Visible Lives: Electronic Health Records
and the Biomedical Surveillance of Gender Nonconformity

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THESIS
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<th>Full Form</th>
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<tr>
<td>ACA</td>
<td>The Affordable Care Act</td>
</tr>
<tr>
<td>AKA</td>
<td>Also Known As</td>
</tr>
<tr>
<td>ARRA</td>
<td>The American Recovery and Reinvestment Act</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>CHC</td>
<td>Community Health Center</td>
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<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
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<tr>
<td>EHR</td>
<td>Electronic Health Records</td>
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<td>EMR</td>
<td>Electronic Medical Records</td>
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<tr>
<td>eCW</td>
<td>e-Clinical Works</td>
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<tr>
<td>FQHC</td>
<td>Federally Qualified Health Center</td>
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<td>FTM</td>
<td>Female-to-Male</td>
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<td>GeniUSS</td>
<td>Gender Identity Inclusion in US Surveys</td>
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<td>GEO</td>
<td>Graduate Employees Organization</td>
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<td>GI</td>
<td>Gender Identity</td>
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<tr>
<td>GNC</td>
<td>Gender Nonconforming</td>
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<tr>
<td>HB</td>
<td>Harry Benjamin (Standards of Care)</td>
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<td>HIE</td>
<td>Health Information Exchange</td>
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<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
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<tr>
<td>HITECH</td>
<td>Health Information Technology for Economic and Clinical Health (Act)</td>
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<td>ICD</td>
<td>International Classification of Diseases</td>
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<td>IGERT</td>
<td>Interdisciplinary Graduate Education Research and Training</td>
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<td>IOM</td>
<td>Institute of Medicine</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>IRRPP</td>
<td>Institute for Research on Race and Public Policy</td>
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<td>IT</td>
<td>Information Technology</td>
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<td>KI</td>
<td>Key Informant</td>
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<tr>
<td>LCR</td>
<td>Lifetime Clinical Repository</td>
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<td>MTF</td>
<td>Male-to-Female</td>
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<td>NLGTF</td>
<td>National Lesbian and Gay Task Force</td>
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<tr>
<td>NOS</td>
<td>Not Otherwise Specified</td>
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<tr>
<td>PHI</td>
<td>Personal Health Information</td>
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<td>POC</td>
<td>Persons of Color</td>
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<td>PrEP</td>
<td>Pre-Exposure Prophylaxis</td>
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<td>RAD</td>
<td>Referral Aggregator Database</td>
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<td>SO</td>
<td>Sexual Orientation</td>
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<td>Sexual Orientation and Gender Identity</td>
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<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>T</td>
<td>Transgender Status</td>
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<td>TG</td>
<td>Transgender</td>
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<tr>
<td>UIC</td>
<td>University of Illinois at Chicago</td>
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<td>WPATH</td>
<td>World Professional Association for Transgender Health</td>
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SUMMARY

This dissertation is nontraditional, whereby the first three chapters provide background for the case study found in chapters IV, V, and VI, followed by a conclusion. Chapters I and II provide the policy and research contexts for this study. Namely, the Affordable Care Act and related federal legislation incentivized the implementation of electronic health records, particularly for providers of underserved individuals such as trans and gender nonconforming (GNC) persons. Very little research exists to understand how such implementations and the subsequent data collection and surveillance have impacted care for and knowledge production about underserved individuals, in general, and care for trans and GNC persons, in particular.

This case study, described in chapter III, draws on several methodological approaches (Burawoy, 1991; Smith, 2005; Star, 1999) to explore the effects of electronic health record (EHR) implementation and data collection in this context. Twenty-seven key informant interviews were conducted with trans healthcare stakeholders in six major metropolitan areas in the United States. Four focus groups were conducted in Chicago, Illinois with a diverse cross-section of trans and GNC individuals about their recent healthcare experiences. The case study toggles between theory, discourse, and the empirical data in order to situate the voices and experiences of those impacted within broader research trajectories related to surveillance and trans health and to offer a critical set of recommendations.

Chapter IV examines how a range of users navigate these infrastructures and what workarounds they have created to overcome barriers and maintain workflows, with special attention to patient privacy and data security. The infrastructures and degrees of staff training are unique to each provider organization. Interviews revealed disproportionate administrative burdens at smaller providers. Most stakeholders have numerous challenges with these systems as
they relate to trans and GNC patients. Notably, stakeholders report that, despite various workarounds, clinicians and staff often mis-gender trans and GNC patients in a range of contexts due to inadequate data fields, algorithms, and lack of staff training. Healthcare providers for trans and GNC persons need to address these infrastructural failures and institute measures to ensure safe access, quality care, and the protection of patient privacy and integrity. A range of recommendations are provided that help ensure quality care and access for trans and GNC patients.

Chapter V departs from Vivian Namaste's call for trans visibility in her seminal work *Invisible Lives* (2000) and considers what the two-step gender identity algorithm means at the clinical and population levels for transgender visibility and vulnerability. The two-step question is a measure developed to identify and count trans and GNC persons in healthcare settings: (1) what sex were you assigned at birth? And (2) what gender do you currently identify with? A range of institutional stakeholders of transgender healthcare have recommended the incorporation of the two-step question into health-related data and surveillance systems in order to identify transgender persons more accurately.

Based on analyses of four focus groups with trans and GNC persons and 27 key informant interviews with stakeholders who work at established providers of transgender healthcare, policy, and research, this chapter examines practical and theoretical implications of incorporating the two-step question into EHRs. The analyses suggest that the algorithm may offer benefits such as perceived cultural humility and quality improvements in clinical settings as well as new population-level, research opportunities. On the other hand, key informant researchers expressed many reliability and validity challenges around EHR-based research.
SUMMARY (continued)

Related to research and measurement biases, the chapter also cautions that the two-step algorithm also functions as an instrument of normalization (Foucault, 2007) that may limit or erase the autonomy and experiences of some patients and detract from the agency of the doctor-patient relationship. Though useful as a classification to some stakeholders, this algorithm constitutes a translation regime (Johnson, 2015) that dovetails with state-centered health strategies (Epstein, 2003) and may compromise the healthcare access, patient privacy, and self-determination of trans and GNC persons, particularly the most marginalized (e.g., HIV positive, immigrant, and/or Black).

Finally, chapter VI explores the new healthcare landscape in the United States through the experiences and voices of trans and GNC persons. Healthcare for trans and GNC persons has transformed rapidly since the passage of the ACA and the subsequent elimination of preexisting conditions and the expansion of coverage for trans-related primary care. The implementation of EHRs has also changed the clinical intake and care delivery processes. This part of the case study extends Foucault’s notion of bio-power and the care of the self to examine the possibilities and limits of gender self-determination, access to care, and patient privacy for trans and GNC persons. Based on analyses of four focus groups of trans and GNC persons in Chicago (N=30), discussions revealed that trans and GNC participants appreciate the relative nuance of the two-step algorithm but, given their experiences, have many concerns around privacy violations, safety, and discrimination if this information is not protected. Some objected altogether to the basis for the algorithm. Many participants, particularly trans and GNC persons of color (assigned male at birth), shared their own workarounds with each other in order to help their peers resolve barriers to care, autonomy, and self-determination. Many experienced rigid administrative
SUMMARY (continued)

systems and infrastructures unpredictably—at times, normalizing and at other times leaving them invisible or denying them access to care and resources—but had strategies and tactics for particular barriers. This creativity, agency, and autonomy in the face of bio-power extends Foucault’s notion of the care of the self and highlights the importance of decentering rigid classifications as well as binary categories and centering the most marginalized in trans and GNC healthcare and health research.

Chapter VII, the conclusion, examines the findings and recommendations in the context of emergent trends. While the visibility of transgender persons in mainstream media has increased, the vulnerability of those perceived as GNC persons has also increased. At the same time, the Department of Health and Human Services and the Centers for Medicare and Medicaid’s have issued a new plan (2015) for reducing health disparities through EHR data collection on marginalized populations. Prioritizing EHR data standards and data collection as the means to health equity for trans and GNC persons may create more harm, the antithesis of CMS’s most important goal for underserved patients and populations. This priority aligns with the centering of the “majority” of trans people or those that fit current norms of masculinity and femininity and feel safe and respected making themselves visible at clinics. Data derived this way are quiet expressions and measures of White, first world, Anglo-centric, middle-class norms rather than objective classification standards. Priority should be on safe access to care (including safe infrastructures) in this new and expanded healthcare landscape for transgender people. The burden for accessing care safely should not rest on trans and GNC individuals; these individuals cannot be counted in records for the purposes of reducing health disparities if they cannot access providers safely.
I. INTRODUCTION

Since the 1990s US healthcare systems have slowly been undergoing transitions from paper to electronic health records (EHR). Although the evidence has not been established, EHRs are said to bring a range of economic efficiencies in the domain of care as well as research (McAlearney, Robbins, Hirsch, Jorina, & Harrop, 2010). Others have identified this electronic transition as part of a much broader expansion of the surveillance state that accelerated with the passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996, the September 11, 2001 terrorist attacks, and the Health Information Technology (HITECH) Act of 2009 (Guzik, 2009; Rule, 2007; Sobel, 2007).

Historically, paper medical records were used longitudinally to record patient-provider interactions vis-à-vis a patient’s health status as well as relevant demographic or personal health information (PHI). Craig Willse (2008) observes that paper records are oriented toward the past and highly contextual to an individual’s health history and relationship with provider. Berg and Bowker (1996) found that the paper version worked to produce a medicalized body constituted through discontinuous sets of doctor-patient narratives and multilayered histories. Though researchers, insurance companies, governments, and hospital boards also have had stakes in acquiring the information held in these records, the paper record was not used effectively or often as a “population-based” data collection or surveillance system. The paper record did not enable this functionality, as a single person’s or even a set of patients’ records were not functionally linked and networked for analytical use; rather, a person’s paper medical records may be scattered across a range of providers’ offices and stored in respective, secure records rooms. The medical record has been considered primarily a repository for confidential PHI and
for assessing health, diagnosing disease, prescribing medications, and documenting the patient-provider exchanges.

Compared to the paper record as a clinical mechanism, electronic ones are said to improve workflow processes and quality of care, particularly for underserved populations (Cahill & Makadon, 2014b; Neame, 2013; North American Opinion Research Center, 2010; Weinfeld, Davidson, & Mohan, 2012b). Providers may order labs, prescriptions, and communicate patient information and billing to other providers and related entities within or outside a provider’s healthcare system at speeds previously impossible (Weinfeld et al., 2012b). Error rates and labor costs for those tasks may also attenuate with EHR implementation. Alert and reminder mechanisms built into EHR systems may improve preventative care, culturally competent care, and chronic disease management (North American Opinion Research Center, 2010). Similarly, advocates and policymakers suggest that patient portals and remote access to EHRs may improve patient engagement and self-care (2010).

Beyond potential clinical efficiencies, EHRs are viewed as an innovative way to conduct population-level research, particularly for hard-to-reach and underserved communities like LGBT communities (Cahill & Makadon, 2014b; Committee on LGBT Health, 2012; North American Opinion Research Center, 2010). When there is not an established sampling frame for “at-risk” groups such as injection drug users, homeless persons, or transgender persons, population-level research is not possible. With the rollout of EHRs among federally funded healthcare providers, policymakers and researchers hope to enumerate a sampling frame for underserved populations like transgender individuals. If an EHR data field for gender, for example, can be populated with “TM” or “TF” in addition to the “M” or “F,” this new standard can generate counts of trans populations by linking them with other provider databases within
and across various jurisdictions (e.g., city, county, state, and United States). Data points, like
gender identity or sexual orientation, can be divorced from their historical and individual context
and aggregated with other cases to generate counts and various analyses that exceed the
individual referents (Willse, 2008). Unlike paper records, this storage and organizational
platform is believed to enable future-oriented, complex analyses and population-type inferences
not previously possible. For underserved communities with which researchers have faced
recruitment and retention challenges, this technology will ostensibly enable new research and
interventions on health inequities not previously possible.

Two sources of pressure to implement EHRs and to collect gender identity-related PHI
warrant an exploratory investigation of the impacts on care, including the privacy and security of
patients and EHR data, respectively. Under the Affordable Care Act (ACA) and American
Recovery and Reinvestment Act (ARRA) the federal government has mandated that any
Medicaid-qualified providers implement EHR systems and meet related benchmarks in order to
continue to qualify for Medicaid reimbursements by 2015. Along with the mandate, governing
bodies like the Department of Health and Human Services (USDHHS) and the Institute of
Medicine (IOM) are calling on providers to develop EHR standards such that data may be
collected on underserved populations like LGBT ones (Committee on LGBT Health, 2012; US
Department of Health and Human Services, 2010).

Those pressures, however, may conflict with existing constraints around both providing
and accessing healthcare when it comes to transgender individuals. The perceived flexibility of
EHR systems for care, surveillance, and research may actually translate to increased rigidity for
providers and their transgender patients. Medical providers that serve Medicare patients will be
penalized, beginning in 2015, if they have not fully implemented these costly EHR systems;
these penalties will impact community health center providers disproportionately (Wright et al., 2013). Although intended to improve quality of care, recommended EHR data elements tied to gender identity (and/or sexual orientation) may create additional barriers for providers. Interoperability challenges around gender classifications within and across provider networks raise questions around the capacity for or efficacy of population-level research. For example, one clinic in a network may use five different gender categories while another uses six, and only four categories between the clinics overlap.

For transgender individuals, EHR implementation may have a range of effects on access to care, quality of care, and, potentially, new systemic and individual forms of discrimination. Attempts to standardize classifications of GNC patients—people who variously cross or reject the gender binary of man/woman and/or sex binary of male/female—may prove futile and very costly. For those codified by such a classification system, new possibilities emerge for discrimination and entanglement among bureaucratic, corporate, and administrative systems, which use different and perhaps conflicting standards of classifications (Currah, 2013; Spade et al., 2008; Willse, 2008). On the other hand, trans patients may appreciate visits to providers whereby their identities are recognized and respected.

Given these possible barriers and facilitators for transgender-related healthcare, this dissertation explores the stakes of the transition to EHRs. The emergence of these database systems, data elements, and classifications has implications for privacy, security, and surveillance of transgender and GNC persons but for providers as well. Both transgender healthcare providers and patients may resist fully engaging in this care as surveillance techniques expand. Deadlines loom for mandated EHR implementation for many trans health providers. Steep penalties will ensue for missed deadlines or for any number of security breaches that are
all-too-common under the current federal guidelines. If their providers survive this transition, some transgender patients may feel more respected and recognized in healthcare settings while others may feel invisible. The imminent EHR infrastructures may enable new kinds of research and clinical decision support for transgender-related healthcare delivery. Yet they may also expose transgender people to new forms of discrimination and privacy violations. Exploring these effects at the outset may inform privacy- and security-preserving standards and research practices that foreclose discrimination and enable rather than constrain the health and self-determination of GNC persons.
II. BACKGROUND AND SIGNIFICANCE

This chapter is organized into five sections. Each section—working definitions, policy background, a statement of the problem, the specific research aims, and the significance—lays foundation for understanding the effects that EHR implementation is having and could have for transgender healthcare and transgender persons.

A. Definitions

1. Transgender, gender nonconforming, genderqueer, and cisgender

In the realm of US public health research, “transgender” or “trans” reflects an umbrella term used to refer to those whose gender identity differs from the sex assigned to them at birth and often the gender norms associated with the assigned sex (Fenway Health, 2010). Unlike popular assumptions, this definition neither requires that someone has medically altered their bodies to align with their gender expression nor does it assume that one has legally changed their gender. Though the definition of transgender in the United States has changed since the term emerged in medical and psychiatric publications in the 1960s, it continues to carry stigmatized and medicalized connotations (Cruz, 2014; Poteat, German, & Kerrigan, 2013).

Many who do not identify with their sex assigned at birth do not identify as transgender either (Spade, 2011; Valentine, 2007). With roots in medical pathology and health research centered on White, middle-class persons crossing from one side of the sex-gender binary to the other via medical interventions, many persons resist the transgender label and identify across a range of gender nonconformity or simply as male or female (Cruz, 2014; Valentine, 2007). For some of those for whom the term purports to represent, “transgender” conflates and appropriates what Dean Spade calls “a set of gender rule-breakers loosely gathered under a ‘trans’ umbrella,”
including identities such as genderqueer, Two Spirit, stud, andro, trans woman, Mahu, agender, gender fluid, gender fabulous, and so on (Spade, 2011, p. 49).

Another term for GNC is genderqueer (Cruz, 2014; Meerkamper, 2013). These identities are often referred to as nonbinary whereby a person does not simply cross from one side of the gender/sex binary (e.g., male) to the presumed other side (e.g., female). Gender nonconforming and genderqueer often signify greater gender fluidity than a transgender identity. For example, a GNC or genderqueer-identified person may identify and appear on the feminine spectrum one day and on the masculine spectrum the next and more androgynously on another; they may prefer gender-neutral pronouns (e.g., they rather than he or she). Agender is another type of gender nonconformity whereby, despite perceptions of fluidity or androgyny, a person may not identify with gender at all.

These definitions may depart from medical and public health definitions in other countries where different legal and medical systems, as well as different languages, help produce different experiences of and words for transgender and gender nonconformity. For example, in some countries, such as China or Iran, the state mandates and pays for surgical and hormonal interventions for transgender people. One may look to the category of Latino/a, officially adopted in 1997 by the US government, for a somewhat analogous conflation and contestation of a range of ethnic identities. To address the limits and contestations of transgender as an identity, this manuscript uses “transgender” and “GNC” to describe those whose gender identity does not fit neatly within the binary sex/gender system; it also uses another imperfect term “cisgender” or “cis” to describe persons (e.g., cis men) whose gender expression and identity are consistent with the sex assigned to them at birth.
The definitions of transgender and GNC may seem relatively clear. The view from 10,000 feet reveals that even traditional binary classifications of both sex and gender are highly contingent and variable depending upon the particular function and level of jurisdiction of a governmental agency or institution (Currah, 2013; Spade et al., 2008). There is no legal transgender category in the United States. Transgender people may choose to change their gender legally from the one assigned to them at birth to the other side of the binary. However, the requirements for changing genders vary across jurisdictions. Transgender people trying to navigate these systems—and they must navigate them at the very least if they want to change their gender status legally or if they seek various services from the state—often bring these contradictions to the fore. The systems’ contradicting classification schemes can ensnare the most vulnerable in particular, and these systems often cite the contradiction(s) as justification for the denial of services or recognition. Paisley Currah highlights New York City’s conflicting classifications systems:

The same person might be housed in a women’s shelter, segregated with men in prison, be given a “pink” bus pass by one agency, have an M on her birth certificate, and an F on her passport—and be denied access to both men’s and women’s residential drug rehabilitation facilities. If such a thing as “transnormativity” exists, it would be very hard to assimilate into the categories when the definitions seem so capricious and arbitrary, and which shift depending on so many factors (Currah, 2013, online).

Gender’s defining attributes vary depending upon the function of the institutions. With such highly variable institutional functions and levels of jurisdiction, any attempt at standardization of the definitions of gender across state entities (or private ones) appears highly complex.

2. **Electronic privacy and security**

This research will critically examine notions of privacy and security in current transgender healthcare contexts, but some commonly used definitions from these literatures will foreground the subsequent discussions. Like the concept of transgender, the concepts of privacy
and security are also complex and culturally and historically specific. In the context of healthcare and information technology, privacy tends to refer to the ability of a patient to control the flow of personal data and health information held by providers to external sources. “Information privacy concerns the collection, maintenance, use, and disclosure of ‘personal information’: the information items that disclose the existence and identity of an individual or which could identify an individual” (Sahama et al., 2013, p. 250).

Security, on the other hand, refers to the range of mechanisms in place to ensure patient data privacy such that patients trust their providers to make health-related disclosures, and the best healthcare may be delivered (Sahama et al., 2013). Legislation, like the HIPAA Security Rule and the HITECH Act, requires providers to take various steps to protect the confidentiality, integrity, and availability of patient data.

3. **Surveillance**

In public health practice, surveillance has a particular meaning not entirely divorced from the way surveillance relates to electronic security and privacy. In this context, surveillance refers to a mode of data collection that is constant rather than intermittent in order to track and intervene upon health and disease at the macro level, and it is distinguished by its practicality rather than its precision or rigor (Porta, 2008, p. 239). A range of instruments have been used for public health surveillance such as death certificates, hospital health records and registries, lab diagnoses, outbreak reports, and sentinel sampling. More recently, health departments have experimented with surveillance of big data—data characterized by its massive volume and complexity as well as rapidity (Asokan and Asokan, 2015). However, the use of tweets, Google searches, radio frequency identification tags, or even EHRs to track disease
outbreaks and trends introduces new privacy and security issues (Araz, Bentley, & Muelleman, 2014; Asokan & Asokan, 2015; Brownstein, Freifeld, & Madoff, 2009).

Privacy and security scholars have extended this concept of surveillance beyond data collection, identifying and examining the ways in which a logic of discrimination and social control undergird and even undermine the utilitarian, life-giving intentions of a surveillance apparatus (Foucault, 1995, 2007; Rule, 2007; Solove, 2008). Constant monitoring, whether by the state or a corporation, can create not only anxiety in the targets of surveillance but also self-censorship and inhibition, such as an unwillingness to access services connected to the surveillance apparatus (Solove, 2008, p. 108). James Rule’s comparative historical analysis of information privacy and surveillance highlights the information asymmetries that surveillance generates, exacerbated by computing power over the last forty years and big data in the last decade. Though the initial or stated intent of sweeping data collection may be beneficial—for national security, economic efficiency, and the health of a nation’s citizenry and workforce—the social sorting that typically results has the effect of stereotyping, stigmatizing, and creating differing levels of access to resources for the various “types” of individuals surveilled over others (Foucault, 1995, 2007; Rule, 2007).

B. Federal Legislation and Healthcare Reform

1. The Health Insurance Portability and Accountability Act and the Health Information Technology for Economic and Clinical Health Act

Patient privacy and confidentiality with care providers have long been fundamental to quality healthcare delivery. When electronic medical record (EMR) formats began to emerge in the 1990s, Congress enacted the Health Insurance Portability and
Accountability Act (HIPAA) of 1996 to address new privacy concerns emergent with the technological shifts. The Acts were passed to account for a baseline of patient privacy and disclosure protections as well as security measures for these new EHR, storage, and transmission systems. Although widely viewed as inadequate (Rule, 2007; Sobel, 2007), the HIPAA Privacy Rule, effective in 2003, and the Security Rule, effective in 2005, mandate protections for patients’ PHI and place parameters around uses and disclosures of PHI without patient knowledge (Stablein, Hall, Nissenbaum, & Anthony, 2012). These mandates serve as a privacy floor rather than a ceiling, however, leaving more stringent standards and protections for the states to enact. According to LaTanya Sweeney (2013), however, only three states—Oregon, West Virginia, and Missouri—have more stringent standards than HIPAA. Additionally, the Act implemented little-to-no enforcement mechanisms and place the burden for correction and oversight of PHI upon patients (Sobel, 2007).

As a corrective, Congress passed the HITECH Act of 2009. This Act mandated more extensive regulation of disclosures of PHI and relieved some of the patient burden via requirements of notice to patients when information is disclosed and when privacy and security breaches occur (Stablein et al., 2012). Besides a corrective, HITECH also expanded federal government programs designed to encourage EHR adoption (North American Opinion Research Center, 2010). The HITECH Act provided temporary monetary incentives and funding, via EHR “meaningful use” objectives, for providers who serve Medicare patients to convert fully from paper record to approved electronic record formats. Meaningful use consists of a three-stage approach to incentivize EHR uptake with the goal of transforming healthcare to a “patient-centered, evidence-based, prevention-oriented, efficient, and equitable” (North American Opinion Research Center, 2010, p. 3). Despite the funding incentives, there are many barriers,
disproportionately born by under-resourced providers, such as costs, capacity, workflow challenges, and interoperability. Nonetheless, all Medicare-eligible providers who do not fulfill the numerous meaningful-use objectives will begin to incur financial penalties in 2015 (Wright et al., 2013, p. 779).

LaTanya Sweeney’s work demonstrates that under HIPAA and HITECH, disclosures of PHI and EHR patient data have mushroomed. In 1997, pre-HIPAA Privacy Rule, one might expect one’s records to be shared with approximately 12 types of providers and related entities such as insurers, pharmacies, employers, and vital statistics bureaus. By 2013, the number of categories of “covered entities” that may see one’s records numbered 53, including debt collectors, law firms, real estate firms, and various media companies and government offices (Sweeney, 2013). Sweeney (2002) has also demonstrated the ease with which one may reidentify de-identified medical data, as defined by HIPAA, by linking de-identified datasets with publicly available ones.

2. **Healthcare reform and health information exchanges**

Another major outcome of healthcare reform are the health information exchanges (HIEs). Under the ACA, state and federal HIEs were established in order to facilitate the sharing of patient health information in order to improve care. Just as the ACA and ARRA provide incentives for healthcare systems to implement EHR systems, the HIEs may facilitate the use and exchange of EHR data across systems and jurisdictions. On the other hand, the demands for participation on the HIEs may disproportionately burden smaller, resource-poor clinics. Medical providers that serve Medicare patients will be penalized, beginning in 2015, if they have not fully implemented an EHR system (Wright et al., 2013). In Illinois, for example, the HIE legislation states:
The creation of a State-level health information exchange system will allow, among other benefits, the widespread utilization of electronic health records by health care providers and patients in order to ensure that Illinois' health care providers can achieve the meaningful use of electronic records, as defined by federal law, and participate fully in the health information technology incentives available from the federal government under the Medicare and Medicaid programs (Executive Branch, 2010).

In Illinois, a Chicago community health center (CHC) could use the health information exchange to verify where her new transgender, Medicare patient may have sought care previously or to see if her new patient is seeking care from multiple providers. In other words, one function of the HIE enables providers to collaborate and to reduce duplication of care for patients; the new doctor, for example, can access lab tests already run by her patient’s previous provider. Similarly, insurance companies, including Medicare, can use HIEs to audit the prescriptions that providers issue for a patient or multiple patients. If an insurance company deems that a provider has overprescribed medication, it may decertify a provider such that they can no longer bill for services (North American Opinion Research Center, 2010).

C. **Statement of the Problem**

In 2011, both the IOM and the National Lesbian and Gay Task Force (NLGTF) released seminal reports concerning the health of transgender people in the United States. Both reports highlight key social determinants of transgender health. The NLGTF, a national LGBT advocacy organization, conducted a nationwide survey that established astonishingly high rates of self-reported discrimination and extreme poverty experienced by transgender and GNC individuals (Grant et al., 2011). According to the report, both factors create barriers to healthcare access. Respondents reported delaying care due to discrimination (28%) and due to the inability to afford care (48%). Another study found that GNC persons disproportionately delayed care due to discrimination (Cruz, 2014). The IOM report similarly cites a lack of training among providers
as well as poverty and lack of insurance coverage as key barriers to care; the IOM report prioritizes these findings for future research (Institute of Medicine Committee on Lesbian, Gay, Bisexual, 2011).

Another key priority of the IOM research agenda is the recommendation to collect gender identity (and sexual orientation) in EHRs in addition to the other “Record Demographics” included in the meaningful-use objectives issued by the USDHHS (Institute of Medicine Committee on Lesbian, Gay, Bisexual, 2011, p. 303). Besides the growing push at the federal level for the transition to EHR systems and their use as a population-level surveillance mechanism, the IOM report sees these infrastructures as a possible way to enumerate what has long been an invisible population. This recommendation, however, raises numerous questions with respect to the capacity to address or exacerbate findings around discrimination and access to healthcare for transgender people. The report itself cautions that “some barriers exist to collecting useful data on sexual orientation and gender identity through EHRs” (Institute of Medicine Committee on Lesbian, Gay, Bisexual, 2011, p. 303). It specifies that providers may not have the tools, such as cultural competency, language, or comfort level, to implement this data collection. Similarly, transgender and GNC healthcare consumers may not want to disclose information this way or as required by a standardized EHR classification. Although the IOM report states that current EHR privacy and security mechanisms offer a high level of protection, electronic privacy and security research suggests otherwise (Custers, Calders, Schermer, & Zarsky, 2013; Guzik, 2009; Rule, 2007; Sobel, 2007; LaTanya Sweeney, 2013).

The costs of EHR design, implementation, training, and maintenance are rather extraordinary though electronic records are believed to create long-term savings and efficiencies (North American Opinion Research Center, 2010). Indeed, community health clinics, where
many transgender individuals access care (Grant et al., 2011), have unique resource challenges and health information technology (IT) constraints both of which may interfere with this data collection process (McAlearney et al., 2010). The IOM report does not explicitly address from where the resources for EHR development or implementation will come, nor does it draw any connections between EHR systems and how their use will address or mitigate the discrimination and poverty that impact the health of trans people. It also provides no evidence for EHRs as an effective, reliable, and valid data collection mechanism.

This proposal specifies three aims that explore the tensions outlined here and may reflect gaps in EHR research related to transgender health. On the one hand, EHRs ostensibly offer innovative ways to improve care and enumerate a transgender and/or GNC population that will enable new research trajectories and trans health-related knowledge generation. This work will establish evidence for these claims or alternative ones. On the other hand, there are a number of barriers to the design, implementation, and maintenance of EHRs as a clinical care and data collection mechanism. Next, I will highlight the research aims and the privacy, security, and surveillance lenses that I will use to explore implementation challenges and potential effects of HER data collection of trans-related health information on stakeholders.

D. **Specific Aims**

Based on a review of the literature, there is both a lack of research around the efficacy of EHRs for improvement of healthcare as well as around the privacy, security, and surveillance aspects of EHR systems and gender identity. More specifically, there is no research around privacy and security concerns related to the standardization and collection of transgender identity-related health information in EHRs. The recent prioritization of gender identity-related
EHR data collection emphasizes the benefits for clinical care and research without explicit concerns for this vulnerable population’s privacy, data security, and the impacts it may have on access and quality of care as well as understandings of gender more broadly.

Although we know that transgender people experience high rates of discrimination in many domains, and in healthcare in particular, EHR implementation raises new questions around how security flaws and privacy violations, including negative feedback loops from research and surveillance, may exacerbate discrimination even as it may improve other areas of transgender-related healthcare. With little federal- and state-level legal protections in place from employment discrimination, the privacy and security of EHRs under the current healthcare reform are particularly fraught.

Additionally, the meaningful-use mandates for EHR system implementation disproportionately impinge upon the already overburdened and under-resourced capacity of community health centers that often serve transgender persons. Moreover, EHR system compliance, particularly around adherence to security guidelines, may also weigh heavily on small healthcare providers. These economies of scale may unduly impact the care of the most marginalized of transgender persons as well as their ability to seek goods and services beyond the clinical setting. The three core research aims of this dissertation critically address these gaps and concerns.

1. **Aim 1**

   The first aim explores the emergent EHR infrastructures in healthcare settings where trans and GNC persons access care. I will generate this analysis from a small, purposive sample of transgender healthcare stakeholders such as clinicians, public policy officials, clinic leadership, technology specialists, researchers, and advocates. Based on in-depth interviews with
them, this aim establishes how these systems function in terms of data collection and care. The aim outlines relationships that stakeholders have to these systems, how they use them in this care setting, and the workarounds that stakeholders have developed to address gaps.

Primarily, I will focus on the smaller, under-resourced health clinics that tend to serve uninsured or publicly insured trans persons, though contrasts will be made with some key larger providers. Specifically, I will query for data collection categories and privacy- and security-preserving mechanisms. Elements provided such as binary algorithms, data segmentation, encryption, access controls, audits, and de-identification of data will map how personal health information flows within the EHR system and to external organizations such as HIPAA’s “covered entities.” This mapping will pinpoint sociotechnical system vulnerabilities, implications of data leakage, and unintended disclosures, as well as potential resolutions.

The EHR infrastructural contexts have been unexplored, and the identification of challenges may illuminate potential impacts upon transgender access to care, care delivery, privacy, security, and the data standardization process. For transgender health providers as well as transgender and GNC individuals, the implications of EHR implementation could mean the redirection of resources from small, specialized clinics to large, more mainstream providers and a massive transformation of access to care. Another related possibility, given new gender-identity related classifications or standards, is that the emergence of networked data will transform the concepts of and treatment approaches to transgender and GNC healthcare consumers.

2. **Aim 2**

Building upon the work in Aim 1, the second aim attempts to understand how gender-related algorithms and data collection in EHRs impacts transgender visibility, care, and
research. Using Vivian Namaste’s seminal work, *Invisible Lives* as a point of departure, this analysis seeks to understand how data collection methods shape important grids of knowledge such as gender identity and health. Namaste urged researchers to include transgender voices in the research design and data collection process so as not to create systemic erasures of transgender people, and survival sex workers in particular. The current push by various national institutions and advocates to implement a two-step question to capture gender identity has a number of implications for understandings of gender in medical and broader social contexts. In particular, these questions may not capture the expressions and needs of GNC persons on the social margins.

