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Finding the Cluster: Balancing Privacy and Public Health Amid the Covid-19 Pandemic

Jessie L. Bekker

FINDING THE CLUSTER: BALANCING PRIVACY AND PUBLIC HEALTH AMID THE COVID-19 PANDEMIC

ABSTRACT

More than 800,000 Americans have died and more than fifty-seven million sickened since March 2020 from the COVID-19 virus and its highly contagious variants. Public health officials urged the public to mask up, socially distance, and stay home in order to curb the virus' spread in the early months of the pandemic before a vaccine was approved. Meanwhile, those same officials blocked access to valuable information pinpointing areas of disease concentration—"hotspots"—which could have alerted members of the public of locations to avoid. Those officials generally—and usually incorrectly—cited the Health Insurance Portability and Accountability Act (HIPAA) as grounds for information blocking, likely to bypass liability if information released was not properly de-identified under the law. While the secrecy may have caused confusion and distrust among the general public, there is insufficient guidance for health officials to determine which health-related data can and cannot be shared. The Office for Civil Rights, housed under the federal Department of Health and Human Services, sanctions HIPAA offenses, and thus can play a uniquely influential role in access to public health information by issuing guidance for health officials that explains HIPAA's privacy rules and their limitations.

I. INTRODUCTION

In the middle of a war against an international pandemic which, by early January 2022, had killed over 800,000 Americans and sickened more than fifty-seven million,[1] a new battleground emerged: the fight for access to public information.[2] Since March 2020, and prior to the mass distribution of vaccines, public health experts urged Americans to stay at home and socially distance to help stop the spread of the SARS-CoV-2 virus, or COVID-19.[3] In an effort to alert Americans to areas of disease concentration, also called "hotspots,"[4] local reporters pressed public health authorities for information to help identify locations where the disease had rampantly spread.[5] Those reporters were joined in their efforts by other members of the general public, including many parents of school children who had also asked their local school districts to publicize disease incidence information to make informed decisions about whether it was safe to send their children to school.[6] These questions seem, at first glance, uncontroversial. But as compliance with public health measures—masking, social distancing, and staying home—became highly politicized under the Trump Administration,[7] data which could help tamper the spread of the deadly COVID-19 virus became harder to access.[8]

1. *United States COVID-19 Cases, Deaths, and Laboratory Testing (NAATs) by State, Territory, and Jurisdiction*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://covid.cdc.gov/covid-data-tracker/#cases_casesper100klast7days (last visited Jan. 6, 2022).

2. *See, e.g.*, Dan Levin, *Covid in the Classroom? Some Schools Are Keeping It Quiet*, N.Y. TIMES (Aug. 22, 2020), https://nyti.ms/329CWFa.

3. *See, e.g.*, Cal. Exec. Order No. N-33-20 (Mar. 19, 2020), https://www.gov.ca.gov/wp-content/uploads/2020/03/3.19.20-attested-EO-N-33-20-COVID-19-HEALTH-ORDER.pdf; *Transcript for the CDC Telebriefing on the COVID-19 Outbreak*, CTRS. FOR DISEASE CONTROL & PREVENTION (Dec. 2, 2020), https://www.cdc.gov/media/releases/2020/t1202-covid-19-telebriefing.html.

4. Alexandra M. Oster et al., *Trends in Number and Distribution of COVID-19 Hotspot Counties—United States, March 8–July 15, 2020*, 69 MORBIDITY & MORTALITY WKLY. REP. 1127, 1127 (2020).

5. Levin, *supra* note 2.

6. *Id.*

7. P. Sol Hart et al., *Politicization and Polarization in COVID-19 News Coverage*, 42 SCI. COMMC'N 679, 680–81 (2020); Anna North, *Why Masks Are (Still) Politicized in America*, VOX (July 22, 2020, 10:45 AM), https://www.vox.com/2020/7/21/21331310/mask-masks-trump-covid19-rule-georgia-alabama.

8. *See, e.g.*, Brianne Pfannenstiel, *Iowa Officials Won't Disclose Coronavirus Outbreaks at Meatpacking Plants Unless Media Asks*, DES MOINES REG., https://www.desmoinesregister.com/story/news/politics/2020/05/27/iowa-wont-disclose-covid-19-outbreaks-businesses-unless-media-asks-kim-reynolds/5267413002/ (May 28, 2020, 6:41 AM). Some locales, including St. Louis County, suspended their contact tracing efforts, highlighting the pressing need for public access to COVID-19 hotspot information as mitigation measures fell primarily in the hands of patients. Though the relevance of hotspot data will, hopefully, diminish as vaccine distribution slows the spread of COVID-19, this issue may resurface in the next pandemic or public health emergency due to a highly communicable disease. *See* Sarah Fentem, *St. Louis County Set Record for*

In many cases, these data-keepers—public health agencies, hospitals, school districts, and counties—are incorrectly citing health privacy laws as a means of restricting access to hotspot information.[9] The federal health information privacy law is the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, enacted in 1996.[10] The rule prohibits covered entities, including health plans, clearinghouses, and providers, from disclosing protected health information (PHI) where such information is individually identifiable.[11] Business associates of covered entities, such as subcontractors, are also prohibited from making such disclosures.[12] While HIPAA protects data that can identify individuals, like their name, address, birth date, and Social Security Number, it does not protect de-identified data.[13] If, for example, a health care provider—perhaps a public health agency providing care—removes all individual identifiers from data related to COVID-19 cases, HIPAA specifically states that its requirements no longer apply.[14] Moreover, "HIPAA itself contemplates that even for covered entities, extreme public health circumstances, like the COVID-19 pandemic, might warrant release of personal health information."[15] HIPAA also allows for the release of PHI where disclosure is "required by law."[16] In these cases, federal and state freedom of information laws may allow for the release of valuable public health information—though exemptions within the federal Freedom of Information Act (FOIA), which call for the concealment of certain records if federal statute so states, may cause confusion.[17] Despite potential stumbling blocks in dealing with federal and state confidentiality and information release laws, the HIPAA provisions are a saving grace for public health authorities and other covered entities fielding questions from reporters, concerned parents, and the general public related to COVID-19 outbreaks and hotspots.

