

Personal Health Data, Surveillance & Biopolitics

Toward a Personal Health Data Information Literacy

by Matthew Weirick Johnson

As consumer wearable health and mobile health technologies become embedded in everyday life, coalescing with the integration and use of personal health data and the personal health record in the sprawling domains of the medical-industrial complex (MIC), health/information literacy (H/IL) and data information literacy (DIL), become more important, both for users of these wearable devices and for undergraduate students who might be folded into the research process as participants or researchers. The present paper argues for the integration of information literacy skills and instruction with a critical understanding of personal health data to provide useful skills for managing the massive amounts of personal health data that users are generating. My goal is to argue for an expansion of data information literacy to provide the necessary skills for users and researchers to critically assess their relationship to personal health data, understanding the concurrent modes of doing and undergoing surveillance.

Personal Health Data, Surveillance & Biopolitical Possibilities

Personal health data allows for what the medical institution views as a positive surveillance that breaks down the false dichotomy of the public/private.¹ Health data can constantly be collected, allowing for data to be collected outside of the space of the medical institution. The personal health record correlates with a move away from medical paternalism and provides patients with the opportunity to be more involved in their own health; however, this patient engagement functions within the neoliberal paradigm to shift the burden from the institution to the individual where individualism is conflated with freedom. Further, the personal health record functions within the neoliberal expectation of self-surveillance,

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where personal health data is continually provided to the record to assist patients and professionals.

Wearable health technology refers to a broad array of technologies worn by an individual to monitor various health or bodily processes to develop data and informatics.² Recently, consumer health wearables have rapidly entered the market as options for self-surveillance, an important objective of the neoliberal subject, to improve health and develop new habits (French and Smith; Rich and Miah; Shilton). These technologies can vary significantly in size and design, including headbands, watches, wristbands, badges, camera clips, and sensor-embedded clothing (Piwek et al. 2). Functionality and data collected also varies significantly, including sleep tracking, pedometer, thermometer, accelerometer, heart rate monitor, altimeter, GPS, oximeter, etc. (Piwek et al. 2). These devices also produce massive amounts of data that can be integrated into the personal health record and made available to the medical institution. Nonetheless, research on these devices has shown that they're unreliable and inconsistent and that they reinforce current habits rather than helping to develop new ones (Bassett, Rowlands and Trost; Evenson, Goto and Furberg; Lee, Kim and Welk; Wen et al.; Yingling et al.; Patel, Asch and Volpp). Further, for consumer devices, the company that produces the device owns the user's health data, putting the user in a precarious position. (Kostkova et al.; Hall).

The quick expansion of these technologies is representative of the technological sublime, a general awe or amazement related to technology and explains the preoccupation with and desire for the newest technology. In relation to surveillance, "[t]he sublime response relies on and resides in the publicity of the technology's grandeur [...] Once it becomes spectacle, surveillance technology can dazzle and intimidate" (Maxwell 9). The technological sublime encourages a fear and anxiety surrounding surveillance technologies; however, the reality of such technologies doesn't always live up to the fear.

Even the systems that surveil us break, which is perhaps a reminder of Susan Leigh Star's claim that infrastructure is invisible until it breaks down, especially for government surveillance and health infrastructure; though, in this case, the breakdown of government surveillance infrastructure is important to reveal these practices to individuals (Star 382). However, the technological sublime explains the desire to enact technological surveillance simply because it is possible, which validates a feeling of paranoia for users. We constantly balance feelings of fear about what technology can do that are exacerbated in the popular imaginary while also attempting to resist the very real possibilities of surveillance technologies. However, we must also be aware of perceptions often generated of limited available modes of life for anyone who chooses not to be technological.

Biopolitics, as popularized by Michel Foucault, refers to disciplinary practices or other mechanisms used by a state to control and manage the

possibilities and ways of living for its subjects. Susan Stryker expands on Foucauldian biopolitics as “the calculus of costs and benefits through which the biological capacities of a population are optimally managed for state or state-like ends” (Stryker 38). Put simply, biopolitics refers to state control over the way its subjects live and die.

Further, personal health data is situated within the commercialization and corporatization of health care inherent in the neoliberal paradigm and the medical-industrial complex, constituting an important facet of the neoliberal carceral archipelago. Stated differently, the medical-industrial complex is a state-like institution that continues to support the state’s ability to control its subject, and the self-surveillance and personal collection of health data provides an easier way for subjects to be controlled and monitored. This trend coincides with the previously mentioned dissolution of the false dichotomy of public and private, coinciding with the rise of social networking and data sharing—both in terms of personal data and research data. Many wearable health and mobile health technologies allow users to share personal health data publicly, supporting social activity and competition. These features are evidence of the learned expectation of control under neoliberalism that supports the functioning of the biopolitical control state. The burden of surveillance is taken from the state and placed on the neoliberal subject, positioning the individual to provide the state the data that allows it to control their biological capacities and ultimately damns them.