Like Aim 1, I will focus predominantly on stakeholders from smaller, under-resourced clinics with some comparisons to those from larger providers. In addition, I will incorporate the voices and experiences of trans and GNC persons in an attempt to sketch a more comprehensive understanding of how algorithms, infrastructures, and administrative systems impact the work and quality of care for providers and their patients. In addition, I will explore the challenges with using these data collection mechanisms for research purposes.

Similar to Namaste’s work, I will explore new understandings of transgender and GNC patients that may emerge through EHR classifications, the EHR database, and EHR networked data. This thread may extend Bowker and Star’s (1999) notion of convergence with respect to categories of gender identity and Willse’s (2008) notion of the database and data elements as instruments of governance. In particular, this chapter may illuminate how, even in the most secure environment with very efficient care, EHR data have the potential to converge upon medicalized and reductive notions of transgender and gender nonconformity to create privacy-violating, negative feedback loops. That is, emergent knowledge from EHR data regarding both
providers and patients may create negative feedback loops that hinder access to appropriate healthcare.

3. **Aim 3**

The third aim will map and examine the privacy concerns that transgender and GNC individuals may have around access to healthcare and the use of EHRs in the clinical encounter and beyond. This aim also seeks to identify how trans and GNC persons maintain their agency in provider settings given more or less rigid understandings of gender and gender identity in healthcare settings and other administrative systems. Based on focus group transcripts and my own experiences with disclosure in healthcare settings, Nissenbaum’s (Nissenbaum, 2011) theory of privacy as contextual integrity and Bowker and Star’s (1999) concept of convergence may guide this exploration. In particular, I seek to better understand transgender healthcare consumers’ levels and types of gender-identity disclosures in various contexts as well as their concerns and practices around privacy. Furthermore, I will explore privacy concerns and access with an intersectional lens (Crenshaw, 1989), critiquing how contextual factors such as private or public health insurance, and incarceration histories, and discrimination may impact or relate to those privacy concerns.

In healthcare settings, for example, where transgender identity categories may be limited or nonexistent on intake forms, I will query their identification and disclosure choices. Similarly, I will probe for how and why participants might vary their gender identity disclosures depending upon the context, upon their health needs, or upon knowledge of future privacy violations, or upon perceived benefits or threats based on their disclosures. Facebook may be an important point of contrast; how do participants identify on Facebook now that there are 51 gender identity options? Extreme social vulnerability such as recent arrest, incarceration, or homelessness may
also impact levels of disclosure or types of disclosure. At the same time, the findings may illustrate how participants actively and creatively forge and self-define particular gender identities in the face of more rigid gender systems of classification.

E. **Significance**

The research derived from these aims will fill key gaps in various literatures. Drawing on perspectives, knowledge, and experiences of stakeholders, I will develop a comprehensive understanding of new privacy concerns around EHR data collection of sensitive health information in general and gender identity-related health information specifically. The findings from this research may inform the development of privacy-enhancing clinical practice protocols and EHR sociotechnical design. Recommendations may include policies and protocols specific to transgender health but these may have broader applications to the health of cisgender persons as well as hard-to-reach and underserved communities also impacted by meaningful-use mandates and healthcare reform. In an age where privacy is often proclaimed to be dead (Abelson, Ledeen, & Lewis, 2008) and where transgender people are more visible than ever, this work will nuance the role privacy and disclosure plays in transgender people’s lives.

This study contributes to the health IT security literature though the assessment of current practices and the identification of electronic security gaps on the margins of the healthcare system. This infrastructural analysis accounts for technological vulnerabilities, human factors, as well as marginalization; the unique focus on the impacts of this aspect of healthcare reform on a relatively marginalized axis of the US healthcare system(s) may identify gaps that could not be identified through a more top-down analysis. It also may point toward the limitations of the traditional threat model used in security analysis: an understanding of the potential security
vulnerabilities is essential, but even anonymized, aggregated data as a form of governance may lead to privacy violations and indicate the broader expansion of the surveillance apparatus in the United States (Rule, 2007).

Transgender health research poses many challenges. There is limited funding and political will for it, and transgender people are not officially counted and are difficult to recruit for health research. For these reasons, researchers of trans health tend to celebrate new opportunities for research such as those that may be generated by EHR data collection. Privacy and security issues may be underexplored here in part because of the perceived constraints they may place upon the possibilities for EHR-based transgender research and surveillance. On the other hand, privacy and security research also presents a new opportunity for trans and LGBT health research. This set of analyses will explore and identify how these innovations in health research may impact the understandings and new ways of regulating sex and gender identities.
III. METHODS

Methodologically, this research constitutes a case study. The case study is a method that fosters theory development through a detailed analysis of a social phenomenon (Walton, 1992). The case study also enables exploration of concepts not yet validated or quantifiable and, historically, has contributed to understanding urban life and the integration of the social ecological resources (Hamel, 1993, p. 15). Most importantly, it is a method that refuses “to accept visible social relationships as ‘the’ social reality” and rejects empirical assumptions (e.g., that gender is binary) (Levi-Strauss in Hamel, 1993, p. 30). This critical, rather than positivist, approach (Greenhalgh, Potts, Wong, Bark, & Swinglehurst, 2009) to community health research uses conceptual and theoretical interventions to question and disrupt traditional health research methods and emergent surveillance apparatuses.

Unlike grounded theory methods, for example, experiences articulated by study participants are not the point of departure for theory. Theory—explored via case study—aims to identify the logics that undergird the social realities that participants may express (1993).

Implicit in the idea of the case is a claim. . . . Cases come wrapped in theories. They are cases because they embody causal processes operating in microcosm. At bottom, the logic of the case study is to demonstrate a causal argument about how general social forces take shape and produce results in specific settings. . . . Cases are always hypotheses (Walton, 1992, p.121–122).

Cases operate in specific, local contexts and provide a window onto broader social phenomena.

Trans healthcare in the United States constitutes an important nexus of social forces and paradoxes to disentangle. The social norms that shape policy and administration of public services or private healthcare rarely consider the most marginalized. “Trickle down” ideologies tend to undergird economics, legal rights, and even or especially healthcare. Transgender advocates have only begun to eliminate discriminatory exclusions from private and public health
insurance policies. To yield these achievements, transgender people have been and are encouraged to be more visible than ever before. In a sense, transgender people are motivated to forego privacy now in order to gain it later.

In this moment of transgender and GNC visibility eliciting more than 50 gender identity categories on Facebook, EHRs, privacy, and transgender health in the context of reform are complicated and highly contextual concepts that defy simple categorization; they cannot be readily operationalized and analyzed quantitatively. Moreover, they are not obviously visible social realities either. Healthcare reform may attract much media attention, but it does not necessarily attract attention in relation to records and the privacy and security of personal health information. Transgender healthcare in the United States is the setting, and I have undertaken a case study of the EHR infrastructure mandated through healthcare reforms to explore the logics of privacy and security around healthcare as well as surveillance. These logics—shaped through multiple forces of technology, healthcare reform, various procedures and protocols, and the agency of stakeholders—may have unintended consequences for trans healthcare and trans people. Although I did not sustain these qualitative methods over several years as traditional ethnographies tend to endure, the use and development of theories; multiple methods; and types of stakeholders engaged, queried, interviewed, and observed in specific contexts constitute a case study.

I draw on three types of ethnographic methods: Burawoy’s extended case method (1991), Smith’s institutional ethnography (Smith, 2005) and Starr’s ethnography of infrastructure (1999). Michael Burawoy (1991) suggests that grounded theory is limited by its micro-level, positivist scope and perhaps overzealous in its claims to theory generation. His extended case method actually extends grounded theory as it conducts extensive fieldwork and analysis to make
inferences. The extended case method, however, reconstructs existing theory. Rather than starting with a blank slate and “discovering” a new theory, Burawoy’s more reflexive approach identifies patterns, processes, anomalies, and paradoxes in the coded data and, in this case, the EHR infrastructure, but also contextualizes the fieldwork within broader discursive, social, economic, transnational, and urban settings. This micro-macro, contextualized approach to ethnography also helps to reconstruct, strengthen, and extend existing theory.

Consistent with the extended case method, Smith’s institutional ethnography (2005) takes a bottom-up approach that privileges the knowledges of impacted communities. Smith rejects asking organizational questions that privilege top-down perspectives and administrative knowledges. In this project, Smith might attend to the everyday human factors—those of nurses, patients, clinic receptionists, and health IT system administrators—rather than privileging the policy or administrator perspectives around EHR implementation. Smith’s method also explicitly extends itself into the community beyond the more epistemological in order to generate praxis (Smith 2005).

Star’s method complements Smith as her approach also avoids privileging top-down explorations of institutions. Infrastructural ethnography critically examines infrastructure itself as part of a study sample or case study. It examines not only the mechanisms of the EHR system itself (e.g., data fields, alerts, and algorithms) but queries the persons connected to it and the knowledge generated from it as well. Taken together, the ecological, sociotechnical, and relational roles of EHR systems are inseparable from the human stakeholders as well as the data that the systems generate. This approach makes infrastructure visible alongside the knowledges it produces and the ostensibly mundane online and offline behaviors it circumscribes (Smith, 2005; Star, 1999).
Similarly, the case study method allows for analysis of multiple forms of texts as data—transcripts of key informant interviews and focus groups, stakeholder blogs, at least one documentary, as well as EHR systems. Interviews and focus groups (see “Key Informant Interviews” and “Focus Groups” sections below for definition and justification) afford qualitative data on the social, clinical, and research contexts of the EHR infrastructure, its use, and effects. Key informant interviews with EHR system administrators, as well as healthcare providers and transgender health researchers and advocates were semi-structured and one-on-one, lasting about one an hour; some of these key informants serve simultaneous roles as trans health researchers, advocates, providers, and trans patients. Focus group interviews were moderated in-person with transgender and GNC adults, ages 18 and over, and lasted approximately two hours including introductions such as an icebreaker and some food and beverages to enjoy together.

Nearly all recruitment and data collection occurred between August 2014 and January 2015. One interview occurred in April of 2015. Prior to institutional review board (IRB) approval in late July, I collected secondary data in terms of blogs and publicly available materials that transgender and GNC persons have posted online about their experiences with healthcare and health information privacy. Key informant interviews began in August. Interview and focus group data was transcribed and then coded using ATLAS.ti. Coded transcripts were analyzed for common themes; those themes informed EHR infrastructural analysis and any observations and interpretations thereof to draw connections between EHR data elements, EHR security and privacy features, protocols, policies, and knowledge production. In sum, this infrastructural, ethnographic case study explores and highlights the mundane, the paradoxical, and the invisible ways in which the EHR infrastructure and its stakeholders foreclose and enhance the health and healthcare for trans and GNC people.
A. **Study Sample and Data Collection**

1. **Electronic health record systems**

   The sample consists of the existing EHR systems through which providers were currently or were have slated to collect gender identity-related PHI. I recruited stakeholders from stand-alone community clinics in addition to ones that are part of larger providers. These entities represent a range of providers across six urban, metropolitan areas in the United States including publicly funded clinics and federally qualified health centers, HMOs, university healthcare systems, LGBT-specific clinics as well as more exclusive, private systems of primary care. While the focus on under-resourced community clinics is a priority, contrasting these infrastructures with larger or wealthier providers may be mutually beneficial for the different types of providers, the respective stakeholders, and patients.

   Virtually all EHR systems have a range of security vulnerabilities (Elkins, 2014). Systems were indirectly assessed for security mechanisms such as various encryption features, protocols, standards and regulations indicated, and audit-logs of data flows. Protocols and policies were assessed for their security- and privacy-preserving capacities. Additionally, the analysis assessed the data fields of intake forms and/or patient portals along with the EHR PHI data fields and any other gender-identity related health data fields. Information about these systems was largely derived via key informant interviews with a range of stakeholders, including health IT staff.
2. **Key informant interviews**

Key informant interviews are an essential component of this study. Electronic privacy and security related to healthcare as well as gender identity are complex and related concepts that I could not easily assess through a survey or by focus groups alone (Millery & Kukafka, 2010; Stablein et al., 2012). The interviews were designed to explore the current electronic privacy- and security-preserving policies, protocols, and practices as they relate to healthcare delivery, understandings of transgender people, and, if applicable, research around transgender and GNC individuals. Key informants are clinicians, medical staff, clinic leadership, public health officials, health researchers, advocates, as well as health IT personnel such as system administrators, database managers, and chief technology or information officers. Key informants are also cisgender, transgender, and GNC.

Through these interviews I seek to understand how these stakeholders experience EHRs in their clinical practice and professional work. Interview data shed light on ways that these infrastructures and instruments improve as well as hinder their ability to provide quality care. Clinic leadership and public health officials discussed how EHRs impact their budgets, resource allocation, and capacity to deliver services. Similarly, clinicians and researchers spoke to EHR functionality, and the reliability and validity of EHR data for public health surveillance and research; they also spoke to the staff and clinicians’ capacity for recording accurate transgender-related data elements. In-depth interviews afforded insights around resolving a client’s conflicting gender identity data drawn from different administrative systems, which can prevent that person’s access to needed services or resources like jobs and housing.

Interviews were conducted in-person when feasible and via phone when necessary due to geographical and travel constraints. Interview questions varied some depending upon the
particular relationship the key informant has to the EHR system as well as to transgender-related healthcare (see Appendix A for Key Informant Interview Script). When possible, I conducted interviews with key informants at their workplace sites. I digitally recorded the interview and took some notes during and following the conversation as well. Additionally, key informant interviews impacted the focus group script topics that I emphasized.

I identified key informants through professional networks and web searches and recruited via email and listservs (see Appendices B and C for Recruitment Letter and Consent Form, respectively). To be eligible, key informants had to have been an employee of or professionally affiliated (e.g., a med student focused on transgender health and healthcare) with a transgender-specific healthcare provider for at least one year; newer employees simply do not have the breadth and depth of experience specific to that provider’s EHR system. The key informants’ profession varied from nurse, doctor, receptionist, therapist, EHR administrator, clinic director, and health IT officer, to public health official and researcher. Some key informants served in multiple stakeholder roles such as clinical psychologist and researcher. Similarly, some of these individuals are transgender or GNC themselves and so also spoke from a patient perspective in addition to their research, advocacy, public health, and/or clinician perspective. Additionally, in the case that there was a transgender person recruited for a focus group who was not “out” among other transgender persons and preferred to talk individually, I was willing to conduct an individual interview to accommodate their privacy. No such cases arose, however. I completed all 27 interviews except one by November 2014; the last interview was conducted in April 2015.

The sample size is N=27 interviews. I aimed to interview one or two employees per organization and wanted a cross-section of types of provider organizations in different parts of the nation. Part of the push for gender identity data collection is to develop gender identity data
classification standards; this development may be aided to the extent that I can establish the uniformity or diversity of gender identity classifications collected in different regions and any privacy and security issues that emerge and need attention. There is no rule on an acceptable number of key informants for a study; in a similar assessment of health technology adoption in under-resourced clinics, researchers conducted eight key informant interviews (Millery and Kukafka, 2010). Given the range of types of key informants, I estimated the threshold for data saturation would be approximately 24 (i.e., 3 x 8). I stopped at 27 interviews, however.

3. **Focus groups**

Focus groups are traditionally associated with the advertising industry and the consumer’s assessment of products. In public health, researchers may use the focus group method as a socially engaging mode of knowledge production whereby the researcher may moderate and a group from the priority population participates with the researcher in a structured discussion (Alex, Fjellman Wiklund, Lundman, Christianson, & Hammarström, 2012). Focus groups have demonstrated effectiveness as a method when researching sensitive topics such as HIV, sexual health, and, in this case, gender identity and healthcare with marginalized populations (Overlien, Aronsson, & Hyden, 2005). Participants may perceive the format as less intrusive than an individual interview and may feel more comfortable outnumbering the moderator. Focus groups also offer more ethnographic potential in that not only is the content a form of data but so is the interactive, subcultural process among participants (Hyde, Howlett, Brady, & Drennan, 2005). With difficult or less familiar concepts such as privacy concerns, focus groups may help stimulate interactive discussion among peers rather than the researcher prompting trans patients for their experiences. The drawback may be that one or two participants
dominate or steer the discussion in directions that foreclose topics and experiences that others may have emphasized.

Another benefit of the focus group format is that it affords a process of collective sense-making among participants and an opportunity for me to witness the collective as well as intersectional language used around gender identity and experiences of affirmation or discrimination (Overlien et al., 2005, p. 334). A collective discussion, rather than a key informant interview, may reveal how identities and expressions fall along lines of age or race. Younger and White subgroups may tend to identify with certain terms and expressions, such as “agender,” while older subgroups may identify with “transsexual.” These differences may be reinforced collectively, whereas in an interview, a researcher may have more difficulty corroborating these differences as intersectional rather than individual.

Building on identity themes, the focus groups (see Appendix D for Focus Group Interview Protocol) elicited discussions around the current quality of care, privacy concerns, and the impacts that both have beyond the care setting. Specifically, I queried levels of awareness around privacy of healthcare data and potential concerns given new conditions of healthcare reform. For example, participants were asked how and why they identify in specific ways in a number of different contexts. How do they disclose personal health-related information such as gender identity to healthcare providers? Upon their first visit? Gradually? As little as possible? Do they identify consistently across settings related to work, landlord, social services, and school? Does their gender marker change frequently for any one of those entities? For example, some participants may identify as “F” at school sometimes and as a trans female or genderqueer other days or months or years.
Participants were shown sample privacy policies from relevant provider settings in order to demonstrate the breadth of entities that access personal health information under fairly standard privacy policies. Currently “covered entities” under HIPAA and HITECH such as shelter systems, Medicare, law firms, researchers, media outlets, life insurance companies, employers, see either “Male” or “Female.” Participants were queried on disclosure strategies and whether their gender marker for those entities is consistent with their gender identity. I asked how, if at all, they might prefer those entities to capture their gender marker. Participants were queried for instances of healthcare and bureaucratic involuntary disclosures, perceived privacy violations and snafus, their current “workarounds,” and whether or not they think new trans classifications will remedy, attenuate, or complicate those entanglements. I also asked about the use of personal health information for research and other data analysis purposes for which covered entities may use PHI.

Focus group participants were recruited via fliers at clinics and other offline sites where potential participants frequent such as drop-in centers (see Appendix E, Sample Recruitment Flier). Facebook ads and listservs also served as recruitment sites. To be eligible for participation, these participants had to be 18 years of age or older, identify as transgender or GNC, and speak English (see Appendix F, Focus Group Eligibility and Screening Questions). Self-identification as transgender or GNC has been the commonly accepted inclusion criteria; I asked a two-part question to reinforce the aforementioned definition of GNC. First, what is your current gender identity? Followed by, what sex were you assigned at birth? The Centers for Disease Control (CDC) has tested this two-part question in select US clinics and testing sites for effectiveness (Rapues, Wilson, Packer, Colfax, & Raymond, 2013). This two-part question also serves as the
proposed basis for standardized gender identity data fields in EHRs and was a central topic for discussion in the focus groups and key informant interviews.

Focus groups were conducted in Chicago during autumn of 2014 and January 2015. The geographic location of focus groups is not particularly relevant except that it requires a significant trans and GNC population. I conducted and moderated all four focus groups and used two digital recorders to ensure data was captured without interruption due to malfunction. I compensated participants for their time and contributions with a $30 cash payment and provided food and beverages to have together. Prior to each focus group, I briefed participants on confidentiality and ensured them that their names would not be linked to any of the focus group transcripts. I also advised participants to keep the information shared during the focus group strictly confidential (see Appendix G, Focus Group Consent Form).

Each focus group consisted of 3–11 participants (N=30). Focus groups larger than ten persons may not provide each participant adequate time and space to participate, and a larger group makes moderation and transcribing increasingly difficult. Eleven people participated in the first focus group because two additional persons attended unexpectedly, and, after determining their eligibility, I enrolled them rather than turning them away. The fourth focus group occurred in early January on an extremely cold day, and only three participants attended. Data saturation was reached after four focus groups.

I recruited a diverse set of individuals for the focus groups; participants included adults from community health clinics, private providers, the LGBT clinic, HIV clinics, and university-based student healthcare. Because there is some evidence that older and younger persons have different sets of privacy concerns as they relate to electronic information in general but also as they relate to EHRs and their healthcare in particular, I recruited participants ranging from ages
18 to approximately 70 (boyd, 2012; Stablein et al., 2012). These groups also represent a range of gender identities as well as racial and ethnic identities and social positionings; for example, a participant may identify as mixed race but be socially perceived as Black or, alternatively, as White. I anticipated participants with privately insured healthcare to differ from participants with publicly insured care; for example, there is evidence that White transgender persons tend to have higher rates of employment and experience less employment discrimination than their non-White counterparts (Grant et al., 2011). Employed persons are more likely to have private insurance than unemployed persons.

B. Data Coding and Analysis

All coding and data management was conducted using ATLAS.ti 7 (ATLAS.ti Version 1.0.16, Scientific Software Development GmbH). I transcribed verbatim and applied for funding to hire an external transcriptionist to help transcribe portions of the key informant and focus group data. I confirmed transcripts with the recordings to ensure accuracy.

Following transcription, I coded all key informant and then focus group data in consultation with the dissertation committee. As I coded, I wrote analytic memos to document coding decisions, definitions, and changes to codes. I also noted emerging themes and major findings in these memos. My coding technique drew on Saldana’s approach (Saldana, 2013). Saldana’s process requires two cycles of various types of coding. Attribute coding occurs first. Attributes include simple participant descriptors such as pseudonym, type of interview (e.g., focus group or KI interview), type of key informant (e.g., database manager), type of focus group (e.g., predominantly Latina trans women), date of interview, and interview setting. Next, structural coding consists of overarching codes under which more detailed coding occurs. For
example, “privacy” or “security protocols” or “EHR gender classifications” may work as structural codes. I derived these codes directly from the interview questions.

An additional step of coding consists of more detailed codes based on participant responses to interview questions. This descriptive coding describes responses with key phrases such as “disk encryption,” “SSL encryption,” “no security training,” “trans masculine,” or “audit process.” Finally, the last step of this first cycle captures the verbatim perspectives of participants—known as in vivo coding; the software demarcates in vivo codes with quotation marks so to capture precise expressions of the values, practices, and experiences of participants.

The second cycle of coding identifies patterns by way of frequency counts and groupings derived from the first cycle. This process allowed me to highlight the major themes based on the common codes that I grouped into similar categories. I repeated this process, not necessarily to ensure an objective accuracy, but to see if my interpretations of the themes remained or if they had shifted based on identification or recognition of new patterns. Themes were assessed across attributes of key informants and focus groups for salient similarities and differences.

Additional analysis is required beyond the coding (Saldana, 2013). I accounted for ethnographic interpretations of the interactive, collective nature of the focus groups. I connected themes from the interview and focus group data to the structures and relations inherent to the EHR system and record designs (Hyde, 2005). I also contextualized the infrastructural ethnographic data with related concepts and theories with respect to privacy, security, surveillance, and gender identity as well as federal and state healthcare and EHR policy data (Star, 1999). My own experiences with healthcare as a patient, community member, researcher, and advocate also informed these interpretations. This additional analysis toggles between the
empirical data and the theoretical frames that inform the study in order to extend the theory into this specific realm of research (Burawoy, 1991).

C. **Conclusion**

To my knowledge this exploratory analysis represents the first case study of EHR infrastructures as they relate to the health and healthcare of trans and GNC persons. This study’s methodological approach uniquely captures multiple, key perspectives on this issue. Often overlooked or devalued, the analysis centers voices and experiences of trans and GNC persons as they navigate healthcare and privacy during these sweeping changes of healthcare reform. Similarly, the ethnographic techniques contextualize stakeholder perspectives so to understand how barriers to workflows and staff creativity generate workarounds specific to provider settings. Finally, this method affords recommendations that can account for specificity and context where a standardized survey could not.
IV. ELECTRONIC HEALTH RECORDS AND CARE FOR TRANSGENDER INDIVIDUALS: AN EXPLORATORY ANALYSIS

A. Background and Aims

Despite the gains of transgender health advocacy in the United States, access to quality healthcare remains fraught for transgender and GNC people.¹ Numerous studies have found evidence of widespread perceived discrimination in healthcare (Grant et al., 2011; Herbst et al., 2008; Operario & Nemoto, 2010; Xavier, J., Honnold, JA, & Bradford, 2007). Transgender and GNC persons express dissatisfaction with the level of cultural competencies among providers. With the passage of the ACA in 2009, persons previously considered to have preexisting conditions may experience improvements in access to quality healthcare. For transgender persons, a transgender-related diagnosis no longer disqualifies one for health insurance coverage. Also under ACA and HITECH, the implementation of EHRs has been highly incentivized, if not required, across provider systems with the hopes of improving the access to and quality of healthcare for all. This chapter examines key stakeholder perspectives on how EHRs are impacting the care for trans and GNC persons.

Since the 1990s healthcare providers have slowly been transitioning from paper to EHRs. Although the evidence has not been established, EHRs are said to bring a range of economic efficiencies in the domain of care as well as research (Dennis, 2010; McAlearney et al., 2010). In

¹ Throughout this dissertation, I use the term transgender, trans, and gender nonconforming to describe any individual who violates the alignment of sex-assigned-at-birth and norms around gender expression and/or gender identity associated with that sex. Cisgender and cis will be used to describe any individual whose sex-assigned-at-birth aligns with their gender expression or identity. Similar to Christoph Hanssmann (2010) and David Valentine (2007), I vary the usage of the trans-related terms, understanding that any term chosen (e.g., transgender, gender nonconforming, non-binary gender, or transsexual) does not necessarily resonate with those to whom I have applied them but reflects more of a social (im)positioning.
conjunction with the ACA, the ARRA and HITECH aim to even the healthcare access and information technology playing fields. The HITECH Act expanded federal programs designed to encourage EHR adoption (North American Opinion Research Center, 2010). It also provided monetary incentives and funding, via EHR “meaningful use” objectives, for providers who serve Medicare patients to convert fully from paper record to approved electronic record formats. Meaningful use consists of a three-stage approach to incentivize EHR uptake with the goal of transforming healthcare into care that is “patient-centered, evidence-based, prevention-oriented, efficient, and equitable” (North American Opinion Research Center, 2010, p. 3). Meaningful use also strives to ensure basic health IT standards that encourage interoperability of database systems so to reduce duplication of services and treatments as well as billing fraud. Despite the incentives, meaningful use has created many new barriers, disproportionately born by under-resourced providers, such as costs, capacity, workflow challenges, and non-interoperability. Nonetheless, all Medicare eligible providers who do not fulfill the numerous meaningful-use objectives began to incur fines in 2015 (Wright et al., 2013, p. 779).

1. **Electronic health records and health disparities**

Very little has been published with respect to the impact of EHRs on care or outcomes for underserved communities in general and trans and GNC persons in particular. The costs of EHR design, implementation, training, and maintenance are extraordinary though electronic records are believed to create long-term savings and efficiencies (North American Opinion Research Center, 2010). A recent literature review (Weinfeld et al., 2012b) found little research on the impact EHR use has on CHCs and the health of underserved settings described as rural, urban, and multipurpose/other. Between 2003 and 2011, only 17 studies had been published. The authors did find evidence—though limited in quantity and quality—for
improvement of documentation, process measures, guideline adherence, and outcome measures (Weinfeld et al., 2012, p. 136).

Whether a CHC or a large, private healthcare system, using electronic formats without greater regulation or standardization of systems generates the absence of interoperability; each health system may use unique, customized, EHR platforms—often multiple platforms within a system—that cannot communicate with each other or interpret information seamlessly. Besides unique technologies, health systems use varying definitions, terms, and codes for a vast array of variables. Although larger, private healthcare systems have more resources to address interoperability, they also have a stronger disincentive to share or exchange information with other systems in order to maintain a competitive advantage. For these reasons, medical providers have expressed skepticism around the capacity for standardizing, aggregating, or sharing data between healthcare systems in the United States (“Leapfrogging EHRs” workshop, Nov. 09, 2013).

One solution for CHCs, around economies of scale and interoperability of EHRs, is to pool resources, and then partition and share the EHR system. For example, the Alliance of Chicago was founded in 2002 by four local CHCs in order to offset the burden of expensive new technologies. Today the Alliance has 25 CHCs in eight states that serve more than 250,000 patients (Alliance of Chicago, 2014). This innovative relationship raises new security, privacy, and surveillance questions. The Alliance, for example, uses its members’ EHR data to conduct research and to monitor performance on quality measures (i.e., meaningful-use reporting requirements). This research relieves the reporting and research burdens from the CHCs, but it may also create new sources of vulnerability for patient privacy and PHI security. Under this model, EHRs are not stored locally at the clinic. Cloud storage and off-site servers expose EHR
data to more sources of vulnerability. Furthermore, the federal fines for security breaches and compliance violations could devastate the sustainability of smaller, under-resourced providers (Elkins, 2014).

Like CHCs, there is limited research on EHRs and transgender-related health information; four recent articles advocate for gender identity data collection but emphasize different benefits (Cahill & Makadon, 2014b; Cahill et al., 2014; Deutsch & Buchholz, 2015; Deutsch et al., 2013). None examine transgender patient perspectives. Deutsch et al. (2013) limit their scope to the patient-provider clinical context recommending the creation of a transgender template. The template would capture specific transgender-related health data based on these five recommendations: (1) to modify sex/gender data fields (e.g., for billing) to capture transgender data; (2) to add demographic fields for preferred name, gender identity, preferred pronoun according to the patient; (3) provide inventory mechanism that captures a patient’s medical transition history and current anatomy; (4) the EHR system should allow for seamless changes to preferred name, legal name, preferred pronoun, gender identity, and anatomy without changing the integrity of the rest of the record; and (5) the EHR system should have a flagging mechanism to alert medical staff of a patient’s preferred name and gender pronoun when they differ from legal ones (Deutsch et al., 2013). More recently, Deutsch has suggested a more practical or limited approach to EHR standards for trans-related healthcare; rather than the comprehensive transgender template, Deutsch and Bucholz (Deutsch & Buchholz, 2015) recommend the two-step sex-and-gender question along with a preferred name and pronoun field.

Cahill and Makadon (2014) take a broader perspective. Advocating for sexual orientation as well as gender identity (SOGI) EHR data collection, they argue that it is essential to the “success of Healthy People 2020’s goal of eliminating LGBT health disparities” (Cahill &
The authors contend that patient disclosure of SOGI may enable providers to better understand their patients’ health risks and may improve quality assurance, access to care, preventive care, and health outcomes. Due to a lack of consensus on how to collect the SOGI data, the Office of the National Coordinator of Health and Information Technology and the Center for Medicare and Medicaid Services did not include SOGI in the Stage 1 or Stage 2 meaningful-use guidelines. Cahill and Makadon (2014) advocate for inclusion of SOGI in the Stage 3 meaningful-use guidelines such that data may be systematically collected and linked across providers and jurisdictions for analysis at the population level. In a subsequent 2014 article, Cahill et al. found a consensus among a cross-section of patients in four US health centers. Although only 5.3% of the sample were trans women and 10.3% trans men, 82% of the sample said that asking about gender identity on registration forms is important. Though some were concerned about answering sensitive questions at intake, the majority were willing to answer SOGI questions in relation to their healthcare and believed such questions were relevant to their care (Cahill et al., 2014).

These authors acknowledge that this mode of data collection and clinical practice introduces new privacy and security threats that may deter patients from disclosure due to fear of discrimination. They address this potential barrier with the following resolutions: (1) patient disclosure is voluntary; (2) providers should educate patients on the overriding importance of disclosure of SOGI; and (3) federal regulations adequately safeguard privacy and security of EHR data. That is, despite the security and privacy flaws that other researchers like LaTanya Sweeney (2013) have identified in the federal regulations of health data collection, Cahill and Makadon strongly advocate for voluntary SOGI disclosure.
Advocates view EHRs as an innovative way to conduct population-level research, particularly for hard-to-reach and underserved communities like LGBT ones (Bradford, Cahill, Grasso, & Makadon, 2012a; Cahill & Makadon, 2014a; Deutsch et al., 2013; Weinfeld, Davidson, & Mohan, 2012a). When there is not an established sampling frame for “at-risk” groups such as injection drug users, homeless persons, or transgender persons, population-level research is not possible. With an EHR mandate, policymakers and researchers hope to enumerate a sampling frame for underserved populations like transgender individuals. Governing bodies like the USDHHS and the IOM are calling on providers to develop EHR standards such that data may be collected and pooled in order to research the health and healthcare of underserved populations like LGBT ones (Committee on LGBT Health, 2012; US Department of Health and Human Services, 2010). If an EHR data field for gender, for example, can be populated with “TM” or “TF” in addition to the “M” or “F,” this new standard can generate counts of various trans populations by linking them with other provider databases within and across various jurisdictions.

