

Survey of Publicly Available State Health Databases

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ABSTRACT

We surveyed every state and the District of Columbia to see what patient specific information states release on hospital visits and how much potentially identifiable information is released in those records. Thirty-three states release hospital discharge data in some form, with varying levels of demographic information and hospital stay details such as hospital name, admission and discharge dates, diagnoses, doctors who attended to the patient, payer, and cost of the stay. We compared the level of demographic and other data to HIPAA standards, which states do not have to adhere to for this type of data. We found that states varied widely in whether their data was HIPAA equivalent, and many were equivalent (or stricter) with demographic fields but not other data fields, and overall only 7 of the 33 states that released data did so in a form that was HIPAA equivalent.

INTRODUCTION

People expect that the information they tell their doctor will remain private, and that expectation extends to doctors they see at the hospital. Doctor-patient confidentiality makes the relationship work to its fullest - if there is no fear the doctor will discuss private medical issues, a patient can feel secure telling his doctor important details, leading to better care and better data. Some states require hospitals to share information about each patient encounter, and the states in turn, may sell or give the data away. The released version does not include people's names, but does include demographic information about the patient and details about the visit. Most people are unaware these data exist, better yet that they are shared publicly. Individuals could be harmed if the data could be matched back to the patient because it contains diagnoses that may include drug and alcohol dependency, tobacco use, venereal diseases, and other sensitive information, even if that was not the reason for the hospitalization. It seems prudent to survey the decisions states make when sharing these data to see how they compare to the federal standard for sharing patient level health information to see if standards are the same.

It is important to understand that sharing data beyond the patient encounter offers many worthy benefits to society. These data may be particularly useful because they contain a complete set of hospital discharges within the state, thereby allowing comparisons across regions and states such as rating hospital and physician performances and assessing variations and trends in care, access, charges and outcomes. Research studies that have used these datasets include: examinations of utilization differences based on proximity

[1], patient safety [2,3], and procedures [4]; and, a comparison of motorcycle accident results in states with and without helmet laws [5]. The very completeness that helps these studies makes it impossible to rely on patients to consent to sharing because the resulting data would not be as complete.

Of course, when data are shared publicly, the information becomes available for many other purposes too, some that may not be as motivating. A recent Bloomberg news article reported that the top multi-state buyers of patient level hospital data are commercial and other for-profit organizations, not researchers [6].

The challenge is to find ways comprehensive patient level data can be shared widely so society can enjoy the benefits of data sharing without risks of harms to individuals.

BACKGROUND

When a person goes to the hospital, information about her is recorded and in most states it is passed on to the state government or a separate nonprofit organization that collects that information for the state. Additionally, many states use the Federal-State-Industry partnership Healthcare Cost and Utilization Project (HCUP) to collect the information for them. Then the state, nonprofit or HCUP distributes this information (with names and some geographic and temporal information redacted) to the public. This flow of information is authorized in most states by a legislative mandate. Depending on the state, different levels of information are publicly available at varying costs, and some states require approval to obtain the information. Some even have different tiers of data, with variable restrictions and costs.

The Health Information Portability and Accountability Act (HIPAA) in the United States is the federal regulation that dictates sharing of medical information beyond the immediate care of the patient, prescribing to whom and how physicians, hospitals, and insurers may share a patient's medical information broadly. For medical data covered by HIPAA, only the patients 5 digit zip code (reduced to the first 2 digits if the population in the ZIP code is less than 20,000) and year of birth can be released.¹ However, the information states distribute about hospital stays is not covered by HIPAA, so states may make different decisions.

METHODS

We performed a survey of the information each state makes publicly available as well as the cost and restrictions for the data. This was done by visiting a state's website, using online search engines to search for "inpatient data" or "discharge data" for each state, and utilizing a subscription service to see what information each state released to the public. Some states were also contacted by email or phone.

We began by using The National Association of Health Data Organizations (NAHDO) website, a membership and educational association that maintains a web site with

¹45 CFR 164.514(b)(2) (2002).

information on 49 states (all but Alabama) and the District of Columbia. Each state has a page with information about the collection and release policies of their healthcare data as well as links related to that information such as the states health care organization or department, contact people, and, where relevant, the law(s) that mandate the availability of the information. Many states also had information on their websites about obtaining this data. A few, like Vermont, were free but most had at least a nominal fee and several were thousands of dollars (see Table 3).

