

## Post-Truth Won't Set Us Free

*Health Law, Patient Autonomy, and the Rise of the Infodemic*

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*“Don't it always seem to go  
That you don't know what you got 'til it's gone”*  
Joni Mitchell, Canadian-American singer-songwriter

### I INTRODUCTION

Numerous interrelated and deep-seated factors helped COVID-19 exact its horrific toll in the United States. Long-standing structural inequities, the depletion of public health departments, a privatized health care system poorly suited to combating a public health disaster, judicial decisions that limited public health powers, and a president who willfully undermined the pandemic response are among the many culprits. Important, too, has been the plethora of misinformation on matters ranging from the value of masks to the purported efficacy of hydroxychloroquine and ivermectin in treating COVID-19. This “infodemic,” as the World Health Organization has called it, has also stymied efforts to control the pandemic through vaccination.<sup>1</sup> Misinformation about plagues and vaccines is not new.<sup>2</sup> The current infodemic, however, goes well beyond familiar forms of science skepticism or vaccine rejection. As reports roll in about people eschewing masks and vaccinations and taking unproven and dangerous drugs, it is hard not to wonder whether the United States has been gripped by a more virulent cynicism that questions whether meaningful truth can be – or need be – found at all.

Lee McIntyre and others refer to this alarming mindset as “post-truth.”<sup>3</sup> As much as any pathogen, post-truth threatens future efforts to contain pandemics and other public health threats. While many scholars have explored the roots of the post-truth

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<sup>1</sup> Vivek H. Murthy, *Confronting Health Misinformation* (2021), [www.hhs.gov/sites/default/files/surgeon-general-misinformation-advisory.pdf](http://www.hhs.gov/sites/default/files/surgeon-general-misinformation-advisory.pdf).

<sup>2</sup> See Heidi J. Larson, *Stuck: How Vaccine Rumors Start – and Why They Don't Go Away* (2020).

<sup>3</sup> Lee McIntyre, *Post-Truth* (2018).

problem,<sup>4</sup> we focus on an overlooked piece of the larger puzzle. In particular, we look at developments within health law, generally adopted for important reasons, that may have inadvertently contributed to the post-truth climate. These developments include the creation and evolution of the doctrine of informed consent and the rise of direct-to-consumer advertising (DTCA). These doctrines, which center on patient autonomy, we suggest, may have had the side effect of encouraging individuals to believe that they can and should navigate tough medical questions without guidance from scientific or medical experts. In so doing, these doctrines may have primed people to accept misinformation and reject vaccines and masking. To prevent a similarly bleak outcome during the next pandemic, we need to consider how health law may have contributed to the post-truth problem during COVID-19. This chapter starts that conversation.

We begin in Part II by providing a brief overview of the COVID-19 infodemic. In Part III, we introduce the concept of post-truth and highlight various “attributes” that distinguish it from the healthy skepticism that accompanies critical thinking.<sup>5</sup> We then link the post-truth phenomenon to broader shifts in cultural attitudes toward individual choice and the embrace of subjectivity.

In Part IV, we turn to developments in health law that emphasize individual choice and have led to an erosion in the role of professional expertise. In Part V, we discuss how these developments created fertile ground for post-truth in ways that undermined efforts to mitigate COVID-19. We conclude by suggesting that if we are to avoid the next post-truth pandemic, health law scholars and policymakers must come to grips with the post-truth phenomenon and the practices within health law that may, however inadvertently, encourage it.

## II THE COVID-19 INFODEMIC

Since the start of the COVID-19 pandemic, misinformation about the coronavirus, its origins, its dangerousness, and ways to mitigate it has been abundant. The falsehoods started early when President Trump lied to the public about the risks of COVID-19 and touted hydroxychloroquine as a remedy.<sup>6</sup> President Trump,

<sup>4</sup> Id.; Margaret McCartney, Evidence in a Post-Truth World, 355 *BMJ* i6363 (2016).

<sup>5</sup> We leave for another day whether truth can exist independently of the observer’s perceptual lenses. See Peter Holtz, Does Postmodernism Really Entail a Disregard for the Truth? Similarities and Differences in Postmodern and Critical Rationalist Conceptualizations of Truth, Progress, and Empirical Research Methods, 11 *Frontiers Psych.* art. 545959 (2020).

<sup>6</sup> Alana Wise, Trump Admits Playing Down Coronavirus’s Severity, According to New Woodward Book, NPR (Sept. 9, 2020), [www.npr.org/2020/09/09/911109247/trump-admitted-to-playing-down-the-coronaviruss-severity-per-new-book](http://www.npr.org/2020/09/09/911109247/trump-admitted-to-playing-down-the-coronaviruss-severity-per-new-book); Andrew Solender, All the Times Trump Has Promoted Hydroxychloroquine, *Forbes* (May 22, 2020), [www.forbes.com/sites/andrewsolender/2020/05/22/all-the-times-trump-promoted-hydroxychloroquine](http://www.forbes.com/sites/andrewsolender/2020/05/22/all-the-times-trump-promoted-hydroxychloroquine); Ana Santos Rutschman, Mapping Misinformation in the Coronavirus Outbreak, *Health Affs.* (Mar. 10, 2020), [www.healthaffairs.org/doi/10.1377/forefront.20200309.826956/full/](http://www.healthaffairs.org/doi/10.1377/forefront.20200309.826956/full/).

however, was not alone in spreading misinformation. Conspiracy groups, such as QAnon, popular news outlets, and prominent anti-vaccinationists spread misinformation prolifically, especially via social media.<sup>7</sup> Unfortunately, many Americans believed the deceptions. A Kaiser Family Foundation poll taken in fall 2021 found that 78 percent of adults either believed one or more of eight falsehoods about the pandemic to be true or expressed uncertainty about whether one or more was true.<sup>8</sup> Over one-third of Americans believed that the government had exaggerated the number of COVID-19 deaths, while over one-third either believed or were unsure if the government was hiding the number of vaccine-related deaths.<sup>9</sup> Other polls have found similar or even more alarming findings.<sup>10</sup>

This misinformation has taken its toll. According to the Surgeon General, it has “led people to decline COVID-19 vaccines, reject public health measures such as masking and social distancing, and use unproven treatments.”<sup>11</sup> It has also incited “harassment of and violence against” public health workers.<sup>12</sup> As we discuss in Part V, it has spurred litigation against health professionals and public health measures. In short, it has made a very bad situation far worse.