2. **Aims**

This analysis uses the case study method to review the emergent EHR infrastructures and the ways in which various stakeholders both engage them and create workarounds to provide quality healthcare and to address administrative and workflow gaps. This chapter has three sections that address the following questions:

1. What are the systems in use, how do they function in terms of data collection, and are there critical distinctions?

2. What are the stakeholders’ relationships to these systems? How are they using them vis-à-vis the health and healthcare of trans and GNC persons?
3. What kinds of workarounds have been developed to address gaps?

Taken together, each of these questions addresses the overall aim to identify and assess the impacts that EHRs are having on healthcare for trans and GNC persons; that is, are these infrastructures achieving the HITECH and meaningful-use objectives of patient-centered, efficient, and equitable care? Finally, the answers to these questions generate preliminary recommendations on implementation strategies at both micro- and macro-levels to help ensure access, care, and the safety and privacy of trans and GNC persons in the United States.

In this chapter, stakeholders share their experiences with EHRs and confirm that, although coverage for transgender persons may have expanded under the ACA, the ubiquity of EHRs under the ACA has created numerous new challenges around ensuring access and quality care. The EHR infrastructures—their templates, data fields, interconnected users, databases, and flexible analytics—constitute and make more visible a range of medicalized populations; for trans and GNC persons, that may mean providers who assume a particular narrative and set of medical interventions for them. Though the pooling and manipulation of EHR data has not been fully realized with trans and GNC patients, the current inflexibility may, paradoxically, also translate into new possibilities for privacy violations, unwanted visibility, discrimination, and entanglement in non-interoperable administrative systems for transgender persons. Similarly, for many healthcare providers of these patients, these EHR mandates constrain the clinician-patient relationships and increasingly burden already under-resourced community-based clinics.

B. **Methods**

This analysis uses the case study method. The case study fosters theory development through a detailed analysis of a social phenomenon (Walton, 1992). The case study also enables
exploration of concepts not yet validated or quantifiable and, historically, has contributed to understanding urban life and the integration of the social ecological resources (Hamel, 1993, p. 15). Most importantly, it is a method that refuses “to accept visible social relationships as ‘the’ social reality” and rejects empirical assumptions (e.g., that gender is binary) (Levi-Strauss in Hamel, 1993, p. 30). Experiences articulated by study participants are not the point of departure for theory; theory—explored via case study—aims to identify the logics that undergird the social realities that participants may express (1993). Cases manifest larger social phenomenon operating locally and particular to specific contexts.

Three approaches inform the analysis: Burawoy’s extended case method (1991), Smith’s institutional ethnography (Smith, 2005) and Starr’s ethnography of infrastructure (1999). Michael Burawoy (1991) suggests that grounded theory is limited by its micro-level, positivist scope and is, perhaps, overzealous in its claims to theory generation. His extended case method actually extends grounded theory as it conducts extensive fieldwork and analysis to make inferences. The extended case method, however, reconstructs existing theory. Rather than starting with a blank slate and discovering a new theory, Burawoy’s reflexive approach identifies patterns, processes, anomalies, and paradoxes in the data and, in this case, the EHR infrastructure, and contextualizes the fieldwork within broader discursive, social, economic, transnational, and urban settings.

Consistent with the extended case method, Smith’s institutional ethnography (2005) takes seriously the knowledge of impacted communities. Smith rejects asking organizational questions that privilege top-down perspectives and administrative knowledge. In this project, Smith might only attend to the everyday human factors—those of nurses, patients, clinic receptionists, and health IT system administrators. Here, a balanced approach toggles between macro and micro,
rather than privileging, say, the federal policy or administrator perspectives around EHR implementation.

Star’s method complements Smith and Burawoy as her approach also avoids privileging top-down analyses. Infrastructural ethnography critically examines infrastructure itself as part of a study sample or case study. It examines the EHR system, its relationships to users, and the knowledge generated from those relations. Taken together, the ecological, sociotechnical, and relational roles of EHR systems are inseparable from the human stakeholders as well as the data that the systems generate. This approach makes infrastructure visible alongside the knowledge it produces and the ostensibly mundane behaviors and workflows that it circumscribes (Smith, 2005; Star, 1999).

1. **Study sample and data collection**

The sample consisted of 27 key informants and their respective EHR systems vis-a-vis transgender and GNC healthcare. I also drew upon textual materials such as clinic intake forms, waiting room materials, policy briefs, blogs, and media representations in my analysis. As a transgender person who actively advocates for improved access to healthcare for transgender people and who actively seeks transgender-related medical care, I also drew upon some of my own experiences and participant observations to inform and interpret the study data. The IRB at UIC approved the research.

a. **Key informants**

Inclusion criteria for the interviews were being at least 18 years of age, and having worked in their position for at least one year; one key informant had only been in his specific position for three months but had worked in transgender healthcare for over a year. Clinicians had to have worked directly with transgender patients, while non-clinicians, with the
exception of health IT staff, had to have worked on policy, protocols, research, or services related to trans health. Health information technologists were not required to have worked directly on trans-related healthcare matters. Email invitations were distributed to key informants based upon recommendations from other key informants or published literature or policy briefs authored by potential key informants. Interviews were semi-structured, one-on-one, and lasted about one an hour on average. There were no financial incentives or compensation for the interviews.

Key informant interviews (see Table 1) were conducted with primary care clinicians, therapists, researchers, advocates, program coordinators, evaluation professionals, policymakers, and health IT experts. More than one-third of key informants (n=10) were trans or GNC, and one-third (n=9) were persons of color (POC). Eight different EHR systems were used among the 27 informants: Centricity (4), Cerner (1), Climacs (1), eClinical Works (6), EPIC (7), Health Revolution (1), LCR (4), and NextGen (3).

I conducted all interviews, each about one hour in length, between August 2014 and April 2015 in six major metropolitan areas considered to have significant transgender communities and well-established transgender healthcare. Purposive sampling (Silverman, 2001) was used to prioritize informants from various leading provider institutions for recruitment as standards and protocols for transgender-related healthcare in the United States tend to emerge, in part, from these leading providers. Leading provider institutions tend to be clustered in three geographic regions: the Northeast, the West coast, and the Midwest; no informants were either available or recruited in other regions. With the exception of six via telephone, the interviews were conducted face-to-face, typically in a key informant’s office, audio-recorded, and transcribed verbatim. Field notes and memos were written following interviews and during the coding process as well.
b. **Interview protocol**

Informants were asked to describe their EHR system and how it impacted care for their patients. Navigation, content structure, classification fields, diagnostic codes, clinical decision supports, and privacy and security features were reviewed and reflected upon. Because many providers had only recently implemented systems, we also discussed comparisons

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>N=27</th>
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<tbody>
<tr>
<td>Community Clinic</td>
<td>7</td>
</tr>
<tr>
<td>Public Health-based</td>
<td>7</td>
</tr>
<tr>
<td>Independent FQHC</td>
<td>7</td>
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<tr>
<td>Hospital-based</td>
<td>4</td>
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<tr>
<td>University-based</td>
<td>3</td>
</tr>
<tr>
<td>Corporate-based</td>
<td>2</td>
</tr>
<tr>
<td>Stand Alone</td>
<td>1</td>
</tr>
<tr>
<td>Tech Company</td>
<td>1</td>
</tr>
<tr>
<td>Independent</td>
<td>1</td>
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<tr>
<td>Non-profit Medical Group</td>
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<table>
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<tr>
<th>Stakeholder Profession</th>
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<tbody>
<tr>
<td>Primary Care Doc</td>
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</tr>
<tr>
<td>Public Health Researcher</td>
<td>7</td>
</tr>
<tr>
<td>Therapist</td>
<td>4</td>
</tr>
<tr>
<td>Health IT/Compliance</td>
<td>3</td>
</tr>
<tr>
<td>Program Evaluation/QA</td>
<td>2</td>
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<tr>
<td>Clinic Leadership</td>
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<tr>
<td>Health Programs Coordinator</td>
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<tr>
<td>Senior Policy</td>
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<tr>
<td>Nurse Practitioner</td>
<td>2</td>
</tr>
<tr>
<td>Trans Health Advocate</td>
<td>1</td>
</tr>
<tr>
<td>Patient Navigator</td>
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</tr>
</tbody>
</table>

* Five of seven researchers had dual roles and spoke from both perspectives.
with previous paper or electronic systems. Some key questions were: (1) Can you talk about how the system logs gender from intake to clinical encounter to billing? (2) What workarounds, if any, have been developed to address the limitations of EHR data fields vis-à-vis preferred name and gender identity? (3) How has this system enabled or prevented counting and/or recognizing trans patients more effectively? (4) What kind of quality improvements has it afforded, if any? (5) What diagnostic codes are used for trans and GNC patients? (6) Can you talk about the privacy policy? (7) Who can access patient data at the clinic, and how is that determined? (8) Can you describe some of the security features of your system? (9) How, if at all, might the EHR data be useful for research or building health information exchanges?

Certain areas of questioning were emphasized and had probing questions, depending upon the informant’s area of expertise. For example, since policymakers do not work with EHRs directly, additional time was spent on comparisons to other classification challenges and policy decisions around ethnicity, race, and sexual orientation. Health IT informants who did not work directly with patients spent more time talking about the development challenges around alignment of interests of clinicians, patients, and the billing and revenue cycles.

2. **Analysis**

   Interview transcripts were coded using ATLAS.ti (version 1.0.16 (82)). Coded transcripts were analyzed for common themes, and Lund’s analytical matrix was used to organize observations (see Table II) (Lund, 2014). As events, patterns, and concepts emerged from the coding process, analytical matrices were constructed and iteratively analyzed with respect to other cases that resonate “from different localities or different times, or both” in order to extend relevant theory (Lund, 2014, p. 226).
Table II. *Case Study Analytical Matrix*

<table>
<thead>
<tr>
<th>Concrete</th>
<th>Abstract</th>
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<tbody>
<tr>
<td>Specific</td>
<td>Observations</td>
</tr>
<tr>
<td>General</td>
<td>Patterns</td>
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</table>

(Lund, 2014)

The coding process began with the selection of six key informant transcripts, chosen to capture a cross-section of stakeholders in terms of professional roles, type of provider, gender status, and geographic location. This process generated more than 100 codes. The codes were organized into five categories: databases, classifications, trans healthcare, privacy, and security. The remaining transcripts were analyzed according to existing codes. The coded data was imported into five groups and reviewed iteratively in order to identify patterns and concepts related to surveillance and trans healthcare in the context of EHR implementation. To help synthesize reflections, observations, and interpretations, field notes were taken following interviews and focus groups, and memos were taken during the coding and analysis processes.

C. **Results**

Three themes emerged from the five domains discussed by key informants, many of which had experience with multiple EHR systems either from working at different providers, or from working on different systems within a provider, or from participating in the provider’s EHR selection processes. First, narratives highlighted critical distinctions between systems themselves, the ways in which they have been implemented, and the resources that informants have available for using them effectively. Despite these differences in systems and resources, narratives indicated a fairly consistent set of frustrations with EHRs and their limited instrumental value for improvements in trans-related care and health research. Finally, narratives revealed many
creative workarounds developed to overcome EHR-related barriers to the delivery of healthcare to trans and GNC patients.

1. **Electronic health record database systems**

Key informants used eight different EHR systems. Two systems, EPIC and Cerner, are primarily exclusive to large healthcare systems and hospital-based clinics although one informant from a small community clinic was in the process of implementing EPIC. The other six systems—Care Revolution, Centricity, Climacs, eClinicalWorks, LCR, and NextGen—were used at independent, ambulatory clinics or as part of a system of clinics. These EHR systems organize information in different ways, some with more flexibility for customization. That flexibility can depend upon the mechanics of the system itself, as well as the organization and what data it has determined relevant to capture. Similarly, how the system is implemented and the degrees of staff training and support vary by organization; these variables then impact the actual workflows (and workarounds). Finally, a provider can store the EHR information locally or on the cloud with the EHR vendor or some other manager of the data.

a. **Governance, algorithms, and decision rules**

Algorithms and decision rules underlie each data field of the EHR and circumscribe what data users can enter into the record often via a checkbox or dropdown menu. Some systems have more “hard-coding” than others, or providers simply do not have the money or expertise to change the pre-coded algorithms; both factors prevent the provider from EHR customization. Most key informant clinicians had very little control over what data are captured in the record and according to what algorithms and decision rules. One primary care doctor explained,

> If [a patient] were diabetic . . . the [EHR will] flag me when they need a hemoglobin A1c… If I’m looking for a hormone protocol [alert], I would have to design it because it
is not a common algorithm. I would have to say to my healthcare system and to EPIC, “Would you be willing to spend your programmers, EPIC’s time and money, to design this reminder algorithm for me?” And they would say, “No…” (KI #16).

Informants referenced EHR data governance committees and working groups as a key mechanism by which larger providers determine what data to collect and how. Informants also noted that relatively major tasks, such as determining rules and algorithms for the new diagnostic codes under ICD-10, consume these groups. When making these determinations, committees tend to consider how each rule will apply to the “majority” or the “average” patient rather than the exceptional or marginal patient (KI #18). This kind of centralized governance aims to “guide providers to make the optimal and the right decisions however the organization defines that to be the case, and also from stopping them or at least preventing them from making the wrong decision” (KI #18). A pregnancy rule, for example, might block clinicians from ordering any pregnancy-related tests or treatments for males and for females who are under 10 years old and over 55 years old. These blocks reduce errors. The data needs of clinicians serving transgender patients, such as ordering a Pap smear for a man without being blocked, or using a two-step algorithm (i.e., sex-assigned-at-birth followed by current gender identity) to collect gender identity data are simply not a priority.

Another touted advantage of a centrally governed and digitally networked record system is that users can generate quality improvements to care through data queries and analyses. One physician explained, “It is much easier to be able to disaggregate data . . . . For example, our clients who are HIV-infected, if you have in there what people’s race and ethnicity is, what their gender identity is, you can actually look a lot deeper. Instead of saying, ‘Oh, we are doing a great job. You know, 98% of people are keeping their appointments.’ But when you look further, it is 60% of African Americans and 100% of Whites. So, it’s like, none of your trans women are
keeping appointments” (KI #12). Such analytics help determine locally relevant interventions such as hiring patient navigators who are trans women of color to improve access for patients who are trans women of color.

b. **Security and privacy features**

While most informants spoke of rigorous compliance with HIPAA protocols, less knew of particular EHR security protocols and deferred to their compliance or IT staff. Informants discussed two EHR mechanisms—data segmentation and the patient portal—as affording limited aspects of patient privacy and data security. For transgender patients, none of these current configurations work seamlessly to protect sensitive gender-related information.

1. **Data segmentation and user-defined access**

   Depending on the organizational structure, data governance committees or a clinic’s leadership usually determine what parts of the record various staff can access. For example, informants reported that the intake staff could only see demographic patient information; in most cases though, even that limited access meant that intake staff see the patient’s legal name and gender rather than their chosen name and current gender. An external lab may also only see legal name and gender and will return results accordingly. The billing office might only see demographic information and diagnostic codes. Patient coordinators might be able to view a record’s medical templates while not having the capacity to alter the information. Primary care physicians and/or nurses may be able to access the entire record of their patients, or even all the clinic’s or all the healthcare system’s patients, although sometimes the mental health section of a record is not accessible. Likewise, mental health clinicians may not be able to access the medical side of a record. At clinics that embrace a more integrated and holistic approach to health, mental health providers, physicians, and nurses could access the
entire record. Similarly, at clinics with very few resources to enable data segmentation, all staff might be able to access all aspects of a patient’s record. When patients are referred to another part of a healthcare system, data segmentation may help keep one’s health conditions and diagnoses confidential from clinicians who are treating the patient for unrelated issues.

2. **Patient portals**

   Although nearly all key informants’ EHR systems have patient portal capabilities, not all provider organizations were currently using them. Providers tend to deploy the portal during later stages of implementation. The EHR vendors tout portals—an encrypted entryway into the EHR system for patients—as a means of increasing efficiency as well as patient engagement in care. For example, patients can complete intake registration via the portal and that allows them to communicate confidential information such as gender identity and sexual orientation at intake or at later dates with enhanced privacy. One informant explained, “Self-reporting is the way identity information should be done. I’m hoping to get that information during registration on the portal because more and more people will want to get their health information that way” (KI #8). If gender identity and sexual orientation data are captured during the intake registration process, the portal’s capacity for keeping sensitive disclosures private rather than exposed to another person in a relatively open space may help identify more transgender patients.

   Efficiencies may also increase due to a portal’s secure and quick way to communicate needs around appointments, prescriptions, labs, or reaching one’s physician. Patients can access and verify key aspects of their records without requiring a clinician or staff person to retrieve and relay the information. This efficient access may also lead to increased engagement. One physician was not aware of the portal until she received a call from a young patient who wanted
to discuss his lab results. “He called me Sunday and said, ‘I don’t understand my labs.’ I said, ‘Your labs?’ He said, ‘Yeah they sent them to me through e-mail.’ I said, ‘For real?’ I said that I was really impressed. So I just explained it to him” (KI #14).

Another reality is that portals introduce new sources of potential security and privacy vulnerabilities. As for security, the portal creates an additional entry point into the system that must be secured and monitored to prevent breaches. One informant, for example, reported favorably on his use of the portal to respond to his patients but mentioned that patients entering incorrect email addresses into the system may have presented some security and privacy problems. At a later date that informant’s provider organization had taken down the portal. Another informant reported that her clinic had decided not to use the portal until it had determined how to maintain the privacy of patients who are minors and whose parents might gain access to the records and confidential health information of youth via the portal.

2. **Key informant relationships to electronic health records**

   a. **Navigation and usability**

      While informants expressed some enthusiasm for specific features of a system, they mostly expressed frustration with the cumbersome navigation of systems in general and specific usability challenges with regard to their trans and GNC patients in particular. Informants who used Epic viewed it as a relatively good system for efficient and easy navigation. On the other hand, informants found Centricity very difficult to navigate to content because of numerous tabbing requirements and hard-stops. A health IT director explained, “When physicians bill, if they have to go through a lot of clicks, that’s something that really annoys them. Also when they’re selecting a diagnosis or . . . procedure, that’s a huge compendium and if they can’t get there very quickly, they get very frustrated . . . . Because they have to click more,
do more, say more. That’s the administrative burden that lots of physicians complain about” (KI #18).

Centricity and eClinicalWorks (eCW) offered what some informants considered superior usability due to its extensive customization abilities. So the Centricity content may be richer but difficult to navigate. One provider developed custom templates in Centricity, for example, in order to enable patients to specify their gender identity at intake and then populate a gender ID template in the medical record. However, clinic administrators seemed to express caution around tailoring the front-end of the EHR to the special needs of a patient population because it inevitably caused them problems on the backend in terms of reporting and communicating with other systems. One informant lamented, “In NextGen, so many things are hard-coded that you cannot change. In eCW there is more variability—it’s just not as robust in terms of the information that you can get out of it. Most of the issues that I’ve heard of with eCW are with reporting” (KI #3). In other words, customizability and tailoring on the front-end may generate data that does not drop into reports on the back-end, leading to relatively useless data, also known as “garbage in, garbage out” (KI #11).

The overwhelming usability barrier is that informants’ systems—and EHR systems in general—have not been designed to accommodate gender identity beyond the cisgender binary. The most obvious effect is that the banners of a record endlessly confuse clinicians and staff who are unable to ascertain whether the banner has correctly identified a trans patient. The banner cannot indicate a trans or GNC patient’s current pronoun and, in many cases, their preferred name if it has not been legally changed. In some cases, even if a patient’s gender has been changed, a system may only capture sex-assigned-at-birth. These limitations can lead to mis-gendering and outing trans and GNC patients in waiting rooms, exam rooms, labs, over the
phone, on bills, and in pharmacies. A related problem, alluded to in an earlier section, is that data fields have decision rules linked to sex that often prevent clinicians from ordering treatments, tests, and making diagnoses for transgender patients.

Although this usability barrier seems simple to resolve with an addition of a data field or two and an amendment of decision rules, limited resources and a vast range of EHR data and workflow problems to resolve often leave this particular problem unaddressed by health IT staff. Furthermore, the providers that have developed EHR solutions within their clinic setting continue to struggle in terms of how to communicate this information seamlessly to other systems or to other parts of their own system without outing patients and exposing them to bureaucratic and administrative snafus. These usability problems can make clinicians and staff seem culturally incompetent and prevent clinical effectiveness in terms of workflow disruptions and unreliable data.

b. **Electronic health record data analytics and health information exchanges**

The barriers around usability have dampened some informants’ outlook on the possibilities for research based on EHR data analysis and HIEs. Other informants simply are not interested in research and, if they prioritize EHR use at all, do so for clinical effectiveness and quality improvements. A few, however, have been active in EHR research while others work for providers where colleagues are conducting studies based on EHR data. One policy official summed up what he and his organization view as the clear benefits of EHR research, “We have enough knowledge to know that there is a problem and we want to . . . collect the data so that we can better understand the disparities that transgender people experience and then be able to hopefully quantify and document that we’re reducing those disparities and improving care” (KI
Conversations with informants indicated a number of limitations and barriers that many have to navigate in order to conduct research that will begin to address transgender health disparities.

A couple informants had conducted studies with their own clinic data, single-site quantitative studies despite limited reliability and validity due to very small and relatively homogenous samples. Multisite studies or the creation of a transgender HIE provide a means for pooling data, creating larger sample sizes, and ostensibly improving reliability and validity of quantitative measures. However, since there are no standards around collection of gender identity data, it is impossible pool data at this point without extracting data first and then reclassifying it according to a study protocol with specified variables. One researcher working on a national, multisite study based in part on EHR data explained some of the barriers she has encountered:

This study presents a special challenge . . . because depending upon [the site] you may or may not have an informatics person, a data manager, or somebody that can pull a report, an electronic system. I know that [other sites] are struggling too, but for us, our challenge is we have an amalgam of medical providers . . . [who] said, ‘Okay, we have this variable, you have this indicator, we don’t have this one, we don’t have this one . . . We are going to create this report for you.’ But when the time came, no report . . . They just don’t have the resources that they thought they did (KI #20).

Informants also indicated a lack of security and privacy standards around EHR data analytics; provider practices vary greatly. Perhaps because a study is internally conducted, or because of severe resource limitations at clinics, providers may not de-identify records for the data collection process. Two informants who conduct data analysis with EHRs and normally have no direct patient contact—though they may know patients from other settings—expressed discomfort around the lack of de-identified records. One researcher described vast security and privacy vulnerabilities at the clinic where they extract EHR data for a larger study, “I can access any patient’s data in the entire clinic . . . I have to be on-site, but I can see anything and
everything. Nothing is segmented . . . I would like to be able to have an assistant de-identify the patient data I see . . . I would like to have the names and Social Security at least removed for my research, but it’s not” (KI #1). Due to differences in resources and capacity, privacy protocols between sites may vary even when working under the same IRB-approved research protocol.

Informants expressed excitement at the concept of a trans HIE, but seemed to agree that until standards have been determined and implemented, HIEs will not generate robust and reliable knowledge. How they are funded may also impact the kind of knowledge HIEs can generate. An informant explained:

[An HIE] is greatly needed but we can’t do that until we have a way to identify trans people consistently . . . We really need an exchange. We just need to make sure that the exchange isn’t driven by HIV money . . . because I have a ton of trans patients with a wide range of psychosocial issues and needs, and they have absolutely nothing that would put them at any kind of HIV risk. I think it’s really essential to identify and count trans people and if we’re not counting them, then we’re not taking care of them (KI #13).

In addition, providers and policymakers need to think through and determine standards around exactly how providers will collect SOGI data; that is, patients may want to disclose such information for the purposes of clinical effectiveness or health research exchanges, but only if they know that providers have properly safeguarded that information.

c. **Workarounds**

Informant narratives suggest that providers cannot effectively care for patients when they cannot identify patients accurately in their databases or respectfully in their waiting rooms and other settings. Informants’ workarounds bridge gaps and workflow disruptions in the domains of clinical effectiveness, cultural competency, privacy, classifications, and non-interoperable databases. Although the different EHR systems create very similar barriers for key informants around identification of their trans patients, the creative strategies to
overcome them—workarounds (Star, 1999)—differ depending upon the specific context and how one responds to that context. One informant observed potential problems with varying workarounds,

Working with county health departments I’m finding that people are working within a system that says they have to document people a certain way . . . [but] most [trans] people might have a legal or medical record that is inconsistent with their gender identity because it’s such a pain to jump through all those hoops . . . . [Providers] need to find ways to communicate, but at the same time recognizing . . . confidentiality and being careful about communicating that information. . . . It’s basically coming down to a whole lot of individuals coming up with their own way to navigate a system that doesn’t understand this at all. With service delivery you want consistency because you don’t want instances of discrimination (KI #9).

Besides the potential for perceived discrimination and privacy violations, workarounds and the lack of standards also create more possibilities for errors. This section highlights workarounds used to overcome common workflow disruptions to trans healthcare caused by the EHR system.

1. **Electronic health record banners**

Several informants reported varying degrees of recent success in the implementation of a more accurate banner. The banner refers to the header of an electronic record that appears regardless of which tab or template is open and identifies the patient. Customized banners tended to include fields for a patient’s preferred name and current gender in addition to the legal name and legal gender or sex-assigned-at birth. These informants worked for healthcare systems that use Epic or for LGBT-focused providers with health IT teams that could devote the resources to this change. But even these implementations left room for error. One informant explained, “We actually pushed for that [preferred name field] and a lot of people do not know where they need to input it, but if you input it in the right place, it appears right on the banner . . . under somebody’s legal name. . . . Of course, it does not mean that somebody is going to pay attention to it, but it’s there” (KI #15). Furthermore, though the customized banner
may correctly inform a clinician or receptionist, often the external entities like labs or payers request legal information only, which can create perceived privacy violations for patients when they receive bills or test results in the mail.

Most informants continue to use workarounds to try to ensure that staff and interfacing entities will recognize trans patients appropriately when pulling up their record. A frustrated physician at a federally qualified health center (FQHC) said, “It’s all on the [clinicians] to deal with the workarounds. Like we have a pop-up that’s designed to help the front-desk staff know which name and pronoun to use, but it’s underneath about 3 other kinds of notes about unpaid bills and other stuff. So do people always see it? No“ (KI #17). Another informant at a youth clinic explained their workaround:

[The clinic] did this weird build where they created for gender: male, female, and an extra checkbox with a ‘T,’ but this could absolutely lead to mis-gendering depending upon the legal status and/or the presentation of the patient. There’s an [also known as] (AKA) field, but it doesn’t show up for the front desk staff. . . . That is my biggest concern . . . because that is a person’s first experience when they walk in the clinic and it can be so traumatic. [Another] issue that happens frequently is providers don’t always get a person’s preferred name [from the AKA field either] before walking out to the waiting room. And they’ll call somebody by their birth name and that’s really a breach of privacy but also dangerous and problematic (KI #2).

Although stating someone’s legal name in a waiting room may not count as a violation of HIPAA, these frequent instances of misnaming and mis-gendering expose trans people’s confidential health histories in that their sex assigned at birth may be inferred. That involuntary disclosure may jeopardize patient safety and access to care.

As noted, even the relatively effective workarounds developed in Epic can cause unwanted disclosure of one’s transgender status. Additional privacy violations can occur when these clinicians refer their trans patients to other parts of the system, for eye care, for example. There are at least two ways at the eye doctor these unwanted disclosures may occur. First, the
patient may not want an eye doctor to know that they are trans, but the doctor may easily infer this by seeing a legal and preferred name that reflect different genders. Second, the staff at the eye clinic may not notice the preferred name and may call the patient by the legal name in front of others. But as one informant explained, it goes beyond the eye doctor. She said,

> The concern I have is about interfaces: me giving information to a lab, or a referral to another entity because the patient needs cardiology—or whatever the referral is—that those systems interface in a way so that when that patient comes in, they are respected and receive healthcare and [aren’t] a barrier that so many folks face when interacting with healthcare and that we are not creating more barriers with EHRs (KI #3).

Another informant, a clinic research coordinator, explained another interface-related barrier for a trans patient. She had run a report on eligible patients to participate in a 12-week women’s health program. Unfortunately, the report pulled from a transgender man’s chart and, after leaving a voicemail, she received a phone call from a very flustered patient who—in that voicemail—had been mis-gendered and alienated by the clinic he had trusted with the care related to his gender transition.

2. **Diagnostic codes and problem lists**

Diagnostic codes and problem lists (i.e., a summary of the most important medical issues from a person’s record) can pose similar unwanted disclosures of one’s trans status to persons or entities beyond one’s primary care physician. One transgender clinician who experienced his ear, nose, and throat doctor seeing his problem of “transsexualism” uses the following workaround for his patients in Epic: “If I know the person is not out within the broader system, I just enter it every time and do not add it to the problem list. If the person is out within the broader system, or out in the world, then I just put it on the problem list as Gender Dysphoria because it is a lot easier, more convenient, when you have a limited amount of time” (KI #15).
Another clinician also expressed frustration at the inability to preserve her patients’ confidentiality in Epic:

We don’t even have the capability to make a note confidential, which is very problematic. They’ve done other things like identifying a number of conditions that would be sensitive or confidential but it makes documenting very challenging if you’re not identifying the note by diagnosis, meaning if maybe you’re not diagnosing substance abuse but you’d like to write a note about one’s use of substances. You know there’s no guarantee that the note wouldn’t be able to be accessed by parents (KI #19).

Clinicians often determine that no documentation is the best solution. This workaround, however, may detract from the patient’s healthcare as well as the richness of doctor-patient relationships. If clinicians feel they cannot precisely or accurately document their patients’ current medical status, it takes away from their ability to make decisions over time and lends the EHR more power to make those clinical decisions for them based on the circumscribed data fields.

Clinicians with more flexibility in what diagnoses they can assign may use Endocrine Disorder Not Otherwise Specified (NOS). Some informants reported Endocrine Disorder NOS as more applicable in general and not simply a way to avoid the stigma of 302.85—the ICD-9 code of Gender Identity Disorder and the ICD-10 code of Gender Dysphoria, required by some clinic protocols and some insurance plans. Clinicians reported that 302.85 is not necessarily applicable to their transgender patients who may express no dysphoria around their gender. Some noted that the ICD-9 code 259.9, or nonspecific endocrine disorder, is more widely applicable to their patients.

The variability in diagnoses poses a couple of problems for providers, clinicians, and researchers. Since gender identity is not reliably tracked in the EHR, diagnostic code is another way to identify and track transgender patients. This method works more reliably when clinicians assign trans persons a consistent and unique diagnosis that is not shared with cisgender persons.

One informant elaborated, “I think the problem is that the [diagnostic] classification in the
system is so clinician-dependent, and so clinic-dependent, and so day-of-the week dependent . . . I mean this is the big question that [her provider system] is trying to answer right now: how to even begin, for research purposes, for clinical purposes, to track who we are serving” (KI #2).

Another informant explained, “What I want to get rid of, from a research perspective particularly, is getting rid of those codes that, um, are going to mix up folks that are trans—people taking hormones or having had surgeries for transgender issues or gender dysphoria issues—from folks that are taking hormones that are not related to gender . . . . You cannot rely on diagnostic codes” (KI #16). These different, often strategic, applications of diagnoses and problem lists make clear the challenges around transgender patient privacy but also the use of EHRs for transgender health research.

3. **Training**

Generally, training is not considered a workaround, but a necessary part of implementing any system or set of protocols and procedures. In this case, training refers to teaching staff to use specific workarounds as an attempt to maintain steady workflows, maximize consistency, and minimize errors and instances of perceived discrimination. A clinic director explains that direct, explicit communication with patients as well as with insurance companies and other entities has become key to ensuring access to care and a positive patient experience:

The workarounds are really amazing communication with the patient . . . . Setting up expectations with the patient and if they don’t want that, then figuring out what we have to change in order to make that happen. There are issues of course with insurances not willing to change gender markers until certain things have been done—that is a big thing that needs to shift . . . because that’s really where a lot of the risk runs, right? The insurance carriers have all this information and don’t have a way to capture it in meaningful ways . . . . The whole purpose of EHRs is decrease waste in the industry—communication waste. And the systems are not yet built to be able to give everyone information they actually need to provide competent care (KI #3).
While this informant’s clinic goes to great lengths to ensure respectful care for trans patients, less sensitive providers in other parts of the country may not devote equitable resources. At UIC, for example, where the trustees passed a trans-inclusive healthcare policy for students in 2013, the provider has yet to institute formal trainings with clinic staff around how to address barriers created by EHRs for trans patients and clinicians or how to provide cultural competent care.