HIPAA's privacy provisions, as discussed in this Article, are a source of great confusion for data-keepers, including government and other health care

Coronavirus Cases, Asks Patients to Do Contract Tracing, ST. LOUIS PUB. RADIO (Nov. 16, 2020, 5:54 PM), https://news.stlpublicradio.org/health-science-environment/2020-11-16/st-louis-county-sets-record-for-coronavirus-cases-asks-patients-to-do-contact-tracing.

9. Levin, *supra* note 2.

10. OFF. FOR C.R., SUMMARY OF THE HIPAA PRIVACY RULE 1 (2003), https://www.hhs.gov/sites/default/files/privacysummary.pdf [hereinafter *HIPAA Summary*].

11. 45 C.F.R. § 160.103 (2020).

12. *Id.*

13. 45 C.F.R. §§ 164.502(d)(2), 164.514(a)–(b) (2019).

14. 45 C.F.R. § 164.502(d)(2).

15. Al-Amyn Sumar & Chuck Tobin, *Coronavirus Tests the Commitment to Government Transparency*, LITIG., Summer 2020, at 10, 11.

16. 45 C.F.R. § 164.512(a) (2019).

17. Catherine J. Cameron, *Jumping Off the Merry-Go-Round: How the Federal Courts Will Reconcile the Circular Deference Problem Between HIPAA and FOIA*, 58 CATH. U. L. REV. 333, 335 (2009); 5 U.S.C. § 552(b)(3).

entities. These data-keepers may be erring on the side of secrecy to avoid risking a HIPAA violation by releasing information which is not properly de-identified or which has incorrectly been sorted under a PHI exception; because HIPAA's provisions leave room for interpretation, data-keepers may face confusion regarding what can and cannot be shared with the public.[18] Still, the hesitancy to issue data which are clearly de-identified or subject to a HIPAA exception is hurting the efforts of those same public health officials to mitigate the spread of COVID-19.[19]

Journalists and public health trade organizations have created guidance documents to help the two groups navigate HIPAA-related hurdles.[20] Unfortunately, lacking legal force, such guidance has proven fruitless.[21] In order to address confusion, and even inconsistency, it is imperative that the agency responsible for sanctioning privacy offenses—namely, the federal Office for Civil Rights (OCR) of the Department of Health and Human Services (HHS)—issue guidance explaining HIPAA's boundaries and interactions with state and federal sunshine laws. By doing so, OCR can promote access to COVID-19 information within HIPAA's privacy framework.

Part II of this Article explores the impact of blocking access to public health information on the spread of COVID-19. Part III then provides an in-depth definition of the HIPAA Privacy Rule and its boundaries. Part IV describes the historical battle between reporters and public agencies for access to public health records, including applicable litigation. Part V details the potential interactions between freedom of information statutes and the "required by law" exception, in addition to the problems posed by state privacy laws. Finally, Part VI recommends that OCR produce guidance documents to help members of the media and health care entities strike a balance between protecting the privacy of individuals and sharing lifesaving public health information.

II. DATA SHIELDING BY HEALTH CARE AGENCIES DURING THE COVID-19 PANDEMIC

Since the start of the COVID-19 pandemic, health care agencies largely kept the public in the dark about emerging hotspots. Meanwhile, the disease spread. At one point, nearly one million Americans tested COVID-positive in one day.[22]

18. *See, e.g.*, Jesse Pines et al., *10 Times HIPAA May Not Apply*, EMERGENCY PHYSICIANS MONTHLY (Sept. 1, 2015), https://epmonthly.com/article/10-times-hipaa-may-not-apply/; Stateside Staff, *HIPAA and You: Erring on the Side of Caution*, MICH. RADIO (Aug. 11, 2015, 4:24 PM), https://www.michiganradio.org/post/hipaa-and-you-erring-side-caution.

19. Pfannenstiel, *supra* note 8.

20. *See infra* Part IV.

21. *See infra* Part II.

22. *COVID Data Tracker, Trends in Number of COVID-19 Cases and Deaths in the US Reported to CDC, by State/Territory*, CTRS. FOR DISEASE CONTROL & PREVENTION,

A report provided to the *Wichita Eagle* by the Columbia University Brown Institute for Media Innovation exemplifies the detrimental impact of such secrecy. The report outlined a list of hotspots health officials actively hid from the public.[23] In a May 2020 email from the Kansas Department of Health and Environment to public health officials, the department, in bold and underlined writing, told officials, "Please do not distribute this list further and please do not make the names of facilities outside of your county known publicly."[24] But outbreaks in churches, nursing homes, prisons, and even keg parties took their toll statewide.[25] In response to reporter inquiries, the Kansas health department, despite warning public health officials that the data was not meant to be shared, deferred to counties to make their own decisions regarding data publicity, apparently switching course, displacing responsibility, and at the very least, inciting confusion among reporters and public health officials alike.[26]

Unfortunately, the response in Kansas is not unique. Universities, school districts, employers, and public health agencies nationwide have declined to release COVID-19 infection information, citing the HIPAA Privacy Rule.[27] The University of Alabama and the University of North Carolina at Chapel Hill each claimed that HIPAA prohibited the release of information about the incidence of COVID-19 on their campuses.[28] Tesla and the Alameda County Public Health Department also declined to share how many Tesla plant workers were infected with COVID-19.[29] In June 2020, Alameda County had the highest COVID-19 outbreak in all of Northern California.[30]

The lack of COVID-19 hotspot information, however, is met by a fierce thirst for information by both reporters and the general public. Parents across the country have expressed concern that they cannot make informed decisions about sending their children to school because the schools are declining to share

https://covid.cdc.gov/covid-data-tracker/#trends_dailytrendscases (last visited Jan. 6, 2022) (Select "View (left axis): Daily Cases" to show the daily total COVID case reports).

