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# Information Systems and Biopower: Evaluating the Exchange of Health Information through Foucault's Philosophy

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## ABSTRACT

Policy makers in the U.S. government laud the electronic exchange of health information as critical to providing more affordable, better quality health care and are investing significant resources to support this initiative. Some believe that the exchange of detailed health information is critical to gaining new knowledge in medical care and should be considered a public good. The philosophical work of Michel Foucault provides an effective lens to critically examine the implementation of health exchanges and new information technology. Foucault's discussion of concepts like knowledge, power, and surveillance are used to argue that a health record is a full representation of the physical body and is a means of controlling populations through information. Foucault's insights help us understand how storing and exchanging complete health data undermines bodily autonomy, leads to greater marginalization of minority groups, extends biopolitical control, and spurs forced conformity to physical norms.

## Keywords

Health Information Technology, Health Information Exchange, Surveillance, Biopower, Foucault.

## INTRODUCTION

Much attention is being paid to the automation of the health care industry in the U.S. Some policy makers believe that the computerization and exchange of health care records will yield both better health outcomes and improved cost efficiencies (Blumenthal, 2009). This belief has encouraged policy makers to actively facilitate the implementation of automation with substantial financial incentives and support (Grossman, Kushner and November, 2008). Policy makers are especially advocating the exchange of health related data among disparate health care providers and organizations as a panacea for our rapidly growing health care costs and mediocre health outcomes.

Even with substantial support from the federal government, health data exchange initiatives are not thriving; some cite concerns about data privacy and security as the main barriers to implementation, while others identify the complex organizational, managerial, technical, and environmental concerns that impact the exchange and use of health related data (Sicotte and Paré, 2010; Vest, 2010). The results of existing research are ambiguous, demonstrating the need to evaluate the premise of the technology. We argue that the basic concept of electronically storing and exchanging information about an individual's health represents a significant virtual representation of that individual and should be examined more critically using a lens available through philosophical literature.

Often considered a philosopher-historian, Foucault's work catalogues and evaluates major shifts in institutional bodies and their uses (Brown, 2000). Foucault is known for his use of rich and variegated histories as the source material for his philosophical theses by evaluating events as loci of philosophical change and exposition (Rouse, 1994). This wealth of empirical/historical data structures Foucault's theories, allowing him to argue that both technological and institutional shifts in record keeping and data management allow authority figures to literally and figuratively police an individual's body.

Using his understanding of organizations and their evolution, Foucault critically engages the topic of knowledge based power acquisition and the control of bodies through institutional development (Vittorio, 2006). Foucault's analysis of power through knowledge is unusually helpful in understanding developments in information systems and specifically, the exchange of health information. Streamlining the compilation of data and making it available to interested parties through the use of database technology represents an historic shift in the approach to gaining and using knowledge. As Foucault might argue, we are operating in a new "episteme" of data collection, where the shift in our methodological approach to information signifies a shift in our philosophical attitudes towards that information (Rouse, 1994).

It is, however, much more common to evaluate how these developments will positively affect the functioning of business, as well as the welfare of societies, than it is to evaluate the negative implications of these events (Fontaine, Ross, Zink and Schilling, 2010). Foucault's theories are a valuable resource in this regard as he appraises the more controversial qualities of

epistemology and the use/misuse of information (Foucault, 1977). For Foucault, power is acquired through information and is found in its collection and use (Rouse, 1994). Information systems and the exchange of health related data represent a transition in data collection that can be effectively analyzed through insights from Foucault. We argue that a complete record of an individual's health history and care represents the physical body alive in database form. While policymakers hope to control costs and improve care, Foucault's work offers insight into some ethical and moral philosophical implications of creating virtual bodies through detailed health care records. We posit that laying the body bare, through epistemic dissection, represents a possible invasion of privacy, a significant extension of biopolitical control over populations, and is the mark of insidious institutional power.

### **INTEGRATING DATA THROUGH HEALTH INFORMATION EXCHANGE**

Each time a patient visits a medical provider in the U.S, data about that visit is usually recorded in the provider's medical records (Adler-Milstein and Bates, 2010). Data recorded about the patient might include (Grossman et al., 2008; Safran, Bloomrosen, Hammond, Labkoff, Markel-Fox, Tang and Detmer, 2007):

- Demographic: Gender, birth date, weight, height and marital status (individual human genomic data may be available and stored in the future);
- Financial: Employment history, insurance company and financial dependency;
- Medical history: Family history of disease, patient past surgeries and prescriptions;
- Behavioral history: Dietary habits, smoking, drinking, sexual conduct and psychological issues;
- Current medical complaint: Symptoms, dates, and home remedies; and
- Clinical treatments: Provider notes/transcripts about patient, test/lab results, diagnosis, prescriptions and follow-up.

