

# COVID-19 & THE MYTH OF HEALTH DATA PRIVACY

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*The coronavirus pandemic held a magnifying glass to how Americans misunderstand health data privacy—especially HIPAA. This paper considers the post-pandemic implications of this reality, the potential impact of this misunderstanding on state and federal efforts to augment privacy protections, and whether this new appreciation can inform novel approaches to privacy education in the future. This paper concludes with cautious optimism, viewing the pandemic’s headline-generating health data privacy misperceptions as an opportunity for targeted public outreach.*

## I. INTRODUCTION

The Health Insurance Portability and Accountability Act (HIPAA)<sup>1</sup> is perhaps one of the most well-known and yet one of the most poorly understood laws.<sup>2</sup> The COVID-19 pandemic has only highlighted the extent of this misunderstanding. One need not look any further than anti-mask and anti-vaccines activists—and even news media, politicians, and public figures—misstating and misrepresenting HIPAA on everything from signs on businesses to homemade exemption cards to understand that confusion abounds.<sup>3</sup> And rightfully so, it is not intuitive that the same or similar information you provide to your physician in a clinical encounter for inclusion in your electronic health record will not necessarily receive the same protections in other contexts.

But these common mistakes, coupled with now undeniable evidence of

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<sup>1</sup> Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104–91, 110 Stat. (1996) (codified as amended in scattered sections of 18 U.S.C., 26 U.S.C., 29 U.S.C., and 42 U.S.C.).

<sup>2</sup> Mark A. Rothstein, *The End of the HIPAA Privacy Rule? Currents in Contemporary Bioethics*, 44 J. L. Med. & Ethics 352 (2016) (referring to HIPAA as one of the “most misunderstood and disrespected of federal regulations”).

<sup>3</sup> See *infra* Part II.

their pervasiveness, raise important questions about how to address the public's complicated relationship with health data privacy beyond the coronavirus pandemic. Put simply, if Americans do not understand how and when health data protections apply—and, indeed, may already think they do<sup>4</sup>—they may be less likely to advocate for improved state and federal data privacy laws and more likely to entrust their deeply personal health information with entities that are neither private nor secure. If privacy advocates hope to be successful in their future efforts to augment health data protections, they may benefit from confronting these attitudes and beliefs head-on.

This paper proceeds in three parts. Part II begins with COVID-19 and describes how pandemic public health interventions raised public outcry about perceived invasions of health data privacy.<sup>5</sup> It uses the examples of masks, vaccines, and contact tracing to illustrate instances where the myth of HIPAA's protections proved far broader than what the law actually provides. Part III briefly considers HIPAA's reach and limitations in the context of the pandemic interventions identified in Part II. Finally, Part IV looks optimistically at how we could use the pandemic's momentum to improve privacy protections but offers that new laws and regulations alone may not be enough. Part IV also argues that efforts to improve data protections should be paired with education campaigns and public outreach to combat common misunderstandings and increase appreciation of the role of health data in public health initiatives. This coupling may lead people to appreciate when it is worth advocating for more protections and, by contrast, when increased health data use is both desirable and socially beneficial.

## II. PANDEMIC HEALTH DATA & THE SPECTER OF HIPAA

COVID-19 became a household name in 2020.<sup>6</sup> The American public,<sup>7</sup> many of whom had spent little time ever considering their personal relationship with public health beyond required vaccine schedules and seasonal flu, suddenly found themselves participating in one of the largest public health responses in recent history.<sup>8</sup> Stopping the spread of COVID-19 and working to

<sup>4</sup> See *infra* notes 18, 27–28.

<sup>5</sup> This paper will refer to the pandemic in the past tense, even though, at the time of writing, it is still ongoing with considerable uncertainty surrounding the Omicron and other variants.

<sup>6</sup> The World Health Organization first declared the novel coronavirus a Public Health Emergency of International Concern in January of 2020. See WORLD HEALTH ORG., *COVID-19 Public Health Emergency of International Concern (PHEIC) Global Research and Innovation Forum: Towards a Research Roadmap* (Feb. 12, 2020), [https://www.who.int/publications/m/item/covid-19-public-health-emergency-of-international-concern-\(pheic\)-global-research-and-innovation-forum](https://www.who.int/publications/m/item/covid-19-public-health-emergency-of-international-concern-(pheic)-global-research-and-innovation-forum) [<https://perma.cc/C3DC-8AHL>].

<sup>7</sup> COVID-19 is a global pandemic. However, this paper focuses exclusively on the United States.

<sup>8</sup> Erika G. Martin & Jessica Kronstadt, *No Longer Invisible: The Critical Role of Local Health Departments in Responding to COVID-19*, HEALTH AFFS. (Apr. 16, 2020) (noting that threats like COVID-19 are unprecedented in modern times and that “[w]hen public health works, [it is] invisible.”), <https://www.healthaffairs.org/doi/10.1377/forefront.20200408.106373/full/> [<https://perma.cc/7KNF-ZZ8E>].

flatten the curve<sup>9</sup> involved an incredible mobilization of science, medical resources, government officials, and the public. To do so effectively and efficiently, flattening the curve also required the generation, synthesis, and utilization of enormous quantities of health-related data.<sup>10</sup>

But while data-driven public health interventions may seem straightforward and universally palatable in the abstract, their real-world applications can come at great personal, professional, and political costs.<sup>11</sup> For example, school and business closures and so-called “lockdowns” are difficult policy decisions with significant consequences for many, especially primary caregivers.<sup>12</sup> And even more minimally burdensome measures, like social distancing and mask-wearing, still came with significant public backlash,<sup>13</sup> with acceptability often splitting along partisan lines.<sup>14</sup> The result was very vocal opposition to nearly every attempt to respond to the COVID-19 pandemic, which seemed even louder when amplified on social media.<sup>15</sup>

But while objections to these public health interventions ran the gamut from individual rights<sup>16</sup> to federalism,<sup>17</sup> one of the common citations for

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<sup>9</sup> “Flatten the curve” was a common rallying cry during the COVID-19 pandemic. It refers to stopping a rate from increasing over a period of time, and often specifically referenced rates of infection and/or rates of hospitalization.

<sup>10</sup> Leah R. Fowler, Jessica L. Roberts & Nicolas P. Terry, *Improving Data Collection and Management*, in COVID-19 POLICY PLAYBOOK II: LEGAL RECOMMENDATIONS FOR A SAFER, MORE EQUITABLE FUTURE 45 (Scott Burris, Sarah de Guia, Lance Gable, Donna E. Levin, Wendy E. Parmet & Nicolas P. Terry eds., 2021).

<sup>11</sup> See, e.g., Jayash Paudel, *Home Alone: Implications of COVID-19 for Mental Health*, 285 SOC. SCI. MED. (Sept. 2021), <https://pubmed.ncbi.nlm.nih.gov/34388621/> [<https://perma.cc/27DV-7DC7>]; Alexander W. Bartik, Marianne Bertrand, Zoe Cullen, Edward L. Glaeser, Michael Luca & Christopher Stanton, *The Impact of COVID-19 on Small Business Outcomes and Expectations*, 117 PROC. OF THE NAT’L ACAD. OF SC. OF THE U.S. (PNAS) 17656 (July 28, 2020), <https://www.pnas.org/content/117/30/17656> [<https://perma.cc/J67Y-37JY>].