Given time and monetary restrictions, we did not acquire every state's health data. However, some of the states data we did acquire differed in the information they released to that reported on their website. For instance, Washington State reported on their website that they release age in years, but in fact release age in months as well in a separate data field. Virginia reported releasing 9 digit zip codes, but the data we received showed only 5 digits. To populate the tables in the Results section, we used fields with naming that we understood such as "AGE_GROUP" or "ZIPCODE" assisted by data dictionaries the states provide to decode the fields. However, some fields may be reporting information not readily apparent to people not intimately aware of that state's data. The information presented here was culled from many sources and the best effort was made to collect the most accurate and up-to-date information

Some states have Data Use Agreements that require acknowledging (by clicking on the state's website) or signing forms agreeing to comply with the agreement. There was a great deal of variability in what the agreements required including restrictions on who could use the data and what they could do with it as well as who they could share it with and how long they were allowed to keep and use the data. Since HIPAA does not allow a Data Use Agreement to offset the its standards, terms of Data Use Agreements are not considered in this paper.

RESULTS

We organized our information into four tables. Thirty-three states provide some publicly available hospital information (see map in Figure 1). Nebraska was listed on HCUP as providing data, but NAHDO says they do not, so we considered Nebraska as not sharing hospital data for the purposes of this paper. The information presented here was culled from many sources and the best effort was made to collect the most accurate and up-to-date information. Please send the authors any updates/corrections for rectification. Check dataprivacylab.org/projects/50states and thedatamap.org for updates.

Table 1 lists the demographic information released by each state including gender, address, and age. All the states that provide data give the patients gender. Address information was the address of the insurance payer, which is usually the patient's home. Almost all release only five (18) or three (10) digit ZIP codes for address, subject to further masking if the zip code has a small population. Maine and South Carolina only provide the county name. West Virginia and Nevada provide no address information and Rhode Island stopped providing any in 2007. While all the geographic information would be HIPAA equivalent, Colorado, New York and Washington State provide birth month

information, which would not be allowed if the data were covered by HIPAA. Seven states released age in age groups, which is stricter than HIPAA regulations. Age groups were variable in size though most were 5-year groups with different size groupings for children and infants. Missouri released the birth year and the rest of the states' age data were released as age in years. Either would be HIPAA compliant.

Table 2 shows if and how admit date, discharge date and discharge status are released. For example, Virginia releases the year and quarter of admission and discharge as well as length of stay. All the states that released discharge data released discharge status, such as "Routine discharge" or "Dsch/Trnf to skilled nursing facility w/Medicare", or if the patient died at the hospital. Five states released the date in the admission and/or discharge data, and 21 others released the month or quarter along with year. None of this data would be HIPAA compliant; only 7 states released HIPAA conforming year-only dates (hour or day of week are not restricted by HIPAA) for both admission and discharge fields.

Table 3 lists where to get the data, cost, and if the state has a mandate to release the data. Forty have a legal mandate to collect hospital data (not all distribute it though). Some states like Washington and New Hampshire distribute the data directly, some like Virginia set up separate nonprofits to do so, while 13 (not including Nebraska) rely on HCUP to collect and distribute the information. Several that distribute directly or through a nonprofit also have their information available through HCUP, though the set available through HCUP may be a different price and may offer different fields than the one from the state. Prices ranged from free to several thousand dollars, and often had discounts for educational institution's or other non-profits and had different pricing for data sets with more potentially identifiable information. The costs reported here are to research institutions for the inpatient-unrestricted version of the public data file from the most recent year available.

Table 4 shows whether a state's data would be HIPAA compliant. The hospital data released by states is not covered under HIPAA, but we assessed whether it would be equivalent to HIPAA rules in Table 4. This was created using Tables 1 and 2 and assessing whether the data was equivalent to HIPAA standards - in this case all dates were in year only and geographic information was only 5 digit zip codes. Interestingly, many states demographic data not only adhered to HIPAA standards, but 18 were stricter. However, since for many the admission and discharge data they release was not HIPAA equivalent, only 7 state's data would be fully HIPAA compliant.