A policymaker who advocates strongly for universal and standardized EHR data collection of sexual orientation and gender identity believes that trainings will bridge gaps created by standards:

I think the training of staff is really critical. That is a really important implementation step. I also think that ensuring nondiscrimination is essential. So, by asking people these questions . . . and collecting these data, on one hand, we are improving our knowledge of this patient population in ways they can improve quality of care and improve health outcomes but at the same time, we’re also opening people up to discrimination (KI #23).

Trainings cost providers money and resources. When a patient population consists of such a small percentage of the total, providers do not prioritize them. It becomes a set of tradeoffs with questionable payoffs for transgender-related healthcare. Data collection via a dropdown box that will include a transgender binary in addition to the cisgender binary, we are told, will improve trans care, but implementation without regular training will most likely lead to errors, discrimination, and barriers to accessing care.

4. **Mergers, cooperatives, and sharing resources**

Key informants from smaller clinics revealed broad-based strategies that probably exceed what is considered a workaround. Merging with larger corporations, entering into health IT collaboratives, and sharing back-office resources all constitute strategies that smaller providers have engaged in order to survive in the current, fast-paced, and very expensive regulatory environment. An informant explained the pressures,
There’s so much to be on top of and that’s constantly changing . . . . The amount of workload that has created for our staff—. . . we get denials all the time and we’re constantly figuring out, “How do we get our patients access to things that they legally have access to?” So we have two full-time positions, and . . . much of [their work] has shifted to getting insurance carriers to cover their referral, and hours on the phone working their systems, and working their denials, and applying for independent medical reviews in order to get access to surgeries . . . . All the experts say that smaller clinics just won’t survive (KI #3).

The large, well-resourced providers are also centralizing their resources. Another informant from a nationwide, private provider discussed how they are centralizing their multiple EHR systems used in different parts of the country into one seamless system governed by one oversight group. He explained that clinical decisions will be made more “holistically—where it doesn’t matter if you go to a hospital in Iowa . . . or in Georgia. You are going to get the same thing” (KI #18). In medical contexts, “holistic” typically describes a non-Western medical approach whereby providers account for each patient’s whole physical and emotional being in terms of wellness; this EHR technology expert completely redefines holistic medicine as a nationally distributed EHR infrastructure governed by one set of algorithms and merged with the financial infrastructure—with the data of both stored together—so that the integrated EHR and revenue cycle will circumscribe decision-making uniformly and across regions.

D. Discussion

Jeff Bowker and Leigh Star’s book, Sorting Things Out (1999), observes that well-functioning infrastructures are largely invisible. It is only an infrastructural failure that makes an infrastructure readily apparent. In the context of trans healthcare and EHR implementation under the ACA, one of the most common experiences of infrastructural breakdown occurs in the waiting room. A receptionist or nurse will call out the legal name accompanied by the gendered honorific that they incorrectly assume precedes the name: “Ms. Andrea Smith?” rather than “Mr.
Andre Smith?” or the non-gendered, “A. Smith?” If they have been captured at all, preferred name and current gender are often buried in a “notes” field not immediately visible to the staff person who is reading the electronic record. A multi-million dollar system implemented as part of an ambitious plan to increase access to healthcare often creates a hostile and potentially dangerous environment for trans and GNC patients from the beginning of the patient encounter. Similarly, this infrastructure creates workflow disruptions, numerous frustrations, and extra work for caregivers. In sum, EHRs have not achieved HITECH’s objective of patient-centered, efficient, and equitable care for transgender persons.

This case study marks the first exploratory examination of key informant narratives around the complex uses of EHR infrastructures with respect to healthcare for transgender and GNC persons. With the ARRA and HITECH Acts, EHRs have been implemented without the data governance in place that might afford the anticipated benefits to all those with stakes in transgender healthcare. Whereas the paper record documented the unique patient-caregiver relationship and that individual’s healthcare, EHR systems represent an infrastructural expansion that promotes healthcare increasingly based on the analytics derived from patient population clinical outcomes and their revenue streams. The key informant narratives indicate that data governance—from meaningful use at the federal level down to the algorithm and decision rules at the level of the data field—may require more attention and scrutiny from a broader swath of stakeholders if expanded access and equitable care is indeed a goal of the ACA. This case study indicates that current implementations alienate patients from providers and clinicians from the patients as well as the EHR system itself. This discussion will use Lund’s case study analytical matrix to make some specific recommendations based on the observed patterns in the findings.
and then, in the following chapters, move into the conceptual and theoretical implications for trans and GNC patient privacy, and population health and surveillance.

1. **Counting gender nonconformity substantively and respectfully**
   
a. **Data governance**

   The federal government will likely need to amend meaningful-use requirements in order to compel EHR vendors to modify certified EHR systems such that they have the capacity to capture additional gender-related data fields. As one informant pointed out, “When it’s coming from the Feds that we have to report out on these things now, it’s no longer an option. [Vendors] are able to make their systems count every other population that [the Feds] want counted—like the homeless and HIV positive—so why not [transgender] too?” (KI #3). Key informants stressed that community clinics or even hospital- and university-based clinics do not have the power to influence vendors to change their systems.

   Data governance must consist of more than top-down mandates. A systematic, horizontal process should generate the substance of such mandates. A range of stakeholders, which includes patients and extends beyond the current working groups at the most well-resourced healthcare systems, needs to provide the input around data governance collectively—from the federal standards to locally determined implementation. As many key informants noted, over-customization can lead to reporting errors and a strategy of minimal data collection might prove most efficacious. Multiple physicians emphasized that trans healthcare is primary care; it is not specialized medicine and does not require granular levels of trans-related data. Based on the findings, the following are minimal recommendations around data governance that may help improve and sustain equitable access to respectful, quality healthcare.
1. **The two-step algorithm**

   The two-step gender identity question begins with, “What was your sex assigned at birth? (Answer options: intersex, female, male, decline to answer)” and is followed by, “What is your current gender identity? (Answer options: GNC, trans masculine, trans feminine, man, woman, other, decline to answer).” Consistent with CDC field-testing and the limited survey research (Cahill et al., 2014), key informants with providers that have already implemented the two-step question report increases in their trans and GNC patient population without jeopardizing the reliability of cisgender patient data. With “decline to answer” as an option, the two-step question will not capture all trans and GNC patients but is necessary to ensure patient privacy and access to care. The contexts in which it is asked and how the data are stored may impact how many persons opt in rather than opt out of responding (see Segmenting section). As this algorithm leaves room for erasures, patients, providers, and advocates should remain focused on other strategies for communication around gender identities.

2. **Preferred name**

   Along with the two-part question, trans and GNC patients must have a space to articulate the name that they currently use, if it differs from their legal name. Although providers should recognize their cisgender patients by their preferred name as well, the safety and privacy of a trans or GNC patient is at stake when they are called by their legal name and potentially mis-gendered in the process. Preferred names should be prioritized in terms of visibility to EHR users on the clinical side.

3. **Segmenting sensitive information**

   Perhaps more important than capturing sex-assigned-at-birth, current gender, and preferred name, is the means by which these data are captured. One key
informant may have said it best: “This is my dream—the person who is interfacing with the system only sees preferred everything, and if they need the other information, they have to go to that place to access it because then you don’t have to create any workarounds. They can just interface with the system” (KI #3). Current gender and preferred name are fields—of both cis and trans patients—that all users should have accessible to them. Legal name, sex-assigned-at-birth, and diagnoses are sensitive information—data fields that should be segmented and only accessible to a patient’s primary care provider.

4. **Patient portal as privacy shield**

Especially during the intake process, the patient portal, though certainly not devoid of privacy and security vulnerabilities, may provide trans and GNC patients an extra layer of privacy to ease disclosure of sensitive information such as sex-assigned-at-birth and legal name versus a current gender identity and name. A similar “low-tech” and more humane practice currently instituted at some LGBT-niche clinics consists of having transgender or trans-friendly patient navigators available to help with the intake process. In order to decide what information is safe to disclose, patients should understand how a provider shares this information after the intake process.

b. **Capacity building: Hiring and training**

Providers should prioritize hiring trans and GNC staff. The presence of trans and GNC staff will help shift the culture and awareness of the work place and help create safer spaces for patients. As one key informant said of his employer—a large healthcare system attempting to implement trans-inclusive medical practices—hiring trans and GNC employees is challenging when the employer itself does not have trans-friendly mechanisms in place, such as
gender-inclusive bathroom access, gender-inclusive healthcare coverage, and a culturally competent staff (KI #27).

Rather than ad hoc trainings, stakeholders and policymakers might consider how to provide sustained support around these infrastructural implementations. Adding data fields and segmenting them appropriately may reduce some of the involuntary disclosures that occur, but with more insured trans and GNC persons seeking care, staff needs explicit training on data governance, patient privacy, and cultural competency. A comprehensive training would address why, for example, the two-part question is very important for more sensitive caregiving and reliable reporting but also has its limitations. Training would help clarify why answering the two-part question is a safety issue for some people and how segmentation of sensitive data offers a level of protection and promotes cultural competency.

2. Increased regulatory, technological, and financial support

In order to prevent a stratified healthcare system or a system that ultimately consists of only wealthy, large, private providers, smaller clinics without the financial, technological, or legal resources may need more support in order to keep up with the fast-paced technology and regulatory environment. Several clinics had already embarked on mergers and pooling resources to make health IT requirements sustainable and scalable. However, the sense was that these infrastructures, no matter the size of the provider, require increasing proportions of providers’ resources and taking away from the focus on patient care. More research and resources may be directed toward ways to support and sustain clinics—or the smallest, most resource-poor providers—and the fulfillment of IT regulations without jeopardizing care. Mechanisms to aid in the pooling of financial, billing, or health IT resources may alleviate the expanding administrative burdens that disproportionately impact small clinics or clinics that
 prioritize underserved communities. Although economies of scale encourage pooling resources both within and across provider networks, research may investigate the new security and privacy vulnerabilities that such pooling may introduce and, likewise, the security and privacy vulnerabilities that such pooling may eliminate or reduce. Similarly, pooling technology resources encourages centralized governance, and it seems that centralized governance may leave marginalized patients’ needs invisible to algorithms based on the majority of a population or on the most profitable revenue cycles.

E. Conclusion

This case study has limitations. Its reliability and validity is not quantifiable. It is an interpretive, critical analysis of narratives regarding a nascent healthcare technology landscape for a very marginalized part of US healthcare systems. Whereas the research thus far has relied on either clinical or policy perspectives, this analysis accounts for multiple stakeholder perspectives and will examine patient perspectives in a subsequent chapter. The exploratory nature has enabled the identification of multiple areas of concern and respective recommendations. The conceptual and theoretical implications for patient privacy, transgender visibility, population health, and surveillance will extend from the findings of both patient and key informant narratives and will also be addressed in subsequent analyses. A single-site case study of a community clinic, or a comprehensive study of EHR user experience, may allow for more in-depth analyses of these exploratory concerns.

The National Transgender Discrimination Survey (Grant et al., 2011) revealed that 19% of trans and GNC people perceive having been refused medical care because of their gender identity, 28% reported having been subjected to harassment in a medical setting, and 50%
reported having had to teach their providers about transgender care. Clearly, both patients and providers alike need more support around effective and equitable caregiving. The EHRs are not the root cause of these statistics, nor can they or will they solve these problems. They likely play a role in both the problems and the solutions. And, while key informants felt like their systems were in full compliance with HIPAA and HITECH privacy and security regulations, their narratives also made clear that compliance does not necessarily equate with actual patient privacy or data security given different contexts.

With more attention to data governance, training, and structural support for small providers, the patient experience, provider workflows, health research, and the patient-caregiver relationships and decision-making processes can all improve and enhance the health of trans and GNC persons. More attention to coding preferred names, pronouns, and current gender along with the segmentation of sensitive patient information will enhance patient-centered and patient-engaged care. A minimalist and cautious strategy toward granular levels of trans health-related data collection and an appreciation for creative workarounds will help preserve patient privacy as well as the agency of the caregiver, the patient, and the caregiver-patient relationship in the context of the expanding rule of the algorithm.

Finally, these infrastructural “fixes” may represent a visibility (or privacy) paradox for trans and GNC persons. On the one hand, the failures of these systems may “out” trans and GNC persons. On the other hand, a more seamless or successful infrastructure may work to normalize aspects of trans and GNC care as an identity per se. Though explored in the following chapters, this normalization process may make certain kinds of transgender expressions or identities visible to the system in ways that create new or different potential privacy violations and opportunities for discrimination.
V. “WHAT SEX WERE YOU ASSIGNED AT BIRTH? WHAT IS YOUR CURRENT GENDER IDENTITY?” THEORIZING THE ALGORITHMIC TURN TO GENDER IDENTITY IN ELECTRONIC HEALTH RECORDS

[Capturing gender identity in EHRs] is about collecting data that can be used to understand public health, to help provide the appropriate care to a patient but also to understand population health at the population level (KI #23 LGBT Policy Advocate).

A. Transgender Visibility: Social Justice or Surveillance

In the wake of the ACA and its mandate for EHR implementation, transgender healthcare advocates are calling for culturally relevant information and surveillance systems that will enable a population-level approach to health research and healthcare. A range of advocates have recommended an algorithmic standardization of the two-step question and its response options to identify trans people in healthcare settings: (1) what sex were you assigned at birth, followed by (2) what is your current gender identity? This measure has been validated in a San Francisco study demonstrating greater reliability for enumerating trans patients (Tate, Ledbetter, & Youssef, 2012) and adopted for use at the CDC in HIV reporting forms and in their electronic surveillance system (Centers for Disease Control and Prevention, 2011). That is to say, advocates argue that this two-step question makes transgender persons increasingly visible in the sociotechnical processes of healthcare and health research settings such that providers and researchers can better address their unique healthcare needs.

This chapter uses the terms transgender and trans as well as gender nonconforming and nonbinary to refer to individuals who violate the alignment of sex-assigned-at-birth and the associated gender expression. Those who embrace or conform to this alignment are referred to as cisgender. The chapter tends to pair “transgender and nonbinary” or “trans and gender nonconforming” together to encompass not only transgender persons but also those who may not identify as transgender but do not identify as cisgender either. Similar to Chris Hanssmann (2010), the chapter deliberately varies the usage of terms, as any terms used do not necessarily resonate with those to whom they have been applied and reflect social position rather than identities per se.
Vivian Namaste’s *Invisible Lives* (2000) champions increased visibility ostensibly to reduce the social stigma associated with being transgender and improve the health and quality of life of transgender people. Distinguishing between sexuality and gender, Namaste argues, is a key strategy to prevent the consistent erasures of transgender persons’ experiences of interpersonal violence in public spaces. Such a distinction allows for the discursive recognition—and visibility—of nonbinary and transgender persons. This visibility affords more appropriate political responses and interventions that go beyond the experiences of White, middle-class gay men. So often urban North American media, policymakers, and academics would (and still do to a lesser degree) reduce transgender persons to the category of men who have sex with men and turn to White gay men for policy solutions regarding homophobic, rather than transphobic (and racist), violence. Namaste explicitly argues for community-generated research and interventions that account for the lived experiences of transgender and GNC persons. That is, context-specific interventions crystallize horizontally into policy rather than doctors, bureaucrats, or academics imposing them.

Fifteen years later, the transgender movement in the United States has taken the cause of visibility into the mainstream (see, for example, Steinmetz, 2014). Visibility has become a portal to human and civil rights for transgender people, but mainstream exposure comes with new vulnerabilities too. Community-driven campaigns and organizations such as We Happy Trans, the Trans 100, the Transgender Law Center’s Authentic Selves Campaign, for example, all encourage and highlight the visibility of transgender people in order to change hearts and minds of the mainstream public. This visibility aims to build public support for transgender justice and equality. A problem, however, is that this visibility emphasizes bodies and faces that resonate with mainstream society as normal or socially acceptable. For example, thin, able-bodied, and
articulate advocates such as Laverne Cox, Janet Mock, and youth advocates like Jazz Jennings, Arin Andrews, and Katie Hill not only “pass” as cisgender persons but also must be understood as what society considers beautiful as they continue to work as fashion models, mainstream media spokespersons, and actors. Juxtaposed against this normative grid are trans and GNC persons who become illegible and abnormal. Scholar-activists Che and Reina Gosset have cautioned that the drive to increase visibility may further marginalize those who are illegible or “non-passing.” They point to the increasing rate of transgender suicides and homicides in recent years—especially for young, poor trans POC (Bruce-Jones, 2015; Kellaway, 2015). Increased visibility means increased exposure to harassment, violence, and transphobia for those who do not “pass” as beautiful or cisgender. As mainstream society yields to a specific transgender norm, those who do not fit those norms may encounter new forms of scrutiny and violence.

In the realm of healthcare and health research, stakeholders are also promoting trans visibility in order to generate health equity. Greta Bauer et al. (2009) explicitly extends Namaste’s work and calls for the elimination of trans erasures through the inclusion of trans people in informational contexts such as research, surveillance, and medical and nursing curricula and training materials. Similarly, the IOM, the CDC, the Fenway Institute, the Center for American Progress, the Williams Institute and the San Francisco Department of Public Health have all issued recommendations, white papers, and original research that advocate for the data collection of gender identity by way of various electronic surveillance systems: EHRs, HIV surveillance, and national health surveys for youths and adults (Bradford et al., 2012a; Cahill & Makadon, 2014a; Cahill et al., 2014; City and County of San Francisco Department of Public Health, 2013; Conron, Lombardi, & Reisner, 2014; Conron, Landers, Reisner, & Sell, 2014).
In 2014–2015 I interviewed 27 key informants who work at the “leading edges” of trans healthcare—that is, at institutions or as clinicians well-established in the provision of healthcare for trans persons. For example, most of the clinicians interviewed work at clinics that have explicitly provided healthcare for trans individuals since the 1990s. I interviewed these informants about the implementation of EHRs and how that implementation has affected care for trans people. Using a case study method, I coded the interviews for patterns and relevant themes. This process enabled the identification of important EHR mechanisms—such as the gender identity algorithm captured via the 2-step question at intake—that both facilitate and create barriers for care and other aspects of daily life such as self-determination, safety, and privacy. This chapter draws upon Namaste’s transgender visibility framework in order to critique current calls for transgender visibility in the context of population health and EHRs systems. I identified a visibility paradox, querying the implications of trans visibility as a population via this specific surveillance mechanism—the two-step, gender identity algorithm—and pondered the potential gains and vulnerabilities generated by this visibility. In sum, I made the following argument: (1) the gender identity algorithm may generate new data collection and research opportunities, but ones quite different from Namaste’s call for community-driven, local-level research in that the algorithm strips away important contextual factors and reifies notions of a medicalized “transgender population”; (2) on an individual level, the reifications of “transgender” and “cisgender” enabled by the two-step algorithm enable assumptions about a patient that generate privacy-violating feedback loops and detract from the agency of and relationship between the doctor and patient; and (3) given the complexities, costs, and technical limitations associated with EHR infrastructures, research derived from this data may have a range of biases that work
to normalize medically trans and GNC identities against the “natural,” or nonmedical, cisgender binary identities.

B. **Emergent Discourse: The Trajectory of Transgender Population Health Research**

Scholars have illuminated how, in the post-Civil Rights era, public health advocates and researchers on the social margins deployed an individualizing approach—focused on special populations and categorical identities—as the basis for health promotion and biomedical research (Epstein, 2003; Krieger, 2012; Shim, 2000; Spade, 2011). Drawing on Wendy Brown’s work on state-centered feminism (1995), Stephen Epstein traces lesbian and gay health research advocates’ state-centered strategies—whereby health outcomes are attributed to individual-level traits and behaviors rather than state-based practices or the structural violence that emanates from them—to the political opportunism afforded by the simultaneous bureaucratization of biomedicine and the sexual liberation movement of late modernity (Epstein, 2003). Epstein, like Nancy Krieger, connects this strategy to more mainstream epidemiological studies from earlier in the twentieth century, such as the Framingham Heart Study and the British Doctors Study, that conducted population-based analyses and made inferences about the “average man” or the “normal majority.” That is, Epstein argues that this strategy extended mainstream approaches as a way to legitimize LGBT research methods but also to justify the need for its existence. For example, federal agencies began to fund cohort studies and randomized controlled trials consisting of samples of lesbian or gay persons rather than simply heterosexual men or women.

1. **From community needs assessments to the meta-analysis**

Transgender health research emerged in the 1990s also using categorical identities as its basis. However, lacking a sampling frame and comparable funding streams, these studies—
often in the form of community needs assessments—were community-based (Hanssmann, 2010). These studies sidestepped inferences to a transgender population that larger studies could attempt and instead deemed the transgender population as “hidden” and “hard-to-reach” (Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Herbst et al., 2008). Namaste (2000) and others in the United States, like Dean Spade (2011) and Chris Hanssmann (2010), have identified these community-based frameworks as effective for health equity at the local level and as a way to center the needs of the most marginalized despite the categorical identity framework.

In 2008, Jeff Herbst and his colleagues at the CDC conducted a meta-analysis by pooling many of the aforementioned needs assessment studies done in the United States. Despite many methodological limitations, the meta-analysis has since been taken up as a more legitimate transgender health research method than community needs assessments. Pooling numerous smaller studies, the meta-analysis enables researchers to make inferences about a transgender population without having access to a sampling frame—that is, a standardized way to define and to estimate the total number of transgender persons. Transgender HIV prevention researchers have used the meta-analysis to demonstrate an association of high HIV prevalence with transgender populations in the United States as well as globally (Baral et al., 2013; Herbst et al., 2008; Operario, Soma, & Underhill, 2008). These meta-analyses, however, suffer from sampling bias whereby the studies selected for pooling have drawn their study samples primarily from street-based sex workers; while many trans persons, particularly young trans women of color, engage in sex work to survive, many do not. To make inferences about a transgender population and declare extraordinarily high odds of HIV prevalence for an entire population helps to create
and perpetuate stereotypes tied to identity rather than, say, the structurally violent practices and policies, such as policing and employment discrimination, that may drive HIV.

Stephen Baral and colleagues’ meta-analysis (2013), for example, examines HIV risk for “trans women” globally. As shown elsewhere (Thompson & King, 2015), this analysis never defines transgender precisely and pools studies that collapse very different historical and contextual categories (e.g., transvestite, hijra, and transsexual) into one “transgender” measure. By pooling samples from 40 studies focused nearly exclusively on street-based sex workers, he and his colleagues conclude that the odds of a trans woman anywhere in the world having HIV is 49 times that of the general population; as others have noted (Bauer & Scheim, 2013), this estimate suffers from severe sampling bias. Curiously, the authors recommend further research on the pharmaceutical, pre-exposure prophylaxis (PrEP), as an effective intervention for “trans women” globally. This kind of population-level research can have coercive and even criminalizing effects on GNC persons and those who care for them, and it clearly flattens the meaning of transgender as it universalizes the associated high risk for having HIV.

2. **Surveys, surveillance, and electronic health records:**

   **The convergence of the two-step algorithm**

   Like lesbian and gay health research in the United States, transgender health researchers and advocates have embraced state-centered strategies that prioritize population health methods. This year the Williams Institute’s Gender Identity Inclusion in US surveys (GeniUSS), Group has issued recommendations for the funding of population-level transgender health research that incorporates the two-step question (see Table III) into national surveys as a way of effectively defining and enumerating a transgender population (The GeniUSS Group, 2014). The GeniUSS group states, “[The two-step] questions are a step toward making
transgender and other gender minority people visible and countable in nationwide surveys. Being countable—including our gender identity and gender expression—is an important step for having the resources we need to live healthy, safe, financially stable lives” (The GeniUSS Group, 2014, p. XV). Confessing and formally registering a marginalized, fixed identity, in this case in terms of gender, into surveillance systems becomes instrumental to one’s ability to access resources and, through that new visibility, also reinforces the fixity and normalization of binary cisgender identities that the “majority” registers.

Implementation of this measure in the nine national surveillance systems and surveys recommended by the GeniUSS Group may lend trans health research unprecedented economies of scale and efficiencies as well as enable inferences at the population-level. The danger, however, is that, like Baral’s meta-analysis, inferences devoid of context and specificity create reified and biased notions of “transgender” and the associated health risks. That is, while the two-step question defines who counts as transgender, it cannot account for the biases introduced by the instrument itself or the contexts from which the data are drawn. For example, White trans and GNC youth in San Francisco schools may have the specific literacy, awareness, and safety to answer the two-step question while their peers in California’s Central Valley may not. Furthermore, youth of color in San Francisco may not identify with the language of the questions compared to their White counterparts; likewise, they may not feel safe answering these questions. Thus, the two-step question may have reliability and validity problems whereby respondents interpret its meanings differently in different geographical or cultural contexts.
Table III Recommended Two-Step Approach to Enumerate Gender Identity

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<tr>
<th>GeniUSS Group's Recommended &quot;Two-Step&quot; Gender ID Measures:</th>
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<tbody>
<tr>
<td><strong>ASSIGNED SEX AT BIRTH</strong></td>
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<tr>
<td>What sex were you assigned at birth, on your original birth certificate?</td>
</tr>
<tr>
<td>__ Male</td>
</tr>
<tr>
<td>__ Female</td>
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<tr>
<td><strong>CURRENT GENDER IDENTITY</strong></td>
</tr>
<tr>
<td>How do you describe yourself? (Check one)</td>
</tr>
<tr>
<td>__ Male</td>
</tr>
<tr>
<td>__ Female</td>
</tr>
<tr>
<td>__ Transgender</td>
</tr>
<tr>
<td>__ Do not identify as female, male, or transgender</td>
</tr>
</tbody>
</table>

**GeniUSS Group's "Promising Measure" for Current Gender ID Step in "Two-Step" Approach**

<table>
<thead>
<tr>
<th>CURRENT GENDER IDENTITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your current gender identity? (Check all that apply)</td>
</tr>
<tr>
<td>__ Male</td>
</tr>
<tr>
<td>__ Female</td>
</tr>
<tr>
<td>__ Trans male/Trans man</td>
</tr>
<tr>
<td>__ Trans female/Trans woman</td>
</tr>
<tr>
<td>__ Genderqueer/GNC</td>
</tr>
<tr>
<td>__ Different identity (please state): _____________</td>
</tr>
</tbody>
</table>

(The GeniUSS Group, 2014, p. V)

This reliability problem, in addition to others not applicable to surveys, will present itself in the healthcare context where patients’ decisions to disclose their gender identity may vary according to a number of factors, such as the nature of their clinical visit, their coverage, and their level of safety. Clinicians, too, may assign diagnoses to transgender people variably and based on contingent contextual factors such as HIV status (e.g., diagnoses and genders may have to be adjusted to qualify for the AIDS Drug Assistance Program and Ryan White Part B), type of
insurance (e.g., diagnoses and genders may have to be adjusted to qualify for one’s veterans benefits or Medicare Part B), level of “outness” as transgender in the world, as well as their particular relationship with a patient. For example, a recent cohort study (G. R. Brown & Jones, 2014) used EHRs to measure breast cancer incidence in the largest US sample of transgender patients to date. Using the Veterans Health Administration data of 5,135 transgender veterans, researchers found that transgender veterans, both female- and male-assigned-at-birth, do not have a greater incidence of breast cancer than the general population. While the sample size is truly impressive, a limitation that the authors do not recognize is that nonbinary and/or nonmedically trans persons are almost certainly severely underrepresented in the sample since diagnostic codes of gender dysphoria determined inclusion. Additionally, the current lifting of the ban on trans military inclusion is limited to medically transitioning, binary-identified trans people (Meronek, 2014). Emphasizing the need to assess the impact that cross-sex hormone use has on breast cancer incidence, the authors need to specify their sample more precisely and recognize the selection bias that the research question and the VA dataset itself introduce.

Like the GeniUSS Group, transgender healthcare research and policy advocates have recommended implementation of the two-step question in EHRs. Ostensibly, their approach, which sometimes offers a nonbinary or genderqueer option, helps identify nonbinary transgender people in addition to binary trans persons. Leading transgender health researchers, advocates, and even clinicians have issued lessons learned and recommendations to collect SOGI data via intake forms (i.e., as demographic information) and EHR databases (Bradford et al., 2012a; Cahill & Makadon, 2014a; Callahan et al., 2014; City and County of San Francisco Department of Public Health, 2013; Deutsch et al., 2013; Ingraham, Pratt, & Gorton, 2015). Although recently Cerf (Harris, 2015) linked the 2010 Census to the Social Security database to try to
determine a sampling frame of the transgender population in the United States, EHR databases and the linking of them have also emerged as a possible means for deriving a sampling frame and enabling population-level research (Cahill et al., 2014). Advocates are proposing transgender health research exchanges—such as TransNet, envisioned by researchers and clinicians at the University of Minnesota’s Program in Human Sexuality. They note, “The integration of clinical and research capabilities into EHR will allow the development of clinical effectiveness research, ultimately on a large scale using a collaboration of practice-based transgender research networks similar to how DARTnet operates for primary care research today” (WPATH, 2014, p. 44). The vision is that pooling trans record data from across the nation would generate sample sizes that become large and representative enough to justify inferences at the population-level. While this chapter’s empirical data analysis exposes problems with the reliability and validity of the data collected via the two-part question in medical settings, studies have found that the two-step question does capture a greater number of trans-identified persons than a single-step question (Conron et al., 2014).

Some of these articles acknowledge that privacy concerns due to histories of discrimination may limit SOGI disclosures and think resistance to disclose will attenuate with education and training of both patients and providers (see, for example, Cahill & Makadon, 2014). Another report acknowledges the problems that healthcare patient privacy concerns may introduce to this kind of data collection but ultimately dismisses them:

Privacy and confidentiality concerns are exacerbated by the increasing computerization of health records . . . the shift underway to EHRs (EHR) and health information exchanges (HIE) could dramatically improve healthcare, increase providers’ ability to determine the most effective treatments and advance health science. It also poses new threats to patient data. . . . However, with the development of proper standards for encoding medical information along with the development of best practices for how to manage a computer infrastructure . . . these threats are manageable (Bradford et al., 2012, p. 6).
Privacy and security literature, however, contradicts this claim. It has established that in spite of HIPAA privacy and security regulations, anonymized EHR data can readily be reidentified using publicly accessible datasets, if not outright stolen via hacking techniques (Ohm, 2010; Latanya Sweeney, 2002). Adversaries could more easily reidentify the anonymized health records that enumerate or capture trans identities via the algorithm. Due to the uniqueness of their gender identities, their diagnoses, and the small number of trans and GNC persons relative to cisgender ones, a transgender person’s de-identified health record would not at all guarantee privacy or anonymity if used for health research.

Jeffrey Johnson (2015) refers to EHRs as sociotechnical systems that constitute translation regimes; despite any standards for encoding or securing medical information, health records are not objective data collection instruments and storage spaces but have been programmed by particular persons and data governance protocols to capture information in very particular ways. A plethora of EHR users must also interpret these ways in a range of contexts such as military hospitals, patient portals in waiting rooms or coffee shops, or provider portals in exam rooms, reception desks, labs, business offices, and even remote locations like a clinician’s kitchen. Put differently, EHR data are unstable and contingent though they are often understood as discrete and fixed.

Another factor impacting this type of data collection and its governance pertains to the capacity of the clinic or healthcare provider. Research suggests that under-resourced clinics, where many trans and GNC persons seek care (Grant et al., 2011), may not have the capacity or organizational culture that enables EHR customization and detailed patient data collection (NORC, 2010). Indeed, community health clinics have unique resource challenges and IT constraints that may interfere with this data collection process (McAlearney et al., 2010). A 2012
IOM report advocating for the collection of gender identity and sexual orientation data in EHRs does not explicitly address from where the resources for EHR customization will come, nor does it draw any connections between EHRs and how their use will address or mitigate the discrimination and poverty that impact the health of trans people. Like the Fenway paper quoted above, it also provides no evidence for EHRs as an effective, reliable, and valid data collection mechanism for population-level research (Committee on LGBT Health, 2012).

In public health, the concept of the population is generally understood as an empirical fact that does not require theorizing but rather requires identification and enumeration. Nancy Krieger’s article, “Who and what is a population?” highlights epidemiology’s consistent failure to define precisely or acknowledge the contextual and relational ways in which populations emerge in and through scientific discourse (Krieger, 2012). Michael Stoto’s article, for example, “Population Health in the Affordable Care Act Era,” is a scan of all the “overlapping meanings of population health” but never does it or the works cited actually define population. Invoking the IOM, he implores,

To improve population health communities must establish and nurture partnerships that include but go beyond state and local public health agencies and health care delivery systems . . . this broad system of partners must share data and adopt a systems focus that identifies accountability for and measures contributions to population health outcomes (Stoto, 2013, p. 3).

Though clearly invoking the capacity for widespread sharing of “population” data beyond the original contexts of data collection, the lack of conceptual precision is what Krieger says may render means—and other key population-level statistics—meaningless (Krieger, 2012), and what Michel Foucault (Foucault, 1990, 2007) says leads to dangerous kinds of categorization and stereotyping for the purposes of management and control. That is, epidemiological methods render individual characteristics of a sample population, such as race, class, and gender, as fixed
categories and, through statistical processes, are linked to negative health outcomes. Baral and colleagues’ meta-analysis and conclusions typify this methodological problem. The data collection processes undergirding “population health” and “population health research” help to naturalize, or reify, certain identities as pathological or intrinsically unhealthy.

