

Attachment 1: Applicable Laws and Regulations

National Center for Health Statistics Legislative Mandate (41 USC 242K)

Sec. 306 [242k]

- (a) There is established in the Department of Health and Services the National Center for Health Statistics (hereinafter in this section referred to as the “Center” which shall be under the direction of a Director who shall be appointed by the Secretary. The Secretary, acting through the Center, shall conduct and support statistical and epidemiological activities for the purpose of improving the effectiveness, efficiency, and quality of health services in the United States.
- (b) In carrying out subsection (a), the Secretary, acting through the Center---
 - (1) shall collect statistics on---
 - (A) the extent and nature of illness and disability of the population of the United States (or of any groupings of the people included in the population), including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality,
 - (B) the impact of illness and disability of the population on the economy on the economy of the United States and on other aspects of the well-being of its population (or of such groupings),
 - (C) environmental , social, and other health hazards,
 - (D) determinants of health
 - (E) health resources, including physicians, dentists, nurses, and other health professionals by specialty and type of practice and the supply of services by hospitals, extended care facilities, home health agencies, and other health institutions,
 - (F) utilization of health care, including utilization of
 - (i) ambulatory health services by specialties, and
 - (ii) services of hospitals, extended care facilities, home health agencies, and other institutions,
 - (G) health care costs and financing, including the trends in health care prices and cost, the sources of payments for health care services, and
 - (H) family formation, growth, and dissolution;
 - (2) shall undertake and support (by grant or contract) research, demonstrations, and evaluations respecting new or improved methods for obtaining new or improved methods for obtaining current data on the matters referred to in paragraph (1);
 - (3) may undertake and support (by grant or contract) epidemiological research, demonstrations, and evaluations on the matters referred to in paragraph (1); and
 - (4) may collect, furnish, tabulate, and analyze statistics, and prepare studies, on matters referred to in paragraph (1) upon request of public and nonprofit private entities under arrangements under which the entities will pay the cost of the service provided.

Amounts appropriated to the Secretary from payments made under arrangements made under paragraph (4) shall be available to the Secretary for obligation until expended.

Sec. 308 [242m]

(d) Information; publication restrictions

No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under section 242b, 242k, or 242l of this title may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Secretary) to its use for such other purpose; and in the case of information obtained in the course of health statistical or epidemiological activities under section 242b or 242k of this title, such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented (as determined under regulations of the Secretary) to its publication or release in other form.

Patient Protection and Affordable Care Act (H.R. 3590) (ACA)

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. 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 H. R. 3590—461 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.

American Recovery and Reinvestment Act of 2009 (ARRA)

SEC. 3001. OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY.

- (a) Establishment.—There is established within the Department of Health and Human Services an Office of the National Coordinator for Health Information Technology (referred to in this section as the ‘Office’). The Office shall be headed by a National Coordinator who shall be appointed by the Secretary and shall report directly to the Secretary.
- (b) Purpose.—The National Coordinator shall perform the duties under subsection (c) in a manner consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information and that—
- (1) ensures that each patient's health information is secure and protected, in accordance with applicable law;
 - (2) improves health care quality, reduces medical errors, reduces health disparities, and advances the delivery of patient-centered medical care;
 - (3) reduces health care costs resulting from inefficiency, medical errors, inappropriate care, duplicative care, and incomplete information;
 - (4) provides appropriate information to help guide medical decisions at the time and place of care;
 - (5) ensures the inclusion of meaningful public input in such development of such infrastructure;
 - (6) improves the coordination of care and information among hospitals, laboratories, physician offices, and other entities through an effective infrastructure for the secure and authorized exchange of health care information;
 - (7) improves public health activities and facilitates the early identification and rapid response to public health threats and emergencies, including bioterror events and infectious disease outbreaks;
 - (8) facilitates health and clinical research and health care quality;
 - (9) promotes early detection, prevention, and management of chronic diseases;
 - (10) promotes a more effective marketplace, greater competition, greater systems analysis, increased consumer choice, and improved outcomes in health care services; and
 - (11) improves efforts to reduce health disparities.

