The Network for Public Health Law

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DE-IDENTIFICATION – SUMMARY OF RELEVANT CASE LAW

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De-Identification: Guidance from the Courts

Confidentiality of individual health data is protected by federal and state privacy laws. These laws generally prohibit disclosure of directly identifiable health information, as well as information which could be used, alone or in combination with other reasonably available data, to identify an individual. Conversely, generally, these laws do not cover de-identified information and permit such information to be freely disclosed. However, laws vary in defining whether data are deemed to be de-identified; or whether the risk of re-identification is sufficiently small to allow disclosure.* Several courts have had occasion to analyze issues relating to de-identification of data, often in the context of freedom of information law requests or discovery disputes. The table below describes a number of these cases in which courts have discussed de-identification and/or evaluated risk of re-identification in some level of depth. Depending on the law, de-identification may require removal of certain data elements and/or a case-by-case determination of the risk of re-identification. Note that this table is not exhaustive, but may provide useful guidance for reference by public health practitioners and their attorneys and privacy officers.

* For examples, see Table of Statutes that is part of this toolkit.

TABLE OF RELEVANT CASE LAW

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Federal Jurisdictions				
Pac. Radiation Oncology, LLC v. Queen's Med. Ctr.	2015	D. Haw.	2015 U.S. Dist. LEXIS 12869 (unpublished opinion).	This dispute between physicians / physician organizations (Plaintiffs) and medical center / medical corporation (Defendants) arises from Defendants' termination of Plaintiffs' clinical privileges due to Plaintiffs allegedly diverting patients with cancer to competing medical facilities. In discovery, Defendants sought disclosure of histories and physicals for a designated list of over 100 cancer patients, who were not parties to the litigation, that Plaintiffs saw at the medical center but then sent to a different center for radiation therapy. Defendants' counsel filed the patient list, containing patient name, patient number, and name of physician, without redaction as an exhibit to a subpoena. A number of the patients whose medical records were requested intervened ("the Patient Intervenors"), objecting to disclosure of their records even in de-identified form. The Patient Intervenors claimed that in addition to the improper public disclosure of the list of patient names, Defendants had also improperly used and disclosed portions of their medical records contained in Defendants' own medical record system; accordingly, the Patient Intervenors asserted that subsequent de-identification of patient histories and physicals would be impossible. **While "in no way condon[ing] the unnecessary disclosure of the list," the Court found that de-identification of patient histories and physicals was not rendered impossible by the prior disclosure of patient names, numbers, and physicians**, because the disclosed list did not include the type of cancer for each patient nor the area where he or she lives. Accordingly, the Court concluded that "even a person who has seen the list would not be able to narrow down the patient's identity to one of a few people" based on the patient's history and physical scrubbed of personal identifiers such as name, patient number, and address. The Court further determined that while it was not possible to de-identify patient records for review by Defendants' representatives who had already reviewed identifiable records, de-identification was possible for review by a different representative of Defendants. The Court ultimately reserved ruling on this discovery issue in order to certify a related question to the Hawaii Supreme Court regarding application of the Hawaii Constitution. The Hawaii Supreme Court relied upon its prior decisions where it found strong privacy protections for patients' medical records. The Court described Hawaiians' right to privacy as "[s]o inviolable. . . that the

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				framers sought to shield individuals from 'possible abuses in the hands of government or private parties . . .'" The Court compared Hawaii's Constitution to the Health Insurance Portability and Accountability Act (HIPAA) and determined that it provides greater privacy to its people, as well as more stringent protection for medical records. In this litigation, the patients were not parties to the suit and had not consented to the disclosure of their medical records in the lawsuit. Additionally, there was no compelling state interest. Citing concerns related to social, psychological and economic harm, the Court found that even where there is no risk of re-identification, there is still an invasion of privacy. The Hawaii Court noted that some patients feel de-humanized when their "'most intimate health information is circulated by an indifferent and faceless infrastructure without any control over the process or content.'" Absent a national, uniform standard for de-identification, the Court determined that the risk of re-identification remains as there is no privacy guarantee. **The Hawaii Supreme Court concluded that release of even de-identified information would violate the Constitution. Specifically, the Court found that "to allow an individual's medical information, even if de-identified, to be used in litigation to which that individual is not a party, would reach beyond what the Hawaii Constitution permits in the absence of a showing of a compelling state interest."** Pac. Radiation Oncology LLC v. Queen's Med. Ctr., 138 Haw. 14; 375 P.3d 1252, *reconsideration denied*, 138 Haw. 50, 375 P.3d 1288 (2016).
Pac. Radiation Oncology, LLC v. Queen's Med. Ctr.	2016	D. Haw.	2016 U.S. Dist. LEXIS 162916 (unpublished opinion).	The District Court reviewed the Hawaii Supreme Court's ruling "that release of even de-identified information would violate the Constitution." After finding that HIPAA does not preempt the Hawaii Constitution's protection of the specific health information sought by the Defendants, the Court reconsidered its earlier ruling regarding whether it is possible to de-identify patient records in lieu of the earlier disclosure and the use of patients' history and physicals. The Court reviewed the information requested by the Defendants: • Type (or location) of cancer; • Type of treatment(s) (e.g., prone breast) and age and model of equipment used in treatment; • Timing and form of disclosure of the Plaintiffs' economic interests; • Patient's residential zip code and place of treatment (Liliha or Leeward); • Insured status (public, private or none).

