

February 5, 2015

Mr. David Watson  
Chief Executive Officer  
Cal INDEX  
1255 Treat Blvd., Suite 300  
Walnut Creek, CA 94597

Dear Mr. Watson,

In light of yesterday's revelation that Anthem Blue Cross was hacked and the personal information of millions of their customers was compromised, we call on you to make the Cal INDEX database an opt-in instead of opt-out exchange.

The Anthem hack makes clear that no company can guarantee their customers' information will be protected. Without that guarantee, consumers must have the ability to prevent their information from being shared before it occurs.

By collecting millions of Californians' private medical information in a database that could become one-stop-shopping for medical information hackers, Cal INDEX, Anthem and Blue Shield have placed all of their customers' data at risk without their consent.

Further, your privacy policies continue to leave consumers' information at risk.

1) Consumers still do not have a real right to opt out. Although you agree to not share the information of a consumer who opts out, you intend to continue collecting and entering that person's information into the database, and consumers will not have a right to delete that information.

2) Cal INDEX does not plan to give consumers access to their entire record until a patient portal is developed at some unidentified time in the future. This places patient health at risk by increasing the likelihood that a medical provider relies on a file that is incorrect.

These failings make it impossible for consumers to be certain their personal health information will be protected at Cal INDEX.

We call on you to change your stated policies before the database goes live by ditching the "opt-out" system in favor of an "opt-in." Failure to do so certainly places patient privacy at risk, and could potentially jeopardize the quality of patient care.

After yesterday's news it should be clear why consumers need the ability to prohibit Cal INDEX from collecting any of their records, and to request deletion of those records that have already been entered into the database. Opting out of just sharing, not retention of records, will not keep consumers' data out of this new candy store for data thieves. Opting out of Cal INDEX must mean that a patient can opt not to have their data collected, affording them maximum protection and control over their information.

Rapid direct access by a patient to their record is important because it is essential to patient safety. For instance, a record might show a patient is taking a certain medication that is no longer the case. Another provider, relying on erroneous data in the Cal INDEX record, could easily provide the wrong treatment. The best safeguard against errors is a patient's ability to quickly check their record and correct any erroneous information. A patient can't seek a correction if they don't know what's there.

While you hold out the possibility of direct access at an unspecified future date, the exchange has begun operations without this essential protection. Your plan to refer patients requesting records to their healthcare plan or providers, and only provide the record if directed to do so by the plan or provider, is unnecessarily cumbersome and will result in confusion and delay in access. It is easy to envision a situation where a consumer simply stops asking because of the back and forth between bureaucratic organizations. There is no legal barrier under HIPAA to Cal INDEX providing this information to patients directly. All you need to do is include that ability in Cal INDEX's contracts with healthcare providers.

Furthermore, serious loopholes remain in the rules about who Cal INDEX will share patient information with – including a broad exception for “research” that we continue to investigate. Without a definition of research, this allowance appears open to serious abuse. For example, Cal INDEX has stated it will not collect HIV test results. However, to a patient who does not want their sensitive health condition to be disclosed to anyone, the research exemption is disturbingly broad. The fact is that the existence of sensitive health conditions can be inferred from the information you do collect. For example, even without HIV test results, you will collect data indicating a person's prescriptions for AIDS medications.

Consumer Watchdog and Patient Privacy Rights are always suspicious when health insurance companies create programs they say are for consumers' benefit, yet make participation mandatory. Health information exchanges that give consumers control of their own information can offer real benefits for patients' health, but Anthem and Blue Shield presumptively signed up their customers for Cal INDEX before adequate protections were in place.

Particularly in light of the Anthem hack, we urge you to stop collecting patient data until every customer of Anthem and Blue Shield can choose whether to opt in, and until you correct the defects in your privacy policies that leave consumers' information unprotected. Then, make the case to consumers that the Cal INDEX health information exchange will improve patient health, and allow us to choose for ourselves.

Sincerely,

Carmen Balber  
Executive Director  
Consumer Watchdog

Deborah C. Peel, MD  
Founder & Chairman  
Patient Privacy Rights

Cc: Andrea Leeb, Cal INDEX chief privacy officer