23. Jonathan Shorman et al., *Secret Document Lists Locations of Kansas Coronavirus Outbreaks. Here's What It Says*, WICHITA EAGLE (June 8, 2020, 7:50 AM), https://www.kansas.com/news/coronavirus/article243305606.html.

24. *Id.*

25. *Id.*

26. *Id.*

27. Meryl Kornfield, *Universities Can't Use Privacy Laws to Withhold Data on Coronavirus Outbreaks, Experts Say*, WASH. POST (Sept. 2, 2020), https://www.washingtonpost.com/education/2020/09/02/college-coronavirus-privacy-laws/.

28. *Id.*

29. Russ Mitchell, *Why You're Being Left in the Dark About Coronavirus Hot Spots in Your Area*, L.A. TIMES (June 15, 2020, 5:00 AM), https://www.latimes.com/business/story/2020-06-15/companies-like-tesla-wont-report-coronavirus-cases-why-arent-the-numbers-public.

30. *Id.*

disease information.[31] A Texas pediatrician said she could determine the safety of sending children to daycare, if only she had "a few more numbers."[32] Based on her experience, the answers to the questions reporters, parents, physicians, and the public-at-large are asking are within reach if data transparency improves. The fear then becomes that, as access to lifesaving data that people can use to identify personal risks associated with their private-life actions becomes restricted, so does the trust in government and health officials who, without disclosing COVID-19 hotspot information, ask the public to blindly trust their warnings and greatly restrict their day-to-day lives.

III. HIPAA AND ITS BOUNDARIES

Despite a clear desire from members of the public to make data-informed decisions regarding their movements during the peak of the COVID-19 pandemic, agencies shielded such information, citing HIPAA. HIPAA's privacy provisions continue to cause confusion, even for experts.[33] Whether an entity is bound by law, whether data is considered "protected health information" as defined below, or even whether data containing protected health information can be released as-is, under an exception to the Privacy Rule, or in a "de-identified" state is a dizzying set of inquiries. The legal complexity may be exactly why schools, public health entities, and government officials err on the side of privacy, even where such sharing could prove lifesaving; simply put, secrecy may be an expression of the adage, "Better safe than sorry."

The frequent citation of HIPAA by agencies as a barrier to sharing public information requires an exploration of the information HIPAA does and does not protect. HIPAA, enacted in 1996 and effective in 2001, requires certain privacy measures and disclosure protections of electronic information.[34] HIPAA applies to covered entities—health care providers, health plans, and clearinghouses—and their business associates, including subcontractors.[35] Under HIPAA, certain information which is individually identifiable is shielded from public disclosure.[36] This information is called "protected health

31. Levin, *supra* note 2; Aliyya Swaby, *Texas Parents Face a Frightening Lack of Information on Coronavirus Risks in Child Care Centers*, TEX. TRIB. (July 9, 2020, 6:00 AM), https://www.texastribune.org/2020/07/09/texas-day-care-coronavirus-risks/.

32. Swaby, *supra* note 31.

33. Colleen Flaherty, *Gag Order or Privacy Concern?*, INSIDE HIGHER ED (Aug. 31, 2020), https://www.insidehighered.com/news/2020/08/31/colleges-want-professors-stay-mum-student-covid-19-cases (HIPAA privacy experts shared concerns that even if HIPAA did not apply to disclosures of student COVID-19-positive tests, the Federal Educational Rights Privacy Act (FERPA) may prohibit these disclosures).

34. 45 C.F.R. § 164.104(a) (2019); *see generally HIPAA Summary*, *supra* note 10.

35. 45 C.F.R. §§ 164.103, 164.500(a) (2019).

36. 45 C.F.R. § 160.103 (2020).

information," or PHI.[37] PHI includes "individually identifiable health information," electronic or otherwise, which a covered entity or business associate handles.[38] It includes demographic data relating to a person's health condition, their own provision of health care, and payment for that provision of care.[39] HHS provides examples of individually identifiable health information: names, birth dates, addresses, and Social Security numbers.[40] Generally, HIPAA regulates how PHI can be used and disclosed to individuals, including when disclosure is permissible for treatment, payment, and health care operations.[41]

Importantly, HIPAA does not regulate de-identified information.[42] "Health information that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual is not individually identifiable health information."[43] In other words, information that cannot identify the specific people from which it stems is not restricted from public disclosure under HIPAA.[44] Public health entities can de-identify data in two ways: either by employing an expert who can determine that data is not individually identifiable or by removing eighteen individual identifiers from the data.[45] In the first case, a person with "appropriate knowledge of and experience with generally accepted statistical and scientific principles" would review data and determine there is a "very small" risk of its use for individually identifying a person.[46] The second method would require the removal of individual identifiers like names, birth dates, and Social Security numbers, among other identifiers.[47] Therefore, in the case where, for example, a school district wishes to share the number of active COVID-19 cases among faculty and staff, such information could easily be de-identified to fall outside of HIPAA's limitations through the use of a statistician's expertise. Some parents seem to understand these rules; Cynthia Johnston, a self-identified mom of two, took to Twitter to question her child's school, which emailed parents that a high school student tested positive for COVID-19, but did not provide any additional information.[48] Johnston questioned,