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				The Court held that the requested inclusion of patients' zip codes would violate HIPAA's de-identification safe harbor standard found in 45 C.F.R. §164.514(b). Further, the Court determined that "in light of the prior disclosure and use of the List Patients' health information, 'there is a reasonable basis to believe' that Defendants' proposed de-identified information could be used to identify the List Patients." The Court ruled that the magistrate erred in ordering production of the health information, even after de-identification.
Pac. Radiation Oncology, LLC v. Queen's Med. Ctr.	2017	D. Haw.	2017 U.S. Dist. LEXIS 3399 (unpublished opinion).	Defendants' motion for reconsideration, with respect to de-identification, states that the Court's prior order was incomplete as it only addressed the patient medical records. "However, reading the Response Opinion as a whole, it is clear that the legal principles the supreme court articulated protect patients' medical information, not just their actual medical records." Rejecting Defendants' arguments that the privacy protections should only have extended to the actual medical records, inter alia, the Court denied the motion for reconsideration.
Pac. Radiation Oncology, LLC v. Queen's Med. Ctr.	2017	D. Haw	2017 U.S. Dist. LEXIS 4043 (unpublished opinion).	The Court addressed the parties' motions in limine. With respect to the de-identification issues, the Court held that "[t]o the extent that any of Plaintiffs' motions in limine seek to exclude any of the List Patients' medical information, Plaintiffs' motions in limine are GRANTED, unless the proponent of the evidence establishes consent."
Baser v. Dept. of Veterans Affairs	2014	E.D. Mich.	2014 U.S. Dist. LEXIS 137602	Plaintiff sought disclosure under FOIA of datasets from patient files that included "patient-level information such as age, gender, race, marital status, means tested income status, homeless status, prisoner of war status, geographic information (including patient's, treatment facility and providers' zip code and state), and up to 64 other distinguishing data elements," but excluded name, address, and identifying patient numbers. The VA refused to release the full datasets requested, explaining that they would lead to a risk of re-identification of patients and were therefore exempted from disclosure under Exemption 3 (information that is prohibited from disclosure by another federal law) and Exemption 6 (information that, if disclosed, would invade another individual's personal privacy). 5 U.S.C. § 552(b)(3) and (6). The VA agreed to release certain redacted and otherwise limited datasets, but Plaintiff claimed the data as provided were not useful to his medical research. Both parties sought summary judgment.

