

117TH CONGRESS
1ST SESSION

S. 1397

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

IN THE SENATE OF THE UNITED STATES

APRIL 27, 2021

Ms. SMITH (for herself, Ms. MURKOWSKI, Mr. TESTER, Mr. DAINES, Ms. WARREN, and Mr. CRAMER) introduced the following bill; which was read twice and referred to the Committee on Indian Affairs

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 Tribal organizations, 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
5 Improvement Act of 2021”.

1 **SEC. 2. COLLECTION AND AVAILABILITY OF HEALTH DATA**
2 **WITH RESPECT TO INDIAN TRIBES.**

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

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

8 (2) in subparagraph (B), by inserting “Tribal,”
9 after “State,”.

10 (b) DATA REPORTING AND DISSEMINATION.—Sec-
11 tion 3101(c) of the Public Health Service Act (42 U.S.C.
12 300kk(c)) is amended—

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

15 “(F) the Indian Health Service, Indian
16 Tribes, Tribal organizations, and epidemiology
17 centers;”; and

18 (2) in paragraph (3), by inserting “Indian
19 Tribes, Tribal organizations, epidemiology centers,”
20 after “Federal agencies,”.

21 (c) PROTECTION AND SHARING OF DATA.—Section
22 3101(e) of the Public Health Service Act (42 U.S.C.
23 300kk(e)) is amended—

24 (1) in paragraph (2)—

25 (A) by striking “.” and inserting “.”;

1 (B) by striking “The Secretary shall” and
2 inserting the following:

3 “(A) IN GENERAL.—The Secretary shall”;
4 and

5 (C) by adding at the end the following:

6 “(B) EPIDEMIOLOGY CENTERS AND IN-
7 DIAN TRIBES.—With respect to data access for
8 epidemiology centers and Indian Tribes, the
9 Secretary shall establish a data sharing strat-
10 egy, in consultation with the Secretary’s Tribal
11 Advisory Committee, for purposes of providing
12 access to data to the epidemiology centers and
13 Indian Tribes that protect data privacy and se-
14 curity and data governance while ensuring that
15 epidemiology centers and Indian Tribes have
16 access to data sources necessary to accomplish
17 their public health responsibilities and plans for
18 use.”; and

19 (2) by adding at the end the following new
20 paragraph:

21 “(3) TRIBAL PUBLIC HEALTH AUTHORITY.—
22 Beginning not later than 180 days after the date of
23 the enactment of the Tribal Health Data Improve-
24 ment Act of 2021, the Secretary shall make avail-
25 able all requested data collected pursuant to this

1 title with respect to health care and public health
2 surveillance programs and activities, including such
3 programs and activities that are federally supported
4 or conducted, to—

5 “(A) the Indian Health Service;

6 “(B) Indian Tribes and Tribal organiza-
7 tions; and

8 “(C) epidemiology centers.”.

9 (d) TECHNICAL UPDATES.—Section 3101 of the
10 Public Health Service Act (42 U.S.C. 300kk) is amend-
11 ed—

12 (1) by striking subsections (g) and (h); and

13 (2) by redesignating subsection (i) as subsection
14 (h).

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

19 “(g) DEFINITIONS.—In this section:

20 “(1) The term ‘epidemiology center’ means an
21 epidemiology center established under section 214 of
22 the Indian Health Care Improvement Act, including
23 any epidemiology center serving Indian Tribes re-
24 gionally or serving urban Indian organizations na-

1 tionally that is receiving funding from the Indian
2 Health Service.

3 “(2) The terms ‘Indian Tribe’ and ‘Tribal orga-
4 nization’ have the meanings given to the terms ‘In-
5 dian tribe’ and ‘tribal organization’, respectively, in
6 section 4 of the Indian Self-Determination and Edu-
7 cation Assistance Act.”.

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

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

15 (a) TECHNICAL AID TO STATES AND LOCALITIES.—
16 Section 306(d) of the Public Health Service Act (42
17 U.S.C. 242k(d)) is amended by inserting “, Indian Tribes,
18 Tribal organizations, and epidemiology centers” after “ju-
19 risdictions”.

20 (b) COOPERATIVE HEALTH STATISTICS SYSTEM.—
21 Section 306(e)(3) of the Public Health Service Act (42
22 U.S.C. 242k(e)(3)) is amended by inserting “, Indian
23 Tribes, Tribal organizations, and epidemiology centers”
24 after “health agencies”.

1 (c) FEDERAL-STATE-TRIBAL COOPERATION.—Sec-
2 tion 306(f) of the Public Health Service Act (42 U.S.C.
3 242k(f)) is amended—

4 (1) by inserting “, the Indian Health Service,”
5 after “Commerce and Labor”;

6 (2) by inserting “, Indian Tribes, Tribal organi-
7 zations, and epidemiology centers” after “State and
8 local health departments and agencies”; and

9 (3) by striking “he shall” and inserting “the
10 Secretary shall”.

11 (d) REGISTRATION AREA RECORDS.—Section
12 306(h)(1) of the Public Health Service Act (42 U.S.C.
13 242k(h)(1)) is amended—

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

16 (2) by striking “Hispanics, Asian Americans,
17 and Pacific Islanders” and inserting “American In-
18 dians and Alaska Natives, Hispanics, Asians, and
19 Native Hawaiian and other Pacific Islanders”.

