

116TH CONGRESS
2D SESSION

H. R. 8205

To amend the Public Health Service Act to expand, enhance, and improve applicable public health data systems used by the Centers for Disease Control and Prevention, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 11, 2020

Ms. CASTOR of Florida (for herself, Ms. UNDERWOOD, and Ms. HAALAND) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Natural Resources, and Oversight and Reform, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend the Public Health Service Act to expand, enhance, and improve applicable public health data systems used by the Centers for Disease Control and Prevention, 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.**

4 This Act may be cited as the “Ensuring Transparent
5 Honest Information on COVID–19 Act” or the “ETHIC
6 Act”.

1 **SEC. 2. REQUIRED REPORTING BY STATE, LOCAL, TRIBAL,**
2 **OR TERRITORIAL GOVERNMENTS REGARD-**
3 **ING COVID-19.**

4 (a) IN GENERAL.—As a condition on receipt of funds
5 through a covered grant or cooperative agreement, a
6 State, local, Tribal, or territorial government shall agree
7 to direct the appropriate State, local, Tribal, or territorial
8 governmental entity (including any public health depart-
9 ment thereof) to report to the Centers for Disease Control
10 and Prevention, with respect to the jurisdiction involved
11 and COVID-19—

12 (1) on a daily basis, the information listed in
13 subsection (c); and

14 (2) on a weekly basis, the information listed in
15 subsection (d).

16 (b) TRIBAL WAIVER.—

17 (1) REVIEW AND DISPOSITION.—Upon the re-
18 ceipt of a written request from a Tribal government,
19 or consortia thereof, for a waiver of the conditions
20 specified in paragraphs (1) and (2) of subsection
21 (a), the Director of the Centers for Disease Control
22 and Prevention shall, not later than 30 days after
23 receipt of such request, approve or deny it.

24 (2) DENIALS.—In the case of a denial of a re-
25 quest under paragraph (1), the Director of the Cen-
26 ters for Disease Control and Prevention shall—

1 (A) provide to the requestor a written ex-
2 planation of the reasons for the denial; and

3 (B) provide the requestor with an oppor-
4 tunity to correct any deficiencies in the request.

5 (c) COVERED GRANT OR COOPERATIVE AGREE-
6 MENT.—For purposes of this section, a covered grant or
7 cooperative agreement is any grant or cooperative agree-
8 ment awarded under any of the following laws (including
9 any amendment made thereby):

10 (1) This Act.

11 (2) The Coronavirus Preparedness and Re-
12 sponse Supplemental Appropriations Act, 2020
13 (Public Law 116–123).

14 (3) The Families First Coronavirus Response
15 Act (Public Law 116–127).

16 (4) The CARES Act (Public Law 116–136).

17 (5) The Paycheck Protection Program and
18 Health Care Enhancement Act (Public Law 116–
19 139).

20 (d) DAILY REPORTING.—The information to be re-
21 ported daily pursuant to subsection (a)(1) consists of the
22 following:

23 (1) Demographic characteristics, including, in a
24 de-identified, disaggregated, and stratified manner,
25 race, ethnicity, age, sex, geographic region, and

1 other relevant factors of individuals tested for or di-
2 agnosed with COVID–19, to the extent such infor-
3 mation is available.

4 (2) The number of adults with a confirmed case
5 of COVID–19 who are hospitalized in an intensive
6 care bed.

7 (3) The number of adults with a suspected case
8 of COVID–19 who are hospitalized in an intensive
9 care bed.

10 (4) The number of adults with a confirmed case
11 of COVID–19 who are hospitalized in an inpatient
12 care bed.

13 (5) The number of adults with a suspected case
14 of COVID–19 who are hospitalized in an inpatient
15 care bed.

16 (6) The number of children with a confirmed
17 case of COVID–19 who are hospitalized in an inten-
18 sive care bed.

19 (7) The number of children with a suspected
20 case of COVID–19 who are hospitalized in an inten-
21 sive care bed.

22 (8) The number of children with a confirmed
23 case of COVID–19 who are hospitalized in an inpa-
24 tient care bed.

