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## Me and My Data

### ABSTRACT

This article examines a recent, unexamined turn in the history of personal data in the last half century: the era when it was re-envisioned as a possession of the individual whom it described or from whom it was obtained. Data—whether scientific, commercial, or bureaucratic—had often been treated as confidential or protected, but it had not typically been conceived in terms of individual ownership. But starting in the later 1960s, more and more people in the industrialized West questioned whether they or the authorities who collected or maintained their data properly had claim to that information. This question was sparked as much by political and economic developments as it was by scientific and technological ones. Citizens’ move to shore up their proprietary claims would prompt new regulations around access, control, and consent that continue to undergird contemporary ideas about personal data. A product of social movements and civil rights reforms as well as market thinking, this bid for authority over one’s “own” information would however reveal its limitations by the turn of the twenty-first century, particularly in the context of a big data economy. This essay is part of a special issue entitled *Histories of Data and the Database* edited by Soraya de Chadarevian and Theodore M. Porter.

KEY WORDS: personal data, intellectual property, civil rights, HeLa, FERPA, Privacy Act of 1974, Stasi files, quantified self, data mining

Are our data in fact “ours”? The question lurks today in court cases as well as made-for-TV movies about the ownership of genetic material.<sup>1</sup> It appears in

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The following abbreviations are used: FCRA, Fair Credit Reporting Act; FERPA, Family Educational Rights and Privacy Act; NCCE, National Committee for Citizens in Education.

1. Daniel J. Kevles, “Can They Patent Your Genes?,” *New York Review of Books*, 7 Mar 2013. Kevles examines a DNA patenting case that “pitted the property rights of innovators and

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contests over who can access data in official files and over what sort of information demands to be “free.”<sup>2</sup> And it surfaces in proposals for how citizens might regain some control over their identifying details—their browsing or purchasing history—in the face of powerful commercial data miners.<sup>3</sup>

But we ought to pause over the question. It is, in the long career of data-collecting and data-making, a novel one. Whether information compiled about or from us is truly our own—not simply confidential or protected but something we can and by rights *should* possess—only recently defines the way many contemporary citizens (in the United States and Europe, at any rate) talk about data. How did these data become, even as a possibility, “theirs”? Certainly, such claims to “personal data” were prompted by ever-more ambitious techniques for extracting, recording, and making use of the material of human lives. And yet that project is an old one, as this special issue well shows.

What has sparked the question—and enabled information pertaining to persons to be reimagined as individual property—is a particular confluence of rights claims and market thinking in the industrialized West, circa 1970. Scholars have examined these broader developments with care, but they have not yet reckoned with their implications for the history of data.<sup>4</sup> This essay does not weigh in on the validity of individuals’ legal or ethical claims. Rather it takes up the significance of this relatively new posture toward “our” information. The note of possession alerts us to the importance of popular data consciousness in delimiting the way we conceive of the stuff in blood banks and data bases, file cabinets and petri dishes—as well as what might be done with it. As such, it offers us a fresh angle on the historical forces, transcending any one field or domain, that are shaping data politics in the present.

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investors in gene-based biotechnology against the rights of free access to and use of human DNA by researchers, physicians, and patients.” *Association for Molecular Pathology v. Myriad Genetics, Inc.*, 133 SCt 2107 (2013).

2. The Freedom of Information Act (FOIA) went into effect in 1967. Recent questions about access to state data have been raised prominently by Wikileaks; see also the international project called Ubiquitous Commons, <http://www.ubiquitouscommons.org>.

3. For one recent statement, see James Rule, “Consumers Need a New Legal Right to Control Personal Data,” *Los Angeles Times*, 3 Aug 2015.

4. Mary Ann Glendon, *Rights Talk: The Impoverishment of Political Discourse* (New York: Free Press, 1991); Daniel T. Rodgers, *Age of Fracture* (Cambridge, MA: Belknap Press of Harvard University Press, 2011).

There is now a broad conviction that personal information, whether biometric, biographical, or financial, might (best?) be treated as individually owned. That the notion rarely gets sustained scrutiny outside of specialist circles in intellectual property or privacy law may simply indicate how commonsensical this idea has become.