Further, privacy, or any separation between public and private, is not universally attainable but a privileged position. Maxwell points out that “workers, the under- and unemployed, the incarcerated, the homeless, and those dependent on welfare (most of whom are women) are the most exposed to surveillance and the least enfranchised of privacy rights” (13). He provides a further exploration of the balancing act between providing information (or allowing surveillance) and rewards, equally applicable to the realm of healthcare, where rewards might be literally life-altering: “And for those who can tap into the privilege of privacy rights, the right to be left alone is sometimes no match for powerful inducements to be watched” (Maxwell 14).

So, what possibilities exist for the biopolitical manipulation of this data both in terms of futuristic imaginaries and present realities? In 2014, Fitbit data was used in a personal injury lawsuit, and, though data in this case was provided willingly, this pushes the responsibility of surveillance from state-like corporations to individuals (Olson; Gibbs). In 2015, Fitbit data was used to delegitimize a women’s rape claim, using self-surveillance data against the owner and making personal data public (Hill; Moon). These two cases set a legal precedent for the admissibility of Fitbit and other consumer health wearable technology data, allowing for future possibilities for personal health data to be used against individuals to control their various ways of life or to deem certain lives less worth living because of conceptions of health (Alba; Hall).

Further, current public and global health interventions using consumer health wearables, mobile health applications, and personal health data have focused on people who have Type II diabetes or who are identified by medical metrics as obese (Gilmore; Heintzman; Klonoff; Rehman et al.). In both cases, these interventions focus on bodies that diverge from an institutionalized construction of health. As the practice continues to move into the workplace and health insurance protocols, additional controls will be placed on the neoliberal worker/workplace to produce more productive workers.³ Hence, the medical-industrial complex targets certain bodies that are deemed unhealthy, and thus lives “unlivable,” as neoliberal subjects for self-surveillance to achieve “health” (and livability) through public and global health interventions as well as product marketing, though consumer health wearable devices have been shown to be less effective in producing positive health behaviors (Omura et al.; Patel, Asch and Volpp; Yingling et al.). The focus is on positive behavioral changes for the purpose of achieving a health status that is beneficial to the state and hence makes a life livable. What other deviant modes of health and life will this technology target, such as queers or sex workers?

Modes of life and health that diverge from this state expectation are deemed unlivable, and hence, become targets for technologies of self-surveillance. Again, positioning the neoliberal subject to supply the data that the state can use to metricize (un)livability of (un)healthy bodies.⁴ Understanding the precarious landscape of personal health data generated from mobile health applications and consumer health wearables, libraries and librarians have a responsibility to prepare users and communities to protect themselves or at least be aware of the possibilities inherent in their self-surveillance.

Personal Health Data & Information Literacies

Much research has focused on developing data information literacy (DIL) skills for students or researchers to ethically maintain, use, and reuse data, but there has been less of a focus on developing data management skills for the protection of personal (health) data (Carlson et al.; Cleveland and Cleveland; Federer; Hoffman; Macy and Coates; Shorish). DIL has also focused on data management for researchers to keep, maintain, and share data, which is perhaps antithetical to the privacy of individual users. As these new modes of generating health data become more common, management of personal health records and personal health data through DIL skills is important. DIL skills can be used in instruction for both medical and health professionals as well as for users and patients to prepare individuals on both sides of the information system for knowledge management and personal protection.

Carlson et al. argue that it’s important to differentiate data information literacy from other literacies, such as information literacy or data literacy, both of which are also relevant here (633). They argue that “data literacy involves understanding what data mean, including how to read graphs and

charts appropriately, draw correct conclusions from data, and recognize when data are being used in misleading or inappropriate ways” (Carlson et al. 633). For Carlson et al. these literacies (data, information, and statistical) build on top of each other, becoming necessary building blocks for the creation of DIL. Carlson et al. define DIL as the merging of “the concepts of researcher-as-producer and researcher-as-consumer” (634). They argue that other literacies focus on the way that data, (health) information, or statistics (for example) are consumed, but DIL requires this dual focus. However, the focus here is still on the individual’s status as a researcher, missing the possibility for non-researchers to produce data through these surveillance mechanisms. Further, it focuses on an intentionality of data production and sharing that is not necessarily inherent and intentional in the individual generation of personal health data. It misses the important possibility of simply creating data in our daily lives, outside of the environment of “research.”

Information literacy refers to knowing when information is required and being able to find and access the necessary information. More importantly, Eamon Tewell describes critical information literacy as a process that “examines the social construction and political dimensions of information, and problematizes information’s development, use, and purposes with the intent of prompting students to think critically about such forces and act upon this knowledge” (Tewell 36).

Expanding this to personal health data, a critical literacy would require the understanding of previously mentioned biopolitical possibilities for data situated in the power relations of neoliberal subjects to state and state-like institutions such as the medical-industrial complex. Further, a focus on critical literacy frees us from the falsehood of library neutrality, allowing this deconstruction of power relations, which is essential for an understanding of how personal health data can impact our lives. Data is constructed in power relations and for non-neutral purposes.

