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## An Epidemic in Enforceability: A Growing Need for Individual Autonomy in Health Care Data-Privacy Protection in an Era of Digital Tracking

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# **An Epidemic in Enforceability: A Growing Need for Individual Autonomy in Health Care Data-Privacy Protection in an Era of Digital Tracking**

## **ABSTRACT**

*The health care system in the United States is under conflicting pressures. From one angle, there is a demand for the highest standard of care, which includes efficient, confidential communications between doctors and patients. From another, however, the technology that has facilitated such efficiency has outpaced the security mechanisms currently in place to protect a long-recognized right to privacy. In an era of data tracking, the important privacy interest that Congress has recognized since 1996 confronts a growing threat of data commodification. Despite significant potential consequences, however, there is neither guaranteed statutory recovery nor cohesion among states for the process of any potential recovery under common law.*

*This Note proposes that a private, statutory cause of action for a violation of one's medical privacy is the best solution to the growing problem arising out of the intersection of digital medical information and data tracking technology. Considering the realities of a medical system under demands that make an efficient return to manual data entry impossible, and digital platforms that have created an endemic of invasive oversharing, the legal system must adopt a solution in the best interest of the public. As this Note urges, there must be a federal right of action to enforce medical privacy in a sociopolitical environment where other solutions do not suffice. This solution finds support in the legislative intent and history of the existing schema, the novel risks created by recent US Supreme Court decisions combined with the inadequacy of common law approaches, and the values held in both the foundational documents of medical privacy and general ideologies of the United States.*

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## I. INTRODUCTION

The Latin maxim *ubi jus, ibi remedium* is well established in American law, meaning where there is a right or wrong, there is a remedy, except in the case of the rights of an individual against a state or of one nation against another.<sup>1</sup> Where the law recognizes a right, by common law or statute, it requires a remedy to enforce it or to redress its violation.<sup>2</sup> While US citizens possess a myriad of well-defined rights, the right to medical privacy has been legally cognizable under the Due Process Clause of the Fifth Amendment, yet its “boundaries . . . have not been exhaustively delineated.”<sup>3</sup> As more health care data is stored and managed electronically, the concern over data security and the lack of confidentiality of individuals’ health information has grown.<sup>4</sup>

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1. See Donald H. Zeigler, *Rights, Rights of Action, and Remedies: An Integrated Approach*, 76 WASH. L. REV. 67, 71 (2001); see also Tracy A. Thomas, *Congress’ Section 5 Power and Remedial Rights*, 34 U.C. DAVIS L. REV. 673, 689–90 (2001) (explaining that the notion of a remedy as a necessary part of any legal substantive right is not a new idea).

2. See, e.g., *State ex rel. Taylor v. Clymer*, 503 S.W.2d 53, 56 (Mo. Ct. App. 1973); *Corleto v. Shore Memorial Hospital*, 350 A.2d 534, 539 (N.J. Super. Ct. 1975); *Rogers v. Wakeman*, 669 N.E.2d 32, 34 (Ohio Ct. App. 1995).

3. *Citizens for Health v. Leavitt*, 428 F.3d 167, 177 (3d Cir. 2005).

4. See Patricia I. Carter, *Health Information Privacy: Can Congress Protect Confidential Medical Information in the “Information Age”?*, 25 WILLIAM MITCHELL L. REV. 223, 230 (1999); Peter A. Winn, *Confidentiality in Cyberspace: The HIPAA Privacy Rules and the Common Law*, 33 RUTGERS L.J. 617, 617–18 (2002).

Currently, in the aftermath of the June 2022 *Dobbs* decision by the Supreme Court, concerns related to medical privacy are amplified.<sup>5</sup> These concerns are especially salient for women, who now face the threat of criminal prosecution for abortions in states that have accepted the Court's decision as a green light for "trigger bans" on abortion.<sup>6</sup> Now, individuals have filed lawsuits that allege Meta, Facebook's parent company, is knowingly not enforcing the Health Insurance Portability and Accountability Act (HIPAA) and that Meta has put the Meta Pixel<sup>7</sup> tracking software on health care organizations' websites despite knowing it would collect personal health information.<sup>8</sup> As a business associate, Meta is bound by the privacy obligations of HIPAA's privacy rule.<sup>9</sup> Under the premise that an individual may reasonably expect his or her right to medical privacy to be enforced, with lackadaisical federal protection, that expectation is insufficiently met.<sup>10</sup> Despite this, however, an individual is still unable to bring a legal claim for a violation of their data privacy under HIPAA.

This Note proposes an individual cause of action as a solution to the current failures of medical privacy enforcement. First, in understanding the development of medical privacy concerns in electronically stored information, this Note tracks the development of legislative responses to such concerns and the supporting ideology.

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5. See *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2230 (2022).

6. *Id.* (holding that the federal constitution does not provide a right to abortion, and authority to regulate abortion must be returned to the people and their elected representatives); see also ARK. CODE ANN. §§ 5-61-301–304; IDAHO CODE ANN. §18-622; KY. REV. STAT. ANN. §311.710; LA. STAT. ANN. § 87.7; MISS. CODE ANN. § 41-41-45; MO. REV. STAT. §188.017; N.D. CENT. CODE §12.1031; OKLA. STAT. tit. 63 §1-731.1; S.D. CODIFIED LAWS § 22-17-5.1; TENN. CODE ANN. § 39-15-2; TEX. HEALTH & SAFETY CODE ANN. § 170A.002; UTAH CODE ANN. §§ 76-7a-101, 76-7a-201, 76-7a-301.

7. See *infra* note 64 and accompanying text.

8. See Complaint, *John Doe v. Meta Platforms, Inc.*, No. 3:22-cv-03580 (N.D. Cal. June 17, 2022); Complaint, *Jane Doe v. Meta Platforms, Inc.*, Case 3:22-cv-04293-AGT (N.D. Cal. July 25, 2022).

9. A "business associate" is a person or entity that performs certain functions or activities that involve the use or disclosure of protected health information on behalf of, or provides services to, a covered entity. A member of the covered entity's workforce is not a business associate. Business associate functions and activities include: claims processing or administration; data analysis, processing or administration; utilization review; quality assurance; billing; benefit management; practice management; and repricing. Business associate services are legal; actuarial; accounting; consulting; data aggregation; management; administrative; accreditation; and financial. See the definition of "business associate" at 45 C.F.R. § 160.103 (2022). See also 45 C.F.R. §§ 164.502(e), 164.504(e), 164.532(d)-(e) (2022).

10. See, e.g., *Breach Portal: Notice to the Secretary of HHS Breach of Unsecured Protected Health Information*, U.S. DEPT. HEALTH & HUM. SERVS., [https://ocrportal.hhs.gov/ocr/breach/breach\\_report.jsf](https://ocrportal.hhs.gov/ocr/breach/breach_report.jsf) [<https://perma.cc/4KTF-8SB3>] (with 883 breaches currently logged at the time of this Note's writing in April 2023) (last visited Apr. 5, 2023).

Next, this Note provides an analysis of why state common law causes of action and the current statutory framework are inadequate to assuage the shortcomings of the current schema against the backdrop of amplified concerns following recent court decisions. Finally, as a means to realign US citizens' hopes for privacy with an efficient system of protection, this Note presents a restructuring of medical privacy protections mirroring existing, efficient regulatory entities.

## II. THE DEVELOPMENT OF MEDICAL PRIVACY

### A. *The Right to Medical Privacy*

Courts have found a federal constitutional right to privacy in medical information, but this right has never been absolute.<sup>11</sup> Prior to 1996, there was no national health privacy law, no limit on how health care information was shared or collected by employers or insurers, and no federal right protecting access to an individual's medical information.<sup>12</sup> Congress recognized informational privacy, however, as part of the Fourth Amendment to the US Constitution, which guarantees that "the right of the people to be secure in their persons, houses, papers and effects, against unreasonable searches and seizures, shall not be violated."<sup>13</sup> Congress noted that, by referring to the need for security of "persons" as well as "papers and effects," the Fourth Amendment suggests enduring values in US law that relate to privacy; "the need for security in 'papers and effects' underscores the importance of protecting information about the person, contained in sources such as personal diaries, medical records, or elsewhere."<sup>14</sup> Additionally, "Americans' concern about the privacy of their health information is part of a broader anxiety about their lack of privacy in an array of areas."<sup>15</sup> This concern noted by Congress in 2000 has not diminished. Currently, approximately 81 percent of the public say that the potential risks they face because of data collection by companies outweigh the benefits, and 66 percent say the same about government data collection.<sup>16</sup> At the same time, a majority of US residents report being

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11. See, e.g., *Whalen v. Roe*, 429 U.S. 589, 602 (1977); *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980).

12. CTR. FOR DEMOCRACY & TECH., *HIPAA AND HEALTH PRIVACY: MYTHS AND FACTS 2* (2009); 45 C.F.R. § 160.101 (2000).

13. U.S. CONST. amend. IV

14. §160.101

15. *Id.*

16. *See Americans and Privacy: Concerned, Confused, and Feeling Lack of Control Over Their Personal Information*, PEW RSCH. CTR. (Nov. 19, 2019)

concerned about the way their data is being used by companies (79 percent) or the government (64 percent).<sup>17</sup>

Under the assumption that privacy is a fundamental right given the congressional justifications for HIPAA's original enactment, Congress's protections must be viewed differently than any "ordinary economic good."<sup>18</sup> It is a right that speaks to individual and collective freedom, but also promotes other fundamental values, like personhood.<sup>19</sup> Even beyond the promotion of intangible values, privacy of medical information promotes broader public welfare; where adequate safeguards for one's intimate medical information are in place—ensuring protection against unwanted disclosure—the social benefits are easily identified. Individuals are more likely to truthfully share medical histories, answer research questions, and even contribute their de-identified medical data to health research projects in pursuit of an expansive understanding and enhancement of the human condition.<sup>20</sup> With such far-reaching impact, the right to privacy has frequently been subjected to judicial reevaluation, redefinition, and public concern.<sup>21</sup>

In conjunction with that concern and recent Supreme Court decisions, the health care system has become a new source of the US citizens' anxiety that was once recognized and prophylactically remedied by Congress.<sup>22</sup> As of 2018, 90 percent of health care organizations in the United States offered patient portal access, with the remaining 10 percent reporting plans to adopt them, but federal efforts to regulate the data protection and standardization of these tools are founded on antiquated concerns as related to the ever-changing tech

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[https://www.pewresearch.org/internet/2019/11/15/americans-and-privacy-concerned-confused-and-feeling-lack-of-control-over-their-personal-information/pi\\_2019-11-14\\_privacy\\_0-02-2/](https://www.pewresearch.org/internet/2019/11/15/americans-and-privacy-concerned-confused-and-feeling-lack-of-control-over-their-personal-information/pi_2019-11-14_privacy_0-02-2/) [https://perma.cc/2U3E-FUBS].