“Our” data was not always ours, though. Take the well-known case of Henrietta Lacks, an African-American woman from Baltimore who had cancerous cervical tissue cut from her body in 1951 during treatment at Johns Hopkins University Hospital. Lacks died eight months later, but from that tissue was derived the “immortal” HeLa cell line, which went on to be used in laboratories the world over. Despite the fact that the cell line was “personified” from the beginning—that “Lacks’s photograph graces many of the accounts [of the cells]; the cell line bears fragments of her name; the cells bear various proportions of the genetic material of which her body was composed when it was alive,” as sociologist Hannah Landecker puts it—no one seems to have contemplated Henrietta Lacks having a proprietary claim to such.<sup>5</sup> Although there was plenty of publicity about the wonders of the HeLa cell line in the 1950s and 1960s, as well as scientific debates about its “race,” Lacks appears in these accounts as the unwitting source or supplier of the cells—never once as their owner.

Fast-forward a few decades and Lacks moves to the center of the story, which now pivots less on discovery than dispossession. By the 1990s, Landecker notes, Henrietta Lacks was fashioned anew as “a figure of economic exploitation, with a contemporary right to sue for compensation.” The woman whose tissue had spawned a prolific and profitable cell line had become akin to a holder of “an investment account, where the original capital was those first biopsy cells,” and her family and descendants “rightful heirs to the proceeds.”<sup>6</sup> This economic analysis of expropriation—interwoven with the harms of racial discrimination and the long history of appropriation and abuse of black bodies—is taken for granted in still more recent accounts: Rebecca Skloot’s

5. Hannah Landecker, “Immortality, In Vitro: A History of the HeLa Cell Line,” in *Biotechnology and Culture: Bodies, Anxieties, Ethics*, ed. Paul Brodwin (Bloomington: Indiana University Press, 2000), 53–72. There were other property claims, however. Whereas the scientist responsible, George Gey, gave away cultures of HeLa freely, a company called Microbial Associates, Inc., began growing cells for commercial sale; 57.

6. Landecker, “Immortality, In Vitro,” *Ibid.*, 66, 68.

best-selling *The Immortal Life of Henrietta Lacks* of 2010, and 2017's Home Box Office version starring Oprah Winfrey.<sup>7</sup>

Genetic material may now seem self-evidently part of a person and thus subject, at least in part, to the wishes of the particular individual from which it came. Winfrey's character summarizes this common sense: "People got rich off my mother without us even knowin about them takin her cells, now we don't get a dime."<sup>8</sup> But as the HeLa case makes clear, genetic material only recently began to be conceived of as a personal possession, not only separable from but also claimable by the individual from whom it is derived. What had changed?

Bioethical norms and regulations around consent had something to do with this shift, as did new technologies of, and awareness about, collecting genetic information.<sup>9</sup> Broader discourses of race and rights after the mid-1960s clearly played a part, too. Finally, the commodification of data in all forms—and its increasing profitability—cannot be ignored in forging propertied conceptions of personal information by the later twentieth century. The debate over genetic ownership kicked off by a patent application for recombinant DNA technology in 1974 was just one sign of emerging contention over who was entitled to reap dividends from data with clear scientific but also economic value.<sup>10</sup>

To weave together these threads would be the task of a much longer article. What I want to suggest here is that we learn something about the recent history of data by considering shifts in who could possess it. Around 1970, something happened to how individuals thought about "their" data, whether biological, biographical, or behavioral. Information that had once been held by the party who compiled it—the individual researcher, the institution, "science" more

7. The HBO movie version of Rebecca Skloot's *The Immortal Life of Henrietta Lacks* (New York: Crown, 2010) aired on April 22, 2017. On the exploitation of black bodies for medical purposes, see Todd Savitt, "The Use of Blacks for Medical Experimentation and Demonstration in the Old South," *Journal of Southern History* 48, no. 3 (1982): 331–48; and Vanessa Northington Gamble, "A Legacy of Distrust: African Americans and Medical Research," *American Journal of Preventive Medicine* 9, 6 Suppl. (1993): 35–38.