Arguing about the *ACRL Framework*, “Joshua Beatty (2014) finds the *Framework* to be a significant improvement to the *Standards*, yet that the document is still articulated in the rhetoric of neoliberalism and reinforces the notion that the way information is produced and commodified is a natural condition that need not be challenged” (Ewell 36).⁵ While preparing users, students, and researchers to protect themselves and their personal health data is important, it’s also important to be aware of the authoritarian institutions that profit from surveillance capitalism and the surveillance of our personal health. The production and commodification of the data itself is the primary site of confrontation.

A Possibility for Personal Health Data Information Literacy

Data information literacy for personal health (DILPH⁶) requires a focus on data and information ethics. It requires confronting surveillance capitalism and modes of authoritarian control that continue to seep into our information

systems. As previously discussed, personal health data has many biopolitical possibilities and is strongly connected to the power relations of the medical-industrial complex and surveillance capitalism. As public health and other medical/health professions continue to see surveillance as a positive component (a sort of surveillance-care), providing greater health benefits, it's necessary to confront continued surveillance, data sharing and networking, and other practices that are imbricated in discussions of data management and DILPH. Providing data to these institutions means allowing them to handle the protection of that data, and the existence of the data itself creates the issue. This data makes us vulnerable.

However, the goal of DILPH shouldn't necessarily be to stop the use of devices that gather personal health data, especially since many smart phones include a health app that can't be deleted. Rather, the focus should be on educating people about these possibilities, about how personal health data is being tracked and used, and about what people can do. We are constantly being surveilled, but DILPH should make individuals more aware of that surveillance while helping them define how they are known by the state: "The political (and epistemological) question is not whether individuals are known and typified. We always are. Rather, it is a question of how individuals are known and typified—by whom, to whom, as what, and toward what end we are made visible" (Phillips 95). How can librarians help individuals make informed decisions about when to "come out" (disclose) or "pass" (conceal) and when these are possible with regard to personal health information?

In this vein, for librarians to be involved in DILPH instruction, they must be able to support the activist initiatives of individuals. While people can limit surveillance and make decisions to limit self-surveillance, the root of the issue is the neoliberal production and commodification of personal health data that makes personal collection unsafe. This is the primary site of confrontation which requires activist initiatives to deconstruct corporate and government control. Maxwell argues that "the more that private corporate interests intercede in the business of surveillance in the name of national security, the more structurally disengaged the American people will become from the processes that determine how surveillance is developed and deployed" (16). Health surveillance, especially for public health, can often be operationalized for national security, but DILPH should provide individuals with the knowledge and ability to engage with how surveillance is developed and deployed. How can we confront the technological sublime without reinscribing/reenacting the fear and anxiety that sublimity creates?

While it seems like a modern fallacy to claim that more data always produces better results, the possibility still exists that providing additional data will allow for improved clinical research and individual outcomes; however, as long as the data exists in the unsafe and volatile domain of the medical-industrial complex and the neoliberal state, there are significant costs and benefits for individuals sharing personal data with institutions.

What changes in medical, data, and information ethics are necessary to achieve important protection for individuals and a separation between health or medicine and the state?

Conclusion

The existence of personal health data makes us vulnerable to a variety of negative possibilities. Data information literacy and critical information literacy skills can be used to provide individuals with the necessary tools to critically assess the collection and dissemination of this information. The library and librarians are uniquely situated to provide these services, to develop instruction related to data information literacy for personal health, and to provide necessary resources for potential social activism.

My goal here is not to move the onus of data protection from institutions, researchers, and technologies to patients and users, but rather, to realize that these things are not perfect and cannot be, to realize that people will act unethically, and to engage (data) information literacy skills to help patients and users protect or limit the creation of personal health data in light of the biopolitical and necropolitical possibilities of the proliferation and dissemination of personal health data, through social networking, consumer wearables, mobile health technologies, or other possibilities that are not yet.

Endnotes

1. See Ara Wilson's "The Infrastructure of Intimacy" for a longer review of literature on the public/private.
2. As a very brief subjectivity statement, I own and wear a Fitbit.
3. It's useful to keep in mind that "freedom" in the neoliberal context primarily refers to freedom of markets but not necessarily freedom for individuals to act, so choice is already an incredibly limited concept.
4. This isn't even to mention the possibilities for algorithmic and mathematical violence, such as using personal health data for actuarial calculations or for algorithms that predict changes in health.
5. The ACRL Framework often reminds me of a quote from Eve Sedgwick about the necessity of a "hermeneutics of suspicion": "It reminds me of the bumper stickers that instruct people in other cars to 'Question Authority.' Excellent advice, perhaps wasted on anyone who does whatever they're ordered to do by a strip of paper glued to an automobile! The imperative framing will do funny things to a hermeneutics of suspicion" (Sedgwick 125).
6. DILPH should be pronounced as DILF, but not like Dad Is Looking Fine, DILF, but rather Dad Isn't Using My Personal Health Data To Control The Modes of Life, DILPH.

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