

IMPACT-BASED INFORMED CONSENT: WHAT PRIVACY LAWS CAN LEARN FROM THE ETHICS OF HUMAN SUBJECTS RESEARCH

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ABSTRACT

In the past twenty years, the rapid growth of data-intensive technologies such as smart devices and social media platforms has resulted in the collection and use of ever-expanding volumes and varieties of personal information. Despite this fundamental reshaping of our relationship with technology, the legal framework for consent that underpins much of this data use has remained relatively static. Given the extraordinary impacts that data has on society and individuals, that framework should change. The traditional privacy and data protection framework relies heavily on notice-and-consent. In this regime, entities that collect and process personal information from individuals are generally required to tell users about the mechanics of what they do: what categories of information will be collected (e.g., online activity), how it may be used (e.g., to personalize ads or improve user experience), and with whom it may be shared (e.g., third-party partners and vendors). The explanations provided in these privacy notices and terms of service rarely, however, describe what the likely impact to individuals or to society will be. Looking at the widely reported example of Instagram teen mental health research alleged by whistleblower Frances Haugen, this paper argues that traditional privacy law has a great deal to learn from the guidelines for informed consent that applies in federally funded biomedical and behavioral research. Under that framework, researchers must notify research subjects not only of what

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information will be collected and how it will be used (i.e., the mechanics of data use) but also what the likely impact of those uses will be, including risk of harm to the study participant, potential benefits to society, and the right to withdraw from the research. Applying this standard to information privacy—requiring entities, including commercial companies, to inform individuals about the likely impact of allowing their information to be used—would go a long way towards creating the conditions for meaningful informed consent: that is, towards creating a framework in which individuals can more fully understand the substantive consequences they are likely to experience if they consent to having their information collected or used.

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I. INTRODUCTION

Data-driven technologies are nearly inescapable in modern life. In 2020, there were more than 5 billion unique mobile phone users in the world, some 4.5 billion internet users, and roughly 3.8 billion active users of social media.¹ By October 2021, those numbers had grown to 5.3 billion unique mobile phone users and 4.55 billion social media users—a growth of more than 1 million new users every day.² The rapid rise of data-driven technologies has revolutionized nearly every aspect of modern life, making it ever-more difficult to fully participate in culture and society without some form of connection to devices, apps, platforms, and services that gather, analyze, and disseminate information about their users. The explosion in data types and uses has underscored the mismatch between existing privacy law frameworks and the ways in which information about individuals is collected and used. Recent allegations about research carried out by social media companies³ raise profound concerns about the lack of an enforceable ethics framework for data-driven companies that perform social science research and experiments using data from or about unwitting users. They also lend new urgency to the search for meaningful legal standards to mitigate the individual and societal harms that can result from this research—and a greater need to identify or create mechanisms for legal redress for the worst abuses.

This Article proposes a new framework for informed consent as one piece of the solution to those gaps. This new framework adopts best practices from the ethics principles governing human subjects research. Under it, the standard for informed consent would move away from its current emphasis on the *mechanics* of data collection and use, instead adopting a new focus on the *impact* of data collection and use. It would no longer be enough for companies to tell people how their data might be used; under this new standard, which could be imposed through consumer protection legislation, companies would have to inform people about what impact or harm they could suffer as a result of this data use.

Part II of this Article provides a summary of recent revelations regarding corporate research carried out by Meta, the company formerly

¹ DIGITAL 2020 GLOBAL OVERVIEW REPORT, <https://wearesocial.com/uk/blog/2020/01/digital-2020-3-8-billion-people-use-social-media/> (last visited Feb. 5, 2022) [<https://perma.cc/XG6N-MDTE>].

² DIGITAL 2021 OCTOBER GLOBAL STATSHOT REPORT, <https://wearesocial.com/uk/blog/2021/10/social-media-users-pass-the-4-5-billion-mark/> (last visited Feb. 5, 2022) [<https://perma.cc/LZ2H-QYAA>].

³ See *infra* Part II.

known as Facebook,⁴ relating to users of its Facebook and Instagram social media platforms, along with an explanation of why the Instagram research into teen mental health matters. Part III of this Article: (a) examines the existing notice-and-consent framework that underpins most data privacy laws; (b) explains the shortcomings of that approach to corporate research into users' online activity; and (c) debunks the myth that existing privacy laws stand as an impediment to transparency regarding corporate research. Part IV of this Article: (a) provides a brief history of the ethical principles governing human subjects research and (b) explains the requirements for "informed consent" in the human subjects research context—with a particular emphasis on the different standards for sufficiency of informed consent under most privacy laws and the ethics regulations for federally funded human subjects research. Part V discusses how Facebook has approached research ethics in its past activities and why the lack of transparency matters.

Against this backdrop, Part VI of this Article offers several approaches that could be used to mitigate the impacts and harms associated with unregulated corporate social science research that relies on the collection and use of personal information. It first focuses on incorporating the informed consent standard of human subjects research into the model for informed consent in privacy laws, by shifting the standard for informed consent to address the impact, rather merely than the mechanics, of data collection and use. It secondly focuses on Congressional establishment of a blue-ribbon commission to undertake a wide-ranging review of ethics in corporate use of personal data, empowered to make recommendations for new laws and regulatory bodies, voluntary ethics standards, public education and awareness campaigns, and more. Part V also briefly raises other possible mitigation measures, including the role of voluntary corporate review boards; forming new select Congressional committees empowered to review data-related issues that cut across the jurisdictional divides of existing committee frameworks; and gathering input for an Internet User's Online Data Bill of Rights.

II. THE FACEBOOK FILES

It's Meta's world, and we're all just living in it.

⁴ Mike Isaac, *Facebook Renames Itself Meta*, N.Y. TIMES (Nov. 10, 2021), <https://www.nytimes.com/2021/10/28/technology/facebook-meta-name-change.html> [https://perma.cc/G4CE-EPW5].

If that proposition had previously been in doubt, the Wall Street Journal's publication of the Facebook Files, a series of articles⁵ and podcasts⁶ based on company documents provided by a former Facebook employee,⁷ should lay any doubts to rest. Based on information provided by data scientist Frances Haugen, an insider-turned-whistleblower,⁸ the series contained

⁵ The Facebook Files were first published as a series of five articles in September 2021, along with a 5-part companion podcast, also released in September 2021. The initial series of articles included: Jeff Horwitz, *Facebook Says Its Rules Apply to All. Company Documents Reveal a Secret Elite That's Exempt*, WALL ST. J. (Sept. 13, 2021), <https://www.wsj.com/articles/facebook-files-xcheck-zuckerberg-elite-rules-11631541353>; Georgia Wells, Jeff Horwitz & Deepa Seetharaman, *Facebook Knows Instagram Is Toxic for Teen Girls, Company Documents Show*, WALL ST. J. (Sept. 14, 2021), <https://www.wsj.com/articles/facebook-knows-instagram-is-toxic-for-teen-girls-company-documents-show-11631620739>; Keach Hagey & Jeff Horwitz, *Facebook Tried to Make Its Platform a Healthier Place. It Got Angrier Instead*, WALL ST. J. (Sept. 15, 2021), <https://www.wsj.com/articles/facebook-algorithm-change-zuckerberg-11631654215>; Justin Scheck, Newley Purnell & Jeff Horwitz, *Facebook Employees Flag Drug Cartels and Human Traffickers. The Company's Response Is Weak, Documents Show*, WALL ST. J. (Sept. 16, 2021), <https://www.wsj.com/articles/facebook-drug-cartels-human-traffickers-response-is-weak-documents-11631812953>; Sam Schechner, Jeff Horwitz & Emily Glazer, *How Facebook Hobbled Mark Zuckerberg's Bid to Get America Vaccinated*, WALL ST. J. (Sept. 17, 2021), <https://www.wsj.com/articles/facebook-mark-zuckerberg-vaccinated-11631880296>.

⁶ The initial run of podcast episodes included *The Journal, The Facebook Files, Part 1: The Whitelist* (Sept. 13, 2021) (downloaded using Spotify); *The Journal, The Facebook Files, Part 2: 'We Make Body Image Issues Worse'* (Sept. 14, 2021) (downloaded using Spotify); *The Journal, The Facebook Files, Part 3: 'This Shouldn't Happen on Facebook'* (Sept. 18, 2021) (downloaded using Spotify); *The Journal, The Facebook Files, Part 4: The Outrage Algorithm* (Sept. 18, 2021) (downloaded using Spotify); *The Journal, The Facebook Files, Part 5: The Push To Attract Younger Users* (Sept. 29, 2021) (downloaded using Spotify). Additional podcasts discussing the Facebook Files have been released since this Article was first written; as more information related to Francis Haugen's whistleblower documents becomes publicly available, it is likely that additional analysis will be generated.

⁷ The corporate entity Facebook changed its name on October 28, 2021, just weeks after publication of the damning series of *Wall Street Journal* articles discussed in this Section. For clarity, this Article uses the company's new name, "Meta," to refer to the corporate parent's current instantiation. It uses "Facebook Files" to refer to the series of articles and associated allegations and whistleblower complaints. It uses "Facebook" to refer to the Facebook social media platform, and it uses "Instagram" to refer to the Instagram social media platform, both of which are owned and operated by Facebook-turned-Meta. Finally, the Article uses "Facebook" to refer to company actions, decisions, and status prior to the October 2021 name change.

⁸ Ryan Mac, *Who is Frances Haugen, the Facebook whistle-blower?*, N.Y. TIMES (Oct. 5, 2021), <https://www.nytimes.com/2021/10/05/technology/who-is-frances-haugen.html> [<https://perma.cc/253Y-PBT9>]; see also Bobby Allyn, *Here are 4 key points from the Facebook whistleblower's testimony on Capitol Hill*, NPR (Oct. 5, 2021), <https://www.npr.org/2021/10/05/1043377310/facebook-whistleblower-frances-haugen-congress> [<https://perma.cc/VQ3B-X2UL>].

explosive allegations charging Facebook (as the company was known at the time) with a wide range of socially and politically unsavory behavior. These included allowing prominent influencers to engage in abusive and other policy-violating behavior online,⁹ reconfiguring algorithms in ways that increased on-platform outrage while consciously choosing not to implement software changes that could blunt those effects,¹⁰ turning a blind eye to human trafficking,¹¹ and—according to a televised interview with Haugen—playing a central role in facilitating the planning of the riots at the U.S. Capitol building in Washington, D.C. on Jan. 6, 2021.¹² Within weeks of the articles’ publication in the *Wall Street Journal*, Haugen disclosed her identity; her story gained unprecedented traction in the brief history of a tech giant that had previously weathered scandal with relatively little impact.¹³ By the first week of October, Haugen had filed eight whistleblower complaints with the Securities and Exchange Commission (SEC),¹⁴ appeared on *60 Minutes*,¹⁵ testified before Congress,¹⁶ participated in panel discussions with academics and activists,¹⁷ and—demonstrating that her story had entered the zeitgeist—

⁹ See Horwitz, *supra* note 5; *The Facebook Files, Part 1: The Whitelist*, *supra* note 6.

¹⁰ See Hagey & Horwitz, *supra* note 5; *The Facebook Files, Part 4: The Outrage Algorithm*, *supra* note 6.

¹¹ Scheck, Purnell & Horwitz, *supra* note 5.

¹² *Whistleblower: Facebook is misleading the public on progress against hate speech, violence, misinformation*, 60 MINUTES (Oct. 3, 2021), <https://www.cbsnews.com/news/facebook-whistleblower-60-minutes-2021-09-30/> [<https://perma.cc/7AJB-F4SZ>].

¹³ See, e.g., Jaclyn Diaz, *Facebook’s new whistleblower is renewing scrutiny of the social media giant*, NPR (Oct. 4, 2021), <https://www.npr.org/2021/10/04/1042921981/facebook-whistleblower-renewing-scrutiny-of-social-media-giant> [<https://perma.cc/EDJ6-3JRQ>]; Day 6, *Episode 567: Facebook’s very bad week, Ted Lasso’s visual effects, WNBA gets vaccination right, the mascot whisperer & more*, CBC LISTEN (Oct. 9, 2021), <https://www.cbc.ca/listen/live-radio/1-14-day-6/clip/15871284-episode-567-facebooks-bad-week-ted-lassos-visual> [<https://perma.cc/4NUZ-R7BF>].

¹⁴ See Keith Zubrow, Maria Gavrilovic & Alex Ortiz, *Whistleblower’s SEC complaint: Facebook knew platform was used to “promote human trafficking and domestic servitude,”* 60 MINUTES OVERTIME (Oct. 4, 2021), <https://www.cbsnews.com/news/facebook-whistleblower-sec-complaint-60-minutes-2021-10-04/> (containing the 8 complaints in pop-out links) [<https://perma.cc/5VRH-BK4T>].

¹⁵ Keith Zubrow, *Facebook whistleblower says company incentivizes “angry, polarizing, divisive content,”* 60 MINUTES OVERTIME (Oct. 4, 2021), <https://www.cbsnews.com/news/facebook-whistleblower-frances-haugen-60-minutes-polarizing-divisive-content/> [<https://perma.cc/FYS7-ZV5U>].

¹⁶ *Protecting Kids Online: Testimony from a Facebook Whistleblower: Hearing Before the Subcomm. on Consumer Prot., Prod. Safety, and Data Sec. of the S. Com. Comm.*, 117th Cong. (2021) [hereinafter *Facebook Whistleblower*] (statement of Frances Haugen), <https://www.commerce.senate.gov/services/files/FC8A558E-824E-4914-BEDB-3A7B1190BD49> [<https://perma.cc/963X-4P3E>].

¹⁷ See, e.g., *The Facebook Files: What Next?*, YALE INFO. SOC’Y PROJECT (Oct. 7, 2021), <https://law.yale.edu/isp/events/facebook-files> [<https://perma.cc/GLE6-FU8K>].

was spoofed in a *Saturday Night Live* skit lampooning U.S. legislators for their blunders when questioning her and when trying to understand the tech industry landscape they sought to regulate.¹⁸

The fallout from the Facebook Files is likely to continue in upcoming months, as the SEC reviews Haugen's complaints, as state Attorneys General review potential consumer protection actions against the tech giant, and as plaintiff's lawyers examine the viability of privacy-related class action lawsuits or shareholder derivative claims.¹⁹ As more of the whistleblower documents become publicly available, these revelations are sure to prompt additional research and scholarship on a wide range of legal theories and regulatory proposals relating to data-driven technologies. In the meantime, this Article focuses on a particular dimension of the Facebook Files' revelations: the allegations that (a) the company conducted internal research on the effects of its social media platforms on the mental health of children and teens; (b) the research demonstrated that the platforms exacerbated a wide range of mental health issues, including anxiety, depression, body dysmorphia, eating disorders, and suicidal ideation; and (c) the company was aware of platform functionality changes that might alleviate those concerns, but chose not to implement those changes for fear that the modifications could reduce user engagement online, thus negatively impacting platform usage and corporate profits.²⁰

A. Why the Instagram Mental Health Research Matters

Haugen's revelations about the significant, negative impact that Instagram use has on teenagers' mental health were, in the words of Sen. Richard Blumenthal and Sen. Ted Cruz, a "bombshell."²¹ The specters of body

¹⁸ Mary Papenfuss, 'SNL's' 'Frances Haugen' Shows Up Congress As Possibly Even Worse Than Facebook, YAHOO NEWS (Oct. 10, 2021), <https://news.yahoo.com/snls-frances-haugen-shows-congress-071735289.html> [https://perma.cc/K5DS-WVCY].

¹⁹ See April Falcon Doss, *SEC Complaints: Fallout from the Facebook Files – Part 3*, JUST SEC. (Oct. 12, 2021), <https://www.justsecurity.org/78553/sec-complaints-fallout-from-the-facebook-files-part-3/> [https://perma.cc/S5K3-BPCN].

²⁰ Wells, Horwitz & Seetharaman, *supra* note 5; *The Facebook Files, Part 2: "We Make Body Image Issues Worse," supra* note 6; *Protecting Kids Online: Facebook, Instagram, and Mental Health Harm: Hearing Before the Subcomm. on Consumer Prot., Prod. Safety, and Data Sec. of the S. Com. Comm.*, 117th Cong. (2021), <https://www.commerce.senate.gov/2021/9/protecting-kids-online-facebook-instagram-and-mental-health-harms> [https://perma.cc/36XS-PU49].