17. *Id.*

18. Standards for Privacy of Individually Identifiable Health Information, 60 Fed. Reg. 82462, 82464 (Dec. 28, 2000) (codified at 45 C.F.R. pts. 160, 164).

19. See Edward J. Bloustein, *Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser*, 39 N.Y.U. L. REV. 962 (1964); Ruth Gavinson, *Privacy and the Limits of Law*, 89 YALE L.J. 421, 444 (1980); Robert C. Post, *Three Concepts of Privacy*, 89 GEO. L.J. 2087 (2001); Daniel J. Solove, *A Taxonomy of Privacy*, 154 U. PA. L. REV. 477, 527 (2006).

20. See James G. Hodge, Jr., Lawrence O. Gostin & Peter D. Jacobson, *Legal Issues Concerning Electronic Health Information: Privacy, Quality, and Liability*, 282 J. AM. MED. ASS'N 1466, 1469 (1999).

21. See, e.g., *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228 (2022) (overruling *Roe v. Wade*, which held that the abortion right is part of a right to privacy that springs from the First, Fourth, Fifth, Ninth, and Fourteenth Amendments. 410 U.S. 113, 152–153 (1973)).

22. See Megan Leonhardt, *66% of Americans Fear They Won't Be Able to Afford Healthcare This Year*, CNBC (Jan. 5, 2021, 12:43 PM), <https://www.cnbc.com/2021/01/05/americans-fear-they-wont-be-able-to-pay-for-health-care-this-year.html> [https://perma.cc/K4P9-7P2U].

arena.<sup>23</sup> These patient portals, however, employ coding technology that intercepts patient medical information for commodification.<sup>24</sup> Patients' medical information is in the hands of individuals who essentially hold such information as leverage against the patients to share for any reason they deem satisfactory,<sup>25</sup> but also in the hands of employees of the tech conglomerates who may pass on secure information based on moral opposition to a patient's choice of medical care.<sup>26</sup> Personal data of this nature, however, can be used in equally harmful ways, like building anti-abortion ad campaigns and dissemination of misinformation about reproductive health;<sup>27</sup> the data being used as evidence against abortion seekers in states where such procedures are outlawed is the worst case scenario.

Even disregarding the worst case—the potential for criminal punishment for one's reproductive decision-making—breaches of privacy and confidentiality can affect a person's dignity and can

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23. Sara Heath, *Patient Portal Adoption Tops 90%, But Strong Patient Use Is Needed*, PATIENT ENGAGEMENT HIT (July 31, 2018), <https://patientengagementhit.com/news/patient-portal-adoption-tops-90-but-strong-patient-use-is-needed> [<https://perma.cc/PP47-T7R9>].

24. Grace Oldham & Dhruv Mehrotra, *Facebook and Anti-Abortion Clinics Are Collecting Highly Sensitive Info on Would-Be Patients*, MARKUP (June 15, 2022, 6:00 AM), <https://themarkup.org/pixel-hunt/2022/06/15/facebook-and-anti-abortion-clinics-are-collecting-highly-sensitive-info-on-would-be-patients> [<https://perma.cc/9WS4-CWZM>]; see also Rule Modifying HIPAA Rules Under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. 5,566, 5,572 (January 25, 2013) (codified at 45 C.F.R. pts. 160, 164) (providing that such a cloud services to a covered entity or business associate that involve creating, receiving, or maintaining (e.g., to process or store) electronic protected health information (ePHI) meet the definition of a business associate, even if the source cannot view the ePHI because it is encrypted, which refutes the assertion that Meta may not be subject to HIPAA compliance as a conduit of personal health information).

25. *Unauthorized Disclosure of PHI Lead to HIPAA Civil Monetary Penalty and Settlement Agreement*, THOMSON REUTERS: TAX & ACCT. (Apr. 14, 2022), <https://tax.thomsonreuters.com/blog/unauthorized-disclosures-of-phi-lead-to-hipaa-civil-monetary-penalty-and-settlement-agreement/> [<https://perma.cc/Z6PX-43TV>] (where OCR found that a dental practice impermissibly disclosed a patient's PHI on a webpage in response to a negative online review).

26. See Dave Muoio & Annie Burky, *Advocate Aurora, WakeMed Get Served with Class Action over Meta's Alleged Patient Data Mining*, FIERCE HEALTHCARE (Nov. 4, 2022, 2:00 PM), <https://www.fiercehealthcare.com/health-tech/report-third-top-hospitals-websites-collecting-patient-data-facebook> [<https://perma.cc/87UD-EHAP>].

27. See, e.g., *Six-Figure Ad Campaign Targets Anti-Choice Officials Putting Lives at Risk During a National Public Health Emergency*, NARAL: PRO-CHOICE AM. FOUND., <https://www.pro-choiceamerica.org/foundation/naral-pro-choice-america-foundation-launches-new-ad-campaign/> [<https://perma.cc/6DHH-5VUR>] (last visited Apr. 5, 2023); see also Zachary Mettler, *After Roe Overturned, Focus on the Family Launches Multimillion Dollar Pro-Life Ad Campaign*, DAILY CITIZEN (June 24, 2022), <https://dailycitizen.focusonthefamily.com/after-roe-overturned-focus-on-the-family-launches-multimillion-dollar-pro-life-ad-campaign/> [<https://perma.cc/3AHA-YW96>].

minimize the social benefit of the health care systems that initially justified legislation like HIPAA.<sup>28</sup> As Congress explained,

No matter how or why a disclosure of personal information is made, the harm to the individual is the same. In the face of industry evolution, the potential benefits of our changing health care system, and the real risks and occurrences of harm, protection of privacy must be built into the routine operations of our healthcare system.<sup>29</sup>

There is no indication that Congress has changed this view on the importance of an individual's right to privacy, but HIPAA's inefficient protection procedure is currently misaligned with its normative regard for privacy. In fact, privacy in the digital tracking era is at the forefront of legislative developments.<sup>30</sup> In 2021, consumer data privacy legislation was introduced in thirty-eight states, indicating that state legislatures simultaneously recognize the gaps in the federal framework and are trying to supplement privacy rights.<sup>31</sup> Interestingly, however, the proposed legislation focused on consumer data privacy would provide more remedial action for individuals than HIPAA.<sup>32</sup> Protecting privacy in the consumer arena, then, is incongruous with protecting privacy in the health care arena. From a policy perspective, however, it is difficult to reconcile why health care data would not be equally, if not more, protected than consumer data.

### *B. The History and Development of HIPAA*

HIPAA was passed on August 21, 1996 with the dual goals of making health care delivery more efficient and increasing the number of Americans with health insurance coverage.<sup>33</sup> In an effort to achieve these goals, the US Department of Health and Human Services (HHS) issued the Privacy Rule to implement the administrative simplification

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28. BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH 75–105 (Sharyl J. Nass, Laura A. Levit & Lawrence O. Gostin eds., 2009).

29. Standards for Privacy of Individually Identifiable Health Information, 60 Fed. Reg. 82462, 82467 (Dec. 28, 2000) (codified at 45 C.F.R. pts. 160, 164).

30. See, e.g., American Data Privacy and Protection Act, H.R. 8152, 117th Cong. (2022) (a bill currently proposed to provide consumers with foundational data privacy rights, create strong oversight mechanisms, and establish meaningful enforcement as it relates to secure information transmitted online).

31. See Pam Greenberg, *2021 Consumer Data Privacy Legislation*, NAT'L. CONF. STATE LEGISLATURES, (Dec. 27, 2021), <https://www.ncsl.org/technology-and-communication/2021-consumer-data-privacy-legislation> [<https://perma.cc/K5GR-UX35>] (Dec. 27, 2021).

32. See H.R. 8152 § 403(a)(1) ("Beginning on the date that is 2 years after the date on which this Act takes effect, any person or class of persons for a violation of this Act or a regulation promulgated under this Act by a covered entity or service provider may bring a civil action against such entity in any Federal court of competent jurisdiction.").

33. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936.



requirement of HIPAA in 2002.<sup>34</sup> The Privacy Rule standards address the use and disclosure of individuals' health information—called “protected health information”—by organizations subject to the Privacy Rule—called “covered entities”—as well as standards for individuals' privacy rights to understand and control how their health information is used.<sup>35</sup> HHS initially proposed a version of the HIPAA Privacy Rule for public comment in 1999, but due to the large number of comments received, the Rule went through several revisions before issuance in 2002.<sup>36</sup>

After considerations from the public following a notice and comment period, HHS set forth the Privacy Rule, which defined and limited the circumstances in which an individual's protected health information may be used or disclosed by covered entities.<sup>37</sup> A covered entity may not use or disclose protected health information, “except either: (1) as the Privacy Rule permits or requires; or (2) as the individual who is the subject of the information (or the individual's personal representative) authorizes in writing.”<sup>38</sup> The Privacy Rule seeks to ensure 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.<sup>39</sup>

Undoubtedly, patient record systems that exist entirely in written form pose significant efficiency and logistical obstacles to a health care system that already faces increasing demands to provide accurate, advanced patient care.<sup>40</sup> Responding to the shortcomings of the manual system, in April 2004, President George W. Bush called for interoperable electronic health records (EHRs) for all Americans within ten years and issued an executive order that established the Office of the National Coordinator for Health Information Technology (ONC)

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34. Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53181 (Aug. 14, 2002) (codified at 45 C.F.R. pts 160, 164).

35. 45 C.F.R. § 160.103 (2022).

36. See generally Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53181.

37. See *id.*

38. *Summary of the HIPAA Privacy Rule*, U.S. DEP'T HEALTH & HUM. SERVS., <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html> [<https://perma.cc/N7YW-Q7QB>] (Oct. 19, 2022).