Janet Shim observes that this population health framework reproduces the health disparities it sets out to dismantle; she notes that typically non-White and poor traits are tied to additive risk factors for poor health outcomes while White and middle-class traits are regularly deemed protective factors (Shim, 2000, p. 179). Though researchers may regularly acknowledge or conjecture about the role of stigma and discrimination, reducing poor health outcomes to significant associations with race, class, and gender serves to essentialize inequality and health disparities rather than identify and highlight the roles of relational social processes such as structural or state violence. That is, the framework creates a kind of visibility through stereotyping whereby poor outcomes and health disparities get statistically tied to intrinsic traits of individuals rather than structural forces.

C. **Case Study Method**

This critique uses the case study method. The case study fosters theory development through a detailed analysis of a social phenomenon (Walton, 1992). The case study also enables exploration of concepts not yet validated or quantifiable and, historically, has contributed to understanding urban life and the integration of the social ecological resources (Hamel, 1993, p. 15). Most importantly, it is a method that refuses “to accept visible social relationships as ‘the’ social reality” and rejects empirical assumptions (e.g., that gender is binary) (Levi-Strauss in Hamel, 1993, p. 30). This critical approach (Greenhalgh et al., 2009), rather than a positivist,
grounded theory approach, uses conceptual interventions to question and disrupt state-based transgender health research strategies and surveillance apparatuses.

Experiences articulated by study participants—researchers, patients, and clinicians, alike—are not the point of departure; theoretical and conceptual frameworks—explored via case study—aimed to identify the logics that undergird the social realities that participants may express (1993). Cases manifested larger social phenomenon operating locally and particular to specific contexts. Drawing on Smith’s ethnographic approach (2005), I centered the particular experiences and knowledges of key stakeholders such as clinicians and patients within conceptual and theoretical frameworks to understand the impacts of healthcare institutions and their EHR administrative systems. This horizontally oriented method avoids privileging top-down understandings of healthcare and its institutions, systems, and practices.

1. **Study sample and data collection**

   The sample consists of 27 key informants and 30 trans and GNC focus group participants, all considered stakeholders in healthcare for transgender and GNC healthcare and users of the EHR infrastructure. In addition to their narratives, I use textual materials such as clinic intake forms and waiting room materials, policy briefs, blogs, and media representations in my analysis. As a transgender person who actively advocates for improved access to healthcare for transgender people and who actively seeks transgender-related medical care, I also drew upon some of my own experiences and participant observations to inform and interpret the study data. The IRB at UIC approved the research.

   a. **Key informants**

      Inclusion criteria for key informant interviews were being at least 18 years of age, and having worked in a position related to trans healthcare for at least one year.
Clinicians had to have worked directly with transgender patients while non-clinicians, with the exception of health IT staff, had to have worked on policy, protocols, research, or services related to trans health. Health information technologists were not required to have worked directly on trans-related healthcare matters. Email invitations were distributed to key informants based upon recommendations from other key informants or published literature or policy briefs authored by potential key informants. Interviews were semi-structured, one-on-one, and lasted about one an hour on average. There were no financial incentives or compensation for the interviews.

I conducted all interviews, each about one hour in length, between August and November 2014 (plus an additional one in April 2015) in six major urban US cities considered to have significant transgender communities and some of the most well-established transgender healthcare. Purposive sampling (Silverman, 2001) was used to prioritize informants from various leading provider institutions for recruitment as standards and protocols for transgender-related healthcare in the United States tend to emerge, in part, from these leading providers. Leading provider institutions tend to be clustered in three geographic regions: the Northeast, the West coast, and the Midwest; no informants were either available or recruited in other regions. With the exception of six via telephone, these in-depth interviews were conducted face-to-face, typically at the key informant’s office, audio-recorded, and transcribed verbatim. Field notes and memos were written following interviews and during the coding process as well.

b. **Focus groups**

Inclusion criteria for focus groups consisted of the following: (1) 18 years of age or older, (2) self-identifying as trans or GNC for one year or more, and (3) the ability to speak English. Focus groups were conducted in Chicago, Illinois between October 2014 and
January 2015. Recruitment occurred via ads posted at local provider sites, social spaces, and one virtual social space, Facebook. Focus groups lasted approximately two to three hours and included sharing a meal or snack together first. Participants received $30 compensation for their contribution to the research.

c. **Interview and focus group protocols**

Key informants were asked to describe their EHR system and how it impacted care for their patients. Navigation, content structure, classification fields, diagnostic codes, clinical decision supports, and privacy and security features were reviewed and reflected upon. Because many providers had only recently implemented systems, we also discussed comparisons with previous paper or electronic systems. Some key questions were: (1) Can you talk about how the system logs gender/legal and preferred name/sexual orientation from intake to clinical encounter to billing? (2) How has this system enabled or prevented the identification of trans patients? (3) What diagnostic codes are used for trans and GNC patients? (4) Who can access patient data at the clinic? And how, if at all, are EHR data segmented according to user-defined roles? Where are data stored? What kind of authentication system is used? What access control models are in place? And (5) How, if at all, are the EHR data used or useful for research or building health research exchanges?

Focus groups centered on the intake process, including sample intake forms, and clinical visits as patients. Questions emphasized decisions around disclosure of one’s trans or GNC status in healthcare settings as well as other settings such as social media, employment, and family. Some key questions were: (1) would you feel comfortable and/or safe completing this intake form? What do you think about the “patient information” section? How do you like the two-step question regarding gender identity versus the single item question? (2) If you have used a patient
portal, can you describe that process? (3) How do you decide to disclose your transgender status in different healthcare settings? (4) Have you ever gone to a different doctor who seemed to have access to the information you gave another doctor? How, if at all, was that helpful or harmful? How do you feel about different doctors, nurses, or other staff having access to the information you give to your primary care doctor particularly around your gender? And (5) what do you think about researchers accessing and using de-identified medical records for trans health research? Would you be okay if you and everyone else in this room were counted as transgender women (or transgender men)?

2. **Analysis**

Transcripts were managed and coded using ATLAS.ti (version 1.0.16 (82)). Coded transcripts were analyzed for common themes, and Lund’s analytical matrix (see Table II in chapter IV) was used to organize observations (Lund, 2014). As events, patterns, and concepts emerge from the coding process, analytical matrices are constructed and iteratively analyzed with respect to other cases that resonate “from different localities or different times, or both” in order to extend relevant theory (Lund, 2014, p.226).

The coding process began with the selection of six key informant transcripts and one focus group, chosen to capture a cross-section of stakeholders. This process generated more than 100 codes. The key informant codes were organized into five categories: databases, classifications, trans healthcare, privacy, and security. Focus group codes were organized into four categories: disclosure/privacy, gender identity and classifications, access to care, and perceived discrimination/safety. The remaining transcripts were coded according to existing codes. The coded data were imported into four groups and reviewed iteratively in order to identify patterns and concepts related to surveillance and trans healthcare in the context of EHR
implementation. To help synthesize reflections, observations, and interpretations, field notes were taken following interviews and focus groups, and memos were taken during the coding and analysis processes.

D. **Results**

1. **Sample characteristics**
   a. **Focus groups**

      Focus group participants (N=30) represent a cross-section of trans and GNC persons in Chicago (see Table IV). Though not representative or comprehensive, participants were in various stages of their medical and/or social transitions, and their ages ranged from 19 to 73 with a median age of 30.5 years. Participants identified primarily as Black (33%), White (30%), Latina (27%), or mixed race (10%). Seventy-seven percent reported sex-assigned-at-birth as male, but gender identities expressed during eligibility screening departed from a simple binary and included: trans man (3%), man (10%), agender or genderqueer (10%), trans woman (37%), and woman (40%). Participants also said that their gender identities shifted somewhat depending upon the context. Though most were open with Facebook friends about their trans or genderqueer or agender status, only two participants recalled having changed their Facebook gender to “trans” or “genderqueer” since the web site began offering more than 50 gender options in 2014.
Table IV. Sample Characteristics of Four Focus Groups Conducted in Chicago, IL, 2014–15

<table>
<thead>
<tr>
<th></th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=11</td>
<td>n=7</td>
<td>n=9</td>
<td>n=3</td>
<td>N=30</td>
</tr>
<tr>
<td><strong>Sex Assigned</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
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<td>3</td>
<td>9</td>
<td>0</td>
<td>23</td>
</tr>
<tr>
<td>Female</td>
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<td>4</td>
<td>0</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td><strong>Current Gender ID</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male/Man</td>
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<td>2</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Female/Woman</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>12</td>
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<tr>
<td>Trans Male</td>
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<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Trans Female</td>
<td>7</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Nonbinary/GQ/Agender</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Race or Ethnic ID</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
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<td>0</td>
<td>7</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Latina/Hispanic</td>
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<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Mixed Race</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Age (Mean, SD)</strong></td>
<td>(34.4, 13.6)</td>
<td>(28.7, 6.1)</td>
<td>(32.6, 15.9)</td>
<td>(46.0, 17.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Jobless in Last Year</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td><strong>Highest Level Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&lt;High School Grad</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>HS Grad/GED</td>
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<td>0</td>
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</tr>
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<td>Grad Degree</td>
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<td><strong>Health Insurance</strong></td>
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<td>7</td>
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</tr>
<tr>
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<td>0</td>
<td>6</td>
<td>1</td>
<td>13</td>
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<td>Private</td>
<td>1</td>
<td>7</td>
<td>3</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>
b. **Key informants**

Key informants (see Table I, chapter IV) held a range of positions in clinics, hospitals, public health systems, research centers, and a medical technology company. More than one-third (n=10) of key informants were trans or GNC, and one-third was POP (n=9). There were eight different EHR systems used among the 27 informants.

2. **Focus group analysis**

In sum, participants expressed caution and skepticism about disclosing gender identity information at intake. Their concerns emphasized personal safety, discrimination, their insurance coverage, and whether or not that information was relevant to all clinicians or staff or others who may have access to the data. Because they found it might create barriers to care or jeopardize personal safety, participants said their willingness to disclose depends upon the context and having that information fixed and easily accessible in the demographic section of an EHR may dissuade them from disclosing.

Participants explained how data generated by algorithms such as the two-step gender identity algorithm could create privacy-violating feedback loops and/or stereotypes. For example, a nonmedically transitioning, genderqueer (i.e., GNC) participant noted the barriers to care that can emerge when doctors use gender identity data to guide their care:

> I think [intake form] questions about your sexual orientation, your gender identity, and to a certain extent sex-assigned-at-birth... don’t tell a lot about me and my body and my health and the situation that I am in right now. The assumptions they are working on are going to feed everybody and in medical situations... that might not be healthy for me, and they put me at risk (Focus Group #2 participant).

Focus group participants expressed the desire to feel understood and respected by their clinicians as well as other staff in these settings. Some felt the very presence of the questions on intake forms, as well as the answers entered into the EHR system, would increase trans awareness
among staff and even other cisgender patients. However, even binary, medically transitioning trans persons who used the LGBT clinic complained of doctors making assumptions around their sexuality that they presumed were based on their gender identity. A White trans man said that his doctor assumed he was not in need of STI testing because his primary partner at the time was a cisgender female; at the time, though, he had multiple partners of multiple genders. Conversely, a trans woman of color said her doctor did not believe her when she reported her safer sexual practices. In other words, despite the experiences of the patients themselves, the doctors operated on assumptions that White trans men are not at risk whereas trans women of color are without asking the right questions, having the important conversations, or listening to the voices of patients.

Some tension in discussions emerged around why gender identity and related demographic information is collected—whether it is directly relevant for care or if it is primarily an instrument to generate funding or research. One of the four participants who reported working in trans healthcare shared her experiences with data collection and how clinics use it:

Sometimes, these can be a little fucked up with some of the questions. However, I feel like this information . . . helps break all that down for people like the doctors and stuff when they come in . . . before they come in with their participants or their clients or whatever, and they see all this . . . That's why they ask you medical history stuff and childhood stuff, family history background and stuff like that. It's just so they could be briefed on it (Focus Group #3).

She articulated that this data collection process by staff may be intrusive, asking personal questions not only about gender identity but also related to childhood and family histories, in order to prepare clinicians for appointments. Participants who worked and volunteered in the field of transgender healthcare articulated the messaging that comes from their employers and advocates—that being visible in healthcare settings, including intake forms, is important for trans equality and access and that disclosure improves quality of care and providers’ abilities to
advocate and generate trans-focused funding. In addition to her optimism for trans visibility, one healthcare worker felt like this kind of data collection can distract from, rather than enhance, clinical effectiveness. She described a kind of profiling process during intake as a prerequisite to access HIV testing. She explained,

I do the same shit every day on the computer. When some of the girls come to have an HIV test, we have to ask them questions . . . ”How much do you make? How many people live in your house?” I had a guy tell me, “Are you gonna do an HIV test, or do you wanna know my whole [expletive] history?” . . . It’s ridiculous . . . I have to waste 20 minutes on every single person . . . I don’t give a damn if you live with a rat, a doper, if you live with another person. It has nothing to do with me giving you an HIV test (Focus Group #1).

These settings enable providers to collect data on patient traits, such as gender identity, race, histories of abuse, or use of illegal substances, that researchers and funders can model as variables and then measure associations with HIV status.

Although they thought it could be clinically beneficial, the groups expressed skepticism around the need to collect sex-assigned-at-birth information at intake. Participants’ objections to this data collection at intake suggest that responses indicating trans or GNC statuses could jeopardize access to care and personal safety depending upon how it is implemented; threats, whether perceived or actual, to access to care or safety shape one’s willingness to disclose one’s identity. The nonbinary participants, who do not identify with either binary gender, felt that disclosure of their nonbinary status in healthcare settings, and especially with a simple two-part question, would not resolve the confusion that they already encounter without disclosure. An agender participant, for example, said that disclosure can exacerbate confusion. “Part of that is knowing whenever I’m going into a medical setting I’m bracing myself for all of it . . . Using pronouns that I don’t identify with. It’s just become part of the medical experience’” (Focus Group #4). Even when doctors have the nonbinary gender identity information, they often do not
use it, or if they do, they misinterpret it and want to impose what they believe are gender-affirming medical interventions onto nonbinary, nonmedically trans patients (Focus Group #2 and #4).

There are also participants who actually do identify with the feminine side of the binary but may not always have the means to express it and so are perceived as nonbinary or gender fluid. One such person and her peers objected to the two-part question via intake forms and EHRs because she believed it would threaten personal safety and could be another source of discrimination and violence. Participants said that these questions were not appropriate for intake or demographic information as the answers reflect very personal medical history—sex assigned at birth. Another participant said giving this information at intake, where persons besides her doctor could access it, jeopardized her safety. “This whole sex assigned at birth, bitch, that’s not your business. Don’t ask me that . . . I got all these ignorant ass clinics, and they is messy . . . . As soon as you say—you come in dressed as female and you say I was born a male. . . . They’ll be like, ‘Oh sir or bro or all that type of shit’” (Focus Group #3 participant). Legally a female, she said that one receptionist threatened to call the police on her when she tried to use the women’s restroom at the clinic.

Similarly, when asked if they thought their de-identified medical record data should be used for research, responses ranged from enthusiasm to ambivalence to skepticism. Persons tended to agree that more health research is needed but were more ambivalent around how useful their own medical record data would be. Given perceived privacy violations that many had experienced in healthcare settings, some expressed concerns around their privacy. “I am anxious about over-access of records without safeguards. The problem is these [HIPAA] rules have more holes in them than a good block of Swiss cheese” (Focus Group #2 participant). Another person
noted that signing HIPAA agreements during an already very anxiety-inducing intake process feels coercive. That is, he had no idea until reading the privacy policy of his provider during the focus group that his medical record data was available for research. Participants suggested that a more clearly marked statement regarding how records will be used beyond the clinical setting and an opt-in (for EHR research) mechanism may resolve some of the problems around using healthcare record data for research.

3. **Key informant interview analysis**

Approximately five informants were affiliated with clinics that had implemented the two-step question and incorporated the data into their EHR system, but most were aware of it as an alternative approach to a single question, and that it may soon be implemented in their own clinics. While many agreed that it more accurately can capture trans-identified patients and could help with cultural competency, most also expressed reservations about the capacity of the EHR systems (and its users), as well as their provider organizations (e.g., data governance policies) to use gender-identity related information in ways that did not also create barriers to effective caregiving. With the exception of one policy official and some informants from well-resourced provider sites, for example, many felt that conducting research with this information may have implications for patients’ ability to access care and clinicians’ ability to give it. Put differently, key informants recognized that gender identity-related algorithms, like two-step question or the diagnostic codes, create different levels of visibility of gender identity, including some kinds of invisibility.

a. **Effectiveness of two-step method**

The two policy officials along with two informants, whose clinic had already implemented it, felt strongly that the two-step question will generate better data in terms
of numbers. One policy informant found that only 13% of the trans persons in their system identified as trans when responding to a single-step question about gender identity (Key Informant #8). The other policy informant reported that the trans patient caseload has tripled at their institution in the last three years, which was the point at which the provider implemented the two-part question at intake (Key Informant #23). For these officials, higher patient counts translate into greater trans visibility. An informant whose clinic had already implemented the two-step question noted,

The Feds are caring more and more about capturing data . . . and they’re really starting to realize that historically they didn’t even have the data to back up how marginalized certain populations are within our community. And so that’s the next big push . . . They can make their systems count every other population—you know, like the homeless and HIV positive, why not transgender too? (Key Informant #3).

An increased visibility ostensibly enables increases in funding for care, training, research, and, ultimately, the Feds say, improved health outcomes (U.S. Department of Health and Human Services, 2010).

At the clinic level, capturing gender identity offers an opportunity for unprecedented quality improvements. An example given was clinic data might show an overall Pap smear screening rate of 98%. When disaggregated by gender and race, however, the data may show that White cisgender patients have a 100% screening rate while Black patients, both trans and cisgender, lagged behind at 60%. This informant reported that their clinic intervened on a similar disparity by hiring more Black and Latina trans-feminine patient navigators to help follow and retain patients for improved screening rates.

Such quality improvements may only emerge in clinics that have the capacity for staff training in cultural humility and to incorporate and analyze data from the two-step algorithm along with other intersections of patient demographics and health indicators. Many clinicians, at
both wealthy research hospitals and under-resourced public health clinics, reported varying
degrees of staff cultural competency training (from none to intensive). Most also reported that
their clinic would not likely incorporate this algorithm any time soon due to so many competing
priorities.

Finally, some key informants noted that the two-step algorithm is not failsafe. Even if a
patient has responded in one way, a clinician may change the response based on his or her own
assessment, and another clinician may change it based on theirs. One therapist, who works with
youth whose gender identities tend to be very dynamic, explained,

[Patients] tend to stay in the ‘T’ pool. There’s no great system for deciding who checks
the T box, who unchecks it, and under what circumstances it would get checked or
unchecked. The patients could request to have it changed . . . but then it’s entirely
possible that someone could uncheck it upon patient request and then another provider
later would be like, “Oh, why isn’t this T checked?” and they would check it again. The
rules around it are so vague (Key Informant #2).

A researcher echoed this dissatisfaction with attempts to encode gender identity into the record:

“Providers want to be able to provide gender-affirming care, but acknowledging that gender
identity is ongoing and not just static at one point in time—that does not get picked up (Key
Informant #1). These informants recognize that the inability to capture the dynamism or fluidity
of some patients’ gender identity and the imposition of fixity may denigrate the accessibility and
effectiveness of care for some patients as well as the integrity of the data itself.

A policy advocate suggested that gender self-determination beyond two or three trans-
related categories (e.g., trans masculine, trans feminine, and gender queer) simply is not practical.

He said, “There is a lot of variation within our communities, and what we try to do is find what
works for the vast majority of people and helps us get the information we need” (Key Informant
#23). This normalizing strategy (i.e., doing what works for the majority) makes certain kinds of
trans persons more visible—medically transitioning, for example—through the erasures of others such as agender or gender-fluid persons.

b. **Differing provider capacities**

Provider capacity is affected by a number of domains—data governance policies, the technical limits of EHR systems themselves, staff capacity, and then broader questions of economic viability in the face of healthcare reform and regulations. I met with some clinicians, for example, who used the best EHR available, called EPIC (Verona, Wisconsin), and had access to health IT teams to assist them with customization and running quality improvement reports. Some clinicians who use EPIC, however, still express great frustration with EPIC and their provider’s unwillingness to expend resources to address customization of data fields specific to trans healthcare (e.g., the two-step gender algorithm and preferred names and pronouns). Most informants did not have access to an EHR like EPIC; they tended to work in severely under-resourced settings using very clumsy systems that had less capacity for customization let alone the staff to implement customizations around gender identity. A wealthy provider may have the system, data governance protocols, and the staff training in place to capture trans identities and a range of nuanced diagnoses, but others may not.

Related to data governance, key informants pointed out technical limits that may create privacy-violating levels of visibility for trans patients: “Whether it’s HIV care or trans care, when you’re dealing with a community-based health center, um, you know, there are resource issues” (Key Informant #20). Two informants, a researcher and quality improvement analyst, for example, work at under-resourced clinics. Neither knew how to de-identify the records that they needed to analyze; that is, they had full access to patient EHR data, which, for them, was too much patient information. For this reason, another data compliance coordinator at a different
The clinic explained that they try to collect as little information as possible. Many EHR systems either do not have the mechanisms to protect different aspects of patient data from different types of users, or, if they do, the provider may not have the IT staff available to program the segmentation according to different users or run de-identified reports with selected variables.

The ACA and EHR implementation have created immense regulatory hurdles and financial expenditures for providers that also impact capacity for effective data collection. These challenges disproportionately impact small, under-resourced providers that may have more cultural humility than some of the larger, wealthier providers but do not have the economies of scale to absorb the costs of these systems nor the staff capacity to keep up with the regulations. One informant, who compared her and her colleagues’ workload to years of running on a hamster wheel, reflected on a recent community clinic’s merger with a larger corporate entity: “I do think [the merger] is part of a trend. All of the ‘experts’ say that smaller clinics just won’t survive. I can tell you as somebody who has been trying to survive, it’s just—you cannot afford—the amount of person power that you need to legally stay on top of everything” (Key Informant #3).

With expanded coverage for transgender people under the ACA, clinic staff often has to spend inordinate amounts of time advocating for patients’ legal rights. According to several informants, medical coverage is regularly (and unlawfully) denied. Payers deem trans-related claims as fraudulent and divert bills to patients because they have not kept up with the new laws and coded transgender medical benefits into their systems. Additionally, informants consistently reported struggles keeping pace with meaningful-use requirements and deadlines, adherence to which guarantee subsidies to help defray the immense costs of EHR systems. For example, many informants said that health IT teams at their sites were preoccupied with programming the new
ICD-10 diagnostic classification codes rather than helping with gender identity-related data problems. In other words, regulations—whether for coverage or for data collection—have social and economic impacts upon providers and their patients.

A researcher’s experience with collecting EHR data—a set of specified variables—from several clinics every six months for a national study bore out these observations. Many of the clinics participating in and receiving funding for the study did not have informatics staff or any capacity for pulling reports from their EHRs, no encrypted emails, not even a fax machine. To follow a small cohort of trans patients in that city, this researcher had to hand-deliver releases of information documents and create the reporting instruments in excel for these clinics herself. At one clinic, staff was unable to locate two of the HIV-positive trans patients in their system. The informant noted, “The challenges are identifying who is trans in the record. You have this disappearing effect, you know, what do they call it? ‘Erasure’— where you just you can’t identify who people are.” (Key Informant #20). At another clinic, a patient could no longer be followed while she was incarcerated. In this light, it is unclear how a two-step algorithm would resolve the multitude of resource problems that clinics face; to reiterate, stigma and violence also contribute to the invisibility of patients in records and to a missing data problem.

c. **Provider versus covered entity algorithms**

Another layer of complication to the EHR infrastructure and patient data is that many users (i.e., what HIPAA refers to as “covered entities” and “business associates”), not just clinicians and patients, require access to patient data. The databases of these users—insurers for example—may have different algorithms than the two-step one that define gender. While the ACA increased coverage for transgender people, the conflicts around how to count, define, and
make visible trans people may also have created new privacy problems and new barriers to access coverage, care, and to generate meaningful statistical estimates derived from EHR data.

A policy official explained how, with the ACA, so much more PHI is shared with entities beyond the provider, and that Medicare and Medicaid may end up determining what aspect of gender identity will be accessible to covered entities and collected as a demographic:

Gender is a little trickier because gender is a mandatory reporting demographic. Sexual orientation, definitely, [patients] can opt in to answer, or refuse to answer—whatever. But . . . the source of it is going to be in the health plan, Medicare and Medicaid. . . . It used to be that so many of our patients weren’t covered. So, we were the only ones who were going to be the holder of that information—that demographic piece of information. Now it’s all being done by the coverage (Key Informant #8).

Even within one well-resourced infrastructure, a health IT specialist noted, algorithms to capture gender might vary. He explained, unironically, “A natural gender-based rule is sort of specific to different companies. Rules differ from one organization to the next and even within plans within one insurance company. If they offer like three or four plans, they could have different rules within those different plans” (Key Informant #18). Researchers, payers, clinicians, and patients all use EHR data differently and define categories like gender differently.

The same health IT specialist explained that because EHR infrastructures hold and move so much information, these systems typically use gender as a way to reduce the energy required to find or move data and as a way to reduce human error. An EHR system at a large hospital or healthcare system often blocks clinicians from ordering procedures for the “wrong” gender, such as Pap smears for men and prostate exams for women, which have been encoded with gender in the system. With inconsistent and greatly varying capacities for organizing and communicating information within and across systems due to staffing, data governance, and/or EHR software capacity, EHR systems generate data that may not be as robust or have the same rigorous
integrity as data generated from a more reliable instrument such as identical scales that have been calibrated across labs according to standard protocols.

E. **Gender Identity in Electronic Health Record Data: The Visibility Trap**

The trans visibility emerging from EHR data then differs from the kind of community-generated visibility Vivian Namaste was calling for in the 1990s. Visibility derived from state-sanctioned EHR algorithms—and one day soon perhaps, standardized algorithms—erases important contextual concerns of communities and the gender self-determination of individuals. Medicalizing gender variation and diversity in a way that reduces it to a few trans categories also helps erase the gender diversity not only across the trans spectrum but also that of the cisgender spectrum. In medical settings, POCs and nonbinary persons may not feel safe answering the two-part question when they understand that any number of EHR users—from clinicians to intake staff to pharmacists—may not know how to interpret the data and may act on dangerous stereotypes, also known as privacy-violating feedback loops. Although the algorithm may work for the “vast majority” of trans patients at an LGBT clinic in a major city, compelling this kind of visibility may create danger rather than liberation for many others, even including some at the LGBT clinic. When clinicians, researchers, policymakers, and payers and other stakeholders use this kind of discrete data rather than interpersonal relationships, dialogue, and a breadth of knowledge, the approach reinforces these privacy-violating feedback loops and discourage trans and GNC persons from accessing care.

Similarly, with the use of EHR data for research, structural and contextual knowledge cannot be modeled from EHR data. Pooling data from personal health records means yet another way to individualize health outcomes, such as HIV or severe depression, in a way that links them
to trans identities rather than, say, the brutal effects that incarceration has on a range of social identities (e.g., POCs, poor people, immigrants, homeless persons). Although studies have shown the two-part algorithm expands the identification of transgender patients, it flattens and reconstitutes identities in order to examine its links with particular health outcomes. As others (Foucault, 2007; Krieger, 2012; Shim, 2000) have shown, these methods create “natures”—reifying types of individuals grouped into populations that are then managed through interventions that address those intrinsic qualities or unique behaviors; that is, the burden of change is placed on individuals rather than social structures.

Like Stephen Epstein’s observations about LGBT health research in the 1990s, advocating for EHR-based research dovetails with the current economic and social interests (i.e., the ACA and its expansion of information technology infrastructures) of the state and, in this case, payers and their ever-expanding surveillance apparatuses. In fact, LGBT advocacy and research institutions that depend on state funding to sustain themselves are eager to conduct population-level studies and recommend gender-affirming, medical, and pharmaceutical interventions that expand the medico-pharmaceutical industrial complex. Clearly, population-level research may impact access to gender-affirming medical interventions; the concern here centers, both ethically, methodologically, and epistemologically, on the potential feedback loops, harms, and erasures that research may create for the most marginalized but also the “majority” in a community as one informant continued to cast the issue.

With EHRs there are added layers of complication around interpreting data derived from them; widely ranging clinic and EHR capacities shape what data are entered and how they are used and shared. The EHR data may appear objective to earnest public health researchers and advocates, but focus group participants and key informants alike spoke to the ways in which
contextual and technological factors impact the effectiveness of the data collection instrument and, subsequently, the statistical processes it enables. Patients and clinicians understand these contingencies, and how they impact patient privacy and what patients and clinicians enter into the EHR. Those factors have not been prioritized when considering potential biases for research and negative impacts upon patients and access to care.

This exploratory study gives voice to a range of stakeholders, including trans and GNC patients, and calls attention to the contexts for the collection of gender identity-related health data in EHRs and how these contexts impact these measures and their various uses, including research. The stakeholder narratives point to many forms of bias that may emerge from attempts to conduct population-level research, let alone clinic-level quality improvements, with EHR data. Although the two-step question does the important work outlined by Krieger (2012), attempting to define transgender more precisely than with a single question, the two-step question in this setting comes with numerous limitations that introduce bias to data derived from it. First, there is selection bias at the individual level. As participants noted, threats and acts of discrimination and violence at clinics may prevent their disclosure whether via patient portal, paper form, or directly with a clinician or staffer. Focus group participants of color and nonbinary White participants in particular said they do not and would not always disclose their trans status at intake as they feel that disclosure may only be relevant to their clinician. Nonbinary participants did not think it was relevant to their providers at all as they were not medically transitioning and only felt more vulnerable when disclosing to staff or clinicians who did not know how to interpret or respond to their disclosures appropriately.

Selection bias may also occur at the clinic level. Though the two-step question may be mandatory at some point, most community clinics currently do not have the resources to
implement the gender identity algorithm in their EHR systems. In fact, informants from larger and wealthier systems did not think their provider would devote the resources to this work soon either given competing priorities, like ICD-10, that affect more or all patients and not just a few. Currently, only clinics with large enough trans patient censuses and enough financial and technical resources are collecting gender identity data in their EHR systems.

Finally, there may also be instrumentation and measurement bias. Because data governance and protocols vary by clinics, the backend of EHRs could vary in the translation of the two-step algorithm. Additionally, clinicians and staff may modify data in the EHR based on their own translation of a patient’s identity. The City and County of San Francisco (City and County of San Francisco Department of Public Health, 2013) have issued a policy to collect gender identity data via the two-step algorithm across their clinic system but even there, implementation and enumeration may vary because clinics have a wide variety of funding mechanisms and reporting systems guiding their practices that impact the ways patients get counted in each system.

One informant assured me that staff cultural competency trainings will address the issue around patient resistance to disclosure, but that strategy only addresses aspects of the selection bias at the individual level and not the other forms of bias. Cultural competency training will not account for selection bias at the clinic level, for example. Plus, cultural competency training does not occur nonrandomly either. The financial and temporal costs associated with it prevent many clinics from conducting adequate cultural competency training. Focus group participants, such as trans persons who were not medically transitioning, did not seem to think that increased cultural competency would induce them to disclose their trans experience, history, or identity, particularly if they did not feel that information was pertinent to their visit.
There are other ethical concerns related to safety around disclosure. Participants expressed resistance to disclose their identities to staff as well as clinicians due to privacy-violating feedback loops. The nonbinary patients, for example, were resistant to disclose because when they did, they felt like their appointments were derailed by the doctor or nurse’s inappropriate medical assumptions (as well as mis-gendering) about their bodies and their health. Medically transitioned participants also reported instances of voyeurism and inappropriate treatments based on assumptions about transgender people and their health. Beyond the focus groups, there are indications (Epstein, 2003; Foucault, 2007; Shim, 2000; Willse, 2008) that population-level research, through its methodological linkage of identities to health outcomes and medical interventions, will exacerbate rather than mitigate these kinds of feedback loops. For example, the findings of the Baral et al. piece (2013), that a global population of trans women has a 50 times greater odds of HIV prevalence than the general population, are now permeating popular and mainstream media stories about trans women in the United States (despite the study’s samples consisting almost exclusively of street-based sex workers).