<sup>12</sup> MCKINSEY & CO., *Seven Charts That Show COVID-19’s Impact on Women’s Employment* (Mar. 8, 2021), <https://www.mckinsey.com/featured-insights/diversity-and-inclusion/seven-charts-that-show-covid-19s-impact-on-womens-employment> [<https://perma.cc/8ZNB-CFLZ>]; Caitlyn Collins, Leah Ruppner, Liana Christin Landivar & William J. Scarborough, *The Gendered Consequences of a Weak Infrastructure of Care: School Reopening Plans and Parents’ Employment During the COVID-19 Pandemic*, 35 GENDER & SOC’Y 180 (2021), <https://osf.io/preprints/socarxiv/qgtue/>.

<sup>13</sup> Anna Maria Barry-Jester, Hannah Recht, Michelle R. Smith & Lauren Weber, *Pandemic Backlash Jeopardizes Public Health Powers, Leaders*, AP NEWS (Dec. 15, 2020), <https://apnews.com/article/pandemics-public-health-michael-brown-kansas-coronavirus-pandemic-3ae3c9e4eba38a6119895a4c3686d53e> [<https://perma.cc/K8A3-HVQX>].

<sup>14</sup> Claudia Deane, Kim Parker & John Gramlich, *A Year of U.S. Public Opinion on the Coronavirus Pandemic*, PEW RSCH. CTR. (Mar. 5, 2021), <https://www.pewresearch.org/2021/03/05/a-year-of-u-s-public-opinion-on-the-coronavirus-pandemic> [<https://perma.cc/9YY7-FM9M>].

<sup>15</sup> Christina Pazzanese, *Battling the ‘Pandemic of Misinformation,’* HARV. GAZETTE (May 8, 2020), <https://news.harvard.edu/gazette/story/2020/05/social-media-used-to-spread-create-covid-19-falsehoods> [<https://perma.cc/74Q4-QSGT>].

<sup>16</sup> Lindsay F. Wiley & Stephen I. Vladeck, *Coronavirus, Civil Liberties, and the Courts: The Case Against “Suspending” Judicial Review*, 133 HARV. L. REV. F. 9 (July 2020).

<sup>17</sup> Jennifer Selin, *How the Constitution’s Federalist Framework is Being Tested by COVID-19*, BROOKINGS (June 8, 2020), <https://www.brookings.edu/blog/fixgov/2020/06/08/how-the-constitutions-federalist-framework-is-being-tested-by-covid-19/> [<https://perma.cc/FS9U-9MD7>].

rejecting attempts at widespread pandemic control measures was one with a rich history of misunderstanding: HIPAA.<sup>18</sup> Three examples of common COVID-19 disease control measures help illustrate some of the ways HIPAA misperceptions and concerns about health data privacy appeared in debates about their use.

First, consider masking. Masks, when worn appropriately, can help reduce the transmission of respiratory diseases like those caused by coronaviruses, especially when coupled with other types of actions and interventions.<sup>19</sup> COVID-19 primarily spreads through droplets in the air,<sup>20</sup> which are generated when an infected individual speaks, coughs, or sneezes.<sup>21</sup> Thus, masks work by reducing dispersion via exhalation of and protecting from inhalation of those droplets.<sup>22</sup>

Mask requirements were common early in the pandemic, especially before widespread access to vaccinations and booster shots were available.<sup>23</sup> Many business establishments independently required mask use,<sup>24</sup> and some states and municipalities also implemented masking in public places.<sup>25</sup> At various times, federal law also obligated masking in various places within their

<sup>18</sup> Misunderstandings about HIPAA are extremely common, even among clinicians and health care institutions. HEALTH INFO. TECH. POL 'Y COMM., REPORT TO CONGRESS: CHALLENGES AND BARRIERS TO INTEROPERABILITY, at 4 (Dec. 2015), [https://www.healthit.gov/facas/sites/faca/files/HITPC\\_Final\\_ITF\\_Report\\_2015-12-16%20v3.pdf](https://www.healthit.gov/facas/sites/faca/files/HITPC_Final_ITF_Report_2015-12-16%20v3.pdf) [https://perma.cc/NAC6-RN4D] [hereinafter Report to Congress].

<sup>19</sup> Yuxin Wang, Zicheng Deng & Donglu Shi, *How Effective Is a Mask in Preventing COVID-19 Infection?*, MED. DEVICES SENS. (Jan. 5, 2021) (e-pub ahead of print), <https://onlinelibrary.wiley.com/doi/10.1002/mds3.10163> [https://perma.cc/Q844-ECDN].

<sup>20</sup> As of writing, there is an ongoing debate about how the novel coronavirus spreads, particularly whether it can be said to be airborne. Tina Hesman Saey, *Why It Matters that Health Agencies Finally Said the Coronavirus Is Airborne*, SCIENCE NEWS (Dec. 16, 2021), <https://www.sciencenews.org/article/coronavirus-covid-airborne-public-health-agencies> [https://perma.cc/MF2T-BRJT].

<sup>21</sup> WORLD HEALTH ORG., *Modes of Transmission of Virus Causing COVID-19: Implications for IPC Precaution Recommendations* (Mar. 29, 2020), <https://www.who.int/news-room/commentaries/detail/modes-of-transmission-of-virus-causing-covid-19-implications-for-ipc-precaution-recommendations> [https://perma.cc/P78T-2JA7].

<sup>22</sup> Wang, *supra* note 19.

<sup>23</sup> It is worth mentioning that some initial public health messaging actively discouraged mask use, and official positions on who should wear masks/when masks should be worn has been an enduring point of confusion. Deborah Netburn, *A Timeline of the CDC's Advice on Face Masks*, LA TIMES (July 27, 2021), <https://www.latimes.com/science/story/2021-07-27/timeline-cdc-mask-guidance-during-covid-19-pandemic> [https://perma.cc/PH35-B3KL]; Marie Fazio, *How Mask Guidelines Have Evolved*, N.Y. TIMES (Apr. 27, 2021), <https://www.nytimes.com/2021/04/27/science/face-mask-guidelines-timeline.html> [https://perma.cc/JT4B-3DG5]. Both decisions to impose and relax mask requirements were highly controversial.

<sup>24</sup> In some states (like Texas) where local governments were prohibited from requiring masks, businesses were allowed to require them for customers and employees. Tex. Exec. Order No. GA-36 (May 18, 2021), [https://gov.texas.gov/uploads/files/press/EO-GA-36\\_prohibition\\_on\\_mandating\\_face\\_coverings\\_response\\_to\\_COVID-19\\_disaster\\_IMAGE\\_05-18-2021.pdf](https://gov.texas.gov/uploads/files/press/EO-GA-36_prohibition_on_mandating_face_coverings_response_to_COVID-19_disaster_IMAGE_05-18-2021.pdf) [https://perma.cc/2EF2-TKGL].

<sup>25</sup> Kaia Hubbard, *These States Have COVID-19 Mask Mandates*, US NEWS (Mar. 28, 2022, 4:16 PM), <https://www.usnews.com/news/best-states/articles/these-are-the-states-with-mask-mandates> [https://perma.cc/Q39G-5AWN].

jurisdiction, including public transportation.<sup>26</sup>

Despite their relative ease of use compared to other interventions, mask mandates were not immune to immense public pushback. While types of objections varied, some opponents focused primarily on the personal health information communicated by choosing to wear or not wear a mask. For example, some groups opposed to wearing a mask in public places asserted—either in good faith or not—that if a business establishment or another person or entity asked them why they were not wearing a mask, it would violate HIPAA.<sup>27</sup> Put differently, these groups argued that an individual had to disclose sensitive health information (e.g., the presence of a disability or medical condition incompatible with mask use) to justify their non-compliance with a mask mandate and that to do so would be a violation of what they understood to be their rights under HIPAA.<sup>28</sup> Some opponents of mask requirements went so far as to make or acquire physical cards to keep in their wallets to show when questioned about their lack of masking, indicating (incorrectly) that HIPAA and the Americans with Disabilities Act permitted them to avoid mask requirements and inquiries.<sup>29</sup>

Second, consider vaccine requirements. For purposes of this paper, this broad category includes vaccination as a prerequisite for certain activities and employment. This category also includes proof of vaccination status, especially requirements to show vaccination cards before entering certain places and other proposed mechanisms of so-called “vaccine passports.”<sup>30</sup>

Even more explicitly than mask mandates, vaccine requirements necessitate the use and disclosure of indefinable information. For example, the information included on the paper CDC COVID-19 vaccination record cards discloses sensitive personal information.<sup>31</sup> When showing proof of vaccination

<sup>26</sup> See, e.g., CTBS. FOR DISEASE CONTROL & PREVENTION, *Order: Wearing of Face Masks While on Conveyances and at Transportation Hubs* (Apr. 18, 2022), <https://www.cdc.gov/quarantine/masks/mask-travel-guidance.html> [<https://perma.cc/JM7C-KYLV>].