39. *Id.*

40. See Johonniuss Chemweno, *The U.S. Healthcare System is Broken: A National Perspective*, MANAGED HEALTHCARE EXEC. (July 27, 2021), <https://www.managedhealthcareexecutive.com/view/the-u-s-healthcare-system-is-broken-a-national-perspective> [<https://perma.cc/E5BQ-CEGW>].

within HHS.<sup>41</sup> ONC's initial responsibilities included the development and implementation of a plan to develop interoperable health information technology (IT) and a Nationwide Health Information Network (NHIN) in both the public and private sectors.<sup>42</sup> It was envisioned that the NHIN would give health plans and providers throughout the nation instant access to medical information from multiple data systems.<sup>43</sup> The President's stated goal was to address longstanding problems of preventable errors, uneven quality, and rising costs in the nation's health care system.<sup>44</sup> This was partly effected by creating a patient-centered system that would give patients critical information necessary for clinical and economic decision-making in communication with health care professionals.<sup>45</sup> With health care workers that needed a more efficient system and patients who benefited from more streamlined services, the Health Information Technology for Economic and Clinical Health (HITECH) Act authorized more than twenty billion dollars in health IT funding and incentives and included new provisions aimed at strengthening and improving enforcement of the HIPAA privacy and security rules.<sup>46</sup>

HIPAA intended to establish a national framework for privacy standards and information practices, but as advances in technology have been made, electronically stored data is at an increased risk for breach in violation of patient confidentiality of health care records.<sup>47</sup> For several years after HIPAA's promulgation, privacy and health IT advocates charged that HHS failed to adequately monitor or hold covered entities and their employees responsible for compliance with the HIPAA privacy and security rules.<sup>48</sup> In the five years following implementation, HHS failed to levy a single penalty against a covered entity for a HIPAA violation, and now, violations render little recovery for those whose rights are violated.<sup>49</sup> In response to these charges, officials said HHS was fulfilling its regulatory role by taking a

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41. Exec. Order No. 13,335, 69 Fed. Reg. 24059 (Apr. 30, 2004).

42. *Id.*

43. *Id.*

44. *Id.*

45. *Id.*

46. See *What is the HITECH Act*, HIPAA J., <https://www.hipaajournal.com/what-is-the-hitech-act/> [<https://perma.cc/R6KK-MA5G>] (last visited Apr. 5, 2023).

47. See *id.*

48. Daniel J. Solove, *HIPAA Turns 10: Analyzing the Past, Present, and Future Impact*, 84 J. AM. HEALTH INFO. MGMT. ASS'N 22, 23 (2013).

49. DEVEN MCGRAW, O'NEILL INST. FOR NAT'L & GLOB. HEALTH L., LEGAL SOLUTIONS IN HEALTH REFORM 30 (2009).

compliance assistance approach, emphasizing education to and cooperating with covered entities to resolve HIPAA complaints.<sup>50</sup>

The HITECH Act signified a move away from the old complaint-based approach, in which HHS relied on patients and providers to report HIPAA violations, toward more proactive enforcement primarily based on compliance reviews and penalties, particularly for violations resulting from “willful neglect.”<sup>51</sup> Despite this, an individual still cannot bring a legal claim for a violation of HIPAA; a covered entity, like a hospital, must have procedures for individuals to complain about its compliance with its privacy policies and procedures and the Privacy Rules.<sup>52</sup> Accordingly, if an individual feels that his or her medical privacy rights have been violated, they do not have the autonomy to bring an action against the institution that violated such rights.

If an individual believes that a HIPAA-covered entity or its business associate violated their own—or someone else’s—health information privacy rights or committed another violation of the Privacy, Security, or Breach Notification Rules,<sup>53</sup> that individual may file a complaint with the Office for Civil Rights (OCR) within HHS.<sup>54</sup> OCR can investigate complaints against covered entities—health plans, health care clearinghouses, or health care providers that conduct certain transactions electronically—and their business associates.<sup>55</sup> However, if a violation is found, one is left with limited recourse. If an entity is determined to have violated HIPAA, the Secretary of the OCR’s developed methodology for compensation is determined by the Comptroller General, but “an individual who is harmed by a HIPAA violation may receive a percentage of any civil monetary penalty or settlement collected with respect to such offense.”<sup>56</sup> Accordingly, if

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50. See 45 C.F.R. §§ 160.300-316 (2013); Solove, *supra* note 48, at 23.

51. See American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5 § 13410, 123 Stat. 115, 271–72 (codified as amended at 42 U.S.C. § 1739).

52. See 45 C.F.R. §§ 164.530(d), § 164.520(b)(1)(vi) (2022).

53. The HIPAA Security Rule establishes national standards to protect individuals’ electronic personal health information that is created, received, used, or maintained by a covered entity. The Security Rule requires appropriate administrative, physical, and technical safeguards to ensure the confidentiality, integrity, and security of electronic protected health information. See 45 C.F.R. pts. 160, 164(a), (c). The Breach Notification Rule requires that a covered entity must notify the Secretary if it discovers a breach of unsecured protected health information. See 45 C.F.R. § 164.408 (2022).

54. *How to File a Health Information Privacy or Security Complaint*, U.S. DEPT. HEALTH & HUM. SERVS., <https://www.hhs.gov/hipaa/filing-a-complaint/complaint-process/index.html?language=es> [<https://perma.cc/9E9B-UGFY>] (Dec. 23, 2022).

55. *Id.*

56. See American Recovery and Reinvestment Act § 13410.

privacy rights are found to be violated, and the entity does not elect to either comply with HIPAA rules or take corrective action, the recovery for a plaintiff will be limited to an entirely discretionary portion of a settlement agreed to with OCR, which averages out at approximately two hundred dollars per victim.<sup>57</sup>

HIPAA does not provide a private cause of action, so it is not possible for a patient to sue directly for a HIPAA violation.<sup>58</sup> Even if HIPAA Rules have clearly been violated by a health care provider, and harm has been suffered as a direct result, it is not possible for patients to seek damages, at least not for the violation of HIPAA Rules directly.<sup>59</sup> Only five states (California, Colorado, Connecticut, Virginia, and Utah) have recognized that violations of relevant consumer rights, including the right of access, form a permissible statutory cause of action under these circumstances, and even then the state actions exempt issues covered by HIPAA.<sup>60</sup> If an individual elects to pursue the route of common law state action—arguing breach of contract or tort—most HIPAA violations do not qualify for civil court because the plaintiff lacks standing, typically justified by determinations that: (1) the breach was accidental or unavoidable; (2) no demonstrable harm was done; or (3) it is impossible to demonstrate culpability to court standards.<sup>61</sup>

Consequently, HIPAA and the HITECH Act are currently deficient for their intended purposes. Now, facing an era where health care institutions increasingly rely on technology for higher levels of efficiency,<sup>62</sup> threats to patient security and a need for recourse when said security is violated are higher than ever. Currently, data-tracking platforms like Meta Platforms Inc., installed on the majority of covered entities patient portal sites, obtain HIPAA-protected information without patient consent.<sup>63</sup> Meta Pixel is an analytical tool that allows a

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57. *Id.*; see also *HIPAA History*, HIPAA J., <https://www.hipaajournal.com/hipaa-history/#:~:text=Key%20Dates%20in%20HIPAA%20History,the%20HIPAA%20Breach%20Enforcement%20Rule> [https://perma.cc/E9G5-N82Z] (last visited Apr. 5, 2023).

58. See, e.g., *Meadows v. United Services, Inc.*, 963 F.3d 240, 244 (2d Cir. 2020); *Acara v. Banks*, 470 F.3d 569, 572 (5th Cir. 2006).

59. See *Bullard v. Texas Dept. of Aging & Disability Servs.*, 19 F. Supp. 3d 699, 706 (E.D. Tex. 2013).

60. See CAL. CIV. CODE §§ 1798.100.–199; COLO. REV. STAT. § 6-1-1300; 2023 CONN. PUB. ACTS 22–25; VA. CODE ANN. § 59.1-575; UTAH CODE ANN. §13-2-1; see also Anokhy Desai, *US State Privacy Legislation Tracker*, INT'L ASS'N PRIV. PROS., <https://iapp.org/resources/article/us-state-privacy-legislation-tracker> [https://perma.cc/HU7D-NWEF] (March 31, 2023).

61. See 45 C.F.R. §§ 160.408, 160.410 (2022).

62. See, e.g., Harold Thimbleby, *Technology and the Future of Healthcare*, 2 J. PUB. HEALTH RSCH. 160, 163 (2013).

63. See *Meta Facing Further Class Action Lawsuit Over Use of Meta Pixel Code on Hospital Websites*, HIPAA J. (Aug. 1, 2023), <https://www.hipaajournal.com/meta-class-action-lawsuit-over-use-of-meta-pixel-code-on-hospital-websites/> [https://perma.cc/5CWW-YAVS].

platform to track its website visitors' activities.<sup>64</sup> It is a piece of code that helps identify Facebook and Instagram users and see how they interact with the content on a website, which includes reading and selling relevant patient portal data.<sup>65</sup> This information can be used to target people with ads based on interests, preferences, and their behavior online.<sup>66</sup> Alarming, this data is used in the health care setting, generating advertisements and recommendations based on illness, physical condition, or reason for seeking care—all facets of privacy that are federally protected under HIPAA—but without remedy for violations stemming from its use.<sup>67</sup> More than 660 HIPAA-covered entities, like MedStar Health as named in *Doe v. Meta Platforms*, use this tracking technology on their patient portals, and Meta illegally collects identifiable patient information for targeted advertising.<sup>68</sup> Confronting these threats requires the interrogation of current regulatory efficiency within HHS as delineated by HIPAA.

With a proliferation of health care privacy invasion, the deficiency stems from the limitations of proxy-based enforcement—enforcement for privacy rights only brought by the US government on behalf of an aggrieved individual—that regulatory agencies were created to combat.<sup>69</sup> Such a litigation strategy is inconsistent with Congress's purpose in enacting HIPAA and ineffective as a device for remediation.<sup>70</sup> Accordingly, HHS and HIPAA enforcement need an overhaul. Overhauling HHS, with HIPAA as the foundational statutory platform, is neither unheard of nor

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64. See *Meta Pixel*, META: META FOR DEVELOPERS, <https://developers.facebook.com/docs/meta-pixel/> [<https://perma.cc/6GYU-FFT8>] (last visited Apr. 5, 2023).

65. *Id.*

66. See *Meta Fined More than \$400 Million Over Ad Targeting Practices*, CBS NEWS (Jan. 4, 2023, 10:44 AM), [cbsnews.com/news/meta-fined-400-million-390-million-euros-ireland-facebook-privacy/](https://www.cbsnews.com/news/meta-fined-400-million-390-million-euros-ireland-facebook-privacy/) [<https://perma.cc/6E3K-XNUC>].

67. 45 C.F.R. §160 (2022).

68. Annelise Gilbert, *Patients Seek to Halt Meta's Alleged Medical Data Collection*, BLOOMBERG L. (Aug. 26, 2022, 1:28 PM), [https://www.bloomberglaw.com/bloomberglawnews/privacy-and-data-security/XEQLSGSC000000?bna\\_news\\_filter=privacy-and-data-security#jcite](https://www.bloomberglaw.com/bloomberglawnews/privacy-and-data-security/XEQLSGSC000000?bna_news_filter=privacy-and-data-security#jcite) [<https://perma.cc/7RNA-KHAT>].

69. See Giandomencio Majone, *From the Positive to the Regulatory State: Causes and Consequences of Change in the Mode of Governance*, 17 J. PUB. POL'Y 139, 139–67 (1997); see also Edward L. Glaeser & Andrei Shleifer, *The Rise of the Regulatory State*, 41 J. ECON. LITERATURE 401, 403 (2003) (describing regulation as a political response to the failure of private litigation to keep up with the community ideas of justice).