1 (9) The number of children with a suspected
2 case of COVID–19 who are hospitalized in an inpa-
3 tient care bed.

4 (10) Out of the maximum number of beds for
5 which hospitals are licensed to operate, the percent-
6 age occupied by confirmed or suspected COVID–19
7 patients.

8 (11) Total staffed hospital beds.

9 (12) The numbers of diagnostic and serological
10 tests administered for COVID–19, disaggregated
11 and stratified by—

12 (A) the type of test; and

13 (B) the testing positivity rate of each type
14 of test.

15 (13) The median turnaround time for diag-
16 nostic tests stratified by molecular and antigen tests.

17 (14) The percentage of new cases of COVID–
18 19 linked to at least one other case, and if such new
19 cases are part of a known outbreak, identification of
20 such outbreak.

21 (15) The rate of transmission of COVID–19.

22 (16) The number of confirmed and probable
23 deaths as a result of COVID–19, de-identified and
24 stratified by race, ethnicity, age, sex, geographic re-
25 gion, and other relevant factors.

1 (17) Such other information as the Director of
2 the Centers for Disease Control and Prevention
3 deems to be relevant.

4 (e) WEEKLY REPORTING.—The information to be re-
5 ported weekly pursuant to subsection (a)(2) consists of the
6 following:

7 (1) New infections of health care workers not
8 confirmed to have contracted COVID–19 outside of
9 the workplace.

10 (2) The median time between collection of
11 specimens for diagnostic tests for COVID–19 and
12 isolation of cases.

13 (3) The percentage of new cases of COVID–19
14 among quarantined contacts.

15 (4) Such other information as the Director of
16 the Centers for Disease Control and Prevention
17 deems to be relevant.

18 (f) PUBLIC POSTING OF REPORTED DATA.—On a
19 daily basis, the Director of the Centers for Disease Control
20 and Prevention shall make the information reported pur-
21 suant to this section, excluding personally identifiable in-
22 formation, publicly available on the website of the Centers
23 for Disease Control and Prevention.

24 (g) APPLICABILITY.—The condition on funding in
25 subsection (a) applies with respect to the obligation and

1 expenditure by the Federal Government of funds through
2 a covered grant or cooperative agreement on or after the
3 date of enactment of this Act, including with respect to
4 covered grants and cooperative agreements awarded before
5 such date.

6 **SEC. 3. PUBLIC HEALTH DATA SYSTEM TRANSFORMATION.**

7 Subtitle C of title XXVIII of the Public Health Serv-
8 ice Act (42 U.S.C. 300hh–31 et seq.) is amended by add-
9 ing at the end the following:

10 **“SEC. 2823. PUBLIC HEALTH DATA SYSTEM TRANS-**
11 **FORMATION.**

12 “(a) EXPANDING CDC AND PUBLIC HEALTH DE-
13 PARTMENT CAPABILITIES.—

14 “(1) IN GENERAL.—The Secretary, acting
15 through the Director of the Centers for Disease
16 Control and Prevention, shall—

17 “(A) conduct activities to expand, enhance,
18 and improve applicable public health data sys-
19 tems used by the Centers for Disease Control
20 and Prevention, related to the interoperability
21 and improvement of such systems (including as
22 it relates to preparedness for, prevention and
23 detection of, and response to public health
24 emergencies); and

1 “(B) award grants or cooperative agree-
2 ments to State, local, Tribal, or territorial pub-
3 lic health departments for the expansion and
4 modernization of public health data systems, to
5 assist public health departments in—

6 “(i) assessing current data infrastruc-
7 ture capabilities and gaps to improve and
8 increase consistency in data collection,
9 storage, and analysis and, as appropriate,
10 to improve dissemination of public health-
11 related information;

12 “(ii) improving secure public health
13 data collection, transmission, exchange,
14 maintenance, and analysis;

15 “(iii) improving the secure exchange
16 of data between the Centers for Disease
17 Control and Prevention, State, local, Trib-
18 al, and territorial public health depart-
19 ments, public health organizations, and
20 health care providers, including by public
21 health officials in multiple jurisdictions
22 within such State, as appropriate, and by
23 simplifying and supporting reporting by
24 health care providers, as applicable, pursu-

