



April 11, 2022

Members of the Assembly Committee on Health
 State Capitol,
 Sacramento, CA 95814

RE: Oppose AB 1797 (Weber): Immunization registry.

Dear Chair Wood and the Members of the Assembly Committee on Health:

On behalf of A Voice for Choice Advocacy (AVFCA), I regret to inform you that we oppose AB 1797, as currently written. AVFCA advocates for people’s rights to be fully informed about the composition, quality, and short- and long-term health effects of all products that go into people’s bodies, such as food, water, air, pharmaceuticals, and cosmetics, and have a choice as to whether to ingest, inject or use them.

AB 1797 claims to make enhancements to the California Immunization Registries. While A Voice for Choice Advocacy agrees that the California Immunization Registries currently have many flaws, we do not feel that AB 1797 addresses them and would create significant privacy issues which circumvent FERPA and HIPAA.

Some background on the California Immunization Registry:

- There are currently three regions in California which have separate immunization registries, which are currently not linked: San Diego, San Joaquin and CAIR-2. It is anticipated that the San Diego Immunization Registry will merge into CAIR-2 this year.
- Data in the California Immunization Registries is inaccurate. There are many duplicate entries for children and many missing entries for adults, as we can see from this report presented to the legislature in 2017

<https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/Immunization/2014-16IZReportLegislature.pdf>:

California Immunization Registry Participation as of 6/30/2016				
	0-5 years	6-18 years	19+ years	All ages
Estimated CA population	3,024,392	6,620,697	30,141,371	39,786,460
Patients in CAIR	3,221,551	6,696,345	14,343,968	24,261,864
% of pop. in CAIR*	106.5%	101.1%	47.6%	61.0%
CAIR patients w/ 2+ doses	2,293,975	5,760,274	7,866,734	15,920,983
% of pop. w/ 2+ doses	75.8%	87.0%	26.1%	40.0%
Total doses in CAIR	35,547,972	118,139,375	67,855,679	221,542,926
*Can be higher than 100% due to limitations in population estimations, duplicate entries. In addition, immunization registries may be incompletely updated when people move out of state or die.				
Source: California Department of Public Health				



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- While the California Immunization Registries website claims the registry is an “opt-out” registry, it is really just a lockable registry where patients or parents of patients can prevent the vaccination information from being shared. There is no way to prevent a person’s vaccination records from being entered into the California Immunization Registries, if the vaccine administrator uses the California Immunization Registries. Per their website, “CA law allows a patient/parent to decline to have their/their child’s information in CAIR shared with other Organizations that use CAIR (‘opt out’). In this case, their information may still be entered into CAIR but it must be ‘locked’ by the Organization.” (<https://cairweb.org/cair-disclosure-policy/>).
- Currently, schools, childcare centers, WIC programs, foster care agencies, and other programs can be authorized to look up vaccination records - but only for the children they serve, and for the specified purposes and with the expressed consent of the parent. The patient’s address and phone number cannot be shared.

A Voice for Choice Advocacy has numerous issues with AB 1797, and would like the following amendments to be made:

- **The multitude of data discrepancies currently in CAIR need to be addressed:** The CA Legislature and the California Department of Public Health should focus their efforts and funding on cleaning up the California Immunization Registries’ databases so the data is actionable and correct.
- **Patients and parents of patients should be allowed to opt-in to the CA Immunization Registries:** With increased sharing and access to the CA Immunization Registries, patients and parents of patients should be able to decide up front if they want their vaccination records housed on a state database. They should be able to opt-in rather than automatically have their vaccinations recorded. If the legislature keeps the registries as required, then patients and parents should have the option to opt-out completely and when they do, to have their data permanently deleted, in line with other California and Federal Privacy laws.
- **Database privacy should be in line with other CA medical databases** such as the California’s Controlled Substance Utilization Review and Evaluation System (CURES) database. There is significant concern that the organizations which will have access to all data during a public health emergency would allow Immigration and Customs Enforcement (ICE) to gain access to personal information, including addresses of immigrants. The legislature needs to ensure that if it does not change to an opt-in system that the privacy measures and access to the CA Immunization Registries can only be accessed by specific entities or persons, rather than anyone from schools, childcare facilities, family childcare homes, and county human services agencies.



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- **Records granted disclosure from the patient should maintain HIPAA and FERPA privacy rights if further shared:** While HIPAA (federal privacy law for doctors) and FERPA (federal privacy law for schools) do not allow medical information to be disclosed without patient or parental consent, once this information is disclosed to another entity, there is nothing stopping that entity from now disclosing it to anyone without further consent. Once the health dept. has it, based on HIPAA they can share it without knowledge or consent. See §164.512(i) Uses and disclosures for which an authorization or opportunity to agree or object is not required. https://www.ecfr.gov/cgi-bin/text-idx?SID=a40311513ce4fe9b16bbbca1ab92baf9&mc=true&node=se45.1.164_1512&rgn=div8

We ask you to oppose AB 1797 and NOT to allow it to pass through the Assembly Committee on Health, unless it is amended to address all the above.

Thank you for your time and consideration. Please feel free to contact me if you have any questions.

Sincerely,

Christina Hildebrand

Christina Hildebrand,

President,

A Voice for Choice Advocacy, Inc.

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Giving issues a voice, A Voice for Choice Advocacy advocates for people's rights to be fully informed about the composition, quality, and short- and long-term health effects of all products that go into people's bodies, such as food, water, air, pharmaceuticals and cosmetics.

CC: Assembly Member Weber, Bill Author

Rosielyn Pulmano, Chief Consultant, Assembly Committee on Health