70. See *What is the Purpose of HIPAA?*, HIPAA J. (Jan. 1, 2023), <https://www.hipaajournal.com/purpose-of-hipaa> [<https://perma.cc/7XZQ-GZHP>].

unprecedented, but if done, would resolve US citizens' current concerns of related to their health care and privacy.<sup>71</sup>

### III. FEDERAL PROTECTION

History shows a persistent concern from US citizens about their privacy. For example, the Privacy Act of 1974 was created in response to concerns about how the creation and use of computerized databases might impact individuals' privacy rights; it safeguards privacy through creating procedural and substantive rights in personal data.<sup>72</sup> The Privacy Act of 1974, however, allows an individual to bring a civil action.<sup>73</sup> Against this backdrop, in tandem with the current proposed legislation related to data privacy upon the consumer platform, it would seem that the US government has mechanisms in place to rectify the current shortcomings of health care data privacy specifically. Additionally, the structure of remediation has changed for troublesome areas in the US legal system.<sup>74</sup> Where statutory change may have once been an exclusive avenue for widespread improvement—significantly limited by extensive political processes—the existing regulatory state has become a more flexible, and more utilized, approach.

#### A. *The Regulatory State*

HIPAA's current condition, in practice, encapsulates legal process theory. Legal process theory is based on the concept that each governmental institution is distinctly competent in its own area.<sup>75</sup> This is a "neutral principle," which is supposed to shield substantive

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71. BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH, *supra* note 28, at 22–23 ("There are three general methods for improving the current system: (1) HHS and its OCR could provide more guidance to IRBs, Privacy Boards, institutions, and other participants and stakeholders, which is the simplest and most direct way to achieve change; (2) regulatory changes to the HIPAA Privacy Rule provisions may be necessary in some cases, but are more difficult to undertake; and (3) statutory change of HIPAA or other legislation at the federal or state level, which is the most difficult to accomplish.").

72. See 5 U.S.C. § 552(a).

73. See § 552(g)(1) ("[T]he individual may bring a civil action against the agency, and the district courts of the United States shall have jurisdiction in the matters under the provisions of this subsection.").

74. See, e.g., American Data Privacy and Protection Act, H.R. 8152, 117th Cong. (2022).

75. See HENRY M. HART, JR. & ALBERT M. SACKS, *THE LEGAL PROCESS* 696, 1009–10, (William Eskridge, Jr. & Philip P. Frickey eds., 1994); David Shapiro, *The Choice of Rulemaking or Adjudication in the Development of Administrative Policy*, 78 HARV. L. REV. 921, 926–42, 962 (1965).

implications from elevation above the legal process.<sup>76</sup> This theory accepts that government institutions act rationally to achieve their goals and imputes significant weight to adherence to procedurally sound choices made by a governmental body.<sup>77</sup> Although legal process has fallen out of favor among the majority of legal scholars, its foundations provide common ground for modern legal scholarship underpinning the current developments in public law.<sup>78</sup> The current approach to legal mechanisms is the balance of efficiency and justice, combining substantive values with the rationality and procedural competence of legal process theory.<sup>79</sup> Now, where procedural requirements are met, governmental actions must strike an appropriate balance with normative value.<sup>80</sup> According to legal process theory, as Congress passed HIPAA with sound procedure, it was valid, and its procedural process intended to shield it from substantive, normative implications.<sup>81</sup> Approaching it from the modern synthesis, however, it fails when reconsidering the procedure alongside the demands of efficiency and justice.

Taking from legal process that each governmental institution is distinctly competent in its own area, the introduction of regulatory agencies by Congress extended Congress's power to oversee specific areas of the economy and to punish socially harmful conduct.<sup>82</sup> As a procedurally valid creation, regulatory agencies attempt to increase both efficiency and justice with the binding force of law under their congressional grant of authority.<sup>83</sup> The current regulatory state, founded on agency legal authority, is claimed to be the best avenue for remedy to US citizens because the regulatory state is removed from corporate influence over the judiciary:

There have been courts in the United States which were controlled by the private interests. There have been supreme courts in our states before which plain men could not get justice. There have been corrupt judges; there have been controlled judges; there have been judges who acted as other men's servants and not as servants of the public.<sup>84</sup>

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76. Herbert Wechsler, *Toward Neutral Principles of Constitutional Law*, 73 HARV. L. REV. 1, 9 (1959).

77. See HART & SACKS, *supra* note 75, at 693–97; Shapiro, *supra* note 75, at 942–58.

78. See Edward L. Rubin, *The New Legal Process, The Synthesis of Discourse, and the Microanalysis of Institutions*, 109 HARV. L. REV. 1393, 1424–29 (1996).

79. *Id.* at 1429.

80. *Id.* at 1436.

81. *Id.* at 1396.

82. See Glaeser & Shleifer, *supra* note 69, at 416.

83. See Rubin, *supra* note 78, at 1431.

84. WOODROW WILSON, *THE NEW FREEDOM: A CALL FOR THE EMANCIPATION OF THE GENEROUS ENERGIES OF A PEOPLE* 240 (1913).

Now, however, such insulation may not exist. Regulatory agencies are perpetually inundated with specialty-group interests and often driven by monetary incentives.<sup>85</sup> Consequently, institutional separation may no longer be the optimally efficient mechanism for legal remedy.

### *B. An Efficient Regulatory Schema*

Agencies, working alongside courts, seem to be the best apparatus for the balance of efficiency and justice. While regulatory agencies are able to intervene in times of US legal dilemmas as experts with prospective and proactive mechanisms enabled by Congress, the conflicting influence of external corporate pressure makes them susceptible in the way that the judiciary was in the Progressive Era; the same pressure that gave the original impetus to regulatory agencies in response.<sup>86</sup> This may be the underlying issue and entry point to solution for HHS and HIPAA enforcement. In being entirely limited to regulatory enforcement, external factors such as corporate influence and internal limitations, which disallow enforcement measures by private individuals, prevent efficient remedies for the general welfare.<sup>87</sup> Consequently, neither the original purpose of privacy protection nor the efficiency mechanisms justify HHS's current intrusion as a governmental entity; the amount of justice purchased and the efficiency costs are no longer in equilibrium for regulatory intrusion.<sup>88</sup>

Where issues are pervasive and their solution requires widespread action, collaborative federal efforts may work best. In order to obtain national cohesion, the congressional delegation authority can work as a remedy. One particularly successful federal regulatory agency is the Equal Employment Opportunity Commission (EEOC). The EEOC is a federal agency established by the Civil Rights Act of 1964 that administers and enforces civil rights laws against workplace discrimination.<sup>89</sup> The EEOC has the authority to investigate and prosecute cases against most organizations, including labor unions and employment agencies employing fifteen workers or more or, in the case

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85. See Randall Holcombe & Christopher Bourdeaux, *Regulation and Corruption*, 164 PUB. CHOICE 75, 75–85 (2015).

86. See Glaeser & Shleifer, *supra* note 69, at 404–07.

87. *Id.* at 408.

88. See Rubin, *supra* note 78, at 1431.

89. See Rory Van Loo, *Regulatory Monitors: Policing Firms in the Compliance Era*, 119 COLUM. L. REV. 369, 394 (2019).



of age discrimination, twenty or more workers.<sup>90</sup> The EEOC is an incredibly successful agency that boasted an almost 96 percent success rate for district court resolutions in its recent data reporting on efficiency.<sup>91</sup> This Note contends, however, that the EEOC's efficiency does not occur in isolation; it relies on individual agency for part of its successes. Although it works independently to conduct investigations and issue guidance—among other responsibilities—if an individual remains dissatisfied, recourse doesn't end at the agency limit.<sup>92</sup>

The EEOC complaint process is necessarily complicated, but efficient. To provide as succinct a summary as possible, the process looks—without any special exceptions and at the most basic level required for its analogy here—as follows: after an incident, an employee notifies the EEOC within forty-five days, and the EEOC then assigns an agency-specific counselor.<sup>93</sup> The counselor informs an aggrieved individual of their rights and responsibilities in the administrative process, which may vary depending on the discrimination statute at issue.<sup>94</sup> Counseling must be completed within thirty days of the date the aggrieved person contacted the agency's EEOC office to request counseling, but if the matter is not resolved in that time period, the counselor then informs the individual in writing of the right to file a discrimination complaint.<sup>95</sup> This notice must inform the individual that a complaint must be filed within fifteen days of receipt of the notice, identify the agency official with whom the complaint must be filed, and state the individual's duty to inform the agency if he or she is represented.<sup>96</sup> From there, the agency reviews the case and develops a factual record.<sup>97</sup> After reviewing the record, the agency issues a notice

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90. *Systemic Enforcement at the EEOC*, U.S. EQUAL EMP. OPPORTUNITY COMM'N, <https://www.eeoc.gov/systemic-enforcement-eeoc> [<https://perma.cc/N3GX-CHY4>] (last visited Apr. 5, 2023).

91. *Enforcement and Litigation Statistics*, U.S. EQUAL EMP. OPPORTUNITY COMM'N, <https://www.eeoc.gov/data/enforcement-and-litigation-statistics-0> [<https://perma.cc/AU99-ZPAE>] (last visited Apr. 5, 2023); Press Release, *EEOC Releases Fiscal Year 2020 Enforcement and Litigation Data*, U.S. EQUAL EMP. OPPORTUNITY COMM'N (Feb. 26, 2021), <https://www.eeoc.gov/newsroom/eeoc-releases-fiscal-year-2020-enforcement-and-litigation-data> [<https://perma.cc/QA3L-YDKY>] (“EEOC legal staff resolved 165 merits lawsuits and filed 93 lawsuits alleging discrimination in FY 2020. EEOC recovered just over \$106 million for charging parties and other aggrieved individuals through litigation, representing the largest recovery through the EEOC's litigation program in the past 16 years. The EEOC achieved a successful outcome in 95.8 percent of all district court resolutions.”).

92. *See infra* note 102 and accompanying text.

93. *See* 29 C.F.R. § 1614.105(a)(1) (2022).

94. *See* § 1614.105(b)(1).

95. *See* § 1614.105(d).

