

LC 413
2025 Regular Session
44300-002
8/29/24 (RH/ps)

D R A F T

SUMMARY

Digest: The Act tells OHA and ODHS to work with the nine tribes in Oregon to adopt rules for collecting tribal data. (Flesch Readability Score: 68.6).

Directs the Oregon Health Authority, in collaboration with the Department of Human Services and the nine federally recognized Indian tribes in Oregon, to adopt rules governing the collection, storage and use of data on tribal affiliation.

Declares an emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to tribal affiliation data; creating new provisions; amending ORS
3 413.161, 413.163, 413.164 and 442.373; and declaring an emergency.

4 **Be It Enacted by the People of the State of Oregon:**

5 **SECTION 1.** ORS 413.161 is amended to read:

6 413.161. (1)(a) The Oregon Health Authority, in collaboration with the
7 Department of Human Services, shall adopt by rule uniform standards, based
8 on local, statewide and national best practices, for the collection of data on
9 race, ethnicity, preferred spoken and written languages, disability status,
10 sexual orientation and gender identity. The authority and the department
11 shall use the standards, to the greatest extent practicable, in surveys con-
12 ducted and in all programs in which the authority or the department collects,
13 records or reports the data described in this subsection. The authority and
14 the department shall review and update the standards at least once every two
15 years to ensure that the standards are efficient, uniform and consistent with
16 best practices.

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

1 [(2)] (b) The authority shall appoint an advisory committee in accordance
2 with ORS 183.333 composed of individuals likely to be affected by the stan-
3 dards **adopted under this subsection** and advocates for individuals likely
4 to be affected by the standards.

5 **(2) The authority, in collaboration with the department and the**
6 **nine federally recognized Indian tribes in Oregon, shall adopt by rule**
7 **uniform standards, based on local, statewide and national best prac-**
8 **tices, for the collection, storage and use of data on tribal affiliation.**
9 **The standards shall protect the right of each tribe to govern the col-**
10 **lection, storage and use of that tribe's data. The authority and the**
11 **department shall use the standards in surveys conducted and in all**
12 **programs in which the authority or the department collects, records**
13 **or reports the data described in this subsection. The authority and the**
14 **department, in collaboration with the nine federally recognized Indian**
15 **tribes in Oregon, shall review and update the standards at least once**
16 **every two years to ensure that the standards are efficient, uniform and**
17 **consistent with best practices.**

18 (3) Any data collected by the authority or the department in accordance
19 with uniform standards adopted under [subsection (1) of] this section is sub-
20 ject to ORS 413.164 (4).

21 **SECTION 2.** ORS 413.163 is amended to read:

22 413.163. The Oregon Health Authority shall establish a data system for
23 data on race, ethnicity, preferred spoken and written languages, disability
24 status, **tribal affiliation**, sexual orientation and gender identity collected
25 under ORS 413.164. The data system established under this section must in-
26 clude:

27 (1) A data registry to receive and store the data described in this section
28 from coordinated care organizations, health care providers and health
29 insurers, patients, clients and members of coordinated care organizations,
30 health care providers and health insurers, the authority and the Department
31 of Human Services. The registry must allow for coordinated care organiza-

1 tions, health care providers and health insurers to:

2 (a) Electronically submit data collected under ORS 413.164; and

3 (b) Query the data registry to determine whether the registry contains
4 current data for a patient, member or client.

5 (2) Functionality that allows a patient, member or client to directly sub-
6 mit to the data system their data described in this section.

7 **SECTION 3.** ORS 413.164 is amended to read:

8 413.164. (1) As used in this section and ORS 413.163 and 413.167:

9 (a) “Board” means the:

10 (A) State Board of Examiners for Speech-Language Pathology and
11 Audiology;

12 (B) State Board of Chiropractic Examiners;

13 (C) State Board of Licensed Social Workers;

14 (D) Oregon Board of Licensed Professional Counselors and Therapists;

15 (E) Oregon Board of Dentistry;

16 (F) State Board of Massage Therapists;

17 (G) Oregon Board of Naturopathic Medicine;

18 (H) Oregon State Board of Nursing;

19 (I) Oregon Board of Optometry;

20 (J) State Board of Pharmacy;

21 (K) Oregon Medical Board;

22 (L) Occupational Therapy Licensing Board;

23 (M) Oregon Board of Physical Therapy;

24 (N) Oregon Board of Psychology;

25 (O) Board of Medical Imaging;

26 (P) Long Term Care Administrators Board;

27 (Q) State Board of Direct Entry Midwifery;

28 (R) State Board of Denture Technology;

29 (S) Respiratory Therapist and Polysomnographic Technologist Licensing
30 Board;

31 (T) Board of Licensed Dietitians; and

1 (U) Oregon Health Authority, to the extent that the authority:

2 (i) Licenses emergency medical services providers under ORS 682.216; and

3 (ii) Regulates traditional health workers under ORS 414.665.