Confidential Information Protection and Statistical Efficiency Act (PL 107-347)

Subtitle A—Confidential Information Protection

SEC. 511. FINDINGS AND PURPOSES.

(a) FINDINGS.—The Congress finds the following:

(1) Individuals, businesses, and other organizations have varying degrees of legal protection when providing information to the agencies for strictly statistical purposes.

(2) Pledges of confidentiality by agencies provide assurances to the public that information about individuals or organizations or provided by individuals or organizations for exclusively statistical purposes will be held in confidence and will not be used against such individuals or organizations in any agency action.

(3) Protecting the confidentiality interests of individuals or organizations who provide information under a pledge of confidentiality for Federal statistical programs serves both the interests of the public and the needs of society.

(4) Declining trust of the public in the protection of information provided under a pledge of confidentiality to the agencies adversely affects both the accuracy and completeness of statistical analyses.

(5) Ensuring that information provided under a pledge of confidentiality for statistical purposes receives protection is essential in continuing public cooperation in statistical programs.

(b) PURPOSES.—The purposes of this subtitle are the following:

(1) To ensure that information supplied by individuals or organizations to an agency for statistical purposes under a pledge of confidentiality is used exclusively for statistical purposes.

(2) To ensure that individuals or organizations who supply information under a pledge of confidentiality to agencies for statistical purposes will neither have that information disclosed in identifiable form to anyone not authorized by this title nor have that information used for any purpose other than a statistical purpose.

(3) To safeguard the confidentiality of individually identifiable information acquired under a pledge of confidentiality for statistical purposes by controlling access to, and uses made of, such information.

SEC. 512. LIMITATIONS ON USE AND DISCLOSURE OF DATA AND INFORMATION.

(a) USE OF STATISTICAL DATA OR INFORMATION.—Data or information acquired by an agency under a pledge of confidentiality and for exclusively statistical purposes shall be used by officers, employees, or agents of the agency exclusively for statistical purposes.

(b) DISCLOSURE OF STATISTICAL DATA OR INFORMATION.—

(1) Data or information acquired by an agency under a pledge of confidentiality for exclusively statistical purposes shall not be disclosed by an agency in identifiable form, for any use other than an exclusively statistical purpose, except with the informed consent of the respondent.

(2) A disclosure pursuant to paragraph (1) is authorized only when the head of the agency approves such disclosure and the disclosure is not prohibited by any other law.

(3) This section does not restrict or diminish any confidentiality protections in law that otherwise apply to data or information acquired by an agency under a pledge of confidentiality for exclusively statistical purposes.

(c) RULE FOR USE OF DATA OR INFORMATION FOR NONSTATISTICAL

PURPOSES.—A statistical agency or unit shall clearly distinguish any data or information it collects for nonstatistical purposes (as authorized by law) and provide notice to the public, before the data or information is collected, that the data or information could be used for nonstatistical purposes.

(d) DESIGNATION OF AGENTS.—A statistical agency or unit may designate agents, by contract or by entering into a special agreement containing the provisions required under section 502(2) for

treatment as an agent under that section, who may perform exclusively statistical activities, subject to the limitations and penalties described in this title.

SEC. 513. FINES AND PENALTIES.

Whoever, being an officer, employee, or agent of an agency acquiring information for exclusively statistical purposes, having taken and subscribed the oath of office, or having sworn to observe the limitations imposed by section 512, comes into possession of such information by reason of his or her being an officer, employee, or agent and, knowing that the disclosure of the specific information is prohibited under the provisions of this title, willfully discloses the information in any manner to a person or agency not entitled to receive it, shall be guilty of a class E felony and imprisoned for not more than 5 years, or fined not more than \$250,000, or both.