96. *Id.*

97. § 1614.108(b).

with essentially two choices for the aggrieved individual: either a hearing by an Administrative Law Judge (ALJ) or, if the individual's record lends itself to a resolution, the acceptance of an agency decision.<sup>98</sup> If the individual elects a hearing, the ALJ must conduct the hearing and issue a decision on the complaint within 180 days, and if the agency does not issue a final order within forty days of receipt, the decision becomes the final action.<sup>99</sup> From there, an aggrieved individual may request an appeal with the EEOC itself.<sup>100</sup> Whatever route taken, either a hearing or resolution from the agency, once a final decision has been issued, the individual will meet the exhaustion requirement required by Title VII of the Civil Rights Act of 1964.<sup>101</sup>

The EEOC, once the exhaustion requirements are met, can then supply a right to sue letter, giving an individual permission to file an employment discrimination lawsuit in federal court.<sup>102</sup> This process, although one of many steps and with many exceptions within the process, preserves agency efficiency and also offers deferral to the judicial branch of the federal government when an individual desires within the limits set by Congress to enforce equal protection of the laws. Accordingly, it is an agency that shares the foundational values of HHS. As a creation of the Civil Rights Act of 1964, the EEOC is founded on principles of equal protection of the laws.<sup>103</sup> HHS, although not a creature of a civil rights statute, has transformed into an agency tasked with creating a system that mandates privacy protection for individually identifiable health information while allowing important uses of the information in health care and research.<sup>104</sup> This task, however, requires the same equal protection for all US citizens under the Constitution's Fifth Amendment, which preserves equal protection as it relates to the federal government.<sup>105</sup>

### *C. The Equal Protection Problem in HIPAA's Current Enforcement*

Imagine the following scenario: a man and a woman engaged in a nonmarital relationship both go to their respective physicians for an

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98. § 1614.109(c).

99. § 1614.109(i).

100. § 1614.108(h).

101. See 42 U.S.C. § 2000e-5(e)(1).

102. See 29 C.F.R. § 1614.201(a) (2022).

103. This was most recently explained by President Biden, who explained that these principles are reflected in the Constitution and "equal protections of the laws." See Exec. Order No. 13,988, 86 Fed. Reg. 7,023 (Jan. 20, 2021).

104. BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH, *supra* note 28.

105. U.S. CONST. amend. V.

annual wellness exam in Tennessee, a state where abortion has been criminalized following the *Dobbs* decision.<sup>106</sup> Recently, the woman experienced an unwanted pregnancy and she performed her own, at-home abortion; the man was not actively involved with the process. At their exams, the man has no need to disclose this information; it has no effect on his health. The woman, however, may be concerned about complications, or may simply be encouraged to disclose her prior history of medical procedures to ensure the best care. While she could refuse disclosure, her health care may suffer as a result. To make sure she receives the most comprehensive care, she reveals this information to her physician who places it in her record within her patient portal. Her physician's patient portal is one of the many that runs on Meta Pixel, which connects her information to her IP address, linking to her specifically, whether her computer profiles or her home address.<sup>107</sup> While Meta's presence on the man's patient portal links to him, the information—although private health data—will be used to construct personalized advertisements.<sup>108</sup> This would likely cause little, if any, harm to the man. The woman, however, under Tennessee law, runs the risk of being charged with a Class C Felony if this information falls into the wrong hands because she performed the abortion on herself.<sup>109</sup> An employee at Meta who morally opposes abortion has every opportunity to submit the woman's action to law enforcement without the warrant required in normal cases of health care information obtained by law enforcement.<sup>110</sup>

Although this might seem far removed, not only has the *Dobbs* decision created the possibility for these scenarios, but similar situations have been increasing in frequency in real time.<sup>111</sup> Even if the current cases have yet to be judicially resolved, the potential to have such a stark disparate effect falls within the purview of the federal government as an equal protection question. HIPAA, while facially neutral, should be evaluated with focus on the consequences of current practice.<sup>112</sup> The jurisprudence on facially neutral discrimination with

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106. See TENN. CODE. ANN. § 9-4-5116.

107. Todd Feathers, Simon Fondrie-Teitler, Angie Waller, & Surya Mattu, *Facebook Is Receiving Sensitive Medical Information from Hospital Websites*, MARKUP, <https://themarkup.org/pixel-hunt/2022/06/16/facebook-is-receiving-sensitive-medical-information-from-hospital-websites> [https://perma.cc/K23R-K8DT] (June 16, 2022, 12:46 PM).

108. *Id.*

109. See TENN. CODE. ANN. § 9-4-5116.

110. See 45 C.F.R. § 164.512(f) (2022).

111. See *supra* notes 24, 25.

112. See *Lau v. Nichols*, 414 U.S. 563, 568 (1974) (providing that in a situation of disparate impact, the investigation focuses on the consequences, rather than the intent of the practices at issue).

requirements for discriminatory intent is less applicable where the discrimination has only recently arisen with the advent of the technological problems facilitating the privacy invasions of issue.<sup>113</sup> Although nowhere in the Constitution is there a guarantee of equality of the sexes, where the law differs in its application based on sex, the government must advance a substantial or important governmental interest in a substantially related way.<sup>114</sup> Presently, the government has a substantial governmental interest in HIPAA's enforcement through two lenses: either it has an interest in regulation of the protection of public health and safety or in respect for fundamental rights. Since *NASA v. Nelson* and *Dobbs*, there is likely no constitutional right of informational privacy that would suffice as a fundamental right to be respected.<sup>115</sup> Whether such a right can be created is beyond the scope of this Note, but the substantial interest in regulation of the protection of public health and safety remains.<sup>116</sup>

For HIPAA to constitutionally further that interest, it must “be reasonable, not arbitrary, and must rest upon some ground of difference having a fair and substantial relation to the object of the legislation so that all persons similarly circumstanced shall be treated alike.”<sup>117</sup> Men and women having different protections under HIPAA, scrutinized under the intermediate scrutiny standard, is not reasonably necessary to the accomplishment of the federal government's goal in regulation of public health. Allowing HIPAA violations to carry differing consequences can only be supported if working under the assumption that the permissible data breaches serve some federal government interest beyond this regulation. The Constitution would suggest, however, that this is not true. Nowhere in the Constitution is there a discussion of health care rights or privacy. HIPAA was enacted as a congressional regulation of interstate commerce, and under this

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113. See *Washington v. Davis*, 426 U.S. 229, 243 (1976) (providing that, in certain circumstances, the impact of a law, rather than its discriminatory purpose, is the critical factor).

114. See *Craig v. Boren*, 429 U.S. 190, 463 (1976) (creating intermediate scrutiny for constitutional considerations of statutory difference based on gender).

115. See *NASA v. Nelson*, 562 U.S. 134, 159–60 (2011) (Scalia, J., concurring) (discussing that a federal constitutional right to “informational privacy” does not exist).

116. Some scholars may utilize Justice Alito's statement in *Dobbs* that noted where concrete reliance interests exist, “like those developed in cases involving property and contract rights,” the court will be more willing to protect a right as fundamental. See *Dobbs v. Jackson Women's Health Organization*, 142 S. Ct. 2228, 2276–77 (2022). There have been creative arguments made along those lines in relation to the access of education. See, e.g., Matthew P. Shaw, *The Public Right to Education*, 89 U. CHI. L. REV. 1179, 1214 (2022) (identifying public education as a due process-protected property interest for children to protect their rights to state-created interests).

117. See *Reed v. Reed*, 404 U.S. 71, 76 (1971).

congressional authority, regulation is a limited power that cannot be allowed to displace all exercise of state police powers.<sup>118</sup> A federal statute that disproportionately allows for the criminal prosecution of women, leaving men unaffected, not only extends into the state police power to define its criminal laws, but applies such laws unequally.<sup>119</sup> Furthermore, protections afforded to US citizens for privacy of health care information do not withstand scrutiny under the assumption that, as the promulgators suggested, HIPAA serves “to improve the efficiency and effectiveness of health care delivery by creating a national framework for health privacy protection that builds on efforts by states, health systems, and individual organizations and individuals.”<sup>120</sup>

If then, the governmental interest is limited to regulation and the means of furthering that regulation provide an unreasonable disparate impact between sexes, HIPAA in its current state fails an equal protection analysis as a result of the current threats presented by abortion laws that do not provide exceptions for self-performed abortion throughout the United States. Although this Note posits the broader problem to be an insufficient mechanism for autonomous enforcement, the disparity created since the criminalization of abortion illustrates the specific and current need for HIPAA’s restructuring.

#### IV. RESTRUCTURING THE HIPAA ENFORCEMENT PROCESS TO ACCOUNT FOR THE FOUNDATIONAL VALUES OF EQUAL PROTECTION USING EXISTING REGULATORY FRAMEWORK

As is present within the EEOC, HIPAA has a foundation built upon the protection of US citizens. HIPAA’s history, like that of the EEOC, is filled with discussions of concern related broadly to vulnerability.<sup>121</sup> In the employment sphere, there was vulnerability to discrimination within the workplace.<sup>122</sup> In the health care sphere, the United States is beginning to shift away from vulnerability to privacy invasion—which was the original impetus of HIPAA’s enactment—toward vulnerability of similar discrimination in

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118. See *United States v. Morrison*, 529 U.S. 598, 618–19 (2000).

119. The power to enact criminal laws belongs almost exclusively to the states. This is because of the Tenth Amendment, which vests in states a police power to provide for the health, safety, and welfare of state citizens. U.S. CONST. amend. X.

120. Standards for Privacy of Individually Identifiable Health Information, 60 Fed. Reg. 82462, 82463 (Dec. 28, 2000) (codified at 45 C.F.R. pts. 160, 164) (emphasis added).

121. H.R. REP. NO. 104–736, at 1–15 (1996); *Systemic Enforcement at the EEOC*, *supra* note 90.

122. See generally Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 241.

criminalization of certain sex-specific activities.<sup>123</sup> At present, without congressional protection for women who choose to terminate a pregnancy, HIPAA's faulty enforcement mechanism lends itself to concerns about the consequential discrimination stemming from state authority to criminalize the behavior.<sup>124</sup> That is not to say, however, that without this equal protection shortcoming HIPAA's current enforcement scheme is permissible.<sup>125</sup> The emerging issues that the post-*Dobbs* laws have revealed demonstrates the greater frailty in the existing regulatory scheme. If left unchecked, HIPAA is simply illusory in its protections; however, the current status of the US health care system does not lend itself to an ambush of judicial action being brought against it by any seemingly aggrieved individual.<sup>126</sup>

As the most successful and efficient regulatory agency, the EEOC provides an analogous process by which HHS and its OCR should be modeled. Restructuring the complaint system this way imposes the appropriate amount of administrative exhaustion burden on individuals who seek reprieve when they feel violated by a breach of privacy. Report requirements with strict deadlines, which could reasonably be modeled after the forty-five day requirement of the EEOC, with the subsequent retainer of a counselor to conduct alternative dispute resolution, counseling, or allow for a formal complaint to be filed, not only limit the action in time, but offer a resolution tailored to the individual and their perceived harm, rather than a one-size-fits-all remedy.<sup>127</sup> Additional time restraints on filing of the formal complaint provide a weed-out system for those who only seek to pursue action for the sake of some monetary settlement later on. With the implementation of agency review, which may again be dismissed for a procedural reason like late filing or limited to 180 days

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123. See statutes listed *supra* note 6.