1 ant to State law, including through the use
2 of health information technology;

3 “(iv) enhancing the interoperability of
4 public health data systems (including sys-
5 tems created or accessed by public health
6 departments) with health information tech-
7 nology, including with health information
8 technology certified under section
9 3001(c)(5);

10 “(v) supporting and training data sys-
11 tems, data science, and informatics per-
12 sonnel;

13 “(vi) supporting earlier disease and
14 health condition detection, such as through
15 near real-time data monitoring, to support
16 rapid public health responses;

17 “(vii) supporting activities within the
18 applicable jurisdiction related to the expan-
19 sion and modernization of electronic case
20 reporting; and

21 “(viii) developing and disseminating
22 information related to the use and impor-
23 tance of public health data.

24 “(2) DATA STANDARDS.—In carrying out para-
25 graph (1), the Secretary, acting through the Direc-

1 tor of the Centers for Disease Control and Preven-
2 tion, shall, as appropriate and in consultation with
3 the National Coordinator for Health Information
4 Technology and the Director of the Indian Health
5 Service, designate data and technology standards
6 (including standards for interoperability) for public
7 health data systems, with deference given to stand-
8 ards published by consensus-based standards devel-
9 opment organizations with public input and vol-
10 untary consensus-based standards bodies.

11 “(3) TRIBAL CONSULTATION.—The Director of
12 the Centers for Disease Control and Prevention, the
13 National Coordinator for Health Information Tech-
14 nology, and Director of the Indian Health Service,
15 shall jointly consult with Indian Tribes and Tribal
16 organizations prior to designating the data and tech-
17 nology standards under paragraph (2).

18 “(4) PUBLIC-PRIVATE PARTNERSHIPS.—The
19 Secretary may develop and utilize public-private
20 partnerships for technical assistance, training, and
21 related implementation support for State, local,
22 Tribal, and territorial public health departments,
23 and the Centers for Disease Control and Prevention,
24 on the expansion and modernization of electronic

1 case reporting and public health data systems, as
2 applicable.

3 “(b) REQUIREMENTS.—

4 “(1) HEALTH INFORMATION TECHNOLOGY
5 STANDARDS.—The Secretary may not award a grant
6 or cooperative agreement under subsection (a)(1)(B)
7 unless the applicant uses or agrees to use standards
8 endorsed by the National Coordinator for Health In-
9 formation Technology pursuant to section
10 3001(e)(1) or adopted by the Secretary under sec-
11 tion 3004.

12 “(2) WAIVER.—The Secretary may waive the
13 requirement under paragraph (1) with respect to an
14 applicant if the Secretary determines that the activi-
15 ties under subsection (a)(1)(B) cannot otherwise be
16 carried out within the applicable jurisdiction.

17 “(3) APPLICATION.—A State, local, Tribal, or
18 territorial health department applying for a grant or
19 cooperative agreement under this section shall sub-
20 mit an application to the Secretary at such time and
21 in such manner as the Secretary may require. Such
22 application shall include information describing—

23 “(A) the activities that will be supported
24 by the grant or cooperative agreement; and

1 “(B) how the modernization of the public
2 health data systems involved will support or im-
3 pact the public health infrastructure of the
4 health department, including a description of
5 remaining gaps, if any, and the actions needed
6 to address such gaps.

7 “(c) STRATEGY AND IMPLEMENTATION PLAN.—Not
8 later than 180 days after the date of enactment of this
9 section, the Secretary, acting through the Director of the
10 Centers for Disease Control and Prevention, shall submit
11 to the Committee on Health, Education, Labor, and Pen-
12 sions of the Senate and the Committee on Energy and
13 Commerce of the House of Representatives a coordinated
14 strategy and an accompanying implementation plan that
15 identifies and demonstrates the measures the Secretary
16 will utilize to—

17 “(1) update and improve applicable public
18 health data systems used by the Centers for Disease
19 Control and Prevention; and

20 “(2) carry out the activities described in this
21 section to support the improvement of State, local,
22 Tribal, and territorial public health data systems.