²¹ *Protecting Kids Online, supra* note 20 (statement of Sen. Blumenthal), <https://www.rev.com/blog/transcripts/facebook-head-of-safety-testimony-on-mental-health-effects-full-senate-hearing-transcript> ("This research is a bombshell. It is powerful, gripping, riveting evidence that Facebook knows of the harmful effects of its site on children and that it has concealed those facts and findings.") [https://perma.cc/N4R5-UMSQ]; *id.* (statement

dysmorphia and eating disorders cast a dark pall across the landscape of teen mental health. Eating disorders have risen worldwide in the 21st century, from 3.5% of the population in 2000–2006 to 7.8% between 2013–2018.²² Some 28 million people in the U.S. suffer from an eating disorder,²³ with one study concluding that nearly one in five female and one in seven male individuals in the U.S. will have an eating disorder by the age of forty, with nearly all first-time cases occurring by the age of twenty-five.²⁴ Over 10,000 deaths each year are the direct result of an eating disorder—estimated at one death every 52 minutes—with 26% of people with eating disorders attempting suicide.²⁵ The statistics have only become more grim during the Covid-19 pandemic, as hospital admissions relating to eating disorders increased 25% for girls between twelve and eighteen years old.²⁶ In a hearing addressing the company’s research on Instagram and teens, Sen. Amy Klobuchar noted that research has shown that eating disorders carry the highest mortality rate among women of any mental health concern.²⁷

To understand the negative impact from Instagram use, it’s necessary to understand how the app functions and the nature of content that appears on it. Instagram’s core features, such as “likes” on photos and the Explore page,

of Sen. Cruz) (“So let me ask you, if 6% of American users trace their desire to kill themselves to Instagram, you just said that’s not bombshell research. Tell me, what would be bombshell research. If 6% is not, what would be? . . . Your characterization that this is not bombshell research is inaccurate. And for the parents who are losing their children, it is a bombshell in their lives.”).

²² Marie Galmiche, Pierre Déchelotte, Gregory Lambert & Marie Pierre Tivolacci, *Prevalence of Eating Disorders over the 2000-2018 Period: A Systematic Literature Review*, 109 AM. J. CLINICAL NUTRITION 1402, 1402 (May 2019), <https://doi.org/10.1093/ajcn/nqy342>.

²³ *Eating Disorder Statistics*, NAT’L ASSOC’N ANOREXIA NERVOSA & ASSOCIATED DISORDERS (2021), <https://anad.org/get-informed/about-eating-disorders/eating-disorders-statistics/> [<https://perma.cc/SS8X-6VTL>].

²⁴ Zachary J. Ward, Patricia Rodriguez, Davene R. Wright, S. Bryn Austin & Michael W. Long, *Estimation of Eating Disorders Prevalence by Age and Associations with Mortality in a Simulated Nationally Representative US Cohort*, JAMA NETWORK OPEN (Oct. 9, 2019), <https://doi.org/10.1001/jamanetworkopen.2019.12925>.

²⁵ *Id.*

²⁶ Dave Little, Adrianna Teriakidis, Eric Lindgren, Steven Allen, Eric Barkley & Lily Rubin-Miller, *Increase in Adolescent Hospitalizations Related to Eating Disorders*, EPIC HEALTH RSCH. NETWORK (Apr. 29, 2021), <https://ehrn.org/articles/increase-in-adolescent-hospitalizations-related-to-eating-disorders> [<https://perma.cc/XFL2-NE96>]; see also Sumathi Reddy, *Eating Disorders Surged Among Adolescents in Pandemic*, WALL ST. J. (June 21, 2021), <https://www.wsj.com/articles/eating-disorders-surged-among-adolescents-in-pandemic-11624302000>.

²⁷ *Protecting Kids Online*, *supra* note 20 (statement of Sen. Klobuchar) (“Studies have found that eating disorders actually have the highest mortality rate of any mental illness for women.”).

show users carefully curated or photoshopped content. Users see content based on algorithms designed to generate the most engagement, which can deeply and negatively impact teenage users' confidence and mental health. According to the information made public thus far, Facebook's research teams wrote that, "The tendency to share only the best moments, a pressure to look perfect and an addictive product can send teens spiraling toward eating disorders, an unhealthy sense of their own bodies and depression."²⁸ Features such as the Explore page, which relies on an algorithm to curate the photos and videos that will be presented in users' feeds, "can send users deep into content that can be harmful."²⁹ The Facebook research team's conclusions were stark: Facebook's own researchers have been quoted as saying that, "Aspects of Instagram exacerbate each other to create a perfect storm."³⁰ The correlation between the app and the outcome is striking: more than 40% of Instagram users who reported feeling unattractive and about 25% of the teens who reported feeling "not good enough" said those feelings started on Instagram, with many also reporting that the app undermined their confidence in the strength of their friendships.³¹ Faced with all of these negative effects, teens found themselves wanting to log off—and also found themselves unable to do so.³²

According to the whistleblower complaint filed with the SEC, Facebook's internal research over the course of "years" concluded that 13.5% of teen girls on Instagram say the platform makes thoughts of "Suicide and Self-Injury" worse; 17% of teen girls on Instagram say the platform makes "Eating Issues" (e.g., anorexia and bulimia) worse; and, perhaps most succinctly, the company's internal documents concluded that "[w]e make body image issues worse for 1 in 3 teen girls."³³ According to the *Wall Street Journal's* report, Facebook's internal research slides declared: "Teens blame Instagram for increases in the rate of anxiety and depression. This reaction was unprompted and consistent across all groups."³⁴

According to Haugen's allegations and the questioning from members of Congress, the company's research was extensive; its findings were undisclosed; the potential harms to users were grave; and proposed remedial actions were purposefully not taken. Taken together, these factors underscore the need for a set of legal standards that impose baseline obligations of

²⁸ See Wells, Horwitz & Seetharaman, *supra* note 5.

²⁹ *Id.*

³⁰ *Id.*

³¹ *Id.*

³² *Id.*

³³ Zubrow, Gavrilovic & Ortiz, *supra* note 14.

³⁴ Wells, Horwitz & Seetharaman, *supra* note 5.

transparency and accountability on corporations that conduct research that relies on users' data.

B. Scope and Limitations of this Article

Two distinct limitations on the scope of this Article should be noted. First, at the time this Article was being revised for publication, the allegations contained in the Facebook Files were only several months old. Although thousands of internal company documents have reportedly been provided to Congressional investigators, only a handful have been publicly released. As additional documents become publicly available, they will likely provide further insights into potential approaches to help stave off corporate misconduct in the future. Second, the full scope of allegations included in the Facebook Files encompass a wide range of harms stemming from the global operations of the company's platforms, from whitelisting accounts that violated terms of service, to human trafficking, to the spread of online disinformation, and more. In the interests of brevity and focus, this Article only attempts to address one: research regarding the harmful effects of Instagram use has on children and teens, as well as the light that those revelations shed on the need for reforming approaches to privacy law and informed consent when companies carry out social science research or experiments on users. It's likely that, as further information emerges and other analyses of the Facebook Files allegations are carried out, lawmakers, privacy advocates, academics, and others will be able to identify meaningful synergies, including ways that reforms developed to address one area of concern could ameliorate multiple harms. Consequently, this Article should be seen as an initial set of proposals—ones that will hopefully be useful for others examining both issues relating to teen mental health on Instagram, as well as the broader set of social harms relating to Meta's platforms and the company's behavioral and social science research relating to its users.

If we're all living in Meta's world now, unavoidable questions arise: Are we satisfied with the current balance of power between the company and individuals? And if not, how should our current approaches to privacy law be changed to address the harms caused by corporate social science research and experimentation that is largely invisible and unconstrained?

III. ONLINE DATA RESEARCH AND THE LIMITS OF PRIVACY LAW

In the 18 years since Facebook's founding, the social media company and its platforms have experienced staggering growth.³⁵ Meta's user base is unprecedented.³⁶ According to one recent set of metrics, the company now has almost 3 billion users worldwide on its primary platform, Facebook.³⁷ It also boasts 1.074 billion users on Instagram.³⁸ With a quarterly revenue of over \$9 billion and a market capitalization of roughly one trillion dollars, the company is also extraordinarily well-resourced.³⁹

Despite its global reach and massive user base, Meta's social media platforms are still only a subset of the Internet's social media ecosystem, and social media platforms offer just one way in which online user behavior can be tracked, catalogued, and assessed for purposes and in ways that users might not be fully cognizant of.

Although a great deal has been written about the challenges of content moderation and other approaches to addressing the harms that can result when users encounter harmful content—such as disinformation, revenge porn, or other objectionable content—while participating in the massive number of online interactions occurring on the company's platforms every day,⁴⁰ less attention has been paid to how the company could manage the safety and

³⁵ Facebook was founded in 2004. See *Facebook*, ENCYCLOPEDIA BRITANNICA, <https://www.britannica.com/topic/Facebook> (last visited Feb. 5, 2022) [<https://perma.cc/S52G-NAK9>].

³⁶ *Id.* (“Facebook became the largest social network in the world, with more than one billion users as of 2012.”).

³⁷ Maryam Moshin, *10 Facebook Statistics Every Marketer Should Know in 2021*, OBERLO (Feb. 16, 2021), <https://www.oberlo.com/blog/facebook-statistics> [<https://perma.cc/BC8S-KMXG>].

³⁸ Maryam Moshin, *10 Instagram Stats Every Marketer Should Know In 2021*, OBERLO (Feb. 16, 2021), <https://www.statista.com/statistics/183585/instagram-number-of-global-users/> [<https://perma.cc/P4BT-JLPG>].

³⁹ Kari Paul, *Facebook profits top \$9bn amid whistleblower revelations*, GUARDIAN (Oct. 25, 2021), <https://www.theguardian.com/technology/2021/oct/25/facebook-profits-earnings-report-latest> [<https://perma.cc/FM4R-S4MU>]; Salvador Rodriguez, *Facebook closes above \$1 trillion market cap for the first time*, CNBC (June 28, 2021), <https://www.cnbc.com/2021/06/28/facebook-hits-trillion-dollar-market-cap-for-first-time.html> [<https://perma.cc/V9SR-FEFP>].

⁴⁰ *Number of daily active Facebook users worldwide as of 3rd quarter 2021*, STATISTA (2021) (“During the third quarter of 2021, Facebook reported approximately 1.93 billion daily active users.”) <https://www.statista.com/statistics/346167/facebook-global-dau/> [<https://perma.cc/8RPJ-FQ9H>]. Instagram is estimated to have 500 million daily users at the beginning of 2021. See, e.g., Brent Barnhart, *The most important Instagram statistics you need to know for 2021*, SPROUTSOCIAL (Feb. 25, 2021), <https://sproutsocial.com/insights/instagram-stats/> [<https://perma.cc/5PX2-W4DW>]. It isn't known how many posts, likes, shares, or other online interactions take place on the platforms every day.

ethical dimensions of activities that users are likely never to be aware of, such as the company's own internal research on user data, and experimentation with ways to influence user behavior online. Ultimately, the Facebook Files' revelations on the psychological and emotional harms of Instagram brings new urgency to scrutinizing the legal and ethical frameworks, as well as potential enforcement mechanisms, that could govern behavioral science research and emotional manipulation experiments carried out by corporate actors under the guise of product improvement and user experience design.

A. The Limits of Existing Privacy Laws

To understand why data privacy laws do so little to prevent companies from undertaking social science research based on user data, it's worth taking a brief detour to discuss how privacy law frameworks generally address issues relating to corporate actors' collection and use of personal information. Additionally, it's useful to examine how the existing notice-and-consent framework gives companies broad latitude to collect and analyze information, and more importantly, considerable leeway to use that data to carry out behavioral science research and experimentation, even when users aren't aware their data is being used for research purposes, or of its potential impacts. This leeway allows companies to create detailed user profiles not only to understand individuals, but also to influence their mindset, shape their attitudes, manipulate their emotional states, and change their behavior. The fact that these activities—so long as they are covered by the fig leaf of online privacy policies and done in-house, rather than via sale of personal data—are generally permissible under most privacy laws makes a compelling case for why privacy law, particularly the existing approach to notice-and-consent, needs to be reformed to provide users with *meaningful* notice of these activities, coupled with clearly-defined mechanisms for legal redress when corporate actors mislead consumers about the scope of the risks associated with their online behavior. To accomplish those goals, this Article suggests shifting away from a legal framework for consent focused on providing notice of the *mechanics* of data use, instead focusing on the *impacts* of data use. This new approach to the sufficiency of informed consent borrows from the ethics principles of human subjects research, and it could be further informed or supplemented by the recommendations of a commission specially designated by Congress to make recommendations regarding the ethics and legal implications of online data use. These proposed approaches are discussed in greater detail *infra* Section VI.B.

As a general matter, privacy regulations within the United States and Europe largely rest on a framework in which individual consent can serve as the basis for nearly any kind of data collection or usage. Beginning with the

adoption of the Fair Information Practice Principles in the United States in the 1970s, and their incorporation into the Privacy Principles adopted by the Organisation for Economic Cooperation and Development (OECD) in 1980,⁴¹ notice and choice have been central components of the legal framework historically relied upon to protect users in all aspects of daily life that implicate data or privacy issues, including their lives online.⁴² As one scholar has put it, the current approach to protecting privacy “takes refuge in consent”; that is, it “provides people with a set of rights to enable them to make decisions about how to manage their data. These rights consist primarily of rights to notice, access, and consent regarding the collection, use, and disclosure of personal data.”⁴³ Under this approach, the law “attempts to be neutral about substance—whether certain forms of collecting, using, or disclosing personal data are good or bad—and instead focuses on whether people consent to various privacy practices. Consent legitimizes nearly any form of collection, use, or disclosure of personal data.”⁴⁴

Indeed, consent forms an integral component of lawful data collection and use within the United States and internationally. This includes a variety of U.S. federal statutes, including: the Graham-Leach-Bliley Act’s provisions regarding privacy of personal financial information;⁴⁵ the provisions of the Health Insurance Portability and Accountability Act (HIPAA) relating to the privacy of protected health information;⁴⁶ the use of consumer report

⁴¹ *OECD Privacy Principles*, OECD (Aug. 9, 2010), <http://oecdprivacy.org> [<https://perma.cc/R4GT-96FG>].

⁴² *See, e.g.*, U.S. FED. TRADE COMM’N, *PRIVACY ONLINE: A REPORT TO CONGRESS*, at 7 (1998) (“Over the past quarter century, government agencies in the United States, Canada, and Europe have studied the manner in which entities collect and user personal information – their “information practices” – and the safeguards required to assure those practices are fair and provide adequate privacy protection. . . . The most fundamental principle is notice. Consumers should be given notice of an entity’s information practices before any personal information is collected from them. Without notice, a consumer cannot make an informed decision as to whether and to what extent to disclose personal information. Moreover, three of the other principles discussed below – choice/ consent, access/ participation, and enforcement/redress – are only meaningful when a consumer has notice of an entity’s policies, and his or her rights with respect thereto.”).

⁴³ Daniel J. Solove, *Introduction: Privacy Self-Management and the Consent Dilemma*, 126 *HARV. L. REV.* 1880, 1880 (2013).

⁴⁴ *Id.*

⁴⁵ Graham-Leach-Bliley Act § 6802(b), 15 U.S.C. §§ 6801–6809 (1999) (regarding disclosures of information to non-affiliates); Graham-Leach-Bliley Act Privacy of Consumer Financial Information Rule, 16 C.F.R. §§ 313.1–313.18 (1999).

⁴⁶ Health Insurance Portability and Accountability Act, Pub. L. No. 104–191 (1996); Health Information Technology for Economic and Clinical Health Act, Pub. L. No. 111–5 (2009); Health Insurance Portability and Accountability Act Privacy and Security Rules, 45 C.F.R. § 164 (2000).

information under the Fair Credit Reporting Act (FCRA);⁴⁷ the use of customer proprietary network information (CPNI) and personally identifiable information (PII) under the Communications Act;⁴⁸ the use of subscriber information under the Cable Communications Policy Act (CCPA);⁴⁹ the use of information relating to videotape rentals under the Video Privacy Protection Act (VPPA);⁵⁰ student education records under the Family Educational Rights and Privacy Act (FERPA);⁵¹ individually identifiable information collected online from a child under the age of 13 under the Children’s Online Privacy Protection Act (COPPA);⁵² the interception of communications in transit or access to stored communications under the Electronic Communications Privacy Act (ECPA),⁵³ including provisions of the Wiretap Act,⁵⁴ the Stored Communications Act (SCA),⁵⁵ and the Pen Register Act,⁵⁶ and unauthorized access to information on a protected computer under the Computer Fraud and Abuse Act (CFAA).⁵⁷ Further, the Federal Trade Commission (FTC), in its consumer protection role, frequently looks to privacy notices of U.S. companies to assess whether a regulated entity’s data practices meet the standard of “unfair or deceptive acts or practices” under Section 5 of the FTC Act,⁵⁸ with a special emphasis not on the yardstick of whether companies’ notices and practices “say what [you] do, and do what [you] say.”⁵⁹ A myriad of U.S. state laws also rely on consent as a basis for collection and use of personal data. The most influential of recent state laws is the California Consumer Privacy Act (CCPA),⁶⁰ and other states are also enacting⁶¹ or

⁴⁷ Fair Credit Reporting Act, 15 U.S.C. § 1681(b) (specifying uses beyond permissible uses).

⁴⁸ Communications Act of 1934, 47 U.S.C. 151 *et seq.*, amended by Telecommunications Act of 1996, 47 U.S.C. § 222 (implementing regulations, 47 C.F.R. § 64).

⁴⁹ Cable Communications Policy Act, 47 U.S.C. § 551(c)(1) (determining PII except names and addresses); 47 U.S.C. § 551(c)(2) (including names and addresses).

⁵⁰ Video Privacy Protection Act, 18 U.S.C. § 2710(2)(B) (imposing opt-in consent obligations for all PII, especially video titles, except names and addresses).

⁵¹ Family Educational Rights and Privacy Act, 20 U.S.C. § 1232g(b)(1) (accounting for all PII except “directory information”).