8. Skloot, *The Immortal Life* (ref. 7), 12.

9. See, for example, National Human Genome Research Institute, Review of the Ethical, Legal and Social Implications Research Program and Related Activities (1990–1995), <http://www.genome.gov/10001747>.

10. Doogab Yi, "Who Owns What? Private Ownership and the Public Interest in Recombinant DNA Technology in the 1970s," *Isis* 102, no. 3 (2011): 446–74.

broadly—now belonged also in some way to the person it described or from whom it derived. Data collected by others was becoming an aspect of one's personhood.

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Individual records preserved in bureaucratic files seem at first glance like a completely different entity from the bodily tissue and cell cultures at stake in the biomedical sphere. Yet the story of their transmutation into personal property roughly parallels that of HeLa. Indeed, forms of data that had long existed in American society were getting much more personal in the same years that Lacks's cells became, at least in the realm of argument, hers. This was true in legal but also colloquial terms, evident in the very spread of the phrase "personal data."

Student records are a case in point. Before 1970 or so, the behavioral reports, psychological tests, disciplinary records, and counseling memos that routinely wound up in U.S. public school filing cabinets firmly belonged to teachers and administrators. But these records—along with those of credit and insurance bureaus, social welfare agencies, and police departments—became objects of intense controversy in the late sixties. The reasons were both political and technological. Rising distrust in authorities and the spread of computerization each played a role in calls for "fair information practices" by the 1970s in the United States as well as in western Europe.<sup>11</sup> By 1973, a legal scholar could write that "the time is ripe for recognizing the property interests of the card-holder in his [credit card] information file." Unauthorized use of that information, he urged, "should constitute an invasion of the individual's property interests."<sup>12</sup>

What was novel was not the files, an old technology. It was the language of access and ownership, born of fresh awareness of record-keepers' capacity to shape individual fates, particularly in a dawning computer age when information could be preserved indefinitely and shared with ease. By the mid-1960s, those items that sociologist Gary Marx calls "starter datem"—facts on file that "generate breeder documents that become central for life chances," for

11. David H. Flaherty, *Protecting Privacy in Surveillance Societies: The Federal Republic of Germany, Sweden, France, Canada, and the United States* (Chapel Hill: University of North Carolina Press, 1989).

12. John T. Westermeier, Jr., "The Privacy Side of the Credit Card," *American University Law Review* 23 (1973): 183–207, on 204.

employment, credit, insurance, and the like—mattered in new ways.<sup>13</sup> This was true both for its collectors, as Dan Bouk notes in this Issue regarding the proposed National Data Center, and for those they described and tracked.<sup>14</sup>

The “school records controversy” was born of new suspicion of powerful gatekeepers.<sup>15</sup> Discrimination and stigmatization, whether on account of race, “character,” ability, or IQ, could be the lasting product of materials in one’s educational file. As a committee of African-American teachers and counselors in San Francisco succinctly put it, “Black students’ folders tend to be at least half an inch thicker than those of white children . . . which tells you something about the child even before you open the folder.”<sup>16</sup>

Parents and pupils only really began to think of student data as *theirs* once the power of these records—their potential biases, lack of accountability, and easy access by everyone, it seemed, but the record subject him or herself—was politicized by grassroots social movements and advocacy organizations in the early 1970s.<sup>17</sup> One of these groups, the National Committee for Citizens in Education (NCCE), sent out a test mailing with a “distinctly attention getting envelope” to promote the message. “Do you know what’s in your child’s school record? It might surprise you . . .,” it tantalized. A string of phrases—“unnaturally interested in girls”; “history of bedwetting”; “too challenging”; “strangely introspective”; “peculiar political ideas”; “alcoholic mother”—dotted its face.<sup>18</sup> The NCCE summoned parents and citizens, heretofore “virtually powerless,” to join the battle with “entrenched bureaucracy.”<sup>19</sup>

13. Gary T. Marx, *Windows into the Soul: Surveillance and Society in an Age of High Technology* (Chicago: University of Chicago Press, 2016), 45.