The vast majority of this data is stored currently in paper files accessible through the provider's office (Ross, Schilling, Fernald, Davidson and West, 2010). Automation of those paper files at the provider level may help reduce errors by encouraging best practices and making complete documentation more readily available, constraining costs by avoiding test and treatment duplication, increasing payments by more accurately coding diagnoses, and facilitating better quality control by providing more complete reporting capabilities (Adler-Milstein and Bates, 2010; Ortega Egea and Román González, 2011; Ross et al., 2010).

Considering those potential benefits for providers to automate their health records, adoption of technology has been slow (Adler-Milstein and Bates, 2010). While the level of automation varies greatly throughout the U.S. by size, type and geographic location of the practice, as well as the age and inclinations of the medical provider (DesRoches, Campbell, Rao, Donelan, Ferris, Jha, Kaushal, Levy, Rosenbaum, Shields and Blumenthal, 2008), a recent government survey found that about half of physicians use some type of health records system beyond financial billing (Hsiao, Hing, Socey and Cai, 2011). However, of that 50%, the majority keep track mainly of patient demographics and prescriptions, with only 10% of providers using a fully functional system including provider notes (Hsiao et al., 2011). Hospitals have an even lower adoption rate for health record automation. A survey found that only 1.5% of hospitals have a fully functional records system (Jha, DesRoches, Campbell, Donelan, Rao, Ferris, Shields, Rosenbaum and Blumenthal, 2009). Thus, while medical providers collect and store extensive information about their patients, most of that information is not available currently for access outside the provider's facility.

### **Introducing the Health Information Exchange**

The U.S. government wants to change the accessibility of health records. As part of the American Recovery and Reinvestment Act of 2009 (ARRA), the federal government is investing \$19 billion to promote the adoption and use of health information technology (HIT) with special focus on implementing electronic health records (EHR) so that health information is readily available in an electronic format (Blumenthal, 2009). The HIT funding of ARRA is labeled the HITECH Act, and some of the funds are intended to be used by states to electronically exchange data among health care providers. A goal of HITECH is to electronically transmit data from provider EHR systems into a regional repository or network that can eventually be collected into a Nationwide Health Information Network (NHIN).

A health information exchange (HIE) is not a specific architecture or technology, but instead is a concept defined by its capabilities and intended benefits. Applying these capabilities and benefits, an HIE is the integration and electronic transfer of clinical information among disparate, independent health-related organizations intended to improve patient safety, the clinical management of chronic disease conditions, and clinical quality and efficiency, most specifically through the reduction of duplicate tests (2010).

### Data available through HIE

The HIE concept is to create a “continuity of care” record that eventually provides complete and detailed background health information about an individual (Grossman et al., 2008). The primary use of HIE data is to support immediate health care decisions about patients with applications such as clinical messaging, pharmacy order fulfillment, test result comparison and quality outcome evaluation. But in addition to primary use, HIE could also facilitate more comprehensive secondary use of data for health related research. Researchers hope to be able to collate huge data sets from HIE in order to identify patterns of symptoms, disease, and diagnoses (Mandl and Kohane, 2008; Safran et al., 2007). This flood of data from HIE could enable researchers to use technology-based data mining algorithms and identify correlations not visible through standard clinical trials. Data including genomic information could be used to identify more clearly genetic predisposition towards disease as well as increase the likelihood of success of potential cures.

The level of detailed data conceptualized for HIE is beyond what has been stored and made previously accessible electronically about a given individual. The data available about a person in a health care system provides almost complete knowledge about his or her family and employment history, personal habits, physical problems, medical treatments, hopes, dreams, and fears.

### FOUCAULT’S VIEW OF KNOWLEDGE AND POWER

For Foucault, knowledge and power are inseparable and at times synonymous; each is facilitated through the use and deployment of the other (Foucault, 1995). Knowledge, as the fact or condition of awareness and inquiry, is the means by which insight and understanding are accumulated and evaluated. Through knowledge, we come to understand and grasp the being and particularities of subjects, objects, bodies, and concepts. Foucault argues that institutions are most notable in their acquisition and use of knowledge as a means of securing/surveying a population (Foucault, 1977). In his discussion of these institutions, and the shifts they undertake as they develop, Foucault argues that our methodology of acquiring knowledge reifies political control over populations (Foucault, 1977).