<sup>27</sup> Lois Shepherd, *COVID-19 State Mask Mandates Can't Be Avoided Using HIPAA or Constitutional 'Exemptions'*, NBC NEWS (Aug. 11, 2020, 4:31 AM), <https://www.nbcnews.com/think/opinion/covid-19-state-mask-mandates-can-t-be-avoided-using-ncna1236342> [<https://perma.cc/J6ZV-UVQZ>].

<sup>28</sup> *Id.*

<sup>29</sup> Colleen Tressler, *COVID Mask Exemption Cards Are Not From the Government*, FTC CONSUMER INFO. (June 29, 2020), <https://www.consumer.ftc.gov/blog/2020/06/covid-mask-exemption-cards-are-not-government> [<https://perma.cc/S298-RUST>].

<sup>30</sup> Anna Rouw, Jennifer Kates & Josh Michaud, *Key Questions About COVID-19 Vaccine Passports and the US*, KAISER FAM. FOUND. (Apr. 15, 2021), <https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-about-covid-19-vaccine-passports-and-the-u-s/> [<https://perma.cc/DY53-EMVG>]; Annie Linskey, Dan Diamond & Tyler Pager, *Republicans Seek to Make Vaccine Passports the Next Battle in the Pandemic Culture Wars*, WASH. POST (Mar. 30, 2021), [https://www.washingtonpost.com/politics/biden-vaccine-passports-desantis/2021/03/30/eeb41124-9171-11eb-966889be11273c09\\_story.html?utm\\_campaign=wp\\_main&utm\\_medium=social&utm\\_source=twitter](https://www.washingtonpost.com/politics/biden-vaccine-passports-desantis/2021/03/30/eeb41124-9171-11eb-966889be11273c09_story.html?utm_campaign=wp_main&utm_medium=social&utm_source=twitter) [<https://perma.cc/G4AU-LLXX>].

<sup>31</sup> CTBS. FOR DISEASE CONTROL & PREVENTION, *Getting Your CDC COVID-19 Vaccination Record and Vaccination Card* (Feb. 7, 2022), <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/vaccination-card.html> [<https://perma.cc/9TZ7-7MYC>].

using one of these cards, the design is such that an individual must also disclose their name, date of birth, medical record number (if included), the type of vaccine received, and the date and location of vaccination.<sup>32</sup>

Vaccines were one of the most hotly contested battlegrounds of the pandemic.<sup>33</sup> Perhaps unsurprisingly, some of the objections were rooted in HIPAA. Professional athletes publicly stated that they believed HIPAA protected them from inquiries about vaccine status at press conferences.<sup>34</sup> Even public figures who should presumably know better—like politicians—invoked “HIPAA” when asked whether they had received the COVID-19 vaccination or in response to other proposed vaccine-focused public health initiatives.<sup>35</sup>

Finally, a third example of a public health intervention is contact tracing. Contact tracing is an effective approach to slowing the spread of infectious diseases.<sup>36</sup> It requires a trained public health professional to speak with an individual who tested positive for COVID-19 to assess who they saw and where they went.<sup>37</sup> As part of this interviewing process, contact tracers will ascertain who had potential exposures and later contact them to encourage them to get tested and, when appropriate, quarantine or isolate.<sup>38</sup> Given how COVID-19 spreads, traditional contact tracing methods were difficult to implement successfully.<sup>39</sup> As a result, some digital contact tracing efforts used technology like smartphone-based GPS or Bluetooth to help augment analog

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<sup>32</sup> *Id.*

<sup>33</sup> Alec Schemmel, *Biden Vaccine Mandate Meets Pushback From Majority of U.S. States*, KATV (Nov. 8, 2021), <http://katv.com/news/nation-world/controversial-biden-vaccine-mandate-meets-pushback-from-majority-of-us-states> [https://perma.cc/C4L4-7ACB]; Challenges to vaccine mandates also made it all the way to the Supreme Court of the United States. *See, e.g.,* *Dr. A v. Hochul*, No. 21A145 (U.S. filed Dec. 13, 2021).

<sup>34</sup> Tom Gatto, *Cowboys' Dak Prescott Sparks Twitter Jokes by Replying 'That's HIPAA' to Vaccine Question*, SPORTING NEWS (July 23, 2021), <https://www.sportingnews.com/us/nfl/news/cowboys-dak-prescott-twitter-thats-hipaa-vaccine-question/1ui8dwleq9xal1qbeua6qbsrkl> [https://perma.cc/8QHU-UVRQ]; Michael Corvo, *Lakers Center Dwight Howard Gets Schooled on HIPAA by Reporter*, CLUTCH POINTS (Sept. 28, 2021), <https://clutchpoints.com/lakers-news-dwight-howard-gets-schooled-on-hipaa-by-reporter/> [https://perma.cc/75EC-NUU3].

<sup>35</sup> Alex Noble, *Marjorie Taylor Greene Claims Vaccination Question is a HIPAA Violation – It Isn't*, THE WRAP (July 20, 2021, 5:38 PM), <https://www.thewrap.com/marjorie-taylor-greene-claims-vaccination-question-is-a-hipa-violation-it-isnt-video/> [https://perma.cc/T9S8-M6LX]; ASSOCIATED PRESS, *NOT REAL NEWS: A Look at What Didn't Happen This Week* (July 16, 2021) (referring to a proposed door-knocking campaign to urge vaccination, Texas Republican congressional candidate Monica De La Cruz-Hernandez wrote in a Facebook post, “[w]hat ever happened to PRIVATE health decisions? Seems like giving these door knockers our vaccination status would [be] a HIPPA violation.”), <https://apnews.com/article/technology-joe-biden-science-government-and-politics-health-451e3778c208d575e27f2e74ab2ae853> [https://perma.cc/9MCS-97W6].

<sup>36</sup> *See* Ken T.D. Eames & Matt J. Keeling, *Contact Tracing and Disease Control*, 270 PROC. OF THE ROYAL SOC'Y OF LONDON. SERIES B: BIOLOGICAL SCI. 2565–2571 (2003).

<sup>37</sup> CTRS. FOR DISEASE CONTROL & PREVENTION, *Contact Tracing* (Jan. 11, 2022), <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/contact-tracing.html> [https://perma.cc/9L7J-66SQ].

<sup>38</sup> *Id.*

<sup>39</sup> James O'Connell & Derek T. O'Keeffe, *Contact Tracing for COVID-19 – A Digital Inoculation Against Future Pandemics* 385:6 N. ENGL. J. MED. 484, 485 (2021).

contact tracing efforts.<sup>40</sup> Regardless of its form, contact tracing involves some amount of identifiable health information.