### III POST-TRUTH

Although health-related misinformation is not new, its impact during the pandemic has been especially worrisome. One reason is that COVID-19-related misinformation landed in a post-truth environment.

Defining “post-truth” is notoriously difficult, but for our purposes we might encapsulate “post-truth” as the widespread abandonment of any metric by which statements about the world can be judged correct or not. Delving into the nature and causes of the current post-truth environment would require exploring factors that include political polarization, the media environment,<sup>13</sup> loss of faith in experts and institutions,<sup>14</sup> and advances in our understanding of how preconceptions influence

<sup>7</sup> Rob Savillo & Tyler Monroe, Fox’s Effort to Undermine Vaccines Has Only Worsened, *Media Matters* (Aug. 9, 2021), [www.mediamatters.org/fox-news/foxs-effort-undermine-vaccines-has-only-worsened](http://www.mediamatters.org/fox-news/foxs-effort-undermine-vaccines-has-only-worsened).

<sup>8</sup> Liz Hamel et al., KFF COVID-19 Vaccine Monitor: Media and Misinformation, Kaiser Fam. Found. (Nov. 8, 2021), [www.kff.org/coronavirus-covid-19/poll-finding/kff-covid-19-vaccine-monitor-media-and-misinformation/](http://www.kff.org/coronavirus-covid-19/poll-finding/kff-covid-19-vaccine-monitor-media-and-misinformation/).

<sup>9</sup> *Id.*

<sup>10</sup> Observatory on Social Media, Tracking Public Opinion About Unsupported Narratives (June 2021), <https://osome.iu.edu/research/white-papers/Tracking%20Public%20Opinion%20Wave%207.pdf>.

<sup>11</sup> Murthy, *supra* note 1, at 4.

<sup>12</sup> *Id.*

<sup>13</sup> See Mark Jurkowitz et al., U.S. Media Polarization and the 2020 Election: A Nation Divided, *Pew Rsch. Ctr.* (Jan. 24, 2020), [www.journalism.org/2020/01/24/u-s-media-polarization-and-the-2020-election-a-nation-divided](http://www.journalism.org/2020/01/24/u-s-media-polarization-and-the-2020-election-a-nation-divided).

<sup>14</sup> Tom Nichols, *The Death of Expertise: The Campaign against Established Knowledge and Why It Matters* (2017).

our perception of the facts.<sup>15</sup> Here, we focus on three key attributes and the forces that helped propel them.

As an illustration, consider the debate over the safety of the measles-mumps-rubella vaccine. A strong scientific consensus affirms that it does not cause autism.<sup>16</sup> Nevertheless, a zealous movement of vaccine skeptics, who spread misinformation across social media and elsewhere, have questioned that consensus.<sup>17</sup>

A political community grounded in truth would ask questions and encourage continued research (which has taken place) and debate the questions raised. In a healthy informational environment, debate would be informed by the best available evidence. To put it another way, the research consensus would matter to and influence skeptics.

Such a search for truth, of course, would not guarantee consensus. On many issues, although not the vaccine–autism link, experts disagree. Moreover, many policy choices blend questions of scientific fact (do vaccines cause autism?) with social/economic/political and value choices (should vaccines be mandated?). Nevertheless, a well-functioning democracy depends upon decision-making processes that include reliance on experts to develop an agreed-upon set of facts and ongoing dialogue among voters and public officials about policy responses.

How might a society slip down the path toward post-truth so that the scientific consensus settles so few questions? Part of the answer may rest in breaches of trust by powerful public and private leaders, as exemplified by the *Pentagon Papers* and the lies leading to the Iraq War.

Deceptions in biomedical research, such as the infamous Tuskegee experiments or Elizabeth Holmes's fantasies about miraculous home blood tests, offer powerful grounds for distrust. Trust can also be undermined when officials offer seemingly inconsistent advice. For example, early statements from government officials, such as Dr. Anthony Fauci,<sup>18</sup> suggesting that masks would not protect the general population (grounded in part by a desire to preserve the limited supply of N95 masks for health care workers) undoubtedly hindered later efforts to encourage masks once scientists knew more about the transmission of COVID-19.

Even the most spectacular fabrications, however, need not generate more than a culture of healthy suspicion. Post-truth also requires the discreditation of science, a process that was fueled by the efforts of powerful industries, such as tobacco

<sup>15</sup> See, for example, Jamin Halberstadt et al., Emotional Conception: How Embodied Emotion Concepts Guide Perception and Facial Action, 20 *Psych. Sci.* 1254 (2009).

<sup>16</sup> Vaccine Safety: Autism and Vaccines, Ctrs. for Disease Control & Prevention, [www.cdc.gov/vaccinesafety/concerns/autism.html](http://www.cdc.gov/vaccinesafety/concerns/autism.html) (last visited Jan. 13, 2021).

<sup>17</sup> See, for example, Michiko Kakutani, *The Death of Truth* (2018); Larson, *supra* note 2; David A. Broniatowski et al., Weaponized Health Communication: Twitter Bots and Russian Trolls Amplify the Vaccine Debate, 108 *Am. J. Pub. Health* 1378 (2018).

