

## Union Calendar No.

116<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 7948

[Report No. 116-]

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.

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### IN THE HOUSE OF REPRESENTATIVES

AUGUST 7, 2020

Mr. GIANFORTE (for himself, Mr. LUJÁN, Mrs. RODGERS of Washington, Mr. MULLIN, Mr. O'HALLERAN, and Mr. RUIZ) introduced the following bill; which was referred to the Committee on Energy and Commerce

SEPTEMBER --, 2020

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italics]

[For text of introduced bill, see copy of bill as introduced on August 7, 2020]

# **A BILL**

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,*

3 **SECTION 1. SHORT TITLE.**

4 *This Act may be cited as the “Tribal Health Data Im-*  
5 *provement Act of 2020”.*

6 **SEC. 2. COLLECTION AND AVAILABILITY OF HEALTH DATA**

7 **WITH RESPECT TO INDIAN TRIBES.**

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

11 *(1) by striking “, by not later than 2 years after*  
12 *the date of enactment of this title,”; and*

13 *(2) in subparagraph (B), by inserting “Tribal,”*  
14 *after “State,”.*

15 *(b) DATA REPORTING AND DISSEMINATION.—Section*  
16 *3101(c) of the Public Health Service Act (42 U.S.C.*  
17 *300kk(c)) is amended—*

18 *(1) by amending subparagraph (F) of paragraph*  
19 *(1) to read as follows:*

20 *“(F) the Indian Health Service, Indian*  
21 *Tribes, Tribal organizations, and epidemiology*  
22 *centers authorized under the Indian Health Care*  
23 *Improvement Act;”;* and

1           (2) *in paragraph (3), by inserting “Indian*  
2           *Tribes, Tribal organizations, and epidemiology cen-*  
3           *ters,” after “Federal agencies,”.*

4           (c) *PROTECTION AND SHARING OF DATA.—Section*  
5           *3101(e) of the Public Health Service Act (42 U.S.C.*  
6           *300kk(e)) is amended by adding at the end the following*  
7           *new paragraphs:*

8                   “(3) *DATA SHARING STRATEGY.—With respect to*  
9                   *data access for Tribal epidemiology centers and*  
10                   *Tribes, the Secretary shall create a data sharing*  
11                   *strategy that takes into consideration recommenda-*  
12                   *tions by the Secretary’s Tribal Advisory Committee*  
13                   *for—*

14                           “(A) *ensuring that Tribal epidemiology cen-*  
15                           *ters and Indian Tribes have access to the data*  
16                           *sources necessary to accomplish their public*  
17                           *health responsibilities; and*

18                                   “(B) *protecting the privacy and security of*  
19                                   *such data.*

20                   “(4) *TRIBAL PUBLIC HEALTH AUTHORITY.—*

21                           “(A) *AVAILABILITY.—Beginning not later*  
22                           *than 180 days after the date of the enactment of*  
23                           *the Tribal Health Data Improvement Act of*  
24                           *2020, the Secretary shall make available to the*  
25                           *entities listed in subparagraph (B) all data that*

1           *is collected pursuant to this title with respect to*  
2           *health care and public health surveillance pro-*  
3           *grams and activities, including such programs*  
4           *and activities that are federally supported or*  
5           *conducted, so long as—*

6                     *“(i) such entities request the data pur-*  
7                     *suant to statute; and*

8                     *“(ii) the data is requested for use—*

9                             *“(I) consistent with Federal law*  
10                            *and obligations; and*

11                            *“(II) to satisfy a particular pur-*  
12                            *pose or carry out a specific function*  
13                            *consistent with the purpose for which*  
14                            *the data was collected.*

15                     *“(B) ENTITIES.—The entities listed in this*  
16                     *subparagraph are—*

17                             *“(i) the Indian Health Service;*

18                             *“(ii) Indian Tribes and Tribal organi-*  
19                             *zations; and*

20                             *“(iii) epidemiology centers.”.*

21           *(d) TECHNICAL UPDATES.—Section 3101 of the Public*  
22           *Health Service Act (42 U.S.C. 300kk) is amended—*

23                     *(1) by striking subsections (g) and (h); and*

24                     *(2) by redesignating subsection (i) as subsection*  
25           *(h).*

1       (e) *DEFINITIONS.*—*After executing the amendments*  
2 *made by subsection (d), section 3101 of the Public Health*  
3 *Service Act (42 U.S.C. 300kk) is amended by inserting after*  
4 *subsection (f) the following new subsection:*

5       “(g) *DEFINITIONS.*—*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 In-*  
14 *dian 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 of the Indian Self-Determination and*  
19 *Education Assistance Act.*

20           “(4) *The term ‘Urban Indian organization’ has*  
21 *the meaning given to that term in section 4 of the In-*  
22 *dian Health Care Improvement Act.”.*

23       (f) *TECHNICAL CORRECTION.*—*Section 3101(b) of the*  
24 *Public Health Service Act (42 U.S.C. 300kk(b)) is amended*  
25 *by striking “DATA ANALYSIS.—” and all that follows*

1 *through “For each federally” and inserting “DATA ANAL-*  
2 *YSIS.—For each federally”.*

3 **SEC. 3. IMPROVING HEALTH STATISTICS REPORTING WITH**  
4 **RESPECT TO INDIAN TRIBES.**

5 (a) *TECHNICAL AID TO STATES AND LOCALITIES.—*  
6 *Section 306(d) of the Public Health Service Act (42 U.S.C.*  
7 *242k(d)) is amended by inserting “, Indian Tribes, Tribal*  
8 *organizations, and epidemiology centers” after “jurisdic-*  
9 *tions”.*