The top-down, algorithmic approach to healthcare denigrates the agency between patient and doctor and, through the positivist research, leads to inferences about what constitutes trans identities and the health risks associated with it. Coercive feedback loops about who and what counts as transgender may create new barriers for accessing care and other necessary services for the most marginalized. As Chris Hanssmann has shown in his work, “Transgender is a provisional, contextual, and mutable term to describe identity and experience; it is challenging to gather meaningful data using it as a stable analytic category” (Hanssmann, 2010, p. 555). These attempts at categorical fixity and stability through algorithms prove useful and beneficial for certain kinds of research and the expansion of the health research industrial complex— as
Epstein has shown with state-based health research on sexual orientation—but they also limit the knowledge generated, and the relationships between patient and doctor.

Stakeholders might reduce the possible harms of EHR data (and population-level research) in a few ways. First, recognize that the statistics derived from EHRs do not reflect the “transgender population.” Given the biases, statistics drawn from these kinds of data require more specificity and more cultural and methodological humility. Labuski and Keo-Meier observe that in health research “‘trans man’ might constitute a proxy for something far more specific and amenable to measurement: ‘people assigned female at birth taking exogenous testosterone at X dose. …’” (Labuski & Keo-Meier, 2015, p. 27). Using their example, inferences about a population of transgender men, rather than one of people assigned female at birth taking testosterone, erase the diversity of bodies and range of technological interventions and transition experiences (i.e., medical and nonmedical) and work to reify and “fix” a category that is very dynamic and unstable. This kind of specificity in research will also serve clinicians and patients well in reducing harm to patients generated by feedback loops. The drive for funding and publications may deter discussions of limitations, but researchers must explicitly identify the biases that limit the results and interpretations of the data.

This exploratory study is not without its own limitations; the data are based on self-report and not actual measurement of EHR keystrokes or observation of EHR user experiences and patient intake form completion and submission. The key informants are a sample of stakeholders working at the leading edges of the field rather than ones who have little experience with trans patients and their care. Stakeholders in one eastern city were less responsive, though still represented, compared to other cities in the sample. A number of clinics in other major cities are not represented. The key informant pool that I recruited and those that chose to respond to my
recruitment surely were influenced by my own ties to the field of transgender health research as well as transgender healthcare. As the sample characteristics reflect, the focus groups were a cross-section of various trans and GNC persons whose identities intersect with other aspects of more-or-less marginalized social positions in Chicago. The focus groups, however, did not have voices from various racial intersections such as Asian American and Arab American experiences. Finally, my own experiences navigating transgender-related healthcare and transgender health research over the last fifteen years have influenced my questions around and interpretations of this research problem.

The panoptic-like architecture of EHR systems fosters a surveillance of not only patients but also virtually all who engage the system. Backend analytics serve as the building blocks for constructing and regulating populations of EHR patients as well as users—physicians, nurses, therapists, social workers, pharmacists, patients, billing administrators, registration staff, and health IT staff. This architecture may have a chilling effect on both patient and clinician who hesitate to register health information that could be used for purposes other than the one central to the clinician-patient relationship—the patient’s health status. As James Rule (Rule, 2007) emphasizes in his book on privacy and surveillance systems, researchers and policymakers need to consider the implications of their surveillance mechanisms before, and not after, implementation because once implementation occurs, it is nearly impossible to stop.

Trans healthcare and health research in the United States constitute an important nexus of social forces and paradoxes to disentangle. The social norms that shape policy and administration of public services or private healthcare rarely consider the most marginalized. “Trickle down” ideologies that center the needs of the “majority” undergird our economics, legal rights, and even or especially healthcare (Spade, 2011). Transgender advocates have only begun to eliminate
discriminatory exclusions from private and public health insurance policies. To build upon these achievements, transgender people have been and are encouraged to be more visible than ever before, not just in the media but on the job, in the doctor’s office, and in the data. In a sense, transgender people are motivated to forego healthcare privacy now, among other forms of privacy, in order to gain access and equity, but as we have seen, visibility brings immense vulnerabilities to those who do not fit those characterizations made visible through the work of the “trans population.” Resonating with Dean Spade’s notion of the generative politics of trans people’s illegibility in the prison industrial complex, the takeaway seems to be that we must work even harder to imagine and enact ways to challenge the ultimate goal of EHR interoperability and patient data standardization as well as the underlying logics of profit maximization and social regulation. Fully realized EHR surveillance and HIEs may further eclipse the self-determination of all patients, not only trans and GNC ones.
VI. CARE OF THE TRANSGENDER SELF: GENDER SELF-DETERMINATION IN THE ERA OF ELECTRONIC HEALTH RECORDS

A. **Background**

This spring I came down with a terrible cold and, upon much prompting, went to my doctor’s office to see if I might need antibiotics. After a thorough exam and interview, both the med student and her supervising physician, who was not my regular primary care doctor, agreed that I did have a terrible cold, but that antibiotics were not warranted. The doctor then reviewed my EHR for my current medications to see if I needed any prescriptions refilled. He asked me if I needed more allergy medication and ordered some when I said yes. He mentioned my testosterone but did not ask if I needed any, presumably because it is classified as a controlled substance and wanted to leave that up to my primary care doctor who was unavailable to see me that day. In closing our appointment, he smiled earnestly and reminded me to wear condoms when having sex and to make sure my vaccinations were up to date.

Despite the problems with EHR infrastructures and transgender patients, at my current provider they have not created problems for me around involuntary outing, mis-gendering, or perceived privacy violations. The physician treating my cold was making an incorrect, though reasonably so, assumption that I am cisgender. Since I was not there for sexual health reasons, I

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3 Like previous analyses, I use the term transgender and trans as well as gender nonconforming and nonbinary interchangeably to describe any individual who violates the alignment of sex-assigned-at-birth and norms around gender expression and/or gender identity. The former set of terms is usually associated with a more gender-conforming expression whereas the latter less so. I use the imperfect terms, cisgender and cis, to describe any individual whose sex-assigned-at-birth aligns with their gender expression or identity. I vary the usage of the terms, understanding that any term chosen (e.g., transgender, gender nonconforming, agender, or transsexual) does not necessarily resonate with those to whom I have applied them but reflects more of a social (im)positioning.
was quite okay with his misguided direction to “always wear condoms.” Yes, it would be wonderful if clinicians in family medicine and primary care were more aware of transgender patients and their range of bodily and gender expressions, but in my world where transphobia, discrimination, and violence is common—even in healthcare settings—I prefer to err on the side of caution and use such oversights as a layer of self-protection.

With the exception of one pharmacist who violated my privacy and additional challenges having testosterone prescriptions ordered and filled in a timely, affordable, and accurate fashion within my provider’s EHR system, my trans status has not been at the front and center of my record nor in the “problem list” that accompanies referrals. In my record, my sex is registered as male, and my diagnosis associated with testosterone that appears on my “problem list” is “other endocrine disorders.” I attribute the seamlessness that I mostly experience to White privilege, passing privilege, and to having transitioned medically and legally nearly 15 years ago. That seamlessness and the relative privacy it affords me could rupture in many unpredictable ways if the federal government implements regulations for the EHR data collection of gender identity without careful attention to implementation.

The healthcare landscape for transgender and GNC persons in the United States has undergone rapid transformation since passage of the ACA. Expanded coverage and the implementation of EHRs have changed the ways in which trans and GNC people access care. For example, rather than going to a special trans clinic at a CHC for the uninsured, trans persons can now use their health insurance to access trans-related healthcare at more mainstream providers, such as the Family Medicine Clinic at UIC that my health plan covers. Both the increased coverage and the expanding digital record infrastructure have helped catalyze trans healthcare policy and research advocates to push for the standardization of a two-step gender identity
question into an algorithm within EHR infrastructures. This algorithm, they contend, will more reliably and respectfully identify, enumerate, and track transgender patients as a population. The algorithm, however, operates in particularly problematic contexts that may impact not only its effectiveness but also the ways in which trans people access care (for examples, see preceding chapters).

This chapter extends Foucault’s notions of bio-power and the care of the self to intervene on the momentum for encoding a two-step gender identity algorithm into EHRs and the algorithm’s tensions with GNC individuals’ capacity for self-determination. Drawing primarily on focus group narratives and some of my own experiences, this case study identifies the innovative ways that trans persons use an ethics akin to a care of the self to navigate twenty-first century mechanisms of bio-power; the case study highlights the ways in which trans persons jockey for control, self-preservation, and self-determination in a complex medical landscape and digitally distributed mechanisms of bio-power that continue to shape identities through their surveillance and disciplinary effects. Viewed through the Foucaultian lens of the care of the self, these narratives reflect a contingent and reflexive process of gender self-determination, also mindful of privacy, safety, and often, survival. Through this lens, I would like to highlight the possibilities and limits for gender self-determination within this increasingly rigid and encoded medical system that is linked with numerous other complex administrative systems, complicate understandings of gender identity, and call into question the current drive not only to continue to medicalize it but to encode it algorithmically.

1. **Theoretical considerations: Bio-power and care of the self**

   In the *History of Sexuality*, Volume I, Michel Foucault provides an analysis of power and its effects as generative and productive rather than repressive vis-à-vis the self and
sexual identity in the modern era (i.e., the eighteenth through the twentieth centuries). Volumes II and III explore ancient Greece and late antiquity, respectively, in order to demonstrate how the constitution of the self, or subjectivation, shifts throughout history as social relationships and the knowledge they generate change. For example, in ancient Greece the practice of pederasty among elite Athenian men with boys was considered a higher form of love than the love found in marriage with a woman. Pederasty was considered a means for the development of a philosophical ethics, a truth of one’s self, and for more evolved friendships than the more animal-like, procreative, conjugal love (Foucault, 1986). In late antiquity, traced in volume III, a reciprocal and relatively austere marriage with a woman displaces pederasty as the site of these ethical practices of the self. What was common to both sets of relations was an ascetic-like set of practices to foster self-control and self-knowledge—reading, writing, listening to, and speaking (Foucault, 1986). Whereas the question of pleasure and mastery over others stimulated this knowledge, as self-control and ethics in pederasty, fidelity, abstinence, and reciprocity in marriage of late antiquity indicated an ethical self (Foucault, 1986).

In the modern era, the sexual subject’s self-knowledge operates differently, taking different forms than late antiquity or ancient Greece. Foucault (1990) identifies two new types of power—bio-power and normalizing power—that have replaced the sovereign power of the Victorian period and have produced shifts in subjectivation, or how the “self” is understood. He suggests that the emergence of public health, psychoanalysis, and modern medicine gave rise to disciplinary, knowledge-generating mechanisms. The health sciences and statistics, for example, created processes of normalization and individuation whereby bodies were monitored, scrutinized, and organized into populations according to norms tied to economic productivity and various deviations from those norms. This surveillance of types of bodies, rather than say types
of practices (i.e., pederasty or reciprocal marriage), produced identities through these classification and normalization processes. The male heterosexual became the norm through the regulation of various deviations—such as the homosexual, or the pervert, or the hysterical woman. These deviants or pathologies became indicators of a kind of self, body, and biology, as well as characterological differences, all of which required understanding, monitoring, and intervention in an attempt to fix, or at least control and manage, them. For example, women’s bodies were pathologized as hypersexual and in need of control via marriage and motherhood (Foucault, 1990, p. 104). Normalization—a mechanism of social control and management in the service of economy or war—gained force in the modern era with panoptical architectures that ensured constant surveillance and, as a result, self-surveillance (Foucault, 1995).

Others (Green, 2010; Heyes, 2007; King, 2003) have extended Foucault’s analysis from sexual identity to examine gender identity in relation to normalization. For example, Lisa King’s (2003) analysis of David Reimer, his twin brother, and Dr. John Money’s gender experiments upon them problematizes assumptions around the nature versus nurture debate: that gender identity emerges from some inner-core self or that gender identity is a matter of socialization. Rather, her analysis highlights the ways that Reimer’s gendered self emerges through embodied practices, mediated by the gender norms enforced through public spectacle and the act of confessing. Heyes, too, uses Foucault’s notion of care of the self to challenge second-wave feminism’s opposition to transgender women whom they, Heyes says, characterize as dupes of patriarchy. Recognizing that no woman is outside normalizing power or the institutions that structure oppression and privilege, she urges cisgender feminists to use that recognition to engage in solidarity and resistant practices to patriarchy alongside transgender women rather than pit themselves against trans women. That is, she invokes a modern-day feminist care of self
that moves from an understanding of binary gender as fixed by biology and nature and transness as pathological and medicalized to one of gender, in all its expressions, as relationally produced; this lens makes room for solidarity-building across those genders marginalized by patriarchy (Heyes, 2007, p. 39).

Similarly, I want to suggest that for trans and GNC persons, resistant practices of the self have emerged in the vastly and intricately distributed nature of digital surveillance, or what Mensink (2011) refers to as post-panopticism. That is, ruptures in surveillance mechanisms like EHR infrastructures offer potential sites of resistance where one may practice self-determination and even engage in solidarity with each other and with sympathetic clinicians and provider staff. Such resistant practices highlight the contingent and conflicting ways in which administrative systems attempt to define, regulate, and produce gender; they also may ultimately call into question the very need for capturing gender identity at the level of the algorithm.

2. **The medicalization of gender identity**

In order to understand the potential effects of gender identity data collection for trans patients, we must understand the current momentum. Engaging the forces of bio-power, advocates and researchers contend that classifying and capturing gender identity in health records will more precisely enumerate a trans population, enable more and better research across and between disciplines, and expand our understandings of trans health at a population level (Bradford, Cahill, Grasso, & Makadon, 2012b; Cahill & Makadon, 2014a; Cahill et al., 2014; Committee on LGBT Health, 2012; Tate et al., 2012). In addition to research, advocates believe that the more accurate identification of trans patients in the clinical setting will also improve cultural competency and, ultimately, health outcomes (City and County of San Francisco Department of Public Health, 2013; Deutsch & Buchholz, 2015). Another case study highlights
the challenges that arise when clinic systems interface with those of billing, labs, and other clinical business associates, and the gender options and algorithms conflict (Ingraham et al., 2015).

The current calls for encoding trans identities into electronic health records via the two-step algorithm mark a continuity with calls in other surveillance domains as well. The Williams Institute (2014), for example, has published a series of reports calling for use of the two-step question to ascertain gender identity in national health surveys on youth and adults and other surveillance systems. In light of this policy and advocacy momentum, prior analyses have examined the EHR landscape for transgender healthcare, the limitations, and the potential for population-level research with EHR data; these analyses identify ways in which EHRs may hinder cultural competency, clinical effectiveness as well as access to care. Although the analyses call into question the need for the medicalization of gender identity and even its impossibility with respect to population-level research, they also suggest greater data privacy and security mechanisms around gender identity-related data in order to facilitate access to care and foster cultural competency.

Disclosure and privacy literatures have been less useful for this analysis despite privacy and disclosure playing key roles in aspects of trans healthcare and gender identity data collection. Historically, and in general, privacy is the province of those with privilege and resources, not persons on the social margins (Solove, 2008; Warren & Brandeis, 1890). In the healthcare setting, HIPAA actually offers minimal privacy to patients and works as a floor, rather than a ceiling on privacy (Sobel, 2007). Only one study has specifically examined how EHRs may complicate privacy concerns and disclosure strategies of sexual, not gender, identity (Stablein et al., 2012). Without encryption, segmentation, or anonymization techniques, digital privacy of health records
is nearly nonexistent (Ohm, 2010; Latanya Sweeney, 2002). Similarly, a literature around disclosure and the ways stigma mediates decisions to disclose statuses related to health and identity, such as HIV (The Center for HIV Law and Policy, 2002) or sexual orientation (Stablein et al., 2012), falls short here. Many transgender persons do not always have the option to disclose their gender identity or not, depending upon the context, for a number of different reasons.

Encoding trans identities into EHR infrastructures may also be seen as continuous with a broader history of the medicalization of gender identities. Historical literature has traced the emergence of a medicalized transsexual identity to the late nineteenth century (see, for example, Hartland, 1871; Kraft-Ebbing, 1892) through the mid-twentieth century when a transgender identity category began to crystallize alongside it (Benjamin, 1966; Oliven, 1965; Rubin, 2003). By the mid- to late-twentieth century this identity was characterized by the patient’s confession of particular narrative to his or her doctor, an evaluation of the patient by a psychologist, followed by both doctor and psychologist monitoring the patient’s behavior for a year, so to verify the inner-truth of the patient’s initial transgender confession. Namaste’s work (2000) traced how these protocols, known as the Harry Benjamin standards of care (HB SOC), and the knowledge generated from it contributed to the construction of a particular transgender narrative arc and the erasures and invisibility of other ones (e.g., those of sex workers) who did not have access to employment or care and may have had very different experiences and relationships to their selves and their bodies.

In the early twenty-first century, bio-power has shifted in that normalization occurs less through what Foucault (1995) called panoptic surveillance and increasingly through what Mensink (2011) refers to as post-panoptic surveillance. That is, post-panoptic digital surveillance systems have displaced the brick-and-mortar architectures of surveillance that required a human
gaze to begin the work of discipline; this shift reduces the agency of the human gaze—and on a collective scale the governmentality of the state—and redistributes it to the algorithms of databases and those that determine its coding. For transgender healthcare, an informed consent model has emerged whereby providers do not require an in-depth psychological evaluation in order for trans and GNC patients to access hormone therapy (Deutsch, 2012). Though it has not displaced the earlier HB SOC model, renamed the World Psychological Association of Transgender Health standards of care (WPATH SOC), it—and some trans activism—has catalyzed reforms of the WPATH SOC too. While WPATH SOC continues to rely on the authority and collaboration of physician and psychologist to determine eligibility for medical intervention, though not as rigidly, the informed consent model reduces the burden on the medical establishment and relies on patient engagement in care. Patient engagement in care is also known as patient-centered care, and reflects a broader trend whereby healthcare reforms aim to reduce costs and improve quality through the inclusion and empowerment of patients in the healthcare decision-making process rather than centering the physician’s knowledge exclusively (Laine & Davidoff, 1996). In this era, how one comes to know one’s self as transgender or GNC relies much less on the doctor-patient relationship and the patient’s meeting a year-long “real-life test” of the now outdated HB standards.

With increasing patient-centered care, the two-step algorithm may serve as one ostensibly efficient and effective way to recognize, make visible, and regulate who counts as a transgender or GNC. Others (Currah, 2013; Spade, 2011) have shown how bureaucratic and administrative regulation of gender identity can create a kind of visibility with coercive and violent effects on trans people. As discussed in the previous manuscript, the visibility called for by Vivian Namaste made more room for gender self-determination and access to care for all trans people rather than
only those who complied with medicalized transgender norms. This chapter explores the tensions in accessing healthcare as a transgender person and the possibilities for the two-step algorithm; focus group narratives reflect on the algorithm, doctor-patient relationships, healthcare privacy, safety, and visibility, revealing a set of resistant practices for self-knowledge and self-determination—a kind of care of the self in the face of rigid distributed digital healthcare infrastructures.

B. **Methods**

This analysis uses the case study method, fostering theory development through a detailed, critical interrogation of a social phenomenon (Walton, 1992). The case study also enables exploration of concepts not yet validated or quantifiable and, historically, has contributed to understanding urban life and the integration of the social ecological resources (Hamel, 1993, p. 15). Most importantly, it is a method that refuses to accept what is visible as reality and rejects empirical assumptions (Levi-Strauss in Hamel, 1993, p. 30). “Implicit in the idea of the case is a claim. . . . Cases come wrapped in theories. They are cases because they embody causal processes operating in microcosm. At bottom, the logic of the case study is to demonstrate a causal argument about how general social forces take shape and produce results in specific settings. . . . Cases are always hypotheses” (Walton, 1992, p. 121–122). Experiences articulated by study participants are not the point of departure for theory; theory—explored via case study—aims to identify the logics that undergird the social realities that participants may express (Levi-Strauss in Hamel, 1993). Cases manifest larger social phenomena operating locally and particular to specific contexts.
I draw on three salient approaches: Burawoy’s extended case method (1991), Smith’s institutional ethnography (Smith, 2005) and Starr’s ethnography of infrastructure (1999).

Michael Burawoy (1991) suggests that grounded theory is limited by its micro-level, positivist scope and perhaps overzealous in its claims to theory generation. His extended case method actually extends grounded theory, which conducts extensive fieldwork and analysis to generate new theory from inferences. The extended case method, however, reconstructs existing theory. Rather than starting with a blank slate and “discovering” a new theory, Burawoy’s more reflexive approach identifies patterns, processes, anomalies, and paradoxes in the coded data and, in this case, the EHR infrastructure, but also contextualizes the fieldwork within broader discursive, social, economic, transnational, and urban settings. This micro-macro, contextualized approach to ethnography also helps to reconstruct, strengthen, and extend existing theory.

Consistent with the extended case method, Smith’s institutional ethnography (2005) takes a bottom-up approach that privileges the knowledges of impacted communities. Smith rejects asking organizational questions that privilege top-down perspectives and administrative knowledges. Her method explicitly extends itself into the community beyond the more epistemological in order to generate praxis (Smith 2005). In this analysis, Smith might attend to the more common elements of EHRs—patient portals, intake and release forms, waiting rooms, lab results, and prescription orders—that trans patients navigate in order to access healthcare.

Star’s method complements Smith as her approach also avoids privileging top-down explorations of institutions. Infrastructural ethnography critically examines infrastructure itself as part of a study sample or case study. It examines not only the EHR system itself but queries the persons connected to it and the knowledge generated from it and transmitted to other databases as well. Taken together, the ecological, sociotechnical, and relational roles of EHR systems are
inseparable from the human stakeholders as well as the data that the systems generate. This approach makes infrastructure visible alongside the knowledges it produces and the ostensibly mundane online and offline behaviors it circumscribes (Smith, 2005; Star, 1999).

1. **Study sample and data collection**

   The sample consisted of 30 trans and GNC persons who participated in one of four two-hour focus groups. Besides the focus group transcripts, I also used textual materials such as clinic intake forms and waiting room materials, policy briefs, and my own EHR. As a transgender person who actively advocates for improved access to healthcare for transgender people and who actively seeks transgender-related medical care, I also drew upon some of my own experiences and participant observations to inform and interpret the study data. The IRB at UIC approved the research.

   a. **Focus groups**

      Focus groups were conducted in Chicago, Illinois between October 2014 and January 2015. Recruitment occurred via local provider networks and social spaces and one virtual social space, Facebook. Inclusion criteria for focus groups consisted of the following: (1) 18 years of age or older, (2) self-identifying as trans or GNC for one year or more, and (3) the ability to speak English. Focus groups lasted approximately two to three hours and included sharing a meal or snack together first. Participants received $30 compensation for their contribution to the research.

   b. **Focus group protocols**

      Focus groups centered on the intake process, including sample intake forms, and clinical visits as patients. Questions emphasized decisions around disclosure of one’s trans or GNC status in healthcare settings as well as other settings such as social media,
employment, and family. Some key questions were: (1) would you feel comfortable and/or safe completing this intake form? What do you think about the “patient information” section? How do you like the two-step question regarding gender identity versus the single item question? (2) If you have used a patient portal, can you describe that process? (3) How do you decide to disclose your transgender status in different healthcare settings? (4) Have you ever gone to a doctor who seemed to have access to the information you gave another doctor? How, if at all, was that helpful or harmful? How do you feel about different doctors, nurses, or other staff having access to the information you give to your primary care doctor particularly around your gender? And (5) what do you think about researchers accessing and using de-identified medical records for trans health research? Would you be ok if you and everyone else in this room were counted as transgender women (or transgender men)?

2. **Analysis**

Field notes were taken following interviews and focus groups, and memos were taken during the coding and analysis processes. Transcripts were managed and coded using ATLAS.ti (Version 1.0.16, Scientific Software Development GmbH). Coded transcripts were analyzed for common themes, and Lund’s analytical matrix (2014) was used to organize observations (see Table IV in chapter V). As events, patterns, and concepts emerge from the coding process, analytical matrices are constructed and iteratively analyzed with respect to other cases that resonate “from different localities or different times, or both” in order to extend relevant theory (Lund, 2014, p. 226).

The coding process began with the selection of one focus group, chosen to capture a cross-section of stakeholders. This process generated more than 100 codes. Focus group codes were organized into five categories: disclosure/privacy, gender identity classifications, quality of
care, discrimination/safety, and what I have termed “crosstalk care.” Briefly, crosstalk care refers to moments when participants interjected to offer another participant advice and potential resolutions to bureaucratic barriers to care and services; this category emerged later in the analysis process realizing that the frequency and content of the crosstalk that occurred had great relevance to my research aims even though these discussions were sidebars to my questions. The remaining transcripts were coded according to existing codes. The coded data was imported into five groups and reviewed iteratively in order to identify patterns and concepts related to gender self-determination and access to quality healthcare in the context of EHR implementation.

C. **Results**

1. **Focus group analysis**

   Focus group participants (N=30) represent a cross-section of trans and GNC persons in Chicago (see Table IV in chapter V). Participants were in various stages of their medical and/or social transitions, and their ages ranged from 19 to 73 with a median age of 30.5 years. Participants identified primarily as Black (33%), White (30%), Latina (27%), or Mixed race (10%). Seventy-seven percent reported sex-assigned-at-birth as male, and gender identities expressed during eligibility screening included: trans man (3%), man (10%), agender or genderqueer (10%), trans woman (37%), and woman (40%). Participants also said that their gender identities shifted somewhat depending upon the context. Though most were open with Facebook friends about their trans or genderqueer or agender status, only two participants recalled having changed their Facebook gender to “trans” or “genderqueer” since the web site began offering more than 50 gender options in 2014. In terms of education, 66% reported at least a college-level education, and the same proportion of participants reported unemployment within
the last twelve months. Another striking statistic is that 87% of participants reported having private or public health insurance—perhaps a function of the ACA and the prohibition of preexisting conditions, such as Gender Dysphoria, as a disqualification for insurance coverage. All participants lived in the city, and two reported living in the suburbs. All but one received primary care in the city, and one of the suburban participants said that she received her primary care “here and there,” including emergency rooms, as needed (Focus Group #3).

a. **The two-step gender question**

Participants reviewed and discussed two sample intake forms from LGBT community clinics in the United States. These familiar forms collect personal, demographic information such as name, contact information, age, race, ethnicity, education, primary language, veteran status, and Social Security number that is subsequently entered into the health record. What might distinguish these forms from non-LGBT community clinic intake forms is that they query for sexual orientation, preferred pronoun, and gender beyond the cisgender binary. That is, these forms represent possible versions of standardized data collection instruments of gender identity. One form had the two-step question that advocates have been vying to standardize across healthcare providers’ forms and EHR infrastructures, while the other form uses one question and requires less precious form “real estate” (see Figure 1). Although some providers have launched patient portals through which patients can directly input their registration information into the EHR system, none of the focus group participants had registered as new patients at their provider via patient portals.

Substantively, participants thought the two-step strategy was an excellent way for a provider or clinician to ascertain which patients might have a trans history or experience even if a patient does not identify as trans. Taken together, the two questions capture more than those
who currently identify as transgender; it captures patients who, similar to many of the focus
group participants, identify as men or as women but were assigned female or male, respectively,
at birth. Two of the four participants who reported that they work in trans-related healthcare
noted that, because of its improved reliability, the use of the two-step question helps clinics
report greater numbers of trans patients and helps attract more funding for trans-related
healthcare.

Participants were critical of the single question from health center #2 for several reasons. First,
some identified a conflation of sex and gender into one category; most obviously, one participant
from Focus Group #3 noted, “intersex” is not a gender, but in the United States we currently tend
to distinguish between male and man as separate constructions of sex and gender respectively.
Besides the conflation, some also criticized limiting the options to two binaries (i.e., M/F and
FTM/MTF) and an offensive “other” term—which literally “others” those whose gender lies
outside the binary constructions. One person in focus group #2 noted that the transgender options,
MTF and FTM, were outdated terms (though perhaps elegant), and the group agreed with him.
Finally, participants in all focus groups appreciated health center #1’s “decline to answer”
option and generally agreed that providers ought always to include that as a response option. As
one nonbinary participant noted, “I do really like that they also have ‘decline to answer.’ Let’s
have a conversation about [my sex-assigned-at-birth and gender identity] in the office in private”
(Focus Group #2). Other participants also wondered about the need to give this information at
intake and if it was more appropriate for a conversation with one’s clinician depending upon the
relevance to one’s appointment.
### LGBT Health Center #1 Intake Form

| Sex Assigned At Birth: | Male          |
|                       | Female        |
|                       | Intersex      |
|                       | Decline to Answer |

| Gender Identity:      | Male/Man      |
|                       | Female/Woman  |
|                       | TransMale/Transman |
|                       | TransFemale/Transwoman |
|                       | Genderqueer/GNC |
|                       | Something Else |
|                       | Decline to Answer |

### LGBT Health Center #2 Intake Form

| Gender:               | Male          |
|                       | Female        |
|                       | Transgender/MTF |
|                       | Transgender/FTM |
|                       | Intersex      |
|                       | Other (specify) |

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**Figure 1.** Assessment of gender identity on two LGBT clinic intake forms.

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b. **Privacy, disclosure, visibility, and safety concerns**

I was in the waiting room, and two nurses decided to discuss me. However, they failed to realize that they had the button for the PA system on. The whole damn waiting area and clinic could hear what they were discussing. . . . I was without hormones for almost a year and a half, which caused havoc with my body and caused my nutrients to lower again when I started over again with Dr. XXXX. It was bad (Focus Group #1).

Although participants found the two-part question more substantively relevant and reliable, many had serious concerns about answering these very personal questions on an intake form, the data from which may be shared with any number of parties (e.g., insurance, employer/human resources, labs, pharmacies, intake staff). Their identities change, they said, depending upon the context and may not even be relevant to their visit. Participants, particularly
those who do not use LGBT clinics, said that, for privacy and safety reasons, they would not answer the sex-assigned-at-birth question for fear of possible discrimination or even violence from intake staff or other patients. One participant described a clinic receptionist, who learned that her legal status was “male” and threatened to call the police on her for using the women’s restroom. She added,

At the end of the day, this is a registration form. You're giving this to the person who's registering you. For me, that could be a safety issue because how do I know after you—after I have identified myself as male or whatever the case may be—this is a very small world. We may be in public, and girl, you may point me out and tell this person, "Oh, girl. That's a man" (Focus Group #3).

Another participant then shared a similar story where she disclosed her sex-assigned-at-birth to the intake person at the ER and “before you knew it all these random people are popping into my room while I'm sitting there, waiting for the doctor. The janitor came in to change the trash. Three students came in. Four doctors came in” (Focus Group #3).

Others were concerned they might lose their jobs if this information reached their employer’s human resources department by way of their insurance coverage. Many participants are not out as trans in their daily lives, especially in their jobs. One Black trans man reported that he was fired after his employer’s human resources department received a health insurance invoice for his Pap smear. Another White trans man, also not out as trans at work, explained that providing his sex-assigned-at birth would exacerbate the anxiety he already feels with his employment-based health insurance. He said he risked one job when he had to out himself to human resources during his first week there in order to determine which insurance plan would cover his trans-related healthcare. Unlike the Black trans man, he was not fired.

Nonbinary participants from two focus groups said that they would hesitate to fill out these forms because, in their experience, clinicians do not know what to do with that information.
and tend to act on a set of assumptions. These stereotypes can be privacy-violating if they are aired in front of others or if they have to be corrected, or if it has to be explained that these stereotypes do not apply to them, their primary care, or other reasons for their care visits. In their experience, doctors and staff very rarely use gender-neutral or gender-expansive pronouns and tend to assume that nonbinary persons want to take or should take hormones. One participant explained, “At this point I’ve given up on most medical providers. I’ve been trying to ask for [non-gendered pronouns]. I do intend to change my name legally, which will make things much easier. The pronouns are still a whole other hurdle to get over” (Focus Group #4). Though the mis-gendering is alienating, another nonbinary participant said that they would rather “pass” as the gender associated with their sex-assigned-at-birth than have to intervene on their clinicians’ erroneous assumptions about their nonbinary gender identities, which tends to derail the central reasons for their visits.

Similar to the nonbinary participant, and even more similar to my doctor visit regarding a cold, some trans women in Focus Group #1 reported preferring not to disclose their trans status when clinicians assume they are cisgender. Rather than correct erroneous assumptions about their bodies, two participants said they instead volunteered answers to questions around their last menstrual cycle. “I just hit it off beautiful with this nurse, and it was wonderful. See, I always say, ‘Like a bird, blend’” (Focus Group #1). In this way, privacy and nondisclosure not only afford safety from confrontation but also a perceived level of rapport that does not seem possible if she disclosed her trans status to the nurse.

Though most participants wanted the option to “blend” if necessary, two of the healthcare workers, in different focus groups, discussed visibility in healthcare settings working as a conduit and part of a larger movement strategy for greater social acceptance of transgender
people. One of them, who also positioned herself as older (i.e., late 50s) relative to her focus group peers, explained:

I’m not a female. I don’t identify as a female. I’m a trans person, and I enjoy being a trans person. We are a contribution to society. So we should be recognized, just like a man or a woman. . . . The only way to do it is to get more voice about it. That’s why the trans coalition and all the organizations that I belong to—for medical reasons, yes, I will put “transgender” (Focus Group #1).