124. It is worth noting that, if Congress passes the Women's Health Protection Act, the concerns of equal protection of the laws may become irrelevant, as a person's ability to determine whether to continue or to end a pregnancy will be statutorily protected unless otherwise invalidated by the Supreme Court. See H.R. 3755, 117th Cong. (2021). This Act has passed in the House of Representatives twice in less than a year. See *Efforts to Advance Women's Health Protection Act Continue After Bill Falls Short of Passage in Historic Senate Vote*, CTR. FOR REPROD. RTS. (Feb. 28, 2022), [https://reproductiverights.org/womens-health-protection-act-in-historic-senate-vote/?s\\_src=22RR1121sb8doj&s\\_src=19GAABORTION&gclid=Cj0KCQiApb2bBhDYARIsACHHC9vt4KPUYBs0Y4lKPnyPP-pRkpIcJM09o3J8LdeJdF2tE-qjEptk0TvkaAiHDEALw\\_wcB](https://reproductiverights.org/womens-health-protection-act-in-historic-senate-vote/?s_src=22RR1121sb8doj&s_src=19GAABORTION&gclid=Cj0KCQiApb2bBhDYARIsACHHC9vt4KPUYBs0Y4lKPnyPP-pRkpIcJM09o3J8LdeJdF2tE-qjEptk0TvkaAiHDEALw_wcB) [<https://perma.cc/3J26-RFY7>].

125. See CTR. FOR DEMOCRACY & TECH, *supra* note 12; 45 C.F.R. § 160.101 (2022).

126. See CTR. FOR DEMOCRACY & TECH, *supra* note 12; see also Eric Berger, *As Omicron Peaks, the US Healthcare System Is Left 'Broken Beyond Repair'*, GUARDIAN (Feb. 03, 2022, 2:00 PM) <https://www.theguardian.com/society/2022/feb/03/us-coronavirus-healthcare-system-providers> [<https://perma.cc/RD2B-7XDG>].

127. 29 C.F.R. § 1614.105(a)(1) (2022).

of investigation, there is more incentive for efficiency and quick resolution.<sup>128</sup> With an agency empowered to issue a decision to which the individual can either agree to the terms of, continue in an appeals process, or challenge in federal court, an individual is granted more autonomy over both their claims and harm suffered.<sup>129</sup> This is obviously a simplification of the EEOC process that could be applicable in the context of health care information breaches, but even at a high level, the values of HIPAA's original enactment, the need for efficiency, the judicial check on the agency system, and the US ideology of independence and autonomy lean in favor of this type of enforcement mechanism.

While this type of process is incredibly agency oriented, it offers deferral to the judicial branch of the federal government to continue its checks on other governmental entities to protect US citizens and their rights. Similarly, this system would impose greater objectivity over a claim; if a counselor, agency, administrative law judge, and then a federal court examines an issue, the likelihood of a fair outcome is much higher. While it may be contended that this imposes too high a burden on both the agency and the court system, this burden does not outweigh the fairness, protection of law, and unbiased need for remedy when wrong has occurred. Furthermore, this multistep, multibranch system of review serves to remedy wrongs in the interest of the individual. For the same standards to remain in place with respect to private health care information and breaches, different individuals may feel violations differently. A process that allows a remedy to be obtained either through counseling or alternative dispute resolution versus federal court allows for the appropriate remedy to be pursued in proportion to the harm suffered. In other words, not every individual feels inclined to pursue claims in federal court where other recourse is available, but people who feel significantly more harmed than others can obtain meaningful remedies unlike the trivial recovery currently available.<sup>130</sup> In such extensive protection processes, implementing these safeguards speak to the value of the right protected by HIPAA and the need for proper procedure. Furthermore, it would be difficult to presume, without any evidence to the contrary, that this system would create an

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128. § 1614.108(f).

129. § 1614.201(a); *see also* Loo, *supra* note 89.

130. Which averages approximately \$200 per victim under the current enforcement scheme, despite health care entities being fined up to \$50,000 per violation. *See HIPAA History*, *supra* note 57.

influx of complaints that outnumber the current complaints received by HHS and OCR.<sup>131</sup>

The EEOC, by contrast, received 67,448 charges in the 2020 fiscal year<sup>132</sup> and resolved 70,804 total during the year.<sup>133</sup> It is worth noting that this efficiency is not necessarily due to lack of resources, given that HHS has historically received, since 2018, over 20 percent of the US federal budget.<sup>134</sup> Since 2018, in contrast, the EEOC has received less than 1 percent of the federal budget.<sup>135</sup> Obviously, it is inaccurate to say that money alone would correlate with efficiency; however, given that the EEOC receives almost double the number of complaints with significantly less budget and a higher rate of successful resolution, it may be reasonable to assume that the HHS process for enforcing HIPAA protections is falling short of what it needs to be. Obviously, HHS does much more than the enforcement of HIPAA, such as administering Medicare and Medicaid, but the central idea is that HHS should reallocate and reorganize its functions, and consequently its funds, given its large budget.<sup>136</sup>

Moreover, this process would allow for HHS to be an avenue, rather than a last resort, for individuals, thus better serving the theory of cooperative governance within the federal government. Although

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131. In 2021, HHS received 34,077 complaints related to HIPAA violations, and resolved 20,661 of those after intake and review (and it is not insignificant to note the 13,416 unresolved complaints). See *Enforcement Results by Year*, DEPT HEALTH & HUM. SERVS., <https://www.hhs.gov/hipaa/for-professionals/compliance-enforcement/data/enforcement-results-by-year/index.html> [https://perma.cc/4NZP-9RQF] (last visited Apr. 6, 2023); *Health Information Privacy Complaints Received by Calendar Year*, U.S. DEPT HEALTH & HUM. SERVS., <https://www.hhs.gov/hipaa/for-professionals/compliance-enforcement/data/complaints-received-by-calendar-year/index.html> [https://perma.cc/4PJ9-5SVQ] (last visited Apr. 6, 2023).

132. While the data for 2021 is available, 2020 was chosen to account for the increasing number of employees who worked from home during the COVID-19 pandemic, which alleviated many of the complaint types received due to the nature of remote work; the numbers for HHS were similar year-to-year, but given the nature of employment during the COVID-19 pandemic, 2020 was selected as a data point to provide the most normal reflection of EEOC numbers received in a given year.

133. The agency responded to over 470,000 calls to its toll-free number and more than 187,000 inquiries in field offices, including 122,775 inquiries through the online intake and appointment scheduling system, reflecting the significant public demand for EEOC's services. See Press Release, *EEOC Releases Fiscal Year 2020 Enforcement and Litigation Data*, *supra* note 91.

134. See *Spending Explorer*, USA SPENDING, <https://www.usaspending.gov/explorer/agency> [https://perma.cc/4GPF-QGED] (last visited Apr. 6, 2023).

135. *Id.*

136. More than one-third of health care costs are on overhead and administration, which has been found to waste \$210 billion per year on unnecessary costs because of the complex and fragmented health care system. The proposal here is that, with a more uniform health care system protecting patients in receiving efficient care, health care costs will ultimately decrease both for US citizens and the federal government. See generally James E. Dalen, *We Can Reduce Healthcare Costs*, 123 AM. J. MED., no. 3, Mar. 2010.



Congress's power to create and oversee agencies is well established, agencies and agency-related action are not isolated within the legislative branch. As the Supreme Court has noted, the allocation of powers was never intended to cause the branches to be "hermetically sealed,"<sup>137</sup> or, in the words of Justice Oliver Wendell Holmes, divided into "fields of black and white."<sup>138</sup> Instead, observed Justice Robert Jackson, the separation of powers "enjoins upon [the] branches separateness but interdependence, autonomy but reciprocity."<sup>139</sup> Having the judiciary as the ultimate check on the congressional effort to protect health care information privacy facilitates the reciprocity needed for remediation and the legitimacy needed for protection. Similarly, this check better ensures uniformity across the United States; with the ability to circumvent state common law recourse by pursuing an individual cause of action, the claims that are resolved on their merit within the agency resolution process and bolstered by judicial decision-making allow consistency with respect to rights and guidelines to be put in place for individuals to understand them.

Finally, by amending the HIPAA enforcement scheme to allow for individuals to bring a private cause of action, HIPAA would preempt contrary state laws. Currently, without "the clear and manifest purpose of Congress"<sup>140</sup> allowing individuals to assert their rights under HIPAA, the patchwork of state laws is a more autonomized mechanism of recovery—including tort and contract claims brought in state courts. This preemption comes from the constitutional authority from which Congress enacted HIPAA in the first place: its Article I Commerce power.<sup>141</sup> Now, more than ever, that authority stands. Health care and all things related to it are becoming one of the largest sources of economic activity in the United States, especially following the COVID-19 pandemic.<sup>142</sup> Keeping with the Supreme Court's

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137. *Immigration & Naturalization Servs. v. Chadha*, 462 U.S. 919, 951 (1983).

138. *See Springer v. Gov't of Philippine Islands*, 277 U.S. 189, 209 (1928) (Holmes, J., dissenting); *see also Trump v. Mazars USA, LLP*, 140 S. Ct. 2019, 2035 (2020) ("A balanced approach is necessary, one that takes a considerable impression from the practice of the government, and resists the pressure inherent within each of the separate Branches to exceed the outer limits of its power.")

139. *Youngstown Sheet & Tube Co. v. Sawyer*, 343 U.S. 579, 635 (1952) (Jackson, J., concurring).

140. *Rice v. Santa Fe Elevator Corp.*, 331 U.S. 218, 230 (1947); *Reid v. Colorado*, 187 U.S. 137, 148 (1902).

141. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191 § 195, 110 Stat. 1936, 1991.

142. The United States has one of the highest costs of health care in the world. In 2020, US health care spending reached \$4.1 trillion, which averages to over \$12,500 per person. *See National Health Expenditure Data*, CTRS. FOR MEDICARE & MEDICAID SERVS.,

understanding of Congress's Commerce Clause authority, health care is undoubtedly economic activity within the purview of congressional regulation.<sup>143</sup> As such, it follows that if Congress allows for the restructuring of the HIPAA enforcement process to grant individuals the right to bring a private cause of action against a health care entity that has violated protected privacies, contrary state laws permitting such actions would be preempted and individuals would have a uniform understanding for enforcement of their rights.