14. Dan Bouk, “The National Data Center and the Rise of the Data Double,” in this Issue.

15. Michael J. Zdeb, “A Student Right of Privacy: The Developing School Records Controversy,” *Loyola University Law Journal* 6, no. 2 (1975): 430–55. On the broader records controversy, see Stanton Wheeler, ed., *On Record: Files and Dossiers in American Life* (New Brunswick, NJ: Transaction Books, 1969); Alan F. Westin and Michael A. Baker, *Databanks in a Free Society: Computers, Record-Keeping and Privacy* (New York: Quadrangle Books, 1972); and James B. Rule, *Private Lives and Public Surveillance: Social Control in the Computer Age* (New York: Schocken Books, 1974).

16. Quoted in Diane Divoky, “Cumulative Records: Assault on Privacy,” *Learning* 2 (Sep 1973), 18–23.

17. See Diane Divoky, “How Secret School Records Can Hurt Your Child,” *Parade Magazine*, 31 Mar 1974; The National Committee for Citizens in Education, *Children, Parents and School Records* (Columbia, MD: 1974).

18. National Committee of Citizens in Education, “Denial of Access and Invasion of Privacy: A Test Mailing in Two Parts” (n.d., ca. 1973/74), box 1, folder 15, Special Collections Library, Penn State University.

19. Ibid.

Public clamor for regulating the record-keepers would result in U.S. federal legislation: the Fair Credit Reporting Act (FCRA) of 1970; the Family Educational Rights and Privacy Act (FERPA) of 1974; and the groundbreaking Privacy Act of 1974, which disallowed secret data-gathering systems, prevented information collected for one use to be used for another, and enabled individuals to know of and to correct material in their records. Each promised U.S. citizens access to their files, albeit through an arduous bureaucratic process, for the first time.<sup>20</sup> Just a decade earlier, this kind of admittance to official records was unimaginable. FERPA and similar laws were celebrated as victories for civil liberties and self-determination, indeed, “the end of a time when the individual will be protected from information about himself.”<sup>21</sup>

Legislation in the 1970s, in the United States and elsewhere, would not just lay down fair information practices. For better or worse, it would also endorse individuals’ growing claim to possession of their virtual selves, those bits of biography distributed across the society’s expanding data systems. In theory, anyway, citizens might be the owners, or co-owners, of their files. Sovereignty over personal data—information compiled by an array of social authorities for their own purposes—would in this way become a legal right but also a form of property.

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As the mingling of rights talk and data practices advanced in the United States and Europe in the 1980s and 1990s, claims to possession of one’s own personal information became more pronounced. This was, perhaps, the most plausible option for bridging the late-twentieth-century tension between the liberal subject and the subject of data, the free-standing individual of democratic theory and the actual person enmeshed in dense informational nets.

This language of ownership could be found, for example, in the dramatic politics around individual Stasi files as the Berlin Wall came down in 1989. East Germans’ protest against the tyranny of the German Democratic Republic and its secret police, historian Paul Betts recounts, manifested itself early on in a spray-painted slogan scrawled on the exterior of the Ministry of State Security: “I Want My File!” Leaders of the new Germany had instead planned for

20. This promise was sharply limited. Regarding FCRA, for example, observers noted that “the subject can not actually see the record or obtain a copy of it. Nor is he or she even advised that the record exists until it has been used for an unfavorable decision”; Robert C. Goldstein and Albert S. Dexter, “Privacy Regulation and Your Computer,” *Business Quarterly* 40, no. 4 (Winter 1975): 31.

21. Jeremiah S. Gutman, “The Right to Know,” *The Hastings Center Report* 3, no. 5 (Nov 1973): 10.

the obliteration of the six million dossiers that had bloomed in a country of only seventeen million. They reasoned that the files were poisonous, exploitable, and inimical to social reconstruction.<sup>22</sup>

East Germans opposed that plan. They meant to hold the state and secret police accountable, to expose spying and persecution. But in the process, they claimed the despised Stasi records as their own. As Betts notes, many “rose to champion the preservation of the files and, more importantly, the citizen’s right to view his or her own file.”<sup>23</sup> In the turn from destruction to possession was a noteworthy irony: that which had been owned by the socialist state would, it seemed, finally be the people’s property.<sup>24</sup> East Germans in fact asserted a collective as well as individual interest in the files, at one point protesting the records’ proposed relocation to the Federal Archives in West Germany because those records were, as one had it, “our dirty laundry.”<sup>25</sup>