23 “(d) CONSULTATION.—The Secretary, acting
24 through the Director of the Centers for Disease Control
25 and Prevention, shall consult with State, local, Tribal, and

1 territorial health departments, professional medical and
2 public health associations, associations representing hos-
3 pitals or other health care entities, health information
4 technology experts, and other appropriate public or private
5 entities regarding the implementation of the grant pro-
6 gram under subsection (a) and the development of the co-
7 ordinated strategy and accompanying implementation plan
8 under subsection (c).

9 “(e) TECHNICAL ASSISTANCE AND TRAINING.—In
10 carrying out this section, the Secretary may provide tech-
11 nical assistance and training related to—

12 “(1) the exchange of information by public
13 health data systems used by relevant health care and
14 public health entities at the local, State, Federal,
15 Tribal, and territorial levels; or

16 “(2) the development and utilization of public-
17 private partnerships for implementation support ap-
18 plicable to this section.

19 “(f) REPORT TO CONGRESS.—Not later than 1 year
20 after the date of enactment of this section, the Secretary
21 shall submit a report to the Committee on Health, Edu-
22 cation, Labor, and Pensions of the Senate and the Com-
23 mittee on Energy and Commerce of the House of Rep-
24 resentatives that includes—

25 “(1) a description of any barriers to—

1 “(A) public health authorities imple-
2 menting interoperable public health data sys-
3 tems and electronic case reporting;

4 “(B) the exchange of information pursuant
5 to electronic case reporting; or

6 “(C) reporting by health care providers
7 using such public health data systems, as ap-
8 propriate, and pursuant to State law;

9 “(2) an assessment of the potential public
10 health impact of implementing electronic case re-
11 porting and interoperable public health data sys-
12 tems; and

13 “(3) a description of the activities carried out
14 pursuant to this section.

15 “(g) ELECTRONIC CASE REPORTING.—In this sec-
16 tion, the term ‘electronic case reporting’ means the auto-
17 mated identification, generation, and bilateral exchange of
18 reports of health events among electronic health record or
19 health information technology systems and public health
20 authorities.

21 “(h) AUTHORIZATION OF APPROPRIATIONS.—To
22 carry out this section, there is authorized to be appro-
23 priated \$450,000,000, to remain available until expended.

24 “(i) TRIBAL SET-ASIDE.—Of the amounts authorized
25 under subsection (h), no less than 3 percent, but up to

1 5 percent of such funds, shall be reserved for noncompeti-
2 tive grants or cooperative agreements to Indian Tribes and
3 Tribal organizations (as those terms are defined under
4 section 4 of the Indian Self-Determination and Education
5 Assistance Act).”.

6 **SEC. 4. CORE PUBLIC HEALTH INFRASTRUCTURE FOR**
7 **STATE, LOCAL, TRIBAL, AND TERRITORIAL**
8 **HEALTH DEPARTMENTS.**

9 (a) PROGRAM.—The Secretary of Health and Human
10 Services (in this section referred to as the “Secretary”),
11 acting through the Director of the Centers for Disease
12 Control and Prevention, shall establish a core public
13 health infrastructure program consisting of awarding
14 grants under subsection (b).

15 (b) GRANTS.—

16 (1) AWARD.—For the purpose of addressing
17 core public health infrastructure needs, the Sec-
18 retary—

19 (A) shall award a grant to each State
20 health department;

21 (B) shall award grants to, or enter into co-
22 operative agreements with, Indian Tribes and
23 Tribal organizations on a noncompetitive basis;
24 and

1 (C) may award grants on a competitive
2 basis to State, local, Tribal, or territorial health
3 departments.

4 (2) ALLOCATION.—Of the total amount of
5 funds awarded as grants under this subsection for a
6 fiscal year—

7 (A) not less than 50 percent shall be for
8 grants to State health departments under para-
9 graph (1)(A);

10 (B) not less than 5 percent shall be for
11 grants awarded to, or cooperative agreements
12 with, Indian Tribes and Tribal organizations
13 under paragraph (1)(B); and

14 (C) not less than 30 percent shall be for
15 grants to State, local, Tribal, or territorial
16 health departments under paragraph (1)(C).