⁵² Children’s Online Privacy Protection Act, 15 U.S.C. § 6502(b).

⁵³ Electronic Communications Privacy Act of 1986, 18 U.S.C. §§ 250–3127.

⁵⁴ Wiretap Act, 18 U.S.C. §§ 2510–2523.

⁵⁵ Stored Communications Act, 18 U.S.C. §§ 2701–2713.

⁵⁶ Pen Register Act, 18 U.S.C. §§ 3121–3127.

⁵⁷ Computer Fraud and Abuse Act, 18 U.S.C. § 1030.

⁵⁸ Federal Trade Commission Act, 15 U.S.C. §§ 41–58.

⁵⁹ Mark MacCarthy, *A Consumer Protection Approach to Platform Content Moderation*, FUNDAMENTAL RTS. PROT. ONLINE: THE FUTURE REGUL. OF INTERMEDIARIES (forthcoming 2019).

⁶⁰ CAL. CIV. CODE §§ 1798.100–1798.199.100 (2018).

⁶¹ *See, e.g.*, Colorado Protect Personal Data Privacy Act, S.B. 21-190, 73d Gen. Assemb., 2021 Reg. Sess. (Colo. 2021); Virginia Consumer Data Protection Act, S.B. 1392, 2021 Spec. Sess. (Va. 2021).

considering⁶² expanded data privacy laws. Notice and consent are core features of global data protection laws as well, such as: the European Union (EU) General Data Protection Regulation (GDPR);⁶³ the EU e-Privacy Directive;⁶⁴ the Canadian national Personal Information Protection and Electronic Documents Act (PIPEDA) legislation;⁶⁵ China's Personal Information Protection Law;⁶⁶ Brazil's General Data Protection Law (the Lei Geral de Protecao de Dados Pessoais or LGPD);⁶⁷ and the South Korean Personal Information Protection Act,⁶⁸ among others.⁶⁹

Even though privacy and data protection laws around the world rely heavily on some form of the notice-and-consent framework, this approach suffers serious shortcomings and has been widely criticized as a result. As noted above, notice-and-consent frameworks in the U.S. and many other countries tend to view privacy-related consent decisions from a content-neutral perspective that assumes that individual users have the capacity to

⁶² The states currently considering data privacy legislation include Massachusetts ((Massachusetts Information Privacy Act, S.B. 46, 192d Gen. Ct. (Ma. 2021)); Minnesota (Minnesota Consumer Data Privacy Act, H.B. 1492, 92d Leg. (Minn. 2021)); New York (New York Privacy Act, S.B. 680 B, 2022 Sess. (N.Y. 2022); Digital Fairness Act, S.B. 6042, 2022 Sess. (N.Y. 2022)); North Carolina (Consumer Privacy Act, S.B. 569, 2021 Sess., Gen. Assemb. (N.C. 2021)); Ohio (Ohio Personal Privacy Act, H.B. 376, 134th Gen. Assemb., Reg. Sess. (Ohio 2021)); and Pennsylvania (Consumer Data Privacy Act, H.B. 1126, Gen Assemb., Reg. Sess. (Pa. 2021)).

⁶³ Regulation 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data and repealing Directive 95/46/EC (General Data Protection Regulation), 2016 O.J. (L 119) 1.

⁶⁴ Directive 2002/58/EC, of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications), 2002 O.J. (L 201) 37.

⁶⁵ Personal Information Protection and Electronic Documents Act, S.C. 2000, c 5, (Can.).

⁶⁶ Geren Xinxu Baohu Fa (个人信息保护法) [Personal Information Protection Law of the People's Republic of China] (promulgated by the Standing Comm. Nat'l People's Cong., Aug. 20, 2021, effective Nov. 1, 2021) art. 74.

⁶⁷ Decreto No 13.709, de 14 de Agosto de 2018, [D.O.U.] de 14.8.2018 (Braz.).

⁶⁸ Gaeinjeongbobohoeop [Personal Information Protection Act], Act No. 16930, Feb. 4, 2020 (S. Kor.).

⁶⁹ This article doesn't attempt to parse the distinctions among the notice-and-consent frameworks in each of these laws. While those distinctions are vitally important for purposes of practical compliance with those laws, the purpose of this article is not to provide a primer on the distinctions between and among the various laws that could apply in any particular situation. Rather, this list of laws is provided in support of the larger point that notice-and-consent frameworks are an integral component of the data privacy and data protection laws of many jurisdictions around the world, and that, as a general matter, none of those approaches are sufficient to prevent or address the harms that were revealed by the documents, testimony, and reporting related to Frances Haugen's insider information so far.

provide informed and meaningful consent to almost any set of provisions they are presented with. They impose relatively few restrictions on data sharing, and even fewer restrictions on what a company can do internally with data collected via lawful means, so long as the company has provided some rudimentary transparency in its privacy notice, terms of service, or similar documentation. Even more notably, these notice-and-consent frameworks primarily address what I describe in this Article as the *mechanics* of data collection and use: that is to say, they focus on what categories of information are collected and with whom it may be shared, but they seldom advise users of the likely *impact* from those uses. The importance of this distinction between mechanics and impact of data use is explored further *infra* Section VI.A.

The result has been an ever-expanding ecosystem of ingenious data uses, many of which are opaque to the users whose information is fueling the business model of the entities who are collecting their data. As critics have noted: “First, websites have adopted a kind of precautionary legalese to inoculate themselves against lawsuits and fines. Second, over the past ten years, a new industry of ‘data brokerage’ has arisen to help sites learn more about the people like you and me on the other side of the screen. . . . Gathering and analyzing that data is big business, and it creates a strong financial incentive for the firms that collect it to make it as difficult as possible for you to opt out of their net.”⁷⁰ Or, to put it another way, when faced with the growing complexity and shrinking choice in digital environments, “[i]t’s important to ask what kinds of information an individual needs in order to be informed in today’s data-rich environment—and whether the data ecosystem has become so complex, and the range of choices so limited, that it’s no longer possible to give meaningful informed consent.”⁷¹ With the explosion of online data-gathering, the Fair Information Principles that seemed to hold such promise in the 1970s have lost some of their luster over time. As I have explained previously, the current notice-and-consent approach does not provide true agency or choice to consumers:

Now, decades on, it isn’t hard to see that the effectiveness of the notice-and-consent model has been eroded by a combination of factors: the proliferation of wordy, unintelligible privacy policies; consumers’ recognition that they’re powerless to negotiate any better or different privacy terms; and the fact that new types of data tracking, collection, and analysis are being developed faster than consumers can become aware of them. In today’s

⁷⁰ Marcus Moretti & Michael Naughton, *Why Privacy Policies Are So Inscrutable*, ATL. (Sept. 5, 2014), <https://www.theatlantic.com/technology/archive/2014/09/why-privacy-policies-are-so-inscrutable/379615/> [<https://perma.cc/3E5T-W4W3>].

⁷¹ APRIL DOSS, *CYBER PRIVACY: WHO HAS YOUR DATA AND WHY YOU SHOULD CARE* 56–57 (BenBella Books, Inc. 2020).

complex data privacy environment, it's more difficult for consumers to understand what they're consenting to: how their data might be collected and used by the owner of a free product or service they've signed up for, how it might be sold to others, and how artificial intelligence algorithms are creating behavioral prediction models about them. The reality is, those prediction models can be used for purposes as ordinary as direct marketing and targeted commercial advertising, as well as for purposes as consequential as political advertising or as sinister as political viewpoint manipulation by hostile foreign government looking to sway public opinion in Western democracies.⁷²

B. The Internet as Social Science Research

Given the scope and scale of data collection, analysis, and use, there is a case to be made that the internet is subjecting all of us to unregulated human subjects research.⁷³ This "research" takes multiple forms: building detailed profiles regarding online personas to characterize a user's demographics, personality traits, interests, inclinations, and more for the purposes of targeted digital advertising;⁷⁴ evaluating user behavior online to increase engagement and time spent on screen;⁷⁵ assessing our emotional state;⁷⁶ making

⁷² *Id.* at 60–61.

⁷³ See, e.g., April Doss, *Time for A New Tech-Centric Church-Pike: Historical Lessons from Intelligence Oversight Could Help Congress Tackle New Data-Driven Technologies*, 15 J. BUS. & TECH. L. 1, 40–42 (2019), <https://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=1308&context=jbtl> [<https://perma.cc/UYR9-ZCFY>]; see also DOSS, *supra* note 71, at 152 (“Artificial intelligence and complex algorithms require lots of data, and lots of people to train the data. It turns out that all of us have been unwitting participants in a multifaceted, loosely designed program of unregulated research. This initiative has an undisclosed threefold effect of extracting our personal information, training AI algorithms, and providing a source of nearly cost-free labor that support the continuation of the first two efforts.”); April Falcon Doss, *The Fallout from the Facebook Files – Part 1*, JUST SEC. (Oct. 5, 2021), <https://www.justsecurity.org/78465/the-fallout-from-the-facebook-files-part-1/> (“[W]e’re all serving as the guinea pigs for tech companies who study how we react and behave when presented with various kinds of technology-driven stimuli.”) [<https://perma.cc/5QWE-EMZY>].

⁷⁴ See Louise Matsakis, *The WIRED Guide to Your Personal Data (and Who Is Using It)*, WIRED, (Feb. 15, 2019), <https://www.wired.com/story/wired-guide-personal-data-collection/> [<https://perma.cc/DE4R-AA4X>]; see also Yael Grauer, *What Are ‘Data Brokers,’ and Why Are They Scooping Up Information About You?*, MOTHERBOARD (Mar. 27, 2018), <https://www.vice.com/en/article/bjpx3w/what-are-data-brokers-and-how-to-stop-my-private-data-collection> [<https://perma.cc/7JM8-Z7TJ>].

⁷⁵ See, e.g., Simone Aiofli, Silvia Bellini & Davide Pellegrini, *Data-Driven Digital Advertising: Benefits and Risks of Online Behavioral Advertising*, 49 INT’L J. RETAIL & DISTRIB. MGMT 1089 (2021).

⁷⁶ See, e.g., Stuart A. Thompson, *These Ads Think They Know You*, N.Y. TIMES (Apr. 30, 2019), <https://www.nytimes.com/interactive/2019/04/30/opinion/privacy-targeted-advertising.html>.

predictions about potential medical conditions;⁷⁷ influencing our political, social, and cultural views;⁷⁸ waging information operations to gain geopolitical advantage or to advance a foreign policy agenda;⁷⁹ and more. In some cases, such as Facebook use by groups attempting to sway political opinion, these experiments are carried out by *users* of online platforms: political campaigns, political consultants, candidates, or individuals and groups working on behalf of foreign governments.⁸⁰ In other instances, such as the allegations detailed in the Facebook Files and in the Senate Commerce Committee Hearing, the research is carried out by the *technology companies themselves*, ostensibly to better understand users' experience on the platforms,⁸¹ but in practice have impacts far beyond that relatively modest- and benign-sounding goal.

Haugen's allegations are not the first time that Meta has been accused of carrying out social science research or experimentation on its users. In 2014, Facebook faced public backlash to a paper it published regarding research into users' emotional states—a paper revealing the company's experiments in manipulating users' emotional states by changing the content served up in their news feeds.⁸² As Michelle Meyer, who at the time was Director of Bioethics policy at the Union Graduate College-Icahn School of Medicine at Mount Sinai Bioethics Program, noted, “the closest any of us who might have participated in Facebook's huge social engineering study came to actually

⁷⁷ See Sumathi Reddy, *Clues to Parkinson's and Alzheimer's From How You Use Your Computer*, WALL ST. J. (May 29, 2018), <https://www.wsj.com/articles/clues-to-parkinsons-disease-from-how-you-use-your-computer-1527600547>.

⁷⁸ See, e.g., *How to Measure Your Behavior Change Digital Marketing*, VONT <https://www.vontweb.com/blog/measure-behavior-change-digital-marketing> [<https://perma.cc/54CK-MX2E>]; Rebecca Walker Rezcak, Christopher Summers & Robert Smith, *Targeted Ads Don't Just Make You More Likely to Buy – They Can Change How You Think About Yourself*, HARV. BUS. REV. (Apr. 4, 2016), <https://hbr.org/2016/04/targeted-ads-dont-just-make-you-more-likely-to-buy-they-can-change-how-you-think-about-yourself> [<https://perma.cc/925P-9Z4Y>].

⁷⁹ See, e.g., 1 SPECIAL COUNS. ROBERT S. MUELLER III, REPORT ON THE INVESTIGATION INTO RUSSIAN INTERFERENCE IN THE 2016 PRESIDENTIAL ELECTION 14–25 (2019), <https://www.justice.gov/archives/sco/file/1373816/download> [<https://perma.cc/4DYM-8GTP>].

⁸⁰ See *id.*; see also Owen Bowcott & Alex Hern, *Facebook and Cambridge Analytica face class action lawsuit*, GUARDIAN (Apr. 10, 2018), <https://www.theguardian.com/news/2018/apr/10/cambridge-analytica-and-facebook-face-class-action-lawsuit> [<https://perma.cc/GBJ6-5T5N>].

⁸¹ *Protecting Kids Online*, *supra* note 20 (statement of Antigone Davis, Dir., Global Head of Safety, Facebook).

⁸² See, e.g., Michelle N. Meyer, *Everything You Need to Know About Facebook's Controversial Emotion Experiment*, WIRED (Jun. 30, 2014), <https://www.wired.com/2014/06/everything-you-need-to-know-about-facebooks-manipulative-experiment/> [<https://perma.cc/EZ5H-XNCX>].

consenting to participate was signing up for the service.”⁸³ Meyer’s op-ed went on to say, “Facebook’s Data Use Policy warns users that Facebook ‘may use the information we receive about you . . . for internal operations, including troubleshooting, data analysis, testing, research and service improvement.’ This has led to charges that the study violated laws designed to protect human research subjects. But it turns out that those laws don’t apply to the study, and even if they did, it could have been approved, perhaps with some tweaks.”⁸⁴ Meyer was hardly the only one to lambast the social media platform for this ethical lapse. According to comments from James Grimmelman, “Facebook users didn’t give informed consent . . . [and] the study harmed participants. . . . This is bad, even for Facebook.”⁸⁵

The paper, titled “Experimental Evidence of Massive-Scale Emotional Contagion Through Social Networks,” summarized the findings from research conducted in 2012, examining how manipulating individual news feeds impacted the emotional states of nearly 700,000 unwitting users.⁸⁶ According to the paper, the large-scale study was designed to test “whether posts with emotional content are more engaging.”⁸⁷ The methodology can be summarized as follows: “The experiment manipulated the extent to which people (N = 689,003) were exposed to emotional expressions in their News Feed.”⁸⁸ In doing so, the company tested “whether exposure to emotions led people to change their own posting behaviors, in particular whether exposure to emotional content led people to post content that was consistent with the exposure”⁸⁹—in other words, whether upbeat posts led others to post upbeat content, and vice versa. Facebook’s algorithms were modified such that, without any awareness on the part of the user, one group of users received less “positive emotional content” in their news feed, and the other group of users

⁸³ *Id.*

⁸⁴ *Id.*

⁸⁵ See James Grimmelman, *As Flies to Wanton Boys*, LABORATORIUM (June 28, 2014), http://laboratorium.net/archive/2014/06/28/as_flies_to_wanton_boys [<https://perma.cc/R6ET-H4XM>]; see also Charles Arthur, *Facebook emotion study breached ethical guidelines, researchers say*, GUARDIAN (June 30, 2014), <https://www.theguardian.com/technology/2014/jun/30/facebook-emotion-study-breached-ethical-guidelines-researchers-say> [<https://perma.cc/MCY6-829N>].

⁸⁶ See Adam D.I. Kramer, Jamie E. Guillory & Jeffrey T. Hancock, *Experimental Evidence Of Massive-Scale Emotional Contagion Through Social Networks*, 111 PROC. NAT’L. ACAD. SCI. 8788, 8788 (2014), <https://www.pnas.org/content/pnas/111/24/8788.full.pdf> (“We test whether emotional contagion occurs outside of in-person interaction between individuals by reducing the amount of emotion content in the News Feed. . . [R]esults indicate that emotions expressed by others on Facebook influence our own emotions, constituting experimental evidence for massive-scale contagion via social networks.”) [<https://perma.cc/7ZEZ-TQJM>].