Figure 2 shows a map of the states whose demographic data would be HIPAA compliant, states whose data release is stricter than HIPAA and the three states that would not be HIPAA equivalent as detailed in Table 1. Figure 3 shows a map of how the 30 states whose demographic data is HIPAA equivalent drops to 7 states when admission and discharge data is screened for HIPAA equivalence.

State	Gender	Address	Age ¹
Alabama			
Alaska			
Arizona	Yes	5 digit zip code	In Years
Arkansas	Yes	3 digit zip code	In Years
California	Yes	3 digit (or nothing if not unique) subject to masking	In Years (subject to masking)
Colorado	Yes	3 digit zip code	Birth month and year
Connecticut			
Delaware			
District of Columbia			
Florida	Yes	5 digit zip code	In Years
Georgia			
Hawaii	Yes	5 digit zip code	Age Group (Birth Year in HCUP)
Idaho			
Illinois	Yes	3 digit zip code	Age Group
Indiana			
Iowa	Yes	5 digit zip code	In years
Kansas			
Kentucky	Yes	5 digit zip code	In years
Louisiana			
Maine	Yes	County	In Years
Maryland	Yes	3 digit zip code	In Years
Massachusetts	Yes	3 digit zip code	In Years

Table 1a. Comparison of demographic data in patient-specific hospital discharge data by state, Alabama through Massachusetts. Diagonal line pattern indicates that State does not release public data. ¹Age groups are variable in size. Many are groups of 5 years with different size groupings for children and infants.

State	Gender	Address	Age ¹
Michigan			
Minnesota			
Mississippi			
Missouri	Yes	First 3 digits if first 3 digits of ZIP has population >20,000	Birth year
Montana			
Nebraska ²			
Nevada	Yes	No	In Years
New Hampshire	Yes	5 digit zip code	In Years
New Jersey	Yes	5 digit zip code	In Years
New Mexico	Yes	3 digit zip code	In Years
New York	Yes	5 digit zip code	Birth month and year
North Carolina	Yes	5 digit zip code	In Years
North Dakota			
Ohio			
Oklahoma	Yes	5 digit zip code	Age Group
Oregon	Yes	3 digit zip code	In Years
Pennsylvania	Yes	5 digit zip code	In Years
Rhode Island	Yes	Removed in 2007	In Years
South Carolina	Yes	County	Age Group
South Dakota	Yes	5 digit zip code	In Years
Tennessee	Yes	State, County, 5 digit zip code	In Years
Texas	Yes	5 digit zip code (first 3 if a ZIP code has fewer than 30 cases)	Age Group (expanded for HIV/drug/alcohol)

Table 1b. Comparison of demographic data in patient-specific hospital discharge data by state, Michigan through Texas. Diagonal line pattern indicates that State does not release public data. ¹Age groups are variable in size. Many are groups of 5 years with different size groupings for children and infants. ²Nebraska (via NAHDO) says they do not release but HCUP says that they release data.

State	Gender	Address	Age ¹
Utah	Yes	5 digit zip code	Age Group
Vermont	Yes	3 digit zip code (categories; 5-digit if pop>10k)	Age Group
Virginia	Yes	5 digit zip code	In Years
Washington	Yes	5 digit zip code	In months
West Virginia	Yes	No	In years
Wisconsin	Yes	5 digit zip code	In years
Wyoming			
Wisconsin	Yes	5 digit zip code	In years
Wyoming			

Table 1c. Comparison of demographic data in patient-specific hospital discharge data by state, Utah through Wyoming. Diagonal line pattern indicates that State does not release public data. ¹Age groups are variable in size. Many are groups of 5 years with different size groupings for children and infants.

State	Admission Date	Discharge Date	Discharge Status
Alabama			
Alaska			
Arizona	Year, Month, Hour	Year, Month, Hour, Length of Stay	Yes
Arkansas	Year, Month, Hour	Year, Month, Hour, Length of Stay	Yes
California	Year, Quarter	Year, Length of Stay	Yes
Colorado	Year, Month, Date, Hour	Year, Month, Day of Week, Length of Stay	Yes
Connecticut			
Delaware			
District of Columbia			
Florida	Year, Hour	Year, Length of Stay	Yes
Georgia			
Hawaii	Year, Month	Year, Month, Length of Stay	Yes
Idaho			
Illinois	Year, Quarter	Year, Quarter	Yes
Indiana			
Iowa	Year, Month, Date	Year, Month, Day of Week	Yes
Kansas			
Kentucky		Year, Quarter, Length of Stay	Yes
Louisiana			
Maine	Date	Date	Yes
Maryland	Year, Month	Year, Length of Stay	Yes
Massachusetts	Year, Month	Year, Length of Stay	Yes

Table 2a. Comparison of admission and discharge fields in patient-specific hospital discharge data by state, Alabama through Massachusetts. Diagonal line pattern indicates that State does not release public data.