4 (b) “Coordinated care organization” has the meaning given that term in
5 ORS 414.025.

6 (c) “Health care provider” means an individual licensed, certified, regis-
7 tered or otherwise authorized to practice by a board.

8 (d) “Health insurer” has the meaning given that term in ORS 746.600.

9 (2) At least once each calendar year and in accordance with timelines
10 established by the authority by rule, a coordinated care organization, a
11 health care provider or health care provider’s designee, or a health insurer
12 shall collect data on race, ethnicity, preferred spoken and written languages,
13 disability status, **tribal affiliation**, sexual orientation and gender identity
14 from the coordinated care organization’s, health care provider’s or health
15 insurer’s patients, clients and members, in accordance with standards
16 adopted by the authority pursuant to ORS 413.161. A coordinated care or-
17 ganization, health care provider or health insurer shall submit the data to
18 the authority in the manner prescribed by the authority by rule.

19 (3)(a) The authority shall adopt rules, including but not limited to rules:

20 (A) Establishing standards for collecting, securely transmitting and re-
21 porting the data described in subsection (2) of this section;

22 (B) Establishing the timelines for collection and submission of data de-
23 scribed in subsection (2) of this section;

24 (C) Permitting coordinated care organizations, health care providers and
25 health insurers to report to the authority that a patient, client or member
26 refused to answer questions regarding race, ethnicity, preferred spoken and
27 written languages, disability status, **tribal affiliation**, sexual orientation
28 and gender identity;

29 (D) Establishing criteria for extensions of timelines established under this
30 subsection and a process for reviewing requests for extensions; and

31 (E) Establishing criteria for exempting certain health care providers or

1 classes of health care providers from the requirements of subsection (2) of
2 this section and a process for reviewing requests for exemptions.

3 (b) In adopting rules under subsection (2) of this section, the authority
4 shall:

5 (A) Consult with the advisory committee established under ORS 413.161;

6 **(B) Collaborate with the nine federally recognized Indian tribes in**
7 **Oregon on rules regarding the collection, storage and use of tribal af-**
8 **filiation data;**

9 ~~[(B)]~~ (C) Allow coordinated care organizations, health care providers and
10 health insurers to collect the data described in subsection (2) of this section
11 on electronic or paper forms; and

12 ~~[(C)]~~ (D) Require coordinated care organizations, health care providers
13 and health insurers to inform patients, clients and members:

14 (i) That data collected under subsection (2) of this section is reported to
15 the authority;

16 (ii) How the authority, coordinated care organization, health care pro-
17 vider and health insurer use the data;

18 (iii) Of the purposes for which the data may not be used; and

19 (iv) That the patient, client or member is not required to answer
20 questions regarding race, ethnicity, preferred spoken and written languages,
21 disability status, **tribal affiliation**, sexual orientation and gender identity.

22 (4)(a) Data collected under this section is confidential and not subject to
23 disclosure under ORS 192.311 to 192.478. The authority may release the data
24 collected under this section only if the data to be released is anonymized and
25 aggregated so that the data released does not reasonably allow an individual
26 whose information is included in the data to be identified.

27 **(b) The authority may not release data collected under this section**
28 **regarding tribal affiliation unless the release of that data is allowed**
29 **by a written data use agreement entered into by the authority and the**
30 **affected tribe.**

31 (5) A coordinated care organization or health insurer transacting insur-

1 ance in this state may not consider any data collected under subsection (2)
2 of this section:

3 (a) In determining whether to deny, limit, cancel, rescind or refuse to
4 renew an insurance policy;

5 (b) To establish premium rates for an insurance policy; or

6 (c) To establish the terms and conditions of an insurance policy.

7 (6) The authority may provide incentives to coordinated care organiza-
8 tions, health care providers and health insurers to assist in deferring the
9 costs of making changes to electronic health records systems or similar sys-
10 tems to facilitate the collection of data described in subsection (2) of this
11 section.