<sup>18</sup> Grace Panetta, Fauci Says He Doesn't Regret Telling Americans Not to Wear Masks at the Beginning of the Pandemic, *Bus. Insider* (July 16, 2020), [www.businessinsider.com/fauci-doesnt-regret-advising-against-masks-early-in-pandemic-2020-7](http://www.businessinsider.com/fauci-doesnt-regret-advising-against-masks-early-in-pandemic-2020-7).

companies and fossil fuel companies, to undermine the very idea of science in order to deflect criticism and regulation.<sup>19</sup> The resulting loss of confidence in science and the value of a productive exchange of views, informed by the guidance of experts, is the first attribute in the slide toward post-truth.

Our polarized era, however, has fostered an acceleration of a second key attribute of the rise of post-truth: a tendency to make decisions by relying on personal intuition and advice from those who share one's background and values, rather than those who have developed knowledge through lengthy study and professional experience. At first glance, asking people to rely on their own best judgment may seem like good old-fashioned American self-reliance. Personal decision-making founders, however, in the face of challenging aspects of contemporary life. Consumer markets, for example, demand that everyone become educated on multiple topics, from electricity rates to health insurance plans.<sup>20</sup> Mastering the many choices we face is impossible.

Yet, without trust in experts, individuals turn to the Internet and social media to glean information that confirms their previous, often uninformed, predilections. In this environment, the wondrous availability of information that originally promised the democratization of knowledge perversely facilitates the manipulation of preferences. Post-truth flourishes when people who must make more choices than they can rationally handle rely on the counsel of nonexperts whose interests or views they share. Thus, just as consumers rely on advertisements on their favorite channels or media sites to make product choices, they begin to base their health decisions on affinity and political affiliation. How else could the wisdom of wearing masks or being vaccinated turn on party affiliation, an observation confirmed in a Gallup survey revealing that as of mid-September 2021, 92 percent of Democrats had been vaccinated against COVID-19, as compared to only 68 percent of Independents and only 56 percent of Republicans.<sup>21</sup>

It gets worse. As individual choices move from reliance on expertise to group affiliation, choices tend to reinforce themselves. Just as sports fans view referee calls through the lens of their team affiliation,<sup>22</sup> people who identify with a social movement, such as anti-vaxxers, are likely to view new evidence through lenses they have already adopted. Cognitive mechanisms, including confirmation bias and the Dunning-Kruger effect, magnify distortions as people weigh new information that reinforces their predispositions more heavily, and those who know little about a

<sup>19</sup> See Naomi Oreskes & Erik M. Conway, *Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Climate Change* (2010).

<sup>20</sup> Barry Schwartz, *The Paradox of Choice: Why More is Less* (2004).

<sup>21</sup> William A. Galston, *For COVID-19 Vaccinations, Party Affiliation Matters More than Race and Ethnicity*, Brookings (Oct. 1, 2021), [www.brookings.edu/blog/fixgov/2021/10/01/for-covid-19-vaccinations-party-affiliation-matters-more-than-race-and-ethnicity/](https://www.brookings.edu/blog/fixgov/2021/10/01/for-covid-19-vaccinations-party-affiliation-matters-more-than-race-and-ethnicity/).

<sup>22</sup> See Albert H. Hastorf & Hadley Cantril, *They Saw a Game: A Case Study*, 49 *J. Abnormal Psych.* 129, 129–34 (1954).

subject are apt to overestimate their knowledge.<sup>23</sup> As people find themselves more deeply attached to the choices of their group, they grow steadily more comfortable with the idea that contestation about which policy to pursue or which health choice to make is more about “winning” the argument than finding the truth. And thus we slide still further toward the third attribute of post-truth: a high comfort level with the idea that there is no such thing as a fact. This “what me, worry?” stance combines rejection of one’s civic duty to remain open-minded toward the ideas of experts and fellow citizens with a self-flattering notion that protects people from accepting that they are ever wrong. The result is a world in which people not only believe and act on misinformation, but in which they dismiss contrary evidence, sometimes even on their deathbeds.<sup>24</sup>

#### IV POST-TRUTH HEALTH – THE RISE OF PATIENT DECISION-MAKING

Why was post-truth so prominent during the pandemic? Why did mounting deaths and overcrowded hospitals not cause more people to follow the advice of experts? In this part, we explore the role that health law and bioethics may have inadvertently played in leading Americans to believe that they, rather than the experts, were both adept at and responsible for making decisions about COVID-19. In so doing, we provide neither a full history nor a critical assessment of the developments we discuss as there is an abundant literature. We also readily acknowledge that many other factors, including the rise of right-wing populism and ideological opposition to legal protections for some rights (e.g., abortion and gay rights), have also fueled doubts about expertise and truth. Nevertheless, accepting that law nurtures and reinforces social norms,<sup>25</sup> we highlight some ways in which legal developments may have altered norms about truth and expertise with respect to health.

##### *A Informed Consent and Patient Decision-Making*

In the fall of 2021, several COVID-19 patients sought court orders requiring their physicians to give them ivermectin and other non-standard treatments.<sup>26</sup> As we discuss

<sup>23</sup> See, for example, Justin Kruger & David Dunning, Unskilled and Unaware of It: How Difficulties in Recognizing One’s Own Incompetence Lead to Inflated Self-Assessments, 77 *J. Pers. Soc. Psych.* 1121 (1999).

<sup>24</sup> Paulina Villegas, South Dakota Nurse Says Many Patients Deny the Coronavirus Exists – Right Up Until Death, *Wash. Post* (Nov. 16, 2020), [www.washingtonpost.com/health/2020/11/16/south-dakota-nurse-coronavirus-deniers/](http://www.washingtonpost.com/health/2020/11/16/south-dakota-nurse-coronavirus-deniers/).

<sup>25</sup> Michael McCann, Law and Social Movements, Contemporary Perspectives, 2 *Ann. Rev. L Soc. Sci.* 17, 21 (2006).