Another participant, who also positioned herself as older (i.e., in her 70s), White, and a “late transitioner,” relative to her focus group peers articulated a more cynical interpretation. She said, “By the way, the background on these [intake] forms, you can write a big dollar sign in the middle of them . . . in terms of grants. They need a lot of information so they can get that money” (Focus Group #3).

Rather than calling for outright trans visibility at their providers, some participants, thought that a clearer or more selective presentation of gender identity-related information in their EHR might help mitigate all the explaining they currently have to do about their identity and the related care they need. Participants reported very high clinician turnover, poor communication systems, long wait-times, and short appointments at the LGBT clinic. One participant said he had gone without hormones for several months because he felt so much anxiety around having to explain his identity and health needs to every new doctor. Another participant recalled,

I filled out this form several times, and the nurse comes in and confirms everything. And the next doctor interprets what was written down in a totally different way, and he is misinterpreting this. . . . How that happens with just a gender marker—several times—there was a lot of mis-gendering (Focus Group #2).

Participants expressed fatigue with having to reorient themselves frequently to new clinicians or related staff and subsequently reeducate them, in part, because the information in the EHR is not legible to clinicians and staff vis-à-vis the patient. Other participants expressed
horror about seeing their legal names on their chart folders and lab stickers and wondered if
clinician confusion comes from the way EHR systems display legal names and genders rather
than the ones they live as.

Participants had mixed reviews around using patient portals. Some appreciated the
efficiency, some being able to minimize interaction with human healthcare workers, while others
questioned whether it afforded added privacy. One participant said, “I like [patient portals].
They are really convenient. You don’t have to run back up to the doctor and get no test results,
and do all that. ’Cuz sometimes, they won’t give you test results over the phone” (Focus Group
#3). Participants also used portals to email their doctors for prescription refills, to schedule
appointments, and to monitor when they need to return for blood draws. One participant
expressed skepticism around the privacy of the portal:

I sent a message to one doctor and then it was a nurse who was working for them that
saw it first and replied. Then they were figuring out where it was supposed to go after as
opposed to just the doctor seeing it. I don’t know how standard that is or who exactly is
seeing those messages (Focus Group #4).

Another said she did not like using the portal: “I’m old fashioned. I like to pick up the phone and
make my appointment and talk to a human being” (Focus Group #1). Healthcare with more and
stronger human connections seem less alienating for some than others.

c. **Navigation of bureaucracy and administrative systems**

Whether due to poor record keeping, poorly trained staff, or some
combination thereof—mis-gendering has driven participants out of care. Trying to make one’s
gender identity more seamless in state and healthcare administrative systems would seem to be
one possible solution or at least one way to reduce the number of conflicting gender markers
with which healthcare staff may be confronted. But changing one’s legal name and gender in
various systems can create new barriers to care rather than simply eliminating them. One young woman explained,

[The mis-gendering] didn't stop until I got female on my ID, and I just literally clapped down my ID and said, "The state recognizes me as female, so obviously, you need to recognize me as well." I wish they would have a healthcare plan for me—'cuz [now], they don't cover Delestrogen. I literally spent $225.00 for a vial of Delestrogen the other week (Focus Group #3).

Although her new gender marker forced the intake person to respect her and her gender identity, her public insurance stopped covering her medications when the gender marker changed. Another participant said she preferred not to change her name and gender marker legally. “It’s a matter of personal preferences . . . I haven’t had my name changed yet . . . because I’m comfortable being me. I’ve worked for over ten years, and I’ve never had any problems” (Focus Group #1). Trans persons have to navigate these complex systems and determine how best to preserve their gender self-determination and maintain access to resources; as many doctors have learned in their work, there are no one-size fits all protocols for these processes.

Several participants—all with public insurance—reported having problems in that they were now having to pay out-of-pocket for their very expensive medications after they legally changed their names and genders. Participants explained that the public insurance offered in Chicago, known as County Care, stops one’s trans health-related coverage when gender markers or names are changed until patients can successfully appeal the decision, ostensibly to prove that the change is not for the purposes of committing fraud. In fact, other participants, who had already changed their gender marker, also found themselves having to pay out-of-pocket once they signed up for their required ACA healthcare plans though some did speak of having clinicians who knew how to adjust their diagnostic coding to avoid having coverage stopped.
Another participant, who had earlier explained that she was an immigrant, shared a harrowing story about her experience with state bureaucracy and barriers to care. Although she changed her gender legally to female on her state ID many years ago, she let her ID expire when she was battling a life-threatening condition. After recovering, she attempted to renew her state ID only to be told that the Secretary of State now deems her male unless she could produce all the required paperwork to change her gender to female for the second time. Unable to reproduce that paperwork, she is now registered as male under her Medicaid plan, and her hormones are no longer covered.

Though not without challenges, trans men did not describe parallel ones around gender markers and administrative systems. One trans man reported that although he had never legally changed his gender from female to male, the Secretary of State’s office staff voluntarily changed his ID’s gender marker from an F to an M because they thought there had been an obvious coding error. “Let me tell you what happened,” he said. “She looked at my ID. She goes, ‘Oh my God! They made a mistake on here.’ I said, ‘You’re right.’ She goes, ‘That should be an ‘M.’ I said, ‘I told them that!’ And she made it an ‘M.’ I’ve been riding the ‘M’ wave all the way” (Focus Group #4). Though he had never changed his name or gender legally, that ‘M’ enabled him to marry, and subsequently divorce, his partner; he was also incarcerated with the male population in the local jail until some familiar trans women—also jailed with male inmates—outed him to jail officials. At that point, jail officials moved him to the jail infirmary rather than to the female unit of the jail.

Another participant reported that at his first and only visit, an intake staff at a minute-clinic informed him that his insurance carrier must have made a clerical error because, in her quick check for his coverage, she saw that he is coded as female. Legally male for years, he does
not know how she retrieved his information so quickly or how he could be registered as a female in the database she checked. He said that the incredible anxiety that he felt would keep him from ever going to another minute clinic.

d. **Expressions of care and conspicuous silences**

In addition to complaints about doctors and painful experiences with healthcare systems, participants also described some very caring clinicians as well as intake staff who go to great lengths to help access the care they need despite the immense bureaucratic barriers. In two focus groups, participants observed that the LGBT clinic had numerous employees that are POCs and/or trans, including caseworkers that “help you find a lot of stuff that you need. . . . They help you get insurance [to enable you] to get the hormones . . . stuff that you need” (Focus Group #1). Beyond the LGBT clinic, participants described how various clinicians and staff had helped them navigate coverage for care and hormones with particular diagnostic coding depending on legal gender markers, type of coverage, veteran status, and other contingent factors that play into access. Participants shared names of excellent doctors, noting those who were immigrants or POCs and those who work at relatively unknown clinics. They were quick to name LGBT ones whom they experienced as particularly disrespectful or transphobic as well as those they appreciated. Participants expressed gratitude for doctors who trusted them with their phone numbers in case of emergencies and for their willingness to listen, learn, and demonstrate humility.

2. **Crosstalk care**

A spirit of mutual caring emerged from all four focus groups. Like they often do with other apparatuses of bio-power, participants used this research as a way to resolve their own and each other’s vexing questions around access and care; for example, participants often found
themselves responding to their peers’ answers to my questions with strategies, tactics, and encouragement. Whether in the clinic working with thoughtful staff and clinicians, or in the midst of a research study, or just surfing on Facebook, this ethical practice helps resolve complicated administrative and healthcare access challenges and creates stronger and more human connections as persons preserve their gender self-determination. Participants believed many of these challenges emerged due to complications around gender identity—including ineffective data fields and algorithms of EHRs—but also discrimination. Participants had different ways and styles of offering support. The elderly White participant, for example, constantly referred her peers to legal doctrines, scientific research, and WPATH medical standards of care as the means to improve navigation of the system, and she did so in ways that were often interpreted as rude and disrespectful by the younger participants who were all POCs. For example, a discussion around changing one’s gender marker on the birth certificate went like this:

Older White participant: “No, no, no. Don’t do that. Mara Keisling will go crazy. Don’t interpret [the law]. It’s up to you and your doctor what’s appropriate for you.”

Younger POC participant: “There’s only other way that you can—“

OWP: “No, no, no, no. Period. . . . There is nothing on the federal government level that takes any more than a short letter. The reason I was rude about it is you don’t want to expand it. That’s one of the whole purposes they got the law changed was so there—it’s between you and your doctor. Personal business.”

YPPOCP: “If you were to—if you wouldn’t have cut me off, I would have explained it better.”

OWP: “I’m sorry . . .” (Focus Group #3).

Others, like the woman in Focus Group #1 who has been working as a woman for 10 years without having legally changed her male name or gender marker, had weaker allegiances to medical and legal doctrine and research as a means to pursue transgender health and personhood.
Some—like the trans man whose gender marker was changed unofficially by the Secretary of State’s office—identified system loopholes to push a system to work in unintended ways on their behalf as another way to enable relatively unfettered, safer access to care. Still others advocated for trusting their own bodies and experiences over medical knowledge or the most recent public policy change. “At the end of the day, hormones is hormones . . . and I want to be fishiest of the fishiest. I don’t believe [the research] about too much estrogen is gonna convert back to testosterone” (Focus Group #3). She went on to explain the excessive doses, relative to protocols, of numerous types of feminizing hormones she takes.

With rare opportunities to come together in physical spaces, participants also expressed that social and support groups, as well as the focus groups themselves, afforded them a unique opportunity to learn from each other and appreciate their varied experiences and diversely intersecting identities: “One thing I noticed about female-to-males is that we complement each other. We look for things to help each other with. . . . That’s why I wanted to go to all these groups, ’cuz I didn’t understand. This [genderqueer culture] is new. I’m old school. When I hear something that’s new with gender, I want to stay hip, right?” (Focus Group #4). Another woman said she viewed the focus group as a learning opportunity as well, “I wasn’t trying to say anything to get anybody disruptive—I’m trying to learn myself. ’Cuz . . . all my life, I never really too much been in the LGBT community to sit around and know everything” (Focus Group #3). Similarly, in Focus Group #2, a participant apologized for making assumptions about trans men’s bodies “Okay, cool. Thank you. I am learning.”

That spirit of caring and support was not uniform across participants. Two of the three women under 25 years of age in Focus Group #1 participated in very uneven ways. That is to say, one did not say much of anything at all besides where she accessed her healthcare. The other
talked at length about her current mental health that was deteriorating due to the recent death of her boyfriend. She also expressed some surprise and dismay when I asked a question in a way that outed myself as transgender. She said, “I thought you were a dude... Oh my god, I thought you was like all man” (Focus Group #1). Her particular style was such that she interrupted and talked over peers, and the elder of the group asked her to stop interrupting people. Feeling like she had been singled out when others were also talking over each other, her participation waned after these exchanges.

One of the relatively older (i.e., mid 30s) participants approached me after the focus group to explain the group’s dynamics and, ostensibly, to help me better understand how I might navigate similar situations differently in the future. She said that many of the “younger girls” (her term) are very competitive when it comes to their femininity. She said that the norm among these girls is not to discuss one’s “T” because their peers are very judgmental. She added that, because of that norm, I might have jeopardized my credibility when I acknowledged my own trans status about half-way through the group. In retrospect, those insights may explain why the two young girls, besides the young healthcare worker, were very hesitant to acknowledge their sex-assigned-at-birth during the screening and perhaps also why they seemed uncomfortably silent among an otherwise very talkative group of women. That norm—to keep one’s trans status and related experiences private—may also help explain why accessing healthcare may be such a fraught or even humiliating experience that they may avoid or have difficulties engaging.

D. Discussion

The trans health literature lacks transgender patient voices and experiences, particularly with respect to EHR implementation and the current push to standardize the two-part gender
identity question as an algorithm to identify and enumerate transgender persons in the healthcare system. This analysis represents the first attempt to center patient perspectives and understand how the collection of this data may impact the care of trans and GNC persons but also their privacy, safety, health, and other aspects of daily living such as employment. Focus group participants and I share a kind of ethos, a set of self-reflexive practices, evocative of Foucault’s notion of the care of the self, whereby we rely on each other to navigate these complex administrative infrastructures depending upon our contingent relationship to them and attempt to use them in positive ways that afford us some freedom of self-determination rather than total gender normalization or medicalization. Strategies for navigation vary, though, from near total endorsement of bio-political forces of WPATH, scientific research, and legal doctrine to different forms of radical resistance such as claiming multiple genders, no gender at all, rejection of the medicalization of gender non-conformity, or listening only to one’s body to determine one’s hormone regimen. Adding another algorithmic layer to fix gender identities within EHR infrastructures not only forecloses much of the fluid and contextual aspects of gender identity for trans and cisgender persons alike, it also works to fix our health histories and decontextualize our health narratives in ways that can literally close off access to healthcare and impose new kinds of administrative violence.

Since medicine created the category “transgender” in the 1960s, transgender people have had to navigate webs of criminal and administrative law and their intersections with medical protocols and standards in order to determine how to achieve their desired gender identity and expressions, while maintaining their freedom and avoiding overt violations of these disciplinary mechanisms. Trans activist and social justice leader, Miss Major, explains that this self-reconstitution meant regurgitating a particular narrative, learned from peers, in order to access
hormones; sometimes this meant speaking one’s truth; for others, it meant avoiding medicine altogether in order to achieve their gender identity; and still for others it meant incarceration (Ophelian, 2010).

Legal and medical infrastructures have changed and expanded since the 1960s both in general and for transgender persons; Foucault characterizes the historical and relational shift as one from disciplinary and panoptical to neoliberal and post-panoptical (Foucault, 2007). In this context, trans and GNC individuals have also adapted and expanded the ways in which to gauge their relationships to these complex systems in order navigate immense bureaucratic barriers and access resources but also to maintain some sense of agency in their own self-determination. Indeed, an ascetic-like set of practices (Foucault, 1986)—reading, writing, listening to, and speaking with each other in various forums, such as the focus groups, a clinic exam room, or platforms like Facebook—have emerged to develop strategies for self-determination and gender identity in the face of normalizing power and bio-power. Trans and GNC persons have taken up these self-reflexive practices, however, on what Wouter Mensink (2011) calls a sliding scale; that is, quite unevenly and in very different ways than the Greek and Roman elite of late antiquity. With respect to the unevenness, a current challenge with standardizing the two-part question into records is that while trans institutions, advocates, and researchers have coalesced their own ascetic practices with neoliberal forms of bio-power and stand to gain funding for research and care from the standardization, the new visibility afforded through this mechanism represents another potentially life-threatening bureaucratic trap for some trans and GNC persons, particularly the most marginalized. For example, the elderly White participant often invoked the institutions of bio-power, such as the WPATH standards of care or policies pushed by Mara Kiesling, while her peers pushed back with resistant strategies of listening to their bodies rather
than scientific research. At the same time, participants appreciated learning from each other’s different perspectives and building solidarity around them.

Though focus group participants understood and appreciated the nuance of the two-part question, the data collection instrument (i.e., the record) and the numerous contexts for its circulation afforded skepticism about its benefits. Both my own experience and the focus group participants’ experiences enable us to anticipate the ways that the data from the two-part questions may work to siphon off access to numerous resources in different, often contingent, unpredictable, and even violent ways. And for those on the margins, that very siphoning represents another threat to an already limited capacity for self-determination.

Technology, gender, and administrative systems have a kind of agency—a bio-political set of forces—against and through which trans people must constitute themselves. Focus group participants shared how they critically and selectively avoid, engage, or transform these normalizing technologies and systems into a positive practice of self-determination. Bureaucratic burdens and medico-legal webs of social control require a “care of self” and find greater force in collaboration, cooperation, and an exchange of ideas and experiences with other trans people—“care of self and others” (Foucault, 1986). Focus group participants offered advice and resources to their peers to help them achieve their desired gender identities with fewer barriers and administrative burdens. These strategies ranged from meticulous compliance with standards of care for medical transition—a strategy Foucault might call subjection to normalizing, disciplinary techniques—to a more critical set of resistant practices such as avoiding medicalization and developing peer networks and alliances with various provider clinicians and staff to help navigate access to public accommodations accessible to gender expansive or nonbinary identified persons. There may be a very fine line between reflexivity and
normalization and surveillance. The silences of the two young women in the first focus group may appear less reflexive in their refusal to discuss how they navigate healthcare as a trans woman. However, living their lives as women rather than trans women also represents a set of resistant practices that likely require meticulous discipline and vigilance and, at the same time, afford them a kind of freedom that an openly trans status does not.

Though focus group participants’ experiences varied, certain intersections of race, class, age, and gender identity surely correlated with specific experiences around perceived benefits as well as discrimination and involuntary disclosures of their sex-assigned-at-birth. Some had fantastic care at LGBT clinics: “It’s been a godsend,” said one Black trans man in Focus Group #4. Many trans women of color, on the other hand, felt clinicians there were particularly disrespectful of them. Similarly, some had wonderful care at non-LGBT clinics and others did not. Perhaps White, employed participants—though not exclusively—shared more perceived privacy violations that threatened their employment and access to respectful care. Participants of color, particularly trans women of color, relayed more stories where discrimination and involuntary disclosures threatened their physical safety or altogether blocked access to care or medications. Whereas the integrity of trans men’s masculinity was privileged over that of bureaucratic systems, and system errors were assumed and quickly amended, transgender women were not afforded such privileges. The trans man’s state ID was changed from F to M without engaging any formal procedures, while the trans woman’s state ID was changed back to M from F even though she had completed the formal procedures and requirements.

Similarly, self-determination and gender expression also differed along axes of race, class, and age but these different strategies and self-expressions afforded common ground and solidarity with respect to some objections to a two-step algorithm to identify them in the health
record. For example, younger, White, female-assigned-at-birth and relatively educated participants had nonbinary and agender expressions while younger POCs, with less formal education and male-assigned-at-birth tended to identify as women or females or girls, not transgender women. Despite their apparent social differences, these participants tended to agree that the two-step algorithm posed threats, though perhaps very different kinds of threats, to their safety and access to healthcare. Two of the four healthcare workers and the older White transgender woman, compared to their peers, endorsed the trans visibility in healthcare that the two-step algorithm may afford; in light of the work they do and the direct and indirect benefits that flow to them from forces of bio-power, the endorsement makes sense.

Privacy and disclosure frameworks only work for those trans persons with relative privilege, in terms of access to resources and in terms of passing as cisgender. Many trans and GNC people do not have the luxury to decide when to disclose: (1) because administrative systems often do not afford trans people privacy, and (2) because many do not have “passing privilege,” they do not necessarily have the opportunities to decide when to disclose their trans status. Trans people on the margins are aware of these limits and have to navigate complex bureaucracies that often operate on differing definitions of binary gender and must weigh the costs and benefits of changing gender markers in one system or certain systems and not others. The two-step algorithm and its potentially infinite digital footprint seem to add layers of potential danger to those most marginalized but also to less marginalized; whereas I may encounter discrimination at one pharmacy, minute clinic, or job, a young woman of color may find her access to housing, healthcare, or employment denied altogether.

This analysis has limitations. It does not examine the numerous other electronic surveillance platforms through which trans and GNC persons engage ethical practices around
care of the self. YouTube channels, Facebook groups, Twitter, Tumblr, and sites such as Trans Lifeline, RAD Remedy, and Original Plumbing afford opportunities to share experiences and resources and ask for help, feedback, and even lifesaving support. All these mechanisms rely on the Internet and are subject to numerous forms of surveillance—commercial, state, peer, and familial to name a few—that impact and complicate strategies for navigating bio-power, for self-determination, and care of the self. At the same time, trans people face such immediate and immense barriers that the short-term gains for self-determination may outweigh the potential surveillance harms. This example appears to illustrate Norberg’s “privacy paradox” whereby online actors claim to want privacy yet disclose freely immense amounts of personal information (Norberg, Horne, & Horne, 2007). However, the privacy paradox is not the most useful, since many trans and GNC persons do not have personal privacy around their trans status in the first place. Further research may be warranted in these domains.

Similarly, my critical interpretation of these groups requires additional research. Inclusion of other geographic regions with different combinations of trans and GNC researchers and participants may generate a more in-depth critique of this transgender care of the self. The conspicuous silences experienced in my first focus group, for example, could also be attributed to the shyness, poorly formed questions, or a group dynamic that both I and the participant who interpreted the dynamic for me were unaware of; on the other hand, one of the trans men of color reinforced our interpretation when he described a subculture of fierce competitiveness among young trans women of color. In future research, the presence of Native-, Asian-, Pacific Islander-, and Arab-American voices may offer important insights on the two-step algorithm and its potential benefits and harms. Focus groups conducted in the South by a GNC POC could generate important new directions for expanding access to care in the South where there are
likely additional challenges. Research from the margins and on the margins requires creative methods and theory that positivist research tends to eclipse by stripping away context and reducing experience to discrete variables and categories; that said, a large-scale survey on this topic may also indicate important general trends within and between different parts of transgender communities that could inform future qualitative studies.

Finally, another limitation is that this analysis does not explore how the two-step algorithm may affect the gender expression and nonconformity of cisgender persons on the gender margins. Though I am not endorsing the medicalization of “high femme” or “dandy” identities, I do understand that cisgender persons with more fluid or nonconforming (yet still perceived as cisgender or binary) gender expressions may feel that trans and nonbinary identities delegitimize their own marginalization along gender axes. The further medicalization of trans and nonbinary identities that the two-step algorithm brings helps foreclose opportunities for solidarity, driving a wedge not only within trans communities (e.g., those who tend to benefit from bio-power and those who do not) but also between trans communities and potential allied communities.

The US healthcare system and health research does not appear anywhere close to abandoning the drive to medicalize various identities, in general, and transgender ones in particular. Since bio-power and normalizing power have institutionalized the individualization of health and disease, EHRs must have better mechanisms to protect the privacy and security of data as well as patients themselves. More and better trainings, more transgender staff, data encryption, and data segmentation of sex-assigned-at-birth, or legal names and genders would help protect staff and patients alike from frequent mis-gendering and would limit the footprint of this personal transgender health information. More importantly, the bio-political forces of
providers and the coalescence of trans advocates and researchers might benefit from expanding their own ascetic practices to listen more actively to the voices and insights of those on the margins and consider technologies and mechanisms that center their needs. This kind of solidarity and ethical practice will help decenter the medicalization and fixity of identity and re-center the health and gender self-determination of patients.
VII. CONCLUSION

*Mis-gendering is not a moment, it’s a structure. It’s a condition. It’s a worldview. It’s having to wake up and not only be erased out of language, out of history, out of family, out of queer community, out of trans community, of media, of movements, of public space. It’s to experience constant and relentless denial of our humanity. What if we are never going to look like women or men? That means that the harassment doesn’t stop. There is no before or after there is just the terror. There is no before or after there is just the terror.* —Alok Vaid-Menon, Darkmatter, Facebook, 9.16.15.

This infrastructural analysis gives voice to the experiences of a range of stakeholder perspectives on the impact of EHR implementation, under the ACA and the HITECH Act, upon trans and GNC persons and their healthcare. As this research evolved, my understanding and critique of the effects of EHRs on the lives of trans and GNC persons has shifted. Not surprisingly, researchers, policymakers, and health IT officers clearly expressed some different stakes in these infrastructures than trans and GNC patients and particularly trans and GNC POCs, assigned male at birth. Clinicians, too, often expressed some of the same concerns as patients around the impacts that EHR systems and their respective procedures have on patient privacy, safety, access, and care. During the analysis stage of the research, disturbing trends have progressed that may deepen these differing stakes. Murders and suicides of trans people, and young trans and nonbinary POCs in particular, have reached alarming levels this year (Bruce-Jones, 2015; Kellaway, 2015).

In this conclusion, I will highlight the major findings and recommendations, and then I will contextualize them within these emerging trends so to highlight the implications of these findings beyond the scope of the analysis and into the broader, current landscape. In short, EHRs instrumentalize healthcare in order to administer various forms of surveillance; algorithms and data fields have bio-political and normalizing logics that, when implemented, may induce and exacerbate great harm and violate patient privacy, particularly for the most marginalized among
trans and GNC patients. Grids of power such as the political economy of US healthcare systems, structural and interpersonal racisms, and trans-misogyny, shape these logics and help create some very different experiences for clinicians and patients across and within these clinical contexts.

A. **Major Findings and Recommendations**

   1. **Findings**

   The development, design, and implementation of EHRs have created some immense barriers to effective care for patients. The crux of the problem lies in how to define and classify sexes and genders, beyond the traditional binary, for the purposes of clinical effectiveness, for billing, and for other covered entities that access these records. Sex and gender in medicine, long treated as binary facts of nature rather than ambiguous measurement constructs, are tied not only to culturally ingrained behavioral norms, but also to various funding streams, research endeavors, and econometric analyses. Vis-à-vis clinical care for trans and GNC persons, mis-gendering has often been attributed to a lack of cultural competency training, but in this study mis-gendering (and misnaming) also occurs due to the ineffective development, design, and implementation of these systems and their underlying logics even when providers are very culturally competent and have used the two-part question as the basis for the sex and gender algorithms in the record. These barriers have forced stakeholders to create numerous workarounds in their daily workflow routines. Sometimes these workarounds bridge the gaps, and sometimes they do not, but indisputably EHRs have created new barriers, anxieties, and extra work in these clinical settings.
For patients, mis-gendering is not necessarily a new problem either. In this study, focus group participants expressed wariness about the efficacy of the two-part algorithm despite an overall appreciation for its departure from the traditional cisgender binary. For GNC and gender fluid persons in particular, gender identities and presentations may not fit within binaries and they may reflect fluidity rather than fixity. The way that care is so dependent upon cisgender and transgender binaries presents problems, even dangers, for those who do not fit neatly within these binaries and for those who may not want medical interventions associated with their gender nonconformity. Similarly, trans persons who identify within a binary gender system and engage medical interventions may also hesitate to answer intake forms that reveal their sensitive medical history (i.e., assignment of a sex-at-birth with which their current gender does not align) to staff and others with whom they do not trust this information. Simply using the patient portal may not alleviate these privacy and safety concerns since a range of staff may have access to the information once the patient seeks care. Trans feminine, GNC, and trans women of color participants reported disproportionate levels of administrative violence and perceived discrimination with clinical intake as well as examination experiences.

In terms of trans health research based on EHR data, the conflation of gender identity to trans masculine and trans feminine categories that may or may not separate out or accurately capture gender queer and nonbinary persons also contributes to the erasures of those on the margins. Currently, for example, the largest study based on EHR data comes from the Veterans Administration hospital database that captures these genders in terms of a medicalized (i.e., with hormonal interventions) binary. Inferences made about a transgender population based on this limited definition and type of sample may perpetuate problematic stereotypes as well as erasures of nonmedically trans and GNC persons. Given the inconsistent reliability and validity of EHRs
as measurement instruments of these identities, any findings based on EHR research should be interpreted with great caution and caveats.

2. **Recommendations**

The challenges identified here require more in-depth ethnographic research in clinical settings in order to determine more effective resolutions to problems stemming from data governance, classifications, and patient privacy. This research suggests that, if providers must collect gender identity and other sensitive data, these infrastructures require better security mechanisms such as data segmentation based on user-defined roles and access. An intake staff does not need to know the legal name and birth-assigned-sex of a patient, for example. An ophthalmologist does not need to know that a patient has a diagnosis of Gender Dysphoria in order to provide effective care. Additional user-experience research will clarify these conclusions.

Given the unique patient populations and staffing across a range of provider types, EHR vendors and developers may need to prioritize usability over surveillance and billing needs. This shift may help return some of the agency to the doctor-patient relationship and the feeling of safety and trust to the patient.

Trans and GNC patients should have some capacity to control what gender-related health data non-primary-care clinicians have access to, given the lack of trans cultural competencies. They also should have the option not to answer intake questions regarding their sex-assigned-at-birth and current gender identity if the response options do not resonate with them or jeopardize their safety. A recent sociological study found that gender identity and expression is fluid for many individuals, including cisgender persons, and determined that a more effective way to capture gender in surveys might be with a scale (Westbrook & Saperstein, 2015). A federal mandate requiring the two-part algorithm for EHR implementation, as recommended by
numerous trans health researchers then, may be premature. Both clinicians and patients expressed dissatisfaction with the fixity of trans status in EHRs; even after transgender desistence (i.e., transitioning back to the gender consistent with one’s sex-assigned-at-birth) patients have remained categorized as trans.

B. **Emerging Trends and Implications**

This fall the Centers for Medicare and Medicaid Services (CMS) released its first ever plan to address health equity. The plan outlines six priority areas by which to reduce health disparities in the next four years and ultimately achieve health equity for underserved populations. To the credit of CMS and numerous trans health advocates, the plan includes transgender populations among those underserved. The plan, however, describes the top priority as the increased “collection, reporting, and analysis of standardized data,” including gender identity data (Office of Minority Health, 2015, p. 2). According to the report, the six priorities align with the overall goals of CMS. The plan states that its top goal is to “make care safer by reducing harm caused in the delivery of care” (Office of Minority Health, 2015, p. 3). Leading the way, CMS has proposed leveraging the big data of EHRs and population health methods in order to make access to care safer for trans and GNC persons.

In terms of this study’s findings, the CMS strategy can only succeed in that it centers the needs of the least marginalized, but it will fail in that it continues to exacerbate marginalization of those whom the EHR systems do not recognize (e.g., patients at under-resourced clinics) and those who may not feel safe disclosing their sex assigned at birth and/or gender identities (e.g., nonbinary persons and Black and Latina trans women). As the research of this dissertation shows, an overreliance on population methods and leveraging big data fails to recognize that
epidemiological methods and EHR algorithms tend not to reliably or validly capture these identities not only because of flawed methods and algorithms but also because of unsafe contexts for disclosure of personal health information. Trans and GNC patients, particularly POCs and nonbinary trans persons, often do not feel safe accessing care that demands them to make themselves visible at intake via algorithms that erase their sense of self. The four-year implementation of the plan will likely spend immense resources on the development and standardization of the two-step algorithm while neglecting fundamental safety, privacy, and security issues. Depending on how the data are analyzed, the reliability and validity may vary greatly, but population health methods center the normal range of samples rather than the tails or the margins where the disparities and harm are disproportionately experienced. In this way, the CMS plan and the EHR infrastructure serve to reproduce or exacerbate rather than alleviate health disparities for trans and GNC persons and POCs.

Prioritizing EHR data standards and data collection as the means to health equity for trans and GNC persons may create more harm, the antithesis of CMS’s most important goal for underserved patients and populations. This priority aligns with the centering of the “majority” of trans people or those that fit the norms of masculinity and femininity and feel safe and respected making themselves visible at clinics. Data derived this way are quiet expressions and measures of White, first world, Anglo-centric, middle-class norms rather than objective standards. Priority should be on safe access to care (including safe infrastructures) in this new and expanded healthcare landscape for transgender people. Trans and GNC POCs are dying at alarming levels due to murder, suicide, and state violence. Ensuring they have safe access to care and prioritizing their safety, respect, and integrity outweighs the need to count them at clinics. The burden for accessing care safely should not rest on trans and GNC individuals as it currently does within so
many healthcare systems. These individuals cannot be counted in records if they do not feel safe at the clinic or in the streets in the first place.

This past year two transgender tech professionals founded Trans Lifeline, a suicide prevention hotline staffed voluntarily by trans and GNC persons. Trans Lifeline leverages the Internet and distributed digital infrastructures to prioritize and provide critical, respectful support for the mental health crises of trans and GNC persons across the United States and Canada. Trans Lifeline prioritizes support, care, and gender self-determination over standard gender categories, data collection, and a secure and private infrastructure (i.e., the Internet). Also rooted in the Internet infrastructure, RAD Remedy is a referral aggregator database that compiles vetted community referral lists and user evaluations of safe and respectful healthcare providers across the United States. A nascent and evolving database, RAD monitors providers to aid trans and GNC persons access a number of health-related services and provide essential information regarding competencies, safety, and quality of care. Trans and GNC persons have established a number of other similar digital health information technology applications as well.