⁸⁷ *Id.*

⁸⁸ *Id.*

⁸⁹ *Id.*

experienced less “negative emotional content” in their feeds.⁹⁰ The results were significant: when people saw less positive content in their news feeds, their own posts became more negative. When people saw less negative content in their news feeds, their own posts became more positive.⁹¹ There was also what the researchers described as a “withdrawal effect: People who were exposed to fewer emotional posts . . . were less expressive overall on the following days.”⁹²

Grimmelman’s summary of the experiment was rather more pithy:

“If you were feeling glum in January 2012, it might not have been you. Facebook ran an experiment on 689,003 users to see if it could manipulate their emotions. One experimental group had stories with positive words like “love” and “nice” filtered out of their News Feeds; another experimental group had stories with negative words like “hurt” and “nasty” filtered out. And indeed, people who saw fewer positive posts created fewer of their own. Facebook made them sad for a psych experiment.”⁹³

In response to criticism, the researchers noted that their manipulation of news feeds and examination of the content of users’ posts was “consistent with Facebook’s Data User Policy, to which all users agree prior to creating an account on Facebook, constituting informed consent for this research.”⁹⁴ They also argued that, although they were affiliated with Cornell University, this research didn’t fall within the purview of Cornell’s Human Research Protection Program because the experiment was “conducted by Facebook, Inc. for internal purposes.”⁹⁵ Despite these protestations, the research prompted so much criticism following publication that the Editor-in-Chief of the journal in which it appeared published a statement a month later titled, “Editorial Expression of Concern,” explaining why the journal had published a study that was conducted without the usual safeguards for human research subjects in place. The Editorial Expression noted that while adherence to the Common Rule of ethics that governs federally funded research in the United States⁹⁶ is both best practice and a policy of the journal, “as a private company Facebook was under no obligation to conform to the provisions of the Common Rule when it collected the data used by the authors, and the Common Rule does not

⁹⁰ *Id.*

⁹¹ *Id.* at 8790.

⁹² *Id.*

⁹³ Grimmelman, *supra* note 85.

⁹⁴ *Editorial Expression of Concern: Experimental Evidence Of Massive-Scale Emotional Contagion Through Social Networks*, PROC. OF THE NAT’L ACAD. OF SCI. (July 22, 2014), <https://www.pnas.org/content/111/29/10779.1> [<https://perma.cc/P9P2-M3CM>]; *see also* Arthur, *supra* note 85.

⁹⁵ *Editorial Expression of Concern, supra* note 94.

⁹⁶ The Common Rule, and its significance for biomedical and behavioral research, is discussed in further detail, *infra* Section IV.B.

preclude their use of the data . . . It is nevertheless a matter of concern that the collection of the data by Facebook may have involved practices that were not fully consistent with the principles of obtaining informed consent and allowing participants to opt out.”⁹⁷

Critics at the time pointed to the important distinction between *observing* what users do online and *manipulating* users online:

For an *observational* study, automated data processing is a meaningful way of avoiding privacy harms to research subjects. . . . But that is because in an observational study, the principal risks to participants come from being observed by the wrong eyes. . . . This, however, was not an observational study. It was an *experimental* study—indeed, a randomized controlled trial—in which participants were treated differently. We wouldn’t tell patients in a drug trial that the study was harmless because only a computer would ever know whether they received the placebo. The unwitting participants in the Facebook study were told (seemingly by their friends) for a week either that the world was a dark and cheerless place or that it was a saccharine paradise. That’s psychological manipulation, even when it’s carried out automatically.⁹⁸

Despite the backlash, subsequent research and experiments by the company suggest that the lessons of 2014 regarding the need for care and caution with respect to users did not stick. In 2017, Facebook experienced a new round of criticism in response to public revelations about its internal research regarding the emotional state of teens. According to reporting at the time, a 23-page document leaked from the company’s Australian office detailed how Facebook executives promoted advertising campaigns designed to exploit users’ emotional states, with the targeting aimed at users as young as 14 years old.⁹⁹ The leaked internal company documents reportedly showed that “Facebook is using sophisticated algorithms to identify and exploit Australians as young as 14, by allowing advertisers to target them at their most vulnerable when they feel emotions including ‘worthless’ and ‘insecure.’”¹⁰⁰ The 23-page report, marked “Confidential: Internal Only” outlined how Facebook could use real-time monitoring of users’ posts, pictures, interactions, and other internet activity to determine when teens feel

⁹⁷ *Editorial Expression of Concern*, *supra* note 94.

⁹⁸ Grimmelman, *supra* note 85.

⁹⁹ *Facebook Targets ‘Insecure’ To Sell Ads*, AUSTRALIAN (May 1, 2017); see also Sam Machkovech, *Report: Facebook Helped Advertisers Target Teens Who Feel ‘Worthless’*, ARS TECHNICA (May 1, 2017), <https://arstechnica.com/information-technology/2017/05/facebook-helped-advertisers-target-teens-who-feel-worthless> [<https://perma.cc/D8MK-7ADZ>]; Lucy Handley, *Facebook Criticized For Analyzing Teenagers’ Feelings, Accused Of Providing Information To Advertiser*, CNBC (May 2, 2017), <https://www.cnbc.com/2017/05/02/facebook-criticized-for-analyzing-teenagers-feelings-emotions.html> [<https://perma.cc/ASJ5-P6XN>].

¹⁰⁰ *Facebook Targets ‘Insecure’ To Sell Ads*, *supra* note 99.

“stressed,” “defeated,” “overwhelmed,” “anxious,” “nervous,” “stupid,” “silly,” “useless,” and like a “failure.”¹⁰¹ The scope and scale noted in the leaked document was massive, reportedly encompassing scrutiny of some 6.4 million high schoolers, students, and “young Australians and New Zealanders . . . in the workforce,” relying in part on a database it had created cataloguing nearly 2 million high schoolers, 1.5 million college-age students, and 3 million young workers.¹⁰² The company’s insights went beyond momentary emotions to tracking users’ emotional trends: “Anticipatory emotions are more likely to be expressed early in the week, while reflective emotions increase on the weekend . . . Monday-Thursday is about building confidence; the weekend is for broadcasting achievements.”¹⁰³

When faced with public concerns over the leaked report, Facebook issued a statement noting that:

While the data on which this research is based was aggregated and presented consistent with applicable privacy and legal protections, including the removal of any personally identifiable information, our internal process sets a standard higher than required by law. . . . Facebook only permits research following a rigorous procedure of review whenever sensitive data, particularly data involving young people or their emotional behaviour, is involved. This research does not appear to have followed this process.¹⁰⁴

Despite these protestations, there seems to have been little meaningful follow up or change from Facebook, as 2021 brought the allegations from Frances Haugen regarding the company’s continued research into the mental health of children and teens.

C. Privacy Protections And Research-Related Transparency Can Co-Exist

Importantly, through the time this Article was published in March 2022, Facebook has declined to make such internal research available to academics, lawmakers, or the public at large. It has also followed a consistent policy of providing researchers with extremely limited information about the operations of algorithms across the company’s platforms, and it has been routinely criticized for offering researchers less access to data on the platform than other tech companies do.¹⁰⁵ For years, Facebook has demurred that “user

¹⁰¹ *Id.*

¹⁰² *Id.*

¹⁰³ *Id.*

¹⁰⁴ *Id.*

¹⁰⁵ In one high-profile kerfuffle, the company disabled the accesses of a team of disinformation researchers who were studying the spread of Covid-19 misinformation and political ads on the company’s primary platform. The researchers at New York University

privacy” concerns prevent it from allowing researchers access to the platform.¹⁰⁶ Researchers have pushed back on that claim as mere pretext intended to disguise the company’s fundamental reluctance to have outsiders look “under-the-hood.”¹⁰⁷ When Antigone Davis, Head of Public Safety for the company (still known as Facebook at the time), testified to the Senate Commerce Committee that the company was unable to commit to releasing its research on teen mental health—stating only that the company was “looking for ways,”¹⁰⁸ consistent with privacy concerns, to release more information—lawmakers were having none of it. Sen. Richard Blumenthal chastised the company representative: “You haven’t provided that access to researchers. You’ve refused to make it available to independent experts and researchers.”¹⁰⁹ Further, Sen. Ben Luján repeatedly pressed for a yes-or-no answer on whether the company would release both the research and

had created a browser extension tool that allowed Facebook users to share with researchers information about which ads they were seeing on Facebook and why those ads were targeted towards those users. Facebook disabled the researchers’ personal accounts, pages, apps, and access to its platform, arguing that the researchers project was relying on “unauthorized means” to collect data from the Facebook platform, in violation of the terms of service. Shannon Bond, *NYU Researchers Were Studying Disinformation on Facebook. The Company Cut Them Off*, NPR (Aug. 4, 2021), <https://www.npr.org/2021/08/04/1024791053/facebook-boots-nyu-disinformation-researchers-off-its-platform-and-critics-cry-f> [<https://perma.cc/73JT-L7BS>].

¹⁰⁶ See, e.g., Davey Alba, *Ahead of 2020, Facebook Falls Short on Plan to Share Data in Disinformation*, N.Y. TIMES (Sept. 29, 2019), <https://www.nytimes.com/2019/09/29/technology/facebook-disinformation.html> [<https://perma.cc/ZJW8-MQG7>]; Marco Bastos & Shawn T. Walker, *Facebook’s data lockdown is a disaster for academic researchers*, CONVERSATION (Apr. 11, 2018), <https://theconversation.com/facebook-data-lockdown-is-a-disaster-for-academic-researchers-94533> [<https://perma.cc/GH69-V5GK>]; Zeynep Tufekci, *Mark Zuckerberg is in Denial*, N.Y. TIMES (Nov. 15, 2016), <https://www.nytimes.com/2016/11/15/opinion/mark-zuckerberg-is-in-denial.html> (“Unfortunately, Facebook exercises complete control over access to this data by independent researchers. It’s as if tobacco companies controlled access to all medical and hospital records.”) [<https://perma.cc/3UKC-S74X>].

¹⁰⁷ See, e.g., *id.*; Damon McCoy, *We Research Misinformation on Facebook. It Just Disabled Our Accounts.*, N.Y. TIMES (Aug. 10, 2021), <https://www.nytimes.com/2021/08/10/opinion/facebook-misinformation.html> [<https://perma.cc/8P9Z-KSTN>]. An associate professor at NYU, who was also cut off from Facebook, said he believes the company is using privacy claims as a pretext because it’s unhappy with the team’s research. *Id.* See also Shirin Ghaffary, *Why no one really knows how bad Facebook’s vaccine misinformation problem is*, VOX (Aug. 16, 2021), <https://www.vox.com/22622070/facebook-data-covid-19-vaccine-misinformation-researchers-access-nyu-academic> [<https://perma.cc/NUW3-MJH5>].

¹⁰⁸ *Protecting Kids Online*, *supra* note 20 (testimony of Antigone Davis) (“We are looking for ways to release our research. There are privacy considerations that we need to take into place, but I think more importantly, we’re actually also looking for ways to give external researchers access to data so that they can do independent research as well.”).

¹⁰⁹ *Id.*

underlying data, minus personally identifiable information, for review; Davis again made vague references to unspecified privacy concerns while reiterating that the company was “looking to” release more research.¹¹⁰

In her written remarks before the Senate Commerce Committee, Frances Haugen testified about the urgent and compelling need for increased transparency from the company:

I came forward because I recognized a frightening truth: almost no one outside of Facebook knows what happens inside Facebook. The company’s leadership keeps vital information from the public, the U.S. government, its shareholders, and governments around the world. . . . The core of the issue is that no one can understand Facebook’s destructive choices better than Facebook, because only Facebook gets to look under the hood. . . . Facebook’s closed design means it has no oversight—even from its own Oversight Board, which is as blind as the public. Only Facebook knows how it personalizes your feed for you. It hides behind walls that keep the eyes of researchers and regulators from understanding the true dynamics of the system.¹¹¹

Because of these concerns, Haugen pleaded with Congress to act.

The claims made by Facebook and Meta over the years that privacy considerations prevent the company from releasing the results of its research are almost certainly overstated.¹¹²

It is certainly true that companies and academics have come under fire when, with the ostensible goal of advancing research, they have shared user data in clumsy, intrusive, or overbroad ways. Two examples illustrate how these attempts can backfire. First, in 2006, AOL decided to release three months’ worth of internet search queries performed by its users. The data file of approximately 20 million searches made by 650,000 users was posted on an AOL website. In under a week, the *New York Times* ran a story unmasking the identity—including true name, age, and city of residence—of one of those AOL users, going so far as to interview her about the nature of her online queries, her reasons for them, and her opinions about AOL’s online privacy practices.¹¹³ Tech watchers were scathing: “The utter stupidity of this is

¹¹⁰ *Id.* (statement of Sen. Lujan) (“Yes or no, will Facebook release the basis of the research, the data set minus any personally identifiable information to allow for independent analysis?”).

¹¹¹ *Facebook Whistleblower*, *supra* note 16 (statement of Frances Haugen).

¹¹² Facebook did not, for example, directly respond to Sen. Luján’s request that researchers be granted access to data which had been stripped of personally identifying information.

¹¹³ Michael Barbaro & Tom Zeller, Jr., *A Face is Exposed for AOL Searcher No. 4417749*, N.Y. TIMES (Aug. 9, 2006), <https://www.nytimes.com/2006/08/09/technology/09aol.html> [<https://perma.cc/76Q5-UZ2V>].

staggering.”¹¹⁴ The resulting class action litigation alleging privacy violations was settled in 2013.¹¹⁵

In a separate incident a decade later, a group of Danish academics publicly released a dataset containing profile information for some 70,000 users of the OKCupid dating app.¹¹⁶ The researchers obtained the profile information through web scraping and argued that the user profile information was “public” by virtue of the manner in which the app operated; consequently, they argued, no ethical concerns stemmed from the researchers’ collection and posting of the data.¹¹⁷ Although the researchers were widely criticized, it was intellectual property law, rather than privacy law or research ethics rules, that provided OKCupid users with some indirect relief: the user profile information posted by the researchers was ultimately taken down when OKCupid successfully filed a takedown request under the Digital Millennium Copyright Act.¹¹⁸

Neither of those cases, however, provide meaningful parallels to the current Facebook Files leaks, in which neither lawmakers nor privacy advocates have called for the *public* release of the user information undergirding the company’s research into the mental health of teenage Instagram users. In this instance, where the goal is to provide some independent review of the company’s internal research and results, not necessarily public transparency of the data itself, it may be possible to develop approaches to provide researchers access to this data while still protecting users’ privacy.

For example, access to this data could be provided to a very limited set of independent researchers, who may only access the data in a secure environment and who must work under non-disclosure agreements with strict confidentiality provisions. Depending on how such arrangements are structured, they might fall within the bounds of Instagram’s existing user terms

¹¹⁴ Michael Arrington, *AOL Proudly Releases Massive Amounts of Private Data*, TECHCRUNCH (Aug. 6, 2006), <https://techcrunch.com/2006/08/06/aol-proudly-releases-massive-amounts-of-user-search-data/> [<https://perma.cc/2S2P-Z63F>].

¹¹⁵ *Landwher v. AOL, Inc.*, 1:1-CV-01014 (E.D. Va. 2013); *see also Court Oks \$7.3 Million Class Settlement With AOL for Posting Member Search Data*, BLOOMBERG LAW (June 4, 2013), <https://news.bloomberglaw.com/tech-and-telecom-law/court-oks-73-million-class-settlement-with-aol-for-posting-member-search-data>.

¹¹⁶ Michael Zimmer, *OKCupid Study Reveals the Perils of Big Data Science*, WIRED (May 14, 2016), <https://www.wired.com/2016/05/okcupid-study-reveals-perils-big-data-science/> [<https://perma.cc/A3BS-TQ6U>].

¹¹⁷ *Id.*

¹¹⁸ Alison McCook, *Publicly Available Data on Thousands of OKCupid Users Pulled Over Copyright Claim*, RETRACTION WATCH (May 16, 2016), <https://retractionwatch.com/2016/05/16/publicly-available-data-on-thousands-of-okcupid-users-pulled-over-copyright-claim/> [<https://perma.cc/6SKQ-P9RR>].

of service and related policies, requiring little further action to underpin the researchers' access. User privacy could be further bolstered by taking computational measures to de-identify the data to the extent possible (e.g., removing certain fields of data, hashing other data fields), imposing clear rules for the research that prohibit attempting to identify any user, implementing an audit mechanism to detect researcher overreach, and erecting oversight and compliance mechanisms for reporting any researcher misconduct. Without knowing how the user data is structured, what fields it contains, how it was tagged for purposes of the platform's mental health research, and a host of other practical questions, it is nearly impossible to predict what combination of technical, legal, and procedural mechanisms could most effectively protect individual user privacy while allowing a limited number of independent researchers to review the company's work.

Meta's lack of transparency about its research process and its underlying data science approaches has a crippling effect on any attempt to develop thoughtful and suitably privacy-protective mechanisms for protecting user privacy while enabling independent researchers to check the company's work. While the focus of this Article is limited to the platforms' role in social science, behavioral research, and mental health, it should be noted that the company's resistance to sharing information with independent researchers is continuing to have detrimental effects in a number of spheres, including, as of the time of publication, efforts to understand the role of platform-fueled misinformation in the run-up to the January 6, 2021 attack on the U.S. Capitol.¹¹⁹

IV. WHAT HUMAN SUBJECTS RESEARCH (HSR) ETHICS CAN TEACH PRIVACY LAW

For several years, I served as the Secretary for the Institutional Review Board (IRB) of a major research university. At each of the IRB's monthly meetings, the faculty members serving on the Board engaged in lengthy and careful debate over each dimension of the research activities being proposed within the university. Some of the closest scrutiny arose in the realm of psychological and behavioral science proposals. For example, researchers seeking to understand social anxiety among children and adolescents were required to: walk through detailed explanations of the level of emotional or other discomfort that their experimentation protocols might cause participants; articulate how, if at all, individual participants might benefit from the research

¹¹⁹ See, e.g., Craig Silverman, Craig Timberg, Jeff Kao & Jeremy Merrill, *Facebook Groups Topped 100,00 Daily Attacks on Election Before Jan. 6, Analysis Shows*, WASH. POST (Jan. 4, 2022), <https://www.washingtonpost.com/technology/2022/01/04/facebook-election-misinformation-capitol-riot/> [<https://perma.cc/6Z3T-R2FB>].

and who else might benefit from the research even if the experiments resulted in risk of harm to the participants; and explain the multiple safeguards for ensuring that participants and, for minors, their parents or guardians, were given full and complete information about their ability to withdraw from the research at any time, along with the mechanisms for how to exercise those rights. My experience is not unique; IRBs around the country demonstrate the powerful effect of independent review, conducted according to clearly defined standards, in supporting ongoing research while protecting the rights and interests of the people being studied. The principles that have governed human subjects research for nearly a half-century can be adapted for the digital era to protect individual rights; through an expanded framework, corporate entities could be covered by new regulations that extend these principles to certain categories of private, as well as federally-funded, research, without becoming unduly burdensome to those corporate actors.