17 (c) USE OF FUNDS.—A State, local, Tribal, or terri-
18 torial health department receiving a grant under sub-
19 section (b) shall use the grant funds to address core public
20 health infrastructure needs, including those identified in
21 the accreditation process under subsection (g).

22 (d) FORMULA GRANTS TO STATE HEALTH DEPART-
23 MENTS.—In making grants under subsection (b)(1)(A),
24 the Secretary shall award funds to each State health de-
25 partment in accordance with—

1 (1) a formula based on population size, burden
2 of preventable disease and disability, and core public
3 health infrastructure gaps, including those identified
4 in the accreditation process under subsection (g);
5 and

6 (2) application requirements established by the
7 Secretary, including a requirement that the State
8 health department submit a plan that demonstrates
9 to the satisfaction of the Secretary that the State’s
10 health department will—

11 (A) address its highest priority core public
12 health infrastructure needs; and

13 (B) as appropriate, allocate funds to local
14 health departments within the State.

15 (e) FORMULA GRANTS TO INDIAN TRIBES AND TRIB-
16 AL ORGANIZATIONS.—In making grants under subsection
17 (b)(1)(B), the Secretary shall coordinate with the Director
18 of the Indian Health Service to award funds to Indian
19 Tribes and Tribal organizations according to—

20 (1) a formula that ensures baseline funding on
21 a noncompetitive basis for each Indian Tribe or
22 Tribal organization, or a consortia thereof, that sub-
23 mits an application; and

24 (2) awards funds above the baseline according
25 to population size, gaps in public health infrastruc-

1 ture, or other criteria derived through consultation
2 with Indian Tribes and Tribal organizations.

3 (f) COMPETITIVE GRANTS TO STATE, LOCAL, TRIB-
4 AL, AND TERRITORIAL HEALTH DEPARTMENTS.—In
5 making grants under subsection (b)(1)(C), the Secretary
6 shall give priority to applicants demonstrating core public
7 health infrastructure needs identified in the accreditation
8 process under subsection (g).

9 (g) MAINTENANCE OF EFFORT.—

10 (1) IN GENERAL.—Except as provided in para-
11 graph (2), the Secretary may award a grant to an
12 entity under subsection (b) only if the entity dem-
13 onstrates to the satisfaction of the Secretary that—

14 (A) funds received through the grant will
15 be expended only to supplement, and not sup-
16 plant, non-Federal and Federal funds otherwise
17 available to the entity for the purpose of ad-
18 dressing core public health infrastructure needs;
19 and

20 (B) with respect to activities for which the
21 grant is awarded, the entity will maintain ex-
22 penditures of non-Federal amounts for such ac-
23 tivities at a level not less than the level of such
24 expenditures maintained by the entity for the

1 fiscal year preceding the fiscal year for which
2 the entity receives the grant.

3 (2) EXCEPTION.—The requirement under para-
4 graph (1) shall not apply with respect to a grant
5 awarded under subsection (b)(1)(B).

6 (h) ESTABLISHMENT OF A PUBLIC HEALTH ACCRED-
7 ITATION PROGRAM.—

8 (1) IN GENERAL.—The Secretary shall—

9 (A) develop, and periodically review and
10 update, standards for voluntary accreditation of
11 State, local, Tribal, and territorial health de-
12 partments and public health laboratories for the
13 purpose of advancing the quality and perform-
14 ance of such departments and laboratories; and

15 (B) implement a program to accredit such
16 health departments and laboratories in accord-
17 ance with such standards.

18 (2) COOPERATIVE AGREEMENT.—The Secretary
19 may enter into a cooperative agreement with a pri-
20 vate nonprofit entity to carry out paragraph (1).

