H. R. 1114

To provide for optimized care, a coordinated Federal Government response, public education, and insurance reimbursement guidance for Long COVID, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 21, 2023

Ms. BLUNT ROCHESTER (for herself, Mr. BEYER, and Ms. PRESSLEY) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for optimized care, a coordinated Federal Government response, public education, and insurance reimbursement guidance for Long COVID, and for other purposes.

1 Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the “Long COVID Response is Care Optimized and Vitally Essential Resources that Yield New Opportunities for Wellness Act” or the “Long COVID RECOVERY NOW Act”.

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(b) Table of Contents.—The table of contents for this Act is as follows:

Sec. 1. Short title; table of contents.
Sec. 2. Targeting resources for equitable access to treatment of Long COVID.
Sec. 3. National Long COVID technical assistance dissemination program.
Sec. 4. Mental health and suicide prevention and treatment.
Sec. 5. ONC best practices for Long COVID data.
Sec. 6. Long COVID Education Website.
Sec. 7. Providing Support for Long COVID Registries.
Sec. 8. Medicaid Health Homes for Individuals with Long COVID.
Sec. 9. State health officials guidance.
Sec. 10. Support under Medicaid for State Collection of Long COVID Data.
Sec. 11. Grants for Pediatric Research on Long COVID.

3 SEC. 2. TARGETING RESOURCES FOR EQUITABLE ACCESS TO TREATMENT OF LONG COVID.

(a) Establishment.—

(1) In general.—Not later than 1 year after the date of the enactment of this Act, the Secretary of Health and Human Services shall award, subject to subsection (f) and in accordance with the provisions of this section, grants described in the following subsections to carry out the purposes described in such subsections.

(2) Eligibility.—The Secretary may establish a process for evaluating and determining the eligibility of Federally qualified health centers and rural health clinics for receiving a grant under this section.

(b) Grants to FQHCs and RHCs.—For purposes of subsection (a), the grants described in this subsection are grants to Federally qualified health centers (as defined
in section 1861(aa)(4) of the Social Security Act (42
U.S.C. 1395x(aa)(4)) and rural health clinics (as defined
in section 1861(aa)(2) of such Act (42 U.S.C.
1395x(aa)(2)) to—

(1) adopt evidence-based Long COVID clinical
practices that have been demonstrated to improve
the wellness of individuals with Long COVID, in-
cluding clinical validation of patient reported symp-
toms using established measures that yield struc-
tured, comparable data;

(2) establish or expand screening, referral, and
navigation processes for health-related social needs
that could interfere with Long COVID treatment,
including food insecurity, housing instability, trans-
portation needs, utility difficulties, and interpersonal
safety; and

(3) submit to the Secretary of Health and
Human Services (in a format consistent with the
standards and activities under the Data Moderniza-
tion Initiative of the Centers for Disease Control
and Prevention) standardized, disaggregated,
deidentified data (as specified by the Secretary) on
the characteristics, diagnoses, and health care serv-
vice utilization of Long COVID patients served under
such grant, including disaggregated data on Long
COVID patient characteristics, including patient age, gender, race, ethnicity, language spoken, disability status, nature and duration of validated symptoms, and other characteristics necessary to inform considerations for effective and equitable treatment for patients with Long COVID.

(c) Grants to Primary Care Practices.—For purposes of subsection (a), the grants described in this subsection are grants to primary care practices (other than Federally qualified health centers and rural health clinics) that satisfy such criteria as may be established by the Secretary to carry out the purposes described in paragraphs (1) and (3) of subsection (b).

(d) Grants for Multidisciplinary Treatment and Coordination.—

(1) In general.—The Secretary of Health and Human Services (in this section referred to as the “Secretary”) shall award grants on a competitive basis to eligible entities for the purpose of creating or enhancing capacity to treat patients with Long COVID through a multidisciplinary approach. The term “multidisciplinary” in this section refers to the coordinated work to provide care or treatment to a patient by physicians and other professionals, such as specialty or subspecialty providers, nurses and
nurse care coordinators, dietitians, nutritionists, social workers, behavioral health professionals, physical and occupational therapists, speech pathologists, or any professionals determined to be appropriate by the State and approved by the Administrator of the Centers for Medicare & Medicaid Services.

(2) USE OF FUNDS.—An eligible entity receiving a grant under this section shall use the grant, for the purpose described in subsection (a), to—

(A) enhance the capacity of one or more existing multidisciplinary Long COVID clinics to serve the Long COVID population; or

(B) create one or more multidisciplinary clinics to address the physical and mental health needs of Long COVID patients.