A. A Brief History of HSR Ethics and the Belmont Report

The history of human subjects research (HSR) regulations in the United States is instructive. In 1974, Congress established a blue-ribbon commission to address grave concerns over research practices in the United States. These included the shocking revelations regarding historical research such as the Tuskegee Institute's syphilis experiments on black men whose medical conditions were deliberately—and without the men's knowledge—allowed to deteriorate so that researchers could observe the progression of the disease. Further, in the wake of the Supreme Court's decision in *Roe v. Wade*, Congress was embroiled in politically-charged debates on whether and how research on stem cells derived from human fetal tissue should be addressed by federal research regulations.¹²⁰ Against that backdrop, in 1974, Congress passed the National Research Act,¹²¹ which established a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. One of the Commission's charges was to “identify the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects and to develop guidelines which

¹²⁰ See, e.g., THE PRESIDENT'S COUNCIL ON BIOETHICS, MONITORING STEM CELL RESEARCH 2–5 (2004), <https://bioethicsarchive.georgetown.edu/pcbe/reports/stemcell/> [<https://perma.cc/MMZ8-CW7H>]; D.C. Wertz, *Embryo and Stem Cell Research in the United States: History and Politics*, 9 GENE THERAPY 674–78 (2002), <https://doi.org/10.1038/sj.gt.3301744>. See also NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, RESEARCH ON THE FETUS: REPORT AND RECOMMENDATIONS (1975) (reprinted at 40 Fed. Reg. 33,526 (1975), https://archives.federalregister.gov/issue_slice/1975/8/8/33504-33537.pdf#page=23 [<https://perma.cc/E22F-WQLH>]).

¹²¹ National Research Act, Pub. L. No. 93-348, 88 Stat. 342 (1974).

should be followed to assure that such research is conducted in accordance with those principles.”¹²² In doing so, the Commission was explicitly to address questions relating to “(i) the boundaries between biomedical and behavioral research and the accepted and routine practice of medicine, (ii) the role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects, (iii) appropriate guidelines for the selection of human subjects for participation in such research and (iv) the nature and definition of informed consent in various research settings.”¹²³

This work was hardly being done in a vacuum. When the Commission was doing its work, the World Medical Association had already adopted the Declaration of Helsinki, a non-binding but widely influential statement of ethical principles governing medical research that reflected a global condemnation of the atrocities of medical experimentation in Nazi concentration camps.¹²⁴

In 1979, the Commission published the Belmont Report, which set forth a set of ethical principles for human subjects research that eventually become both widely recognized and (in many circumstances) legally binding. In the U.S., the Belmont Report’s key principles have been incorporated into the Common Rule, a set of federal regulations governing federally-funded research.¹²⁵ Similar principles are incorporated in the Declaration of Helsinki, as well as the more than 1,000 laws governing human subjects research around the globe.¹²⁶ To be clear, this Article does not attempt to parse the nuanced distinctions among all of the international frameworks for human subjects research, nor does it offer a line-by-line walkthrough of how the Common Rule might apply if Meta were federally funded. Instead, the Article focuses on the importance of the key conceptual attributes of the Common Rule—including the role of informed consent, assessment of research risks and benefits, and ethical selection of research subjects—and how they have been

¹²² OFFICE OF THE SEC’Y, U.S. DEP’T OF HEALTH & HUMAN SERVS., THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1979), <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html> [<https://perma.cc/4K4Z-7WEZ>].

¹²³ *Id.*

¹²⁴ WORLD MED. ASS’N, DECLARATION OF HELSINKI, ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS (1964), <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> [<https://perma.cc/ZYU7-BXLP>].

¹²⁵ 45 C.F.R. § 46 (2018).

¹²⁶ See U.S. DEP’T OF HEALTH & HUMAN SERVS., INTERNATIONAL COMPILATION OF HUMAN RESEARCH STANDARDS (2020 ed.), <https://www.hhs.gov/ohrp/international/compilation-human-research-standards/index.html> [<https://perma.cc/J6EE-VFCV>].

incorporated into practical, concrete obligations for researchers whose work involves people.

The Belmont Report sought to serve as an enduring framework for human subjects research. To achieve that goal, it articulated three foundational ethical principles—respect for persons, beneficence, and justice—that formed a succinct analytical framework and that were accompanied by three components of practical “application” guidance.¹²⁷ The first principle, respect for persons, generally demands that “subjects enter into the research voluntarily and with adequate information.”¹²⁸ This principle incorporates two ethical convictions: “first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.”¹²⁹ Second, fulfilling the principle of beneficence entails “not only . . . respecting [individuals’] decisions and protecting them from harm, but also by making efforts to secure their well-being.”¹³⁰ Here, the report calls out research involving children as deserving of particular scrutiny.¹³¹ Lastly, the principle of justice requires asking “[w]ho ought to receive the benefits of research and bear its burdens?”¹³²

Of all the principles in the Belmont Report, respect for persons might be the most important, foundational one because it constitutes a “threshold condition,” as proceeding with the research in the first place requires adequate informed consent.¹³³ The Report makes this clear in its statement that, “[r]espect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them,” which requires informed consent, a process that relies on adequacy of information provided to subjects, comprehension of that information, and

¹²⁷ THE BELMONT REPORT, *supra* note 122, at 4–5 (“The objective is to provide an analytical framework that will guide the resolution of ethical problems arising from research involving human subjects.”).

¹²⁸ *Id.* at 4.

¹²⁹ *Id.*

¹³⁰ *Id.* at 5.

¹³¹ *Id.*

¹³² *Id.*

¹³³ *Belmont Report Oral History Project, Interview with Tom Lamar Beauchamp, Ph.D., OFF. HUM. RSCH. PROTECTIONS* (Sept. 22, 2004), <https://www.hhs.gov/ohrp/education-and-outreach/luminaries-lecture-series/belmont-report-25th-anniversary-interview-tbeacham/index.html> [<https://perma.cc/NY2V-B684>]. According to Dr. Beauchamp, who served as staff author of the Belmont Report, “I think that respect for persons, actually, is the most important principle. And for this reason: It becomes a kind of threshold condition. If you don’t have adequate informed-consent, either of a first-party or a third-party, you can’t proceed with the research. So, it has a kind of priority position in terms of telling you what can be done and what can’t be done. The next-most important principle, by far, is the principle of beneficence and justice, then, is sort of a trailing third.” *Id.*

voluntariness of any decision to participate in the research.¹³⁴ Further, respect for persons requires an assessment of the risks and benefits of the proposed research, where the risks include risks of psychological harm, physical harm, legal harm, social harm and economic harm; and beneficence “requires that we protect against risk of harm to subjects and also that we be concerned about the loss of the substantial benefits that might be gained from research.”¹³⁵

B. Common Rule Standards for Informed Consent

When the Belmont Report’s ethical principles were translated into binding rules for federally funded research, the resulting regulations required investigators to obtain legally effective informed consent from research subjects (or their authorized representatives) in nearly all cases. Exceptions to the requirement for informed consent are limited to circumstances in which the research meets certain narrow criteria for exemption or a duly constituted body, known as an Institutional Review Board, finds and documents an appropriate basis upon which informed consent can be waived.¹³⁶ The U.S. Department of Health and Human Services (HHS) explains that the informed consent requirement is “one of the central protections” of the regulatory scheme, reflecting the idea that “respect for persons requires that prospective research subjects ‘be given the opportunity to choose what shall or shall not happen to them.’”¹³⁷ HHS goes on to explain the key components of informed consent: (1) disclosing to potential research subjects the need to make an informed decision; (2) helping research subjects understand the disclosures they’ve been given; and (3) “promoting the voluntariness” of the individual’s decision whether to participate in the research.¹³⁸

Further, according to the HHS interpretive guidance:

Prospective subjects should be provided with ample opportunity to ask questions and seek clarification from the investigator. The prospective subjects should be in a position to freely decide whether to initially enroll in the research, or later, to withdraw or continue participating in the research. The informed consent process should ensure that all critical information about a study is completely disclosed, and that prospective subjects or their legally authorized representatives adequately understand the research so that they can make informed choices. . . . In all circumstances, however, individuals should

¹³⁴ THE BELMONT REPORT, *supra* note 122, at 6.

¹³⁵ *Id.* at 6–7.

¹³⁶ See 45 C.F.R. § 46.101(b) (2018); 45 C.F.R. § 116(c)–(d) (2021).

¹³⁷ *Informed Consent FAQs*, OFF. HUM. RSCH. PROTECTIONS (Jan. 15, 2022),

<https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/informed-consent/index.html> [<https://perma.cc/Z3SR-8KBR>].

¹³⁸ *Id.*

be provided with an opportunity to have their questions and concerns addressed on an individual basis.¹³⁹

Measured against these standards, there is no evidence that Facebook or Instagram attempted to inform the platforms' users of the studies that would be carried out, to help users understand the nature of those studies, or to advise users that their participation in the studies was voluntary.

Even the most casual review of the Instagram testimony thus far makes clear that, if the factual allegations are accurate, the approach taken by Facebook and the Meta family of companies to carrying out research and experimentation with adults and children on its platforms is completely at odds with the principles that have governed responsible social science research for the past half-century.

C. Internet User Data as Human Subjects Research

In considering how the Belmont Principles might apply to online research, it is important to differentiate between two different kinds of activity: studies of information that has been gathered from or about internet users, and interactions with users in which researchers attempt to manipulate the users' responses to online stimuli.¹⁴⁰ In both cases, there is a strong argument to be made for the application of ethical principles.¹⁴¹ In the second case, however, the stakes are higher—and the second category is arguably where some of the most striking growth is taking place, with a steady drumbeat of online actors trying to shape people's moods, perspectives, online interactions and in-real-

¹³⁹ *Id.*

¹⁴⁰ Similar distinctions have been recognized in literature on social science research conducted on the internet. *See, e.g.,* Icy Fresno Anabo, Iciar Elexpuru-Albizuri & Lourdes Villardón-Gallego, *Revisiting the Belmont Report's Ethical Principles in Internet-Mediated Research: Perspectives from Disciplinary Associations in the Social Sciences*, 21 ETHICS & INFO. TECH. 137, 138 (2019), <https://doi.org/10.1007/s10676-018-9495-z> (“Active analysis refers to a generally participative approach in internet research that reveals the identity of the researcher and allows his or her participation in data creation. Meanwhile, passive analysis alludes to . . . unobtrusive methods and . . . covert research wherein researchers act as observers without direct interaction with the data's creator or source and participants are unaware that they are being observed for research purposes. These include social network analysis, hyperlink analysis, and analysis of ‘found’ data. This method also includes big data or blog mining and web scraping implemented in social media-based market research.”).

¹⁴¹ *See, e.g.,* Jacob Metcalf & Kate Crawford, *Where Are Human Subjects In Big Data Research? The Emerging Ethics Divide*, BIG DATA & SOC'Y (June 1, 2016), <https://doi.org/10.1177/2053951716650211> (“U.S. research regulations (both the current and proposed revisions) exempt projects that make use of already existing, publicly available datasets on the assumption that they pose only minimal risks to the human subjects they document. But this assumption is founded on a misconception. Publicly available data can be put to a wide range of secondary uses, including being combined with other data sets, that can pose serious risks to individual and communities.”).

life (IRL) relationships, and more. In both cases, the challenges are multivariate. As one set of researchers put it, “Big Data . . . moves ethical inquiry away from traditional harms such as physical pain or a shortened lifespan to less tangible concepts such as information privacy impact and data discrimination. . . . Further, data science methods create an abstract relationship between researchers and subjects, where work is being done at a distant remove from the communities most concerned, and where consent often amounts to an unread terms of service or a vague privacy policy.”¹⁴² These shortcomings were on full display in the whistleblower testimony about Facebook’s research into Instagram’s impact on the mental health of teens. But they did first surface years before.

For example, data science researchers Kate Crawford and Jacob Metcalf have argued that the Common Rule’s ethics framework ought to be applied to data science in ways that are more similar to traditional social science research.¹⁴³ This idea has been incorporated into ethics courses taught at Columbia’s Data Science Institute by Chris Wiggins, the Chief Data Scientist at the New York Times.¹⁴⁴ Wiggins explained that “[s]tudying how ethics have been operationalized via the Belmont principles can be very informative, as they have for almost 40 years been stress-tested via real-world implementations, and there is copious literature about their utility and limitations.”¹⁴⁵ And, not surprisingly, the question has been raised in law review articles: in a 2015 article, James Grimmelman argued that “[t]o the extent that the Common Rule reflects a consensus about academic research on social media users, it should extend also to corporate research on social media users, because the ethical argument for regulating the latter is at least as strong as the argument for regulating the former.”¹⁴⁶

One scholarly review of the Belmont Rules’ applicability to Internet research summarized the ethical principles this way: “the Belmont Report recommends that informed consent be sought, that benefits and risks be evaluated, and the selection, representation, and the burden of participation be fair and equitable. The negative effects of the lack of these principles’ application would translate to coercion, harm, and undue involvement of vulnerable and burdened subjects.”¹⁴⁷

¹⁴² *Id.*

¹⁴³ Metcalf & Crawford, *supra* note 141.

¹⁴⁴ Rachel Thomas & Chris Wiggins, *A Conversation about Tech Ethics with the New York Times Chief Data Scientist*, FAST.AI (Mar. 4, 2019), <https://www.fast.ai/2019/03/04/ethics-framework/#belmont> [<https://perma.cc/8W7C-M2VP>].

¹⁴⁵ *Id.*

¹⁴⁶ James Grimmelman, *The Law and Ethics of Experiments on Social Media Users*, 13 COLO. TECH. L.J. 219, 254 (2015).

¹⁴⁷ Anabo, Elexpuru-Albizuri, & Villardón-Gallego, *supra* note 140, at 139.

By this measure, Facebook’s experiments on the mental health impact of Instagram on children and teens seems to fail on every dimension of the Belmont Report’s ethical framework.¹⁴⁸ Facebook’s research was clearly proactive—it included focus groups, online surveys, and diary studies, not simple reviews of passively generated information.¹⁴⁹ The research focused on teenage users who are a core part of the company’s product growth and profit strategy.¹⁵⁰ Facebook’s researchers specifically concluded that mental health and body image problems associated with social comparison were worse on Instagram than on other social media platforms.¹⁵¹ And, most damning of all, “[t]he features that Instagram identifies as most harmful to teens appear to be at the platform’s core.”¹⁵²

V. FACEBOOK’S APPROACH TO RESEARCH ETHICS, AND WHY TRANSPARENCY MATTERS

A. Why Meta’s Voluntary Research Review Process is Different from an IRB

Following criticisms of its 2014 emotional manipulation experiment, Facebook made several public statements about how it intended to approach research on its platforms. According to a blog post by Mike Schroepfer, then Facebook’s Chief Technology Officer, “[w]e’re committed to doing research to make Facebook better, but we want to do it in the most responsible way.”¹⁵³ Nonetheless (and perhaps unsurprisingly), Facebook’s goals were articulated within a framework focused on the company’s own priorities and needs. According to Schroepfer, although the span of research was wide (“Facebook does research in a variety of fields, from systems infrastructure to user experience to artificial intelligence to social science”)¹⁵⁴, its goals were narrowly focused on product improvements: “[w]e do this work to understand

¹⁴⁸ In keeping with the naming convention adopted throughout this Article, the parent company is referred to here as “Facebook,” as all of the actions being discussed in this Section were undertaken during a timeframe when the parent company was named Facebook, prior to changing its name to Meta.

¹⁴⁹ See Wells, Horwitz & Seetharaman, *supra* note 5 (“Its effort includes focus groups, online surveys and diary studies . . . it also includes large-scale surveys of tens of thousands of people in 2021 that paired user responses with Facebook’s own data about how much time users spent on Instagram and what they saw there.”).

¹⁵⁰ See *generally id.*

¹⁵¹ *Id.* (“Social comparison is worse on Instagram. . .”).

¹⁵² *Id.*

¹⁵³ Mike Schroepfer, *Research at Facebook*, META (Oct. 2, 2014), <https://about.fb.com/news/2014/10/research-at-facebook/> [<https://perma.cc/HJ28-ALT9>].