### Biopower is derived from knowledge of the body

As institutions gain more knowledge about the people they survey, so too do they gain power and control over the very bodies of the populace. Naming this biopower, literally power over the body, Foucault argues that knowledge is a means of facilitating control over that which had remained, historically, inaccessible (Foucault, 1995). The body is, for Foucault, the physical form; the literal body of an individual directed by power structures. Knowledge is, for Foucault, never a pure or innocent account; it exists as a mechanism of control over that which it examines (Rouse, 1994). Knowledge establishes a power dynamic between the one who studies/records and the one who is studied/recorded. The purpose of knowledge is to be able to exercise control over that which is known.

Foucault traces the shifts in knowledge acquisition through technological and societal evolutions; he argues that methodologies of attaining knowledge have morphed from broad-based inferences concerning large scale beings to more parceled out, systemized, and categorical evaluations of the body. Using the medical and prison systems as his model, Foucault argues that our approach to understanding the body has become increasingly selective, atomized, and particular (Foucault, 1973; Rouse, 1994). No longer content to treat the body holistically, as a physical and immutable object, the medical community has begun to tease apart the foundations of the body and systematically ask for greater detail in information. He writes, “it was a question not of treating the body *en masse*, ‘wholesale,’ as if it were an indissociable unity, but of working it ‘retail,’ individually; of exercising upon it a subtle coercion, of obtaining holds upon it at the level of the mechanism itself” (Foucault, 1995, p.137).

This inquiry into the mechanism of the body—the very gestures, attitudes, intricacies, and emotions ascribed to the physical form—is a movement of biopolitical control and an extension of institutionalized power. Power, as a relational and dynamic entity, is exercised through the compilation and development of complete, accurate, bodily histories. A complete record of the body, an inquiry into the recesses of the physical form and their elucidation on a page, allows “disciplinary power to be absolutely discrete” since “its very principle leaves no zone of shade and constantly supervises the very individuals” (Foucault, 1995, p.177) it uses to enforce its systems. Foucault argues that the bastions of shade where one could remain ambiguous and free have been eliminated (Foucault, 1973).

Moreover, the practices of surveillance, documentation, and elicitation manage to constrain and determine behavior. As people’s actions and habits become more visible, so too does their desire to “normalize” yet remain personally hidden. A sort of negative feedback loop, the public availability of information and the revelation of our inherent differences/uniqueness makes us wish to normalize/remain hidden. Fine-grained knowledge enables “a more continuous and pervasive control of what people do” (Rouse, 1994, p.99), furthering the possibilities of even more inquiry and control.

### **Biopower facilitated through HIE**

HIEs could be considered extensions of institutional record keeping and contemporary modalities of epistemic biopolitical control. Detailed records accessible electronically through HIE mark a new episteme in the use of technology to support healthcare and research. As a complete history, HIEs fundamentally act as the elucidation and transcription of the physical body into digital form. Moreover, HIEs establish loci of control over the physical bodies of the populace by cataloguing their intricacies, especially focusing on weaknesses, and making the body exceedingly visible. By recording every detail of the body, HIEs make possible and practical the complete and utter surveillance of the body as a medical object. The completeness of the history, as well as its availability, leaves no shade by which to hide or remain unseen. They render the body passive to the activity of medical practitioners and researchers, thereby solidifying the hierarchical “power-over” that Foucault describes. HIEs are the physical manifestations of institutional power over the body.

It has been argued that HIE is nothing more than a small step in the evolution of networked database technology and data collection (Adler-Milstein and Bates, 2010). An underlying epistemic presupposition is that medical information is no different than financial information or preferences about clothing, movies, or music. It is our contention, however, that medical histories are the digital manifestation of the body and must, therefore, be analyzed through a different lens. We do not choose our medical histories nor can we escape them. Our participation in the financial world is a comparatively free and independent event. For example: I choose to purchase a sweater online, I choose to bank online, I choose to fill out a survey about Lady Gaga. Our bodies and our medical problems are, however, largely outside our control. It is the rare individual who chooses to have his or her appendix burst or to suffer from clinical depression. These facts about the body are an extension of the body; they are not chosen nor do we willingly request that they occur. As a permanent part of the body their transcription into a medical database must be treated more cautiously than the common approach to personal information; completely new processes must be used to educate people about the impact of this data so that they can make better informed decisions about its potential use.