State	Admission Date	Discharge Date	Discharge Status
Michigan			
Minnesota			
Mississippi			
Missouri	Year, Hour	Year, Hour, Length of Stay	Yes
Montana			
Nebraska ¹			
Nevada	Year, Month, Hour	Year, Month, Hour, Length of Stay	Yes
New Hampshire	Year, Hour	Year, Hour	Yes
New Jersey	Year, Month, Hour	Year, Hour, Length of Stay	Yes
New Mexico	Year, Month, Hour	Year, Month, Hour, Length of Stay	Yes
New York	Year, Month	Date	Yes
North Carolina	Year, Month	Year, Month	Yes
North Dakota			
Ohio			
Oklahoma	Year, Month, Day of Week	Year, Month, Day of Week	Yes
Oregon		Year, Length of Stay	Yes
Pennsylvania	Year, Day of Week, Hour	Year, Day of Week, Hour, Length of Stay	Yes
Rhode Island	Year, Month	Year, Month, Length of Stay	Yes
South Carolina	Year, Month, Day of Week	Year, Month, Day of Week, Length of Stay	Yes
South Dakota	Year, Month	Year, Length of Stay	Yes
Tennessee	Date, Hour	Date	Yes
Texas	Year, Day of Week	Year, Quarter, Length of Stay	Yes

Table 2b. Comparison of admission and discharge fields in patient-specific hospital discharge data by state, Michigan through Texas. Diagonal line pattern indicates that State does not release public data. Nebraska (via NAHDO) says they do not release but HCUP says that they release data.

State	Admission Date	Discharge Date	Discharge Status
Utah		Year, Quarter, Length of Stay	Yes
Vermont		Year, Length of Stay	Yes
Virginia	Year, Quarter	Year, Quarter, Length of Stay	Yes
Washington	Year, Hour	Month, Hour, Length of Stay	Yes
West Virginia		Year, Length of Stay	Yes
Wisconsin		Year, Quarter, Length of Stay	Yes
Wyoming			

Table 2c. Comparison of admission and discharge fields in patient-specific hospital discharge data by state, Utah through Wyoming. Diagonal line pattern indicates that State does not release public data.

State	Mandate	Organization	Through HCUP	Cost (per year unless noted)
Alabama		www.alaha.org		Not Release
Alaska	No	Alaska State Hospital and Nursing Home Association. http://www.ashnha.com/		Not Release
Arizona	Yes	Arizona Department of Health Services. http://www.azdhs.gov/	Yes	\$135
Arkansas	Yes	Arkansas Department of Health. http://www.healthy.arkansas.gov/	Yes	\$485
California	Yes	California Office of Statewide Health Planning & Development. http://www.oshpd.ca.gov/	Option ²	\$200
Colorado	No	Colorado Hospital Association. http://www.cha.com/		\$0.02 for record
Connecticut	Yes	Connecticut Office of Health Care Access. http://www.ct.gov/ohca/		Not Release
Delaware	Yes	Delaware Health Statistics Center, Division of Public Health. http://www.dhss.delaware.gov/dhss/dph/hp/healthstats.html		Not Release
District of Columbia	No	District of Columbia Hospital Association. http://www.dcha.org/		Not Release
Florida	Yes	Florida Center for Health Information and Policy Analysis. http://ahca.myflorida.com/SCHS/	Option ²	\$100 / year (\$25/quarter)
Georgia	Yes	GHA: An Association of Hospitals & Health Systems. http://www.gha.org/		Not Release
Hawaii	No	Hawaii Health Information Corporation. http://www.hhic.org/	Yes	\$1,035
Idaho		Idaho Hospital Association. http://www.teamiha.org/		Not Release
Illinois	Yes	Illinois Department of Public Health. http://www.idph.state.il.us/		\$100+
Indiana	Yes	Indiana Hospital Association. http://www.ihaconnect.org/		Not Release
Iowa	Yes	Iowa Hospital Association. http://www.ihaonline.org/	Yes	\$585
Kansas	Yes	Kansas Hospital Association. http://www.kha-net.org/		Not Release
Kentucky	Yes	Kentucky Cabinet for Health and Family Services-Office of Health Policy. http://www.chfs.ky.gov/ohp/	Yes	\$1,535
Louisiana	Yes	Louisiana Department of Health and Hospitals. http://www.dhh.louisiana.gov/		Not Release
Maine	Yes	Maine Health Data Organization. http://www.maine.gov/mhdo/	Option for some years ²	\$675
Maryland	Yes	Health Services Cost Review Commission. http://www.hsrc.state.md.us/	Yes	\$35
Massachusetts	Yes	Division of Health Care Finance and Policy. http://www.mass.gov/dhcfp	Yes	\$835