21 (i) REPORT.—The Secretary shall submit to the Con-
22 gress an annual report on progress being made to accredit
23 entities under subsection (g), including—

24 (1) a strategy, including goals and objectives,
25 for accrediting entities under subsection (g) and

1 achieving the purpose described in subsection
2 (g)(1)(A);

3 (2) identification of gaps in research related to
4 core public health infrastructure; and

5 (3) recommendations of priority areas for such
6 research.

7 (j) DEFINITION.—In this section, the term “core pub-
8 lic health infrastructure” includes—

9 (1) workforce capacity and competency;

10 (2) laboratory systems;

11 (3) testing capacity, including test platforms,
12 mobile testing units, and personnel;

13 (4) health information, health information sys-
14 tems, and health information analysis;

15 (5) disease surveillance;

16 (6) contact tracing;

17 (7) communications;

18 (8) financing;

19 (9) other relevant components of organizational
20 capacity; and

21 (10) other related activities.

22 (k) AUTHORIZATION OF APPROPRIATIONS.—To carry
23 out this section, there is authorized to be appropriated
24 \$6,000,000,000, to remain available until expended.

1 **SEC. 5. CORE PUBLIC HEALTH INFRASTRUCTURE AND AC-**
2 **TIVITIES FOR CDC.**

3 (a) IN GENERAL.—The Secretary of Health and
4 Human Services (in this section referred to as the “Sec-
5 retary”), acting through the Director of the Centers for
6 Disease Control and Prevention, shall expand and improve
7 the core public health infrastructure and activities of the
8 Centers for Disease Control and Prevention to address
9 unmet and emerging public health needs.

10 (b) REPORT.—The Secretary shall submit to the Con-
11 gress an annual report on the activities funded through
12 this section.

13 (c) DEFINITION.—In this section, the term “core
14 public health infrastructure” has the meaning given to
15 such term in section 3.

16 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
17 out this section, there is authorized to be appropriated
18 \$1,000,000,000, to remain available until expended.

19 **SEC. 6. MODERNIZATION OF STATE AND LOCAL HEALTH IN-**
20 **EQUITIES DATA.**

21 (a) IN GENERAL.—Not later than 6 months after the
22 date of enactment of this Act, the Secretary of Health and
23 Human Services (in this section referred to as the “Sec-
24 retary”), acting through the Director of the Centers for
25 Disease Control and Prevention, shall award grants to
26 State, local, and territorial health departments in order

1 to support the modernization of data collection methods
2 and infrastructure for the purposes of increasing data re-
3 lated to health inequities, such as racial, ethnic, socio-
4 economic, sex, gender, and disability disparities. The Sec-
5 retary shall—

6 (1) provide guidance, technical assistance, and
7 information to grantees under this section on best
8 practices regarding culturally competent, accurate,
9 and increased data collection and transmission; and

10 (2) track performance of grantees under this
11 section to help improve their health inequities data
12 collection by identifying gaps and taking effective
13 steps to support States, localities, and territories in
14 addressing the gaps.

15 (b) REPORT.—Not later than 1 year after the date
16 on which the first grant is awarded under this section,
17 the Secretary shall submit to the Committee on Energy
18 and Commerce of the House of Representatives and the
19 Committee on Health, Education, Labor, and Pensions of
20 the Senate an initial report detailing—

21 (1) nationwide best practices for ensuring
22 States and localities collect and transmit health in-
23 equities data;

24 (2) nationwide trends which hinder the collec-
25 tion and transmission of health inequities data;

1 (3) Federal best practices for working with
2 States and localities to ensure culturally competent,
3 accurate, and increased data collection and trans-
4 mission; and

5 (4) any recommended changes to legislative or
6 regulatory authority to help improve and increase
7 health inequities data collection.

8 (c) FINAL REPORT.—Not later than December 31,
9 2023, the Secretary shall—

10 (1) update and finalize the initial report under
11 subsection (b); and

12 (2) submit such final report to the committees
13 specified in such subsection.

14 (d) AUTHORIZATION OF APPROPRIATIONS.—There is
15 authorized to be appropriated to carry out this section
16 \$100,000,000, to remain available until expended.