<sup>26</sup> See Jennifer Bard, Legal and Ethical Analysis of Court-Ordered Ivermectin Treatment for COVID-19, *Bill of Health* (Sept. 2, 2021), <https://blog.petrieflom.law.harvard.edu/2021/09/02/court-ordered-ivermectin-covid/>.

in Part V, such cases constitute the problematic but logical endpoint of health law's long march to promoting informed consent and patient decision-making.

An important early impetus for this march was the revulsion against the "experiments" by Nazi physicians on concentration camp victims. In 1947, the judges presiding over the doctors' trial issued the Nuremberg Code, which declared that "voluntary consent" of human subjects was "absolutely essential" to the ethical conduct of medical research.<sup>27</sup> The following year, the World Medical Association included patient autonomy as a key component of the "physician's pledge."<sup>28</sup>

Despite these advances, the abuse of human subjects continued. In the United States, the most notable (but hardly only) atrocity was the Tuskegee syphilis study, which tracked, but did not treat or inform, hundreds of Black men who had syphilis, even after the development of antibiotics.<sup>29</sup> Following the uproar that greeted public reports about the study, Congress in 1974 established the National Commission for the Protection of Human Subjects of Biomedical Research.<sup>30</sup> In 1976, the Commission released the *Belmont Report*, which cited informed consent for human subjects as its first ethical principle.<sup>31</sup> This principle featured prominently in the Common Rule, which regulates human subject research conducted with federal funds.<sup>32</sup> Although the Rule has been criticized for insufficiently protecting human subjects,<sup>33</sup> and has been amended to tighten some provisions while providing further exemptions,<sup>34</sup> it helped recalibrate "the power imbalance between researchers and their subjects, and more broadly between physicians and patients."<sup>35</sup>

The law's support for informed consent extends to therapeutic encounters. In 1914, in *Schloendorff v. Society of New York Hospital*,<sup>36</sup> Justice Benjamin Cardozo stated that "every human being of adult years and sound mind has a right to determine what shall be done with his own body."<sup>37</sup> *Schloendorff*, however, did not

<sup>27</sup> Evelyne Shuster, *Fifty Years Later: The Significance of the Nuremberg Code*, 337 *New Eng. J. Med.* 1436, 1436 (1997).

<sup>28</sup> WMA Declaration of Geneva, World Med. Ass'n (July 9, 2018), [www.wma.net/policies-post/wma-declaration-of-geneva/](http://www.wma.net/policies-post/wma-declaration-of-geneva/).

<sup>29</sup> The Tuskegee Timeline, Ctrs. for Disease Control & Prevention, [www.cdc.gov/tuskegee/timeline.htm](http://www.cdc.gov/tuskegee/timeline.htm) (last visited Mar. 2, 2020); David M. Smolin, *The Tuskegee Syphilis Experiment, Social Change, and the Future of Bioethics*, 3 *Faulkner L. Rev.* 229, 229–33 (2012).

<sup>30</sup> Smolin, *supra* note 29, at 240.

<sup>31</sup> Nat'l Comm'n for the Prot. of Hum. Subjects of Biomed. & Behav. Rsch., *The Belmont Report* (Apr. 18, 1979), [www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c\\_FINAL.pdf](http://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf).

<sup>32</sup> Federal Policy for the Protection of Human Subjects ('Common Rule'), HHS.gov, [www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html](http://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html) (last visited Sept. 7, 2021).

<sup>33</sup> See Scott Jaschik, *New 'Common Rule' for Research, Inside Higher Ed* (Jan. 19, 2017), [www.insidehighered.com/news/2017/01/19/us-issues-final-version-common-rule-research-involving-humans](http://www.insidehighered.com/news/2017/01/19/us-issues-final-version-common-rule-research-involving-humans).

<sup>34</sup> Paul Smith & Andrea Frey, *Modernizing the Common Rule: Federal Agencies Revise Rule on the Protection of Human Subjects*, 29 *Health L. 10*, 10–11 (2017).

<sup>35</sup> Smolin, *supra* note 29, at 240.

<sup>36</sup> 105 N.E. 92 (NY 1914).

<sup>37</sup> *Id.* at 93.

establish a cause of action for informed consent.<sup>38</sup> That came only after the social movements of the 1960s and 1970s invigorated a “profound suspicion and distrust of constituted authority,” including medical authority.<sup>39</sup>

In 1972, in *Cobbs v. Grant* and *Canterbury v. Spence*, the Supreme Court of California and the DC Court of Appeals, respectively, held that physicians had a duty to inform patients about the risks relating to treatment that a reasonable patient would find material.<sup>40</sup> Each court rooted this duty in both the patient’s right to self-determination and the physician’s expertise. The *Cobbs* court explained:

[T]o the physician whose training and experience enable a self-satisfying evaluation, the particular treatment which should be undertaken may seem evident, but it is the prerogative of the patient, not the physician, to determine for himself the direction in which he believes his interests lie. To enable the patient to chart his course knowledgeably, reasonable familiarity with the therapeutic alternatives and their hazards becomes essential.<sup>41</sup>

True, the tort of informed consent, as opposed to the ethical principle, always promised more to patient autonomy than it delivered.<sup>42</sup> For one thing, not all jurisdictions adopted the “reasonable patient” standard.<sup>43</sup> Moreover, those that did required only that physicians provide the information that a reasonable patient, rather than the actual patient, would find material.<sup>44</sup> Courts also limited claims to cases in which patients could show an adverse health outcome; they also recognized several exceptions, including when physicians believed that obtaining informed consent would be harmful to a patient.<sup>45</sup>

Nevertheless, the doctrine promoted the “ethical shift away from professional paternalism (following the doctor’s identification of the patient’s best interest) and toward individual autonomy (letting the patient decide, once fully informed, what was best).”<sup>46</sup> This approach was quickly embraced by the burgeoning field of bioethics, which treated autonomy as its most important principle.<sup>47</sup> Ultimately, medical practice and the larger culture adopted this shift.