Table 3a. Administrative information by state, Alabama through Massachusetts.²Data available through HCUP may be different price and may offer different fields than one from state [7]. ³Cost to research institutions for inpatient unrestricted version of public data file for most recent year available.

State	Mandate	Organization	Through HCUP	Cost (per year unless noted)
Michigan	No	Michigan Health & Hospital Association. http://www.mha.org/		Not Release
Minnesota	Yes	Minnesota Hospital Association. http://www.mnhospitals.org/		Not Release
Mississippi	Yes	Mississippi Dept of Health, Office of Health Informatics. http://www.msdh.ms.gov/phs		Not Release
Missouri	Yes	Missouri Department of Health and Senior Services. http://www.dhss.mo.gov/		\$150+
Montana	No	MHA - An Association of Montana Health Care Providers. http://www.mtha.org/		Not Release
Nebraska	No	Nebraska Hospital Association. http://www.nhanet.org/	Yes ¹	Not Release
Nevada	Yes	Center for Health Information Analysis at University of Nevada at Las Vegas. http://chia.unlv.edu/index.htm	Option	\$1,200
New Hampshire	Yes	New Hampshire Department of Health & Human Service. http://www.dhhs.nh.gov/		Free
New Jersey	Yes	New Jersey Department of Health & Senior Services. http://www.state.nj.us/health/	Yes	\$60
New Mexico	Yes	New Mexico Department of Health. http://www.health.state.nm.us/	Yes	\$485 (2009 and 2010 available)
New York	Yes	New York State Dept of Health. http://www.health.state.ny.us/	Option ²	~\$350, final price at request time
North Carolina	Yes	Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill. http://www.shepscenter.unc.edu	Yes	\$535
North Dakota	Yes	North Dakota Department of Health. http://www.ndhealth.gov/		Not Release
Ohio	No	OHA: Ohio Hospital Association. http://www.ohanet.org/		Not Release
Oklahoma	Yes	Oklahoma State Department of Health. http://www.ok.gov/health/		\$50-7500
Oregon	Yes	Office for Oregon Health Policy and Research. http://www.oregon.gov/OHPPR/		\$250
Pennsylvania	Yes	Pennsylvania Health Care Cost Containment Council (PHC4). http://www.phc4.org/		\$4,500
Rhode Island	Yes	Rhode Island Department of Health. http://www.health.state.ri.us/	Option ²	\$115
South Carolina	Yes	South Carolina State Budget & Control Board, Office of Research and Statistics. http://ors.sc.gov/	Option ²	\$1.25 per 1,000 records with a minimum \$100
South Dakota	Yes	South Dakota Association of Healthcare Organizations. http://www.sdaho.org/	Yes	\$785
Tennessee	Yes	Office of Health Statistics, Tennessee Department of Health. http://health.state.tn.us/statistics/index.htm		\$300/quarter
Texas	Yes	Texas Health Care Information Collection, Center for Health Statistics, Texas Department of State Health Services. www.dshs.state.tx.us/thcic/		\$6,000 recent years, 1999-2006 free

Table 3b. Administrative information by state, Michigan through Texas. ¹Nebraska (via NAHDO) does not release but HCUP says they release data. ²Data available through HCUP may be different price and offer different fields than one from state [7]. ³Cost to research institutions for inpatient unrestricted public data file for most recent year available.