12 (7)(a) The authority shall monitor coordinated care organizations, health
13 care providers and health insurers for compliance with the standards estab-
14 lished under subsection (1) of this section.

15 (b) The authority may impose on a coordinated care organization, health
16 care provider or health insurer a civil penalty for a violation of the re-
17 quirements of this section or rules adopted under this section:

18 (A) Not to exceed \$200 for the first violation;

19 (B) Not to exceed \$400 for the second violation; and

20 (C) Not to exceed \$500 for the third and subsequent violations.

21 (c) Prior to imposing a penalty under paragraph (b) of this subsection, the
22 authority shall provide notice to the coordinated care organization, health
23 care provider or health insurer of the alleged violation and provide the co-
24 ordinated care organization, health care provider or health insurer a rea-
25 sonable time in which to correct the violation.

26 **SECTION 4.** ORS 442.373 is amended to read:

27 442.373. (1) The Oregon Health Authority shall establish and maintain a
28 program that requires reporting entities to report health care data for the
29 following purposes:

30 (a) Determining the maximum capacity and distribution of existing re-
31 sources allocated to health care.

1 (b) Identifying the demands for health care.

2 (c) Allowing health care policymakers to make informed choices.

3 (d) Evaluating the effectiveness of intervention programs in improving
4 health outcomes.

5 (e) Comparing the costs and effectiveness of various treatment settings
6 and approaches.

7 (f) Providing information to consumers and purchasers of health care.

8 (g) Improving the quality and affordability of health care and health care
9 coverage.

10 (h) Assisting the authority in furthering the health policies expressed by
11 the Legislative Assembly in ORS 442.310.

12 (i) Evaluating health disparities, including but not limited to disparities
13 related to race and ethnicity.

14 (2) The authority shall prescribe by rule standards that:

15 (a) Establish the time, place, form and manner of reporting data under
16 this section, including but not limited to:

17 (A) Requiring the use of unique patient and provider identifiers;

18 (B) Specifying a uniform coding system that reflects all health care
19 utilization and costs for health care services provided to Oregon residents
20 in other states; and

21 (C) Establishing enrollment thresholds below which reporting will not be
22 required.

23 (b) Establish the types of data to be reported under this section, including
24 but not limited to:

25 (A) Health care claims and enrollment data used by reporting entities and
26 paid health care claims data;

27 (B) Reports, schedules, statistics or other data relating to health care
28 costs, prices, quality, utilization or resources determined by the authority to
29 be necessary to carry out the purposes of this section; and

30 (C) Data related to race, ethnicity, disability, **tribal affiliation**, sexual
31 orientation, gender identity and primary language collected in a manner

1 consistent with ORS 413.161.

2 (3) Any third party administrator that is not required to obtain a license
3 under ORS 744.702 and that is legally responsible for payment of a claim for
4 a health care item or service provided to an Oregon resident may report to
5 the authority the health care data described in subsection (2) of this section.

6 (4) The authority shall adopt rules establishing requirements for reporting
7 entities to train providers on protocols for collecting race, ethnicity, disa-
8 bility, **tribal affiliation**, sexual orientation, gender identity and primary
9 language data in a culturally competent manner.

10 (5)(a) The authority shall use data collected under this section to provide
11 information to consumers of health care to empower the consumers to make
12 economically sound and medically appropriate decisions. The information
13 must include, but not be limited to, the prices and quality of health care
14 services.

15 (b) The authority shall, using only data collected under this section from
16 reporting entities described in ORS 442.372 (1) to (3), post to its website
17 health care price information including the median prices paid by the re-
18 porting entities to hospitals and hospital outpatient clinics for, at a mini-
19 mum, the 50 most common inpatient procedures and the 100 most common
20 outpatient procedures.

21 (c) The health care price information posted to the website must be:

22 (A) Displayed in a consumer friendly format;

23 (B) Easily accessible by consumers; and

24 (C) Updated at least annually to reflect the most recent data available.

25 (d) The authority shall apply for and receive donations, gifts and grants
26 from any public or private source to pay the cost of posting health care price
27 information to its website in accordance with this subsection. Moneys re-
28 ceived shall be deposited to the Oregon Health Authority Fund.

29 (e) The obligation of the authority to post health care price information
30 to its website as required by this subsection is limited to the extent of any
31 moneys specifically appropriated for that purpose or available from do-

1 nations, gifts and grants from private or public sources.