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

23 (1) in paragraph (3), by striking “, not later
24 than 60 days after the date of the enactment of the

1 Health Insurance Portability and Accountability Act
2 of 1996,” each place it appears; and

3 (2) in paragraph (7), by striking “Not later
4 than 1 year after the date of the enactment of the
5 Health Insurance Portability and Accountability Act
6 of 1996, and annually thereafter, the Committee
7 shall” and inserting “The Committee shall, on a bi-
8 ennial basis,”.

9 (f) GRANTS FOR ASSEMBLY AND ANALYSIS OF DATA
10 ON ETHNIC AND RACIAL POPULATIONS.—Section
11 306(m)(4) of the Public Health Service Act (42 U.S.C.
12 242k(m)(4)) is amended—

13 (1) in subparagraph (A)—

14 (A) by striking “Subject to subparagraph
15 (B), the” and inserting “The”; and

16 (B) by striking “and major Hispanic sub-
17 population groups and American Indians” and
18 inserting “, major Hispanic subgroups, and
19 American Indians and Alaska Natives”; and

20 (2) by amending subparagraph (B) to read as
21 follows:

22 “(B) In carrying out subparagraph (A), with respect
23 to American Indians and Alaska Natives, the Secretary
24 shall—

1 “(i) in consultation with Indian Tribes, Tribal
2 organizations, the Tribal Technical Advisory Group
3 of the Centers for Medicare & Medicaid Services
4 maintained under section 5006(e) of the American
5 Recovery and Reinvestment Act of 2009, and the
6 Tribal Advisory Committee established by the Cen-
7 ters for Disease Control and Prevention, and in co-
8 ordination with epidemiology centers, develop guid-
9 ance for State and local health agencies to improve
10 the quality and accuracy of data with respect to the
11 birth and death records of American Indians and
12 Alaska Natives;

13 “(ii) confer with urban Indian organizations to
14 develop guidance for State and local health agencies
15 to improve the quality and accuracy of data with re-
16 spect to the birth and death records of American In-
17 dians and Alaska Natives;

18 “(iii) enter into cooperative agreements with In-
19 dian Tribes, Tribal organizations, Urban Indian or-
20 ganizations, and epidemiology centers to analyze and
21 address misclassification and undersampling of
22 American Indians and Alaska Natives in data sys-
23 tems at the Federal, State, and local levels, with re-
24 spect to—

25 “(I) birth and death records; and

1 “(II) Federal, State, and local health care
2 and public health surveillance systems, includ-
3 ing with respect to chronic and infectious dis-
4 eases, unintentional injuries, environmental
5 health, child and adolescent health, maternal
6 health and mortality, foodborne and waterborne
7 illness, reproductive health, and any other
8 notifiable disease or condition;

9 “(iv) adopt, based on local, statewide, Tribal,
10 and national best practices, uniform standards for
11 the collection of health data on race and ethnicity;

12 “(v) encourage States to enter into data shar-
13 ing agreements with Indian Tribes and epidemiology
14 centers to improve the quality and accuracy of public
15 health data regarding American Indians and Alaska
16 natives, including by addressing misclassification
17 and undersampling of American Indians and Alaska
18 Natives in State and local public health data sys-
19 tems, including with respect to vital statistics, chron-
20 ic and infectious diseases, unintentional injuries, en-
21 vironmental health, child and adolescent health, ma-
22 ternal health and mortality, foodborne and water-
23 borne illness, reproductive health, and any other
24 notifiable disease or condition;

1 “(vi) encourage States to adopt, based on local,
2 statewide, Tribal, and national best practices, uni-
3 form standards for the collection of health data on
4 race and ethnicity; and

5 “(vii) 180 days after the date of enactment of
6 the Tribal Health Data Improvement Act of 2021
7 and biennially thereafter, issue a report on—

8 “(I) which States have data sharing agree-
9 ments with Indian Tribes, Tribal Organizations,
10 urban Indian organizations, or epidemiology
11 centers to improve the quality and accuracy of
12 health data, listed by data system name; and

13 “(II) actions taken by the Director of the
14 Centers for Disease Control and Prevention to
15 encourage States to enter into data sharing
16 agreements with Indian Tribes, Tribal Organi-
17 zations, urban Indian organizations, and epide-
18 miology centers to improve the quality and ac-
19 curacy of health data.”.

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

22 (1) by redesignating subsection (n) as sub-
23 section (o); and

24 (2) by inserting after subsection (m) the fol-
25 lowing:

1 “(n) 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 any epidemiology center serving Indian Tribes re-
6 gionally or serving urban Indian organizations na-
7 tionally that is receiving funding from the Indian
8 Health Service.

9 “(2) The terms ‘Indian Tribe’ and ‘Tribal orga-
10 nization’ have the meanings given to the terms ‘In-
11 dian tribe’ and ‘tribal organization’, respectively, in
12 section 4 of the Indian Self-Determination and Edu-
13 cation Assistance Act.

14 “(3) The term ‘Urban Indian organization’ has
15 the meaning given to that term in section 4 of the
16 Indian Health Care Improvement Act.”.

17 (h) AUTHORIZATION OF APPROPRIATIONS.—Section
18 306(o) of the Public Health Service Act, as redesignated
19 by subsection (g), is amended to read as follows:

20 “(o) To carry out this section, there is authorized to
21 be appropriated \$185,000,000 for each of the fiscal years
22 2021 through 2025.”.

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