

118TH CONGRESS  
1ST SESSION

# 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.

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## 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

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## 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 Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

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

1 (b) TABLE OF CONTENTS.—The table of contents for  
 2 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**  
 4 **TO TREATMENT OF LONG COVID.**

5 (a) ESTABLISHMENT.—

6 (1) IN GENERAL.—Not later than 1 year after  
 7 the date of the enactment of this Act, the Secretary  
 8 of Health and Human Services shall award, subject  
 9 to subsection (f) and in accordance with the provi-  
 10 sions of this section, grants described in the fol-  
 11 lowing subsections to carry out the purposes de-  
 12 scribed in such subsections.

13 (2) ELIGIBILITY.—The Secretary may establish  
 14 a process for evaluating and determining the eligi-  
 15 bility of Federally qualified health centers and rural  
 16 health clinics for receiving a grant under this sec-  
 17 tion.

18 (b) GRANTS TO FQHCS AND RHCS.—For purposes  
 19 of subsection (a), the grants described in this subsection  
 20 are grants to Federally qualified health centers (as defined

1 in section 1861(aa)(4) of the Social Security Act (42  
2 U.S.C. 1395x(aa)(4)) and rural health clinics (as defined  
3 in section 1861(aa)(2) of such Act (42 U.S.C.  
4 1395x(aa)(2)) to—

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

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

17 (3) submit to the Secretary of Health and  
18 Human Services (in a format consistent with the  
19 standards and activities under the Data Moderniza-  
20 tion Initiative of the Centers for Disease Control  
21 and Prevention) standardized, disaggregated,  
22 deidentified data (as specified by the Secretary) on  
23 the characteristics, diagnoses, and health care serv-  
24 ice utilization of Long COVID patients served under  
25 such grant, including disaggregated data on Long

1 COVID patient characteristics, including patient  
2 age, gender, race, ethnicity, language spoken, dis-  
3 ability status, nature and duration of validated  
4 symptoms, and other characteristics necessary to in-  
5 form considerations for effective and equitable treat-  
6 ment for patients with Long COVID.

7 (c) GRANTS TO PRIMARY CARE PRACTICES.—For  
8 purposes of subsection (a), the grants described in this  
9 subsection are grants to primary care practices (other  
10 than Federally qualified health centers and rural health  
11 clinics) that satisfy such criteria as may be established by  
12 the Secretary to carry out the purposes described in para-  
13 graphs (1) and (3) of subsection (b).

14 (d) GRANTS FOR MULTIDISCIPLINARY TREATMENT  
15 AND COORDINATION.—

16 (1) IN GENERAL.—The Secretary of Health and  
17 Human Services (in this section referred to as the  
18 “Secretary”) shall award grants on a competitive  
19 basis to eligible entities for the purpose of creating  
20 or enhancing capacity to treat patients with Long  
21 COVID through a multidisciplinary approach. The  
22 term “multidisciplinary” in this section refers to the  
23 coordinated work to provide care or treatment to a  
24 patient by physicians and other professionals, such  
25 as specialty or subspecialty providers, nurses and

1 nurse care coordinators, dietitians, nutritionists, so-  
2 cial workers, behavioral health professionals, phys-  
3 ical and occupational therapists, speech pathologists,  
4 or any professionals determined to be appropriate by  
5 the State and approved by the Administrator of the  
6 Centers for Medicare & Medicaid Services.

7 (2) USE OF FUNDS.—An eligible entity receiv-  
8 ing a grant under this section shall use the grant,  
9 for the purpose described in subsection (a), to—

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

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

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

23 (A)(i) operates an existing multidisci-  
24 plinary Long COVID clinic or other specialized  
25 Long COVID program; or

1 (ii) is an existing health care provider with  
2 experience providing care for individuals with  
3 Long COVID and who demonstrates an intent  
4 to create a multidisciplinary Long COVID clinic  
5 or other specialized Long COVID program;

6 (B) submits to the Secretary an applica-  
7 tion at such time, in such manner, and con-  
8 taining such information and assurances as the  
9 Secretary may require; and

10 (C) employs a framework that incentivizes  
11 participants to attain the program's goals to es-  
12 tablish and disseminate best practices, and allo-  
13 cates funds based on such attainment.