State	Mandate	Organization	Through HCUP	Cost (per year unless noted)
Utah	Yes	Office of Health Care Statistics, Utah Department of Health. http://www.health.utah.gov/hda/	Option ²	\$3,150
Vermont	Yes	Division of Health Care Administration. http://www.bishca.state.vt.us/	Option ²	Free
Virginia	Yes	Virginia Health Information. http://www.vhi.org/		\$975-\$2500
Washington	Yes	Washington State Department of Health. http://www.doh.wa.gov/		\$50
West Virginia	Yes	West Virginia Health Care Authority. http://www.hcawv.org/	Yes	\$510
Wisconsin	Yes	Wisconsin Hospital Association. http://www.wha.org/	Yes	\$835
Wyoming	No	Wyoming Hospital Association. http://www.wyohospitals.com/		Not Release

Table 3c. Administrative information by state, Utah through Wyoming. ²Data available through HCUP may be different price and offer different fields than one from state [7]. ³Cost to research institutions for inpatient unrestricted public data file for most recent year available.

State	HIPAA Equivalence for Demographic Data ¹	HIPAA Equivalence for Admission and Discharge ²	HIPAA Equivalence or Better for Both ³
Alabama			
Alaska			
Arizona	Yes	No	
Arkansas	Stricter	No	
California	Stricter	No	
Colorado	Stricter on ZIP, Less strict on Age	No	
Connecticut			
Delaware			
District of Columbia			
Florida	Yes	Yes	Yes
Georgia			
Hawaii	Stricter	No	
Idaho			
Illinois	Stricter	No	
Indiana			
Iowa	Yes	No	
Kansas			
Kentucky	Yes	No	
Louisiana			
Maine	Stricter	No	
Maryland	Stricter	No	
Massachusetts	Stricter	No	

Table 4a. Assessment of HIPAA equivalence by state, Alabama through Massachusetts. Diagonal line pattern indicates that State does not release public data. ¹HIPAA equivalent if ZIP is only 5 digits and dates given only in years. "Stricter" if all fields were HIPAA equivalent or stricter. "Less strict" if any fields were not equivalent to HIPAA standard. ³Only "yes" responses reported. All blanks that do not have diagonal pattern are "no".

State	HIPAA Equivalence for Demographic Data ¹	HIPAA Equivalence for Admission and Discharge ²	HIPAA Equivalence or Better for Both ³
Michigan			
Minnesota			
Mississippi			
Missouri	Stricter	Yes	Yes
Montana			
Nebraska ⁴			
Nevada	Stricter	No	
New Hampshire	Yes	Yes	Yes
New Jersey	Yes	No	
New Mexico	Stricter	No	
New York	No	No	
North Carolina	Yes	No	
North Dakota			
Ohio			
Oklahoma	Stricter	No	
Oregon	Stricter	Yes	Yes
Pennsylvania	Yes	Yes	Yes
Rhode Island	Stricter	No	
South Carolina	Stricter	No	
South Dakota	Yes	No	
Tennessee	Yes	No	
Texas	Stricter	No	

Table 4b. Assessment of HIPAA equivalence by state, Michigan through Texas. Diagonal line pattern indicates that State does not release public data. ¹HIPAA equivalent if ZIP is only 5 digits and dates given only in years. "Stricter" if all fields were HIPAA equivalent or stricter. "Less strict" if any fields were not equivalent to HIPAA standard. ³Only "yes" in rightmost column; blanks that do not have diagonal pattern are "no". ⁴Nebreska says it does not release, but HCUP includes it.

State	HIPAA Equivalence for Demographic Data ¹	HIPAA Equivalence for Admission and Discharge ²	HIPAA Equivalence or Better for Both ³
Utah	Stricter	No	
Vermont	Stricter	Yes	Yes
Virginia	Yes	No	
Washington	No	No	
West Virginia	Stricter	Yes	Yes
Wisconsin	Yes	No	
Wyoming			

Table 4c. Assessment of HIPAA equivalence by state, Utah through Wyoming. Diagonal line pattern indicates that State does not release public data. ¹HIPAA equivalent if ZIP is only 5 digits and dates given only in years. "Stricter" if all fields were HIPAA equivalent or stricter. "Less strict" if any fields were not equivalent to HIPAA standard. ³Only "yes" responses reported. All blanks that do not have diagonal pattern are "no".