<sup>38</sup> *Id.* at 95.

<sup>39</sup> David Rothman, *The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective*, 9 *Health Care Analysis* 255, 256 (2001).

<sup>40</sup> *Canterbury v. Spence*, 464 F.2d 772, 786–87 (D.C. Cir. 1972); *Cobbs v. Grant*, 502 P.2d 1, 11 (Cal. 1972).

<sup>41</sup> 502 P.2d at 10.

<sup>42</sup> See Jay Katz, *Informed Consent – Must It Remain a Fairy Tale?*, 10 *J. Contemp. Health L. Pol’y* 69, 71, 84–85 (1994).

<sup>43</sup> See S. Allan Adelman, *The Evolution of Patient Rights: Individual Benefits and Provider Burdens*, 10 *J. Health Life Sci. L.* 66, 69 (2017).

<sup>44</sup> See *Canterbury*, 464 F.2d at 781–82, 785–87; *Cobbs*, 502 P.2d at 12.

<sup>45</sup> See Katz, *supra* note 42, at 77–78.

<sup>46</sup> Charity Scott, *Why Law Pervades Medicine: An Essay on Ethics in Health Care*, 14 *Notre Dame J. L. Ethics Pub. Pol’y* 245, 266 (2000).

<sup>47</sup> Leslie Francis et al., *How Infectious Disease Got Left Out – and What This Omission Might Have Meant for Bioethics*, 19 *Bioethics* 307, 311–13 (2005); Jonathan F. Will, *A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part 2: The Autonomy Model*, 139 *Chest J.* 1491, 1495–96 (2011).



The embrace of patient autonomy was also evident in the recognition that competent patients could choose whether to continue life-sustaining care, and that the wishes of formerly competent patients should be followed even after they were no longer competent.<sup>48</sup> In *Cruzan v. Director, Missouri Department of Health*, the majority of the justices of the Supreme Court even seemed to accept that the Constitution offered some protection for patient decision-making regarding end-of-life treatment.<sup>49</sup> While states currently employ different ways of respecting private decision-making, the idea that the decision should be reserved to the patient, rather than the physician, is now widely accepted.

### B *The Women's Health Movement and Reproductive Rights*

Doctrines that developed in the second half of the twentieth century around reproductive rights furthered the idea that patients should have a right to determine their own health care.

The story begins in 1965, when in *Griswold v. Connecticut* the Supreme Court struck down a Connecticut law prohibiting married couples from using contraceptives as violating the “right to privacy.”<sup>50</sup> Eight years later, in *Roe v. Wade*, the Court held that “the right of personal privacy includes the abortion decision.”<sup>51</sup> The *Roe* Court, however, did not see that right as one of personal decision-making. Rather, it held that in the first trimester, the choice should be “left to the medical judgment of the pregnant woman’s attending physician.” Despite the *Roe* Court’s attempt to tie the “right to an abortion” to medical judgment, the battle over abortion quickly transformed into one between a “woman’s right to choose” and the state’s interest in protecting “the right to life.”<sup>52</sup> Without recounting those debates and the many doctrinal detours, suffice it to say that, for many, support for abortion became synonymous with the claim that patients have a right to “choose” what happens to their body. At the same, litigation over abortion restrictions has highlighted questions of “expertise and credibility,” as abortion opponents began relying on the claim, unsupported by credible science, that abortion harmed women’s health.<sup>53</sup> Thus abortion became another arena in which many trumpeted patient decision-making, while science itself became discredited.<sup>54</sup>

<sup>48</sup> James Bopp, Jr. & Daniel Avila, Trends in the Law: From Death to Life, 27 *Idaho L. Rev.* 1, 9–10 (1990).

<sup>49</sup> *Cruzan v. Dir., Mo. Dep’t Health*, 497 U.S. 261, 270 (1990).

<sup>50</sup> 381 U.S. 479, 484–85 (1965).

<sup>51</sup> 410 U.S. 113, 154 (1973).

<sup>52</sup> David J. Garrow, Abortion before and after *Roe v. Wade*: An Historical Perspective, 62 *Albany L. Rev.* 833, 837, 841 (1999).

<sup>53</sup> See Mary Ziegler, Abortion Politics Polarized Before *Roe*. When It’s Gone, the Fighting Won’t Stop, *Wash. Post* (Oct. 22, 2020), [www.washingtonpost.com/outlook/2020/10/22/roe-polarize-abortion-politics/](https://www.washingtonpost.com/outlook/2020/10/22/roe-polarize-abortion-politics/).

<sup>54</sup> See Aziza Ahmed, Medical Evidence and Expertise in Abortion Jurisprudence, 41 *Am. J. L. Med.* 85, 89–90, 99–103 (2015). As this chapter was in publication *Roe v. Wade* was overruled. *Dobbs v. Jackson Women’s Health Org.*, 142 S.Ct. 2228 (2022).

Importantly, the women's health movement supported not merely abortion rights but broader access for women to information about their health, sexuality, and reproduction. It also "expressed general dissatisfaction with the treatment of women by a patriarchal, technocratic medical system,"<sup>55</sup> and pressured regulatory agencies to more fully respect women's autonomy. It is not, therefore, surprising that the first foray by the Food and Drug Administration (FDA) into mandating direct-to-consumer labeling concerned oral contraceptives.<sup>56</sup> A few years later, the agency required patient labeling for estrogen replacements.<sup>57</sup> These changes were followed in 1979 by a proposal by the FDA that would have required most prescription drugs to be labeled "in nontechnical language that is directed to the patient."<sup>58</sup>

Courts also began to recognize patients' independent role by holding that drug-makers have a duty to warn patients, and not only their doctors, about the risks associated with birth control. As the Eighth Circuit explained in *Hill v. Searle Laboratories*, "[i]n the case of birth control, ... the patient makes an independent decision as to whether she desires a prescription drug for birth control, and if so, which method she prefers, with only limited input from the prescribing physician."<sup>59</sup> Such doctrinal and regulatory changes helped alter how patients and experts understood their relationship. Where the doctrine of informed consent initially assumed that patients required their physician's help to understand medical information, patients were now deemed capable of comprehending and assessing that information on their own, even as scientific evidence became increasingly contested.