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

16 (5) PRIORITY.—In awarding grants under this  
17 subsection, the Secretary shall give priority to eligi-  
18 ble entities that—

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

22 (B) demonstrate capacity (or an intent to  
23 build capacity) to provide personalized treat-  
24 ment and facilitate patient access to multidisci-  
25 plinary health care providers with expertise in

1           treating Long COVID symptoms, including  
2           such providers who are primary and specialty  
3           care physicians (such as psychiatrists, neurolo-  
4           gists, cardiologists, immunologists, and  
5           pulmonologists), therapists, nurses, care coordi-  
6           nators, social workers, nutritionists, and behav-  
7           ioral health specialists; and

8                   (C) submit a plan to ensure ongoing multi-  
9           disciplinary continuing education on infection-  
10          triggered conditions for—

11                   (i) physicians treating Long COVID;

12                   and

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

17          (e) **EQUITABLE ACCESS.**—In order to ensure equi-  
18          table access treatment—

19                   (1) no grantee under this section shall deny ac-  
20          cess to treatment with respect to Long COVID  
21          based on insurance coverage, date of diagnosis, or  
22          previous hospitalization;

23                   (2) a grantee under this section shall with re-  
24          spect to Long COVID—

1 (A) offer equity-centered resources (such  
2 as the ability to offer resources in various lan-  
3 guages), information, and training to safety net  
4 health systems; and

5 (B) disseminate to individuals and organi-  
6 zations that provide care best practices and  
7 treatment approaches that enhance access to  
8 high-quality care to everyone where they live;  
9 and

10 (3) treatment for Long COVID shall be in-  
11 cluded as a COVID–19 treatment, consistent with  
12 the American Rescue Plan Act of 2021 (Public Law  
13 117–2).

14 (f) DEVELOPMENT OF EVIDENCE-BASED STRATE-  
15 GIES FOR HIGH-VALUE CARE FOR INDIVIDUALS WITH  
16 LONG COVID.—

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

24 (A) supporting the generation of evidence  
25 about how to deliver high quality, high-value



1 health care for individuals with Long COVID  
2 for the treatment of the condition;

3 (B) creating tools and strategies to help  
4 health systems and hospitals, primary and spe-  
5 cialty physicians, nurses, allied health care pro-  
6 fessionals, and caregivers provide high-quality,  
7 high-value care for individuals with Long  
8 COVID; and

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

13 (2) ELIGIBILITY.—The Secretary shall, through  
14 rulemaking, specify a process for evaluating and de-  
15 termining the eligibility of primary care providers in-  
16 cluding Federally qualified health centers and rural  
17 health clinics; specialty care providers, hospitals,  
18 health systems, academic medical centers; and other  
19 entities for receiving a grant under this subsection.  
20 Such rules shall prohibit grant funds from being  
21 used to compensate or reimburse individuals or orga-  
22 nizations excluded pursuant to section 1128 of the  
23 Social Security Act (42 U.S.C. 1320a–7) from par-  
24 ticipation under the Medicare program under title  
25 XVIII of such Act.

1 (g) LONG COVID DEFINED.—For purposes of this  
2 Act, the term “Long COVID” (also referred to as “post-  
3 acute sequelae of COVID–19”, “post-COVID conditions”,  
4 or “persistent symptoms post-COVID”) means the ongoing  
5 sequelae of COVID–19 that some individuals experience  
6 after infection with the SARS–CoV–2 virus, as diagnosed  
7 by a qualified health care provider. Such sequelae  
8 are defined as the “Post-COVID Conditions” identified  
9 and defined by the Centers for Disease Control and Prevention  
10 in 2021, or in subsequent revisions by the Centers  
11 for Disease Control and Prevention.

12 (h) REPORTS.—

13 (1) ANNUAL REPORTS BY GRANTEES TO SECRETARY.—On an annual basis, a recipient of a grant  
14 under this section shall—  
15

16 (A) submit to the Secretary, and make  
17 publicly available, a report on the activities carried out through the grant; and  
18

19 (B) include evaluations of such activities,  
20 including the experience of individuals who received health care through such grant.  
21

22 (2) ANNUAL REPORTS BY SECRETARY TO CONGRESS.—Not later than the end of each of fiscal  
23 years 2024 through 2026, the Secretary shall submit  
24

1 to the Congress, and make publicly available, a re-  
2 port that—

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

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

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

10 (i) AUTHORIZATION OF APPROPRIATIONS.—

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

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

20 **SEC. 3. NATIONAL LONG COVID TECHNICAL ASSISTANCE**  
21 **DISSEMINATION PROGRAM.**

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

24 (1) establish a structured process to seek ongo-  
25 ing input from medical societies representing pri-

1       mary care, specialty care, and subspecialty care re-  
2       garding the proven and promising practices for  
3       treating individuals who are diagnosed with Long  
4       COVID to support their wellness and recovery; and

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

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

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

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

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

22              (4) The organization consults with medical spe-  
23      cialty associations for purposes of developing and  
24      distributing clinical best practices for Long COVID  
25      diagnosis and treatment.