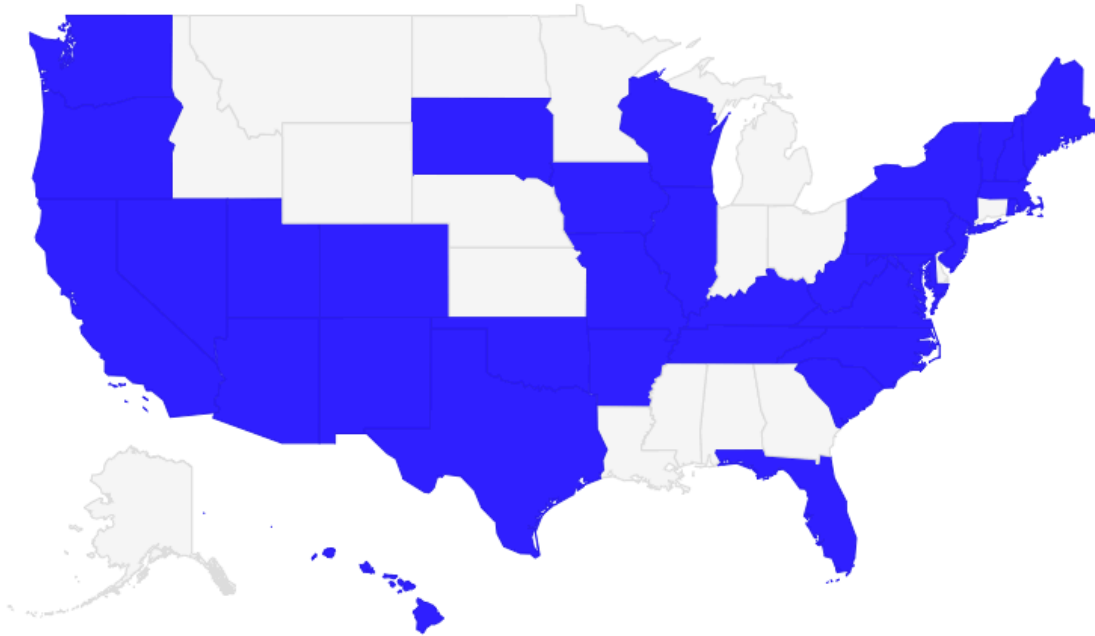


Figure 1. United States map showing states that release patient-level hospital data in blue, for a total of 33 states.