### C AIDS Activism and the Right to Treatment

The push for a patient's right to choose a treatment over the objections of medical authority or the state extended beyond reproductive and sexual health. In the 1970s, in a battle that foreshadowed today's fight over ivermectin, some cancer patients began to demand that the FDA approve laetrile, a derivative of apricots that its supporters claimed – without any scientific proof – cured cancer.<sup>60</sup> Protests and hearings were held; court battles ensued. In 1979, the Supreme Court upheld the FDA's determination that laetrile was not reasonably safe or

<sup>55</sup> Lewis Grossman, FDA and the Rise of the Empowered Consumer, 66 *Admin. L. Rev.* 627, 638 (2014).

<sup>56</sup> 21 C.F.R. § 310.501 (1970).

<sup>57</sup> Grossman, *supra* note 55, at 653–54; see also Requirement of Labeling Directed to the Patient, 21 C.F.R. § 310.515 (1977).

<sup>58</sup> Prescription Drug Products; Patient Labeling Requirements, 44 Fed. Reg. 40,016, 40,016 (July 6, 1979). For current regulations related to labeling directed at laypersons, see 21 C.F.R. § 208 et seq.

<sup>59</sup> 884 F.2d 1064 (8th Cir. 1989); see also *Odgers v. Ortho Pharmaceutical Corp.*, 609 F.Supp. 867 (E.D. Mich. 1985).

<sup>60</sup> See generally *Politics, Science and Cancer: The Laetrile Phenomenon* (Gerald E. Markle & James C. Petersen eds., 2019).

effective.<sup>61</sup> Nevertheless, as Lewis Grossman explains, the controversy “demonstrated how popular movements for freedom of choice could shake FDA to its foundations.”<sup>62</sup>

AIDS activists posed a far greater, and more lasting, threat to the FDA’s authority. People living with HIV and AIDS and their allies pushed for a dramatic expansion of research into HIV/AIDS, as well as a greater role for patients in the design and implementation of clinical trials.<sup>63</sup> Their efforts helped “introduce into the mainstream the argument, now often deployed, that patients, in consultation with their doctors, should be able to perform their own risk-benefit balancing, particularly when fatal and disabling diseases are at issue.”<sup>64</sup> Their demands also spurred statutory and regulatory changes diminishing the FDA’s gatekeeping role. For example, in 1986, the FDA allowed the investigational AIDS drug AZT to be prescribed outside of clinical trials.<sup>65</sup> The agency also proposed a new rule formalizing the compassionate use of investigational drugs.<sup>66</sup> In 1997, Congress passed the FDA Modernization Act of 1997, which created a new “fast track” procedure to expedite approval of life-saving drugs.<sup>67</sup>

Advocates for patients with other diseases soon followed the “model for direct patient involvement in FDA decision-making employed by AIDS activists.”<sup>68</sup> Their combined efforts led to significant expansion of so-called compassionate use policies, culminating in the 21st Century Cures Act, which requires pharmaceutical companies to make those policies publicly available.<sup>69</sup>

Concomitantly, manufacturers worked with consumer groups to push for the Dietary Supplement Health Education Act of 1994, which allowed manufacturers to sell dietary supplements (including herbs, vitamins and botanicals) “without submitting proof of efficacy or safety.” Only after several widely reported incidents of harm associated with dietary supplements did Congress in 2007 require manufacturers to report adverse events to the FDA.<sup>70</sup> These regulations still do not require pre-marketing review. They leave it to the consumer to assess the risks and benefits

<sup>61</sup> *United States v. Rutherford*, 442 U.S. 544, 555–59 (1979).

<sup>62</sup> Grossman, *supra* note 55, at 668. See also Lewis A. Grossman, *Choose Your Medicine: Freedom of Therapeutic Choice in America* 149–61 (2021).

<sup>63</sup> Raymond A. Smith & Patricia D. Siplon, *Drugs into Bodies: Global AIDS Treatment Activism* (2006); Steven Epstein, *The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in Reform of Clinical Trials*, 20 *Sci. Tech. Hum. Values* 408, 415–16 (1995).

<sup>64</sup> Grossman, *supra* note 55, at 673.

<sup>65</sup> *Id.* at 669.

<sup>66</sup> *Id.* at 669.

<sup>67</sup> Grossman, *supra* note 55, at 671–72.

<sup>68</sup> Grossman, *Choose Your Medicine*, *supra* note 62 at 192.

<sup>69</sup> 21st Century Cures Act, Pub. L. No. 114-255, § 3032, 130 Stat. 1033, 1100 (2016) (codified at 21 U.S.C. 360bbb-o (2018)).

<sup>70</sup> Bimal H. Ashar, *The Dietary Supplement Health and Education Act: Time for a Reassessment*, 170 *Arch. Intern. Med.* 261, 261 (2010) (discussing Dietary Supplement Health and Education Act of 1994, Pub. L. No. 103-417, 108 Stat. 4325).

associated with a supplement.<sup>71</sup> Yet as Bimal H. Ashar has explained: “for a choice to be truly autonomous, there needs to be a substantial degree of understanding. Research suggests that this level of understanding is not typically present among patients regarding dietary supplement regulation.”<sup>72</sup>

#### D Commercial Speech

Even as health law and bioethics promoted patient decision-making, the Supreme Court’s evolving commercial speech doctrine handcuffed regulators’ ability to oversee health-related information conveyed by commercial entities. The Supreme Court’s early commercial speech decisions reflected the same anti-paternalistic sentiments that animated the law of informed consent and the right to make treatment decisions. For example, in one of its earliest commercial speech cases, *State Board of Pharmacy v. Virginia Citizens Consumer Council, Inc.*,<sup>73</sup> the Court emphasized the value of granting individuals access to information about drug costs. In recent years, however, the Court has granted more weight to the interests of commercial speakers and has made it increasingly difficult for regulators to protect the public against potentially harmful information about pharmaceuticals,<sup>74</sup> tobacco,<sup>75</sup> and other potentially dangerous products. The Court has also limited the government’s capacity to compel truthful health-related information,<sup>76</sup> even as patients are left with greater responsibility for making decisions related to their health.