37. *Id.*
38. *Id.*
39. *Id.*
40. *HIPAA Summary*, *supra* note 10, at 4.
41. 45 C.F.R. § 164.506(a) (2019).
42. 45 C.F.R. § 164.514(a) (2019).
43. *Id.*
44. 45 C.F.R. §§ 164.502(d)(2), 164.514(a)–(b).
45. 45 C.F.R. § 164.514(b)(1)–(2).
46. 45 C.F.R. § 164.514(b)(1).
47. 45 C.F.R. § 164.514(b)(2).
48. Cynthia Johnston (@cdjohnst), TWITTER (Aug. 13, 2021, 5:08 PM), https://twitter.com/cdjohnst/status/1426304691290316801.

> How is that even helpful? … I feel like the school could say: Your child has been in a class with a person who tested Covid positive. Or your child has a common lunch period with a person who tested positive. Since there are like 45+ kids in each class it's not like they are breaking confidentiality.[49]

The first de-identification method also becomes particularly useful when releasing information by zip code, which may be pertinent in the discussion of COVID-19 hotspot data. While zip codes are an identifying feature which can be removed along with other individual identifiers, a zip code does not have to be removed from data for it to constitute de-identified information, as long as an expert has confirmed the data is, indeed, de-identified.[50]

Though seemingly simple, the idea of "de-identification" clearly leads to frustration for data-keepers and data-seekers alike because the analysis is fact-specific and high-risk. If an entity does not sufficiently de-identify data, it is at risk of accruing federal fines.[51] In some cases, the sample size may be small enough—for example, in a small town—that entities worry those familiar with the sample population will be able to readily identify the subjects of the data.[52] Or it is possible the process of determining HIPAA applicability and how to properly de-identify is so daunting or resource-consuming, an entity chooses to mark the data private under HIPAA rather than go through the exercise of determining whether and how it can be released. Of course, the journalist battling for public records is likely tempted to take the cynical view, and it is true that in some instances, data-keepers shield public information in bad faith. It is also likely true, however, that in most cases, the law has caused such confusion, and the risk is so much greater than the reward that privacy simply becomes the only seemingly reasonable outlet.

Where de-identification is not possible, HIPAA contemplates the disclosure even of PHI for public health purposes.[53] Although HIPAA permits—not requires—these disclosures,[54] at the least, the exception undermines claims by public health agencies that HIPAA categorically prohibits the disclosure of all COVID-19 data. Under this exception, those receiving data must enter into a

49. *Id.*

50. Many agencies release health statistics organized by zip code, and to suggest that each of these agencies is violating HIPAA's Privacy Rule is an absurd conclusion. *See, e.g.*, *COVID-19 Statistics*, ILL. DEP'T PUB. HEALTH, https://dph.illinois.gov/covid19/data.html (last visited Jan. 6, 2022).

51. *HIPAA Summary*, *supra* note 10, at 17.

52. *See, e.g.*, Mary Constantine, *Did a Roane County EMS Worker Break Federal Law with a Facebook Post About an Emergency Call?*, KNOX NEWS (May 30, 2018, 4:23 PM), https://www.knoxnews.com/story/news/2018/05/30/hipaa-law-violations-tennessee-paramedic-roane-county-ems/655603002/ (where the wife of a man who died in a chicken coop argued her husband's HIPAA rights were violated by a Facebook post where an EMS worker noted only the location of death, but in a small town where "everyone knows where my husband died.").

53. 45 C.F.R. § 164.514(e) (2019); *HIPAA Summary*, *supra* note 10, at 9.

54. 45 C.F.R. § 164.514(e); *HIPAA Summary*, *supra* note 10, at 9.

data use agreement for what is termed a "limited data set."[55] Limited data sets can be used "only for the purposes of research, public health, or health care operations."[56] While it is fathomable that a newspaper reporter could use such data for the purpose of COVID-19-related research, a parent curious about the number of COVID-19 cases at his child's school district likely could not rely on this exception to obtain data otherwise protected under HIPAA.

Finally, HIPAA contemplates disclosure of PHI where it is "required by law." For example, disclosure may be contemplated under freedom of information laws, as discussed in detail in the next section.[57] This becomes especially important in cases where state public information or public health laws call for the disclosure of data otherwise protected under HIPAA's PHI provision.[58]

HIPAA does not provide citizens a private right of action but allows OCR to execute civil monetary penalties against covered entities and their business associates for violations.[59] According to HHS, the Privacy Rule "assure[s] that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being."[60] The rule, according to HHS, "strikes a balance that permits important uses of information, while protecting the privacy of people who seek care and healing."[61]

IV. HISTORICAL TOOLS TO COMBAT PUBLIC INFORMATION BLOCKING

The public's thirst for information—and reporters' battle for it in the face of HIPAA regulations and despite its exceptions—predates COVID-19. A decade ago, the Association of Health Care Journalists teamed up with the National Association of County and City Health Officials and the Association of State and Territorial Health Officials to create guidance "for journalists and public health officials to consult when decisions must be made about what information should be released about deaths, epidemics, emerging diseases or illnesses."[62] The guidelines explain:

> The meeting was prompted by the wide variation in information released by state and local public health officials about people in their localities who died in the

55. 45 C.F.R. § 164.514(e)(1).