1 **SEC. 4. MENTAL HEALTH AND SUICIDE PREVENTION AND**  
2 **TREATMENT.**

3 Section 1911(b)(1) of the Public Health Service Act  
4 (42 U.S.C. 300x(b)(1)) is amended by inserting “and, for  
5 each of fiscal years 2024 through 2026, individuals with  
6 Long COVID (as defined in section 2 of the Long COVID  
7 RECOVERY NOW Act) who have also been diagnosed  
8 with a mental health condition (such as a serious mental  
9 illness or a serious emotional disturbance)” after  
10 “1912(c)”.

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

12 (a) IN GENERAL.—Not later than 6 months after the  
13 date of the enactment of this Act, the Secretary of Health  
14 and Human Services, acting through the National Coordi-  
15 nator for Health Information Technology, shall convene  
16 health care stakeholders to identify potential best prac-  
17 tices for collecting, aggregating, and disseminating to  
18 health care researchers deidentified data that promotes  
19 learning about Long COVID and supports the further re-  
20 search of the characteristics of individuals diagnosed with  
21 Long COVID.

22 (b) REPORT.—Not later than 160 days after the first  
23 meeting of such stakeholders pursuant to subsection (a),  
24 the Secretary shall submit to Congress (and make publicly  
25 available on the website of the Office of the National Coordi-  
26 nator of Health Information Technology) a report sum-

1 marizing the meetings and findings of the stakeholders as  
2 well as any recommendations, including recommendations  
3 on ways that federal health care policy can better support  
4 an understanding of the etiology, characteristics, care and  
5 potential treatments for individuals Long COVID to sup-  
6 port individuals' recovery and wellness. Such recommenda-  
7 tions shall—

8           (1) take into account the perspectives of health  
9       data scientists, health services researchers, medical  
10      providers, health plans, hospitals and health sys-  
11      tems, epidemiologists, public health experts, patient  
12      representatives and groups, health information tech-  
13      nology companies, and other stakeholders; and

14           (2) be informed by public and private sector ef-  
15      forts to characterize Long COVID, aggregate and  
16      disaggregate data, and promote data standardiza-  
17      tion, data standards, or open data access for fur-  
18      thering a greater understanding of Long COVID.

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

20       Not later than 6 months after the date of the enact-  
21      ment of this Act, the Secretary of Health and Human  
22      Services shall, in consultation with medical societies rep-  
23      resenting the perspectives of primary care, specialty care,  
24      mental health professionals, medical researchers (includ-  
25      ing through the National Institutes of Health), public

1 health experts (including the Centers for Disease Control  
2 and Prevention), and patient advocates, implement a Fed-  
3 eral website (which may be implemented through an exist-  
4 ing public website of the Department of Health and  
5 Human Services) that—

6           (1) collects, and curates educational materials  
7           for health care providers and consumers about Long  
8           COVID (as defined in section 2(e)) symptoms, diag-  
9           nosis, characteristics, treatment, and access to care;  
10          and

11          (2) includes, or provides a link to, comprehen-  
12          sive educational resources for health care providers,  
13          such as the interim guidance (and subsequent up-  
14          dates) for health care providers published by the  
15          Centers for Disease Control and Prevention on how  
16          to treat individuals with Long COVID.

