	NR	Follow up happens 3 months after the	Initial visit is usually	Insurance
MD, MS (Assistant		first visit.	virtual	modiance
Professor of Clinical				
Physical Medicine and				
Co-Founder and Co-				
Director of COVID				
Recovery Clinic)				
Sarah De Ferranti, MD,	NR	NR	Initial visits are	Insurance
MPH (Chief, Division of			usually telehealth	
Ambulatory Cardiology,				
Associate Professor of				
Pediatrics, Harvard				
Medical School)				
David Putrino, PhD, PT	Staff have undergone specialty training,	Initial intake lasts 1 hour, and patients	Initial visits are	Funded by clinical funds and
(Director of	including a Continuing Medical Education	are followed up monthly until they	usually telehealth,	by billing insurance.
Rehabilitation	course for long COVID. Once a month, a	experience noticeable gains in	and telehealth is used	Formulations pharmacies are
Innovation for the	neuropsychologist works with the entire	functions.	in followup	used to cut costs.
Mount Sinai Health	team in a group therapy environment.		appointments in	
System, Professor in			patients who find it	
the Department of			difficult to get to the	
Rehabilitation and			clinic. Dr. Putrino has	
Human Performance at			also piloted the	
the Icahn School of			Precision Recovery	
Medicine at Mount			app, which is used for	
Sinai)			acute COVID	
			monitoring.	
Laura Malone, MD,	Internal documents and protocols, such as	Initial visit is 4-5 hours long. Followup	Teleservices are	Primarily insurance based for
PhD (Co-Director,	common school accommodations and	visits with the nurse practitioner is 1	utilized after the initial	funding. They have applied for
Pediatric Post-COVID-	educational materials on long COVID. They	hour and followups with the full team	evaluation (for in-	government funding
19 Rehabilitation	have a semi-flexible battery for	are ~4 hours. Frequency of visits	state patients).	
Clinic, Kennedy	neurocognitive testing that is standardized,	depends on logistics of the family (out		
Krieger Institute,	and use modified CHOP Dallas protocols for	of state versus in state and		
Physician Scientist,	patients with POTS. The day rehabilitation	number/severity of symptoms). They		
Kennedy Krieger's	program has a rough protocol that is	try to see patients at least twice a		
Center for Movement	adapted to each patient's needs.	year, more recently visits for more		
Studies, Assistant		local patients are between 3-6x/year.		
Professor, Neurology				
and Physical Medicine				
and Rehabilitation,				
Johns Hopkins				
University School of				
Medicine)				

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Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System) <sup>a</sup>	Staff are encouraged to attend the VA Echo series, the Post-acute and Long term outcomes of COVID19 lecture series, and the VA Long COVID Community of Practice lectures that occur every other week. Staff can also access the Veteran's health library. There is also a Whole Health PACT guide on the most common symptoms of Long COVID that includes education, evaluation, and management. For patients, they have created a small booklet that has information on signs and symptoms of acute and long COVID as well as resources within the book. For smell training, they use the smell project guide that is included in the box that is mailed to veterans.	Patients are followed up with every 3 months.	All virtual	Government
Hanh Trinh, MD (Assistant Professor of Medicine, Division of Geriatrics, Gerontology and Palliative Medicine, University of Texas Health Science Center at San Antonio, Staff Geriatrician, Rural Home-Based Primary Care at the South Texas Veterans Health Care System)	Staff are encouraged to attend the VA Echo series, the Post-acute and Long term outcomes of COVID19 lecture series, and the VA Long COVID Community of Practice lectures that occur every other week. Staff can also access the Veteran's health library. There is also a Whole Health PACT guide on the most common symptoms of Long COVID that includes education, evaluation, and management. For patients, they have created a small booklet that has information on signs and symptoms of acute and long COVID as well as resources within the book. For smell training, they use the smell project guide that is included in the box that is mailed to veterans.	Typically visits are every 3 months or as needed depending on the provider.	All virtual	Government

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Monica Verduzco- Gutierrez, MD (Professor and Chair, Department of Rehabilitation Medicine at the Long School of Medicine at UT Health San Antonio) Summer Rolin, PsyD (Assistant Professor of Rehabilitation	There are standardized templates for what to what to look for in a patient, and what workups and education they might need that is centered on protocols for screening for autonomic function.	Followup visits every 3 months	Clinic is primarily telehealth based	Insurance
Medicine, UT Health San Antonio)				
Karyn Bishof (Founder of COVID-19 Longhauler Advocacy Project, Founding Member of Long COVID Alliance)	Centers should also focus on data collection and research, as well as community education and resources. A focus should be on creating a national database where all centers can share information with each other. Ms. Bishof's team would also like to see a commitment to centralizing data and care, a commitment to partnering with patient organizations and advocates for advisory boards, commitment to a comprehensive systemic care teams, and commitment to quarterly all-site workshops, where centers share information to propel and move forward the long COVID community to find solutions. It would be beneficial to have biweekly or monthly site meetings, where each site's care teams meet with one another, and a bimonthly webinar for the patient community and external patient providers, who may be looking for more updates and guidance.	Repeated specialty testing at least every 4-6 months. Patients and providers should have the opportunity to sit down with the entire care team every 6 months to talk through the patient's case and create an updated plan of care for the next 6 months. Patients should be able to get an appointment within 45 days, have a second appointment within 30 days, and have another appointment 90 days after treatment is initiated. After another 60 days, patients get a 6 month assessment. The fourth appointment happens 30 days later, and then there is another 90 day appointments happen as needed after that, then adjust plan of care at the 1 year mark.	Telehealth is used as needed. Most visits would be telehealth. Patients would only come to the clinic in person for testing, labs, or exams.	Government, grants, billing insurance, and/or a combination
Yochai Re'em, MD (Clinical Assistant Professor of	No specific protocols, but often refers patients to The Long COVID Survival Guide as a resource, as well as ME Action's	For medication management only (someone else is doing psychotherapy), Dr. Re'em typically	Telehealth is utilized for follow up, except in the case of patients	Headway
Psychiatry, Assistant Attending Psychiatrist, Weill Cornell Medicine)	website (https://www.meaction.net/resources/).	meets with patients once a month. For psychotherapy 1-2x/week, for group therapy once a week.	who will be prescribed controlled substances.	

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Boris Bayerman, DO (Family Medicine	There is a long COVID educational group visit (which can be done virtually) and	Patients are followed up with 2 weeks after the initial visit.	,	Insurance
Specialist, Kaiser	educational class with Dr. Bayerman and a		person	
Permanente Colorado)	psychologist, to help patients with self-			
	management.			

Abbreviations: AAP = American Academy of Pediatrics; CHOP = Children's Hospital of Philadelphia; COVID = coronavirus disease; ME = myalgic encephalomyelitis ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NYU = New York University; POTS = postural orthostatic tachycardia syndrome; PT = physical therapy; VA = Veteran's Affairs; VAMC = Veteran's Affairs Medical Center.

<sup>a</sup> These Key Informants described more than one model of care. There is some overlap between the different models they described.