56. 45 C.F.R. § 164.514(e)(3).

57. 45 C.F.R. § 164.512(a) (2019).

58. *See, e.g.*, OHIO REV. CODE ANN. § 149.43 (West 2007) (amended 2018); State *ex rel.* Cincinnati Enquirer v. Daniels, 844 N.E.2d 1181, 1183, 1186 (Ohio 2006).

59. *HIPAA Summary*, *supra* note 10, at 17.

60. *HIPAA Summary*, *supra* note 10.

61. *Id.*

62. *Guidance on the Release of Information Concerning Deaths, Epidemics or Emerging Diseases*, ASS'N HEALTH CARE JOURNALISTS, https://healthjournalism.org/releaseguidance (last visited Jan. 6, 2022).

> H1N1 pandemic of 2009. The disparate approaches – with some jurisdictions releasing specific information about the age, gender and residence of victims and others releasing little or no personal information – became the subject of news reports, distracting from health messages and inadvertently undermining public trust.[63]

The document, though thorough and compiled through the collaboration of journalists *and* health professionals, is an example of why trade organizations cannot solve the problem of public health information shielding. To put it simply, if such guidance documents exist—and this example does not stand alone[64]—and health care entities continue to deny access to public health data under the guise of HIPAA protection,[65] it suggests that decision-makers at health care entities and public health agencies are not interested in what journalists or trade organizations have to say because those entities do not have enforcement power.

Moreover, guidelines exist for reporters to learn to navigate conversations with public officials who regularly inaccurately cite HIPAA, or its privacy rule "cousin," the Family Educational Rights and Privacy Act (FERPA), as a means of withholding information.[66] Still, agencies are quick to deny public records requests, citing these laws—though obtaining public information not only helps inform the general citizenry about issues which may impact their health and well-being, but acts as a tool for the public to hold its taxpayer-funded service-people accountable.[67] The existence of guidelines related to this very topic, and the simultaneous continuation of a trend toward unsupported secrecy and privacy, suggests guidelines created by any agency other than the enforcer of penalties—here, OCR—cannot effectively turn the tide toward accurate data-sharing which is both HIPAA-compliant and for the benefit of public health.

Public information denials have been the subject of many lawsuits by newspapers seeking to compel turnover of information deemed public under state law.[68] In *State ex rel. Cincinnati Enquirer v. Daniels*, the Supreme Court of Ohio compelled the Cincinnati Health Department to grant the *Cincinnati Enquirer* access to copies of 173 citations for lead contamination issued to

63. *Id.*

64. *Understanding HIPAA: A Brief Overview*, ASS'N HEALTH CARE JOURNALISTS, https://healthjournalism.org/resources-tips-details.php?id=12#.YBIVUuhKibi (last visited Jan. 6, 2022) (noting that both OCR and the American Hospital Association have promulgated HIPAA guidance); Annie Waldman, *How Health and Education Journalists Can Turn Privacy Laws to Their Advantage*, PROPUBLICA (Mar. 19, 2018, 5:00 AM), https://www.propublica.org/article/how-health-and-education-journalists-can-turn-privacy-laws-to-their-advantage (providing various strategies and resources reporters can use to gain information while still complying with HIPAA).

65. *See supra* Parts II and III.

66. Waldman, *supra* note 64.

67. *See id.* (noting that these laws are often used as barricades against disclosing information that is vital to public interest).

68. *E.g.*, State *ex rel.* Cincinnati Enquirer v. Daniels, 844 N.E.2d 1181, 1184 (Ohio 2006).

single-family residence owners.[69] More recently, an Arizona state court dismissed a lawsuit against the Arizona Department of Health Services and its director by several news organizations which requested access to the number of COVID-19 cases at nursing homes in the state.[70] News organizations in North Carolina, Mississippi, and Idaho, to name a few, have filed similar lawsuits seeking COVID-19-related records from government agencies.[71] Though lawsuits may be one avenue to obtaining information owed to the public, they are an option of last resort. The attorneys representing media groups in North Carolina said they spent weeks negotiating with agency attorneys for public data, to no avail.[72] Lawsuits take time, are costly, and, as the Arizona nursing home lawsuit shows, do not always result in access to public data, a major drawback in comparison to establishing a culture of responsible information sharing.

This leaves news organizations as the primary and sometimes only outlet for what should be publicly accessible information. In Iowa, for example, it is the Department of Public Health's *policy* to release outbreak information at businesses *only* to media and *only* if they request it.[73] It is a practice which leaves reporters, the public's watchdogs, as the only source of information—and it shows that, in some instances, only reporters have the leverage necessary to obtain lifesaving public health information.

In areas where at least some data was made available to news organizations to track COVID-19 cases, news organizations proved how influential that access

69. *Id.* at 1184, 1188.

70. *Civil Court Case Information – Case History*, JUD. BRANCH ARIZ. MARICOPA CNTY., http://www.superiorcourt.maricopa.gov/docket/CivilCourtCases/caseInfo.asp?caseNumber=CV2020-005385 (last visited July 3, 2021); Complaint for Statutory Special Action to Secure Right to Inspect and Copy Public Records at 2, Phoenix Newspapers Inc., v. Ariz. Dep't of Health Servs., No. CV2020-005385 (Ariz. Super. May 5, 2020), 2020 WL 2303032.