The Court’s increasing solicitude for commercial speech aligns with a deregulatory agenda that furthers the interests of powerful industries whose products endanger the health of consumers.<sup>77</sup> It has also spurred the FDA to loosen the regulation of commercial speech in the name of patient empowerment.<sup>78</sup> These developments in turn helped to unleash the proliferation of DTCA of pharmaceuticals and other health-related products. By 2005, DTCA comprised 40 percent of total pharmaceutical promotional expenditures.<sup>79</sup>

DTCA allows pharmaceutical companies to bypass physicians as gatekeepers. Ideally, patients use the information they learn through DTCA to communicate

<sup>71</sup> Dietary Supplement and Nonprescription Drug Consumer Protection Act, Pub. L. No. 109-462, 120 Stat. 3469 (2006).

<sup>72</sup> George Kennett, Time for Change: Stepping up the FDA’s Regulation of Dietary Supplements to Promote Consumer Safety and Awareness, 33 *J. L. Health* 47, 60 (2019).

<sup>73</sup> Ashar, *supra* note 70, at 262.

<sup>74</sup> 425 U.S. 748 (1976).

<sup>75</sup> *Thompson v. Western States Med. Ctr.*, 535 U.S. 357 (2002).

<sup>76</sup> See, for example, *R.J. Reynolds Tobacco Co. v. FDA*, 845 F.Supp.2d 266 (D.D.C. 2012).

<sup>77</sup> *Nat’l Institute of Fam. & Life Advocs. v. Becerra*, 138 S.Ct. 2361 (2018).

<sup>78</sup> See Morgan N. Weiland, Expanding the Periphery and Threatening the Core: The Ascendant Libertarian Speech Tradition, 69 *Stan. L. Rev.* 1389, 1454 (2017).

<sup>79</sup> See Julie Donohue, A History of Drug Advertising: The Evolving Roles of Consumers and Consumer Protection, 84 *Milbank Q.* 659 (2006).

effectively with their physician.<sup>80</sup> Less positively, DTCA can stimulate unwarranted demand for prescriptions and weaken the physician–patient relationship,<sup>81</sup> as patients no longer need to rely on their physicians to learn about treatments. Indeed, in some instances, patients who learn about a medication through DTCA need not even contact (never mind rely on) their health care provider, as advertisers willingly supply them with physicians who will (without any in-person examination or existing relationship) prescribe the advertised medication.<sup>82</sup> In such cases, the original ideal of informed consent – in which physicians provide patients with information they need to know – remains only in form, as health care decisions increasingly become detached from professional expertise.

## V POST-TRUTH DURING A PANDEMIC

In early November 2021, Aaron Rodgers, star quarterback for the Green Bay Packers, announced that he had contracted COVID-19. Rodgers, who had previously said he was “immunized” against COVID-19, explained that he was unvaccinated, and that while conferring with his physician, he was also consulting podcast host Joe Rogan, and taking not only monoclonal antibodies (which had been authorized to treat COVID-19) but also ivermectin, hydroxychloroquine, and vitamins, none of which have been shown to be effective.<sup>83</sup> Rodgers’ announcement was startling only because of his fame. His reliance on nonexperts and his willingness to take unproven (and potentially harmful) drugs was far too common. Indeed, across the country, COVID-19 patients insisted that their physicians prescribe unapproved elixirs. In at least two dozen cases, patients went to court to force their physicians to provide such “treatments.”<sup>84</sup> A few lower court judges granted such orders.<sup>85</sup>

In one sense, such cases are a perversion of informed consent and patient empowerment.

Again, in its initial formulation, informed consent imposed a duty on physicians to share their expertise with patients. It did not dispense with the idea of expertise, or suggest that patients could force physicians to provide treatments that

<sup>80</sup> *Id.*

<sup>81</sup> *Id.* at 683–85.

<sup>82</sup> Jessica T. DeFrank et al., Direct-to-Consumer Advertising of Prescription Drugs and the Patient–Prescriber Encounter: A Systematic Review, 35 *Health Comm.* 739 (2020); Anna A. Filipova, Relationship of Direct-to-Consumer Advertising to Efficiency of Care, Quality of Care, and Health Outcomes, 42 *J. Healthcare Quality* e18 (2020).

<sup>83</sup> Example, How Do I Get It?, Anovera, [www.annovera.com/how-do-i-get-it](http://www.annovera.com/how-do-i-get-it) (last visited Jan. 24, 2021).

<sup>84</sup> Aaron Rodgers Explains Decision to Not Get COVID-19 Vaccination in His First Comments Since Positive Test, NFL (Nov. 5, 2021), [www.nfl.com/news/aaron-rodgers-explains-decision-to-not-get-covid-19-vaccination-in-first-comment](http://www.nfl.com/news/aaron-rodgers-explains-decision-to-not-get-covid-19-vaccination-in-first-comment).