To initiate contact tracing efforts, health experts (or technology) gather information about an individual's infection status and how to contact the infected person.<sup>41</sup> That data set then grows to include information about symptoms and mitigation measures.<sup>42</sup> Further, it involves where a person went and who a person saw, which may implicate other types of health information via the types of conclusions one might draw about a person's actions and whereabouts.<sup>43</sup>

But despite its potential to help stop the spread, contact tracing was likewise poorly received in certain circles.<sup>44</sup> For example, many people refused to answer phone calls from contact tracers or comply with requests for information about places they visited while infectious and individuals they may have exposed.<sup>45</sup> Others likewise pushed back fiercely against digital contact tracing, unwilling to download or opt-in to contact tracing apps on their phones that could use GPS or Bluetooth to assist in contact tracing efforts out of concerns for, among other things, privacy.<sup>46</sup>

In some ways, this opposition is not surprising. Matters of public health inevitably implicate an age-old debate between balancing individual rights with the collective good.<sup>47</sup> COVID-19 was no exception. While some participated enthusiastically in these prevention efforts, others did so against their will or not at all, perceiving it as an unacceptable intrusion.<sup>48</sup> Moreover, as prevention measures increased, so did the use of HIPAA and privacy as a rationale for opposing and avoiding them.<sup>49</sup> However, the problem is that HIPAA's scope is far more limited than these pervasive but inaccurate

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<sup>40</sup> Muhammad Shahroz, Farooq Ahmad, Muhammad Shahzad Younis, Nadeem Ahmad, Maged N. Kamel Boulos, Ricardo Vinuesa, and Junaid Qadir, *COVID-19 Digital Contact Tracing Applications and Techniques: A Review Post Initial Deployments*, 5 TRANSP. ENG'G 1, 2 (2021).

<sup>41</sup> Johannes Müller & Mirjam Kretzschmar, *Contact Tracing – Old Models and New Challenges*, 6 INFECTIOUS DISEASE MODELLING 222, 222 (2021).

<sup>42</sup> *Id.*

<sup>43</sup> Anya Prince, *Location as Health*, 21 HOUS. J. HEALTH L. & POL'Y 1, 1 (2021).

<sup>44</sup> Will Stone, *Local Public Health Workers Report Hostile Threats and Fears About Contact Tracing*, NPR (June 3, 2020, 11:01 AM), <https://www.npr.org/sections/health-shots/2020/06/03/868566600/local-public-health-workers-report-hostile-threats-and-fears-about-contact-traci> [<https://perma.cc/V9XJ-83GR>].

<sup>45</sup> Colleen McClain & Lee Rainie, *The Challenges of Contact Tracing as U.S. Battles COVID-19*, PEW RSCH. CTR. (Oct. 30, 2020), <https://www.pewresearch.org/internet/2020/10/30/the-challenges-of-contact-tracing-as-u-s-battles-covid-19/> [<https://perma.cc/272Q-UQ7G>].

<sup>46</sup> *Majority of Americans Say They Won't Use COVID Contact Tracing Apps*, AVIRA (last visited May 3, 2022), <https://www.avira.com/en/covid-contact-tracing-app-report> [<https://perma.cc/GNH3-TCR5>]; See also Emily Berman, Leah R. Fowler & Jessica L. Roberts, *Trustworthy Digital Contact Tracing*, U. RICHMOND. L. REV. (forthcoming 2022).

<sup>47</sup> John D. Blum & Norchaya Talib, *Balancing Individual Rights Versus Collective Good in Public Health Enforcement*, NAT'L LIBR. OF MED. (2006), <https://pubmed.ncbi.nlm.nih.gov/16929806/> [<https://perma.cc/2JC9-L4TQ>].

<sup>48</sup> See *supra* Part II.

<sup>49</sup> Noble, *supra* note 35.

objections would suggest.<sup>50</sup>

### III. THE LIMITS OF HEALTH DATA PRIVACY

The three examples above show that HIPAA<sup>51</sup> is a well-known but poorly understood law.<sup>52</sup> General observation tells us that all people are at least passingly familiar with it from the stacks of authorization forms and notices of privacy practices they have received and signed throughout their lifetime.<sup>53</sup> But most people do not read the fine print before signing,<sup>54</sup> and even fewer will ever undertake independent research to understand HIPAA's nuances.<sup>55</sup> As a result, the connection between the word "HIPAA" and the act of protecting health data is deeply entrenched in public life, but the details of those protections are, for many, amorphous.

That is not to say HIPAA and its state-level counterparts<sup>56</sup> do not protect health data privacy. Indeed, as some scholars have noted, "although the term 'privacy' does not appear in HIPAA's title, attention to privacy is critical to achieving its goals."<sup>57</sup> In general, HIPAA provides privacy and security

<sup>50</sup> See *infra* Part III.

<sup>51</sup> Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936.

<sup>52</sup> Sara Morrison, *HIPAA, The Health Privacy Law That's More Limited Than You Think, Explained*, VOX (July 30, 2021, 8:41 AM), <https://www.vox.com/recode/22363011/hipaa-not-hippa-explained-health-privacy> (last visited May 3, 2022).

<sup>53</sup> *Health Privacy: HIPAA Basics*, PRIV. RTS. CLEARINGHOUSE (last visited May 3, 2022), <https://privacyrights.org/consumer-guides/health-privacy-hipaa-basics> [<https://perma.cc/SF35-JL-LV>].

<sup>54</sup> Yannis Bakos, Florencia Marotta-Wurgler & David R. Trossen, *Does Anyone Read the Fine Print? Consumer Attention to Standard Form Contracts*, 195 N.Y.U. L. & ECON. WORKING PAPERS 1, 1 (2014).

<sup>55</sup> Mark Hochhauser, *Why Patients Won't Understand Their HIPAA Privacy Notices*, PRIV. RTS. CLEARINGHOUSE (Apr. 10, 2003), <https://privacyrights.org/resources/why-patients-wont-understand-their-hipaa-privacy-notices-hochhauser> [<https://perma.cc/745P-NTRE>].

<sup>56</sup> And, while HIPAA establishes a federal floor to protect certain types of personal health information in certain contexts, state laws can be stricter and broader in scope. See Stacey A. Tovino, *Going Rogue: Mobile Research Applications and the Right to Privacy*, 95 NOTRE DAME L. REV. 155, 190 (2019) ("assessing nonsectoral state statutes that are potentially applicable to mobile-app-mediated research conducted by independent scientists"). For example, Texas expands the definition of "covered entity" to include any person who, under certain circumstances, possesses, obtains, or stores protected health information. Texas Health and Safety Code Ch. 181.001(b)(2) ("Covered entity means any person who: (A) for commercial, financial, or professional gain, monetary fees, or dues, or on a cooperative, nonprofit, or pro bono basis, engages, in whole or in part, and with real or constructive knowledge, in the practice of assembling, collecting, analyzing, using, evaluating, storing, or transmitting protected health information. The term includes a business associate, health care payer, governmental unit, information or computer management entity, school, health researcher, health care facility, clinic, health care provider, or person who maintains an Internet site; (B) comes into possession of protected health information; (C) obtains or stores protected health information under this chapter; or (D) is an employee, agent, or contractor of a person described by Paragraph (A), (B), or (C) insofar as the employee, agent, or contractor creates, receives, obtains, maintains, uses, or transmits protected health information.").

<sup>57</sup> Mary Anderlik Majumder & Christi J. Guerrini, *Federal Privacy Protections: Ethical*



protection for certain types of identifiable information<sup>58</sup> possessed or controlled by covered entities—such as health plans, health care clearinghouses, and health care providers—and their business associates.<sup>59</sup> In most cases, HIPAA restricts what a covered entity or its business associate can do with an individual's identifiable personal health information absent a signed authorization form.<sup>60</sup>

Thus, in many cases, broad assumptions of privacy and security are simply incorrect. But they are understandable. It is easy to believe that the same or similar information you give to your doctor in a routine clinical encounter would enjoy the same protections in other contexts as it does in the confines of your medical record. But this assumption, however understandable it may be, is nevertheless inaccurate. Consider some relevant characteristics of HIPAA that make it inapplicable in many contexts in which it was raised during the COVID-19 pandemic.