17 **SEC. 7. PROVIDING SUPPORT FOR LONG COVID REG-**  
18 **ISTRIES.**

19          (a) IN GENERAL.—Not later than one year after the  
20 date of the enactment of this Act, the Secretary of Health  
21 and Human Services, acting through the Director of the  
22 Agency for Healthcare Research and Quality shall, subject  
23 to appropriations pursuant to subsection (d), award multi-  
24 year grants to eligible entities described in subsection (b)  
25 for the purposes of—

1           (1) supporting existing or creating new Longi-  
2           tudinal registries of patients with Long COVID (as  
3           defined in section 2(g));

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

8           (3) utilize data from such registries to help in-  
9           form understanding regarding the efficacy of care,  
10          diagnostics, therapeutics, care pathways, behavioral  
11          health interventions, and other dynamics regarding  
12          individuals with Long COVID; and

13          (4) informing health care providers' efforts re-  
14          lated to improving equitable access to health care by  
15          collecting data through such registries from individ-  
16          uals with Long COVID, including social needs, med-  
17          ical history, race and ethnicity, language, gender,  
18          and disability status, as specified by the Secretary of  
19          Health and Human Services.

20          (b) ELIGIBLE ENTITIES.—

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

23                         (A) submit an application to the Secretary  
24                         in such form and manner as the Secretary may  
25                         require;



1 (B) agree to adhere to such data defini-  
2 tions and standards as the Secretary may re-  
3 quire, including privacy and security require-  
4 ments, requirements to make findings of the or-  
5 ganization, and the use of open-source tech-  
6 nology to promote the dissemination of informa-  
7 tion related to Long COVID;

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

12 (D) demonstrate to the Secretary, in a  
13 form and manner specified by the Secretary,  
14 that the entity has in place appropriate stand-  
15 ards for handling proprietary, confidential, and  
16 medical information securely and in a manner  
17 that is compliant with applicable law;

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

22 (F) be an organization described in para-  
23 graph (2).



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

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

5 (3) by adding at the end the following new sub-  
6 clause:

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

10 (b) HEALTH HOMES FOR CHILDREN WITH MEDI-  
11 CALLY COMPLEX CONDITIONS.—Section  
12 1945A(i)(1)(A)(ii) of the Social Security Act (42 U.S.C.  
13 1396w-4a(i)(1)(A)(ii)) is amended—

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

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

18 (3) by adding at the end the following new sub-  
19 clause:

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

23 **SEC. 9. STATE HEALTH OFFICIALS GUIDANCE.**

24 Not later than 18 months after the date of the enact-  
25 ment of this Act, the Secretary of Health and Human

1 Services shall issue guidance to State health officials speci-  
2 fying tools and strategies that may help States improve  
3 the health and wellness of individuals enrolled under the  
4 Medicaid program under title XIX of the Social Security  
5 Act or the Children’s Health Insurance Program under  
6 title XXI of such Act who have been diagnosed with Long  
7 COVID by facilitating strong primary care and supporting  
8 linkages to specialists, relevant social supports, or commu-  
9 nity-based organizations at the local level, that can help  
10 support the recovery and wellness of such individuals.

11 **SEC. 10. SUPPORT UNDER MEDICAID FOR STATE COLLEC-**  
12 **TION OF LONG COVID DATA.**

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

16 “(I) 75 percent of the sums expended during a  
17 fiscal year quarter in 2024, 2025, or 2026 as are at-  
18 tributable to the collection and reporting of claims  
19 and encounter data on Long COVID (including  
20 identification of race, language, ethnicity, and dura-  
21 tion of treatment) using the ICD–10 code U09.9  
22 post COVID–19 condition, unspecified (or any suc-  
23 cessor to such code);”.

1 **SEC. 11. GRANTS FOR PEDIATRIC RESEARCH ON LONG**  
2 **COVID.**

3 (a) **IN GENERAL.**—The Secretary of Health and  
4 Human Services, acting through the Director of the Na-  
5 tional Institutes of Health (in this section, referred to as  
6 the “Secretary”), shall award grants to eligible entities to  
7 conduct research on Long COVID in pediatric popu-  
8 lations.

9 (b) **USE OF FUNDS.**—An eligible entity selected to  
10 receive a grant under this subsection may use funds re-  
11 ceived through the grant to conduct research described in  
12 subsection (a), with a focus on pediatric immune system  
13 responses and neurodevelopment.

14 (c) **ELIGIBLE ENTITY DEFINED.**—In this section, the  
15 term “eligible entity” means a children’s hospital, pedi-  
16 atric researcher, pediatrician, academic medical center, or  
17 other organization determined appropriate by the Sec-  
18 retary.

19 (d) **AUTHORIZATION OF APPROPRIATIONS.**—To carry  
20 out this section, there are authorized to be appropriated  
21 such sums as may be necessary for each of fiscal years  
22 2024 through 2026.

○