71. Kate Martin et al., *Media Coalition Sues Cooper, Cabinet Agencies for COVID-19 Records*, CITIZEN TIMES (May 28, 2020, 9:00 PM), https://www.citizen-times.com/story/news/local/2020/05/28/media-coalition-sues-cooper-cabinet-agencies-covid-19-records-asheville-lawsuit/5280275002/; Emily Wagster Pettus, *Judge: Health Dept. Must Respond to Public Records Request*, CLARION LEDGER (May 27, 2020, 11:52 AM), https://www.clarionledger.com/story/news/2020/05/27/mississippi-health-dept-must-respond-public-records-request/5265004002/; *Idaho Newspaper Plans Lawsuit over COVID-19 Records Denial*, ASSOCIATED PRESS (May 29, 2020), https://apnews.com/article/9ffa69ff4001cc8a48b98202d041bcd1.

72. Martin et al., *supra* note 71.

73. Pfannenstiel, *supra* note 8. In addition, the Texas Health and Human Services Commission gives case data in childcare centers to reporters who ask, but it will not publish the data online, confusingly, citing state privacy laws. *See* Swaby, *supra* note 31.

was in sharing lifesaving information.[74] In a listicle[75] published April 2020—just one month into a widespread national shutdown in response to the pandemic—the Knight Foundation, a non-profit foundation supporting free press, detailed all the reasons local journalists were essential to COVID-19 mitigation efforts.[76] Among a long list, the Knight Foundation first pointed to journalists who leveraged their data-scouting and analysis resources to assemble community hotspot maps and datasets.[77] For example, in New York City, non-profit news organization The City used emergency room admission data to track tests, cases, and hospitalizations by age and zip code.[78] Without their tool, the public had no way to access case information in their own neighborhoods.[79]

V. THE HIPAA "REQUIRED BY LAW" EXCEPTION AND STATE PRIVACY LAWS

At the crux of many information-seeking lawsuits filed by newspapers are freedom of information laws at the federal and state levels, which interact with HIPAA's "required by law" exception, often causing confusion for recordkeepers who must decide which law to apply.[80] Specifically, because both the federal Freedom of Information Act (FOIA) and HIPAA defer to the other, determining applicability becomes problematic.[81] Generally, FOIA states that government records are public unless they fall into an enumerated exception.[82] Exemption Six requires concealment of medical records that would cause an "unwarranted invasion of personal privacy."[83] FOIA's Exemption Three is also relevant here; it allows government agencies to shield records if another federal statute "establishes particular criteria for withholding" them.[84] Not all health care providers covered under HIPAA will fall into FOIA's purview, but several important ones in the time of COVID-19 do: namely, the Centers for Disease Control and Prevention and state and local public health agencies, all of which collect communicable disease reports, including COVID-19 data.[85]

74. Mark Glaser, *6 Ways Local News Makes a Crucial Impact Covering COVID-19*, KNIGHT FOUND. (Apr. 20, 2020), https://knightfoundation.org/articles/6-ways-local-news-makes-a-crucial-impact-covering-covid-19/.

75. A "listicle" is defined by Merriam-Webster as "an article consisting of a series of items presented as a list." *Listicle*, MERRIAM-WEBSTER, https://www.merriam-webster.com/dictionary/listicle (last visited Jan. 6, 2022).

76. Glaser, *supra* note 74.

77. *Id.*

78. *Id.*

79. *Id.*

80. Cameron, *supra* note 17, at 335–36.

81. *Id.*

82. 5 U.S.C. § 552(a)(3)(A).

83. 5 U.S.C. § 552(b)(6); Cameron, *supra* note 17, at 341.

84. 5 U.S.C. § 552(b)(3)(A)(ii); Cameron, *supra* note 17, at 341.

85. Cameron, *supra* note 17, at 342.

The 2006 Ohio Supreme Court *Cincinnati Enquirer* case, in which the court ordered the release of lead contamination citations,[86] provides an example of the interaction between HIPAA and state freedom of information laws. The court considered the conflict between the Ohio Public Records Act—the state's sunshine law—and the HIPAA Privacy Rule.[87] The court found the requested records did not contain PHI and that HIPAA's Privacy Rule was, therefore, inapplicable to the records.[88] Though it could have terminated its examination here, it continued to consider how the Ohio law would interact with records that do contain PHI.[89] According to the court, "even if the records did contain protected health information, they would still be subject to release in accordance with the 'required by law' exception to HIPAA."[90] "[W]e are confronted here with a problem of circular reference," the court explained, "because the Ohio Public Records Act requires disclosure of information unless prohibited by federal law, while federal law allows disclosure of protected health information if required by state law."[91] The court concluded, "the Ohio Public Records Law requires disclosure of these reports, and HIPAA does not supersede state disclosure requirements."[92] More than being an example of the interaction between HIPAA and FOIA, the case serves as an example that even records which contain PHI are subject to laws mandating disclosure.

The *Cincinnati Enquirer* case has not been cited in connection with a COVID-19-related public records request, perhaps because since that case was decided (and others like it),[93] the Ohio state legislature amended its public records law to exclude PHI from its definition of "public records."[94] Though undermined in Ohio by the state law amendment, the "required by law" exception to HIPAA privacy still exists on a federal level and may be viable in states that have not taken steps to exclude PHI from their public records laws. In circumstances where a state FOIA bars access to PHI, it may still be possible to obtain information from a public health entity, which is allowed, under HIPAA's privacy exceptions, to disclose information to people potentially exposed to a communicable disease.[95]

86. State *ex rel.* Cincinnati Enquirer v. Daniels, 844 N.E.2d 1181, 1189 (Ohio 2006).

87. *Id.* at 1183.

88. *Id.* at 1186.

89. *Id.*

90. *Id.*

91. *Cincinnati Enquirer*, 844 N.E.2d at 1187.

92. *Id.* at 1188.