### **HIE marketed under the banner of public good**

Communities in the U.S. have been experimenting with the HIE concept for at least twenty years (Fontaine et al., 2010). Even though there is much government support for HIE, there are surprisingly few successful, ongoing initiatives. A recent study found only 55 operational HIEs in the U.S. in 2008 actively participating in the exchange of health information (Adler-Milstein, Bates and Jha, 2009). According to Grossman et al, 2008, p.2, “Despite the potential benefits to patients, practitioners, hospitals and others, few HIEs existed before the federal government’s efforts to promote their development.” Researchers have found that CEO’s are more willing to participate in HIE than CFO’s or COO’s, because CEO’s view participation as a public good, rather than as a way to save money or produce better medical outcomes for their facilities (Grossman et al., 2008). Increasingly, this banner of “public good”—where HIE’s represent a rendered service to hospitals, their patients, and medical researchers—is being discussed as a way to justify the implementation of HIE (Adler-Milstein, Landefeld and Jha, 2010; Angst, 2009; Sicotte and Paré, 2010).

This discussion of the public good, and the seemingly moral importance of implementing HIE’s, operates at both the institutional and the personal level. The rhetoric employed to market HIE has become increasingly emotional when experts claim that “health care that people receive is not based on the best available scientific evidence” and that “44,000 to 98,000 people die every year as a result of medical errors” (McGraw, 2009, p.419). Kenneth Goodman, professor of medicine and philosophy at University of Miami, argues that HIE’s are a moral issue, as “physicians and nurses have duties to people who are not their patients” seeing as the “clinician-patient relationship entails duties to public health” (Goodman, 2010, p.59). Goodman concludes by stating, “the idea—the very idea—that a patient would identify a self-interest in withholding anonymized health data from public health analysis is an ethico-socio-political tragedy” (Goodman, 2010, p.62).

This discussion of the public good, and the unquantifiable moralizing that exists in the literature surrounding HIE’s, effectively illustrates two Foucaultian hallmarks of biopower. First, for Foucault, power is never exercised as a conscious desire to claim control; rather, it moves through multiple institutions as the articulated “production or enhancement of various ‘goods,’ such as knowledge, health, wealth, or social cohesion” (Rouse, 1994, p.102). Instead of outright grabbing power and demanding absolute knowledge of a population, institutions subconsciously acquire control by consciously demanding information that will lead to perceived social benefits. Because this knowledge will be used for the greater good, it would be immoral and therefore unthinkable *not* to give away details and facts about the body.

Secondly, however, is that power is never top-down for Foucault and therefore requires a dispersed field of dynamic power relationships (Foucault, 1995). Foucault argues that power does not just extend from authority or institutions at the top of social strata in a “vertical” fashion, but from all sides through “horizontal” means (Brown, 2000). Biopower is insidious and moves through variegated and seemingly incongruous institutions; the mechanics of epistemic surveillance cannot be pinpointed to a single sovereign entity. Power is manifested through social interaction, through discursive techniques, through the stress and pressure of peers, colleagues, and strangers (Rouse, 1994). Control is therefore assumed and maintained as a dynamic and fluctuating operation between all individuals and is essentially asserted/enforced by the demands of the populace as a whole. HIEs are the epitome of this insidious field of power relationships because people feel pressured to supply information as it will benefit their society, their neighbors, and their friends. HIEs are a biopolitical threat not just because of what they collect, but because of the rhetoric that describes their function. It is presented as immoral to avoid the collection and public use of one’s medical data; therefore, people are pressured to share their most intimate personal information. This threat of immorality, and the “horizontal” application of power, illustrates the fundamental biopolitical qualities of HIEs and medical information systems.

### **PRACTICAL IMPLICATIONS OF BIOPOWER**

For Foucault, the most obvious implication of epistemic surveillance is its ability to marginalize or exclude already threatened or minority communities (Foucault, 1973). No longer able to hide in the shadows, to remain ambiguous and therefore free, epistemic surveillance lays bare the collective identity of communities or the personal identities of individuals, making their conditions and ways of life visible. Knowledge is the final act of completely dominating a subject, of being able to exercise control over the subject. For Foucault, power is established through knowledge of identity and the maintenance of categories (Foucault, 1995). Knowledge is an act of possession, of capture, of knowing that which had previously exceeded our limits of cognition.