<sup>85</sup> Deepti Hajela, Lawsuits Demand Unproven Ivermectin for COVID Patients, AP News (Oct. 16, 2021), <https://apnews.com/article/coronavirus-pandemic-business-health-new-york-lawsuits-7ab397f269d1fb9083bb782f9bfc2317>.

the profession viewed as harmful. In other ways, however, such cases are a logical extension of legal protections for patient decision-making, which emphasize patients' own agency. Patients' insistence on treatments that their physicians do not recommend also flows naturally from DTCA, where manufacturers bypass physicians to speak directly to patients. Indeed, the web presence of groups such as America's Frontline Doctors,<sup>86</sup> which promotes ivermectin and other unproven treatments, sells tee shirts, and offers to connect patients to physicians who will prescribe ivermectin for a \$90 fee, relies on patients expecting to make their own decisions and a legal regime that permits DTCA. Such groups also depend on the erosion of trust of regulatory agencies, such as the FDA and Centers for Disease Control and Prevention (CDC).

Health law's embrace of patient decision-making devoid of expertise has perhaps been most evident in resistance to vaccine and mask mandates. As noted above, misinformation about masking and vaccines has been rampant. More troubling, and more connected to post-truth, is the common refrain that lay individuals should have the "right" to decide the benefits of both masking and vaccines. At times, even CDC director Dr. Rochelle Walensky has seemed to agree, stating, "[w]e really want to empower people to take this responsibility [to mask] into their own hands."<sup>87</sup> Some governors have joined the refrain, arguing that mandates undermine "freedom."<sup>88</sup>

The principle of informed consent has always co-existed uneasily with vaccine mandates.<sup>89</sup> Nevertheless, until COVID-19, their constitutionality was well-established.<sup>90</sup> In the post-truth environment, that is no longer certain, as the cry for individual decision-making has led to a deluge of cases challenging vaccine mandates. Although the legal claims raised and the doctrines implicated vary (and are beyond the scope of this discussion), the plaintiffs share the view that individuals, rather than experts, should decide whether the risks of vaccination outweigh the benefits. Further, they conceptualize vaccination as a personal, rather than a public health, issue. To the plaintiffs, and at least some judges,<sup>91</sup> neither expertise, medical authority, nor the public's welfare seems to count as much as individuals' subjective determination of what is true and false and what they want to do.

<sup>86</sup> Id.

<sup>87</sup> America's Frontline Doctors, <https://americasfrontlinedoctors.org/>.

<sup>88</sup> Ed Yong, *The Fundamental Question of the Pandemic Is Shifting: We Understand How This Will End. But Who Bears the Risk that Remains?*, Atlantic (June 9, 2021), [www.theatlantic.com/health/archive/2021/06/individualism-still-spoiling-pandemic-response/619133/](http://www.theatlantic.com/health/archive/2021/06/individualism-still-spoiling-pandemic-response/619133/).

<sup>89</sup> Memorandum from Taryn Fenske, Dir. of Commc'ns, Governor Ron DeSantis to Members of the Press, Governor DeSantis Issues an Executive Order Ensuring Parents' Freedom to Choose (July 30, 2021), [www.flgov.com/2021/07/30/governor-desantis-issues-an-executive-order-ensuring-parents-freedom-to-choose/](http://www.flgov.com/2021/07/30/governor-desantis-issues-an-executive-order-ensuring-parents-freedom-to-choose/).

<sup>90</sup> Wendy E. Parmet, *Informed Consent and Public Health: Are They Compatible When It Comes to Vaccines?*, 8 *J. Health Care L. Pol'y* 71 (2005).

<sup>91</sup> Example, *Zucht v. King*, 260 U.S. 174 (1922); *Jacobson v. Massachusetts*, 197 U.S. 11 (1905); *Does 1-3 v. Mills*, 142 S.Ct. 17 (2021) (Gorsuch, J., dissenting).

The outcome of this litigation remains for now uncertain. What is clear is that the proliferation of misinformation and the insistence on the rights of individuals to rely upon it helped to inflame the controversy over vaccination (and masking), adding to COVID-19's death toll. Perhaps even worse, it appears poised to spill over to other well-established public health tools, including vaccine mandates for schoolchildren. A world in which everyone gets to decide, bereft of evidence, which facts are true and which public health measures they should follow is a world endangered.

## VI CONCLUSION

So here we are with our post-truth, epistemologically subjective pandemic. In connecting the developments that we have outlined in health law to the post-truth pandemic, we hardly mean to suggest that health law and bioethics are solely or even primarily responsible for this crisis.

Indeed, we believe that the transformation of health law that we have described is as much symptom as cause. Still, this is an important moment for health law scholars to consider how health law and bioethics may have nurtured the seeds of post-truth and complicated our battle against COVID-19 and future threats.

By prioritizing individual choice and castigating paternalism, health law may have helped – however unintentionally – to erode trust in medical and scientific expertise. At the same time, health law has sent the message that each individual must be the decision-maker and therefore must determine what is true and not true regarding their own health, without having to consider the impact of their decisions on others. Faced with such a burden and power, patients understandably rely on their social media “friends,” DTCA, and the rabbit holes that algorithms send them down.

We readily acknowledge that there are no easy fixes. We certainly would not suggest that health law should – even if it could – go back to the time when “the doctor knows best.” As we have shown, the move to patient empowerment arose in response to significant abuses. We do, however, believe that it is critical to consider how laws that have aimed to enhance patient autonomy and weaken regulatory oversight of markets have facilitated post-truth. We must also explore how autonomy over one's own medical decisions can be respected without endangering public health and undermining respect for expertise. While we should not go back to the bad old days, we need to find a recalibration that values the common good and recognizes that its attainment requires that discourse be informed by science.

What COVID-19 has sadly taught us is that our descent into the post-truth world, augmented by our political divisions, can be deadly. In the wake of the pandemic, not to mention the climate crisis, we need to find ways to reject the epistemological nihilism of post-truth, and the overbearing insistence on an autonomy that elevates uninformed individual choice over the common good. Nature, alas, is not bemused by our subjectivity.