(3) ELIGIBLE ENTITIES.—To be eligible to receive a grant under this section, an entity shall be a health care provider, Federally qualified health center (as defined in section 1861(aa) of the Social Security Act (42 U.S.C. 1395x(aa))), rural health clinic, urban Indian health center, or State or local public health department, that—

(A)(i) operates an existing multidisciplinary Long COVID clinic or other specialized Long COVID program; or
(ii) is an existing health care provider with experience providing care for individuals with Long COVID and who demonstrates an intent to create a multidisciplinary Long COVID clinic or other specialized Long COVID program;

(B) submits to the Secretary an application at such time, in such manner, and containing such information and assurances as the Secretary may require; and

(C) employs a framework that incentivizes participants to attain the program’s goals to establish and disseminate best practices, and allocates funds based on such attainment.

(4) SPECIAL RULE.—A physical clinical facility is not a requirement for eligibility.

(5) PRIORITY.—In awarding grants under this subsection, the Secretary shall give priority to eligible entities that—

(A) submit a plan to engage with medically underserved communities, and with populations disproportionately impacted by COVID–19;

(B) demonstrate capacity (or an intent to build capacity) to provide personalized treatment and facilitate patient access to multidisciplinary health care providers with expertise in
treating Long COVID symptoms, including such providers who are primary and specialty care physicians (such as physiatrists, neurologists, cardiologists, immunologists, and pulmonologists), therapists, nurses, care coordinators, social workers, nutritionists, and behavioral health specialists; and (C) submit a plan to ensure ongoing multidisciplinary continuing education on infection-triggered conditions for—

(i) physicians treating Long COVID; and

(ii) other physicians and health care workers who are not treating Long COVID, but are otherwise serving patients in the community.

(c) **Equitable Access.**—In order to ensure equitable access treatment—

(1) no grantee under this section shall deny access to treatment with respect to Long COVID based on insurance coverage, date of diagnosis, or previous hospitalization;

(2) a grantee under this section shall with respect to Long COVID—
(A) offer equity-centered resources (such as the ability to offer resources in various languages), information, and training to safety net health systems; and

(B) disseminate to individuals and organizations that provide care best practices and treatment approaches that enhance access to high-quality care to everyone where they live; and

(3) treatment for Long COVID shall be included as a COVID–19 treatment, consistent with the American Rescue Plan Act of 2021 (Public Law 117–2).

(f) Development of Evidence-Based Strategies for High-Value Care for Individuals With Long COVID.—

(1) In General.—Not later than 1 year after the date of the enactment of this Act, the Agency for Healthcare Research and Quality shall, subject to appropriations pursuant to subsection (i), award multi-year grants to eligible entities meeting such criteria as specified by the Secretary through rule-making for the purposes of—

(A) supporting the generation of evidence about how to deliver high quality, high-value
health care for individuals with Long COVID for the treatment of the condition;

(B) creating tools and strategies to help health systems and hospitals, primary and specialty physicians, nurses, allied health care professionals, and caregivers provide high-quality, high-value care for individuals with Long COVID; and

(C) providing educational materials for health care providers, payers, and consumers on high-value care for individuals with Long COVID.

(2) ELIGIBILITY.—The Secretary shall, through rulemaking, specify a process for evaluating and determining the eligibility of primary care providers including Federally qualified health centers and rural health clinics; specialty care providers, hospitals, health systems, academic medical centers; and other entities for receiving a grant under this subsection. Such rules shall prohibit grant funds from being used to compensate or reimburse individuals or organizations excluded pursuant to section 1128 of the Social Security Act (42 U.S.C. 1320a–7) from participation under the Medicare program under title XVIII of such Act.
(g) **Long COVID Defined.**—For purposes of this Act, the term “Long COVID” (also referred to as “post-acute sequelae of COVID–19”, “post-COVID conditions”, or “persistent symptoms post-COVID”) means the ongoing sequelae of COVID–19 that some individuals experience after infection with the SARS–CoV–2 virus, as diagnosed by a qualified health care provider. Such sequelae are defined as the “Post-COVID Conditions” identified and defined by the Centers for Disease Control and Prevention in 2021, or in subsequent revisions by the Centers for Disease Control and Prevention.

(h) **Reports.**—

(1) **Annual reports by grantees to Secretary.**—On an annual basis, a recipient of a grant under this section shall—

(A) submit to the Secretary, and make publicly available, a report on the activities carried out through the grant; and

(B) include evaluations of such activities, including the experience of individuals who received health care through such grant.

(2) **Annual reports by Secretary to Congress.**—Not later than the end of each of fiscal years 2024 through 2026, the Secretary shall submit
to the Congress, and make publicly available, a re-
port that—

(A) summarizes the reports received under
paragraph (1);

(B) evaluates the effectiveness of grants
under this section; and

(C) makes recommendations with respect
to expanding coverage for clinical care for Long
COVID.

(i) AUTHORIZATION OF APPROPRIATIONS.—

(1) IN GENERAL.—To carry out this section,
there are authorized to be appropriated such sums
as may be necessary for each of fiscal years 2024
through 2026.

