

Support HB4088A – A9 Amendment Protect Health Researcher Access to Critical Data

Introduction

HB4088A takes important steps to improve the privacy of patients and physicians relating to reproductive or gender-affirming health care – but inadvertently restricts access by researchers and the general public to critical public health information about these health care activities. In doing so, the bill may actually harm patients seeking this care.

Section 3 prevents even “private citizens” from accessing information about reproductive and gender-affirming health care activities

Effect of -A9 Amendment:

- Removes “private citizen” from scope and clarifies in text that this is really about “federal and interstate investigations”
- Allows patients and journalists to access information about legal reproductive and gender affirming health care activities in Oregon

Section 9 would block public health researchers from using APAC “Limited Data Sets” in a manner consistent with Oregon and Federal law

Effect of -A9 Amendment:

- Clarifies that the bill doesn’t restrict the existing [All Payer All Claims reporting program](#), under which researchers can access redacted health claims data under strict oversight by the Oregon Health Authority
- Aligns text to Federal HIPAA regulations [[45 C.F.R. § 164.514\(e\)](#)] for “limited data sets” for research purposes
- Researchers – including the pharmaceutical companies that make the “puberty blocker” and cross-sex hormone drugs that transgender patients depend upon – need access to this data to ensure patient safety and product effectiveness

Requested by Senator THATCHER

**PROPOSED AMENDMENTS TO
A-ENGROSSED HOUSE BILL 4088**

1 On page 2 of the printed A-engrossed bill, line 24, delete “, a private cit-
2 izen” and delete “an investigation or”.

3 In line 25, delete “inquiry” and insert “a federal or interstate investi-
4 gation”.

5 On page 4, delete lines 26 through 40 and insert:

6 **“SECTION 9. Confidentiality of individually identifiable informa-**
7 **tion.** (1) As used in this section, ‘individually identifiable
8 information’ means any oral or written health information in any
9 form or medium that is identifiable to an individual, including demo-
10 graphic information that identifies the individual, or for which there
11 is a reasonable basis to believe the information can be used to identify
12 an individual, and that relates to applications for or receipt of legally
13 protected reproductive or gender-affirming health care activities paid
14 for in part or in whole by the Oregon Health Authority.

15 **“(2) Individually identifiable information obtained by the authority:**

16 **“(a) Is confidential and not subject to disclosure under ORS 192.311**
17 **to 192.478;**

18 **“(b) May be disclosed only as necessary and directly connected with**
19 **the administration of the state medical assistance program or the**
20 **authority’s duties and responsibilities under ORS 435.230; and**

21 **“(c) Is confidential, nondiscoverable and inadmissible in any judicial**

1 or administrative proceeding that is not directly connected with the
2 authority's administration of the state medical assistance program or
3 the programs described in ORS 435.230.

4 “(3) Nothing in this section prohibits the authority from including
5 data derived from information related to a legally protected reproduc-
6 tive or gender-affirming health care activity in the limited use data
7 sets included in the comprehensive health care information system
8 developed under ORS 442.373, provided the following direct identifiers
9 of the individual or of relatives, employers or household members of
10 the individual are excluded:

11 “(a) Names;

12 “(b) Postal address information, other than town or city, state and
13 zip code;

14 “(c) Telephone numbers;

15 “(d) Facsimile numbers;

16 “(e) Email addresses;

17 “(f) Social Security numbers;

18 “(g) Medical record numbers;

19 “(h) Health plan beneficiary numbers;

20 “(i) Account numbers;

21 “(j) Certificate or license numbers;

22 “(k) Vehicle identifiers and serial numbers, including license plate
23 numbers;

24 “(L) Device identifiers and serial numbers;

25 “(m) Internet universal resource locators;

26 “(n) Internet Protocol address numbers;

27 “(o) Biometric identifiers, including finger and voice prints; and

28 “(p) Full face photographic images and any comparable images.”

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