## <sup>116TH CONGRESS</sup> 2D SESSION H.R. 7948

### AN ACT

- To amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes, 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,

#### 1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the "Tribal Health Data3 Improvement Act of 2020".

## 4 SEC. 2. COLLECTION AND AVAILABILITY OF HEALTH DATA 5 WITH RESPECT TO INDIAN TRIBES.

6 (a) DATA COLLECTION.—Section 3101(a)(1) of the
7 Public Health Service Act (42 U.S.C. 300kk(a)(1)) is
8 amended—

9 (1) by striking ", by not later than 2 years
10 after the date of enactment of this title,"; and

11 (2) in subparagraph (B), by inserting "Tribal,"12 after "State,".

(b) DATA REPORTING AND DISSEMINATION.—Section 3101(c) of the Public Health Service Act (42 U.S.C.
300kk(c)) is amended—

16 (1) by amending subparagraph (F) of para-17 graph (1) to read as follows:

"(F) the Indian Health Service, Indian
Tribes, Tribal organizations, and epidemiology
centers authorized under the Indian Health
Care Improvement Act;"; and

(2) in paragraph (3), by inserting "Indian
Tribes, Tribal organizations, and epidemiology centers," after "Federal agencies,".

25 (c) PROTECTION AND SHARING OF DATA.—Section
26 3101(e) of the Public Health Service Act (42 U.S.C.
•HR 7948 EH

1 300kk(e)) is amended by adding at the end the following2 new paragraphs:

3	"(3) DATA SHARING STRATEGY.—With respect
4	to data access for Tribal epidemiology centers and
5	Tribes, the Secretary shall create a data sharing
6	strategy that takes into consideration recommenda-
7	tions by the Secretary's Tribal Advisory Committee
8	for—
9	"(A) ensuring that Tribal epidemiology
10	centers and Indian Tribes have access to the
11	data sources necessary to accomplish their pub-
12	lic health responsibilities; and
13	"(B) protecting the privacy and security of
14	such data.
15	"(4) TRIBAL PUBLIC HEALTH AUTHORITY.—
16	"(A) AVAILABILITY.—Beginning not later
17	then 190 days after the data of the exactment
	than 180 days after the date of the enactment
18	of the Tribal Health Data Improvement Act of
18 19	
	of the Tribal Health Data Improvement Act of
19	of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the
19 20	of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the entities listed in subparagraph (B) all data that
19 20 21	of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the entities listed in subparagraph (B) all data that is collected pursuant to this title with respect to
19 20 21 22	of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the entities listed in subparagraph (B) all data that is collected pursuant to this title with respect to health care and public health surveillance pro-

"(i) such entities request the data 1 2 pursuant to statute; and "(ii) the data is requested for use— 3 "(I) consistent with Federal law 4 5 and obligations; and 6 "(II) to satisfy a particular pur-7 pose or carry out a specific function 8 consistent with the purpose for which 9 the data was collected. "(B) ENTITIES.—The entities listed in this 10 11 subparagraph are— "(i) the Indian Health Service; 12 "(ii) Indian Tribes and Tribal organi-13 14 zations; and "(iii) epidemiology centers.". 15 16 (d) TECHNICAL UPDATES.—Section 3101 of the Public Health Service Act (42 U.S.C. 300kk) is amend-17 18 ed— 19 (1) by striking subsections (g) and (h); and 20 (2) by redesignating subsection (i) as subsection 21 (h). 22 (e) DEFINITIONS.—After executing the amendments 23 made by subsection (d), section 3101 of the Public Health 24 Service Act (42 U.S.C. 300kk) is amended by inserting

after subsection (f) the following new subsection:

25

1 "(g) DEFINITIONS.—In this section:

2 "(1) The term 'epidemiology center' means an
3 epidemiology center established under section 214 of
4 the Indian Health Care Improvement Act, including
5 such Tribal epidemiology centers serving Indian
6 Tribes regionally and any Tribal epidemiology center
7 serving Urban Indian organizations nationally.

8 "(2) The term 'Indian Tribe' has the meaning 9 given to the term 'Indian tribe' in section 4 of the 10 Indian Self-Determination and Education Assistance 11 Act.

