

42 U.S. Code § 300kk

Data collection, analysis, and quality

(a) Data collection

(1) In general

The Secretary shall ensure that, by not later than 2 years after March 23, 2010, 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—

- (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 794f of title 29; 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 [1] by race, ethnicity, sex, primary language, and disability status.
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