¹⁵⁴ *Id.*

what we should build and how we should build it, with the goal of improving the products and services we make available each day.”¹⁵⁵

In 2016, Facebook further elaborated on that approach in a blog post and a law review article. The post explained that “[r]esearch is one of the most important tools we have to give people a good experience on Facebook.”¹⁵⁶ Facebook then embarked on what might be cynically viewed as a reputation-laundering campaign, part of which was to publish a law review article articulating its approach to future research.¹⁵⁷ In the abstract, the authors set out noble goals, “Increasingly companies are conducting research so that they can make informed decisions about what products to build and what features to change. These data-driven insights enable companies to make responsible decisions that will improve peoples’ experiences with their products. Importantly, companies must also be responsible in how they conduct research.”¹⁵⁸ They argued that because existing ethical guidelines “do not always robustly address the considerations that industry researchers face . . . [c]ompanies should develop principles and practices around research that are appropriate to the environments in which they operate, taking into account the values set out in law and ethics.”¹⁵⁹ The authors began with an argument for industry exceptionalism: industry research had unique needs and opportunities that justified different approaches, so the ethical guidelines that applied to traditional social science research should not apply.¹⁶⁰ The authors then discussed the Belmont Report and the federal research regulations that were implemented in its wake, and explained why, for most of the company’s research, they were not adopting the Belmont Report’s approach.¹⁶¹

The remainder of the article described Facebook’s internal research review process, involving internal training for company researchers, internal review by company employees and research team managers who have substantive expertise in particular areas of research, and the opportunity for

¹⁵⁵ *Id.*

¹⁵⁶ Molly Cohn Jackman, *Facebook Research*, META (June 14, 2016), <https://research.fb.com/blog/2016/06/research-review-at-facebook/> [<https://perma.cc/46NT-W5ZH>].

¹⁵⁷ Molly Jackman & Lauri Kanerva, *Evolving the IRB: Building Robust Review for Industry Research*, 72 WASH. & LEE L. REV. ONLINE 442 (2016), <https://scholarlycommons.law.wlu.edu/wlulr-online/vol72/iss3/8> [<https://perma.cc/PP8K-33FL>].

¹⁵⁸ *Id.* at 442.

¹⁵⁹ *Id.*

¹⁶⁰ *Id.* at 446 (“For example, A/B testing – comparing outcomes for a treatment and control group to determine differences in performance – can provide insights into what people find more useful and relevant. . . . Intuition often drives innovation: in Facebook’s case, anything from allowing replies to comments to incorporate suicide prevention features – are improving people’s experience on a small scale before being implemented for a broader population.”).

¹⁶¹ *Id.* at 447–50.

review by an internal research review group comprised of a committee of five Facebook employees with backgrounds in research, law, ethics, communications, and policy.¹⁶² Facebook’s internal research evaluations rely on four criteria: (a) how the research will improve “our society, our community, and Facebook”; (b) whether there are potentially adverse consequences from the study and what efforts are proposed to minimize those; (c) whether the research is “consistent with people’s expectations”; and (d) what precautions have been taken to protect individual information.¹⁶³ However, the framework lacks an explanation of who within the company has the authority to raise objections to research, whether anyone has authority to block or stop research, or what internal oversight mechanisms exist to ensure after-the-fact review of decisions and their resulting consequences. In other words, unlike traditional IRBs, there is no clear mechanism through which an independent voice is authorized to require Facebook to halt its research, to review its harms, to provide notification or redress to victims, or to take any other actions that could elevate the importance of research ethics obligations above corporate self-interest.¹⁶⁴

In addition to these measures, Facebook announced the creation of its “Oversight Board,”¹⁶⁵ a blue-ribbon panel of independent experts who would be empowered to review the company’s content moderation decisions and make recommendations to the company on how to proceed.¹⁶⁶ It didn’t take long before the rose fell off that particular oversight bloom. It became clear—even before the whistleblower’s testimony regarding Facebook’s XCheck program—that Facebook’s Oversight Board was insufficient to manage online harms posed by the company’s content moderation and account management decisions.¹⁶⁷ As I have noted elsewhere, when Facebook’s Oversight Board released its report analyzing the company’s decision to terminate former President Donald Trump’s account:

¹⁶² *Id.* at 451–52.

¹⁶³ *Id.* at 454–55.

¹⁶⁴ At the time of this Article’s publication, it is not clear whether Facebook’s research review process might have been affected by the parent company’s corporate name change – i.e., whether the research review process remains within “Facebook,” now a single platform, or is applied company-wide to all Meta platforms and activities. This Article assumes that the research review process previously announced by Facebook applies across the Meta family of products.

¹⁶⁵ Nick Clegg, *Welcoming the Oversight Board*, META (May 6, 2020), <https://about.fb.com/news/2020/05/welcoming-the-oversight-board/> [<https://perma.cc/MH2S-5NLP>].

¹⁶⁶ OVERSIGHT BD., <https://oversightboard.com/> (last visited Feb. 24, 2022) [<https://perma.cc/9DGB-3QSF>].

¹⁶⁷ See, e.g., April Doss, *Facebook’s Oversight Board Didn’t Solve the Content Moderation Riddle. We Shouldn’t Be Surprised*, JUST SEC. (May 10, 2021), <https://www.justsecurity.org/76061/facebook-oversight-board-didnt-solve-the-content-moderation-riddle-we-shouldnt-be-surprised/> [<https://perma.cc/KAV6-MR69>].

The release of the Board’s report led to countless hot takes as well as thoughtful analysis. Why, then, has it seemed like such a letdown? The answer may lie in the fact that an advisory board, no matter how well constructed or how independent, isn’t sufficient to counter all the ills associated with disinformation on the internet. The [Oversight Board] is empowered to issue instructions to Facebook on individual content moderation decisions, or user bans like the Trump case. But in order to be meaningful, oversight mechanisms need to have teeth – some ability to impose penalties or sanctions. The Board lacks the ability to do that, just as it lacks the ability to require that Facebook implement new policies or procedures. (Facebook has said that it will treat OSB decisions as “binding.” However, the Board’s Charter includes a number of escape clauses, noting that Facebook’s response to decisions and recommendations will be modulated by the company’s assessment of issues such as technical and operational feasibility. More importantly, there does not appear to be any contract or other framework that makes the Board’s decisions legally enforceable, either by the Board or by any third party. With less than a dozen decisions from the OSB so far, only time will tell whether the “binding” nature of Board decisions has genuine legal substance or is merely the window dressing of public relations.)”¹⁶⁸

Despite its shortcomings, the Oversight Board has nonetheless provided valuable transparency into its process and decisions. In contrast, Facebook’s internal research review process has not provided transparency into the details of its research deliberations or decisions, nor has it made its findings available to the broader research community in a meaningful manner—that is to say, although Facebook says that it hopes that its research can improve the world, there is no indication that it has shared any of its findings in ways that would allow those broader societal benefits to emerge.

B. Has Facebook Learned Anything, and Have We?

Against this backdrop, it is shocking that Facebook would first experiment with how to change users’ moods in 2014; then study how to exploit teens’ vulnerability to sell advertising in 2017; and then conceal its research on Instagrams’ harms to teen mental health harms in 2019 and beyond. Facebook reportedly knew that it was in possession of uniquely meaningful research findings that had eluded the broader scientific community, and—in the face of ethical obligations and pressure from U.S. lawmakers¹⁶⁹ and despite its own protestations that it intends its research to be

¹⁶⁸ *Id.*

¹⁶⁹ *See, e.g., Protecting Kids Online, supra* note 20 (statement of Antigone Davis) (“We are looking for ways to release our research. There are privacy considerations that we need to

a force for good in the world¹⁷⁰—it has thus far refused to share that research with the world. That lack of transparency may have stemmed from reasons as prosaic as a desire to shield the company from external criticism, but the effect has been to hamper broader efforts to understand and address the mental health impact of social media.

A 2019 scholarly article illustrates the ways the company's lack of transparency has undermined public health knowledge and contributed to gaps in social science research. The article describes a literature review in which researchers conducted a meta-analysis of many studies conducted over time on the correlation between "body image disturbance" and social media use.¹⁷¹ The researchers had access only to published scholarly articles, not any of Facebook's internal research. The study concluded that while there was a positive correlation between social media use and body image disturbance, that relationship was lower than might be expected,¹⁷² and the researchers were unable to identify any meaningful distinctions tied to the use of particular social media platforms.¹⁷³ Specifically, they hypothesized that Instagram users might experience greater body dissatisfaction than users of other social media platforms, but they were unable to substantiate that hypothesis—in part

take into place, but I think more importantly, we're actually also looking for ways to give external researchers access to data so that they can do independent research as well").

¹⁷⁰ Facebook's blog post announcing its research review process noted that, "We also think research, when conducted in the open, can be important in understanding some of the world's most challenging problems—from increasing internet access in the developing world to building servers that can connect billions of people to each other. Facebook researchers participate in conferences, publish in peer-reviewed journals, and partner with experts from academic institutions around the world. Innovation occurs most quickly when large and diverse sets of researchers build on each other's work, and we are grateful for the feedback we receive as members of the broader research community." Jackman, *supra* note 156.

¹⁷¹ Alyssa N. Saiphoo & Zahra Vahedi, *A Meta-Analytic Review of the Relationship Between Social Media Use and Body Image Disturbance*, COMPUTERS IN HUMAN BEHAVIOR 259 (2019), <https://doi.org/10.1016/j.chb.2019.07.028>.

¹⁷² *Id.* at 272 ("To conclude, the results of this meta-analysis indicate that body image disturbance is associated with social media use. . . . The magnitude of this effect was not as large as might have been predicted based on previous research and common views amongst the public, which suggests that general social media use may not be as harmful as predicted for users in general.").

¹⁷³ *Id.* ("Relatedly, while we attempted to investigate the possibility that different social media platforms may have different relationships with body image disturbance by including this as a moderator variable, this analysis was not significant. While we did not have any a priori hypotheses about this analysis, this finding is surprising given that each social media platform that we investigated is quite different. For example, Facebook is a multi-media platform where users can share different forms of content (e.g., photos, videos, text, links, etc.), whereas Instagram is mainly a visual content platform. One may expect that because of this, the use of Instagram may be more strongly associated with body image disturbance, however, this is not what our results suggest.").

because there were so few academic studies tied specifically to Instagram use.¹⁷⁴ They also hypothesized that social media use might be particularly harmful for certain users engaging in certain behaviors, such as younger users spending their time on appearance-focused social media, but once again were unable to substantiate that hypothesis because of the paucity of published studies that differentiated among types of platforms.¹⁷⁵ Had they been granted access to the conclusions from Facebook's internal research on Instagram (which does demonstrate the devastating impact of Instagram on teen girls and documents how Instagram results in markedly worse mental health outcomes for teen girls in comparison to other platforms), their hypotheses might have been better informed, and their conclusions might have been concrete. In fact, the researchers even suggested studies of precisely the type that appear to have been carried out by Facebook in order to better understand how factors like age and the nature of the platform might affect body dysmorphia.¹⁷⁶ These are not merely academic questions: the researchers point out that these kinds of studies constitute "an important future direction, as these findings could be used to develop interventions targeted at particular types of users who more frequently engage in certain types of social media behaviours." In other words, access to this information could not only help researchers understand the harm that people were suffering, but might also help clinicians develop better-informed approaches to working with patients who were suffering from platform-related, or platform-exacerbated, mental health concerns.

¹⁷⁴ *Id.* ("For example, Facebook is a multi-media platform where users can share different forms of content (e.g., photos, videos, text, links, etc.), whereas Instagram is mainly a visual content platform. One may expect that because of this, the use of Instagram may be more strongly associated with body image disturbance, however, this is not what our results suggest. Nonetheless, this finding should be considered within the context of the existing literature, specifically, the imbalance of research investigating individual social media platforms. Most of the included studies investigated use of social media platforms in general (e.g., hours per day spent on *all* social media sites), or only Facebook. Only a small number of studies investigated other social media sites ($k = 5$ for Instagram, and $k = 4$ for other platforms, including Twitter and Hyves.nl).").

¹⁷⁵ *Id.* ("However, it may be particularly more harmful for certain users (e.g., younger users) who are engaging in certain behaviours (i.e., engaging in appearance-focused social media use).").

¹⁷⁶ *Id.* ("An interesting and important future direction to investigate would be to look at the interactions between these variables. For example, what body image outcome is associated with younger social media users engaging in appearance-focused use? . . . While many studies have investigated this specific type of social media use (e.g., 16 studies in this analysis), more research needs to be done . . . This is an important future direction, as these findings could be used to develop interventions targeted at particular types of users who more frequently engage in certain types of social media behaviours.").

Given the credentials and sophistication of many members of Facebook's internal research team,¹⁷⁷ it is plausible that the company was aware of the extensive social science literature on these issues. We can certainly expect that, had they looked, they would easily have been able to find it. By withholding its research from the academic community and the public at large, however, Facebook enabled executives like Mark Zuckerberg to testify that the academic research findings on these issues were unclear.¹⁷⁸ Facebook's external-facing hands were clean, but at a heavy cost: public health researchers, doctors, psychiatrists, therapists, parents—and teen girls themselves—were left in the dark about simple steps—like staying off of Instagram—that might have improved the well-being of teens at risk of devastating illness, hospitalization, suicide attempts, and death.

To those who would argue that Meta and other data-driven technology companies are sufficiently competent to perform ethical analyses and that they should be allowed to self-regulate the ways that they handle their users' personal information, Meta's track record provides little basis for confidence. With regard to the company's own assurances about the rigor and effectiveness of its processes, the allegations regarding Facebook's studies on Instagram and teen mental health shows the opposite. Frances Haugen testified that "the company's leadership knows how to make Facebook and Instagram safer but won't make the necessary changes because they have put their astronomical profits before people."¹⁷⁹ Whether the company considered the ethics—the risk to teens, the impact on individual lives, the importance of the information to public health researchers, and how to weigh individual rights and social good against platform growth and company profits—and concluded their actions and associated tradeoffs were acceptable, or failed to consider ethics at all, the outcomes underscore the need to revisit the question of how to bolster ethics standards in corporate data research, including how to articulate legally cognizable rights and to create how to create mechanisms, in appropriate circumstances.

¹⁷⁷ Frances Haugen testified that "Facebook has many researchers with PhDs," including some with psychology degrees. *Facebook Whistleblower*, *supra* note 16.

¹⁷⁸ See, e.g., *Protecting Kids Online*, *supra* note 20 (statement of Sen. Richard Blumenthal), ("In August ahead of this hearing Senator Blackburn and I wrote to Mark Zuckerberg, and we asked, as you can see from this poster board, "Has Facebook research ever found that it's platforms and products and have a negative effect on children's and teens' mental health or wellbeing such as increased suicidal thoughts, heightened anxiety, unhealthy usage patterns, negative self-image or other indications of lower well-being?" Facebook's response was, "We are not aware. We are not aware of a consensus among studies or experts about how much screen time is too much.").

¹⁷⁹ *Facebook Whistleblower*, *supra* note 16.

VI. HOW LESSONS FROM HUMAN SUBJECTS RESEARCH MIGHT BE APPLIED HERE

The whistleblower's allegations about Instagram teen mental health research, along with the examples of other online research and experiments described in the preceding sections, underscore a set of conclusions that many internet users intuitively suspect may be true. First, social media, smart devices, and a host of other data-driven apps and services are reshaping our everyday behavior, opinions, and moods in ways that appear to have profound impact on individuals and on society as a whole. Second, our collective understanding of those forces remains incomplete. Third, any attempt to forecast those consequences ahead of time can be particularly murky when individuals are faced with a decision whether to agree to a particular privacy notice or terms of use. And fourth, compounding each of the other challenges, the laws and regulations governing online data collection and use have not been transformed at the same rate or in a manner as revolutionary as the ways in which technology, and our everyday relationship with it, has changed.

The traditional privacy and data protection framework relies heavily on notice-and-consent, where entities that provide a service or device and collect and process personal information from individuals are generally required to tell users about the *mechanics* of what they do: what categories of information will be collected (e.g., online activity), how it may be used (e.g., to personalize ads or improve user experience), and with whom it may be shared (e.g., third-party partners and vendors). The explanations provided in these privacy notices and terms of service rarely, however, describe what the likely *impact* will be. By and large, the applicable legal frameworks do not require that type of impact disclosure. However, in light of the extraordinary impacts that data has on society and individuals, that framework should change.