"(3) The term 'Tribal organization' has the
meaning given to the term 'tribal organization' in
section 4 of the of the Indian Self-Determination
and Education Assistance Act.

"(4) The term 'Urban Indian organization' has
the meaning given to that term in section 4 of the
Indian Health Care Improvement Act.".

(f) TECHNICAL CORRECTION.—Section 3101(b) of
the Public Health Service Act (42 U.S.C. 300kk(b)) is
amended by striking "DATA ANALYSIS.—" and all that
follows through "For each federally" and inserting "DATA
ANALYSIS.—For each federally".

#### **RESPECT TO INDIAN TRIBES.**

1

2

3 (a) TECHNICAL AID TO STATES AND LOCALITIES.—
4 Section 306(d) of the Public Health Service Act (42
5 U.S.C. 242k(d)) is amended by inserting ", Indian Tribes,
6 Tribal organizations, and epidemiology centers" after "ju7 risdictions".

8 (b) COOPERATIVE HEALTH STATISTICS SYSTEM.—
9 Section 306(e)(3) of the Public Health Service Act (42
10 U.S.C. 242k(e)(3)) is amended by inserting ", Indian
11 Tribes, Tribal organizations, and epidemiology centers"
12 after "health agencies".

13 (c) FEDERAL-STATE-TRIBAL COOPERATION.—Sec14 tion 306(f) of the Public Health Service Act (42 U.S.C.
15 242k(f)) is amended—

- 16 (1) by inserting "the Indian Health Service,"17 before "the Departments of Commerce";
- 18 (2) by inserting a comma after "the Depart-19 ments of Commerce and Labor";
- 20 (3) by inserting ", Indian Tribes, Tribal organi21 zations, and epidemiology centers" after "State and
  22 local health departments and agencies"; and

23 (4) by striking "he shall" and inserting "the24 Secretary shall".

(d) REGISTRATION AREA RECORDS.—Section
 306(h)(1) of the Public Health Service Act (42 U.S.C.
 242k(h)(1)) is amended—

4 (1) by striking "in his discretion" and inserting
5 "in the discretion of the Secretary"; and

6 (2) by striking "Hispanics, Asian Americans, 7 and Pacific Islanders" and inserting "American In-8 dians and Alaska Natives, Hispanics, Asian Ameri-9 cans, and Native Hawaiian and other Pacific Island-10 ers".

(e) NATIONAL COMMITTEE ON VITAL AND HEALTH
STATISTICS.—Section 306(k) of the Public Health Service
Act (42 U.S.C. 242k(k)) is amended—

(1) in paragraph (3), by striking ", not later
than 60 days after the date of the enactment of the
Health Insurance Portability and Accountability Act
of 1996," each place it appears; and

(2) in paragraph (7), by striking "Not later
than 1 year after the date of the enactment of the
Health Insurance Portability and Accountability Act
of 1996, and annually thereafter, the Committee
shall" and inserting "The Committee shall, on an biennial basis,".

24 (f) GRANTS FOR ASSEMBLY AND ANALYSIS OF DATA25 ON ETHNIC AND RACIAL POPULATIONS.—Section

306(m)(4) of the Public Health Service Act (42 U.S.C. 1 2 242k(m)(4)) is amended— 3 (1) in subparagraph (A)— (A) by striking "Subject to subparagraph 4 (B), the" and inserting "The"; and 5 6 (B) by striking "and major Hispanic sub-7 population groups and American Indians" and inserting ", major Hispanic subgroups, and 8 9 American Indians and Alaska Natives"; and 10 (2) by amending subparagraph (B) to read as 11 follows: 12 "(B) In carrying out subparagraph (A), with respect 13 to American Indians and Alaska Natives, the Secretary 14 shall— "(i) consult with Indian Tribes, Tribal organi-15 16 zations, the Tribal Technical Advisory Group of the 17 Centers for Medicare & Medicaid Services main-18 tained under section 5006(e) of the American Recov-19 ery and Reinvestment Act of 2009, and the Tribal 20 Advisory Committee established by the Centers for 21 Disease Control and Prevention, in coordination with epidemiology centers, to develop guidelines for State 22 23 and local health agencies to improve the quality and 24 accuracy of data with respect to the birth and death 25 records of American Indians and Alaska Natives;