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				The parties submitted conflicting expert testimony. The VA's experts claimed that the data elements requested, if linked with other publicly available or commercial data files, could be used to re-identify patients. The VA further claimed that the risk of re-identification would remain even if the HIPAA Safe Harbor guidance found at 45 C.F.R. § 164.514(b)(2) was applied. In contrast, Plaintiff's experts claimed that the risk of re-identification was minimal given the data requested, the cost, the difficulty to a lay person to understand the data, and the amount of specific knowledge required about a person to make an attempt at re-identification. Plaintiff further argued that "HIPAA is not a standard that governs in the FOIA context"; that the VA should not have used both HIPAA de-identification methods (i.e. both the HIPAA safe harbor method and expert determination method); and that the public interest supports disclosure. Without significant analysis of the parties' opposing arguments, the Court denied the VA's motion and struck Plaintiff's cross-motion due to a violation of Court rules (though noting that it would have denied Plaintiff's cross-motion as well), finding a genuine issue of material fact as to "whether the VA can balance the patient's right to privacy against the public's interest in disclosure of the information." **The Court emphasized that the parties' "experts do not agree that the patient's information cannot be re-identified."**
Steinberg v. CVS Caremark Corp.	2012	E.D. Pa.	899 F.Supp.2 d 331	Plaintiff prescription drug purchasers filed suit against Defendant retail pharmacies and pharmacy benefits manager based on Defendants' alleged sale to third parties of information provided by patients when having prescriptions filled. Among other claims, Plaintiffs alleged that Defendants publicly represented that they maintained confidentiality of consumers' prescription information, but in fact packaged and sold consumer data to third parties. Defendants moved to dismiss Plaintiffs' complaint for failure to state a claim. At oral argument, Plaintiffs acknowledged that information sold by Defendants was de-identified: it included medical history, prescription drugs given, dates of prescriptions, diagnoses, and physician names, but did not contain patient names, birth dates, or Social Security numbers. However, **Plaintiffs claimed that there was a risk of re-identification, directing the Court to an academic journal article discussing re-identification risks. Plaintiffs did not apply the theory to the case,** but indicated that their re-identification argument "would take the form of expert testimony that a re-identification risk exists with respect to de-identified information generally, not as to the plaintiffs

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				in this case." In addition to being untimely, **the Court found Plaintiffs' lack of specificity insufficient to state a plausible claim for relief and dismissed the complaint with prejudice.**
Speaker v. HHS and CDC "Round 1"	2009	N.D. Ga.	680 F.Supp.2d 1359	Andrew Speaker, who got worldwide attention in 2007 after flying overseas while knowing he had tuberculosis, sued the CDC in Federal District Court for violating the federal Privacy Act by disclosing his identity and confidential medical information relating to the treatment of his tuberculosis. Speaker claimed that the CDC directly disclosed his identity. Alternatively, he claimed that even if the CDC had not identified him directly, it did so indirectly by providing sufficient details about him that the media was able to use – along with its other sources – to publicly identify him. These CDC disclosures included details of his medical history and his alleged medical condition (including a detailed timeline of his medical treatment), details of his profession and residence, details of the purpose of his trip (to Greece to get married) and details of his flights. On November 23, 2009 the District Court dismissed Speaker's lawsuit for failure to state a cause of action and found that Speaker alleged no specific facts establishing that a CDC employee or agent revealed Speaker's identity. If a news agency identified Speaker, it was because it discovered Speaker's identity using other sources. For example, Speaker's identity could have been revealed by state or local public health agencies, law enforcement, health care providers or others who knew it. The District Court also rejected Speaker's claim that the CDC violated the Privacy Act by releasing detailed information about him. **The Court held that information provided by the CDC had a public health purpose, that it was not identifying and that the CDC did not violate its responsibility to protect privacy just because the press was able to use information that it obtained from multiple sources to publish Speaker's identity.** "By the Act's terms, an 'identifying particular' is limited to those particulars that identify a unique, particular individual. 'Identifying particular' does not include general information about an unidentified person who might or might not be identifiable by gathering and piecing together information collected through further investigation and from other sources. Plaintiff here does not allege the disclosure of a 'record.' At most he alleges that a disclosure may have occurred and that discovery was required to determine if a disclosure of a record was made in violation of the Privacy Act." The Court observed that "[i]f releases at issue here were to constitute a Privacy Act violation as Speaker alleges, it would severely inhibit the