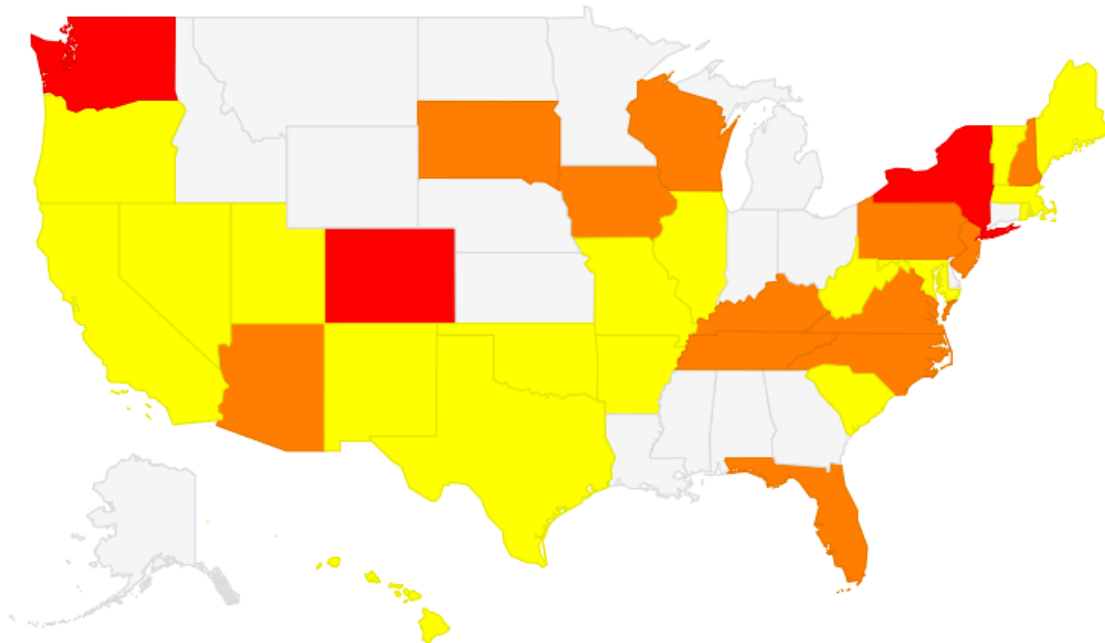


Figure 2. United States map showing states where demographic data is HIPAA equivalent (orange), stricter than HIPAA (yellow) or non-HIPAA equivalent (red). White states do not release data.

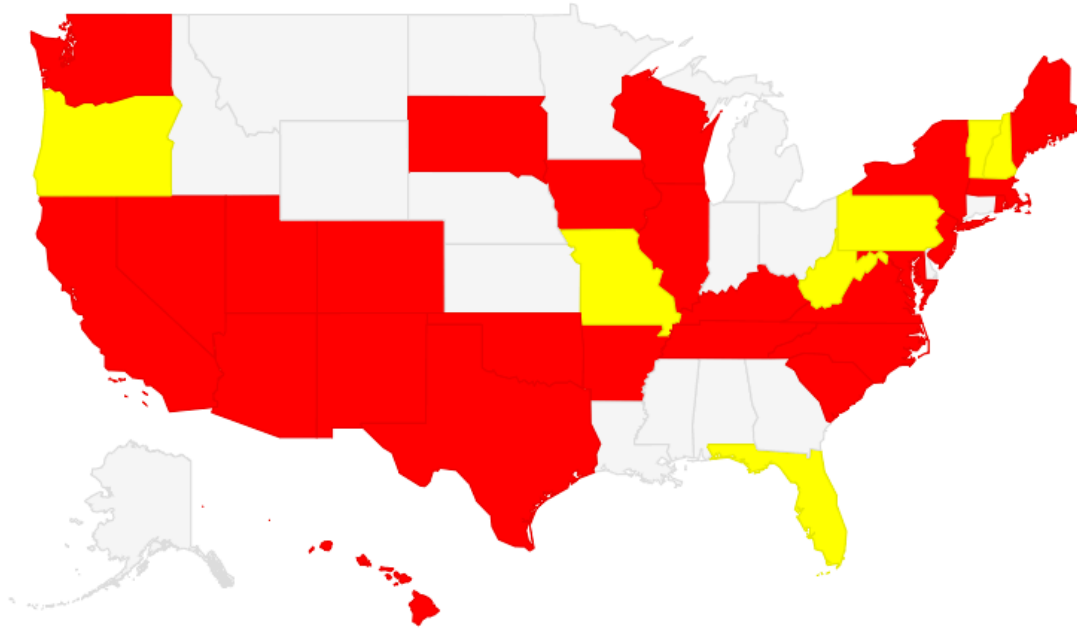


Figure 3. United States map showing states where demographic and admission/discharge data is HIPAA equivalent (yellow) versus non-HIPAA equivalent (red). White states do not release data.

DISCUSSION

Only 3 states have demographic data not equivalent to the HIPAA standard, and 18 states have stricter values. However, if these data were covered under HIPAA, the standards would apply to all dates, including dates of admission and discharge, where the HIPAA standard was only met by 7 states.

Is there vulnerability with using a standard less than HIPAA's? Washington State releases data less strict than the HIPAA standard and in recent work, Sweeney showed how patients could be matched to records in the Washington State dataset to put names to the records [8]. Table 4 shows that Washington does not seem to be alone in its vulnerability to re-identification; re-identifications may be as possible on data from the other 26 states that release fields less than the HIPAA equivalent. If so, these vulnerabilities may threaten worthy and viable uses of the data unnecessarily.

Having more identifiable data readily available makes it difficult for other entities to share their data widely too. Data with some of the same fields as these hospital records becomes vulnerable to re-identification if the data to be shared can be linked to the more identifiable hospital data.

The goal is not to deprive society from the many worthy uses of the data made possible by sharing, but to match access requirements with risk, so society can enjoy the benefits of data sharing without unnecessary risks to patients. This seems achievable by making a public version of the data HIPAA equivalent and making more detailed information available under more stringent requirements.

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