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.
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.
Be it enacted by the Senate and House of Representa-
tives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

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

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

(1) by striking “, by not later than 2 years after
the date of enactment of this title,”; and
(2) in subparagraph (B), by inserting “Tribal,”
after “State,”.

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

(1) by amending subparagraph (F) of paragraph
(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,”.

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

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

“(A) ensuring that Tribal epidemiology centers and Indian Tribes have access to the data sources necessary to accomplish their public health responsibilities; and

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

“(4) TRIBAL PUBLIC HEALTH AUTHORITY.—

“(A) AVAILABILITY.—Beginning not later than 180 days after the date of the enactment 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 programs and activities, including such programs and activities that are federally supported or conducted, so long as—

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

“(ii) the data is requested for use—

“(I) consistent with Federal law and obligations; and

“(II) to satisfy a particular purpose or carry out a specific function consistent with the purpose for which the data was collected.

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

“(i) the Indian Health Service;

“(ii) Indian Tribes and Tribal organizations; and

“(iii) epidemiology centers.”.

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

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

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

“(g) DEFINITIONS.—In this section:

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

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

“(3) The term ‘Tribal organization’ has the meaning given to the term ‘tribal organization’ in section 4 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”.

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

(a) TECHNICAL AID TO STATES AND LOCALITIES.—

Section 306(d) of the Public Health Service Act (42 U.S.C. 242k(d)) is amended by inserting “, Indian Tribes, Tribal organizations, and epidemiology centers” after “jurisdictions”.

(b) COOPERATIVE HEALTH STATISTICS SYSTEM.—

Section 306(e)(3) of the Public Health Service Act (42 U.S.C. 242k(e)(3)) is amended by inserting “, Indian Tribes, Tribal organizations, and epidemiology centers” after “health agencies”.

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

(1) by inserting “the Indian Health Service,” before “the Departments of Commerce”;

(2) by inserting a comma after “the Departments of Commerce and Labor”;

(3) by inserting “, Indian Tribes, Tribal organizations, and epidemiology centers” after “State and local health departments and agencies”; and
(4) by striking “he shall” and inserting “the 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—

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

(2) by striking “Hispanics, Asian Americans, and Pacific Islanders” and inserting “American Indians and Alaska Natives, Hispanics, Asian Americans, and Native Hawaiian and other Pacific Islanders”.

(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,”.
(f) **Grants for Assembly and Analysis of Data on Ethnic and Racial Populations.**—Section 306(m)(4) of the Public Health Service Act (42 U.S.C. 242k(m)(4)) is amended—

(1) in subparagraph (A)—

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

(B) by striking “and major Hispanic subpopulation groups and American Indians” and inserting “, major Hispanic subgroups, and American Indians and Alaska Natives”; and

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

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

“(i) consult with Indian Tribes, Tribal organizations, the Tribal Technical Advisory Group of the Centers for Medicare & Medicaid Services maintained under section 5006(e) of the American Recovery and Reinvestment Act of 2009, and the Tribal Advisory Committee established by the Centers for Disease Control and Prevention, in coordination with epidemiology centers, to develop guidelines for State and local health agencies to improve the quality and accuracy
of data with respect to the birth and death records of American Indians and Alaska Natives;

“(ii) confer with Urban Indian organizations to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

“(iii) enter into cooperative agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and epidemiology centers to address misclassification and undersampling of American Indians and Alaska Natives with respect to—

“(I) birth and death records; and

“(II) health care and public health surveillance systems, including, but not limited to, data with respect to chronic and infectious diseases, unintentional injuries, environmental health, child and adolescent health, maternal health and mortality, foodborne and waterborne illness, reproductive health, and any other notifiable disease or condition;

“(iv) encourage States to enter into data sharing agreements with Indian Tribes, Tribal organizations, and epidemiology centers to improve the quality and accuracy of public health data; and
“(v) not later than 180 days after the date of enactment of the Tribal Health Data Improvement Act of 2020, and biennially thereafter, issue a report on the following:

“(I) Which States have data sharing agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers to improve the quality and accuracy of health data.

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

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

(g) DEFINITIONS.—Section 306 of the Public Health Service Act (42 U.S.C. 242k) is amended—
(1) by redesignating subsection (n) as subsection (o); and

(2) by inserting after subsection (m) the following:

“(n) In this section:

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

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

“(3) The term ‘Tribal organization’ has the meaning given to the term ‘tribal organization’ in section 4 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.”.

(h) AUTHORIZATION OF APPROPRIATIONS.—Section 306(o) of the Public Health Service Act, as redesignated 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.

“(2) Of the amount authorized to be appropriated to carry out this section for a fiscal year, the Secretary shall not use more than 10 percent for the combined costs of—

“(A) administration of this section; and

“(B) carrying out subsection (m)(2).”.