A. To Obtain Meaningful Consent, We Need to Shift Focus from the *Mechanics* of Data Use to the *Impact* of Data Use

Currently, legal frameworks in the U.S. and Europe that emphasize consent as a basis for collecting and processing personal information tend to focus on mechanics: what kind of information is being collected, by whom, and how it will be used. It is widely acknowledged that these consent forms are seldom read; even when read, they are often difficult to understand.¹⁸⁰ The

¹⁸⁰ See, e.g., Alexis C. Madrigal, *Reading the Privacy Policies You Encounter in a Year Would Take 76 Work Days*, ATL. (Mar. 1, 2012), <https://www.theatlantic.com/technology/archive/2012/03/reading-the-privacy-policies-you-encounter-in-a-year-would-take-76-work-days/253851/> [<https://perma.cc/M37T-JKVP>]; Marcus Moretti & Michael Naughton, *Why*

effectiveness of consent is further limited because the dominant nature of a few mainstream tech platforms means that there are typically few services or devices that provide equally effective alternatives to the product in question—a result, perhaps, of market forces or of improper anticompetitive pressures.¹⁸¹ Elsewhere, I’ve tried to make the case that “privacy is about more than data breaches; that personal data is about more than credit card numbers; that notice must be meaningful and choices must be real; and that, as important as it is to understand how data is created and collected about us, it’s even more important to consider the ways that our data is used and the myriad impacts those uses can have on our lives.”¹⁸² The revelations regarding Facebook’s internal research on the mental health harms of Instagram brings those concerns into stark relief, highlighting the urgency of defining and adopting new frameworks that will be more protective of the impact that data usage and manipulation can have on individuals and societies.¹⁸³

Privacy Policies are so Inscrutable, ATL. (Sept. 5, 2014) <https://www.theatlantic.com/technology/archive/2014/09/why-privacy-policies-are-so-inscrutable/379615/> [<https://perma.cc/44NQ-BA26>]; see also, Pretrial Order No. 20: Granting in Part and Denying in Part Motion to Dismiss First Amended Complaint at 792, *In re Facebook, Inc.*, Consumer Privacy User Profile Litigation, 402 F. Supp. 3d 767 (N.D. Cal. 2019) (No. 18-md-02843-VC) (“To be sure, for the rare person who actually read the contractual language, it would have been difficult to isolate and understand the pertinent language among all of Facebook’s complicated disclosures. Thus, in reality, virtually no one “consented” in a layperson’s sense to Facebook’s dissemination of this information to app developers.”).¹⁸¹ See, e.g., Substitute Amended Complaint for Injunctive and Other Equitable Relief, Federal Trade Commission v. Facebook, Inc., No. 1:20-cv-03590-JEB (alleging, inter alia, that Facebook has engaged in an “anticompetitive acquisition strategy” and “anticompetitive conditional dealing policies, designed to erect or maintain entry barriers and to neutralize perceived competitive threats.” Substitute Amended Complaint at 2. Further, the complaint alleges, “Facebook’s course of conduct has eliminated nascent rivals and extinguished the possibility that such rivals’ independent existence might allow other internet platforms to overcome the substantial barriers to entry that protect Facebook’s monopoly position. In doing so, Facebook deprives personal social networking users in the United States of the benefits of competition, including increased choice, quality, and innovation.” Substitute Amended Complaint at 5.) https://www.ftc.gov/system/files/documents/cases/2021-09-08_redacted_substitute_amended_complaint_ecf_no._82.pdf [<https://perma.cc/ZZ47-USJB>].

¹⁸² Doss, *supra* note 71, at 261–62.

¹⁸³ In the interests of brevity and focus, this Article does not attempt to address the full range of harms illuminated by the whistleblower’s revelations. For example, it does not address the grave concerns about the ways in which Facebook’s business model and algorithms can amplify online misinformation, undermine civic discourse and confidence in elections, lead to devastating public health consequences, support human trafficking, and lead to violence, hate crimes, and genocide. All of these harms are in need of urgent attention, and it may be possible to mitigate them through measures similar to the ones described in this Article—such as, for example, reframing notice-and-consent to inform users that time spent on the platforms has been found to lead people to adopt extremist philosophies, embrace conspiracy theories, ignore public health advice from credible sources, and so forth. A

For consent to become a meaningful framework for protecting individuals, we need to change the way we approach user consent in privacy notices and terms of service, shifting the focus away from consent that focuses on the *mechanics* of data usage and towards consent to the *impact* on the people to whom the data pertains. Changing the focus of notice-and-consent along these lines could be accomplished through new legislation, as well as through amendments to existing statutes and regulations, which in many instances already prescribe specific requirements for notice-and-consent.¹⁸⁴ As legislation captures society's evolving understanding of what constitutes meaningful informed consent, a new approach might also emerge in how common law and contract principles are applied.¹⁸⁵

Following a typical mechanics-of-use model, Instagram's current Terms of Service (ToS), Privacy Policy, and related online documents advise users about the types of data collected and how that data is used. For example, the Instagram Data Policy states that:

comprehensive set of solutions to these other ills would include a wider range of approaches than those outlined here, and the solutions proposed to remediate those harms might be helpful in this instance, as well.

¹⁸⁴ See, e.g., California Consumer Privacy Act, *supra* note 60; Children's Online Privacy Protection Act (COPPA), 15 U.S.C. §§ 6501–6506 (1998); Children's Online Privacy Protection Rule, 16 C.F.R. § 312 (1998); see also, General Data Protection Regulation, *supra* note 63.

¹⁸⁵ See Paul M. Schwartz & Karl-Nikolaus Peifer, *Transatlantic Data Privacy Law*, 106 GEO L.J. 115, 142–43, 151–52 (2017).

Data Policy

This policy describes the information we process to support Facebook, Instagram, Messenger and other products and features offered by Meta Platforms, Inc. ([Meta Products](#) or Products). You can find additional tools and information in the [Facebook Settings](#) and

I. What kinds of information do we collect?

To provide the Meta Products, we must process information about you. The types of information we collect depend on how you use our Products. You can learn how to access and delete information we collect by visiting the [Facebook Settings](#) and [Instagram Settings](#).

Things you and others do and provide.

- **Information and content you provide.** We collect the content, communications and other information you provide when you use our Products, including when you sign up for an account, create or share content, and message or communicate with others. This can include information in or about the content you provide (like metadata), such as the location of a photo or the date a file was created. It can also include what you see through features we provide, such as our [camera](#), so we can do things like suggest masks and filters that you might like, or give you tips on using camera formats. Our systems automatically process content and communications you and others provide to analyze context and what's in them for the purposes described [below](#). Learn more about how you can control who can see the things you [share](#).
- **Your usage.** We collect information about how you use our Products, such as the types of content you view or engage with; the features you use; the actions you take; the people or accounts you interact with; and the time, frequency and duration of your activities. For example, we log when you're using and have last used our Products, and what posts, videos and other content you view on our Products. We also collect information about how you use features like our camera.

II. How do we use this information?

We use the information we have (subject to choices you make) as described below and to provide and support the Meta Products and related services described in the [Meta Terms](#) and [Instagram Terms](#). Here's how:

Provide, personalize and improve our Products.

We use the information we have to deliver our Products, including to personalize features and content (including your ads, [Facebook News Feed](#), [Instagram Feed](#), and Instagram Stories) and make suggestions for you (such as groups or [events](#) you may be interested in or topics you may want to follow) on and [off our Products](#). To create personalized Products that are unique and relevant to you, we use your connections, preferences, interests and activities based on the data we collect and learn from you and others (including any [data with special protections](#) you choose to provide); how you use and interact with our Products; and the people, places, or things you're connected to and interested in on and off our Products. Learn more about how we use information about you to personalize your Facebook and Instagram experience, including features, content and recommendations in Meta Products; you can also learn more about how we choose the [ads](#) that you see.

- **Product research and development:** We use the information we have to develop, test and improve our Products, including by conducting surveys and research, and testing and troubleshooting new products and features.

Research and innovate for social good.

We use the information we have (including from research partners we collaborate with) to conduct and support [research](#) and innovation on topics of general social welfare, technological advancement, public interest, health and well-being. For example, [we analyze information we have about migration patterns during crises](#) to aid relief efforts. [Learn more](#) about our research programs.

Figure 1: Instagram's Data Policy¹⁸⁶

Several things about Facebook's policies are noteworthy. First, the Data Policy alone, if printed on standard letter paper, runs to many pages. Second, the Data Policy is only one part of a bundle of lengthy and complicated documents that address various aspects of how personal information of users is collected and used, including "Data Policy,"¹⁸⁷ "Terms

¹⁸⁶ *Data Policy*, INSTAGRAM, https://help.instagram.com/519522125107875/?helpref=hc_fnav [<https://perma.cc/X6PD-Y5Z8>].

¹⁸⁷ *Id.*

of Use,”¹⁸⁸ “Platform Policy,”¹⁸⁹ “Cookies Policy,”¹⁹⁰ “Community Guidelines,”¹⁹¹ “Managing Your Privacy Settings,”¹⁹² “Privacy Settings and Information,”¹⁹³ “Controlling Your Visibility,”¹⁹⁴ “Staying Safe,”¹⁹⁵ and more. Collectively, the policies relating to data usage, privacy settings, and the options that users have regarding their personal data run to dozens of pages, much of it in dense legalese.¹⁹⁶ Interestingly, there is a section (undated) under “Privacy, Safety, and Security” that is titled “About Eating Disorders.”¹⁹⁷ That section addresses two points only: (a) “I’m struggling with an eating disorder or negative body image” and (b) “What should I do if a friend posted something on Instagram that suggests they have an eating disorder?”¹⁹⁸ The website contains contact information for various eating disorder information and help sites. But nowhere does the page indicate that Instagram usage heightens body image dissatisfaction or increases the risk or severity of eating disorders. Nowhere does it indicate that the company is expressly researching eating disorders and related issues among its users. And it certainly does not explain that the company’s own researchers have recommended changes to the platform that could mitigate those harms and the company has thus far rejected making those changes. More broadly, even if a user were to attempt

¹⁸⁸ *Terms of Use*, INSTAGRAM, https://help.instagram.com/581066165581870/?helpref=uf_share [<https://perma.cc/3PVK-JL8D>].

¹⁸⁹ *Facebook Platform Terms*, META, <https://developers.facebook.com/terms> [<https://perma.cc/D9XF-YY39>].

¹⁹⁰ *Cookies Policy*, INSTAGRAM, https://help.instagram.com/1896641480634370/?helpref=hc_fnav [<https://perma.cc/XKU6-J59L>].

¹⁹¹ *Community Guidelines*, INSTAGRAM, http://help.instagram.com/477434105621119/?helpref=uf_share [<https://perma.cc/P96A-5ZJ4>].

¹⁹² *Managing Your Privacy Settings*, INSTAGRAM, https://help.instagram.com/811572406418223/?helpref=hc_fnav [<https://perma.cc/5GHL-HRLG>].

¹⁹³ *Privacy Settings & Information*, INSTAGRAM, https://help.instagram.com/196883487377501/?helpref=hc_fnav [<https://perma.cc/5DN4-MVLY>].

¹⁹⁴ *Controlling Your Visibility*, INSTAGRAM, https://help.instagram.com/116024195217477/?helpref=hc_fnav [<https://perma.cc/XE5T-5XTN>].

¹⁹⁵ *Staying Safe*, INSTAGRAM, https://help.instagram.com/1502695926736394/?helpref=hc_fnav [<https://perma.cc/3GQA-4JLA>].

¹⁹⁶ For example, Instagram’s “Terms of Use” sternly admonishes that any complaints or concerns are subject to arbitration and that users expressly waive their right to participate in any class action lawsuits against Facebook regarding Instagram. *See Terms of Use*, INSTAGRAM, https://help.instagram.com/581066165581870/?helpref=hc_fnav (“Arbitration Notice: You agree that disputes between you and us will be resolved by binding, individual arbitration and you waive your right to participate in a class action lawsuit or class-wide arbitration. We explain some exceptions and how you can opt out of arbitration below.”) [<https://perma.cc/PKW7-CR39>].

¹⁹⁷ *About Eating Disorders*, INSTAGRAM, https://help.instagram.com/252214974954612/?helpref=hc_fnav [<https://perma.cc/VJC9-BPJY>].

¹⁹⁸ *Id.*

to read all of the pages of these many policies, none of them advise the user that Facebook is assessing the mental health of Instagram users or that Facebook knows that teens who use Instagram suffer from higher levels of mental health distress.

Although the legal frameworks for notice-and-consent tend to focus on the mechanics of data collection and usage, the ethical framework for consent in human subjects research carries a different focus, requiring disclosure of risks to participants, emphasizing the holistic nature of what must be disclosed, and prohibiting researchers from requiring participants to waive any of their legal rights.¹⁹⁹ Specifically, when seeking consent, researchers must inform participants about the purposes and duration of the research, along with: a description of the research procedures to be followed and whether any of the procedures are experimental; a description of any reasonably-foreseeable risks or discomforts to the individual; a description of any reasonably-expected benefits to the subject or others; a disclosure of any existing alternatives that might be advantageous to the subject; an explanation of what compensation and treatments are available to subjects for research involving more than minimal risk; a statement that participation is voluntary and may be discontinued at any time; and an explanation about how personal information will be handled.²⁰⁰ I have argued elsewhere that when it comes to notice-and-consent models, “[a] key challenge for the future will be how to clearly present people with useful information in an economic environment that empowers them to consciously decide what privacy is worth to them, and then choose what trade-offs they are willing to make.”²⁰¹ Incorporating key facets of the Common Rule’s informed consent approach into the consent processes for commercial use of online data could help close that gap.

Under an impact-of-data-usage model, Facebook has faced a higher obligation: not simply to inform users what data it collects, but also to inform users that it would be conducting mental health research based on their information and that use of the platform carries with it known and quantifiable mental health risks. Under this approach, it would not have been enough in 2012 for Facebook to ask users to consent to the company testing different designs for its algorithms to assess user experience. Instead, to run experiments on emotional contagion, Facebook’s Terms of Service would be required to notify users that it would attempt to manipulate their emotional states in ways that would not be disclosed until after the fact, if at all. In 2017, to study teen mental health, Facebook’s Terms of Service would be required to notify users that it would be running experiments to identify depressed and

¹⁹⁹ 45 C.F.R. § 46.116(a) (2018).

²⁰⁰ 45 C.F.R. § 46.116(b) (2018).

²⁰¹ DOSS, *supra* note 71, at 56–57.

at-risk teenagers and to see how changes in the platform made teenagers' feelings of anxiety, depression, and despair worse. In 2021, Instagram's Terms of Service would be required to advise children and teens that if they spend time on the platform, they are more likely to feel socially isolated, anxious, depressed, bad about themselves, and more likely to develop an eating disorder which could result in severe physical illness or death.

Under an impact-focused approach to consent, Instagram's Data Policy and Terms of Use would state something like this:

By using our platform, you acknowledge that we will analyze your activities both on and off this platform to understand your online behavior and what that behavior indicates about your interests, activities, relationships, personality, shopping habits, and the status of your physical and mental health. We may ask you to participate in online surveys and we may conduct experiments to see how you respond to the time you spend on our platform and to changes we make in it.

Based on our internal research to date, it is likely that if you use our platform, you will suffer increased rates of anxiety, depression, and feelings of inadequacy associated with social depression. There's a 1-in-3 chance that you'll have increased body image issues, a 25% chance you'll start doubting the strength of your friendships, and a 40% change that you'll start feeling unattractive if you spend time on this platform. You'll face a significantly increased risk of eating disorders and suicidal ideation.

We might identify ways to reduce those negative impacts associated with platform use, but we reserve the sole and absolute right to determine whether those changes are consistent with the company's best interests, as defined by standards that include revenue growth and shareholder profits. We believe that we are under no ethical or legal obligation to make changes to the platform that could reduce risk of harm to users, including children and teens, if those changes could result in fewer users on the platform, less time spent by each user on the platform, reduced virality of content on the platform, or any other impacts that could negatively impact the growth of users, revenue, or profits.

No matter how miserable Instagram makes you feel, our research indicates that our platform functions as intended and therefore it's likely that you'll find yourself unable to log off, even if you want to limit or altogether quit spending time on our platform.

And if your parents are concerned about your use of the platform, we'll make it easy for you to set up fake accounts that aren't tied to your real age,

date of birth, or other accounts, so that it's easy for you to use the platform without parental monitoring or oversight.

Much like the Surgeon General's warning on a pack of cigarettes, *those* would be meaningful disclosures to include in a privacy notice and user consent.

B. A New Belmont Commission

The original Belmont Commission was chartered by an Act of Congress in response to a growing recognition that the medical and behavioral science communities could not—based on the example of past abuses—be left to voluntarily regulate themselves.