First, one of the critical limitations of HIPAA is the entities to which it applies. HIPAA only applies to covered entities and their business associates.<sup>61</sup> On any given day, an individual's interactions with a covered entity or its business associate will be shockingly limited. For example, while a physician is a covered entity, a grocery store is not. So, if a grocery store requires that customers wear masks inside, HIPAA will not apply. Even if a customer asserts that wearing—or, more likely, not wearing—a mask is forcing them to communicate information about their health status, the grocery store is not a covered entity. That information is not protected health information.

Second, HIPAA has no private right of action. So, an individual who suffered some kind of actual or imagined health data privacy violation cannot simply sue for disclosing their medical information.<sup>62</sup> While HIPAA provides both civil and criminal penalties,<sup>63</sup> the language of the statute limits

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*Foundations, Sources of Confusion in Clinical Medicine, and Controversies in Biomedical Research*, 18 AM. MED. ASSOC. J. ETHICS 288, 288 (2016).

<sup>58</sup> HIPAA does not regulate properly de-identified data. See 45 C.F.R. § 164.514(a) (2019).

<sup>59</sup> See 45 C.F.R. § 160.103 (2018); *id.* §§ 160.102(a)-(b) (applying HIPAA rules to covered entities and their business associates). Protected health information is defined as “individually identifiable health information [including demographic information] that is: (i) Transmitted by electronic media; (ii) Maintained in electronic media; or (iii) Transmitted or maintained in any other form or medium.” HIPAA § 262(a), 42 U.S.C.S. § 1320d-6 (Westlaw through Pub. L. No. 117-120); 45 C.F.R. § 160.103 (2009); see also Office For Civil Rights, *Your Rights Under HIPAA*, U.S. DEP’T OF HEALTH & HUM. SERVS. (Jan. 19, 2022), <https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html> [<https://perma.cc/NAH6-T4LK>].

<sup>60</sup> See generally 45 C.F.R. § 160.103 (2019).

<sup>61</sup> See 45 C.F.R. § 160.103 (2018) (defining covered entity); 45 C.F.R. § 160.102(a) (2018) (applying the HIPAA Rules to covered entities); see 45 C.F.R. § 160.103 (2018) (defining business associate); *id.* § 160.102(b) (applying the HIPAA Rules to business associates).

<sup>62</sup> Joshua D.W. Collins, *Toothless HIPAA: Searching for a Private Right of Action to Remedy Privacy Rule Violations*, 60 VAND. L. REV. 199, 201 (2007) (“[HIPAA] does not explicitly create any individual rights for patients affected by medical privacy violations.”).

<sup>63</sup> See Health Insurance Portability and Accountability Act §§ 1176-77 (adding 42 U.S.C.S. § 1320d-5 (Westlaw through Pub. L. No. 117-120) (establishing civil penalties for violations of the HIPAA Rules) and 42 U.S.C.S. § 1320d-6 (Westlaw through Pub. L. No. 117-120) (establishing

enforcement to the Department of Health and Human Services and state attorneys general.<sup>64</sup> Thus, if a restaurant requires proof of vaccination to enter and a patron threatens to sue the establishment for a perceived violation of their rights, HIPAA does not apply.<sup>65</sup>

Finally, even if HIPAA does apply in a given context—to both the type of information and entity in question—it does not always require that an individual provide explicit permission to share information.<sup>66</sup> HIPAA requires that the patient or authorized representative provide authorization for particular communication of protected health information with some exceptions.<sup>67</sup> Protected health information (PHI)<sup>68</sup> is broadly defined and includes any information in a designated record set that can be used to identify an individual.<sup>69</sup> But the law also allows for certain permitted disclosures without written authorization. Those permitted disclosures include treatment, payment, health care operations, certain law enforcement functions, and, importantly, public health activities.<sup>70</sup> Even pandemic mitigation measures that might implicate PHI or covered entities, like some permutations of contact tracing, likely fall into broad public health exceptions.<sup>71</sup> And finally, many actors engaging in disease control are frequently not themselves covered entities.<sup>72</sup> Thus, public health activities often do not run afoul of HIPAA's protections.<sup>73</sup>

This extremely brief and incomplete summary of HIPAA's role in protecting health data privacy shows how people know certain health data is

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criminal penalties for violations of the HIPAA Rules)); Health Information Technology for Economic and Clinical Health Act § 13410(d) (revising the amount of the civil penalties authorized by HIPAA).

<sup>64</sup> Cf. *Lee-Thomas v. LabCorp*, 316 F. Supp.3d 471, 474 (D.D.C. 2018).

<sup>65</sup> See Collins, *supra* note 62, at 201.

<sup>66</sup> 45 C.F.R. § 164.512(b) (2018) (describing the uses and disclosures for which an authorization or opportunity to agree or object is not required).

<sup>67</sup> Consent is distinct from authorization. The Privacy Rule permits but does not require consent for use or disclosure of certain protected health information in certain contexts. By contrast, the Privacy Rule requires authorization for uses and disclosures of protected health information not otherwise allowed by the Rule. Office for Civil Rights, *What is the Difference Between "Consent" and "Authorization" Under the HIPAA Privacy Rule?*, U.S. DEP'T OF HEALTH & HUM. SERVS. (last visited May 3, 2022), <https://www.hhs.gov/hipaa/for-professionals/faq/264/what-is-the-difference-between-consent-and-authorization/index.html> [<https://perma.cc/HAH8-P7QL>].

<sup>68</sup> HIPAA 'Protected Health Information': What Does PHI Include?, HIPAA.COM (last visited May 3, 2022), <https://www.hipaa.com/2009/09/01/hipaa-protected-health-information-what-does-phi-include/> [<https://perma.cc/3WZV-FCXT>].

<sup>69</sup> 45 CFR § 160.103 (2018).

<sup>70</sup> 45 C.F.R. § 164.502(a)(1) (2018). Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make. Office for Civil Rights, *Summary of the HIPAA Privacy Rule*, U.S. DEP'T OF HEALTH & HUM. SERVS. (last visited May 3, 2022), <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html> [<https://perma.cc/P5KB-RZFP>].

<sup>71</sup> 45 CFR § 164.512(b) (2018).

<sup>72</sup> Sallie Milam & Melissa Moorehead, *Becoming a Hybrid Entity: A Policy Option for Public Health*, AM. SOC'Y OF L., MED. & ETHICS (July 12, 2019), <https://journals.sagepub.com/doi/full/10.1177/1073110519857321> (last visited May 3, 2022).

<sup>73</sup> *Id.*

entitled to protections but misjudge when those protections apply. The protections HIPAA actually confers are surprisingly limited against the scope of its apparent hold on the American imagination. While health experts have long understood this, the sheer extent of this disconnect by the general public was hard to appreciate until simply existing in a pandemic world seemed to require the use and disclosure of health data in even the most mundane facets of life. With COVID-19 shining a spotlight on the problem, increased attention to common HIPAA myths also presents opportunities.

