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(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R. _____

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.

IN THE HOUSE OF REPRESENTATIVES

Mr. MULLIN introduced the following bill; which was referred to the Committee on _____

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
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 authorized under the Indian Health
18 Care Improvement Act;”; and

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

22 (c) PROTECTION AND SHARING OF DATA.—Section
23 3101(e) of the Public Health Service Act (42 U.S.C.
24 300kk(e)) is amended by adding at the end the following
25 new paragraphs:

1 “(3) DATA SHARING STRATEGY.—With respect
2 to data access for Tribal epidemiology centers and
3 Tribes, the Secretary shall create a data sharing
4 strategy that takes into consideration recommenda-
5 tions by the Secretary’s Tribal Advisory Committee
6 for—

7 “(A) ensuring that Tribal epidemiology
8 centers and Indian Tribes have access to the
9 data sources necessary to accomplish their pub-
10 lic health responsibilities; and

11 “(B) protecting the privacy and security of
12 such data.

13 “(4) TRIBAL PUBLIC HEALTH AUTHORITY.—

14 “(A) AVAILABILITY.—Beginning not later
15 than 180 days after the date of the enactment
16 of the Tribal Health Data Improvement Act of
17 2021, the Secretary shall make available to the
18 entities listed in subparagraph (B) all data that
19 is collected pursuant to this title with respect to
20 health care and public health surveillance pro-
21 grams and activities, including such programs
22 and activities that are federally supported or
23 conducted, so long as—

24 “(i) such entities request the data
25 pursuant to statute; and

1 “(ii) the data is requested for use—
2 “(I) consistent with Federal law
3 and obligations; and
4 “(II) to satisfy a particular pur-
5 pose or carry out a specific function
6 consistent with the purpose for which
7 the data was collected.

8 “(B) ENTITIES.—The entities listed in this
9 subparagraph are—

10 “(i) the Indian Health Service;
11 “(ii) Indian Tribes and Tribal organi-
12 zations; and
13 “(iii) epidemiology centers.”.

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

17 (1) by striking subsections (g) and (h); and
18 (2) by redesignating subsection (i) as subsection
19 (h).

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

24 “(g) DEFINITIONS.—In this section:

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

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

11 “(3) The term ‘Tribal organization’ has the
12 meaning given to the term ‘tribal organization’ in
13 section 4 of the of the Indian Self-Determination
14 and Education Assistance Act.

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

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

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

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 “ju-
7 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.—Sec-
14 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 organi-
21 zations, and epidemiology centers” after “State and
22 local health departments and agencies”; and

23 (4) by striking “he shall” and inserting “the
24 Secretary shall”.

1 (d) REGISTRATION AREA RECORDS.—Section
2 306(h)(1) of the Public Health Service Act (42 U.S.C.
3 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”.

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

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

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

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

1 306(m)(4) of the Public Health Service Act (42 U.S.C.
2 242k(m)(4)) is amended—

3 (1) in subparagraph (A)—

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

6 (B) by striking “and major Hispanic sub-
7 population groups and American Indians” and
8 inserting “, major Hispanic subgroups, and
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—

15 “(i) consult with Indian Tribes, Tribal organi-
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
22 epidemiology centers, to develop guidelines for State
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 “(II) 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

1 Act of 2021, and biennially thereafter, issue a report
2 on the following:

3 “(I) Which States have data sharing agree-
4 ments with Indian Tribes, Tribal organizations,
5 Urban Indian organizations, and Tribal epide-
6 miology centers to improve the quality and ac-
7 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.

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

20 “(IV) Best practices and guidance for
21 local, State, Tribal, and Federal uniform stand-
22 ards for the collection of data on race and eth-
23 nicity.”.

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 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:

1 “(o)(1) To carry out this section, there is authorized
2 to be appropriated \$185,000,000 for each of the fiscal
3 years 2022 through 2026.

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).”.