

SEC. 4302. UNDERSTANDING HEALTH DISPARITIES: DATA COLLECTION AND ANALYSIS.

(a) UNIFORM CATEGORIES AND COLLECTION REQUIREMENTS.—The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following:

**“TITLE XXXI—DATA COLLECTION,
ANALYSIS, AND QUALITY**

“SEC. 3101 [42 U.S.C. 300k]. DATA COLLECTION, ANALYSIS, AND QUALITY.

“(a) DATA COLLECTION.—

“(1) IN GENERAL.—The Secretary shall ensure that, by not later than 2 years after the date of enactment of this title, any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) collects and reports, to the extent practicable—

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“(A) data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants;

“(B) data at the smallest geographic level such as State, local, or institutional levels if such data can be aggregated;

“(C) sufficient data to generate statistically reliable estimates by racial, ethnic, sex, primary language, and disability status subgroups for applicants, recipients or participants using, if needed, statistical oversamples of these subpopulations; and

“(D) any other demographic data as deemed appropriate by the Secretary regarding health disparities.

“(2) COLLECTION STANDARDS.—In collecting data described in paragraph (1), the Secretary or designee shall—

“(A) use Office of Management and Budget standards, at a minimum, for race and ethnicity measures;

“(B) develop standards for the measurement of sex, primary language, and disability status;

“(C) develop standards for the collection of data described in paragraph (1) that, at a minimum—

“(i) collects self-reported data by the applicant, recipient, or participant; and

“(ii) collects data from a parent or legal guardian if the applicant, recipient, or participant is a minor or legally incapacitated;

“(D) survey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify—

“(i) locations where individuals with disabilities access primary, acute (including intensive), and long-term care;

“(ii) the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria set forth in section 510 of the Rehabilitation Act of 1973; and

“(iii) the number of employees of health care providers trained in disability awareness and patient care of individuals with disabilities; and

“(E) require that any reporting requirement imposed for purposes of measuring quality under any ongoing or federally conducted or supported health care or public health program, activity, or survey includes requirements for the collection of data on individuals receiving health care items or services under such programs activities by race, ethnicity, sex, primary language, and disability status.

“(3) DATA MANAGEMENT.—In collecting data described in paragraph (1), the Secretary, acting through the National Coordinator for Health Information Technology shall—

“(A) develop national standards for the management of data collected; and

- “(B) develop interoperability and security systems for data management.
- “(b) DATA ANALYSIS.—
- “(1) IN GENERAL.—For each federally conducted or supported health care or public health program or activity, the Secretary shall analyze data collected under paragraph (a) to detect and monitor trends in health disparities (as defined for purposes of section 485E) at the Federal and State levels.
- “(c) DATA REPORTING AND DISSEMINATION.—
- “(1) IN GENERAL.—The Secretary shall make the analyses described in (b) available to—
- “(A) the Office of Minority Health;
 - “(B) the National Center on Minority Health and Health Disparities;
 - “(C) the Agency for Healthcare Research and Quality;
 - “(D) the Centers for Disease Control and Prevention;
 - “(E) the Centers for Medicare & Medicaid Services;
 - “(F) the Indian Health Service and epidemiology centers funded under the Indian Health Care Improvement Act;
 - “(G) the Office of Rural health;
 - “(H) other agencies within the Department of Health and Human Services; and
 - “(I) other entities as determined appropriate by the Secretary.
- “(2) REPORTING OF DATA.—The Secretary shall report data and analyses described in (a) and (b) through—
- “(A) public postings on the Internet websites of the Department of Health and Human Services; and
 - “(B) any other reporting or dissemination mechanisms determined appropriate by the Secretary.
- “(3) AVAILABILITY OF DATA.—The Secretary may make data described in (a) and (b) available for additional research, analyses, and dissemination to other Federal agencies, non-governmental entities, and the public, in accordance with any Federal agency’s data user agreements.
- “(d) LIMITATIONS ON USE OF DATA.—Nothing in this section shall be construed to permit the use of information collected under this section in a manner that would adversely affect any individual.
- “(e) PROTECTION AND SHARING OF DATA.—
- “(1) PRIVACY AND OTHER SAFEGUARDS.—The Secretary shall ensure (through the promulgation of regulations or otherwise) that—
- “(A) all data collected pursuant to subsection (a) is protected—
 - “(i) under privacy protections that are at least as broad as those that the Secretary applies to other health data under the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104–191; 110 Stat. 2033); and
 - “(ii) from all inappropriate internal use by any entity that collects, stores, or receives the data, including use of such data in determinations of eligibility (or

continued eligibility) in health plans, and from other inappropriate uses, as defined by the Secretary; and

“(B) all appropriate information security safeguards are used in the collection, analysis, and sharing of data collected pursuant to subsection (a).