#### **Examples of marginalization of communities**

Thirty-four states criminalize the transmission of HIV/AIDS, if the transmitting individual knew they had HIV/AIDS prior to unsafe contact (Lazzarini, Bray and Burris, 2002). The existence of these laws makes possible new legislation that might demand infectious/positive individuals make available their medical histories on command. The most likely scenario for this kind of requirement might be if an individual works in a job requiring frequent public contact, such as a health care provider or a teacher. It is even possible to imagine that certain communities heavily hit by the HIV/AIDS epidemic be required to reveal their medical health records upon request. This kind of stigma will further mark a community of individuals as unhealthy and marginalize them to the periphery in ways that are unpredictable and potentially frightening. In the more extreme version of this example, communities that are already historically maligned will become further associated with and/or defined by the body. For example, LBGT individuals could be further coupled with sexuality, disease, and pushed to the periphery of what is considered “normal.”

It isn’t hard to imagine future employers demanding a list of an individual’s medical records to determine whether or not they are capable of performing job-related tasks. Some jobs already require frequent medical examinations to determine relative fitness – airline pilots have their eyesight and heart functions checked, mine workers have their lead levels checked. After the implementation of HIE, the medical information provided wouldn’t just pertain to the necessary and pertinent physical information, it might contain data concerning the individual’s mental health, including history and treatment of depression, past sexual health visits, and dietary habits.

There is also grave possibility of intentional misuse of the data accessible via HIE. In the U.S., we saw the impact of “leaking” mental health records during a political campaign; Thomas Eagleton was essentially forced to resign as a vice-presidential candidate in 1972. We assert that “leaking” information about an abortion would be extremely detrimental to the campaign of a female candidate for office.

Individuals appear to understand intuitively this threat. A 2006 national survey reported that 80% of individuals were concerned about the use of medical information for commercial purposes, 55% were worried about insurers viewing their medical data, and 56% were concerned about employers accessing/viewing their medical data (McGraw, 2009). Most notably, individuals who suffer from chronic illness and/or are members of racial, ethnic, and social minorities show even more marked concern about the use/misuse of their medical data and are even more likely to withhold information for fear of its being improperly used (Teixeira, Gordon, Camhi and Bakken, 2010) (McGraw, 2009).

### Questionable current legal protection

Many studies question the efficacy of current laws for the protection of data after the implementation of HIE (Choi, Capitan, Krause and Streeper, 2006; Safran et al., 2007; Terry and Francis, 2007). The Health Insurance Portability and Accountability Act (HIPAA) of 1996 includes both privacy and security rules to protect the privacy of individually identifiable health information held by those entities that the act considers to be covered. A few of the concerns about HIPAA include: whether the act protects data once it is electronically collected and is accessible outside of a covered entity; whether it is necessary to notify individuals each time data is accessed; how data will be identified accurately in the absence of a universal identifier; whether the definition of covered entities should be expanded; and whether to safeguard more stringently de-identified and anonymous data. An additional major concern is the enforcement of HIPAA regulations. Compliance with HIPAA privacy standards was required as of April, 2003. Since that date, the federal government has received 58,199 complaints with 12,781 considered eligible for enforcement. Of that total, 6,102 were found to violate regulations, but only 4 violations were prosecuted with monetary penalties. The vast majority of enforcement consisted of encouraging more training or establishing new policies for those entities breaking the law (Government-Agency, 2011).

### CONCLUSION

Many studies are trying to understand why the automation and exchange of health information has been slow and incomplete. Foucault's theories help explicate the reasons behind the nagging doubt at the back of our minds concerning privacy issues, institutional knowledge, and epistemic normalization. HIEs represent a significant practical development in information technology that affects and threatens the well-being and bodily autonomy of the populace. As we continue to lay bare the body and analyze its mysteries through the use of database technology, surveillance measures, and medical informatics, we exert institutional control and formulate newly problematic extensions of biopower. While institutions continue to develop detailed and theoretical knowledge about the body-politic, so too does the insidious and dynamic field of bureaucratic power continue to grow. Foucault's theories provide a compelling framework by which to evaluate these developments and force us to reconsider the progression of information systems into the automation of health records.

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