17 **SEC. 7. TRIBAL FUNDING TO RESEARCH HEALTH INEQUI-**
18 **TIES INCLUDING COVID-19.**

19 (a) IN GENERAL.—Not later than 6 months after the
20 date of enactment of this Act, the Director of the Indian
21 Health Service, in coordination with Tribal epidemiology
22 centers and other Federal agencies, as appropriate, shall
23 conduct or support research and field studies for the pur-
24 poses of improved understanding of Tribal health inequi-

1 ties among American Indians and Alaska Natives, includ-
2 ing with respect to—

- 3 (1) disparities related to COVID–19;
- 4 (2) public health surveillance and infrastructure
5 regarding unmet needs in Indian country and Urban
6 Indian communities;
- 7 (3) population-based health disparities;
- 8 (4) barriers to health care services;
- 9 (5) the impact of socioeconomic status; and
- 10 (6) factors contributing to Tribal health inequi-
11 ties.

12 (b) CONSULTATION, CONFER, AND COORDINATION.—
13 In carrying out this section, the Director of the Indian
14 Health Service shall—

- 15 (1) consult with Indian Tribes and Tribal orga-
16 nizations;
- 17 (2) confer with Urban Indian organizations;
- 18 and
- 19 (3) coordinate with the Director of the Centers
20 for Disease Control and Prevention and the Director
21 of the National Institutes of Health.

22 (c) PROCESS.—Not later than 60 days after the date
23 of enactment of this Act, the Director of the Indian Health
24 Service shall establish a nationally representative panel to
25 establish processes and procedures for the research and

1 field studies conducted or supported under subsection (a).
2 The Director shall ensure that, at a minimum, the panel
3 consists of the following individuals:

4 (1) Elected Tribal leaders or their designees.

5 (2) Tribal public health practitioners and ex-
6 perts from the national and regional levels.

7 (d) DUTIES.—The panel established under subsection
8 (c) shall, at a minimum—

9 (1) advise the Director of the Indian Health
10 Service on the processes and procedures regarding
11 the design, implementation, and evaluation of, and
12 reporting on, research and field studies conducted or
13 supported under this section;

14 (2) develop and share resources on Tribal pub-
15 lic health data surveillance and reporting, including
16 best practices; and

17 (3) carry out such other activities as may be
18 appropriate to establish processes and procedures for
19 the research and field studies conducted or sup-
20 ported under subsection (a).

21 (e) REPORT.—Not later than 1 year after expending
22 all funds made available to carry out this section, the Di-
23 rector of the Indian Health Service, in coordination with
24 the panel established under subsection (c), shall submit

1 an initial report on the results of the research and field
2 studies under this section to—

3 (1) the Committee on Energy and Commerce
4 and the Committee on Natural Resources of the
5 House of Representatives; and

6 (2) the Committee on Indian Affairs and the
7 Committee on Health, Education, Labor, and Pen-
8 sions of the Senate.

9 (f) TRIBAL DATA SOVEREIGNTY.—The Director of
10 the Indian Health Service shall ensure that all research
11 and field studies conducted or supported under this sec-
12 tion are tribally directed and carried out in a manner
13 which ensures Tribal-direction of all data collected under
14 this section—

15 (1) according to Tribal best practices regarding
16 research design and implementation, including by
17 ensuring the consent of the Tribes involved to public
18 reporting of Tribal data;

19 (2) according to all relevant and applicable
20 Tribal, professional, institutional, and Federal
21 standards for conducting research and governing re-
22 search ethics;

23 (3) with the prior and informed consent of any
24 Indian Tribe participating in the research or sharing
25 data for use under this section; and

1 (4) in a manner that respects the inherent sov-
2 ereignty of Indian Tribes, including Tribal govern-
3 ance of data and research.

4 (g) FINAL REPORT.—Not later than December 31,
5 2023, the Director of the Indian Health Service shall—

6 (1) update and finalize the initial report under
7 subsection (e); and

8 (2) submit such final report to the committees
9 specified in such subsection.

10 (h) DEFINITIONS.—In this section:

11 (1) The terms “Indian Tribe” and “Tribal or-
12 ganization” have the meanings given to such terms
13 in section 4 of the Indian Self-Determination and
14 Education Assistance Act (25 U.S.C. 5304).