1	"(ii) confer with Urban Indian organizations to
2	develop guidelines for State and local health agencies
3	to improve the quality and accuracy of data with re-
4	spect to the birth and death records of American In-
5	dians and Alaska Natives;
6	"(iii) enter into cooperative agreements with In-
7	dian Tribes, Tribal organizations, Urban Indian or-
8	ganizations, and epidemiology centers to address
9	misclassification and undersampling of American In-
10	dians and Alaska Natives with respect to—
11	"(I) birth and death records; and
12	$((\Pi)$ health care and public health surveil-
13	lance systems, including, but not limited to,
14	data with respect to chronic and infectious dis-
15	eases, unintentional injuries, environmental
16	health, child and adolescent health, maternal
17	health and mortality, foodborne and waterborne
18	illness, reproductive health, and any other
19	notifiable disease or condition;
20	"(iv) encourage States to enter into data shar-
21	ing agreements with Indian Tribes, Tribal organiza-
22	tions, and epidemiology centers to improve the qual-
23	ity and accuracy of public health data; and
24	"(v) not later than 180 days after the date of
25	enactment of the Tribal Health Data Improvement

Act of 2020, and biennially thereafter, issue a report
 on the following:

3 "(I) Which States have data sharing agree4 ments with Indian Tribes, Tribal organizations,
5 Urban Indian organizations, and Tribal epide6 miology centers to improve the quality and ac7 curacy of health data.

8 "(II) What the Centers for Disease Control 9 and Prevention is doing to encourage States to 10 enter into data sharing agreements with Indian 11 Tribes, Tribal organizations, Urban Indian or-12 ganizations, and Tribal epidemiology centers to 13 improve the quality and accuracy of health 14 data.

"(III) Best practices and guidance for
States, Indian Tribes, Tribal organizations,
Urban Indian organizations, and Tribal epidemiology centers that wish to enter into data
sharing agreements.

20 "(IV) Best practices and guidance for
21 local, State, Tribal, and Federal uniform stand22 ards for the collection of data on race and eth23 nicity.".

24 (g) DEFINITIONS.—Section 306 of the Public Health
25 Service Act (42 U.S.C. 242k) is amended—

	11 I.
1	(1) by redesignating subsection (n) as sub-
2	section (o); and
3	(2) by inserting after subsection (m) the fol-
4	lowing:
5	"(n) In this section:
6	"(1) The term 'epidemiology center' means an
7	epidemiology center established under section 214 of
8	the Indian Health Care Improvement Act, including
9	such Tribal epidemiology centers serving Indian
10	Tribes regionally and any Tribal epidemiology center
11	serving Urban Indian organizations nationally.
12	((2) The term 'Indian Tribe' has the meaning
13	given to the term 'Indian tribe' in section 4 of the
14	Indian Self-Determination and Education Assistance
15	Act.
16	"(3) The term 'Tribal organization' has the
17	meaning given to the term 'tribal organization' in
18	section 4 of the Indian Self-Determination and Edu-
19	cation Assistance Act.
20	"(4) The term 'Urban Indian organization' has
21	the meaning given to that term in section 4 of the
22	Indian Health Care Improvement Act.".
23	(h) Authorization of Appropriations.—Section
24	306(o) of the Public Health Service Act, as redesignated
25	by subsection (g), is amended to read as follows:

"(o)(1) To carry out this section, there is authorized
 to be appropriated \$185,000,000 for each of the fiscal
 years 2021 through 2025.

4 "(2) Of the amount authorized to be appropriated to
5 carry out this section for a fiscal year, the Secretary shall
6 not use more than 10 percent for the combined costs of—
7 "(A) administration of this section; and
8 "(B) carrying out subsection (m)(2).".

Passed the House of Representatives September 29, 2020.

Attest:

Clerk.

<sup>116</sup>TH CONGRESS H. R. 7948

# AN ACT

To amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes, and for other purposes.