2 (6) The authority may contract with a third party to collect and process
3 the health care data reported under this section. The contract must prohibit
4 the collection of Social Security numbers and must prohibit the disclosure
5 or use of the data for any purpose other than those specifically authorized
6 by the contract. The contract must require the third party to transmit all
7 data collected and processed under the contract to the authority.

8 (7) The authority shall facilitate a collaboration between the Department
9 of Human Services, the authority, the Department of Consumer and Business
10 Services and interested stakeholders to develop a comprehensive health care
11 information system using the data reported under this section and collected
12 by the authority under ORS 442.370 and 442.400 to 442.463. The authority, in
13 consultation with interested stakeholders, shall:

14 (a) Formulate the data sets that will be included in the system;

15 (b) Establish the criteria and procedures for the development of limited
16 use data sets;

17 (c) Establish the criteria and procedures to ensure that limited use data
18 sets are accessible and compliant with federal and state privacy laws; and

19 (d) Establish a time frame for the creation of the comprehensive health
20 care information system.

21 (8) Information disclosed through the comprehensive health care infor-
22 mation system described in subsection (7) of this section:

23 (a) Shall be available, when disclosed in a form and manner that ensures
24 the privacy and security of personal health information as required by state
25 and federal laws, as a resource to researchers, insurers, employers, providers,
26 purchasers of health care and state agencies to allow for continuous review
27 of health care utilization, expenditures and performance in this state;

28 (b) Shall be available to Oregon programs for quality in health care for
29 use in improving health care in Oregon, subject to rules prescribed by the
30 authority conforming to state and federal privacy laws or limiting access to
31 limited use data sets;

1 (c) Shall be presented to allow for comparisons of geographic, demo-
2 graphic and economic factors and institutional size; and

3 (d) May not disclose trade secrets of reporting entities or self-funded,
4 employer-sponsored health insurance plans regulated under the Employee
5 Retirement Income Security Act of 1974, as codified and amended at 29
6 U.S.C. 1001, et seq., that report health care data voluntarily.

7 (9) The collection, storage and release of health care data and other in-
8 formation under this section is subject to the requirements of the federal
9 Health Insurance Portability and Accountability Act.

10 (10)(a) Notwithstanding subsection (9) of this section, in addition to the
11 comprehensive health care information system described in subsection (7) of
12 this section, the Department of Consumer and Business Services shall be al-
13 lowed to access, use and disclose data collected under this section by certi-
14 fying in writing that the data will be used only to carry out the department's
15 duties.

16 (b) Personally identifiable information disclosed to the department under
17 paragraph (a) of this subsection, including a consumer's name, address, tele-
18 phone number or electronic mail address, is confidential and not subject to
19 further disclosure under ORS 192.311 to 192.478.

20 (11) The authority may impose a charge for information disclosed to re-
21 searchers, insurers, employers, providers and purchasers of health care under
22 subsection (8) of this section in an amount necessary to cover the authority's
23 actual costs for collecting and releasing the information that is requested.

24 **SECTION 5. The Oregon Health Authority and the Department of**
25 **Human Services may not collect, store or use any tribal affiliation**
26 **data until the authority, in collaboration with the department and the**
27 **nine federally recognized Indian tribes in Oregon, has adopted, in ac-**
28 **cordance with ORS 413.161, uniform standards for the collection, stor-**
29 **age and use of such data.**

30 **SECTION 6. (1) The amendments to ORS 413.161, 413.163, 413.164 and**
31 **442.373 by sections 1 to 4 of this 2025 Act become operative on January**

1 **1, 2026.**

2 **(2) The Oregon Health Authority and the Department of Human**
3 **Services may take any action before the operative date specified in**
4 **subsection (1) of this section that is necessary to enable the authority**
5 **and the department to exercise, on and after the operative date spec-**
6 **ified in subsection (1) of this section, all the duties, functions and**
7 **powers conferred on the authority and the department by the amend-**
8 **ments to ORS 413.161, 413.163, 413.164 and 442.373 by sections 1 to 4 of**
9 **this 2025 Act.**

10 **SECTION 7. This 2025 Act being necessary for the immediate pres-**
11 **ervation of the public peace, health and safety, an emergency is de-**
12 **clared to exist, and this 2025 Act takes effect on its passage.**

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