#### V. THE REALITY OF RESTRUCTURING THE EXISTING HIPAA LANDSCAPE

The federal government, for all it does, is not known for its speed in acting.<sup>144</sup> The most obvious counter to a proposition that HIPAA be restructured and HHS overhauled is that it would be unachievable because of the legislative hurdles required to be jumped for such a process. Yet it is imperative that such a process be undertaken, and it is essential that it must be done in an efficient and expeditious way. Meta Platforms was recently subjected to the largest settlement in a digital privacy case, agreeing to pay \$725 million to settle a long-running lawsuit that claimed Facebook illegally shared user data with the research firm Cambridge Analytica.<sup>145</sup> According to case records, the company has strengthened its ability to restrict and monitor how third parties acquire and use Facebook users' information, and improved its methods for telling users what information Facebook collects and shares about them.<sup>146</sup> Despite this claim in 2018, Meta has not affirmed any changes to its policy within the United States.<sup>147</sup> Instead, a judge last month approved a ninety million dollar Meta deal

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<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData> [<https://perma.cc/2CTG-GUVE>] (Dec. 1, 2021, 7:02 PM).

143. Despite the argument that health care is not interstate in the traditional sense, Congress is also permitted to regulate purely intrastate activity that is not itself "commercial," i.e., not produced for sale, if it concludes that failure to regulate that class of activity would undercut the regulation of the interstate market in that commodity. See *Gonzales v. Raich*, 545 U.S. 1, 16 (2005). Additionally, as an existing entity of commercial activity, the health care industry is subject to regulation where Congress has not created the activity to be regulated. See *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 550 (2012).

144. As anecdotal and opinionated as this may seem, many articles have documented the procedural process and its now-notorious pace. See, e.g., Rachel Augustine Potter, *Slow-Rolling, Fast-Tracking, and the Pace of Bureaucratic Decisions in Rulemaking*, 79 J. POL. 841 (2017).

145. Joel Rosenblatt, *Meta Agrees to Pay \$725 Million Over Cambridge Analytica Scandal*, BLOOMBERG L. (Dec. 23, 2022, 3:38 AM), <https://news.bloomberglaw.com/tech-and-telecom-law/meta-agrees-to-pay-725-million-over-cambridge-analytica-scandal> [<https://perma.cc/GVT5-S8ZN>].

146. *Id.*

147. *See id.*

to settle a suit over the use of browser cookies and the tracking of user activity, but the privacy policies and tactics remain in place.<sup>148</sup>

The problem is not limited to Meta Platforms; Google—another well-known digital platform—agreed to pay a total of \$391.5 million to forty US states to resolve a probe into controversial location-tracking practices that the Alphabet Inc. unit says it already discarded several years ago, in what state officials are calling the largest privacy settlement of its kind in US history.<sup>149</sup> As digital search engines and data storage platforms are becoming more integral in the average person's conduct, the risks to privacy are growing exponentially—even outside of the health care arena.<sup>150</sup> As such, the timeline to implement change where privacy breaches threaten such an essential aspect of modern society must be concise. For the current enforcement mechanisms' efficiency to lie in state law alone, the individual who suffers irreparable harm to their privacy is subjected to the protective interests of state political insiders at the victim's expense.

Obviously, however, identifying the risk alone is not enough for change to be made. The US political system requires procedural steps to be followed for a change to the law to take place and, in this circumstance, an agency to be restructured. Here, there is both a statute and agency at play.<sup>151</sup> While HIPAA may be amended to account for all changes needed, the reality that the legislature could do so quickly and effectively to protect the interests of individuals is unlikely to come to fruition. The power to amend statutes belongs exclusively to the legislature, so the existing legislation—here, HIPAA—is subject to amendment in any manner consistent with constitutional limitations.<sup>152</sup> To circumvent bureaucratic hurdles that congressional restructuring of an agency may bring, perhaps the best solution would

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148. *Id.*; see also Christopher Brown, *Facebook's \$90 Million 'Like' Button Tracking Suit Pact Approved*, BLOOMBERG L. (Nov. 14, 2022, 11:17 AM), <https://www.bloomberglaw.com/document/RLCILEDWX2PS> [<https://perma.cc/H4SA-8KVP>].

149. Erik Larson, *Google to Pay \$391 Million Over 'Crafty' Location Tracking*, BLOOMBERG LAW, <https://www.bloomberg.com/news/articles/2022-11-14/google-to-pay-391-5-million-to-states-over-location-tracking#:~:text=Google%20agreed%20to%20pay%20a,privacy%20settlement%20in%20US%20history> [<https://perma.cc/549P-MLF9>] (Nov. 14, 2022, 3:43 PM).

150. See Barbara L. Filkins, Ju Young Kim, Bruce Roberts, Winston Armstrong, Mark A. Miller, Michael L. Hultner, Anthony P. Castillo, Jean-Christophe Ducom, Eric J. Tupol & Steven R. Steinhubl, *Privacy and Security in the Era of Digital Health: What Should Translational Researchers Know and Do About It?*, 8 AM. J. TRANSLATIONAL RSCH. 1560 (2016).

151. See 42 U.S.C. § 1320; *Office for Civil Rights*, U.S. DEPT HEALTH & HUM. SERVS., <https://www.hhs.gov/ocr/index.html> [<https://perma.cc/EXF4-Y5Q3>] (last visited Apr. 5, 2023).

152. Generally, a statute merely expresses current government policy, and future legislatures are free to change that policy. See *Frazier v. City of Chattanooga*, 841 F.3d 433 (6th Cir. 2016); see also *Community-Service Broad. of Mid-America, Inc. v. F.C.C.*, 593 F.2d 1102 (D.C. Cir. 1978).

come from the presidential authority to reorganize the agency. Under this authority, Congress would only need to amend HIPAA to provide for a private right of action within the agency's jurisdiction. The President, pursuant to reorganization authority, would be able to propose changes in the organization of HHS.<sup>153</sup> The ability for the President to restructure HHS would require an investigation into the purpose of the restriction, a structure pursuant to US policy, and a plan for reorganization.<sup>154</sup>

As detailed above, an investigation into the organization of HHS would reveal the shortcomings in privacy protections for US citizens; Meta has been found to propagate significant data leaks outside the United States, is suspected to have done so within the United States, and internally has recognized the massive data breach risks.<sup>155</sup> The reorganization of HHS under the President's authority would thus clearly fall within the requirement by statute that the action conforms with "the policy of the United States to promote the better execution of the laws, the more effective management of the executive branch and of its agencies and functions, and the expeditious administration of the public business."<sup>156</sup> From there, the consolidation or coordination of part of HHS or the functions thereof, or the abolition of functions not pertinent in order to provide for those that are, fall within the President's purview.<sup>157</sup> These powers authorizing the President to realign federal agencies and their powers to promote efficiency, economy, and better service are sufficiently restrictive that they do not contain an unconstitutional delegation of power.<sup>158</sup>

This avenue for the overhaul of HHS might allow the avoidance of parliamentary issues of Congress undertaking the task. Although not necessarily common, when such authority has been employed, it has

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153. See 5 U.S.C. § 903.

154. *Id.*

155. A leaked internal document written in 2021 by privacy engineers on Facebook's Meta Platform for Ad and Business Products shows that the organization faces a nearly insurmountable task to become compliant with global privacy regulations that need it to know how user data flows through its systems so the company can apply policies that control what's done with people's information and perform basic functions like reflecting people's privacy choices. See Lorenzo Franceschi-Bicchierai, *Facebook Doesn't Know What It Does with Your Data, Or Where It Goes: Leaked Document*, VICE (Apr. 26, 2022, 8:02 AM), <https://www.vice.com/en/article/ak-vmke/facebook-doesnt-know-what-it-does-with-your-data-or-where-it-goes> [<https://perma.cc/6QAK-8CGY>].

156. §§ 901(a)(1), 903(a).

157. § 903(a)(2)-(3).

158. See *EEOC v. Ingersoll Johnson Steel Co.*, 583 F. Supp. 983 (S.D. Ind. 1984).

historically been with significant benefits.<sup>159</sup> The ability to streamline the agency restructuring through this process would undoubtedly be simplified with only one individual primarily responsible. The issue with this approach, however, is that there is a political schism over the issues of privacy and surveillance.<sup>160</sup> In 2018, a poll on surveillance from the Annenberg School for Communication at the University of Pennsylvania found that Americans are deeply divided over tracking, both online and in real life.<sup>161</sup> Since 2018, however, the issue is not as divisive.<sup>162</sup> Perhaps unsurprisingly given the aftermath of an international pandemic that left millions reliant on digital platforms for work and personal endeavors, in a survey from 2021 across both major political parties, 97.8 percent of US citizens said that they valued their online privacy and 87.3 percent of US citizens said they wanted the current President, Joe Biden, to support legislation that protects their online privacy.<sup>163</sup> In a political environment marked by incredible popular division, this amount of agreement is at a level to be capitalized on in making substantive changes to HHS in support of digital media privacy, especially as it relates to health records.

This is, admittedly, only in the abstract, because the impetus for such change does not end with the broad idea that privacy is among the essential freedoms of US citizenship. The Republican Party platform states that “the unborn child has a fundamental right to life which cannot be infringed,”<sup>164</sup> while the Democratic equivalent supports

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159. For example, Richard Nixon used his reorganization authority granted by the 91st Congress under the 1969 Amendments to establish the Environmental Protection Agency under his Reorganization Plan No. 3. See HENRY HOGUE, CONG. RSCH. SERV., R42852, PRESIDENTIAL REORGANIZATION AUTHORITY: HISTORY, RECENT INITIATIVES, AND OPTIONS FOR CONGRESS 2 (2012).

160. See Natasha Singer, *Creepy or Not? Your Privacy Concerns Probably Reflect Your Politics*, N.Y. TIMES (Apr. 30, 2018), <https://www.nytimes.com/2018/04/30/technology/privacy-concerns-politics.html> [<https://perma.cc/89GN-SVLX>].

161. “The Republicans are most likely to be positive about surveillance,” said Joseph Turow, a professor at the University of Pennsylvania and the lead author of the study. “The Democrats are most likely to be negative, and independents are always in the middle.” See Singer, *supra* note 160. It is worth noting, however, that the study cited in this article and linked here has been removed by the author or institution. For another example of a similar study, see Press Release, Sam Hinds García, *Privacy, Security, and Digital Inequality*, DATA & SCI. (Sept. 27, 2017), [https://datasociety.net/pubs/prv/DataAndSociety\\_PrivacySecurityandDigitalInequalityPressRelease.pdf](https://datasociety.net/pubs/prv/DataAndSociety_PrivacySecurityandDigitalInequalityPressRelease.pdf) [<https://perma.cc/4RNW-PWHC>].

162. See David Janssen, *Survey: Republicans’ and Democrats’ Views About Online Privacy Under Biden*, VPN OVERVIEW, <https://vpnoverview.com/privacy/laws-regulations/joe-biden-privacy/> [<https://perma.cc/NFM5-CZNC>] (Mar. 22, 2023).