Ultimately, the records remained in East Germany and citizens were permitted full access to “their” files. A special commission described this process as compensatory, a necessary step toward social justice and a means of furthering “the individual’s self-determination and sovereign citizenship.” Writes Betts, the reclamation of one’s biography through this act of “private repossession” of a file became “East Germany’s uniquely popular version of coming to terms with the Communist past.”<sup>26</sup>

Hailed as a step toward a liberal democratic future, once-damaging information collected and deployed by the state was now placed in private citizens’ hands. In East Germans’ determination to own rather than disown these particular kinds of records, arguments over whether the files should exist at all receded from view.

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22. Among others, the East German parliament, the West German Interior Minister, and the West German Chancellor all advocated for the destruction of the files. Paul Betts, “I Want My File!: The Private Side of German Reunification,” *History Today* 59, no. 10 (Oct 2009): 34–38.

23. *Ibid.*, 36.

24. Cornelia Vismann writes that files can “pit state against society and administration against citizenry. The state compiles records, society demands their disclosure.” *Files: Law and Media Technology*, trans. Geoffrey Winthrop-Young (Stanford, CA: Stanford University Press, 2008), 147.

25. Betts, “I Want My File!” (ref. 22), 37.

26. *Ibid.*, 36, 38.



If in a different key, many Americans in the twenty-first century also spoke of data ownership as empowering. The Quantified Self movement—also referred to as lifelogging, personal informatics, and personal analytics—is the most obvious example. Founded by two former editors of *Wired* magazine in 2007, it brought together enthusiasts around the project of harnessing “self-knowledge through numbers.” Citizens would gather data about themselves not to monitor the state but to monitor (and optimize) themselves: their personal health, fitness, stress levels, emotional well-being, and productivity.<sup>27</sup>

As an industry was built on the promise of “technologically assisted self-regulation,” however, the limits of ownership as a viable data politics became clear.<sup>28</sup> Although billed as a voluntary, individual practice, self-tracking offered ample opportunities for others to follow along.<sup>29</sup> In some contexts, explains sociologist Deborah Lupton, self-monitoring (whether through Fitbits, watches, or apps) is “being encouraged, or even enforced on people, predominantly so that the objectives of others are met.”<sup>30</sup> Insurance companies, workplaces, and schools—enterprises that have long sought better data on the people in their sights—have all grasped at the new devices and the information they provide, whether to supervise students’ physical movements or employees’ adherence to corporate wellness policies. In other contexts, the data streaming from tracking devices are monitored silently by the developers of software, third-party purchasers, or data-mining companies.<sup>31</sup>

Indeed, the rhetoric of ownership coexists uneasily with ample recognition, in our age of big data, of the implausibility of anything approximating sovereignty over what we might think of as “personal” information. Legal scholar Julie Cohen views all of us as raw material awaiting commodification in a dawning “political economy of informational capitalism.”<sup>32</sup> Philosopher Colin Koopman points to the “new political power that can be built out of

27. See <http://quantifiedself.com/about/>; Gary Wolf, “Know Thyself: Tracking Every Facet of Life, From Sleep to Mood, to Pain, 24/7/365,” *Wired*, 22 Jun 2009; Gary Wolf, “The Data-Driven Life,” *New York Times Magazine*, 28 Apr 2010.

28. Natasha Dow Schüll, “Data for Life: Wearable Technology and the Design of Self-Care,” *BioSocieties* (2016): 317–33, on 320.

29. Deborah Lupton, *The Quantified Self: A Sociology of Self-Tracking* (Malden, MA: Polity, 2016); Rebecca Lemov, “On Not Being There: The Data-Driven Body at Work and at Play,” *The Hedgehog Review* 17, no. 2 (Summer 2015).