#### IV. CONCERNS AND OPPORTUNITIES

While it is easy to mock,<sup>74</sup> confusion about the limits of HIPAA is arguably justified. It is not intuitive that the same or similar information that an individual provides to a physician in a clinical encounter for inclusion in an electronic health record will often not receive the same protections when that person gives it to other people, or it appears in other places. There is also little incentive for the average person to learn what HIPAA does (and does not) do.<sup>75</sup> HIPAA authorizations are just one of many long and difficult-to-understand documents we encounter in our lives that we begrudgingly sign but likely never bother to read to comprehension.<sup>76</sup> People hear and see HIPAA mentioned enough to know it exists and what it generally applies to, but not in such a way that they understand what it means with any specificity.

But while the confusion surrounding HIPAA is understandable, it is still problematic. Its problematic nature is particularly evident in the context of the COVID-19 pandemic, where it created hurdles to effective disease control and distracted from other key public health messaging.<sup>77</sup> But the confusion about HIPAA and health data privacy at the core of many of these objections could also create significant challenges in other, less obvious ways that will endure long after the pandemic ends. Left unaddressed, those same mistakes and misunderstandings will loom in the background as we enter into a critical point

<sup>74</sup> HIPAA misunderstandings produce a range of jokes from memes to satirical tweets. See, e.g., Marina Pitofsky, *Dallas Cowboys' Dak Prescott Inspires HIPAA Memes on Social Media After COVID Vaccine Reply*, USA TODAY (July 24, 2021, 1:54 PM), <https://www.usatoday.com/story/sports/2021/07/23/dak-prescott-inspires-hipaa-memes-twitter-over-covid-vaccine-reply/8078286002/> [https://perma.cc/MW8U-RKJF]. HIPAA misunderstandings have also inspired a dedicated Twitter account. See the twitter account “Bad HIPPA Takes” @BadHippa, TWITTER (last visited May 3, 2022), <https://twitter.com/BadHippa> [https://perma.cc/FR9D-PXBG].

<sup>75</sup> See *id.*

<sup>76</sup> Nina Collins, Nancy L. Novotny & Amy Light, *A Cross-Section of Readability of Health Information Portability and Accountability Act Authorizations Required with Health Care Research*, NAT'L LIBR. OF MED. (Winter 2006), <https://pubmed.ncbi.nlm.nih.gov/17243437/> [https://perma.cc/RP22-XHWN]; Yannis Bakos, Florencia Marotta-Wurgler & David R. Trossen, *Does Anyone Read the Fine Print? Consumer Attention to Standard Form Contracts*, 195 N.Y.U. L. & ECON. WORKING PAPERS 1, 1 (2014).

<sup>77</sup> Jennifer Rainey Marquez, *A Failure to Communicate*, GA. STATE UNIV. RSCH. MAG. (Sept. 3, 2020), <https://news.gsu.edu/research-magazine/a-failure-to-communicate-covid-19-pandemic-public-health-messaging> [https://perma.cc/3GJV-AZ5H]; See also Meeta Shah, *The Failure of Public Health Messaging About COVID-19*, SCI. AM. (Sept. 3, 2020), <https://www.scientificamerican.com/article/the-failure-of-public-health-messaging-about-covid-19/> [https://perma.cc/QY5J-2DVG].

for consumer data privacy in the United States.<sup>78</sup> The confusion surrounding health data protections raises at least three concerns and opportunities.

First, the experience of COVID-19 suggests that many people mistakenly believe that HIPAA's health data protections already apply to any information with a colorable connection to health. If that is the case, they may be more likely to entrust their sensitive information with entities that are neither private nor secure.

As described in Part II, many people were quick to object to public health interventions because they implicated health information, which they believed to be a special category of information.<sup>79</sup> Those people also mistakenly concluded that HIPAA would apply. But, as noted in Part III, HIPAA applies only to a select few entities and only certain kinds of information.<sup>80</sup> This misunderstanding raises concerns about other circumstances in which people have either provided or withheld information based on false assumptions—of which there may be many. And the list of entities not subject to HIPAA that hold sensitive health information is only growing as consumer health technologies gain popularity.<sup>81</sup>

Consider the example of health-related smartphone applications (apps) and wearables. These consumer technologies can collect far more and sometimes more accurate health-related information than an annual checkup at the doctor's office.<sup>82</sup> And the market for these products is enormous, valued at over \$40 billion in 2020 and only projected to grow.<sup>83</sup> But, problematically, most health apps and wearables are not subject to HIPAA or most of its state analogs because these digital products usually are not affiliated with covered entities or their business associates.<sup>84</sup> As a result, consumers' data harvested from health apps and wearables often do not have HIPAA protections.<sup>85</sup>

More complicated still, rulemaking efforts to improve the interoperability

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<sup>78</sup> Jennifer Bryant, 2021 'Best Chance' for US Privacy Legislation, IAPP (Dec. 7, 2021), <https://iapp.org/news/a/2021-best-chance-for-federal-privacy-legislation/> [<https://perma.cc/CJ79-XUF9>]; Woodrow Hartzog & Neil Richards, *Privacy's Constitutional Moment and the Limits of Data Protection*, 61 B.C. L. REV. 1687, 1695 (2020).

<sup>79</sup> Report to Congress, *supra* note 18.

<sup>80</sup> See HIPAA § 262(a), 42 U.S.C.S. § 1320d-6 (Westlaw through Pub. L. No. 117-120); 45 C.F.R. § 160, *supra* note 60; See 45 C.F.R. § 160.103, §§ 160.102(a)–(b), *supra* note 61.

<sup>81</sup> See Stacey Tovino, *Assumed Compliance*, 72 ALA. L. REV. 279, 280–81 (2020).

<sup>82</sup> See Nathan G. Cortez, I. Glenn Cohen & Aaron S. Kesselheim, *FDA Regulation of Mobile Health Technologies*, NEW ENGL. J. MED. 371, 372–79 (July 24, 2014).

<sup>83</sup> *mHealth Apps Market Size, Share & Trends Analysis Report By Type (Fitness, Medical), By Region (North America, Europe, Asia Pacific, Latin America, Middle East & Africa), And Segment Forecasts, 2022-2030*, GRAND VIEW RSCH. (Jan. 2020), <https://www.grandviewresearch.com/industry-analysis/mhealth-app-market> [<https://perma.cc/85ZE-LP5G>].

<sup>84</sup> Tovino, *supra* note 56, at 158–59 (providing examples of individuals and institutions not regulated by the HIPAA Rules).

<sup>85</sup> The question of which federal laws apply to which health apps is one that arises frequently. In response, the Federal Trade Commission (FTC) maintains an online tool to help determine if an app is subject to HIPAA, the FD&C Act, FTC, or others. *Mobile Health Apps Interactive Tool*, FTC (last visited May 3, 2022), <https://www.ftc.gov/tips-advice/business-center/guidance/mobile-health-apps-interactive-tool> [<https://perma.cc/W97W-Z8G7>].

of electronic medical records<sup>86</sup> may make it easier for individuals to move their comprehensive health records from a covered entity to one that is not.<sup>87</sup> While these developments are exciting from an innovation and health data ownership perspective, they are concerning for unsuspecting consumers who may find that information once protected by HIPAA is now subject to secondary use without their knowledge or express consent.<sup>88</sup> And if COVID-19's HIPAA confusion tells us anything, the number of people this misunderstanding may impact in the future is likely significant.

Second, if people already believe that HIPAA applies to any health-related data, they are also likely unaware of the significant gaps in data protection at the state and national levels. And, if the general public is unaware that those gaps exist in the first place, they are less likely to advocate for or support needed changes to consumer data protections.<sup>89</sup>

The public response to health data privacy during the COVID-19 pandemic raises the possibility that the lack of public demand for increased health data protections is because the public mistakenly believes those protections already exist. However, even if this scenario is not true and every single COVID-19 HIPAA misstatement was bad-faith political posturing, working to raise public awareness about the limits of existing health data privacy is still worthwhile.