93. *See, e.g.*, Abbott v. Tex. Dep't Mental Health & Mental Retardation, 212 S.W.3d 648, 651 (Tex. App. 2006).

94. OHIO REV. CODE ANN. § 149.43 (West 2018), *invalidated by* State v. Delvallie, 2021-Ohio-1809, 173 N.E.3d 544 (the court held on a criminal law issue, which falls outside the scope of this Article).

95. 45 C.F.R. § 164.512(b)(1)(iv) (2019); OFF. FOR C.R., U.S. DEP'T OF HEALTH & HUM. SERVS., DISCLOSURES FOR PUBLIC HEALTH ACTIVITIES 3 (2003),

Besides HIPAA, certain state-enacted privacy laws contribute to difficulties accessing public health data.[96] Though these laws protect personal privacy, they also impede reasonable efforts to release public health data. These state laws will provide an obstacle to information-seekers even with a clear interpretation of HIPAA that favors public data release, and when strictly interpreted, these laws may interfere with the balance between privacy and public health.[97]

VI. RECOMMENDATIONS

If there is any clear consensus regarding HIPAA's privacy provisions, it is only that its applicability is a source of great confusion. Even in cases where HIPAA contemplates the release of PHI or de-identified data, determining to what extent data must be altered to be sufficiently de-identified serves as a block to data release. Such ambiguity may be the reason HIPAA's Privacy Rule is so often incorrectly cited; rather than risk releasing data, which is not sufficiently de-identified, organizations will choose (perhaps not surprisingly so) to refuse to provide potentially lifesaving information. Though private entities, such as trade organizations, have created guidance documents resolving at least some of these ambiguities,[98] the problem of incorrect HIPAA citation persists. Frankly, though these guidance documents may be useful for journalists as an educational tool when pressing health care entities for data, the documents carry no legal force in the face of discipline for HIPAA violation and cost valuable resources to develop. Despite fast-paced advances in COVID-19 vaccine dissemination, we will face disease outbreaks again, as evidenced by the virus' resurgence in the form of its Delta variant, the predominant COVID-19 virus strain in the United States by July 2021, and later, its Omicron variant.[99] It is therefore imperative that public health entities are equipped with the tools they need to properly and promptly release data which can help the public make informed choices which better the health of the United States population.

https://www.hhsgov/sites/default/files/ocr/privacy/hipaa/understanding/special/publichealth/publichealth.pdf. Ultimately, the circular deference between FOIA and HIPAA remains problematic but falls beyond the scope of this article.

96. *See Health Privacy: Disclosure of Medical Information Chart*, BLOOMBERG L., https://www.bloomberglaw.com/product/blaw/bbna/chart/41/403/d78fe3e5fa95897ba62326e22ffcaf14 (last visited Mar. 10, 2021). This source is created from Bloomberg Chart Builder, using "Disclosure of Medical Information" for all fifty states and D.C. including topics "Applicable Law" and "Confidentiality and Consent to Disclose."

97. *See id.*; *see, e.g.*, King v. Cook County Health and Hospitals Systems, No. 1-19-0925, 2020 WL 3287316, at *1 (Ill. App. June 18, 2020). The issue of state privacy law falls outside the scope of this article.

98. *See supra* Part IV.

99. *COVID Data Tracker*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://covid.cdc.gov/covid-data-tracker/#variant-proportions (last updated Jan. 4, 2022).

OCR, as the enforcing agency of the HIPAA Privacy Rule, is in a unique position to provide useful guidance to covered entities, business associates, and public agencies generally to explain which data can be freely provided to the public. First, because OCR is the enforcement agency doling out civil monetary penalties to organizations which breach HIPAA laws, it may be that guidance issued by OCR has more influence than that drafted by other interested organizations, including trade groups.[100] Second, OCR is well-versed in the arena of guidance issuance and can take language from existing documents and tailor it to address media members and entities handling public record requests.[101] Finally, by providing guidance which favors disclosure, OCR can signal to health care entities that public information access is possible while maintaining privacy. This is, perhaps, the most notable impact of such guidance. Easing the fears of legal and compliance personnel within covered health entities can open access to lifesaving data, which in turn can help curb the spread of COVID-19 or other infectious disease outbreaks and lessen the impact of future public health emergencies.

In addition to guidance drafted by organizations like the Association of Health Care Journalists, Poynter, and the Reporters Committee for Freedom of the Press, which are generally informative and thorough, OCR has authored its own guidance documents.[102] Therefore, much of OCR's task is already complete. Moreover, in May 2020, OCR released guidance for health professionals on handling media requests related to COVID-19.[103] The guidance is laid out in an easy-to understand, question-and-answer format, including references to the HIPAA rule.[104] This existing guidance, however, does not address the issue outlined in this Article. While OCR anticipated questions related to filming patients in health care settings, it did not anticipate that questions regarding de-identification of statistical information would arise in HIPAA's grey areas, and the guidance is limited to two pages in length, answering only three hypothetical, HIPAA-related questions.[105] OCR should

100. *HIPAA Summary*, *supra* note 10, at 17.

101. In December 2020, OCR issued guidance to help health insurance exchanges understand how it could disclose COVID-19-related PHI for public health purposes. OFF. FOR C.R., HIPAA, HEALTH INFORMATION EXCHANGES, AND DISCLOSURES OF PROTECTED HEALTH INFORMATION FOR PUBLIC HEALTH PURPOSES (2020), https://www.hhs.gov/sites/default/files/hie-faqs.pdf.