According to Duane Alexander, who at the time was Medical Director for the National Institute for Child Health and Development at the National Institutes of Health and formerly a staff member on the Commission:

The Commission was established by Congress, I think, in large part to get the debate on biomedical ethics issues off the floor of the Congress and provide a cooling-off time while the Commission could deliberate the issues in public but without the political pressures the Congress was having placed on them. At the time, they were dealing with the issues of the Tuskegee syphilis study, psychosurgery, research with prisoners, research with people who had mental impairment, and then the crowning blow was fetal research. . . research on the human fetus after abortion. And there was so much time being taken up in discussion and debate on the floor of both the House and Senate on these issues that they needed to try to get a resolution off the floor and move this to a commission for discussion – fact-finding – rather than legislating in haste to put bans on all kinds of things, which we were facing, that could have been harmful in the long run. So the Commission was the perfect solution. It got these issues off the floor of the Congress. It got them into the realm of a commission of people with expertise in the area; respected scientists and civilians and ethicists who could deliberate these in public, but without the political pressures on them that the members of the Congress felt, and come up with recommendations.²⁰²

Congress faces similar changes with respect to the use of personal information by data-driven technologies today. Congress is consumed with debates over content moderation and the reform of Section 230 of the Communications Decency Act, with years' worth of proposals for federal data

²⁰² *Interview with Dr. Duane Alexander, Belmont Oral History Project*, OFF. HUM. RSCH. PROTECTIONS (July 9, 2004), <https://www.hhs.gov/ohrp/education-and-outreach/luminaries-lecture-series/belmont-report-25th-anniversary-interview-dalexander/index.html> [https://perma.cc/QJC9-5EFC].

privacy legislation, countless bills aimed at regulating online targeted advertising, child safety online, and more.²⁰³ The topics are complex, with debates that are often emotionally charged and at times politically fraught. The longstanding mechanism of creating a Congressional Committee of experts appointed to study and report on a particular set of complex issues could prove to be an effective approach for Congress to receive a comprehensive and well-informed set of recommendations from a bipartisan group.²⁰⁴ Congress could take this opportunity to pass legislation that establishes a blue ribbon, bipartisan commission that is charged with:

- Examining the key risks and harms to individuals, communities, and democratic institutions from the commercial use of personal information;
- Articulating a set of ethical principles to govern the use of personal data; and
- Offering a full range of recommendations which could include, but would not be limited to, items such as:
 - Recommending that those ethical parameters be made binding on all commercial entities that contract with the federal government of that otherwise (e.g., in the form of recent grants) receive federal funding;
 - Establishing a framework through which companies can self-certify that they comply with the standards set forth in

²⁰³ See, e.g., April Falcon Doss, *A Whistleblower's Testimony – Fallout from the Facebook Files: Part 2*, JUST SEC. (Oct. 6, 2021), <https://www.justsecurity.org/78488/a-whistleblowers-testimony-fallout-from-the-facebook-files-part-2/> (“Throughout the hearing, senators referred to bills that they had introduced or co-sponsored, including federal privacy legislation such as the Consumer Online Privacy Rights Act, the Filter Bubble Transparency Act, the Platform Accountability Transparency Act, and the Kids Internet Design and Safety (KIDS) Act. Some of these proposals address algorithmic design, and others propose reforms to Section 230 of the Communications Decency Act, the provision of law that grants internet platforms immunity from liability for the content posted online by their users. Sen. Amy Klobuchar (D-MN) noted that while federal privacy legislation may not be enough, it is nonetheless necessary; her denunciation of the power and role of tech industry lobbyists in blocking such legislation was particularly noteworthy in its precision-guided vehemence.”) [<https://perma.cc/3JULY-LU62>].

²⁰⁴ The history of congressional commissions goes back at least a century, with a handful—and up to a dozen—commissions authorized in each Congress. See *Congressional Commissions: Overview, Structure, and Legislative Considerations*, CONG. RSCH SERV. (Nov. 17, 2017), <https://crsreports.congress.gov/product/pdf/R/R40076/18>; *Congressional Commissions: Overview and Considerations for Congress*, CONG. RSCH SERV. (Jan. 14, 2022), <https://sgp.fas.org/crs/misc/R40076.pdf> (listing commissions from 1936 to present and analyzing key characteristics of congressional commissions) [<https://perma.cc/XQJ8-NBKW>].

- the ethical framework, User’s Bill of Rights, or other recommendations of the Commission;
- Recommending that any such self-certification program form the basis for consumer protection enforcement under the unfair and deceptive acts and practices authority of the Federal Trade Commission and similar state consumer protection laws as enforced by state Attorneys General;
 - Recommending a program of public awareness and education, ranging from a Schoolhouse Rock for online data rights to programming for senior centers, public libraries, K-12 and post-secondary education system, and more.

The scope of authority should be broad, and the latitude to make recommendations should be equally wide, like the scope granted to the Cyber Solarium Commission.²⁰⁵ Alternatively, an advisory committee could be established under the auspices of an appropriate Executive Branch agency, much as the Belmont Commission’s work laid the foundation for much of the work discussed in this Article.²⁰⁶

C. An Online Data Bill of Rights

On October 8, 2021, the White House Office of Science and Technology Policy (OSTP) announced that it was soliciting comments for the establishment of an “AI Bill of Rights.”²⁰⁷

This announcement was almost certainly in planning prior to Haugen’s revelations. But Facebook’s research on the mental health impact of Instagram

²⁰⁵ The U.S. Cyberspace Solarium Commission was established by Congress in the John S. McCain National Defense Authorization Act for Fiscal Year 2019 and issued its final report in 2021. *See Introduction*, CYBERSPACE SOLARIUM COMM’N, <https://www.solarium.gov/> [https://perma.cc/N37G-E8V4].

²⁰⁶ The Federal Advisory Committee Act prescribes the scope and contours of various categories of advisory committees. Federal Advisory Committee Act (FACA), Pub. L. 92–463, 86 Stat. 770 (1972). *See also* Federal Advisory Committee Management, 41 C.F.R. Parts 101-6 and 102-3 (July 19, 2001). FACA and its implementing regulations provide the guidance with which any such advisory committee would have to comply. However, a detailed discussion of the types of committees authorized under FACA, the obligations arising under its implementing regulations, and the precise contours – sponsoring agency, membership, duration, etc. – that might be most effective for an advisory committee charged with reviewing issues of information privacy and informed consent in the digital age lie outside the scope of this article.

²⁰⁷ Eric Lander & Alondra Nelson, *Americans Need a Bill of Rights for an AI-Powered World*, WIRED (Oct. 8, 2021), <https://www.wired.com/story/opinion-bill-of-rights-artificial-intelligence/> [https://perma.cc/G3XN-KJYR].

on children and teens provides a perfect and timely illustration of why OSTP's move is so necessary. In an opinion piece for *Wired* magazine, White House scientific advisor Eric Lander and OSTP deputy director Alondra Nelson wrote that “[i]n a competitive marketplace, it may seem easier to cut corners. But it’s unacceptable to create AI systems that will harm many people, just as it’s unacceptable to create pharmaceuticals and other products—whether cars, children’s toys, or medical devices—that will harm many people. Americans have a right to expect better. Powerful technologies should be required to respect our democratic values and abide by the central tenet that everyone should be treated fairly.”²⁰⁸

A formal Notice of Request for Information (RFI) on Public and Private Biometric Technologies was published in the Federal Register on the same day as the OSTP's announcement.²⁰⁹ Comments remained open until January 15, 2022, allowing academic, civil society groups, technology industry associations, and the general public to provide input on the potential scope and shape of an AI “Bill of Rights,” presumably informing the administration's approach to legislative proposals, rulemaking, enforcement, and other administrative actions in the future.

Although the current request for information focuses on biometric identification technologies, it is conceivable that OSTP may issue similar calls for input on other AI-related technologies in the future. After all, given the wide scope of AI technologies and their uses, no singular AI “Bill of Rights” could be complete if its focus was limited solely to biometric identification. Given the allegations regarding Facebook's research into the mental health of Instagram-using teens, and the manner in which the principles of the Belmont Report and the Common Rule shed light on the ethics of that work, it seems clear that the use of AI in contexts assessing and impacting mental and physical health should be on the short list of topics deemed vital to OSTP's work in this area; one can only hope that those topics will be included in a future request for information.

²⁰⁸ Eric Lander & Alondra Nelson, *Americans Need a Bill of Rights for an AI-Powered World*, WIRED (Oct. 8, 2021), <https://www.wired.com/story/opinion-bill-of-rights-artificial-intelligence/> [https://perma.cc/G3XN-KJYR].

²⁰⁹ *Notice of Request for Information (RFI) on Public and Private Biometric Technologies*, 86 Fed. Reg. 56300 (Oct. 8, 2021), <https://www.federalregister.gov/documents/2021/10/08/2021-21975/notice-of-request-for-information-rfi-on-public-and-private-sector-uses-of-biometric-technologies> [https://perma.cc/PM4Z-GASY].

D. What Other Ethics, Oversight, or Legal Approaches Could Apply?

Some academics have proposed the creation of Consumer Safety Review Boards, or CSRBs.²¹⁰ Under these proposed frameworks, CSRBs “could inject a measure of objective, independent, ethical oversight, not captured by bottom-line considerations and isolated from pressures imposed by management and marketing teams.”²¹¹ Facebook itself attempted something similar with the creation of its extended review group (ERG) and the Oversight Board.²¹²

The revelations from Frances Haugen demonstrate that Facebook’s ERG has failed to deliver on the potential positive outcomes that many observers optimistically hoped might come about with CSRBs. Although it is theoretically possible that a CSRB could provide that measure of “objective, independent, ethical oversight not captured by bottom-line considerations and isolated from pressures imposed by management and marketing teams,” all accounts so far demonstrated the emptiness of that promise. That is to say, either the work of Facebook’s internal research teams was not, in fact, separated from management, marketing, and the bottom line, or the research teams were indeed separate from those corporate entities but their efforts to protect users from harm were overrun by the implacable drive for growth. The push for increased revenue, user base, time on screen, and virality—what Haugen summarized as putting profits over people—trumped any ethical concerns that were raised by the internal research teams.

Despite these failings, internal and non-binding oversight mechanisms can have a beneficial effect when incorporated as part of a comprehensive oversight and compliance framework. In examining the shortcomings of the Facebook Oversight Board, I asked elsewhere:

Does that mean the Board’s work is fruitless? Not at all. Tech companies, like other corporations, should be encouraged to implement strong compliance mechanisms, and setting up a blue ribbon panel to provide scrutiny is one useful tool to do that. The rest of the oversight toolkit, however, that could potentially guide and constrain Facebook’s actions remains bare. Anyone who has been responsible for oversight and compliance programs in large and complex organizations (as I was at the NSA) knows that a critical feature of oversight includes a culture of compliance that is both anchored at the working level through extensive and repeated training and a cadre of

²¹⁰ See Ryan Calo, *Consumer Subject Review Boards: A Thought Experiment*, 66 STAN. L. REV. ONLINE 97 (2013); see also Jules Polonetsky, Omer Tene & Joseph Jerome, *Beyond the Common Rule: Ethical Structures for Data Research in Non-Academic Settings*, 13 COLO. TECH. L. J. 333 (2015).

²¹¹ Polonetsky, Tene & Jerome, *supra* note 210, at 339.

²¹² See *supra* Section V.A.

compliance professionals and that is repeatedly and clearly stated and sustained by the “tone from the top” – the unequivocal statements from senior leadership that oversight and compliance and corporate ethics are integral values of the organization, inseparable from the mission itself. This gets us to another indispensable feature: integration of compliance goals with the business mission: ensuring that ethical values and practical oversight mechanisms are incorporated into the organization’s business operations at every stage, from product design to productization. And, of course, it helps immensely if there is a clear legislative or regulatory standard – with penalties for noncompliance – that guides organizations in what they can and can’t do. . . . Until the approaches to countering disinformation become as wide-ranging as the problem – until we address everything from civics education to digital literacy, federal election law reform and commitment to democratic processes over culture wars – decisions like the recent one from the Board will continue to be a letdown, as the problems with content moderation go beyond anything that this Board, or even a more rigorous and empowered Board, can fix.”²¹³

Facebook’s example is important not only in its own right, but because of its global reach and its status as a repeat offender in misuse of personal data and amplification of social ills. It is also important as a comparator for other data-driven companies. To put that comparison in context: as one of the world’s largest companies, Meta is able to field large internal research teams of data scientists, psychologists, and other skilled specialists in a wide range of fields. It is able to devote resources to initiatives like a research extended review group and an Oversight Board—mechanisms that can help curry public favor, soothe the bite of backlash, offer recommendations for change, and perhaps provide researchers with internal assurances that their work will be used for good. A great many companies, however, lack Meta’s resources; of those that are well-resourced, not all companies will share the inclination to voluntarily undertake reforms, however modest. As James Grimmelman noted in 2015, “If every social media company had a research ethics review process like Facebook’s, then self-regulation might be worth taking more seriously. But the factors that led Facebook to create one were a product of its unique circumstances, including the immense public outcry over the emotional contagion experiment. For every Facebook, there is an OKCupid, an Ashley Madison, and an Uber,” each of which had engaged in questionable research involving their users.²¹⁴ “If

²¹³ Doss, *supra* note 167.

²¹⁴ Grimmelman, *supra* note 146, at 259, 224 (explaining that, according to various news accounts, Ashley Madison read its users’ private correspondence as part of internal research concluding that most of its users are in committed relationships; Uber analyzed user data to ferret out when users were hailing an Uber to get home from a one-night stand; OKCupid ran experiments designed to test which aspects of a person’s profile has the most influence

companies like Facebook and OKCupid . . . believe that they fall outside [the Common Rule], they will fight tooth and nail to continue in their unregulated ethical free-fire zone.”²¹⁵

There are other potential remedial measures as well. For example, Congress could establish, in each chamber, special select committees on data-driven technologies, conceptually modeled after the Church and Pike Committees that revolutionized intelligence oversight and reform in the 1970s.²¹⁶ Such special committees could address the complex issues relating to personal data that currently span across multiple committees in both chambers, ranging from privacy to consumer protection, algorithmic bias to labor standards and the gig economy, policing and surveillance to foreign malign influence, political advertising online to climate change, and more. Federal privacy legislation could impose heightened, enforceable obligations and provide additional resources for existing oversight bodies such as the Federal Trade Commission (FTC) or the creation of new independent oversight bodies that are empowered to govern private sector use of data.²¹⁷ Properly scoped, established, and resourced, such frameworks could impose meaningful oversight, requiring private sector entities to provide levels of transparency and reporting similar to those required for highly regulated components of government.²¹⁸ I have also argued that many of the harms from social media algorithms—such as amplification of online disinformation and the undermining of democratic processes—create an inextricable linkage between consumer data privacy and national security.²¹⁹ Addressing anti-democratic and public health harms like the spread of QAnon and other conspiracy theories, election-related disinformation, anti-vaccine misinformation and conspiracy theories, and extremist movements exhorting

in attracting other users—a set of experiments that at times involved misleading their own users).

²¹⁵ *Id.* at 259.

²¹⁶ *See* Doss, *supra* note 73.

²¹⁷ *See, e.g.*, Social Media Privacy Protection and Consumer Rights Act of 2021, S. 1667, 117th Cong. (2021) (proposing to grant users of online platforms the right to opt out of data collection and tracking and mandate establishment of privacy and security programs); Data Protection Act of 2021, S. 2134, 117th Cong. (2021) (proposing to establish an independent federal data protection agency); April F. Doss, *Data Privacy & National Security: A Rubik’s Cube of Challenges and Opportunities That Are Inextricably Linked*, 59 DUQ. L. REV. 231, 264, 266–67 (2021) (“If privacy legislation includes obligations of transparency and mechanisms for oversight and redress of violations, then private sector use of information can be removed from the current landscape, in which individuals are often out-leveraged by large corporations”; “Such a regulatory framework could expand the staffing, authority, and role of the FTC, or create one or more new regulatory bodies to carry out investigations and oversight.”).

²¹⁸ Doss, *supra* note 167.

²¹⁹ *See generally id.*

political and ethnic violence will require a whole series of measures that includes public education and online literacy campaigns, as well as government regulatory approaches designed to curb civil rights and other substantive abuses online while preserving free speech protections.²²⁰

As noted above, it appears that we have only seen the tip of the Facebook Files iceberg thus far. If indeed it is the case that thousands of documents have been provided to Congress and dozens more to the SEC, potential investigations in those bodies will likely reveal more details to inform forward-looking measures to help circumscribe this kind of conduct—the reckless use of personal data in the service of profits over people. As Frances Haugen noted, “[a] critical starting point for effective regulation is transparency: full access to data for research not directed by Facebook. On this foundation, we can build sensible rules and standards to address consumer harms, illegal content, data protection, anticompetitive practices, algorithmic systems and more.”²²¹ The suggestions in this Article should, therefore, be treated as a starting point, offered up in the early days of these revelations, and not as a final or fully comprehensive set of conclusions.

VII. CONCLUSION

Facebook’s global reach demonstrates the pervasive manner in which social media platforms and other online services permeate the daily lives of billions of people around the globe. The revelations from the Facebook Files provide a precise articulation of the ways these platforms are largely free, under existing legal structures, to carry out unregulated human subjects research and, in the process, inflict incalculable harm on the very people whose online activities fuel their profits. A few simple measures—such as making ethical guidelines mandatory for commercial activities involving research on the online behaviors of minors, modifying consent laws to focus on the impact of data and product usage rather than the mechanics of data usage, enacting legislation to establish a new Belmont Commission for data-driven technologies, and exploring mechanisms similar to an online bill of rights for algorithmic manipulation of data—could allow constructive and transparent online research to continue, provide meaningful improvements in consumer protection, ensure greater accountability from companies profiting off of data-driven technologies, and mitigate the impact of a host of online harms. Although these measures are conceptually simple, it would be a

²²⁰ See April Doss, *Data and Democracy: Three Things the Biden-Harris administration Should Do to Tackle Big Tech*, JUST SEC. (Nov. 30, 2020), <https://www.justsecurity.org/73538/data-and-democracy-three-things-the-biden-harris-administration-should-do-to-tackle-big-tech/> [<https://perma.cc/FA8G-3HAV>].

²²¹ *Facebook Whistleblower*, *supra* note 16 (statement of Frances Haugen).

mistake to construe them as easy.²²² However, the decade-long practice of carrying out unethical research experiments underscores the grave harms enabled by the current legal status quo. Against the backdrop of those harms, solutions such as these merit further exploration and urgent action.

²²² In common parlance, “simple” means “direct and uncomplicated”; “easy” means “without effort.” There is a world of difference between the two.