The United States sorely needs better consumer data protections for both health information, like the type we enter into health apps and wearables, and other types of consumer data.<sup>90</sup> While current data protection laws are, as a general matter, lacking, the good news is that there is a renewed push to improve privacy.<sup>91</sup> Privacy advocates and stakeholders are vocally advocating

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<sup>86</sup> 21<sup>st</sup> Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642, 25647 (May 1, 2020) (codified at 45 C.F.R. pts. 170, 171); Interoperability and Patient Access, 85 Fed. Reg. 25510, 25511 (May 1, 2020) (codified at 42 C.F.R. pts. 406, 407, 422, 423, 431, 438, 457, 482, 485 & 45 C.F.R. pt. 156).

<sup>87</sup> *HHS Releases Final Interoperability and Information Blocking Rules*, HIPAA J. (Mar. 9, 2020), <https://www.hipaajournal.com/hhs-interoperability-and-information-blocking-rules/> [<https://perma.cc/39R5-QUD5>].

<sup>88</sup> *Id.*

<sup>89</sup> *Americans and Privacy: Concerned, Confused and Feeling Lack of Control Over Their Personal Information*, PEW RSCH. CTR. (Nov. 15, 2019), <https://www.pewresearch.org/internet/2019/11/15/americans-and-privacy-concerned-confused-and-feeling-lack-of-control-over-their-personal-information/> [<https://perma.cc/AB47-WSBS>] (noting that “63% of Americans say they understand very little or nothing at all about the laws and regulations that are currently in place to protect their data privacy.”).

<sup>90</sup> Thorin Klosowski, *The State of Consumer Data Privacy Laws in the US (And Why It Matters)*, WIRECUTTER (Sept. 6, 2021), <https://www.nytimes.com/wirecutter/blog/state-of-privacy-laws-in-us/> [<https://perma.cc/ZG3C-6WZQ>].

<sup>91</sup> Cameron F. Kerry & Jules Polonetsky, *Could the Facebook Papers Close the Deal on Privacy Legislation?*, BROOKINGS (Dec. 1, 2021), [https://www.brookings.edu/blog/techtank/2021/12/01/could-the-facebook-papers-close-the-deal-on-privacy-legislation/?utm\\_campaign=Center%20for%20Technology%20Innovation&utm\\_medium=email&utm\\_content=195349241&utm\\_source=hs\\_email](https://www.brookings.edu/blog/techtank/2021/12/01/could-the-facebook-papers-close-the-deal-on-privacy-legislation/?utm_campaign=Center%20for%20Technology%20Innovation&utm_medium=email&utm_content=195349241&utm_source=hs_email) [<https://perma.cc/P9YN-WNWA>]. For descriptions of recent federal efforts to shore up data privacy, see Tovino, *supra* note 82, at 280–81.

for new legislation.<sup>92</sup> Some states are making considerable progress, with California, Virginia, and Colorado leading the charge.<sup>93</sup> But even the most comprehensive state laws can be limited in their reach.<sup>94</sup>

Federal agencies are likewise working toward more robust protections for consumer privacy. For example, in recognition of the myriad of locations health data may exist outside the scope of state and federal laws—especially smartphone apps—the Federal Trade Commission (FTC) issued a policy statement about its position on the Health Breach Notification Rule (HBNR).<sup>95</sup> The HBNR imposes reporting requirements and fines for breaches and applies to entities like apps and other technologies that contain a “personal health record.”<sup>96</sup> It defines a “personal health record” as an “electronic record that can be drawn from multiple sources.”<sup>97</sup> Interestingly, the FTC has stated that it will interpret “breach” to include not only “cybersecurity intrusions” but also “sharing of covered information without an individual’s authorization.”<sup>98</sup> Since then, the FTC has continued to release guidance further clarifying what compliance will look like, essential definitions, and what must happen in the event of a breach.<sup>99</sup>

But this move is controversial, even among FTC commissioners.<sup>100</sup> And this new approach to the HBNR has created more questions than answers.<sup>101</sup>

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<sup>92</sup> Christine S. Wilson, Comm’r, FTC Remarks at the Future of Privacy Forum: A Defining Moment for Privacy: The Time is Ripe for Federal Privacy Legislation (Feb. 6, 2020).

<sup>93</sup> California Consumer Privacy Act of 2018, CAL. CIV. CODE § 1798.100(a) (West 2020), amended by California Privacy Rights Act of 2020, Proposition 24 (codified at CAL. CIV. CODE § 1798.100–199) (effective Jan. 1, 2023); Consumer Data Protection Act, Va. Code Ann. § 59.1-578 (West); Colorado Privacy Act, COLO. REV. STAT. ANN. § 6-1-1301 (West).

<sup>94</sup> For example, the laws only protect people who live in those states. Others are limited in the size of businesses to which the law applies.

<sup>95</sup> *Statement of the Commission on Breaches by Health Apps and Other Connected Devices*, FTC (Sept. 15, 2021), <https://www.ftc.gov/legal-library/browse/statement-commission-breaches-health-apps-other-connected-devices> [https://perma.cc/3PG6-XRPD].

<sup>96</sup> *Id.*; 16 C.F.R. Part 318.

<sup>97</sup> *Statement of the Commission*, *supra* note 96. The Commission considers apps covered by the Rule if they are capable of drawing information from multiple sources, such as through a combination of consumer inputs and application programming interfaces (“APIs”). For example, an app is covered if it collects information directly from consumers and has the technical capacity to draw information through an API that enables syncing with a consumer’s fitness tracker. Similarly, an app that draws information from multiple sources is covered even if the health information comes from only one source. For example, if a blood sugar monitoring app draws health information from only one source (e.g., a consumer’s inputted blood sugar levels), but also takes non-health information from another source (e.g., dates from your phone’s calendar), then it is covered under the Rule.

<sup>98</sup> *Id.*

<sup>99</sup> *Complying with FTC’s Health Breach Notification Rule*, FTC (Jan. 2022), <https://www.ftc.gov/business-guidance/resources/complying-ftcs-health-breach-notification-rule-0> [https://perma.cc/VLK4-KYY5].

<sup>100</sup> Christine S. Wilson, Comm’r, FTC, Dissenting Statement Regarding the Policy Statement on Breaches by Health Apps and Other Connected Devices (Sept. 15, 2021).

<sup>101</sup> Christopher Brown, *Data Breach Rule for Health Apps Leaves Developers in the Dark*, BLOOMBERG LAW (Nov. 16, 2021, 4:36 AM), <https://news.bloomberglaw.com/health-law-and-business/data-breach-rule-for-health-apps-leaves-developers-in-the-dark> [https://perma.cc/8NAS-

As of this writing, the FTC has never enforced the HBNR in its over ten-year existence, and some legal experts have offered that the new interpretation may be subject to legal challenge in the future.<sup>102</sup>

While the HBNR and new federal privacy legislation are needed, they are not enough. It is also important to correct the HIPAA misperceptions laid bare by the COVID-19 pandemic. Legislators passing more and better consumer-focused privacy laws is one necessary approach, though it certainly is not one without staunch industry opposition.<sup>103</sup> Given the number of powerful opponents to creating meaningful consumer data privacy protections, policymakers will need the support of an educated public to advance consumer protection goals. But to mobilize the public, the public first needs to appreciate the problem.

Finally, the COVID-19 vaccine inquiry pushback and contact tracing opposition highlighted public opposition to even valuable data uses. Correcting common HIPAA misperceptions that form the basis of some of these objections can be part of a broader public education effort intentionally designed to influence how people understand data sharing. Should we choose to pursue them,<sup>104</sup> these initiatives could have the added benefit of helping develop a culture that values privacy *and* promotes beneficial uses of health data.