(2) ADMINISTRATIVE EXPENSES.—Not more
than 15 percent of the amounts made available to
carry out this section for any fiscal year may be
used for administrative expenses to operate the
grants under this section.

SEC. 3. NATIONAL LONG COVID TECHNICAL ASSISTANCE
DISSEMINATION PROGRAM.

(a) IN GENERAL.—The Secretary of Health and
Human Services shall—

(1) establish a structured process to seek ongo-
ing input from medical societies representing pri-
mary care, specialty care, and subspecialty care re-
garding the proven and promising practices for
treating individuals who are diagnosed with Long
COVID to support their wellness and recovery; and

(2) enter into a memorandum of understanding
with one or more organizations with specific medical
knowledge on Long COVID or experience providing
care and medical treatment to individuals with Long
COVID to support the ongoing dissemination to the
broader medical community of existing open source
evidence, tools and strategies.

(b) ORGANIZATION DESCRIBED.—For purposes of
subsection (a), and organization described in this para-
graph is an organization that satisfies at least the fol-
lowing:

(1) The organization has clinical expertise re-
lated to the treatment of Long COVID.

(2) The organization has a robust under-
standing of clinical and business practices.

(3) The organization has the ability to convene
groups and disseminate information nationally.

(4) The organization consults with medical spe-
cialty associations for purposes of developing and
distributing clinical best practices for Long COVID
diagnosis and treatment.
SEC. 4. MENTAL HEALTH AND SUICIDE PREVENTION AND
TREATMENT.

Section 1911(b)(1) of the Public Health Service Act (42 U.S.C. 300x(b)(1)) is amended by inserting “and, for each of fiscal years 2024 through 2026, individuals with Long COVID (as defined in section 2 of the Long COVID RECOVERY NOW Act) who have also been diagnosed with a mental health condition (such as a serious mental illness or a serious emotional disturbance)” after “1912(c)”.

SEC. 5. ONC BEST PRACTICES FOR LONG COVID DATA.

(a) IN GENERAL.—Not later than 6 months after the date of the enactment of this Act, the Secretary of Health and Human Services, acting through the National Coordinator for Health Information Technology, shall convene health care stakeholders to identify potential best practices for collecting, aggregating, and disseminating to health care researchers deidentified data that promotes learning about Long COVID and supports the further research of the characteristics of individuals diagnosed with Long COVID.

(b) REPORT.—Not later than 160 days after the first meeting of such stakeholders pursuant to subsection (a), the Secretary shall submit to Congress (and make publicly available on the website of the Office of the National Coordinator of Health Information Technology) a report sum-
marizing the meetings and findings of the stakeholders as well as any recommendations, including recommendations on ways that federal health care policy can better support an understanding of the etiology, characteristics, care and potential treatments for individuals Long COVID to support individuals’ recovery and wellness. Such recommendations shall—

(1) take into account the perspectives of health data scientists, health services researchers, medical providers, health plans, hospitals and health systems, epidemiologists, public health experts, patient representatives and groups, health information technology companies, and other stakeholders; and

(2) be informed by public and private sector efforts to characterize Long COVID, aggregate and disaggregate data, and promote data standardization, data standards, or open data access for furthering a greater understanding of Long COVID.

**SEC. 6. LONG COVID EDUCATION WEBSITE.**

Not later than 6 months after the date of the enactment of this Act, the Secretary of Health and Human Services shall, in consultation with medical societies representing the perspectives of primary care, specialty care, mental health professionals, medical researchers (including through the National Institutes of Health), public
health experts (including the Centers for Disease Control and Prevention), and patient advocates, implement a Federal website (which may be implemented through an existing public website of the Department of Health and Human Services) that—

(1) collects, and curates educational materials for health care providers and consumers about Long COVID (as defined in section 2(e)) symptoms, diagnosis, characteristics, treatment, and access to care; and

(2) includes, or provides a link to, comprehensive educational resources for health care providers, such as the interim guidance (and subsequent updates) for health care providers published by the Centers for Disease Control and Prevention on how to treat individuals with Long COVID.

SEC. 7. PROVIDING SUPPORT FOR LONG COVID REGISTRIES.

(a) IN GENERAL.—Not later than one year after the date of the enactment of this Act, the Secretary of Health and Human Services, acting through the Director of the Agency for Healthcare Research and Quality shall, subject to appropriations pursuant to subsection (d), award multi-year grants to eligible entities described in subsection (b) for the purposes of—
(1) supporting existing or creating new Longitudinal registries of patients with Long COVID (as defined in section 2(g));

(2) establishing voluntary standards for such registries that include common data elements and clear data definitions to enable the comparability and synchronization of data by researchers;

(3) utilize data from such registries to help inform understanding regarding the efficacy of care, diagnostics, therapeutics, care pathways, behavioral health interventions, and other dynamics regarding individuals with Long COVID; and

(4) informing health care providers’ efforts related to improving equitable access to health care by collecting data through such registries from individuals with Long COVID, including social needs, medical history, race and ethnicity, language, gender, and disability status, as specified by the Secretary of Health and Human Services.