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				reasonable and appropriate conduct of public health officials responding to possible public health emergencies."
"Round 2"	2010	11th Cir.	623 F.3d 1371	Speaker appealed and the United States Court of Appeals, Eleventh Circuit, reversed in an opinion issued on October 22, 2010, ruling that Speaker sufficiently alleged in his amended complaint that the CDC made the disclosure of his identity, and remanded the case to the District Court for further proceedings.
"Round 3"	2012	N.D. Ga.	Case No. 1:09-cv-1137-WSD, unpublished Opinion and Order granting CDC's Motion for Summary Judgement	On March 14, 2012, the District Court once again dismissed Speaker's lawsuit. Instead of general allegations, Speaker claimed that his name was disclosed by a specific CDC employee within the CDC's media relations office. However, after discovery, Speaker was unable to present evidence that supported his claim. In fact, there was evidence that Speaker had identified himself to the press prior to the publication of his name in the media. Thus, the Court granted summary judgment to CDC based on Speaker's failure to show a genuine dispute of material facts to support his claim. Speaker abandoned his previous claim that CDC's disclosure of information other than his identity "enabled the media to ascertain his name," so the Court did not address this issue. Finally, the Court rejected Speaker's claim that the CDC violated the Privacy Act by maintaining and disseminating inaccurate, irrelevant or unnecessary information about him to increase funding for its TB programs by publicizing the public health threat that TB posed.
"Round 4"	2012	11th Cir.	Unpublished Decision, No. 12-11967.	Undeterred, Speaker again appealed to the United States Court of Appeals, Eleventh Circuit. On September 14, 2012, in a brief per curium opinion, the court held that appellant's arguments had no merit and upheld the District Court's order issued on March 14, 2012, granting the CDC's Motion for Summary Judgment.
State Jurisdictions				
Cuyahoga Cnty Bd. of Health v. Lipson O'Shea Legal Group	2016	Ohio Supreme Court	145 Ohio St. 3d 446	Defendant law firm requested from the Cuyahoga County Board of Health (BOH) "documentation or information of all homes … where a minor child was found to have elevated blood lead levels in excess of 10 [mg/dl]." The BOH concluded it could not disclose the requested records because they contained protected health information (PHI) under Ohio law and sought a declaratory judgment

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				confirming its position. The Supreme Court agreed, distinguishing its conclusion from that in *State ex rel. Cincinnati Enquirer v. Daniels* (described below) because in this case, **the public records request itself was linked to a specific blood lead level and therefore "inextricably linked" to PHI.** The Court found it "undeniable that the address of a home where a child has an elevated blood lead level can be used to identify the afflicted child." Accordingly, "[e]ven if it were possible to comply with the request by redacting protected health information, the release of merely the address of a house in response to the public-records request at issue means that a child at the house had 'elevated blood lead levels in excess of 10 [mg/dl],' which is protected health information." On remand, the Court ordered the trial court to review the records to determine whether any portion of them could be released following redaction of PHI.* * Ohio State Department of Health released homes that remain a lead hazard state-wide. http://www.cleveland.com/healthfit/index.ssf/2017/03/ohio_department_of_health_to_p.html
State ex rel. Cincinnati Enquirer v. Daniels	2006	Ohio Supreme Court	108 Ohio St.3d 518	A Cincinnati newspaper requested lead-risk-assessment reports and lead-citation notices from the Cincinnati Health Department ("the Department"). The notices had been issued by the Department to property owners of residences inhabited by children whose blood tests indicated elevated levels of lead. The Department refused to release the requested records because they referred to blood test results for children living at particular addresses; thus, the Department concluded the records contained protected health information. After mediation, the Department released 170 of the lead citations relating to non-single-family residences, and, citing privacy concerns, continued to safeguard all lead citations pertaining to owners of single-family residential property. The Court disagreed and ordered release of the records to the newspaper, explaining that **the records were not protected health information under HIPAA because they included only "a mere nondescript reference to 'a' child with 'an' elevated lead level" and did not include other identifying information**, such as name, age, birth date, social security number, telephone number, family information, or photograph, nor did they include specific medical information. **The Court applied the same conclusion to both single family and multi-family residences, concluding "the single sentence" indicating the presence of a child with an elevated blood lead level did not constitute a reasonable basis for believing the information could be traced to an individual.** The Court went on to note that even if the records contained protected health

