Amend HB4088 – Protect Public Access to Research Data about Reproductive and Gender Affirming Treatment

While HB4088 takes important steps to protect patient and provider privacy and security, it also blocks access to important public health information – not just about “gender affirming health care” but about ANY reproductive health care – including “prenatal, postnatal and delivery care.”

For gender medicine, everyone interested in this issue needs access to the kind of good facts and data that Oregon can provide. Nobody is helped when we hide important data from researchers – patients suffer the most.

Specific Concerns:

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

<u>Problem:</u>

- The section caption (title) has no legal weight. See section 18 at the bottom of the bill. So this isn’t just about “federal and interstate investigations” – it is about ANY “inquiry into a reproductive or gender-affirming health care activity” by anyone, even “a private citizen” in Oregon.
- This would prevent public health researchers from accessing information about “prenatal, postnatal and delivery care,” “treatments for sexually transmitted infections,” or “any other health care and medical services related to reproductive health” – not just gender affirming treatment or pregnancy termination.
- Taken to the logical extreme, <u>*it could even prevent patients from learning about the health care services available to them*</u>.

<u>Recommendations:</u>

- Delete “a private citizen” from page 2, line 21.
    - Allows private citizens to get access to information about reproductive and gender-affirming health care activities.
- Add clarifying language to the text that this is really about “federal and interstate investigations” – NOT blocking public health research or inquiries by patients or providers.

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

Problem:

Individually identifiable health information must be guarded very carefully.

However, Federal HIPAA regulations [45 C.F.R. § 164.514(e)] do allow limited release of protected health information to researchers – as long as all "direct identifiers" (like names, addresses, social security numbers) are removed. Researchers must follow strict contractual controls, in close coordination with the Oregon Health Authority. [See https://www.law.cornell.edu/cfr/text/45/164.514]

Oregon's "All Payer All Claims Reporting Program" provides this data to public health researchers under a carefully controlled program that is highly effective at preventing misuse. This "real world data" is critical to developing new medicines, improving medical technology, and identifying or resolving concerns about potential risks and side effects. [See https://www.oregon.gov/oha/hpa/analytics/pages/all-payer-all-claims.aspx and ORS 442.373].

Section 9 could prevent public health researchers from accessing this critical "real world evidence" – for any topic relating to "reproductive and gender-affirming health care."

Recommendation:

- Add a provision to section 9 allowing release of "limited data sets" for research purposes in a manner consistent with Federal law [45 C.F.R. § 164.514]

Additional Recommendation – Sunset Provision

The bill should "sunset" in 2030 – giving the legislature an opportunity revisit this important issue after the current political furor settles down.