163. *Id.*

164. REPUBLICAN NAT’L COMM., REPUBLICAN PLATFORM 2016 13 (2016), [https://prod-cdn-static.gop.com/docs/Resolution\\_Platform\\_2020.pdf](https://prod-cdn-static.gop.com/docs/Resolution_Platform_2020.pdf) [<https://perma.cc/K9AK-R58X>] (note that the RNC elected not to update its platform for the 2020 election).

access to “safe and legal abortion.”<sup>165</sup> The idea that those capable of pregnancy have some unadulterated right to their reproductive medical decisions is not as universal as the desire to protect a right of privacy generally.<sup>166</sup> Yet, while these issues may seem unrelated, an equal system for strong enforcement of medical privacy rights collapses under the democratic system if only truly guaranteed to those incapable of carrying children. To have universal, federal protections for medical privacy and data, a person capable of pregnancy must be guaranteed the right to terminate it within the confines of existing law related to the procedure without those records being impermissibly released. This kind of protection would have to transcend the moral partisan lines that have been drawn since the 2022 decision in *Dobbs* regarding the right to abortion. Without these protections, essential information about one’s medical decisions may be withheld in an attempt to avoid privacy risks, undermining the purpose of HIPAA and destroying the effectiveness of an efficient health care system. If accepting that medical privacy protections and reproductive freedom go hand-in-hand, with one requiring the other, the President can theoretically cut across political party lines that typically erect barriers for governmental action to restructure HHS under the reorganization authority.

Congress may have this same foundation for agency restructuring, but allowing Congress to perform this action also opens the door to potential persuasion by the wealthy conglomerates that act in the corporate, rather than the individual, interest. With the influence of lobbyists or interest groups, the idea that regulatory agencies are in the most efficient positions to protect US citizens from market failures and threats is corrupted. It undermines the basic principle that where the government intervenes, it should do so efficiently and in the interest of the people from which it derives its power.<sup>167</sup> The ideal system to be implemented would correct for the defects in the political process, meaning its construction is best removed from these defects.

Whatever avenue by which HHS is restructured and HIPAA is amended, a private right of action is essential. The significant threats that data breaches of medical information pose in the current legal landscape—as evidenced by hefty settlements paid by, and pending

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165. *Achieving Universal, Affordable, Quality Healthcare*, DEMOCRATIC NAT’L COMM., <https://democrats.org/where-we-stand/party-platform/achieving-universal-affordable-quality-health-care/> [https://perma.cc/GL82-FK2N] (last visited Apr. 5, 2023).

166. *See America’s Abortion Quandary*, PEW RSCH. CTR. (May 6, 2022), <https://www.pewresearch.org/religion/2022/05/06/americas-abortion-quandary/> [https://perma.cc/X6D2-WJLZ].

167. “A dependence on the people is, no doubt, the primary control on the government.” *See* THE FEDERALIST NO. 51 (Alexander Hamilton, James Madison).

cases against, digital platforms<sup>168</sup>—are irreparable without individual ability to enforce rights recognized since HIPAA's enactment. Despite the federal government's unwillingness to recognize a general right to privacy, the right to medical privacy specifically remains, at least in theory, a critical component of the US health care system and the governmental guarantee to right of privacy in one's personhood.<sup>169</sup> Unless Congress is to override medical privacy by nullifying HIPAA in its entirety, without either the President or the legislature altering the enforcement mechanisms, the current statute is illusory in its protection.

#### A. *The Role of the Judiciary in the Restructuring Process*

Through the lens of equal protection, although existing circumstances with Meta show vulnerability, the judiciary may serve in its role as a catalyst for achieving equal privacy protections for all US citizens. Although the core of the Fourteenth Amendment is the prevention of meaningful and unjustified official distinctions based on race,<sup>170</sup> cases involving discrimination on the basis of gender have been provided additional protection from the court—albeit less strict than the scrutiny applied to racial discrimination.<sup>171</sup> Because HIPAA affords differing protections of law to men and women, it may be appropriate for the judiciary to find it fails the relevant scrutiny test and declare its current state unconstitutional. In that event, the legislature would be given an impetus to restructure HIPAA and its privacy protections.

The dilemma in the case of HIPAA, however, is that privacy is protected along a nonlinear scale. On one end of this complicated spectrum, in cases involving gender, the Court has defined a constitutional right of privacy upon which the government may not intrude.<sup>172</sup> The Supreme Court in *Griswold*, for example, in defining the constitutional right to privacy, recognized that there are behavioral matters into which the government may not intrude—specifically adult consensual marital sexual relations.<sup>173</sup> Applying this reasoning to the current issue, it might be reasonable to conclude that in the context of

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168. See Larson, *supra* note 149.

169. Standards for Privacy of Individually Identifiable Health Information, 60 Fed. Reg. 82462, 82467 (Dec. 28, 2000) (codified at 45 C.F.R. pts. 160, 164).

170. See, e.g., Slaughter-House Cases, 16 Wall. 36, 71 (1873); Strauder v. West Virginia, 100 U.S. 303, 307–308 (1880); Ex parte Virginia, 100 U.S. 339, 344–345 (1880); McLaughlin v. Florida, 379 U.S. 184, 192 (1964); Loving v. Virginia, 388 U.S. 1, 10 (1967).

171. See Craig v. Boren, 429 U.S. 190 (1976).

172. See *Griswold v. Connecticut*, 381 U.S. 479 (1965).

173. *Id.* at 485.

consensual marital sexual relations, reproductive decisions would fall within the protections as a facet of those relations, thereby warranting protection. That conclusion, however, may only withstand scrutiny if acting under the ideology present in 1965, the year that *Griswold* was decided. Women and men alike are now marrying less and reproducing more outside of marriage compared to 1960.<sup>174</sup> Marriage has lost its compulsory status as a feature of adult life, and as such, limiting protections to the reproductive decisions that happen within marital relationships alone communicates a social judgment that the courts are neither equipped nor entitled to make. The composition of US family life, while a justification at the time of *Griswold*, cannot be the hinge upon which the door to privacy opens.<sup>175</sup>

At the other end of the spectrum, informational privacy does not seem to be worthy of the Court's protection, even about one's medical decisions.<sup>176</sup> In the *NASA* case, assuming that the Constitution protects a right to informational privacy, the Supreme Court found that such a right was not violated when an employee was made to reveal medical privacy information.<sup>177</sup> Scholars have argued that the Court's decision marks a distinction between bodily or physical privacy and information privacy.<sup>178</sup> HIPAA and reproductive decisions cannot adequately fall into one or the other category: the patient records are informational and the decisions that are included within them are bodily.<sup>179</sup> Even still, the right of privacy as a person's right to control the dissemination of information about themselves in a basic sense remains good law.<sup>180</sup> The way that intersects with employer disclosures, as in *NASA*, is inapplicable in the case of privacy here and is an unsatisfactory counter to the need for privacy regarding reproductive decisions.

Even the recent decision in *Dobbs* does not defeat the right to privacy in the way that many feared it did.<sup>181</sup> Yet while it did not

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174. See generally Kathleen E. Hull, Ann Meier & Timothy Ortyl, *The Changing Landscape of Love and Marriage*, 9 CONTEXTS 32 (2010).

175. See *Griswold*, 381 U.S. 479 at 485 (reasoning that since marriage is such a protected association, and the Connecticut statute was unnecessarily destructive to this association, it was therefore unconstitutional).

176. See *NASA v. Nelson*, 562 U.S. 134 (2011) (holding that the government's interest and protections against public dissemination provided by statute satisfy any interest in avoiding disclosure).

177. *Id.* at 154, 159.

178. See Tiffany C. Li, *Post-Pandemic Privacy Law*, 70 AM. U. L. REV. 1681, 1708–09 (2021).

179. See *id.*; *Nelson*, 562 U.S. at 154, 159.

180. See *U.S. Dep't of Justice v. Reporters Comm. for Freedom of Press*, 489 U.S. 749, 763 (1989).

181. The *Dobbs* court ruled that there is no constitutional right to *abortion* rather than privacy. Although relevant to what this ruling means for HIPAA protections, it does not directly



directly change the privacy protections, the decision inherently made clear that those who elect to pursue reproductive choices outside of carrying a child to term may not be afforded the same protected relationship with their physicians as others.<sup>182</sup> The decision left data managers as the guards of morality judgments made by states, a role they have no capacity or authority to play. In its wake, it is thus imperative that the Court take steps to recognize that all US citizens maintain a right to privacy that has yet to be abrogated and constitutionally must be applied equally to all citizens of the United States.

## VI. CONCLUSIONS

There is no better moment to address the shortcomings of HIPAA and HHS as an enforcement agency than now.<sup>183</sup> Not only is the health care industry growing at an impressive pace, but it is becoming regulated and confined by a legal landscape that directly affects medical decision-making in a way that impacts its effectiveness.<sup>184</sup> To support its growth, the health care industry has come to rely on digital platforms that can no longer be removed from the system; without them, purportedly confidential physician-patient communications and recordkeeping would be impractical.<sup>185</sup> The emphasis, however, is that these records and communications are only ostensibly confidential.<sup>186</sup> Within the current framework, despite the proclamation that health care information belongs to an individual, records transmitted on patient platforms coded by corporations like Meta Platforms are accessible and shareable by those who are not bound by HIPAA and who may not face adequate consequences for violating it.<sup>187</sup>

As the United States faces a surge in the creation of state laws that seek to delineate the legality of medical decision-making, the federal government must assume a stronger role in protecting the values of privacy for that medical decision-making that underpins the

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impact the Court's definition of what is privacy, despite Justice Thomas's concurrence suggesting otherwise. *See Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228 (2022) (overruling *Roe v. Wade*).

182. *See id.*

183. *See id.*

184. *See Chemweno, supra* note 40.

185. *See Carter, supra* note 4, at 226.

186. *See Daniel Solove, Is HIPAA Enforcement Too Lax?*, TEACHPRIVACY : PRIV. + SEC. BLOG (Jan. 19, 2016), <https://teachprivacy.com/hipaa-enforcement-lax/> [<https://perma.cc/72RH-GCQ6>].

187. *See Gilbert, supra* note 68.

country more broadly.<sup>188</sup> Using agency frameworks already in place, HHS may be reasonably restructured to allow individual US citizens to assume greater responsibility, autonomy, and privacy over the information Congress once recognized as essential to the citizens of the United States when it enacted HIPAA.<sup>189</sup> This would better effectuate a health care system that promotes the well-being of US citizens both as individuals and as citizens who are guaranteed equal protection of the laws, which undoubtedly has rippling effects on the greater well-being of US society.<sup>190</sup> It is thus imperative that the federal government rectify the current shortcomings of HIPAA enforcement within HHS to realign itself with the principles of equality, efficiency, and popular welfare.

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188. See Carter, *supra* note 4, at 226.

189. See 5 U.S.C. §§ 901, 903.

190. BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH, *supra* note 28, at 5.

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