15 (2) The term “Urban Indian organization” has
16 the meaning given to such term in section 4 of the
17 Indian Health Care Improvement Act (25 U.S.C.
18 1603).

19 (i) AUTHORIZATION OF APPROPRIATIONS.—There is
20 authorized to be appropriated to carry out this section
21 \$25,000,000, to remain available until expended.

1 **SEC. 8. STUDY EXAMINING PUBLIC HEALTH DATA AND IN-**
2 **FRASTRUCTURE NECESSARY DURING AND**
3 **AFTER THE COVID-19 PUBLIC HEALTH EMER-**
4 **GENCY.**

5 (a) IN GENERAL.—The Secretary of Health and
6 Human Services (in this section referred to as the “Sec-
7 retary”) shall seek to enter into a contract with the Na-
8 tional Academies of Sciences, Engineering, and Medicine
9 (referred to in this section as the “National Academies”)
10 not later than 30 days after the date of enactment of this
11 Act, under which the National Academies agree to conduct
12 a study with stakeholders from Federal agencies, State,
13 Tribal, territorial, and local governments, research institu-
14 tions, industry, and nonprofit organizations that would re-
15 view the current system for public health data infrastruc-
16 ture and reporting and provide recommendations on need-
17 ed data and system improvements for future pandemics
18 and ongoing public health needs.

19 (b) SUBMISSION OF REPORT.—The contract under
20 subsection (a) shall require that the study under such sub-
21 section be completed, and a report on the resulting rec-
22 ommendations be submitted to the Secretary, the Com-
23 mittee on Health, Education, Labor, and Pensions of the
24 Senate and the Committee on Energy and Commerce of
25 the House of Representatives, not later than 12 months
26 after the date the contract was executed.

1 (c) STUDY TOPICS.—The contract under subsection
2 (a) shall require the study under such subsection to—

3 (1) review the current public health data sys-
4 tems and the reporting structure for Federal, State,
5 Tribal, territorial, and local public health informa-
6 tion, including vital records;

7 (2) review current standards for reporting,
8 quality controls, and transparency of the data;

9 (3) examine data gaps and barriers to timely
10 and accurate reporting and identify ways to fill
11 those gaps;

12 (4) examine how systems can be accessed and
13 used by a wide range of users, including external re-
14 searchers;

15 (5) examine how different data systems interact
16 and how different data sources can be integrated;

17 (6) examine nontraditional data sources or al-
18 ternative data gathering methods that could be used
19 to complement traditionally collected data;

20 (7) identify needed improvements to the public
21 health data systems and structure, especially with
22 regard to the needs of Tribal systems;

23 (8) identify core elements of a “minimum data
24 set” that might be used for State population surveil-
25 lance, including demographic components that are

1 necessary to ensure health equity in public health
2 decision making;

3 (9) examine how surveillance systems can be ex-
4 plicitly designed to ensure vulnerable populations
5 (which may include racial and ethnic minorities, im-
6 migrants, individuals in nursing homes, other insti-
7 tutionalized populations, and individuals experi-
8 encing homelessness) are included in reporting;

9 (10) consider how traditional and nontradi-
10 tional data might be used to promote health equity
11 across the United States and reduce racial, Tribal,
12 and other demographic disparities;

13 (11) examine data gaps and barriers to col-
14 lecting, analyzing, and using demographic data to
15 characterize the COVID–19 pandemic for public
16 health action and research to improve public health
17 actions and identify ways to fill those gaps; and

18 (12) report on what is known based on existing
19 data about how COVID–19 is impacting subgroups
20 of the population with respect to access to testing
21 and treatment (hospitalization and access to drugs
22 and medical equipment), and health outcomes (mor-
23 bidity and mortality).

24 (d) DISAGGREGATION OF DATA.—To the extent fea-
25 sible, the contract under subsection (a) shall require data

- 1 to be disaggregated by race, ethnicity, age, gender, dis-
- 2 ability, geography, language, socioeconomic status, and
- 3 other factors.

