

or to be collected, reviewed, gathered, analyzed, or used in conjunction with the data mining activity, to the extent applicable in the context of the data mining activity.

(G) A thorough discussion of the policies, procedures, and guidelines that are in place or that are to be developed and applied in the use of such data mining activity in order to—

(i) protect the privacy and due process rights of individuals, such as redress procedures; and

(ii) ensure that only accurate and complete information is collected, reviewed, gathered, analyzed, or used, and guard against any harmful consequences of potential inaccuracies.

(3) Annex

(A) In general

A report under subparagraph (A)² shall include in an annex any necessary—

- (i) classified information;
- (ii) law enforcement sensitive information;
- (iii) proprietary business information; or
- (iv) trade secrets (as that term is defined in section 1839 of title 18).

(B) Availability

Any annex described in clause (i)—

(i) shall be available, as appropriate, and consistent with the National Security Act of 1947 (50 U.S.C. 401 et seq.), to the Committee on Homeland Security and Governmental Affairs, the Committee on the Judiciary, the Select Committee on Intelligence, the Committee on Appropriations, and the Committee on Banking, Housing, and Urban Affairs of the Senate and the Committee on Homeland Security, the Committee on the Judiciary, the Permanent Select Committee on Intelligence, the Committee on Appropriations, and the Committee on Financial Services of the House of Representatives; and

(ii) shall not be made available to the public.

(4) Time for report

Each report required under subparagraph (A)² shall be—

(A) submitted not later than 180 days after August 3, 2007; and

(B) updated not less frequently than annually thereafter, to include any activity to use or develop data mining engaged in after the date of the prior report submitted under subparagraph (A).²

(Pub. L. 110–53, title VIII, §804, Aug. 3, 2007, 121 Stat. 362.)

REFERENCES IN TEXT

The National Security Act of 1947, referred to in subsec. (c)(3)(B)(i), is act July 26, 1947, ch. 343, 61 Stat. 495. For complete classification of this Act to the Code, see Short Title note set out under section 401 of Title 50, War and National Defense, and Tables.

CHAPTER 21F—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

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2000ff. Definitions.

Sec.

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§ 2000ff. Definitions

In this chapter:

(1) Commission

The term “Commission” means the Equal Employment Opportunity Commission as created by section 2000e–4 of this title.

(2) Employee; employer; employment agency; labor organization; member

(A) In general

The term “employee” means—

- (i) an employee (including an applicant), as defined in section 2000e(f) of this title;
- (ii) a State employee (including an applicant) described in section 2000e–16c(a) of this title;
- (iii) a covered employee (including an applicant), as defined in section 1301 of title 2;
- (iv) a covered employee (including an applicant), as defined in section 411(c) of title 3; or
- (v) an employee or applicant to which section 2000e–16(a) of this title applies.

(B) Employer

The term “employer” means—

- (i) an employer (as defined in section 2000e(b) of this title);
- (ii) an entity employing a State employee described in section 2000e–16c(a) of this title;
- (iii) an employing office, as defined in section 1301 of title 2;
- (iv) an employing office, as defined in section 411(c) of title 3; or
- (v) an entity to which section 2000e–16(a) of this title applies.

(C) Employment agency; labor organization

The terms “employment agency” and “labor organization” have the meanings given the terms in section 2000e of this title.

(D) Member

The term “member”, with respect to a labor organization, includes an applicant for membership in a labor organization.

(3) Family member

The term “family member” means, with respect to an individual—

- (A) a dependent (as such term is used for purposes of section 1181(f)(2) of title 29) of such individual, and
- (B) any other individual who is a first-degree, second-degree, third-degree, or fourth-degree relative of such individual or of an individual described in subparagraph (A).

(4) Genetic information**(A) In general**

The term “genetic information” means, with respect to any individual, information about—

- (i) such individual’s genetic tests,
- (ii) the genetic tests of family members of such individual, and
- (iii) the manifestation of a disease or disorder in family members of such individual.

(B) Inclusion of genetic services and participation in genetic research

Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

(C) Exclusions

The term “genetic information” shall not include information about the sex or age of any individual.