Though these new organizations have experienced great support and acclaim for much needed work, their sustainability is unclear. Resource-poor organizations like these can only provide a small Band-Aid for the gaping wounds created by the complex intersections of the ACA, behemoth industries of health IT and health insurance, and the funding for and methods of big data and population research. Furthermore, the volunteer bases tend to consist—not of the most marginalized—but primarily of those trans and GNC persons who have the capacity, resources, and able-bodies to participate and to contribute sweat equity. The resolution is unclear, but in the interim providers and health insurance companies alike need to increase their resources for bridging these dangerous gaps and at the very least subsidize the volunteer-driven efforts of
trans organizations, help pay for staff, and hire and train their own trans and GNC patient navigators, advocates, staff, and clinicians. An economic argument can be made to justify such capacity building, but as the CMS report notes, the case for equity and justice supersedes the economic value of human life. Trans and GNC patients cannot appreciate the benefits of quality improvements in care or increased knowledge production without institutional support that goes well beyond data standardization and collection and instead centers safe access, gender self-determination, and the active participation of the most marginalized trans and GNC persons.
CITED LITERATURE


ETTINGS#4


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APPENDICES
APPENDIX A

Key Informant Interview Guide

Script for ensuring informed consent. Read immediately before interview begins.

Hello, my name is Hale. I am conducting the study on electronic privacy and security pertaining to health records and the collection of health information related to gender identity. I am here/calling because you agreed to be interviewed as part of this study, and we agreed upon this time to talk. Is this still a good time?

Before we get started with the interview, I want to be sure that you understand your rights as a participant in this study. I emailed you, on behalf of UIC, a document that gives details about your participation. Do you recall seeing that email and the information in the document? I can re-send (email) that to you now if that would be helpful.

[Pause for a reply after each question. Discuss as needed to clarify for the participant.]

To clarify your rights, do you understand that:
   a) This interview will take approximately one hour?
   b) This interview is about your EHR system and how it is used in relation to gender nonconforming and transgender patients?
   c) You can stop the interview at any time?
   d) You can refuse to answer any question?
   e) Your participation will not affect your relationship with UIC?
   f) There is no incentive to participate in the interview for EHR use and the collection of gender identity-related information?
   g) There are minimal risks involved in participating in the interview?
   h) I will be audio-recording this conversation but the recording will be erased once we have the transcript?
   i) I will keep your name and the name of your organization confidential by not using those names in any report, presentation or publication?

If you have no further questions, we will start the interview.
APPENDIX A (continued)

1. Before we get started, can you please state your position/title?
   a. How long have you worked in this position?
   b. How long have you worked at this organization?

2. CLINIC DESCRIPTIVES: Can you describe the records system(s) that your clinic uses and describe how, if at all, it has changed the care provided for your transgender patients? (Probes below)
   a. How long have you been using them at the clinic?
      i. Have you experienced the transition(s) from one system to another? (If yes, go to ii. If no, go to 3.)
      ii. How has the shift to EHRs impacted your ability to deliver quality care to trans patients?
         1. Increased or reduced errors in lab and prescriptions (e.g., clinical decision support/alerts built into EHR)?
         2. Increased or reduced charting/coding requirements?
         3. Increased distance from clients due to working on computer during appts? Or more time with clients due to time saved on charting?
         4. How do you think the public access to Medicare billing data might impact the clinic or care it provides?
      iii. Did the barriers decline over time? What changes were made? Did the facilitators grow over time? What changes were made?

3. How does system log/capture gender for billing purposes? Gender for patient-provider purposes (i.e., “preferred gender identity” if not legally changed)? Legal name? Preferred name? Sexual orientation/Sexual partner’s gender? How has this classification system impacted your ability to give culturally competent care?
   [For interviewer, mark below the predominant model for logging gender ID: field for billing only, or are there two different fields—one for billing and one for patient-provider purposes.]
   1. Billing M F Undetermined or ________________
   2. Patient-Provider
      a. M F TM TF Other
      b. 2-part gender question
      c. Sexual Orientation Homo Hetero Bi Qr Qs Other
      d. Sexual Partner Gender M F TM TF Other
      e. Sexual behavior field? MSM WSW .....  

4. What kind of gender identity related health info, if any, do you think is important to capture in these records?
   a. Can you specify how the EHR system captures the following? (Probes, examples below)
APPENDIX A (continued)

i. Gender ID legal/nonlegal
ii. ICD-9/ICD-10 diagnoses: gender dysphoria, hormone imbal, etc.
iii. Hormones
iv. Surgeries

b. How does the record reflect changes that occur in patients gender ID? [Is it a static category, once it’s used? Or can patients request that it be changed if they de-transition or decide that they are genderqueer, etc.]

5. USE CASES: Can you talk about some examples of how you use this system consistently or very differently for trans and gender nonconforming patients with different circumstances?
   a. Probe: a genderqueer patient, no hormones, various surgeries
   b. Probe: a trans masculine patient, hormones, wants pregnancy
   c. Probe: a trans feminine patient, hormones, needs/wants to maintain ‘M’ on all records for various access to services such as housing and veteran benefits.
   d. To better understand how you might navigate your EHR system, can we look at some “use cases” that your system has (e.g., “dummy” records) or that I have with me?

6. COMPLIANCE
   a. What standards and/or regulations does this system satisfy? (Probes below) Have there been any breaches?
      i. HIPAA
      ii. ARRA/HITECH/Meaningful Use
      iii. State-level
      iv. Clinic-level
         1. Are “pseudo” anonymity techniques in place (e.g., patient identifier rather than PHI)?
         2. Data segmentation between different users (psych vs. md providers vs. pharmacist vs. insurance)?
   b. Can you tell me about the privacy policy here and how it works?

7. INFO SYSTEM ACCESS/ENCRYPTION (Health IT Staff only)
   a. Is there a policy on use of cryptography and key management?
   b. Are the users’ data encrypted?
   c. Can you describe the encryption? (e.g., full disk encryption, SSL/network encryption, etc.)

8. ACCESS CONTROL/POLICY (Health IT staff only)
   a. What authentication system(s) is used?
   b. What access control models are in place (i.e., for user registration)?
APPENDIX A (continued)

c. Can access policies be overridden in emergency (e.g., “break the glass”)? Can you describe a time when that has happened?
d. If system requires user roles, who defines them? Who grants access to the data (i.e., info access restriction policies)?
e. Can you/providers access EHR system remotely? How (e.g., via VPN)? Can you give an example or tell me about the last time you accessed the system remotely?
f. Can patients access their records/doctor via a patient portal to the EHR system? I’ve seen one system where the patient has a secure/password-encrypted connection but the Doctor then emails response/data back to the patient (i.e., not as secure). How does the communication work between patient-provider via EHR system?
   Can you give an example of how this has worked (or NOT worked)?
   What does a patient have to do to get a copy of their records? What if they want to make sure something is changed/corrected in their records (e.g., incorrect gender id)?
g. Can the EHR system “manager/storage org” (e.g., Alliance of Chicago) access patient records? How and to what degree (segmented data? De-identified? Full access?)? For what purposes? Where are the servers located?

9. COMMUNICATION AND OPERATIONS MANAGEMENT (Health IT or Officer)
a. What policies and procedures are in place around accessing and sharing information on Health Information Exchanges?
b. What kind of information can be exchanged? Will data be segmented by default (patient opt-in or opt-out)?
c. Can you describe the policies and procedures in place around audit logs of access and exchange of data?

10. HUMAN RESOURCES SECURITY
a. How much training do users/staff have around patient info security and privacy?
   Can you give examples of training that’s happened recently?
b. How do you think this training impacts care?

11. RESEARCH AND SURVEILLANCE
a. Who accesses records for surveillance or reporting? Research?
b. How does the EHR data appear to them? Is it already de-identified? Segmented?
   Are they responsible for de-identifying?
c. What are the protocols for de-identification of EHR data for research?
d. How is gender identity captured in reports or for research?
e. How do you feel about using EHR data for trans research?

Before we end, is there anyone else you think I should definitely interview for this research?

That’s the end of my questions. If there is anything else, you think is important to understand regarding the security and privacy features of the system please go ahead.
Thanks again so much for your time and attention. All of your insights and thoughts are very important and valued.
APPENDIX B

*Key Informant Recruitment Letter*

XX July 2014

Key Informant
XYZ Clinic
AB UUUUUU Street
City, STATE 99999

Dear Key Informant:
I am writing to inform you about my dissertation research at the University of Illinois at Chicago where I am a PhD candidate. Gender Hack is an exploratory analysis of the impacts of mandated EHR (EHR) implementation and the related electronic privacy and security issues on transgender healthcare.

My research will consist of three methodological pieces: (1) 4 focus groups with transgender and gender nonconforming patients, (2) analysis of EHR infrastructures, and (3) key informant interviews. Based on the data collection, I will articulate a critical best practices around privacy- and security-aware EHR implementation and collection of gender identity-related health data.

You have been identified as a potential key informant who has extensive knowledge and/or investment in healthcare for transgender and gender nonconforming persons. If you have worked at your current place of employment for at least one year, and you are available to be interviewed, your input will expand the knowledge base regarding effective EHR implementation to enhance quality transgender healthcare. This information is crucial for the sustainability of quality transgender healthcare that can meet the requirements of healthcare reform and meaningful use.

The purpose of the key informant interview is to collect information from a wide range of persons considered to be “experts” on aspects of transgender healthcare and/or EHRs. The interviews will focus generally on transgender healthcare and the EHR barriers and facilitators to quality care, and how electronic privacy and security issues may impact the clinician-patient relationship.

I anticipate conducting these interviews between August 1 and December 1. Please let me know your level of interest and availability, and I would also be happy to answer any questions and provide more details.

Sincerely,
Hale Thompson
APPENDIX C

Key Informant Consent Form

Introduction:
Hale Thompson’s dissertation research is supported by University of Illinois at Chicago, School of Public Health, Division of Community Health Sciences.

The purpose of the interview is to establish how stakeholders are navigating patient privacy and data security concerns in transgender healthcare settings; in particular, the research will critically examine how providers capture gender identity information about trans and gender nonconforming persons in healthcare settings. All discussion during the interview shall be kept confidential among participants. Any personal information learned about participants is not to be shared outside the interview.

You will be asked questions related to your experiences as a healthcare provider/researcher/information technologist in general and the ways in which EHRs and their privacy and security features enable or hinder the delivery of quality care to transgender persons in particular. You do not have to answer any of the questions you do not feel comfortable answering. Your participation in this interview is voluntary and you are free to leave at any time. The interview, which I will conduct over the phone or with you in person, should last no longer than 1–1.5 hours.

Confidentiality:
You are being asked to participate in this interview because you have been identified as a potential key informant. The interview is confidential. Your name or any information that could identify you personally will not be used in any presentations, reports, papers, or publications that may result from this interview. Any contact or personally identifying information, that we have for you will be kept separately from all recorded data and will not be used as part of any presentations, reports, papers, or publications. This is your copy of this consent form.

Because of the amount of information that the interview will generate, the interview will be audio-recorded. Files will be stored on an encrypted, password-protected computer until they have been completely transcribed. At that time, the files will be deleted. Your contact information will be destroyed upon completion of the interview.

Benefits and Risks:
There is no direct benefit to key informants for participation. Your input will inform and expand the knowledge base regarding patient privacy and data security as they relate to transgender and gender nonconforming healthcare. This information is crucial for the effective implementation of healthcare reforms in healthcare settings that transgender and gender nonconforming persons access.

Some of the questions may cause a sense of discomfort or loss of privacy. The risks associated with the research are a breach of privacy (i.e. participation in research exposed to others) and confidentiality (i.e. accidental disclosure of identifiable data). As stated in the confidentiality
section, audio files will be encrypted and then deleted after transcription, and your name or personal details will not be shared in any presentations or papers. If at any point you wish to end the interview, you are free to do so. In no way will participation or lack of participation in the interview affect your work or status in your employment.

Questions, Contact Information, and Signature for Consent to Participate:
You have communicated with Hale Thompson about this research and have had an opportunity to have your questions answered. If you have any further questions or concerns, you can email Hale Thompson at lthomp10@uic.edu or call at 222.333.4444.

This is your copy of the consent form. Please print and retain it for your records.
APPENDIX D

Focus Group Interview Protocol

Script for ensuring informed consent. Read immediately before focus group begins.

Good evening and thank you for being here. My name is Hale. I am conducting research on the effects of the Affordable Care Act on healthcare for trans and gender nonconforming people. For example, I am very interested in the requirement that healthcare providers use EHRs for our care. So, what kind of new privacy problems do electronic health records create? And, what kind of problems remain around disclosing our identities safely in healthcare settings and other settings? And do our identities change in different settings?

We are all here today because you agreed to participate in this focus group as part of this research. Our discussion may last about two hours. I will be facilitating the discussion so that everyone has a chance to speak, and I will be taking a few notes as well. I am audio-recording the discussion, but no names will be transcribed in the notes and strict confidentiality will be maintained.

Please remember that you are the experts on your healthcare. Please do not feel like you have to tell me what you think I want to hear. Please feel free to express your views and experiences—whatever they may be.

Before we get started, I want to be sure that you understand your rights as a participant. Has everyone had an opportunity to read the informed consent document?

[Read and discuss as needed to clarify for the participant.]

To clarify your rights, please understand the following:

a) This focus group will take approximately two hours.

b) This focus group aims to explore your experiences accessing healthcare and other essential services and any concerns for privacy that you may have around your gender identity and the health information related to it.

c) You can exit the focus group at any time should you feel inclined.

d) You can refuse to answer any question.

e) Your participation will not affect your relationship with UIC or with your healthcare provider.

f) The incentive to participate in the focus group is that you will receive a $30 gift card.

g) There are minimal risks involved in participating in the focus group.

h) I will be audio-recording this conversation but the recording will be erased once we have the transcript.

i) I will keep your name completely confidential by not using your name or personally identifying information in any report, presentation or publication?

If you have no questions, we will start the focus group.
APPENDIX D (continued)

INTROS: Can you make sure your nametag and pronouns are visible for all to see. First let’s go around and introduce ourselves with name and pronouns.

Name & pronoun

GROUND RULES: Before we get started, we will establish ground rules together to ensure this space feels safe, respectful, and confidential for our discussion. Does anyone have any guidelines they’d like the group to follow? (Offer a couple to get started if necessary:)

1) Respect
2) Confidentiality
3) Step up, step back (ONE SPEAKER AT A TIME)

1. First, I want to get a sense of how people view doctors and health. Does everyone have a doctor or nurse that they see regularly? Let’s go around the room and say where we get our primary care.

2. Next, I want everyone to think about a positive and negative experience they’ve had at the doctor’s. Preferably relatively recently, but if you have to go far back into your past, that’s ok too.

   i. Ex. From past research: Going to the dermatologist and knowing that the medical team has info on trans status AND treats it as a nonissue from waiting room to nurse to doc and resident. Were electronic health records instrumental in that treatment? Probably not but certainly did not seem to present a barrier.

3. What about a negative experience? Can you talk about a bad experience you’ve had at the doctor’s and say what about it made the experience poor?

   i. Ex. Pharmacist violating my privacy and changing my prescription.
   ii. Ex. Provider assuming I was a raver kid on drugs.

4. What do you like or don’t like about going to the doctor?

5. What about the doctor’s office helps make you feel safe? Unsafe?

6. INTAKE FORMS and ID DISCLOSURE (Attn. to sample intake form)

   First we are going to look at this example of an intake form from a clinic that provides primary care for trans and GNC persons. What do you think about the ‘patient information’ section of this this form? Why do you think this information is collected?

   PROBE: What do you think of legal vs. chosen/preferred name? PGP? What about ‘Gender’? Sexual orientation?

   PROBE: Anything about the other categories—‘Race’? ‘Ethnic Background’?

   PROBE: Do you feel comfortable or safe completing this form? How do you think this information is used? (Cultural comp or/and medical?)
APPENDIX D (continued)

PROBE: Has anyone filled out an intake form in an electronic ‘patient portal’? (So, instead of filling out paper forms, you filled out a form on a computer before your first appointment either in the waiting room or from your home?) How was that experience? (If no one has had the experience, ask if they think they would prefer that?)

PROBE: Have they encountered any different/unique experiences completing these forms with a particular specialist?

PROBE: Have you ever gone to a different doctor—like an ER doctor or a specialist who seemed to have access to the information you gave another doctor? How do you feel about different doctors having access to the information you give one doctor for one purpose (i.e., trans healthcare)?

7. The US government aims to have all Americans’ medical records computerized by 2015. Are all of you familiar with electronic health records (explain paper to EHR)? So, now what we write on these forms gets entered into a computer instead of put in a folder in a file cabinet. Has anyone ever requested a copy of your health record? Did you see how your gender identity from the intake form was entered into the health record? Were you surprised by any of the information in your record?

PROBE: For example, if you look at the screen shot of the electronic health record, and you identify as two spirit or Mahu, would it be ok if all the record captured your identity as ‘MTF’ or ‘other’? ‘Gay’ ‘Straight’ ‘Bisexual’ or ‘Something Else’?

PROBE: What if your decision to disclose varies across medical settings? That is, does it change if you are in the ER or seeing another specialist unrelated to your trans status? Why might it matter that your gender identity info may be accessible across different medical settings (medical or/and discrimin/access denied)?

PROBE: What if your identity changes personally (and not just around disclosure in different settings)—for example from transgender at your hormone doctor to ‘woman’ with your boyfriend to ‘man’ with your family—or from Gay to Heterosexual or Queer? How do you decide which identity to disclose in your health records or at the doctor? And, what is the problem if that information is accessible to others who see your records?

PROBE: What if your medical needs change such that your identity needs to change for the purposes of getting the best care? Has anyone ever experienced this? For example, a trans man decides to have a baby and needs to be recategorized as female for insurance to cover the care.

Or, what if personal needs change: You move from Chicago to a small town in Iowa and need your ID to be consistently female across all your records in order to get a
APPENDIX D (continued)

job or get into school? Or to get housing? Has anyone been denied access to services due to conflicting records in a background check?

8. CLINICAL RELEVANCE—Now we’re going to talk about the medical setting you experience with your doctor or primary care clinician—beyond initial intake process.
   a. Do any of you have doctors who currently use EHRs during your appointment? (state for recording how many raise hands). How has the quality of your healthcare changed, if at all, since your Dr. started using electronic health records during your appointment?
      i. Efficient doc visits?
      ii. Impersonal doc visits?
      iii. Easier to fill prescriptions? See specialists? Reach your doc?
      iv. Easier or harder to make an appointment?

   b. Can you access your records remotely through a patient portal on the Internet?
      i. How do you use this feature? (Or can you imagine how you might use this feature? Prescriptions requested, questions for doc)
      ii. Has it made your access to care easier? More complicated?
      iii. Do any of you use your cell phones or email to communicate directly with your doctor or nurse about your health needs? Can you describe how that works for you or an example from when you have done that?

   c. How has the quality of your healthcare changed, if at all, since you transitioned genders? How has your care changed for the better? Worse?

   d. Are there any other ways you’d like to share that the quality of your care has changed over the course of your transition or over the course of your lifetime? For example, since you moved to the Chicago, how has the quality of your care changed?

   e. Why is it important (or not) for you to have your doctor recognize your gender identity in your medical record? That is, why do you think having that info in your record might or might not improve your care and/or during your appt?
      i. PROBE: What about sexual orientation?
      ii. PROBE: What about race or ethnicity?
      iii. PROBE: How do you decide what to disclose to them in your appointment?
      iv. PROBE: How has disclosing this info to your provider affected the quality of your care? Do you think it’s improved care?
      v. PROBE: Has it ever led to perceived discrimination OR what you think was stigmatizing treatment because this information was available to clinicians? Describe…
APPENDIX D (continued)

f. Do you know what diagnostic category your provider currently uses to treat you for trans health related conditions? Does it matter to you? How might it impact other areas of your life?
   i. Ex. For accessing hormones:
   1. Gender Dysphoria
   2. Endocrine Disorder Unspecified/Generalized Endo Disorder
   3. Intersex condition
      ii. Why, if at all, does it matter to you which category they use?
      iii. Have you ever asked your provider what diagnostic code they use for your gender-id related care? Do you feel comfortable asking?

g. Would you like electronic health records to collect trans health related info in one ‘transgender’ section of your record? (e.g., what mental health therapy have you had? What surgeries? What hormones? What gender identities? Sexual orientations related to gender change?)
   i. Turn to example from Deutsch et al., 2013
   ii. How would this be helpful for medical providers to have access to? Should access to this part of your EHR be limited to only certain providers?
   iii. Can you imagine ‘cis’ persons also having a ‘cis’ section marking all their cisgender-related care? (E.g., birth control, breast enlargement, erectile dysfunction, therapy, etc.) What is the effect, do you think, of creating a ‘trans’ medical page and not a ‘cis’ medical page in EHRs? (Or, rather than binarizing this part of the record—call it gender-related health segment…)

9. PRIVACY POLICY

a. Can anyone share with us roughly the terms of your provider’s privacy policy? (Review sample privacy policy—e.g., law enforcement or HR depts.).
   i. Do you understand what this means in terms of who may have access to your records without you giving specific consent?
   ii. Do you know how this has changed over time? Do you think electronic health records will make it easier or harder to share your records with other entities?

b. [SKIP] Show healthmap.org slide and growth of covered entities under HIPAA
   i. Do you have any concerns about these entities accessing your health records? Can you share some concerns?
   ii. Have you had any experiences with social security or your employer or other entity seeing your health records that you can describe?

c. Has anyone ever had their privacy violated by a provider or in the medical provider setting? Can you share? (Ex. Pharmacist outing patient’s medication.)
APPENDIX D (continued)

Or Waiting room outings). Do you think electronic health records make privacy violations more or less likely? Explain.

d. The mainstream media often suggests that young people in general care much less about privacy than older people.
   i. Considering your own experiences, in what ways do you think this is true or false about differences for younger and older trans and gender nonconforming people?
   ii. Do you think other factors account for different levels of concern for privacy? What are they? (Ex. Think about people you know who are ‘stealth’—what are their reasons? Do they tend to be older? Younger? Live in rural areas? Have passing privileges? Etc.)
   iii. In the medical setting, do you think young trans and GNC people care less about privacy when it comes to disclosing aspects related to gender and sexual orientation?

10. SHARING EHR DATA: What do you think about the idea of researchers accessing and using your medical records for trans-related health research?
   a. For example, would you be comfortable with a researcher looking at your records in order to investigate long-term effects of hormone use as long as your name and address and birth date were omitted?

   b. What about the relationship between trans identities and stress or mental health?

   c. Do you think this research would fail to account for those trans and GNC persons who are not “OUT” to their doctors (e.g., not currently using hormones)?

   d. Would you be comfortable with a researcher looking at the records of everyone in the room and counting 5 of us a trans-male and the other 6 as trans-females for “research purposes”? What if some of us ID as males and females or gender nonconforming? Do you think it’s more important that precise identities are captured?

   e. How do you think researchers would categorize the following in terms of gender and sexual orientation for the purposes of HIV prevention research?
      i. Example: White, genderqueer, FAB, on t, no surgeries. Has sex with cis men for work, partner is female, queer ID’d.
      ii. Example: Two spirit, on estradiol and progesterone, no surgeries. Has sex with cis men.
      iii. Transsexual woman, on hormones, lower surgeries, silicone injections in various places….
      iv. Why do you think it’s useful—or harmful—or maybe altogether beside the point—to call all these examples transgender even though none of them may identify as transgender?
APPENDIX D (continued)

f. How much privacy in your healthcare are you willing to tradeoff (allow) for the sake of scientific or health research? Do you think everyone should be given the opportunity to “opt-in” their records for medical research? That is, make an active choice to participate rather than automatically be included, OR given the opportunity to opt-out (see intake example) similar to the intake form we’ve looked at?

That’s the end of my questions. Does anyone have any final thoughts to share or questions?

Thanks again so much for your time and attention. All your insights and thoughts are very important and valued. And, please remember to respect the privacy of everyone in the room and keep your peers’ thoughts and experiences confidential.
APPENDIX E

Sample Recruitment Flier

Be the Change that You Want to See!

Do you identify as trans or gender nonconforming?
Are you 18 or older?

This is an exciting opportunity to contribute to the improvement of healthcare under current healthcare reform!

As a participant in this research, you will be compensated for your participation ($30) and may shape the future of healthcare delivery.

For more information or to participate, Please contact lthomp10@uic.edu or call 222.333.4444.

This research is for a doctoral dissertation at the University of Illinois at Chicago.
APPENDIX F

Focus Group Eligibility and Screening Questions

Thank you for your inquiry! The purpose of this research is to examine the impact of healthcare reform—and in particular, implementation of electronic health records—on transgender healthcare. The focus groups will help understand the disclosure strategies and privacy concerns around gender identity for trans and gender nonconforming persons in healthcare settings. We will also explore various privacy concerns around identity in other contexts such as employment, education, family, social media, and others. At the beginning of the focus group, ground rules will be established collectively to ensure safety and confidentiality among participants. That is, all discussion during the focus group shall be kept confidential among participants. Any personal information learned about participants is not to be shared outside the focus group.

This screening requires that I collect some personal information to determine whether you are eligible, waitlist-eligible, or not eligible. The screening is confidential and completely voluntary; you are free to withdraw at any time.

For the purposes of this research, we consider you to be transgender or gender nonconforming if you:

• Were assigned a sex at birth that differs from the gender with which you currently primarily identify

Based on this definition, please answer the following questions:

1) What sex were you assigned at birth?  ____F  ____M

2) What gender do you currently identify with?

   ____(Trans)F  ____(Trans)M  ____GQ  ______________Other (specify)

3) How long have you identified this way? ______________

4) How old are you? _____

(If eligible so far) To help ensure that we recruit a diverse cross-section of trans and gender nonconforming participants, please consider the following questions:

   a) What is your highest level of education?
   b) Have you been unemployed in the last year?
   c) What race and/or ethnicity do you primarily identify with?
   d) Do you currently have health insurance?

Inform recruit of their status (eligible, eligible-waitlist, or ineligible), the focus group dates and locations and time commitment, and determine in which group it is best for recruit to enroll. Collect preferred email and notify that informed consent form will be sent.
APPENDIX G

Focus Group Consent Form

Introduction:
This study is Hale Thompson’s dissertation supported by University of Illinois at Chicago, School of Public Health, Division of Community Health Sciences.

The purpose of this focus group is to establish the disclosure strategies and privacy concerns around gender identity for trans and gender nonconforming persons in healthcare settings. We will also explore various privacy concerns around identity in other contexts such as employment, education, family, social media, and others. At the beginning of the focus group, ground rules will be established collectively to ensure safety and confidentiality among participants. That is, all discussion during the focus group shall be kept confidential among participants. Any personal information learned about participants is not to be shared outside the focus group.

As a participant, you will receive $30 for your participation.

Confidentiality:
You are being asked to participate in this focus group because you have self-identified as transgender, gender nonconforming, and you live your life and identify with a gender other than the one associated with your sex assigned at birth, whether or not you are taking hormones or have undergone gender-related medical or surgical interventions. The focus group is strictly confidential, and your name will not be attached to the information that we collect during this focus group. Your name or any information that could identify you personally will not be used in any presentations, reports, papers, or publications that may result from this focus group. Although focus group participants are asked to keep all information confidential, there is a risk for breach of confidentiality. Any contact information or personally identifying information that I have for you will be kept separately from all recorded data and will not be used as part of any presentations, reports, papers, or publications. You will receive a copy of this consent form.

Because of the amount of information that the interview will generate, the interview will be audio-recorded. Files will be stored on an encrypted, password-protected computer until they have been completely transcribed. At that time, the files will be deleted. Your contact information will be destroyed upon completion of the focus groups.

You will be asked questions related to your healthcare experiences in general and your decisions around disclosure of gender identity in healthcare and other settings in particular. You do not have to answer any of the questions you do not feel comfortable answering. Your participation in this focus group is voluntary and you are free to leave at any time. Once we begin, the focus group should last no longer than two hours.

Benefits and Risks:
There are no direct benefits to this research study. Your input will inform and expand the knowledge base regarding patient privacy and transgender and gender nonconforming related healthcare. It may also contribute to a best practices. This information is crucial for the effective
implementation of healthcare reforms in healthcare settings that transgender and gender nonconforming persons access.

Some of the questions may feel personal in nature and may cause a sense of discomfort or loss of privacy. The risks associated with the research are a breach of privacy (i.e., participation in research exposed to others) and confidentiality (i.e. accidental disclosure of identifiable data). As stated in the confidentiality section, audio files will be encrypted and then deleted after transcription, and your name or personal details will not be shared in any presentations or papers. Because of the nature of the subject matter and the varied experiences of participants, we will collaboratively establish ground rules to address safety for all participants. Also, if at any point you wish to leave, you are free to do so. In no way will participation or lack of participation in this focus group affect the services you receive or your privacy.

Questions and Contact Information:
You have communicated with Hale Thompson about this research and have had an opportunity to have your questions answered. If you have any further questions or concerns you can email Hale Thompson at lthomp10@uic.edu or call at 222.333.4444.

1) Do you have any questions?
2) Have you read and do you understand the description of the focus group as well as the risks and benefits of participation, if you choose to participate?

Please sign and date below and retain the extra copy of this consent document for your records.

Signature ________________________________________________________________

Date __________________________
Hale Thompson
Curriculum Vitae
September 2015

Address: 1603 W. Taylor Street, 6th Floor
Chicago, IL 60612

A. EDUCATION
PhD Candidate, Community Health Sciences, University of Illinois at Chicago
Master of Science, Epidemiology, University of Minnesota
Graduate Certificate, Community Development, University of Illinois at Chicago
Master of Arts, Sociology, University of Illinois
Bachelor of Arts, Economics, The University of Chicago

B. ACADEMIC EMPLOYMENT AND FELLOWSHIPS
2012–Present National Science Foundation Integrative Graduate Education Research
Traineeship in Electronic Security & Privacy, Associate & Fellow,
University of Illinois at Chicago (UIC)
2009–2013 University of Minnesota, UIC, Research Assistantships
2012 National Science Foundation Training Fellowship, Values in Design
Workshop, University of California at Irvine
2011 National Institutes of Health Training Fellowship, Summer Institute in
Population Health, The Fenway Institute & Boston University School of
Public Health
2010 University of Minnesota, Teaching Assistant, Introduction to
Epidemiological Methods, Global Reproductive Health

C. PEER-REVIEWED PUBLICATIONS
2015 Thompson, H., & King, L. “Who counts as transgender?
Epidemiological methods and a critical intervention.” Transgender
2015 Thompson, H., Reisner, S., VanKim, N., & Raymond, H. F. “Quality of
life measurement: Assessing the WHOQOL-BREF Scale in a sample of
high HIV-risk transgender women in San Francisco, CA.” International
2013 Thompson, H., Koepfler, J., Sydenham, K., & Hoffman, A. “Real Talk: A
Toolkit for community engagement, transparency, and mobile
governance.” ACM Conference Proceedings.
2011 Chen, S., McFarland, W., Thompson, H. & Raymond, H. F.
“Transmen in San Francisco: What do we know from HIV test site
D. GRANTS AND AWARDS
2013 UIC School of Public Health Delegate to the Centers For Disease Control Millennial Health Leader’s Summit (Atlanta, GA).
2008 Principal Investigator: Thompson, Hale. San Francisco Department of Public Health, HIV Prevention Research Grant to Conduct a Rapid Community Needs Assessment, $40,000 (San Francisco, CA).
2005 Stand Grant for New Directors, Film Arts Foundation, $1,000 (San Francisco, CA).

E. SCHOLARLY PRESENTATIONS (Refereed)
2014 “Electronic Health Records and Biomedical Surveillance of Gender Nonconformity.” American Studies Association Annual Meeting (Los Angeles, CA).
2013 “Quality of Life Measures and Discrimination and Violence Against Transgender Women.” Gender Matters Conference (Chicago, IL).
2013 Traverse City: the Politics of Representation in Film, Video, and Social Media.” Gender Matters Conference (Chicago, IL).
2012 “Local Health Department Collaborations in Maternal, Child, and Adolescent Health.” Co-author. 18th Annual Maternal and Child Health Epidemiology Conference Poster Session (San Antonio, TX).
2009 “All Gender Health Online Formative Research Findings” co-presented with Principal Investigator, Walter Bockting, PhD at Sex::Tech Conference (San Francisco, CA).
F. GUEST LECTURES AND PRESENTATIONS

2015  “Sex Assignment: Disciplinary Frameworks that Make Gender Nonconforming and Intersex Subjects Legible.” Queer Theory Course. The Pratt Institute. (Brooklyn, NY).


2011  “Quality of Life Measurements in Transgender Research: Respondent Driven Sampling & Confirmatory Factor Analysis in the San Francisco TEACH Study.” The Fenway Institute (Boston, MA).

2010  “Global HIV Epidemiology.” Guest Lecture for Global Reproductive Health, University of Minnesota School of Public Health.


2009  “Findings and Recommendations from the Transgender Men Rapid HIV Needs Assessment.” Co-presented with Sean Saifa Wall to the HIV Prevention Planning Council (San Francisco, CA) and the Institute of Medicine (San Francisco, CA).


2006  “Adapting Effective HIV Prevention Interventions for Transgender Populations.” HIV Prevention Leadership Summit (Dallas, TX).

I. PROFESSIONAL MEMBERSHIPS

2015  American Public Health Association

2014– Present  American Studies Association