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				information, the Department would be required to release them anyway since the disclosure was required by state law and permitted under the "required by law" exception to HIPAA, located at 45 C.F.R. § 164.512(a)(1).
Southern Illinoisan v. Dept. of Public Health	2006	Supreme Court of Illinois	218 Ill.2d 390	The Illinois Department of Public Health (DPH) denied Plaintiff newspaper's FOIA request, in which the newspaper sought disclosure of Cancer Registry information relating to incidence of neuroblastoma, including type of cancer, date of diagnosis, and patient's zip code, to determine whether the cancer occurred in clusters. The DPH claimed the disclosure was prohibited by the Illinois Health and Hazardous Substances Registry Act (the Registry Act) since the information requested "tends to lead to the identity" of individuals. The DPH offered the testimony of an expert in data anonymity as evidence that the information requested, combined with other publicly available information, could be used to identify individuals. The Supreme Court rejected this argument, noting that although the equipment and data sets used by the expert were readily available to the public, the six-step methodology she employed to re-identify the data was "unique to her education, training and experience, and not easily duplicated by the general public." **The Court concluded that "information 'tends to lead to the identity' of Registry patients only if that information can be used by the general public to make those identifications." Balancing the competing interests of public access to information against the risk of invasion of privacy, t**he Court further noted that the word "tend" allows for flexibility and case-by-case determinations regarding release of data, but emphasized that the burden of proof was on the DPH to justify non-disclosure. Finally, the Supreme Court affirmed the Circuit Court's decision to prohibit re-identification of any individuals on the Cancer Registry List, thus ensuring privacy.
Williams Law Firm v. Bd. of Sup. of La. State Univ.	2004	First Circuit Court of Appeal of Louisiana	878 So.2d 557	Plaintiff law firm requested records from the Louisiana Tumor Registry (LTR), a state central cancer registry administered by Defendant university. Plaintiff requested raw numerical data reflecting incidence of adult and pediatric cancers by parish and by year for a specified time frame (zip code was requested as well but since data by zip code was not retrievable by the LTR, the Court dismissed this request). The LTR refused to disclose any results revealing an incidence of zero or one of a type of cancer. The LTR claimed this information was case specific data since it pertained to one specific case and was therefore protected from disclosure by the Tumor Registry Law. Plaintiff disagreed, claiming that revealing zeros and ones "would only be case specific if there were only one person

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				in the parish," which is never the case. The Court agreed with Plaintiff and ordered disclosure of zeros and ones, explaining that **zeros and ones in this case are not case-specific data, but rather expressions of group level data**. Thus, without other identifiable characteristics, the zeros and ones did not tend to reveal the identities of individuals and did not compromise individual privacy. The Court further noted that omitting zeros and ones was substantively significant in this case since the omission could have the effect of concealing incidences of rare cancer.
Hassig v. New York State Dept. of Health	2002	Appellate Division of the Supreme Court of New York, Third Dept.	742 N.Y.S.2d 442	A grassroots organization seeking to develop a county-based cancer prevention program requested records from the State Cancer Registry disclosing "site specific cancer diagnoses and deaths" for a specified time frame for the county, including data for all age groups but excluding instances where there were two or fewer cancer site specific records for a particular year and zip code. The Department of Health (DOH) denied the request, citing New York state law and 42 U.S.C. § 280e (governing the National Program of Cancer Registries), which prohibit disclosure of identifying information. The DOH explained that the information sought, in combination with other readily available information such as personal knowledge of individuals in the community, could lead to disclosure of identifying information. In particular, the DOH noted that several children would be easily identified because they had a "unique combination of age group, gender, year of diagnosis and ZIP code." **The Court ruled in favor of the DOH because it "articulated a particularized and specific justification for denying access to the records in question—namely, that such records, when combined with other readily available information, including community knowledge, could identify or lead to the identification of individual cancer patients."**
Marine Shale Processors Inc. v. State, Through Dept. of Health & Hosp.	1990	First Circuit Court of Appeal of Louisiana	572 So.2d 280	Plaintiff corporation sought preservation of records associated with an investigative public health study regarding five cases of neuroblastoma conducted for the Department of Health and Hospitals (DHH). The corporation sought to preserve these records for use as evidence in pending and anticipated tort litigation alleging a connection between the corporation's activities at a nearby plant and the occurrence of neuroblastoma. The study had been prompted by public concern and involved a questionnaire administered to the parents of the five children diagnosed with neuroblastoma as well as the parents of thirty-two control group children. The questionnaire included questions about prenatal activities of the parents (e.g. use of alcohol, illegal drugs,

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				contraception), prior pregnancies, family medical histories, and family income, among other things. DHH argued that the requested records were exempted from disclosure under the Public Records Act since they would "tend to reveal the identity" of a subject of a public health disease investigation. The Court agreed, **explaining that "the specificity of the questions coupled with the small number of cases and the fact that the identity of all five was known, compels the conclusion" that the case abstracts and questionnaires must be excluded in their entirety.** The Court observed that every element of data in the questionnaires and abstracts – including date of diagnosis, age at diagnosis, sex, race, religion, family medical histories, diagnostic information, treatment, and vital status – would tend to reveal to which of the five cases they applied. The Court further prohibited disclosure of handwritten notes containing ratios that compared the case members to those in the control group, as well as any other records referencing the protected case abstracts and questionnaires.

SUPPORTERS

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