“(2) DATA SHARING.—The Secretary shall establish procedures for sharing data collected pursuant to subsection (a), measures relating to such data, and analyses of such data, with other relevant Federal and State agencies including the agencies, centers, and entities within the Department of Health and Human Services specified in subsection (c)(1)..

“(f) DATA ON RURAL UNDERSERVED POPULATIONS.—The Secretary shall ensure that any data collected in accordance with this section regarding racial and ethnic minority groups are also collected regarding underserved rural and frontier populations.

“(g) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2010 through 2014.

“(h) REQUIREMENT FOR IMPLEMENTATION.—Notwithstanding any other provision of this section, data may not be collected under this section unless funds are directly appropriated for such purpose in an appropriations Act.

“(i) CONSULTATION.—The Secretary shall consult with the Director of the Office of Personnel Management, the Secretary of Defense, the Secretary of Veterans Affairs, the Director of the Bureau of the Census, the Commissioner of Social Security, and the head of other appropriate Federal agencies in carrying out this section.”.

(b) ADDRESSING HEALTH CARE DISPARITIES IN MEDICAID AND CHIP.—

(1) STANDARDIZED COLLECTION REQUIREMENTS INCLUDED IN STATE PLANS.—

(A) MEDICAID.—Section 1902(a) of the Social Security Act (42 U.S.C. 1396a(a)), as amended by section 2001(d), is amended—

(i) in paragraph 4), by striking “and” at the end;

(ii) in paragraph (75), by striking the period at the end and inserting “; and”; and

(iii) by inserting after paragraph (75) the following new paragraph:

“(76) provide that any data collected under the State plan meets the requirements of section 3101 of the Public Health Service Act.”.

(B) CHIP.—Section 2108(e) of the Social Security Act (42 U.S.C. 1397hh(e)) is amended by adding at the end the following new paragraph:

“(7) Data collected and reported in accordance with section 3101 of the Public Health Service Act, with respect to individuals enrolled in the State child health plan (and, in the case of enrollees under 19 years of age, their parents or legal guardians), including data regarding the primary language of such individuals, parents, and legal guardians.”.

(2) EXTENDING MEDICARE REQUIREMENT TO ADDRESS HEALTH DISPARITIES DATA COLLECTION TO MEDICAID AND

CHIP.—Title XIX of the Social Security Act (42 U.S.C. 1396 et seq.), as amended by section 2703 is amended by adding at the end the following new section:

“SEC. 1946 [42 U.S.C. 1396w–5]. ADDRESSING HEALTH CARE DISPARITIES.

“(a) **EVALUATING DATA COLLECTION APPROACHES.**—The Secretary shall evaluate approaches for the collection of data under this title and title XXI, to be performed in conjunction with existing quality reporting requirements and programs under this title and title XXI, that allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of race, ethnicity, sex, primary language, and disability status. In conducting such evaluation, the Secretary shall consider the following objectives:

“(1) Protecting patient privacy.

“(2) Minimizing the administrative burdens of data collection and reporting on States, providers, and health plans participating under this title or title XXI.

“(3) Improving program data under this title and title XXI on race, ethnicity, sex, primary language, and disability status.

“(b) **REPORTS TO CONGRESS.**—

“(1) **REPORT ON EVALUATION.**—Not later than 18 months after the date of the enactment of this section, the Secretary shall submit to Congress a report on the evaluation conducted under subsection (a). Such report shall, taking into consideration the results of such evaluation—

“(A) identify approaches (including defining methodologies) for identifying and collecting and evaluating data on health care disparities on the basis of race, ethnicity, sex, primary language, and disability status for the programs under this title and title XXI; and

“(B) include recommendations on the most effective strategies and approaches to reporting HEDIS quality measures as required under section 1852(e)(3) and other nationally recognized quality performance measures, as appropriate, on such bases.

“(2) **REPORTS ON DATA ANALYSES.**—Not later than 4 years after the date of the enactment of this section, and 4 years thereafter, the Secretary shall submit to Congress a report that includes recommendations for improving the identification of health care disparities for beneficiaries under this title and under title XXI based on analyses of the data collected under subsection (c).

“(c) **IMPLEMENTING EFFECTIVE APPROACHES.**—Not later than 24 months after the date of the enactment of this section, the Secretary shall implement the approaches identified in the report submitted under subsection (b)(1) for the ongoing, accurate, and timely collection and evaluation of data on health care disparities on the basis of race, ethnicity, sex, primary language, and disability status.”.