Viewed optimistically, HIPAA-based objections to public health interventions could create significant momentum for addressing the larger problem of how people understand and value health data privacy. The media has done a laudable job correcting these mistakes when they make national headlines.<sup>105</sup> However, while important, these approaches are still reactionary

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<sup>102</sup> *Id.*

<sup>103</sup> Jeffrey Dastin, Chris Kirkham & Aditya Kalra, *Amazon Wages Secret War on Americans' Privacy, Documents Show*, REUTERS (Nov. 19, 2021, 11:00 AM), <https://www.reuters.com/investigates/special-report/amazon-privacy-lobbying/> [https://perma.cc/NXV3-F26J].

<sup>104</sup> COVID-19 highlighted several important divisions and problems in the United States. This paper takes no position as to whether privacy should be prioritized over other competing concerns.

<sup>105</sup> See, e.g., Allyson Chiu, *Explaining HIPAA: No, It Doesn't Ban Questions About Your Vaccination Status*, WASH. POST (May 22, 2021, 8:00 AM), [https://www.washingtonpost.com/lifestyle/wellness/hipaa-vaccine-covid-privacy-violation/2021/05/22/f5f145ec-b9ad-11eb-a6b1-81296da0339b\\_story.html](https://www.washingtonpost.com/lifestyle/wellness/hipaa-vaccine-covid-privacy-violation/2021/05/22/f5f145ec-b9ad-11eb-a6b1-81296da0339b_story.html) [https://perma.cc/9PPF-UW4R]; Katrina Neeper, *VERIFY: Does Contact Tracing Violate HIPAA Laws?*, WUSA9 (Dec. 30, 2020, 4:15 PM), <https://www.wusa9.com/article/news/verify/verify-does-contact-tracing-violate-hipaa-laws/65-e635b547-0b87-4f02-aa73-997096c0aab5> [https://perma.cc/WP48-9HSX]; *Knoxville Attorney Says Suing Over Mask Mandates, Citing HIPAA is a "Waste of Time and Money"*, WLVT (May 21, 2021, 3:49 PM), <https://www.wvlt.tv/2021/05/21/knoxville-attorney-says-suing-over-mask-mandates-when-citing-hipaa-is-a-waste-of-time-and-money/> (last visited May 3, 2022); Robert H. Shmerling, *Does HIPAA Prohibit Questions About Vaccination?*, HARV. HEALTH PUBL'G (Aug. 19, 2021), <https://www.health.harvard.edu/blog/does-hipaa-prohibit-questions-about-vaccination-202108192575> [https://perma.cc/5Y79-5XS5]; Kayla Brooks, *Vaccine Mandates and HIPAA, Experts Weigh In*, WHSV (Sept. 8, 2021, 4:51 PM), <https://www.whsv.com/2021/09/08/vaccine-mandates-hipaa-experts-weigh/> (last visited May 3, 2022); Camille Caldera, *Fact Check: No Mask? You Can Ask Why – It Isn't Against HIPAA or the Fourth or Fifth Amendments*, USA

and limited in what they can achieve.

In the future, privacy education could be proactive instead of reactive. For example, consider how efforts to raise awareness about the health risks of tobacco use helped support policy decisions that transformed society from one in which smoking was commonplace to one in which smoking is more taboo, and the public essentially appreciates its risks.<sup>106</sup> This shift in public perception was possible even though tobacco use was once socially acceptable and even desirable.<sup>107</sup> In the future, a proactive approach could help raise awareness about the scope and limits of existing health data privacy protections, the risks of harm,<sup>108</sup> and how consumers can best protect their sensitive information in an increasingly technology-dependent world.

But more than that, working to improve public understanding of the data privacy landscape in the United States can also influence how society thinks about data sharing. If done well, these efforts could be rewarded with meaningful social changes to how we present important information in HIPAA authorizations and other types of “fine print.” It could present an opportunity to shift away from the “notice and choice”<sup>109</sup> framework that fails consumers and the flaws in current conceptions of consent to terms of service and privacy policies.<sup>110</sup>

Moreover, the type of privacy education envisioned in this paper is not about simply pushing the idea that nobody should ever access or use an individual’s data under any circumstance. The pandemic provides clear examples of how we can leverage health data to serve important goals.<sup>111</sup> Not all instances of the generation and use of health data are bad, and it need not always be so intensely guarded that it is unusable for other important endeavors.<sup>112</sup> But creating a society with a more nuanced view of privacy, like

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TODAY (July 19, 2020), <https://www.usatoday.com/story/news/factcheck/2020/07/19/fact-check-asking-face-masks-wont-violate-hipaa-4th-amendment/5430339002/> [<https://perma.cc/F4NL-8WK8>]; Joe Parris, *What and Who Does HIPAA Cover?*, KTVB (May 21, 2021, 5:41 PM), <https://www.ktvb.com/article/news/local/208/what-and-who-does-hipaa-cover/277-2e705c9e-1cf0-4f0b-b49b-32b75b8a0317> [<https://perma.cc/V7KT-SRT7>]; Aishvarya Kavi, *How the HIPAA Law Works and Why People Get It Wrong*, NY TIMES (July 24, 2021), <https://www.nytimes.com/article/hipaa-law.html> [<https://perma.cc/3RE5-NFVQ>].

<sup>106</sup> Andrea C. Villanti, M. Justin Byron, Melissa Mercincavage & Lauren R. Pacek, *Misperceptions of Nicotine and Nicotine Reduction: The Importance of Public Education to Maximize the Benefits of a Nicotine Reduction Standard*, 21 NICOTINE & TOBACCO RSCH. S88, S88–S90 (2019); See also Thomas R. Frieden, Farzad Mostashari, Bonnie D. Kerker, Nancy Miller, Anjum Hajat & Martin Frankel, *Adult Tobacco Use Levels After Intensive Tobacco Control Measures: New York City, 2002–2003*, 99 AM. J. PUB. HEALTH 1016, 1016–23 (2005).

<sup>107</sup> See BARBARA S. LYNCH & RICHARD J. BONNIE, *GROWING UP TOBACCO FREE: PREVENTING NICOTINE ADDICTION IN CHILDREN AND YOUTHS* (NAT’L ACAD. PRESS 1994).

<sup>108</sup> Danielle Keats Citron & Daniel J. Solove, *Privacy Harms*, 102 B.U. L. REV. (forthcoming 2022).

<sup>109</sup> Fred H. Cate, *The Limits of Notice and Choice*, 8 IEEE SEC. & PRIV. 59, 59–60 (2010).

<sup>110</sup> Charlotte A. Tschider, *The Consent Myth: Improving Choice for Patients of the Future*, 96 WASH. U. L. REV. 1505 (2019).

<sup>111</sup> Fowler, *supra* note 10.

<sup>112</sup> Charlotte A. Tschider, *AI’s Legitimate Interest: Towards a Public Benefit Privacy Model*, 21 HOUS. J. HEALTH L. & POL’Y 1 (2021).



the one envisioned in this Part, will take dedicated efforts. The time to start is now.

## V. CONCLUSION

We are at a tipping point for privacy in the United States,<sup>113</sup> and the HIPAA misperceptions illuminated by the COVID-19 pandemic have shone a light on just how high the stakes have become. However, highlighting common health data privacy misunderstandings on a national level also presents an opportunity. While greater privacy protections are needed, simply adding more laws may not be enough. If advocates for more comprehensive protections—especially protections for sensitive health-related data—want to be successful at garnering public support and helping shift culture and behaviors, those effecting change must couple policy efforts with public outreach.

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<sup>113</sup> See Bryant, *supra* note 79; See also Hartzog, *supra* note 79.