(b) ELIGIBLE ENTITIES.—

(1) IN GENERAL.—To be eligible for a grant under subsection (a) an entity shall—

(A) submit an application to the Secretary in such form and manner as the Secretary may require;
(B) agree to adhere to such data definitions and standards as the Secretary may require, including privacy and security requirements, requirements to make findings of the organization, and the use of open-source technology to promote the dissemination of information related to Long COVID;

(C) agree to make any information collected or produced by the entity pursuant to the grant available to the public through secure, non-proprietary means without a paywall or fee;

(D) demonstrate to the Secretary, in a form and manner specified by the Secretary, that the entity has in place appropriate standards for handling proprietary, confidential, and medical information securely and in a manner that is compliant with applicable law;

(E) have in place and demonstrate to the Secretary the adequacy of a plan for the Longer-term financial sustainability of such registry; and

(F) be an organization described in paragraph (2).
(2) Organizations.—For purposes of paragraph (1), an organization described in this paragraph is any of the following:

(A) A non-profit organization representative of individuals with Long COVID.

(B) An organization of health care providers, such as health systems and hospitals.

(C) An organization of data scientists.

(D) Multi-sector groups that consist of organizations described in 2 or more of the preceding subparagraphs that meet such standards as the Secretary may require.

(e) Consideration.—In carrying out the purposes described in subsection (a), an eligible entity shall take into consideration the report made available under section 4(b).

(d) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section $10,000,000 for each of fiscal years 2024 through 2028.

SEC. 8. MEDICAID HEALTH HOMES FOR INDIVIDUALS WITH LONG COVID.

(a) Health Homes for Individuals With Chronic Conditions.—Section 1945(h)(1)(A)(ii) of the Social Security Act (42 U.S.C. 1396w–4(h)(1)(A)(ii)) is amended—
(1) in subclause (II), by striking at the end “or”;

(2) in subclause (III), by striking at the end the period and inserting “; or”; and

(3) by adding at the end the following new subclause:

“(IV) Long COVID (as defined in section 2(g) of the Long COVID RECOVERY NOW Act).”.

(b) HEALTH HOMES FOR CHILDREN WITH MEDICALLY COMPLEX CONDITIONS.—Section 1945A(i)(1)(A)(ii) of the Social Security Act (42 U.S.C. 1396w–4a(i)(1)(A)(ii)) is amended—

(1) in subclause (I), by striking at the end “or”;

(2) in subclause (II), by striking at the end the period and inserting “; or”; and

(3) by adding at the end the following new subclause:

“(III) Long COVID (as defined in section 2(g) of the Long COVID RECOVERY NOW Act).”.

SEC. 9. STATE HEALTH OFFICIALS GUIDANCE.

Not later than 18 months after the date of the enactment of this Act, the Secretary of Health and Human
Services shall issue guidance to State health officials specifying tools and strategies that may help States improve the health and wellness of individuals enrolled under the Medicaid program under title XIX of the Social Security Act or the Children’s Health Insurance Program under title XXI of such Act who have been diagnosed with Long COVID by facilitating strong primary care and supporting linkages to specialists, relevant social supports, or community-based organizations at the local level, that can help support the recovery and wellness of such individuals.

**SEC. 10. SUPPORT UNDER MEDICAID FOR STATE COLLECTION OF LONG COVID DATA.**

Section 1903(a)(3) of the Social Security Act (42 U.S.C. 1396b(a)(3)) is amended by adding at the end the following new subparagraph:

“(I) 75 percent of the sums expended during a fiscal year quarter in 2024, 2025, or 2026 as are attributable to the collection and reporting of claims and encounter data on Long COVID (including identification of race, language, ethnicity, and duration of treatment) using the ICD–10 code U09.9 post COVID–19 condition, unspecified (or any successor to such code);”.
SEC. 11. GRANTS FOR PEDIATRIC RESEARCH ON LONG COVID.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Director of the National Institutes of Health (in this section, referred to as the “Secretary”), shall award grants to eligible entities to conduct research on Long COVID in pediatric populations.

(b) USE OF FUNDS.—An eligible entity selected to receive a grant under this subsection may use funds received through the grant to conduct research described in subsection (a), with a focus on pediatric immune system responses and neurodevelopment.

(c) ELIGIBLE ENTITY DEFINED.—In this section, the term “eligible entity” means a children’s hospital, pediatric researcher, pediatrician, academic medical center, or other organization determined appropriate by the Secretary.

(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2024 through 2026.