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

15 (c) *FEDERAL-STATE-TRIBAL COOPERATION.—Section*  
16 *306(f) of the Public Health Service Act (42 U.S.C. 242k(f))*  
17 *is amended—*

18 (1) *by inserting “the Indian Health Service,” be-*  
19 *fore “the Departments of Commerce”;*

20 (2) *by inserting a comma after “the Depart-*  
21 *ments of Commerce and Labor”;*

22 (3) *by inserting “, Indian Tribes, Tribal organi-*  
23 *zations, and epidemiology centers” after “State and*  
24 *local health departments and agencies”; and*

1           (4) by striking “he shall” and inserting “the Sec-  
2           retary shall”.

3           (d) *REGISTRATION AREA RECORDS.*—Section  
4           306(h)(1) of the Public Health Service Act (42 U.S.C.  
5           242k(h)(1)) is amended—

6           (1) by striking “in his discretion” and inserting  
7           “in the discretion of the Secretary”; and

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

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

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

20          (2) in paragraph (7), by striking “Not later than  
21          1 year after the date of the enactment of the Health  
22          Insurance Portability and Accountability Act of 1996,  
23          and annually thereafter, the Committee shall” and in-  
24          serting “The Committee shall, on an biennial basis,”.

1           (f) *GRANTS FOR ASSEMBLY AND ANALYSIS OF DATA*  
2 *ON ETHNIC AND RACIAL POPULATIONS.*—Section  
3 *306(m)(4) of the Public Health Service Act (42 U.S.C.*  
4 *242k(m)(4)) is amended—*

5           (1) *in subparagraph (A)—*

6           (A) *by striking “Subject to subparagraph*  
7 *(B), the” and inserting “The”; and*

8           (B) *by striking “and major Hispanic sub-*  
9 *population groups and American Indians” and*  
10 *inserting “, major Hispanic subgroups, and*  
11 *American Indians and Alaska Natives”; and*

12           (2) *by amending subparagraph (B) to read as*  
13 *follows:*

14           “(B) *In carrying out subparagraph (A), with respect*  
15 *to American Indians and Alaska Natives, the Secretary*  
16 *shall—*

17           *“(i) consult with Indian Tribes, Tribal organiza-*  
18 *tions, the Tribal Technical Advisory Group of the*  
19 *Centers for Medicare & Medicaid Services maintained*  
20 *under section 5006(e) of the American Recovery and*  
21 *Reinvestment Act of 2009, and the Tribal Advisory*  
22 *Committee established by the Centers for Disease Con-*  
23 *trol and Prevention, in coordination with epidemi-*  
24 *ology centers, to develop guidelines for State and local*  
25 *health agencies to improve the quality and accuracy*

1       *of data with respect to the birth and death records of*  
2       *American Indians and Alaska Natives;*

3           “(ii) confer with Urban Indian organizations to  
4       develop guidelines for State and local health agencies  
5       to improve the quality and accuracy of data with re-  
6       spect to the birth and death records of American Indi-  
7       ans and Alaska Natives;

8           “(iii) enter into cooperative agreements with In-  
9       dian Tribes, Tribal organizations, Urban Indian or-  
10      ganizations, and epidemiology centers to address  
11      misclassification and undersampling of American In-  
12      dians and Alaska Natives with respect to—

13           “(I) birth and death records; and

14           “(II) health care and public health surveil-  
15      lance systems, including, but not limited to, data  
16      with respect to chronic and infectious diseases,  
17      unintentional injuries, environmental health,  
18      child and adolescent health, maternal health and  
19      mortality, foodborne and waterborne illness, re-  
20      productive health, and any other notifiable dis-  
21      ease or condition;

22           “(iv) encourage States to enter into data sharing  
23      agreements with Indian Tribes, Tribal organizations,  
24      and epidemiology centers to improve the quality and  
25      accuracy of public health data; and

1           “(v) not later than 180 days after the date of en-  
2           actment of the Tribal Health Data Improvement Act  
3           of 2020, and biennially thereafter, issue a report on  
4           the following:

5                   “(I) Which States have data sharing agree-  
6                   ments with Indian Tribes, Tribal organizations,  
7                   Urban Indian organizations, and Tribal epide-  
8                   miology centers to improve the quality and accu-  
9                   racy of health data.

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

16                   “(III) Best practices and guidance for  
17                   States, Indian Tribes, Tribal organizations,  
18                   Urban Indian organizations, and Tribal epide-  
19                   miology centers that wish to enter into data  
20                   sharing agreements.

21                   “(IV) Best practices and guidance for local,  
22                   State, Tribal, and Federal uniform standards for  
23                   the collection of data on race and ethnicity.”.

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

1           (1) *by redesignating subsection (n) as subsection*  
2           *(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           *servicing 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 In-*  
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 In-*  
22           *Indian Health Care Improvement Act.”.*

23           (h) *AUTHORIZATION OF APPROPRIATIONS.—Section*  
24           *306(o) of the Public Health Service Act, as redesignated by*  
25           *subsection (g), is amended to read as follows:*

1           “(o)(1) To carry out this section, there is authorized  
2 to be appropriated \$185,000,000 for each of the fiscal years  
3 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).”.