102. *Id.* at 2; OFF. FOR C.R., GUIDANCE ON COVERED HEALTH CARE PROVIDERS AND RESTRICTIONS ON MEDIA ACCESS TO PROTECTED HEALTH INFORMATION ABOUT INDIVIDUALS IN THEIR FACILITIES (2020), https://www.hhs.gov/sites/default/files/guidance-on-media-and-film-crews-access-to-phi.pdf [hereinafter OCR Media Guidance]; Adam A. Marshall & Gunita Singh, *Journalists' Guide to HIPAA During the COVID-19 Health Crisis*, REPS. COMM. FOR FREEDOM PRESS (Apr. 28, 2020), https://www.rcfp.org/covid-19-journalists-hipaa-guide/.

103. OCR Media Guidance, *supra* note 102, at 1.

104. *Id.*

105. *Id.* at 1–2.

build off its existing media guidance to help covered health entities understand how to release information that is HIPAA compliant.

OCR's guidance should address three distinct methods of data release that balance the privacy of individuals and the health of the public. First, OCR's guidance should outline methods of compliant data de-identification of PHI, using prototypical examples of media and public data requests to guide its recommendations. The HIPAA Privacy Rule outlines two methods for de-identification.[106] Under the first, a health care entity can remove a list of eighteen identifiers.[107] Though effective, this can slim down the content of the data request to the point that the data's value is lost. Accordingly, OCR should clarify who will qualify as "a person with appropriate knowledge of and experience with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable" under the law.[108] Whether a health care entity, newspaper, or trade organization—like the Association for Health Care Journalists—retains the services of such a statistician, either privately or through a local university, for example, OCR's guidance could open doors for health care entities and media to work together to promote the flow of public information. Moreover, guidance will re-enforce trust in public health among the general population by clarifying which types of professionals will be able to make a determination under the law. These guidelines, by showing the accessibility of an expert de-identification determination, can serve both as permission to covered health entities to release public health data—whether it constitutes PHI or not—and as a reminder of the value of such data.

Second, OCR should clarify that HIPAA's "required by law" exception allows for the release of PHI where state laws—statute, regulation, or court order—so require, and such disclosures do not constitute HIPAA violations.[109] Though OCR does not enforce FOIA compliance, it has explained this interaction of state public information laws and HIPAA.[110] Similar language in future guidance documents created by OCR to guide covered health entities in data release activities would be appropriate.

Finally, even in situations where the "required by law" exception is inapplicable, in some instances, disclosure will be appropriate and not in violation of HIPAA based on other HIPAA provisions. For example, though likely out of reach for the average parent seeking COVID-19-related school

106. 45 C.F.R. § 164.514(b) (2019).

107. 45 C.F.R. § 164.514(b)(2).

108. 45 C.F.R. § 164.514(b)(1).

109. *HIPAA Summary*, *supra* note 10, at 6–7.

110. Off. for C.R., *State Public Records Laws, Also Known as Open Records or Freedom of Information Laws, All Provide for Certain Public Access to Government Records. How Does the HIPAA Privacy Rule Relate to These State Laws?*, U.S. DEP'T OF HEALTH & HUM. SERVS., https://www.hhs.gov/hipaa/for-professionals/faq/506/how-does-the-hipaa-rule-relate-to-freedom-of-information-laws/index.html (last reviewed July 26, 2013).

district data, HIPAA's "limited data set" exception may be beneficial for reporters. Per this rule, "[a] limited data set may be used and disclosed for . . . public health purposes, provided the recipient enters into a data use agreement promising specified safeguards for the protected health information within the limited data set."[111] This may have been pertinent in Kansas, for example, where the state Department of Health and Education kept COVID-19 outbreak data from the public as people fell ill and died.[112] Instead, state officials and a local newspaper—perhaps the *Wichita Eagle*, which eventually broke the news story—could have created a safe channel of data communication which was HIPAA compliant and in favor of public safety ahead of the disease's spread.

Ultimately, OCR is uniquely positioned to help covered health entities strike a delicate balance between protecting the privacy of their patients and aiding in the furtherance of public health. Current OCR guidelines act as a deterrent to public information sharing. When the enforcement agency warns only against information sharing and does not explain when information sharing is appropriate, it sends one message: "Sharing public health information will be sanctioned." To be clear, this is not a simple balance to strike. Given the unique nature of each data request, there cannot be a bright-line rule to easily determine when data should be released. This obstacle does not warrant ignorance, however. Because OCR makes the final call regarding what warrants penalty under HIPAA, only OCR can give covered entities the OK to publicize data it would otherwise hide behind the excuse of privacy.

VII. CONCLUSION

Finding the balance between securing individuals' privacy rights and helping the public make educated health decisions—in the midst of the deadliest pandemic the United States has faced in a century—is a difficult task without a clear-cut rule. However, the history and continuing practice of shielding COVID-19 hotspot data out of fear its revelation could lead to sanctions must end. Health care entities, school districts, and other organizations that could help the general public make informed decisions regarding the places they go during the pandemic have a duty to use that information for the public good. Moreover, the HIPAA Privacy Rule, often cited as the legal roadblock to such data release, itself contemplates and allows for this data sharing.[113] It is now up to OCR to take the initiative, to recognize the role only it can play in alleviating this longstanding problem, and to release a guidance document that provides the permission its covered entities lack today to open access to COVID-19 hotspot data. If OCR could save even one life from COVID-19—much less, slow the

111. *HIPAA Summary*, *supra* note 10, at 9.

112. Shorman et al., *supra* note 23.

113. 45 C.F.R. § 164.502(a)(1) (2019); Sumar & Tobin, *supra* note 15.

spread of the disease and others like it to come—by releasing a guidance document, it will have been worth it.

JESSIE L. BEKKER*

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