(5) Genetic monitoring

The term “genetic monitoring” means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.

(6) Genetic services

The term “genetic services” means—

- (A) a genetic test;
- (B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or
- (C) genetic education.

(7) Genetic test**(A) In general**

The term “genetic test” means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

(B) Exceptions

The term “genetic test” does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes.

(Pub. L. 110-233, title II, §201, May 21, 2008, 122 Stat. 905.)

EFFECTIVE DATE

Pub. L. 110-233, title II, §213, May 21, 2008, 122 Stat. 920, provided that: “This title [enacting this chapter] takes effect on the date that is 18 months after the date of enactment of this Act [May 21, 2008].”

SHORT TITLE

Pub. L. 110-233, §1(a), May 21, 2008, 122 Stat. 881, provided that: “This Act [enacting this chapter, sections

300gg-53 and 1320d-9 of this title, and section 9834 of Title 26, Internal Revenue Code, amending sections 300gg-1, 300gg-21, 300gg-22, 300gg-61, 300gg-91, and 1395ss of this title, sections 9802 and 9832 of Title 26, and sections 216, 1132, 1182, and 1191b of Title 29, Labor, and enacting provisions set out as notes under this section, sections 300gg-1, 1320d-9, and 1395ss of this title, section 9802 of Title 26, and sections 216 and 1132 of Title 29] may be cited as the ‘Genetic Information Non-discrimination Act of 2008’.”

SEVERABILITY

Pub. L. 110-233, title III, §301, May 21, 2008, 122 Stat. 920, provided that: “If any provision of this Act [see Short Title note above], an amendment made by this Act, or the application of such provision or amendment to any person or circumstance is held to be unconstitutional, the remainder of this Act, the amendments made by this Act, and the application of such provisions to any person or circumstance shall not be affected thereby.”

FINDINGS

Pub. L. 110-233, §2, May 21, 2008, 122 Stat. 881, as amended by Pub. L. 111-256, §2(j), Oct. 5, 2010, 124 Stat. 2644, provided that: “Congress makes the following findings:

“(1) Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract a particular disorder. New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.

“(2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic ‘defects’ such as intellectual disabilities, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to ‘correct’ apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

“(3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African-Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act [Pub. L. 92-294, see Tables for classification], which withholds Federal funding from States unless sickle cell testing is voluntary.

“(4) Congress has been informed of examples of genetic discrimination in the workplace. These include

the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case [sic] *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.

“(5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections. Moreover, while many States have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”

[For meaning of references to an intellectual disability and to individuals with intellectual disabilities in provisions amended by section 2 of Pub. L. 111-256, see section 2(k) of Pub. L. 111-256, set out as a note under section 1400 of Title 20, Education.]

§ 2000ff-1. Employer practices

(a) Discrimination based on genetic information

It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee; or

(2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.

(b) Acquisition of genetic information

It shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee except—

(1) where an employer inadvertently requests or requires family medical history of the employee or family member of the employee;

(2) where—

(A) health or genetic services are offered by the employer, including such services offered as part of a wellness program;

(B) the employee provides prior, knowing, voluntary, and written authorization;

(C) only the employee (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph

(C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employer except in aggregate terms that do not disclose the identity of specific employees;

(3) where an employer requests or requires family medical history from the employee to comply with the certification provisions of section 2613 of title 29 or such requirements under State family and medical leave laws;

(4) where an employer purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history;

(5) where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only if—

(A) the employer provides written notice of the genetic monitoring to the employee;

(B)(i) the employee provides prior, knowing, voluntary, and written authorization; or

(ii) the genetic monitoring is required by Federal or State law;

(C) the employee is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific employees; or

(6) where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information of such employer's employees, but only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.

(c) Preservation of protections

In the case of information to which any of paragraphs (1) through (6) of subsection (b) applies, such information may not be used in violation of paragraph (1) or (2) of subsection (a) or treated or disclosed in a manner that violates section 2000ff-5 of this title.

(Pub. L. 110-233, title II, §202, May 21, 2008, 122 Stat. 907.)