30. Lupton, *The Quantified Self* (ref. 29), 4–5.

31. Kate Crawford, “When Fitbit is the Expert Witness,” *The Atlantic*, 19 Nov 2014.

32. Julie E. Cohen, “The Biopolitical Public Domain: The Legal Construction of the Surveillance Economy,” *Philosophy & Technology* 31, no. 2 (2018): 213–33.

all this data.”<sup>33</sup> And social psychologist Shoshona Zuboff describes an emergent “surveillance capitalism,” marked by “illegible mechanisms of extraction, commodification, and control that effectively exile persons from their own behavior while producing new markets of behavioral prediction and modification.”<sup>34</sup> According to a 2014 study conducted by the Pew Research Center, citizens at large are also broadly concerned about—if resigned to—their lack of control over commercial and governmental uses of personal information.<sup>35</sup> The Equifax breach of 2017 was just one, and surely not the last, demonstration of contemporary data precarity.<sup>36</sup>

Yet the acknowledged ability of powerful agents to “gather what is voluntarily radiated, unwittingly left behind, or silently and effortlessly made available by breaking borders that traditionally protected information” has not yet dimmed the allure of either legal rights or private ownership as a solution to our data woes.<sup>37</sup> Calling personal data the “most important raw material of the twenty-first century,” Amazon’s former chief scientist and founder of the Social Data Lab proposed in 2017 a whole new bundle of individual entitlements to it. These included rights to access one’s own data and to inspect data companies; and to amend, blur, experiment with, or port one’s data to other holders. Only then would “digital citizens” fully take charge of their own information in a “post-privacy economy.”<sup>38</sup>

Others have floated market-based solutions that would reward savvy practices of evaluating individual returns on data. Those exploring this option have proposed a “privacy-preserving marketplace” that could compensate people according to the level of risk they take in disclosing personal details.<sup>39</sup> Still others have suggested a system of micro-payments for the use of such data, reasoning that some of the profits derived from geo-location information, buying and browsing preferences, and behavioral patterns rightly belong to

33. Colin Koopman, “The Algorithm and the Watchtower,” *The New Inquiry*, 9 Sep 2015.

34. Shoshona Zuboff, “Big Other: Surveillance Capitalism and the Prospects of an Information Civilization,” *Journal of Information Technology* 30, no. 1 (2015): 75–89.

35. Mary Madden, Lee Rainie, Kathryn Zickuhr, Maeve Duggan, and Aaron Smith, “Public Perceptions of Privacy and Security in the Post-Snowden Era,” Pew Research Center, 12 Nov 2014, <http://www.pewinternet.org/2014/11/12/public-privacy-perceptions/>.

36. Sarah E. Igo, “The Equifax Breach Has Potentially Catastrophic Consequences, But We Can’t Let It Obscure the Even Bigger Problem,” *Washington Post*, 26 Sep 2017.

37. Marx, *Windows into the Soul* (ref. 13), 117.

38. Andreas Weigend, *Data for the People: How to Make Our Post-Privacy Economy Work for You* (New York: Basic Books, 2017), 13, 177.

39. Caroline Perry, “You’re Not So Anonymous,” *Harvard Gazette*, 18 Oct 2011.

the people from whom such information is harvested.<sup>40</sup> Different as this constellation of proposals is from the East German protests of 1989, they partake of the same assumption: that data, no matter the evidence to the contrary, can ultimately be made to be “ours.” This assumption tilts the discussion toward access and ownership, and away from destruction or dissolution. It forecloses prior questions we might ask about collection, and about the categories of information we may not want to exist.

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I have deliberately moved among rather different episodes of making data “ours”—from cell lines and school files to state records, step counts, and search strings—to highlight the historically specific way that citizens have encountered and made sense of such information in the last half century. The notion of owning one’s data has complex political roots, bound up perhaps more than we have realized with post-1960s movements around discrimination, exploitation, and social justice. Those roots go deep, still informing the way we think about “personal data,” even in today’s decidedly different soil. The belief that our data are indeed ours—or can be made to be so—is seductive. It is perhaps particularly appealing at a time when individual control over personal information is so very elusive. But probing the limits of these stories of sovereignty and ownership may clear the way for other, better stances toward the data world we now inhabit.

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40. Jaron Lanier, *Who Owns the Future?* (New York: Simon & Schuster, 2013).